

# Palliative Care Toolkit

Improving care from the roots up  
in resource-limited settings



## About Help the Hospices

Help the Hospices is the national charity for the hospice movement in the UK.

We are also involved in supporting services around the world, especially in resource-poor countries.

In all that we do, we aim to make a real difference to the care given to patients and their loved ones.

## About the Worldwide Palliative Care Alliance

The Worldwide Palliative Care Alliance is the network of national and regional hospice and palliative care organisations around the world. The Alliance works to support efforts to develop hospice and palliative care services globally.

Vision - A world with universal access to affordable, high quality palliative care.

Mission - To promote universal access to affordable quality palliative care through the support of regional and national hospice and palliative care organisations.

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# List of Abbreviations

<b>HIV</b>	Human immunodeficiency virus
<b>AIDS</b>	Acquired immunodeficiency syndrome
<b>TB</b>	Tuberculosis
<b>PCP</b>	Pneumocystis carinii pneumonia
<b>ARVs</b>	Antiretroviral drugs
<b>ART</b>	Antiretroviral therapy
<b>SCC</b>	Spinal cord compression
<b>UTI</b>	Urinary tract infection
<b>ORS</b>	Oral rehydration salts
<b>NSAID</b>	Non-steroidal anti-inflammatory drug
<b>NR</b>	Normal release
<b>MR</b>	Modified release
<b>GV</b>	Gentian violet
<b>CD</b>	Controlled drug

<b>HBC</b>	Home-based care
<b>OPD</b>	Outpatient department
<b>NGO</b>	Non-governmental organisation
<b>FBO</b>	Faith-based organisation
<b>PLHIV</b>	People living with HIV
<b>IGA</b>	Income generating activity
<b>OVC</b>	Orphans and vulnerable children
<b>WHO</b>	World Health Organization

<b>o.d.</b>	once a day
<b>b.d.</b>	twice a day
<b>t.d.s.</b>	three times a day
<b>q.d.s.</b>	four times a day
<b>p.r.n.</b>	as required
<b>PO</b>	by mouth
<b>PR</b>	by rectum
<b>IM</b>	intramuscular
<b>IV</b>	intravenous
<b>SC</b>	subcutaneous
<b>kg</b>	kilogrammes
<b>g</b>	grammes
<b>mg</b>	milligrammes
<b>l</b>	litres
<b>ml</b>	millilitres
<b>eg</b>	for example

# Introduction

The need for wide coverage of palliative care has never been greater. The incidence of cancer is rising all over the world, and in resource-poor settings palliative care is often the mainstay of treatment. In Africa HIV affects almost every community directly or indirectly and it is becoming more common in other parts of the world too. In many countries the proportion of elderly people is growing, increasing the need for ongoing care of those with progressive and incurable diseases.

Basic symptom control and holistic support are not expensive and do not require highly specialised personnel, but are often lacking even where health structures and HBC programmes are in place. Inadequate drug supplies are partly to blame, but equally important is a lack of basic understanding of palliative care amongst healthcare workers at all levels, a lack of confidence in communication skills and lack of knowledge of symptom control techniques. Communities and health workers can be overwhelmed by palliative care needs that they do not feel equipped to meet.

This toolkit has been written to empower health workers in resource-poor settings to integrate palliative care into the work they are doing by grafting the missing elements of care onto what is already in place. It takes a ‘can-do’ approach,

“This is an issue that affects literally every one on the planet. We would all like our lives, and the lives of those we love, to end peacefully and comfortably.”

Archbishop Desmond Tutu  
2005

showing that good basic palliative care can be delivered within existing community and health structures by people without specialist training, and that other members of the community can be involved too. The symptom control guide gives advice for volunteers and carers as well as information on drug treatments. Communication skills and psychological and spiritual support are addressed, with attention paid to the special needs of children. A set of tools to be used in the field includes forms for patient records and data collection, advocacy material, teaching aids and a basic drug list.

**This toolkit can be used by:**

- |                              |                           |                            |
|------------------------------|---------------------------|----------------------------|
| <b>Nurses</b>                | <b>Doctors</b>            | <b>Traditional healers</b> |
| <b>HBC workers</b>           | <b>Programme managers</b> | <b>Counsellors</b>         |
| <b>Social workers</b>        | <b>Children’s workers</b> | <b>Pharmacists</b>         |
| <b>Spiritual counsellors</b> | <b>Volunteers</b>         | <b>Family carers</b>       |

...and anyone who wants to find out about palliative care

## **What is palliative care?**

Palliative care is all about looking after people with illnesses that cannot be cured, relieving their suffering and supporting them through difficult times.

## **Why do we need palliative care?**

To help people suffering from:

- Cancer
- HIV
- Progressive neurological illnesses
- Severe kidney or heart failure
- End-stage lung disease
- Other life-limiting illnesses

## **What is different about palliative care?**

The holistic approach to problems

- Physical
- Psychological
- Social
- Spiritual

## **Palliative care is about living as well as dying**

“Put life into their days, not just days into their life”

## **Palliative care works alongside and within other programmes**

## **Palliative care never says “there is nothing we can do”**

# Chapter 1: What is palliative care?

## What is palliative care?

What do we do when sick people do not get better? All over the world, even in places where there are many healthcare workers, plenty of drugs and the most modern equipment, there are patients who cannot be cured. Can anything be done to help them? Palliative care seeks to do just that. The WHO has written a definition of palliative care (see below). It may be a new term for many of us, but it simply means looking after people with incurable illnesses, relieving their suffering and supporting them through difficult times. As health workers, most of us have done some of this kind of caring at work and in our everyday lives but may have been unable to deal with many problems and felt powerless and discouraged. This toolkit has been written to help us to care more effectively by teaching simple skills and putting together basic information to use when we are caring for sick people who will not get better.

## Why do we need palliative care?

Modern medicine first set out to cure diseases with drugs, surgery and other treatments. Then we realised that prevention is even better than cure, and set about putting in place public health measures, vaccination programmes and health education. Most of our health services are designed for treatment and prevention of disease. But as we work in these services, many of us have found that there is a big need that is not being met: the ongoing care for those who do not get better.

### WHO definition of palliative care

*Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

<http://www.who.int/cancer/palliative/definition/en/>



The need for palliative care is enormous.

- Over seven million people died from cancer in 2007<sup>1</sup>.
- Two million people died from AIDS in 2007<sup>2</sup>.
- Over 70% of people with advanced cancer or AIDS experience severe pain<sup>3</sup>.
- Thirty-three million people are currently living with HIV worldwide<sup>2</sup>.
- It is estimated that 100 million people worldwide could benefit from basic palliative care<sup>4</sup>.

The modern hospice and palliative care movement started in England in the 1960s with cancer patients. However, the need is even greater in resource-poor settings where cure is often impossible because of late presentation and limited treatment. The HIV epidemic has focussed attention on the need for palliative care. Even where antiretroviral therapy (ART) is available, patients still suffer difficult symptoms. Healthworkers can become demoralised as they see many patients whom they cannot help.

Palliative care is useful for people with many different diseases. It can help anyone with a life-limiting illness - in hospital or at home, young or old, rich or poor.

1 American Cancer Society (ACS). Global cancer facts and figures 2007. Atlanta: ACS; 2007.

2 UNAIDS/World Health Organization (WHO). AIDS epidemic update. Geneva: UNAIDS/WHO; December 2007.

3 National Hospice and Palliative Care Associations' 2nd global summit 2005. Korea declaration on hospice and palliative care [online]. Available from: [http://www.worldday.org/documents/Korea\\_Declaration.doc](http://www.worldday.org/documents/Korea_Declaration.doc) [Accessed 9 January 2008].

4 Stjernsward J and Clark D. Palliative medicine – a global perspective. In Doyle D, Hanks G, Cherny N and Calman K (eds). Oxford textbook of palliative medicine (3rd ed). Oxford: Oxford University Press; 2004.

**Palliative care can help people with:**

- HIV
- Cancer
- Severe kidney or heart failure
- End-stage lung disease
- Progressive neurological illnesses
- Other life-limiting illnesses

**What is different about palliative care?**

Health workers tend to focus on physical problems – diseases and treatments. But palliative care recognises that people are much more than just bodies – our minds, our spirits and our emotions are part of who we are, as are the families and communities to which we belong. So the problems facing a sick person and their family are not just physical; there may be psychological, social and spiritual issues which are just as important as the illness itself. Sometimes problems in one area may worsen others, eg pain is often worse when people are anxious or depressed. It is only when we address all these areas that we are helping the whole person. This is called **holistic care**.

The **holistic approach** looks at problems in four groups:

- **Physical** – symptoms (complaints), eg pain, cough, tiredness, fever
- **Psychological** – worries, fears, sadness, anger
- **Social** – needs of the family, issues of food, work, housing and relationships
- **Spiritual** – questions of the meaning of life and death, the need to be at peace.

**Imagine a young woman with three children...**

she lives in a shanty town. Her husband died six months ago and the neighbours say he must have had HIV. Now she is becoming sick, has lost weight and she is scared that she may also die. Recently she developed a painful ulcerating swelling on her leg which stops her sleeping. Some days she can barely get out of bed to care for her children, but her parents are far away in the village. The landlord is asking for rent but she has no income since her husband died. The neighbours are gossiping, saying that the family is cursed, and she wonders if they are right, since she has prayed for help but none has come.

**If you were that woman, what would be on your mind?**

We can imagine that her illness is only one of her many problems. Her greatest worry might be how to put food on the table for her family, or what will happen to her children if she dies. She has no financial support, she is isolated and feels rejected by God.

Palliative care is about people rather than diseases and seeks to address the problems which are of most concern to the patient. We will look at ways of helping in the next few chapters.

**Palliative care is about living as well as dying**

Many people think that palliative care is just about looking after someone in the last few days of their life, but in fact it is about relieving suffering and improving quality of life right from the time when a person first finds out that they have an incurable illness. The aim of palliative care is not to lengthen – or shorten – life but to improve **quality of life** so that the time remaining, be it days, or months, or years, can be as peaceful and fruitful as possible.

# “Put life into their days, not just days into their life.”

Nairobi Hospice 1988

Dame Cicely Saunders, the founder of the palliative care movement, said:

*“You matter because you are. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but also to live until you die”.*

## Palliative care works alongside and within other programmes

Palliative care does not replace other forms of care. It can be integrated into existing programmes and should be a part of the care given to everyone with a life-limiting illness.

Many HBC programmes are very good at providing supportive care such as counselling and practical help, but are not so good at helping patients with physical problems such as pain and other symptoms. Sometimes HBC workers are unaware of what can be done to help.

*“There was an assumption that because there were centuries of tradition of dying at home, there was also a tradition of knowing how to care for people at home, and, sadly, that turned out to be an incorrect assumption. People were wanting to die at home, but most of the people were going home to die in a place where no-one knew how to care for them, where there was no-one to relieve their symptoms. There were great difficulties for families being able to talk to somebody who was dying, about their dying – about what that would mean for the family. There was a lot of secrecy about it.”*

Mark Jacobson, Tanzania

Many hospital programmes, such as ARV clinics, chemotherapy or radiotherapy services, are good at providing treatment for diseases but not as good at helping patients with psychosocial problems such as anxiety, grief, isolation and stigma.

Palliative care can be integrated into both of these kinds of programme so that they provide holistic care.

Pain and symptom control

+

Psychosocial support

= Palliative care

Patients will need different kinds of care depending on their individual circumstances and on how sick they are.

At the time when someone first finds out that their disease cannot be cured, they may be active, still at work and busy at home, and may be on treatment such as ARVs or chemotherapy. Palliative care should begin alongside these other treatments, helping with difficult symptoms and side-effects, and giving emotional and spiritual support to the patient and their family. As time goes by, their needs will change and they may need more symptom control. Other treatments may be stopped if they are no longer helping and holistic palliative care is what will help the most. Even after death, palliative care can be continued by giving bereavement support to family, friends and children.

## Palliative care never says “there is nothing we can do”

Like the woman described above, many patients with life-limiting illnesses have so many problems that health workers and carers can feel overwhelmed and powerless to help. People are often sent home and told not to return because “there is nothing we can do”. But we need to focus on what we can do, rather than be discouraged by what we cannot do.

- We cannot cure the incurable, but we can control many of the symptoms which cause distress.
- We cannot take away the pain of loss, but we can stand with those who are grieving and share their sadness.
- We do not have all the answers, but we can listen to all the questions.

*“I can remember seeing the first patient who was ever referred to me when I started palliative care in an overcrowded, under-resourced government hospital. I walked into a side room on the children’s ward and saw a teenage girl lying on a mattress, wasted, semi-conscious, moribund. Her grandmother was sitting in the corner of the room. I wanted to run away – I could not think what on earth I had to offer in this hopeless situation. But then I determined to look at what I could do, rather than what I could not do. So we taught the grandmother to clean her dry mouth and applied some GV paint for the thrush. We found an extra pillow and used one of grandma’s cloth wraps to make the bed more comfortable, and adjusted her position. We explained about turning her regularly to prevent bed sores, and gave some cream to put on her dry skin. We encouraged the grandmother to sit close and talk to her even though she would not talk back. Small things, but they showed that we were not giving up, that they were not alone.”*

Palliative care clinician, Malawi

*“I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said: “For someone to look as if they are trying to understand me”. Indeed it is impossible to understand fully another person, but I never forgot that he did not ask for success, but only that someone should care enough to try.”*

Dame Cicely Saunders

The very act of trying to understand the problems someone is facing and seeking a way to help shows that person that they matter, that they are worthy of our time and attention. These are perhaps the greatest gifts we can give to our patients.



## You can do palliative care in your setting

The way palliative care is carried out will vary according to local circumstances.

- Who needs palliative care where we are working?
- What are their main problems?
- What help are they getting at present?
- What could be added to improve their care and make it holistic?

There are many resources in our communities if we look for them, to help with different aspects of holistic care.

- Physical
- Psychological
- Social
- Spiritual

Different models of Palliative care delivery include:

- Palliative care within HBC
- Palliative care clinic
- Day care support
- Hospital palliative care team
- Inpatient unit

We can't do everything, but we mustn't do nothing

## Chapter 2: You can do palliative care in your setting

When you want to eat an elephant you need to decide where to start and then just eat a little bit at a time.

Indian proverb

### You can do palliative care in your setting

Where do you work? Are you in a community centre or a hospital ward? Do you see patients in their homes, or in a clinic, or under a tree? When the palliative care movement began, most patients were looked after in hospices, where people stayed as inpatients until they died. Now palliative care is done in many different settings; “hospice” does not mean just a building, it refers to the whole approach of patient-centred holistic care. There is no single best way to provide palliative care, it will be different in different situations. There are four questions we need to ask:

- **Who needs palliative care where we are working?**
- **What are their main problems?**
- **What help are they getting at present?**
- **What could be added to improve their care and make it more holistic?**

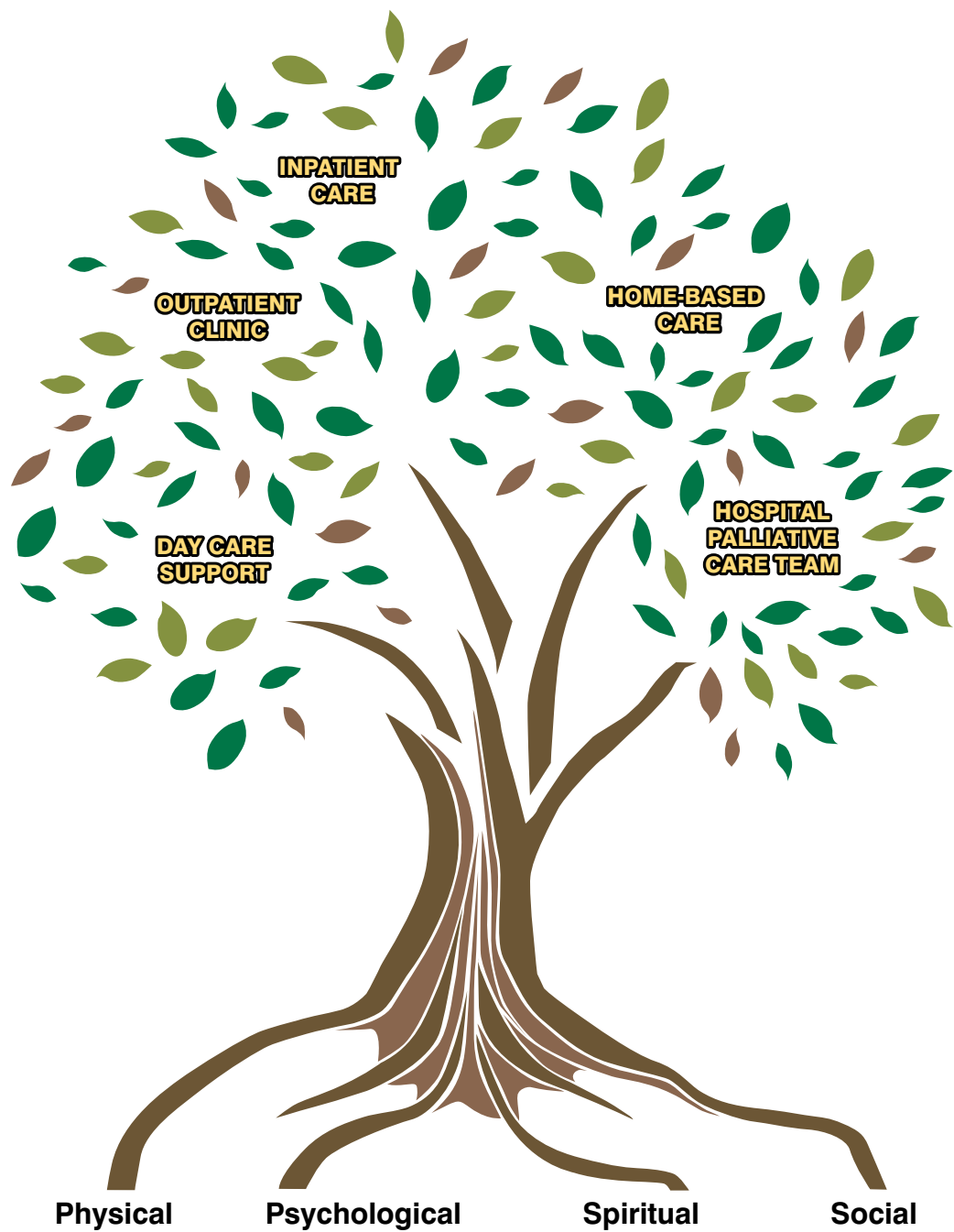
The first two questions look at the needs in our setting and the last two questions look at the resources already in place and what we might do to supplement or complement them. Many successful palliative care projects started very small, when someone noticed a group of people who needed help. They made the most of what was already available and added the elements of care which were lacking, using personnel who were there. This is more affordable and achievable than starting a whole new service and it leads to different organisations working in partnership, which enhances holistic care.

It may seem as if there are very few resources available which we could use to improve our services. However, because palliative care is not just about the treatment of physical problems, we can find help in many different places if we look for it. There are a lot of people interested in helping others. We may find individuals and groups involved in social work in health, poverty eradication, literacy and other programmes. Many of them may be willing to collaborate with us and support our work.

The picture on the following page shows palliative care as a tree. Its roots are the four elements of holistic care: physical, psychological, social and spiritual. Each of these roots can be made up from different components, eg existing clinics, faith communities, local NGOs. These are just examples of possible resources – you won’t find all of them in your community and you may find others we haven’t mentioned. The branches and leaves which grow from these roots represent holistic palliative care in its different forms – different “models of care”.



Growing a model of care from available resources



PHYSICAL	PSYCHOLOGICAL	SPIRITUAL	SOCIAL
<p><b>PATIENT CARE</b></p> <p>Health centre Local hospital Private clinics Traditional healers NGOs doing healthcare ART clinic</p> <p><b>DRUG SUPPLY</b></p> <p>Hospital pharmacy Local pharmacy shops</p> <p><b>ADVICE AND SUPPORT</b></p> <p>Local doctor/nurse/clinician Local physiotherapist National palliative care association</p>	<p><b>COUNSELLING</b></p> <p>Social worker Trained volunteer HIV counsellor Patient advocates – others with the same illness</p> <p><b>SUPPORT GROUPS</b></p> <p>PLHIV group Women’s group Youth organisations</p> <p><b>SUPPORT AT HOME</b></p> <p>HBC volunteers Family members</p>	<p><b>INDIVIDUALS</b></p> <p>Local religious leaders Volunteers from faith communities Social workers Family members</p> <p><b>GROUPS</b></p> <p>Faith community, eg church, mosque, temple, synagogue Women’s groups Hospital visiting team Children’s groups</p>	<p>NGOs FBOs Food supply work OVC groups Income generation schemes Small loan schemes</p> <p><b>INDIVIDUAL PROFESSIONALS</b></p> <p>Social worker Legal advisor, for making wills</p> <p><b>INVOLVING OTHERS</b></p> <p>Community leaders Local schools and colleges Community groups</p>

## Making the most of local resources

Building holistic care is about making relationships. We need to visit those who are – or could be – involved in the care of incurable patients and talk about working together. We may be able to offer help to them, and we must be courageous and ask them to support us.

We can ask other healthcare workers to help by giving advice and teaching, seeing patients with us, or allowing us to run a clinic in their building. We may be able to help them with symptom control problems or by visiting their patients at home. We may be able to get drugs from the hospital pharmacy, but we might also get help from local pharmacy shops who could order some for us.

Many people see traditional healers as their main source of healthcare. If we meet with local healers we can discuss the problems patients experience and the many ways in which they can be helped. We may learn about effective herbal remedies and could teach some palliative care skills. We can offer to see patients who might benefit from our help.

Just as we can work together with other healthcare providers, we can invite local counsellors or spiritual leaders to be part of our team or send patients to them. We may get help from different support groups and faith communities and we might be able to help them by giving advice and treatment to their members.

We could make a partnership with local NGOs or FBOs doing work on things such as food security, income generation and orphan work, etc, involving their skills and resources to help our patients with social problems.

It is important to visit local leaders and explain what we are doing so that we gain their support and they make our work known. There are many groups we can involve to raise awareness and help in practical ways both with our patients and with fundraising.

## Different models of palliative care

Depending on the local needs and local resources, palliative care can be delivered in many different ways. Many people prefer to be looked after in their own homes rather than in an inpatient unit and it is often easier for the family too as they do not have to travel to and from a hospital. HBC programmes are an excellent way of delivering holistic palliative care if families and volunteers are taught how to do basic symptom control and health workers provide the necessary drugs and backup support. HBC educates and empowers the community and it reduces the isolation and stigma which often comes with incurable illness.

Another way of caring for people in their communities is by running a palliative care clinic where patients come regularly. This can be combined with 'day care', when patients spend time with one another at the clinic or a local centre, giving them emotional and social support.

In some circumstances inpatient care is a good option. This might be done by a hospital palliative care team which provides symptom control and holistic support to patients with incurable illnesses on different wards. Sometimes a number of beds or a ward may be made into a hospital palliative care unit, or a whole inpatient hospice may be built. This is an expensive way of providing care, and where resources are limited, a community approach can reach more people in need.



**Palliative care in different settings**

Where and how palliative care services start depends on local needs and resources. Some services have started in the community and spread into clinics and hospitals while others have started from hospital and spread to the community. Here are some examples of how different palliative care services around the world have started.

**Neighbourhood Network in Palliative Care (NNPC), Kerala, India**

**A community group starts HBC**

NNPC began as a small group of lay people meeting to discuss what they could do for incurable patients in their neighbourhood. They were joined by some doctors interested in palliative care. This has grown into a large network of trained volunteers who identify and care for patients in the community, with backup from health workers. People have a chance to talk and obtain social support, if family income has been lost because of the illness, in the form of a loan which can be used to start a small business.

Personal communication, Dr Suresh Kumar, Kerala



**Selian Lutheran Hospital Hospice, Tanzania**

**Spiritual support develops into holistic HBC**



A hospice team started with the local church community visiting sick people in their homes to pray with them. By adding practical skills to this spiritual support, holistic HBC began. The doctor there says: “When somebody put before them the idea of marrying together a medical model with a spiritual model of caring for people who were at home dying, people got very excited and that gave rise to our whole volunteer based approach”.

Hospice and Palliative Care in Africa – Michael Wright and David Clark, OUP 2006

**The Beacon Foundation, Guyana, South America**

**A social welfare group starts HBC**

A social welfare group was started in 1985, funded by fast food stalls selling snacks. They set up projects to help different groups of people including the homeless, the hungry and street children. They saw that cancer patients also needed help as many died in pain, away from home and family, so they set up a HBC service run by two nurses. Now other healthcare workers refer patients to them both from hospital and at home.

Hospice Information Bulletin, vol. 6, issue 1, November 2007



## **The Lighthouse, Malawi**

### **Hospital staff see the need for HBC**



A group of hospital staff saw that many HIV patients were not receiving adequate care and follow up after discharge. They began visiting patients at home in their spare time but soon realised that there was too much work for them to cope with, so community leaders helped them recruit volunteers to look after patients at home. Two full-time community nurses were allocated to the project, and they have now trained more than 300 volunteers who each care for a small number of patients. Once a week a nurse or a clinical officer visits each community to meet with the volunteers and see patients together with them.

Personal communication, Mr Lameck Thambo, Lilongwe

## **U Hla Tun Hospice (Cancer) Foundation, Myanmar, South East Asia**

### **A bereaved father founds a HBC team and hospice**

This was started by a man who wanted to help others after his daughter died of cancer. A home care team of social workers, nurses and a doctor began visiting patients in the community and later an inpatient hospice was built. Many of the patients have cancer of the cervix and are often deserted by their husbands. The hospice team has created a special fund so that these patients can receive the necessary funeral rites.



Asia Pacific Hospice Palliative Care Network [www.aphn.org](http://www.aphn.org)

## **PASADA, Tanzania (Pastoral Activities and Services for People with AIDS, Dar es Salaam Archdiocese)**

### **A PLHIV support group starts HBC and a clinic**



PASADA began when some people living with HIV got together to form a self help group to do something for themselves and for others in similar situations. The church gave them a small building where they could meet and in due course a dispensary was opened to give basic medical help. Now it is a well-known urban outreach programme offering a variety of services.

International Observatory of End of Life Care: [www.eolc-observatory.net/global\\_analysis/index.htm](http://www.eolc-observatory.net/global_analysis/index.htm)

## **CanSupport, Delhi, India**

### **A cancer survivor starts a HBC programme**

CanSupport was started by a cancer survivor who recognised a lack of support and information for people diagnosed with cancer. She visited hospital patients to offer advice and support, and a telephone helpline was started. Together with a nurse she developed a home care service visiting the poorer areas of Delhi. Now five multidisciplinary teams cover the city, and CanSupport has been granted its own license for prescribing morphine.

Personal communication, Harmala Gupta



We can't do everything, but we mustn't do nothing.

## **Umodzi ('Unity') Palliative Care, Malawi**

### **Hospital team supporting children after discharge with clinic and day care**



Umodzi started on the malnutrition unit of a government hospital where children with end-stage HIV disease sometimes stay for long periods, often spending the last weeks of their lives in hospital rather than at home with their families. It started with a part-time doctor and a nurse getting children home earlier by counselling mothers about their children's illnesses and teaching basic symptom control. A weekly clinic was started in a hallway next to the ward to support them after discharge. The team has grown and also cares for children with cancer, both on the ward and as outpatients. The clinic provides medical review but also play time for the children and group support for their carers.

Personal communication, Dr Vicky Lavy

## **'For Quality for Life,' Osh, Kyrgyzstan, Central Asia**

### **A doctor starts HBC and a clinic**

An oncologist saw that there was very little help available for cancer patients with advanced disease so he approached a family doctor and together they started visiting patients in their homes. They renovated a disused oncology building as a clinic and held courses in palliative medicine for local doctors and nurses. Families who have been helped are advising others to contact 'For Quality for Life'. "God works through people, and you are the people that God is sending to help me."

- Elderly Muslim patient in Osh

Hospice Information Bulletin, vol. 5, issue 4, July 2007



## **Kidzpositive, South Africa**

### **Medical clinic introduces day care support group and income generation**



Kidzpositive is a clinic providing AIDS care for children. Clinic staff saw that the children were receiving good medical care and symptom control, but the social isolation and financial problems affecting their mothers were not being addressed. Now they stay at the clinic for the whole morning, chatting together over tea and bread. The mothers do bead work at the clinic, or take it home, making items to sell. This project supports 130 families with enough money to put food on their tables.

Personal communication, Dr Paul Roux, Capetown

## **Tiyanjane Clinic, Malawi ('Let's come together')**

### **Hospital care linked with HBC**



Staff in the government hospital saw that many HIV patients were sent home without a chance to talk about their illness or be directed to places where they could get help after discharge. A clinic was started in a small room in the department where a nurse, a counsellor and a part-time doctor see patients before they leave for home. A team nurse based at a nearby health centre provides care in cooperation with local HBC programmes.

Personal communication, Dr Jane Bates, Blantyre

## **Palliative Care Unit, Christian Medical College, Vellore, India**

### **Growth of a hospital palliative care team and clinic**

A doctor saw the need for palliative care at the hospital in Vellore and started giving three hours a week to hold a clinic and see patients on different wards, adding symptom control to the care they were already receiving. She was joined by a volunteer nurse and chaplain, and then a social worker to add emotional and spiritual support. In time, the hospital agreed to fund a palliative care team, and they are linked with a Catholic religious community which has opened an inpatient hospice.



Personal communication, Dr Reena George, Vellore

## **Pallium Latinoamerica, Argentina**

### **A doctor is inspired by a book to start palliative care**



A travelling bookseller met a young doctor working in a rural area of Argentina and persuaded him to buy a book by Cicely Saunders about palliative care. A few weeks later the doctor was called to see a man with terminal cancer who was in severe pain. He had learnt about curing cancer in his training and found he had even treated this very patient in the past, but now he felt powerless to help since the treatment had not worked. He turned to the book he had bought and found there was much he could do to help by giving pain relief and spending time with the patient and his family. He was inspired to develop palliative care and started Pallium, which now provides home care, inpatient and outpatient care in public and university hospitals, as well as bereavement support and day care.

Hospice Bulletin, vol. 7, issue 4, January 2000

We can see that different projects have started in different ways according to different needs and different resources. We do not need to have everything in place before we start because the work can develop and grow in time.

**We can't do everything, but we mustn't do nothing.**

If you want to find out more about these and other projects, contact Hospice Information (see "Further Resources") or go to the International Observatory of End of Life Care website: [www.eolc-observatory.net/global\\_analysis/index.htm](http://www.eolc-observatory.net/global_analysis/index.htm)



## You can build a team

### Teamwork

- Valuing each others' different contributions and skills
- Sharing the burden of care and supporting each other
- Good communication
- Acknowledging our differences and resolving disagreements

### Training

People enjoy working when they know what is expected of them, they feel competent to do it and their work is appreciated.

Training includes:

- Teaching sessions
- On-going supervision and support

### Caring for carers

- Caring is hard work
- Watch for signs of stress
- Prevent burn-out by good support

**T**ogether  
**E**ach  
**A**chieves  
**M**ore

## Chapter 3: You can build a team

If you want to travel quickly, go alone. But if you want to travel far, you must go together.

African proverb



In settings where palliative care is well established and well resourced, it is often carried out by a multidisciplinary team, which may consist of nurses, doctors, social workers, counsellors, spiritual leaders and others. However, where you are, there may be only a handful of people to help, or perhaps you are alone. We need to build a team because we cannot do palliative care on our own – we might manage for a while, but we will become exhausted and discouraged, and the work may collapse.

On the tree (p6) we have seen some of the resources and people who might help us to develop holistic palliative care. Some may help occasionally, such as a spiritual leader whom we can call if we have a patient of that particular faith, or a local pharmacist who orders certain drugs for us when we need them. Others may work in partnership with us, such as a hospital clinic sending patients to a HBC team when they need care at home, and that same team sending patients to the clinic when they need a review by a doctor. We need people who will join us to make a team which meets together regularly and coordinates its activities to provide holistic care. This will involve care that is:

- **Physical** – nursing, treating, prescribing
- **Psychological** – listening, counselling, being there
- **Social** – help with finances, housing, family support
- **Spiritual** – prayer, counselling, carrying out rituals or rites.

We need someone on our team who can help with each aspect of care. A health worker is essential but they may train others to share this work, such as volunteers who can learn to give excellent nursing care. One person may work in more than one aspect of care, such as a nurse who also offers spiritual support, or a social worker who is good at counselling but also runs an income generating project. It may be necessary to seek out someone with a particular skill, eg in a place where nurses are not allowed to prescribe drugs, we will need to get a doctor on the team. We could also send one of our team for training in a particular skill, such as sending a volunteer who is a good listener on a counselling course so that the team has a trained counsellor. As more people become involved, separate teams which connect with each other may be necessary, such as a team of volunteers working in one area whose coordinator or supervisor attends the central team meetings.

### Teamwork

A team does not have to be big to be effective – two people can be a team – but the **way they work together** is important.

Building a team requires mutual respect, support and good communication. Recognising the importance of team members' different contributions and verbalising it is vital, ie noticing when someone has done something well and appreciating their hard work. Palliative care can be emotionally draining and we need to support one another, noticing when someone is exhausted and sharing their load.

Good communication is what cements a team together. We must keep each other in the picture about what is going on – not just about our patients but about how we are feeling. Hurts and disagreements can happen in any team, and we need to speak about them and resolve them rather than bury them.

## Training

*People enjoy working when they know what is expected of them, they feel competent to do it and their work is appreciated.*

If people feel unprepared or unsupported, they will not work well and may leave the team. Therefore, training and supervision is very important. It can be done in teaching sessions and on-the-job, working alongside someone with experience.

All members of our team need to understand the concept of the holistic approach and appreciate the importance of physical, psychological, social and spiritual components of care. Some team members may be involved in just one of these aspects, but it is good to understand what others are doing and to see how everything fits together.

Volunteers can be a great resource for palliative care and are vital in many teams, as we have seen in the stories of different projects. There are usually many people in a community who want to help others. If we want them to be involved, we need to let them know how much their help is needed (for some ideas on this see “You can tell others” p59). Training ensures that they can work effectively.

## Suggested training topics for volunteers

- Palliative care and the holistic approach
- Concept of community HBC
- Basic facts about the diseases the volunteers will see
- Assessment of a patient and family to list their needs
- Communication skills
- Emotional and spiritual support
- Nursing care and infection prevention
- Basic symptom control techniques
- Supervising drugs(eg analgesics, ART, TB drugs)
- Nutrition
- Needs of children
- Approach to the dying patient
- Bereavement support
- Looking after yourself
- Record keeping

## Nursing care teaching

- Pain assessment and management
- Skin care and prevention of pressure sores
- Wound care
- Mouth care
- Feeding a patient
- Bathing a patient
- Dealing with incontinence, urinary retention and constipation
- Diarrhoea and vomiting
- Lifting, moving and turning a patient

## Ongoing support and supervision

Training does not end when a teaching session finishes; we all need to continue learning as we work. Everyone, including team leaders, should have someone who will talk things over, answer questions and see patients with us if possible. This can be called ‘mentorship’ or ‘supervision.’ You may be a mentor for one person, but you also need to find a mentor for you. You may not be able to meet very often, but you can save up questions and issues to discuss on the telephone, by letter or email.

## Caring for carers

Caring for people with chronic illnesses is very stressful, whether you are a health worker, a volunteer or a family member. Sometimes carers can become overwhelmed by the work and feel unable to carry on; this is called 'burn-out'. It is important that we look out for signs of stress both in ourselves and our team and in the families we are caring for.

### Signs of stress

- Tiredness
- Poor concentration
- Loss of interest in work
- Neglect of duties
- Irritability
- Anger
- Withdrawal – avoiding patients and colleagues
- Feelings of inadequacy, helplessness and guilt
- Depression – lack of pleasure, tearfulness

### Looking after yourself and your team

- Make sure everyone has regular time off.
- Make a regular time to discuss patients and problems.
- Make sure everyone knows how to get help (eg how volunteers and family can contact a health worker for backup).
- On-going training and supervision increases confidence and competence.
- When a patient dies, take time to reflect; recognise that multiple losses are inevitably stressful.
- Make time to relax together – over tea, or a shared meal.
- Take pride in your work and in the difference you are making to your patients. Encourage one another when things are done well.

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Together  
Each  
Achieves  
More





## You can talk about difficult issues

### Listening

- Sit at the patient's level
- Active listening, allow silences
- Check you have understood

### Talking

- Be respectful and polite
- Avoid complicated language
- Check they have understood

### Breaking bad news

- Don't withhold information from someone who wants to know
- Don't force information on someone who is not ready
- Don't lie

**B**e prepared

**R**elatives

**E**xpectations

**A**ssess what is appropriate

**K**nowledge sharing

**N**ever "nothing we can do"

**E**mpathise

**W**ay forward

**S**top and reflect

### Spiritual support

**H**ope

**O**rganised religion

**P**ersonal issues

**E**ffect on our care

### Bereavement

- Many different reactions to loss
- Empathy and support are part of palliative care

# Chapter 4: You can talk about difficult issues

“Be quick to listen and slow to speak.”

James the Apostle



## You can talk about difficult issues

Talking with patients and families is a very important part of palliative care. The good news is that we can do it even if we have no drugs, equipment or special premises. However, we do need some basic skills which health workers are not always taught during their training. Some people find communication easier than others, but these are skills which we can all learn and practise.

## Communication skills – listening

Listening to patients is as important as talking. It not only helps us to get information, it makes people feel valued when we listen to their stories. Being able to voice their questions and worries can bring great relief and take away some of the isolation and fear they may be feeling.

If possible, find a quiet place where you will not be interrupted. It is good to be sitting down together, rather than standing over a patient who is in bed. If the patient cannot sit up, get down to their level – you may have to kneel on the floor or crouch beside the bed. You must pay attention and keep eye contact. You can nod to show you understand, or make small comments such as

“I see” “Yes” “That must be hard for you”. This is called ‘active listening’.

Sometimes it feels uncomfortable when there is silence during a conversation, but it can be helpful and we need to learn to be patient and not interrupt. People often pause before they say something important or painful. If you interrupt, you may never hear what is in their heart.

*One study showed that doctors interrupt their patients after an average of 18 seconds.*

It is good to check we have understood and summarise what the patient has said, eg “Do you mean that...” “I think what you are saying is...” “So the main things worrying you are...”.

When hearing about physical symptoms, we may need to ask many questions to get a good picture of the problems, eg: “How long have you had this cough? Is it getting better or worse, or staying the same?” or “How often does your baby have a fit? Every day, about once a week, or once a month?”.

### Listening skills

- Find a quiet place if possible
- Sit at the patient's level
- Pay attention, keep eye contact
- Active listening
- Allow silence, do not interrupt
- Clarify and summarise

### Communication skills – talking

- Always be respectful and polite. This makes the patient feel valued.
- Avoid medical terms that the patient may not understand.
- Give information rather than advice – then they can decide for themselves what to do.
- Only give accurate information. It is all right to say you do not know.
- It is good to check the patient has understood you. If you have given instructions, ask them to explain to you what they are going to do or how they will explain this to a family member. See if they have any more questions for you.

### How much should we say?

In many cultures sickness is not discussed openly, but, as palliative care is developing around the world, things are changing. People often think that telling a patient they have an incurable illness will only make them worse. Families often want to protect their loved ones from bad news and will ask the health worker not to say anything to them, but studies from different settings have shown that people usually do want to know the truth and cope better if they do. We may need to spend time counselling families about this, explaining why it is important for the patient to know, and offering our help and support with difficult discussions.

It can be tempting to give false reassurance: “Don’t worry, you will be fine”. But the patient usually knows in his heart that he will not be fine and is left to cope with his doubts, fears and questions on his own.

### Why is it good to tell the truth?

- To maintain a relationship of trust. Lying destroys trust.
- To reduce uncertainty. People usually cope better with truth than with uncertainty, even if the truth is painful.
- To prevent unrealistic hope. Sometimes people spend much time and money going from clinic to clinic looking for treatment because no one has been brave enough to tell them that there is no cure for their illness.
- To give opportunity for mending difficult relationships or exploring spiritual issues.
- To allow patients and families to prepare for the future – this might involve writing a will, travelling to the family home, planning a funeral, or many other things which they want to do before they die, and which may not be done if they do not hear the truth.

*“Truth is one of the most powerful medicines available to us, but we still need to develop a proper understanding of the right timing and dosage for each patient.”*

Adapted from Simpson (1979)

### Breaking bad news

Nobody finds this easy. Telling someone that they have cancer or HIV, or that there is no cure for their illness, can be traumatic as we don’t like causing pain. We may feel we won’t know how to handle their reaction. However, the good news is that it is a skill we can learn. There will be differences in how it is done in different

cultures, but here are some general guidelines – remember them by spelling **BREAK NEWS**.

### **Be prepared**

Make sure you have read or heard all the information that is available about the patient. Make sure you have enough time – do not start to break bad news when you only have a few minutes. Try to prevent interruptions; if you have a phone, turn it off.

### **Relatives**

It is usually best to give bad news when the patient has a close family member with them for support, and to share the information – most people only remember a small part of what is said when they are anxious or upset. It is important to check first who should be there to receive the news; this will vary according to the patient's culture and the setting. You might say: "We have some important things to discuss; are you happy for your mother to stay?" or "Who would you like to have with you while we talk?".

### **Expectations**

What is the patient expecting to hear? Find out what they already know: "What have you been told about your illness? How do you think things are going?". This is very important even if it seems obvious to us, or even if we know they have already been told something by someone else. What has been said and what has been heard are not always the same. Listening to their thoughts will tell us what level of understanding they have, and what sort of language they use to talk about their illness.

### **Assess what is appropriate**

Try to assess how much they would like to know: "Have you been wondering what this is about? Would you like me to tell you what I think is going on?". It is not right to force information on someone who is not ready to hear it, just as it is not right to withhold information from someone

who does want to know. We don't have to say everything in one visit – they may be ready to hear more next time.

### **Knowledge sharing**

Share the knowledge you have slowly and gently, being careful to avoid words they won't understand. It is often helpful to let patients know you are about to tell them something important – you can give a warning such as: "We need to sit down and talk, things are quite serious". As you talk, give them time to absorb what you are saying, and at the end, check they have understood.

People often want to know how much longer they will live. They may ask about this directly: "How long have I got left?" or indirectly: "When will I be able to go back to work?". It is usually unwise to give a precise answer because people are all individuals and often surprise us. However, it is helpful to give a rough idea to help people to plan realistically. Generally, if the patient's condition is deteriorating each month, they probably have some months left; if it is changing week by week, then it will be a matter of weeks; and if they are deteriorating every day, they may only have a few days left.

### **Never say "there is nothing we can do"**

It is important to give positives as well as negatives: "We cannot cure the cancer, but we have medicine that will stop the pain." "We are always here to help if new problems arise".

### **Empathise**

It can be hard to allow the patient to express their feelings because we want to take away their sadness, or we are alarmed by their anger or despair. We cannot remove their feelings, but we can empathise – this means trying to understand how they feel, putting yourself in their shoes. We can say simple things like: "This must be very difficult for you to hear" or "I can

# “Death is not something to be feared. It is something to be acknowledged and accepted.”

Buddha

understand that you feel angry”. It is not helpful to stop a person from crying – it is a normal and helpful reaction. Sit patiently – they will stop when they are ready.

## Way forward

It is important to talk about what will happen next and how you can help. Fix a time when you will see them again. Make sure they know you will not give up on them and let them know how they can get help if problems arise before they see you next.

## Stop and reflect

Breaking bad news is difficult for us as well as for the patient. It is good to pause for a moment before we move on to our next task, to reflect on the conversation and how we are feeling.

## Spiritual support

Our spiritual dimension is much more than what kind of temple, mosque or church we go to, if any. It includes our understanding of what purpose or meaning life has and how we make sense of the world. Spiritual issues are often very important to people who know that they are coming to the end of their lives. A person who has been religious may find themselves questioning their beliefs. Someone who has never been religious may find themselves asking questions such as:

- What will happen when I die – is there life after death?
- Why am I ill – is it a punishment from God?
- What value has my life had?

Some people find themselves struggling with guilt, anger or despair. Some are searching for forgiveness, peace or hope. If these issues are not addressed, we may deal with a person's physical symptoms but still leave them in 'spiritual pain'. In order to understand how best to give spiritual support, we have to find out about the patient's real beliefs and concerns. Sometimes we find it hard to ask about these things so we only see someone as 'Hindu' or 'Christian' or 'Muslim', instead of finding out about the spiritual journey that is behind these labels. Some useful questions are:

- What is most important to you?
- What helps you through difficult times?
- Do you have a faith which helps you make sense of life?
- Do you ever pray?

Listening is one of the most important tools we have for giving spiritual support. Our role is not to tell people what they should think, but to be with them as they seek answers to their questions.

*Meaning cannot be given by another, it must be sought and found.*

If we are asked about our own beliefs, it may be helpful to share them, but we must never force our views on someone else. Praying with or for a patient can bring comfort if they and the carer are comfortable to do so.

Helping with practical issues such as appropriate food and clothing, washing before prayer and the need for certain sacred items can be important. Paying attention to these details may make a big difference to a patient and enable them to practise their religion and find peace.

It may be possible to include someone in our team whose focus is spiritual support, or we may need to identify members and leaders of local faith communities who we can call upon to spend time with patients, carry out important rituals or advise on customs and practices surrounding death.

We can use the word **HOPE** as a checklist for spiritual support:

**Hope** – what are the sources of hope, comfort, meaning, peace for this person?

**Organised religion** – is organised religion and culture important to this person?

**Personal issues** – what are their questions, doubts, struggles?

**Effect** – what effect will this have on the way we care for and support them?

## Bereavement

When a person dies, we say that their family and friends are 'bereaved'. This means they have lost something precious to them and are grieving. Grieving may take place before death – when someone is told they have HIV, or that their cancer treatment has not worked, or they become unable to care for themselves; they and their family may grieve the loss of their independence, their health or their future.

People have studied the process of grieving and described different emotions that the bereaved experience, such as:

- shock or disbelief
- anguish and severe distress
- anger
- searching for the lost one
- depression, fatigue, loss of interest in life
- acceptance and planning for the future.

Different individuals move back and forth through these emotions in different ways, and it is important for us as carers to recognise that bereavement leads to different feelings at different times. We do not need to panic in the face of these strong emotions, but to recognise and accept them. This can be particularly important when there is anger, as it may be

directed at us and we may feel hurt or angry in return. But if we recognise that what they are really angry about is their loss, we can accept and absorb their feelings.

It is not helpful to make people feel that it is wrong to feel the way they do, eg: "You shouldn't still be so depressed, it's months since your son died" or "You shouldn't be angry like this, it's not their fault". Such comments won't make their feelings go away, it will simply make them feel guilty and add to their burden. It is more helpful to acknowledge the feelings and explain that they are part of a normal grief reaction.

## *Going through the painful process of grief is the pathway to acceptance of the loss*

Most cultures have rituals and customs which take place when someone dies. These are usually very helpful for the family. However, we should not assume that once the funeral is over, grieving is complete. It may take many months for someone to reach the stage of accepting their loss and rebuilding their life. Supporting them through this process is part of palliative care.

"Suffering is not a problem that demands a solution; it is not a question that demands an answer; it is a mystery that demands a presence."

John Wyatt 1998



## You can control pain and other symptoms

- Treat what is treatable
- Care for the patient
- Prescribe palliative drugs

## Head-to-toe guide to pain and symptom control

**Pain** p26

Assessment of pain p26

Use of analgesics pp26-31

- By the mouth
- By the clock
- By the analgesic ladder

How to prescribe morphine p27

Adjuvant drugs p29

- Steroids for pain from swelling and inflammation
- Antidepressants and anticonvulsants for neuropathic pain
- Muscle relaxants for painful spasm
- Antispasmodics for abdominal colic

continued overleaf...

## Other symptoms

■ Fever	p32
■ Rashes and itching	p33
■ Wounds	p34
■ Seizures	p35
■ Confusion	p36
■ Anxiety and sleeplessness	p37
■ Depression	p38
■ Poor appetite and weight loss	p39
■ Sore mouth and difficulty swallowing	p40
■ Nausea and vomiting	p41
■ Indigestion and Hiccups	p42
■ Cough	p43
■ Breathlessness	p44
■ Diarrhoea	p45
■ Constipation	p46
■ Vaginal discharge	p47
■ Urinary difficulties	pp47-48
■ Mobility problems	p49

## When medication cannot be given by mouth p50

## End of life care p51

# Chapter 5: You can control pain and other symptoms

Pain relief and symptom control are vitally important. Without pain and symptom management, we may give excellent psychosocial support but we will not be providing palliative care. The good news is that much can be achieved with good nursing care and inexpensive drugs. This section provides a head-to-toe guide to relief of symptoms, starting with those such as pain that may affect any part of the body. For each symptom the suggested management is arranged under three headings:

- **Treat** what is treatable
- **Care** for the patient
- **Prescribe** palliative drugs

You may not be able to use all the suggestions given – this will depend on your training, whether you are licensed to prescribe in your country and which drugs are available. But remember: “there is never nothing we can do”. All of the suggestions in the ‘Care’ sections should be achievable, so use whichever parts of this chapter are helpful in your situation.

## Treat the treatable

Palliative care seeks to relieve the distressing symptoms of an illness. The obvious place to start is with the illness itself. If you can treat the illness you will reduce the symptoms.

- ARVs should be used to treat HIV if available. They will improve the patient’s condition and reduce their symptoms even though they will not cure HIV. Other symptom control measures can be used at the same time if needed.
- If chemotherapy or radiotherapy is available to treat cancer, this may be the best way of improving the condition of the patient even if it cannot cure the cancer.
- Some complications of an illness may be treatable, eg treating pneumonia with antibiotics to improve a patient’s cough, or treating constipation to improve abdominal pain.

Whenever we address a symptom, we need to think whether there could be a treatable cause.



In this section we have not given details of how to give treatments such as ARVs, antibiotics, TB drugs or chemotherapy. If these are available, then local guidelines should be followed. **Only those who are licensed to prescribe should initiate drug treatment.**

We also have to consider whether the treatment itself might cause distress and *weigh up benefit against burden* for that particular patient in their situation. This needs to be discussed with the patient and their family, eg treating anaemia with a blood transfusion may not be in the patient’s best interest if they are unlikely to live much longer and would have to travel to hospital to receive the transfusion. Reducing the size of a tumour with chemotherapy may not be worthwhile if it will have severe side-effects or cost a lot of money for only temporary benefit.

The following are factors that need to be thought about before starting a treatment for a patient with an incurable illness:

- Is the patient fit enough to cope with the treatment and the journey to hospital if this is needed?
- What side-effects might the treatment have? Could these be worse than the symptoms they already have?

- Can the patient and family afford the treatment and the journey to the hospital? If a treatment needs to carry on for months to be effective and the family can only afford to pay for a few days or weeks, is it wise for them to start on this treatment?

### Care for the patient

This is usually the largest section for each symptom and outlines the practical 'hands-on' care and advice that may help the patient. Good nursing care is vital and can control some symptoms without any drugs at all. It is often 'doing the simple things well' and paying attention to the details of care that makes the biggest difference for the patient. Each patient has different needs and these must be assessed and communicated between all those caring for the patient. One way of doing this effectively is to use a patient held record (see Tool 5) which documents the patient's needs and can be added to by each person caring for the patient.

There are situations in palliative care where symptoms are difficult to control and you feel there is little you can do. In these situations never underestimate the value of human presence: touch; kind, honest words; and careful listening to the patient.

In the patient's home, nursing care may be given by:

- Family or friends
- Health professionals from the primary care team
- Volunteers who are working with a HBC or palliative care programme.

The palliative care team cannot do all the nursing themselves, so part of our role is to teach the family and volunteers. They can learn to do everything that is suggested in the care sections, and we want to give them the encouraging message that there is always something they can do to help.

### Prescribe palliative drugs

This section outlines which drugs may be helpful to relieve symptoms and how they should be used. In some cases this may be a different use of the drug to the one with which you are familiar, eg using antidepressants or anticonvulsants to treat pain. Although the drugs can only be prescribed by certain health workers (according to national regulations), non-prescribers may also find this section useful for advising patients about which drugs they might request from their clinic or pharmacy.

Control of most common symptoms can be achieved with a fairly small number of drugs. You may not have all of the drugs suggested in the toolkit, but there may be alternative drugs available where you are. Many of the drugs mentioned are cheap and may be available from private pharmacies even if they are not in the local health centre.

A comprehensive guide to the use of drugs in palliative care and alternatives to those suggested can be found online at

[www.palliativedrugs.com](http://www.palliativedrugs.com)

A comprehensive list of essential medicines for palliative care is available from the International Association for Hospice and Palliative Care:

[www.hospicecare.com/resources/emedicine.htm](http://www.hospicecare.com/resources/emedicine.htm)

The following four principles are important in the safe and effective use of drugs:

#### 1. Only give drugs that are doing some good

Almost all drugs have some unwanted side-effects. The beneficial effects of taking a drug must be greater than the side-effects; otherwise the drug will be doing the patient harm.

## 2. Educate the patient and their carers about the drugs

Patients are more likely to continue taking a drug if they understand the reasons for taking it. It is important to offer them education about their drugs, and the following points should be discussed:

- The beneficial effects
- The possible side-effects and how they can be managed
- How to take the drug – frequency, timing, with or without food (use Tool 6)
- The length of time before they may get benefit from the drug (sometimes the side-effects come before the beneficial effects)
- How long they should continue to take the drug.

## 3. Keep the number of drugs to a minimum

Taking drugs can be a burden for the patient. Patients with advanced illness sometimes have to take large numbers of different drugs each day. It is very important to stop drugs that are no longer needed.

## 4. Review symptoms and drugs on a regular basis.

Symptoms change over time:

- If symptoms improve, drug doses can often be reduced or the drug stopped.
- If symptoms get worse, doses may need to be increased or a new drug be tried.
- If there are side-effects, a drug may need to be reduced or stopped.

It is important to make arrangements to review patients' symptoms and drugs on a regular basis.



# Head-to-toe guide to symptom control



## Pain

Over 70% of people with advanced cancer or HIV disease experience pain. Some pains are short term such as those caused by HIV-related opportunistic infections. Many pains associated with advanced cancer and HIV are long term and may get worse over time.

### Assessment of pain

It is important to ask about pain in every patient. A person who has had pain a long time may not show the usual signs of being in pain (facial expression, sweating, pale with fast pulse). They may just be quiet or depressed. Careful assessment of pain is essential to identify causes of pain that can be treated and to determine what type of pain it is and how it can best be helped. Questions you will need to ask include:

- How many different pains are there?  
It is useful to record them on a body map (see Tool 1). Ask about each one.
- Where is the pain and what does it feel like?
- How long has the pain been there?
- What makes it better or worse?
- Has any medication helped?
- Does the pain get worse with movement?  
Are the bones or joints tender?  
(This may indicate bony metastases if the patient has cancer.)
- Are there any changes in feeling of the skin at the site of pain?  
(This may indicate nerve pain – see below.)
- Are the muscles tense or tender?  
(This may indicate pain from muscle spasm – see below.)

You can ask patients to score their pain to give you some idea of how bad it is. If they score their pain every day it will help you to know whether it is getting better or worse and whether your treatment is effective. There are different ways of scoring pain to suit different people – Tool 2 gives three useful options.

### Treat

- Painful infections: skin; mouth; chest; urinary tract; meningitis
- Wounds (see p34)
- Constipation (see p46) – if the main cause of pain is constipation then giving opioids may make it worse (see p29)
- Bone metastases with radiotherapy if available
- Isoniazid-related nerve pain by giving pyridoxine to all patients taking isoniazid for TB treatment

### Care

- Find the most comfortable position for the patient.
- Make sure that the patient takes their analgesics regularly.
- Listen to the patient's concerns and explain what is happening.
- Try gentle massage or rocking.
- Try hot or cold compresses.
- Try slow, deep breathing.
- Use distraction, eg music or radio.
- Involve prayer and other religious or cultural practices (if appropriate).

### Prescribe

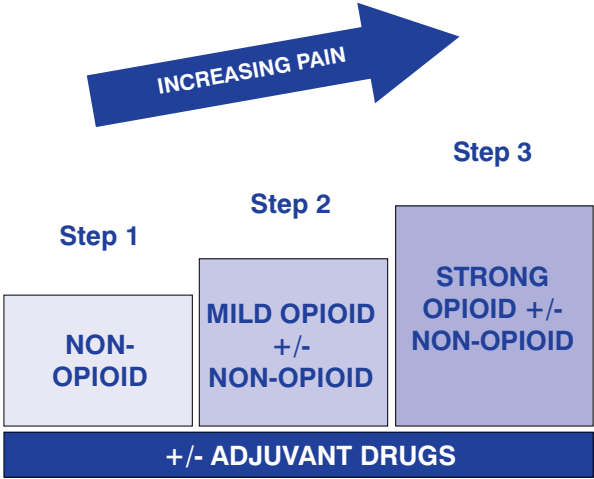
Analgesics (pain medicines) can be divided into two groups:

1. **Non-opioids** – These include **paracetamol (acetaminophen)** and the non-steroidal anti-inflammatory drugs (NSAIDs), eg **aspirin**, **ibuprofen** and **diclofenac**. The main side-effect of aspirin and other NSAIDs is stomach irritation, so they should, if possible, be taken with food. NSAIDs should not be used in patients who are very dehydrated as they may cause renal failure. They can also interfere with blood clotting. NSAIDs are useful in managing pain from bones and joints.

2. **Opioids:** These are the morphine-like drugs and include **codeine, tramadol** and **morphine**. Their side-effects are described below.

Analgesics should be given:

- **By the mouth** – Giving analgesics by mouth is the simplest and most reliable method for most patients. If the patient cannot take tablets by mouth, then the subcutaneous, rectal, and buccal routes are alternatives.
- **By the clock** – Constant pain needs regular analgesics to keep it away. Pain that is allowed to build up is more difficult to control. Do not wait for the pain to return but give analgesics at regular intervals according to their duration of action, eg **codeine** 30mg every four hours.
- **By the ladder** – The WHO analgesic ladder gives a logical way of increasing the strength of analgesia in steps as pain increases (see below).



Explain to the patient:

- The medicine is to keep the pain away. Take it regularly and do not wait for the pain to return before taking the next dose.
- The medicine needs to be continued as long as the cause of the pain is still there:
  - If the cause of the pain was an infection that has now been treated, they may be able to reduce or stop the medicine.
  - If the cause of the pain is something for which there is no available treatment,

then they must continue to take the medicine indefinitely otherwise the pain will return.

Non-opioid analgesics	Dose	Duration of action
Paracetamol	500mg-1g q.d.s.	4-6 hours
Aspirin	300-600mg q.d.s.	6 hours
Ibuprofen	200-400mg q.d.s.	6-8 hours
Diclofenac	50mg t.d.s.	8 hours
Opioid analgesics	Dose	Duration of action
Codeine (Step 2)	30-60mg q.d.s.	4-6 hours
Tramadol (Step 2)	50-100mg q.d.s.	6 hours
Morphine (Step 3)	No dose limit but increase dose gradually	
Normal release morphine (NR)	Starting doses: 2.5-5mg 4 hourly	4 hours
Modified release morphine (MR)	10-20mg 12 hourly	12 hours

Prescribing morphine

Morphine is a strong painkiller. It is a safe and effective drug when used properly. If it is abused and taken by someone without pain, it can be addictive and can cause respiratory depression. This does not happen if the correct dose is taken to relieve pain.

Preparations

Morphine comes in two forms:

1. **Normal release morphine (NR)** – This comes as a tablet or solution which is made up to a certain strength, eg 5mg/5ml or 10mg/5ml. Always prescribe the dose in mg not in ml and make sure you know the strength of the solution. NR Morphine begins to work after about 20 minutes and analgesia lasts four hours.

2. **Modified Release morphine (MR)** – These are morphine tablets designed to give longer lasting analgesia. The most common forms last 12 hours and should be taken twice a day exactly 12 hours apart, eg 6am and 6pm or 8am and 8pm.

**Doses**

**NR morphine:** Start with 2.5- 5mg every four hours. Use the smaller dose in the very frail or elderly. If they have been taking regular **codeine**, then you can start at 5-10mg every four hours. A double dose may be taken at bedtime to avoid the need for a dose in the middle of the night. They can also take extra **breakthrough doses** (same amount) at any time for pain that is not controlled by the regular doses. Encourage the patient to take a breakthrough dose as soon they feel pain to stop it from building up. If the patient can keep a record of how many extra doses they need, it will show whether the regular dose needs to be increased. If the patient's pain gets worse with movement, it can help to take a breakthrough dose half an hour before they move.

**MR morphine:** Always start a patient on four hourly NR morphine if it is available. Once you know how much morphine they need you can change to 12 hourly MR morphine. To calculate the MR morphine dose: add up all the NR morphine taken in the last 24 hours (this is the **total daily dose** of morphine); divide this by two to give the 12 hourly MR morphine dose. If you only have MR morphine start with 10mg every 12 hours. If there is NR morphine (morphine solution) available, they can take this at any time as a breakthrough dose. The breakthrough dose should be one sixth of the total daily dose.

**Example:** changing regular NR morphine to regular MR morphine:  
A patient is taking 10mg NR morphine every four hours.  
**Total daily dose** of morphine = 60mg  
**Equivalent dose** of MR morphine = will be 60/2 = 30mg 12 hourly  
**Breakthrough dose** = 60/6 = 10mg NR morphine p.r.n.

**Increasing the dose**

If the patient is still in pain after 24 hours and there is no sign of toxicity (see below), increase the morphine dose by 50%. Continue to increase the dose by 30-50% every few days until the patient is pain free or there are signs of toxicity. Alternatively, you can increase the dose by adding the additional breakthrough doses that have been taken in the last 24 hours to the regular morphine dose. Remember to check whether the breakthrough doses have been effective. If the patient has taken several doses with no effect, you should review the pain as it may not be sensitive to morphine.

**Example:** with NR morphine only:  
A patient is taking 20mg NR morphine every four hours:  
They have also taken three breakthrough doses of 20mg in the last 24 hours  
**Total daily dose** = 120 + 60 = 180mg  
**Regular dose** = 180/6 = 30mg NR morphine every four hours  
**Breakthrough dose** = 180/6 = 30mg NR morphine p.r.n.

**Example:** with NR and MR morphine:  
A patient is taking 60mg MR morphine every 12 hours:  
They have also taken three breakthrough doses of 20mg NR morphine in the last 24 hours  
**Total daily dose** = 120 + 60 = 180mg  
**Regular dose** = 180/2 = 90mg MR morphine every 12 hours  
**Breakthrough dose** = 180/6 = 30mg NR morphine p.r.n.

There is no maximum dose for morphine. The more pain a patient has, the more morphine they will usually be able to tolerate. The correct dose for each patient is the dose that takes away the pain without giving unacceptable side-effects or toxicity.

Stopping morphine

If a patient has been taking morphine for several weeks it should not usually be stopped suddenly as this may cause withdrawal symptoms (sweating, agitation and nausea). The dose should be reduced every few days and then stopped. It may need to be stopped more quickly if the patient has opioid toxicity (see below).

Side-effects of opioid drugs

- **Constipation** – Morphine usually causes constipation, so it should always be prescribed with a laxative (see p46) unless the patient also has diarrhoea.
- **Nausea** – Some patients develop nausea when they start morphine and will need an antiemetic (see p41) for the first few days.
- **Drowsiness** – It is common to get drowsy when first starting on morphine or when the dose is increased. This usually improves after three to four days. If it does not improve, then it may be a sign that the morphine dose is too high.
- **Sweating and itching** – These are less common side-effects that may be associated with taking morphine.

Toxicity and overdose

The following may be signs that the morphine dose is too high and the patient is toxic:

- Drowsiness that does not improve
- Confusion
- Hallucinations
- Myoclonus (sudden jerking of the limbs)
- Respiratory depression (breathing rate slowed down).

Patients may also become toxic if they are very dehydrated or in renal failure, which causes morphine to accumulate in the body.

Managing Toxicity

If you are concerned that the patient is becoming toxic, reduce the morphine dose by 50%. If you are very concerned, stop the morphine.  
**Haloperidol** 1.5-5mg at night may help with hallucinations and confusion caused by morphine.

Adjuvant analgesics

These are drugs which were not designed as analgesics but may help in certain kinds of pain alongside standard analgesics. They can be started at any step of the analgesic ladder. Examples of commonly used adjuvants:

Adjuvant analgesic	Pain that may be helped
Corticosteroids eg dexamethasone, prednisolone (1mg dexamethasone= 7mg prednisolone)	Pain from severe swelling or inflammation
Tricyclic antidepressants eg amitriptyline, imipramine	Nerve damage pain (neuropathic pain)
Anticonvulsants eg valproate, gabapentin, carbamazepine, phenytoin	Nerve damage pain (neuropathic pain)
Benzodiazepenes eg diazepam, lorazepam	Skeletal muscle spasm
Anticholinergics eg hyoscine butylbromide	Smooth muscle spasm, eg abdominal colic

Pains that can be helped by adjuvants

1. Pain from severe swelling or inflammation

Cancer causes local inflammation and swelling. When it spreads to an area of the body where there is very little room for this swelling, it may result in considerable pain. This is commonly seen in the:

- Brain – headache from raised intracranial pressure
- Spinal cord – spinal cord compression
- Liver – abdominal pain from stretching of the liver capsule
- Neck – axilla (armpit) or groin from pressure on nerves.

Opportunistic infections in HIV disease may also lead to severe inflammation and swelling. This is commonly seen in the:

- Mouth – severe mucositis
- Oesophagus – severe candidiasis
- Meninges – cryptococcal or TB meningitis.

Use of high dose corticosteroids

High dose corticosteroids have an anti-inflammatory action which reduces swelling and thereby relieves pain. However, they have serious side-effects (see below) so should be stopped if there is no benefit. They must be used with caution in HIV as they may suppress the immune system which is already damaged. Only use them for patients with severe symptoms or those who already have very advanced disease. Use short courses (two to four weeks) and give antifungal treatment at the same time (see p40).

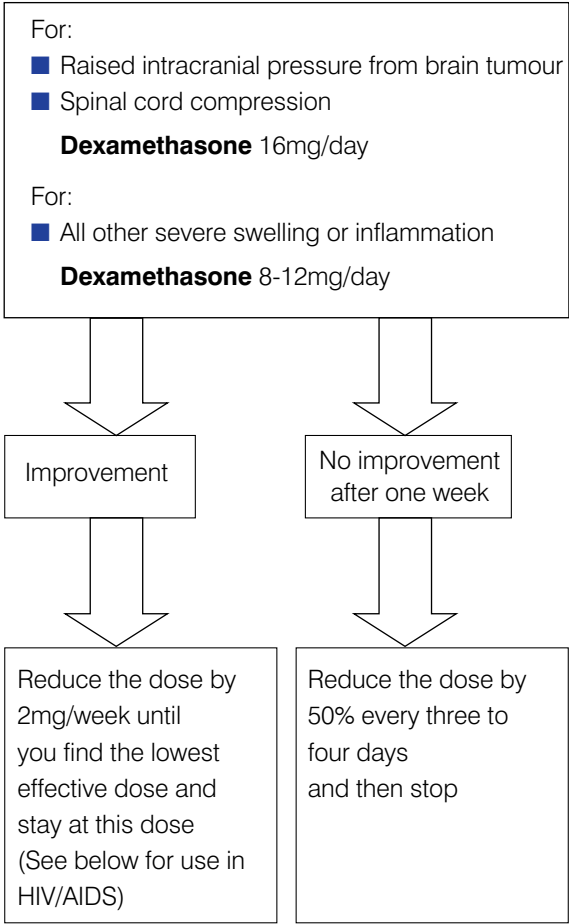
Side-effects of steroids

In the short term, most patients tolerate steroids well although a few patients may become agitated, in which case the steroids should be stopped and **haloperidol** or **chlorpromazine** prescribed (see p36).

Steroids may have significant side-effects over the long term, so always use the lowest effective dose. Side-effects include:

- Suppression of the immune system
- Swelling of face and ankles
- Thinning of the skin and bruising
- Weakness of the muscles at the top of the arms and legs
- Raised blood sugar (in diabetics monitor blood sugar as their treatment may need to be increased).

Patients who have been on high dose corticosteroids for more than one week should not stop them suddenly because this may cause low blood pressure and changes in blood chemistry (adrenocortical suppression).



2. Nerve damage pain (neuropathic pain)

Damage to nerves can cause pain that is greater than you would expect for the extent of injury. It is difficult to treat with opioids and NSAIDs alone.

This is known as neuropathic pain, eg:

- Nerve compression by cancer
- Viral damage to nerves: Herpes Zoster (shingles) or HIV
- Nerve damage from drugs (some ARVs or TB drugs)
- Severe diabetes causing neuropathy of hands and feet.

Neuropathic pain can be difficult to recognise, but the following features may suggest that there is nerve damage:

- The patient describes the pain as unusual in some way, eg burning, shooting, electric shocks or other strange sensations.
- There is an area of skin near the site of the pain which is either numb or very sensitive so that even light touch or clothes may be painful.

Nerve damage pain may be helped by the following adjuvants:

#### *Tricyclic antidepressants*

These are used in lower doses than for depression. Warn the patient that it may be three to four days before they begin to work. The most commonly used is **amitriptyline** 12.5-25mg at night (can be increased to 50-75mg if tolerated).

#### *Anticonvulsants*

These are drugs usually used in epilepsy. The dose should be started low and gradually increased if necessary over a few weeks until the pain improves. Examples include:

- **Valproate** 200mg b.d. (increase to 600mg b.d. if necessary)
- **Gabapentin** 300mg t.d.s. (increase to 900mg t.d.s. if necessary)

■ **Carbamazepine** 100mg b.d. (increase to 400mg b.d. if necessary)

■ **Phenytoin** 100mg b.d. (increase to 200mg b.d. if necessary).

Note: **carbamazepine** and **phenytoin** interact with some ARVs.

#### *High dose corticosteroids*

These may help if there is severe swelling or inflammation around nerves (see above).

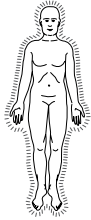
### **3. Muscle spasm**

Painful muscle spasm can occur in neurological disease and in bed-ridden patients.

Benzodiazepines may help, eg **diazepam** 5-20mg at night. If available, **baclofen** 5-20mg t.d.s. may help in severe spasm.

### **4. Abdominal cramp and colic**

This may be helped by anticholinergic drugs, eg **hyoscine butylbromide (buscopan)** 20mg q.d.s. Make sure the patient is not constipated (see p46) as hyoscine will make this worse.



## Fever

Fever is commonly caused by viral infections, malaria and many of the opportunistic infections associated with HIV. It is important to look for and treat infections.

Cancers, particularly lymphomas, may also cause fever as may HIV itself.

### Treat

- Malaria
- TB
- Chest infection
- Urinary tract infection
- Gastroenteritis
- Meningitis
- Septicaemia
- Abscess
- If specific infections cannot be identified consider 'blind' treatment:
  - For malaria (follow local guidelines)
  - With a broad spectrum antibiotic combination such as **chloramphenicol** or **ciprofloxacin** with a **penicillin**
  - For TB – refer to your local TB clinic.

### Care

- Look for abscesses/areas of skin infection.
- Ask about:
  - Confusion (see p36)
  - Seizures (see p35)
  - Vomiting (see p41).
- Check for dehydration.
- Encourage high fluid intake (at least six to eight cups a day if possible).
- Sponge/wash the patient with lukewarm water.
- Open windows to allow air to circulate – use a fan if available or fan the patient with a book or newspaper.
- Encourage wearing light clothes only.

### Prescribe

To reduce fever prescribe:

- **Paracetamol** 1g q.d.s. or
- **Ibuprofen** 200-400mg t.d.s. or
- **Aspirin** 300-600mg q.d.s. (avoid in children).



## Rashes and itching

Rashes and skin problems are common in people with HIV disease and can cause pain, itching and embarrassment. Some are due to opportunistic infections, others are part of the HIV infection itself such as dry skin and papular pruritic eruptions ('itchy bump disease'). It is sometimes difficult to make a diagnosis and you may need to try different treatments until you find one that is effective.

Itch can be a symptom of various conditions with or without a rash, eg liver disease, renal failure, and certain cancers. It can cause sleep disturbance.

### ■ Treat

- Scabies – **benzyl benzoate paint** applied all over on two consecutive nights; use clean clothes and sheets after this. This may need to be repeated after a week.
- Fungal skin infections – topical antifungal, eg **Whitfield's ointment**, **miconazole** or **clotrimazole cream** for simple ringworm. Treat multiple lesions for three weeks with oral **griseofulvin** 500mg o.d. or **ketoconazole** 200mg o.d. Treat nail or scalp infections orally for three to six months.
- Bacterial skin infections – **GV paint**, oral antibiotics if widespread.
- Shingles (Herpes Zoster) with **aciclovir** 200mg x five/day for five days if available; must be started within 72 hours of rash appearing to be effective.
- Drug reactions – rash and itching usually related to starting a new drug. Stop the drug and give antihistamines, eg **chlorpheniramine** 4mg t.d.s. Severe reactions may require steroids. Seek advice first in the case of TB drugs or ARVs as the reaction may stop after a few days, and it is important not to interrupt these treatments unnecessarily.

### Care

- For dry skin apply a moisturiser or petroleum jelly (Vaseline).
- Avoid too much washing with soap; use a moisturiser such as aqueous cream instead, or add one tablespoon of vegetable oil to five litres of water when washing.
- Washing with sodium bicarbonate solution (one tablespoon in a bowl of water) can be effective for generalised itch.
- Use warm rather than hot water when washing.
- Try a cold fan on the affected skin.
- Itching may be helped by calamine lotion.
- If the patient is scratching, keep fingernails short and smooth.
- Sunlight can help some skin conditions and worsen others.

### Prescribe

#### Topical creams:

- **Aqueous cream** or **UEA with menthol** 1% applied may help relieve itch.
- Steroid creams, eg **hydrocortisone** 1% may help areas of inflammation.
- **GV paint** can be applied to blisters from shingles or molluscum contagiosum that have burst to prevent infection.
- For multiple areas of skin infection, rinse with **chlorhexidine** 0.5% solution after bathing.

#### Drugs:

- **Antihistamines** – help with drug reactions and with itch caused by inflammation. They are also a sedative and will help with sleep, eg:
  - **Chlorpheniramine** 4mg t.d.s.
  - **Promethazine** 10-25mg at night
  - **Hydroxyzine** 25-50mg at night.
- Steroids should be prescribed for severe drug reactions, eg **prednisolone** 30mg o.d. for five days (60mg if severe).



## Wounds

### Treat

- Bacterial skin infections (see p33)
- Fungal skin infections (see p33)
- Abscesses (drain with needle or scalpel blade)

### Care

Patients who are in bed much of the time are at risk of developing pressure sores. These can be prevented by:

- Encouraging patients to mobilise or sit up if they are able
- Changing a bed-bound patient's position every two hours
- Using a foam mattress if possible
- Using pillows to help positioning keep a pillow between the legs if a patient is lying on their side
- Lifting the patient up the bed – do not drag as this can break the skin
- Keeping bedding clean and dry; use soft material if possible
- Keeping the skin in good condition over pressure areas (back, sacrum, buttocks, shoulders, elbows and heels). Rub in petroleum jelly or zinc oxide cream to these areas and massage to improve the circulation
- Encouraging a high protein diet if possible.

### If wounds occur:

- Record the position and size of wounds on a body map (see Tool 1). Assess whether they are improving or getting worse.
- Bathe wounds daily with salt water. If there are perineal wounds, these may be helped by sitting in a bowl of salt water.
- Apply clean dressings daily. These can be made from local materials.

- Fresh pawpaw (papaya) may be helpful as a dressing if the wound has a lot of dead tissue. Unripe pawpaw grated and mixed with a wound gel is more effective but should be stopped if it causes bleeding.
- Very smelly wounds may be helped by applying honey or sugar before covering with a dressing and leaving for two to three days (watch out for ants).
- If there are maggots in a wound:
  - Soak a pad or cloth in turpentine oil and hold it close to, but not touching, the wound
  - Remove the maggots by hand as they come to the surface of the wound.
- Manage pain with regular analgesics (see p26).

### Prescribe

- For smelly and offensive wounds, **metronidazole** tablets may be ground into a powder and sprinkled directly onto the wound daily underneath the dressing.
- **GV paint** can be useful for drying up small wounds.
- Genital ulcers can be treated with **GV paint** or **Uganda miracle paint**. This is made by mixing:
  - The contents of one opened capsule of **aciclovir** (200mg)
  - 5ml of **nystatin** suspension (500,000 units)
  - **Metronidazole**: two 200mg tablets crushed.
- To help reduce bleeding from wounds, **tranexamic acid** 500mg tablets or **sucralfate** 1g tablets may be ground into a powder and sprinkled directly onto the wound daily underneath the dressing.
- Bleeding from any site may be helped by **tranexamic acid** PO 500mg – 1g t.d.s.



# Seizures

Seizures (fits, convulsions) can happen in many ways. The most common pattern is rhythmic jerking, but there may be stiffening of the body, single twitches or episodes of unresponsiveness.

## Treat

- Fever (a common cause of fits in children)
- Malaria
- Meningitis
- Raised intra-cranial pressure (see p30)
- Epilepsy
- Low blood sugar
- Sudden withdrawal of drugs such as benzodiazepines or anticonvulsants
- Alcohol withdrawal

## Care

- During the seizure:
  - Protect the airway of the patient so they can breathe (loosen clothing, lie on side)
  - Prevent the patient from injuring themselves on sharp objects or fires.
- After the seizure:
  - Put the patient in the recovery position
  - Stay with the patient and observe them until they are conscious.
- Observe how long seizures are lasting and how frequently they are occurring.
- Educate the patient and carers about the causes of seizures.
- Address any concerns the patient and carers may have about the spiritual significance of seizures.

## Prescribe

- To stop seizures if they are lasting more than five minutes:
  - **Diazepam** 10mg PR or IM, repeated if necessary after 10 minutes
  - **Midazolam** 5mg SC if available, or given buccally (inside the cheek)
  - **Paraldehyde** 5-10mls diluted in normal saline as rectal enema
  - **Phenobarbital** 200mg IM for seizures not responding to **diazepam**.
- To stop or reduce frequency of seizures:
  - Follow local guidelines for treatment of epilepsy and use the anticonvulsant drugs that are available
  - Be aware that anticonvulsants often interact with other drugs. If the patient is on ART, then **valproate** (valproic acid) is the anticonvulsant of choice.



## Confusion

Confusion is very common in severe illness and there are many potential causes. *Delirium* is confusion that comes over a short period of time, often from a reversible cause such as an infection or a new drug. The confusion may improve after a few days once the cause is removed. *Dementia* is chronic, ongoing confusion which comes from a cause that is not easily reversible such as senile dementia or HIV infection of the brain (can be improved with ARVs if available).

If a patient suddenly becomes confused, always think:

- Have any new drugs been started? Could these be the cause?
- Is there an infection that could be treated?

### Treat

- Infections (see Fever p32) especially:
  - Malaria
  - Meningitis
- Urinary retention
- Dehydration
- Low blood sugar
- Constipation (may cause confusion in the elderly)
- Renal failure – if treatment is available
- Liver failure – if treatment is available
- Stop new drugs that may be the cause of confusion

### Care

- Try to be as calm and reassuring as possible with the patient.
- A close relative or friend should stay with the patient.
- Minimise the number of people (particularly strangers) dealing with the patient.
- Avoid physical restraint unless it is absolutely necessary for the patient's safety (it will usually make them more agitated).
- Keep the patient in familiar surroundings as much as possible.
- Keep reminding the patient where they are, what time it is and who is with them.
- Check for dehydration and give oral rehydration solution (ORS) if necessary.
- Manage fever (see p32).

### Prescribe

In many cases of confusion the measures above will be enough. If the patient is very agitated or aggressive, the following medication can help:

- **Haloperidol** 1.5-5 mg up to t.d.s. until they are settled
- **Chlorpromazine** 25-50 mg up to t.d.s. until they are settled
- Add **diazepam** 5-10mg at night if necessary but do not use this without **haloperidol** or **chlorpromazine** or confusion may become worse
- In severe cases that do not respond to these drugs, consider **phenobarbital** 200mg SC q.d.s.



## Anxiety and sleeplessness

Serious illness frequently causes anxiety because of distressing symptoms and fears about the future. Sleeplessness may result from physical problems such as pain or from anxiety or depression.

### Treat

- Is the patient in pain? (see p26) for management of pain)
- Urinary problems (see pp47-48)
- Depression (see below)

### Care

- Encourage the patient to talk about their worries or concerns (see Chapter 4):
  - Do they have questions or fears about their illness?
  - Are there difficult relationships in the family?
  - Are there worries about food or finances?
  - Are there any anxieties related to their religion or spiritual beliefs?
- You may not have answers to all their worries but listening and supporting them will help.

- Respect the patient and family's confidentiality.
- Address any misunderstandings they have about the illness.
- Teach them to slow and control their breathing (see p44).
- Is it appropriate to pray with the patient or to ask someone from their faith group to visit?
- Would it be useful for you or another member of the team to visit again?

**Prescribe** (Only if the anxiety does not resolve with a counselling approach)

- **Diazepam** 2.5-10mg at night – acts for 24 hours in some patients and may cause sleepiness during the day. (Try not to use for more than a week unless the patient is terminally ill.)
- **Temazepam** 10-20mg at night – acts for eight hours and is useful for sleeplessness. (Try not to use for more than a week unless the patient is terminally ill.)
- **Trazadone** 25-50mg at night – sedative and mild antidepressant which may help with sleep and anxiety.



## Depression

Some sadness and depression are almost always to be expected in advanced, incurable illness. Depression may become a 'depressive illness' which may benefit from treatment with antidepressant drugs. Diagnosis of depressive illness is difficult in palliative care. Symptoms such as loss of appetite, weight loss, loss of energy, loss of sex drive and sleeplessness may be caused by the illness itself.

The following symptoms can be useful in diagnosing depressive illness when someone has incurable disease:

- Low mood more than 50% of each day
- Loss of any enjoyment or interest
- Excessive or inappropriate guilt
- Thoughts of suicide.

### Treat

- Anxiety (see above) as this is often a major part of depression.
- Pain (see p26) – Unrelieved chronic pain is a major cause of depression in patients who have incurable illness.

### Care (see care for anxiety p37)

- Make sure that the patient is not uncomfortable or in pain.
- Ask about any other physical symptoms that may be troubling the patient.
- If the patient is overwhelmed by depression or anxiety:
  - Encourage them to identify small steps they can take to deal with some of their problems and to plan things that they may enjoy
  - Some patients benefit from setting aside a certain time each day to discuss their worries so that they are not thinking about them all the time.
- If the patient has a religious faith, visits from their faith group may help.

- If the patient has thoughts of suicide:
  - Don't be afraid to ask about this – you will not make it worse, eg "Have you ever felt so low that you have thought of harming yourself?"
  - "Have you ever wished that you were no longer alive?"
  - They may feel safer if someone is with them all the time
  - You may need to agree with them that someone else supervises their tablets
  - Encourage carers to seek help quickly if they are worried.

**Prescribe** (only for depressive illness not responsive to a counselling approach)

- **Amitriptyline** - starting at 25mg at night and increasing gradually to 75-150mg. Main side-effects: drowsiness, dry mouth, constipation.
- **Imipramine** and **dosulepin** (dothiepin) are alternatives that may be less sedating.
- Warn the patient and carers that it may take two weeks before the antidepressants begin to work.



## Poor appetite and weight loss

### Treat

- HIV with ARVs if they are available (follow national guidelines)
- Oral and oesophageal candidiasis (see p40)
- Diarrhoea (see p45)
- TB (follow national guidelines)
- Nausea and vomiting (see p41)
- Constipation (see p46)
- Depression (see p38)
- Malnutrition

### Care

- Give small, frequent meals.
- If the patient has very advanced cancer or HIV disease, their body will not be able to make good use of food:
  - Explain to the family that eating less is a normal part of their illness and forcing them to eat will not make them live longer or feel better.
  - Worrying about how little they eat makes mealtimes tense and unhappy. In this situation just give the patient the amount and type of food that they enjoy.
- Give high calorie, high protein food if available, eg milk or yoghurt.
- Encourage mobility and gentle exercise to maintain muscle strength as much as they are able, but do not let them exhaust themselves.
- Pay careful attention to skin care and pressure areas. With weight loss the skin becomes easier to damage (see p34).

### Prescribe

- If the patient becomes full very quickly on eating you can try **metoclopramide** 10-20mg half an hour before meals up to three times a day. This may help the stomach to empty more quickly. Stop if it has no benefit.
- Steroids may help improve appetite for some weeks. They cause troublesome side-effects over the long term (see p30) and for this reason are best saved until the patient has a life expectancy of a few months or less.
- To help appetite prescribe:
  - **Dexamethasone** 2-4mg in the morning
  - **Prednisolone** 15-30mg in the morning.
 If effective after a one week trial, reduce to the lowest effective dose. Stop if there is no benefit.



## Sore mouth and difficulty swallowing

Infection and ulceration of the mouth are common and very distressing for patients with advanced cancer or HIV. Candidiasis (thrush) does not always give white coating to the tongue or palate and the only sign may be areas of soreness or disturbed taste. If swallowing is painful, the patient may have oesophageal candidiasis even if there is no sign of it in the mouth. Many problems with the mouth may be prevented by good mouth care, keeping the mouth moist and treating infections quickly.

### Treat

- Oral candidiasis:
  - **GV paint** applied to the areas of candidiasis t.d.s.
  - **Nystatin** oral drops 1-2ml q.d.s. after food
  - **Clotrimazole** and **nystatin** pessaries are effective if sucked as lozenges daily for five days
  - **Fluconazole** 50mg o.d. for five days or 200mg PO o.d. for three days
- Oesophageal or recurrent oral candidiasis:
  - **Fluconazole** 200mg PO o.d. for two weeks
  - **Ketoconazole** 200mg PO b.d. for two weeks
- Infection (penicillin plus **metronidazole**)
- Herpes simplex (**aciclovir** 200mg PO five times a day if available)

### Care

- Check the mouth, teeth, gums, tongue and palate on a regular basis for dryness, inflammation, candidiasis, ulcers, and infection of teeth and gums.
- Brush teeth with a chew stick or soft toothbrush after eating and at night. Use with toothpaste if available or with a mouthwash as below (avoid brushing if it is very painful).

- Use a mouthwash after eating and at night, eg:
  - One pinch of salt or sodium bicarbonate in a cup of boiled water (cooled)
  - One teaspoon of vinegar or lemon juice in one litre of boiled water (cooled).
- For a dry mouth:
  - Moisten the mouth with regular sips of cold water (or ice if available)
  - Suck pieces of fruit, eg pineapple, passion fruit, lemon, etc
  - Use petroleum jelly on the lips.
- Nasogastric tubes – Some patients with head and neck cancer can be given liquidised food via a nasogastric tube. This should be inserted by someone with appropriate training and should be regularly flushed with salt and water to prevent blockage.

### Prescribe

- Manage pain according to the analgesic ladder (see p27).
- **Soluble aspirin** 600mg q.d.s. for a painful mouth. Dissolve in water – rinse around mouth, gargle and swallow.
- **GV paint** is useful for all kinds of sores as it has antibiotic, antiviral and antifungal action. Apply t.d.s.
- **Metronidazole mouthwash** for smelly mouth from oral cancer: mix a crushed tablet or liquid for injection with fruit juice and rinse round mouth.
- **Uganda miracle paint** can be used on oral sores (see p34).
- **Prednisolone** half tablet may be placed against aphthous ulcers (mouth ulcers) to give relief, or crushed into powder and sprinkled on the ulcers.
- Where other measures have not helped, high-dose steroids can be used for severe oral or oesophageal inflammation that prevents swallowing: **dexamethasone** 8-12mg o.d. PO for a week. Always prescribe with an antifungal because steroids can worsen fungal infections (see above for doses).



# Nausea and vomiting

## Treat

- Oral or oesophageal candidiasis (see p40)
- Constipation (see p46)
- Infections: malaria, gastroenteritis, urinary tract infection, etc (see p32)
- Raised intracranial pressure with steroids (see p30)
- Indigestion/heartburn (see p42)

## Care

- Review new medication that may have caused the vomiting.
- Encourage fluids – small frequent sips are better absorbed.
- If the patient is dehydrated, give fluid as ORS if available. Alternatives are tender coconut water or rice water.

- Cold drinks and cold food are often best.
- Encourage caregivers to prepare small, appetising meals and to avoid fatty food.
- Prepare food away from the patient.
- Ginger chewed or boiled as a drink may help.

## Prescribe

Nausea and vomiting can arise from many different causes. The pattern of symptoms depends on the cause and different causes respond better to particular drugs. (See table below). If you do not have a large range of drugs, then simply use whatever you have available.

If the vomiting is severe or frequent then tablets will not be absorbed and injectable antiemetic drugs should be used if available until the vomiting is controlled (see p50).

Pattern of nausea and vomiting	Causes	Suggested drugs
<b>Poor stomach emptying</b> <ul style="list-style-type: none"><li>• Vomiting is the main symptom</li><li>• Vomiting often relieves nausea</li><li>• Patient feels full quickly when eating</li><li>• May have gastro-oesophageal reflux</li></ul>	<ul style="list-style-type: none"><li>• Opioids</li><li>• Constipation</li><li>• Stomach and bowel conditions</li></ul>	<ul style="list-style-type: none"><li>• <b>Metoclopramide</b> or 10-20mg t.d.s. before meals</li><li>• <b>Domperidone</b> 20-30mg b.d.</li></ul>
<b>Blood chemistry disturbance/toxins</b> <ul style="list-style-type: none"><li>• Nausea is the main symptom</li><li>• Vomiting often does not relieve nausea</li></ul>	<ul style="list-style-type: none"><li>• Drugs</li><li>• Renal failure</li><li>• Hypercalcaemia</li></ul>	<ul style="list-style-type: none"><li>• <b>Haloperidol</b> 1-5mg at night or</li><li>• <b>Prochlorperazine</b> 5-10mg t.d.s.</li></ul>
<b>Inflammation or swelling in the head #</b> <ul style="list-style-type: none"><li>• May be worse on movement</li><li>• Vomiting often does not relieve nausea</li><li>• May be worse in the morning</li></ul>	<ul style="list-style-type: none"><li>• Ear infections</li><li>• Brain tumours</li><li>• Meningitis</li><li>• Malaria</li></ul>	<ul style="list-style-type: none"><li>• <b>Cyclizine</b> 25-50mg t.d.s. or</li><li>• <b>Promethazine</b> 25mg t.d.s. or</li><li>• <b>Prochlorperazine</b> 5-10mg t.d.s</li></ul>
<b>Vomiting with diarrhoea</b> (exclude 'overflow diarrhoea' (see p46))	<ul style="list-style-type: none"><li>• Infectious diarrhoea</li></ul>	<ul style="list-style-type: none"><li>• <b>Cyclizine</b> 25-50mg t.d.s. or</li><li>• <b>Promethazine</b> 25mg t.d.s</li></ul>
<b>Partial bowel obstruction *</b> <ul style="list-style-type: none"><li>• Large volume vomiting</li><li>• The patient is still passing occasional flatus and faeces</li></ul>	<ul style="list-style-type: none"><li>• Constipation</li><li>• Abdominal and pelvic tumour</li></ul>	<ul style="list-style-type: none"><li>• <b>Metoclopramide</b> 20mg SC q.d.s. Stop if they develop increasing abdominal pain and prescribe as for complete bowel obstruction</li></ul>
<b>Complete bowel obstruction *</b> <ul style="list-style-type: none"><li>• Large volume vomiting</li><li>• The patient is not passing any flatus or faeces and they are not strong enough for surgery</li></ul>	<ul style="list-style-type: none"><li>• Abdominal and pelvic tumour</li></ul>	<ul style="list-style-type: none"><li>• <b>Promethazine</b> 25mg SC t.d.s. or</li><li>• <b>Cyclizine</b> SC 50mg t.d.s. or</li><li>• <b>Chlorpromazine</b> SC 10 -25mg t.d.s.</li><li>• <b>Hyoscine butylbromide</b> SC 20-40mg q.d.s. will reduce vomiting and pain</li></ul>

# Vomiting due to brain tumours may be helped by steroids (see p30).

\* If surgical facilities are available and the patient is strong enough, surgical help should be sought.

If nausea and vomiting is difficult to control try:  
1/ **Cyclizine** or **promethazine** plus **haloperidol**  
2/ **Chlorpromazine** 10-25mg t.d.s.



## Indigestion/ gastro-oesophageal reflux

This is common when there is pressure on the diaphragm from an abdominal tumour or ascites, and in neurological disease.

### Treat

- Consider stopping NSAIDs or aspirin if these could be the cause.

### Care

- Nurse the patient in a sitting position.
- Give drugs after food.
- Try giving milk.

### Prescribe

- Antacid, eg **magnesium trisilicate** suspension 10ml t.d.s.
- If persistent: **cimetidine** 200mg b.d. or **ranitidine** 300mg b.d. or **omeprazole** 20-40mg o.d.



## Hiccups

These can be distressing and exhausting for the patient if they are frequent or do not resolve quickly. They are usually caused by distension (stretching) of the stomach but may also result from anything pressing on the diaphragm or from renal failure.

### Treat

- Constipation (see p46)
- Urinary retention (see p48)

### Care

- To stop hiccups get the patient to:
  - Swallow dry bread or crushed ice or
  - Breathe from a paper bag or
  - Quickly swallow two large teaspoons of sugar.
- Try nursing the patient sitting up.

### Prescribe

If the hiccups do not go away prescribe:

- **Metoclopramide** 10-20mg t.d.s. or
- **Haloperidol** 3mg at night or
- **Chlorpromazine** 25-50mg at night
- **Baclofen** 5-10mg t.d.s. (may help hiccups not responding to the above).



## Cough

### Treat

- Chest infection
- TB
- Asthma
- COPD (chronic obstructive pulmonary disease)
- Oral and oesophageal candidiasis (see p40)
- Sinusitis
- Indigestion/reflux (see p42)

### Care

- For patients on TB treatment, make sure that they are taking their tablets regularly and attending clinic for follow up.
- Avoid smoke from cooking fires or cigarettes near the patient.
- Help the patient to cough up sputum by sitting them up.
- Instruct patients to cough in a direction away from caregivers and into a container which can be covered.
- If sputum is thick and difficult to cough up try:
  - Steam inhalation – the patient sits with their head over a pan of boiling water and breathes deeply

- Clapping on the patients back with 'cupped' hands in each position
- Postural drainage: the patient is moved into different positions to help drain sputum from different parts of the lung.
- For dry cough, warm drinks made with honey, cinnamon and ginger may be helpful.

### Prescribe

- Dry cough that does not go away can be helped by:
  - **Codeine** 30mg q.d.s.
  - **Morphine** 2.5-5mg every four hours.
- Large amounts of thin sputum may be helped by anticholinergic drugs, eg:
  - **Amitriptyline** 10-50mg at night
  - **Propantheline** 15mg t.d.s.
  - **Hyoscine butylbromide** 20mg q.d.s.
  - **Atropine** 1mg t.d.s.

(Do not use these drugs if the sputum is very thick as it will make the sputum harder to cough up.)



## Breathlessness

Difficulty in breathing is a frightening symptom with advanced illness and almost always causes anxiety for the patient and their family. The anxiety needs to be managed as well as the breathlessness.

### Treat

- Chest infection: TB, bacterial pneumonia or PCP (pneumocystis)
- Anaemia
- Asthma
- Heart failure
- Pleural effusion
- Cough (see p43)

### Care

- Find the most comfortable position for the patient (usually sitting up).
- Open windows to allow air to circulate, and use a fan if available or fan the patient with a book or newspaper.
- Teach the patient to move slowly and carefully to avoid increasing the breathlessness.
- If the patient is very anxious or panics:
  - Explain that their breathing will improve if they slow it down. Show them how to slow their breathing by pursing their lips as if they were going to whistle when they breathe out

- Teach the patient to breathe with their diaphragm rather than the top of the chest by putting one hand on their chest and one on the top of their abdomen so they can feel where they are breathing from. The hand on the abdomen should move more if they are breathing with their diaphragm.
- Manage anxiety (see p37).

### Prescribe

When the cause of the shortness of breath cannot be improved, the symptom may be helped by:

- **Morphine** 2.5-5mg every four hours
- **Diazepam** 2.5-5mg up to t.d.s. (especially if there is anxiety and panic). If a patient is dying with shortness of breath, they may need larger doses.

If the shortness of breath is due to a swelling obstructing the respiratory tract, medium-dose steroids may help:

- Dexamethasone 8-12mg o.d. (see p30).



## Diarrhoea

Acute episodes of diarrhoea do not usually need treatment except fluid replacement, though diarrhoea with blood (dysentery) or high fever may need antibiotics, eg **ciprofloxacin** or **cotrimoxazole** (follow local guidelines).

Persistent diarrhoea, lasting more than two weeks, is distressing and exhausting and should be controlled if possible. If stool microscopy and culture is possible, it may help to determine the cause.

### Treat

- Dehydration with ORS (Severe dehydration may require IV fluids)
- Constipation (can sometimes cause overflow diarrhoea). Do a rectal examination if there is any history of previous constipation to see if there is impacted stool in the rectum.
- Review drugs (eg some ARVs and antibiotics can cause diarrhoea)
- If antibiotics have not been tried, a systematic trial of a week of **cotrimoxazole**, a week of high dose **metronidazole** and finally two weeks of **albendazole** should eliminate treatable HIV-related gut infections, but symptomatic treatment is often necessary as well.

### Care

- Give plenty of drinks and use ORS if diarrhoea is frequent or in large volume. Alternatives are tender coconut water or rice water.
- Encourage the patient to take sips of fluid very frequently rather than a large drink all at once.
- Encourage the patient to continue eating if hungry.

- Suggest that the patient eats small amounts frequently rather than large meals.
- Rice, bread or potatoes are good for diarrhoea.
- Bananas and tomatoes are good for replacing potassium.
- Yoghurt is better tolerated than milk and cheese.
- Encourage good hygiene, eg hand washing, using latrine if possible, changing soiled linen.
- Protect the skin around the anus with petroleum jelly.
- A 'commode' can be made by cutting a hole in a chair and putting a bucket underneath.

### Prescribe

- If the diarrhoea becomes chronic and is not helped by the above measures, drugs can be used to stop it. They should not be used if there is fever or blood in the stool (suggesting an infection needing antibiotics) and should be avoided in children under the age of one. Drugs to try include:
- **Loperamide** 2mg t.d.s. and after each loose stool, up to 16mg/day
- **Codeine** 10mg t.d.s. (up to 30mg four hourly)
- **Oral morphine** 2.5-5mg every four hours (if severe).



## Constipation

If possible, the patient should be examined to see why they are not passing stool. A rectal examination will show whether there is a mass obstructing the stool, or hard stool which cannot be passed. If the rectum is empty, the problem is higher up. When patients are coming to the terminal stage, they often pass very little stool due to small oral intake. This does not need treatment.

### Treat

- Prevent constipation by always prescribing a laxative when giving opioids (eg **morphine** or **codeine**).
- Review drugs which can cause constipation (tricyclic antidepressants, eg **amitriptyline**, and anticholinergics, eg **hyoscine**).
- Dehydration

### Care

- Encourage plenty of drinks.
- Encourage fruit and vegetables in diet.
- Give a tablespoon of vegetable oil before breakfast.
- If available, dried paw-paw seeds can be chewed (five to 30 seeds at night) or crushed and mixed with water to drink.
- If there is hard stool which is painful to pass, putting petroleum jelly inside the anus may help, or inserting a small piece of soap (moistened and smoothed into a pellet).
- If the rectum is full of hard stool, a 'soap enema' can help. Gently push a urinary catheter into the rectum and then pour soapy water in through a funnel.

- Manual evacuation (removing the stool by hand) may be necessary, sometimes on a regular basis. This is done as follows:
  - Explain to the patient what you are going to do. If possible, give some oral analgesia or **diazepam** 5-10mg 30 minutes before you begin
  - Prepare newspaper or equivalent to receive the stool once removed
  - Put on gloves and apply petroleum jelly to the first finger
  - Stroke the outside of the anus to relax the sphincter then gently insert the finger, stopping if spasm occurs, giving time for muscles to relax
  - Remove small pieces of stool piece by piece. Break up large pieces with finger before removal
  - Talk to the patient throughout the procedure, asking them to take deep breaths to help them relax. If discomfort is too much, finish and continue another day.

### Prescribe

- **Bisacodyl** 5mg at night, increasing to 15mg if needed.
- **Senna** one to two tablets at night, increasing if necessary.
- **Glycerol** or **bisacodyl suppositories** can be helpful if available.



# Vaginal discharge

Vaginal discharge is a common symptom of cancer of the cervix. It is usually smelly and causes embarrassment, distress and stigma, but it can be effectively managed.

## Treat

- Sexually transmitted disease (follow local guidelines)
- Vulvo-vaginal candida (thrush) with antifungal pessaries, eg **clotrimazole**, **miconazole** or single oral dose of **fluconazole** 150mg

## Care

- Sit in basin of water with a pinch of salt twice daily.
- Use cotton pads made from old clothes.
- Plastic pants with elastic can be made locally.
- Make sure soiled pads and linen are washed and changed regularly.
- Discourage putting foreign bodies in the vagina.

## Prescribe

- **Metronidazole tablet** (200mg) can be inserted daily as a pessary into the vagina or crushed and the powder applied.



# Urinary incontinence

## Treat

- UTI
- Retention with overflow (see below)
- Spinal cord compression (see p30)

## Care

- Plastic bottle over the penis for men and boys.
- Cotton pads for women (make from old clothes) with plastic pants if available.

- Change and wash pads and bed linen regularly, aiming to keep patient dry.
- Protect skin with petroleum jelly.
- Encourage fluids – sometimes patients stop drinking for fear of incontinence, but dehydration will not help their overall condition.

## Prescribe

- Consider a catheter if available.



## Urinary retention

### Treat

- Faecal impaction due to constipation (see p46)
- Urinary tract infection
- Drug – induced (tricyclic antidepressants, eg **amitriptyline**, **opiates** – temporary effect)
- Spinal cord compression (see p49)

### Care

- Catheterisation will relieve the retention. If an underlying cause is treated (see above), the problem may resolve once the urine has drained away and the catheter can be removed.

- Sometimes a catheter may be needed long term. It can become blocked (eg by blood clots from bladder cancer). Washing out the bladder with a 50ml syringe and boiled water with salt can clear this. Teach the patient to do a bladder wash-out every two weeks. Change the catheter every four weeks if possible.

### Prescribe

- Pain relief using the analgesic ladder (see p27).
- **Loperamide** 2mg t.d.s and after each loose stool, up to 16mg/day
- **Codeine** 10mg t.d.s (up to 30mg four hourly)
- **Oral morphine** 2.5-5mg every four hours (if severe).



## Bladder spasms

Sudden, severe pain can be felt in the bladder and urethra especially in patients with bladder or prostate cancer, but also following catheterisation or infection.

### Treat

- UTI

### Care

- Encourage plenty of fluids.

### Prescribe

- Anticholinergic drugs, eg **amitriptyline** 25-50mg at night or **hyoscine butylbromide** 10-20mg q.d.s. or **propantheline** 15mg t.d.s.
- Analgesic ladder.



## Mobility problems

### Treat

- **Spinal cord compression (SCC)** – This occurs when a cancer mass presses on the spinal cord. The first sign is pain in the back at the level of the tumour, which may be felt as a band around the body and may also spread down the legs. Both legs may become weak and there may be a loss of sensation below the level of the tumour. It can also cause changes in bladder and bowel function, with either incontinence or retention.
- Suspicion of SCC must be treated as a palliative care emergency and high dose steroids should be given as soon as symptoms start. This helps to preserve function in the legs, either until treatment is available (eg radiotherapy) or to improve quality of life for a limited time: **dexamethasone** 16mg o.d. (see p30).

### Care

- If the patient cannot move in the bed, he/she is at risk of developing pressure sores (bedsores). Prevent these by good pressure area care (see p34).
- Limbs that are not used become stiff and develop contractures:
  - Encourage the patient to move as much as they are able, helping them to change position frequently
  - If the patient is immobile, do passive exercises at least twice a day. Keep the joints flexible by gently bending and straightening the wrists, elbows, shoulders, ankles, knees, hips and neck. Protect the joint by supporting the limb above and below while moving it
  - Massage limbs, back and neck if the patient finds this helpful.

### Prescribe

- Analgesia can help improve mobility.
- Adjuvants for muscle spasm (see p31).

# When medication cannot be given by mouth

In the following situations, patients may no longer be able to take tablets or liquid medications by mouth:

- Persistent vomiting
- Severe candidiasis of the mouth and oesophagus
- Cancers of the head, neck, oesophagus and stomach
- Decreased consciousness due to a brain tumour or meningitis
- The patient is dying.

## Alternative ways of giving medication

- Subcutaneous – This is the preferred route in palliative care. A 'butterfly' needle can be placed under the skin and taped into place for repeated injections. It is less painful than intramuscular injection and is much easier to use than the intravenous route. It is not effective where the skin is oedematous or inflamed and should not be used in these areas.
- Rectal – Some drugs are produced as suppositories to be given rectally but some tablets can be used this way if there is no other route available.
- Buccal – Some medications can be placed inside the mouth, between the cheek and the teeth, to be absorbed by the lining of the mouth (without swallowing it).
- Intramuscular – This route is more painful for the patient than the subcutaneous route and an intramuscular needle cannot be left in place.
- Intravenous – This requires intravenous cannulation skills and is usually reserved for emergency medication in a clinic or hospital.
- Nasogastric – Some patients may be discharged from hospital with a nasogastric tube, which can be used to give drugs.

## Specific medications

### Morphine

If a patient has been taking morphine for pain, it is important to continue this if they can no longer swallow otherwise they may be in pain and may suffer symptoms of morphine withdrawal (see

p29) If available, injectable morphine should be given every four hours by the subcutaneous route.

**Morphine is twice as strong when given by injection compared to when it is given by mouth.** When changing from the oral to injectable route, the dose must be divided by two:

**Example:** changing regular oral NR morphine to regular SC morphine:

A patient is taking 10mg oral NR morphine every four hours:

The patient will need  $10/2 = 5\text{mg}$  of SC morphine every four hours.

**Example:** changing regular oral MR morphine to regular SC morphine:

A patient is taking 30mg oral MR morphine every 12 hours:

**Total daily dose** of oral morphine = 60mg

**Total daily dose** of SC morphine in 24 hours =  $60/2 = 30\text{mg}$

**The four hourly dose** of SC morphine is  $30/6 = 5\text{mg}$

The patient will need 5mg SC morphine every four hours.

If injectable morphine is not available:

- **Morphine solution** can be given 'buccally' by placing it inside the mouth against the cheek every four hours
- **Morphine NR** suppositories or tablets can be given rectally every four hours
- **Morphine MR** tablets can be given rectally every 12 hours.

## Other Drugs

- **Paracetamol** suppositories or tablets can be given rectally every six hours for pain or fever.
- **Diazepam** 5-10mg t.d.s. can be given rectally for seizures, agitation or restlessness (for other antiepileptic drugs see p35).
- Antiemetics: **metoclopramide**, **promethazine** and **haloperidol** come in injectable forms which can be given SC. **Domperidone** can be given PR.

# End of life care

When the patient is getting close to death, it is good to talk about this with the patient and their family if this can be done in a way that is culturally acceptable (see Chapter 4). This allows the patient to make plans for their funeral, to address spiritual issues, to say 'goodbye' and to have important conversations with their friends and family. It is not an easy subject to raise but patients and older members of the family are often already aware when death is near. Signs that death is approaching (the 'terminal phase'):

- The patient's condition is getting worse day by day or hour by hour
- Sleeping much of the time, may be confused, comatose
- Minimal oral intake – no hunger or thirst
- Reduced bowel and urine function, may be incontinent
- Breathing becomes irregular, sometimes noisy ('death rattle')
- Change in colour – skin becomes grey or purple, hands and feet cold.

## Treat

Once the patient is dying it is usually no longer appropriate or possible to treat infections and other specific conditions. The family may find this hard to accept. It may be best to counsel them against taking the patient to a clinic or hospital if:

- It is likely that they may die on the way
- The patient would wish to die at home and there is nothing that the clinic or hospital will be able to do to prolong their life.

## Care

- Encourage the family to be present, holding a hand or talking to the patient even if there is no visible response, and remembering that the patient may be able to hear even if they cannot respond.
- Explain that things like noisy breathing or incontinence can be distressing for the relatives but are not usually distressing for the patient.
- Advise the family not to try and feed the patient if they are no longer able to swallow as this may cause choking and distress.
- The patient can take sips of water as long as they are able, but giving intravenous fluid at this stage will not prolong life and will not prevent thirst – keeping the mouth moist is sufficient.
- Teach the family to:
  - Keep the patient clean and dry
  - Turn the patient every two hours to prevent pressure sores
  - Clean the mouth with moist cloth wrapped round a finger
  - Apply petroleum jelly to lips to prevent drying and cracking.



**Prescribe**

- Taking medication is a burden and it should be kept to a minimum at this stage.
- Only give medication that is going to help keep the patient comfortable.
- Medication for infections, heart or blood pressure problems can usually be stopped.
- Diabetic tablets should be stopped once the patient stops eating.
- Anticonvulsants should be kept going as long as the patient is able to swallow and then replaced by rectal diazepam (see p50).

Some medication can be continued even after the patient is no longer able to swallow it by mouth (see p50).

“In life, you try your best to hold tight to your dignity,  
in death sometimes others have to hold onto it for you.”

Bono

## You can help children and families

### Talking with children

*Children understand more than we think*

- Talk with the child rather than to them or about them
- Have important conversations when a parent is there
- Encourage the family to share information with the child. Say that you will not give information to the child without their permission, but that you will not lie

### Supporting children

- Even sick children need to play
- Continue at school where possible
- Involve children in family and community life
- Make space for spiritual support
- Understand different reactions to loss
- Give extra love and attention

### Supporting families

- Appreciate their hard work
- Avoid scolding and blame
- Involve them in decisions – they are partners in care
- Encourage them to share out the work of caring
- Don't forget to pay attention to siblings

### Assessing pain in children

- Listen to the child
- Listen to the carer
- Observe with your eyes for signs of pain

continued overleaf...

## Simple measures to help pain

- Care for children at home if possible
- Don't leave them alone
- Use touch – cuddling, carrying, rocking, massage, breastfeeding
- Feeding – never force-feed but often a snack will help
- Heat or cold – eg using a damp cloth
- Play with them – distraction is good medicine for children

## Drug treatment for pain

- By the clock
- By the mouth
- By the ladder

## Symptom control

- Treat what is treatable
- Care for the child
- Prescribe palliative drugs
- Physical examination is important
- Think about nutrition and hydration
- Encourage good hygiene

# Chapter 6: You can help children and families

## My neighbour's child is my child too

African proverb

Sick children are among the most vulnerable people in the world. They are often unable to state their needs and are totally dependent on their carers to help them. When those carers are busy, sick or absent, their needs may go unmet or even unnoticed. Often their opinions are disregarded or not even sought, but they usually understand far more about their situation than we realise.

While the principles of palliative care for children are the same as for adults – holistic, patient-centred care aiming at quality of life – they also have some special needs to consider.

- Children are not small adults – they have their own needs.
- Children are people – they have opinions to be heard and can make choices.
- Children usually know much more than we realise and are often more capable than we think.

### Talking with children

In many cultures children are supposed to be 'seen but not heard'. They are not expected to be part of important discussions about such things as sickness and death. It can be very hard to know how much to say to children of different ages about their own illness or about someone else in the family who is sick. We should remember that children often know much more than we think they do, because they can sense anxiety in others, they overhear conversations

and they see the effects of sickness in other families.

One example is talking about HIV. Children are sometimes taught about it at school, may hear about it on the radio and see health education posters in the clinic but it may not be spoken about when it is affecting them and their own families. Sometimes it may be right to gently challenge the belief that children should not be told things which will worry them.



- Hearing the truth can be a relief, it may not be as bad as their secret fears.
- Talking allows them to express their fears, sadness and to ask questions.
- Knowing the truth enables children to make choices.

## We cannot protect children from sadness but we can support them through it.

### Communicating

There is a lot of evidence to show that children and families cope better when there is openness rather than secrecy. We have to respect the views of parents or guardians when talking with their child, so we may need to spend time counselling families about the importance of honesty and speak up for the rights of the child.

Many communication skills are the same for children as for adults, but there are also some special considerations.

#### Communication skills for all

- Be respectful and polite. Address the child if they are old enough to understand, not just the parent.
- Talk with the child rather than to them or about them.
- Get down to their level – this may mean sitting next to them on the floor or kneeling beside a bed.
- Do not interrupt when they are speaking, be patient.
- Avoid using words they will not understand – this will vary according to the age of the child.
- Make sure they know it is all right to ask questions.
- Never force too much information on someone.
- Never lie as it destroys your relationship of trust.

#### Communication skills especially for children

- Generally, important conversations are best carried out when a parent or guardian is with the child, unless the child requests to be alone. Negotiate with parents/guardians about one-to-one conversations with the child.
- Direct eye contact may be too threatening. Children often find it easier to talk when they are playing or drawing.

- Tell the family that you will not give information to the child without their permission, but that you will not lie.

### Dealing with difficult questions

Just like adults, children may ask questions such as “Will I get better?” or “Is my mother going to die?” which we find difficult to answer, especially if we are not sure what their parents have said or are willing to say. Sometimes reflecting the question back can be helpful in finding out what they know and what they are most anxious about.

We might say:

- “I wonder what's made you ask that question?”
- “Have you asked your mother/father/grandmother about that? What did they say?”
- “We need to talk about that. Tell me what you think first, then I will tell you what I think”.

We want children to feel free to ask questions, even if we cannot answer them fully at the time: “That is an important question. I want to discuss it when I have talked with your mother”.

If the parents are unwilling for the child to be given information, we can counsel them that it is usually helpful for families to be open, but ultimately we have to pass the responsibility back to them: “That is an important question; have you talked to your parents about it?”.

### Emotional support for children

Even when they are sick, children need to play and learn. It is not only ‘distraction therapy’, it is part of their normal development. We may need to find new ways of playing that are not too physically demanding, such as drawing or music instead of running and skipping. They should continue at school as long as they are able. They need to be involved in family life and the life of their community; they may be too sick

to play football, but sitting outside watching and being a part of things is often better than lying inside alone.

Similarly, if they are a part of a faith community, they should be included and involved in its activities as much as possible. Even the very young can have a real faith which supports them and also very real questions which they need to explore.

### Bereavement in children

Children's understanding of death and dying changes as they grow older, and they react to loss in different ways at different ages. Younger children may regress and behave like babies or may become naughty. They may become very passive, or behave as if nothing has happened. Like adults, children may experience anger, guilt, depression or anxiety. They may have physical symptoms such as headaches or abdominal pain. Grief often lasts much longer in children than most adults recognise. Children will reprocess the bereavement at different developmental stages, when the meaning of the loss may change for them.

#### Supporting children

- Care for children at home if possible.
- Even sick children need to play.
- They should continue at school where possible.
- Involve children in family and community life.
- Make space for spiritual support.
- Understand different reactions to loss.
- Give extra love and attention.

### Emotional support for families

Looking after a sick child is very demanding, especially when you know that the child will not get better. It can be hard to care for an orphan when you are struggling to care for your own children. It is important that we appreciate and encourage families and treat them as partners with us in the care of the child.



It is hard for siblings when so much time, attention and scarce resources have to be devoted to their brother or sister, so we can encourage them by involving them in the care and appreciating their contribution. We must also allow them time to play with other friends.

#### Supporting families

- Appreciate their hard work and tell them how well they are doing.
- Avoid blaming them if care has not been good – understand their difficulties and look at ways of improving care from now on.
- Involve them in decisions – they are partners in care.
- Encourage them to share out the work of caring in the family and draw on support from their community – everyone needs a break sometimes.
- Don't forget to pay attention to siblings.

## Pain in children

Assessing pain in children can be difficult. They may be too young to say how they feel, or fear and anxiety may prevent them from speaking. Parents and carers can underestimate or overestimate pain. We have to use extra skill when dealing with children, but the good news is that the most important skill is simple but careful observation. Even if children cannot tell us about their pain, they show us by how they behave.

### Signs that a child is in pain

- Crying and distressed facial expression (may be confused with anxiety)
- Not wanting to move
- Not wanting to eat
- Poor concentration
- Irritability or restlessness
- Difficulty sleeping
- Increased breathing rate or heart rate

It is very useful to watch children while you are talking to their mothers, or while they are playing – when they do not realise you are watching them and are not anxious about what you are going to do to them.

- **Listen to the child**
- **Listen to the carer**
- **Observe with your eyes**

Older children may be able to use a simple pain score, such as showing the severity of pain by the number of fingers they hold up, or by pointing at pictures of smiling, sad or distressed faces (see Tool 2).

The principles of pain control are the same as for adults: give drugs by mouth, by the clock, by the ladder. Avoiding injections is particularly important with children, and the rectal route may be useful for some drugs. Dosages of important drugs are given in Tool 16. Avoid aspirin in

children (it can cause a potentially fatal liver disease, Reye's syndrome) but other NSAIDs (eg ibuprofen, diclofenac) and paracetamol are very helpful.

As well as medication, there are many other ways to reduce pain which we can use and teach families and carers. We can show them that “there is never nothing they can do” to help their child.

### Non-drug measures to reduce pain in children

- **Make them feel secure** – don't leave them alone if they are in pain.
- **Keep them in familiar surroundings** – care for them at home if at all possible or encourage families to stay with them in hospital and bring familiar toys or food from home.
- **Make them feel valued** – listen to them and show them that you think their needs are important.
- **Use touch** – cuddling, carrying, breastfeeding, massage.
- **Feeding** – never force-feed but often a snack will help.
- **Heat or cold** – eg using a damp cloth.
- **Play with them** – distraction is good medicine for children.
- **Use music and stories.**

## Symptom control

Great attention has to be paid to assessment of symptoms in children as they cannot always tell us what is distressing them and parents may not notice all the relevant signs. Observation and examination are very important and it is always good to check:

- Inside the mouth
- Skin all over, including nappy area and scalp
- Ears – external examination is useful, use auroscope if available
- For swollen lymph nodes
- For anaemia in palms and conjunctiva
- For signs of respiratory distress (fast breathing, rib recession, flaring nostrils)
- For signs of dehydration (dry tongue, reduced skin turgor, sunken eyes).

The principles of symptom control in children are the same as for adults:

- **Treat what is treatable**
- **Care for the patient**
- **Prescribe palliative drugs**

Use Chapter 5 for the treatment of specific symptoms; see tool 16 for paediatric doses.

## Common problems in children

### Nutrition

- Good nutrition is important for sick children; give nutritional supplements if possible.
- Try different foods to see what they will eat.
- Feed a little and often.
- Sore mouth is a common treatable cause of poor feeding (see p40).
- When very sick, advise carers that children will not eat much (see p39) and avoid force-feeding.

## Skin problems

- Some are treatable (eg scabies, ringworm) (see p33).
- Generalised rashes are often caused by viral infections and are self-limiting.
- Watch out for drug reactions.
- Keep fingernails short if the child is scratching.
- Treat nappy rash by exposure to the air when possible, and use a barrier cream such as zinc oxide or petroleum jelly.

## Upper respiratory tract infections (URTI)

- URIs with runny nose, cough and fever are very common.
- Avoid antibiotics as they do not help.
- Treat with paracetamol for fever and plenty of fluids.
- Watch for signs of respiratory distress (see above) which suggest the infection is in the lungs and antibiotics are needed. (Follow local guidelines.)

## Discharging ears

- Acute otitis media (infection for less than 14 days) should be treated with antibiotics (amoxicillin, change to co-amoxiclav if no response).
- Chronic discharge is a common and difficult problem in immunosuppressed children. The main treatment is cleaning with dry cloth made into a wick. Avoid pushing it in with a stick – use a finger only. Antibiotic drops (eye drops can be used) may help but repeated courses of oral antibiotics do not.



### Gastro-intestinal symptoms

- Treat acute gastro-enteritis with fluid replacement only.
- Use antidiarrhoeals and antiemetics for chronic diarrhoea or vomiting (more than 2 weeks).
- Constipation is common in children with neurological disorders and children taking opioids.

### Spasticity and muscle spasm

- Common problem in cerebral palsy and other neurological illness.
- Position the child (using pillows or other supports) to counteract spastic posture and maintain normal joint position as far as possible (eg a U-shaped cushion, made with a rolled-up blanket, can prevent back arching by cradling the head in a gently flexed position).
- Prevent contractures and pressure sores (see p49,34).
- Make a corner seat with a tray in front for the child to sit in if possible; this enables them to watch what is going on and be part of family life.
- Diazepam can be useful, especially before handling or physiotherapy.

### Supporting orphans and vulnerable children

It is beyond the scope of this toolkit to look at ways of caring for orphans, but in general, a community approach which empowers families to care for extra children is most successful. Where possible, siblings should stay together and sometimes a child-headed household may be the best alternative. Neighbours, support groups and welfare organisations can all help in different ways and if we are doing palliative care we need to network with them.

**Find out who is helping orphans in your community. See how you can support these groups and make use of them.**

## **You can tell others**

### **Important messages**

- Many people could benefit from palliative care
- Treatment exists to relieve pain
- Palliative care can improve quality of life
- Palliative care can be delivered in different ways

### **Ideas for publicising palliative care in our communities**

- Counselling individual patients and families
- Informing key people
- Publicity in public places and gatherings
- Special events
- Health talks
- Drama and music
- Patients telling their stories
- Leaflets and posters

### **Ideas for telling those we work with**

- Lead a discussion at staff meeting
- Give a teaching session
- Run a short training course
- Give out information sheets

### **Ideas for raising awareness in our countries**

- Article in the newspaper
- Interview on the radio
- Posters and leaflets
- Involve politicians/celebrities

Start doing what's necessary, then do what's possible and suddenly you are doing the impossible

## Chapter 7: You can tell others

“You must be the change you wish to see in the world.”

Mahatma Gandhi

### Advocacy

If palliative care is to develop in our communities and workplaces, we have to tell people about it. We need to tell patients so that they can receive care, health workers and lay people so that they can join the work and community leaders so that they can support our endeavours. Ultimately, we need to tell governments and ministries of health so that they can make policies which promote palliative care and ensure that the necessary drugs and training are available. This process of informing and influencing people in order to bring about change is called advocacy. It may involve educating, publicising, lobbying and campaigning.

### Advocacy begins at home

The place to begin advocacy is right where we are. We need to start doing some palliative care in our own setting before we can think about approaching policy makers. We need to find out what others are doing in our country. There may be a national association which can help us. If we want to involve volunteers, we will need to make the needs known and show people how they could help. We can inform and involve our communities in different ways according to our local setting.



#### What are the messages we want to give?

- There are many people with incurable diseases who could benefit from palliative care.
- Treatment exists to relieve pain and other symptoms.
- Palliative care can improve quality of life.
- Palliative care involves emotional and spiritual support as well as addressing physical problems.
- Palliative care can be delivered in different ways.
- Many people in the community can be involved in palliative care.
- Palliative care is not expensive and relieves pressure on hospital services.

#### Ideas for publicising palliative care in our communities

- Counselling individual patients and families.
- Informing key people, eg community leaders, local businesses, teachers, shops selling medicines, religious leaders.
- Publicity in public places and at different gatherings, eg clinics, hospitals, village hall, schools, churches, mosques, temples, shops, women's groups, support groups, youth clubs, community meetings, student groups.
- Hold an event such as a sponsored walk, or an 'awareness day'.
- Make use of media, eg local newspapers or radio stations.

**Use:**

- Health talks
- Drama and music
- Patients telling their stories
- Leaflets (eg Tool 11)
- Posters (eg Tool 12)

**Advocacy in the health services**

It is important to raise awareness among health workers at all levels. The concept of palliative care and the holistic approach may be new to many of them.

**Ideas for telling those we work with**

- Lead a discussion at staff/team meetings.
- Arrange a teaching session – this could be half an hour or half a day. The summaries at the start of each chapter could be used as a framework for a teaching session, eg “What is palliative care?” “Communication skills”.
- Run a short training course – you may be able to invite others with expertise to help you teach.
- Give out information sheets (see Tools 11, 12 and 14).

It is good to include different groups of workers. They will need different types of information but they can all contribute to patient care, eg:

- Community volunteers
- Pharmacists and assistants
- Counsellors
- Traditional healers
- Ward attendants
- Cleaners
- Receptionists, clerks
- Nurses
- Clinicians

This does not need to be done all at once. We can start with one session for one group and go on from there.

**Data collection**

It is good to have basic statistics at our fingertips to use when talking about the work we are doing. In the Toolkit there is a monthly report sheet which can be used to collect data (Tool 10).

A palliative care team should be able to say:

- How many patients are being cared for
- What sorts of diseases they have
- How many referrals are received and where they come from
- How many patient contacts are made – these may be home visits, clinic attendances, visits to hospital inpatients, ward rounds
- What is the outcome for the patients – death or referral to another service.

If we are requesting analgesics such as morphine, or food supplements, it is useful to know how many of our patients need treatment for pain and how many are underweight.

We also need to be able to describe:

- What services we offer
- What drugs and other supplies we use and where we get them from
- How much money we spend
- Training activities that take place.



“Start doing what’s necessary, then do what’s possible and suddenly you are doing the impossible.”

St Francis of Assisi

## Advocacy on the wider horizon

As things develop we may get involved in campaigning for palliative care on a national level, raising awareness both in the general public and in the government. It is useful to have statistics on disease prevalence in the country, what drugs are available and what palliative care is being provided in different places.

### Ideas for raising awareness in our countries

- Article in the newspaper, eg about a palliative care project that has begun, or about a patient whose life has been changed.
- Interview on the radio with a health professional or a patient, or a famous person who has had contact with palliative care work.
- Send posters/leaflets to all hospitals in the country.
- Write to senior health officials in referral hospitals, teaching institutions and the ministry of health.
- Write to NGOs and other groups involved in healthcare.
- Organise an event for World Hospice and Palliative Care Day.

### Write about:

- The need for care – which people can benefit, include statistics if you can
- The need for morphine and other drugs to be made available (see Tool 13)
- Palliative care initiatives already happening
- Real stories – put a human face to your issue
- Ways forward, eg reviewing drug policies, supporting training, including palliative care in health plans. Present constructive, realistic suggestions.





# Toolkit

These are tools for you to use. Pick out which ones would be helpful in your setting and photocopy or adapt them as you wish. You may want to translate some of them into your local language.

## 1. Palliative care patient assessment

To be filled in by health workers on first patient contact and then used for note keeping

## 2. Pain assessment tool

Questions and pain scores to use with patients

## 3. Patient register

To record each patient seen by the team, filled in on the first visit

## 4. Home visit record for care provider

Kept by the home care worker or coordinator, to record each visit made by the worker or team

## 5. Home-based care patient-held record

Kept by the patient and filled in every time he/she is visited by the care team

## 6. Patient-held drug chart

To remind the patient and carers of times and doses of drugs to be taken

## 7. Patient-held morphine dose record

To keep track of how much morphine a patient is using and to help the health worker adjust the dose

## 8. Home-based care volunteer kit

List of useful things for the team to take on visits

## 9. Referral form

To give to other organisations/individuals to use when referring patients for palliative care

## **10. Palliative care monthly report form for data collection**

Filled in every month to record patient numbers, etc

## **11. Information leaflet about palliative care**

For advocacy/publicity (fold into 3 sections)

## **12. Poster about palliative care for display**

For advocacy/publicity

## **13. Sample letter requesting morphine**

A model letter to be adapted for your setting

## **14. Analgesic ladder chart for display on clinic wall**

A reminder for health workers

## **15. Confidence rating scale**

Used for personal assessment or in training

## **16. Paediatric drug doses**

Handy guide for health workers

## **17. Drug list**

List of basic drugs needed for palliative care, with list of additional drugs if available

## **18. Further resources**

List of publications, web addresses and organisations to help you find out more

# Palliative care patient assessment

Patient name		Patient number	Start date
Sex	Age	Resides	

Referred from

☐ HBC team    ☐ Health centre    ☐ OPD    ☐ Hospital ward    ☐ other

Diagnosis

☐ HIV  
☐ Cancer  
☐ Other

Brief history of illness

What does patient understand about their illness?

HIV status:    +ve    -ve    not tested    not discussed    (please circle)

Recent medications    ☐ Chemo    ☐ ARVs    ☐ TB drugs    ☐ other

Details (including start date)

Any known previous drug reaction?

Family members	Social issues
Emotional issues	Spiritual issues

## Examination

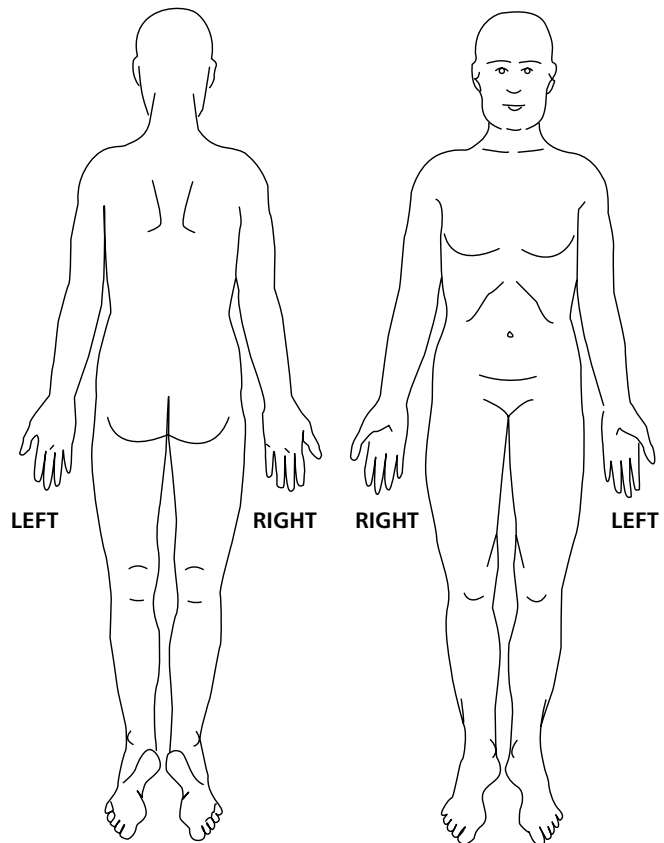
General condition	Weight/kg
-------------------	-----------

**Body chart:** Mark on and describe sites of pain, swelling, rashes, wounds, etc.

Chest

## Abdomen

Neurological



## Problem List

[illegible]

# Pain assessment tool

Choose the pain score that is most helpful for your patient:

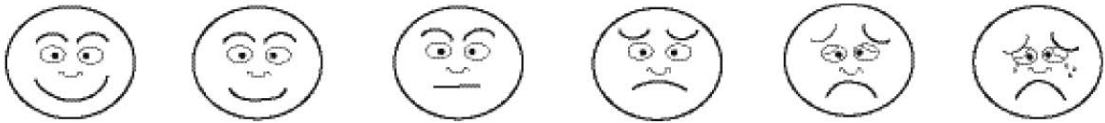
## Five-finger score

Ask the patient to show how bad the pain is with their hand



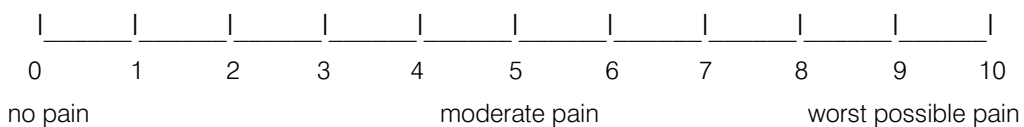
## Faces score

Ask the patient to point to the face which shows how bad their pain is



## Number score

Ask the patient to show where their pain comes on the scale of 1 – 10



## Seven important questions to ask the patient

- **Where** is the pain? (there may be more than one pain)
- **When** did it start?
- **What** does it feel like? (eg stabbing, cramping, burning, etc)
- **Timing** - Is the pain there all the time or does it come and go?
- **Treatment** - Has any treatment been tried and has it helped?
- **Changing** - What makes it better or worse (eg movement, eating, time of day, etc)?
- **Causing** - What do you (the patient) think is causing the pain?

# Palliative care patient register

[illegible]

# Home visit record for care providers

PATIENT NUMBER	DATE	PATIENT NAME	LOCATION	VISITED BY	MAIN PROBLEMS	CARE GIVEN A B C D E F G H I J	OTHER NOTES (PSYCHOSOCIAL, SPIRITUAL ISSUES)

CARE GIVEN:

A BATHING  
F TOILETING

B TURNING  
G WASHING

C PRESSURE AREA CARE  
H SUPERVISION OF MEDICINES

D FEEDING  
I PASSIVE AND ACTIVE EXERCISES

E MOUTH CARE  
J DRUGS PROVIDED (SPECIFY WHICH)

# Patient-held record for Home-based care

PATIENT NAME

AGE

SEX

RECORD NUMBER

DATE FIRST SEEN

LOCATION


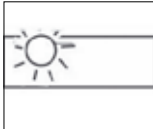



MAIN GUARDIAN NAME

VISIT DATE	VISIT DONE BY	CONDITION OF PATIENT 1 2 3 4	MAIN PROBLEMS	CARE GIVEN A B C D E F G H I J	OTHER NOTES (PSYCHOSOCIAL ISSUES, SPIRITUAL ISSUES)

**CONDITION OF PATIENT**   **0** WELL   **1** ACTIVE; ABLE TO DO LIGHT WORK   **2** SELF-CARING BUT UNABLE TO WORK   **3** BEDRIDDEN>50% OF DAY   **4** BEDDRIDDEN ALL TIME; NO SELF CARE

**CARE GIVEN:**   **A** BATHING   **B** TURNING   **C** PRESSURE AREA CARE   **D** FEEDING   **E** MOUTH CARE  
**F** TOILETING   **G** WASHING   **H** SUPERVISION OF MEDICINES   **I** PASSIVE AND ACTIVE EXERCISES   **J** DRUGS PROVIDED

# Patient-held drug chart

PATIENT NAME		DATE CHART GIVEN				
Number of tablets or ml of liquid to take at each time of day						
NAME AND PURPOSE OF DRUG	Early morning (6am)	Mid morning (10am)	Afternoon (2pm)	Evening (6pm)	Bedtime (10pm)	
						

- Keep all medicines out of reach of children
- Do not give your medicine to anyone else
- Do not stop taking your medicine without consulting the health worker

## Patient-held morphine dose record

Patient name \_\_\_\_\_ Date chart given \_\_\_\_\_

Form of morphine used: oral morphine solution / tablets / injection (please circle)

Strength of formulation: solution \_\_\_\_mg/5ml

tablets	___ mg	normal release / modified release (please circle)
---------	--------	---

[illegible]

- Tick the chart each time a regular dose is given
- Record the total number of extra 'breakthrough' doses given in the 24 hour period

# Home-based care volunteer kit

## Basic contents

- |  |   |
|--|---|
| Plastic gloves                                 | Gentian violet paint                                  |
| Plastic sheeting                               | Paracetamol tablets                                   |
| Plastic bags                                   | Aspirin   |
| Soap   | Laxatives (eg bisacodyl tablets or suppositories)     |
| Washing powder                                 | Oral rehydration salts                                |
| Plastic bottle to use for incontinent patients | Metronidazole tablets (crushed) for putting on wounds |
| Pieces of clean cloth for cleaning wounds      | Home visit record sheet                               |
| Clean dressings                                | Patient-held record to leave with patient             |
| Sticky tape                                    | Pen   |
| Vaseline                                       |   |

## Health worker kit

If the kit is to be carried by a health worker, some extra things can be added, such as:

- |                |                         |
|----------------|-------------------------|
| Ibuprofen      | Cotrimoxazole           |
| Codeine*       | Metronidazole           |
| Morphine*      | Ketoconazole            |
| Amitriptyline  | Catheters               |
| Diazepam       | Drug dosage lists       |
| Metoclopramide | Patient assessment form |
| Amoxycillin    |                         |

\* National regulations about the storage and carrying of controlled drugs must be followed.

# Referral to palliative care team

Address of palliative care team: \_\_\_\_\_  
\_\_\_\_\_ Phone: \_\_\_\_\_

**Referral made by:**

\_\_\_\_\_ Date: \_\_\_\_\_

Contact details of person/organisation making  
referral:

**Name of patient:**

Address/directions/contact details for patient: \_\_\_\_\_  
\_\_\_\_\_

Nearest health facility to patient's home: \_\_\_\_\_

Age:                      Sex:                      Main carer:

**Diagnosis:**

Patient aware of diagnosis Y/ N                      Carer aware of diagnosis Y/N

**Main problems:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Current treatment:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Reason for referral:**

Advice on symptom management ☐                      Counselling ☐  
Take over care ☐                      Shared care ☐

Signature: \_\_\_\_\_ Print name: \_\_\_\_\_

# Palliative care monthly report

month

year

patients under care

at start of month	new referrals	death/discharge /moved away	at end of month
-------------------	---------------	-----------------------------	-----------------

new referrals from

HBC volunteer	health centre	hospital OPD	hospital ward
---------------	---------------	--------------	---------------

end of care outcome

died	discharged to other service	moved away
------	-----------------------------	------------

patients discharged to

HBC	O/P clinic	hospital admission	other
-----	------------	--------------------	-------

diagnosis for patients under care at end of month

Cancer	HIV	other
--------	-----	-------

patient/family contacts

home visit	clinic attendance	inpatient visit	bereavement visit
------------	-------------------	-----------------	-------------------

training sessions held

topic	teacher	no. trained
topic	teacher	no. trained

# Palliative care

is the active, holistic care of patients with advanced, progressive illness...

Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount.

The goal of palliative care is achievement of the best quality of life for patients and their families.

Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatment.<sup>(2)</sup>

(2) World Health Organization (WHO).  
Cancer pain relief and palliative care. Geneva: WHO; 1990.

Palliative care services are being developed all over the world in many different settings.

Care can be given:

- In hospital
- At home
- In an outpatient clinic
- In a hospice
- In a local health centre
- In a mobile clinic
- In a day care centre.

Palliative care does not exclude other therapies.

It can be used alongside:

- Antiretroviral therapy for HIV
- Chemotherapy for cancer
- Radiotherapy
- ...and other treatment.

# Palliative care



# What is palliative care?

...care for sick people who won't get better; the ones that medicine cannot cure.

## Palliative care helps with:

- Physical symptoms using drugs and good nursing care
- Psychological and spiritual distress by counselling, listening and prayer
- Social problems by involving families and communities.

This needs a team approach.

relieving suffering  
controlling pain  
sharing problems  
giving support

# Who needs palliative care? we do!

Palliative care can help people with a variety of illnesses.

These include:

- Cancer
- HIV
- Progressive neurological disease
- End-stage heart or kidney failure
- Other life-limiting illnesses.

The aim in all these cases is to add life to days, not just days to life.

# Palliative care pain control

The WHO analgesic ladder<sup>(1)</sup> is a guide on appropriate ways to control pain.

There is no need for people to live with pain

**Morphine is a strong and effective medicine for pain. It is not addictive when used correctly to treat pain.**

**Morphine does need to be prescribed and monitored by qualified personnel.**

(1) World Health Organization. **Pain relief ladder** [online]. Available from: <http://www.who.int/cancer/palliative/painladder/en>

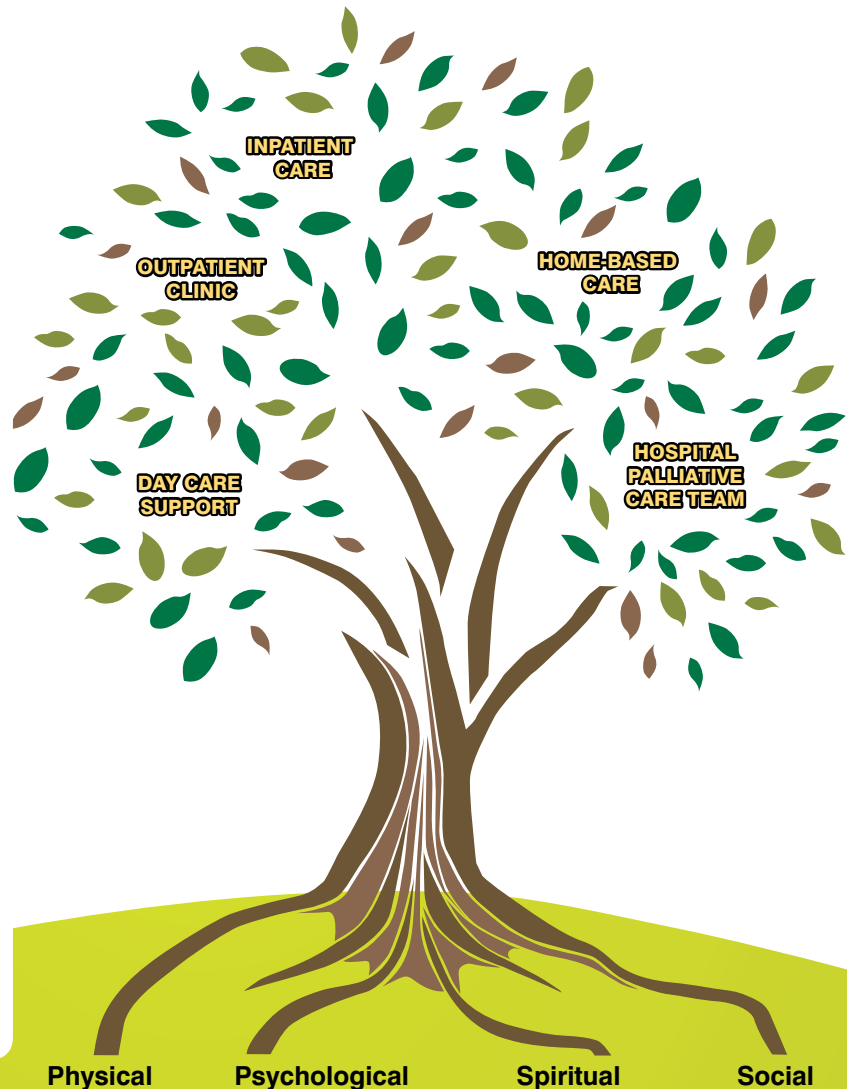
# Palliative care

...is care for people with illnesses that cannot be cured.

Improving quality of life for those with advanced disease

...by helping with:

- Pain and other physical symptoms
- Psychological and spiritual distress
- Social problems.



**There is no need for people to live with pain**

Palliative care can help people with a variety of illnesses and can be practised in different settings: in hospital, clinics and at home

**Adding life to days, not just days to life**

controlling pain

sharing problems

relieving suffering

giving support

# Sample letter requesting morphine

Address  
Date

Dear.....

Re; drug supplies for palliative care

I write to you as a nurse/home-based care coordinator/doctor involved in giving palliative care to people with cancer/HIV/advanced illness. Palliative care aims to help those whose illness cannot be cured, by controlling pain and other distressing symptoms. In most cases this can be achieved using inexpensive drugs and it greatly improves the quality of life of those who are cared for. It is estimated that 70% of those with advanced cancer or HIV have uncontrolled pain<sup>(1)</sup> and here in..... programme/community/clinic/hospital I see many patients suffering unnecessarily in this way.

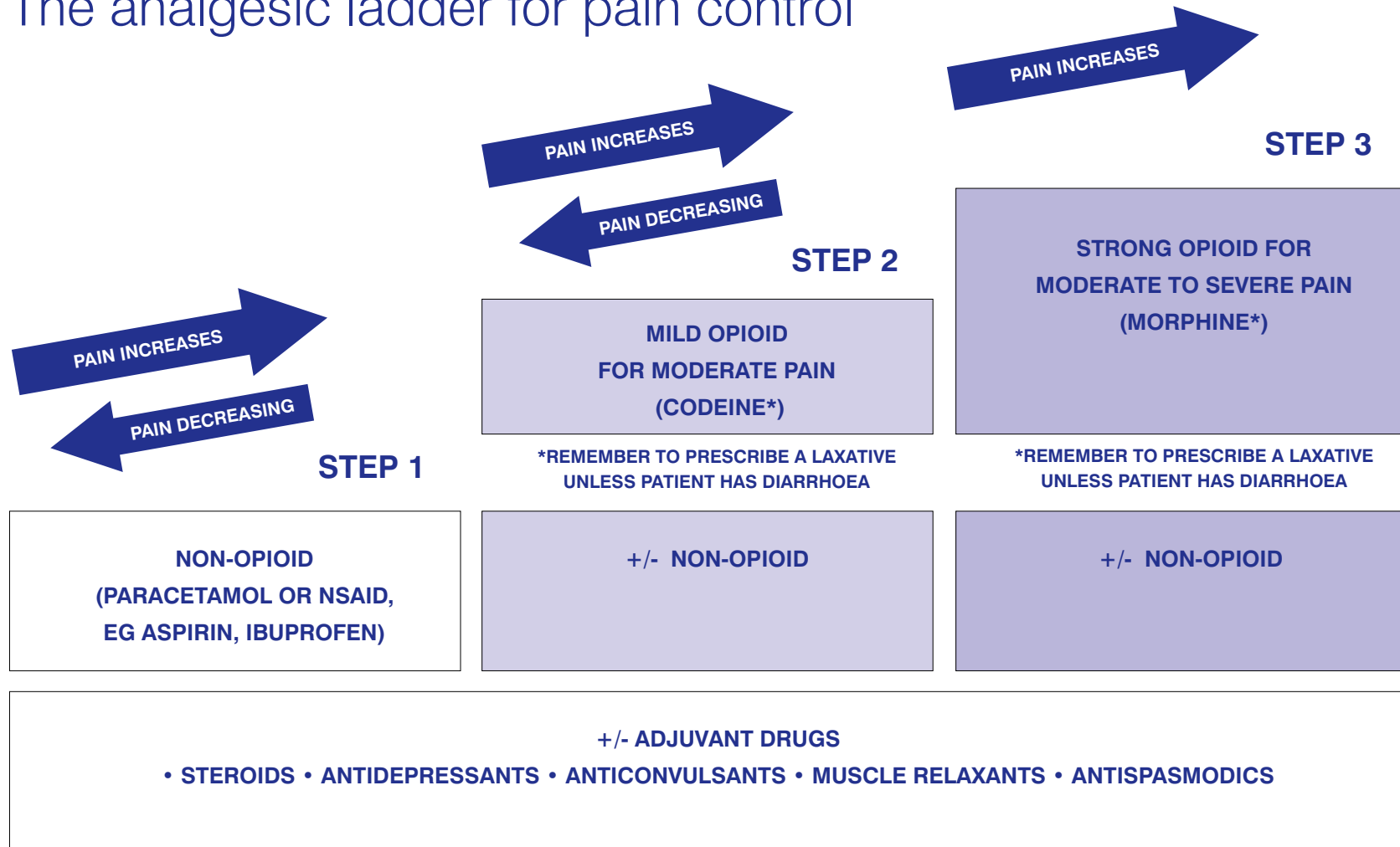
The World Health Organization (WHO) has produced a three-step analgesic ladder for pain control<sup>(2)</sup>. This starts with non-opioid analgesics for mild pain and proceeds to morphine for severe pain. The WHO essential drug list recommends that morphine should be available in any basic healthcare system for the relief of pain which does not respond to weaker analgesics<sup>(3)</sup>.

I am unable to relieve the pain of many of my patients with the mild analgesics currently available. Therefore, I am writing to request that morphine be made available to our clinic/programme/hospital to enable me to follow the WHO guidelines. I would of course ensure that national regulations for the safe storage and prescribing of opioid drugs are followed.

Yours faithfully,

<sup>1</sup> 2nd Global Summit of National Hospice and Palliative Care Associations, March 2005  
<sup>2</sup> Cancer Pain Relief WHO 1986  
<sup>3</sup> WHO Model List of Essential Medicines, March 2007

# The analgesic ladder for pain control



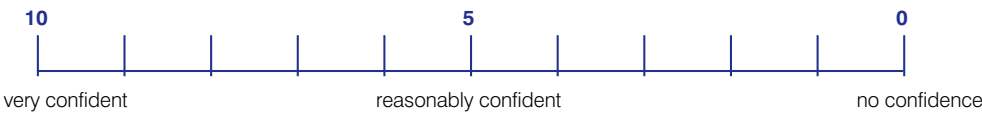
Give analgesics: • by the mouth • by the clock • by the ladder

# Confidence rating scale

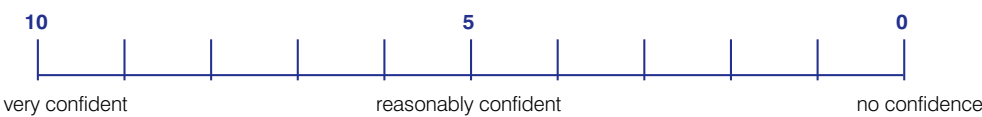
NAME:

DATE:

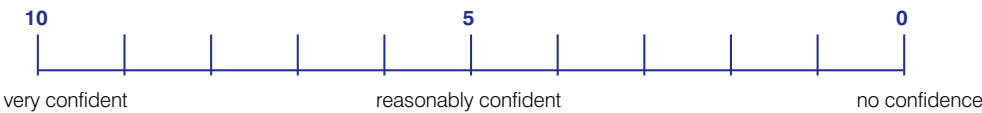
**I can assess a palliative care patient’s pain**



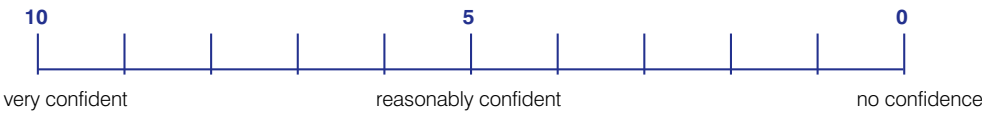
**I understand the WHO three-step analgesic ladder**



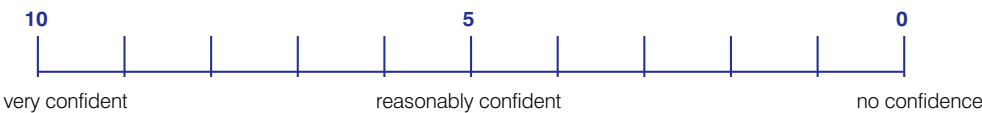
**I understand how to prescribe opioid analgesic drugs such as morphine**



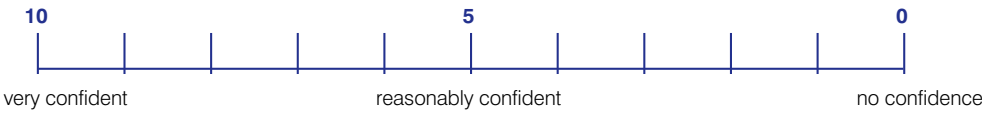
**I understand the role of palliative care for patients with cancer and HIV/AIDS**



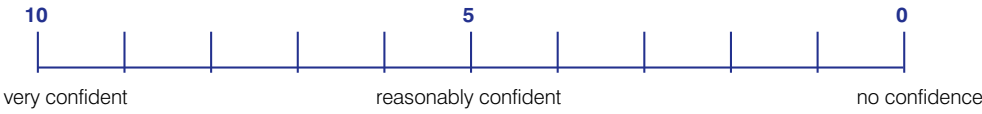
**I understand what is meant by holistic history taking**



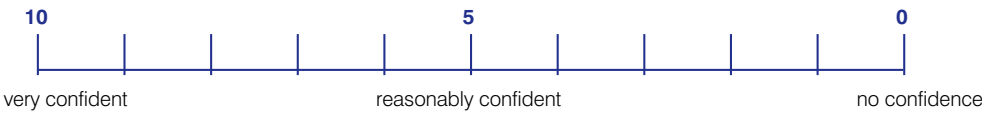
**I can discuss anxiety with a palliative care patient**



**I understand the different models/settings for palliative care**



**I feel equipped to break bad news to patients**



# Paediatric drug doses

Drug	No. times/day	Single dose by weight	Approximate single dose by age*		
			< 1	1 - 5	6 - 12
Paracetamol for pain or fever	4	10 - 20mg/kg	62.5mg	125mg	250 - 500mg
Ibuprofen for pain or fever	3	5 - 10mg/kg	50mg	100mg	100 - 200mg
Codeine for moderate pain or diarrhoea	4 - 6	0.5 - 1mg/kg	7.5mg	15mg	30mg
Oral morphine for severe pain	6	starting dose 0.1 - 0.3mg/kg	1 - 2mg	2.5mg	2.5 - 5mg
Bisacodyl for constipation	1	5mg total	5mg	5mg	5mg
Dexamethasone **	2, morning & lunchtime	0.1 - 0.5mg/kg	0.5 - 1mg	2mg	4mg
Prednisolone ** (if dexamethasone not available)	2, morning & lunchtime	1 - 2mg/kg	5mg	15mg	30mg
Amitriptyline for neuropathic pain	1 at night	0.2 - 0.5mg/kg max 2mg/kg	-	6.25mg	12.5mg
Metoclopramide for nausea/vomiting	3	0.1 - 0.5mg/kg	5mg	10mg	10mg
Loperamide for chronic diarrhoea (NB not for use in acute GE)	3	0.1 - 0.2 mg/kg	-	1mg	2mg
Diazepam for muscle spasm or agitation	2	0.25mg/kg	1.25mg	2.5mg	5mg
Chlorpheniramine for itching or night sedation	3	0.1mg/kg	0.5mg	1mg	2mg
Ketoconazole for severe candida	1	3mg/kg	25mg	50mg	100mg

\*These doses are given for guidance, taking into account the formulations most commonly available.  
Where liquid formulations are available, more accurate dosing using mg/kg is advised

\*\* High doses are used for spinal cord compression and raised intracranial pressure.  
Lower doses (given above by weight) are used for reducing tumour mass causing obstruction, oedema or nerve compression.  
Short courses are advised, which can be repeated.  
If given for more than a week, steroids should be tailed off gradually.  
In some cases a maintenance dose may be necessary; this should be the lowest dose needed to control symptoms.  
Cover with antifungals in the immunosuppressed and those on long courses.

# Basic drugs for palliative care

Drug name	Class	Clinical uses	Alternative drugs
Paracetamol	Non-opioid analgesic	Pain control p26 Fever p32	
Aspirin	Non-opioid analgesic	Pain control p26 Fever p32 Sore mouth p40	
Ibuprofen	NSAID (Non-opioid analgesic)	Pain control p26 Inflammation Fever p32	Diclofenac Naproxen Indomethacin
Codeine	Weak opioid analgesic	Pain control p27 Diarrhoea p45 Cough p43	Dihydrocodeine
Morphine	Strong opioid analgesic	Pain control p27 Breathlessness, cough pp43-44 Severe diarrhoea p45	Tramadol Oxycodone
Dexamethasone	Corticosteroid Adjuvant analgesic	Painful swelling and inflammation p30 Poor appetite p39 Drug reactions p33	Prednisolone
Amitriptyline	Tricyclic antidepressant Adjuvant analgesic	Nerve pain p30 Depression p38	Imipramine Lofepramine
Diazepam	Benzodiazepine Adjuvant analgesic	Muscle spasm p31 Anxiety and sleep p37 Shortness of breath p44 Seizure treatment p35	Lorazepam
Metoclopramide	Antiemetic	Vomiting p41 Poor appetite p39	Domperidone
Haloperidol	Antiemetic Antipsychotic	Vomiting p41 Hiccups p42 Confusion and agitation p36	Chlorpromazine
Magnesium trisilicate	Antacid	Indigestion p42 Gastro-oesophageal reflux p42	Aluminium hydroxide Magnesium hydroxide
Loperamide	Antidiarrhoeal	Diarrhoea p45	Codeine Lomotil
Senna	Laxative	Constipation p46	Bisacodyl Magnesium hydroxide
ORS	Oral rehydration salts	Diarrhoea p45 Rehydration	Ricewater Coconut milk
Chlorpheniramine	Antihistamine	Itch p33 Drug reactions p33	Promethazine Hydroxyzine

<b>Antibiotics</b>			
Metronidazole	Antibacterial for anaerobic infections	Infection of gums/teeth p40 Infective diarrhoea (PO) p45 Offensive wounds (top) p34 Vaginal discharge (PV) p47	Co-amoxiclav Tinidazole
Amoxycillin	Antibacterial	Chest infection p43 Skin infections p33	Erythromycin
Co-trimoxazole	Broad spectrum antibacterial	Infective diarrhoea p45 in HIV/AIDS Urinary tract infection pp47-48 PCP prophylaxis	Chloramphenicol Doxycycline
Fluconazole	Antifungal	Oral and oesophageal candidiasis p40	Ketoconazole
Nystatin susp.	Antifungal	Oral candidiasis p40	GV paint Clotrimazole pessaries
<b>Skin preparations</b>			
Vaseline	Skin moisturizer and protector	Dry skin p33 Skin protection p33	Aqueous cream
Gentian violet paint		Bacterial, fungal and viral skin infections p33	
Benzyl benzoate lotion	Scabicide	Scabies p33	Permethrin cream/lotion
Clotrimazole 1% cream	Topical antifungal	Fungal skin infections p33	Whitfields ointment Miconazole cream
Chlorhexidine 0.05%	Antiseptic	Bacterial skin infection p33	Gentian violet

# Additional drugs for palliative care

Drug name	Class	Clinical uses	Alternative drugs
Baclofen Pyridoxine	Muscle relaxant Vitamin	Muscle spasm p31 Pyridoxine deficiency with isoniazid causing nerve pain	Diazepam
Promethazine	Antiemetic Antihistamine	Vomiting p41 Itch p33	Cyclizine
Hyoscine Butylbromide	Antimuscurinic (Anticholinergic)	Abdominal colic p31	Propantheline
Propantheline	Antimuscurinic (Anticholinergic) Antacid	Bladder spasm p48 Abdominal colic p31 Watery sputum p43	Hyoscine butylbromide
Valproate	Anticonvulsant Adjuvant analgesic	Seizure prevention p35 Nerve pain pp30-31	Carbamezapine Phenytoin Gabapentin
Quinine	Antimalarial	Night muscle cramps Malaria treatment p32	Diazepam
Paraldehyde	Anticonvulsant	Seizure treatment p35	Diazepam
Phenobarbital injection	Anticonvulsant	Seizure treatment p35 Severe agitation and confusion p36	Diazepam
Cimetidine	Antacid	Indigestion p42 Gastro-oesophageal reflux p42	Ranitidine Omeprazole
Antibiotics			
Ciprofloxacin	Broad-spectrum antibacterial	Bacterial infections p32	Chloramphenical
Acyclovir	Antiviral	Herpes zoster and herpes simplex infections p33	
Clotrimazole pessary	Topical antifungal	Vaginal candidiasis p47 Oral candidiasis p40	Nystatin pessary
Skin preparations			
Calamine lotion	Itch	Rash p33	Aqueous cream with 1% menthol
Aqeous cream/UEA with 1% menthol	Skin moisturizer	Rash p33	Itch

## Further resources

There are many resources available to help you find out more. Some can be downloaded from the internet; click on the links given below when you are online and follow instructions to download. For those available in printed form, email addresses have been given where you can order a copy.

### **WHO integrated management of adult and adolescent illness (IMAI)**

Five practical, easy-to-use booklets

- Palliative care – a handy, portable guide to symptom control
- Caregiver booklet – helpful instructions for family and volunteer care-givers
- Chronic care with ARV therapy and prevention – how to prescribe ARVs
- General principles of good chronic care – guidelines for health workers
- Acute care – guidelines on management of common illnesses

Available online at: [www.who.int/3by5/publications/documents/imai/en/](http://www.who.int/3by5/publications/documents/imai/en/)

Order free hard copies: [imaimail@who.int](mailto:imaimail@who.int)

### **Pain and symptom control in the cancer and/or AIDS patient in Uganda and other African countries**

A more detailed guide to symptom control produced by Hospice Africa, Uganda but usable all over the world. It contains a section on ARVs in palliative care.

Online: [www.hospiceafrica.or.ug/redesign/docs/bluebk40506.pdf](http://www.hospiceafrica.or.ug/redesign/docs/bluebk40506.pdf)

Order: [info@hospiceafrica.or.ug](mailto:info@hospiceafrica.or.ug)

### **A clinical guide to supportive and palliative care for HIV/AIDS in Sub-Saharan Africa**

A comprehensive text book with an extensive list of resources of all kinds.

Online: [www.fhssa.org/i4a/pages/Index.cfm?pageID=3361](http://www.fhssa.org/i4a/pages/Index.cfm?pageID=3361)

Order a CD-ROM: [info@hospiceafrica.or.ug](mailto:info@hospiceafrica.or.ug)

### **Cancer pain relief: guide to opioid availability**

WHO document giving clinical information on pain relief but also guidelines on introducing opioid use to governments.

Short version online: [www.medsch.wisc.edu/painpolicy/publicat/cprguid.htm](http://www.medsch.wisc.edu/painpolicy/publicat/cprguid.htm)

Order: [bookorders@who.int](mailto:bookorders@who.int)

### **IAHPC manual (International Association for Hospice and Palliative Care)**

A user-friendly online manual covering all aspects of palliative care.

Online: [www.hospicecare.com/manual/IAHPCmanual.htm](http://www.hospicecare.com/manual/IAHPCmanual.htm)

### **Introducing palliative care by Robert Twycross**

An excellent basic textbook of palliative care which has recently been updated.

Published by Radcliffe Medical Press, Oxford.

Available in India at low cost from:

The Institute of Palliative Medicine, Medical College, Calicut, Kerala, India

Email: [pain@vsnl.com](mailto:pain@vsnl.com)

Available in Africa at low cost from:

Wits Palliative – training, PO Box 212, Pimville, 1808, Soweto, South Africa

Email: [palliative.training@wits.ac.za](mailto:palliative.training@wits.ac.za)

### **Palliativedrugs.com**

An online formulary containing information about all drugs used in palliative care. A large selection of palliative care books can be ordered through the website.

Online: [www.palliativedrugs.com](http://www.palliativedrugs.com)

### **HIV, health and your community**

A guide to setting up HIV programmes including home-based care, with advice on writing proposals and training others.

Online: [www.hesperian.org/mm5/merchant.mvc?Store\\_Code=HB&Screen=PROD&Product\\_Code=B200](http://www.hesperian.org/mm5/merchant.mvc?Store_Code=HB&Screen=PROD&Product_Code=B200)

Order: [hesperian@hesperian.org](mailto:hesperian@hesperian.org)

### **Red Cross guide to setting up CHBC programmes**

Contains useful principles and planning tools.

Online: [www.ifrc.org/cgi/pdf\\_pubs.pl?health/hivaids/hbc.pdf](http://www.ifrc.org/cgi/pdf_pubs.pl?health/hivaids/hbc.pdf)

### **Teaching-aids at Low Cost (TALC)**

A charity providing free and low cost healthcare books and accessories on a wide range of topics.

To order free resources from their catalogue, contact by:

Email: [info@talcuk.org](mailto:info@talcuk.org)

Post: TALC, PO Box 49, St Albans, Herts, AL1 5TX, UK

Online: [www.talcuk.org/index.htm](http://www.talcuk.org/index.htm)

### **Hospice Information**

A service promoting palliative care work around the world by providing information on existing services and national associations, educational resources, advocacy, funding and how to start up a new service. Also produces a free e-newsletter and a magazine, and manages an up-to-date database of training courses, seminars and vacancies in the sector. Run by Help the Hospices in association with St Christopher's Hospice, Hospice Information enables easy access to wider resources offered by these two organisations.

Online: [www.hospiceinformation.info](http://www.hospiceinformation.info)

Email for guidance and information: [info@hospiceinformation.info](mailto:info@hospiceinformation.info)

### **Advocacy material**

The Korea Declaration is a statement which was produced at the Second Global Summit for National Hospice and Palliative Care Associations in Korea 2005 at which 35 countries were represented. It can be quoted in letters to governments and publicity material.

Online: [www.worldday.org/documents/Korea\\_Declaration.doc](http://www.worldday.org/documents/Korea_Declaration.doc)

# Feedback form

We would like to receive your comments on the toolkit as we plan to revise and update it in the future based on feedback from those who have used it.

Please fill in this form or send comments to Claire Morris at Help the Hospices

Email: [international@helpthehospices.org.uk](mailto:international@helpthehospices.org.uk)

Post: Hospice House, 34-44 Britannia St, London WC1X 9JG, UK

Which country are you working in? \_\_\_\_\_

What kind of setting are you working in? (eg rural, urban, home based care, clinic, in-patient unit etc) \_\_\_\_\_

How did you get a copy of the toolkit? \_\_\_\_\_

How long have you been using it? \_\_\_\_\_

How have you used it? (eg for personal learning, as a handbook at work, for training others etc) \_\_\_\_\_  
\_\_\_\_\_

Which parts of the toolkit are most useful? \_\_\_\_\_  
\_\_\_\_\_

What additional issues / areas would you like to have included in the toolkit? \_\_\_\_\_  
\_\_\_\_\_

Which parts of the toolkit are not useful? \_\_\_\_\_  
\_\_\_\_\_

Which of the tools (forms, advocacy material etc) did you use? \_\_\_\_\_  
\_\_\_\_\_

How could the tools be improved? \_\_\_\_\_  
\_\_\_\_\_

Other comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_