

## CR23 - End of Life Care Planning Policy and Procedure

### Purpose

- ▮ To provide a framework to guide best practice care and support of Service Users who have been identified as nearing the end of their life.

### Scope

- ▮ Service Users who have been identified as nearing the end of their life.

### Policy

- ▮ This Policy has extracted from the National End of Life Care Programme those elements which are consistent with the best practice identified within the Review, in particular the individualised assessment and Care Planning.
- ▮ Users of the QCS Care Planning system will have in any case, notwithstanding the specifics of the National End of Life Care Programme, been following best practice due to the long standing emphasis on individualised Care Planning in the QCS system.
- ▮ The organisation will carry out Advance Care Planning where it is assessed that a risk of death while receiving services from the organisation is a possibility, for any reason, in order to provide a framework within which the care and support valued by the Service User is delivered whenever possible.
- ▮ The Service Users will be comfortable and as pain free as possible.
- ▮ Spiritual and emotional support will be available for all Service Users to choose if they should so wish.
- ▮ End of life Care will be in accordance with the Deprivation of Liberty Safeguards Policy and Procedure assessments and subsequent entries in the Care Plan, and in particular end of life guidance relating to mental capacity.
- ▮ The following procedures are intended to acknowledge best practice in the care of the dying, and also to ensure that effective co-ordination takes place between the various persons and agencies which are involved in end of life care.

### Care setting

- ▮ Care of the dying is a requirement which can occur in any care setting.
- ▮ The NHS, in the event of a known prognosis of imminent death, may drive the design of end of life care, but they will, in only a minority of cases, be the only provider of end of life care, and even that will often be of short duration. It is far more likely that the NHS will provide some temporary support and that, if most people's personal wishes are met, end of life will actually occur in the Service User's home, be that a care home or their family home.

### Summary

#### There are generally considered to be six steps in providing effective end of life care

- ▮ Step 1 - Discussions as the end of life approaches.
- ▮ Step 2 - Individualised Assessment, Care Planning and review.
- ▮ Step 3 - Co-ordination of care.
- ▮ Step 4 - Delivery of high quality services in different settings.
- ▮ Step 5 - Care in the last days of life.

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- Step 6 - Care after death .

### Discussions as the end of life approaches

- Research has suggested that a planned approach to advance Care Planning can be effective, and this includes difficult communication. This approach can be broken down into:
  - Raising the topic and giving information;
  - Facilitating a structured discussion;
  - Completing the statement and recording it;
  - Periodically reviewing and updating the directives;
  - Bringing prior wishes to bear on actual decisions.
- Refer to the article “End of life care – Discussions as the end of life approaches” in the News section of the QCS web site for a more full discussion of the issues.

### Individualised Assessment and Care Planning

- The steps for individualised assessment and Care Planning, as structured within the QCS Care Planning system are:
  - Assess;
  - Document;
  - Develop;
  - Discuss;
  - Choose;
  - Plan;
  - Record;
  - Review.
- See the QCS Care Planning Policy and Procedure for more details.
- Note that the Independent Review of the LCP was critical of template approaches to Care Planning, and considered that this was incompatible with good end of life care. The QCS approach is that template Care Planning is incompatible with any effective care delivery, and should be avoided. Staff entrusted with Care Planning must be trained to implement fully personalised and individual assessments and Care Plans.
- Refer to the article “End of life care – Assessment and Care Planning” in the News section of the QCS web site for a more full discussion of the issues.

### Coordination of care

- Services providing, or planning to provide, end of life care must ensure that all the staff involved are appropriately trained and the service needs to be co-ordinated by a highly capable and skilled person, with the ability to manage detail and cut through organisational inadequacies to achieve a quality outcome for the Service User.
- To this end you should:
  - Be alerted by a Healthcare professional if an end of life Care Plan has been created for a Service User;

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- i Request a copy of the end of life Care Plan and assessment;
  - i Review the Eleven Sisters Community Support Services Ltd Care Plan ensuring that the detail reflects the Healthcare professional's plan to ensure a cohesive service is provided;
  - i Ensure an appropriate person on behalf of Eleven Sisters Community Support Services Ltd attends all multidisciplinary review meetings;
  - i Ensure practical and emotional support is offered to the Service User's family and Carers at all times whilst an end of life Care Plan is in place.
- i Refer to the article "End of life care – Coordination of care" in the News section of the QCS web site for a more full discussion of the issues.

### Service delivery

- i Best practice is that individuals and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless of the care setting.
- i Individualised assessment and Care Planning are the lynchpin of effective end of life care. Without excellent wide ranging assessment, the full needs of the Service User are unlikely to be consistently met, and Care Planning will not be comprehensive. Without comprehensive Care Planning, effective care was not possible.
- i Extensive, comprehensive and detailed training in the issues involved in end of life care is essential for all employees within a service providing end of life care. End of life care is significantly different in content and scope from other care in that informal methods of training are generally inadequate to provide best practice levels of service.
- i It is the responsibility of the primary care giver to ensure that effective co-ordination takes place – see above "Coordination of care".
- i Some essential practical day to day procedural matters include:
  - i Service Users will have access to a medical specialist in palliative care.
  - i Pain management measurement will be ongoing.
  - i The Service User has comfort needs attended to; chair, bed etc.
  - i The Service User has diversional therapy e.g. music, radio etc.
  - i The Service User has a carer/nurse of their own choice, with whom they can spend some one-to-one quality time each day.
  - i The Service User's environment will be clean, odour free and comfortable.
  - i The Service User will have a member of staff to sit with them if they request it.
  - i The Service User will have a Support Worker or Carer to sit with them if they are alone at the end of life.
  - i The Service User's family are treated with empathy and offered support and refreshments according to their needs.
  - i Relatives will be informed about any changes in the condition of the Service User.
  - i Relatives will be informed of the death of a Service User at a time to minimise distress, e.g. in the morning after a death in the night, unless otherwise requested by the family.

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- i Other Service Users who know the Service User will be informed of the death by a senior member of staff.
  - n Where the Agency is not the prime deliverer of any of the above services, such as pain control, the staff should be trained to be aware that the service should be being provided by another service, and who to contact in the event that they observe or become aware of any problems, or distress to the Service User.
- i Refer to the article “End of life care – Service delivery” in the News section of the QCS web site for a more full discussion of the issues.

### Last days of life

- i Best practice is that the point comes when an individual enters the dying phase. It is vital that staff can recognise that this person is dying, so they can deliver the care that is needed. How someone dies remains a lasting memory for the individual's relatives, friends and the care staff involved.
- i Individualised planning, Individualised assessment, further planning, recording and review, and information giving are essential components of delivering care and support during the last days of life.
- i Effective documentation, such as detailed individualised Care Planning and review are essential supports for effective delivery. Some form of Care Planning may be carried out by each of the agencies responsible for elements of the total service, with the risk of lack of co-ordination. It is the responsibility of the primary care giver to ensure that effective co-ordination take place, particularly during the final days. It is also important that the primary care giver ensures that Care Plans are individualised, including those of other agencies, and negotiate rectification of they are not.
- i Refer to the article “End of life care – Last days of life” in the News section of the QCS web site for a more full discussion of the issues.

### Care after death

- i Best practice is that good end of life care doesn't stop at the point of death. When someone dies all staff need to follow good practice, which includes being responsive to family wishes. The support and care provided to relatives will help them cope with their loss.
- i Care after death includes:
  - i Honouring the spiritual or cultural wishes of the deceased person and their family/carers, while ensuring legal obligations are met;
  - i Preparing the body for transfer to the mortuary or the funeral director's premises;
  - i Offering family and carers present the opportunity to participate in the process and supporting them to do so;
  - i Ensuring that the privacy and dignity of the deceased person is maintained;
  - i Ensuring that the health and safety of everyone who comes into contact with the body is protected;
  - i Honouring people's wishes for organ and tissue donation;
  - i Returning the deceased person's personal possessions to their relatives.
- i Refer to the article “End of life care – Care after death” in the News section of the QCS web site for a more full discussion of the issues.
- i An effective end of life support plan will also contain four elements of care which should be present throughout the six steps listed above.
  - i Support for carers;

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- i Information for patients and carers;
  - i Spiritual care;
  - i Social care.
- i Refer to the article “End of life care – Elements of care” in the News section of the QCS web site for a more full discussion of the issues

### Resources

- i Social Care Institute for Excellence (SCIE) Dementia Gateway.  
<http://www.scie.org.uk/publications/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/index.asp>
- i NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE.
- i Quality standard for end of life care for adults.
- i Quality standard advice to the Secretary of State for Health:  
<https://www.nice.org.uk/guidance/qs13>
- i The report of the Independent Review of the Liverpool Care Pathway:  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.p](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.p)

### Key Lines of Enquiry Table

Key Line of Enquiry (KLOE)	Supporting
C1 - How does the service ensure that people are treated with kindness, respect and compassion, and that they are given emotional support when needed?	✓
C3 - How are people's privacy, dignity and independence respected and promoted?	✓
E7 - Is consent to care and treatment always sought in line with legislation and guidance?	✓
R3 - How people are supported at the end of their life to have a comfortable, dignified and pain free death?	✓

**Note: All QCS Policies are reviewed annually, more frequently, or as necessary.**

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