

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

F Doubal¹, E Cowey², F Bailey³, SA Murray⁴, S Borthwick⁵, M Somerville⁶, C Lerpiniere⁷, L Reid⁸, K Boyd⁹, G Hynd¹⁰, GE Mead¹¹

Appendix 1 Questionnaire

Question	Response options
1. What is your background?	Nurse, Physiotherapist, Occupational Therapist, Emergency Physician, Acute Physician, Geriatrician, Stroke Physician, General Practitioner, Dietician, Speech and Language Therapist, Social Worker, Support Worker, Student, Other (specify)
2. How many years have you been qualified?	0–5 6–10 11–15 16–20 21–25 26+
3. Where do you work? (please tick all that apply)	Emergency Department/Acute admissions ward/Acute medical ward/Medicine of Elderly ward/Acute stroke unit/Rehabilitation stroke unit/Integrated stroke unit/Community setting/Other (please specify)
4. In the past year, how many patients following an acute stroke who required end-of-life care have you been involved with?	0–5 6–10 11–15 16–20 21–25 26+
5. What do you find the most difficult aspect of having conversations with stroke patients and their families about end-of-life after acute stroke? (please add text below)	Freetext response

¹Honorary Senior Lecturer, ⁷Senior Research Nurse, Centre for Clinical Brain Sciences, University of Edinburgh, UK; ²Lecturer, Nursing & Health Care School, University of Glasgow, UK; ³E-learning Project Manager, ⁶Director of Services, ⁸Head of Education, Chest Heart & Stroke Scotland, UK; ⁴St Columba's Hospice Chair of Primary Palliative Care, The Usher Institute of Population Health Sciences and Informatics, University of Edinburgh, UK; ⁵Service Lead Speech and Language Therapist, ¹⁰Registered General Nurse, NHS Lothian Clinical Nurse Manager, Medicine of the Elderly, Stroke & Delayed Discharge Teams, NHS Lothian, UK; ⁹Honorary Clinical Senior Lecturer, Primary Palliative Care Research Group, University of Edinburgh, UK; ¹¹MD Professor of Stroke and Elderly Care Medicine, Royal Infirmary of Edinburgh, UK

Appendix 1 cont.

Question	Response options
6. Would you value educational resources on the following topics? (definitely yes, probably yes, unsure, probably no, definitely no)	<ul style="list-style-type: none">• Discussing/resolving conflict within families about decisions• Discussions with family members who live abroad or who can only be reached by phone• How to ensure a consistent message to patients and families from all healthcare professionals within the multidisciplinary team• How to provide support to the family after the patient has died• Discussing organ donation or post mortem sensitively• How to have conversations with, and provide peer group support to, other members of the multidisciplinary team after the patient has died
7. Would you value educational resources on the following topics? (definitely yes, probably yes, unsure, probably no, definitely no)	<ul style="list-style-type: none">• Discussing whether to start nasogastric feeding• Discussing whether to withdraw nasogastric feeding• Discussing whether to start intravenous fluids• Discussing oral feeding as part of 'comfort care' accepting the risk of possible aspiration• Discussing cardiopulmonary resuscitation• Discussing appropriateness of antibiotics if infection occurs
8. Would you value educational resources on the following topics? (definitely yes, probably yes, unsure, probably no, definitely no)	<ul style="list-style-type: none">• Discussing appropriateness of escalating treatment to high dependency or intensive care units• Discussing uncertainty of prognosis with patients and families• Likely mode of death and how long this might take• Preferred place of death if a choice is appropriate e.g. hospital, home or alternative care• How to deal with unrealistic expectations from patients or families• How to involve families in decision-making but without making them feel solely responsible for the decision
9. Your memorable case? If you would like to share some information about a memorable or difficult case scenario, please do so in the comment box. Please ensure that any information you provide cannot identify the patient or family	Freetext response