

*“Although I would never have invited this disease into my household, I am glad that I am able to be there for them at their time of greatest need.”*

*Older carer*

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

*Older carer*

## Psychosocial support for older carers: a summary

Millions of older people are caring for orphaned children and for family members living with AIDS-related illnesses, but they are often overlooked by development programmes. These guidelines, aimed at programme managers, explain the issues facing older carers and set out ways to give them the emotional and social support they need to carry out their vital role.

Most people expect their caring duties to ease off in later life. But around the world, millions of older people find themselves looking after their adult children as they become ill or die as a result of HIV and AIDS, and taking on care of grandchildren. In east and southern Africa, older people care for at least 40 per cent of the 12 million children orphaned by AIDS, according to studies by UNICEF and HelpAge.

For many older carers, caring for children is a great privilege, but it is also a huge responsibility that comes at a time when they are grieving for the loss of their son or daughter.

All carers need a range of support, including emotional and social support, as well as practical things such as adequate shelter, nutritious food, clothing, healthcare and income. But often carers' needs are not met, and their caring duties leave them physically and psychologically overwhelmed and financially struggling. Older carers, in particular, face a number of specific challenges.

### What challenges do older carers face?

The demands of caring can put a great strain on an older person's sense of wellbeing. Older carers, most of whom are women, frequently lack regular income and enough food. Many have to sell assets, including land, to enable them to meet the needs of children in their care. Time spent on caring leaves them with little or no time to earn an income.

Many struggle to make sure that their grandchildren receive an education. Many have difficulty maintaining their own health and that of their grandchildren. Older carers often find it hard to pass on life skills to their grandchildren and give them emotional support. All these factors can have a severe impact on the relationship between older carers and children.

Every carer's situation is different, but older carers often describe difficulties in the following areas:

- **The caregiving role** Older carers face the physical strain of looking after sick adults and children, and the responsibility for providing children with care, love, affection, protection, information and discipline.
- **Material needs** They have to cover the cost of housing, food, clothing, shelter, schooling, healthcare and funerals, often made worse by the lack of any regular income such as a pension, or time to generate an income.
- **Entitlements** They have to find out what benefits and services they and their family members are entitled to, and how to access them. For example, older people are often excluded from HIV prevention programmes, while parenting programmes are often open only to

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

*Older carer*

mothers.

- **Staying healthy** They often have limited time to rest, a poor diet or difficulty accessing health services because they are too busy or tired, or cannot afford transport or medicines.
- **Emotional needs** They face the mental strain of coping with family sickness and bereavement while caring for others.
- **Relationships with families** They may have difficulty communicating with the children they care for (especially teenagers) and coping with family disputes on issues such as childcare, money or inheritance.
- **Discrimination and abuse** Older carers who are vulnerable themselves are at risk of neglect or violence, which puts the whole family at risk.
- **Relationships in the community** Older carers may be isolated by HIV-related stigma and a weak social support network - the “web” of people around the carer, including family, neighbours, community groups, and community or religious leaders.

## What is psychosocial support?

Psychosocial support for older carers can be defined as showing love and respect for them, and connecting them to social support systems, so that they regularly receive care and appreciation from their families and communities.

Psychosocial support covers a range of activities focusing on carers’ emotional needs, relationships with families, discrimination and abuse, and relationships in the community. It can include setting up a support group, providing one-to-one counselling or training, helping the local community to become more aware of the older carers in their midst and the support they need, or helping family members to talk through their differences.

When psychosocial support is set up to suit an individual carer, it can make a big difference to their quality of life and their ability to care. The best place to start is by consulting the carers themselves, so that they can determine what they would find most helpful. You could do this by running a group discussion or visiting individuals in their homes. Then you can decide what services or systems to set up, and review and improve them over time.

## What psychosocial support is most needed?

### Case study: South Africa

In South Africa, Muthande Society for the Aged (MUSA) trains older carers as volunteer counsellors and peer educators. The volunteers provide support and advice, ranging from HIV prevention to recognising and reporting cases of abuse. The training also helps volunteers to cope with their own grief.

### Boosting social networks

Social support networks are extremely important for older carers and those they care for. These may include older carers’ groups, or linking older carers to women’s groups. Support can be provided through regular contact with the carer, encouraging them to talk about problems, helping with chores, bringing them food or money, or praying together.

Sometimes relations and neighbours do not offer to help because they are not aware of the difficulties the carer is facing, or they are not sure what to say. Sometimes they are aware of older carers’ difficulties, but they are facing similar hardships themselves, making it difficult for them to assist others. Stigma, discrimination and fear of HIV are also reasons why people may not offer to help. You can encourage the community to be more supportive by helping them to understand older carers’ needs and dispelling myths about HIV and AIDS.

You can help carers find out what help is available and how to access it. You could also set up support groups and drop-in centres. For many people, particularly those with more stable income, leisure activities such as singing groups or lunch clubs, can help to relieve stress.

### **Strengthening relationships**

Children whose parents have died often say they want to live with their grandparents, because they receive more love and affection than they would if they joined the household of an aunt or uncle. Children who live with their grandparents often help with household chores and care for their grandparents when they become older. However, the wide age gap can lead to conflict and a lack of understanding on both sides.

Grandparents often ask for help with issues such as discipline, communication, and drug or alcohol use. Programmes can provide information, advice or counselling and help families to work through disagreements. It is important always to promote mutual respect and to emphasise that children need love as well as boundaries.

#### **Case study: Tanzania**

In Tanzania, KwaWazee runs separate psychosocial support groups for grandparents and grandchildren to share their experiences, discuss problems and find solutions.

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

*Older carer*

### **Helping with bereavement**

Many older carers are caring at a time of intense grief, having recently lost a son or daughter. Their son or daughter may have been an important source of emotional support, economic security, hope for the future, freedom and autonomy. Grieving for all this loss can result in a range of feelings, including anger, sadness, shock and guilt. It can take a long time for them to heal. Even years later, the person may be deeply affected – especially on special days such as anniversaries or family celebrations.

Older carers need care and support to heal in their own way. It is important to support carers who are bereaved, help families discuss complex issues, and help carers to comfort the children they are caring for. If the person shows signs of “complicated grief”, where they are unable to cope for extended periods or are neglecting themselves or the children, they should be referred to specialist psychological or counselling services.

### **Dealing with abuse**

Older carers and the children they care for may be vulnerable to a range of abuse and exploitation, including exclusion from community activities or vital services, accusations of witchcraft, discrimination because of HIV and AIDS, property grabbing, sexual or physical abuse, child labour, theft, violence or neglect.

If there are signs of possible abuse, it is important to respond with care. A sensitive approach to the family may be all that is needed, or the person may simply need information about rights and entitlements. Other responses may include putting people in touch with agencies or support groups or, in serious cases, contacting specialist organisations or the authorities.

### **Including male carers**

Older men who are caring may need additional support because of cultural and social attitudes. Programmes are often designed to meet the needs of women, but men may need specific support in certain areas. For example, they may need help with parenting skills, managing the household, maintaining social ties, coping with their own emotional wellbeing and caring for people who are sick. Useful responses include educating community leaders and the community about the importance of involving men, providing mixed-sex and single-sex discussion forums,

#### **Case study: Kenya**

Nazareth Mission Hospital, Kenya, runs a clinic and support groups for older carers to ensure they receive equal access to healthcare. The clinic is staffed by a team trained to communicate well with older people.

and creating role models for male carers.

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

*Older carer*

### Encouraging self-care

Caring for children and people who are sick can be very rewarding, but it can also be draining. Older carers may need to take a break from time to time. They may also benefit from structured activities that help to relieve stress, burnout or compassion fatigue. Helpful initiatives include support for carers (both one-to-one and in groups), clubs and social activities, and training.

Carers can be encouraged to care for their own health – for example, by getting enough sleep and exercise and eating well. They can also be encouraged use social support systems, including links with other carers, to share their concerns and talk through difficulties. They may need help to become aware of their limitations and to find ways to have a break from caring duties.

### Home-based care policies

Many national home-based care policies and guidelines do not include references to the specific needs of older carers, children orphaned by AIDS or people living with HIV and AIDS. Consequently, home-based care provider training programmes do not focus on how to support older carers. There is a need to advocate for their inclusion in national home-based care policies and guidelines.

### Key points

- Older women and men play a vital role in caring for children and people who are sick, but they face serious difficulties.
- Programmes can provide older carers with psychosocial support to help them carry out their caring duties.
- Many interventions focus on enabling carers and communities to support each other.
- Support to older carers should be included in national home-based care policies and guidelines.

### Find out more

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

Full guidelines on which this summary is based.

HelpAge International, Nairobi, 2011

[www.helpage.org/resources/publications](http://www.helpage.org/resources/publications)

*Building bridges: a home-based care model for supporting older carers of people living with HIV*

Describes a model developed by HelpAge International in Tanzania.

HelpAge International, London, 2010

[www.helpage.org/resources/publications](http://www.helpage.org/resources/publications)

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