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Pennine Care NHS
NHS Foundation Trust

Evidence Based Scan for My Health My Community (MHMC)

Pennine Care NHS Foundation Trust

Stroke and end-of-life care

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Executive summary

This evidence based scan (EBS) provides the evidence base around stroke and end-of-Life (EoL) care. It complements the General EoL EBS submitted to the My Health, My Community (MHMC) team at Pennine Care NHS Foundation Trust on 30th April 2015.

The concept of stroke and EoL care is a difficult one because of prognostic uncertainty about illness and dying trajectories. The position at the moment is that, in the UK there are several critical decision points in stroke at which difficult and important treatment choices need to be made, especially in the acute phase. The issues and decisions involved in stroke prognosis are examined in some detail within this EBS, because they affect when EoL care is initiated. Most patients with severe stroke who die, do so in the setting of withdrawal of life-sustaining treatment (LST), and this decision is usually made by physicians who predict a poor outcome and patient surrogates who are asked to articulate the patient's preferences. Thus, when prognosis is certain and the outcome unacceptable, the decision to withdraw or withhold LST may be relatively straightforward. In most severe strokes, however, decisions are made when prognosis is uncertain and when what constitutes an acceptable outcome is unknown. This is a difficult and sometimes uncomfortable scenario for patients, carers and health care professionals (HCPs). As a disorder of consciousness, stroke patients can lose their ability to communicate their views about EoL decisions and may not be able to alter previous wishes they may have made in the light of a new future disability and quality of life that they did not envisage (The Lancet 2014). This document provides discussion on various stroke scenarios including locked in syndrome and the ethics of decision making in stroke.

More research into prognostication is needed and there are on-going studies attempting to research and redress these difficulties, however, the current situation is that the prevailing tendency of relatives in terms of treatment proposals is to follow physician advice and recommendations. This seems reasonable bearing in mind that a patient's relatives cannot make or determine healthcare decisions. Family/multi-disciplinary meetings with explanations to families of the implications of treatment decisions could help make decisions which often have to be made very quickly.

International, National, regional and local guidelines in stroke care are outlined including prognostic indicators specifically for stroke. The Centre for Palliative Care in Victoria, Australia has some excellent resources and ideas for stroke and EoL care.

Training for HCPs has been explored because many lack end of life training and knowledge, including neurologists, and there are some excellent training courses for them including many short films which can be shared with patients and carers.

For family carers involved in stroke and EoL care, various terms used in the medical setting should be explained clearly to them. There is the potential for carers to be able to look after people with stroke and specialist staff consider that they could learn some nursing skills. However, given the uncertainty of stroke, there may not be time for them to undertake and feel confident about practicing these. In terms of resources, there are excellent films with real carers and patients and courses on moving and handling which would be vital for home caring. Examples of one to one carer education programmes have been included from the General End of Life EBS because they pertain to all EoL care and address pain management and emergency medication issues.

The methods in this EBS include a grey literature search, an academic scan, and an expert information gathering exercise which was undertaken with 16 various HCPs caring for stroke patients. This added to the contextual evidence in stroke and highlighted the everyday complexity involved in the diagnosis and care of people who may be at the EoL with Stroke. Family carer needs were explored and centred on the following:

- The EoL feels fragmented and confusing
- Family carers need to be informed to make choices about treatments and care and require consistent information from professionals.
- Prognostic uncertainty in stroke is one that carers may need to have explained to them in order to confront and address this issue.

Recommendations

- Patients and carers should be made aware of definitions such as ‘End of Life’ which are clearly explained in such documents as the Gold Standard Framework (GSF) and other best practice statements specifically relating to stroke, in order to help them make decisions.
- They should also be made aware of the complex care involved in the process of dying with stroke and which can include, pain, depression, confusion and agitation and medical problems with nutrition and hydration.
- HCPs in stroke teams all need to be trained in all aspects of EoL and palliative care in stroke. Palliative care teams should be trained in stroke care.
- The use of a dying pathway could be beneficial in stroke
- Barriers to care cited for stroke patients included resource and time limitation, competing priorities, difficulties in prognostication and communication and not knowing patients´ wishes
- Caring at home for people with stroke at the EoL could be an onerous for family carers

Main Conclusion Reached

Caring for someone with stroke at the end of their life could be, potentially, a very demanding caring situation with perhaps little clarity over how long it will go on for because of the prognostic uncertainty.

Section1. Introduction to stroke and end-of-life care

Stroke is the third most common cause of deaths in England and a leading cause of death and disability across the world (Payne, Burton et al. 2010). Around 110,000 strokes occur annually in England, three quarters of patients being over 65. Overall incidence rates under the age of 45 range from 7 to 15 in 100 000 people/year for all stroke (ischaemic and haemorrhagic) with higher rates reported in some countries. A few studies reporting similar incidence rates have examined all stroke in the 15 to 44 year old age group or ischaemic stroke only in the 15 to 49 year old age group (6.6 to 11.4 in 100 000 people/year). Under the age of 35, rates are less than 10 in 100 000 people/year (ranging from 0 to 9). Within the 35 to 44 year old age range, rates range from 22 to 45 in 100 000 people/year (Griffiths and Sturm 2011).

20–30% of patients die in the acute phase (i.e. in the first 30 days). Thus, death after stroke is not uncommon, occurring in 5% to 7% of cases in the acute care hospital, in 13% to 15% of cases at 30 days, and in 25% to 30% of cases at 1 year (Katzan, Spertus et al. 2014). In the US approximately 50% of deaths occur in hospitals (including emergency departments and acute rehabilitation facilities), 35% occur in nursing homes, and 15% occur in the home or other places. These deaths occurring mainly as a result of brain death, or in the setting of withholding or withdrawing life-sustaining therapies when prognosis for recovery is believed to be poor (Holloway, Arnold et al. 2014). In the UK, , there are several critical decision points in stroke at which difficult and important treatment choices need to be made, especially in the acute phase (Payne, Burton et al. 2010).

1.1 Methods

1.1.1 Expert information gathering exercise

Given the nature of stroke, and that each stroke is different, methods in this section of the EBS vary slightly from previous phases. That is, in addition to a scan of the evidence base and the grey literature, an exercise gathering expert opinion on the concept of stroke and EoL care was undertaken. For this purpose, the author made the following contacts by e-mail, telephone, personal and group discussions and which included the following experts and associations:

1) Academic and NHS Consultant Stroke physician.
2) Professor of Stroke Medicine
3) National Consultant in Palliative Medicine
4) Professor in Rehabilitation
5) Clinical Lead for Stroke, NHS and Academic
6) Academic researcher
7) Stroke Association
8) NHS Stroke services coordinator/ Stroke facilitator
9) CLAHRC Programme Manager for Stroke
10) CLAHRC Facilitator
11) 4 Stroke Nurse Specialists
12) Stroke Association, North West
13) Stroke Nurse Consultant

They were asked the following questions:

- I understand that identifying EoL in stroke is a difficult area and wondered what your thoughts were on this issue please?
- Is there a role for family carers to care for someone with stroke at home at the end of their life?

1.1.2 Replies

Q. I understand that identifying end of life in stroke is a difficult area and wondered what your thoughts were on this issue please?

People with stroke at the end of their life require the same kind of care as any other dying patient. However, they present in a very different way to say, that of a cancer patient (4).

Identifying EoL in stroke is a particularly difficult one (1, 10) and not clear cut (11).

The challenge with stroke is diagnosing whether someone is likely to recover or not and this is immensely difficult because people may fluctuate in their condition. Around 24% do not die immediately but have a short dying trajectory of within one month and few of these are transferred home, instead dying in hospital. It is difficult to recognise which of these people may or may not recover; some may die in 3 months’ time from pneumonia for example (4).

The issue is not what you do but when you do it (1) and the moments after acute stroke are a particularly important phase (10).

In the context of a massive stroke, the scenario could include sitting and waiting for up to a month until someone does or does not recover. Even Locked In Syndrome is uncertain in terms of recovery (11) [1]

There is uncertainty at which point EoL care is considered and particular issues such as neurological deficits, swallowing difficulties for example need consideration. If people are put on an EoL pathway, they can survive for longer than if they had not. If a clinician sees someone they consider will not survive they may put them on the EoL pathway immediately. Similarly, a person who has been identified as being at the end of their life using the Gold Standard Framework (GSF) may be put on and EoL pathway (1). This could also be the case following a CT scan which delivered a devastating prognosis in which case a person would probably die in hospital (11).

For those patients who are not likely to recover, there are no formal palliative pathways which acknowledge this and, unlike in a cancer scenario, not many HCPs initiate conversations around EoL and issues such as 'do not resuscitate' (DNR) orders with family members because they are unskilled in this kind of communication (4).

Q. Is there a role for family carers to care for someone with stroke at home at the end of their life?

EoL care for people with stroke is an untapped area and patients' care needs and preferences and family carer support needs are not known. People are sent home completely dependent on others and it is assumed family carers will cope. Therefore families need support. In terms of EoL patients should be asked if they want to return home. People may die of pneumonia, kidney failure or have another stroke. Those with cardio vascular dementia may not have a full stroke but then may have another stroke on top of this. Carers and patients need to know about this kind of scenario (4).

Not many people with stroke on the dying trajectory go home although discharge to home is offered with a 48 hour care plan (1).

In the personal experience of one individual, she had not seen anyone discharged home in 7 years of practice notwithstanding the existence of the 48 hours discharge facilities with primary care staff availability (11).

Yes this is true – the group of stroke survivors you are considering here are the more severe strokes who have survived the incident stroke in question and are perhaps also the frail elderly with multiple co-morbidities. Depending on various factors it can be very difficult

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[1] *There is a section on Locked in Syndrome below on page 20*

to say whether we are looking at weeks or months as it may be that it is the susceptibility to further stroke or complications of their stroke e.g. pneumonia that will trigger the further deterioration into EoL care. Whilst I am not experienced, for instance in cancer care, my sense is this cancer could be more predictable as it relates to measurable progression of an on-going disease rather than the interplay of several factors (13) in stroke.

In terms of caring for someone at the EoL it was considered that there was not much that could not be taught to carers including, suction, swallowing and positioning techniques, nursing skills including catheter care, PEG medications, injecting and giving breakthrough medications. In addition, someone who has a stroke may already be palliative so requires such care anyway or, the stroke may cause pulmonary embolism, swallowing and aspirational problems, urinary infections, chest infections (which can lead to pneumonia) and hospital acquired infections (11).

Yes, families can support their relatives care at home. The option is usually care at home or in a 24 hour care setting as relatively few stroke patients will meet hospice criteria which tend to link to complex needs for symptom control issues. Depending on how close to end of life someone is would depend on how care is being provided at home by support agencies. That is, is it NHS funded with 3 x a day visits by District Nurses, or social care provided up to 4 times a day. In Salford, Macmillan nurses are available for support and advice but there is no night sitting service unless sourced privately. Hence it is a very potentially demanding caring situation with perhaps little clarity over how long it will go on for because of the prognostic uncertainty. We as a team will always support any family to care for their relative at home providing training and guiding through funding and assessment processes, but I always counsel families carefully re the demands of this and the need for a support network and ideas re contingency plans if strain develops e.g. It is more doable if there is a large family ready to support one another than if it is only 1 or 2 carers (13).

The comments of these HCPs highlight the uncertain nature of stroke and difficulties in prognosis and give an insight into everyday clinical practice in EoL care in Stroke. Their thoughts and comments are incorporated into the sections below.

Section 2. Academic search criterion

1, describes the academic search. The search strategy included papers in the English language published between 2005 and 2015 with one relevant French paper being included. An individual online search of the Journal, Stroke, from 2011 to 2015 was also undertaken. Additional papers were identified from previous phases and following a second brief search when the EBS was near completion.

Table 1. Academic search criterion

Sources	Terms	No of papers	Relevant
U o M Library Search[2] End of Life guidelines for STROKE Google scholar Health Foundation Kings fund SIGN (The Scottish Intercollegiate SCIE (Guidelines Network Social Care Institute for Excellence) SIGLE (System for Information on Grey Literature) **Journals:** Stroke (2011 – 2015) **Web sites** “Different Strokes” “Stroke association” “Chest Heart and Stroke Scotland” “Patient voices”	*‘Stroke and end of life care’*	198	20
	‘Stroke and end of life care and		
	… ‘home care’ and ‘home caregivers’	135	4
	… ‘death’ and ‘home caregivers’ and ‘nursing tasks’	190	1
	… ‘family caregivers‘ and education needs’ and ‘knowledge’	28	2
	…’and ‘family caregivers’ and palliative care’	128	1
	… ‘and family care givers and training and palliative care treatment’	37	0
	… ‘and family care givers and terminal care’	107	1
	…’and family care givers’	80	1
	… ‘and dying trajectories’	5	2
	‘end of life in Stroke’	32	2
	‘stroke and prognosis and end of life decision making’	58	1
	‘end of life prognosis in stroke’	73	1
	‘stroke and end of life decision making’	21	1
Total number of papers		1092	37

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[2] *This search covered; Taylor & Francis Online – Journals,* ***,*** *SpringerLink Open Access SpringerLink SciVerse ScienceDirect (Elsevier) SAGE Journals Public Information Online (Dandy Booksellers) PMC (PuBAMEd Central) Oxford Journals (Oxford University Press) MEDLINE/PuBAMEd (NLM) Literature Resource Center (Gale) C.E.E.O.L Journals Karger Journals IngentaConnect Emerald Journals (Emerald Group Publishing) Duke University Press Journals Online Directory of Open Access Journals (DOAJ) Cambridge Journals (Cambridge University Press) BioMed Central ACM Digital Library ERIC*

Final number of relevant papers	37

2.1 Flag system for appraising evidence and resources

✹	**Very relevent** to the My Health My Community (MHMC project team and Pennine Care NHS Foundation Trust
✡✡	**Denotes very good practice** *This could mean that the programme/ guideline/ initiative/ is established practice*
✡	**Deontes good practice**
?	**Pilot study**
👥	**Co-designed initiative**
✦	**Denotes potential to contact**
🤝	**Black, Asion and minority ethinc (BAME) element**
☑	**Completed initiative**

Section 3. Influences on clinical decision making in stroke

Hundreds of patients each year require care at the end of their lives following a stroke. This section will examine the evidence, influences and implications of recognizing/ diagnosing/ decision making about whether a patient may be at the end of their life following stroke because this is a major clinical issue in the field. The evidence highlights the uncertain nature of stroke and EoL and the issues and challenges facing patients, doctors and carers. Peer reviewed papers and some ongoing studies exploring this issue are described and appraised below.

3.1 Prognostic difficulties

Stroke prognosis is a very difficult issue. Difficulties can arise in knowing when to initiate EoL care when the trajectory of the disease is not necessarily predictable. Anecdotally, stroke care professionals describe difficulties in recognising when patients are dying. Withdrawing and withholding treatments are usually decided when neurological prognosis is considered to be ‘‘catastrophic’’ (NHS and Scotland 2010). Most in-hospital deaths after severe brain injury follow decisions to withdraw or withhold a potentially life-sustaining intervention. These decisions are fraught with difficulty for all concerned (The Lancet 2014).

In addition, other factors, such as an individual doctor’s perceptions of what significant ‘disability’ is, or hospital use of aggressive procedures, certain daily routines or organisational constraints, (such as criterion for who can access EoL care and at what point in their disease trajectory) can also affect a prognosis (Crozier 2012). “Common, disabling, and deadly”, one in 15 stroke patients requires mechanical ventilation on admission, 1 in 20 patients are discharged from the acute care hospital with a feeding tube, and 1 in 5 patients require institutional care at 3 months after Stroke. Most patients with severe stroke who die, do so in the setting of withdrawal of life-sustaining treatment (LST). This decision is typically made by physicians who predict a poor outcome and patient surrogates who are asked to articulate the patient’s preferences. When prognosis is certain and the outcome unacceptable, the decision to withdraw or withhold LST may be relatively straightforward. In most severe strokes, however, decisions are made when prognosis is uncertain and when what constitutes an acceptable outcome is unknown. A study exploring uncertainties and biases that influence these life-and-death decisions found that these can lead to errors in decision making and ultimately the overuse or underuse of LST. Research needs to address and understand better the factors that contribute to optimal decision making (Creutzfeldt and Holloway 2012).

“Do not attempt cardiopulmonary resuscitation“, (DNACPR) orders are challenging for doctors. These are not always discussed with patients or their families and decisions can differ according to the doctor’s speciality, for example being a geriatrician rather than an acute physician could affect a decision to DNACPR, despite local clear policies and pathways (Mbriwa and Limaye 2014). A recent NCEPOD report reviewed patients who underwent cardiopulmonary resuscitation as a result of an in-hospital cardiorespiratory arrest has highlighted the need to make such decisions as regularly and early as possible (Findlay, Shotton et al. 2012).

Likely outcomes of patients can be hard to predict, because study results do not necessarily apply to every patient and the sensitivity and specificity of prognostic models are not always high. Decisions such as “do not resuscitate” have even been suggested to affect decisions regarding care by becoming a self-fulfilling prophecy. Patients can lose any ability to communicate their views about end of-life decisions after such a brain injury. They cannot alter previous wishes they may have made in the light of future disability and quality of life they did not envisage (The Lancet 2014). Younger people experiencing stroke may not have had time to think about advance wishes in this context.

Stroke prognosis remains difficult to determine, depending on many things including: stroke severity, patient's age and patient’s ability to rehabilitate. Do-not-resuscitate orders are given in up to 30% of acute stroke; more than 50% of these are given upon admission and within the first 24 hours of stroke. Ascertaining neurological severity can be related to many factors including low blood pressure or hypothermia (Crozier 2012).

Clinicians, patients, and their families want to know a person’s outcome after stroke. Clinicians have various resources at their disposal, their past experience or weight risk factors are known to influence stroke outcomes and diagnostic tests. There are also several stroke risk prognostic scores to predict different outcome measures and, when applied to large populations, risk scores can provide useful prognostic estimates. In particular, the THRIVE score is a simple tool that helps clinicians estimate good outcome and death after ischemic stroke (Saposnik 2014).

Blood markers for the diagnosis and prognosis of stroke have also been considered in a recent thesis which set out to determine whether blood markers can be applied to: (i) improve the accuracy of the clinical diagnosis of stroke or transient ischaemic attack (TIA), and/or (ii) improve the prediction of poor outcome in patients who are still symptomatic at the time of admission with stroke or TIA in over 400 patients. Assessments of emergency room nurses and doctors performance in assessing a TIA or stroke (‘acute cerebrovascular disease’) in patients presenting with symptoms of suspected stroke was compared with a number of stroke diagnostic scales, (using the diagnosis by an emergency department clinician of ‘probable or definite acute cerebrovascular disease’ as the best clinical performance reference standard). Blood was also taken from the patients and examined by accredited research laboratories who measured biological markers which may have positive association with poor outcome in stroke. Each marker did not add diagnostic value to the diagnosis of an emergency department doctor or nurse. No individual marker improved the prediction of poor outcome when added to a validated prognostic model based on clinical variables alone. Of 405 patients with suspected stroke, 285 patients had a confirmed diagnosis by nurses and doctors. After adjustment for clinical predictors (age, prior MI, stroke, or TI), the work concluded that no marker measured could improve on the diagnostic accuracy of an emergency department clinician for acute cerebrovascular disease, nor improve the prediction of poor outcome by a prognostic model based upon clinical variables (Whiteley, Wardlaw et al. 2011).

The Gold Standard Framework (GSF) contains a definition of End of Life care from the General Medical Council as including people likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

Advanced, progressive, incurable conditions
General frailty and co-existing conditions that mean they are expected to die within 12 months
Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
Life-threatening acute conditions caused by sudden catastrophic events.

Specific clinical indicators in stroke include;
Persistent vegetative or minimal conscious state or dense paralysis, medical complications, lack of improvement within 3 months of onset and cognitive impairment/post stroke dementia

(RCGP. 2011)

3.2 Ethical issues

Ethical issues arise in the care of patients with disorders of consciousness (DOC) rooted in the challenges of accurate diagnosis and prognostic uncertainty. Current neuroimaging research on these disorders could eventually improve the accuracy of diagnoses and prognoses and therefore change the context of end-of-life decision making. A qualitative study undertaken with HCPs addressed a research gap in terms of their experiences of participants with DOC. Although the literature cites accurate diagnosis among DOC as challenging, the HCPs in this particular study reported high confidence in DOC diagnoses. However, they struggled with prognosis, especially because of its essential role for EoL decision making and communicating this to families. Variability of opinion between HCPs was reported and identified by some as a minor issue while others stressed how families struggle with different medical opinions. EoL decision making encompassed a large proportion of ethical challenges and taking away artificial nutrition and hydration was a significantly uncomfortable task for some HCPs. The concept of futility was subject to wide-ranging understandings with both favourable and unfavourable opinions. In order to ensure the incorporation of new evidence-based advances, attention should be directed to the real world practices and challenges of accurate diagnosis and prognosis. Given pervasive challenges in EoL care, the authors recommend improved training of healthcare professionals in the care of patients with DOC, particularly in EoL care, understanding the context of decision making, and determining how to optimally integrate new neuroscience research on the care of patients with DOC (Rodrigue, Riopelle et al. 2013). The effect of stroke on communication, cognition and consciousness is a major consideration (Jeffries, Shipman et al. 2011). As a disorder of consciousness (DOC), stroke has implications for young people who may have not considered their EoL care and, for older people, previously made advance directives/decisions about their EoL care could alter should they find themselves with a loss of capacity to articulate what they now want in the light of what has happened to them (Rhodes 2015). “EoL” decisions in severe stroke have several ethical issues such as the definition of what could be an "unacceptable" outcome for the individual and/or society and it can be decided to withdraw and withhold treatments when neurological prognosis is considered to be “catastrophic”. The case of Hillsborough disaster victim Tony Bland, who remained in a coma for 3 years until his parents won an historic court ruling to have Tony’s life-sustaining systems removed, is a case to consider in this context (Crozier 2012).

3.3 Mechanically ventilated Stroke patients

An increasing number of deaths following severe stroke are due to terminal extubations. Overall mortality among mechanically ventilated stroke patients is high, with a 30-day death rate approximating 58%. Variation in withdrawal-of-care practices suggests the possibility of unnecessary prolongation of suffering or of unwanted deaths. One study reviewed the available evidence on prognosis in mechanically ventilated stroke patients and identified factors that influence, and decision-making biases that may result, in overuse or underuse of life-sustaining therapies in this context. It provided an overall framework to optimise decision making for clinicians, patients, and families. Decisions about withdrawing care for these patients are often affected by ‘decision-making biases’ including:

- erroneous prognostic estimates
- inappropriate methods of communicating evidence
- misunderstanding patient values and expectations
- failing to appreciate the extent to which patients can physically and psychologically adapt.

Although prognosis among mechanically ventilated stroke patients is generally poor, a minority do survive without severe disability. Prognosis can be assessed according to clinical presentation and patient characteristics. This prognosis can be further refined according to knowledge of stroke syndromes, early patient characteristics, use of clinical prediction rules, and the need for continuing interventions. Factors influencing preferences for life-sustaining treatments include the severity and pattern of future clinical deficits, the probability of these deficits, and treatment burden. Thus there is an urgent need to better understand the marked variation in the care of these patients and to reliably measure and improve the patient-centeredness of such decisions. As many as one third may have no or only slight disability, yet many others have severe disability (Holloway, Benesch et al. 2005).

3.4 Locked in syndrome (LIS)

There is little guidance about EoL decisions for this condition which can leave patients awake and conscious but severely disabled and in a state of almost complete immobility with a loss of verbal communication'. LIS is a condition which requires consideration of a person's quality of life with that condition. One study offered data that strongly question assumptions among doctors, health-care workers, lay persons, and politicians that severe motor disability necessarily is intolerable and leads to EoL decisions or euthanasia. Notwithstanding that depression can be an issue for these patients, many of them maintain a good quality of life apparently unrelated to their state of physical functioning and especially with social support systems in place (perceived social support appearing to be the strongest predictor of psychosocial adjustment). However, their quality of life can be rated by primary caregivers or spouses as significantly lower than patients' own assessment. Additionally, new communication devices and assistive technology offers an increasing number of LIS patients the opportunity to resume a meaningful life and an active role in society. This is related to successful psychological adjustment to the disease and related to problem-oriented coping strategies. Existing evidence supports that biased clinicians provide less-aggressive medical treatment in LIS patients. Thus, psychological treatment for depression, effective strategies for coping with the disease, and support concerning the maintenance of the social network are needed to cope with what becomes a longer term disease scenario, rather than EoL in stroke (Lulé, Zickler et al. 2009).

LIS is commonly associated with a poor prognosis, particularly if the aetiology is stroke. Dealing with individuals with LIS and a poor prognosis raises the issue of introducing EoL discussions with the patient and/or family in the acute period of the illness. Existing literature regarding LIS provides little guidance about EoL decision-making in the acute management phase. Education and support should be given during this period in terms of adjusting to catastrophic changes that have occurred before further EoL discussions continue (Anderson, Augoustakis et al. 2010). Anderson et al, aimed to provide some guidance for clinicians holding EoL discussions in the acute management period using two case reports of relatively young individuals with LIS secondary to brainstem stroke and a very poor prognosis. EoL discussions were commenced by the treating team in the acute phase. Despite the severity of their conditions, in neither case were EoL discussions well tolerated by the family in the weeks following admission. The authors suggest that LIS patients and their families, who have chosen to persist with full medical management after diagnosis of LIS, should be provided with sufficient time to adjust to the catastrophic changes that have occurred before further EoL discussions are pursued. If they have insisted on full medical management, these will facilitate patient and family in developing a realistic understanding of the likely outcomes of their decisions (Anderson, Augoustakis et al. 2010).

3.5 The study protocol of: 'Initiating end of life care in stroke: clinical decision-making around prognosis' (Burton, Payne et al. 2014)

? ✡ ✡

This following study was considered by expert informant number 1, to be the best study to date in terms of decisions about end of life care in stroke

3.5.1 Background: The initiation of EoL care in an acute stroke context should be focused on those patients and families with greatest need. This requires clinicians to synthesise information on prognosis, patterns (trajectories) of dying and patient and family preferences. Within acute stroke, prognostic models are available to identify risks of dying, but variability in dying trajectories makes it difficult for clinicians to know when to commence palliative interventions. This study aims to investigate clinicians' use of different types of evidence in decisions to initiate EoL care within trajectories typical of the acute stroke population.

3.5.2 Methods/design: This two-phase, mixed methods study comprises investigation of dying trajectories in acute stroke (Phase 1), and the use of clinical scenarios to investigate clinical decision-making in the initiation of palliative care (Phase 2). It will be conducted in four acute stroke services in North Wales and North West England. Patient and public involvement is integral to this research, with service users involved at each stage.

3.5.3 Discussion: This study will be the first to examine whether patterns of dying reported in other diagnostic groups are transferable to acute stroke care. The strengths and limitations of the study will be considered. This research will produce comprehensive understanding of the nature of clinical decision-making around end of life care in an acute stroke context, which in turn will inform the development of interventions to further build staff knowledge, skills and confidence in this challenging aspect of acute stroke care.

3.6 Stroke and EoL pathways

The use of EoL care pathways is widely recommended as best practice (Cowey, Smith et al, 2015). The Scottish Government in particular being committed to supporting the implementation of End of Life care pathways in all care settings (NHS and Scotland 2010). However there is little knowledge about what actually happens at the end of life for stroke patients in acute stroke units. A study interviewing 17 relatives of deceased stroke patients and 23 HCPs indicated that family carers are involved in aspects of care at a level of vetoing or triggering aspects of EoL care. They felt a responsibility for deciding whether to use a care pathway and for resuscitation or hydration. Where a relative’s death was expected early in the post-stroke period, and this did not occur, a prolonged dying process, particularly where patients had severe dysphagia, added to distress for families. Significantly, preferences for place of care were not often discussed (Cowey, Smith et al. 2015).

3.7 Carers experience of the decision making process

Given the complexity of prognosis, carers face challenges in EoL stroke care and one paper identified four categories reflecting relatives’ experiences of decision making processes in EoL in stroke:

- making decisions under time pressure and coping with unexpected changes
- the feeling of ‘who am I’ to decide
- reluctance in saying ‘let her die’
- reliance on clinicians (following the treatment proposal of the physician was found to be the prevailing tendency of relatives in the decision-making process). (de Boer, Depla et al. 2015)**.**

3.7.1 Comment

Carers must be prepared for some complexity in terms of the prognosis of their cared for in the context of stroke. In the French context EoL decisions are guided by the law on patients' rights and EoL rulings (Crozier 2012). This is not the case in the UK however and the evidence above illustrates clearly the uncertainty involved in deciding who is at the end of their life in the context of severe stroke (Rodrigue, Riopelle et al. 2013). There are difficulties in prognostication and communication (Jeffries, Shipman et al. 2011) and differences in HCPs opinions (Rodrigue, Riopelle et al. 2013). Sometimes it is just not clear whether to operate or leave a patient in peace (de Schweinitz 2010). Family caregivers need to have all the information they need to be involved or consulted in EoL decision making (Wee, Adams et al. 2010) (de Boer, Depla et al. 2015).

Section4. Support for HCPs

The following section provides International, National, regional and local guidelines for health professionals.

4.1 The Amber Care Bundle Dying well at home: the case for integrated working

The Amber Care Bundle is a staged process in which a person who has had a stroke is supported to make their wishes and preferences about EoL known. It is not about stopping treatment but about identifying and carrying out what the person wants in a timely and pre-planned manner. It also keeps the patient and their relatives or carers up to date with what is happening, ensuring that staff talk to patients and those close to them about treatment options and where they want to be cared for.

Taking the Amber Care Bundle approach, a number of key decisions have to be made, including whether or not the person wants cardiopulmonary resuscitation and what they want to happen if they become unwell. This approach emphasizes the importance of involving patients in decision making, allowing time for consideration and in line with their assessed mental capacity on a daily basis.

The approach is being piloted at the Royal Bournemouth Hospital where patients in the end stages of life following stroke are referred to the palliative care team. The ward team of therapists and nurses work with the palliative care team, care agencies and families/carers to give education and condition-specific information and handling advice/equipment. Therapists give information on activities of daily living that the patient is able to participate in and how best family/carers can support them to do this.

The neuro-therapy team offers telephone support or home visits after discharge, usually in the first few weeks to aid transition to community teams.

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4.2 Best Practice Statement - EoL care following acute stroke (NHS and Scotland 2010)

http://labyrinth.mvm.ed.ac.uk/files/1427/BestPracticeStatement_Endoflifecarefollowingacutestroke1.pdf

The term EoL care is used rather than palliative care throughout the text. In the statements below, the term ‘patient’ refers to patients affected specifically by stroke.

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 2008 action plan, ‘Living and Dying Well’, suggests that patient preferences for place of care at the EoL should always be sought.

4.3 NHS Quality Improvement Scotland

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Best Practice Statement which addresses EoL 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 statement can be downloaded at:

www.nhshealthquality.org or www.glasgow.ac.uk/nursing

4.3.1 Referral to specialist palliative care services

- People receiving EoL care following acute stroke have access to specialist palliative care services.
- Staff caring for the patient who has had an acute stroke and is at the EoL may require support from specialist palliative care services.
- The needs, opinions and participation of the family/carer are considered during EoL care.
- EoL care is provided by healthcare professionals experienced in stroke care.
- EoL care is individualised.

4.3.2 The multidisciplinary team

- Staff should be equipped with the appropriate knowledge and skills to care for the patient at the EoL following acute stroke.
- EoL stroke care is characterised by team working.

4.3.3 Ethical aspects of care - EoL issues including withdrawal of treatment

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

4.3.4 Decision-making

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

4.3.5 Symptom management and nursing care

- Symptoms are managed effectively with regular review and on-going evaluation.
- 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.
- Advance/anticipatory care planning is considered. This includes discussion of anticipatory prescribing in relation to symptoms.
- Communication with the family/carer is proactive.

4.3.6 Nutrition and hydration

- 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.
- 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.
- 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 EoL care. Nurses contribute to the decision-making within a multidisciplinary context.
- 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.

4.3.7 Spiritual and religious care

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

4.3.8 Family/carer support

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

4.4 The National Clinical Guidelines for Stroke (RCP 2014).

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Main recommendations:

- Access to specialist palliative care expertise when needed and should be given the opportunity of timely/fast-track discharge home or to a hospice or care home according to wishes of the patient and/or carers.
- EoL care and the skilled management of a patient where death is inevitable after stroke is a core role of the stroke team. Even when death is inevitable, stroke may cause a range of distressing symptoms that need to be managed. These may include pain, depression, confusion and agitation and problems with nutrition and hydration.
- Stroke teams should be taught how to recognise patients who might benefit from palliative care and all staff caring for people dying with a stroke should be trained in the principles and practice of palliative care.
- After stroke, all EoL decisions to withhold or withdraw life-prolonging treatments (including artificial nutrition and hydration) should be in the best interests of the patient and take prior directives into consideration.
- Professionals involved in the management of stroke patients should be familiar with, and adhere to, the policies defined in the Mental Capacity Act 2005. In particular, the advice on factors to be taken into account when deciding on best interests and recognising that relatives cannot make or determine healthcare decisions.
- Personnel in stroke teams will need to increase their awareness of and expertise in positive end-of-life palliative care, and to accept that this is part of the work of a comprehensive stroke service.

4.5 Palliative care after stroke and stroke palliative care pathway (DoH 2010)

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This project is an initiative of the Victorian Department of Health (formerly Department of Human Services) and funded by the Australian Government, Department of Health and Ageing, under the National Palliative Care Program

The Service provides specialist advice in a range of areas related to patient and carer support for clinical staff including:

- symptom assessment and management (including pain management, nausea, shortness of breath and restlessness)
- recognition and management of the dying/terminal phase and supporting staff in this process
- patient prognosis and rate of illness progression
- input into decision-making regarding cessation or non- commencement of treatment
- issues related to fluid and food management, modification or cessation
- issues related to medication rationalisation/cessation
- advance care planning and power of medical attorney appointment

4.5.1 What is the stroke palliative care pathway?

The Stroke Palliative Approach Care Pathway (SPAP) is a structured, multidisciplinary care plan which details essential steps in the care of palliative stroke patients. It provides guidance on key aspects of care including:

- discontinuation of non-essential medications
- discontinuation of active treatment interventions
- anticipatory prescribing of comfort medications
- general comfort measures
- various psychosocial and spiritual needs, including information for carers

The pathway is divided into four sections, corresponding with the phases of patient management:

- Initial assessment and initiation of the palliative approach
- On-going care and assessment
- Discharge home
- Verification of death

It also includes protocols for comfort measures such as pain management

4.5.2 Criteria for commencing the SPAP

The multidisciplinary stroke team has considered the clinical situation and the wishes of the patient and family/carer, and agrees that, as a result of severe stroke and/or other concurrent co-morbidities:

- there is an anticipation of imminent death or
- an expectation of poor prognostic outcome or
- the patient is in a semi-comatose or comatose state and not expected to improve.

4.6 Carer support, evidence based clinical practice guidelines

These evidence based guidelines are from the Centre for Palliative Care in Australia and on various topics.

They are endorsed by a number of Australian organisations, and by St Christopher's Hospice, London and the International Observatory of End of Life Care in the United Kingdom.

They are Copyright (2010) but can be downloaded for use.

- EMRPCC: End of life care: Management of respiratory secretions (2013)
- EMRPCC: Opioid conversion ratios - Guide to practice 2013 v. 2 (Nov 2014)
- MRPCC: Syringe driver drug compatibilities - Practice guidelines 2013 v. 2 (Nov 2014)
- Palliative care nurse practitioner - Symptom assessment guide (2011)
- Palliative care nurse practitioner candidate - Clinical competencies (2011)
- EOLRSF: Noisy breathing at end of life (2013)

4.7 Gold Standard Framework - Prognostic Indicator tool (PIG) (RCGP. 2011)

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http://www.goldstandardsframework.org.uk/cdcontent/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

In terms of identifying patients at the EoL (and potentially their carers) the National GSF Centre’s guidance for clinicians supports earlier recognition of patients nearing the EoL. By identifying people who are in their last year of life clinically, GPs can then ensure their patients are more likely to receive high quality EoL care, have fewer emergency admissions to hospital and have a good death in the place of their choosing (Davidson and Gentry 2013).

This and the GSF Prognostic Indicator Guidance (PIG) endorsed by NICE, and QOF guidance 2011/2012 aims to enhance GPs’ ability to, amongst other things, put EoL care plans in place. This not only boosts the chances of early identification, it can help determine what stage the patient is at through the prognostic indicator guidance tool. The tool can be used by individual clinicians or by multi-disciplinary teams to judge whether patients are entering the dying phase of their lives. If this is the case, a discussion should be initiated with patients (and potentially carers) about their wishes.

This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

4.7.1 Specific clinical indicators in stroke include:

- persistent vegetative or minimal conscious state
- dense paralysis,
- medical complications
- lack of improvement within 3 months of onset
- cognitive impairment/post stroke dementia.

4.8 NICE Quality standards

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http://www.nice.org.uk/guidance/qs13/chapter/Introduction-and-overview

For families, carers and patients with advanced, progressive, incurable conditions; adults who may die within 12 months; and for those with life-threatening acute conditions.

4.9 Multidisciplinary clinical practice guidelines - family meetings in palliative care

A multi-media resource, “Conducting Family Meetings: a resource for health professionals working in cancer and palliative care”, demonstrates how to use these guidelines

http://centreforpallcare.org/assets/uploads/Family_Meetings_in_PC_Multidisciplinary_Clinical_Practice_Guidelines.pdf

www.pallcare.unimelb.edu.au

Support for family carers is a core function of palliative care service provision. Service providers therefore, have a responsibility to offer family meetings based on need. These provide an opportunity to enhance the quality of care provided to palliative care patients and their family carers.

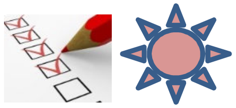
Family meetings can be a useful way to assist patients and family members to clarify goals of care, consider site of care options, and to share information. They also offer facilitation for the airing and resolution of family conflict (pc, TA, 13/4/2015). They provide a safe environment where issues and questions can be raised and appropriate strategies agreed upon. They are not only potentially valuable for patients and family carers; they also make clear what services can and cannot offer. Such meetings provide an opportunity to triage priority issues and a way to make referrals to other health professionals or other institutions early in the care planning phase. Rather than reaching a ‘crisis’ situation, family meetings represent a preventative approach where issues are anticipated (proaction) before they become major dilemmas (reaction). HCP’s facilitating family meetings require appropriate skills in group work, therapeutic communication and palliative care. Pre-planning for the actual meeting is imperative and there should be a comprehensive follow up after the meeting. Pre and post-family meeting primary family carer questionnaires are available for evaluation purposes. Appropriate resources should be available to patients and family members who attend the meeting in order to complement verbal information (e.g. brochures about services available, carer guidebooks, treatment and drug information, etc). These clinical guidelines offer a very detailed and comprehensive framework for preparing, conducting and evaluating family meetings.

Section 5. Training for HCPs

Care of patients at the EoL 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 alongside making important decisions. Whether working in stroke units or care homes, nurses are important members of the multidisciplinary team, caring for stroke patients at the EoL 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) (NHS and Scotland 2010).

HCPs caring for dying neurologic patients may not be knowledgeable about the principles and practice of palliative care. The pivotal point of death may be used as a lever to promote and improve palliative care principles and skills in existing services by including palliative care expertise. This can also be useful earlier in the disease course (Voltz, Nubling et al. 2013).

5.1 Stroke specific education framework (SSEF)



A freely available resource for anyone interested in stroke care to use http://www.stroke-education.org.uk/framework.htm

People who are not likely to recover from their stroke receive care at the end of their lives, which takes account of their needs and choices.

- This module engenders knowledge and understanding of:
- EoL care strategies, advanced directives, and palliative care tools in relation to stroke
- The implications of the Mental Capacity Act for stroke patients
- Advocates for stroke patients when there is a legal duty to instruct an IMCA, taking account of religious and cultural aspirations
- The range of support groups and services for those affected by stroke with palliative care needs
- The needs and aspirations of those affected by stroke (i.e. patient, carer and family)

- The assessment and management of problems, how they can be controlled and the implications for prognosis: psychological and emotional; social and relationship; cognitive and communication; physiological, physical and functional; neurological, visual and sensory impairments and pain;
- Medical, pharmacological and non-pharmacological interventions for EoLcare after stroke
- The side effects of pharmacological and non-pharmacological interventions for EoL care after stroke

And the skills and ability to:

- Take and interpret a thorough history, including information from carers, relatives and other agencies where possible, and assess mental capacity
- Determine, plan and initiate appropriate assessments/investigations and interventions/treatments; provide information, relevant to individual needs and aspirations (personalise information)
- Communicate and discuss: current event; interventions/treatments and their timeframes; rationale for treatment; possible side effects of treatment; and provide advice and prognosis
- Assess capacity and “best interests” according to the statutory principles
- Provide sufficient information to enable informed choice and decision making by those affected by stroke
- Identify need and when to refer for more specialist or differing treatments where necessary: agree referral
- Recognise and manage symptoms taking account of individual needs and aspirations
- Use palliative care, or other relevant tools, and care pathways
- Identify local services and resources, including waiting times and implications for those affected by stroke
- Use strategies to help with breaking bad news, managing emotions and obtaining information on advanced directives
- Develop mechanisms to support the palliative care team and provide opportunities for debriefing sessions.

5.2 STARS (Stroke Training and Awareness Resources)

http://www.strokecorecompetencies.org/node.asp?id=home

This e-learning resource provides a learning tool for health and social care staff to enable them to become more knowledgeable and skilful in the challenging area of stroke care.

The resource is based on the Stroke Core Competencies which were published by NHS Education for Scotland (NES) in 2005. These have now been updated (NHS and Scotland 2010).

5.3 Information and links for professionals who support people and their families at the EoL

http://www.scie.org.uk/adults/endoflifecare/index.asp

This resource is for people who work with adults who are approaching the EoL. Some 500,000 people die each year and, because of the ageing population, that number is predicted to rise over the next few years. It’s important that social care and health professionals who work with people at the EoL and their families have access to high quality resources and information so they can give the best care possible.

5.3.1 Film: Case Study

http://www.scie.org.uk/adults/endoflifecare/ideasforpractice/holisticpalliativecare.asp

Covers the following areas:

- End of life - Ideas for practice
- End of life care - Holistic palliative care

Kate is a 51 year old woman with late stage ovarian cancer. She is a single mother with five children aged 24, 23, 17, 15 and 11. She is also guardian for her 13 year-old grandson. This film describes how HCPs and family resolves issues for her in order to offer holistic palliative care

5.4 End of life care: why supporting family carers is vital

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http://www.scie.org.uk/socialcaretv/video-player.asp?v=supportingthecarers

Leicestershire and Rutland Hospice run a family support service for the families and carers of people who are at the end of their lives. Social Workers work with other staff members to identify families who are in need of support. They can offer a sitting service to enable carers to have some time away from their caring responsibilities and bereavement support and counselling to those who have lost a loved one. We hear from Benita who looks after her mother and has regular support from a sitter and Trevor, a bereaved man, explains how he was initially reluctant to have counselling but came to find it helpful and supportive in dealing with his grief.

Messages for practice:

- Many families and friends want to support a person at the EoL whether that person is dying at home or in a care setting.
- Social care staff should be able to offer support not only to the dying person, but also to their carers.
- Support for carers may be needed while their relative is dying, as well as after the death when the carer is grieving.

Carers can find support helpful in dealing with the death of a loved one.

Section 6. Needs of carers of people with stroke at the end of their life

The following section outlines the findings of six relevant peer reviewed studies which examined the needs of carers of those with stroke who are at the end of their life. The original abstracts from the papers are in Appendix 1 on page 69.

6.1 "Integrating palliative care within acute stroke services: developing a programme theory of patient and family needs, preferences and staff perspectives” (Burton and Payne 2012)

A recent study offers the first, empirical explanation of the integration of palliative and acute stroke care arguing that palliative care should be integrated early into the care trajectories of people with life threatening illness such as stroke. Published guidance focuses primarily on the EoL and there exists a lacuna in the evidence about how the palliative care needs of acute stroke patients and families should be addressed.

Data from a survey of patient-reported palliative care needs and from over 50 interviews with patients and family members were explored in group interviews with 29 staff from 3 UK stroke services. An explanatory theoretical framework for the integration of palliative and acute stroke care included two cognitive mechanisms through which staff integrate palliative and stroke care:

- the legitimacy of palliative care and individual capacity, and
- behavioural mechanisms (engaging with family, the timing of intervention, working with complexity and the recognition of dying)

A range of clinical (whether patients are being ‘actively treated’, prognostic uncertainty) and service (leadership, specialty status and neurological focus) factors appear to influence how palliative care needs are attended to and implemented.

The specification in the framework of factors that mediate integration can inform service development to improve the outcomes and experiences of patients and families in this context. (Burton and Payne 2012)

6.2 “What is good end of life care after stroke?” (Jeffries, Shipman et al. 2011)

Professionals believed the following were important aspects of EoL care:

- Treating patients as individuals
- Providing care in a dignified manner and in a comfortable environment
- Good personal care and symptom control
- Ascertaining the needs and monitoring patients
- Recognising death
- Ensuring the team is aware of the care plan
- Informing families and involving them in decisions
- Facilitating patient communication and patient-family interaction is valued
- Good team structure, function and training

Recommendations include:

- Using a care of the dying pathway
- Encouraging patients with capacity to discuss their care needs and wishes
- Discussion of dying patients care at multidisciplinary meetings
- Facilitating patient communication
- Educating stroke team in palliative care and palliative care teams in stroke care
- Research into prognostication is needed

6.3 “End-of-life issues in acute stroke care: a qualitative study of the experiences and preferences of patients and families (Payne, Burton et al. 2010)

- Communication between patients and family members and healthcare professionals was consistently highlighted as central to a positive experience of stroke care.
- Honesty and clarity of information was required, even where prognoses were bleak or uncertain.
- Patients and family members appeared to attach as much importance to the style of communication as to the substance of the transfer of information.

- Where decisions had been made to shift the focus of care from active to more passive support, families, and where possible patients, still wished to be included in on-going dialogue with professionals.
- Where patients were thought to be dying, family members were keen to ensure that the death was peaceful and dignified.
- Families reported few opportunities for engagement in any form of choice over place or style of EoL care.

N.B. No family member reported being offered the possibility of the patient dying at home.

6.4 “Palliative and end-of-life care for people with stroke” (Wee, Adams et al. 2010)

- Palliative care services involved in care of stroke patients are more frequently involved in issues related to communication and difficult decisions related to food and fluids.
- Caregivers have significant needs, particularly around information provision, communication and involvement in, or consultation about, decision-making.

6.5 “Evaluating an Organized Palliative Care Approach in Patients with Severe Stroke” (Blacquiere, Gubitz et al. 2009)

Concerns raised by family members centred around:

- hydration and feeding
- doubts about palliative care and patient comfort

A formal approach to palliation results in timely decisions regarding EoL care with relatively few conflicts. Further work to address the specific concerns of families is needed.

6.6 "The palliative care needs of acute stroke patients: a prospective study of hospital admissions" (Burton, Payne et al. 2010)

Collecting data from stroke patients, (some at greater risk of death than others) is beset with difficulties and should be gathered in ways that maximise the collection of a minimum of data with minimal inconvenience to patients. Some of this depends on the ability of research network staff to approach patients and families in a timely manner (Burton, Payne et al. 2014). An early study however, managed to collate the following information from patients themselves and found that:

- 50% reported moderate to significant fatigue-related problems
- Approximately 50% reported symptom-related problems (e.g. pain) or psychological distress (e.g. anxiety)
- Approximately 25% had concerns about death or dying
- 66% had concerns about dependence and disability
- Over 50% were worried about the impact of stroke on family members

Section 7. Clarification of terms for carers

An issue for patients and carers involves the understanding the terminology used by HCPs and this was flagged in the early stages of this EBS and again, in the General End of Life EBS that accompanies this document.. Terms below will be familiar to HCPs but these need unravelling and explaining to patients and carers. These comprise:

“end of life”,

“general palliative care”,

“palliative care”,

“specialist palliative care”,

“end of life care”,

“acute stroke care”,

“stroke care”.

The following paragraph will help explain these in more detail and these explanations can be transmitted to stroke patients and their families depending on individual contexts.The definition adopted in this document of the term ‘end of life’ is that used by the General Medical Council, that is, where death is expected within 12 months. This definition includes people with advanced, progressive, incurable conditions.

http://www.nice.org.uk/guidance/qs13/chapter/quality-statement-1-identification

More effective *general palliative care* is required for those dying in stroke units along with greater education on this level of care and communication about End of Life issues for staff in stroke units. Access to *specialist palliative care* is desirable for certain patients. Patients with stroke however, tend not to get referred to *palliative care* or hospice services.

The UK National Clinical Guidelines for stroke advocate that all stroke patients should have access to *specialist palliative care* expertise.

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

"…applicable early in the course of an illness, in conjunction with other therapies that are intended to prolong life".

http://www.who.int/cancer/palliative/definition/en/

By contrast, care provided at the *end of life* is recognised as being one component of *palliative care* and concerned with a 30 day period and because stroke can be a sudden event (NHS and Scotland 2010). *End of Life Care* in Stroke however, has been known to last up to five years (Patient Voices > The stories > Soulmate Copyright 2015 Pilgrim Projects Limited. "Soulmate")

High-quality palliative and EoL care are advocated for patients not expected to recover from stroke. Given the uncertain nature of stroke, although health professionals recognised *palliative care* as an important component of *stroke care*, patients and HCPs experience uncertainty about initiating transitions to palliative care in stroke, and with the integration of acute stroke care and palliative care (Gardiner, Harrison et al. 2013). Most patients when acutely ill or dying want to be relieved of any suffering; help in minimising the burden on their families, closer relationships with loved ones, and a sense of control. *Palliative care* has much to offer in the provision of *stroke care*. It should be viewed not as an alternative to offering life-sustaining therapies or other evidence based stroke treatments but as an important supplement that can enhance care delivery for patients, families, and providers alike (Holloway, Arnold et al. 2014).

Patients who have had a stroke should not be excluded from *acute stroke care* at the end of their life however and there is a national drive to improve the quality of *End of Life care* in all clinical areas, including for stroke patients (Cowey, Smith et al. 2015). The evidence shows that *palliative* and *end-of-life care* have been adopted as key components of *specialist stroke care* in UK stroke units although many patients stand to benefit from earlier identification of *palliative care* need and a consideration of quality-of-life approaches during active care. Encouraging collaboration and partnership when working with *specialist palliative care* services would optimise palliative care service delivery and may provide patients and their families with greater opportunities for documenting and achieving preferences for care and achieving a better quality of death (Gardiner, Harrison et al. 2013).

End of Life care is an important aspect of acute stroke nursing because stroke mortality rates remain high, despite advances in care. *Palliative care specialists* may provide support where patients' needs are complex, while decisions to withhold cardiopulmonary resuscitation should be avoided immediately following stroke. Although more research is required about stroke care at the *End of Life*, providing high-quality, patient-centred services for patients who have had a stroke and their families during this time is achievable (Cowey, Smith et al. 2015).

Another definition of palliative care from The Centre for Palliative Care, St Vincent's Hospital and Collaborative Centre of The University of Melbourne, is that it seeks to improve quality of life for patients and carers who are facing the challenges associated with a life-threatening illness. It covers the full spectrum of patient care including their practical, clinical, psychosocial and spiritual needs. Carers are highly valued members of the palliative care team and practical support and encouragement for carers is an essential part of the holistic approach.

7.1 Comment

The papers identified above offer the best evidence for the needs of carers in the context of caring for those with stroke at the end of their life. The preferences of stroke patients and their families in relation to palliative care services are not well known and there is a paucity of data in regard to the distinction between provision of palliative care services for patients who die in the acute phase of stroke and for those patients who die later (Stevens, Payne et al. 2007). Clarifying terminology will help carers understand and negotiate the situation for their patients and is an important need for all carers.

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 their relatives would prefer at the EoL and in where (e.g. hospital or home) (NHS and Scotland 2010). Hydration is a particular issue in EoL care. Maintaining or withholding fluids at the end of life remains a controversial issue in terms of whether dehydration is painful, and/or could lessen obnoxious symptoms which could be stressful for patients at the end of life (Mentes and Kang 2013). Barriers to care cited for stroke patients included resource and time limitation, competing priorities, difficulties in prognostication and communication and not knowing patients´ wishes (Jordan and Kauffmann 2010).

In summary, carers needs and concerns centre around the following:

- Carers have reported that the end of life feels fragmented and confusing
- Carers have problems accessing the care they need.
- Carers experience increasing physical and financial stress as well as isolation and fear.
- In order to care for their patients, carers need to be informed to make choices about treatments and care and require consistent and truthful information from professionals.
- Prognostic uncertainty in stroke is one that carers may need to have explained to them in order to confront and address this issue.

Section 8. Training and support for carers – The Stroke Association North West UK

This section describes what the Stroke Association North West offers to carers and this is outlined below.

The Stroke Association in this geographical area offer a range of carer training including Caring with Confidence, BOOST and a range of educational / support courses in partnership with stroke teams, IAPT, stroke psychologists etc. Some of these are described below. This is in addition to carer support groups, coffee mornings and other events. They also offer formal commissioned training for HCPs, via their training department (PC. CL, July 2015).

https://www.stroke.org.uk/professionals/stroke-training

8.1 BOOST

Free 8 week course including a pre-session and a follow up reunion session

BOOST is a structured course to improve mental wellbeing. It is accessible by vulnerable groups and focuses on positive mental wellbeing with a view to increasing resilience and coping.

The course includes teaching a series of techniques and strategies including:

- relaxation techniques
- confidence building
- assertiveness and
- positive thinking

Delivered to groups of between 8 and 12 people at informal community venues by 33 trained facilitators including, health improvement workers, psychological wellbeing practitioners, volunteers and group workers.

The course is delivered as an ‘open access’ programme at community venues across the City and on a bespoke basis for the users of organisations working in partnership with Manchester Public Health Development Service (MPHDS).

The course contains adaptations which ensure that it is accessible for people that have additional needs.

8.1.1 Appraisal

This course appears to be a generic mental well-being course. However, it could be appropriate for carers of patients at the end of life or after they have been bereaved. It offers strategies for them to cope with the aftermath of their caring experience and the opportunity to meet and keep in contact with others in the same or similar situations.

The people of Manchester have poorer mental wellbeing compared with the North West average, and this course appears to have improved this for participants.

8.1.2 Contact for more details

Nicola Wood
Nicola.wood@mhsc.nhs.uk

Barbara Drummon
B.drummond@manchester.gov.uk

8.2 Life after stroke (LAS)

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http://www.stroke.org.uk/sites/default/files/files/LAS%20training%20proposal%20080612(1).pdf

8.2.1 Stroke and EoL care module

This module can be either delivered as part of the 3 day course, Life after Stroke or, in a bespoke half day or one day specific individual unit.

Module aims and key messages:

- It aims to offer an understanding of how to support End of Life care after stroke.
- It is educative and not therapeutic
- The course content draws on evidence based cognitive behaviour therapy principles as a framework for understanding our mental wellbeing and promoting self help
- It is not a psychological 'intervention' for treating mental health problems.

8.2.2 Module learning outcomes

To be aware of:

- How stroke could impact on End of Life care
- How the individual's needs and choices can be understood and implemented with dignity
- Best practice in line with current policy and guidelines on how to deal with difficult situations and conversations

8.2.3 Module aims

- To promote self-care
- To build levels of resilience
- To increase participant's ability to make positive changes to improve their mental wellbeing

8.2.4 What is included?

The course incorporates tools and techniques for improving wellbeing based around a series of themes:

- Session 1. Understanding wellbeing and emotional resilience
- Session 2. Stress: managing the physical symptoms of stress.
- Session 3. Recognising and managing unhelpful styles of thinking.
- Session 4. Communicating needs and solving problems
- Session 5. Improving assertiveness and self esteem
- Session 6. Identifying wellbeing needs, action planning for integrating wellbeing activity into your life

Each session includes practical tools or ‘skills’ that people can use in everyday life. For example:

- expressing needs and communicating more assertively
- breathing skills for managing the effects of stress
- recognising and tackling unhelpful thinking styles.

The sessions are delivered informally and incorporate low level physical exercises

8.2.5 Appraisal

This bespoke course appears to be a welcomed, useful addition to general End of Life courses and the only one specific to stroke identified in this scope.

The half-day session for family or lay-carers could be very beneficial; the MHMC project team should consider this as part of their programme

8.3 POPP (Manchester Partnership for Older People Projects)

A partnership funded by POPP and run by The Stroke Association in co-operation with Manchester Carers Forum with trainers from ‘Extend’ https://www.manchestercommunitycentral.org/news/stroke-association-groups

This is an 8 week programme of health promotion and supported exercise focusing on exercise and healthy lifestyle choices for both patients and carers delivered in Manchester.

It includes a programme of education to aid self-management and is aimed at stroke survivors mostly. However carers do attend some sessions which include exercise, fatigue management, emotional resilience, medication management etc.

For more information, visit: www.stroke.org.uk, or contact Helen Gilbertson, Information, Advice and Support Coordinator at the Stroke Association, on 0161 972 0559 or 0798 334 3003, or email: helen.gilbertson@stroke.org.uk.

8.4 Moving and Handling

http://carersinwiltshire.co.uk/training/

This course involves:

- Wiltshire Council currently offer 4 ½ hour long courses on;
- Handling equipment
- Manual handling
- Moving and handling
- Moving and people handling
- Advanced handling and
- First aid for carers
- Food safety, Nutrition and Hydration

8.5 Films and other resources

8.5.1 "End of life care: why talking about death and dying matters"

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10 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=endoflifecarepersonalisation

For people moving towards the EoL a personalised approach gives them a voice and influence over their care. This film looks at how personalised care can be achieved through the Living Well tool, which involves creating a simple one page profile to record a person's needs and wishes. It is shared by everyone involved in their care so that they can quickly get to know and understand the person, even if they have communication difficulties. The film shows how the scheme is used in settings in Stockport and in Hull and features case studies showing how profiles work successfully in practice.

Messages for practice

- Personalised care for people at the end of life requires a planned and coordinated approach to care. Recording the likes, dislikes and preferences of a person at the end life in one place is a simple but important step towards achieving personalised care, whether from health or social care services.
- People who receive care which reflects what’s important for them helps to make them feel more in control and more secure.
- An understanding of what’s important for a person at the end of life means staff will have better ideas of how to support and reassure them.

A simple tool which records people’s preferences is also useful if they have to change care setting and can facilitate better working between health and social care.

8.5.2 “End of life and palliative care: thinking about the words we use”

4 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=palliative-care-or-end-of-life-care

In this film a palliative care social worker is interviewed about the skills and understanding that are needed to make sure people can die with dignity and respect. It shows members of the support team in Lancashire discussing care preferences with a man at the end of life and then making sure the practical “HOSPICE AT HOME” services he needs are in place.

Appraisal

Although this film is for HCPs primarily, it would be useful to go through with patients and their families perhaps in order to initiate discussion and clarification of terminology used in the Stroke and EoL context

8.5.3 “End of life care: dying at home”

11 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=dyingathome ditto live link

In this film a palliative care social worker is interviewed about the skills and understanding that are needed to make sure people can die with dignity and respect. It shows members of the support team in Lancashire discussing care preferences with a man at the end of life and then making sure the practical “Hospice at home” services he needs are in place

Appraisal

This is an in depth look at ways of keeping people at home to die should they so wish. It includes a BAME element and describes how culturally sensitive trained carers are necessary in this context.

8.5.4 “End of life care: what matters to the person who's dying”

11 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=holisticassessment

A palliative care specialist nurse from St Joseph’s Hospice, London, defines holistic assessment as an on-going process involving the physical, social, psychological and spiritual care of a person at the EoL. Through an interview with a woman with a familial, chronic health condition, holistic assessment is shown working in practice; we see how she is supported to develop a plan which states her wishes about her EoL care. This provides clarity for the family of the person as well as her health and social care team. There is also an interview with a woman who was initially reluctant to make plans about her EoL care but, with the help of a social worker, has now done so and feels more confident, in control and supported.

Messages for practice

- Holistic assessment is about the physical, social, psychological and spiritual needs of a person at the EoL
- Holistic assessment can result in a plan which records the wishes and decisions of a person at the EoL. This may be useful for family and everyone involved in their care.
- Holistic assessment is an on-going process which can be updated and changed as the person’s choices and preferences change.

The process of making a holistic assessment may increase the confidence and trust of a person at the EoL.

8.5.5 “No Greater Gift” – DVD

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For a copy of the DVD please email centreforpallcare@svhm.org.au

In *No Greater Gift* you will hear from past and current carers who have undertaken this important role on a variety of levels with the support offered to them by palliative care. They share their unique and personal stories in the hope that others will benefit from their experience.

No Greater Gift is suitable for individuals and their families who are embarking on the carer role. It can also be used to generate discussion during a support group or counselling session.

NB: Viewers are cautioned that Part 2 – EoL and Bereavement contains detailed accounts of EoL planning and reflections on the grief experience

8.5.6 “Soulmate”

http://www.patientvoices.org.uk/flv/0377pv384.htm

The story of a man who cared for his wife over many years.

Section 9. Two examples of one-to-one carer education

The following two examples are included the General End of Life EBS. However, they are also described here because they could be relevant for stroke and EoL care.

9.1 An educational package to support lay-carers to manage breakthrough subcutaneous injections. Development and evaluation of a service quality improvement[3] (Healy, Israel et al. 2013)

9.1.1 Abstract (abridged)

Palliative care services strive to support people to live and die well in their chosen environment, with optimal symptom control and a pattern of care supportive of laycarers. The likelihood of patients remaining at home often depends upon laycarers, who may be required to manage subcutaneous medications. Structured education programmes for laycarers result in positive patient and laycarer outcomes relating to symptom management, provide lay-carers with the knowledge to understand the rationale of good symptom management and adds to their confidence in administering the right drug for the right symptom at the right time. This generates improved patient outcomes and decreases unwanted and inappropriate admissions to acute care facilities. There is some literature confirming the ability of laycarers to successfully administer pre-prepared syringes for symptom control, but few studies concern themselves with the practice of also teaching laycarers to prepare these injections.There is resistance from some palliative care service providers about the appropriateness of teaching lay-carers to prepare and administer subcutaneous injections in part due to the perception that the task is too burdensome for family members. In addition, there is organisational and individual uncertainty related to legal, jurisdictional and scope of practice issues for registered nurses and lay-carers.

This study reports on the development, trial and evaluation of a package that teaches lay-carers to manage subcutaneous medications used for symptom control in home-based patients. The package was developed by palliative care stakeholders and comprises an educational session, delivered by nurses, and a range of demonstrative, audiovisual and written resources. It was trialled across 24

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[3] This project was funded and supported by the Australian Government, Department of Health and Ageing under the *Supporting Carers of People Requiring Palliative Care At Home* projects.

sites and was finally evaluated by 76 lay-carers (pre and post-use) and 53 nurses. Lay-carers and nurses rated the usefulness and relevance of the package highly – all ratings were above 5 on a 7-point scale. The study is described below.

9.1.2 Backgraound to the package

The package was developed by palliative care stakeholders

It is suitable for delivery in a one-on-one format in the laycarer's home

It can be implemented across various health and geographical settings

Different teaching materials and modalities allow for individual differences in rates and style of learning.

76 laycarers and 26 nurses highly rated the usefulness and relevance of the package.

9.1.3 Delivery of the package

An education session delivered by nurses with a range of demonstrative, audiovisual and written resources that educated and supported laycarers to competently and safely:

- prepare, store and administer subcutaneous injections
- to monitor subcutaneous sites
- to manage a medication administration record suitable for easy assessment by health professionals
- to understand the uses of common medications used in palliative care.

The education session required between 20 and 60 minutes to complete and was used to introduce the suite of 8 resources developed for the study.

The session included:

- Standardised information content, focusing on safety, competency and skills (inclusive of preparation, storage and administration of breakthrough injections) and deliverable by registered nurses to lay-carers.

- A training manual was developed to guide clinically registered nurses in the delivery of the education session. A suite of resources was developed for use within the education session and to provide lay-carers ongoing support in their day-to-day management of subcutaneous medications.

All the materials produced by this study can be accessed via http://www.caresearch.com.au/caresearch/tabid/2145/Default.aspx

9.1.4 Feedback on the package

Lay-carers perceived the overall usefulness of the package as soon as they had completed their one-on-one education session. This perception was maintained after they had had the experience of symptom management using subcutaneous medications. They were satisfied that the package information was relevant to them and the content provided necessary technical skills to manage subcutaneous medications. Importantly, they felt confident that they could safely pre-prepare and inject subcutaneous medications. In addition, the package decreased their stresses surrounding subcutaneous injections, and they were satisfied that they could assist with symptom management. The package, by allowing access to standardised and relevant information, empowers lay-carers to care safely for loved ones at home.

Nurses rated the education session highly for aspects such as appropriateness to the needs of lay-carers, providing the necessary information to allow lay-carers to safely pre-prepare and administer subcutaneous injections. Similarly, they indicated that the issues relevant to subcutaneous injections of palliative care medications had been well explained and the components of the package provided useful resources for lay-carers.

Nurses felt that the education session was easy to deliver, adequately explained injecting issues and recommended its continued use. Notwithstanding this, delivery of the standardised education challenged some nurses, possibly because it encompassed practice change. Clinical opinion varied as to the appropriate time in the patient’s palliative care trajectory to present the education session. The consensus was that the time for package introduction depended upon each particular clinical situation and laycarer. Some commented on the clinical load imposed due to the time required to deliver the session depending upon the clinician and individual lay-carers abilities and learning styles. They concurred however, that with continued experience in education delivery, the time required to introduce the package would decrease.

Nursing opinion was divided concerning whether it is safe and appropriate for lay-carers to manage subcutaneous injections. Some nurses reiterated their concerns about safety issues related to lay-carers managing symptoms and the burdensomeness of that task. However, given lay-carers high level of satisfaction with the package, it may be that nurses, and other health-care professionals, have been overprotective or gatekeeping in their attitudes to lay-carers.

The package showed that lay-carers can learn to manage subcutaneous injections, thus contributing to breakthrough symptom control in a timely and effective way. It is likely that use of the package can contribute to more patients being able to die in the environment of their choice, their home. Potentially, this will result in an improved quality of death and decrease the cost burden to the health-care system incurred when distressed patients are unnecessarily transferred to acute care facilities. If the ability of lay-carers to provide symptom management is improved by initiatives such as the package described here, then the capacity of professional palliative care staff, particularly nurses, to care for more people will be enhanced.

9.1.5 Safe practice measures[4]

The issue of safe practice was a fundamental consideration throughout the package development. To reinforce written medication information, a colour coding system, adapted from anaesthetic drugs safety Standards and advocated by an Australian national labelling project, helped lay-carers to identify correct medications, and avoid errors, through the use of labelling pre-prepared syringes. The importance of the colour coding system was emphasised during the education session. Lay-carers were taught that they could use the coloured labels on the pre-prepared syringes as a cue to help distinguish between medications, even when they were tired or distressed. All the pre-prepared injections were stored in secure containers in the refrigerator. The fridge door magnet incorporated the colour-coding system, thus further consolidating the colour prompt for the lay carer. The magnets were designed to be written on, so changes in medication could be easily updated by nurses or laycarers. The colour coding system was uniform across all package resources including the medication booklet and DVD.

Another safe practice measure was the diary provided to lay-carers that encouraged the recording of every injection given as well as the effectiveness of the medication for symptom relief. This clinical tool proved to be of great value to both lay-carers and visiting health professionals. lay-carers experiencing a sense of security in having a record of injection administration as pressures associated with the caring role often led to an inability to accurately recollect medical detail. Indeed, most lay-carers chose to continue using the diary even after study completion. Nurses reported that they could easily interpret the information contained within the standard diary and this helped them monitor medication effectiveness, progress of symptom evolution and patient condition.

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[4] *To clarify issues about the legal, jurisdictional and scope of practice issues related to the common palliative care practice of preparing subcutaneous injections and leaving them in the home for subsequent administration by lay-carers the Brisbane South Palliative Care Collaborative prepared a document entitled Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland. This document has been endorsed by Queensland Health, Australia and complies with the Health (Drug and Poisons) Regulation 1996, the Queensland Powers of Attorney Act 19982, and the Guardianship and Administration Act 2000.*

9.1.6 Conclusion

This study demonstrates that if lay-carers are supported with education and resources, tailored to their needs, they can confidently, safely and competently manage breakthrough subcutaneous medications to relieve symptoms in home-based palliative care patients[5] (Healy, Israel et al. 2013).

9.2 Audit of the use of ‘just-in case’ boxes as part of a Local Enhanced Service agreement for EoL Care

This project resonates with the idea of carers being able to administer pain relief to ther patients in their own home when they need it (Westwood, Bagshaw et al. 2012).

9.2.1 Abstract

Background: The local enhanced service for end of life care was started by Worcestershire Primary Care Trust in 2009, with the aim of developing good practice and improving EoL care. GPs were asked to sign up to and fully adopt the Gold Standards Framework (GSF). Access to palliative care medications and proactive management of symptom control are key components of GSF, and to support this ‘just-in case’ boxes were launched in April 2010. It was anticipated that the use of the boxes would avoid the distress caused by poor access to medications in out of hours, by anticipating symptom control needs and enabling availability of key medications in the patient’s home.

Outcomes: To assess the success of this initiative a 6 month audit was undertaken between May and October 2010.

Results: A total of 66 boxes were placed in patients homes. Fifteen of those boxes were not used. No patients were transferred into the acute trust (one patient was transferred to a care home), meaning that 65 people remained in their own home at time of death, with 48 of those patients’ EoL care being supported by provision of anticipatory medication. Only 6% of the responses reported any resistance to use of the boxes, either by the patient or their family. Provision of the boxes improved symptom control in 55% of the cases, and 89% of the boxes were reported as containing the most appropriate drugs. A cost saving of at least £69,140 was made. This was calculated by multiplying the number of times the provision of the just-in case box prevented use of a further healthcare

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[5] Findings may not be directly applicable across all palliative care service populations. And this study is not applicable across countries due to differences in legal codes.

service by the average cost for that specific episode of care. This can be compared favourably to the cost of providing the drugs, being £3,346.

9.2.2 Comment

Both the Stroke and EoL care module in **Error! Reference source not found.** course, and the **Error! Reference source not found.** course aims to promote resilience and improve mental wellbeing, it being the case that people with good mental wellbeing cope better when faced with difficult life situations. It can improve relationships generally, give people the confidence to make positive life changes and feel that they have more control. However, depending on the time scale of each individual patient's illness trajectory, carers may not have sufficient time to attend and utilise the coping strategies used in the programmes.

In terms of nursing skills, the two one-to-one education and training for carers' are examples of support available to support lay-carers to manage breakthrough subcutaneous injections and control pain. These, potentially, could be developed for PCFT although there are concerns about carers undertaking nursing tasks and administering pain relief to patients. Although these two examples offer ideas of how carers could be empowered to care safely for loved ones at home, in the context of Stroke there may not be sufficient time for carers to learn and consolidate these skills. The various films are very useful and could aid carers after bereavement having seen that people are able to talk about their experiences retrospectively. Moving and handling skills could be useful in an in-patient context as well as at home and carers could potentially benefit from a short practical course of instruction.

Section 10. Recommendations

This section draws together in et all guidelines cited above.

2 below the evidence gained from: the expert opinion gathering exercise, the grey and academic literature search, stroke guidelines and previous, relevant resources from the General End of Life's EBS. As evidenced in the Expert Opinion Gathering Exercise, caring for people with stroke at the EoL at home was not a usual occurrence and this is reflected in some of the literature. For example, Payne, Burton et al, 2010, found that no family member in this study reported being offered the possibility of the patient dying at home (Payne, Burton et al. 2010) and some of the expert opinion panel also said it was usually the case that EoL care was in a hospital setting.

In terms of care at home, the difficult nature of stroke can make this difficult to achieve. However, a group of Stroke Nurse Specialists did suggest that carers could learn nursing skills for EoL care in this context and there is evidence in the literature for education and training for carers. The educational package to support lay-carers to manage breakthrough subcutaneous injections (Healy, Israel et al. 2013) and the audit of the Just-in Case boxes for pain relief (Westwood, Bagshaw et al. 2012) are described above.

The recommendations below for training and supporting carers are specific to stroke and EoL care and, if implemented, could fulfil all guidelines and offer the support and training necessary for carers in this context. Included, where appropriate, are resources from the original General End of Life Care EBS, and some new ones including the BAME context.

Table 2 is entitled "Preparing for caring in stroke" because it has already been identified that carers are inadquately prepared for their role. They need information on signs of impending death, symptoms, implications of the symptoms, what to expect next, and instructions on what to do. This involves time and listening to carers,engendering their trust, repeating information, collaboration with other disciplines for them, and demonstrations of skills required. Content and delivery of messages can be tailored to individual patient context and carer factors (Kehl 2015).

The information in table 2 should be read alongside the mapping exercise from the General End of Life Care EBS which offered resources for, and identified gaps in the proposed MHMC education programe for general EoL training programmefor carers, consulting this document along with the recommendations below, will offer the MHMC team, Pennine Care NHS Foundation Trust and

HCPs working in stroke, a complete picture of what carers for people with stroke at the end of their life require in order to support the patient, care for themselves and for Pennine Care NHS Foundation Trust to meet all guidelines cited above.

Table 2. Preparing for caring for stroke

Issue	Details	Resources
Terminology Clarification of what each term means • Palliative Care • Specialist Palliative Care • Stroke Care • End of Life Care • Holistic care		**Discussions with HCPs** **FILMS** End of life and palliative care: thinking about the words we use 4 minute film (see page 49) http://www.scie.org.uk/socialcaretv/video-player.asp?v=palliative-care-or-end-of-life-care End of life care: what matters to the person who's dying 11 minute film (see page 50) http://www.scie.org.uk/socialcaretv/video-player.asp?v=holisticassessment End of life care: why talking about death and dying matters 10 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=endoflifecarepersonalisation For people moving towards the EoL a personalised approach gives them a voice and influence over their care. This film looks at how personalised care can be achieved through the Living Well tool, which involves creating a simple one page profile to record a person's needs and wishes. It is shared by everyone involved in their care so that they can quickly get to know and understand the person, even if they have communication difficulties. The film shows how the scheme is used in settings in Stockport and in Hull and features case studies showing how profiles

Issue	Details	Resources
		work successfully in practice. **Messages for practice** Personalised care for people at the end of life requires a planned and coordinated approach to care. Recording the likes, dislikes and preferences of a person at the EoL in one place is a simple but important step towards achieving personalised care, whether from health or social care services. People who receive care which reflects what's important for them helps to make them feel more in control and more secure. An understanding of what's important for a person at the end of life means staff will have better ideas of how to support and reassure them. A simple tool which records people's preferences is also useful if they have to change care setting and can facilitate better working between health and social care. **End of life care: dying at home** 11 minute film (see page 49) http://www.scie.org.uk/socialcaretv/video-player.asp?v=dyingathome ditto live link In this film a palliative care social worker is interviewed about the skills and understanding that are needed to make sure people can die with dignity and respect. It shows members of the support team in Lancashire discussing care preferences with a man at the EoL and then making sure the practical services he needs are in place. **"No Greater Gift".** See page 51 above. DVD developed by The Centre for Palliative Care, St Vincent's Hospital and the Collaborative Centre of the University of Melbourne. Centreforpallcare@svhm.org.uk (MHMC project team have a copy of the DVD)
Training for End of Life care in stroke		**Best Practice Statement** End of life care following acute stroke (see page **Error! Bookmark not defined.**) (NHS and Scotland 2010)

Issue	Details	Resources
		Life after Stroke – Training programme (see page 5) **NICE Quality Standards** (see page 31) http://www.nice.org.uk/guidance/qs13/chapter/Introduction-and-overview
Transitions • Dealing with uncertainties • Fluctuating illness trajectories. • Difficulties in prognosis.		**GOLD STANDARD FRAMEWORK. Prognostic Indicator Guidelines (PIG)** (see page 30) **Specific clinical indicators in stroke.** • persistent vegetative or minimal conscious state or dense paralysis • medical complications • lack of improvement within 3 months of onset and • cognitive impairment/post stroke dementia (RCGP. 2011) **Sue Ryder, Hospice UK, NCPC** **What to expect when someone important to you is dying. A guide for carers, families and friends of dying people** This document is excellent and clearly maps out the dying process for lay people in a sensitive manner and in a very accessible format. It poses and answers questions lay-carers may ask. In addition, there are some pages giving more formal advice on the whole process and End of Life trajectory. Altogether a very good resource. http://www.ncpc.org.uk/sites/default/files/What_to_Expect_FINAL_WEB.pdf
Information requirements • Knowledge about the potentially onerous		**Patient voices** Film: Soulmate. http://www.patientvoices.org.uk/flv/0377pv384.htm

Issue	Details	Resources
caching situation - Knowledge in order to make decisions about a care plan/pathway		The opportunity of timely/fast-track discharge home or to a hospice or care home according to wishes of the patient and/or carers should be offered or an explanation of why it would be in a patient's best interest to remain in hospital care.
Nursing skills - Suction, swallowing - Positioning techniques - Catheter care - PEG medications - Injecting and giving breakthrough medications - Hydration - Moving and Handling - Personal hygiene and elimination		An educational package to support lay-carers to manage breakthrough subcutaneous injections. Development and evaluation of a service quality improvement**.** See page 51.(Healy, Israel et al. 2013). **Hospice UK** Recommends for carers, 'information, training or education' on how to provide specific care tasks http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **NHS End of Life Care; Managing pain and other symptoms** Deals with other symptoms such as nausea, vomiting, loss of appetite and constipation www.nhs.uk/Planners/end-of-life-care/Pages/controlling-pain-and-other-symptoms.aspx **Hospice UK** Recommends for carers, 'information, training or education' in strategies for safe moving and handling of the patient. http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **Macmillan**: **Hello and how are You? A guide for carers by carers. Booklet** Sections on; Moving and handling Organising equipment and transport http://be.macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.pdf **Princess Royal Trust for Carers** (PRTC). Moving and handling 2015 in Scotland http://www.prtlcc.org.uk/en-us/courses/courses-movinghandling.aspx

Issue	Details	Resources
		Marie Curie – film guides • Helping a person to wash • Helping with mouth care • Making a person comfortable in bed • Rolling a person in bed • Helping a person take medication • Helping a person to relax mariecurie.org.uk/patientsandcarers **Macmillan. Hello and how are You? A guide for carers by carers booklet** Section on personal care http://be.macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.pdf
Risk Assessment (1) The assessment and management of physiological, physical and psychological problems. How they can be controlled and the implications for prognosis	• Anxiety • Panic attacks • Depression • Agitation • Pain • Social and relationship related • Cognitive impairments • Communication • Neurological, visual and • Sensory impairment	**Macmillan. Hello and how are You?A guide for carers by carers** Sections for carers and patients on: • Depression • Anxiety • Anger • Frustration • Fear http://be.macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.pdf
Risk assessment (2) Clinical issues	• Pulmonary embolism • Aspirational	Carers to be made aware by HCPs, thatcaring for Stroke patients dying at home may be a very difficult option for carers

Issue	Details	Resources
	problems - Urinary infections - Chest infections - Hospital acquired infections - Incontinence - Hydration issues	
Recognising and coping with approaching death		**Hospice UK** Information resources on disease process, trajectory and prognosis. Information about the dying process and symptom management. http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers NICE quality-statement-2-communication-and-information Information about treatment and care options, medication and what to expect at each stage of the journey towards the EoL. http://www.nice.org.uk/guidance/qs13/chapter/quality-statement-2-communication-and-information **Just in case boxes** See page 56 (Westwood, Bagshaw et al. 2012).
Meaning, faith & belief	**BAME**	**End of life care: dying at home** 11 minute film Described above on page 49, this film also features the Majlish Home Care Service in East London, which provides culturally-appropriate services to people in the

Issue	Details	Resources
Carer views on EoL film	**DVD**	Bangladeshi and Bengali communities who choose to die at home. The care workers employed are all from the same communities as the people they work with. http://www.scie.org.uk/socialcaretv/video-player.asp?v=dyingathome **"Through our eyes"** A DVD resource which includes excerpts of interviews with volunteers from Afro-Caribbean, Hindu, Jewish, and Muslim communities, talking about their experiences of end of life care for a loved one (details on page **Error! Bookmark not defined.**, above) . To obtain a copy of the DVD please contact denise.woolrich@nhs.net Copy given to KM. (PCFT)
NICE quality standards for families, carers and patients with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. [QS13]		**Statement 1**. People approaching EoL are idenitified in a timely way **Statement 2**. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences. **Statement 7**. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences. **Statement 13**. Families and carers of people who have died receive timely verification and certification of the death. **Statement 15.** Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers. **Statement 16.** Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary

Issue	Details	Resources
		workforce sufficient in number and skill mix to provide high-quality care and support. http://www.nice.org.uk/guidance/qs13/chapter/Introduction-and-overview

10.1 Final comments

Stroke can be a sudden and catastrophic event and does carry a significant risk of death (NHS and Scotland 2010). However, the length of time this process may take in very often unknown. The main challenge with stroke is diagnosing whether someone is likely to recover or not and this is immensely difficult to determine. Some people die immediately, some have a short dying trajectory and others can be transferred home if it is appropriate

The preferences of stroke patients and their families in relation to palliative care services are largely unknown and there is a paucity of data in regard to the distinction between provision of palliative care services for patients who die in the acute phase of stroke and for those patients who die later (Stevens, Payne et al. 2007). Stroke and EoL care has specific issues to be acknowledged – in particular the neurological needs of these patients deserve more attention. This area of care is challenging generally because patients can have varying levels of cognitive impairment, therefore care needs are unpredictable and neurologists are often not trained in EoL care (The Lancet 2014).

Rapid and unexpected deaths provide little opportunity for staff to implement anything other than palliative care at the very end of life (Burton & Payne, 2014) and this is usually in a hospital setting. On the other hand, there are cases of ‘uncertain reprieve’ Rhodes, E. (2015) p. 546, which can occur when a person receiving EoL care unexpectedly improves and moves back onto palliative care. However, this can trigger post-traumatic stress-type symptoms in patients, and their carers, who have already begun their grieving process and they can also experience a range of psychological symptoms in response to this (Rhodes 2015).

The evidence also shows that younger people are also experiencing stroke thus parents can be carers for their own children. This is in addition to the more common scenario of older people (with their own health issues) caring for other older people. People who are dying from any condition, can experience depression, anxiety, fear and panic attacks for the first time and these symptoms need to be recognised and treated rapidly.

Do Not Resuscitate and EoL discussions can be difficult to initiate with stroke patients and their families because many HCPs are often not trained in this aspect of care and the ethical issues aligned with these discussions are complex. Families and patients, however, should be involved in these discussions should they want to be.

What comes over clearly in the expert opinion gathering exercise is that the complexity in stroke appears to mitigate against home care at the end of life because this could turn out to be a very onerous, complex and emotional task for a lay carer. Carers need to be made aware of this and the alternatives open to them and their patients. The opportunity of timely/fast-track discharge home or to a hospice or care home according to wishes of the patient and/or carers should be offered or an explanation of why it would be in a patient's best interest to remain in hospital care.

The Melbourne Palliative care after sroke and stroke palliative care pathway appears to be comprehensive providing guidance on key aspects of care including:

- discontinuation of non-essential medications
- discontinuation of active treatment interventions
- anticipatory prescribing of comfort medications
- general comfort measures
- various psychosocial and spiritual needs, including information for carers

The stroke palliative care pathway from the Victorian Department of Health and the evidence based clinical practice guidelines and guidelines for conducting family meetings from the Centre for Palliative Care both in Australia also offer a good resource and others they have developed which are described in this report are worth noting.

Family carers of people with stroke at the end of their life have particular issues to address and these are documented above. It may be the case that family carers can support people with stroke at the end of their lives either in a hospital or home setting with appropriate knowledge and training. This could be in co-operation with additional, professional carers.

11. Conclusions

Stroke is a condition where it is difficult to advocate that family carers can care for the patients at home because of its unexpected trajectories/complications and subsequent complexities in treatments. These can include:

- Pulmonary embolism
- Aspirational problems
- Urinary infections
- Chest infections
- Hospital acquired infections
- Incontinence
- Hydration issues

However, the following points are offered to guide the MHMC project team:

- Patient preferences for place of care at the EoL should always be sought.
- The opportunity of timely/fast-track discharge home or to a hospice or care home according to wishes of the patient and/or carers should be offered or an explanation of why it would be in a patient's best interest to remain in hospital care.
- Care plans presented to family carers will inform them of the complex requirements of caring at home
- Discussions about preferences for place of care are rarely initiated by HCPs.
- People with stroke at the end of their life should have access to special palliative care services
- Family carers can be given condition specific information and handling advice/equipment/how best to support their patient at home or in hospital
- Just in case boxes could lessen the distress of not having access to pain relief out of hours
- Medication for breakthrough symptom control and training in how to administer this could contribute to more patients being able to die in the environment of their choice, their home.
- Family members may not have anticipated or thought about what care their relatives would prefer at the end of life and in where (e.g. hospital or home)

The main message which emerges from this EBS is that caring for someone with stroke at the end of their life could be, potentially, a very demanding caring situation with perhaps little clarity over how long it will go on for because of the prognostic uncertainty.

Valerie Featherstone 17th July 2015

Appendix 1. Abstracts of articles relating to the needs of carers of stroke patients who are the end of their life

Reference	Abstract
"Integrating palliative care within acute stroke services: developing a programme theory of patient and family needs, preferences and staff perspectives." **(Burton and Payne 2012)**	Palliative care should be integrated early into the care trajectories of people with life threatening illness such as stroke. However published guidance focuses primarily on the end of life, and there is a gap in the evidence about how the palliative care needs of acute stroke patients and families should be addressed. Synthesising data across a programme of related studies, this paper presents an explanatory framework for the integration of palliative and acute stroke care. Methods: Data from a survey (n=191) of patient-reported palliative care needs and interviews (n=53) exploring experiences with patients and family members were explored in group interviews with 29 staff from 3 United Kingdom stroke services. A realist approach to theory building was used, constructed around the mechanisms that characterise integration, their impacts, and mediating, contextual influences. Results: The framework includes two cognitive mechanisms (the legitimacy of palliative care and individual capacity), and behavioural mechanisms (engaging with family; the timing of intervention; working with complexity; and the recognition of dying) through which staff integrate palliative and stroke care. A range of clinical (whether patients are being 'actively treated' and prognostic uncertainty) and service (leadership, specialty status and neurological focus) factors appear to influence how palliative care needs are attended to. Conclusions: Our framework is the first, empirical explanation of the integration of palliative and acute stroke care. The specification in the framework of factors that mediate integration can inform service development to improve the outcomes and experiences of patients and families.
What is good end of life care after stroke? **(Jeffries, Shipman et al. 2011)**	**Introduction** Stroke is the third commonest cause of death and causes significant symptoms and disability. Acute stroke care in the UK predominantly occurs in hospital. Guidelines recommend that patients should be cared for in stroke units to improve survival and disability. The End of Life Care (EOLC) Strategy aims to improve care for all irrespective of diagnosis and place of care. Previous research suggests that stroke patients and families have unmet palliative care needs. Researching these needs presents challenges due to the effect of stroke on communication, cognition and consciousness. **Aims** 1. To determine what healthcare professionals on a stroke unit believe constitutes good EOLC for stroke

	patients. 2. To determine any barriers exist to implementing good care. **Methods** 15 healthcare workers from an acute stroke unit were purposively sampled. Semi-structured interviews were recorded, transcribed and analysed using framework analysis. **Results** Professionals believed the following were important aspects of end of life care: ▸ Treating patients as individuals ▸ Providing care in a dignified manner and in a comfortable environment ▸ Good personal care and symptom control ▸ Ascertaining the needs and monitoring patients ▸ Recognising death ▸ For the team to be aware of the care plan ▸ Informing families and involving them in decisions ▸ Facilitating patient communication and patient-family interaction was also valued ▸ Good team structure, function and training. Barriers to care included resource and time limitation, competing priorities, difficulties in prognostication and communication and not knowing patients´ wishes. **Conclusion** Important aspects of care are identified. Healthcare professionals' views led to recommendations which include: ▸ Using a care of the dying pathway ▸ Encouraging patients with capacity to discuss their care needs and wishes at multidisciplinary meetings ▸ Discussion of dying patients care ▸ Facilitating patient communication ▸ Educating stroke team in palliative care and palliative care teams in stroke care ▸ Research into prognostication is needed.
End-of-life issues in acute stroke care: a qualitative study of the experiences and	The aims of this qualitative study were to identify patients' and family members' experiences of acute stroke and their preferences for end-of-life care. Twenty-eight purposely sampled patients with an acute stroke who had high (n¼13) and low (n¼15) disability were selected from 191 sequential cases admitted to two general hospitals in north-east England.

preferences of patients and families **(Payne, Burton et al. 2010)**	In addition, 25 family members of other stroke patients were recruited. Views about current stroke services and preferences for end-of-life care were elicited in semi-structured interviews. Communication between patients and family members and healthcare professionals was consistently highlighted as central to a positive experience of stroke care. Honesty and clarity of information was required, even where prognoses were bleak or uncertain. Patients and family members appeared to attach as much importance to the style of communication as to the substance of the transfer of information. Where decisions had been made to shift the focus of care from active to more passive support, families, and where possible patients, still wished to be included in on-going dialogue with professionals. Where patients were thought to be dying, family members were keen to ensure that the death was peaceful and dignified. Families reported few opportunities for engagement in any form of choice over place or style of end-of-life care. No family member reported being offered the possibility of the patient dying at home. Uncertainty about prognosis is inevitable in clinical practice, and this can be difficult for patients and families. Our findings demonstrate the importance of improving communication between patient, family and health professionals for seriously ill patients with stroke in UK hospitals.
The palliative care needs of acute stroke patients: a prospective study of hospital admissions. **(Burton, Payne et al. 2010)**	Background: despite a mortality rate of approximately 30% in acute stroke, little is known about the palliative care needs of this group of patients. Design: prospective study of 191 acute stroke patients admitted to hospital in England. Biographical, medical and stroke related data were collected. Participants completed the Sheffield Profile for Assessment and Referral to Care (SPARC), a screening tool for referral to specialist palliative care. Findings: over 50% reported moderate to significant fatigue-related problems. Approximately 50% reported symptom-related problems (e.g. pain) or psychological distress (e.g. anxiety). Approximately 25% had concerns about death or dying, and 66% had concerns about dependence and disability. Over 50% were worried about the impact of stroke on family members. There were significant main effects of dependence (Barthel Index) ($F_{1,123} = 12.640$ $P = 0.001$) and age ($F_{4,123} = 3.022$ $P = 0.020$), and a significant three-factor interaction between dependence, age and co-morbidities ($F_{9,123} = 2.199$ $P = 0.026$) in predicting total SPARC scores. Conclusions: acute stroke patients have a high prevalence of palliative care needs. Acute stroke services should use the SPARC for needs assessment. Priority for assessment should be given to patients with a score of <15/20 on the Barthel Index, a tool already used in most stroke services.
Palliative and end-of-life care for people with stroke	Purpose of review: Stroke is a devastating illness. Significant progress has been made in the prevention, acute treatment and rehabilitation of stroke. Yet many people still die from stroke. The role of palliative and end-of-life care for stroke has received considerably less attention. This review presents an overview

(Wee, Adams et al. 2010)	of the current understanding of palliative and end-of-life care for people with stroke. Recent findings: The impact of stroke is wide-ranging and long lasting. It affects both patients and those who become their caregivers. Those who are dying from stroke experience a similar symptom profile to many other dying people. Palliative care services involved in care of stroke patients are more frequently involved in issues related to communication and difficult decisions related to food and fluids. Caregivers have significant needs, particularly around information provision, communication and involvement in, or consultation about, decision-making. Those who survive the immediate aftermath of a stroke are often left with significant psychological and social limitations in addition to physical disability. Summary: It is clear that patients with stroke have palliative care needs. Palliative and end-of-life care services can contribute to the care of people with stroke, and their families, but the way in which stroke and palliative care services should interlink remains unclear.
Evaluating an Organized Palliative Care Approach in Patients with Severe Stroke **(Blacquiere, Gubitz et al. 2009)**	Given that there were few guidelines on the provision of palliative care following stroke at this time nor examined the efficacy or results of any such process or the role of the patient's family in decision making including conflicts with staff, these authors sought to formally evaluate the use of locally-developed palliative care guidelines on their Acute Stroke Unit (ASU). A retrospective examination of 104 patient records that died on the ASU over a two-year period to determine if existing palliative guidelines were reflected in clinical practice, and to identify conflicts that arose. Data on medical and nursing care, palliative decisions, and medication use were compared to the ASU's existing palliative care guidelines. Family concerns about the palliative process were also reviewed. ***Results:*** Of patients admitted to the stroke unit, 104 (16% of total admissions) died. Ninety-four (90.4%) of these were palliated; all received routine nursing and comfort care prior to death. Median time from admission to palliation was 3.6 days; median time from admission to death was 8.5 days. Most had vital signs (98.9%), investigations (100%) and non-palliative medications (95.7%) stopped, and had nasogastric feeding (96.8%) and intravenous fluids (87.2%) withdrawn or never begun. Most were treated with morphine (93.6%) and scopolamine (81.9%). Concerns raised by family members centred around hydration and feeding (45.7%), doubts about palliative care (27.8%) and patient comfort (18.2%). ***Conclusions:*** A formal approach to palliation results in timely decisions regarding end of life care with relatively few conflicts. Further work to address the specific concerns of families is needed.
Palliative care in stroke: a critical review of the literature	The aim of this literature review was to identify the palliative care needs of stroke patients. Stroke results in high levels of mortality and morbidity, yet very little is known about the nature and extent of palliative care services that are available to this patient group, and the ways in which such services could be delivered. A critical review of the international literature found only seven papers that attempted to

(Stevens, Payne et al. 2007)	identify the palliative care needs of patients diagnosed with stroke. The results of the review showed that the preferences of stroke patients and their families in relation to palliative care services are largely unknown. The review also indicated the paucity of data in regard to the distinction between provision of palliative care services for patients who die in the acute phase of stroke and for those patients who die later. Establishing reliable assessments of need are central to designing and implementing effective interventions and further research is required in this area. Further data on how the input of palliative care experts and expertise could be of benefit to patients, and the most effective ways these inputs could be targeted and delivered is required.

Appendix 2. Clinical decision making in stroke. Included papers

Title and date of study	Abstract
Life can be worth living in locked-in syndrome **(Lulé, Zickler et al. 2009)**	The locked-in syndrome (LIS) describes patients who are awake and conscious but left in a state of almost complete immobility and loss of verbal communication. The etiology ranges from acute (e.g., brainstem stroke, which is the most frequent cause of LIS) to chronic causes (e.g., amyotrophic lateral sclerosis; ALS). In this article we review and present new data on the psychosocial adjustment to LIS. We refer to quality of life (QoL) and the degree of depressive symptoms as a measure of psychosocial adjustment. Various studies suggest that despite their extreme motor impairment, a significant number of LIS patients maintain a good QoL that seems unrelated to their state of physical functioning. Likewise, depression is not predicted by the physical state of the patients. A successful psychological adjustment to the disease was shown to be related to problem-oriented coping strategies, like seeking for information, and emotional coping strategies like denial — the latter may, nevertheless, vary with disease stage. Perceived social support seems to be the strongest predictor of psychosocial adjustment. QoL in LIS patients is often in the same range as in age-matched healthy individuals. Interestingly, there is evidence that significant others, like primary caregivers or spouses, rate LIS patients' QoL significantly lower than the patients themselves. With regard to depressed mood, ALS patients without symptoms focus significantly more often on internal factors that can be retained in the course of the disease contrary to patients with depressive symptoms who preferably name external factors as very important, such as health, which will degrade in the course of the disease. Typically, ALS patients with a higher degree of depressive symptoms experience significantly less ''very pleasant'' situations. The herein presented data strongly question the assumption among doctors, health-care workers, lay persons, and politicians that severe motor disability necessarily is intolerable and leads to end-of-life decisions or euthanasia. Existing evidence supports that biased clinicians provide less-aggressive medical treatment in LIS patients. Thus, psychological treatment for depression, effective strategies for coping with the disease, and support concerning the maintenance of the social network are needed to cope with the disease. Novel communication devices and assistive technology now offers an increasing number of LIS patients to resume a meaningful life and an active role in society.
"End-of-life decision-making in individuals with locked-in syndrome in the acute period	Locked-in syndrome (LIS) is commonly associated with a poor prognosis, particularly if the aetiology is stroke. Dealing with individuals with LIS and a poor prognosis raises the issue of introducing end-of-life discussions with the patient and/or family in the acute period of the illness. Existing literature regarding LIS provides little guidance about end-of-life decision-making in the acute management phase. We aim to provide some guidance for clinicians holding end-of-life discussions in the acute management period. Two

after brainstem stroke." **Anderson, J. F., et al. (2010).**	case reports of relatively young individuals with LIS secondary to brainstem stroke are described. Both cases had a very poor prognosis and end-of-life discussions were commenced by the treating team in the acute phase. Despite the severity of their conditions, in neither case were end-of-life discussions well tolerated by the family in the weeks following admission. We suggest that LIS patients and their families, who have chosen to persist with full medical management after diagnosis of LIS, should be provided with sufficient time to adjust to the catastrophic changes that have occurred before further end-of-life discussions are pursued. Education and support are likely to be highly beneficial in the acute period post stroke as they allow the patient and family to develop a realistic understanding of the likely outcomes of their decisions.
Withdrawing and withholding treatments in acute severe stroke patients: clinical and ethical issues. [Review] **(Crozier 2012)**	Stroke prognosis remains difficult to determine. It depends on stroke severity, patient's age and his rehabilitation ability. In essence, individual prediction is uncertain. Neurological severity is related to many factors such as low blood pressure or hyperthermia, which are important to consider before prognosticate. Do-not-resuscitate orders are given in up to 30% of acute stroke. More than 50% of them are given upon admission (in the first 24 h of stroke). Withdrawing and withholding treatments are usually decided when neurological prognosis is supposed to be ‘‘catastrophic’’. Other factors, such as physician's disability representation or hospital use of aggressive procedures, certain daily routines or organizational constraints, are also probably implied. In France, end-of-life decisions are guided by the law: Palliative approach in severe stroke remains unknown and rarely developed, but is necessary to implement in such situations with high mortality rates.
Prognosis and Decision Making in Severe Stroke **(Holloway, Benesch et al. 2005)**	An increasing number of deaths following severe stroke are due to terminal extubations. Variation in withdrawal-of-care practices suggests the possibility of unnecessary prolongation of suffering or of unwanted deaths. **Objectives** To review the available evidence on prognosis in mechanically ventilated stroke patients and to provide an overall framework to optimize decision making for clinicians, patients, and families. **Data Sources** Search of MEDLINE from 1980 through March 2005 for English language articles addressing prognosis in mechanically ventilated stroke patients. From 689 articles identified, we selected 17 for further review. We also identified factors that influence, and decision-making biases that may result, in overuse or underuse of life-sustaining therapies, with a particular emphasis on mechanical ventilation. **Evidence Synthesis** Overall mortality among mechanically ventilated stroke patients is high, with a 30-day death rate approximating 58% (range in literature, 46%- 75%). Although data are limited, among survivors as many as one third may have no or only slight disability, yet many others have severe disability. One can further refine prognosis according to knowledge of stroke syndromes, early patient characteristics, use of clinical prediction rules, and the need for continuing interventions. Factors influencing preferences for life-sustaining treatments include the severity and pattern of future clinical deficits, the probability of these

	deficits, and the burdens of treatments. Decision-making biases that may affect withdrawal-of-treatment decisions include erroneous prognostic estimates, inappropriate methods of communicating evidence, misunderstanding patient values and expectations, and failing to appreciate the extent to which patients can physically and psychologically adapt. **Conclusions** Although prognosis among mechanically ventilated stroke patients is generally poor, a minority do survive without severe disability. Prognosis can be assessed according to clinical presentation and patient characteristics. There is an urgent need to better understand the marked variation in the care of these patients and to reliably measure and improve the patient-centeredness of such decisions.
Life-and-death decision-making in the acute phase after a severe stroke: Interviews with relatives **(de Boer, Depla et al. 2015)**	Decision-making in the acute phase after a severe stroke is complex and may involve life-and-death decisions. Apart from the medical condition and prognosis, quality of life and the deliberation of palliative care should be part of the decision-making process. Relatives play an important role by informing physicians about the patient's values and preferences. However, little is known about how the patients' relatives experience the decision-making process. Aim: To elicit the perspective of relatives of severe stroke patients with regard to the decision-making process in the acute phase in order to understand how they participate in treatment decisions. Design: An exploratory qualitative interview approach guided by the principles of grounded theory. Settings/participants: Relatives of severe stroke patients (n=15) were interviewed about their experiences in the decision-making process in the acute phase. Results: Four categories reflecting relatives' experiences were identified: (1) making decisions under time pressure, (2) the feeling of 'who am I' to decide, (3) reluctance in saying 'let her die' and (4) coping with unexpected changes. Following the treatment proposal of the physician was found to be the prevailing tendency of relatives in the decision-making process. Conclusion: A better understanding of the latent world of experiences of relatives that influence the decision-making process may help physicians and other health-care providers to better involve relatives in decision-making and enhance the care, including palliative care, for patients with severe stroke in line with their values and preferences. Communication between physician and relatives seems vital in this process.

Treatment Decisions After Severe Stroke. Uncertainty and Biases **(Creutzfeldt and Holloway 2012)**	Stroke demands our attention because it is common, disabling, and deadly. One in 15 patients requires mechanical ventilation on admission, 1 in 20 patients is discharged from the acute care hospital with a feeding tube, and 1 in 5 patients require institutional care at 3 months after stroke. Most patients with severe stroke who die, do so in the setting of withdrawal of life-sustaining treatment (LST), and this decision is typically made by physicians who predict a poor outcome and surrogates who are asked to articulate the patient's preferences. When prognosis is certain and the outcome unacceptable, the decision to withdraw or withhold LST may be relatively straightforward, although emotionally challenging. In most severe strokes, however, decisions are made when prognosis is uncertain and when what constitutes an acceptable outcome is unknown. This study explored the uncertainties and biases that influence these life-and-death decisions. Such biases can lead to errors in decision making and ultimately the overuse or underuse of LST. Hence, the need is urgent to understand better the factors that contribute to optimal decision making.
Is there a Shaman in the House? **(de Schweinitz 2010)**	This nonfictional narrative recounts a story of shared decision making between a veteran neurosurgeon and the family of a comatose patient who had suffered a haemorrhagic stroke. After reviewing the option of surgery within the context of informed consent, the family remains frozen in indecision. Leaving behind him the world of the rational, the neurosurgeon makes a statement that reconnects the family to their deepest values. The neurosurgeon is portrayed as a modern equivalent of a shaman. A call is made for consideration of the complex topic of spiritual engagement during patient care.
Perspectives and Experience of Healthcare Professionals on Diagnosis, Prognosis, and End-of-Life Decision Making in Patients with Disorders of Consciousness **(Rodrigue, Riopelle et al. 2013)**	In the care of patients with disorders of consciousness (DOC), some ethical difficulties stem from the challenges of accurate diagnosis and the uncertainty of prognosis. Current neuroimaging research on these disorders could eventually improve the accuracy of diagnoses and prognoses and therefore change the context of end-of-life decision making. However, the perspective of healthcare professionals on these disorders remains poorly understood and may constitute an obstacle to the integration of research. We conducted a qualitative study involving healthcare professionals from an acute care university medical centre. A short questionnaire captured demographic data as well as the experience of participants with DOC patients. A semi-structured interview was used to explore attitudes toward ethical issues identified in a previous literature review. Qualitative content analysis of interviews was conducted with the NVivo software. Accurate diagnosis among DOC is often regarded as a challenge, but this was generally not the case for our participants because most reported high confidence in DOC diagnoses. However, participants reported struggling with prognosis, especially because of its essential role for end-of-life decision making and communication with families. Variability of opinion between healthcare professionals was reported and identified by some as a minor issue while others stressed how families struggle with different medical opinions. End-of-life decision making encompassed a large proportion of ethical challenges in these patients,

	and the removal of artificial nutrition and hydration created significant discomfort in a minority of participants. The concept of futility was subject to wide-ranging understandings with both favourable and unfavourable opinions. Our data suggest that to ensure the incorporation of new evidence-based advances, attention should be directed to the real world practices and challenges of accurate diagnosis and prognosis. Given pervasive challenges in end-of-life care, we recommend improved training of healthcare professionals in the care of patients with DOC, particularly in end-of life care, understanding the context of decision making, and determining how to optimally integrate new neuroscience research on the care of patients with DOC.
The study protocol of: ‘Initiating end of life care in stroke: clinical decision-making around prognosis’ **(Burton, Payne et al. 2014)**	Background: The initiation of end of life care in an acute stroke context should be focused on those patients and families with greatest need. This requires clinicians to synthesise information on prognosis, patterns (trajectories) of dying and patient and family preferences. Within acute stroke, prognostic models are available to identify risks of dying, but variability in dying trajectories makes it difficult for clinicians to know when to commence palliative interventions. This study aims to investigate clinicians’ use of different types of evidence in decisions to initiate end of life care within trajectories typical of the acute stroke population. Methods/design: This two-phase, mixed methods study comprises investigation of dying trajectories in acute stroke (Phase 1), and the use of clinical scenarios to investigate clinical decision-making in the initiation of palliative care (Phase 2). It will be conducted in four acute stroke services in North Wales and North West England. Patient and public involvement is integral to this research, with service users involved at each stage. Discussion: This study will be the first to examine whether patterns of dying reported in other diagnostic groups are transferable to acute stroke care. The strengths and limitations of the study will be considered. This research will produce comprehensive understanding of the nature of clinical decision-making around end of life care in an acute stroke context, which in turn will inform the development of interventions to further build staff knowledge, skills and confidence in this challenging aspect of acute stroke care.
The Art of Estimating Outcomes and Treating Patients With Stroke in the 21st Century **(Saposnik 2014)**	Clinicians, patients, and their families usually inquire about an expected outcome after an acute event, the response to thrombolysis, and endovascular therapy. Some clinicians use their past experience or weight risk factors known to influence stroke outcomes. These factors can be categorized as follows: (1) patient-level factors (e.g., age, stroke severity, comorbid conditions), (2) physician-level factors (e.g., specialty, years of experience), and (3) institutional-level factors. The development of novel diagnostic tests (i.e., computed tomographic perfusion, assessment of collateral flow, MRI perfusion), risk prognostic scores (i.e., ischemic stroke risk score [iSCORE], stroke prognostication using age and NIHSS-100 totalled health risks in vascular events [THRIVE], sugar, early infarct signs, dense cerebral artery sign, age, and NIH stroke scale [SEDAN], among others), and therapeutic opportunities (i.e., new agents for intravenous/intra-arterial thrombolysis, new catheters for endovascular treatment) provide relevant information when discussing and counselling patients

	with stroke and their families. Currently, there are several stroke risk prognostic scores to predict different outcome measures, including early- and long- term mortality, disability, discharge disposition, response to tissue-type plasminogen activator, and risk of intracerebral haemorrhage after thrombolysis. When applied to large populations, risk scores can provide useful prognostic estimates. Similar to other risk scores, the THRIVE is a clinical scoring system (range, 0–9) designed to help clinicians better understand a patient's chances of having a good outcome after an acute ischemic stroke.9 It assigns points for age (+1 for age 60–79, +2 for age >80 years), stroke severity (0 if National Institutes of Health Stroke Scale score <10, +2 if National Institutes of Health Stroke Scale score=11–20; +4 if National Institutes of Health Stroke Scale score ≥21), and history of hypertension (+1), diabetes mellitus (+1), and atrial fibrillation (AF; +1). In previous studies, scores ≥5 were associated with unfavourable outcomes. In the present study, Dr Lei et al analysed the relationships between THRIVE score and clinical outcomes in patients with (n=505) and without (n=3374) cardio embolic stroke. The authors found that a higher THRIVE score was independently associated with decreasing likelihood of favourable outcome (modified Rankin Scale score of 0–2) and an increased likelihood of death (cardio embolic stroke: odds ratio, 1.48; 95% confidence interval, 1.28–1.70; noncardioembolic stroke: odds ratio, 1.95; 95% confidence interval, 1.76–2.16). However, there was a low sensitivity associated with good outcome (68.3%), death (63.2%), and haemorrhagic transformation (62.5%) among patients with cardioembolic stroke. Slightly higher values were observed for patients with noncardioembolic stroke. The areas under the curves were similar between both groups of patients for good clinical outcome (0.729 versus 0.708; *P*=0.39), but lower for haemorrhagic transformation (0.602 versus 0.608; *P*=0.45). The authors concluded by saying that the THRIVE score is a simple tool that helps clinicians estimate good outcome and death after ischemic stroke.

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