



SURVIVORS SUPPORTING SURVIVORS

www.differentstrokes.co.uk

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Private Group: differentstrokesuk
Public Page: differentstrokescharity



@diffstrokes



differentstrokescharity



uk.pinterest.com/diffstrokes

GET REGULAR UPDATES

We hope that you enjoy reading about everything we are involved with at Different Strokes, and if you'd like to hear more, why not join our e-mail list? Subscribers to this list receive monthly updates from us in the form of an e-newsletter. It's a great way for you to hear more regularly about all our activities.

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If you would like to share your thoughts, questions or your own story with us get in touch with us by emailing
info@differentstrokes.co.uk

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Cover photo of fundraisers Val and Jo taken at our abseil event by photographer James McNulty

WELCOME

A very warm welcome to our Autumn/Winter 2019 newsletter.

The last six months has, as always, been a very busy time for Different Strokes with lots of activity taking place. In collaboration with Chest Heart Stroke Scotland (CHSS), we held a conference for younger stroke survivors in Perth in May, which was a very well attended and inspiring day. We will be working more closely with CHSS going forward, and we're delighted that in partnership with CHSS and Northern Ireland Chest Heart Stroke, we have been chosen as Charity of the Year of Scotmid for 2019-20.

In our last newsletter we highlighted the issue of PFO closures, and the lack of routine funding on the NHS for PFO closures for stroke survivors. We are very pleased that NHS England has now reinstated funding for PFO closures for eligible patients, and we know how much of a difference this will make to the lives of many people that we support.

The broad theme of this newsletter is peer support. Peer support is at the heart of all that we do, and through the activities we provide – our local groups, online support and telephone support – we follow the ethos of survivors supporting survivors. In this issue we focus on specific stories of stroke survivors who have developed strong relationships via Different Strokes, and how these have helped in terms of ongoing recovery and rehabilitation.



Austin Willett, CEO

To further enhance our services, this summer we held our initial training day for ambassadors for Different Strokes, which will enable us to attend more events and further raise awareness of younger stroke and how we support people. Meanwhile, we are now well into the planning of our teen and young adult befriending service, which should be going live at the start of 2020.

I'd also like to mention our online shop, which now has a number of new items available, so please do have a look at these great new products – further details are on page 27.

As always, I'd like to thank everyone for their contributions to this newsletter, and express my appreciation to the individuals, community groups, companies, and trusts & foundations that have supported us financially or through raising awareness of what we do. Your support really makes a difference and enables us to support thousands of stroke survivors.

NHS REINSTATE FUNDING FOR PFO CLOSURES



We are delighted to report that NHS England has now taken the decision to start funding PFO closures in stroke survivors.

Professor Stephen Powis, medical director for NHS England, said:

"This truly lifesaving and life-changing procedure will now be available across the NHS, and will mean people can live without the worry of having a stroke."

In our last newsletter we focused on PFO closures. A PFO (patent foramen ovale) is a hole in the heart, which is present in around 25% of the population. Ordinarily this causes no problem, but in some people it can allow a blood clot to access the left side of the heart, and then pass into the brain, causing a stroke. We shared stories from a number of stroke survivors whose stroke was caused by a PFO, who told us how not being able to have a PFO closure operation on the NHS was affecting every aspect of their lives, and how they lived with the constant worry of having another stroke.

As part of the NHS Long Term Plan, we will continue to test the most advanced procedures available anywhere across the globe, collecting real world evidence to ensure NHS patients receive world-class care while delivering value for the taxpayers' pound."

The new measure is expected to benefit around 1,500 people per year, and we know how significant this is for stroke survivors and their families. This outcome will not only prevent further strokes, but will allow everyone who has been affected by this issue to no longer feel that they are living in limbo and to move on with their lives.

Earlier this year the NHS held a consultation on this issue, to look into whether the NHS should fund PFO closures for stroke survivors. We played our part in this consultation by raising awareness to our beneficiaries, in this newsletter, through our social media sources, by directly contacting neurologists and cardiologists, and by appearing on a number of radio stations to a combined audience of over 8 million people.

If you are currently waiting for an operation to close a PFO or were previously denied funding before this announcement, we advise you to make an appointment with your GP and ask them to refer you to a cardiologist.

THE NUMBER OF YOUNG PEOPLE SUFFERING STROKES IS "RISING DRAMATICALLY", BUT 84% OF PEOPLE STILL BELIEVE IT ONLY HAPPENS TO THE ELDERLY

Despite being the leading cause of death and disability in the UK awareness of stroke in the under 65's remains dangerously low. We recently did a poll with Consumer Intelligence that showed 84% of people still believe stroke only happens to the elderly.

World Stroke Day is on October 29th and this year, we need your help! We would like to come together as a community of younger stroke survivors and raise awareness that stroke can happen at any age.

We are partaking in a number of activities listed below and we would love you to get involved. From contacting your local paper and sharing your story, to updating your profile picture on Facebook no contribution is too small.

Press & Media

We will be sending press releases sharing survivors' stories to all major UK media outlets and trying our best to get as much media coverage as possible. Could you contact your local radio and newspapers and ask them to feature your story?

Events

Alongside other stroke organisations we will be attending UCL World Stroke Day Forum in London on Tuesday 29th October - a free event to empower stroke survivors to contribute to and influence research and rehabilitation at University College London.

NOT JUST THE ELDERLY



Social Media

We will be creating a twibbon which overlays your profile pictures on social media. We would love to see lots of you raising awareness by updating your profile picture.

A link and instructions on how to download our twibbon can be found in the news section of our website:
www.differentstrokes.co.uk/news

Get involved by sharing your story on October 29th using the hashtag
#notjusttheelderly



ASK THE EXPERT: PHYSIOFUNCTION

Q:

"I had my stroke 10 years ago and since then my gait has been affected which is causing all sorts of issues. I have had three herniated disks, ankle problems and I find myself tripping, even on flat surfaces. What would you recommend to improve my gait to help reduce all of the other issues?"



Matt White
Neurological
Physiotherapist

A:

After a Stroke there is disruption to the signals travelling between your body and brain...

The good news is that both your body and brain still work, and due to a process called neuroplasticity, even after 10 years (and longer) it is still possible to form new connections and restore the signals. There are many ways of achieving this.

Firstly, it is important that you exercise. This can be very difficult when balance and walking is affected, but activities such as swimming and cycling can help you build strength and endurance, whilst helping to lose weight and improve your general health.

Additionally, strengthening exercises, particularly exercises to improve core stability, can be invaluable in reducing all the other issues (such as herniated discs that you mention). Examples of this could be pilates, or even just sitting on uneven or wobbly surfaces without any back support, making you work harder through your stomach and back muscles and helping with your stability. Activities such as these are best undertaken, at least initially, under the supervision of a physiotherapist or trained and experienced professional who understands how to adapt and tailor exercises to your individual needs.



Strengthening the small muscles in your lower leg which lift your foot and prevent you tripping can be more challenging, however alongside exercises, there are two main ways that this can be managed to help you walk more easily, without tripping and causing injuries.

The first is the use of an Ankle-Foot Orthosis (AFO). This is a plastic or carbon support that is designed to fit under your foot and keep your ankle supported. Other supports can fit onto the outside of your shoe and provide a more dynamic support to allow some ankle movement yet still provide you with the required support.

The second is the use of a Functional Electrical Stimulation (FES) foot drop system. FES delivers small electrical currents to the muscles in your shin to actively lift your toes. The benefits of this over an AFO are that it is your muscles that are causing your foot to lift, and regular use can help to strengthen the muscles further so you not only get the effect when the device is on, you may also get some training effect that lasts when the device is switched off. After ten years you are likely to have a lot of weakness and muscle wastage in the muscles of your shin, so you may need some time to condition your muscles before you are able to use an FES system for functional walking, **but the key message to remember is that it is never too late to start!**



		
Hands On Therapy	Technology	Exercise
Neurological Physiotherapy	Rehabilitation Technology for walking difficulties	FES Cycling & Neurofit classes for fitness

Our stroke rehabilitation programmes are always tailored exactly to your needs.

Our clinics & centres of excellence are based in the Midlands.
Services vary by location, so please call to check prior to booking.

www.physiofunction.co.uk

Speak to our team on **0800 043 0327** and find out how we can help you

Understanding Sialorrhea:

information for adults with drooling of saliva

This article has been written and funded by Merz Pharma UK Ltd.

What is sialorrhea?

Sialorrhea is a term to describe drooling or excess saliva that you cannot control. It can lead to chapped lips, skin breakdown, odour, and infection of your mouth. Drooling can affect your sleep or voice, making it sound different or it may make you gurgle. Sialorrhea may reduce your quality of life. It can cause embarrassment and some people find it difficult to socialise. Severe sialorrhea may cause dehydration or choking. It is important to know that you are not alone; many stroke survivors are thought to suffer from sialorrhea.

What can cause sialorrhea?

Excess saliva in the mouth does not necessarily mean that you are producing more saliva than before, especially if this is an ongoing problem. An increased amount of saliva in the mouth may also be caused by a decreased clearance of saliva, for example, problems with swallowing and the inability to retain saliva within the mouth. Sialorrhea in adults is most commonly caused by neurological conditions; such as stroke, motor neurone disease, Parkinson's and cerebral palsy, which lead to weakness of the oral and facial muscles. This weakness of the muscles can make it difficult to swallow and/or to close your lips properly.

What will my treatment involve?

The type of treatment you receive will depend on how severe your drooling is and how much it affects your quality of life. The types of people who may be involved in your treatment include Speech and language therapists, Physiotherapists, Rehabilitation Consultants or Otolaryngologists (ear, nose and throat specialists).

Please ask one of your healthcare professionals if you want to learn more about how each of these specialists can support you during your post-stroke care programme. After a complete assessment, an agreed treatment plan should be developed by your healthcare professionals team, you, and your carers.

Treatment for drooling often starts with simple measures that don't involve medication; neck collars and head-back wheelchairs to improve posture, speech therapy, oral prosthetic devices, swallow reminders and portable suction devices. Other treatment options may include oral medication, injections, radiotherapy or surgery.

How can I make the most of my appointments?

- Bring a caregiver or family member to the appointment
- Try to rate your symptoms and progress. An example could be using “drooling severity” to explain your symptoms using a scale 0-5, where 1 is never drools and 5 is profuse drooling. Also, a “drooling frequency” scale 1-4 where 1 is no drooling and 4 is constant drooling.
- Think about the daily activities that you can't do, what you would like to be able to do and how you think your excessive drooling might be impacting you.
- Ask questions & take notes.

What happens if I am already on medication?

You may already be taking other medications or you may be prescribed a new medication to help alleviate any drooling symptoms that you are experiencing. Treatments can include oral and/or non-oral medications, for example, injections. The use of more than one medication may lead to interactions, so it is important to discuss any other medications (including those which you have purchased over the counter) with your healthcare professional.

What support might I receive?

The support that you will be offered may be related to the stroke, which is the underlying cause of your drooling. You may also be offered:

- **Regular physiotherapy** to help you strengthen your face and mouth muscles so you can control your saliva.

- **Oral prosthetic devices**, for example, chin cups or customised dental appliances to help better lip closure, tongue positioning and swallowing.
- **Speech therapy** to improve your jaw stability and closure, to increase your tongue mobility, strength and positioning, to improve lip closure and to decrease nasal regurgitation during swallowing.

Communicate

Share your treatment plan for drooling with all of your healthcare providers. If you want to know more about any medication that you have been prescribed, ask your healthcare professionals or pharmacist.

Talk to your healthcare professionals immediately if you are experiencing any unwanted effects from your treatment. You can also report side effects from any medication you are taking directly via the yellow card scheme at:
www.mhra.gov.uk/yellowcard.

Seek support from patient support groups and also make the most of the support from your carers and friends.



VOLUNTEER AWARDS



It takes a special person to give up their time for free and volunteer to make a difference to others. At Different Strokes we know how much volunteering helps our charity in supporting stroke survivors and their families. To acknowledge the amazing dedication of our volunteers we asked for nominations for the Different Strokes Volunteer of the Year Awards 2019.

To try and celebrate the many wonderful things our volunteers do we had four different categories for our awards this year. We were overwhelmed at the number of nominees, every single one of whom is thoroughly deserving of an award. This made selecting our winners a very difficult task!

After much deliberation we are pleased to announce our winners for 2019:

- **Peter Shave Award** – Diane Summers-Long
- **Fundraising Hero** – Helen White
- **Peer Support Champion** – Olga Mathews
- **Outstanding Contribution Award** – John Murray

NEW SUPPORT GROUP IN KENT

We are thrilled to have a new support group opening in Chatham, Kent on Thursday 24th October. The group has been set up by young stroke survivor Carly Edwards-Day and will be held at the Travelodge Chatham Maritime, Western Avenue, Chatham Historic Dockyard, ME4 4NT. The group will be meeting on the last Thursday of each month between 11.00 – 13.00 and is open to younger stroke survivors and their families. The venue is fully accessible with disabled parking so if you are local to Chatham please come along and meet with other stroke survivors in a relaxed and friendly environment.

For more information please contact Carly on 07538 990 463 or chatham@differentstrokes.co.uk



MEET THE VOLUNTEER

MEET GERRY LAMBERT FROM OUR BRISTOL EXERCISE & SUPPORT GROUP

"I was 53 when I had my stroke and really couldn't believe that it had happened to me. I felt far too young and stroke didn't happen to young people!

18 months after my stroke I was contacted by a physiotherapist from the neuro ward, who told me there was going to be a talk from Donal O'Kelly at a local hotel in Bristol. Donal had a stroke at a young age and had gone on to start Different Strokes after realising there was little support for younger stroke survivors. I went to the talk and found Donal inspiring, so much so, I went on to set up a Different Strokes group in Bristol with Alan Clark.

In 1999 we had our first meeting at the Horfield Sports Centre. In the early days we had a fitness instructor and an exercise group once a week with around ten members. Twenty years later our group has grown to forty members. We meet every Wednesday where we have use of a gym and every Saturday for seated exercise. We also have lots of social events such as an annual quiz, crazy golf and even weekends away.

To celebrate twenty years of being active, in August we attended The Arnos Court Hotel for a lovely afternoon tea comprising of sandwiches, gorgeous scones with jam & cream along with homemade cakes. The group has more celebrations to come later in the year when some of the members are going on a coach trip for an all-inclusive party weekend in Torquay!



I would definitely recommend setting up a Different Strokes group. Before I had a stroke I was very active and I wasn't going to give that up! I knew it was important to create the right atmosphere and environment to get everyone moving. The Bristol group is a mix of ages from 30 upwards and everyone is made to feel welcome. I enjoy being with other people who have had a stroke; I have made some great friends through the group and really enjoy volunteering.

Since having a stroke my greatest achievement has been completing the annual 5k walk/run around the cross-country course at Badminton House. I did this with three friends in the pouring rain and had great fun tackling the Horse Trials obstacles with some help from local young farmers! I completed the course, not in record time, but I did it and am rightly proud of myself for doing so!

If you would like to be a volunteer or start a group in your area email
info@differentstrokes.co.uk

Life Insurance for stroke-survivors

01564 791179 

www.plusprotect.co.uk 

Obtaining Life Insurance after suffering a stroke can be extremely challenging. If the providers believe the risk to insure you is outside of their normal underwriting rules, they are likely to decline your application for cover.

If you are looking to take out any form of Life Insurance, I would strongly recommend you seek the advice of an FCA-regulated Protection Adviser who will be able to assess your options, carry out pre-underwriting research with providers and recommend the most suitable policies based on your individual circumstances.

We are currently working with a specialist insurer who can provide cover for people living with a serious medical condition and medical impairments that would normally be rejected by most other insurers. This includes stroke-survivors.

Interestingly, most decent Critical Illness policies these days will pay out if the policyholder suffers a stroke. Whilst this might not benefit you, it certainly pays to ensure that your family and loved ones have the right cover in place.



Matt Chapman
Snr. Protection Adviser
Plus Protect



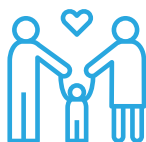
OUR IMPACT

Our closed Facebook group provides a safe space for stroke survivors and close family members to share their stories and support each other. The group now has more than 5,000 members, and 91% of people who have used the group rated it as excellent or good



We support approximately 1,000 people per year by telephone and email. 84% of people who have used our helpline rated it as excellent or good

We have a national network of 40 peer support and exercise groups, supporting around 900 people. 80% of those who have attended a local group rated their experience as excellent or good



For children of stroke survivors, we provide a special information pack to help them understand what has happened to Mum or Dad. 90% of people who have used this rated it as excellent or good



We send out around 350 information packs a year, and 91% of recipients rated this as excellent or good

91%

91% of beneficiaries rate their overall experience of Different Strokes as excellent or good



For every £1 invested we provide £4 of benefit to our beneficiaries

For more information about our impact, please see our Social Impact report at differentstrokes.co.uk/about-us/impact

THE POWER OF PEER SUPPORT: EDDIE AND PHIL'S STORY

Eddie Pleban had a massive stroke in 2011 and in 2012 he became the Volunteer Coordinator for Different Strokes Norwich. The group meet in a café each week for support and friendship. In 2016 Phil Cullum had a life changing stroke and started to attend Eddie's group. We met with them both to discuss how peer support had helped them to reclaim their lives.

Eddie says:

"When I started volunteering for the Norwich group, we had just four members. Seven years later we have seventeen. We meet weekly and support and encourage each other with our recoveries. We have made great connections with organisations and we signpost our members when they need help with post-stroke care or benefits. Over the years we have supported lots of survivors who have since returned to work. We are always sad to see them go, but happy that they are taking steps to move forward. Our group provides us all with lots of laughs and friendship."

Phil Cullum was six months post-stroke and his relationship was ending when a concerned family friend suggested that he went along to a Different Strokes meeting.

Phil says:

"I was feeling very low, sitting in the house crying all day, when Corina, a fellow stroke survivor, recommended going to the Different Strokes meeting. At the time I thought anything was worth a try! I didn't know what to expect before my first meeting and I was extremely nervous. The first person I saw was Eddie - he instantly put me at ease."



"Afterwards, I realised how great it was to get out the house! The meetings became something that I looked forward to; the highlight of my week."

Eddie and Phil share a great sense of humour and a deep understanding of life post-stroke. Eddie feels that they have become a mirror for each other, reflecting back the parallel effects their strokes have had on their personalities.

"Although our strokes have affected us differently, some of the effects are similar. We both don't know when to stop talking and often get lost halfway through a conversation. We see and recognise those moments in each other and are able to laugh it off together!"

Many survivors report that their friendships suffer after a stroke and Eddie's experience was no different:

"When you have a stroke, you might lose a lot of people, a lot of my friends and colleagues disappeared. My friendship group is now mostly fellow stroke survivors from both the online and local group. This network is invaluable and keeps me from being isolated."

In my experience so many survivors suffer from loneliness and loss of confidence. The group has meant that I have to get out and meet people. In the early days, I couldn't look people in the eyes - because of our group I can do this again."

Phil credits Eddie and the support network he found in Different Strokes for turning his life around:

"The support of survivors and Eddie has helped me no end. All of us had different experiences and different outcomes - but we share so much too. The group is a place where we can be open with no judgement or embarrassment - we can all just talk about how we are feeling. Empathy is the biggest thing, not just sympathy, empathy."

I was looking for work when I joined the group but have struggled to find a job that is suitable. Earlier this year funding became available to work for Different Strokes. It was Eddie who encouraged me to just go for it!

In July I became the Regional Coordinator for East Anglia. I get to support survivors in the local area and the Norwich group. We recently set up an additional arts and craft group which is going really well. I also raise awareness of younger stroke - I am now able to use my own difficult experiences for good."

”

"I believe that peer support is vital in combatting the loneliness and fear that comes hand in hand with a stroke."

We asked Eddie and Phil what peer support has meant to them:

Phil:

"Peer support is coming together and giving to each other. You have to be willing to go that extra mile with the people that you're supporting and be patient with them. Peer support is not a one-way road, it's a relationship built on give and take. Sometimes you need the support and other times you are the person giving it."

Eddie:

"I believe that peer support is vital in combatting the loneliness and fear that comes hand in hand with a stroke. That solidarity helps you to move forward with a network of people cheering you on - every step that you take."



Eddie at the new arts & crafts group

MEET THE AMBASSADORS



From left to right, Frances, Anthony, Sas, Sue and Jim

Different Strokes recently held an inaugural training and awareness day for our new ambassadors. As a very small charity with only seven head office based staff and two regional coordinators, there is a finite amount of activities and events that we are able to get involved with or attend. Often we get invited to community events, or to give a talk to a local school, business or community group, or to appear on radio, and sadly we have to say no, purely because we don't have the resources to do this. We'd love to say yes much more often though, which is why we have introduced the ambassador programme!

The day was attended by Frances, Anthony, Sas, Sue and Jim. It was great to speak to them all about our future plans for Different Strokes, along with their own experiences of stroke. As with all that we do, this personal experience of stroke is so important, enhancing the emphasis that we place on peer support and of survivors supporting survivors.

In the short-term our ambassadors will represent us at events that we have been invited to, but we hope to expand this programme in future years to not only cover as much of the country as possible with a network of Different Strokes ambassadors, but to be more proactive with the role, helping to further promote the charity.

We're so grateful to the new ambassadors – and the new group coordinators – for not only giving up their time on the day, but for volunteering for us going forward, making time to support other stroke survivors. We know that everyone will do a great job helping to promote Different Strokes in their local areas, ensuring that we have a higher profile and that as a result more people who need our support become aware of us.

We will be continuing to recruit more ambassadors and would love to run this training day twice a year, so would be delighted to hear from anyone else interested in the ambassador role.

THE POWER OF PEER SUPPORT: BELINDA AND JOSIANNE

In July 2015, Belinda had a stroke which affected her executive functions. She lives with dysarthria (a speech disorder), extreme cognitive fatigue and is hypersensitive to sound and light. In 2017, she joined the Different Strokes Community. Here she reflects on what peer support has meant to her and her friendship with fellow survivor, Josianne:

“The friendships I’ve made through Different Strokes have been so important to my recovery and wellbeing since my stroke. I have met people at our local group and some of the friendships were made online.

I remember that the first time I ‘spoke’ to Josianne was on a post in the Facebook group about medical ID bracelets, we started to chat privately via messenger. Jo was about to go to rehab, and we chatted about where we were at in our recoveries. Since then we’ve laughed, we’ve cried, we’ve shared ideas, we’ve listened when things have been tough, we’ve celebrated each other’s achievements, we’ve egged each other on with our crazy ideas and we’ve been proud of just being daft!

We understand that some days we don’t have the energy to chat and know we’ll answer when we can. We’ve had conversations with emojis when words are just too much.

I’ve followed Jo’s art journey, from her first paintings in rehab, to the beautiful canvasses that she’s now painting and using to raise awareness of strokes and money for Different Strokes.



Josianne (left) & Belinda (right)

Over the last couple of years, we’ve often talked about how great it would be to meet up, but distance and practicalities hadn’t allowed for that. Earlier this year my friends put on a charity event and Different Strokes were a beneficiary. Jo had donated one of her paintings for the auction and unbeknown to me my friends had arranged for her to come up to the function, in secret. I was completely unaware until the afternoon of the event. I was gobsmacked and happy tears were flowing in abundance!

Walking into the event that evening and seeing each other there was very emotional for both of us. Two friends sharing the biggest of hugs who met through something horrible, but who found one of the most important things in life – a treasured friendship.”

TEEN AND YOUNG ADULT BEFRIENDING SERVICE



This year we have had the pleasure of recruiting a small group of stroke survivors to become volunteer befrienders. The volunteers will be supporting fellow survivors aged between 16 - 25 as part of our Teen and Young Adult befriending pilot project. We currently have a team of six, who have all had strokes at different stages in their young lives.

We identified that there was gap in our services for this age range quite a while ago, but lack of time and resources meant it remained on our 'wish list'. Fortunately, Sainsburys Logistics kindly fundraised for us in 2018 and the proceeds from this will help us run this pilot in 2020.

The need for a befriending service was reinforced earlier this year when Genise and Lauren attended a young person's support workshop. A survivor of seventeen shared his own experience of stroke, nursed in a local stroke unit where everyone was much older than him; he felt so lonely and that he was the only young person to have had a stroke.

Many younger survivors at the event also related to feeling isolated. The general consensus was that the survivors would have benefitted greatly from being able to talk to someone near to their age when they had had their stroke.

Transitioning from a child to a young adult is already full of complexities, let alone when recovering from a stroke. Our hope is that young stroke survivors will benefit from being supported by someone who knows exactly where they are coming from.

Over the next few months the training programme will be finalised and the training day itself will take place at the end of October. The pilot will go live in January 2020. Email us on **info@differentstrokes.co.uk** if you are aged between 16-25 and would like to access this new service.

We are really excited to be able to offer this much needed service and hope that those who benefit from it will feel empowered to take charge of their own recovery, feel supported in adjusting to their 'new normal' and feel ready to reclaim their lives.

PEER SUPPORT THROUGH OUR HELPLINE

Our services are designed to support the whole family. Our helpline is another way for anyone affected by stroke to access peer support. The line is open Monday to Friday from 9am to 5pm. Here Nicky shares how being able to talk on the helpline with Genise helped her when her husband, Nigel had a stroke aged forty-six.

"When Nigel had his stroke, I went into complete shock. I was distraught and I didn't know if I was ever going to have my husband back again. I was frightened. How would we survive financially? Where were all the bills? He was the rock of the whole family - who would take care of us all now? I didn't sleep properly for days.

I looked through the information given to us by the hospital and found a leaflet with Different Strokes' number on; I contacted them just days after Nigel was discharged from hospital.

Nigel slept so much in the first few months - he was asleep more than he was awake! When he slept, I would call Different Strokes for reassurance and guidance.

I spoke to Genise regularly and as a frightened carer she was invaluable to me. Nigel also called the helpline and spoke for hours about what he was feeling - everyone was so supportive, kind, and helpful. We referred to them as our lifeline.

Life now is very different to how it was previously. We see life through different eyes.



Nigel's memory is not as sharp as it was, and I must remember and take care of things I never used to deal with. Life for me now is tougher than it was before. The responsibility is heavy on my shoulders. Albeit I am very grateful he is doing so amazingly well in his recovery and I am blessed with a lovely family around me. I try to socialise as much as I can with friends to hold on to my identity.

Being able to talk to people who know what you're going through has been invaluable. Genise helped me to find the answer to any questions I had and if she didn't know she pointed me in the right direction to find it. Speaking to stroke survivors is useful, even if you are a carer. They can reassure you about what is happening in your life and help you understand what is happening to the person that you are caring for."

**If you would like to speak with us
call us on 0345 130 7172**

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dorset
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ottobock.

LIVING WELL AFTER STROKE WITH CHEST HEART STROKE SCOTLAND

In recent months Different Strokes has been working closely with Chest Heart Stroke Scotland (CHSS), to ensure that we can positively impact on the lives of young stroke survivors across Scotland. The highlight of this was a joint conference which we held in Perth in May, 'Living Well After Stroke'.



The event included inspirational talks from two stroke survivors, focus groups to identify issues that are most important to younger stroke survivors and workshops in areas including the journey back to work, dealing with stress & anxiety, managing money and the effect on children & family life. Seventy seven people attended the event, including three staff and two trustees from Different Strokes.

The feedback we received was excellent, and comments received included:

"Fantastic day. Really good to hear stories of how other people have coped, adapted and rebuilt their lives – so important to hear."

"The highlight for me was the final speaker describing how to let go of the old you after a stroke and move on with the new you."

We regard this event as just the start of our relationship with CHSS, and are talking with them about how further collaborations will enable us to jointly provide better services for younger stroke survivors. Going forward, we will be promoting each other's services where appropriate, looking at potential joint service delivery, and holding a further joint conference in 2020.

Equally excitingly... we have been part of a consortium led by CHSS, and also including Northern Ireland Chest Heart Stroke, which has successfully applied to be the 2019-20 Charity of the Year for Scotmid Co-operative. This will entail Scotmid employees raising funds for the three charities over the next 12 months, with monies raised via their SemiChem and Lakes & Dales stores in the North of England directly benefitting Different Strokes. A huge thank you to Scotmid for their support.

WHAT IS ATRIAL FIBRILLATION?

Atrial Fibrillation (AF) is an abnormal heart rhythm, characterised by rapid and irregular beating of the atria, the two upper chambers of the heart. It affects approximately 2% of the population, meaning that in the UK more than 1.1m have been diagnosed with AF. AF causes increased risk of heart failure, dementia or stroke – the risk of stroke is five times higher than in someone that does not have the condition.



How can AF cause a stroke?

When the heart is in a normal rhythm, there is a pocket at the back of the heart which contracts and empties fully with each beat. When it is in atrial fibrillation, though, the wall of this pocket does not contract. Blood can then pool in the pocket and when blood is stationary it tends to clot. A bit of clot can then break off and enter the circulation, where it may be carried into the brain and block an artery there, causing a stroke.

Causes and symptoms

AF can affect anyone, but there are certain factors that will increase the chances of developing it. These include high blood pressure, heart disease, excessive alcohol consumption, use of illegal substances, smoking, a sedentary lifestyle, and a family history of AF.

Symptoms can include heart palpitations, fainting, light-headedness, shortness of breath or chest pains, although often people with AF have no symptoms at all.

Diagnosis

AF can sometimes be detected by a healthcare professional checking your pulse, and if it shows signs of being irregular or very fast, this could be a sign that you have the condition. Further tests to confirm whether you have AF may include an electrocardiogram to test the electrical activity of your heart, an echocardiogram (a scan to view the structures of the heart), blood tests or a chest X-ray.

How to prevent stroke in patients with AF

Most people with AF are at increased risk of stroke. In many patients with AF, including for example those who have already had a stroke, the recommendation is to take a type of blood thinner called an anticoagulant. This kind of medication reduces the blood's tendency to form clots, thereby reducing the risk of stroke.

WHAT IS ATRIAL FIBRILLATION?

Anticoagulants include warfarin (a vitamin K antagonist) and direct oral anticoagulants (DOACs) which are also known as non vitamin k oral anticoagulants (NOACs). Studies have shown that anticoagulation is extremely effective at preventing strokes.

Over the past four years anticoagulation prescribing has increased by around 50%. During this period the use of warfarin has slightly decreased, while the use of DOACs has significantly increased. This trend has also led to a reduction in the level of ongoing monitoring which is required, as while the use of warfarin requires frequent monitoring by healthcare professionals - every day or two when it is started and then typically once a month - DOACs only need a check of kidney function once a year.

Between 2011 and 2016 the number of patients admitted to hospital with a diagnosis of AF-related stroke decreased from 98 per week per 100,000 patients to 86 per week. While this decrease is not down to any single cause, it is likely that the better identification of AF and greater use of DOACs are contributing factors.

Looking ahead, Public Health England and NHS England are focused on identifying more AF patients at risk of stroke and providing preventative treatment; over the next ten years they plan to increase the detection rates of people with AF from 79% to 85%, and increase adequate anticoagulation for people with AF and who are at high risk of stroke from 84% to 90%.

What option to take

If you are at risk of stroke due to AF you should discuss with your doctor your treatment options, along with their risks and benefits. It is very important that you disclose to your doctor any other medications that you are taking, and if you feel unwell after starting treatment you should similarly discuss this with your doctor, and not just stop taking your medication.

Accurate diagnosis of AF, and then receiving the appropriate treatment is very important; it is estimated that around 7,000 strokes could be prevented and over 2,000 lives saved every year if people with AF were adequately treated.



THE JACK RADLEY CUP: CHARITY FOOTBALL TOURNAMENT



Jack Radley nominated Different Strokes as the benefactor of this year's annual Jack Radley Cup, an annual charity football tournament held in Melbourne, Derby. A special thank you to Jules Raine and everyone involved in the organisation of the tournament which took place on 24th August. Everyone had a fantastic day and the event has raised in the region of £2,500, which is an amazing amount. We would like to extend a big thank you to everyone who sponsored the event, donated or took part.

Organisers said:



"We take so much pride in organising the Jack Radley Cup. To us, it's more than just a tournament, more than just a "kick about", more than "just a game". This year's tournament has already seen our community come together, with sponsors, raffle donors and volunteers... and well not just Melbourne, but across the U.K. The response for such a wonderful cause has been incredible!"



ABSEIL EVENT 2019

Saturday 14th September proved to be a memorable day for everybody involved in the Different Strokes abseil. Despite the nerves and fear everyone was in high spirits and raring to go. This is the third abseil event held by Different Strokes and it has become apparent that this event is about more than just raising money, it's about getting our community of stroke survivors and supporters together, facing fears, overcoming barriers and saying 'I can do this!' Almost £14k was raised which will truly make a difference to younger stroke survivors and their families. Thank you to everyone who took part, donated or volunteered on the day.

HOG FEST AT THE VINE INN



The Vine Inn in Hannington proudly hosted HogFest on the 24th August. Thank you to the organisers Jon and Jo Whitfield for choosing Different Strokes to benefit from the wonderful £500 raised on the day. Thanks also to the Vine Inn and the musicians.

Jo Whitfield said:



"My husband Jon has run HogFest for a few years. It is a music festival held in the large pub garden with a Hog roast to feed the music lovers! All musicians give their time freely and have great fun in helping to make it a special day.

This is the second year supporting Different Strokes, highlighted to us when a young friend, Hannah, had a stroke whilst training for a run. Emotional support and shared experiences for similar young people must help immensely."

Different Strokes is currently recruiting volunteer community fundraisers. The role of a community fundraiser is to seek opportunities in your local area to raise funds for Different Strokes. These opportunities could include holding bake sales, asking your local school to have a dress down day, asking your local pub to run a quiz night, attending craft/gift fairs and selling items made or donated and any other interesting and ingenious ways to raise funds. Our team of wonderful volunteers would be contributing to the running of our core services. Perhaps you could raise enough in a year to seed fund a new support group (£350) or to provide two information packs a month, for a whole year (£120). Every contribution will be supporting younger stroke survivors to reclaim their lives.

If you would be interested in this role please contact Jo Aurora for more information.

MEET THE FUNDRAISER



On 9th March 2019 Nigel Paling completed a park run. He had done the same run fifty six times before, but this time it was different. In April 2018, Nigel, aged 46, had suffered a life-changing stroke; this was the first park run he completed as a stroke survivor.

Nigel raised an amazing £1,640 for Different Strokes and we were lucky enough to meet Nigel and his wife Nicky at our offices in July. We found out more about Nigel and what inspired him to become a fundraiser.

"Immediately after my stroke, I couldn't walk and recovery has been a long process. I was discharged from the hospital within a week and whilst I was glad to be at home, we were shocked by the sudden lack of support available to me.

When we left the hospital, Nicky was given the name of a charity, Different Strokes. It was with the support of Different Strokes, that Nicky got the best care for me; they provided the most incredible listening ear when times were tough. Don't get me wrong, stroke recovery, both the physical and emotional, has to be driven from within, but some help, advice, direction and the occasional bit of tough love is needed!

I was back working full-time after 6 months and I am increasingly taking on more and more responsibility each day. I still have a visual field challenge that prevents me from driving. This may improve further, or it may not. My mobility is good and still improving.

I am thankful I am still here for my family and I have met many new people. I have completed cycle rides and runs in the past for charities, only now though do I fully appreciate the importance of what they do. This park run was a little slower than the many that I did before, I didn't set myself a target this time and I walked some of the way. It was all worth it because I wanted to give something back to those who have helped me and others like me."

We're also hugely grateful to Nigel for successfully applying for a grant from his employer, who have very generously donated £1,000 to Different Strokes to go towards training our new teen and young adult befrienders. Do you work for a company that operates a similar scheme or that runs a Charity of the Year programme? If so, please consider nominating Different Strokes!

ONLINE SHOP



We decided to expand our little online shop this Christmas. We asked members of our Facebook group what items they wanted to see and even had a vote on what slogan would be used on some limited edition totes and sweatshirts - 'Survivors Supporting Survivors' was chosen and we love it!

We also have a selection of Christmas cards and some beautiful gift items for all the family, all of which can be ordered now.

All proceeds from these sales will be supporting services for younger survivors. We hope you love everything as much as we do!

www.differentstrokesshop.co.uk



REMEMBER TO
**"Pass on
something
wonderful"**
BY LEAVING A GIFT IN YOUR WILL



REMEMBER A CHARITY
IN YOUR WILL WEEK

This September Different Strokes took part in the 1970's inspired Remember a Charity week, to highlight remembering charities in your will, and to dispel some of the common myths about writing a will.

For more information about leaving a gift in your will, please contact Jo Aurora on 0345 130 7172 or email jo.aurora@differentstrokes.co.uk

KEEP IN TOUCH

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