



Call to Action

Autumn 2015

ocdaction
it's time to act

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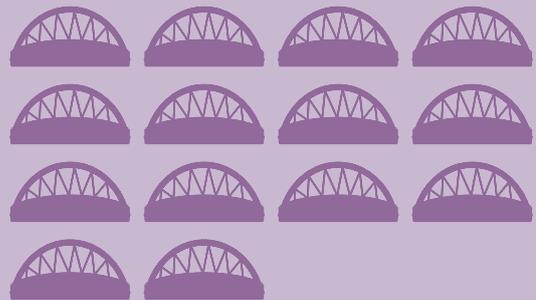
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A full glossary of the terms used in this document can be found on page 9.

Approximately, 1.3 million people in the UK are affected by OCD



That's the equivalent of filling Wembley stadium 14 times



That 1.3 million includes 130,000 children. That's 650 primary schools



Welcome



For many years, the health care system in England has treated mental health services and the people who use them unfairly. The government has worked hard to

redress this and the historic failure to properly value mental health services is now finally beginning to be reversed through changes in the law and through establishing standards of access to evidence-based treatments in mental health in the same way that has existed for many years in physical health.

In order to meet our vision of “parity of esteem” by 2020 we also need to see real change on

the ground. This is certainly the case when it comes to helping people with OCD. It is simply unacceptable that too many people with this severe but treatable disorder cannot access the quality treatment that they need.

We share OCD Action’s belief that everyone with OCD should receive appropriate quality treatment and will work with them to make this a reality.

The Rt Hon Norman Lamb MP
Minister for Care and Support



I developed OCD back in the 1970s when I was 12 years old but I wasn’t diagnosed until I was 26.

During those 14 years I visited doctors and tried to talk to family and friends. The nature of my bizarre thoughts and rituals made it difficult for me to open up about what I was thinking and doctors didn’t really probe. I was given pills for depression which didn’t help and my misery continued. I had never heard of OCD and I imagined I was the only person in the world with these uncontrollable thoughts, urges and worries. Being diagnosed at 26 finally gave me a whole new perspective, the opportunity of appropriate medication, which was very helpful, and suitable psychological help.

Although this was back in the 70s and 80s, a huge number of people today remain undiagnosed for many years and miss out

on the opportunity of treatment. And OCD continues to be misunderstood, in part due to the media’s unhelpful portrayal of it as an amusing eccentricity of keeping a sparkling clean home or liking a tidy desk rather than the debilitating and distressing condition it is.

The NICE Guideline for OCD, published in 2005, with which I was involved gave clear guidance for healthcare professionals on questions to ask patients, appropriate medication to prescribe and psychological treatment options. In many cases this is still not happening and implementation of the guideline is at best patchy.

OCD Action campaigns for better recognition and appropriate treatment and support for those with what can be a life destroying condition.

Gillian Knight
Chair OCD Action

What we are calling for

Summary

We want everyone with OCD to receive appropriate quality treatment and where necessary to have their care stepped up in a smooth and timely fashion in accordance with National Institute for Health and Care Excellence (NICE) Guidelines.

We want to see this happen in the next three years and we will bring together clinicians, service users and leaders in the NHS and NHS England to make our vision a reality.

In particular this means:

1) Better Understanding

All mental health professionals and GPs will have a better understanding and knowledge of OCD, its treatment and the recommended “stepped care” model of treatment. They will know how and when to make appropriate referrals and how to help a person with OCD to exercise their right to choose their treatment provider.

2) Clear Treatment Pathways

No matter where they are in the UK, there will be a clear care pathway for people diagnosed with OCD that sets out what help and support they can expect through their treatment journey. This pathway will show how different levels of services and different service providers should work together. In England and Wales, pathways should be in accordance with the guidelines published by NICE. They should also consider how best to support people moving from Young Persons to Adult Services.

3) Appropriate Diagnosis and Reporting

People with OCD will receive a diagnosis before starting treatment and a standardised method of reporting outcomes will be used by all services delivering OCD treatment. Information about each service provider’s outcomes will be publically available to enable people with OCD to make informed choices.

“I’ve been bullied by OCD for so long, now I can finally say that I am in charge. Quality treatment was the answer.”

OCD Action volunteer

Background information

About OCD Action

OCD Action works to help achieve a society where Obsessive Compulsive Disorder (OCD) is better understood and diagnosed quickly, where appropriate treatment options are open and accessible, where support and information is readily available and where nobody feels ashamed to ask for help.

OCD is a clinically recognised disorder which affects around one million people in the UK. It is debilitating and paralysing. People with OCD experience intensely negative, repetitive and intrusive thoughts, combined with a chronic feeling of doubt or danger. In order to quell the thought or quieten the anxiety, they will often repeat an action again and again.

We are here because OCD tears families apart and leaves people isolated and exhausted. OCD ruins lives. It is a sad fact that many people with OCD delay seeking help. They put up with it for too long, not knowing what is wrong, thinking that nothing can be done or just not knowing where to turn.

OCD Action believes in taking action. We want people affected by OCD to seek help, to understand their treatment options and find the support they need. We help people to do this through our range of support services, our work with front line professionals, raising awareness of OCD, tackling misconceptions about the disorder and through our campaigning for better treatment.

Our team of Trustees, volunteers and staff brings together people with personal experience of OCD and others with key areas of expertise to ensure that not only do we really understand the impact of OCD but we also have the skills and experience needed

to deliver our work. Since our foundation in 1994 we have grown and developed and we are now seen as a leading provider of support for people affected by OCD in the UK and the centre of the OCD community.

Last year we directly helped over 2,000 people through our Helpline, Advocacy Service and project work and provided online support and information to more than 300,000 people through our website. Every day people contact us because they have had enough of their OCD and the misery and isolation it causes. They come to us because we believe that it can get better and because we can help.

About this Document

This document sets out our vision of how people with OCD should be treated by statutory health services and the specific steps to make this vision a reality. We have written this document for our members, supporters and the people who use our services. It is also for those healthcare professionals, service providers and leaders who want to work with us to improve the lives of people with OCD.

To develop this document we collected information on the experiences people with OCD had in accessing quality treatment via our annual stakeholder meeting, a national user survey and through the Charity's Advocacy and Helpline services. We also brought together leading OCD clinicians and academics to canvass their views on how access to quality treatment can be improved, and we used Freedom of Information requests and published data from the Health and Social Care Information Centre (HSCIC) to get a better understanding of the state of services nationwide.

1. Better understanding

What we want

All mental health professionals and GPs to have a better understanding of OCD, its treatment and the stepped care model of the NICE Guideline. They will know how and when to make appropriate referrals and how to help a person with OCD to exercise their right to choose a treatment provider.

The Problem

We know from people who contact our Helpline and those we support through our Advocacy Service that mental health professionals and GPs are often unaware of the range of symptoms or severity of the condition. We often hear from callers who have plucked up courage to approach their GP only to find that their symptoms are not recognised or taken seriously and, if they are, then their GP is at a loss as to what treatment to suggest.

Approximately 60% of the 520 cases our Advocacy Service has worked on over the last five years have involved us supporting people to access specialist care and treatment. In a large number of these cases the client's mental health provider seemed unaware of the NICE Guideline's recommendation to refer a person to specialist care when more help is needed.

Actions to take

1) Publication of best practice in CBT

Local CBT providers should have access to OCD Action's guidance on what good quality OCD-specific CBT should involve. They should audit their services against this guidance to ensure best practice.

2) OCD specialism in-house

Every CMHT, CAMHS or Psychological Therapies service should have a member of staff who has specific knowledge about the diagnosis and treatment of OCD. This member of staff should be a designated psychologist and CBT therapist with a special interest in OCD.

3) Local specialist support

Centres of excellence should be able to provide support and advice to local CBT providers to help them provide the best treatment locally.

4) GP, CMHT, CAMHS, IAPT and PWP training provision

Training materials and Continuing Professional Development (CPD) training opportunities should be available to all health and social care service providers. This training should focus on the clinical assessment, diagnosis and treatment of OCD.

5) Self-assessment of CBT competency

All CBT providers should utilise self-assessment tools to better rate the quality of the treatment that they provide and identify where improvements could be made.

"It took years to build up the courage to go to my GP. When I finally went they gave me some pills and told me not to worry. I just went home and carried on with the pain of OCD."

Recent Helpline caller

2. Clear treatment pathways

What we want

No matter where they are in the UK, there will be a clear care pathway for people diagnosed with OCD that sets out what help and support they can expect through their treatment journey. This pathway will show how different levels of services and different service providers should work together. In England and Wales pathways must meet the NICE Guideline for the treatment of OCD.

The Problem

Users of our Helpline and our Advocacy Services tell us that they often get “stuck in the system” and are not offered the additional help that they need if their first round of treatment locally has not helped them. The NICE Guideline sets out a clear stepped care approach allowing people to access more specialist treatment where necessary.

Actions to take

1) Connecting local service and specialist care

Local services should be better connected to the existing centres of excellence for OCD treatment. They should be aware of the treatment that centres of excellence can provide and how they can be accessed.

2) Publication of treatment pathways by MHTs

We want to see all Mental Health Trusts (MHTs) publish care pathways for the treatment of OCD including how an individual can access each stage. We want these pathways to be easily accessible.

3) Follow up and handover

We want to see people with OCD ‘followed up’ as part of the care pathway with their progress monitored by and between services so that they can have quick access to further treatment if needed. Special attention should be given to people moving from Young Persons to Adult Services.

4) The right to choose

We want to see the recent legislation enabling people to choose their service provider to be fully implemented.

5) Self-referral to IAPT services

Currently around half of local IAPT services offer self-referral. We want to see all IAPT services offer this. Self-referral makes it significantly more likely that a person with OCD will seek help.

6) Appropriate funding

We want to see appropriate funding put in place to enable Commissioners and Mental Health Trusts to ensure that the NICE Guideline for the treatment of OCD can be followed.

“The doctor sent me for some CBT. The therapist was very nice but couldn't help. I needed more help but the doctors said that there was nothing more they could do.”

Recent Advocacy Service user

3. Appropriate diagnosis and reporting

What we want

People with OCD will receive a diagnosis before starting treatment and a standardised method of reporting outcomes will be used by all services delivering OCD treatment. Information about each service provider's outcomes will be publically available to enable people with OCD to make informed choices

The Problem

Since April 2014 people accessing mental health services have been able to choose any service provider for outpatient treatment but in order to exercise that right fully people need to know what experience a service has in the treatment of OCD and how effective that treatment has been. We have had many calls from people wanting to find local services that have knowledge and expertise in the treatment of OCD but currently there is no clear way to find this information.

Through Freedom of Information requests to IAPT providers and our studying of HSCIC reports we know that only around 50% of IAPT services are recording a provisional diagnosis. Fewer are providing information on the numbers they treat or the outcomes of that treatment.

Actions to take

1) Service provider diagnosis

We want all service providers to use the short form of the Obsessive Compulsive Index (OCI) scale as a standardised tool for diagnosis when initially assessing patients. They should also use an appropriate quality of life measure.

2) IAPT, CMHT CAMHS data reporting

We would like to see all service providers publishing their outcome data for the treatment of people with OCD. The publication of treatment outcome data should be made a contractual requirement for NHS service providers.

3) Better understanding of "dropout"

We want clinicians to track individuals who drop out of treatment and do more to understand why this has occurred and what can be done to reduce dropout rates.

4) Service user feedback

We want to gather more feedback from individuals who use services. We shall then publish it on our website along with outcome data from services as we feel the information about user experiences should be widely shared.

"It's great that I can now choose where to go for help and even self-refer for my CBT but what's the point if I have no way of knowing how good a place is? what if I make the wrong decision?"

Forum User

Summary of actions to take

1. Better understanding

Action	By Who
All mental health professionals and GPs to have better understanding of OCD, its treatment and the stepped care model set out in the NICE Guideline	
The wider publication and dissemination of best practice CBT guidance	OCD Action
The development of in-house OCD specialisation	Clinicians
CBT expertise available to support local service providers	Commissioners
CPD training available for Health and Social Care workers	OCD Action
Self-assessment of CBT	Clinicians

2. Clear treatment pathways

Action	By Who
Clear care pathway for someone diagnosed with OCD and integration between primary, secondary and tertiary services.	
Specialist treatment centres connect with local service providers	Clinicians
MHTs publish treatment pathways including transition between Young Persons and Adult Services	Commissioners
Follow-up processes in place and quick access to top-up treatment	Commissioners
Systems and processes are put in place to enable choice	Commissioners
All IAPT services offer access via self-referral	Commissioners
MHTs and Commissioning Groups have funding needed to meet the NICE Guideline on OCD	National Governments

3. Appropriate diagnosis and reporting

Action	By Who
Clear standardised outcome reporting for all services delivering OCD treatment in order to enable people with OCD to make informed choices.	
Service providers use standardised diagnosis tools on first assessment	Clinicians
Outcome data based on standard measure collected and published	Commissioners
Better understanding of why people drop out of treatment	Clinicians
User experience information made available	OCD Action

A shared commitment

OCD Action

The Charity is committed to working to help get a better deal for people affected by OCD. The Charity will do all it can to ensure:

- The wider publication and dissemination of best practice CBT guidance
- That CPD training is available for Health and Social Care workers
- That user experience information is made available

As well as this we will continue to:

- Work with service users and clinicians to identify where services fall short
- Identify and celebrate areas of excellent practice
- Work in collaboration with other organisations to improve mental health services for all
- Work with NHS England to identify and act on areas of improvement
- Bring together service users, clinicians and the managers and Commissioners of mental health services

Commissioners of Services

In order to help us meet our vision, we are calling on commissioners to ensure that:

- CBT expertise is available to support local service providers
- MHTs publish treatment pathways
- Follow-up processes are in place and quick access to top-up treatment is available
- Systems and processes are put in place to enable choice

- All IAPT services offer access via self-referral
- Outcome data based on standard measures is collected and published

Clinicians

Clinicians play a vital role in helping to make our vision a reality. We want to support them so that they can provide the best service possible and ensure that:

- A process of self-assessment of CBT is in place
- In-house OCD specialisation is developed
- Specialist treatment centres connect with local service providers
- Service providers use standardised diagnosis tools on first assessment
- They have a better understanding of why people drop out of treatment

National Governments and NHS authorities

Without adequate funding, commissioners and local NHS authorities are unable to meet the needs of people with OCD. OCD Action is calling on Governments, Politicians and policy makers across the UK and NHS authorities to ensure that funding is in place to meet the cost of delivering treatment for OCD as set out in the NICE Guideline.

"OCD has dominated my life for as long as I can remember. Without the unwavering and impeccable support of organisations like OCD Action I wouldn't even be able to consider this challenge possible."

Community Fundraiser

Let's act now – A national working group for OCD

Let's act now

We want to see these actions happen by the end of 2018 and we will work with clinicians, Commissioners, the Governments, Politicians and policy makers across the UK and the NHS to make our vision a reality. We believe that these actions are achievable. But we have to acknowledge that there are obstacles along the way

and recognise that the best way forward is for all stakeholders to work together.

We want to create a national working group bringing together leaders from NHS England and the NHS, clinicians, service users and Commissioners to examine the actions listed above, determine the best way to undertake them and to set clear targets and time frames for action.

Terms Used

CBT: Cognitive Behavioural Therapy, the recommended talking treatment for OCD.

CAMHS: Child and Adolescent Mental Health Services, specialist local services for children and young adults up to the age of 18.

CMHT: Community Mental Health Team, the multi-disciplinary team offering specialist assessment, treatment and care to people in their own homes and their community.

CPD: Continuing Professional Development, additional on the job training that is required or recommended for a number of professionals including social and healthcare workers.

HSCIC: Health and Social Care Information Centre, the body responsible for collating and publishing health care information.

IAPT: Improving Access to Psychological Therapies, a national program to improve access to talking therapies by providing more local services and psychological therapists.

MHTs: Mental Health Foundation Trusts, responsible for mental health support in a given area.

NICE: National Institute for Health and Care Excellence, the body responsible for producing best practice treatment guidelines.

OCD: Obsessive Compulsive Disorder

PWP: Psychological Well Being Practitioner, work within IAPT services where the impact of the disorder is less pronounced.

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OCD

it's time to **act**

Obsessive Compulsive Disorder (OCD)
can be severe and debilitating
– but it can also be *treated*.

For support and information,
call our helpline or visit our website.

You'll find that you're not alone.

www.ocdaction.org.uk
0845 390 6232

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