

# This Pack and Your Journey

Whether you are personally struggling with an obsessive-compulsive condition or supporting someone who does, this pack has been designed to support you to navigate the NHS mental health system and understand what should be happening at each step. Accessing treatment can be a challenge, especially if the professionals you are speaking to don't know what the best action to take is. Often, getting the right support can come down to knowing what someone is entitled to and how to ask for it.

You can use the chart on the next page to find where you or your loved one fit in the 'stepped care' system, and which of our factsheets might be most useful to read through. The table is a basic-language version of the one that can be found in the NICE 'quick-reference' version of the guidelines for OCD and BDD.

## The NICE guidelines for OCD and BDD

The National Institute for Health and Care Excellence (NICE) publishes guidelines for health and social care. Guidelines have been published for many conditions as well as particular practices and provide evidence-based recommendations and advice. These guidelines apply to England and Wales, but as Scotland and Northern Ireland don't have their own OCD/BDD treatment guidelines, these are considered best practice and should still be followed.

Although NICE guidelines are considered best practice, studies show that 25-30% of GPs don't consider them particularly relevant and go against them on a regular basis. The guidelines are not legally binding, but through case law it can be considered medically negligent to ignore them. The decision to act against the guidelines must be supported by a reasonable body of experts. This can either be an already existing clinical practice that the doctor can refer to, or can come from a specialist assessment.

Put simply, this means that if the guidelines are clear and explicit about what you should be offered or how you should be treated, a doctor or service cannot take a different action simply because they disagree. They must be able to give a medical reason, and their individual opinion is not considered enough, it has to be backed up by something official.

The guidelines for OCD and BDD are very in depth and clear, and we can help you to find yourself in them and put together information to show your doctor what should be happening. In most cases, this is all that is needed to move on to the appropriate next step in treatment.

If a doctor refuses to follow the guidelines, you can ask them to write that down in your medical record. You can specify that you want the note to reflect that you asked for the NICE-recommended treatment and were refused. You can also ask that your doctor provide you with a clear, written breakdown of their reasons for doing so.

If that still doesn't work, you now have a list of reasons that you can appeal against. We can support you to put together your arguments and give you contact details for who to contact about this in your area.

There are actually 4 versions of the guidelines for OCD/BDD!

The NICE Guideline is a list of all of the recommendations

The guide for the public is a simplified version written specifically for patients/carers

The quick-reference guide uses flowcharts and tables to help doctors figure out what should happen next in your care

The full guidelines include all the recommendations, outlines of all the research behind them, and accounts by people affected by OCD

Where?	For who?	What should happen?
Specialist OCD/BDD services CAMHS Tier 4	Symptoms present risk of severe disability, neglect, or suicide	Reassessment of needs and options > Medication, therapy, or both > Medication combinations > Consider hospital admission or supported living arrangements
Local or national specialist OCD/BDD services CAMHS Tiers 3 and 4	> Severe impact of symptoms on life and functioning > Significant secondary condition or diagnosis > No results, limited success, or quick relapse at previous levels	Reassessment of needs and options Adults: > Medication, therapy, or both > Consider medication combinations > Consider social care and care coordination Children and young people: > Therapy, possibly with medication > Consider national specialist referral levels
A service with a mix of professionals (i.e. not just therapists) CAMHS Tiers 2 or 3	> Secondary condition or diagnosis > No results, limited success, or quick relapse at previous level	Assessment of needs and options Adults: > Medication, therapy, or both Children and young people: > Therapy > Consider medication
GP Surgery Primary Care mental health services CAMHS Tiers 1 and 2	> Mild symptoms (management) > Moderate symptoms (initial treatment)	Adults: > Low-intensity therapy / guided self-help > Medication, therapy, or both > Consider involving family / carers Children and young people: > Guided self-help > Therapy > consider involving family / school
GPs, nurses, and other frontline health professionals in various settings CAMHS Tier 1	Suspected / possible OCD or BDD symptoms	> Discussion of symptoms > Information, education, and contacts > Discussion of treatment options > Referral to any of the appropriate steps above
You, OCD Action, your loved ones, and the NHS	Suspected / possible OCD or BDD symptoms	Information, education, and contact details



