University of Glasgow

College of Medical, Veterinary & Life Sciences
Nursing & Health Care School

NHS
Quality Improvement Scotland

Best Practice Statement ~ December 2010

End of life care following acute stroke

NHS Quality Improvement Scotland is committed to equality and diversity. We have assessed this Best Practice Statement for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation. For a summary of the equality and diversity impact assessment, please see our website (www.nhshealthquality.org). The full report in electronic or paper form is available on request from the NHS QIS Equality and Diversity Officer.

First published December 2010

www.**nhshealthquality**.org

Contents

Introduction

NHS Quality Improvement Scotland (NHS QIS) leads the use of knowledge to promote improvement in the quality of health for the people of Scotland and performs three key functions:

- providing advice and guidance on effective clinical practice, including setting standards
- driving and supporting implementation of improvements in quality, and
- assessing the performance of the NHS, reporting and publishing the findings.

In addition, NHS QIS also has central responsibility for patient safety and clinical governance across NHSScotland.

This best practice statement was produced by the University of Glasgow using the NHS QIS methodology and with project support from NHS QIS. Funding for the project was granted by the National Advisory Committee on Stroke with support from NHS Greater Glasgow and Clyde Stroke Managed Clinical Network. It is a consensus statement agreed by a representative working group of stroke care professionals. It is not a systematic review or a clinical guideline but is based upon a review of the available literature, conducted in a systematic and logical way.

Key principles of best practice statements

A series of best practice statements has been produced by NHS QIS, designed to offer guidance on best and achievable practice in a specific area of care. These statements reflect the current emphasis on delivering care that is patient-centred, cost-effective and fair. They reflect the commitment of NHS QIS to sharing local excellence at a national level.

Best practice statements are produced by a systematic process, outlined overleaf, and underpinned by a number of key principles.

- They are intended to guide practice and promote a consistent, cohesive and achievable approach to care. Their aims are realistic but challenging.
- They are primarily intended for use by registered nurses, midwives, allied health professionals, and the staff who support them, but will also be of relevance to medical professionals.
- They are developed where variation in practice exists and seek to establish an agreed approach for practitioners.
- Responsibility for implementation of these statements rests at local level.

Best practice statements are periodically reviewed, and, if necessary, updated in order to ensure the statements continue to reflect current thinking with regard to best practice.

This best practice statement is accessible electronically on the NHS QIS website **(www.nhshealthquality.org)** and the University of Glasgow website **(www.glasgow.ac.uk/nursing)**.

Supporting implementation

In the interests of supporting implementation, readers are encouraged to use the tools in Appendix 1 and 2, either for reflection on individual competence, confidence and practice, or for audit at an organisational level.

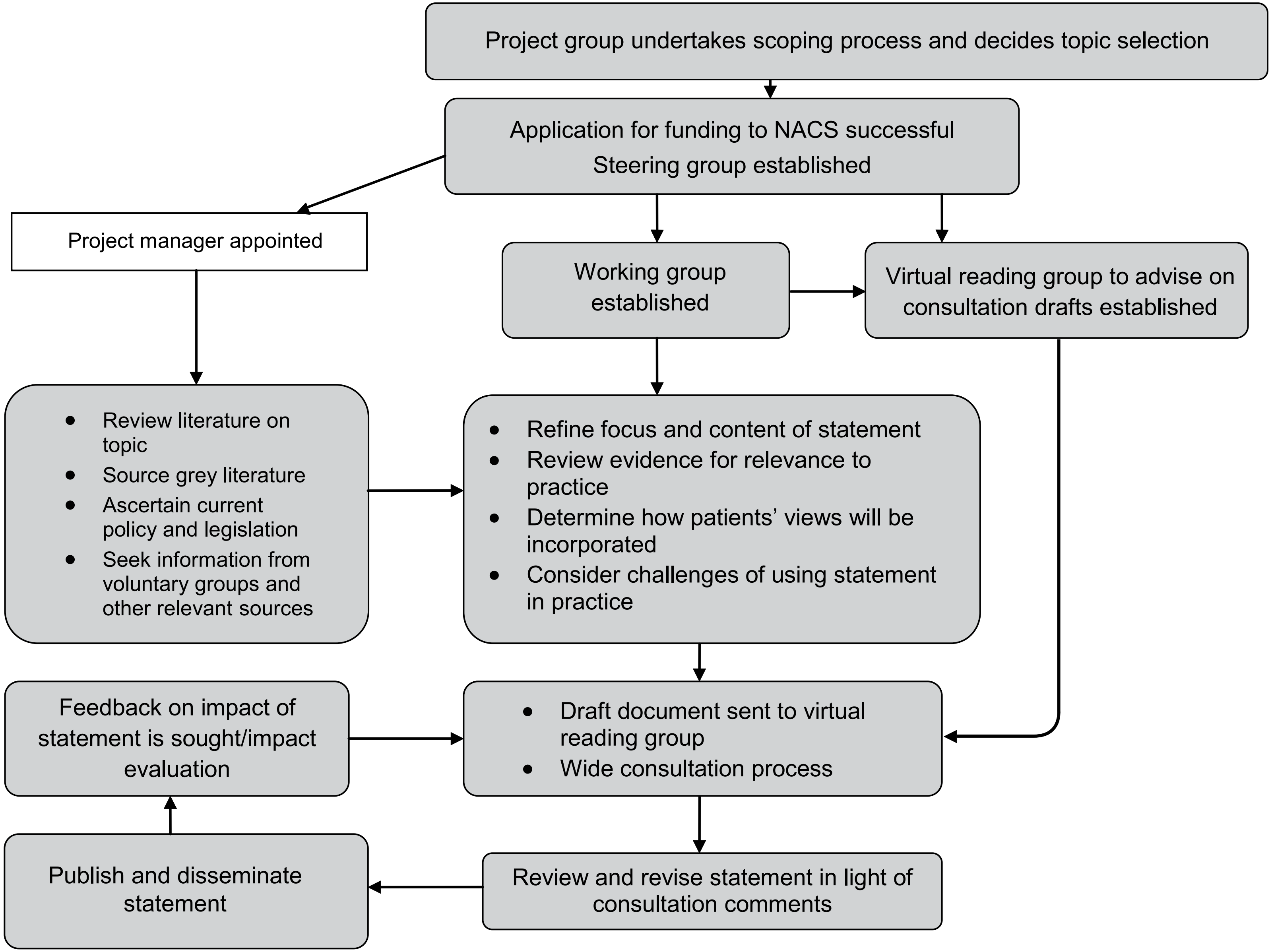
Comments on best practice statements are very much welcomed. We are always keen to hear from anyone who has been involved with using the statements in their own area of practice. In particular, we would like to hear about specific successes or challenges relating to implementation and impact on quality of care provision.

Any information provided will be used to inform the next review of the statement.

Please forward any comments to: **qis.bestpracticestatements@nhs.net**

Privacy note: We will only use your email details to reply to your comment. Your address will not be passed on to any third parties.

Key stages in the development of this best practice statement



Background

Stroke can be a sudden and catastrophic event, carrying a significant risk of death. It is, along with cancer and heart disease, one of the three biggest killers in Scotland[1] and remains a national clinical priority[2]. However caring for stroke patients in dedicated stroke units has been shown to result in lower levels of mortality and disability[3]. In 2008, 19% (1,740) of adult patients admitted to Scottish hospitals with a stroke died within 30 days[4]. Therefore hundreds of patients each year require care at the end of their lives following a stroke.

Palliative care as defined by the World Health Organization is wide-ranging and may be provided many months or even years before death. Palliative care is defined by the World Health Organization (2002) as:

> "…an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual…" [5,p84]

By contrast, care provided at the end of life is recognised as being one component of palliative care[6]. Since this statement is concerned with a 30 day period and as stroke can be a sudden event, the steering group decided to use the term 'end of life care' rather than palliative care. Therefore for the purposes of this statement, the term end of life care is used rather than palliative care throughout the text.

It may be useful when using this best practice statement to consider that within the first 30 days following stroke, patients may fall into three possible categories or pathways.

1. Those patients for whom a degree of recovery is anticipated and who are very likely to gain benefit from full rehabilitative measures.
2. Those where the extent of stroke and/or the irreversible damage is moderate or unclear. There is associated uncertainty as to the patient's likely survival. It is possible or likely that the patient might not survive the next 30 days.
3. Those patients where there appears to be an extensive stroke with profound irreversible damage (and/or co-morbidities) such that death in a matter of days is a probable outcome.

The Scottish Government is committed to supporting implementation of end of life care pathways in all care settings[7]. Additionally, the 2008 action plan, 'Living and Dying Well', suggests that patient preferences for place of care at the end of life should always be sought. Throughout this statement, the term 'patient' refers to patients affected specifically by stroke unless otherwise indicated.

Care of patients at the end of life is an important clinical issue for stroke nurses and the teams and family/carers with whom they work. Because of the rapid onset of acute stroke, patients and carers may require support in coping with the pace of events while making important decisions, and stroke nurses have a role to play here. Whether working in stroke units or care homes, nurses are important members of the multidisciplinary team, caring for stroke patients at the end of life and liaising with other disciplines in clinical decision-making and the planning of care. In addition, at times nurses are responsible for making decisions not to initiate cardiopulmonary resuscitation (CPR)[8].

Communication within the clinical team as well as with patients and family/carers is paramount. Decisions about treatment may have to be made on the patient's behalf, and the patient and family/carer may not have anticipated or thought about what care they would prefer at the end of life and in what setting (eg hospital or home).

Difficulties can arise in knowing when to initiate end of life care when the trajectory of the disease is not necessarily predictable. Anecdotally, stroke care professionals describe difficulties in recognising when stroke patients are dying and there may be a need for future research in this area.

Search strategy

Literature was searched systematically to answer the search question, 'What is the best practice in end of life care following an acute stroke?' where acute stroke was defined as 30 days following the stroke event. Databases searched were:

- All Evidence Based Medicine Reviews
- The Cochrane Library
- Medline
- CINAHL
- AMED
- PsychBite
- PsychInfo
- IBSS
- Web of Science
- British Nursing Index

Search priorities

1. To identify any systematic reviews
2. To identify any literature searches done systematically
3. To identify observational literature
4. Identification of grey literature, ie

> 'Grey literature is best defined as literature which cannot readily be acquired through normal bookselling channels and which is therefore difficult to identify and obtain. Other terms, such as 'non-conventional' or 'semi-published' are also used to describe it. Examples of grey literature include technical or research reports, doctoral dissertations, some conference papers and pre-prints, some official publications, discussion and policy papers.'[9]

Keywords

Stroke, end of life, palliative care, Liverpool Care Pathway, withdrawal or withholding of treatment, terminal, multidisciplinary team, nurses, patient, hospital, stroke units, care homes, continuing care units, rehabilitation units, referrals, religious, spiritual, cultural, carers, supporting families, symptom control, seizure, pain, restlessness, dehydration, feeding, nutrition and futility.

Exclusions from searches

Literature relating to hospices or community/primary care was excluded by the steering group on the grounds that the target audience are nurses working in hospitals or care homes, and that hospices and primary care have guidelines and frameworks which are particular to their specialty.

Other exclusions included paediatric literature as this statement concerns care of adult patients and any papers relating to subarachnoid haemorrhage, which although meeting the classic World Health Organization definition of stroke, has been chosen more recently by some authors to be excluded from consideration[10,11].

Search parameters

- written in English
- relates to studies of humans
- contains abstracts
- published between 2003 and 2010
- a proviso allowed consideration of papers published between 1997 and 2002 if necessary, but this was not required.

Search results

2,509 papers were identified.

Methodology

Rapid evidence assessments

A rapid evidence assessment (REA) methodology was used. While similar in principle to systematic reviews, REAs have a narrower focus with a specific search question, inclusion/exclusion criteria, condensed timescales (2-6 months) and review processes allowing a quick, feasible evaluation of good quality information[12,13]. They have been used effectively in mental health[12] and social science reviews[14].

Identification of literature and handling of results

The search strategy was devised with support from a University of Glasgow librarian. Results of searches were reduced to 194 relevant references by using the search question when reading the abstracts. Results were further reduced to 120 following a cull by a second independent reviewer. Papers fell into five topic areas. The 120 papers were distributed to the working group and evaluated using relevant data evaluation tools.

Data evaluation

Standard Scottish Intercollegiate Guidelines Network (SIGN) methodological checklists were used to evaluate systematic reviews, randomised controlled trials, cohort studies and case-control studies[15].

In order to identify a relevant tool to evaluate qualitative research, we reviewed literature and consulted with experienced systematic reviewers. Following appraisal of each identified tool (eg Newcastle Ottawa Scale[16], Joanna Briggs Institute tools[17]), it was decided to adapt a checklist devised by the Critical Appraisal Skills Programme (CASP)[18], on the grounds that it was user friendly and has been widely used. The CASP employs statements as prompts for evaluation. These were turned into questions, eg 'Consider: if the findings are explicit, if there is adequate discussion of the evidence' became 'Consider: are the findings explicit? Is there adequate discussion of the evidence both for and against the researcher's arguments?" Evidence summary sheets were adapted from SIGN[15].

The working group

The working group was made up of healthcare professionals with a range of experience and expertise in stroke or palliative care, from eight NHS boards in Scotland. A patient representative was a member of this group.

Distribution of tools to working group

A questionnaire was sent to all working group members to gauge familiarity with systematic reviewing. Results showed that there was a range of experience in terms of systematic reviewing, eg participation in SIGN guidelines but that none had authored or co-authored a systematic review.

Papers were allocated to five topic subgroups (2-4 members in each) of the working group. In identifying topic groups, consideration was given to professional background and reviewing experience so there was a blend of knowledge and skill. Each paper was sent with appropriate reviewing tools and evidence summary sheets. Working group members used the checklists and evidence summaries to make statements about the evidence base or to reject papers. Group members read papers individually and collaborated on evaluating evidence, making consensus statements of best practice where evidence was absent. Decisions and justifications to accept or reject papers and their findings, or to make statements of best practice had to be agreed with other subgroup members.

Virtual reading group

Similar to the working group, the virtual reading group comprised healthcare professionals, educationalists and academics with an interest in stroke or palliative care. Members of this group read and commented on the statement in draft form. In addition there was widespread consultation on the document with distribution through the stroke managed clinical networks, NHS QIS networks, and the Scottish Stroke Nurses' Forum and other groups. All consultation comments were considered and responded to by the working group with changes made to the statement as necessary.

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[a] Further information about this checklist may be obtained by contacting the University of Glasgow project team at www.glasgow.ac.uk/nursing

Format of statement

The statement is divided into four sections covering:

Section 1: Delivery of stroke services

Section 2: Delivery of care

Section 3: Ethical aspects of care

Section 4: Family/carer support

The sections are designed to provide a logical, coherent information flow. Each section contains a table corresponding to the what, why and how of best practice, ie summarising the statement, the reason for the statement and how to achieve the statement or to demonstrate that it is being achieved and highlights the underpinning philosophy of the statement and/or explicit skill requirements to achieve best practice. Key challenges highlight areas that may require specific action or development.

How can the statement be used?

This best practice statement can be used in a variety of ways, although primarily it is intended to serve as a guide to best practice and promote a consistent and cohesive approach to care. The target audience for this statement is registered nurses working in acute stroke units and care homes. The statement is intended to be challenging but realistic and can be used:

- as a basis for developing and improving care directly and indirectly
- to stimulate learning among multidisciplinary teams
- to promote effective multiprofessional team working and enhance partnerships with patients, carer(s) and relevant others, and
- to stimulate ideas and priorities for research.

Section 1: Delivery of stroke services

Section 1a: Referral to specialist palliative care services

Key points:

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 individualised.

Statement	Reason for statement	How to demonstrate statement is being achieved
Stroke patients receiving end of life care and the staff who care for them have access to specialist palliative care services when necessary. (See Section 2a.)	This improves end of life care for patients. 'Specialists in palliative care may be able to support their colleagues working in stroke by assisting decision-making at the end of life and help minimise tensions and distress within teams.'[19 p328] 'Generalists and specialists should be working together to ensure that specialist care is available to patients with complex needs while general provision is available to all.'[20,p8]	This is documented in the patient notes.
End of life acute stroke care is provided by healthcare professional teams experienced in stroke care.	There are particular challenges in the stroke population eg cognition, dysphagia and problems with communication[21]. Stroke core competencies have been identified and are required for healthcare professionals working in stroke care[22].	Training records demonstrate this eg use of Stroke Training and Awareness Resources (STARS)[23].
All stroke staff providing end of life care undergo appropriate training including communication skills.	Most end of life care is provided by staff who are not specialists in palliative care[20]. 'Communication skills are paramount in end of life care and staff should have access to high quality education and support in this area.' [24,p2171]	Training records demonstrate this.
The needs and participation of family/carers are considered during end of life care.	This is considered good practice. Carers of stroke patients tend to have a different needs profile from, for example, carers of those with cancer and may well have needs of their own[19].	This is documented in the patient notes. Family/carer satisfaction audits are conducted and complaints responded to in writing.

Statement	Reason for statement	How to demonstrate statement is being achieved
Communication with family/carers about the patient's treatment, specifics related to the condition and the decision-making process is paramount in palliative care and end of life care.	Results from a retrospective qualitative study suggest that relatives want to be actively involved in discussions with nurses and doctors about the condition of the patient[24].	Communication with the family/carer is documented in the patient notes. Family/carer satisfaction audits will identify involvement in discussions.
Care is tailored to the individual.	Individualised end of life care increases satisfaction[24].	There is evidence that an end of life care pathway is used.

Key challenges:

- Bridging the gap between specialist palliative care services and acute stroke care services.
- Differentiating between the needs of patients who die in the acute phase of stroke and those who die later.
- Providing staff training on end of life care following acute stroke.
- Building the evidence base for end of life care in the acute phase of stroke.

Section 1b: Multidisciplinary team

Key points:

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

Statement	Reason for statement	How to demonstrate statement is being achieved
Members of the multidisciplinary team are employed in end of life care for acute stroke patients. This is not in their usual role for rehabilitation, but for: • symptom control • patient comfort and • family/carer support.	A recommendation of Living and Dying Well[7] (Action Point 5) states that: 'Patients with any condition who have been assessed as having … end of life care needs … are supported by a multidisciplinary team.' [7, p15]	The outcome of multidisciplinary team discussions are documented in the patient notes.
All healthcare and social care professionals caring for stroke patients at the end of life are equipped with the appropriate knowledge, skills, competence and confidence.	This is good practice[7,25].	The appraisal and continuing professional development (CPD) system and training records demonstrate this.
Members of the multidisciplinary team have a role in individual case discussions and case management.	This is a recommendation of Living and Dying Well[7].	The outcome of multidisciplinary team discussions are documented in the patient notes.

Key challenge:

- Equipping staff with necessary skills.

Section 2: Delivery of care

Section 2a: Symptom management and nursing care

Key points:

1. A pathway such as the Liverpool Care Pathway for the Dying Patient (LCP)[26] is used for care in the last days of life following acute stroke.
2. Communication with families is proactive.

Statement	Reason for statement	How to demonstrate statement is being achieved
Patients expected to die within the first 30 days following an acute stroke are identified by the multidisciplinary team.	Early identification of the palliative care needs of people with progressive life limiting conditions is a key component of palliative care[7].	The outcome of multidisciplinary team discussions is documented in the patient notes.
Identification of expected death may be supported by the use of prognostic indicators.	Evidence suggests that the following are some of the indicators of a poor prognosis following a stroke: • advanced age[27] • severity of stroke[28] • elevated blood pressure, glucose or temperature[28] • early onset seizures in ischaemic stroke or status epilepticus[29,30]. Validated scoring systems may be used to estimate prognosis following intracerebral haemorrhage[31]. However, the limitations of these tools should be recognised[31].	The use of the indicator is documented in the patient notes.
A pathway document such as the LCP is used for patients who are identified as being in the last days of life.	The LCP or an equivalent pathway should be implemented in all care settings for patients dying from any advanced progressive condition[7].	There is evidence of use of a pathway such as the LCP.
There is regular assessment of patients' symptoms and palliative care needs following an acute stroke.	Accurate and regular assessment is important for early identification and management of symptoms in patients with palliative care needs[7]. There is evidence that the following symptoms are common post stroke: • dyspnoea • pain • mouth dryness • constipation • anxiety[32].	Regular assessment of symptoms is documented in the patient notes.

Statement	Reason for statement	How to demonstrate statement is being achieved
Consideration is given to the use of a validated symptom assessment tool.	A range of tools is available that have been validated for patients with palliative care needs.	Use of symptom assessment tools is documented in the patient notes.
Symptoms are managed effectively with regular review and evaluation.	Local/national palliative care guidelines are used for patients with palliative care needs[7].	Symptom management and its regular review is documented in the patient notes.
Patients' preferences and priorities regarding their end of life care are elicited and taken into account when plans for care are determined.	This ensures that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person-centred and appropriate to each stage of care[7].	There is documentation of multidisciplinary team discussions with relevant parties.
Advance/anticipatory care planning is considered. This includes discussion of anticipatory prescribing in relation to symptoms.	Proactive care planning can improve the quality of life for patients and family/carers[7]. Approaches such as the LCP are used in the very last days of life and patients with stroke may have symptoms prior to this.	Advance/anticipatory care planning is documented in the patient notes.
Accurate documentation including an advance/anticipatory care plan is shared at any transitions in care, eg moving from acute stroke unit to own home or care home for continued end of life care.	Sharing of accurate documentation leads to improved transfer of information between care settings[7].	Patient notes including care plans are up to date and accurate.
Ongoing emotional support is provided for the patient and family/carer during the end of life phase.	Provision of emotional support is good practice.	This is documented in the patient notes.
Consultation with, and/or referral to the specialist palliative care team is considered: • to aid the patient, family/carer and healthcare professionals in difficult end of life decision-making • for the management of complex symptoms. (See Section 1a.)	Patients, family/carers and healthcare professionals may welcome and benefit from support from the specialist palliative care team with difficult decision-making, eg withdrawal of treatment(s), nutrition and hydration, and with complex symptom management issues[25,29,30].	Consideration of referral to specialist palliative care team is documented in the patient notes.

Key challenges:

- Diagnosing dying.
- Taking into consideration communication and cognitive impairments as a result of acute stroke.
- Implementing an organised approach to end of life care following acute stroke.
- Expanding the evidence base for end of life care following acute stroke[33]. There is a lack of formal evidence on aspects of care, most notably airway/respiratory management, positioning, continence care, bowel management, pressure area care and personal hygiene. This is relevant for patients throughout the end of life phase or where there is uncertainty regarding the length of the patient's survival.
- Equipping staff with the knowledge and skills to implement an organised approach to end of life care following acute stroke.

Section 2b: Nutrition and hydration

Key points:

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.
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[b].

Statement	Reason for statement	How to demonstrate statement is being achieved
Patients who have difficulty swallowing (dysphagia) and at risk of malnutrition are identified during the nurse assessment.	Dysphagia is common following acute stroke, particularly in those patients who are identified as being at the end of life[35]. Identification of end of life care needs in patients with acute stroke is likely to run in parallel with assessments of the patient's functional status including ability to feed orally[36,37].	Assessment for, or presence, of dysphagia or malnutrition risk is documented in the patient notes. Audits of nutritional and swallow screening will demonstrate this.
Patients requiring fuller assessment are referred to speech and language therapy, and dietetic services.	Speech and language therapists identify the presence and severity of any dysphagia. They also consider the prognosis for recovery. Together with the dietitian, they clarify the options for delivery of nutrition and hydration to inform the decision-making regarding ongoing management of nutrition and hydration[35].	Referral to speech and language therapy or to dietetic services is documented in the patient notes.

[b] Note: The term 'clinically assisted nutrition and hydration' is adopted here because of recent guidance from the General Medical Council[34], where the term is defined thus: "Clinically assisted nutrition includes intravenous feeding, and feeding by nasogastric tube and by percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy (RIG) feeding tubes through the abdominal wall. All these means of providing nutrition also provide fluids necessary to keep patients hydrated. Clinically assisted hydration can also be provided by intravenous or subcutaneous infusion of fluids through a 'drip'. The terms 'clinically assisted nutrition' and 'clinically assisted hydration' do not refer to help given to patients to eat or drink, for example by spoon feeding." (Page 54, paragraph 112)

Statement	Reason for statement	How to demonstrate statement is being achieved
Decisions regarding provision of nutrition and hydration are made: • in a multidisciplinary context • involving the patient and family/carer, and • in the patient's best interest.	Ethical principles should be applied to the decisions regarding interventions for nutrition and hydration in end of life care and the need to have a patient centred approach[32,35-38].	This is documented in the patient notes.
The decision-making process gives consideration to the patient's ability to give informed consent. (See Section 3.)	Where a patient is able to give informed consent, their wishes should always be respected. The elements required to demonstrate capacity include understanding and retaining information on the options and their associated risks and benefits, and being able to weigh up this information to make a consistent decision free from pressure. It is important to assume capacity unless incapacity is demonstrated[39,40].	Consideration of capacity is documented in the patient notes.
The decision-making process gives consideration to the family/carer's views on the patient's wishes. (See Sections 3 and 4b.)	Where the patient is unable to consent, unless they have legally appointed a nominated representative, the clinician in charge of the patient's care makes a decision in the patient's best interest in consultation with the multidisciplinary team and the patient's family/carer[39,41,42].	The consideration of family/carer views on the patient's wishes is documented in the patient notes.
The decision-making process gives consideration to the patient's response to core care such as oral care.	Experience of hunger and thirst are difficult to establish after a severe stroke.	Patient response to core care is documented in the patient notes.
Information in an appropriate format is given to the patient and family/carer throughout the decision-making process. (See Section 4a.)	When the goal is to ensure relief from symptoms, additional observations during the provision of care can inform the decision-making process[40]. Those involved in the decision-making process are likely to require information on the risks and benefits of any intervention[41]. This should also include information on: • expected outcome with or without clinically assisted feeding and hydration[43] • the risks associated with nasogastric (NG) tube feeding[42], and • the risks associated with insertion and maintenance of percutaneous endoscopic gastrostomy (PEG) tubes[42,44,45].	Information given to patient and family/carer is documented in the patient notes.

Statement	Reason for statement	How to demonstrate statement is being achieved
Information is provided in a consistent and clear manner.	The team should have a shared appreciation of the patient's condition and prognosis.' [46, p719] Clear information reduces confusion among multidisciplinary team members and for the family/carer.	The outcome of multidisciplinary team discussions is documented in the patient notes. The giving of information is documented in the patient notes. There is a range of consistent, clear information in a variety of formats for the patient and their family/carer.
Where there is doubt or lack of consensus surrounding the benefits of supporting nutrition and hydration, a time-limited trial of clinically assisted feeding is considered.	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[34,40,47,48]. Clear goals and objectives allow evaluation and the potential to withdraw treatment if the goals are not met.	The outcome of multidisciplinary team discussions is documented in the patient notes. The timeframe and objectives related to the trial are clearly documented. There is evidence of clear communication with the patient and family/carer.
Nursing staff monitor the patient throughout the time-limited trial of feeding, noting any improvements or adverse responses to the treatment.	There is potential for adverse effects such as tube displacement, gastrointestinal intolerance, reflux and metabolic complications. Continued removal of the nasogastric tube by the patient may be interpreted as refusal but is likely to be an unreliable indicator of non-consent[35,36,40].	The time-limited trial of feeding is documented in the patient notes.
The provision of nutrition and hydration is monitored and reviewed throughout the end of life phase. This usually takes one of three forms: • oral provision with or without compensatory strategies, • clinically assisted nutrition and hydration, and • careful feeding of small amounts orally to improve quality of life.	Provision of oral fluid and nutrition is part of core care and should not be withdrawn unless the patient refuses, is unable to participate, for example because of a low conscious level, or there is recognised concern regarding safety of swallowing. In the end of life phase the patient's ability and desire to eat and drink are likely to lessen and at this stage maintaining oral hygiene is likely to be the most appropriate intervention[40]. Close monitoring of nutritional markers is essential during the provision of clinically assisted nutrition and hydration during the end of life[42,44]. As the patient's condition deteriorates, it may be appropriate to discontinue clinically assisted nutrition. Hydration may also be withdrawn as this can lead to pulmonary oedema and increased secretions which add to the burden for the patient[40]. The speech and language therapist in consultation with the multidisciplinary team can recommend a risk management approach to oral feeding for a patient with recognised risks around swallowing. This requires a careful feeding approach with regular monitoring noting symptoms such as unacceptable coughing, choking or breathlessness which are a considerable burden for the patient[40].	A summary of any discussion with family/carer is documented in the patient notes. There is clear documentation of observations in relation to any provision of nutrition and hydration.

Key challenges:

- Ensuring good communication within the multidisciplinary team and with the patient and family/carer.
- Providing an appropriate nutrition and hydration care plan.
- Ensuring that the nursing team has sufficient skill, knowledge and confidence to provide the nutrition and hydration care plan.

Section 2c:- Spiritual and religious care

Key points:

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 is offered access to spiritual and religious leaders.
4. Resources and information are available.

Statement	Reason for statement	How to demonstrate statement is being achieved
Staff have an understanding of different spiritual and religious beliefs.	Although most of the literature reviewed did not directly refer to end of life care for stroke patients, it is good practice for staff to be aware of different approaches and beliefs[49]. Spiritual care is an integral part of the total care provided to patients and families/carers[20,50] and is part of the role of many healthcare professionals[51].	Training records document this information has been given to staff.
Staff have knowledge and skills to recognise and respond to spiritual and religious practices and needs of the patient and family/carer.	It is good practice to recognise the practices and customs of the main religions and beliefs, eg attitudes to touching, gender, dressing and hygiene customs.	This is documented in training records.
Each patient is assessed individually and without assumptions being made.	There can be considerable differences in how individuals practise their religion.	Discussion is documented in the patient notes.
Staff have an awareness that spiritual and religious care can act as a possible protective factor against emotional distress.	Research suggests that 'spiritual beliefs may protect individuals with stroke from emotional distress.' [52, p308; 53]	Training records document this information has been given to staff.
Staff are open to patients and families/carers who wish to discuss their spiritual and religious beliefs and needs.	It is good practice to offer holistic care. Staff should be aware of the need to avoid 'coercion, proselytising or religious activities based on unrecognised assumptions.' [49 p1159] Spiritual and religious beliefs can be complex and staff may wish to refer the patient for more specialised spiritual and religious care. Hospital chaplaincy services can provide support and have expertise in this area of care.	Discussion is documented in the patient notes.

Statement	Reason for statement	How to demonstrate statement is being achieved
The patient and family/carer are offered access to spiritual and religious leaders, eg chaplains.	A type of positive religious coping mechanism is from access to congregational groups, clergy and religious leaders[49]. Local hospital chaplains have a list of local faith community and belief group representatives.	Offer of access to spiritual and religious leaders is documented in the patient notes.
Information resources are available for staff, the patient and family/carer.	Additional resources may be available from the local chaplaincy or spiritual care department and from NHS Education for Scotland[50,51,54].	There are resources available in the ward.

Key challenges:

- Ensuring staff training needs are met.
- Ensuring availability of resources and information.
- Providing access to appropriate spiritual and religious leaders.

Section 3: Ethical aspects of care - end of life issues including withdrawal of treatment

Key points:

1. 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.
2. Early decisions about withholding cardiopulmonary resuscitation are avoided.
3. There is accurate documentation of plans of care and discussions between the multidisciplinary team, the patient and family/carer.

Statement	Reason for statement	How to demonstrate statement is being achieved
The options surrounding the futility of treatment are discussed with the patient and family/carer, and with the multidisciplinary team.	A key issue in quality of end of life care is the involvement of the patient and their family/carer in discussions and decisions about care. It is also critical that the nurse has an understanding of the treatment goals and that these are clearly documented. Research has shown that patients' concerns focused on expected quality of life, emotional costs, likelihood of treatment success and expected effect on longevity[55,56].	The decision-making process including who was involved in the process is documented in the patient notes.
If capacity is impaired then the patient is provided with all the appropriate help and support to understand, retain, use or weigh up the information in order to make an informed decision regarding their care needs. Speech and language therapists may be able to assist with information provided in suitable formats.	The patient's capacity to make a decision may be impaired following an acute stroke. Assessment of capacity to make decisions includes understanding and retaining information on the treatment options available and the risks and benefits and being able to weigh up this information. Individuals who are competent to make decisions about their care have the right to make a decision about whether they will accept or refuse life-sustaining therapies[39,56].	Discussion and barriers to communication, eg aphasia, and the support offered are documented in the patient notes. The use of the Adults with Incapacity (Scotland) Act 2000[39] form is monitored through internal audit. Discussion with the patient and family/carer, including why decisions were made is documented in the patient notes.
The capacity to make a decision may vary and is re-assessed as required.	Patients' capacity and conditions can change, eg through both improvement and deterioration. Therefore it is important to re-assess capacity on a regular basis. As a patient's condition can be dynamic and evolving it may be necessary to have discussions about end of life care a number of times with the family/carer and/or patient in the acute period as situations change[56].	In the patient notes there is evidence of reassessment of the patient in relation to the Adults with Incapacity (Scotland) Act 2000[39] form.
The potential anxiety the family/carer and healthcare staff may have about withdrawing or withholding of any life-sustaining treatment is considered.	It is essential that healthcare staff understand the complex issues regarding withdrawal and withholding of treatment which may not be beneficial and therefore, not in the patient's best interest[57]. People may find it more difficult to consider withdrawing treatment than not starting it – sometimes relatives fear they may feel responsible for the patient's death if they agree to treatment withdrawal[34].	Discussions within the multidisciplinary team are documented in the patient notes.

Statement	Reason for statement	How to demonstrate statement is being achieved
The patient's condition is kept under review with frequent re-assessments, for example, of the need for clinically assisted hydration or nutrition[58]. (See Section 2b)	While some predictors have been identified, there are no fully accurate methods of predicting outcome after severe stroke[58]. For some conditions such as motor neurone disease or advanced metastatic cancer the progress of the disease is easier to predict. In stroke, particularly in intracerebral haemorrhage, recovery prediction is much less reliable[59]. Physicians frequently use patients' poor clinical status as a criterion for recommending withdrawal of support[59]. However, it is important to be aware that: 'Even individuals in the worst initial prognostic category can have meaningful recovery when offered full aggressive care.' [59 p1654]	Reviews are documented in the patient notes.
Decisions about withholding resuscitation are not made immediately after acute stroke.	Recovery is not easily predicted. After adjustment for case-mix, there is evidence that patients in whom an early decision has been made not to resuscitate are more likely to die than patients with a stroke of similar severity in whom such a decision was not made[59-61].	Decisions about resuscitation status are documented in the patient notes.
Decisions about withholding cardiopulmonary resuscitation, ie Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) are based on the circumstances and wishes of the individual patient. This may involve discussions with the patient's family/carer and with the multidisciplinary team. It is current policy that this must include: • whether cardiopulmonary resuscitation could succeed • the clinical needs of the patient • the patient's wishes and their judgement of the benefit provided by cardiopulmonary resuscitation • a mechanism to ensure that staff, patients and relevant others have appropriate information on making advance decisions about cardiopulmonary resuscitation and that they understand the process[8].	Where a patient lacks capacity, the responsibility for deciding if resuscitation is in the patient's best interest lies with the most senior clinician (doctor or nurse) who has clinical responsibility for the patient during that episode of care[8]. The family/carer does not have decision-making rights or responsibilities in this circumstance. Discussion with the family/carer has the primary aim of trying to clarify the patient's views prior to incapacity[8].	There is a record of discussions with the patient and family/carer in the patient notes. Local protocols for DNACPR discussions and decisions are used. There is evidence of local education of staff about the process and its implications. The use of DNACPR documentation is monitored.

Statement	Reason for statement	How to demonstrate statement is being achieved
If a DNACPR decision is agreed, it is made clear to the patient and their family/carer that this does not imply that other treatments and quality of care will be compromised.	DNACPR orders are fundamentally different from orders to withdraw medical support[61]. Decisions regarding DNACPR should not influence treatment including admission to stroke units[60]. The patient or their family/carer must be assured that other treatments are not being withheld as a result of the DNACPR decision and that any other treatments will be provided if it is clinically appropriate and agreed through discussions. It is acknowledged that DNACPR should not have an influence in the overall quality of nursing care that is provided[61].	In the patient notes there is a record of communication with the family/carer. There are relevant protocols which are regularly reviewed and their completion is audited. Patients and family/carers express satisfaction with information given from staff.
Local training and support for nursing staff is available.	This ensures that nursing staff have the relevant skills and knowledge to be able to discuss sensitive issues such as withdrawal of life-sustaining treatment. Nursing staff must be confident in having early discussions with the patient and family/carer about end of life issues. Early discussions are usually readily accepted and agreements between the multidisciplinary team and family/carers are rarely problematic[56]. The patient's condition can be dynamic and evolving and it may be necessary to have such discussions a number of times as situations arise[56].	The appraisal and continuing professional development system and training records demonstrate this.

Key challenges:

- Educating nursing staff to maintain knowledge, competence and confidence surrounding end of life issues.
- Ensuring nursing staff have an active role in contributing to end of life discussions.
- Ensuring that discussions with the family/carer are accurately documented, dated and signed.

Section 4: Family/carer support

Section 4a:- Information

Key points:

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 patients and families/carers.
3. A private quiet room is provided for staff to speak with the family/carer.

Statement	Reason for statement	How to demonstrate statement is being achieved
The multidisciplinary team provides the patient and their family/carer with information and updates on the patient's condition in a timely way.	The provision of verbal and written information is known to improve the patient's and their family's/carer's understanding of their illness. It also provides them with the knowledge and confidence to make decisions about their end of life care[7,34,62].	There is documentation of multidisciplinary team discussions with relevant parties. A record of strategies to improve communication for those who are aphasic is detailed by a speech and language therapist. There is evidence that, if necessary, interpreters have been sought.
The multidisciplinary team develops a resource folder on the provision of palliative care.	This is good practice as recognised in Living and Dying Well[7].	The resource folder is available in the care area. Local audit shows that the multidisciplinary team refers to and uses the folder.
There is proactive involvement of the family/carer in discussions regarding prognosis and end of life care.	Family/carer discussions are a vital intervention to explain prognosis, establish goals of care, discuss withdrawal of treatment(s) and to ensure all family members/carers are aware of the current plan of care[31]. Families/carers value compassionate and practical support when their relatives are dying in an acute hospital[38].	There is documentation of multidisciplinary team discussions with family/carer.
Practical information is provided for the family/carer throughout the end of life phase.	This is good practice.	There is evidence that verbal and written information has been provided to the family/carer.

Key challenges:

- Availability of information in different formats.
- Availability of a quiet space/room.
- Keeping the resource folder current.

Section 4b:- Decision-making

Key points:

1. The patients and their family/carer 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.

Statement	Reason for statement	How to demonstrate statement is being achieved
Nurses are aware of the importance of communication/participation of the stroke patient and their family/carer in deciding when active treatments cease.	Stroke is the third most common cause of death in Scotland[1] and mortality in the first 30 days is approximately 20%[4]. Communication/participation helps to identify the needs of the patients and their families/carers involved in end of life care[7]. The sudden onset of stroke can mean that patients and families/carers are unprepared to deal with the experience[63]	The LCP and equivalent pathways identify the nurse's role in providing support and information. Documentation reflects that end of life care being delivered is acceptable to the stroke patient and their family/carer. Documentation records if the family/carer want to be contacted at the end of life final stages.
Nursing staff are knowledgeable about the services available locally for end of life options and share this information with the patient and their family/carer.	All patients should have care planning which covers their needs, preferences and wishes at every stage[7].	The patient's comments, needs or wishes and the outcome of multidisciplinary team discussion about these are clearly documented in the patient notes.
Advance care directives are recognised by the multidisciplinary team and are used to support decision-making.	Advance care directives reflect the wishes and treatment that the patient has decided on prior to stroke illness.	The patient notes document that the advance care directive has been viewed, and considered.

Key challenges:

- Training staff in end of life issues.
- Recording the information given to family/carer and the patient accurately.
- Ensuring nursing staff have access to or knowledge of the services available.
- Fulfilling the needs of the patients who wish to return home for end of life care.

Section 4c:- Initial bereavement care

Key points:

1. Nursing staff support the family/carer at the start of their bereavement by being available and sensitive to their grief.

Statement	Reason for statement	How to demonstrate statement is being achieved
Nursing staff provide the bereaved family/carer with support, information and assistance.	Every individual response to death and bereavement is different[7].	The offer of involvement of other team members such as the chaplain or bereavement care team is documented. It is recorded that the family/carer has been given practical advice eg a copy of 'What to do after a death in Scotland: practical advice for times of bereavement.' (9th Edition, Scottish Government, 2009)[64].

Key challenges:

- Training and education of all nurses in managing bereavement.
- Supporting the bereaved family/carer.

Appendix 1: A sample reflective tool for individual practitioners

This tool is not for audit but is for individual practitioners to reflect on their practice in light of the best practice statement. It is to encourage self-assessment of knowledge and skills in providing end of life care.

In setting up a goal for improving there should be an aim (what do I want to achieve?), and consideration of two questions:

- How will I know this change is an improvement?
- What changes can I make that will result in improvement?

This tool has been developed from the best practice statement; it should be used in conjunction with the statement and not in isolation.

As a nurse caring for patients who are at the end of life following an acute stroke:		
I have a clear understanding of my role in the multidisciplinary team	Yes	No

	Two examples of using my knowledge and skills to undertake my role in providing end of life care to stroke patients are:

I am confident in undertaking my role in providing end of life care	Yes	No
I communicate with others in the multidisciplinary team	Yes	No

	I do this by: (specify method, eg team meeting, notes, communication folder, phone)

	I am confident in communicating about care provision, patient assessment, etc with others in the multidisciplinary team	not confident 1	2	3	4	fully confident 5

As a nurse caring for patients who are at the end of life following an acute stroke:

I communicate with the patient	Yes	No

	I am confident in communicating with patients	not confident 1	2	3	4	fully confident 5

I communicate with families/carers	Yes	No

	I am confident in communicating with families/carers	not confident 1	2	3	4	fully confident 5

I can get help to support my practice from the following sources:	a:
	b:
	c:

Having reflected on my practice, I will undertake the following actions to address the gaps this reflection has identified:	

Appendix 2: An improvement framework using case notes

The following framework is for those practitioners who would like to identify areas for improvement in end of life care following acute stroke. This could also support healthcare professionals and organisations who would like to audit current practice. This should be used in conjunction with the best practice statement and not in isolation.

In identifying areas for improvement it is suggested that the stroke team first identifies a 'gap' in the service they are providing and agrees an area for improvement. A small number of case notes is extracted at random from the unit and surveyed for evidence that this particular aspect of care is being undertaken and recorded in the notes. 100% compliance with this would suggest that this area is working well and that a different area of care could be identified for improvement. As with all change for improvement, it is important that all the team members identify and agree what the area for improvement is, what will be done, who will do it, and by when.

For example, it could be that the team agrees that an appropriate area for improvement is communication with carers. An agreed index of communication, for example the giving of bereavement advice, is selected. Five case notes are surveyed to indicate if this was given to all family/carers (or if the reason for the variance from this was documented). If the notes indicate that information is not being given and recorded systematically, this could form the focus of an improvement activity. A typical aim would be that a small sample of case notes identifies 100% compliance with the giving of bereavement advice to the family/carers within, for example, one month's time.

1	There is evidence the following aspects of care are being delivered:	Yes	No
a	Symptom control evidenced by: (identify one aspect of this for improvement)		
b	Patient comfort evidenced by: (identify one aspect of this for improvement)		
c	Family support evidenced by: (identify one aspect of this for improvement eg information given, conversations documented)		

2	This clinical area has the following characteristics:	Yes	No
a	There are training opportunities for different professional groups in end of life care If Yes: What is the frequency? Are they tailored to stroke staff? Are there gaps in this provision?		

2	This clinical area has the following characteristics:	Yes	No
b	Referrals to specialist palliative care can be made.		
c	There are clear criteria for any change to the care regime and staff are aware of these e.g. the introduction of end of life pathways, changes to the provision of hydration and nutrition.		
d	Information is available for families/carers on bereavement care and local sources of help.		
e	A palliative care resource folder is available in the unit.		

A negative answer to any of these questions would indicate that action is necessary.

Glossary

advance care directive or advance directive	Document drawn up by individuals, while well, to express their wishes as to their future care and medical treatment, when they may be unable to express those wishes themselves.
clinically assisted nutrition and/or hydration	Ways of giving fluids and nutrition to patients using a number of tube or drip methods. This is different from helping patients to eat or drink. See Section 2b.
end of life care	Helps anyone with an incurable illness to live as well as possible until they die. End of life care also helps the patient to plan ahead in case they can't do so later, and provides support for the person's family/carer.
futility of treatment	When the effect of treatment will be of no benefit to the patient.
intracerebral haemorrhage	When a blood vessel breaks and causes a bleed inside the brain. This is different from the more common type of stroke – ischaemic stroke – caused by blockage to blood vessels supplying an area or areas of the brain.
Liverpool Care Pathway (LCP)	Developed to transfer the hospice model of care into other care settings. It is a multiprofessional document which provides an evidence-based framework for end of life care. The LCP provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. Additionally, psychological and spiritual care and family support is included.
multidisciplinary team (MDT)	A group of people from different fields such as medicine, nursing, and social work who work together to provide care for patients with a particular condition. Team members may come from different organisations.
nasogastric (NG) tube	A narrow tube that is passed into the nose and down the oesophagus (food pipe) into the stomach. This allows feed to be delivered directly into the stomach.
National Advisory Committee on Stroke (NACS)	A committee set up in October 2002, to oversee the recommendations in the stroke part of Scotland's coronary heart disease and stroke strategy. The Membership of the Committee reflects the multidisciplinary nature of stroke care. Website address: www.sehd.scot.nhs.uk/stroke/NAC.htm

percutaneous endoscopic gastrostomy (PEG) tube	Method of feeding via a small tube directly into the stomach.
radiologically inserted gastrostomy (RIG) tube	Method of feeding via a small tube directly into the stomach. Similar to a PEG tube, but using X-ray scanning equipment to position it.
speech and language therapist (SALT)	Works to assess, diagnose and develop a programme of care to maximise the communication potential of the people under their care/referred to them. Speech and language therapists also work to support people with swallowing, eating and drinking difficulties. Such work will involve direct contact with people with communication difficulties as well as their carers and significant others in their lives (Royal College of Speech and Language Therapists).
Scottish Stroke Nurse Forum (SSNF)	Aims to promote the essential role of nurses in stroke, and to: • share and develop knowledge, expertise and best practice; • incorporate research–based evidence into practice, and promote research to improve outcomes; • help develop core competencies, education and training initiatives for stroke nurses; • advise and influence the provision of stroke nursing services, which impinge on patient care and carers at local and national level. Website address: www.chss.org.uk/links/ssnf/ssnf.shtml#intro
Stroke Training and Awareness Resources (STARS)	A website resource which focuses on core knowledge and skills required by multidisciplinary staff when delivering stroke care. Website address: www.strokecorecompetencies.org/node.asp?id=home

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