

It can take nine years to make an OCD diagnosis, say researchers

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Credit: AI-generated image (disclaimer)

Obsessive compulsive disorder, or OCD, is a <u>misunderstood</u> mental illness despite affecting <u>about one in 50 people</u>—that's about half a million Australians.



Our <u>new research</u> shows how long and fraught the path to diagnosis and treatment can be.

This initial study showed it takes an average of almost nine years to receive a diagnosis of OCD and about four months to get some form of help.

What is OCD?

OCD affects children, adolescents and adults. <u>About 60%</u> report symptoms before the age of 20.

One misconception is that OCD is mild: someone who is extra tidy or likes cleaning. You might have even heard someone say they are "a little bit OCD" while joking about having beautiful stationery.

But OCD is not enjoyable. Obsessions are highly distressing and there are repetitive, <u>intrusive thoughts</u> a person with OCD can't control. They might believe, for instance, they or their loved ones are in grave danger.

Compulsions are actions that temporarily alleviate, but ultimately exacerbate, this distress, such as checking the door is locked. People with OCD spend hours each day consumed by this cycle, instead of their normal activities, such as school, work or having a social life.

It can also be very distressing for <u>family members</u> who often end up completing rituals or providing excessive reassurance to the person with OCD.

How is it diagnosed?

People with OCD often don't tell others about their disturbing thoughts



or repetitive rituals. They often feel <u>ashamed or worried</u> that by telling someone their disturbing thoughts, they might become true.

Doctors don't always ask about OCD symptoms when people first seek treatment.

Both lead to delays getting correctly diagnosed.

When people do feel comfortable talking about their OCD symptoms, a diagnosis might be made by a GP, psychologist or other health-care professional, such as a psychiatrist.

Sometimes OCD can be <u>tricky to differentiate</u> from other conditions, such as eating disorders, anxiety disorders or autism.

Having an additional mental health diagnosis is common in people with OCD. In those cases, a health-care provider experienced in OCD is helpful.

To diagnose OCD, the health professional asks people and/or their families questions about the presence of obsessions and/or compulsions, and how this impacts their life and family.

How is it treated?

After someone receives a diagnosis, it helps to learn more about OCD and what treatment involves. Great places to start are the <u>International OCD Foundation</u> and <u>OCD UK</u>.

Next, they will need to find a health-care provider, usually a psychologist, who offers a special type of psychological therapy called "exposure and response prevention" or ERP.



This is a type of cognitive-behavioral therapy that is a <u>powerful</u>, <u>effective treatment</u> for OCD. It's recommended people with OCD try this first.

It involves therapists helping people to understand the cycle of OCD and how to break that cycle. They support people to deliberately enter anxiety-provoking situations while resisting completing a compulsion.

Importantly, people and their ERP therapist <u>decide together</u> what steps to take to truly tackle their fears.

People with OCD learn new thoughts, for example, "germs don't always lead to illness" rather than "germs are dangerous."

There are a range of medications that also <u>effectively treat</u> OCD. But more research is needed to know more about when a medication should be added. For most people these are best considered a "boost" to help ERP.

But not everything goes to plan

Delays in being diagnosed is only the start:

- treatment is challenging to access. Only 30% of clinicians in the United States offer ERP therapy. There is likely a similar situation in Australia
- many people receive therapies that appear credible, <u>but lack</u>
 <u>evidence</u>, such as general cognitive therapy that is not tailored to
 the mechanisms maintaining OCD. Inappropriate treatments
 waste valuable time and effort that the person could use to
 recover. Ineffective treatments can make OCD symptoms worse



- even when someone receives first-line, evidence-based treatments, about 40-60% of people don't get better
- there are no Australian clinical treatment guidelines, nor state or national clinical service plans for OCD. This makes it hard for health-care providers to know how to treat it
- there has been <u>relatively little research funding</u> spent on OCD in the past ten years, compared with, for example, psychosis or dementia.

What can we do?

Real change demands collaboration between health-care professionals, researchers, government, people with OCD and their families to advocate for proportionate funding for research and clinical services to:

- deliver <u>public health</u> messaging to improve general knowledge about OCD and reduce the stigma so people feel more comfortable disclosing their worries
- upskill and support health professionals to speed up diagnosis so people can receive targeted early intervention
- support health-care professionals to offer evidence-based treatment for OCD, so more people can access these treatments
- develop state and national service plans and clinical guidelines.
 For example, the Australian government funds the <u>National</u>
 <u>Eating Disorders Collaboration</u> to develop and implement a nationally consistent approach to preventing and treating eating disorders



• research to discover new, and enhance existing, treatments. These include ones for people who don't get better after "exposure and response prevention" therapy.

What if I think I have OCD?

The most common barrier to getting help is not knowing who to see or where to go. Start with your GP: tell them you think you might have OCD and ask to discuss treatment options. These might include therapy and/or medication and a referral to a psychologist or psychiatrist.

If you choose therapy, it's important to find a clinician that offers specific and effective treatment for OCD. To help, we've started <u>a</u> <u>directory</u> of clinicians with a special interest in treating OCD.

You <u>can ask</u> any potential health professional if they offer "exposure and response prevention." If they don't, it's a sign this isn't their area of expertise. But you still can ask them if they know of a colleague who does. You might need to call around, so hang in there. Good <u>treatment</u> can be life changing.

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