The Courage to Ask: Advocating for Your Child in New Zealand's Healthcare System

An Introduction for Parents and Whānau

As a parent, you are your child's most important advocate. You know them better than anyone – their history, their personality, their baseline of what is "normal." When your child is unwell or needs medical care, navigating the healthcare system can feel overwhelming and intimidating. It is a world with its own language, rules, and pressures.

This guide is here to empower you. It is designed to give you the confidence, skills, and knowledge to work effectively with healthcare professionals and ensure your child receives the best possible care. Advocacy is not about being confrontational; it is about being a prepared, confident, and collaborative member of your child's healthcare team. This guide will provide you with the practical tools to make your voice heard.

Understanding Your Rights: The Foundation of Advocacy

Every person using a health service in New Zealand is protected by the Code of Health and Disability Services Consumers' Rights (the Code). These rights apply to your child, and to you as their support person. Understanding them is the first step to effective advocacy.

Here are the 10 rights, explained simply:

1. **The Right to be Treated with Respect:** Your family's values, culture, and beliefs must be respected.
2. **The Right to Freedom from Discrimination:** Your child must be treated fairly, regardless of their background, identity, or disability.
3. **The Right to Dignity and Independence:** Your child's privacy should be protected, and they should be treated with compassion.

4. The Right to Services of an Appropriate Standard: Healthcare professionals must provide care with reasonable skill and meet professional standards.
5. The Right to Effective Communication: You have the right to receive information in a way you can understand. If you need an interpreter or information explained differently, you can ask for it.
6. The Right to be Fully Informed: You must be told about your child's condition, treatment options (including risks and benefits), and the expected costs.
7. The Right to Make an Informed Choice and Give Consent: You have the right to make decisions about your child's care, and you must give your permission before any treatment begins.
8. The Right to Support: You are entitled to have a support person (a partner, friend, or advocate) with you during appointments.
9. Rights in Respect of Teaching or Research: You must consent before your child can be included in any teaching or research study.
10. The Right to Complain: You have the right to raise concerns, and to have them taken seriously and investigated properly.

Part 1: Before the Appointment – The Power of Preparation

Effective advocacy begins before you even step into the doctor's office. Being prepared can reduce anxiety and help you make the most of your limited time with a provider.

Your Pre-Appointment Checklist:

- [ ] Define Your Goal: What is the number one thing you want to achieve with this appointment? Is it getting a diagnosis, understanding a test result, or discussing a new symptom?
- [ ] Create a Timeline: Write a simple, chronological list of your child's symptoms. When did they start? How often do they happen? What makes them better or worse?
- [ ] List Your Questions: Write down every question that comes to mind. No question is too small or silly. Organise them from most important to least important.

- [ ] Organise Your Documents: Bring a folder with any relevant medical records, test results, or a list of current medications.
- [ ] Consider a Support Person: Ask your partner, a trusted friend, or a family member to come with you. They can take notes and be a second set of ears.

Part 2: During the Appointment – Making Your Voice Heard

This is your opportunity to build a partnership with the healthcare provider. Your approach can make a significant difference.

Strategies for Effective Communication:

- State Your Goal Early: At the beginning of the appointment, clearly state your main concern. For example: *"Thank you for seeing us. Our main concern today is understanding why Leo has had a persistent cough for three weeks."*
- Use Your Written List: Refer to your list of questions. It shows you are prepared and ensures you don't forget anything important.
- Ask Open-Ended Questions: Encourage detailed answers.
    - Instead of: *"Is this the only option?"*
    - Try: *"What are all of the different treatment options we could consider?"*
- Take Notes: Write down key information, medical terms, and instructions. It’s hard to remember everything later.
- The "BRAIN" Acronym: Use this tool when a new treatment or test is proposed:
    - Benefits: What are the benefits of this?
    - Risks: What are the risks involved?
    - Alternatives: What are the alternatives?
    - Intuition: What is my gut feeling about this?
    - Nothing: What happens if we do nothing for now?

- Confirm You Understand: Before you leave, summarise what you've heard. For example: *"Just to make sure I have this right, you're suggesting we try this new medication, and the next step is to book a blood test. Is that correct?"*

Part 3: When You Feel Unheard – Escalating Your Concerns

Sometimes, despite your best efforts, you may leave an appointment feeling dismissed, confused, or that your concerns were not taken seriously. It is crucial to trust your instincts. You have the right to seek a second opinion and to have your complaint addressed.

A Step-by-Step Approach to Escalation:

Step 1: Seek a Second Opinion You are always entitled to ask for a second opinion from another doctor or specialist. You can ask your GP for a referral to a different professional. This is a normal and respected part of the healthcare process.

Step 2: Try to Resolve it Directly If you have a concern with a service, first try to resolve it with the person you saw. If you are not comfortable with that, ask to speak with the manager of the clinic or the charge nurse of the hospital ward. A clear, calm explanation of your experience can often lead to a resolution.

Step 3: Contact a Health and Disability Advocate If you cannot resolve the issue directly, or if you feel you need support, you can contact the Nationwide Health and Disability Advocacy Service.

- Freephone: 0800 555 050
- This service is free, independent, and confidential.
- An advocate can listen to your concerns, explain your options, and support you in meetings or in writing a formal complaint. They are on your side.

Step 4: Make a Formal Complaint to the Health and Disability Commissioner (HDC) If you are still not satisfied, you can make a formal complaint to the HDC. This is the official body that upholds the Code of Rights.

- You can make a complaint online at www.hdc.org.nz or by calling 0800 11 22 33.

- An advocate can help you with this process. The HDC will assess your complaint and decide on the most appropriate course of action, which may include a formal investigation.

Key Contacts & Whānau Resources

Healthline: For free health advice from a registered nurse, 24/7. **Phone: 0800 611 116**

Nationwide Health and Disability Advocacy Service: For free, independent support in raising a concern. **Phone: 0800 555 050 Website: advocacy.org.nz**

Health and Disability Commissioner (HDC): To understand your rights or make a formal complaint. **Phone: 0800 11 22 33 Website: hdc.org.nz**

KidsHealth New Zealand: A trusted source of information on children's health and wellbeing. **Website: kidshealth.org.nz**

A Final Word of Encouragement

Remember, you are the expert on your child. Your observations, intuition, and love are powerful tools. Building a positive relationship with your healthcare team is the goal, but never be afraid to ask questions, seek clarity, or push for answers when you feel something isn't right. You have the courage to ask, and you have the right to be heard.