Learning difficulties and brain tumours in children

If your child has, or has had, a brain tumour, you may find that they experience learning difficulties to some degree. These difficulties could be due to a number of factors, including long periods of absence from school, side-effects of treatment, and indirect effects, such as anxiety and lowered confidence.

This fact sheet gives an overview of some of the common learning difficulties your child may experience as the result of a brain tumour and provides information about the support available to assist them in their learning.

# In this fact sheet:

* Learning difficulties and brain tumours
* Possible reasons behind the difficulties
* What support is available to help my child?
* Answers to some common questions you may have about learning difficulties.

## Learning difficulties and brain tumours

The National Cancer Institute (NCI) estimates that more than half of children who are treated for a brain tumour experience a learning difficulty of some sort. These vary, but commonly include difficulties with:

* Learning that is highly dependent on short-term memory, meaning that your child may struggle with, for example, multiplication tables, grammar and foreign languages.
* Reasoning and problem solving, including transferring knowledge gained in one situation to a new context.
* Attention span, which may make 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.

As a result of these difficulties, your child’s IQ score could be lower than is expected at their stage in development. You may find this upsetting, but it is important to remember that IQ scores can be misleading, as the tests do not always reflect an individual’s situation and how they perform in a test situation. For example, just because your child’s short-term memory is affected by their brain tumour, it does not mean that they are now less intelligent, but rather that they have difficulty recalling information.

Your child may experience decreased self-esteem, frustration and emotional upset as a result of their learning difficulties and they could need support to cope with the emotional impacts of having a learning difficulty before the difficulty itself can be addressed.

Generally speaking, the younger a child is when they are diagnosed and treated for a brain tumour, the more pronounced their learning difficulties will be. This is due to their brain being affected whilst still growing and developing. Support is available to help you and your child cope, as this fact sheet outlines.

## Possible reasons behind the learning difficulties

Learning difficulties can be a direct or an indirect consequence of your child’s brain tumour. Direct impacts are those that result from the tumour itself. An example is if a tumour is located in a part of the brain that plays a key role in learning or if the tumour presses on surrounding structures with this role. A tumour located in the parietal lobe, for example, could lead to problems with writing, understanding and reading (*For further information, see our The human brain fact sheet*).

Learning difficulties that can arise as an indirect result of your child’s brain tumour are wide-ranging and depend on various factors, including your child’s age and the size and location of their tumour. Children who have, or are treated for, a brain tumour in the first twelve months of their life are highly likely to experience learning difficulties.

The reasons underlying learning difficulties can be complex, but may arise from:

* The time your child has out of school for hospital appointments, both in terms of missing lessons and being away from friends, which could also affect social development.
* Complications following surgery. Although uncommon, an example is spending a long time on a ventilator after surgery. This can increase the risk of problems relating to behaviour, memory and attention span.
* Effects of treatments, such as radiotherapy, on the developing brain.
* Emotional impacts – for example, stress and anxiety, which could negatively affect your child’s learning.

## What support is available to help my child?

There are several sources of support to help your child with their social and educational development. Studies suggest that children who have had a brain tumour leave school with qualifications at comparable rates to their peers who have not had a brain tumour. They are, however, far more likely to require special educational input to support them to do so.

The National Cancer Institute estimates that over half of children treated for a brain tumour need additional educational support with their learning, which can include:

* **Support from an educational psychologist**

Educational psychologists can work with your child to support their social and educational development. They may administer a range of tests, interview and observe your child with a view to assessing any underlying difficulties. They can liaise with teachers at your child’s school to help put measures in place to support your child’s learning. This could include recommending 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. You can speak to your child’s health team about the educational psychology services available in your area and how to access them.

* **A statement of Special Educational Needs (SEN)**

This is a report that sets out your child’s learning needs and the support they should receive. A statement of SEN is usually given by your Local Authority (council) if the support that your child’s school is able to provide from their internal resources is not sufficient to fully support your child. The SEN statement is reviewed each year so that its recommendations can be adapted according to your child’s changing needs. You can find out more about SEN statements, including how to request one, on the Department for Education’s website:

[*www.education.gov.uk/popularquestions/childrenandfamilies/specialeducationalneeds/*](http://www.education.gov.uk/popularquestions/childrenandfamilies/specialeducationalneeds/)

* **Help with exams for older children**

For older children taking their GCSEs or A-levels, it may be possible to get extra time and/or other help with their exams. It is best to apply for this at the beginning of the academic year or as soon as they are diagnosed and the SENCO or Exams Officer at your child’s school/college or exam centre will be able to help with this. For more information, see the Joint Council for Qualifications - Access Arrangements and Reasonable Adjustments

*http://www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration*

Your child’s health team will be able to guide you as to the support the school should provide, but it is recommended that you also let your council know as soon as possible if you wish to request a statement of SEN, as the process can take some time .

It can be extremely beneficial for you and your child to speak about their experiences and anything they are struggling with or that concerns them. This can help to alleviate stress and anxiety for your child. It also gives you an opportunity to identify any difficulties for your child, which can in turn help you to 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 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 to support them through anxieties they may have, and to increase their self-esteem. An example of when your child might see a clinical psychologist may be in supporting them with some of the long-term impacts of having a brain tumour.

## How will my child’s learning difficulties be identified?

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, as well as teacher observations and reports. It may take some time for a learning difficulty to

be identified if it is subtle and it is possible that a learning difficulty may become more pronounced as your child grows and attempts more complex tasks. Your child may also be referred to an educational psychologist to assess any underlying difficulties.

## Are we entitled to a statement of SEN if we would like one?

You are entitled to request a statement of SEN and can do so through your child’s school, which should have a ‘SENCO’ (Special Educational Needs Co-ordinator). If your child is not in school, you can speak to your local council or your family GP about getting a statement of SEN. Requesting a statement does not automatically mean that you will get one. However, if the council 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.

## Won’t having a statement of SEN or being ‘labelled’ as having a learning difficulty hinder my child in later life?

A statement of SEN simply outlines any learning difficulties your child may have and sets out what support they should receive. It is intended, therefore, to be supportive and helpful, rather than a hindrance. Classmates do not need to know that your child has a statement of SEN. In terms of prospects later in life, universities and employers are more concerned with qualifications, experience and attitude. Indeed, your child’s achievements may be even more highly valued given the difficulties they have faced.

## Resources

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

**The UK Government website**

Contains information about SEN statements and how to request one.

*www.gov.uk/children-with-special-educational-needs/statements*

**CLIC Sargent**

CLIC Sargent’s website contains information about returning to school.

*www.clicsargent.org.uk/content/returning-school*

**Cerebra**

Cerebra publish a book about pupils who have a brain tumour returning to school. Although the book is primarily for teachers, you may still find it useful. You can request a free copy - Tel: 01267 244200 or download a free copy:

[*www.cerebra.org.uk/English/getinformation/publications/Pages/ReturningToSchoolBook.aspx*](http://www.cerebra.org.uk/English/getinformation/publications/Pages/ReturningToSchoolBook.aspx)

**Disclaimer:**

*The Brain Tumour Charity provides the details of other organisations for information only. Inclusion in this fact sheet does not constitute a recommendation or endorsement*

# What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team, which includes a dedicated Children and Families Worker:

* Call 0808 800 0004 (free from landlines and most mobiles including 3, O2, Orange, T-mobile, EE, Virgin and Vodafone)
* Email support@thebraintumourcharity.org
* Join our closed Facebook group: bit.ly/supportonfacebook

# About us

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours. We hope that these will add to the medical advice you have already been given.

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 to increase survival, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including fundraising, leaving a gift in your will or giving in memory, please visit us at thebraintumourcharity.org , call us on 01252 749043 or email fundraising@thebraintumourcharity.org

# About this fact sheet

This fact sheet has been written and edited by The Brain Tumour Charity’s Support and Information Team and is supported by the Children’s Cancer and Leukaemia Group (CCLG).

The accuracy of medical information has been verified by leading health professionals specialising in neuro-oncology. Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence. If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.

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# Your notes



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