End-of-life Care Policy

Policy Statement

The home service is committed to providing high-quality and compassionate care and support for service users and their relatives, carers and loved ones during the end stage of their life. The service will treat everyone with the utmost respect, compassion and dignity, supporting them where possible to make advance decisions relating to their care and treatment, and respecting their preferences. It will comply with all standards and regulations for high-quality end-of-life care as described below.

This policy sets out the values, principles and practices underpinning the services approach to the care of service users who are terminally ill and whose death may be imminent.

The recent coronavirus (COVID-19) pandemic raised specific challenges for care home service users, care at home, their families and the staff with regard to End of life Care provision.

Care home service users are particularly vulnerable to infection during any pandemic and therefore outbreaks in care homes may prove to be devastating.

Restrictions on visiting and social isolation or shielding have resulted in particular issues for those at the end of life and for service users with dementia.

The services policy is to comply with guidance on Public Health England (PHE) residential care provision and ensure up to date guidance is accessed and followed during any pandemic.

Staff are aware of and comply with PHE: Care of the deceased with suspected or confirmed coronavirus (COVID-19) in the event of the death of a service user with suspected or confirmed coronavirus

The policy is written in line with the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, which contains the following with respect to end-of-life care:

- Regulation 9: Person-centred Care requires service providers to ensure that the care and treatment of service users must be appropriate, must meet their needs, and must reflect their preferences. The regulation specifically requires service providers to act in accordance with the Mental Capacity Act 2005 for people who may lack capacity, acting on their behalf where a valid advance decision to refuse treatment is in place.

With regard to the dynamic situation caused by the COVID-19 pandemic, where a service user lacks the capacity, guidance that it is reasonable to develop a plan following best interest guidelines with the involvement of family members or other appropriate individual. To comply with current guidance and shield service users, video conferencing software on smartphones, tablets and portable computers may need to be used to safely include family members in such discussions.
During the pandemic there was no relaxation of Deprivation of Liberty Safeguards (DoLS) associated with the coronavirus pandemic and care homes had to ensure that they adhere to DoLS guidance.

Whilst CQC inspections were suspended during the coronavirus pandemic, there are no changes to the requirements to make notifications or the system used to make them. The CQC will be notified of deaths and events that, during this period, preclude continuation of providing service ‘safely and properly’ (regulation 18).

This entails informing the CQC if service operation is being negatively affected by COVID-19 or any pandemic, but not informing the CQC of minor or solitary infection related issues.

This service’s service users are supported at the end of their life to have a comfortable, dignified and pain free death. In response to the relevant questions included in the CQC’s Key Lines of Enquiry, and we ensures that:

- people’s preferences and choices for their end-of-life care are clearly recorded, communicated, kept under review and acted upon.
- people, and those that matter to them, are fully involved in the planning, decisionmaking and management of their end-of-life care.
- people are supported to make advance decisions to refuse treatment or appoint someone with lasting powers of attorney in line with their wishes.
- people have access to and support from specialist palliative care professionals.
- staff know how to manage, respect and follow people’s choices and wishes for their end-of-life care.
- people have the equipment and pain management to meet their end-of-life care needs.

Principles of End-of-life Care

The service implements as fully as possible the guidance on palliative care produced by the Department of Health and Social Care and the end of life quality standards produced by the National Institute for Health and Care Excellence (NICE).

It is committed to continuing the care of its residents who choose to remain there when terminally ill or in a terminal condition, unless there are good reasons for seeking an alternative. These are determined by the nature of the condition or illness, the home’s capacity to provide or procure the necessary care and support, and medical guidance and advice. The views of relatives are also fully considered, though the person’s own views, where stated, are the most important.

The service ensures that where it offers terminal care and support, the individual and those close to them are treated with respect and dignity and their rights to spend time alone with one another are fully respected. The service thus tries to follow the principle that a person should be cared for in their final days as if he or she was in their own home if that is their wish.

The service makes every effort to provide and procure all the care and support available from health and local services to make the service user feel comfortable, safe and as free from as much pain and discomfort as possible. This includes where appropriate the involvement of community healthcare staff and palliative care practitioners and services and provision of counselling and other forms of psychological support.

People who are undergoing palliative care possibly involving specialist community medical and nursing staff require specific care plans. These end-of-life plans are additional to the general service user plan and are used in association with established clinical procedures and recording tools, including for any “just in case” (anticipatory) medication, which is determined by local arrangements and protocols.

During the COVID -19 pandemic, for services users having an advanced care plan (ACP) in place or being able to review existing ACPs is of high importance. This incorporates discussion around how COVID-19 may cause service users to become critically unwell, and a clear decision about whether hospital admission would be considered.

Provision of adequate support for service users to make informed decisions during this unprecedented time involves liaising with General Practitioners, community healthcare staff and community geriatricians and other relevant health care professionals to discuss emergency care planning and treatment in person centered discussons.

Each aspect of the end-of-life care is handled sensitively with the aim of ensuring people can die in a dignified, respectful manner, as free from pain and distress as possible and in accordance with their own wishes.

Care staff responsible for the monitoring and administration of any pain relieving medication should receive training and supervision to ensure they are competent to undertake this and must follow other relevant policies and protocols of the organisation.

The NHS is likely to become overwhelmed by the volume of COVID-19 or of a similar outbreak, this will have an impact on care homes in the UK and determine how and where many service users with COVID-19 are likely to be cared for at end of life.

Staff are likely to have in depth knowledge of their service users, being able to recognise deterioration in their condition. Expertise in supporting service users with cognitive impairment and behavioral symptoms and the provision in skilled in end-of-life care will be fundamental during this time.

Care providers will need to liaise closely with the GPs, and community healthcare staff and community geriatricians to ensure they have palliative care requirements in place and ensure they have anticipatory medications available for end of life care provision.

It is hoped that regularly used anticipatory medicines will be made available to care providers to ensure they can be accessed, prescribed and dispensed at short notice during any pandemic.

Developing an End-of-life Care Plan

The service recognises that service users who are suffering from terminal illness and who are in the last stages of that illness need total care, including emotional care and frequent attention.

It achieves this by drawing up an end-of-life care plan, which is based on a detailed needs assessment. To draw up the care plan it receives the help of the medical team involved, who makes the necessary decisions and recommendations which can be followed up in the plan of care. Any changes to the person’s medication regime because of any changes to their condition, which have been authorised by the medical practitioner, are fully recorded and acted upon.

The care plan will usually include descriptions of how to:
- reduce or control a person’s pain and discomfort
- reduce or control signs of restlessness, anxiety or agitation
- manage or control respiratory secretions
- manage or control any nausea/vomiting
- maintain mouth care

- manage or control elimination of urine or faeces
- relieve pressure, reduce or manage pressure points and sores.

The care plan will also contain details of any new procedures or interventions to be made in the light of the person’s changing condition and of any current procedures or interventions that have been modified.

All medication and prescriptions, including the use of controlled drugs are recorded on the person’s MAR charts in line with established procedures.
At all times, care staff are made aware of the service user’s condition and are in constant contact with the service user’s GP and community nurses who may be involved to ensure that the service user is in the best possible place and to provide the care required.

The service makes every effort to ensure that the service user’s wishes in respect of their religious or cultural practices are fully respected. In most instances, the service is aware of these as they will have been recorded previously in their service user plan of care or as an advanced directive.

Where the person’s wishes remain unclear and they have lost the mental capacity to clarify and communicate these, the manager will make every effort to ascertain them from relatives, friends and professional who know the person. This then should enable the arrangements made to be as close as possible to what the person would probably have wished. The services policy in these matters is accordingly worked out in line with the “best interests” principle of the Mental Capacity Act 2005.

Monitoring and Observation

Care staff as well as nursing staff will contribute to the care plan by making detailed observations on the person’s conditions and changes that occur.

The arrangements for monitoring and observing the person’s condition are carefully structured, eg hourly, two-hourly, etc.

Care staff are expected to make sure that the records of the observations or checks made match those that have been agreed as needed on the care plan.

Communication: Keeping Everyone Informed

The service undertakes to keep everyone involved in the person’s care of changes and developments in the person’s condition. A record is kept of all their contact details to assist communication and information passing, eg of next of kin, other family members, friends, GP, specialist medical staff from the Palliative Care team, including Macmillan and community nurses, key worker and other care staff involved, religious/spiritual advisors such as priest, rabbi, imam, social worker/care manager and other representatives such as advocate and legal guardian.

Staff Roles and Responsibilities

The end-of-life care plan identifies staff roles and responsibilities and the practices and procedures that they should follow. Staff are expected to:

- always maintain the user’s need for privacy and dignity
- accept that each situation is an individual one and not to be treated as routine and make sure that the person feels that their wishes are being listened to and respected
- respect the individual’s wishes
- resolve constructively any conflicts of interest or differences of opinion with reference to the individual’s wishes
- work in partnership with the user and their relatives and friends

- ensure all cultural and religious preferences are observed and assisted (including secular preferences for those who are non-religious)
- work in partnership with the GP and other healthcare professionals involved
- attend to physical needs to ensure the person is as comfortable as possible and to help make sure that any experience of pain is being managed as effectively as possible — with resources to achieve this made available
- respond to emotional needs as well as physical needs and to spend time listening and talking to the service user as well as caring wherever appropriate
- respond to the needs for support of relatives and staff who had a close relationship with the dying person.

Service managers may find it a real challenge to support staff who feel isolated from the rest of the health and social care system during any pandemic, therefore, It is important that proactive efforts are made to try to address the impact of any pandemic on the mental health on service staff.
For managers coping with this complex situation, acknowledging issues staff face whilst trying to minimise risks inherent in dealing with such the pandemic will provide ongoing challenges.
Multi-professional support networks may help to support staff through this. Some local health and social care systems have set up local systems to try to support care providers and staff.

Procedures and Processes

1. Attendance and companionship

The service accepts that the involvement of family and close friends is essential to the wellbeing of the service user. It encourages close family members to remain with the person and friends to visit as the person wishes and is able to see them.
Social isolation and shielding must be followed during any pandemic.

The service encourages its staff to build a relationship of trust with the service user and family members so that they remain sensitive and responsive to the service user’s needs.

Staff are expected to spend time listening and talking to the service user as well as caring. They are expected to respond directly and promptly to requests for arrangements to be made so that the service user feels that their wishes and decisions are respected.

Staff are always expected to be aware and sensitive of what is happening. For example, when caring for someone who appears unconscious, staff are instructed to be aware of that the person could still hear what is being said to and about them.
Accordingly, they should be taking care taken not to discuss the service user’s condition within the room.

2. Comfort

Care staff (and nursing staff where used) must make the person as comfortable as possible and make regular checks to make sure they remain comfortable and free of pain.

Care staff must continue to treat the person with dignity and respect and help to maintain all aspects of the person’s personal care such as washing, grooming, mouth care, etc as directed by the person’s plan of care.

Care staff must adopt all procedures to risk assess, monitor and treat pressure sores, tissue viability, oral hygiene and dehydration.

3. Nutrition

Care staff will regularly provide refreshing drinks, mouth swabs and fluids to ensure that the person consumes enough fluid, and does not feel thirsty and does not dehydrate.

Care is taken to provide a diet that meets the person's nutritional needs, which might include liquidised food, soups and food supplements. Where food has to be provided through peg feeds, the service will ensures it receives full medical guidance on the protocols and procedures it is expected to follow and advice from a qualified nutritionist.
All efforts are made to provide the person with food and drinks that they enjoy and ask for.

4. Pain management

The service receives full medical guidance, including from palliative care specialist teams to implement a pain management plan for every terminally ill person.
Care staff responsible for the monitoring and administration of any pain-relieving medication receive training and supervision to ensure that they are competent to follow the agreed plan.

5. Staff support and supervision

Care staff closely involved in the implementation of a care plan for a terminally ill person receive supervision and good emotional support to help them provide a high standard of care. The service works on the basis that care staff involved in these situations should feel that they can discuss their feelings and experiences with other staff members in, eg supervision and staff meetings.

Care staff receive training and supervision in palliative care processes so that they can respond to people's feelings and thoughts, which may be connected directly or indirectly to their impending death.

Staff are expected to engage in, rather than to avoid, awkward conversation, also to talk naturally to the person following their agenda.

6. Social relationships

Dependent on the services policy for visitors during any pandemic, visiting is likely to be prohibited. Where face to face visits are not possible, use of video conferencing software on smartphones, tablets and portable computers may be possible.
The service encourages relatives and friends to visit as often as possible and at any time. It remains in constant contact with them to make sure they are informed of all important developments.
The service ensures that the service user is not isolated from interacting with other people unless it is his or her wish to be alone.

7. Involving relatives

Relatives are offered emotional comfort and support and are given opportunities to share their fears and experiences with caring staff. This helps both staff and relatives come to term with the situation.

The service encourages relatives who wish to become involved in caring for the dying person. Care staff make every effort to involve them in the daily routine, eg if a relative wishes to help feed the service user or help the service user to bed for the night the relative is made aware of the service user's normal routine and is encouraged to participate.

The service accepts that family and friends of the person may wish to share in the companionship of the dying resident and considers it is important that they are not excluded.

The service considers, that in a care home environment, it is essential for residents to realise that the impact of any death within the home becomes a shared experience and everyone can expect to have the same level of devoted care under those circumstances.
Relatives are provided with information about bereavement support as needed.

Review of Issues Raised by a Service User's Death

After a resident has died, having been cared for under an end-of-life plan of care, the service reviews its practice and the process followed with those involved (staff team, other professionals and relatives). The purpose of the review is to assess if as much was done as possible to ensure that the process was managed as well as possible and to consider any improvements that could be made to the procedures.

Training

The care of terminally ill residents in the service and the service's policy are included in induction training programmes for new staff, particularly the younger staff who might not have experience of people who are dying. Induction training involving end-of-life care is developed in relation to the Care Certificate framework.

The service also provides or enables key staff to attend specialist training in palliative care in end of life care that meet the Skills for Care / Skills for Health competences frameworks at the appropriate levels.

The service uses the services of local palliative care specialists to provide staff training so that all staff are competent in the care of terminally ill service users.

Signed: Ian Booy (MD)

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