

Tips to stay on top of it all

Taking a break



Becoming a parent can have rewards and challenges. It's important to know "it's ok to look after yourself". Try to create *space* for yourself, both inside and outside of the home. This could simply be taking a walk by yourself, or spending time with a friend.

Without breaks it's easy for things to get on top of you, time out gives you a chance to 'recharge' your batteries.

Friends and family/whānau (your natural networks) may be able to help you to have regular breaks. You may be able to get breaks from funding through your local [NASC](#) (Needs Assessment and Service Coordination) service.

If you have people coming into your home (to provide paid support) then remember, 'what happens in the home should stay in the home'. Clearly communicate your expectations and boundaries.

Refer also to 'Tips for Time Out' under Looking After Myself on the Resources menu.

Looking after my family ...



It's easy for any relationship to become second to the needs of the family/whānau. Try and find time for just you and your partner. This might be hard to achieve at first, so don't worry if it's just for a short time or something simple like a cuppa at the end of the day.

If it helps, schedule in a regular time that works for you both, or have a regular date night. Look for things you may be able to do as a couple, or interests that you can share.

The other members of the family (ie. siblings) may also need to have their own *space*, or time out. They may want some planned one on one time with you so talk with them and work out how this might be achieved.

Siblings may also want to talk to other siblings who have similar life experiences. You may be able to do this by connecting to local support groups. Parent to Parent offers [SibDays](#) which are one day events for 8-18 year olds. These occur throughout New Zealand and provide siblings with an opportunity for discussion, sharing, games and activities.

I need encouragement



- ✚ It can be very useful to link up with other parents who understand what you are going through. Organisations like [Parent to Parent](#), [NZDSA](#) (New Zealand Down Syndrome Association), and [Autism New Zealand](#) have local support groups throughout the country. Or you can contact groups like the Complex Care Group and be added to their closed Facebook page.
- ✚ Have someone you can talk to who can provide positive encouragement and support (this can be family/whānau, a friend or a professional). They need to be able to listen and not judge.
- ✚ Connect with like-minded positive people.
- ✚ Subscribe to links that publish insightful and motivating articles.

- ✚ Describe your child or adult family member in a 'positive light' using positive language. Ask people to be mindful of this. Positivity can help challenge and identify negative thinking or thought patterns.
- ✚ Stay connected with what's going on in your community, it's too easy to become disconnected from community life.

Help – things are not moving!



- ✚ It might be time to re-group – get your key supports together (this could be friends, family/whānau, professionals) and talk about what needs to happen next.
- ✚ Take time to think about where you are at and who can help you think, plan and do?
- ✚ If it's not clear, make a plan. That can sound daunting, but a plan is simply stating what you or your family/whānau wants and how you will be supported to get there.

- ✚ If you already have a plan like an IEP (Individual Education Plan) or Transition Plan, organise a meeting with the school to re-look at the plan and get things moving again.
- ✚ Sometimes learning seems to be on an upward curve, then suddenly stops, check to see if the person is taking time to fully understand what they have learnt. Give them the space to do this, before moving on.
- ✚ Check energy levels – this will change and vary over time. Do you need a break? Does your family/whānau need a break? It's ok to take time to recharge before moving forward.
- ✚ If you or your family/whānau are ready for a new challenge think about what to focus your energy on and what will make a difference? Make a list and prioritise what will have the best outcome. It may be helpful to talk with someone who is not emotionally connected with your situation.
- ✚ Right from the start make sure your child/adult family member is involved in the discussions about their life, and that they are supported to make choices and informed decisions. Some people may not be able to do this verbally but they can let you and others know what they like or don't like.

How do I communicate what I need effectively?



It can be challenging to negotiate what you want particularly when things aren't going well or when the relationship with the professional does not feel equal.

There are some resources on the Care Matters website aimed at helping to make this easier, such as; managing conflict, communication, influencing change. Effective communication skills can help you advocate for your family/whānau member.

Remember to pick your BATTLES, know which ones to roll up your sleeves for and which ones' to leave. You cannot fight every battle, so choose which ones are going to make a difference.



Working with professionals

- ✓ You are likely to have other 'professionals' in your life and in your home. Try to build good relationships with these supports. They may become pivotal to you and your family/whānau. BUT, if it's *not* working with that person, or they aren't the right fit for your family/whānau, ask for someone else.
- ✓ It's ok to say 'NO', you don't have to explain why. You're *allowed* to set boundaries for you and your family/whānau.
- ✓ It can be useful to keep an electronic diary or calendar with ALL your appointments in it so that you can schedule appointments together (ie. at the hospital)
- ✓ Try to limit professional visits in your home e.g. one day per week (if possible). You decide what's right for you and your family.
- ✓ While it's important to understand the diagnosis, always focus on the person and their unique attributes (one size does NOT fit all).
- ✓ Change the thinking by focussing on what the person 'can do'. Often the focus is on what the person 'can't do' (for funding purposes).
- ✓ Take time to understand the system, and challenge it when you need to. The system is NOT always right, but it IS what we have to LIVE with. And remember, the system is made up of people who make policies and therefore people and policies can be challenged and changed if they are not working.
- ✓ Language is powerful - use the language the 'system' uses to describe what you need.
- ✓ Refer also to 'Managing Relationships with Professionals' under Looking After Myself on the Resources menu.

Help – I'm in crisis



There may be times when it just all feels too much and life's getting harder. Talk to someone you trust, a friend, family/whānau, someone from church, or other parents (in similar situations). There are people who are out there who care.

If there is no one from your personal networks you can talk to you can call the 24/7 [Depression \(and anxiety\) Helpline](#) on 0800 111 757 or text 4202.

Remember you are important.

Understand those transitional times and the impact of grief which can rear its head when you least expect it. A comment made, a careless word, a 'milestone' that won't be reached, can sometimes bring the world crashing down.

It can be very helpful to share the load by talking to others in similar situations and telling it 'like it is' to someone who understands.

Family/whānau often talk about how important it is to laugh. Sometimes finding that person who 'gets it', to laugh at the unlaughable can help pull you through.

Making a difference

- ✦ Family/whānau have started (and govern) many trusts that support families throughout New Zealand.
- ✦ Pass on your own insights and learnings to support others in their journey.
- ✦ Get involved and contribute to making things better, for yourself and your family, or for others.
- ✦ It's family/whānau voices who have created the greatest change.
- ✦ It's family/whānau united who can make the greatest difference.

