

Supporting a Family Affected by Childhood Dementia

A guide for grandparents,
family members & close friends

**childhood
dementia**
INITIATIVE

Understanding childhood dementia

Learning that a child in your family or close circle has been diagnosed with a childhood dementia condition can be overwhelming. This may be the first time you've heard this term. You may feel confused, shocked or deeply saddened. These feelings are normal and valid.

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

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

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

Impact on the child

Each child's experience with childhood dementia is unique. The progression varies widely between conditions and even between children with the same condition. Some common experiences include:

Cognitive changes:

- Memory difficulties
- Problems with learning and understanding
- Difficulty communicating

Physical changes:

- Changes in mobility
- Seizures in some conditions
- Vision or hearing changes
- Coordination difficulties

Behavioural and emotional changes:

- Changes in personality
- Sleep disturbances
- Changes in social interactions

What the family is going through

When a child is diagnosed with childhood dementia, the entire family experiences significant changes:

- **Parents** become advocates, medical coordinators, and carers while processing their own grief, including anticipatory grief
- **Siblings** may feel confused, worried, or receive less attention than usual. They can take on a young carer role.
- **Daily life** becomes filled with appointments, research, and adapting to changing needs
- **The future** suddenly feels uncertain and requires new planning

Parents must navigate complex healthcare, disability, and education systems while providing emotional support to their child and managing their own feelings.

How you can support the family

Your support is invaluable. Here are practical ways to help:

Do:

- ✓ **Ask about the child** - Ask how they are and what might be happening
- ✓ **Listen without judgement** - Sometimes they just need someone to hear them
- ✓ **Offer specific help** rather than saying "let me know if you need anything"
 - Provide meals or help with household tasks
 - Offer childcare for siblings
 - Assist with transport to appointments
 - Research support services in your area
- ✓ **Work out what is helpful with the family** and then do it
- ✓ **Learn about the child's specific condition** - This both shows you care and helps you to understand
- ✓ **Be present consistently** - Your ongoing support means everything
- ✓ **Remember the siblings** - They need attention and support too
- ✓ **Respect the parents' decisions** about treatment and care
- ✓ **Allow all emotions** - Grief, anger, hope, and everything in between are normal

Don't:

- ✗ **Offer unsolicited advice or miracle cures** - The family will be working closely with medical specialists
- ✗ **Disappear because you don't know what to say** - Your presence is more important than perfect words
- ✗ **Compare their situation to others** - Each child and family's journey is unique
- ✗ **Say "it could be worse"** - this experience is worse than anything the family could have anticipated
- ✗ **Tell them to "stay positive"** or minimise their challenges
- ✗ **Take it personally if they decline invitations** - Their energy, time and capacity are limited
- ✗ **Make promises you can't keep** - Consistency and reliability are crucial
- ✗ **Stop asking or offering invitations** - The timing may not have been right the first time, but that may change. Keep checking in. This is a long journey and a long path.

Supporting yourself

Supporting a family affected by childhood dementia can be emotionally challenging. Remember to:

- **Acknowledge your own feelings** - Your grief and sadness are valid
- **Seek information** - Understanding the condition helps to process emotions
- **Find support** - Connect with others in similar situations
- **Take care of yourself** - You can provide better support when you're well
- **Be patient with yourself** - This is a learning process for everyone
- **Respect the family's limits and boundaries** - try not to take things personally

The importance of hope

Hope remains essential for families facing childhood dementia. While the journey may be difficult, holding onto hope provides strength and purpose:

- Research into childhood dementia is ongoing, with scientists working to understand these conditions better
- Progress is being made in developing potential treatments for some conditions
- Every child's journey is unique, and many children continue to experience joy, connection, and meaningful development
- Focusing on what's possible rather than limitations can transform the experience for everyone

Creating meaningful moments

One of the most precious gifts you can offer is helping create meaningful experiences and memories:

- Participate in favourite activities
- Take photos and videos
- Help maintain connections with friends and community
- Celebrate milestones and achievements of all sizes
- Experiences and activities can be a better gift than an item for birthdays and celebrations
- Focus on the present moment and what brings joy

Resources and support

For more information:

Childhood Dementia Initiative
Website: childhooddementia.org

Additional support:

Beyond Blue
Phone: 1300 22 4636
Website: beyondblue.org.au

Lifeline
Phone: 13 11 14
Website: lifeline.org.au

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