mha
Live later life well

MHA End of Life Care Strategy 2021-2024

Our purpose

In April 2019 MHA launched a new five year strategy outlining how we would support people to live later life well. Our strategy has four key areas to enable us to achieve this including:

- MHA in the Community
- MHA Enhancing Later Life
- MHA People
- MHA Fit for the Future

The End of Life Care Strategy builds upon the content discussed in MHA's strategy to ensure we are able to **enhance and support quality end of life care for residents, members, families and staff**. The aim of the End of Life Care Strategy is to guide us over the next three years to ensure we achieve our **mission, values and vision**.

Our **Mission**

As a charity, our mission is to enable people to live later life well.

Our **Values**

Inspired by our Methodist roots, we:

Respect every person, treating them with dignity

Nurture mind, body and spirit

Inspire the best in each other

Our **Vision**

By 2024, we will have increased the quality, impact and reach of our services by connecting our communities and realising our potential as One MHA.

Introduction

Throughout our 78 year history, we've been dedicated to holistic care from the moment a person comes into contact with our services to the moment they leave. We train and encourage all our colleagues to be confident in talking about death and dying and in 2017 we were given a Third Sector Care Award for our 'Final Lap' training programme.

We know that most people come to MHA to live, not to die; but we also know that in our care homes, in particular, many residents will spend their final days with us. We will continue to build on our history and experience as we develop this work to bring the best possible support and end of life care to those we serve, putting residents, members and families at the centre of all we do.

Everyone is different. When it comes to talking about death and dying, that's still true. We will treat every person as an individual and take their preferences and wishes into account, involving each person who is dying every step of the way. At the same time, we recognise that people belong to a variety of communities and we will explore these conversations in the context of those wider networks.

If you ask older people if they want to talk about death, many of them do – but many struggle to find someone willing to have that conversation (Owen, 2005). At MHA we want people to be confident that we're ready to have those conversations whenever a person is ready.

Defining End of Life Care:

Palliative care is for people living with a terminal illness where a cure is no longer possible or for people who have a complex illness and need their symptoms controlled. Palliative care treats or manages pain and other physical symptoms and also helps with any psychological, social or spiritual needs. Palliative care helps people with advanced or terminal illnesses have the best possible quality of life. This also includes support for their families.

Specialist palliative care is typically delivered by a team with diverse expertise in caring for people with progressive and life-limiting illness.

End of life care is an important part of palliative care for people who are nearing the end of their life. It's for people who are considered to be in the last year of life, but this time frame can be difficult to predict. Effective end of life care is holistic and helps people live as well as possible and to die with dignity, It continues for as long as it is needed.

Development of the strategy

All our commitments are based on what our residents, members, families and colleagues have told us is important to them. We gathered this information through interviews, surveys and observation. Our commitments also align with recent research and the national agendas outlined in:

- One Chance to Get it Right (June 2014, Leadership Alliance of the Care of Dying People)
- Priorities of Care for the Dying Person (June 2014, Leadership Alliance of the Care of Dying People)
- Ambitions for Palliative and End of Life Care (2015, National Palliative and End of Life Care Partnership)
- NICE guideline [NG142] (October 2019) End of life care for adults: service delivery

Our commitment to offering the best possible end of life care and support

Commitment one

We will put you at the centre of your support and care, enabling you to make decisions as long as you are able, and ensuring comfort and peace at the end of your life.

Commitment two

We will ensure that death and dying can be talked about openly and sensitively in all our services and communications.

Commitment three

We will support your family and friends for as long as is needed, helping them to say goodbye and celebrate your life.

Commitment four

We will ensure that our colleagues and volunteers have the necessary attitudes, knowledge, skills and support to care for you.

Commitment one

We will put you at the centre of your support and care, enabling you to make decisions as long as you are able, and ensuring comfort and peace at the end of your life.

- We will ask you how you would like your end of life care and support to be. If you can no longer tell us and you do not have a power of attorney, we will ask those closest to you, taking your preferences and wishes into account.
- We will support you as an individual, ensuring that you have access to the best physical, spiritual, religious and cultural care, according to your needs and wishes. Chaplaincy, where available will remain for all, free of charge and irrespective of beliefs.
- Every home and scheme will have access to information about the typical needs at end of life of those practicing any of the most common faiths in the UK. We will seek contact with other faith leaders as requested.
- We will support you to be you, not making assumptions about you and your family, but recognising your family of choice as those in relationships of intimacy and support with you.
- We will pay attention to all the ways you communicate your preferences, wishes and grief, including if you are living with dementia, and we will support you to express your feelings.
- We will review your holistic care needs regularly and will prioritise your comfort at the end of your life, using all available means and external expertise to keep you as comfortable and as free as possible from pain and distress.
- We will ensure that music is used to support you in a sensitive and appropriate way, following your personal preferences and wishes.
- We will work with local services including GPs, District Nurses, Macmillan Nurses, and local Specialist Palliative Care Teams.
- We will support you to make an Advanced Care Plan and/or an Advanced Directive to Refuse Treatment. We will help you to access independent legal advice if you wish to make a will or appoint attorneys.
- In MHA Communities we will work with members and colleagues to develop support appropriate to each service.

"(We must show people) dignity at all times and treat them as if they were family."

MHA colleague

"If I'm not involved in anything and things happen without my knowledge I would be very concerned about it…because it's my mum."

Family member

"Staff know exactly what she likes and doesn't like."

Family member

"Those that have filled in end of life care forms, should be given them again, during the time of the person being there…every so often…it might be something that needs to be readdressed."

Family member

"They were all adamant that the end of life should be as pain free as possible."

Retirement living chaplain

"It's important to always make sure (residents) leave with the same amount of dignity as they came in with."

MHA colleague

"Good palliative care is built on good relationships. With a gentle approach, people with dementia continue to connect in lots of ways – a squeeze of the hand, a wink, a smile, a kiss on the cheek. Even in the advanced stages, people with dementia are still fully present and open to connecting – when we have the courage to be present – beyond words."

Dr Julie Watson, University of Edinburgh

What does the research say?

"Research has found that person-centred care can… improve the experience people have of care and help them feel more satisfied…encourage people to be more involved in decisions about their care so they get services and support that are appropriate for their needs."

Health Innovation Network (2014).

"Practitioner and staff attitudes towards sexual identities influences the quality of care offered and received."

Neville and Henrickson (2006).

"If LGBT people are not confident about services or staff, they may not seek support and/or may not feel able to be open about themselves and the people who are important to them – factors that are crucial to dying well."

Marie Curie (2017).

Commitment two

We will ensure that death and dying can be talked about openly and sensitively in all our services and communications.

- We will support you to live your later life as well as possible, right to the end.
- We will be ready to listen when you are ready to talk.
- We will help you talk with your family and friends – if that's what you want.
- We will be sensitive about the timing of conversations about final wishes and Do Not Attempt Resuscitation (DNAR) and revisit those conversations as and when you wish.
- If you don't want to talk about death and dying, that's fine too.
- If you have a care plan, we will keep a record of your wishes so that all care staff can understand them, and we will be ready to update those wishes if and when they change.
- We will help you to prepare, practically, spiritually and emotionally for the end of your life, however far away that might be.
- We will support you to make choices regarding your place of death.
- We will ensure you are sensitively informed when other residents have died in your home or retirement living scheme.
- In MHA Communities we will work with individuals and their family to sensitively identify and inform close friends, members and volunteers when a member has died.

"Life is for living."
MHA retirement living resident

"I want to be heavily involved in planning my end of life care."
MHA care home resident

"It isn't something I'd like to think about now."
MHA care home resident

"I would like my daughter to handle everything."
MHA care home resident

"For me, it is being straight, not softening the edges or skirting around it, being absolutely frank and saying it as it is, so that we are quite clear about the situation."
Family member

"It was handled very matter of factly, but very sensitively, lots of listening to me and what (we) would want."
Family member

"You matter because you are you, and you matter to the end of your life."
Dame Cecily Saunders

"Living is precious, and is perhaps best appreciated when we live with the end in mind. It's time to talk about dying."
Kathryn Mannix (2018)

"systems enabling adults approaching the end of their life to have regular discussions with a member of their care team about changes in their health and social care needs…repeat assessments of their holistic needs and reviews of their advance care plan when needed."
NICE (2019)

What does the research say?

In a 2017 survey commissioned by Macmillan and carried out by ICM Unlimited, respondents were asked: "To what extent would you agree or disagree with the following statement about death? We don't talk about death and dying enough in this country". 64% of people agreed (18% strongly, 47% somewhat).

Macmillan & ISM Unlimited (2017).

Commitment three

We will support your family and friends for as long as is needed, helping them to visit, say goodbye and celebrate your life.

- We will continue to treat you with dignity and respect for as long as you are within our care, including after you have died.
- We will ask how you would like to be remembered, both within MHA and at your funeral service; and we will share this information with your family and friends to help them plan your funeral.
- We will ask who you would like to know first when you have died.
- We will pay attention to any tension between your family of choice and others and continue to put your needs and wishes first, whilst respecting all parties.
- We will ensure that your family and friends are told of your death sensitively and respectfully.
- We will continue to respect your privacy and follow GDPR, but will also make sure that we understand when it doesn't apply.
- We will continue to support your family and friends to visit you during end of life care, if that's what you wish. If they are not able to visit, we will facilitate contact through other means.
- We will offer ongoing bereavement support to your family and friends through groups or individual care.
- We will offer opportunities to those closest to you to take part in memorial services and create online tribute pages.
- We will encourage those closest to you to keep in touch with the scheme if this is what they want.

"My mother no longer knows me but it would still be important for me to be there."

Family member

"I heard that the deceased goes out the front doors because they came (in) through the front door, as a mark of respect. Now I think that's lovely."

Family member

Commitment four

We will ensure that our colleagues and volunteers have the necessary attitudes, knowledge, skills and support to care for you.

- We will take into account the MHA values during our recruitment process, to support colleagues to fulfil the aims of this strategy.
- We will train all our colleagues in the necessary skills to hold a conversation about death, dying, and end of life care.
- We will train our care teams in the practical, physical, emotional and spiritual aspects of end of life care, using outside organisations when necessary.
- We will train all our colleagues and any volunteers who wish, in understanding loss, grief and bereavement and how best to support themselves and others through this.
- We will use our Music Therapists to advise on appropriate use of music for residents at the end of their lives.
- We will ensure consistent, person centred and responsive care through detailed handover between shifts.
- We will offer support for colleagues, including through chaplaincy, peer support, clinical supervision and mentoring for less experienced colleagues.
- We will train and advise how best to prioritise care needs when looking after someone at the end of life.
- We will follow research-based best practice for continuous improvement of our end of life care.

"It's very important that the staff know exactly who to contact in the event of a death."

MHA care home resident

"How people die remains in the memory of those who live on."

Dame Cicely Saunders

"It's a constant spinning of plates... Just because I work in care doesn't make it easier necessarily."

Scottish Care report (2017)

In times of a pandemic

- Covid-19 has taught us a lot and we will use this experience if facing other pandemics in the future.
- We will offer you opportunities to speak with your family and friends through the use of technology, when they are unable to visit; whether this is due to a pandemic or other factors such as distance.
- We will continue to lobby government to provide the necessary resources to allow your family members to visit safely, including routine testing and PPE.
- In the case of an outbreak, we will do everything we can to ensure that you are cared for in accordance with your 'Final Wishes' as far as possible within any restrictions.
- We will provide resources for events (both faith-based and secular) in your home or scheme to mark the death of a resident, for those unable to attend the funeral.
- We understand that the levels of fear, mortality and grief during a pandemic can be traumatic for both residents and colleagues. We will offer extra support to homes and schemes affected in this way.

"We use full PPE to protect individuals and…encourage families to…so they are able to spend time with their loved ones when they are coming to the end of their life."

MHA colleague

"It's so much easier face to face when talking about something so sensitive and that's the struggle at the moment."

Family member

Implementing the End of Life Care Strategy

We acknowledge that the implementation and promotion of this strategy is the key to its success. This is why we will be introducing a number of new initiatives, including:

- Providing a resource to support all those experiencing loss due to the Covid-19 pandemic; including **information about loss and grief** and signposting to further support.
- Developing the network of specially trained and well connected **End of Life Care Advocates** across MHA: to promote best practice, to offer support to colleagues, and to ensure training is provided.
- Rolling out an updated **Final Lap training** programme for all colleagues, supported by additional role specific training for carers, nurses and chaplains, seeking support from outside agencies such as Specialist Palliative Care teams (Macmillan Nurses, Hospice Teams), GPs, and District Nurses.
- **Reviewing our processes** around prescribing, storing and administering medications to relieve common physical symptoms of nearing the end of life.
- Exploring the possibility of seeking accreditation with the **Gold Standards Framework** programme across MHA, which is deemed a mark of quality by CQC.

Implementing the End of Life Care Strategy

- Continuing and developing **collaboration** with other organisations including Marie Curie and Lippy People.
- Providing colleagues with guidance surrounding best practice and the requirements of the **General Data Protection Regulation (GDPR)** when informing residents and members of another's death in a scheme.
- Consulting more widely with **MHA Communities members** when Covid-19 restrictions allow.
- Developing the programme of **volunteer befrienders** in MHA Communities to support families who are facing loss, grief or bereavement.
- Providing all homes and schemes with the necessary information to deliver end of life care using **non-pharmacological resources** and supplies to enhance symptom control e.g. end of life care bags or boxes.
- Facilitating focus groups with **music therapists**, colleagues and residents to find a more consistent way in which we can incorporate music into end of life care that is person-centred.

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