

Communicating with families of children with dementia

A guide for support workers, teachers and professionals

childhood
dementia
INITIATIVE

| Before you start the conversation

Let the family set the pace

- Take a trauma-informed approach by recognising that families affected by childhood dementia often carry the weight of previous difficult conversations - diagnosis, hospital admissions, or watching their child's condition progress. This means prioritising the family's sense of safety, trust and control throughout the conversation, rather than focusing only on the information you need to share. In practice, follow the family's lead rather than your own agenda. Some families will want to talk in detail and others need to take things in stages. Don't press for information they're not ready to share.

Choose a private, unhurried moment

- These conversations deserve a time and space where the family won't be interrupted or rushed - not a corridor or drop-off exchange, or as they are walking out the door.

Understand emotional energy

- These conversations can be draining for parents in ways that aren't always visible. A short, calm exchange can still leave a family depleted for the rest of the day.

Ask specific, not open-ended, questions

- "How is [child] finding the new routine at school?" or "How has [child] adjusted to the change in [service or worker]?" is easier to answer than "How's everything going?" Specific questions give a family something manageable to respond to.

| What helps and what to avoid

What helps

- Listen without trying to fix everything
- Accept the family's reality without denial or false reassurance
- Respect their decisions, even if you don't fully understand them
- Keep showing up, especially as things get harder
- Let them know it's okay not to talk about what you wanted to discuss today. Offer to meet at a time that suits them

What to avoid

- Offering unsolicited advice, miracle cures, or "have you tried..."
- Saying "stay positive" or "don't think about the future"
- Comparing their child's milestones to other children's without being asked
- Making the moment about your own feelings or fears
- Pushing for details the family hasn't chosen to share

| If a family becomes upset or shuts down

That's a normal response, not a sign you've done something wrong. Acknowledge it gently – "I can see this is a lot, there's no pressure to talk more now" – and let them know you're there when they're ready.

| Different ways families may want to communicate

- Some families may prefer written communication over a conversation, such as an email or a note, particularly for sensitive updates.
- Parents may nominate a trusted support person to communicate on their behalf. Confirm early on who to direct updates or questions to, so they aren't repeating themselves.
- Sometimes parents will share something with you informally and unplanned, such as during an appointment, a home visit, or in passing conversation. Follow their lead in that moment rather than asking for more detail.
- With parents' consent, keep other staff or team members who interact with them briefed, so information isn't repeated unnecessarily across different people.

| 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