
End of Life Care Policy & Procedure

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1 Introduction

Brainkind will support the person's right to die with dignity, without pain and in a place their choice where possible; surrounded by people they know and trust.

Brainkind believes standards of high-quality care should not be compromised when patients are receiving palliative and end of life care.

Brainkind recognises that there is 'one chance to get it right' when caring for people who are receiving palliative and end of life care. This should be reflected in the care and support provided for persons and those that are important to them.

Brainkind will ensure that relevant services are involved, effective communication is maintained, and a holistic and person-centred approach is taken in providing care for persons who require palliative and end of life care.

Brainkind will ensure that those delivering palliative, and end of life care are effectively trained to do so. A confident and competent approach should be taken, ensuring sensitivity and compassion is maintained at all times.

1.1 Scope

Palliative and end of life care is not routinely delivered within Brainkind settings, however it is recognised that in some circumstances this is the most appropriate setting for the care to be provided. The Registered Manager and Regional Manager should be involved in decisions to provide such care, taking into consideration the person's preference, the medical needs of the person, the level of training within the staff team and the registration of the service.

It is important to recognise that as a person's care needs evolve, palliative and end of life care may become the primary care need of individuals in our services. In these instances, Brainkind will make reasonable adjustments to empower persons to identify and communicate their wishes for the end of life. This may include who the person wants to be involved in their care, where they would prefer to reside at the end of life, and what their key care preferences are.

2 Purpose and Principles

This policy sets out the values, principles and procedures underpinning Brainkind's approach to the care and treatment of dying persons in line with the Gold Standards Framework (2013).



2.1 The Gold Standards Framework (2013)

For end of life care it outlines the importance of helping people to live well before they die and enabling people to die in the place and manner of their choosing.

The Gold Standards Framework (2013) outlines 5 key steps to Advance/ Anticipatory/ Care Planning:

- THINK about the future, what is important to you. What do / don't you want to happen?
- TALK with friends and family. Consider appointing a Lasting Power of Attorney in the event of a loss of Capacity.
- RECORD your thoughts in your Advance/ Anticipatory Care Plan.
- DISCUSS plans with healthcare professionals. Consider DNACPR and Advance Decisions to Refuse Treatment.
- SHARE information with others (GP, specialist services, family, hospital admissions / transfers).

2.2 The Daffodil Standards (National Palliative and end of life care partnership 2020)

Outlines 8 quality improvement statements for palliative and end of life care:

- Professional and competent staff
- Early identification of patients and carers
- Carer support – before and after death
- Seamless, planned, co-ordinated care
- Assessment of unique needs of the patient
- Quality care during the last days of life
- Care after death
- General practices being hubs within compassionate communities.



3 Definitions

3.1 Palliative care (Marie Curie, 2021) –

'Palliative care is treatment, care and support for people with a life-limiting illness. The aim of palliative care is to help maintain a good quality of life.' This can involve:

- Managing physical symptoms such as pain
- Emotional, spiritual and psychological support
- Social care, including help with things like washing, dressing or eating
- Support for the person, their family and friends

3.2 End of life care (Marie Curie, 2021) –

Care that helps those with advanced, progressive and incurable illnesses to live as well as possible until they die. This is usually thought to be within the last year of a person's life however it is acknowledged that it is often hard to predict and therefore this may be delivered within the last weeks or even days of a person's life.

3.3 Advance/ Anticipatory Care Planning –

The process of considering and discussing preferences and wishes about future treatment and care, in order to ensure patient care is holistic and person centred. (Compassion in Dying, 2018).

Advance/ Anticipatory Care Planning can cover any aspect of future care preferences; however, this is not legally binding. An Advance/ Anticipatory Care Plan may discuss an 'Advance Decision' which is a legally binding decision to refuse specific treatment. (GSF, 2013).



3.4 Advance Decision to Refuse Treatment (Compassion in Dying, 2018) –

A legally binding document (when specific requirements are met) which outlines any treatments that you do not want to have in the future. This would only be used if you are not able to communicate a decision for yourself.

When making an Advance Decision to Refuse Treatment, the individual must have capacity to make this decision.

Information in an Advance Decision to Refuse Treatment document must be clear and specify what treatment the individual would want to refuse, and in what event this would be applicable.

4 Responsibilities

4.1 Managers

It is the responsibility and accountability of the service manager to ensure staff are familiar with this policy, that staff receive appropriate training to enable someone end of life care to be applied in a kind, caring and competent way.

4.2 Employee Responsibilities

It is the responsibility for all appropriate staff to be aware of this policy and its contents. All staff will receive appropriate training and it is the responsibility of individual staff members to ensure that they have received that training.



5 Procedure

5.1 Person Wishes

The people we support with capacity around their health and care needs should be supported to devise an Advance/ Anticipatory Care Plan using the Gold Standards Framework Advance Care Plan Template.

(Appendix 1)

https://thedisabilitiestrust.sharepoint.com/:b:/s/thehub/documents/EQYEQE-qg-FcNbhcn8vYsLYBwmBwHdmGsyRhb3OZ4a_i2w?e=XdHdYI

This is an evidence-based template, devised using national guidelines and policies to enable people to explore and communicate their care preferences, wishes, beliefs and concerns when they are able .

An appropriate staff member will be identified to have a conversation regarding this subject and will agree an appropriate plan to discuss individual needs. It is acknowledged that the timing of this conversation will need to be managed sensitively and it may be appropriate to wait until the person has established a trusting relationship with the staff that supports them.

The staff member will discuss what is important to the individual and their needs and preferences for the future using the Advance Care Plan template.

If a person chooses not to discuss this matter this should be documented clearly within the person narrative and reviewed at agreed intervals for that individual person.

Staff must ensure that they follow Brainkind policy and legal requirements as outlined in the Mental Capacity Act (2005) or Adults with Incapacity Act 2000 when making considerations around end of life / palliative care for a person who lacks capacity. In these instances, a best interest meeting should occur, involving the person (where appropriate), their MDT, family, lasting power of attorney, advocate and any other relevant contacts. The persons views and preferences (past and present) must be considered, and the persons best interests must remain at the heart of the discussion.

When assessing a person's capacity to make a particular decision, reasonable adjustments must be made to maximise the persons capacity should be taken as outlined in the Equality Act (2010) and The Mental Capacity Act (2005).



If an Advance Decision to Refuse Treatment is in place and valid, this will be respected, and an appropriate plan of care will be arranged with the persons team in the service and family when appropriate.

5.2 Recognition of End of Life

When a person has been deemed to be nearing the end of life by a medical practitioner, all steps should be taken to gather the patients views and wishes. Care plans (including their Advance/ Anticipatory Care Plan) should be reviewed and adjusted to include any alterations around the persons views and wishes.

Any discussion should involve the management team and where available clinical team to ensure the wishes can be met by the service.

The management team should ensure the funding authority is informed of any change of condition and seek support to meet the persons wishes.

If the person has capacity, they should be supported to make an Advance Decision to Refuse Treatment if they wish to do so. This can be done by an appropriate person in the service

When a person is deemed not to have the capacity to make decisions about end of life care, a best interest decision must be taken in accordance with the Mental Capacity Act (2005). The best interest decision maker must take all reasonable steps to consult:

- Anybody named by the person as someone to be consulted on either the decision in question or similar issues.
- Anyone engaged in caring for the person, close relatives, friends or others who take an interest in the person's welfare.
- Any holder of a lasting power of attorney.
- Any deputy appointed by the court to make decisions for the person.

When a person's health and or condition deteriorates unexpectedly the appropriate medical practitioner/emergency services should be contacted to assess the person as a priority.

If the doctor deems that the change in condition is potentially reversible, prompt action must be taken to attempt this, if this is in accordance with the person's wishes or in their best interests.

A plan of care must be developed, documented, and the person must be regularly medically reviewed at agreed intervals, to check that the plan of care remains

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appropriate and to respond to changes in the person's condition, needs and preferences.

When death is deemed inevitable by a medical practitioner, persons will be supported, and their wishes followed as agreed in their care plan. All staff will support the death of a person with sensitivity and respect. The person's wishes regarding end-of-life care and death will be discussed, documented, respected and carried out by all involved in the persons care. The persons religious and cultural needs / beliefs must be discussed and considered and incorporated into person centred care plans.

5.3 Communication

Staff must make reasonable adjustments to adapt communication and maximise the person's capacity to enable them to understand their health and care and support needs, and to facilitate patient involvement.

Staff must facilitate and respond to any questions that the person has around their care. An open dialogue around the end of life is encouraged. The same communication must take place with those people identified as being important to the dying person and others involved in that person's care.

Individualised treatment goals and care will be discussed and agreed with the person, involving those identified as important to them and the multidisciplinary team caring for the person. Any planned care and treatment will be clearly documented and accessible to all those involved in the person's care.

The team supporting the person must acknowledge, accept and communicate any uncertainty that exists about the prognosis.

5.4 Decisions Regarding Treatment and Care

Persons should be supported to make decisions around all aspects of their care and treatment. Staff will support the person with clear and sensitive communication ensuring their wishes are always respected.

Staff must liaise with other external professionals involved in the case and support of the individual.

If the person lacks capacity to make a decision, a best interests meeting must be facilitated in accordance with the Mental Capacity Act (2005).



The person's family and friends will be supported by staff. All aspects of care as agreed with the person will be communicated sensitively and clearly. If the person identifies that they would like friends / family to be involved in their care, staff must take reasonable steps to facilitate this.

5.5 Family Support

When appropriate, people who have been identified as important to the person must be kept updated about their condition and supported with their own individual needs.

Staff should be available to listen and communicate sensitively with people who have been identified as important to persons who are nearing the end of their life.

Where a person lacks capacity around end-of-life care, their family should be closely involved in any best interest decisions.

Consideration should be made into the staff resources required to support relatives during the end-of-life period.

Liaison with the local authority or Continuing Healthcare Funding should be considered.

5.6 Care Planning

An individual plan of care, meeting the wishes and needs of the person will be developed by the MDT, (preferably prior to any deterioration) in consultation with the person, those identified as being important to them, and any other relevant services.

Nutrition, hydration, symptom control, psychological, social and spiritual support will be planned and delivered with compassion, this may be done jointly with community nursing support in the local area. The Head of Nursing within Brainkind should be contacted regarding support as required for care plan development.

A plan for care and treatment will be developed to meet the persons' own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. When requested by those involved, or by external practitioners an agreed person will make a referral within 24 hours to the palliative care team when identified as necessary.



Any plan of care will be written so that consistent information about the person's needs and wishes are shared with those involved in the person's care. There will be agreed review times and information will be shared with those involved. As new services become involved in the person's care, the plan of care must be effectively communicated and shared to ensure consistency in care delivery.

The care plan should include any involvement with any external services and include named contacts where possible and their contact details. These should be shared with all involved. Palliative care may be managed in residential units if deemed appropriate and identified as a preference by the person. The changing needs of the person will be reviewed regularly to ensure person care is of a high standard, and to maximise the person's capacity and involvement.

Supporting staff will acknowledge and facilitate any religious needs. All spiritual and religious needs of the person will be documented in the care plan.

The person's wishes regarding the involvement of relatives and friends will be supported and encouraged. This will include an agreed plan of the extent of involvement they would like each person to have in their care. If a Person has no close relatives or friends, or if they are unable to be present when the end of life is near a member of staff known to the person will remain with them.

5.7 Choice of Location

Persons will be supported to choose the location in which they would like to reside when at the end of their life. If the person wishes to remain in their current location, where practical this will be facilitated.

Regular liaison will occur between the person's MDT and the palliative care team to ensure that any care delivered is appropriate and evidence based.

If it is deemed appropriate that the person transfer to an alternative setting at the end of life (EG. home or hospice) a comprehensive handover must be provided, and assessments must be completed prior to this to assess whether this is feasible.

5.8 Sudden Death

In some situations, persons may die unexpectedly. In these circumstances where possible the priorities for care should be implemented. If a person's health deteriorates suddenly or unexpectedly, relevant services must be contacted at the first opportunity to enable relevant steps around end-of-life care to be implemented as soon as possible.

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5.9 Death Under DoLs and Mental Health Section

When a person who is detained under the Mental Health Act (1983) or Scottish Mental Health Act 2003 the coroner will need to be informed.

If a person is subject to authorisations under DoLS coroners will no longer be under a duty to investigate a death solely because a DoLS authorisation is in place. Such deaths will only be reported to the coroner if the cause of death is unknown or where there are concerns that the death was violent or unnatural. Staff must ensure that any external authorities responding to the incident/death

i.e. Paramedic / Doctor, would also need to be informed of the status of the section or DoLS.

The staff should ensure that regulatory bodies are informed as per requirements.

5.10 5.10 Support After Bereavement

Families and others close to a person should be offered support in the service during the end of life and immediately thereafter. Families will be signposted to appropriate counselling services.

Other persons in the service will need to be informed of the loss of a peer and this will be managed sensitively and with careful consideration given to their needs and appropriate support implemented.

Staff who have been affected by the death of a person will be supported by the team and will have access to the counselling service provided by Brainkind.



5.11 Notification of Death

5.11.1 If death was expected:

The Medical Practitioner should be informed immediately and requested to attend to confirm the death of the person.

- The person may have expressed personal preferences within their care plan, these preferences should be followed where possible.
- If family and friends are present, support should be provided, and their wishes considered regarding spending time in the room with the deceased.
- If the family are not present the most senior staff member on duty should inform them of the death and offer support by asking if they would like to attend the service or discuss over the phone if appropriate. They should also be asked if they have a support network at home.
- Following confirmation of the death by a medical practitioner, staff should position the Person's body flat, respecting dignity throughout.
- Any jewellery should be removed if this was specified by the person and recorded in the presence of two staff. This must then be kept safe for collection by their relatives or documented in the narrative that jewellery remains on the deceased.
- Ensure all personal care needs are met showing respect and maintaining dignity throughout the process. This should be completed by 2 competent staff members, clean attire and bed linen should be used.
- Consideration should be given that the family may want to spend some time with the deceased, and this should be respected. Support should be offered by staff if required while they do this.
- Ensure the room is left in a tidy manner and that privacy is respected.
- If relatives express a desire to perform any of these tasks, their wishes should be considered and supported where appropriate.

If the person has a pacemaker in situ, the GP must be informed so that arrangements can be made for removal before cremation.



5.11.2 If the Death was Unexpected

- The surrounding area must be secured and left untouched; and emergency services must be called on 999.
- Formal guidance must then be followed as instructed by the Coroner's Office prior to carrying out any of the previously mentioned points.
- All documentation maybe taken by police and consideration should be given to making copies of the documents so they can be retained in service.

5.11.3 In the Event of any Death

When a Person dies, the regulatory body must be notified without delay,

- Name, age, and sex of the deceased
- Date of admission
- Date and time of death
- Whether referred to the Coroner
- The cause of death, if known
- In the event of an inquest, the date if known
- The conclusion of the inquest (within 24 hours of conclusion)
- The Person register must be completed with full details within 24 hours
- The Service Director, Director of Quality Assurance and Director of Communications should also be notified

5.12 Religious Considerations

Different religions have special requirements which must be adhered to when a person dies:

Christianity - After death Christians should be clothed in a shroud or own night attire and wrapped in a sheet. The arms are placed at the side. There is no religious objection to post- mortem or cremation.

Jewish - When a Jewish person dies, staff must not lay out the body until at least one hour has expired. Usually arrangements for the funeral are made quickly after death by relatives. An exception is made by allowing for registration of Jewish deaths on Saturday and burial on Sundays. If there are no relatives available to arrange the burial, the Jewish Burial Society or local Synagogue should be contacted immediately. Post-mortems are allowed only by the order of the Coroner. Cremation is not allowed (except in the cases of very liberal Jews).



Islam - When a person who is a Muslim die, they should normally be left untouched, if possible, until they can be washed by another Muslim of the same sex and left uncovered. The body should be left in a position where it faces Mecca (approximately South East in the UK). It is important to release the body to the undertakers as soon as possible as relatives prefer to say prayers at a Mosque.

Sikhism - Post-mortems on Sikhs are generally not allowed. A cremation rather than burial will usually be arranged. For men, religious significance is given to wearing a steel bracelet, a dagger and steel comb, together with a turban which, if possible, should not be removed and should be left on the body after death. Hair and beard should not be cut.

5.13 Documentation

During end of life care it is part of professional practice that all staff keep clear and accurate records about all treatment and care given.

Staff must keep clear and accurate records of any discussions, assessments, treatments and medicines provided, and must provide insight to how effective these have been.

Staff must not tamper with original records in any way.

Staff must ensure any entries made in a person's paper records are clearly documented and legibly signed, dated and timed.

Staff must ensure any entries made in a person's electronic records are clearly attributable to the person making the entry.

Staff must ensure all records are kept securely. All documentation must be kept for 6 years after the date of death. All medication should be retained for 7 days after death.

5.14 The Funeral

If there are no family members or friends available, the service Manager will carry out the wishes of the Person. In the event of staff / persons wanting to attend the funeral this will be in agreement with person wishes, after family discussion and dependent on the needs of the service.



5.15 Person's Property

Person's possessions should be listed, packaged and stored safely and passed on to the relevant person as per the Person's wishes and a record kept of the persons receiving. This process should be completed by a minimum of two staff members.

5.16 Registration of Death

Notification of death must be done within five days. To do this you will need:

- A Death Certificate this should be collected by the family, a social worker or legal Power of Attorney where possible.
- Details of deceased's date and place of birth, occupation and marital status, maiden name if married and husband's name and occupation if widowed, date and place of death and details of any state pension or allowances
- NHS medical card and the 'pink form' (form 100) (following a post-mortem)
- If the death has been referred to the Coroner, registration will not be possible until the Coroner has given authority to the Registrar.
- The Registrar will issue a Certificate of Registration (form BD8 rev) that informs the DWP about the death. This should be forwarded to the relatives of the deceased. A Certificate for Burial or Cremation (the green form) is to be taken to the funeral director so that the funeral can be held.



6 References and Associated Policies and Procedures

6.1 References

- Leadership Alliance for the Care of the Dying People (2014)
- NICE Guidance NG31
- NICE Quality Standard 13
- NMC documentation Guidance (2015)
- One chance to get it right
- Marie Curie (2021)
- Compassion in Dying (2018)
- Gold Standards Framework (2013)
- National Palliative and End of Life Care Partnership (2020)

6.2 Policies

- Health and Social Care Act (2012)
- Care Standards Act (2000)
- Equality Act (2010)
- Mental Health Act (1983)
- Mental Capacity Act (2005)
- Human Rights Act (1998)

7 Monitoring, Audit and Review

This policy remains under the control of the Director of Governance and Quality and resides within the Hub. The Director of Governance and Quality also maintains the document control database for tracking and monitoring Brainkind-wide controlled documents within the hub system. It is the responsibility of Quality Assurance Regional Advisors to audit compliance with all policies as part of their normal audit cycle and undertake remedial action as required.

This policy will be reviewed every 3 years.