

Stroke Advocacy Stories



Table of Contents

Introduction	1
About Advocacy	3
Phillip	4
Alec	5
Chris	6
Robert	7
Geordie	8
Sadie	10
Mark	12
Hugh & John	13
James	14
Anne	15
Madeleine	16
Advocates' Word	17
Pilot Organisations	18
Useful Organisations	20

Introduction

Personal stories are powerful things and this little book of stroke advocacy stories speaks for itself. This leaves the pleasant task of thanking everyone who made this stroke advocacy story book possible and giving some brief background information on where the stories came from.

Stroke is the major cause of acquired disability in Scotland with approximately 12,500 new strokes each year. Stroke can change lives in an instant, bringing complex issues for the individual and their families. Very few people affected by stroke can currently access independent advocacy; few in fact know what independent advocacy is or the potential benefits it can bring.

The Scottish Government, in recognition of this gap in provision, made limited funding available to The Stroke Association to develop advocacy for people affected by stroke. Working in partnership with The Scottish Independent Advocacy Alliance, making best use of resources, three established independent advocacy organisations were chosen to pilot a range of collective and individual advocacy approaches. A further peer advocacy pilot grew from a Stroke Association user involvement project.

Stroke reflects life; it could happen to any of us. Understandably the stories here tell of both similar and unique experiences. Each stroke however is an individual event for the person concerned so first and foremost thank you to the stroke survivors and family members whose stories appear here. By describing the challenges you face and the difference your advocate makes you have enabled us to bring it to life, to show advocacy in action.

Thanks also to the four organisations delivering the pilots: Advocacy Highland; Lomond and Argyll Advocacy in West Dunbartonshire; Partners in Advocacy in their Edinburgh Physical Disability Service and Forth Valley Advocacy. All of these organisations shared not only their experience and commitment but also significant “in kind” resources, without which the activity would have been much more limited.

Final thanks go to our partner in this development, The Scottish Independent Advocacy Alliance and to our funders The Scottish Government. The Stroke Association’s work in Scotland has a firm commitment to bringing the voices of stroke survivors and their families more firmly and effectively into focus. Advocacy does just that. Read the stories and see.

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Advocacy Development,
The Stroke Association in Scotland

About Advocacy

Independent advocacy aims to help people by supporting them to express their own needs, views and wishes and make their own informed decisions. Independent advocates support people to gain access to information and explore and understand their options. They speak on behalf of

people who are unable to speak for themselves, or choose not to do so. They safeguard people who are vulnerable or discriminated against or whom services find difficult to support.

Advocacy is about broadening horizons and widening the options that people have. It is about speaking up if you notice that something is wrong. An effective advocate will observe the whole person and all aspects of their life. They will notice what is wrong in the person's life, things that the person tolerates perhaps because they do not know any different, and tries to address them.

Phillip

Phillip had a stroke in December 2008. At that time he was in his mid forties with a young family. Over the following 6 months he made an excellent recovery and, in May 2009, felt he was well enough to return to work.

Over the next few months he started to settle in to work and had two assessments by Occupational Health. Despite the assessment finding that he was able to manage more than 90% of his job his employers wrote saying that he was to be retired on the grounds of ill health and would receive a half pension.

It was at this point that Phillip heard about the advocacy service from an Occupational Therapist. He contacted the advocacy organisation. Within a few days he met his advocate, explained his situation, that he did not want to retire and said that he was concerned about how he and his young family would manage financially if they had only his half pension to live on.

The advocate supported Phillip to find what his rights were under Employment legislation.

With the support of his advocate he approached his employer to point out the lack of proper support on his return to work after several months off sick and to discuss the possibility of other positions within the firm. Phillip expressed interest in applying for other posts but was told he was not suitable for them.

Phillip was very concerned about the financial situation but told the advocate that he no longer trusted his employer and was less keen to continue to fight for a return to working for them. The advocate supported him to write to his employer outlining what his experience had been and pointing out possible breaches of Employment law and the Disability Discrimination Act. His employer then wrote to offer him medical retirement with a full pension. He and his advocate met with his former manager to discuss the terms and conditions associated with the company's offer.

He agreed to accept the offer and, with the financial pressure off, is now looking into education and training opportunities to help him make a career change. Phillip believes that, without the support of the advocate he might not have been in this position today.

Alec

Alec was in his late forties when he had a stroke. This has left him with mobility and memory problems, he finds it difficult to plan and organise things.

When he was referred to the advocacy service by his Occupational Therapist he was having severe financial problems and his relationship with his wife and family was very difficult. Shortly after first meeting his advocate his marriage broke down and his wife put him out of the family home.

He was found temporary accommodation in a B&B where he stayed for several weeks. He found life in the B&B very difficult, he had to go out by 9am and could not return until 10pm. He told his advocate that he felt his situation was hopeless.

The advocate supported him to speak to Social Services about applying for other accommodation. For several weeks his advocate kept contacting Social Services on his behalf to ask about finding other accommodation. Finally he was offered a flat which he has now moved into.

While he and his advocate were working to have him rehoused Alec was also having problems dealing with his financial situation. He had been declared bankrupt and his family home was to be sold. The advocate supported him in the necessary contact with accountants and lawyers.

Alec's main concern throughout all these difficulties was his relationship with his family, particularly with his children. His relationship with his wife had broken down completely and she had said that she did not want him to see his children. His advocate supported him in reopening communication with his wife. After some time his wife then agreed to allow him some contact with his children.

There are still ongoing issues for Alec that the advocate continues to support him with. However things are slowly improving, he has his flat and some contact with his children. Alec now feels that he has some hope and that he can begin to look ahead once more.

Chris

Chris first heard about the advocacy organisation from a friend at the day centre he attends.

He contacted the organisation to ask for an advocate to help him speak to someone about very noisy neighbours. He said that he had tried to deal with this over several months but that he felt no-one was listening to him.

The advocate helped him to explain his concerns to the agency responsible for letting the neighbour's flat. This seems to have helped as he is now much less disturbed by loud noise from the neighbour's flat.

While the advocate was supporting him with that problem Chris also spoke about the fact that his sight, which had already been very poor, was getting much worse. He said that he was now unable to cook or make a cup of tea as he was concerned that he might scald or burn himself. The advocate helped him to find out what support he might be able to get.

With his advocate's support Chris contacted the Social Work department and the RNIB. The Social Work department told Chris that someone from RNIB would visit Chris to assess what support he needed. When, after some time, Chris had not had any contact from RNIB his advocate contacted them on his behalf. Very soon after that contact someone from RNIB visited Chris and he now has the support he needs to help him manage at home.

Robert

Robert is 67 years old and lives alone in a small house close to Loch Lomond. He left school at 14 without much in the way of qualifications but always worked hard and over the years built up a successful business, which prospered. Times were good until Robert had his first stroke at the age of 52.

Although he made a partial recovery, Robert was unable to work after this and, in subsequent years had a number of further strokes, which have left him with physical disabilities.

Although he has a lively sense of humour and a generally positive outlook, Robert often feels frustrated by his current circumstances.

He has a long-term partner and although they live separately they are very fond of each other and spend a lot of time together.

Robert wishes that he had made better financial provision for his future but says ill health was the last thing on his mind when he was busy running his business.

Although Robert's partner, Jean, keeps in reasonable health she too has had a difficult time over the past few years due to bereavements and some family problems. She and Robert have been a great support to each other during this time.

Robert wanted to take Jean on a short holiday to "get away from it all" and as a thank you for all her support, but found that he could not afford to.

Robert spoke to his social worker about this and although it was suggested that some respite might be available this was unlikely to involve Jean and didn't sound like the type of break Robert had in mind. His social worker put him in touch with the advocacy service.

Robert's advocate arranged for a benefits check, which established that he wasn't receiving all of the benefits to which he was entitled. She also helped Robert to investigate the availability of grants and trust funds, which might contribute to the cost of a short holiday for him and Jean.

The advocate helped Robert to make an application to The Stroke Association, which was successful and a short time later the advocate was able to pass on a cheque for £200. Robert and Jean are now planning a holiday together in the North of England.

Geordie

Geordie was born in the North East of Scotland during the last year of the Second World War. He knows nothing of his birth parents but was adopted as a child by an Austrian father who had served in the Merchant Navy and married a local girl. Geordie's adoptive father died while he was still young and he moved with his mother from the city of Aberdeen to a small town in rural Argyll, where he lived for most of his life.

Following the death of his mother, Geordie worked in a variety of manual and agricultural jobs, between periods of unemployment. He continued to live in the local authority house he had shared with his mother, never married and has no known relatives. Much of Geordie's social life revolved around the local pubs and drinking sessions with his pals. He openly acknowledges that he was a heavy drinker and reflects that he "smoked too much, ate too little and got into the odd scrape".

In spite of this, Geordie sometimes helped out as a volunteer with a local youth club and had a long association with the Salvation Army, which he regarded as a valued source of support when life was difficult.

About four years ago, while in his early sixties, Geordie had a major stroke. He was initially taken to his local hospital but was quickly transferred, by air ambulance, to the Southern General Hospital in Glasgow, where he spent several months. Although Geordie has made a partial recovery he has been left frail and has a physical impairment, which means he can only walk short distances with the aid of a walking frame. His short-term memory is also poor. Following discharge from hospital social workers arranged a placement for Geordie in a nursing home on the outskirts of Glasgow.

To Geordie, much of the time following his stroke is “a blur” and he finds it difficult to remember how long he was in hospital and how long he has been living in the nursing home.

At some stage Geordie relinquished the tenancy on his council house in Argyll, but he doesn't remember the circumstances around this or the reason behind the decision.

Geordie has had no visitors, other than professionals, since he moved into the nursing home several years ago and he often feels isolated. He looks forward to visits from his advocate and enjoys the opportunity to reminisce and talk about the past. Geordie's main aspiration is to return to the small town where he spent most of his life.

His advocate has established that there is a nursing home in Geordie's former hometown, but that vacancies do not occur often and there is always a waiting list for placements. This has been exacerbated by requirements from the Care Commission that facilities within the home be upgraded to meet new standards and the resultant reduction in the number of placements available.

Geordie and his advocate feel that some professionals have been reluctant to support his return to Argyll because of judgements about his former life style and concerns that re-establishing links with his former “drinking pals” might lead to problems and not be in his “best interests”. Even fairly minor issues such as who would pay for his transfer have been sited as obstacles.

Despite this Geordie's advocate has supported him to make an application for a placement in the nursing home in his hometown. She makes regular enquiries as to how his application is progressing and keeps Geordie informed of this. Geordie remains hopeful that he may some day be able to “go back home.”

Sadie

Sadie met her advocate, while in hospital, after a referral was made by her Mental Health Officer, who was pursuing an application for a short-term detention order under the Mental Health Act.

Sadie is 74 years and has had several strokes over recent years. She is physically quite frail and also has significant short-term memory difficulties.

Sadie has been married to her husband, Jim, for many years and they have a large family. In the past, Sadie's relationship with her husband has sometimes been volatile and occasionally even violent. Both Sadie and Jim are fiercely independent and somewhat suspicious of social work services. In the past they have been reluctant to engage with social workers and have been unwilling to accept support at home. Jim has a power of attorney for both financial and welfare matters concerning Sadie.

Over recent years Jim has found it increasingly difficult to care for Sadie on his own and had an informal arrangement with family members who he "paid" to provide help. This broke down recently when those involved felt no longer able to cope and expressed the view that Sadie needed to go into care. This is something that neither Sadie nor Jim want.

Concerns about Sadie's welfare were brought to the attention of social workers, although the source of these concerns is not entirely clear. This has led to some friction within the family.

During a heated meeting with social workers Jim admits to making reference to an alleged "suicide pact" between Sadie and himself, which he feels is behind objections to Sadie being at home and a challenge by the local authority to his power of attorney under the Adults with Incapacity Act.

Sadie has willingly engaged with her advocacy worker and seems reassured by the workers independence from statutory agencies. At times she can be quite talkative and lucid and is consistent in her view that she wants to be “at home with Jim”. She feels that they have both “mellowed” over recent years and that their relationship is now better than at times in the past. They want, she insists, to spend their final years together.

Sadie feels that she was “duped” into going into hospital and claims that she was told it was for treatment for a minor physical ailment. She is also annoyed at Jim, who she says told her that she was “going on holiday”. She does not think that she needs to be in hospital and is angry about her predicament.

Sadie’s advocate continues to support her at Mental Health Tribunals and in ongoing proceedings under the Adults with Incapacity Act, ensuring that she is able to voice her views and play as full a part as possible in decisions about her future.

Mark

Mark is 37 years old and lives at home with the eldest of his two sons, who is 19. He served in the armed forces and had what he describes as an “ordinary life” until he had a stroke shortly after his 34th birthday.

Mark is now only able to walk short distances with the aid of a walking stick. His short-term memory is very poor and he finds it very difficult to retain information.

Following his stroke, Mark came to depend heavily on his wife who cared for him at home and also took care of practical matters, including the family finances. The family had little social work involvement. Mark was confronted with a major tragedy when his wife died suddenly following an unexpected and major heart attack two years ago.

Before her death, Mark’s wife, had acted as his appointee with the benefits agency and all of the family’s finances were handled through a bank account in her name. Mark continued to have benefits paid into his late wife’s account for some time after her death and relied on his teenage son to make regular withdrawals of cash from an automated cash dispenser. When his late wife’s account was frozen some considerable time later, the family were plunged into financial difficulties and

unable to access funds to meet the normal costs of daily life.

A family friend encouraged Mark to contact the advocacy service. Mark’s advocate was able to visit him the following day and make arrangements for emergency assistance from social work. She was also able to arrange for a home visit by a welfare rights worker, although demands on the welfare rights service meant that this took several weeks to achieve. The advocate was able to help Mark to explain his financial dealings in the period following his wife’s death and to establish new banking arrangements. Mark’s son has recently been appointed his financial guardian.

Mark is relieved that his financial affairs are now in order, but still finds it difficult to plan for the future, living life a day at a time.

His advocate has encouraged him to contact the service again when he feels better able to consider his longer-term aspirations.

Hugh & John

Hugh

I went to see Hugh and he was happy to speak to us and said we could advocate for him. He said he would like a house of his own, not sharing with anyone. He likes to be independent and would not like to go to another residential home. His preference was for sheltered accommodation where he could get help with cooking his meals.

John

I visited John and he was happy to speak to us and for us to advocate for him. He said he would like to have his own house and to be closer to family and friends. He likes staying on his own and would need help with cooking.

Hugh and John both have mental health problems and as the advocate my role was to help them express their wishes, where they would like to stay when the home where they were currently residing in, was to shut down.

They were both very able and looked after themselves and their rooms very well but said they would need help with the cooking, in the past I might not have understood why this would be an issue, but the training on stroke, helped as I realised they might not be able to feel hot/cold. This is why, even though they could Hoover or dust their rooms, cooking was not easy or safe.

The other thing the training helped with was that I understood what they meant when they repeated a certain word; the training gave me an insight as to why some people do this and what it might mean. Using a note pad with John to write down his feelings was very helpful too.

James

James was taken to hospital following a stroke, he was prescribed quetiapine, and was put on a short term detention because of his aggressive behaviour (seemingly this can be side effect of this drug). This behaviour was out of character and the advocate raised this on James' behalf. A Mental Health Tribunal was arranged to apply for a six month Compulsory Treatment Order but only a 28 day one was granted. He was assessed by a psychiatrist and then taken off quetiapine and prescribed new medication. His behaviour since the change of medication has improved dramatically, so much so, that medical staff said that they didn't see the need for a Compulsory Treatment Order. He is no longer aggressive and is lucid and clear in what he wants.

As an advocate I have found this pilot project has made me think more carefully about the referrals we receive e.g. this originally was referred as a mental health issue and we were asked to support James at the Mental Health Tribunal.

Anne

My new advocacy partner had been referred by her Social Worker: “Anne has had a stroke and can’t really speak. Her house is on the market so she’ll have to move soon and she disagrees with our plans for her care, can you help her say what she does want?”

I went to meet her at home while the Community Nurse was making one of her weekly visits. Anne seemed much younger than her years, with a ready laugh and a warm, friendly, direct manner. I was charmed by a feisty hostess who whisked around the kitchen to make tea as fast as her electric wheelchair would allow.

Anne responded to my initially tentative questions with “Yes” or “No”, and though she sometimes got these words mixed up, it was evident from her expressions of delight and triumphant gestures when I’d understood a particular point correctly. Anne quickly got upset when we talked

about Social Services’ recommendation that she should move into a care home when her house was sold.

Anne’s emotional responses ensured we communicated effectively though it was very tiring for her. When mime, or writing key words on her pad didn’t get through to me, Anne would show me things on the internet; she couldn’t type very well but she clicked like a demon! I gained confidence, we really were chatting and laughing in a way I hadn’t realised would be possible.

Over the next couple of weeks I found out that Anne’s animals were the most important things in her life, that she valued her independence and was very proud about how she managed her routines and organised her life with the minimum of help. She was often overwhelmed by her feelings, acting out joy and despair with an intensity that was awe-inspiring; this passionate lady had no doubts about anything and very clear views about what she wanted out of life.

When her house was sold Anne was able to have her animals nearby while she was in temporary respite. She has since left the area but I often think about her with admiration: she taught me that the spoken word really is the least part of communication, and that there are many ways to listen.

Madeleine

Madeleine had a stroke several years ago affecting her mobility, speech and emotions. She is now in a power driven wheelchair in a new house that has been made fully accessible to her needs.

Madeleine contacted Advocacy when the Housing Association arranged a meeting with her about some issues including having too many cats. As Madeleine adores her 2 cats she was terribly anxious and upset that she would be required to part with one and she thought she may lose her home as she was not prepared to give up her cats. Madeleine was concerned that she would cry and find it difficult to put her point across at the meeting.

Val spent some time with Madeleine as her stroke had affected her ability to understand language and express herself in the way she wanted to. Madeleine did become upset during the meeting but her advocate was able to stand up for her and explain her views. The outcome was that Madeleine was allowed to keep both her beloved cats. Madeleine says “I feel particularly vulnerable dealing with people in certain circumstances. The advocacy service provides the support I require at these difficult times. I am delighted that The Stroke Association is funding this much needed and much appreciated service.”

Advocates' Words

Advocates report that frequently people are referred with other presenting illnesses or conditions such as Huntingtons, Depression or Dementia and often have small strokes as part of their illness. We need to get better at recognising that stroke can be a factor in the difficulties people face when they come to us for advocacy support.

Each person is very different in terms of the effect that stroke has had on their lives. One person gets emotional, another has “dementia” type symptoms. The third person was a notorious alcoholic who was often in trouble with the police. Since his stroke he drinks very little and is a model citizen in every way.

The issues are also varied – meetings with mediation service, social work reviews, housing association, appointments at CAB and GP; the list is as individual as each person.

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Pilot Organisations

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www.advocacy-highland.org.uk

Lomond & Argyll Advocacy Service

155 Glasgow Road

Dumbarton

G82 1RH

T: 01389 726 543

F: 01389 726 694

laasadvocacy@aol.co.uk

www.laas.org.uk

Partners in Advocacy

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10 Sunnyside

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edinburgh@partnersinadvocacy.org.uk

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Forth Valley Advocacy

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F: 01324 574 316

FV-UHB.FVAdvocacy@nhs.net

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satisfactions

Useful Organisations

The Stroke Association

The Stroke Association Scotland
Office

Links House

15 Links Place

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EH6 7EZ

T: 0131 555 7240

F: 0131 555 7259

scotland@stroke.org.uk

www.stroke.org.uk

Scottish Independent Advocacy

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Melrose House

69a George Street

Edinburgh

EH2 2JG

T: 0131 260 5380

F: 0131 260 5381

enquiry@siaa.org.uk

www.siaa.org.uk

Aphasia Now

www.aphasianow.org

Chest, Heart & Stroke Scotland

Head Office

65 North Castle Street

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T: 0131 225 6963

F: 0131 220 6313

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7 King Edward Court

King Edward Street

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T: 0115 9240800

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Helpline: 0808 800 2244

helpline@headway.org.uk

www.headway.org.uk

Long Term Conditions Alliance

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Venlaw Building

349 Bath Street

Glasgow

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F: 0141 246 0348

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Scottish Disability Equality Forum

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speakability@speakability.org.uk

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The Scottish Independent Advocacy Alliance is a membership organisation devoted to the promotion, support and defence of independent advocacy across Scotland.

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.



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