


# Raising a child WITH A RARE DISORDER

A GUIDE FOR PARENTS AND CAREGIVERS  
LIVING IN AOTEAROA NEW ZEALAND





**1 IN 17**  
PEOPLE  
ARE LIVING  
WITH A RARE  
DISORDER

# About this guide

---

**Caring for a child with a rare disorder is a unique experience that can be challenging. Between waiting for a diagnosis, adjusting to a new way of life, and coping with ongoing uncertainty, it can feel like an emotional roller-coaster ride. But while the journey can be demanding, it is important to remember that there is a way forward.**

This booklet has been created by Rare Disorders New Zealand to help parents and caregivers navigate the path in caring for a child with a rare disorder in New Zealand. By gathering insights and advice from parents and caregivers who share this journey, as well as information and resources that may help along the way, we hope to provide a guide of sorts – to help you find what works best for your whānau. While we do not have all the answers, we hope this guide reassures you that you are not alone, and that support is available.

## What is a rare disorder?

At the time of writing, New Zealand does not have an official definition of what makes a disorder 'rare'. At Rare Disorders NZ, we follow the definition set forth by the European Union: that a disease or disorder is rare when it affects no more than one person in every 2,000 people. Currently, there are more than 6,000 different types of rare conditions affecting an estimated 300 million people worldwide. Around half of all individuals with a rare disorder are children.

Because rare disorders are rare, there is often very little information available on specific conditions. This can make dealing with the diagnosis of a rare disorder particularly frustrating. In New Zealand specifically, the lack of a national strategy for rare disorders can translate to significant barriers in obtaining adequate healthcare services.

Rare Disorders NZ is committed to improving the lives of people living with a rare disorder in New Zealand, and we are pleased to have recently received assurance from the Government that a

National Strategy for Rare Disorders is finally set to be developed by the end of 2023. This will include an official definition of what is considered a rare disorder in New Zealand.

## About Rare Disorders New Zealand

Rare Disorders NZ is the respected voice of rare disorders in New Zealand. We are the national peak body organisation, supporting the 300 000 New Zealanders with a rare disorder and the people who care for them. We help those affected by rare disorders navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

We proudly advocate for public health policy and a future healthcare system that works for those with rare disorders – using a strong and unified voice to collaborate with the Government, clinicians, researchers, and industry experts, to promote diagnosis, treatment, services, and research.

Our vision is for New Zealand to become a country where people living with a rare disorder are fully recognised and supported with equitable access to health and social care.

### Rare Disorders NZ contact details

**Email:** [enquiries@raredisorders.org.nz](mailto:enquiries@raredisorders.org.nz)

**Phone:** +64 4 385 1119

**Website:** [www.raredisorders.org.nz](http://www.raredisorders.org.nz)



# The emotional journey

---



The whole thing has been a grieving process from day one. Accepting the process is like a grieving journey. There are times you feel guilty, times you feel happy, times you feel sad, and times you feel overwhelmed. The number of emotions that come and go is just mind-blowing. And it's kind of like riding a wave to get through them. So, it's about accepting all the emotions that come and venting them as they surface, rather than bottling them up. Because they are all completely normal.

**Chauntel. Mum of Zoey, aged 3.**

## Receiving your child's diagnosis

Receiving the diagnosis of your child's rare disorder can be a deeply distressing experience – and for a time, you may feel completely overwhelmed. Confusion, powerlessness, sadness, and even disappointment are all normal emotional reactions. Initially, you may feel angry or in denial about the diagnosis. You may question the fairness of your situation, your doctor's expertise, or even the diagnosis itself. Alternatively, you might feel numb, going through those first few days in a zombie-like state. It is important to remember that people react and respond differently during difficult times – and there is no right or wrong way to process this experience.

Grief is one of the most challenging emotions to deal with following the diagnosis of a rare disorder. Parents or caregivers may find themselves grieving the experiences they imagined having with their child or the loss of what might be considered a 'typical' family.

While this grief can be painful, it is normal. Give yourself time to grieve and be gentle with yourself during this time. While it may seem like your grief will never pass, parents of children with rare disorders say it does ease over time.

Remember to give yourself space to figure out how your family can adapt to your child's ongoing needs. Like most families, you will have good days and bad days. You will have times when everything seems to come together and days when it feels like everything has fallen apart. Partners and whānau can also react in ways that can be difficult to understand. Give yourself and your loved ones time to grieve. When you find yourself struggling, remember that you are human and that most people would find it difficult to cope during these situations.

# When there is no diagnosis

---



**Obtaining a diagnosis for a rare disorder is not always a straightforward process. There may be weeks, months, or even years in which medical appointments and ongoing testing result in little more than disappointment. Living in 'diagnosis limbo' can be highly stressful, and misdiagnosis is not uncommon due to the nature of rare disorders. While this is incredibly frustrating, it does not mean you will never receive a diagnosis – or that you will be unable to give your child the care they need without one.**

Research in rare disorders reveals an average wait of four to nine years for a definitive diagnosis. In New Zealand specifically, there are limitations when it comes to specialised diagnostic testing and medical resources that can make accurate diagnoses especially problematic. Another explanation for a lack of diagnosis includes the possibility that your child's condition has not yet been discovered.

Advances in medicine – and genetics in particular – mean that diagnostic tests are now available for conditions that were unheard of just a few short years ago. As research and medical science continue to advance, there will likely be similar breakthroughs in testing and treatments for other rare disorders. While diving head-first into online websites to find answers is tempting, this should be done with caution. [See doing your own research.](#)



# Opening the lines of communication

---



I grew up on a marae, and we speak Te Reo Māori. I'm so grateful for that. I always taught Khy everything that I knew. As much as I could. She knows English, sign language, and Te Reo Māori now. She also has an iPad with a communication app. We moved home for her. She needed to be on the Marae and stand with her Koro when he did karakia. She needed to sing the hīmene that I did as a child. And she does.

**Misty. Mum of Khy Noa, aged 14.**

## Talking to your child about their rare disorder

Good communication is an essential part of any relationship. And while talking to your child about their rare disorder can be a distressing thought, it can also help your child to cope better with the realities of their condition. Children are incredibly observant and will often notice when something is wrong. But because young children do not understand things the way adults do, they can often let their imaginations run wild with frightening scenarios. Being told about their rare disorder and included in appropriate decisions around their care, gives a child the opportunity to learn about their body and health.

A parent or caregiver is usually the best person to talk to a child about their rare disorder – and to determine the right time for this discussion. Timing can be tricky. Some parents or caregivers worry that telling their children about their condition when they are young will burden them prematurely. Conversely, some worry that keeping their child

in the dark will lead to them feeling deceived. Talking with trusted family or whānau, friends, or your child's medical team can help when deciding on timing. Remember that you do not need to tell your child everything at once – view the discussion as an ongoing dialogue rather than a single conversation.

When telling your child about their rare disorder, make sure to do so in a safe place where you are unlikely to be interrupted. Communicate with your child in a way they can understand and allow them to ask questions. Set aside plenty of time and avoid making promises you cannot keep. Do not be afraid to say, 'I don't know'. Try not to push your child to talk about their condition until they are ready – give them time to process what they've learnt and answer questions as they arise.

Because older children can 'Google' their condition, it is especially important to be accurate and honest during discussions. It can also be helpful to educate older children on the potential pitfalls of internet research – [see doing your own research](#) – and to



suggest that they come to you or another trusted adult with any questions they may have. Encouraging children to make a note of trickier questions for discussion at their next medical appointment can also help to discourage online investigations. If you feel your child needs additional support in coping with their condition, speak to your family doctor or a member of your child's medical team.

### **Talking to siblings**

Talking to siblings about their brother or sister's condition is a necessary reality. Remember to tailor information in a way that is appropriate for 'age and stage' and give your children the opportunity to ask questions. Reassure them that they can continue to ask questions in future. Children are naturally curious, and as they get older, they are likely to have more questions about their sibling's condition and care. Keeping them informed when treatments or routines change allows siblings to feel included in the care of their brother or sister. Regular routines also help

siblings develop a sense of security around what is likely to happen during the day or night.

### **Talking to others**

Talking to others about your child's diagnosis or condition can be an upsetting experience. While friends and whānau are generally well-meaning, they may ask for updates when you are still struggling to come to terms with new information. Remember that there are many ways to share information with others when you feel ready. Non-direct means of sharing information – such as through family or whānau, social media, or text messages – can be helpful. Creating a fact sheet with information on your child's condition and how friends and whānau can help is another way to share details with those you trust. These fact sheets can also be tailored for use with key individuals, such as your child's teachers or family doctor.

# Caring for yourself and your relationships

---



I had a hard time going to mum's groups. It's hard to go into those environments and hear about other children thriving and reaching all their milestones while knowing the reality of your child. There were a couple of months where I really isolated myself from those situations with friends.

**Chauntel. Mum of Zoey, aged 3**

## Your relationships with others

Like all children, children with rare disorders need love and security so they can learn about the world they live in at their own pace. But because children with rare disorders often have additional needs, you may find that you and your family have experiences that differ from other families. Caring for a child with specialised needs can sometimes feel overwhelming, and it is normal to feel concerned about the effects of this on your friendships with others.

While it may be tricky, making time for close friends and whānau is important. A quick phone call during the week, a catch-up over coffee in a place that feels safe for your child, or a late dinner at home once the kids are in bed are all ways to nurture your relationships with others.

## When you have other children

When a parent or caregiver discovers that their child has a rare disorder, they naturally devote enormous amounts of time and energy to ensuring the best possible outcomes for their child. But between ongoing appointments, day-to-day care, and reductions in parental availability, siblings of children with rare disorders may feel overlooked. While talking to children about their sibling's diagnosis can help – it is also important to nurture the connection you share with each of your children. Above all, children appreciate time with their parents or caregivers to help reassure them that they are loved, seen, and valued. Nightly bedtime stories, a weekend treat at a local café, or a special movie night are all ways to nourish parent-child relationships.





## → Your relationship with your partner

Having children can place a strain on even the strongest partnerships. Less time, less sleep, and less capacity can mean we neglect our most meaningful relationships – like the one we share with our partner. Tending to a romantic relationship while raising a child with a rare disorder does not have to be burdensome. Most of the time, it is the small things that count, such as:

- **Talking about the good stuff.** When you have a child with a rare disorder, it is easy for discussions to center around medical appointments or day-to-day care. Remember to talk about the good stuff too, such as the interests you share or personal goals you have achieved during the week.
- **Letting your partner parent.** When you are the primary caregiver for your child, it is tempting to think that your way is the best way. Allow your partner the opportunity to take on parenting tasks and try not to criticise them as they learn.
- **Making time for togetherness.** Try to spend time alone as a couple – even if this means a regular ‘date-night’ at home once the kids are in bed. Talk, listen, and reconnect.
- **Sharing information.** When caring for a child with a rare disorder, one parent or caregiver often takes on the responsibility of attending healthcare appointments. Make sure to discuss important information with your partner so they are kept in the loop and can offer support when needed.
- **Don’t play the blame game.** You – and your partner – are human and will make mistakes as you go through the parenting journey. Instead of blaming, discuss issues from a place of love and respect.
- **Playing to your strengths.** You might be excellent at organisation, while your partner is a whiz in the kitchen. Focus on individual strengths when deciding on domestic and child-care responsibilities.





## → Looking after yourself

When days are busy and time is short, it is tempting to push our own needs to the back burner. But while it may seem counter-intuitive, your physical, mental, and emotional wellbeing are essential to giving your child the love and support they need. Self-care looks different to different people but can include:

- **Talking it out.** Talking about our thoughts and feelings with someone we trust can help us process difficult situations. Whether we share our experiences with our friends, family, whānau, or partner, it is better to talk to people who love and care about us than to try keep things bottled up.
- **Regular time out.** Part of practicing effective self-care is remembering to take regular time out. While this can seem impossible at times, there are many ways to work 'mini-breaks' into your regular routine. Try meditating in the morning, taking a warm bubble bath at night, or enjoying a walk with a close friend.
- **Focus on physical health.** Our physical health is strongly connected to our mental health and wellbeing. It helps us feel good, function well, and gives us the energy we need to tackle challenges. Taking care of our physical health means developing healthy behaviours, such as eating a balanced diet, getting enough sleep, and ensuring we stay fit and active. Healthy behaviours can be challenging to maintain, especially when life gets busy or we feel overwhelmed. Do not be afraid to reach out to loved ones when you need support. A homecooked meal or an offer of childcare can make a world of difference.
- **Talking to your GP.** If you feel like you need additional support with your mental health or wellbeing, make sure to talk to your family doctor.

# Where to find support

---



I'm still learning. We've been on this journey for a year and a half now, and I'm still not clued up. There is so much out there if you know what you are looking for. For example, the Wilson Home Trust they do grants for equipment and activities. We've been able to secure funding for a trampoline. Ava is going to love it.

**Louise. Mum of Ava, aged 3.**

## Asking for help

Raising a child with specialised needs can make a parent or caregiver feel like they need to do everything themselves. And while this is understandable, it is important to remember that you – just like everybody else – will need help at times. The following is a list of health and disability services for when you need support:

## Health services

Genetic Health Services. Genetic Health Services provide expert genetic diagnostic and genetic counselling services, as well as assistance, advice and education in managing genetic conditions. Their services are publicly funded for NZ residents as part of New Zealand's public health system.

Ministry of Health Disability Support Services. This link provides information on the role of Disability Support Services, the disability support services that are funded, current projects, and programmes.

Your Guide to Disability Support Services.

A directory of general information, services, and community support available for people who have a disability and their families.

The Nationwide Health and Disability Advocacy Service. The Health and Disability Advocacy Service offers free, independent, and confidential advice and support to help you resolve issues with health and disability services.

Health Navigator New Zealand. Health Navigator provides one place to find reliable and trustworthy health information and self-care resources.

KidsHealth. KidsHealth provides accurate and reliable information for NZ parents and whānau about the health and wellbeing of tamariki and rangatahi in Aotearoa New Zealand.

Parent to Parent. Parent to parent is a nationwide not-for-profit organisation formed in 1983 by parents and professionals to support the families of babies, children, teens and adults with any type of disability or health impairment.





## Health resources

CrowdMed. CrowdMed provides a collaborative approach for solving complex medical cases online. The extensive knowledge of the case-solving community allows patients to explore all possible medical diagnoses and solutions, providing clear paths for them to follow towards a cure.

Rare Chromosome & Gene Disorder Guides. Link to free Information Guides for specific chromosome and gene disorders – as well as guides translated into various languages.

Disability Support Guide. A guide designed to help parents and families of children and young people who have been recently diagnosed with a disability.

## Online support Groups

Online support groups are essential for many parents and caregivers when raising a child with a rare disorder. These groups represent places where parents can ask questions, receive recommendations for health services, find potential funding sources, and provide support to other parents.

Rare Disorders NZ supports over 140 individual support groups in our collective and can help connect you to one of these groups.

On the Rare Disorders NZ website, you can search for individual support groups that may be relevant for your whānau. If you would like to set up a support group, please contact Rare Disorders NZ directly at [enquiries@raredisorders.org.nz](mailto:enquiries@raredisorders.org.nz).

General support groups for parents include:

Rare Disorders NZ Facebook page. Stay updated on our news and on important developments and events in the sector, both nationally and internationally.

Community Group on Facebook. For anyone in New Zealand with a rare disorder and their whānau to share stories and information, or just to connect with people going through similar experiences as yourself.

Facebook group specific to Māori. A private group for Māori who live with a rare disorder and their whānau to share stories, information and experiences.

## Mental health services

Anxiety New Zealand. Anxiety NZ provides a free and confidential 24/7 helpline for people of any age who experience all forms of anxiety, including Panic Attacks, Phobias and Obsessive Compulsive Disorders and to family, whānau, or friends supporting someone with anxiety. Call 0800 269 438.



**I think the biggest turning point was when we found the spinal muscular atrophy Facebook community online. That helped a lot. Finding a good support network with others, whether it's the same disorder or a completely different one, is really important. Centre yourself around people who are kind of going through similar circumstances.**

**Chauntel. Mum of Zoey, aged 3.**

Lifeline Aotearoa. Lifeline Aotearoa is a free and confidential 24/7 helpline and text services for people in distress or crisis. Call 0800 54 33 54 or text 4357.

Mental Health Foundation (Accessing Mental Health Services). An online information page detailing free, low-cost, and private mental health services and therapists available for those who need support with their mental health.

Ministry of Health (Mental Health & Wellbeing). A link to an online information page at the Ministry of Health website, detailing digital tools, downloadable apps, resources, and helplines available free for people who need support with their mental health.

Samaritans Aotearoa New Zealand. Samaritans Aotearoa New Zealand is a free and confidential (non-religious) 24/7 helpline for people who are experiencing loneliness, despair, distress, or depression. Call 0800 72 66 66.

The Depression Helpline. A free and confidential 24/7 helpline where you can speak with a trained counsellor about how you are feeling or to ask any questions you may have. Call 0800 111 757 or text 4202.

1737, Need to Talk? 1737, Need to Talk? provides free and confidential one-on-one counselling services to anyone feeling stressed, overwhelmed, or out of sorts. Call or text 1737.

If you feel you require urgent and immediate help, please call 111.

## **Additional support**

### **Accepting support from others.**

Close family and whānau or friends can be an excellent support when you feel overwhelmed or exhausted. Talking to someone you trust or taking some much-needed time out is essential in caring for yourself and your child. While asking for help from others can be challenging, remember that this is a sign of strength, not weakness.

### **Other parents.**

Parents of children with rare disorders offer a unique form of support in that they share similar experiences. If their child is older, they may also have a wealth of knowledge about support services, funding, and credible online resources. Don't be afraid to reach out to parents on a similar journey to your own – they were once where you are now.



# Doing your own research

---



## The Google rabbit hole

When faced with uncertainty, it is tempting to turn to 'Dr Google' for answers. But while the internet can be a source of credible information, it can also be a rabbit hole of misinformation, pseudoscience, and dangerous advice. The trick is learning to separate reputable, trustworthy sources from biased or inaccurate content.

## Clinical trials and treatments abroad

Clinical trials are research studies performed with a specific group of people to evaluate a medical, surgical, or behavioural treatment or intervention. As part of these trials, people are placed into different treatment or intervention groups so that researchers can compare results. On any day, there are thousands of clinical

trials taking place around the world. The largest clinical trials database is [clinicaltrials.gov](https://clinicaltrials.gov) – which lists medical research studies from over 200 countries worldwide.

Parents of children with rare disorders are often interested in clinical trials that allow their child access to an otherwise unavailable treatment. We strongly recommend discussing the implications of specific trials and treatments with your child's medical specialists before enrolling in research studies. It is also important to know that acceptance to a clinical trial does not guarantee access to treatment – some studies use placebos (an inactive substance with no therapeutic effect). Financial costs such as airfares, accommodation, childcare, and time away from work are also significant considerations.



“It really does consume you. How fixated you get with the condition or the treatment. All the Googling and the research, it took up a good few months of my life and during that time, I missed out on time I could have spent with Zoey. You get so caught up on, “what’s going to happen?” instead of focusing on the now. And it turns into a kind of rabbit hole, and you go down it, and it’s hard to find your way back.

**Chauntel. Mum of Zoey, aged 3.**

## → Trusting sources

The following is a list of tips for identifying trustworthy sources when online:

- **Who has published the information?** Something to remember about the internet is that anyone can publish anything. Make sure to check that the information you are reading is from a reliable, respected source. Government, not-for-profit organisations, and university websites are often a good starting point.
- **Are they experts in the field?** If you were looking for a good muffin recipe, you probably wouldn’t check the local shoe shop. The same applies when looking for medical information. Make sure to look for reputable sources that specialise in the type of information you seek. If you were looking for information on diabetes, for example, Diabetes New Zealand would be a good place to start.
- **Are they selling something?** Be wary of company websites (usually ending in .com) that are trying to sell you something or making unsupported claims about treatments or medicines. This is not to say that company sites should be avoided altogether, but rather that information may be biased towards the products they sell.
- **When was it written?** In the world of scientific medicine, research is constantly developing. Because of this, medical information can become outdated over time. When gathering information from a credible source, make sure to check when the article was written.
- **Site design, sources, and writing style?** While this can be somewhat subjective, a credible website will often be well-designed. Authors will provide references to research or scientific information, and writing will be free from poor spelling or grammar.
- **What is the next step?** When doing your own research, it is good practice to consider the internet as ‘step one’. Once you are satisfied that your information is trustworthy, make sure to take the next step and discuss it with your child’s doctor or medical team. Remember that while your information might be accurate, it may not necessarily relate to your child’s specific condition.
- **Rare Disorder Databases.** There are several research databases specific to rare disorders. These databases represent trustworthy sources of evidence-based information. To find out more, contact Rare Disorders NZ, or see our website for a list of credible [Rare Disorder databases](#).



# A new normal

---



**She's a real crack-up. She has my personality. Sometimes we have to be serious, but most of the time, we are just being funny. We pretend we are at concerts and listen to music. She loves singing, and I sing a lot now too. She's a real performer. Loves being on the stage. She does swimming lessons and horse-riding lessons. She does star jam with other special kids, and so she has little mates now. It's really cool.**

**Misty. Mum of Khy Noa, aged 14.**

Raising a child with a rare disorder can leave life looking different to what is considered 'normal'. Between medical appointments, daily care, and an entourage of health professionals, it is not surprising that families can struggle to adapt. Effectively managing the medical administration that comes with raising a child with a rare disorder is one way to ease the transition to a new 'normal'. While this may seem overwhelming initially, it does get easier with time.

## Preparing for appointments

The following is a list of tips when preparing for medical appointments:

- **Arrive early.** Arriving early for medical appointments ensures that you can find parking, check-in, and complete any necessary paperwork without cutting into your appointment time. This may mean packing a bag the night before, getting up a little earlier, or shuffling your usual routine. Planning your route can also be helpful when an appointment is in an unfamiliar location.
- **Prepare for fussing.** Taking some of your child's favourite toys or books to an appointment can be helpful when they become bored or fussy. If you allow screens, an iPad or cell phone can provide a welcome distraction for older children. Some clinics do not allow food or drink on their premises, so you may need to give your child a drink or snack before heading inside.
- **List and prioritise.** Think about what you are hoping to get from the appointment. There may be a new symptom you would like to discuss, or you may have questions about a new medication. Make sure to write down your questions and concerns and prioritise them in order of most to least important. Remember that you may not get through all the items on your list, and that your doctor likely has things they would also like to discuss.
- **Make a medical folder.** Medical professionals are not always aware of your child's complete medical history or who has been involved in their care. Creating a medical folder of past and present medications, consultations, and treatments, can help keep medical professionals updated and informed. Recording consultations is another helpful way to store information for later use – just make sure to check with medical professionals first. You can also ask for copies of consultation notes to be sent to your child's GP so that you can collect information from a single source.
- **Consider a support person.** Asking someone you trust to accompany you to an appointment can be helpful in many ways. A support person can take notes, so you can listen to your medical provider and ask questions. They can also tend to your child when they become bored or fussy, so you are free from distractions. Make sure to tell your support person what you hope to achieve from your appointment and how they can be most helpful.





## → Keeping track

Keeping track of the family schedule can be challenging for any parent. Add to this the additional medical appointments that often come with a rare disorder – as well as your own appointments – and things can begin to feel out of hand. Luckily, there are many ways to keep track of appointments. Here are some tips:

- **Write it down.** Make sure to write down appointments immediately after scheduling. Record this information on a calendar in plain sight – one that you look at daily. An additional whiteboard to display appointments week to week may also be helpful. Writing up the week's appointments can also serve as a reminder to plan travel routes or prepare any necessary paperwork.
- **Take advantage of tech.** If you prefer to keep track of your schedule using your mobile phone, make sure to enter appointment information as soon as it is received. You can also download scheduling apps to help keep track of appointments. Before you download an app, spend some time researching reviews and features – so you can choose the app that will work best for you.
- **Avoid rescheduling.** If possible, it is best to avoid rescheduling appointments. Specialist doctors tend to have long waiting lists, and you may have to push out other appointments due to scheduling conflicts. If you do need to reschedule an appointment, remember to record the new appointment information as soon as possible. Consider communicating with your employer about your situation. They may be more supportive than you expect around your need to attend appointments during working hours.
- **Welcome reminders.** Medical clinics and doctors' rooms will often send a reminder text or email a day or two before your appointment. Make sure administration staff have your correct contact details on file, and ask to be signed up for a reminder service if this is available.





I think writing down just a couple of key questions helps. Because you do tend to forget. You have questions, but you've forgotten what you wanted to say by the time your appointment comes around. Keeping any information you have received over time is also beneficial. A lot of my stuff is on my phone, in folders, so I always have it on me. I write questions on my phone, so I have everything there, and if I need it, I can just pull my phone out and access it.

**Chauntel. Mum of Zoey, aged 3.**

## Engaging with medical professionals

Medical appointments can be overwhelming – especially when they involve the wellbeing of someone you love. Being a health advocate for your child means interacting openly with their doctor, so you can work together to reach the best possible health outcomes. The following are some helpful tips for engaging effectively with medical professionals:

- **Be honest.** Be honest when discussing your child's health or wellbeing. Make sure to share relevant information about lifestyle, family and whānau, daily routines, and social or professional obligations. While it is tempting to withhold concerns that may seem silly or embarrassing, your child's doctor is there to help and wants to know what is on your mind.
- **Ask questions.** Asking questions when you do not understand or when you need more information allows you to make informed decisions on behalf of your child. Questions also provide the opportunity to learn more about available treatments or diagnostic testing, and to understand why your child's doctor is recommending a specific course of action. Discuss with your support person any questions they may like to ask before the appointment. Involving friends or whānau in this way can help them feel included and may highlight how they may help support you and your child.
- **Listen.** When emotions run high during medical appointments, we tend to focus on our worries or concerns instead of listening to the information or advice of medical professionals. Make eye contact with your child's doctor and give them your full attention. If you don't understand something they are saying, ask them to explain it again.
- **Think ahead.** It is not uncommon to have new questions arise once you have left the doctors' office. Ask your child's doctor if you can have their work email address, so you can contact them with later concerns. Some doctors are happy to give out their contact details, while others may feel it best to schedule a follow-up appointment.

**For more information on any of the topics in this guide, please contact Rare Disorders NZ**

**Email:** [enquiries@raredisorders.org.nz](mailto:enquiries@raredisorders.org.nz)

**Phone:** +64 4 385 1119

**Website:** [www.raredisorders.org.nz](http://www.raredisorders.org.nz)

**Join us on social media:**

**LinkedIn** [raredisordersnz](https://www.linkedin.com/company/raredisordersnz)

**Facebook** [@RareDisordersNZ](https://www.facebook.com/RareDisordersNZ)

**Twitter** [@RareDisordersNZ](https://twitter.com/RareDisordersNZ)



---

**Rare Disorders New Zealand is the respected voice of rare disorders in New Zealand. We are the national peak body organisation, supporting the 300 000 New Zealanders with a rare disorder and the people who care for them.**

**Our vision is for New Zealand to become a country where people living with a rare disorder are fully recognised and supported with equitable access to health and social care**

**IF YOU WOULD LIKE TO SUPPORT THE WORK OF RARE DISORDERS NZ, PLEASE VISIT [RAREDISORDERS.ORG.NZ/DONATE](https://raredisorders.org.nz/donate)**

---

Thank you to Kiwi Gaming Foundation for generously providing the funding to make this much-needed guide possible.

Thank you also to the rare families who were interviewed and photographed for this guide, and to the individuals and rare disorder support groups who provided feedback to help produce this guide.

Photo Credit: Janneth Gil, [www.jannethgil.com](http://www.jannethgil.com)

