ESSENTIALS OF NURSING CRITICALLY ILL ADULTS

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SUPPORTING THOSE AT THE END OF LIFE IN CRITICAL CARE

16

KAREN HEGGS

> Cure sometimes, relieve often, comfort always.
>
> Bion and Coombs (2015: 289)

LEARNING OUTCOMES

When you have finished studying this chapter you will understand:

- What end of life care means
- How care in the last days of life is managed in the critical care setting
- The role of the **multi-professional team** in end of life care
- The role of the nurse in supporting the patient and their family carers at end of life, in the last days of life and into bereavement
- The need to ensure your own emotional health and wellbeing

INTRODUCTION

Despite developments and advances in **interventions** and extensive support for the patient in the critical care environment, recovery is not always possible, and, in this situation, there is acknowledgement that the patient will die and that they are approaching the end of their life. It is important that we acknowledge death as part of life; but this can be challenging in a care environment where the focus is to provide 'life-sustaining therapies with the goal of restoring or maintaining organ function' (Mercadante et al., 2018: 1). In our society, we have an increasingly ageing population, who are living with multiple complex co-morbidities. The developments in advancing treatment options for many conditions and diseases leads to a greater risk of complexity and this also bring with it many challenges in the management of the patient in the critical care setting and with this, the possibility that the person may die in the critical care setting.

Between 2018 and 2019, over half of admissions to critical care settings in the UK were unexpected or transfers following a complex planned surgical procedure for those with additional health needs and co-morbidities (NHS Digital, 2019). It has been identified that over the last 2-year period in England, approximately 8% of patients admitted to the critical care setting died during their stay in critical care unit. Alongside this population, many younger people who have been involved in trauma such as road traffic accidents or assaults will be cared for and die in the critical care setting. This brings with it a range of complex issues including organ and tissue donation.

THIS TOPIC IS ALSO COVERED IN CHAPTER 3

This chapter will provide an outline of the provision of end of life care in the critical care setting, including an overview of how end of life care is managed. We will consider some of the nuances specific to critical care; the role of the multi-professional team and, importantly, the central role of the nurse in the delivery of end of life care for the critically ill person and their family. We will also consider the challenges of the delivery of **palliative care** in critical care and the importance of self-care for the nurse working in this area in order that end of life care provision is effective for the person as well as the nurse.

The following activity will help you to begin to consider your own perceptions of end of life care and what this means to you as an emerging practitioner.

ACTIVITY 16.1: REFLECTIVE PRACTICE

1. What does end of life care mean to you?
2. Have you cared for a person at the end of their life?
3. Was this in a critical care setting or in another care setting?
4. What differences do you think you may find in the delivery of end of life care in a critical care setting?

There is no template answer to this activity as it is based on your own reflection. However, do note down your thoughts to these questions – they will support you as you move through this chapter.

DEFINING END OF LIFE

There have been many developments over recent years with regards to defining 'end of life' with a drive to raise awareness of the need to identify those felt to be approaching the end of their life, in order that they and their family can be involved in decision-making and delivery of care. It has also been suggested that effective identification of those at the end of their life can lead to greater opportunity for open dialogue about death, clear communication with all involved and, subsequently, better care planning.

In recent years, there was a suggested change in nomenclature and how the term 'end of life care' was utilised, in order to facilitate more open communication between patients, their families and healthcare professionals and support with care planning. The North West end of life care model (North West Strategic Clinical Networks, 2015) present this in a linear framework. There is acknowledgement that end of life care is the last 12 months of life (or beyond), care in the **last days of life** and then into the bereavement, which can be extended.

For the purpose of this chapter, we will continue to use this language.

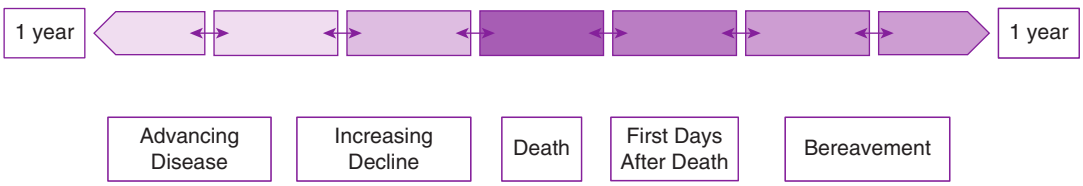

Figure 16.1 The North West End of Life Care Model

Source: North West Strategic Clinic Networks (2015). Contains public sector information licensed under the Open Government Licence v3.0. License.

DECISION-MAKING AT END OF LIFE

There are a number of factors that need to be considered in the identification of someone who is felt to be in the last year of their life. In 2000, Kerry Thomas strived to develop a tool that may support this process in order to initiate a systematic change to how people in the last year of their life are supported. The Gold Standards Framework (GSF) sought to break down barriers with the introduction of a simple process. The 'surprise question' (Thomas et al., 2011) is used as a trigger by clinicians to help them to identify those whose condition may be deteriorating following their assessment, by asking 'would you be surprised if this person died in the next 12 months?' If the answer to the question is 'no' this would then be a prompt for the practitioner to open dialogue with the person and their family and begin communication with others involved in the delivery of their care. The GSF has its roots firmly grounded in primary care; with community practitioners engaging in regular meetings to discuss those identified to be in the last year of life, and to ensure that appropriate services are in place for them. It is important that this information is communicated across care settings; and many areas of the UK now have electronic communication systems where this can be shared across primary and secondary care, including ambulance services. It is important that we have an awareness of this in the critical care setting, to help aid discussion and care planning for the people in our care.

It is acknowledged that diagnosing end of life is not an exact science and can be influenced by many factors, including disease and the typical trajectory that this may follow. The variations of this are demonstrated in Figure 16.2, where the sudden and rapid deterioration often seen in those with a cancer diagnosis contrasts significantly with the gradual and stepped deterioration of those living with organ failure such as heart failure or Chronic Obstructive Pulmonary Disease (COPD). This may be further complicated by the fact that many people now live with a number of co-morbidities, so there may be blurring of these identified disease trajectories and one may supersede the other. The use of clinical judgement alongside supporting prognostic indicator guidance can support healthcare professionals in the identification of deterioration and whether a person may be at the end of their life.

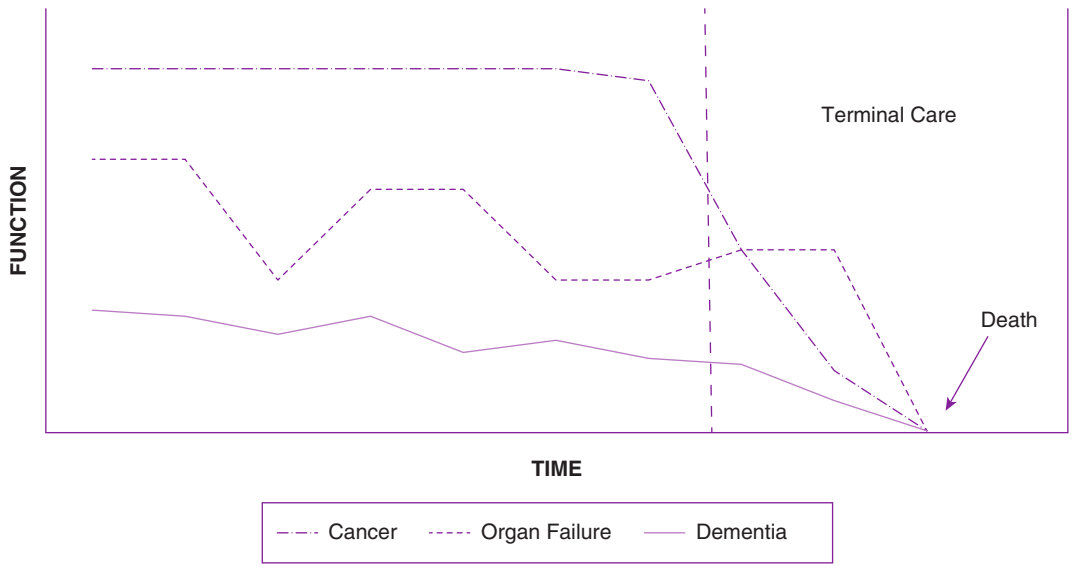

Figure 16.2 Disease trajectory

The opportunity to identify the stage of disease and end of life allows for the facilitation of discussion and the opportunity to consider advance care planning options with the person and their family. This may in turn reduce the need for critical care admission with planning in the event of deterioration and the need for critical care input. There is also the opportunity here for early engagement of palliative care services, which may lead to facilitated discussion about care needs and effective **holistic** care and support, which we will discuss in more detail later in this chapter (Ma et al., 2019). As complexity continues to be an issue and to facilitate decision-making, a possible solution to this could be the development and use of decision-making tools to support critical care clinicians in identifying when to consider palliative care and when to seek specialist input to care. Adler et al. (2019) suggest that there is limited evidence in the use of decision-making tools in critical care to support this important aspect of care; and that the development of such trigger tools must be developed at grass root level.

The need to address decision-making, uncertainty and end of life care in the critical care setting was acknowledged by The Faculty of Intensive Care Medicine by the publication of a key paper 'Care at the end of life: A guide to best practice, discussion and decision making in and around critical care' in

September 2019 (Cosgrove et al., 2019) with the proactive development of a number aide memoires in the form of decision-making. The key tools developed are designed to support critical care practitioners in their decision-making process, when it is identified that someone is at the end of their life. These tools have a specific focus for care in the last days of life, in addition to the need to consider a change of focus in treatment through an achieved consensus.

The following activity will allow you to begin to consider some of the challenges of end of life care and care in the last days of life in the critical care setting and how communication is central to this.

ACTIVITY 16.2: RESEARCH AND EVIDENCE-BASED PRACTICE

Review the tools developed in the publication by The Faculty of Intensive Care Medicine (Cosgrove et al., 2019) 'Care at the end of life: A guide to best practice, discussion and decision making in and around critical care'.

Look at the following tools:

- Dealing with dilemma on p. 9
- Aide memoire for end-of-life care on the critical care unit on p. 15
- Aide memoire for achieving consensus on p. 27

Consider how these tools could support decision-making for those at the end of their life and also those in the last days of life

1. Do you feel that they would facilitate communication?

CARE IN THE LAST DAYS OF LIFE IN THE CRITICAL CARE SETTING

The critical care setting allows for the opportunity for excellence in the delivery of care in the last days of life. Often people may have been in the setting for a long period; allowing for the development of an effective therapeutic relationship between the patient, family and the nurse and healthcare team (Stokes et al., 2019). In addition to this, the high ratio of staff to patients lends itself to the delivery of individualised and intensive care in the last days of life and for continuity of care from the team.

But the complexity of the cases that require critical care and the intensity of the care interventions, with ongoing developments of what can be achieved in the drive to save lives, can lead to often complex and challenging decision making for practitioners and the people that they care for and their families. One of the significant challenges is the shift of care from lifesaving care to care in the last days of life (Kisorio and Langley, 2016). This can involve the withdrawal and withholding of life sustaining treatments and situations where a person may lack capacity due to their condition and the use of medications to facilitate **sedation** (Mercadante et al., 2018). Critical care nurses are often at the forefront of these care decisions and are active in the changes in care delivery; they are the face that the family see and engage with at a time of great vulnerability and emotional distress.

Nurses in the critical care setting may also provide care in the last days of life for people who are organ donors following diagnosis of brain stem death. Interestingly, over the last 2 years less than 0.5% of those who have died in the critical care setting have been organ donors (both heartbeat and non-heartbeat or cadaveric donation) (NHS Digital, 2019). With this in mind and minimal occurrence the opportunity for nurses to experience caring for a person at the end of life in this situation is limited and requires the input of specialist support. The implementation of the role of the Specialist Nurse for Organ Donation (SNOD) has ensured that the critically ill person, their family, and critical care nurses are supported with this often complex and challenging area of end of life care, with the key role of the SNOD (Noyes et al., 2019) including:

- Education
- Support for family
- Support for staff
- Consent

THIS TOPIC IS ALSO COVERED IN CHAPTER 11

The change to UK law in 2020 and the move to an opt-out system for organ donation may lead to an increase in the number of **organ donation** cases and increased opportunity for critical care nurses to engage in this end of life care delivery.

WHAT'S THE EVIDENCE?

There is a developing evidence base looking at the role of the nurse in both decision-making and delivery of care for people in the last days of life. It is suggested that although this is a significant part of their role, there is the need to develop knowledge and skills for critical nurses to support them in the delivery of care in the last days of life (Jang et al., 2019; Kisorio and Langley, 2016; Todaro-Franceschi, 2013). As interventions advance and develop and complexity of health increases, there will be a continued need and drive to ensure that critical care nurses continue their own professional development in the delivery of end of life care.

However, in 2013 the European Association for Palliative Care presented a white paper that identified a three-tier approach to support in the delivery of education (Gamondi et al., 2013). The three tiers are presented here in Table 16.1.

Table 16.1 Three tier approach to support the delivery of education

Palliative care approach	Integrating the ethos of palliative care into all settings
	Education provided to all staff across a range of care
	Staff access education in pre-registration programmes and also post-registration education
General palliative care	Education accessible to all healthcare professionals who regularly provide palliative care as part of their work
	Staff access education in pre-registration programmes and also post-registration education
Specialist palliative care	Palliative care for patients with complex and challenging needs
	Accessed when generalist input and treatment plans have not been effective
	Higher level of education required due to the complexity of the care requirements

Source: Based on the work of Gamondi et al. (2013).

It would be interesting for you to consider here where there may be a merge in the educational requirements of the nurse working in the critical care setting.

1. Do you feel that nurses in critical care would require education targeted at both general and specialist palliative care?
2. Do you feel that the level of complexity of cases that nurses working in critical care are managing would impact this?

There is no template answer to this activity as it is based on your own reflection.

Nurses working in critical care require advanced communication skills to ensure that they can communicate effectively in complex situations, transferring often complex information to the patient, their family and to members of the wider multi-professional team, in order that effective care can be delivered. There is also the challenge for the critical care nurse to ensure that communication to the patient and their family is clear, easy to understand and readily available at the time that this is needed. A study published by Nelson et al. (2010) sought to hear the voices of patients and their families in the critical care setting. The findings identified that communication was central to their entire experience, with a need for information that was consistent and delivered in a compassionate and considered way. Communication has also been identified as a key priority by Cosgrove et al. (2019) who have highlighted the need to ensure transparency in communication to reduce the potential for confusion and conflict between healthcare teams, the patient and family members.

ACTIVITY 16.3: CASE STUDY

Elizabeth is a 62-year-old woman who has a diagnosis of COPD and type 2 diabetes. She has a good quality of life and continues to work in her local library 3 days each week. She is active and enjoys attending the gym and walking with a local walking group – she does this following her recent diagnosis and after a recent admission to hospital with an **exacerbation** of her COPD and a programme of respiratory rehabilitation.

Elizabeth is the main carer for her husband Reginald, who has early stage Lewy Body dementia. He lives at home with her and is able to manage many activities of daily living with support. Elizabeth and Reginald have 2 adult children who live locally, and they have 3 young grandchildren. Elizabeth performs childcare for her grandchildren 2 days each week. They are a close family unit and are supportive of each other.

Elizabeth has been admitted to hospital via the acute medical admissions unit where she has presented with a severe exacerbation of her COPD. She was reviewed by the medical consultant on call and was then transferred to the critical care unit after her condition deteriorated further. She has been diagnosed with pneumonia and required intubation and ventilation. She also required **inotropic** support and haemofiltration. Elizabeth has been in the critical care unit for the last 6 weeks and was initially showing signs of improvement; however, she has developed a further infection, and this is not responding to treatment as her team would have hoped.

Despite these interventions Elizabeth's condition continues to deteriorate and following review by her medical teams, the decision has been made to withdraw supportive interventions.

(Continued)

Think about the shift in care focus here.

1. How would the nurse in the critical care environment manage the transition of care to care in the last days of life?
2. What do you feel would be the nurses' main priorities?
3. How would the nurse support Elizabeth's family?
4. What feelings do you feel the nurse may be experiencing in this situation? How would they manage their own emotions in this situation?

PALLIATIVE CARE IN THE CRITICAL CARE SETTING

The involvement of the palliative care team earlier in the trajectory of admission can have a positive impact, including initiation of discussions with family carers at an earlier point and facilitation of communication to support effective decision making for the critical care team (Mercadante et al., 2018). In addition to this the ethos of care delivery from a critical care and palliative care perspective are inextricably linked, with many similarities in their approach and principles such as multiprofessional working and a person-centred and holistic approach to care delivery (Bion and Coombs, 2015; Matthews and Nelson, 2019). There may not be the disparity that was suggested in the introduction at the opening of this chapter; but it is acknowledged that there is a need to identify a sense of balance between the drive to treat and the need to ensure that we consider the wishes of a person who is at the end of their life (Bloomer, 2019).

Only 0.6% of critical care patients are transferred to a palliative care provider (i.e. a hospice) over last 2 years (NHS Digital, 2019). There are a number of reasons that this may be the case, including the complexity of care and the issue of rapid deterioration once life-sustaining treatments such as inotropic and ventilator support are removed; often it is not safe, practical or in the best interests of the person to move them at this stage. A study by Ma et al. (2019), identified that early intervention of specialist palliative care services in the critical care environment led to increased access to hospice care provision and also advance care planning such as 'do not attempt CPR' and also decisions about future care plans. This also led to more effective utilisation of critical care provision and appropriate management of person-centred care. But this does not preclude the delivery of effective palliative care in the critical care setting (see Figure 16.3).

Palliative care is defined as the care of a person living with and dying from a life-limiting condition; the World Health Organisation (2013) provides a detailed insight into its view of palliative care with a clear vision on the importance of person-and family-centred holistic care that is both life and death affirming:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends to neither hasten nor postpone death
- Integration of emotional and spiritual care
- Offers a support system to help families cope throughout disease and into bereavement
- For the affected person to live the best quality of life they can

- Using a team approach, care and interventions are utilised to enhance quality of life alongside life prolonging treatments
- Ensures that investigations are considered to support in the management of symptoms and to enhance quality of life

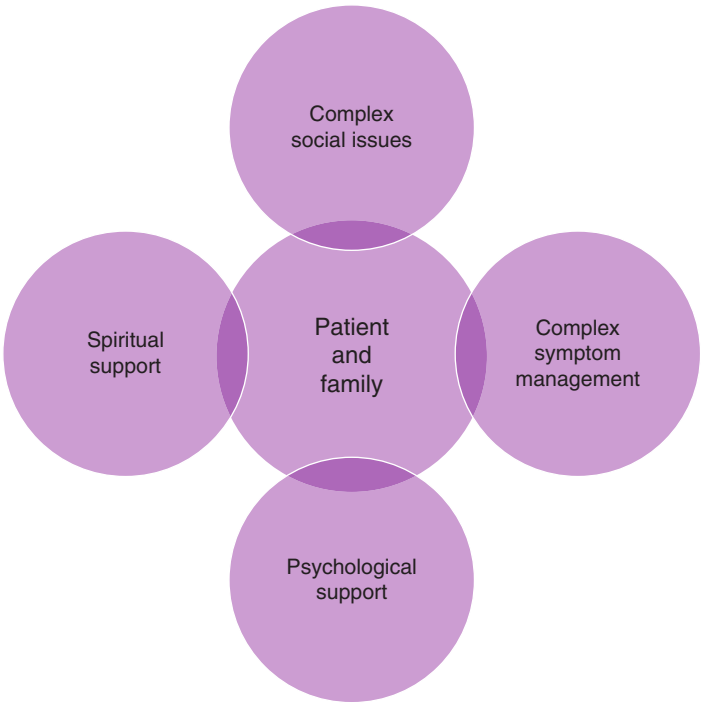

Figure 16.3 The ethos of palliative care in the critical care setting

The delivery of palliative care is the responsibility of every healthcare professional and in the UK, recent policy development is ensuring that the profile of palliative care is raised and that initiatives such as advance care planning are promoted. In 2015, the National Palliative and End of Life Care Partnership published a positive and ambitious national framework to raise the profile of palliative care across a range of care settings, ensuring that everyone has access to palliative and end of life care when they need this.

A National Framework for Palliative and End of Life Care – The six key aims

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is coordinated

- All staff are prepared to care
- Each community is prepared to help

Source: adapted from National Palliative and End of Life Care Partnership, 2015: 11.

THE ROLE OF THE MDT IN THE PROVISION OF END OF LIFE CARE

As we have already identified, care delivery in the critical care setting can be complex due to a number of multifaceted issues. With a number of key teams engaged in decision-making and in the delivery of care, the nurse plays a significant role in ensuring communication across teams and the co-ordination of care delivery in response to this. It is essential that the patient and their family are central to this and that this is facilitated to ensure that the complexity is managed. It will also ensure that a team approach to delivery of palliative care, as indicated by the World Health Organisation, is facilitated. In addition to this, it has been advised that there is a significant need to work in a joint manner to ensure the co-ordination of care delivery for people at the end of their life (The Choice in End of Life Care Programme Board, 2015).

The following activity will encourage you to reflect on your appreciation of multi-professional working in the context of critical care.

ACTIVITY 16.4: REFLECTIVE PRACTICE

Consider your own experiences from practice.

1. How can multi-professional working be effectively facilitated?
2. What actions and interventions have you observed that could facilitate this in the critical care setting?

There is no template answer to question 2 as it is based on your own reflection.

In 2003 Skilbeck and Paye developed an understanding of the difference between generalist and specialist palliative care; their work allowed greater clarity in this field. However, since the publication of their work, there have been many advances in healthcare interventions, and we have many people now living with multiple complex needs requiring critical care input. Ryan and Johnston (2018) provide further and more current discussion about the differentiation between generalist and specialist palliative care. With the drive to ensure that palliative care is delivered alongside potentially curative or intensive treatments and management, there is a real need for team working, and the specialist teams contribute significantly to the delivery of this care by the main care team (see Figure 16.4). It is suggested that this may need to be reconsidered for the critical care setting as all patients who require critical care input will also have a higher level of complexity and thus need for specialist palliative

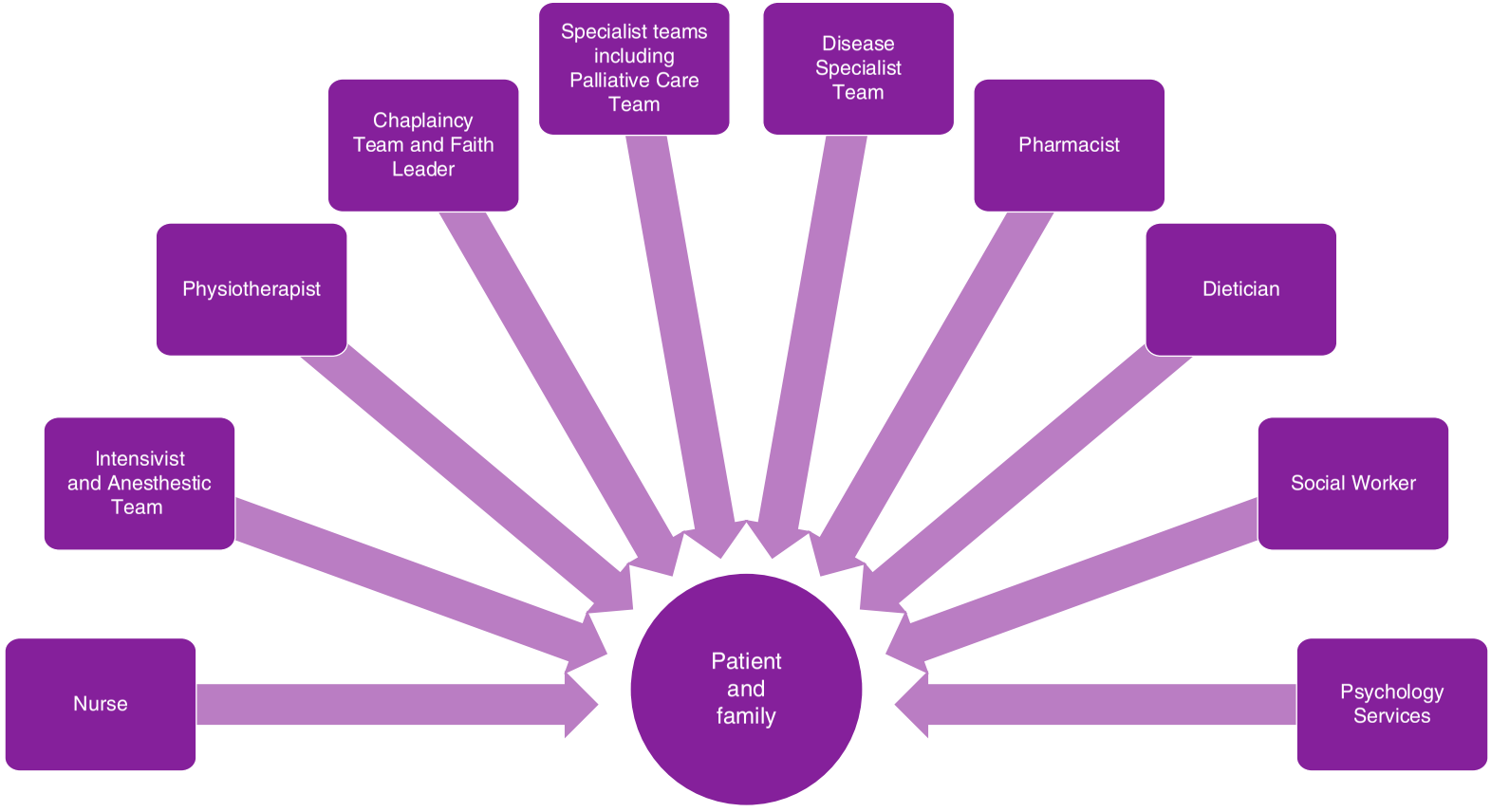

Figure 16.4 The wider multi-professional team engaged with a patient and their family in the delivery of end of life care

care intervention. In contrast to this, the level of intensity of nursing and medical care in the critical care setting may preclude the need for specialist palliative care input; we will consider the role of the **specialist palliative care team** later in this chapter. The next activity will encourage you to reflect on the differences between generalist and palliative care; understanding this can help in your decision to engage the specialist palliative care team.

ACTIVITY 16.5: THEORY STOP POINT

1. What are the differences between generalist palliative care and specialist palliative care?

Read the paper by Skilbeck and Payne (2003) (doi.org/10.1046/j.1365-2648.2003.02749.x) and the chapter written by Ryan and Johnston (2018).

2. Are there any clear differences in the approach over the span of 15 years?

THE SPECIALIST PALLIATIVE CARE TEAM

Bion and Coobs (2015) acknowledge the advances in intervention and treatment options in the critical care setting, and that many people with complex co-morbidities may have considered the option to not be admitted to a critical care environment for care. The value of advance care planning discussions allows the patient, their family and their healthcare providers to identify a ceiling of care, which would support decision-making and reduce the need for critical care admissions. The involvement of palliative care teams can complement the delivery of this aspect of care and also support the development of future care planning for those living with complex and life-limiting conditions.

There appears to be a lack of clarity and consensus about the best timeframe for the involvement and engagement of the specialist palliative care team in the delivery of care in the critical care setting. Matthews and Nelson (2017) (see Figure 16.5) identified that there are many similarities in the development of both critical care and palliative care delivery over the last 2 decades. A point of significance is the drive to acknowledge the value of palliative care intervention at any point in a person's **disease trajectory**; end of life care may be a part of this, but specialist palliative care services can also offer so much more. This lends itself to the concept of supportive care and that the specialist palliative care teams can provide input to patient care, even if the intention of the treatment is curative in nature.

In the UK in 2004, NICE provided a definition of supportive care that shares many similarities with the NICE (2004) and WHO (2019) views of palliative care; extending and emphasising the value of supportive care at any point in a person's illness and disease trajectory and also ensuring that there is equal emphasis on supportive care and treatment with curative intent. This should lead to the inclusion of palliative care for support and guidance for all as needed throughout the critical care admission. It is suggested that it may be useful to consider if a person is already known to palliative care services prior to their involvement and admission in the community setting.

It is also helpful to know that community and acute specialist palliative care services work in close proximity and that the palliative care team can be a useful source of information and guidance. Mercadante et al. (2019) propose two possible models for the integration of palliative care delivery in the critical care setting; the first being the 'integrative' approach, which is that the founding principles of palliative care are a part of day-to-day care delivery in the critical care setting. The second approach is the 'consultative' approach, where the palliative care team are invited into care delivery for their expertise and opinion.

Matthews and Nelson (2017) also acknowledge the need to future proof this aspect of care and linking this with the advances in care delivery, leading to important issues such as survivorship, mirroring the developments in cancer care delivery over recent years.

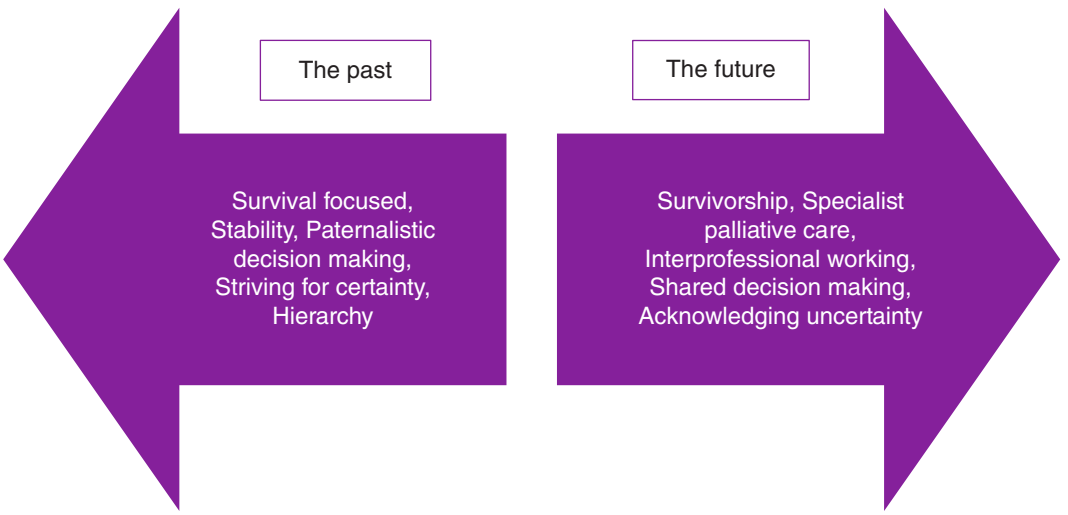

Figure 16.5 Changes in palliative care approaches

Source: Mathews and Nelson (2017); adapted and reprinted by kind permission of Springer Nature.

ACTIVITY 16.6: RESEARCH AND EVIDENCE-BASED PRACTICE

The role of the SPC team in the delivery of EoLC

Listen to this podcast from the Society of Critical Care Medicine – Enfield and Kollef discuss their study that looked at the value of early intervention from the specialist palliative care team in the critical care setting.

1. What key factors are identified in the study?

As you will have found from the last activity, Specialist palliative care teams can offer expert advice and opinion in a number of areas of complexity, linking with the identified ethos of palliative care defined by the World Health Organisation. Their care delivery is holistic in its approach across the physical, spiritual, emotional and social needs of the person and their family. Symptom control is a significant part of the role of the specialist palliative care team, with many people in the critical care setting experiencing a range of symptoms at the end of life and in the last days of life. Cosgrove et al. (2019) have identified this as a priority, with the acknowledgement of a number of key symptoms that may be experienced by patients at the end of their life in the critical care setting. These symptoms are not unique to critical care and are akin to those experienced by many people at the end of their life, regardless of the care setting. But the need to seek specialist support when they cannot be managed by the critical care team is vital to ensure comfort and dignity at the end of life and in the last days of life (Mercadante et al., 2018).

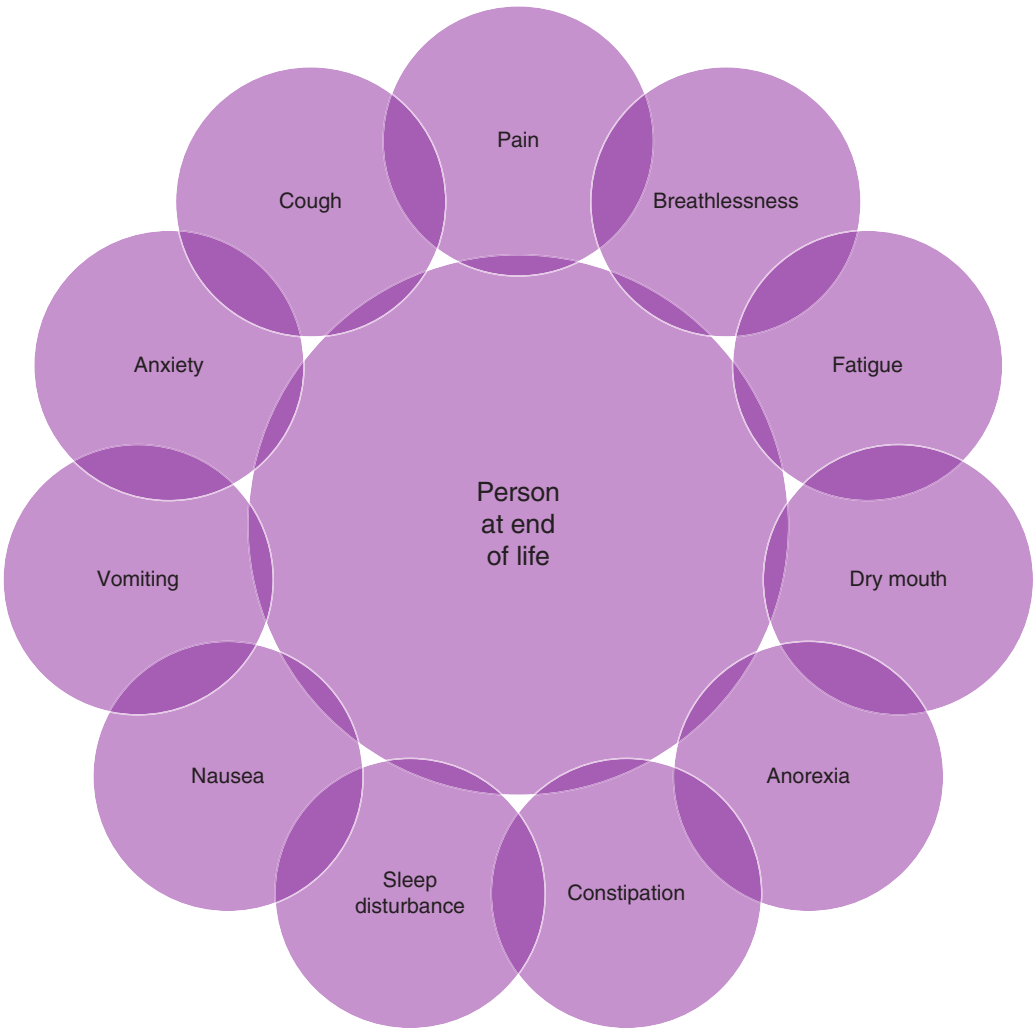

Figure 16.6 Symptoms that may be experienced by a person at the end of life

ACTIVITY 16.7: CASE STUDY

Peter is a 37-year-old man who was admitted to the critical care unit following a cardiac arrest whilst playing football with his friends. Before this event, Peter was a fit and active man who also enjoyed running and cycling regularly. He had no previous medical issues at all and this event has come as a huge shock to his family and friends.

Peter is married to Kelly; they have been together for 21 years and met at school. They have two children, Daniel is 8 and Olivia is 4. They are a very close family unit and both Peter's and Kelly's parents live very close by and play an active part in the family and in the provision of childcare. Kelly is a ward sister on an acute surgical ward in the hospital and Peter works as a manager at a local supermarket.

Peter has been on the critical care unit for 2 weeks and despite the support of inotropic drugs, ventilator support and renal support via filtration, he continues to deteriorate. Following multidisciplinary assessment and discussion this morning and discussion with his family, the decision has been made that there is no further treatment that can be considered to support Peter and that he is at the end of his life.

The team have discussed with Kelly that they will withdraw inotropic support over the course of the day, they will not continue with renal support, but as Peter is sedated and ventilated, they will look to his need for ventilator support and will ensure that Peter is assessed regularly for symptoms to ensure that these are effectively managed.

Kelly has expressed concern that Peter will be in pain and that he may experience discomfort at the end of his life. She has expressed that as a nurse, she has cared for many people at the end of their life and wants to ensure that his symptoms are well controlled. Kelly asks if it would be possible for her to be involved in some aspects of care for Peter.

1. How would the nurse support Kelly in this situation?
2. How would involvement of the hospital palliative care team support the nurse, team, Peter and Kelly in this situation?

SELF-CARE – ESSENTIAL FOR ONGOING CARE DELIVERY

Nurses working in the critical care setting deal with a number of challenging and often distressing situations; it is important for nurses to feel supported and to have an awareness of their own emotional health and wellbeing to ensure safe and effective care delivery; a point supported by the Nursing and Midwifery Council (2018) in The Code.

For nurses working in critical care there are a number of significant factors that may affect the emotional health and wellbeing of the nurse including:

- Intensity of relationship with patient and their family
- Complex ethical dilemmas and decision-making
- Withdrawal of treatments and interventions
- Time pressures
- Multiple interventions and treatments

There is evidence to suggest that there is an increased risk of emotional burnout for nurses in the critical care setting. A systematic review by Van Mol et al. (2015) identified 40 studies that had identified

the risks of burnout in the critical care setting. The study suggests the need for ongoing research into this area as advances in treatments continue and the complexity of care needs increases, suggesting the need to ensure that support is available to nurses in order that they can maintain their emotional health and wellbeing.

Burnout can have a number of causes including the personality traits of the individual, control in a situation and work pressures. It is characterised by 'emotional exhaustion, depersonalization, and a sense of low personal accomplishment' (Kim Wong and Olusanya, 2017).

There are many interventions that could be considered in the critical care setting, with the importance of working as a team and supporting each other in addition to the opportunity for debrief within the team, following the death of a patient. The use of debrief has been suggested to offer nurses an opportunity to discuss the situation and to learn from their experiences (Kisorio and Langley, 2016).

THIS TOPIC IS ALSO COVERED IN CHAPTER 1

It is important too that critical care nurses are aware of the support mechanisms that may be available to them in their own organisations, with many offering opportunities for counselling and debrief in addition to the Schwartz rounds in which complex cases are discussed in a supportive and reflective environment. It is suggested that engagement with their employing organisations is essential to ensure that the workforce feels supported and their voice is heard (Barker and Ford, 2018).

ACTIVITY 16.8: REFLECTIVE PRACTICE

Think back to your notes from Activity 16.1 at the opening of this chapter.

- What does end of life care mean to you?
- Have you cared for a person at the end of their life?
- Was this in a critical care setting or in another care setting?
- What differences do you think you may find in the delivery of end of life care in a critical care setting?

1. Reflect on your initial notes and consider your learning from this chapter. Do you have further learning needs?
2. How might you meet these learning needs through your own practice learning experiences?

Consider the further reading that is suggested in the 'go further' section at the end of the chapter. There is no template answer to this activity as it is based on your own reflection.

In an ever-changing healthcare system, with developments and advances in treatment options and complexity in the healthcare needs of the population; one constant is the need to deliver good quality and dignified end of life care. Although we are looking to prognosticate and identify when it is believed a person is at the end of their life, it is not always possible to plan effectively for their needs or for these needs to be met. It is essential for us to consider that we do not just focus on the physical needs of the patient at the end of their life, but also the needs of their family and that we consider their holistic needs too (Bloomer, 2019). The implementation of palliative care as part of care delivered by all in the critical care setting, alongside specialist team input in areas of complexity can add significant value to the care of people at the end of their life and in the last days of their life.

In this chapter, we have identified some of the challenges in the delivery of end of life care in the critical care setting, we have considered the role of the multi-professional team and importantly the role of the nurse in the co-ordination of care delivery. We have considered the drive over recent years to move the focus of the delivery of care in the critical care setting and also the imperative importance of facilitating effective communication with all in a range of contexts to ensure that end of life care is person-centred at its heart. Finally, we have considered the impact of end of life care for the nurse and the need to ensure our own health and wellbeing in the delivery of quality care.

CHAPTER SUMMARY

This chapter has supported you to gain greater insight into the following topics:

- Defining end of life care
- How care in the last days of life is managed in the critical care setting
- The role of the multi-professional team in end of life care
- The need to ensure your own emotional health and wellbeing
- Palliative care in the critical care setting

GO FURTHER

Books

Dixon, J. (2018) 'Issues of referral to and accessing palliative care', in C. Walshe, N. Preston and B. Johnston (eds) *Palliative Care Nursing – Principles and Evidence for Practice* (3rd edition). London: McGraw Hill.

- If you want to develop further understanding of the differences between generalist and specialist palliative care and the role of the specialist palliative care team in the delivery of care; this book chapter provides detail and further context to help expand your understanding.

Costello, J. (ed) (2018) *Adult Palliative Care for Nursing, Health and Social Care*. London: Sage.

- If you want to gain greater insight into the needs of people living with a range of diseases and some of the current key issues in adult palliative care across health and social care provision, this book provides expert opinion and identifies current practice developments and challenges.

Russell, S., Coombs, M. and Loney, J. (2018) 'The last days and hours of life', in C. Walshe, N. Preston and B. Johnston (eds) *Palliative Care Nursing – Principles and Evidence for Practice* (3rd edition). London: McGraw Hill.

- If you want to extend your knowledge and understanding of the care of a person in the last days of their life and the role of the nurse in care delivery; this chapter provides a valuable overview of this important aspect of nursing care, with a holistic approach to the management of person and family centred care.

Journal articles

Mullick, A., Martin, J. and Sallnow, L. (2013) 'An introduction to advance care planning in practice', *BMJ,* 13: Article #347. doi.org/10.1136/bmj.f6064

- This article will help you to develop a further understanding of the legal issues associated with advance care planning and an overview of current approaches to advance care planning in the UK from a medical perspective, including some of the barriers and the facilitators to advance care planning.

Metaxa, V., Anagnostou, D., Vlachos, S., Arulkumaran, N., van Dusseldorp, I., Bensemmane, S., Aslakson, R., Davidson, J.E., Gerritsen, R., Hartog, C. and Curtis, R. (2019) 'Palliative care interventions in intensive care unit patients – A systematic review protocol', *Systematic Reviews*, 8: Article #148. doi.org/10.1186/s13643-019-1064-y

- This systematic review provides interesting consideration of how palliative care is facilitated in a range of critical cares settings across a range of countries.

Anderson, R.J., Bloch, S. Armstrong, M., Stone, P.C. and Low, J.T.S. (2019) 'Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence', *Palliative Medicine*, 33: 8. doi.org/ 10.1177/0269216319852007

- This systematic review engages with the qualitative evidence about communication between healthcare professionals and family members when a person is at the end of life. It provides some interesting insight into strategies utilised by healthcare professionals and how these may be enhanced.

Useful websites

www.eapcnet.eu/

- The European Association for Palliative Care is a valuable website that provides detail on current policy development and research in the field of palliative care. Here you can also access a range of resources including some national policies.

http://advancecareplan.org.uk/ (accessed November 13, 2020).

- Advance Care Plan is a resource for people living in England and Wales, which contains a range of valuable information about advance care planning and tools to support people to consider advance care plans.

https://goldstandardsframework.org.uk/ (accessed November 13, 2020).

- The Gold Standards Framework (GSF) is a useful website that provides insight and overview into the role of the framework in the delivery of excellent end of life care. The website provides information on the aims of GSF and how the national GSF centre provides support to healthcare professionals in their role.

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