

# **The refinement of a booklet on stroke care at home**

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## **Declaration**

I, the undersigned, hereby declare that the work contained in this thesis is my original work and that I have not previously submitted it, in its entirety or in part, at any university for a degree.

Signature:

Date:

# Abstract

Stroke is the second commonest cause of mortality worldwide and remains a leading cause of adult physical disability. It is estimated that sixty percent of South African stroke survivors require assistance with at least one activity of daily living. This burden is predominantly on the shoulders of mostly untrained caregivers.

The process of enabling caregivers to make choices conducive to their own health as well as the health of the stroke survivors is multidimensional. One of the cornerstones of this process is the provision of information. In 1995, the Centre for Rehabilitation Studies of the University of Stellenbosch started to develop a training package for stroke care at home. The training takes the form of an interactive workshop and a booklet with practical information. The aim of this study was to refine and pilot this booklet for implementation with the training.

The study found that existing guidelines to evaluate the appropriateness of written material for developing communities (measured by Hugo's grading model), were inadequate. Consequently, a new checklist, based on twenty existing checklists, was compiled. This list, as well as the Suitability Assessment of Material (SAM), was used to evaluate the booklet and make recommendations for a pre-pilot refinement. Even though this checklist has not been validated, it revealed similar results to the SAM when applied to the booklet. After consultation with the authors, improvements were effected to the booklet

The booklet was tested with four samples of the target audience. The functional literacy of the participants was determined using a standardised literacy test. A fifth sample completed a questionnaire on their preference between the pre- and post-refined booklet. Experts in the field of rehabilitation and graphic design also commented on the booklet.

This study confirmed the need of stroke survivors and their caregivers for written health information. The refined booklet was found to be an appropriate tool to address the needs of the target audience. The participants perceived the booklet as useful and comprehensible and the readability level was shown to correspond with the

tested literacy level of the samples. However, there is a need for printed material on topics related to stroke not currently covered in the booklet, e.g. spasticity.

This study showed that the checklist could be used to tailor written health information that is preferred by the target audience. It confirmed that the testing of printed material with stakeholders could expose additional gaps after applying the checklist. Recommendations for further improvements were made based on the comments of the participants.

It is foreseen that the new checklist could be a valuable tool for developing future written health material. Finally, it is recommended that an interdisciplinary team that includes a graphic designer be involvement from the planning stages.

# Opsomming

Beroerte is die tweede mees algemene oorsaak van sterftes wêreldwyd en is een van die elangrikste oorsake van gestremtheid in volwassenes. In Suid-Afrika word beraam dat sestig persent van mense wat 'n beroerte oorleef, hulp met ten minste een aktiwiteit van daaglikse lewe benodig. Hierdie las lê hoofsaaklik op die skouers van onopgeleide versorgers.

Die proses om versorgers te bemagtig om keuses te maak wat voordelig is vir hulle eie sowel as as beroerte pasiënte se gesondheid is veelsydig. Een van die hoekstene van hierdie proses is inligting. In 1995 het die Sentrum vir Rehabilitasiestudies van die Universiteit van Stellenbosch, 'n opleidingspakket begin ontwikkel vir tuisversorging van beroete pasiënte. Die pakket bestaan uit 'n vier-uur lange interaktiewe opleidingswerkswinkel en 'n boekie met praktiese inligting oor beroertes en die versorging van mense wat 'n beroerte gehad het. Die doel van hierdie studie was om die boekie te hersien en te loots vir verdere gebruik saam met die opleiding.

Die studie het bestaande riglyne vir die toepaslikheid van geskrewe materiaal aan ontwikkelende gemeenskappe (gemeet deur middel van Hugo se graderings model), ontoereikend gevind. Gevolglik is 'n nuwe kontrolelys opgestel gebaseer op twintig bestaande lysse. Hierdie kontrolelys sowel as die Toepaslikheids Evaluering van Materiaal (TEM) is gebruik om die boekie te evalueer en voorstelle te maak vir die verbetering daarvan. Ten spyte daarvan dat die nuwe lys nog nie vir geldigheid getoets is nie, het dit ten opsigte van die boekie soortgelyke resultate as die TEM gelewer. Na konsultasie met die outeurs is verbeteringe aan die boekie aangebring.

Die boekie is toe getoets in vier proefsteke van die beoogde lesers. Die funksionele geletterdheid van die deelnemers is getoets met 'n gestandaardiseerde geletterdheidstoets. 'n Vyfde proefsteek het 'n vraelys ingevul oor hulle voorkeure tussen die oorspronklike en die hersiende boekie. Kenners op die gebied van rehabilitasie en grafiese ontwerp het ook kommentaar op die boekie gelewer.

Die studie het die behoefte van beroerte pasiënte en hulle versorgers vir geskrewe gesondheidsinligting bevestig. Die hersiende boekie het geblyk 'n toepaslike hulpmiddel te wees om behoeftes aan te spreek. Die deelnemers het die boekie as

nuttig en verstaanbaar beskryf en die leesbaarheidsvlak het ooreengestem met die getoetsde geletterdheidsvlak van die proefsteke. Daar is egter 'n behoefte aan inligting oor onderwerpe met betrekking tot beroete wat nie tans volledig in die boekie behandel word nie, bv spastisiteit.

Die studie het agetoon dat 'n kontrolelys geruik kanword om geskewe gesondheidsinligting aan te pas by die voorkeure van die beoogde lesers. Addisionle tekortkominge is egter uitgewys deur dit met belanghebbens te toets. Aanbevelings vir verdere verbeteringe is gemaak op grond van die kommentaar van hierdie deelnemers, asook versorging deur 'n taalkundige.

Vir die toekomstige ontwikkeling van geskrewe gesondheidsinligting word voorsien dat die nuwe kontrolelys 'n waardevolle hulpmiddel kan wees. Verder word aanbeveel dat 'n interdisiplinêre span, wat 'n grafiese ontwerper insluit, van die begin af betrokke behoort teweens by die ontwikkeling van sulke materiaal.

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**Jud 1:25 To the only God, our Saviour, through Jesus Christ our Lord, be glory, majesty, dominion, and authority, before all time and now and forever. Amen.**

# Definition of terms

The following terms are used in the study:

## **1. Activities of daily living (ADL)**

Any daily activity performed for self-care (such as feeding, bathing, dressing and grooming), work, homemaking or leisure.<sup>1</sup>

## **2. Caregiver**

A person who provides care to those who need supervision or assistance in illness or disability. The care may be provided in a home, a hospital, or an institution. Although “caregiver” in the first place refers to parents, spouses or other family members, the concept also includes trained medical, nursing, and other health personnel, friends, members of the clergy, teachers, social workers, fellow patients, etc.<sup>2</sup>

## **3. Client**

A person who is receiving the benefits, services, etc., of a social welfare agency, a government bureau, etc.<sup>3</sup> In this study persons who receive services of health care professionals, other than medical treatment in a hospital, are referred to as clients.

## **4. Community Based Rehabilitation**

The strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities, and appropriate health, education and social services.<sup>4</sup>

## **5. Disability**

Disability is an umbrella term for impairment, activity limitation and participation restriction. It denotes the negative aspects of interaction between an individual who has a health condition and that individual’s contextual factors, which are environmental and personal factors.<sup>5</sup>

## **6. Functional literacy**

A functional literacy approach is a method used in education to enable people to read well enough to function in a complex society. It incorporates reading materials that relate directly to community development and to teaching of applicable or useful life skills.<sup>6</sup>

## **7. Health education**

The process related to activities that enable people to make informed decisions affecting their personal, family and community well-being, which has intellectual, psychological, emotional and social dimensions.<sup>7</sup>

## **8. Health literacy**

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use the information in ways that promote and maintain good health.<sup>8</sup>

## **9. Health promotion**

The process of enabling people to increase control over and improve their health. It supports personal and social development through providing information, education for health, and enhancing life skills.<sup>9</sup>

## **10. Layout**

The overall design of a page, spread or book, including elements such as page and type size, typeface, and the arrangement of titles and page numbers.<sup>10</sup>

## **11. Lexical Density**

This refers to the density of information in a portion of text and the average number of content words per clause.<sup>11</sup>

## **12. Patient**

A person receiving medical care or treatment or who is under a physician's care for a particular disease or condition.<sup>12</sup> In this study "patient" is used specifically for persons receiving medical care in a hospital setting.

**13. Rehabilitation**

Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.<sup>13</sup>

**14. Stroke survivors**

Any person who survived a stroke, regardless of the cause of the stroke or the severity of the subsequent disability.<sup>14</sup>

**15. Typeface**

The style or design of a font. Other independent parameters are size, boldness (thickness of lines), and obliqueness.<sup>15</sup>

**16. Readability**

The quality of written language that makes it easy to read and understand.<sup>16</sup>

**17. Visual literacy**

The ability to apprehend and interpret pictures or other visual images.<sup>17</sup>

**18. Written health information**

Written information for non-professionals about conditions, treatments, procedures, examinations, surgery and services. This can be in the form of leaflets, booklets, single pages or posters.<sup>18</sup>

## List of acronyms

ADL	Activities of daily living
AIDS	Acquired Immune Deficiency Syndrome
AfriNEAD	African Network for Evidence-to-Action in Disability
APD	Association of Physical Disabled People
CBR	Community based Rehabilitation
CHC	Community Health Centre
CRS	Centre for Rehabilitation Studies, University of Stellenbosch
CVA	Cerebral vascular accident
gsm	gram per square meter
HAMSOC	Health Education, Appropriate Media and Technology, and Socio-cultural Sensitivity
MASA	Medical Association of South Africa
MMSE	Mini Mental State Examination
NGO	Non-governmental organisation
REALM	Rapid Estimate of Adult Literacy in Medicine
SAM	Suitability Assessment of Material
SASPI	Southern African Stroke Prevention Initiative
SSEAD	Stellenbosch Symposium on Evidence-to-Action in Disability
SMOG	Simple Measurement of Gobbledygook
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organisation

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# Chapter 1

## Introduction

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### 1.1 Introduction

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This chapter is an introduction to the study. It presents the background of the study and the work that preceded it, as well as the subsequent problem statement. The main aim and objectives of the study are stated and the conceptual framework is discussed. The chapter concludes with the significance of the study and a brief overview of the methodology.

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### 1.2 Background of the study

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#### 1.2.1 The burden of stroke

The term “stroke” is derived from the Greek word “apoplexy”, meaning to strike. The Greeks believed that stroke was a blow from the gods and thus first documented the effects of stroke roughly 2,400 years ago in the medical treatises attributed to Hippocrates.<sup>19</sup>

In 1989, the World Health Organisation (WHO) defined a stroke as:

*“a clinical syndrome characterized by rapidly developing clinical symptoms and/or signs of focal and at times global (applied to patients in deep coma and to those with subarachnoid haemorrhage) loss of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no other apparent cause other than that of vascular origin.”<sup>20</sup>*

Stroke is thus a sudden event with an immediate impact. The most common symptoms and/or signs following a stroke are impaired motor function, sensory deficits and abnormal tone (usually affecting only one side of the body) as well as cognitive limitations, speech impairments and depression.

It is the second commonest cause of mortality worldwide and remains a leading cause of adult physical disability.<sup>21</sup> Developments in stroke care over the past two decades,

particularly in acute management as well as in rehabilitation and long-term care, have greatly reduced mortality and dependence in many developed countries. By contrast, there has been limited progress in the management of patients with stroke in developing countries, despite increasing incidence of stroke and high stroke mortality rates that account for over two-thirds of stroke deaths worldwide.<sup>22</sup>

In developed countries approximately 30% of stroke patients die within the first 3 weeks, and up to 30% of survivors are permanently disabled.<sup>23,24,25</sup> Evidence in sub-Saharan Africa indicates that case fatality rates for stroke can be higher than those in industrialised societies. Furthermore, stroke affects younger people in developing nations - possibly 10 to 15 years earlier compared to developed countries.<sup>24</sup> Although the reasons for this are still unclear, it is postulated that different ethiological causes might play a role.

Hence, stroke places a huge burden on society in terms of premature death, disability, and cost of care. The estimated direct and indirect cost of Cardio Vascular Disease in the United States for 2007 is \$431.8 billion.<sup>26</sup> In 2002, costs after hospital discharge for stroke patients were estimated to amount to 2.9 billion euros in France.<sup>27</sup> Clearly, even a fraction of such amounts could cause enormous economic damage to low-income countries.

Although many of the advances associated with reduced stroke mortality and morbidity would be equally applicable to developing countries, differences in types and causes of stroke, limitations posed by geography, accessibility of health care, availability of resources, social beliefs, and cultural expectations need to be taken into account when extrapolating stroke-management strategies from the developed to developing countries.<sup>23</sup>

### **1.2.2 Management of stroke survivors in the Western Cape**

In South Africa, the public health sector is under pressure to deliver services to about 80% of the population.<sup>28</sup> The Western Cape Department of Health, in accordance with the strategy of the National Department of Health, has adopted an approach of Primary Health Care whereby they aim to have 90% of health contacts at primary level and District Hospitals; 8% of contacts at the level of Regional Hospitals; and 2% at the level of Central or Academic Teaching Hospitals.<sup>29</sup>

In practice this means that persons who have had an uncomplicated stroke are not necessarily admitted to hospital. The criteria for admission and discharge for those admitted to a hospital are mostly based on medical stability and therefore most of the time determined by the attending medical doctor.

Rehabilitation services take place at all three levels of care.<sup>a</sup> The comprehensiveness of these programmes is often dependant on the availability of therapists, the therapist's interests or specific programme drivers like universities or Non Governmental Organisations (NGO's). Newly developed stroke units exist at the two tertiary hospitals and there is one inpatient rehabilitation hospital – the Western Cape Rehabilitation Centre (WCRC). Referral to these services also mostly depends on the decision of the attending doctor during the acute presentation of the stroke. Furthermore, due to inaccessible public transport and the long waiting list for mobility assistive devices<sup>b</sup>, attending services, even in the community, is extremely difficult.

This results in two major challenges:

1. Stroke survivors are often discharged from hospital without receiving any rehabilitation or assistive devices. This predisposes to the development of preventable complications such as pressure sores and contractures. Not only does this affect their quality of life but can lead to premature death.<sup>31</sup> Stroke survivors in the Cape Town Metropole were found to engage in health risk behaviours such as physical inactivity, substance usage, non-compliance to medication use and inappropriate diet modification. Lack of financial resources, facilities and access to information predisposes them to involvement in these risky health behaviours. In addition, they are vulnerable to emotional disorders due to low psycho-social status and self-perception, which adversely increases their involvement in substance usage.<sup>32</sup>

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<sup>a</sup> Primary, secondary and tertiary health care operate on a coordinated referral system. The primary level is the first contact with the health care services (usually at community clinics or health centres). Secondary care is delivered at the first level of referral after the primary contact (usually the community or district hospital). Tertiary care is provided at the second level of referral (usually an academic hospital).<sup>30</sup>

<sup>b</sup> Mobility assistive devices are devices needed for safe and functional mobility in the home and community. It includes wheelchairs, crutches and walking frames.

2. It is estimated that sixty percent of stroke survivors in South Africa require assistance with at least one activity of daily living.<sup>33</sup> With only about 2% of stroke survivors in the Metropole living in old age homes, this burden is lying on the shoulders of mostly untrained family members and caregivers. According to international studies, caregivers are at risk for not only physical injury but also burn out and subsequent psychological impairments. They can often not return to work without compromising the health and safety of the person they are caring for. These factors thus lead to dual impairment.

The needs of caregivers of stroke survivors are complex and multilayered. On the forefront of these needs is the need for practical “how to do” information.

### **1.2.3 Preliminary work**

In the early 1990's the Centre for Rehabilitation Studies of the University of Stellenbosch (CRS), with its clinical site at Karl Bremer Hospital, became aware of the need for information among its clients. It was especially prominent in peri-urban areas and informal settlements, where health and other support services were still very limited. Stroke survivors as well as their caregivers described difficulties with self care activities (e.g. dressing, grooming and transfers) as a priority. Improper and inappropriate execution of these activities often led to preventable complications.

In 1995, the CRS defined a goal to address the functional management of common problems experienced by stroke survivors by training either their family members, caregivers or community based carers. They applied for funding of the project at the Reconstruction and Development Programme of Portnet. Portnet has since been integrated into the National Port Authorities of South Africa.

The training package that was developed was based on the theory that adult learning should be interactive with opportunities to apply new knowledge.<sup>34</sup> The training takes the form of a four-hour interactive workshop and the provision of a booklet. The workshop consists of a lecture with a slide presentation and a practical session. The aim is to show participants the optimal way to assist stroke survivors with their activities of daily living. Complications that may occur with incorrect assistance are also discussed. Afterwards, the participants get the opportunity to practise the new skills on each other under the supervision of a professional facilitator. Over a period

of 10 years, the training package has been refined and modified, according to needs expressed and feedback received from both trainees and stroke survivors. Because of the great need for this training, therapists of the Western Cape Rehabilitation Centre (WCRC)<sup>c</sup> started to use the slides and sections of the booklet as it became available. Training was done in institutions of caring, in old-age homes and as part of courses for continuous professional nursing development.

The booklet that trainees receive is to be a reference tool concerning the skills transferred during the workshop and is not intended to replace the training. Although it contains a small amount of theory on the causes and consequences of stroke, it is predominantly practical information and instructions for the most common activities of daily living under the following headings:

- Communication;
- Cognitive (“thinking & reasoning”) & behavioural problems;
- Positioning;
- Feeding, swallowing & dental care;
- Shoulder Care;
- Bed Mobility;
- Transfers;
- Self Care;
- Assisted gait; and
- Typical complications.

The bulk of the booklet consists of line drawings that give step-by-step instructions with limited explanatory text. It is written in English with the intention to be translated into both other official languages of the Western Cape (Afrikaans and isiXhosa).

The booklet is presently in its final stage of development, but requires evaluation before further implementation. As soon as the booklet is available, the training module can be formally structured and evaluated. Trainers will need to be trained, who will then in turn attend to the training of caregivers at grassroots level.

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<sup>c</sup> The Karl Bremer clinical site of the CRS merged with the Conradie Rehabilitation unit in 2003 to form the WCRC

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## 1.3 Problem statement

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The aim of educating stroke survivors and their caregivers is to inform, reduce anxiety, change behaviour, empower individuals, and thereby prevent illness progression, complications or unnecessary impairments.<sup>35</sup> American laypersons and professional caregivers described vivid negative images of stroke that were based on past experiences. Negative emotions such as fear, shame, avoidance, and desire for control were also described.<sup>36</sup> These findings support the need to further educate both professional and lay people about stroke risk factors, symptoms, treatment, and prognosis. The development of a training package for caregivers is a multifaceted process. No single training method on its own can be effective to achieve this goal.

To ensure a final product that fulfils what was set out to achieve, continual evaluation and feedback would be necessary. Although the training package is intended to be used as a whole, each individual part has to be evaluated and refined separately before the parts can be implemented jointly. This model of re-evaluation is an important consideration since “one size fits all” information is almost never effective. In an example from the field of HIV/AIDS education Wellings stated:

*“Blanket messages aimed at a homogenous at-risk population will be inappropriate because, for the purpose of preventing Aids, such a population does not exist”.*<sup>37</sup>

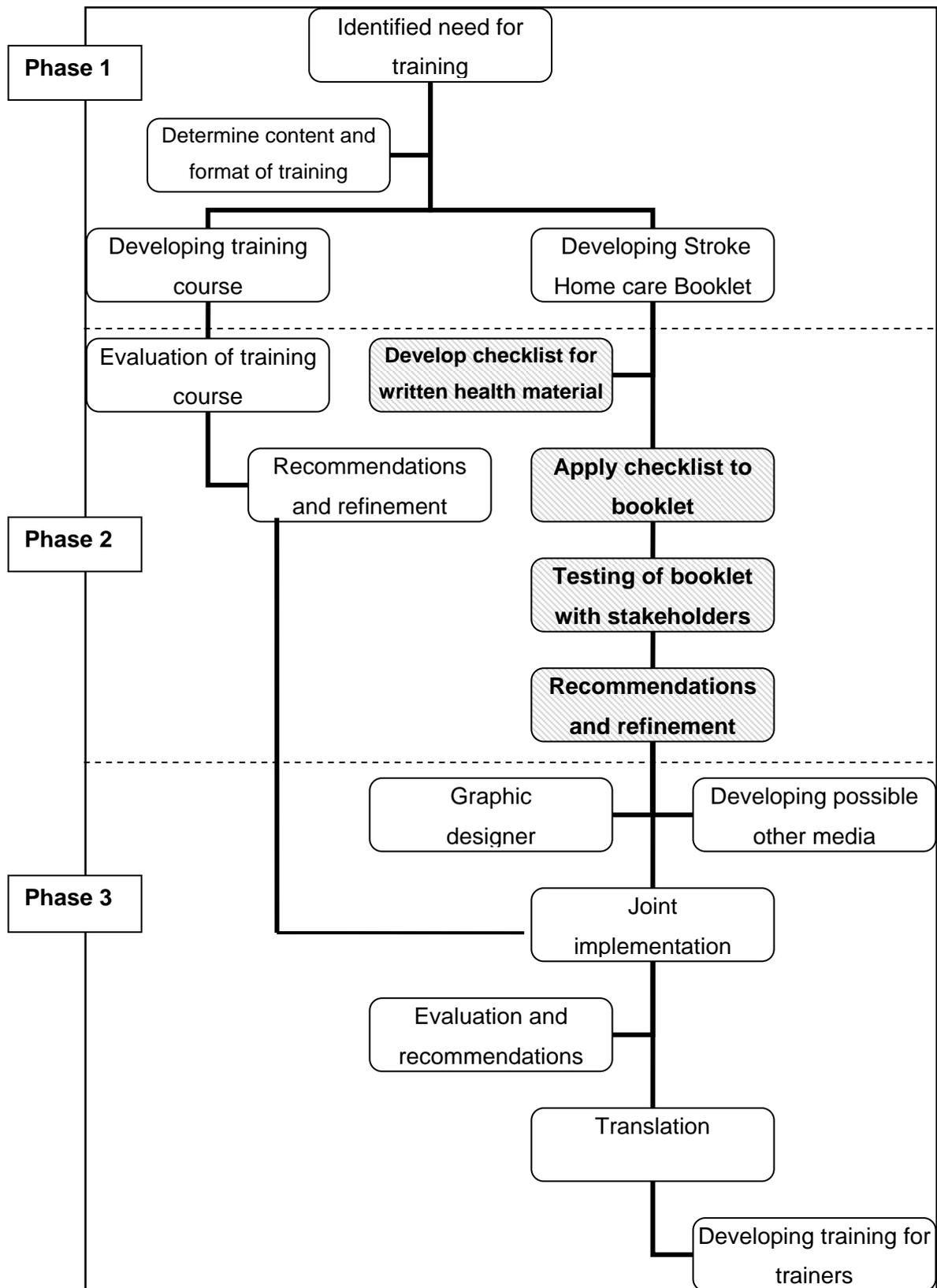
This comment could not be truer of a condition like stroke. Hoffman and McKenna<sup>38</sup> accentuate this by stating that health professionals should give stroke patients and their caregivers information tailored by their expressed needs.

Clinicians in the field of rehabilitation wrote a booklet based on the problems and needs they identified in working with stroke survivors and their caregivers. Although great care was taken to ensure the technical correctness of the information and the drawings, the authors had little experience in the field of evaluating written health information for low literacy readers.

Numerous checklists and guidelines exist to evaluate different aspects of written health information. Unfortunately, very few of these are custom fit for developing communities. Even before making recommendations regarding the refinement of the booklet, there is thus a need to develop a checklist for the evaluation of written information for developing communities.

Furthermore, the information is primarily aimed at caregivers with basic reading skills, but with no or little medical background. The health literacy of these caregivers has however not been tested, making it very difficult to determine the optimal level of readability for the material. It follows that the health literacy of the proposed users should first be measured to make meaningful recommendations regarding the factors that impact on readability.

Once recommendations regarding readability and other issues that influence written health material have been made and implemented, the booklet needs to be tested with different samples of stakeholders. This forms part of tailoring the total training package. Figure 1-1 gives an overview of this process. Phase one was done by the staff of Karl Bremer hospital. Phase two will be directed by the CRS and phase 3 will be a joint effort between the CRS and the Provincial Department of Health. The coloured spaces highlight the contribution this study will make to the overall project.



**Figure 1-1: Outline of project process**

The shaded areas represent the stages of this study's contribution.

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## **1.4 Aim**

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The aim of the study was to refine and pilot a training booklet for caregivers of stroke survivors for further implementation.

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## **1.5 Objectives of the study**

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The objectives of the study were to:

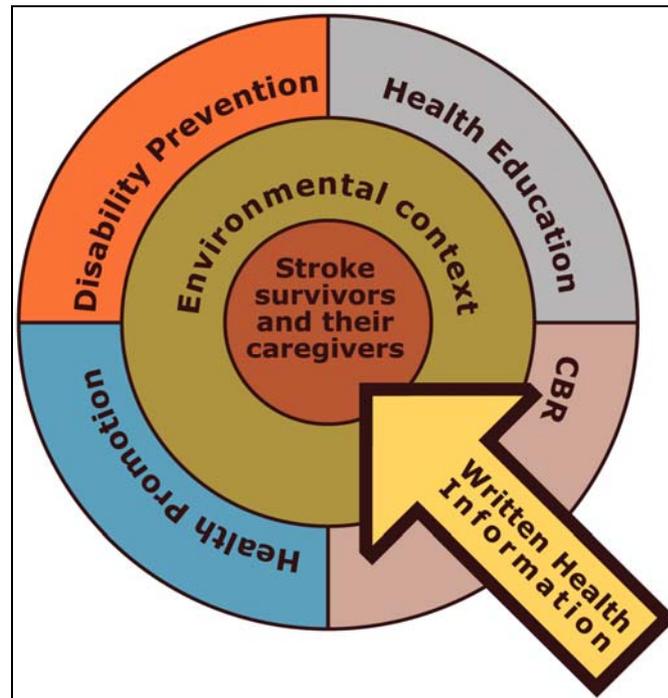
1. Review literature and evaluate existing tools to guide the researcher in the development of the research tool.
2. Assess the appropriateness of the booklet using the Suitability Assessment of Material as well as the new research tool.
3. Evaluate the literacy level of the target audience
4. Examine the target audience's perception regarding the comprehensibility and appropriateness of the refined version of the booklet
5. Explore the opinion of discipline specific professionals regarding the booklet
6. Make recommendations regarding further steps to the implementation of the booklet.

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## **1.6 Conceptual framework**

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This study aims to tailor written health information for a target audience of stroke survivors and their caregivers. This target audience functions within the context of the prevailing circumstances in South Africa, including its health system. In turn, this environmental context is influenced by the development in several health related disciplines. With regard to this study, four of these disciplines are in the forefront: Community Based Rehabilitation (CBR), Health Promotion, Disability Prevention and Health Education. In Figure 1-2 the arrow illustrates the written information aimed at the target – the stroke survivors and their caregivers within their environmental context. This context is influenced by development and research within health related disciplines.



**Figure 1-2: The study's target audience**

**CBR** is the strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities, as well as the appropriate health, education and social services. One of the principles of CBR is that knowledge and skills for the basic training of disabled people are transferred to disabled adults themselves, to their families and to community members.<sup>4</sup> The development of a booklet for Stroke Home Care is thus a step in this direction. This transfer of skills and knowledge will lead to the empowerment and subsequent participation of people with disabilities in issues surrounding their health. This pillar of CBR intersects with the Ottawa Charter's<sup>9</sup> discussion of Health Promotion.

According to this Charter, **Health Promotion** is the process of enabling people to increase control over, and to improve, their health. It supports personal and social development through providing information, education for health, and enhancing life skills. By so doing, it increases the options available to people to exercise more control over their own health and environment, and to make choices conducive to health.

The 2005 Bangkok Charter of Health Promotion<sup>39</sup> recommitted the WHO's members to health promotion. It also specifically names the increasing marginalisation of people with disabilities as a growing challenge.

People with disabilities have on average a narrower margin of health and, therefore, represent significant health needs. It is of great importance that health promotion encompasses a wide variety of overlapping and interlinking initiatives in order to maintain and enhance existing levels of health and well-being for people with disabilities.<sup>40</sup>

Promoting health by training caregivers also has implications for the field of **Disability Prevention**. According to the World Health Organisation, primary, secondary and tertiary prevention must be attended to.<sup>41</sup> Training the caregivers of stroke survivors includes primary, secondary and tertiary prevention of disabilities. Primary prevention entails minimising injuries that lead to disability. An example of this is correct transfer techniques, which can prevent low back injury of the caregiver and falling of the patient.

Secondary prevention prevents the development of other or more impairments in the stroke survivors. Most stroke survivors have a compromised vascular system due to diseases like hypertension or diabetes. Further strokes or cardiovascular incidents (e.g. Myocardial infarction) can be prevented or limited by correct treatment. Secondary complications like pressure sores and contractions can also largely be prevented. Caregivers play an important role in administering or reminding stroke survivors about treatments and preventing complications.

Tertiary prevention limits or reduces the stroke survivor's impairment, activity limitation and participation restriction. The caregiver helps in this process by giving the correct form and amount of assistance.<sup>41,42</sup>

The main methodological strategy to generate the changes proposed by Disability Prevention, CBR and Health Promotion, is education. **Health Education** is the process related to activities that enable people to make informed decisions affecting their personal, family and community well-being, which has intellectual, psychological, emotional; and social dimensions.<sup>43</sup> While Health Promotion is viewed as the broad process, Health Education entails the action of educating.<sup>7</sup> This discipline is focused

on best methods, tools and techniques to reach a specific target group. Although this is clearly wider than written health material, the development of appropriate written health material forms part of health education and communication. To determine appropriateness, issues related to literacy become of utmost importance. This includes fields like functional literacy, visual literacy and health literacy.

It is evident why the National Rehabilitation Policy<sup>44</sup> embraces all four these fields as part of the strategy to improve quality of life of disabled people. According to this policy, a situational analysis conducted in 1997, confirmed that rehabilitation services in South Africa are largely underdeveloped. Although advances have been made to establish mechanisms to extend these services to the majority of the population, such services are still inaccessible for many disabled persons. Since the rehabilitation services rendered to stroke survivors will often be limited to the care provided by their caregivers, it follows that the training of these caregivers should receive priority attention.

The researcher, who is a general practitioner, was first confronted with this challenge while working in an acute hospital in the public sector. Because of the shortage of beds for patients in hospitals, persons who suffered a stroke were sent home as soon as they were medically stable. This meant that many such persons were not even admitted to hospital. Those who were admitted, received mainly medical treatment with minimal input from therapists. On discharge they were advised to make an appointment at a therapist working in the nearest Community Health Centre. With the inaccessible public transport and the long waiting list for mobility assistive devices, it was almost impossible for many patients to attend such appointments.

Later, working at the Karl Bremer site of the CRS, a dedicated rehabilitation unit, the researcher saw many preventable complications in stroke survivors whose caregivers received little or no training. This was not only true of clients cared for at home, but also those coming from institutions of caring, e.g. old age homes.

The process of enabling caregivers to make choices conducive to their own health as well as the health of the stroke survivors is multidimensional. One of the cornerstones of this process is the provision of information. The Health Promotion in Developing Countries: A Call for Action<sup>45</sup> lists appropriate learning material as one the strategies that is an essential tool for community health promotion.

Various studies have highlighted the inadequacies of education provided to stroke survivors and their caregivers<sup>46,47</sup> Although different methods are used, written material is used most commonly. All of these materials are written with good intentions but trials to evaluate their effectiveness are limited and have inadequate statistical weight.<sup>47</sup> These facts challenged the researcher to critically evaluate the booklet being developed.

Part of the challenge to evaluate the effectiveness of written material is the multitude of factors that influence it. Studies often focus on one of these factors or on a loose combination of factors. Few models are described that demonstrate the relationship between different factors and even less that focus on the needs of developing communities. A model that incorporates both these aspects is the HAMSOC model created by Hugo<sup>37</sup> for appropriate health education messages in developing communities. This model is based on the interaction between three cornerstones: Health Education, Appropriate Media and Technology and Socio-cultural Sensitivity (HAMSOC is an acronym for these three cornerstones). This study will use the HAMSOC model as a framework for the evaluation of written health information.

The conceptual framework for this study is built on the notion that caregivers of stroke survivors need training. This training must adhere to the principles of Health Promotion within the context of CBR. It must be underpinned by strategies of Disability Prevention and comply with models of best practice within Health Education. Such training must include the provision of appropriate written health information.

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## **1.7 Significance of the study**

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The evaluation of written health information is receiving increased attention in literature. Despite this, very little is published on the development of this field in developing communities. Even though multiple checklists and guidelines already exist, no study has been identified comparing different lists or measuring the appropriateness and comprehensiveness of these lists. This particular study is a step in this process.

Although the checklist developed for the evaluation of written health material for readers with a functional literacy needs to be validated, it might be a useful tool for future evaluation of such material. It is a first checklist that measures the

appropriateness of written health material in terms of health education, media and technology and cultural sensitivity relative to each other. These measurements will give an indication of the appropriateness of material for target audiences in developing communities.

Rehabilitation professionals often use written health information to inform clients. Yet they are in general not trained to develop or evaluate such material. Existing lists that are not comprehensive and have limited detail can give a false sense of appropriateness of material to these professionals. The new checklist is proposed to be a useful, comprehensive guideline for them.

The most immediate significance of the study will be the recommendations made to refine the booklet. It is already more than ten years since the initial need for such a tool has been identified. Although trainers of the WCRC have already used parts of the booklet for training, there is an urgency for a final product that is not only has a professional appearance but is also appropriate for the target audience. After the implementation of these recommendations, it can then be further implemented as part of the complete training package.

Ensuring and improving the appropriateness of the booklet will allow for better trained caregivers. This will ultimately alleviate the lack of capacity in rehabilitation services for stroke survivors. Better trained caregivers will reduce complications in stroke survivors and should also benefit caregivers to suffer less frustration and burnout. <sup>48</sup>

This study will focus on the needs of the caregivers that the project initially set out to serve – caregivers in informal settlements and peri-urban areas surrounding Cape Town. However, it is proposed that due to the practical nature of the booklet, stakeholders in different socio-economic circumstances may find it useful with little or no adaptations. It is also foreseen that the booklet could be a useful tool in the academic training of several undergraduate courses, including the medical curriculum.

Finally, the health literacy tests that will be conducted will give an indication of the relationship between reported years of formal education and actual literacy. Although the sample sizes are small, it will serve as a guideline towards the optimal readability level of health related written information for this study population.

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## 1.8 Outline of the study process

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This study was conducted in four stages:

### **Stage 1**

In this stage, existing checklists for the assessment of written material were evaluated. Subsequently, a new checklist was compiled based on the principles of the HAMSOC model.

### **Stage 2**

Secondly, the booklet on stroke home care was tested against the new checklist as well as one standardised measurement instrument. The limitations and shortcomings identified by this evaluation were reformulated into recommendations to refine the booklet. After consultation with the authors, the relevant changes were implemented.

### **Stage 3**

The booklet was then piloted with a sample of the target audience. They gave feedback in focus group discussions to determine the booklet's perceived usefulness and understandability. The literacy levels of the group's participants were also measured to determine the optimal readability level for the booklet. In addition, expert opinions were obtained on various aspects of the booklet.

### **Stage 4**

Finally, the results of the focus group discussion and the experts' opinions were used to formulate recommendations for further tailoring of the booklet and steps for its implementation.

The nature of the study was developmental with repeated feedback, refinement and evaluation of the booklet.

The study will be discussed in detail in the following chapters:

- In Chapter 2 there is a literature review on issues pertaining to the study. International and national policies related to the study will be reviewed. The needs of stroke survivors and their caregivers will be discussed with emphasis on information needs. Literacy and its different aspects will be evaluated as well as measuring the suitability of written health material. Since one of the objectives of the study is to develop a checklist for evaluating written material using information

from existing lists, the detailed discussion of these lists will only follow in Chapter 4. Chapter 2 will conclude with an exploration of the cornerstones of the model (HAMSOC) that was chosen for this study.

- Chapter 3 is a discussion of the study methodology including the research design.
- Chapter 4 is dedicated to development of the new research tool. The evaluation of existing checklists and the subsequent newly developed checklist is presented and discussed.
- The results of the different data collected for the research are provided in Chapter 4.
- Chapter 5 will discuss the results and draw conclusions within the framework of the study objectives. This will include the discussion of the factors to consider when evaluating written material that was used in compiling the new checklist.
- In Chapter 6 the researcher will make some recommendations based on the conclusions of the study.

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## 1.9 Chapter summary

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In this chapter an introduction to the study was given. As background the burden of stroke in South Africa has been outlined and the preliminary process of the development of a training package for caregivers of stroke survivors has been described. Existing training packages are limited and mostly inappropriate for the needs of the majority of South Africans. The need exists for a training package customised to the particular circumstances prevailing in South Africa. The development of such a package should adhere to the principles of CBR, Health Promotion, Disability Prevention and Health Education.

This process included the writing of an instructional booklet on stroke home care. The booklet now has to be evaluated by different measures in order to make recommendations regarding its appropriateness. Since most existing measurements are not focused on the needs of persons in culturally diverse communities, a new checklist based on the HAMSOC model will be developed. This checklist will be used to expose gaps in the booklet.

After an initial refinement, the booklet will be piloted with the target audience. This will include the measurement of the health literacy levels of proposed users to determine the optimal level of readability of the booklet.

The aim of the study is to make recommendations to refine this booklet for further implementation.

The significance of the study is the provision of a more appropriate booklet that will contribute to the relief of the burden of care of caregivers. It is envisaged that the checklist for the evaluation of written material within developing communities, will be a useful tool for future use in the field of rehabilitation.

The study will be described in six chapters and an outline of the chapters was presented.

# Chapter 2

## Literature Review

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### 2.1 Introduction

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Chapter 2 is a literature review of the underlying premises of this study.

Since very few peer reviewed and published studies are available focussing specifically on the Western Cape or the Metropole, literature on the epidemiology and the available resources for stroke treatment in South Africa is considered. This is followed by a discussion of literature concerning the current issues in the four disciplines that, with regard to this study, influence the environmental context i.e. community based rehabilitation, disability prevention, health promotion and health education.<sup>a</sup>

The discussion of these factors will lay the foundation for describing the appropriate tailoring of information for the target audience. Understanding the information needs of an audience is another crucial aspect of this process and is consequently explored. Furthermore, to address these information needs concepts surrounding literacy, including its measurement, must be explored. For the purpose of this study, the emphasis will be on health literacy, functional literacy and visual literacy as well as the level of literacy in South Africa.

The discussion of literacy raises questions about the appropriateness of written health material which will thus be reviewed. The challenges of assessing the appropriateness of such material, as well as a brief discussion of the available resources, are then presented. This will lead to the motivation of using the HAMSOC model. The model will be explained and literature concerning each of its cornerstones explored.

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<sup>a</sup>Health education, also being one of the cornerstones of the model chosen for evaluation of written health information, will be explored under the discussion of the model in paragraph 2.11.1.

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## 2.2 Stroke in South Africa

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Stroke is the most important cause of death and disability for people over 50 years of age in South Africa.<sup>49</sup> According to the Southern African Stroke Prevention Initiative (SASPI), who studied 42 378 people age >15 years in Limpopo Province, the crude prevalence of stroke is 300 per 100 000. This is two or three times lower than in developed countries. Unfortunately, without community-based incidence studies with follow-up, determining whether the low prevalence results from low incidence or high case fatality or both is impossible.<sup>51</sup>

In South Africa two-thirds of stroke survivors needed help with at least one activity of daily living.<sup>33</sup> This is in contrast with more developed countries, where only a fifth of stroke survivors were reported to be dependent on help.<sup>50</sup> SASPI concluded that the prevalence of disability after stroke in rural South Africa is similar to that of more affluent countries, despite the prevalence of stroke itself being lower.<sup>33</sup>

This tendency was also observed by Connor *et al*'s systematic review on the prevalence of stroke in sub-Saharan Africa.<sup>51</sup> They concluded that the prevalence is less than half that found in high-income regions, but disabling stroke prevalence may be at least as high as in high-income areas.

Another important difference between developed and developing countries is that stroke affects younger people in developing nations, possibly 10 to 15 years earlier than in developed countries.<sup>22</sup> Although the reason for this is still poorly understood it is thought to be related to the fact that cerebral haemorrhage is much more common in developing countries and cerebral infarction more common in developed countries.<sup>24</sup> Compared to cerebral infarction, cerebral haemorrhage is associated with a higher risk of fatality and greater impairment at admission, but better functional gain during recovery and rehabilitation.<sup>52,53</sup> Not only does this affect the years of potential life lost from stroke, but it also has significant socio-economic consequences.<sup>22</sup>

Stroke in sub-Saharan Africa is probably entering a health transition and if the risk factors increase, so the burden of stroke will increase unless interventions are set in place.<sup>51</sup> This epidemiological transition is likely a result of rapid urbanisation and industrialisation. Many developing regions are exhibiting increased life expectancy,

as well as changes in diet and other risk behaviours, such as smoking. This is contributing to a looming epidemic of stroke in sub-Saharan Africa.<sup>54</sup>

It follows that although issues like prevention of stroke, early diagnosis and acute management of stroke are of great importance, rehabilitation services should be a priority. There are many studies advocating the benefits of multidisciplinary rehabilitation in dedicated stroke units. They report improved activities of daily living (ADL) and gait, shorter hospital stay and faster rate of discharge to home.<sup>31,55,56,57,58</sup> A systematic review demonstrated that organised inpatient multidisciplinary rehabilitation in the post acute period could result in substantial benefit with lower risk of death, institutionalisation and dependency.<sup>59</sup> Despite this fact, it is estimated that only about 10-20% of the South African population has access to stroke units and stroke rehabilitation.<sup>49</sup>

Some studies have indicated that home-based rehabilitation for stroke can have similar functional outcomes to inpatient neuro-rehabilitation,<sup>60</sup> and that it is likely to be less costly and possibly more appropriate in developing countries. Yet, even at a primary level from which such services should be rendered, the services in South Africa are very limited. Misbach<sup>61</sup> described the rehabilitation services at Community Health Centres (CHC) in the Cape Town Metropole in 2004. Only 35% of the CHCs have a therapy service available, while an even smaller proportion (14%) have a combined occupational therapy and physiotherapy service. Only 27% of the CHCs have a daily service. The limited access is directly related to the poor availability of rehabilitation staff as seen in the population to therapist ratio of 1: 139 189, in contrast to the long-term policy ratio of 1: 30 000. She concluded that access to rehabilitation services at Primary Health Care level remains a problem.

Green *et al*<sup>62</sup> conducted a comparative study investigating the differences in stroke rehabilitation between Australia, Finland and South Africa. Even though the data for South Africa (995 episodes from 23 hospitals) came only from the private sector, it showed significant differences to the other countries. In the other countries rehabilitation is started immediately after the acute treatment, whereas in South Africa, there is often a long interval between the acute admission and the rehabilitation admission. South African patients were admitted and discharged with much lower functional status and were mostly discharged to live with family or friends. This is confirmed by a study of stroke survivors attending CHCs, reporting that 69,1%

lived in their own or a rented house, 28,5% with family and only 2% in an old age home.<sup>32</sup>

Patients discharged with a lower functional status will require more assistance. Where in the other countries assistance is more likely to be given by professional staff in institutions, this burden is mostly on the family and friends of South Africans. In addition, the interval between the acute and the rehabilitation admission is also a gap that has to be filled by these caregivers. The mostly untrained and unsupported caregivers of stroke survivors are thus burdened with a task that is often beyond what they anticipated and agreed to. All of these findings reflect a higher burden of care and accentuate the need for information on stroke care at home.

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## 2.3 The burden of caregiving

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Caregivers for people who have survived a stroke are required to cope instantly with the sudden change in the stroke survivor's mobility, communication skills, moods, and personality.<sup>63,64</sup> This burden of care can be excessive and can have an impact on carers' health and well-being, placing them at risk of burnout.<sup>65,66,67</sup> Several studies have been conducted to describe and categorise the needs of caregivers. The golden thread through all these studies is the need for information and psychosocial support.<sup>63,67,68,69,70</sup>

Unfortunately, very little information is available regarding the needs of caregivers from developing countries, especially in Africa. A comparative study from Nigeria found that stroke caregivers had significantly higher anxiety and depression scores. They also had significantly lower mean scores on the four Quality of Life domains measured (physical health, psychological health, social relationships and environment).<sup>71</sup>

Anxiety and depression are common among stroke survivors and their caregivers and are determinants for the burden of care. Thorogood, McCullagh *et al*<sup>72</sup> concluded that social services support or interventions aimed at the emotional support of caregivers have little effect on reducing this burden. Even so, "hands on" training in the day - to - day management of stroke survivors was associated with lower anxiety and burden of care levels. This emphasises the appropriateness of the training package developed by the CRS and the WCRC as presented in Figure 1-1 (page 8). It also suggests that

shifting the current rehabilitation philosophy from a patient-centred approach to a patient- and caregiver-centred approach will empower caregivers and may have better long-term outcomes.<sup>73,74</sup>

Such an approach is less likely to evolve from a medical model or hospital based service than from a community driven approach. An approach that is born off and driven by the community will be more prone to be patient- and caregiver-centred. Community Based Rehabilitation (CBR) is the community development strategy with such an approach. Since one of the principles of CBR is that knowledge and skills are transferred to disabled persons, their families and to community members,<sup>4</sup> this strategy can significantly reduce caregivers' burden of care.

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## 2.4 Community Based Rehabilitation (CBR)

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The National Rehabilitation policy has adopted the strategy of CBR. It describes CBR as an **approach** to delivering service and not the service itself. It is therefore applicable to all levels of service. According to the policy "It is not 'what' we do, but 'how' we do it."<sup>44</sup>

The implication of this definition is however not evident in the National Guideline on Stroke Management,<sup>75</sup> which chooses rather to focus on the "what" instead of the "how". It seems to regard CBR as a mere alternative to institution based rehabilitation and outreach services. The Guideline states that stroke rehabilitation "may continue at a community level". This implies that rehabilitation cannot be comprehensively done in the community and secondly, that community involvement is not imperative.

There are also discrepancies between the Department of Health's Stroke Guidelines and the Guidelines on Stroke Management of the South African Medical Association (SAMA) - Neurological Association of South Africa Stroke Working Group.<sup>76</sup> SAMA proposes that persons who suffered a moderate stroke should receive institution based rehabilitation and that mild and severe strokes be managed in the community. The rationale is that impairments following a mild stroke probably need fewer interventions in order for the person to have optimal function. After a severe stroke, therapy would rather focus on management strategies at home. Persons who suffered a moderate stroke are proposed to benefit most from intensive therapy by a full interdisciplinary team. In contrast the Stroke Guidelines of the Department of

Health, state that persons with moderate and **severe** stroke should receive more intensive, multi disciplinary rehabilitation.<sup>75</sup>

A study of rehabilitation in the private sector in South Africa, found that the worst affected and younger patients were more likely to receive in-patient rehabilitation.<sup>62</sup> This reflects a tendency, although the findings might differ if the majority of South Africans, who do not have access to private medical insurance, were also to be taken in account.

Although comprehensive research on this is still needed, the impression is that the contradiction between policies and guidelines in South Africa is at least partly responsible for the uncoordinated approach to stroke rehabilitation.

This apparent contradiction between what the WHO defines as CBR and rehabilitation that takes place in the community or at home, is not a problem unique to South Africa. Hale<sup>77</sup> reviewed several studies on home based rehabilitation and concluded that none of them truly investigated community based stroke rehabilitation. In the studies investigating “home-based” rehabilitation, it would appear that these rehabilitation services have been driven by the health providers with little consultation or involvement of the community in the decision making process regarding the preferred service and its implementation.

A review of all types of home based stroke rehabilitation, concluded that home-based stroke rehabilitation *per se* appears to improve independence in personal activities and extended daily living activities, and also minimises the chances of deterioration or death.<sup>78</sup> Alas, Chatterjee<sup>79</sup> points out that just because a service is community-based, it does not necessarily mean it is “community driven”. Active partnerships of people with stroke, their advocates and service providers - true to the ideology of CBR - may result in even better outcomes.<sup>77</sup>

Furthermore, a service that is only delivered in the community is more likely to be focused on existing disabilities, whereas true CBR is also concerned with disability prevention.<sup>80</sup> Since stroke is a highly preventable cause of disability and suitable management of stroke can prevent disability on several levels, it is clear that a comprehensive CBR strategy for stroke management should include disability prevention efforts.

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## 2.5 Disability prevention

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Disability resulting from stroke can be prevented at a primary, secondary and tertiary level.

At a primary level, stroke along with its subsequent disability is highly preventable. The goal of stroke prevention strategies is to identify high-risk clients through the presence of modifiable and nonmodifiable risk factors and to target these modifiable risk factors through the use of appropriate pharmacologic and nonpharmacologic interventions.<sup>81</sup> Some risk factors, such as smoking, can be eliminated; others, such as hypertension and carotid artery stenosis, can be controlled or treated to reduce the risk of stroke.<sup>19,82</sup> Most of these strategies are also applicable for secondary prevention – i.e. preventing recurrence of stroke.

Hypertension is the most consistent and powerful predictor of stroke and is causally involved in nearly 70% of all stroke cases.<sup>24</sup> This is also evident in a study from Limpopo, South Africa, where 71% of persons who had a stroke, were diagnosed with hypertension. Yet only 8% of these persons were taking anti-hypertensive treatment.<sup>83</sup> A study of risk factors for stroke among patients of general practitioners in South Africa found that 55% had hypertension. Alarming, only 47% of those taking hypertensive treatment, had a controlled blood pressure.<sup>84</sup>

Implementation of effective primary and secondary prevention strategies is likely to have an enormous benefit in reducing the burden of stroke, particularly in developing regions.<sup>24</sup> In South Africa, numerous policies and guidelines already exist,<sup>75,85,86</sup> but there still seems to be a gap between policy and implementation. Thorogood<sup>83</sup> identified barriers to this implementation that included cost of treatment, reluctance to use pills, difficulties with access to drugs, and lack of equipment to measure blood pressure. Training caregivers regarding the importance of hypertension treatment, where and how to access drugs and how to administer them, can thus play a significant role in preventing stroke.

Tertiary prevention of stroke is done by preventing further disability after the stroke occurred. Since disability is defined by not only the impairment, but also the activity limitation and participation restriction,<sup>5</sup> preventive strategies should also be balanced between participation and safety.

Falls are a common complication following stroke. Incidences of 51%<sup>87</sup> and 40%<sup>88</sup> are reported among strokes survivors in the community. However, by only focusing on preventing falls, and subsequently restricting their participation, persons can actually be further disabled. Activity limitation and restricted participation were found to be significant predictors of dissatisfaction with life in stroke survivors dwelling in the community, one-year post onset.<sup>89</sup> A study of Russian women who had a mild stroke revealed that one of the factors that limited their participation in ADL was overprotection from relatives.<sup>90</sup>

Identifying clients with a high risk to fall<sup>87,88,91</sup> can be a useful step in preventing overprotection. The National Guideline on the Prevention of Falls of Older Persons<sup>92</sup> is a step in this direction, even though it does not focus on persons who had a stroke. It follows that the training of caregivers to assist stroke survivors to participate safely in activities must be part of the disability prevention strategy. The training of caregivers will also prevent caregivers' disability due to incorrect transfers and assistance.

By providing information that supports personal and social development, disability is prevented. Health is thus promoted by enabling people to exercise more control over their own health and make choices conducive to health. According to the WHO's definition, this falls in the category of health promotion.<sup>8</sup> This intersection of the fields of disability prevention and health promotion is essential in guiding the development of written health information such as the booklet on stroke home care.

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## 2.6 Health promotion

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In 1986, the Ottawa Charter for Health Promotion<sup>9</sup> set the agenda for what has now developed into a matured field. Since then, a significant number of resolutions, both at national and global level, have been adopted in support of health promotion, but these have not always been followed by action.<sup>39</sup>

Although health promotion has shown its effectiveness in a number of fields, particularly in high income countries, the Charter and its ideals have been widely discussed and criticised. Labonte<sup>93</sup> is of opinion that although efforts were made to deal with underlying health determinants such as poverty, they have been insufficient

to make much of a difference. Wolfbring<sup>94</sup> supports this opinion and argues that by not dealing with the challenges posed to health promotion, its ability to deal with global health problems - in particular, disabled people- are being impaired.

One of these challenges is the limited involvement and understanding of disabled people and their different models of disability in the context of global health and health promotion. An example of this limited understanding was shown by Biggs,<sup>32</sup> who examined the health promotion needs of stroke survivors in the Cape Town Metropole. She concluded that stroke survivors had a number of health promotion needs resulting mainly from their involvement in health risk behaviours, such as physical inactivity, smoking, consuming alcohol, non compliance to prescriptions by doctors, and unhealthy eating habits. In addition, participants were vulnerable to emotional disorders due to low psycho-social status and self-perception. These psycho-social factors adversely increased participants' involvement in substance usage.<sup>32</sup>

The Bangkok Charter, of 2005, recognises this neglected need by remarking that:

*“The vulnerability of children and exclusion of marginalised, disabled and indigenous peoples have increased”.*

Porter<sup>95</sup> however maintains that the discourse of the Bangkok Charter from the Ottawa Charter scales back health promotion goals from striving for social justice to simply improving health opportunities. If the United Nations maintains that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being, empowering disabled people to increase control over their health, should be a priority.

To succeed in this objective, lessons can be drawn from other health promotion programs. Jackson *et al*<sup>96</sup> summarises six lessons from eight reviews on such programs since 1999, as follows:

1. The investment in building healthy public policy is a key strategy;
2. supportive environments need to be created at the individual, social and structural levels;
3. the effectiveness of strengthening community action is unclear and more research and evidence is required;
4. personal skills development must be combined with other strategies to be effective;

5. interventions employing multiple strategies and actions at multiple levels are most effective; and
6. certain actions are central to effectiveness, such as intersectoral action and interorganisational partnerships at all levels, community engagement and participation in planning and decision-making, creating healthy settings, political commitment, funding and infrastructure and awareness of the socio-environmental context.

The development of the training package for caregivers of stroke survivors adheres to the last five of these lessons. This does not only demonstrate the likeliness of this programme succeeding but also the progressive thinking of the developers in the early 1990's.

From this discussion it is clear that the empowerment of disabled persons through the process of health promotion must be a united effort. Despite its apparent failure to do that to date, the researcher agrees with Labonte<sup>93</sup> that:

*“Health promotion remains an emancipating ideal for those working in the health sector. It describes an ideology and a set of practices by which we invite ourselves into the movement of enhancing social justice and environmental sustainability.”*

Central to this ideal is the need for information. Without sufficient and appropriate information, people cannot make informed choices on health related behaviour in order to promote their health.

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## **2.7 The need for information**

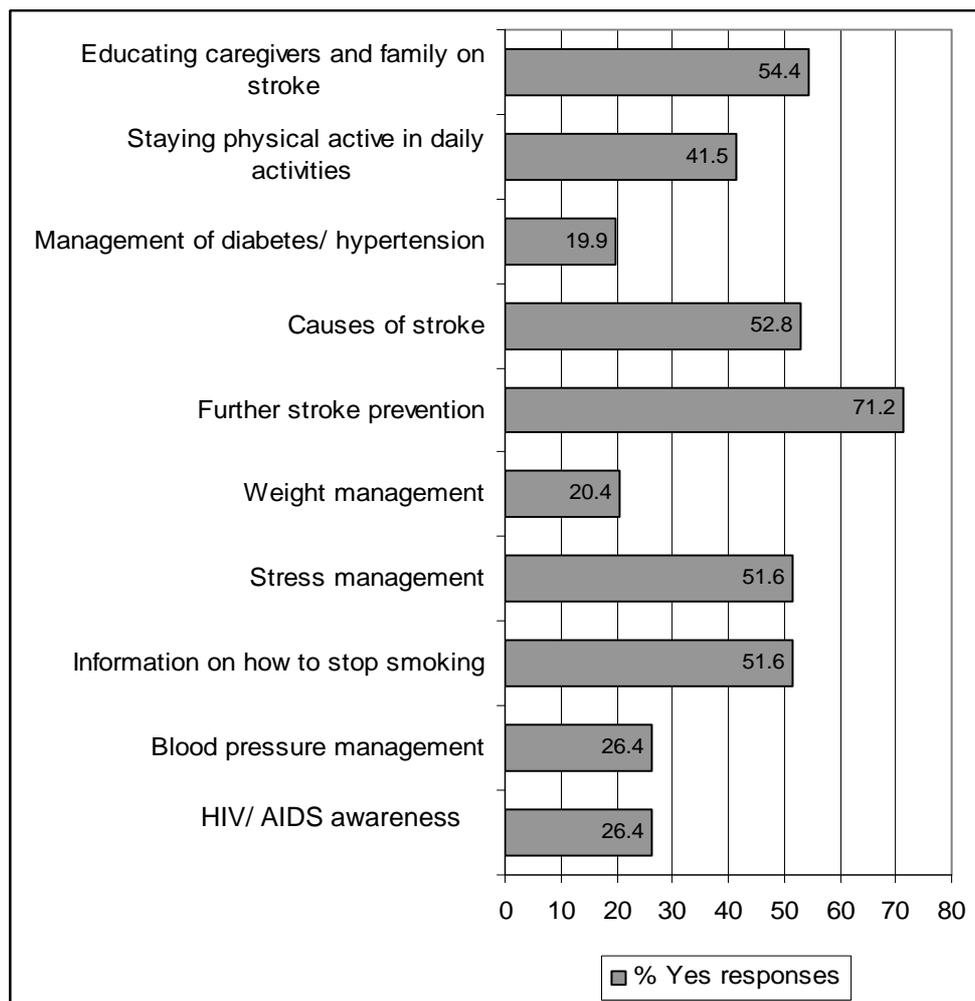
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### **2.7.1 The information needs of stroke survivors**

Several studies in developed countries have indicated that stroke survivors feel inadequately informed about their strokes.<sup>70,97,98</sup> This is despite the fact that most of these studies were conducted in centres where information on stroke was given routinely through various programs. They have also indicated that the type of questions change over time<sup>97</sup> and that the perceived information needs and priorities differ between clients and professionals.<sup>99</sup>

According to a study of 417 stroke survivors in the Western Cape, informational support was one of the major resources that influenced the health-related behaviours

of stroke patients. Only 30.5% of patients reported receiving information about what a stroke is from health care professionals, whilst a mere 9.6% were educated about the complications of stroke and how to manage them. Only 29.7% of participants recalled being educated about how to prevent a further stroke by incorporating health-enhancing behaviours into their lives. Figure 2-1 is a summary of information related to health promotion that these stroke survivors expressed a need for. At the forefront is a need for information on preventing further stroke.



**Figure 2-1: Perceived health-related information needs of stroke survivors in the Cape Town Metropole<sup>32</sup>**

Despite this observation, Foster *et al's* Cochrane database review on information provision for stroke patients and their caregivers<sup>47</sup> was inconclusive on the effectiveness of information provision. They expressed the need to identify appropriate teaching strategies that can be successfully implemented within clinical practice.

There is thus a need to understand the principles of adult learning as well as the unique barriers to learning in persons who had a stroke. Russel<sup>72</sup> argues that adults learn best when convinced of the need for knowing the information. Often a life experience (e.g. stroke) or situation stimulates the motivation to learn. Knowels<sup>34</sup> (the first author to theorise on adult learning) described the following characteristics of adult learners:

1. Autonomous and self-directed
2. Accumulated foundation of experiences and knowledge
3. Goal orientated
4. Relevancy oriented
5. Practical
6. Need to be shown respect.

All of these are applicable to adults who had a stroke. Their need for practical, relevant and goal-orientated information is evident. Yet, their autonomy and need to receive information in a respectful manner must not be ignored. Their experience of suffering a stroke provides them with excellent insight into their specific challenges. Another consideration is that most stroke survivors are older adults<sup>49</sup> and have different learning abilities and styles compared to younger adults.<sup>100</sup> Moreover, the cognitive problems (e.g. memory, orientation and planning) associated with stroke also influence their learning process.

### **2.7.2 The information needs of caregivers**

Caregivers are not only confronted by the choices concerning their own health but are often held responsible for the management of stroke survivors. As discussed above, one of the key ingredients to optimise their decisions is access to accurate and suitable information. Despite this identification of the need for information, a systematic review found that interventions to support stroke caregivers by using information packages, specialist nurses or family support workers have had limited impact on patients and modest psychological or social benefits for caregivers.<sup>47</sup>

In contrast, a randomised controlled trial by Kalra *et al*<sup>101</sup> showed that training caregivers in basic nursing, moving, and handling and facilitation of activities of daily living, significantly reduced their burden, anxiety, and depression and improves

quality of life and satisfaction. Although caregiver training did not influence patients' mortality, institutionalisation, and disability, patients whose caregivers received training reported better quality of life and psychological outcomes.

In another study, carers expressed the view that had they been educated on how to begin rehabilitation in the home, they might have been able to prevent a decline in the physical and psychological state of the survivor.<sup>102</sup> Information about dealing with psychological, emotional, and behavioural problems and local service information were said to be priorities before and after discharge.<sup>103</sup>

Since the periods of hospitalisation have decreased, healthcare professionals have less opportunity to educate stroke patients and their families regarding self-care before the patient is discharged home. Consequently, families often need continued education.<sup>104</sup> In Pierce *et al*'s<sup>104</sup> study to identify the self-care needs about which people dealing with stroke most frequently want information, 24 people responded to a survey that listed 48 self-care needs. The top five self-care needs for which information was desired were:

- Preventing falls;
- maintaining adequate nutrition;
- staying active;
- managing stress and
- dealing with emotional and mood changes.

The booklet on stroke home care that is being evaluated in this study addresses all five of these needs directly or indirectly. However, the usability of this information is highly dependent on the literacy level of the intended users and the readability of the material. Literacy remains one of the major factors that influence whether people comprehend and subsequently implement information that is provided in a written format.

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## 2.8 Literacy

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Literacy is an important aspect of modern life and has featured prominently in many world conference pronouncements over the years.<sup>105</sup>

The United States Department of Education defines literacy as:

*“Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential”.*<sup>106</sup>

This implies the functional use and application of the knowledge gained and goes beyond the traditional definition namely the ability to read and write. The approach known as “New Literacy Studies” has challenged this view and introduced a wider notion of literacy. Nowadays, one frequently comes across references to “visual literacy”, “computer literacy”, “television literacy” and the like. This extension of the literacy concept beyond the domain of verbal language is the result of a parallel change in conceptions of the proper scope of education.<sup>107</sup>

For the purpose of evaluating written health information, two of these literacy concepts are most prominent:

- Visual literacy; and
- Health literacy.

Both of these are also relevant to the evaluation of the booklet on stroke home care. Without an understanding of these concepts, it will be impossible to comment on the appropriateness of material for any intended audience.

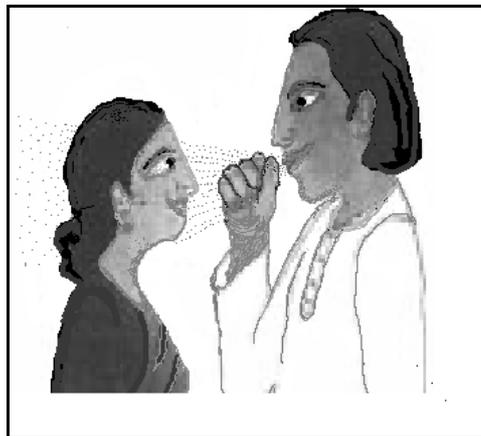
### **2.8.1 Visual literacy**

The term visual literacy was first used by John Debes, an American who organised the first conference on the subject in 1969. It has come to embrace, among others things, familiarity with film, television and electronic media, particularly in developed, technologically advanced countries. This wide use of the term visual literacy to encompass many divergent areas of study signals a problem of definition.<sup>108</sup>

In the context of adult basic education in South Africa, a field primarily concerned with reading and writing texts, Arbuckle<sup>108</sup> suggests a narrowed-down interpretation that is best described as pictorial literacy. A simple definition of pictorial literacy is the ability to understand pictures through an awareness of basic pictorial conventions, techniques and codes.

An extensive review by Houts *et al*<sup>109</sup> showed that adding pictures to written and spoken language could significantly increase patient attention, comprehension, recall and adherence. Research suggests that pictures can be especially helpful to patients with low literacy skills, provided that they understand the elements being communicated.

It is important to remember that pictures are mainly a representation of objects and that abstract notions, like movement, are represented by convention. Someone that does not know the convention is unlikely to interpret the picture accurately.<sup>110</sup> Figure 2-2 is intended to be a picture of a man who is coughing. Since, in reality, such particles are not visible to the naked eye, this image is open to misinterpretation. Some viewers thought that the couple were surrounded by a swarm of gnats.<sup>108</sup>



**Figure 2-2: Coughing or a swarm of gnats?<sup>108</sup>**

The interpretation of central perspective is another learned skill that influences the ability to understand a picture. Figure 2-3 illustrates detail from a poster demonstrating land care. A group of rural small-scale farmers identified the pipe running from the dam to the river as a worm, indicating a lack of understanding of the conventions of perspective and scale.<sup>108</sup>



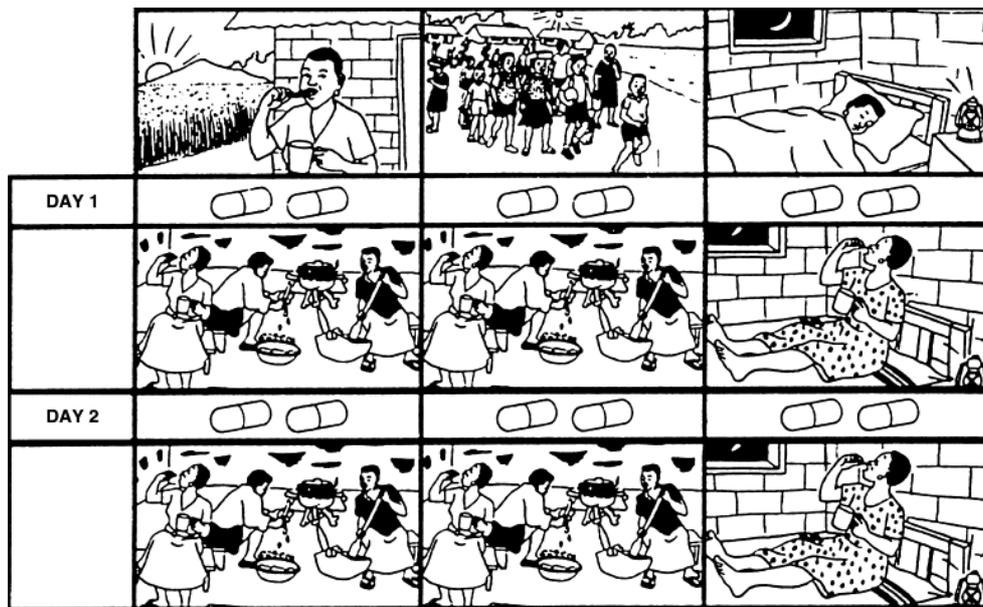
Figure 2-3: Detail from a poster demonstrating land care<sup>108</sup>

'Comic strips' (Figure 2-4) represent another type of highly complex visual message, and are not as easy to read as is generally thought. Conventions of visual communications such as frames, speech bubbles, varieties in angle, varieties in text appearance, and imagined action between the frames require an entirely different eye co-ordination than for conventional reading.<sup>108</sup>



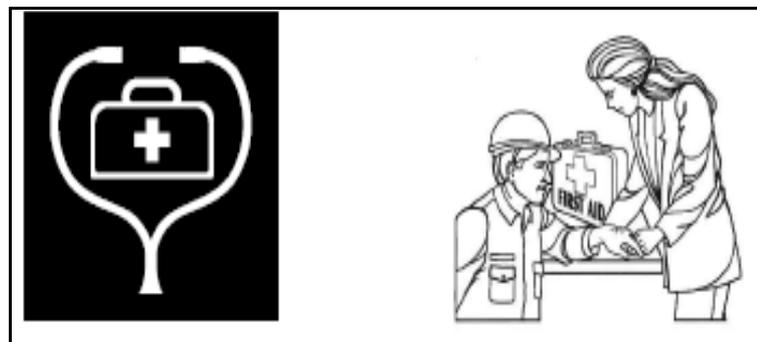
Figure 2-4: Example of the Mkhize picture story<sup>108</sup>

In a Cameroon study, Ngoh and Shepherd<sup>111</sup> concluded that for pictures to be effective, they must be meaningful to people in the audience (i.e. culturally relevant). Figure 2-5 is an example from their study of pictures given to illiterate women to explain when to take medication. Activities that they are likely to be involved in at that time of the day are illustrated in order to give meaning to the pictures.



**Figure 2-5: Examples of pictures given to illiterate women in rural Cameroon to explain when to take pills<sup>111</sup>**

It can thus be concluded that meaningfulness is often related to an action rather than an object. Figure 2-6 firstly shows a symbol that indicates the presence of a first aid kit. The understanding of this symbol depends on the learned meaning of the convention. The second picture is a meaningful illustration, showing two workers using the kit.<sup>112</sup>



**Figure 2-6: Illustrations indicating the presence of a first aid kit<sup>112</sup>**

Visual literacy is a skill that is frequently neglected in the formal curriculum, and is usually acquired informally through constant exposure to pictorial material and to the mass media. Being read to as a young child and having the meaning of pictures repeatedly explained enable the acquisition of visual literacy skills at an early age. However, for many people in South Africa, books are a rare commodity and there is limited opportunity for this informal educational process to occur, resulting in a reduced ability to interpret visual media.<sup>113</sup>

## 2.8.2 Health literacy

Just as a broader, more modern concept of health includes physical, mental and social well-being, a broader understanding of literacy includes a range of skills to navigate and apply knowledge. Both health and literacy are dynamic concepts that influence, and to some extent determine, our ability to function in a rapidly changing society. Consequently, the more recent thinking on literacy shows a close affinity to the approaches developed in the health promotion field around the Ottawa Charter.<sup>8</sup>

The WHO defines health literacy as follows:

*“Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use the information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is crucial to empowerment.”<sup>114</sup>*

Although health literacy goes beyond the mere understanding of written health information, limited reading skills will clearly influence a person’s capacity to use this information effectively. Several studies have confirmed that individuals with poor reading skills often have poorer health, higher medical expenses, and an increased number of hospital and outpatient visits compared with those who have a higher literacy level.<sup>115,116,117</sup>

Literature on the subject reveals several possible reasons and contributing factors for these findings. People’s literacy directly influences their access to crucial information about their rights and their health care. It involves following instructions for care, taking medicine, comprehending disease-related information, and learning about

disease prevention and health promotion.<sup>117,118</sup> Contreras,<sup>118</sup> found that people with low literacy skills tend to make more errors in their medication or treatment and are less likely to follow through with treatments. Another study in a public hospital found one-third of English-speaking patients could not read basic health materials. More than a quarter could not read appointment slips and forty-two percent did not understand labels on prescription bottles.<sup>119</sup>

Similar findings were made in South Africa showing that persons with low literacy have problems following the signs in clinics and hospitals. In addition, the information on clinic cards is not clearly understood. The result is that time is wasted sitting in wrong queues or missing appointments. More serious is that persons with low reading skills do not always take the correct medicinal dosage. Reading and completing forms are also a major problem, resulting in delayed service delivering.<sup>120</sup>

Table 1 is a summary of how low literacy can influence health.

**Table 1: Summary of how low literacy can influence health**

<b>Factors related to literacy that influence health</b>	<b>Possible consequences</b>	<b>Reference</b>
Knowledge regarding rights.	Less likely to demand health care within their basic human rights.	Rudd <sup>117</sup>
Reading information on disease and health promotion.	Less likely to take timely actions to reduce their health risks,.	Rudd, <sup>117</sup> Williams, <sup>119</sup> Schloman, <sup>116</sup> Doak <sup>115</sup>
Knowledge of personal conditions.	Misinterpretation of information	Schloman, <sup>116</sup> US Dept Education. <sup>106</sup>
Following signs in hospital.	Loss of time.	Desmond <sup>120</sup>
Understanding information on clinic cards, including appointments.	Not attending appointments.	Desmond <sup>120</sup> , Williams <sup>119</sup> , Schloman <sup>116</sup> .
Reading labels including dosages on medicine.	Not taking the right medication at correct dosages.	Desmond, <sup>120</sup> Williams, <sup>119</sup> Contreras, <sup>118</sup> Rudd, <sup>117</sup> Schloman, <sup>116</sup> US Dept Education. <sup>106</sup>
Reading and completing forms.	Slower service delivery.	Desmond. <sup>120</sup>
Interpreting charts.	Misinterpretation of information.	US Dept Education. <sup>106</sup>
Decisions about participating in research studies.	Uniformed decision making.	US Dept Education. <sup>106</sup>
Using medical tools for personal or family health care—such as a peak flow meter or thermometer.	More dependent on the assistance of health care workers	US Dept Education. <sup>106</sup>

Reasons for these consequences are related to the way in which people with a low literacy read. They read word-for-word and often spend considerable time trying to understand multi-syllabic words. Their eyes move slowly across each line of text. This gives them a narrow field of view and they therefore miss objects outside the main flow of the text they are reading.<sup>121</sup> It is clear that a person who is impaired because of low literacy is at a higher risk of health related problems, including disability. Low functional literacy thus has serious consequences for individual health and places added demands on the health care system.

Furthermore, it is important to clarify the issue of power in the health literacy debate, so that the promotion of health literacy does not focus just on compliance issues. The WHO's definition of health literacy stresses its role in the empowerment of people. Kickbusch<sup>114</sup> suggested that a lack of concern with empowerment has been one of the reasons why large-scale literacy efforts around the world have failed.

One of the obstacles to overcome is the measurement of literacy. It is well known that neither formal education levels nor self-reported literacy levels are particularly good predictors of functional literacy.<sup>113</sup> International studies using the REALM (Rapid Estimate of Adult Literacy in Medicine) screening test also show a two to four grade discrepancy between reported years of schooling and measured literacy.<sup>38,124</sup> Direct measurements of functional literacy is however a lengthy process and subsequently not widely used.

### **2.8.3 Measurement of literacy**

In 2003 The United States Department of Education developed a four category scale for the assessment of adult literacy.<sup>106</sup> Categorising was done by the successful completion of tasks representing a range of literacy activities that adults are likely to face in their daily lives. Measurements were taken in three skill areas: prose (both expository and narrative), document (short forms or graphically displayed information), and quantitative (graphs/charts or numerical display). Five levels, ranging from below basic to proficient, were described. Although this is a very comprehensive scale, it is time consuming to administer and the tasks are specific for the American context.

In a similar study in 1992, less complex measurements were used (see Table 2).<sup>116</sup> Although less comprehensive, these functional descriptions can give an indication of the literacy level of a reader. As a rule of thumb, those of Level 1 read below a 5th grade of formal education level.<sup>122</sup>

**Table 2: The United States Department of Education scale for the assessment of adult literacy (1992)<sup>116</sup>**

Level 1:Functionally illiterate	Fill in the blanks on a job application form. Complete a deposit slip that lists two cheques.
Level 2: Marginally illiterate	Given a wage and tax statement that comes with a pay cheque, identify the gross pay for this year to date. Locate an intersection on a street map.
Level 3:	Answer simple questions relating to a newspaper article. Interpret a simple bar graph to answer a question.
Level 4	Read a bus schedule to determine the next available bus for a given location. Compute a 10% tip for a dinner restaurant bill.
Level 5:	Interpret a lengthy magazine article. Compute the total interest to be paid on a home equity loan.

In spite of these available measurements, clients with limited health literacy skills can be hard to identify. They can be very skilled at hiding any problems they might have with reading.<sup>116,118</sup> These clients often develop ways to hide their inadequacy. Table 3 gives a summary of styles of behaviour or phrases of verbal communication that may indicate low literacy.

**Table 3: Strategies or phrases that may indicate low literacy<sup>116,118</sup>**

Possible strategies	Phrases that should raise awareness
Watch for a chronic pattern of non compliance like missed appointments and not following directions	"I forgot/ lost my glasses. I'll read this later." or "Can you read this to me?"
Take note if forms are incompletely filled out, possibly only with name provided.	"I'll read this when I get home."
Observe if a surrogate reader accompanies patient.	"Let me discuss this with ....."
Handing written materials to a relative or other person at an appointment	
Be alert for possible vision and/or hearing problems.	
Clients report following directions, but no improvement occurs	

Several screening tests have been developed to aid health providers in identifying patients with low functional health literacy. The most widely used are:

- REALM (Rapid Estimate of Adult Literacy in Medicine): A word recognition test that uses medical terms of various levels of difficulty; estimated two minutes to administer.
- S-TOFHLA (short form Test of Functional Health Literacy in Adults): Measures reading and comprehension of health-related materials; estimated twelve minutes to administer.
- WRAT-R-III (Wide Range Achievement Test-Revised): Another word recognition test, but not specific to health care; estimated two to three minutes to administer.<sup>116,124</sup>

The advantage of these screening tests is that they are useful tools in a clinical setup where time is limited. The major constraint is that although some have been translated into different languages, no record of translation into any of South Africa's indigenous languages could be found.

### 2.8.4 Literacy in South Africa

According to the 2001 census, 17,9 percent of the South African population received no formal schooling, and 16 percent received some primary schooling, but did not complete primary school (see Figure 2-7).<sup>123</sup>

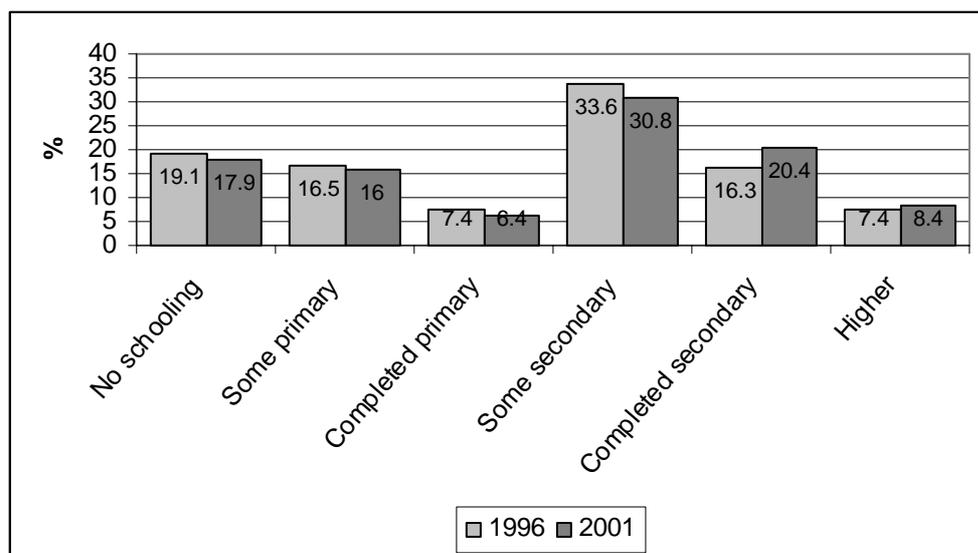


Figure 2-7: Literacy levels in South Africa<sup>123</sup>

If a definition of functional literacy is taken as being able to read at the fifth grade level or higher,<sup>123</sup> it means that about a third of the South African population is functionally illiterate. The implication is that a third or more of adult South Africans cannot read newspapers, health instructions, or directions on a box of cake mix, among other things.

In the American survey older people were overrepresented among those with low literacy skills. One of the causes is thought to be the incidence of cognitive diseases, something that is prevalent in stroke survivors.<sup>124</sup> This tendency is likely to be similar in South Africa – especially among people who suffered from a stroke.

As already discussed, formal education is not a good predictor of functional literacy. By using this method to describe literacy it is likely to underestimate the literacy problem in South African society. Unfortunately, with the lack of translated literacy tests, or even better, locally developed tests, the use of years of schooling and self reported literacy remain the main measurement tools in South Africa.

The limitations of this method is evident from several South African studies. Dowse and Ehlers found that 23% of persons who had proclaimed literacy in English, displayed a very poor understanding of the test material.<sup>113</sup> According to Horne,<sup>125</sup> this difference is already evident in grade 11 learners. He tested bursary applicants and found their functional literacy up to five grades lower than their school grade.

With these challenges in mind, one could argue that written material is of limited value to stroke survivors and their caregivers in developing communities. Yet, it remains one of the major methods for delivering information. The question thus arises: What is the role of written health information in developing communities?

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## **2.9 The role of written health information**

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Moris<sup>126</sup> concludes that even in communities where printed material could be regarded unsuitable, people actively seek these material and regard it as superior to other information (i.e. verbal information). He is of opinion that this is partly due to what is described as “group literacy”. A community needs to have only one (willing) literate member or even sympathetic non-member to be able to access printed information. The concept applies equally to households as well as to other informal social

arrangements that facilitate the sharing of the fruits of reading, thereby effectively enhancing the literacy potential of the community as a whole.

A number of researchers concluded that printed material has advantages for developing communities. These advantages can be summarised under the following headings:

### **1. Portability**

Printed material is highly portable and easily transported from place to place; it is easy to store and can be used repeatedly. The equipment required to interact with visual media, such as television or film, is not as mobile and might require an appropriate venue and specialised technology (notably electricity) for users to hear the message.<sup>127,128,129</sup>

### **2. Technological complexity and cost**

Print is a low-technology medium, requiring no equipment to transmit and decode its information content. The technology for producing print, is generally widely available at least in urban areas.<sup>127,129</sup>

### **3. Reviewability**

Reviewability is the element that allows the receiver not only to receive the message once (such as a visit to the movie theatre) but to receive it as many times as he/she wishes. Printed materials possess such a characteristic in that the user can refer to the printed material whenever needed. It provides a comparatively permanent information source that is likely to remain in use as a reference for many years.<sup>127,129,130</sup>

Carter<sup>in126</sup> relates a striking example of the value of printed materials as a handy reference source through her observation of how a farmer in Western Kenya treasured his notes from agricultural training undergone twenty years previously. He regularly consults these notes (as his only written source of information) to answer fellow farmers' questions. In the field of rehabilitation, a patient focus group exploring patient education found that patients sought answers to their questions at the time they formulate their questions.<sup>130</sup> Since professionals are not always available at such a time, printed information can fill this gap.

#### **4. Credibility**

People tend to trust printed rather than verbal information because the source of information usually emanates from outside the community and the message can be seen before them in 'black-and-white'.<sup>127</sup>

#### **5. Precision and consistency**

Print allows for greater accuracy of content, precision of expression and consistency of information.<sup>127,129,130</sup> The message can be clearly stated without interference and bias that may be introduced by other channels of transmission.<sup>127</sup> It can be tailored to specific geographical, and linguistic and cultural needs with relative ease.<sup>128,130</sup>

#### **6. Literacy promotion**

The use of printed material enhances the visual and verbal reading skills of the users.<sup>128</sup>

#### **7. Choice of level and amount of information.**

Hoffman and Worrall<sup>129</sup> commented that written materials may also be able to assist persons in answering the questions that occur when they are not interacting with a health professional. People can choose the level and amount of information that best suit, them as their needs change.<sup>38,129</sup>

These advantages are probably the reason that printed material remains the most widely applied medium in information systems and services.<sup>127,129</sup> With specific reference to stroke Hoffman and McKenna's<sup>38</sup> review found that written information is the most used in patient education, provided either as part of a multi-component intervention or as a stand-alone intervention. A Cochrane review recommends the use of both verbal and written health information when communicating care issues to patients and caregivers on discharge from hospital to home. The combination of verbal and written health information appears to improve knowledge and satisfaction.<sup>131</sup>

It follows that despite its limitations, printed information has enough advantages to make it an appropriate medium for message delivery to developing communities, provided there is a match between the material and the client's needs. This match is referred to as the suitability of material.

## 2.10 Suitability of material

The match between materials and client needs has been extensively examined in the literature. Providing written information does not necessarily mean that it will facilitate a client's learning, particularly if it is not written at a level that can be easily read and understood.

The most frequently used measurement to determine the match between material and clients is readability formulas. They are objective quantitative tools to estimate the reading difficulty of a passage. This estimate of reading difficulty is based on the lengths of sentences and the number of polysyllabic words used in a sentence. The results are given as a score or index number that indicates how readable the text is. There are more than 40 readability formulas but those most extensively used in health care are the Fry, Flesch-Kincaid, and Simple Measure of Gobbledygook (SMOG).<sup>132</sup> In Figure 2-8 examples are shown of health related text written at different grade levels.

<p><b>College Reading Level</b></p> <p>With the onset of nausea, diarrhoea or other gastrointestinal disturbances, consult your physician immediately.</p>
<p><b>12th Grade Reading Level</b></p> <p>If you experience nausea, diarrhoea or other stomach or bowel problems, call your physician immediately.</p>
<p><b>8th Grade Reading Level</b></p> <p>If you start having nausea, loose bowel movements or other stomach problems, call your doctor immediately.</p>
<p><b>4th Grade Reading Level</b></p> <p>If you start having an upset stomach, loose bowel movements, or other problems, call your doctor right away.</p>

**Figure 2-8: Examples of text written at different grade levels**<sup>138</sup>

These formulas are mostly easy to use and give valuable information on reading difficulty of written material. However, critics cite several shortcomings. Meade and Smith<sup>127</sup> warn that the power and precision of readability indices may “*give a false*

*sense of the validity of the process of assigning grade level equivalencies to text . . . [and] cause one to overlook the other important factors associated with being able to read.”* These formulas do not consider presentation of information in terms of its layout and design, format, complexity of the subject, familiarity of the reader with the subject, or reader interest.<sup>130,132</sup>

There are a growing number of studies finding that the written health material often have a readability level that is too high for the majority of the intended audience.<sup>133,134,135,136,137</sup> Much less frequently conducted are studies that have analysed the suitability of written materials according to factors other than just readability.<sup>129</sup>

A variety of instruments, methodologies and tools has been described to evaluate various aspects of the quality of print information materials. These include stepwise guides to the materials' development and evaluation process,<sup>138,139</sup> checklists for evaluating various aspects of materials<sup>124,129,130</sup> and detailed instruments for comprehensive assessment of specific factors like cultural sensitivity<sup>140</sup> and pictures.<sup>141</sup>

Although there is consensus about the majority of aspects that should be taken into consideration, Carstens<sup>128</sup> is of the opinion that, in general, the literature provides limited (or no) evidence of whether the strategies used to meet the needs of low-literates are research-based. She refers to the study by Moris and Stillwell<sup>127</sup> as an impressive attempt at eliciting research-based guidelines from the available literature. Consequently, she summarises the guidelines in table form as a set of heuristics for designing the textual elements (content, structure, style) as well as the graphic elements (visuals, typography, colour and layout) for low-literacy public information documents. Unique to other guidelines, these are linked to their purported effects on how low-literate users process verbal and visual materials. Unfortunately, most of these guidelines and checklists lack a method of grading. An exception is the Suitability Assessment of Material (SAM).<sup>122</sup> This is the standardised tool used most widely to evaluate health literature.

The SAM was developed by Doak, Doak and Root<sup>123</sup> in 1996, in an attempt to confront the inadequacies of readability formulas (i.e. the narrow focus on the complexity of words and sentences). It rates written materials on 22 items grouped

under six factors (content, literacy demand, graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness) to the extent which they meet set criteria on an ordinal scale. The scoring sheet is very basic but the explanation of the criteria is quite lengthy (+/- eight pages). First time users are expected to take 30-45 minutes to evaluate a piece of material.

A limitation of the SAM is that it can give an overall score of “adequate” while some of the subfields may be critically inappropriate. A study by Weintraub<sup>142</sup> on the suitability of material on prostate cancer, highlights this. An evaluation of 29 materials demonstrated that although the majority, 22 (75.8%), scored "adequate" for their overall suitability, 26 materials (90%) scored "not suitable" for their reading grade level, while 55% of the materials could not be rated on cultural appropriateness because of lack of cues about the intended audience. Nevertheless, the SAM has the advantage that it produces both quantitative and qualitative data: Next to the suitability score that can be calculated, rich explanatory data can be generated in a section for comments.<sup>128</sup>

Although many of the different guidelines and checklists (including the SAM) are extensive in the factors to evaluate, the balance and relative importance of the factors in relationship to each other are seldom discussed. Even though many are focussed on the needs of low literacy readers, few mention the specific needs of people in developing communities.

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## **2.11 Conclusions drawn from this literature review to guide the choice of a model to evaluate written health material**

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The principles of CBR, disability prevention and health promotion all accentuate the empowerment of people through informed choices. One of the key ingredients of this empowerment is the need for information. Although this need has been well described among stroke survivors and their caregivers, literacy remains one of the important doors to access information. Not only do people need to comprehend the written text and graphic presentation, they must also be able integrate and apply the information functionally.

Literacy statistics from South Africa raise the question of the appropriateness of written information for large parts of the population. Even so, literature provides enough evidence to support the use of written material, provided that it is suitable for the target audience. However, the assessment of this suitability is a challenging process. Although the golden standard for such assessments is testing with the target audience, many guidelines exist that can guide a pre testing refinement of material. There is however little evidence in the literature of comparison and evaluation of the actual guidelines. The gap in these guidelines of guidance for material for developing communities is also alarming.<sup>37</sup>

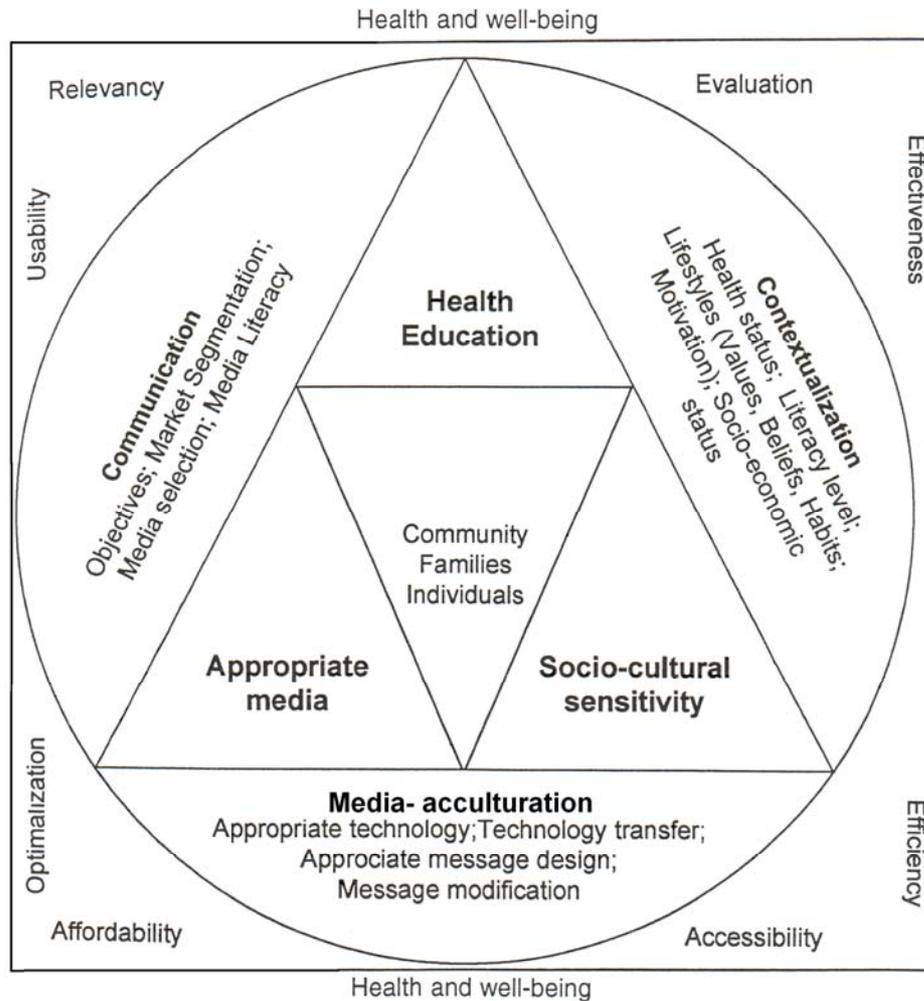
Before determining and describing the detail of such guidance there is a need for a model that can be an overarching umbrella of principles for material that is suitable for developing communities. The HAMSOC model is such a model. Not only can it be used as the foundation to set the agenda for evaluating material but also for the development of a grading scale for existing guidelines and checklists.

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## **2.12 A model for evaluating written material for developing communities**

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Hugo and Smit<sup>37</sup> created a model for appropriate health education messages in developing communities. The HAMSOC model is based on three cornerstones: Health Education, Appropriate Media and Technology, and Socio-cultural Sensitivity. Each cornerstone is of equal importance and each affects the other. Figure 2-9 is a diagrammed illustration of this interaction as well as the secondary components and eight generic principles for effective media use.



**Figure 2-9: HAMSOC model**<sup>37</sup>

Although the different contributing components have varying levels of importance, none should be ignored. The underlying principle is that all factors on the same level must carry equal weight. This model does not provide detailed checklists for evaluating written information but sets a framework for the relationship between factors that influence its effectiveness.

The creators of the model offered some practical guidelines for its implementation. This includes modifying inappropriate message designs, participation by the target audience and pre-testing of prototype learning materials. Moreover, they advise to use the guidelines as a starting point to compile a suitable checklist in each of these areas to evaluate learning material. This study sets out to follow that recommendation.

Literature concerning each of the cornerstones of this model will now be explored.

### 2.12.1 Health education

Health education in the developing world is emerging as a mature discipline with a proven track record across the range of health issues.<sup>143</sup> Although this discipline goes far beyond the use of written health material, for the purpose of this discussion it will focus on this method.

In the HAMSOC model the cornerstone of Health Education is based on the principle that it is the message (in the medium) that counts. It is ultimately concerned with the “what” question. Moris and Stilwell<sup>127</sup> mention three aspects to consider when deciding on the content: Accuracy, Appropriateness and Relevance.

In order to ensure **accuracy** the information must be based on current best available evidence.<sup>129,130</sup> Inaccuracies can be eliminated by carefully checking and validating facts and through a process of peer consultation and review.<sup>127</sup> The authors and publishing date should be mentioned and depending on the target audience, references need to be included or be available on request.<sup>112,118,129,138</sup> In a systematic review Coulter, Entwistle *et al*<sup>144</sup> reviewed 58 health related printed materials. They concluded that most material omitted relevant information, failed to give a balanced view of treatment options and avoided discussing uncertainties. Almost a third did not include a publication date and few contained references to primary resources. The **appropriateness** of the content include factors like the number of concepts addressed and technical detail of the material.<sup>127</sup> The information should be appropriate to the age, gender, educational level, ethnicity, socio-economic status and lifestyle of the target audience. This can only be determined if the target audience is well defined.<sup>138</sup>

Central to the matter of **relevance** is whether the information addresses the target audience’s needs and concerns. Hence, feedback from users is essential to ensure relevance.<sup>118,129,130</sup> If the information presented reflects the needs and interests of readers, they will be motivated to consider whether they could apply the given guidelines and recommendations in their own particular situation.<sup>127</sup> Practical information, broken down into doable tasks, facilitates learning and motivates people to change their behaviour.<sup>123,145</sup>

Kreuter and Holt<sup>146</sup> remarked that most people will probably prefer information tailored to their specific needs. Their conclusion from a number of well-designed randomised studies were that tailored print material have been found more effective than non-tailored ones to helping individuals change their behaviour. What has not yet been established is the optimal amount of tailoring. Cost and input should be weighed against the change in behaviour. In other words: How much tailoring is necessary to achieve an effect and is this influenced by the behaviour targeted?

### **2.12.2 Appropriate Media and Technology**

The concept of appropriate media and technology entails the selection of the most suitable medium in the most suitable format. It focuses on the “How” question. The technology used to inform people should be accessible, cost effective and manageable by the target audience.

For example: The internet can be a very appropriate method for disabled persons to access information. They can use it in the comfort of their own home and it allows for interaction with other disabled persons and health professionals.<sup>147</sup> Understandably, several studies are nowadays focused on the accessibility and accuracy of information for disabled person on the internet.<sup>147,148,149,150</sup> However, in order to use the internet resources, a person needs the necessary literacy and computer skills as well as a computer, electricity and an internet connection. It is thus inappropriate technology to reach the majority of people in developing communities.

The most appropriate technology to use is not only influenced by the target audience’s capabilities but also by the physical environment and the message that needs to be conveyed. For some messages, mass media, like television or radio, might be most appropriate, for example warnings about the risks of Ultra Violet radiation.<sup>151</sup> Other health messages, like motivation to undergo HIV tests, can suitably be addressed by plays or dramas.<sup>152</sup>

Hugo and Smit<sup>37</sup> further highlight that no single medium of instruction or information technology tool in itself can bring about change in health behaviour. Media use in health education is most effective when used in combination with different forms of personal interaction.

As already discussed, printed material can be an appropriate medium to use in such a combination, also in developing communities. Once it has been decided to use printed information, the appropriate media (communication codes and media formats) have to be determined. This embraces factors like readability and layout as well as the effective usage of pictures and graphs.

The communication differences between readers with high and low literacy skills (Table 4) should be kept in mind when evaluating or designing such material.<sup>115</sup> This stresses the fact that readability in terms of length of words, should not be the only consideration.

**Table 4: The communication differences between readers with high and low literacy skills<sup>115</sup>**

<b>Patients with High Literacy Skills</b>	<b>Patients with Low Literacy Skills</b>
Have vocabulary fluency.	Read slowly, and may sound out letters in words.
Find meanings for uncommon words.	Skip uncommon words.
Can systematically scan visuals to find key concept.	Have difficulty finding key concept. Eyes wander about page.
Can separate key points from details.	Focus on details: Cannot prioritise them.
Interpret word meanings.	Take words literally.

Doak and Doak et al<sup>115</sup> give a powerful illustration of how to apply this knowledge in two pamphlets urging women to have a mammogram. In the first example (Figure 2-10) the mechanics of the radiography take precedence over the information the patient needs to know to decide whether to have a mammogram. The readability is on a 12<sup>th</sup> grade. It is written primarily in the "Medical Model". In the second example (Figure 2-11), which is written on a grade 4-5 level, priority is given to information on patient action and motivation. The instruction includes a telephone number and invites calls for additional information. This format recognises that access to information is necessary and expected. It specifies the actions the patient needs to take, an important first step in patient self-efficacy. This is written in the "Health Belief

Model”. In addition, example 1 is printed in a typeface 10 size and has no subheadings. Example 2 is broken down into subsections using a question - answer format. The print is a typeface 12 size with ample space in-between.

### **An Extra Step: Mammography**

Women in the three high risk categories—age 50 or more, age 40 or more with a family history of breast cancer, age 35 or more with a personal history of breast cancer— may consider an additional routine screening method. This is x-ray mammography. Mammography uses radiation

(x-rays) to create an image of the breast on film or paper called a mammogram. It can reveal tumors too small to be felt by palpation. It shows other changes in the structure of the breast which doctors believe point to very early cancer. A mammographic examination usually consists of two x-rays of each breast, one taken from the top and one from the side. Exposure to x-rays should always be carried out to assure that the lowest possible dose will be absorbed by the body. Radiologists are not yet certain if there is any risk from one mammogram, although most studies indicate that the risk, if it does exist, is small relative to the benefit. Recent equipment modifications and improved techniques are reducing radiation absorption and thus the possible risk.

**Figure 2-10: Example of “Medical Model” writing<sup>115</sup>**

**What is a mammogram and why should I have one?**

A mammogram is an x-ray picture of the breast. It can find breast cancer that is too small for you, your doctor, or nurse to feel. Studies show that if you are in your forties or older, having a mammogram every 1 to 2 years could save your life.

**How do I know if I need a mammogram?**

Talk with your doctor about your chances of getting breast cancer. Your doctor can help you decide when you should start having mammograms and how often you should have them.

**Why do I need a mammogram every 1 to 2 years?**

As you get older, your chances of getting breast cancer get higher. Cancer can show up at any time—so one mammogram is not enough. Decide on a plan with your doctor and follow it for the rest of your life.

**Where can I get a mammogram?**

To find out where you can get a mammogram:

- \_ Ask your doctor or nurse
- \_ Ask your local health department or clinic
- \_ Call the National Cancer Institute's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

Figure 2-11: Example of writing in the "health belief model"<sup>115</sup>

Equally, the use of appropriate pictures must be considered. Houte, Doak *et al*<sup>109</sup> propose seven factors that educators should consider regarding the use of pictures:

1. Use pictures to support key points;
2. minimize distracting details in pictures;
3. use simple language in conjunction with pictures;
4. closely link pictures to text and/or captions;
5. include people from the intended audience in designing pictures;
6. have health professionals plan the pictures, not artists; and
7. evaluate pictures' effects by comparing response to materials with and without pictures?

Dowse and Ehlers<sup>113</sup> compared responses to pictures representing the same actions, but developed for different target groups. One set of pictures came from the US Pharmacopeia and the other was developed in close consultation with local users from developing communities. Interviews with a sample of 46 people with low literacy skills in South Africa showed significantly higher comprehension of the locally developed pictures in comparison to the standardised pictures. Examples of the two sets of pictures are shown in Figure 2-12. Interestingly, the differences in the pictures appear to be small. Yet, these small differences were important to the people viewing the pictures. In order to capture these subtle but important culturally relevant differences, Dowse and Ehlers recommend a multistage, iterative process in which the target population is involved at all stages of design and evaluation.

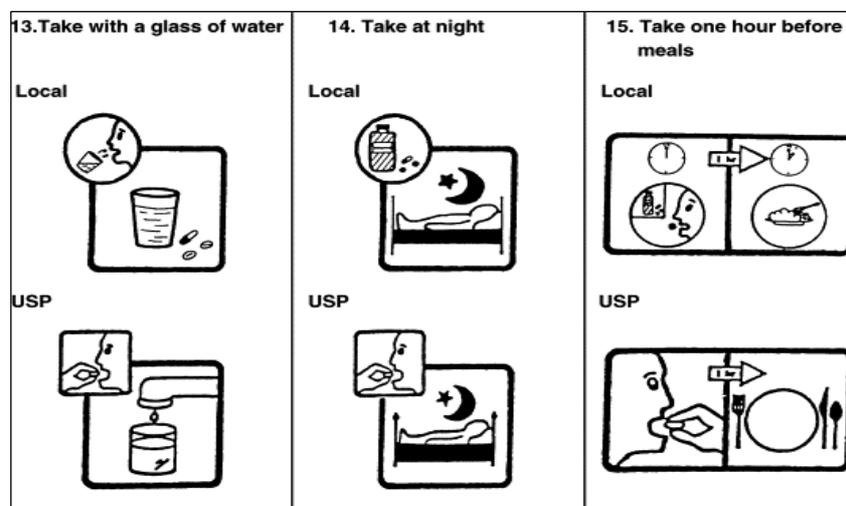


Figure 2-12: Examples of drawings made locally and from the US Pharmacopeia<sup>113</sup>

### 2.12.3 Socio-cultural sensitivity

The third cornerstone is sensitivity to socio-cultural variables. Insensitivity to these variables could lead to misunderstanding and antagonism towards the information provided.

Culturally sensitive written health information generally refers to the appropriateness of, and representation of the target group in the printed information. How diverse cultural groups interpret written materials is determined by their values, rules of behaviour consistent with their culture and whether the information fits in with their own health care practices.<sup>138</sup>

Fourie, Saphiro *et al*'s<sup>153</sup> study on the perceptions of female health care workers in Khayelitsha on obesity is a good example of the complexity of this challenge. Based on their cultural background the woman generally valued a moderately obese woman but at the same time thought it would be more desirable if they were thin. On the one hand they want to be what they are supposed to be according to their own cultural values; on the other hand they want to conform to values of other cultures. In addition, the women in the study perceived moderate obesity as a sign of health due to the stigma of persons with AIDS, who are usually very thin. The study concluded that understanding the beliefs and attitudes of these health promoters towards obesity is valuable in guiding the development of **culturally sensitive** intervention strategies.

Interventions to improve clinical cultural competence are aimed at providers and should involve more than awareness of generalities about values and behaviours. This is categorical knowledge that can sometimes better promote stereotypes than inform quality care. Rather, better attention to communication styles and sensitivity to cultural specificities are needed.<sup>154</sup> Culture and communication patterns have an integral relationship. Each cultural group has codes, symbols, language and values that are meaningful attributes of their communication patterns. Without a basis for clear communication, both client and provider will have difficulty during the teaching and learning process.<sup>124</sup>

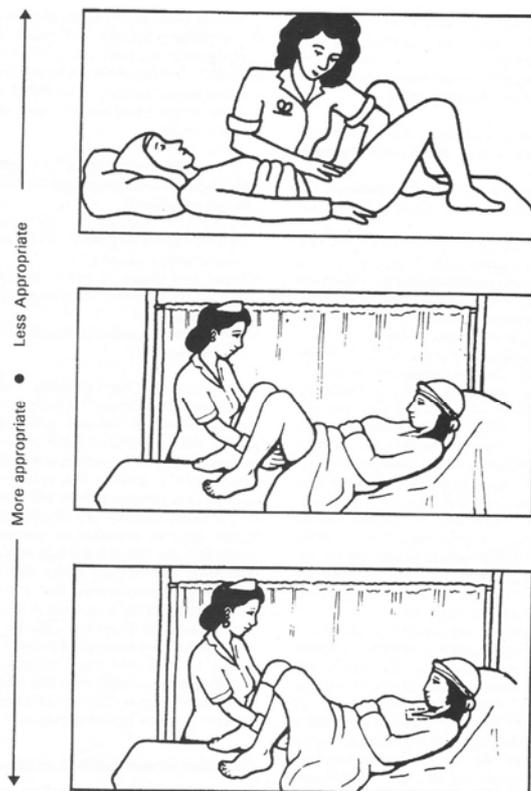
Interventions to enhance the different levels of cultural competence will provide a vital complement to best practices.<sup>154</sup> Several authors have suggested such interventions and assessments.

1. Doak, Doak *et al*<sup>122</sup> state that for instruction to be culturally appropriate, it must match the logic, language and experience of the intended audience. For example, giving the nutritional instruction to eat asparagus and romaine lettuce is inappropriate if the vegetables are not regularly eaten in the culture and are not available in the local markets. They also concluded that cultural images must be presented in a positive and realistic way.
2. The Printed Cancer Education Materials for African Americans Cultural Sensitivity Tool<sup>155</sup> is a standardised tool to evaluate material in three categories: format, written message and visual image. Although it is aimed at African Americans and cancer prevention material, most of the principles included in the tool can be used for general assessment of cultural sensitivity.
3. Byrne, Weddle *et al*<sup>156</sup> view cultural sensitivity in terms of bias. They summarised the ways in which written material can be biased towards specific groups under six categories namely: Invisibility or omission; Stereotyping; Imbalance and selectivity; Unreality; Fragmentation and isolation; and Linguistic bias.
4. Wilson and Racine<sup>124</sup> used the Bloch's Ethnic/Cultural Assessment Guide to measure the cultural sensitivity of written anticoagulation therapy patient education materials. They derived the following questions from the assessment guide:
  - Did the written information identify or target particular groups?
  - Did the written information contain statements about the target groups' beliefs and attitudes towards life, health or illness?
  - Was the written information presented in the language of the target group?
  - Did the written information address cultural healing systems or healing practices adhered to by the target group?
  - Were food preferences and restrictions addressed in the written materials?

The common denominator in all these different interventions is an urgency for writers of health information to be more aware of cultural differences. Writers must thus be sensitive to how their personal beliefs and biases influence the way they portray information. This insensitivity is evident even in countries that are much less culturally

diverse than South Africa. For example, Wilson and Racine<sup>124</sup> found the material they evaluated, 95% culturally inappropriate for urban, older African Americans.

Although cultural sensitivity relates to ethnicity, subcultures within ethnic groups should also be considered. Such subcultures could include groups defined by gender, age and religion. Hugo and Smit<sup>157</sup> gives an example (Figure 2-13) of how pictures were modified to be more appropriate to women in Muslim communities.



**Figure 2-13: Graphic modification to increase cultural appropriateness<sup>157</sup>**

Since women of this religion are attentive of wearing clothes that cover most of their bodies, pictures portraying more discrete use of clothing and privacy, are considered more sensitive.

Similarly, the unique needs of persons with disabilities must be understood when determining the cultural sensitivity of material. Too often it is assumed that health promotion interventions aimed at the general population will result in the same outcomes for persons with disabilities. This universal approach fails to consider limitations of time, energy, and mobility often associated with disability. Individuals

with disabilities may need additional or special health-related information that does not apply to the general population.<sup>158</sup>

Language that is sensitive towards disabled people is another example of cultural sensitivity. Many lists and guidelines exist regarding preferred terminology for people with disabilities.<sup>159,160,161</sup> Although there are some discrepancies between these recommendations, they are all based on the principle of “people first language”. People First Language puts the person before the disability and it describes what a person has, not who a person is.<sup>160</sup> Although some disabled people prefer the terms "physically challenged" or "differently abled", these terms are not generally used.<sup>159, 160</sup> The disability rights movement of South Africa accepts both the terms "disabled person" and "people with disabilities".<sup>160</sup> Table 5 shows examples from one such list with people first language opposed to insensitive language.<sup>161</sup>

**Table 5: Examples of People First Language<sup>161</sup>**

Say:	Instead of:
People with disabilities.	The handicapped or disabled.
Paul has a cognitive disability.	He's mentally retarded.
Kate has autism	She's autistic.
Ryan has Down syndrome	He's Down's; mongoloid.
Sara has a learning disability	She's learning disabled.
Bob has a physical disability	He's a quadriplegic/is crippled.
Tom has a mental health condition.	He's emotionally disturbed/mentally ill.
Nora uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
Tonya has a developmental delay.	She's developmentally delayed.
Children without disabilities	Normal/healthy/typical children

Although such lists can serve as guidelines, the advice from the National Rehabilitation Association<sup>162</sup> is:

*"There are no laws governing the terminology any one organisation or community might prefer. There are no hard and fast rules. There is, though, a point of sensitivity"*

This stresses the importance of testing material with target audiences and involving them from the planning stage.

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## 2.13 Chapter summary

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In this Chapter literature concerning the underlying issues of the study was reviewed.

Stroke is a leading cause of disability worldwide. In South Africa, there is an increase in the incidence of stroke, most likely due to an epidemiological transition.

Furthermore, the profile of South Africans who get strokes is different from developed regions. Not only are South African stroke survivors younger but they are usually also more severely disabled by the stroke. Rehabilitation services for these stroke survivors are very limited and they are most often cared for by untrained family members. All of these factors place a tremendous burden of care on their caregivers.

CBR has been identified as a strategy that can be client and caregiver driven and consequently can relieve this burden of care. The confusion between true CBR and rehabilitation that is provided at a community level seems to hamper the positive outcomes of this strategy. It was also discussed that comprehensive CBR must include a disability prevention programme. Stroke is a highly preventable disease and its consequent disability can be prevented at a primary, secondary and tertiary level. Although South Africa has numerous policies in this regard, there is an apparent gap between the policies and their implementation. Many health promotion strategies appear to face the same challenge. Yet, the ideal of empowerment through informed decisions remains a worthy goal.

One of the central needs for successful CBR, disability prevention and health promotion is the need for information. This need is also well described among both stroke survivors and their caregivers although, access to information is often limited due to problems related to literacy. Not only do people need to comprehend the written text and graphic presentation, they must also be able to integrate and apply the information functionally.

Literacy statistics from South Africa raise the question of the appropriateness of written information for large parts of the population. Even so, literature provides enough evidence to support the use of written material, provided that it is suitable for the target audience. However, the assessment of this suitability is a challenging process.

Testing written health material against checklists and guidelines can make a valuable contribution in the refinement of material before testing it with the target audience. The HAMSOC model provides a framework for such evaluation. It is based on three cornerstones of equal importance: Health Education, Appropriate Media and Technology, and Socio-cultural Sensitivity. This means that what is said, is as important as how it is said and whether it is conveyed in a cultural sensitive manner. This cultural sensitivity also includes sensitivity towards disability related issues and language. In developing a new checklist based on these principles, the details to be considered under each cornerstone will be fully explored.

# Chapter 3

## Methodology

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### 3.1 Introduction

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This Chapter sets out the methodology of the study. The aim, objectives and research design are presented, after which a description of the methodology follows. This includes an exposition of the sampling method and criteria, methods of data collection and data analysis. The chapter concludes with a discussion of the study's ethical considerations.

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### 3.2 Aim

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The aim of the study was to refine and pilot a training booklet for caregivers of stroke survivors for further implementation.

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### 3.3 Objectives

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The objectives of the study were to:

1. Review literature and evaluate existing tools to guide the researcher in the development of the research tool.
2. Assess the appropriateness of the booklet using the Suitability Assessment of Material as well as the new research tool.
3. Evaluate the literacy level of the target audience
4. Examine the target audience's perception regarding the comprehensibility and appropriateness of the refined version of the booklet
5. Explore the opinion of discipline specific professionals regarding the booklet
6. Make recommendations regarding further steps to the implementation of the booklet.

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## **3.4 Research Design**

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In this study, Hugo's grading model was used as a quantitative method to evaluate existing checklists for the assessment of written material. Since none of these lists were comprehensive for material aimed at developing communities, a new checklist was compiled based on the HAMSOC model. This checklist was used to retrospectively evaluate a booklet on stroke home care, developed by the CRS. The limitations and shortcomings identified by the evaluation were reformulated into recommendations. These were subsequently implemented.

Prospectively, the booklet was piloted in the study population. Focus groups were utilised to qualitatively determine the booklet's perceived usefulness and understandability. The literacy levels of the group's participants were measured using a standardised quantitative tool. In addition experts opinions were obtained on various aspects of the booklet. These results and opinions were once again formulated into recommendations for further tailoring of the booklet.

The nature of the study was developmental, with repeated feedback, refinement and evaluation of the booklet.

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## **3.5 Outline of methodology**

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As outlined in Chapter 1, this study forms part of a project to develop a training package for caregivers of stroke survivors. In this phase of the project (phase 2) the training course and the booklet are separately evaluated and refined for joint implementation and evaluation in phase 3 (See Figure 1-1 p8). Figure 3-1 is an extract from Figure 1-1, illustrating the four stages of this study. The following list is a stepwise outline of the methodology in each stage. A description of each step follows after the outline.

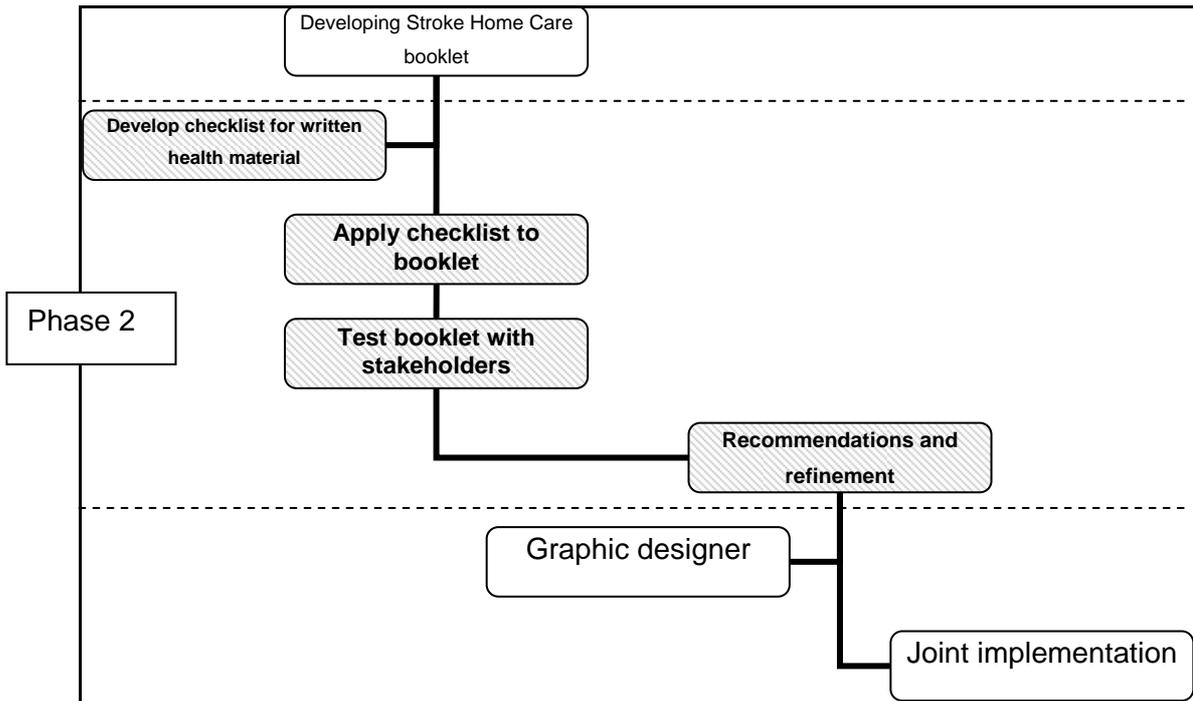


Figure 3-1: Extract from Fig 1.1, illustrating the four stages of the study

### Stage 1

1. Explore literature regarding existing checklists and grade existing checklists;
2. Develop a checklist to evaluate written health information for low literacy readers in the South African context;
3. Review of checklist by experts and potential users;

### Stage 2

4. Apply the checklist and the SAM to the booklet and make recommendations for a pre-refinement of the booklet;

### Stage 3

5. Description of tools for data collection;
6. Identification of study population;
7. Sampling of study population;
- Pilot of focus group methodology;
8. Test the booklet with samples of study population.;
9. Completion of questionnaires;
10. Expert opinions;
11. Data analysis;

#### **Stage 4**

13. Make recommendations for the tailoring and implementation of the booklet.

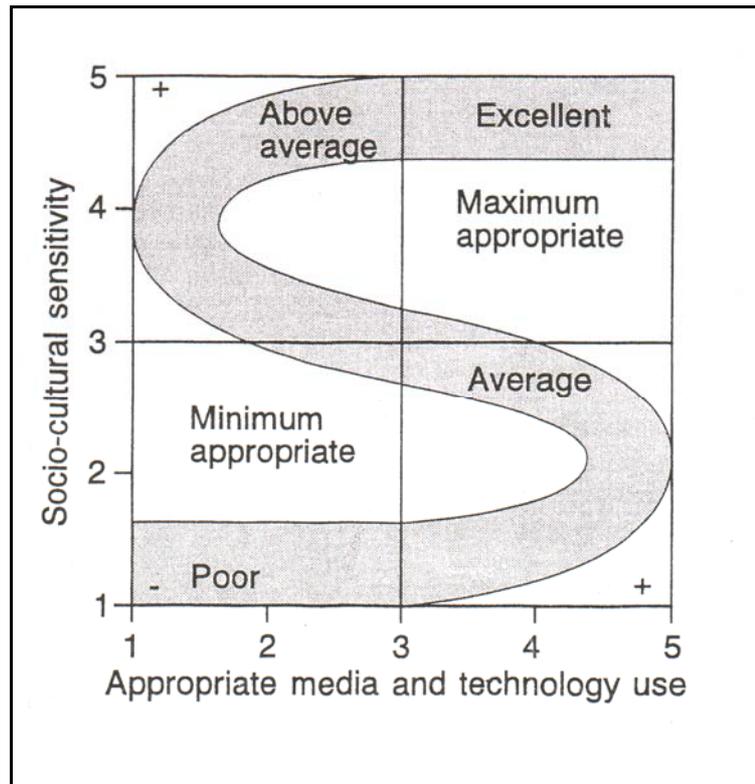
### **3.5.1 Explore literature regarding existing checklists and grade existing checklists**

Existing checklists to evaluate written patient information were identified by conducting searches of the PubMed® database as well as Google® and Google Scholar® search engines. The following terms and combinations thereof were used in the searches: 'written patient information', 'evaluating written material', 'low literacy readers', 'designing effective written information', 'guidelines for health education', 'written information in developing countries', 'cultural sensitive material' and 'readability'. Additional articles were subsequently located from the reference lists of retrieved articles and hyperlinks on relevant web pages.

Retrieved lists were evaluated for their suitability to evaluate written material for developing communities, by using Hugo's grading model.<sup>163</sup> New lists were searched until six consecutive lists revealed no new themes (as will be discussed in paragraph 3.5.2).

#### **3.5.1.1 Hugo's grading model**

Based on the cornerstones of the HAMSOC model, Hugo describes a grading model to assess and indicate the level of appropriateness of health learning materials. Each of the three cornerstones is placed on x/y axis system in relation to each of the other, thus giving rise to three graphs or diagrams. Figure 3-2 illustrates the graphic model combining media appropriateness and socio-cultural sensitivity in quality assessment.



**Figure 3-2: Graphic model combining media appropriateness and socio-cultural sensitivity in quality assessment<sup>163</sup>**

The diagram also shows an 'S'-shaped structure (called the "success curve") that is superimposed over the four window segments. Media appropriateness is viewed as a quality with different variations on a continuum. It runs through all four segments. This curve is used to plot the relative appropriateness of a certain product. In this way one can categorise the product as highly inappropriate, moderately inappropriate, moderately appropriate or highly appropriate. By combining the results of the success curves of all three diagrams a balanced grading can be given to a specific product's appropriateness and suitability. Each component (cornerstone) has both a negative and a positive dimension, indicated by a five point measuring scale.

Regarding **appropriate media and technology**, the measuring points for a checklist will be:

1. No measurement of media.
2. Measuring some educational use of media features.
3. Limited measurement of multimedia in teaching and learning.
4. Clear measurement of the multimedia approach for teaching and learning.

5. Optimal measurement of the multi media approach to promote learning. (For the purpose of this study, measurement of "multi media" was applied as measuring both text and pictures.)

As far as **socio-cultural sensitivity** is concerned, the five measuring points are:

1. No measurement of socio-cultural sensitivity.
2. Broad attention to some socio- cultural aspects.
3. Limited attention to socio- cultural differences of some target groups.
4. Reflection of general socio-cultural characteristics of a specific target group.
5. Reflection of all critically important socio- cultural characteristics of a specific target group.

The measuring points regarding **health education** are:

1. No measurement of content.
2. Measuring some aspects regarding content.
3. Limited measurement of content and sources.
4. Measuring general reliability of content.
5. Reflection of evidence based information

### **3.5.2 Develop a checklist to evaluate written health information for low literacy readers in the South African context**

Since none of the existing lists were found to comprehensively evaluate written material in developing communities, a new list was developed using the information of existing lists. The existing checklists and guidelines were then broken down into individual recommendations or checkpoints. These were referenced, coded and grouped together under similar themes. New lists were searched until ten consecutive lists revealed no new themes.

The themes were then grouped together under the three cornerstones of the HAMSOC model (appropriate media and technology, health education and cultural sensitivity). Conflicting recommendations were marked as such but also grouped together under the appropriate heading.

A new checklist was compiled by putting the concept of each theme in question format. In the case of conflicting points, they were so noted and further explored before deciding on the most appropriate question.

### **3.5.3 Review of checklist by experts and potential users of the checklist**

The checklist was sent to four experts or expected users for comments. The author of the booklet, a graphic designer, an occupational therapist and a medical practitioner who writes patient information leaflets, were consulted. Their comments and suggestions were considered and incorporated in the checklist. A biostatistician gave input into the grading method of the checklist.

### **3.5.4 Test the booklet against the checklist and make subsequent recommendation for its refinement**

The researcher applied the new checklist as well as the SAM to the booklet and compared the results of the two assessments. Remedies for the exposed gaps were suggested and presented to the authors and co-authors. Changes were subsequently made to the booklet in agreement with the authors. Although the independence of the researcher in applying the checklist can be questioned, the purpose of the checklist in this study was not so much to grade the booklet as to advise to areas that needed revision. Completing the scoring sheet of the two measurements before and after the revision guided the researcher in the extent of the changes made and whether or not more changes would be necessary.

An overarching principle of the checklist is the need to test the written material with the target population. As a result the rest of the methodology of this study is focused on receiving, analysing and implementing input from relevant stakeholders.

## **3.5.5 Description of tools for data collection**

### **3.5.5.1 REALM literacy test**

As discussed in the literature review, adults often do not read at a level corresponding with the level of years of schooling they completed. In order to match the readability level of materials to the reading skills of clients, testing of literacy skills of the intended audience is essential.

The REALM (Rapid Estimate of Adult Literacy in Medicine) test was chosen to test the participants' reading skills in this study. In the REALM the client reads from a list of 66 health / medical-related words (see Table 6). These words are arranged in three columns beginning with short words like "fat" and "flu" and proceeding to more difficult words like "medications" and "osteoporosis". Participants are asked to read the words aloud, starting at the top. The tester uses a corresponding list to check whether the words are pronounced correctly. The raw score is the number of words pronounced correctly. This is converted to a reading grade range (see Table 7).

**Table 6: REALM test word list<sup>123</sup>**

List 1	List 2	List 3
fat	fatigue	allergic
flu	pelvic	menstrual
pill	jaundice	testicle
dose	infection	colitis
eye	exercise	emergency
stress	behaviour	medication
smear	prescription	occupation
nerves	notify	sexually
germs	gallbladder	alcoholism
meals	calories	irritation
disease	depression	constipation
cancer	miscarriage	gonorrhoea
caffeine	pregnancy	inflammatory
attack	arthritis	diabetes
kidney	nutrition	hepatitis
hormones	menopause	antibiotics
herpes	appendix	diagnosis
seizure	abnormal	potassium
bowel	syphilis	anemia
asthma	hemorrhoids	obesity
rectal	nausea	osteoporosis
incest	directed	impetigo

**Table 7: REALM scoring chart<sup>123</sup>**

Raw score	Grade range
0-18	3 <sup>rd</sup> grade and below
19-44	4 <sup>th</sup> to 6 <sup>th</sup> grades
45-60	7 <sup>th</sup> to 8 <sup>th</sup> grades
61-66	9 <sup>th</sup> grade and above

**Advantages of the REALM**

- It is a standardised test.
- It is more likely to be accepted by people in a health care setting because of the health related word.
- It takes less time to administer than other standardised tests.
- It is easier to score than other standardised tests.
- Although the REALM is copyrighted there is no cost to use or copy the test, provided that acknowledgement is given.

**Disadvantages of the REALM**

- It does not test comprehension.
- It is less specific than other tests in as much that it gives scores as a range of grade levels. This was found to be of little consequences in the health setting.
- It is only available in English.
- The spelling used in the list is American. This can potentially influence readers that received formal education in South African or British English.

**3.5.5.2 Focus group discussion**

Learning and knowledge improvement are influenced by a multitude of factors. Moreover, since the booklet was not intended to be used in isolation, trying to evaluate separately the booklet's strength in improving knowledge would not be fair.

Nevertheless, this study is interested in the target audience's opinion as to whether they think the booklet is a helpful tool and whether they found it easy to understand. This information can then be used to tailor the booklet for the intended users. Focus group discussions were chosen to gain insight into the target audience's perception of the usability and understandability of the booklet. Focus group interviews are

considered an appropriate method to assist in identifying and clarifying problems. Insight is gained into people's experiences that the facilitators may not see from their own perspective.<sup>164</sup> The interactive nature of focus groups stimulates participants to form and give opinions not only based on what their own initial experience was, but also to respond to the experience of other participants.<sup>165</sup> This enriches the data that is collected.

Furthermore, the conversation among group participants will reveal expressions and specific words used by the users.<sup>164</sup> These words can be used to clarify meanings within the written text of the booklet.

A focus group guideline (Appendix 8) was set up to guide the discussions.

### **3.5.5.3 Questionnaire on preference for pre- or post- refinement version of the booklet**

After the focus groups discussions, the question arose whether the target audience actually prefers the refined booklet to the original booklet. In addition to the changes prompted by the checklist, the original booklet was printed in A5 format (Appendix 12). A questionnaire (Appendix 9) was set up in consultation with the biostatistician, to investigate clients' preferences of the two booklets. Since the participants of the first focus group had already been discharged, a separate sample was selected based on the same criteria, to complete this brief questionnaire.

### **3.5.6 Identification of study population**

The target audience of the booklet on Stroke Home Care is stroke survivors and their caregivers – specifically persons living in lower socio-economic backgrounds and who are at least functionally literate. Since it was developed after identifying a problem at the WCRC, the study population was identified within the client base of the Centre. Therefore, the study population for this study is functionally literate stroke survivors, and caregivers of stroke survivors, in the Cape Town Metropole.

The population census for 2001 estimated the total population for the Western Cape to be 4,5 million people, of whom almost 2,9 million live in the Cape Town Metropole. Afrikaans is 55% of the population's first language, Xhosa 22,7% and only 19,3% English.<sup>166</sup>

According to the census 86.5% of households in the Western Cape have a flush or chemical toilet, 67.5% have running water inside their dwellings, 85.2% have running water on their property, and 78,8% of households use electricity.

### **3.5.7 Sampling of study population**

The main purpose of testing the booklet in the study population was to get qualitative information to direct the tailoring of the booklet. Although quantitative data (REALM literacy test) were also collected the samples were purposefully selected to best suit the qualitative part of the study.

Horsburgh,<sup>167</sup> concluded that for sampling in qualitative work, randomness and representation are of less concern than relevance. Thus, initial sampling decisions should be purposive, in that selection of participants is based on their ability to provide relevant data in the area under investigation. Based on this theory, three samples of convenience were initially chosen.

Horsburgh<sup>167</sup> further comments that the initial data analysis should indicate the future direction of the sampling, in order to develop a theory from data analysis. Hence, two more samples were selected. Sample 4 was selected because of the non-representation of family members and of Xhosa speakers in the first two samples. The inclusion of this sector of the study population in the samples is important because 22,7% of the Western Cape's population as well as the majority of persons living in informal settlements in the Metropole are Xhosa speaking.<sup>168</sup> Sample 5 was selected based on new questions that arose after the initial data analysis.

#### **3.5.7.1 Sample 1- Stroke patients in the WCRC**

The WCRC has a large concentration of stroke survivors receiving inpatient rehabilitation. A representative sample of the study population was expected by drawing a sample from this facility. All clients that met the inclusion and exclusion criteria were invited to take part in the discussion.

##### **Inclusion criteria:**

- Experienced a stroke;
- Older than twenty one years;
- Voluntary participation;

- Admitted between 4 - 9 June 2007; and
- Able to speak and read English.

**Exclusion criteria:**

- Significant speech or language problems; participants must be able to partake in a group discussion; and /or
- Mini mental state examination (MMSE) score of less than 22 (Appendix 6). The MMSE is regarded a suitable screening test for cognitive problems. In general, a score lower than 22 represents dementia.<sup>169,170</sup>

**3.5.7.2 Sample 2 - Family members or other caregivers of stroke patients in the WCRC**

Family and friends likely to be involved with caring for stroke survivors after their discharge from the WCRC were invited to partake in a group discussion.

**Inclusion criteria:**

- Family members and anticipated caregivers of patients in the WCRC (during 22 June to 29 June 2007) who suffered a stroke;
- Able to speak and read English;
- Older than twenty one years;
- Voluntary participation; and
- Independent transport to the group discussion.

**Exclusion criteria:**

- None

**3.5.7.3 Sample 3 – Home based caregivers attending the caregivers training by staff of the WCRC on 13 June 2007**

The WCRC is involved in training caregivers from a variety of institutions and organisations. The majority of these caregivers either work in institutions of caring (i.e. old age homes and step- down- facilities), or are volunteers at disabled people's organisations or are family members of disabled persons. The booklet and other training material developed as part of the original project funded by Portnet are currently used for this purpose. Dates for these training sessions are set at the beginning of the year, and people or organisations who are interested can book in advance to attend.

The participants of the training session held on 13 June 2007 were invited to partake in the study.

**Inclusion criteria**

- Older than twenty years
- Voluntary
- Able to speak and read English

**Exclusion criteria**

- None

**3.5.7.4 Sample 4 – Stroke survivors and their caregivers participating in the University of the Western Cape’s home based care programme in Nyanga**

The samples drawn at the WCRC were expected to be representative of the demographic distribution in the province. Unfortunately, at the time of the study there were no Xhosa speaking stroke patients admitted to the WCRC who met the criteria of the study. In addition, a nationwide strike of health workers at the time when the study was conducted made it unsafe for visitors at the Centre. Consequently, only one family member joined the discussion.

In an effort to involve Xhosa speaking stroke survivors and caregivers in the study, the researcher contacted the Home Based Care programme of the University of the Western Cape. The programme operates in Nyanga, an informal settlement near Cape Town and provides an outreach service to disabled persons in the community. Purposeful sampling was done via the coordinator. Stroke survivors and their caregivers who met the same inclusion and exclusion criteria as the first two samples (except admission date) were invited to participate.

**3.5.7.5 Sample 5 – Stroke patients in the WCRC**

Ten stroke patients who met the inclusion and exclusion criteria were asked to complete a questionnaire on their preference for either the pre-refined or post-refined booklet. Ten consecutive in-patients admitted to the WCRC that adhered to the criteria were identified by a trained research assistant.

**Inclusion criteria:**

- Experienced a stroke;
- Older than twenty one years;
- Voluntary participation; and

- Able to speak and read English.

**Exclusion criteria:**

- Significant speech or language problems; and/ or
- MMSE score of less than 22.

### **3.5.8 Pilot of the focus group methodology**

In order to test the comprehensiveness and appropriateness of the focus group guideline, a pilot focus group was held.

The researcher obtained consent from the management of Riverfield Lodge Rehabilitation Hospital in Johannesburg to conduct the pilot study there. (Appendix 3) Although this is a private hospital, the patient population with regard to distribution of diagnosis, is similar to that of WCRC.

Based on the inclusion and exclusion criteria, the rehabilitation team identified three participants. The two men and one woman were all older than 60 years and residing in the Johannesburg area. One was Afrikaans speaking and the other English speaking. After written informed consent was obtained, each participant completed the REALM literacy test and received a booklet to read. The group discussion was held four days later.

The researcher facilitated the focus group discussion based on the focus group guideline. The discussion was recorded on tape and afterwards transcribed. All three participants had more than twelve years of formal education. Two scored gr 9+ in the REALM, and one below gr 3. The researcher suspects that this was due to cognitive problems related to the stroke. No need for alterations of the guidelines was identified.

### **3.5.9 Test the booklet with samples of study population.**

Permission was requested from and granted by the head of the WCRC to conduct the study at the Centre (Appendix 2).

All participants in the focus group discussion gave written consent (Appendix 4) and completed a REALM literacy test (Appendix 7). After receiving the booklet,

participants were given four days to read it before the discussion. The researcher emphasised the fact that the group discussion would not be a test of their knowledge of the booklet but feedback on how clear and helpful they found it.

From the first two samples, one focus groups was compiled. In sample 1 eleven participants were identified and invited by the team facilitator of the WCRC. All eleven agreed to partake. In sample 2 the team facilitator identified four possible participants. Due to the strike of health care workers, only one family member could attend the discussion. This person joined the group discussion of the stroke survivors. The majority of this group preferred to speak Afrikaans and everyone in the group understood Afrikaans. The discussion was held in both English and Afrikaans with most group members responding in Afrikaans. It was held on 13 June 2007 at the WCRC.

The second group was the caregivers at the WCRC training session. This group consisted of four home based carers from the Association of Physical Disabled People (APD) and 22 student nursing assistants. After their training these nursing assistants will be responsible for the caring of persons (including stroke survivors) in institutions and private homes. The booklets were distributed to the trainees four days before the training and the discussion was held on 20 June 2007 at the WCRC, before the training commenced

The third group consisted of four caregivers and four stroke survivors of the Home Based Care Programme (Nyanga) of the University of Western Cape. They were identified and invited by the programme coordinator, who is one of the local home based carers. Unfortunately, one of the stroke survivors had significant cognitive impairment (MMSE < 22) that was not recognised by the programme coordinator. He did not read the booklet and a REALM literacy test was not completed for him. Everyone in the group understood English but the programme coordinator translated between Xhosa and English when necessary. This discussion was conducted on 20 June 2007 at the offices of the Home Based Care Programme.

The focus group guideline (Appendix 8) was used to structure all three conversations. The researcher made notes during the discussions and also audio taped and transcribed the conversations.

### **3.5.10 Completion of questionnaires**

A trained research assistant identified ten participants for the fifth sample. She obtained written consent from everyone (see Appendix 5) after which they were shown the two booklets and requested to complete the questionnaire. The participants completed the questionnaires individually without the presence of any of any of the other participants. The research assistant was present to assist with any questions or uncertainties.

### **3.5.11 Expert opinions**

Experts from various related fields were invited to comment on the booklet with specific reference to their own field of expertise. Two graphic designers, a medical practitioner, an occupational therapist and physiotherapist working in a rehabilitation centre participated. Their views were gathered through individual interviews.

### **3.5.12 Data analysis**

Four sets of data with regard to different stakeholders were analysed:

#### **3.5.12.1 REALM literacy tests**

The data was captured and sorted on an Excel<sup>®</sup> spreadsheet. A statistician analysed the data with Statistica<sup>®</sup>. The responses were first tested for normality and most responses were found not normally distributed. Consequently, the statistician recommended that the median and not the mean of the REALM scores be used to determine the proposed readability level.

#### **3.5.12.2 Focus group discussions**

The audiotapes of the three focus group discussions were transcribed verbatim. The responses were clustered and common themes established. All responses that referred to parts of the booklet that were unclear were reformulated into recommendations for improving the booklet.

#### **3.5.12.3 Questionnaires**

The responses to the questionnaire were captured on an Excel<sup>®</sup> datasheet. It was analysed with the help of a statistician.

#### **3.5.12.4 Expert interviews**

The comments of the experts were written in note form. The responses were clustered into similar themes that arose from the focus group discussions. Recommendations for refinement of the booklet were subsequently formulated.

#### **3.5.13 Recommendations for further refinement of the booklet**

The interpreted results were consolidated into recommendations for the further tailoring of the booklet. After consultation with the authors the relevant recommendations were implemented.

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### **3.6 Ethical considerations**

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- Ethical clearance was obtained from Ethical Committee C of the Stellenbosch University (reference: N06/11/220).
- No person was excluded from the study on grounds of gender or race.
- All participants in the study were invited to participate on a voluntary basis.
- Written informed consent (Appendix 4 and 5) was obtained from all participants after explaining the aim and the nature of the study to the participants in writing as well as during an interview.
- All information gathered was treated with confidentiality.
- No participant was paid for participation.
- There was no cost for participants.
- There were no risks for participants in this study.
- It is foreseen that participants will benefit from receiving the booklet as a future resource.
- The content of this thesis remains the intellectual property of the University of Stellenbosch. Relevant permission to publish or present these results will be obtained.

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### **3.7 Chapter summary**

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In Chapter 3 the methodology of the study was described. The aim and study objectives provided the framework for this methodology. The nature of the study is

developmental and both quantitative and qualitative methods were used do make recommendations towards the refinement of the booklet on stroke homecare.

After the grading of existing checklists, a new checklist was compiled based on the principles of the HAMSOC model. This new checklist as well as the SAM was used to evaluate the booklet and make recommendations for a pre test refinement. The other tools used for data collection were subsequently identified and discussed.

The study population was identified as functionally literate stroke survivors and caregivers of stroke survivors in the Cape Town Metropole. Five samples were used and the sampling criteria and methods were described.

After a pilot focus group the booklet was tested with the four samples of the target audience. The fifth sample was asked to complete a questionnaire on their preference between pre and post refined booklet. Practitioners in the field of rehabilitation and graphic design were also invited to give feedback regarding the booklet.

The analysis of the different sets of data was also described. The results of these analyses will be used to formulate recommendations for further tailoring of the booklet and steps for its implementation.

Finally, the researcher described how this study fulfills ethical requirements.

# Chapter 4

## The development of a new checklist

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### 4.1 Introduction

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In the first stage of the study existing list were assessed for their appropriateness to comprehensively assess written health material for developing communities. Consequently, twenty existing checklists were graded using Hugo's grading model. Since none of these lists fulfilled all the criteria of this model, a new list was compiled. The new list was developed from the collective themes that emerged from the twenty existing lists.

In this Chapter the results of the evaluation of the existing lists as well as their breakdown into themes are presented and discussed. This is followed by an exposition of the development of the new checklist as well as its proposed scoring system. Finally, each question in the checklist is discussed and the research base for each provided. The information in this chapter is regarded as results of the study but is presented in a separate chapter to assist in organising the information.

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### 4.2 Measurement of existing checklists

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The following twenty lists were identified in the literature and graded using Hugo's grading model:

1. The Suitability Assessment of Material (SAM) (Doak,Doak and Root, 1996)<sup>123</sup>
2. Cancer prevention materials for African American Assessment Cultural Sensitivity Tool (Guidry, updated 2007)<sup>155</sup>
3. Questions with regard to the picture and syntax of the picture (De Lange,1999)<sup>141</sup>

4. A guide for choosing and designing easy-to-read print materials (Cantrera et al, 2004)<sup>118</sup>
5. General guidance on writing information for patients (NHS, updated 2006)<sup>145</sup>
6. Guidelines for preparing patient education handouts (UC Davis Health System, updated 2007)<sup>138</sup>
7. Clear & Simple (National Cancer Institute, updated 2003)<sup>171</sup>
8. Design heuristics for print materials aimed at low-literate audiences (Carstens 2003)<sup>128</sup>
9. Making myself clear (Mencap, 2002)<sup>139</sup>
10. Recommendations for designing effective written health education materials (Hoffmann, Worral, 2004)<sup>129</sup>
11. Area Health Education Center Assessment Checklist (Wilson, Williams , 2003)<sup>132</sup>
12. Principles for designing effective written educational materials (Griffin, McKenna, Tooth, 2003)<sup>130</sup>
13. Simply Put (Centres for Disease control and prevention, 1999)<sup>112</sup>
14. Comprehension review Matrix (Carstens, Snyman, 2003)<sup>172</sup>
15. Writing for a Changing World: Reaching Low Literacy Audiences With Print Material<sup>173</sup>
16. Patient/Family Education Print Material Guidelines (Capital Health Patient Education Advisory Committee, 2004)<sup>174</sup>
17. How to create and assess print materials (Rudd RE, 2005)<sup>175</sup>
18. You Can Prepare Easy-to-Read Materials (Centre for Substance Abuse Prevention, 1994)<sup>176</sup>
19. Developing and evaluating patient education materials (Monsivais, Reynolds, 2003)<sup>177</sup>
20. Criteria for evaluating nutrition education leaflets (Perkins, 2000)<sup>178</sup>

Hugo's grading model (par. 3.5.1.1) was used to grade these twenty lists in order to assess the level of appropriateness to measure written health information. The results of the measurements are presented in Table 8. The first two columns show the number and name of the evaluated list. The third column ("scoring"), indicates lists that had a scoring mechanism or provided a means of interpretation. The following three columns give a score out of five for the suitability to measure each of the three cornerstones of the HAMSOC model.<sup>e</sup>

The score in the column "level of appropriateness" was determined by the combination of the three scores and deduced from Figure 3-2. If any of the three measurements scored one, the appropriateness level was marked as highly inappropriate, regardless of the other scores. The last column gives a short description of the list. The rows in bold indicate the lists that scored highest grading.

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<sup>e</sup> Regarding appropriate media and technology (AMT) the measuring points were:

1. No measurement of media
2. Measuring some educational use of media features
3. Limited measurement of multimedia in teaching and learning
4. Clear measurement of the multimedia approach for teaching and learning
5. Optimal measurement of the multi media approach to promote learning

As far as socio-cultural sensitivity (SCS) is concerned, the five measuring points were:

1. No measurement of socio-cultural sensitivity
2. Broad attention to some socio- cultural aspects
3. Limited attention to socio- cultural differences of some target groups
4. Reflection of general socio-cultural characteristics of a specific target group
5. Reflection of all critically important socio- cultural characteristics of a target group

The measuring points regarding health education (HE) were:

1. No measurement of content
2. Measuring some aspects regarding content
3. Limited measurement of content and sources
4. Measuring general reliability of content
5. Reflection of evidence based information

**Table 8: Results of Hugo's grading model applied to 20 existing checklists**

Nu	Name of list	scoring	AMT	SCS	HE	Level of appropriateness	Description
1	<b>Suitability Assessment of Material (SAM)</b>	Yes	5	3	4	Highly appropriate	Widely used standardised tool
2	Cancer prevention materials for African American Assessment Cultural Sensitivity Tool	Yes	2	5	2	Moderately inappropriate	Standardised tool to assess cultural sensitivity
3	Questions with regard to the picture and syntax of the picture	No	2	2	2	Highly inappropriate	Comprehensive list to evaluate usefulness of pictures for educational purposes
4	<b>A guide for choosing and designing easy-to-read print materials</b>	Yes	5	2	5	Moderately appropriate	<b>A comprehensive checklist on layout and content</b>
5	General guidance on writing information for patients	No	3	1	3	Highly inappropriate	Online toolkit of the United Kingdom Health Services
6	Guidelines for preparing patient education handouts	No	3	1	4	Highly inappropriate	Descriptive guidelines with many examples
7	Clear & Simple	No	4	1	4	Highly inappropriate	Checklist is a summary of comprehensive manual on topic
8	Design heuristics for print materials aimed at low-literate audiences	No	5	3	4	Highly appropriate	A checklist with a description of the proposed reader effect of each aspect
9	Making myself clear	No	3	1	2	Highly inappropriate	Guidelines to write easy-to-understand material for persons with intellectual disabilities
10	Recommendations for designing effective written health education materials	No	5	1	5	Highly inappropriate	Comprehensive, detailed recommendations, no reference to cultural sensitivity
11	Area Health Education Center Assessment Checklist	Yes	4	2	2	Moderately inappropriate	Short easy to use checklist
12	<b>Principles for designing effective written educational materials</b>	No	4	2	5	Moderately appropriate	<b>Short, list of principles</b>
13	Simply Put	No	5	2	2	Moderately inappropriate	A 48 page downloadable manual with a 15 point checklist at the end
14	Comprehension review Matrix	Yes	3	1	5	Highly inappropriate	Easy to use matrix that claims to be specific for the need of South Africans, there is however no referral to cultural sensitivity
15	Writing for a Changing World: Reaching Low Literacy Audiences With Print material	No	3	1	2	Highly inappropriate	A short list of recommendations, contrasted with recommendations for web pages
16	Patient/Family Education Print Material Guidelines	Yes	4	2	5	Moderately appropriate	Manual on writing patient information; extensive questions and guidelines on content, includes questionnaires for users
17	How to create and assess print materials	Yes	3	1	3	Highly inappropriate	Step-by step guideline to create print materials
18	You Can Prepare Easy-to-Read Materials	No	4	2	2	Moderately inappropriate	A descriptive five step guideline with specific reference to substance abuse
19	Developing and evaluating patient education materials	No	3	1	2	Moderately inappropriate	Summary of recommendations from academic article
20	<b>Criteria for evaluating nutrition education leaflets</b>	No	3	2	4	Moderately appropriate	<b>Short list for specific use in developing nutritional pamphlets</b>

**AMT:** Appropriate Media and technology, **SCS:** Socio-cultural Sensitivity, **HE:** Health Education.

Of the twenty lists, twelve had no scoring system. Ten of the lists gave a clear to optimal measurement of media appropriateness, and nine measured health education adequately. However, socio-cultural sensitivity was effectively measured by one list only. (This is a list specifically designed for socio-cultural sensitivity). Nine lists made no reference to socio-cultural sensitivity and eight only gave attention to broad cultural aspects. Thirteen of the lists were inappropriate to comprehensively measure written health information and only the SAM was found “highly appropriate”. Unfortunately, the list gave only “limited attention” to socio-cultural aspects. In practice, a document that scores “inadequate” (0) for cultural sensitivity could still overall be rated as “superior”.

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### 4.3 Unpacking of existing lists

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An initial five lists were unpacked into specific component elements and thereafter grouped together in themes. The themes were then sorted under three headings, based on the cornerstones of the HAMSOC model. Within the group of appropriate media, six subcategories were established, namely: Language, layout, typography and visual appearance, production, organisation, readability and illustrations.

Fifteen more lists were unpacked and the elements were grouped under these headings and subcategories. New themes that arose were captured under the relevant heading. New themes were identified in the first ten lists, the other ten lists revealed no new themes, and the search for more checklists was concluded.

A total of 75 themes were identified. Appendix 10(p195) shows the distribution of the themes in the twenty lists. The lists revealed remarkable similarities, with most themes occurring in two or more lists and 31 occurring in five or more lists. Only fifteen themes occurred only once. Of these fifteen, ten came from two lists guiding specific facets of written material, the *Cultural Sensitivity Tool* and *Questions with regard to the picture and syntax of the picture*. In all the lists only two discrepancies occurred: The preferred typeface (font) to use and whether or not to use numeric numbers or written words for numbers under twenty. This is fully discussed in Chapter 5. Table 9 shows extracts from the table in Appendix 11, demonstrating some of the themes that occurred most and least. All twenty lists are represented in the numbered columns.

**Table 9: Extracts from Appendix 10**

	Themes	Existing list ( as numbered in par 4.2)																			
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
19	Are difficult concepts explained using common, everyday words and are confusing or unknown terms clearly defined?	X	X			X	X	X	X	X	X	X	X	X	X	X	X		X	X	
26	Do the pages appear uncluttered with ample white space?	X			X	X	X		X	X		X	X	X			X	X	X	X	
36	Is the most important information presented first and sequenced in a logical order?				X	X	X	X	X	X	X		X	X		X	X		X	X	
52	Are the legends easy to understand?			X																	
63	If the information is not individualised or compiled for a specific cultural grouping, does the material reflect respect for the cultural, ethnic and/or religious diversity of society?		X																		
64	Are the words, phrases, and expressions free from stereotypical meaning?		X																		
67	Are the referral sources accessible to the intended audience?		X														X				

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## 4.4 The new checklist

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Based on the themes deduced from the existing lists, a new checklist (see Appendix 11, p200) was compiled. All the themes were used and reformulated as questions. Where necessary, explanatory notes and comments were added underneath a question. Since a readability check is suggested, the SMOG methodology was added at the end of the checklist. The list commences with a brief introduction and an outline of its underlying principles.

The 75 questions are grouped together in the three categories of the HAMSOC model. The category of appropriate media and technology has six subcategories namely: Language, layout, typography and visual appearance, production, organisation, readability and illustrations.

Each question can be marked as "yes" or "no" and in some instances as "not applicable". One mark is allocated for each "yes" and none for a "no" answer. The total for each category is counted and a score out of five is calculated by a simple mathematical calculation. The total of the three scores is used to determine a level of appropriateness (see Table 10). The calculation is based on the statistical principle of comparing mean values. The interpretation of the scores is once again based on Hugo's grading model.<sup>163</sup>

**Table 10: Interpretation of the developed checklist's score**

<b>Total of three scores</b>	<b>Level of appropriateness</b>
If any of the three sections score 2.0 and below	Highly inappropriate
< 8.0	Highly inappropriate
8.0 – 9.9	Moderately inappropriate
10.0 -11.9	Moderately appropriate
12.0 -15.0	Highly appropriate

The experts who were invited to comment on the list all agreed that it was comprehensive and can be a valuable guideline for professionals writing health information.

The motivation and research base for each of the questions are subsequently presented. This serves as the explanation and the foundation for including criteria to evaluate written health information aimed at developing communities.

#### **4.4.1 Evaluating Cornerstone 1: Health Education**

As discussed in the literature review (Chapter 2), Accuracy, Appropriateness and Relevance are the three aspects to consider when evaluating the content of written health material.

The information must not only be accurate but also up-to-date, evidence-based and appropriately referenced. Depending on the target audience, all references need not be included, but must be available on request. This will ensure reviewability by experts and clinicians and increase credibility. The credibility<sup>128,129</sup> and reviewability are further enhanced by including the names of the authors and publishing dates. If other resources, where similar or more information can be obtained, are mentioned and the information is consistent with other information given to the client, it increases the persuasiveness of the material.<sup>128</sup> Information reinforced by the health professional, letters, leaflets and appointments is more likely to lead clients to comply with recommendations.<sup>128</sup>

To assess the appropriateness of the information, it is important that the intended audience and the purpose of the material is clearly stated. For instance, information aimed at parents will (must) differ from information aimed at teenagers. Although the optimum amount of tailoring has not yet been established, individualised information was shown to be more effective to change health related behaviour.<sup>146</sup> It is recommended that the number of concepts be limited to reduce the cognitive load and enhance comprehension.

According to adult education theories, people are interested in information that helps them solve their problems or improve their well-being.<sup>129</sup> Therefore, the emphasis should be on providing information that is behaviour-focused. Furthermore, if the

content stimulates the readers to feel something after reading the message (i.e. happiness, confidence, gladness or enthusiasm) recall through emotional involvement is stimulated.<sup>128</sup>

The relevance of material is enhanced by giving information that is motivating and leads to self-efficacy. People are more motivated to learn when they believe the tasks/ behaviour are doable by them.<sup>122</sup> The use of concrete examples rather than abstract concepts also stimulates motivation.<sup>128</sup> The motivation is increased if the material is interactive and allows for audience involvement. Interaction can be attained by the use of questionnaires, space to make personal notes and instructions for self-do activities.

Lastly, the content must adhere to copyright law. Permission to use illustrations must be obtained where applicable, with due recognition given to the author. The parameters for use of the new copyrighted material must be clearly stated.<sup>112</sup>

## **4.4.2 Evaluating Cornerstone 2: Appropriate Media and Technology**

### **4.4.2.1 Language**

The comprehension of written health material is highly dependable on its language, grammatical and syntactic construction.<sup>126,129,130</sup>

Short words and phrases that are familiar to the audience increase the readability of any material and should be used as far as possible. Fifteen of the twenty lists evaluated stressed that jargon and technical words must be avoided. If for the sake of accuracy, medical terminology has to be used, it must be properly explained. The following example from The Plain English Campaign illustrates how technical terms can be rewritten in plain English:

(Original)

*“This adult nasal spray is for local application in the nose to give symptomatic relief of nasal congestion (including in colds), perennial and allergic rhinitis (including hay fever) and sinusitis.”*

(A plainer version)

*“Use this spray on adults only. It will help relieve stuffed-up nose, inflamed sinuses and hay fever. Spray directly into the nose.”<sup>179</sup>*

This example also shows how shorter sentences enhance the comprehensibility of information. Although there is some debate as to the optimal sentence length,<sup>129</sup> 15-20 words are the recommended maximum.<sup>124</sup> It is also agreed that only one idea should be expressed per sentence and that the use of multiple phrase sentences (using “and” or commas) should be avoided as they slow down reading and hinder comprehension.<sup>129,138,145</sup> However, sentences should not be overly compressed as this could disrupt the reading flow.<sup>126</sup>

The use of paragraphs also enhances comprehension and recall as “chunking” of the material decreases cognitive load.<sup>128</sup> Paragraphs should be short and presented in small boxes of text<sup>128</sup> with simple punctuation. Semicolons (;), colons (:) and hyphens (-) should be avoided.<sup>139</sup>

Another principle that is constantly recommended is that materials be written in active voice and conversational style.<sup>122,128, 129,179</sup> This has three advantages: (a) The reading level of the material will be lower, (b) the material will be more interesting to the readers<sup>126</sup> and (c) it decreases cognitive load caused by limiting syntactic transformation.<sup>128</sup> Personalising the information by writing in the second person, such as using the pronoun ‘you’, further assists in engaging and motivating the reader as well as enhancing comprehension.<sup>128,138,145</sup>

Guidelines differ in the recommendations whether to use numbers or words. The differentiation seems to be on the ground of reading speed. The National Health Services of the United Kingdom advises in their guidelines that:

*“numbers from one to nine are easier to read if they are written in words, and numbers from 10 can be represented as numbers.”<sup>145</sup>*

These guidelines are however, not specific towards clients with low literacy skills. The only other list evaluated in this study that comment on the use of numbers is ‘Making Myself Clear’ of Mencap. These guidelines are specific for clients with learning disabilities. It advises as follows:

*“If you are writing largely for people with a learning disability, always use the*

*number and not the word even for small numbers. Use 3 instead of 'three'. Try not to use percentages or large numbers. You could say 'a few' instead of 7% and 'many' instead of 1,552.*<sup>139</sup>

Even though people with low literacy skills by no means all have learning disabilities, it was decided rather to use this guideline. For fluent readers numbers written in words may be faster to read but it can be expected that readers who read word by word will read numbers easier.

Finally, the language must be consistent throughout the text as this reduces the chance for confusion and misunderstanding.<sup>139,174,176</sup>

#### **4.4.2.2 Layout and typography and visual appearance**

Moris<sup>126</sup> suggests that elements of layout are perhaps more rightly termed 'design tools' and include choice of a cover, use of white space and margins, variation in line length and text justification. This should attract and capture the reader's attention so that he or she will want to pick it up and read it. It must enhance the text with visual queuing and highlighting without interfering with the readability.

The first step to ensure this is the use of ample white space. Layout balances white space with words and illustrations. Therefore, the use of at least 1.2- 1.5 line spacing is recommended. The space between letters must be less than the space between words, and word space must be less than the space between lines as this facilitates word recognition.<sup>128</sup> Margins should be at least 1.2cm wide<sup>112</sup> and enough white space left between paragraphs. This decreases the cognitive load by helping to encode fewer chunks of information in the working memory.<sup>128</sup>

The text should only be left justified and the right margin be left ragged. This facilitates readability as unequal spaces between words reduce reading speed, and justification could lead to lines being reread or skipped. To illustrate this effect Figure 4-1 shows the same paragraph first with the recommended left justification and 1,5 line spacing and then fully justified with single line spacing.

**Paragraph 1: left justified and 1,5 line spacing**

Stroke is a complex condition by nature and caring for the stroke survivor is a challenge. This situation is worsened by little community rehabilitation services. Caretakers get inadequate or no training and support. Often stroke survivors are discharged home within 48 hours after their admission to a hospital. Many people that require hospitalisation are not even admitted to a hospital. Untrained or inadequately trained caregivers have to cope as best as they can.

**Paragraph 2: justified and single line spacing**

Stroke is a complex condition by nature and caring for the stroke survivor is a challenge. This situation is worsened by little community rehabilitation services. Caretakers get inadequate or no training and support. Often stroke survivors are discharged home within 48 hours after their admission to a hospital. Many people that require hospitalisation are not even admitted to a hospital. Untrained or inadequately trained caregivers have to cope as best as they can.

**Figure 4-1: Example of different justification and line spacing**

The headings and subheadings must be clear, consistent and close to the related text. There should be more space above a heading than below to indicate their affiliations<sup>128</sup> The headings should be in a substantially bolder and larger type face (at least 14 point) than the rest of the text. This will assist the reader in providing an overview of the text and make the overall appearance of the text more interesting and less “grey”. It also facilitates reader comprehension and recall.<sup>128</sup>

The typefaces (or “fonts” as they are commonly named in software programs) should be clear and easy to read. Fancy scripts should be avoided as they are more difficult to read. The most common classification of typefaces is serif and sans-serif. Serif typefaces have serifs – the finishing strokes at the end of letters, and sans-serif typefaces do not. Figure 4-2 shows some example of these typefaces. Literature is divided on recommendations as to what the best typeface is to use in written health material. Some recommend a serif typeface because it increases visual perception, decoding and reading speed by emphasising queuing of information.<sup>112,128,129</sup> Others prefer a sans-serif typeface because it is cleaner and clearer<sup>139,145</sup> Of more value is that several authors agree that the type of typeface is less important than its weight and the size.<sup>126,180,181</sup> Moris<sup>126</sup> even concludes that there is room for author

preference and that in certain circumstances a more informal font might be more appropriate.

<i>Fancy scripts are difficult to read</i>	
Fancy scripts are difficult to read	
<b>Serif typefaces</b>	<b>Sans Serif typefaces</b>
New Times Roman	Ariel
Palatino Linotype	Century Gothic
Garamond	Estrangelo Edessa
This is New Times Roman font size 9	Papyrus is a light font
This is New Times Roman font size 10	Ariel Black is a heavy font
This is New Times Roman font size 11	<b>Comic Sans MS is a more informal font</b>
This is New Times Roman font size 12	
This is New Times Roman font size 14	

**Figure 4-2: Examples of different typefaces**

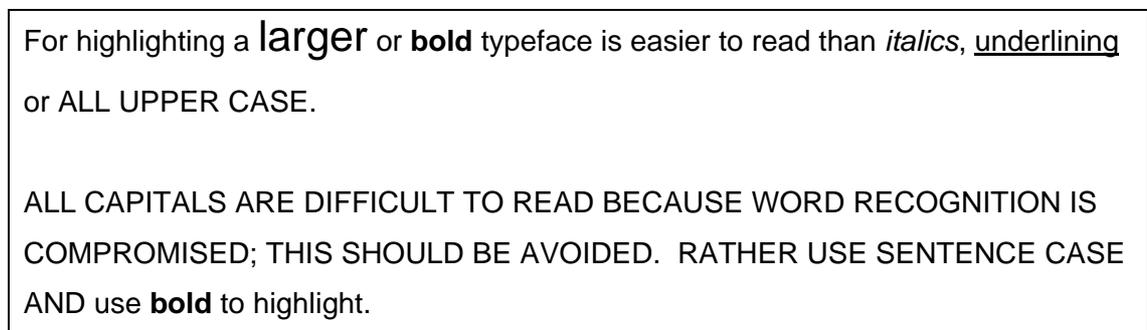
Although most authors agree that a 12 point font size should be used for the general public and a 14 point size for visually impaired persons, note must be taken that the actual size differs from typeface to typeface. In turn, this influences the word and line spacing<sup>180</sup> (see Figure 4-3).

<p>This is Sylfaen font size 12 and 1,5 linespacing</p> <p>This is Sylfaen font size 12 and 1,5 linespacing</p> <p>This is Sylfaen font size 12 and 1,5 linespacing</p> <p>This is Sylfaen font size 12 and 1,5 linespacing</p>
<p>This is Microsoft Sans Serif font size 12 and 1,5 line spacing</p> <p>This is Microsoft Sans Serif font size 12 and 1,5 line spacing</p> <p>This is Microsoft Sans Serif font size 12 and 1,5 line spacing</p> <p>This is Microsoft Sans Serif font size 12 and 1,5 line spacing</p>
<p>This is Lucinda console font size 12 and 1,5 line spacing</p> <p>This is Lucinda console font size 12 and 1,5 line spacing</p> <p>This is Lucinda console font size 12 and 1,5 line spacing</p>

**Figure 4-3: Example of 12-point typeface**

Taking all of the above into consideration, the most important aspect of choosing a typeface and size is that it must be clear and easy to read for the specific target audience. To avoid confusion and cognitive load, the use of no more than two different typefaces in one document is recommended.<sup>128</sup>

For highlighting a larger or bold typeface is recommended.<sup>139</sup> This is easier to read than italics, underlining or upper case. Sentence case, where capital letters are used only at the beginning of sentences and for names, should be used throughout the material. The use of all capitals affects the perception and word recognition of the reader and reduces reading speed<sup>128</sup> (see Figure 4-4).



**Figure 4-4: Examples of highlighting techniques**

The typeface and size, spacing and margins should be used to limit the general eye span to less than 60 -70 characters. This increases perception, encoding and subsequent readability.<sup>126,128</sup> In spacing the words, care must be taken that words are not hyphenated at the end of lines and sentences do not overflow to the next page.<sup>139</sup>

Colour can be used to enhance the attractiveness of information materials and for highlighting important text. It is very effective when used for queuing and filtering purposes, such as identifying the main points of the content.<sup>128,181</sup> Two aspects of colour to consider are the colour of the paper (background colour) and the colour of the print (type).<sup>126</sup> The most important aspect to consider is good contrast between the print and the paper.<sup>129,132</sup> Yellow type, dark or bright backgrounds and reverse type (white out of a colour) should be avoided. Although colour can be used to stimulate perception and have an emotional appeal, people's preferences tend to be idiosyncratic.<sup>171</sup> It is recommended that the chosen colour scheme be pretested on the intended audience.<sup>126,128</sup>

The cover should make the purpose of the document clear and create a favourable first impression.<sup>181</sup> The use of graphics and visuals on the cover is recommended because it attracts attention, motivates the reader to open the document, sets the tone and mood and facilitates comprehension by acting as an advance organiser.<sup>128</sup>

Finally, the layout must be consistent throughout the document.<sup>122,129,138</sup>

#### 4.4.2.3 Production

The paper weight used for written health information must be at least 130 to 150 grams per square meter (gsm). This will ensure that the reverse side print is not visible from the frontside.<sup>138</sup> In addition, the paper should have a matt finish so that it does not reflect light and consequently makes reading print on it more difficult.<sup>118,139</sup>

#### 4.4.2.4 Organisation

Both the internal and external structure of the material must be well organised. The internal structure refers to the presentation of information. According to the natural geometry of reading, information presented at the beginning of the document attracts more attention than information presented in the middle and especially near the end.<sup>181</sup> Therefore, the most important facts must be stated first. Thereafter, a sequence that is logic to the target audience must be followed.<sup>129</sup> In constructing sentences, the context must be given before any new information.<sup>122</sup> Doak gives the following example to illustrate this:

*“to find out what is wrong with you (context first), the doctor will take a sample of our blood for test (new information).”<sup>122</sup>*

To facilitate such a sequence, a question-answer format might be useful.<sup>129</sup> This will also stimulate reader interest and encourage people to examine what they are reading and to look for related facts.

Headings and subheadings are essential for the external organisation of the material. Many readers will only read the material's headlines, subheadings and highlighted information. Therefore, material should be structured so that the key points or a general overview can be gained by reading only these elements.<sup>129</sup>

The use of other advance organisers<sup>a</sup> has a number of advantages.

- Advance organisers help the reader to create a thought framework before new information is presented.<sup>122,129</sup>
- They can be used to stimulate reader interest.<sup>129</sup>
- By breaking the text into smaller blocks, they assist in making the text look less formidable. This decreases cognitive load, and enhances comprehension and recall.<sup>128,129</sup>
- It helps to develop a sight vocabulary (lexical storage), and thereby aids word recognition (through lexical access).<sup>128</sup>

An example from this thesis is the flow chart in Chapter 1 (Figure 1-1) to introduce the flow of the study.

The organisation of the material can be further enhanced by the use of bullets or lists.<sup>112,129,139</sup> Hoffmann and Worrall concluded that bullet points are more successful than solid text in gaining the reader's attention, that they help people to follow procedures, and that they are remembered and understood better than paragraphs.<sup>129</sup> Lists should preferably have less than five points each, and be labelled descriptively.<sup>122</sup>

Cognition is also facilitated by emphasising important information and summarising the main points. This can be done by drawing the attention of a reader to the key elements of content through visual cues. Such cues can include text boxes, graphics, arrows or highlighting.<sup>127</sup> These should all be used with discretion and should stress the most important facts and "what to do" information.

#### 4.4.2.5 Readability

Although readability formulas have several limitations they are still widely recommended as part of the holistic evaluation of written material.<sup>122,129,138,171</sup>

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<sup>a</sup> Introductory material which is presented in advance of actual learning material to stimulate the learner to interact with the material at a cognitive level. Examples include:

1. Familiar concepts and illustrations to introduce new ones
2. Analogies to explain core concepts up front
3. Diagrams to provide a cognitive structure to enhance learning by relating unfamiliar content to familiar content

Most of these formulas are easy to apply and interpret. Note must be taken that computer software that test readability often produces readability scores that are at least two grade levels below the actual reading level.<sup>118</sup>

Readability formulas also do not consider factors such as format, layout, complexity of the subject, familiarity of the reader with the subject, or reader interest.<sup>132</sup> Moris and Stilwell summarise this problem by stating that readability is not inherent in text only but depends on the interaction between text and readers.<sup>127</sup>

For this reason Clerehan *et al*<sup>11</sup> recommend the use of the average number of content words per clause or lexical density. Language is made up of what they call 'content' words (e.g. "stroke", "spasticity", "assistance") and 'non-content' words (e.g. "in", "and", "whether"). The average lexical density for written English is between 3 and 6, depending on the level of formality of the writing. They recommend that the lexical density in patient information leaflets needs to be nearer the spoken end, aiming for the 3–4 range. In their study they used two linguists to calculate the lexical density of leaflets and did not comment on other professionals' capability to do so.

Since the checklist developed in this study is for the use of health professionals, the use of a readability formula is advised.

#### 4.4.2.6 Illustrations

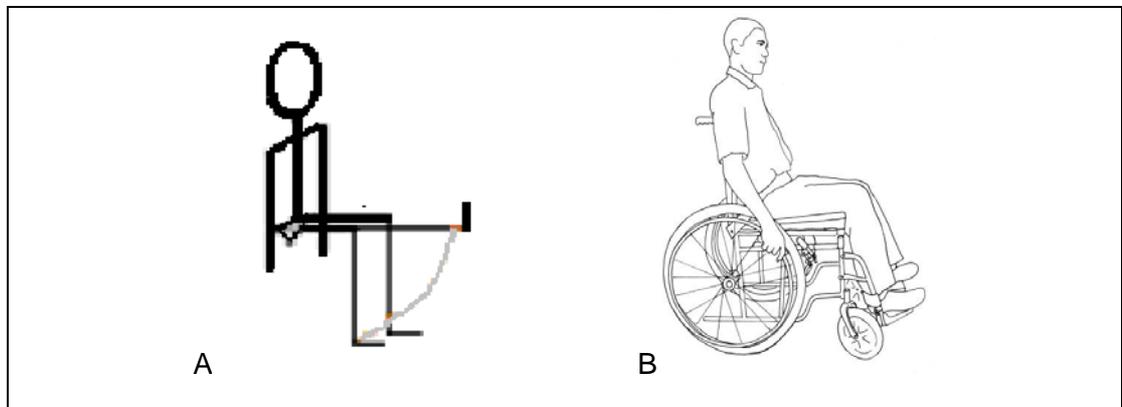
Despite the lack of consensus regarding the effectiveness of illustrations, patients frequently report valuing illustrations<sup>108</sup>, as was again the case in the current study.

Illustrations should only be used to improve the understanding of essential information. Pictures should provide information that is central to the text<sup>112,141</sup> and must agree with the content of the text.<sup>118,122,130</sup>

Realistic pictures are the best for educational purposes. They should be presented in a clear style with no writing over the images.<sup>171</sup> A picture's legibility is better if there is no distracting background detail. This also facilitates encoding and comprehension.<sup>128</sup> Detailed, realistic drawings with tonal values, and photographs, are two suitable styles. Although not always possible, borders and implied borders, which cut off images and figures, must be avoided. People with a low visual literacy may find such

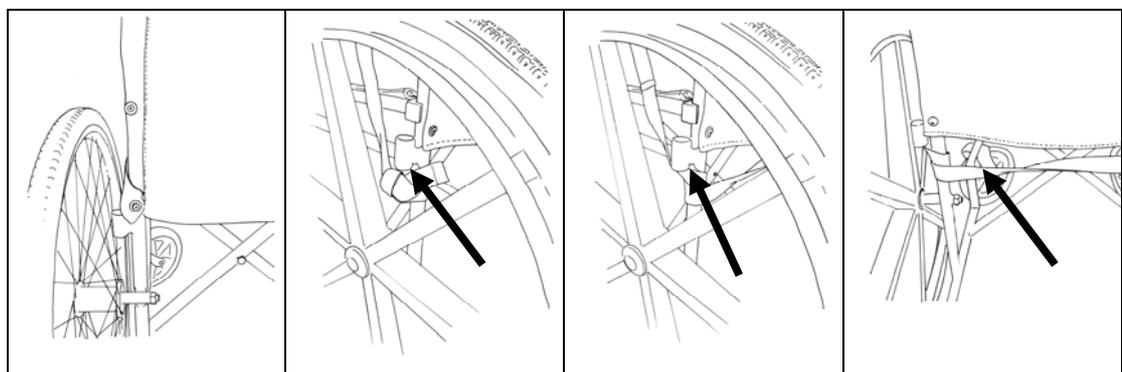
pictures difficult to interpret. If the intended audience consists of adults, adult rather than childlike images should be used.<sup>155</sup>

Figure 4-5 represents illustrations of two persons sitting. The A figure is from the National Guidelines to prevent falls in older people<sup>92</sup> and the B figure is from the booklet on stroke home care (Appendix 12). Both illustrations are clear with no background detail. However, even if the lines in figure A were understood to be a person, someone with low literacy skills may find it difficult to understand why there are three legs and how the person maintains this “impossible” position. Figure B is a realistic drawing of an adult in a wheelchair with no implied borders.



**Figure 4-5: Unrealistic and realistic illustration of a person sitting**

The pictures that the caregivers from the focus group identified as difficult to understand, are shown in Figure 4-6. The fact that the wheelchair is not shown as a whole and that there are numerous implied borders in all of the pictures may be contributing to this. Even though arrows are used to indicate the key points, the detail in the pictures can be seen as distracting and confusing.



**Figure 4-6: Illustrations from the booklet on stroke home care that caregivers found difficult to understand**

Graphic cues in the pictures, namely arrows or lines, directing attention to a particular area of the picture should be used to point out key information. It also optimises visual perception through enhancing acuity.<sup>128</sup> If the pictures are in colour, colour can also be used to emphasise important parts of the picture. In a black and white picture tonal values can be used to achieve this.<sup>141</sup>

To facilitate comprehension and recall through dual coding, all pictures should have captions and legends.<sup>173,174,176</sup> The legends should be easy to understand, relate to the picture and be instructive and explanatory in nature. Pictures should be visually linked to legends<sup>141</sup> and should be as near as possible to the relevant text. If the function of the picture is to act as an advanced organiser, the picture should appear before the text. If the function of the picture is to repeat information that is presented in the text, the picture should appear after the text.<sup>141</sup>

Although clipart available in software programs are easy and inexpensive to use they do not necessarily enhance a professional image of the material. It is therefore advisable rather to use custom made pictures.<sup>139,145</sup>

### **4.4.3 Evaluating Cornerstone 3: Cultural Sensitivity**

Language that is culturally sensitive uses words that carry positive meanings and is written in a friendly tone.<sup>129,130,132</sup> This implies the use of non-patronising, non-alarmist language. For example, instructions should not be given without providing the context and the reason. If the information is not individualised, gender free or gender neutral language should be used where appropriate. Person-first language is another example of cultural sensitive language.<sup>160</sup> If peer language is used appropriately it increases personal identification and improves readability.<sup>132,174</sup> An example from the focus group discussion is the stroke survivors' use of the word "stiffness" or "styfheid" instead of "spasticity". However, care must be taken that words, phrases, and expressions are free from stereotypical meaning.<sup>155</sup>

One of the challenges of written material is that it is often used for a culturally diverse target audience.<sup>163</sup> If the information is not individualised or compiled for a specific cultural grouping, the material should reflect respect for the cultural, ethnic and/or religious diversity of society. The statistics presented must be representative of the intended audience and the messages must be linked to sources credible and

accessible to the intended audience.<sup>128</sup> The message must address stereotypes and myths.<sup>141,155</sup>

The need for and advantages of cultural sensitive graphics and pictures are increasingly researched.<sup>37,141,182</sup> If graphic elements are used that are familiar and acceptable to the intended audience it increases motivation through positive affect and facilitates comprehension through linking to cultural schemata.<sup>128</sup> Therefore it is advised that the physical appearances of people in the pictures must be representative of the target audience. The stature and poise of the individuals should be representative of the gender and social roles of the audience. Attention should be given to details like body language, particularly whether touching or proximity is permitted in specific situations.<sup>118,129,130</sup> The social network structures, accepted roles for men and women and their interaction should be portrayed accurately, believable and contemporary. This should also be taken into account for the context of pictures including portrayed customs, food and environmental settings.<sup>128,155</sup> All visual elements must be suitable for the level of visual literacy of the target audience. Western pictorial conventions, namely motion, movement and perspective, can cause problems for viewers unaccustomed to these conventions.<sup>110,</sup>

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## 4.5 Chapter summary

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In this Chapter the reasons for and the development of a checklist for the assessment of written health material for developing communities were described.

Twenty existing checklists were graded for their appropriateness to evaluate written health material. Of the twenty lists only one was found highly appropriate. Still, this list (the SAM) only had limited measurement of cultural sensitivity. In comparing and unpacking the lists, it was found that although individually they lacked comprehensiveness, the total of the themes addressed by these lists provided more balanced and detailed guidance. Furthermore, the lists had remarkable similarities and new themes only occurred in ten of the lists.

A new list was compiled using all 75 themes that emerged from the existing lists. The questions were grouped according to the pillars of the HAMSOC model and a grading system was suggested. Each of the questions in the checklist was consequently discussed. This discussion serves as the foundation for the checklist and states the anticipated benefits of each aspect.

# Chapter 5

## Results

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### 5.1 Introduction

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In this chapter the results of the analysed data are presented. This data was captured and analysed during the second and third stage of the study. Firstly, both the new checklist and the SAM were applied to the booklet. The results are compared and the recommendations that followed are presented.

The refined booklet was then evaluated by samples of stroke survivors and caregivers who gave feedback in focus group discussions. To determine the optimal level of readability for the booklet, the health literacy of the focus group participants was measured with the REALM literacy test. These results were analysed by a statistician and are also presented. The chapter concludes with a summary of the focus group discussions, the results of the questionnaire on the preference between the original and the refined booklet and the expert opinions with regard to refining the booklet.

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### 5.2 The evaluation of the booklet

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The booklet on stroke home care (Appendix 12) was tested against the new checklist and the SAM. According to the checklist the booklet was “moderately appropriate” and according to the SAM, “adequate”. The SMOG readability level was grade 9. Table 11 presents a summary of these results.

**Table 11: Results of original and refined booklet tests**

<b>Measure</b>	<b>Original booklet</b>	<b>Refined booklet</b>
Health Education	<b>4.2</b>	<b>4.2</b>
Appropriate Media and Technology	<b>3.1</b>	<b>4.3</b>
Socio-cultural sensitivity	<b>4.2</b>	<b>4.6</b>
Total:	<b>11.5</b>	<b>13.1</b>
Level of appropriateness	<b>Moderately appropriate</b>	<b>Highly appropriate</b>
SMOG readability	<b>9</b>	<b>7</b>
SAM percentage	<b>61%</b>	<b>79%</b>
SAM	<b>adequate</b>	<b>superior</b>

By using the SAM several limitations were exposed. With regard to the content, the scope of the information in the booklet is limited and the thrust of the material is the application of knowledge aimed at reader behaviour. Although the purpose is implied in the title, it is not explicitly stated and the booklet contains no summaries or reviews.

The readability score was not satisfactory and more than 50% of the text was written in the passive voice and not in a conversational style. Although common words were frequently used and the technical words explained, the context was often (about 50%) provided before new information was introduced. Apart from the chapter headings there was no advance organisers or “road signs”.

The graphics measured “superior” in all sections except the cover page and the absence of captions for many of the illustrations. The layout was also “superior” even though there were single line spacing and no visual cuing devices. The typography was a 12 point in the original version, but since the booklet was used in an A5 format the actual letter size was much smaller and thus insufficient. The headings were written in all upper case/capitals. Lists were frequently used but often with more than seven items.

The information in the booklet was motivating and behaviour focused, but was not presented in way to stimulate interactive learning. About 50% of the central concepts

in the material appeared to match the language, logic and experience of the target audience and there was a neutral presentation of cultural images.

In comparing the results of the SAM and the checklist, the checklist only exposed an additional three limitations: a) The information was not individualised; b) many of the pictures had implied borders; and c) the information was not linked to sources that were credible to the target audience

Based on the gaps exposed by these tools, the following recommendations were made to the authors:

- Use a question and answer format;
- Write the questions in the second person;
- Use a graphic cue for every question (reversed out question mark);
- Put the pictures and their legends in table form in order to keep the information visually linked to the graphics;
- Use 1 ½ line spacing;
- Summarise main points;
- Highlight important information in text boxes;
- Move the disclaimer and the acknowledgements to the back of the booklet;
- Change sentences written in passive voice to active voice where appropriate;
- Revisit the language readability level;
- Revise the cover page (the use of a graphic designer is recommended). Include a space for the client's name and the name and contact details of the person / therapist who did the training; and
- Although the illustrations were clear line drawings, many of them had implied borders. Figure 5-1 shows examples of such pictures. This must be tested with the target audience for comprehensibility.



**Figure 5-1: Example of pictures with implied borders**

Although after consultation with the authors, it was decided not to change the entire document's readability level before a literacy assessment of the target audience was done, the following words were replaced throughout the booklet:

- "Affected" replaced with "weak"
- "Unaffected" replaced with "strong"
- "Assist" replaced with "help"

To limit the number of pages to a minimum, it was decided to keep the single line spacing and not to insert summaries. The remainder of the suggestions were accepted and changes subsequently made (See revised booklet in Appendix 13). After the adaptation, the measurements were repeated (see Table 11). The revised booklet was measured as "highly appropriate" by the new checklist and as "superior" by the SAM. Remarkably, even after the limited replacements of words, the readability level of the revised booklet was two grades lower than the original version.

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### **5.3 Demographic information of participants**

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A total of 46 persons participated in the focus group discussions; twelve in the first, 26 in the second and eight in the last group. A REALM literacy test was completed for everyone except one of the stroke survivors who had a MMSE score of less than 22. Fifteen stroke survivors and 31 caregivers participated, of whom ten were males and 24 females (12 caregivers' genders were not filled in on the scoring sheet). Afrikaans was the first language of the majority (23), sixteen persons were Xhosa speakers and only seven indicated English as a first language. The majority were between 20 and

45 years old and only six were older than 60 years. Table 12 summarises this representation.

**Table 12: Demographic information of participants**

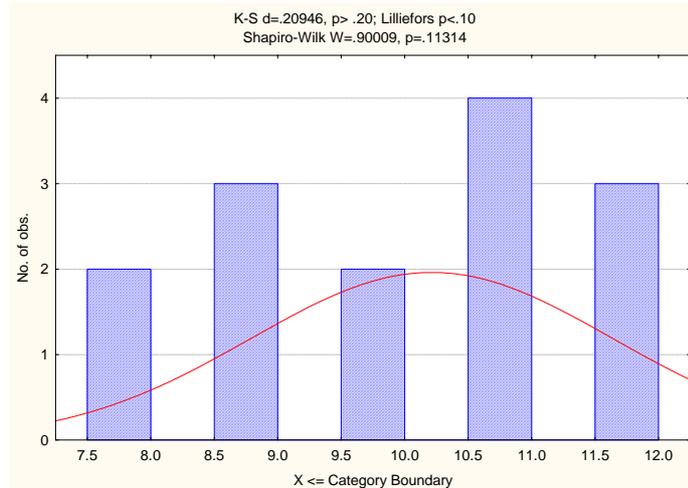
	<b>Total</b>		<b>Group 1</b>		<b>Group 2</b>		<b>Group 3</b>	
	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers
<b>Total</b>	15	31	11	1		26	4	4
<b>Gender</b>								
Male	8	2	4			2	4	
Female	7	17	7	1		12		4
Not indicated		12				12		
<b>Language</b>								
Afrikaans	8	15	8	1		14		
English	3	4	3			4		
isiXhosa	4	12				8	4	4
<b>Age</b>								
20-45	2	22	2			22		
46-60	7	8	4			4	3	4
>60	6	1	5	1			1	

---

## 5.4 REALM literacy tests results

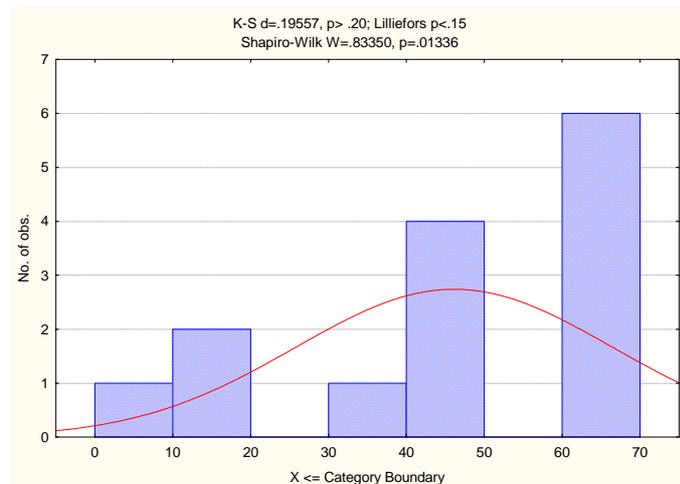
---

The REALM literacy scores were divided into stroke survivors and caregivers. The results as well as the reported years of school education were plotted on histograms. Figure 5-2 is a histogram illustrating the distribution of the school years completed by the stroke survivor group.



**Figure 5-2: Histogram of school grades completed by stroke survivors**

Even though persons with a school education of five years and more are considered functionally literate the lowest school grade was grade 8. This is probably due to the small sample size. Figure 5-3 shows the distribution of the REALM scores of the same clients.

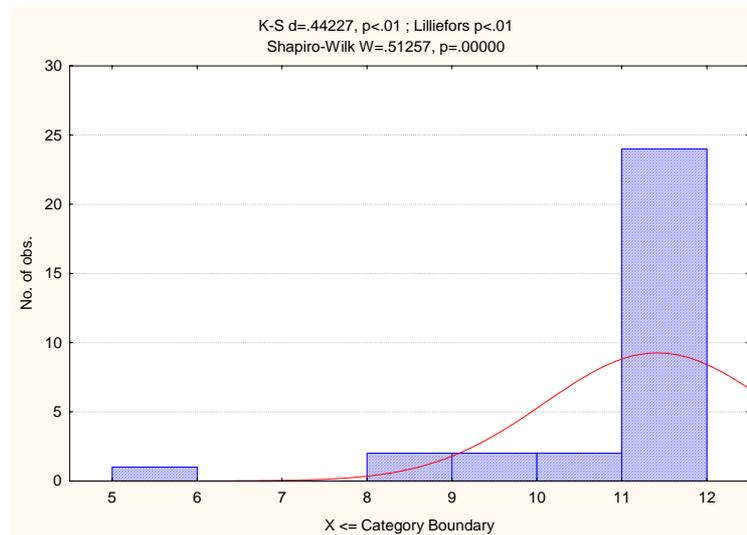


**Figure 5-3: Histogram of REALM scores of stroke survivors**

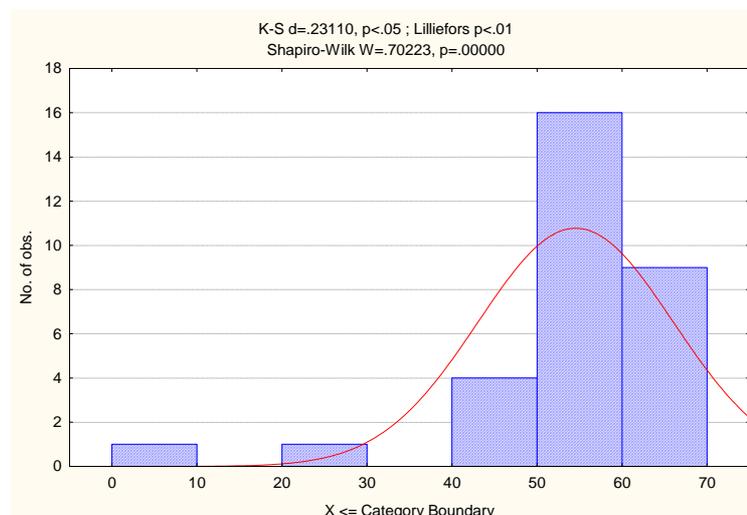
If the REALM scores are converted to grade levels (Table 7, page 68) it can be deduced that only six persons' measured literacy was higher than the ninth grade (REALM raw score >61). This is in contrast with the eleven persons that completed grade 9 and higher at school.

The caregivers' distribution of school grades completed and measured literacy is presented in Figure 5-4 and Figure 5-5, respectively.

The high representations of persons who completed grade 12 is probably due to nursing assistant students that formed the majority of this group. (Grade 12 is a minimum requirement for their course.)



**Figure 5-4: Histogram of school grades completed by caregivers**



**Figure 5-5: Histogram of REALM scores of caregivers**

As in the case of the stroke survivors, the deduction can be made that although 31 reported completing a school grade above the ninth grade, only ten had a measured literacy level above grade 9.

Table 13 presents the breakdown of the REALM literacy tests results. The breakdown of the stroke survivors (patients), caregivers as well as the combination of the two

groups is set out. Since there is not a normal distribution of the data, the statistician recommended using the median rather than the mean to determine the level of readability of written material. The scores in the table are the raw (unconverted) results of the REALM tests. However, the converted scores' (Table 7, p68), mean and median values for the groups separately and combined are all grade 7-8 (REALM score 45-60). The mean and the median for completed school years was grade 11.

**Table 13: Descriptive statistics of REALM results**

Breakdown Table of Descriptive Statistics (DATA in REALM DATA 20070815.stw)								
N=45 (No missing data in dep. var. list)								
GROUP	rawREALM Means	rawREALM N	rawREALM Std.Dev.	rawREALM Minimum	rawREALM Maximum	rawREALM Q25	rawREALM Median	rawREALM Q75
Patients	<b>46.14</b>	14	20.38	7	66	40	<b>50</b>	63
Caregivers	<b>54.55</b>	31	11.48	10	65	53	<b>58</b>	61
All groups	<b>51.93</b>	45	15.10	7	66	49	<b>58</b>	61

Thus, even though the majority of participants have completed a senior secondary (gr11) education they read only at the level expected at a senior primary level (gr7).

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## 5.5 Focus group discussion

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The three focus group discussions revealed similar themes and are consequently grouped together. The five themes that emerged from the discussion were:

- The booklet as a tool that fulfils an unmet need,
- the perceived usability of the booklet;
  - the booklet as a reference and
  - a tool for empowerment;
- its perceived comprehensibility;
- the need for translation; and
- points of critique or recommendations.

### 5.5.1 The booklet as a tool to fulfil an unmet need for written information

There was an overwhelming positive response towards the booklet in all three focus groups. None of the participants reported receiving any written material on stroke

before this booklet. It was received as a welcomed and sometimes long awaited tool. One stroke survivor remarked:

F1P1 *“Ek het dit vir my vrou gewys. Sy het gesê as sy dit vroeër gehad het, sou dit ons baie gehelp het. Ek het na my stroke huis toe gegaan sonder enige training, nou leer ek al die goed eers wat ek in rehab is.”*

The manner in which the stroke survivors cared for and handled their booklets left the interviewer with the impression that they valued it as a treasured possession. Most of them showed it to friends and visitors but reported that they gave clear instructions to bring it back and to handle it with care.

The need for information on stroke related issues in all the groups was highlighted by the discussions. The information conveyed in the booklet served as an organiser of the questions and remarks of the participants. The stroke survivors had specific questions on the recovery after stroke, spasticity and the description of independent activities.

The caregivers that were already caring for stroke survivors had more questions regarding the causes of stroke and the prevention of further stroke, whereas caregivers in training had questions regarding transfer techniques and other specific activities like tooth brushing.

Irrespective of whether the information was new or reinforcing old information, receiving it in a written format was valued and appreciated by all the participants.

## **5.5.2 The perceived usability of the booklet**

Both stroke survivors and the caregivers said that they found the booklet very useful. The different emphasis of the stroke survivors opposed to the caregivers gave rise to two sub-categories: 1) the booklet as a reference and 2) the booklet as a tool for empowerment.

### **5.5.2.1 The booklet as a reference**

The caregivers in both groups agreed that the booklet is practical and a useful tool to refer back to when caring for persons who had a stroke. The descriptions of how

assistive devices (e.g. plate guards) can be self-made or self-adapted were of special interest to them. In addition, the group that included the nursing students thought that the booklet could be of use for community nurses attending to clients in primary care clinics.

### **5.5.2.2 The booklet as a tool for empowerment**

The stroke survivors in both groups viewed the usability of the booklet in terms of its empowerment. They expressed the desire to show the booklet to their friends and family as a way to communicate information about their stroke that they found hard to explain themselves. The group that consisted of inpatients at the rehabilitation centre discussed the possibility of giving the booklet to the nursing staff:

F1P2: *“Kan ons dit vir die nurses gee? Ek sien in die boekie hoe moet hulle eintlik met ons maak.”*

F1P3: *“Hulle moet ons nie so rondgooi nie, as hulle hierdie lees sal hulle mos weet hoe hulle moet maak.”*

A participant from the community group remarked:

F2P1 *“I want to take it out and paste it on the wall, everyone must see it.”*

The empowerment value was also expressed in relation to learning of new skills. One participant mentioned that he had learnt skills to wash himself:

F2 P4 *“Ek het baie geleer soos van die prentjie wat wys hoe jy die waslap op jou been sit en dan die seep smeer. Nou weet ek om te was.”*

The written format of the information carried an apparent authority that gave them confidence and freedom to express and discuss certain facts. This came forth in an attitude of “I have proof”.

### **5.5.3 The perceived comprehensibility of the booklet**

Both the stroke survivors and the caregivers perceived the booklet as easy to understand. They appreciated the use of plain English and that the booklet was developed with their specific needs in mind. The step-by-step pictures illustrating

selfcare activities were mentioned by all three groups as being very helpful and clarifying, as the following quotes highlight:

F1P5: *“Ja als was ‘simple English’, ons kon alles verstaan.”*

F2P4: *“The pictures show exactly what the words say.”*

F3P3: *“I like to see and to read, see and read.”*

#### **5.5.4 The need for translation**

All three groups asked whether the booklet was available in Afrikaans or isiXhosa. Most participants agreed that even though the pictures were clear and often self-explanatory, they would prefer to have the text in their own language. The stroke survivor in the third group who had a MMSE lower than 22 remarked:

F3P4: *“If it was in Xhosa I could give it to my children to read for me.”*

#### **5.5.5 Points of critique and recommendations**

From the three discussions it came out that two things were difficult to understand. One remark was made about representation of gender and one recommendation for further implementation.

1. The word “post” was not understood by the first group<sup>a</sup>. One person mentioned this, saying:

F1P6: *“Daar was ‘n woord met ‘n ‘post’ vooraan. Ek het nie geweet wat dit beteken nie, maar ek het iemand gevra. Hule het vir my verduidelik dit kom van Italiaans af maar ek weet nog nie wat dit beteken nie.’*

Although no one else in the group remembered reading the word, no one in the group knew what it meant. Unfortunately, since he could not immediately show where he read the word, it could not be discussed further.

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<sup>a</sup> “Post” was used in the booklet in the context of the back post of a wheelchair and not as the participant was informed meaning “after”.

2. In the caregiver group the pictures showing how to secure a lap strap to a wheelchair were perceived as difficult to understand and unclear.
3. One of the nursing students mentioned that the pictures were mostly of males. Although the group agreed, they did not find this disturbing or offensive. They did express the view that they would prefer a more representative presentation of gender in the pictures.
4. In two of the groups the idea of having "take outs" or "posters" to put against the wall or above someone's bed was discussed. There seems to be a need not only to have the information in book form but also to have some vital or important pictures as constant reminders.

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## 5.6 Experts' comments and recommendations

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The comments and recommendations by the experts can be divided into three themes: Content, language and layout.

### 5.6.1 Content

All the experts agreed that the content of the booklet is superior. The occupational therapist commented that she has never seen such a comprehensive document for caregivers on this topic. The medical practitioner reported that she learned several practical points by reading the booklet. Only two content related recommendations was made;

- In the section of "Typical complications", under depression, to add a psychologist to the list of professionals.
- In the section of "Positioning in bed" it should be the "the wall must be on the **strong side**".

### 5.6.2 Language

Concerning language, one expert stated that it was evident that the booklet was written by Afrikaans speaking therapists. They agreed that the language and grammar of the booklet should be revised by a language expert. Suggested language and grammar that need correction include:

- Punctuation;
- the use of articles (“the”/”a”);
- consistency;
- long and unclear sentences;
- the use of “him/her”;
- unnecessary repetition; and
- technical phrases.

Table 14 presents examples of some of these errors.

**Table 14: Examples of language errors in the booklet**

Quotation from booklet	Error
Once the shoulder blade is in the outwards and forwards position gently take the person’s upper arm above the elbow and turn the arm outwards away from the body.	Long, unclear sentence.
11 Slide up to touch nose. Only continue further if no pain is experienced 12 Slide further upwards to top of head. Only continue further if there is no pain. 13... stretch the arms upwards all the way or as high as possible without causing pain	Unnecessary repetition.
.....confusion with regards to person, place and time..... .....opening of the shoulder joint.....	Technical phrases.
<ul style="list-style-type: none"> <li>• Dressing is a slow process. Allow enough time</li> <li>• Give positive feedback</li> <li>• If the person cannot perform the entire task, break it down into steps e.g. only put arms into sleeves</li> </ul>	Inconsistent punctuation.

Although the use of the question-answer format has some advantages, it leads to unnecessarily long sentences. Since these questions serve as subheadings, shorter sentences might be more appropriate. In addition, since the booklet is specifically for problems related to stroke, many sentences could be shorter and clearer if the repetitive use of “a person who had a stroke” is limited. Although this is Person First Language, it is cumbersome to read and does not provide new or essential information.

### 5.6.3 Layout

Regarding the layout the most general comment was the lack of layout consistency. This included alignment of bullets and pictures, and consistent use of space in text boxes. This is partly due to the use of an inappropriate software programme for the layout. Examples of this can be seen in Appendix 13

Other recommendations included:

- Broader left margin to allow for stapling of the pages
- Bolder and larger typeface for the headings;
- The boxes with highlighted information should also be larger and bolder;
- Highlighting important words in the text with bold to have a less “grey” appearance of the page;
- To make the pages less cluttered, remove the “*sponsored by National Port Authorities of South Africa – Cape Town*” in the footer of each page;
- Put the picture of the cover page central, the names of the authors and sponsors lower and allows more space to fill in the name of the client; and
- Not to have lines with only a single word.

Although they agreed that putting the pictures and legends in boxes increases the visual linkage, they advised putting the legend and the picture in the same box.

Figure 5-6 (A) demonstrates the separate boxes and (B), the recommended one box.

A	B
 <p data-bbox="475 1608 491 1637">1</p>	
<p data-bbox="475 1666 807 1794">1 Use a sturdy box, large enough for both forearms to rest comfortably on it</p>	<p data-bbox="879 1659 1246 1794">Use a sturdy box, large enough for both forearms to rest comfortably on it</p>

**Figure 5-6: Example of legends and pictures in separate boxes (A) and of the recommended one box (B)**

Both graphic designers noted the effectiveness of the question marks as visual cues and one recommended using a similar cue to indicate the answer to each question. Even if the authors were to decide not to use the question-answer format, similar cues can still be used to serve as advanced organisers.

The graphic designers also advised the use of a layout grid in a specialised layout software programme. This will automatically eliminate some of the layout inconsistencies.

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## **5.7 Questionnaires regarding preference of booklets**

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The participants were identified and the questionnaires administered by a trained research assistant.

Ten stroke survivors completed the questionnaire of whom seven were male, two female and one person who did not indicate gender. Six were Afrikaans, three English and one Xhosa speaking. Eight were younger than 45 years and two between 46 and 60 years old.

All ten preferred the refined booklet to the original booklet. Everyone also preferred the larger typeface of the refined booklet and six mentioned this as one of the reasons they preferred the refined booklet. Six persons mentioned that the clearer illustrations of the refined booklet made this booklet superior to the original.

All the participants also preferred the A4 size to the A5 size. One person commented that it was because the bigger size handles easier for people who had a stroke.

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## **5.8 Chapter summary**

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In this chapter the results of the study were presented.

Firstly, the new list and the SAM were applied to the booklet. They revealed comparable results but the new checklist highlighted additional limitations.

The limitations exposed in the booklet were restructured into recommendations for the refinement of the booklet and implemented after consultation with the authors.

The refined booklet was subsequently tested with samples of the target audience. In order to assist describing the target population and determining the optimal level of readability for written material for this population, REALM literacy tests were conducted. The literacy test revealed a significant difference between the reported years of schooling and the measured literacy skills. Although these results came from small samples it highlights the need to test the literacy of intended target audiences before deciding on an appropriate readability level of the material.

The focus group discussions of the samples revealed that the booklet was addressing an unmet need for written information. In addition, the participants experienced the booklet as comprehensible and usable. The usability was viewed both in terms of a reference value and its empowerment. Apart from the need to translate the booklet the participants also made valuable recommendations for the refinement of the booklet. When stroke survivors were presented with the pre-refined and the refined booklet, all of them preferred the refined booklet. This suggests that using the new checklist to guide the refinement of material, is a meaningful process.

Experts that reviewed the booklet made further recommendations towards the booklet's tailoring. All of their recommendations are in line with the checklist and are either directly or indirectly implied by the checklist. It is anticipated that these recommendations will all be met if a linguist and a graphic designer were to revise the booklet.

# Chapter 6

## Discussion and Conclusions

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### 6.1 Introduction

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In this Chapter the results of the study are discussed and conclusions drawn. This discussion follows the study objectives, which are to:

The objectives of the study were to:

1. Review literature and evaluate existing tools to guide the researcher in the development of the research tool.
2. Assess the appropriateness of the booklet using the Suitability Assessment of Material as well as the new research tool.
3. Evaluate the literacy level of the target audience
4. Examine the target audience's perception regarding the comprehensibility and appropriateness of the refined version of the booklet
5. Explore the opinion of discipline specific professionals regarding the booklet.

The sixth objective, - to make recommendations regarding further steps to the implementation of the booklet, will be discussed in chapter 7, which deals with the recommendations that follow from the study.

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### 6.2 Objective 1: Review literature and evaluate existing tools to guide the researcher in the development of the research tool

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The evaluation of written health information is receiving increased attention in literature and guidelines for writing such material are widely available. The HAMSOC model together with Hugo's grading model proved to be a valuable tool to compare and evaluate the comprehensiveness of these guidelines for developing communities. Most significantly, it highlighted the lack of measurement or guidance on socio-cultural sensitivity in most of the lists. This confirms Hugo's concern that the progress in research and development of designing appropriate health messages within a particular cultural context, is rather slow.<sup>157</sup> Exposing the limitations of the lists also

confirms Moris' observation that literature concerning guidelines for the production of readable and useful print materials is fragmented and dispersed, largely available as tips on specific aspects rather than as an integrated set of guidelines.<sup>126</sup>

Exploring the individual themes of guidelines, the similarities between them were remarkable. New themes only emerged in the first ten of the twenty lists. The re-occurrence of many of the themes suggests that there are general consensus on their acceptability. This consensus was also observed by other reviewers.<sup>128,129</sup> Yet, some of the important considerations occurred only once or twice - fifteen out of 75 themes occurred in only one list. Since most of the lists were lacking in the area of cultural sensitivity, most of the themes that occurred once only fell under that section.

Examples are:

- If the information is not individualised or compiled for a specific cultural grouping, does the material reflect respect for the cultural, ethnic and/or religious diversity of society?
- Are the words, phrases and expressions free from stereotypical meaning?
- Are the referral sources accessible to the intended audience?

The discrepancies in existing lists (what typeface to use and the use of numbers) are most likely because all of the guidelines are not specific aimed at readers with low literacy skills. Keeping in mind the communication differences between readers with high and those with low literacy skills (Table 4), these discrepancies can be expected. One of the important differences is that low literacy readers tend to read words one by one. Consequently, the clarity of a specific typeface and length of individual words (or numbers) were taken as a guideline for the new checklist. This view is supported by several guidelines specific for low literacy readers.<sup>126,139,183,184</sup>

Hugo and Smit<sup>37</sup> concluded the description of the HAMSOC model with the recommendation to compile a suitable checklist in each of the three areas to evaluate learning material. In addition, Doak *et al*<sup>115</sup> (the authors of the SAM) expressed that there is a continuing need for more comprehensive evaluation instruments. Based on these recommendations and the exposed limitations of existing lists, the development of a new checklist is not only justified but is imperative.

The researcher agrees with Carstens<sup>128</sup> observation that most guidelines towards writing for low literacy readers provide limited evidence of whether the proposed

strategies are research-based. It is often unclear whether the strategies are based on reader research or on text-focused evaluation by editors, subject-field experts, or document designers. Therefore, this study provided a literature based motivation for each question in the checklist. This is proposed to be a contribution towards the comprehensive description of appropriate written information for developing communities.

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### **6.3 Objective 2: Assess the appropriateness of the booklet using the Suitability Assessment of Material as well as the new research tool.**

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To expose possible areas of improvement, the booklet was tested against both the SAM and the new checklist. The new checklist revealed only three additional shortcomings in the booklet. Although this could raise the question of the need for a new checklist, the results must be viewed against the fact that the cultural sensitivity of the booklet was measured “suitable”. If the booklet was less culturally sensitive, a greater difference in the two scores could have been expected. Furthermore, since the new checklist gives a breakdown of the results between the different sections, it was clear that Appropriate Media and Technology use was the weakest area of the booklet.

The most likely reason for the lower score for Appropriate Media and Technology, is that the editors and most of the developers of the booklet are all rehabilitation clinicians. This suggests that rehabilitation professionals engaging in the development of written client information may not be adequately aware of the requirements to optimise such material. This was also the finding of a study on consideration for Australian health professionals on writing written health information.<sup>129</sup> They concluded that although rehabilitation professionals commonly use written health education materials when educating patients, few receive training in the preparation of such materials. While health professionals may be aware of the need to ensure that the written materials they use with patients have an appropriate readability level, it is likely that awareness of the other factors that contribute to a suitable written education material is limited. The new checklist can be used in addition to literature on the development of written health material to educate and raise the awareness of health care workers on these issues.

After the relevant changes were made to the booklet, both the SAM and the new checklist measured the booklet in the highest possible range. An interesting observation was that even though the readability level as such was not revised, the changes from passive to active voice and the four word substitutions resulted in a SMOG readability of two levels lower than that of the original version. Although readability formulas are criticised for their lack of comprehensiveness<sup>127,132</sup> the observation from this study demonstrates the integration between the readability level and other language related factors.

The overwhelming preference for the refined booklet over the original version supports the notion that written material can be meaningfully changed by alterations made according to the newly developed checklist. Research is still inconclusive regarding the effectiveness of written materials that contain the recommended features in an integrated form.<sup>129</sup> Although this study did not test effectiveness, the findings suggest that this is a worthwhile approach to follow. Furthermore, it is important to remember that a checklist should be used as a first stage or a supplementary measure to reader focused evaluation. A checklist is therefore just a departure point that necessitates further research.<sup>181</sup>

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## **6.4 Objective 3: Evaluate the literacy level of the target audience.**

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Although the needs of these stroke survivors and their caregivers are multilayered, the need for information is one of the priorities. Written information has many advantages for developing communities and since it is estimated that about 75% of the population in the Western Cape are functionally literate,<sup>168</sup> this medium can be used successfully to distribute information to this target audience if it is presented in a style and format that match the audience's language, logic and experience.<sup>115</sup> One method to address some of these factors, is testing the literacy level of an intended audience and matching it with the readability level of the written material.

This study only included participants who perceived themselves as literate. The caregivers' mean of formal years of education (gr11) is probably falsely raised due the number of student nurses who participated and who must have a grade 12 qualification. The lack of representation of persons who completed between five and eight years of schooling (according to the census it should be about 20 %<sup>123</sup> but in the

study only one participant had less than eight years of schooling.) is probably due to the small sample size.

The results of the REALM literacy tests done in this study show that the actual literacy level of the participants was three to four years lower than the reported years of schooling. This is an even greater discrepancy than disclosed by international studies, which found an average of a two year difference between years of schooling and measured literacy.<sup>38,124</sup> Although no record of using the REALM tests in South Africa could be found, this study confirms other South African author's findings that tested literacy is often lower than the reported years of formal education.<sup>113,125</sup>

This study suggests that the maximum readability of written material for stroke survivors and their caregivers in the Cape Town Metropole should be the seventh grade. Although a general readability level for printed health material can not be deducted from this, it highlights the importance of measuring the literacy of intended target populations.

An alarming observation was the literacy levels of the student nurses. As part of their studies they will receive reading and study material that are much more complicated than the booklet evaluated in this study. Yet, many of them struggled reading words commonly used in the health sector e.g. antibiotics, diabetes, syphilis and obesity. Since the REALM test is only a screening test based on reading and pronunciation and not comprehension these findings certainly prompt for further investigation.

Although the REALM test has several limitations it proved to be an easy to use and quick screening test with possible future use in the South African context. However, taking into account that English is a second language for the majority of South Africans the scoring of the REALM test should probably be validated within the South African context. Such customising of the test should also include changing the spelling used in the test from American to British (or South African).

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## 6.5 Objective 4: 4. Examine the target audience's perception regarding the comprehensibility and appropriateness of the refined version of the booklet

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The tremendously positive reception of the booklet among both stroke survivors and the caregivers stressed the need for such a resource. The perceived comprehensibility was very high. Although only ten participants were asked to comment on their preference between the original and refined version of the booklet, their overwhelming choice of the refined version suggests that the changes are indeed improvements. This supports National and international studies that the pre-refinement of written health material by the use of a checklist, enhances its acceptability and comprehensibility to the target audience.<sup>134,155,181,185,186</sup>

Although the group discussions were focussed on the appropriateness and comprehensibility of the booklet the perceived need and value of such a tool emerged in all the discussions. Stroke survivors not only saw the booklet as a tool to gain personal knowledge and understanding, but they also expressed great excitement in showing the booklet to others.. They felt that the booklet could converse information about stroke in an authoritative yet comprehensible way. In addition, they thought that the booklet would help their family and friends not only to know how to assist them, but also to understand better the changes they are experiencing. This observation is not described in international literature regarding information provision to stroke survivors. It could be argued that low general health literacy levels in South Africa<sup>120</sup> as well as poor general knowledge regarding stroke<sup>49</sup> are underlying reasons for this. These observations translate to the sense of empowerment participants experienced in receiving the booklet. This stresses Johansson, Salenterä *et al's* conclusion that although empowerment relies crucially upon information, the achievement of empowerment depends on how a client understands the information he or she receives.<sup>185</sup>

In relation to stroke Hofmann and McKenna.<sup>38</sup> concluded that, education can assist patients and carers to understand what has happened, to cope with the immediate and ongoing consequences of stroke, and to know what actions they can take to reduce the risk of recurrent stroke. Although the current study did not test the actual knowledge gain of participants, their perception was certainly that they gained valuable information. This is in contrast with the Cochrane review that was

inconclusive regarding the effectiveness of information provision to stroke survivors and their caregivers.<sup>47</sup> Two possible reasons for this discrepancy can be offered:

1. that this study only explored perception of participants and did not measure effectiveness; and
2. that the studies reviewed for the Cochrane review are mainly from developed countries where there often is a saturation of and sometimes overload of information. This is opposed to local clients who reported receiving very limited information on stroke.<sup>32</sup>

The language distribution as presented in the census findings, underlines the importance of translating of the booklet. This was also a key theme from the focus group discussion and confirms the observation of studies on other health related material in South Africa.<sup>181, 186</sup> Interestingly, in one of the studies 30% of 60 Xhosa participants, chose to read the English version of the material even though they were literate in isiXhosa. Some stated that they were more comfortable reading English as they routinely used it in their studies and at work. They considered the English words to be easier to understand and simpler than the isiXhosa translations yet they were appreciative of being able to choose the language of the material.<sup>186</sup> A similar response to the translated version of the booklet on stroke home care, would not be surprising.

Even though many of the pictures have implied borders, this apparently did not negatively influence the comprehensibility of the pictures for this target audience. The most likely cause is that this urban and peri-urban population have been exposed to a variety of media such as television, newspapers and posters. Even though there is still a high rate of illiteracy among them, they are probably used to modern or “Western” graphic conventions.

The focus group discussion exposed only a few yet very meaningful gaps in the booklet. Their contributions support the conclusions of similar international studies that the benefits of involving patients in the design and piloting of written materials cannot be disputed.<sup>129</sup>

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## 6.6 Objective 5: Explore the opinion of discipline specific professionals regarding the booklet

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The majority of the recommendations made by the experts were either directly included or implied by the checklist. This observation suggests two conclusions:

1. The checklist is comprehensive in its guidance; but
2. The use of the checklist by someone not experienced in the evaluation of written health material does not exclude the need for expert input.

A possible reason why the limitations identified by the experts were not identified earlier is that all of the professionals involved in producing the booklet are all rehabilitation health workers. This can influence their reading of the material since they read with proverbial glasses of “what it is supposed to say”.

Furthermore, to the knowledge of the researcher, none of the involved therapists has any training in the development or evaluation of written health information. Even with the guidance of the checklist the finer nuances of the evaluation of such material is a specialised field built on knowledge and experience. Thus, even though the checklist can be a useful instrument to guide health professionals, the importance of an interdisciplinary approach must not be overlooked. This interdisciplinary approach should not only include a variety of rehabilitation professionals (as was the case in this booklet), but also artists, graphic designers and other stakeholders. A multidisciplinary approach, where the different contributors give their input at various stages of the material development (as was the case with this booklet) will likely be less cost and time effective than an interdisciplinary approach where the whole team is involved from the planning stages.

This is well-described by the comments of one of the graphic designers consulted;

*“Just because I have a stethoscope does not mean I can make accurate diagnoses. In the same way, just because someone has a layout programme does not mean they can do a good layout.”*

The involvement of trained, experienced experts in the process of developing written health information can thus not be emphasised enough.

This study confirms the findings of similar research on psychiatric health information material in South Africa, where Snyman concluded:

*“Scientists should not regard the repackaging of information as a simple and menial task. Producing ineffective print material wastes money and time. Perspicuous print materials require large measures of hard work and discernment.”<sup>181</sup>*

Despite the apparent move to a more involved process in the development of written health materials, little is known about whether subjecting materials to these processes results in commensurate increases in effectiveness, particularly in terms of behaviour change.<sup>187</sup> This should thus be a future research focus in this field.

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## **6.7 Conclusions of this study**

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The prevalence of stroke and the specific needs of stroke survivors in the Western Cape are not well described and need to be researched further. This should include the needs of caregivers. Nevertheless, this study confirmed the need of stroke survivors and their caregivers for written information similar to that described in the reviewed literature. Despite the limitations, such as literacy, printed health material was shown to be an empowering tool to appropriately address some of their needs, provided that the material match the audience’s language, logic and experience.

The refined booklet was perceived to be useful and comprehensible by samples of the target audience and the tailored readability level was appropriate for the tested literacy level of the audience. However, even though the content of the booklet with regard to selfcare activities is appropriate, there is a need for printed material on topics related to stroke not currently covered in the booklet. In addition, other media, such as bedside posters, should be investigated as a means to inform and remind clients of important facts. Since the majority of people in the Western Cape do not have English as their first language, there is therefore an urgency to translate the booklet.

This study showed that the new checklist can be used to refine and tailor written health information that is preferred by the target audience. It also confirmed that the testing of printed material with samples of the target audience could expose additional gaps after applying the checklist. The involvement of an interdisciplinary team of experts, including graphic design expertise from the start of the development of new material could be a cost and time effective approach. Even so, more research is

needed to establish whether an interdisciplinary approach to writing health information results in increased effectiveness and behavioural changes.

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## 6.8 Study limitations and restrictions

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No single medium of instruction or information technology tool, in itself, can educate or bring about change of health behaviour.<sup>37</sup> Thus, to evaluate the booklet in isolation from the training programme will certainly not expose all problem areas related to its effectiveness. The participants of the focus groups were required to comment on their perception of the booklet's understandability and the study did not test their actual understanding of the information. Since the booklet is intended to be used as an auxiliary tool to the training this should be tested when the programme is evaluated holistically.

The evaluation of the booklet based on the checklists as well as its subsequent revision was only done by the researcher. Although the purpose of using the checklists in this study was to guide the researcher in the booklet's revision, a combination of evaluators will likely give a more independent score of material. This is recommended for future use of the checklist. In this study the experts that commented on the booklet were not asked to apply the checklist in order to determine whether their comments add areas to evaluate that were not exposed by the checklist.

The samples used in the study were very small. This was partly due to a national strike of health care workers at the time of the study. Since a purposeful study sample of convenience was used the sample is possibly not a representative reflection of the whole study population. Participants were selected based on their own perception of their ability to read and understand English. Since the literacy test was done in English and the booklet only provided in English, possible users of health literature in other languages were excluded. In addition, the responses and results of persons who did participate, but whose first language is not English, might have been different had they taken part in their language of choice.

Furthermore, the sample of caregivers consisted mainly of nursing students. Since a minimum requirement for this course is grade 12, the mean of completed school years for this group is probably unrealistically high. The fifth sample consisted of stroke survivors only, leaving the possibility that caregivers might have different preferences.

The tailoring based on these results is just a part of the refinement of the complete training package (as discussed in Chapter 1). Further evaluations will follow the translation of the booklet.

Finally, one of the tools used in the study (the new checklist) has not been validated. However, it gave similar results to the standardised SAM.

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## **6.9 Chapter summary**

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In Chapter 5 the results presented in Chapter 4 were discussed and conclusions drawn. The study objectives served as a framework for this discussion.

The study population was described and their need for written health information emphasised. The discrepancy between the reported completed school years and the measured literacy of the sample was also shown.

The lack of comprehensiveness in existing lists has been shown. Twenty of these lists were unpacked and the emerged themes used to develop a new checklist. This checklist revealed results similar to a standardised test and the findings were used to refine the booklet on stroke home care.

Samples of the target audience that read the booklet found it both comprehensible and usable. Experts made recommendations for its further refinement. These recommendations were all directly or indirectly implied by the checklist. This suggests the comprehensiveness of the checklist and also highlights the need to incorporate professionals such as linguists and graphic designers in the development of written material.

Finally, the limitations of study were discussed.

# Chapter 7

## Recommendations

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### 7.1 Introduction

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In this Chapter recommendations are made based on the findings of the study. Suggestions for the further refinement and implementation of the booklet are discussed, where after recommendations are made concerning the refinement and applications of the developed checklist. Finally, recommendations for future development of written health material are made.

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### 7.2 Recommendations for further refinement of the booklet

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After pre-testing the booklet with the target audience and obtaining advice from other professionals in developing written health information, it is advised that the booklet be revised by a linguist and a graphic designer and that the two content errors described by the experts should be corrected. It is also recommended that the booklet be rewritten in a specialised layout software programme (e.g. Freehand® or InDesign®). All of these changes must be done within the guidelines of the checklist and must be submitted to the authors for discussion and approval.

Recommendations following the critique that emerged from the target audience's focus group discussions is as follows:

1. The section on the positioning of a lap strap to a wheelchair:  
In the group discussion a reference to where the word was used could not be given. Without the context, no one in the group could explain what the word meant. The only place where the word "post" is used in the booklet is on page 12 "Loop it around the opposite back **post**". Although it is doubtful that no one in the group would understand the word if presented in this context, the word "pole" could be an alternative.

The pictures show only the relevant parts of the wheelchair and have numerous implied borders. Clarity could be enhanced by including at least one illustration of a full wheelchair and by using toning as a highlighting technique (e.g. colour the strap in the illustration dark grey or black) and/ or an arrow as a visual clue.

2. The representation of the gender distribution of the target audience in the illustrations:

Contrary to the perception that the pictures concerned were of males, most of the illustrations of the caregiver were made from slides of a female therapist who was dressed in trousers and has short hair. The fact that the illustrations were perceived to be of a male stresses the importance of presenting people in pictures representative and appropriate of the customs of the target audience.

With regard to this specific booklet the purpose of the illustrations is to show certain techniques. Since the exact positioning of the hands and the legs needs to be shown, the trousers and short hair help to clarify the illustrations. The illustrations presenting the stroke survivor made use of a male since methods of dressing and washing are shown. The presentation of a bare upper body of a male is more acceptable with the majority of the target audience than a bare female upper body. Since the pictures were not regarded as offensive by any of the participants it is not recommended to change all the illustrations. The need for illustration to be sensitive to issues of gender should be kept in mind for future publications.

3. Information on causes of stroke and on spasticity.

This need came forth in both group discussions with stroke survivors. Since one of the characteristics of appropriate written material is to be limited in scope, it is not recommended that this booklet be further expanded. This might be an area for future information packages.

Finally, one of the limitations exposed by the new checklist was that the booklet was not individualised. Software programs provide the possibility of such individualised information. The sections of the booklet could easily be structured so that only the relevant parts be printed out for a stroke survivor. For example, for one client only the sections on speech and independent self care may be necessary. In addition, the

possibility of putting these printouts in a reusable file could be explored. This will allow therapists to include information as it becomes relevant and to remove irrelevant information. This will also provide space for personal notes and other information. Hoffmann, Russel et al, described a similar approach. Their preliminary results of the system evaluated by health professionals, patients and carers were positive.<sup>188</sup>

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### **7.3 Recommendations for further implementation of the booklet**

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After the refinement as describe above, the booklet will be ready for further roll-out with the training programme. The total package (training and booklet) should then be evaluated for effectiveness. The use of posters that can be put up in client's homes with important information and reminders can also be explored in this phase.

Although the booklet is aimed at stroke survivors and their caregivers in the Cape Town Metropole, it is likely that the practical nature of the information will be useful for clients from other areas as well. If an individualised approach is used as recommended, the information for clients with different needs could easily be tailored and included.

Such tailoring could possibly also be used for clients with different disabilities. The practical description of aspects like bed mobility and transfers are in many instances also applicable to persons who had a traumatic brain injury, cerebral palsy, multiple sclerosis and other.

It is also foreseen that the booklet can be used in the training of various health care workers. The Centre for Rehabilitation Studies is involved in the training of undergraduate medical students. They expressed interest in using the booklet for this training. Although it is unlikely that most doctors will be involved in the physical care of stroke survivors, they are still in many cases the gatekeepers to determine who receive rehabilitation. A more comprehensive understanding of the needs of these clients and their carers can certainly facilitate this process. With the implementation of community services for physio and occupational therapists, junior therapists are often employed in areas were there are no senior therapists. The functional nature of the booklet can be useful both the junior therapists and their clients.

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## 7.4 Recommendations for further refinement and application of the checklist

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In this study the checklist revealed a result similar to a standardised test (the SAM) even though it has not yet been validated. Firstly, a Chronbach alpha measurement is recommended to determine the reliability to measure appropriateness of the individual questions in the list. Thereafter measurements by the new checklist can be compared to measurements by standardised tests.

Even though this study did consult some experts, it is recommended that the list be further discussed, tested and refined by an interdisciplinary team. Such an approach will more likely lead to an accurate, comprehensive and user-friendly list.

This study found that the majority of existing checklists do not comprehensively measure the appropriateness of written health material. The new checklist is a step towards comprehensive evaluation of such material for developing communities. Not only does it give an indication of the level of appropriateness of the material, but it can also serve as a guideline for the refinement of material and the development of new material.

The checklist proved to be a useful tool to do an initial refinement of the booklet on stroke homecare. It is therefore foreseen that this checklist could have numerous other applications. Although it initially set out to be specific to the field of rehabilitation, none of the questions in the list is limited to rehabilitation. Thus, the checklist could probably be used in a variety of other disciplines that make use of written client information. This can include:

- Exercise programs by physiotherapists;
- Dietary advice by dieticians;
- Instructions for the administration of medication by pharmacists;
- Advice on wound care by nurses; and
- Information on specific conditions by medical practitioners.

The current format of the checklist allows only for “Yes/ No” answers. However, there are often scenarios when the most appropriate answer would be “most of the time” or “occasionally”. The SAM overcomes this problem by dividing each section into

“superior”, “adequate” and “not suitable”. It also uses guidelines such as “at least 40%....” and “more than 50%....”. Similar phrases may be helpful to use the new checklist as a grading tool. This can be developed in consultation with a statistician.

Although no checklist can replace the input of trained experts, such expertise or resources to involve them are not always available in developing communities. This checklist can be a valuable tool to guide health professionals who do not have access to an interdisciplinary team to tailor written information for their clients.

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## **7.5 Recommendations for future development of written health material**

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The most significant recommendation for developing written health material that emerged from this study is the involvement of an interdisciplinary team during planning stages and throughout the process. Such a team should include content experts and although word processing programs are widely used, this is not recommended. Rewriting of material in different programs amounts to unnecessary time loss and it is therefore recommended to use a programme specifically for this purpose from the start. Deciding on a basic style grid and the format of the information before the actual writing of the content will probably be time and cost effective in the long run. The checklist for evaluating appropriateness of written health material could be a useful guideline in this process. In addition, the involvement of a graphic designer, preferably a medical or technical illustrator from the start of the process may prove time and cost effective.

However, none of the above recommendations can replace the need for pre testing of material with the target audience.

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## **7.6 Evidence to action**

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Researchers are generating an increasing body of evidence. There is however a danger that the researcher community may simply supply and accumulate evidence rather than address the ways in which society can become responsive to it, and become more inclusive of the abilities of people with disability.<sup>189</sup> Hence, at the recent Symposium on Evidence –to-Action in Disability (SSEAD), the African Network for

Action-to-Evidence in Disability (AfriNEAD) was initiated. In line with the strategy of this network, the following immediate actions have been or will be taken following this study:

- The recommendations regarding the refinement of the booklet were discussed with the authors. They agreed to all the rewriting and redrawing of the unclear section. The two content errors were also corrected. The CRS agreed to the recommendation of revision by a graphic designer and a linguist and are awaiting quotations for this work.
- The development of posters and software were discussed with the CRS and will be further explored with stakeholders.
- A summary of the REALM literacy tests' results will be sent to the WCRC to prompt them for more in depth research regarding the true literacy of especially their nursing students.
- The concerns and information needs of the stroke survivors that emerged from the focus group discussion will be presented to the head of the WCRC.
- The researcher will prepare two articles to submit for academic journal publication.

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## **7.7 Summary of the study**

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This study aimed at refining a booklet for stroke survivors and their caregivers. In this process existing tools for the assessment of written health information were found to be incomprehensive for developing communities. Subsequently a new checklist was compiled based on the HAMSOC model.

This checklist as well as a standardised test was used to do a pre-pilot refinement of the booklet. Afterwards the booklet was tested by samples of the target audience and field experts. Overall, the booklet was positively received and the refined booklet was seen as superior to the original.

Further recommendations were made for the refinement and the implementation of the booklet. Recommendations for the validation and possible future use of the checklist were also made.

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## 7.8 Chapter summary

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In Chapter 6 recommendations were made for the implementation of the findings of the study.

Firstly, recommendations for the further refinement of the booklet were made. All of these will probably be met if the booklet were to be revised by a linguist and a graphic designer. The development of posters of important sections was also recommended. This was followed with recommendations for the implementation of the booklet. Although the booklet is proposed to be piloted and used with the training course (as discussed in Chapter 1), other implementation options were also discussed.

The future validation and foreseen uses of the checklist that was developed in the study were proposed. Finally, recommendations for the writing of other health information were made. The Chapter concluded with a brief summary of the study.

# Closing remark

Joseph Pulitzer of the Pulitzer Prize for Journalism was as quoted saying:

*“Put it to them briefly so they will read it, clearly so they will appreciate it, picturesquely so they will remember it, and above all accurately so they will be guided by its light”*

The researcher hopes that this study will make a contribution in this process especially for stroke survivors and their caregivers.

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Nov 27-28

## **Appendix 1: Letter of request to head of WCRC (1)**

20 April 2007

The Head  
Western Cape Rehabilitation Centre  
Cape Town

Dear Ms Hendry

### **REQUEST TO INVITE PATIENTS OF WCRC AND THEIR FAMILY MEMBERS TO PARTAKE IN A STUDY TO REFINE A INFORMATION BOOKLET**

I request permission to invite in patients of the WCRC and their family members to participate in a study to refine a booklet for caregivers of stroke survivors. I am currently busy with my M.Sc Medical Sciences (Rehabilitation). This study forms part of the fulfillment of the requirements for this degree. The study received ethical clearance from the Ethical Committee C of the University of Stellenbosch (N06/11/220).

The booklet that has been co-written by therapists of your centre is now in it's final stages of development. As part of it's refinement I plan to pilot it with samples of stakeholders. Participants will be required to read the booklet and partake in a focus group discussion one week after receiving it.

I propose to invite all stroke survivors that meet the in and exclusion criteria of the study and that are inpatients at your facility at the time of the study (4- 8 June 2007) to take part. I will personally be responsible for obtaining informed consent from the participants and will also conduct the focus group discussion. I will arrange the time for these contact sessions with the relevant therapist to minimize the impact on the patient's therapy. I will inform the case manger of each client that they received the booklet so that he /she can individualise the information for the client.

I also plan to invite the family members and caregivers of stroke survivors in the WCRC to participate on the same basis.

I will appreciate it if I could use a group or team room on your premises for the focus group discussions.

Please contact me if you require any other information.

Dr Janine Botha

Student number: 14511371

M G Mji

Study supervisor

## Appendix 2: Letter of request to head of WCRC (2)

PO Box 11831  
Erasmuskloof  
0048

8 May 2007

The Head  
Western Cape Rehabilitation Centre  
Cape Town

Dear Ms Hendry

### **REQUEST TO INVITE HOME CAREGIVER TRAINEES TO PARTAKE IN A STUDY TO REFINE A INFORMATION BOOKLET**

I request permission to invite home caregivers trainees to participate in a study to refine a booklet for caregivers of stroke survivors. I am currently busy with my M.Sc Medical Sciences (Rehabilitation). This study forms part of the fulfillment of the requirements for this degree. The study received ethical clearance from the Ethical Committee C of the University of Stellenbosch (N06/11/220).

The booklet that has been co-written by therapists of your centre is now in it's final stages of development. As part of it's refinement I plan to pilot it with samples of stakeholders. Participants will be required to read the booklet and partake in a focus group discussion.

I propose to invite all trainees attending the training on 13 June to participate. The booklet already forms part of the training and participants will be asked to comment on the understandability and perceived usefulness of the booklet. I will personally be responsible for obtaining informed consent from the participants and will also conduct the focus group discussion.

If this in order I will appreciate it if you can give me the contact details of the relevant persons to finalise the logistic arrangements.

Please contact me if you require any other information.

Dr Janine Botha

Student number: 14511371

M G Mji

Study supervisor

## **Appendix 3: Letter of request to Manager Riverfield Lodge: Life hospital**

PO Box 11831  
Erasmuskloof  
0048

21 May 2007

Dr Marinda Overbeek  
Life Healthcare Riverfield Lodge

Dear Marinda

### **REQUEST TO INVITE PATIENT OF RIVERFIELD LODGE TO PARTAKE IN A PILOT STUDY**

I request permission to invite patients of Riverfield Lodge to participate in a study to refine a booklet for caregivers of stroke survivors. I am currently busy with my M.Sc Medical Sciences (Rehabilitation). This study forms part of the fulfillment of the requirements for this degree. The study received ethical clearance from the Ethical Committee C of the University of Stellenbosch (N06/11/220).

The booklet that has been written by the Centre for Rehabilitation Studies of the University of Stellenbosch therapists of the Western Cape Rehabilitation Centre is in it's final stages of development. As part of it's refinement I plan to pilot it with samples of stakeholders. Participants will be required to read the booklet and partake in a focus group discussion one week after receiving it.

I propose to invite five to ten stroke survivors and their family members that meet the in and exclusion criteria of the study to take part. I will personally be responsible for obtaining informed consent from the participants and will also conduct the focus group discussion. I will arrange the time and venue for these contact sessions with the with the relevant therapists.

I will appreciate it if I could use a group or team room on your premises for the focus group discussions.

Please contact me if you require any other information.

Dr Janine Botha

Student number: 14511371

M G Mji

Study supervisor

## **Appendix 4: Participant information and consent form (pilot study and samples 1-4)**

**Title of The Research Project:**

Refinement of an information booklet for the caregivers of stroke survivors

**Principal Investigator:**

Dr Janine Botha

**Address:**

PO Box 11831

Erasmuskloof

0048

[janine@cybersmart.co.za](mailto:janine@cybersmart.co.za)

**Contact Number:**

083 3828118

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

The Centre for Rehabilitation Studies of the University of Stellenbosch has developed a booklet with practical guidelines on caring for someone who suffered from a stroke. Before this booklet is distributed and used more widely it must first be refined. Part of this process is to get the opinion of people who will actually use this booklet. These opinions will be used to make recommendations to produce a more user-friendly booklet.

Participants will receive the booklet and will be given one week to read it. Almost half of the 44 pages of the booklet consists of pictures. After a few days the principle investigator will conduct focus group discussions where the opinion of participants will be discussed. These discussions will be tape recorded.

### **Who are invited to participate?**

People who suffered from a stroke and are in patients at Life Health Care Riverfield Lodge (Pilot) or Western Cape Rehabilitation Centre at the time of the study are invited. Because the booklet is written for caregivers, family members of patients are also invited to partake as well as caregivers undergoing training at the Western Cape Rehabilitation Centre.

All the participants must be able to speak and read English and be older than 20 years. Unfortunately people with speech and language problems secondary to their stroke and people with dementia (problems with orientation and planning) will not be able to participate.

Separate focus group discussions will be held for each group.

### **What will your responsibilities be?**

Participants will be expected to read the booklet within one week of reception. On the receiving the booklet, the date, time and venue of the focus group will also be given. Participants are requested to give their honest opinion on the booklet during the discussion. Typical questions that will be asked are: "Did you understand everything you read?", "Were the pictures clear?" and "What would you like to be different?" A health literacy test will also be conducted; this will take about 3 minutes.

Participants will also be asked to describe their general living conditions. Question will include: “Do you live in a rural or urban area?” and “How far is your nearest clinic?”

The discussions will not exceed 1 hour.

**Will you benefit from taking part in this research?**

You will be allowed to keep the booklet that is expected to be a future resource for yourself.

**Are there any risks involved in your taking part in this research?**

There are no anticipated risks for participants in this study

**If you do not agree to take part, what will happen?**

You are free not to take part in this study or to withdraw at any time. There will in no way be discriminated against you or your family members if you do so. It will however be appreciated if once you agreed to take part and then want to withdraw, you let dr Janine Botha know.

**Who will have access to your medical records?**

This study will not make use of any information from medical records. All information will be gathered in the focus group discussions and will be voluntary.

**Will you be paid to take part in this study and are there costs involved?**

You will not be paid to participate in the study. You will be required to make use of your own transport to attend the group discussion. The focus group for in patients of the WCRC will be held on the premises. The focus group for family members of WCRC patients will be on a Friday afternoon in order to coincide with patient's weekend leave departure. Light snacks and drinks will be offered after the group discussion.

**Is there any thing else that you should know or do?**

- You can phone Dr. Janine Botha at 0833828118 if you have any inquiries.
- You can contact the Committee for Human Research at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the principle investigator
- You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled: Refinement of an information booklet for the caregivers of stroke survivors

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2007.

**Signature of participant**

**Signature of witness**

**Declaration by investigator**

I, Janine Botha declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*)..... On (*date*) ..... 2007.

Signature of investigator

Signature of witness

## Appendix 5: Participant information and consent form (sample 5)

**Title Of The Research Project:**

Refinement of an information booklet for the caregivers of stroke survivors

**Principal Investigator:**

Dr Janine Botha

**Address:**

PO Box 11831

Erasmuskloof

0048

[janine@cybersmart.co.za](mailto:janine@cybersmart.co.za)

**Contact Number:**

083 3828118

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

**What is this research study all about?**

The Centre for Rehabilitation Studies of the University of Stellenbosch has developed a booklet with practical guidelines on caring for someone who suffered from a stroke. Before this booklet is distributed and used more widely it must first be refined. Part of this process is to get the opinion of people who will actually use this booklet. These opinions will be used to make recommendations to produce a more user-friendly booklet.

**Who are invited to participate?**

People who suffered from a stroke and Western Cape Rehabilitation Centre at the time of the study are invited. Because the booklet is written for caregivers, family members of patients are also invited to partake as well as caregivers undergoing training at the Western Cape Rehabilitation Centre.

All the participants must be able to speak and read English and be older than 21 years. Unfortunately people with speech and language problems secondary to their stroke and people with dementia (problems with orientation and planning) will not be able to participate.

**What will your responsibilities be?**

You will be shown two samples of the booklet and asked about your preference.

**Are there any risks involved in your taking part in this research?**

There are no anticipated risks for participants in this study

**If you do not agree to take part, what will happen?**

You are free not to take part in this study or to withdraw at any time. There will in no way be discriminated against you or your family members if you do so. It will however be appreciated if once you agreed to take part and then want to withdraw, you let dr Janine Botha know.

**Who will have access to your medical records?**

This study will not make use of any information from medical records. All information will be gathered in the focus group discussions and will be voluntary.

**Will you be paid to take part in this study and are there costs involved?**

You will not be paid to participate in the study.

**Is there any thing else that you should know or do?**

- You can phone Dr. Janine Botha at 0833828118 if you have any inquiries.
- You can contact the Committee for Human Research at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the principle investigator
- You will receive a copy of this information and consent form for your own record

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled: Refinement of an information booklet for the caregivers of stroke survivors

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2007.

**Signature of participant**

**Signature of witness**

**Declaration by investigator**

I, Janine Botha declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*)..... On (*date*) ..... 2007.

**Signature of investigator**

**Signature of witness**

## Appendix 6: Mini Mental State Examination

Test	Max Score	Patient Score
<b>Orientation</b>		
What is the year?	1	
What is the season?	1	
What is the date?	1	
What is the day?	1	
What is the month?	1	
In what country are you?	1	
In what province are you?	1	
In what town are you?	1	
In what hospital are you?	1	
In what ward are you?	1	
<b>Retention</b>		
Name three objects and ask client to repeat them	3	
<b>Attention</b>		
Serial 7's OR spell the word "WORLD" backwards	5	
<b>Recall</b>		
Ask client to recall three objects learned earlier	3	
<b>Language</b>		
Name a pencil and a watch	2	
Ask client to repeat a short sentence	1	
Three stage command	3	
Read and obey "close your eyes"	1	
Ask client to write a sentence of his/her choice	1	
Ask client to copy two interceding pentagons	1	
<b>TOTAL</b>	<b>30</b>	

## Appendix 7: REALM literacy test

Name:..... Language: .....

Date:..... Highest school grade completed:.....

Examiner:..... Gender:.....

### REALM test word list

List 1	List 2	List 3
fat	fatigue	allergic
flu	pelvic	menstrual
pill	jaundice	testicle
dose	infection	colitis
eye	exercise	emergency
stress	behaviour	medication
smear	prescription	occupation
nerves	notify	sexually
germs	gallbladder	alcoholism
meals	calories	irritation
disease	depression	constipation
cancer	miscarriage	gonorrhoea
caffeine	pregnancy	inflammatory
attack	arthritis	diabetes
kidney	nutrition	hepatitis
hormones	menopause	antibiotics
herpes	appendix	diagnosis
seizure	abnormal	potassium
bowel	syphilis	anemia
asthma	hemorrhoids	obesity
rectal	nausea	osteoporosis
incest	directed	impetigo
<b>Total</b>		

**REALM scoring chart**

<i>Raw score</i>	<b>Grade range</b>
0-18	3 <sup>rd</sup> grade and below
19-44	4 <sup>th</sup> to 6 <sup>th</sup> grades
45-60	7 <sup>th</sup> to 8 <sup>th</sup> grades
61-66	9 <sup>th</sup> grade and above

## **Appendix 8: Focus Group Guideline**

### **General Principles**

- Always be friendly.
- Speak clearly.
- Make eye contact and use open body language.
- Be sensitive to ensure that all participants get equal opportunities to voice their opinions.
- Acknowledge non verbal communication.
- Beware of medical or technical jargon.
- Remember that the guideline questions are guidelines. Be flexible enough to explore opinions that arise.

### **Introduction (+/- 5 minutes)**

- Welcome all participants.
- Take note of the time and reassure the group that the discussion will not finish later than..... (1 hour after starting).
- Invite participants to enjoy light snacks and drinks after the discussion.
- Remind the group that the discussion will be recorded on tape, but that their responses will be confidential.
- Let everyone introduce themselves to the group and state whether they are a stroke survivor, family member or caregiver.

### **Questions regarding understanding of the booklet (+/- 15 minutes)**

- Did all of you have a chance to read through the booklet?
- Did you understand everything you read?
- What was unclear?
- Was there any words or phrases that were difficult to understand?
- Did you find it easy or difficult to read?
- Were the pictures helpful?
- Was it clear what the pictures intended to show?

- Would it be helpful if someone first demonstrate to you how to do e.g. transfers?

**Questions regarding usefulness of the booklet (+/- 15 minutes)**

- Did you learn anything new from the booklet?
- Did you find the information helpful?
- Would you recommend this booklet to other stroke survivors or caregivers?
- What would you tell about the booklet to a friend that did not read it?

**Questions regarding recommendations (+/- 10 minutes)**

- What would you like to read more of in the booklet?
- Was there information that you found unnecessary?
- What would you change in the booklet?

**Closure (+/- 5 minutes)**

- Is there anything anyone would like to add?
- Is there anything regarding stroke or caring for stroke survivors that you would like to ask?

Thank group members for their participation. Encourage them to use the booklet for future reference. Invite them to call or write if they have any other comments or questions

## Appendix 9: Questionnaire for preference of pre- and post- refinement of stroke home care booklet

Fill in or cross relevant block

1. Name.....

2. Age.....

3. Grade finished at school.....

4. Home language

English	Afrikaans	Xhosa	Other.....
---------	-----------	-------	------------

5. Category

Stroke survivor	Caregiver
-----------------	-----------

6. Which booklet do you prefer?

1 (small A5)	2 (big A4)
--------------	------------

7. Why? (give any reasons for your preference)

1.....  
.....  
2.....  
.....  
3.....  
.....  
4.....  
.....

8. Which booklet's size do you prefer?

1 (small A5)	2 (big A4)
--------------	------------

8. Which booklet's font size (type /print) do you prefer?

1 (small A5)	2 (big A4)
--------------	------------

Thank you for your participation

Dr Janine Botha

## Appendix 10: Themes and subcategories from existing lists

		Existing lists (par 4.2)																			
Themes		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
	Involve target audience				X		X		X		X		X		X				X		
<b>HEALTH EDUCATION</b>																					
1	Is the purpose of the material clear?	X			X		X		X		X				X		X				
2	Is it clear who the indented audience are?						X														
3	Is the number of concepts limited to three to four?	X			X	X		X	X			X	X	X	X		X		X		
4	Is the information consistent with other information given to the client?					X			X				X								
5	Is the focus on providing information that is behaviour-focussed? Are concepts presented in a clear, "how to" manner?	X			X	X	X	X	X	X	X	X		X	X		X	X			
6	Is the information motivating and leading to self-efficacy?	X				X			X												
7	Is the material interactive and does it allow for audience involvement?	X			X	X		X	X		X	X									
8	Is the content accurate, up-to-date, evidence-based, and sources appropriately referenced?		X		X	X	X		X		X		X				X				X
9	Make readers feel something after reading the message, such as happiness, confidence, gladness or enthusiasm								X												
10	Does the material use concrete examples rather than abstract concepts?							X								X					
11	Is the information individualised?								X												
12	Are there no copyright infringements?				X																
<b>APPROPRIATE MEDIA AND TECHNOLOGY</b>																					
<b>Language</b>																					
13	Are short words, preferably one to two syllables, where possible used?						X				X		X				X			X	
14	Are short sentences with one idea per sentence					X	X	X		X	X		X		X	X			X	X	
15	Are simple grammatical structures and punctuation used?						X			X							X			X	

		Existing lists (par 4.2)																			
Themes		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
16	Are the paragraphs short and express only one idea per paragraph?					X					X		X			X	X			X	
17	Is the text written in the active voice?	X				X	X			X	X	X	X	X	X	X			X	X	
18	Are difficult concepts explained using common, everyday words and are confusing or unknown terms clearly defined?	X	X		X	X	X	X	X	X	X	X	X		X	X	X		X	X	
19	Is the text written in the second person?					X	X				X						X			X	
20	Are numbers used and not words?					X				X							X				
21	Is the language consistent?									X							X			X	
<b>Layout, typography and visual appearance</b>																					
22	Is the font at least 12 point?	X	X			X	X			X	X	X	X	X		X	X	X	X		
23	Is a clear typeface used?	X	X		X	X			X	X				X					X		X
24	Is sentence case used/	X	X		X	X	X	X	X		X	X	X	X							
25	Is there good contrast between the print and the paper?	X				X			X	X	X	X	X				X	X			
26	Do the pages appear uncluttered with ample white space?	X			X	X	X		X	X		X	X	X			X	X	X	X	
27	Are the headings clear, consistent and close to the related text?					X		X	X												
28	Is the general eye span less than 60- 70 characters?	X					X		X	X									X		
29	Are the words not hyphenated at the end of lines and sentences ending on the same page?									X											
30	Is the text only justified to the left?				X	X			X	X				X		X	X		X		
31	Is the use of colour appropriate and not distracting?				X	X		X	X						X						X
32	Is the cover attractive and does it indicate the core content and intended audience?	X							X			X		X	X						
33	Is the layout consistent?	X					X			X								X			
<b>Production</b>																					
34	Is the weight of the paper at least 130 to 150 grams per square metre (gsm)?						X														
35	Does the paper have a matt finish?	X			X	X				X											
<b>Organisation</b>																					

		Existing lists (par 4.2)																			
Themes		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
36	Is the most important information presented first and sequenced in a logical order?				X	X	X	X	X	X	X		X	X		X	X		X	X	
37	Are the sentences structured so that the context or old information is presented before new information?	X							X		X										
38	Is a structured format with headings and subheadings used that serve as advanced organisers?	X			X	X	X	X	X	X	X	X	X	X						X	
39	Are bullet points or boxes used to group or list relevant information?	X			X	X			X		X		X	X			X		X		
40	Are important information emphasised using text boxes, bold type, colour, lines or larger print size?	X			X	X	X		X	X	X		X	X			X				
41	Are main points summarised?	X			X			X			X	X	X		X	X			X		X
<b>Readability</b>																					
42	Does a readability check confirm the piece is at a reading level appropriate for your audience?	X			X		X	X			X		X		X		X		X		
<b>Illustrations</b>																					
43	Are the pictures realistic?	X							X								X				
44	Do the pictures agree with the content of the text?	X		X	X		X						X		X		X				
45	Do the pictures provide information that is central to the text?			X					X	X	X	X	X	X					X		X
46	Are the graphic cues in the pictures, namely arrows or lines, directing attention to a particular area of the picture?			X					X												
47	If the pictures are in colour does the colour emphasise important			X																	
48	Do the pictures have captions?	X		X				X	X		X		X	X			X	X	X		
49	Do the pictures have legends with more information than just the name?			X	X																
50	Are the legends instructive and explanative in nature?			X																X	
51	Are the legends easy to understand?			X																	
52	Do the legends relate to the picture?			X																	
53	If the function of the picture is to act as an advanced organiser, does the picture appear before the text?	X		X										X			X		X		
	If the function of the picture is to repeat information that is presented in the text, does the picture appear after the text?					X											X				

		Existing lists (par 4.2)																			
Themes		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
54	Are no clipart used?					X				X											
55	Is there no writing over images?							X													
56	If the intended audience is adults, are adult rather than childlike images used?		X													X					
57	Do the word choices carry positive meanings?					X		X			X	X	X				X				
<b>SOCIO-CULTURAL SENSITIVITY</b>																					
58	Do the word choices carry positive meanings?	X	X																		
59	Is it written in a friendly tone?	X	X			X		X			X			X					X		
60	Is peer language used whenever appropriate to increase personal identification and improve readability?									X		X					X				
61	If the information is not individualised, is gender free language used where appropriate?		X									X					X				
62	If the information is not individualised or compiled for a specific cultural grouping, does the material reflect respect for the cultural, ethnic and/o religious diversity of society?		X																		
63	Are the words, phrases, and expressions free from stereotypical meaning?		X																		
64	Are the statistics presented are representative of the intended audience?		X																		
65	Are the messages linked to sources credible to the intended audience?		X							X											
66	Are the referral sources accessible to the intended audience?		X														X				
67	Do the messages address stereotypes and myths?		X	X																	
68	Are the graphics suitable for the level of visual literacy of the target group?	X	X		X																
69	Are physical appearances of people in the pictures representative and appropriate of the target audience?	X			X																
70	Are the context of pictures and descriptive examples representative and appropriate of the target audience?	X	X							X											
71	Do the graphics illustrate contemporary activities of the intended audience?	X	X																		
72	Are the symbols that are used familiar and acceptable to the intended audience?		X																		
73	Are the social network structures (family, friends, etc.) accurately portrayed?		X																		

		Existing lists (par 4.2)																			
Themes		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
74	Are the interactions between the characters believable?		X																		
75	Are the stature and poise of the individuals representative of the gender and social roles of the intended audience?				X		X				X		X		X					X	

## Appendix 11: Developed checklist

### Checklist to evaluate the appropriateness of written health information

#### Introduction to the checklist:

The goal of this checklist is to serve as a guideline to evaluate written client information for readers with a low literacy level in the field of rehabilitation. Authors of new material or health professionals that want to evaluate the appropriateness of existing material can apply it to any written material given to clients (e.g. information sheets on diseases and conditions, exercise programs, treatment plans, dietary advice ect.). The checklist will give an indication of the appropriateness of the material and will highlight areas that can be considered for improvement.

The checklist is based on the HAMSOC model that describes three cornerstones of equal importance for appropriate health education messages. The cornerstones are:

- Health education;
- Appropriate Media and
- Socio-cultural sensitivity

#### Aspects to keep in mind when using the checklist:

- It is important to keep in mind that written information may not always be the most appropriate medium for a specific target group or message.
- Ideally, an interdisciplinary team that include health professionals, designers and linguists should develop and test the material.
- When evaluating material keep the purpose of the material in mind.
- This checklist is a guideline to refine written health information. It can never replace testing and piloting the material with the actual target audience.
- When evaluating the material keep the target audience in mind.
  - What language does the intended audience speak?
  - What gender is the intended audience?
  - What is the age range of the intended audience?
  - What is the literacy level of the intended audience?
  - What is the location of the intended audience? (e.g. urban area, suburban area or rural area)

## Evaluating Cornerstone 1: Health Education

The cornerstone of Health Education is based on the principle that it is the message (in the medium) that counts. The selection of relevant content and the most suitable methods of delivery thereof are the most important factors to be evaluated.

		Yes	No
1.1	<b>Is the purpose of the material clear?</b> Is the purpose to give information, change behaviour or give instruction?		
1.2	<b>Is it clear who the intended audience are?</b>		
1.3	<b>Is the number of concepts limited to three to four?</b> Keep content clear, simple and concise. Do not confuse people by covering several topics in one document.		
1.4	<b>Is the information consistent with other information given to the client?</b> Is the information reinforced by what the health professional say, letters, leaflets and appointments?		
1.5	<b>Is the focus on providing information that is behaviour-focussed?</b> Are concepts presented in a clear, "how to" manner? Behaviour changes and actions to be taken must be stressed. The information should help people to make decisions.		
1.6	<b>Does the content stimulate readers to feel something after reading the message, such as happiness, confidence, gladness or enthusiasm?</b>		
1.7	<b>Is the information motivating and leading to self-efficacy?</b> People are more motivated to learn when they believe the tasks or behaviour are doable by them. Complex topics should be subdivided into smaller parts that readers may experience small successes.		
1.8	<b>Is the material interactive and does it allow for audience involvement?</b> Interaction is invited via questions, responses and suggested action. Give contact details of a health professional or other resource.		
1.9	<b>Is the content accurate, up-to-date, evidence-based, and sources appropriately referenced?</b> This includes listing of authors and publishing date. Depending on the target audience, all references need not be included but must be available on request. Name at least two to three other resources where similar or more information can be obtained.		
1.10	<b>Does the material use concrete examples rather than abstract concepts?</b> The information must be relevant and of practical use for the reader.		
1.11	<b>Is the information individualised?</b>		
1.12	<b>Are there no copyright infringements?</b>		

## Evaluating Cornerstone 2: Appropriate media

Appropriate Media and Technology includes the selection of the most suitable medium used in the most suitable format. It embraces factors like readability and layout as well as the effective usage of pictures and graphs.

		Yes	No
<b>2.1</b>	<b>Language</b>		
2.1.1	<b>Are short words, preferably one to two syllables, where possible used?</b>		
2.1.2	<b>Are short sentences with one idea per sentence used?</b> In general, a sentence should not have more than 15 to 20 words. Sentences using commas or joined with 'and' should be avoided.		
2.1.3	<b>Are simple grammatical structures and punctuation used?</b> Semicolons (;), colons (:), hyphens (-) should be avoided.		
2.1.4	<b>Are the paragraphs short and expressing a single idea?</b> Use small blocks of text.		
2.1.5	<b>Is the text written in the active voice?</b>		
2.1.6	<b>Are difficult concepts explained using common, everyday words and are confusing or unknown terms clearly defined?</b> Avoid the use of jargon and abbreviations. Define technical terms in words that are familiar to the reader.		
2.1.7	<b>Is the text written in the second person?</b> Talk to your readers directly using active and personal language. The use of "you" and "we" makes writing more direct and understandable.		
2.1.8	<b>Are numbers used and not words?</b> Use 3 instead of 'three'. Try not to use percentages or large numbers. You could say 'a few' instead of 7% and 'many' instead of 1,552. Do not use Roman numerals.		
2.1.9	<b>Is the language consistent?</b> For important concepts, use the same words and phrases consistently even if it sounds repetitive.		
<b>2.2</b>	<b>Layout and typography and visual appearance</b>		
2.2.1	<b>Is the font at least 12 point?</b> If the information is intended for elderly people or people with sight difficulties, use 14 point or larger.		
2.2.2	<b>Is a clear typeface used?</b> Do not use more than two font styles.		
2.2.3	<b>Is sentence case used?</b> Avoid the use of all capitals.		
2.2.4	<b>Is there good contrast between the print and the paper?</b> Avoid yellow type. Avoid reverse type (white out of a colour).		

2.2.5	<b>Do the pages appear uncluttered with ample white space?</b> The layout must balance white space with words and illustrations. Use at least 1.2- 1. line spacing. The space between letters must be less than the space between words, and word space must be less than the space between lines. Margins must be at least 1.2cm.		
2.2.6	<b>Are the headings clear, consistent and close to the related text?</b> There should be more space above a heading than below.		
2.2.7	<b>Is the general eye span less than 60- 70 characters?</b>		
2.2.8	<b>Are words not hyphenated at the end of lines and sentences not continuing on a next page?</b>		
2.2.9	<b>Is the text only justified to the left?</b> The right edge should rather be ragged,		
2.2.10	<b>Is the use of colour appropriate and not distracting?</b> Colour is very effective when used for queuing and filtering purposes, such as identifying the main points of the content.		
2.2.11	<b>Is the cover attractive and does it indicate the core content and intended audience?</b>		
2.2.12	<b>Is the layout consistent?</b> Do not use more than two styles.		
<b>2.3</b>	<b>Production</b>		
2.3.1	<b>Is the weight of the paper at least 130 to 150 grams per square metre (gsm)?</b> The reverse side print must not be visible from the front.		
2.3.2	<b>Does the paper have a matt finish?</b> The paper must not reflect light.		
<b>2.4</b>	<b>Organisation</b>		
2.4.1	<b>Is the most important information presented first and sequenced in a logical order?</b> A question answer format may be useful.		
2.4.2	<b>Are the sentences structured so that the context or old information is presented before new information?</b> E.g. 'To lower your risk of stroke {context}, you will need to make changes to what you eat' {new information}.		
2.4.3	<b>Is a structured format with headings and subheadings used that serve as advanced organisers?</b> Too many headings can be confusing.		
2.4.4	<b>Are bullet points or boxes used to group or list relevant information?</b> List no more than 5 points in each list, and label each list descriptively.		
2.4.5	<b>Are the important information emphasised using text boxes, bold type, colour, lines or larger print size?</b> Avoid all capital, italics and underlining		
2.4.6	<b>Are the main points summarised?</b> The summary should stress "what to do" information.		

<b>2.5</b>	<b>Readability</b>		
2.5.1	<p><b>Does a readability check confirm the document is at a reading level appropriate for the target audience?</b>            Aim for a 5<sup>th</sup> to 6<sup>th</sup> grade reading level if the literacy level of audience was not tested.            Computer software that tests readability often produces a readability score that is at least two grade levels below the actual reading level.            A copy of the Instructions for using the SMOG readability formula is included at the end of the checklist.</p>		
<b>2.6</b>	<b>Illustrations</b>		
2.6.1	<p><b>Are the pictures realistic?</b>            Borders and implied borders that cut off images and figures can negatively affect the comprehension of a picture.</p>		
2.6.2	<b>Do the pictures agree with the content of the text?</b>		
2.6.3	<p><b>Are the pictures presented in a clear style?</b>            A picture's legibility is better if there is no distracting background detail. Detailed realistic drawings with tonal values, and photographs, are two suitable styles.</p>		
2.6.4	<b>Do the pictures provide information that is central to the text?</b>		
2.6.5	<p><b>Are the graphic cues in the pictures, namely arrows or lines, directing attention to a particular area of the picture?</b>            Cues, such as circles or arrows, point out key information.</p>		
2.6.6	<p><b>If the pictures are in colour, does the colour emphasise important part of the picture?</b>  <b>OR</b>  <b>If the picture is in black and white, are there tonal values in the picture to emphasise important parts?</b></p>		
2.6.7	<b>Do the pictures have captions?</b>		
2.6.8	<b>Do the pictures have legends with more information than just the name?</b>		
2.6.9	<p><b>Are the legends instructive and explanative in nature?</b>            The legend and the picture should show actions that the reader musts take.</p>		
2.6.10	<b>Are the legends easy to understand?</b>		
2.6.11	<b>Do the legends relate to the picture?</b>		
2.6.12	<p><b>If the function of the picture is to act as an advanced organiser, does the picture appear before the text?</b>  <b>OR</b>  <b>If the function of the picture is to repeat information that is presented in the text, does the picture appear after the text?</b>            The picture should be as near as possible to the relevant text and be visually linked to the picture. (E.g. use boxes or arrows)</p>		
2.6.13	<b>Are no clipart used?</b>		
2.6.14	<b>Is there no writing over images?</b>		
2.6.15	<b>If the intended audience are adults, are adult rather than childlike images used?</b>		

## Evaluating Cornerstone 3: Cultural Sensitivity

The third cornerstone is Sensitivity to socio-cultural variables. Insensitivity to these variables could lead to misunderstanding and antagonism towards the information given. Keep both the culture related to the ethnicity and disability in mind when evaluating material for persons with disability.

		Yes	No	N/A
3.1	<b>Do the word choices carry positive meanings?</b>			X
3.2	<b>Is it written in a friendly tone?</b> Non-patronising, non-alarmist language should be used. Avoid instructions. For example, do not just say “do not eat anything for six hours before an operation” – explain why.			X
3.3	<b>Is peer language used whenever appropriate to increase personal identification and improve readability?</b> Use everyday language. “Write as you speak”			X
3.4	<b>If the information is not individualised, is gender free language used where appropriate?</b>			
3.5	<b>If the information is not individualised or compiled for a specific cultural grouping, does the material reflect respect for the cultural, ethnic and/o religious diversity of society?</b>			
3.6	<b>Are the words, phrases, and expressions free from stereotypical meaning?</b>			X
3.7	<b>Are the statistics presented representative of the intended audience?</b>			
3.8	<b>Are the messages linked to sources credible to the intended audience?</b>			X
3.9	<b>Are the referral sources accessible to the intended audience?</b>			X
3.10	<b>Do the messages address stereotypes and myths?</b>			X
3.11	<b>Are the graphics suitable for the level of visual literacy of the target group?</b> Pictorial conventions, namely motion, movement and perspective, can cause problems for viewers unaccustomed to these conventions.			X
3.12	<b>Are physical appearances of people in the pictures representative and appropriate of the target audience?</b>			
3.13	<b>Are the context of pictures and descriptive examples representative and appropriate of the target audience?</b> This includes interaction between people, portrayed customs, food and environmental settings.			
3.14	<b>Do the graphics illustrate contemporary activities of the intended audience?</b>			

3.15	<b>Are the symbols that are used familiar and acceptable to the intended audience?</b>			
3.16	<b>Are the social network structures (family, friends, etc.) accurately portrayed?</b> Keep accepted roles for men and women in mind.			
3.17	<b>Are the interactions between the characters believable?</b> This includes social network structures (family, friends ect.) and acceptable role for men and women.			
3.18	<b>Are the stature and poise of the people representative of the gender and social roles of the intended audience?</b> This includes body language, particularly whether touching or proximity is acceptable in specific situations.			

**Instructions for using the SMOG readability formula**

1. Select 30 sentences from the material to be assessed. Count out 10 consecutive sentences near the beginning, 10 consecutive from the middle and 10 from the end. For this purpose, a sentence is any string of words punctuated by a period, an exclamation mark, or a question mark.
2. From the entire 30 sentences, count the words containing three or more syllables, including repetitions.
3. Calculate the grade level by determining the nearest perfect square root of the total number of words of three or more syllables and then adding a constant of 3 to the square root.

Example:

Total number of words containing three or more syllables – 67

Nearest perfect square – 64

Square root – 8

Add 3 – 11

In this example, the grade level of the material is – 11

## Interpretation of checklist

Health education:

Total "yes" answers ÷ 12 x5=  
 \_\_\_\_\_ ÷ 12 x5 =

Appropriate Media:

Total "yes" answers ÷ 9(÷45x5) =  
 \_\_\_\_\_ ÷ 9 =

Socio-cultural sensitivity

Total "yes" answers ÷ (18- total of N/A answers) x 5  
 \_\_\_\_\_ ÷ (18 - \_\_\_\_\_) x 5 =

Total of three scores	Level of appropriateness
If any of the three sections score 2.0 and below	Highly inappropriate
< 8.0	Highly inappropriate
8.0 – 9.9	Moderately inappropriate
10.0 -11.9	Moderately appropriate
12.0 -15	Highly appropriate

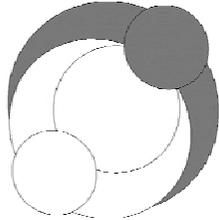
Name of material.....

Level of appropriateness.....

## **Appendix 12: Unrevised booklet**

This version of the booklet was printed in a A5 format and bound into a booklet. For the purpose of referencing the page numbering is continuous with the rest of the thesis. The booklet used in the study was numbered from page one.

# STROKE CARE at HOME



**CENTRE FOR REHABILITATION STUDIES,  
UNIVERSITY OF STELLENBOSCH**

in conjunction with



**westerncaperehabilitationcentre**

**DEPARTMENT OF HEALTH,  
PROVINCIAL GOVERNMENT OF THE WESTERN CAPE**

Compiled and edited by ES Scheffler & SJ Visagie

Sponsored by National Port Authorities of South Africa – Cape Town

February 2007

## MOTIVATION

Stroke is a complex condition by nature and caring for the stroke survivor is a challenge. In the Western Cape this situation is aggravated by limited community-based rehabilitation services and inadequate or no training and support of caretakers. Often stroke survivors are discharged home within 48 hours after their admission to an acute care facility. Many people are often not even admitted to a hospital. Untrained or inadequately trained caregivers have to cope as best as they can.

Staff from the clinical component, of the then Centre for Care and Rehabilitation of Stellenbosch University, situated at Karl Bremer Hospital, noted that caretakers experienced difficulty in assisting persons with a stroke with physical activities such as dressing and transfers. Many caregivers struggled to communicate and failed to understand behaviour problems caused by the stroke. Furthermore preventable secondary complications were commonly seen, e.g. painful shoulders and hands, contractures and poor habit patterns.

In 1995, the then manager, Jenny Hendry, and senior physiotherapist at the Centre, Elsje Scheffler, started with the motivation for the funding and development of a training package to address abovementioned needs. Funding was obtained from the then Portnet company as part of its restructuring and development plan. Portnet has since been integrated into The National Ports Authority of South Africa.

The training package includes a 4 hour training programme for home carers and other care institutions e.g. old age homes, as well as a training manual that re-inforces the practical aspects addressed during training. The training sessions commenced in 1996 and are still running currently.

Over a period of 10 years, the training package has been refined and modified, according to needs expressed and feedback received from both trainees and stroke survivors. The complete product is now available.

The authors hope to provide an easy, accessible guide for caretakers to use as a reference at home. This tool should only be given to caretakers to aid memory after training has been completed. The purpose of the manual is not to replace training. Adequate time should be spent with carers to ensure appropriate and adequate skills training.

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The Head  
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Private Bag X19  
Mitchell's Plain  
7789

for the appropriate consent and conditions attached thereto. The content of this manual may not be used in any other manner.

## ACKNOWLEDGEMENTS

The authors would like to express their sincere appreciation to the following persons, without whose assistance this document would not have been possible:

- Jenny Hendry, who initiated the project, assisted with the motivation for funding, played a valuable role during the planning phase and provided input during final editing.
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- Kim McDonald, for the balance of the line drawings and the precision and accuracy with which she continued from the previous artists.
- Sheena Irwin-Carruthers, Helen Sammons and Jacqui Goeller for proof reading the final product.

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## 1. INTRODUCTION

### ***What is a stroke?***

A stroke is caused by failure of the blood supply to a part of the brain. Damage or disease can cause blocking or narrowing of a blood vessel which will stop the flow of blood. Therefore oxygen (air) and nutrients (food) cannot reach certain areas. This causes damage to these areas and they may stop working. Alternatively a blood vessel can burst. The blood flooding the brain causes damage.

### ***Recovery after stroke***

Recovery is a long, slow process and is almost never 100%. Most patients learn to walk again, although slowly and with an uneven gait, but they often do not regain full control of their hand and arm. Sometimes movement in the arm and leg returns in definite fixed patterns that prevent normal function. These rigid movement patterns are caused by stiffness in the muscles. Following a stroke some people, find that their physical abilities might return to almost normal while their mental functions, like decision making or recognising potentially dangerous situations, are negatively affected. Each stroke is different depending on the area of the brain that was affected.

It is important to find out what caused the stroke. It is not possible to make dead brain cells come alive again, but one can try to prevent further strokes.

Common causes are: Diabetes, High blood pressure and Heart problems.

### ***Problems often caused by a stroke***

- Weakness or paralysis of one side of the body
- Stiffness of arm, hand and / or leg
- Poor balance in sitting and standing
- Difficulty in speaking or understanding language
- Loss of bladder and bowel control, which is usually temporary
- Loss of feeling on the weak side
- Unawareness / ignoring of the weak side
- Problems with vision (seeing)
- Confusion and disorientation
- Mood and personality changes
- Spatial and perceptual problems

### ***How to approach someone who has had a stroke***

- Treat the person as an adult.
- Do not allow him/her to stay in bed or in pajamas during the day.
- Allow him/her more time to perform tasks. Be patient.
- Encourage him/her to do things for him/herself.
- Allow the person to take part in decisions.
- Following a stroke, it is common to cry more easily. If the crying is not caused by a depressed mood the person can be distracted by asking him/her to count to ten or to focus on breathing deeply. Giving sympathy will aggravate the crying.

## 2. COMMUNICATION

### ***What is communication?***

Communication is the ability to listen and understand, as well as the ability to formulate and deliver answers in an understandable way.

### ***Possible communication problems***

- Deafness or hard of hearing – This is part of the aging process and is often not related to the stroke. Ensure that there is no blockage of outer ear e.g. with wax.
- Poor understanding
- Cannot plan speech (Cannot order sounds and words appropriately)
- Cannot find words
- Cannot control speech muscles to form words e.g. tongue, jaw

### ***Handling communication problems***

#### ***When talking to someone who had a stroke:***

- be patient
- turn your face towards the person
- maintain eye contact
- stay close to the person
- talk slowly and clearly, especially if the person is tired
- use your natural voice. Do not shout.
- repeat yourself if the person does not understand
- use short sentences
- wait between sentences
- use gestures (demonstrate) while talking
- talk about well known topics
- if the person cannot speak, ask questions that can be answered with a simple “yes” or “no”

#### ***While listening to a person that had a stroke:***

- be patient
- watch the persons` lips
- ask the person to repeat important information that you have told him/her
- remind the person to talk slowly and clearly
- remind him/her to concentrate harder when using difficult words
- ask the person to repeat if you cannot understand. Do not pretend to understand
- encourage the person to use the names of friends and family
- encourage the person to use common words like “Hello” or “Thank you”
- encourage the person to use gestures and point to objects, if he/she cannot speak

#### ***In general:***

- avoid background noise
- turn the TV or radio down

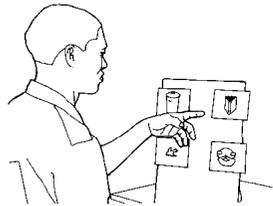
## Other options to assist with communication

A	B	C	D	E	F	G
H	I	J	K	L	M	N
O	P	R	S	T	U	V
W	Q	1	2	3	4	5
6	7	8	9	10	Yes	No

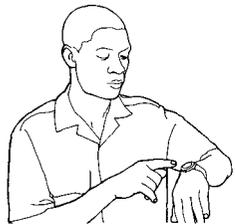
Use an alphabet board



Use a chart with words and/or pictures



Use pictures



Use gestures



## 3. COGNITIVE (“THINKING & REASONING”) & BEHAVIOURAL PROBLEMS

Damage to the brain can lead to problems with the ability to understand, interpret, plan, and control emotions and urges, motivation, memory etc.

Remember that this is not true for everybody who has suffered a stroke. An occupational therapist will be able to determine if any of these problems exist, their severity and how to treat / manage them.

### Possible signs & typical behaviour

- Disorientation with regards to person, place and time
- Poor short term memory (E.g. cannot remember what was said an hour ago)
- Poor inner drive (E.g. does not get out of bed without being told)
- Struggles to perform simple tasks (like putting on a sweater)
- Cannot control temper, or sexual desires, or may have an urge to eat too much.
- Inappropriate behaviour (E.g. laughing at someone getting hurt)
- The person may become very demanding and want immediate attention and satisfaction of needs
- Cannot find objects, especially on the affected side of the body
- Ignoring the affected side of body
- Cannot see towards the affected side of body
- Becomes easily frustrated
- It may not be safe to leave him/her alone, because he/she might accidentally injure him/herself
- Sometimes the person cannot manage own affairs e.g. money (Does not understand the value of money)
- In some instances the person may not acknowledge these problems and will justify their actions with long explanations

### Management

- Seek professional help from an occupational therapist or a behavioural psychologist
- Orientate the person frequently to the date, day, time etc. (Put a clock and a calendar in the room and draw attention to them on a regular basis)
- Follow a set daily routine, with meals, personal care and periods for rest at the same time and in the same way every day
- Explain any changes in routine, e.g. visits to the shops, clinic etc. well in advance. Repeat the information frequently.
- Be firm and consistent as to what is acceptable behaviour. Do not allow certain things one day and refuse them on other days.
- Do not allow the person to manipulate you with bad behaviour. E.g. shouting until you give him/her what he/she wants.
- Give clear rules for unacceptable behaviour. E.g. Do not shout. I will not answer you if you shout.
- Do not laugh at inappropriate actions even if they are “funny”. E.g. swearing or undressing in public.
- Acknowledge appropriate behaviour. E.g. I enjoy helping you when you are so thankful.
- Allow the person to do as much as possible for him/herself, but stay close enough to ensure safety e.g. in bathroom and kitchen.

## 4. POSITIONING

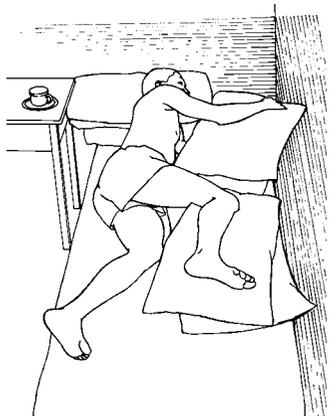
The way a person lies or sits can help or hinder his/her progress and function.

### Lying

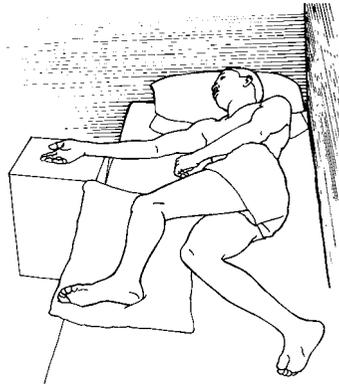
#### General guidelines:

- Use a firm mattress or wooden board under the mattress
- The wall should always be on the person's **unaffected** side
- The person should be positioned with his affected side towards the door, TV, visitors chair etc.
- Approach from the affected side
- Turn the person every 2-3 hours to prevent stiffness and pressure areas
- The person should spend as little time as possible in bed
- If in bed, he/she should preferably lie on alternative sides instead of on his/her back

#### Sleep on both sides



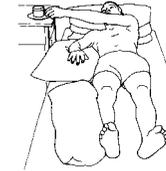
Lying on unaffected side



Lying on affected side

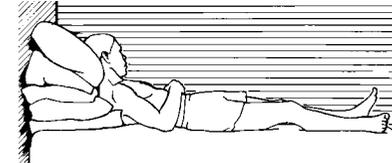
#### Principles to follow:

- Keep affected arm straight
- Keep affected hand open
- Do not put anything into the affected hand
- The affected elbow and hand must be fully supported
- Position shoulder in front of chest and not underneath the body (The person should not lie on his/her shoulder joint)
- Bend uppermost knee
- Uppermost knee and foot must be fully supported by pillows
- If the bed is too narrow, the affected hand and arm can be supported on a cardboard box or table of similar height to the bed



Lying on back

The person may lie on his back only for short periods of time.  
The bedside table should be on the affected side

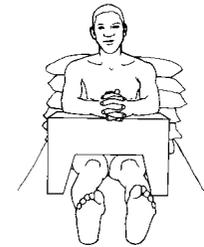


No!!!

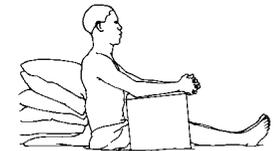
Lying in bed propped up on cushions (like in the drawing on the left) may result in:

- Pressure sores
- Breathing problems
- Difficulty with swallowing
- Stiffness of neck, back, arm and leg

#### Sitting up in bed (only if person is unable to get out of bed)



- Sit up straight with hips bent 90°
- Back against wall or back board of bed
- Support back with pillows / folded blanket etc.
- Make bedside table from a sturdy box



#### Making your own bed table from a cardboard box:



Use a sturdy box, large enough for both forearms to rest comfortably on it



Cut off flaps on or glue them to the inside of the box to re-inforce the sides



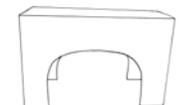
Draw an arch big enough to clear the legs on both sides of the box



Completed arch



Cut out the arch along the line



Completed bed table from a cardboard box

## Sitting

### General guidelines:

- The chair must be as narrow as possible
- The chair must be firm. Use a hardback chair with firm seat instead of an easy chair
- The seat-back angle must be 90° or less to prevent the person from sliding forwards
- The person's bottom must be against the back of the chair
- His / her hips, knees and ankles must be bent at least 90°
- Feet must be supported on floor or footrests. If feet do not reach the ground, use a wooden block to support them from underneath.

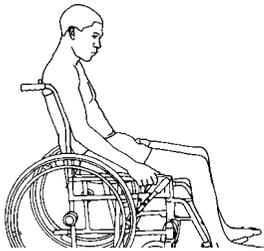
### Sitting in a chair or wheelchair:



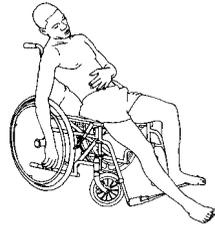
SideView



Frontal View



No!!!



No!!!

### Poor sitting posture may result in:

- Pain
- Stiffness
- Swelling of hand and arm
- Sliding out of chair

### Prevention of sliding with a strap:



Yes!!!

Strap at a 45° angle from the back corners of the chair across the hips



No!!!

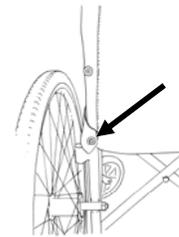
Do not strap around tummy or chest



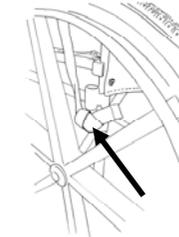
No!!!

If strapped around tummy or chest the person will still slide even with the strap

### Fixing a lap belt to a chair



a



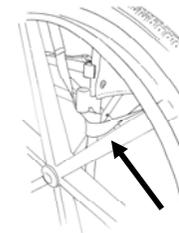
b

#### On Wheelchair:

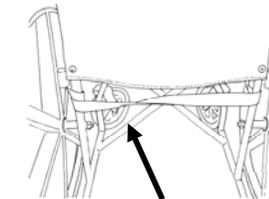
a) Fix the belt to chair frame by using the bottom screw of the wheelchair upholstery

or

b) Tie belt to vertical part of wheelchair frame just below the back armrest socket



ci



cii

ci) If one long belt, that fastens in front of the person, is used, hook it around the wheelchair frame, below the armrest socket and

cii) Loop it around the back opposite back post



#### On ordinary chair:

Tie belt to back leg of the chair, just below the seat.

## 5. FEEDING, SWALLOWING & DENTAL CARE

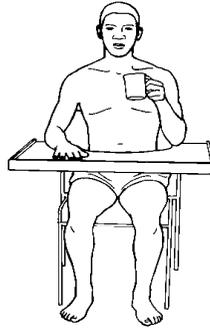
### Arm and hand support

#### General guidelines:

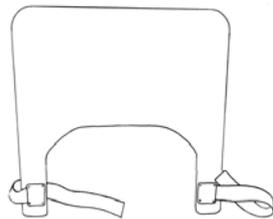
- Always support the entire forearm including the elbow and hand, with hand open and palm down flat on supporting surface
- **Do not put the arm in a sling !!!**



On table



On lap tray



Lap tray

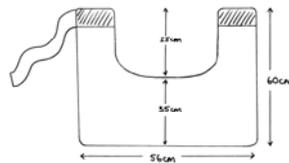


Diagram: Lap tray

Do not use pillows to support the affected arm while sitting, as this usually cause either the hand to hang or unsupported, with resultant swelling of the hand or opening of the shoulder joint (See chapter 6 on shoulder care).

### Feeding and swallowing

#### Basic principles during eating:

- Sit up at a table or use a tray table on armrests of chair
- Bend head and neck slightly forward
- Look at food
- Take small bites and sips
- Place food into stronger side of mouth, between teeth
- The person should move the chewed food to the middle of the tongue before swallowing
- Drink from a full glass or use a straw to prevent the head from tipping back
- Thick fluids and smooth textured food e.g. yogurt, custard and thick soup are easier to swallow
- Sit up for at least 20 – 30 minutes after eating to promote digestion

#### Assisted feeding



Place spoon on front of tongue  
If tongue comes out push lightly down with spoon



Close lips around spoon



Place food between teeth  
on good side

#### Guidelines for person who needs assistance:

- Sit up straight
- Head slightly forwards
- Look at food
- Arms supported on table
- Feet flat on footrests of wheelchair or floor

#### Guidelines for assistant:

- Sit/stand close to person
- Either stand next to person or sit in front of person
- When standing, support one foot on a low support
- Keep back straight
- Use arm closest to person to support his/her head



**Yes!!!**



**No!!!**



Assist lip / mouth closure with fingers on cheek, chin and lower jaw



**Independent eating**

Use deep plate or plate guard to prevent food from sliding off plate



**Home made plate guard**

**Deep plate**

**Making your own plate guard:**



Use empty 1/2 litre plastic milk /juice bottle



Draw a horizontal line 5 cm from the bottom of the bottle



Draw a connecting line from the middle of the narrow side of the bottle to the other side



Cut along the horizontal line to free the bottom of the bottle



Separated bottom



Cut bottom into 2 pieces along a line drawn through the middle



2 Loose pieces of bottle bottom



Trim the one side of one of the two removed halves to fit the width of the edge of the plate



Attach to edge of plate with clothes pegs

**Prevent:**

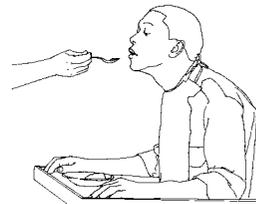
- Sideways or backward tilting of head
- The affected arm from dangling or falling off the table or lap tray
- The feet from slipping off the footrests of the wheelchair
- Upwards or forwards straining with neck and head to reach food – This hampers swallowing. Hold spoon directly in front of mouth
- The assistant must not bend her back
- Take spoon to person's mouth, person should not reach for spoon with his head



**Yes!!!**

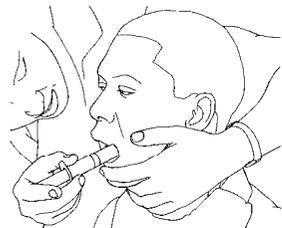


**No!!!**



**No!!!**

**Assisted drinking**



If person struggles to swallow:

- Use syringe without needle to insert fluids into mouth
- Place it on strong side of mouth against cheek
- Squirt fluid in direction of cheek



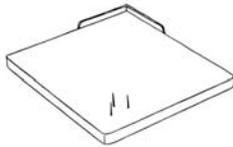
- Always place straw on strong side against cheek



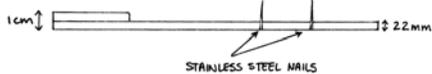
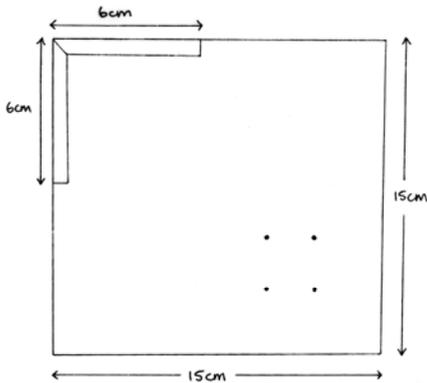
Spreading with one hand



Peeling with one hand



One hand spreading & peeling board



**Making your own one hand spreading and peeling board:**

You need:

- A flat piece of wood etc covered with a washable strip 15cm x 15cm
- 3 x 8cm nails; 4 short nails
- Strip of metal 6cm long & 1 cm higher than wood piece

Method:

- Hammer long nails into one corner of board in a triangle or square as shown on picture
- Bend metal strip to 90° in middle
- Attach around opposite corner of board with short nails

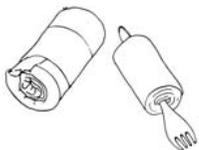
**Making your own built-up grip:**

You need:

- Spoon or fork
- More or less 6 x 10 cm of high density foam (Depending on length of spoon grip and thickness of desired built-up)
- Elastoplast

Method:

- Roll the foam around grip of spoon / fork to enlarge grip
- Fasten with elastoplast



Built up grips

**Oral & dental hygiene**

**Assisted brushing**

**General guidelines:**

- Sit up straight
- Keep head upright
- Affected arm supported on table or edge of basin
- Mirror in front
- Assistant stands at person's back and looks in mirror
- Do not tilt the person's head backwards or sideways



Yes!!!

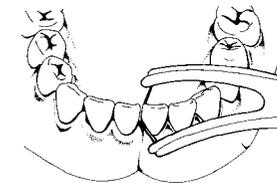
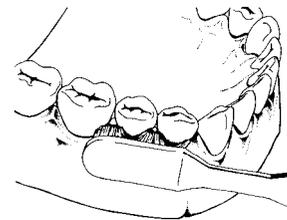
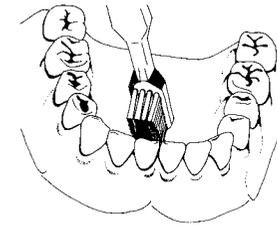
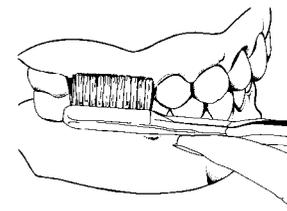


No!!!

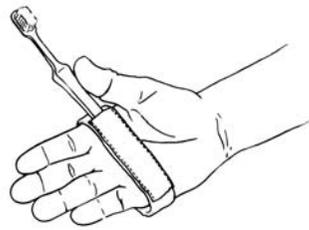
**Placement of brush and dental floss**

**General guidelines:**

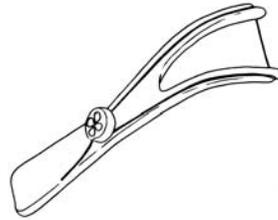
- Angle brush at 45° to gums and teeth
- Brush by using small circular movements
- Brush both in- and outsides of teeth
- Use a floss holder to floss between teeth



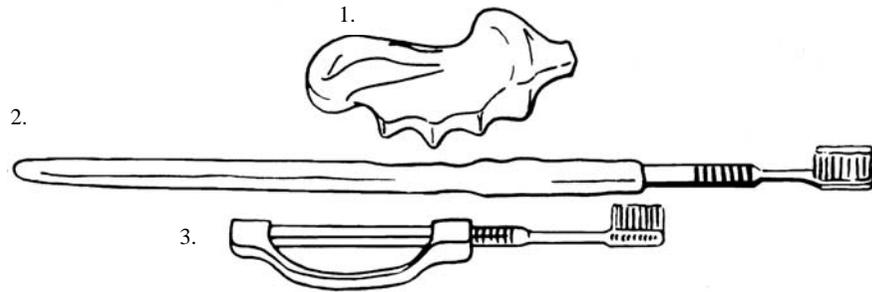
**For weak grips**



**Brush holder**



**Floss holder**



**From top to bottom:**

1. An enlarged grip
2. An extended handle. This is useful for persons with limited upper limb range of movement
3. A brush holder

**6. SHOULDER CARE**

Complications such as a painful and/or stiff shoulder are quite common following a stroke. This can be prevented by correct handling and positioning of the shoulder.

**Principles of shoulder management:**

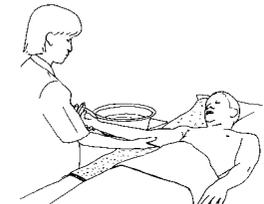
- Never pull on the person's arm in order to help him roll, sit up, stand up etc. Support him/her around the rib cage.
- Before washing or dressing the affected arm always ensure that the shoulder is loose (free to move). This is done in the following way:
  - Position your hand around the shoulder blade.
  - Gently move the shoulder blade outwards and forwards on the ribcage.
  - If tightness occurs repeat the movement a few times slowly until you can move the shoulder blade freely.
  - Once the shoulder blade is in the outwards and forwards position gently take the person's upper arm above the elbow and turn the arm outwards away from the body. **DO NOT TUSE THE FOREARM AS A LEVER**
  - This movement must be done slowly and with extreme caution. Stop if pain or resistance is felt. Repeat movement a few (5) times.
  - Only once shoulder blade is free and upper arm is rotated outwards can arm be lifted for dressing and washing. (See pictures below)



Hook hand around shoulder blade and pull shoulder blade gently outwards and forwards. Repeat movement a few times until shoulder moves freely.



Keep shoulder blade positioned forward Grip arm just above elbow and carefully turn arm outwards. Stop if person feels pain. Do not do this while gripping the hand or lower arm as it may cause pain / damage to the elbow.



Straighten elbow. Now you can move the shoulder joint carefully upwards and/or sideways

- Before turning the person onto his/her affected side the shoulder blade must be loosened in the same way as described above and then pulled forward (on rib cage). Support the arm and shoulder in the forwards position. While you maintain this forward position the person can roll onto the affected side. Ensure that the person does not lie on top of the shoulder joint.
- In sitting the elbow must be supported at the side of the body to keep the shoulder joint properly aligned. If the support is too low, the upper arm bone will drop out of the socket and the shoulder joint will stretch open with resultant pain. If it is supported too far to the side of the body, the top part of the upper arm may slip in and downwards with the same result as above.
- A sling that rests the arm in front of the body will cause shortening of muscles around the shoulder and make it impossible to turn the upper arm out. This in turn will cause pinching of muscles when the arm is lifted for dressing etc.

**A simple exercise sequence to keep shoulder, elbow and wrist mobile and pain free**



Use a firm chair with good back support. Sit with bottom well back and feet supported on floor



Bend forwards and bring affected elbow gently to the inside of the knee



Take affected shoulder blade with unaffected hand and gently pull down upper body towards unaffected knee. Repeat until shoulder blade has moved maximally forward



Bring hands over to the middle of the body and slide them up the chest



Slide up to touch nose. Only continue further if no pain is experienced



Slide further upwards to top of head. Only continue further if no pain is experienced



Maintain the body position and take affected hand at the wrist, while gently starting to straighten the elbow using the knee as a pivot point



Slowly straighten the arm between the knees towards the feet until maximum range is achieved at the elbow



If possible stretch down to the floor



If the shoulder is not painful or stiff stretch the arms upwards all the way or as high as possible without causing pain



Slide arms sideways until they are on either side of the affected knee. Hands remain as close as possible to foot



Start sliding the hands up the shin



Continue to slide hands up affected thigh

Repeat this exercise 5 – 10 times in a session at least once a day. Each time you do the exercise try to stretch the joints a little further. Always stay in pain free range. If you experience pain decrease the range or intensity of the stretch.

Never give a person a ball to squeeze with the affected hand. This will increase stiffness of the hand and in time it will become difficult to open the fingers to wash and dry the hand.

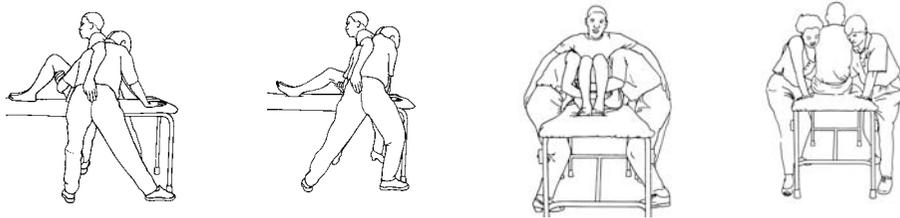
## 7. BED MOBILITY

### Principles of assisting with bed mobility:

- Never pull on an arm or a leg!!!
- Always explain what you want to do
- Ask the person to help as much as possible
- Be as close as possible to the person
- Bend your knees and keep your back straight

### Assisted bed mobility (2 assistants)

#### High bed



### Principles of lifting and moving a person on a high bed:

- Assistants stand one on each side of bed, facing person
- Feet shoulder width apart; Back feet in line with person's body; Back knee slightly bend; Front foot facing the direction of movement
- Position your shoulder against the person's body just below the armpit
- Do not push your shoulder into the person's armpit
- Support yourself on hand furthest away from the person
- Wrap your other hand around persons' upper leg / bottom
- To lift the person, both assistants squeeze their shoulders against his/her trunk, lock their arms around his/her legs, grip the person's legs, and straighten their knees
- Once lifted, the assistants shift their weight onto the front leg and supporting arm and move the person at the same time.

#### Low bed

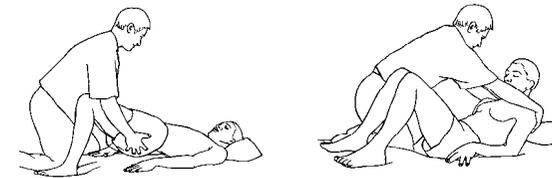


### Principles of lifting and moving a person on a low bed:

- Face person
- Kneel on bed with your leg closest to the person
- Position your shoulder against the person's body just below the armpit
- Do not push shoulder into armpit
- Support yourself on hand furthest away from the person
- Wrap other hand around person's upper leg / bottom
- Both assistants squeeze their shoulders against person's trunk, lock arms closest to person around person's legs, grip, straighten outside leg, lift and move person

### Assisted bed mobility (1 assistant)

#### Moving in bed



### Principles:

- Assistant kneel with one knee on bed next to person
- Assist person to bent his knees
- Person's feet stays flat on bed; Assistant might need to prevent feet from sliding by putting his knee in front of feet
- Assist person to lift his hips
- Once hips are lifted assist person to move them sideways
- Ask person to lift his/her head
- Assist with lifting and moving head and shoulders by gripping firmly behind shoulders
- Do not pull on neck or arms
- The person move sideways by alternately lifting and moving head and shoulders and hips

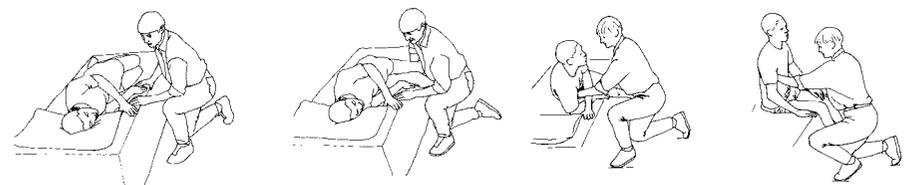
### Rolling onto affected and non affected sides



### Principles:

- Ask person to clasp hands and pull the affected shoulder forwards
- Ask person to lift head and shoulders
- Person bends knee opposite to the side that he/she wants to roll to and roll
- Assist at hips and shoulder blades

### Sitting up from lying



### Principles:

- Roll onto affected side and
- Swing legs over edge of bed

### The assistant supports:

1. Under rib cage or
2. on both shoulders or
3. 1 hand on shoulder and 1 hand on hip

### The assistant asks the person to:

- Push up with strong hand
- Not to pull on assistant's neck

## Independent bed mobility

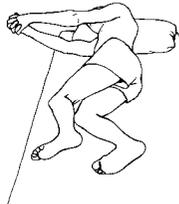
### Moving sideways up or down



#### Principles:

- Bend knees
  - Keep feet flat
  - Lift hips by pushing down on feet
- Shift to side / Push upwards

### Rolling



#### Principles:

- Shift to side of bed as described above
- Clasp hands together
- Lift arms until hands are shoulder height
- Pull affected shoulder forwards
- Lift head, shoulders & leg
- Bend knee up and lift leg over midline to other side
- Roll over

### Sitting up



#### Principles:

- Roll onto affected side
- Hook unaffected foot behind affected one and swing legs over edge of bed
- Come up onto affected elbow
- Push upon hand to straighten elbow and come to sitting
- Above principles are for sitting up over the affected side. However sitting up should be practiced both to affected and unaffected side. Follow the same principles as above, but substitute affected for unaffected.

## 8. TRANSFERS

### Transfer from low bed to chair (2 Assistants)



#### Persons position

Person fold his arms



#### Position of first assistant

Assistant at back slides arms in between upper arms and rib cage of person  
He/she grips both the person's forearms close to the elbows



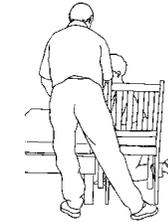
#### Position of second assistant

The second assistant kneels in front of bed  
He/she put his/her arms under knees and upper thighs as close as possible to buttocks of person



#### Step 1:

Both assistants lift and move person to the edge of the bed



#### Step 2:

The assistant at the back stands with her legs apart and slightly bent  
He/she lifts the person by straightening his/her legs  
The assistant in front lifts persons legs and hold them close to his/her body



#### Step 3:

The assistant at the back shifts his/her weight onto leg behind chair and transfers person  
The assistant in front sits back onto his/her knees as they lower the person onto the chair

#### In General:

It is important that the assistants work in unison  
One should indicate when they start the lift, either by counting to three or saying one, two, Lift.  
Decide beforehand who will give the commands and what commands to use

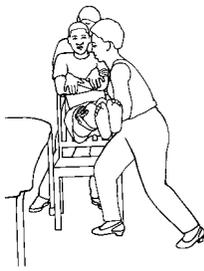


Reverse the sequence to transfer person back to bed

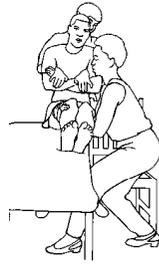
## Transfer from chair to high bed (2 Assistants)



**Step 1:**  
Assistants position themselves as in previous sequence



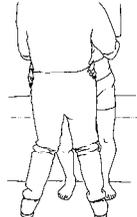
**Step 2:**  
Assistant at back performs lift as described in previous sequence  
Assistant in front lifts person's buttocks and legs by standing up



**Step 3:**  
Assistant at back transfers his/her weight onto leg behind bed and moves person  
Assistant in front steps forwards with his/her rear leg and moves the person's legs onto the bed

Reverse sequence to move person to chair

## Transfer from bed to chair (1 Assistant) Through standing



### Principles:

- Position chair next to bed
- Support affected knee on both sides
- Do not block knee in front
- Bring person forward and up by moving the shoulders forwards and upwards
- Twist towards bed and sit person down gently

(This method can be used for a person who can take some weight through his/her legs)

### With sliding board

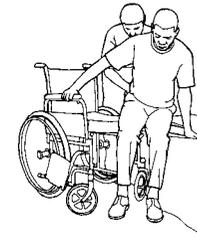
Use flat piece of wood for person to slide onto. Ensure that surface and edges of wood are free of splinters. Person must always wear clothes if a board is used.



### Principles:

- As with transfer through standing
1. Insert board
  2. Ask person to begin to stand up
  3. Move bottom over when weight is lifted off board

## Supporting from the back



### Principles:

1. Insert board
2. Ask person to push on hands and lift up
3. Slide person when weight is off bottom
4. Repeat until person is on bed or chair

(Both these methods can be used when person can take a small amount of weight through his/her knees)

### Alternatives for a very weak person and 1 assistant



### Principles:

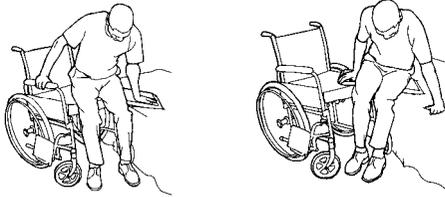
1. Lean person forward
2. Assistant supports person's shoulders against his/her trunk
3. Grip persons' elbows or hips and squeeze the elbows tightly and in towards persons body
4. If you grip at the elbows ask the person to push down with his/her shoulders
5. Lean back onto your rear leg and bring person's weight with you
6. Once weight is off the person's bottom swing his/her hips sideways onto chair/bed

### An extremely weak person can be transferred in the following way as well:



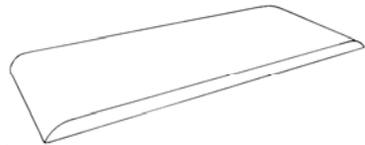
1. Slide a transfer board under his/her bottom
2. Lean his/her upper trunk forward onto his/her knees
3. The assistant holds the person around his/her trunk and by the back of his pants or belt
4. His/her weight is now off his/her bottom
5. Slide bottom over
6. Assist him/her to sit up

**Unassisted transfer with board**

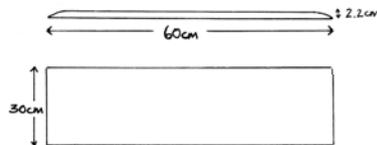


**Principles:**

- Insert board under bottom
- Lean forward and take some weight through feet
- Don't stand up all the way
- Push down through arms
- Move over by making repeated short shifts in a sideways direction



**Transfer board**



**Diagram of a transfer board**

**Assisted sitting to standing**



Assist person to walk on his/her bottom to edge of bed



Support affected arm on assistant's hip  
If the arm is stiff or painful it can be left hanging between person's knees  
Person's feet are slightly apart, in line with each other and slightly behind the knees



Grip person around shoulder blade on trunk, not on upper arm  
Support his arm with your forearm



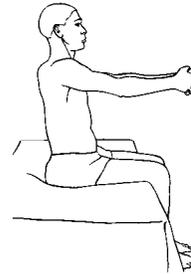
Assistant moves persons shoulders forward by shifting her weight onto her back leg



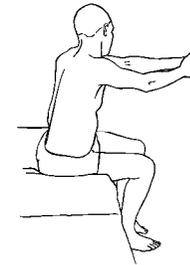
Assist person to stand

**Unassisted sitting to standing**

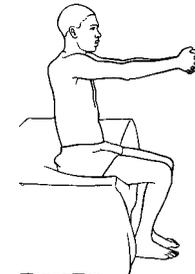
**To stand up correctly:**



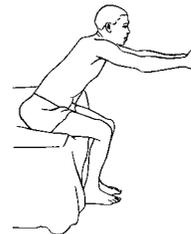
Sit up straight  
Hands clasp together



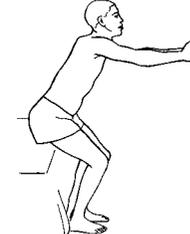
Walk forward on buttocks



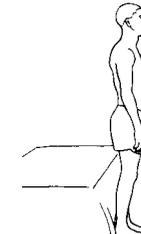
Stop at edge of bed  
Feet slightly apart, in line with each other and slightly behind knees



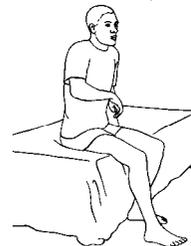
Lean forward from hips until shoulders are in front of knees and feet.  
Reach forward with hands to help to bring weight forward



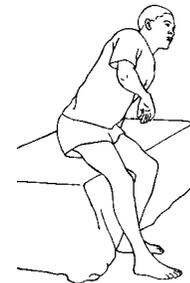
Start lifting buttocks and straightening knees  
Do not push knees back against bed / chair



Stand up straight



**No!!!**



**No!!!**

Using only the unaffected side of body will result in increased weakness and stiffness on the affected side

## 9. SELF CARE

### Bladder and bowel control

There are many causes for poor or no bladder or bowel control. Any person who experiences these problems should see a doctor to exclude treatable causes and to consider the use of medication to improve control.

The following are general management guidelines.

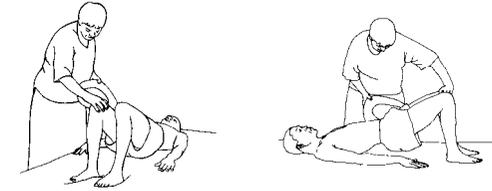
#### Bladder control

- Drink 6 – 8 glasses of water a day. Fill a 2 litre bottle with water every day and put it in the fridge or next to the person's bed or chair.
- Do not drink less to prevent accidents.
- If night time wetting occurs do not drink any fluids at least an hour before bedtime.
- Go to the toilet the last thing before bedtime and the first thing in the morning.
- Cover the mattress with a plastic sheet and cover plastic with towel or sheet. The person must never lie or sit directly on the plastic cover.
- Remind the person to go to the toilet every 2 hours or take him/her to the toilet every 2 hours. Gradually prolong the time to every 4 hours.
- The colour of the urine should only be slightly darker than water. If it is darkly coloured, foul smelling or blood stained, the person should be referred to the clinic to be examined for possible infection. Urine with a dark colour usually means the person is not drinking enough water.
- Catheters (Pipe and bag):
  - Always wash hands before and after working with catheter.
  - Empty the bag regularly.
  - Do not strap the leg bag too tight.
  - If there is no urine in the bag after 4 hours the pipe may be blocked – refer to clinic.

#### Bowel control

- If the person has no sensation of when he/she needs to go to the toilet he/she should be put on a bowel programme by a doctor.
- Try to set a bowel routine. E.g. going to the toilet every morning after breakfast.
- Sit up on toilet or commode.
- To prevent constipation:
  - Drink 6-8 glasses of water a day.
  - Spend as much time as possible out of bed during the day.
  - Be as active as possible.
  - Eat food containing roughage e.g. unpeeled fruit, vegetables, dried fruit, bran, brown bread and brown rice.
- If diarrhea is present for more than three days – refer to clinic.

### Using a bedpan in bed



#### Principles:

- Support affected knee while person lifts hips. By drawing the knee forward and downwards over the foot you can prevent the foot from slipping or shooting out.
- Insert bedpan
- Use bedpan only for urinating
- Sit person up for bowel action

### Toilet transfer (1 Assistant)



Position chair at as much of an angle as possible to the toilet.

Move forwards on chair and then assists the person into standing

Once in standing support the affected knee with your knees and slide your hands to the person's hips to assist with his balance



Swivel around until the person is standing in front of the toilet. Assist with the removing of clothing

Slowly guide him/her to sit down

## Independent toilet transfer



### Step 1:

Move forwards in wheelchair  
Clasp hands  
Stand up

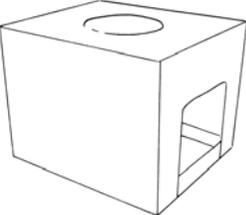
### Step 2:

Swivel around  
Put clasped hands on chair for support if necessary

### Step 3:

Sit down on toilet  
If person cannot stand up without hand support he/she can use a grab rail and allow affected hand to hang between legs

## Assistive devices for toileting

 <p><b>Raised toilet seat</b></p>	 <p><b>Plastic chair with hole in seat and bucket underneath</b></p>	 <p><b>Wooden box commode</b></p>
<p>Practical for tall people, when toilet is very low and for the elderly with hip and knee problems</p>		
 <p><b>Bedpan on chair with hard surface</b></p>		 <p><b>Bedpan on wheelchair</b></p>

## Washing

### Assisted bed wash



Approach from affected side.



Move person away from side of bed by lifting head and shoulders and moving them to the middle of the bed.



Move hips by lifting the bottom and scooting to the middle of the bed.



Loosen shoulder before you lift the arm.

Hook hand around shoulder blade and pull shoulder blade gently outwards and forwards. Repeat movement a few times until shoulder moves freely.



Grip arm just above elbow and carefully turn arm outwards. Stop if person feels pain. Do not do this while gripping the hand or lower arm as it may cause pain / damage to the elbow.



Straighten elbow.



Maintain the outward turn. Move arm upwards/ forwards. Stop if person feels pain.



Wash and dry arm and axilla.



To wash back: Roll onto side. Loosen affected arm as described above. Place arm to the side before rolling person over.



Wash back.

Use towel under body. Sheets can be changed at same time.



To wash bottom: Assist at affected knee while person lift buttocks. Wash underneath.

## Independent bed wash

### Principles:

- Sit on edge of bed
- Feet supported on floor or block
- A small table, with basin, cloth, soap towel etc. in front
- Keep affected hand and elbow supported on table to maintain balance while washing upper body



Wet cloth.



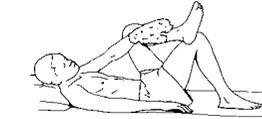
Wash underneath affected arm.



Wash underneath unaffected arm.



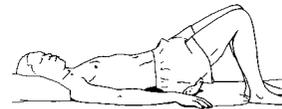
Wash back with back brush.



If balance is poor lie down on back and cross one ankle over other knee to wash lower limbs.



Wash lower limbs in sitting if balance is adequate.



Lie down to wash buttocks.

## Bathing

Use a non-slip rubber mat inside bath to prevent slipping.

### Assisted bath transfer



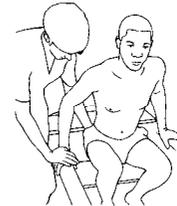
Transfer from chair to side of bath / bath board.



Sit on bath board. Lift legs into bath.

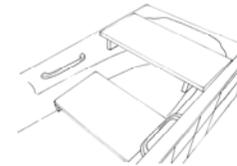


Move down to bath seat. Person must support firmly with unaffected hand on side of bath or rail. Affected arm rests on person's thigh.



If the affected arm has some power, the assistant must support the affected hand on the edge of the bath or bath rail

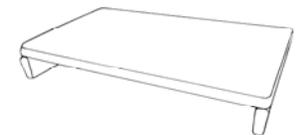
### Assistive devices if person cannot sit down in bath



Bath board on top of bath, with bath seat inside bath



Bath board  
(Diagram on page 39)



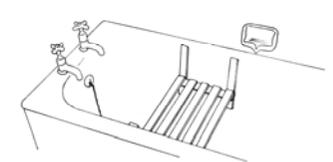
Bath seat  
(Diagram on page 39)



a & b) Swivel bath chair



b



Slated bath seat  
(Diagram on page 39)

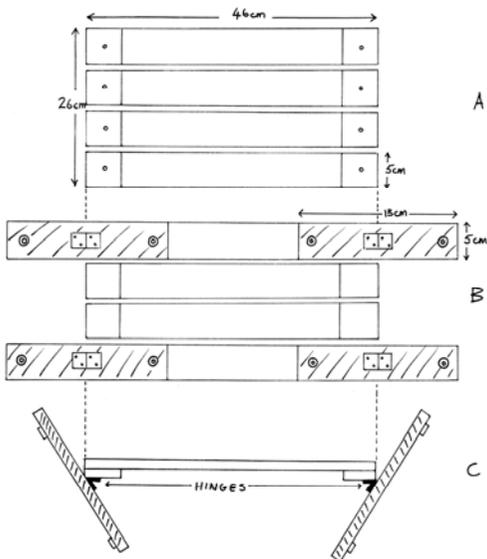
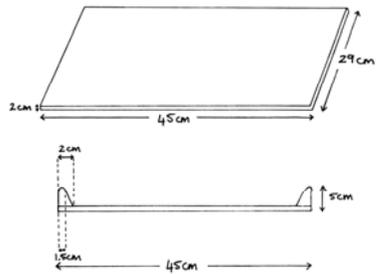
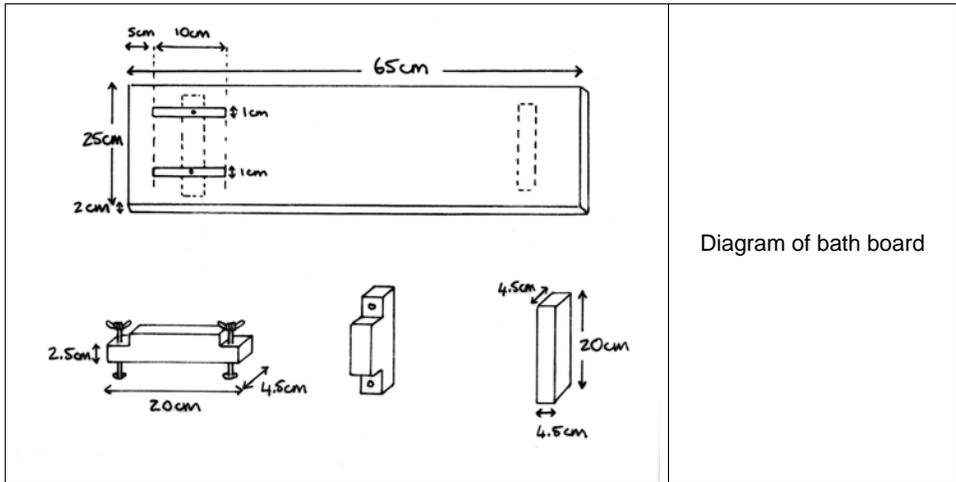


Diagram of bath seat

Diagram of slatted bath seat

- A. Diagram of seat
- B. Diagram of sides
- C. Schematic presentation of how to join seat and sides

**Independent bath transfer and washing in bath**



With hands clasped stand symmetrically up from chair



Swivel and sit down on bath board



Support affected leg around knee and lift into bath



Push with hands on edge of bath



If affected hand is too weak, place it on opposite thigh and lower body down onto bath stool or into bath



Wash trunk



**Soap on a rope**  
Make a hole in the soap and tie onto a rope. Hang around neck. This prevents the soap from falling and slipping away



Drape cloth over knee to soap.



**Back brush**  
Back brush made of a coat hanger and sponge covered with toweling material



Sponge with elastic to go around back of hand

## Dressing

### Principles:

- Allow the person to do as much as possible for him/herself
- Start practicing with undressing, because it is easier
- Use wide, loose fitting clothes
- Do not use clothes with complicated fasteners
- Dressing is a slow process. Allow enough time
- Give positive feedback
- If the person cannot perform the entire task, break it down into steps e.g. only put arms into sleeves
- Always dress the affected side first and undress the unaffected side first
- Sit over edge of bed. Feet supported on floor. If person cannot balance on bed, he can sit on a chair with a firm seat and backrest

### Putting on shirt



Put shirt on lap  
Inside facing upwards  
Collar towards knees  
Affected arm's sleeve  
hanging between legs



Bring affected arm  
towards lap



Put affected hand into  
sleeve opening



Pull sleeve up over affected  
hand and arm until hand is  
visible  
Throw rest of shirt  
backwards



Pull sleeve up over  
elbow



Pull sleeve up and over  
shoulder



Bring shirt around back



Put unaffected arm into  
sleeve



Fasten buttons

### Putting on pants



Place pants on unaffected  
side



Cross affected leg over  
unaffected one



Put affected foot into pants  
leg



Pull pants up over knee  
and uncross legs



Put unaffected leg into  
pants leg



Pull pants up over knees



**Weaker person**  
Pull over buttocks by,  
hooking unaffected foot  
underneath affected leg,  
pivoting on elbow and lying  
down on bed



**Person who can stand  
with  
assistance**  
Stand up with assistance  
(Assistant on the affected  
side)  
Assistant pulls pants up



**Person who can stand  
independently**  
If person is strong enough  
to stand independently he  
can stand up to pull pants  
over bottom and to fasten  
zip and belt



**Putting on jersey**



Put jersey on lap  
Back facing person  
Bottom end towards body  
and neck at knees



Open from bottom and find  
sleeve opening for affected  
arm



Put sleeve between  
knees  
Open sleeve entrance  
with unaffected hand



Put affected hand in



Pull up over elbow



Pull up over upper arm



Pull up over shoulder



Either put unaffected arm  
through



And then head



Or put head through



And then unaffected arm



Pull down at back and  
neaten up

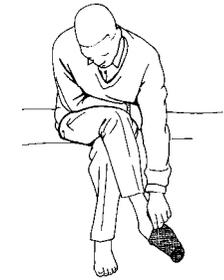
**Putting on sock**



Fold sock half way back  
to the heel cap



Cross affected leg over  
unaffected leg



Pull sock over toes



Pull up over rest of foot  
and ankle

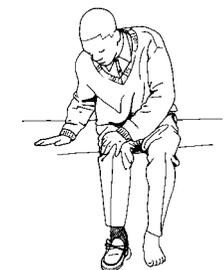
**Putting on shoe**



Cross affected leg over  
unaffected leg  
Pull shoe over toes



Pull foot in

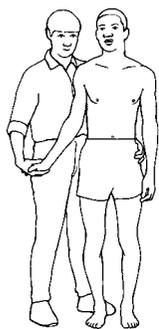


Put foot on floor and  
press on knee to slip  
heel in

## 10. ASSISTED GAIT

### Principles:

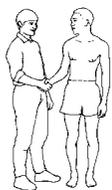
- Support from affected side
- Assistant's hip against back of affected hip
- Assistant's foot assists affected foot if necessary
- One hand firmly around the person's body
- Other hand holds affected hand
- Allow person space to move his body
- If you stand too close or hold too tightly both of you will struggle to maintain balance and walking will be more difficult



Front

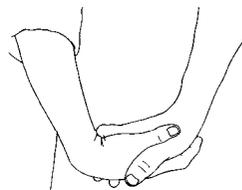


Rear



### The correct grip:

- Start as if shaking hands, but turn your palm up while holding the person's hand
- Grip the affected hand
- Do not pull on the affected arm



- Support arm by giving pressure upwards through the hand
- Keep elbow straight against assistant's body
- This way the arm remains straight and the person can lean on your hand for support
- You can assist him/her better with balancing

### Alternative grip:

(This is a good grip to use if the person has a stiff wrist)

- Hook thumbs together
- Grip person's hand along base of thumb
- Make sure that the person does not feel any pain in his wrist

- If the person is very weak a walking stick can be used on unaffected side.
- Both assistant and person being assisted must wear comfortable, sturdy, non-slip shoes or walk barefoot. Do not walk on socks!!!

## 11. TYPICAL COMPLICATIONS

Complication	Seek assistance from
Shoulder pain / Shoulder and hand pain	Physiotherapist/Occupational therapist
Urinary tract infections	Clinic/General practitioner/Nurse
Constipation / Diarrhea	Clinic/General practitioner/Nurse
Sliding or falling out of wheelchair	Seating clinic/Professional with specialised training in seating
Behavioural problems	Occupational therapist/Clinical psychologist
Aspiration (Choking or poor swallowing)	Speech therapist/Nurse
Pressure sores	Clinic/General practitioner/Nurse
Shortening of muscles / Tightness of muscles / Spasticity	Physiotherapist
Depression	Clinic/General practitioner

Adhere strictly to any prescription e.g. for medicine.

## **Appendix 13: Revised booklet**

Name:.....  
Trainer/ Therapist:.....  
Tel. number: .....

# STROKE CARE at HOME



**Compiled and edited by ES Scheffler & SJ Visagie**  
Sponsored by National Port Authorities of South Africa – Cape Town  
February 2007



Centre For Rehabilitation Studies,  
University of Stellenbosch

in conjunction with



westerncaperehabilitationcentre

**Department of Health,  
Provincial Government of the  
Western Cape**

## MOTIVATION

Stroke is a complex condition by nature and caring for the stroke survivor is a challenge. This situation is worsened by little community rehabilitation services. Caretakers get inadequate or no training and support. Often stroke survivors are discharged home within 48 hours after their admission to a hospital. Many people that require hospitalisation are not even admitted to a hospital. Untrained or inadequately trained caregivers have to cope as best as they can.

Staff from the then Centre for Care and Rehabilitation of Stellenbosch University, situated at Karl Bremer Hospital, noted these and other problems. Caregivers found it difficult to assist persons who had a stroke with physical activities such as dressing and transfers. They struggled to communicate with the person. They did not understand behaviour problems caused by the stroke. Preventable problems caused by the stroke were commonly seen, e.g. painful shoulders and hands, contractures and poor habit patterns.

In 1995, the then manager, Jenny Hendry, and senior physiotherapist at the Centre, Elsje Scheffler, motivate for funding to develop a training package to address abovementioned needs. Funding was obtained from the then Portnet company as part of its restructuring and development plan. Portnet has since been integrated into The National Port Authorities of South Africa.

The training package includes a 4 hour training programme for home carers and other care institutions e.g. old age homes, as well as a training manual that re-inforces the practical aspects addressed during training. The training sessions commenced in 1996 and are still running currently.

Over a period of 10 years, the training package has been refined and modified, according to needs expressed and feedback received from both trainees and stroke survivors. The complete product is now available in first draft form.

The authors hope to provide an easy, accessible guide for caregivers to use as a reference at home. This tool should only be given to caregivers to aid memory after training has been completed. The purpose of the manual is not to replace training. Adequate time should be spent with carers to ensure appropriate and adequate skills training.

This document is a draft. Should you through reading or using it find that you want to make suggestions towards improving it please contact:

Dr J. Botha  
PO Box 11831  
Erasmuskloof  
0084

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# 1. Introduction

## **?** What is a stroke?

Failure of the blood supply to a part of the brain causes strokes. Damage or disease can cause blocking or narrowing of a blood vessel, which will stop the flow of blood. Oxygen (air) and nutrients (food) can then not reach certain areas of the brain. This causes damage to these areas and they may stop working. Blood vessel can also burst. The blood flooding the brain causes damage.

## **?** Do people get better after a stroke?

Each stroke is different depending on the area of the brain that was affected. Persons that survive a stroke slowly get better over a long time. Recovery is almost never 100%.

Most patients learn to walk again but walk slowly and can fall easily. They often do not get all the control of their hand and arm back. Sometimes stiffness in the muscles causes rigid movement patterns.

Following a stroke some people, find that their physical abilities might return to almost normal while their mental functions, like decision making or recognising potentially dangerous situations, are difficult.

## **?** Can medicine make a stroke better?

It is not possible to make dead brain cells come alive again. You can try to prevent further strokes by treating the causes.

Common causes are Diabetes (high sugar), High blood pressure, High cholesterol (fat in the blood) and Heart problems.

## **?** What problems are often caused by a stroke?

- Weakness or paralysis of one side of the body
- Stiffness of arm, hand and / or leg
- Poor balance in sitting and standing (can fall easily)
- Difficulty in speaking or understanding language
- Loss of bladder and bowel control, which usually get better
- Loss of feeling on the weak side
- Unawareness / ignoring of the weak side
- Problems with vision (seeing)
- Confusion and memory problems
- Mood and personality changes
- Knowing how to do everyday tasks

## **?** How do I approach someone who has had a stroke?

- Treat the person as an adult.
- Allow him/her more time to perform tasks. Be patient.
- Encourage him/her to do things for him/herself. Do not allow him/her to stay in bed or in pyjamas during the day.
- Allow the person to take part in decisions.

## 2. Communication Problems

### **?** What is communication?

Communication is the ability to listen and understand, as well as the ability to formulate and deliver answers in an understandable way.

### **?** What communication problems can someone who had a stroke have?

- Deafness or hard of hearing. This is often a part of the aging process and not related to the stroke. At the clinic the nurse can make sure that there is no blockage of outer ear e.g. with wax.
- Poor understanding
- Cannot plan speech (Cannot put the right sounds together to form words)
- Cannot find words
- Cannot control speech muscles to form words e.g. tongue, jaw

### **?** How can these communication problems be handled?

When talking to someone who had a stroke:

- Be patient
- Turn your face towards the person
- Maintain eye contact
- Stay close to the person
- Talk slowly and clearly, especially if the person is tired
- Use your usual voice. Do not shout.
- Repeat yourself if the person does not understand
- Use short sentences
- Wait between sentences
- Use gestures (show with you hands) while talking
- Talk about well known topics
- If the person cannot speak, ask questions that can be answered with a simple “yes” or “no”

While listening to a person that had a stroke:

- Be patient
- Watch the persons` lips
- Ask the person to repeat important information that you have told him/her
- Remind the person to talk slowly and clearly
- Remind him/her to concentrate harder when using difficult words
- Ask the person to repeat if you cannot understand. Do not pretend to understand
- Encourage the person to use the names of friends and family
- Encourage the person to use common words like “Hello” or “Thank you”
- Encourage the person to use gestures and point to objects, if he/she cannot speak

In general:

- Avoid background noise
- Turn the TV or radio down



### 3. Cognitive (Thinking and reasoning) and Behavioural problems

Damage to the brain can lead to problems with how the brain think and reason. Some people who had a stroke may have problems with their memory or with the ability to understand. Others may find it difficult to control their emotions and urges and can behave in strange ways.

Remember that this is not true for everybody who has suffered a stroke. An occupational therapist will be able to determine if any of these problems exist.



#### What are possible signs of someone who has this type of problem?

- Confusion with regards to person, place and time
- Poor short term memory (E.g. cannot remember what was said an hour ago)
- Poor inner drive (E.g. does not get out of bed without being told)
- Struggles to perform simple tasks (like putting on a sweater)
- Cannot control temper, or sexual desires, or may have an urge to eat too much.
- Inappropriate behaviour (E.g. laughing at someone getting hurt)
- The person may become very demanding and frustrated, wanting immediate attention
- Ignoring the weak side of body ( E.g. cannot find objects, especially on the weak side of the body)
- Does not understand the value of money (The person may not be able to manage his/her own affairs e.g. money)
- In some instances the person may not be aware of these problems and will justify their actions with long explanations



#### How can these problems be managed?

- Seek professional help from an occupational therapist or a behavioural psychologist (ask your local clinic to refer you to such a person)
- Tell the person often what the date, day, time is. (Put a clock and a calendar in the room and show it to the person regularly)
- Follow a set daily routine, with meals, personal care and periods for rest at the same time and in the same way every day
- Explain any changes in routine, e.g. visits to the shops, clinic etc. well in advance. Repeat the information often
- Be firm and consistent as to what is acceptable behaviour. Do not allow certain things one day and refuse them on other days.
- Do not allow the person to manipulate you with bad behaviour. E.g. shouting until you give him/her what he/she wants.
- Give clear rules for unacceptable behaviour. E.g., do not shout. I will not answer you if you shout.
- Do not laugh at inappropriate actions even if they are “funny”. E.g. swearing.
- Acknowledge appropriate behaviour. E.g., I enjoy helping you when you are thankful.
- Allow the person to do as much as possible for him/herself, but stay close enough to ensure safety e.g. in bathroom and kitchen.
- Following a stroke, it is common to cry more easily. If the crying is not caused by a depressed mood, the person can be distracted by asking him/her to count to ten or to focus on breathing deeply. Giving sympathy will make the crying worse

## 4. How to position someone who had a stroke

The way a person lies or sits can help or hinder his/her progress and function.



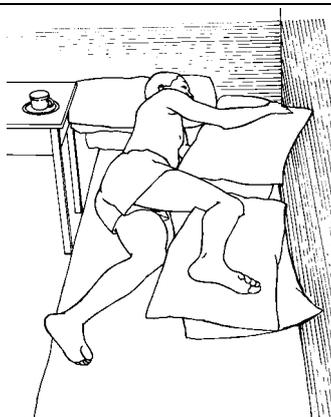
### How should someone who had a stroke lie in bed?

General guidelines:

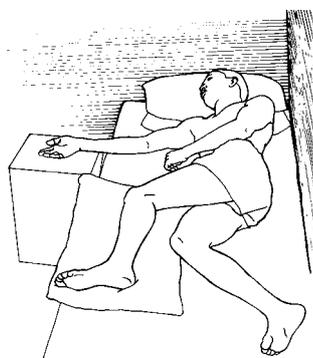
- Use a firm mattress or wooden board under the mattress
- The wall should always be on the person's weak side
- The person should be lie with his weak side towards the door, TV, visitors chair etc. to help him/ her to be aware of the weak side
- Turn the person every 2-3 hours to prevent stiffness and pressure areas
- The person should spend as little time as possible in bed
- If in bed, the person should rather lie on his/her sides instead of on the back

#### Sleep on both sides

Lying on strong side

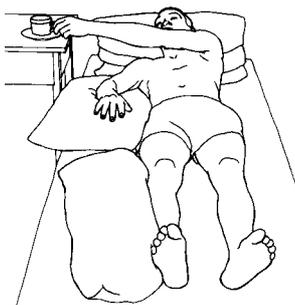


Lying on weak side

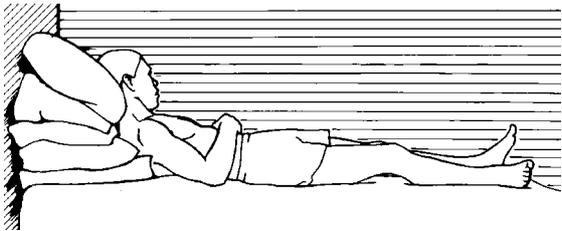


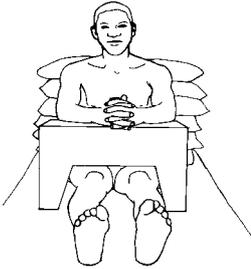
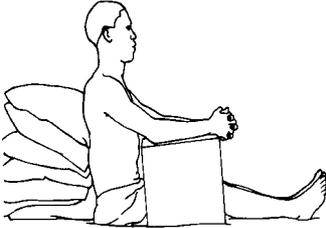
- Keep weak arm straight
- Keep weak hand open
- Do not put anything into the weak hand
- The weak elbow and hand must have support under it
- Put the shoulder in front of chest and not under the body (The person should not lie on his/her shoulder joint)
- Bend upper knee
- The upper knee and foot must be fully supported by pillows
- If the bed is too narrow, the weak hand and arm can be supported on a cardboard box or table of same height to the bed

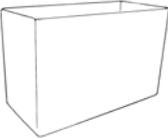
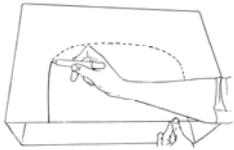
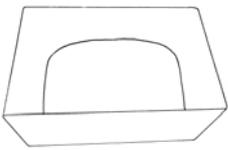
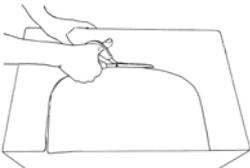
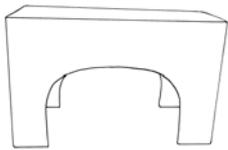
#### Lying on back in bed



- The person may lie on his back only for a short time.
- The bedside table should be on the weak side

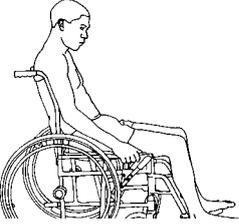
 <p data-bbox="363 360 443 394">☒ No</p>	<p>Lying in bed propped up on cushions (like in the drawing on the left) may result in:</p> <ul style="list-style-type: none"> <li>• Pressure sores</li> <li>• Breathing problems</li> <li>• Difficulty with swallowing</li> <li>• Stiffness of neck, back, arm and leg</li> </ul>
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<b>Sitting up in bed (only if person is unable to get out of bed)</b>	
	<ul style="list-style-type: none"> <li>• Sit up straight with hips bent 90o</li> <li>• Back against wall or back board of bed</li> <li>• Support back with pillows / folded blanket etc.</li> <li>• Make bedside table from a sturdy box</li> </ul>
	

<b>Making your own bed table from a cardboard box:</b>		
 <p data-bbox="165 1518 181 1552">1</p>	 <p data-bbox="603 1507 619 1541">2</p>	 <p data-bbox="1002 1507 1018 1541">3</p>
<p>1 Use a sturdy box, large enough for both forearms to rest comfortably on it</p>	<p>2 Cut off flaps on or glue them to the inside of the box to re-inforce the sides</p>	<p>3 Draw an arch big enough to clear the legs on both sides of the box</p>
 <p data-bbox="165 1906 181 1939">4</p>	 <p data-bbox="603 1917 619 1951">5</p>	 <p data-bbox="1002 1906 1018 1939">6</p>
<p>4 Completed arch</p>	<p>5 Cut out the arch along the line</p>	<p>6 Completed bed table from a cardboard box</p>

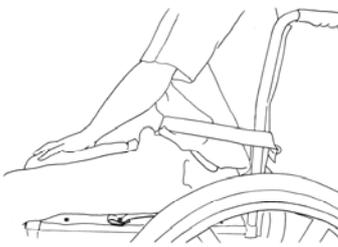


## How should someone who had a stroke sit?

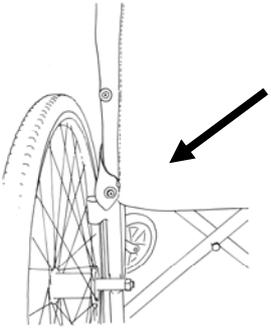
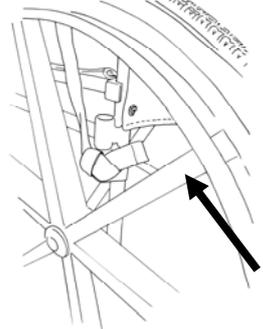
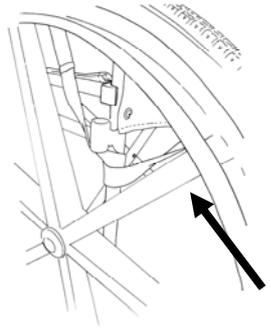
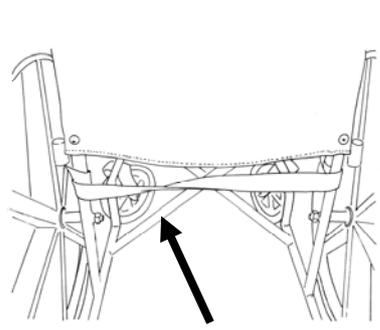
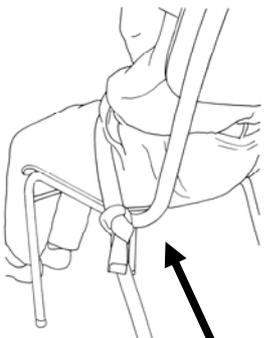
Sitting in a chair or wheelchair	
 <p><input checked="" type="checkbox"/> Yes</p>	<p>General guidelines:</p> <ul style="list-style-type: none"> <li>• The chair must be as narrow as possible</li> <li>• The chair must be firm. Use a hardback chair with firm seat instead of an easy chair</li> <li>• The seat-back angle must be 90° or less to prevent the person from sliding forwards</li> <li>• The person's bottom must be against the back of the chair</li> <li>• His / her hips, knees and ankles must be bent at least 90°</li> <li>• The feet must be supported on floor or footrests. If feet do not reach the ground, use a wooden block to support them from underneath.</li> </ul>
 <p><input checked="" type="checkbox"/> Yes</p>	
 <p><input checked="" type="checkbox"/> No</p>	<p>Poor sitting posture may result in:</p> <ul style="list-style-type: none"> <li>• Pain</li> <li>• Stiffness</li> <li>• Swelling of hand and arm</li> <li>• Sliding out of chair</li> </ul>



## How can I prevent someone from sliding out of a chair by using straps?

 <p><input checked="" type="checkbox"/> Yes</p>	 <p><input checked="" type="checkbox"/> No</p>	 <p><input checked="" type="checkbox"/> No</p>
<p>Strap at a 45° angle from the back corners of the chair across the hips</p>	<p>Do not strap around tummy or chest</p>	<p>If strapped around tummy or chest the person will still slide even with the strap</p>

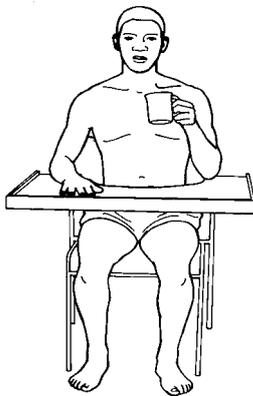
**?** How must a lap belt be fixed to a chair?

 <p>1</p>	 <p>2</p>	<p>On Wheelchair:</p> <ol style="list-style-type: none"> <li>1) Fix the belt to chair frame by using the bottom screw of the wheelchair upholstery</li> <li>or</li> <li>2) Tie belt to vertical part of wheelchair frame just below the back armrest socket</li> </ol>
 <p>3</p>	 <p>4</p>	<ol style="list-style-type: none"> <li>3) If one long belt, that fastens in front of the person, is used, hook it around the wheelchair frame, below the armrest socket and</li> <li>4) Loop it around the back opposite back post</li> </ol>
	<p>On ordinary chair: Tie belt to back leg of the chair, just below the seat.</p>	

# ? How must the arms and hands be support?



On a table



On a lap tray

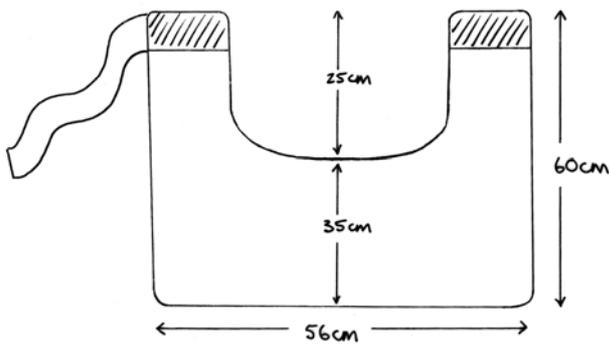
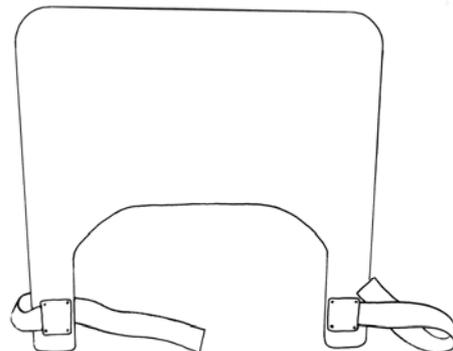


Diagram of a lap tray

## General guidelines:

Always support the entire forearm including the elbow and hand, with hand open and palm down flat on supporting surface

Do not use pillows to support the weak arm while sitting, as this usually cause either the hand to hang or unsupported, with resultant swelling of the hand or opening of the shoulder joint (See chapter 6 on shoulder care).



Do not put the arm in a sling!

## 5. Eating, Swallowing and Dental care



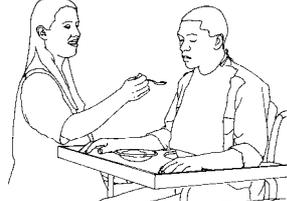
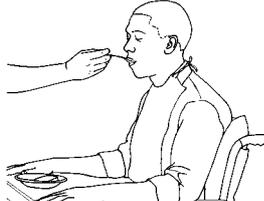
### How should a person who had a stroke be helped to eat?

The person that had the stroke must:

- Sit up straight
- Head slightly forwards
- Look at food
- Arms supported on table
- Feet flat on footrests of wheelchair or floor
- Take small bites and sips
- Move the chewed food to the middle of the tongue before swallowing
- Drink from a full glass or use a straw to prevent the head from tipping back
- Sit up for at least 20 – 30 minutes after eating to promote digestion

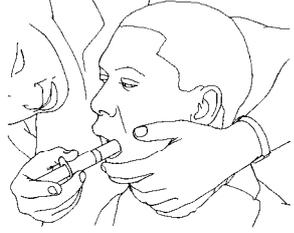
The carer must:

- Sit/stand close to person
- Either stand next to person or sit in front of person
- When standing, support one foot on a low support
- Keep back straight
- Use arm closest to person to support his/her head
- Place food into stronger side of mouth, between teeth
- Thick fluids and smooth textured food e.g. yogurt, custard and thick soup are easier to swallow

 <p style="text-align: right;"><input checked="" type="checkbox"/> No</p>	 <p style="text-align: right;"><input checked="" type="checkbox"/> Yes</p>	 <p style="text-align: center;"><input checked="" type="checkbox"/> No</p>	 <p style="text-align: center;"><input checked="" type="checkbox"/> No</p>
<p>Prevent:</p> <ul style="list-style-type: none"> <li>• Sideways or backward tilting of head</li> <li>• The weak arm from dangling or falling off the table or lap tray</li> <li>• The feet from slipping off the footrests of the wheelchair</li> <li>• The carer must not bend her back</li> </ul>		<p>Prevent upwards or forwards straining with neck and head to reach food – This hampers swallowing. Hold spoon directly in front of mouth</p>	<p>Take spoon to person's mouth, person should not reach for spoon with his head</p>
 <p style="text-align: left;"><input checked="" type="checkbox"/> Yes</p>	 <p style="text-align: left;"><input checked="" type="checkbox"/> Yes</p>	 <p style="text-align: left;"><input checked="" type="checkbox"/> Yes</p>	 <p style="text-align: left;"><input checked="" type="checkbox"/> Yes</p>
<p>Place spoon on front of tongue If tongue comes out push lightly down with spoon</p>		<p>Close lips around spoon</p>	<p>Place food between teeth on good side</p>

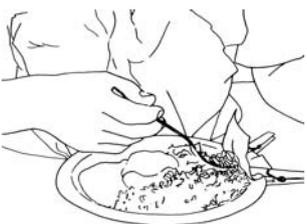


## How can a person who had a stroke be helped to drink?

			
<ul style="list-style-type: none"> <li>• Use syringe without needle to insert fluids into mouth</li> <li>• Place it on strong side of mouth against cheek</li> </ul>	Always place straw on strong side against cheek Squirt fluid in direction of cheek	Assist lip / mouth closure with fingers on cheek, chin and lower jaw	



## What can be given to a person who struggles to get the food on the fork / spoon with one hand?

<b>Use deep plate or plate guard to prevent food from sliding off plate</b>				
				
	Home made plate guard	Deep plate		
<b>Making your own plate guard:</b>				
				
Use empty 1/2 litre plastic milk /juice bottle	Draw a horizontal line 5 cm from the bottom of the bottle	Draw a connecting line from the middle of the narrow side of the bottle to the other side	Cut along the horizontal line to free the bottom of the bottle	Separated bottom
				
Cut bottom into 2 pieces along a line drawn through the middle	2 Loose pieces of bottle bottom	Trim the one side of one of the two removed halves to fit the width of the edge of the plate	Attach to edge of plate with clothes pegs	

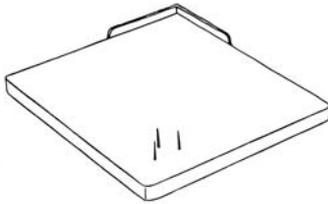
## Making your own one hand spreading and peeling board



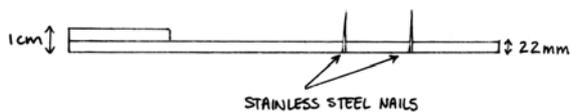
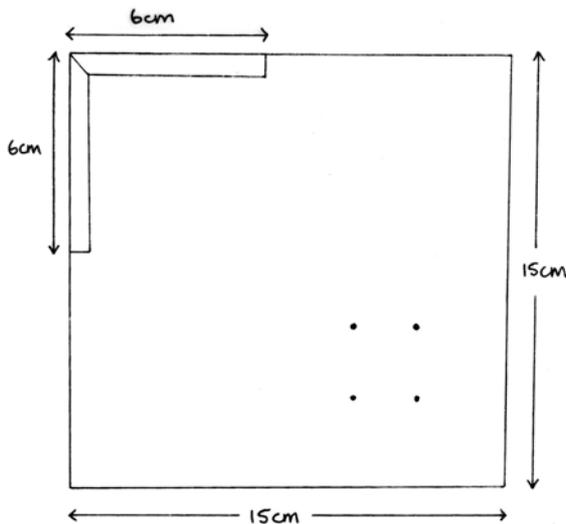
Spreading with one hand



Peeling with one hand



One hand spreading & peeling board



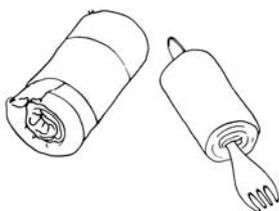
### You need:

- A flat piece of wood etc covered with a washable strip 15cm x 15cm
- 3 x 8cm nails; 4 short nails
- Strip of metal 6cm long & 1 cm higher than wood piece

### Method:

Hammer long nails into one corner of board in a triangle or square as shown on picture  
Bend metal strip to 90o in middle  
Attach around opposite corner of board with short nails

## Making your own built-up grip



Built up grips

### You need:

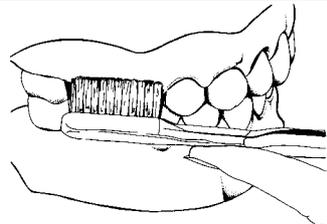
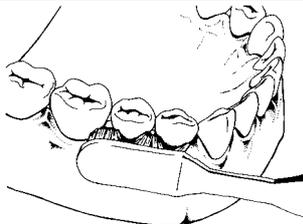
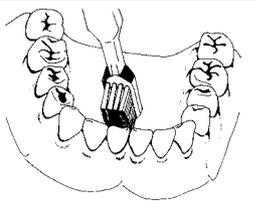
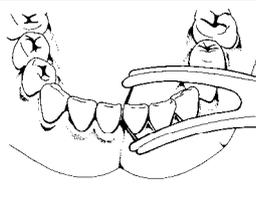
- Spoon or fork
- More or less 6 x 10 cm of high density foam (Depending on length of spoon grip and thickness of desired built-up)
- Elastoplast

### Method:

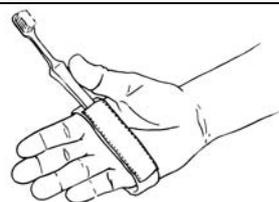
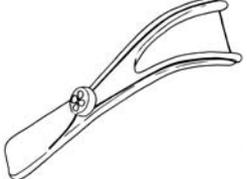
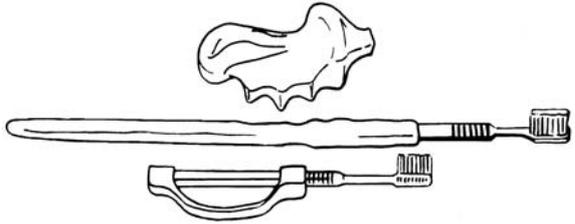
Roll the foam around grip of spoon / fork to enlarge grip  
Fasten with elastoplast

**?** How can I help someone to brush his/her teeth?

 <p><input checked="" type="checkbox"/> Yes</p>	 <p><input checked="" type="checkbox"/> No</p>
<p>The person must sit up straight Keep the head upright The weak arm must be supported on table or edge of basin Sit in front of mirror Carer stands at the person's back and looks in mirror</p>	<p>Do not tilt the person's head backwards or sideways</p>

			
<p>Angle brush at 45° to gums and teeth Brush by using small circular movements</p>		<p>Brush both in- and outsides of teeth</p>	<p>Use a floss holder to floss between teeth</p>

**?** What can someone use whose hand is too weak to hold a toothbrush?

	<p>Brush holder</p>
	<p>Floss holder</p>
	<p>An enlarged grip An extended handle. This is useful for persons with limited upper limb range of movement A brush holder</p>

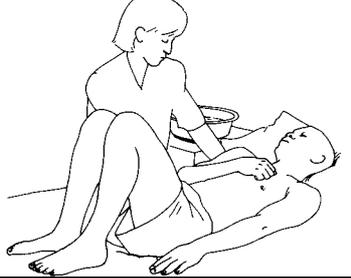
## 6. Shoulder care

Complications such as a painful and/or stiff shoulder are quite common following a stroke. You can prevent this by correct handling and positioning of the shoulder.

### **?** What is the correct way to handle a painful or stiff shoulder?

Never pull on the person's arm to help him roll, sit up, stand up etc. Support him/her around the rib cage.

Before washing or dressing the weak arm, always make sure that the shoulder is loose (free to move). This is done in the following way:

	<p>Hook hand around shoulder blade and pull shoulder blade gently outwards and forwards. Repeat movement a few times until shoulder moves freely.</p>
	<p>Keep the shoulder blade positioned forward Grip the arm just above elbow and carefully turn the arm outwards. Stop if person feels pain. Do not do this while gripping the hand or lower arm as it may cause pain / damage to the elbow.</p>
	<p>Once the shoulder blade is in the outwards and forwards position gently, take the person's upper arm above the elbow and turn the arm outwards away from the body. Straighten elbow. Now you can move the shoulder joint carefully upwards and/or sideways for dressing and washing.</p>



Do not use the arm as a lever

### **?** What should I do with the shoulder when turning someone in bed?

Before turning the person onto his/her, weak side the shoulder blade must be loosened in the same way as described above and then pulled forward (on rib cage). Support the arm and shoulder in the forwards position. While you keep this forward position, the person can roll onto the weak side.

Ensure that the person does not lie on top of the shoulder joint.

## ? How should I support the shoulder in sitting?

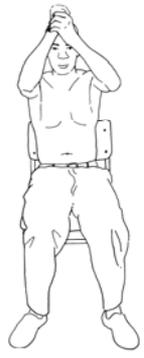
In sitting, you should support the elbow at the side of the body to keep the shoulder joint in safe position. If the support is too low, the upper arm bone will drop out of the socket and the shoulder joint will stretch open and cause pain. If you support it too far to the side of the body, the top part of the upper arm may slip in and downwards with the same result.

## ? Why must I not use a sling?

A sling that rests the arm in front of the body will cause shortening of muscles around the shoulder and make it impossible to turn the upper arm out. This in turn will cause pinching of muscles when the arm is lifted for dressing etc.

## ? Is there a good exercise for the shoulder?

A simple exercise to keep shoulder, elbow and wrist mobile and pain free		
 <p>1</p>	 <p>2</p>	 <p>3</p>
<p>1 Use a firm chair with good back support. Sit with bottom well back and feet supported on floor</p>	<p>2 Bend forwards and bring weak elbow gently to the inside of the knee</p>	<p>3 Take weak shoulder blade with strong hand and gently pull down upper body towards strong knee. Repeat until shoulder blade has moved forward as far as possible</p>
 <p>4</p>	 <p>5</p>	 <p>6</p>
<p>4 Keep the body position and take weak hand at the wrist, while gently starting to straighten the elbow using the knee as a pivot point</p>	<p>5 Slowly straighten the arm between the knees towards the feet until the elbow is as straight as possible</p>	<p>6 If possible stretch down to the floor</p>

 <p>7</p>	 <p>8</p>	 <p>9</p>
<p>7 Slide arms sideways until they are on either side of the weak knee. Hands remain as close as possible to foot</p>	<p>8 Start sliding the hands up the lower leg</p>	<p>9 Continue to slide hands up weak thigh</p>
 <p>10</p>	 <p>11</p>	 <p>12</p>
<p>10 Bring hands over to the middle of the body and slide them up the chest</p>	<p>11 Slide up to touch nose. Only continue further if no pain is experienced</p>	<p>12 Slide further upwards to top of head. Only continue further if there is no pain.</p>
	 <p>13</p>	
	<p>If the shoulder is not painful or stiff stretch the arms upwards all the way or as high as possible without causing pain</p>	

Repeat this exercise 5 – 10 times in a session at least once a day. Each time you do the exercise try to stretch the joints a little further. Always stay in pain free range. If you experience pain, decrease the range or intensity of the stretch.

## **?** Why must I never give a person who had a stroke a ball to squeeze?

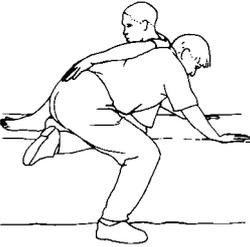
Never give a person a ball to squeeze with the weak hand. This will increase stiffness of the hand and in time, it will become difficult to open the fingers to wash and dry the hand.

## 7. Moving a person in bed

**?** What are the general principles of helping someone to move in bed?

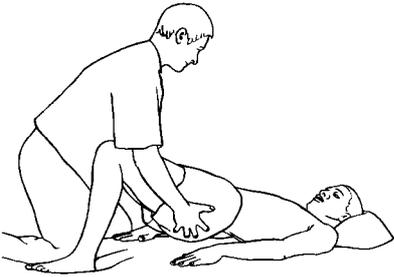
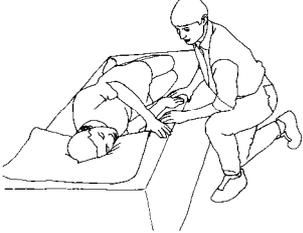
- Never pull on an arm or a leg!
- Always explain what you want to do
- Ask the person to help as much as possible
- Be as close as possible to the person
- Bend your knees and keep your back straight

**?** How should someone be moved in bed if there are two carers?

In a low bed	
	<ul style="list-style-type: none"> <li>• Face person</li> <li>• Kneel on bed with your leg closest to the person</li> <li>• Position your shoulder against the person's body just below the armpit</li> <li>• Do not push shoulder into armpit</li> <li>• Support yourself on hand furthest away from the person</li> <li>• Wrap other hand around person's upper leg / bottom</li> </ul>
	<ul style="list-style-type: none"> <li>• Both assistants squeeze their shoulders against person's trunk, lock arms closest to person around person's legs, grip, straighten outside leg, lift and move person</li> </ul>
In a high bed	
 	<ul style="list-style-type: none"> <li>• Carers stand one on each side of bed, facing person</li> <li>• Carer's feet shoulder width apart; Back feet inline with person's body; Back knee slightly bend; Front foot facing the direction of movement</li> <li>• Put your shoulder against the person's body just below the armpit</li> <li>• Do not push your shoulder into the person's armpit</li> <li>• Support yourself on hand furthest away from the person</li> <li>• Wrap your other hand around persons` upper leg / bottom</li> <li>• To lift the person, both assistants squeeze their shoulders against his/her trunk, lock their arms around his/her legs, grip the person's legs, and straighten their knees</li> </ul>
	<ul style="list-style-type: none"> <li>• Once lifted, the assistants shift their weight onto the front leg and supporting arm and move the person at the same time.</li> </ul>

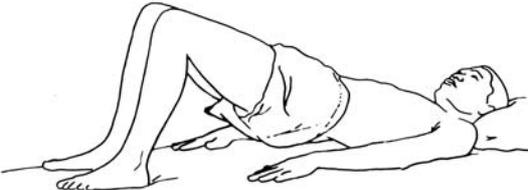
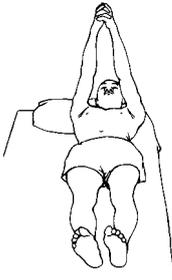
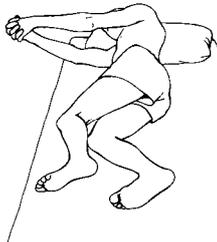


## How must I move someone if I am alone?

	<ul style="list-style-type: none"> <li>• The carer kneel with one knee on bed next to person</li> <li>• Help the person to bent his knees</li> <li>• Person's feet stays flat on bed; Carer might need to prevent feet from sliding by putting his knee in front of feet</li> <li>• Help person to lift his hips</li> <li>• Once hips are lifted help person to move them sideways</li> <li>• Ask person to lift his/her head</li> </ul>		
	<ul style="list-style-type: none"> <li>• Help with lifting and moving head and shoulders by gripping firmly behind shoulders</li> <li>• Do not pull on neck or arms</li> <li>• The person move sideways by alternately lifting and moving head and shoulders and hips</li> </ul>		
<b>Rolling onto weak and non weak sides</b>			
	<ul style="list-style-type: none"> <li>• Ask person to clasp hands and pull the weak shoulder forwards</li> <li>• Ask person to lift head and shoulders</li> <li>• Person bends knee opposite to the side that he/she wants to role to and roll</li> <li>• Help at hips and shoulder blades</li> </ul>		
<b>Sitting from lying</b>			
			
<p>Roll onto weak side and</p>	<p>Swing legs over edge of bed</p>	<p>Carer give support under rib cage or on both shoulders or</p>	<p>1 hand on shoulder and 1 hand on hip The carer asks the person to: Push up with strong hand Not to pull on assistant's neck</p>



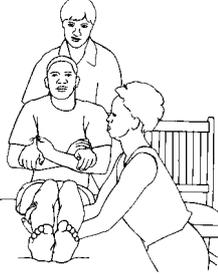
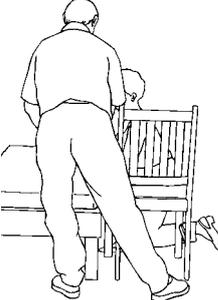
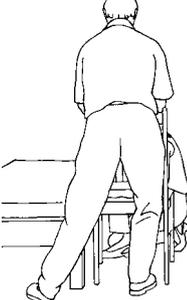
## How should someone move in bed without the help of a carer?

<b>Moving sideways up or down</b>			
		<ul style="list-style-type: none"> <li>• Bend knees</li> <li>• Keep feet flat</li> <li>• Lift hips by pushing down on feet</li> <li>• Shift to side / Push upwards</li> </ul>	
<b>Rolling</b>			
			
<ul style="list-style-type: none"> <li>• Shift to side of bed as described above</li> <li>• Clasp hands together</li> <li>• Lift arms until hands are shoulder height</li> <li>• Pull weak shoulder forwards</li> </ul>	<ul style="list-style-type: none"> <li>• Lift head, shoulders &amp; leg</li> <li>• Bend knee up and lift leg over midline to other side</li> </ul>	<ul style="list-style-type: none"> <li>• Roll over</li> </ul>	
<b>Sitting up</b>			
			
<p>Roll onto weak side Hook strong foot behind weak one and swing legs over edge of bed</p>	<p>Come up onto weak elbow</p>	<p>Push upon hand to straighten elbow and come to sitting</p>	<p>Above principles are for sitting up over the weak side. Sitting up should be practiced both sides. Follow the same principles as above, but replace weak for strong</p>

## 8. Transfers



**How should two persons help someone move from a low bed to a chair?**

		
<p><b>Persons position</b></p> <p>Person fold his arms</p>	<p><b>Position of first assistant</b></p> <p>Assistant at back slides arms in between upper arms and rib cage of person He/she grips both the person's forearms close to the elbows</p>	<p><b>Position of second assistant</b></p> <p>The second assistant kneels in front of bed He/she put his/her arms under knees and upper thighs as close as possible to buttocks of person</p>
		
<p><b>Step 1:</b> Both assistants lift and move person to the edge of the bed</p>	<p><b>Step 2:</b> The assistant at the back stands with her legs apart and slightly bent He/she lifts the person by straightening his/her legs The assistant in front lifts persons legs and hold them close to his/her body</p>	<p><b>Step 3:</b> The assistant at the back shifts his/her weight onto leg behind chair and transfers person The assistant in front sits back onto his/her knees as they lower the person onto the chair</p>
	<p><b>In General:</b> It is important that the assistants work in unison One should indicate when they start the lift, either by counting to three or saying one, two, Lift. Decide beforehand who will give the commands and what commands to use</p>	

Reverse the sequence to transfer person back to bed



## How should two persons help someone move from a chair to a high bed?

<b>Step 1:</b> Assistants position themselves as in previous sequence	<b>Step 2:</b> Assistant at back performs lift as described in previous sequence Assistant in front lifts person's buttocks and legs by standing up	<b>Step 3:</b> Assistant at back transfers his/her weight onto leg behind bed and moves person Assistant in front steps forwards with his/her rear leg and moves the person's legs onto the bed

Reverse sequence to move person to chair



## How should one person help someone move from a bed to a chair?

**Through standing** .(This method can be used for a person who can take some weight through his/her legs)

Position chair next to bed Support weak knee on both sides Do not block knee in front	Bring person forward and up by moving the shoulders forwards and upwards Twist towards bed and sit person down gently

**With sliding board.** Use flat piece of wood for person to slide onto. Ensure that surface and edges of wood are free of splinters. Person must always wear clothes if a board is used.

	As with transfer through standing Insert board Ask person to begin to stand up Move bottom over when weight is lifted off board
--	--

## Supporting from the back



- Insert board
- Ask person to push on hands and lift up



- Slide person when weight is off bottom
- Repeat until person is on bed or chair

(Both these methods can be used when person can take a small amount of weight through his/her knees)



**How should one person help someone who is very weak move from a bed to a chair?**



- Lean person forward
- Assistant supports person's shoulders against his/her trunk
- Grip persons` elbows or hips and squeeze the elbows tightly and in towards persons body
- If you grip at the elbows ask the person to push down with his/her shoulders



- Lean back onto your rear leg and bring person's weight with you
- Once weight is off the person's bottom swing his/her hips sideways onto chair/bed

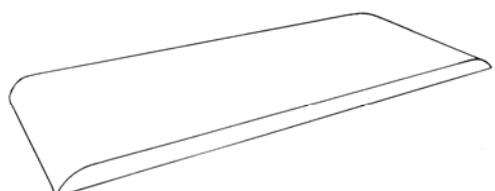
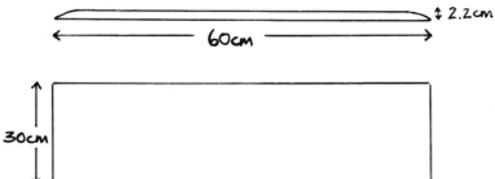


**Is there another way to transfer someone who is extremely weak?**



- Slide a transfer board under his/her bottom
- Lean his/her upper trunk forward onto his/her knees
- The assistant holds the person around his/her trunk and by the back of his pants or belt
- His/her weight is now off his/her bottom
- Slide bottom over
- Assist him/her to sit up

## ? How can someone transfer without help?

transfer with board	
	
<ul style="list-style-type: none"> <li>• Insert board under bottom</li> <li>• Lean forward and take some weight through feet</li> <li>• Don't stand up all the way</li> </ul>	<ul style="list-style-type: none"> <li>• Push down through arms</li> <li>• Move over by making repeated short shifts in a sideways direction</li> </ul>
Diagram of a transfer board	
	

## ? How can I help someone from sitting to standing?

		
Help the person to walk on his/her bottom to edge of bed	<ul style="list-style-type: none"> <li>• Support weak arm on assistant's hip</li> <li>• If the arm is stiff or painful it can be left hanging between person's knees</li> <li>• Person's feet are slightly apart, in line with each other and slightly behind the knees</li> </ul>	<ul style="list-style-type: none"> <li>• Grip person around shoulder blade on trunk, not on upper arm</li> <li>• Support his arm with your forearm</li> </ul>
		
Assistant moves persons shoulders forward by shifting her weight onto her back leg	Help person to stand	



## How should someone stand up without help?

<p>Sit up straight Hands clasp together</p>	<p>Walk forward on buttocks</p>	<p>Stop at edge of bed Feet slightly apart, in line with each other and slightly behind knees</p>
<p>Lean forward from hips until shoulders are in front of knees and feet. Reach forward with hands to help to bring weight forward</p>	<p>Start lifting buttocks and straightening knees Do not push knees back against bed / chair</p>	<p>Stand up straight</p>
 <input checked="" type="checkbox"/> No	 <input checked="" type="checkbox"/> No	<p>Using only the strong side of body will result in increased weakness and stiffness on the weak side</p>

## 9. Self care

### Bladder and bowel control

There are many causes for poor or no bladder or bowel control. Any person who experiences these problems should see a doctor to exclude treatable causes and to consider the use of medication to improve control.

The following are general management guidelines.



#### What are guidelines to help a person who does not have bladder control?

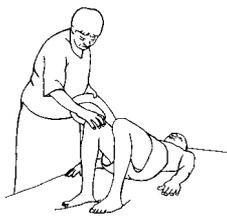
- Drink 6 – 8 glasses of water a day. Fill a 2 litre bottle with water every day and put it in the fridge or next to the person's bed or chair.
- Do not drink less to prevent accidents.
- If night time wetting occurs do not drink any fluids at least an hour before bedtime.
- Go to the toilet the last thing before bedtime and the first thing in the morning.
- Cover the mattress with a plastic sheet and cover plastic with towel or sheet. The person must never lie or sit directly on the plastic cover.
- Remind the person to go to the toilet every 2 hours or take him/her to the toilet every 2 hours. Gradually prolong the time to every 4 hours.
- The colour of the urine should only be slightly darker than water. If it is darkly coloured, foul smelling or blood stained, the person should be referred to the clinic to be examined for possible infection. Urine with a dark colour usually means the person is not drinking enough water.
- Catheters (Pipe and bag):
  - Always wash hands before and after working with catheter.
  - Empty the bag regularly.
  - Do not strap the leg bag too tight.
  - If there is no urine in the bag after 4 hours the pipe may be blocked – refer to clinic.



#### What are guidelines to help a person who does not have bowel control?

- If the person has no sensation of when he/she needs to go to the toilet he/she should be put on a bowel programme by a doctor.
- Try to set a bowel routine. E.g. going to the toilet every morning after breakfast.
- Sit up on toilet or commode.
- To prevent constipation:
  - Drink 6-8 glasses of water a day.
  - Spend as much time as possible out of bed during the day.
  - Be as active as possible.
  - Eat food containing roughage e.g. unpeeled fruit, vegetables, dried fruit, bran, brown bread and brown rice.
- If diarrhoea is present for more than three days – refer to clinic.

**?** How should a bedpan be used?

	
<p>Support weak knee while person lifts hips. By drawing the knee forward and downwards over the foot you can prevent the foot from slipping or shooting out.</p>	<p>Insert bedpan</p>

**!** Use bedpan only for urinating  
Sit person up for bowel action

**?** How should one person help someone to transfer to a toilet?

		
<p>Position chair at as much of an angle as possible to the toilet.</p>	<p>Move forwards on chair and then assists the person into standing</p>	<p>Once in standing support the weak knee with your knees and slide your hands to the person's hips to assist with his balance</p>
		
<p>Swivel around until the person is standing in front of the toilet. Assist with the removing of clothing</p>	<p>Slowly guide him/her to sit down</p>	

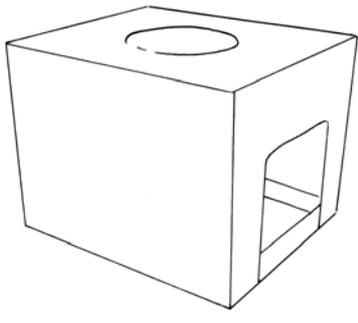
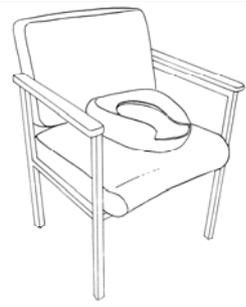


## How can someone transfer to a toilet without help?

		
<p><b>Step 1:</b> Move forwards in wheelchair Clasp hands Stand up</p>	<p><b>Step 2:</b> Swivel around Put clasped hands on chair for support if necessary</p>	<p><b>Step 3:</b> Sit down on toilet If person cannot stand up without hand support he/she can use a grab rail and allow weak hand to hang between legs</p>



## What assistive devices can be used to help with toileting?

		
<p><b>Raised toilet seat</b></p> <p>Practical for tall people, when toilet is very low and for the elderly with hip and knee problems</p>	<p><b>Plastic chair with hole in seat and bucket underneath</b></p>	<p><b>Wooden box commode</b></p>
		
<p><b>Bedpan on chair with hard surface</b></p>		<p><b>Bedpan on wheelchair</b></p>

# Washing



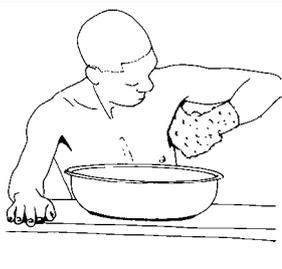
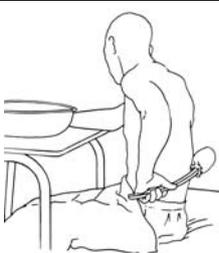
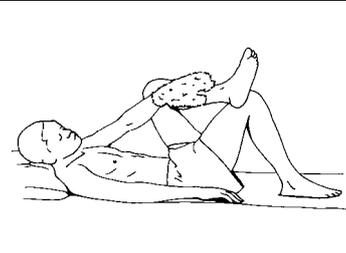
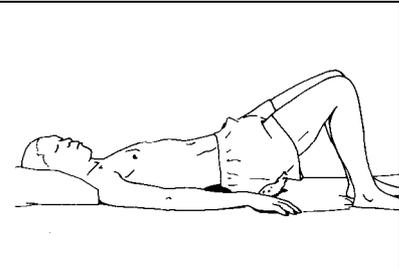
## How should I wash someone in bed?

<p>Approach from weak side.</p>	<p>Move person away from side of bed by lifting head and shoulders and moving them to the middle of the bed.</p>	<p>Move hips by lifting the bottom and scooting to the middle of the bed.</p>
<p>Loosen shoulder before you lift the arm. Hook hand around shoulder blade and pull shoulder blade gently outwards and forwards. Repeat movement a few times until shoulder moves freely.</p>	<p>Grip arm just above elbow and carefully turn arm outwards. Stop if person feels pain. Do not do this while gripping the hand or lower arm as it may cause pain / damage to the elbow.</p>	<p>Straighten elbow.</p>
<p>Maintain the outward turn. Move arm upwards/ forwards. Stop if person feels pain.</p>	<p>Wash and dry arm and axilla.</p>	<p>To wash back: Roll onto side. Loosen weak arm as described above Place arm to the side before rolling person over</p>
<p>Wash back. Use towel under body. Sheets can be changed at same time.</p>	<p>To wash bottom: Assist at weak knee while person lift buttocks. Wash underneath.</p>	



## What are the principles if someone can wash without help?

- Sit on edge of bed
- Feet supported on floor or block
- A small table, with basin, cloth, soap towel etc. in front
- Keep weak hand and elbow supported on table to maintain balance while washing upper body

		
Wet cloth.	Wash underneath weak arm.	Wash underneath strong arm.
		
Wash back with back brush.		If balance is poor lie down on back and cross one ankle over other knee to wash lower limbs.
		
Wash lower limbs in sitting if balance is adequate.	Lie down to wash buttocks.	



**Bathing**  
Use a non-slip rubber mat inside bath to prevent slipping.



## How should someone be transferred to a bath?

Transfer from chair to side of bath / bath board.	Sit on bath board. Lift legs into bath.	Move down to bath seat. Person must support firmly with strong hand on side of bath or rail. Weak arm rests on person's thigh.
	If the weak arm has some power, the assistant must support the weak hand on the edge of the bath or bath rail	



## What assistive devices can be used if person cannot sit down in bath?

Bath board on top of bath, with bath seat inside bath	Bath board (Diagram on page 39)	Bath seat (Diagram on page 39)
a & b) Swivel bath chair		Slated bath seat (Diagram on page 39)

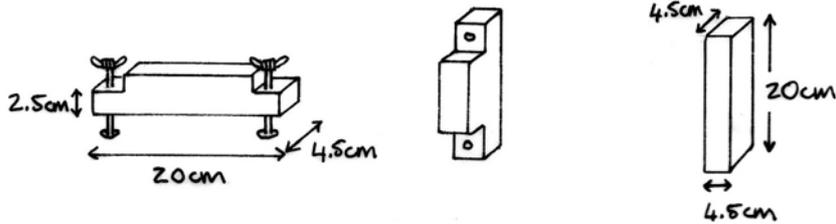
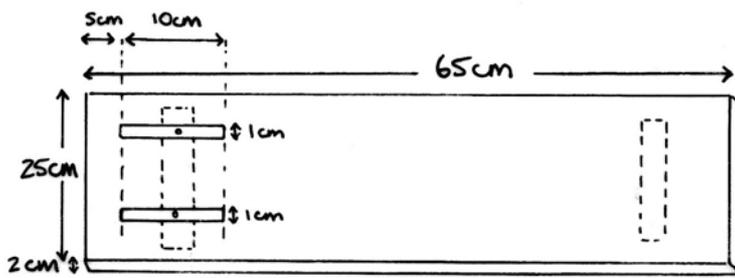


Diagram of bath board

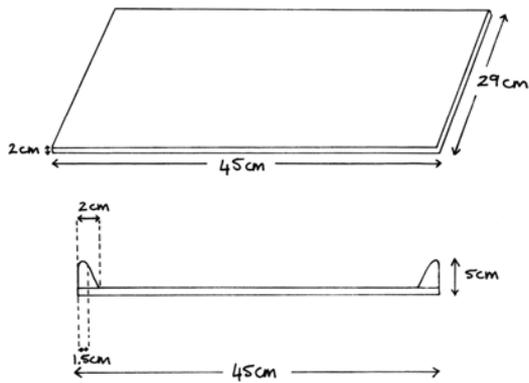


Diagram of bath seat

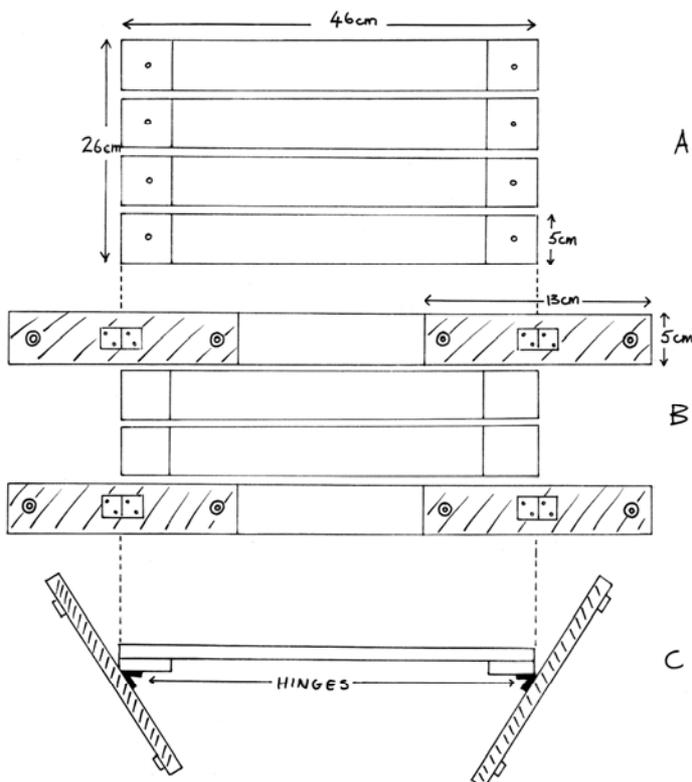


Diagram of slated bath seat

Diagram of seat  
Diagram of sides  
Schematic presentation of how to join seat and sides



## How should someone transfer to a bath without help?

<p>With hands clasped stand symmetrically up from chair</p>	<p>Swivel and sit down on bath board</p>	<p>Support weak leg around knee and lift into bath</p>
<p>Push with hands on edge of bath</p>	<p>If weak hand is too weak, place it on opposite thigh and lower body down onto bath stool or into bath</p>	<p>Wash trunk</p>
<p>Soap on a rope Make a hole in the soap and tie onto a rope. Hang around neck This prevents the soap from falling and slipping away</p>	<p>Drape cloth over knee to soap.</p>	<p>Back brush Back brush made of a coat hanger and sponge covered with towelling material</p>
	<p>Sponge with elastic to go around back of hand</p>	

## Dressing



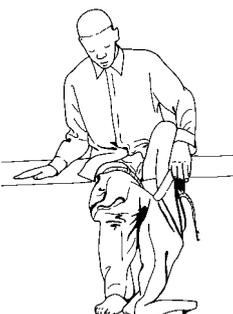
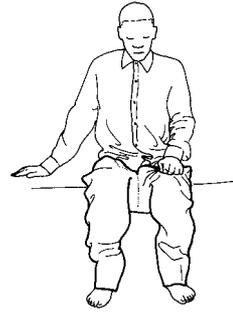
### What are the principles to follow when helping someone to dress?

Allow the person to do as much as possible for him/herself

- Start practicing with undressing, because it is easier
- Use wide, loose fitting clothes
- Do not use clothes with complicated fasteners
- Dressing is a slow process. Allow enough time
- Give positive feedback
- If the person cannot perform the entire task, break it down into steps e.g. only put arms into sleeves
- Always dress the weak side first and undress the strong side first
- Sit over edge of bed. Feet supported on floor. If person cannot balance on bed, he can sit on a chair with a firm seat and backrest

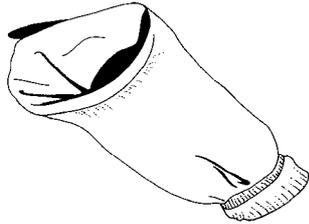
Putting on shirt		
		
Put shirt on lap Inside facing upwards Collar towards knees weak arm's sleeve hanging between legs	Bring weak arm towards lap	Put weak hand into sleeve opening
		
Pull sleeve up over weak hand and arm until hand is visible Throw rest of shirt backwards	Pull sleeve up over elbow	Pull sleeve up and over shoulder
		
Bring shirt around back	Put strong arm into sleeve	Fasten buttons

## Putting on pants

		
<p>Place pants on strong side</p>	<p>Cross weak leg over strong one</p>	<p>Put weak foot into pants leg</p>
		
<p>Pull pants up over knee and uncross legs</p>	<p>Put strong leg into pants leg</p>	<p>Pull pants up over knees</p>
		
<p><b>Weaker person</b> Pull over buttocks by, hooking strong foot underneath weak leg, pivoting on elbow and lying down on bed</p>	<p>Bend knees Lift bottom Pull pants up over bottom Drop bottom Fasten zip and belt Sit up again</p>	<p><b>Person who can stand with assistance</b> Stand up with assistance (Assistant on the weak side) Assistant pulls pants up</p>
		<p>Person who can stand independently If person is strong enough to stand independently he can stand up to pull pants over bottom and to fasten zip and belt</p>

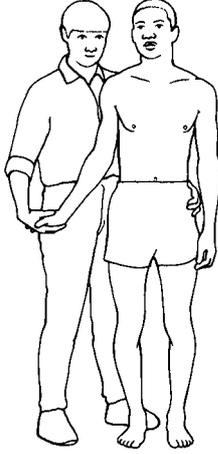
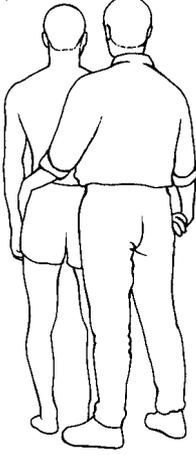
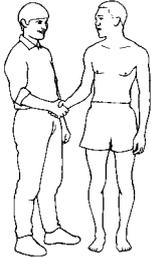
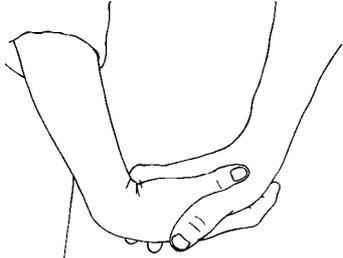
**Putting on jersey**

		
<p>Put jersey on lap Back facing person Bottom end towards body and neck at knees</p>	<p>Open from bottom and find sleeve opening for weak arm</p>	<p>Put sleeve between knees Open sleeve entrance with strong hand</p>
		
<p>Put weak hand in</p>	<p>Pull up over elbow</p>	<p>Pull up over upper arm</p>
		
<p>Pull up over shoulder</p>	<p>Either put strong arm through</p>	<p>And then head</p>
		
<p>Or put head through</p>	<p>And then strong arm</p>	<p>Pull down at back and neaten up</p>

<b>Putting on sock</b>		
		
Fold sock half way back to the heel cap	Cross weak leg over strong leg	Pull sock over toes
		
Pull up over rest of foot and ankle		
<b>Putting on shoe</b>		
		
Cross weak leg over strong leg Pull shoe over toes	Pull foot in	Put foot on floor and press on knee to slip heel in

# 10. Walking with help

**?** What is the correct way to help someone to walk?

 <p>Front</p>	 <p>Rear</p>	<p>Principles:</p> <ul style="list-style-type: none"> <li>• Support from weak side</li> <li>• Assistant's hip against back of weak hip</li> <li>• Assistant's foot assists weak foot if necessary</li> <li>• One hand firmly around the person's body</li> <li>• Other hand holds weak hand</li> <li>• Allow person space to move his body</li> <li>• If you stand too close or hold too tightly both of you will struggle to maintain balance and walking will be more difficult</li> </ul>
		
<p><b>The correct grip:</b> Start as if shaking hands, but turn your palm up while holding the person's hand Grip the weak hand Do not pull on the weak arm</p>	<ul style="list-style-type: none"> <li>• Support arm by giving pressure upwards through the hand</li> <li>• Keep elbow straight against assistant's body</li> <li>• This way the arm remains straight and the person can lean on your hand for support</li> </ul> <p>You can assist him/her better with balancing</p>	<p><b>Alternative grip:</b> (This is a good grip to use if the person has a stiff wrist) Hook thumbs together Grip person's hand along base of thumb Make sure that the person does not feel any pain in his wrist</p>

 If the person is very weak, a walking stick can be used on strong side. Both assistant and person being assisted must wear comfortable, sturdy, non-slip shoes or walk barefoot. Do not walk on socks!

# 11. Typical complications

Complication	Seek assistance from
Shoulder pain / Shoulder and hand pain	Physiotherapist/Occupational therapist
Urinary tract infections	Clinic/General practitioner/Nurse
Constipation / Diarrhoea	Clinic/General practitioner/Nurse
Sliding or falling out of wheelchair	Seating clinic/Professional with specialised training in seating
Behavioural problems	Occupational therapist/Clinical psychologist
Aspiration (Choking or poor swallowing)	Speech therapist/Nurse
Pressure sores	Clinic/General practitioner/Nurse
Shortening of muscles / Tightness of muscles / Spasticity	Physiotherapist
Depression	Clinic/General practitioner



Adhere strictly to any prescription e.g. for medicine

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