



Your voice. Your story. Your impact.

Living with Neurofibromatosis, caring for someone with NF, or loving someone affected by NF gives you a powerful perspective. Your lived experience can help decision-makers better understand what is working, what is missing, and what needs to change.

Advocacy simply means speaking up for change.

It can be as simple as sharing your story with a local Member of Parliament, writing a letter to the editor, asking for better support, or helping others understand the real-life impact of NF. You do not need to be a policy expert, researcher, or professional advocate. You are the expert in your own experience.

Advocacy takes courage and every story matters.

Advocacy doesn't always create change overnight. Sometimes success is being heard, starting a conversation, or helping others understand a problem they didn't know existed, like a pebble that creates gentle ripples in water.

How to SHARE your story

Below is a step-by-step tool to empower your voice, so your lived experience is clear and respectful message.



S Say who you are
Introduce yourself and your connection to NF.

H Highlight your experience
Share what happened and why it matters.

A Affect
Explain how it affected you, your family, or your care.

R Recommend a solution
Suggest what could be improved.

E End with your request
Ask for a meeting, a response, support, or action.

Who do you help when you SHARE?

When people affected by NF share their stories, they help governments, health professionals, and decision-makers see the human impact behind policies and services.

Your voice can help shape better care, better awareness, and better support for the NF community and other people with a rare disease.

You are not alone; the Children's Tumour Foundation is an advocacy body who will continue to advocate alongside the Neurofibromatosis community and the rare disease community. They can help also help with information, resources and support as you prepare to share your story and advocate for change.

For support, contact (02) 9713 611