

Using the term 'childhood dementia'

A guide for teachers and school staff



| A student with childhood dementia may be in your school

You may have a student in your school or class who has been diagnosed with a condition resulting in childhood dementia whose family uses that term to describe their condition.

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 prefer this term to be used

Families reported that 'childhood dementia' is the most effective term to communicate their child's condition to family members, healthcare professionals, service providers, their child's teachers and school and the general community. While many found the term confronting at first, it quickly became the clearest and most useful language they had. '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

Teachers and school staff may encounter the term 'childhood dementia' from families, or in communications with allied health professionals. Here is how to use it well:

- Follow the family's lead on language. Some families use 'childhood dementia' readily and find it helpful; others may still be processing the diagnosis and prefer the specific condition name. Ask if you are unsure.
- Share diagnosis information only with those who need it, and only use the term with the family's knowledge and consent.
- With consent, use the term with other staff, external professionals, or services where it helps convey the nature and seriousness of the student's needs quickly and accurately.
- Be cautious about using the term in front of the student, siblings, classmates or other parents, many children are not fully aware of their prognosis.
- If colleagues question or are unfamiliar with the term, explain that it is an umbrella term used by families, clinicians, and researchers to describe more than 145 rare genetic conditions that share the characteristic of progressive neurological decline in children.
- Acknowledge that the term can be confronting for families who are newly diagnosed or still adjusting. Cultural background can also shape how a family understands and talks about dementia, disability or life-limiting illnesses. Approach every conversation with sensitivity and openness, and be guided by the family on the language and level of detail that feels right for them.

| Key takeaways

✓ It's a legitimate umbrella term

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

✓ Confronting, but helpful

Most families found the directness clarifying rather than distressing once they used it.

✓ It's the clearest way families can communicate

Their child's condition to school staff and the community.

✓ Follow the family's lead

Never use the term with a student or in front of classmates without confirming this is appropriate with the family.

| 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