

Stroke Training Pack

Independent advocacy for
people affected by stroke



Acknowledgements

Principal partners



The Scottish Independent Advocacy Alliance (SIAA) is a membership organisation. The aim of the SIAA is to promote, support and defend the principles and practice of independent advocacy across Scotland. Membership of the SIAA is made up from advocacy organisations around Scotland. *Scottish Charity No. SC033576 • Company No. 236526*

The Stroke Association is a UK wide charity whose mission is to prevent strokes, and reduce their effect through providing services, campaigning, education and research. *Scottish Charity No. SC037789 • Company No. 61274*

With support from



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Foreword

In 2008 the Scottish Independent Advocacy Alliance (SIAA) and The Stroke Association Scotland office began working in partnership to develop independent advocacy for people affected by stroke. They successfully applied to the Scottish Government for financial support and were awarded a three year Section 10 grant to develop an advocacy and stroke project.

Three established independent advocacy organisations were chosen to pilot a range of collective and individual advocacy approaches for people affected by stroke. A further peer advocacy pilot grew from a Stroke Association user involvement project in Forth Valley.

In preparation for their work with those affected by stroke, Advocacy Highland, one of the selected pilot sites, developed training for advocates designed around advocacy and stroke. This training pack is the result of this work.

The work of the pilots evidenced how important the empowering nature of independent advocacy is for those affected by stroke, especially for those experiencing difficulties with communication. Individuals value the feeling of being in control of the advocacy process as much as valuing the results. It is therefore important that advocates take time to understand what is being communicated.

The SIAA and The Stroke Association Scotland will disseminate the learning from the advocacy and stroke project and encourage and support further development of independent advocacy for people affected by stroke across Scotland. Publication and distribution of this training pack will support these aims.

We are also keen to gather the views of participants of this training. This will inform consideration of any need for further adaptation and development. To that end an evaluation form is included on the CD enclosed in this pack. We would encourage organisations using this training pack to ask all trainees to complete this form and then to return all completed forms to the SIAA or The Stroke Association at the addresses detailed on the form.

A note from Advocacy Highland

Advocacy Highland has developed this training pack specifically for independent advocates working with people affected by stroke. It has been developed as part of a one year project funded by The Stroke Association.

The information included has been sourced from a number of individuals and organisations and our thanks specifically go to the following:

- The many advocacy partners Advocacy Highland supported in particular Madeleine, John and Anne for sharing their stories with us
- Advocacy Highland staff and volunteers
- Linda Campbell, Stroke Co-ordinator NHS Highland
- Sandra Hewitt, Speech & Language Therapist for Stroke Services NHS Highland
- Margaret Somerville, Director of Advice & Support Chest Heart & Stroke Scotland
- Scottish Independent Advocacy Alliance (SIAA)

Finally, Advocacy Highland would like to thank The Stroke Association for their funding to develop this training pack and the Scottish Independent Advocacy Alliance for their funding to publish it.

Sheilis Mackay
Manager, Advocacy Highland

How to use this pack

This pack is designed on the basis that it will be delivered by someone who understands independent advocacy. It is recommended that a co-trainer who is themselves a stroke survivor is recruited to co-deliver the training.

If co-training with a stroke survivor please go through the material with them before delivering the training to discuss their input. Ask if they are willing to discuss their personal experience and, if they are, how much or little of their experience they are willing to share. Make sure they know at what points in the day this will arise. Be sensitive to their situation.

The facilitator's notes and the Microsoft PowerPoint slides should be read in advance by the facilitator. This gives a general overview of the information with each slide e.g. when handouts are given.

The morning session will take approximately 2½ hours; the afternoon will be around 2 hours. The trainer may wish to negotiate timings of breaks at the start of the session. They should remember that if the co-trainer is a stroke survivor they may need more frequent breaks.

The facilitator's notes for all slides can be found on pages 5–16. Electronic versions of the handouts and case studies as listed are available on the enclosed CD and can be printed from there.

The CD also contains the PowerPoint slides. The PowerPoint presentation, YouTube stories and electronic copies of handouts and case studies can also be found on the SIAA website www.siaa.org.uk and The Stroke Association web site www.stroke.org.uk. Also included in the pack is a copy of the Chest Heart & Stroke Scotland Conversation Support Book and The Stroke Association FAST leaflet along with various factsheets.

Allow 5–10 minutes for case study discussions.

Programme

Independent Advocacy for People Affected by stroke

Welcome and introductions *5 minutes*

- Ice breaker *10 minutes*

What is a stroke? *2 hours approx.*

- Stroke facts
- A personal experience of stroke
- Stroke effects
- Possible problems after stroke, Case study: Joan, Michael's wife
- Possible problems after stroke, Case study: Phillip
- Rehabilitation, Case study: Sarah
- Supporting a full life after stroke

Lunch

Advocacy and communication *2 hours approx.*

- Advocacy is...
- Non-instructed advocacy, Case study: Tom
- Tackling stigmas and discrimination
- Communication
- Improving access to advocacy
- What changes can you make?
- Evaluation

End

Facilitator's notes

These notes and the notes included with some of the PowerPoint slides should be read in advance by the facilitator. This gives a general overview of the information with each slide e.g. when handouts are given etc.

If you are working with a co-trainer who has had a stroke discuss in advance their input and when you will ask them to speak about their experience. Allow 5–10 minutes for this input and follow up discussion with the whole group.

The slides are self explanatory and facilitator's notes are also included under some of the slides – see PowerPoint presentation included on the enclosed CD.

Welcome *5 minutes*

Introduce yourself and co-trainer and explain in-house arrangements. You may want to negotiate an agreed time for breaks and lunch.

Ice breaker *10 minutes*

You may have an ice breaker that you use for training. If not here's an example: get the participants into pairs; if possible sit with people you do not know. Introduce yourselves, what job you do and also discuss who your hero is and why. Introduce your partner to the full group.



What is a stroke?

PowerPoint presentation *2 hours approximately*



Slide 2

Aims of the presentation



Slide 3 and 4

Stroke facts

- Third most common cause of mortality
- Annually 12,500–15,000 people in Scotland have a stroke
- Main cause of adult disability in Scotland

- 20–30% of people who have had a stroke will die within one month
- There are around 110,000 stroke survivors in Scotland
- 75% of strokes occur in people over 65 years
- A stroke can happen at any age.

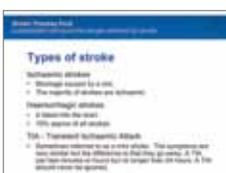


Slide 5
Handout 1



Slide 6
What is a stroke?

- Brain attack
- A syndrome — a collection of symptoms and signs pointing to a diagnosis
- Caused by disruption of the blood supply to brain tissue
- Effect depends upon extent of the injury and the area of the brain involved
- Some cells may recover, some may die and other cells may take over from damaged cells
- Stroke affects each individual differently.



Slide 7
Types of stroke
Ischaemic strokes

- Blockage caused by a clot
- The majority of strokes are ischaemic.

Haemorrhagic strokes

- A bleed into the brain
- 15% approximately of all strokes.

TIA (Transient Ischaemic Attack)

- Sometimes referred to as a mini stroke. The symptoms are very similar but the difference is that they go away. A TIA can last minutes or hours but no longer than 24 hours. A TIA should never be ignored. It should be considered as a possible warning sign of a major stroke.



Slide 8

Anyone can have a stroke

In the group discuss possible risk factors and write up on flipchart. Following discussion give out **Handout 2: Stroke risk and protective factors**.

Risk factors which can't be changed:

- Ageing: everyone's risk of stroke increases with age
- Ethnicity: some minority ethnic groups have increased risk of stroke such as people from the Indian Sub-continent and of Afro Caribbean origin
- Malformation of the blood vessels in the brain — some people are born with these and they can cause a bleed into the brain.

Risk Factors which can be changed:

- Cardio-vascular disease: high blood pressure, high cholesterol, heart problems (such as irregular heart beat)
- Other health problems such as obesity, type 2 diabetes and stress which are risk factors for cardio-vascular disease and therefore stroke
- Socio-economic factors: people on lower incomes are at greater risk of cardio-vascular disease and therefore stroke, especially under 65
- Problem drug use (especially amphetamines and cocaine)
- Vascular problems following surgery, head injury or injury to the neck and face.

Protective factors for cardio-vascular health which can reduce the risk of cardio-vascular disease and stroke:

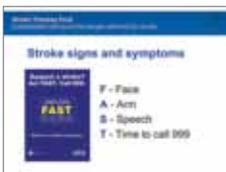
- Not smoking
- Drinking alcohol moderately
- Eating healthily
- Regular physical activity
- Good mental health
- An adequate income.



Slide 9

Stroke symptoms

Stroke symptoms are nearly always negative – you get loss of something: loss of movement, loss of power, loss of sensation, loss of speech, loss of vision, loss of ability to swallow.



Slide 10

Handout 3: The Stroke Association FAST leaflet

FAST represents the most common symptoms – Face, Arm, Speech, Time to call 999. The campaign is think FAST save a life – dial 999.



Slide 11

Group discussion: ask the group to give any examples of people they know affected by stroke.

Ask the group to think about the advocacy issues for the person and their family or carers.



Slide 12 and 13

A personal experience of stroke – see PowerPoint slide. Input from person who has had a stroke on their personal experience or if this is not possible use

Case study 1: Margaret’s story.



Slide 14

The event

- May be traumatic (but not always)
- No warning
- For example, you may be physically able this morning and disabled this afternoon.



Slide 15

Stroke effects—some possible examples

There are lots of symptoms that can happen when you have a stroke and these can have a major impact on your life.

Handout 4: The Stroke Association Communication problems after stroke Factsheet 3

Handout 5: The Stroke Association Factsheet 7 for more information on cognition and perception.

Handout 6: The Stroke Association Stroke related glossary of terms.



Slide 16

Possible problems after stroke for individuals

- Affects the person who had the stroke and their family
- Physically e.g. walking, speech and eating
- Emotionally e.g. emotional lability (uncontrolled crying, laughter and swearing)
- Socially: often due to lack of confidence and/or communication difficulties
- Economically e.g. loss of job
- Uncertainty about the future and how their stroke might affect this.



Slide 17

Case study

Divide trainees into groups of 4–5

Give out **Case study 2: Joan, Michael's wife** — give 10 minutes for discussion and ask them to be prepared to feed back on the two questions.

Bring the groups together and gather feedback from all groups.



Slide 18

Changes to everyday life can include changes to home, work, finance, leisure and social life. With the right support and care people can achieve a good quality of life after stroke, but stroke can bring many challenges to a stroke survivor's life:

- Their home or where they live (may need to adapt their home or move to sheltered or residential care)
- Their family and other relationships
- Their social life and hobbies
- Ability to walk and take exercise
- Ability to learn and to work
- Income.



Slide 19

Relationships can also change. The impact on relationships can be huge and shouldn't be underestimated.



Slide 20

Stroke survivors can experience feelings of

- Frustration
- Anxiety
- Emotional distress
- Depression.



Slide 21

Case study

Divide trainees into groups of 4–5

Give out **Case study 3: Philip** — give 10 minutes for discussion and ask them to be prepared to feed back on the two questions.

Bring the groups together and gather feedback from all groups.



Slide 22

The patient's ideal journey

Generally, every person should be admitted to hospital as soon as possible following a stroke or suspected stroke and should be admitted to a specialist stroke unit on the actual day or day following admission. Tests and treatment should include brain scans, blood tests, chest X-ray and thrombolysis (if appropriate but needs to be within 4½ hours of the stroke). In some remote areas it may not be possible to get to a large general hospital within the 4½ hour time frame. Rehabilitation from day one is essential for maximum recovery and improvement. Discharge may be to home, sheltered housing, residential care or nursing home.

In the longer term the individual should be able to access community rehabilitation services and, where needed, long term support in the community. There can be issues around equity of access to rehabilitation services with those able to pay finding it easier to access services. It is important that it is not assumed that a person cannot continue to improve months or even years after a stroke. Treatment should be needs led and directed in response to the individual.



Slide 23

Rehabilitation

Divide trainees into groups of 4–5. Give out **Case study 4: Sarah** – give 10 minutes for discussion and ask them to be prepared to feed back on the two questions. Bring the groups together and gather feedback from all groups.



Slide 24

Supporting a full life after stroke

Ask group to discuss “If you were to have a stroke...

- How might your life change;
- What would you want from your advocate?”



Lunch



Advocacy and communication

It should be stressed how important the empowering nature of advocacy is for those affected by stroke, especially for those experiencing difficulties with communication. Individuals value the feeling of being in control of the advocacy process as much as valuing the results. It is therefore important that advocates take time to understand what is being communicated.



Slide 27

Advocacy is...

- Supporting someone to make their views and wishes known
- Supporting people to take control, gain respect and grow in confidence.



Slide 28

Non-instructed advocacy

Divide trainees into groups of 4–5. Give out **Case study 5: Tom** – give 10 minutes for discussion and ask them to be prepared to feed back on the two questions. Bring the groups together and gather feedback from all groups.



Slide 29

Non-instructed advocacy

The SIAA Non-instructed advocacy guidelines provide guidance for advocates. Advocacy Service Aberdeen have also produced guidelines for good practice. Both documents can be found on the SIAA website.



Slide 30

Tackling stigma and discrimination

If your co-trainer has experience of stigma or discrimination and they are willing to talk about this, then the discussion can be focused around their input. If not then the group should discuss potential areas for stigma and discrimination and the role of the advocate.



Slide 31
Communication



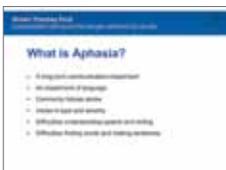
Slide 32
How we communicate
Ask the group to consider the example of arriving at Beijing airport and discuss how they might feel and how they might communicate.



Slide 33
Communication
It isn't just about speech. In the large group discuss what other methods have you used or could you use to communicate e.g. body language, words, vocal tone/pitch/speed, anything else?



Slide 34
Communication can be affected by
Refer the group to the *Stroke related glossary of terms* handout from the morning and The Stroke Association *Communications problems Factsheet*.



Slide 35
What is Aphasia?



Slide 36

What is Dysarthria?

At this stage you can show one of The Stroke Association's 'Lost without Words' series available on YouTube at www.youtube.com/user/thestrokeassociation or at www.stroke.org.uk/campaigns/campaign_archive/lost_without_words/online_exhibition/your_films

Amber's story 6:27 minutes

Alan's story 7:14 minutes

or a **Carer's story Susie** 6.40 minutes



Slide 37 and 38

Vision and stroke

If possible borrow disability awareness glasses which give the feeling of visual problems from the local sensory impairment centre. Refer to **Handout 8: TSA Vision and stroke Factsheet**.



Slide 39

Making our way in life

Unless you live alone on a desert island life is a series of exchanges and interactions. This may be one to one or in a group.

In pairs think about a communication you have had in the last few days that went wrong and what happened as a result.

- What can go wrong with an interaction?
- How does this make you feel?

If participants are happy to do this ask them to share examples.



Slide 40

How can we communicate more effectively?

Refer to the *Conversation Support Book* – Chest Heart & Stroke Scotland – an excellent book of pictures which can be useful to point at to aid communication.

Group discussion around what might go wrong in communication and strategies and resources for dealing with this. Refer to the resources and tips in **Handout 7: Making communication easier**.



Slide 41

Why is the environment important in communication?

This is one person's example of the 'right' environment for meeting. The 'right' environment for meeting is a very individual issue and may change depending on the person's health and the stage of your advocacy relationship.

Discuss the different places that advocates have used to meet their advocacy partner:

- What was it about the environment that made it helpful/unhelpful?
- Did this change over time? If so in what way?



Slide 42

Communication top tips

At a first meeting an advocate could consider taking along a photograph of themselves along with a short written description of what an advocate is and what they would do.

To help ensure that the advocacy partner is supported to take control of the process the advocate should make and agree brief notes of each discussion, a copy of which should be left with the advocacy partner.

When writing to the advocacy partner the advocate could consider attaching a photograph of themselves to the letter to help the partner recognise who is writing to them.

Think about what is most likely to suit the individual.



Slide 43

Improving access to advocacy

What changes could your advocacy organisation make to improve access?



Slide 44

What changes can you make?

What changes can you make?
Ask participants to think about how they would support someone affected by stroke. Ask them to write down two changes they could make and feed these back to the group.



Slide 45

Useful References

The list of Useful Organisations/Contacts can be copied and distributed as a handout.



Slide 46

Ask participants to complete an evaluation form.

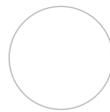


Slide 47

Acknowledgements



End



Contents of the CD

PowerPoint presentation

PDF

- Training pack handbook
- Handouts 1–9
- Case studies 1–5
- Useful Organisations/Contacts

If the CD is missing or damaged please contact the SIAA. The PowerPoint and PDF files are also available to download from www.siaa.org.uk or www.stroke.org.uk.

