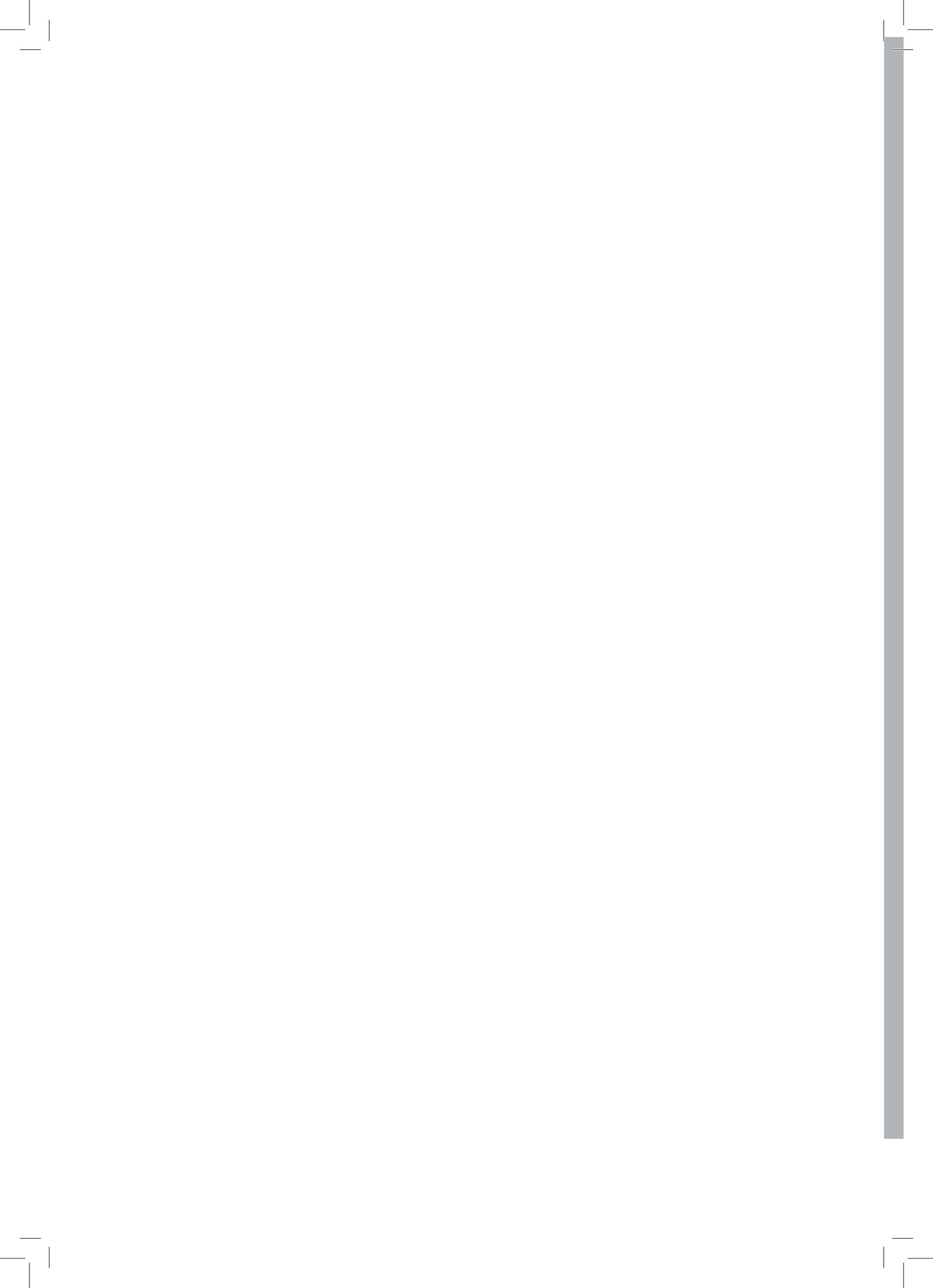


# Places to Flourish

*A pattern-based approach to foster change in residential care*

Dying, Death And After Death Care



# Dying, Death and After Death Care

## Introduction

*“Dying, death and bereavement can be the most troubling aspects of our human existence. They can also be sources of wisdom, fortitude and, indeed, peace. For those who care for and support us as we leave this life, and for those who live on, the end of life is something deeply profound but it is also something with very practical consequences”*

Mary McAleese, President of Ireland

These words by The President of Ireland reflect the complexity of feelings, emotions and issues raised through death and dying. In a residential care setting, dying and death should reflect the values of 'dying at home' with friends and family rather than how it can be experienced in a more clinical/hospital setting. For many residents who die in a residential setting, the home they leave may have been a significant part of their life and they leave behind friends who they have lived with or received care from over many years. In this section we explore patterns associated with dying, death and after death care. The way that care is given and received during the dying period itself, at the time of death and after death influences the way in which life is reflected upon by those left behind, as such, it is a critical part of a quality care experience.

*“ I am so grateful for the time that Padraig had at Lough View. I can't say that we are the easiest of families to be with and Padraig didn't deserve to have these troubles continue in his dying days. The care, love, attention and dedication he was shown by Gill, Moll and other people at the home helped us to put these things to one side and focus on him – I will be forever grateful for that ”*

## Dying, Death and After Death Care: A Typical Example

Padraig had lived in Lough View Nursing Home for 4 years. He is a member of a large extended farming family, with 7 brothers, 2 sisters, 16 grandchildren and 4 great-grandchildren. Padraig has been single all his life and lived and worked on the family farm until he moved into Lough View. The year before moving into the nursing home Padraig had a stroke and was found slumped in his chair by a neighbour. Padraig made a good recovery and spent 4 months in a rehabilitation unit prior to moving to Lough View. However, despite intensive rehabilitation, he continued to have a right-sided weakness, poor/unsteady mobility, incontinence of urine and slurred speech. Padraig was very determined and independent, and as he said “I've survived much worse than this!” Padraig liked the company of other men and so his family specifically chose Lough View because it had a number of other male residents from the same local area that they thought Padraig could relate with. He enjoyed a daily Guinness (bottled) and listening to the radio (he never watched TV). When he lived at home his social life revolved around the local cattle market (every fortnight) and a trip to his local pub every Thursday and Friday night where he played poker. Padraig didn't have a very strong connection with his brothers and sisters (except for 2 of his sisters) as there had been trouble when their father died over the family 'Will' and Padraig was left the farm. This caused a significant family feud that had never been resolved properly.

Padraig made the transition to Lough View very well. He said “I'm glad to be here as don't think I could have gone back to that farm and survived”. However he also missed the

farm hugely (which was now being managed by his brother and grandsons) and hated the idea of giving it up. The home had agreed that his sisters could bring his dogs (2 Border Collies) into visit whenever they wanted and he was delighted about that. Lough View also operated from a 'Teaghlach model' which meant that they took considerable care to ensure that Padraig had a plan of care that reflected his usual life pattern. Part of his assessment included a life review and the development of a care plan that reflected his usual patterns. This meant that Padraig was able to get his breakfast when he woke at 4am, listen to the radio for a few hours before getting up. During the spring and summer months he would tend to the vegetable garden and in the winter he swept the paths (with assistance). Each night he had a bottle of Guinness after his tea and he would sit in the kitchen chatting with John-Joe and Eamonn (2 residents who came from the same Parish as him). On a Friday night the home had an arrangement with the owner of the local pub who sent a taxi to take the men there where they drank Guinness and played poker. Padraig had a good relationship with the care staff who worked with him. He particularly liked his 'primary care workers' (Gill the registered nurse and Moll the Care Attendant), one of whom worked with him every day at least. He needed a lot of supervision with his personal care needs and Gill ensured that he remained active through maximising opportunities for Padraig to be active. Gill had also managed to get his incontinence under better control – she did this by detailed assessment over a week, the planning of a fluid intake and toileting plan and the use of more appropriate pads at night. Padraig was particularly pleased with this as it enabled him to be more independent, go to the pub and sleep through the night.

Padraig lived like this for over 3 years until one morning he was found unconscious in his bedroom. The GP was called and suggested Padraig be transferred to the local hospital as he had an extension of his stroke. Gill and the care home manager advocated on Padraig's behalf as he had made an expressed wish (written in his care records) that he didn't want to be transferred to hospital if anything happened to him but to have whatever care he could have in the Lough View Nursing Home. His sisters were contacted (his formal next of kin) and they supported this decision.

Padraig was cared for by Gill, Moll and his sisters for 3 days during which time he didn't regain consciousness. This involved attending to Padraig's personal care needs, his need for comfort (including fluids and pain relief), spiritual needs and continued connection with his family through touch, chat, laughter and gentle massage. His dogs were brought to the home where they lay beside his bed for most of the day. At 5.30pm on the 3<sup>rd</sup> day, Padraig died peacefully.

Gill and Moll worked to create a space that enabled Padraig's family members, friends from his parish and friends from Lough View to spend time with him, pay their respects and reminisce about their lives together. Throughout that time, the household staff provided teas/coffees and the local pub donated light refreshments, beer and Guinness for family and friends. Padraig's funeral was a 'family and friends' event. The week after the funeral, Gill and Moll facilitated a 'remembering Padraig' session with his friends in the home. As a part of that process, a framed photograph of Padraig, with a message from each of his friends in the home was hung on the wall of the kitchen – a ritual the home had developed over time.

# But Think . . .

**The Challenges:** Padraig has complicated family connections, so it is not just a case of providing his care but also remembering the family dynamics and how they play out. Padraig's GP was supportive of his expressed wishes for no active treatment, but this may not be the case for other residents with different GPs. This can pose complex ethical dilemmas for families and for staff working with the resident. In addition, families may not want to go along with the resident's expressed wishes in the way that Padraig's sisters did, thus causing further potential conflict and ethical challenges. Gill and Moll were able to manage their shifts as they worked in a 'self-managed team' where they had the autonomy to adjust their hours according to Padraig's needs. However they also had other residents to think about, so they had to negotiate these changes with other colleagues too. Some staff may struggle with these values of flexibility and adaptability that Gill and Moll demonstrated and may feel it is 'unhealthy' to get so involved and they may be less-willing to cooperate with the changes required. The care home may not have been as connected with the local community as Lough View and so it may have been more challenging to organise for the community to be as involved in his after-death care as they were.

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## Reflective Activity

Think about what 'dying and death' mean to you – you may want to do this by doodling images, drawing, writing a short poem or a creative story/account, as one of these processes may be easier than trying to find the 'right words'. What kinds of feelings and emotions do your images/words reflect? Consider how these feelings and emotions relate to how you provide care at times of dying, death and after-death. Make 2 lists- 1) 'What would I want when I am dying?' 2) 'What would I not want when I am dying?' \* Consider your lists in the context of how care is currently provided in your care setting.

## Dying, Death and After Death Care: Patterns of Activity

There is little doubt that the topics of dying and death are some of the most difficult to address. Care workers generally find the topics of death and dying difficult to communicate with others about and difficult to find the best approach to decision making. It is further complicated in residential care facilities for older people where the process of dying can be prolonged over a long period of time and can be confused with or complicated by the multiple pathologies associated with ageing.

Unlike a more acute care setting, it is usually the case that death is rarely 'sudden' but instead the period of decline can take place over many months or even years and so there is not a defined point when a resident becomes 'palliative'. Palliative care refers to care that is no longer curative in intent, but instead is focused on the relief of symptoms associated with disease processes that are no longer curable, and where the primary intent is one of comfort and maintaining quality of life. However, when we consider many residents in care homes, it can be the case that these symptoms are associated with a prolonged period of decline, are part of the person's usual way of life and so the point when a resident is considered to be 'dying' is difficult to identify. For some commentators, this issue complicates the division between palliative care and care of older people in a residential setting (Froggatt & Payne 2006) and so in some countries the term a 'palliative approach' has been adopted (Department of Health & Ageing Australia 2006).

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*“When the resident's condition is not amenable to cure and the symptoms of the disease require effective symptom management, a palliative approach is appropriate. Providing active treatment for the resident's disease may also still be important and may be provided concurrently with a palliative approach. However, the primary goal of a palliative approach is to improve the resident's level of comfort and function, and to address their psychological, spiritual and social needs”*

Department of Health & Ageing Australia 2006, p37

“  
*Walk with me on my journey  
I need to know you're there  
To listen, guide and comfort me  
My wounded self-repair  
Walk with me on my journey  
Be it to health or death  
Work with me at my  
chosen pace  
Show me that caring is love  
and grace  
Walk with me on my journey  
A difference you can make  
A smile, your presence,  
a gentle touch  
Can mean so very much  
Walk with me on my journey  
A companion for me be  
Be a therapeutic carer  
Make this bearable for me  
Walk with me*”

Disley & McCormack, 2002

So this approach to care focuses on alleviating symptoms of disease whilst at the same time providing active treatment in managing the disease. In many ways this is the essence of excellent care for older people in residential care generally and so is something that needs to be considered in the way that care is organised and managed. The use of the phrase 'palliative approach' does not suggest that care is not active, that residents do not lead full and meaningful lives, or that residents and staff do not flourish as people through meaningful relationships. The opposite is true in fact, as the approach suggests that living and dying are normal parts of life and every opportunity is availed of to ensure that the older person lives their life with dignity, respect and fulfilment.

Residential care settings can provide an ethos that values life whilst at the same time recognising that dying and death are aspects of the life of the home. It has been suggested that in Western cultures, death is managed by the careful management of the boundary between life and death. In hospital wards for example this boundary is maintained by (for example) the drawing of curtains/closing of doors so that patients don't observe the removal of the deceased person from the ward. Unfortunately the same practices have existed in residential care facilities. However, in a household oriented approach then the opportunities to erode the boundary between life and death are important to accommodate. Residents develop friendships, relationships and belong to a community of others that connect them as persons. They live with and through each other's lives and so are as much a part of the other person's death as they are their life. So developing ways of working that honour death and celebrate life are critical to effective care practices. Just like in any family, the residential care setting can foster the same dimensions and characteristics and these can influence the responses to death from other residents and staff.

Residents in residential care facilities have the same needs for palliation and symptom management as those in other settings. However the evidence highlights that older people in residential facilities experience much poorer levels of pain management than in other settings (Hanlon et al 2010). Pain is particularly problematic for older people as they age and for carers who work with older people, knowing when to intervene can be challenging. This is further complicated by confusion and dementia where the verbal expression of pain may be difficult or impossible. Care teams need to be highly sensitive to behavioural and emotional responses that may be associated with pain, to assess these appropriately and ensure that effective management plans are in place. We have highlighted pain as a particular focus of symptom management, however attention also needs to be paid to a variety of needs that a person who is dying has. Goff (1999) suggests a hierarchy of needs (Figure 1)

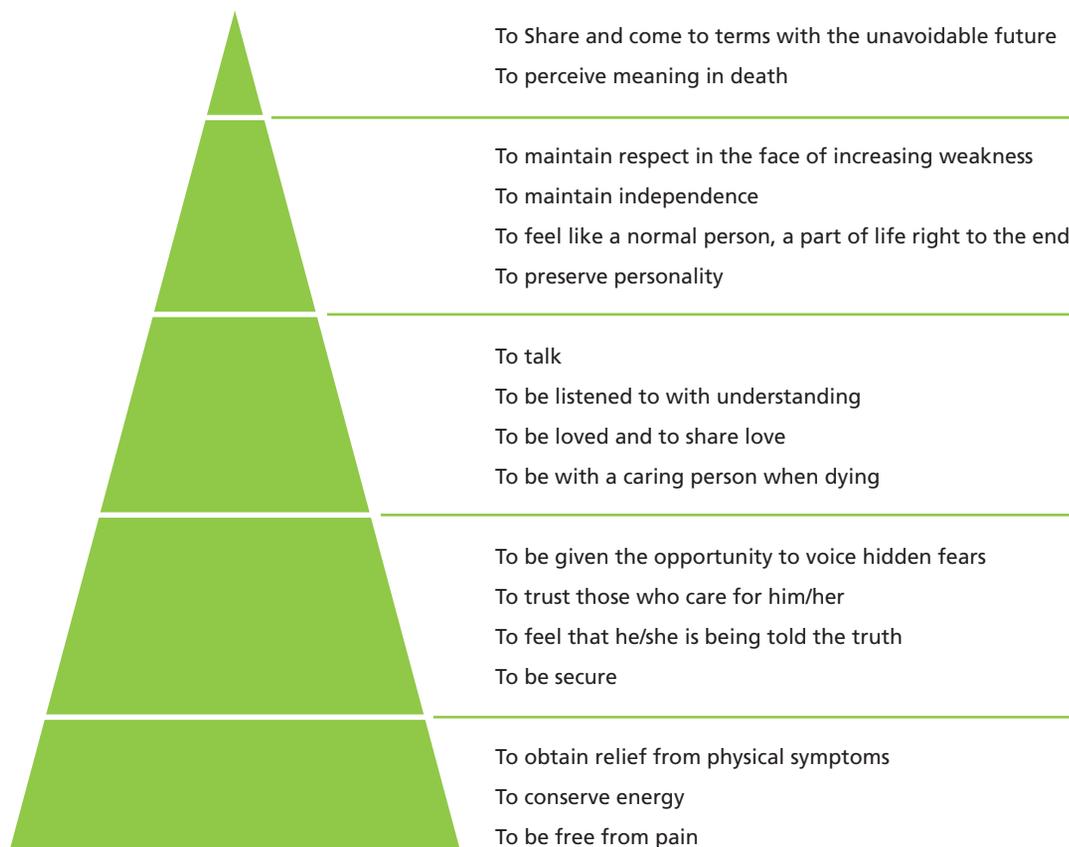


Fig 1 Hierarchy of the Dying Person's Needs (Goff 1999)

Like all 'hierarchies' there is a danger of seeing this framework as a prescription – it is certainly not that. Your starting point in the framework should be that of 'what matters most to the person' and so you need to ensure that you know or try to find out what it is that the person 'wants'. The hierarchy as described by Goff (1999) identifies the importance of paying attention to physical needs and symptom management as the foundation for enabling a fulfilled and meaningful life towards death. The hierarchy of issues is not as important as the issues themselves, and together they provide a useful framework for considering the holistic needs of a person who is dying in a residential care setting.

So in the context of dying, death and after death, when thinking about how to deliver high quality person-centred evidence informed care we should think about the following issues:

### Privacy and Dignity

For most people, dying and death are highly personal experiences. Therefore in a residential care setting, ensuring that the dying person and their families have the kind of privacy they want is a key consideration. How do you afford privacy for residents and their families during the dying period? Many residents will want their family and friends around them whilst others want to be alone 'with themselves'. Do you know what residents in your setting want and need? Have the resident's wishes been included in the assessment or included as part of their life review? Have family members participated in the process. Some family members may 'struggle' with the wishes of their family member and this can lead to conflict, or family members may have different needs to those of the resident. It is therefore important to consider these as separate yet connected needs. For people with dementia, expressing their needs may not be possible. Additionally, family members may not know or may not want to think about these needs. Being sensitive in these situations is important, but it is also important not to avoid such conversations. How does the care setting in which you work have these conversations with residents and their families? No matter how 'hard' these conversations are, it is important to have them before the person loses capacity and the ability to express preferences.

'Death with dignity' is a well-trodden phrase and one that is central to excellence in care for a person who is dying, at the time of death and after-death. Dignity means many different things to different people. Being treated with dignity is a human right. Whilst as a concept, dignity is hard to define, we all know it intuitively and we tend to define it according to its presence or absence in our experiences. What values does your care setting hold about 'dying with dignity'? Goff's (1999) hierarchy of care needs provides a useful framework for considering the different needs of a person and together they can help to consider the different dimensions of a dignified death. How can you use these dimensions to help consider issues of dignity? A holistic approach to dying, death and after-death care incorporates all aspects of the person's well-being, the well-being of their family and friends, and of care workers

## Autonomy and Independence

Being person-centred requires us to ensure that a person's autonomy is respected, that they can exercise freedom of choice and that we are flexible in our ways of working. Person-centred care extends to care in death and after-death and the same values of respecting the person apply here also.

## Freedom and Choice

Many people hold strong views about dying and death. These views may be influenced by a variety of values and beliefs that are shaped by social, societal, religious and spiritual perspectives. The idea of preserving autonomy at the time of death and in after-death care is a challenging issue and requires a deep understanding of autonomy as a concept. McCormack (2001) argued that in decision-making with older people an understanding of autonomy as 'independence' is unhelpful, but instead we need to think about 'connected autonomy'

## Person-Centred

The argument being that in working with older people, a connected relationship between care workers and the older person is the essence of an effective relationship and thus decision-making is also connected. Therefore the decisions made by the older person or me will impact on the other and indeed are integrated with the other with the intent of nurturing, growth and development. So the choices the person makes about their death will impact on the care worker too and can cause conflict if there is a clash of values and or views. Do you know what views you hold about dying and death? Do you know how you would feel and react if a person expressed views and wishes that are contrary to yours? For example you may hold strong religious beliefs about 'cremation' – how would you feel about a resident requesting cremation? How would you work with these feelings?

## Flexibility and Adaptability

Sometimes an older person might be 'resigned to death' in a way that a younger person might not be. For some people their view of life may be influenced by the view that life is a passage of time and that death comes with and is a natural part of ageing. For others, their experiences of illness, their connection with God and the coping resources they use can shape the way they view death and the way they deal with it. However we should never assume that all older people feel a particular way about their death and we need to be flexible and adaptable in the way we provide choices, options and services. A residential care setting that is truly person-centred will have no difficulty in accommodating the various perspectives, views and needs held by residents and care workers.

The poem below reflects on woman's perspective:

*Come to me death with all your mystery  
Hold me in your arms of contentment  
Take me forward like champagne bubbling  
Flowing over my lips to your light filled space  
Bring forward my friends to surround me with love  
Stay with me as life transcends*

To ensure that death is managed as the 'final transition' then having care plans in place that respond to often dynamic and unpredictable changes and circumstances is important. How do you adjust care plans to take account of these changing circumstances? How do you involve family and friends where ever appropriate? Paying attention to the care of family/friends, team members and other residents after a death is an important consideration in breaking down the boundaries between 'life and death'. Helping families/friends to celebrate the person's life, mourn the loss and to say 'goodbye' to the setting that had become the person's home are important areas of practice. Constructing oral histories with those who are grieving can help with celebrating life, reminiscing on important events and thus providing import memories and foci of conversation, as well as providing closure on a life. Families and friends can be encouraged to remain part of the community of the care setting, as volunteers, visitors to other residents and in participating in social events. Does your care setting engage in such activities? If not, then how could you integrate these into practice? The care team are also members of the person's extended 'family' and need to time to grieve – these same practices can help, as well as using supported discussion groups to talk about the person in the context of being a resident in the care facility.

### Quality of Place and the Physical Environment

The quality of the environment plays an important part in the quality of the dying experience. It is not surprising that the quality of the place of death plays a significant role in how people view the quality of care at the time of death. Facilities that ensure privacy, comfort and safety are highly valued by family and friends of a dying person as it enables the challenges and contradictions of death to be lived through with privacy and dignity. Recent development work by Yalden (Yalden & McCormack 2010) focused on creating a sense of 'community' for family and friends of people who were dying in a residential facility. Care workers developed resources that 'normalised' the dying process and ensured that facilities were available to ensure comfort, dignity and care. For example, a chest of drawers with personal care resources, spiritual needs resources and resources for family and friends (such as books and play equipment for children) were developed. The 'chest of drawers' became symbolic of a dignified death and a commitment to person-centred care. How does your care setting facilitate a dignified death and promote comfort, dignity and care? What resources do you have in place?

## Suggested Areas for Place and Practice Improvement

In considering the patterns in the previous section, you may have identified some aspects of practice that could be changed or developed or changes to the environment that may enhance the care experience or indeed team developments that could improve the overall quality of care. So you may want to consider these as some potential areas to address in order to enhance the experience of dying, death and after-death care for residents, families/friends and the care team. These ideas are in no way exhaustive, but they may provide you with some options for consideration:

- Consider the reflection you undertook earlier about what dying and death mean to you and share this with your immediate colleagues. Use the reflection to initiate discussion about their views and how these are similar or contrast with yours. Are you able to develop some shared values about dying and death?
- Use the work you did in the previous exercise to begin the process of developing shared values. Involve others in the team/care setting generally by using the process set out in Values and Beliefs Template to develop a values statement. When you have these values developed, consider what adjustments you may need to make to your ways of working in order to operationalise these.
- Review the care plans of residents you work with and observe how/if views and choices about dying and death are recorded. Discuss your findings with team members and identify simple changes that could be made to improve resident's records regarding this aspect of care.
- Identify from life review documents residents' views about dying and death and adjust individual care plans to reflect these views.
- Discuss with colleagues (such as 'activities helper') how you could collect oral histories from residents as a means of celebrating the person's life and gaining insights into what they want when they are dying.
- Consider the environment you work in and identify adjustments that could be made to the environment that could enhance dying and death experiences.

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