



How the Brain Charity
can help you:

at a difficult time





A letter from our CEO...

**Nanette
Mellor**



Dear friend,

I wanted to let you know about our charity and how we can help.

The Brain Charity offers emotional support and practical help to parents or children who have been affected by a neurological condition.

We have two dedicated staff members who support families receiving care from Liverpool Women's' NHS Trust.

It might be that you have received some really bad news, or you may be facing a tough journey ahead. We hope that by being able to help with some of the practical issues you need to think about, we can support you to take the time you need to get through the coming weeks and months.

We can help you find your way around medical and social care systems or gather information together for you on different topics. We can also support you to sort out money problems, issues with work or help to make important decisions.

We can also help you fill in forms, arrange appointments and even sort out car parking if that's what you need us to do.

All you need to do is pick up the phone or send us an email letting us know you need help, and we will be in touch as soon as we can.

We hope it goes without saying too, that if you need someone to talk to, we will of course be there for you.

All the best,

Nanette Mellor
CEO, The Brain Charity



About The Brain Charity



The Brain Charity is a national charity based in Liverpool city centre. We help people with all forms of neurological condition to lead longer, healthier, happier lives.

Each year, we provide practical help, emotional support, and social activities to thousands of people from all over the UK.

There are more than 600 conditions affecting the brain, spine and nervous system; we're the only national charity to be here for every single one.

For someone newly diagnosed with a neurological condition, life can quickly become very lonely and frightening. People lose control of their lives and many face unemployment, poverty and social isolation.

At The Brain Charity, we help anyone affected by a neurological condition to pick up the pieces so they can rebuild their lives and achieve their potential.





By your side at Liverpool Women's Hospital

If you're having to spend a lot of time in hospital or have recently had some bad news, things may feel frightening.

The Brain Charity has two Information and Advice Officers, Sue and Maria, dedicated to supporting patients at Liverpool Women's Hospital affected by neurological conditions, genetic illnesses and brain injuries.



Maria, left, and Sue, right, The Brain Charity's Information and Advice Officers based in The Women's Hospital

They will provide one-to-one support to parents affected by new diagnoses or the loss of a child.

It's easy to feel overwhelmed by medical jargon. Our staff can tell you in plain English what a diagnosis means.



They can help you apply for emergency funding (if eligible) for travel and toiletries, grants, welfare benefits and adaptations to your home.

They can also assist you to make calls to loved ones and organise other arrangements so you don't have to worry, and are also there to give you emotional support and offer a listening ear.

Our Information and Advice Officers can support you with managing caring responsibilities and knowing your rights at work – as well as help you get expert legal advice.

They can also introduce you to a like-minded community via The Brain Charity's other services, such as free counselling, befriending, social activities and support groups.



Ask hospital staff to put you in touch with The Brain Charity's staff at The Women's Hospital today.

Alternatively, email womens@thebraincharity.org.uk or call our free helpline on 0800 008 6417.



How we can

Support your mental health

At The Brain Charity, we work with a wide range of issues affecting mental health, including bereavement, PTSD, anxiety and depression.

We offer free eight-week counselling courses and our trained counsellors understand the issues you may experience. They offer a range of psychotherapies, including CBT, person-centred and integrated.

Your counsellor will work with you as an individual to meet your needs and provide a safe space where you can talk about your problems and feelings.



Counselling appointments are scheduled between 9am and 5pm, Monday to Friday and can take place in our centre in Liverpool, via video call or over the phone. If you're feeling lonely and would like someone to talk to, The Brain Charity also runs a phone befriending service. One of our friendly volunteers can call you each week for a chat to make sure you aren't left on your own.

Helping you

Prepare for appointments & meetings



Receiving a serious diagnosis or having a loved one who is extremely unwell can throw up endless challenges, which might sometimes leave you feeling like you have a mountain to climb.

The Brain Charity's Information & Advice Officers can help you prepare for medical appointments and meetings, so you feel ready to advocate for yourself and your

family and ask the right questions to receive the information you need.

Knowledge is power, so we can provide information about the nature of different neurological conditions and their impact. They can also explain complex terminology phrases in plain English so you understand what medical professionals are referring to, and help you come up with a checklist to take with you to your next meeting.



How we can help:

Marie's story



When Marie was going through an incredibly traumatic time, she found The Brain Charity's emotional support life-changing.

In 2015, the 45-year-old was diagnosed with a golf ball-sized meningioma brain tumour less than six weeks after giving birth to daughter Amelia.

The mum-of-one underwent 3 brain surgeries before battling meningitis. She was also diagnosed with chiari malformation and hydrocephalus and had to learn to walk again.

Amelia, now 6, was diagnosed with severe learning disabilities before her first birthday;

she has global development delay, epilepsy and is non-verbal.

Marie said the free counselling she received at The Brain Charity was a lifeline – in helping her come to terms with not just her own experience but Amelia's diagnosis too.

She said:



"At one point I was waking up and didn't want to be awake. I was in a dark place.

"My counsellor was absolutely amazing and supportive, it was the best thing I could ever have done.

"The Brain Charity gave me an incredible gift – it was life-changing.

"I needed a specialist who understood neurological conditions – not many people know what a wide-reaching impact they can have.

"They helped me put the pieces of my brain back together."



The importance of looking after yourself during a difficult time



If you have experienced a difficult or traumatic event or diagnosis, it may feel like the overwhelming feelings you are struggling with may never end.

Self-care – looking after yourself to keep mentally and physically well – is of vital importance at this time.

Here are six simple things you can do to help ensure you are meeting your own needs and setting yourself up for emotional resilience.



Give yourself time

It may feel like a huge cliché to be told ‘time is the greatest healer’ at times of hardship, but in this instance it is definitely true. Don’t rush into feeling like you have to force yourself back to work, socialising or any sense of normality after experiencing something traumatic. Allow yourself time to sit with the feelings, process what has happened and start to come to terms with it.



Notice how you’re feeling

It’s important to be aware of your feelings as they are very powerful and should not be ignored. Feelings of depression and anger are part of the recognised stages of grief, and trying to discount or dampen them will only result in you feeling worse further down the line. Allow yourself time to sit with your feelings and notice how your thoughts and emotions change day-to-day. A journal can be a useful way of capturing this.



3

Talk to someone – whether professional or support group

Don't bottle things up – make sure you have someone you can talk to. This might be a counsellor (The Brain Charity provides free counselling), trusted friend or family member. If you are hoping to speak to someone affected by the same issue or diagnosis as you, check out The Brain Charity's support groups.



4

Don't be afraid to ask for help

Many people may want to help, but feel unsure how to bring up the subject or worried they might not use the right words. Don't be afraid to ask them for practical help, or emotional support – whatever you need. Whether it's a catch up over a cup of tea or a supermarket trip for you, they are probably glad to have been given something they can do to help.

5

Stick to routines as best you can

You are probably feeling as though your sleeping, eating and exercise patterns are completely all over the place. Sticking to your routines and trying to keep yourself as physically healthy as possible by eating well, engaging in gentle exercise and getting enough shut-eye will make a huge difference to how you're feeling.

6

Make plans to ensure you're not spending too much time alone

Book plans in the diary to ensure you're not spending too much time alone. Why not pop into our centre? The Brain Food Café is open every week day and our regular social activities are a great way to meet new people.



Read more stories and blogs about neurological conditions at www.thebraincharity.org.uk/news

How we can help:

Donna's story*



Donna's granddaughter Amy* was born in April 2021 with agenesis of the corpus callosum, a brain condition where the two hemispheres of the brain do not merge together properly.

This rare congenital condition can cause a variety of symptoms, and in Amy's case means she has complex needs, is registered blind and will need extra support when she starts school.

Amy's mum Eva* was naturally very shocked by the diagnosis, but she and her husband quickly started to grapple with Amy's medical needs.

They also have a three-year-old daughter and had an enormous amount to contend with, so asked Donna, Amy's grandmother, to look for support available.

Donna approached The Brain Charity when Amy was five months old, initially looking for help to find an appropriate therapeutic intervention for the youngster.

The Brain Charity's Information and Advice Officer Maria signposted the family to a local conductive education centre who could provide 12 months' free holistic therapeutic interventions for Amy.

Maria also provided information to Donna and Eva about the financial support they were entitled to, including special educational needs funding, a disabled facilities grant for adaptations to their home and welfare benefits.

Donna said:



"It was so good to talk to Maria. I felt much better for having done so as she had so much vital information and knowledge, which was incredibly helpful to our family."



* Donna, Amy and Eva are all pseudonyms.

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or email communications@thebraincharity.org.uk

Get in touch



Find The Brain Charity's centre



The Brain Charity
Norton Street
Liverpool, L3 8LR



Opening times:
Monday - Friday
9am - 5pm



Our centre in
Liverpool is fully
wheelchair accessible.

Parking is available for Blue Badge holders and we are close to Liverpool Lime Street station and multiple bus stops.

Find more directions at

www.thebraincharity.org.uk/findus
or call reception on 0151 298 2999

Contact us



The Brain Charity has staff based in Liverpool Women's Hospital. Ask your ward to put you in touch with us.

Alternatively, to speak to our staff email womens@thebraincharity.org.uk
or call our free helpline on **0800 008 6417**.

www.thebraincharity.org.uk | National support for all neurological conditions

    @TheBrainCharity

Charity number: 1114999