Understanding Your Child's Diagnosis

A guide for parents of children with childhood dementia conditions

childhood dementia
INITIATIVE

Dear parent,

Receiving a diagnosis of childhood dementia for your child is life-changing. You might not have heard of childhood dementia before or the specific condition your child has been diagnosed with - there are over 140 genetic conditions under this umbrella. It's completely normal to experience a range of emotions including shock, grief and disbelief at this time.

We want you to know that while this journey will be challenging, you are not alone. Other parents have stood where you stand now, and they have found their way forward.

Take things one day at a time. It's okay if you can't process all the information right now. This guide will be here when you're ready.

> **"Whatever terminology you're going to use [about your child] is going to be confronting. But using 'childhood dementia' would have given me a better path, to know where to go and look for information."**
>
> **—Parent of a child with a childhood dementia condition**

> **"I honestly sat up for months and months and months on end Googling everything."**
>
> **—Parent of a child with childhood dementia**

What is childhood dementia?

Childhood dementia is an umbrella term for more than 140 rare genetic disorders that cause progressive brain damage.

- These conditions are caused by genetic changes
- They affect approximately 1 in 2,900 babies
- Symptoms can begin in infancy, later in childhood or adolescence
- Symptoms impact multiple parts of the body, not just the brain

The key feature of childhood dementia is the progressive loss of previously acquired developmental skills after a period of typical or near-typical development.

How childhood dementia affects your child

Every child's experience with childhood dementia is unique. Your child might not be experiencing any symptoms yet, or their symptoms may be mild and subtle at first. The progression varies widely from one condition to another and even between children with the same condition.

While each condition follows its own pattern, your child may experience:

Cognitive changes:

- Memory loss and confusion
- Difficulty concentrating, understanding and learning
- Problems with thinking and reasoning
- Difficulty communicating

Behavioural and emotional changes:

- Personality changes
- Emotional disturbances such as anxiety and fear
- Sleep disturbances
- Changes in social skills

Physical changes:

- Difficulties with movement and coordination
- Seizures
- Vision or hearing changes
- Effects on other body systems (heart, digestive system, bones, etc.)

While childhood dementia conditions are currently life-limiting, ongoing research continues to look for treatments. In the meantime, you can aim to give your child the best possible quality of life and create meaningful experiences and memories together.

Your rights as a parent

You and your child have important rights as you navigate this journey:

The right to be recognised as the expert on your child

- You know your child best
- Your understanding and insight are essential to providing appropriate care
- You are best positioned to make healthcare decisions for your child, in consultation with your medical team. You are entitled to seek further medical advice if you need to
- It can take time to build this expertise, especially around your child's diagnosis. This is ok

The right to clear information and understanding

- You deserve healthcare providers who take time to research your child's specific condition
- You <u>should</u> receive explanations in terms that make sense to you
- Your healthcare team should check that their understanding of your circumstances and needs matches yours
- You have the right to seek advice about family planning and / or genetic counselling if you choose.

The right to learn about treatments, research and clinical trials

- You <u>can</u> ask about current research, clinical trials and potential treatments
- You <u>can</u> connect with other specialists who are knowledgeable about your child's condition
- You can reject the status quo and push boundaries until all possible opportunities for therapeutic intervention have been exhausted.
- You should be connected with quality of life support for your child through the palliative care team; palliative care is not only end-of-life support.

The right to compassionate care

- You and your child deserve to be treated with respect, care, dignity and kindness
- Your healthcare team and service providers should listen attentively and follow through on commitments
- Your healthcare team should recognise how childhood dementia impacts your entire family

The right to hope

- While childhood dementia is life-limiting, hope takes many forms
- Your hope might focus on ensuring your child won't suffer unnecessarily
- You can hope for effective symptom management and quality care
- Hope includes creating meaningful experiences and memories with your child

When you're ready: next steps

As you navigate this challenging journey:

Document everything

- Keep a record of appointments, medications and observations about your child
- Prepare questions before appointments and take notes during them
- Consider bringing someone with you to appointments to help listen, record and remember information

Navigate healthcare, disability and education systems

- Work with healthcare specialists who understand rare conditions
- Connect with the National Disability Insurance Scheme (NDIS) for support
- Engage with your child's school/childcare about their changing educational needs
- Consider reaching out to your local Member of Parliament (State and Federal) to inform them about your child and family facing this challenging diagnosis. Increasing their knowledge and understanding of childhood dementia may enable them to advocate on your behalf.

Build your support team

- Look for healthcare providers who listen to you and respect your knowledge of your child
- Connect with other parents facing similar challenges, when you're ready
- Accept help from others when it's offered

Take care of your whole family

- Childhood dementia affects everyone in your family
- Seek support for yourself and for your child's siblings
- Remember that taking care of yourself is an essential part of caring for your child

Where to find help

Childhood Dementia Initiative

Website:
childhooddementia.org

Join the Childhood Dementia Online Community:
https://www.childhooddementia.org/join-us/for-families/online-community

If you're struggling with the emotional impact of the diagnosis:

Lifeline: 13 11 14

Beyond Blue: 1300 22 4636

Practical tip: Consider researching the specific genetic condition your child has been diagnosed with. Each condition has unique characteristics and may have dedicated support groups.

Remember: You don't have to navigate this journey alone. Many parents have walked this path before you and found strength they didn't know they had.

> "Despite the challenges, we're committed to giving our child the best possible life."
>
> **—Parent of child with childhood dementia**

This guide is intended as general information about childhood dementia.
For specific information about your child's medical condition please consult a healthcare professional.

Co-designed with parents whose lived experience with childhood dementia has shaped every aspect of this resource.
For more information: www.childhooddementia.org