



The
Brain
Charity



How the Brain Charity
can help you:

with your new arrival





A letter from our CEO...

Nanette Mellor

Dear friend,

Firstly, I wanted to say congratulations. Having a baby (or babies!) is one of the most rewarding, challenging and exciting times of our lives.

For most of us, the love we feel for our little ones is unparalleled and gives us a new purpose and meaning in life.

You may not have heard of The Brain Charity before. We have designed this pack to say 'hello' and let you know a little about how we can support you on your journey. The Brain Charity offers emotional support, practical help and social activities to parents and children who have a neurological condition.

We have two dedicated staff members who support families receiving services from Liverpool Women's NHS Foundation Trust. It might be that you have been informed that your child has or could have a neurological condition, or that you yourself have one. In either case, our staff will be able to help with some of the practical issues you might need to think about and support you to take the time you need to look after yourself and your baby.



We can help you find practical information about a neurological condition, navigate your way around health and social care systems, put you in touch with other families and help you make decisions on important issues.

All you need to do is pick up the phone or send us an e-mail to let us know you need help, and we will do our very best for you. You can find our contact details on the back page of this leaflet.

We very much look forward to meeting you and your family,

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 during a pregnancy or after a new arrival, 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.

They will provide one-to-one support to parents and with babies who have neurological conditions, genetic illnesses and brain injuries, as well as pregnant women with neurological conditions.



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

It's easy to feel overwhelmed by medical jargon. Our staff can tell you in plain English what a diagnosis means and what living with a condition might look like.

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 your ward, midwife or consultant 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.

The Brain Changer

Arts Project

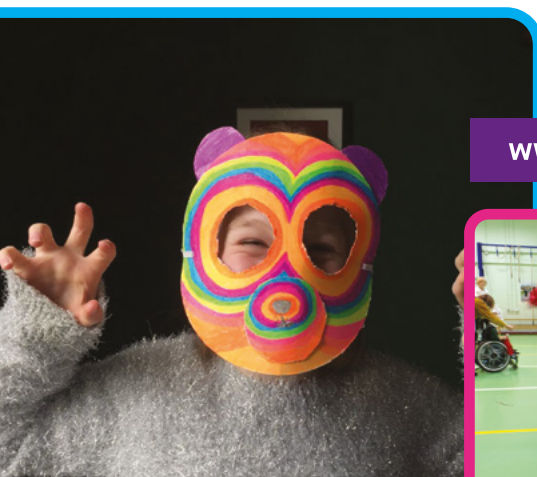
The Brain Charity also runs The Brain Changer Arts Project, which provides free workshops for young people with neurological conditions across Merseyside.

The fun, innovative and rewarding sessions provide physiotherapy through dance and occupational therapy through art and craft to help kids and young people engage with vital therapies in an enjoyable format.

This improves communication, confidence, fine motor skills, dexterity and hand-eye coordination.

Find out more at

www.thebraincharity.org.uk/children



Occupational
Therapy through
Art and Craft

Physiotherapy
through Dance

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.



How we can help:

Sarah's story

In 2014, Sarah suffered a head injury which caused a serious brain trauma. Her neck and walking were affected and she developed spasms, tremors, fits, paralysis and fatigue.

Eventually, Sarah was diagnosed with dystonia - a condition which causes involuntary muscle spasms - and Functional Neurological Disorder (FND), the name given for a variety of medically unexplained neurological symptoms.

Sarah struggled with feelings of isolation after having to give up her job, but found solace in The Brain Charity's social activities.

When she recently discovered she was pregnant after going through IVF therapy, she let our staff know so they could support her if needed.

Due to her conditions, when she became pregnant Sarah was offered extra scans, joint appointments with a specialist obstetrician and neurologist, neuro-physiotherapy and a planned caesarean section.

She said:



"The Brain Charity has supported me through so many situations - I'm so grateful for it.

"I've felt really supported at The Women's too - pregnancy has been a massive change, but I've been able to feel excited and positive as a new mum, not someone defined by their disability.

"If you are pregnant and have a neurological condition, I'd definitely advise you to come and speak to The Brain Charity's staff at The Women's Hospital - every different condition is a different journey, but they can cater for your individuality."



Six things no one tells you when your child is diagnosed with a neurological condition



A mum whose daughter had a postnatal stroke 12 hours after she was born shares her advice

Caring for someone you love can be overwhelming, especially when it involves a life-changing diagnosis. Michelle's daughter had a postnatal stroke 12 hours after she was born, which resulted in her developing epilepsy. Though everyone's experience is unique, these are Michelle's six top tips for parents caring for children with neurological conditions that she wishes she had known as a new mum.

1

Google isn't always your friend

Of course it is important to do your research when it comes to looking into your child's condition. Google is certainly the easiest way to find information, but it isn't always the most reliable. There are some people out there trying to sell products that they'll convince you are necessary for your child's health. This is where it is important to have a community around you who can help you filter out those with a less than helpful motive for 'support'.

2

Be honest with yourself about your emotions

As a parent, it's natural to have hopes and dreams for your child and often we don't even realise what they are until we are faced with the possibility that all might not all be possible. You want your child to have as smooth as path as possible through life, so when you learn your child might not be able to do everything other children might be able to do, grief is only natural. Every time you get a new piece of information the process feels the same, you grieve for what could have been then remind yourself of the delight of what is right in front of you. Be excited for the future but at the same time be honest with yourself about your emotions. It's okay not to be okay.



3

It isn't all about what they can't do

Society has a habit of looking at the world through a 'deficit-based process', where we judge people and things by what they can't do. Instead, we should look at what they can do and at all the incredible abilities your child has available to them. This will help you paint a mental picture of what they might be able to do, rather than what they might have trouble with doing.

In addition to this, it helps to assume your child either can or will be able to do something and then give them all the support they may need to do it. This helps to cultivate a mindset in both yourself and your child that 'practice makes permanent'. Learning to express themselves through art and music, instruments and even dance will help build new neural pathways. These new neural pathways will help the child with their development in the long term. Just one minute a day can be enough to help in spectacular ways so remember, little and often is key.

4

Support groups can be useful

Support groups can be vital for emotional support and practical help. Some of those at support groups will have already faced the same barriers you are facing and will have great advice or be able to share their experience with you. However, bear in mind that while the people there are going through a similar situation to you, none of you are going through the exact same thing – what works for them may not work for you, and vice versa.

5

Work on activities

Talk with your child's pediatrician or physiotherapist to develop an activity plan of activities to suit your child's abilities and how often your child can do them per day. For babies, you may be able to start working on tummy time activities and midline crossing activities as soon as possible. Repeat tasks little and often – less is more (remember neural pathways). These activities are essential for the development for any child, by setting some time aside to really focus on doing them regularly the long term results you will see from your child will be nothing short of amazing. Make them fun, quick, varied and engaging. Stick with them and the results will speak for themselves.

6

See the person in front of you

Finally, it's easy to feel a bit hopeless when you read your child's report. The way these reports are written may inadvertently encourage you to think your child will grow to be capable of very little. Your child is capable of incredible things. These reports are important diagnostic tools that help us care for our children and to access funding they may need, but they can't capture everything about your child; their creativity, their adaptability.

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



My daughter had surgery to disconnect the right side of her brain – it's never held her back

Lisa shares daughter Angelina's journey with Sturge-Weber syndrome and hemispherectomy

Lisa's daughter Angelina, now 12, was born with a rare neurological condition called Sturge-Weber syndrome (SWS), which affects the skin and nervous system. Lisa and Angelina's dad Stephen struggled to get an SWS diagnosis, and when they did, struggled to find information and support.

Lisa said: "It would have taken so much stress from us if we'd had someone to talk to, like the Brain Charity's support workers based at Liverpool Women's Hospital. Instead, I had to trawl the internet. You don't just see positive articles, so it can be a very frightening and lonely time."

When Angelina was 13 months old, she had a hemispherectomy operation to disconnect the right part of her brain, which was causing frequent seizures and stroke-like episodes due to her condition.

Lisa said: "Angelina had surgery when she was 13 months old, a day I'll never forget, but thankfully now celebrate. She will always battle daily with complications, but, importantly, she remains seizure free."



Over the years, Lisa has raised awareness in newspapers, magazines and on TV. In 2012, she carried the Olympic Torch through her local area to raise awareness of SWS.

Lisa said: "Angelina will never regain sight in the left side of both eyes or be able to use her left hand for fine motor skills due to the right side of her brain being affected. Despite this, she thrives with determination and doesn't let her disabilities get in her way."

"I am so proud of what she has accomplished and achieved. She has taught me so many things in the last 12 years, and I feel privileged to be her mum."



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Easy



Read

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Text

Or another format or language?

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

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