

Ageways

ISSUE

61

Practical issues in ageing and development

DECEMBER 2002



HIV/AIDS and older people



How HIV/AIDS affects older people

Reaching older people with HIV/AIDS education

How to reduce stigma

Caring for children

Home care for people with AIDS

HelpAge
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Comment

Impact of HIV/AIDS

Welcome to Ageways 61. This issue looks at the devastating impact that HIV/AIDS is having on older people. In particular, growing numbers of older people are caring for family members with AIDS and for orphaned grandchildren, often with little or no support.

Lack of recognition and support for older people affected by HIV/AIDS not only places them under enormous strain, but also increases the risk of HIV infection among older people, their families and communities.

This issue emphasises the need to include older people in HIV/AIDS control strategies and suggests ways of doing so. We hope you find it useful, and we welcome any further ideas for publication in a future issue.

**Celia Till and Godfred Paul
Editors**

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Themes of future issues

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Letters

Professional approach to care

Congratulations on publishing articles about elder abuse (**Ageways** 59). In India, most parents believe that a son is an 'insurance' in old age, so they would never like to complain, even if their own son becomes an 'abuser' to them. But it is a fact that many people are victims of elder abuse.

The National Institute of Social Defence has announced a six-month professional certificate course in geriatric care. The first part covers theory and the second part includes practical assignments in old age homes.

It is gratifying that awareness of older people's needs in India is rising, and old age care is becoming an attractive career opportunity too.

Mahindar Singh, Member, Governing Council, Indian Federation on Ageing, S-314, Panch Shila Park, New Delhi 110017, India.

Financial and social support

The analysis of problems related to elder abuse in **Ageways** 59 is quite comprehensive, and points out directions for services. I have been serving older people for over 25 years in Uttar Pradesh, India. There are many types of elder abuse. Financial independence for older people can help to prevent these and other problems.

Next comes association with an organisation that promotes strong social contacts.

Problems and their solutions differ from place to place. We have achieved a lot though income-generating programmes. However, this is not possible in all cases. Our society is thus planning to launch a pilot programme for arranging old age pensions, old age

homes and 'halfway houses' providing medical care, entertainment, income-generating activities and relief measures for older people in great need.

Bajrang Tripathi, Manager, All India Care & Educational Development Society, Near Railway Station, Azamgarh, 276 001 UP, India. Email: ccaisc@rediffmail.com

Exercise makes us feel young

We are a group of retired older people, mainly professionals. A few years ago we formed an older people's association, Años Dorados (Golden Years), with two aims – to improve our quality of life by exercising, and to do voluntary work.

We organise walks three times a week, celebrate birthdays and arrange religious activities and outings. We recently went on a walking expedition. We reached a great height, but in spite of our age (many over 70) we had no problem with altitude sickness.

This experience leads us to believe that we are young and we have the energy to help those who need it most. Thanks to our awareness-raising activities about the effects of Alzheimer's on families, we have been given a plot of land to build a temporary care home for people with Alzheimer's. As volunteers we try to take some of the pressure off family carers.

*Ing. Hugo Centurion, President, Años Dorados, Peru.
Email: hugocenturion@lared.net.pe*

We welcome letters from readers. Please write to: The Editor, Ageways, HelpAge International, PO Box 32832, London N1 9ZN, UK. Fax: +44 20 7713 7993 Email: ctill@helpage.org Letters may be edited.

News

Participatory research book

Participatory research with older people: a sourcebook draws on the experience of HelpAge International programmes and partners to provide guidelines for older people's participation in planning, carrying out and disseminating research.

The book also contains case studies, participatory exercises and tools, examples of materials and sources of further information, with a foreword by leading participatory development proponent, Robert Chambers.

Written by Amanda Heslop, Research and Training Manager HelpAge International. Available from: Publications Orders, HelpAge International, London (address on back page) and as a PDF at: <http://www.helpage.org>

Obituary: Timothy Ramtu

Condolences to the family and friends of Timothy (Tim) Ramtu, who died in April 2002 aged 79. Tim Ramtu served as chairman of the board of HelpAge International for two terms, as well as chairman of the HelpAge Kenya board.

He had a distinguished career first in education and then in government. As founder member of HelpAge Kenya, he played a crucial role in the creation of HelpAge International, of which HelpAge Kenya was one of five original member organisations.

Building new social networks

Older people living away from their home communities can find it difficult to build a new social network. In Sweden, Jaime Barrios Peña has helped fellow Latin Americans to do this by organising social activities in the Rinkeby Service House in Stockholm.

He has written a book about his work, *Somos viejos y seguimos naciendo* (*We are old and we keep being born*), describing how a ceramics project begun ten years ago has helped to develop a multicultural society. 'Isolation is an illness,' he says. 'Being creative can help to relieve feelings of anxiety and nostalgia.'

More information:
Jaime.Barrios@swipnet.se

Courses

Ageing in Africa

Five-day course on demographic situation, HIV/AIDS, gender, poverty and policies.

17-21 March 2003

Nairobi, Kenya

US\$400 (US\$150 non-residents)

More information:
HelpAge International
Africa Regional Development Centre
(address on page 15).

Ageing, Health and Well-being in Older Populations

Five-day course for health and social workers, policy makers, planners, service providers and researchers.

7-11 April 2003

London, UK

£575 (excluding transport, accommodation and meals).

Limited number of bursaries available.

More information: Deborah Curle, Course Administrator, London School of Hygiene and Tropical Medicine, 50 Bedford Square, London WC1B 3DP, UK. Tel: +44 20 7927 2489 Fax: +44 20 7927 4668 Email: deborah.curle@lshtm.ac.uk <http://www.lshtm.ac.uk>

Schools drawing competition

HelpAge International Africa Regional Development Centre is organising a third annual schools drawing competition to raise awareness about older people in Africa.

Themes for this year are: abuse of older people within the family and community (ages 14-18); the role of older people in the HIV/AIDS pandemic (ages 7-13); and the young and the old together (age up to 6).

More information: HelpAge International Africa Regional Development Centre (address on page 15).



Winning drawing by Emanuel Mathias, Tanzania on the theme of 'AIDS and older people' in last year's Africa schools drawing competition.

How HIV/AIDS affects older people

Godfred Paul explains how HIV/AIDS is having a devastating impact on older people, and why support to older people is necessary to benefit the whole community.



Brent Madison/HelpAge International

More and more older people are becoming foster-parents to orphaned grandchildren.



In 2001, there were 40 million people with HIV. The epidemic is worst in sub-Saharan Africa – but infection rates are increasing fastest in Asia/Pacific and Eastern Europe.

HIV/AIDS has huge social and economic impacts, as well as being an enormous health problem. In already poor communities, HIV/AIDS makes poverty worse, by striking mainly at the middle generation. A study in Zambia showed that two-thirds of urban households that had lost their main breadwinner to AIDS had seen their income fall by 80 per cent.

HIV/AIDS has a devastating but largely unreported impact on older people. In developing countries, there are few state social or economic 'safety nets' for older people. Traditionally, adult children have supported their parents in old age. Because of HIV/AIDS, the roles have been reversed. Increasing numbers of older people are not only losing the support that they might expect to receive from their adult children, but are also now required to care for and support their children and grandchildren.

Women are particularly affected, since it is traditionally the role of the woman to care for the sick in the family.

What is HIV/AIDS?

HIV stands for 'human immunodeficiency virus'. The virus attacks the body's immune system, making it hard to fight off infections.

AIDS stands for 'acquired immune deficiency syndrome'. AIDS is caused by HIV. A person is said to have AIDS when their immune system has become weak and cannot prevent illnesses such as cancer, pneumonia and tuberculosis (TB).

A person can become infected with HIV (HIV positive) when enough HIV gets into their blood. The body fluids that contain enough HIV to infect someone are blood, semen, vaginal fluids and breastmilk.

The most common ways for HIV to be passed from one person to another are through unprotected vaginal or anal sex (without a condom), sharing syringes and needles, blood transfusions, and from mother to child during pregnancy or breastfeeding.

A person with HIV may live for several years before showing symptoms, and for several more years after showing symptoms, depending on their general health and treatment.

There is no vaccine or cure for HIV. However, a combination of anti-HIV drugs can slow down the damaging effect of HIV on the immune system.

'I sold all my land trying to buy medicine for my daughter... She died in 1996 and now I am without my child and without land.'

Older woman in Kenya

'An HIV-positive person is largely a financial burden on the family, but the isolation from the community is worse.'

Older woman in Vietnam

A study in Thailand found that 70 per cent of people living with HIV were in the care of older parents or relatives before their death. Some of the carers were over 70 years old and in need of care themselves. Mothers were more likely than fathers to be the main carer.

In sub-Saharan Africa, more than five million grandparents are estimated to be taking care of orphaned grandchildren. Many care for several grandchildren. In northern Thailand, a study of 24 older people found that they were fostering 37 grandchildren whose parents had died of AIDS.

Huge pressures

Caring for sick adult children puts huge pressures on older people. They must sustain an income, nurse the sick, and care for the young, at high cost to their own livelihoods, health and wellbeing. They are carrying out this added responsibility with deteriorating health, low income, limited information and little support. Often their children have spent all the family's money on treatment, and have nothing left to support grandchildren.

Research in Africa and Asia points to a wide range of problems experienced by older carers. These include exhaustion, financial hardship, grief and emotional upheaval, lack of knowledge and resources for dealing with adult children with HIV, conflicts with grandchildren, social stigma, discrimination and rejection, and exclusion from information and support services.

Older people are also at risk of HIV transmission through sexual activity. Contrary to general belief, many older people are sexually active. But most statistics published by UNAIDS, the World Health Organization and governments do not include people above 50 years. However, in Thailand, 5.4 per cent of the cases reported to the Ministry of Health in 1998 were in persons aged 50 years and over.

The risks are multiplied by the fact that older people are rarely addressed by public information campaigns, and are not educated about how to protect themselves, or others. Moreover, HIV in older people often goes undiagnosed, because the symptoms can be mistaken for other conditions affecting older people.

Managing HIV/AIDS

Support to older people must play a central part in any strategy to manage the effects of HIV/AIDS. It is generally agreed that children orphaned by HIV/AIDS are best cared for within the extended family. Older relatives are often the first choice of carer. An approach to HIV/AIDS that looks at the community's needs and recognises and supports older people in their roles as carers and educators is essential.

From a broader perspective, internationally agreed development goals to halt the spread of AIDS by 2015 will fail if older people are excluded. International and national agencies, including government and community-based organisations, need to:

- include older people in policy development and programme planning
- conduct research into the impact of HIV/AIDS on older people, as carers and infected
- develop programmes which support older people affected by HIV/AIDS economically and socially
- educate older people to help them protect themselves and others
- ensure treatment and support for older people with HIV/AIDS
- educate younger members of the community and service providers about the roles and needs of older people
- promote collaboration between government agencies and organisations working with children, youth and older persons on HIV/AIDS.

Godfred Paul is regional project manager with responsibility for HIV/AIDS at HelpAge International Regional Development Centre for Asia/Pacific (address on page 15). Email: goddy@helpageasia.com

Support to older carers in Thailand

Loans issued by older people's associations form part of a range of activities that have helped to improve the lives of older people affected by HIV/AIDS in northern Thailand.

With one of the highest HIV infection rates in Asia, Thailand is home to many older people caring for sick relatives and their dependants. In 1996, HelpAge International consulted older people in Sanpatong, one of the worst-affected districts, about their needs.

As a result, a three-year project was developed with the Thai NGO, Mother Child Concern Foundation (then known as Women Against AIDS). The project aimed to strengthen older people's associations, support income-generation activities, develop an older volunteer scheme to assist older carers, and provide information about care of people with HIV/AIDS.

Older people's associations in 11 villages were given funds to provide loans at low interest rates to disadvantaged older people, especially those affected by HIV/AIDS. The associations contributed up to half the funds themselves, from their own fundraising activities and local government grants.

The loans were used mainly for agricultural activities. Most were provided in kind. In many cases, older people passed the loans on to their children or grandchildren, because they were too frail or busy to use them. However, receiving the loan increased their status in the family and their involvement in decision-making.

Repayment rates, at around 80 per cent, were high compared with rates in similar schemes for younger people.



Ruen Ruenkaew, who received a loan after his son died.

Most of the interest on the loans was returned to the loan funds. A small proportion was used to assist older people living with HIV/AIDS or caring for people with HIV/AIDS – for example, to visit them at home, bring them things or take them to hospital.

Kamol Kamdang, a 79-year-old widow living with her HIV-positive daughter and two granddaughters, received a 5,000 baht (US\$115) loan to expand her business making pork crackling. Besides running the business in the afternoons, she did a full day's housework, getting up at four o'clock each morning to do the cooking, cleaning, washing and collecting fuel. She was constantly worried about making ends meet.

By expanding her business, she was able to pay for her daughter's medical

costs and her granddaughters' school fees. Sometimes her repayments were late, but the older people's association was sympathetic.

Ruen Ruenkaew, a 74-year-old widower whose son had died of AIDS, received a loan to buy fertiliser and pesticides. He lived with his two unmarried daughters, farming maize and other crops. He was still owed payment for his last crop of onions. 'The loans are good as the money doesn't disappear – it stays with the older people's association and is always there to help older people in the village,' he said.

Project staff held monthly meetings with older people's associations to provide technical support, such as writing funding proposals, and encourage associations to network with each other and coordinate approaches to government and NGOs.

Another need identified by older people was support to older carers. The project team trained 165 people, three-quarters of them older people themselves, as volunteer home visitors. The home visitors provided information about caring for people with HIV-related illness, accompanied sick older people to hospital, and provided information on health issues for older people.

The Foundation also trained 130 older carers in caring for people living with HIV/AIDS and they organised a public seminar to raise awareness about older people affected by HIV/AIDS.

The project was funded by the World Health Organization, States of Jersey and Mercury Phoenix Trust.

More information: Usa Khiewrord, HelpAge International Asia/Pacific Regional Development Centre (address on page 15). Email: usa@helpageasia.com

Older counsellors

educate the community

Charles Lumori Rubena describes how members of older people's committees in Juba, southern Sudan are educating their community about HIV/AIDS.



Alison Geldart/HelpAge International

Social gathering at which songs and drama about HIV/AIDS are performed.

Prolonged conflict, population displacement and poverty in southern Sudan have contributed to increasing HIV infection rates. Many older people are severely affected by HIV/AIDS, but lack knowledge of the disease, because they are not targeted by HIV/AIDS education programmes.

HelpAge International has been working in Juba, the largest town in southern Sudan, since 1998, supporting older people's committees at 23 displaced people's centres. An assessment of older people's knowledge of HIV/AIDS showed that existing programmes did not reach older people, because they were not appropriate.

Most programmes were targeted at groups such as young people, school students, government workers or the army. Some were carried out by doctors using complicated medical language, or were in English, which people found difficult to understand. No data was being collected on older

people, either as carers or as people living with HIV/AIDS.

Older people asked HelpAge International to involve them in a community education programme, and in identifying older carers. A meeting was arranged, bringing together five older people from each of the 23 centres. From these 115 older people, ten were nominated to be trained as counsellors.

A five-day training programme was conducted by a doctor, professional counsellor and the HelpAge International programme coordinator, supported by lectures, videos from Uganda, leaflets from the national AIDS programme, songs and drama developed by the older people themselves, and a talk by an HIV-positive woman.

The programme covered basic facts about HIV/AIDS, counselling, community mobilisation, problem-solving, gender, older people's issues and rights, coordination, data collection, public awareness-raising

and reporting, and living positively with HIV/AIDS.

After their training, the counsellors started making house-to-house visits, and discussing HIV/AIDS at social gatherings, such as social events at the displaced people's centres, Sunday prayers, weddings, circumcision ceremonies and funerals.

The counsellors, who are paid expenses, also identify older people caring for children or sick adults, who need material support such as cloth, bedpans or money for school fees.

'I first faced difficulties on how to approach the community, but when we were taken round by HelpAge International staff during their visits to the housebound, I started to see that older people were really suffering and needed help,' said one counsellor. 'Now I know many people and am accepted whenever I visit a family.'

Issues discussed by counsellors include hygiene when caring for people who are sick, or when washing bodies, and risks associated with traditional practices, such as shaving heads at funerals, when the same razorblade may be used for more than one person.

The programme has the support of the Sudan government, which is developing a national HIV/AIDS strategy. HelpAge International has established links between the counsellors and the Ministry of Health and Education. Counsellors are also disseminating information through the Juba teaching hospital and schools, to ensure that the same messages are carried to the whole community.

Charles Lumori Rubena is HelpAge International Field Officer in Juba.

More information: Erich Beining, Programme Director, HelpAge International Sudan (address on page 15).

Reaching older people with HIV/AIDS education

Educating older people about HIV/AIDS is essential for reducing the risks to the whole community. Here are some ideas.



Hein du Plessis/HelpAge International

Older people train to become volunteer home visitors in Mozambique.

Work with HIV/AIDS programmes

If you are working for a non-HIV/AIDS organisation, liaise with HIV/AIDS programmes in the area. Make sure they are sensitised to the needs of older people, and that they involve older people when assessing the community's needs and developing programmes.

Involve older people in planning

Consult older people when planning your HIV/AIDS education programme, and involve them in deciding the programme's priorities. They understand the issues that affect them. They may identify issues that only older people are aware of. In one project, for example, older people continued to have unprotected sex, even though condoms were freely available, because they felt embarrassed about asking for condoms.

Gain the support of leaders

Find out who provides advice and

information in the family or community. Often older people, as village elders, heads of families, traditional healers, priests, or traditional birth attendants, function as information 'gatekeepers'. If you can draw on established networks and develop a good relationship with respected leaders, their support will be invaluable.

Reducing the risk of HIV/AIDS can mean having to persuade people to change their behaviour. It may be more effective to explain the risks to community leaders, and for them to pass on the information to the rest of the community, rather than try to reach other community members direct.

Train older people as educators

Older people themselves can become effective educators. In Botswana, for example, older women were trained by community nurse-students to

become community educators. Before the training, the women knew that HIV could be transmitted through sexual activity; however, they believed that AIDS was *boswagadi* (widow's disease) which could be cured by traditional healers.

After the training, most knew that AIDS was caused by a virus and could not be cured. They also learned about other sexually transmitted infections and safer sex. They were better able to discuss sexual health problems with partners, peers, daughters, sons, daughters-in-law, grandchildren and other youth.

In Sudan, older people have been trained as counsellors (see page 7).

Use appropriate media

Use communication methods that are suited to your audience. Traditional methods such as songs and drama developed by older people, followed by a discussion, have been used successfully in Kenya and Sudan to explain the facts about HIV/AIDS, raise awareness of risks associated with traditional practices, and suggest ideas for behaviour change.

It is important to use language that your audience will understand. For example, avoid complicated medical language, foreign languages, or phrases that may not be clear, such as 'protected sex' (say 'sex using a condom'). It may be necessary to adapt existing materials, such as videos, posters or leaflets, or develop new ones.

Consider problems that older people might have with hearing, sight and mobility. For example, if you are working with a group, you may need to adapt some activities to make them less energetic.

Think about group structure

If possible, work with existing groups, such as older people's committees, pensioners' associations or women's groups. These are likely to have more credibility than a new group set up by an outside organisation.

Consider the age and sex of people in the group. It may be best to work with a group of people of the same age and sex. Peer groups (groups of people of similar status) have been shown to work best for counselling, research and education. People are likely to feel

more relaxed with their peers and communicate more easily with them. For example, older men may be reluctant to discuss using condoms in front of either women or younger men, but feel able to do so in a group of older men.

Older people who are poor or disabled may be less 'visible' and less mobile than others in the community. They may work long hours. Make sure they can be included, by arranging meetings at times and in places that are convenient to them.

Develop appropriate messages

Older people need to learn the facts about HIV/AIDS and how to reduce the risk of transmission – both through sexual activity and as carers. They also need to learn how to communicate about sensitive issues with young people – both those in their care, and other young people in their family or community who may look to them for advice.

Consider gender differences

Men and women have different experiences of HIV/AIDS, and different concerns. For example, women are more likely to have to care for sick relatives or orphaned children, while men may be expected to make the decisions in the family or community. It is important to reach both men and women, using approaches that take their different situations into account.

'We want to help our grandchildren, to help them escape the pandemic. Give us information on the disease and equip us with the relevant skills.'

Statement by older people who took part in the World NGO Forum on Ageing in Madrid in April 2002

Changing situation

The situation of older people affected by HIV/AIDS changes over time. Older people need different kinds of support at different stages.

Stage 1: Only the family is aware that a member is HIV positive.

Older people need information to enable them to plan for the future, including how they will look after grandchildren who may be left in their care.

Stage 2: The person with HIV/AIDS is sick and needs care.

Older carers need practical support. They may also need financial support, especially if the sick person had been a wage earner. They may benefit from an income-generating project, if they

are not too busy caring for the person with HIV/AIDS.

Stage 3: The person with HIV/AIDS has just died.

The older person needs emotional support to help them cope with their grief. They also need practical and financial assistance with the funeral.

Stage 4: The older person is left to look after themselves and/or grandchildren.

The older person may need practical and financial support to help them and their grandchildren move on with their lives, such as access to income-generating opportunities or help with obtaining a foster care grant.

Self-help groups of people living with HIV/AIDS might be appropriate

to support older people during stages 1 and 2, particularly stage 2, because they are in the same situation, so there is no fear of discrimination.

Older people's associations could be more suitable during stage 3 and 4, to help the person move on with their life. However, older people's associations should be sensitised to HIV/AIDS issues, including the danger of marginalising older people affected by HIV/AIDS, and the reasons why these people are particularly vulnerable.

Older people caring for children could also receive support through child networks sensitised to the needs of older people, especially networks focusing on 'AIDS orphans'.

How to reduce stigma

Social stigma can add greatly to the problems of people affected by HIV/AIDS. This activity is designed to improve people's understanding of HIV/AIDS and its effect on older people.

David Woodroffe/HelpAge International. Source: Where there is no artist



This activity can be carried out with groups such as staff or volunteers, committees, older people's associations or other community groups.

You will need a flipchart and marker pens. Start by writing the letters 'HIV/AIDS' on the flipchart and ask participants what they stand for. Give the correct answer (see box on page 4).

Explain that this activity looks at how HIV/AIDS affects older people, not just in terms of their physical health, but also socially and economically.

Part 1

Check how much participants already know about HIV/AIDS. Ask the following questions, allowing time for participants to give as much of the answer as they can. Then correct or build on the answer (see box on page 4).

- How does HIV enter the body?
- What happens after it has entered the body?
- What does it mean to be HIV positive or HIV negative?
- What happens when you are HIV positive?
- How do you recognise that a person is HIV positive?
- How do older people get HIV/AIDS?

Part 2

Divide participants into three groups and give each group a sheet of flipchart paper. Explain the task: Group A is to consider how HIV/AIDS affects older people socially; Group B will look at economic effects; and Group C will explore psychological effects. Ask groups to list their responses on the flipchart paper.

Allow about 15 minutes for the task. Then ask each group to report back what they have written. Encourage the other groups to add suggestions to the lists. Responses should include:

Social effects

- Older people become the main carers of children, younger relatives and partners who are HIV-positive, or whose family members have died from HIV-related illnesses.
- Becoming a full-time carer may isolate them socially.
- They lose their own carers to HIV/AIDS.

Economic effects

- Older people use their finances to support sick family members.
- They can no longer work for cash because they are carers at home.
- They may sell their assets to buy food and medicines.

Psychological effects

- Older people feel drained from watching their children die and looking after grandchildren.
- They become increasingly lonely as others around them die.

In the big group, go through the lists and ask participants to suggest what can be done to support older people affected by HIV/AIDS. Record suggestions on the flipchart (see 'Changing situation' on page 9).

Conclusion

Point out that the HIV/AIDS crisis shows how important it is to consult older people directly. They are best placed to voice their emotional, physical, cultural, educational and economic needs. As well as practical help, strategic interventions are necessary, such as lobbying for support for older people, and research into the impact of HIV/AIDS on older people.

Adapted with thanks from Training manual on ageing in Africa, produced by HelpAge International's Africa Regional Development Centre (address on page 15).

Caring for children

Pauline Motaung is bringing up three grandchildren, with support from a local voluntary organisation.

Pauline Motaung has been looking after three grandchildren since her daughter died of AIDS two years ago – the last of her four adult children to die.

At the age of 87, Pauline finds that being a parent again is not easy, especially without her husband, who died almost forty years ago. 'If the parents leave the children, you just carry on with it,' she says. 'You have no choice.'

The family, who live in Mamelodi on the outskirts of Pretoria, South Africa, survive on Pauline's pension of 640 rands (about US\$64) a month, and a foster-care grant of a similar amount, secured for them by Tateni Home Care Services.

Volunteers from Tateni helped Pauline nurse her dying daughter and get over the death, and are now helping her bring up her grandchildren. They have brought food parcels, helped find school uniforms, cared for the family when Pauline was sick, and negotiated with the local school to waive school fees until the foster-care grant came through.

Tateni Home Care Services was established in 1995 by Veronica Khosa, a community nurse. 'The hospitals didn't want to know about AIDS patients, but the families were not equipped to care, and didn't know how to do so safely,' she says.

A team of 42 volunteers, many of them former nurses, visit families with HIV-positive members to provide advice and practical help. They usually start by helping the sick person, and move on to helping



John Cobb/HelpAge International

Pauline Motaung is 'mother' to her three grandchildren.

the rest of the family – and the orphans after the person with AIDS has died.

Often, the volunteers try to find aunts or other relatives who might care for orphans. But usually grandparents become the carers. 'Of the 180 families we are working with right now, over a hundred are run by grandparents, usually with only their pensions for income,' says Veronica.

More information: Veronica Khosa, Tateni Home Care Services, PO Box 77980, Mamelodi 0101, South Africa

'We love grandma because she is very patient telling us right from wrong.'

Pauline Motaung's granddaughter, Fikile

Need for support

Older people have always cared for children, for a variety of reasons. But with HIV/AIDS, increasing numbers are doing so. In many cases the children being cared for have HIV.

Older carers need:

Emotional support

- to help a child cope with the death of their parents
- to cope with their own grief at the death of their son or daughter
- to cope with grief at the death of a child
- day-to-day support to prevent isolation

HIV/AIDS education

- about how HIV is transmitted and prevented
- symptoms of HIV in young children
- how to care for children with HIV (including treating common infections)
- access to HIV/AIDS support groups and services
- how to talk to a child or teenager about HIV/AIDS

Economic support

- for children's food, clothing, education, healthcare and other costs
- for treatment and travel to clinics to care for sick children
- to compensate for loss of earnings or family support

Practical and legal support

- practical support with parenting
- acceptance by authorities as adoptive or foster parents
- information and access to children's services such as nutrition and immunisation
- advocacy support, such as protecting rights of widows and children to inherit land.

Home care

for people with AIDS

In areas with high HIV infection rates, much of the care of people who are ill rests with their families, especially the older generation. Carers need information and practical support, as well as emotional support.

Neighbours need to know that it is safe to visit someone with AIDS.



David Woodroffe/HelpAge International Source: Ministry of Health, Cameroon



Useful equipment

It is useful for carers to keep and know how to use:

- painkillers
- vitamins to supplement nutrition
- antiseptic cream to apply to broken skin
- sterile dressings or clean strips of cloth and tape to cover sores on the sick person
- soothing lotion to relieve itchy rashes
- salt and sugar to make a rehydration solution
- plastic gloves to use when nursing
- waterproof plasters to cover any cuts that the carer has
- bleach to disinfect whenever necessary
- notebook and pen to record medication and to list questions to ask the health visitor.

Carers need to know how to deal with HIV-related illnesses, reduce the risk of new infections, and protect themselves and others from HIV itself.

People with HIV-related illnesses often have several of the following:

- sores in the mouth and on the lips, white patches on the tongue, pain in the throat
- chronic rashes and open sores on the skin
- chronic tiredness and weakness
- fevers that come and go
- chronic pain and discomfort
- chronic diarrhoea
- chronic cough, difficulty in breathing, infections in the lungs.

Two illnesses to watch out for are tuberculosis (TB) and diarrhoea. TB is contagious (can be spread by contact with the person or clothing), but it can be treated effectively with modern medicine. If the sick person starts spitting blood or has a new fever or chest pain, they and their carer should go to a health facility.

A person with chronic diarrhoea can easily become dehydrated. Carers need to know about giving plenty of fluids.

One of the most important things that a person with HIV and their carer need to know is how HIV is – and is not – transmitted. HIV can only be transmitted if infected blood, semen or vaginal fluid gets into a person's body, or through breastfeeding. There is not enough HIV in body fluids such as sweat, tears, nasal discharge, spit, blister fluid, vomit, urine or faeces, to infect someone. HIV cannot be spread by eating with, talking to or hugging someone with HIV.

Carers must avoid contact with the sick person's blood and body fluids to protect themselves from HIV and also from other infections, such as TB. This may be difficult, as the person may have open sores, chronic diarrhoea or persistent vomiting. Carers should:

- wear rubber gloves (or plastic bags) when changing sheets or blankets, washing a sick person, cleaning sores or giving other intimate care
- cover any cuts or bruises with waterproof adhesive plasters.

If a carer does any of these things without wearing gloves, they should immediately wash their hands with soap and water.

Nutrition Good nutrition is important, as it will boost the sick person's immune system. Often people who have HIV-related illnesses feel nauseous, lose their appetite or have chronic diarrhoea or vomiting. Eating and swallowing may be painful. Carers need to:

- encourage the sick person to eat little and often
- encourage them to drink frequently – water, juice, tea or broth – especially if they have diarrhoea
- include varied foods to ensure balanced nutrition, including starchy foods (rice, porridge, yams), fresh fruit and vegetables, and protein (pulses, meat or dairy products)
- choose foods that the sick person likes
- keep the person away from cooking smells that may make them feel sick
- choose soft foods to make it easier to swallow, but make sure the person has some solid food
- make sure food is fresh and thoroughly cooked, as food poisoning can be very dangerous for people with HIV.

Hygiene Good hygiene is essential, both to reduce the risk of HIV transmission and to protect the sick person from germs that can cause further illnesses. Everyone in the house should:

- wash their hands before cooking or eating
- wash their hands after going to the toilet
- wash dishes and clothes with soap and water
- cover their mouths when coughing and then wash their hands.

Rubbish such as waste food should be buried or burned, or disposed of in covered containers. This stops it attracting vermin and insects, which can cause disease.

The sick person should be encouraged to cough or spit into a container, rather than on the ground. The container should be emptied into a pit latrine, or have disinfectant added if emptied elsewhere, and washed thoroughly before being used again.

After death Immediately after death, carers must continue to protect their hands when washing the body and laying it out. But the virus will die a short while later, as it can only live inside a living person. So the family need not take special precautions at the funeral.

Comfort for the carer

Carers themselves need comfort and support. Many carers suffer from stigma and isolation. Explain to neighbours that it is safe to visit. Suggest that they sit with the sick person for a little while to help the carer.

Respite care, when the sick person is cared for by someone else for a few hours or days, can be a great help to the carer. It may be possible to arrange respite care through a group of volunteers in the community.

Be ready to speak about death and dying with the sick person or their carer if they want to do so. The sick person may be worried about what will happen after they die, especially if they have young children. Older carers may be worried about how they will look after grandchildren, or how they will be cared for themselves when they are very old. Listen and do what you can to reassure them.

Adapted with thanks from: AIDS home care handbook, Caring for people with AIDS at home, AIDS Action 50 (details on page 14).



'I feel so frustrated and worried. I miss my children who passed away. I have to look after my granddaughter. I don't have enough to feed her. What little there is, I give my granddaughter to eat first.'

Older woman in Laos

Resources

Caring for people with AIDS at home

Booklet for teaching families how to provide nursing care to people with AIDS or other chronic illness.

International Federation of Red Cross and Red Crescent Societies (IFRC), 1994.
Price Sw.fr.5. IFRC, PO Box 372, CH-1211, Geneva 19, Switzerland. Tel: +41 22 730 4222 Fax: +41 22 733 0395
Email: secretariat@ifrc.org
<http://www.ifrc.org>

AIDS home care handbook

Handbook for health workers to help individuals, families and communities manage AIDS-related problems.

World Health Organization, 1993.
Price Sw.fr.18 (Sw.fr.12.60 developing countries). WHO sales agents, booksellers or WHO Marketing and Dissemination, CH-1211 Geneva 27, Switzerland.
Tel: +41 22 791 24 76 Fax: +41 22 791 48 57
Email: publications@who.int
<http://www.who.int>

AIDS Action

Issue 41:

Caring for people who are very sick

Issue 50:

Supporting community carers

Healthlink Worldwide, Cityside,
40 Adler Street, London E1 1EE, UK.
Tel: +44 20 7539 1570 Fax: +44 20 7539 1580 Email: info@healthlink.org.uk.
Available in regional editions, and as a PDF at: <http://www.healthlink.org.uk>

Ageways

Issue 57:

When someone has died (article)

Issue 58:

Home care and volunteers

HelpAge International London office
(address on page 16) and PDF at:
<http://www.helpage.org>

Voices

Issue 62:

Ideas and information for making radio programmes about HIV/AIDS

Developing Countries Farm Radio Network, Suite 101-416 Moore Avenue, Toronto, Ontario, Canada M4G 1C9.
Fax: +1 416 971 5299
Email: info@farmradio.org
<http://www.farmradio.org>

Breaking the silence: Kenyan families coping with HIV/AIDS

Book of case studies describing how individuals, including older people, are coping with HIV/AIDS, and support given to families.

Published by Family Planning Private Section (K), PO Box 46042, Nairobi.
Tel: +254 02 715002 Fax: +254 02 515115
Email: fpps_k@net2000ke.com

Older people and HIV/AIDS in Asia

Pack of materials including posters, leaflet and factsheet.

HelpAge International Asia/Pacific Regional Development Centre
(address on page 15).

HIV/AIDS and older people: the African situation

Leaflet on the situation of older people and needs for policy, research and support.

HelpAge International Africa Regional Development Centre (address on page 15) and PDF at: <http://www.helpage.org>

Impact of HIV/AIDS on older populations

Factsheet produced by UNAIDS.
http://www.unaids.org/fact_sheets

HIV/AIDS and older people

Four-minute video on the impact of HIV/AIDS on older people in Africa. IFRC (see above).

Old is gold (HIV/AIDS)

Fifteen-minute radio drama designed to raise awareness of the impact of HIV/AIDS on older people, available on compact disk.

HelpAge International Africa Regional Development Centre (address on page 15).

UNAIDS

Joint United Nations Programme on HIV/AIDS.

20, avenue Appia, CH-1211 Geneva 27, Switzerland. Tel: +41 22 791 3666
Fax: +41 22 791 4187
Email: unaids@unaids.org
<http://www.unaids.org>

International Federation of Red Cross and Red Crescent Societies (IFRC)

Federation of national societies providing emergency and longer-term humanitarian assistance, including HIV/AIDS prevention and care programmes.
Address above.

International HIV/AIDS Alliance

International development organisation which works through in-country organisations to support communities' responses to HIV/AIDS.

Queensberry House, 104-106 Queens Road, Brighton BN1 3XF, UK.

Tel: +44 1273 718 900

Fax: +44 1273 718 901

E-mail: mail@aidsalliance.org

<http://www.aidsalliance.org/>

World AIDS Day

Takes place on 1 December each year. The theme for 2002 is 'Stigma and discrimination', which is also the theme of the World AIDS Campaign 2002-2003.

National AIDS organisations and UNAIDS (see above).

HIV/AIDS research with older people

Guidelines being developed by HelpAge International.
Amanda Heslop, Research and Training Manager, HelpAge International, London (address on page 16).
Email: mheslop@helpage.org

Stop AIDS campaign

Campaign by fifteen leading UK charities, including HelpAge International.

<http://www.stopaidscampaign.org.uk>

International agreements

The **Millennium Declaration**, agreed at the Millennium Summit in 2000, includes a goal to halt and begin to reverse the spread of HIV/AIDS by 2015.

The **Declaration of Commitment on HIV/AIDS**, agreed at the United Nations Special Session on HIV/AIDS in 2001, specifically mentions older people in article 68.

The **International Plan of Action on Ageing**, agreed at the Second World Assembly on Ageing in 2002, has a section on HIV/AIDS, committing governments to improving the assessment of the impact of HIV/AIDS on older people, and to providing information, training and support. The **Policy Framework and Plan of Action on Ageing**, adopted by the African Union in 2002, recommends protecting the rights and needs of older people affected by HIV/AIDS.

HelpAge International Members

Caribbean

Action Ageing Jamaica
Extended Care Through Hope and Optimism (ECHO), Grenada
HelpAge Barbados/Barbados National Council on Aging*
Haitian Society for the Blind
HelpAge Belize*
National Council of and for Older Persons/HelpAge St Lucia
Old People's Welfare Association (OPWA), Montserrat
REACH Dominica*
Society of St Vincent de Paul (SVP), Antigua

Africa

Associação dos Aposentados de Moçambique (APOSEMO)
Elim Hlanganani Society for the Care of the Aged, South Africa
HelpAge Ghana (HAG)*
HelpAge Kenya*
HelpAge Zimbabwe*

Maseru Women Senior Citizen Association, Lesotho
Mauritius Family Planning Association
Muthande Society for the Aged (MUSA), South Africa*
Regional Centre for Welfare of Ageing Persons in Cameroon (RECEWAPEC)
Senior Citizens' Council, Mauritius
Sierra Leone Society for the Welfare of the Aged
Sudanese Society in Care of Older People (SSCOP)
Uganda Reach the Aged Association

Asia/Pacific

Bangladesh Women's Health Coalition (BWHC)
China National Committee on Aging (CNCA)*
Coalition of Services of the Elderly (COSE), Philippines*
Council on the Ageing (Australia)
Fiji Council of Social Services
Foundation for Older People's Development (FOPDEV), Thailand
HelpAge India*
HelpAge Korea*
HelpAge Sri Lanka*

Helping Hand Hong Kong*
Instituto de Acção Social de Macau
Mongolian Association of Elderly People
NACSCOM, Malaysia*
Office of Seniors Interests, Australia
Pakistan Medico International
Positive Ageing Foundation, Australia
Resource Integration Centre (RIC), Bangladesh
Senior Citizen Association of Thailand*
Singapore Action Group of Elders
Tsao Foundation, Singapore
USIAMAS, Malaysia*

Europe

Caritas Malta HelpAge, Malta
Centre for Policy on Ageing, UK
Cordaid, Netherlands
Counsel and Care, UK
DaneAge Association, Denmark
Elderly Woman's Activities Centre, Lithuania
EuroLink Age, UK
Help the Aged*
London School of Hygiene and Tropical Medicine (LSHTM), UK
Mission Armenia

Slovenska Filantropja (Slovene Philanthropy)
Zivot 90, Czech Republic

Latin America

Asociación Gerontológica Costarricense (AGECO), Costa Rica*
Caritas Chile
CooperAcción, Peru
FAIAF, Argentina
Fundación Centro de Estudios e Investigaciones del Trabajo (CESTRAT), Colombia*
Mesa de Trabajo de ONGs sobre Personas Mayores (Lima Co-ordinating Group), Peru*
Red de Programas Para al Adulto Mayor, Chile
Pro Vida Bolivia
Pro Vida Colombia*
Pro Vida Ecuador
Pro Vida Perú

North America

American Association of Retired Persons (AARP)*
Help the Aged (Canada)
West Virginia University Center on Aging

* Full member

HelpAge International Regional development centres

These offices can put you in touch with members in their region.

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PO Box 14888, Westlands, 00800 Nairobi, Kenya
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East and Central Europe network

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Fax: +249 11 461594
Email: hlpgsd@sudanmail.net

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To go on the mailing list for *Ageways*, please complete this form using CAPITAL LETTERS and send it to: Publications, HelpAge International, PO Box 32832, London N1 9ZN, UK Fax: +44 20 7713 7993. Alternatively, email your details to: publications@helpage.org

If anyone else in your organisation would like to receive *Ageways*, please photocopy this form and ask them to complete and return it.

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Sharing lives across continents

Exchange visits between older people's organisations in the Netherlands and the Philippines have helped to create a bond of solidarity.



Yvonne Witter/Unie KBO

Relaxing welcome for Dutch visitors to the Philippines.

In January 2002, five members of the Dutch older people's organisation, Unie KBO, and two staff members went to the Philippines, to visit activities supported by the Coalition of Services of the Elderly (COSE). Six months later, a return visit was made by a delegation from COSE.

The aim of the exchange, funded by the Dutch organisation Cordaid, was to share experiences, knowledge and skills, and to look at the way older people's organisations work in different parts of the world.

Although the two countries are very different, the organisations have much in common. Both work on the 'old-to-old' principle, recognising the huge contribution to society that older people make, and facilitating older people to take care of themselves and each other. For example, COSE educates older community health workers, and Unie KBO trains older advisors.

The Netherlands group learned that older people in the Philippines have

to work to earn money. Many older people have to care for their grandchildren while their children work overseas. However, they were impressed by the sense of community. 'In the Philippines, if someone needs support after suffering from a stroke, there is no need to arrange help – it already is there,' said Yvonne Witter of Unie KBO.

On the return trip, the COSE delegates were struck by the loneliness of some older people, particularly that of an older woman who was dying alone. 'While both our countries have a good dose of volunteerism, it seems to be different in each country,' said Ed Gerlock, COSE advocacy officer. 'In the Netherlands it is an individual thing – you pick your clients and your time. In the Philippines, it is more of a communal thing and one does not have the luxury of setting limits on it.'

The visits inspired the two organisations to continue working together. 'What we saw makes us want to strengthen our own advocacy movement and help people to be more self-reliant,' said Ed Gerlock.

HelpAge International is a global network of not-for-profit organisations with a mission to work with and for disadvantaged older people worldwide to achieve a lasting improvement in the quality of their lives.

Ageways exchanges practical information on ageing and agecare issues, particularly good practice developed in the HelpAge International network. It is published three times a year by HelpAge International, with funding from Help the Aged (UK).

Copies are available in English, Spanish (*Horizontes*), Russian and Ukrainian, free of charge on request to project staff, carers and older people's organisations. Please write to Publications, HelpAge International at the address below to request an order form, or email: publications@helpage.org

Ageways is also available on the web at: <http://www.helpage.org>

Edited by Celia Till with Godfred Paul
Thanks to the International HIV/AIDS Alliance for technical support
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Designed by Solutions Design Consultants, SW20
Printed by APG Limited
ISSN 1469-6223

Front cover photo: Irene Lusiasi cares for eight orphaned grandchildren in Chiwaya, Malawi.
John Cobb/HelpAge International