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# The key challenges of discussing end-of-life stroke care with patients and families: a mixed-methods electronic survey of hospital and community healthcare professionals

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**Background** Communication between professionals, patients and families about palliative and end-of-life care after stroke is complex and there is a need for educational resources in this area.

**Methods** To explore the key learning needs of healthcare professionals, a multidisciplinary, expert group developed a short electronic survey with open and closed questions, and then distributed it to six UK multiprofessional networks and two groups of local clinicians.

**Results** A total of 599 healthcare professionals responded. Educational topics that were either definitely or probably needed were: ensuring consistent messages to families and patients (88%); resolving conflicts among family members (83%); handling unrealistic expectations (88%); involving families in discussions without them feeling responsible for decisions (82%); discussion of prognostic uncertainties (79%); likely mode of death (72%); and oral feeding for 'comfort' in patients at risk of aspiration (71%). The free-text responses (n = 489) and 82 'memorable' cases identified similar themes.

**Conclusion** Key topics of unmet need for education in end-of-life care in stroke have been identified and these have influenced the content of an open access, web-based educational resource.

**Keywords:** acute stroke, healthcare survey, health communication, health personnel, palliative care, terminal care

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## Introduction

Despite important advances in acute stroke treatment and care, stroke remains a leading cause of death worldwide.<sup>1</sup> Patients dying after stroke have physical, psychological, emotional and existential needs,<sup>4–6</sup> yet few are able to communicate their needs directly.<sup>5,6</sup> Thus, treatment decisions need to be informed by advance directives, legally appointed proxy decision-makers, such as a welfare attorney, or by eliciting information about the likely views

and preferences of a patient from their close family or friends.<sup>6</sup> Patients who are deteriorating and dying after stroke and their families should have opportunities to discuss their needs and preferences.<sup>7,8</sup> The American Heart Association guidelines recommend that discussions regarding prognosis, preferences and goals of care should begin at the time of stroke onset and be regularly reviewed.<sup>9</sup>

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In the UK, suboptimal communication between healthcare professionals and patients and their families feature commonly in complaints about end-of-life care.<sup>10</sup> International research suggests that discussing palliative and end-of-life care after acute stroke is difficult for patients, families and clinicians.

The rapidity of stroke onset limits the time available for decision-making.<sup>11</sup> Establishing patient preferences from proxies may be challenging<sup>12</sup> and some proxies report an enduring sense of unwanted responsibility for treatment decisions.<sup>11,13</sup> Two UK studies reported that families of dying stroke patients welcomed opportunities for honest discussions about outcomes,<sup>14</sup> but preferences for place of care were seldom discussed.<sup>13,14</sup> A Swedish registry study reported that end-of-life care discussions and bereavement support were less frequent in stroke care than in cancer care.<sup>15</sup> A Canadian survey has shown that families were less satisfied with communication, including discussions about feeding, than with other aspects of palliative stroke care.<sup>16</sup>

In the UK, clinical guidance and government policies state that healthcare professionals should have the necessary knowledge and skills to enable them to communicate sensitively about end-of-life care<sup>17</sup> and to provide person-centred care for all patients, including those with stroke.<sup>18</sup> We obtained Scottish Government funding to develop an open access, web-based educational resource [Stroke Training and Awareness resource (STARS)] as a collaborative project between the University of Edinburgh and Chest Heart & Stroke Scotland (CHSS). To inform the content of this resource, we aimed to identify the key learning needs of healthcare professionals through conducting a UK web-based survey.

## Methods

Using Survey Monkey™ (<https://www.surveymonkey.com/>), we surveyed UK healthcare professionals involved in stroke care to identify key learning needs. Survey monkey is a widely used online cloud-based survey tool that has been used in other studies of palliative care by organisations, such as NHS England, the National Council for Palliative Care and Hospice UK.

The survey (Appendix 1) was developed by an interdisciplinary, expert group, including hospital and community healthcare professionals with educational expertise. The group included: consultant physicians in palliative care in the acute hospital and community (with over 20 years' experience); consultant stroke physicians (with over 20 years' experience); representatives from a charity with extensive involvement in the Scottish Partnership for Palliative Care; allied health professionals with over 20 years' experience in speech and language therapy and occupational therapy in stroke; and individuals with nursing experience in acute stroke units, including having completed a PhD in end-of-life care in the acute stroke unit. Potential topics for inclusion in a web-based educational resource were identified from the literature; through contact with national organisations, for

example the Scottish Stroke Nurse Forum, and the Stroke Association and CHSS, two UK-based stroke charities with experience of providing assistance to patients and families affected by stroke; and from project group members' own clinical and teaching experience. There is evidence from the literature that there is an unmet need for patients, families and healthcare professionals in end-of-life care following stroke,<sup>9</sup> including concerns from patients about support for other family members<sup>4</sup> and concerns from families about the suddenness of stroke and the seriousness of the decisions that need to be made about potentially life-prolonging interventions.<sup>11</sup> Families often felt responsible for making decisions about their relative in this situation and communicating uncertainty around prognosis with the potential for a prolonged dying process were other areas of concern.<sup>13</sup> In choosing the topics for this survey the group took areas demonstrated in the published literature as being relevant and adjusted these using clinical judgement until a consensus was achieved.

These topics included anticipatory care planning, symptom management, discussing uncertainty, withholding or withdrawing treatment including artificial feeding, and bereavement support. We asked respondents to rate the extent to which they felt that they required education on these topics using a five-point Likert scale. Two free-text items elicited the most difficult aspects of conversations about palliative and end-of-life care; and invited respondents to recall memorable cases. The questionnaire was refined through iterative group email discussions and two group meetings. Piloting to ensure that the form was acceptable was conducted amongst doctors working on one of our stroke units and no further adjustments made following this.

The survey was distributed in April 2015 to six national multiprofessional and NHS networks: British Association of Stroke Physicians, the Royal College of Physicians of Edinburgh, the Royal College of Emergency Medicine, the Scottish Stroke Nurse Forum, the Scottish Stroke Allied Health Care Professionals Forum, and the Royal College of General Practitioners. Professionals from a regional Stroke Managed Clinical Network and local emergency medicine physicians also took part. The survey closed after 3 weeks. We aimed to include a range of multidisciplinary team members, including doctors, nurses, therapists, researchers, psychologists, support workers and chaplains, involved in palliative and end-of-life stroke care in acute hospitals or primary care. We did not send the survey to stroke patients and their carers because our primary aim was to obtain healthcare professionals' views about their learning needs. Two recent studies have explored the views and experiences of patients and carers in some depth.<sup>13,19</sup>

We attempted to optimise response rates by ensuring that the survey was short, indicating in a covering email the likely time required for completion, embedding the survey link in the email and sending an email reminder after 2 weeks.<sup>20</sup> Survey Monkey automatically anonymised the data and provided the number of responses in each category. We manually

calculated responses to each question taking account of non-responders.

Free-text responses were analysed using a qualitative thematic approach<sup>21</sup> employing NVivo 1.9 to organise the data. Initially, free-text data were aggregated and printed out. The printouts were read and re-read to familiarise the coder (EC) with the data, then coded with a short summary label of a few words marked in the paper margin beside each section of text. Initial codes were established on paper, constantly comparing new codes against previously read data. The text files were imported into NVivo, the coding categories were established as nodes and further coding was completed electronically. Sections of text with similar codes were then grouped together into themes. To enhance the credibility, confirmability and dependability of the analysis, coding labels and final themes were agreed with two independent reviewers (FD, SAM), and illustrative quotations are presented here. We also maintained an auditable record of data collection and analysis procedures. Additionally, deviant or negative cases,<sup>22</sup> where participants stated they had no knowledge or experience of the topic, were also coded to ensure the widest range of perspectives were analysed. Furthermore, we triangulated between the two data types, using qualitative findings to deepen our understanding of quantitative responses. To aid transferability, we recorded participant demographics such as current clinical setting and duration of experience in end-of-life stroke care and these are presented in Table 1.

We consulted the South East Scotland Research Ethics Service who confirmed that this survey of healthcare professionals did not fulfil the criteria for research according to Health Research Authority guidance and therefore did not require ethical approval. Completing the questionnaire implied consent to participate.

## Results

There were 599 respondents. Not all respondents answered every individual question.

### Quantitative analyses

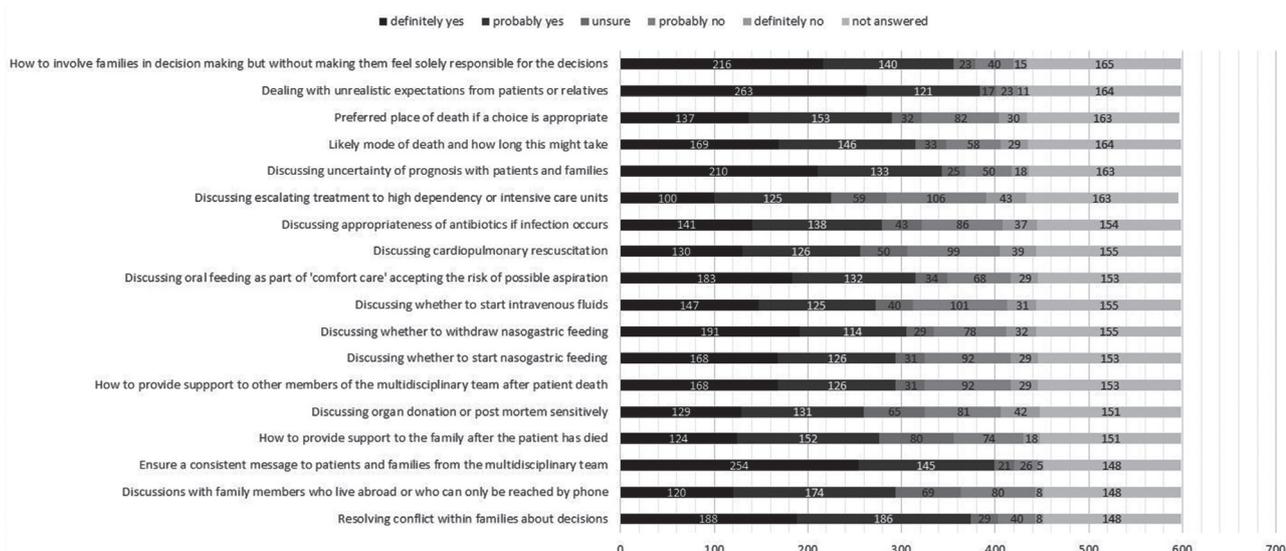
Respondents were from a wide range of disciplinary backgrounds (Table 1) and worked in a range of different settings (with some working in more than one setting). Over 80% had been qualified for more than 10 years, and just under half had been involved with at least six acute stroke patients requiring end-of-life care in the previous year.

Figure 1 shows the topics for which the respondents would value educational resources. The most popular topics were: ensuring consistent messages to families and patients (rated by 88% of those responding to this question as 'definitely or probably' wanting educational resource); resolving intrafamily conflict (83%); handling unrealistic expectations (88%); involving families in discussions without making them feel responsible for decisions (82%); discussing prognostic uncertainties (79%); discussing likely mode of death (72%); and discussing oral feeding for 'comfort' in patients at risk of aspiration (71%).

**Table 1** Demographics of the survey respondents

Demographic	Number (% of 599 respondents)
<b>Discipline background</b>	
Nurse	164 (27.4)
Emergency Physician	54 (9.0)
Acute Physician	8 (1.3)
Geriatrician	25 (4.2)
Stroke Physician	67 (11.2)
General Practitioner	49 (8.2)
Palliative Care Team	24 (4.0)
Physiotherapist	38 (6.3)
Occupational Therapist	41 (6.8)
Speech and Language Therapist	63 (10.5)
Dietician	6 (1.0)
Social Worker	4 (0.7)
Support Worker	13 (2.2)
Student	1 (0.2)
Other	38 (6.3)
Non-responder	4 (0.7)
<b>Place of work (some worked in several areas)</b>	
Emergency department	89 (14.9)
Acute admissions ward	72 (12.0)
Acute medical ward	73 (12.2)
Medicine of the elderly ward	72 (12.0)
Acute stroke unit	152 (25.4)
Rehabilitation stroke unit	120 (20.0)
Integrated stroke unit	72 (12.0)
Palliative care team	45 (7.5)
Community setting	189 (31.6)
Other	78 (13.0)
Non-responder	21 (3.5)
<b>Years qualified</b>	
0–5	66 (11.0)
6–10	79 (13.2)
11–15	93 (15.5)
16–20	76 (12.7)
21–25	97 (16.2)
26+	172 (28.7)
Non-responder	16 (2.7)
<b>Number of dying stroke patients cared for in previous year</b>	
0–5	311 (51.9)
6–10	86 (14.4)
11–15	51 (8.5)
16–20	41 (6.8)
21–25	23 (3.8)
26+	48 (8.0)
Non-responder	39 (6.5)

**Figure 1** Responses to the ‘closed questions’



**Qualitative analyses**

There were 489 free-text responses to the question ‘What do you find the most difficult aspect of having conversations with stroke patients and their families about end-of-life care?’ Eighty-two ‘memorable’ cases were shared; responses ranged from a single word to short descriptive paragraphs. Fifty respondents (8.3%) stated that discussing end-of-life care with patients and families was not difficult or was not part of their job. Otherwise, respondents indicated difficulties arising from uncertainty of outcomes, the clinical features of stroke, the expectations of families and care teams, a perceived lack of communication skills, or deficiencies in services or resources. Similar themes arose from both free-text survey questions. In all, five major themes were identified, with related subthemes (Table 2).

**Theme: Prognostic uncertainty**

For emergency and stroke physicians, prognostic uncertainty was the most frequently reported concern. Clinical uncertainties hampered discussions with families about possible outcomes, and the likely course or duration of dying. These uncertainties made clinical management difficult:

The unpredictable nature of the first days after a big stroke... The fact that you often know patients will not have a good outcome and you have to consider a discussion of what to do if complications such as infection occur - to treat or not to treat. (Geriatrician – acute stroke unit)

Staff felt under pressure to give precise estimates of time remaining. Some found it difficult to convey uncertainty about dying without raising false hopes for families:

Why it takes so long and when will the patient pass away [sic] Difficult to answer as they don’t want to hear that you don’t know. (Nurse – rehabilitation stroke unit)

**Theme: Stroke-related clinical issues**

Dysphagia was the most commonly cited clinical issue creating difficulty in discussions about interventions after severe stroke. At least half of respondents reporting the issue were speech and language therapists, working in acute hospitals and the community. Respondents reported uncomfortable conversations about managing risks:

Patient with very unsafe swallow, very upset relative telling me we were asking her to choose between starving her mother or allowing her to choke or drown. (Speech and language therapist – rehabilitation stroke unit)

Whether to start or stop treatments, such as clinically assisted nutrition or hydration, and poor outcomes after CPR were also difficult to discuss:

Conversations required with a family around DNACPR decisions and ‘not for tube feeding’ - eventually we made the decisions despite some family members dissenting but felt very uncomfortable. (Stroke physician – emergency department, acute stroke unit/rehabilitation stroke unit)

The sudden onset of stroke was said to be shocking for families and created understandable difficulties for them in adjusting. Handling this suddenness was one of the most frequently reported difficulties encountered by nurses:

Due to the sudden nature of stroke families are often in a state of shock and then to have to be told about end-of-life care, it is a lot to take in. (Nurse – acute stroke unit)

Aphasia was an additional difficulty that hampered direct communication with stroke patients, making it much harder to elicit their care preferences:

Theme	Subtheme
Prognostic uncertainty	
Stroke-related clinical issues	<ul style="list-style-type: none"> <li>• Dysphagia</li> <li>• Suddenness of illness onset</li> <li>• Stopping or not starting treatment</li> <li>• Aphasia</li> <li>• Young patients</li> </ul>
Expectations and priorities (families and teams)	<ul style="list-style-type: none"> <li>• Family understanding or expectations</li> <li>• Conflicting messages or priorities</li> <li>• Interdepartmental or team malfunction</li> <li>• Angry or complaining families</li> <li>• Prolonged dying</li> </ul>
Skills for holding conversations	<ul style="list-style-type: none"> <li>• Talking about uncertainty</li> <li>• Breaking bad news</li> <li>• Opening conversations</li> <li>• Handling distress</li> <li>• Getting the timing right</li> </ul>
Logistics and infrastructure	<ul style="list-style-type: none"> <li>• Place of care</li> <li>• Infrastructure or resource limitations</li> <li>• Families at a distance</li> </ul>

**Table 2** Themes identified from analysis of free-text responses and 'memorable cases'

Ability to communicate is often affected by stroke and the person and their family are anxious and getting used to the new ways to communicate with each other. This adds to the stress (for the person, those who matter to them and staff) of having difficult conversations. (Nurse – community)

Twelve respondents said it was particularly difficult to have conversations about the imminent death of younger patients. No respondents defined what a 'young patient' was, but several of the memorable cases related to patients in their forties or fifties.

If the stroke happens in relatively young and previously healthy and active patient, there is a long and difficult process of accepting the fact the patient has had a stroke and is dying or will be dying in a near future. (Stroke physician – acute stroke unit)

**Theme: Skills for holding conversations**

Over 100 respondents reported concerns about their skills in conducting conversations with patients and families after stroke.

Some respondents (n = 27) said it was difficult to tell patients and families that death was likely. Others said it was difficult to discuss management of fluids and nutrition or to advise on summoning relatives from other countries. Several emergency physicians said they found it hard to tell families that no specific treatment could be offered:

Having to say there is nothing specific we can do. (Emergency physician – emergency department)

Opening conversations was said to be a challenge, both in gauging whether patients or relatives were ready to talk

and in finding the right words to use. Seven respondents said it was difficult to cope with patients' and relatives' distress:

Having to broach the subject at all can be quite difficult. Especially when a family keeps asking how long the recovery will take and you know that is not going to happen. (Nurse – acute stroke unit, community)

A small number of respondents generally found it difficult to support or console families, although one physician said they maintained their normal clinical routines of reviewing patients as an action designed to support families:

When patients are on end-of-life care, we still go through the process of going into the room and seeing them - family appreciate it. (Stroke physician – acute medicine/medicine of elderly, acute stroke unit, rehabilitation stroke unit, integrated stroke unit)

**Theme: Expectations and priorities**

An inability of families to grasp the realities of a poor prognosis was frequently reported (n = 82). Many participants said families could harbour improbable expectations of recovery that were difficult for the stroke team to handle:

Unrealistic expectations of families - in a small community many of them know other stroke survivors who have made very good recoveries - they assume all strokes are the same and expect their family member to also recover. (Physiotherapist – medicine of the elderly and acute stroke unit)

Many participants (n = 43) described situations where inconsistent messages from healthcare professionals caused

confusion for families, contributing to unrealistic expectations of outcome:

As prognosis can be difficult to predict, giving concrete responses to people looking for certainty. Talking to people who have wrongly been told their relative will die is also challenging! (Stroke physician – acute medicine, acute rehabilitation and integrated stroke units)

Six respondents reported that prolonged dying processes were difficult to witness or manage, with two explicitly linking discomfort with prolonged dying to unmet expectations about the duration of the dying process. Three said that an absence of advance discussions about end-of-life care made conversations about dying after acute stroke more difficult and could lead to conflicting family views about likely patient preferences. A few participants suggested ways to manage expectations, by being honest with families, giving a consistent message from the whole team, breaking bad news well, gauging relatives' knowledge levels and timing conversations differently for patients and relatives according to need:

From my experience, the best way to communicate with a stroke patient's family is to show the CT scan and use it as an integral part of the communication. It helps people to understand better and imagine the extension and accept the severity of a stroke. (Stroke physician – acute stroke unit)

Two emergency physicians reported lack of support from stroke or neurosurgical specialties in talking with families. Overall, eight respondents indicated conversations about end-of-life care were made more difficult because colleagues or services did not function as they should:

Patient boarding into the ward - different medical team members visited only after lots of requests, extremely poor communication and frustration from both family and nursing team. Patient died needlessly in hospital due to no proper discussion with the family when the patient and family wished the patient to die at home. Very messy and difficult death as everyone felt let down. (Nurse – clinical education and development)

Sixteen respondents found it difficult to deal with angry families or worried about complaints from relatives. Unmet family expectations or differing priorities between family members were said to cause conflict:

Initially the patient had been identified as palliative care - however, she rallied - this threw the family for they were prepared for death. We prepared for the lady to go home and have all care needs met at home - however, just as quickly, she deteriorated. The family were in a state of confusion - which came out as blame - to the whole team - for misleading their expectations. (Occupational therapist – acute medical/rehabilitation stroke unit/integrated stroke unit/community)

### **Theme: Logistics and infrastructure**

Eighteen respondents reported that discussing the logistics of end-of-life care could be problematic. Place of care was a difficult issue and the layout of stroke units sometimes precluded finding a quiet private space to conduct sensitive conversations:

Discussing discharge planning if the patient is to go home for end-of-life care... Discussing care needs and continence at home and how needs may change with deterioration. It is also difficult having such conversations with a large group of family members at the bedside when it is not a planned discussion, but when relatives 'catch you' for a question on the ward. (Occupational therapist – rehabilitation stroke unit)

Dealing with geographically distant families also made it difficult to communicate clearly to all involved:

Recent case of young male with bilateral embolic stroke. Mother living abroad and was unaware of the poor prognosis. Huge family wanting to get updated on a daily basis. Made it very difficult to manage on day-to-day basis. (Stroke physician – acute stroke unit)

## **Discussion**

### **Main findings/results of the study**

The healthcare professionals in this survey reported that discussing issues around palliative and end-of-life care with patients and their families was challenging and that educational support would be welcome. The key themes identified were: ensuring consistent messages from the healthcare team, discussing expectations and priorities, withholding treatment, discussing prognostic uncertainty, handling conflicts, involving families meaningfully in discussions and discussing the likely mode of death.

### **Strengths and weaknesses/limitations of the study**

This survey, which is the first to our knowledge to identify learning needs of healthcare professionals with regards to end-of-life care in stroke, has several strengths. We received almost 600 responses, we obtained both quantitative and qualitative data, and our analysis of the free-text comments provided a rich and nuanced understanding of clinicians' concerns. There are some weaknesses. First, the survey was distributed electronically via professional networks so there is no predefined study group or response rate. This is a potential weakness because without response rates it is more difficult to infer generalisability of the data (although in mitigation the sample size was relatively large), which may lead to sampling bias and an inaccurate assessment of non-response bias.<sup>23,24</sup> Second, we only surveyed UK-based professionals. Third, we did not require every question to be answered, and so the final 'closed' question was answered by 434 out of 599 (72%); we have included the non-responders to individual items in Figure 1. However, the themes that emerged are likely to be common

internationally, particularly in healthcare systems that are similar to the UK's. The number of responses over a short time period may indicate a high level of interest in further training to improve communication by professionals caring for people after stroke.<sup>9</sup>

### What this study adds

Discussing prognostic uncertainty is also a key challenge in other serious illnesses, including advanced liver disease<sup>25</sup> and cancer.<sup>26</sup> In stroke, bereaved relatives reported that while staff discussed with them the likelihood of early death after stroke, they were unprepared for a prolonged dying process.<sup>13</sup> In our study, some professionals said they felt that patients and families did not like being told that the future was uncertain, and this appeared to stop them talking about prognostic uncertainty effectively.

Some themes, such as decisions about clinically assisted enteral feeding, were reported as more problematic after acute stroke than in other life-threatening conditions; in the UK, the National Institute for Clinical Excellence (NICE) quality statement on 'Care of dying adults in the last days of life' provides advice about how to make decisions around clinically assisted hydration, but not about tube feeding.<sup>7</sup> Hydration is sometimes distinguished from nutrition in clinical situations – certainly in one single centre study of end-of-life care following stroke in Germany, all 117 patients who died received intravenous fluids yet only 2% were receiving nutrition at the point of death.<sup>6</sup> This mirrors clinical practice, although intravenous fluids are not always continued in these situations. This highlights a difference between palliative care in stroke and other conditions. Future NICE guidance could usefully include quality statements and guidance on tube feeding after stroke.

We incorporated the topics and themes identified by clinicians into an educational resource, 'Sensitive and effective conversations about end-of-life care after acute stroke' hosted by University of Edinburgh and developed with CHSS. This open access, online-learning resource includes interactive questions, video clips showing conversations between clinicians and families, and guidance about how to address these difficult topics. The module is available at <http://www.strokeadvancingmodules.org/node.asp?id=palliative>. There are questions embedded in the module, and for those successfully completing the module, a certificate is available. It has already been accessed over 800 times, mainly by nurses.

This mixed-methods survey has identified a number of key learning needs of clinicians in relation to difficult conversations about end-of-life care after stroke; and these learning needs have informed development of an open access, online-learning module that is available worldwide. **1**

### Acknowledgements

We are grateful to all the respondents, to the various organisations that kindly circulated the survey, and to Chest Heart & Stroke Scotland for developing the learning module. Maggie Grundy (formerly NHS Education Scotland) provided useful information about CPR policies.

### Data management and sharing

The results of the survey are available on allocation from Professor G Mead.

### Online Supplementary Material

Appendix 1 is available with the online version of this paper; accessed via [www.rcpe.ac.uk/journal](http://www.rcpe.ac.uk/journal).

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