



# Palliative Care Toolkit

## Trainer's Manual By Dr Vicky Lavy

## **About Help the Hospices**

Help the Hospices is the leading charity supporting hospice care throughout the UK.

Help the Hospices also has an international programme that supports the development of hospice and palliative care worldwide, particularly in developing countries.

## **About the Worldwide Palliative Care Alliance**

The Worldwide Palliative Care Alliance (WPCA) is a network of national and regional hospice and palliative care organisations from around the world. The WPCA works 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.

While great care has been taken to ensure the accuracy of information contained in this publication, it is necessarily of a general nature and Help the Hospices cannot accept legal responsibility for any errors or omissions that may occur. The publishers and authors make no representation, express or implied, with regard to the accuracy of the information contained in this publication. The views expressed in this publication may not necessarily be those of Help the Hospices. Specific advice should be sought from professional advisers for specific situations.

The materials in this guide may be reproduced for non-commercial use by hospices, other palliative care organisations and health workers, and the necessary copyright permission have been sought and granted for this purpose. Copying for any other purpose is strictly prohibited without the written consent of Help the Hospices.

The right of Vicky Lavy to be identified as the author of this work has been asserted by her in accordance with the Copyright, Designs and Patents Act 1988.

© Vicky Lavy 2009

Published in 2009 by Help the Hospices. Registered Charity in England and Wales, Help the Hospices no. 1014851. Company Limited by Guarantee registered in England No. 2751549. Registered office: Hospice House, 34-44 Britannia Street, London, WC1X 9JG, UK.

# ACKNOWLEDGEMENTS

## **Author**

Dr Vicky Lavy lived and worked in Malawi for 10 years where she set up Umodzi Palliative Care for children. She designed Malawi's first basic palliative care training course and was involved in its subsequent development into a national training programme.

## **Editorial team**

Dr Karilyn Collins spent six years working in palliative care in Tanzania. She founded Muheza Hospice Care, the first independent NGO dedicated to palliative care in the country, and has a special interest in palliative care in ARV programmes. She is a board member of the Tanzania Palliative Care Association.

Gillian Chowns has combined a role as a specialist palliative care social worker with a senior lecturer post in the School of Health and Social Care at Oxford Brookes University during the past 10 years. She has lived and taught in Kenya for several periods and has researched the impact of palliative care education on day-to-day practice in East and Southern Africa.

Dr Mhoira Leng is a palliative care specialist with 18 years experience both in Scotland and internationally. As founder and medical director of Cairdeas International Palliative Care Trust, she has taught in different parts of India, in Malawi and Uganda. She is now Head of Palliative Care at Makerere University and Mulago Hospital, Kampala.

Dr Charlie Bond is a consultant at Severn Hospice in the UK with an interest in the delivery of palliative care in resource-poor settings. He has worked in several African countries and has been involved in palliative care training in Malawi, Sierra Leone and China.

Ruth Wooldridge is a palliative care nurse who has lived and worked in India and Kenya and is a co-founder of Nairobi Hospice and CanSupport in Delhi. She is a member of the Help the Hospices International Palliative Care Reference Group and is currently involved in starting palliative care in Rwanda.

## **Pilot course**

The training material was piloted in Tanzania as part of the Muheza Hospice Care roll-out programme for Tanga region in November 2008.

# CONTENTS

## ACKNOWLEDGEMENTS

<b>INTRODUCTION</b>	1
<b>TEACHING TECHNIQUES</b> YOU CAN HELP OTHERS TO LEARN	2
<b>THE TEACHING MODULES EXPLAINED</b>	17
<b>MODULES</b>	
<b>MODULE 1</b> WHAT IS PALLIATIVE CARE?	18
<b>MODULE 2</b> YOU CAN DO PALLIATIVE CARE IN YOUR SETTING	26
<b>MODULE 3</b> YOU CAN IMPROVE YOUR COMMUNICATION SKILLS	30
<b>MODULE 4</b> YOU CAN BREAK BAD NEWS WELL	36
<b>MODULE 5</b> YOU CAN GIVE SPIRITUAL CARE	41
<b>MODULE 6</b> YOU CAN GIVE BEREAVEMENT SUPPORT	47
<b>MODULE 7</b> YOU CAN ASSESS PAIN AND OTHER PROBLEMS	52
<b>MODULE 8</b> YOU CAN TREAT, CARE AND PRESCRIBE	58
<b>MODULE 9</b> YOU CAN CONTROL PAIN	63
<b>MODULE 10</b> YOU CAN USE MORPHINE	67
<b>MODULE 11</b> YOU CAN HELP DIFFERENT SYMPTOMS 1	73
<b>MODULE 12</b> YOU CAN GIVE END OF LIFE CARE	77
<b>MODULE 13</b> YOU CAN HELP CHILDREN AND FAMILIES	83
<b>MODULE 14</b> YOU CAN HELP DIFFERENT SYMPTOMS 2	89
<b>MODULE 15</b> YOU CAN TELL OTHERS	93
<b>MODULE 16</b> YOU CAN BUILD A TEAM	97
<b>MODULE 17</b> CONFIDENTIALITY	102
<b>ADDITIONAL SESSIONS</b>	106
INTRODUCTORY SESSION	106
FINAL SESSION	108
ASSESSMENTS FOR THE END OF THE COURSE	111
<b>RESOURCES</b>	
<b>RESOURCE 1</b> ROLE PLAY SCENARIOS FOR COMMUNICATION SKILLS	112
<b>RESOURCE 2</b> SCENARIOS FOR BREAKING BAD NEWS	113
<b>RESOURCE 3</b> SCENARIOS FOR HOLISTIC HISTORIES	114
<b>RESOURCE 4</b> BENEFIT AND BURDEN	116
<b>RESOURCE 5</b> PRESCRIPTIONS TO USE WITH TOOL 6 OF THE TOOLKIT	117
<b>RESOURCE 6</b> QUIZ ON THE ANALGESIC LADDER	118
<b>RESOURCE 7</b> MORPHINE CALCULATIONS	120
<b>RESOURCE 7A</b> ANSWERS TO MORPHINE CALCULATIONS	122
<b>RESOURCE 8</b> SCENARIOS FOR SYMPTOM CONTROL 1	124
<b>RESOURCE 9</b> SCENARIOS FOR END OF LIFE CARE	126
<b>RESOURCE 10</b> DIFFICULT QUESTIONS	127
<b>RESOURCE 11</b> SCENARIOS FOR COMMUNICATING WITH CHILDREN	128
<b>RESOURCE 12</b> SCENARIOS FOR SYMPTOM CONTROL 2	129
<b>RESOURCE 13</b> COURSE EVALUATION	131
<b>RESOURCE 14</b> END OF COURSE ASSESSMENT IN PALLIATIVE CARE	132
<b>RESOURCE 15</b> SCENARIOS FOR CONFIDENTIALITY	138

# INTRODUCTION

## What is this manual?

This manual is a companion to the Palliative Care Toolkit. It contains structured teaching modules and resources which can be used to help others explore and learn the material contained in the Toolkit. It includes ideas and suggestions for those who are training and information about teaching methods, but it is not a comprehensive 'training of trainers' manual.

The modules can be used as single sessions on specific topics, or put together to create courses. Courses can be made to suit different audiences by choosing the modules which are relevant in each situation. Some suggestions for structuring courses and programmes are given on pages 15–16 of this manual.

The manual is meant to be a guide and can be adapted to suit your own situation. You may already be an experienced teacher and can use that experience and skill, bringing in your own stories and case studies.

## Who is it for?

It is written for those with some experience in palliative care who want to help others learn too. Trainers will usually be health professionals but some of the material could be taught by those in allied professions, eg social workers, counsellors and others.

## Using the manual:

- Intended for teaching a group, ideally between 10–25 people.
- Must be used alongside the Toolkit because all the learning material is in the Toolkit and is not repeated in the manual.
- The manual is for the trainer, not the participants.
- If possible, each participant should have a copy of the Toolkit to use during the session/course and to keep afterwards.
- If this is not possible, or you are teaching an isolated session, the pages needed can be photocopied or downloaded and given out as handouts. The Toolkit is available as a book, a CD ROM and online at [www.helpthehospices.org.uk/international/toolkit](http://www.helpthehospices.org.uk/international/toolkit).
- The first section, 'You can help others to learn', is not part of the teaching material, but is an introduction to adult learning for trainers and explains how to use the different teaching methods in the manual.

# TEACHING TECHNIQUES YOU CAN HELP OTHERS TO LEARN

Teaching is more than just passing on information. It is also about getting people interested and excited about what they are learning and about changing attitudes and building skills. It is about encouraging people as they learn and drawing out the knowledge and experience they already have. It is about building a trust relationship with those who wish to learn and helping people to continue learning even after the formal training session or course has finished.

This may sound a daunting task but this manual has been written to help those who want to help others learn about palliative care, using the Toolkit as a resource.

## How do adults learn?

Part of being an effective teacher involves understanding how adults learn. They have different needs and requirements to children and teenagers:

- Adults already have a foundation of knowledge and experience from their previous education, their work and their life experiences. Teaching involves recognising and drawing out this knowledge and connecting it to what is being taught. Members of the group may learn as much from each other as from the teacher, who is also a lifelong learner.
- Adults are self-directed and take responsibility for their learning. They are used to making decisions in other areas of their lives, so need to be involved in setting goals for their learning and in the learning process itself. Teachers act as trainers, guiding participants to their own knowledge as well as supplying them with facts. Participants take responsibility for presentations and leading group discussions.
- Adults can feel vulnerable and anxious about revealing their lack of knowledge in new areas. They need to be treated with respect. They should feel free to say when and how they are having problems, and need encouragement.
- Adults want to use their knowledge in their work. They may not be interested in gaining knowledge for its own sake, but want to learn things that will be useful in their work. Teaching must be relevant and practical.
- Adults are busy people. They have many responsibilities that they must balance with the demands of learning. Time must be used effectively.

## Different learning styles

Different people learn in different ways. Many of us received most of our training through lectures, where learning takes place by listening, but this is not the way that everyone learns best. Some people remember visual images better than spoken information and find pictures and diagrams helpful. Some people learn best by discussing questions with a group and working together to solve a problem. Others learn by practising skills and remember the things they have actually done, such as examining a patient or role-playing communication skills. Some learn best by looking back and reflecting on events and situations they have experienced.

Different people can learn by:

- **watching**
- **listening**
- **thinking**
- **doing**
- **feeling.**

?

WHAT KIND OF LEARNER ARE YOU?

THINK OF SOMETHING YOU HAVE LEARNT – PERHAPS RIDING A BICYCLE OR LEARNING A LANGUAGE. WHAT HELPED YOU TO LEARN? THINK ABOUT YOUR FEELINGS, THE CIRCUMSTANCES, THE TEACHER, YOUR MOTIVATION, THE BENEFITS OF LEARNING THIS SKILL AND THE KEY STEPS ALONG THE WAY.

In any group there will be people with different learning styles. In the same way, different subjects require different teaching methods – learning facts, practising skills and understanding new concepts require different kinds of teaching.

It is good to use a variety of teaching styles and methods to help different learners and teach different subjects. Several methods can be used within one teaching session.

**What I discover, I use**

**What I hear, I forget**

**What I see, I remember**

**What I do, I understand**

Chinese proverb

## What makes a good teacher?

Teaching involves different skills. Some are related to the content of what is taught, but equally important is the way the content is put across, which is related to the interpersonal skills of the teacher.

Important skills are:

- preparation of subject matter
- planning sessions carefully
- communication skills
- managing the group dynamics
- ability to adapt to the learners' needs and respond to what participants bring to the session
- nurturing skills to encourage and support students as they learn.



WHO WAS THE BEST TEACHER YOU EVER HAD?

WHAT WAS HE/SHE LIKE?

WHAT WERE THE THINGS WHICH MADE HIM/HER AN EFFECTIVE TEACHER?

NOW THINK ABOUT A BAD TEACHER.

WHAT MADE IT DIFFICULT TO LEARN FROM HIM/HER?

WHAT DID OTHER STUDENTS THINK?

## Different teaching methods



LIST THE DIFFERENT TEACHING METHODS YOU HAVE EXPERIENCED OR USED.  
WHICH ONES DO YOU FIND HELPFUL?

ARE THERE SOME METHODS WHICH ARE USEFUL IN PARTICULAR SETTINGS?

Hopefully your list will have included some of the methods we describe below. You may have included others as well; ours is not an exhaustive list. It is good to try new ways of doing things but it is more important to use the methods well than to use all of them.



## Question and answer

The trainer asks questions and participants answer by:

- calling out answers
- noting down their answers on paper and giving themselves a score
- in a team quiz, or in pairs.

This can be useful for finding out how much participants know, or for reviewing what has been learned in a previous session.

- Encourage less vocal members to join in by saying “let’s hear from someone who hasn’t spoken yet” or “what about someone on this side of the room?”
- Be encouraging when people contribute, recognising the value of what they have said, but be clear if an answer is completely wrong so that the rest of the group is not misled, eg “That’s an interesting suggestion but in fact the answer is...” or get others to comment, eg “That’s an interesting answer, what do others think?”
- Giving out small prizes (eg sweets) for correct answers can be a light-hearted way of making it fun.

The questions can be used to lead into a discussion, with the trainer inviting others to comment on the answers and share their experiences and opinions. The trainer needs to guide the discussion and prevent it straying from the topic.

## Buzz groups

Participants turn to those sitting next to them (groups of two or three) and discuss a question briefly, for two to five minutes. At the end of the time there can be feedback to the whole group by calling out. It is not always necessary to hear from every buzz group. This is a non-threatening way of getting people involved as they are usually much more ready to speak out in the whole group if they have already discussed it with their neighbours. If you are teaching a smaller group who know each other well and are interactive, buzz groups may not be needed.

If you are running a course over several days, encourage people to sit in different places each day so that they have different ‘buzz group partners’.

## Lecture/presentation

Lectures can impart a lot of information to a lot of people at one time, but much of this information may be forgotten.



HOW MUCH CAN YOU REMEMBER OF THE LECTURES YOU HEARD?

ONE STUDY SHOWED THAT STUDENTS’ RECALL AT ONE WEEK WAS 20%.

When teaching the Toolkit, all the factual information the participants need is contained in the Toolkit which they should have with them throughout the course. Because of this, the sessions do not use the lecture method a great deal. Instead, the participants should be encouraged to turn to the relevant page of the Toolkit during the session. This brings in visual learning as well as listening and it helps participants to become familiar with using the Toolkit as a resource.

Lectures:

- can be a good way to impart factual information
- require thorough preparation by the presenter
- should be kept short or broken up with activities or discussion to prevent people from becoming bored and 'switching off'
- should not be used for an entire session. Participatory work is important
- can be enhanced by visual aids, eg overhead projector, PowerPoint presentation, flipchart.

### Visual aids

?

LIST THE VISUAL AIDS YOU HAVE SEEN BEING USED.  
WHICH ONES DO YOU LIKE BEST AND WHY?

Your list may include:

- flipchart
- overhead projector (OHP)
- PowerPoint presentation
- blackboard and chalk or whiteboard and pens.

All of these can help participants to focus and follow a lecture, and act as prompts for the trainer, but they can be a distraction if they are not prepared well. Beware of relying on visual aids which require electricity if the supply is erratic. You should either choose a different way of presenting, or make sure you can still give your presentation without the visual aids.

- Prepare well in advance.
- Writing must be large enough to be read easily from the back of the room.
- Do not put too much information on one slide/sheet/transparency. Try to use no more than five or six lines of writing.

- Use brief headings and talk around them; avoid simply reading out your slides.
- Try to avoid giving someone else's presentation without adapting it or putting in some of your own material, otherwise it can sound very 'second hand'.
- Pictures and diagrams can say a lot and are sometimes more memorable.

#### PowerPoint

- **Looks very professional**
- **Can use pictures/diagrams/photos**
- **Can be used alongside other things, eg flipchart for interactive parts of session**
- **Requires careful preparation**
- **Requires expensive equipment and electricity**
- **It is important to encourage participation otherwise students may simply sit back and watch.**

#### Flipchart

**The flipchart is one of the most useful and adaptable visual aids. It is a large pad of paper (poster size) which is put on a stand so that everyone can see it. If a ready-made flipchart is not available, large pieces of paper stuck to the wall are just as good.**

- **Sheets can be prepared in advance as visual aids for a presentation.**
- **Can be used during sessions to note down important points as they are brought up by participants, very good for interactive teaching.**
- **Can be used by participants during group work.**
- **Sheets can be kept and displayed to remind participants later/the next day of learning points – remember to bring something to fix them to the wall.**
- **Requires no electricity.**
- **Easily transportable.**
- **Try to get someone else (another trainer or a participant) to write while you are teaching so that you can keep the discussion moving. Listening, talking and writing at the same time usually leads to bad handwriting and spelling mistakes.**
- **Make sure you have plenty of pens – these should be thick markers if available.**

Other sorts of visual aids include:

- pictures, eg postcards to pass around, or those in the Toolkit
- equipment, eg syringe, drug chart
- other objects to help people remember a point.

### **Small group discussion**

Participants divide into smaller groups and discuss questions prepared in advance by the trainer. These may be the same or different for each group. They could be around a case study, or a problem to be solved, or a controversial issue.

- Give questions to each group on paper or write them on a board or flipchart so that everyone is clear what they are being asked to discuss.
- Trainer (s) can move around the room and 'drop in on' the groups to help as necessary.
- Mix up the groups during the day so that participants work with different people. You can do this by numbering people around the room using the number of groups you want, then all those with number one form a group, those with number two form another and so on.

### **Feeding back after group work**

Always allow as much time for feedback as for the actual group work:

- Before they begin, suggest that groups appoint a spokesman who will take notes and report back.
- It is sometimes helpful for a group to write their points on flipchart paper to present when reporting back.
- The trainer asks each group to report back in turn. Encourage spokesmen not to repeat what other groups have already said.
- If you are short of time, you can ask each group to choose the one thing they think is most important.
- Do not always start with the same group.
- It may be useful for the trainer to note down the main points on the flipchart – if possible, get someone to help with this so that you are not trying to write and facilitate at the same time.
- Have a list of the main learning points ready so that you can add to the feedback if important points have been missed, or put the list up for participants to compare with their answers.

**'The walking wall' is an alternative to verbal reporting back – each group puts their written reports on the wall and everyone walks around and reads. They can ask each other questions as they go. This gets everyone moving which can be helpful if people are tired. Afterwards there can be questions or comments, perhaps picking out the common elements or the differences in each group's findings.**

### **Brainstorm**

This can be done in the whole group or in small groups. A question or problem is given, then everyone calls out ideas and suggestions and they are all written down (eg on flipchart or overhead projector) without criticism or discussion. At the end of the brainstorm the list is reviewed and discussed.

### **Role play**

Role play is an unrehearsed acting out of a real-life situation which can give insight into the thoughts and feelings of those in that situation and allow participants to practise skills such as history taking, breaking bad news etc.

- Participants volunteer to do role play – trainers can also take part.
- A previously prepared or volunteered scenario is given to those doing the role play and they are given a short time to 'think themselves into' their character.
- Make sure the scenario chosen reflects a real life situation for the participants, but they should not undertake roles that are too close to their own experience, eg it would be unwise for someone who has recently lost a family member to play the role of someone who has been bereaved.
- The scenario is acted, the actors responding and reacting to each other as they feel their character would do. They can use whatever language they are most comfortable with.
- Actors can call for 'time out' if they are struggling.
- The rest of the group watch and observe, taking note of learning points.
- When the role play is over, each actor is invited to comment on:
  - how they felt during the scenario
  - what went well
  - what could have been done differently.
- Those observing the role play are then invited to comment, remembering to give positive feedback first and to be constructive with any criticism.
- Role play must be done in an atmosphere of mutual respect and confidentiality. Make sure that those who play the acting roles are able to debrief and return to their usual role afterwards.

### **Interactive role play (sometimes called ‘Goldfish bowl’)**

This is a form of role play in which the observers can direct what happens. Volunteers act out a scenario to the whole group and at certain points the facilitator will ‘freeze’ the action and ask the group what should happen next and then the actors try out their suggestions. This shows that there may be different ways of doing things, and the responsibility of ‘getting it right’ is on the whole group and not just the actors.

The facilitator asks questions such as:

- How do you imagine X is feeling right now? What should Y do next?
- Has X explained this well? What else does he/she need to say?
- X has asked a question. What are the different ways Y could answer? Let’s try them each in turn and see which works best.

Different people can swap in to become an actor at any point:

- Let’s give X a break, who would like to take the role of the doctor/nurse/counsellor now?

This type of role play keeps the whole class involved but needs good facilitating.

If the group is large it could be split if there are enough trainers to manage two groups.

It can be useful to start off with facilitators in one or more of the roles. If a facilitator plays the health worker and does it badly, one of the participants can swap in and do a better job.

### **Patient testimony**

Sometimes it is very powerful to invite a patient or relative to your session. They can tell their story, answer questions or even be interviewed by the facilitator or one of the course participants.

Make sure you prepare the patient and group well and allow the patient to opt out if it gets difficult. They may need a chance to debrief afterwards and of course confidentiality is essential.

### **Story telling**

Telling stories from real life is a powerful and memorable teaching tool. This will often be a story about a patient or family, but it might be from outside the work context, eg stories about the different ways people behave and react.

### **Reflection**

Reflection involves learning from experiences, often interactions with patients but also life experiences. A simple structure guides the reflective process, eg:

- describe the situation
- what went well

- what could have been better
- what would have allowed me to do this better (eg skill to be learned or practised, knowledge required).

To start off it may be helpful to model this process, giving an example of your own work, or even the way you facilitated the previous session.

Reflective learning can form part of a teaching session when time is given for participants to reflect, perhaps writing down their thoughts which may or may not be shared with others. It is also a useful skill to introduce because it is an excellent way for participants to continue learning after formal teaching is over. Keeping a reflective diary of encounters and events in our work is a useful way of learning from our experiences.

### **Practical experience**

This might involve learning a particular skill such as measuring out and dispensing a drug, or dressing a wound. The trainer should give a demonstration, making clear the different steps involved. Then participants take turns to practise, either all together or in small groups. As with role play, the participants are invited first to say what they did well and what they should have done differently. Then other members of the group can be invited to comment.

It might involve field visits to see patients in home-based settings, or seeing patients in a clinic or hospital ward. Make it clear what you want the participants to do and ask them to take notes of their experiences. Assignments might include taking a history from a patient, making a problem list, interviewing patients or volunteers about their experiences or observing how a clinic/programme runs. At the end of the trip participants come back together and discuss:

- what they did/saw/heard
- what was good
- what was difficult
- what could have been done differently
- how they felt about the experience.

### **Ice breakers**

An ice-breaker is a short, fun exercise used at the beginning of a session to make people feel relaxed and to help them get to know each other a little. It gives the message that the session is going to be interactive and encourages them to take part.

Examples are:

- Introduce yourself to your neighbour and tell them why you have come on this course, what is your favourite food and what toothpaste you use.
- Tell your neighbour three things about yourself, two true and one false – they have to guess which one is false.

- Discuss with your neighbour if you were an animal, what animal you would be and why.

You can make up your own.

## Energisers

These are brief exercises which give everyone a break from concentrating to be refreshed and re-energised for the rest of the session. They can be put in half way through, to keep people going, or used whenever the trainer notices that people are looking tired or distracted. They are useful after lunch.

Examples are:

- Everyone stands up, turns around, stretches and runs on the spot for five seconds.
- Everyone moves around the room and greets five people.
- Everyone sings a song that most people know.
- Get the participants to stand up and “write” their names using their body.

You can make up many more.

## Planning sessions

Careful planning is essential. A plan should include:

- aim of the session – topic to be covered
- learning objectives – what you want participants to know/understand by the end of the session
- teaching methods to be used in the session
- timing of each part of the session.

### Learning objectives

**These are the key points that you want the participants to have learned by the end of the session. Some educational models use ‘SMART’ to create objectives that are clear and easily measurable:**

**Specific**  
**Measurable**  
**Attainable**  
**Realistic**  
**Time bound**

**This is a helpful overview for preparation and encourages clarity. You may need to be more flexible when the objective is exploring new concepts or changing attitudes.**



When planning group work, carefully prepare the assignments you will give to the groups, eg discussion questions, case studies, role play scenarios. The resources at the end of the manual provide material for group work – you may want to adapt them or write new ones to make them relevant to your setting. It may be helpful to translate them into your local language.

Think ahead about what you want them to find out or achieve from the group work. This might involve writing a checklist of important points for yourself so that you can reinforce them and make sure you bring in points which participants did not mention. Many checklists are provided in the modules, which can be put on visual aids if desired.

Try to stick to the timing of your lesson plan. This will mean keeping a close eye on the clock when you are talking, and being firm with participants when doing group work – they must stop when the time is up, even if they have not finished the exercise. It is good to give them a warning a few minutes before the end.

It can be frustrating to stop interesting discussions or leave out some stories or examples you planned to include. However, if you do not stick to time, you will either miss whole sections at the end of sessions, or overrun the session into a lunch or tea break.

## Ten tips for interactive teaching and managing groups

- Try to learn the names of your students (unless the group is very large and it is a very short, one-off session). Ask students to say their names and say one thing about themselves, and do a quick sketch plan of where they are sitting. This enables you to personally ask individual students for a response, to begin to establish a more personal relationship, and gives you greater control of the group – participants are likely to be more engaged and attentive if they know you may ask them, “Now, Grace, what would your answer be?”
- Always get your group speaking or moving or contributing in some way in the first 10 minutes. Otherwise you have set an assumption that it is you who will deliver and who have the expertise and that they do not need/have nothing to contribute.
- Allow as much time for feedback as you do for the actual exercise. This validates the students’ discussion and allows you to encourage or challenge as necessary which sets a standard as to the depth of discussion you expect.
- Model the fact that it is OK not to know – be prepared to admit this in response to a student’s question. You can then ask if anyone in the class can help which demonstrates that learning is reciprocal and interactive. If no one knows, suggest ways/sources to find out.
- Use culturally relevant everyday metaphors/analogies to make a point and give examples and stories from real life.
- Revise the previous session at the beginning of the next one. This sets an expectation that they will have learned and remembered/revised/reflected on the last session and that while sessions may be delivered separately they are interlinked and overlap.
- When getting students’ opinions, try to develop a deeper debate by using phrases such as, “So, what makes you come to that conclusion?” or “Tell me a bit more about why you would choose that option” or “What is the evidence for that statement/answer?”
- At the start of a course or series of sessions, ask more conscientious students (if you have been able to identify them) to go first when giving feedback from group work. This helps to set the standard for the following days/weeks.
- If the whole group is unresponsive, disinterested and you feel you are ‘losing them’ put them into pairs (preferably not with the person sitting next to them) and ask them to discuss, define or otherwise work on some task and then to report back. Even if they do not want to respond to you, they will certainly respond to each other – and the physical act of moving often stimulates them emotionally and intellectually.
- Deal with the dominating or over-talkative student by saying something like, “John, you’ve done your share of the work in this session, so let’s hear from some of those who haven’t had an opportunity...” If the problem persists, you may need to take the student aside at the end of the session, acknowledge their enthusiasm, explain your concern to involve others and invite him/her to be your ally by holding back next time.

## Different course timetables

These are examples to show how different courses can be built from the modules according to the purpose, audience and time available.

You will notice that the modules do not appear in numerical order; this is done to balance sessions containing a lot of factual information with more reflective sessions, to provide a 'balanced diet' for each day.

There are two modules (16 & 17) at the end of the manual which are not included in the suggested five-day course below. You might want to use these if you are creating a longer course or a course for non-health workers.

## Five-day introduction to palliative care

	<b>Monday</b>	<b>Tuesday</b>	<b>Wednesday</b>	<b>Thursday</b>	<b>Friday</b>
8.15am–8.30am	Registration	Report on previous day	Report on previous day	Report on previous day	Report on previous day
8.30am–10am	Introductory session	<b>Module 7</b> You can assess pain and other problems	<b>Module 9</b> You can control pain	<b>Module 14</b> You can help different symptoms 2	<b>Module 15</b> You can tell others
10am–10.30am	Refreshments	Refreshments	Refreshments	Refreshments	Refreshments
10.30–12pm	<b>Module 1</b> What is palliative care	<b>Module 8</b> You can treat, care and prescribe	<b>Module 10</b> You can use morphine	<b>Module 12</b> You can give end of life care	Final session implementation
12pm–1pm	Lunch	Lunch	Lunch	Lunch	Lunch
1pm–2.30pm	<b>Module 2</b> You can do palliative care in your setting	<b>Module 4</b> You can break bad news well	<b>Module 11</b> You can help different symptoms 1	<b>Module 6</b> You can give bereavement support	End of course test
2.30pm–3pm	Refreshments	Refreshments	Refreshments	Refreshments	Refreshments
3pm–4.30pm	<b>Module 3</b> You can improve your communication skills	<b>Module 5</b> You can give spiritual care	<b>Module 13</b> You can help children and families	Session free for home visiting or patient case studies	Presentation of certificates

You can rearrange this timetable to suit your needs, eg if you do not have morphine, or you are not working with children, you might leave out these modules and have more time for a field visit.

### Three day Introduction to palliative care for basic health workers

	<b>Monday</b>	<b>Tuesday</b>	<b>Wednesday</b>
8.15am–8.30am	Registration	Feedback	Feedback
8.30–10am	Introductory session	<b>Module 7</b> You can assess pain and other problems	<b>Module 13</b> You can help children and families
10am–10.30am	<b>Refreshments</b>	<b>Refreshments</b>	<b>Refreshments</b>
10.30am–12pm	<b>Module 1</b> What is palliative care?	<b>Module 8</b> You can treat, care and prescribe	<b>Module 6</b> You can give bereavement support
12pm–1pm	<b>Lunch</b>	<b>Lunch</b>	<b>Lunch</b>
1pm–2.30pm	<b>Module 2</b> You can do palliative care in your setting	<b>Module 5</b> You can give spiritual care	Final session and short quiz
2.30pm–3pm	<b>Refreshments</b>	<b>Refreshments</b>	<b>Refreshments</b>
3pm–4.30pm	<b>Module 3</b> You can improve your communication skills	<b>Module 11</b> You can help different symptoms 1	Certificate presentation Close

### One day Introduction to palliative care for health workers

8.15am–8.30am	Short introductory session
8.30am–10am	<b>Module 1</b> What is palliative care?
10am–10.30am	<b>Refreshments</b>
10.30am–12pm	<b>Module 2</b> You can do palliative care in your setting
12pm–1pm	<b>Lunch</b>
1pm–2.30pm	<b>Module 7</b> You can assess pain and other problems
2.30pm–3pm	<b>Refreshments</b>
3pm–4.30pm	<b>Module 9</b> You can control pain

# THE TEACHING MODULES EXPLAINED

## The teaching modules explained:

- Each module has a lesson plan showing the main points to be covered, and a guide of the timing within a 90-minute teaching session.
- Encourage the participants to look at the relevant pages as you are teaching. The more familiar they become with the Toolkit, the more they will use it as a reference book after the course.
- You may need to adapt the material to suit your circumstances. If you have less time, it is best to divide the modules rather than trying to teach all the material in a shorter time.

If you have more time, some of the group exercises can be given extra time, eg role play, case studies. This will be beneficial, especially if the participants are unfamiliar with this type of learning.

If you modify the sessions it is helpful to create a new lesson plan, adjusting the timing accordingly.

## Key to explain the modules

- — — — — Interactive exercises (group discussion, role play etc)
- ? — Questions to put to the whole group (could be used on a visual aid).
- Important learning points.
- ➔ Important teaching points.

Almost all of the important learning points are in the Toolkit so the participants can turn to the page and read as you are explaining, and should not need to write many notes. It may also be helpful to put them on a visual aid, eg flipchart, PowerPoint, overhead projector, which should be prepared before the session.

# MODULE 1 WHAT IS PALLIATIVE CARE?

## AIM OF SESSION

To introduce participants to the principles of palliative care.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- define palliative care
- describe why palliative care is needed and who needs it
- describe the holistic approach
- explain the concept of total pain
- explain that palliative care is about quality of life
- describe how palliative care can be introduced early in the disease and work alongside other treatments
- describe examples of the many ways of giving care.

Topic	Teaching methods	Time (minutes)
Definitions of palliative care	Buzz groups, writing, explanations	15
The need for palliative care	Buzz groups, presentation of statistics	15
The holistic approach	Imagination exercise, explanation	15
Total pain	Mini lecture	10
Living as well as dying – quality of life	Mini lecture, participants reflect/discuss	10
Integrating with other treatments	Mini lecture	10
Never nothing we can do	Brainstorm	10
Summing up	Reflection	5

## Definitions of palliative care (15 minutes)

Find out what the participants understand by 'palliative care' – possible ways of doing this are:

Ask them to write down their definition on a piece of paper, pass a bowl around to collect them and then read out a selection.	Buzz groups – participants discuss with their neighbour (five minutes) then tell answers to whole group; you could write some up on a flipchart.	With a group who are confident or who know each other already, you could simply take answers from participants with the group all together.
--	--	---

They may say terminal care, pain control, home-based care – all sorts of things.

All of these are true but incomplete – palliative care is bigger than any one of these things.

This is how the Toolkit defines palliative care:

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

Help people to take this in by:

- having it written out on a flipchart
- putting it on a powerpoint slide or on the overhead projector
- asking everyone to read it from the start of Chapter 1.

It's not complicated – it's just about how we can care for those who won't get better.

Now read the World Health Organization definition from page 1 of the Toolkit – it's helpful to ask everyone to turn to it so they know where to find it and so they don't have to try to write it out.

## The need for palliative care (15 minutes)



ASK THE PARTICIPANTS IF THEY EVER SEE PATIENTS WHO CAN'T BE CURED. WHAT KIND OF PATIENTS ARE THEY? (Call out answers)

### **BUZZ GROUPS** (three minutes)

How do we feel when these patients come to us?

Feed back answers to whole group (eg discouraged, sad, weary, we have nothing to offer etc).

→ Palliative care has something to offer these patients even though they can't be cured

→ Global statistics – read them from page 1 of the Toolkit – you can put them on a visual aid or ask people to look at them on the page. If you have figures for your country or your place of work, you could include them too.

→ The need is enormous.

→ Who needs palliative care?  
Draw on what the participants have said – hopefully they have given a variety of patients – and explain that palliative care is not just for cancer and HIV.

Palliative care can help people with:

- **HIV and AIDS**
- **cancer**
- **progressive neurological illnesses**
- **end-stage lung disease**
- **severe kidney or heart failure**
- **other progressive, incurable diseases.**

Turn to the list on page 2 of the Toolkit, or put it up on a visual aid.



### What's different about palliative care? – the holistic approach (15 minutes)

Medical work is often about curing disease, using drugs or surgery. Usually our training focuses on diagnosis, treatment and cure.

Palliative care has a different approach. It sees that people are more than just physical bodies and recognises we have a mind and a spirit and we are part of a family and a community. This is called the 'holistic approach' – looking at the 'whole person'.

#### IMAGINATION EXERCISE

**Aim :** to show that a sick person's problems are not just physical.

Use the story on page 2 of the Toolkit, or make up a story of your own.

Ask the participants to close their eyes and imagine they are the woman whose story you are about to read to them. Read it slowly so they have time to 'think themselves into' the life of the woman.

At the end, ask them what their worries would be if they were that woman.

Brainstorm a list of problems and concerns (participants call out, write on flip chart).

You might end up with a list such as:

- worry about her children
- grieving for her husband
- pain
- cannot sleep
- fear of dying
- no money
- exhaustion
- isolation, family far away
- stigma
- unanswered prayer
- feels far from God.

**TOP TIP** The aim is not necessarily to make an exhaustive list, just to demonstrate that many problems are non-physical.

The holistic approach looks at problems in four groups

Explain these terms and:

- have them written out on a flipchart
- put it on powerpoint or overhead projector
- ask everyone to look at the list on page 2 of the Toolkit.

The holistic approach is:

- **physical**
- **psychological**
- **social**
- **spiritual.**

Now go back to the problem list you made for the woman and see which ones fit into each group. You may need to add some more if the list did not include many psycho-spiritual problems.

### Total pain (10 minutes)

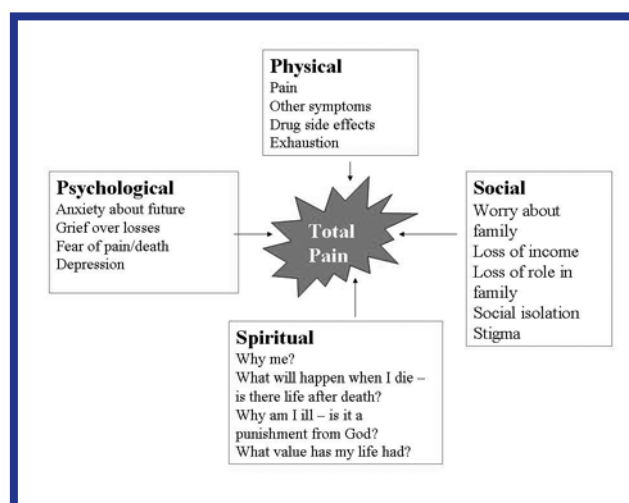
Palliative care emphasises that all these four areas of need are important and that problems in one area affect problems in other areas.

For example:

- Emotional problems such as anxiety and depression can worsen many symptoms, eg pain, breathlessness.
- Physical problems can worsen psychological ones, eg pain can lead to depression.
- Social problems, eg lack of income or loss of carers, affects physical symptoms.
- Spiritual issues affect psychological wellbeing.

- ➔ The concept of 'total pain' shows how all the areas of need contribute to pain and other physical symptoms.

Show the diagram of total pain on a flipchart, overhead projector or PowerPoint. You could refer back to the woman in the story, thinking about how her problems might interact and contribute to her pain.



- ➔ Palliative care has a patient-centred approach, focussing on the problems which are of most concern to the patient (eg a patient with HIV may be more concerned with discussing who can help her care for her children than with diagnosing her rash).

## **Palliative care is about living as well as dying – quality of life** (10 minutes)

- ➔ Palliative care is not just about end of life care – it can start from the time of diagnosis of an incurable illness.
- ➔ The aim is not to prolong life or to shorten it, but to improve quality of life for all the time that is left.
- ➔ What is quality of life? Physical and emotional well-being – not the absence of disease but comfort and peace within it.

Quality of life means being able to carry out the things which are important to that person. This will be different for different people – it might be being able to carry out activities of daily living, being able to talk with friends or being able to enjoy food. It may not be possible to achieve the desired goal but improving quality of life is about helping people to set realistic goals and getting as near to that goal as possible.

Ask the participants to reflect what would be 'quality of life' for them.

Ask everyone to think of two things that are important to their own quality of life, then:

- write them down or
- discuss with their neighbour or
- share them with the whole group.

**"You matter because you are you.**

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

**Dame Cicely Saunders**

- ➔ The kind of care someone needs will change as the disease progresses.

Explain how the balance of active treatment and palliative care changes – see page 3 of the Toolkit.

### **Palliative care works alongside and within other programmes (10 minutes)**

- ➔ Palliative care can be provided at the same time as other treatments, eg treatments for cancer such as chemotherapy, radiotherapy or surgery, ART, treatment of opportunistic infections, rehabilitation such as physiotherapy, nutritional support and others.
- ➔ Palliative care can complement what is going on already so that care is more holistic.

Many hospital programmes, such as anti-retroviral treatment (ARV) clinics, chemotherapy or radiotherapy services, are good at providing treatment for diseases but not as good at helping patients with psychosocial problems such as anxiety, grief, isolation and stigma. Home-based care often provides good support but little symptom control.

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



ASK PARTICIPANTS WHO ARE WORKING IN THESE KINDS OF SETTINGS WHAT TYPE OF CARE THEY PROVIDE AND WHETHER OR NOT THEY FEEL IT IS HOLISTIC PALLIATIVE CARE.

Pain control without holistic support is NOT palliative care.

Psychosocial support without pain and symptom control is NOT palliative care.

**Pain and symptom control + psychosocial support = palliative care**

### **Never nothing we can do (10 minutes)**



ASK PARTICIPANTS – WHO HAS EVER HEARD A PATIENT BEING TOLD “THERE IS NOTHING WE CAN DO”? WHAT EFFECT MIGHT THIS HAVE ON THE PATIENT? IS IT TRUE?

- ➔ It is not true – there is never nothing we can do. We may feel overwhelmed by so many problems that we cannot solve – but there are many ways we can help even if we cannot cure the illness.

## **\_BRAINSTORM EXERCISE WITH WHOLE GROUP**

**Aim:** To show that there are many different ways we can help.

Ask the group to call out different ways of helping and write them on the flipchart.

You can refer back to the woman in the imagination exercise or talk in general terms, or both.

You may want to start with buzz groups to get people talking, then the whole group calls out as many different ways of caring as possible.

Possibilities are:

- nursing care – positioning, washing, dressing wounds, turning, helping feeding
- medicines for pain or other symptoms
- supervising other medicines, eg ARV, TB
- listening
- explaining
- taking to clinic/hospital
- praying, arranging visit from spiritual leader
- volunteer to give practical help – washing, cleaning, shopping, child care
- help with writing a will, making plans for children after death
- income-generating activities/small loan programme
- mobilising family, neighbours, community groups
- being there.

**TOP TIP** The aim is not necessarily to make an exhaustive list, just to demonstrate that there are many different ways of helping and we can always find something we can do.

Read out the quote from Dame Cicely Saunders on page 4 of the Toolkit. “I once asked a man....”

### **Summing up** (five minutes)

Run over important points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should write this down on a piece of paper/notebook to keep for themselves. They can add to this as they learn more during further sessions.

# MODULE 2 YOU CAN DO PALLIATIVE CARE IN YOUR SETTING

## AIM OF SESSION

To show that palliative care can be done in different ways, using local resources.

## LEARNING OBJECTIVES

By the end of the session, participants should be able to:

- describe different models of care
- discuss the needs and resources in different settings
- describe who could make up a palliative care team.

Topic	Teaching methods	Time (minutes)
Palliative care in different settings	Mini lecture	15
The palliative care tree	Explanation, brainstorm	15
Needs and resources	Group work	20
	Flip chart, feedback and discussion	20
Palliative care team	Whole group discussion	15
Summing up	Reflection	5

### **Palliative care in different settings** (15 minutes) (page 5 of the Toolkit)

- ➔ Palliative care can be provided in different ways depending on what is possible and what works best in different places. What works in one country may not work in other countries, and vice versa.
- ➔ Palliative care can be given at home, in hospital, in a clinic and in other ways – these are all different ‘models of care’.
- ➔ The model of care we use will depend on the needs and the resources where we are. Palliative care grows and develops as we add different aspects of care onto what is already in place, to make holistic care.

Tell a few real-life stories of different projects or services to illustrate this. Use examples from your own setting if you have them, or use some of the stories in the Toolkit on pages 8–11. Stress that these projects started when somebody saw a need: they started small, building on what was already there, adding extra help to make holistic care.

### **The palliative care tree** (15 minutes)

- ➔ Ask everyone to look at the tree on the front of the Toolkit. Explain that its four roots are the four elements of holistic care. When these roots come together, the ‘palliative care tree’ can grow. You could draw the tree on the flipchart as you speak to help explain.
- ➔ The resources to feed each root can be found in communities.

#### **„BRAINSTORM ON RESOURCES (WHOLE GROUP)“**

**Aim:** to show that there are many resources which can create holistic care.

Ask participants to call out things which could make up the different roots of the tree – you may need to give some examples to help them understand the concept. Referring back to the stories you told may help.

Write the examples on the tree if you have drawn one, and all turn and look at page 6 together when they have run out of ideas. Compare what is there to what they have thought of.

Explain that the fruit of the tree is the care that grows out of the resources you have. The tree shows different fruits that might grow – these are different models of care. In a particular setting there may be just one kind of fruit, eg a home-based care programme. Or there may be more than one, eg a home-based care programme working together with an outpatient clinic.

### **Needs and resources in our own settings** (20 minutes)

To think about what will work in our settings, we need to ask four questions (page 5 of the Toolkit).

Explain these questions, giving some examples:

- **Who needs palliative care where we are working? (What type of patients? How many?)**
- **What are their main problems? (eg lack of drugs, transport, poor health education etc)**
- **What help are they getting at present? (eg existing healthcare services, community groups, NGOs etc)**
- **What could be added to improve their care and make it holistic?**

### **GROUP WORK ON NEEDS AND RESOURCES** (20 minutes)

Aim: to discuss local needs and resources.

Divide participants into groups of about six people. If there are several people working in the same place, they should go in the same group.

Each person should describe to the group the situation where he/she works.

Discuss as a group the four questions on page 5 of the Toolkit for each person's setting.

Write your answers on flipchart paper to be presented during feedback time.

Be thorough and specific, eg estimating numbers of patients, range of problems, details about current care etc.

Be realistic about what you could add to the care and to explain how you could do it.

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

### **FEEDBACK** (20 minutes)

Each group presents their answers for one situation.

**TOP TIP** Keep these flipchart sheets if you are planning an implementation session at the end of a course.



### **Palliative care team** (15 minutes) (page 13 of the Toolkit)

Many of the resources available to us are human resources, eg different health workers, counsellors, volunteers. Some of these will make up a palliative care team. The core team will work together and meet regularly. Others may work in partnership; some will contribute occasionally when their skills are required.

With the group all together, look again at the feedback from the small groups and pick out the human resources they identified. Discuss:



- WHO SHOULD BE IN THE PALLIATIVE CARE TEAM? (BEING REALISTIC ABOUT WHAT IS POSSIBLE AND PRACTICAL)
- WHAT WILL THEIR ROLES BE? (EG SOME MEMBERS MAY PERFORM SEVERAL FUNCTIONS AND SOME TASKS MAY BE SHARED BY SEVERAL TEAM MEMBERS)
- HOW WILL THEY COVER ALL THE ASPECTS OF CARE THAT THE TEAM NEEDS TO DELIVER?
- WHAT OTHER PEOPLE WILL CONTRIBUTE, THOUGH NOT AS PART OF THE CORE TEAM? (EG HOSPITAL PHARMACIST, VISITING PASTOR ETC)

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learnt and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 3 COMMUNICATION SKILLS

## AIM OF SESSION

To improve communication skills.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- explain what communication is and why it is important
- demonstrate active listening
- describe some non-verbal and verbal communication skills
- demonstrate good communication skills.

Topic	Teaching methods	Time (minutes)
How bad communication feels	Listening exercise in pairs	15
What is communication?	Presentation	5
Why is communication important?	Buzz groups	10
Listening skills	Whole group discussion	15
	Demonstration, flipchart feedback	10
Practise skills	Role play	25
Summing up	Comments from group, reflection	10

Tell the participants they are going to do an exercise which involves some acting. Do not tell them what the purpose of the exercise is – let them discover how it feels when they are not listened to.

#### **LISTENING EXERCISE** (15 minutes)

The participants are divided into pairs and each pair into A and B.

The As go outside and are told they will go back and tell their best friend B something very exciting that they have wanted to tell them for a very long time. They can speak in whatever language they prefer.

The Bs are told that they are going to demonstrate bad communication skills. They should start listening to whatever they are told but then get bored and show by body language that they are not really interested. (five minutes)

Reverse A and B. Take the Bs outside and tell them they will go and tell their friend something very sad. Explain to the As that they are going to be poor listeners. They should keep interrupting and start to talk about themselves. (three minutes)

The aim of this exercise is to see what bad communication feels like.

**FEEDBACK** (seven minutes) with the whole group.

How did it feel for one who was talking?

What made them feel they weren't being listened to? (eg no eye contact, poor attention)

#### **What is communication?** (five minutes)

What do we mean by communication? You could ask the group for their ideas.

Explain:

- ➔ it is a two-way process, giving and receiving messages
- ➔ the aim is to reach understanding – giving a message that is not received is not communication
- ➔ communication is very important in palliative care
- ➔ good news – everyone can learn and practise communication skills.

## Why is communication important? (10 minutes)

### BUZZ GROUPS (five minutes)

Discuss why good communication is important and how it helps our patients.

Then hear feedback from the group; you may want to write their answers on the flipchart. Here are some examples you could have prepared.

#### Good communication:

- **creates relationships**
- **gives value to the other person**
- **reduces isolation**
- **gathers information**
- **gives information**
- **enables expression of feelings**
- **reduces uncertainty**

## Listening skills (15 minutes) (page 17 and 18 of the Toolkit)

- ➔ We sometimes think communication is all about getting our message across. Listening is just as important as talking and in palliative care it is often more important.
- ➔ Listening is not simply being present while someone else speaks. It is a skill which can be learned and practised – this is sometimes called ‘active listening’.

### Non-verbal skills

- ➔ Explain the concept of non-verbal communication: ‘actions speak louder than words’. How we appear with our bodies (body language) gives out many messages.
- ➔ The exercise at the beginning should have produced some ideas about unhelpful body language. Ask the group to call out other listening skills to add to these.

#### Non-verbal listening skills

- **Keep eye contact, pay attention**
- **Sit near the patient at their level**
- **Relaxed posture, sit forwards and keep still**
- **Allow silence, don’t interrupt**
- **Encouraging responses, eg nodding, small noises/phrases**
- **Facial expression**
- **Touch (discuss what is/is not appropriate in this culture)**

Some listening skills are listed on page 18 of the Toolkit.

You could put this list up on a visual aid and demonstrate some of them, eg posture, nodding, encouraging responses.



THE WAY PEOPLE LISTEN MAY VARY IN DIFFERENT CULTURES. WHAT IS IMPORTANT IN THIS CULTURE? ENCOURAGE THE PARTICIPANTS TO THINK ABOUT PEOPLE THEY KNOW WHO LISTEN TO THEM AND WHAT MAKES THEM GOOD LISTENERS.

### Verbal skills

Explain what is meant by:

- Clarifying – making sure you have really understood the patient, by asking appropriate questions, eg “You said you are having frequent fevers. Is that once a day, or more?”
- Summarising – feeding back the most important points of the patient’s story, to check that you have understood.

#### **DEMONSTRATION ROLE PLAY OF POOR COMMUNICATION** (three minutes)

**Aim:** to illustrate the different skills you have discussed.

Two trainers (or one plus a participant) role play a consultation in which a healthcare worker (eg doctor) has very bad communication skills. Include as many skills as possible from the list (ie the lack of them) and arrange interruptions (eg another nurse coming in, the phone ringing etc).

The participants take notes on what goes wrong.

**FEEDBACK** (seven minutes) with flipchart – you could use the list above and put a cross by the ones which were missing and add others, eg interruptions, summarising incorrectly etc.

### Practising communication skills – groups of three or four (25 minutes)

The participants now practise using the skills they have discussed by role-playing consultations between a patient and a health worker (see guidelines for role play, pages 9–10 of this training manual). They should focus on good communication rather than on trying to make a diagnosis.

Another option which may be easier for those who are not used to role play is to use a true story from their own life.

#### ROLE PLAY OF PATIENT AND

##### HEALTH WORKER (three minutes)

Aim: to practise communication skills.

Use Resource 1

Two people role play a consultation.

The 'patient' can use a scenario from Resource 1 and they can enlarge upon the story however they want, or they can make up their own story. They should speak in whatever language they are most comfortable with. The 'health worker' has to listen and use the skills that have been discussed, asking questions when appropriate. The exercise is about communication skills, not finding a diagnosis. There is no need to examine the patient.

The others watch carefully, they can note down their observations if they want.

Then they swap, using different scenarios – encourage them to keep the scenes short so that there is time for everyone to play the health worker.

After each role play or conversation, the actors comment first on:

- how it felt
- what went well
- what could have been better.

The observers can then comment, giving positive feedback and then constructive criticism.

##### REAL LIFE STORIES

Aim: to practise communication skills.

One participant tells another a story from their own life, preferably something that has been difficult (eg an illness or a loss).

They should speak in whatever language they are most comfortable with. The other participant listens and uses the skills that have been discussed, asking questions when appropriate.

The other group members watch carefully, they can note down their observations if they want.

Then they swap – encourage them to keep the conversations short so that there is time for everyone to be the listener.

After each role play or conversation, the actors comment first on:

- how it felt
- what went well
- what could have been better.

The observers can then comment, giving positive feedback and then constructive criticism. Make it clear that the group must keep the stories they hear confidential.

### **Summing up as whole group (10 minutes)**

Come back into whole group and discuss general learning points from the exercise: what was difficult, what was surprising, what they have learned, what they need to practise more, how they could put it into practice in their work.

Run through the main points of the session.

### **Reflection**

Ask everyone to think of the most important thing they have learned from this session and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 4 YOU CAN BREAK BAD NEWS WELL

## AIM OF SESSION

To teach participants skills in breaking bad news.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- discuss the value of telling the truth to patients
- demonstrate the steps in 'BREAK NEWS'
- explain the importance of confidentiality.

Topic	Teaching methods	Time (minutes)
<b>The value of telling the truth</b>	Buzz groups, discussion	20
<b>Breaking bad news</b>	Demonstration and flipchart feedback	10
	Presentation BREAK NEWS	10
<b>Role play</b>	Small group role play	25
	Whole group feedback	5
<b>Confidentiality</b>	Whole group discussion	15
<b>Summing up</b>	Reflection	5

The last session was mainly concerned with listening. This session will look at what we say to patients and how we say it.



### **Telling the truth when the news is bad** (20 minutes) (page 18 of the Toolkit)

How much bad news should we tell patients? Should we always tell the truth? We often find it difficult to give people bad news. Ask the participants to discuss a scenario briefly, in buzz groups:

**BUZZ GROUPS** (three minutes)

You are seeing a 54-year-old man at home who has come from the hospital where he has had some tests done. The medical note says that the tests show advanced cancer of the oesophagus. Should you tell him the truth? Why or why not?

Feedback on flipchart – make a list of advantages and disadvantages of telling the truth. Hopefully you will end up with more advantages. These could include:

**Telling the truth:**

- **reduces uncertainty and helps to answer unanswered questions that the patient may be afraid to express**
- **reduces unrealistic hope and continual searching for a cure**
- **allows the patient to make informed choices and reduce expenditure on futile treatments**
- **allows the patient to make realistic plans (writing wills etc) for those left behind and for their own remaining time**
- **allows honest communication with family and health workers**
- **if done well, can build on the relationship of trust between patient and carer.**

Now add to the scenario...

While you are thinking what to tell him, his daughter asks to speak to you outside. She says: "You must not tell him anything that may upset him. He will not cope with any bad news and it will make him worse."

Should you agree to the daughter's request? Why or why not?

You could use buzz groups again, or discuss it as a whole group.

Feedback – hear from those who would agree with the daughter and those who would disagree; you could list the arguments on two sides of the flipchart.

There may be a lively discussion here and people may have different opinions. Try to include the following points:

- It is always important to listen to the family and hear their concerns.
- Families want to protect their loved ones and themselves but may not recognise the advantages of telling the truth (see list made in last exercise).
- We may need to counsel families about the advantages of telling the truth.
- Being able to talk about things honestly within the family and in the healthcare setting is helpful for most people.
- The patient is the centre of our care; we must do what is best for him or her, which is not always what the family want.
- The way things are done 'in our culture' is not always the best way of doing things.
- The patient should always be given the opportunity to know more, but doesn't have to be told if they don't want to know.

### **Breaking bad news** (20 minutes)

#### **DEMONSTRATION** (10 minutes)

**Aim:** to illustrate unhelpful ways of breaking bad news.

Two trainers do a role play of a consultation in which bad news is communicated badly. You could include poor communication skills, being in a hurry, using medical language, being unsympathetic etc. You will need to think through the story and rehearse the role play beforehand.

Get the participants to comment on what they have seen.

Was it a good consultation?

Why not?

Ask them to pick out the things which were not helpful.

Why do they think the health worker did it badly? (He was possibly unconfident how to do it, or he was afraid of the patient getting upset, or of them taking too much of his time).

## **BREAK NEWS** (10 minutes) (page 19 of the Toolkit)

Ask everyone to turn to page 19 of the Toolkit and go through the 'Break news' checklist of how to break bad news well, explaining each point and giving examples.

## **Practising breaking bad news** (25 minutes)

You can use role play in small groups (see page 9 of this training manual), or you could do an interactive role play with the whole group all together (see page 10 of this training manual).

<b>_ROLE PLAY IN GROUPS OF FOUR_</b>	<b>_INTERACTIVE ROLE PLAY_</b>
<p>Aim: to practise breaking bad news. Use Resource 2</p> <p>Start by using the scenario that was demonstrated, this time doing it well and incorporating steps from the 'Break news' guidelines. Other group members can join in as relatives, or can observe.</p> <p><b>FEEDBACK</b></p> <p>Ask the group:</p> <ul style="list-style-type: none"><li>● how it felt</li><li>● what went well</li><li>● what could have been better.</li></ul> <p>Swap around so that everyone has a chance to be the health worker. Use the scenarios in Resource 2. There are two pages – one for the health worker to read, one for the patient.</p>	<p>Aim: to practise breaking bad news. Use Resource 2</p> <p>Two participants role play the scenario that was demonstrated, this time doing it well and incorporating steps from the 'Break news' guideline. The trainer 'freezes' the action from time to time, asking the class to comment, or suggest what the health worker should do next. Participants can swap to take turns in the different roles.</p> <p>You can move on to use the other scenarios from Resource 2.</p>

## **Brief feedback in whole group** (five minutes)

Discuss general learning points from the exercise – how it felt to be the health worker/patient, what was difficult, what was done well. Were there any surprises? How can they imagine putting it into practice in their work? What do they need to practise more?

## Confidentiality (15 minutes)



ASK PARTICIPANTS WHAT THEY UNDERSTAND BY CONFIDENTIALITY – THEY MAY HAVE A VARIETY OF ANSWERS.

- ➔ In simple terms, confidentiality is the keeping of secrets. Maintaining confidentiality means not disclosing information about a patient to other people unless you have the patient's permission to do so.

Health workers have a lot of personal information about other people. They must always be careful when they are chatting to others that they do not reveal anything which should be kept confidential, even if they do not identify the patient by name.

### WHOLE GROUP DISCUSSION ON CONFIDENTIALITY

Aim: to increase understanding of confidentiality.

- Why is confidentiality important? (eg to maintain trust, to show respect for the patient's rights, to prevent them coming to harm)
- Sometimes you may want to encourage a patient to share information with their family, but you cannot force them to do so. Can you think of some examples? (eg telling a spouse about a positive HIV result, telling family that you have a short time to live)

This is an important subject. There is a module looking at it in detail, which you could use according to the needs of your group and the time you have available.

## Summing up (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 5 YOU CAN GIVE SPIRITUAL CARE

## AIM OF SESSION

To raise awareness of spiritual issues and support.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- discuss what is meant by 'spirituality'
- explain the importance of spiritual support in palliative care
- describe how to take a spiritual history
- explain what is meant by the HOPE checklist
- discuss different ways of giving spiritual support
- discuss their own feelings about spirituality.

Topic	Teaching methods	Time (minutes)
<b>What is spirituality?</b>	Answers in a bowl, flipchart	10
<b>Why is spiritual support important?</b>	Buzz groups and presentation	15
<b>Awareness of our own spirituality</b>	Reflection	5
<b>Taking a spiritual history</b>	Group work and flipchart feedback	30
<b>HOPE checklist</b>	Presentation	5
<b>Giving spiritual support</b>	Whole group brainstorm	10
<b>Different views about spiritual care</b>	Agree/disagree exercise	10
<b>Summing up</b>	Review and reflection	5

## What is spirituality? (10 minutes) (page 20 of the Toolkit)



DOES EVERYONE HAVE A SPIRITUAL SIDE? WHAT DO THE PARTICIPANTS THINK?

### WHAT IS SPIRITUALITY?

**Aim:** to show that spirituality has several aspects.

Ask participants to write their answer on a piece of paper (three minutes).

Pass around a bowl to collect the papers and then read them out. Note down different answers on flipchart. If possible, you could group them together (see below) (seven minutes).

People from different backgrounds and cultures may have different ideas; it is good to hear them all. The important thing is not to arrive at one 'correct' answer or definition, but to show that there are many parts to spirituality and it is much more than just 'religion'.

If the group only comes up with 'religious' definitions, you will need to mention other aspects.

#### Different aspects of spirituality

- **Meaning (Who am I? Why am I here? What is life about?)**
- **Transcendence (belief in God or spiritual powers/forces, creation, afterlife)**
- **Harmony (at peace with other people, need to forgive/be forgiven, fitting in with culture and heritage)**

Have these aspects prepared on a visual aid. Show how the different definitions participants have given refer to different aspects.

## Why is spiritual support important? (15 minutes)

At times of crisis and at the end of life people often ask spiritual questions, eg "Why has God allowed this to happen to me?"

### BUZZ GROUPS (five minutes)

What questions do people ask when coming to the end of life?

Have you seen a patient or family member troubled by spiritual issues?

Hear feedback from around the room – you may want to write some of their comments on the flipchart. Here are some examples you could have prepared.

**Spiritual issues people face**

- **Why has this happened to me?**
- **Does God exist and if so, why has he allowed this to happen?**
- **Am I being punished?**
- **Who or what has caused my suffering?**
- **What meaning does my life have?**
- **What will happen when I die?**

➔ We do not have to know the answers to all these questions, but we can support the patient as they seek the answers for themselves in different ways. If we don't address this side of care, we may treat their physical pain but leave them in 'spiritual pain.'

**Reflection** (five minutes)

**\_REFLECTION EXERCISE** (five minutes)

Aim: to be aware of our own spirituality.

Ask participants to reflect for a few minutes, in silence, on their own spirituality. They may want to close their eyes, or note down their thoughts on paper.

How do they feel about their own spirituality?

How will this affect their work?

Are there questions they need to explore for themselves? How will they do this?

**Spiritual histories** (30 minutes)

➔ We need to explore a person's spiritual journey in order to understand people's needs and assess "spiritual pain".

### **\_SMALL GROUP WORK ON TALKING ABOUT SPIRITUAL ISSUES (15 minutes) \_**

Aim: to make a list of useful questions for taking spiritual histories.

- What questions have you found to be useful?
- Do you find it easy to explore spiritual issues with patients?
- Why or why not?

#### **FEEDBACK (15 minutes)**

The groups feed back useful questions and any other points from their discussion.

Make a flipchart list – you can also suggest the ones on page 20 and see if people think they are useful.

➔ Listening is one of most important tools in spiritual support. Taking the history is not just information-gathering, it is part of our care to listen and try to understand.



ASK IF ANYONE HAS A STORY OF A CONVERSATION ABOUT SPIRITUAL ISSUES WHICH HAS GONE WELL OR GONE BADLY – OR TELL A STORY YOURSELF.

### **HOPE (five minutes) (page 21 of the Toolkit)**

Present the checklist and explain each point.

#### Different aspects of spirituality

- **Hope – what are the sources of hope, meaning, peace for that person**
- **Organised religion – what is its role for that person**
- **Problems/issues/questions they are facing**
- **Effect on care – how**

➔ The first three letters are about taking a spiritual history, finding out what is concerning the patient, the last is about how we care and support.

### **\_BRAINSTORM WITH WHOLE GROUP (10 minutes) \_**

Aim: To show that there are many different ways we can help.

Call out as many ways as possible in which we can give spiritual support. Write them on the flipchart.



The list may include:

- asking a chaplain or counsellor to see them
- finding a faith leader from their own religion to visit
- arranging for them to go to their place of worship
- providing a place where they can reflect/pray
- praying with them
- providing things such as a Bible, Koran, or other scriptures
- reading their scriptures to them
- arranging for certain rituals to be carried out, eg Holy Communion
- playing music which they find helpful.

**TOP TIP** The aim is not necessarily to make an exhaustive list, just to demonstrate that there are many different ways of helping and that we can always find something we can do.

#### **DIFFERENT VIEWS ABOUT SPIRITUAL CARE** (10 minutes)

Aim: to become more aware of our own feelings about spiritual care.

- Each participant is given a paper with a statement written on it in big letters. It is good if some have the same statement. They must decide whether or not they agree with the statement.
- One side of the room is designated as 'Agree' and the other side as 'Disagree'.
- Each participant stands up in turn and reads out their statement and says in one sentence whether or not they agree and why, then sticks it on the appropriate wall, or somewhere in between if they only partly agree.
- Explain that others are not allowed to comment at this stage so there will be no debate with the whole group – encourage people to discuss with each other during a tea break if they wish.
- Explain that this is not a test, there are no 'right' answers to some of the statements – the aim is to get people thinking

**TOP TIP** If you think people will be anxious or unwilling to share their opinions with the whole group, you could get them to put the papers in an 'Agree box' and a 'Disagree box' then read them out and put them on the wall. Observe the similarities and differences in people's views.

Statements could include:

- I would be willing to share my own beliefs with someone who is dying.
- Every person is a spiritual being.
- Helping someone undergo a religious conversion is wrong.
- Spirituality has nothing to do with formal religion.
- I would feel comfortable praying with a patient.
- I can give spiritual support to people of different faiths.
- I would never take a patient to church.
- I am afraid of dying.
- There is always a purpose in suffering.
- A person must make peace with God before death.
- Prayer always gets results.
- Forgiveness is important before death.
- I learn about spirituality from my patients.
- It is essential to refer to a person's faith advisor for spiritual support.
- My faith helps me give palliative care.
- Only faith makes sense of death.

### Summing up (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 6 YOU CAN GIVE BEREAVEMENT SUPPORT

## AIM OF SESSION

To improve understanding of grief and bereavement.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- define bereavement, grief and mourning
- describe emotional reactions to loss
- describe signs of stress in palliative care workers
- explain ways of preventing burn-out
- discuss cultural practices around death
- discuss bereavement care.

Topic	Teaching methods	Time (minutes)
Introduction	Definitions	5
Grief reactions	Group work on grief call out, explanation	20 5
Looking after ourselves	Whole group discussion	20
Bereavement customs and support	Group work	35
Summing up	Reflection	5

## **Bereavement** (five minutes) (Page 21 of the Toolkit)

Families' needs do not end when their loved one dies. Bereavement support is part of palliative care.

Explain the following terms:

- Bereavement is the loss of something of value (not only of a person but could be loss of health, job, role, body image etc).
- Grief is a person's reaction to the loss and includes a range of emotions. It can happen before the loss occurs, eg when someone first finds out that they have a life-threatening illness ('anticipatory grief')
- Mourning usually refers to the behaviour and actions of someone who is bereaved; it includes traditional customs and practices around death.

### **GROUP WORK ON GRIEF** (20 minutes)

**Aim:** to explore reactions to loss in patients, families and health workers.

Read out the following scenario to the whole group:

Amina is a 32-year-old woman with three children aged between five and 15. She is married and has a younger unmarried sister with whom she is particularly close to. She was found to have a brain tumour a few weeks ago. The family cannot afford any treatment. The doctor has discharged Amina from hospital to die at home.

Now divide into three groups (or more, depending on numbers – if more, then some groups will work on the same character). Each group should think about one character from the scenario, imagining and discussing how they might feel.  
(10 minutes)

Group 1 is Amina

Group 2 is her sister

Group 3 is her home care nurse or volunteer.

Each group has a flip chart paper and writes down all their thoughts and feelings.

### **FEEDBACK** (10 minutes)

Put the papers alongside each other and see the similarities and differences across all three. (You could use the 'walking wall' – see page 3 – especially if there are more than three groups)

There will probably be many similarities in the three groups, eg helpless, hopeless, "its not fair".

Patients, families and healthcare workers go through many of the same feelings when facing death and loss. It can help others to know you feel the same way as they do.

### **Grief reactions** (five minutes) (page 21 of the Toolkit)

Make a list of different emotions that people experience when someone dies. Use the feedback from the exercise above, and ask the participants to call out others.

Look at the list on page 21 of the Toolkit.

#### Grief reactions

- **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**

### **Looking after ourselves** (20 minutes)

From the exercise we have seen that as palliative care workers, we are affected by the demands of caring for very sick people, and experience repeated losses of the patients we have known.

Sometimes we may become overwhelmed and are unable to carry on working; this is called 'burn-out'.

?

ASK THE GROUP TO THINK OF TIMES WHEN THEY OR THEIR COLLEAGUES HAVE FELT OVER-BURDENED. WHAT HAPPENED?

WHAT ARE SOME OF THE SIGNS OF STRESS?

CALL OUT ANSWERS – YOU CAN WRITE THEM UP IF YOU WISH, THEN TURN TO THE LIST ON PAGE 15.

#### 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**

We need to develop ways of preventing this from happening. We should not wait until someone is at the point of burn-out. Prevention is better than cure.

?

ASK THE GROUP FOR WAYS OF PREVENTING BURN-OUT – CALL OUT IDEAS, YOU CAN REFER TO THE LIST ON PAGE 15 OF THE TOOLKIT AND ADD OTHERS.

Looking after ourselves and our 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 who they can ring for advice about patients)**
- **Ongoing training and supervision increases confidence and competence**
- **When a patient dies, take time to reflect, recognising that multiple losses are inevitably stressful**
- **Make time to relax together – over tea, or a shared meal**

### **Supporting bereaved families (35 minutes)**

Bereavement support is part of palliative care. How we do this will depend on cultural beliefs and practices surrounding death and dying. Different cultures and faith groups have different customs. Many are helpful, some may not be. Our cultures are precious but they change over time and mean different things to different people at different stages. Sometimes we have to protect our cultures, and sometimes we have to challenge them.

### **GROUP WORK ON BEREAVEMENT** (35 minutes)

**Aim:** to examine bereavement customs and discuss their value.

Make groups of five to six people. If possible, put people of similar traditions together, eg those of the same faith group or tribe should work together.

#### **Discuss** (20 minutes)

- What are the customs, beliefs and practices around death in your culture/area/faith group?
- Which of these are helpful and why?
- Are any unhelpful and why?
- How could a palliative care team give bereavement support in this setting?

#### **FEEDBACK** (15 minutes)

Each group presents helpful/unhelpful customs, and their ideas about bereavement support. Others can comment and discuss.

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 7 YOU CAN ASSESS PAIN AND OTHER PROBLEMS

## AIM OF SESSION

To improve pain assessment and history-taking skills.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- describe how to carry out a pain assessment
- take a holistic history and make a problem list
- explain the use of Tools 1 and 2.

Topic	Teaching methods	Time (minutes)
Pain assessment	Presentation, looking at Tools 1 and 2	20
	Whole group discussion on different pains	20
Holistic histories	Presentation	5
	Group work	25
	Feedback	15
Summing up	Reflection	5



### **Pain Assessment** (25 minutes) **Presentation** (page 26 of the Toolkit)

This may be a presentation with flip chart, overhead projector or PowerPoint but involves some group participation. The points to cover are:

- ➔ Pain assessment is very important and it is often dealt with very badly. Pain often remains undiagnosed and inadequately treated.
- ➔ You may like to show this box as a flip chart or PowerPoint slide or on the overhead projector. Pain is what the patient says hurts, not what the health worker thinks it should be. Always believe your patient.
- ➔ Go through the assessment of pain on page 26.
- ➔ Look at the body chart on Tool 1. You could have an enlargement of it on a flip chart.
- ➔ Look at Tool 2 and discuss the different ways of scoring pain. Discuss which they think would be most appropriate for their setting. For those dealing with children, the faces may be most useful.
- ➔ Look at the seven important questions to ask the patient in Tool 2.
- ➔ Some patients are not able to answer questions, eg small children or those who are unconscious or confused. We need to pay extra attention, listening to the carers and observing with our eyes for signs of pain.

**Pain is what the patient says hurts.**

### **WHOLE GROUP DISCUSSION ON DIFFERENT PAINS** (20 minutes)

**Aim:** to discuss assessment of different types of pain.

- Ask everyone to think of a pain which they have experienced in the past (eg labour pain, a broken bone, a headache with malaria, toothache, etc) and to remember how it felt. There is no need to tell the rest of the group.
- Ask them to score their pain using the five finger score – everyone can hold up their hands at the same time.
- Ask what types of pain their patients have. As a type of pain is called out, the trainer can discuss that type of pain and its assessment with the group (see examples below). The participant could come up and fill the position of the pain on the body chart previously drawn on the flip chart.
- If participants do not produce many examples, provide them yourself or use those below.
- The trainer could pretend to have the conditions listed below and the participants can ask questions and either fill in a sample sheet of Tool 1 or a large body chart on a flip chart or blackboard.

<p><b>A painful wound, eg a burn</b></p> <ul style="list-style-type: none"> <li>● The pain is due to tissue damage.</li> <li>● How do patients usually describe the feeling?</li> <li>● The history should include how the wound started, has the pain got worse, and the effects of movement, positioning, drugs etc.</li> <li>● How severe is the pain? This should be assessed using Tool 2.</li> <li>● The position and size of the wound can be marked on the body chart.</li> </ul>	<p><b>A painful swelling, eg a tumour</b></p> <ul style="list-style-type: none"> <li>● The pain is due to inflammation and pressure effects as well as tissue damage.</li> <li>● What is the usual story?</li> <li>● How would you assess the pain using the body chart and pain score?</li> </ul>
<p><b>Peripheral neuropathy</b></p> <ul style="list-style-type: none"> <li>● The position and size of the wound can be marked on the body chart.</li> <li>● Can occur in HIV, or can be caused by ARVs or isoniazid.</li> <li>● The pain is due to damaged nerves sending abnormal signals to the brain.</li> <li>● How do patients describe this?</li> <li>● How would this pain be assessed using the pain score and body chart?</li> </ul>	<p><b>Painful muscle spasm</b></p> <ul style="list-style-type: none"> <li>● Can occur in a bed-bound patient, or cerebral palsy or stroke.</li> <li>● How could this be assessed, especially if the patient is not able to speak?</li> <li>● Again the trainer could demonstrate this (eg observing position and posture, feeling muscle tone and watching for signs of pain).</li> <li>● A participant can fill in the body chart.</li> </ul>

### **Holistic histories presentation** (five minutes)

- ➔ Taking a good history is important when assessing any problem. It involves listening to the patient and also family members and other carers.
- ➔ This is a good time to have a brief revision of communication skills. Get the participants to call them out.
- ➔ Stress that a problem in one area affects other areas so the history is not just about the specific symptom in question.
- ➔ A holistic history will need to include all the elements of palliative care – social, emotional and spiritual as well as physical and will finish with a problem list.

### **GROUP WORK ON HOLISTIC HISTORY TAKING** (25 minutes)

Aim: to teach a holistic approach to patient assessment.

Use Resource 3

Work through the first case together, the participants calling out ideas and the trainer writing them on the flip chart.

Then divide into three smaller groups and give each one a different case to discuss.

They can write their ideas on flipchart paper to present to the class at the end.

For each case, discuss:

- How would you assess this patient? What might be the cause of some of the problems? What questions would you like to ask? Try to group them into the four areas of holistic care
- Write a short list of the problems you imagine are most important for this patient. Remember that these may be physical, emotional, social and spiritual.

**FEEDBACK** (15 minutes) – each group presents and others comment.

**TOP TIP** Suggested answers to case 1 are given below. Work through the other cases yourself before the session so that you are ready with ideas if the participants do not come up with many.

### **Suggested answers to Case 1**

You visit a 24-year-old woman with advanced cancer of the cervix. You have been treating her with morphine for abdominal pain. Now she is lying silently in the house. There is a very bad smell in the room, which is untidy, and the floor has not been swept. Her 12-year-old niece is with her.

What questions do you need to ask her?

- **Physical**

- Questions about her pain – this should be assessed using the seven questions and pain scales on Tool 2
- How much morphine is she taking?
- Does she take it properly?
- Does she have a discharge?
- How is her urinary function?
- Are her bowels OK?
- Is she able to eat?

- **Emotional**

- How is she feeling?
- Is she depressed?

- **Social**

- Who is caring for her?
- Is she isolated because of the smell?

- **Spiritual**

- Does she have a faith that is important to her?
- Is she receiving any spiritual support?

What questions would you like to ask her niece? They may include:

- Is anyone else helping you look after your aunt?
- Do you need more help?
- Are you missing school?

What do you think would be on her problem list?

Get the group to think of the possible problems and then choose the three they think are most important. In the example above they may choose:

- pain
- smell
- social isolation and lack of care.

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 8 YOU CAN TREAT, CARE AND PRESCRIBE

## AIM OF SESSION

To introduce the principles of pain and symptom control.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- describe the principles of treat, care, prescribe
- discuss the concept of a balance between benefit and burden
- explain the principles of good prescribing
- practise explaining drug regimes and using Tool 6.

Topic	Teaching methods	Time (minutes)
<b>Treat, care, prescribe</b>	Presentation	5
<b>Treatment</b>	Explanation	5
<b>Benefit/burden balance</b>	Small group work	15
	Feedback and discussion	10
<b>Care for patient</b>	Presentation	5
<b>Principles good prescribing</b>	Presentation, look at Tools 6 and 17	15
<b>Group work on educating patients</b>	Case studies, role play	20
<b>Feedback</b>	Whole group discussion	10

## **Principles of symptom control** (five minutes) (page 23 of the Toolkit)

Symptom control is a vital part of palliative care.

**Pain and symptom control + Psychosocial support = Palliative care**

We can do a lot with few resources – even if we cannot do everything we would like, there is never nothing we can do.

We need to use our resources well, to maximise their potential.

Symptom control is not just about drugs – a lot can be done with good nursing care. The Toolkit looks at symptom control under three headings.

Each symptom will be dealt with in this way when we come to the ‘Head-to-toe guide.’

### **Principles of symptom control**

- **treat**
- **care**
- **prescribe**

## **Treat the treatable** (five minutes)

- ➔ Explain the concept as on page 23 of the Toolkit, giving examples of treatments which may relieve symptoms.
- ➔ Explain the concept of benefit against burden as on page 23 of the Toolkit.

### **GROUP WORK ON BENEFIT AND BURDEN (15 minutes)**

Aim: to think about the benefits and burdens of different treatments.

Use Resource 4

Groups work through some of the examples in Resource 3. Choose the ones which are most suitable for your setting. Make sure different groups look at different examples.

Ask them to create a list of possible benefits and burdens for each situation and write the list on flipchart sheets.

The idea is not to come up with an answer of whether or not the treatment is worthwhile, but rather to think about the benefit/burden balance.

### **FEEDBACK (10 minutes)**

The groups present the cases they have looked at and feed back their lists – members of the wider group can add comments.

Emphasise that there are no absolute answers – the benefit/burden balance will depend on the individual patient and circumstances. But these are the things that we should discuss with patients and families when considering a treatment.

### **Care for the patient (five minutes) (page 24 of the Toolkit)**

- ➔ Explain the concept as on page 24 of the Toolkit.
- ➔ It includes nursing care, practical help, explanations and advice, emotional support etc.
- ➔ Families and volunteers should be able to do everything in the 'care' section for each symptom. The palliative care team needs to teach and encourage them in this.

### **Prescribe palliative drugs (15 minutes)**

- ➔ Explain the principles of good prescribing on pages 24-25 of the Toolkit.
- ➔ Emphasise that only those licensed in their country can prescribe these drugs but it is important for others (eg nurses and volunteers) to know about them as they may be able to give advice to patients/prescribers.
- ➔ Make sure participants are aware of specific legal requirements in their country, eg prescribing controlled drugs, which groups of health professionals can prescribe which drugs etc.
- ➔ Explaining the drug regime clearly to the patient is vital. The drugs will not work if they are not taken properly (page 25 of the Toolkit). Tool 6 is designed for the patient to keep as a reminder.
- ➔ Look at Tool 6 together and explain how to fill it in.

#### **Principles of good prescribing**

- **Only give drugs that help**
- **Educate patients and carers**
- **Keep drugs to a minimum**
- **Review drugs and symptoms**



## **EXERCISE TO PRACTISE EDUCATING PATIENTS ABOUT DRUGS** (20 minutes)

**Aim:** To practise using Tool 6 and 17.

To practise explaining drug regimes to patients.

Use Resource 5 and copies of Tool 6

### **1) Demonstration**

Use the first example prescription in Resource 5 and show how you would fill in Tool 6 to explain this regime. (You could draw a big version of Tool 6 on the flipchart and write the drugs on it, or pass around a completed form for people to see).

Now role play explaining the drug regime to a patient – a participant or another trainer can play the patient.

### **2) Work in pairs**

Participants fill in Tool 6 for the second prescription in Resource 5.

Role play explaining the regime to a patient.

Participants can use their existing knowledge of side effects etc, and also look up information on drugs using Tool 17.

Work through as many prescriptions from Resource 5 as possible.

**TOP TIP** **If you want to make it easier, have some Tool 6 forms already filled in according to the prescriptions in Resource 5 and the participants role play explaining the regimes.**

Emphasise that this is not just for prescribers – everyone caring for a patient should be able to explain and help a patient follow a drug regime even if they haven't prescribed it themselves.

## **Feedback to whole group** (10 minutes)

Groups feed back general observations – call out rather than give presentations

- Did they find it easy using the charts?
- If they role played a patient, did they understand easily?
- Did they learn anything new?
- Do they have any tips they use for explaining drugs to patients?

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

Encourage everyone to look briefly at the Head-to-Toe guide (page 26 of the Toolkit) in their own time.

# MODULE 9 YOU CAN CONTROL PAIN

If the participants have access to morphine or will have in the near future, 'Module 10: You can use morphine', must be taught straight after this one:

## AIM OF SESSION

To teach the analgesic ladder.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- describe the three steps of the analgesic ladder
- give examples of drugs from each step of the ladder
- explain the use of adjuvant drugs.

Topic	Teaching methods	Time (minutes)
Recap pain assessment	Q and A whole group	5
Analgesic ladder	Presentation	20
Morphine facts and fears	Whole group discussion	10
Adjuvant drugs	Presentation	20
Analgesic ladder	Quiz	20
	Answers to quiz	10
Summary	Reflection	5

### Revise pain assessment (five minutes) (page 26 and Tool 2 of the Toolkit)

Start with a question and answer session with the whole group on pain assessment, revising the questions to ask, what to look out for, and how to use the pain scales.

### Analgesic Ladder (20 minutes)

- ➔ Go through 'Treat, Care' section on page 26.  
Emphasise the importance of non-drug measures.
- ➔ 'Prescribe' – Explain the principles of pain control – by the mouth, by the clock, and by the ladder (page 27 of the Toolkit).
- ➔ Emphasise that 'by the clock' may be a new concept for many, and will need to be explained to patients and carers.
- ➔ It is also important to explain to patients that pain will return if a drug is stopped – analgesia doesn't cure the pain, it only controls it.
- ➔ Explain the concept of the stepwise approach (use Tool 14 as a visual aid or draw the ladder on a flip chart). Ask the class to give examples of drugs in the different steps.
- ➔ Remember that step 1 drugs can continue in steps 2 and 3, working alongside the opioids. However step 2 drugs are not used alongside step 3 drugs. When morphine is started, weak opioids are stopped as they will not add any extra analgesic effect, but the step 1 drugs can continue if they are helping.
- ➔ Finish the presentation with a chance for participants to ask questions.

#### Principles of pain control

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

### Morphine facts and fears (10 minutes)

Note: the use of morphine is taught as a separate module which must be included if the participants have, or will soon have, access to morphine.



- ASK ABOUT THE AVAILABILITY OF MORPHINE IN THE COUNTRY AND IN PARTICIPANTS' PLACES OF WORK.
- CLARIFY LOCAL REGULATIONS ON MORPHINE USE (WHO CAN PRESCRIBE, DISPENSE IT ETC).
- ASK ABOUT PEOPLE'S EXPERIENCE OF USING MORPHINE – HAVE THEY EVER SEEN IT USED?
- ASK WHAT THEIR CONCERNS ABOUT MORPHINE ARE.

Fears about morphine include:

- That it causes addiction. (This does not happen when it is taken for pain – see page 27 of the Toolkit).
- That it is a lethal drug causing respiratory depression. (It will only cause respiratory depression in an overdose and in fact it can be used very effectively for breathlessness (page 44 of the Toolkit).
- That it is very sedating and consequently patients taking it won't be able to live a normal life. (The sedating effect of morphine wears off over a few days and a patient is capable of leading a normal life while using morphine for pain).
- That starting a patient on morphine means the end is near. (This is not true as patients may use morphine for pain for many years, or they may be able to discontinue it if the pain gets better).

#### **Adjuvant drugs** (20 minutes) (Pages 29–31 of the Toolkit)

- ➔ There are four different types of pain helped by adjuvants.
- ➔ Teach the importance of recognising these different pains in order to give the right drug. There is an opportunity here to revise some of the pain assessment session.
- ➔ Remember adjuvants can be used on all three steps of the pain ladder.

Pains helped by adjuvant drugs

- 1. Severe swelling or inflammation = steroids**
- 2. Nerve damage pain (neuropathic pain) = antidepressants or anticonvulsants**
- 3. Muscle spasm = Diazepam or Baclofen**
- 4. Abdominal cramp = Hyoscine Butylbromide ('buscopan')**

#### **\_QUIZ ON THE ANALGESIC LADDER** (30 minutes)

Aim: to check understanding of the analgesic ladder.

Use Resource 6

Let the participants work alone or in pairs.

Give each one a copy of Resource 6.

They have 10 minutes to answer the questions – encourage them to use the Toolkit to help them.

Go through the quiz and discuss all the answers. Use the Toolkit together to check wrong answers.

Check if the participants have any further problems.

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 10 YOU CAN USE MORPHINE

This teaching module should be used in situations where morphine is available or will be available very soon. If there is no access to morphine, it can be left out.

## AIM OF SESSION

To improve knowledge and confidence in the use of morphine.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- Explain the place of morphine in the World Health Organization pain ladder.
- Describe the side effects of morphine and how to deal with them.
- Explain how to deal with break through pain.
- Calculate and adjust the dose of morphine.
- State the legal requirements for prescribing morphine.
- Describe the signs of morphine overdose.

Topic	Teaching methods	Time (minutes)
Preparations	Presentation	5
Side effects	Presentation and quiz	15
Morphine Prescribing	Lecture and demonstration	25
Morphine calculations	Working in pairs or threes	15
	Reporting back	15
Legal requirements	Presentation	5
Morphine overdose	Calling out	5
Summing up	Reflection	5

### **Morphine preparations** (five minutes)

There are several preparations of morphine (see page 27 and 28). Find out which is available in your country.

If it is liquid morphine, make sure you know which dilution is being used. This is commonly 5mg/5ml or 10mg/5ml. A strong solution, 50mg/5ml may also be used.

If MST tablets are available, make sure the participants understand how to use these (see page 28 of the Toolkit).

### **Side effects of morphine** (five minutes)

These are listed on page 29 of the Toolkit.

You could also put them up on an overhead projector, PowerPoint slide or flipchart (prepared beforehand).

Explain that sometimes the side effects may be useful, eg treating diarrhoea (see page 45 of the Toolkit).

#### **Side effects of morphine**

- **Constipation – prescribe laxative  
Never gets better.**
- **Nausea – prescribe anti-emetic.  
Improves 3-4 days.**
- **Drowsiness – improves 3-4 days.**
- **Sweating and Itching – less common.**



After you have taught the side effects of morphine, cover the flip chart list and do the following quiz. It will help you to know if the participants have understood so far.

**TRUE/FALSE EXERCISE, WHOLE GROUP** (10 minutes)

**Aim:** to assess participants' understanding of the side effects of morphine.

Prepare sheets of paper, two for each participant. One has a smiley face and says TRUE. The other has a sad face and says FALSE.

Read out the questions below one by one. For each question the participants must hold up their papers, or if you prefer, ask participants to stand up if they agree with the statements and remain seated if they disagree.

**Questions**

- 1) Nausea caused by morphine continues as long as you keep taking it. (F)
- 2) If the patient is itching you must stop the morphine. (F)
- 3) Constipation always occurs when taking morphine. (T)
- 4) Patients on morphine will always be drowsy and cannot do any useful work. (F)
- 5) If a patient on morphine has diarrhoea you should continue to prescribe a laxative. (F)
- 6) Morphine must not be prescribed with anti-emetics. (F)
- 7) Patients starting morphine must be warned about addiction. (F)
- 8) Constipation caused by morphine improves after 3-4 days. (F)
- 9) If a patient on morphine is very drowsy after a few days of starting it is best to decrease the dose. (T)
- 10) Morphine may be used to help breathlessness in a patient who has no pain. (T)

You may want to add some questions of your own. When the cards are put up, if everyone is correct you can be reassured they have understood you so far.

### **Morphine Prescribing (25 minutes) (page 28 of the Toolkit)**

- ➔ The most important thing to teach about morphine is that, unlike any other drug, there is no standard dose. The correct dose is the dose which controls the pain. There is no upper limit to the amount that can be given.
- ➔ All patients should be started on a low dose which is increased until the pain improves. The starting dose may be as low as 1.25mg 4 hourly in elderly or frail patients.
- ➔ If the patient has already had a step 2 weak opioid like codeine or tramadol then the dose of morphine should start a little higher, eg 5mg 4 hourly. The weak opioid must be stopped.
- ➔ The pain must be re-assessed frequently, at least daily.
- ➔ Morphine must be given four hourly if it is a normal release formulation (eg liquid morphine). If it is given six hourly the pain will return before the next dose is given.
- ➔ Always check that the patient has been receiving the prescribed dose before you consider increasing it.
- ➔ If the pain is not controlled, increase the dose by 30–50% (see page 28 of the Toolkit).
- ➔ If the patient has pain between the four hourly doses it is possible to give a breakthrough dose. This should be equal to the four hourly dose and the next four hourly dose is still given at the correct time. These must be recorded and the patient must be asked if they were effective.
- ➔ When the patient is taking four hourly morphine, give a double dose before sleeping at 10pm and miss out the dose in the middle of the night (2am).
- ➔ If you have long acting MST tablets available you must also teach about these. To find the appropriate dose for these, start the patient on normal release (NR) morphine. Add up the total dose they have taken in 24 hours and divide this by two. This will be the strength of tablet you will need (see example page 28 of the Toolkit).
- ➔ Look at the chart for recording morphine doses (Tool 7).

If you are going to be using liquid morphine it is useful to bring a bottle to show participants.

#### **Demonstration of dispensing morphine**

- | Have a 2.5ml, 5ml, and 10ml syringe and a medicine bottle full of coloured water.
- | If the solution is 5mg/5ml, get a volunteer participant to come up and draw up a 2.5mg dose.
- | Try this with a few more doses and volunteers.
- | Change to 50mg /5ml solution and ask a volunteer to draw up a dose of 60mg.

#### **MORPHINE CALCULATION EXERCISE (15 minutes)**

Aim: to improve competence in adjusting morphine.  
Use Resource 7

- | Divide into pairs or threes and give out the papers of morphine calculations.
- | Do at least the first two or three together with the whole group so they can see what is expected of them, then let them work through as many as they can.

#### **FEEDBACK (15 minutes)**

Work around the room getting answers from each pair to a different question. Sort out problems as you go.

#### **Legal requirements (five minutes)**

Each country will have its own legal requirements and these must be known by the lecturer.

Points to cover must include:

- ➔ Where morphine is obtained from.
- ➔ Where and how morphine is stored.
- ➔ Who is legally allowed to prescribe it (eg doctors, clinical officers, nurses).
- ➔ On what form it must be prescribed.
- ➔ What records must be kept, eg a controlled drug book.

### **Morphine overdose** (five minutes)

The signs of morphine toxicity are on page 29 of the Toolkit.

Let participants shout out any they know of.

Have a slide, overhead projector or flip chart prepared to refer to after they have finished calling out.

Go through the points.

Explain that dehydration or renal failure can cause morphine to accumulate in the body, causing toxicity.

#### **Signs of morphine overdose**

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

### **Managing toxicity**

- ➔ Reduce the dose by 50% or stop a dose and start again at half the dose.
- ➔ If you are very concerned stop completely.
- ➔ If it is available, naloxone will reverse the action of morphine.

### **Summing up** (five minutes)

This module contains some very important information for those about to use morphine for the first time. Summarise the main points and give time for questions.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 11 YOU CAN HELP DIFFERENT SYMPTOMS 1

## AIM OF SESSION

To demonstrate the use of the Head-to-toe guide for symptom control.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- Find and explain symptom control measures in the Head-to-toe guide.

Topic	Teaching methods	Time (minutes)
Recap of analgesic ladder	Question and answer large group	5
Explain Head-to-toe guide	Presentation	10
Demonstration	Work through two examples	15
Group work on case studies	Group discussions	30
Feedback on cases	Each group presents with flipchart	25
Summing Up	Reflection	5

### **Revision of analgesic ladder** (five minutes)

Briefly go over the analgesic ladder – you could invite a participant to draw the ladder on the flipchart and other participants call out the drugs for each step including adjuvant drugs.

### **Head-to-toe symptom control** (10 minutes)

Ask the group to call out different symptoms they see in their patients.

You may have replies such as cough, breathlessness, pain, vomiting etc.

Ask which of these they find easy to help and which are difficult.

Ask the group if they have read chapter 5 (page 23) and if they have any questions.

- ➔ Revise treat, care, prescribe algorithm.
- ➔ Explain the Head-to-toe approach:
  - ➔ This starts with general whole body symptoms like pain (page 26), fever (page 32), rashes (page 33), wounds (page 34), seizures or convulsions (page 35) confusion (page 36), anxiety and sleeplessness (page 37) and depression (page 38).
  - ➔ It then goes through the body from head to toe with other symptoms like poor appetite and weight loss (page 39), sore mouth and difficulty swallowing (page 40), nausea and vomiting (page 41) etc.
  - ➔ Several options are given for managing each symptom. Not all of them will be appropriate in every situation.
  - ➔ Explain you are not going to work through each symptom together as all the information is there in the Toolkit.

### **DEMONSTRATION OF HEAD-TO-TOE GUIDE (15 minutes)**

Use Resource 8

Work through the first two examples from Resource 8 together.

- 1) You are a nurse visiting a man at home with renal failure. He is very swollen all over and very breathless. His wife died a year ago and now his 18-year-old daughter is caring for him.

What could you do for his breathlessness? (page 44 of the Toolkit)

This could be acted out to make it more memorable.

Get a volunteer to be the patient.

Get everyone to turn to page 44 of the Toolkit.

As a nurse you could not treat but you could do all the things in the care panel.

Demonstrate positioning the patient, fanning them, teaching them to slow their breathing etc.

What might you ask the doctor to prescribe?

Work through the second example using page 41 of the Toolkit.

### **GROUP WORK – CASE STUDIES (30 minutes)**

Aim: to improve knowledge of symptom control.

Use Resource 8

Divide into groups of four to six people.

Work through the case studies in Resource 8.

Using the Toolkit, describe what can be done to help the patient. This will depend on what the health worker in the case study can do (eg volunteers will be limited to the 'care' measures, doctors can prescribe etc).

If using drugs they should give specific details such as dose and frequency of administration.

Each group should start with a different case.

#### **FEEDBACK (25 minutes)**

Each group presents a case in turn.

Make sure the cases presented cover different symptoms.

Then go around again, presenting as many cases as time allows.

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).



# MODULE 12 YOU CAN GIVE END OF LIFE CARE

## AIM OF SESSION

To improve knowledge of end of life care.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- list the signs of the terminal phase
- discuss ways of caring at the end of life
- explain non-oral routes of drug administration
- discuss ethical issues around end of life care.

Topic	Teaching methods	Time (minutes)
What is end of life?	Presentation, calling out	10
Fears of patient and family	Buzz groups and feedback	15
Treat, care, prescribe	Presentation	15
Difficult decisions	Presentation	10
Case studies	Discussion/small groups/ buzz groups	35
Summing up	Reflection	5

### What do we mean by end of life? (10 minutes)

It can be very difficult to predict or define the 'end of life'. Usually when people talk about end-of-life care, or terminal care, they mean care during the last few days or weeks of life.

Sometimes people think that palliative care is the same as terminal care. This is wrong because as we have already seen, palliative care has much to offer from the early stages of a life-threatening illness and is about quality of life, not just quality of death.

It is not always easy to know when a person is coming to the end of life, or is in the 'terminal phase'. Sometimes they may appear to be dying and then improve, so it is important to keep an open mind and not to make fixed predictions. It is also important to monitor the patient carefully and explain to them and the family what is happening, so that they can prepare themselves for death as much as possible.

?

ASK THE GROUP WHAT CHANGES THEY SEE IN PATIENTS WHO ARE NEAR TO DEATH.

Turn to page 51 of the Toolkit all together and go through the list given in the first paragraph.

### Fears of the patient and family (15 minutes)

Patients can be fearful when they know the end is near, though not always. For some it comes as a relief. It can also be a frightening time for family, especially if they have not cared for a dying person before. Understanding and addressing these fears is a major part of end of life care.

#### BUZZ GROUPS

Divide the room in half. Buzz groups in one half discuss fears the patient may have, the other half discuss what the family may fear (five minutes).

**FEEDBACK** – with the flipchart, making lists for the family and the patient (10 minutes).

There are many possibilities – there are no ‘right’ answers, the aim is to get people thinking. Here are some examples:

#### Patient

- Dying in pain
- Loss of dignity, eg incontinence, confusion
- Dying alone
- Dying with many people around
- What will happen to them after death?

#### Family

- Being alone with loved one when they die
- Not knowing what to do if the patient is in pain
- Not being able to cope with nursing care at the end
- Grief reaction

➔ We need to reassure the patient and family that:

- Pain and distressing symptoms can almost always be controlled.
- The palliative care team will continue supporting throughout.

➔ Explaining what is happening and what is likely to happen reduces fears and anxiety.

### **Treat, Care and Prescribe at the end of life** (15 minutes) (page 51 of the Toolkit)

#### 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 and we may need to spend time counselling them, explaining the situation and looking at the benefits and burdens of treatment (see below).

#### Care

Ask everyone to turn to page 51 of the Toolkit and go through the points on care at the end of life.

#### Prescribe (page 52 of the Toolkit)

Ask everyone to turn to page 52 and go through the points on prescribing – most medication can be stopped but continue symptom control drugs as long as they are needed.

### Non-oral routes (page 50 of the Toolkit)

What you teach here will depend on local drug and equipment availability and also the skill mix of the participants. Subcutaneous and nasogastric routes may be feasible and can be particularly useful if there is a problem such as cancer of the mouth. However, rectal administration of simple drugs such as paracetamol, NSAIDs and diazepam is achievable and if available, oral morphine solution works well buccally.

### Difficult decisions in end of life care (presentation 10 minutes)

It can be hard to decide about:

- withdrawing treatment – if/when it is right to stop treatment which is no longer helpful
- withholding treatment – deciding not to give a certain treatment because you think it will not help.

Both professional and family carers may be concerned about how to make ethical (morally correct) decisions. They may feel that they are responsible for causing the death of a patient if they withhold or withdraw treatment.

Guiding principles:

- Always look at the benefit/burden balance page 23 of the Toolkit.
- The aim of palliative care is not to prolong life at any cost, but to give quality of life.
- Palliative care does not aim to shorten life in the face of suffering, but to alleviate the suffering.
- We must listen to the patient's and family's wishes, although sometimes these may contradict each other and we are not necessarily bound to obey them. This is where the decisions can be very hard.

#### Principles for end of life care

- **Benefit/burden balance**
- **Not aiming to prolong life**
- **Not aiming to shorten life**
- **Aim is quality of life**
- **Listen to patient and family**

### Case studies – Resource 9 (35 minutes)

There are four cases in Resource 9 which illustrate some of these points.

You could use them in different ways according to how the participants interact and how much time you have.

It may be good to work through one case all together first, to demonstrate how to apply the principles.

WHOLE GROUP DISCUSSION	- BUZZ GROUPS -	- SMALL GROUPS -
Read out one case and discuss it all together, then move through the cases as time allows. If the group participates well, this will get through more cases in the time.	Read out a case and then everyone discusses it with their neighbour before discussing in the whole group. Then move on to the next case in the same way.	Give out Resource 9. Each group works on a different case and then presents to the class. This will take the most time.

### Trainer's notes for the cases

#### Case 1:

- The woman is dying.
- Giving food and fluid would be prolonging the dying process, not alleviating suffering.
- The aim is to keep her comfortable, not prolong life.
- Our first duty is to the patient, not to the son.

#### Case 2:

- The man has a progressive, incurable disease.
- He might die on the way to hospital.
- A transfusion will give only temporary benefit, if any.
- Our first duty is to the patient, not to the brother.

**Case 3:**

- The woman knows that her disease cannot be cured.
- She has decided that the burden of treatment outweighs benefit.
- The patient's wishes should be respected.

**Case 4:**

- The child is going to die soon whatever we do.
- Morphine will alleviate his suffering.
- If he is distressed by the oxygen it should be stopped – our aim is to make him comfortable.

**Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 13 YOU CAN HELP CHILDREN AND FAMILIES

## AIM OF SESSION

To improve understanding of the needs and support of children in a palliative care setting.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- list things that children need when they are healthy and when they are sick
- describe important communication skills for children
- discuss the value of telling the truth to children
- identify ways of supporting families
- respond confidently to difficult questions.

Topic	Teaching methods	Time (minutes)
Children's needs	Participants call out	10
Parents and siblings	Group work	20
Communicating with children	Q&A revision, presentation	10
How much should we say?	Buzz groups, presentation	10
Breaking bad news	Q&A revision, presentation	10
Practising talking with children	Interactive role play/difficult questions in pairs	25
Summing up	Reflection	5

### What do children need to be physically and emotionally healthy? (five minutes)

?

ASK THE CLASS TO CALL OUT AS MANY PHYSICAL AND EMOTIONAL NEEDS AS THEY CAN THINK OF AND WRITE THEM ON THE FLIPCHART.

The list may include:

#### Physical

- food
- safety
- housing
- clothes
- physical exercise

#### Emotional

- love
- physical affection
- play
- learning, stimulation
- attention and value
- encouragement, affirmation
- being part of a family or community

### What do children need when they are sick? (five minutes)

?

ASK THE CLASS TO CALL OUT THE ADDITIONAL THINGS THAT SICK CHILDREN NEED AND WRITE THEM ON THE FLIPCHART.

The list may include:

- medical treatment
- symptom control
- to have family around them
- to be in familiar surroundings if possible
- to have their questions answered
- not to be scolded for their reactions to their situation, eg anger, withdrawal
- to be reassured that they will be cared for.

➔ Emphasise that as well as medical treatment, children still need all the things in the first list when they are sick. They still need play, learning, stimulation etc – these things are often neglected but are part of our holistic care for sick children.



## **Parents and Siblings** (20 minutes) (page 55 of the Toolkit)

Looking after a sick child is very demanding, especially when you know that the child will not get better.

### **GROUP WORK ON PARENTS AND SIBLINGS** (10 minutes)

**Aim:** to discuss the needs of the families of sick children.

- 1) What are some of the challenges families face – parents, siblings, other relatives?
- 2) In what ways can we support them?

### **FEEDBACK** (10 minutes)

Answers to 1) may include:

- finance – cost of medicines, loss of income due to caring
- tiredness – work of caring, no time for their own needs
- anxiety/grief/stress/anger/guilt
- siblings – lack of attention, missing school
- extra burden of orphans in addition to own responsibilities
- strain on family relationships.

Answers to 2) may include:

- Appreciate their hard work, tell them how well they are doing.
- Avoid scolding and blame if their 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 sometime.
- Don't forget to pay attention to siblings.

Refer to the list on page 55 of the Toolkit.

#### **Supporting families**

- **Appreciation**
- **Avoid blame**
- **Involve them in decisions**
- **Share the work**

### **Communicating with children** (10 minutes) (page 54 of the Toolkit)

Recap communication skills from session 5 – ask for as many non-verbal and verbal skills as they can remember.

All these skills are important when talking with children.

Special considerations are:

- ➔ Talk with children, not about them, to the parents.
- ➔ Get on the same level – don't stand up if you are talking to a child who is on the floor – get down to where the child is.
- ➔ Don't rush them and don't interrupt.
- ➔ Listen attentively and show that you value their opinion.
- ➔ Use language they can understand – this will vary according to the age of the child.
- ➔ Answer questions honestly.
- ➔ Never lie.
- ➔ Never make promises that you cannot keep.
- ➔ For the first meeting, talk with a parent/guardian present so that they feel safe. Later, they may want privacy with you.
- ➔ Respect their personal space. Wait until they come to you, or at least wait to be invited in before you touch them.
- ➔ Try to create a child-friendly environment with some toys, pictures or crayons.

### **How much should we say to children?** (10 minutes)

#### **BUZZ GROUPS**

The trainer reads out the following scenario.

Buzz groups discuss in what their response would be. Encourage them to say what they think, not what they think you want to hear.

You are looking after a 12-year-old with a bone tumour in his leg which has spread to his lungs. There is no treatment available. He asks you “Am I going to get better?”

Should you tell him the truth?

You could take a poll of the whole group and see how many people took each point of view, or hear comments from a few groups.

- ➔ Breaking bad news to children or answering difficult questions about illness and death is not easy. Some people feel that children should not be told anything that might upset them. Many health workers are frightened of talking about difficult issues with children and so they say nothing. Parents often don't want their children to be told anything.

However:

- ➔ Children usually know much more than we think.
- ➔ The evidence shows that children and families cope better with illness when there is open communication.
- ➔ Children have the right to have their questions answered honestly.
- ➔ Talking about their illness allows them to express their fears and feelings and reduces their sense of isolation.

For these reasons, when parents do not want their child to be told anything, we need to explore their reasons and explain the points above. Ultimately we have to respect their wishes even if we do not agree with them. However, we should be clear that we will not lie to a child even if the parents ask us to.

### **Breaking bad news to children (10 minutes) (page 54 of the Toolkit)**

Recap the BREAK NEWS checklist, participants calling out the steps. All these steps are relevant for children, although we may be more likely to use them when responding to children's questions than sitting down with the intention of breaking bad news. Children's questions often come at unexpected times so it is important to have thought through ways of responding.

- ➔ These conversations take time. If you are feeling rushed, take a deep breath and prepare yourself.
- ➔ Answer questions with questions until you are sure you are on the right wavelength. Remember, children and adults think differently and see the world differently. You could respond to the question above "What do you think is going to happen?" "What has made you ask that now?"
- ➔ But do give an honest answer at some point – children will lose trust in you if they think you are avoiding the issue. It gives the message that the answer is too terrible to bear and that you do not respect the questioner.
- ➔ Be prepared to say you don't know: "I know you really want to know the answer, and if I knew it I promise I would tell you. But I am afraid I honestly don't know at the moment."

### **Practising communicating with children** (25 minutes)

Here are two options for practising. The interactive role play is a good learning tool but requires careful facilitation (see page 10 of this training manual). Participants who are less familiar with role play may find the 'difficult questions' easier.

<b>_DIFFICULT QUESTIONS _ _ _ _ _</b>	<b>_INTERACTIVE ROLE PLAY _ _ _ _ _</b>
<b>Aim: to practise communicating with children.</b>	<b>Aim: to practise communicating with children and carers.</b>
<b>Use Resource 10</b>	<b>Use Resource 11</b>
Participants work in pairs.	Reassure the participants that we all recognise this is a challenging area so we will all learn together.
For each question, discuss how you might answer the question with a question (see above and page 54 of the Toolkit).	Explain the interactive role play method as on page 10 of this training manual.
Think how the child might then respond and where the conversation may lead.	If possible, start with a trainer in one or more of the roles and then swap participants in quickly.
Role play the scenario to practise using the questions.	Work through as many scenarios as time allows.

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).
--

# MODULE 14 YOU CAN HELP DIFFERENT SYMPTOMS 2

## AIM OF SESSION

To demonstrate the use of the Head-to-toe guide for symptom control in children and adults.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- describe how to assess pain in children
- list non-drug treatments for pain in children
- find and explain symptom control measures in the Head-to-toe guide.

Topic	Teaching methods	Time (minutes)
Pain in children	Presentation, calling out	20
Symptom control principles	Presentation, calling out	10
Symptom control cases	Group work	30
Feedback on cases	Groups present	25
Summing up	Reflection	5

### **Pain in children** (20 minutes) (page 56 of the Toolkit)

- ➔ We need to think about pain in every child we see because often they do not or cannot tell us they are in pain.

How do we know a child is in pain?

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

- ➔ What are the signs that a child is in pain?

?

ASK THE PARTICIPANTS TO CALL OUT SOME SUGGESTIONS, AND HAVE A LIST READY (EG ON FLIPCHART) OR ASK EVERYONE TO TURN TO THE LIST ON PAGE 56 OF THE TOOLKIT.

#### **Signs that a child is in pain**

- **crying and distressed facial expression**
- **not wanting to move**
- **poor concentration**
- **irritability or restlessness**
- **difficulty sleeping**
- **increased breathing rate or heart rate**

- ➔ Look at the 'faces score' pain scale for children in Tool 2.
- ➔ There are non-drug measures that can help to reduce a child's pain.

Ask participants to call out suggestions and have a list ready, or look at page 56 from the Toolkit together.

- ➔ The drug treatment of pain is the same as for adults, but using Tool 16 to find paediatric doses.

(You can revise the analgesic ladder briefly if appropriate).

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

- **make them feel secure**
- **keep them in familiar surroundings**
- **make them feel valued**
- **use touch**
- **feeding**
- **heat or cold**
- **play**
- **use music or stories**
- **increased breathing rate or heart rate**

#### Symptom control in children (10 minutes)

?

ASK THE PARTICIPANTS WHAT SYMPTOMS THEY HAVE SEEN IN CHILDREN. THE GROUP CAN CALL OUT THEIR ANSWERS.

ASK THEM WHICH ONES THEY FIND EASY TO HELP AND WHICH ARE DIFFICULT.

Revise treat, care, prescribe.

Explain that you are not going to work through each symptom together as all the information is in the Toolkit, in the Head-to-toe guide and also:

- Pages 57-58 of the Toolkit
- Paediatric drug doses Tool 16.

It may be useful to turn to these pages all together, to see where the information can be found.

The group will use case studies to learn and to practise using the guide, in the same way as they did in Module 11. Some of the examples are paediatric cases, some are for adults.

### **GROUP WORK – CASE STUDIES** (30 minutes)

Aim: to improve knowledge of symptom control.

Use Resource 12

Divide into groups of four to six people.

Work through the case studies in Resource 12 – these are slightly more challenging than those for Module 11. It may be helpful to work through the first one all together.

Using the toolkit, describe what can be done to help the patient. This will depend on what the health worker in the case study can do (eg volunteers will be limited to the 'care' measures, doctors can prescribe etc).

If using drugs, give specific details such as dose and frequency of administration.

Each group should start with a different case.

### **FEEDBACK** (25 minutes)

Each group presents a case in turn.

Make sure the cases presented cover different symptoms.

Then go round again, presenting as many cases as time allows.

### **Summing up** (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned from this session and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).



# MODULE 15 YOU CAN TELL OTHERS

## AIM OF SESSION

To improve palliative care advocacy skills.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- define advocacy
- explain who should to be informed about palliative care
- create appropriate advocacy messages
- describe effective ways of presenting advocacy messages.

Topic	Teaching methods	Time (minutes)
Who do we need to inform?	Buzz groups, flipchart feedback	15
What messages should we give?	Small group work	25
How will we tell them?	Small group work	30
General principles	Mini-lecture	15
Summing up	Review and reflection	5

### **What is advocacy?** (page 59 of the Toolkit)

Advocacy is the process of informing and influencing people in order to bring about change.

### **Who do you want to inform about palliative care?** (15 minutes)

**BUZZ GROUPS**

Make a list of groups and individuals who should be informed about palliative care.

**FEEDBACK** (10 minutes) – go around the room and compile list on flipchart (eg general public, nurses, doctors, community leaders, government, church leaders etc).

### **What messages do we want to give about palliative care?** (25 minutes) (page 59 of the Toolkit)

If we want to spread the word about palliative care, we need to think about what we want to say. This may vary for the different people we want to inform.

**GROUP WORK ON PALLIATIVE CARE MESSAGES** (25 minutes)

Aim: to create appropriate advocacy messages.

- Make a list of the messages you would like to give about palliative care.
- If you could only present three messages, which would you choose?
- Then select the most important message for each of the groups listed above (15 minutes).

**FEEDBACK** (10 minutes) – each group presents their messages. See list on p59 for ideas – but there are many other possibilities.

## Ideas for getting the messages across

After giving feedback on advocacy messages and discussing these with the whole group, the participants return to their small groups to discuss ways of presenting these messages.

Give each group a target 'audience' eg:

- colleagues in workplace
- local community leaders
- healthworkers nationally
- general public
- government policy makers
- others (could be patient groups, religious groups etc).

### **\_GROUP WORK ON ADVOCACY METHODS (30 minutes)**

**Aim:** to discuss how to present messages to different groups.

The group discusses advocacy ideas for their target audience (15 minutes)

Encourage them to be specific, practical and realistic, eg if they suggest doing drama, what will they put in the drama? If writing a letter, what will they write? They should look at the advantages and disadvantages of different ideas, what each might achieve and which would be most effective.

**FEEDBACK** (15 minutes) – each group presents, others comment and add their ideas. See list on pages 59-61 but there are many other possibilities.

- ➔ Look together at advocacy tools 11,12,13 – ask all the participants to turn to them and discuss briefly how they might use them. If possible, print or copy a few leaflets (Tool 11) and fold them into three sections so that participants can see how they look.

### Principles of advocacy (15 minutes)

Give a brief presentation on some of the guiding principles of advocacy (put headings on a visual aid if you wish).

- ➔ Be positive, presenting possible ways forward.
- ➔ Be realistic, presenting ways forward that are achievable.
- ➔ Present important, relevant facts and statistics, but do not overwhelm with too much information. Make sure you collect data about your own work – you can use and adapt the data collection form for this (Tool 10).
- ➔ Use real-life stories of people and projects as well as statistics.
- ➔ Find out who are the key people making the decisions, and target them.
- ➔ Try to understand those people's concerns, assumptions and prejudices.
- ➔ Meeting face-to-face is important for relationship-building, but have facts and proposals down on paper to leave with the person so that they will not forget what you have said.

#### Some principles of advocacy

- **Be positive**
- **Be realistic**
- **Know your facts**
- **Use real stories**
- **Meet face to face**

### Summing up (five minutes)

Run through the key points of the session

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 16 YOU CAN BUILD A TEAM

Some aspects of teamwork are discussed in modules 2 and 6 (page 29 and 49 of this training manual). You might want to use this module as well for groups who are not used to working in teams, or who are forming new teams to deliver palliative care.

## AIM OF SESSION

To improve understanding of good teamwork.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- describe characteristics of good and bad teams
- explain the need for teamwork in palliative care
- discuss how team members can be trained.

Topic	Teaching methods	Time (minutes)
Team exercise	Building a giraffe	15
What makes a good team	Group work and feedback	30
Importance of teams in palliative care	Call out, ideas	10
Training the team	Group work and feedback	30
Summing up	Reflection	5

## What is a team?

A group of individuals working to achieve a common goal.

**TEAM EXERCISE** (15 minutes).

Aim: to have a taste of teamwork.

Form 'teams' of five people.

Give each team a large pile of newspapers and a roll of cellotape. Their task is to make a model of a giraffe out of the newspaper in five minutes.

Hopefully this will generate plenty of laughter. At the end you could give a prize for the best giraffe.

## What makes a good team? (page 13 of the Toolkit)

**TEAM EXERCISE** (15 minutes).

Aim: to discuss how teams work.

Return to the groups which made the giraffes in the teams and ask them to:

- discuss how (or if) they worked as a team to build their giraffe
- reflect on other teams they have experienced
- list the characteristics of good and bad teams.

When you give them these questions, explain what you mean, eg:

- Discussing how they worked together.
- Did someone become the leader?
- Did they work together well?
- Did they disagree about how they would do it? How did they decide what to do?
- Was there anyone who didn't join in? If so, why?

Reflecting on teams you have been part of (could be work-related but also think of others, eg committees, sports, choir, youth work etc)

Was it a good team? Did you enjoy being a part of it? Did it achieve its goals?

What made the team good/bad?

### **Feedback (15 min)**

The groups report back on their discussions.

Make lists of characteristics which are good and bad.

Some possibilities are:

#### **Good**

- Everyone understands and is committed to the goal.
- Members respect each other.
- People know their roles.
- Understand others' roles.
- Feel valued and appreciated.
- Communication good, everyone kept in the picture.
- Members help each other when one is struggling.
- Work for common aim rather than own glory.
- Approachable leader.
- Members encouraged to develop skills.
- Team has fun together.
- Disagreements are discussed and dealt with.

#### **Bad**

- Unclear of the goal.
- Members do not care about the goal.
- Critical of each other (unconstructive criticism).
- Members are lazy.
- Disagreements and hurts are buried and never discussed.
- No development of individual skills or learning.
- Members unconfident to do their task.
- Competing rather than complementing each other.

**TOP TIP** It is not necessary to elicit all of these points – see what participants come up with – but the key points to include are:

Good teamwork

- Commitment to the goal and to each other
- Clear roles
- Respect for each other
- Sharing and support
- Good communication
- Dealing well with conflict

**The importance of teams in palliative care** (10 minutes) (page 13 of the Toolkit)

Possible members of a palliative care team are discussed in Module 2.

Why is a team important for palliative care?

- Holistic approach – the different aspects of care call for a mixture of skills and one person may not have all the skills which are needed. A multidisciplinary team is the ideal.
- It is hard work – emotionally draining.

?

ASK THE GROUP TO CALL OUT SOME OF THE CHALLENGES AND STRESSES AND WRITE THEM ON THE FLIPCHART.

The list might include:

- physical – tiredness, lack of sleep, no time to meet our own needs
- emotional – sadness, frustration, anxiety
- social – overwork can result in less time for other tasks and for family/ social activities
- spiritual – facing questions of suffering, loss of hope, questioning our own beliefs.

Some of the ways of dealing with these stresses are discussed in Module 12.



### Training the team (page 14 of the Toolkit)

Training and supervision is important for:

- improving patient care
- personal development of team members
- increasing confidence and giving support to team members
- job satisfaction
- team building.

#### **GROUP WORK ON TRAINING THE TEAM** (15 minutes)

Aim: to discuss different training needs and methods.

You could mix the groups for this exercise.

- List some of the members of a palliative care team.
- What training might each of these need? (eg priority topics).
- How could this training be given? (eg lectures, attachments, demonstrations).

#### **FEEDBACK** (15 minutes)

**TOP TIP** The aim is not to create an exhaustive list but to get people thinking about different options.

### Summing up (five minutes)

Run through the key points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# MODULE 17 CONFIDENTIALITY

Confidentiality is discussed briefly in Module 4 (page 40 of this training manual). You might want to use this more detailed module if you have time in your course.

## AIM OF SESSION

To improve understanding of confidentiality and how it applies to palliative care.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- understand the meaning of confidentiality
- know the reasons why it is important
- see the value and place of the team in confidential issues
- look at some difficult problems involving confidentiality.

Topic	Teaching methods	Time (minutes)
What is confidentiality?	Call out definition on flip chart	5
Why do we need it?	Buzz groups, short talk	15
How is the team involved?	Thought exercise, lecture	10
Case studies	Worked example, group work,	35
	Feed back on group work	20
Summary	Reflection	5

## What is confidentiality? (five minutes)



TRY TO GET THE PARTICIPANTS TO GIVE YOU THEIR IDEAS AS TO WHAT CONFIDENTIALITY IS. IF THE GROUP IS CONFIDENT YOU CAN GET THEM TO CALL OUT. OTHERWISE USE THE BUZZ GROUP METHOD.

You may get answers like:

- not talking about a patient
- not revealing the results of an HIV test
- keeping things secret
- being careful about what you say.

### Confidentiality

**...is the keeping of secrets. Maintaining confidentiality means not disclosing information about a patient to other people unless you have the patient's permission to do so.**

## Why do we need confidentiality? (10 minutes)

Explain that it is very important to be able to trust someone who you give personal information to or who has information about yourself.

### THOUGHT EXERCISE (15 minutes)

Aim: to think why confidentiality is important.

Ask participants to close their eyes and imagine they have a serious illness.

Ask yourself:

- What do I want others to know about my illness?
- Are there some people who I don't want to know something about myself?
- Why don't I want this information shared with them?

Either in buzz groups or calling out, get the participants to look at why confidentiality is important.

Write their answers on the flip chart then compare their answers with a chart you have prepared with these points on it.

- ➔ Explain that once trust has been broken, that person may never trust you again.
- ➔ The relationship between you and the person whose trust you have broken will change.
- ➔ Agreeing with the patient on what should remain confidential shows the patient you respect them even if you do not agree with their decision. This particularly involves the problem of a husband or wife who refuses to tell their respective partner they are infected with HIV.
- ➔ This point may also involve the fourth point on the slide, a wife may fear physical or mental abuse if her 'secret' becomes public.
- ➔ Emphasise that confidentiality is about a lot more than just HIV. It applies equally to information about any disease, and it applies to information we have about our colleagues as well as our patients.

#### Why do we need to respect confidentiality?

- **To maintain trust**
- **To show respect**
- **To value the person**
- **To prevent the person coming to harm**

#### How is the team involved? (10 minutes)

We have seen that in palliative care we do not work in isolation, but in a team.

So where is the team involved in confidentiality?

Put up the following on a flip chart, overhead projector or slide and work through each point.

#### Confidentiality in the team

- **Who do we share information with?**
- **Where do we write information?**
- **Who has access to this information?**
- **Will the patient benefit if we share the information?**
- **Has the patient given permission to share their information?**

## Case studies

Resource 15 – Case studies on confidentiality.

Confidentiality is not always simple.

The following cases have no absolute answers but have some points that will stimulate discussion.

### **GROUP WORK** (40 minutes)

Aim: to increase understanding of the issues around confidentiality.

Use Resource 15

Work through this case together as a whole group (10 minutes)

Salim is a 14-year-old patient who has HIV. He is an orphan and his guardians have asked several times that you do not mention HIV in front of him as they do not want him to know his HIV status. He is on ARVs. One day he appears on his own and asks why he has to take medicine. **How will you respond?**

He eventually finds out his status and becomes very depressed and anorexic. He is refusing to take his medication. **How do you deal with this?**

Salim is in standard 7 at the local primary school and the head of the school is a good friend of yours. He is at your house one evening and starts to talk about Salim. He is very fond of the boy and shows great concern and asks you what is his problem and how can he help? **What will you say?**

Divide the participants into groups and give each one a different scenario from Resource 15.

They have 30 minutes to discuss their case and note down their comments. If they want, they can look at the other questions after they have finished their own.

### **Presentation of Group Work** (20 minutes)

Each team lets a representative report on their case. The other participants should have a chance to add their comments. There is five minutes for each team to present.

You can see from these cases that confidentiality is not a case of right and wrong and is sometimes a matter of conscience.

### **Summing up** (five minutes)

Run over the main points of the session.

Ask everyone to think of the most important thing they have learned and what one thing they want to do differently as a result. They should add this to their list of personal learning points (see Module 1).

# ADDITIONAL SESSIONS

## INTRODUCTORY SESSION

This session is for use at the start of a course – you may not need to use it for a one-day programme, or you could use a shortened version.

### Introductions

Go around the room and ask each person to introduce themselves – names, where they work etc.

### Ice-breakers

You could use some ‘ice-breakers’ (see page 11) to get people talking and interacting with each other.

### Expectations



ASK PARTICIPANTS TO CALL OUT THEIR EXPECTATIONS OF THE COURSE – WHY THEY HAVE COME, WHAT THEY ARE HOPING TO LEARN ETC.

Write these up on the flipchart.

### Ground rules



ASK PARTICIPANTS TO SUGGEST GROUND RULES FOR THE COURSE AND WRITE THEM UP. THESE SHOULD INCLUDE:

- confidentiality
- mutual respect (eg listening when others are talking, not interrupting)
- share responsibility for learning (eg helping fellow participants, taking part in group work, allowing others to speak)
- always ask if you don’t understand
- turn off mobile phones.

### Leaders within the group

It may be helpful for the participants to nominate/elect leaders who can represent the participants during the course, eg chairman, secretary, time-keeper.

### Housekeeping

Explain the arrangements for meals and refreshments, toilets and other administrative details. If you plan to take a register every day, explain how this will be done.

## **Introducing the Toolkit**

The course uses the Toolkit throughout. It is hoped that participants will become familiar with it so that they will continue to use it after the course to find information and resources to help them in their work.

### **Explain briefly what the Toolkit is (see Introduction page IV of the Toolkit)**

Get everyone to look through it together so they can begin to find their way around its sections.

Look at the tools contained in the Toolkit.

Encourage the participants to use it during the course, looking things up during the sessions. They will find almost all of what is being taught in the Toolkit, so they should not need to take many notes.

## **Teaching methods on the course**

Explain that the course will use a variety of teaching methods, some of which they may not be familiar with. Most of the course uses participatory methods rather than lectures. These methods help people to remember what they have learned, and enable them to learn from one another.

## **Confidence rating**

Have a copy of the confidence rating scale (Tool 15 in the Toolkit) for each participant – give them five minutes to fill it in. This shows how confident they feel about palliative care skills. They will be asked to rate their confidence at the end of the course, which will give an indication of how effective the teaching has been.

# FINAL SESSION – IMPLEMENTATION

## AIM OF SESSION

To encourage participants to implement what they have learned on the course.

## LEARNING OBJECTIVES

**By the end of the session, participants should be able to:**

- describe how they intend to use the knowledge they have gained on the course
- describe sources of support and further information.

Topic	Teaching methods	Time (minutes)
The local story of palliative care	Presentation	10
The Toolkit tree	Whole group discussion	10
Developing palliative care in your setting	Group work	25
	Feedback	25
Further support	Looking at the Toolkit	10
Summing up	Reflection	10

How you teach this final session will depend on who your participants are and what the local situation is. The main aim of the session is to encourage them to start practising palliative care, or to improve what they are already doing, using the knowledge and enthusiasm they have gained on the course.



### **The story of palliative care in this region (10 minutes)**

Tell the story of the development of palliative care in this country. If it has already begun in this locality, ask participants who are involved to describe how it started and what is happening now.

**The course participants are the next chapter of the story.**

For some, implementing what they have learned may involve forming a team and setting up a service. Others may not be in a position to do this, but should be encouraged that they can all use their new palliative care skills as they care for patients in their work. Even if they have no palliative care drugs, improving their communication skills can make a difference to the care they give.

They may be able to find someone – possibly another participant on the course – who they could meet for encouragement and support.

### **The Toolkit tree**

#### **\_WHOLE GROUP DISCUSSION ON THE TOOLKIT TREE (10 minutes)\_**

- Have a tree already drawn on a flip chart and let the group call out the four roots.
- Then let them call out the local resources available to make up each root. These were discussed in groups in Module 2 – you could look at the flipchart feedback sheets from that session if you have kept them. They may have more ideas now that they have done the rest of the course.
- Look at the fruits on the tree. These are the different ways in which palliative care can be delivered. There are five fruits on page 6 but they may think of others.
- If there is some palliative care already happening discuss what kind of ‘fruit’ this is. What other kinds of ‘fruit’ might grow well in this area?

## Developing palliative care in your own setting

### **GROUP WORK ON DEVELOPING PALLIATIVE CARE IN YOUR AREA OF WORK** (25 minutes)

Aim: to discuss implementation of palliative care.

Participants working in the same place should be in the same groups – these will be similar to the groups in Module 2.

The questions you set will depend on local circumstances. Here are some suggestions:

- Who is, or could be, on your team? (Be specific, giving names)
- Who else would you like to include?
- When and where will you meet together?
- What 'fruit' are you hoping to grow, ie how do you plan to deliver palliative care? (eg as a hospital team, or within a HBC programme etc)
- What challenges will you face and how will you overcome them?
- What resources are missing and how will you get them? (eg morphine or other drugs)
- What further training will you need?
- What training will you need to give? (eg to volunteers)
- Who could give you further help and support?

**FEEDBACK** (25 minutes) – each group presents their ideas/plans; others add their comments and suggestions.

### **Further support** (10 minutes)

- Identify sources of support they can use as they start to practise palliative care – both individuals (eg the course facilitators) and organisations (eg national association).
- Look briefly together at the tools in the Toolkit, to make sure they know what practical resources are available for use in their work. The ones they want to use can be photocopied or downloaded.
- Look at the list of further resources in Tool 18.

### **Summing up** (10 minutes)

Bring together the ideas which have been generated. Encourage the participants that they can do palliative care in their setting.

Ask everyone to think of the three most important things they have learned on the course and what they plan to do differently as a result. How will they do this? They should write their plans on their list of personal learning points (see Module 1). Encourage them to look at these plans in two months' time and see how they are getting on.

# ASSESSMENTS FOR THE END OF THE COURSE

There are three assessment tools to use at the end of a course. These are useful for the trainers as well as the participants.

## **Course evaluation** (Resource 13)

Resource 13 is an evaluation form for the course. Make time for participants to fill this in on the last day, eg before the test or before certificates are presented. Ask them to be honest and give them 10 minutes to do it.

The feedback will be helpful for you in your development as a trainer and will also be useful for us at Help the Hospices. Please let us know how the course went and what the participants thought of it by emailing [international@helpthehospices.org.uk](mailto:international@helpthehospices.org.uk)

## **End of course test** (Resource 14)

Resource 14 is a test that can be used at the end of a course to show participants how much they have learned and to bring out areas where clarification is needed. It should not take more than 30 minutes to complete. Afterwards, go through all the answers together – this can be a useful way of clearing up misunderstandings and clarifying important points.

If you have not used all the modules, you will need to take out the questions relating to those modules.

## **Confidence rating scale** (Tool 15 in the Toolkit)

Repeat the confidence rating scale that participants did at the start of the course. Comparing the results will give you an idea of how effective the course has been.



# RESOURCE 1 ROLE PLAY SCENARIOS FOR COMMUNICATION SKILLS (Module 3)

The following scenarios are all patients attending a small clinic where they are met by a health professional who does not know them. One person is to play the patient and the other the health professional. **There is no need to examine your 'patient'**. The exercise is about practising communication skills, not necessarily arriving at a diagnosis. The patient can expand on the story below in any direction they want.

- 1) An elderly man lost his wife a few months ago. He lives in a village but his children all live in the city and have returned there to their families. The man wants to stay in his familiar surroundings but feels isolated without any family around him. He has painful joints and is short of breath. The painful joints stop him working on the land and he is worried about how he can get his field planted for the next harvest.
- 2) A young woman discovered an ulcer in a very private place. She has been told by her sister that it may be a sexually transmitted disease and is worried her husband may have been unfaithful. She has never slept with anyone else but she is afraid to tell him about the ulcer in case he accuses her of unfaithfulness. He is a lorry driver and brings home a very good salary which pays school fees for their two children.
- 3) A woman of 40 has breast cancer which has spread to her ribs and back. She has been given medicine from the hospital which is controlling her pain, but she has come to you because she is very worried about the future of her three children. She knows there is no treatment for her cancer and realises that her life is short. Her husband is a drunkard and she fears he will not look after the children well when she dies.
- 4) A young single man who is a school teacher has an itchy rash all over his body. He is living away from home and has a girlfriend. They are planning to get married as soon as he can afford it. He is very worried about the rash as he has a friend who is HIV positive that had a similar rash. He has never had an HIV test and does not want to have one.
- 5) A father of a 14-year-old girl who is dying of cancer. He is a successful business man and has plenty of money to pay for treatment but he has been told that nothing can be done. He is very angry with the doctors who have been caring for his daughter because he feels they have failed her.

# RESOURCE 2 SCENARIOS FOR BREAKING BADS NEWS (Module 4)

## Patient

- 1) You are Mariam, a young woman of 30 years, married but with no children. You have had some pelvic pain and have been bleeding a lot. You have come for the result of a biopsy of your cervix.
- 2) You are Peter and have come for the result of your HIV test. You have been advised to have one because you have been diagnosed as having TB. You have been faithful to your wife who you married five years ago and are sure your result will be negative.
- 3) You have brought your 18-month-old child Juma with you for the result of his HIV test. You did not really want the test to be done but he has been very ill with a recurrent cough and has had difficulty breathing. He is well today after his medicine from the hospital.

## Health professional

- 1) You are the doctor who saw Mariam and took the biopsy. She has invasive cancer of the cervix and you will have to arrange for her to have a hysterectomy as soon as possible.
- 2) You saw Peter at the TB clinic last week and you now have his positive HIV result in front of you to give him.
- 3) You are the ward doctor who saw Juma. He has been admitted four times so far this year with pneumonia and the last occasion you treated him with high dose co-trimoxazole and he responded well. You had great difficulty persuading the mother to let you do an HIV test. You must now give her the positive result.

# RESOURCE 3 SCENARIOS FOR HOLISTIC HISTORIES (Module 7)

## Case 1

You visit a 24-year-old woman with advanced cancer of the cervix. You have been treating her with morphine for abdominal pain. Now she is lying silently in the house. There is a very bad smell in the room, which is untidy and the floor has not been swept. Her 12-year-old niece is with her.

What questions do you need to ask her?

What questions do you need to ask her niece?

What do you think would be on your problem list?

Which three are most important?

## Case 2

A 23-year-old school teacher comes to your clinic complaining of pain in his feet. You have not met him before. He is also finding it painful to swallow and is losing weight. He says he does not sleep properly and is finding it difficult to go to work.

What questions do you need to ask him?

What do you think would be on your problem list?

Which three are most important?

## Case 3

You are asked to see a 60-year-old woman on a general medical ward who has a cancer of her breast. The swelling is discharging pus. She is very weak and her husband tells you that she is not eating the hospital food. She complains of pain in her back and has a large wound on her sacrum.

What questions do you need to ask her?

What questions do you need to ask her husband?

What do you think would be on your problem list?

Which three are most important?

#### Case 4

You are asked to visit a 45-year-old man with a spinal tumour who has become paralysed during the past few weeks. He has severe pain in his back and right leg. He has tried various medicines for this. He owns a small shop which his wife is currently running. They have four children, three are at secondary school. You see him at home, with his wife who is very tearful.

What questions do you need to ask him?

What questions do you need to ask his wife?

What do you think would be on your problem list?

Which three are most important?

#### Case 5

You are asked to visit a 12-year-old boy who has an osteosarcoma. His parents and an aunt come into his room with you but it is the father who takes the lead in the conversation. The aunt strokes the boy's hair but the mother neither touches nor speaks to him. The boy's two brothers stand at the door of the house but do not come in.

What questions do you need to ask the boy?

What questions do you need to ask his brothers?

What questions do you need to ask his parents and aunt?

What do you think would be on your problem list?

Which three are most important?



# RESOURCE 4 BENEFIT AND BURDEN

## (Module 8)

- 1) Mwanaidi is a 58-year-old woman with HIV. She has not started antiretroviral drugs (ARVs) yet as her state of health has been so poor and she has not attended regularly for her adherence counselling sessions. She develops severe pneumonia and is vomiting.

**What are the benefits and burdens of being admitted to hospital for intravenous antibiotics?**

- 2) James, four, has a huge swelling of his left face and eye. He lives in the village. He is diagnosed as having Burkitt's lymphoma. The hospital advises that he should go to the referral hospital for chemotherapy but it is a very long way and his mother has five other children and no husband.

**What are the benefits and burdens of chemotherapy?**

- 3) Happy, four, has AIDS and a severe wasting disease. There are no ARVs available in this area. She has three siblings and her mother's job is the only source of income for the family.

**What are the benefits and burdens of admission to a nutritional rehabilitation unit?**

- 4) Jane is 76 and lives with her son, daughter-in-law and their four children. She has a huge ulcerating breast cancer. It is very smelly and she already has disease in the lymph nodes under her arm.

**What are the benefits and burdens of a mastectomy?**

- 5) Mohammed lives in a remote village and the bus fare to the hospital and back is the equivalent of several days' wages. He has been on the ward for a long time having treatment for TB and Cryptococcal meningitis. He is now well and is going home.

**What are the benefits and burdens of starting ARVs?**

- 6) Christopher has cancer of the bowel and is very thin and wasted. He no longer enjoys food.

**What are the benefits and burdens of admitting him to hospital for nasogastric (NG) tube feeding?**

- 7) Rama has lung cancer and gets recurrent pleural effusions. His breathing is better for a short time after his chest is drained. He lives 30km from the hospital.

**What are the benefits and burdens of continuing to drain the pleural effusion?**

## **RESOURCE 5** PRESCRIPTIONS TO USE WITH TOOL 6 OF THE TOOLKIT (Module 8)

1) Fill in a drug chart for:

- Paracetamol (two tablets) four times a day
- Ibuprofen 200mg (one tablet) three times a day

Now explain this to your partner.

2) Fill in a drug chart for:

- Amitriptyline 25mg (one tablet) at night
- Metoclopramide 10mg (one tablet) three times a day before meals

Now explain this to your partner.

3) Fill in a drug chart for:

- Loperamide 2mg (one tablet) three times a day and after each loose stool up to 16mg (eight tablets ) in a day

Now explain this to your partner.

4) Fill in a drug chart for:

- Metronidazole 400mg (two 200mg tablets ) three times a day for five days
- Fluconazole 150mg (one tablet) daily for two weeks

Now explain this to your partner.

5) Write a prescription for:

- Haloperidol 5mg (one tablet) at night
- Acyclovir 200mg (one tablet) five time a day for five days

Now explain this to your partner.

6) Write a prescription for:

- Chlorpheniramine 4mg (one tablet) three times a day
- Prednisolone 30mg (six tablets) daily for five days

Now explain this to your partner.

## RESOURCE 6 QUIZ ON THE ANALGESIC LADDER

- 1) How many steps are there on the analgesic ladder?  
a) Two steps                      b) Four steps                      c) Three steps
- 2) On which step can you use paracetamol?  
a) Step one only                      b) Steps one and two                      c) Every step
- 3) Is it possible to use NSAIDs like Ibuprofen together with morphine?  
a) Yes                      b) No
- 4) Is it possible to use paracetamol together with an adjuvant drug?  
a) Yes                      b) No
- 5) A patient with HIV has burning pain and numbness in his feet. Is this due to:  
a) infection in the skin?      b) neuropathic pain?                      c) muscle spasm?
- 6) The patient in question five should be treated with:  
a) paracetamol                      b) amitriptyline                      c) flucloxacillin
- 7) Hyoscine butylbromide should be used:  
a) on step three of the ladder only      b) for abdominal colic                      c) for neuropathic pain
- 8) A patient with a brain tumour and raised intra cranial pressure should:  
a) start on step three of the ladder      b) be given parenteral analgesic (injection)                      c) be started on steroids
- 9) What dose of dexamethazone should be used for the patient in question eight?  
a) 2mg three times a day      b) 16mg daily                      c) one tablet
10. If the patient in question eight takes steroids for a long time, he may develop:  
a) agitation                      b) constipation                      c) low blood sugar

- 11) Carbamazepine is used to control convulsions but may also be used for:  
a) constipation                      b) confusion                      c) neuropathic pain
- 12) The dose of carbamazepine should start at:  
a) 10mg daily                      b) 400mg tds                      c) 100mg bd
- 13) Neuropathic pain is produced by:  
a) tissue damage                      b) severe infection                      c) nerve damage
- 14) Neuropathic pain may be treated with:  
a) acyclovir                      c) valproate                      d) phenyl barbitone
- 15) Step two of the analgesic pain ladder adds weak opioids. Which of the following are weak opioids?  
a) Aspirin                      b) Codeine                      c) Morphine
- 16) The most common side-effect seen with all opioids is:  
a) confusion                      b) constipation                      c) diarrhoea
- 17) Morphine should never be prescribed with:  
a) ibuprofen                      b) codeine                      c) amitriptyline
- 18) The pain from Herpes Zoster may be helped by:  
a) amoxicillin                      b) amitriptyline 25mg nocte                      c) amitriptyline 150mg tds

# RESOURCE 7 MORPHINE CALCULATIONS

## (Module 10)

- 1) A patient is taking 10mg of morphine every four hours and his pain is not well controlled.
  - a) What would you increase the dose to?
- 2) A patient has just started on 2.5mg of morphine every four hours. His pain is improved a little but could still be improved more.
  - a) What would you increase his daily dose to?
  - b) What would you give him last thing at night?
- 3) A patient has been taking 30mg of morphine every four hours and still has pain about an hour after each dose.
  - a) What would you increase the dose to?
- 4) A patient at home who is taking 10mg of morphine every four hours says he still has occasional quite severe pain but not every day.
  - a) What would you advise him to do?
  - b) What would the breakthrough dose be?
- 5) A patient is taking 60mg of morphine every four hours. He gets pain when he needs to move, but otherwise he is free from pain. His morphine solution is 5mg/5ml strength.
  - a) Would you use a breakthrough dose? If so, when?
  - b) He is taking a large volume of liquid (60ml) every four hours. How could this be made easier?
- 6) A patient is taking 20mg of morphine every four hours and took one breakthrough dose in the middle of the night. He says the pain is still at level six most of the time.
  - a) Would you increase the dose?
  - b) What is the new dose?
  - c) What is the new breakthrough dose?
- 7) A patient taking 10mg of morphine every four hours becomes unable to swallow.
  - a) What could you do for him?
- 8) A patient with bone metastases comes home after radiotherapy. He is on 30mg of morphine every four hours and starts to get confused and hallucinate.
  - a) What could be the problem?
  - b) How would you deal with it?
- 9) A patient aged six is on morphine 2.5mg every four hours and is still in pain.
  - a) Can you increase the dose and if so what to?

- 10) A patient on a regular dose of 20mg of morphine every four hours vomits after his night-time dose.
- a) What should you do?
- 11) A patient on 15mg of morphine every four hours has had six breakthrough doses in 24-hours.
- a) What is the total daily dose?
- b) How would you change the regular dose?
- c) What is the new breakthrough dose?
- 12) A patient is on 45mg of morphine every four hours. He needs a very occasional breakthrough dose.
- a) What breakthrough dose would you use?
- b) What strength of morphine solution would you use and why?
- c) If the pain got worse, what would the increased dose be?
- 13) A patient on 100mg of morphine every four hours is still complaining of pain.
- a) Can the dose be increased further or have you reached the maximum dose?
- b) If it can be increased, what would you increase it to?

The following calculations are for use if MST tablets are available.

- 14) A patient has been taking 5mg of morphine liquid (NR) every four hours and her pain is well controlled.
- a) What dose of MST should she use?
15. A patient who has had 60mg of MST twice daily for a week now complains his pain is getting worse.
- a) What would you increase the dose to?
- b) What would you give as a breakthrough dose (dose and preparation)?
16. A patient has been taking 45mg of NR liquid morphine every four hours. MST now becomes available.
- a) What is her total daily dose?
- b) What would her dose of MST be?
- c) What would her breakthrough dose be?

## RESOURCE 7A ANSWERS TO MORPHINE CALCULATIONS (Module 10)

- 1a) Answer: 15mg
  
- 2a) Answer: 5mg (anything from 3.75–5mg is okay)
- 2b) Answer: 10mg (or twice the four-hourly dose)
  
- 3a) Answer: 45mg
  
- 4a) Answer: Stay on the same dose but use a breakthrough dose when he needs it.
- 4b) Answer: 10mg
  
- 5a) Answer: Yes. Use a breakthrough dose half an hour before moving.
- 5b) Answer: Use 50mg/5ml solution. The patient will need only 6ml of this strength solution.
  
- 6a) Answer: Yes
- 6b) Answer: 30mg every four hours
- 6c) Answer: 30 mg
  
- 7a) Answer: Use 50mg/5ml solution. He then only needs 1ml which could be absorbed through the buccal mucosa.
  
- 8a) Answer: His pain is reduced and he is showing signs of morphine overdose.
- 8b) Answer: Stop the morphine for one dose and restart at half the dose. It may need to be cut even more than this.
  
- 9a) Answer: Yes. With children morphine is increased exactly as with adults so the new dose would be 5mg.
  
- 10a) Answer: Give him an antiemetic and give him the dose again.

- 11a) Answer: 180mg
- 11b) Answer: Double it to 30mg (This is the total dose for 24 hours divided into six doses.)
- 11c) Answer: 30mg
- 
- 12a) Answer: 45mg
- 12b) Answer: 50mg/5ml to reduce the volume of liquid for the patient.
- 12c) Answer: 67.5mg. This is a rather strange amount and in practice you would probably give 65mg.
- 
- 13a) Answer: Yes it can be increased. There is no maximum dose.
- 13b) Answer: 150mg
- 
- 14a) Answer: MST 15mg bd (every 12 hours)
- 
- 15a) Answer: MST 90mg bd
- 15b) Answer: 30mg of NR morphine (liquid morphine)
- 
- 16a) Answer: 270mg
- 16b) Answer: 135mg bd (In practice this would be impossible and they would have to take 1x100mg + 1x30mg.)
- 16c) Answer: 45mg NR morphine



# RESOURCE 8 SCENARIOS FOR SYMPTOM CONTROL 1 (Module 11)

- 1) You are a nurse visiting a man at home with renal failure. He is very swollen all over and very breathless. His wife died a year ago and now his 18-year-old daughter is caring for him.

**What can you do for his breathlessness? (page 44 of the Toolkit)**

- 2) You are the doctor looking after a woman with widespread cancer. She is very nauseated and vomits intermittently.

**What can you do to help her nausea and vomiting? (page 41 of the Toolkit)**

- 3) You are a doctor in paediatric outpatients and a thin child is brought to you with a large tumour in his leg which is extremely tender. He has been seen at several private clinics and been given some treatments which have not helped. He is screaming in pain and very frightened.

**What can you do for his pain? (page 27 of the Toolkit)**

- 4) You are a clinical officer working in a general medical ward of a district hospital. You are asked to see a woman with AIDS who has been brought by her elderly mother because she is saying strange things, is wandering from the house at night and burnt herself yesterday because she knocked a pot of boiling water over. Now she is distressed and shouting.

**What can you do to help her confusion? (page 36 of the Toolkit)**

- 5) You are a home-based care (HBC) volunteer who is visiting a woman with breast cancer at home. You have a HBC kit with you. She has had pain in her back and has been given morphine. That pain has improved but now she has abdominal pain and has not had her bowels open for a week.

**What can you do to help her constipation? (page 46 of the Toolkit)**

- 6) You are the clinician seeing a recently diagnosed patient in your HIV clinic. His main complaint is irritation of the whole body and his skin is scratched and infected in places.

**What can you do to help his itchy skin? (page 33 of the Toolkit)**

- 7) You are a palliative care nurse visiting a 65-year-old widow with a large cancer of the vulva which is discharging pus. She lives with her son, daughter-in-law and grandchildren and is distressed about the smell in the house.

**What can you do to help her smelly wound? (page 34 of the Toolkit)**

- 8) You are a relative of an elderly lady with cervical cancer and a vesico-vaginal fistula. She has a smelly vaginal discharge and is incontinent of urine.

**What can you do to help her incontinence and discharge? (page 47 of the Toolkit)**

- 9) You are the clinical officer on the paediatric ward. A young HIV positive child is brought in having a convulsion. His mother thinks he is dying and is hysterical.  
**What can you do to help his seizure (convulsion)? (page 35 of the Toolkit)**
- 10) You are the pastor visiting a man with multiple lymphomas. He has been unable to sleep for several weeks and is very anxious.  
**What can you do to help his insomnia and anxiety? (page 37 of the Toolkit)**
- 11) You are a counsellor. Today a client has returned who you saw a month ago when you gave him his positive HIV result. He walks in slowly, looks unwashed and scruffy, and says he needs to talk to you urgently.  
**What can you do to help his depression? (page 38 of the Toolkit)**
- 12) You are the palliative care doctor looking after a patient with cancer of the breast who has very short life expectancy. Her sister visits you and says the patient has no appetite, is losing weight and will not eat.  
**What can you do to help her poor appetite and weight loss? (page 39 of the Toolkit)**
- 13) You are the clinical officer in a HBC programme. You are asked to visit a patient who is complaining she cannot swallow even water as her mouth and throat are so painful. She has severe candida.  
**What can you do to help her difficulty swallowing? (page 40 of the Toolkit )**
- 14) You are the ward nurse looking after a patient who has liver cancer and ascities (fluid in the abdomen). He has intermittent hiccups and complains of burning in his chest. He is very anxious to get home as he says the hospital is not making him better.  
**What can you do to help his hiccups and indigestion? (page 42 of the Toolkit )**
- 15) You are a doctor seeing an elderly man with lung cancer. He can't sleep at night because he is coughing so much.  
**What can you do to help his cough? (page 43 of the Toolkit)**
- 16) You are the ward auxiliary nurse. The old man in the corner of the ward with no relatives has developed profuse diarrhoea.  
**What can you do to help his diarrhoea? (page 45 of the Toolkit)**
- 17) You are the carer for your elderly father. He had recurrent schistosomiasis (a parasitic disease of the urinary tract) as a boy. Recently he has had pain and difficulty passing urine and has passed some blood. He says he does not want to waste money going to the health centre. Today he is in agony and has not passed water since he got up.  
**What can you do to help with his retention of urine? (page 48 of the Toolkit)**

## RESOURCE 9 SCENARIOS FOR END OF LIFE CARE

- 1) A 78-year-old widow has metastatic breast cancer and no further treatment is available. She is increasingly confused and now bed bound. She is very thin and taking only sips of water. She has been in hospital for a week and is on an IV drip because she is not drinking. Her daughter wants to take her home and care for her there. Her son is adamant that she should stay in hospital and be given NG feeding “to fight the cancer”.

What would you do and why?

How would you counsel the family?

- 2) Sunil is a 45-year-old man who has advanced stomach cancer. He had surgery a few months ago but the tumour has come back and he has had some episodes of gastric bleeding. He has had repeated blood transfusions, which involved long journeys to hospital, but he remains very anaemic and his overall condition is frail. You are called to see him at home because he has vomited a large amount of blood. He is semi-conscious. His brother is with him and anxious he goes to the hospital for another transfusion and says: “You can’t just let him die.”

What would you do and why?

How would you counsel the brother?

- 3) A 47-year-old woman has Kaposi’s sarcoma. She has had a course of chemotherapy in the past which helped for a time but the tumour has spread and she has deteriorated. She does not want further treatment as she does not want to use up all the money which has been set aside for her grandchildren’s school fees, and she knows the effect of the treatment will not last. The family ask you to persuade her to accept further treatment. They say that she is depressed, and that she has just “given up”.

What would you do and why?

How would you counsel the family?

- 4) A 10-year-old boy is dying of renal failure. His whole body is swollen and he is very breathless and frightened. He is being given oxygen but keeps pulling the mask off. Regular oral morphine has been prescribed to alleviate the breathlessness and it seems to be helping, but when you come to give the next dose, his grandmother refuses, saying that the morphine will kill him. She is a retired nurse.

What would you do and why?

How would you counsel the grandmother?

# RESOURCE 10 DIFFICULT QUESTIONS

## (Module 13)

For each question, discuss how you might answer using a question, and how the conversation might proceed after that. Then, briefly role play the scenario to practise using the questions.

- 1) An eight-year-old girl whose mother is dying of cancer and is now semi-conscious asks: "When will my mother start to get better?"
- 2) A 13-year-old boy has started taking antiretroviral drugs (ARVs). He asks: "What is this medicine I have to take? My mother won't tell me."
- 3) A 10-year-old boy has advanced cancer for which there is no treatment. He asks: "What is going to happen to me?"
- 4) A 14-year-old girl is dying of leukaemia. She asks: "Why has this happened to me?"
- 5) A nine-year-old boy has lost both his parents over the past two years. He now has advanced HIV disease and cannot access antiretroviral therapy (ART). He asks: "Am I going to die?"
- 6) A seven-year-old boy has end-stage heart failure. He is deteriorating despite medication. He asks: "Can I try some different medicine? This one is not working."
- 7) A five-year-old girl has two older siblings, both of whom are seriously ill. She asks: "Why do you get ill once you go to school?"
- 8) An 11-year-old whose father is very ill asks: "Why does everyone stop talking when I come into the room?"

# **RESOURCE 11** SCENARIOS FOR COMMUNICATING WITH CHILDREN (Module 13)

- 1) You visit a 12-year-old girl at home who has widespread Kaposi's sarcoma (KS) and is bed bound and breathless. She is on TB treatment but it is not helping and you suspect she has KS in her lungs. Her mother died of TB six months ago and her grandmother is now looking after her. The girl is very frightened and asks: "What will happen to me? Am I going to die like my mother?"

**Role play the child, grandmother and health worker.**

- 2) The mother of a 10-year-old boy comes to see you. He is HIV positive but has not been told. He has been losing weight and his mother wants him to be assessed for antiretroviral treatment (ART) but is adamant that he must not be told his HIV status. His father died of HIV disease three months ago and she thinks that he will "give up hope" if he knows he is HIV positive as well.

**Role play a conversation with the mother about disclosing the boy's status – exploring her fears, discussing the possible advantages of disclosure and how it might be done. Then bring the child into the role play (he has been waiting outside) and continue.**

- 3) You are visiting a 40-year-old woman at home with breast cancer which has spread into her bones. She is bed bound and on morphine for pain. Her 12 year old daughter is caring for her and for two younger siblings. When you leave the house, the daughter follows you outside and asks: "What is going to happen to my mother? I don't know how I can manage to look after my brothers if she doesn't get better soon."

**Role play the girl and the health worker.**

- 4) You are asked to see a 10-year-old girl who is having treatment for leukaemia but is refusing any further medication because she is scared of needles. When she was in hospital, another child on the ward died. She screams when her parents try to take her to hospital.

**Role play a conversation with the child and parents.**

# RESOURCE 12 SCENARIOS FOR SYMPTOM CONTROL 2 (Module 14)

- 1) You are a home-based care (HBC) volunteer visiting an eight-year-old child who has cerebral palsy. She is lying on a mat with an arched back and her legs and arms are very stiff. The skin on one of her hips is red.

What can you do to help her spasticity? (pages 49 and 58 of the Toolkit)

How can you protect her skin from pressure sores? (page 34 of the Toolkit)

- 2) You are a doctor in a health centre. You see a six-year-old boy who weighs 12kg. He has AIDS but there are no antiretroviral drugs (ARVs) in your area. The boy has been having loose stools five to six times a day for the past month. He is not dehydrated and is eating okay. You have seen him twice before and treated him with co-trimoxazole, metronidazole and albendazole but he is no better.

What can you do to help his chronic diarrhoea? (page 45 of the Toolkit)

- 3) You are a nurse visiting an old lady at home who is dying from cancer. The hospital says there is nothing it can do to help. She is semi-conscious and unable to eat or drink.

What can you do to care for this lady? (page 51 of the Toolkit)

- 4) You are a doctor looking after a man with stomach cancer who vomits every time he eats and feels nauseated and bloated.

What is the most likely cause of his nausea and vomiting? (page 41 of the Toolkit)

What can you do to help?

- 5) You are a clinical officer in a district hospital. A young man is being treated with fluconazole for cryptococcal meningitis. He has a severe headache.

What more can you do to help his headache? (pages 27-30 of the Toolkit)

- 6) You are a nurse seeing a boy with Burkitt's lymphoma. He has had several courses of treatment and the hospital says there is nothing more it can do. He has a large tumour inside his mouth which smells bad and is making it difficult for him to swallow.

What can you do to help the smelly tumour? (page 40 of the Toolkit)

- 7) You are a doctor doing home visits for patients referred by the HBC nurse. You see a 55-year-old woman who has cervical cancer. During the past week she has been vomiting large amounts, and she has colicky abdominal pain and increasing swelling of her abdomen.

**What is the most likely cause of her vomiting? (page 41 of the Toolkit)**

**What can you do to help?**

- 8) You are a HBC volunteer visiting a two-year-old girl with HIV disease. Her ears have been discharging pus on and off for two months. She has had two courses of antibiotics; now her mother asks you for some more.

**What can you do to help the discharge? (page 56 of the Toolkit)**

- 9) You are a doctor seeing an elderly man with prostate cancer. Today he cannot walk. You find him paralysed in a wet bed.

**What is the likely cause of his mobility problem and incontinence? (page 49 of the Toolkit)**

**What can you do to help?**

- 10) You are a nurse in a rural clinic. You see a five-year-old boy with severe HIV disease. He has widespread scabies and is distressed and scratching constantly. He is not able to sleep at night.

**What can you do to help? (page 33 of the Toolkit)**

- 11) You are a doctor on a general paediatric ward. You see a two-year-old child with a bulging right eye which you think is a cancer. He is screaming and agitated. His mother says he does not sleep and will not eat, but he is still breast feeding.

**What can you do to help his pain? (page 27 of the Toolkit)**

- 12) You are a nurse visiting a woman with breast cancer. Her tumour is discharging pus onto her skin and there is a bad smell.

**What can you do to help? (page 34 of the Toolkit)**

- 13) You are a volunteer visiting a man who has had radiotherapy for cancer of the tongue. He is distressed by a painful, dry mouth.

**What can you do to help? (page 40 of the Toolkit)**

## RESOURCE 13 COURSE EVALUATION

Overall assessment of the course (circle as appropriate)

Excellent

Very good

Good

Not so good

Poor

Which session did you enjoy most?

---

Which session will be most useful in your daily work?

---

Which session was least helpful?

---

Is there any subject that you wanted more teaching on? Which?

---

Which teaching method did you find most helpful?

---

Which teaching method did you find least helpful?

---

Any other comments

---

---

---

---

---

Thank you for your help



# RESOURCE 14 END OF COURSE ASSESSMENT IN PALLIATIVE CARE

Each question contains five statements about a topic. For each statement mark 'Y' if you agree and 'N' if you disagree.

- 1) Palliative care
  - a) Is only about pain and symptom control Y / N
  - b) Can be used alongside ARV treatment Y / N
  - c) Should always be done at home Y / N
  - d) Should begin when the patient is very sick Y / N
  - e) Is only needed in cancer and HIV disease Y / N
  
- 2) The holistic approach
  - a) Involves the patient's disease only Y / N
  - b) Involves the patient and the family Y / N
  - c) Uses all the team when necessary Y / N
  - d) Can be used in the ARV clinic Y / N
  - e) Is only used in the terminal stage of illness Y / N
  
- 3) The analgesic ladder
  - a) Has four steps Y / N
  - b) Step one drugs can be given together with morphine Y / N
  - c) Should only be used with cancer patients Y / N
  - d) A three-year-old child should be given 400mg ibuprofen tds Y / N
  - e) Includes the use of adjuvant analgesic drugs Y / N
  
- 4) Oral morphine
  - a) Must be taken for life once it has been started Y / N
  - b) Should only be given when the patient has a few days to live Y / N
  - c) Can be given when the patient is at work Y / N
  - d) Can cause severe constipation Y / N
  - e) Has a high risk of addiction Y / N
  
- 5) Chronic pain
  - a) Should be reassessed regularly Y / N
  - b) May be managed with paracetamol alone Y / N
  - c) Is best managed with PRN medication Y / N
  - d) May be worsened by anxiety Y / N
  - e) Is usually treated by injection Y / N

- 6) Neuropathic pain
- a) May present as burning pain Y / N
  - b) Is common in AIDS Y / N
  - c) Can be treated with acyclovir Y / N
  - d) Can be assessed with a pain score Y / N
  - e) Is always mild Y / N
- 7) Emotional pain
- a) Only affects the patient Y / N
  - b) Can be treated Y / N
  - c) Should always be treated by a counsellor or spiritual advisor Y / N
  - d) Is often relieved by helping people talk about their concerns Y / N
  - e) May increase physical pain Y / N
- 8) End of life care
- a) The patient's own wishes should always be respected Y / N
  - b) Patients should always be fed by NG tube if they cannot swallow Y / N
  - c) It is okay to tell the patient he/she is dying Y / N
  - d) We must keep the patient alive as long as possible Y / N
  - e) Patients should continue all their drugs until the end Y / N
- 9) Confidentiality
- a) Means respecting patients' privacy Y / N
  - b) Is only important in HIV disease Y / N
  - c) Means revealing personal information to others Y / N
  - d) Patients' information can be revealed to an employer Y / N
  - e) Is less important when someone is close to death Y / N
- 10) Symptom control
- a) Cotrimoxazole is useful for bad smelling wounds Y / N
  - b) AIDS related diarrhoea can be helped by morphine Y / N
  - c) Raised intra-cranial pressure can be helped by steroids Y / N
  - d) Nausea can be treated with haloperidol Y / N
  - e) Morphine should be taken every three hours Y / N

- 11) Symptom control
- a) Breathlessness may respond to low dose oral morphine Y / N
  - b) Hiccups can be helped by metronidazole Y / N
  - c) A confused patient should be given 150mg haloperidol Y / N
  - d) Itching can be helped by chlorpheniramine 4mg tds Y / N
  - e) The starting dose of morphine in a child is 0.1mg/kg 4 hourly Y / N
- 12) Good communications skills
- a) May increase a patient's anxiety Y / N
  - b) Can be learned Y / N
  - c) Involves body language as well as listening skills Y / N
  - d) Are only used when breaking bad news Y / N
  - e) Help us to make an assessment of the patient's condition Y / N
- 13) Children with terminal illness
- a) Often know they are dying before they are told Y / N
  - b) Can be helped by play Y / N
  - c) Should always eat three healthy meals a day Y / N
  - d) May need regular morphine Y / N
  - e) Should always be cared for in hospital Y / N
- 14) Spirituality and bereavement
- a) It is helpful to understand our patients' faith Y / N
  - b) Spiritual problems can affect physical pain Y / N
  - c) Only a trained counsellor should give spiritual support Y / N
  - d) Anger can be a part of grief reaction Y / N
  - e) Palliative care workers can be affected by bereavement Y / N

# RESOURCE 14a END OF COURSE ASSESSMENT IN PALLIATIVE CARE answer sheet

- 1) Palliative care
  - a) Is only about pain and symptom control N
  - b) Can be used alongside ARV treatment Y
  - c) Should always be done at home N
  - d) Should begin when the patient is very sick N
  - e) Is only needed in cancer and HIV disease N
  
- 2) The holistic approach
  - a) Involves the patient's disease only N
  - b) Involves the patient and the family Y
  - c) Uses all the team when necessary Y
  - d) Can be used in the ARV clinic Y
  - e) Is only used in the terminal stage of illness N
  
- 3) The analgesic ladder
  - a) Has four steps N
  - b) Step one drugs can be given together with morphine Y
  - c) Should only be used with cancer patients N
  - d) A three-year-old child should be given 400mg ibuprofen tds N
  - e) Includes the use of adjuvant analgesic drugs Y
  
- 4) Oral morphine
  - a) Must be taken for life once it has been started N
  - b) Should only be given when the patient has a few days to live N
  - c) Can be given when the patient is at work Y
  - d) Can cause severe constipation Y
  - e) Has a high risk of addiction N
  
- 5) Chronic pain
  - a) Should be reassessed regularly Y
  - b) May be managed with paracetamol alone Y
  - c) Is best managed with PRN medication N
  - d) May be worsened by anxiety Y
  - e) Is usually treated by injection N

- 6) Neuropathic pain
- a) May present as burning pain Y
  - b) Is common in AIDS Y
  - c) Can be treated with acyclovir N
  - d) Can be assessed with a pain score Y
  - e) Is always mild N
- 7) Emotional pain
- a) Only affects the patient N
  - b) Can be treated Y
  - c) Should always be treated by a counsellor or spiritual advisor N
  - d) Is often relieved by helping people talk about their concerns Y
  - e) May increase physical pain N
- 8) End of life care
- a) The patient's own wishes should always be respected Y
  - b) Patients should always be fed by NG tube if they cannot swallow N
  - c) It is okay to tell the patient he/she is dying Y
  - d) We must keep the patient alive as long as possible N
  - e) Patients should continue all their drugs until the end N
- 9) Confidentiality
- a) Means respecting patients' privacy Y
  - b) Is only important in HIV disease N
  - c) Means revealing personal information to others N
  - d) Patients' information can be revealed to an employer N
  - e) Is less important when someone is close to death N
- 10) Symptom control
- a) Cotrimoxazole is useful for bad smelling wounds Y
  - b) AIDS related diarrhoea can be helped by morphine Y
  - c) Raised intra-cranial pressure can be helped by steroids Y
  - d) Nausea can be treated with haloperidol Y
  - e) Morphine should be taken every three hours N

- 11) Symptom control
- a) Breathlessness may respond to low dose oral morphine Y
  - b) Hiccups can be helped by metronidazole N
  - c) A confused patient should be given 150mg haloperidol N
  - d) Itching can be helped by chlorpheniramine 4mg tds Y
  - e) The starting dose of morphine in a child is 0.1mg/kg four hourly Y
- 12) Good communications skills
- a) May increase a patient's anxiety N
  - b) Can be learned Y
  - c) Involves body language as well as listening skills Y
  - d) Are only used when breaking bad news N
  - e) Help us to make an assessment of the patient's condition Y
- 13) Children with terminal illness
- a) Often know they are dying before they are told Y
  - b) Can be helped by play Y
  - c) Should always eat three healthy meals a day N
  - d) May need regular morphine Y
  - e) Should always be cared for in hospital N
- 14) Spirituality and bereavement
- a) It is helpful to understand our patients' faith Y
  - b) Spiritual problems can affect physical pain Y
  - c) Only a trained counsellor should give spiritual support N
  - d) Anger can be a part of grief reaction Y
  - e) Palliative care workers can be affected by bereavement Y

## RESOURCE 15 SCENARIOS FOR CONFIDENTIALITY (Module 16)

- 1) Amina is a 35-year-old lady with HIV. She has five small children all under 10. She has a very low CD4 and has now been admitted to the ward with cryptococcal meningitis. She is very confused and is not really responding to treatment. You know she has not revealed her HIV status to her husband and has always stressed that she is unable to do so as she is afraid of his temper. In hospital she is being cared for by her sister and brothers. One brother is particularly concerned and has asked to see you; he wants to know if you have tested her for HIV? **How would you respond?**

Sadly Amina dies and the next day her husband comes to see you to thank you for looking after her. He says he knows she has died from meningitis. **How would you respond?**

- 2) You are working in a busy hospital and a close friend of yours is the surgeon. He comes to you one day saying he is not feeling too well, and he has lost a lot of weight. You think he may be infected with HIV. **What would you do?**

It turns out that he is HIV positive and he has a very low CD4. What should be your advice about work?

He is extremely anxious that no one should know about his status, not even his wife who is the nurse working with you in your ward. You know they have several small children. **Should you break his confidentiality?**

He goes on to antiretroviral drugs (ARVs) and recovers well. A little later your own wife needs surgery and your friend is the most competent person to do this. **How would you respond?**

Should there be rules which stop infected surgeons doing invasive procedures?

- 3) You are sitting on a minibus going home after work. Behind you there are a group of hospital nurses talking together. One of them starts to talk about a patient on the ward who has carcinoma of the cervix. She mentions her by name and continues to tell her friends how they had learned that this was an AIDS defining illness. **How would you react?**

The next day, the patient says her friend was on a minibus yesterday and heard the nurses talking and saying she was HIV positive. She has actually refused an HIV test and wants to know if you have tested her without permission? **What would you say?**

You go to the nurse in charge to ask if the nurses can have some teaching on confidentiality. You tell her the minibus story and she demands to know the name of the nurse. **How would you respond?**

- 4) Angela has cancer of the breast. You have told her that if she could get to the referral hospital they would be able to give her treatment. The treatment is expensive and will not cure her cancer. She says she needs all her money for school fees for her three children, so she asks you not to tell her husband that there is treatment available. **How would you respond?**

Her husband sees you in the hospital corridor and asks what you are planning for his wife and why she is not getting better. He has no idea what is wrong with her.

**How would you respond?**

Angela's condition deteriorates and her children are due home on holiday. She does not want them to know she is seriously ill. **How would you respond?**

- 5) You are counselling a man who has just had a positive HIV test. You ask him if he will disclose this to his wife and he is adamant that he will not tell her. You know, however, that she is pregnant and that antiretroviral therapy (ART) for prevention of mother-to-child transmission is available. You tell him the importance of his wife being tested so that she can be offered treatment if she is positive. He remains adamant that he will not disclose his status to anyone. **What should you do?**



