Our vision is a world where all care homes are great places to live, die, visit and work.

Supporting good end-of-life

This updated research briefing paper was written by Aisling McBride and based on a review of the literature on quality of life in care homes, undertaken by the National Care Research and Development Forum in 2006[1], which was later updated by a review of reviews (2006-2016), undertaken by the My Home Life team. My Home Life is an international programme of work aimed at promoting the quality of life for those who are living, dying, visiting, or working in care homes for older people.

- Overall, research on supporting good end-of-life seems to reflect many of the findings of the original review (NCHRD, 2007). Post 2007, new evidence suggests:

- There remains insufficient data related to resident outcomes for end of life care (Hall et al.,2014; Parker and Hodgkinson, 2011).

- Family members may have an expectation that highly skilled medical professionals should be more involved in end of life care (Fosse et al., 2014).

- During end of life care, residents reported a desire to remain connected to their previous life roles (Carlson, 2007).

Introduction

High-quality-end-of-life care for people living in care homes is both a necessity and a challenge. The quality of a person's dying is, in many ways, as important as their quality of life. Many older people who are facing the end of their life begin to come to terms with their mortality in care homes (Fisher et al., 2000). This may prompt a process where they become more aware that time is limited and become preoccupied with focusing on the past rather than the future. They may also want this aspect of their life to be good and may have a need to control their end (Fisher et al., 2000).

Standards for those who are dying in care homes are present (see standard 11 of the National Minimum Standards). However, the very nature of multiple, often chronic, health problems, such as many older people experience, makes it difficult to define when someone can actually be said to be dying. This uncertainty can sometimes lead to impersonal, reactive and inadequate care (Sidell and Komaromy, 2003; Kristjanson et al.,2005).

This lack of clarity as to when it is right to start providing care for the dying is perhaps a reflection of societies' reluctance for face mortality more generally. There is consensus that a culture of care should be developed that values older peoples dying just as much as their living. Promoting end-of-life-care in care homes requires an awareness of and openness to such a process (Katz, 2004; Nolan et al., 2003; Froggatt 2001).

Death and dying should not be denied or hidden in a care home. We propose five areas for consideration that address important aspects of care towards the end of life:

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[1]NCHR&D Forum (2007) My Home Life: Quality of *life in care homes – Literature review, London: Help the Aged.*

1: developing a culture of openness;

2: facilitation of the dying process,

3: support for residents in their last days,

4: leadership and support and

5: respecting and remembering.

Developing a culture of openness

As already noted, we find it difficult at times to address the issues that dying and death bring us as care workers or relatives. It may be more useful to move from trying to define a point of dying to making good care that supports people who are dying something that is integral and normal within life of a care home, while also doing everything to enhance the quality of care for those who are not in this position (Seymour and Hanson, 2001; Nolan et al., 2003).

Many of the practical approaches to enhancing someone's sense of self and dignity may offer a way of encouraging more openness about dying (Nolan et al., 2003). Care home culture does not always facilitate discussion with residents on their wishes and needs as they face the end of life (Sidell and Komaromy, 2003). A conversation with each new resident that encourages them to express any thoughts or anxieties they have about their future, including dying, allows them to know that they will be supported by caring staff until the end (Sander and Russell 2001). This may enable them to raise any issues they have in future.

Staff members need to know what they can do to make the process better. This includes being aware of their own attitudes (Moyle et al., 2002; Lloyd and Cameron, 2005); recognising the value of palliative care (Davies and Seymour, 2002); being open in communication (Komaromy, 2003); supporting families who have a dying relative (Davies and Seymour, 2002); ensuring that the dying person is not left alone; supporting other residents at this time (Komaromy, 2003); and supporting fellow staff (Holman and Jackson, 2001; Holman et al., 2004).

Facilitation of the dying process

A good death can be achieved only if staff recognise and take the necessary responsibility in managing the process of dying (Sidell and Komaromy, 2003). There is a range of supporting principles and measures that can be helpful.

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards death as a normal process; integrates the psychological and spiritual aspects of care; offers support to help patients live as actively as possible until death and helps families to cope during the relative's illness and in bereavement. It can be used early in an illness together with other therapies intended to prolong life, including managing distressing clinical complications (National Council for Palliative Care, 2005; NICE 2004).

A number of national initiatives are being used to improve the experience of dying in care homes: the Gold Standard Framework (Thomas, 2003), the integrated pathway for the dying (Ellershaw and Wilkinson 2003), and the preferred place of care initiative (NHS Cancer Plan 2000). Kinley and colleagues (2014) carried out a review specifically to look at the impact of the Gold Standard Framework in relation to end of life care in addition to the Liverpool Care Pathway initiative and other educational training interventions designed to improve end of life care provision in the UK. They concluded that there was some demonstrable evidence of improved outcomes for residents in care homes that have implemented these initiatives, including communication, continuity of dying and reduction in emergency admissions.

Various other resources and training materials have been developed specifically for care homes. The aim is to acknowledge that a person-centred approach, based on the individual needs of all those living in a care home, is pivotal to the delivery of high quality end-of-life (Sander and Russell, 2001).

Quality of life in care homes

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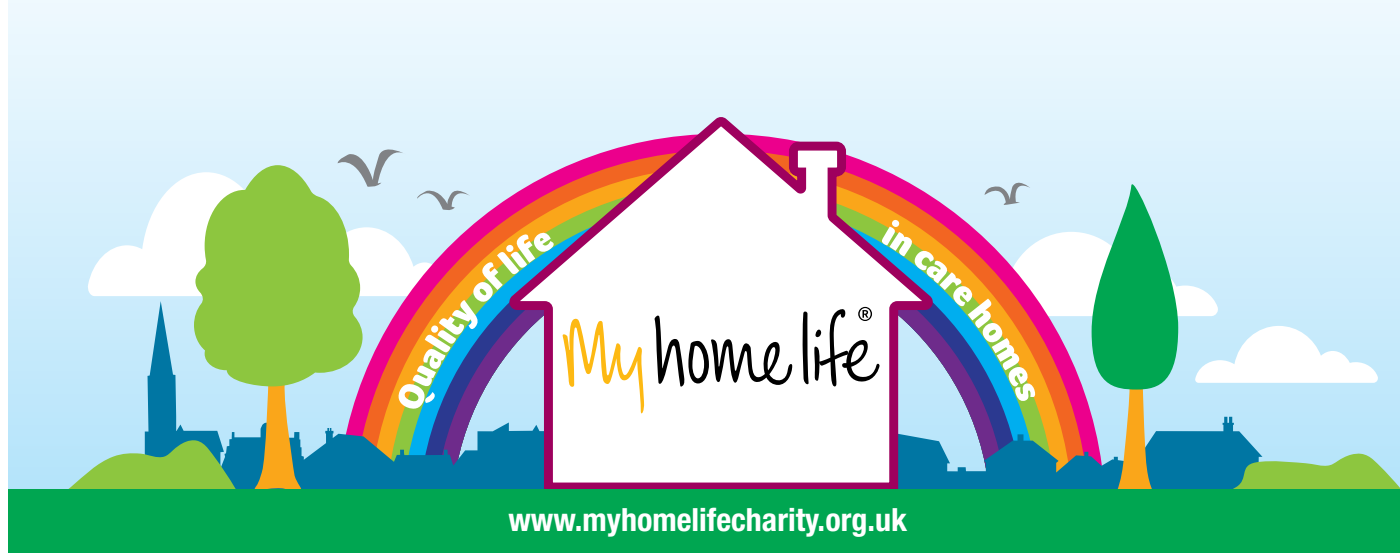
Staff support for residents in their last days

Alongside the delivery of good supportive and palliative care to residents who have such needs it is important that home staff recognise their role in the provision of appropriate care to residents and their family members. This requires staff to:

- Understand and be aware of their own attitude to death and dying, and how that may influence decisions about care;

- Recognise and value the principles of palliative care and a good death;

- Have an ability and willingness to involve outside support and understand what the local support services are (e.g. GP, district nurses, palliative care and hospice services) and how to access them (Katz and Peace, 2003);

- Make sure that communication is open and sensitive; accepting that death is coming, yet recognising that some residents and family may not want to talk openly about what is happening: family members may be reluctant to face the imminent death of their relative and can create problems for staff and resident alike;

- Make sure that those relatives who may wish to be with a dying family member in the last few days are given the support they need: this means not only emotional support from staff but practical arrangements, such as providing refreshments or a comfortable chair;

- Recognise the importance of not leaving the dying person alone and ensuring that, for example, enough staff are on shift at such a time for someone to sit with the person, or using volunteers for this purpose, either with or in place of a family member (Gross, 2000);

- Support other residents when someone is dying: it is valuable to recognise formally that someone has died and offer bereavement support to residents and family members (Katz, 2004; Komaromy, 2003);

- Offer family and friends the opportunity to gather at the home after the funeral, which makes it easier for residents to join them for the occasion if they wish to do so.

Hall and colleagues (2014) conducted a comprehensive review of interventions for improving palliative care for older people living in care homes. They concluded that while there was some limited evidence that the palliative care interventions examined in these studies have increased relatives perceptions of quality of care provided to their family members there is insufficient data related to resident outcomes.

The dying process is a significant one for all of us and the quality of the care afforded at this time needs to be as high as for that afforded to the living. Dying is a part of life and the care given at different times of life may be different but it is part of a continuum.

Support and leadership for staff

The experience and effect of accumulated losses for older people and staff in care homes receives little attention, yet it is significant. Often there is a difficult tension between the professional and personal in care homes (Holman and Jackson 2001). Staff members often feel like 'family' to the resident, so when that person dies, it is important to recognise the need of the staff to be supported (Touhy et al., 2005; Moss et al., 2003 Katz et al., 2001).

Working with loss requires a systematic approach within the care home. Clinical supervision and support of the managerial leadership are important in shaping care home culture and sustaining open awareness to dying (Holman et al., 2004). External support structures, such as access and availability of a GP, community nursing and palliative care teams are also needed (The National Council for Palliative Care, 2005). Fosse et al., (2014) looked at the received role of medical professionals in providing end of life care. They found that there was a view that highly skilled medical staff should be more involved in end of life care to provide symptom relief and
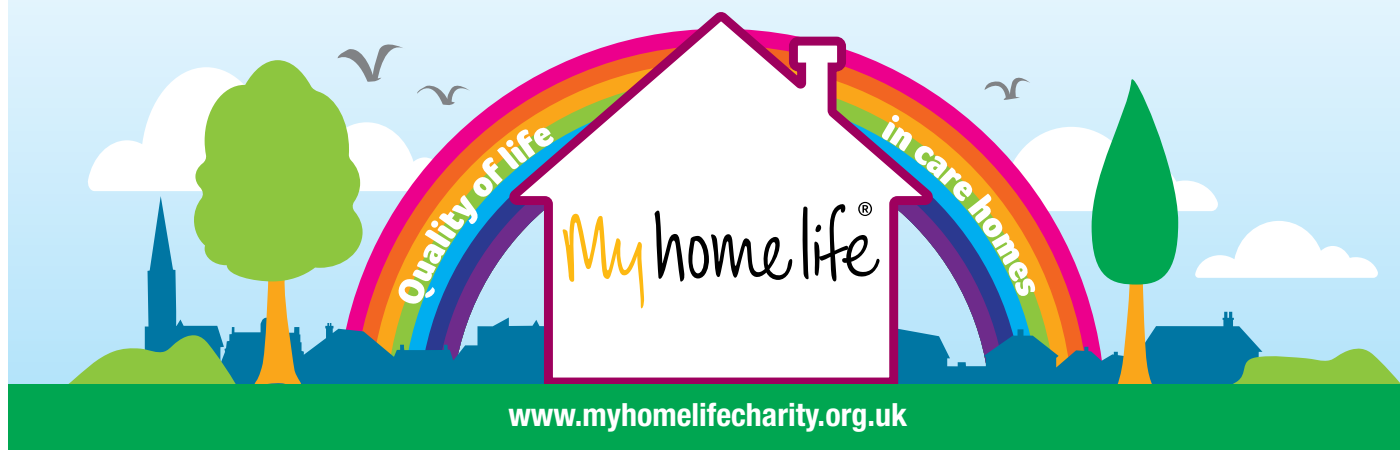
also be aware of the patients' preferences. However, even in the most well-resourced care home setting, medical professionals may not be readily available. Additionally, doctors who were involved in end of life care often felt ill equipped to handle sensitive end of life questions from relatives.

Carlson (2007) made an important contribution to the body of knowledge with a literature review titled 'death in the nursing home'. The review found that residents had a desire to retain a connection to their previous life role especially contributing to the care of their family members. Some residents suggested they did not wish to prolong the dying process through 'futile treatments'. For care home staff, their appreciation of the essential concepts of end of life care were often extremely limited yet they provided the majority of care. For family, Carlson found that whilst relatives overwhelmingly felt that care home staff were trying their upmost to meet the end of life care needs of their loved ones, there was still a widespread perception that the care services offered needed improvement.

Respecting and remembering

The respect paid to dying individuals, their bereaved family and friends and support staff is one indication of the extent to which a particular care home is open to the presence of dying in the midst (Komaromy ,2003; Page and Komaromy ,2005; Berndt, 2004). The use of rituals of remembrance is one way to facilitate culture of openness about dying and support for residents, relatives, and staff.

Respecting the body of a resident who has died and maintaining their dignity can be achieved through ways of remembering:

- Placing a favourite article of the deceased over the trolley and allowing the body to be removed through the front door of the home (Berndt ,2004);

- Ensuring that the news of the resident's death is communicated sensitively to staff and residents. Some homes pin a photograph on the notice boards, place a flower vase or have a candle with a photograph nearby (Parker and McLeod,2002; Katz and Peace, 2003);

- Providing opportunities for the home to stop for a moment of 'quiet' in order to respect the significance of the residents life and death: for example, bedside prayer (Berndt, 2004);

- Facilitating sharing memories of the deceased, for example, a book of remembrance;

- Allowing residents and staff personal acts of commemoration, such as attending a funeral or planting a flower in the care home garden.

Such commemoration facilitates mourning and powerfully voices the idea to remaining residents that they will be remembered when they die.

Annual services of remembrance for those who have died in the past year can be held and relatives invited. Homes could be made available to host receptions after funerals, which would allow other residents to attend.

A teaching resource is available through Macmillan's professional resources quality assurance framework, including a rigorous peer review process. It enables care homes to address standard 11 of the national minimum standards for care homes for older people.

Further information on resources is available within the My Home Life shared space.

The review of the literature reviews (2007-2017) found that research on end of life care in care homes has not progressed significantly since the previous review (NCHRD, 2007). Almost every review in the review of the literature determined the research uncovered to be of low quality and has as its main recommendations that future research is needed.
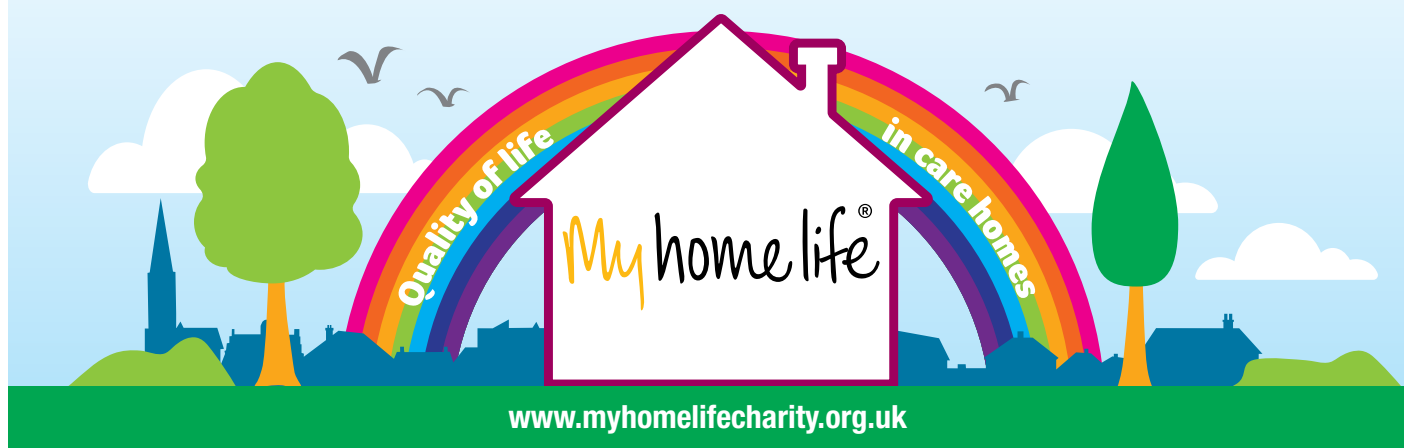
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