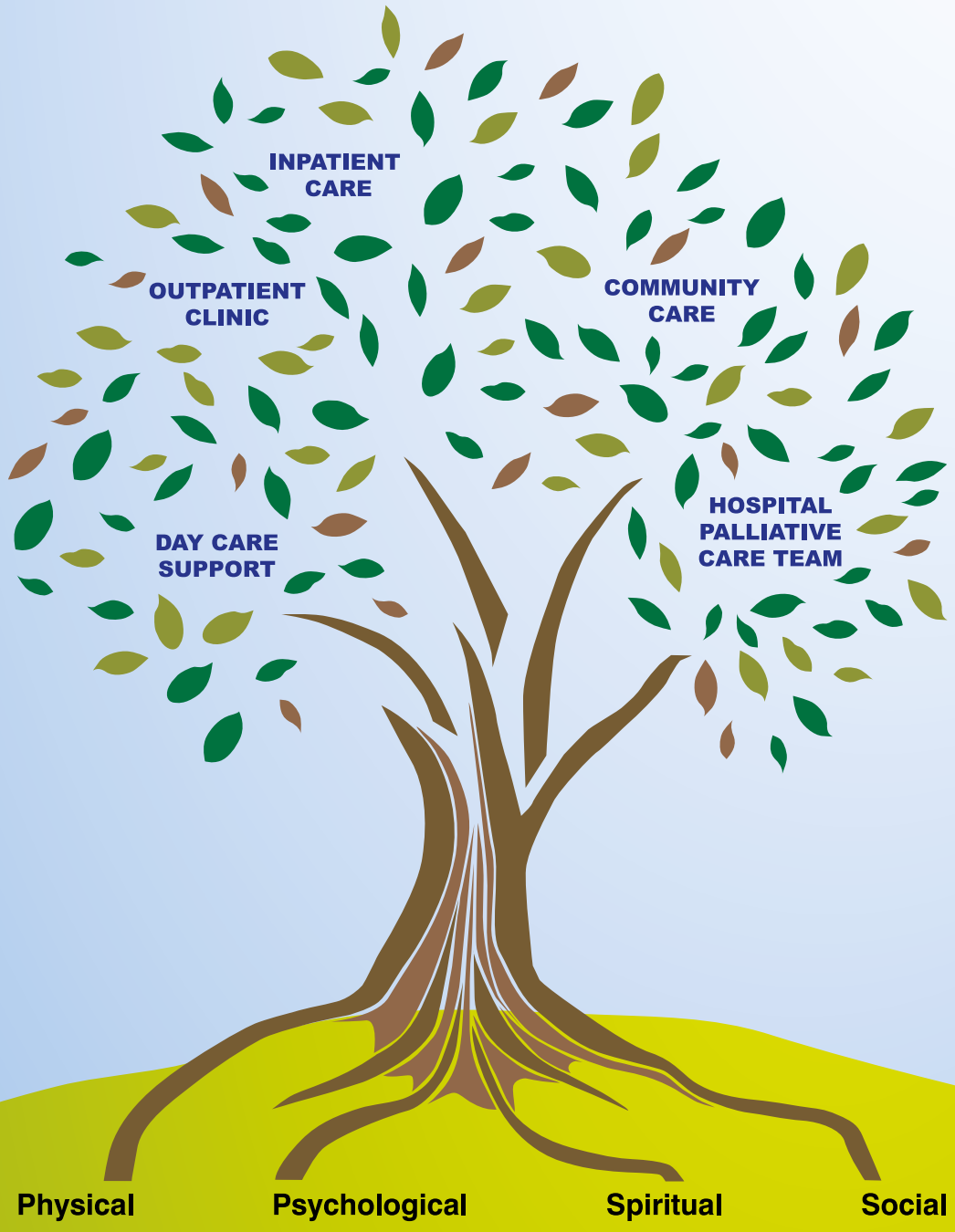



# Palliative Care Toolkit

## Improving care from the roots up in resource-limited settings

by Dr Vicky Lavy, Dr Charlie Bond and Ruth Wooldridge

whpca worldwide hospice palliative care alliance
hospice UK
PCW Palliative Care Works

## About Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families.

## About the Worldwide Hospice Palliative Care Alliance

The Worldwide Hospice Palliative Care Alliance is the alliance 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.

## About Palliative Care Works

Palliative Care Works (www.palliativecareworks.org) is a Charitable Incorporated Organisation (no 1161919) which aims to support and develop palliative care services in resource-limited settings, in collaboration with existing initiatives and organisations. It has delivered teaching, training, workshops and mentoring in Tanzania, Zambia, Rwanda, Kenya, Ghana and India, and elsewhere. It has a multiprofessional staff of experienced palliative care practitioners, managers and educators, all of whom were involved in the production of the original Toolkit, either as authors or as contributors. The current revision of the Toolkit has been a collaborative undertaking by PCW members, led by Dr Charlie Bond.

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# List of Abbreviations

| | |
|---|---|
| **HIV** | Human immunodeficiency virus |
| **AIDS** | Acquired immunodeficiency syndrome |
| **TB** | Tuberculosis |
| **PCP** | Pneumocystis carinii pneumonia |
| **ARVs** | Antiretroviral drugs |
| **ART** | Antiretroviral therapy |
| **SCC** | Spinal cord compression |
| **UTI** | Urinary tract infection |
| **ORS** | Oral rehydration salts |
| **NSAID** | Non-steroidal anti-inflammatory drug |
| **IR** | Immediate release |
| **NR** | Normal release |
| **MR** | Modified release |
| **GV** | Gentian violet |
| **CD** | Controlled drug |
| | |
| **HBC** | Home-based care |
| **OPD** | Outpatient department |
| **NGO** | Non-governmental organisation |
| **FBO** | Faith-based organisation |
| **PLHIV** | People living with HIV |
| **IGA** | Income generating activity |
| **OVC** | Orphans and vulnerable children |
| **WHO** | World Health Organization |

| | |
|---|---|
| **o.d.** | once a day |
| **b.d.** | twice a day |
| **t.d.s.** | three times a day |
| **q.d.s.** | four times a day |
| **p.r.n.** | as required |
| **PO** | by mouth |
| **PR** | by rectum |
| **IM** | intramuscular |
| **IV** | intravenous |
| **SC** | subcutaneous |
| **TD** | transdermal |
| **NG** | Naso-gastric tube |
| **PEG** | Percutaneous Gastrostomy |
| **kg** | kilogrammes |
| **g** | grammes |
| **mg** | milligrammes |
| **l** | litres |
| **ml** | millilitres |
| **eg** | 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 Sub-Saharan 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.

> "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

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 community care 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, 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 (chapter 5) gives advice for volunteers and carers as well as information on drug treatments. Communication skills and psychological and spiritual support are addressed (chapter 4), with attention paid to the special needs of children (chapter 6). At the end of the toolkit a set of tools to be used in the field includes forms for patient records and data collection, advocacy material, teaching aids and basic drug lists. These tools can be used as they are or to give you ideas and models to help develop tools for your own service.

This toolkit is an introduction and basic text in palliative care. At the end of each chapter are references to help you find more detail on the topics covered.

For teaching this toolkit is best used in combination with the Palliative Care Toolkit Trainer's Manual (www.thewhpca.org/resources/category/palliative-care-toolkits-and-training-manual) This contains ready-made teaching sessions and courses based on the topics covered in the Palliative Care Toolkit.

**This toolkit can be used by:**

| | | |
|---|---|---|
| **Nurses** | **Doctors** | **Traditional healers** |
| **HBC workers** | **Programme managers** | **Counsellors** |
| **Social workers** | **Children's workers** | **Pharmacists** |
| **Spiritual counsellors** | **Volunteers** | **Family carers** |

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

# Chapter 1: 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 children and adults suffering from:

- Cancer
- HIV
- Progressive neurological illnesses, including dementia
- Severe kidney, liver 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 says

“there is always something we can do”

# Chapter 1: What is palliative care?

**Palliative care is all about looking after people with life-limiting illnesses, relieving their suffering and supporting them through difficult times.**

## 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 life-limiting 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.



The need for palliative care is enormous.

- Over eight million people died from cancer in 2012. 5.3 million of these were in developing countries[1].
- One and a half million people died from AIDS in 2012[2].
- Over 70% of people with advanced cancer or AIDS experience severe pain[3].
- Over thirty five million people are currently living with HIV worldwide[2]. Only one third of them will have access to ARV's[5].
- It is estimated that worldwide at least 40 million people require palliative care each year. 78% of the adults and 96% of the children requiring palliative care are in low and middle-income countries[4].

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. Health workers can become demoralised as they see many patients whom they cannot help.

**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.*

www.who.int/cancer/palliative/definition/en

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.

**Palliative care can help people with**:

- Cancer
- HIV
- Heart Disease
- End-stage lung disease
- Renal Failure
- Liver failure
- Progressive neurological illnesses
- Multi-drug resistant tuberculosis
- Dementia
- End stage Diabetes
- 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.

"Put life into their days, not just days into their life."

Ruth Wooldridge 1988

## 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.

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 community care 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 community 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 chemotherapy and radiotherapy services or ARV clinics 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**
**+**
**Psychological, Social and Spiritual 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 chemotherapy or ARV's. 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.

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 chemotherapy or ARV's. 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 says "there is always something 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.



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2. Global report: UNAIDS report on the global AIDS epidemic 2013.
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   Available from: www.worldday.org/documents/Korea_Declaration.doc [Accessed 9 January 2008].
4. Global Atlas of Palliative Care at the End of Life WHPCA, WHO January 2014
   www.who.int/cancer/publications/palliative-care-atlas/en
5. United Nations World Mortality Report 2013


## Further resources

1. **WHO definition of Palliative Care** (Adults and children)
   www.who.int/cancer/palliative/definition/en
2. **WHO Global atlas on palliative care at the end of life 2014**. A global overview of palliative care needs and development.
   www.thewhpca.org/resources/global-atlas-on-end-of-life-care
3. **Worldwide Hospice and Palliative Care Alliance**. Global membership organization with extensive resources.
   www.thewhpca.org
4. **International Association of Hospice and Palliative Care**. International organization providing technical assistance and promoting collaboration between palliative care providers
   http://hospicecare.com/home
5. **e hospice**. International news and information resource for palliative and end of life care.
   www.ehospice.com

# Chapter 2: 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 can always do something

# 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 the community or on a hospital ward? Do you see patients in their homes, a health centre or in a mobile clinic?

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?**

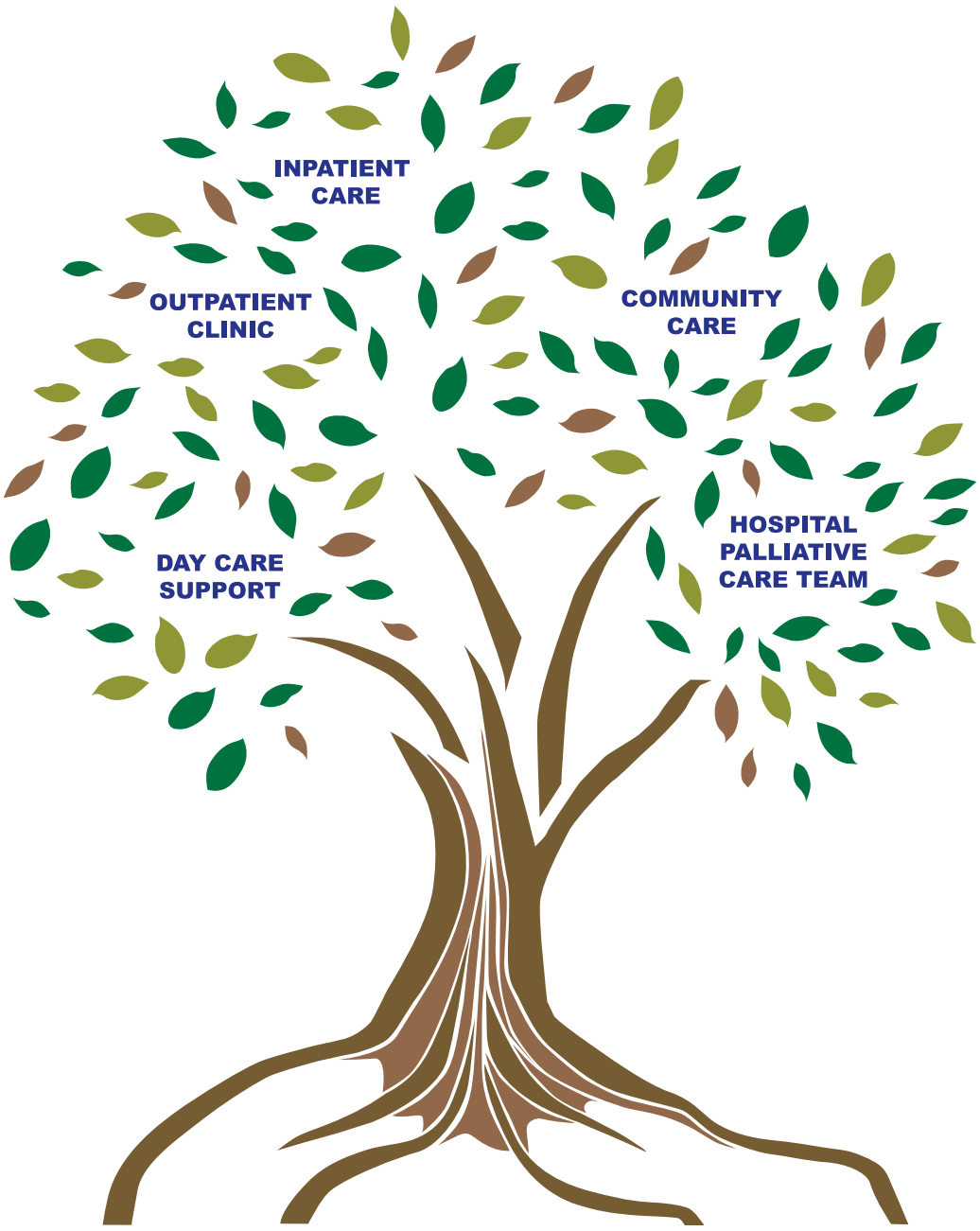
The first two questions look at the needs in our setting and the last two questions look at the resources already in place and what we might do to supplement or complement them. Many successful palliative care projects started very small, when someone noticed a group of people who needed help. They made 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

**Patient care**
Health centre
Local hospital
Private clinics
Traditional healers
NGOs doing healthcare
ARV clinic

**Drug supply**
Hospital pharmacy
Local pharmacy shops

**Advice and support**
Local doctor/nurse/clinician
Local physiotherapist
National palliative care association

### Psychological

**Counselling**
Social worker
Trained volunteer
HIV counsellor
Patient advocates – others with the same illness

**Support groups**
PLHIV group
Women's group
Youth organisations

**Support at home**
HBC volunteers
Family members

### Spiritual

**Individuals**
Local religious leaders
Volunteers from faith communities
Social workers
Family members

**Groups**
Faith community, eg church, mosque, temple, synagogue
Women's groups
Hospital visiting team
Children's groups

### Social

NGOs
FBOs
Food supply work
OVC groups
Income generation schemes
Small loan schemes

**Individual professionals**
Social worker
Legal advisor, for making wills

**Involving others**
Community leaders
Local schools and colleges
Community groups

## 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. Some patients and families may need help with legal issues such as writing a will and protection of children, vulnerable adults and property.

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. Home based care 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. Training family members and friends in basic nursing care gives confidence to those close to the patient. Home based care 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 and necessary 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.



"Go around and see what is being done and then see how your own circumstances can produce another version; there is need for diversity in this field"

Dame Cicely Saunders

## 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 Mongolian Palliative Care Society

#### A doctor introduces Palliative Care through education and advocacy.



In 2000 a doctor in the Medical University of Mongolia attended the European Palliative Care Association Conference in Stockholm. At that time Palliative Care was unknown in Mongolia. On her return she did a survey to identify patients with a poor prognosis and visited them at home. She attended courses in Palliative Care and translated WHO guidelines and examples of models of care from other countries. In 2002 she organised a Leadership Conference on Palliative Care to address policy-makers. She founded the Mongolian Palliative Care Society and started courses in Palliative Care. Advocacy materials on Palliative Care were provided for healthcare policy-makers, healthcare workers, patients, caregivers and the general population via TV, radio and leaflets. Palliative Care has now been integrated into the medical, legal and educational systems in Mongolia and affordable morphine has been available since 2006.

OhioHealth International Palliative Care Leadership Development Initiative, Dec 2013

### 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

### 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

### 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 twenty 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 can always do something.

### 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

### Hospice Ethiopia

#### Using traditional burial societies or "iddirs" to make referrals to palliative care



An "iddir", or local traditional burial society, is an Ethiopian financial and social institution. Originally these groups were formed to help communities bury their dead. The groups are now more wide-ranging and give financial and material assistance to group members. Hospice Ethiopia is using iddirs to create awareness about palliative care and the services that they provide for the local community. The iddirs also work with community volunteers to identify needy patients that would benefit from palliative care. By working with culturally appropriate groups, Hospice Ethiopia is better able to reach those patients in need of its services.

Sr Tsigereda Yisafowessen, Worldwide Hospice Palliative Care Alliance & Hospice Ethiopia

### 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 can always do something.**

## Further resources

The WHPCA, e hospice and the Global Atlas of Palliative Care at the end of life have further information and case studies on the development of palliative care services around the world.

1. **IAHPC: Global Directory of Palliative Care Services, Hospices and Organizations**
   http://hospicecare.com/global-directory-of-providers-organizations

### Regional Palliative Care Associations

These provide support and networking for palliative care organizations as well as providing locally appropriate resources. They can provide contacts for national palliative care associations and individual service providers.

2. **APCA: African Palliative Care Association**
   www.africanpalliativecare.org
3. **IAPC: Indian Association of Palliative Care**
   http://palliativecare.in
4. **Institute of Palliative Medicine, Kerala**
   www.instituteofpalliativemedicine.org/index.php
5. **Pallium India**
   http://palliumindia.org
6. **Asia Pacific Hospice Palliative Care Network**
   http://aphn.org
7. **Latin American Palliative Care Association**
   (ALCP: Asociación Latinoamericana de Cuidados Paliativos)
   http://cuidadospaliativos.org/home

The following two references address the development of palliative care within cancer and HIV services:

8. **Cancer Control, Knowledge into Action WHO Guide for Effective Programmes Palliative Care WHO 2007**
   www.who.int/cancer/publications/cancer_control_palliative/en
9. **Integrating palliative care into HIV services. A practical toolkit for implementers. FHI360 and The Diana, Princess of Wales Memorial Fund 2012**
   www.fhi360.org/sites/default/files/media/documents/Integrating%20Palliative%20Care%20into%20HIV%20Services%20Toolkit.pdf

# Chapter 3: 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

## Together
## Each
## Achieves
## More

## 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

## Ethical principles for Palliative Care

- Autonomy
- Do Good
- Minimize Harm
- Justice

# 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 (p9) 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. Shared values and a common goal are essential.

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.

# Together Each Achieves More

## Training

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

*(The Palliative Care Toolkit Trainer's Manual has ready-made teaching sessions and courses based on the Palliative Care Toolkit. See "Further resources").*

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" p72). 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. Palliative care always faces us with new challenges and it can be helpful to reflect on these with other members of the team. 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.



## Ethical principles for Palliative Care

As a team we need to work to the same agreed ethical principles. The four principles listed below are those that are used generally to guide health and social care workers in their decision making. They become particularly important towards the end of life.

### 1 Autonomy

(Respecting patient's wishes)

- Help the patient to have choice and control over their life and what happens to them.
- Help them to set achievable goals
- Give accurate and truthful information to the patient (see chapter 4)
- Respect confidentiality (see chapter 4 p27)
- Get informed consent for changes in treatment (see chapter 5 p30)

### 2 Do Good

- Communicate well (see chapter 4)
- Give care and treatment that will give overall benefit to the patient (see chapter 5 p30-33)
- Support the patient (see chapter 5)
- Control pain and other symptoms (see chapter 5)

### 3 Minimize harm

- Avoid treatments/drugs that may harm or have no overall benefit for the patient
- Stop treatments/drugs that are no longer helpful (see chapter 5)
- Be aware of the social and financial cost of treatments
- Avoid interventions that stop patients achieving their goals

### 4 Justice

- Respect patients' human rights
- Balance the needs of the individual with those of the family and society
- Use available resources fairly

These are guiding principles, not laws and are not always easy to follow in practice. It is often helpful to discuss these issues together as a team.

## Further resources

1. **Palliative Care Toolkit Training Manual**. This manual is a companion to the Palliative Care Toolkit. It contains structured modules and courses for teaching the material contained in the Toolkit and a chapter on teaching methods; "You can help others to learn".
   www.thewhpca.org/resources/category/palliative-care-toolkits-and-training-manual

**Cardiff/e-cancer e-learning courses**: These consist of twenty e-learning modules covering a good range of palliative care topics, each taking one hour. The courses are freely available and can be accessed by registering with the e-cancer website.

2. **Palliative care e-learning course for health professionals in Africa**. This course has been developed as a collaboration between Cardiff University,e-cancer, Capetown University, the Institute for Hospice and Palliative Care in Africa and the African Palliative Care Association.
   http://ecancer.org/education/course/1-palliative-care-e-learning-course-for-healthcare-professionals-in-africa.php
3. **Palliative care e-learning course for health professionals in India**. The course has been developed as a collaboration between Cardiff University/e-cancer and Bangaluru Hospice Trust, Karunashraya.
   http://ecancer.org/education/course/16-palliative-care-e-learning-course-for-healthcare-professionals-in-india.php

4. **University of Edinburgh Global Health Academy Resources**. These include a toolkit to help integrate palliative care into a teaching curriculum for health-workers and power point presentations on Palliative Care topics from the Makerere Palliative Care unit, Uganda.
   www.ed.ac.uk/global-health/research/project-profiles/health-systems-strengthening/thet/resources
5. **Cairdeas**. A Scottish international charity building capacity in the developing world through clinical education in palliative care. The website has extensive resources including powerpoint presentations on the Palliative Care Toolkit training sessions and protocols for symptom control from countries in sub-saharan Africa.
   www.cairdeas.org.uk
6. **A framework of core competencies for palliative care providers in Africa (2012) (APCA)**. This has been developed by APCA to help service providers and educators in palliative care service development.
   https://www.africanpalliativecare.org/resources-centre
7. **Teaching-aids at Low Cost (TALC)**. A charity providing free and low cost healthcare books and accessories on a wide range of topics including palliative care.
   www.talcuk.org/index.htm
8. **ICPCN's free on-line e-learning courses** www.icpcn.org/icpcns-elearning-programme

# Chapter 4: 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

- Ask the person how much they want to know
- 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 1.19

## 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 and social care 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 alright 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 allow people to make informed decisions about their treatment and care.
- 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"

There is always something we can do and 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".

> "Death is not something to be feared. It is something to be acknowledged and accepted."
>
> Buddha

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

## Way forward

It may be important to discuss 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. Others 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?
- How has your illness affected your beliefs?

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.

One way of thinking about spirituality is to use the word **HOPE** as a checklist for spiritual support:

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

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

**P**ersonal issues – what are their questions, doubts, struggles?

**E**ffect – 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 an incurable illness,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.

> *"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

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 can be 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 point of accepting their loss and rebuilding their life. Supporting them through this process is part of palliative care.

## Confidentiality

We need to remember that any information about a patient is private and must not be shared without their consent. It is often important for the team to share information to help in planning care for the patient but always with their permission. Breaking confidentiality will lead to a break down in trust between the patient and the team.

## Further resources

The Cardiff/ecancer e-learning courses for Africa and India listed at the end of chapter 3 have good modules on communication skills.

# Chapter 5: You can control pain and other symptoms

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

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


**Pain** p34

**Assessment of pain** p34

**Use of analgesics** p34–40

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

**How to prescribe morphine** p36

**Adjuvant drugs** p38

- 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 and sweating p41
- Rashes and itching p42
- Wounds p43
- Seizures p44
- Confusion p45
- Anxiety and sleeplessness p46
- Depression p47
- Poor appetite and weight loss p48
- Fatigue p49
- Sore mouth and difficulty swallowing p50
- Nausea and vomiting p51
- Indigestion and Hiccups p52
- Cough p53
- Breathlessness p54
- Diarrhoea p55
- Constipation p56
- Vaginal discharge p57
- Urinary difficulties p57–58
- Mobility problems p59

**When medication cannot be given by mouth** p60

**End of life care** p61

# 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 the following headings:

- **Assess** the patient
- **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 always something 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.

Remember to always give the patient accurate information and involve them as much as possible in decisions about their care. Where possible you should always ask their consent before starting or stopping drugs or treatments. In this way you will be helping them to give **informed consent** – (see ethical principles p20)

## Assess the patient

A comprehensive assessment of the patient, their situation and the support they have from family/carers is an essential first step to providing good palliative care. Listen to the patient's story. A good history will give you most of the information you need. Remember that the history needs to be holistic – it should focus on psychological, social and spiritual factors as well as physical ones.



**Palliative care patient assessment**
(This can be recorded using Tool 1 see p79)

1. **Diagnosis:**
   - What is their main illness?
   - How long have they suffered from it?
   - What does the patient understand about their illness?
   - What does the family understand about their illness?
   - What treatment have they had?
   - Is the patient affected by any other illnesses?
2. **Medication:**
   - What medication are they taking?
   - What medication have they tried in the past?
   - Has the medication been beneficial?
   - Have they suffered side effects?
3. **Holistic Assessment:**
   - How are they coping?
   - What support do they have?
   - Do they have any spiritual concerns?
   - What are their priorities and goals?

4. **Examination:** (you can use the body map to record what you find). See Tool 1. p80
   - What is their general condition – do they have significant weight loss?
   - Are they alert and able to communicate clearly?
   - How is their mobility?
   - How much are they able to do for themselves?
   - What can physical examination tell you about what is causing their symptoms?
5. **Problem list**:
   - Focus on the symptoms and problems that are most affecting their quality of life.
   - Try and establish what is causing each symptom.
   - Work out and discuss with the patient a clear plan to address each problem.
   - If a new symptom or problem arises then assess again to establish the cause.

## 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 (see ethics chapter 3 p20) 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, p84) 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. A list of essential medicines for palliative care is available from the International Association for Hospice and Palliative Care (IAHPC): See "Further resources" at the end of the chapter.

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

1. **Only give drugs that are doing some good** (see ethics chapter 3, p20)
   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, p85)
- 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, p80). Ask about each one.
- Where is the pain and what does it feel like?
- How long has the pain been there?
- How does the pain affect your life/work/sleep
- 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, p81 gives three useful options.

### Treat

- Painful infections: skin; mouth; chest; urinary tract; meningitis
- Wounds (see p43)
- Constipation (see p56) – if the main cause of pain is constipation then giving opioids may make it worse (see p37)
- 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.
- Support painful or swollen limbs
- 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. If available ranitidine or omeprazole can be prescribed alongside the NSAID to help reduce the chance of stomach irritation or ulceration (see "indigestion and acid reflux" p52).

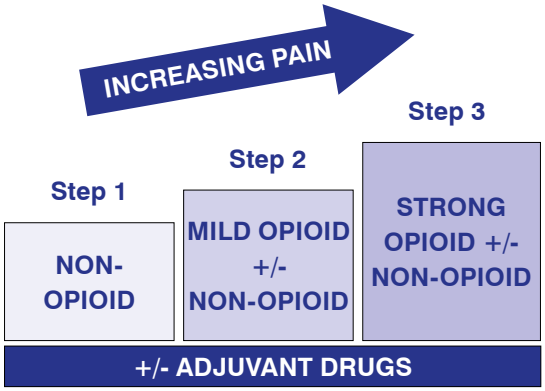
NSAIDS should not be used in patients who are very dehydrated as they may cause renal failure or in patients who have existing renal problems. They can also interfere with blood clotting. They are useful in managing pain from bones and joints and pain from areas of inflammation.

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 IR morphine 5mg 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).

     Low dose IR morphine (2.5-5mg) can be used in place of a mild opioid at step 2.




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, or a cancer that has been reduced by chemotherapy or radiotherapy 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 2 and 3) | No dose limit but increase dose gradually | |
| | **Starting doses**: | |
| Immediate release morphine (IR) | 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. This does not happen if the correct dose is taken to relieve pain.

### Preparations

Morphine comes in two forms:

1. **Immediate release morphine (IR)** – This comes as a tablet or solution which is made up to a certain strength, eg 10mg/5ml or 5mg/5ml. Always prescribe the dose in mg not in ml and make sure you know the strength of the solution. IR 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

**IR 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 5mg 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) up to hourly 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 IR 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 IR 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 IR 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 IR morphine to regular MR morphine:
>
> A patient is taking 10mg IR 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 IR 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 30-50%. 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 IR morphine only:

A patient is taking 20mg IR 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 IR morphine every four hours
**Breakthrough dose** = 180/6 = 30mg IR morphine p.r.n.

**Example**: with IR and MR morphine:

A patient is taking 60mg MR morphine every 12 hours:

They have also taken three breakthrough doses of 20mg IR 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 IR 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, nausea, diarrhoea and confusion). 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 p56) unless the patient also has diarrhoea.
- **Nausea** – Some patients develop nausea when they start morphine so it is good practice to make available an antiemetic (see p51) . This nausea often settles after the first week .
- **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 or is severe
- Confusion
- Hallucinations
- Myoclonus (sudden jerking of the limbs)
- Respiratory depression (breathing rate slowed down). It is rare to get this as a first sign of toxicity if the morphine has been started at low dose and increased slowly to match the level of the pain.

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 (eg the patient has respiratory depression), stop the morphine. **Haloperidol** 1.5-5mg at night may help with hallucinations and confusion caused by morphine.

It is good practice to prescribe morphine in combination with a regular laxative and a PRN anti-emetic. eg

IR Morphine 2.5-5 mg every 4 hrs.

+ Senna 7.5-15mg at night (1-2 tablets)
+ Metoclopramide 10mg 6 hourly PRN

**Alternative Strong Opioids**:

These are other strong painkillers which are similar to morphine.

1. **Oxycodone**: This is twice as strong as morphine so someone changing from Morphine only needs to take half the same dose of Oxycodone. It comes in Immediate Release (IR) and Modified Release (MR) forms and can be used in the same way as morphine.
2. **Fentanyl (Trans-Dermal)**: This comes in the form of a patch that is applied to dry, flat areas of skin and changed every 3 days. It takes 24 hours for the patch to reach full strength after it is applied and 24 hours to come out of the body when the patch is removed. It is therefore difficult to change the dose quickly and it is only suitable for patients with stable pain. Patients should generally be started on morphine first before changing to Fentanyl patches. Fentanyl is much stronger than morphine:

| Fentanyl TD patch size | Equivalent total daily dose of morphine |
|---|---|
| 25mcg/hour | 60mg |
| 50mcg/hour | 120mg |
| 75mcg/hour | 180mg |
| 100mcg/hour | 240mg |

More information on alternative opioids can be found in the Palliative Care Formulary www.palliativedrugs.com

## 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, carbamezapine (caution – interaction with ARV's (see p40) | Nerve damage pain (neuropathic pain) |
| Benzodiazepenes eg diazepam, lorazepam Baclofen | 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 (eg by metastatic cancer)
   - Neck, axilla (armpit) and groin from pressure on nerves.

### 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. If they are of benefit, reduce to the lowest effective dose (see below).

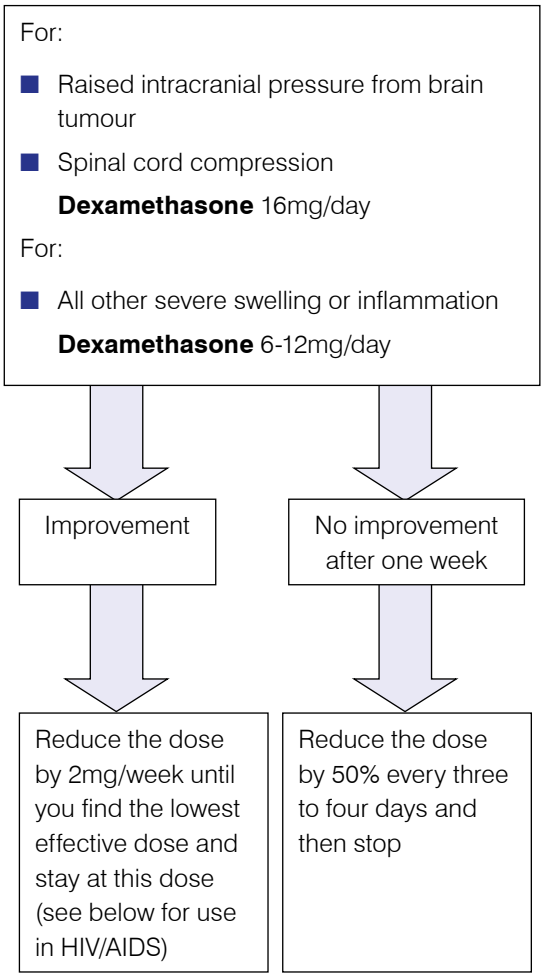
### Side-effects of steroids

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** may need to be prescribed (see p45).

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 **(they should be used with caution in HIV. Check with ARV team before use.)**
- 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)
- **Carbamezapine** 100mg b.d. (increase to 400mg b.d. if necessary)

Note: **carbamezapine** interacts with some ARVs. Check with ARV team before use.

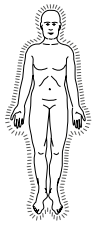
### High dose corticosteroids

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 p56) as hyoscine will make this worse.

# Fever and sweating



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

## Assess the patient

## 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)
  - For possible opportunistic infections in HIV (follow local guidelines)
  - For TB – refer to your local TB clinic

## Care

- Look for signs of infection such as abscesses, cellulitis, urinary infection or chest infection.
- Ask about:
  - Confusion (see p45)
  - Seizures (see p44)
  - Vomiting (see p51).
- Check for dehydration.
- Encourage high fluid intake of cold drinks (at least six to eight cups a day if possible).
- Try ice in drinks or sucking ice.
- 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.
- Use light cotton bedding and clothes.

## 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).

To reduce sweating prescribe:

- **Paracetamol**, **Ibuprofen** or **Aspirin** as above. If not effective try;
- **Amitriptyline** 10-25mg at night

Main side- effects: drowsiness, dry mouth, constipation, confusion.

# 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.

## Assess the patient

## 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 if available.
- Washing with sodium bicarbonate solution (one tablespoon in a bowl of water) can be effective for generalised itch.
- Use lukewarm 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 clean.
- Sunlight can help some skin conditions and worsen others.
- Use light cotton bedding and clothes.

## 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. (Chlorhexidine often comes in a concentrated form and needs diluting with clean water)

**Drugs:**

- **Antihistamines** – help with drug reactions and with itch caused by inflammation.

  **Sedative(will help with sleep)**
  - **Chlorpheniramine** 4mg t.d.s.
  - **Promethazine** 10-25mg at night

  **Non-sedative**
  - Loratidine 10mg o.d
  - Cetirazine 10mg o.d
- Steroids should be prescribed for severe drug reactions, eg **prednisolone** 30mg o.d. for five days (60mg if severe).

# Wounds



## Assess the patient

## Treat

- Bacterial skin infections (see p42)
- Fungal skin infections (see p42)
- Viral skin infections (see p42)
- 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 and moving their limbs if they are not able.
- 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 clean condition over pressure areas (back, sacrum, buttocks, shoulders, elbows and heals).
- Encouraging a high protein diet if possible.

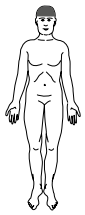
### If wounds occur:

- Record the position and size of wounds on a body map (see Tool 1) and add them to the problem list (see Tool 4). 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 like soft cotton.
- Fresh papaya may be helpful as a dressing if the wound has a lot of dead tissue. Unripe papaya grated and mixed with a wound gel is more effective but should be stopped if it causes bleeding.
- If Metronidazole is not available (see below), 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.
- Bleeding wounds may require packing and pressure bandaging with a pad.

## 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.
- 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. Make sure that they are not taking Aspirin.
- Manage pain with regular analgesics (see p34).
- Pain from fungating wounds may be helped by lidocaine 5% gel/ointment applied with each dressing

# 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.

## Assess the patient

## Treat

- Fever (a common cause of fits in children)
- Malaria
- Meningitis
- Raised intra-cranial pressure (see p38-39)
- Epilepsy
- Low blood sugar
- Sudden withdrawal of drugs such as benzodiazepines or anticonvulsants. Re-start and withdraw gradually if they need to be stopped.
- Alcohol withdrawal

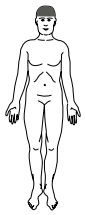
## Care

- During the seizure:
  - Protect the airway of the patient so they can breathe (loosen clothing, lie on side)
  - Don't try to force anything into the patients' mouth
  - Prevent the patient from injuring themselves on sharp objects or fires.
  - Stay with the patient and reassure them
  - Ensure privacy for the patient
- 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 (and record on Tool 1, p80)
- 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).

## Assess the patient

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 p41) 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
- High blood Calcium level with IV fluids and bisphosphonates (IV Pamidronate or Zolendronic acid) if available.
- Stop new drugs that may be the cause of confusion

## Care

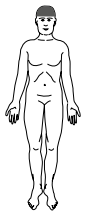
- Try to be as calm and reassuring as possible with the patient.
- A close relative or friend should stay with the patient.
- Minimise the number of people (particularly strangers) dealing with the patient.
- Avoid physical restraint unless it is absolutely necessary for the patient's safety (it will 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 p41).

## 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 or lorazepam 0.5-1mg bd to the Haloperidol if sedation is needed.
- 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.

## Assess the patient

## Treat

- Is the patient in pain? (see p34 for management of pain)
- Urinary problems (see p57-58)
- Depression (see p47)

## Care (Anxiety)

- 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.
- Teach them to slow their breathing (see p54)
- Would it be useful for you or another member of the team to visit again?

## Care (Sleeplessness)

- Take medication for pain or sleep before bed time.
- Avoid coffee and tea in the evening.
- Ensure the room is quiet.
- Reduce sunlight in the room.
- Assist the patient to find a comfortable sleeping position
- Try relaxing music.

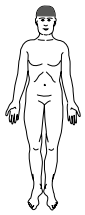
## Prescribe (Only if the anxiety does not resolve with a counselling approach)

1. **Benzodiazepenes** – Try not to use for more than a week unless the patient is terminally ill eg
   - **Diazepam** 2.5-10mg at night – acts for 24 hours in some patients and may cause sleepiness during the day
   - **Lorazepam** 0.5-1mg at night – acts for over 12 hours and may cause sleepiness during the day.
   - **Temazepam** 10-20mg at night – acts for eight hours and is useful for sleeplessness.

Or

2. **Trazadone** 25-50mg at night. This is a sedative antidepressant which may help with sleep and anxiety. **Amitriptyline** 10-25mg at night causes drowsiness which can help sleep but it can also cause constipation, dry mouth and confusion.

# 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.

## Assess the patient

The following symptoms can be useful in diagnosing depressive illness when someone has life-limiting 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 p34) – Unrelieved chronic pain is a major cause of depression in patients who have life-limiting illness.
- Poor Thyroid function

## Care (see care for anxiety p46)

- 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 medication.
  - Encourage carers to seek help quickly if they are worried.

## Prescribe (patients with more severe symptoms may need anti-depressant medication in addition to a counselling approach)

- **Amitriptyline** – starting at 25mg at night and increasing gradually to 75-150mg. Main side-effects: drowsiness, dry mouth, constipation, confusion.
- **Fluoxetine** 20mg once a day. Not sedating but may cause nausea, diarrhoea and some increase in anxiety in the first month of treatment.
- **Sertraline** 25mg od increasing to 50mg od after one week is a similar alternative.
- Warn the patient and carers that it may take two weeks before the antidepressants begin to work.

# Poor appetite and weight loss



Poor appetite (anorexia) is common with any illness and can lead to weight loss. Chronic diseases like cancer, TB and HIV often cause weight loss even when the patient is eating well.

## Assess the patient

## Treat

- HIV with ARVs if they are available (follow national guidelines)
- Oral and oesophageal candidiasis (see p50)
- Diarrhoea (see p55)
- TB (follow national guidelines)
- Nausea and vomiting (see p51)
- Constipation (see p56)
- Depression (see p47)
- 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 and wanted by the patient, 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 p43).

## 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.

# Fatigue



Fatigue is a common symptom of any chronic illness and can also be a side effect of treatments such as chemotherapy, radiotherapy and drugs for TB and HIV. Poor appetite and nutrition can also contribute to fatigue.

## Assess the patient

## Treat

- Anaemia
- Infections including TB
- Malnutrition
- Heart Failure
- Depression
- Poor Thyroid Function

## Care

- Encourage rest
- Regular gentle exercise may help but do not let them exhaust themselves.
- Help with poor appetite as above.
- Help them to set small achievable goals.
- Advise them to save energy for those things that are most important to them.

## Prescribe

Steroids may help improve fatigue for some weeks and should be used in the same way as for poor appetite above.

# 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..

## Assess the patient

## Treat

- Oral candidiasis:
  - **GV paint** (0.5-1%) 1.5mls applied to the areas of candidiasis bd.
  - **Nystatin** oral drops 1-2ml q.d.s. after food. Hold in mouth for one minute before swallowing.
  - **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** 100mg-200mg o.d. for two weeks
  - **Ketoconazole** 200mg PO b.d. for two weeks
- Infection (penicillin plus **metronidazole**)
- Herpes simplex (**aciclovir** 800mg 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 a mouthwash.
- If infection is present 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 p34).
- **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 bd.
- **Metronidazole mouthwash** for smelly mouth from oral cancer: mix a crushed tablet or liquid for injection with fruit juice and rinse round mouth.
- **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



## Assess the patient

## Treat

- Oral or oesophageal candidiasis (see p50)
- Constipation (see p56)
- Infections: malaria, gastroenteritis, urinary tract infection, etc (see p41)
- Raised intracranial pressure with steroids (see p38 & p39)
- Indigestion/heartburn (see p52)

## Care

- Review likely causes of nausea and vomiting including new medication (see above)
- Encourage fluids – small frequent sips are better absorbed.
- If the patient is dehydrated, give fluid as ORS if available. Alternatives are fresh 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 to avoid cooking smells
- Ensure anti-emetics are taken (see below).
- 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 p60).

| Pattern of nausea and vomiting | Causes | Suggested drugs |
|---|---|---|
| **Poor stomach emptying**<br>■ Vomiting is the main symptom<br>■ Vomiting often relieves nausea<br>■ Patient feels full quickly when eating<br>■ May have gastro-oesophageal reflux | ■ Opioids<br>■ Constipation<br>■ Stomach and bowel conditions | ■ **Metoclopromide** or 10-20mg t.d.s. before meals<br>■ **Domperidone** 10-20mg tds |
| **Blood chemistry disturbance/toxins**<br>■ Nausea is the main symptom<br>■ Vomiting often does not relieve nausea | ■ Drugs<br>■ Renal failure<br>■ Hypercalcaemia | ■ **Haloperidol** 1-5mg at night or<br>■ **Prochlorperazine** 5-10mg t.d.s. |
| **Inflammation or swelling in the head**#<br>■ May be worse on movement<br>■ Vomiting often does not relieve nausea<br>■ May be worse in the morning | ■ Ear infections<br>■ Brain tumours<br>■ Meningitis<br>■ Malaria | ■ **Cyclizine** 25-50mg t.d.s. or<br>■ **Promethazine** 25mg t.d.s. or<br>■ **Prochlorperazine** 5-10mg t.d.s |
| **Vomiting with diarrhoea**<br>(exclude 'overflow diarrhoea' (see p55) | ■ Infectious diarrhoea | ■ **Cyclizine** 25-50mg t.d.s. or<br>■ **Promethazine** 25mg t.d.s |
| **Partial bowel obstruction***<br>■ Large volume vomiting<br>■ The patient is still passing occasional flatus and faeces | ■ Constipation<br>■ Abdominal and pelvic tumour | ■ **Metoclopromide** 10-20mg SC q.d.s. Stop if they develop increasing abdominal pain and prescribe as for complete bowel obstruction |
| **Complete bowel obstruction***<br>■ Large volume vomiting<br>■ The patient is not passing any flatus or faeces and they are not strong enough for surgery | ■ Abdominal and pelvic tumour | ■ **Cyclizine** SC 50mg t.d.s.or<br>■ **Promethazine** 25mg SC t.d.s.<br>■ **Hyoscine butylbromide** SC 20-40mg q.d.s. in addition to an anti-emetic will reduce vomiting and pain. |

# Vomiting due to brain tumours may be helped by steroids (see p39).
* 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: **Cyclizine** or **promethazine** plus **haloperidol**



# Indigestion/gastro-oesophageal reflux

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

## Assess the patient

## 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.
- Avoid spicy foods and alcohol.

## 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 or irritating the diaphragm or from renal failure.

## Assess the patient

## Treat

- Constipation (see p56)
- Urinary retention (see p58)

### 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.
- Lean the patient forward with knees pulled up to the chest
- Try nursing the patient sitting up.

## Prescribe

If the hiccups do not go away prescribe:

- **Metoclopramide** 10-20mg t.d.s. or
- **Haloperidol** 1.5-3mg at night or
- **Chlorpromazine** 25-50mg at night

If the hiccups do not respond to the above drugs they may be helped by:

- **Baclofen** 5-10mg t.d.s. (may help hiccups not responding to the above).



# Cough

## Assess the patient

## Treat

- Chest infection
- TB
- Asthma
- COPD (chronic obstructive pulmonary disease)
- Oral and oesophageal candidiasis (see p50)
- Sinusitis
- Indigestion/reflux (see p52)

## 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 steaming water and breathes deeply. A towel over the head can be used to contain the steam
  - Postural drainage: the patient is moved into different positions to help drain sputum from different parts of the lung
  - Clapping on the patients back with 'cupped' hands in each position.
- 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.
  - IR Morphine 2.5-5mg every four hours.
- Large amounts of thin sputum may be helped by anticholinergic drugs, eg:
  - Amitriptyline 10-25mg 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.

## Assess the patient

## Treat

- Chest infection: TB, bacterial pneumonia or PCP (pneumocystis)
- Anaemia
- Asthma
- Heart failure
- Pleural effusion
- Cough (see p53)

## 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.
- Arrange pillows so that the patient can rest forwards on table or firm surface
- 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 p46).

## Prescribe

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

- **IRMorphine** 2.5-5mg every four hours

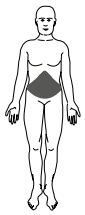
If there is anxiety and panic with the breathlessness these may be helped by:

- **Diazepam** 2.5-5mg up to t.d.s. (especially if there is anxiety and panic)or
- **Lorazepam** 0.5-1mg bd

If a patient is dying with distress from shortness of breath, they may need larger doses of morphine and benzodiazepenes.

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

- Dexamethasone 6-12mg o.d. (see p39).



# 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.

## Assess the patient

## Treat

- Dehydration with ORS (Severe dehydration may require IV fluids)
- Constipation (can sometimes cause overflow diarrhoea). Do an abdominal and rectal examination if there is any history of previous constipation to see if there is impacted stool in the rectum or colon.
- 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.

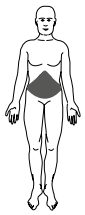
## Care

- 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 and abdominal 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.

## Assess the patient

## 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.
- Encourage the patient to be as mobile as possible.
- Encourage the patient to take laxatives with opioids as prescribed (see page )
- If available, dried papaya seeds can be chewed (five to 30 seeds at night) or crushed and mixed with a strong-flavoured 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.
- Review toilet facilities. If they are having difficulty using a hole in the ground, a seat may help.
- 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.

Patient's with hard stool may also need a laxative which softens or lubricates. Use what is available locally. Examples are:

- Lactulose 10-20mls b.d.
- Docusate Sodium 100-200mg b.d.
- Magnesium Hydroxide Mixture BP 10-20mls b.d.



# 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.

## Assess the patient

## 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

In cervical cancer this may be caused by a fistula between the bladder and vagina.

## Assess the patient

## Treat

- UTI
- Retention with overflow (see below)
- Spinal cord compression (see p38,39&59)

## 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 or barrier cream.
- Encourage fluids – sometimes patients stop drinking for fear of incontinence, but dehydration will not help their overall condition.
- Encourage regular toileting throughout the day and before bedtime

## Prescribe

- Consider a catheter if available (this may not help if there is a fistula present).



# Urinary retention

## Assess the patient

## Treat

- Faecal impaction due to constipation (see p56)
- Urinary tract infection
- Drug – induced (tricyclic antidepressants, eg **amitriptyline**, **opiates** – temporary effect)
- Spinal cord compression (see p38,39&59).

## 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 or more frequently if necessary.

## Prescribe

- A Urinary catheter (see above).



# 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.

## Assess the patient

## Treat

- UTI

## Care

- Encourage plenty of fluids.
- If catheterized, try reducing the volume of water in the catheter balloon by 2-3mls and changing the position of the catheter.

## Prescribe

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



# Mobility problems

In chronic illness mobility may be reduced by many factors including weakness and fatigue, muscle loss, pain and nerve damage.

## Assess the patient

## 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 p39).

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## 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 p43).
- 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.
  - Consider the use of walking aids such as walking sticks (these could be made locally)

## Prescribe

- Analgesia can help improve mobility.
- Adjuvants for muscle spasm (see p40).

# 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/Percutaneous gastrostomy – Some patients may be discharged from hospital with an NG tube or PEG, 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 p37) If available, injectable morphine should be given every four hours by the subcutaneous route.

Only 50% of morphine taken by mouth is absorbed. **Morphine is therefore 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 IR morphine to regular SC morphine:

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

The patient will need 10/2 = 5mg 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 = 30mg

**The four hourly dose** of SC morphine is 30/6 = 5mg

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 IR** 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: **metoclopromide**, **cyclizine** 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 – little 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.

## Assess the patient

## 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 to swallow and keeping the mouth moist is the priority. IV or SC fluids are generally not necessary at this stage to prevent thirst.
- 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 p60).

Painkillers should be continued if possible even after the patient is unconscious (see p60).

Medication can be continued even after the patient is no longer able to swallow it by mouth (see p60).

If injectable medications are available, the following may be useful in end of life care:

**Morphine** SC 4 hourly for pain.

**Midazolam** SC 2.5-5mg 4 hourly for restlessness

**Midazolam** SC 5mg prn for seizures.

**Haloperidol** SC 1-5 mg od for nausea

**Haloperidol** SC 2.5-10mg od for agitation

**Hyoscine Butylbromide** SC 20mg qds for secretions in chest/upper airway (noisy breathing)

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

Bono

## Further resources

1. **Palliative drugs.com**

   An on-line formulary containing detailed information about drugs used in palliative care. There is also a "Bulletin board" where you can ask advice from other users of the site. If you are working in a HINARI A or B list country then access to the site is free (see: www.who.int/hinari/eligibility/en). When you register for the site you will be sent an e mail explaining the process.
   www.palliativedrugs.com

2. **IAHPC Palliative Care Essentials**:

   Essential medicines for palliative care (WHO) adults 2013
   Essential medicines for palliative care (WHO) children 2013
   IAHPC list of essential practices in palliative care 2012
   hospicecare.com/resources/projects/palliative-care-essentials

3. **The IAHPC Manual of Palliative Care 3rd Ed**. A user-friendly online manual covering all aspects of palliative care.
   hospicecare.com/about-iahpc/publications/manuals-guidelines-books/manual-of-palliative-care

4. **Introducing palliative care by Robert Twycross**
   An excellent basic textbook of palliative care. The 5th edition was published in 2016 by Radcliffe Medical Press, Oxford.

   The 4th addition is available at low cost:

   In India from the Institute of Palliative Medicine, Medical College, Calicut, Kerala, India
   Email: pain@vsnl.com

   In Africa from Wits Palliative – training, PO Box 212, Pimville, 1808, Soweto, South Africa
   Email: palliative.training@wits.ac.za

5. **A clinical guide to supportive and palliative care for HIV/AIDS in Sub-saharan Africa**. A comprehensive textbook with an extensive list of resources.
   www.globalpartnersincare.org/education-0/publications

6. **Palliative care: A Handbook of Palliative Care in Africa (2010) (APCA)**. A useful handbook covering adult and paediatric palliative care.
   https://www.africanpalliativecare.org/resources-centre

7. **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.
   www.hospiceafrica.or.ug/index.php/publications/blue-book

8. **NCCN Distress Thermometer and problem list**: A holistic tool for measuring distress in patients
   https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf

   Distress management guidelines incorporating the Distress Thermometer. You need to register with the National Comprehensive Cancer Network website to access the guidelines.
   https://www.nccn.org/about/permissions/thermometer.aspx

# Chapter 6: 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

continued overleaf…

# Assessment in children

- Focus on the child
- Listen to the child
- Listen to the carer
- Observe closely
- Think holistically

# Symptom control in children

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

# 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

# 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.

The UN Convention on the Rights of the Child reminds us that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times and particularly to older children and teenagers.

## 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.

The older the child the more possible it is for them to make their own decisions and to have some control over their life. Generally young people will be well aware of what is happening but may want to avoid difficult issues and conversations. Teenagers don't always want to talk. We can offer them the space to talk privately and alone if this is helpful for 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. What children know about death and dying changes with age and development and it can be useful, where possible to explore this.

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 and 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 their age and development.
- Make sure they know it is all right to ask questions.
- Never force too much information on someone.
- Never lie or make promises you can't keep as this will damage 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. Young people may become withdrawn and uncommunicative or their behaviour may become more challenging.

**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
- Give them choices and respect their abilities.
- Make space for spiritual support.
- Understand different reactions to loss.
- Give extra love and attention but maintain normal routines and rules as far as possible.

## 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 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.

## Assessment and symptom control in children

Key Principles of Assessment:

- Focus on the child
- Listen to the child
- Listen to the carer
- Observe closely
- Think holistically

Great attention has to be paid to assessment of symptoms in children as they cannot always tell us what is distressing them. Parents and carers may not notice all the relevant signs. It is very useful to observe children while you are talking to their parents 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.

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:

- Assess the child
- Treat what is treatable
- Care for the child
- Prescribe palliative drugs

Use chapter 5 for the treatment of specific symptoms; Tool 16, p96 for paediatric doses.

## 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

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, p81).

The principles of pain control are the same as for adults: give drugs by mouth, by the clock, by the ladder. Codeine is not recommended for children under 12 so the ladder goes straight from non-opioids to low dose morphine. 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, p96. 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 always something 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**.

## 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 p50).
- When very sick, advise carers that children will not eat much (see p48) and avoid force-feeding.

### Skin problems

- Some are treatable (eg scabies, ringworm) (see p42).
- 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)

- URTIs 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. (Refer to WHO guidance on diarrhoea in children. See link in Further resources.)
- 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 p43 & 59).
- 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 option. Don't forget to ask the child or young person what they would prefer – even if it is not possible to provide this, it is important to understand their hopes and fears. 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.**

## Further resources

1. **International Palliative Care Children's Network (IPCN)**. Membership organization that supports the development of childrens' palliative care services internationally. The website has extensive links and resources. www.icpcn.org
2. **No secrets** by Dr Mary Bunn. A practical guide to helping families and carers to talk to children about life-limiting illness, written for health care workers in Malawi. www.icpcn.org/document-downloads
3. **A Really Practical Handbook of children's Palliative Care** by Dr Justin Amery. A free downloadable text on children's palliative care which is comprehensive and written "for doctors and nurses anywhere in the world". www.icpcn.org/a-really-practical-handbook-of-childrens-palliative-care
4. **Association for Paediatric Palliative Medicine Master Formulary 2015 (3rd edition).** This has detailed information on drug dosing and administration for children's palliative care. www.appm.org.uk/10.html
5. **WHO guidelines on persistent pain in children** www.who.int/medicines/areas/quality_safety/guide_perspainchild/en
6. **aboutkidshealth** (UK-based on line resource). More detailed information on pain assessment in children including the FLACC scale www.aboutkidshealth.ca/en/resourcecentres/pain/painassessment/measurementofpain/pages/tools-for-measuring-pain.aspx
7. **WHO guidance on children's diarrhoea** www.who.int/maternal_child_adolescent/documents/diarrhoea/en

# Chapter 7: 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 Ghandi

## 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.
- Palliative care is increasingly being recognized as a human right

**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 and 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 and 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, p90 & 91)
- Posters (eg Tool 12, p92)

## 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. The Palliative Care Toolkit Trainer's Manual has ready-made teaching sessions and courses based on the Palliative Care Toolkit (see Further resources p21)
- 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 essential to have basic statistics at our fingertips to use when talking about the work we are doing in order to provide evidence of the need for pain relief and palliative care. In the Toolkit there is a monthly report sheet which can be used to collect data (Tool 10, p89).

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
- How many died, how many transferred to hospital/community care service.
- What the outcome for the patients is eg relief of pain and/or distressing symptoms, improvements in quality of life, support for the patients' family etc The "Further resources" section at the end of the chapter includes two outcome measurement tools.

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, p93)
- 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.




**Worldwide Advocacy for Palliative Care**

Internationally palliative care is increasingly being recognized as a human right. The need for palliative care worldwide is huge and growing. Less than 14% of those who need it have access to palliative care services. We need to lobby for palliative care to be available to all those who need it as part of **Universal Health Coverage**. This is a move to make healthcare, including palliative care, available to all who need it globally and to protect the poorest people from financial risk due to health care costs.

References:

1. Open Society Foundation (2015) Palliative Care as a Human right -factsheet
2. WHPCA (2014) Universal Health Coverage and Palliative Care

## Further resources

1. **Resources listed at the end of chapter 1**: The WHPCA, e hospice and IAHPC all have extensive resources that can be useful in advocacy.
2. **Resources listed at the end of chapter 2**: The regional palliative care associations also have useful and locally appropriate resources for advocacy.
3. **Advocacy Toolkit**. A downloadable toolkit on advocacy from the WHPCA website
   www.thewhpca.org/resources/category/advocacy-resources
4. **Successful Advocacy for Palliative Care: A Toolkit (2011) (APCA)**. A toolkit for palliative care advocacy in Africa downloadable from the African Palliative Care Association website
   https://www.africanpalliativecare.org/resources-centre
5. **WHO fact sheet on palliative care**; A helpful summary of key facts relating to palliative care advocacy.
   www.who.int/mediacentre/factsheets/fs402/en
6. **WHO infographics sheet on palliative care**. Clear and well- presented poster giving information on improving access to palliative care.
   www.who.int/ncds/management/palliative-care/pc-infographics/en
7. **World Hospice and Palliative Care Day**. A unified day of action in October to celebrate and support hospice and palliative care around the world which is coordinated by WHPCA.
   www.thewhpca.org/world-hospice-and-palliative-care-day
8. **POS: Palliative Care Outcome Scale**. A validated tool for collecting outcome data about palliative care. You need to register on the website to get access to the tools. The website contains detailed information and education on how to use the POS tool.
   pos-pal.org/maix

   The African Palliative Care Association (APCA) has developed an African POS which is available on the resources section of their website.
   https://www.africanpalliativecare.org/resources-centre/apca-african-pos
9. **NCCN Distress Thermometer**: A holistic tool for measuring distress in patients listed at the end of chapter 5 which can also be used to provide outcome data for palliative care.

# 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. Community 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. Community 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. Basic drug list

List of basic drugs needed for palliative care.

## 18. Additional Drug list

List of additional drugs that can be useful if available.

# Palliative care patient assessment

| Patient name | Patient number | Start date |
|---|---|---|
| Sex / Age / Resides | | |

Referred from

☐ HBC tea ☐ 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

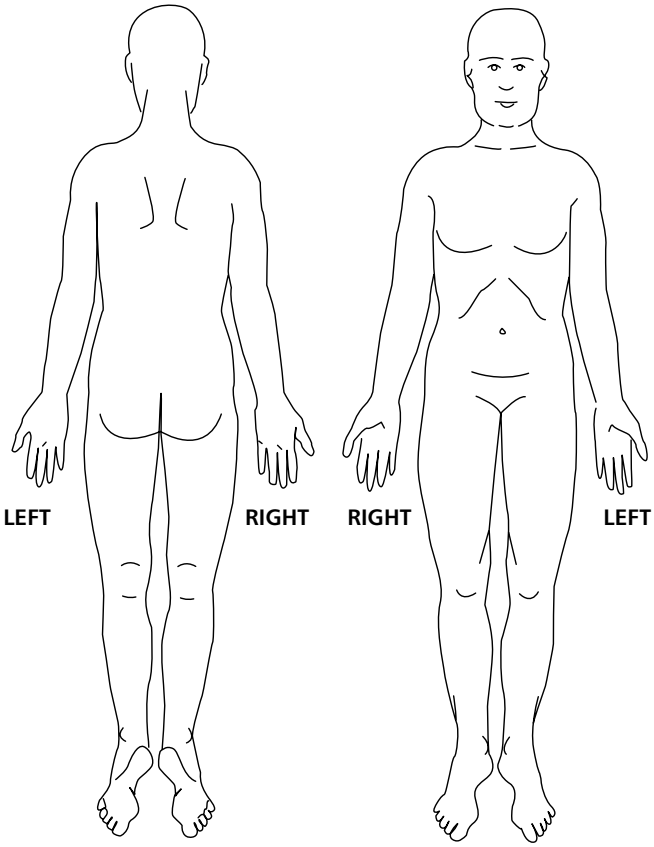
| General condition | Weight/kg |
|---|---|
| | |

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

Chest

Abdomen

Neurological




### Problem list

| Date | Problem<br>physical / psychosocial / spiritual | Action plan | Date resolved |
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# Pain assessment tool

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

### Five-finger score

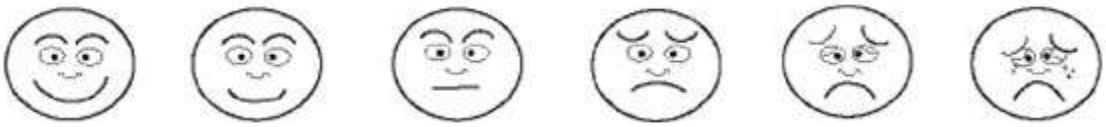
Ask the patient to show how bad the pain is with their hand



**0** no hurt | **1** hurts little bit | **2** hurts little more | **3** hurts even more | **4** hurts whole lot | **5** hurts worse

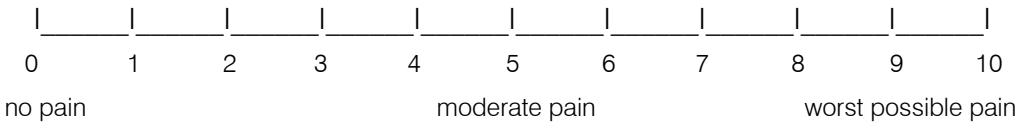
### Faces score

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




## Eight important questions to ask the patient

- **Where** is the pain? (there may be more than one pain)
- **When** did it start?
- **What** effect does the pain have on life/work/sleep
- **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

| PATIENT NUMBER | START DATE | PATIENT NAME | SEX | AGE | LOCATION | REFERRED FROM | DIAGNOSIS | END OF CARE DATE | OUTCOME: DEATH/ MOVED/ DISCHARGED |
|---|---|---|---|---|---|---|---|---|---|
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# 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) |
|---|---|---|---|---|---|---|---|
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**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 (SPECIFY WHICH)

# Patient-held record for community care

| PATIENT NAME | AGE | SEX | RECORD NUMBER |
|---|---|---|---|
| | | | |

| DATE FIRST SEEN | LOCATION | MAIN GUARDIAN NAME |
|---|---|---|
| | | |

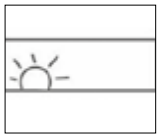
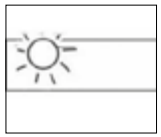
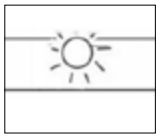
| VISIT DATE | VISIT DONE BY | CONDITION OF PATIENT 1 2 3 4 | MAIN PROBLEMS | CARE GIVEN A B C D E F G H I J | OTHER NOTES (PSYCHOSOCIAL, SPIRITUAL ISSUES) |
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**CONDITION OF PATIENT:** **0** WELL **1** ACTIVE; ABLE TO DO LIGHT WORK **2** SELF-CARING 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)**  |
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- **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)*

| Date | Dose | 6am | 10am | 2pm | 6pm | 10pm | 2am | Number of extra doses |
|---|---|---|---|---|---|---|---|---|
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- Tick the chart each time a regular dose is given
- Record the total number of extra 'breakthrough' doses given in the 24 hour period

# Community care volunteer kit

## Basic contents

Plastic gloves

Plastic sheeting

Plastic bags

Soap

Washing powder

Plastic bottle to use for incontinent patients

Pieces of clean cloth for cleaning wounds

Clean dressings

Sticky tape

Vaseline

Gentian violet paint

Paracetamol tablets

Aspirin

Laxatives (eg bisacodyl tablets or suppositories)

Oral rehydration salts

Metronidazole tablets (crushed) for putting on wounds

Home visit record sheet

Patient-held record to leave with patient

Pen

## Health worker kit

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

Ibuprofen

Codeine*

Morphine*

Amitriptyline

Diazepam

Metoclopramide

Amoxycillin

Cotrimoxazole

Metronidazole

Ketoconazole

Catheters

Drug dosage lists

Patient assessment form

* 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.**[2]

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:**

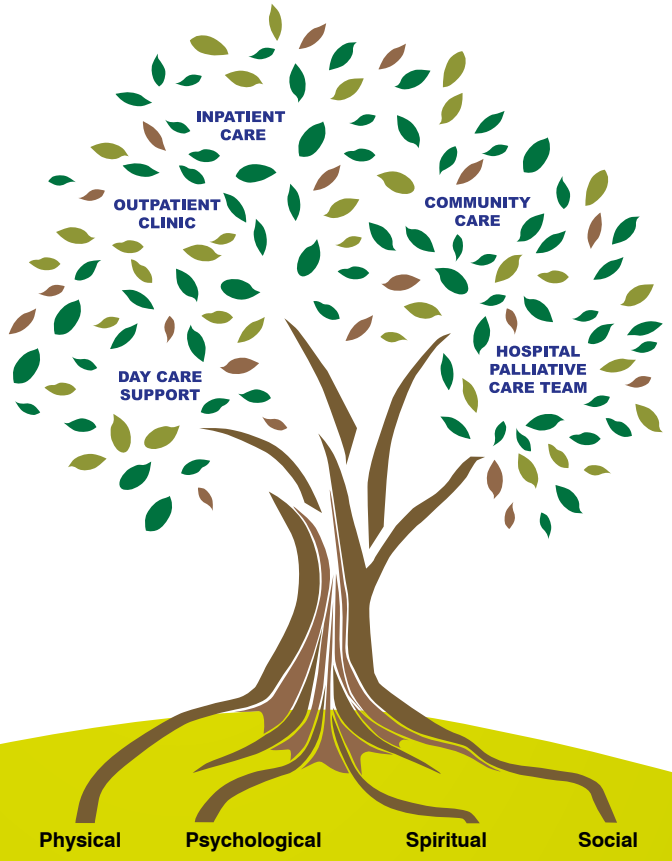
- **In hospital**
- **At home**
- **In an outpatient clinic**
- **In a hospice**
- **In a local health centre**
- **In a mobile clinic**
- **In a day care centre.**

**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




## Improving quality of life for those with advanced disease

# 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[1] 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: www.who.int/cancer/palliative/painladder/en

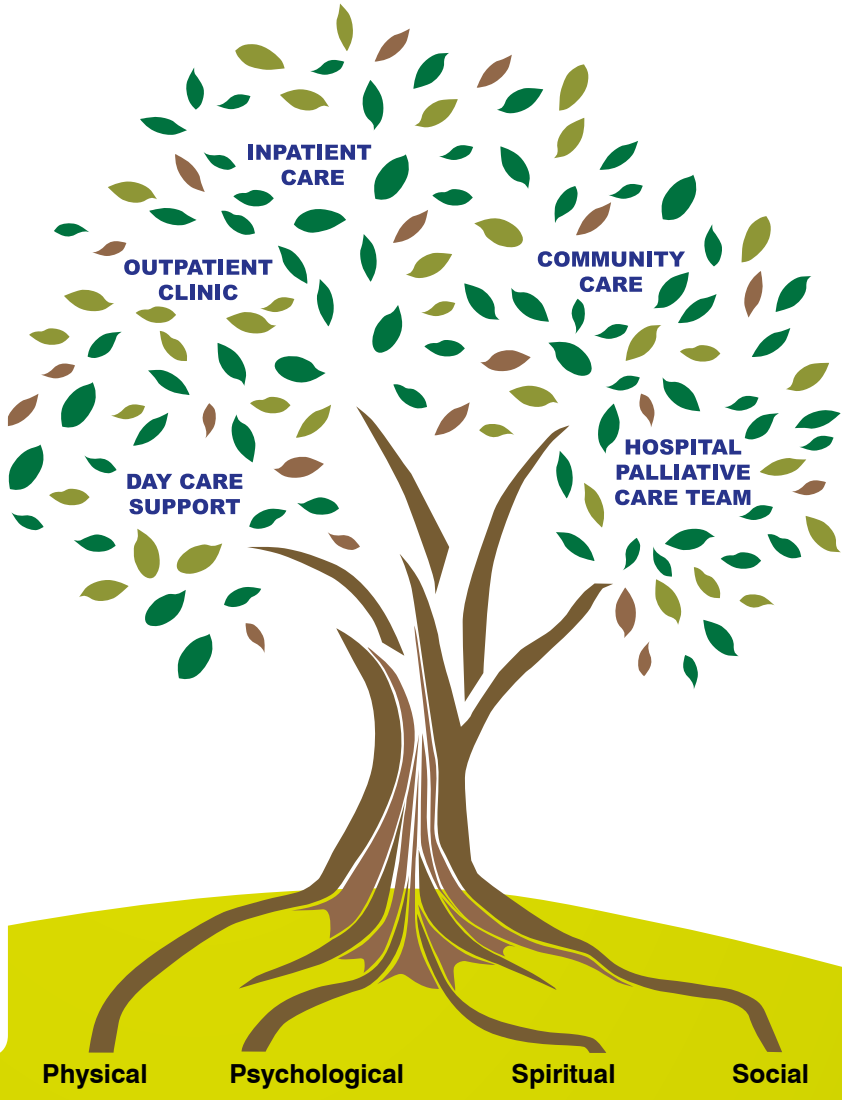
# Palliative care

**...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/community care coordinator/doctor involved in giving palliative care to people with cancer/HIV/advanced illness. Palliative care aims to help those with life-limiting illness, 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[1] and here in..... programme/community/clinic/hospital I see many patients suffering unnecessarily in this way.

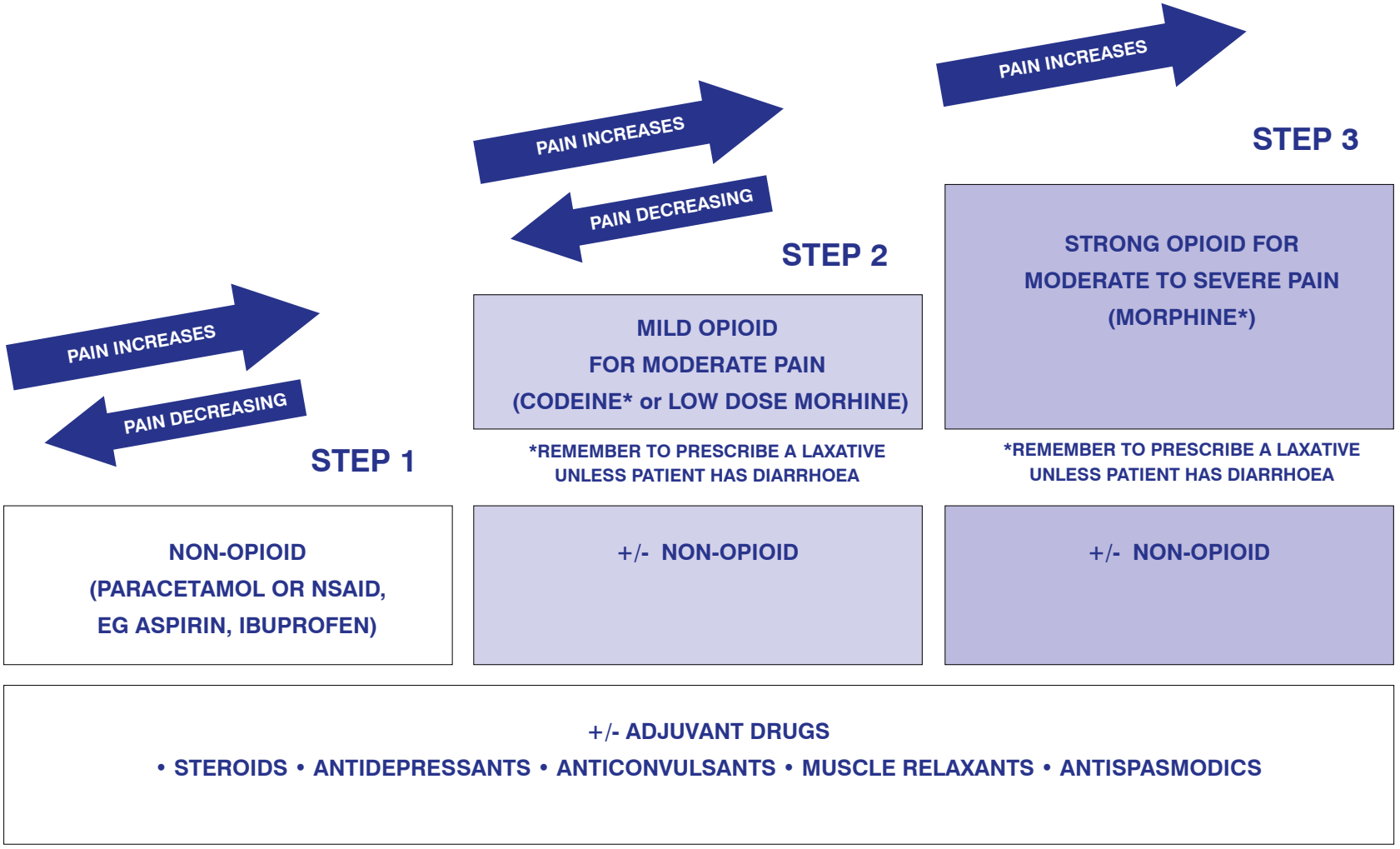
The World Health Organization (WHO) has produced a three-step analgesic ladder for pain control[2]. This starts with non-opioid analgesics for mild pain and proceeds to morphine for severe pain. The WHO essential drug list recommends that morphine should be available in any basic healthcare system for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

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,

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

# The analgesic ladder for pain control



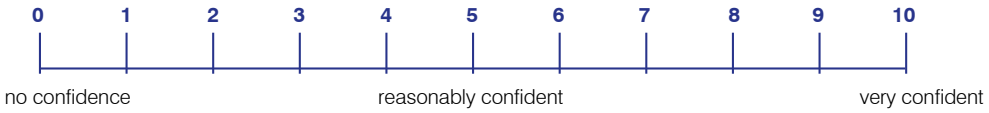

Give analgesics: • by the mouth • by the clock • by the ladder

Source: World Health Organization

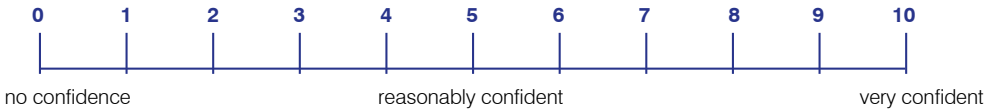
# Confidence rating scale

**NAME:** **DATE:**

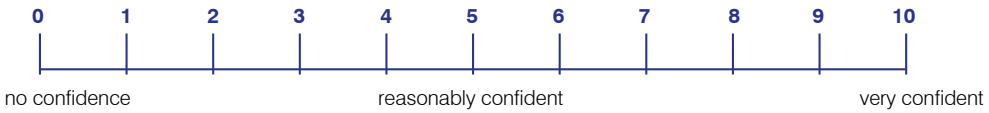
**I can assess a palliative care patient's pain**



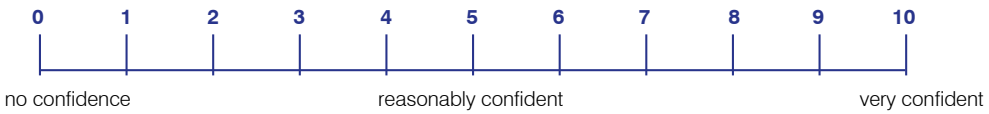

**I understand the WHO three-step analgesic ladder**



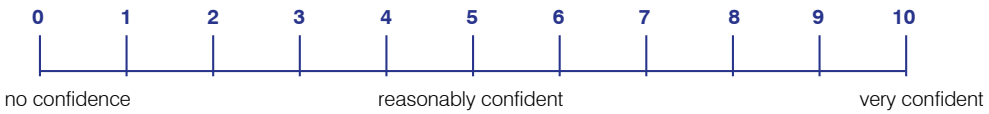

**I understand how to prescribe opioid analgesic drugs such as morphine**



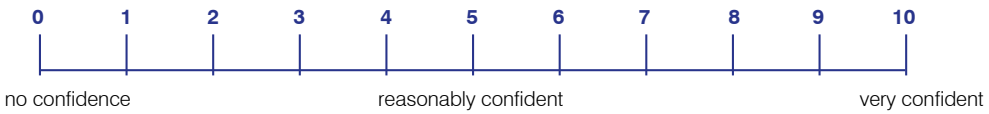

**I understand the role of palliative care for patients with cancer and HIV/AIDS**



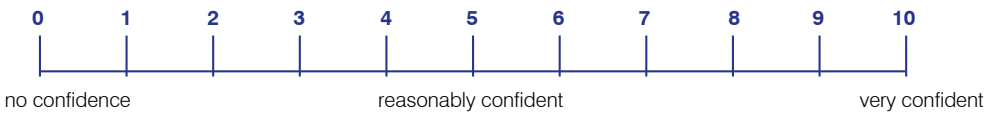

**I understand what is meant by holistic history taking**



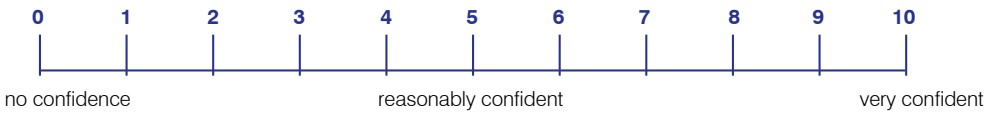

**I can discuss anxiety with a palliative care patient**




**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 |
| Amitriptyline for neuropathic pain | 1 at night | Starting dose 0.2 mg/kg Max. dose 10mg | – | 6.25mg | 10mg |
| Bisacodyl for constipation | 1 | 5mg total | 5mg | 5mg | 5-10 mg |
| Chlorpheniramine for itching or night sedation | 3 | 0.1mg/kg | 0.5mg | 1mg | 2mg |
| Cyclizine for nausea/vomiting | 3 | 0.5-1mg/kg | 3-6.25mg | 6.25-12.5mg | 12.5-25mg |
| Dexamethasone** | 2, morning & lunchtime | 0.1-0.5mg/kg | 0.5-1mg | 1-2mg | 2-4mg |
| Diazepam for anxiety or agitation | 3 | – | – | 1-2mg | 1-2mg |
| Diazepam for muscle spasm | 2 | 0.25mg/kg | 1.25mg | 2.5mg | 5mg |
| Diazepam – Rectal, for prolonged seizures/status epilepticus | 1 Single dose | 0.3-0.4mg/kg | 1.25-2.5mg | 5mg | 5-10mg |
| Domperidone for nausea/vomiting | 3 | 0.25mg/kg | 0.75-2.5mg | 2.5-5mg | 5-10mg |
| Ibuprofen for pain or fever | 3 | 5-10mg/kg | 50mg | 100mg | 100-200mg |
| Ketoconazole for severe candida | 1 | 3mg/kg | 25mg | 50mg | 100mg |
| Loperamide for chronic diarrhoea (NB not for use in acute GE) | 3 | 0.1-0.2 mg/kg | By weight | 1mg | 2mg |
| Oral morphine for pain (and breathlessness) | 6 | starting dose 0.1-0.3mg/kg | 1-2mg | 2.5mg | 2.5-5mg |
| Paraldehyde (50:50 mix with oil) – Rectal, for prolonged seizures/ status epilepticus | 1 single dose | 0.8ml/kg | Max 20ml | | |
| Prednisolone** (if dexamethasone not available. See notes under dexamethasone above) | 2, morning & lunchtime | 1-2mg/kg | | | |

* 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 for long courses.

A more comprehensive list of drug doses is available in the "Master Formulary" from the Association of Paediatric Palliative Medicine in the UK: www.appm.org.uk/10.html

# Basic drugs for palliative care

| Drug name | Class | Clinical uses | Alternative drugs |
|---|---|---|---|
| Amitriptyline | Tricyclic antidepressant<br>Adjuvant analgesic | Nerve pain p38-40<br>Depression p47<br>Sweating p41 | Dosulepin<br>Lofepramine |
| Amoxycillin | Antibacterial | Chest Infection p53&54<br>Skin infections p42 | Erythromycin |
| Aspirin | Non-opioid analgesic | Pain control p34<br>Fever p41<br>Sore mouth p50 | Paracetamol |
| Chlorpheniramine | Antihistamine | Itch p42<br>Drug reactions p42 | Promethazine<br>Hydroxyzine |
| Codeine | Weak opioid analgesic | Pain control p35<br>Diarrhoea p55<br>Cough p53 | Dihydrocodeine |
| Co-trimoxazole | Broad spectrum antibacterial | Infective diarrhoea in HIV/AIDS p55<br>Urinary Tract infection p57-58<br>PCP prophylaxis | Chloramphenicol<br>Doxycycline |
| Dexamethasone | Corticosteroid<br>Adjuvant analgesic | Painful swelling and inflammation p39<br>Poor appetite p48<br>Drug reactions p42 | Prednisolone |
| Diazepam | Benzodiazepine<br>Adjuvant analgesic | Muscle spasm p40<br>Anxiety and sleep p46<br>Shortness of breath p54<br>Seizure treatment p44 | Lorazepam |
| Docusate Sodium | Laxative | Constipation p56 | Magnesium Hydroxide |
| Fluconazole | Antifungal | Oral and oesophageal candidiasis p50 | Ketoconazole |
| Haloperidol | Antiemetic<br>Antipsychotic | Vomiting p51<br>Hiccups p52<br>Confusion and agitation p45 | Chlorpromazine<br>Olanzapine |
| Ibuprofen | NSAID<br>(Non-opioid analgesic) | Pain control p34<br>Inflammation<br>Fever p41 | Diclofenac<br>Naproxen<br>Indomethacin |
| Loperamide | Antidiarrhoeal | Diarrhoea p55 | Codeine<br>Lomotil |
| Midazolam | Benzodiazepene | Seizures p44 | Diazepam |
| Magnesium trisilicate | Antacid | Indigestion p52<br>Gastro-oesophageal reflux p52 | Aluminium hydroxide<br>Magnesium hydroxide |
| Metoclopramide | Antiemetic | Vomiting p51<br>Poor appetite p48 | Domperidone |

| Drug name | Class | Clinical uses | Alternative drugs |
|---|---|---|---|
| Metronidazole | Antibacterial for anaerobic infections | Infection of gums/teeth p50<br>Infective diarrhoea (PO) p55<br>Offensive wounds (top) p43<br>Vaginal discharge (PV) p57 | Co-Amoxiclav<br>Tinidazole |
| Morphine | Strong opioid analgesic | Pain control p37<br>Breathlessness, cough p53-54<br>Severe diarrhoea p55 | Tramadol<br>Oxycodone |
| Nystatin susp. | Antifungal | Oral and oesophageal candidiasis p50 | Ketoconazole |
| ORS | Oral rehydration salts | Diarrhoea p55<br>Rehydration | Ricewater<br>Coconut milk |
| Paracetamol | Non-opioid analgesic | Pain control p34<br>Fever p41 | |
| Senna | Laxative | Constipation p56 | Bisacodyl |

**Skin preparations**

| | | | |
|---|---|---|---|
| Benzyl benzoate | Scabicide | Scabies p42 | Permethrin cream/ lotion |
| Chlorhexidine 0.05% | Antiseptic | Bacterial skin infection p42 | Gentian violet |
| Clotrimazole 1% cream | Topical antifungal | Fungal skin infections p42 | Whitfields ointment<br>Miconazole cream |
| Gentian violet paint (0.5-1%) | Topical anti-septic | Bacterial, fungal and viral skin infections p42 | |
| Vaseline | Skin moisturizer | Dry skin p42 | Aqueous cream |

# Additional drugs for palliative care

| Drug name | Class | Clinical uses | Alternative drugs |
|---|---|---|---|
| Acyclovir | Antiviral | Herpes zoster and herpes Simplex infections | |
| Baclofen | Muscle relaxant | Muscle spasm p40 | Diazepam |
| Cimetidine | Antacid | Indigestion p52<br>Gastro-oesophageal reflux p52 | Ranitidine<br>Omeprazole |
| Ciprofloxacin | Broad-spectrum antibacterial | Bacterial infections p41 | Chloramphenical |
| Clotrimazole pessary | Topical antifungal | Vaginal candidiasis p57<br>Oral candidiasis p50 | Nystatin pessary |
| Cyclizine | Anti-emetic | Vomiting p51 | Diphenhydramine<br>Promethazine |
| Fluoxetine | SSRI anti-depressant | Depression p47 | Citalopram<br>Sertraline |
| Hyoscine Butylbromide | Antimuscurinic | Abdominal colic p40 | Propantheline |
| Paraldehyde | Anticonvulsant | Seizure treatment p44 | Diazepam |
| Phenobarbital injection | Anticonvulsant | Seizure treatment p44<br>Severe agitation and confusion p45 | Diazepam |
| Propantheline | Antimuscurinic (Anticholinergic) | Bladder spasm p58<br>Abdominal colic p40<br>Watery sputum p53 | Hyoscine butylbromide |
| Pyridoxine | Vitamin | Pyridoxine deficiency with Isoniazid causing nerve pain | |
| Tramadol | Weak opioid analgesic | Pain control p35 | Codeine |
| Tranexamic acid | Haemostatic | Bleeding wounds p43 | |
| Trazadone | Anti-depressant | Anxiety and sleeplessness p46 | Amitriptyline |
| Quinine | Antimalarial | Night muscle cramps<br>Malaria treatment p41 | Diazepam |
| Valproate | Anticonvulsant<br>Adjuvant analgesic | Seizure prevention p44<br>Nerve pain p38-40 | Gabapentin<br>Carbamezapine |

**Skin preparations**

| | | | |
|---|---|---|---|
| Aqeous cream/UEA ith 1% menthol | Skin moisturizer | Rash p42 | Itch |
| Calamine lotion | Itch | Rash p42 | Aqueous cream W with 1% menthol |
| Lidocaine 5% gel or ointment | Local anaesthetic | Painful fungating wounds p43<br>Sore Mouth p50 | |

# Feedback

We would  like to receive your comments on your experience of using the toolkit as these can then be used to inform any future revisions or updates.

Please send comments to:

Email: info@thewhpca.org

or through the PCW website: www.palliativecareworks.org

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

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