

Fact Sheet 8 HIV palliative and terminal care

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• **Introduction:**

This Fact Sheet includes information about terminal and palliative care, and addresses the principles and practices of caring for people living with an illness for which there is no cure. Palliative care is the combination of active and compassionate therapies to comfort and support individuals and families living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual needs, while remaining sensitive to personal, cultural, and religious values, beliefs and practices. Palliative care should start at the time of diagnosis and can be combined with therapies for treating opportunistic illness; or it may be the total focus of care.

Palliative care requires a team approach including the PLHA, the family, caregivers and other health and social service providers and considers the needs of the whole person. It includes medical and nursing care, social and emotional support, counselling and spiritual care. It emphasizes living, encourages hope, and helps people to make the most of each day. The palliative caregiver must treat the PLHA with respect and acceptance, acknowledge their right to privacy and confidentiality, and respond caringly to their individual needs.

Terminal care aims to improve the quality of 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.

• **Palliative care philosophy**

affirms the right of the individual and family to participate in informed discussions and make treatment choices
affirms life and regards dying as a normal process
neither hastens nor postpones death
provides relief from pain and other distressing symptoms
integrates psychological and spiritual aspects of care
provides a support system to help PLHA live as actively as possible until death
provides a support system to help the family and loved ones cope during the person's illness and/or bereavement.

With HIV/AIDS, there is a growing realization that comprehensive care must include care associated with death and dying. Caring for the PLHA in the terminal stages of AIDS puts a great strain on everyone involved. For individuals who choose to die at home, where resources are scarce, care for the dying has traditionally been provided by communities and families, and might involve spiritual support. Families, friends, communities, hospice, health care and social service agency workers, volunteers, and others will be affected in this process.

One of the most difficult aspects of caring for PLHA is deciding when to stop active treatment and to begin to prepare the person and his/her family for dying. In practice, the boundary between the two activities is often indistinct, with both terminal and interventional care continuing in tandem. The decision to stop treatment requires considerable skill, and sensitivity. Whenever possible, the decision should be taken by health care professionals, the PLHA, family members and loved ones.

It is often difficult to decide when aggressive medical treatment should end and when palliative care might begin. Palliative care would begin when:

medical treatment is no longer effective, or the side-effects outweigh the benefits
the PLHA says she/he does not want to continue aggressive therapy
the body's vital organs begin to fail

The principles of palliative and terminal care

enhance patient/family control and the quality of life
provide practical support/advice for the PLHA and their loved ones
provide adequate pain relief and symptom control
maintain the comfort and dignity of the individual
provide spiritual and emotional/grieving support for the PLHA and their loved ones
prepare the PLHA, their families and caregivers for death. This includes advice concerning avoiding any traditional death rites which could spread infection.
ensuring that appropriate provision is made for the children involved and that their rights are respected
provide bereavement support to the family and loved ones following death.

• Challenges in terminal and palliative care of PLHA

HIV poses a unique set of challenges to the caregivers, the PLHA, the families, the communities and health and social service workers. These challenges include the following factors: AIDS may affect whole families when parents and children become infected.

People who die from AIDS usually die at a young age.

The stigma and fear associated with HIV/AIDS often means that the illness and death are not

openly discussed and adequate preparations for death might not be made.

Estrangement of family and friends often occurs. Sometimes the PLHA loses contact with family and friends due to conflicting values related to sexuality or lifestyle choices.

Community and family support might be lacking because of the stigma, fear and isolation associated with HIV.

The care of the terminally ill person is often left to the family (and to women in particular), who are often both unprepared and untrained.

The course of terminal care for the PLHA is unpredictable. Opportunistic infections and illnesses are often unpleasant and difficult to manage. These can include: foul odour, chronic diarrhoea, vomiting, skin lesions, seeing the person in pain, dementia, confusion, aggression, and depression.

The caregiver can develop feelings of powerlessness and helplessness.

Caring for someone who is dying at home is expensive. The caregiver must consider the loss of income, the cost of medical and pharmaceutical supplies, and the expense of a funeral.

Problems or complications with inheritance can further increase the poverty of women and children.

The physical burden of caring for PLHA.

The emotional burden for the carers of seeing a loved one dying.

Remember: An essential part of effective palliative care is the provision of support for caregivers and service providers. Such support will enable them to work through their own emotions and grief related to the care they are providing.

• Terminal/Palliative care for PLHA

Care for the PLHA at the end stage of the illness might occur in a hospice or a special terminal care facility. In most cases, however, the PLHA will die at home. In some resource poor countries, dying at home is the only option. The primary concern in terminal and palliative care is to make the PLHA as comfortable as possible by providing medical, spiritual, emotional, practical, and psychosocial support both to the individual and to his/her loved ones. Even where resources are severely limited, good palliative care can be given. The decision to stop medical treatment must be made by the PLHA (if this is possible) and the family or loved ones, and in conjunction with the health workers. Care then shifts to make the dying person as comfortable as possible, and to prepare emotionally and spiritually for death. Such care includes both practical and nursing care issues, as discussed below.

Practical issues:

The PLHA (if able) should make the choice about a suitable place to die. This choice might include a hospice or terminal care facility, or their own home. In most instances, the person will remain at home to die. Hospice and terminal care centres usually have specially trained staff to care for both the person who is dying and their loved ones. If the PLHA remains at home, then the family, and other caregivers will require special training to provide appropriate terminal care for the PLHA.

The following considerations for providing good palliative/terminal home care will be dependent upon adequate resources. However, whenever possible, care should include:

- **Providing health service support. The local health centre should be briefed about the person's condition, so that staff can provide the people caring for the PLHA with advice and appropriate medical supplies.**
- **Ensuring adequate community and family support. This will help reduce the pressure on the caregivers, who are usually the women in the family. It will mobilise relatives and friends to help in household or other work, and will provide companionship for the sick person. The health worker should discuss how to mobilise the support of local community leaders, non-governmental agencies, neighbours, and members of community or religious associations . This might be an important time to facilitate reconciliation with estranged family and/or friends.**
- **Placing the PLHA in a light, well ventilated room that is quiet, comfortable, and yet close enough to the rest of the family to remain involved in family life.**

Nursing care issues

Providing effective pain relief

The nurse can help the PLHA and caregiver by providing the appropriate medications to control pain. Where adequate resources are available, even in the terminal stages of AIDS, the PLHA should be able to remain pain free. Being pain free involves giving routine doses of a suitable analgesic. Pain relief is a three stage approach:

1. aspirin or paracetamol may be given.
2. If pain relief is not maintained, give codeine or dihydrocodeine (with or without non-steroidal anti-inflammatory drugs such as ibuprofen or diclofenac).
3. If the pain persists, morphine can be given, with or without a co-analgesic) or synthetic pethidine and fentanyl should be given. Some form of sedation such as valium might also be considered.

It is essential to maintain pain control. This means that the person might require more than the usually prescribed 3-4 hour regimen. Nurses and midwives should consult their local treatment protocols for pain relief for the terminally ill PLHA. Many AIDS patients have more than one pain related to different opportunistic illnesses. Each needs to be diagnosed and treated. Psychological and spiritual concerns related to HIV may make physical pain worse. These psychological and spiritual concerns should be addressed at the same time as treating the physical pain. At this stage of the illness, there is no fear of patient addiction to medications; the overall concern is for patient comfort. Other nursing care measures might include placing a cool,

clean, moist cloth over the painful site, or applying heat if necessary. Massage and deep breathing exercises might also help the patient to relax.

Keeping the patient nourished and hydrated

Diarrhoea can be a major problem, sometimes persisting for several months, with stools that may be mucoid and foul smelling with pus. Nourishment should be light and given at frequent intervals. Dehydration can be prevented by administering fluids such as water, unsweetened fruit juices, soup, rice water, and weak tea. If the person is vomiting, sips of water should be given frequently. Oral rehydration therapies such as homemade sugar and salt solutions may be given. In some circumstances, intravenous rehydration may be necessary. Medicines (see Fact Sheets 4 & 5) might also be prescribed. Always use Universal Precautions (Fact Sheet 11) when handling faecally contaminated articles.

Maintain basic physical care

This includes keeping the PLHA clean, dry, and comfortable should be maintained. It is important to change the person's position frequently, and to keep the room well ventilated. Air freshener sprays, although expensive, are useful, as is the burning of incense or other herbal mixes. See Fact Sheets 4 & 5 for other suggestions for providing physical care for the PLHA.

Mental confusion or dementia

These affect many people with HIV-related illness. The individual may move clumsily and become unaware of what is happening around them. They may be forgetful and unable to think clearly. Their awareness of being confused may come and go, which can be very upsetting for the caregivers.

Those who are confused need constant attention and reassurance, and might also need to be restrained from hurting themselves. Dangerous objects (and medications) should be removed from their reach. Severe dementia may require sedation (consult local drug protocols).

Looking after a confused person is exhausting and distressing. Caregivers need to be encouraged to take turns in caring for the PLHA. Nurses and midwives should help the family understand that the individual's behaviour is not intentional. They must also ensure that adequate care for the PLHA is available. Medication lists should be reviewed regularly in order to assess whether some medication might be compounding the problem.

Severe skin abscesses or ulcers can become infected

Nursing care should include dressing the skin lesions, lancing boils, and keeping the area clean (See Fact Sheet 11 on Universal Precautions). In addition medications given locally, orally or by injection might be necessary (see Fact Sheet 4 & 5 for further treatment regimens). Nurses are advised to consult their local drug protocols.

Emotional distress is a common experience

It can be experienced by the PLHA, the family members or other caregivers. It is particularly likely at the first disclosure of the individual's HIV status. Counselling can help in these situations.

Issues that might need to be addressed during counselling include:

Fear of death

Fear is a normal reaction and can make people angry, depressed, or aggressive. Caregivers should not give false reassurances, but should encourage the person to talk about their fears. Spiritual support might also be helpful.

Loneliness and depression

Sometimes when someone is dying, people stop coming to visit because they fear death, or do not know how to react. Such isolation can lead to a sense of loneliness and depression. People should be encouraged to visit (if the PLHA wishes). In some cultures, people will also need an opportunity to discuss their feelings about being with someone who is dying.

Feelings of guilt and regret

The PLHA may feel responsible for exposing his/her partner to infection, or may feel guilty for having brought shame to their family or friends. Failure to settle debts, fulfill ambitions, or attend to their responsibilities to children can all cause feelings of guilt, sorrow, and regret. A person may seek forgiveness or wish to discuss ways of resolving problems for which he/she feels responsible.

Spiritual support

This support can come either through an organized religion, or through the exploration of the PLHA's own spirituality, beliefs and values is very important. The PLHA might have been cut off (whether by him/herself or by their community) from his/her religion. Caregivers 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 observances to be performed, including funeral arrangements, in the event of their death.

Making a will

A will helps to make clear what a person wishes to happen after his/her death. The surviving women and children are often left impoverished and unprovided for unless a will is made.

A will must be made in accordance with local law and may:

ensure that property, land and valuables are passed on to people that the PLHA stipulates

make clear who has custody of children; and, if there is no partner, appoint guardians

specify trustees or executors who will ensure the will is acted upon

provide instructions about funeral arrangements

To be valid, a will must usually be:

written in permanent ink or typed

signed by the person and clearly dated. Signing and dating must be witnessed. (Those who benefit from the will should not be witnesses.)

written when the person is of sound mind, and not being forced to do so by someone else.

When death comes it is important not to leave the dying person alone.

Many people are very afraid of dying alone. Respect should be given to rituals, observances, and customs related to laying out the body. Mourners can be given time alone with the body if they wish. However, all persons should be warned about the risk of contamination.

• Caring for the caregivers

Family members, loved ones, caregivers and health care workers all need to be supported and cared for as they provide terminal care to the PLHA. Support groups, counselling (both individual and group), and instrumental care are all helpful strategies to support the caregivers. Instrumental support includes the provision of adequate resources (medical supplies, medicines, and personnel) to make effective terminal care possible. Emotional and spiritual support should also be available. The kind of support that caregivers need will vary. Acknowledging the need for such support and providing ways to access such support are essential. If such support is not available, the burden of care can become too great and caregiver exhaustion may follow.

• Bereavement counselling

Families and friends often have little social support, or may have become isolated while caring for the PLHA. Bereavement support should be made available before the person dies, and for as long afterwards as people need it. People react to death in different ways, and need different types of support. For some, it can take months or years to come to terms with loss. Additionally, people's responses may be affected by the way the person died: for example, whether the PLHA died alone and in pain, or died peacefully, surrounded by loved ones. Those left behind often blame themselves if they think they could have done more.

Bereavement counselling should:

give people an opportunity to talk about events leading up to the death, about the death itself, and the observances and rituals immediately after the death
reassure people that feelings of disbelief, denial, sadness, pain and anger are normal
allow people to express their feeling and concerns, especially if it is difficult for them to do this with friends and family
enable people to accept their loss and start to look to the future.

Questions for reflection and discussion

What are some of the major issues that might get in the way of effective palliative care?

How can these issues be overcome?

What is the basic philosophy of palliative care?

Why can good palliative care be provided without the benefits

of adequate financial and other practical resources?

Why is making a will important?

How can you help provide emotional support to PLHA, the caregivers and others (including yourself). Why is such support important?

What are the essential characteristics of bereavement counselling? Do you think you could help conduct bereavement counselling?

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