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Caring for people who are very sick



IN THIS ISSUE

- A Better Life and Death
- Helping Carers to Cope
- Controlling Pain
- Passing Through

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Most people would like to die with dignity and in peace. However, carers often lack the support that they need to relieve the pain and distress of people who are nearing death. Prejudice and fear of HIV can make the experience particularly distressing.

This issue of *AIDS Action* provides practical advice to those who are caring for very sick people. It emphasises that the quality of life of someone who is dying is not just related to medical care, but that social, spiritual and emotional support are equally important.

Severe pain is a common symptom of HIV-related illness and can cause much suffering. However, there are many ways of reducing pain. This issue looks at how to make the person more comfortable, and discusses pain-killing drugs for HIV-related illnesses.

Often the biggest fear that very sick people face is fear of what might happen to their loved ones after they have died. Helping them with practical arrangements, such as making a will, can reduce their anxiety. Guidelines for this are included.

The needs of carers themselves must not be overlooked. Care for very sick people is often provided by family, partners and friends, as well as health workers. Carers need practical and emotional support to enable them to give good care, including information about HIV itself, training in how to make a sick person comfortable, and bereavement counselling to help them cope when the person dies.

Death and dying are subjects that many people find difficult to talk about. But by being better prepared for the end of life, people with HIV may feel more able to have a good quality of life, even when very sick. 

W A Better Life and Death

When someone is in pain or fears dying, carers, family and friends can help by giving the person as much information and appropriate care as possible. The quality of life of someone who is dying is not just related to medical care. Social, spiritual and emotional support, resolving unfinished business and making practical arrangements are equally important.

• Physical treatment

HIV-positive people should be able to decide about their treatment and about how and where they wish to die. They may need to consider in advance what treatment they want to receive towards the end of their life, who will make treatment decisions on their behalf if they develop dementia (confusion), and where they wish to die.

Sick people need skilled medical and nursing care for physical problems such as pain, weight loss, diarrhoea, and skin problems. Relieving symptoms such as pain can improve quality of life. Some people find it helpful to use traditional or complementary medicine to relieve pain.

• Emotional needs

Towards the end of life, people may need to discuss issues related to their life or to dying. They may need to decide whether or not to disclose their HIV status to family or friends if they have not already done so.

One of the best things that a carer can do is to be there, to listen, talk and encourage the person to talk about their feelings, and let them know that they care. However sick someone is, they can still be included in daily activities and watch what is going on around them. The need for love and acceptance from carers is particularly important, especially for people who are experiencing loneliness, isolation and rejection.

People approaching the end of life may find that counselling helps them to accept and understand what is happening. They may deny their illness, or become angry or blame others. They may despair because of the absence of a cure, be anxious about partners and family, or feel grief, fear of death, and guilt. It can be helpful to talk to others in the same situation. It can be very useful to put people in touch with a local support group for people with AIDS.

• Spiritual needs

People with HIV may need spiritual support. They may feel cut off from their religion or religious community, or there may be problems with funeral arrangements. Some people find it helps

to talk to someone with the same religious background, or to practise their religion even if they have not done so for a while. Others may feel pressured into talking about religious issues when they would prefer not to.

Carers should acknowledge a person's spiritual needs, respect their religious beliefs or lack of them, identify an appropriate person who can provide spiritual support, and discuss whether the person wants any religious rituals to be performed.

• Practical arrangements

People often worry about what will happen to their loved ones after they die. It is helpful to make practical arrangements as early as possible for debts, school fees, funeral costs, family support and so on. Although it can be distressing to think about these things, making plans can reduce anxiety. Making a will (see box) can prevent family conflict and ensure that partners, especially same sex or unmarried partners, and children are not disinherited or left destitute.

• When death comes

During the last hours of a person's life, carers should focus on minimising pain, reducing shortness of breath, and reducing the risk of seizures and choking. If symptoms and distress are not easily controlled it may be appropriate to use sedation if this is


acceptable to the person (see page 6).

Although it is not always easy to know when death is near, the person usually becomes very weak and immobile, uninterested in food and drink, and is drowsy or asleep much of the time. It is important not to leave them alone, as many people are afraid of dying alone.

If a person dies in a hospital or hospice, health workers should respect rituals and customs related to laying out the body, and allow mourners time alone with the body if they wish. Trauma, grief, anger and other feelings can be reduced if practical arrangements follow the wishes of the person, their family and friends.

Doctors need to think about what goes on the death certificate. It may cause problems for families if the word 'AIDS' is written, because death certificates are not confidential. It may be better to write the immediate cause of death, such as pneumonia.

Ian Kramer, UK Coalition of People Living with HIV/AIDS, 250 Kennington Lane, London SE11 5RD, UK.

The UK Coalition has produced discussion guidelines on end of life issues. Please contact Ian Kramer to obtain a copy or to participate in the debate. 

*Preparing for death
can make the end
of life a less
worrying and more
positive experience
for sick people
and their carers.*

Patients' Rights

- Everyone has dignity and value as a human being and one's life, body and personality should be respected.
- Everyone has the right to considerate and respectful care.
- Everyone has the right to complete information about one's diagnosis, treatment and prognosis. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in the patient's behalf.
- Everyone has the right to the information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information should include the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation.
- Everyone has the right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of such action.
- Everyone has the right to privacy concerning one's medical care program. Case discussion, consultation, examination and treatment are confidential and should be conducted discreetly. Those not directly involved in the patient's care must have the permission of the patient to be present.
- Everyone has the right to expect that all communications and records pertaining to one's care should be treated as confidential.
- Everyone has the right to expect that within its capacity, a hospital must respond to the request of a patient for services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case.
- Everyone has the right to obtain information as to any relationship of the hospital to other health care and educational institutions insofar as one's care is concerned.
- Everyone has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting one's care or treatment. The patient has the right to refuse to participate in such research projects.
- Everyone has the right to expect reasonable continuity of care. Everyone has the right to know in advance what appointment times and physicians are available and where.
- Everyone has the right to examine and receive an explanation of the hospital bill regardless of source of payment.
- Everyone has the right to know what hospital rules and regulations apply to one's conduct as a patient. Everyone has the right to be informed of one's rights and responsibilities.

Source: Adapted from "A Patient's Bill of Rights" by the American Hospital Association and "Declaration of Patient's Rights" by the Citizen's Alliance for Consumer Protection (Korea)

TYPES OF CARE

People who are approaching the end of life need both palliative care and terminal care.

PALLIATIVE CARE considers the needs of the whole person. It includes medical and nursing care, social and emotional support, counselling and spiritual care. It emphasises living, helping people to make the most of each day and to maintain a sense of hope. It includes organising things for the person to look forward to, and encouraging them to eat healthily and live as normal a life as possible. It means caring for them, treating them with respect and acceptance, acknowledging their right to privacy and confidentiality, and responding to their individual needs.

TERMINAL CARE aims to improve the quality of daily life at the end of life, by relieving symptoms and enabling a person to die in comfort, with dignity and in keeping with their wishes and religious requirements.

Health workers need to consider:

- what treatment and care are available to improve quality of the end of life
- what minimum standards of care should be expected at the end of life in health facilities or at home, and what training and support is needed to provide these
- how better standards of care can be promoted
- what guidelines exist for hospital discharges and home care support
- how to ensure that the wishes of people who are dying are respected
- how to ensure that people with HIV/AIDS have the opportunity to discuss anxieties, loneliness and other emotions
- what spiritual support is available to people at the end of life
- how people who are dying can be helped to find peace and to come to terms with their life and death, whether they have religious faith or not
- how to help people with HIV to make plans for the future
- what changes in law, policy or custom are needed to ensure that people's wishes are respected after death.

Helping Carers to Cope

Health workers can teach simple nursing techniques to people who are looking after a sick person at home. These can make a big difference to the person's comfort, and can give carers more confidence.

Care of the sick and dying is often provided by family, partners and friends. These people need support to help them give good care.

Carers also need practical and emotional support. If they themselves are tired or distressed, they cannot give sick people the care they need. Counselling can help carers to deal with fears and feelings of isolation, helplessness, depression or anxiety, both during the person's illness and after their death.

Carers may feel reluctant to talk about the problems they are facing and fear being judged an inadequate carer. They may not want to put their needs before those of the patient. They may believe that problems are unavoidable and cannot be resolved.

Health workers can help carers to:

- plan how they will manage the care of someone who is dying and share the responsibility with others
- keep simple records of medications given to the person, so that it is easy for other carers to see what the person has been given and when
- take time off, have enough rest, eat well and look after their own health
- talk with a friend, relative or trusted health worker
- join or start a support group for carers.

Bereavement support

Families and friends often have very

little social support, or may have become isolated while the person was very sick. Bereavement support should be available before the person dies, and for as long afterwards as people need it.

Different people react to death in different ways, and need different types of support. It can take months or years to come to terms with loss. People's response may be affected by the way the person died - whether they were alone and in pain, or whether they died peacefully surrounded by those they loved. Those left behind may blame themselves if they feel that things could have been done better.

Bereavement counselling can:

- give people an opportunity to talk about events leading up to the death, about the death itself and rituals immediately after the death
- reassure people that feelings of disbelief, denial, sadness, pain and anger are normal
- allow people to express their feelings and concerns, especially if it is difficult for them to do this with friends and family
- enable people to accept the reality of their loss and start to look to the future
- provide information about HIV transmission if people lack knowledge or have concerns and unresolved fears.

Dr Veronica Moss, Medical Director, Mildmay International, 1 Nelson Mews, Southend-on-Sea, Essex SS1 1AL, UK. With thanks also to Sister Margaret Moran in Ghana, Chris Green in Indonesia, and Ditch Townsend in Malaysia.

Sources: A comprehensive guide for the care of persons with HIV disease, Module 4: palliative care. See page 8. Palliative care for people with AIDS. See page 8.

Simple Techniques for Nursing at Home

Pressure sores

These develop when a person lies in one position for long periods, or because of pressure on bony parts of the body. Keep skin clean and dry, change the person's position every 2-4 hours, and use pillows or soft clothes to protect bony areas. Treat sores by washing daily with salty water (tasting like tears) and covering with a clean dressing. It can help to put honey, fresh pawpaw pulp (from just inside the skin of the fruit) or yoghurt on sores 1-2 times a day under the dressing.

Conjunctivitis and other eye infections

Dip clean cotton wool into a solution of boiled water and salt (tasting no saltier than tears) and wipe gently across one eye. Repeat with a new piece of cotton wool for the other eye. Throw away used cotton wool.

Mouth care and oral thrush

Clean the teeth and use a mouthwash made with boiled water and a little potassium permanganate, or bicarbonate of soda and lemon juice. If the person is too weak to do this, clean their teeth gently with a small soft toothbrush, or a stick with the end chewed to make it soft, or a soft cloth around the finger. A person with oral thrush may find it difficult to swallow liquids. Give small sips of fluid as often as possible to keep the mouth moist.

Muscle aches and pains

Massage can relieve aching muscles and headaches and improve circulation. When someone has sores on the skin due to Kaposi's sarcoma (KS), massage carefully to avoid opening sores.

Wounds or ulcers

Keep these clean, using freshly prepared salt solution and covering with clean dressings. A wound that smells bad is probably infected. Antibiotics can help. Oozing wounds can be covered with pawpaw skin (placing the inside of the skin against the wound). Apply metronidazole gel or liquid to the wound to control infection and smell. Change dressings daily or weekly as required.

Oedema (Swelling) associated with KS or heart failure

Relieve discomfort by raising the limb onto a pillow or pile of straw or banana leaves covered with a cloth. Massage very gently, starting from the foot and moving upwards. The skin may be very sensitive to touch. In cases of heart failure and oedema of feet and ankles, the best treatment is diuretic medication, under a doctor's supervision. Keep feet raised on a low stool when the person is sitting up. Diuretic tablets do not usually help when oedema is associated with KS.

Eating or swallowing difficulties

Treat thrush in the mouth or throat with ketaconazole tablets or another antifungal drug, or nystatin suspension, or gentian violet. Mouthwashes (see 'Mouth care and oral thrush') can also help. Give drinks and food that are cold or warm but not hot. Give soft food that is not spicy, such as soups or mashed banana with milk. Offer small amounts every few hours.

Breathing difficulties or cough

It is easier to breathe in a sitting position. Coughing can hurt the throat, cause breathing problems, prevent sleep and cause tiredness. Helping someone to walk about or sit up can reduce coughing.

Anxiety and fear

Do not leave a person alone if they are anxious or frightened. Try to reassure them by holding their hand and speaking soothingly.

Neurological problems

A very sick person may experience confusion, loss of memory or personality changes and may be at risk of hurting themselves. Keep potential dangers such as boiling water or medicine out of reach. Speak calmly and quietly. Avoid arguing. Say 'no' gently but firmly when necessary, or leave the room for a short while. Be prepared to repeat what you say.

Moving and changing positions

A person who is weak can be helped to sit up, and to stand and walk with support. Take care to avoid hurting someone, especially if they are sensitive to touch. Carers need to know how to lift and move a person without hurting their own backs, by bending from the hips and keeping their back straight.

Changing dirty bedclothes

Turn the person onto their side. Roll up dirty bedclothes towards the person's back. Clean and dry the person's skin and apply lubricating oil, such as Vaseline. Place a clean sheet, rolled up lengthways, half way down the bed, against the person's back. Roll the person back onto the clean sheet. Remove the dirty sheet. Unroll the clean sheet to cover the rest of the bed.

Making a sick person comfortable

Back rests and foot rests make sitting up more comfortable and breathing easier. Rubbing oil into dry skin can relieve itching. Itching can also be soothed by applying calamine lotion. A backrub, using oil or lotion, can moisten dry skin, stimulate circulation and relieve numbness. Clean bedding and clothing also help. 🧼

What Carers Need to Know

Carers need information and training about:

- how HIV is and is not spread, to reduce fears about looking after someone with HIV/AIDS, and to reduce the risk of transmission
- symptom control
- services and support available, including where to obtain resources such as gloves and soap
- how to care for a sick person's physical, emotional and spiritual needs
- progression of the illness
- sudden changes in the person's condition, particularly changes that signal that death may be near
- care of someone who is dying.

Controlling PAIN

Effective control of pain can greatly improve quality of life, both at home and in hospital.

Pain is common in HIV-related illness. It may be sudden or last a long time. Sometimes carers may not believe a person is in severe pain and therefore not deal with it. But no one should have to suffer from uncontrolled pain. Pain is caused by:

- HIV, which can affect the nerve fibres (peripheral neuropathy)
- opportunistic infections, such as herpes zoster and cancers such as Kaposi's sarcoma (KS) or non-Hodgkins lymphoma
- lying still, leading to sores, general weakness or muscle ache.

Persistent or recurring pain should be treated by following the three steps in the WHO 'analgesic ladder' (see right).

Drugs for persistent pain should be given regularly, according to how long their effect lasts. For example, instructions suggest that paracetamol should be taken every four hours, and diclofenac

Effective control of pain can greatly improve quality of life, both at home and in hospital.

every eight hours. Health workers should also be guided by the response of the patient. Patients should never be left in pain waiting for the next dose. They should be reviewed regularly to ensure that the right drugs and dosages are being given.

Use the least invasive route of administration—preferably oral tablets or liquids, or suppositories. Avoid injections if possible.

Pain-relieving drugs taken over a period of time should be given under medical or nursing supervision, partly because of their side effects:

- Aspirin may cause stomach bleeding or ulceration. Aspirin should be stopped if the patient complains of indigestion or the stool becomes very black - black stools suggest bleeding in the intestinal tract.
- Codeine and morphine cause constipation. This may not be a problem for patients with persistent diarrhoea, but others may need to change their diet or use laxatives.
- An overdose of paracetamol can cause severe liver damage and subsequent death.

Many doctors and nurses are unwilling to give morphine or other opioid drugs (derived from opium) because they associate these drugs with illegal drug use or are concerned about addiction. However, denying patients these drugs can cause unnecessary suffering. If opioid drugs are given properly by trained health workers there is no problem with addiction. These drugs need to be made more widely accessible to patients with severe pain, and health workers need to be trained in their use (see page 7).

Dr Veronica Moss, Mildmay International (address on page 5). 

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<p>ASPIRIN or PARACETAMOL Simplest and most widely available analgesics (pain-relieving drugs). Give for one or two days.</p> <p>If they do not relieve the pain, move to Step 2.</p>	<p>CODEINE or DIHYDROCODEINE with or without non-steroidal anti-inflammatory drugs (NSAIDs) such as IBUPROFEN or DICLOFENAC</p> <p>If severe pain persists, move to Step 3.</p>	<p>MORPHINE with or without co-analgesic Morphine is the strongest analgesic available and the easiest to control and monitor accurately.</p> <p>Other strong opioid drugs include SYNTHETIC PETHIDINE and FENTANYL. The effects of pethidine only last for three hours at most, so pethidine is unsuitable for treating chronic pain or for long-term use.</p>
<p>If, after following the three steps, the pain is still uncontrolled, the patient should be referred to a specialist.</p>		

HOMEMEDICATIONS

PROBLEM	MEDICATION	DOSE	SIDE EFFECTS
General aches and pains including headache	Aspirin	600mg every 4 hrs	May cause indigestion Liver disease with prolonged use Constipation/confusion Stomach ulceration Stomach ulceration
	Paracetamol	1000mg every 4 hrs	
	Codeine phosphate*	60mg every 6-8 hrs	
	Ibuprofen Diclofenac	400mg every 6 hrs 50mg every 8 hrs	
Itching and sore skin (fungal infection)	Clotrimazole or Miconazole cream	Apply twice daily for 2 weeks	
Herpes zoster (shingles)	Acyclovir	800mg 5 times a day for 5 days	Works best if started at first sign of infection
Abscesses	Flucloxacillin	250-500mg every 8 hrs for 5 days	
Oral or vaginal thrush (candida)	Nystatin oral suspension (100,000 units per ml)	2-3ml after food	
	Ketoconazole	200-400mg once a day for 7 days	
	Clotrimazole cream or pessaries	200-500mg pessaries	
Anxiety/agitation	Diazepam*	2-5mg every 6 hrs	Drowsiness Drowsiness
	Chlorpromazine*	25-50mg every	

* In many countries, these drugs need special prescriptions

Passing Through

Michael L. Tan

Because HIV infection is incurable, one of the greatest burdens faced by people with HIV/AIDS (PHA) is the anticipation of death. The fear of death is universal, but there are distinct cultural variations that characterise the way we deal with dying and death itself. Health care givers need to be sensitive to these variations, and to learn to tap culture to help PHAs.

All religions offer ways of dealing with death. Most Asians believe in Buddhism, Hinduism, and many animist religions, all of which incorporate beliefs in reincarnation or the transmigration of souls. Death is therefore seen not so much as the end of life, but as part of a cycle.

In Islam and Christianity, life after death is tied to concepts of the good going to heaven and the bad going to hell. Such beliefs about reward and punishment may become counter-productive for people with HIV because the disease is too often depicted as being the result of sexual "sin" with threats of punishment in the afterlife.

However, Islam and Christianity also offer many ways of helping people with HIV with its messages of compassion. Ideas of atonement are strong in both religions, including a chance to make amends even as death approaches. Muslim and Christian care-givers can help PHAs to make peace with the world and to forgive those who had "sinned" by mistreating them or discriminating against them.

With many PHAs, the problems in dealing with death are not so much religious than those that come from more secular concerns. PHAs sometimes feel they have wronged their families, bringing shame and disgrace. Care-givers need to reassure PHAs that it is society's narrow-minded people who create the shame,

and that a PHA can rise above such bigotry and prejudice to live and die with honor and dignity.

Other PHAs are burdened with the guilt of having to leave behind a family to fend for themselves. Because HIV infections occur mainly among young people, the fear of death becomes even more intense because in many Asian cultures, to die ahead of one's parents is seen as a lack of filial piety.

Again, it is up to caregivers to work together with PHAs to convince them that they can still be productive and that they can continue to provide for their families. The preference by many PHAs for the term "people living with HIV/AIDS"



reflects the need to emphasize HIV as a chronic condition that one can live with, rather than as an incurable fatal illness.

The emphasis needs to be on life and the living. Even those who are seriously ill should be reminded that they can overcome many of the opportunistic illnesses that come with AIDS.

While caregivers may see it important to help PHAs to keep fighting for life, there will be also times when they have to accept a PHA's decision not to continue with medication or life-support systems. PHAs have the right to choose to die peacefully and with dignity. A caregiver can help by providing the social support – including bringing in family and friends – to be with the dying patient. Religious rituals are important to many people, a sense that one is being blessed as they move on to another life.

Caregivers must not forget, too, that after the death of a PHA, one has to find ways of helping the living left behind. Counseling and support are even more important in these moments of bereavement and grief. Again, an emphasis on life will be important, eulogising the deceased PHA's contributions to society and reminding the living that they need to live up to the expectations of their loved ones. ☺

AIDS care outside the hospital describes home care including pain relief in simple terms. Available from Malaysian AIDS Care, 21 Jalan Sultan Abdul Sanad, Brickfields, 50470, Kuala Lumpur, Malaysia.

AIDS home care handbook is a practical handbook for families and communities to provide safe and compassionate AIDS care at home, with information about what can be done at home to alleviate illnesses. Available for Sw.fr.12.60 (developing countries), Sw.fr.18 (elsewhere) from UNAIDS, CH-1211 Geneva 27, Switzerland. E-mail: info@unaids.org (WHO/GPA/IDS/HCS/93.2)

Cancer pain relief describes how to alleviate and treat pain at home, and includes information on opioid availability. It is useful for all carers providing pain relief. Available for Sw.fr.17 from WHO, CH-1211 Geneva 27, Switzerland.

A comprehensive guide for the care of persons with HIV disease, Module 4: palliative care covers palliative nursing and home care issues. Available in English and French for Can.\$20 (single copies free

to Canadian organisations) from Canadian HIV/AIDS Clearinghouse, Suite 400, 1565 Carling Avenue, Ottawa, Ontario, Canada K1Z 8R1.

Pain and symptom control in the terminal cancer and AIDS patient explains the principles of palliative care methods for pain and symptom control. Available for US\$4 from Hospice Africa (Uganda), PO Box 7757, Kampala, Uganda.

Palliative care for people with AIDS covers nursing and care issues for HIV-related pain. Available for œ13.99 from booksellers (isbn 0340 613 718)

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Love & Remembrance

When a person dies of AIDS, the family, friends and lovers left behind seek to heal their grief and to remember their departed loved one. In many countries, the AIDS Memorial Quilt is a way of expressing love and remembrance.

The NAMES Project Foundation, which coordinates activities related to the Quilt, was established in San Francisco in 1987. Starting with just one panel, the Quilt has grown to more than 41,000 individual panels — each one commemorating the life of someone who has died of AIDS.

Among the goals of the Quilt are to:

- Provide a creative means for remembrance and healing
- Illustrate the enormity of the AIDS pandemic
- Increase public awareness of HIV/AIDS
- Assist with HIV prevention education

- Raise funds for community-based AIDS service organisations

The Quilt is the largest example of a community art project in the world. It was nominated for the Nobel Peace Prize in 1989.

The NAMES Project Foundation has 38 affiliates from around the world. In the Asia-Pacific region, NAMES Project affiliates are found in the following countries: Australia, Guam, Hong Kong, Japan, New Zealand, Philippines, Taiwan and Thailand.

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