Stroke is one of the three biggest killers in Scotland. In 2008, 19% (1,740) of adult patients admitted to hospitals in Scotland with a stroke died in the acute phase i.e. within the first 30 days. This Quick Reference Guide summarises the main points of a Best Practice Statement which addresses end of life care for patients who have had an acute stroke. This is recognised as being a component of palliative care. The target audiences for this statement are nurses working in stroke units or care homes. The full best practice statement can be downloaded at www.nhshealthquality.org or www.glasgow.ac.uk/nursing.

Referral to specialist palliative care services

1. Patients receiving end of life care following acute stroke have access to specialist palliative care services.
2. Staff caring for the patient who has had an acute stroke and is at the end of life may require support from specialist palliative care services.
3. The needs, opinions and participation of the family/carer are considered during end of life care.
4. End of life care is provided by healthcare professionals experienced in stroke care.
5. End of life care is individualised.

The multidisciplinary team

1. Staff are equipped with the appropriate knowledge and skills to care for the patient at the end of life following acute stroke.
2. End of life stroke care is characterised by team working.

Ethical aspects of care - end of life issues including withdrawal of treatment

1. Early decisions about withholding cardiopulmonary resuscitation are avoided.
2. There is full discussion with the patient (if possible) and family/carer about reasons for withdrawal/futility of treatment to allow all concerned to understand treatment goals.
3. There is accurate documentation of plans of care and discussions between the multidisciplinary team, the patient and family/carer.

Decision-making

1. Patients and their families/carers participate in the decision-making process of their treatment.
2. The patient’s needs, wishes and preferences are discussed and planned at every stage of care.
3. Advanced care directives are recognised by the multidisciplinary team and are used to support decision making.
Symptom management and nursing care

1. Symptoms are managed effectively with regular review and ongoing evaluation.
2. A pathway such as the Liverpool Care Pathway for the Dying Patient (LCP) is used for care in the last days of life following acute stroke.
3. Advance/anticipatory care planning is considered. This includes discussion of anticipatory prescribing in relation to symptoms.
4. Communication with the family/carer is proactive.

Nutrition and hydration

1. Staff understand that provision of oral fluid and nutrition is part of core care and is not to be withdrawn unless the patient refuses or is unable to participate. Nurses have a key role in nutritional and swallowing screening.
2. Staff understand that clinically assisted nutrition and hydration are considered medical treatments within law and therefore can be withheld or withdrawn if considered to be of no benefit for the patient. Where there is doubt or lack of consensus surrounding the benefit of supporting nutrition or hydration a time limited trial of clinically assisted nutrition or hydration is considered.
3. Staff understand that in patients with problems with oral feeding, decisions regarding supporting nutrition and hydration are often made in tandem with the recognition that the patient is entering end of life care. Nurses contribute to the decision-making within a multidisciplinary context.
4. Nutrition and hydration where appropriate are provided according to the individualised care plan. Nurses have a key role in the provision and monitoring of oral and clinically assisted nutrition and hydration.

Spiritual and religious care

1. In the multidisciplinary team there is recognition, knowledge and understanding of spiritual and religious beliefs and practices and their impact on health.
2. There is openness to discussing spiritual and religious beliefs and needs with the patient and family/carer.
3. The patient and family/carer are offered access to spiritual and religious leaders.
4. Resources and information are available for staff, the patient and family/carer to support religious and spiritual care.

Family/carer support

1. Information is selected to meet the needs of the patient and their family/carer.
2. A range of stroke information in various formats is displayed and accessible to the patient and family/carer.
3. A private quiet room is provided for staff to speak with family/carers.
4. Nursing staff provide the bereaved family/carer with practical support, information and assistance.
5. Nursing staff support the family/carer at the start of their bereavement by being available, and sensitive to their grief.