

Psychosocial care and support for older carers of orphaned and vulnerable children: Programming guidelines



Acknowledgements

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- Ministry of Local Government, Community Development Office, Luwero
- Red Cross Uganda
- Uganda Moslem Supreme Council
- Uganda Reach the Aged Association
- Women Organisation, Luwero District

HelpAge International helps older people claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives.

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Foreword

REPSSI is a regional non-governmental organisation working with partners to promote psychosocial care and support (PSS) for children affected by HIV and AIDS, poverty and conflict in East and Southern Africa. REPSSI advocates that services, programmes and policies designed to support vulnerable communities need to respond holistically to the needs and rights of children and communities. HelpAge's vision is to ensure that the needs and rights of older people in Africa are addressed and met so that they can continue to enhance their capacity in the community. As outlined in our strategy for 2010-2015, we are working towards ensuring a major increase in the delivery of quality health, HIV and AIDS and care services for older people and those they support. The role of older people in our societies is often overlooked. As HelpAge, we are committed to ensuring that older people are valued, not just in terms of their human rights, but for their contributions in society.

Currently, the African continent is burdened by the impact of HIV and AIDS, among other challenges. A major impact of HIV and AIDS on older people is in their role as caregivers to their children living with AIDS and grandchildren who have been left as orphans as a result of AIDS. In many African countries it is mostly the grandmothers who have assumed the parenting/caring role. This has resulted in a drastic change in the traditional family structures in Africa. Older people can no longer rely on their families in their old age for support, partly because they have additional responsibilities as income earners and caregivers for orphaned and vulnerable children.

UNAIDS/WHO (2008) estimated that 12 million children have lost one or both parents to HIV in sub-Saharan Africa, and UNICEF and HelpAge studies indicate that at least 40 – 60 per cent of children orphaned by AIDS are being cared for an older caregiver, mainly older women. As they perform the caring role, older carers encounter a number of problems including lack of knowledge on HIV and AIDS, poverty, stigma, grief and hopelessness. These problems may consequently affect their psychosocial wellbeing.

In recognition of the need to address the psychosocial needs of older caregivers HelpAge collaborated with REPSSI to develop Policy Guidelines and a Programming Guidelines for Psychosocial Care and Support for Older Carers of Orphaned and Vulnerable Children affected by HIV and AIDS. The Policy Guidelines document is intended to offer a concise description of the concept of psychosocial support and how it relates to older caregivers of orphaned and vulnerable children in a time of HIV and AIDS. It offers recommended strategic focus areas which may be used to influence policies which provide support for older carers. Policy makers may find the guidelines helpful in providing ideas to effect changes that will improve the wellbeing of older carers. The guidelines include resource materials to enable community caregivers, development facilitators, educators and peer counselors to have relevant information and guidance on strengthening psychosocial care and support to older carers.

We hope that these guidelines will provide the necessary information to offer much-needed psychosocial support to older carers and support older people as they tackle the added roles they now have of caring for the sick, orphans and vulnerable children.

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Introduction

“But then there emerged – suddenly, almost miraculously, magnificently – one solid wall of protection, a wall so strong that it withstood all the misfortune heaped on the orphans of Africa. It is the wall of grandmothers. You couldn’t penetrate it. You couldn’t destroy it. It stands today as the protective embrace for the orphan children of the continent.” Stephen Lewis

These words by Stephen Lewis, addressing the African Grandmothers’ gathering in Swaziland on the 6th of May 2010, so movingly describe the role of older carers in bringing hope to the HIV and AIDS pandemic. Older carers are playing an increasingly valuable role in caring for children who have lost their parents due to AIDS and other illnesses. Such older carers include grandmothers, grandfathers, older aunts and uncles, and even neighbours. It is becoming recognised that older carers have become the backbone of support to orphaned and vulnerable children and people living with HIV and AIDS.

HelpAge International (HelpAge) conducted a baseline survey amongst selected regions of 11 Sub-Saharan African countries. They found that older carers are providing on average 55 per cent of the care to children orphaned by AIDS and 44 per cent of the care of family members who are chronically ill or living with AIDS. Older people have taken on the triple roles of carer, homemaker and income earner in many households. In the same baseline survey, HelpAge found that on average each older carer is caring for 3 orphaned children¹. The number of men becoming involved in this care is also growing. HelpAge studies show that 80 per cent of older carers are female and 20 per cent are male.

*“It is a great privilege to be able to look after my grandchildren. At least I feel that I am able to do something for my own children who have passed on.”
Older carer*

“The children bring a lot of energy and joy into the home. They are keeping me young.” Older carer

“Although I would never have invited this disease into my household, I feel that it is a gift to have my children back at home with me, and I am glad that I am able to be there for them at their time of greatest need.” Older carer

Many older carers describe the joy they experience in caring for grandchildren. Others speak of being grateful to be able to be the ones who care for sick family members in their time of need. At the same time, many have said that they would appreciate more support in managing these challenging roles. In consultation sessions, older carers have spoken of the need for both practical support and love and care. As one older carer said it beautifully “As older people we need to be visited and to know that we are loved.” These resource materials offer ideas for both practical and psychosocial care and support of older carers.

¹ *The Burden of Care for Older Women Carers of OVC and PLWA : Key Baseline Indicators for communities in Ethiopia, Kenya, South Africa, Tanzania, Uganda and Zimbabwe, HelpAge, 2006*

Aims and intended users of the guideline

These guidelines were especially developed with the aim of impacting on the wellbeing of older carers living in situations of poverty and in a time of HIV and AIDS.

The aim of this set of resource materials is to enable home based caregivers, development facilitators and peer counsellors to have relevant information and guidance on strengthening psychosocial care and support to older carers. The ideas proposed can be used individually or in groups as resource materials.

Note: While this guideline was developed for people working with older carers who are supporting orphaned and vulnerable children and people living with HIV, it is important to mention that all older people need and deserve psychosocial care and support, not just on the basis of their role as carers.

The structure of the guideline

The guideline comes in eight Units:

Unit 1

This discusses different elements that contribute towards the overall psychosocial wellbeing of older carers, reminding us to pay attention to wellbeing holistically, such as considering the material needs of older carers.

Unit 2

This looks at psychosocial care and support and how community caregivers can practically apply the principles of psychosocial support as they care for older carers.

Unit 3

This unit discusses how community caregivers could help to build social support systems around the older carer and those in their care by encouraging the involvement of family members, neighbours and community members to provide assistance and support to grandparent headed households.

Unit 4

This unit covers how community caregivers can contribute towards the promotion of supportive relationships between older carers and their grandchildren.

Unit 5

This discusses how community caregivers can assist older carers through the process of grieving and adjusting into an environment in which their adult children are no longer there.

Unit 6

This discusses the ways in which community caregivers and older carers could help older carers to protect themselves and the children in their care from abuse and exploitation.

Unit 7

This unit looks at providing support to older male carers.

Unit 8

This unit tackles how community carers and older carers can promote or develop self care skills so as to cope with stress and burnout resultant from their caring responsibilities.

The term “older carers” is used in this document to refer to older people caring for orphaned children and people living with HIV and AIDS.

The term “community caregivers” is used in this document to refer to anyone who is working with families and communities affected by HIV and AIDS.

Each unit begins with an introductory section which gives community caregivers important background information about the topic being discussed.

Each section is accompanied by four types of activities: reflection exercises, case studies, practical application and finally planning exercises and general tips.

Practical exercises

These are activities that you can do individually, with others in your organisation, or with older carers in your community.

Case studies

These provide concrete examples of real-life situations. The case studies provide practical examples as well as aiding reflection on some issues discussed in the units. The reflection questions may be helpful for you to answer as a reader, or to discuss in groups within your organisation.

Action planning

These sections challenge you to make concrete action points or plans to implement what you have learnt. This does not mean that you have to carry the burden of putting your lessons into action all on your own. The responsibility of ensuring the psychosocial wellbeing of older carers is a collective responsibility that should involve your organisation and other stakeholders.

Helpful ideas and tips

These are helpful ideas to assist with future action and practical application.

A range of annexes is appended to this guideline for more detailed reference to issues raised in the unit discussions.

Although the guideline is for both male and female community caregivers and both male and female older carers, the terms “her” or “she” are used for ease of reading the document.

Summary of Key Learning Points

Many older carers describe their appreciation in being able to care for orphaned and vulnerable children and people living with HIV and AIDS. At the same time they have said that they would be grateful for more support in undertaking these roles of caring.

Psychosocial Wellbeing

Older carers have different needs, including the need for adequate shelter, nutritious food, clothing, health care etc – both for themselves and the children and adults in their care. Addressing these needs is important for their overall wellbeing. Making changes at higher levels, like introducing country policies, can help many older carers for the future.

Psychosocial Care and Support of Older Carers

Psychosocial care and support is showing love and respect for older carers. It is connecting them to social support so that they experience everyday care and appreciation from their families and communities.

Family and Community Support

Some of the most meaningful psychosocial support comes from the people in our own families and communities, rather than from outside professionals. Family members and community members can be encouraged to support older carers. Awareness raising about the needs of older carers may help to strengthen the circles of support around the older carer.

Developing Supportive Relationships Between Older Carers and Children

Many older carers consulted in the development of these materials said that they would appreciate support on how to improve their relationships with their grandchildren. This re-emphasises the importance of building a caring and open relationship as a foundation for healthy parenting relationships. This includes showing children that they are loved.

Supporting Grief Processes

The process of grieving for lost loved ones is an important and normal process. Many older carers are grieving the loss of their own children, and they can benefit from being shown care and being given opportunities to heal in their own way.

Protecting Against Abuse and Exploitation

Some older carers and orphaned children may be experiencing abuse and exploitation because of their relative vulnerability. When signs of possible abuse are identified, a sensitive family approach may be helpful to assess and to try to positively change the situation. Relevant authorities and specialist organisations may need to be contacted to assist in ensuring that the rights of older carers and children are upheld.

Supporting Older Male Carers

There is an increase in older men who are involved in caring for children and people living with HIV

and AIDS. As community caregivers we can encourage male involvement in caring. Older male carers may be supported directly, or through the facilitation of support groups for men, and through positively changing the attitudes that prevent men from becoming involved in caring for others.

Self Care

Caring for children and people who are sick can be both rewarding and emotionally exhausting. Older carers may be assisted to take time off from their caring responsibilities and to participate in activities that reduce their stress.



older peoples' rights

are human rights

Unit 1

Psychosocial wellbeing of older carers

This unit covers the following topics:

- *The types of responsibilities and challenges older carers face*
- *An explanation of the concept of psychosocial wellbeing*
- *Factors that contribute towards psychosocial wellbeing*
- *Examples and promising practices of how to meet different needs of older caregivers*

*“It is a heavy load because of the age.”
Older carer*

1.1. Responsibilities of older carers

The responsibilities of older carers are many and they usually include:

- caring for the sick and for young children (such as feeding children, bathing them, administering treatment, taking them to the clinic, etc.)
- meeting costs for medicines, health care, and funerals
- providing food, clothing, and shelter for themselves and for those under their care
- meeting school expenses for children
- socialisation of children
- providing love, affection and protection to children
- comforting children on the death of their parents.

*“I had ideas about how I would like to spend this time of my life. Now I feel like I am starting all over again.”
Older carer*

It is clear that the role played by older carers is very valuable as they contribute significantly to the social capital needed to cope with the impact of HIV and AIDS and other life predicaments on children, families and communities. The reality, however, is that these responsibilities come at a time when older people might be expecting

to receive support from their adult children and families, and instead they find themselves confronted with huge responsibilities of caring for the sick and vulnerable children. This may be overwhelming, both physically, psychologically and socially for the older carers.

1.2. Challenges faced by older carers

Case example:

The CINDI Network (www.cindi.org.za) facilitated a participatory survey to ask older carers what they felt created the most stress in their everyday lives. Their comments were clustered and this is what the older carers said they struggled most with:

- *health care (for themselves and their families)*
- *discipline (especially of adolescents)*
- *materials needs (especially providing food for the family)*
- *school fees and school uniforms*
- *accessing social grants (like pensions and foster care grants) and documents (such as identity documents and birth certificates of children)*

The multiple responsibilities faced by older carers usually lead to certain common challenges, especially when carers are living in under-resourced communities.

Some of the common challenges which older carers experience in trying to provide care for the children and sick people in their household include:

- poverty, social exclusion and discrimination
- lack of regular income to help them with the costs of care, and to avoid distress, sales of assets
- being neglected by special support programmes, which tend to target women and children, rather than older carers
- limited time to engage in income-generating activities due to responsibilities of caring for the sick and young children

- living in dilapidated houses, resulting in insecurity, poor hygiene and limited protection from adverse weather
- difficulties in meeting the educational expenses/needs of their grandchildren
- lack of information and difficulty accessing rights and entitlements
- challenges in parenting and imparting skills to children who belong to a different generation
- difficulties in meeting the emotional, and psychosocial needs of children due to their own experiences of loss and grief
- challenges in keeping healthy and accessing health services for themselves and those in their care
- finding out that they or the children in their care are HIV positive
- lack of information and knowledge about HIV and AIDS
- difficulty to cope with questions of sexuality and reproductive health of the growing grandchildren – especially of boys living with grandmothers
- danger of exposure to neglect and violence.

“Older people want to be visited and to know that they are loved.” Older carer

Older people need psychosocial support so that they are able to better cope with the demands of caring and to enable them to experience personal wellbeing. Ensuring the psychosocial wellbeing of older carers not only ensures their fundamental rights but underpins the very survival of a significant number of children and sick people in their care.

It is important not to make assumptions on behalf of older carers. Rather, we should involve older carers actively in identifying their own needs and priorities for support. Use the following activity with older carers in the community where you work or live.

Practical exercise:

What are the challenges faced by the older carers in your community?

Ask the older carers you work with to discuss in groups the challenges that they face in their lives. They may wish to think about challenges relating to:

- *economic or material needs*
- *health-related issues*
- *their role as caregivers*
- *their relationship with their families*
- *their relationships in the community*
- *emotional needs*

You may wish to discuss:

- *what have the carers found works well in dealing with these challenges?*
- *what are the ways in which carers may be able to support one another to deal with these challenges?*
- *which of their challenges need to be addressed at higher levels, for example with community leaders or government service providers?*

All of the challenges described by the older carers affect their psychosocial wellbeing. The next section looks further at this idea of wellbeing, and gives a structure for assessing the needs of older carers in a holistic way. Ideas are also given about ways in which some of these needs have been addressed by different projects.

1.3. Psychosocial wellbeing

Our overall wellbeing depends on many other things – like the need for food, shelter and clothing. Psychosocial wellbeing is about holistic wellbeing and a sense of feeling complete or satisfied about one’s life. It includes physical, mental, economic, social, emotional and spiritual parts of our lives – which contribute to total wellbeing². If psychosocial wellbeing is to be achieved in the lives of the older carers and those under their care, it is important to ensure that their various challenges and needs are met holistically.

Older carers have different needs and psychosocial wellbeing includes physical, mental, economic, social and emotional needs. It is important to reflect holistically on the wellbeing of older carers.

² REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS treatment*, 2008

Read the table below which categorises the needs of older carers and gives examples of each of these types of needs.

Needs of older carers

Type of needs	Examples	Why this can be a concern for older carers
Physical needs	Food, clothes, shelter. This can also relate to a person's physical health.	Many older carers do not know where the next meal will come from. They live in broken down houses and struggle to access health services. They struggle to provide clothing, school uniforms, books and pay school fees for children in their care.
Economic needs	Source of income, employment and a sustainable livelihood.	Older people make up a significant proportion of the poor in our society. ³ Poverty limits older carers' ability to access food, clothing, water, shelter, health services etc. this causes a lot of psychological stress for older carers as they struggle to care for children and PLHIV. Older carers' may feel inadequate, and may have a sense that they have failed their sick adult children and grand children.
Social needs	To be part of a family or community. It relates to the relationships that one has with others in the family and community. Good relationships allow for relaxation, enjoyment and fun in the company of others. It includes people's need to be listened to, understood and treated with respect. All these relationships are shaped and influenced by culture.	Older people's households which are affected by HIV may experience isolation and discrimination as a result of the stigma associated with the AIDS pandemic.
Spiritual needs	May be met by connecting through religion, poetry, music, meditation or quiet reflection.	Stress and hardships may lead older carers to feel disconnected from God. Many older carers say that they struggle to find time to be part of church groups because of their child care responsibilities.

³ HelpAge International and The HIV/AIDS Alliance, 2003

<p>Emotional needs</p>	<p>To be loved and cared for by others and to offer love and affection in return. To be acknowledged and appreciated, and to be supported to cope with difficulties in the family and community.</p>	<p>Limited social networks result in isolation and thus a lack of caring people to provide older carers with emotional support. Male older carers are especially vulnerable as they have limited social networks.</p>
<p>Cognitive (mental) needs</p>	<p>Opportunities for learning and challenges.</p>	<p>Older carers have been largely excluded and deprived of important information (and skills) including information about HIV and AIDS, palliative care, and parenting.</p>

The wheel of psychosocial wellbeing given below tries to explain how all the elements given above work together to produce a sense of wellness in people’s lives. If one or more of these elements is not adequately addressed this can compromise an individual’s sense of psychosocial wellbeing. Older carers and those under their care are especially vulnerable to a lack of several elements given above.



With a little support

older people can make a big difference

The Wheel of Psychosocial Wellbeing



Explanation of the wheel model

- All needs are equally important and they depend on one another for fulfilment.
- If one of the needs is not met, the wheel is incomplete and therefore cannot function properly. Similarly if any of the needs of older carers are not met this can compromise their psychosocial wellbeing.
- A lack of any of the needs can be a source of psychological and emotional distress for older carers and those in their care and therefore the provision of all needs should be taken seriously.

Adapted from REPSSI, 2007

1.4. Some examples and promising practices of how to meet different needs of older carers

There are many different ways in which we can work towards the psychosocial wellbeing of older carers. We can learn from the ideas that other organisations supporting older carers have tried and tested. The table below shows some of these ideas.

Promising practices of how to meet the different needs of older carers

Programme	Description of Promising Practices
Access to health for older carers - Nazareth Hospital, Kenya	<p>Older carers may be subjected to poor treatment by health workers due to negative attitudes towards ageing. They may have to stand in long queues in hospitals and health centres. Older carers may go away without having received any health services, but will have incurred transport expenses. Medicines are also usually too expensive, or may be unavailable.</p> <p>Nazareth mission hospital started in 1964 and has been running a HIV programme since 2001. The hospital has designed the following interventions to care for older people:</p> <ul style="list-style-type: none"> • provision of a special day for clinic appointments for older carers • prioritisation of older carers' needs • provision of staff that communicate effectively and respectfully with older carers using a language that

	<p>they understand</p> <ul style="list-style-type: none"> • facilitation of support groups for older carers at the hospital • conducts needs-assessment for older carers who come to the hospital to identify needs such as food, clothing, shelter etc • provision of economic support through income generating projects e.g. dairy goat programme and micro finance • offers of pill boxes for older carers to promote adherence to treatment for themselves and those in their care.
<p>Cash transfers/non contributory pensions for older people - Kwa Wazee Project in Tanzania Kagera region</p>	<p>Kwa Wazee began at the end of 2003 as a small-scale project. The aim was to provide poor and vulnerable people over the age of 60 years, including those caring for children without parents, with a regular cash income in the form of pension and child benefits. By the end of 2007 nearly 600 older people were receiving a regular monthly pension of USD5. In addition, the main carers received a child benefit of USD2.50 for each child. They also set up psychosocial support groups in which grand-parents and grand-children met separately to share their experiences. The project has produced the following benefits for older carers and the children in their care:</p> <ul style="list-style-type: none"> • improvement in the food security status and psychosocial wellbeing of older people and children • the proportion of older people who had to sell assets such as farmland has halved • people who received the pension reported improved health • children from homes receiving cash transfers not only ate better but also had enough soap to last most of the month and were absent from school less often • more than 1/4 of pension recipients were able to make modest savings three times more than non pension recipients.
<p>Improving nutrition of older carers and those in their care - Help Age Mozambique and Muthande Society for the Aged (MUSA)</p>	<p>HelpAge partners working in Mozambique in the Tete and Gaza Provinces provide nutritional support to older carers by undertaking the following initiatives:</p> <ul style="list-style-type: none"> • through the support of the World Food Program (WFP), HelpAge Mozambique provides supplementary food to older carers • active older carers are supported in the preparation of fields and the buying of necessary inputs for ploughing and growing food crops • the programme also supports horticulture projects which involve older carers • older carers are supported with goats in a rotation system

	<ul style="list-style-type: none"> • Older carers receive training to enhance their nutrition using local foods. <p>MUSA</p> <ul style="list-style-type: none"> • the programme responds by distributing high protein porridge and providing food to older carers and their families • older carers are educated in nutrition and in how to plan well-balanced meals • MUSA operates drop-in centres in communities for older people to receive a well-balanced meal daily • the program has also started door-sized garden projects for older carers • the local municipality supports MUSA by providing garden implements and seeds which contribute to the garden projects.
<p>Training older people as peer counsellors for HIV - Muthande Society for the Aged (MUSA)</p>	<p>MUSA realised that by training older people as peer educators it would be easier to reach older carers who are affected and infected with HIV. The peer educator’s programme started in October 2007. Selected trainees were trained in the following areas:</p> <ul style="list-style-type: none"> • HIV prevention • signs and symptoms of HIV and AIDS • the importance of antiretroviral therapy and adherence • examining labels and myths about older people, for example as being bewitched • tuberculosis • gastric problems and dementia associated with old age • nutritional supplements • rights to pensions and other benefits • how to recognise and report cases of abuse. <p>Training by MUSA of older people as counsellors and peer educators has provided emotional support, enabling them to cope with their own grief at the death of their adult children or grand children. Older carers also have access to HIV and AIDS support groups.</p>

Comprehensive programmes that address different needs and concerns of older carers have greater impact on the psychosocial wellbeing of older carers and those under their care. It may not be possible for many programs to offer all the services shown above, however it is essential that organisations and government departments work together and complement each other to improve service delivery to older carers and their families.

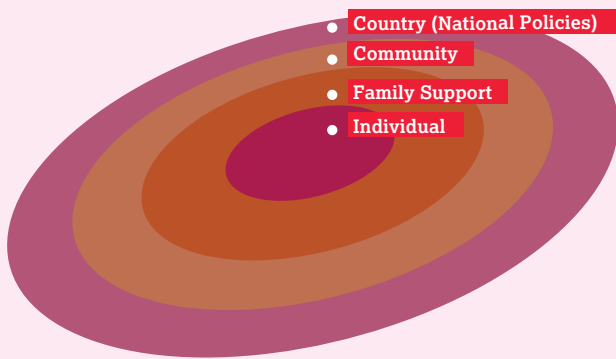
1.5. Levels of addressing psychosocial wellbeing

We have said that psychosocial wellbeing includes many different aspects of our lives, such as physical and material aspects, and psychological, social, cultural and spiritual aspects. The focus of psychosocial wellbeing is therefore not just on the individual, but on households, families and communities.

Your work may be mostly focusing on a community or family level, but it is helpful to bear in mind that there are other ways of supporting older carers. There are also ways of helping older carers directly, and ways of helping many carers in the whole country. There are also ways of preventing exposure to harm of older carers, not just alleviating the suffering that they have already experienced.

Have a look at this diagram and see at which level you are working. There may be other levels of support you would like to think about for the future:

Levels of Support



Individual:

Support is provided directly to older carers. This may include giving material support, grief counselling, parenting skills training etc.

Family:

Here support is provided to improve the wellbeing of the whole family, like helping older carers to have better relationships with the children in their care, helping carers to access grants, grow food gardens, or gain access to free schooling for children.

Community:

The focus at this level is on encouraging the community to give support to all older carers in their community. For example, leadership could encourage positive attitudes and challenge discrimination. Or youth groups or churches could organise child care projects to assist older carers to have time to do their shopping and attend church meetings.

National:

At this level we try to change country laws, policies and programmes to provide support to all older carers. This may include policies about pensions for older carers, special grants, school fee exemptions, and priority health care.

Another way of addressing the various needs of older carers is through networking with other organisations. This means that you do not have to necessarily provide every type of service for older carers, but instead you can refer older carers for different types of support. When doing this, it is important not to simply give older carers an address or contact number for a service. It is better to refer them to a specific person with whom you have developed a mutual working relationship.

We can apply this model of “levels of support” to addressing the material or economic needs of older carers. This next section looks specifically at strengthening economic support of older carers, and how this may be done at the individual, family, community and national level.

1.6. Economic strengthening activities

Older carers may be neglected in economic strengthening programmes, which often tend to focus on men, youth and mothers of young children. The financial stress of caring for people who are sick, or for orphaned children, is often cited by older carers, and is one of their primary sources of stress. Economic strengthening programmes should include older carers. They may be facilitated in a way that builds the income of the older carer, while also facilitating strengthening of social support and dignity.

Economic strengthening activities may include a focus on:

- helping older carers access pensions, child care grants, school fee remission and foster care grants.
- accessing transport, health care and other subsidies for all older people
- sustainable livelihoods and income generating projects
- subsistence agriculture
- encouraging the extended families of older carers to support them financially
- donations of material goods, such as school uniforms for orphaned children.



Teach older people new skills

and they regain their dignity

Access to identity documents in order to access resources such as social grants may be a challenge for older carers, and investing in processes to overcome this challenge may make a sustainable difference to the psychosocial wellbeing of many older carers and the children they support. At a national level, policies to unlock these resources for older carers may be developed and passed as legislation. At a community level, the capacity of community based structures (like traditional leadership,

local municipalities, churches, schools and community-based organisations) may be developed to assist older carers in the community to access these resources. At a family level, conflicts around competition for resources may be resolved, or families may be given information about the resources available and how to help older carers in their family to access them. At an individual level, older carers may be assisted with the application for resources or they may participate directly in economic strengthening projects.

1.7. Action planning

Based on the needs identified by the older carers in your community, list the organisations, groups, and institutions that you are considering working with so that you can provide more holistic care and support services to older carers and those under their care.

Need identified by older carers	Name of organisation	Services they offer to older people, orphaned children and people living with HIV	Contact details

Unit 2

Psychosocial care and support of older carers

This unit covers the following topics:

- *An explanation of psychosocial care and support and other related concepts*
- *The important principles when providing psychosocial care and support to older carers*
- *How community caregivers can practically apply the principles of psychosocial care and support in daily interactions with older carers and their families*

In the previous unit we looked holistically at the needs of older carers. These needs included social, emotional and spiritual needs. The challenges of older carers may put enormous demands on their emotional and social wellbeing. This unit looks more specifically at ways of addressing these emotional and social needs of older carers. We refer to this specific aspect of addressing wellbeing as “psychosocial care and support”.

2.1. What is psychosocial care and support?

The word “psychosocial” comes from two words: psycho and social.

- Psycho refers to our thoughts, feelings, beliefs, attitudes and values. These things cannot be seen or heard by anyone—they exist “inside” each one of us.
- Social refers to our relationships with our family, community, workplace and friends. It is often linked to the African concept of “ubuntu” – “I am, because we are, and we are, because I am”.
- The psycho (internal) part and social (relational) part interact and influence each other all the time. A person therefore has both “psycho” and “social” needs. If these needs are not met, it will affect the psychosocial health of that person and consequently the overall wellbeing of the individual. This can also impact on others in the household.

*“The children are crying, especially at bedtime.”
Older carer*

4 *Mainstreaming Psychosocial Support within Paediatric HIV and AIDS Treatment, REPSI, 2008*

5 *Richter, Foster and Sherr: Where the heart is. Bernard Van Leer Foundation, 2006*

Psychosocial care and support is expressed through caring and nurturing relationships that communicate understanding, unconditional love, tolerance and acceptance⁴.

The most important, powerful and long lasting form of psychosocial care and support is provided in people’s daily lives by family members, friends, neighbours, and community members⁵. All carers and children have a right to psychosocial care and support.

Psychosocial care and support is about enhancing the social and emotional wellbeing of older carers.

Psychosocial care and support programmes may enhance the impact of other forms of support for older carers, such as economic strengthening programmes. These programmes enable older carers to be more connected to one another, their families and the community, thus drawing on a range of resources to contribute to their wellbeing and the wellbeing of those in their care.

Practical exercise

Develop your own working definition of psychosocial care and support

In your organisation, present the definitions of psychosocial care and support described above. In groups draw a picture of two older carers from your community. The older carer you draw has many unmet psychosocial needs and the second older carer you draw has good psychosocial wellbeing. Ask the members of the group to write words around the picture of each carer to show how their different psychosocial needs are met or neglected. Discuss these drawings and come up with your own working definition of what psychosocial care and support means in your setting.

2.2. Psychosocial care and support for older carers

Older carers need to feel loved, encouraged, appreciated, and honoured. They need to be supported to cope with the challenges that they experience in their role as carers and be given opportunities to express their thoughts and feelings individually as well as in groups. It is important that older carers feel that they are valued members of families, communities and the larger society.

“I worry a lot about what will happen to the children after I am gone, and my own health is not so good these days.” Older carer

It is possible to provide psychosocial care and support (PSS) in everything you do with older carers. This is about showing care and respect in each interaction you have with carers such that it builds their dignity, reduces their stress and brings hope and appreciation even in difficult circumstances. The following are some ideas of how community caregivers can provide PSS to older carers:

“Older people do not need to be rushed. Treat them with patience and care.” Older carer

- Visit older carers and talk to them. Show them that they are valued.
- Listen respectfully to older carers when they express their concerns, leaving them with the understanding that you have taken them seriously.
- Ask the older carers and those under their care to talk about their needs and find ways to support them to have their needs met (not just the needs you think they have!). Try to follow up on issues until they are resolved and remember to refer matters that you cannot deal with relevant services such as Social Welfare, Home Affairs, Legal Aid etc.
- Identify which types of assistance, support and entitlement programs are already operating in the community which might potentially benefit the older carer and those under her care.
- Promote networks and circles of support around the older carers so as to challenge feelings of loneliness and isolation.
- Provide the older carer with relevant information about HIV and AIDS, their rights and entitlements and how to access important services. Encourage a trusted caring person to help the older carer to remember about health check-ups and to go with the older carer so that the visits to the clinic are less overwhelming.
- Provide space to talk about fears, such as fear of the death of their adult children whom they may be nursing, or worries about what will happen to the children who may remain.

Practical exercise:

What are the psychosocial needs and wishes of older carers in my community?

(Based on the Solution-Focused Approach “Miracle Question”)

Ask the older carers you work with to imagine that when they go to sleep tonight a miracle happens. It is a miracle in which all their wishes are fulfilled. When they wake up, their lives are exactly as they would like them to be. Ask them to think about the following:

- 1. When they wake up in this “perfect” life, how do they know that things have changed?*
- 2. What do they do with their day?*
- 3. How do they behave differently towards the people in their lives?*
- 4. How do others around them behave differently?*

Use these reflections to discuss the psychosocial needs of older carers and any insights which they may have had about their wishes for their lives.

Note to the facilitator: this exercise may initially bring up some sadness and it is helpful to contain this sadness gently without being anxious or rushing to give solutions. Rather, acknowledge the value of their vision and then when the group is ready move on to some discussions about how they might find solutions to eventually reach their vision.

It is helpful if older carers strategise together to find their own ways of improving their psychosocial support, especially the support received from their families and one another. As community caregivers we can assist by facilitating this planning. While you are planning any psychosocial care and support interventions with older carers, it is helpful to keep the following principles in mind.

2.3. Principles to guide your psychosocial care and support work with older carers

The following core concepts about psychosocial care and support of older carers are recommended as foundational principles for all interventions⁶. These principles should guide every intervention aiming to improve the psychosocial support of older carers.

⁶ REPSSI. 2009. *Psychosocial Care and Support Mainstreaming Guide*. www.repssi.org.

Principles of psychosocial support of older carers

Principle of Psychosocial Care and Support	Application of the Principle to Older Carers
Access to rights	Strive to support the protection of older carers and their access to their rights and entitlements.
Respect and kindness	Psychosocial care and support may be provided simply by changing the way we behave towards older carers. This is about showing respect and kindness at all times in a way that builds the dignity of all people.
Participation	Use a participatory approach where older carers are involved in identifying their needs, planning, facilitating and evaluating interventions.
Family-based care	Use a family approach which supports the carer within the context of his or her family environment.
Strengthen existing resources	Start from strengths, by acknowledging the existing knowledge, skills and expertise that the older person brings to each situation.
Build on locally appropriate practices	Research and strengthen locally appropriate ways of supporting older carers so that one is not encountering resistance to practices which are considered foreign. Older people in particular may appreciate traditional approaches rather than unfamiliar ways of receiving support.
Consideration of gender	Be gender sensitive, understanding that the needs of older women may be different from those of older men.
Strategic leverage and prevention	Think about ideas of how you might more broadly influence the lives of older carers, both in the local community, or more or widely, maybe even at a national level. Include a focus on prevention of suffering in older carers and their families, rather than just the alleviation of suffering. This principle includes consideration of the “do no harm” principles for every intervention with older carers.

2.4. Professional development in psychosocial care and support

While the principles of psychosocial care and support are very important, providing psychosocial care and support also has a lot to do with who you are as a person - the attitudes you show, and how you behave towards others. We can keep developing ourselves to grow professionally and personally in terms of psychosocial care and support.

Have a look at this checklist to see which areas you are already doing well, and where you may wish to invest more energy in developing yourself in your psychosocial care and support development.

How is your psychosocial care and support professional development?

Use this checklist to identify useful characteristics, beliefs and knowledge that can help you to effectively meet the psychosocial needs of the older carers. Rate yourself from 1 (limited knowledge in this area) to 5 (if you are confident in this area).

Characteristic	Scale of 1 to 5
1. I have basic skills in counselling	
2. I generally have great love and respect towards older people	
3. I have problem solving skills that can help me to support the older carer to deal with the challenges that they face	
4. I am well aware of the rights/entitlements of the older as well as the services that are available in my community to assist them to cope with different problems	
5. Older people have valuable knowledge, skills and wisdom that can be very helpful in their caring roles especially for the children under their care	
6. I am aware of the different challenges that older male and older women carers experience	
7. Older carers need HIV counselling services appropriate to their age group as some of them are sexually active and others are infected with HIV	
8. The welfare of vulnerable children and people living with HIV is very important to older people who look after them - therefore we need to care for them too so that older carers feel supported	
9. Support groups are a very important structure or tool that can challenge feelings of loneliness and isolation and also help the older to cope with stigma and discrimination	

Each statement that you have responded to with a low score reflects an area where you may wish to improve your knowledge and skills as a community caregiver providing PSS to older carers. Take time to think about what you can do to develop yourself further so that you can become more effective as a psychosocial care and support provider for older carers.

Here is a case study with some reflection questions to remind you of some of the concepts covered in this first section:

Case example and reflection questions

“The children are in poor health and one is malnourished. I cannot provide the needed care because I have no money and none of my relatives or friends helps me. Sometimes there has been no money and the kids were ill and hungry and I have felt that I just wanted to leave”

Source: The International HIV/AIDS Alliance and HelpAge, Building Blocks- Africa wide briefing notes “Supporting older carers” 2004

Reflection questions:

- 1. What practical challenges is the older carer experiencing?*
- 2. What psychosocial challenges is the older carer experiencing?*
- 3. Look at the list below and select the likely emotional and social struggles that the carer could be experiencing.
Feels overwhelmed, feels like giving up, feels useless and incompetent, feels alone, feels helpless, feels desperate, feels sad, feels discouraged, feels unsupported, feels neglected.*
- 4. What can a community caregiver do to support the older carer in the case study?*

Helpful ideas and tips

Organisations can do the following to assist community caregivers in the provision of PSS to older carers:

- Provide community caregivers opportunities to be trained in basic counselling skills and in basic psychosocial care and support.*
- Provide support and resources to set up support groups for older carers in communities.*
- Arrange for “time out” activities for the older carer so that they have time away from caring responsibilities and focus on themselves and their needs.*
- Set up a directory of services for all institutions and organisations that work with older carers so that you can refer them for relevant services.*
- Provide support and resources to conduct awareness campaigns so as to mobilise communities to provide care and support to older caregivers and their families.*
- Offer resources and support to older carers to implement their own community projects and income generating activities.*
- Provide age appropriate HIV counselling services for the older people.*
- Involve older people and children in consultation and planning programs intended for their benefit.*

Write down your thoughts (or discuss) of the kinds of actions that you think community caregivers can carry out to provide PSS to older carers?



With a little support

older people make a big difference

Unit 3

Building social support systems around older carers and those under their care

One of the most important ways of providing psychosocial care and support is to strengthen the connections between older carers, their families and communities. This is because psychosocial care and support coming from one's family and community care is more valuable and sustainable (lasting) than psychosocial care and support by outside "experts".

This unit covers the following topics:

- *What is a social support system and why it is important for older carers and their families*
- *How community caregivers can help to identify and enrich social support systems for older carers and those in their care*

3.1. The importance of social support systems

Being connected to other people is very important to our wellbeing. Think of a time when you faced a difficult situation – you hopefully had other people to turn to for support. In times of trouble, what we usually want is to be with our family and loved ones. Research shows us that people who tend to cope best – even with very serious life situations - are those who have good social support. To have other people supporting us in our struggle gives us strength to deal with these difficulties. Older carers who are disconnected from others and face their challenges alone are at risk of becoming frustrated, depressed and lonely. Children who are not socially integrated are also at risk of developing low self-esteem.

Thus the most valuable and sustainable psychosocial support may be provided within families and communities, as these are the people who have regular and direct contact with the older and those under their care.

Social support may be defined as the helpful things that others do for us to reduce our stress and enhance our psychosocial wellbeing. These may be

family members, friends, and neighbours. There are several types of social supports that people who are important to them can offer to older carers:

“The neighbours said she became increasingly stressed about how she was going to pay for the school uniforms of all the children. Finally she had a heart attack from the stress. I wish she had spoken to us about her worries – we could have done something to help.” Family member of an older carer

1. Emotional support

This is about interactions with carers that bring about feelings of respect, comfort, sense of self worth, encouragement, recognition, acceptance and a sense of being valued etc. This also involves giving reassurance to the carer.

2. Cognitive support

“Cognitive” means “to do with the mind” – it is things like information and thinking and problem-solving. This form of support involves the giving of knowledge and information to equip carers to solve problems and challenges.

3. Material or practical support

This refers to the support that people give when they provide the older carer with goods (things) and services e.g. food, clothing, housing, transport, assisting with daily living chores, etc.

4. Spiritual support

This is when people visit the older carer to share their faith and pray together with them or invite them to places of worship.

The importance of social support systems for older carers

Social support is important because it ensures that:

- A community of caring and helpful relationships surrounds the older carer and her or his family.
- It minimises negative emotional experiences in older carers.
- It increases community-based protection for vulnerable families and households.
- When the caring capacity of older carers is compromised or limited, other people may provide

support for the older carer, vulnerable children and people living with HIV and AIDS.

- Members of the community can spread awareness about the needs of the older person and those in their care. They can mobilise everyone to share in the responsibility of providing the relevant support.
- When the problems facing vulnerable individuals and families are addressed together in a community, this unites and strengthens the community.
- Local solutions to local problems often work best, especially where family and community members come up with these solutions and take responsibility for them.
- It creates a sense of belonging and reduces loneliness and the sense of “being alone” in this task of caring for others.
- Families and communities can mobilise local resources to take care of those who are most vulnerable. This is more sustainable in the long term than relying on external funding and resources.

One of the most important ways of providing psychosocial support is by strengthening the connections between older carers and their family and community. This is called social support.

Have a look at this checklist to see how well the older carers in your community are socially connected.

“Many older persons have a very strong attachment to God, but some of the Pastors, Reverends and Sheiks do not visit them. When they are visited at least once, they can feel much better.” Older carer

How is the social support of older carers in my community?

Rate the social support in your community from:

1 (limited support in this area)

to 5 (if there is extensive support for older carers).

Social support outcomes	Scale of 1 to 5
1. Older carers are visited often by their families	
2. Older carers are included in family functions as valued and honoured members	
3. Older carers have regular opportunities to socialise and network with one another in our community	
4. Older carers are included in community functions as valued and honoured members	
5. Older carers are able to attend and participate in church or cultural practices in our community	
6. Older carers receive spiritual support and home visits from our local religious or cultural leaders	
7. Older carers are treated with respect by children, youth and adults in our community	
8. Older carers are supported by neighbours and family members if there is a need for urgent assistance	

Each statement that you have responded to with a low score reflects an area where you may wish to strengthen the social support of older carers in your community.

While you were doing this exercise, did you find yourself thinking about the older people in your own family? Without creating unhealthy guilt, it is helpful to remind ourselves that psychosocial care and support of all older people begins at home.

There are various tools and methodologies that can be used to facilitate conversations with older carers and their families to strengthen their support systems. The first of these is about raising awareness of communities and our society about how much older people appreciate social support. Raising awareness of the plight of older carers who are carrying a heavy load is an important way of increasing their social support from all levels of society.

3.2. Community awareness on the needs of older carers

A lot of people lack understanding and awareness of the challenges that are faced by older people who care for orphaned children and people living with HIV. Community caregivers can make families and communities more aware of the challenges faced by older carers. Awareness-raising may include:

- Being a role model or an ambassador for the older person in one's family and community by demonstrating a personal understanding that the older person needs to be cared for and that they have rights and entitlements.
- Talking to people: community caregivers can talk to people one to one or in small groups about the simple acts of care and support that people can do for the older carers and their families, for example that all people, with or without money, can provide emotional support and encouragement to the older carer. Public media like radio shows and newspapers can help to remind families to provide better care for the older people in their family.

- Community caregivers can also participate in public meetings in the community, such as in churches, and bring awareness of the need to provide support the older, children and people living with HIV.
- Public events can be held during holidays e.g. International Day of Older People, Human Rights Day, World AIDS Day to specifically focus on the rights and entitlements of the older carers. Awareness during these events could include putting up posters, giving out handouts and T-shirts, performing street theatre, using the press for publicity and organising joint marches. Radio shows and newspaper articles can help to raise awareness and remind family members to support older carers. All these events must include older people.
- Older people can be supported to form self advocacy groups. Self advocacy groups could consist of several older people who meet regularly to look at the needs of older people. They can advocate to key stakeholders like local authorities and social services that the rights and entitlements of older carers are met. Members may receive training on the needs of older carers; rights and entitlements of people living with HIV and older carers and children's rights. They can visit local leadership and government departments, write letters or newspaper articles to change the conditions for all older people in their country.
- Some of the most powerful and dignified community awareness raising may be done by older carers themselves. Facilitating older carers to plan and implement their own community awareness campaign may be a rewarding way to support their cause.

It may be possible to draw on the existing community and family networks surrounding the older carer, and find ways to strengthen these networks. One way to facilitate this is by using the tool "social support network mapping."

3.3. Social support mapping

A social support network map is a tool or methodology that can be used to help people to map out or identify the helpful relationships that are in their lives. When people face problems or

become overwhelmed it is quite easy for them to forget about the supportive relationships that they have. They may feel alone, neglected and invisible. It is therefore helpful for community caregivers to invest some time in helping older people and their families to be aware of people that they can depend on or ask for help from during difficult times. The social support network map will help older carers and their families to identify relationships that provide emotional, cognitive, material and spiritual support for them. The following steps will guide the community caregiver to use this methodology with older carers and their families.

*Practical exercise:
Social support networking map*

- a) Explain to the carer and her family that you would like to assist them to identify and to enrich their social support network.*
- b) Say that you will assist them to identify the different types of relationships that they have with members of their families and communities.*
- c) Tell them that they may come up with different symbols to represent the different relationships e.g. things found in the natural surroundings like different parts of a tree, objects like stones/rocks or different shapes.*
- d) Using paper and a pen/pencil, draw a picture of the older carers and her family in the middle of the page. Put a circle around them.*
- e) Let them choose a type of object (for example a leaf) to represent the emotionally supportive relationships that the carer and her family have with important others. These are relationships that make them feel loved, cared for, encouraged, valued, and supported during difficult times. They should think about the people who provide such kind of support to them and the caring actions that these people perform. Position these people represented by objects from the centre and draw a straight line from the centre to link to the objects. See the example given below.*
- f) Identify relationships that provide cognitive support (such as information, knowledge and skills).*
- g) Continue to map out relationships that provide*

material and finally spiritual support, following the same process. We need to consider physical support. These families have health and nutritional needs.

h) Once the map is complete, discuss about the following with the carer and her family:

- Where are the strongest relationships?
- Where do relationships need to be strengthened?

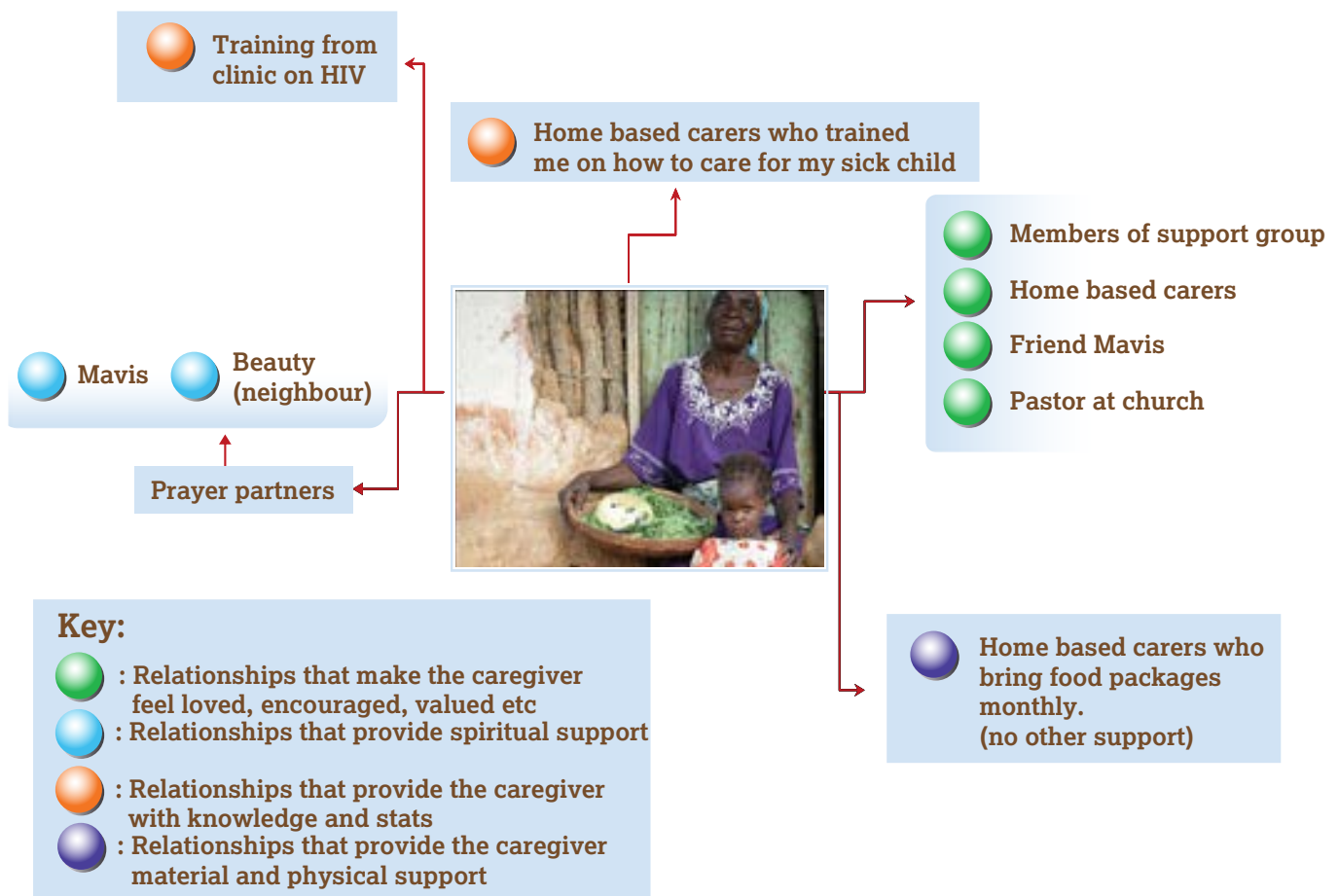
• What makes the strong relationships strong and the weak relationships weak?

• What can be done to improve or increase supportive relationships for the older carer and the family?

i) Come up with some points of action for the family with regards to strengthening their social support networks

Example of a social support network map

Social support network map



See another useful tool/methodology for helping community caregivers and their families to have stronger social support networks in Annexure 3. It is called the “Club of Life”.

The third recommended way of strengthening the social support of older carers is through the creation of support groups.

3.4. Social support groups

Support groups for the older carers can help them to cope with the isolation that they often experience when tackling their responsibilities. Older carers' groups can have anything from 8 to 50 members. They can meet once or twice a month or every two months, depending on the needs of the group. The number of people at any meeting depends on people's health, personal circumstances etc.

Support groups enable group members to share experiences, offer one another advice, and provide emotional and practical support to each other. For example the members of the support group may support one another when they are sick by:

- visiting
- bringing food
- taking the person to the hospital
- taking money from joint savings to pay for medicine or hospital bills

Helpful points to consider when starting a support group for older people are suggested here:

- Identify older people with common interests, such as those who are carers of orphaned children or people living with HIV.
- Identify a venue that is accessible to the carers and does not require transportation to and from group meetings.
- Agree with group members on logistics, such as when to meet, how often, the length of meetings etc.
- Agree on group rules and norms such as:
 - keeping confidentiality
 - treating one another with respect
 - showing acceptance towards all members
 - facilitating equal participation.
- Consult group members on the topics and issues

that they would like to discuss during the support group meetings. Make sure everyone's opinion is taken seriously.

- Encourage older carers to facilitate or lead some of the discussions.
- Prepare a clear programme in advance and arrange for facilitators for the meetings/sessions in good time.

Experienced community caregivers should be responsible for setting up and guiding the groups.

3.5. Drop-in centres for the older carer

Community caregivers can play an instrumental role to encourage organisations and government departments to set up drop in centres for the older carer. Drop in centres are an extension of support groups. They are community based facilities that open their doors to the older carer to drop in and be involved in a wide range of activities. They are usually open for several days in a week and could include some of the following activities:

- Nutritional support programmes
- Training and skills development, educational talks etc
- Practical assistance (such as accessing identity documents or social grants)
- Counselling, emotional and spiritual support
- HIV testing and treatment assistance
- Child care
- OVC psychosocial support

Case example:

Comments from older carers about the Muthande Society for the Aged (MUSA) Drop In Centre

- *Muthande gives us joy and love, we feel welcome; we talk, sing, read the bible together as older people, we eat good food that we cannot afford in our homes, we visit places like the beach, we swim, we go to places that we never knew, we pray before we do anything, we celebrate special occasions like the*

cultural days, we go for “joy rides” on luxury buses, we eat bread with RAMA spread that we cannot afford in our homes

- *Muthande teaches our grandchildren how to respect us and not to give us stress, to support and help us around the house*
- *We rest at Muthande; we rest our minds*
- *We receive gifts/presents from Muthande*
- *We go for field trips dressed in our Muthande T shirts/attires, looking GOOD*
- *We make things, sew, get creative. This relaxes our minds and gives us time away from daily stress in our homes. We feel refreshed, happy and supported, and forget our problems for a while.*
- *We do modelling shows like “Glamorous Gran”, we play games, we laugh a lot*
- *We share ideas about how to solve problems that we face in our homes*
- *We are treated well and we are respected at Muthande*
- *When we eat here it helps us to save our food at home*
- *We come to Muthande every day - that is Monday to Friday. Even when we are sick we say, “I would rather go and die at Muthande”.*
- *Muthande also gives us gloves and condoms so that we can protect ourselves from infections. We also receive health talks that help us to care for our health.*

carers and plan leisure time together, rather than assuming what would be enjoyable for them. Being involved in the planning and organising of the leisure activities can strengthen social support too.

3.6. Leisure activities for older carers

The value of leisure activities was emphasised by many of the older carers consulted in the development of this guide. Leisure activities could be social functions, outings and the building of leisure facilities for older people. Older carers may be assisted with child care support to ensure that they have free time to enjoy leisure activities.

Once again, the principle of participation is important, and it is a good idea to consult older

3.7. Action planning

What have you found works well in supporting older carers in your communities? What other steps or actions do you think you will take to help older carers to strengthen their social support networks in your place of work or community? Write your plans as steps to be taken in strengthening the social support of older carers.

Steps to strengthen the social support of older carers	
Step 1	
Step 2	
Step 3	
Step 4	

Helpful ideas and tips

1. Remember that older people have a lot of experience and skills and therefore it is important to work with them as partners. Include them in all processes and decisions with regards to their lives.

2. Older people should be key spokespersons and can make the greatest impact in raising awareness in the community about the needs of older carers.

3. When working with communities to mobilise care and support for older people, go beyond communities

that share geographical boundaries to include:

a) Groups that share specific interests or lifestyles e.g. churches, sporting communities

b) People belonging to a cultural or language group

c) People belonging to a particular institution

d) People working in a particular occupation

Unit 4

Building more supportive relationships between older carers and children under their care

This unit covers the following topics:

- *The importance of mutually supportive relationships between older caregivers and their grandchildren*
- *Potential challenges and barriers to the formation of mutually supportive relationships between older caregivers and their grandchildren*
- *Strategies of how to support households to build mutually supportive relationships*
- *How a community caregiver can protect herself when working with families*

4.1. The importance of supportive relationships between older carers and children under their care

Studies show that children prefer to live with their grandparents after the death of their parents rather than with other relatives⁷. They feel that their grandparents provide more love and affection than other relatives. In caring for their orphaned grandchildren, the grandparents are ensuring that they grow up together as a family group, rather than in an institution or separated from each other in different families. As children become older, they may provide their grandparents with economic and emotional security, and care for them when they are ill or in need of special attention⁸.

Case example

“Our grandmother looked after my sister and me after our mother’s death two years ago, but then she had a bad fall and now she cannot walk anymore. Now we help her with the housework and look after her.”

Naomi aged 14 years, Kenya, cared for by her 82 year-old grandmother

Source: The International HIV/AIDS Alliance and HelpAge, Building Blocks Africa-Wide briefing notes “Supporting Older Carers”

⁷ International HIV/AIDS Alliance and HELPAGE, Building Blocks-Africa Wide briefing notes on supporting older carers, 2004

⁸ International HIV/AIDS Alliance and HELPAGE, Building Blocks-Africa Wide briefing notes on supporting older carers, 2004

Supportive relationships between older carers and their grandchildren are therefore important for the following reasons:

- Children remain together in a family environment under the care of their grandparent where they can receive consistent love and nurturing
- Grandparents can comfort their grandchildren during difficult times
- Children can learn a lot about their identity from their grandparents, for example about their deceased parents, family history, norms and values, culture and origins
- Both the older people and the children appreciate time together when they can laugh, tell stories and enjoy themselves
- Grandparents provide a social support system for their grandchildren
- Grandparents who may be weak, sick and frail can be taken care of by their adolescent and adult grandchildren.

Practical exercise:

What we appreciate about one another

Bring together a group of older carers and the children / adolescents in their care. Divide the group into older carers and adolescents. Ask each group to list some of the things that they appreciate about their older carers or the children / adolescents in their care. They may wish to also express what they would miss if they no longer lived together in the same household with one another.

Each group should share their findings together with everyone in the plenary.

4.2. Some reasons why relationships between older carers and their grandchildren may be challenging

The relationship between a grandparent and grandchildren is often very rewarding. However, as with all parenting relationships, this is not always easy. For a number of reasons, including the large generation gap, older carers may sometimes struggle to bring harmony and understanding into

their relationships with their grandchildren and thus may need to be supported.

Bear in mind that limited resources and high levels of stress are almost always a recipe for family conflict. Think even in your own family about a time when you were stressed about money and how this added tension and conflict in your family. Also, think about a time when you were tired, overworked and feeling emotionally under-resourced. This also tends to create misunderstanding and conflict in families. Many older carers and the children in their care are struggling with multiple stresses, which, when added to the generation gap, can cause serious tensions and conflict over resources.

Older carers have described these potential barriers and challenges to healthy relationships between older carers and their grandchildren:

*“Older people want the way they have grown up to be respected. They take time to get used to new ideas.”
Older carer*

- The generation gap, which may include a cultural disconnection between the two groups or differences in values and the ways things are seen
- Children who move to rural areas from urban areas may be used to different values and ways of doing things
- Children may have had more freedom and adult responsibilities in the past which may mean that they struggle to cope with discipline and boundaries
- Lack of effective communication
- High stress levels in the family
- Struggle for control of limited family resources
- Drug and alcohol abuse, especially amongst older children
- Accusations of favouritism
- Lack of family and community support structures
- Lack information and skills to deal with children and youth at different developmental stages

- Challenges of guiding children who are the opposite sex to the older carer

- Excessive control of adolescents, especially females

- Differences in religious belief systems.

Practical exercise:

What are the psychosocial challenges experienced within the relationship of older carers and the children in their care?

Bring together a group of older carers and the young people / adolescents in their care. Divide the group into older carers and adolescents. Ask each group to list some of the things that they struggle with in their relationship with one another.

Select some of the common challenges that they have identified. Now divide up the participants again, with each group having a balance of older carers and adolescents. Ask the groups to work together to prepare some roleplays (drama) where they act out the way this challenge usually unfolds. But in these roleplays, the older carers and adolescents should swap identities. So the adolescents must act the role of the older carer and the older carer must take on the role of the adolescent.

After each group shows their roleplay, discuss what happened together in the plenary group, highlighting misunderstandings and factors which contributed towards the stress of the challenging situation.

Now ask the groups to again prepare a roleplay on the same challenge, but this time they should work out a way of handling the situation constructively. In other words, they should role model helpful ways of coping with the challenge. They may still swap roles to do this.

Once again after each group has presented their roleplay, discuss the results in the plenary.

Note to the facilitator: preparing roleplays on challenges can become a bit “wild”. Care should be taken that people’s feelings are not hurt. To do this, the facilitator should visit the groups while they are preparing their role play and encourage the roleplay to be constructive, even if they are showing a difficult situation. Make sure this does not turn into a “blame” game.

This exercise works much better if one has first facilitated the exercise on “What we appreciate about one another.” The facilitator can remind everyone of the positive aspects of their relationship as a foundation for finding ways of handling common challenges together.

Challenged between older carers and children in their care may be addressed by focusing on strengthening the relationship of mutual care and appreciation.

4.3. Strategies for improving the relationships between older carers and children in their care

Many older carers say that one of their main sources of stress is discipline of children in their care, especially adolescents. They feel that they do not have the authority of a parent and therefore struggle to set limits. For example, they say that it is difficult to tell an adolescent what time to be home, when often these young people have been caring for sick parents and living independent lives with serious responsibilities almost as young adults. Building a caring relationship between the older carer and the young people in their care can be the best foundation for discipline. This means that negotiations around behaviour come out of a foundation of care and respect, rather than the young person suddenly being treated like a child or having her freedom taken away.

Community caregivers can play a very important role to support grandparent households to enjoy mutually supportive relationships. The responsibility for the relationships however is not that of the community caregiver. The community caregiver facilitates and plays a supportive role and the main actors should be the members of the household.

Two principles may be helpful in strengthening a caring relationship between carers and children in their care:

1. Children need to know that they are loved: carers often think that children know that they are loved, but children need to hear this often. They need to feel respected, cared for and valued.

2. Young children need safe, predictable routines and boundaries: young children respond well to having the same daily structure, limits about times for playing, times for sleeping, what they may eat etc.

The following are some ideas about how community caregivers can assist older carers and their families to cope with some specific commonly experienced challenges and issues.

Strategies for improving the relationships between older carers and children in their care

Possible Issues	Strategies
<p>Generation gap</p> <p>It is not always easy for two generations to live together harmoniously. There may be differences in values and beliefs</p>	<p>As a community caregiver you can set aside time which will give older carers and their grandchildren opportunities to think and talk about:</p> <ul style="list-style-type: none"> • The contributions that they are making in each other’s lives and the value of their relationship • What they would miss if they had to live without each other • Valuable lessons that they can learn from each other • Ways in which they can live together successfully and enjoy healthy and loving relationships • What could go wrong in their relationship and how to plan to avoid such pitfalls <p>Community caregivers can also facilitate talks about what each of them values and believes in so that they can better understand each other. Here are some other ideas that people have found helpful:</p> <ul style="list-style-type: none"> • Role-swaps in groups – where the children act like the older carer and the older carers act like children. This highlights some of the positive and hurtful behaviour, but often in a fun way that is not too sensitive. • Older carers may draw on other family or community members to have discussions about topics like sex and sexuality, where the generation gap feels challenging to overcome. • Encourage carers to fulfil an important role of older people – to tell stories to children. They can have a specific time each night to gather together and tell stories. Let younger children choose their favourite stories and make the story telling interactive, where the children can speak out different parts of the story. Many older carers who have started this daily practice have said how much it has improved their relationships with their children and how much they have enjoyed the story telling themselves.
<p>Lack of effective communication</p> <p>With the generational gap between older carers and the children they look after, communication can be difficult between them</p>	<p>As a community caregiver you may wish to:</p> <ul style="list-style-type: none"> • Talk about the importance of effective communication in a family. • Encourage regular family meetings and discussions to talk about matters affecting the family. Try to have these often and not only when there are problems so that the family stays in touch with what is happening in each other’s lives. • Help the family to decide on healthy communication styles to be used towards both the older carer and the younger members of the family. • Assist the family to agree on important communication

	<p>principles e.g. openness and truth even about difficult issues.</p> <ul style="list-style-type: none"> • Try to teach carers and children to reframe their criticisms and limit-setting as concerns. For example “I am worried about your safety – what time can I start worrying if you are not home?” <p>Remember that as a community caregiver you can model effective and respectful communication skills. Throughout the sessions, the family will observe you. Give them an opportunity to practice essential communication skills in your presence so that they will be able to cope with the challenges that they are faced with.</p>
<p>High stress levels in the family</p> <p>When people are highly stressed they can be emotionally charged, irritable and very sensitive, making it easy for conflicts to occur</p>	<p>As a community caregiver it may be helpful to:</p> <ul style="list-style-type: none"> • Encourage a culture of mutual respect for one another and the way things are said to one another, even under times of stress. • Assist family members to be supportive and empathetic towards those who are stressed and going through difficult times. • Encourage family members to talk about their stress to one another. For example “I would really like to buy you some new school shoes, but I am worried about whether we will have enough money to pay for your school fees.”
<p>Family problems, disagreements or disputes</p> <p>Due to the age difference within the family, structure issues may arise within the family that may prompt conflict</p>	<p>As a community caregiver, the following steps may be followed:</p> <ol style="list-style-type: none"> 1. Assess the situation <ul style="list-style-type: none"> • What situation is causing stress for the family? • What difficulties of coping are evident in the family? • What support is available in the family? • What are the family options for solving the situation? • What options does the family want to try first? • What existing skills, knowledge, strengths etc are available within the family to improve the situation? 2. Set goals using family strengths <ul style="list-style-type: none"> • Assist the family to agree on a plan on how they will move towards their goals. • Help the family to agree on responsibilities and time frames. • Monitor and support as the family works on bringing about the desired change. • Teach new skills where necessary and possible. • Have meetings with the family to assess progress and evaluate etc.
<p>Struggle for control of limited family resources</p> <p>Due to limited resources, mistrust may occur between the children towards the older carer</p>	<p>Support the older carer to be open about family resources and for joint decisions where possible about how resources should be managed, for example:</p> <ul style="list-style-type: none"> • Include children in budgeting and financial discussions (as age appropriate). • When there is some extra income, encourage family members to discuss how it can be used so that everyone

	<p>members to discuss how it can be used so that everyone benefits.</p> <ul style="list-style-type: none"> • Think about encouraging older carers to give children a weekly or monthly allowance, however small, so that they can develop a sense of responsibility and save for things that are important to them. • Older children can be assigned responsibilities such as doing family shopping, paying bills etc. This will give them a better understanding about how resources are being utilised. • Support older carers and youth to start income generating projects. • Older children might also want to become involved in income generating activities, either for pocket money or for family income. This has to be balanced with “allowing children to remain children and to have adequate time to play.”
<p>Drug and alcohol abuse specially amongst older children</p> <p>Children may abuse drugs and alcohol due to problems and frustrations in their lives including</p> <ul style="list-style-type: none"> • Unemployment • Feeling worthless, lack of confidence • To try and forget problems • Peer pressure or peer influence • Lack of adult support, guidance and supervision • Experimenting • Rebelling against authority • Imitating adult members of the family <p>Drug and alcohol abuse in children may lead to:</p> <ul style="list-style-type: none"> • Physical and mental health problems • Family conflict • Crime e.g. stealing, vandalising properties etc • School drop out • Missed opportunities • Addictions • Antisocial behaviours • Suicide 	<p>As a community caregiver, you may wish to support older carers and their families in the following way:</p> <ul style="list-style-type: none"> • Encourage the carer to be proactive about talking to the children under her care about drug and alcohol abuse and not to make the issue a taboo. Stories in the media or television can help start a conversation with children. • Older carers may need to be supported to talk to children about this matter. Explain to children that you would like to talk to them about an important matter and help them to make the right decisions about their lives and future. • Let them know that you are not there to pass judgements or immediately report them, but rather to help them know about the effects of drug and alcohol abuse. • Encourage carers to invite children into the conversation as equal partners. Encourage them to listen to them with respect and sensitivity and not to get angry when they say something you disagree with. They may have different opinions. • Pick a time to talk when there are no distractions. • If you think that the children are already using drugs don't talk to them when they have recently used them. • Help them to deal with denial as some young people may believe that their drug use is safe. • Let them know that you are available to talk and support them. • Refer serious cases to relevant services.

<p>Accusations of favouritism</p> <p>It is very common for grandparents to be accused of favouritism especially when they are caring for several grandchildren. It can be tempting for grandparents to show a preference for those children who are particularly well behaved and doing well at school.</p> <p>Those who may not be doing as well may be constantly compared to the good children and labelled negatively. This can result in a lot of resentment and conflict in the family.</p>	<p>Here are some ideas to encourage older carers to show all children in their care that they are loved:</p> <ul style="list-style-type: none"> • Support older carers to understand that children are different and unique and thus should not be compared. • Children in the family who may not be doing as well need support, encouragement and should not be labelled negatively or called names. • Support the older carer to identify the children’s strengths, talents, gifts and encourage them in what they do best. • Encourage the children to be supportive and caring towards each other. • Explain that children will often live up to one’s expectations of them, so if you treat a child like he or she is not doing well at school, they start to do even worse at school and this becomes part of their identity (how they see themselves). Encourage older carers to focus more on the things that the child is doing well and to make a big fuss about any small successes. • Encourage carers to find ways of sharing resources equally amongst children. They can make this explicit to children – for example saying “Yesterday it was Nomhle’s turn to choose the story, and today it is Mandla’s turn.” • Help older carers to talk through resentments (grudges) that may be carried over from other family members onto specific children.
<p>Children may struggle with being disciplined</p> <p>Discipline issues can be challenging for older carers especially if they have not brought up the children from earlier on. Children can take advantage of situations where there are fewer controls and this may be unhelpful to them in the long run.</p> <p>When children’s behaviour is undesirable, carers may be tempted to punish them physically however it is important to note that this can be very harmful for the following reasons:</p> <ul style="list-style-type: none"> • It teaches children that hurting others is alright • It breaks down the relationship of trust between a carer and child • It can damage children physically • It opens opportunities for physical and sexual abuse • It can damage children’s 	<p>Community caregivers may help carers to understand that:</p> <ul style="list-style-type: none"> • There is a difference between punishing and disciplining children. • Children resent punishments if they are very harsh and tend to go too far beyond what the child has done wrong. • Punishments usually embarrass, humiliate and compromise children’s dignity and sense of self worth. • Respectful caring relationships are the foundation of good discipline. Many carers report that once the relationships with the children became more caring, the discipline aspects fell into place. • Young children love daily rituals and these can help to create a sense of discipline and boundaries. Encourage carers to come up with fun daily rituals, like taking turns to each say a prayer, or taking everyday activities and turning them into fun rituals or games, like lighting candles at night, or going to bed. • Values and attitudes underlie all discipline. If children are not taught values in the home they may pick them up from media and society. They often accept inappropriate values shown in violent and sexually explicit television stories and song-videos. They may also learn from the media and society glamorous greed, selfishness and self indulgence. <p>It is important to set limits for children as this can protect them. The following can be possible ways to discipline children:</p> <ul style="list-style-type: none"> • The family should jointly set clear ground rules, for example

<p>development</p> <ul style="list-style-type: none"> • It is not effective in the long term as it does not change a child's underlying attitude and values 	<p>what time children should go to bed, what time they should be at home, allocation of responsibilities in the household, or how to care for younger children.</p> <ul style="list-style-type: none"> • The older carer should be firm (but respectful) about keeping the house rules. However if flexibility is necessary it is important to allow for it. If they are older children in the family they can assist to ensure that the family rules are kept. • The family can agree in advance what the consequences for not doing as expected should be. • Children need to be always understand why they are being disciplined. • Point out the value of sitting down with children to talk about their concerns about their behaviour and conduct these talks in a loving but firm manner. • Older carers should model good behaviour at all times.
<p>Adolescence</p> <p>Adolescence is a stage between childhood and adulthood. Children at this stage are usually trying to find their true identity, usually in reaction to the values of their parents or carers. They usually want independence and autonomy. They may express a lot strong values and attitudes about life and living.</p> <p>They develop rapidly physically, emotionally, socially etc. Some children begin to experiment with sex, alcohol, and drugs at this stage of development. They may have mood swings and irritability, and they tend to be embarrassed by their carers' ways of doing things.</p> <p>Many parents and older carers fear this stage as it is usually characterised by a lot of challenges/conflicts between them and their children; however it is not to be necessarily dreaded especially if parents and older carers prepare for it through open and honest relationships with their children.</p>	<p>Older carers can be supported to understand the changes that take place physically, emotionally, mentally and socially in their grandchildren at this stage.</p> <ul style="list-style-type: none"> • Older carers should be encouraged to talk to their grandchildren about growing up and what they know about caring for oneself at this critical time. They can share stories with the children about their own experiences as an adolescent and how they were initiated into adulthood. • This can create space for important conversations between the adolescents and their grandparents. • Older carers can share openly with the children about the mistakes that they made during this time in their lives and the lessons that they learnt. • They can talk about the hopes that they have for the children's lives and offer them support at all times. <p>It is important for the grandparents to be aware that at this stage adolescents do not like being treated like children and therefore they need to be accorded the respect and space that they need; however this needs to be guided. Adolescents can be more involved in decision making processes on matters affecting the family.</p> <p>Regular talks are necessary to try and keep the children as close to the older carer as possible and support them in making decisions about their lives and future.</p> <ul style="list-style-type: none"> • Talk to the older carers about gender differences - the different experiences of boys and girls as they go through this stage and how boys and girls need to be supported. • If the adolescents are not free to talk to their older carer, they can be supported to find someone else that they feel comfortable to talk to who can guide them and be their mentor. • Adolescents may feel more comfortable talking about life issues and growing up with someone of their own sex and someone outside of the family. Older carers can support male

children to identify suitable male mentors in the family and/or community.

- Encourage carers to allow children to have friends and engage in appropriate activities such as sports. Explain that if one becomes too controlling over children they may learn to be deceitful and rebellious.

4.4. Supporting families

Working with families is very rewarding. It is one of the best ways of providing psychosocial care and support to both the carers and the children in the family. A small investment in improving relationships in the family can change the lives of everyone in the family. Supporting families takes a lot of patience, friendliness and respect for everyone in the family. Here are some ideas of the skills that need to be developed in order to become more professional at supporting families.

Skills needed to work with families:

- Offer genuine warmth, kindness, and compassion.
- Respect the family and where they are coming from emotionally and culturally
- Be kind to people in need
- Be peaceful and show love and care to others
- Be friendly and warm to families
- Be impartial
- Form an alliance or partnership with all members of the family so that all of them feel they can trust you. If anyone feels that you are more on the side of one part of the family, the others may lose trust
- Give each person a chance to speak, and listen to their responses
- Give family members opportunities to talk to each other and make joint decisions
- Use appropriate body language (such as smiling and nodding) to convey warmth and understanding
- Draw in more resistant family members by

consulting their opinions and asking for their assistance

- Conflict is often created in a family when they misinterpret what each other is saying as an accusation. Try to reframe what people are saying as a positive and caring comment. For example, if someone says “You never phone me to tell me where you are”, you can reframe this as “It sounds like you care a lot for him/her and you become worried when you do not know where he or she is.”

Practical exercise: Positive reframing

Positive reframing is when you say something in a constructive and caring way. Together with others in your organisation or with older carers, try to positively reframe the following negative statements. In other words, re-write these sentences in a way that builds a person up, rather than breaking him or her down.

- *You never let me know where you are going*
- *You always shout at me when I am late*
- *You always criticise what I am doing*
- *You never have money for the things I want*
- *You never clean up after yourself*
- *Your school marks are terrible*

Here are some tips about positive reframing:

- *Take ownership of the issue, for example by saying “I think ...” or “I feel ...”*
- *Express how you are feeling “When you do this, I feel worried” or “When you do this, I can’t help thinking that you don’t care about me”*

- *Focus on the times when something worked well, rather than on all the times it didn't work well. For example "When you cleaned the kitchen last week I felt so pleased." Or "When you passed your exam I felt so proud"*

Think about other good ways of positively reframing comments in a way that build the relationship between you and which build up the confidence of the person you are with.

Important principles when supporting families:

- Families should be approached in a respectful and positive manner
- Work in partnership with older carers, other family members and community structures
- Help and support families to fulfil their potential
- Respect families' culture and values and the support offered should be flexible to suit each family's needs
- Children and older people have a right to be part of a safe family
- Parents and older carers should be supported and respected in their efforts to nurture their children
- Engaging families respectfully means involving everyone and focusing on strengths (the things that the family is already doing well). Identifying family knowledge and skills (strengths) will inspire hope
- Families have the ability, with support, to overcome adverse life circumstances
- Families can grow and change through identifying and building upon their knowledge and skills
- It is always helpful to work with families together with someone else, so that you may give each other feedback and support one another to deal with sensitive issues
- Encourage families in their religious faith and practices
- Encourage prevention rather than only focusing

on treatment

- Mobilise community support for families
- Encourage referrals for other forms of assistance
- Know the relevant laws of the country about the issues affecting families and encourage them to access their rights.

Case example and reflection questions

Statements from Muthande Society for the Aged (MUSA) older carers about some of the challenges that they face caring for children:

- *"Sometimes the grandchildren are very disrespectful and demanding"*
- *"Dealing with issues of discipline with some of the grandchildren can be very difficult. Sometimes they demand the social grant from us and call us bad names trying to intimidate us so that we give them the money".*

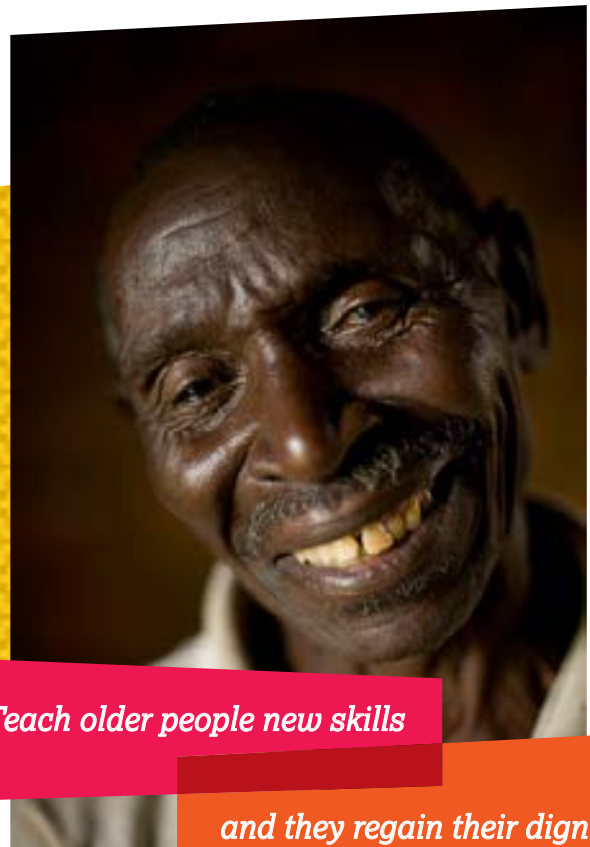
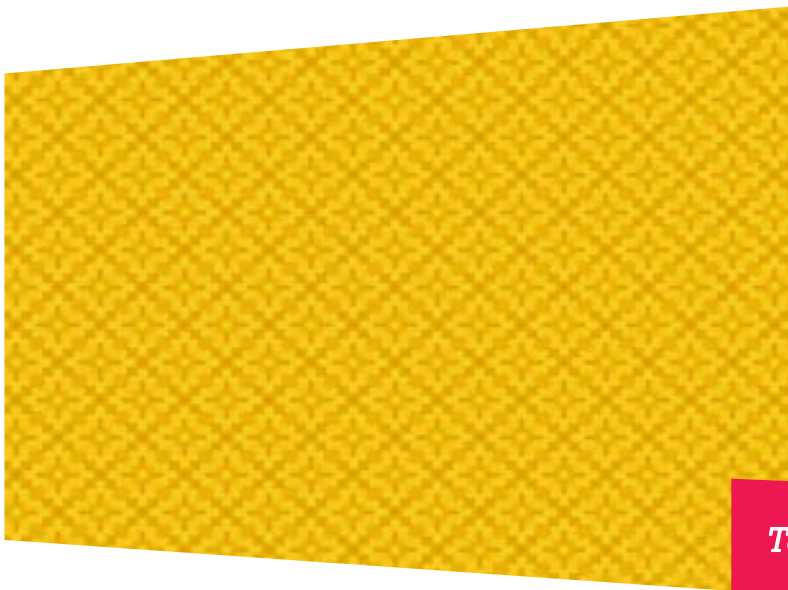
Source: HelpAge report on a consultation with MUSA older carers, 2009

Reflection question:

Reflect on your work with older carers and their grandchildren in the communities that you work with, or on your own relationships with your grandchildren or grandparents. What are some of the reasons why misunderstandings and strained relationships

develop between the two generations? What have you found helpful in strengthening the relationship between yourselves?

Write your ideas in the space provided or discuss with people in the group



Teach older people new skills

and they regain their dignity



When older people speak

we are listening

Unit 5

Supporting older carers through the grief process

The following topics are covered in this unit:

- *An understanding of grief and normal grief reactions*
- *What you can do to provide emotional support to a grieving older caregivers*
- *Identifying signs of complicated grief*

5.1. Loss, bereavement and grief

There is a common saying “No-one should have to outlive their children”. It captures the intense grief and shock of losing one’s own children. It is especially difficult for the older carer if he or she has lost several children in a very short space of time. The experiences of grief and the worries about the future make it difficult for the older carers to cope with caring for children left in their care. Apart from the intense loss of one’s loved ones, when older carers are faced with the death of their adult children they may experience loss in several areas of their lives:

- Loss of love and care
- Loss of social support
- Loss of economic security
- Loss of hope for the future
- Loss of freedom and autonomy (especially when you have to care for young children or people who are ill)
- Loss of property (many older carers sell their land and other properties to get money to buy medication to treat their sick children and later to bury them and take care of the children that remain behind).

Grief is the normal and necessary emotional reaction to the death of a loved one. It is the emotional suffering that people feel when someone or something that they love is taken away⁹. As a response to loss people may feel anger, sadness,

shock, and guilt. While these feelings can be frightening and sometimes overwhelming, they are normal reactions to loss. Such reactions may last a long time (sometimes many years), and it is important not to rush the grief process.

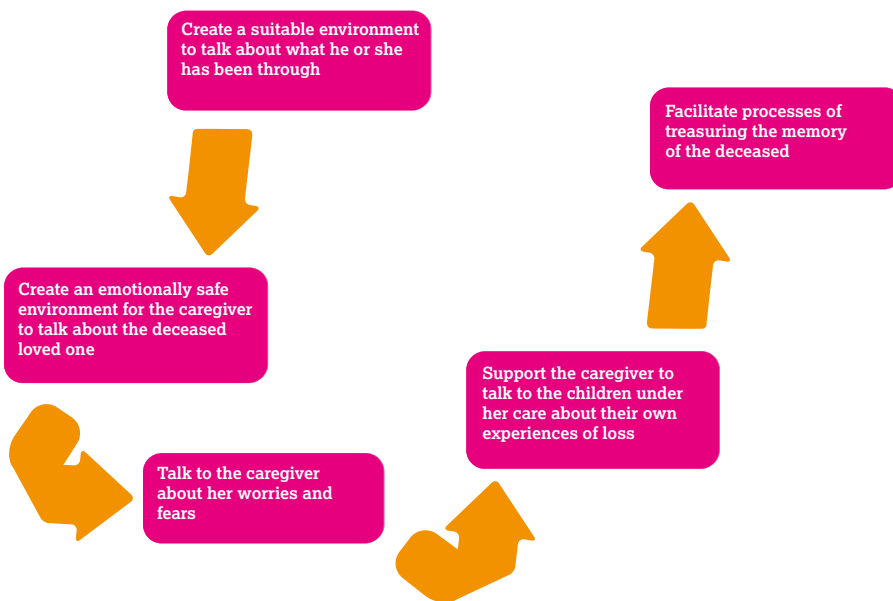
There is no right or wrong way to grieve - but there are helpful ways to cope, like talking to others about your thoughts and feelings. It is important to note that grief is a unique personal experience and thus individuals’ grief experiences should not be compared.

When someone we care about deeply passes away, it takes time to heal. Talking about our memories of the deceased and finding ways of honouring these memories may be helpful to those who are grieving.

⁹ Thogomelo Psychosocial Support Skills Development Programme Community Caregivers, 2009

5.2. How to provide emotional support to grieving carers

Providing emotional support to grieving people is difficult, because there is nothing that one can say to take the loss away. Almost all of our cultures also do not equip us well to talk about death and dying, apart from specific rituals around certain moments of loss or anniversaries of losses. Here are some ideas gained from people with many years of experience of supporting grieving people. The ideas are structured in the following way:



Create a suitable environment to talk about what she has been through:

- Tell the carer that you are aware that she has been through a lot of difficulties by losing someone close to her and that you would like to support her in any way that you can. For example you could say “I am so sorry to hear about your loss. Please know that I am here for you and would like to support you through this difficult time.”
- Do not make false promises or quick interpretations. For example, don’t say “You will feel better soon” or “God must have had a reason to take your child away from you.” Rather spend time listening.
- Invite the carer to feel free to talk to you about the loss when he she feels ready.

- When you have the conversation make sure that the place where you are talking is free from distractions.

- Assure the older carer that everything she talks to you about will not be discussed with any other person without her approval.

Create an emotionally safe environment for the carer to talk about the deceased loved one:

- Allow the care giver to express how she feels. It is often difficult for people to talk about feelings which are so intense that they are difficult to describe. Instead, people may find it helpful to share memories of their loved ones. This is helpful, and try to listen well. You may even ask more questions about specific times that the person wishes to remember.

- In the early stages of grief, people may need to talk more about the time of illness, the actual death moment and the funeral.
- Some carers may be hesitant to talk openly about their feelings and experiences. Instead, they may talk in terms of action or practical matters about the loss. For example they may say “I need to make sure that the house is clean before the funeral visitors arrive” or “I really need to go and cut the grass around the grave site” or “I must make sure that all the policies are in order.” Such actions are healthy and it may be helpful to assist with these practical arrangements where possible. Often people are only ready to talk about memories and feelings of loss much later in the grief process.
- Acknowledge the feelings expressed. Try to make sure that the conversation is not only about the sad thoughts/feelings and what is likely to go wrong in the absence of the deceased, as this can be emotionally draining for the older person.

Practical exercise:

Helpful and unhelpful responses to grief

This exercise may be done with other people in your organisation, with community caregivers as an exercise or with older carers to facilitate bereavement. It is an intense exercise which tends to evoke strong emotional responses of grief in participants. So it should only be undertaken by experienced facilitators. Enough time should be allowed to give each participant the space to say what they want to say (preferably a full day). Participants should be warned well in advance that the exercise will be on loss and will involve thinking about their own losses. Participants should attend voluntarily. Never trick anyone into becoming emotional when they were not expecting this.

Ask the participants to remember a time when someone they knew passed away. If participants prefer, they can choose to remember someone who was not very close to them. Or if they prefer, they can think about someone else's loss and what they observed.

Ask the following questions, allowing time for people to think about what happened:

- *How were you given the news that this person*

passed away?

- *What did people say to you or do?*
- *What did you find unhelpful about what they said?*
- *What did you find helpful about what they said?*
- *What did you do that helped you to cope with the loss?*
- *What did you do to honour the memory of the deceased?*

You may wish to comment that loss is an issue that affects us all, and the sadness that we feel when we remember our loss is a way of honouring the importance of that relationship to us.

When participants are ready, ask them to share their answers in small groups. Encourage each group to give each person enough time to talk about their experience. Explain that participation is voluntary.

Take time afterwards to reflect on the discussions in the plenary. Draw out the themes of what is helpful for people when they experience loss. Discuss if the group would like to do anything to honour the memory of the deceased, like saying a prayer together, lighting candles or writing their names on a large piece of paper on the wall, with a message to that person.

At the end of the session, facilitate a go-around where you ask each person how they are feeling after sharing their experiences. Follow up individually with any people who need extra support. Especially listen out for anyone who lost someone under traumatic circumstances.

You will find other useful prompts or questions that you can use to have an emotionally safe discussion with the older carers in Appendix 1.

It is also helpful to make space to talk to older carers about her worries and fears about the future. Here are some ideas about how to do this in a safe and constructive way:

- Ask the older carer if she wants to discuss her concerns and fears about the future.
- Help the older carer to identify the skills and

knowledge/expertise that she has that can help her to cope with some of the fears that she may have about the present and the future.

- Think together about other family members who may be able to assist.
- If the children are old enough, conduct a joint family session to discuss resources the family has to deal with some of the problems that they are facing or are likely to face in the future.
- The community caregiver can make suggestions about how other service providers such as social welfare, local organisations and institutions could come in and be of help. It is equally important to help the family to understand that they have a lot strengths and resources to deal with some of the identified problems.

Another way you may support older carers is to assist her to talk to the children under her care about their own experiences of loss. Here are some ideas about how to do this in a safe way:

- Sometimes due to their own experiences of loss and grief older carers may find it difficult to comfort and support the children under their care to cope with the loss of their parents. Thus they may need the assistance from the community caregiver.
- Explain to the older carer that children, like adults, experience grief and thus they need to be supported. If children do not receive the necessary support this can complicate their lives and even disturb the functioning of the family. Be sensitive to cultural beliefs, especially when working with the older carer.
- Agree with the older carer about what should happen and what should be said during the conversation with the children.

The following points may be useful when talking to children about their experiences of grief:

- Encourage the children to talk freely about the person who has died.
- Tell the children that everyone dies although we do not know when someone will die. Some people die old and some people die when they are still young.

- Encourage them to ask any questions about the deceased even long after the person has died.
- Encourage the inclusion of children in the grieving rituals practiced in their families, exploring culturally appropriate ways for children to be involved.
- Children should be given the chance to find their own ways of expressing their grief, such as writing a letter or poem to the deceased, saying a special prayer, laying flowers, or bringing a special picture to the grave.
- Be honest (and age sensitive) about what has happened to the person who has died.
- Explain the changes that are likely to happen in the children's lives due to the death of the loved one.
- Where possible children should be given some choices about what will happen in the future, for example regarding living arrangements.

Facilitating processes of treasuring the memory of the deceased is a way of honouring their departure. Here are some ideas about how to facilitate processes of remembrance:

- Ask the older carer and the children if they would like to do special things to treasure the memories of their loved ones. You can facilitate remembering through memory books, putting together a photo album, recording special songs, writing letters/poems, making memory blankets, or making memory boxes/baskets.
- Allow the children to keep special objects in memory of their loved one.

For more information about different types of memory work, see the manuals available free of charge at www.repssi.org, or speak to your REPSSI sub-regional manager.

5.3. Complicated Grief

The sadness of losing someone special may never disappear completely but it should not be so central to a person's life such that it becomes disabling for them. Grief should not stop people from moving on with their lives. If this is the case it may mean that

such an individual is suffering from what is called complicated grief.

Signs of complicated grief in older carers could include the following (however it is important to note that these signs might be from other causes):

- Depression (intense prolonged sadness)
- Poor appetite for long periods of time
- Hopelessness
- Neglect towards children and self
- Not wanting to interact with others
- Overwhelming thoughts or images of the deceased much of the time
- Denial or a continued sense of disbelief about the death of the loved one
- Avoiding all things that remind the older carer of the loved one
- Intense anger and bitterness
- Feeling that life is empty or meaningless, to a point of even wanting to end one's life
- Intense yearning or physically searching for the deceased loved one
- Inability to perform normal everyday activities
- Lack of trust in others
- Emotional numbness or detachment from others.

Many of these signs are normal grief responses for several months after the loss of a loved one. However, if they continue longer than six months after the loss, or become gradually worse over time, this may be cause for concern. Community caregivers should then refer older carers for specialised counselling services that can be provided by social workers, psychologists, lay and professional counsellors. However, even if older carers are referred for specialised counselling services, ongoing encouragement and emotional support from the community caregiver are still

very necessary. Support groups where older carers assist one another through complicated grief may also be helpful.

5.4. The importance of future planning and opportunities to say goodbye

Community caregivers can be proactive in dealing with matters of death and bereavement. Long before a person dies family members begin to grieve as they anticipate the likelihood that their loved one will eventually die. This is called anticipatory grief. Anticipatory grief is associated with discussing the possibility of death, thinking about what will happen should the person die, what the future will be like without the person, discussing death with the ill person and trying to adjust to new roles¹⁰

Where possible, community caregivers can facilitate discussions between the older carer, children and the ill person so that planning for the future is done jointly. This will help to alleviate stress for both the older carer and the children who remain behind. It also provides precious opportunities to say good bye. Issues that can be discussed include:

- The wishes of the dying parent about the future of the children
- Funeral arrangements e.g. whether the ill person is a member of a burial society
- Writing of wills and protecting property that should benefit the children that remain behind
- Disclosure of sensitive issues e.g. the whereabouts of another parent of the children for easier access to birth registration
- Disclosure about the cause of illness
- The whereabouts of important documents e.g. life insurance policies, birth certificates, marriage certificates.

Often the wish to discuss these important matters comes from the person who is dying. It is as if they know what is helpful to talk about in order to relieve their stress. So try to be sensitive to listen for small clues about a person who wishes to talk about dying. Here are some common things that

¹⁰ Shebi M, *The experiences and coping strategies of HIV/AIDS primary caregivers, 2006*

people say to show that they are ready to talk about sensitive aspects of death and dying:

- I worry about what will happen when I am gone
- I wish I had more time to sort things out
- Do you believe in heaven? Or: What do you think about the afterlife?
- Do you really think God can forgive any sin?

If you do not pick up any clues that someone wants to talk about death or dying, it can be helpful to say to someone “Many people who are sick find it helpful to talk about things that are worrying them. Please know that I am here to listen if there are things you want to talk about.”

When you hear these clues, try to stay calm and use this as a gentle opportunity to ask more about what that person is thinking. Try not to rush in with your answers or advice, but use it as an opportunity to listen. For example you could say “I have also often wondered about that question. What is your take on it?”

Once you have listened well, you can offer reassurances where appropriate. For example you could say “That is a difficult question, but what I do know is that everyone I have been with who has passed away looked very peaceful and happy. Even if they were scared earlier on – when the time finally came, it was like they went into a very peaceful rest.”

Look at the quiz given in the table below and indicate with an X whether the statements given are True or False

Quiz about grief

Statements about loss and bereavement	True	False
1. Grief is an normal and important emotional response to loss		
2. Multiple losses over a short period of time can lead to complicated grief		
3. Talking to others about your pain and feelings after the death of a loved one can reduce the burden of grief		
4. There is no one correct way to grieve. The way people grieve can be influenced by many factors including an individual’s personality and coping style etc.		

5. Complicated grief is like being stuck in an intense state of mourning		
6. Older carers need to be supported to talk openly to the children under their care about the deaths that have occurred in the family especially the death of their parents		
7. Treasuring the memories of the deceased loved one can be healing for both the older carer and the children that remain behind		
8. Talking about a deceased loved one should not always be sad.		
9. People can be supported to celebrate the lives of special people who have died by recalling the wonderful times that they shared with them.		

By now you have probably realised that all the answers to the statements above are TRUE.

5.5. Action planning

Think about the organisation that you work with. How effective do you think it is currently in providing bereavement support to older carers and their families? Reflect on each of the questions given below and score how well you think your organisation is doing on each of the attributes given. You can give a score of between 1 and 5 where 1 is a very poor score and 5 is an excellent score. After giving a score, suggest what needs to be done in the organisation to improve its' scores.

How our organisation is supporting older carers with loss

Question	Rating					What needs to improve?
	1=poor	2	3	4	5=excellent	
• Community caregivers in my organisation are trained in basic counselling skills and specifically in bereavement counselling	1	2	3	4	5	
• We provide special support like visiting older carers and attending the funeral when they have lost someone close to them	1	2	3	4	5	
• We have developed tools and methodologies to help us to assess how well an older carer and the children under her care are coping after the loss of a loved one	1	2	3	4	5	

<ul style="list-style-type: none"> Community caregivers set aside time to talk regularly to older carers and children about their feelings and experiences after the loss of a loved one 	1	2	3	4	5	
<ul style="list-style-type: none"> Community caregivers offer different memory work tools to facilitate remembering of loved ones as a way to help older carers and children to heal 	1	2	3	4	5	
<ul style="list-style-type: none"> We are very gender sensitive and thus we are aware of the different ways in which older men and women grieve and try to assist them accordingly 	1	2	3	4	5	
<ul style="list-style-type: none"> We encourage the involvement of children in family rituals held in memory of deceased loved ones 	1	2	3	4	5	
<ul style="list-style-type: none"> The organisation provides opportunities for debriefing and self care for community caregivers so that they do not experience emotional overload and burnout as a result of tackling difficult issues such as loss and bereavement 	1	2	3	4	5	

Having completed the assessment above, what steps do you think your organisation will need to take to provide more effective bereavement counselling to older carers and their families? Write the steps below or discuss them with others in the group.

Write your ideas in the space provided or discuss with people in the group

Helpful ideas and tips

- *Remember that people who have lost a loved one go through difficult times, such as the anniversary of the death, birthdays, Christmas, etc. It is important for the community caregiver to be mindful of these times and offer additional support to those who are affected.*
- *Sharing religious memorial ceremonies and holding some form of memorial ritual on the deceased loved one's birthday may be helpful. The older carer should be consulted about whether or not this would be helpful for her, and if so, how it should be done.*
- *Community caregivers involved in bereavement counselling and dealing with emotional issues affecting the lives of people need to have self care skills so that they do not become emotionally exhausted by this work.*

Case study and reflection questions

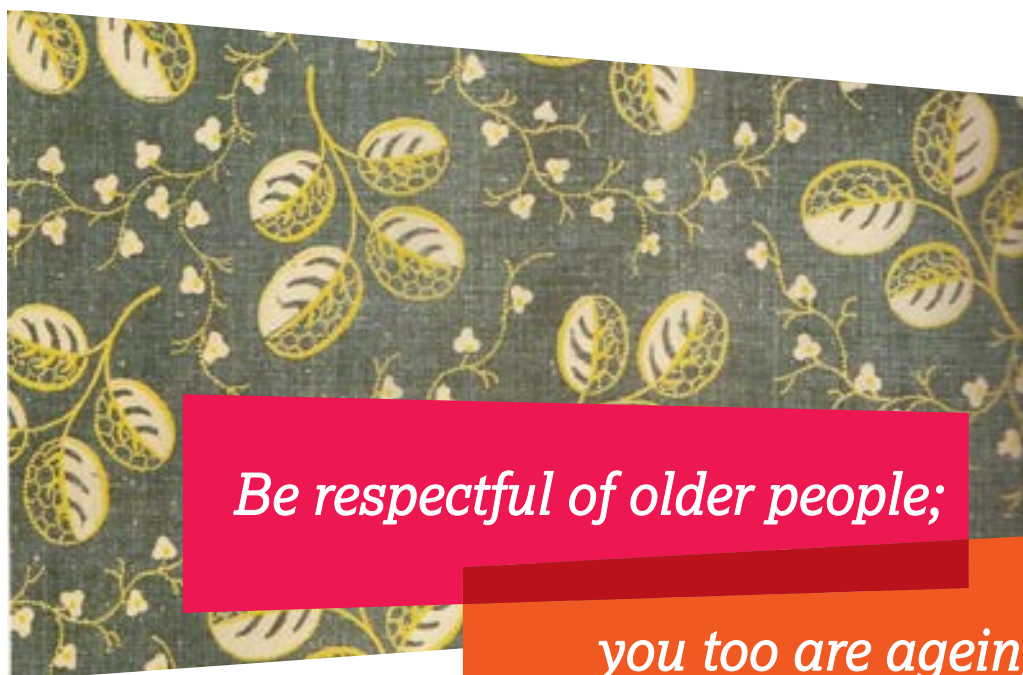
"I am taking care of 13 orphans left behind by my seven sons. We used to own a lot of land on which my sons built their homes, so whenever I leave my house I can see their houses mostly in ruins as well as the graves of my sons and their wives. Thus I am often reminded of them and their deaths, and feel sad." – Rivonia, a 70-year-old woman in Uganda.

UWESO Uganda. The HIV/AIDS Alliance and HelpAge, Building Blocks- Africa wide briefing notes "Supporting older carers" 2004

Reflection questions

How can Rivonia be supported to cope with her experience of grief?

If you were a community caregiver working with Rivonia, what support would you provide to her and the children under her care so that they are able to cope with the losses that they have experienced in their family?



Be respectful of older people;

you too are ageing

Unit 6

Protecting against abuse and exploitation

What you will learn in this unit:

- *Types of abuse older caregivers and those under their care experience*
- *Strategies that community caregivers can use to protect and support older caregivers and their families from abuse*
- *How to develop your own organisational policy about how to deal with cases of abuse of older carers*
- *How to identify children who have been abused and distressed families*
- *Staying safe as a community caregiver*

6.1. Experiences of abuse that older carers and those under their care go through

Abuse and exploitation are often a result of extreme stress and poverty. However, older people, people living with HIV, and children all have rights and entitlements that need to be protected, but these people are at risk of many kinds of abuse and forms of exploitation because of being seen as relatively vulnerable. Furthermore, these groups are often not aware of their rights. Even when they are informed they often feel that they can do little to protect or enjoy their rights.

Community caregivers can help older carers and those under their care to protect themselves from abuse and exploitation. Cycles of abuse are unhealthy for everyone involved, and cycles of abuse may often be broken with caring support and attention to the needs of different people in the family. Your presence as a community caregiver can help to bring accountability and respect into a family affected by abuse.

Common abuse experienced by older carers and members of their households

- Exclusion from community activities
- Stigma and discrimination of HIV and AIDS

affected households

- Accusations of witchcraft
- Property grabbing and disinheritance
- Sexual abuse
- Emotional abuse
- Physical abuse
- Child labour
- Neglect
- Theft
- Violence
- Denial of access to important services e.g. health care, housing, for identity document.

6.2. Strategies that community caregivers can use to support older carers and those under their care to deal with different forms of abuse

Sometimes it is helpful to have someone from outside the family hear about what is happening in order to promote change (this is called accountability).

Here are some other helpful ideas about how to support carers in situations of abuse:

- Provide age appropriate information to older carers, people living with HIV, and orphaned and vulnerable children about their rights and entitlements. Let them know about existing laws that protect them. Help them through the procedures and to secure correct documentation so that they can access the necessary support
- Inform the older carers and children about protective agencies that they may need to contact for specific assistance
- Help older people to protect the property rights of the children in their care by ensuring that they are well informed about their own and the children's rights and know how to protect them

- Involve legal professionals and community leaders in resolving issues of land security, inheritance, and other disputes. Advocate for paralegal services so that older carers, people living with HIV and orphaned children can access legal support/advice as and when necessary
- Report cases of abuse to relevant authorities
- Provide counselling and guidance to affected individuals and families
- Assist by accompanying older carers to health facilities, social welfare offices etc
- Lobby for transportation of older carers and those under their care to and from different service points
- Help individuals who have experienced abuse to join support groups
- Participate in community education and awareness on the needs of the older carer, PLHIV, and OVC discouraging all forms of abuse
- Support access to education for OVC, especially where policies for school fees exemptions exist
- Visit family members or community members involved in abuse to hear about their needs and to understand the underlying reasons why they may be abusing older carers.

It is important to point out that it is not the sole responsibility of the community caregivers to apply the above strategies. Organisations and other stakeholders need to participate so that the efforts of community caregivers become fruitful.

6.3. Identifying signs of abuse in children

Children may be the victims of abuse in a family under extreme stress. Here are some signs to look out for in identifying children who have been abused, either by neglect, physical abuse and violence or sexual abuse.

- Sudden changes in behaviour - like becoming suddenly aggressive or withdrawn or dependent
- Bruises, repeated injuries such as broken arms or legs

- Children becoming clinging, and fearful, especially of adults (although this is normal for a short period around the age of 1 to 2 years, and we call this separation anxiety)
- Flinching (reacting with fear) when someone raises their hand or expresses anger
- Inappropriate knowledge of sexuality for their age, usually shown in language, drawings or actions which may be shown through playing sexual games, or seductive behaviour, although bear in mind that some interest in bodies and sexual behaviour is appropriate at certain ages
- Loss of appetite or compulsive eating
- Restlessness, very attention seeking or bad behaviour
- Regressing to a “younger” behaviour such as thumb sucking, bed wetting and baby-talk
- The child may seem generally unhappy and worries a lot
- Sudden drop in school performance
- Refusal to go to school and even fear of going out of the house
- Fear about going to specific people or places
- Not able to concentrate or pay attention.

6.4. Staying safe as a community caregiver

Working with families can be quite challenging, especially when one is dealing with very sensitive conflict issues. Family issues where there is violence or abuse taking place need to be referred to specialised services such as traditional leadership, welfare departments, police etc. Protect yourself as a community worker at all costs by avoiding situations that could result in you being harmed. The checklist below will help you to assess potentially dangerous situations that you need to stay away from.

Risk Assessment Checklist

These questions identify a number of danger signs in the situations and behaviours of individuals/families in conflict/dispute. When there is potential for harm, safety measures may be necessary to protect family members and community caregivers. Danger signs should be assessed before, during, and after contacts with families.

Situations

- Does the family have a history of child abuse/neglect or other forms of family violence?
- Is there any information to suggest a family member is (or may be) emotionally unstable?
- Is there any information regarding the family's access to guns or other weapons?
- Does the family live in an extremely isolated location, in a dangerous neighbourhood?
- Does the family keep any dangerous animals in the home or yard?
- Does the home environment appear unsafe for children due to deteriorating physical conditions or a lack of other basic necessities?
- Do you sense that the family situation is unsafe? Are your instincts signalling danger?

Behaviours

- Is violent or aggressive behaviour displayed by the family, friends, and/or relatives?
- Is substance abuse or drug dealing an issue in the family?
- Has an adult family member ever shown sharp mood swings or other types of volatile behaviour?
- Has an adult family member ever made verbal threats, screamed, or cursed at you?
- Has an adult family member ever caused property damage at home or elsewhere during an outburst of anger?

- Has an adult family member ever physically assaulted anyone?
- Has an adult family member ever been arrested for physical assault, disorderly conduct, or property damage?
- Is any family member threatening to harm himself/herself or someone else?
- Have there been any reports of reckless driving on the part of a family member?
- Has a family member ever talked about committing a violent act?
- Has a family member ever expressed fears or concerns about losing control, taking a drug overdose, or harming someone?
- Do family member's words or actions suggest being out of touch with reality?
- Being suicidal? Being severely depressed?
- During conversations with family members, have you noticed any bodily signs of escalating aggression such as changes in breathing patterns, or posture?
- During conversations with family members, have you noticed a sudden increase in anger, brooding, or; irritability; verbal outbursts; pacing; restlessness; agitation; or testing limits?
- Have the behaviours of any family member ever frightened you?

Source: Emthunzini Family Preservation Manual, 2008

If you have any doubts about the safety of a family visit, make sure that you bring someone with you to the visit, and rather refer the situation to a professional.

6.5. How your organisation deals with cases of abuse

No matter what type of work your organisation is involved in, we all have a responsibility to do something about abuse of older carers, families or

children. It will depend on what type of work your organisation does just how involved you become in situations of family abuse. It is a good idea to be clear about what your staff and volunteers are expected to do when they come across situations of abuse. Once you have agreed on what is expected in your organisation, you may even wish to write this out in a policy. Here is a simple example from an organisation involved in home based care:

Dealing with Cases of Suspected Abuse Organisational Policy

Our organisation recognises the right of all family members to safety from abuse, neglect and harm. This applies to older carers, adults and children. When we come across cases of emotional, physical or sexual abuse and neglect, we will do the following:

- Report the matter to a member of management in the organisation who will supervise the case
- Visit the family to see what the conditions are like and to assess if our suspicions of abuse are confirmed or strengthened
- If we think there is no actual abuse yet but there is a risk of potential abuse we will build a relationship with that family and monitor the situation. We will try to understand the risk factors and provide support to reduce the risk of abuse. If we feel that the risk remains high we will report the situation to the Department of Welfare
- If there are any signs of possible abuse or neglect we will report the situation to the Department of Welfare
- We will inform the family of our intention to seek assistance from the Department of Welfare if we feel that it is safe to do so
- We will follow up the situation within a week to see that there has been a formal assessment and response
- If there is an immediate risk of child abuse, or ongoing abuse, we will insist on urgent action by the Department of Welfare and make necessary safety arrangements

- We will continue to build a relationship with the family to support them through this process
- When common issues about abuse come from several families, we will take these suggestions forward to the relevant government departments to promote change.

Your own organisational policy might look quite different, depending on the type of work that you do, and depending on how far down the journey of developing your capacity to provide psychosocial and practical support for cases of abuse you are.

Practical exercise:

Develop your own organisational policy on abuse

Here are some things for you to think about if you decide to develop your own policy about suspected abuse:

- *In what situations do you have to report suspected abuse? Many countries have specific laws about this, for example in South Africa if you even think (suspect) that maybe a child might be neglected or abused you have to report it to the Department of Social Development (Welfare) or Police.*
- *To whom do you report this suspected abuse – within the organisation and to which authorities?*
- *Do you assess this abuse yourselves or simply report it and make sure that the case is followed up?*
- *What type of support do you provide for families affected by abuse? For example do you offer counselling, do you go with them to report the abuse, do you accompany them in all the legal aspects, do you provide shelter or material support?*
- *When you think it is not a case of abuse as such, but a case of potential risk for abuse, what do you do?*
- *How much do you involve the family in the decisions and how much do you keep them informed of the situation?*

HelpAge has a Protection Policy for protection against abuse. For a full version of this comprehensive policy, please email: protection@helpage.org.

6.6. Action planning

Write down four practical steps that you think your organisation should take to improve its strategies or ways of supporting older carers and their families to deal with abuse:

Step 1	
Step 2	
Step 3	
Step 4	

Helpful ideas and tips

- *Ensure the best interest of children at all times. In very intense situations of violence children or perpetrators of the violence may need to be temporarily removed. This can be done with the intervention of social welfare departments.*
- *Where there is a specific perpetrator that has been identified, it is better to arrange for the removal of the perpetrator rather than the children, so that the children's lives stay calm and similar to what they were.*
- *At all times, situations of suspected abuse should be handled calmly and quietly. Unnecessary drama makes the experience worse for the family and especially children.*
- *Children usually interpret situations by watching how their parents or carers respond. Try to keep parents calm in front of children.*
- *When working with families that are highly conflicted it is advisable that community caregivers should attend such situations accompanied by other team members.*
- *Your safety as a community caregiver is very important. If you sense danger, inform your supervisor and other members of your team.*

Case study and reflection questions

“When my daughter Martha died of AIDS three years ago, her husbands’ family came to loot everything in the house. They literally left us with nothing; now I am suffering with the children. The youngest child is malnourished and is often very sick. No one helps me to look after the four children that my daughter and her husband left behind. We struggle with food, blankets, clothing for the children, school supplies and medicine for the sick child. I am constantly hurting inside as my grandchildren tell me about the horrible things that people in our village say about us. I sometimes want to give up but when I look at the children I am driven to tears because I know they need me.” - Gogo Marema - 74 years, Zimbabwe

Source: From consultations made by author, 2009

Reflection questions

1. *In what ways has Gogo Marema’s family suffered abuse and exploitation?*
2. *How do the experiences of Gogo Marema and the children affect them emotionally and physically?*
3. *What rights and entitlements is this family not able to access?*
4. *What are some of the reasons why this family and*

other similar families are vulnerable to abuse and exploitation?

5. Who are the people who commit such abuse to older carers and those in their care? Why do some people commit these abuses?

6. What can we do to help such families?

From the observations that you have made in the communities that you work with, what forms of abuse/exploitation do you see older carers and those under their care experience? Write your ideas in the space below or discuss with others in the group:

Unit 7

Working with male older carers

What you will learn in this unit:

- *Why men's involvement in caring is important*
- *Barriers to men's involvement in caring*
- *Ways that older male caregivers can be supported to provide care to orphaned and vulnerable children and people living with HIV*
- *Strategies for encouraging men's involvement in caring*

"The one who really helps me is my uncle. He takes me to the clinic and makes sure that I take my medicine every day." Child living with AIDS

7.1. Men's involvement in the provision of care

At family level the burden of care for PLHIV and OVC is borne predominantly by older women and girls¹¹. Research by HelpAge shows that it is the grandmothers, rather than the grandfathers, who tend to provide care at family level. The ratio is that 80 per cent of grandmothers as compared to 20 per cent of grandfathers provide of the burden of care that is provided at household level. There is evidence to show that in some countries in Africa men are increasingly willing to take an active role in the physical care of sick family members and children. However, the involvement of men is often limited and thus needs to be encouraged.

"I would like to be more involved in taking care of my sick wife and cleaning the house, but the neighbours keep laughing at me and chasing me away, saying that this is women's work. It makes me frustrated because I end up just sitting outside and not doing anything." Comment by a grandfather

Why men's involvement in caring is important

Encouraging men to be more involved in caring for children and people living with HIV is very rewarding because:

- It reduces the burden of caring for OVC and PLHIV on women and girls
- In the absence of female carers due to death or other social responsibilities, children and the sick can still receive good quality care
- It challenges gender stereotypes that limit choices for men and women
- It creates new role-models of men as carers making it more possible for younger men to step comfortably into caring responsibilities
- Men become equal partners with women in the fight against HIV and AIDS
- It can lead to behaviour change in men as they confront more directly the consequences of HIV and AIDS through their caring responsibilities
- Men may have a lot of influence within communities, hence their involvement in caring sets an example to everyone
- Men may have the opportunity to form support groups to provide psychosocial care and support to one another.

7.2. Barriers to men's involvement in caring

Practical exercise:

Understanding people's reactions to male involvement in caring

This is a fun exercise which may be facilitated with others in your organisation or with older carers.

Divide participants into 3 groups and ask each group to develop a roleplay (drama) on one of the following 3 scenarios:

- *An older male carer takes an orphaned child to the clinic for treatment*
- *An older male carer wishes to learn home based care skills to take care of his sick wife*
- *A community leader holds a public meeting with older men to encourage them to be involved in caring for children and people living with HIV in the community*

¹¹ Reducing the Burden of HIV and AIDS Care on Women and Girls, VSO, 2006

The roleplays should show various reactions of various community members to the involvement of men in caring roles.

Once each group has presented their roleplay, spend some time discussing the responses of the community members to the role of men in caring. Discuss the following questions:

- *What are the underlying reasons why people react like this?*
- *How do both men and women contribute towards this challenge?*
- *What may be done to encourage older men to be more involved in caring for others?*

Here are some further thoughts about what often stops men from being more involved in the care of children and sick people.

Cultural and social barriers

- Community based caring initiatives generally lack male presence. This means that male involvement may be an intimidating experience for the few men who try it out; they are usually outnumbered and may face criticism from women.
- Men often lack confidence in their parenting skills, intergenerational communication (particularly regarding sexuality), domestic skills, child care skills, and in caring for the sick.
- Men are sometimes teased when they are assuming caring roles.
- Women may feel uncomfortable working side by side men when providing care.
- In traditional African society men rarely seek counselling or form support clubs with each other to seek psychosocial support.
- Men fear being labelled as less masculine when they are involved in child care and care of the sick.
- Male carers believe that they are the bread winners in the family and the burden of care hinders men from getting involved in caring.
- Men with polygamous families may see it very

complicated to be involved in caring and they may feel underrated.

- Men may fear having their caring actions misinterpreted as some form of opportunity for abuse.

Traditional attitudes in many cultures towards childcare are that it is a woman's job. Traditional norms of masculinity also portray men as the providers and not a carer. Unfortunately, especially in the case of non-residential fathers, society tends to emphasise men's role as provider at the expense of the other roles of carer and protector.

Individual and family level barriers

- Work commitments make it difficult for some men to be involved in caring responsibilities.
- Family conflict, such as divorce, can be a barrier to fathers' or men's involvement in the lives of their children.
- There may be a lack of knowledge about the importance of fathers' or men's involvement and its impact on children's development.
- Personal characteristics – shyness and lack of confidence may be a barrier for some men. It often takes quite a confident man to go against social stereotypes.

Programme level barriers

- Programme managers and staff can be a barrier if they do not understand the importance and need for men in caring initiatives.
- Even if they understand the importance of male involvement, community caregivers may lack the skills to facilitate their involvement.
- When activities are arranged during normal office hours, they may automatically exclude men as most are engaged in their traditional role of family provider.
- If female dominated care giving programmes do not plan carefully, activities may be biased towards female participation.

- Passing jokes that make fun of men who are involved in caring could make some men uncomfortable about their involvement.

7.3. How to support older male carers in caring roles

Skills that older male carers may be assisted to develop include:

1. Parenting skills

- Support older male carers by arranging opportunities for them to get together with other older carers (men and women) and talk about parenting, sharing skills and knowledge about how to deal with different parenting problems etc.
- Offer home based counselling and support on parenting matters when you visit older male headed households.
- Make opportunities to have sessions with the children being cared for by the older male carer. In these sessions you can talk to the children about how they can be supportive to their carer, discipline etc.
- Joint sessions between the children and the carer can also be a very useful platform for discussing matters affecting the family.

2. Household management skills

- Offer training on household management to older carers and the children in their care so that they can support each other to manage the household.
- Community caregivers can occasionally support the older carer by doing some of the house work.
- Mobilise support from other family members, Faith Based Organisations (FBOs), neighbours and youth organisations that can drop in occasionally to support the older male carer household with domestic chores.

3. Limited social networking skills

- Encourage older male carers to join support groups for the older in their communities. If these support groups do not exist you can assist by starting such a support group.

- Support carers to identify people in their families, communities etc who can be supportive to them in anyway. Assist the older carer to make contact with such people.

- Older male carers can be encouraged to join local churches, clubs and associations where possible.

- Encourage men that they have resources to offer others that may be valued.

4. Caring for the sick

- Provide age appropriate training in palliative care and HIV prevention, ARV adherence for children who need such treatment, recognition of common childhood illnesses and referral to health facilities.

5. Male carers may not be as open about their feelings, problems and emotional problems as women

- Build a trusting relationship with men by focusing on practical matters, asking their advice where appropriate and linking them with other men who are in similar positions.
- Focus on what men are doing well.
- Explain the value of talking about one's experiences and thoughts. Emphasise that a problem shared is half solved.

- Where possible male community caregivers may work directly with older male carers heading households as this can make it easier for the carers to open up to another male.

7.4. Action planning

Read the ideas or strategies given below for encouraging men's involvement in caring and plan how your organisation could go about implementing the different strategies. Use the table given to fill in your ideas

1. Educating community and religious leaders, and traditional leaders about the importance of involving men.
2. Sensitising the community to the involvement of men, and obtaining their buy-in.

3. Providing both mixed-sex and single-sex discussion forums, to allow people to address concerns about involving men.
4. Considering both monetary and non-monetary incentives (such as training, food or food gardens) for men and women.
5. Challenging gender stereotypes.
6. Creating new role-models for men as carers.

Encouraging male involvement in caring

Strategy	Plan of Action	Responsible person
Community mobilisation and sensitisation	Example <ul style="list-style-type: none"> • Mobilise male community caregivers to make presentations to community, religious and traditional leaders about the importance of men involvement in caring • Come up with dramas, songs etc that communicate the importance of men’s involvement in caring • Organise children and PLHIV to talk about how it has been or would be helpful to them if men were more involved in caring 	Supervisor, Programme Manager and community caregivers

Helpful ideas and tips

- *Share good practices about men’s involvement in caring by arranging regular opportunities to discuss and share experiences through community meetings, story-telling, local theatre etc*
- *Encourage existing male caregivers to take the lead in encouraging the greater involvement of men in caring*

Case study and reflection questions

“Looking after orphans is like starting life over again because I have to work on the farm, clean the house, feed the children, buy school uniforms”, said a 65 years old man in Manicaland, Zimbabwe who has

become the main carer of three school-age children. “I thought I would never do these things again.”

Adapted from The International HIV/AIDS Alliance and HelpAge, Building Blocks- Africa wide briefing notes “Supporting older carers” 2004

Reflection questions

- 1. If you were working in a community with the older carer mentioned in the case study, how would you support him as a community caregiver?*
- 2. What skills do you think older male carers lack?*
- 3. What other ways can older carers be supported to care for children and people living with HIV?*

Write down your ideas in the space below, or discuss them with your group



With a little support

older people make a big difference

Unit 8

Self care skills for older carers

What you will learn in this unit:

- The importance of self care
- To identify signs of burnout and compassion fatigue of older carers
- Helpful self care practices for older carers

8.1. The value of self care

People with caring roles that involve looking after people who are sick and dying, listening to stories of fear, pain and suffering of others may feel similar fear, pain and suffering because they care. Older carers are vulnerable to stress, burnout and compassion fatigue because of the nature of their role. Self care is an important skill that all people with caring responsibilities need to have.

Read the definitions below and answer the questions that follow

Useful self care definitions

Stress

Stress is normal. It is our bodies' reaction to challenging situations. However, if stress lasts too long, the body's resources will be exhausted and the person will develop harmful or negative forms of stress reactions..

Burnout

Burnout happens when there is too much stress over a long time. The body and mind become exhausted from coping with so much stress. Signs of burnout include: loss of interest in the world, caring less about the suffering of others, irritability or temper outbursts, substance abuse, loss of meaning in work, absenteeism, and sudden resignation.

Compassion fatigue

Compassion fatigue is when we have used up a lot of our care and compassion for others while working with the suffering of others. We become emotionally exhausted and find it difficult to be kind to others. We may become hardened and seem uncaring to others^{1,2}

Practical exercise:

How stressed are you?

1. *Have you ever experienced any the signs and symptoms described above?*
2. *How does it affect your work and family life when you experience these signs and symptoms?*
3. *How do you cope and get better after going through these experiences?*
4. *Who are the people who support you when you go through these experiences?*
5. *Draw a picture of your personal social support network*

8.2. Common causes for stress, burnout and compassion fatigue among older carers and possible solutions

Older carers often carry a heavy emotional load. Many carers have been through multiple losses and grief. This is made worse if there is a lack of emotional support and if there are other daily stressors like the struggle to provide food and clothing for the family. This table shows some of the causes of stress that are commonly reported by older carers and which can lead to burnout and compassion fatigue.

^{1,2} Professor Alta C. Van Dyk, Occupational stress experienced by caregivers working in the HIV and AIDS field in South Africa, 2006

Stressors and possible support for older carers

Stressors	Possible ways to support older carers to deal with stressors
Bereavement overload	<ul style="list-style-type: none"> • Encourage older carers to talk about their pain and fears and help them to identify self comforting measures e.g. prayer, singing, taking walks, or talking to a friend.
Stigmatisation	<ul style="list-style-type: none"> • Encourage the carer to get into the habit of thinking positively about themselves and practicing self encouragement. They should not focus on the negative things that are said about them in the family or community. • Challenge community stigma by raising awareness and improving the knowledge of the community about specific aspects relating to stigma and discrimination.
Lack of support from family and community members	<ul style="list-style-type: none"> • Help the older carer to understand that she has the capacity to form or develop relationships. Support her and those in her care to form or develop new connections with people who share similar experiences. • Encourage the involvement of family and community members.
Lack of training and skills to care for PLHIV and OVC, and fear of infection of HIV.	<ul style="list-style-type: none"> • Offer training and knowledge about HIV, parenting skills etc. • Encourage older carers and the children under their care to go for HIV testing.
Lack of property ownership	<ul style="list-style-type: none"> • Encourage families and support organisations to assist older carers to legally own their properties and organise inheritance rights to chosen family members.
Illiteracy	<ul style="list-style-type: none"> • Literacy support programmes may assist older carers. Sensitisation about this issue may help community members find ways of assisting illiterate carers.

8.3. Identifying signs of stress, burnout and compassion fatigue

It is important to be able to notice signs of stress, burnout or compassion fatigue in older carers. This will help them to seek the necessary counselling and support.

Examples of Compassion Fatigue and Burnout

Cognitive	Emotional	Behavioural	Spiritual
<ul style="list-style-type: none"> Lowered concentration Decreased self esteem Apathy Rigidity Disorientation Perfectionism Minimization Preoccupation with trauma Thoughts of self harm or harming others 	<ul style="list-style-type: none"> Powerlessness Anxiety Guilt Anger/Rage Numbness Fear Helplessness Sadness Depression Emotional Roller Coaster Depleted Overly sensitive 	<ul style="list-style-type: none"> Impatient Irritable Withdrawn Moody Regression Sleep disturbance Nightmares Appetite changes Hyper vigilance Elevated startle response Accident proneness Losing things 	<ul style="list-style-type: none"> Questioning the meaning of life Loss of purpose Lack of self satisfaction Hopelessness Anger at God Questioning prior religious beliefs Loss of faith in higher power Greater scepticism about religion

Examples of Compassion Fatigue and Burnout (continued)

Personal Relationships	Physical/Somatic	Work Performance
<ul style="list-style-type: none"> • Withdrawal • Decreased interest in intimacy or sex • Mistrust • Isolation from others • Over protection as a parent • Projection of anger or blame • Intolerance • Loneliness • Increased interpersonal conflicts 	<ul style="list-style-type: none"> • Shock • Sweating • Rapid heartbeat • Breathing difficulties • Aches and pains • Dizziness • Increased number and intensity of medical maladies • Impaired immune system • Other somatic complaints 	<ul style="list-style-type: none"> • Low morale • Low motivation • Avoiding tasks • Obsession about detail • Apathy • Negativity • Lack of appreciation • Detachment • Poor communication • Staff conflict • Absenteeism • Exhaustion • Withdrawal from colleagues

8.4. General self care skills

Burnout and compassion fatigue are becoming increasingly common and there is a lot of writing being done about the importance of carers taking better care of themselves. Here are some ideas about self care:

- Help carers to be aware of their limitations or weaknesses and be honest with others when they cannot give certain types of help. It is alright to say, “Sorry I cannot attend to this right now” or “Sorry I am not available on that day.”
- Carers may be assisted to structure their day. Help them to decide on the hours of the day when they will work and when they will rest. Encourage them to have at least one day of rest each week if

possible.

- Encourage carers to take time out to do leisure or fun activities and spend quality time with family and friends. If they are rested they may be more caring to the children and sick people in their care. They will also enjoy a healthier life.
- Encourage carers to ask for help from trusted friends and family members. It is important to invest in relationships with others who can become an ongoing source of strength and support.
- When there are problems in the family or in the community, encourage carers to try to sit down and talk them through immediately so that they are not carrying them around.

- Religious faith is a powerful source of comfort to many people. Many older carers say that talking to God, praying or reading spiritual books is helpful to them.

Older people may neglect to care for themselves because their focus is more about ensuring the wellbeing of those under their care. Self care is particularly important for older carers as they may be frail, weak and advanced in age, making them very vulnerable to ill health and stress. The following points could assist you to impart self care skills to older carers:

- Explain to older carers about stress, burnout, physical and emotional exhaustion, and how they are vulnerable to these conditions if they do not practice self care.
- Discuss some of the signs and symptoms of stress and burnout as outlined in the above table and emphasise the importance for carers to be able to recognise those signs in themselves.
- Discuss helpful self care practices that could be useful to older carers e.g. using their social support systems to share and discuss the problems that they are facing.
- Emphasise the importance of taking “time out” - that is for carers to have time for themselves to relax, have fun and forget about their problems at home.
- Encourage older carers to work together with friends to arrange cost effective special outings or holidays or family visits that they can look forward to.
- Encourage older carers and their families to celebrate life by finding special but cost effective ways of celebrating special occasions like birthdays, special holidays, anniversaries, achievements in the family e.g. when children have been awarded prizes at school the family can celebrate together.
- Encourage older carers to attend support groups and drop in centres where possible.
- Assist carers with reminders for clinic visits and taking treatment appropriately if they are required

to do so. Treatment partners are helpful for older carers and children under their care taking anti-retroviral treatment (ART).

- Healthy eating is an important part of self-care. Older carers can be supported on how to plan and cook healthy meals using locally available and cost effective food.
- Regular exercise in the form of walks in and around the community and engaging in work that they enjoy around their yard, such as gardening, can provide good exercise for older carers.
- Utilise their own knowledge about self care and healthy living.
- Identify enabling factors that can be used to promote self care.

8.5. Action planning

What steps or actions do you think your organisation should carry out to improve or encourage self-care among older carers so that they experience improved psychosocial wellbeing?

Step 1	
Step 2	
Step 3	
Step 4	

Assessing your progress

You may wish to keep track of your growth in terms of psychosocial care and support of older carers. Use the following as a checklist to track your progress, rating yourself from 1 to 5 according to how well you are doing in providing psychosocial support for older carers.

Measuring the progress of offering psychosocial support to older carers

Self-assessment criteria	Rating From 1 to 5
Our organisation recognises the valuable role that older people are playing in caring for orphaned and vulnerable children, and people living with HIV and AIDS.	
We provide care and support for older carers by treating them with respect and appreciation at all times	
We listen to their ideas, experiences and needs	
We design projects together with older carers to reduce their stress and meet their needs	
We arrange child care so that older carers are able to participate in the activities of our organisation	
We visit older carers who have lost family members and support them through the grief process	
We set aside a portion of our annual budget specifically for psychosocial care and support work of older carers	
We prioritise older carers when it comes to distributing resources that we may have to offer our community partners	
We involve older carers in evaluating the impact of our work on their psychosocial wellbeing	
When common issues come from several older carers and different communities, we take these suggestions forward to the relevant government departments to promote change	

Monitoring and Evaluation

The design of systems of monitoring and evaluation of the increase of psychosocial support towards older carers is an important contribution to policy and programme development.

Table 1: Examples of Broad Indicators for Monitoring and Evaluating the Implementation of the Principles of Psychosocial Support of Older **Carers**

Principle of Psychosocial Support	Indicator for Monitoring Implementation of Action	Indicator for Impact Assessment and Monitoring
Access to rights	The holistic wellbeing of older carers is explicitly included in all policy development and programming, including their right basic safety, shelter, nutrition, health care and psychosocial support	All older carers have access to basic safety, shelter, nutrition, health care and psychosocial support. The living conditions and wellbeing of older carers improves. Their stress around their wellbeing and the wellbeing of the children in their care decreases.
Participation	Older carers are consulted and involved in identification of their needs and priorities, planning, implementation and evaluation of policies and projects addressing their wellbeing.	The programmes and policies developed match the priorities and needs identified by older carers. Older carers make a meaningful contribution towards the planning, implementation and evaluation of policies and programmes addressing their needs.
Family-based care	Policies and programmes supporting older carers include a focus on strengthening psychosocial support within the family.	The psychosocial support received by older carers from their families increases, which may include increased number of visits and telephone calls to older carers, including older carers to join in family functions, and increase in material and financial support. There is increased lobbying by family members for the wellbeing of older carers (for example accompanying them on visits to the clinic, ensuring they receive social grants, assisting them to connect with other community members).

<p>Strengthen existing resources</p>	<p>Policies and programmes for psychosocial support of older carers are based on identification and strengthening of existing community-based resources, rather than starting new programmes.</p>	<p>There is growth of the existing community-based responses towards older carers.</p>
<p>Build on locally appropriate practices</p>	<p>Policies and programmes for support of older carers are based on identification and strengthening of local and traditional approaches to psychosocial care, rather than only importing new ideas.</p>	<p>Older carers receive locally appropriate forms of psychosocial support which suit their wishes and local context.</p>
<p>Consideration of gender</p>	<p>Policies and programmes for psychosocial support consult and include both male and female older carers to address their needs and priorities.</p>	<p>Both male and female older carers are actively involved in determining and implementing psychosocial support programmes according to their needs and priorities.</p>
<p>Focus on strategic leverage and prevention</p>	<p>Policies and programmes for psychosocial support include a focus on:</p> <ul style="list-style-type: none"> • reaching as many older carers as possible, even within resource-constrained contexts • prevention of exposure of older people to suffering • consideration of the “do no harm” principle in all intervention. 	<p>All older carers receive an increase in psychosocial support. The exposure of older carers to suffering (abuse, loss, poor living conditions, health problems, breakdown in family relationships etc) is decreased.</p>

Table 2: Examples of Broad Indicators for Monitoring and Evaluating the Impact of the Key Strategic Focus Areas of Psychosocial Support of Older Carers

Key Strategic Focus Area	Indicator for Monitoring Implementation of Action	Indicator for Impact Assessment and Monitoring
Building social support systems	Community and family based forms of psychosocial support are strengthened	Older carers receive everyday psychosocial support from their family and surrounding community such that there is a continuum of care without risk of harm or neglect
Building more supportive relationships between older carers and children under their care	The capacity of older carers to deal with the challenges associated with parenting is improved through training and sharing opportunities. This is based on strengthening a mutual relationship of care and support between older carers and the children in their care.	Older carers feel competent to handle parenting and everyday issues around caring for children. Children feel loved and cared for within a safe and structured relationship. Older carers feel supported in their caring role towards children.
Supporting older carers through the grief process	Older carers are given opportunities to process their grief and receive support from family and community in healing from their grief.	Older carers and the children in their care are able to honour the memory of their lost loved ones and are able to remember them without feeling devastated each time a memory is triggered. Their loss does not lead to complicated grief or depression.
Protecting against abuse and exploitation	Policies and programmes for older carers prioritise their safety and protection against abuse.	Older carers are free from fear, abuse and exploitation and are able to live and move safely in their community.
Working with male older carers	Policies and programmes include an explicit focus on supporting the development of male older carers.	There is an increase in the involvement of older men in caring roles, and the men involved in care feel supported and acknowledged in their role.
Self care skills for older carers	Programmes supporting the care of older carers are implemented and policies include a specific focus on care of the carer.	Older carers are able to take time out of their caring roles to care for themselves, including opportunities for rest and leisure.

Table 3: Examples of Broad Indicators for Monitoring and Evaluating the Impact of the Mainstreaming of Psychosocial Support of Older Carers

Mainstreaming Processes	Indicator for Monitoring Implementation of Action	Indicator for Impact Assessment and Monitoring
Provision of psychosocially sensitive services	Capacity building and awareness raising about the psychosocial needs of older carers is facilitated with all government and civil society service providers.	There is an increase of respect and kindness shown to all older carers by government services and civil society. There is an increase of services to older carers formerly neglected by such services.
Referral for specialised psychosocial support	Capacity building and awareness raising to identify and refer the most vulnerable older carers is facilitated with all government and civil society service providers.	The most vulnerable older carers are referred for specialised psychosocial support.
Maintaining a holistic focus on the wellbeing of older carers	The holistic needs and rights of older carers is recognised and referrals are made for older carers to access different forms of support to address all their needs.	Older carers receive access to physical and psychosocial care such that their living conditions and wellbeing improves. There is an increase in referrals across government and civil society services such that the needs of older carers are met.
Development of support programmes for older carers	The capacity of programmes for the psychosocial support of older carers is improved. Access to recommended practices and tools is made available.	There is an increase in programmes supporting older carers. There is an improvement in the types of psychosocial support offered by programmes for older carers, such that they make use of recommended tools, practices and principles.
Policy development	National and organisational policies are developed to have an explicit focus on the psychosocial support of older carers.	There is increased attention, resources and programming for the psychosocial support of older carers.
Monitoring and evaluation	Monitoring and evaluation systems and indicators are developed, implemented and revised to track the psychosocial support of older carers.	There is accountability and ongoing improvement of policies, programmes and services for the psychosocial support of older carers.

The development of monitoring and evaluation systems may be a cyclical process, whereby ongoing improvements are made to policies and programmes supporting older carers. These changes may be continually based on re-assessment of the needs and priorities of older

carers using participatory approaches. In so doing, the wellbeing of all older carers and the children in their care may be enhanced, to move towards the vision of a society where older carers are supported in every aspect of their lives.

Conclusion

Older carers are contributing an enormous amount to the care of orphaned and vulnerable children and people living with HIV and AIDS. Their contribution to families affected by HIV and AIDS is greatly valued. It is hoped that this guideline will contribute towards the psychosocial wellbeing of all older carers who are providing support to others. HelpAge and REPSSI would like to support others in this journey to grow the movement of psychosocial care and support for older carers. Please visit our websites, as shown below, to find out more about regional offices and support programmes.



www.helpage.org



www.repssi.org

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Annexe 1: Key learning, knowledge and skills

Unit Focus	Key learning	Added knowledge	Skills to strengthen
Introduction	Older carers often value their role, but require support	Terms “older carers” and “community caregivers”	Being able to appreciate both the benefits and challenges of being an older carer
1.Psychosocial wellbeing	It is important to look at the older carer holistically. Carers should be consulted about their needs and priorities for support. There are different levels at which support may be offered in order to improve the wellbeing of many older carers.	Wellbeing includes physical, material, social, emotional and spiritual needs being met. Levels of intervention model.	Participatory consultation processes with carers in order to hear their needs and priorities. Assessing the needs of older carers strategically when planning support interventions.
2.Psychosocial care and support	Psychosocial support is about enhancing the social and emotional wellbeing of older carers. A large part of psychosocial support is simply about treating older carers with respect and kindness.	Term “psychosocial support”. Principles of psychosocial support. Ongoing self-development of one’s own psychosocial support.	Participatory processes of consulting older carers about their psychosocial needs. Behaving with respect and kindness towards older carers.
3.Social support	The most important source of psychosocial support is from older carer’s own family and communities.	Social network mapping. Social support groups for older carers. Community awareness raising.	Facilitating social network mapping. Facilitating social support groups for older carers.
4.Relationships between carers and children	Strengthening a constructive mutually caring relationship between older carers	Common challenges faced in the caring relationship between older carers and	Participatory approaches for eliciting appreciation

	and children in their care is the foundation of improving their communication.	children.	between older carers and children and for sharing strategies about how to address common challenges together. Positive reframing.
5.Grief	Grief is a normal response to loss. It takes time and gentle support in order to heal.	Structure for supporting someone through the grief process. Knowledge about helpful and unhelpful things to say to people who are grieving.	Consulting carers in what is helpful for them in grieving. Being able to contain feelings of intense sadness which are a normal part of grieving.
6.Abuse and exploitation	Situations of suspected abuse must be dealt with. Approaching the family in a respectful and cooperative manner is preferable where there is hope that the situation may be able to change positively.	Identification of situations of abuse. Managing cases of abuse constructively. Organisational policies on abuse.	How to develop your own organisational policy on handling cases of abuse constructively.
7.Involving males in caring	Societal attitudes often prevent men from becoming involved in caring for children and people living with HIV.	Understanding of factors preventing male involvement in caring. Strategies to encourage male involvement in caring.	Participatory processes for encouraging men's involvement in caring.
8.Care of caregivers	The role of caring is stressful and may result in compassion fatigue, burnout or stress. Older carers need to be encouraged to set limits on their role as carers and to find ways of taking good	Definitions of "stress", "burnout" and "compassion fatigue". Factors contributing to stress of older carers. Strategies to promote self care in older carers.	Self reflection of own levels of stress. Participatory practical approaches for promoting self care in older carers.

	care of themselves emotionally and socially.		
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Annexe 2: Remembering Exercise

Take time to think about someone who was special or important to you that you have since lost or who has passed away.

1. Did you have lovely times with this person?
2. What was special about this person?
3. Would this person like it if you remember them in these ways?
4. What kind of lessons and values did they leave behind for you that you hold precious?
5. What did he/she appreciate about you?
6. What do you think you offered and gave him/her that made you a special person in his/her life?
7. If they were here today, what do you think they would say about what made your relationship with him/her special?
8. What does your having known this person make possible for your future life?
9. What do you want to preserve the most of your experiences of this person?
10. If given a chance, what would you like to say to him/her?

* Participants may want to write a letter to their lost loved ones to express their thoughts and feelings.

Annexe 3: Family Exercise (Tree of life)

Draw a tree and use its different parts to tell a story about your family.

Roots

Where your family come from i.e. roots; origins, ancestry or anything that you can think about that identifies your family

Ground

where you live now and how often you in touch with your family

Trunk

(a trunk has two sides; write the answers to the questions below on different sides of the trunk

- What are some of your special and favourite memories/times/events that you have spent with your families that you can tell a story about?
- What values does you family live by that have helped you in your life?

Fruits of your tree

- What gifts has your family given to you and how have you contributed to your family?
- What are the things that your family has achieved that you are most proud of?
- What strengths, knowledge and skills does your family have?

Leaves of your tree (The leaves in your tree represent different members of your family)

- What makes the different leaves in your tree special? (Tell a small story that illustrates what makes each or some of your family members' special to you)
- What do you think your family members appreciate the most about you?

Branches of your Tree

- What direction do you see you family going towards, in other words what are your hopes and dreams for your family?
- What are these hopes about?

Questions to think about

1. What makes you an important member of your family?
2. If I asked other members of your family what makes you an important member of your family, what do you think they would say?
3. What contributions are you making towards your family so as to ensure that your family achieves the hopes and dreams that you have spoken about?
4. What has doing this family exercise done for you?

Adapted by Ncazelo Mlilo from Training for Transformation. Hope and Timmel, 1995

Annexe 4: Club of Life

The club of life metaphor introduces the idea that our identities are formed through our relationships with other people. Our lives have membership and this membership influences our experience of ourselves. How others see us, how we experience ourselves with others, how we participate with others all influence who we are becoming as people (“Umuntu ngumuntu ngabantu”). The members to our “club of life” have particular parts to play in how we have come to know and experience ourselves. These members of our “club of life” have status and ranks within the “club”. We pay more attention and give more credibility to what one person thinks about us than another.

The person or persons whose views matter most to us, who influence who we are most significantly, can be seen to have highly regarded and respected membership status within our “club of life”. Take a few minutes to think about the different member of your “clubs of life”. These could be family members, friends, work colleagues, members of a social club or religious group that you are a part of; these people should be people that you regard as important to your life.

- Which club of your life have you decided to talk about today?
- What makes your club of life special to you?
- Tell me a small story about some of the members of your club of life which illustrates what makes them special to you?
- What values does your club of life live by?
- What is the history of these values; in other words where do these values come from?
- Tell me about someone or something that has been most influential to your club of life that you often talk about or refer to in your club.
- What contributions has this person or thing made to your lives? How do you feel about the contributions made? How has this touched your life personally? How do you hope to take these contributions forward in your life?
- What contributions are you making to members of your club of life?

- If the members of your club of life were sitting here with you, what do you imagine they would say they appreciate about you?
- What do the contributions that you are making to your club members say about the values, hopes and dreams that you have for the members of your club of life?
- Where do these values and hopes and dreams for your family come from?
- The fact that you have these values and hopes and dreams for your club members, what kind of person are you? Who knows that you are such kind of a person? How do they know this?
- Who else knows about these hopes and dreams that you have for your club of life members?
- How do they know this?
- What plans do you have to pursue or carry forward these values, hopes and dreams for your club of life members?
- What has responding to these questions gotten you thinking about yourself and the members of your club of life?

Annexe 5: Resilience exercise

I AM, I CAN AND I HAVE

The, “I am, I can, I have” exercise enables us to explore further into ourselves and find positive things about ourselves that can help us to cope during difficult times

I am - reflects how the older carer views herself. It brings out the way that she defines herself, her personal attitudes about how she sees herself.

I can - helps the older carer to appreciate her abilities. It is important for the carer to define what she can do that is proud of; this will help her to see that she has a lot to offer to those in her care.

I have - relates to both inner and external resources. It is those gifts or resources that the older carer has, what she feels she possess as an individual. It is very important for people to view themselves as “having”. One cannot give until they feel that they have something to give and to offer. The role of counsellor or community caregiver is to give: time, love, support, encouragement and guidance as you take the older carer through this exercise.

Source: Edith Grothberg (1995), “A guide to promoting resilience in children”

Write down what the older carer says so that you can read her statements back to her

I AM,

I CAN

I HAVE



When old people speak

we are listening

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