

Ageways

ISSUE
63

Practical issues in ageing and development

AUGUST 2003



End of life

A stage of life that comes to us all

A time to be remembered

Planning for a proper burial

Care of the person who is dying

Learning to give emotional support

HelpAge
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Comment

Dying with dignity

Welcome to *Ageways* 63. Death comes to us all, but the manner in which we end our lives varies enormously, depending on our personal circumstances.

This issue of *Ageways* looks at the emotional and practical issues facing older people as they approach the end of their lives, and at what can be done to enable more older people to fulfil their right to a dignified death.

Death affects us all personally and individually. If you have anything to add from your own experience, we would welcome your contribution for a future issue.

**Celia Till and Ed Gerlock
Editors**

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Themes of future issues

Issue 64 (November 2003) **Disability**
Issue 65 (March 2004) **Mental health**
Issue 66 (June 2004) **Media**

We welcome articles for consideration. They should be received three months before the month of publication.

Letters

'A hard rock of age'

I came across this article in *Spore* number 102. At a recent workshop in Dodoma, among major problems discussed was ageing and agriculture. Hence the article interested me, as it discussed the need to adapt farming processes and tools to suit older people.

Another point mentioned in our workshop was that youngsters are not educated about ageing. They think they will remain young forever. Very few talk about becoming older. One man told his son of 25 years that he should prepare for becoming older, but the young man said very seriously that 'it is a long time to go and we don't bother about that'. Thus this area should be addressed in more detail by youngsters.

Dr B B O Mmbaga, Executive Secretary, Central Eye Health Foundation, PO Box 76, Dodoma, Tanzania.

Editor's note: *Spore* is published by the Technical Centre for Agricultural and Rural Cooperation (CTA) to provide information for agricultural development in Africa, Caribbean and Pacific countries.

More information:
CTA, Postbus 380, 6700 AJ Wageningen, Netherlands. Web: <http://spore.cta.int>

Huge untapped resource

In India, better medical care and low fertility have made persons above 60 years of age the fastest growing section of society. Older people who are physically fit could be provided with opportunities without age discrimination, and older people who are sick should be given proper care and treatment.

The national policy recognises the 60-plus age group as a huge untapped resource. Their abilities should be

boosted to enable them to have a healthy and cheerful life.

Karuna K Gupta, Assistant Coordinator, Breastfeeding Promotion Network of India, 624 Vikas Kunj, Vikas Puri, New Delhi – 110018, India. Email: karuna_kaura@yahoo.com

Links with local government

I obtained a copy of *Ageways* from a colleague who knows about my work in local government. It is extremely interesting to read how older people can contribute so much, not only to their families, but also to their whole community.

It also struck me as important that *Ageways* deals solely with older people, given that in my country, local governments have a legal requirement to implement an older persons' programme, which includes training workshops, health programmes, cultural activities and so on.

Nancy Narvaéz Torero, Peru. Email: nancynarvaez27@hotmail.com

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.

Ageways index

To help you get the most out of *Ageways*, this issue includes a subject index for issues 54-63. It can be found on page 14.

For back copies of *Ageways*, write to the editor or visit our website: www.helpage.org/publications/newsletters/newsletters.html

New resources

Lynette McGowan/HelpAge International



Learning to use a video camera.

Older people and the media

Older people in Asia welcome access to all kinds of media, but feel they could be better represented, finds a new report published by HelpAge International.

Older people and the media: a community survey used participatory research methods to examine how older people access news, information and entertainment, what they prefer, how they are represented in the media, and how others see them.

The survey found that oral communication still plays a central role in providing information and entertainment for older people. However, broadcast media, particularly television, are becoming more important. The older people consulted also felt that there should be more for older people in all types of media, and that they would like to be more involved in media production.

Older people make a video describes a training workshop in which older people in Sri Lanka made a short video about their community. It is intended as a practical guide.

More information or to request a copy: HelpAge International Asia-Pacific Regional Development Centre (address on page 15).

The rights of older people

HelpAge International Africa Regional Development Centre has produced a number of resources on the rights of older people in Africa. Two video documentaries, *The mark of a noble society* and *Possible solutions*, highlight some of the issues facing older people, such as abandonment, witchcraft, displacement, access to healthcare and home care. The videos draw on discussions with older people, policy makers, and those working with and for older people.

A series of five radio plays, *Old is gold*, address the rights of older people. The plays, each lasting 15 minutes, cover abandonment, access to healthcare, witchcraft and violence, HIV/AIDS, and poverty.

A poster, *Older people's rights are human rights*, is also available.

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

HIV/AIDS and ageing

HIV/AIDS and ageing: a briefing paper describes the impact of HIV/AIDS on older women and men; explains how to make older people visible in HIV/AIDS research; highlights the need for older people to be included in strategies to address HIV/AIDS; and sets out an agenda for action.

Available from HelpAge International London (address on page 2).
Email: publications@helpage.org.
Also available on the web at: <http://www.helpage.org/publications/PapersEtc/PapersEtc.html>

'Young hopes in elderly arms' video

Nearly twenty years after HIV was first detected in Thailand, the HIV/AIDS epidemic has left many older people caring for their sick children and orphaned grandchildren. This video tells the story of an older couple in the Sanpatong district in the northern Thai province of Chiang Mai, whose lives changed forever after the untimely deaths of their daughter and son-in-law.

Available in English (video and DVD) and Thai (video). More information: HelpAge International Asia-Pacific Regional Development Centre (address on page 15).

Project update

Older citizens monitor government services

Older people in Bangladesh, Bolivia, Jamaica, Kenya and Tanzania are learning how to monitor changes in health services and pension schemes. This is part of a project coordinated by HelpAge International to support older people to press their governments to implement the Madrid International Plan of Action on Ageing and other development agreements.

The project began with an audit of poverty reduction programmes, using literature reviews and consultations with older people and policy makers. It found that poor older people hardly feature in national poverty reduction programmes, nor are they included in national consultations on poverty reduction.

More information: www.helpage.org

A stage of life that comes to us all

Ed Gerlock outlines some of the issues facing those close to death and their carers.



Remembering dead relatives during All Souls Day celebrations in the Philippines.

It has been said that the one certainty in life is death. Most of us first reflect on death when we struggle to come to terms with the loss of a loved one. Gradually, we become aware of the approach of our own death.

As people grow older, the path ahead may seem increasingly devoid of choice, with only one outcome. First, perhaps, we may no longer be able to see as well as before, or walk as far. Then we may need help with everyday activities. And then we may start to depend on others to enable us to wash, dress or walk. For many older people, this can be a sad, frustrating and perhaps frightening situation.

Thankfully, many people give their time and their love to older people – to family members, or as volunteers or

professional carers. And organisations, such as my own, have programmes to support these activities.

Many people remain positive whatever the physical limitations that age or illness brings along, and they can be an inspiration. I learnt something about what the end of life can be like from a friend of mine who died recently. He wrote:

‘Ever since I was first diagnosed, I’ve been searching for ways to make sense out of my situation... [I now] understand how I have moved from being a man of action... making things happen... to a life wherein I am being acted upon by circumstances I cannot control... I am being asked to understand that waiting is a virtuous activity... Such seems to be my challenge.’

Right to respect

My friend was cared for in a hospice, receiving medical, emotional and spiritual support. But many people experience the most pain, discomfort and loss of dignity at the end of their lives. For someone who cannot do things themselves, something as basic as forgetting to offer them a drink amounts to neglect.

Sometimes physical care is provided without heed to the person’s emotional needs, such as separating husbands and wives in old age, to be looked after by different sons or daughters.

Many older people do not receive adequate healthcare because they cannot travel to health centres, cannot afford to pay, or face discrimination because of their age. Conditions that severely limit function and quality of life often remain undiagnosed and untreated, because of families’ and medical staff’s attitudes that ‘the person is already old and expensive’.

This is a serious misunderstanding, since many conditions affecting older people, such as cataracts, can be treated effectively and relatively cheaply, enabling the person to continue leading an active life.

We may find it difficult to recognise that people with severe physical disabilities or mental illness can still make a contribution – perhaps by recalling events in their life, since older people often have a sharper memory for the distant past. In any case, we need to remember that an older person remains a fellow human being, one we should treat with kindness and whose rights we should respect.

Preparing for death

Older people who know they are nearing the end of their life will want to prepare for it. They may wish to go over their life to make sense of it, or to become reconciled with someone they have quarrelled with, particularly a son or daughter. They may wish to prepare themselves in a spiritual way, and ask to see a representative of their faith.

They may also be concerned with practical arrangements, such as who will inherit what, and how their funeral will be organised. Burial funds are a longstanding and widespread means of ensuring that there is enough money to meet social obligations around funerals.

In some parts of the world, increasing numbers of deaths from HIV/AIDS are putting tremendous pressure on burial funds and people's ability to meet their social obligations. The HIV/AIDS epidemic has also greatly increased the number of older people who are caring for people who are dying. Many are then left to bring up orphaned grandchildren. For these older people, preparations for their own death may include making provisions for their grandchildren, after they have died.

Help for the living

People who are close to the person who is dying, whether family, friends or professionals, may need a lot of help, both to deal with the stress of looking after someone who is dying, and, afterwards, to live with the grief and loss associated with their death.

The wish to keep in touch with the spirits of the dead is widespread. In many cultures and faiths, ceremonies are held to link the living and the dead.

In the Philippines, a predominantly Catholic country, families celebrate

All Souls Day by moving to the cemetery for around a week. They erect tents or spread mats on top of the graves of deceased relatives. While prayers are offered at various times, normal life continues on top of the graves. People sing and share food with the spirits of the dead, while children continue to play.

Better understanding

Last year, members of older people's organisations from the Netherlands and the Philippines visited each other to learn about each other's work.

The Dutch delegation was moved by the way that people in the Philippines took care of others in the community.

Those of us from the Philippines saw an openness among the Dutch people we met, especially on a visit to a hospice – we were touched by the way they acknowledged death and mourning.

Experiences such as these, which increase our understanding of the issues around the end of life, can help enrich us all.

Ed Gerlock is advocacy officer, Coalition of Services of the Elderly (COSE), 14D Manhattan Street, Cubao, Quezon City, Philippines. Email: gerlock@pworld.net.ph

Stage of life	Effect could include	Support may be needed
Older person		
Death of partner and/ or contemporaries	Grief Loneliness Depression Loss of income	Emotional support e.g. bereavement counselling Financial support Claiming inheritance (especially women)
Deaths of children and/or younger people	Grief Search for explanation Loss of income Concern for children whose parents have died	Emotional support Practical and financial support, especially if caring for children Support to help children who are bereaved
Own approaching death	Frailty and vulnerability to abuse Fear of death Longing for death to relieve suffering Wish for reconciliation Concerns about funeral and other practical matters Concern for children	Discuss care options and develop plan Access to physical, emotional and spiritual care Help with practical preparations e.g. funeral, will, children's welfare
Carer		
Older person approaching death	Stress and worry Physical exhaustion	Care training Emotional support e.g. counselling, self-help groups Taking a break
Older person has died	Grief Loss of role	Emotional support Finding a new role
Older people's organisations		
All stages	Need for issues to be understood	Awareness-raising and advocacy to promote older people's rights Develop standards of care that can lead to a dignified death

A time to be remembered

Ageways looks at people's hopes and fears surrounding death.



John Cobb/HelpAge International

Hoping for help with her funeral is Maggie Kaduya, who cares for ten children in Malawi.

Dona Francisca Vicarra, a 73-year-old woman living in the high plains of Bolivia, keeps a number of small stones in her pocket. Asked why, she explains that the stones are an important reminder, each one representing a child in the village who has died.

Deaths of children and young people bring a particular sadness, and often a sense of anger and bewilderment. In many societies, people search for a reason for these untimely deaths. They may see them as a sign that they have angered their ancestors, or that evil spirits are at work.

In contrast, the death of a person who has reached old age is more readily accepted. In a study in Ghana (details on page 13), older people emphasised that death was not something to be afraid of, but rather a welcome visitor that would bring the peace and rest for which they had longed.

'What I am afraid of is to lie in bed for a long time with sickness, but if you become old and die peacefully, it is a nice thing,' said one older man.

A key concern for people approaching the end of their life is for their death to be noticed. For those living in isolation, this can be a source of great anxiety. In Juba, Sudan, which has a large internally-displaced population, some older people sleep outside their rooms, so that if they die in the night, someone will notice.

In La Paz, Bolivia, Dona Victoria Mamani, a 92-year-old widow, lives in a communal house with the *awichas* (grandmothers). She had ten children but they all died young. She says: 'I know that when I die, the *awichas* will cry for me. They will call my name "Victoria". They will remember me.'

In Malawi, the Elderly People's Association has been approached by many people needing money for coffins. 'It is very important in our culture to give the deceased a respectful burial,' explains director

Hellen Chasowa. 'There is a traditional belief that if the dead are neglected, any ill fortune to fall upon the family, such as sickness, is attributed to this.'

Remembering friends and family who have died is important to those left behind. Pictures, graves, libations, personal reminders such as the stones in Dona Francisca's pocket, and large, public ceremonies, such as All Souls Day in the Philippines (see page 5) are all ways of keeping in touch with the dead.

In Cambodia, the importance of the Pchum Ben festival is such that older people are now helping each other to take part. In this festival, families prepare special food and sticky rice cake which they take to the pagoda to remember their dead parents and ancestors. Relatives who live away from their families come home and bring money. Recently, members of some older people's associations have started to join together to prepare food to take to the pagoda.

As people approach the end of their lives, they tend to look back more than they look forward. Many maintain a close connection with people from their past. Kamkeu Emmanuel, from EPV, a community-based organisation in Cameroon, describes how one older woman is reluctant to leave her home for any length of time because she does not want to face the wrath of her late husband and ancestors. 'When she cleans the compound and lights the fire every day, these bygone people come and warm themselves.'

'A good death is when a person dies a natural death, after having put his things in order.'

Òkyame Opoku, Kwahu-Tafo, Ghana

Planning for a *proper burial*

Many people worry more about how much their funeral will cost their family than they do about dying itself. Ed Gerlock describes a scheme that helps to relieve this anxiety.



COSE

Burial fund members at a monthly meeting.

In the Philippines, communities organise burial schemes to help cover funeral expenses.

In some schemes, a collection is taken when a person dies – either from burial fund members only, or, in tight-knit communities, from everyone in the neighbourhood.

In other schemes, members contribute a specific amount regularly. However, this does not always generate enough funds, so neighbours may then host card games during the overnight vigil, in which winners agree to donate a portion of their winnings to the funeral fund.

Since 1992, the Philippines NGO, Coalition of Services of the Elderly (COSE), has operated a scheme which guarantees families enough to cover all the expenses of a decent burial. Members – who are all older people – contribute the equivalent of US\$0.25 a month. When a member dies, their family receives US\$150.

Membership is open to members of COSE's community-based programmes for the elderly (CBPEs) in Metro Manila

or affiliated groups elsewhere in the archipelago. There are 34 programmes, each with 40-100 members. Most CBPE members belong to the group's burial fund.

Burial fund members must come to monthly CBPE meetings. If they are too sick to come, they are asked to send someone in their place.

A CBPE member acts as treasurer, collecting and recording monthly dues, and forwarding the money to COSE. COSE gives staff time, but does not contribute financially. COSE holds the money from all the burial funds in a bank account, and keeps records of contributions. Cheating can happen – one group discovered, after their collector had died, that she had not passed on the money to COSE.

Representatives of the CBPEs agree policies for the overall burial fund scheme, which are printed in a booklet. These include:

- minimum age for joining (55)
- not being diagnosed with a terminal illness at the time of joining

- full benefits only being paid after a member has belonged to the scheme for at least six months
- reduced benefits being paid if contributions have not been maintained.

Representatives of the CBPEs in Metro Manila elect a central burial fund committee to oversee banking transactions, report to members, and help make decisions. Treasurers meet monthly to review and plan activities, especially fundraising.

Fundraising is necessary because monthly dues are not enough to cover all the benefits – only about 30 per cent. Both CBPE members and COSE organise fundraising. Prizes for raffles are solicited from companies and well-off individuals, and members sell tickets everywhere they can.

Because the idea of burial funds is deeply embedded in traditional culture, local fundraising is generally successful. Company employees organise their own fundraising. Some money also comes from the interest-bearing bank account.

A recent evaluation of COSE's burial fund scheme concluded that older people join CBPEs mainly because they want to be in each other's company – but that being eligible for burial fund benefits is definitely an attraction.

Members mentioned that they would like improvements, including a lower minimum joining age and better benefits. One suggestion is for the burial fund to branch out into livelihood and health projects 'to improve the chances of extending a member's life, so that he or she does not have to claim benefits just yet'.

Ed Gerlock is advocacy officer, COSE (address on page 5).

Care of the person who is dying

If you are caring for a person who is dying, how can you help them have a dignified death?



EWAC

Members of the Elderly Woman's Activities Centre, Lithuania, learn nursing techniques.

The right to dignity is one of five United Nations Principles for Older Persons adopted in 1991, along with independence, participation, care and self-fulfilment. But for many older people, particularly those in need of care, these rights are often overlooked.

The Madrid International Plan of Action on Ageing 2002, goes further, committing governments to promoting older people's active participation in society, and to providing a 'continuum' of healthcare services, from prevention to palliative care, to meet their changing healthcare needs.

Palliative care means total care of the person who is dying. The term originated in the hospice movement which has developed over the past

ten years to care for people who are terminally ill, for example with AIDS or cancer.

Palliative care seeks neither to hasten nor postpone death. It includes medical and nursing care to control pain and other symptoms, and psychological, social and spiritual support, both to the dying person and their family. It may include organising things for the person to do and encouraging them to eat well. It means treating them with respect, acknowledging their right to privacy, and responding to their individual needs.

People who are suffering from severe pain or disability may wish death to come quickly to bring them relief. The use of medical technology that prolongs people's lives raises many ethical questions.

Care organisations – whether providing services in the person's own home, a care home, hospital or hospice – should develop standards of care that take patients' rights into account.

In Moldova, eastern Europe, the gerontological association Second Breath runs a 'hospice at home' service for people with terminal illnesses. An individual programme is planned for each patient, including conversation and spiritual support, physical care and nursing care. The programme also helps dying people and their families to share their thoughts and feelings. Second Breath has developed a bill of rights for the patient and carer, and a carers' ethical code.

In Canada, the Living Lessons campaign has developed bills of rights for the patient, carer and family (listed on page 12).

Physical care

There are many things a carer can do to help someone who is dying. If the person is ill, find out as much as you can about the illness. The more you know, the better prepared you will be. If the person is in pain, try to find out what is causing the pain, and whether this can be treated, or, if not, how the pain can be relieved.

There are many reasons why a person who is frail may be in discomfort, such as loss of appetite, nausea, a dry mouth, breathing difficulties, dry skin or pressure sores. Be sensitive to the person's situation and help them be as comfortable as possible.

Incontinence can be very distressing, for both the person and the carer. It may be caused by loss of mobility, illness, side-effect of drugs, or confusion. Make the toilet more accessible, attend to wetness promptly and without blame, and use a barrier cream to protect affected areas of skin. The person should not cut down on liquids, as this would increase risk of infection. For bowel incontinence, consult a health professional to find out and treat the cause.

Companionship

Emotional support for a person who is dying is just as important as physical care, though it often gets overlooked.

Knowing that things have been put in order can help bring the person peace of mind. One role for carers is to find out if the person has worries and help sort out any practical issues – for example, who will receive their possessions, or what will happen to children in their care (see 'Making a will' and 'Memory books' on page 13).

The person may find it difficult to talk about their concerns, and it can help to develop good listening skills (see 'Learning to give emotional support' on page 10).

People often know when they are dying, because of a deterioration in their health or a change in treatment. They may know how to relate to different people – they can tell who is anxious or who is not afraid. They may be suffering, knowing that death is approaching, but they can also make the most of each moment they have left.

Someone approaching the end of their life is essentially the same person that they have always been. If they seem serious, this is probably because they are a serious person. If humorous, they will probably still retain a sparkle. However, a person's personality may change as a result of their illness or disability. If you find the person difficult, remember that this may be the cause.

When you talk to a dying person, speak as normally as possible. Speaking in a hushed voice, or avoiding certain topics of conversation, can make them feel excluded or patronised. Remember to give the person news of people they know – they are still part of their community.

Touching the person tells them that you are there with them. If it is comfortable for both of you, hold their hand or give them a gentle hug.

Be there. Sometimes, the most thoughtful way to reach out to a dying person is simply by being there with them.

Look after yourself

Carers need a lot of support to cope with the physical demands and emotional strain of looking after someone who is dying. Training, information, counselling, joining a self-help group and taking time off are all important. Try not to do too much, so that you can carry on as long as necessary. Decide what is important and leave the rest. Remember that this situation will not last forever.

After the person has died, allow yourself to grieve. Most bereaved people go through a range of recognisable emotions. Realising that these are normal can help you gradually move forward. Bereavement is a process. Like a wound, it heals, but the scars don't go away.

Ways to deal with grief may include learning about grief, being prepared for mood swings, respecting your feelings, taking time out, talking about the person who has died, living in hope, planning your future without the person, and, if you need help, asking for help.

We are grateful to the TSAO Foundation, Singapore (email: tsao1@pacific.net.sg) and Isa de Jaramillo, psychologist and president of the Omega Foundation, Colombia, (email: correo@isadejaramillo.com) for their contributions to this article.

Ideas for emotional support

Have you any ideas on how organisations working with older people can provide emotional support to those who have been bereaved through HIV/AIDS and lack proper resources to support orphans? We would like to hear from you.

Learning to give emotional support

People who know that death is close often want to recall events in their life.

These exercises are designed to help carers listen and ask helpful questions.

Some older people may look back on a life fulfilled. But many remember failures, missed opportunities and bitter memories, which they may find difficult to talk about. Carers need to listen and respond in a way that enables the person to reach an understanding about the events in their life. By being sensitive to the person's emotional needs, carers can assist them in their final weeks and days.

Most of the following exercises are for two people, taking it in turns to speak and listen.

1 Active listening

When we listen to someone, we may be reminded of situations and feelings of our own. However, when we are with an older person whom we are taking care of, we need to be able to put our own thoughts and feelings to one side.

Truly listening to what another person is telling us means focusing entirely on what they are saying. It is called 'active listening'. If we listen in this way, we are able afterwards to show the person that we have properly understood. We can do this either by 'mirroring' their words or by summarising what they have said.

Active listening also means actively watching how the person is behaving. It means noticing if their facial expression or tone of voice changes. Or there might be small but sudden movements of their hands or feet. All of these can indicate levels of emotion.

If we listen in an 'active' way, we may nod our head, or make a small sound. This is valuable, as it indicates to the person that they are really being listened to.

Exercise

Speaker: Tell the listener about some experience you have found moving. It could be a situation from your childhood or present-day life. It could be happy, sad or perhaps anger-provoking.

Listener: Listen for three minutes, then stop your partner. Now reflect back what you have heard. This means summarising what you have heard and, at the same time, mentioning any emotional reactions which you noticed as the speaker was talking.

Change roles. Then reflect together on how well you picked up on the feelings behind the words, and how you did this.

2 Being non-judgemental

When you listen accurately and indicate this to the speaker, an atmosphere of trust is created. When you convey to the speaker that you are accepting what they say, without making any criticism, you are being non-judgemental. If the speaker can trust the listener not to criticise, they are able to be more open about their feelings and thoughts.

As children, adults told us what we should and should not do. These lessons differ from place to place and culture to culture. Even within a common culture, we will each have been taught different lessons.



Especially if we are working with an older person from a different culture, we must attempt to keep a truly non-judgemental view of the speaker and their world. As carers, we have to be aware of our own values and attitudes. If we are not, we will not truly hear what the other person is saying.

Exercise

Speaker: Talk for about two minutes about feelings you find unacceptable or difficult in others – for example: anger, jealousy or sexual feelings.

Listener: Just listen, without any other response. Notice what is happening inside you as you listen.

Change roles. When you have finished, share what it was like to disclose these feelings to another person. Share what it was like to listen to another person without openly judging.

3 Having empathy

Having empathy means 'standing in the place' of the other person, as if we are feeling their feelings. When we listen and notice carefully, and view problems as the other person does, we are being empathic.

Exercise

This exercise needs three people. Give each person a chance to play all three roles. Do not discuss your reactions until everyone has played each role.

One person is an older person who has had a stroke, which has left them temporarily speechless. One person is a doctor. One person is either a nurse or a social worker – decide according to your own interest.

The older person lies down and remains silent. The doctor and the nurse (or social worker) speak to each other across the person as they discuss the treatment plan. They do not speak to the older person.

When you have done this three times, discuss how you each of you felt when you were playing each of the parts. Notice whether empathy was being used at any time.

4 Useful questions

Questions can encourage an older person to explore their situation further. But if questions are used inappropriately, they can stop someone from talking, or leave them feeling misunderstood, pressurised or angry. Asking useful questions is a very important skill to practise.

Not all questions are useful. 'Why?' can be useful, but it may be threatening if used too often. Closed questions (where the listener feels they are expected to answer just 'yes', 'no' or 'I don't know') are not really useful. Leading questions (which are phrased in such a way that they suggest what answer is expected) are not useful either.

Open questions, on the other hand, allow the listener to continue from their own starting point. Open questions include those starting with: 'How?', 'What?', 'In what way?' or 'Can you say more about?' An open question will allow a person space to talk.

'It's not really part of life to ignore death or not talk about it.'

Eufemia Arroyo, COSE member, Philippines

Exercise

Working with a partner, together think of as many closed questions as you can. Then, together, turn them into open questions.

Repeat the exercise, this time changing leading questions into open questions.

5 Being specific

Another useful skill is encouraging the older person to be more specific about what they are saying. This will help them identify what the real problem is and perhaps take some action to put things right. We can help the older person to focus by asking a question.

So, if someone says: 'My life is a mess,' we can help them by reflecting their statement and asking an open question: 'You say your life is a mess. Perhaps you can tell me the ways in which it is a mess.'

Exercise

Speaker: Make a general statement about yourself.

Questioner: Ask a question to encourage your partner to be more specific. Notice what happens.

Change roles. Share your experience in each role.

Adapted from Learning to listen – counselling skills for helpers of older people by Maggie Comley, published by HelpAge International, 1996 (out of print).

Standards of care that recognise rights

Care organisations should develop a set of values or principles that recognise older people's rights. The following bills of rights were developed by the Living Lessons campaign.

Patient bill of rights

As a person facing the end of my life, I have the right to:

- ✓ Be treated as a living human being until I die.
- ✓ Live free of pain.
- ✓ Participate in the decisions that affect me and my quality of life.
- ✓ Have my decisions and choices respected and followed, even though they may be contrary to the wishes of others.
- ✓ Be treated with openness and honesty without deception or half-truths.
- ✓ Receive ongoing medical and nursing care even though the goals must be changed from cure to comfort.
- ✓ Express my feelings and emotions about my approaching death in my own way.
- ✓ Maintain a sense of hopefulness, however changing its focus might be.
- ✓ Be cared for by those who can maintain a sense of hopefulness, however changing its focus might be.
- ✓ Discuss and enlarge my spiritual and religious experiences, regardless of what they mean to others.
- ✓ Be cared for by compassionate, sensitive and knowledgeable people who will attempt to understand my needs and try to meet them.
- ✓ Receive support from and for my loved ones in learning how to accept my death.
- ✓ Die in peace and with dignity.

Caregiver bill of rights

As a caregiver for a loved one, I have the right to:

- ✓ Take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- ✓ Seek help from others, even though my loved one may object. I recognise the limits of my own endurance and strength.
- ✓ Maintain facets of my own life that do not include the person I care for, just as if he or she were healthy. I know that I do everything that I reasonably can for my loved one; I have the right to do some things just for me without feeling guilty.
- ✓ Get angry, be depressed or happy, experience frustration, laugh and cry and express the normal range of human emotions.
- ✓ Reject any conscious or unconscious attempts by my loved one to manipulate me through guilt, anger or depression.
- ✓ Receive consideration, affection, forgiveness and acceptance from my loved one for what I do for them on a daily basis.
- ✓ Take pride in what I am accomplishing and to applaud my own courage in taking on the responsibility for caring for my loved one.
- ✓ Protect my individuality and maintain a life for myself that will sustain me once my loved one has passed on.
- ✓ Expect and demand that, as government makes strides in finding resources to support afflicted persons, similar strides are made toward aiding and supporting caregivers.

Family member bill of rights

As a relative to a dying person, I have the right to:

- ✓ Enjoy my own good health without feeling guilty. It is not my fault that someone I love is dying.
- ✓ Choose whom I will talk to about my relative's disease. If someone's feelings are hurt because I do not wish to answer their questions, it is not my fault.
- ✓ Know what is going on in our family, even if I am a child.
- ✓ Be told the truth about my relative's disease, condition and prognosis in words I can understand.
- ✓ Disagree or get angry with someone, even if they are dying. Sickness does not stop someone from being human.
- ✓ Feel what I am feeling, not what someone else says I 'should' be feeling.
- ✓ Look after my own needs, even if they do not seem as great as the needs of my dying relative. I can take a 'time out' without feeling disloyal.
- ✓ Get outside help for my dying relative and family members if we cannot cope by ourselves.
- ✓ Get help for myself, even if others in my family choose not to get help.
- ✓ Maintain hope, in whatever form that might be. No one has the right to take my hope away from me.

Living Lessons is a campaign developed by the Canadian hospice palliative care movement in partnership with the GlaxoSmithKline Foundation to encourage an open dialogue on death and dying.
Web: www.living-lessons.org

Memory books



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

In Zimbabwe, Red Cross Society volunteers are helping parents who are dying to create memory books (or boxes) for their children. The books contain family stories, photos and drawings. The books help parents communicate with their children, and they help children learn about their heritage, so that they retain some sense of identity and security after their parents die.

The project includes a group of carers of children whose parents have already died, mainly grandparents, who hold family memories which can help give the children that crucial sense of belonging.

Source: 'Memories of the past provide hope for the future', 20 November 2002, IFRC website: www.ifrc.org/docs/news/02/02112001

Resources

Hospice Information

Membership organisation for those providing palliative care, a joint initiative of St Christopher's Hospice and Help the Hospices. Free to resource-poor countries. Publishes *Worldwide Hospice and Palliative Care Online* (also available in print). Avril Jackson, *Hospice Information*, St Christopher's Hospice, 51- 59 Lawrie Park Road, Sydenham, SE26 6DZ, UK. Email: avril@hospiceinformation.info

AARP

Website includes end of life issues. Web: www.aarp.org/endoflife/

Gentle Endings

Website from US-based Novartis Foundation for Gerontology providing information for people who are dying and their carers, including page on 'Dying when very old'. Web: www.healthandage.com/html/min/gentle_endings/web/index.htm

Cruse Bereavement Care

UK charity specialising in bereavement.

Website includes practical advice including how to help children. Web: www.crusebereavementcare.org.uk

Where there is no doctor

Healthcare handbook including chapter on older people. David Werner, *Hesperian Foundation*. Revised 1992, updated 2002. ISBN 0-942364-15-5 Price: (developing countries) £4.50 plus 20% (surface mail) or 40% (air) from TALC, PO Box 49, St Albans, Herts AL1 5TX, UK. Fax: +44 1727 846852 Email: talc@talcuk.org

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Issue 58: Home care and volunteers

Issue 57: When someone has died – coping with bereavement

Issue 56: Running a residential home

Article (quoted on page 6)

'I want to go!' How older people in Ghana look forward to death, Sjaak van der Geest, *Ageing and Society*, Jan 2002, vol. 22 part 1, 7-28.

Making a will

A will is a written document that makes clear what a person wishes to happen after their death. A will must be made in accordance with local law.

A will can:

- ensure that property, land and valuables are passed on to people that the person would like to receive them
- make clear who has custody of children in the family, for example by appointing guardians for orphaned grandchildren when there is no parent alive or willing to take care of them
- specify who will make sure the will is acted upon – these are the trustees or the executors
- provide instructions about funeral arrangements.

To be valid, a will must be:

- written in permanent ink or typed
- signed by the person and clearly dated
- witnessed by persons present at the same time as the will is signed and dated – the number of witnesses required depends on the country. Those who will benefit from the will should not be witnesses
- written when the person is of sound mind and is not being forced to do so by someone else.

Source: *AIDS Action 41*, 1998, *Healthlink Worldwide*, from material originally developed in Tanzania

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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)
 CEM Outreach, Sierra Leone
 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
 Senior Citizens Council 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
 DaneAge Association, Denmark
 Elderly Woman's Activities Centre, Lithuania
 Eurolink Age, UK
 Help the Aged, UK
 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 (CESTR), 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

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

<p>Title _____ First name _____ Surname _____ Job title _____ Organisation name _____ _____ Address _____ _____ _____ _____ City _____ Postal code _____ Country _____ Tel _____ Fax _____ Email _____</p>	<p>How old are you? <input type="checkbox"/> Under 30 <input type="checkbox"/> 30-60 <input type="checkbox"/> Over 60</p> <p>Do you have access to the web? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>What is your job? <input type="checkbox"/> Social worker <input type="checkbox"/> Health worker <input type="checkbox"/> Trainer <input type="checkbox"/> Administrator <input type="checkbox"/> Student <input type="checkbox"/> Librarian <input type="checkbox"/> Emergency relief worker <input type="checkbox"/> Other (please specify) _____</p> <p>What sort of area do you work in? <input type="checkbox"/> Urban <input type="checkbox"/> Rural</p> <p>Does your work focus primarily on older people? <input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>Do you work for an organisation? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>If yes, which of the following describes your organisation? <input type="checkbox"/> Older people's organisation / pensioners' association <input type="checkbox"/> Community-based organisation <input type="checkbox"/> Local or national NGO/religious organisation <input type="checkbox"/> Government organisation <input type="checkbox"/> International NGO/religious organisation <input type="checkbox"/> International government or multilateral agency (e.g. WHO) <input type="checkbox"/> Training/educational institution <input type="checkbox"/> Other (please specify) _____</p>	<p>How many copies of <i>Ageways</i> do you need? <input type="checkbox"/> English <input type="checkbox"/> Spanish (<i>Horizontes</i>) <input type="checkbox"/> Russian <input type="checkbox"/> Ukrainian</p> <p>If 10 or more please say how you will use them _____ _____ _____</p> <p>We will use this information to distribute <i>Ageways</i>. We may also use it to distribute other HelpAge International materials, or pass it to other organisations to distribute their materials.</p> <p>If you would like to receive information other than <i>Ageways</i>, please tick this box. <input type="checkbox"/></p>
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Expanding the role of *burial societies*

Traditional community organisations in Ethiopia are expanding their roles as a result of the impact of HIV/AIDS.

Many people in Ethiopia belong to self-help community organisations called *iddrs*, which provide financial and emotional support to bereaved families. Members pay a monthly fee and must meet certain obligations, such as attending funerals, cooking for bereaved families and going to meetings.

Mary Joy Aid Through Development, an Ethiopian NGO which runs integrated development programmes, is currently working with 42 *iddrs* in Addis Ababa on HIV/AIDS awareness-raising and practical support. It has found that *iddrs* provide an opportunity to develop a community-based response to the economic and social problems created by HIV/AIDS.

Now, Mary Joy is developing a pilot programme with HelpAge International to extend its support to older people who have lost family members to AIDS, or who are themselves HIV positive.

Trained volunteers will provide counselling and home care to 150 people living with HIV/AIDS aged over 45, and to vulnerable older carers. These people are also receiving basic food supplies for three months. The first group of volunteers to be trained as counsellors have been recruited from older *idder* members, who are respected members of the community.

At the same time, the impact of HIV/AIDS on family income has put pressure on *iddrs* to provide more support to alleviate the poverty of



Polly Mathewson/HelpAge International

Sahele Degafa with one of the children in his care.

members affected by HIV/AIDS. *idder* members are having to face important decisions about when and to whom financial support should be given.

Sahele Degafa, aged 67, has been caring for his wife's three children since she died from AIDS. His *idder* paid for his wife's funeral. He himself is HIV positive. He says of his *idder*: 'When I die they will pay 2,000 birr [US\$237]. But it would be better to have 1,000 birr before death and 1,000 birr after death. That is why I am attending meetings concerning these changes to the *idder*.'

More information: HelpAge International Ethiopia programme (address on page 15).

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.

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 as a pdf at: <http://www.helpage.org>

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Designed by Solutions Design Consultants, SW20
Printed by APG Limited
ISSN 1469-6223

Front cover photo: Dona Victoria Mamani will be remembered when she dies (see page 6).
Antonio Olmos/HelpAge International