

BRIAN: Our global brain tumour databank

Patient Information Sheet (for a child aged 0-11 years)

To be shown and read by parent/guardian if required

We're asking whether you would like to share some information about your brain that we will keep safely in our new database called BRIAN. Your parents will use a web app on their mobile phone or computer to share with BRIAN how you're feeling, and to help look after you. BRIAN will also pass your information onto scientists and doctors, with information from lots of other children, to help with their research or work.

Before you decide if you'd like to take part and share your information with BRIAN, it's really important that you understand what we are doing, why we are doing it and what it will mean if you take part. Please read this leaflet carefully with your parents and speak to your doctor, nurse, family or friends about it.

If you have any questions you can ask your parents to call us on the details at the bottom of this leaflet and we will discuss it with you.

1. What are you doing?

We're asking anyone with a brain tumour like yourself, to let us have a copy of the information that the doctors and hospitals have about your brain. We will then hold a copy of it in our databank called BRIAN (a secure computer that stores information). We're also asking your parents to tell BRIAN how you're feeling after you've taken some medicine or been to the hospital. They will use a web app on their computer or phone to do this.

BRIAN will keep all of this information about you and your brain and will store it safely. When other people want to find out more about brain tumours, they will be able to ask BRIAN to share your information, along with information from lots of other children with the same tumour. They won't be able to see your name or any details about just you.

2. Why do you want me to help?

You have been asked because you have a little lump inside your brain called a brain tumour. It is made up of cells, or building blocks, that have grown when they shouldn't have.

The scientists want to understand why they have grown and how to stop them from growing. The tests, or research, that they do will be much better if they have information from lots and lots of people like you with the same type of brain tumour. That's why we're asking you and anyone else with a brain tumour to share their information with BRIAN.

It will also help the doctors and nurses know what might help other children with the same tumour as you.

And one more thing. It will also help other children with the same tumour and their parents know what to expect.

3. So, why are you doing this?

We're collecting as much information from as many children and grown-ups with brain tumours as possible. All of this information will be really useful to help lots of different people.

Your parents might want to see how other children with the same brain tumour feel after a trip to the hospital or taking a particular type of medicine.

Doctors will want to see how other children with brain tumours feel after their treatment or operation so that they can give you the best treatment.

Also, scientists doing research will want to test their questions on everyone's information to help find a cure for brain tumours.

4. Who will see the information about me?

When we collect a copy of your information BRIAN will store it safely and will only share it with people who need to see it. It will be anonymous or secret, so they won't be told your name.

The types of people that might need to see information about your brain are:

Doctors
Scientists
Parents

5. Do I have to take part?

No you do not. It is up to you. We would like you to read this leaflet. If you agree to take part, we will also ask your parents or guardian to fill in a form called a "consent form". You can still change your mind later. If you don't want to take part, just say no.

6. What if I change my mind after I've said 'yes'?

Just tell your parents or guardian at any time and they will contact us at the details included at the bottom of this leaflet. You will still get the same care and you won't upset anybody.

Your parents, guardian or another grown-up you trust may be able to answer your questions. The doctors and nurses looking after you can also help you find out more. Or you can ask your parents to contact us by phone on 01252 413164 or email at brian@thebraintumourcharity.org.

Thank you for taking the time to read this – please ask any questions you have.

If you have any questions, please call us on 01252 413164, email us at brian@thebraintumourcharity.org, or write to us at The Brain Tumour Charity, Hartshead House, 61-65 Victoria Road, Farnborough GU14 7PA.

Why not have a go at our very own word search? Good luck spotting all of the words listed below!

M M D M C E Y B R A I N	SHARE
N I N F O R M A T I O N	WEBAPP
A B N U H A L R Y V S R	BRIAN
O V P Y U H A W I F D K	BRAIN
R B G H D S T G G B R W	DOCTOR
W M K W W R O T C O D B	HOSPITAL
T E T S I T N E I C S C	INFORMATION
O R B W O R L W A C R T	SCIENTIST
W D G A R B D B R I A N	
I D J O P Y F R E L C J	
J C F U N P V I Y U M I	
L A T I P S O H D G D J	