

Life after Stroke in Scotland: Research Priorities

Thank-you for taking part in our project to find out the top priorities for future research relating to life after stroke in Scotland.

We have gathered 226 questions about treatments, which need further research. These questions have come from stroke survivors, carers and health professionals.

These questions are listed in this booklet. To help you find the questions that matter most to you, we have grouped them into a number of different topics:

Communication	Risk and prevention
Mobility and movement	Care setting
Cognitive impairment	Carers & families
Mood disorders	Acute care and pharmacology
Coming to terms with life after stroke	General rehabilitation
Basic care	

We now want you to choose the 10 questions which you feel are highest priority for future research.

These might all come from one topic, a few different topics, or they might all come from different topics.

What is important is that they are **your personal top 10**.

- ✿ We know that this is a challenging task, however your personal top 10 is very important to us, and could change future stroke research.
- ✿ Your top 10 will be combined with those of other stroke survivors, carers and health professionals from throughout Scotland and discussed at a Consensus meeting in November. At this meeting the overall Top 10 research priorities for life after stroke will be agreed on. These will be used to influence what future research is carried out.

INSTRUCTIONS:

1. Read through the questions in the topics which matter to you. Make a mark or a note next to the questions which are important to you.
2. Go back through looking only at the questions you have marked as important and choose **the 10 which are most important to you**. Place the ID number of these questions in the table on page 5. You may find it useful to write the full question in the final column, but this is not essential.
3. **Rank your ten** using 1 = most important, working through to 10 = least important, and enter the rank order in the second column.
4. Return the completed form to us.

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Please return before 30th September 2011.

THANK-YOU.

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Glossary of terms

See appendix

MY TOP 10 QUESTIONS

Chosen 10 questions ID	Priority <i>1 = most important</i> <i>10 = least important</i>	Full text of question (optional) This may help you rank your 10.

It would help us if you could tell us who these replies come from:

Individual stroke survivor

Individual carer

Individual health professional

Group of stroke survivors
(please state number in group)

Group of carers
(please state number in group)

Group of health professionals
(please state number in group)

Other
(please state)

COMMUNICATION

Aphasia

	General management strategies	Notes
1	What is the best way to help people recover from aphasia?	
2	Which speech and language therapy treatments work best for aphasia?	
3	What is the best amount and intensity of speech and language therapy for aphasia?	
4	When is the best time after stroke to deliver speech and language therapy?	
5	Is speech and language therapy helpful for patients more than 1 year after stroke?	
6	Where is the best place to receive speech and language therapy (community or hospital)?	
7	What is the best way to help people with aphasia return to work?	
8	What is the best way to help people with aphasia to return to driving after stroke?	
9	What is the best way to manage pain in patients with communication problems?	
10	What is the best way to manage feelings of panic due to aphasia?	
11	How can stroke survivors and families be helped to cope with speech problems?	
12	Has the National Stroke Strategy impacted on the provision of services for patients with long term communication problems following stroke?	
	Specific treatments	
13	Can music or art therapy help people with aphasia?	
14	Can playing an instrument help improve communication problems?	
15	Can cognitive behavioural therapy (CBT) help recovery of speech?	
16	Can transcranial magnetic stimulation help people with aphasia?	
17	Is group speech and language therapy better and does it cost less than individual speech and language therapy?	
18	What is the best way to improve the production of structured sentences in people with aphasia?	
19	Is conversation partner training useful in the management of aphasia after stroke?	

20	Is non-linguistic cognitive training effective for aphasia?	
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Communicating with someone with aphasia

21	Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia?	
22	What is the best way of giving information about stroke to someone with aphasia?	
23	Do communication aids and software packages improve communication in patients with aphasia?	
24	Do social communication groups improve confidence in people with communication problems after stroke?	
25	Does a 'day diary' to record activities etc., completed by visitors, help people with communication problems share what has been happening?	

Aphasia & depression

26	What is the best way to diagnose and assess depression in people with aphasia following stroke?	
27	What is the best way to treat depression in people with aphasia following stroke?	

Dysarthria & Dyspraxia of speech

28	What are the best treatments for dysarthria?	
29	What are the best treatments for speech dyspraxia?	

(see also Aphasia under Carers & Families topic, page 18)

Mobility & Movement

General mobility & movement problems

	General management strategies	Notes
30	What is the best physiotherapy regime for recovery after stroke?	
	Specific treatments	
31	Does hydrotherapy improve physical fitness, mood, fatigue and spasticity?	
32	Does visual feedback improve movement during rehabilitation exercises?	
33	Does Botox improve function in activities of daily living?	
34	Do commercially available gaming devices (e.g Wii), in addition to routine therapy, improve exercise and mobility after stroke?	
35	Does functional electrical stimulation improve outcome after stroke?	
36	Are endurance and strength training effective components of rehabilitation after stroke?	
37	Are electromechanical assisted gait training and electromechanical and robot-assisted arm training useful and cost effective?	
38	What are the best motor relearning strategies for patients with cognitive or language deficits?	
39	Is self-practice of repetitive, high intensity, task-specific activities beneficial to motor recovery?	

Upper limb / arm

	General management strategies	
40	What are the best treatments for arm recovery and function?	
41	What is the best amount of arm treatment after stroke?	
42	What is the best timing, content and dosage for upper limb rehabilitation?	
43	Are community-based upper limb movement re-education programmes useful one year after stroke?	
	Specific treatments	
44	Can electrical stimulation improve arm function?	

45	Can upper limb splints improve arm function and prevent complications after stroke?	
46	How can overuse of the affected arm best be addressed?	

Balance, gait & mobility

	General management strategies	
47	What are the best treatments to improve balance, gait and mobility?	
	Specific treatments	
48	Can auditory feedback improve walking, independence and quality of life after stroke?	
49	Can leg splints improve balance and walking after stroke?	

Spasticity & spasms

	General management strategies	
50	What is the best way to deal with cramp, spasms and/or restless legs?	
51	What are the best treatments for spasticity?	
	Specific treatments	
52	What is the best way to manage involuntary reactions following stroke?	

Cognitive impairment

Cognition

53	What is the best way to improve understanding (cognition) after stroke?	
54	What is the best way to address 'false beliefs' (impaired perception) after stroke?	
55	What stimulation techniques are useful for enhancing the engagement of stroke patients with severe cognition and communication impairment?	
56	Does thrombolysis have an adverse effect on cognitive abilities?	
57	Can Adult Education improve stroke acquired literacy/numeracy problems?	

Memory

58	How can memory problems after stroke be improved?	
59	What is the best way to help stroke survivors and families cope with memory loss?	

Mood disorders

General mood disorders

60	What is the best way to manage altered mood and emotion after stroke?	
61	Which psychological treatments are effective after stroke?	
62	Which psychological treatments improve mood after stroke?	
63	How can behaviour changes best be addressed after stroke?	
64	Can physiotherapy improve mood disorders after stroke?	

Anxiety

65	What is the best way to manage anxiety and panic after stroke?	
66	What is the best way to improve confidence after stroke?	

Depression

67	Which treatments are best at reducing/preventing depression in patients after stroke?	
68	Which nursing treatments are best at preventing depression?	
69	Can counselling prevent depression following stroke?	
70	Is counselling better than anti-depressants for treating depression following stroke?	
71	Is mental-health self-help literature useful for preventing or treating depression after stroke?	

Emotional lability

72	What is the best way to treat emotional lability after stroke?	
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Coming to terms with life after stroke

General coming to terms

	General management strategies	Notes
73	What are the best ways of helping people come to terms with the long term consequences of stroke?	
74	What is the best way to promote self-management and self-help after stroke?	
75	What is the best way to support independent living after stroke?	
76	What is the best way to help people deal constructively with the uncertainty of prognosis?	
77	What is the best way to manage psycho-social problems after stroke?	
78	What is the best way to help people address the long term emotional effects of stress?	
79	What is the best way to address social isolation after stroke?	
80	Is early psychological support helpful after stroke?	
81	Can early psychological support increasing confidence and awareness of choices?	
82	Can emotional support improve ability for self-help?	
83	Is stroke-specific counselling helpful after stroke?	
84	What is the best way to support a 'positive sense of self' after stroke?	
85	What are the effects of religious beliefs on recovery after stroke?	
	Specific treatments	
86	How can a sense of male identify be restored following stroke?	
87	Can buddy systems (volunteers) improve quality of life after stroke?	
88	Can talking books help people relearn social skills after stroke?	
89	Is peer-support useful following hospital discharge?	
90	Are stroke groups/clubs helpful at improving the sense of well-being among stroke survivors?	

Information provision

91	What is the best way to provide information after stroke?	
92	What is the best way of providing information in the long term?	
93	Can volunteers help the process of information provision?	

Basic care

Bladder & bowel impairment (incontinence)

94	What are the best ways to manage urinary and faecal incontinence?	
95	How can nurses help prevent urinary incontinence?	
96	Can bladder training help continence problems ?	

Nursing

97	Are specialist stroke nurses better than non-specialist nurses at improving recovery after stroke?	
98	What are the best ways for nurses to prevent complications after stroke?	
99	Can therapeutic positioning improving outcome after stroke?	
100	What is the best way for nurses to prevent malnutrition after stroke?	
101	What is the best way for nurses to prevent post-stroke nausea?	
102	Is regular monitoring (for example, of blood pressure) by a stroke specialist nurse helpful after stroke?	

Oral health (mouth care)

103	What is the best way to improve oral care after stroke?	
104	What is the best way to manage problems with false teeth after stroke?	

Pain

105	What is the best way to manage central post-stroke (neuropathic) pain?	
106	Can alternative therapies reduce central post stroke pain?	
107	Does acupuncture help central pain or provide a holistic 'well-being' effect?	
108	What is the best way to manage and prevent shoulder pain after stroke?	
109	What are the best ways to reduce or prevent shoulder subluxation, decrease pain and increase function after stroke?	
110	Which treatments are best for management of long-term headache/migraine after stroke?	

Sleep disorders

111	Can non-drug treatments improve insomnia after stroke?	
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Swallowing difficulties (dysphagia)

	General management strategies	Notes
112	What are the best treatments for swallowing difficulties?	
113	Can nurses assess swallowing in patients after stroke?	
114	Is information provision about swallowing problems adequate after stroke?	
115	Has the National Stroke Strategy impacted on the provision of services for patients with dysphagia?	
	Specific treatments	
116	Can nurses decide whether and when to insert a naso-gastric (feeding) tube?	
117	Is PEG insertion (feeding tube directly into the tummy) better than naso-gastric tubes (feeding tube via the nose) at helping people move from being 'nil-by-mouth' to being able to eat/drink?	
118	Do thickened fluids cause dehydration after stroke?	
119	Is thickened fluid or plain water best at stopping aspiration (choking)?	
120	Is the water swallow test or puree swallow test best in the assessment of swallow in acute stroke patients?	
121	What is the best way to keep feeding tubes in place?	

Vision and visual perceptual problems

122	What is the best way to treat visual problems after stroke?	
123	What are the best treatments for visual inattention (neglect)?	
124	Which orthoptic treatments are best at improving quality of life after stroke?	
125	Do prisms improve visual field loss after stroke?	
126	Can a neuro-vision technology package improve functional ability and quality of life after stroke?	
127	Which treatments are best for nystagmus (involuntary eye movements) after stroke?	

Risk & prevention

Lifestyle

128	Is lifestyle advice useful at promoting lifestyle improvements and reducing risk of stroke?	
129	Can information technology (IT) improve information given about preventative lifestyles?	
130	What can carers do to help prevent further strokes?	

Prevention

131	Which treatment are the best at preventing stroke and subsequent stroke?	
132	Are secondary prevention drugs effective in preventing subsequent strokes?	
133	Can a daily routine help stroke prevention?	
134	Can self-monitoring of blood pressure help stroke prevention?	

Risk factors

135	What is the best way to increase awareness of risk of stroke amongst general public and health professionals?	
136	How can the risk of anaesthetic induced strokes be reduced?	
137	Does reduction in stress reduce risk of stroke?	

Diagnosis & screening

138	Can admission of people with suspected stroke prevent or reduce subsequent stroke?	
139	Can screening programmes reduce the risk of subsequent stroke?	

Care setting

140	What is the best way to deliver stroke care in remote and rural settings?	
141	What is the best way of managing people who have Transient Ischaemic Attack (TIA) (e.g. General Practitioner or hospital consultant clinics; direct access or onward referral)?	
142	When is the best time to move someone from a major stroke unit to a smaller rehabilitation unit nearer to their home?	
143	What are the key components of an effective stroke unit?	
144	Is early supported discharge clinically and cost-effective?	
145	Is community-based stroke care clinically and cost-effective?	
146	What is the best way to deliver rehabilitation and manage stroke patients within nursing homes?	
147	What is the cost and clinical effectiveness of admission to general medical (acute admission) wards with onward referral to a stroke unit, compared with direct admission to a stroke unit?	
148	Is telemedicine useful in the prevention, treatment and rehabilitation of stroke?	
149	What is the best way to ensure continuity of care?	
150	What is the best way of delivering stroke care in a primary care setting?	
151	Does direct access to a multidisciplinary team (MDT) by stroke patients in the community improve recovery?	

Carers & families

General support

152	What is the best way to manage carer guilt?	
153	What is the best way to assess, address and support the needs of carers?	
154	What is the best way of supporting family members of stroke survivors?	
155	What is the best way of supporting families when someone dies or is likely to die following stroke?	
156	What is the best way to teach carers to allow stroke survivors to do things for themselves?	
157	Is training for carers and 'befrienders' useful at promoting/supporting cognitive or occupational therapy activities?	

Aphasia

158	How can carers be helped to communicate with someone with aphasia?	
159	Can trained volunteers and carers help improve communication after stroke?	
160	Can supported communication training for carers help prevent relationship breakdown?	
161	What is the best way for carers to manage depression in people with aphasia following stroke?	

Relationship problems

162	What is the best way to address relationship difficulties after stroke?	
163	Can counselling help couples address relationship difficulties after stroke?	
164	What is the best way to support people with stroke during divorce?	

Acute care & pharmacology (drugs)

Drug therapy

165	What are the relative risks and benefits of Statins after stroke?	
166	What determines adherence and what is the effect of non-adherence of drugs?	
167	Is Botox effective after stroke?	
168	What is the impact of Thrombolysis on emotion, cognition and communication?	
169	Is long term aspirin therapy beneficial for stroke caused by clot?	
170	Do Ace Inhibitors cause weight gain following stroke?	
171	Is Tissue Plasminogen Activator (TPA) helpful in the long-term recovery of stroke?	
172	What are the best drug treatments to manage seizures?	
173	Is stem cell therapy beneficial for recovery after stroke?	
174	How often should General Practitioners check drugs and blood pressure (BP)?	

Early intervention

175	Is early mobilisation (within 48 hours) beneficial after stroke?	
176	Does intensive physiotherapy (e.g. stroking/moving limbs - maybe using volunteers) early after stroke help recovery?	
177	Is physiotherapy early after stroke beneficial?	
178	What is the effect of early mobilisation after stroke?	

Emergency care

179	What is the best way to avoid delayed diagnosis?	
180	How can the delivery of Thrombolysis be improved?	
181	What is the best way for emergency management of stroke?	

General rehabilitation

General stroke recovery

	General management strategies	Notes
182	What is the optimal amount and intensity of therapy for patients with stroke?	
183	What are the optimal staffing levels within stroke units?	
184	What is the best way to prevent deterioration in function after discharge from rehabilitation?	
185	Can a goal setting approach help recovery after stroke?	
186	Are vocational and recreational activities better than impairment-based treatments?	
187	What is the cost effectiveness of increased intensity of therapy in stroke units?	
188	What is the impact of increased intensity, frequency and duration of physiotherapy on stroke recovery?	
189	What is the best way to address participation restrictions?	
190	Are stroke co-ordinators / liaison workers beneficial in the management of stroke?	
	Specific treatments	
191	Can arts-based interventions and art therapy improve recovery after stroke?	
192	Are relaxation techniques beneficial after stroke?	
193	Can cognitive behavioural therapy (CBT) help attainment of goals after stroke?	
194	Are alternative therapies (massage, acupuncture) beneficial after stroke?	
195	Are home visits helpful after stroke?	
196	Can imagery improve outcomes after stroke?	
197	Can transcranial magnetic stimulation (TMS) help recovery after stroke?	
198	Can music therapy help recovery after stroke?	
199	Can treatments arising from social and environmental psychology improve recovery after stroke?	
200	What is the best way of helping patients understand their rehabilitation programme?	
201	Are health professionals or the voluntary sector best at helping people achieve independence after stroke?	

Exercise & fitness

202	Are exercise and fitness programmes beneficial at improving function and quality of life and avoiding subsequent stroke?	
203	Does exercise improve mood after stroke?	
204	Can psychological support help increase participation in physical activity after stroke?	
205	Does outdoor walking (in groups) improve physical fitness, mood and fatigue after stroke?	

Fatigue

206	What are the best ways to manage and/or prevent fatigue?	
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Late / long-term rehabilitation

207	Does involvement of the GP (General Practitioner) during stroke admission help improve medium and long term outcomes?	
208	What is the impact and cost-effectiveness of long term or lifelong physiotherapy?	
209	What is the impact and cost-effectiveness of long term or lifelong rehabilitation?	
210	What is the best way of managing the long term needs of stroke survivors? (including the roles of primary care health practitioners and consultants)	
211	Is intensive inpatient rehabilitation beneficial late (5-10 years) after stroke?	
212	Is long term physiotherapy review of exercise programmes beneficial after stroke?	
213	Is participation in activities (e.g. Stroke clubs, ongoing therapy) beneficial at achieving later improvement after stroke?	

Return to work

214	What is the best way to support return to work after stroke?	
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Young stroke survivors

215	Is a 'young stroke environment' better than a geriatric/ stroke rehabilitation environment at improving recovery of young people after stroke?	
216	What are the best services to support young stroke survivors in occupational rehabilitation within a work-place environment?	

Other / miscellaneous

217	Does high morale within the stroke team service improve stroke recovery?	
218	What is the best way to support stroke survivors to form learning alliances and relationships to inform their own care and treatment and influence others?	
219	What is the best way of implementing research findings to improve patient outcomes?	
220	How can computer programmes be used to identify specific patient problems and strategies to deal with these problems?	
221	What is the best way to improve recognition of unusual symptoms of stroke?	
222	Has the FAST (Face-Arm-Speech-Time to call) campaign improved stroke management?	
223	Can electrofacial stimulation improve facial muscle weakness after stroke?	
224	What are the best treatments for tinnitus following stroke?	
225	What is the best way to treat a reduction in the sense of smell following stroke?	
226	Is stimulation provided by relatives during open visiting effective at improving recovery after stroke?	