Hemispherectomy Foundation AUSTRALIA

Supporting children after hemispherectomy: A guide for early childhood educators

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Early childhood inclusion after hemispherectomy: A practical guide for educators

About this guide

This guide has been prepared for early childhood educators to support a better understanding of the safety, accessibility, and inclusion considerations for children who have undergone hemispherectomy surgery in early childhood education and care (ECEC) settings. It provides practical information to assist educators in promoting the safety, wellbeing, and inclusion of the child, enabling them to participate as fully as possible in their play and learning experiences.

The Hemispherectomy Foundation Australia acknowledges the expertise of ECEC educators in fostering the learning, development and participation of young children. Educators 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

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Hemi hero Eleanor

Hemi hero Malu

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).

A hemispherectomy may be performed when seizures 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.

Common challenges in children

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 explains these challenges, along with important safety, accessibility and inclusion considerations for early childhood educators and carers supporting these remarkable children. In addition to information in this guide it is important that Individualised support available through the Commonwealth Inclusion Support Program also be explored to help address barriers to inclusion that children may experience following hemispherectomy.

Physical disability

Because the motor cortex of one brain hemisphere is removed or disconnected during a hemispherectomy, all children will experience a hemiplegia, which is weakness and paralysis on one side of the body. Most children walk after surgery, usually with the support of an ankle and foot orthosis (AFO), such as the one below. Some young children may require the use of a wheelie walker while their muscles and balance develop for independent walking.

Fostering safety, inclusion and accessibility

- **Hemiplegia affects balance and coordination**. Most children will require a stabilising ankle and foot orthosis to walk safely. **Hemiplegia makes children more vulnerable to falls** and being knocked over, particularly in busy preschool environments. Participation in play is important but be aware of uneven surfaces, busy environments and play equipment that may pose risks.

- **Handrails** on both sides of stairs and steps will be needed to provide balance and support to prevent trips and falls.

- **All children will lose fine motor function in one hand**. This loss will affect 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 effected 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 drawing or painting. Links to helpful aids for preschoolers can be found on the Hemispherectomy Foundation Australia website

Remain open and receptive to the strategies of the child's occupational therapist and physiotherapist to support their safety, participation and inclusion. Collaboration between educators and therapists will also support a whole-of-team approach in which everyone working with the child is providing consistent and aligned support.

The Best Practice Framework for Early Childhood Intervention has many tools and resources to guide and support best practice team approaches.

Hemi hero Shakaia

Educators 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, 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 offer outreach services and can provide strategies on supporting safety while also optimising the participation of the child in their play and 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).

Hemi hero Goldie

Fostering safety, inclusion and accessibility

In an ECEC setting, the child may be unable to see the educator if children are seated (eg on a floor mat) and the educator is in their blind field. A central seating location is important.

Children may bump into other children in a crowded environment, such as in a bathroom when all the children are washing hands before meals or when collecting bags.

A child may need close supervision during these times to ensure their safety.

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

Fatigue

Physical, cognitive and emotional fatigue is prevalent in hemispherectomy children. Fatigue has a physiological basis in children as one brain hemisphere is required to do the work of two.

Combined with their with physical and visual disability young children can become tired much sooner than their peers. Sleep disturbances are also common.

Educators and carers need to be aware of the child's vulnerability to fatigue and provide appropriate breaks for rest.

Fostering 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 activity for when the child is less likely to be fatigued and become familiar with the signs the child is becoming fatigued (such as zoning out or slower response times) and arrange appropriate rest breaks and quiet time.

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 and significantly effect a child's participation.

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:

- **Delays in language development**
- **Difficulty with learning to read**
- **Auditory processing disorder**
- **Challenges with spatial awareness**
- **Difficulties with memory and attention**

Fostering safety, inclusion and accessibility

* Repeat and simplify instructions and try and reduce background noise. Children may need a skill or activity 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 child to demonstrate.
* A visual schedule or poster can be used to outline or model the task. Some children may find it easier if they can use gestures or to point to the correct answer instead of talking.
* Like all children, hemispherectomy children will learn best when learning is fun - include music and simple games in their learning experiences.

Hemi hero Mikey

Hemispherectomy children are unique learners

Emotional considerations and sensory overstimulation

Medical trauma

A child 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 disorder can occur in children following hemispherectomy and educators need to be cognisant of these experiences and how they may affect the child in their early childhood environment.

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 toys or pencils, or similar behaviour. They may over-respond to light, sound, certain food or play item textures (e.g. Play Doh), and find them extremely difficult.

Acquired disability

A child may also experience frustration as they adjust to new physical limitations from hemispherectomy.

Fostering safety, inclusion and accessibility

Significant 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, how escalating situations can be avoided or reduced, and how they can best be calmed and comforted, or supported to calm themselves. A behavioural support therapist can provide advice and assistance.

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. Apply your professional expertise in understanding how to best support children experiencing emotional dysregulation and/or overstimulation.

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 language 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 hemispherectomy child, other children can develop empathy, social skills and lays the foundation for inclusive behaviours and attitudes. This 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. Here are some books and TV episodes to help young children develop an understanding of disability. Strategies to support peer connection are also available (allmeansall.org.au)

Parents

Ongoing communication between early childhood educators and parents is also crucial for ensuring the best possible care and education for these unique learners.

The National Best Practice Guide for Early Childhood Intervention has resources for ECEC educators on developing positive partnerships with parents and carers.

Fostering safety, inclusion and accessibility

It is recommended that an in-depth meeting with parents/carers occurs prior to ECEC attendance. This should gather information about the child's current abilities and challenges to understand their specific needs and any ongoing therapies they are receiving. A medical plan will be required if the child has a shunt or experiences seizures.

Establish a communication plan to determine preferred methods of communication (e.g., communication book, daily logs, emails, face-to-face meetings) and establish a regular schedule for updates. Involve therapists when necessary. (e.g. occupational therapists, speech therapists).

Consider asking parents to prepare a social story or share our social story ("I am me") with the child's peers to help them understand, encourage questions, highlight the child's strengths and reinforce inclusive attitudes.

Some activities to help preschooler peers build empathy and understanding

Here are some gentle, guided activities that educators might like to use to help preschoolers explore the experiences of a child who has had a hemispherectomy. The goal isn't to imitate disability in a way that feels like playacting but rather to help the child's peers build empathy and awareness of how everyone children can have different abilities yet fully participate.

One-Hand Challenge

Purpose: to help children to understand what it's like to do things with one hand.

Activity ideas:

- Have children try to button a shirt, open a container, or draw using only one hand.

Pair children so each uses one hand — one child uses their left hand, the other their right — to complete a task together (like building a block tower; completing a puzzle).

Discuss: What happens when we work together? Was it tricky?

Seeing Game

Purpose: To explore the impact of having a visual field cut.

Activity idea:

To create a "hemianopia" simulator that mimics the loss of vision on one side, take some old eyeglasses and opaque tape to cover the outer side of one lens and the inner side of the other. Ask the children to find objects in the room while looking straight ahead.

Discuss: What did that feel like? Did they need to turn their head more to see?

Feelings and Story Time

Purpose: To build empathy and emotional understanding.

Activity:

- Read our social story "I am me" about a child who has had a hemispherectomy or some of the picture books about children with disability recommended by the Association of Children with Disability

Discuss: Talk about how everyone's brain and body work differently, and that's okay.

Key messages and strategies

Children who have had hemispherectomy are capable, resilient and unique learners. With thoughtful support, they can thrive, participate and belong in early childhood environments.

Key messages

Every child is unique, but common experiences include:

- **Physical:** Weakness on one side impacting balance and coordination
- **Vision:** Loss of half the visual field affecting peripheral and central vision
- **Cognitive:** Differences in learning, attention, memory and processing
- **Fatigue:** Physical, emotional and cognitive tiredness occurs more quickly
- **Communication:** Possible speech and language challenges
- **Emotional & Sensory:** Effects of medical trauma and sensory sensitivities

Key strategies

- Provide clear, uncluttered spaces and supervise in busy environments
- Ensure support for mobility (e.g. handrails, safe play surfaces)
- Use adaptive tools to support participation
- Position the child centrally during group activities
- Encourage scanning of environments and materials
- Break tasks into small, manageable steps
- Provide rest breaks and quiet spaces
- Celebrate strengths and achievements to build confidence

Further information and resources

Hemispherectomy Foundation Australia
https://hemispherectomyaustralia.org.au/

Paediatric Epilepsy Surgery Alliance
https://epilepsysurgeryalliance.org/

Evidence-based information on hemispherectomy and hemispherectomy outcomes. 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.

All Play Learn
https://www.allplaylearn.org.au/early/

Resources, information and strengths- and evidence-based strategies for early childhood educators to help create inclusive education environments for children with disabilities and developmental challenges.

ACD - Advocating for Children with a disability
https://acd.org.au/professional-development-for-early-childhood-educators/

Provides information on how to support children with additional needs or disability in early childhood settings to help ensure that all children are supported and included.

The Royal Children's Hospital
https://www.rch.org.au/kidsinfo/fact_sheets/Brain_injury_Cognitive_fatigue/

A helpful fact sheet explaining fatigue following paediatric brain injury

The National Best Practice Framework for Early Childhood Intervention
https://www.health.gov.au/our-work/national-best-practice-framework-for-early-childhood-intervention

Helpful tools and strategies to support whole of team approaches for children with developmental delays and disability.

Australian Alliance for Inclusive Education
https://allmeansall.org.au/

Provides and Inclusion Toolkit for Educators to assist educators to welcome and support diverse learners .

About my child

MY CHILD LIKES:

MY CHILD DOES NOT LIKE:

MY CHILD NEEDS HELP WITH:

MY CHILD CAN INDEPENDENTLY:

MY CHILD IS FATIGUED WHEN THEY:

MY CHILD NEEDS THE FOLLOWING WHEN THEY ARE FATIGUED:

MY CHILD IS EXPERIENCING SENSORY OVERLOAD WHEN:

MY CHILD NEEDS THE FOLLOWING WHEN THEY ARE EXPERIENCING SENSORY OVERLOAD:

OTHER THINGS TO KNOW ABOUT MY CHILD ARE: