CCLG The Children & Young People's Cancer Association

Posterior fossa syndrome (PFS)

An information guide for parents, carers and families

The purpose of this guide is to help you understand 'posterior fossa syndrome' (PFS) and provide information about symptoms, rehabilitation and recovery.

Information in this guide should be used to support professional advice specific to your child's diagnosis. If you have any questions, it is important to ask your child's medical team.

What is posterior fossa syndrome (PFS)?

Posterior fossa syndrome (PFS) is the name given to a collection of symptoms that occur together following surgery to the back of the brain (called the cerebellum). It is also known as 'cerebellar mutism syndrome'.

Symptoms are not always present immediately after surgery, but often develop in the next few days. Early symptoms include difficulties with speech, movement, swallowing and mood swings. Mood swings may also be called 'emotional lability'.

If your child develops PFS, their appearance and behaviour may change. It is natural for this to be upsetting and difficult to see; it helps to remember that your child is still the same person as before.

When does PFS occur and how long does it last?

PFS occurs in up to 30% of children undergoing surgery to the back of the brain. The severity of the condition can vary a lot from one child to the next, so it is difficult to predict the extent or duration of recovery.

However, the majority of children will make significant improvements. The extent of any long term difficulties may not be obvious to start with and could become clear later as the child returns to education and home life. Ongoing rehabilitation and support may be required for months or even years.

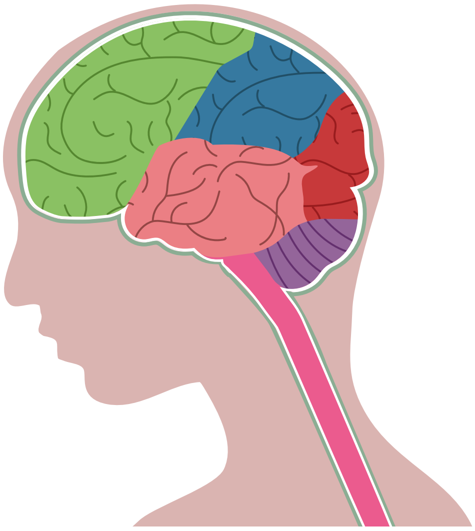
Causes of PFS

The exact cause of PFS is unknown. It occurs following operations to the cerebellum or brain stem. The cerebellum controls balance, co-ordination and speech. It also plays a role in cognition, emotions and behaviour. The brainstem controls basic functions such as breathing, heart rate and body temperature. PFS is more common after operations to remove a type of brain tumour called medulloblastoma. Larger tumours that involve the brain stem and are located in the cerebellar midline are also associated with PFS.

It is unclear why it affects some children and not others, and there is ongoing research to try and find out. Current evidence suggests that PFS is caused by an interruption to a particular pathway in the brain, called the 'cerebellar outflow pathway'. This pathway sends signals from the cerebellum to the frontal part of the brain that processes information, sensations and body movements.

Areas of the brain and their functions

The brain and spinal cord are two complex organs that form the central nervous system. They work together to interpret the messages from our senses and tell our bodies how to respond. As the brain and spinal cord have so much control over how we function, from walking to talking and organising our thoughts, PFS includes a wide range of symptoms.



🟩 **Frontal lobe**
movement, behaviour, cognitive functions

🟥 **Occipital lobe**
sight and understanding what you can see

🟥 **Temporal lobe**
learning and memory, understanding language, hearing

🟦 **Parietal lobe**
integrating information from other senses, touch, spatial skills

🟪 **Cerebellum**
co-ordination, balance and movement

🟥 **Brain stem**
blood pressure, breathing, heart rate, body temperature, eye movements, and swallowing

Symptoms of PFS

PFS is identified by a collection of symptoms that can affect the following functions:

Reduced or absent speech

This is often one of the most striking features, which is why PFS is sometimes called ‘cerebellar mutism’. Children may not speak at all or their speech may be reduced, slow or slurred and difficult to understand. This usually occurs within the first few days after surgery but may not be obvious immediately.

Lack of body coordination and movement

Children can display low muscle tone (hypotonia), unsteadiness and problems with coordination (ataxia). They may not be able to co-ordinate voluntary movements, and can find it difficult to hold their head up or sit up.

PFS can affect the movements involved in chewing and swallowing. In severe cases, children may have difficulty swallowing their saliva, making it unsafe for them to have anything to eat and drink by mouth. Usually, children regain the voluntary movements of the lips and tongue first before being able to eat and drink, for example, being able to stick out their tongue and move it from side to side. Children who have been severely affected may need tube feeding, especially when radiotherapy and chemotherapy are given at the same time.

Changes in emotions and behaviour

Many children and young people experience ‘emotional lability’, a term used to describe rapid changes of mood and can include sudden uncontrolled laughter or tears. Some children appear flat in mood and withdrawn and may not show interest in activities they previously enjoyed. Children may also be irritable and agitated. They may display angry behaviour such as shouting or swearing, which may seem out of character.

Changes in mood and behaviour can be very distressing for families to see and can be particularly obvious after the initial stages of recovery following brain surgery. This can be made worse by a child feeling scared, or being unable to communicate.

Changes in learning and cognition

Cognition is the process of learning, understanding, thinking and reasoning. It includes attention and memory. Due to the speech and movement problems seen in PFS, it can be difficult to assess the impact on children’s cognitive abilities until they have made a significant recovery.

It is important to consider that thinking and reasoning could be impaired and processing speed is likely to be slowed. This means that children may find it harder to focus, find it difficult to make decisions, and can take a long time to understand things or respond to questions.

Rehabilitation

Rehabilitation can take place in hospital, at home, and occasionally at a specialist rehabilitation centre, depending upon your child's individual needs. Children who have more severe symptoms of PFS early on are more likely to have symptoms that last longer.

The aim of rehabilitation is usually to recover skills, but sometimes other ongoing treatment can affect your child's functioning so the aim at that point can be to help your child maintain skills.

A child may appear uncooperative and be reluctant or unwilling to undertake therapy during their rehabilitation and may need lots of patience and understanding. At first, therapy might focus on encouraging a feeling of safety and play.

Your child's rehabilitation team will include the following specialists:

- **Speech and language therapists** can provide support for any speech, language and communication difficulties. They can help with swallowing difficulties, supporting eating and drinking and ensuring it is safe and pleasurable.
- **Physiotherapists** can help with strength, balance and co-ordination of movements, helping children regain their physical skills.
- **Occupational therapists** support children to participate in everyday activities, enabling children to regain their independence.
- **Clinical psychologists or neuropsychologists** can help to identify and support any difficulties with cognition, as well as supporting children and their families with emotional or behavioural issues as they adjust to what has happened to them.

Other therapists, for example, play therapists, art therapists and music therapists, may also be involved in your child's rehabilitation.

Initial symptoms of PFS will improve with time but recovery is different for each child. Depending on their individual difficulties, your child will need ongoing rehabilitation from a team of therapists to help their recovery.

Recovery and long-term prognosis

Speech and communication

In most cases, communication comes back gradually, with more spontaneous sounds, such as laughing and crying returning first. This is usually followed by individual sounds, slowly developing into single words and extending into short phrases. Some children may communicate non-verbally using head-nods/shakes and gestures. The use of visuals and written language, for example, communication boards, can support your child's communication initially and in the longer term.

Body movements (motor control)

Some children will take many months to regain their physical abilities. Most, but not all, will be able to walk independently. However, ongoing difficulties with balance, coordination and body movement are common.

Emotional difficulties

Most significant emotional and behavioural problems tend to improve when the child's speech returns, but emotional difficulties can persist after recovery has been made in many other areas. In addition to sudden emotional distress (often crying or appearing agitated), some children experience emotional, behavioural and social problems. Children with neurological problems that significantly affect their daily activities and learning are at higher risk of these difficulties. Children often feel frustrated if they are unable to participate in the activities that they used to enjoy. This may affect their confidence as well as social relationships. If you are concerned about ongoing low mood or behaviour problems, do discuss this with a member of your child's rehabilitation team.

Learning and cognition

There are many factors that can affect learning and cognition in children with brain tumours, such as the tumour itself and the treatment given. It is therefore difficult to predict an individual child's cognitive abilities in the long-term. Research comparing children with the same type of tumour and treatment, with or without PFS, has found that children with PFS can have more difficulties with cognition generally. These particularly affect processing speed, skills for monitoring and controlling behaviour, paying attention and psychomotor skills, such as hand-eye coordination. Research suggests that processing speed is the most affected area. Giving children extra time to respond, make decisions and complete activities, as well as breaking information and instructions down into smaller chunks, can help. Neuropsychological assessment can provide further recommendations for supporting cognitive difficulties.

Returning home

Preparation for your child's discharge from hospital begins as soon as your child is admitted to hospital, as it can take some time to arrange the right support.

The medical and nursing team will work closely with other professionals to assess your child's needs and any additional support required, both in the short and long term. This assessment should consider medical needs, physical needs, psychological and practical needs, and returning to school.

Medical needs

Information about any ongoing treatment for your child's tumour will be explained to you in detail, and you will receive information on how to care for your child at home. Your hospital team will make referrals to the appropriate community nursing team and other services you may need.

Physical needs

Your child will have an assessment to see how they will cope at home. If any equipment is needed, this will be ordered by the occupational therapy team. If required, information about more permanent adaptations to your home will be provided.

Psychological and practical needs

Members of your hospital team, including the outreach nurses and Young Lives vs Cancer social worker, will be able to support you and your child, and also advise on other support available locally. Your child may have a cognitive assessment to understand their strengths and weaknesses, which can help everyone to understand their needs both at home and at school.

There may be practical arrangements that are needed, including equipment and sometimes alterations to your home. Talk to your outreach nurses or Young Lives vs Cancer social worker about what help you may need, including financial support.

It is important to remember any cognitive difficulties will vary for each child. It may be helpful for your child to have a neurocognitive assessment by a clinical psychologist, clinical neuropsychologist or educational psychologist to identify their particular strengths and weaknesses.

Going back to school

Going back to school is an essential part of your child's ongoing rehabilitation. It is usually possible for your child to return to school on a reduced timetable and slowly build up the time they spend at school. Although your child may tire easily, being back at school will help your child get back into a routine and give them the opportunity to see their friends. School can help rebuild confidence and reduce the isolation and loneliness that many children with brain tumours face.

The process of returning to school can be made much easier through planning and preparation. Communication between family, school, medical teams, and as much as possible your child, is key. Make sure the school understands your child's needs so appropriate support is in place and your child can be included in normal school life as much as possible.

Download or order free of charge 'A school's guide to supporting a pupil with cancer'.
www.cclg.org.uk/publications

Getting support in education

Every mainstream school or nursery has a Special Educational Needs Coordinator (SENCo) who is responsible for ensuring that the needs of children with disabilities or special educational needs are met. Within colleges there is also a designated person for this role but they may not be called a SENCo.

To ensure that your child is supported effectively, it is helpful to discuss their needs with the school SENCo as early as possible. A member of the hospital or therapy team may be able to support you with this. It may also be possible to invite the SENCo or another senior member of school staff to the multidisciplinary team meeting (MDT) or discharge meeting so they can begin to understand your child's needs and ask questions.

Additional support for most pupils can be provided by their school. If your child's needs have changed significantly, it might be necessary to apply for an Education, Health and Care Plan (EHCP). These look at all of your child's needs across education, health and social care, to ensure that they receive the right support by engaging everyone involved. An assessment can be requested by the school, hospital or parents, and is carried out by the local authority.

An EHCP will not be applied for or granted in all cases, and will depend on the needs of your child and the support your school can provide. Whether or not your child has an EHC plan, their progress and level of support should be regularly reviewed.

Additional support after leaving hospital

While your child is attending hospital regularly, it is likely that you will be able to access support from within the hospital. The hospital team should refer you to appropriate professionals in the community for support when you go home. This can include community physiotherapy, occupational therapy, speech and language therapy, clinical psychology and social workers.

If you feel that your child has needs that are not being met, discuss this with your specialist nurse or consultant who will be able to liaise with the relevant professional.

Leaving hospital can often be a difficult time for families, who can feel that they are losing the safety net of the professionals who understand their child's unique needs. It may be useful to discuss these concerns with members of your hospital team, including the outreach nurses, clinical psychologists and Young Lives vs Cancer social worker, who will be able to support you and advise on other support available locally.

Supporting your child

Your child will need ongoing support, and parents understandably find it very stressful to see their child upset. It is natural to try to find out what your child is upset about to make things easier for them. However, as biological changes in the brain can be associated with strong emotional reactions without any apparent trigger, your child may not know why they are upset. While it is important to encourage your child to talk about their feelings, it is also important to know that, at times, they will have no answer.

On those occasions, it is helpful to have a plan in place of how you can help your child to manage their reaction until it passes. They may simply benefit from a hug, some quiet time, giving them an object that is special to them, or distracting them with an activity.

Taking care of yourself

Seeing your child suffer from the symptoms of PFS is distressing. It is normal to feel overwhelmed at times, especially as you have already had to deal with your child's diagnosis and treatment. Being there for your child and providing reassurance and familiarity will help them begin their gradual process of recovery.

While your natural instinct as a parent may be to give up everything to support your child, you also need to look after yourself. Taking care of your own health as much as possible will help you to best support them.

The recovery process from PFS may take a long time. Do ask family, friends and professionals involved in your child's care and relevant charities for help. If you are finding it difficult to cope or are continually feeling overwhelmed and anxious, speak to your GP or your child's medical team.

It is important that you plan time for yourself and ensure that you seek the support you need so you can be there for your child throughout their journey of recovery.

Useful information

The Brain Tumour Charity provides information about brain tumours and their treatment.
www.thebraintumourcharity.org
www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/education-resources

The Child Brain Injury Trust provides information on children's acquired brain injury and offers training and support for professionals, including school staff.
www.childbraininjurytrust.org.uk
Helpline: 0303 303 2248

The Children's Trust Brain Injury Hub provides information about acquired brain injury, advice for families and education resources.
www.thechildrenstrust.org.uk
www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/return-to-education

The Danny Green Fund is a charity set up by the family of a child who experienced PFS. Provides information and funding for equipment and therapy. Also has a closed facebook group for parents.
www.thedannygreenfund.org.uk

The Royal Marsden 'Returning to school: A teacher's guide for pupils with brain tumours'.
patientinfolibrary.royalmarsden.nhs.uk/returning-school-guide-teachers-students-brain-tumours

Young Lives vs Cancer provides practical support and advice for children and young people affected by cancer and their families.
www.younglivesvscancer.org.uk
www.younglivesvscancer.org.uk/cancer-info-support/education/my-student-has-cancer
Helpline: 0300 303 5220

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CCLG: The Children & Young People's Cancer Association provides trusted information and guidance for children and young people with cancer, their families, and everyone supporting them. Our expertise helps them navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

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www.cclg.org.uk/publications

'A guide to brain and spinal cord tumours' booklet

www.cclg.org.uk/brain-spinal-cord

Join our closed Facebook group for parents and carers

www.facebook.com/groups/cclgparentcarergroup

Notes

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Patient Information Forum

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We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

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