Abstract

Carers have a vital role in end of life care in all settings. They are essential in enabling people to live at home at the end of their lives. Carers give and receive care, and have a range of support needs related to this complex role. This article explores the context of caring at the end of life and considers the experience of carers, in particular those who have a non-professional and unpaid relationship with someone who is at the end of life, and the support they require.

Author details

Beth Hardy, lecturer in nursing, the University of York, York, England

Keywords

bereavement, bereavement support, carers, death, dying at home, end of life care, family carers, good death, grief, informal carers, palliative care

Aims and intended learning outcomes

The aim of this article is to enhance the reader’s understanding of the experience and support needs of end of life care givers, including how their needs can be met. After reading this article and completing the time out activities you should be able to:

» Describe the context of care delivered by unpaid carers of people at the end of life.

» Recognise the effect on carers of being involved with end of life care.

» Identify a range of carer support needs.

» Reflect on the challenges of identifying and supporting carers.

» Understand how health and social care professionals can support carers in end of life care.

» Identify local and national organisations that have a role in supporting carers.

Introduction

Carers are vital in end of life care, contributing significant time and money to support people daily (Rowland et al 2017). They are important in enabling people to live with advanced illness at the end of life and to die at home, which is most people’s preference (Department of Health (DH) 2008). It is vital to remember that carers will continue this role in the secondary care setting and they should be considered an important part of the healthcare team.

The term ‘carer’ is used in a variety of ways in the literature. In this article, it refers to people who have a non-professional and unpaid relationship with someone who is at the end of life (Payne et al 2010). A carer will usually be a spouse, partner, family member or friend and in considering the needs of carers providing physical and psychosocial care, this existing personal relationship is particularly significant (Caswell et al 2017). In addition to the care they provide, carers have to manage their feelings of grief and loss at the impending death of the person they care for. They also often have to continue with several other previously held roles, such as work and family responsibilities. Being a carer for someone at the end of life is challenging, but many people find it to be rewarding and brings them closer to the person they care for (Wong and Ussher 2009).

Nurses work with carers in a variety of health and social care settings and can assist in addressing carer support needs in end of life contexts. Effective support for carers can have
End of life care

People are considered to be at the end of life when they are likely to die within the next 12 months (National Institute for Health and Care Excellence 2017). Most people die in hospital, with data related to England showing that in 2016, 47% of all deaths occurred in this setting, 22% of deaths took place in a care home, 24% of deaths were at home and 6% of deaths occurred in a hospice (Public Health England 2016). However, most people will spend the majority of their final year of life living at home. Research has suggested that 85% of people would like to be cared for at home in their final year of life and 63% of people want to die at home (Wood and Salter 2013). Barriers to enabling these preferences to be met include the availability and responsiveness of services to support carers (Social Care Institute for Excellence (SCIE) 2013a).

End of life care occurs in the context of a palliative approach to care. Palliative care aims to improve the quality of life of patients and their families and/or carers when they are living with life-threatening illnesses (World Health Organization 2018). Palliative care involves a holistic approach that focuses on quality of life by providing psychological, social and spiritual support, and symptom management. A palliative approach to care also includes support for family and carers during the person’s illness and into bereavement (National Council for Palliative Care (NCPC) 2015). Palliative care has sometimes been associated with only the final few weeks or days of a person’s life. However, the earlier a palliative care approach can be adopted for people with incurable illness and their carers, the greater the benefits (Murray et al 2017, Preisler et al 2018).

Palliative care was traditionally considered in relation to people with cancer, but it is now widely recognised that its principles should be applied to everyone at the end of life. Exploring cause of death provides an indication of the illnesses people have at this time in their lives. The leading cause of death by diagnosis in England and Wales is dementia and Alzheimer’s disease, which account for 12% of all registered deaths, followed by ischaemic heart disease, cerebrovascular disease, chronic lower respiratory diseases and lung cancer (Office for National Statistics 2017). However, when all cancers are grouped together, they account for 28.5% of all registered deaths. While more people will die from cancer, long-term conditions and dementia and Alzheimer’s disease are a significant factor at the end of life for many people. All carers of people at the end of life will have support needs, but different diagnoses will give rise to different carer experiences and supportive care needs (Aoun et al 2013).

Carers in end of life care

NHS England (2014) has estimated that around half a million carers are involved in end of life care, a figure that correlates with the number of people who die every year in England. However, it is likely that the true number of carers is higher. The estimate is based on each person at the end of life having one carer. In reality, many family members and friends may be providing care, and those who are not the next of kin may not be immediately obvious to the health and social care teams involved in the person’s care (Burns et al 2013).

Identification of carers is an important, but challenging, aspect of providing support. People who undertake the carer role may be the spouse, partner, family member or friend of the dying person. However, the term carer is not one with which everyone in this role will self-identify, since the care they provide is often viewed as a normal and intrinsic part of family life (Corden and Hirst 2011, Carduff et al 2014), a continuation of the commitment made in their relationship (Jo et al 2007), or a role borne out of a sense of duty and responsibility (Petreault et al 2004). Those caring for a person with a long-term condition may have experienced the slow expansion of their caring role over several years, with caring activities now forming part of the normal pattern of life. Carers of older people who live alone, such as neighbours, friends and visiting family, may be particularly challenging to identify (Pleschberger and Wosko 2017), especially if they are not present during healthcare consultations. Thus, the term carer be the spouse, partner, family member or friend of the dying person. However, the term carer carers when they are living with life-threatening illnesses (World Health Organization 2018). Palliative care involves a holistic approach that focuses on quality of life by providing psychological, social and spiritual support, and symptom management. A palliative approach to care also includes support for family and carers during the person’s illness and into bereavement (National Council for Palliative Care (NCPC) 2015). Palliative care has sometimes been associated with only the final few weeks or days of a person’s life. However, the earlier a palliative care approach can be adopted for people with incurable illness and their carers, the greater the benefits (Murray et al 2017, Preisler et al 2018). Palliative care was traditionally considered in relation to people with cancer, but it is now widely recognised that its principles should be applied to everyone at the end of life. Exploring cause of death provides an indication of the illnesses people have at this time in their lives. The leading cause of death by diagnosis in England and Wales is dementia and Alzheimer’s disease, which account for 12% of all registered deaths, followed by ischaemic heart disease, cerebrovascular disease, chronic lower respiratory diseases and lung cancer (Office for National Statistics 2017). However, when all cancers are grouped together, they account for 28.5% of all registered deaths. While more people will die from cancer, long-term conditions and dementia and Alzheimer’s disease are a significant factor at the end of life for many people. All carers of people at the end of life will have support needs, but different diagnoses will give rise to different carer experiences and supportive care needs (Aoun et al 2013).
through public or private sector organisations. Health and social care professionals working in any of these settings with people at the end of life should consider the experience of carers and their role in supporting these individuals.

TIME OUT 1
Reflect on your experience of caring for someone: this may be in your capacity as a nurse, parent, family member or friend. What were the circumstances of this care? What were the positive and/or negative aspects of this experience that may assist you in understanding the role of other carers?

Experience of being a carer
Being a carer for someone at the end of life is often a new experience. People rarely choose to become a carer and this position is often borne out of circumstance, rather than preference, specific skills or previous experience. However, carers bring a range of transferable skills to the role. For example, they may be skilled in managing their own lives, in coordinating families and managing household budgets (Kellehear 2007). Recognising the presence and transferability of these skills can enhance their confidence as carers.

Being a carer affects all domains of a person’s life. The experience will be individual, affected by the circumstances of the person’s caring role and their previous experience, expectations, knowledge and resilience. Providing care at the end of life is associated with several demands and challenges that may result in compromised social, financial, emotional and physical well-being (Williams et al 2016). Carers have to balance their existing circumstances of the person’s caring role and their previous experience. However, they may be skilled in managing their own lives, in coordinating families and managing household budgets (Kellehear 2007). Recognising the presence and transferability of these skills can enhance their confidence as carers.

In addition to the challenges, there may also be positive aspects to being a carer. These include the development and deepening of the relationship with the person they are caring for, the discovery of emotional strength and resilience (Wong et al 2009), and the ability to provide care that enables the person to stay and potentially die at home (Morris et al 2015).

Carers often report feeling unprepared for the role (Wilkinson 2010). They may receive little support from formal health and social care providers, instead accessing most of their support from family and friends (Williams et al 2016). Lack of practical and emotional support and inadequate information sharing contribute to the challenge of being a carer (Morris et al 2015).

In conclusion, being a carer for someone at the end of life is often a new experience. People rarely choose to become a carer and this position is often borne out of circumstance, rather than preference, specific skills or previous experience. However, carers bring a range of transferable skills to the role. For example, they may be skilled in managing their own lives, in coordinating families and managing household budgets (Kellehear 2007). Recognising the presence and transferability of these skills can enhance their confidence as carers.

Key points

- NHS England (2014) has estimated that around half a million carers are involved in end of life care, a figure that correlates with the number of people who die every year in England. However, it is likely that the true number of carers is higher.

- Research has suggested that 85% of people would like to be cared for at home in their final year of life and 63% of people want to die at home (Wood and Salter 2013).

- Supporting carers is a central tenet of palliative care (National Palliative and End of Life Care Partnership 2015), and assists in meeting national agendas, such as increasing the number of people who are enabled to live and die in the place of their choosing (Department of Health (DH) 2008, 2016), and making the last stage of people’s lives as comfortable as possible (DH 2017).

- Carers often report they do not feel their expertise and observations are recognised by health and social care professionals, despite the fact the care being planned and discussed will often be delivered by the carers themselves (Social Care Institute for Excellence 2013b).

- Considering carers as healthcare co-workers in end of life care recognises the essential contribution they make to caring for the dying person.

BOX 1. Activities undertaken by carers

- Physical tasks – assisting with or providing personal care, moving and handling
- Medical tasks – administering medicines, emptying catheter bags, arranging supply of equipment, identifying symptoms and side effects
- Financial administration – managing household finances, applying for benefits and managing direct payments from personal budgets to pay for support
- Patient advocacy – attending appointments and acting as a lasting power of attorney
- Decision-making – deciding who to contact in crises and emergencies, in collaboration with the person at the end of life and the healthcare team
- Emotional support – supporting the person at the end of life and other family members and friends
- Coordination of care – arranging appointments, communicating information between services, arranging transport to appointments

(Adapted from Stajduhar and Cohen 2009)
Supporting carers

Carers undertake a wide range of activities, are pivotal in care provision and generally want health and social care professionals to guide them through the end of life process because it is often new and unknown (Newbury 2011). Patients want the needs of their carers to be considered, including how they will be affected by the death (Choice in End of Life Care Programme Board 2015). Despite this, carers may often feel their needs are overlooked (Stajduhar et al 2013, Turner et al 2016).

**Assessment of needs**

In England, carers have a legal right to an assessment of their needs by the local authority under the Care Act 2014, and similar legislation exists for Scotland, Wales and Northern Ireland (Betts and Thompson 2016). This assessment considers the effect of caring on the carer’s well-being and important aspects of their lives, including what they want to achieve on a day-to-day basis (NHS Choices 2015). If carers qualify for assistance and are eligible for services, this may include home adaptations to assist them in their role or direct support for the carer, such as respite (Marie Curie 2017).

In end of life care, it is also appropriate that an assessment is undertaken by health and social care professionals focusing on support needs specifically arising in a palliative care context. Carers’ support needs should be reviewed at significant time points for both the person at the end of life and the carer, such as diagnosis, during treatment and exacerbations, when moving between care settings, and in the last days of life (DH 2008). Assessment tools include the Caregiver Reaction Assessment, Caregiver’s Burden Scale in End of Life Care and the Zarit Burden Interview (Aslakson et al 2017). However, these tools can be problematic in the end of life care context because some have been developed for research purposes, where the intention may be to evaluate the effectiveness of an intervention. Assessment tools are also often lengthy and may therefore be time consuming (Hudson et al 2010). Health and social care professionals should be mindful of the evidence base and the validity of any tools they use.

**TIME OUT 4**

Consider what assessment your clinical area undertakes with carers in end of life care. Are any specific tools used? What is the evidence for the validity of the tools used? Put simply, the evidence that the tool achieves what it sets out to achieve.

Research undertaken in the UK has identified that carer support needs can be classified into two broad domains: support for them to deliver care; and support with their own health and well-being. Tools have been developed to assess needs in these areas (Ewing et al 2013, Knighting et al 2015). The Carer Support Needs Assessment Tool (CSNAT) (Ewing et al 2013) has been developed from the evidence base for health and social care professionals to enable carer assessment and support.

The CSNAT encourages carers to consider their needs in 14 domains (Ewing et al 2015). Seven domains relate to their caring role, such as how well they understand their relative’s illness, how they feel about talking to their relative about their illness, and whether they have the knowledge to provide personal care and manage their relative’s symptoms. The remaining seven domains relate to their own health and well-being, such as dealing with feelings, beliefs and spiritual concerns, having time to themselves, looking after their own physical health and having a break from caring.

Carers are given the tool and time to reflect on their support needs. They indicate whether they require more support in each of the domains by responding ‘no’, ‘a little more’, ‘quite a bit more’ or ‘very much more’. This leads to a conversation between the carer and health and social care professionals about which support needs are a priority for the carer at the time, what might assist the carer in relation to these needs, exploration of existing support the carer could use and any additional support the carer might be able to access (Ewing et al 2015).
The CSNAT enables carers to identify their specific support needs and has been shown to provide a ‘good’ level of validity for use in end of life care (Ewing et al 2015). Nurses have found it useful to incorporate the CSNAT in their practice and report that it legitimises the time spent with carers, which they can sometimes find challenging to justify (Aoun et al 2015a). Carers also report that the assessment process is straightforward and, by participating in assessment, they find their needs are increasingly apparent and their role validated (Aoun et al 2015b). Research has shown that when the CSNAT is used with carers, their psychological and physical health improves and early grief, that immediately following death, is reduced (Grande et al 2017b).

The Carers’ Alert Thermometer (CAT) (Knighting et al 2015) is another tool developed in the UK. Researchers worked with carers and health and social care professionals to identify priorities for carers to address, resulting in the development of the CAT (Knighting et al 2016). The CAT contains ten questions. Five questions relate to the caring situation, such as whether the carer has any concerns about caring, whether they need help with providing physical emotional or spiritual care, and whether they know who to contact in an emergency. The remaining five questions relate to carers’ health and well-being, such as whether a carer feels involved in discussions with health and social professionals and whether they need help to balance their own needs with the demands of caring.

In collaboration between the carer and health and social care professionals, and in response to each of the ten questions, a decision is made about the risk of challenges arising for the carer. This is marked on a traffic light system of low (green), intermediate (amber) or high (red) alert. The total number of intermediate and high alerts is noted on the thermometer, available in the assessment documentation, providing a visual indicator of priority areas to be addressed. This information is used to develop a care plan (Knighting et al 2015).

TIME OUT 5
Research the CSNAT (Ewing et al 2015) and the CAT (Knighting et al 2015), and answer the following questions:

- Would either of these tools be appropriate for use in your workplace?
- What steps would you take to incorporate these tools into your practice, for example this might include developing an implementation plan and speaking with key stakeholders such as your clinical manager, local specialist palliative care teams, patients and carers, and your colleagues?
- What challenges might you encounter when attempting to implement these tools, and how might you overcome these?
- How would you know whether any changes in practice had been successful and how would you measure this?

Support interventions
Supporting carers depends on their individual needs and circumstances and on the relationship that exists between themselves and the person at the end of life (Parker et al 2016). Simple interventions can often have a significant effect, such as providing the right information at the right time (NCPC 2013). Health and social care professionals should avoid assumptions about carers’ level of confidence and competence to undertake care-related activities, and ask themselves the following questions:

- Does the carer understand how to provide personal care?
- Has the carer received appropriate advice about how best to undertake moving and handling activities?
- Does the carer understand how the timing of administration of medicines to manage pain can optimise the comfort of the person at the end of life?

This information will increase carers’ confidence and improve their practical care abilities. Equally, carers may already have care experience, so tailoring information to the individual is important and assists in developing a trusting relationship between the health and social care professionals and the carer.

Carers require information about what to do in situations where they observe changes in the person they are caring for, such as symptoms worsening or what to expect as death approaches. Feelings of preparedness can contribute to lower levels of carer anxiety (Henriksson and Årestedt 2013). Effective provision of information may reduce uncertainty and potentially inappropriate hospital admissions.

While carers identify that support for themselves would be helpful, often their primary concern is achieving the best possible care for the person at the end of life (Funk et al 2009). The delivery of optimal care in other domains, such as symptom management, effective coordination of care, and access to advice and care 24 hours per day, will also have benefits for carers (Choice in End of Life Care Programme Board 2015). Additionally, enabling patients to participate in activities such as hospice day care will provide an opportunity for carer respite.

Specific support interventions, including peer support, counselling and therapeutic activities may often be delivered by third sector organisations, such as hospices or charities that focus on a specific condition. Health and social care professionals should be familiar with their local support networks, so they can direct carers to organisations that might be able to offer them additional support. Several national charities, such as Dying Matters (www.dyingmatters.org) and Marie Curie (www.mariecurie.org.uk) provide information about caring and carer support, some of which is designed for carers and some for health and social care professionals.

TIME OUT 6
Identify any local third sector organisations that offer support for carers, and what services they offer so that you can provide carers with this information.

Support into bereavement
The death of the person who is being cared for does not signal the end of carer support needs.
Immediately after the death, carers may require support and advice about practical matters, for example how to register the death, who they need to contact to arrange a funeral and how to inform family and friends (Carers UK 2014). In addition to experiencing the loss of someone they have been close to, carers also experience the loss of their caring role and, potentially, their contacts with a large number of people working in health and social care. Carers may feel isolated and require support to rebuild social networks (Small et al 2009). Bereaved carers who develop health issues such as anxiety or depression, experience prolonged grief or feel unable to cope should be encouraged to see their GP (NHS Choices 2016).

Many third sector organisations can offer support to people who have been bereaved and AtaLoss.org (www.ataloss.org) has a searchable database of these. It should be noted that grief affects people in various ways and not all bereaved carers will require additional support (Breen et al 2014).

**TIME OUT 7**

Think about a time when you were involved with a carer who had recently experienced a bereavement. Were they invited to discuss their loss? Was there an assessment of their needs? Using the information in this article, consider how you might change your practice in the future.

**Conclusion**

Carers are essential members of the healthcare team and vital in enabling people to live at home at the end of life. They have a complex range of needs that are affected by their relationship with the person they care for, the illness, their own experience and the support they receive. Carers’ support needs are dynamic and will evolve throughout the end of life period and into bereavement. Regular assessment assists in identifying when carers have unmet support needs.

Health and social care professionals are important in supporting carers in end of life care, whether through comprehensive assessment, planning and delivery of care; facilitating carers’ inclusion in health and social care teams; communicating essential information to carers; or directing carers to local or national organisations that offer specific support. Working in partnership with carers will assist them and the people they care for and contribute to the aspiration of enabling a good death for everyone.

**TIME OUT 8**

Consider how meeting the needs of carers of people at the end of life relates to The Code: Professional Standards of Practice and Behaviour for Nurses and Midwives (Nursing and Midwifery Council 2015) or, for non-UK readers, the requirements of your professional body.

**TIME OUT 9**

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account: rcni.com/reflective-account

---

**References**


