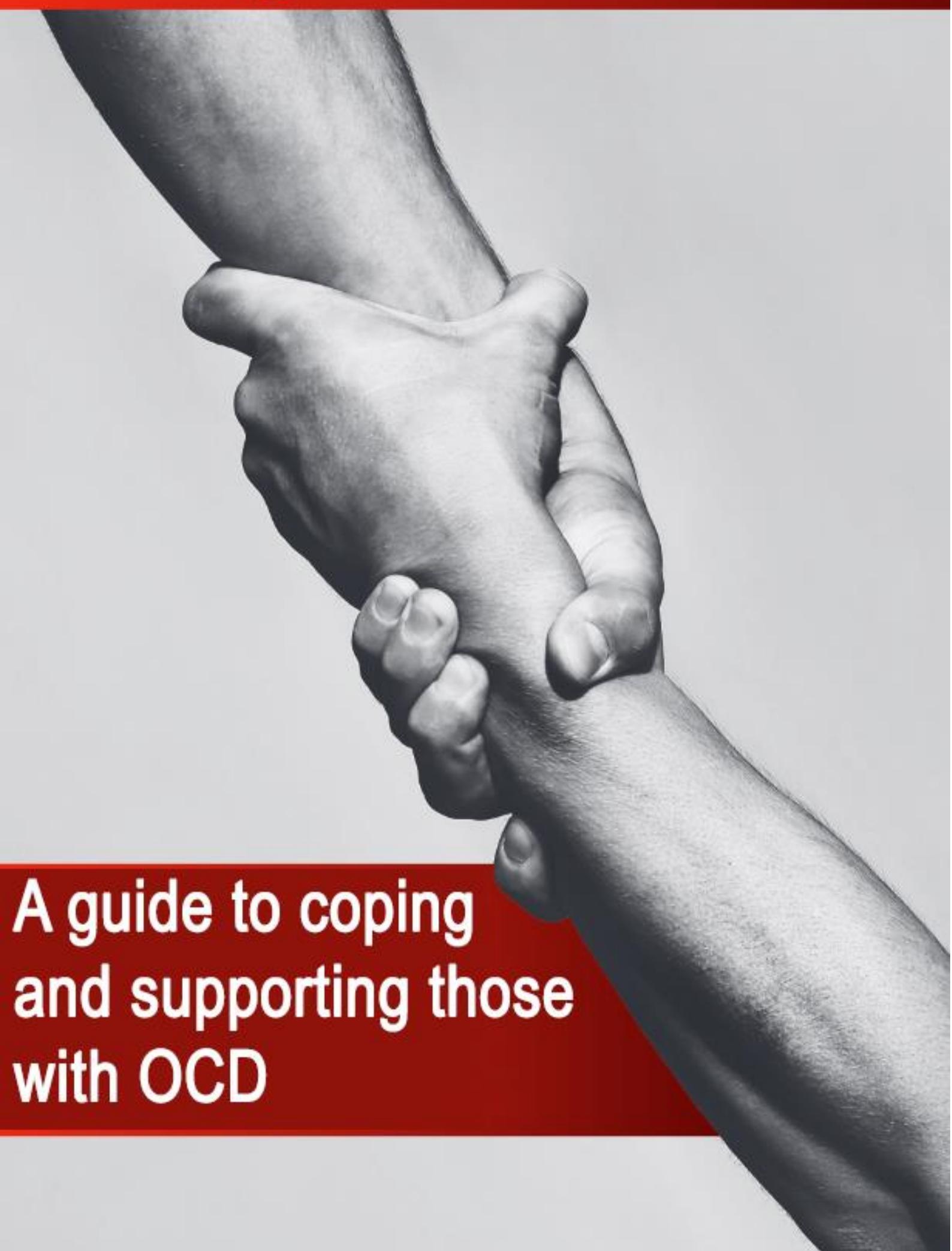




ACTION AWARENESS EAST MIDLANDS
FOR ALL OF YOUR TRAINING NEEDS & ASSISTANCE



**A guide to coping
and supporting those
with OCD**



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What is OCD?

Obsessive-Compulsive Disorder (OCD) is a mental health condition that involves two key components: **obsessions** and **compulsions**. These can significantly impact a person's daily life, relationships, and well-being.

Obsessions: These are unwanted, intrusive thoughts, images, or urges that cause significant anxiety or distress. They can feel overwhelming, persistent, and often go against a person's values or desires. Examples include fears of contamination, doubts about safety, or disturbing thoughts about harm.

Compulsions: These are repetitive behaviors or mental acts that a person feels driven to perform to reduce the anxiety caused by obsessions. While these actions might provide temporary relief, they can become time-consuming and interfere with daily life. Examples include excessive cleaning, checking, repeating actions, or mentally reassuring oneself.

Based on current estimates for the UK population, there are around three quarters of a million people living with OCD at any one time. What we know about OCD is that the condition affects as many as 12 in every 1,000 people (1.2% of the population) from young children to adults, regardless of gender, social or cultural background.

Why It's Not Just a Quirk

Many people misunderstand OCD as simply being overly tidy or perfectionistic. In reality, it's much deeper and often quite painful. OCD is not about being meticulous; it's about feeling trapped in a cycle of distressing for those experiencing the thoughts and actions associated with the condition.

Imagine feeling constantly unsure if you've locked the door, even after checking multiple times. Or worrying that a fleeting, irrational thought makes you a bad person. This can lead to a lot of shame, confusion, and frustration.

It's important to separate OCD from everyday habits or preferences. Wanting a clean room or double-checking your schedule doesn't mean you have OCD. The difference is that for someone with OCD, these thoughts and actions feel **uncontrollable, intrusive**, and often conflict with what they actually value or want.

People with OCD often feel misunderstood or judged, so offering a listening ear and being nonjudgmental can make a huge difference. Phrases like "Just stop worrying" or "You're being dramatic" can inadvertently dismiss their experience. Instead, try saying, "I'm here for you" or "It must be really hard to feel that way."

Diagnosing OCD

The key difference that segregates little quirks, often referred to by people as being 'a bit OCD', from the actual disorder is when the distressing and unwanted experience of obsessions and compulsions impacts to a significant level upon a person's everyday functioning – this represents a principal component in the clinical diagnosis of Obsessive-Compulsive Disorder. If a person's trait does not cause anxiety or impact or disorder to



their life, then it is unlikely to be OCD, although a health professional will need to conduct an assessment to confirm a diagnosis or not.

When someone seeks help for their OCD, healthcare professionals will consider how distressing the symptoms are for that person and how much their life is affected. Generally, OCD might be diagnosed if symptoms take more than a hour each and every day.

In terms of what health professionals will look for when assessing and diagnosing OCD, the NICE Guidelines for OCD stated that “the diagnostic criteria for the two main international classification systems, ICD and DSM are virtually identical and must include the presence of either obsessions or compulsions.” The NICE Guidelines then go on to state:

- The patient must acknowledge that the obsessional thoughts, impulses, or images are a product of their mind and are not imposed by an outside person or influence.
- At least one obsession or compulsion must be acknowledged as excessive or unreasonable.
- Furthermore, the obsessions or compulsions must cause marked distress, or significantly interfere with the patient’s occupational and/or social functioning, usually by wasting time.
- Traditionally it has been believed that insight (the ability to recognise the senselessness of the obsessions) is a key feature of OCD. However, there is growing recognition that the level of insight is highly variable. Thus some people with OCD may show stable but low levels of insight, others may show insight when not confronted with a feared situation, but lose this insight when their anxiety is high in situations associated with their obsessive fears.

For those of us with OCD, actually getting that diagnosis will require an assessment with a trained health professional. Usually this can be arranged by speaking to a GP who will refer you to the right part of the NHS for an assessment or you can self-refer for assessment and therapy if you’re in England, we discuss treatment access more in the Overcoming OCD chapter. The assessment with a health professional will take place over the phone (for IAPT services in England) or face-to-face and last about an hour. The health professional will ask a series of questions, either on forms or verbally, to consider whether you may have OCD. They may ask the following questions (as suggested by the NICE Guidelines for the treatment of OCD):

- Do you wash or clean a lot?
- Do you check things a lot?
- Is there any thought that keeps bothering you that you’d like to get rid of but can’t?
- Do your activities take a long time to finish?
- Are you concerned about putting things in a special order or are you very upset by mess?
- Do these problems trouble you?

Don’t worry if these diagnostic descriptions are not similar to what you’re experiencing, OCD covers a vast array of themes and it’s not possible to fully cover them all. The questions above are also merely a guidance and starting point for health professionals, a good assessment will ask far more and relevant questions for your problems.

If you don’t think these questions help explain your OCD, then it can be helpful to prepare a way to explain your OCD symptoms in advance of your assessment.



Coping Strategies

As OCD is a well understood condition there are many different coping strategies and treatments to help reduce the symptoms and impact of the condition. As OCD is rooted in how the brain processes thoughts and anxiety. Research suggests it involves dysfunctions in brain areas linked to **habit formation, error detection, and emotional regulation**. Since it's often influenced by genetic and neurobiological factors, it doesn't simply "go away" and is considered a chronic condition that can be regulated and reduce but not completely "cured".

Here are a range of coping strategies and treatments available to those with OCD:

1. Cognitive-Behavioral Therapy (CBT)

CBT is currently considered the most effective treatment for OCD and is a specific form of CBT called **Exposure and Response Prevention (ERP)**.

- **Exposure:** Gradually facing the feared thoughts or situations without performing compulsive behaviors.
- **Response Prevention:** Learning to resist the urge to perform compulsions.
- **Example:** If someone fears contamination, they might practice touching a doorknob without washing their hands immediately after.

Why It Works: Over time, the brain learns that the feared outcome is unlikely or not as distressing as anticipated.

2. Mindfulness and Acceptance Techniques

OCD often thrives on resistance—trying to push away or “fix” unwanted thoughts. Mindfulness encourages acceptance rather than resistance.

- **Mindful Observation:** Acknowledge the thought without judgment—like watching a cloud pass by.
- **Grounding Exercises:** Focus on the present using sensory experiences (e.g., noticing five things you see or hear).

Why It Helps: Reduces the emotional impact of intrusive thoughts by allowing them to exist without reaction.

3. Self-Compassion Practices

People with OCD often feel guilt or shame about their thoughts. Practicing self-kindness is crucial.

- **Affirmations:** “It’s okay to have these thoughts—they don’t define me.”



- **Journaling:** Write down intrusive thoughts and respond with a compassionate statement.

Why It Helps: Reduces self-blame and builds resilience against obsessive thinking.

4. Building a Support System

OCD can feel isolating, so having supportive friends, family, or therapy groups makes a difference.

- **Talk Openly:** Share your experiences with those you trust.
- **Educate Your Circle:** Help loved ones understand what OCD really is.
- **Join a Group:** Online or in-person support groups can offer encouragement and reduce isolation.

5. Medication (if needed)

For some, medication can significantly reduce symptoms. Commonly prescribed are **SSRIs (Selective Serotonin Reuptake Inhibitors)**, which help balance brain chemistry related to mood and anxiety.

- **Consult a Professional:** Always discuss the pros and cons with a healthcare provider.
- **Combine with Therapy:** Medication is often more effective when paired with CBT.

6. Lifestyle Changes

Simple routines can reduce stress and make symptoms more manageable.

- **Exercise:** Regular physical activity lowers anxiety levels.
- **Sleep Hygiene:** Maintaining a consistent sleep schedule can reduce stress.
- **Healthy Diet:** Reducing caffeine and sugar helps minimize anxiety spikes.

7. Creative Outlets

Sometimes expressing feelings creatively can help process them.

- **Art Therapy:** Drawing or painting your thoughts can help externalize them.
- **Writing:** Keeping a journal or creating stories where characters face similar struggles can provide insight and relief.



- **Music:** Listening to calming tunes or playing an instrument can help redirect obsessive energy.

8. Setting Small, Realistic Goals

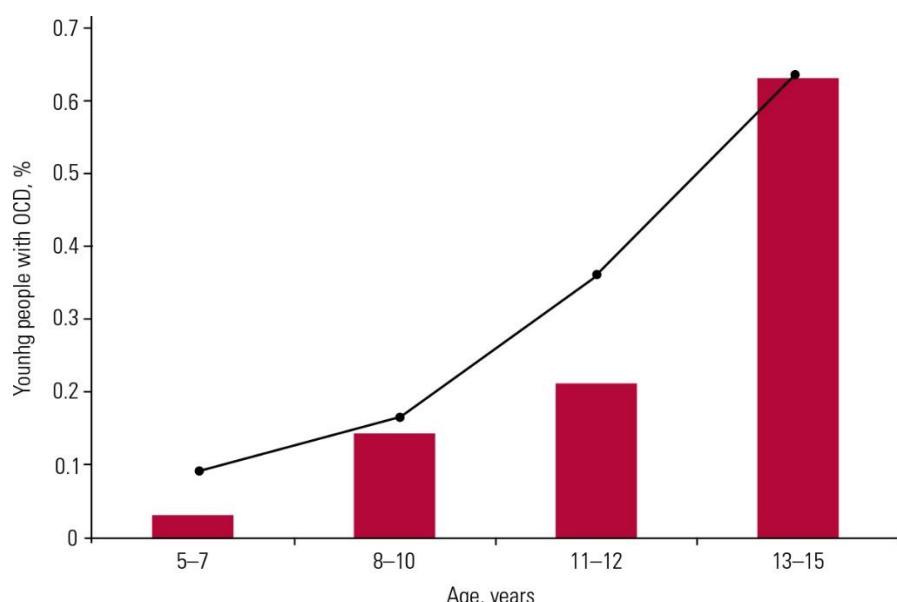
Breaking big challenges into smaller, manageable steps prevents feeling overwhelmed.

- **Daily Achievements:** Acknowledge small victories, like resisting a single compulsion.
- **Track Progress:** Use a journal or app to record successes.
- **Celebrate Wins:** Reward yourself for progress, no matter how small.

Management vs. Cure

Think of managing OCD as similar to managing a chronic physical condition (like diabetes or asthma). With the right treatment, symptoms can become minimal or even absent for long periods, but it requires ongoing maintenance and awareness.

- **Recovery Doesn't Mean Perfection:** Even if symptoms decrease significantly, occasional intrusive thoughts may still occur. What changes is how a person **responds** to those thoughts.
- **Living Well with OCD:** Many people with managed OCD lead fulfilling, symptom-light lives, equipped with skills to cope if symptoms resurface.



A graph showing prevalence of OCD in children aged 5-15 showing a spike once children reach puberty
Source: <https://www.cambridge.org/core/journals/bjpsych-advances/article/obsessivecompulsive-disorder-in-young-people/>



What is “Pure O”?

Purely obsessional’ or ‘Pure O’ is a term commonly used to refer to a form of obsessive-compulsive disorder which people mistakenly believe has no outward compulsions and only features distressing internal intrusive thoughts.

But does ‘Pure O’ exist?

Well as an online term yes, but as a form of OCD, not really, it’s merely a phrase. It’s certainly not a medically listed term, and we will try and explain why we don’t consider it a separate form of OCD.

**“Like any person suffering from OCD, a person with
‘Pure O’ will have compulsions.” OCD-UK**

Like any person suffering from OCD, a person with ‘Pure O’ will have compulsions, some will manifest as unseen mental rituals, but importantly there will nearly always be physical outward compulsions too, making the term ‘Pure O’ imprecise.

Examples of physical compulsions include checking (various types of checking, from checking on Google to checking for own body reactions/sensations), seeking reassurance from loved ones or avoidance of particular objects, places or people that trigger obsessional thoughts. Watching movies of an adult nature to check if there is arousal. They’re all compulsions (mental or physical), which is why the term ‘Pure O’ is both unhelpful and imprecise.

It’s unhelpful because a person suffering with OCD might fail to recognise their own symptoms (compulsions) hindering their recovery.

Summary

In summary, what we’re saying is that ‘Pure O’ is like any other form of OCD, it will involve both obsessions and compulsions, and treatment approaches would be no different. A person doesn’t need a ‘Pure O’ specialist, ‘Pure O’ would be treated using standard traditional treatment methods, the same that are used for every other type of OCD.

It’s for this reason that OCD-UK have chosen to not use the term, and proactively highlight how misleading it can be.



Sophie's story

Sophie is a 26-year-old mental health advocate who has lived with OCD for 11 years. She won a Bill Pringle Award with Rethink Mental Illness for her poem on managing OCD in 2019 and has spoken publicly about her experience on radio and on social media. She is open and vocal about mental health and mental illness because she knows first-hand how isolating and scary it can be in the beginning.



“I just felt guilty all the time about every small thing that, before OCD, wouldn’t really have bothered me at all, and I needed people to tell me I was a good person.” – Sophie

My symptoms

When my OCD first started, I thought it was simply anxiety, but after doing some research into mental health I realised it was OCD. I felt guilty and paranoid for most of the day with very little relief, overthinking every little bit of whatever thought or image was in my head at the time. I would wake up with palpitations and struggle sleeping because I couldn’t stop ruminating. Logical thought takes a back seat with OCD. When your brain wants to convince you that you’re a bad person, it will give you lots of evidence to try and support it. When you don’t know how to fight back, it can be truly terrifying – you’re defenseless.

My lowest moments

I began to worry about leaving the house because I couldn’t determine what situation might trigger another intrusive thought, and that lack of control over your own thought process can completely take over your daily life. When I did leave the house, I would avoid the people or things that were involved in my thoughts, otherwise I struggled to cope. I would experience the same recurring intrusive thought or image for months at a time and would only find (albeit short-lived) peace when I was completely distracted.

I haven’t experienced many compulsions, but my primary one was reassurance-seeking or “confessing.” I constantly felt guilty for my thoughts and at my lowest point, when it



became overwhelming, I would find myself asking my mum or partner to remind me that I am a good person, but my brain didn't seem to want to believe it. It was a terrifying circle – an intrusive thought would come in, I'd panic and ruminate, find someone to "confess" to and the process would start all over again. This lasted for a number of years before I discovered that it was only making my OCD worse.

My way forward

After two failed attempts at seeking help via public and private mental health services, I admittedly haven't been very lucky with professional help and so had to learn to manage my OCD on my own, with the additional support of a select few trusted friends and family. As such, I trained in mental health first aid and undertook a lot of personal research, not only to help myself but to help others like me. I'm the nominated mental health champion at my place of work, though I generally remain a passionate advocate for mental health in all aspects of my life, and I will continue to help others for as long as I possibly can. I also love to write and have found solace in writing about my OCD via reflective poetry.

Why I'm sharing my story

When I felt my lowest, when I felt there was no escape, it wasn't professional help that ultimately helped me but the experiences of others with OCD or who know about OCD. It was the advice of mental health charities, the blog pages of people with lived experience and the never-ending stream of support I had that helped me to help myself. I'm very proud that I can now manage my OCD successfully and, if I ever find myself feeling low or overwhelmed, I know that I can overcome it. I see my OCD as an enduring and experienced reflection of myself – it is no longer a threat.

The myths that annoy me – and the truth about them

OCD is characterized by the desire to keep yourself and/or your space clean.

False. While the compulsion to clean isn't unheard of among individuals with OCD, cleanliness and OCD aren't mutually exclusive and the compulsion to clean shouldn't be considered a choice or desire. Instead, they may feel that it is mandatory in order to find relief.

Everyone is "a little bit OCD."

False. You cannot be a "little bit" OCD. OCD isn't an adjective – it's a complex disorder that affects only 1-2% of people and can be incredibly difficult to manage without the appropriate treatment and care.

OCD can be cured.

False. While this may sound daunting, OCD can be effectively controlled and managed with treatment that suits the individual, allowing them to live a healthy, happy life.



Supporting other adults with OCD

Supporting an adult with OCD can make a huge difference in their well-being. Here's how to offer help in a compassionate and effective way:

1. Educate Yourself About OCD

Understanding the condition is the first step. OCD is not just about being overly tidy or perfectionistic—it's a complex anxiety disorder.

- Learn the Basics: Know the difference between obsessions (intrusive thoughts) and compulsions (repetitive behaviors).
- Avoid Stereotypes: Phrases like “I’m so OCD about cleaning” can feel dismissive.
- Resources: Websites like the International OCD Foundation (IOCDF) offer helpful insights.

2. Be a Supportive Listener

People with OCD often feel misunderstood or judged. Listening without criticism can help them feel seen and validated.

- Active Listening: Show empathy by saying things like, “That sounds really tough.”
- Avoid Giving Advice: Sometimes they just need someone to hear them, not fix the problem.
- Validate Feelings: Even if their fears seem irrational to you, they feel real to them.

3. Don't Enable Compulsions

This can be tricky because it's natural to want to reduce their distress. However, participating in compulsions (like checking things for them) can reinforce the OCD cycle.

- Gently Set Boundaries: Say, “I care about you, and I want to help in ways that support your long-term well-being.”
- Encourage Exposure: If they're practicing ERP therapy, support their efforts by not giving in to reassurance-seeking.
- Be Patient: Reducing compulsions is hard and may take time.

4. Encourage Professional Help

Suggest therapy without making it feel like an ultimatum.

- Frame It Positively: “Therapy might give you tools to feel more in control.”
- Offer to Help Find Resources: Sometimes, just the act of researching can feel overwhelming.



- Normalize Therapy: Share that many people benefit from talking to a professional.

5. Practice Compassionate Communication

Words matter. Try to avoid phrases that can sound dismissive, like:

- “Just stop worrying.”
- “You’re being irrational.”
- “It’s all in your head.”

Instead, say:

- “I’m here for you, no matter what.”
- “It must be really tough to feel that way.”
- “How can I support you right now?”

6. Be Patient with Relapses

OCD can wax and wane. If symptoms resurface, avoid showing frustration or disappointment.

- Acknowledge the Effort: Say, “I see how hard you’re working to manage this.”
- Offer Stability: Be a consistent presence without focusing too much on setbacks.
- Celebrate Progress: Even small victories deserve recognition.

7. Take Care of Yourself, Too

Supporting someone with OCD can be emotionally taxing, so self-care is essential.

- Set Boundaries: It’s okay to say, “I’m here for you, but I also need some time to recharge.”
- Seek Your Own Support: Talking to a therapist or joining a support group can help you navigate the challenges.
- Practice Self-Compassion: Acknowledge that it’s okay not to have all the answers.

8. Encourage Self-Advocacy

Empower them to make their own choices and take ownership of their recovery.

- Respect Their Process: Everyone’s journey with OCD looks different.
- Offer Practical Help: Whether it’s attending a therapy session with them or helping with daily tasks, practical support shows you care.
- Celebrate Resilience: Remind them of their strength, even on difficult days.



Supporting Children and Teens with OCD

Supporting children and teens with OCD requires a slightly different approach since they might not fully understand their own symptoms or know how to express their struggles. Here's how to help them:

1. Learn to Recognise OCD in children

Children might not always describe their intrusive thoughts or compulsions clearly. Look out for signs like:

- **Repetitive Behaviors:** Excessive handwashing, checking, or repeating actions.
- **Unusual Rituals:** Needing things arranged "just right" or repeating phrases for reassurance.
- **Distress When Interrupted:** If they can't complete a ritual, they may become visibly upset.
- **Avoidance:** Not wanting to go to certain places or do specific activities.
- **Seeking Reassurance:** Frequently asking questions to confirm safety or correctness.

2. Create a Safe, Nonjudgmental Environment

Kids might feel embarrassed or ashamed of their thoughts. Make it clear that you're a safe person to talk to.

- **Reassure Them:** Let them know that intrusive thoughts don't make them a bad person.
- **Normalize Feelings:** Say things like, "It's okay to feel worried sometimes—we'll figure it out together."
- **Be Curious, Not Critical:** Ask open-ended questions like, "Can you help me understand what's going on in your mind right now?"

3. Avoid Accommodating OCD

It's natural to want to reduce their distress, but constantly helping them complete rituals can reinforce the OCD cycle.

- **Explain Why You Can't Help with Rituals:** "I love you and want to help you get stronger. Doing this together might actually make the worry grow."
- **Support Exposure Efforts:** If they're practicing facing fears, encourage them gently without taking over.
- **Use Positive Reinforcement:** Praise their efforts to resist compulsions: "I know that was hard—you did great trying!"



4. Educate Them (at Their Level)

- **Younger Kids:** Use simple language: “Sometimes our brain gets stuck on a worry like a broken record.”
- **Teens:** Be more direct: “OCD tricks your brain into thinking something bad will happen unless you do a certain thing.”
- **Books and Stories:** There are kid-friendly resources like “*What to Do When Your Brain Gets Stuck*” by Dawn Huebner.

5. Support Emotional Regulation

OCD can make kids feel anxious or frustrated, teaching them coping skills is crucial.

- **Breathing Techniques:** Practice slow, deep breathing to calm their body.
- **Name the Feeling:** Saying, “I’m feeling worried because my brain is telling me something scary,” can help them externalize the thought.
- **Creative Outlets:** Drawing or writing can help them express complex feelings.

6. Involve a Professional Early

Early intervention makes a big difference in long-term outcomes.

- **Child Therapists who specialise:** Look for professionals trained in CBT and ERP.
- **Family Therapy:** It helps everyone understand how to support without enabling.
- **School Involvement:** Teachers and counselors can be part of the support system.

7. Stay Patient and Positive

- **Celebrate Small Wins:** Even minor progress deserves recognition.
- **Avoid Punishment:** OCD-driven behaviors aren’t intentional misbehavior.
- **Stay Consistent:** Establish routines that reduce stress, like a regular bedtime

8. Take Care of Yourself, Too

Parenting a child with OCD can be exhausting and emotionally draining.

- **Get Support:** Parent groups can offer guidance and empathy.
- **Learn Coping Skills:** Your calm and consistent reactions can model resilience.
- **Practice Self-Compassion:** It’s okay not to have all the answers or feel overwhelmed sometimes.



Useful Contacts

1. OCD-UK

A national charity run by and for people with OCD, offering information, support, and advocacy. [OCD-UK+1Mind+1](#)

- Website: www.ocduk.org
- Helpline: 01332 588112 (Available 10am–2pm, Monday to Friday; availability may vary)
- Email: support@ocduk.org
- Support Groups: Offers free online support groups facilitated by individuals with lived experience. [OCD-UK Forums+4OCD-UK+4OCD-UK+4Mind+4OCD-UK+4sussexpartnership.nhs.uk+4](#)

2. OCD Action

The UK's largest OCD charity, providing support and information for those affected by OCD and related disorders. [Wirral Info Bank+1ocdaction.org.uk+1](#)

- Website: www.ocdaction.org.uk
- Helpline: 0300 636 5478
- Email: support@ocdaction.org.uk
- Support Groups: Offers a variety of online and phone support groups, including those for specific themes like Pure O, contamination OCD, and groups for carers and young people. [Contact+2MindWell+2Mind+2ocdaction.org.uk](#)

3. Mind

A mental health charity providing information and support for various mental health conditions, including OCD.

- Website: www.mind.org.uk
- Useful Contacts for OCD: [Mind's OCD Contacts](#)

4. Triumph Over Phobia (TOP UK)

A charity that offers self-help therapy groups for individuals dealing with OCD, phobias, and related anxiety disorders.

- Website: www.topuk.org
- Email: info@topuk.org



5. Hub of Hope

A UK-wide mental health service database that allows users to search for local, national, peer, community, charity, private, and NHS mental health support: [Mind](#)

- Website: www.hubofhope.co.uk
- Website: Mind+1sussexpartnership.nhs.uk+1

6. NHS Services

The National Health Service provides information and access to treatment for OCD.

- NHS OCD Overview: www.nhs.uk/mental-health/conditions/obsessive-compulsive-disorder-ocd/overview/
- Find NHS Talking Therapies: www.nhs.uk/service-search/mental-health/find-an-nhs-talking-therapies-service

7. Samaritans

Provides 24/7 support for anyone in emotional distress.

- Website: www.samaritans.org
- Helpline: 116 123 (Free, available 24/7)

Contact Us:

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