

Using the term 'childhood dementia'

A guide for disability support workers
and professionals

childhood
dementia
INITIATIVE

| What is childhood dementia?

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.

| Why families use this term

The specific medical names for conditions that cause childhood dementia are long, complex, and largely unknown to the general public and many professionals. When families use the diagnosis name alone (such as Mucopolysaccharidosis 3 type A, or Niemann-Pick type C), they are frequently met with blank responses and must spend considerable time and emotional energy explaining the condition from scratch.

The term 'childhood dementia' bridges this gap. It draws on existing public understanding of dementia, and families reported it is the most effective term to communicate their child's condition to family members, healthcare professionals, service providers, educators and the community. While many found the term confronting at first, it quickly became the clearest and most useful language they had.

The term 'childhood dementia'

- Encapsulates what their child is going through in just two words
- Helps others understand regression and loss of skills, rather than just labelling the child
- Creates immediate recognition, as people understand dementia even if they have never heard the specific condition name

| How families respond to the term

Many families found the term confronting when they first encountered it. But for most, that initial discomfort quickly gave way to clarity and relief.

"I just think that it makes people understand really what she's going through. It's just been the easiest way to tell her story."

Parent, Childhood Dementia Initiative focus group

| Using the term respectfully

You may encounter the term 'childhood dementia' in care plans, referrals, assessments, professional handovers and conversations with families. Here is how to use the term well:

- Follow the family's lead on language. Some families use 'childhood dementia' readily and find it helpful; others may still be adjusting to the diagnosis and prefer to use the specific condition name. Ask if you are unsure.
- Use the term when communicating with other professionals or services where it helps convey the complexity and seriousness of the child's needs quickly and accurately.
- Be cautious using the term in front of the child and siblings unless the family has confirmed this is appropriate. Many children are not fully aware of their prognosis.
- If someone questions or challenges the term, you can explain that it is an umbrella descriptor used by families, clinicians, and researchers to describe more than 145 conditions with shared characteristics.
- Cultural background can also influence how a family understands and talks about childhood dementia, disability or life-limiting illnesses.
- Acknowledge that the term can be confronting for families who have received a recent diagnosis. Respond with patience, sensitivity, and openness.

| Key takeaways

✓ It's a legitimate umbrella term

For more than 145 rare conditions causing progressive neurological decline in children.

✓ Confronting, but helpful

The term is confronting initially, but families have found this directness helpful rather than harmful. It conveys appropriate gravity and prompts better professional responses.

✓ Follow the family's lead

Never use the term in front of the child without first confirming this is appropriate with the family.

✓ The clearest way families can communicate

It's the most effective tool families have for communicating their child's needs across health, disability, education and community systems.

✓ Supports faster understanding

Using the term in professional contexts, with appropriate sensitivity to the family's preferences, supports faster understanding and more suitable service responses.

| 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