

Healthcare Rights Guide

For parents of children with a childhood dementia condition

**childhood
dementia**
INITIATIVE

What is this guide?

When your child has a childhood dementia condition, the healthcare system can feel overwhelming. This guide gives you practical ways to talk with healthcare providers and stand up for your child's needs.

Your rights as a parent

As a parent, you have the right to:

- Be seen as the expert on your child
- Get clear information you can understand
- Ask questions until things make sense
- Have specialists talk to each other
- Ask for second opinions without being judged
- Be treated with respect and kindness
- Question medical advice when you have concerns
- Hope and look for the best treatment options

Getting ready for medical appointments

Good preparation helps

- **Make a summary about your child for new doctors**
 - Include their diagnosis, main symptoms, medicines, allergies, and specialists' names
 - List recent changes or worries you want to talk about
- **Write down your questions in order of importance**
 - Don't rely on your memory in stressful situations
 - Focus on what you really need to know
- **Bring important papers**
 - Test results or reports
 - List of current medicines and doses
 - Notes from other specialists
- **Bring someone with you**
 - A family member or friend can help remember what was said
 - Ask them to take notes while you focus on talking and listening to what the doctor has to say
- **Request a longer appointment if you have a number of issues to discuss**
- **Ask for an interpreter if you have difficulty communicating in English**

Helpful things you can try saying:

When meeting a new specialist

- ➔ Before we start, I'd like to know what your role will be in my child's care.
- ➔ Do you know about [condition]?
- ➔ Will you talk with my child's other doctors?
- ➔ How long will you be part of my child's care team?
- ➔ I've made a summary of my child's medical history. Would you like to see it now to help understand our situation?

When you need better explanations

- ➔ I don't quite understand. Could you please explain that in a different way?
- ➔ I need to explain this to my family. Could you help me understand the main points?

When you don't agree with what's suggested

- ➔ I understand what you're suggesting, but I'm worried about [specific concern]. Could we talk about other options?
- ➔ From what I know about my child, I think [different approach] might work better because [reason]. Could we try that?
- ➔ Please help me understand how this approach will help us reach our goals.

When you need doctors to talk to each other

- ➔ My child sees several specialists. How will you talk with Dr. [Name] who helps with my child's [specific issue]?
- ➔ Could we set up a meeting with all the doctors involved in my child's care? It's hard for me to keep everyone updated.

When you feel rushed or not heard

- ➔ I know you're busy, but I need to talk about [specific concern] today. It's important for my child's care.
- ➔ I've noticed [specific symptom/change] that seems important. I'd like to make time to talk about this today.

When asking for a second opinion

- ➔ I'd like to learn as much as possible about my child's condition. Could you suggest another specialist who might help?
- ➔ I value your opinion, and I'd also like to talk with another specialist about this issue. Could you refer me?

When waiting for a follow up or referral

- ➔ Did you send my referral to [the other doctor]? Can you send me a copy and their contact details so I can follow up?

Keeping track of medical information

Make a medical folder or computer file

Include:

- Medical reports and test results
- Medicine/ medication history
- Appointment notes
- Questions and concerns
- Contact details for all doctors

Ask for copies

- Ask for copies of notes, test results, and treatment plans, either hard copy or sent by email
- Check them for mistakes and follow up if needed
- Share them with other healthcare providers

Keep a symptom diary

- Write down symptoms, medicine changes, and how they worked, including days dates and times of day, if relevant
- Look for patterns that might help your child's care
- Share these notes with doctors

When you're not being heard

1. Be clear about your concerns

- Stick to the relevant facts rather than feelings
- Explain how the issue directly affects your child and / or your family

2. Take the right steps

- Start by talking directly with the doctor
- If that doesn't work, talk to the manager or department head
- Ask for a different doctor if needed

3. Use formal complaint paths when needed

- Learn the complaint process for the hospital or clinic
- Contact the patient liaison officer
- Keep records of all talks and emails

Dealing with multiple specialists

1. Ask for a care coordinator

- Some hospitals have staff who can help manage complex cases
- If not available, ask which doctor should take the lead

2. Create your own central record

- Keep your own complete file
- Bring copies to all appointments
- Make sure all doctors have the same information

3. Ask for team meetings

- Request meetings that include all relevant specialists
- Take an active part in these talks

Looking after yourself

Know when you need help

- Standing up for your child can be tiring
- It's okay to take breaks - a break can be as simple as a cup of tea, or as big as a weekend away

Talk with other parents

- Share experiences and ideas
- Learn from others who've been through this

Use help that's available

- Accept help. Be open to this, more than you may have been in the past.
- Patient support services
- Support groups
- Patient/condition - specific organisations
- Childhood Dementia Initiative resources

Remember that being a good advocate for your child and family is not a sprint – it can be a long journey. Be firm and stand your ground when you need to, but also be kind to yourself along the way.

Resources

- **Childhood Dementia Initiative:** childhooddementia.org
- **Australian Commission on Safety and Quality in Healthcare** - Information about healthcare complaints: <https://www.safetyandquality.gov.au/consumers/information-about-healthcare-complaints>