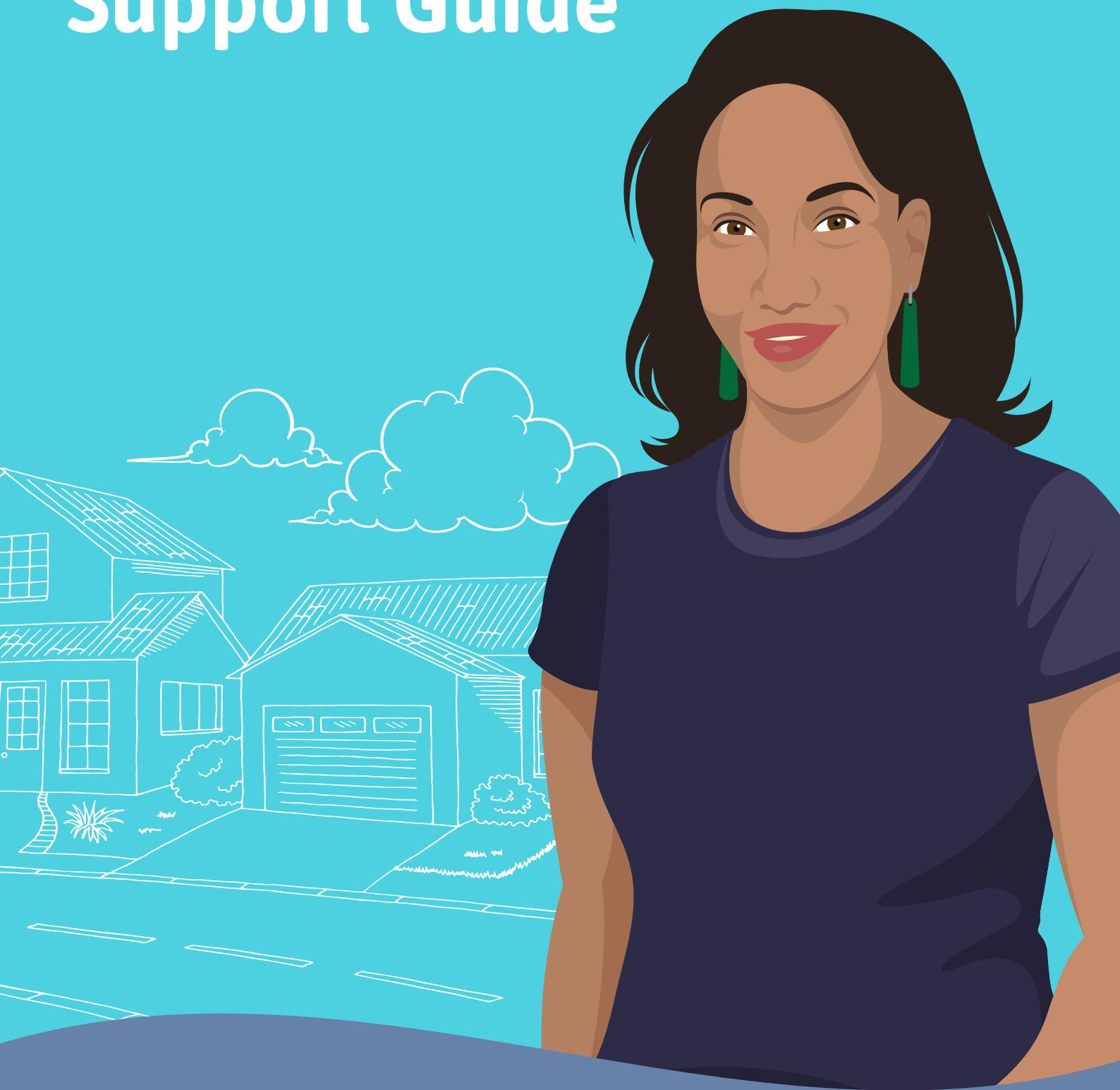


# Whānau OCD Support Guide



# Whānau OCD support guide

This resource is for carers and loved ones of people struggling with Obsessive Compulsive Disorder (OCD). It offers answers to some commonly asked questions and provides ideas for supporting yourself and your loved one through their journey with OCD.

OCD can have a massive impact on a person's life, and those around them. OCD often becomes a family condition. It's important for carers, supporters and family members to get to know OCD as a condition and try to understand how people can get stuck, and how it can be managed and overcome.

There's no 'one size fits all' in terms of symptoms or treatment for OCD. Not everyone experiencing OCD wants to involve others in their treatment, and people become ready to make change at different times. If the person in your life experiencing OCD isn't ready, or doesn't want you involved right now, that's okay. You can still learn about the condition to help you better understand what they are going through.

It's also important to know that some information in this resource may be helpful and relate to the challenges your loved one is going through, and other parts might not. It might help to read through this resource together and talk about what fits.

We'd like to thank the members of Fixate, a NZ based OCD support organisation, who've helped put this resource together.. Fixate provides a wealth of information and resources for people living with OCD and their loved ones.. For further information about Fixate go to -  
<https://www.ocd.org.nz/about-us/>



## What is OCD?

OCD is a specific type of anxiety that has two major parts to it - obsessive thoughts and compulsions. While people with OCD often experience both, some people may experience only one or the other.

## **Obsessive thoughts**

Obsessive thoughts refer to scary or distressing thoughts, images, impulses, or urges that someone experiencing OCD may have. We call these 'intrusive thoughts' because they show up without an invite and stay around often much longer than people want them to.

The distress and doubt that goes along with these experiences can lead people to try and push them away, or try to get rid of them. Unfortunately, this can have the opposite effect on the thoughts, making the brain 'look out for them', making them return more frequently and cause more distress.



## **Compulsions**

Compulsions naturally develop in OCD to serve a purpose of trying to get rid of obsessive thoughts and the distress they cause. Compulsions can be mental behaviours like thinking certain thoughts or repeating things, counting or praying, or physical behaviours like checking, lining things up, washing hands and performing rituals or routines. Compulsions can also serve to try and stop the 'bad things' happening that are contained within intrusive thoughts. The compulsions may be directly related to a feared event, for example washing hands to prevent the spread of potentially dangerous bacteria to a family member, or totally unrelated such as repeating a song backwards perfectly ten times so a loved one gets home from work safely.

Compulsive behaviours provide short-term relief, as they either help anxiety go down by giving people a greater sense of safety and certainty or helping people feel more in control and giving a sense that things have been 'put right'. However, they're also one of the biggest factors that keep the cycle of OCD going. When people use compulsions to reduce anxiety and stop 'bad things' happening, they don't get to learn that:

- intrusive thoughts are just thoughts and often not based on reality
- they can cope with the anxiety OCD causes, and
- after a period of time, anxiety will come down naturally on its own without the need for compulsive behaviours, even when intrusive thoughts and experiences are around.

# How common is OCD?

About 1 in every 100 people in New Zealand have OCD. Most people develop OCD in childhood, adolescence or as a young adult.

It's common to experience other challenges alongside OCD like depression, worry, problems sleeping or eating, and relationship issues.

OCD, despite being relatively common, can be hard for health professionals to detect. This is in part due to a lack of knowledge and understanding, even within our healthcare sector, however, is also because of the self-stigma, distress, shame, embarrassment and fear people with the condition can experience. OCD can bring about a range of distressing thoughts, urges and imagery that can be extremely difficult to share with others. These experiences may make a person worry they will be judged by others. It can therefore take a very long time for people to become brave enough to tell people what they are experiencing and ask for help.

# What are intrusive thoughts?

Intrusive thoughts are a common part of our human experience – it's just we don't really talk about them, perhaps because they tend to be a bit 'strange' and at times distressing. In fact, research shows people without OCD have exactly the same types of intrusive thoughts as people with OCD.

## These may include:

- Thoughts about being dirty and catching germs.
- Thoughts about safety including leaving appliances on.
- Thoughts or images of being violent towards others.
- Images or thoughts of sexual activities that we don't think are okay or appropriate.
- Images and thoughts of being harmed or someone else being harmed.
- Imagining acting in a way that's rude or wrong (like yelling out swear words or 'flashing').



Intrusive thoughts can be thought of as the ‘by-product’ of all the information our brains gather in our day-to-day lives. They are like our dreams in a way – our brain’s attempt to process all the things happening around us. And just like dreams, intrusive thoughts are often not based on reality, facts or the things we wish to do but instead fueled by our imaginations and many of the things we fear or are repulsed by.

It isn’t common for people to actually want to act on an intrusive thought – say a thought of jumping off a high bridge(yes, these types thoughts are very common!). In fact, often intrusive thoughts are the exact opposite of what we want to do. They don’t sit with what we believe, with our values and how we want to behave. This makes the thoughts so much more distressing, if we misinterpret the meaning of them, and think they are in fact underlying desires or things we might be at risk of doing subconsciously (without knowing).

We know from research that people with OCD seem to have a lot more intrusive thoughts and experience them in a way that makes them seem more real and upsetting compared with people who don’t have the condition. This forms a large part of the problem in OCD, and one that treatment looks to address.

## What causes OCD?

It still isn’t clear what causes OCD however researchers think it may be to do with differences in how brain pathways communicate with each other, making people more prone to having a fear response to everyday triggers (such as intrusive thoughts) that other people don’t get as affected by.

Factors in a person’s environment can contribute to the development of OCD, and there may be some genetic factors too. It may well be a combination of several things, however it’s important to know that it’s no one’s fault.

We know people experiencing OCD see their thoughts differently. They appear to experience a greater sense of alarm when they have distressing thoughts, making the thoughts appear more harmful and dangerous. People experiencing OCD may interpret their thoughts as:

- Being real -or the events might actually happen
- there is something bad or wrong with them for having the thoughts

When we worry that our thoughts are dangerous and true, we get distressed and try to push them away. When we react in this way, our thoughts become more intense and show up more often. It's our mind's way of trying to stop us forgetting information that seems important for our safety.

### **People with OCD often try to:**

- not think of their intrusive thoughts by pushing them away
- get rid of them or 'undo' them in some way (for example, using compulsions like checking or praying over and over, asking others if they're OK, or researching their worries online)
- avoid situations, feelings or physical sensations that trigger them.

These responses, which are understandable when you think of the distress these thoughts cause, unfortunately get people stuck in a vicious cycle where OCD takes more and more control over a person's life.

## **Can OCD be treated?**

Yes! Research shows that effective treatment, which is often a combination of medication and psychological therapy, can make a huge difference to someone living with OCD. Research shows the most effective psychological treatment is cognitive behavioural therapy (or CBT as it is often referred to) specifically tailored for OCD..

CBT for OCD helps people learn about their experience of OCD and identify the ways they get 'stuck' in it. Because people experiencing OCD often affects the people close to them, it's important for loved ones and important people around them to learn about OCD too, so they can act as supporters and ensure they know how to help and not hinder treatment.

The goal shouldn't be about getting rid of OCD altogether. OCD symptoms may still linger in the background within a person's life or may show up again at stressful times or during big life events or changes. The goal should be about learning how to ensure OCD doesn't take control so that people experiencing the condition and their family and friends are able to live a meaningful, enjoyable life.

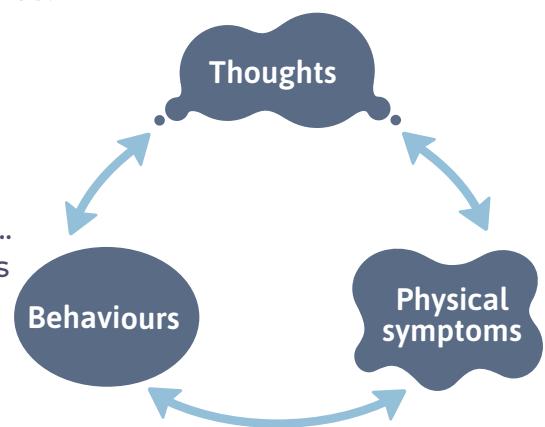
There are some great examples of personal stories from New Zealanders living with OCD on our Just a Thought OCD course page - <https://www.justathought.co.nz/ocd>.

# What does treatment involve?

Many people with OCD will need the support of medication at the start of their journey in using psychological treatment. Medication can assist people at the beginning of treatment when it can feel particularly overwhelming.

CBT for OCD largely involves learning about the vicious cycles of OCD and working with the thoughts and behaviours that get people stuck in it. Part of the way CBT works is by getting people to start doing 'behavioural experiments' where people expose themselves to the things they fear to see if there is real risk, whilst they attempt to drop the compulsions they use to help them feel safe. This is called Exposure and Response Prevention. An example of this might be working up to not washing their hands to see if they really are at risk of passing on harmful germs, or avoiding things like using knives where they worry they could become a danger to others. As you can imagine, this can be really scary. Exposure therapy like this requires a lot of courage and willpower which can take time. This is where supporters can make all the difference with encouragement and praise!

CBT also involves learning to live with anxiety, because we all experience it and we can't remove it from our lives. Interestingly, the more we are able to accept anxiety when it shows up, and not battle to try and get rid of it, the easier it becomes to live with.. When anxiety begins to reduce on its own, our brains start to realise the things we worried about may actually not be a real or a risk to us and others, so we can begin to manage it.



CBT involves learning to identify and challenge anxious OCD thoughts, learning how to respond when they show up and identifying behaviours that get people stuck and new behaviours that will take people towards the life they want to live.

CBT for OCD can be overwhelming for people, as it gets them to start facing things that cause real distress, and that they have often worked very hard to avoid. People need to learn to back themselves and need lots of encouragement and understanding along the way. That's where you come in!

# What is accommodation?

Accommodation is a term we use to describe behaviours loved ones and those living around a person with OCD adopt to try reduce distress. The person living with OCD may ask their supporters to engage in certain behaviours, like not using a certain set of utensils, avoiding using a bathroom or keeping distance from them. They seek a lot of reassurance. You might find yourself beginning to do these behaviours without being asked to try and ease your loved ones distress, avoid fights or make your own life easier.

These are referred to as ‘safety behaviours’. And while they might help in the short-term, they don’t give the person the necessary skills they need to learn to manage their OCD. Unfortunately, over time, people often need themselves and others to engage in more and more of these behaviours to feel okay. That’s why the behavioural experiments using Exposure and Response Prevention work so well. The Just a Thought OCD course encourages your loved one to make up an Exposure Stepladder, to plan a list of feared experiences and things to expose themselves to that they have been avoiding WITHOUT using their safety behaviours and compulsions. This means loved ones also have to start to drop the safety behaviours they use to try and accommodate the OCD. Exposure Stepladders help to work on the easiest to manage tasks first so people can build confidence. You could help identify with your person the accommodation behaviours you do, and get them to rank which would be the easiest for you to stop doing first, and plan experiments to drop these as they work on their own Exposure Stepladders.

## Setbacks

Like anything in life that we want to learn or change, we have to be prepared to face setbacks. Setbacks are a normal part of growth and learning.

When people with OCD begin feeling better, it can feel wonderful for everyone involved. There’s always the hope OCD will one day ‘go away’, and improvements can increase this hope. But most people live with a great fear that they’ll never get rid of OCD and won’t be able to get back to who they felt they were, or what life was like before OCD . This fear tends to surface just as people are beginning to feel more in control.

It’s important to know, that like most of our worries, this thought isn’t true, and people can recover to live amazing, meaningful lives where they aren’t controlled by OCD. But it takes a lot of time, patience and determination. AND a willingness to struggle and sometimes fail.

As their supporter, you can help your person to see this and continue to believe in themselves and the progress they have already made when a setback arises. In fact, it can helpful to discuss the reality of setbacks and how the person can approach them before they even happen. That way, the level of disappointment, distress and possible loss of motivation may be lessened, and they will have a set plan of how to tackle challenges.

Thinking ahead about the things in life that might trigger a setback can be helpful too (increased stress, becoming a parent, exams, a death, illness etc), so that if these things happen, you can work together to stick to the plans that you’ve put in place!

# Can I help my loved one with their OCD treatment?

Absolutely, but it's important to know that like any major life change or goal, we can't do 'make people better' - they have to ultimately make the changes themselves. Not everyone is ready to change, or to bring other people onboard. People might move in and out of being ready to change, and ready to share their experiences with others. All you can do is be there and be ready to help when they need you.



## How can I help in a practical way?

One of the most helpful things you can do is to learn about OCD and how treatment works. You too can go through the Just a Thought OCD course and resources. It is free for anyone to sign up and do!

Communication is key! It's super important to talk with your loved one about how they would like you to be involved, what they want you to do, and what they don't want you to do. This might include:

- How much support they need, and how often (and this can change as time goes by).
- How they want you to deliver that support (in person, via phone, text, doing some of the therapy sessions together, spending time together).
- How you might be able to help with their Exposure work and other parts of their CBT treatment.
- Which behaviours and affirmations from you might help, and which don't.
- Which behaviour from you don't help in the long-term, and how you/they can work to change these together. This is especially helpful for any accommodation behaviours that are already present.
- How you can encourage and praise them, and how you can point out when they may slip back into 'old OCD responses' that don't help.
- What you as their supporter, are willing to do and what you can't do – having boundaries and looking after yourself along the way is essential.

# What to if you feel your loved one is in crisis?

If your loved one is in crisis, it's important to know if there is risk of suicide or not. This can be hard to think about or know how to ask, but asking at the right time can help save someone's life.

It might feel like a difficult topic to bring up because suicide is a very uncomfortable, taboo subject, however the reality is most of us experience thoughts of suicide from time-to-time in life. Thinking about suicide doesn't mean we will actually do it, or that we even want to do it. It can just be our brains way of trying to problem solve very difficult situations where we feel stuck and a bit hopeless.

Talking about suicide can help people to think through how they feel, what they are struggling with and what they need to feel better. It can actually help people make a decision that they want to live and recover. It's all about how you approach the discussion, and how willing the person is to talk about it too. It's essential to stay open, try and be brave and use direct language around suicide. Stay supportive and hopeful, non-judgmental and know when to just listen. Sometimes it can help to share your own thoughts or experiences of suicide - you just have to get a sense of what to say, how much to say and when to let the person talk about their own experience. Often, if we can manage our own anxiety during these difficult conversations, they are easier and go better than we expect them to.

Ensuring people have the right crisis contact numbers they need, when they need is important too. We have a 'Get Help Now' page on our website that directs people to their local crisis mental health team. Calling 111 or going to a local accident and emergency department at a hospital or medical centre can be the most helpful thing to do in life-threatening situations.

If people are experiencing suicidal thoughts with some potential risk of acting on them, it can be essential for them to have a safety plan. This should be done preferably with their health professional and can be most helpful when loved ones and supporters are involved (so long as the person is comfortable) so everyone knows what to do.

Our friends at Le Va and the Mental Health Foundation have some amazing resources to support people and their whānau and friends around suicide. Check these out below:

[Find the help you need - Le Va](#)

[If you are worried about someone - Le Va](#)

[Suicide: worried about someone? | Mental Health Foundation](#)

In terms of non-suicide crises, again a plan of support can help. It might include information about where the person might want to stay if they are struggling, what activities and interventions help when distress is high, which health professionals to get in contact with and what you and other supporters can do.

Remember, crises pass, and most of the worst things we worry about in life don't actually happen. Crises give people a chance to learn what resources they have, what they are capable of surviving and what to do to overcome challenges and get even further ahead.

## Where can I learn more about OCD?

There are some great books and resources on the internet from New Zealand and overseas that can help you learn more about OCD. See our list below:

### OCD NZ / Fixate

OCD NZ have a great resource page full of videos, podcasts, books and websites. Also their facebook page 'Fixate' is a wonderful support group for people with OCD and their supporters and loved ones.

### Anxiety NZ

Anxiety New Zealand has a 24/7 anxiety helpline, loads of great resources and therapy options. Check them out.

### PADA - Perinatal Anxiety & Depression Aotearoa

PADA is a wonderful charity providing advocacy and awareness through training and facilitating connections and tools for health care providers who are supporting families with anxiety & depression due to pregnancy, childbirth and early parenting. They have a bunch of great resources on OCD and information on other types of anxiety, grief and loss, pregnancy and parenting issues on their website.

### Stuff that's Loud

Stuff that's Loud is a great Facebook page run by Clinical Psychologist and OCD expert Ben Sedley offering information, news, interesting articles and events to support people living with OCD. Check it out!

## The OCD Stories

The OCD Stories podcast is a show that aims to offer hope and inspiration. Host Stuart Ralph interviews some of the best minds in OCD treatment and recovery to share their advice, to both entertain and educate listeners towards a healthier life.

## IOCDF

The International OCD Foundation is a donor-supported nonprofit organization. Founded in 1986 by a small group of individuals with OCD, the Foundation has grown into an international membership-based organization serving a broad community of individuals with OCD and related disorders, their family members and loved ones, and mental health professionals and researchers around the world.

## OCD Action

OCD Action is a UK charity formed in 1994 to help those affected with OCD. Their website has great resources on OCD and different treatments, and an online forum to support people affected by OCD.

## The Mental Health Foundation

The Mental Health Foundation has a helpful page full of information, links and services here in New Zealand.

## Health Navigator NZ

Health Navigator provides all sorts of information for people and professionals on OCD.

## **More helpful tips**

Reducing sources of stress in life really helps reduce the triggers for OCD on a daily basis and over time. Helping your loved one identify where stress comes from, and working out how to limit stressors together (reducing working hours, getting in more help around the home, avoiding taking on unnecessary responsibility) can really help reduce anxiety overall, which can help OCD symptoms reduce too.

Looking after your basic wellbeing is important for everyone, especially if you are either struggling with your mental health or supporting someone who is. Getting enough sleep, eating well, exercising for good health and mental wellbeing and engaging in activities that bring joy, a sense of meaning, connection and achievement improves our mood and increases our resilience.

## Summary

This resource provides some ideas about how to support someone living with OCD and gives information on treatment. Recovering from OCD can involve lots of ups and downs. Working together to get ahead of OCD can be challenging, and at times, really distressing. Communicating clearly about how you can work as a team is essential. It's also helpful to understand that people have to be ready to put in the hard work and need to take responsibility for making the changes they need for themselves.

We wish you and your loved one all the very best. Thank you for showing up for them!

Get in contact if you have any feedback or further questions!  
Email us at [hello@justathought.co.nz](mailto:hello@justathought.co.nz).

All the best,

The team at Just a Thought

[www.justathought.co.nz](http://www.justathought.co.nz)