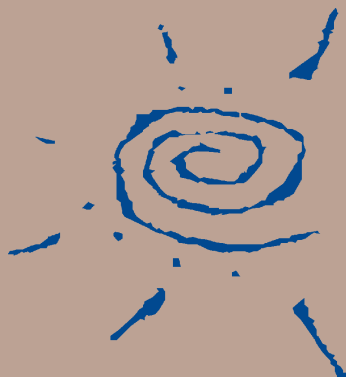


HIV Counselling Series No. 3



Counselling Guidelines on Palliative Care and Bereavement



CANADIAN PUBLIC HEALTH ASSOCIATION
ASSOCIATION CANADIENNE DE SANTÉ PUBLIQUE



Canadian International
Development Agency

Agence canadienne
de développement international

Counselling Guidelines on Palliative Care and Bereavement

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First Edition May 2001

Produced by the

Southern African AIDS Training (SAT) Programme

With funding from the Canadian International Development Agency
(CIDA)

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ISBN: 0-7974-2270-6

Foreword

This publication is one in a series of guidelines on counselling people who are infected with HIV, who are concerned about being infected with HIV, or who are living with or caring for people with AIDS. Each booklet in the series is designed to offer practical guidance on specific counselling issues. The publications are designed for use by volunteer counsellors, non-professional counsellors, and professional counsellors who do not have extensive experience in counselling in the context of HIV.

Each booklet is the result of a workshop organised under the SAT Programme's "School Without Walls" that brought together professional counsellors in Palliative Care & Bereavement, people living with HIV, and staff of AIDS Service Organisations from Southern Africa. This edition was put together by Island Hospice in collaboration with the SAT Programme. The booklet reflects their unique experience and takes account of their specific expertise. Further publications on different counselling issues are in production, eventually making up a complete counselling kit to be used as reference material.

The SAT Programme is a project of the Canadian International Development Agency implemented by the Canadian Public Health Association. It has been at the forefront of supporting the community response to AIDS in Southern Africa since 1991. The School Without Walls is an initiative of the SAT Programme to validate, promote, and diffuse the unique Southern African experience and expertise in responding to HIV. The SAT Programme is profoundly grateful to the volunteers and professionals who have made this publication possible and who are supporting SAT in the preparation of further publications.

The publication was edited and designed by the Southern Africa AIDS Information Dissemination Service (SAfAIDS), a regional non-profit organisation dedicated to information service on HIV in Southern Africa. In the past, the SAT Programme has assisted in the organisational development of SAfAIDS. Presently, SAfAIDS has a standing offer to provide technical support for the production of SAT Programme publications.



SAT Programme



Island Hospice Service

SAfAIDS



Counselling Guidelines on Palliative Care and Bereavement

Creating these guidelines

These guidelines are based on the experiences and advice of people from across Southern Africa who are either living with HIV or who have extensive experience of counselling people who are terminally ill. The guidelines were produced by the Southern African AIDS Training Programme (SAT) and Island Hospice with funding from the Canadian International Development Agency. The Southern African AIDS Information Dissemination Service (SAfAIDS) edited and designed the publication. Cartoons were drawn by Joel Chikware.

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Important terms

Palliative care is the care of someone who has an illness that cannot be cured, e.g. AIDS, cancer, etc. It involves the control of pain, as well as support for psychological, social, and spiritual problems. It allows the patient to make choices about daily living. Dying is treated as a normal process and is neither hastened nor delayed.

Bereavement is the consequence of the loss of something of value. In this booklet bereavement refers to the death of someone close. Bereavement also occurs following a divorce, miscarriage, job redundancy, or any other loss in a person's life.

Grief is the pain and the experience of bereavement. It is how we feel the loss, which affects us physically, emotionally and spiritually.

Mourning is the expression of grief. It is the external activities or behaviour following bereavement. This will vary from person to person.

Patient, in this booklet, means someone who has been diagnosed with an illness that cannot be cured.

Counsellor is someone who is trained and skilled in helping others work through their difficulties.

Client is used to describe anyone who receives counselling support, e.g. patient, family members, or friends.

Counselling is a structured conversation between a counsellor and one or more clients (e.g. patients or family members) that assists the client to work through particular problems he or she faces. Counsellors encourage people to recognise and develop ways in which they can deal more effectively with problems.

Principles of palliative care

In order to understand palliative care, counsellors need to be aware of the following principles:

- **Best possible quality of life**

The patient should have the opportunity to live as fulfilling a life as possible until death.

- **Accept that dying is inevitable**

Death is a part of life, although it is often seen as coming too soon.

- **Palliative care neither hastens nor delays death**

The dying process is not prolonged unnecessarily causing additional pain or suffering to the patient; however, nothing is done to deliberately shorten life.

- **Palliative care covers all aspects of a patient's care**

Palliative care provides medical care, psychological, spiritual, and social support to patients and their families.

- **Support for the family**

Palliative care recognises the suffering of the family of the patient, and provides support for them.

- **Ideal in a home situation**

Patients may be more comfortable and peaceful in their own home, and palliative care is possible at home.

- **Palliative care is team work**

Most of the time several people are involved in the care of a patient. These include family members, health care workers, social workers, community volunteers, as well as counsellors where available. For optimal care, these people should work together to offer the best possible support to the patient.

The need for counselling

Despite their need for support, many people find it difficult to talk to relatives or friends about dying. The diagnosis of a terminal illness is a traumatic event and patients are often overwhelmed by their thoughts and fears. A counsellor can provide the emotional support and information they require.

General guidelines for effective counselling

These are some basic, practical guidelines for those without formal counselling training who find themselves in a situation where counselling is required.

- Be patient. Listen attentively to the patients. Give them time to say what they need. Help them express their feelings and emotions. Show warmth and care for the person.
- Treat clients (patients and their families) with respect. Be reliable and consistent. Accept people as they are and avoid moralistic judgements.
- Keep information about patients and family members confidential. Do not discuss information from counselling sessions with anybody else.
- Avoid giving advice. Help patients work through issues. Assist them in reaching their own decisions.
- Help clients focus on areas where they can achieve some positive change, rather than being overwhelmed by their problems. Help them identify others they can rely on and receive help from.
- Do not pretend to have skills, knowledge, or resources you do not have – know when (and where) to refer clients for more specialised help.
- Encourage communication within the family. Include children in this process wherever possible using language a child can understand.

Talking about AIDS

The principles of counselling in palliative care are the same whatever the patient's illness. It is important to assess the patient's understanding of the illness. If the cause is AIDS, you must be aware that the patient may not know the diagnosis. The issue of HIV needs to be introduced with sensitivity.

If a patient knows or suspects that he or she is HIV positive then issues of disclosure (if, whom, and how to tell) need to be carefully talked through. You can refer to another booklet in this series under the title "Counselling guidelines on disclosure of HIV status".

The stigma attached to AIDS can make it difficult for a patient to discuss their illness openly. Be supportive and never judgmental. If the patient agrees, involve the family in discussions about HIV and AIDS. This is an opportunity to consider prevention issues with other family members.

Palliative care and bereavement counselling - what to do

Some of the counselling needs of a dying person are specific. The following advice for counsellors is particularly relevant for palliative care:

- Ask the patient to talk about needs, fears, and worries about dying.
- Respect the patient's desire to be independent and make his or her own decisions. Do not take over. Dying people still need to feel in control.
- Be a good listener. Very ill people may take longer to talk or say what they mean.
- Acknowledge that this is a difficult time.
- Ask them about other hard times in their life and how they managed to get through those times.
- Allow time for thought and silence.
- Encourage communication within the family. Include children in family talks about the illness. It is often helpful to hear from everyone in the family what worries them most.
- Answer questions honestly. Never lie to the patient. Do not avoid using words such as death or dying.

Testimony 1: Children may know more than you expect

”When my husband began to get very ill, I was concerned to let my children be with him. I didn’t know what to say to them. My counsellor was right when she told me that maybe they know just what is going on. When I was brave enough to talk to them about their dad’s illness they shocked me by what they had seen and knew. Now we can talk together, even with my husband. He loves to have my youngest child playing in the room where he is, and she loves to spend time there. They are so close. Maybe I was more frightened than she was.”

They shocked me by what they had seen and knew.



Feelings and emotions of the patient during the illness

It is important for the counsellor to understand that patients will respond to their illness in different ways, and the following may be some of the feelings and emotions that may be expressed.

Anticipatory Grief

When someone discovers that he or she has an incurable illness, a process of grieving starts for both the patient and the family. This is called anticipatory grief. Feelings may include fear, anxiety, and sadness about what is to come. This is a normal process and helps people prepare for change.

Depression

Depression is a feeling of sadness and discouragement. The patient or family member may show one or several of the following signs:

- a short temper or irritability;
- less interest in daily activities;
- less interest in the usual daily communications;
- inability to sleep, waking very early in the morning, and as a consequence always being tired;
- feelings of worthlessness;
- loss of appetite or weight loss;
- having recurrent thoughts about death;
- tearfulness;
- being anxious.

Someone who has been ill for a long time has many reasons to be depressed. This depression is often related to the length of the illness or the level of pain. Counsellors should:

- encourage clients to talk about their feelings;
- do not try to cheer the clients up, but allow them to express their sorrow;

- do not try to stop the patient or family member from crying. Tears can be helpful in relieving stress.

Anger

Patients may feel angry because they are going to die. In the case of an AIDS patient, anger may be directed at the assumed cause of the infection, i.e. the person they think that they contracted the HIV virus from. Anger is sometimes directed at the counsellor or at those people who are closest to the patient, such as friends or family. It is important:

- to encourage patients to express their anger safely, for example, by punching or shouting into a cushion or through physical exercise;
- not to take the anger personally – patients are angry with the illness not with you;
- not to be alarmed by the anger – try to stay calm.

Fears

A patient with a terminal illness may have many fears including fear of:

- pain, choking or suffocating;
- not knowing what is going to happen at the time of death;
- dying if they go to sleep;
- being uncared for and dying alone;
- losing bodily functions;
- what will happen to the body and soul after death;
- what will happen to the family members left behind;
- what will happen to his or her possessions.

It is important to:

- encourage the patient to talk about his or her fears;
- help the patient and family members to identify people or organisations who can provide support, e.g. friends, relatives, health workers, or the church;

- if possible, provide information on how to deal with distressing symptoms (e.g. in the booklet "Home Care for the Terminally Ill")* ;
- encourage the patient to talk about what will happen to the family after his or her death;
- find out if the patient has discussed what will happen to his or her possessions with family members. Is there a will? Does the patient need assistance making a will?
- explore the patient's religious and cultural beliefs and help contact appropriate sources of spiritual support, e.g. church elders, traditional healers, etc.

* *This booklet is available from Island Hospice Service, Box CY7, Causeway, Harare, Zimbabwe.*

Testimony 2: Making a difference for the future

“I had lived with HIV for many years, but it was when I started really getting ill that I realised I needed help to make sure my family could be prepared for my death. What worried me most was members of my extended family causing problems for my wife and kids once I was gone. Counselling has helped me to make plans and sort out some problems in advance. What feels good for me is that I can still make a difference in my family’s future even though I will not be around for much longer. I have made a will and this should make sure that everyone is clear about what I want to happen. This has also given me a chance to discuss such difficult issues like my death with my brothers and other relatives. It has been hard, but I think we have made progress.”

It has been hard but I think we have made progress.



Losses

Patients may also be concerned about experiencing losses, for example, loss of:

- a job or an income;
- looks, e.g. loss of weight;
- good health;
- love;
- position in the family, e.g. father, husband;
- position in the community, e.g. community leader, church leader;
- control of life, e.g. not being included in decisions and not being able to make choices;
- future, e.g. seeing children grow up.

It is important to:

- acknowledge the importance of losses;
- help ensure that patients are allowed to remain in control of decisions; (Even when a patient has lost consciousness, family members should still hold discussions in the patient's presence)
- explore alternative sources of income;
- bring the family together to discuss future plans.

Counselling someone with AIDS

When you are counselling someone who is dying because of AIDS there are specific points to remember:

- Keep up to date with information about HIV and AIDS, the illnesses and their treatments. Advice is changing all the time and you need to be aware of the latest recommendations. Give as much up to date information as possible to the patient and the family members.
- Because HIV can be passed on from one person to another this can cause resentment, blame, guilt and anger between couples and families. You will need to make sure such feelings are identified and expressed

safely; otherwise, carers may find it hard to look after someone they are feeling angry towards.

- Somebody who has AIDS can experience periods of illness and periods of well being over a long time. Many patients are young and their organs (e.g. heart or kidneys) are strong so their bodies keep going, despite the illnesses. This "emotional see-saw" is exhausting. It is tiring and frustrating for the patient and family as the periods in between illness give them hope that the patient may recover. It can be very distressing to watch somebody experience a combination of illnesses over a long period of time. You need to prepare the family for this and make sure that they have good support.
- The effect of AIDS on the brain can affect a patient's behaviour. This can be very distressing and you will need to explain to the family what is happening and that the patient cannot help his or her behaviour.
- The patient may need your help in dealing with employers and other health professionals to ensure that he or she is not stigmatised, and that human rights are respected.

What to do at the time of death

- At the time of death encourage family members to stay with the deceased for as long as they need.
- Encourage the family to hold the patient's hands or to say goodbye in whichever way they want.
- Do not refer to the deceased as "the body", but by his or her name.
- If the family was not present at the time of death, give as much detail as possible.
- Involve children and explain to them what is happening.
- Be comfortable with the expression of feelings, e.g. crying, shouting, wailing, at the time of death and later.
- Encourage repetition of the story of the illness and death.
- Make sure a religious person is present if requested.
- Take time. Go slowly.

What not to do:

- Do not tell family members what they should or should not do.
- Do not panic when strong emotions are expressed or when there is a lot of crying. Just listen and try to understand.
- Do not try to tell grieving family members how they feel. Every experience is different.
- Do not talk about your own experience.
- Do not make a bereaved person feel you are in a hurry.
- Do not use certain phrases, such as "God only takes the best" or "time will heal" as the bereaved do not find them useful.
- Do not tell the bereaved person that they will "get over" this.
- Do not stop a grieving person from crying.

What to do during bereavement

- Encourage family members to talk to each other and to share feelings, such as guilt, relief, pain, or anger.
- Listen rather than talk.
- Discourage a bereaved person from making big decisions whenever possible, e.g. change of job, home, town. Their emotional state makes it hard for practical decisions to be taken.
- Encourage the use of rituals that help channel the grieving process, e.g. memorials.
- Be aware of your own losses and feelings.
- Encourage family members to tell you about the person who has died.
- Make a point of remembering special dates, e.g. birthdays and death anniversaries.

What to expect during bereavement

"People expect me to feel fine again by now and it is just four months since I buried my husband. No one uses his name to me, and they don't talk about him. It hurts me to think they have forgotten him. I need to talk about him a lot so that I will never forget him."

There is no specific time when grief should end. Each loss is different. It often takes longer than many people think. Immediately following death there is a sense of shock and disbelief, but the family members may also feel a sense of relief both for the deceased and for themselves now that the stress of the illness is over. This is a normal and acceptable emotion. It is important to understand that things often get worse after several months, not better. This is because it can take up to seven months before the reality of the death sinks in.



These are some of the possible experiences during bereavement:

Immediate	Later (several months)	Long term
Emotions		
Numbness	Anger/guilt	Some guilt and sadness
Emptiness	Sadness	Adjustment to situation
Disbelief of death	Depression	New relationships
Fear of being alone	Anxiety	Want independence
Need to talk about the event	Feeling of "going mad"	Don't feel "mad" any more
Physical		
Crying/wailing	Nightmares	Fewer bad dreams
Cannot eat/sleep	Restlessness	Appetite/sleep improve
Signs of shock	Withdrawal	Physical symptoms fade
Aches and pains	Symptoms of deceased's illness	
Collapse, breathlessness, exhaustion, or headaches	Forgetfulness	
Spiritual		
Blame God	Question beliefs	Readjustment of spiritual beliefs
Questioning	Spiritual confusion	
Lack of meaning in life	Lack of purpose	New direction
Wants to die too	Tries to contact deceased	May accept death as part of life
Tasks		
Accept the reality of the loss	Working through feelings	Adjusting to life without the deceased and finding a place for the memories of the deceased in their future.

AIDS and bereavement

When someone has died because of AIDS there are specific issues you need to be aware of when counselling bereaved persons:

- Sometimes the look of the patient dying due to AIDS is distressing and stays with the bereaved person in a frightening way. Encourage the person to describe in detail what they saw and what they found the worst part of the death, as this helps to lessen the painful memories.
- Because of the social stigma surrounding AIDS, there may be secrecy about why and how the patient died. This may mean that the bereaved person cannot use the social support of friends and relatives in the way that they normally would. Your role will be to provide some of that support and to help them to identify people who they can be honest with.
- Help the bereaved family prepare an acceptable account of what happened. Help parents develop a story about what happened for the children so that they too can cope with questions from their friends. There may be judgemental comments from others and the bereaved will need your support in dealing with them.
- Discuss the issue of HIV testing for the bereaved family so that people can make choices about testing for themselves.
- If the bereaved person is also HIV positive explore their fears for the future as they may now expect a similar death. Encourage expression of feelings such as anger, fear and hopelessness and remember that crying can be healing. Give information on how to stay healthy.
- Help bereaved people to assess what they did well in caring for their loved one, and what could be done differently should they need to look after another family member dying from AIDS. Sometimes a bereaved person has to start looking after another family member immediately. It is important that the bereaved person gets enough sleep and food, and takes short breaks to deal with their own thoughts and feelings.

Children

"My sister died a year ago, and my mother still cries for her. I am scared I might die too. Sometimes I get so frightened I cannot listen to the teacher at school and she gets cross with me. Nothing seems easy anymore and life is hard."

If children do not see adults grieve they may think that no one else cared about the person who has died. How you talk to children is very much dependent on their age. Do not tell young children that God wanted their grandmother in heaven. Rather explain that her body wore out like old clothes and she just couldn't live in it anymore.

When someone young dies you will need to explain honestly and simply what happened. Children will be frightened that someone else will die. You will need to reassure them as much as possible, but you cannot make promises. Let them know there will always be someone to look after them, and that adults have made the necessary arrangements. Let the family know that school work may be affected as the child's memory and concentration will be lessened. Help teachers to understand the child's grief and ask them to reduce pressure on the child.



Universal precautions

In the care for a terminally ill person, universal precautions are necessary to protect both the carer and the patient. Anybody can be the carrier of a number of infectious diseases, including hepatitis, HIV, tuberculosis, or intestinal parasites. You cannot tell by looking at a person. People dying of AIDS are especially susceptible to infections. The rules to protect yourself and the patient apply to anybody, including the counsellor.

- Wash your hands with soap and water before and after you touch a patient, especially if you are providing intimate care like washing the patient or cleaning sores. Hand washing is the MOST EFFECTIVE way of preventing transmission of infections.
- Do not touch a patient if you have open sores on your hands. If it is unavoidable, use rubber gloves or put plastic bags over your hands. Put an elastoplast over the cut or sore.
- If you have to handle any secretions such as urine, faeces, vomit, drainage from wounds, vaginal secretions, semen, sputum, use rubber gloves. If there are no gloves available use plastic bags or wash your hands thoroughly with soap and water.
- When you are cleaning up large spills of blood or any body fluid, protect yourself with a plastic apron. These can be made from empty maize or fertiliser bags.
- Use plastic bags to dispose of old dressings. If there is no rubbish collection service, burn or bury the rubbish. Do not bury plastic bags.
- Clean household utensils and surfaces such as tables that have been contaminated with a patient's secretions thoroughly using water and bleach. A bleach solution is made up of 1 part bleach to 10 parts of water.
- Wash toilet equipment after use with a bleach solution.

In order to maintain a trusting relationship with the patient and the family, explain that the reason you are taking these precautions is for their protection as well as yours.

