

# Appendix 2: palliative care study day

The educational needs of generic health and social care professionals identified through our consultation exercise were used to develop a study day, which has been successfully piloted with 136 participants in six different venues throughout Scotland. The study day content has been developed for use beyond the life of the project. The following pages contain the programme, individual study day sessions and information on the teaching methodology used. The study day programme and sessions can also be downloaded as a single item from the Partnership's website on [www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk).

## Study day programme

### Does this patient need palliative care?

#### Recognising the need for palliative care for people with non-malignant conditions

##### 09.00 – 09.15 Registration

##### 09.15 – 10.00 What do we mean by palliative care?

- a holistic approach to care
- principles of general palliative care
- the role of specialist palliative care

##### Meeting the palliative care needs of people with non-malignant conditions

- what are the palliative care needs of people with non-malignant conditions?
- how can they best be met?
- by whom?

##### 10.00 – 10.15 Coffee

##### 10.15 – 12.30 Assessing and responding to some difficult symptoms

##### How to recognise when someone is in pain

- defining and recognising pain
- accessing help, support and advice



### **Causes of fatigue and its effects on quality of life**

- what might this mean for people with non-malignant conditions and their carers?
- how to access help, support and advice

### **Dealing with anxiety and emotional distress**

- identifying and responding to distress
- answering difficult questions
- helping people express their feelings and anxieties and being able to deal with this
- identifying and meeting information needs of patients and carers from diagnosis onwards
- identifying and accessing appropriate support (for patients, families and professionals)

### **12.30 – 13.15 Lunch**

### **13.15 – 14.15 Assessing and responding to key issues towards the end of life**

- recognising patient and family transition to this phase
- supporting the acknowledgment that things have changed
- identifying relevant issues (physical, social, emotional)
- identifying and agreeing appropriate care settings
- addressing concerns and expectations
- accessing help, support and advice (for patients, families and professionals)

### **14.15 – 14.30 Tea**

### **14.30 – 16.00 Understanding the patient's journey**

**Interactive case studies will be used to further explore issues arising at key stages of the patient's journey**

- at the time of diagnosis
- whilst the person is living with the condition as it progresses
- towards the end of life

### **16.00 – 16.30 Evaluation and close**

## Study day session I – what do we mean by palliative care?

### Study day session I (1 hour)

#### Aim

- to develop an understanding of the potential need for palliative care for people with a non-malignant condition

#### Learning outcomes

At the end of the session, participants will be able to:

- discuss the meaning and scope of palliative care
- describe the philosophy and principles of palliative care within a multi-professional context
- analyse how the palliative care approach can be applied to people with a non-malignant illness
- discuss how palliative care needs can be met and by whom.

#### Overview

This session aims to enable participants to develop an understanding of the palliative care needs of people with non-malignant conditions and sets the overall scene for the unfolding content of the study day. The focus is on the general nature of palliative care, its philosophy and principles and how these may be applied to the care of people with non-malignant conditions. Contemporary statements are referred to when considering the palliative care needs of this group. The spectrum of palliative care, definitions and applications are discussed eg the palliative care approach, general palliative care and specialist palliative care. The responsibilities of all health and social care professionals and the first order ethical principles are explained using the palliative care approach as a template of care for people with life-threatening conditions other than cancer, and attention is drawn to the influence of changing epidemiology and health needs.

Participants are asked to reflect on their own practice experience and to think about the key issues of care for the person with a life-threatening condition other than cancer, their family and the health and social care professionals involved in their care. A brief overview of how these needs might be met is given. The role of specialist palliative care is outlined and possible levels of intervention discussed in terms of supporting generic health and social care professionals in the care of people with advancing non-malignant illness.



## Key content

- philosophy and principles of palliative care
- defining the scope of palliative care
- palliative care approach
- palliative interventions
- general palliative care
- specialist palliative care
- changes in epidemiology and health needs
- diagnosing the need
- key issues for care
- ethical considerations

## Teaching approach

Because it is known that overall knowledge about palliative care is weak, this session is delivered using a modified or structured lecture. Reflective issues are elicited from the participants by continual relation to practice.

## Supporting literature

Connolly, M (2000) *Patients with non-malignant disease deserve an equitable service*. International Journal of Palliative Nursing. Vol 6 (2).

Fallon, M and Neill, B (1998) *ABC of palliative care*. BMJ Books.

The National Council for Palliative Care (2005). *The shape of the future for palliative care*. 20:20 Vision.

Trau, D and Ross, J (2005) *Palliative care in non-malignant disease*. Journal of the Royal Society of Medicine. Vol. 98.

## Study day session 2 – how to recognise when someone is in pain

### Study day session 2 (½ hour)

#### Aims

- to explore the concept of total pain
- to explore the role of the multidisciplinary team in the management of pain

#### Learning outcomes

At the end of the session, participants will be able to:

- define pain and total pain
- describe how pain can be assessed
- identify and discuss good practice in the management of pain
- reflect upon practice and discuss other influencing factors in the management of pain.

#### Overview

The aim of this session is to introduce participants to the concept of total pain and to explore the role of the multidisciplinary team members in assessment. Some approaches to management are also explored.

The key issue in this session is to provide a basic foundation of knowledge to an audience of mixed experience and to facilitate their appreciation of the skills they have in their own professional role.

For this session a modified lecture is used with some discussion and reflection on current practice. This enables the identification of experience and possible future training needs. To provide this level of information, some definitions of pain are given. The concept of total pain is explored in relation to pain assessment and some examples of common assessment tools are discussed. The World Health Organization (WHO) analgesic ladder is described along with other aspects of good practice in pain management eg accurate assessment and the multi-professionals approach with effective communication between team members. A brief mention is made of the importance of the fact that consideration of psychosocial aspects can affect the level of pain experienced.



## Key content

- definitions of pain
- pain assessment, including examples of pain assessment tools
- approaches to pain management, including use of the WHO analgesic ladder
- complementary approaches
- psychosocial influences on pain
- evidence of best practice
- how to access help and advice

## Teaching approach

- learning outcomes will be achieved by a modified lecture and interactive discussion using reflection on delegates' individual practice issues and roles.

## Supporting literature

Davies, J and McVicar, A (2000). *Issues in effective pain control 2: From assessment to management*. International Journal of Palliative Care Nursing. 6 (4) 162-168.

Scottish Intercollegiate Guidelines Network (2000). *Control of pain in patients with cancer: a national clinical guideline*. SIGN Publication number 44. ([www.sign.ac.uk](http://www.sign.ac.uk)).

Twycross, R (1999) *Introducing palliative care*. Radcliffe Medical Press 3rd Ed. Part 3 p61-95.

## Study day session 3 – causes of fatigue and its effects on quality of life

### Study day session 3 (½ hour)

#### Aim

- to understand the effects of fatigue on people with an advanced illness

#### Learning outcomes

At the end of the session, participants will be able to:

- understand the concept of fatigue
- examine the causes and assessment of fatigue
- discuss the possible reversible causes of fatigue
- explore and discuss the meaning of fatigue for the patient and the family
- consider some approaches to fatigue management.

#### Overview

The aim of this session is for participants to appreciate and understand the causes and effects of fatigue on a person with advancing illness.

The key focus in this session is to highlight the relatively poorly understood phenomenon of fatigue and its prevalence and impact on function and quality of life.

The presentation follows a modified lecture approach which encourages participants to think about their own practice experiences and to develop a multi-professional perspective on management.

The session identifies the multidimensional concept of fatigue, its definition and subjective experience and its comparison to other distressing symptoms experienced by people with advancing illness.

Key approaches to assessment and some measurement tools are outlined. The importance of assessing for possible reversible causes eg anaemia, depression, infection etc are explained and the importance of individualised approaches and regular monitoring are discussed. Some suggestions are given as to the management of fatigue.



## Key content

- definitions of fatigue
- assessment of fatigue, including examples of assessment tools
- potential reversible causes
- impact of fatigue on quality of life
- approaches to management
- support for the patient and family

## Teaching approach

- learning outcomes will be achieved by a modified lecture and interactive discussion using reflection on delegates individual practice issues and roles

## Supporting literature

Loge, J (2003) *Unpacking fatigue*. European Journal of Palliative Care. 10 (2) Supplement.

Ream, E and Richardson, A (1999) *From theory to practice: designing interventions to reduce fatigue in patients with cancer*. Oncology nursing forum 26 (8): 1295-1303.

## Study session 4 – dealing with anxiety and emotional distress

### Study day session 4 (1-1½ hours)

#### Aim

- to explore aspects of the role of the multidisciplinary team in identifying and responding to emotional distress within families dealing with a life-threatening illness

#### Learning outcomes

At the end of the session, participants will be able to:

- examine and discuss the importance of good communication skills in the care of individuals and their families
- discuss and acknowledge the situations that can affect the connection between people with life-threatening conditions and their families
- explore the continuing information needs of patients and their informal carers through their disease trajectory
- gain insight into some of the difficulties in identifying and accessing appropriate support for patients, families and health and social care professionals.

#### Overview

The aim of this session is to explore aspects of the supporting role of each member of the multidisciplinary team in identifying and responding to disclosure of emotional distress within families dealing with a life-threatening illness. After a brief introduction to the basic theory of communication skills and reflection on what makes communication difficult, the session is developed by use of sculpting to reveal the following important issues:

- answering difficult questions
- helping people to express their feelings
- identifying and accessing appropriate support for patients, families and professionals
- identifying and meeting information needs
- identifying and responding to distress.



## Key content

- basic communication skills
- barriers to communication
- exploring significant relationships for patients
- facilitating disclosure of emotions
- addressing key issues in anxiety and emotional distress
- identifying key professional roles throughout the patient's journey

## Teaching approach

The teaching methodology for this session is sculpting, which is a form of dynamic non-verbal role play in which the scene is set from a given scenario representing a clinical situation in which participants arrange themselves in positions that symbolise feelings, conflicts and power relationships. This technique can be used to improve communication skills, explore family relationships and enhance team working.

## Management of the sculpting session

Ideally the technique involves a group of participants and two facilitators. The number of participants will be dependent on what learning is anticipated from the case scenario. One facilitator takes a lead in conducting the exercise, the other has the work of detecting any signs of distress amongst the participants and to intervene if necessary. The method and purpose needs to be carefully explained to participants as it is a powerful way of exploring feelings and emotions that may not be expressed in a verbal communications exercise.

The tools used for this session are:

- the case scenario, outlining a clinical and social situation
- a list of roles with a brief biographical account of each.

The session takes the following format:

- a facilitator reads the case scenario
- roles are assigned to participants
- the key focus is identified – ie the person with the condition
- information cards depicting their role are given to participants
- participants read the information but do not disclose it to other participants
- the person taking the role of the person with the condition is asked to place themselves in the centre of the room
- participants are then asked to place themselves where they would perceive they should be in relation to supporting the person with the condition

- the participant playing the person with the condition is then asked if they would like to move any of the other participants (in relation to their role in the scenario)
- each participant is asked how they feel about their position
- participants are asked if they think individuals are where they would have imagined they would be or if they are surprised by the positions adopted
- the facilitator asks each person to divulge more about their role from their information cards
- the group participates in further reflection and dynamic repositioning
- the group participates in verbal feedback and group conclusion
- at the end of the sculpting session and before the evaluation the facilitator asks the participants to leave their roles and return to their seats
- evaluation (eg a discussion which identifies learning points and can be summarised on a flip chart by the facilitator).

### Sculpting Scenario

Lucy is a 17 year old who was diagnosed with cystic fibrosis at the age of four months after a failure to thrive. After years of severe chest infections and now a deteriorating pulmonary function, she has been referred for consideration for a place on the lung transplant list.

Lucy lives with her parents Alan and Mary. Both have been well until Mary was diagnosed with multiple sclerosis last year which has affected her energy and mobility levels. There are two siblings, Lisa aged 20 and Mark aged 11.

Family life has frequently been disrupted by Lucy's admissions to hospital and home therapies, and although she is keen to lead as normal a life as possible, the strain of the illness and the responsibility on her parents and siblings is beginning to become an issue.

Many health and social care professionals may gradually become involved due to the evolving issues of caring for this family.

### Sculpting session roles

#### Lucy

You are 17 years old and were diagnosed with cystic fibrosis when you were four months old. You have recently been placed on the lung transplant list. Your Mum has been your main carer and has overseen your daily activities, monitored your diet and dealt with your physiotherapy needs. She and Claire (your best friend) were your main confidants until Ross, your boyfriend, came on the scene. You are very distressed about your Mum's recent diagnosis. You are close to your Dad but feel he has a closer relationship with your siblings. You and Lisa argue a lot and you think it is because you receive more attention from your Mum than she does.



### **Mary (mum)**

You are married to Alan and have three children. You were devastated when Lucy was diagnosed as you were unaware you carried the cystic fibrosis gene. You already had one healthy child who is a carrier of this gene, and this has not been discussed openly in your family. You were diagnosed with multiple sclerosis eight months ago and although you frequently feel tired you are coping. Your anxieties lie with who will help with Lucy's physiotherapy and other health needs. Alan has always maintained he is no help and Lisa barely talks to Lucy without arguing.

### **Alan (dad)**

You are an only child. Both your parents have died – your mother from pancreatic cancer when you were 18 years old and your father more recently in a car accident. You are a carrier of the cystic fibrosis gene. You found this out only after Lucy's diagnosis. You are currently in turmoil. Your youngest daughter Lucy is on the lung transplant list to treat her cystic fibrosis and your wife has been diagnosed with multiple sclerosis. There is friction between Lucy and her sister Lisa and you are feeling overwhelmed and torn as to who in your family needs you more. To escape you tend to spend most weekends with your rugby friends.

### **Lisa (older sister)**

You are finding the family situation difficult. You have recently come home after your second year at university and are planning to delay returning for your third year. Your Mum has been diagnosed with multiple sclerosis and your sister Lucy is on the lung transplant list. Your relationship with both your Mum and Lucy is strained. You find Lucy irritating and feel she always gets her own way just because she has cystic fibrosis. As the eldest so much more is expected of you and you are healthy. You have great concerns about having children in the future. You are aware your aunt Anne has made a decision not to have children but feel unable to talk to your parents about this. You feel they have enough worries but feel angry that they haven't taken time to talk about the reality of your situation. This is in fact why you react to Lucy in the way you do – it is more fear that you could be responsible for having a child with cystic fibrosis than any perceived jealousy. You have a strong bond with your brother Mark.

### **Mark (younger brother)**

You are a keen footballer and your grandfather (Mary's Dad) shares your interest. Your Dad prefers rugby so doesn't share your passion. You spend at least two evenings each week training. Your grandfather is your taxi and companion and weekends are spent playing/attending football matches with him. You are sad about your sister's and Mum's situation but try not to think about it. Lisa is your main support at home, and takes you to football if your grandfather is unable to.

### **Gran (Mary's mum)**

You come from a reserved family. You try to support Mary but often find that she snaps at you for no reason and blames you for Lucy's cystic fibrosis. You were unaware that you carried the cystic fibrosis gene until Lucy's diagnosis. Mary is convinced you did know as there were very few children on her side of the family.

### **Grandfather (Mary's dad)**

This is a very difficult situation which you are struggling with. Your daughter and your granddaughter are both ill. You feel guilty and wish it was you that were ill and not them. You were devastated to find that you too were a carrier of the cystic fibrosis gene after Lucy's diagnosis. You try to be there for everyone in the family but your main concern is Mark – you have a close bond with all your grandchildren but especially with Mark.

### **Anne (Mary's sister)**

You are Mary's younger sister; there is a 12 year age gap. You feel particularly close to Mary's children. When Lucy was diagnosed you made the decision to confirm whether you were a carrier of the cystic fibrosis gene. You consciously decided not to have children when it was confirmed that you are a carrier.

### **General practitioner**

You work in a busy medical centre. You are supportive when the family attend with problems. If they have any concerns relating to cystic fibrosis or multiple sclerosis you refer them to the local hospital team.

### **Community physiotherapist**

You are unaware of this family.

### **Clinical nurse specialist for cystic fibrosis**

You are hospital based and have met Lucy and some members of her family on several occasions. With the potential of a lung transplant for Lucy, you are working more closely with the transplant coordinator and hope to set up a family meeting.

### **Transplant coordinator**

You are based with the hospital transplant team and have had one meeting with Lucy and her parents.

### **Social worker**

You are unaware of this family.



### **Occupational therapist**

You are unaware of this family.

### **Hospital neurological consultant**

You met Mary eight months ago when she was diagnosed with multiple sclerosis. She is currently reviewed on a six monthly basis. You have referred her to the multiple sclerosis clinical nurse specialist who has made telephone contact.

### **Hospital Respiratory Consultant**

You have known this family for 17 years and have a very good relationship with them all. You are very supportive and have made yourself readily available.

### **Claire – best friend**

You have been friends with Lucy since primary one and have never argued! You are aware of her illness and have been quite involved with the changing pattern of her illness. You share a lot together.

### **Ross – boyfriend**

You have been Lucy's boyfriend for six months and in that time your relationship has deepened. You have had a physical relationship and are now concerned about her frailty. Although you do not fully understand her illness you try to support her as best you can but feel frightened yourself.

### **School guidance teacher**

You are aware of the situation and monitor Lucy when she is at school.

### **Psychologist**

Lucy has only recently been referred to you because of her pending lung transplant.

### **Multiple sclerosis clinical nurse specialist**

You have made telephone contact with Mary but she has declined a visit at this stage. Contact numbers have been left.

### **Dietician**

The only contact you have had with Lucy and her family is during in-patient admissions.

### **Health Visitor**

You are based in the GP practice building and aware of the family, but have no regular contact.

### Supporting literature

Dunne, K (2005) *Effective communication in palliative care*. Nursing standard. 20.13, 57 – 64.

Jeffrey, D (2002) *Teaching in palliative care: a practical guide*. Radcliffe Medical Press.

Lloyd-Williams, M (2003) *Psychosocial issues in palliative care*. Oxford University Press.

Wallace, P (2001) *Improving palliative care through effective communication*. International Journal of Palliative Nursing 7 (2): 86-90.



## Study day session 5 – assessing and responding to key issues towards the end of life

### Study session 5 (1¼ hours)

#### Aims

- to develop an understanding of the psychological, physical, social, spiritual and ethical implications for patients and their families towards the end of life
- to critically examine the role of the multi-professional team in recognising and preparing for this stage

#### Learning outcomes

At the end of the session, participants will be able to:

- recognise and support the transition to end of life care
- identify the relevant issues for patients and families
- consider the appropriate management of end of life care
- discuss appropriate health and social care professional input and care settings.

#### Overview

At the pilot study days, this session was delivered by a local consultant in palliative medicine. The intention of the session is to enable participants to:

- develop an appreciation of the complex disease trajectories experienced by people with life-threatening conditions other than cancer
- recognise the signs and symptoms of impending death.

The session highlights the importance of communication with the dying person and their family as well as some of the ethical issues around delivering appropriate treatment and care. Key points discussed in this session are:

- the goals for the last days of life
- the role of the multidisciplinary team
- the role of specialist palliative care services
- the importance of considering and supporting the individual needs of the patient and their families eg their values, needs and preferences.

Issues around difficult conversations and responding to the preferred place of care are examined in the context of choices and resources. Participants are introduced to the value of awareness of and access to standards and clinical guidelines for use across all care settings to disseminate best practice palliative care.

The Liverpool Integrated Care Pathway for the Dying Patient, which highlights the need to deliver holistic care during the dying phase and gives guidance on the different aspects of care required, is used to illustrate optimum end of life care.

### Key content

- understanding disease trajectories in non-malignant conditions
- triggers for palliative care
- estimating prognosis
- recognising when someone is dying – clinical indicators
- responses to a terminal diagnosis
- ethical issues around delivering treatment/care
- assessment of patients/relatives needs
- goals for the last days of life, including the Liverpool Care Pathway for the Dying Patient
- place of care
- the role of the multidisciplinary team
- the role of specialist palliative care

### Teaching approach

- learning outcomes are achieved through a modified lecture, reflective discussion and questions on practical issues

### Supporting literature

Ellershaw, J and Wilkinson, S (2003) *Care of the dying: a pathway to excellence*. Oxford University Press.

Fallowfield, LJ, Jenkins, VA and Beveridge, HA (2002) *Truth may hurt but deceit hurts more: communication in palliative care*. *Palliative Medicine*. 16: 297 – 303.



## Study day session 6 – understanding the patient’s journey

### Study session 6 (1 hour)

#### Aim

- to develop an understanding of the different issues arising throughout the different stages of a life-threatening illness

#### Learning outcomes

At the end of the session, participants will be able to:

- consider and reflect upon the key issues of the impact of a life-threatening illness on the person and their family
- critically consider the issues that may be important for a person with a life-threatening condition and their family at different stages of an illness
- explore the professional roles and health and social care services that may be relevant at different stages of the patient’s journey.

#### Overview

The aim of this session is for participants to develop an understanding of the different issues and needs which may arise throughout the different stages of a life-threatening illness.

A problem-based learning approach is used, with three fictional case studies depicting different stages of the illness trajectory. These are:

- diagnosis
- living with a non-malignant condition
- dying from a non-malignant condition.

Case studies usually involve making decisions about particular courses of action and to some extent capture the reality of actual situations. For this session the participants are placed in three groups with an equal representation from the attending professional groups wherever possible. A brief scenario is outlined and the participants in each group are asked to consider some questions which are relevant to the particular stage of the patient’s journey. Each group then feeds back to the whole group.

#### Key content

- the illness trajectory – diagnosis, the journey (living with a life-threatening condition and dying from a life-threatening condition)
- key issues for each stage
- proactive management

- person-centred care
- the palliative approach
- general palliative care
- specialist palliative care
- supporting the patient and their family
- communication

## Case studies

### Case Study 1: diagnosis

Paul is a 45 year old man who initially complained of weakness in his legs. This was first attributed to stress as it coincided with establishing his own car hire business.

He has recently been diagnosed with progressive supranuclear palsy (PSP). He is married with three teenage children, his wife Carol has a part-time job and at other times helps him with the administration of his business.

The group is given the following questions to consider:

- what are some of the potential consequences of the diagnosis?
- what are the likely questions to be asked following the diagnosis?
- what are the important issues of management at this stage?
- what professional health and social care services might be beneficial for Paul and his family?

### Case study 2: living with a non-malignant condition

Janet is a 40 year old woman with severe respiratory disease. She lives alone and has recently had several emergency admissions to hospital due to breathlessness. Her frailty has increased. Janet is a very independent lady and has few social contacts other than a sister and friends from a reading group who meet up regularly in a local club.

The group is given the following questions to consider:

- what potential problems may need to be addressed at this stage?
- what are the implications for clinical management and proactive care?
- what professional health and social care services might be necessary and why?



### Case study 3: dying from a non-malignant condition

Lily is an 82 year old lady with multiple medical problems and mild dementia. Her condition is deteriorating and her family want to have all her medication stopped and to let nature take its course. Lily is a retired headmistress and has always been very clear about and involved with her medical care. She has been living in a private nursing home for the past 18 months and for the last few weeks has been unable to leave her room.

The group are asked to consider the following questions:

- what discussions or plans could have been addressed prior to her deterioration?
- what important issues around the care of Lily need to be considered at this stage?
- how might you support and communicate with Lily's family?
- what professional and specialist services could be involved at this stage?

### Supporting literature

Addington-Hall, JM (1998) *Reaching out: specialist palliative care for adults with non-malignant disease*. Occasional paper 14. London: National Council for Hospices and Specialist Palliative Care Services.

Murtgage, FP and Higginson, I (2004). *Patterns of dying: palliative care for non-malignant disease*. Clinical Medicine Vol 4 (1) January/February.

### Additional palliative care education and training

Further information on palliative care education and training can be found at:

[www.ayrshirehospice.org.uk](http://www.ayrshirehospice.org.uk)

[www.dundee.ac.uk](http://www.dundee.ac.uk)

[www.gcal.ac.uk](http://www.gcal.ac.uk)

[www.gla.ac.uk](http://www.gla.ac.uk)

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

[www.napier.ac.uk](http://www.napier.ac.uk)

[www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk)

[www.paisley.ac.uk](http://www.paisley.ac.uk)

[www.standrews-hospice.com](http://www.standrews-hospice.com)

[www.stcolumbushospice.org.uk](http://www.stcolumbushospice.org.uk)

[www.stir.ac.uk](http://www.stir.ac.uk)

[www.strathcarronhospice.org.uk](http://www.strathcarronhospice.org.uk)