FOR DISABILITY PROFESSIONALS

Working with a child with dementia

A guide for disability professionals

childhood dementia INITIATIVE

What is childhood dementia?

A child you are currently working with, or about to start working with, has childhood dementia. This may be the first time you've heard the term, and you may be unsure how it will shape the work you do with this child and their family. This guide will help you get started.

Childhood dementia is an umbrella term for a group of serious conditions that cause a child's brain to progressively lose function over time. Unlike the dementia most people know in older adults, it begins before the age of 18.

These conditions are life-limiting, and there's currently no cure, although research is ongoing and gives hope for future treatment.

Children affected by childhood dementia gradually lose the ability to write, read, talk, walk and play. They may also experience seizures, changes in behaviour, and difficulties with sleep and feeding.

How childhood dementia presents and how quickly it progresses is different for every child.

What this means for your work with this child and their family

Each child's experience with dementia is unique, and their needs will change over time. You may see:

- Cognitive changes such as memory difficulties, problems with learning and understanding, and reduced attention or concentration
- Physical changes such as mobility or coordination difficulties, seizures in some conditions, vision or hearing loss in some conditions, and problems with feeding or swallowing
- Behavioural and emotional changes such as personality changes, sleep disturbances, difficulty with social interactions, and emotional disturbances such as anxiety and fear

Three things to keep in mind:

Skills and abilities will change

The skills and abilities the child has now will change as the condition progresses. Assessments, plans and therapy goals need to anticipate change and be flexible.

Early support matters

For a progressive condition, time matters. Early adjustments and interventions may help the child build and / or maintain skills, and support the family through change.

Goals need a different approach

For a child with dementia, goal setting looks different. The focus is on maintaining current skills and supporting comfort, quality of life and meaningful experiences.

What the family is going through

When a child is diagnosed with dementia, the entire family experiences significant changes. Understanding this helps you work well with the child and their family.

- Parents have become advocates, medical coordinators, and full-time carers while processing their own grief, including grief about what's ahead (This is known as anticipatory grief).
- Siblings may feel confused or worried, may receive less attention than usual, and can sometimes take on a young carer role.
- Daily life is filled with appointments, paperwork, phone calls and adapting to changing needs.
- There is a lot to navigate: families deal with health, education, disability and therapy, often across many providers with scattered information and having to retell their story over and over.

Some families have more than one child with childhood dementia. Because the conditions are genetic, siblings can have the same diagnosis. If this is the case, the family will be carrying even more.

How you can support the child and family

Families impacted by childhood dementia have shared some requests of the professionals working with them and their child.

Treat the family with respect, care and kindness

Listen carefully, confirm your understanding, and deliver on what you commit to. These small acts of respect show the family you see them as more than their child's diagnosis.

Acknowledge that parents are the experts on their child

Parents know their child better than any professional will. They are with their child day and night. Take their expertise seriously and bring your own experience alongside it. Work in partnership with parents using your expertise to reduce their burden, not add to it.

Get to know the child and their condition

Families don't expect you to know everything. A willingness to learn about the child's condition, and to be honest about what you don't know, goes a long way.

The Childhood Dementia Initiative website is a good starting point for learning about childhood dementia https://www.childhooddementia.org

How you can support the child and family (cont')

Set aside time for your first conversation with the family

Ask where they are with the diagnosis, what goals matter most to them, and who else is on the team.

Use your knowledge of the child's dementia to guide your work

Focus on what the child can still do, plan for changes, and expect skills to regress. When something becomes harder, adapt your support to meet the child where they are now.

Recognise the impact of childhood dementia on the whole family

When you work with the child, keep the whole family in view. Siblings and parents have their own needs, which may or may not be visible to you. Where it sits within your role, connect the family to supports for parents and siblings, or point them to someone who can.

What families have told us is...

Helpful

- **Come to the family well-briefed.**
- Review the file, care plan or referral in advance so the family isn't asked to repeat information already on record.
- Respond to concerns as they arise.
- For a child with a progressive condition, delay has real consequences. Where something comes to your attention between sessions or reviews, act on it rather than waiting.
- Reduce the family's administrative load where you can.
- Every task you take on is one less for them to manage.

Not helpful

- Overlooking what parents tell you.
- Parents live with the child's condition every day and often notice changes before anyone else does. Their observations carry real weight.
- Making promises you cannot keep.
- Families have often been let down before.
- Becoming less available as circumstances become more difficult.
- The family's needs will change. Maintaining contact matters.

Preparing for your first contact

A small amount of preparation goes a long way. Before your first call, meeting or session with the family:

- **Read the information your service already has,** including anything the family has already shared. Don't ask them to repeat what's already there
- **Learn about the child's condition,** so you have a sense of what the child is experiencing and what may lie ahead
- **Come with questions** rather than expecting parents to lead. Something like "What's working well right now?" can help start the conversation
- **Be clear about your role:** what you can offer, and who else is involved
- **Allow more time than usual.** First conversations with a family affected by childhood dementia take longer and can be more emotionally demanding than routine ones.

Working with the wider team

The child's care involves many people: parents, direct support workers, allied health professionals, medical specialists, teachers, and other services. Everyone works better when the team communicates well.

- Be a consistent point of contact for the family in the parts of their care that you're responsible for, and make sure they know who to speak to if you're away.
- Share relevant information with others involved in the child's care, with the family's consent, so the family doesn't have to repeat themselves.
- Hand over thoroughly if your role passes to another colleague. The family shouldn't lose history when staff change.

The importance of hope

Hope matters for the child, the family, and you. Providing hope doesn't mean minimising what the family is facing or promising outcomes. It means holding onto what's meaningful in the child's life now, staying honest about uncertainty, and pointing to what you do know and can do.

In practice, this looks like:

- Seeing the whole child, not only the condition they live with
- Recognising the things the child can still do and enjoy, being guided by parents who know their child best
- Being honest when you don't have answers, and clear about what you can offer
- Staying informed about developments in the field, and letting families know when something relevant emerges

Looking after yourself

Working with a child whose condition is progressing can be emotionally demanding, and it stays demanding regardless of experience. Support is available to you, both within your organisation and beyond it.

- Recognise your own emotional response. Grief, sadness and uncertainty are valid.
- Debrief with your manager or team after difficult conversations or sessions.
- Use your organisation's wellbeing supports where available.

Resources and support

FOR MORE INFORMATION

Childhood Dementia Initiative
childhooddementia.org/professionals

FOR FAMILIES

Childhood Dementia Initiative
childhooddementia.org/for-families

ADDITIONAL SUPPORT

Beyond Blue: 1300 22 4636

Lifeline: 13 11 14

This resource is based on Childhood Dementia Matters 2: **What families want health professionals and service providers to know, 2022** *and insights shared by families in associated focus groups*