

Annual Review

2016-2017

Life after a Subarachnoid Haemorrhage

A one day conference for patients and carers

5 November 2016

The National Hospital for Neurology and Neurosurgery
33 Queen Square, London WC1N 3BG



Brain & Spine
Foundation

kindly supported by

christchurch
University Hospital
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Brain & Spine

Information

Support

Research

Education

Advocacy



Brain & Spine
Foundation

Note from the CEO

Whilst neurological conditions are often considered rare, there are, in fact, over 350 different conditions of the brain and spine that together affect more than 12 million people in the UK. In many cases these conditions have long-term impacts without the prospect of a cure.

A shortage of specialist support in the UK means that many people with neurological problems experience long waits for diagnosis, referral and treatment. This year, a survey by the Neurological Alliance found that for many patients their experience is actually getting worse. 42% of patients surveyed saw their GP five or more times before seeing a neurological specialist (31.5% in 2014), and 19% waited over a year to see a neurological specialist after seeing a GP.

The Brain & Spine Foundation was set up in response to a lack of services and support and sadly, 25 years on, the charity is needed more than ever. The emotional and practical support we offer helps to bridge the gap for patients and carers waiting to see a specialist. When symptoms first appear, throughout diagnosis and treatment and in the longer term, we're here to answer questions and provide expert support.

This year, increasing our income has allowed us to grow our support services and improve the lives of more people than ever. We have developed:

- specialist services and resources for people with conditions we frequently support, including subarachnoid haemorrhage, Chiari malformations and head injury;
- support groups and an events programme for patients and carers;
- our work with health professionals, to increase understanding and encourage them to signpost patients to our services.

As the stories in this review illustrate, our work has provided a lifeline for people who don't know where to turn. We're so grateful to everyone who contributed to this work; we couldn't do what we do without the hundreds of volunteers who help by fundraising, donating and raising awareness.

We want to be there for even more people affected by neurological problems, and we need your support to continue this important work. Enjoy reading our review of the year and consider; what could you do to help?



Alice Doyle
CEO Brain & Spine Foundation



At the **Brain & Spine Foundation**, our mission is to improve the quality of life of people affected by neurological problems, by providing expert information, support and education.

There are **four main goals** that drive our work forward:



1. **Provide expert support and information**

Our freephone Helpline is staffed by trained neuroscience nurses who offer information and support to anyone affected by a neurological problem, and our high quality patient information publications are also freely available to anyone who needs them.



2. **Raise awareness and improve understanding**

We are always working to build the Brain & Spine Foundation's national profile and raise awareness of the work that we do. We are committed to increasing understanding within both the health professional community and the general public of the impact that neurological problems can have on people's lives.



3. **Reach more people**

Our aim is to ensure that our services continue to reach increasing numbers of people who could benefit from them.



4. **Maintain sustainable income**

Reliable and diverse income streams are essential to ensuring that we can continue to fund our important work.

Our year in numbers

25

years supporting
people affected by
**neuro
problems**



101,940

**booklets and fact
sheets distributed to
people**



3,029

**people benefitted
from one-to-one
expert support**



170

**different
neuro topics
covered through
Helpline support**



662

**health professionals
in neurology reached
by our
Outreach
Programme**

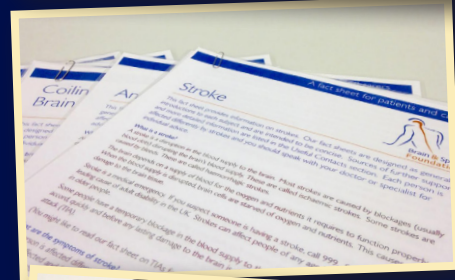


Provide expert support and information

We are passionate about providing services that reduce people's anxiety, boost their knowledge and understanding, and ultimately empower them to take control of their own lives.

Highlights from this year

- Supported 3029 individuals through our Helpline on 170 different neurological problems.
- Distributed 101,940 fact sheets and booklets accredited by the NHS Information Standard – almost 117% more than last year.
- An expanded team of three full-time neuroscience nurses, and increased Helpline hours, have increased the number of calls we answer first time. The Helpline is now available for 32 hours each week.
- Revised and updated 13 of our patient information resources and maintained our Information Standard certification, demonstrating our commitment to providing clear and reliable information for the public.
- Launched our first app, *My Brain and Me*, for young people with a brain injury (available free of charge on Android and iOS devices).
- Established a new Facebook group, *Subarachnoid Haemorrhage Group – A Space for You*, where people can share experiences and offer peer support.



82% of people felt more informed after using our services

93% of people were satisfied or very satisfied with our Helpline

95% of people were satisfied or very satisfied with our booklets and fact sheets

[Figures based on the results of 2016-17 beneficiary survey]



“The services have been invaluable”

The breadth of knowledge and experience of our brilliant neuroscience nurses means we are the only UK-wide charity providing support for all neurological conditions and problems.

Our expertise makes us one of the few places that people with a rare neurological condition can turn to, and we've become specialists in particular conditions, such as subarachnoid haemorrhage (a type of bleed on the brain).



Darren

Darren is one of the many people who reached out to us after he had a subarachnoid haemorrhage.

“The information, advice, understanding and reassurance provided to my family by the Brain & Spine Foundation during my recovery from a subarachnoid haemorrhage were essential. Their video on “What is a head injury?” is a must watch to understand this type of injury.”

Julie

After surviving her subarachnoid haemorrhage, Julie found support and information from the Brain & Spine Foundation offered her a lifeline.

“After the operation, the surgeon gave my husband some very helpful information from the Brain & Spine Foundation, about what had happened, the procedure and what to expect afterwards, which I still have today. He also recommended the website, which has been an amazing resource and comfort during my recovery.”

“The services have been invaluable: from the calls to the Helpline, to information for me or for passing on to friends and family so they could understand.”



"Contacting our Helpline can change people's lives"



Our freephone Helpline is open five days a week and is staffed by trained neuroscience nurses. It is a vital service for many people who are anxious, confused or just need somebody to talk to. Here, one of our nurses, Eva, explains what it's like to work on our Helpline.

"Each day is different on our busy Helpline.

The morning usually starts with phone calls – some days I've spoken to more than seven people by midday. In between calls, I answer emails sent from patients and those who care about them, and I arrange posting out any orders that we've received for patient information booklets. When I'm not responding to Helpline enquiries, I keep myself up to date with the latest neuro research and produce information articles for our website.

People will call us for various reasons. Some will be looking for guidance on their next steps following treatment or diagnosis; others will just want to be listened to, as they feel that their health worries will burden their family and friends.

It's not easy for everyone to pick up the phone and talk about their health and the impact it's having on their personal life with a nurse they've never met. However, by the end of our conversation, many callers leave with a sense of relief knowing someone has listened to them and with information to empower them in their recovery.

Many people who contact our Helpline don't know where to turn, and it is incredibly rewarding to be able to offer them the support they need to keep moving on with their lives. Contacting our Helpline can change people's lives, and it's amazing to be a part of that."



Life After a Subarachnoid Haemorrhage conference

On 5 November 2016, we ran the UK's first patient conference dedicated to subarachnoid haemorrhage (SAH) at the National Hospital for Neurology and Neurosurgery, London. Over 120 people from across the UK attended, travelling from as far as Aberdeenshire and Glamorgan.

Attendees heard presentations from specialists in neuroradiology, neuropsychology, clinical psychology and occupational therapy on topics from diagnosis and treatment through to recovery and coping with after effects.

The one-day conference gave attendees the opportunity not only to hear from specialist health professionals, but also to meet other people who've experienced an SAH.

"The conference was a life-changer for me, the speakers were fantastic and to meet and talk to other survivors was amazing. In three years, it was the first time I had met and spoken to others 'just like me'."

The event was kindly supported by Christchurch Group.

Plans for the future

- Expand the helpline team, to increase the number of calls we're able to answer first time.
- Increase our range of patient information resources to cover more topics, including back and neck problems.
- Develop the support we offer to individuals with neurological problems but no formal diagnosis.
- Grow our range of online support resources, including Facebook groups.
- Redesign our website to make it easier to use and compatible with mobiles and tablets.

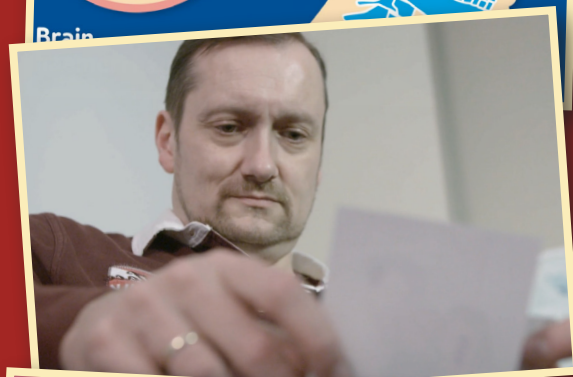


Raise awareness and improve understanding

Better awareness and understanding are the first steps towards improving services and support for patients. We are using our voice to draw attention to the true scale and impact of neurological conditions and to highlight the need for change.

Highlights from this year

- Produced two new videos – a film and an animation – to increase awareness and understanding of head injury and the after effects.
- Used our expert knowledge to comment on National Institute of Clinical Excellence (NICE) guidelines, including those for neuropathic pain and head injury, in order to improve the standard of services provided to these groups of patients.
- Supported the World Brain Day campaign to highlight the implications of neurological conditions for the health of the ageing population.
- Partnered with the Neurological Alliance and Brain Research Trust for Brain Awareness Week (13-19 March) to highlight the impact of neurological conditions and push for positive change.
- Got involved in social media campaigns for Transverse Myelitis Awareness Day, Spinal Cord Injury Day, World Alzheimer's Day and Purple Day (epilepsy awareness).



- Continued to represent the interests of patients with neurological conditions as members of Rare Disease UK, Brain Tumour Research Group and Wales Neurological Alliance.
- Joined the ABI Alliance, a new group of charities supporting people affected by head injury, working together in partnership to raise awareness and campaign for better support.



"We got my dad back again"

Alexina's story

"My father had a subarachnoid haemorrhage at the end of July 2016 that was almost fatal. I will never forget the Brain & Spine Foundation logo, as it was all over every kind of information booklet we were given. Because of the Foundation, as a family we felt informed and this was reassuring in such a worrying time.

Unfortunately, he began to deteriorate and we weren't getting adequate care at home and we were struggling to cope. My mother turned to the Brain & Spine Foundation and spoke to a nurse through the Helpline.

As a result of this phone call, my mother took my father back to hospital the next morning where he was admitted for emergency surgery to drain excess fluid that had built up on his brain. When my father came round from the surgery he was a new man. He could walk, talk, he knew where he was; we got my dad back again.

Without the Helpline my mother would never have had the courage or the inclination to take my father back to hospital so urgently and things may have been quite different."

Plans for the future

- Continue to campaign and work in partnership with other key neuro organisations and charities.
- Produce more videos and animations focusing on key conditions.
- Run a programme of events for patients, carers and health professionals to improve understanding and self-management of neurological conditions.
- Feedback on more upcoming NICE guidelines, to improve the care of people with neurological problems.



Photo credit: Flickr/SupportPDx



Reach more people

We are continuously striving to raise awareness of the charity amongst health professionals and the general public so that more people know about the services and support we can offer them.

Highlights from this year

- Enquiries to the Helpline have increased by approximately 12% since last year – that's 315 more people helped.
- We distributed 54,940 more information resources for patients and carers than last year
- Visits to our website have increased by almost 20%.
- 17% more twitter followers, with tweets reaching almost 87,000 people on a monthly basis (up 38% from last year).
- 25% more likes on Facebook and engagement levels up 147%.



Our **Outreach Programme** is all about connecting with health professionals, such as GPs, clinical nurse specialists and rehabilitation staff, so that through them we can reach and support even more people affected by neurological problems. This year has been very successful for the Outreach Programme.

- Directly engaged with 662 health professionals working within neurology.
- Delivered presentations to multidisciplinary neuro teams across London, including the Royal Free Neurological Rehabilitation Centre.
- Actively engaged with London's 'Neuro Navigator' system; a framework of clinical specialists working in the NHS who manage complex neuro patient pathways.
- Raised our national profile by attending the Therapy Expo in Birmingham (2000 attendees), a national conference of speech and language therapists, and the Neuro Rehab Expo (1000 attendees).



- 15% of our service users found out about BSF via a health professional – compared to just 6% in 2014, showing the difference made by this work.

The Outreach Programme is kindly sponsored by The Richard Burns Foundation.



Supporting health professionals

"Thank you for coming – the service the Brain & Spine Foundation offers is amazing."

– Clinical Service Lead Therapist in Neurosciences,
Charing Cross Hospital

"Our patients and their relatives find the booklets very helpful. They are also good to help with our learning and teaching."

– Advanced Nurse Practitioner in Neurosurgery,
Dundee Ninewells Hospital

"We are so impressed with all of your booklets. All of them are relevant to the patients we see."

– Rehabilitation Therapy Department,
St Austell Community Hospital

"I'm a GP and wanted to thank you for such an informative booklet, I know many of my patients have found it very helpful – as I have."

– General Practitioner, Bow, referring to our Dizziness and balance problems booklet



Plans for the future

- Develop the Outreach Programme to involve closer working with primary care, particularly GPs.
- Trial face-to-face support provision through a pilot programme at the Royal London Hospital.
- Exhibit at healthcare conferences across the UK to continue building our national profile.
- Develop and pilot an 'outreach pack' for primary care settings.
- Ensure all specialist neuro centres and neuro-rehab centres across the UK have access to our resources.



Maintain sustainable income

We are constantly working to raise more money to invest back into the charity's services. We deeply value our many supporters who donate and raise funds, and we work hard to ensure that our fundraising practices are respectful to their dedication and commitment.

Highlights from this year

- Legacy donations amounted to £409,000, many coming from people who benefitted from our services.
- Participation events raised £170,000, reflecting the dedication of our volunteer fundraisers.
- Grant-making trusts and foundations donated £119,000 towards our work – an increase of 80% on the previous year.

- **The Henry Smith Charity** is supporting us by generously funding our Helpline and Information service for a three year period.

- **The Masonic Charitable Foundation** has kindly agreed to support another of our three nurses over two years.

- **Christchurch Group** sponsored our one-day patient conference, Life After a Subarachnoid Haemorrhage; the UK's first conference on this topic.

- **Hudgell Solicitors** sponsored our two new educational videos: 'What is a head injury?' and 'Understanding head injury'.

- **The Richard Burns Foundation** sponsored our Outreach Programme, improving connections between health professionals and the charity.



Head Injury in Sport gala dinner

Our Head Injury in Sport gala dinner raised a staggering £110,000. The event was supported by the Professional Footballers Association and an array of sports stars, including David Coulthard, Johnny Herbert, Damon Hill, Brian Moore, David Seaman and Michael Watson.



25th Anniversary Supporters Reception

This year we hosted our 25th Anniversary Supporters Reception to show our appreciation to our fundraisers, donors and sponsors. Special guest, TV chef and 'Hairy Biker' Si King, spoke about his own experiences of a subarachnoid haemorrhage and emphasised the need for better awareness of neurological problems and the ongoing support that is available.

London Marathon

The London Marathon team raised £107,000, in partnership with The Daily Telegraph and team captain Brian Moore, former England rugby hooker. Runners benefitted from expert advice from Gary Lewin, former lead physiotherapist to the England football team, and post-race massages from the Runningods of Marylebone Physio.



"I'm proud to be a 'chiarian' and raise awareness of neurological conditions"



Jamie's story

Jamie contacted us after being diagnosed with a Chiari malformation at 22 years old (a rare neurological condition where part of the brain extends out of the bottom of the skull). Jamie raised vital funds to support our work and raised awareness of neurological conditions amongst young people.

"I was told I'd never be able to run long distances again due to my balance and coordination, but on 2nd October 2016 I completed the great Scottish Run in aid of the Brain & Spine Foundation, even though I walked it."

"I take on each day as it comes and I am proving myself and everyone wrong on a daily basis. I'm proud to be a 'chiarian' and raise awareness of neurological conditions."

Plans for the future

- Secure necessary funds for the Brain & Spine Foundation's ambitious plans, including funds to hire an additional Helpline and Information Officer to enable further expansion of our support services.
- Diversify our funding base further by growing income from companies and community fundraising.
- Get to know our current supporters even better and attract new supporters.
- Expand the fundraising team to increase capacity to raise funds from grant-giving trusts and foundations.
- Ensure our policies adhere to the Fundraising Regulator's new Code of Conduct for fundraisers.
- Prepare for new General Data Protection Regulations that come into force in May 2018.



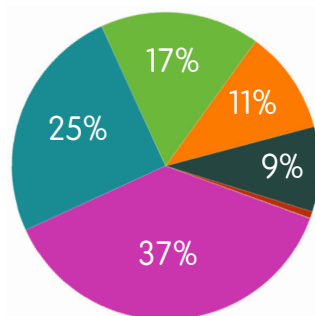
Financial report

This year, we continued to diversify and grow our income for a sustainable, long-term future. It is with great pride we can announce that **our income reached over £1 million for the first time ever.**

As has always been the case, we receive no government funding and remain very grateful to all our volunteers and supporters who have helped us to reach this milestone. Our fundraising efforts increased across a number of streams, including a very successful gala dinner; support from trusts and participation events, such as the London Marathon. We also received a large number of legacies this year, many from people who had been supported by the Brain & Spine Foundation.

Investment in fundraising this year has enabled us to grow the team and launch new fundraising programmes, which has increased our costs in the short term and will pay dividends in the coming years. Surplus healthy reserves at year end have allowed us to designate funds to invest back into the charity's work, which is reflected by the ambitious future plans detailed throughout this review.

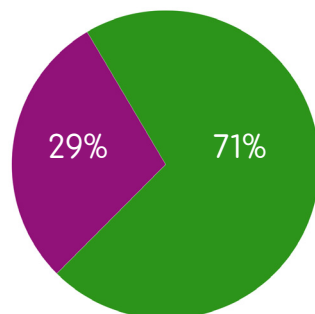
Income breakdown



£409,416 | legacies
£272,685 | fundraising events
£182,797 | gifts in kind
£118,900 | charitable activities
£97,441 | donations and appeals
£8,146 | sponsorship / other earned (0.6%)

£1,089,385 | total income

Expenditure breakdown



£245,076 | raising funds
£600,734 | charitable activities

£845,810 | total expenditure



Thank you

With thanks to all our supporters, especially Alex Beard, Alexander Mosley Charitable Trust, Christchurch Group, David Phillips, Fiona & Rod MacLean, Henry Smith Charity, Hudgell Solicitors, the team at Influence Sports and Media, John Kedge, Masonic Charitable Foundation, Professional Football Association, Richard Burns Foundation and The Spine Surgery London.

We would also like to thank everyone who was involved with and supported our gala dinner, especially the organising committee, Peter Hamlyn, Gary Lewin, Amanda Walsh, Alistair Watkins and Chris Welch.


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