

Learning difficulties in children with brain tumours

Children who have, or had, a brain tumour, may develop learning difficulties at some time.

This could be due to a number of reasons - the side-effects of the tumour and its treatment, the periods of absence from education, or the indirect effects, such as anxiety and lowered confidence, caused by missing out on normal school life and not keeping up with their friends. They may require some extra help.

This fact sheet gives an overview of some of the learning difficulties your child may experience as the result of a brain tumour and also of the support and possible plans of action (strategies) available to help them in their learning.

In this fact sheet:

- Is my child likely to have learning difficulties?
- What sort of learning difficulties might my child have?
- What support is available and where do I find it?
- Answers to some common questions you may have about learning difficulties

Is my child likely to have learning difficulties?

Unfortunately, many children are likely to be affected in some way¹.

Important points to remember

- Not all children with a brain tumour will have learning difficulties
- The learning difficulties may be mild
- The learning difficulties may be only temporary
- Learning difficulties may be a secondary effect
 - your child may still have good memory and thinking skills, but may fall behind due to missing school or feeling too tired
- There are many strategies that can be used to help your child if they have any learning difficulties
- Being aware of the possible learning difficulties can help you spot them and get help early

There are several factors which can affect how likely your child is to have learning difficulties.

Generally speaking, the younger your child is when they are diagnosed (and treated), the more likely they are to develop learning difficulties, particularly if they are under three years.

This is because their brain is still growing and developing, and so is more susceptible to being affected by treatments.

This is particularly the case with the radiation used in radiotherapy, and is why radiotherapy is not often included in the treatment for the under three's. Particular careful consideration is also given for children under five years.

¹ *Losing My Place: The Reality of Childhood with a Brain Tumour*, The Brain Tumour Charity, 2015

Please see the *Radiotherapy for children* web page and fact sheet for more information.

Sometimes learning difficulties may not develop, or may not become obvious, until a few months or even years later. This is called a 'delayed effect'.

What learning difficulties might my child have?

Each child is different and much will depend on where their tumour is in the brain. This is because different parts of the brain control different parts of learning.

For example, a tumour in the 'parietal lobe' might cause difficulties with writing, reading or understanding language.

For information about the lobes of the brain and their functions, see *The human brain* web page and fact sheet.

The age of your child and the size of their tumour may also affect their type of learning difficulty.

Common learning difficulties in people with brain tumours include issues with:

- Short-term memory, meaning that your child may struggle with multiplication tables, grammar or foreign languages, for example
- Reasoning and problem-solving, including using knowledge gained in one situation and applying it in another situation



- Delayed processing speed, meaning your child will take longer to work things out
- Attention span, making it difficult for your child to listen to what their teacher is saying for lengthy periods, or to concentrate on reading for a long time, for example.

And all these can be made worse by fatigue - another common issue for people who have or had a brain tumour.

You may find this upsetting – it can be a difficult time for both your child and for you.

It is important to remember that having learning difficulties does not mean that your child is now less intelligent, but rather that they have difficulty recalling or processing information.

Your child may feel frustrated, anxious and stressed. Their self-esteem may take a knock, and time out of school for hospital appointments, both in terms of missing lessons and being away from friends, can affect their social development.

These emotional impacts can negatively affect your child's learning. As a result, they may need support to cope with the emotional impacts of having a learning difficulty before the difficulty itself can be addressed.



The sooner your child's difficulties are identified and dealt with:

- the less their education will suffer
- the more successfully they will learn
- the less their self-esteem and self-confidence will be affected

What should I do if I think my child has learning difficulties?

There are various ways that your child's learning difficulties may come to light. These may include your own observations as a parent or carer, or from teacher observations and reports.

Some treatment centres offer neuropsychological testing before and after treatment to check for any early signs of learning difficulties. Speak to your child's health team about this.

The health team can also be a good source of information about finding alternative sources of education if your child cannot go back to school, either at all or in the short term. (Hospital schools can bridge the gap if they are in hospital.)

It may take some time for a learning difficulty to be identified if it is subtle. It is also possible that a learning difficulty may become more pronounced as your child grows and attempts more complex tasks.

Alternatively if your child has had radiotherapy, the learning difficulty may develop later, so the gap between your child and their peers may grow.



In the first instance, talk to your child's teacher/tutor.

They can discuss your concerns and give feedback on how your child is doing in the classroom. They should work closely with you if concerns arise.

The Special Educational Needs Co-ordinator (SENCO) for your child's school should be involved as soon as your child goes back to school. Their role is to make sure that children with special educational needs and disabilities within a school receive the support they need.

They can co-ordinate the support for your child and involve other professionals, such as educational psychologists.

There is a lot of support available for children with learning difficulties, but sometimes it is difficult for parents and teachers/tutors to know what is available, what you are entitled to and where to find it.

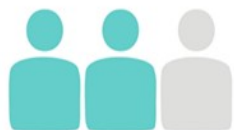
Nurseries, schools and colleges want to be supportive, but sometimes lack of awareness of rarer health conditions and their effects on learning ability, adds to the problem. This can be the case with brain tumours.

In addition, these problems may only become evident many years after treatment, which other professionals may not realise.

It is also easy for communication between busy teachers/tutors, healthcare professionals and parents to slip.

As a result parents may have to be proactive in making sure their child gets the support they need.

To help give parents and teachers (and, where appropriate, the young person themselves) the information, knowledge and confidence to work together to overcome these issues, The Brain Tumour Charity has created a set of practical, downloadable **Education Resources**. Find them at thebraintumourcharity.org/education-resources



Nearly two-thirds of those whose education has been affected needed extra help and support

Resources for returning to nursery, school or college

We have developed education resources that can provide help and support to a child, their parents and teachers when they return to school following a brain tumour diagnosis or treatment.

These resources:

- Are specific to brain tumours
- Can be individualised to suit your child's particular support needs

They include:

- Symptoms and behaviours to look out for
- How to plan effective support
 - for their learning, emotional and social needs
- Effective support strategies
- Legal rights and responsibilities

In short, they can be used with your child's teachers and healthcare team to reduce the negative impact that brain tumours can have on a young person's educational life.

They can also be used to provide evidence for other, more formal, support strategies.

What other support is available to help my child?

There are a variety of other means of support that can be used alongside the education resources to help your child with their learning and social development.

Support from an Educational Psychologist (EP)

Educational psychologists help children or young people who are having problems that get in the way of their learning and of taking part in school and other activities. These problems can include emotional and social problems as well as learning difficulties.

They will watch and talk to your child and give them various tests. From this they work out what difficulties your child is having and work with you, your child and the teachers to put measures in place to support your child's learning.

This could include one-to-one support in certain subjects, advising teachers on teaching styles and techniques that may help your child, or referring on to another health professional, such as a speech and language therapist.

They can also give in-house training to teachers on issues such as behaviour and stress management.

In addition, they can write formal reports and attend case conferences to help put in place more formal support strategies. This includes Education, Health and Care Plans (EHCPs) or Statements of SEN (Special Educational Needs).

Different schools have different arrangements with the Educational Psychology Service in their area and the waiting time for an appointment with a local authority EP can be long.

It is possible to employ a private EP, but their costs can vary enormously, so, if you choose to do this, it is worth getting a few quotes.

Speak to your child's school about the educational psychology services available in your area and how to access them.

**Education, Health and Care Plan (EHCP),
Co-ordinated Support Plan (CSP)
or Statement of Special Educational Needs (SEN)**

Much of the additional support your child may need can usually be provided through the normal learning and teaching that takes place in the class.

Using the various strategies listed in The Brain Tumour Charity's **Education resources** can help.

Find them at **thebraintumourcharity.org/education-resources**

However, occasionally extra support may be needed - for example, if your child has more complex needs. This is where various statements or plans comes in - EHCP or SEN Statement in England & Wales; Co-ordinated Support Plan (CSP) in Scotland; or Statement of SEN in Northern Ireland.

Education, Health and Care Plans (EHCPs) have replaced Statements of Special Educational Needs (SEN) in England and Wales.

Those already on SEN statements are gradually being transferred to EHCPs.

Either you, your child's teacher or someone in your child's health team can request an assessment for a plan from your local authority (LA), council or Education Authority (EA), if you feel this is something your child needs.

You can apply for a plan for physical/medical needs as well as cognitive/learning needs.

In England and Wales, a young person can also request an assessment themselves if they're aged 16 to 25. A request can also be made by anyone who thinks an assessment may be necessary e.g. doctors, health visitors and family friends.

The LA/council/EA has a limited amount of time to let you know if they will carry out an assessment. (The time varies according to which nation in the UK you live in).

Requesting an assessment for an EHCP, CSP or statement does not automatically mean that you will get one. However, if the LA/council/EA says that they will not provide one, they will explain in writing why not and how your child will be supported inside or outside of school.

If they do agree to carry out an assessment, they will ask for evidence from various professionals, such as your child's healthcare team and teachers. This will be used to decide whether they will create a plan/statement for your child.

The LA/council/EA has to tell you within a limited time if a plan or statement is going to be made. Again the time will depend on which nation you live in, within the UK.



It is recommended that you let your LA/council/EA know as soon as possible, if you wish to request an assessment for an EHCP, CSP or statement of SEN, as the process can take some time.

You have the right of appeal if a plan is refused. There may also be other assessment plans, such as an Early Help Assessment, that may be able to identify your child's needs and the support they need.

If an EHCP is made, it is a legally binding document - the support laid out in the plan must be provided. If needed, the plan stays with your child until they are 25 years old, but is reviewed regularly and amended, if required.

More information about asking for an assessment for a plan/statement, including how to request one and what happens during the assessment, can be found in the *Resources* section at the end of this fact sheet.

Resources about Personal Budgets (Self-Directed Support, in Scotland and NI) are also listed. If your child is eligible for these, you/your child can be involved in arranging the provision of support.

If your child has additional support needs, you can also request a specific assessment at any time, such as an educational, psychological, physical or medical assessment.

Being labelled

Some people worry that having an EHC plan or statement of SEN or 'labelling' their child as having a learning difficulty will hinder them later in life.

However, an EHC plan or statement of SEN :

- Simply outlines any issues your child may have and sets out what support they should receive
- Is intended to be supportive and helpful, rather than acts as a hindrance
- Classmates do not need to know that your child has a plan or statement.

In terms of prospects later in life:

- Universities and employers are more concerned with qualifications, experience and attitude than whether someone has learning difficulties. They will also continue to support educational needs
- Various laws, such as the Equality Act 2010, protect people from direct and indirect discrimination in education and employment

Help with exams for older children

For older children taking their GCSEs or A-levels/Highers, it may be possible to get extra time and/or other help with their exams, such as breaks during the exam or help from a scribe. It is best to apply for this early, but discuss the timing of the application with the SENCO or Exams Officer at your child's school/college /exam centre, as if you apply too early, the application may run out-of-date.

For more information, see the Joint Council for Qualifications - Access Arrangements and Reasonable Adjustments:

jcq.org.uk/exams-office/access-arrangements-and-special-consideration

Support for the emotional impact of having a brain tumour

It can help if you and your child talk about how they are getting on and anything they are struggling with or that concerns them. This can help relieve stress and anxiety for your child. It also gives you the chance to find out any difficulties your child is having that you are unaware of, which can help you find appropriate support for them.

Don't be afraid to seek support from your child's health team – they will be able to direct you to appropriate support for specific issues. Most teachers are also very happy to provide any extra support for your child that they can.

There are also a range of professionals who can support your child with the emotional impacts of a brain tumour diagnosis, including:

- **Paediatric neuro-oncology clinical nurse specialist**

These nurses are specialists in working with children who have a brain tumour and act as a link between you and your child and the rest of your child's health team. They are often good people to answer any questions relating to your child's brain tumour and treatment.

- **Play therapists**

Play therapists can support your child through the stress and anxiety they may feel about certain treatments or procedures, such as having an MRI scan or being treated with radiotherapy. They do this through play, for example, using toys, puppets and books.

- **Clinical psychologists**
Clinical psychologists can work with your child with the long-term impacts of having a brain tumour, supporting them through anxieties they may have, and increasing their self-esteem.
- **Community paediatrician**
Community paediatricians are children's doctors who specialise in childhood development and learning issues, as well as physical and social issues. They regularly work with schools, school nurses and the Education Authority to help children who are struggling at school.

Resources you may find helpful

The Brain Tumour Charity Education Resources

- thebraintumourcharity.org/get-support/children-and-families-service/education-resources/

While The Brain Tumour Charity cannot recommend any specific organisations or resources, you may find the following helpful:

England and Wales

- gov.uk/children-with-special-educational-needs
- ipsea.org.uk/what-you-need-to-know/ehc-needs-assessments
- [cafamily.org.uk/advice-and-support/education-health-and-social-care/education/education-health-and-care-\(ehc\)-needs-assessments/](http://cafamily.org.uk/advice-and-support/education-health-and-social-care/education/education-health-and-care-(ehc)-needs-assessments/)
- kids.org.uk
- kids.org.uk/yp-personal-budgets

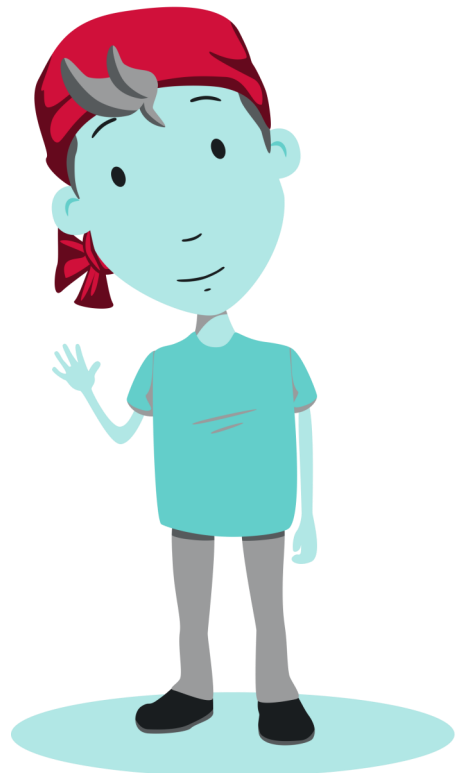
Scotland

- gov.scot/Publications/2011/04/04090720/8
- autism.org.uk/about/in-education/extra-help-in-school/scotland.aspx
- selfdirectedsupportscotland.org.uk

Northern Ireland

- nidirect.gov.uk/articles/special-educational-needs-statements
- autism.org.uk/about/in-education/extra-help-in-school.aspx
- cilni.org/content/self-directed-support-and-personal-budgets

(Though some are written by charities not related to brain tumours, they still include useful information.)



What if I have further questions or need other support?

You can contact our Information and Support Team in the following ways:



0808 800 0004

(Free from landlines and most mobiles:
3, O2, EE, Virgin and Vodafone)



support@thebraintumourcharity.org



Live Chat

Get in touch with us online via
thebraintumourcharity.org/live-chat



Join one (or more) of our
closed Facebook groups:
bit.ly/FBSupportGroups



thebraintumourcharity.org/getsupport

Disclaimer: This resource contains information and general advice. It should not be used as a substitute for personalised advice from a qualified specialist professional. We strive to make sure that the content is accurate and up-to-date, but information can change over time. Patients must seek advice from their medical teams before beginning or refraining from taking any medication or treatment. The Brain Tumour Charity does not accept any liability to any person arising from the use of this resource.

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard - an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology.

Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you have already been given. Please do continue to talk to your medical team if you are worried about any medical issues.

If you would like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on **0808 800 0004** or **support@thebraintumourcharity.org**

About The Brain Tumour Charity

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research worldwide, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We wouldn't be able to make the progress we have without the incredible input we receive from you, our community.

Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make a difference.

To find out more about the different ways you can get involved, please visit thebraintumourcharity.org/volunteering

We rely 100% on charitable donations to fund our work.

If you would like to make a donation, or find out more about other ways to support us, including leaving a gift in your Will or fundraising through an event, please get in touch:

Visit

thebraintumourcharity.org/get-involved
call us on 01252 749043 or email
fundraising@thebraintumourcharity.org



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Registered Office:

Hartshead House
61-65 Victoria Road
Farnborough
Hampshire
GU14 7PA

01252 749990
enquiries@thebraintumourcharity.org

