



**Hemispherectomy  
Foundation**  
AUSTRALIA

# Supporting children after hemispherectomy: A guide for primary school teachers



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# **Supporting a safe, inclusive and accessible environment for the primary school hemispherectomy child: A guide for primary school teachers**

## **About this guide**

This guide has been prepared specifically for primary school teachers to better understand safety, accessibility and inclusion considerations for children who have had hemispherectomy surgery and who are participating in primary school education.

The purpose of this guide is to provide practical information to help primary school teachers support the safety, wellbeing, and inclusion of children after hemispherectomy surgery, enabling them to participate as fully as possible in their primary school education.

The Hemispherectomy Foundation Australia acknowledges the expertise of primary school teachers in fostering the learning, development and participation of children of all abilities. Teachers are in a special position to make a positive difference to a unique child who is living their life fully, despite the challenges of having one brain hemisphere.

## **An important note**

The contents of this guide are not intended as medical advice and child/children refers to a child who has had hemispherectomy surgery.

## **Acknowledgement**

The Hemispherectomy Foundation Australia is grateful for funding received from the Australian Government Department of Health, Disability and Ageing to produce this resource.



## About hemispherectomy

A hemispherectomy is a paediatric brain surgery where one half of the brain is removed or disconnected to stop catastrophic childhood epilepsy originating from one side of the brain (hemisphere). Hemispherectomy is most commonly performed in young children, however surgery can also occur in older children. It is most effective in children because the young brain has a remarkable ability to reorganise itself through neuroplasticity, allowing the remaining healthy hemisphere to take over many functions of the removed or disconnected side.

A hemispherectomy may be performed when seizures are severe, frequent, confined or mostly confined to one hemisphere of the brain and cannot be controlled by anti-epileptic medications. While it is a radical surgery, the development and quality of life for the child usually greatly improves as they are no longer affected by uncontrolled epilepsy on their young brain and the healthy side of the brain has an opportunity to develop.



Hemi hero Eleanor

# Key messages



## **Every child is different**

The impacts of hemispherectomy vary from child to child. Take the time to understand the child's strengths, challenges, interests and support needs.



## **Inclusion matters**

Children should be supported to participate as fully as possible in all aspects of school life, including learning, play, sport, excursions and social activities. Safety and accessibility are essential as children will experience physical disability, visual impairment, fatigue and cognitive challenges that affect safety, mobility and participation. Reasonable adjustments and accommodations will be needed.



## **Fatigue is real**

Fatigue after hemispherectomy is common and can significantly affect concentration, learning, emotional regulation and physical safety. Rest breaks, flexibility and pacing are important.



## **Communication and collaboration are key**

Strong communication between teachers, parents, therapists and the child helps ensure consistent and effective support. Regular student support meetings and an Individual Education Plan are important.



## **Focus on strengths**

Children after hemispherectomy often show remarkable resilience, determination, creativity and problem-solving skills. Encouraging confidence, independence and participation supports wellbeing and belonging.



## **Small adjustments can make a big difference**

Simple strategies such as reducing background noise and adjusting seating arrangements can greatly improve participation and learning.



## **Peer understanding supports inclusion**

Helping classmates understand disability, difference and inclusion can foster empathy, friendships and a stronger sense of belonging for the child.



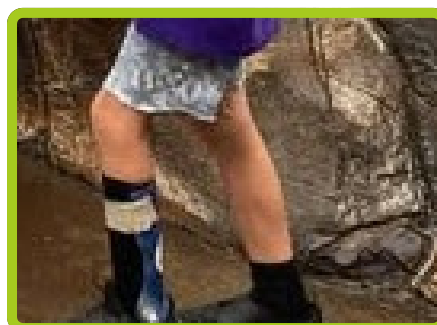
Hemi heroes  
Malu and  
Sheppy

# Common challenges in children following hemispherectomy

While the effects of hemispherectomy are unique to each child, there are a number of common challenges experienced by children who have undergone this surgery. This guide outlines these challenges, together with important safety, accessibility and inclusion considerations for primary school teachers supporting these remarkable children in the classroom. In addition to the information provided in this guide, it is important that individualised disability supports are explored through relevant state-based programs to help address the barriers to inclusion that children may experience following hemispherectomy.


## Physical disability

After hemispherectomy, all children will experience a weakness and paralysis on one side of the body known as hemiplegia. This is due to the disconnection or removal of the motor cortex on one hemisphere of the brain during the surgery. Most children walk after surgery, usually with the support of an ankle and foot orthosis, such as the one below. Fine motor function in one hand is permanently lost.



## Supporting safety, inclusion and accessibility

- **Hemiplegia affects balance and coordination and makes children more vulnerable to falls and being knocked over**, particularly in busy school environments. Participation in sport and play is important but be aware of uneven surfaces, busy environments and play equipment that may pose risks.
- **Handrails** on both sides of all internal and external stairs and steps will be needed to provide balance support and prevent trips and falls. This is a **reasonable adjustment** required for children. Children using wheelchairs will require ramps.
- **As all children lose fine motor function in one hand** this will impact their ability to perform bi-manual activities (activities that require both hands) such as using scissors to cut paper. Children should be encouraged to use their affected hand as a 'helper' such as stabilising paper or creating a fist grip to hold a marker to take the lid off.
- There are many **adaptive aids** that can help children participate in the same activities as their peers. Helpful adaptive aids include adaptive cutters or grippy mats to prevent paper moving around when writing. Links to helpful school aids can be found here on the [Hemispherectomy Foundation Australia website](#)



Remain open and receptive to the strategies of the child's occupational therapist and physiotherapist to support safety, participation and inclusion in their learning environment. This will ensure therapy is integrated with their educational goals, helping children apply strategies during their learning activities.


Collaboration between teachers and therapists will also support a whole-of-team approach in which everyone working with the child is providing consistent and aligned support.



Hemi hero  
Alicia



Teachers can encourage independence while providing necessary assistance.



# Vision loss

After hemispherectomy all children experience vision loss called homonymous hemianopsia. This is a loss of half the visual field on the same side in both eyes, opposite the removed/disconnected hemisphere. For example, after right hemispherectomy, the child will lose peripheral vision on the left and a central field of vision.

This visual loss can dramatically affect the child's ability to navigate their environment and orientation is particularly affected. They are vulnerable to accidents. The child may bump into other children or objects, trip on objects on the floor, obstacles on paths, or be startled when something suddenly appears in the remaining field of vision.

Children do adapt to their visual loss by learning to search their blind fields with their intact vision, but this search may be slow and not fast enough to avoid obstacles.



Vision Australia or the Guide Dogs can offer outreach services and provide strategies on supporting safety while also optimising the participation of the child in their play and learning. Note that in South Australia, Western Australia and Tasmania, this service is provided by Visability (WA and Tas) or the Guide Dogs Association (SA) exclusively.



Hemi hero Shaikia

## Supporting safety, inclusion and accessibility

- In a classroom, the child may be unable to see the teacher or whiteboard if these are in their blind field. It is essential that an individual visual assessment is provided by an occupational or vision therapist so that a **seating plan** is developed. Let the child lead on what they can see and cannot see.
- When reading with a child, encourage them to scan the entire page, so that they are not missing words or pictures. Other helpful educational strategies for children with hemianopia can be found [here](#).
- Be aware that children may bump into other children in a crowded environment and a **safety plan** should be in place. The therapist can help with this.
- Both the seating and safety plan should be part of the child's Individual Education Plan.

# Fatigue

Physical, cognitive, and emotional fatigue are common in children who have undergone hemispherectomy. This fatigue has a physiological basis, resulting from changes to brain structures and the increased demands placed on the remaining hemisphere, which must take on the functions of both sides of the brain.

Physical movement often requires greater energy, and cognitive processing may be slower and more effortful. It is important for teachers to recognise the child's heightened vulnerability to fatigue and to be attentive to signs that the child is becoming fatigued, so that appropriate support can be provided.

## Supporting safety, inclusion and accessibility

- When a child is fatigued, they are much more likely to trip, fall, have trouble concentrating, or exhibit behavioural difficulties. This is true for all children but more so for children who have had a hemispherectomy.
- Schedule tests (or other classroom work requiring extra focus) for when the child is less likely to be fatigued and become familiar with the signs the child is becoming fatigued and arrange appropriate rest breaks and extra time for activities and tests. **This information should be incorporated into the child's individual education plan.**
- More information about fatigue following childhood brain injury can be found [here](#)



Fatigue in their child is one of the most prevalent issues reported by parents. Fatigue can be physical, emotional and cognitive. Fatigue goes far beyond normal tiredness and significantly impacts a child's ability to participate in their learning. This fatigue is caused by injury to the brain.



Hemi hero Isla

# Cognitive and learning challenges

Cognitive and learning challenges will be unique to each child. Most children make cognitive and learning gains after hemispherectomy as their developing brains are no longer impacted by relentless epileptic seizures and the effects of multiple anti-epileptic medications. However, possible cognitive and learning challenges following hemispherectomy include:

Impacts on expressive and receptive language

Difficulty with learning to read

Auditory processing disorder

Challenges with spatial awareness

Difficulties with memory and attention

## Supporting safety, inclusion and accessibility

- Repeat and simplify instructions and try and reduce background noise as auditory processing challenges are prevalent in children. More information about auditory processing impairment after hemispherectomy can be found in this [resource](#).
- Children may need an instruction broken down into smaller steps, or have instructions repeated multiple times.
- Visual instructions about how to do a skill might be needed.
- Consider demonstrating the task or asking another student to demonstrate.



Hemi hero Freya

More detailed information about the cognitive and learning impacts of hemispherectomy can be found in this [resource](#) prepared by the Pediatric Epilepsy Surgery Alliance.

# Learning specific considerations

## Art classes

Adapted materials may be needed so that the child can fully participate in all art activities. For example, thicker pencils and paintbrushes might help with grip. Paper can be taped down, sticky mats can be used, and there are cutting tools for one-handed use.



A full range of adaptive equipment that can assist children in art activities can be found here on the Hemispherectomy Foundation Australia [website](#).

## Typing

Children can learn to type with one hand. Have the child centre their fingers over the FGHIJ keys. Offset the keyboard to whichever hand is being used. If the child is right-handed, then the keyboard is moved to the right of their and if left-handed, move the keyboard to the left of body. There are also one-handed typing programs available such as [five-finger typist](#). The child's occupational therapist can assist with recommending the most appropriate software or program.

## Physical education

Children should be given the opportunity to enjoy the same physical, mental and social benefits from physical education (PE) as their peers. This is important for their sense of school belonging and the development of motor skills. Accommodating a child's needs in PE can contribute to a broader school culture of acceptance and respect.

While some children can run and jump following hemispherectomy others find these more challenging. Sport teachers can support inclusion by changing the activity, not excluding the child. For example, change distance, pace, equipment size, or the number of players involved. Be led by the child regarding how they would like to participate. Some helpful strategies to support the inclusion of children with disability in PE can be found [here](#).



Hemi hero  
Tommy

# Emotional considerations and sensory overstimulation



## Medical trauma

A child who has had hemispherectomy will likely have undergone many traumatic medical experiences, including countless seizures, medical and surgical procedures, and long periods of hospitalisation.

Medical trauma and post-traumatic stress disorder can occur in children following hemispherectomy and teachers need to be cognisant of these experiences and how they may affect the child at school.

## Sensory processing

Children may be vulnerable to sensory overstimulation or sensory processing differences as hemispherectomy removes or disconnects the sensory strip on one side of the brain, meaning sensation, proprioception and kinesthesia can be profoundly affected.

Children may have an aversity to certain food tastes or textures, have sensory-seeking behaviours such as biting/chewing on pencils, or similar behaviour. They may over-respond to light, sound, certain food or textures and find them extremely difficult.

## Acquired disability

A child may also experience frustration as they adjust to new physical limitations from hemispherectomy. They will be aware of their physical limitations compared to their classmates and are vulnerable to exclusion during physical play.



## Supporting safety, inclusion and accessibility

- Behavioural challenges have been reported in approximately 27% of children after hemispherectomy and can include: impulsivity; Attention Deficit Hyperactivity Disorder (ADHD); autism/autistic characteristics and impaired social skills.
- Recognise that emotional dysregulation may also be because of medical trauma or adapting to new disabilities. Learn the triggers for the child and how they can best be calmed and escalations prevented. Apply your professional expertise in understanding how to best support children experiencing emotional dysregulation and/or overstimulation. InclusionED has a range of strategies and professional development on creating a positive learning environment and meeting sensory needs.
- Encourage and celebrate the child's accomplishments, no matter how small to help promote a positive self-image. Focus on the child's strengths and abilities.

# Communication

## Children

Many children will have communication difficulties after hemispherectomy, particularly when the dominant hemisphere has been removed or disconnected (in approximately 95% of typically developing children, speech and language is a function of the left hemisphere of the brain). Following a left hemispherectomy surgery, approximately 44 – 76% of children have expressive and receptive language skills. More information about speech after hemispherectomy can be found [here](#).

## Peers

Encouraging the participation of children by their peers is essential to their inclusion and safety. Through interacting with and learning about the child, other children can develop empathy, social skills that are the foundation for inclusive behaviours and attitudes.

These behaviours and attitudes will contribute to a more supportive and cohesive learning environment where all children can thrive and learn from one another's unique strengths and perspectives.

## Parents

Like any relationship, good communication with parents is built on transparency, respect and empathy.

**Student support groups** and the development of the child's **Individual Education Plan** are important opportunities to discuss how ongoing, effective communication can best occur. Agree how you would like to communicate outside of student support group meetings.



## Supporting safety, inclusion and accessibility

- It is recommended that teachers meet with parents prior to the child's primary school attendance to gather information about the child's current abilities and challenges. This will help understand their specific needs and any ongoing therapies they are receiving. **An individual education plan will be required.**
- **Regular student support meetings will need to occur.** Involve the child's therapists whenever possible. (e.g., occupational therapists, speech therapists).
- For younger primary school aged children, consider asking parents to prepare a social story that can be shared with other students to help them understand, encourage questions, highlight the child's strengths and reinforce inclusive attitudes. [Here](#) are some resources from the Human Rights Commission to help primary school aged children build understanding of disability. This [video series](#) from the Victorian Department of Education is also helpful.

# Further information and resources

## Hemispherectomy specific

Hemispherectomy Foundation Australia

<https://hemispherectomyaustralia.org.au/>

Paediatric Epilepsy Surgery Alliance

<https://epilepsysurgeryalliance.org/>

Some of the information in this guide has been sourced from the Paediatric Epilepsy Surgery Alliance (PESA). We are very grateful to PESA for allowing the sharing of their research and resources.

## Educational inclusion for children with disability

InclusionED

<https://www.inclusioned.edu.au/>

All Play Learn

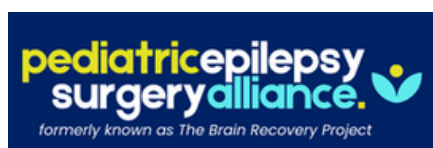
<https://www.allplaylearn.org.au/primary/teacher/disability-strategies/>

ACD - Advocating for Children with Disability

<https://acd.org.au/>

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