



Hemispherectomy
Foundation
AUSTRALIA

SUPPORTING YOUNG PEOPLE AFTER HEMISPHERECTOMY

Securing futures together

Practical
guidance for
Australian
secondary
school teachers



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Supporting a safe, inclusive and accessible secondary school experience

About this guide

This guide has been prepared to support secondary school teachers in understanding the safety, accessibility and inclusion considerations for young people who have undergone hemispherectomy brain surgery and are participating in secondary school education.

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

The Hemispherectomy Foundation Australia acknowledges the expertise and dedication of secondary school teachers in fostering the learning, development and participation of young people of all abilities. Teachers are uniquely placed to make a meaningful difference in the life of a young person who is living fully and courageously despite the challenges associated with having one brain hemisphere.

We encourage teachers to explore the links to additional information provided throughout this guide to further support their understanding and practice.

An important note

Note that the contents of this guide are not intended as medical advice and the term young person refers to a young person who has had hemispherectomy surgery. References to “children” in this guide reflect that for most young people, hemispherectomy will have been performed during their childhood.

Acknowledgement

This guide was developed with clinical, lived experience and educator input from Inclusion and Accessibility grant funding from the Australian Government Department of Health, Disability and Ageing.

Cover photo: Our cover photo is of our hemispherectomy young people Stephanie, Gemma and Freya.

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 and adolescents.

A hemispherectomy may be performed when seizures are severe and frequent 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.

The conditions that may lead to hemispherectomy include:

Rasmussen's Encephalitis: A progressive neurological disorder in typically developing children causing inflammation and seizures in one half of the brain. This leads to frequent drug-resistant focal seizures, weakness on one side of the body, and cognitive decline.

Sturge-Weber Syndrome: A congenital neurological condition marked by abnormal blood vessels in the brain, eyes and skin, and a facial birthmark. Symptoms include seizures, glaucoma, developmental delays and cognitive impairment, headaches and stroke-like episodes.

Perinatal Stroke or Brain Injury: Damage occurring before or around birth that later results in epilepsy. Seizures may be a consequence of the brain injury.

Hemi convulsion-Hemiplegia-Epilepsy Syndrome: A congenital neurological condition beginning with prolonged seizures on one side of the body, often associated with a fever and followed by weakness on one side of the body. Focal epilepsy develops later.

Hemimegalencephaly: A congenital neurological disorder causing one half of the brain to abnormally overgrow, leading to severe epilepsy, developmental delays, and progressive weakness on one side of the body.



Key messages



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Every young person is different

The impacts of hemispherectomy vary significantly depending on factors such as the age at surgery, the hemisphere affected and the underlying condition.



School transition is a big step

Use the transition statement provided by the young person's primary school to inform planning and provide tailored transition and orientation support to promote a positive start to secondary school. This should include an assessment of school accessibility.



Inclusion matters

Young people should be supported to participate as fully as possible in all aspects of their school life, including sport, excursions and social activities.



Adjustments will be needed

Physical disability, visual impairment, fatigue and cognitive challenges may affect safety, mobility and participation, requiring reasonable adjustments and accommodations.



Fatigue is real

Fatigue after hemispherectomy is common and can significantly affect concentration, learning, emotional regulation and physical safety.



Communication and collaboration are key

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



Focus on strengths

Young people 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.



Recovery is ongoing

Young people continue adapting physically, cognitively and emotionally. Teachers do not need specialist medical expertise to make a meaningful difference. Compassion, flexibility, inclusion and respectful understanding are powerful supports.

Quick reference - key support strategies



Accessibility

- Allow extra time for moving between classes and activities
- Ensure safe, uncluttered access to classrooms, walkways, learning spaces and school grounds
- Utilise the reports provided by physiotherapists and occupational therapists to guide what adaptive equipment and technology is needed



Vision

- Be aware that all young people after hemispherectomy have a vision loss
- Provide an accessible locker and clear pathways around the school
- Follow recommendations from vision specialists and vision plans



Fatigue

- Recognise that fatigue has a neurological cause
- Schedule demanding learning tasks earlier in the day where possible
- Provide regular rest breaks before fatigue becomes overwhelming
- Allow extra time for tests, exams and assignments



Learning

- Develop and regularly review the Individual Education Plan (IEP)
- Use neuropsychological and educational assessments to guide supports
- Provide instruction in quiet environments, highlight key information and provide clear, step-by-step instructions
- Use assistive technology, visual supports, calculators and audiobooks as needed
- Provide additional support for reading, language, mathematics and organisational skills where required



Wellbeing

- Build a safe, trusting and respectful relationship using trauma-informed approaches and provide regular check-ins
- Encourage participation in school, leadership, extracurricular and social activities
- Support peer understanding and inclusion



Collaboration

- Maintain regular communication with parents/carers
- Collaborate with therapists, wellbeing staff and disability inclusion staff
- Review supports regularly and adjust them if needs change

Common challenges following hemispherectomy

Physical disability



Because the motor cortex of one brain hemisphere is removed or disconnected during a hemispherectomy, all young people will experience a hemiplegia, which is weakness and paralysis on one side of the body. Most people walk after surgery, usually with the support of an ankle and foot orthosis (leg brace). Fine motor function in one hand is permanently lost.

Hemiplegia affects balance and coordination and makes young people 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 sporting equipment that may pose risks.

As all young people will have lost fine motor function in one hand after hemispherectomy this will impact their ability to perform bi-manual activities (activities that require both hands). Young people will often use their affected hand as a 'helper' such as stabilising paper.



The young person's physio and occupational therapists can provide helpful school-based strategies to best support their inclusion in everyday school activities.

Practical strategies for physical disability

- ✓ There are many adaptive aids that can help young people participate in the same activities as their peers. Helpful adaptive aids include smaller keyboards, one-handed typing programs and grippy mats to prevent paper moving around when writing.
- ✓ Links to helpful school aids can be found here on the [Hemispherectomy Foundation Australia](https://www.hemispherectomyfoundation.org.au) website.
- ✓ Because of their physical disability, young people will need more time for activities such as moving between classrooms and changing clothes for physical education.
- ✓ Handrails on both sides of all internal and external stairs and steps will be needed to provide balance support and prevent trips and falls. Young people using wheelchairs or mobility scooters will require ramps.



These strategies include reasonable adjustments required for young people to support their safety, accessibility and inclusion at school.

Common challenges following hemispherectomy

Vision loss



After hemispherectomy all children and young people experience permanent 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, their will be a loss of lose peripheral vision on the left and a central field of vision.

This visual loss can dramatically affect the young person's ability to navigate their environment and orientation is particularly affected. They are vulnerable to accidents. They may bump into other students, especially in crowded environments, or trip on objects on the floor or paths. Young people do adapt to their visual loss by learning to scan their blind fields with their intact vision, but this scan may be slow and not fast enough to avoid obstacles.

How hemispherectomy young people see

The Pediatric Epilepsy Surgery Alliance has produced practical, easy to follow information on how vision is impacted following hemispherectomy. Access this information [here](#) to better understand how young people see.

Practical strategies for vision loss

There are several practical accommodations and considerations that can be made to mitigate risks to young people associated with their vision loss. These include:

- ✓ The development of a vision plan by a vision or occupational therapist to provide advice on optimal classroom seating arrangements
- ✓ Keeping paths and corridors free of obstacles and clutter
- ✓ Providing an accessible locker such as the top locker at the end of a row.
- ✓ Being flexible in physical education activities, understanding that ball sports can often pose risks as the young person will not see a ball coming from their blind side.

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

Common challenges following hemispherectomy

Fatigue



Why fatigue occurs

Physical, cognitive and emotional fatigue are common after hemispherectomy and can significantly affect concentration, learning, emotional regulation and physical safety.

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. As a result, physical movement and cognitive processing often require greater effort and energy.

It is important for teachers to recognise that fatigue extends far beyond ordinary tiredness and should not be mistaken for laziness. Many young people mask their fatigue because they are determined to keep up with their peers.

What fatigue might look like

Behavioural changes: Increased irritability, more easily distracted, tearfulness, restlessness, hyperactivity, or being quieter than usual.



Cognitive Decline: Difficulty maintaining concentration or attention, "brain fog" or confusion, and giving up easily on thinking tasks or needing information to be repeated or deterioration in work accuracy.



Physical Signs: Heavy limbs, yawning, heavy or blurred eyes, and headaches.

Practical strategies for fatigue

✓ Encourage the young person to take short, frequent breaks before they feel tired. Where possible, schedule the most demanding cognitive tasks such as tests, earlier in the day. Understand that fatigue can build up over the day or week.

✓ Provide alternatives to spaces that might cause environmental overstimulation, which heavily taxes the brain. This includes providing quiet areas for work that requires concentration.

✓ Reasonable adjustments such as extra time for tests and exams (and assignments when needed) should be provided. Rest breaks during exams and tests may also be required.



Cognitive and learning impacts



The following information is not intended as a comprehensive guide to all the learning issues that may affect a young person's secondary education after hemispherectomy. Cognitive, learning, and educational challenges will vary greatly between young people and are influenced by many factors. However, there are a number of potential long-term cognitive and learning challenges that may arise after hemispherectomy, as outlined below.

It is important that an Individual Education Plan (IEP) is prepared for the young person to identify challenges and support their educational achievement.

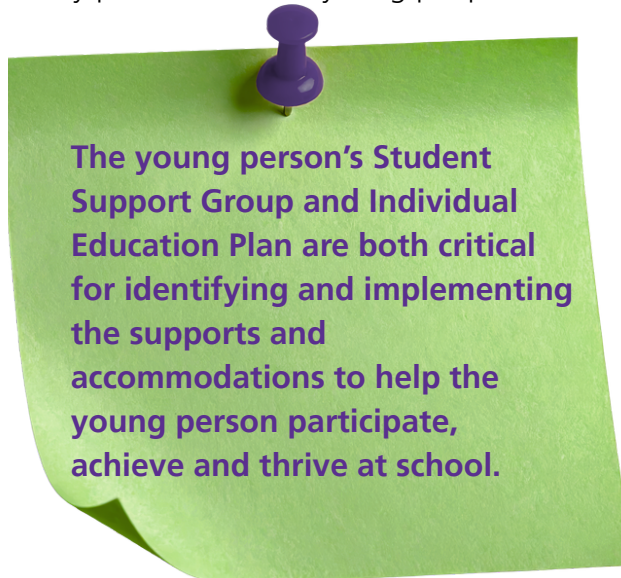
A neuropsychological or psychoeducational assessment prior to secondary school commencement can assist in identifying learning strengths and challenges to inform the IEP. A modified curriculum may be required in mainstream schools.

Impacts on expressive and receptive language



The risk of language impairment after hemispherectomy is high. If the dominant (most people are left hemisphere dominant) brain hemisphere is removed or disconnected during a hemispherectomy, then ongoing challenges with speech, comprehension and reading may occur. For language recovery, much depends on the age at hemispherectomy and the underlying condition that required the surgery.

Most young people will have received intensive earlier interventions to support language recovery after their hemispherectomy, however, challenges may persist for some young people.



The young person's Student Support Group and Individual Education Plan are both critical for identifying and implementing the supports and accommodations to help the young person participate, achieve and thrive at school.

Cognitive and learning impacts continued

Central auditory processing disorder



Central auditory processing disorder affects how the brain processes sound rather than how the ears hear them. When the single hemisphere is required to process sounds coming into both ears at the same time, problems can arise. Young people may be easily distracted by noise, struggle to follow directions or conversations, and find it difficult to process complex or abstract information.

After hemispherectomy, young people often hear well in quiet environments but can have significant difficulty when there are background noise or competing sounds, which are common in classrooms.

Explicit instruction provided in a quiet environment gives the young person the best chance of successfully receiving the information.

Reading



Similar to language, the young person's reading ability will be influenced by age at hemispherectomy and the underlying condition requiring the hemispherectomy.

Many young people will have received reading interventions in primary school to support their reading skills. A reading assessment at the commencement of secondary school can help identify the young person's reading strengths and areas where additional support may be needed.



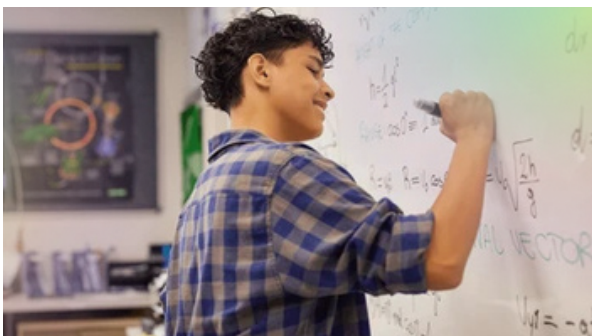
Quiet spaces for instruction and work requiring focus are extremely important

Maths and spatial skills



As with reading and language, the young person's maths skills will be influenced by age at hemispherectomy and the underlying condition requiring the hemispherectomy.

There is limited research on math skill development following hemispherectomy, however it is understood that maths and spatial skill challenges are usually greater for young people that have had a right hemispherectomy. This is because processing complex visual-spatial information is a function of the right hemisphere.



It is highly likely that the young person will need extra support with math and/or a modified curriculum.

Practical strategies to support cognitive challenges

- ✓ Support the use of audio books if reading is a challenge.
- ✓ Highlight important passages in instructional materials.
- ✓ Place the young person in the classroom to optimise their hearing and minimise any auditory distractions, ideally close to the teacher and away from noise external to the classroom.
- ✓ Ensure that instruction is provided in a low noise environment to support effective learning and comprehension. Provide a quiet study/work area for individual testing or tutoring.
- ✓ Assistive tools such as calculators, visual aids, and step-by-step written instructions can offset memory and spatial challenges. Math instruction should be reinforced with verbal explanations to minimise demands on compromised visual-spatial skills.

Psychosocial and emotional considerations

The complex neurological history and neurological make up of young people that have undergone hemispherectomy can affect mood, behavior, communication, and emotional regulation. Young people may be more vulnerable to some of the following issues.

Medical trauma

A young person who has had hemispherectomy will have undergone many traumatic medical experiences, including countless seizures, medical and surgical procedures, and long periods of hospitalisation. Medical trauma and post-traumatic stress can occur following hemispherectomy surgery and may have long-term impacts on a young person's wellbeing and participation at school.

Teachers play an important role in recognising these experiences, understanding how they may present in the classroom, and ensuring information is shared effectively so support is consistent and response to the young person's needs.

Ongoing communication with the young person and their parents/carers is essential to help identify signs of medical trauma and respond in a trauma-informed way that acknowledges the significant physical, psychological and emotional impacts of hemispherectomy.

Behavioural issues

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.

Anxiety and stress

Young people who have had a hemispherectomy are significantly more likely to experience anxiety or be formally diagnosed with an anxiety disorder. There is a strong correlation between brain injury and vulnerability to anxiety, depression and other mental health challenges.



Practical strategies to support wellbeing

Build a safe and trusting relationship

A consistent, respectful relationship with trusted teachers is one of the strongest protective factors for student wellbeing. Teachers can support wellbeing by:

- checking in privately and regularly
- listening without judgement
- avoiding assumptions about capability
- recognising effort and resilience

Use a trauma-informed approach

Some students may experience medical trauma or symptoms consistent with post-traumatic stress following years of uncontrolled seizures, emergency admissions, intensive rehabilitation or surgery. Trauma-informed approaches may include:

- preparing the student in advance for changes to routine
- allowing extra processing or transition time
- recognising that shutdown, withdrawal, irritability or fatigue may reflect stress rather than defiance

Support peer connection and social inclusion

Many young people after hemispherectomy report feeling socially isolated or different from peers, particularly if they have visible physical disability, fatigue, seizures or learning challenges.

Teachers can support social wellbeing by:

- facilitating group participation and peer connection
- being mindful of seating arrangements and friendship supports
- support peers to understand disability respectfully

Collaborate with families

Open communication with families is essential as they hold critical insight into the young person's presentation, coping strategies and recovery journey.

Teachers are encouraged to:

- seek guidance from parents/carers regarding triggers, fatigue and emotional needs
- communicate concerns early
- work collaboratively with disability inclusion staff, school psychologists and wellbeing staff
- understand any mental health plans or safety plans

Practical strategies to support wellbeing

Believe in abilities while providing appropriate support

Young people benefit when teachers believe in their abilities while also understanding their support needs.

Helpful approaches include:

- focusing on strengths and interests
- celebrating progress, not just academic achievement
- avoiding deficit-focused language
- encouraging independence where appropriate
- providing adjustments discreetly
- ensuring supports preserve dignity and autonomy



With support and encouragement, young people can achieve and thrive in their secondary school education

Support identity, confidence and future aspirations

Adolescence is a critical period for identity development. Young people after hemispherectomy may experience challenges related to:

- confidence
- body image
- fear of judgement
- uncertainty about the future
- grief regarding changed abilities

Teachers can positively influence self-esteem by:

- recognising the student beyond their disability
- encouraging participation in leadership and interests
- supporting realistic but optimistic future pathways
- affirming resilience and capability



Freya at her Year 12 Graduation

Further information about hemispherectomy

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.

Resources to support educational inclusion for students with disability

InclusionED

InclusionED is a professional learning platform dedicated to fostering inclusive school communities and offers evidence-based practices and resources for teachers and school leadership

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

Australian Education Research Organisation

Provides practice guides on:

- planning adjustments
- classroom inclusion
- explicit teaching
- behaviour support

<https://www.edresearch.edu.au/resource-collections/supporting-diverse-needs-students>

All Play Learn

Resources, information and strengths- and evidence-based strategies for secondary school teachers and education support staff that aim to help create inclusive education environments for young people with disabilities and developmental challenges.

<https://www.allplaylearn.org.au/secondary/>

