

My stroke victory

Inspiring stories from stroke
survivors and their families



We're pleased to announce that the Life After Stroke campaign is proudly sponsored by

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Stories to inspire you

This booklet is for all those who have had a stroke and for their families, friends and carers.

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Introduction

We hear countless stories from stroke survivors every day who have achieved personal goals which may have once seemed impossible to them.

We've asked some of them to tell us about their experiences in their own words to show what life after stroke means to them and to inspire you along the way.

No matter how gradual your recovery may seem in the early days, these stories show what some people can achieve. A stroke victory can be anything from cooking a meal for your family to climbing the stairs so that you can once again sleep in your own bed. It can be starting a new job, volunteering in your community or the pleasure of reading a book.

Here, stroke survivors share their stories of recovery from the difficult early days and tell us how they adjusted to life after a stroke. For many it was a long and hard journey.

Each victory, no matter how big or small, is significant and sharing these experiences is a great way to inspire others during their individual recovery.

We also hear what it is like caring for someone who has had a stroke.

Here you can find out what helped others to look to the future and what inspired them. These stories explain that life won't necessarily go back to how it was before, but it can often bring new beginnings.

Read their practical tips and find out how the Stroke Association can help you get the information, advice and support you need along the way. If you have questions about getting back a life after stroke, call our **Stroke Helpline** on **0303 3033 100** or visit **stroke.org.uk**



“For me, it was the day I first walked again.”

Adam Fontaine

Adam is setting his sights on the Paralympics. Adam Fontaine, 20, had a stroke at the age of seven. He's since become an international sporting champion.

"I was a normal active child in school until I was seven years old when I had my first stroke. A year later I suffered a second stroke. This left me unable to walk or use my left arm. I had to spend three months in hospital. I was allowed home but had to use a wheelchair. My father gave up his job to look after me.

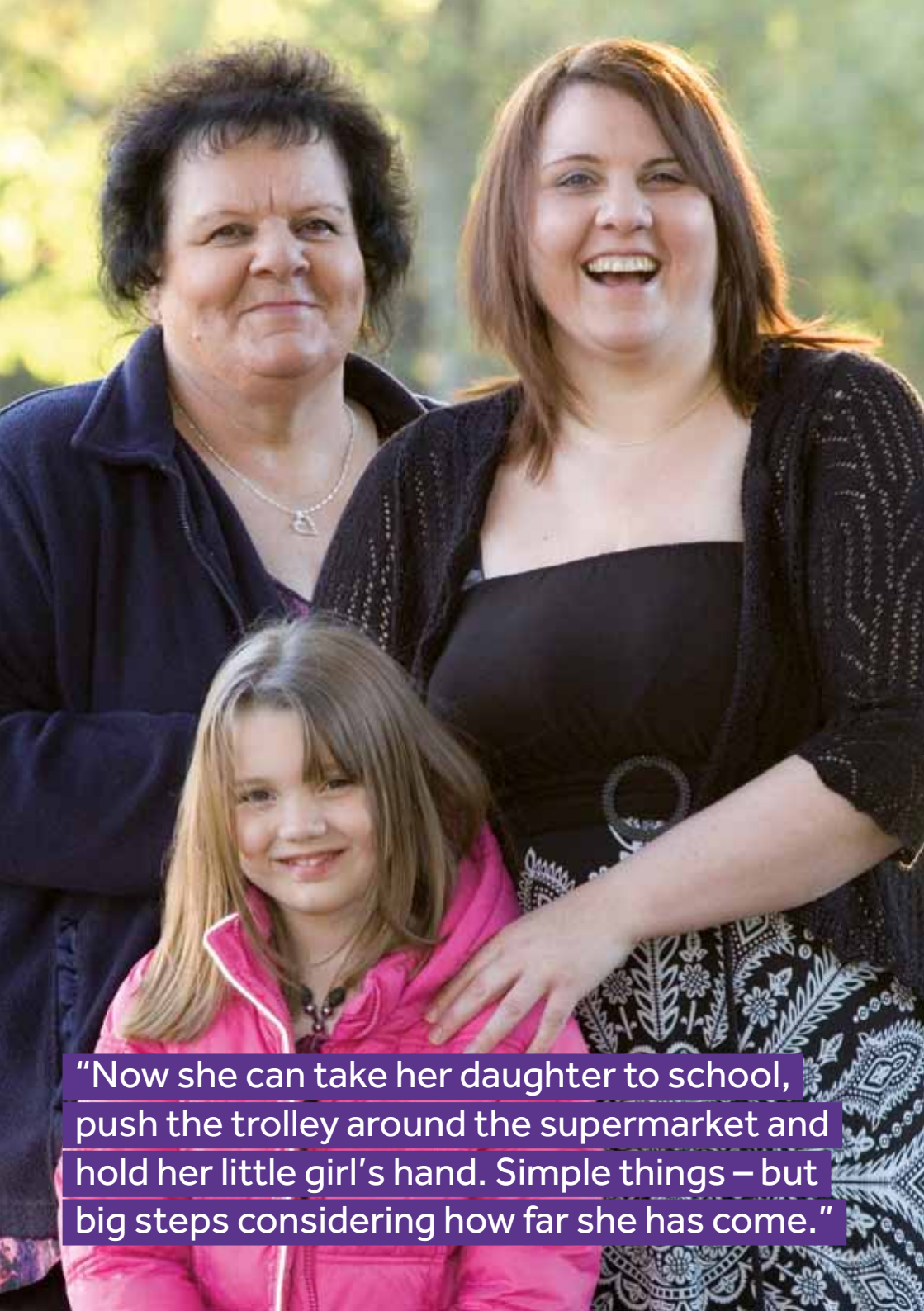
I was very determined to walk again – it took about eight months to learn to walk using splints. Dad put in a handrail to help me get up the stairs. I couldn't get in and out of the bath so we had to get a walk-in shower installed. I also had to have speech therapy to help me talk again.

About three years after my strokes, I found a local disabled sports club, where I got interested in air rifle shooting. This helped me to build up my confidence and realise what I was capable of achieving.

Since joining the sports club, I have represented Great Britain in swimming and shooting. I won a silver and bronze medal in my first-ever international shooting event. It was a really great feeling. I'm now barely at home as I'm training most of the time or competing with the British Paralympic shooting team. My big target now is to make it into the Paralympics for 2012."

Adam's Tip

"Don't hide away thinking that you can't do anything. Get out there and find something you can do, and enjoy it."



"Now she can take her daughter to school, push the trolley around the supermarket and hold her little girl's hand. Simple things – but big steps considering how far she has come."

Claire O'Kane

Claire O'Kane and her mother, Ann, tell how looking after her daughter is helping Claire in her recovery.

"For me it was the day I could hold my little girl's hand again."

Claire: "I was a full-time mother to three-year old daughter Caitlin when I had my stroke four years ago aged 26. Before I had my daughter, I had been having headaches but the doctor had diagnosed migraines. After my stroke, I was desperate to sleep in my bedroom rather than in the bed we'd put in the living room."

Ann: "She signed to us that she wanted to go upstairs, so we had one of us pushing from behind and another pulling her up. It wasn't easy but we managed."

Claire: "Because I've got Caitlin, I had to get better so I could get her into a routine. I wanted to be normal again, whatever that is. I used to be right-handed but had to teach myself to be left-handed. I'm learning to write again but find it hard to read more than short paragraphs. Now I want to help other people to show them there is life after stroke."

I have lost nearly two stone in the last six months and have started jogging and boxing on my Wii. I also have a machine that stimulates my hand to help it open up. I can grasp but I can't release anything – yet."

Ann: "The Stroke Association has been fantastic. We wouldn't have sorted out the disability benefits without them and they helped to arrange the conversion of our downstairs toilet into a shower and organised a wheelchair. A woman from the Association comes round regularly and we know we can always ring her for advice."

Claire's Tip

"There is light at the end of the tunnel. Take one day at a time and every day try to reach a goal, however small."



"I fell in love with the mountains and decided that would be my motivation to recover even more."

Lafrance Gordon

Lafrance Gordon likes to learn new skills. Lafrance couldn't climb the stairs when he first got home – but sheer determination helped him get there, and he didn't stop at stairs... he's gone on to climb mountains too.

"I had my stroke nine years ago when I was 41 and living with my partner and two children. I worked as a welder and music promoter. I started the first Ms Caribbean UK beauty contest and had played cricket for my local team for 25 years.

When I first got back home it was awful. I felt isolated as I had to be downstairs. I remember creeping out of bed, putting my feet on the ground and trying to walk. I made it to the hallway and looked up the staircase. I knew with sheer determination I could get up there.

I had a really good physiotherapist who worked with me for six months, took me to the gym and on my first walk. I wanted to walk to the cricket ground where I used to play. I practised every day and would go 10 yards, 20, 30 and then stop. I would try to stop less each time.

Through the Stroke Association, I became involved in the Bristol Half Marathon and then went on to climb Pen Y Fan in the Brecon Beacons. I fell in love with the mountains and decided that would be my motivation to recover even more. In May 2008, I reached the summit of Snowdon.

I have become a media volunteer for the Stroke Association and appeared on TV and radio. After a course in journalism, I began working on a radio station and now host a popular programme. I like to learn new skills."

Lafrance's Tip

"Try to get out every day and set yourself little targets to achieve, for example, walking an extra 10 yards each day."

Your stories

What's your s

"Having a bath and washing my own hair for the first time in months without feeling scared I might fall over or have to call in someone in to help me." Victoria

"Overcoming aphasia!" John

"Surviving over 30 years."

Carole

"Being able to drive again. I think I'm a better driver now than before my stroke." Helen

"Travelling to Australia on my own to see my daughter." Terry

"Giving help to the people who helped me." Chris

stroke victory?

"As a man, standing up for my first pee." Gordon

"Putting my bra on by myself!" Lyn

"I learned to love again!" Steve

"To be able to write again! It seems miraculous!" Paul

"Changing my boy's nappy with one hand and my foot!" Anna

"Walking up and down the stairwell near my hospital bed." Mick

"Being able to talk and walk! And driving again." Annette

Visit our website
stroke.org.uk/mystrokevictory
and add your stroke victory.

Michael Bell

Michael Bell has discovered a talent for art. Michael, 69, has had to learn to walk, speak, read and overcome the dread of going outdoors since having his stroke.

“Before I had my stroke, I was retired and would spend a lot of time helping my wife Christine, who has MS. After the stroke, I spent three months in hospital. I became very depressed. When I realised that I didn’t recognise the alphabet and couldn’t read, I became very frightened. I didn’t want to go outside of the hospital.

I didn’t want my friends to visit. I was ashamed of being the way I was. I didn’t know what to say to them. I didn’t want to be cheered up. I only wanted my wife to see me.

Occupational therapists started me on the road to recovery. Then I began physiotherapy. That was a big stepping stone as I thought I would never walk again. I was so pleased to go home. But my depression returned and I cried a lot.

The Stroke Association gave me back my life. A lady came to see us to offer me things I could

do – without that I would still be sitting in my home. At first I was reluctant but my wife encouraged me. I started a communication class and an art class – I had never painted before my stroke. These classes made me feel there was a life after a stroke and gave me hope. I tried everything that was offered.

Setting goals was important – simple tasks first, like walking down the path or reading simple words. Now I am no longer incontinent, can walk to the shop without a stick, recognise the paper I want and read the TV section. Life is good again.”

Michael's Tip

“You need to make constant efforts to reach the targets you have set yourself, and those that other people have set for you. Don’t be afraid to ask for help.”



**"The Stroke Association gave
me back my life."**

Irene Thompson

Irene chairs a stroke club. Irene Thompson, 80, has run a stroke club for 18 years – here she tells her story of sheer determination.

"I first had a stroke in 1988 and have had five TIAs or mini-strokes since. The doctors said I wouldn't accept I'd had a stroke. My arm didn't work, I was dribbling and it was hard to get dressed. I couldn't get in the bath. My husband had to help me walk to the end of our block. I found the noise of traffic louder than it used to be – it gave me terrible headaches. I also knew I was saying something but it was hard to know if I was making sense.

It was important to do exercises, such as putting my finger in my mouth and pulling my lips up, patting the side of my face, lying on the floor and lifting one leg up, moving my arm up and down and going up and down one stair at a time. I did all of this at least twice a day.

I also found it useful to try to get out and do something. One day, I heard about the Stroke Association on the radio, so I called and spoke to somebody who was more like a counsellor. She sent me a lot of information.

I went along to my local stroke club and saw other people worse off than myself. I've now been the chair for 17 years. Three out of every four weeks we have a physiotherapist who gives talks and helps us to do exercises."

Irene's Tips

"Accept you need help but don't allow yourself to be mollycoddled.

Families should let you try to do things so that you can become independent.

Get all the factsheets from the Stroke Association. These can help to explain the situation to your families and friends."



"Life improved dramatically the day I went to my first stroke club."

Linda Walls

Linda cares for her husband, Ed, who had a stroke four months after his 50th birthday. She helped him in his remarkable recovery and had great support from family and friends.

“The doctors in intensive care said if Ed did survive, he may be left unable to walk, swallow, eat or talk, and also added ‘but he might make a full recovery’. Although I didn’t know if he could understand me, I told Ed he could recover but it would be hard work for him. His determination and fighting spirit carried us all along. Six weeks later, he walked and came home.

After a stroke, people have to relearn what they knew before. We tried to stimulate Ed to help the pathways in his brain reconnect. We chatted to him and played music and radio programmes.

We put up photos, articles, pictures and motivational messages on Ed’s hospital wall for him to read. This also gave nurses and visitors something to talk to him about.

When Ed came home there were times when I felt overwhelmed physically and emotionally from adjusting to the changes in our life. My mum had a stroke six weeks later. My GP diagnosed delayed shock and I saw a counsellor to help me find coping strategies.

Fifteen months on, Ed has come a long way. He attends speech and language therapy weekly and, despite developing epilepsy, enjoys photography and home movie-making.”

Linda's Tips

“Accept help and delegate tasks – people will feel useful at a time when they don’t know what to do to help.

Have a discharge plan so when the time comes, you have a support system in place.”

"Don't give up hope. You need to recognise that progress happens in small steps."



You are not alone

Remember you're a carer and there is a range of support available. Visit www.carersuk.org or call the carer's helpline on **0808 808 777**.

Moving forward

We can help

We're here to listen to your concerns, to support you and answer your questions. We can tell you what help and services are available in your area, what should be happening in hospital, and what to do if things aren't going to plan. We can also provide you with factsheets and leaflets on a wide range of issues after stroke.

Call the Stroke Helpline:

0303 3033 100

From a textphone, dial:

18001 0303 3033 100

We have access to Language Line, a free interpreting service for callers to the Stroke Helpline whose first language is not English.

Email us: info@stroke.org.uk

Or write to us:

Stroke Information Service,
Life After Stroke Centre,
Church Lane, Bromsgrove B61 8RA

Get support from our services

There are Life After Stroke Services in some parts of England, Wales and Northern Ireland offering practical advice and emotional support. There are also a range of services from

communications groups to carers' support or stroke prevention advice. Call the Helpline for further information.

What you can do

- Keep a diary of your recovery – you can then look back and see how far you have come. Be prepared for the bad days and remember that recovery takes time but try to be patient.
- Recognise and celebrate every achievement you make, whether it is making a cup of tea, or running a marathon.
- Make a list of any questions and concerns as they come up and take it to your next appointment with your consultant or GP. If you are feeling depressed or anxious, you can talk to your GP – there is help available to you.
- Allow yourself to rest. Tiredness is very common after a stroke and you may find you need to take breaks more often than you did before.
- Try to stay healthy. Plenty of sleep, a good diet and regular physical exercise are all important to your progress, especially the exercises your therapists have taught you.

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- If you can, take someone with you to appointments, for moral support and to help you remember what you wanted to say.
 - Confide in someone. Talk about your feelings – don't be afraid to be honest about what is happening. This could be a family member, friend, our helpline or someone in a support group.

Where to find extra support

There are many groups (called stroke clubs) which provide a meeting place and valuable support to stroke survivors and sometimes their carers too. Call us for details. You may also like to join TalkStroke, the discussion group on our website stroke.org.uk/talkstroke

Speak to Social Services. They may be able to provide practical help at home. You'll find their contact details in the phone book under the name of your local authority.

Be honest about your difficulties. This gives the professionals working with you a better idea of how they can support you.

Get financial help – your financial situation may have changed after your stroke and working out what help you are entitled to can be complex. There is specialist advice available – contact us to find out where you can go for help.

How other people have coped

If you'd like to read similar stories from other peoples' life after stroke or to share your own, please visit stroke.org.uk/mystrokevictory

Thank you to all the stroke survivors and their families who have told us their stories or offered their views, tips and suggestions for making this booklet better. We hope that you have found this information useful.

Every year thousands of people affected by stroke receive information and support from the Stroke Association. If you would like to help us continue this vital service, please make a donation on our website or by calling **01604 687 777**.

Stroke can have a big impact on many areas of your life. This booklet offers inspiring stories of people's journeys towards recovery and practical tips to help you cope with life after stroke.

The Stroke Association believes in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And why we fund research into new treatments and ways of preventing stroke.

We are a charity. We rely on your support to change lives.

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100

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