



End of Life Care

1. Background

This policy has been developed to ensure Abbeyfield The Dales (ATD) services provide high quality care for residents as they approach the end of life.

2. Objectives

ATD is committed to providing services that enhance the quality of life for older people and developing services that will meet the needs of future generations. This commitment is based on the Mission and Values of ATD. ATD will also comply with all relevant and current legislation.

The aim of this policy is to:

- Assure residents that as they approach the end of life and at the time of death staff will treat them and their family with dignity, sensitivity and respect and that their personal wishes and preferences will always be considered paramount; and
- Ensure ATD complies with relevant legislation and regulations.

Advance care planning is a key element of the end of life care planning process; ensuring that an individual's wishes and preferences remains at the heart of care planning and service provision.

3. Scope

All established staff, agency staff and volunteers.

4. Policy

4.1. Introduction to End of Life Care

The National End of Life Care Strategy highlights the importance of assessment and care planning in terms of eliciting a person's wishes and preferences about their care, and also where they would like to be cared for at the end of their life. The National Institute for Health and Care Excellence (NICE) also highlights the benefits and importance of a comprehensive holistic assessment.

ATD have introduced 'My Future Wishes' plan which is a voluntary process appropriate for people who may want to make specific statements about their wishes as they approach the end of their lives.

'My Future Wishes' is about the resident's care and their choices they would like to make, including saying where they would want to be when they die.

Information about choices and who might be involved in their care can also be recorded, so any care staff can read about what matters to the individual, thereby ensuring continuity of care. A resident's views may change over time and if anything changes this can be written in the plan, so it stays up to date; it would be advisable to review this plan regularly.

Residents can initiate their 'My Future Wishes' at any time and this will help staff follow the resident's wishes in making best interest decisions if the resident loses capacity towards the end of their life. The plan is an example of an advance care plan and a link to this policy.

The Gold Standards Framework in Care Homes Programme (GSFCH) has evolved to optimise the organisation, communication and proactive planning for people in the last years of life in care homes. It focuses particularly on improving the collaboration with GPs who look after residents in care homes and promotes the involvement of primary care and specialist teams to ensure integrated end of life care.

In July 2013 the findings from an independent review into the Liverpool Care Pathway (LCP) were published. The report highlighted failings in the implementation of the LCP and recommended that the Government replace it with individual care plans by 14 July 2014.

Following the publication of the report, the Leadership Alliance for the Care of Dying People (LACDP) was formed by statutory and regulatory organisations such as Care Quality Commission (CQC), National Institute for Health Research and Health Education England, to whom the review panel addressed recommendations.

In June 2014, the alliance published a report which set out a new approach to care of the dying in England based on the needs and wishes of the person and those close to them. The approach, which is outlined in *One Chance to Get it Right*, is based on five Priorities for Care as the basis for caring for someone at the end of their life.

4.1.1. The Five Priorities for Care:

When it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly, decisions made, and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed, and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

4.2. Discussions as End of Life Approaches

Talking to people nearing the end of life and their families about their wishes can be a daunting prospect for any health or social care professional. However, finding the right time, place and words can make a significant difference to how the person and their family prepare for death and its aftermath.

It would be a failure of care if we did not act to manage needs effectively at the end of life. If we are to ensure the services we provide for people approaching the end of life are, as far as possible, responsive to their needs and preferences, we must first understand and respect what each individual's needs and preferences are, including spirituality.

Residents must be given the opportunity to consider what care they wish to receive, based on the best available information about what may lie ahead of them and what services are available. However, it must also be recognised that some residents will not wish to confront or discuss their own mortality with staff or their relatives.

The trigger for a discussion about the end of life may not necessarily be related to a clinical event or deterioration in health. Changes in social circumstances, such as a move from independent living into a care home may be a suitable time to initiate discussions. A resident's GP may assist with such discussions as they are likely to have known the resident

for many years and will be aware of their medical history and social circumstances. Or it may be initiated at any time by the resident when they feel comfortable and supported with family/friends to participate in the discussion.

4.3. Assessment, Care Planning and Review

As residents approach the end of life it's important to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in their care plan.

Palliative care is care of people with serious illness from which recovery is not expected. Dealing with pain and other symptoms is important, but palliative care also looks at the person as a whole, including their overall sense of wellbeing as well as their physical condition. Palliative and end of life care are a positive part of health and social care, for the resident and their family.

The assessment with a person approaching end of life must include their wishes and preferences and also those of their family. End of life care planning should include a holistic assessment regarding both the type of care the resident would wish to receive and the setting or location in which they wish to be cared for. Palliative care tackles four main types of need that may arise towards the end of life. The needs are:

- Physical – managing symptoms such as pain, sickness, tiredness or loss of appetite; good “tender loving care” such as preventing pressure sores
- Psychological – giving emotional support to the resident and those who care about them, giving time to listen to them and understand their concerns
- Social – giving support and advice on practical matters such as getting their affairs in order
- Spiritual – a need to explore thoughts about the meaning of life, or concerns about what happens after death. All people are likely to have spiritual needs and some may also have practical things they need to do because of their religious beliefs including rituals after death.

Such an assessment serves to identify any areas of unmet need and/or the need to involve other practitioners, for example, where a person is not already eligible for NHS Continuing Healthcare. When a person moves into a care home, their financial position and eligibility for benefits should, therefore, also be explored.

In some cases, residents may want to make an advance decision to refuse treatment, should they lack capacity to make such a decision in the future. (See Advance Decisions to Refuse Treatment policy). Any such decisions should be incorporated into their care plan.

The care plan should be subject to review by all those involved in the resident's care and the care plan should be available to all who have legitimate reason to access it, for example, out of hours and emergency services.

Advance Care Planning (ACP) is the process of planning for possible health care decisions that may arise in the future and it particularly relates to end of life care. The outcome of ACP may be the completion of an advance statement or decision, but this is not mandatory or automatic and will depend on the person's wishes.

Whilst a statement of wishes and preferences documented in a PPC is not legally binding, the Mental Capacity Act 2005 requires that anybody making a decision about the care or treatment of an individual who has been assessed as lacking capacity to make that decision for themselves will be required to take any statement of wishes and preferences into account when assessing that person's best interests.

An individual may decide to appoint a person to make treatment decisions on their behalf by authorising the person to do so under a Lasting Power of Attorney (LPA). If a resident has appointed an LPA to make decisions about their health and welfare it will be important to ascertain the terms of the appointment, i.e. what sort of decisions the resident has agreed that the attorney should make on their behalf in the event that they lose capacity. A copy of the LPA should be filed with the resident's care documentation.

4.4. Coordination of Care

The wishes of the resident must be respected at all times. If a resident wish is not to be admitted to hospital but to spend their final days in their home, then everyone involved in the health and wellbeing of the resident must ensure all is done to facilitate their wishes.

Once a care plan has been agreed, it is essential all services required are effectively coordinated. As a person's condition may change rapidly it is also imperative that services are accessed without delay. The provision of the right services can avoid unnecessary emergency admissions to hospital and can enable more people at the end of their life to live and die in the place of their choice.

The care home should establish links with the district nursing team and specialist palliative care nurse where available. The Specialist Palliative Care Team is a team of specialist doctors, nurses and sometimes pharmacists, social workers and therapy staff, who provide expert advice to patients or their professional carers (such as GPs, district nurses or care home staff). They may be from the NHS or from a voluntary sector hospice and they may work in the hospital or community.

Care homes can also access the services of Clinical Nurse Specialists in Palliative Care (often called Macmillan Nurses). Macmillan Nurses, who usually work as part of the NHS team, are experienced qualified nurses with extra training and experience in care for people with cancer. Some work mainly with care homes to train staff or give advice on individual resident's needs.

Marie Curie Nurses offer expert home nursing care and emotional support to families affected by cancer in partnership with local health services. Marie Curie Nurses can be qualified nurses or nursing assistants, depending on what care the resident needs. They are available by prior arrangement during the day or through the night and provide practical care.

Other specialist nurses may be available in some areas. For example, the British Heart Foundation heart failure nurses, British Lung Foundation respiratory nurses, Parkinson's disease nurses and Admiral Nurses who work with people with dementia and their families.

4.5. Delivery of High-Quality Services

All staff will observe and respect each resident's wishes and ensure that care is provided in accordance with their care plan.

Every effort will be made to minimise any distress, pain or discomfort for the resident.

Care staff should ensure that the resident has access to all available health care services, include specialist palliative care, according to their needs.

The care home will liaise with health care specialists and health and social care equipment stores to ensure suitable aids and equipment, such as specialist beds and pressure relieving mattresses, are provided according to individual need.

The resident will at all times be treated with dignity and their personal privacy will be respected.

The physical environment can have a direct impact on the experience of care for people at the end of life and on their carers and families. Central to providing high quality care is the provision of a setting which promotes the dignity and respect of the resident and also of their family. Ideal facilities include:

- Somewhere where the resident and their family can talk privately
- Informal gathering spaces where family and friends can meet to confer and talk with staff
- A guest room or suitable facility to enable close family and friends to stay overnight.

ATD staff are appropriately trained to deliver high quality end of life care. The registered manager will liaise with the Specialist Palliative Care Team and other relevant healthcare professionals to support staff and enable them to meet the particular end of life care needs of the resident.

4.6. Care in the Last Days of Life

A point comes in the care pathway when the resident enters the dying phase. Identifying that the resident is dying is potentially challenging but, in the context of a deteriorating or progressive life-limiting illness and in the absence of any potentially reversible factors, various signs will suggest that the resident may be in their last days, or hours of life. They may become more withdrawn and slip in and out of consciousness, and they are likely to stop taking food and only take small amounts of fluid, if any. It is vital that staff should recognise when the resident is dying, and that appropriate action is taken.

Wherever possible, relatives and those nominated in the ACP should be alerted when a resident appears to be dying. Every effort will be made to ensure that those closest to the resident are able to stay with the resident during this time.

ATD staff and all healthcare professionals involved must be aware of the resident's preferences and wishes, especially of any advance decision to refuse treatment they may have made.

It may be the resident's wish that a member of the clergy attends to take care of the ritual aspects of their religious or spiritual beliefs and staff must ensure that any such wishes are acted upon.

Residents should be able to spend their final days in their own room, surrounded by their own personal belongings, if this is what they want, unless there are significant medical reasons why this is not possible.

The focus at this time will be the physical and spiritual comfort of the resident to ensure, as far as is possible, a peaceful and dignified death.

4.7. Care After Death

Good end of life care does not stop at the point of death. When a resident dies all staff need to be familiar with good practice for the care and viewing of the body and be responsive to carer and family wishes and cultural or religious and spiritual needs.

Where the death of a resident has been expected the senior member of staff on duty should report the death to the GP who will normally attend to verify that the resident has died and will complete the death certificate. In cases where it is out of hours then out of hours procedures should be followed.

Where relatives are not present, they should be contacted and informed of the death. Relatives should never be advised about the death of a resident by a message unless, exceptionally, this has been expressly agreed beforehand.

Some relatives will want to be informed straight away whilst others may have stated that if death occurs during the night, they wish to be contacted the next day. Once relatives have been informed this should be noted in the care plan.

Senior staff should be familiar with the role of the coroner and understand whether the coroner needs to become involved in a particular case. The way that this is carried out, and the support and care provided to carers and relatives, will help them cope with their loss and is essential to achieving a “good death”. Therefore, it is important that all staff who care for residents who are dying and after death, are appropriately trained and supported.

The date and time of death should be recorded in the care plan. Details of all those informed, including how, when and by whom they were informed, should also be recorded.

Once verification of death is confirmed, staff may attend to the resident, performing Last Offices as specified in the care plan or requested by the relatives. Some relatives may wish to do this themselves. Some cultures and religions have very specific rites or requirements and staff should always ascertain the wishes of the resident or their relatives before performing Last Offices.

Once the GP has attended and if the family request it, staff may contact the undertakers to collect the body of the deceased resident so arrangements for the funeral can be made.

Where a resident has no next of kin and no person acting for them, the senior member of staff on duty should contact social services before any arrangements are made. The local authority is responsible for making funeral arrangements for those without funds. The home should never make any arrangements without authority from the next of kin or other responsible authority e.g. social services, Lasting Power of Attorney, since the home may become liable for costs incurred.

The Social Worker and any other involved professional should also be notified of the death.

All medication should be retained in the home for seven days, before being returned to the pharmacy.

The registered manager is responsible for ensuring that the CQC is notified of the death in accordance with Outcome 18 of the Essential Standards of Quality and Safety and Regulation 16 of the Care Quality Commission (Registration) Regulations 2009.

4.8. Procedure Following an Unexpected Death

If the death of a resident is unexpected, the senior member of staff on duty should ensure that the resident, and the room in which the resident has died, remains untouched.

The GP, the police and, if necessary, the emergency services should be contacted.

The relatives should be informed in accordance with any agreed instructions and in a sensitive manner. Relatives should be informed that the care home has contacted the authorities as the death was unexpected. Relatives should never be advised about the unexpected death of a resident by a message.

The date and time of death should be recorded in the care plan. Details of all those informed, including how, when and by whom they were informed, should also be recorded.

In the event of an unexpected death the GP will be unable to issue a death certificate and the coroner will be informed. This will usually be followed by a post mortem to determine the cause of death. No Last Offices should be carried out as this may affect the investigations. The police and the coroner’s office should be given the details of the resident’s next of kin, who they may wish to contact.

The registered manager should ensure that the CQC are notified of the death, and that a RIDDOR notification is completed where the circumstances require it.

The registered manager should ensure that CQC are notified when a resident has died in hospital.

The Social Worker and any other professional involved should also be notified of the death and a record kept of this.

The registered manager should notify the Director of Operations in the event of an unexpected death and the Nominated Individual. Where there are suspicious circumstances surrounding a death and the death occurs out of hours, the senior member of staff on duty must notify the agreed on-call member of the Senior Leadership Team (SLT).

All medication should be retained in the care home for seven days.

4.9. Support for Carers and Families

The resident's family and friends should be involved in planning for and dealing with serious ill health, terminal illness and death, if the resident so wishes.

The resident's family should be kept fully informed as their relative approaches the end of life.

The family and friends of a resident who is dying will be able to stay with the resident for as long as they wish, unless the resident has made it clear that they do not want them to.

Other residents and staff should be supported to offer comfort to a resident who is dying if they wish to do so.

The significant impact of the death of a resident on other residents, staff, and relatives and friends must be recognised and comfort and support provided.

4.10. Personal Property and Valuables

There should be a clear understanding of the named person or next of kin who has the right to remove the resident's property in the event of their death. This person should be informed that the resident's property may be collected at any reasonable time and a signed receipt should be obtained for any property removed. If there is any uncertainty about who has the authority to remove the resident's property, the registered manager is responsible for seeking clarification and ensuring that property is not released unless it is appropriate to do so.

Any money or valuables held by the care home for safekeeping on behalf of the resident should be handed over to the named person or next of kin authorised to receive them and a receipt obtained.

Where the police are involved, they should be consulted before any property is removed as their permission will normally be required.

4.11. Care Home Contracts

Following the death of a resident, care home fees will be charged in accordance with the contractual terms and conditions of residence agreed with the resident and any other party involved e.g. local authority.

Where the resident is in receipt of funding from a local authority and or health authority, the funding authority must be notified of the death in accordance with the contractual arrangements in place, and within 72 hours of the death. A written record of the notification must be kept at the care home.

5. Finance, Value for Money & Social Value

N/A

6. Supported Appendices

N/A

7. Linked Policies

Medication Administration - Domiciliary/Extra Care (C035P)

Statutory Notification of Events (C028P)

Care Planning and Key Working (C008P)

Mental Capacity Act (C015P)

Advance Decisions to Refuse Treatment (C003P)

8. Legislation/Regulation

Section 20 regulations of the Health & Social Care Act 2008

Essential Standards of Quality and Safety

Outcome 1: Respecting and involving people who use services

Outcome 2: Consent to care and treatment

Outcome 4: Care and welfare of people who use services

9. Review

Every 3 years, subject to any regulatory or legislative updates.

10. Procedure/Guidance

<http://www.goldstandardsframework.org.uk/>

<http://www.mariecurie.org.uk/>

<http://www.dementiauk.org/what-we-do/admiral-nurses/>

<http://www.nhs.uk/resource-search/publications/eolc-acp-guide.aspx>

<http://www.scie.org.uk/adults/endoflifecare/nicequalitystandards.asp>