Children's Tumour Foundation
CONQUERING NF

A guide to self-advocacy

Your lived experience is powerful. Use this guide to help decision makers improve care and support for NF.

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Part 1: Understanding advocacy

What is Advocacy?

Advocacy, or to advocate, means to courageously speak out for yourself, or for someone else. It can bring about change, improve services, or raise awareness of an issue. There is no wrong way to start, and no experience too small to share.

Why your lived experience is expertise

You don't need to be a researcher or a policy expert to make a difference. You are the expert in your own experience. By sharing your story respectfully and constructively, you help decision-makers understand the real impact of the systems they create.

Sharing your lived experience journey can:

- Highlight gaps between policy and what happens in people's lives.
- Put a human story behind statistics and reports.
- Help other families feel less alone and show them that speaking up is possible.
- Build a record, over time, of the issues that matter most to the NF community.
- Influence how services, funding and support are designed in future.

Our Collective Voices

Before you write a single word, remember that you are not alone. Around 2 million Australians live with a rare disease. While every person's experience is different, many of the challenges faced by people living with NF are shared across the broader rare disease community.

The Children's Tumour Foundation

The Children's Tumour Foundation of Australia (CTF) is Australia's only dedicated advocacy and support service for children, adults and families affected by Neurofibromatosis: NF type 1, NF type 2- Schwannomatosis and Shwannomatosis.

More than 13,000 people live with NF in Australia, and on average a child is born with NF every three days.

CTF exists to raise awareness, provide support and connection, and advocate for NF as a national health priority. Our advocacy is strongest when we stand alongside and amplify the voices of the NF community. Every story shared, letter written and conversation started strengthens our collective voice and helps build momentum for change.

The NF Health and Social Impact Assessment

In June 2024, CTF launched Australia's first NF Health and Social Impact Assessment, at an event held at Parliament House with representatives from across the political spectrum in attendance. Built from the shared experiences of people living with NF and their families, the report set out six key findings and recommendations that now guide CTF's ongoing advocacy, a roadmap toward policy reform and better healthcare delivery, nationally.

Why this matters for your advocacy

The Assessment shows that many of the challenges people affected by NF describe: delayed diagnosis, difficulty accessing specialists, fragmented care between services are shared patterns, not isolated incidents. You may not be the only person this has happened to. When you share your story, you're adding another data point to an already-documented pattern, which makes it harder to dismiss as a one-off, and together makes the case for change at a national level.

Know Your Rights:
The Australian Charter of Healthcare Rights

Before you advocate, it helps to know what you are entitled to. The Australian Charter of Healthcare Rights describes the rights that you, or someone you care for, can expect when receiving health care anywhere in Australia. This means public or private hospitals, day procedure services, general practice, specialist clinics and community health centres.

Advocacy isn't just about asking for a favour. Often, you are exercising a right that already exists.

The Charter describes seven key rights:

1. **Access:** You have the right to access health care and services that meet your needs.
2. **Safety:** You have the right to receive safe and high-quality care that meets the national standards.
3. **Respect:** the right to be treated with dignity, and to have your culture, identity, beliefs and choices respected.
4. **Partnership:** the right to be included in decisions and choices about your own care, or the care of the person you look after.
5. **Information:** the right to clear information about your condition, treatment options, services and costs, given in a way you understand.
6. **Privacy:** the right to have your personal information kept private and confidential.
7. **Give feedback:** the right to comment on your care and to have any concerns you raise addressed.

Knowing these rights can help you frame your advocacy. Instead of "I'm complaining," you can say: "Under the Charter of Healthcare Rights, I have a right to Partnership, to be included in decisions about my care and I didn't feel that happened."

Advocating for a child

If you're advocating on behalf of a child or young person with NF, a companion document, the Charter of Rights for Children and Young People in Healthcare Services sets out additional rights specific to paediatric care, including the child's right to be heard and involved in decisions at a level appropriate to their age. It's worth mentioning this Charter by name if a hospital's paediatric service isn't involving your child in conversations about their own care.

Part 2: Getting started

The SHARE Framework: A Simple Way to Tell Your Story

Below is a step-by-step tool to empower your voice to be clear and solution-focused.

S	**Say who you are**	Introduce yourself. Are you a constituent, a person living with NF, a parent or carer? Where do you live?
H	**Highlight your experience**	Describe what happened. Keep it specific and factual, what service, what date, what occurred.
A	**Affect**	Explain how it affected you, or your family. This is where your lived experience carries the most weight.
R	**Recommend a solution**	If you can see a gap, suggest how it could be improved. You don't need all the answers even a small idea helps.
E	**End with your request**	Be clear about what you are asking for a meeting, a response, support for an issue, or an answer to a question.

Examples of requests:

- "I'd like a meeting to discuss this further."
- "Please consider raising this issue with the Department of Health."
- "Could your office look into why this service isn't available in our region?"
- "I'd appreciate your support for improved access to NF specialists."
- "Can you tell me what is being done about this issue?"

Asking questions is a great way to encourage a response.

Know your message

Before you write, speak or meet with anyone, take a few minutes to think through your message and your emotions.

Healthcare is deeply personal, and sometimes a letter written fast, with raw emotions is not the most helpful approach.

Useful reflection questions, like: What happened? What worked well? What am I concerned about? What could have been better? What change would I like to see? How did it make me feel?

Where can you advocate?

Advocacy doesn't only happen through Parliament. Depending on the issue, there are several places your voice can go. Choose the space that matches what you want to change.

1. A local hospital or health service

Every public hospital and health service in Australia has a feedback or complaints process, sometimes called Patient Liaison, Consumer Feedback, or a Feedback and Complaints line. This is often the fastest way to raise an issue directly with the service involved, and it exercises your right to Give Feedback under the Charter.

- Ask reception or check the hospital's website for its "Feedback and Complaints" or "Patient Experience" contact.
- Most services can accept feedback by phone, online form, email or in person.
- You can give positive feedback too it helps good practice continue.

For Hospital care related advocacy this is a great place to start.

2. Your state or territory Health Complaints Commissioner

If a concern is about the quality or safety of care, or you're not satisfied with a hospital's own response, you can contact your state or territory's independent health complaints body. These services are free.

NSW	Health Care Complaints Commission (HCCC)
VIC	Health Complaints Commissioner and Mental Health Complaints Commissioner
QLD	Office of the Health Ombudsman
WA	Health and Disability Services Complaints Office (HaDSCO)
SA	Health and Community Services Complaints Commissioner (HCSCC)
TAS	Health Complaints Commissioner
ACT	ACT Human Rights Commission (Health Services Commissioner)
NT	Health and Community Services Complaints Commission (HCSCC)

Details change from time to timesearch "[your state] health complaints commissioner" to confirm current contact details or ask the Foundation for help finding the right one.

3. The NDIS

The NDIS is reviewed and reshaped through ongoing parliamentary inquiries and public consultations, and lived experience is central to that process. This is different from advocating for your own individual plan or a provider issue. It is about contributing your story to shape how the Scheme works for the whole NF and rare disease community.

Ways to take part in systemic NDIS advocacy:

- **Parliamentary Joint Standing Committee on the NDIS:** regularly runs public inquiries into how the Scheme is working. Anyone can make a written submission describing their experience.
- **NDIS consultations and reviews:** the NDIA and Department sometimes open public consultations on specific changes. Anyone can write or sometimes attend these.
- **Sharing your story with the Children's Tumour Foundation:** CTF can use collected and de-identified experiences (like those gathered for the NF Health and Social Impact Assessment) to help advocate for NDIS access for the NF community.

If your issue is about your own individual NDIS plan, a specific decision, or a provider that calls for a different kind of support, and is covered in a separate, dedicated guide to individual NDIS advocacy.

4. Public and community advocacy

- Open letters shared publicly (e.g. on social media) can raise awareness.
- Sharing your story with the Children's Tumour Foundation helps build a collective picture of the issues affecting the NF community, which strengthens broader advocacy.
- Media and community events can also be powerful spaces to raise awareness, when you feel ready.

5. Your Member of Parliament

Members of Parliament (MPs) represent the people and communities who elect them. Sharing your lived experience can help an MP understand how policies and services are working in people's everyday lives. They may be interested in what is working well, where gaps exist and where change may be needed. You don't need to be a political expert to contact an MP. Your expertise is your lived experience.

State or Federal: Who Should I Contact?
Not sure who to contact? That's okay. Your local MP's office can often help direct your enquiry, even if the issue falls outside their area of responsibility.

I want to talk about:	I should contact:
Australian healthcare policy	Federal Health Minister
Medicare or the PBS	Federal Health Minister
A hospital in your state	State Health Minister
A local issue	Your local MP
National policy	Your Federal MP
State services	Your State MP

Remember:

- You don't need to understand every level of government before speaking out.
- Use the SHARE framework to structure your experience.

Finding your representative:

1. Visit Australian Electoral Commission
2. Enter your postcode
3. Find your local representative
4. Locate their email, or phone number

Writing a letter: Helpful tips

- Include your name and address so your recipient knows you are.
- Keep your letter to one or two pages that have a clear, concise message.
- Be respectful. You can be honest about your experience while remaining polite.
- Share your lived experience, using the SHARE framework
- Follow up if needed. If you haven't received a response after a few weeks, it is okay to politely follow up.
- Sharing your letter publicly? Remove your address and personal details and identify it as an Open Letter. If possible, send it to the recipient before posting it on social media.
- Avoid assuming the reader knows about NF. Include a description.
- Get support, if you need it. You can ask someone you trust to help organise your ideas, improve spelling or turn your notes into a clear letter. If using AI, use the SHARE framework in your prompt and instruct it to be respectful in its response. Never share personal and private information with AI, like your address or medical records.

Remember:
Good advocacy isn't about perfect writing. It's about communicating what matters to you. Ensure your letter politely presents your experience, your opinions and your ask.

An example letter:

Dear the Hon. [Member Name] MP,

My name is Kirsty and I am writing to share my experience as a Mumma bear of two young adults who live with Neurofibromatosis Type 1 (NF1). The Children's Tumour Foundation describes Neurofibromatosis (NF) as 'a group of rare and complex genetic conditions that cause tumours to form on nerves throughout the body. NF can lead to a range of significant health issues such as deafness, blindness, physical differences, bone abnormalities, learning difficulties, itch, chronic pain and even cancer.' Over many years, our family has navigated complex healthcare involving numerous specialists, hospitals and services.

S: Say who you are

NF is a lifelong condition that for my children, this has meant needing care from multiple medical specialties at different stages of their lives. While we have encountered many dedicated and highly skilled health professionals, their care has not always been connected. As their parent and carer, I have often been the person carrying information between services, following up appointments and results, and trying to ensure that each clinician understands the bigger picture.

The impact of fragmented care extends beyond attending additional appointments. It places responsibility on families to coordinate complex healthcare while also managing the emotional, practical and financial impacts of living with a lifelong condition. When communication or coordination breaks down, families can be left wondering whether important information has been shared, who is responsible for the next step, and whether something has been missed. In my son and daughter's case, a brain bleed and spinal tumour were missed. This not only created a risk but has added another emotional burden of living with NF.

A: Explain how it affected you

I believe people living with complex rare conditions would benefit from stronger coordination between specialist, hospital and primary healthcare services. Clearer referral pathways coordinated models of care and better communication between services could reduce the navigation burden carried by families while supporting clinicians to provide more connected, person-centred care.

R: Recommend or request

I ask that you consider opportunities to strengthen coordinated care for people living with rare diseases and ensure that the experiences of patients and families are included in developing those solutions.

I would welcome the opportunity to meet with you or your office to share our experience and discuss this further.

E: End with your ask

Thank you for taking the time to hear our story and I look forward to hearing from you soon.

Yours sincerely,

Kirsty

(INSERT ADDRESS)

What happens next?

Advocacy is rarely one conversation. It takes time. Here's a general guide of what to expect:

Timeframe	What to expect
Week 1–2	Allow time for the office to receive and review your correspondence.
Week 3–4	If you haven't received a response, send a polite follow-up email or call the office.
If offered a meeting	Prepare 2–3 key talking points, be clear about the change you are seeking, and consider taking notes. Ask who will be at the meeting.
After a meeting or response	Advocacy often continues in stages. A first letter may lead to further conversations, referrals, or an invitation to contribute to a broader review. It is important to send a thank you email after the meeting.
Follow Up	Whether it is with your health care provider or a minister, people are busy. If an action was discussed in the meeting, email and ask how the subject is progressing.

Before a meeting:

- Bring a copy of your key points or letter.
- Know how much time you have.
- If others are attending, agree beforehand on who will cover each point.
- Write down any commitments or next steps discussed.
- Send a short thank-you afterwards and follow up on agreed actions

Would you like support ?

You don't have to attend a meeting with a Member of Parliament alone.

If you would like support, you can ask whether a member of the Children's Tumour Foundation team is available to attend with you.

We can help you prepare for the meeting, understand the advocacy process and support you to communicate the issues that matter to you.

Meeting Preparation: A Checklist

Before you send your letter or attend a meeting, take a moment prepare.

- [ ] **Do I know who I am contacting and why?**
- [ ] **What is my key message?**
  If they remember only one thing, what do I want it to be?
- [ ] **What change am I seeking?**
- [ ] **What lived experience will I SHARE?**
  Choose one or two examples that demonstrate why the issue matters.
- [ ] **Have I explained the impact?**
  What did this mean for me, my family or others?
- [ ] **What am I asking them to do?**
  Be as clear and specific as you can.
- [ ] **What outcome would I like from this conversation?**
  A meeting, further discussion, support, information, action or another connection?
- [ ] **Have I prepared one or two key facts?**
  Your lived experience is important. Evidence can help strengthen your message.
- [ ] **Do I know what is already being done?**
  Acknowledging what is working well can strengthen your advocacy.
- [ ] **Am I prepared for questions?**
  It is okay to say, "I don't know, but I can find out."
- [ ] **Have I kept my letter to 1–2 pages?**
- [ ] **Have I included my name and address?**
  Remove your address and other personal information if sharing your letter publicly.
- [ ] **Have I been clear and respectful throughout?**
- [ ] **Have I decided what happens next?**

Consider when you will follow up, who will do it, and whether you need to provide any further information.

A final note

- Advocacy begins with courage and finding the confidence to speak from the heart.
- The clinicians caring for you or your child want the best for them.
- Often, the problem isn't the people; it's the gaps between the systems around them.
- Sharing your story can create positive change. Some change is small. Some change is more significant.
- Advocacy is a little like planting seeds. Sometimes you see them grow. Sometimes someone else waters them. Sometimes another family plants a seed beside yours, and change begins to take root in places you may never see. That is why your voice matters.

We are here to help

The Children's Tumour Foundation advocates on behalf of every person in Australia with neurofibromatosis, and more broadly, every person with a rare disease. We are also here to help you. You can reach out to our support team at anytime at support@ctf.org.au

You can also connect with Kirst Whitehead, the National Advocacy & Partnerships Manager to discuss individual or self-advocacy support.

Thank you,

Kirsty Whitehead

National Advocacy & Partnerships Manager

(02) 9713 611

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www.ctf.org.au

Disclaimer

This guide has been developed by the Children's Tumour Foundation to support people affected by Neurofibromatosis to participate in advocacy and share their lived experience.

The information provided is general guidance only and does not constitute legal, medical or political advice. Individuals are encouraged to share their own experiences and views. Any views expressed by individuals using this resource are their own and do not necessarily represent the views or policy positions of the Children's Tumour Foundation.

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Use of this guide does not guarantee a response, meeting, policy change or other advocacy outcome.