

POLICY & PROCEDURES ON DEATH & DYING AND BEREAVEMENT

STATEMENT

DRH believe that every service user has the right to die with dignity, without pain and in their own familiar surroundings, with people they know and trust nearby. The quality of care a service user receives in their last days is as important as the quality of life that they experienced prior to this time.

DRH recognises the complexities associated with death, dying and bereavement and the impact these processes have on our vulnerable client groups. Particular communication difficulties can add further complications to complex and emotive issues. We also recognise the additional emotional intensity resulting from the long-term relationships built up over many years between staff and service users.

DRH adheres fully to the National Minimum Standards (Care Quality Commission) which relates to the degree to which homes ensure that the ageing, illness and death of a service user are handled with sensitivity and respect. The staff team will take full account of the individual's physical, emotional, cultural and spiritual needs and wishes.

DRH also believe that service users and staff should have appropriate counselling and support to help them through the bereavement process.

AIM OF THE POLICY

This policy is intended to set out the values, principles policies and procedures underpinning the approach to the treatment of dying service users and support through the bereavement process.

1. Preparing for death

1.1 Home Managers should ensure that every reasonable effort is taken to ascertain the views of service users towards their own death. This may include an *advance medical directive*, which will contain specific instructions to the health care team in the event that the service user is no longer able to express their own wishes in the context of a future serious medical condition (Appendix A "Living Will")

1.2 When death appears imminent it may be necessary to consider the appropriateness of resuscitation in the event of cardiopulmonary failure. Any decision not to resuscitate should always be taken following full and open discussion between everyone who is concerned for the welfare of that service user. (Ref: DRH Policy on Decisions Regarding Cardiopulmonary Resuscitation)

1.3 The staff team should ensure that all service users with the assistance of their family and friends (if that is what the service user desires) are given the opportunity to discuss and plan for ageing, terminal care and death.

1.4 The service users needs and wishes should be fully documented and should take into account any specific requirements i.e.

- Cultural needs
- Religious/Spiritual needs
- Financial considerations
- Palliative care arrangements
- Who, when, how information about dying-death is shared
- Specific requirements for burial/cremation
- Specific funeral service requirements

1.5 There should be clear written guidelines for staff detailing preferred ways of communicating with a service user about these issues. For example, do staff agree that direct and open discussion with the service user about their death is a preferred option? These guidelines should also assist staff to know how best to reassure and support the service user.

2. Care of the Dying

1. Service users should be allowed to die in peace, quietly and reverently.
2. All staff should deal with the death of the service user with sensitivity and respect.
3. Service user's wishes concerning terminal care and death should be discussed, respected and carried out, including observation of religious and cultural customs.
4. Specialist professionals or agencies can provide palliative care, bereavement counselling, practical assistance and advice if the service user wishes. (Appendix B "resources")
5. Service users should be able to die at home, if that is their wish, unless there is a medical reason for an alternative setting.
6. Service users, especially those who have been terminally ill for some time, should be offered the choice of dying at home or in a hospice if this is possible.
7. Other service users and staff in the home should be supported to deal with the illness or death of the service user.
8. The daily routine of washing, bathing, grooming should continue as far as possible to preserve the dignity of the service user.
9. Care plans and guidelines for individual service users should take full account of the need to eliminate or minimise distressing symptoms:

i) Pain:

- Every effort should be made to prevent and minimise pain.
- Pain and pain control measures should be continuously assessed utilising an explicit criteria relevant to the individual
- Any criteria should take account of non-verbal as well as verbal indicators of pain
- The team should seek to identify all factors that relieve or aggravate pain for that individual (e.g. heat, cold, noise, touch)

ii) Anorexia, nausea and vomiting:

- Offer small appetising, easily digested foods
- Keep the mouth and teeth fresh and clean at all times in order to prevent infections such as candida
- Administer anti-emetic medication appropriately

iii) Difficulty in swallowing/dehydration:

- Offer frequent drinks of choice in small amounts

- ❑ Anaesthetic gel may assist if swallowing is painful
- ❑ Maintain good mouth care, apply glycerine or similar to lips to prevent soreness
- ❑ Record fluid input/output to check on fluid balance
- ❑ Watch for signs of dehydration, if present seek immediate medical assistance

iv) Difficulty with elimination:

- ❑ All staff should be aware of the distress experienced by service users with urinary and or faecal incontinence
- ❑ Staff should deal urgently and sympathetically with episodes of incontinence
- ❑ Structured regimes should be in place for avoiding constipation
- ❑ Staff should be aware of the risk of urinary retention and should take appropriate action which may include temporary or longer term catheterisation

v) Skin Integrity:

- ❑ Maintain appropriate diet and fluid intake so as to improve tissue resistance to pressure
- ❑ Ensure regular standardised assessment of tissue viability
- ❑ Prevent skin damage utilising good practice in the way that the service user is handled and moved
- ❑ Ensure that the consequences are dealt with promptly and adequately
- ❑ Position service users in ways that avoid potentially damaging and localised pressure, regular and frequent changes of position are an integral part of the service users care plan. Appropriate specialist equipment should be utilised

vi) Difficulty with Breathing:

- ❑ Ensure adequate ventilation in room
- ❑ Monitor respiratory function
- ❑ Help service user to maintain posture consistent with good respiratory function
- ❑ Ensure clear airway assisting service user if required
- ❑ To administer prescribed respiratory therapy (O2)

vii) Personal Care:

- ❑ Where ever possible the service user should be encouraged to continue to care for themselves
- ❑ Where staff are increasingly required to contribute to the service users personal care every effort should made to ensure maximum privacy and dignity
- ❑ Particular care should be taken with eyes, mouth perineal area, hair and feet/nail care

viii) Psychological and Emotional issues:

- ❑ Every one is an individual and will express fear of death, dying or pain in different ways
- ❑ Staff should make every effort to spend time in the company of the service user – who may well be feeling very lonely at times
- ❑ Service users should be enabled to express their thoughts and feelings in a safe and secure environment

- ❑ Service users may benefit from visits from representatives of their chosen faith – if any
- ❑ Service users should be given every opportunity to maintain a positive self image
- ❑ The staff team should be aware of and respond to the changing emotional needs of the dying service user.
- ❑ Staff should be open and honest in their communication.
- ❑ Special care should be taken to ensure that no member of staff can be overheard discussing the condition of the service user.

3. Actions following a death

- The GP should be notified immediately and the time and persons present at death must be recorded. The GP will confirm that death has taken place and in most cases will issue a death certificate.
- When the cause of death is sudden, uncertain or through injury the GP will notify the local coroner, who will investigate the cause of death and issue the certificates required.
- The staff team should immediately notify any relatives/friends as agreed in the service users care plan
- The home should notify either Connaught House during the day or on-call during out of office hours that a death has occurred.
- The final care of the service user should be carried out by 2 members of staff, one of whom should preferably be a senior member of the team.
- Unless the death is unexpected/untoward or cultural requirements dictate the body should be washed and cleansed, clean nightclothes should be put on, the hair should be brushed, eyelids closed and mouth closed. The body should be covered with a clean sheet.
- Jewellery/personal items should either be removed and logged or accounted for within the service users notes.
- The appropriate funeral director should be notified to remove the body to the appropriate/agreed place.
- Staff must ensure that all these tasks are carried out with sensitivity maintaining privacy and dignity at all times.
- The Home Manager is responsible for notifying the appropriate registration body i.e. CQC (Care Quality Commission) within 24 hours.
- Notification should also be made to the relevant purchasing agency e.g. South West Dorset NHS PCT; Dorset Social Services; Dorset Healthcare NHS Trust.
- DRH may also register the death where there are no relatives or the relatives wish the home to do so on their behalf. The Home Manager should seek advice and guidance from their LO.
- Specific attention should be given to supporting the other service users and staff team following a death. If required time should be given to allow for the normal grieving process, staff should remain open and honest with other service users ensuring they have the opportunity to talk through their feelings.
- The staff team may be asked to support relatives with the process of arranging the funeral or may be required to carry out the whole process themselves, the team should ensure they observe any expressed needs, wishes or desires of the service user.
- If appropriate staff should ensure that other service users have some involvement in these preparations and in attending any funeral service.

4. Bereavement:

4.1 The loss of someone close to us is always a painful and traumatic experience. For people with a learning disability or a history of long-term mental illness, bereavement can present additional difficulties. Staff often deny the loss or play down its significance to service users. Staff may also give inappropriate emotional responses to the service users while discouraging their own emotional response. We need to appreciate that service users may express grief in very different ways, which may be open to misinterpretation by those around them.

4.2 Staff can assist service users through the phases of bereavement, in the following ways:

- Finding out what the service user knows or needs and identifying what can be done to help them
- Acknowledging the service users loss and its importance and significance to them
- Communicating simply, clearly and truthfully
- Involving the service user as much as possible, and as much as they want to, with what is happening before, during and after death. The opportunity to participate in the rituals surrounding death is very important
- Letting your genuine concern show
- Trying alternative methods of communication to help service users make sense of what is happening around them (e.g. story books, artwork, photographs)
- Helping the service user to learn an emotional vocabulary – encouraging the person to use words, draw pictures or paint to express feelings and emotions
- Offering the service user time – to be there when they need you most

(S.Reed 1999 Emap Healthcare Ltd)

4.3 The responses to grief are many and varied:

GRIEF RESPONSES (Worden, 1991)

Emotional	Physical	Behavioural	Psychological
<input type="checkbox"/> Sadness <input type="checkbox"/> Anger <input type="checkbox"/> Guilt <input type="checkbox"/> Self-reproach <input type="checkbox"/> Anxiety <input type="checkbox"/> Loneliness <input type="checkbox"/> Fatigue <input type="checkbox"/> Helplessness <input type="checkbox"/> Shock <input type="checkbox"/> Yearning <input type="checkbox"/> Relief <input type="checkbox"/> Numbness	<input type="checkbox"/> Hollowness in the stomach <input type="checkbox"/> Tightness in the chest <input type="checkbox"/> Tightness in the throat <input type="checkbox"/> Over sensitivity to noise <input type="checkbox"/> A sense of depersonalisation <input type="checkbox"/> Breathlessness <input type="checkbox"/> Muscle weakness <input type="checkbox"/> Lack of energy <input type="checkbox"/> Dry mouth	<input type="checkbox"/> Sleep disturbance <input type="checkbox"/> Appetite disturbance <input type="checkbox"/> Absent - 'mindlessness' <input type="checkbox"/> Social withdrawal <input type="checkbox"/> Dreaming <input type="checkbox"/> Searching <input type="checkbox"/> Crying <input type="checkbox"/> Sighing <input type="checkbox"/> Restless over-activity <input type="checkbox"/> Visiting old haunts	<input type="checkbox"/> Disbelief <input type="checkbox"/> Confusion <input type="checkbox"/> Preoccupation <input type="checkbox"/> Sense of the deceased persons presence <input type="checkbox"/> Hallucinations

4.4 There are a number of organisations that can offer counselling and support to people who have been bereaved, details are provided on our resource page (appendix B)

5. TRAINING

- 5.1** All staff should familiarise themselves with the content of this policy.
- 5.2** All new staff should read the policy on dying service users as part of their induction process.
- 5.3** DRH intend to identify and to train several staff with additional expertise in palliative care who will be a resource for all DRH Homes.

References:

Bereavement and people with a Learning Disability. Sue Read. NT Monograph. N.30
1999

Last Rights: A study of how death and dying are handled in service userial care and nursing homes. Jef Smith et al. Counsel & Care.

Living Will. Kings College/Terence Higgins Trust. 2000

National Minimum Standards & Regulations: Independent Health Care
Department of Health London: The Stationery Office 2002

National Minimum Standards for Care Homes. Care Quality Commission:.
Department of Health London: The Stationery Office 2002

Understanding Grief: Working with people who have learning disabilities. Hollins &
Sireling. Pavilion/Dept.of Psychiatry and Disability, St.Georges Medical School.

APPENDIX A

LIVING WILLS

A "Living Will" enables someone to tell people about their wishes regarding medical care when they are no longer able to exercise meaningful choice. The statements the individual makes about future treatment are known as "advance directives"

An individual wishing to make a "Living Will" may appoint someone called a "health care proxy" to take part in decisions about medical treatment on their behalf.

The "Living Will" is only about medical care and treatment.

A "Living Will" and nomination of "health care proxy" can be recorded on a form published by the Kings Fund and Terence Higgins Trust and available through DRH at Connaught House.

If any DRH staff are approached by a service user wishing to make a "Living Will" they should assist the service user to obtain independent advice. No-one in the employ of DRH should agree to act as a "health care proxy".

A "Living Will" can only be made by someone who is competent to do so.

DRH Policy on Death Dying and Bereavement.....

APPENDIX B

DEATH, DYING & BEREAVEMENT RESOURCES:

CRUSE BEREAVEMENT LINE: Helpline for bereaved people and those caring for bereaved people. Tel 0870 167 1677

THE COMPASSIONATE FRIENDS: Support and friendship for bereaved parents and their families.

Tel: 01202 387929

SAMARITANS: offer befriending to people who are suicidal or experiencing despair/loneliness etc

Tel: 01305 771777/8

DORSET ADVOCACY: Develops one to one partnerships between people who have a learning disability and volunteer advocates. Advocates help people speak up to protect their rights and ensure their wishes and concerns are heard.

Tel: 01305 251033

MACMILLAN CANCER RELIEF: UK Charity supporting people living with cancer. Provides information, advice and guidance.

Tel: 01202 426546

SAMM SUPPORT (SUPPORT AFTER MURDER AND MANSLAUGHTER): A Charity run by people who have been bereaved as a result of murder or manslaughter. Provides information, advice and guidance for the victims' friends and family

Tel: 01305 787869
0277353838

OCCUPATIONAL HEALTH: Provides guidance and advice to staff and also access to counselling services if required. Referral via Home Manager or directly to Forston Clinic

Tel: 01305 361361

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