Caring for
The Elderly

Best Practice in Person-centred Care

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What inspired this manual?

Suggestions for this manual came both from Carers as well as from people who themselves need care, at least at times. The most important thing said by both groups was this: too many people who need care find themselves being treated as if they were small children, or stupid, or just 'a lump of flesh'. What they want is to be treated as **real human beings**, with their own individuality and desires.

People who need care still want to be the centre of their own lives. They say that many of the Carers they encounter could treat them better. And the supervisors of Carers say the same thing.

- If you are a **Carer**, this manual suggests ways of looking at your work to see if you are doing it well – and if necessary, how you could improve.
- If you are a **supervisor or manager of Carers**, this manual can help you improve your work with both clients and Carers and start to build a team – the best way of delivering good care.

Exercises for learning Skills

Learning new knowledge, attitudes and activities is important in order to become a good Carer. But to transform these into new skills involves practice.

Most of a Carer's work involves three different skills:

- Physical skills
- Decision-making skills
- Communication and empathy skills

The **exercises** in this manual will guide you in developing these skills. You may have to carry them out more than once before you feel you are competent.

Checklists will make sure you are working to a high enough standard.

You can follow the manual by yourself or, better, with a small **support group** of colleagues (see Section 2) or better yet, with your supervisor.

You can learn the **physical skills** – such as measuring a dose of cough syrup – to some extent on your own. But how will you motivate the person with the cough to take something that tastes nasty? And will you be able to discuss the medicine so that they see the value for themselves?

You will learn d**ecision-making and communication skills** better if other people can give you feedback and enthusiasm. They can give you insight into what would work – or not – in real life and whether your standards are high enough.

Section One: What a Carer needs to learn

1.1 Introducing 'Person-centred Care'

In the field of care for the elderly, resources have been insufficient for a long time. Traditionally, care programs have been developed by:

a) looking at groups of people in need,

b) estimating the characteristics of each group, noting what others are doing; and then

c) doing the same – but with no proper dialogue with the users.

With the elderly this may involve the use of care homes and strong medications.

But today (2015), thinking has advanced. Clients have become more vocal and organised. And Carers have observed, discussed, thought about and learned how to do their work in a more professional way. They have adopted a different mind set – putting the client at the centre of his or her own life. They call this 'Person-centred Care'. What does this mean?

Person-centred Care =
The client is central; (s)he is offered quality care, with respect;
the care is adapted according to the wishes expressed by the client.

This involves five things:

1. The client is central.
2. The care offered is as good as the circumstances allow.
3. The client is involved in decisions and has a deciding vote.
4. Each client should have their own Person-centred Care Plan.
5. Some clients will need advocacy.

1.2 How does caring for the elderly fit into Person-centred Care?

In Person-centred care, you need to understand each individual with whom you work. You need to remember that everyone is as different and as complicated as you are. The more you can identify differences in people the better you can understand them.

1.3 The elderly and Advocacy

Many elderly people – especially women and those with mental illness, dementia, stroke or aphasia – feel emotionally and/or physically unable to speak for themselves and express their own needs, choices and wishes. They are unable to be assertive in asking for help or support, especially where cultural norms are also acting as a barrier.

Such people need an Advocate: somebody to speak up for them, whether it be a trusted friend, relative, neighbour or Carer; this person should be able to communicate on their behalf, getting them the help and support they really need.

1.4 Life Journeys

One way of looking at your clients is to think about their lives so far as part of a life journey.

EXERCISE: THE JOURNEY – PART 1

- Make a list of the people aged 65 or over who you know, perhaps through your work or your family.
- Choose one male and one female, people whose past story is known to you. Keep them in mind as you read through this text on the physical and mental journeys we all make.

The physical journey – up to retirement:
As we go through life our physical bodies develop, reach their peak and gradually decline.

Men usually reach physical peak at age 18-20 although some may not reach it until they are 25 and others may be earlier. Once the peak has been reached, muscles and endurance are as good as they will ever be. Men who go into a physical job may stay strong and fit for several decades, however some noticeable decline sets in around age 35 (the typical retirement age for a pro footballer). Repetitive and physically stressful work is also likely to cause wear and tear on the body, including small accidents and damage to joints. Around age 50 or 60, health problems linked to age may show themselves,like arthritis or prostate cancer. When males have had a reasonable diet and some exercise, many will reach the typical retirement age of 65 in good physical shape.

Women usually reach a physical peak a little earlier, at around age 16-18, followed by a period of peak fertility aged 19-26. Many start childbearing, breastfeeding and child raising at this time. After the age of 40 or 50 comes the menopause. All of these changes in the body may leave it in a weakened state. Women are more likely than men to put on weight at a younger age, lose physical strength, and seek help for a health condition. With the menopause they may also face illness such as breast cancer. Yet while women tend to be less fit than men on reaching 'retirement age' (65), on average they will live longer.

The physical journey – after retirement:

When men and women reach retirement age, they are likely to already have some **limitations** to their physical fitness. They may have the start of diseases caused by parts of the body wearing out. They may have diabetes or narrowing of the arteries, or suffer strokes which kill small areas of the brain.

The quality of their old age will depend on their past history but also on whether they can find a regime that maintains their **health**. Most important is to keep physically and mentally active. Some men find retirement very difficult, they may feel without purpose in life any more – which can contribute to them dying quickly. And of course in some countries, for many people, retirement is not possible because they have no financial provision. They must go on working.

One of the key issues for each individual is maintaining physical **mobility** – the ability to walk around their living space, use their hands to prepare meals, hear the phone or doorbell and give a sensible response, use the phone to order food

and so forth. If this mobility is maintained, then the individual is assured of continued independence. If it starts to be eroded by poor health, it has many negative knock-on effects for personal wellbeing, the performing of daily tasks and the need for financial support. Carers need to be aware of the range of simple aids and adaptations that exist, which can ensure that people retain as much physical independence as possible – walking frames, sticks, tripods, grab-rails by steps and stairs, raised toilet seats, commodes (portable chairs with potties in the seats) and so on.

Some of the differences between countries and genders are shown by **life expectancies**. In Europe, a baby boy can expect to live to the age of around 80, a baby girl to 85. In the better-off countries south of the Sahara it is more likely to be 50 (male) and 55 (female). But in the poorest countries, average life expectancy is just 45 (male) and 50 (female).

- What is the life expectancy in your country?
- How does this compare to the rest of the world?

The mental journey:

Mental ill-health happens at all ages but the picture is different in the two genders. Women are more likely to admit to having **mental problems** (such as anxiety and phobias) and to seek help for their issues. Men are more likely to have problems linked to addictions such as gambling or alcohol – and they are more likely to hide the problem.

In the North, up to 20% of those aged 65+ have been classified as suffering from **depression**. This is linked to the way the elderly are seen and treated in their society.

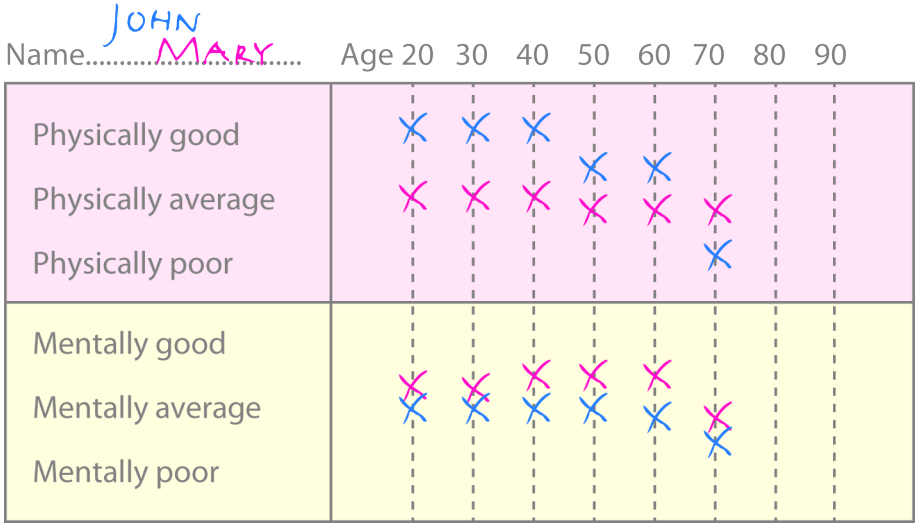
The mind, like the body, suffers from wear and tear. Almost every older person knows that they do not remember as well as they used to. Or they remember the distant past better than the recent past. Worsening **memory** is partly due to not using the brains enough. A group of problems may build up around this – forgetting, confusion and mood changes. This may be labelled “pre-dementia” or “dementia”. There is more on this in Section **3.6**.

Bear in mind the following:
i) that people are generally as complicated as you are, and
ii) that each individual person is as different from one another as they are from you.

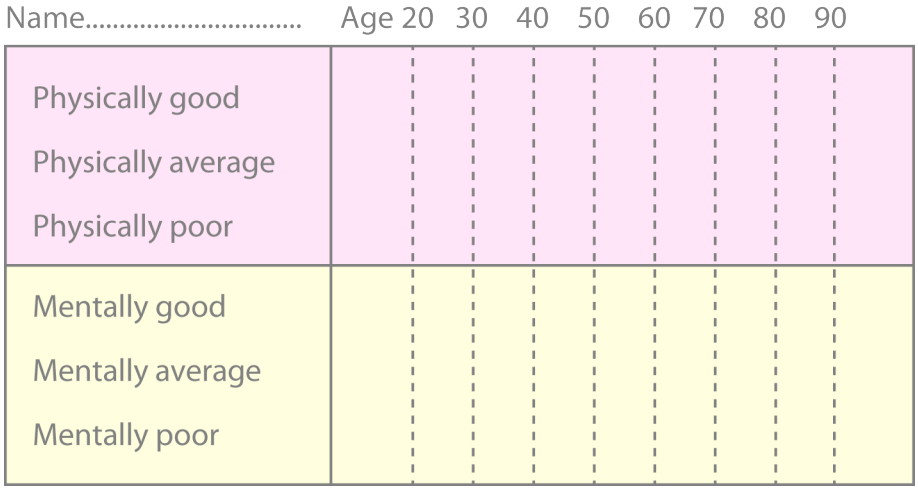
EXERCISE: THE JOURNEY – PART 2

- Consider the two elderly people that you picked out of your list. Think of the physical and mental journeys they have made in terms of a simple chart – like the example below. This shows the journey for two relatives of one of the authors. The male is in blue and the female is in pink.

Example chart:



Your chart:



- Fill your selected male and female person on this chart using pens with different coloured inks. How do they differ?
- Now look at your full list of elderly people and consider each, one by one. — Is each one “just another oldie” with their age central in your thinking? — Or are you beginning to see each as an individual person, and put that individuality at the centre? This is the first step towards Person-centred Care.

1.5 Understanding the elderly as a group that deserves good care

In any country it is older people that have contributed most to society. Because:

- **They raised us**
  — Who were the older people looking after you when you were a young child?
  Take time to remember any good caring that you got (it is hoped that you got some).
- **They are responsible for the country's history**
  — Have the older people in your community bored you with long tales of their part in the struggle and their suffering?
  Some of it is true and most of them deserve respect. Now they need care, and have earned it. One day you will probably need care yourself – something to remember.
- **They are still contributing**
  The elderly form a large group of the population. Usually, they have some time to spare. They can therefore play a strong role in the politics of the country. In northern countries, most elderly have had education and a working career, they have paid taxes and they still vote. Depending on how well they are organised, they have some political power – and are able to fight for some of their own needs, such as a reasonable share of the Health budget. In the UK, for example, the elderly have the right to free travel on public transport and winter fuel allowances. But still many do not have an adequate pension and are cold and poorly fed in the winter.

In your country, where does the Health budget go? Do the elderly get a reasonable share?

1.6 Understanding individuals as part of families

EXERCISE: THE ELDERLY AS ELDERS

- Consider how the elderly have traditionally been sources of information and opinion.
- What are the alternative sources that people draw upon today – newspapers, radios, computers and the internet…?
- How have these resources changed the way we look at the elderly?

In many places in the world, the elderly have lost their role as the Experts. At the same time, as healthcare and nutrition improves they are living longer and, sooner or later, needing care. What does this 'care' look like? And how well does it fit what the elderly themselves want?

In the South, care for the elderly is usually provided by families – and in practice there are few other alternatives. People say that family-based care is the best possible model. But sometimes it comes at the expense of somebody else. When you hear someone (e.g. a politician) say how good it is, ask whether the speaker is him- or herself caring for anyone at the moment – every day and every night? Most often:

Care = mother, daughter or daughter-in-law.

Sometimes this care is impressively good and loving.

Sometimes it is woefully poor.

And, often, family-based care means particular family members are exploited:

Example» *A friend received an email to say her father was dying and she must come home. She left her business and travelled to his bedside to do all she could. She cared for him for six months. Her family expected this of her. But her two brothers saw their role differently – as men. They paid brief visits once a week and each time left a pile of banknotes under the sugar canister. My friend did not need the money – what she needed was physical help moving her father onto the toilet etc, and occasionally a weekend break. But her brothers would not discuss divisions of care. Meanwhile her business was suffering…*

The elderly are not just objects of physical care within their family. Before they became incapacitated they had a role and a status – perhaps even as Family Elder. They invested resources into the family and in return got some of what they needed.

EXERCISE: UNDERSTANDING THE FAMILY SITUATION

- Select two of the elderly from your list and consider how each fits within their family.
  - Financially – are they earners or consumers of family resources?
  - Emotionally – are they constantly draining energy from the family?
    Or do they radiate positive emotional energy and love?
    Or do they change between these two roles?
  - Which of these elderly people would you most like in your own family?

1.7 Understanding individuals as part of Communities

Example» *In West Africa, people often move from small inland towns to big cities on the coast, looking for education or work. The older migrants form groups to maintain their own identity and look after the younger people – they realise that migrants can get into all sorts of trouble. Such groups provides social contacts, guidance and even small loans when necessary. These groups are ideal for involving elderly people and using their life experience to help others.*

Within such a group, each elderly individual can feel fairly equal and able to do what makes them comfortable, without having to contend with ‘normal’ expectations.

A client may well be a part of other local groups and communities that consist of all kinds of people. Or they may be part of a situation that is changing rapidly – as their Carer, you may then be the best person to help them find new roles.

Other type of groups and networks are faith-based. The right sort of community faith group, one with compassionate leadership and inclusive culture, can provide a useful social structure in addition to the spiritual support. Being part of an inclusive group of people who “care” in the wider sense can give an individual a strong feeling of worth and belonging.

1.8 Ensuring your clients' Human Rights

We have considered the elderly as part of different groups, part of a family and as individuals. But we can also look at them – and their needs – through the lens of Human Rights. Your elderly clients, like everyone else, are entitled to basic rights and freedoms. It is important for them to be aware of these – if they are not, this is also an infringement of their rights. Carers can point out those actions, practices and treatments which their clients can refuse to accept.

Human Rights are now everywhere being taken more seriously and in some countries are legal requirements that have led to actions. You can see the full 'Universal Declaration of Human Rights' (UDHR) – which was adopted by the United Nations in 1948 – at http://usgovinfo.about.com/bldechumanrights.htm

- The elderly are specifically included (for example in Article 25, paragraph 1) and have the same rights as everyone else. They have full equality under the law. They have the right, for example, to non-discrimination.
- In 1990, the 'Cairo Declaration on Human Rights in Islam' was made, to give an overview on the Islamic perspective and resolve contradictions between the UN declaration and Sharia law: http://en.wikipedia.org/wiki/Cairo_Declaration_on_Human_Rights_in_Islam

Not every government has signed the Declaration and others have not ratified the signing. Ratifying means that a government is obliged to take appropriate action – which costs money. Often they will commit as part of a bigger agreement about aid. Only treaties which are binding can force governments to take action.

The Human Rights that are usually of most importance for the Elderly are of two types:

Protection:

Where there is no protection, the following Human Rights are threatened:

- the right to life
- the right to a good death
- the right to liberty
- the right to have private and family life respected
- the right to be protected from danger and harm
- the right to access a range of services and facilities that may benefit health and wellbeing
- the right to be free from discrimination in respect of these rights and freedoms.

This first group of rights is based on a view of the Elderly as weakened and vulnerable people – which many are. One of their most important needs is security. This not only includes a home with good locks but also good healthcare and an adequate standard of living. To have one right usually depends on others being in place. For example, good healthcare depends on adequate nutrition (which depends on adequate living standard) – and on the availability of support systems, including transport.

The right to live without torture and abuse is another important protection – as particularly elderly women are at greater risk, whether from accusations of witchcraft or swindlers after their money.

Participation and image:

Where the Elderly are seen merely as people without a role or potential victims, then the Human Rights under threat include:

- the right to be respected,
- the right to be treated in a dignified way, and
- the right to freedom of expression

Here is an example of a project supporting the elderly's 'right to be respected':

> ***Example»*** *The Taraqui Association in Karachi, Pakistan works in new urban communities, mostly very poor. People usually leave their extended families behind in the villages when they move to the cities to find work. But sometimes they bring their parents with them, partly to care for the children. It is difficult for people over 50 to find paid work so these elderly have lost their roles as wage earners. And for grandfathers the role of child carer is fairly demeaning. The respect that would traditionally be given to them by their children and grandchildren has been fractured. One way of repairing this is to invite the elderly to visit the local primary schools. There they tell stories of their past, important events, festivals, struggles and sacrifice – often the events that led to their country gaining independence. The children see teachers listening with respect and they too learn to respect and enjoy their grandparents in a new way. Instead of the miserable picture of the elderly created by the media, they start to see them as expert sources of information regarding their history.*

This second group of rights sees the elderly as people with experience and wisdom which they are ready to offer. But sometimes the rules do not allow it or others do not see them as capable. For example, an elderly person might wish to sit on a committee or stand as a local representative but this right is threatened when the image of the elderly in society is bad.

> ***Example»*** *In a lot of countries, jokes are made about members of parliament or members of the second chamber when they have white hair. The jokes suggest that as oldies they have poor memory, make mistakes or are incontinent. Politicians do better in practice if they dye their hair brown or black.*

Section Two: Learning More

2.1 Training and educating yourself

The exercises in Section One will have helped you see the individuality of each client. Keep this viewpoint for the rest of your working days.

This Section outlines how you can **strengthen your abilities** as a Carer,

- **by learning more information** – about your clients, the available services and the possibilities. You can do this by reading, discussing and thinking.
- **by identifying new knowledge and skills** that you need. You can learn by practicing, either to strengthen existing skills or to learn new ones from scratch.
- And **by learning about the attitudes that you already hold** – some will be useful but some attitudes do damage. You need to sort these out.

EXERCISE: ATTITUDES & DECISIONS

- Read this story and note your impressions:

  "I am a manager of Care Workers. Recently I was asked to resolve a problem for a family.

  The husband is a very respect-worthy businessman here in the city. His mother is an elderly woman (73) from a rural district nearby. She recently fell and broke her leg and was two months in hospital. What to do next? The son has a roomy apartment so I advised that he took his mother in to live with him. He took my advice and moved her quickly. There was no need for time in a Convalescent Home because the son has servants; the old woman does not need to shop or cook any more. Ria the daughter-in law is in charge. The mother has a small room with a bed, a chair, a trunk and a small TV.

  The important thing is that she does not fall again so she should be kept sitting in her room. She tries to come out and help with the shopping or cooking. She tries to go for walks. Ria and the maid can hear If she opens her door and can go and settle her down again. I have advised them to keep the front door locked. They can take her a tray if they have visitors in the best rooms. She would not enjoy the company of smart or professional people. She has a TV, which she never had before!"

Consider the basic questions…:

- Did the manager lady do a nice job?
- Were the manager and the family guided by a good principle – the importance of of ensuring the old lady did not have another fall?
- Did they put together a good life for the old lady?
  Remember that:
  — the elderly have a right to a say on what happens to them, indeed to be the person whose wishes matter most.
  — the elderly need safe housing and good nutrition.

— the elderly need to feel that they have a useful role and that they are respected.
— in principal all humans should be free to go out when they want.

…the wider issues:

- How "old" is 73?
- Who should decide on the future of a 73-year-old lady with no loss of mental abilities? And who did decide?
- What could the old lady do before that she could be able to do again, given training and help?
- Does the current situation make everybody happy?
- Suppose that, later on, this old lady becomes your client. And she says she wants to move back to her village and live independently. She says she is willing to be more at risk from accidents in order to be more independent.
  — Would you support her?
  — And what should you do before saying that she is ready? (think about her leg, the practicalities of shopping and cooking, and her personal security).

…the Manager's attitudes:

- Can you identify any attitudes held by the Manager which you would like to see changed?
- Do you share any of the Manager's attitudes?

You can begin to question your own attitudes by slowing down, thinking twice, observing well and checking with others – especially your clients. You can discover whatever needs to be changed, and gradually relearn how to do certain things.

2.2 Finding 'helpful friends' – a Support Group for further learning and training

One way of upgrading your skills is to form a **Support Group** of Carers who are prepared to meet regularly and help each other. Work out a few rules to ensure client confidentiality, (e.g. 'We promise that what is said here, stays here'). You could then discuss the clients you are helping and the problems you are meeting.

This kind of group is particularly useful if you are working with an issue for which there are few resource materials available. For example you could be working with someone who may have signs of dementia, an elderly person who has had a stroke… other Carers may be working with these same issues in your district. Ideally, you could all meet up regularly and each could contribute insights and approaches to share. If people need contact more frequently, see who has mobile phones and form supportive pairs.

Another way of upgrading knowledge and skills is through a **computer.** Find one that you can use regularly, perhaps once a month. Try the Public libraries and Internet Cafes. Visit and read **websites, newsletters** and **manuals.**

Example» **Internet research – dementia/Alzheimer and strokes**

Information *is available in quantity, firstly through the specialist NGOs such as the Alzheimer's society. Their website, www.alz.org offers among other things 'The 10 signs of Alzheimer's' www.alz.org/national/documents/checklist_10signs.pdf*

There are resources for stroke victims at, for example, www.stroke.org

With a little searching you will find that there are ***online courses*** *designed for trainee nurses. These courses are made up of learning 'units' – one such unit might be "Alzheimer's" or "Strokes". Such courses can be of good quality (but check).*

Currently, these courses are almost always aimed at people in the North. But online courses are likely to become increasingly available in the South. Think about the fees – are there NGOs in the neighbourhood who could help, or an employer?

EXERCISE: MAKING A DATABASE OF RESOURCES

- Find out and write down every local individual and institute that can help elderly people – physiotherapists, lunch clubs etc.

  If you write each item of information in a computer file, or on separate cards stored alphabetically, you will be able to retrieve the information fast when you need it.

2.3 Getting the client's perspective

It is often said that in order to understand somebody you need to walk in their shoes for a while. For example, to get a disabled person's perspective try going out in public in a wheelchair.

Dressing as an elderly person and walking around is no less difficult. You risk having an accident or being mistreated in some way or even mugged. So if you decide you want to give it a go please make sure that you have a friend with you.

To **transform yourself into an old person**, you could:

- cover your hair with a scarf
- put grease on a pair of spectacles so that your vision is blurry
- wrap bandages around your legs and knees so that they are stiff and slow
- put a stone in each shoe so that walking is painful and difficult
- put on lots of layers of dark clothes
- hunch over a bit and see if you can shuffle.
- if you live in a town big enough to have a group of actors, ask their help; they might also have props like grey wigs.

So now go out into public spaces. As well as the general experience, do some specific test activities such as:

- going into a shop and dropping a purse full of pennies…
- joining a queue for a bus and moving very slowly…

If you are not able to do this role-play yourself, the next best thing is to invite someone old for a walk and explain what you are doing. Then observe her/his experience, all the time asking:

- How do people treat this elderly person?
- What are they saying to her/him?
- What are they saying *about* her/him?

2.4 Role-plays for decision making and communication

What are Role-plays for?

In training courses and text books you learn a lot of knowledge. But to be effective as a Carer, the knowledge has to be adapted to reality.

A lot of learnt knowledge is never used. Instead, face to face with an elderly person needing help, what you need are skills. You need the skills to be able to ask the right questions, using understandable words and showing the right attitudes of caring and respect.

And you need to practice often, so that these skills become habits. If you learned to drive a car, how much practice did you need before you were good enough – and the skills were habitual? Good communication is the same. But you cannot practice on clients. Role-plays with observation and feedback can be done instead. These can give a fairly close feel for the reality. In addition you have the chance to discuss situations you may encounter so that you already have some solutions to specific problems.

EXERCISE: GOOD COMMUNICATION

- Select a role-play at random (see Section **6.4**).
- Look at the 'Check-list for Interviewing Skills' (Section **6.5**) and decide whether your group can use it as it is or want to change anything on the list.
- Split into two groups.
  — One group chooses and supports the Carer, who is meeting the client for the first time.
  — The other group supports the client or family member, choosing who will act the role, deciding what they will say and what they hope to hear.
- With each elderly person or family member, try to feel what it is like to be that person.
  — What are the pleasures of your life?
  — What burdens are you carrying?
- After the role-play is acted out, each group gives feedback and fills in the Interviewing Checklist.

Over time, do more role-plays. When it feels right, you can switch to working in groups of three – Client, Carer and Observer, again filling in the Interviewing Checklist.

In a **good interview**, the Carer should score at least seven out of 10 'Yes' answers on the Interviewing Checklist.

If one person in the group performs consistently poorly in the role of Carer, they can go on practicing and receiving feedback until they get good enough.

If most of the Support Group is doing poorly it means that you need to go back to basics. For this, a useful resource is *"Interviewing & Counselling at the Grass Roots"*, in particular Section 2: Interviewing Skills, where the factors covered by the checklist are discussed one by one with exercises. Download it from http://www.networklearning.org/index.php/library/interviewing-counselling-at-the-grass-roots

2.5 Real-life communication problems and solutions

There may be **extra factors** at work that hinder good communication, for example:

- A client's limited ability to use language to express themselves effectively.
- Medical conditions such as cerebral palsy or a stroke, which affect the client's ability to speak.
- Brain damage or memory loss, affecting a client's ability to understand.
- Sometimes, with age, the client goes back to speaking in their native language. So you may need an interpreter.

If someone does not speak clearly, people may think that they are understanding nothing at all and have no opinions. Here are ways of helping you be a **better listener**:

1. Spend more time practising '**active listening**' – that means not just 'hearing' but listening with all senses, with your full concentration. Let the speaker see that you are paying attention to what they are saying and they will feel encouraged to open up more. Be patient at developing this skill, it can be difficult to master.
2. Be **creative** in your questioning. Ask around an issue using different questions in order to get different replies. Together these will give you a fuller picture.
3. Talk to the client using **open questions**, not leading (closed) questions. Ask 'How did you find that leaflet I gave you?" This is an open-ended question. Do not say 'That leaflet was great, wasn't it?" This question leads only to a "yes" or "no" answer - so it is closed. Discussions where the Carer talks much more than the client are closed discussions. If you take an open-ended approach to a discussion, the information you gain will be more, and more useful. And you will have shown respect.
4. **Share** your experience with your Supervisor or Support Group and ask for feedback.

For clients who have **difficulties in understanding** your questions or comments, use other means of communicating:

- Pen and paper, so they can write down responses or what they need.
- For clients who cannot read or write you could use Prompt Cards. These are easy to make yourself. For example, a set could show the main food choices available so that clients can point to what they need; another set could show faces expressing different emotions so that they can point to how they are feeling.

For **deaf people**, you may need signers in the short term. In the long term you may need a hospital department that can supply hearing aids. Be aware that clients who get hearing aids may be reluctant to keep them in their ears and turned on. This may be because what they hear is unpleasant (e.g. a family always fighting or old people talking all the time about

sickness and death) or perhaps because the aid is uncomfortable, with sharp edges or whining noises. Try to sort out the problem – s sympathetic technician at the hospital may be the ally you need.

2.6 Supervision

Good supervision helps you gain better skills. If you work for an NGO you would normally have a Supervisor. Some are real and active – but some exist mainly on paper. If that is the case, ask for more supervision or to be supervised by someone else, preferably a person with a good reputation. If your efforts fail to get results, you can look outside for your own 'mentor' – somebody more experienced who can give guidance. For example, a Carer who is now retired may well be glad to share their wisdom.

Suggestions for Supervisors

You may already be a supervisor or may become one in the future. An ideal supervisor does the following:

- spends the right amount of **time** with their supervisees (those supervised).
- **praises** what the supervisee does well.
- points out what needs to be improved and **how to do better**.
- is **realistic** when writing reports, since reports play a role in promotion.

2.7 Caring For the Carers

This is an issue the Support Group should discuss – most jobs in the caring professions are very taxing (and low-paid). Carers need to draw from their own inner strength every day. They may feel some reward from seeing people being helped and their lives improving – but some fields are more “rewarding” than others. It is important that every Carer learns to know themselves. They need to find out how to keep well on all levels – emotional, mental and physical.

In addition to helping improve skills, a Support group can also play an important role keeping its members in good health:

- Members can **tell each other how they are doing and feeling** – a problem shared is a problem halved.
- **Specific issues can be discussed**, such as the effects of working long-term with the dying (palliative care) and how to recognise the symptoms of burnout.
- It is also important to discuss **ways of keeping physical and emotional balance**. Everyone needs to find their own way of sleeping well, eating well and keeping their private life alive and healthy. Many Carers practice meditation or yoga to keep relaxed and fit. Or a Carer may have a little ritual between leaving work and arriving home where they stop for a few minutes, puff out their frustrations and mentally shut the door on work.

Outside of the group meetings, members can also ask for and give support by phone. It is important, though, to limit the time spent discussing troubles or the group will get depressed.

2.8 Family Carers

In any family, at any time, a tragedy may strike. For example, a relative may suddenly require care after having a stroke. As the family tries to respond, there is usually one person who takes on the key role of organising their care. That person may suddenly acquire a whole range of new responsibilities, such as:

- making sure visits to doctors or physiotherapists happen.
- organising the daily care of providing food, washing and clean bed sheets.
- being the main source of stimulation and encouragement.

Now the family has a Carer – whose own life has been turned upside down. Playing such a huge new role can be overwhelming. It may feel like being handed a lifetime prison sentence. However the Carer will not say that in front of the person for whom they are caring. They develop a public face for everyday show – and a secret face which they only show from time to time.

Example» **Advice for Family Carers**

The following Advice List is given out to family Carers who use a General Practice in Australia. The Health Workers there had seen how demanding and difficult the Caring role can be:

- *Maintain your relationships with your friends and society*
- *Be prepared to put pressure (in the nicest way) on the cared-for to help themselves*
- *Accept help without assuming you have an obligation. Those who have helped you will be helped in their turn. Use all the services available*
- *Tell your helpers, if necessary behind the cared-for's back, exactly what the situation is – without exaggeration. Especially tell people when the cared-for has pain*
- *Accept respite (taking a break) from care. You MUST have time out – half a day in every week, a week-end in every month, a week in every three months. You must go away to where you can truly relax – not necessarily with your family*
- *If things are going wrong with your support, seek an outsider to discuss the problem (mediation). Do not let things go too far*
- *Look on the bright side, smile and see the humour in the situation. There is usually a bit somewhere! Admit to yourself that you are under stress. Do not worry if you get upset: we know how much stress you are under*
- *Look after your own health*
- *Keep your use of helping "substances" to a minimum. This includes caffeine, nicotine, and of course alcohol; but especially it means sleeping tablets, which should be used a maximum of once a week*
- *Make sure you get sufficient sleep. These things may help: keep your use of helping substances to a minimum; have your main*

meal at midday; relax before bedtime with no TV news or violent programmes; take only short naps in the day time

- *Exercise regularly: do something every day*
- *Lower your standards to conserve time – for example do less house scrubbing*
- *Know when it's time to bail out – to stop.*

Example» **The elderly can be Carers too**

In Tanzania, some NGOs looked at people with AIDS (PWAs) in the community and realised that 90% of their caring was being done by family and community – at least half of this by elderly relatives.

The National Guidelines make it clear: the Government assumes that care by the family is the best. However this also assumes:
— that these family Carers are literate, mobile, energetic and economically productive;
— that families with PWAs can pay for medication, food and shelter.

The reality was that responsibility had fallen mostly on a group of grandmothers who were already poor and badly housed – and becoming a Carer usually had a huge effect on their budgets, health and emotions.

HelpAge and its partner organisations realised the need for a model way of supporting older home-based Carers, one that would at least keep them safe from infection. So:

- *They ran one-week trainings on home-based care, covering:*
  — risks and prevention of infection
  — counselling
  — pain relief
  — nutrition
  — services available in the district
- *They set up mutual support groups for the Carers*
- *They distributed free Homecare HIV+ kits (aspirins, ORS powders, rubber sheets, old cloths etc.)*
- *They linked the Carers to local traditional healers and to local services*
- *They ran sessions for local HIV+ people on advocacy and how to claim their rights and allowances*

Reference: www.helpage.org/resources/practical-guidelines/hiv-and-aids-guidelines/

2.9 Helpers in the Home

When an elderly person gets too burdensome, you as a Carer may help families make decisions about helpers. You may meet the people who are hired to help. In many countries, routine household tasks, plus the care of small children or the elderly, are often done by

children. Such **child labour** is cheap. But it is unacceptable if a full-time helper is under 16. You are in the caring business, so:

- Find out the laws in your country on child labour and, if they are being broken, inform people.
- Help families to be more aware of the limited capacity of young children. To leave a ten-year-old in full charge of a toddler or a confused elderly person is to run a high risk of a disaster.
- Have suggestions as to how young domestic helpers should be treated – for example sending them to half-day schools in the neighbourhood.
- Foreign Domestic help: in richer countries, for example those in the Middle East, people get domestic help from countries such as Sri Lanka or the Philippines. Some of these women stay for a few years, get on well with the family, are treated and paid acceptably – and then they go home. But they can also have their passports confiscated, their pay withheld, their hours made too long and suffer sexual abuse. Do not turn your back.

Section Three: The work of a Carer – what the elderly need

3.1 The elderly need a range of services

Whether or not people are elderly, they all have physical, psychological and social needs. Life is partly about finding ways of meeting these. With clients, some needs can be met through self-help and help from the people closest to them. But they usually have several unmet needs. Some of these can be met by government or NGO services.

In more developed regions, among the services you might find are:

- support groups for clients and their families
- paid home cleaners
- social, educational and sporting clubs
- centres that provide day care, respite care, or residential care for those too ill to be looked after at home
- providers of telephones with alarm buttons
- services that provide meals
- HIV care kits
- laundry services
- accessible transport
- home adaptations or insulation services

Building up your own district-wide list of services & resources

Many of the services listed above are probably not in place where you live. A client is lucky if they live in a region with a few basic services. Sometimes the lack of one service makes other facilities unusable, for example if there is no transport or no interpreter. In poorer regions there may be hardly any services at all.

It is important to gain a broad understanding of what services and facilities are available in your district (see the Exercise in Section 2.2). You will need this when clients require information and encouragement to take the next step and, after that, further steps. People need different services as they age and change.

If you work with an NGO and are faced with a clear need but no services, you can consider these possibilities:

- finding creative solutions within family and neighbours
- starting services yourselves
- supporting Advocacy groups
- supporting existing groups that are managed by those involved – e.g. spaces for meetings set up for the elderly, or educational groups organised by retired people

Example» *In Australia, Men's Groups, mainly retired people, meet up once a week in 'Men's Sheds'; one of their occupations is to gather dead wood from public forests, chop it up and distribute it to people with wood-burning stoves who cannot afford to purchase fuel.*

3.2 The elderly need work or occupation

It is sometimes assumed that older people cannot work. But work means engaging oneself in something useful, whether or not it is paid. Most people have an important need to do this as long as they can.

Think of those you know who have had to stop with their job – perhaps a male who reached retirement age; a mother whose children have left home; a gardener who had a heart attack. Many people find it difficult when they have to stop against their wishes.

On the other hand, some elderly people may be unable to retire even if they want to, because they do not have savings or a pension.

3.3 The elderly need good nutrition

For a number of reasons the elderly often eat badly. They may be:

- **physically unable** to get out and shop, or to do the cooking.
- **without appetite** owing to e.g. depression, medications, or problems with digestion.
- having difficulty eating due to **problems with teeth**. (You may find "Where there is no Dentist" helpful, downloadable from http://hesperian.org/books-and-resources)
- **unable to afford** the food they need.

Sometimes the elderly person is part of a family or social group that does not prepare the kind of food they need – e.g. living with a son and his wife who work long hours and bring back sugary drinks and biscuits for the evening meal; or there is one communal dish and the younger people eat faster. Or perhaps they live on their own and have no wish to cook etc. In this case they would benefit from sharing tasks with others.

Knowledge of what is available in your district will enable you to recommend food that is affordable as well as nutritious. Eating the 'right' food will help the elderly maintain their levels of energy, resist infections and chronic conditions, heal and recover more quickly. Elderly people should eat:

- Enough of the foods that supply **energy**, e.g. cereals including rice and maize, bread and potatoes. If the foods are whole grain they will provide more nutrition – and fibre, which prevents constipation and weight gain.
- Plenty of **fruit and vegetables**
- Some **dairy** food daily such as milk, yoghourt, cheese; these foods help keep bones strong in combination with sunshine
- Some **protein** daily – e.g. beans, eggs, (meat and fish for the rich and non-vegetarians)
- **Limited** amounts only of fatty food, sugar and salt. This includes almost all processed or 'convenience' foods e.g. shop biscuits. Small amounts are good for energy but too

much can upset the working of the body and promote chronic diseases – and many people eat far too much of these things.

- Enough **water** or other non-sugary drinks. Alcohol should be limited to a few glasses a week.
- Elderly people do better with five or six **small meals** a day rather than one or two big meals.
- **Sunlight** works with diet to keeps bones strong, so the elderly need to get outside and catch some sunlight each day.

For more information, *"Good nutrition in later life"* can be downloaded from http://www.helpage.org/resources/practical-guidelines/health-and-care-guidelines/

3.4 The elderly need to keep mobile through exercise

Every elderly client needs to stay mobile as long as possible. It is a key part of staying independent. Within the house, this means being able to get in and out of bed, move from the kitchen to one's sitting place, make tea, open the door for a visitor or use a phone, etc.

Some elderly people may have little mobility. They may need Carers and/or pulleys or other devices to help with essential movements such as getting in and out of bed or a bath. After an episode such as a fall or stroke, therapy is needed to help restore mobility.

Physical exercise:

People need to work at staying mobile and fit as they get older. Following an illness or accident, a healthy body will recover more speedily and help the mind to keep active. And a positive mental attitude will help physical recovery.

For these reasons, almost every client needs to have exercise included in their care plan. For any individual or group, different physical activities can be identified and supported.

However, some clients may be unwilling. They may never have done regular physical exercise before. Think of ways to encourage them to give it a go. If clients can participate in activities that make them feel good, they are more likely to continue. Often this means an activity that is familiar – e.g. a local dance session that friends have gone to. It can help when there is a social as well as a physical aspect, e.g. after the dancing everyone enjoys lemonade and gossip.

Strength and stamina can be built or maintained by, for example, swimming, using weights or riding exercise bikes. Carers can develop local methods that make expensive equipment unnecessary: e.g. tins and wooden bars can be used for weightlifting; a normal bicycle can be anchored on the ground.

For the very elderly and those with little mobility or arthritis, a good start would be a programme of gentle stretching exercises, some which can be done sitting. This could be done with helpers at home or in a group. They could eventually progress to other activities such as short walks.

Different activities contribute in differing ways to a person's fitness. Find out about activities and gentle exercises that can benefit flexibility and suppleness, heart functioning, digestion, sleep, hand-eye co-ordination or breathing. For example there are different yoga practices that can help with all these, as well as all-round mental and psychological health.

Example» **Sally's exercise classes for elderly clients with various problems**

Sally runs an exercise class which is suitable for different groups, including people recovering from a stroke or heart bypass operation and people with chronic conditions such as diabetes.

This sixty-minute "circuit class with stations" takes place in a room or open space big enough for the class to walk or run round. Sally takes up to 40 participants who split into groups of two or three for each of the station exercises. By the walls are the stations, with a notice by each explaining the exercise to be done there.

The exercises can all be done by beginners but can be carried out faster or harder by the fitter clients.

When Sally blows her whistle, everyone moves to the next station. A good tape of music helps keep up the energy and concentration. Clients bring water and are given breaks to take a drink.Towards the end everyone slows down and stretches.

Online are many useful **free instructional videos**, from individual exercises to whole classes suitable for the elderly. For example,

- Seated Exercises for Older Adults: www.youtube.com/watch?v=8BcPHWGQO44
- Balance & Coordination Exercises for Seniors: www.youtube.com/watch?v=QLU0P1mIosA
- Actively Aging with Energizing Chair Yoga: www.youtube.com/watch?v=k4ST1j9PfrA
- Daily Qigong - 4 minute exercise: www.youtube.com/watch?v=EaEZVfhn07o

3.5 The elderly need helpful devices when their mobility is reduced

Keeping the elderly mobile – and safe – in their own home should be seen as a priority. There are many devices which are cheap to make and can effectively enlarge an elderly person's range of activities – such as walking frames, sticks, tripods, grab-rails on steps and stairs, raised seats on toilet pedestals, commodes (chairs with removable potties in the seat for indoor use) etc.

For your Care Plan, consider the simple low-tech aids and adaptations that can ensure your client retains as much physical independence as possible. Do research into what is available, or can be improvised, in your region.

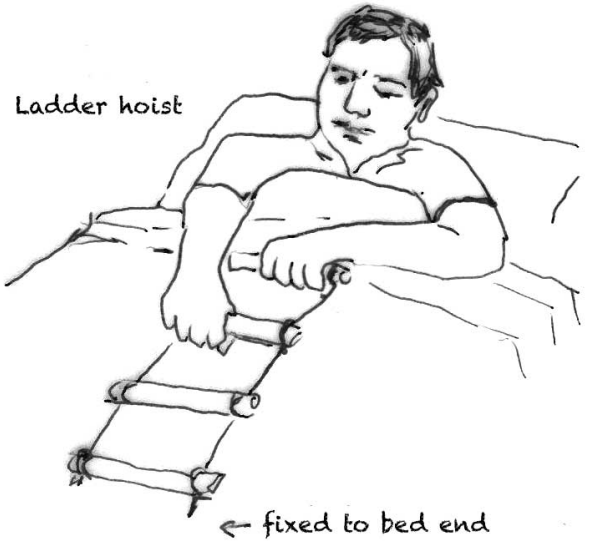
Example» **A "grabber"**

This device can help an elderly person to pick up something they have dropped or to reach under the bed – or a high shelf where their helper placed their food package. Check that the client can stay balanced when they use one.

mechanical grabber

Example» **A bed ladder hoist**

This can be a very useful device for a client whose mobility is more limited and needs a small amount of support in order to come to a sitting position.



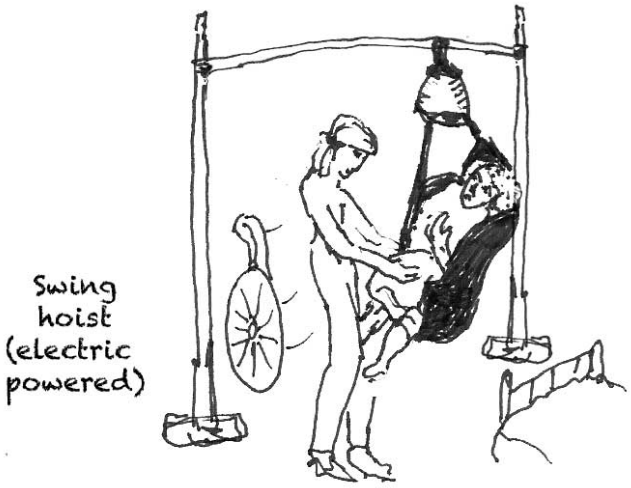
Bear in mind there may be **hidden dangers** for the client using the device – resulting in sores, for example. Therefore:

- Carers must be vigilant and aware of pressure areas.
- The device needs to be checked regularly to make sure it is not broken or worn.
- Also regularly check that the device still matches the client's needs. Clients change over time – some get better and some get worse. Perhaps, after a time, using the grabber stops the client from using their hands enough, in which case it may need to be put away.
- Another factor is cleanliness. Not only the devices but the surroundings of the client need to be cleaned regularly.

Some devices are extremely useful yet quite **difficult to use in practice**.

Example» **A swing hoist**

This is based on a simple idea, even if the types used in the North are technically complicated. Such a device can be used to swing someone in and out of a chair, bed or bath – or help get them using their feet.



It is very important, with this or indeed any device, that Carers **take the client's role** at least once and use the hoist (or grabber, bed ladder, etc.) themselves in order to experience what it is actually like for the client.

Too often, when clients are asked what it is like using such a device, they say that they feel helpless and ignored, or treated like a baby or object. When in a wheelchair or a hoist, people may talk across their heads as if they are invisible. The elderly person may be tipped or bumped around as if they have no feelings, at risk of falling or bruising. It is a big lesson for Carers to go through the experience of being handled by others. Having really experienced this for themselves, they will be more effective in building the confidence of a client when a new aid is introduced.

- Carers need to **explain** the actions they are going to carry out each time they use a device such as a hoist.
- The client can be asked to **participate**, perhaps by leaning in the most helpful way – this gives a nervous individual something on which to focus.

Digital devices

In many parts of the world, mobile phones are becoming the technology most used for keeping in touch and getting help when needed etc. Many elderly people cannot manage much of the new technology and cost remains an issue. However a simple telephone can be programmed to do a few vital tasks which can make a difference: for example, to call the number of Emergency Care via a single button press; or to ring when medication needs to be taken.

A loan service for devices?

At the beginning of this section it was suggested that you build up a list of services and resources available in your district – and that if you work with an NGO and are faced with a clear need but no services, you could consider providing such a service. One service that is needed in many districts is **loans of equipment**. The kinds of devices needed by the elderly overlap with those needed by the disabled, so the service could cater for both groups.

3.6 The elderly need help when their mental ability starts to fail

Dementia is the word used to describe the loss of mental capabilities in old age. It can include some or all of the following:

- Forgetting things
- Misplacing things
- Muddling speech
- Getting lost
- Mood changes
- States of sadness, anxiety or aggressiveness.

If these symptoms are recognised, the Carer needs to check whether they are not just the result of the client's life being disrupted in some way. The symptoms can be triggered by other causes.

> ***Example»*** *Joan is a widow. Her children had all moved away from the home town. They told her she needed to move near one of her children and very soon found her a new flat, packed her up and moved her. She was confused and angry and for several months her speech became muddled up.*

When an elderly person shows symptoms for the first time, or after a gap with no symptoms, Carers should perform the following checks:

- check for **physical causes** such as constipation.
- check the physical **environment** – perhaps they normally sit with a view through a window and somebody moved the chair.
- check whether their **routine** has been disrupted.

- check whether there is **interference** from over-anxious relatives or too-rigid staff who may be e.g. overmedicating a condition.

For an elderly person with dementia, the following **interventions** slow the progress of the condition:

- Cognitive behaviour therapy (CBT).
- Exercise (physical and mental)
- Group therapies with games to help the mind
- 'Reminiscent therapy': taking clients back to their past by e.g. handling objects or singing old songs. This can trigger better memory and word use.
- Depression or aggression may be controllable by more specialist therapy or medication. If the condition is serious it may be impossible for the client to stay in their home or facility.

More information: http://www.alz.co.uk/caring-for-a-person-with-dementia

Example» **A father with Alzheimer's**

Mia realised that her father had a problem when he went out for his routine walks and started getting lost. Then he began losing things in his house.

So Mia invited her father to move into her house. Soon their relationship began to change – in fact their roles reversed as she became his Carer and he, the father, became the cared-for.

Luckily they had a good, loving relationship to build on. In the first stages of his illness there was still room for lots of joy and happiness, with jokes and laughter.

But over the years there was a slow decline as Mia's father lost the ability to do things, changed in personality, and eventually began to need round-the-clock care. For five years Mia continued to work part-time.

Mia found it really helped to have a structure for the day: "at this time you go out for a walk around the house, at this time you take your medication and then get yourself lunch". She would remind him via their mobile phones. Once she had a timetable that her father was happy with, it was important to stick to it and be consistent.

Her father needed as much stimulation as possible during the day. Otherwise he would just sleep. Music made him happy and soothed him; he remembered all the words of old songs and liked singing. It helped to cuddle or stroke him. He had his tasks in the home such as the washing up (though Mia usually had to do the tasks again). Jokes could be told over and over because he forgot them immediately.

As he got worse her father would come into her room repeatedly during the night saying he was going out to visit his (dead) brother. She found that if he had enough exercise during the day it ensured he kept sleeping at night. But she needed respite, even though it

made her feel guilty. Helpers would come in for one night a week, then gradually for longer periods. Her father developed health complications which meant some stays in hospital but the care available in the geriatric wards was very poor.

Outside Carers had to be taught to engage with him person to person – to make direct eye contact and to talk in a friendly, respectful way. They needed to explain what they were doing before they did it, whether it was giving an injection or washing a part of his body.

Mia's father died quietly in his sleep.

3.7 The elderly need Carers who keep good records

Keeping records helps keep the client central and ensures that:

- you, the current Carer, remain actively involved with the client.
- the client knows that his/her opinion is important and was written down.
- any future Carers will know what was agreed to.

Records need to be kept of each new development – for example, when a client agrees to a change in their care. Always record a summary of the client's comments, too – and ask them to check and agree that you have recorded them correctly and accurately. Provide feedback to the client as much as possible.

Records should always be:

- **readable**
- **authenticated** (with date, time and signature).
- **accurate**, with factual data.
- **relevant** and truthful.
- **complete**, with full details of care and treatment including identified risks.
- **protected**, with measures taken so that confidentiality is maintained.
- **original** (any alterations must be signed and dated).

Records and literacy

When programmes are set up, the organisers often want records to be kept in a certain format. This can mean they insist on workers who are literate. However they should consider the following:

- In many countries, insisting on literacy screens out the poorest, including most women. These may be the groups that the project most needs to involve.
- Record-keeping systems based on pictograms have been developed which can be used effectively by non-literates.
- Alternatively, non-literate workers can find a literate helper – a relative or neighbour – who can help them fill in key information.

Section Four: Making and implementing a Care Plan

Every Care Plan will vary according to individual circumstances. This Section lists typical important considerations. To what extent is each item relevant for your clients – and is it covered in the Care Plans you are currently using?

4.1 Coping with a diagnosis

A generation ago, certain conditions like cancer or syphilis were barely mentioned. The hospital may have informed the family of the condition but did not tell the patient. Now everyone agrees that clients need to be fully informed about their diagnosis, even if it is bad news. They have the right to know.

In your culture, what are the words that continue to carry great fear? How would you respond if you were told that your father or mother has Alzheimer's… or cancer… or in some other way terminally ill?

Imagine that a family have just been told some bad news – how can you help? The first thing you can always do is take time to listen. Sit in silence when you hear their story, making sure you have an open posture that encourages communication.

The family and/or the client may have an initial reaction that includes one or all of the following:

- shock
- anger
- denial – a refusal to acknowledge the issues
- fear of losing someone beloved or fear of that person becoming different
- fear of the consequences, including expanding costs and dependency
- demands for more information about the condition, its symptoms, treatments and long-term outcome
- tears and no words
- requests for emotional support

As a Carer from outside the home, your initial role is to accept every reaction and be supportive. There will be time tomorrow to get realistic. Clients and others will make it clear when they want to hear more. Tomorrow or the next day they will start looking for a better understanding of what is happening, and start planning for the future.

4.2 Setting reasonable expectations

After a certain time, the client and family start to accept the diagnosis. Now there needs to be a period of discussion.

What are the future possibilities and difficulties? Perhaps the client has to accept that independent living is in doubt – that it will not be possible without a lot of help and money. Perhaps the only source of help is a relative they dislike. These types of issues need

negotiation. A spirit of good will, with a sense of working together towards the best solutions, needs to be established.

An issue that may come up is that you, the Carer, believe you know what is best but the client has other ideas.

Problem analysis: Once the Carer and client have sorted out what the "reasonable expectations" are, a thorough 'Problem analysis' should be done. This will support the creation of a practical Care Plan. The problem analysis takes into consideration the total reality of the client's problems and what is possible within a specific culture and a specific budget. Never forget that at its centre is the client's identity – a unique set of needs and abilities.

4.3 Setting goals for the Care Plan

The goals you set will depend on the client and their problems – so always involve the client in setting goals! Everyone has the capacity to make their own decisions until proven otherwise.

Example» **Overall and Specific Goals**

Irma is a middle-aged widow living alone, who has had a stroke. This has affected her right side and she has difficulties with household tasks. The hospital physiotherapist says that if she follows a programme of hospital-based physiotherapy, and does certain daily physical exercises on her own, she will regain ability. She also needs a diet with fewer calories and less fat to reduce the risk of another stroke.

Irma and her Carers together set the following goals:

Overall goal – to help Irma stay independent, by:

1. *preventing further strokes*
2. *helping her regain hand skills, and*
3. *helping her get fitter by exercise and diet*

Specific goals:

1. *to ensure Irma attends all the physiotherapy appointments by having her family arrange the* ***transport***
2. *to make her kitchen as* ***adapted*** *as possible to her limitations*
3. *to find ways for her to* ***exercise*** *regularly*
4. *to keep central her position as a* ***loved*** *mother and aunt*
5. *to discuss with the family how to support Irma in* ***caring for herself*** *– not to take away her abilities and independence*
6. *to ensure that any support does* ***not burden just one*** *family member. A chart on the wall might help with this.*
7. *to make a month-long* ***meal plan*** *that includes some meals cooked by Irma plus others that the family bring in. The meals have to suit Irma's taste but also help her lose weight. Another big chart will be made for this and put on her wall. Agree a*

suitable positive affirmation to write on it, e.g. "I eat super food for super health!"

8. *to ensure Irma stays **in control** of when and what she eats*

When Irma returns home she will find cooking tricky with only the one hand working properly. The potatoes will be badly peeled, the kitchen will be messy. But the family and Carer must not move in and take over. Irma will get more skilled. She wants – and has the right to – independent living, as part of her human rights. Sometimes she will act scared and helpless but people must not take over her tasks.

4.4 Agreeing responsibilities

The client should be encouraged to take as much responsibility as possible in accessing services and facilities.

There needs to be agreement on the extent to which the client has responsibility for any activity that is planned. The family, if there is one, should also be involved in order to decide on their share of responsibilities.

Carers need to remain aware that they should not take on a responsibility that someone else could do. Most Carers are overburdened to start with – and it is not in the interest of the client to do things for them which they could do themselves.

4.5 Awareness of barriers to using services

There are various kinds of barriers that can often prevent clients using services that are available. The individual may need help with strategies to overcome these:

Physical barriers:
- stairs or lack of ramps
- lifts whose controls are out of reach
- lack of adapted toilets, etc.

Technology barriers:
- computers
- mobile phones, etc.

Psychological barriers:
- fear of losing independence
- anxiety about being cared for by others
- a perceived stigma
- services delivered in a patronising way
- lack of confidentiality for information communication etc.

Barriers associated with mental ill-health:
- unreasonable fear of authority or discussing personal information, etc.

Financial barriers:
- charges/fees
- lack of transport
- too great a demand for services, or under-resourced services

Social & cultural barriers:

- discrimination
- social exclusion
- language barriers, e.g. services or information in majority language only
- concepts about modesty
- clients wanting care only from same-sex providers
- treatments being unacceptable culturally.

You should have a broad knowledge of what services and facilities are available in order to inform clients.

Example» **Overcoming barriers to using services**

Initially Irma was fairly uncooperative about her Care Plan – she was reluctant even to discuss it. The Carer realised after the meeting that Irma was small, quiet and shy, and had been surrounded by the men of her family who are all big and loud. So afterward she co-opted the matriarch of the family, the first wife, to go through the plan with herself and Irma – slowly and quietly. It became clear that Irma was scared (rightly) that if the family got involved she would get laughed at, treated like a kid and belittled. Strategies were discussed – they included finding Irma a new outfit for going to a movement class (to boost her morale) and for the matriarch to talk separately to key individuals.

4.6 Monitoring & Evaluating

Monitoring is a continuous process, something which you do whenever you visit a client.

For all clients, you can regularly monitor:

- **Health, mobility and general well-being**.
  Any changes should be marked on a check card or otherwise put in writing. These changes might indicate good progress or a decline.
- **Progress towards the Goals agreed in the Care Plan.**
  When Goals are both practical and measurable, they become very useful. With the elderly Irma for example (see Section **4.3**), one Goal was *"to ensure Irma stays in control of when and what she eats"* – this is something you can monitor easily on a visit with just a few questions.

As well as monitoring you need to carry out **periodic reviews** – from time to time, step back from each client and take a longer view of them, their home, helpers and devices. Is everything going well – or is it time to change and adapt? Are you sure that everyone is getting the best help available?

Evaluating needs to be done less often but is just as important. In an evaluation you reconsider the goals that were set at the beginning:

- Did we set the right Overall Goal?
- Were the smaller goals well chosen for achieving this Overall Goal?

For example: did we plan an Overall Goal of ‘Independence’ and then build a bunch of activities that took away all the client’s responsibilities?

Perhaps circumstances have changed and we need to rethink. Consider whether all the goals are still valid and whether it is time to adapt one or more goals.

4.7 Saying goodbye

Some of your clients will need help for the rest of their lives. But some, after a time, will no longer need you. This should be reflected in the Goals and the Care Plan. With someone who has been operated on for cataracts, for example, the goal might be: to help them until they are seeing and carrying out normal tasks independently.

If the client is reluctant to return to independence you could put a time frame on the Goals – agree to help them, say, for six weeks. When the time comes to say goodbye, it is worthwhile acknowledging that you have completed a task.

At other times you will have clients who die. Feeling sadness is normal. It is worth talking it over with your supervisor or support group.

EXERCISE:

- If you worked through exercise **2.1** go and look at it again and at your notes. — Have you learnt since then? Give yourself a pat if you think you know a lot more now.

Section Five: The politics around ageing

5.1 The grey 'time bomb' for the economy

In many countries, the elderly are growing faster in number than any other group. This makes demands on the economy of those lands. Elderly people are usually no longer in work and contributing taxes but instead receiving state services and/or pension. And more of them are living longer. In particular, health services have to meet increasing demands for their care.

- In the UK, over 20% of the total health care budget goes on costs incurred during the last year of life.
- Some years ago in China, the government passed laws which limited families to having only one child. Now they are wondering who will keep the economy productive enough to pay the pensions, keep the nursing homes going etc. They are starting to permit some groups to have second babies.

5.2 The elderly, state pensions and power

In the South, the proportion of people with occupational pensions is very small. A number of countries are now paying state pensions to everyone over a certain age, most notably in South America, e.g. Mexico, Bolivia and Brazil. Other countries with a pension scheme include South Africa and, despite its poverty, Nepal. The amount may be small but it makes a big psychological difference to both the elderly and their families. It is hoped that the potentially powerful voice of this group – backed by its numbers, its spending power and its ability to vote – will be heard increasingly widely.

- Global AgeWatch has developed a 'Wellbeing Index' for the elderly, based on a mix of measurements that include income security, health, education, employment opportunities, and social connectedness. Check it to see how well your own country is doing: www.helpage.org/global-agewatch

5.3 Whose data counts? The invisibility of older people in data sets

Despite initiatives such as the Wellbeing Index, many data collection systems have upper age limits: above a certain age people are not included – they become "invisible". This means the elderly are often left out of development policy-making and its implementation. For example:

- Labour force surveys collect data for working people of all ages, but information is rarely broken down to show the numbers over 65.
- Data may fail to be broken down in other important ways – e.g. to show that a lot of the elderly are also poor and in rural areas.
- Official records of HIV status in many countries stop at age 49. So there are no HIV strategies to meet the needs of older HIV-positive men and women.

5.4 Ethical Issues around End of Life (EOL) care

Health professionals work in a sector that has overall budget limits. A lot of what they do for the elderly extends life – but often this does not provide a life of sufficient quality. Every hospital has a group of very elderly bed-bound patients, who have no hope of returning to independent living. These patients (if they can talk) may express their helplessness and frustration. For some, being kept alive may feel very negative – not because they suffer, but because they suffer in a way that seems to have no meaning. Some patients want the choice of ending their own lives. But only in a few countries, for example the Netherlands and Switzerland, is this legal.

Health professionals believe that patients must have autonomy – i.e. the freedom to decide about their own treatment. However around half of their patients aged over 85 will likely have dementia and be unable to make meaningful decisions. When patients are not capable of making decisions, the burden passes to their next-of-kin – who are often overwhelmed. And the different health professionals involved have different ethical codes they are trying to follow when making decisions about end-of-life care.

5.5 Carers, Gender and Ageing

Factors linked to Gender are important in the business of caring. In most cultures, caring is seen as an activity belonging to women. Often, little girls are taught early on that looking after both girls and boys is part of what they do. A majority of the workers in the caring professions – nurses, physiotherapists, social workers – are female. The characteristics of these professions are:

- The workers get lower pay than workers in jobs which are male-dominated
- Men occupy many of the management posts
- The job carries little status. Consider how, in your country, nurses are regarded compared to doctors. Compare the political clout of the two professions.

So, when the professions working in care need to bring about change for their clients, they may have to fight twice as hard.

5.6 Institutions that can help – or harm

“Institutionalisation” is a fairly new word. It describes the damaging effects of long-term housing in old-age homes, hospitals, prisons, orphanages, etc. And although it is now a known problem, the use of institutions is increasing, for the elderly as well as other groups. Everywhere it is seen that older people who are moved to Homes tend to function less well and are more likely to die quickly. Not only the uprooting itself but an often poor standard of care given, even in rich countries’ nursing homes, can be lethal.

Most individuals do better if they stay in their **own family** – even if that creates problems. Most normally functioning families are used to having problems, after all. If staying within their own family is not possible, the next best alternative is **fostering** – the placing of the elderly individual in an unrelated but suitable caring family, under supervision, for which the foster parents receive some payment. This is a relatively new approach for the dependent elderly, with much promise.

Section Six: Resources and References

6.1 HelpAge International

This "global movement for the rights of older people", offer a series of **Practical guidelines** covering Emergencies, HIV and AIDs, Health and care, Rights and Advocacy. You can use them for your own work and training or as a basis for producing more detailed, locally relevant materials:

» www.helpage.org/resources/practical-guidelines/

Their international newsletter, ***Ageways***, published twice a year, contains practical information on ageing and development, and shares good practice for those working with older people:

» www.helpage.org/resources/helpage-newsletters/?nl_id=5447dd5e81484

More HelpAge newsletters (regional and project):

» www.helpage.org/resources/helpage-newsletters/

6.2 Networklearning

The following **manuals** may be relevant to your work. They are free to download from the Networklearning Library (networklearning.org):

» *Finding Mental Health after Conflict* (also in Arabic) – this manual is written for workers in districts where there has been a war or natural catastrophe, and where no services exist.
www.networklearning.org/index.php/library/finding-mental-health-after-conflict

» *Interviewing & Counselling at the Grass Roots* (also in Arabic, French and Somali)
www.networklearning.org/index.php/library/interviewing-counselling-at-the-grass-roots

» *How to Build a Good Small NGO* (also in Arabic, French and Vietnamese)
www.networklearning.org/index.php/library/how-to-build-a-good-small-ngo

» *Free Online Higher Education* (news article)
www.networklearning.org/index.php/blog/networklearning-news/221-free-online-higher-education

For **Record keeping and non-literates** (Section 3.7), see Chapter 7 of *Testing and Evaluating Manuals* (also in French):

www.networklearning.org/index.php/library/testing-and-evaluating-manuals

6.3 Hesperian

Many of the **health guides** at Hesperian can be downloaded as PDFs for free or even read online. For further reading on keeping good teeth (Section 3.3) see "Where There Is No Dentist":

» hesperian.org/books-and-resources

6.4 ROLE-PLAYS

Use these role-plays for the Exercise in Section **2.4**.

1. **Two demanding elderly men**
   "*I am Miriam. I was a trained Community Worker. I have a husband and two kids. I used to have a full-time job. But my father and then my father-in-law lost their wives. They are both nearly 70. Neither has ever learned to look after himself. Their families moved them in with me. So I had to give up my own job in order to be their Carer. They are both reasonably healthy but stubborn and demand a high standard of care. Now my health is suffering – the doctor says take it easy. I wish they would start helping – just a little."*

2. **A dignified old couple**
   Anya (68) and Math (67) had five children and a number of grandchildren. They all moved away to find work, and some of them are in and out of prison. The elderly couple owns a small plot of land but are not strong enough to farm it. They live on their two social pensions – these are very small but still they send more than half to their younger relatives. And they pay a small part of the pension into a funeral fund; having a dignified burial is very important for then. But both Anya and Math are clearly too thin. We have been asked to make contact by their neighbours.

3. **A widow, aged 69**
   Hawah is a 69-year-old, a widow. She has arthritis and it's difficult for her to move around. She demands help several times each day from her children (three boys) and lives mainly on the money earned by them doing casual work. They want to get better jobs, get married and move out. But she has got comfortable with her life and with the role of victim, with prayer and gossip. Now we need to talk to her about her responsibility to let her children become more independent.

4. **A solitary man, aged 72**
   "I lost my wife in a car accident. It was my fault. God must hate me. Now I spend most of my time in our hut. I have a small pension which I spend mostly on cigarettes. I do not eat much and hate cooking. I used to go out a bit into the village but I have no friends there now. So now I am happier in the hut". His son has asked us to make contact.

5. **A God-fearing man, aged 67**
   "They call me the Reverend. I, with my wife, have worked all my life in this community in East Africa. But I got diabetes and had a stroke. Now my speech is slower and one leg moves slowly when I walk. I remember so many times, over the years, when I have sinned. Mostly they were small sins. But sometimes I was greedy – for cakes and biscuits. Was the stroke a punishment? Should I take the pills the doctor prescribed – or refuse them and accept what God wants for me?" The man's doctor has asked us to make contact.

6. **80-year-old at risk**
   "I am worried. Duka, my great grandmother, lives alone. She is nearly 80. She had a heart attack and her speech is poor. She is also becoming forgetful and does not eat properly. She does silly things that put her at risk. I am the only family member still living in the same village. Three brothers are in the city. I have five children, aged 14, 12, 9, 8 and 6. I work all day in the market. We do not have any spare money. The children go to school and three of them have quite a lot of homework". She has asked us to make an initial visit.

7. **70-year-old driving the kids mad**
   Sophey lives with her daughter and three children. The local nurse says that she does not fully understand the situation because Sophey has become very self-absorbed. She is miserable and will only talk about her illnesses. This she does in a continuous rush if you talk to her. Her daughter says she goes on for hours. Her grandchildren avoid her and resent her presence. The nurse has asked us to make initial contact.
8. **A TBA with a blind spot**
   Talia is a TBA in her 60s. She has a high reputation in the community for delivering babies safely. Now she has started to visit young men returning from working outside the province. She discusses HIV with them. She carries condoms and speaks her mind. She encourages high-risk women to get tested during pregnancy (and if HIV+ to get anti-viral treatment during childbirth). But she will not wear her latex gloves when delivering, so is running a risk of infection herself. We need to make an initial visit.
9. **A couple in their late 60s**
   Fred and Jan retired when Fred reached 65. Just before, he developed some heart problems – these were not too severe; he got a prescription of pills and exercise. But now he follows Jan around the house and will not go out alone although he is supposed to go walking for his health. She misses her women friends and is going crazy. We need to make an initial visit.
10. **Three destitute older women**
    The village says that there are three old women living together on the edge of the village. They are all widows with no family left in the village. They are very poor. One villager says that they do not come out together because they do not have enough clothes for all three to be decent at once. Sometimes one or two of them walk to the town to beg by the buildings where they hold religious services. But today they are all at home. We need to visit.
11. **A struggling elderly couple**
    Thomas and his wife are both 66. They receive two pensions, Thomas feels that they are much less well-off than they used to be and that life is a struggle: “All your money is gone on just the basics”. Thomas has various health problems, including breathlessness, and receives medication free of charge from a nearby government clinic. But he has little faith in government doctors, so prefers to pay for private consultations and medicines from the private pharmacy. We are making an initial visit.

6.5 CHECK-LIST FOR INTERVIEWING SKILLS

Did the interviewer do the following?	Yes	No
1. Welcome the client politely		
2. Use clear language		
3. Have good positioning and body language		
4. Ask good questions and listen well		
5. Show respect		
6. Sort out the main problems and priorities		
7. Give good information		
8. Be clear about who will do what		
9. Make a further appointment		
10. Say goodbye nicely		