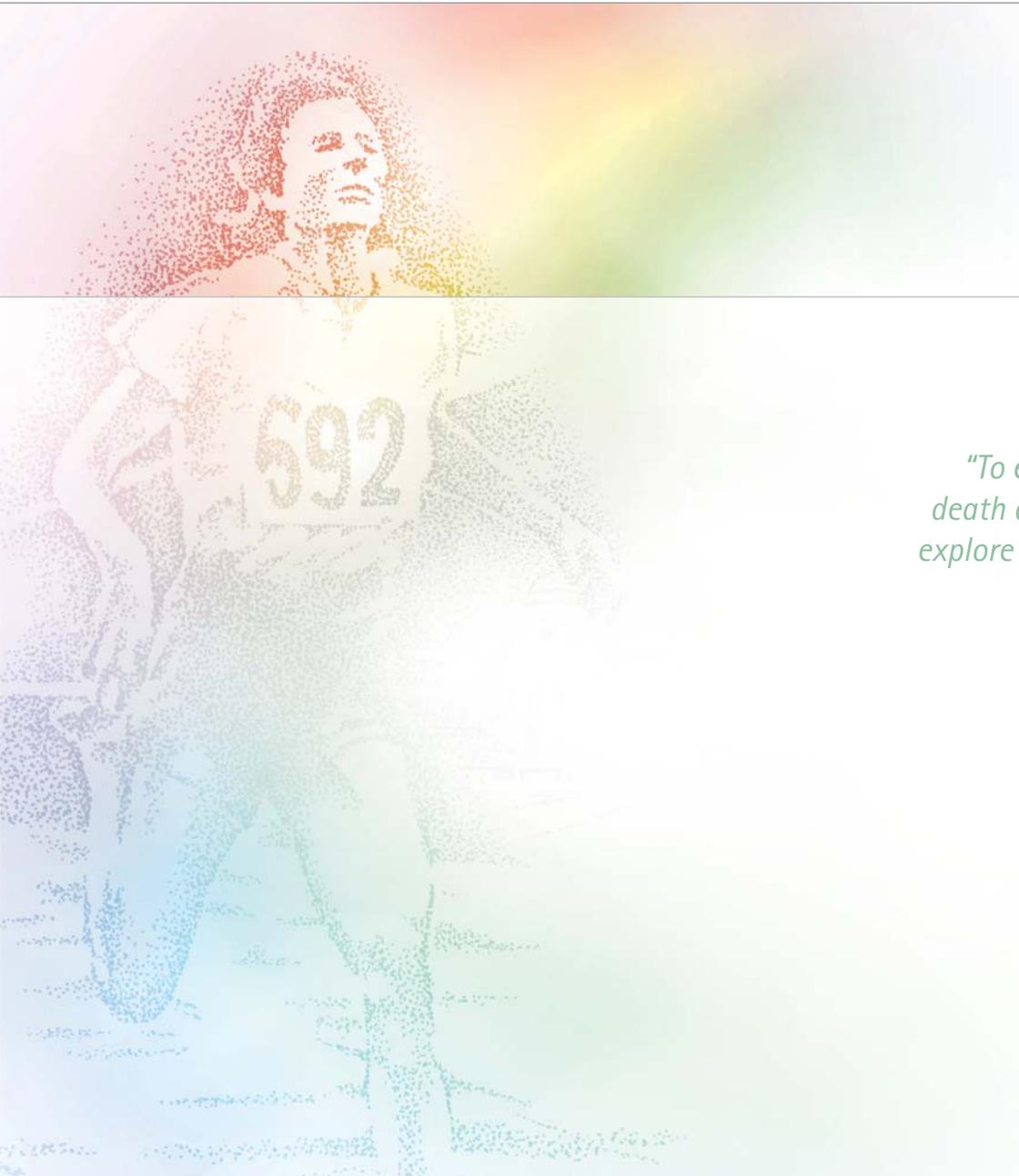


The Final Lap

Supporting End of Life Care



The Final Lap has one overarching aim:

"To ensure that MHA Homes are places where dying and death are faced openly and positively, with support, and to explore what this might mean for Care Homes, for residents and their families, and for staff and volunteers."



Foreword

Traditionally the Olympic Games Marathon begins in the stadium, with a lap or two of the track, before the athletes head out into the streets for a couple of hours of hard running. Only then does the stadium crowd witness their return and, after a final lap of the track, greet the medallists and the rest of the field straggling in behind.

It is that image of the athlete entering the stadium for the final lap that lies behind this material. An older person becoming a resident in a Care Home does so at a later stage of life than ever before and most are well aware that the Care Home will be their last home on earth. However, if facing the end of life is a reality for older people, they do so in a society that, for too long, has demonstrated an astonishing ability to deny that reality; and a sad inability to talk openly about the issues surrounding death.

As a Christian-based care provider, MHA is in an excellent position to address this situation in a positive and creative way. We have always focused on the importance of addressing the spiritual needs of residents alongside the other aspects of care and nowhere should this be clearer than in accompanying them on their final lap. But making that journey in as supportive a way as possible will make demands upon all of us – care staff, relatives, other residents and volunteers. It is my hope that The Final Lap will be a resource that will help to equip us, and so fire our imaginations that offering good end of life care is not simply an aspiration, but quickly becomes a reality in all of our Homes.

The Final Lap has been developed in collaboration with Professor Malcolm Johnson, a member of our Charity Board, and I am indebted to him and his team for their work in the pilot project. It has also drawn on work carried out in Care Homes in Australia as well as materials produced by Macmillan Cancer Relief.

The Final Lap has one overarching aim:

"To ensure that MHA Homes are places where dying and death are faced openly and positively, with support, and to explore what this might mean for the Homes, for residents and their families, and for staff and volunteers."

In addition, it recognises that end of life care must begin from the start of our relationship with any resident, and that for each one, their observations of how we deal with another resident's death has the potential to help or hinder their own final lap. If we get it right for Mrs Jones, then Mrs Smith will gain confidence that her own dying and death will be dealt with in an appropriate way.

Each older person is a unique individual, and their attitudes towards dying will be very much their own. Similarly, each MHA Home is a different collection of individuals, and in Homes specialising in dementia and/or nursing care, there will be particular issues that require a different approach. Nevertheless, The Final Lap invites us to explore the issues and ensure that an MHA Home is one characterised by excellent end of life care.

In the following sections the areas that will be covered in the training are outlined. They begin with a resident's admission to a Home; explore ways of raising the subject of the end of life with residents and how to respond when residents raise the subject themselves. Planning for funerals and for what residents hope to do in the rest of their lives leads into a consideration of the needs of those who accompany the resident on their final lap. An exploration of a palliative approach to caring, particularly as death draws near, brings us to the time of death and ways of marking it, and of remembering the one who has died. Each section includes stories and examples from the pilot project that ran in five Homes during 2004-2005, and concludes with a summary of the points covered.

Keith Albans, Director of Chaplaincy & Spirituality



1. Dying Well – Aims and Introduction

Most of us find death a difficult subject. We naturally think about it in a very negative way, seeing it as something terrible, bad or tragic; and so we try to avoid thinking about it at all, in an attempt to protect ourselves from painful feelings. While this is entirely understandable, this attitude hasn't helped older people, their families or the people that care for them. Indeed it has led to a lack of understanding, unnecessary fear and anxiety and often means that end of life care is not directly addressed at all.

Death as part of life

If we are to find better ways of dealing with death, we have to begin by looking at it differently. Instead of viewing death as separate from life, it helps to accept that dying is a natural consequence of living – the end of life is simply a different stage of life alongside all the others.

Of course there are parts of this stage that make it particularly difficult, but they are not made any easier by ignoring them. Working with older people means that we are regularly forced to confront the reality of dying. By facing up to our own difficulties with dying and death we can begin to become better prepared to accompany others on their final lap, and work together to improve the way our residents experience the last stages of their life in our Homes. It isn't easy, but here's how two of the Home Managers from the pilot project put it:

"When we first started many carers felt shock and horror. Now they are getting over it and feel pleased at being able to deal with it and help others to do the same."

"The Home is now more open in general with issues of dying and death – it was generally the staff that needed the help to change, rather than the residents."

Everyone is different

There isn't one 'right' way to care for someone who is dying, because every person's needs are different. Therefore we need to find ways of supporting each resident individually. By respecting their views and honouring their wishes, we will be able to help them reach the end of their lives in as peaceful and as positive way as is possible.

Providing good end of life care to one resident will also benefit others. Seeing someone receive the loving support they need will reassure other residents, and help them feel that when the time comes their death will be dealt with in a similar way and their wishes respected. This in turn will help overcome some of the fears and anxieties they have about dying.

Look after yourself

It isn't just the residents who need support – staff do as well. Caring for a resident during the final days of their life can be very demanding, but with the right support it can also be very rewarding. The Final Lap will help us to explore what sort of support each of us needs if we are to give our residents the best end of life care. Here is what a couple of staff discovered through The Final Lap:

"We now discuss dying and death at induction and staff meetings. Our training programme has helped staff to become more comfortable with end of life issues, so we can help residents to speak about subjects they might find difficult."

"I've got a lot out of this course. I'm not scared any more, but very interested."

Summary

- We want to create a culture of care that faces the reality of death openly, as part of human life, and to deliver support that makes it a more positive experience for everyone.
- Different people have different ideas about what makes a 'good death', so end of life care should be based around the individual resident and their wishes.
- Providing good end of life care to one resident will reassure other residents that their own death will also be handled with the respect and support they need.
- Caring for someone who is dying can be difficult, but it can also be very rewarding. Final Lap training will help individual care teams identify and address their support needs more effectively.



2. Becoming a Resident – Admission and Assessment

Good end of life care begins at day one – from the initial domiciliary assessment visit and from the moment a resident moves in. It might not be a great idea to greet a new resident with questions about how they'd like to die but, once they've settled in, it is important to find out about their views and wishes, so that we can plan the care and support they need. Similarly there will be occasions when, planned or spontaneously, residents make their views and wishes known. Such information needs to be recorded and passed on wherever possible.

If the resident's ability to communicate their wishes is limited we can still try to find out as much as possible about their life history and beliefs by consulting family members or friends in order to understand how we can meet their needs in the best way.

Assessing spiritual needs

Responding to residents' spiritual needs is one of the most important steps in helping them to maintain a good quality of life – right up until the end. Religion and worship are not the only aspects of spirituality we need to think about; they are just two ways that individuals have to demonstrate and express what is important to them. Discovering what a resident uses as a source of spiritual strength, and ways in which they are helped to

become more peaceful and less anxious, are other means by which we can help assess a resident's spiritual needs. In addition, we should be aware of the challenges our residents face as they approach the end of their lives, and be sensitive to them. This will help to enhance their spiritual well-being, and our own.

A time of change

Moving house is always an upheaval, whatever our age. So new residents are having to cope with a major change in their lifestyle when they move into an MHA Home. Alongside the physical and emotional changes of moving home, there can be an increasing awareness of mobility or health problems and a feeling that death is getting closer. It is also the case that some will move into our Homes as a result of the death of a spouse or a carer, while others may no longer be able to visit their wife or husband's grave any more. Each situation will be different, but by being aware and sensitive we can provide a listening and supportive ear. One participant in The Final Lap recognised how important this can be:

"Key workers are now more perceptive and can respond better when someone hints at their wishes or concern. Discussing residents' end of life wishes is something we do as a priority now."

Summary

- Increased age and frailty, together with an awareness of the approach of death, can affect a person's spiritual wellbeing. All involved in caring for a resident should be aware of this.
- Some people will become a resident shortly after being bereaved. Others may no longer be able to visit a grave they went to regularly – acknowledging this and supporting them as they settle in will be most helpful.
- Assessing a resident's spiritual needs involves much more than establishing whether or not they are used to attending religious services; everyone is different and we need to tailor our approach to the individual.
- MHA's assessment procedures will help us to explore spiritual issues and place each resident's spiritual needs at the heart of their care plan.



3. Talking about Dying – Communication and Funeral Planning

If someone begins to talk about the possibility of dying, it is a natural reaction to try and jolly them out of it. "Come off it – you'll outlive me by years!" is one typical response. But it isn't true, and it isn't actually helpful. And while we may be trying to lighten the mood, and we might think we're helping the resident(s), all too often we are really trying to protect ourselves by avoiding a difficult and emotional topic.

In a recent report from Help the Aged, older people expressed the view that they struggled to find anyone who was willing to help them explore their attitudes to dying and death. It's as if there is a conspiracy of silence, which older people want to be broken.

Today, most of us have no direct experience of someone dying, and we usually rely on other professionals, such as doctors and funeral directors, to sort out the necessary arrangements when someone dies. It's hardly surprising then that we don't feel confident enough to answer residents' questions about the end of life. However, most of our residents grew up in a very different era, when death was part of domestic family life, and funerals were a community affair. They will generally be much more comfortable talking about death, as one Manager discovered during the pilot project:

"Once they start talking, it's hard to get them to stop!"

We want to encourage residents to feel comfortable in raising the subject of dying. We can encourage them to communicate by showing interest in and respect for what they have to say. We can also make it easier for them to ask questions if we answer them sensitively and honestly and help them to address their hopes, fears or concerns.

By learning to listen better and to communicate more effectively, we can provide appropriate information about end of life issues, offer practical support, discover what residents and families know and don't know and, hopefully, reduce their fears about dying and the end of life.

As well as addressing people's general concerns, it is also possible to offer practical help about funeral planning. Many older people want to find ways of helping family and friends by being involved in planning their funeral. Some have very definite ideas, for example about the choice between burial and cremation. Others will want certain hymns or poems including in the ceremony, while others simply have no views at all. Whatever an individual's opinion, we can help them think things through and give them information about what possibilities or options are available, so that they can make an informed choice. One of the Homes which took part in the pilot project has come up with a very practical suggestion:

"We are building an end of life resource book; it includes funeral information and guidance for relatives on various aspects of death and dying."

Of course residents are always able to change their minds, and they might express their thoughts to carers at any time. All care staff should be aware of this and try to make sure that a resident's records reflect the current situation accurately; so that their values and choices are respected as far as possible.

Summary

- Most of our residents grew up at a time when dying and death were much more public affairs than they are today. We will be of most help if we can encourage them to identify and express their thoughts about dying and the end of life.
- We need to communicate openly and honestly to encourage residents to talk about issues like end of life planning and funerals. Avoiding their questions or jollyng them out of it will usually mean an opportunity is lost.
- Residents may mention end of life issues to carers informally and their views can change over time. All staff need to ensure that records reflect a resident's current wishes accurately.
- While it is not our role to recommend one Funeral Director or another, having information on what's available locally is encouraged.



4. Magic Moments – Making the Most of What’s Left

Unfinished business

In writing about the tasks that are part of an older person's final years, Erik Erikson identifies two in particular which concern us here:

- Putting one's past in order.
- Becoming reconciled to death.

It is perhaps hard to imagine asking as direct a question as, "What is it important for you to do before you die?" Nevertheless it is helpful to think of ways of raising it, directly or indirectly. The ways in which it is answered will say a lot, both about the things that must be done as well as about those things someone wants to do.

The importance of "putting one's past in order" implies that we need to help residents to explore whether there are any emotional loose ends that need tying up. It might be as simple as saying "thank you", "I love you", or "goodbye!" to a friend. It might go deeper and involve an attempt to put a wrong right. This can help people to let go of old hurts or regrets and help them to achieve a sense of peace.

Magic Moments

If death is seen as part of life, then these final wishes are as much about the living that people have shared, and their relationships, as they are about the reality of dying. Some residents might want to leave written or recorded messages of courage, wisdom or love for their families and friends, others might simply want to explore the options for their funeral and make detailed plans in advance.

Creating a memory box or life album is a good way to share meaningful times from the past and offers a legacy for the future. Contents might include photographs, poetry, pictures, personal items and records. One Home has followed up this idea.

"We are thinking of putting together a 'forever' book – an album of residents' thoughts and wishes that gives inspiration and guidance to others".

It's also important to help residents consider what they'd still like to do, in a positive way, by focusing on what they can, rather than can't, do. Some suggestions may be impossible to meet, but the sharing the dream can be helpful. Other residents might have very simple wishes which they have lacked the courage or the opportunity to express. One resident said wistfully, "I'd like to go a little further into the park!" The Manager explained:

"We have introduced a last wish workshop. It helps residents to focus on what they'd like to do and achieve before they die. One resident is having a helicopter flight on his 100th birthday, another wants to use a spinning top."

By thinking about activities creatively we can also help our residents, and their relatives, to rediscover a sense of fun, and even create a lot of laughter and light-hearted moments; special memories we helped them to make, which we can keep and remember them by. The Manager of one of our Dementia Care Homes described what they had tried:

"We've held themed days for residents with dementia and their families. They've been very popular – Thirty relatives came to the holidays one. We built a beach and dressed up to bring the seaside to us. It helped people to focus on positive aspects of their lives, was great fun for all, and very rewarding."

Summary

- A resident's sense of 'unfinished business' affects their spiritual wellbeing. By helping residents to explore what they wish to do before they die we can help them achieve a sense of life closure and peace.
- Reminiscence activities can be an enjoyable way of reviewing life and sharing experiences with family members and friends.
- We can help residents create and share their magic moments with loved ones by providing creative activities or imaginative ways for people to remember and share important life events.



5. A caring community – considering everyone's needs

Whenever a resident is dying it is at least possible that every other resident and every member of staff will be affected, as well as the resident's family and friends. Sometimes we may be surprised by how much people are affected, and often we will be taken aback by our own reactions. It underlines the emotional nature of end of life care, and points to the importance of trying to give each individual whatever support, care, attention and time they need to be prepared in advance of the death, to deal with the dying process and to adjust to the loss.

Sadly this has not always been common practice in Care Homes in the UK, with residents only being informed after someone has died and the body already removed by the Funeral Director. If we are serious about being a caring community then there are issues here that we can address. To begin with, there is the question of communication. A Manager from the pilot project explains their changes:

"All residents are now informed if someone is dying. The loss does not come as so much of a shock now."

We can support fellow residents and staff by giving them opportunities to visit the dying resident. Care staff can take better care of residents by learning to take care of themselves, recognising limits and seeking help when they need it. It is important to remember that friendships between residents mean that they too may want to be involved, as one carer explains:

"Residents like to have the chance to sit with someone who is dying."

When someone has died, it is important to ensure that relatives, residents and staff members are informed sensitively and are given the opportunity to say their last goodbyes, if they wish to do so. It is equally important to maintain a resident's dignity after death and to ensure that their body is treated with respect as they leave the Home. One way of addressing this is to ensure that a coffin rather than a body bag is used and that they leave through the front door. One Home Manager has instigated another change:

"We don't have night time removal of bodies now, so all our residents and staff have an opportunity to say their goodbyes."

Considering everyone's needs means precisely that, and may involve balancing different people's wishes which seem mutually exclusive. However, with imagination, preparation and sensitivity it should be possible to succeed.

Caring doesn't end with a person's death. Support with loss and bereavement is an important aspect of end of life care. For some, the process may take weeks or months; for others, grieving may take a year or more. Maintaining contact with a deceased resident's relatives at regular intervals following the death can demonstrate that we valued the life of their loved one, and offer our continued support.

Summary

- We should provide opportunities for staff and residents to sit with those who are dying, and support them with loss, both before and after the death has occurred.
- The removal of bodies at night should be discouraged wherever possible and Funeral Directors should be asked to use a coffin to remove a body unless it is not practically possible.
- Residents should be informed individually when a death has occurred, with particular care given to those who were closest to the deceased. Consideration should also be given to other relatives and regular visitors.



6. Person-Centred End of Life Care – A Palliative Approach

Most people probably associate the term 'palliative care' with the hospice movement, and see it as inextricably linked with cancer and morphine. However, the term is now used much more widely, and describes an approach to caring which looks beyond the symptoms and addresses people's deeper spiritual needs. What is more, it is now recognised that it is particularly relevant to older people, and in particular where conditions that are common in older age, such as chronic chest disease, heart failure, Parkinson's disease or dementia, are present.

While palliative care often involves medical and nursing care to control physical pain and other distressing symptoms, it is by definition multidisciplinary, and involves offering spiritual and emotional support to individuals who are dying, and to their families. In a Residential Home a palliative approach will also encompass the Home's family, including carers and other residents.

Care planning in the last phase of a resident's life will need to draw upon the resident's expressed wishes, which will be documented, and will need to be communicated clearly at each handover, with all relevant information recorded and passed on.

Historically the ability of Care Homes to access community nursing and support services has been patchy at best, but things are gradually beginning to improve. Because of the complexity of care needs and the organisation of our healthcare systems, we need to develop a network of other professionals to supplement our skills and knowledge and help us deliver the best possible care. As well as developing relationships with GPs and District Nurses, we may need advice from hospital palliative or geriatric care teams, or support from hospices, mental health professionals and bereavement counselling services regarding social, emotional or psychological issues.

One issue that often raises itself occurs when a resident has expressed a wish to die in the Care Home, but the GP is unwilling to offer the necessary support. As an organisation, MHA is looking to empower and equip Managers and staff to fulfil our residents' wishes. It is hoped that The Final Lap will help in this regard. Two Managers from the pilot project certainly bear witness to what is possible.

"We recently changed a GP's policy of admitting dying residents to hospital regardless of their wishes, by asking him to think about what he'd want for his own mum."

"The project has been so successful that the local hospital now sends older people to the Home to receive end of life care."

Summary

- We can support dying residents by creating an environment and care plan for their last days in accordance with their expressed wishes.
- A palliative approach involves the management of pain and other symptoms; and addresses residents' psychological, social and spiritual needs alongside physical or medical care.
- We need to work alongside other healthcare professionals to deliver a palliative approach so building good relationships is vital.



7. The Finishing Line – Care During the Last Days and Hours

Many deaths occur peacefully and unexpectedly, without warning. However it is often possible to be aware that a resident is moving towards the end of their life, and likely to die within a matter of hours or days. This gives us an opportunity to alert relatives and friends so that they can make decisions about visiting. An important aspect of care is helping relatives to spend time with their loved one by providing accommodation, meals and refreshments, as well as a place to take a break, collect their thoughts and grieve. In one of our Homes staff have developed a special garden area with a water feature so that they have a private place for peaceful reflection.

Not all residents have close family, relatives or friends to be with them, so key workers can have an especially important role to play at this time. It is vital to try and ensure that an individual's wishes are respected regarding cultural or religious practices such as prayers, vigils, or ministries, and the presence and involvement of relatives, other residents or friends. The services of the Chaplain are available to all within the Home, and advising them that a resident is dying should be done as soon as possible.

Maintaining privacy and dignity is equally important. Personal care tasks such as washing and attending to bodily functions should always be done in private, and we should never assume that the

resident can't hear what is being said in their presence – even if they can't respond. Mouth care can also be particularly important in the final hours.

A resident's room, in which they are dying, should be as homely as possible. Soft lighting and music can provide a comforting background and create a peaceful atmosphere. Music is useful when words aren't needed or when communication is limited – it can directly affect a resident's mood, even in the latest stages of dementia. Hopefully this is an area where a resident has expressed some likes and dislikes, and your knowledge of their personality will guide your thinking.

When a resident has died, there need be no rush to do anything. Some relatives will want to leave immediately; others may want to remain with the body for some time. Staff need to be sensitive at all times, and aware of others within the Home who may wish to say a personal goodbye.

Sharing someone's death is probably one of the deepest emotional experiences that we can ever have. It is often a bitter-sweet experience, with understandable sadness mixed with thankfulness for a long life and many memories. In the pilot project we heard of a lady who on reaching 99, declared that she had no wish whatsoever to be 100. However, her birthday approached and preparations to mark her centenary had to be made. Then, at 11.30pm on the day before her 100th birthday, she died. The Home Manager told us:

"We helped her daughter by using the cards, telegrams, flowers and food that were there for a birthday party, in what was in effect a wake. Her body wasn't removed until everyone had 'celebrated' her 100 years. Her daughter thanked us and said we'd made things much easier, including planning for the funeral."

Summary

- We can support dying residents by creating a dignified setting for their death, in accordance with their expressed wishes.
- We should alert relatives and friends when the end of life is approaching whenever possible, and try to allow our residents to die in the place they want to, by asserting their wishes to GPs and family members on their behalf.
- The time before and immediately after a death has occurred is special. Take your time, and remember the needs of other residents, staff and relatives.



8. Memorialising – Marking Death and Celebrating Life

News of a resident's death should be announced in a respectful, gentle way. Wherever possible it is best to inform residents individually and privately, and similarly with staff. Only then should it be announced publicly at a mealtime or by a notice on the noticeboard. Appropriate ways of acknowledging the death might include a minute's silence at an appropriate time, or placing a candle and photograph or personal tribute in a suitable place. This can be particularly helpful for other relatives and visitors who may have known the resident or their family, and offers them the opportunity to pass on their condolences.

Every society has some form of ceremony to help the living mark, accept and come to terms with the death of someone they knew. The first opportunity comes at the point when the Funeral Director comes to remove the deceased person's body. Some residents and staff may wish to gather quietly in the entrance hall when this takes place, while others may want to absent themselves at this point.

When the family or friends come to plan a funeral service, we should inform them if the resident had expressed a particular wish, perhaps regarding a preference for cremation or burial, or some other aspect of a funeral service. However, whilst some people will appreciate this and find it helpful to know they're doing what their loved one wanted, others may prefer to make different choices and undertake funeral planning tasks alone.

Increasingly it is difficult for our residents to attend a funeral service outside the Home. It may be possible to hold the funeral service at the Home or, alternatively, we can hold a parallel service so that residents and staff can still mark the death and pay their last respects. Depending on individual wishes it may be appropriate for the funeral cortege to leave from the Home, or for it to pass the Home during its journey, or for those who have attended the funeral to come to the Home for refreshments afterwards.

A third opportunity to mark the life of the person who has died comes through remembrance activities and thanksgiving services. In some Homes people are remembered in regular or special services, in which symbols such as flowers and candles can provide avenues for people to focus on their personal memories and reflect on happy times. An annual memorial service is held in some Homes to which relatives of those who have died in the past year are invited back to take part. Memorial gardens can honour collective memories and provide a place for people to visit and focus on those who have made a difference to their lives. One Home which took part in the pilot project holds a service each January:

"We have just held our second annual Celebration of Life service. The names of all the residents who had left or entered the Home were called out, and a flower for each resident was placed in oasis. The flowers formed a beautiful display for a week afterwards."

It is inevitable that as each resident reaches the end of their final lap, another one will come in their place to begin their own final lap. Making them welcome and helping them settle in is, of course, a vital part of our care. But they will be the only member of the community who probably didn't know the resident who has recently died. So as part of making them welcome, it might be appropriate to say a little word about the one they have replaced. In time, they will become the resident who has died, and another will need to hear their story. After all, the final lap is a circle.

Summary

- Close friends and staff should be informed individually when a resident has died, followed by a more public announcement or acknowledgement to inform others of the death.
- Staff can be advocates for the resident who has died and help with funeral arrangements; it can help relatives to know they are following their loved one's wishes.
- Providing an opportunity to mark a resident's death is very important. If residents are unable to attend the funeral, they should be given alternative ways to mark the loss within the Home.
- We should provide residents and relatives with meaningful ways to remember their loved ones and honour their memory, such as thanksgiving services or memorials.





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