

Palliative Care in Nursing and Healthcare

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Palliative care past, present and the future

This chapter will explore:

- the philosophy underpinning palliative care
- the journey that palliative care provision has taken and where we are now
- the tools available to help care for those with a life-limiting condition
- the palliative care needs of patients with a life-limiting illness including those with a non-cancer diagnosis.

Reflection points

Start by thinking about these reflection points:

- What is palliative care?
- Who can access palliative care services?
- Who delivers palliative care?

Palliative care and its goals

You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die. (Saunders 1976: 3–4)

As nurses, we work with patients in order to promote and achieve individualised care. This is because we recognise that a patient is not just a set of physical symptoms or a diagnosis, they are also a physical being with psychological, social, spiritual and

emotional needs. Identifying what is important to each individual patient helps us to prioritise their care needs and helps to ensure that we support them and create the optimum quality of life for that individual right up until their death. The concept of a 'good death' is what we all strive for as professionals, and therefore assisting a patient in achieving that should be our ultimate goal and indeed our responsibility.

Palliative care from the beginning

The Hospice movement developed its impetus in the 1960s and 1970s. One of the key drivers in initiating this dynamic change was Cicely Saunders (later to become Dame). She generated a new vision surrounding caring for those at the end of life. It was one which incorporated a holistic view of the patient rather than seeing them as a set of physical symptoms. She achieved this vision by engaging and listening to the individuals in her care and noted that they were experiencing more than just physical symptoms, believing that these physical symptoms had psychological, emotional, social and spiritual components.

The goal of palliative care is to achieve the best possible quality of life for patients and their families (World Health Organization 1990). 'Palliativus' is a Latin term meaning 'to cloak or conceal', therefore palliative care involves utilising comprehensive holistic assessments and adopting appropriate treatment strategies in order to improve quality of life for those with a life-limiting illness (Claxton-Oldfield et al. 2004). There are a number of ways that we can treat a patient with a life-limiting illness; for example, medical palliation is the active relief of a symptom or a problem which does not necessarily affect lifespan. Palliative care does not simply involve the administration of a cocktail of drugs (pharmacotherapy), but also involves a multitude of interventions in order to help, support and care for those patients and their carer and/or relative. Symptoms may be multidimensional, meaning they do not only derive from a physical problem. An example could be a patient who has heart failure and feels that she is dying. She may have other psychological issues as her husband died in a distressed state from heart failure five years before. In addition, she may have severed contact with friends because she may not want to burden them or feel like socialising due to her current state of health. This would mean that she has emotional, psychological and social issues which may be exacerbating her condition, so dealing with only physical symptoms would not address the whole problem. Holistic assessment is the key to addressing any issues or aspects that may be contributing to the patient's diminished quality of life.

Palliative care: the present

There have been dynamic changes in palliative care provision within the UK to improve palliative and supportive care provision. These changes have been driven by research, recommendations, strategies and policy. The pivotal points include the introduction of the Department of Health's (DH) *End of Life Care Strategy* in 2008 and the introduction of the Gold Standards Framework (Thomas 2003; National

Health Service, Royal College of General Practitioners 2006). These frameworks alongside many other publications suggest standards of care that should be employed when caring for a patient and their family approaching the end of life, including the opportunity to decide where and how they would like their care to be delivered (National Health Service 2014). The preferred place of care (PPC) allows a person to be cared for in an environment of their choice, which may be home, hospital nursing home or hospice (see Chapters 9 and 10 for further discussion). The National Institute for Health and Care Excellence (NICE) (2011) stated that we should optimise the amount of time people spend in their PPC during the last year of life. To enable this to happen, coordinated, high-quality care is needed so that the individual feels confident that the care delivered is meeting their needs and that they are comfortable in the PPC. NICE have, in addition, produced standards that focus on 'improving supportive and palliative care for adults with cancer' (2004), lung cancer guidance (2011), standards for care at the end of life (2011b) and the use of Opioids in end of life care (2012). In addition, organisations have been developed and work in collaboration with the National Health Service and Department of Health, such as the National Coalition for Hospice and Palliative Care (NCHPC), National End of Life Care Intelligence Network (NEoLCIN) and The Marie Curie Palliative Care Institute Liverpool (MCPCIL), to drive the quality of services in palliative and end of life care. The guidance available embraces common themes, which include the recognition that clear communication between all the members of the multi-disciplinary team and the patient is paramount. In addition, education and support for staff caring for individuals with a life-limiting illness and the need to ensure that patients are central to all decision making using enhanced and effective communication skills are vital.

The issues are that worldwide there is a lack of education and knowledge in those caring for people in the palliative phase of illness, yet the need for palliative and end of life care is significant and increasing (World Health Organization (WHO) 2014). Over 19 million people worldwide need palliative care, with 69 per cent of those being over the age of 65 (WHO 2014), so this sets an enormous task as health and social care professionals need to have some understanding about how to care for these individuals using the philosophies and standards suggested (see Figure 1.1).

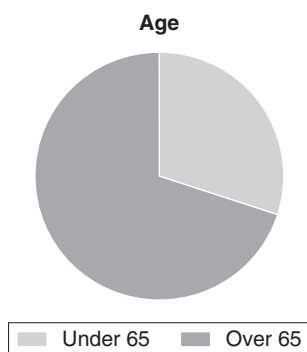


Figure 1.1 Age of people requiring palliative care (WHO 2012)

This cannot be achieved without addressing people's educational needs and supporting them in achieving the competence and confidence required to provide the high-quality palliative and end of life care everyone deserves. There are inherent difficulties in ensuring that patients receive high-quality palliative and end of life care, no matter where the patient is. In acute hospitals this may be challenging due to the environment itself (e.g. lack of privacy, lack of peace and quiet if they require it). There are challenges for staff regarding the need to spend time with those nearing end of life and to give them the care they need whilst at the same time attending to patients with acute ill health who need urgent attention. Trying to meet everyone's needs is a dilemma in itself.

Palliative care models and tools

Tools have been designed and introduced to assist in the delivery of integrated high-quality end of life care no matter where it is delivered. The Liverpool Care Pathway introduced in the 1990s was adopted as best practice by NICE and the DH (Ellershaw et al 1997; DH 2008; NICE 2004). This was an integrated care pathway and was developed as a tool to help those caring for patients in the last weeks or days of life. Its philosophy emanated from the hospice approach to care at the end of life, which is regarded as 'gold standard'. As very few people at the end of life have access to the hospice environment the tool was developed to aid equity in end of life care (Kinder and Ellershaw 2003; National Audit Office (NAO) 2008). The aim was to prompt healthcare professionals to consider communication needs and signpost staff and patients through the last days of life in order to ensure that a good standard of care was achieved. Although this was the aim, The Marie Curie Palliative Care Institute Liverpool and the Royal College of Physicians conducted an investigation which focused on the care received by patients who had been placed on the pathway (2007). The final report suggested that the physical domains of care demonstrated good compliance with the pathway but the spiritual and psychological domains demonstrated minimal compliance, with communication between the healthcare and professional once again being poor. The Liverpool Care Pathway received negative attention, although the premise regarding its ethos is widely accepted as positive. There may be numerous reasons why this tool created such public and professional outcry; these could include misunderstanding through lack of knowledge and education surrounding its implementation amongst healthcare professionals. The Liverpool Care Pathway was phased out, and in its place came further guidance surrounding end of life care planning in the publication *More Care, Less Pathway* (Independent Review Panel of the Liverpool Care Pathway 2013). This recommends that end of life care plans which are unique and individualised should be the preferred approach. One may still argue that the implementation of this requires a robust approach, that ensures staff have undergone adequate training and possess sufficient knowledge to not only develop the plan, but also have the ability and communication skills to discuss choices at the end of life. In addition,

comprehensive, disease-specific guides will be introduced, as well as manuals which reflect the principles of good palliative care. If this strategy for caring at the end of life is accomplished, then a calm and informed approach may be adopted for those approaching the end of life rather than the frenetic, ill-informed management which often resulted in a less than adequate experience for all concerned, and we must remember that this is not something we can go back and change.

The palliative care approach

Internationally, palliative care has been provided for hundreds of years, but today's philosophy promotes a patient-centred approach which should be delivered by knowledgeable and skilled healthcare professionals in order to ensure that high-standard, evidence-based care is achieved. Palliative care involves treating symptoms to maximise quality of life, it should not attempt to postpone or hasten death (WHO 1990). It perceives death and dying as normal processes rather than failures, and affirms life and living but not at the expense of quality of life (National Council for Hospice and Palliative Care Services 2001). The staff delivering palliative care may be diverse, for example, dietician, physiotherapist, social worker. One recommendation within the NICE standards (2004) and the *End of Life Care Strategy* (DH 2008) is that a professional with specialist expertise in the field of practice should be employed to help support the patient throughout their journey and refer to other disciplines as necessary. This may not be accessible to all, and Skilbeck and Payne (2005) suggest that for patients requiring a 'palliative care approach', this can be delivered by staff who have been supported and educated appropriately, but that there may be patients who have complex symptoms or a range of needs which require more specialist input, and it is this specialist input that NICE (2004, 2011) and the Department of Health (2008) are suggesting must meet these needs. This should be available for patients with cancer and non-cancer diagnoses. The difficulty is knowing whether or not all of this can be achieved. Being able to coordinate care delivery in negotiation with the patient is a privileged role but one that requires a sound evidence base, continuous professional development and higher-level understanding. NICE (2004) suggested that this member of staff should undergo communication assessment in order to ensure that they have the necessary enhanced skills to support the patient and their relatives through a difficult journey. This member of staff could not see all the patients in that specialist area, therefore organisations need to invest in their staff to ensure that those involved in caring for patients at the end of life have an adequate skill and knowledge base to provide effective care that is of a good standard.

Many of the frameworks elaborate and suggest standards surrounding end of life care (DH 2008; NICE 2004, 2011). Palliative care however, does not only involve care at the end of life. It is paramount that definitions are clearly explained. Palliative care entails care delivered by a diverse range of professionals using a holistic approach to a patient whose illness is deemed incurable. The aim should be to improve a

patient's quality of life and that of their carer (WHO 2002). End of life or terminal care should focus on the few last weeks, days or hours of a patients' life, where the focus becomes patient comfort, and a great deal of preparation surrounding needs and wishes at the end of life are essential. Advance directives are a means of establishing patient's wishes as they approach the end of life (see Chapter 8 for further discussion). They need to be clear and can be implemented if a patient no longer has the capacity to make decisions about treatments or interventions (see Chapter 8). The National Council for Palliative Care (2014) suggest that individuals approaching the end of life have the right to the highest-quality care and support, wherever they live and whatever their condition, and that those with a life-limiting condition other than cancer should have the same equity of access to high-quality palliative care as those with a cancer diagnosis. This is not a new idea but it has taken some time to address this challenge. There does now appear to be a greater equity in access, but with this comes significant challenges in educating those healthcare professionals who are to deliver this high standard of palliative care.

Let us consider some definitions synonymous with a patient's journey through palliative care to end of life.

Case scenario: George

George was 55 when he was diagnosed with prostate cancer. He underwent radical (potentially curative) surgery to remove the cancer. At this point he was in the curative phase of his illness. Eighteen months after his surgery the cancer had returned and it was deemed incurable but treatable with hormonal manipulation therapy. This would not cure him but would keep the disease stable for a period of time. One could then suggest that George is in the palliative phase of illness, and this may be a protracted period where he has symptoms relating to his disease or treatments and these may be distressing. Intervention revolves around treating any symptoms in order to maximise his quality of life.

George continues on this treatment for five years, but at his follow-up his blood tests suggest his cancer is now growing again and he complains of back pain. On investigation George was informed that his cancer was now advancing and treatments would involve trying to slow the progression rate and treat his symptoms. This could be radiotherapy (X-ray treatment) to his back alongside pain relief together with an attempt at further drug management for the cancer.

George deteriorates further over the next six months and it is clear that his disease is extremely advanced. He is suffering with severe pain, nausea, constipation, fatigue and anorexia. He needs regular rest and his blood tests suggest that the cancer has spread beyond the prostate and bones. The prognosis is poor, with an advancing decline evident. George is now entering the terminal phase of his illness with the expectation that time may be quite short. Care at this point should focus on George's comfort, using medication and complementary therapies to promote his dignity in the last days of life.

Reflection points

- Can you see how George's illness progresses?
- What physical, psychological, spiritual and social needs do you think George will have as his illness progresses?

An environment of calm where loved ones can be near and where everyone feels supported is paramount to aid a dignified and peaceful death. This exemplar is quite clear when dealing with a patient with cancer but can become extremely difficult when a patient has a non-cancer diagnosis, as the unpredictability regarding the course of the condition can make planning for a peaceful and dignified death a challenge. Decisions may have to be made swiftly, and lack of recognition that a patient is entering the terminal phase of illness is a common issue. The nature of the diseases (e.g. multiple sclerosis, COPD, heart failure etc.) all entail periods of exacerbations and remissions and the challenge is to identify when an exacerbation precedes the terminal phase of illness. There may also be difficulty in initiating a discussion surrounding wishes for end of life care, as deterioration may have no definite or significant time-point, which may be more apparent for those with a cancer diagnosis. Access to specialist services may be hindered by the time constraints involved in recognising that a patient is approaching the end of life.

Care delivery should be underpinned with a holistic philosophy: caring for the whole person and ensuring that their anxieties and fears are given just as much attention as more physical symptoms such as vomiting or constipation. The following chapters in this book should help you to identify George's needs as his illness progresses.

Palliative care needs internationally

Internationally there are many commonalities in the requirements that patients and relatives have at the end of life. Dy et al. (2007) conducted a systematic review focusing on satisfaction with care at the end of life. Satisfaction was an important aspect regarding perceived quality of care, and the key themes emerging from this review were the accessibility to end of life care services and the coordination of those services (see Figure 1.2). Although the review presented an international perspective one may argue that this is a generalisable view of many who are receiving palliative and end of life care. In addition to these requirements, symptom management, comfort in death, communication and education as well as spiritual and emotional support were all prerequisites to a 'good death'.



Figure 1.2 Factors influencing a 'good death' (Dy et al. 2007)

These themes were not disease specific but common amongst the numerous conditions. The aims for palliative care within the UK concur with the perceptions from these patients and relatives within the studies examined in the review. High-quality palliative care is not a luxury but should be seen as a significant international public health concern (WHO 2014; Foley 2003). What appears to be the undeniable requirement in achieving these goals for patients and their carers is knowledgeable, compassionate staff. Improving satisfaction is a means of improving the experience of those approaching the end of life (Dy et al. 2007).

Supportive and palliative care

Palliative care has undergone continued changes, with the acknowledgement that terming the specialist field 'supportive and palliative care' may be a more accurate representation of the interventions it employs. Patients and their relatives may be suffering physically, psychologically, emotionally, socially and/or spiritually at diagnosis. Specialist teams may be competent in managing a range of issues presented, but in addition the palliative care team may be able to offer a different but complementary dimension to the disease-specific specialist team. One may argue that introducing palliative care at an earlier stage may also dispel the myths and image of palliative care specialism as end of life care, therefore encouraging people who are struggling with symptoms to be less apprehensive and fearful of palliative care involvement or referral should it be needed.

Within the UK, Palliative care as a specialist field of practice has been a relatively recent provision. The teamwork and collaborative approach involved in helping and caring for patients and their loved ones is essential in ensuring that a seamless multidimensional approach is adopted. Patients often have complex needs which incorporate more than just physical symptoms or in some cases may not even include any physical presentation. In a study by Skilbeck et al. (2002), 57 per cent of the 814 referrals the palliative care team received were for emotional support. This suggests that a large number of patients are struggling psychologically and emotionally with their diagnosis. Despite this research preceding many of the policies and standards introduced over the last decade which aimed to address these concerns, psychosocial issues and communication skills remain unacknowledged and unresolved for many patients (Healthcare Commission 2008). The holistic assessment should be fundamental and initiate caring for the whole person rather than the physical symptoms alone.

Long-term conditions and palliative care

Traditionally those accessing palliative care services were patients with a cancer diagnosis, but there has been a growing recognition that this has provided an inequitable service for those with a non-cancer diagnosis but still suffer with a life-limiting illness. Skilbeck and Payne (2005) argue that palliative and end of life care for those with a chronic long-term condition (LTC) remains fragmented, with poor symptom control and limited access to specialist palliative care services. This demonstrates that significant inequities continue to exist, and one may argue that effective symptom control and support will be needed no matter what the diagnosis. In Skilbeck et al.'s study (2002), although a little dated, they found that when examining the referrals made to the specialist palliative care team over a 1-year duration, only 3 per cent of the referrals had a non-cancer diagnosis. When a patient is facing a life-limiting condition they have a number of needs, including dealing with anxieties about their own mortality and death. In a United States' (US) study, Tilden and Thompson (1999) identified that Americans fear how they die more than the death itself because of the advancements in medical technology which may lead to extensive, aggressive medical management of those with a life-limiting illness. This may be exacerbated when there are difficulties in identifying the end of life for those with a non-malignant disease. Therefore admissions to critical care areas when in fact a patient is nearing the end of life may be difficult to manage for the staff, patients and relatives due to conflicts regarding what is in the best interest of the patient and the high expectations of the patient and relatives. These dilemmas were identified in Beckstrand et al.'s (2006) multicentre study examining nurses' perceptions of a 'good death' in critical care. The environment where end of life care is delivered can have an impact on the perceived quality of that care. The intensive care unit can often witness a degree of conflict, and this was evident in the participants' responses. These were extremely varied and the dominant themes are shown in Figure 1.3.

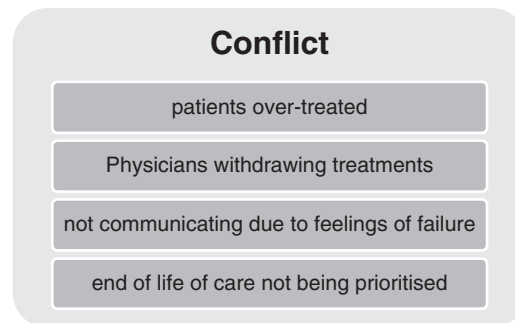


Figure 1.3 Influences on conflict (Beckstrand et al. 2006)

Most reported lack of knowledge when it comes to optimising a good death as they felt that both their pre-registration and post-registration education did not prepare them adequately. What is apparent from this study is that end of life care creates a great deal of anxiety for the staff attempting to provide high-quality care and a good death. Lack of preparation for dealing with these end of life issues appear to affect the care given. Education and training appear to be clear key messages from this study, and it is likely that this is transferable to other intensive treatment units as well as to many other healthcare settings and specialist areas. These issues will be examined in more detail throughout this book.

The profile of those needing palliative care is shifting due to the changing nature of health needs. As the number of adults over the age of 65 increases, there is a rising incidence of diagnosed LTCs. More people die due to LTCs than cancer (Office for National Statistics 2008). It is estimated that 70 per cent of the National Health Service budget is spent on treating patients for their long-term condition (Joint Commission Panel for Mental Health (JCPMH) 2012). These LTCs can present with a multitude of difficulties for the patient and their carer, as generally the older person may present with multiple problems incorporating other co-morbidities which may make the management and care more demanding and complex (Ridgway 2011). The JCPMH (2012) identify that LTCs are generally associated with more mental health issues, therefore they require comprehensive, holistic assessment and treatment in order to meet and address their needs. A myriad of psychosocial, physical and spiritual issues may have a negative impact on the quality of life not only for the patients but once again present numerous issues for the carer. One example would be the incidence of low mood. Those with a LTC may be two or three times more likely to suffer significant depression (Haddad 2010). This may have an impact on their desire to seek interventions and could affect them in the physical, spiritual and social domains, restricting their desire to socialise and induce feelings of worthlessness. The incidence of depression and impact a diagnosis of COPD (COPD) has on individuals equates to the significant symptom presentations a patient with lung cancer may have. The difference is that the patient with COPD may experience a protracted illness where quality of life gradually diminishes (Shuttleworth 2005). Ahmedzai (2003) examined the burden of progressive non-malignant lung disease in some depth and identified that patients require

supportive care throughout their journey and that holistic assessment should be the cornerstone of nursing care delivery in order to maximise quality of life. The Royal College of Psychiatrists (2009) identified that one-quarter of the patients in their studies with physical illness developed a mental illness. It was felt that trying to live with the burden of disease and for those with a potential life-threatening disorder, this may be more pronounced. These issues will have a significant impact on our practice as we may find ourselves providing significantly more palliative and terminal-phase care than ever before as demand increases from those suffering with LTCs. Providing palliative care demands a certain level of self-awareness and clarity regarding our own beliefs, values and knowledge (Baldwin 2011). Dealing with significant distress can have a long-term impact on our own wellbeing as we too experience grief and bereavement, therefore the last chapter of this book will examine ways of helping ourselves and strategies we can use to identify our own distress and burden.

Within the UK there is now recognition that any patient with a life-limiting illness should have access to any service or support they require when they need it no matter what their diagnosis. This has ensured a fair and just provision for all who are suffering. This applies not only to justice for those with any illness, but includes justice for all individuals who may be marginalised (e.g. the elderly, those in prison, travellers and culturally diverse groups). Although these groups have been traditionally 'hard to reach' and may find accessing services difficult, there is a growing need to restructure service provision in order to meet their needs. To reiterate however, access may be available but this relies on the recognition that the patient is at the point where they need end of life care.

Communication

The Department of Health (2008) and NICE (2004) introduced strategies and guidance in order to promote access for all and suggested a clear minimum standard of care. They recommended improvements in the communication strategies currently employed and that more collaborative working within the multidisciplinary team should be encompassed in order to facilitate high-quality end of life care. Effective communication strategies are needed to ensure that this comprehensive approach is seamlessly channelled to all those aiming to achieve similar goals for the benefit of the patient and their relatives. Those requiring palliative care input may have complex needs; consequently health and social care providers need to meet these multiple aspects of patient need. Patient-centred care, inclusivity in decision making and empowerment incorporate the essence of palliative care delivery. Effective communication throughout the patient's journey is fundamental in delivering these goals (DH 2008).

Knowledge

Palliative care is not only delivered by palliative care teams. In the Royal Liverpool Hospital the Palliative Care Team had contact with only 15 per cent of those who died in the hospital (Kinder and Ellershaw 2003). When one considers that 65 per cent of

deaths occur in hospital, there are a significant number of patients who die in hospital under the care of the nursing staff on the ward. What this shows is that ward staff are often providing palliative care to a large patient group, so it is vital that they are knowledgeable and properly equipped to care for these patients. In the community setting, including nursing homes, many district nursing teams and nursing home staff provide excellent nursing care to those with a life-limiting illness. The Parliamentary and Health Service Ombudsman (2015) stated that individuals should have access to specialist palliative care services no matter what diagnosis, when they need it, but also that those providing care at the end of life should be knowledgeable and confident enough to ensure that symptoms are addressed and managed to prevent suffering. This may mean that specialist palliative care teams take on a more educational role and then intervene when a patient is suffering due to very complex problems.

The Department of Health (DH) in 2008 had identified similar issues, suggesting that, suboptimal end of life care was prolific throughout National Health Service provision (NHS) and attributed this to poor knowledge base and lack of educational opportunities. As a consequence investment in staff was viewed as paramount to ensure that those vulnerable groups with life-limiting illness could be assured a more proactive approach to their care that was evidence based and delivered by knowledgeable practitioners. What one should acknowledge is that support and education for these staff needs to be on-going. Nurses have a responsibility to ensure the patient and their carer's receive high quality, evidence based care (Nursing and Midwifery Council 2015).

Conclusion

The need to provide equity in palliative care delivery is not only a UK goal but has been recognised as a significant issue globally. As far back as 2005, the 2nd Global Summit of National Hospice and Palliative Care Associations (PCA) identified the need to ensure that equity in access was paramount no matter what race, gender, diagnosis, sexual orientation, culture or religion. As a result the Korean Declaration on Hospice and Palliative Care was developed (IAHPC 2005). Within the UK, the end of life care strategy demanded that equity is a human right and therefore access to high-quality palliative and end of life care should be facilitated and provided to all who need it (DH 2008). Ensuring that we have adequate training and education both pre-registration and post-registration is the nurse's responsibility (Nursing and Midwifery Council 2008). The delivery of services should be compassion-led, creating a therapeutic relationship with our patients, carers and service users. One outcome of the Francis report, *Compassion in Practice* (DH 2012), supported the concept of 'the 6 Cs' (care, compassion, competence, courage, communication and commitment). Additional guidance was launched, which included ensuring shared decision making and communication with those in our care and collaboration with others. These are pertinent goals when one considers that living well and dying well are the fundamental needs of patients approaching the end of life. We can deliver the high-quality care needed to ensure dignity and serenity as the end of life approaches.

Reflection points

- Has your understanding changed?
- What is your understanding of palliative care now?
- Consider this scenario and complete the reflection points at the end

Case scenario: Beryl

Beryl is 47 and she has been referred to the district nursing team having received a diagnosis of lung cancer. She felt overwhelmed when the news came. There were a number of professionals in the room but she cannot recall much of what was said. Her first thought when she was told was her children and what would happen to them. The only recollection was that it wasn't curable and she was awaiting palliative treatment which would help her symptoms.

She is a single parent and works full time as a secretary. She has two children, Thomas 14 and Jessica 9. Her husband died six years earlier following a road traffic accident. The children have accepted the loss of their father although it was extremely difficult for a number of months afterwards. Beryl has some contact with her mother but she lives 240 miles away and therefore contact is generally via the telephone. She has friends but does not really socialise as she prefers to spend her time with the children.

Beryl has a mortgage on her house, she struggles but manages to have a reasonable standard of living.

The diagnosis has been a great shock and she is struggling to think about what is going to happen and make plans for the future. She does feel that she needs some help with this as she does not seem to be able to think straight.

Currently her symptoms include pain, nausea, insomnia, breathlessness and fatigue. The distressing symptom is her fatigue because she feels she needs to be as active as possible for the sake of the children.

Reflection point

- What is important when you discuss Beryl's care with her?
- List the health and social care professionals that may help to support and care for Beryl.
- How can we help the children?
- Are there any agencies that may be able to help Beryl?
- Think about why you have made your decisions.
- Why would a holistic assessment be important here?

Suggested reading

Department of Health (2008) *End of Life Care Strategy*. London: DH.
 Department of Health (2012) *Compassion in Practice*. London: DH.

Useful websites

National Council for Palliative Care: www.ncpc.org.uk

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