The only OCD magazine, packed full of features, news and personal stories, it's

OMPU

LORA

D-UK publication

( ᠿ

**₽**{

D)

# IN THIS ISSUE

OCD

UK

Workshops to offer hope for parents of children with OCD

-





Vicki's Anxiety coping tips

## WELCOME to...

# AT A GLANCE

4 WE ARE OCD-UK Who we are and what we do

6 COVID-19 SUMMARY OCD-UK summary about OCD and Coronavirus (COVID-19)

**10** OCD and Obsessional **Problems during COVID-19** Advice leaflet from the Oxford Health NHS Foundation Trust

**16 PARENTS PROJECT** COVER STORY: An update on our national lottery funded parents project

**20 HOW HANDWASHING BECAME AN OBSESSION** Elizabeth Carr-Ellis shares her story

8 OCD and COVID-19 SURVIVAL TIPS Advice from the OCD-UK team

**30 GLOBAL PANDEMIC vs** OCD Hannah shares her story

**34 SMALL STEPS** Millie-Grace shares her story

**35 WALKING FOR MOOD** Mental well-being through walking

**38 FEELING ANXIOUS?** OCD-UK member Vicki shares some of her top coping strategies

**40 GETTING THE MOST OUT OF REMOTE THERAPY** The OCD-UK team prepare advice for those having remote therapy

42 COPING WITH LOCKDOWN OCD-UK Young Ambassador Emma shares her tips

46 PLEASE STOP USING OCD AS AN ADJECTIVE Naomi Caplan shares her thoughts

**50 MY BRAIN IS NOT THE** 

**ISSUE HERE** Clare Griffin shares her thoughts about the media and OCD

**55 EMOTIONAL CONTINUUM** Audrey blogs about her recent OCD experience



# EDITORIAL

Since early March and throughout the developing pandemic, we are proud of the proactive work that our charity has achieved in supporting people affected by OCD.

We have seen a significant jump in demand for our support services these last 6 weeks, with a 35% increase in call volume alone.

This magazine is an extension of that work and we hope this edition offers our readers practical advice and support in addition to being a comfort and offering some hope in these challenging times.

The magazine is more than a newsletter, it's a support resource and we are sure our members will understand why we have decided to make this edition free to download.

We've also taken the decision to refrain from asking for your fundraising support or donations within the magazine. All we ask is that if you value our work and the magazine we would be grateful if you continue your membership. Thank you



## **COMPULSIVE READING**



# **Purpose**, Vision and Values

# **Our Purpose**

Is to make a positive and meaningful difference in the everyday lives of children and adults affected by Obsessive-Compulsive Disorder (OCD).

# **Our Vision**

Is of a world where the devastating impact of **O**bsessive-**C**ompulsive **D**isorder (OCD) is reduced through effective and safe treatment.

# **Our Values**

We are **supportive** and **innovative**.

We are caring and compassionate.

We have **lived experience** and real understanding.

We deliver **hope** and **inspiration**.

## Supportive and Innovative

We support all children and adults affected by Obsessive-Compulsive Disorder through the difficult times, right through to recovery and everything in between.

We are forward thinking, always seeking ways to improve and innovate in everything that we deliver to ensure we reach all those affected by OCD.

# **Lived Experience** and Understanding

Everything we do is based on the experiences of the people we serve, people affected by Obsessive-Compulsive Disorder.

We reach out to everybody within the OCD community, regardless of where they are in their own recovery journey.

We are OCD-UK, and we are here for you!

# Caring and **Compassionate**

We provide emotional and practical advice or support in a non-judgemental way and will always demonstrate empathy, respect and dignity to the person we are working with.

We don't just listen, we hear, we understand and we see the individual not just the OCD.

# Hope and Inspiration

Our passion and determination inspire those around us, we provide help and bring hope to people when they need it most.

We work together as one organisation, united behind one shared vision.

OCD-UK COMMENT

# 夺 CORONAVIRUS DCD & COVID19

A summary of how coronavirus is impacting on people living with Obsessive-Compulsive Disorder.

Article written: 19th MARCH 2020

bsessive-Compulsive Disorder (or more routinely referred to as OCD) is a serious anxietyrelated condition where a person experiences frequent intrusive and unwelcome thoughts, commonly referred to as obsessions.

Obsessions are unwanted intrusive thoughts, images, impulses or feelings that bring someone's attention to a threat or perceived danger, hence why they are so horrible and distressing. **Obsessions** result in a person carrying out repetitive behaviours or rituals, called compulsions, in order to prevent this perceived danger or threat. Unfortunately, instead of solving the problem, compulsions cause additional anxiety and obsessions, resulting in even more time-consuming and mentally draining compulsions, the cycle of OCD.





#### Resources

For many of us right now life seems stressful and anxiety provoking, even before we add OCD into the mix. To try and alleviate some of that we have collated some of the helpful resources for those living with anxiety and/or OCD during this coronavirus crisis. Check these resources at: www.ocduk.org/ocd-and-coronavirusresources/

OCD impacts on people in many shapes and guises, from obsessive fears around germs and contamination to unwanted and distressing intrusive thoughts about harming a loved one, perhaps violently or sexually.

The present global public health crisis around coronavirus (COVID-19) has led to a number of additional worries for those affected by Obsessive-Compulsive Disorder. This is a list of some of the main areas of concerns users are reporting:

- Contamination fears leading to additional washing/cleaning
- Intrusive thoughts around passing virus on to loved ones / elderly
- Harm related obsessions such as; 'Have I been careless? Does this mean I secretly want people to die?'
- Increase in health anxiety/worrying about being more vulnerable
- Worries about not being able to do exercise or other activities that help maintain mental well-being if isolated

It's important to highlight that all of the above are normal worries that will cause anxiety for many people even for those without OCD, but for people with OCD everyday normal worries can create additional anxiety and anguish.

For those without OCD many of these worries will be fleeting and will certainly pass once the present public health crisis is over. Likewise the extra hand washing is not worry driven, people are simply following recommended advice, even if it is slightly anxiety provoking.

Try to remember it's perfectly normal for people to wash their hands to minimise the risk of a highly contagious virus, that is a normal rational response to a genuine and significant threat. But when that hand washing becomes extreme, then the safety seeking behaviour is arguably causing more harm than the virus itself.

### WHAT IS CORONAVIRUS?

TELEVILLECCULUCTURE



Coronaviruses are a family of viruses that cause disease in animals. Seven, including the new virus, COVID-19, have made the jump to humans, but most just cause cold-like symptoms.

COVID-19 is closely related to severe acute respiratory syndrome (SARS) which swept around the world in 2002 to 2003. That virus infected around 8.000 people and killed about 800 but it soon ran itself out.

Another coronavirus is Middle East respiratory syndrome (MERS), cases of which have been occurring sporadically since it first emerged in 2012 - there have been around 2,500 cases and nearly 900 deaths.

COVID-19 is different to these two other coronaviruses in that the spectrum of disease is broad, with around 80 per cent of cases leading to a mild infection. There may also be many people carrying the disease and displaying no symptoms, making it even harder to control. Source: www.telegraph.co.uk



# SUMMARY OCD & CORONAVIRUS

Most people will not be worrying if they've washed their hands sufficiently once the tap stops. Which is why this is not OCD behaviour and why people commenting that they're 'a little bit OCD' about hand washing remains as inaccurate and inappropriate as ever. By comparison for someone with OCD the worries are not fleeting and create significant anxiety that lasts long after the initial intrusive thoughts, long after the taps are turned off and will impact on their ability to function for hours or even an entire day. For some, the impact of COVID-19 will last long after the public health crisis passes.

#### Will everybody with OCD be struggling now?

In terms of beyond the general worry the entire population has, then no, not at all. Some people's OCD is severely affected by coronavirus, but as mentioned opposite, OCD is complex and affects people in a variety of ways, and not all with OCD will be affected with worries that lead to excessive washing compulsions. What we are discovering is that at the moment those of us living with OCD that are affected are generally falling into two categories, and each face their own unique challenges. Group 1

Those currently receiving therapy and/or have had therapy and are making good progress along the recovery journey:

Worries about being able to even attend therapy

- Where is the line between what is common sense to protect ourselves and what is an OCD compulsion?
- How do I challenge my OCD when the government's advice is contradicting my therapist? E.g. My therapist is encouraging me not to engage with hand washing rituals/ patterns and this is counter to government advice?

#### Group 2

Those yet to receive any kind of therapy, or those where therapy is yet to be effective:

- No therapy to turn to for help in these challenging times No alternative strategies in place
- to challenge regular OCD, without the added extreme level of anxiety brought on by COVID-19.

Short term the charity advises people to follow the public health advice, and if at all possible do not allow OCD to take you beyond what is recommended.

However, if your anxiety and OCD dictate that, be kind to yourself, do not feel guilty for going beyond the recommended advice at this time. What we can do is ensure that we come back to challenging OCD once the crisis has passed.

The charity and other resources are there to offer advice and support, and in due course to ensure we all receive access to helpful and effective treatment.

### How to stop infection spreading

OCD

UK

There are things you can do to help reduce the risk of you and anyone you live with getting ill with coronavirus.

## DO



Wash your hands with soap and water often - do this for at least 20 seconds.



Use hand sanitiser gel if soap and water are not available.



Wash your hands as soon as you get back home.



Cover your mouth and nose with a tissue or the (not your hands) when you cough or sneeze.



Put used tissues in the bin immediately and wash your hands afterwards.

## DON'T



Ox Do not touch your eyes, nose or mouth if your hands are not clean.

Source: 27th March 2020 https://www.nhs.uk/conditions/coronavirus-covid-19/

# $\bigcirc ) \bigvee P (\bigcup)$ READING

# **Continuing our look** back on the last 16 years of the **OCD-UK** magazine.

It's been 16 years of the OCD-UK newsletter, **Compulsive Reading!** 

And as you have seen in the last two editions, the magazine has come a long way.

Check out pages 35 and 51 for a look back at past features, we will re-publish more in the next magazine.



Long term member and volunteer Kirstie proudly clutching her copy of last June's magazine.

















# THANK YOU FOR READING





















# **OCD** and **Obsessional Problems** during COVID-19



his feature is from a series of leaflets about coronavirus and mental health created by the **Oxford Health Specialist Psychological** Interventions Centre.

The leaflets contain information about how the coronavirus outbreak might affect your mental health, how to look after yourself, what to do if a problem persists, and where to find further information.

Other leaflets in this coronavirus series cover worry and uncertainty, bereavement, fatigue, recovering from trauma, and coping with depression.

# Coronavirus Key Facts

- This is a widespread outbreak, not limited to one area.
- It can occur at any time rather than being concentrated in wintertime; unlike the influenza virus, coronavirus is not seasonal.
- For some people who are older or have pre-existing physical health conditions (such as diabetes, lung conditions, heart disease, severe asthma) it is more likely to be severe, and may even be fatal, whereas for the majority of others it may be a relatively mild condition.

Whilst all of us are familiar with challenges in life, coronavirus and its consequences is a particularly difficult and stressful experience for

> everyone. Some people may have to cope with being unwell, looking after family members or dealing with loss and bereavement.

> Coming to terms with the consequences that coronavirus has had for you and those close to you can take some time. This leaflet focuses on coping with

obsessional problems in general and Obsessive-Compulsive Disorder (OCD) specifically.

# What are obsessional problems and OCD?

Almost everyone is finding coronavirus and the lockdown measures particularly stressful and disturbing. Those with pre-existing mental health problems will typically find these worsen, and some people will understandably experience high levels of distress which were not an issue for them previously. OCD is one of the problems which will often be worsened by current circumstances, and some people may find that they develop this problem.

Obsessive-Compulsive Disorder (OCD) is a persistent and often disabling problem in which people experience intrusive thoughts, images, impulses and/or doubts as a sign that they might be responsible for causing or preventing harm to themselves or other people.

These thoughts are seen as warnings about threats in our environment (or our own minds or bodies), and lead to attempts to avoid or 'neutralise' such threats. This tends to involve behaviours such as checking (trying to make sure things are safe), washing (to get rid of the danger), excessive reassurance seeking from information sources and other people, and avoidance (removing yourself from any and all risks).

All obsessional problems and OCD begin as worries which could be regarded as reasonable from the perspective of the person experiencing them.

However, sometimes these worries go too far and interfere with, or even take over the person's life, which is when obsessional worries become a 'disorder'.

eing fearful of coronavirus and its consequences for yourself and other people is perfectly normal and understandable, until it takes you past the 'government guidelines' to a place where it paralyses you in terms of your daily activities and the happiness of yourself and your loved ones. If that is happening for you, then this leaflet may be of some help.

If you know that OCD is or has been a problem for you before the coronavirus pandemic, this leaflet may help you if your OCD is worse at this time. For other people, you may find that similar issues are becoming a problem for you without having previously had such issues to any significant extent.

## How can I tell if I have OCD?

### **Obsessions and Compulsions and Avoidance**

Most people experience intrusive, unpleasant and sometimes unacceptable thoughts, images, impulses or doubts.

Here are some examples of thoughts or obsessions that are known to occur throughout the population. These are just a few examples, there are many, many more which people commonly experience.

Note that typically they concern things which are unacceptable to you.

#### Thoughts:

- I'm contaminated
  - I might pass on contamination to other people/ cause others to become ill or die
- I might have done things wrong
- The door is not locked
- I'll be unlucky as it's Friday 13th
- I might abuse a vulnerable person or child
- That is contaminated with germs

#### Urges:

- To touch something in a particular way or I won't feel right
- To jump in front of a train
- To assault someone
- To spit at someone
- To touch someone inappropriately

#### Images:

- A family member dying in hospital
- Awful things happening to those you love
- People you love being ill or dying
- Harming a baby or child





#### **Doubts:**

- Have I left the hair straighteners plugged in and set the house on fire?
- Did I lock the door?
- Did I run someone over without realising it?
- Did I touch something dirty?
- Did I wash my hands properly?
- Am I sure that I have done all that I can to make myself • and others safe?

#### It's very important to realise that these intrusions occur in everyone, not just people with OCD.

Although obsessional intrusions tend to be upsetting (especially if they are taken as signs of danger), they are just thoughts, odd ideas which just pop into your mind - the brain equivalent of junk mail, which we all experience at different times

The bigger problems tend to come if we then try to do things to stop these obsessions, or make sure that the things they concern don't happen. That might mean avoidance of places, people or activities which trigger obsessions, or feeling that you must do things - compulsions - that you think might reduce the likelihood that you would be responsible for the occurrence of harm. What is particularly problematic is when people try to be completely, 100% certain, that they have prevented harm. However hard you try, there will always be doubt. And, just to make matters even worse, the harder we try to be certain, the less confident we become about whether or not we have managed to prevent bad things from happening, and the more anxious we become.

The harder we try, the less certain we get - the solution becomes the problem. Handwashing becomes all consuming, trying to get reassurance just increases your doubts, gives you more things to be frightened of or uncertain about, and typically leaves you feeling more reliant on others and less confident in your ability to cope. Unfortunately, we know that it's the compulsions that lead to OCD persisting and becoming a serious problem.

Responding to thoughts, urges, images and doubts in a compulsive, excessive way can take several forms including, active compulsions, heightened levels of avoidance or requiring others to respond in a certain way.

Examples of each of these are listed on the next page.

The harder we try, the less certain we get - the solution becomes the problem.

# NHS

## **Examples of** Compulsions

- Neutralising e.g., praying to try to 'cancel out' a bad thought about someone dying from coronavirus
- Washing to eliminate a feeling of contamination
- Repeated checking of body temperature of yourself or others
- Spending hours a day on the internet to try to get the latest information about transmission or any new information about minor symptoms
- Asking others for reassurance about, for example, symptoms, cleanliness
- Rumination going over and over what you have touched or who you have seen and trying to work out whether there is any possibility of transmission

#### Examples of 'hidden' compulsions

- Thought suppression, that is, trying NOT to think about worrying things
- Your attention being drawn to 'bad thinas': looking for trouble, feeling on 'high alert' for things linked to your worries

#### Avoidance

- Avoiding leaving the house at all despite being able to do so under the government guidelines
- Avoiding the news to avoid triggering disturbing images
- Avoiding the news or other information about coronavirus as thinking about it might make it more likely to happen, or give you 'bad luck'
- Avoiding going past homes of people in 'high risk' groups in case you sneeze or cough by their door

#### Involving others and requiring others to...

- Wash their hands in a routinised way before completing tasks
- Repeat phrases in certain ways
- Check that the house is secure
- Clean items, clothes, bedding beyond the amount they would ordinarily consider acceptable
- Buy particular products such as antibacterial cleaners
- Not leave the house or see certain • people
- Follow de-contamination routines after leaving the house/ before preparing food or having any form of contact

#### Emotions or feelings linked to OCD

- Feeling worried, anxious or fearful most of the time, especially in situations which trigger intrusive thoughts, images impulses and doubts.
- Feeling generally uncomfortable
- Being more angry or miserable/sad than usual.
- Feeling disgusted by things or people around you

#### What are the actual risks and how can I reduce them?

Make sure that you get accurate information from reliable sources, specifically: www.nhs.uk/conditions/coronavirus-covid-19/ or www.gov.uk/ coronavirus

Some media or internet sources may exaggerate the dangers. Estimates suggest that many people will have a mild form of the illness and will not even require hospital treatment.

Those that are older or have an existing long-term condition may be more at risk of developing a more severe illness. Most of those who get ill will recover. For the vast majority of us coronavirus is not likely to be more than a temporary illness.

#### Isn't this just a normal response to the coronavirus threat? How to tell if this could be OCD and what to do about it?

Most people are worried or concerned in these unprecedented circumstances when we are being instructed to stay at home, avoid social contact, and to wash our hands in a specific way. The threat is real, and the behaviours we should use to reduce the risk to ourselves and others are clearly specified.

However, that's not OCD. If you find that you have routinely gone beyond the recommendations, and that thoughts and behaviours related to coronavirus begin to dominate your life, then it moves into OCD territory. Twenty seconds washing with soap or hand sanitiser after coming into contact with the outside world is recommended. Several minutes washing, using disinfectant and doing it when you have come into contact with anything you are not sure about - this is the transformation from being careful, into OCD.

The signs of emerging OCD are when the things you are doing to try to be completely safe actually become problematic - the solution becomes the **problem**. For example (see the table on the right).  $\rightarrow$ 

## How can I reduce obsessional problems?

#### Recognise unhelpful worrying and behaviour

If you are doing the appropriate amount to reduce the risks, then further effort is pointless and unhelpful. The harder you try to make yourself sure that you are uncontaminated and safe, the less sure you will find you are. It's like digging to get out of a hole. OCD is the hole, and compulsions and avoidance is the digging. No one ever felt better about their obsessional fears by doing compulsions, and the more you do the more you will worry. And that's before you consider how much the compulsions are interfering with your life. Again, we would remind you that the solution becomes the problem with obsessional fears.

#### Accepting uncertainty

One of the most important sources of obsessional worrying is aiming for complete certainty. This is just not possible to achieve. Of course we would all like it if someone could convince us that we or our loved ones will be 100 per cent safe. The reality is that no-one can do that, either about coronavirus or about many other worries.

Try to remember that you and everyone else actually lives with uncertainty all the time, because we have no choice. Every time we cross the road, start a new relationship, or move house, we cannot be certain about what will happen, but we cope anyway. In fact we can almost never be certain, either about good events or bad events.

Tomorrow, you might win the lottery - or a meteor could crash down on your house. Even such extreme events are not completely impossible.

They are just very unlikely. The fact that many things in life are uncertain does not mean that they are probable - you might win the lottery, but it would not be wise to assume that you will.

Similarly, the risks from coronavirus are not zero, but nevertheless it is likely that most people will be okay.

	How this 'solution' becomes a problem	What to try to do instead
Washing in response to a doubt (e.g 'are my hands actually clean?').	OCD feeds on doubt – the more you react to a doubt, more doubts occur.	Wash your hands according to the government guidelines
Avoiding touching items in your own home.	The more you avoid, the more you will want to avoid.	Touch items in your own home as you usually would or as others in your home are doing.
Washing after touching any object.	The urge to wash will increase and you will never be able to satisfy yourself that it is enough.	Wash your hands according to the government guidelines
Trying to feel completely certain that your hands are clean.	Complete certainty is an impossibility. You will lose confidence in your judgment	Wash your hands according to the government guidelines. First impressions are better and more accurate. Tolerate or accept the feeling of uncertainty.
Trying to wash your hands 'perfectly'.	You will never reach perfection and trying to do so will result in ever increasing fear and feelings of guilt and responsibility.	Follow the government guidelines. Remind yourself that the guidelines state 20 seconds, not 'to the point of perfection.'
Use strong chemicals to clean your hands or other parts of your body.	To 'feel' clean the next time, you will want to use these chemicals again, which will cause you harm.	Wash your hands according to the government guidelines. Remind yourself that if we needed strong chemicals to eliminate coronavirus, this would be in the recommendations – they are not needed.
Looking for possible coronavirus contaminants in your own home.	The harder you are 'looking for trouble', the more you will believe you have found trouble, and the more frightened you will feel.	Follow the government guidelines.
Seeking reassurance from others to try to feel certain about e.g. a symptom, an aspect of the transmission of the virus.	Repeated requests for reassurance increases the feeling of doubt, uncertainty and anxiety.	Share your fears with others rather than asking for reassurance e.g. rather than saying 'can the virus be transmitted via?', tell your friend /loved one that 'I'm feeling so anxious about everything and I need a bit of comfort / distraction / solidarity'.
Repeated checking of the internet.	Repeated searching for information increases the feeling of doubt, uncertainty and anxiety.	Set specific times of the day and lengths of time to look at the internet and choose the sources of information carefully.
Trying to work out how 'chains' of contamination might be spreading coronavirus around your environment.	The more you focus on this, the more you will find to worry about.	Tolerate or accept some uncertainty about the nature and spread of the virus – there are teams of scientists around the world working on this – it's not up to you to work it out.

## If I'm trying to break free from OCD, then what else can I do?

As far as possible, engage with activities which you CAN do under coronavirus restrictions. These include:

- Being in touch with friends and family, through things like FaceTime, Skype, Zoom. Physical distancing does not have to mean social distancing!!
- You could share some mealtimes online. You might even set up games, pub guizzes and so on (requires more organisation of course!)
- Watch films, streamed performances. Listen to music!
- Go outdoors within the limits set by the current rules.
- Why not plan what you are going to do when you are free to do so? Plan a holiday, shopping trip, visit to friends or family?
- Do anything that you find relaxing relaxation itself will not help you to get rid of OCD but the opportunity to unwind is helpful and may help with sleep.
- Be kind to yourself this is an exceptionally difficult time for everyone, and you may be finding it harder than most. If you have a bad day today, you can still have a better day tomorrow.



For many people, the abrupt and at times brutal changes in routine can be really upsetting. Try to develop new routines, for example, setting a wake up time, taking your daily exercise, eating with friends or family online and so on. This will help ground you in what is clearly an abnormal situation.

#### When should you seek professional help?

For some, the stress of coronavirus, including the impact on their loved ones, can lead to or increase thoughts of self harm. It's important to seek help if you feel this way. If you continue to suffer from OCD for a significant period after the outbreak and this is significantly interfering with your life, then you may want to consult your GP to see whether further help is needed.

Other leaflets from this coronavirus series can be found at: www.oxfordhealth.nhs.uk/leaflets

#### Further reading

- Break Free from OCD
- Overcoming OCD
- Pulling the trigger: OCD, anxiety, panic attacks & related depression

#### Further support

- Oxford Health Specialist Psychological Intervention Centre (OHSPIC) https://oxicptr.web.ox.ac.uk/clini
- National IAPT Database search for a local therapist www.nhs.uk/service-search/find-a-psychological-therapies-service/

# PARENTS EDUCATIONAL WORKSHOPS

ast year we reported on our success in securing a National Lottery Community Fund grant of almost £113,000 to develop much needed education and support for parents of children that suffer from Obsessive-Compulsive Disorder.

We're delighted to report that the project is now underway.

### WELCOME TO PEP TALK

The project is called OCD 'PEP' Talk (Parents Education Project) and its ultimate objective is to improve the quality of life for children (aged 5-18) suffering from OCD and their families. We plan to achieve this through the education, support and empowerment of parents.

PEP Talk will create, design and deliver:

- Freely accessible OCD educational courses for parents of children with OCD across the East Midlands
- A library of online video resources for parents to address the top 50 frequently asked questions about OCD and treatment
- Additional online self-help resources for parents
- Regular webinars offering practical support and advice for parents Presentations at our annual conference, specifically for parents of children suffering from OCD - The first of these took place in November with some of the videos already available on our website at: www.ocduk.org/parents.

Over the course of two years, we will be delivering workshops across the East Midlands, 8 per year and possibly more if we can. We are mindful that parents who live outside of the East Midlands would also greatly benefit from the services that this grant is allowing us to deliver, which is why these workshops are open to anyone, regardless of location, provided they can travel.

The workshops are free of charge and focus on children suffering from OCD in the CAMHS stage (Children and Adolescent Mental Health Services). The objectives we aim to achieve during these workshops are the following:

- Restore hope
- Reassure you as parents
- Gain a better understanding of the OCD bully and how it works •
- Understand how to work together •
- Understand different pathways to recovery

The workshops will be delivered by Zoë Wilson, who is our project lead for children, young people and parents (see right).

For more information about the project or to book onto one of our parents workshops (after lockdown) then please visit our webpage at: www.ocduk.org/parents





#### **FRONT COVER STORY**

2002

Zoë Wilson is the project leader of our Parents Educational Project and she has lived experience of Obsessive-Compulsive Disorder.

Zoë is passionate about this project and is determined to make a difference to as many families' lives as possible. Diagnosed with OCD in her early 20s, Zoë has witnessed the effects that the disorder has on the whole family, not just the sufferer.

The shaping of this project has been a collaborative effort between service users and health professionals as the picture above of Zoë working alongside Professor Paul Salkovskis in the development of our parents project shows.

#### 2020 PEP TALK WORKSHOP **LOCATIONS & DATES**

- Nottingham, Date TBC Northampton, Date TBC
- Derby, 6th June (TBC)
- Leicester, 1st July (TBC)
- Buxton, 10th October
- Online version, Date TBC

By now the Nottingham event should have already been hosted, but because of the ongoing coronavirus pandemic we have postponed the first three events, hopefully to be rescheduled for the summer. We have also taken the decision to postpone bookings for all workshops until such time we know it is safe to proceed.

But rest assured, all events will go ahead later in the year and through 2021.

Post lockdown we will be adding additional workshops in Nottingham and Northampton.

We're also delighted to say that through an additional funding source in Wales we will also be able to deliver a parents workshop in Wales during 2020 and 2021.

www.ocduk.org/parents/



Dr Lauren Callaghan, co-author of OCD, Anxiety and Related Depression is posting a series of helpful CBT based tips via her Instagram account @compassionatepsychologist.

In her words..."After working in the field of anxiety and obsessional problems for years, I know that many people suffering from anxiety, OCD and health anxiety will be finding the current climate particularly stressful. So, I thought it might be helpful to post a daily reminder or helpful tip for those who are feeling anxious in the hope that some might find it helpful." We have summarised some of those tips on this page.

### Threat is real, keep responses proportionate

Therapists tell their anxious clients that the thing they are worried about - 'the threat' - is not real, or so minuscule that they shouldn't worry about it, and that their responses are 'disproportionate' to the actual threat. Well, this time the threat is real. So what should you do now? If the threat is real you need to keep your responses proportionate to the threat. Wash your hands after being out, touching things outside, before eating and after using the toilet - but for only 20 seconds. Not 5 minutes. Not 20 times 20 seconds. Not until it 'feels

#### right'. Just 20 seconds.

You should keep your distance from people and stay at home where possible, but you don't need to shower or 'decontaminate' for 4 hours and wash your clothes 20 times if you have had to go out the front door.

You can read the symptoms of COVID-19 but you don't need to Google check them every hour when you feel a sensation in your throat.

On the other hand, don't avoid the threat either (pretend it is not real or test it out) - don't go around pretending everything is as it was. Avoidance can be just as dangerous as overcompensating

responses (possibly even more so with a pandemic). Please. be sensible, and measured in vour responses. Posted: 22<sup>nd</sup> March 2020.

### Make a plan, in a non **OCD** way

This is a period of great change for everyone - wherever you are around the world you are likely in some form of lockdown at home, or social distancing at best. You will have a lot more time on your own and at home, and there is nothing that worries, intrusions, obsessions or doubts like more than empty time! They can run amok and cause havoc and make you feel very anxious and distressed.

The best thing you can do is have a plan for the day, the week, and try to stick at it. Get up in the morning, have a shower and get changed into 'day' clothes, eat breakfast and start work or writing your blog, or whatever you have to do.

It can be tempting to just loll around and take the day as it comes, but a plan will make you more productive and keep the worrying thoughts at bay. Make one for the week - keep it realistic and flexible, and include breaks for lunch and book in some Zoom or Skype calls with family and friends.

If you don't have any tasks that need completing, make some goals for each day, practising a skill or a new hobby (for example I'm resurrecting my role as a Connect Four champion).

If you have OCD and are prone to list writing if it becomes an OCD problem on it's own, then stop it. Posted: 29<sup>nd</sup> March 2020.

Accept the uncertainty

Anxiety and obsessional problems love uncertainty. They thrive on 'not knowing' what happens in the future or as responses to our actions. Socially anxious people worry about what other people think; those with OCD worry about the outcome of their actions or thoughts; those with BDD worry about other people noticing a flaw in their appearance; people with generalised anxiety disorder worry about...well most things in the future!

We all feel uncertain about the future. even more so in the current COVID-19 crisis. But uncertainty in life is nothing new. In fact, pretty much everything in life is uncertain. Uncertainty on a global scale feels very overwhelming, but again, it is nothing new. The world has been here before. Everyone remembers the recent global recession, and those of us who are a bit older will remember WW2, the Cold War and international nuclear stand-off to name a few more.

Therapists love to tell their anxious clients 'you need to tolerate the anxiety'. Well, that's all well and good but how do you suddenly start to 'tolerate' it when you have spent significant time trying to avoid or minimise uncertainty?

I suggest you are in fact tolerating it, it's just that it is very uncomfortable, and you wish you didn't have to. I prefer to tell people to 'accept the uncertainty', which in turn will increase tolerance. In acceptance, you often find a way through - acknowledging you cannot change what is uncertain, and that whilst it feels uncomfortable or unpleasant, it will not last forever (another certainty – nothing lasts forever!). This is tolerating uncertainty.

Posted: 24th March 2020.

#### You are not your anxiety, you are not vour OCD

I have worked with a lot of people over the years helping them overcome their anxiety and obsessional problems.

One thing that keeps coming up is that people find it hard to separate themselves from the anxiety or obsessions. They've often had the anxiety or OCD so long they don't know what it feels like to not have it. But this does not mean that it is your identity or that it defines vou.

You define you. The anxiety or OCD may be part of your experiences, and may have been present for as long as you know. But you are still many things outside of this. You are you. Don't become defined by your anxiety or OCD. Accept it, live with it, know that it can be part of your identity if you choose it to be, but it does not own you. Your value and worth far exceeds your anxiety or OCD. You are you!

Posted: 25<sup>th</sup> March 2020.

will subside pretty auickly.

There is no time like the present for exposure exercises whatever your anxiety problem - build them in to your day and when the social distancing, lockdown, staying home has finished, you'll be surprised at the progress you have made. Any opportunity to challenge your anxiety is a good one. Posted: 25th March 2020.

hanging on.

moment's peace.

Posted: 27th March 2020

#### **Ultra exposure!**

This pandemic will create an ongoing and constant exposure experience for many people with anxiety, OCD, health anxiety and GAD. They will be forced to face their fears, whether they had planned to or not. Whilst it may not have been your preferred option, an exposure opportunity is still an opportunity. Exposure exercises are integral in the treatment of anxiety and obsessional problems, and whilst they are often planned out in treatment, some of the best exposures happen when they are not expected.

So, those of you who are forced to face your fears, whether it is contamination or harm worries, hygiene worries, health worries, or any other worry with content related to COVID-19 – use the opportunities to let the intrusions or worries be there, and not respond to them - or if possible - do the opposite!

For example, if you are worried about your health, spend 10 minutes focusing on your body and any twinges you notice without googling COVID-19 symptoms. For those of you avoiding anything about COVID-19, leave the news on TV for the day. For those of you plagued by worries about COVID-19, record your worries onto your phone and play them back to yourself for 15 minutes a couple of times a day (exposure to worries). These are only examples, but you get the drift.

Just make sure your exposure exercises target the specific thing you are worried about - or it won't work. You'll know if you are doing exposure - you will feel very anxious, but if you don't give into any safety behaviours or rituals or avoidance, it

#### Seeking reassurance is still seeking reassurance

In anxiety, and especially OCD, seeking reassurance is part of the problem. It is a way of propping up anxieties without testing them out and undermines your confidence in your judgment.

During these stressful times it can be tempting to seek more reassurance from others or the internet. It can be tempting to seek reassurance for a quick fix even with the threat of COVID-19, but please understand that it is not helping. If you are seeking reassurance for an anxiety or obsessional problem it is not helping you, you are just reassuring the anxiety or OCD and giving it more room to take hold. Not only that - the relief never lasts. It might feel good in the short term, but you will come back wanting more and more and more.

Take a breath, pause, and try and notice when you are seeking reassurance. Ask yourself - is this really for me, or is this to make my anxiety problem go away (for a bit)? If it is the latter, then try your best to either hold off seeking reassurance or reduce how much you are doing it. It is hard, but it will help you overcome your anxiety in the long term.

Posted: 24th March 2020.

#### Hey you, yeah you, you are doing GREAT!

This is a strange time for everyone all over the world. We are being told to stay home, socially distance ourselves and access to important services has been suspended, including psychological treatments for those with mental health problems. It is what it is, frustrating as it may be.

Amongst all of this, please remember you are doing great! You are here. You are

There will be tough days, there will be easier days. There will be days when you are motivated to challenge yourself, and there will be days when you just can't face the idea of challenging your anxiety.

There will be days when your obsessions are quiet and you feel 'normal', there will be days when your worries and obsessions are raging and won't give you a

You are doing great by getting through each day at a time. You are doing great by surviving the anxiety and obsessions. You are doing great by tolerating what you can and distracting yourself when you need too. You are doing great by getting up each day and doing what you need to do. You are doing great.

Well done you. Keep up being great!

# OCD: How Handwashing Can Become an Obsession

Hey there! My name is **Elizabeth Carr-Ellis** and I'm a proud Geordie, journalist, editor, campaigner and writer for *www.50sense.net* a website for women not afraid of growing older.

oronavirus has us all washing our hands, which is brilliant because time and time again it's being proven as the best way to stay safe. I sing *God Save the Queen* while doing it because I can whizz through '*Happy Birthday*' in no time and there's no way you can jazz up the national anthem. I think you go to the Tower if you do.

However, it doesn't only monitor how long I wash, it also gives me a time to stop and that's very important.

Let me take you back a few years to explain...

#### My biggest secret

It's 1am on a Friday in the early 1990s – around 1994-5 – and I'm in my kitchen. I've been out with friends, but this isn't a late-night drunken run on toast. Instead, I'm washing my hands. I can't remember why, but it'll have been something like I'd touched a dirty glass in the pub, a glass with something as simple as a mark on it, or stepped on something that looked like a blood stain or someone's spit. It could have been that my leg had brushed the side of the pub loo as I hovered over it to pee, or perhaps I touched the sanitary towel bin. So many reasons.

In the living room, spread out on plastic bags, is my handbag and all its contents, soaking wet because I've washed them – yes, even my purse and the money and cards – before putting my clothes straight into the washing machine to contain any "contamination" and having a bath myself.

Normally, that ritual is enough. I go to bed, but after a few seconds my brain starts.

"What if you'd touched the oven without realising it?"

If that had happened, then the oven was dirty and what if I'd touched it



OCD can feel like a monster in the back of your mind, constantly stalking your thoughts.

again going in and out of the kitchen. My bath was in vain.

A little voice popped up. "You didn't touch the oven."

"But what if you did?"

"I didn't."

"Are you sure? Are you 100% sure?"

OCD can feel like a monster in the back of your mind, constantly stalking your thoughts

I replay going in and out of the kitchen, knowing – knowing – I haven't touched the oven. That this is all in my mind. But it isn't enough. The doubt is there, niggling and crawling and growing.

#### Washing away the fear

Eventually, after trying to ignore the voice for 30 minutes, I get up to examine the space between the wall and the oven. I walk past it, trying to see if there is any way I can have touched the oven. It's practically impossible without knowing it.

But what if ...?

There's no way my body has touched the oven now – I know that – but I'm no longer sure about before my bath and I start to wonder if my hand has brushed against it when I was checking the gap a few minutes ago.

I wash my hands and tell myself to go to bed.



Leaving, I pass the oven and the whole voice starts again and within minutes, I'm back in the kitchen washing my hands.

#### And again. And again.

I clean the oven and wash my hands once more. I'm tired and mentally exhausted from arguing with the fear. Drying my hands, my befuddled brain wonders about the towel and how many times I've used it tonight. How can I be sure I'm not dirtying my hands again?

My mind leaps to the one conclusion that seems logical at 1am: put a little bleach in the water, wash my hands and then let them drip-dry, all of which I do – after putting the towel in the washing machine with my dirty clothes, arching my body away from the door to prevent any touching.

Hands dry, I go to bed, crying myself to sleep because I know what I've just done is the most stupid thing in the world.

#### Why was I like this?

OCD – Obsessive-Compulsive Disorder – crept up on me. I have no idea when or how it started. Growing up in the 1980s was a scary time: if it wasn't the threat of nuclear war looming, we had the Aids epidemic, together with the constant worry about money and jobs (there were surprisingly few yuppies in the north-east).

Conversely enough, it came at a time when life was actually getting better, I'd gradually become obsessed with dirt and germs and contamination.

When I look back on my mid-20s, OCD is the one thing that sticks out. It feels as if it dominated my every moment and stopped me enjoying life. Everything was viewed through a prism of fear and danger.

You will, no doubt, have seen the "jokes" on social media with perfectly aligned objects and one slightly out of place with a comment about OCD. I'm that person who pops up and spoils the joke with statistics: that people with OCD are ten times more likely to die by suicide than the general population. It is no laughing matter. I know.

#### What is OCD?

OCD is not a desire for perfectionism, for wanting everything neat and tidy. It is a mental health condition where you get obsessive thoughts and you feel the only way to stop them is by repeatedly doing something or carrying out a ritual. For me, washing my hands or checking something such as the gap between the door and the oven was about reassurance.

Sometimes I'd ask people for that reassurance: "Do you think you can shag someone without realising it?" (yes, I asked that) and their reply would bring the relief I needed, like a warm shower washing over me as my body relaxed.

It never lasted, though, and something else would come and taint my thoughts and I'd look for that relief again.

#### How does OCD feel?

It isn't always about contamination and germs. For some, it's about checking the door seven times to reassure themselves it's locked. If not, burglars can get in and steal all your things, destroy your house and kill your pet, slicing it open or hanging it up with wire.

No, that's not a nice image. OCD doesn't do nice images. It takes a simple idea and blows it up into a true Wes Craven horror flick. It leaves you doubting reality.

The only limit is your imagination and dreams show us how wild that can be.

More often than not, sufferers know this is ridiculous, but logic and reasoning plays no part in this.

Indeed, they add to the anguish. I'd sit in meetings at work, telling myself I was being irrational, but a speckle of spit from a colleague had landed on my notebook and that was it.

OCD for me was a tingling in whatever part of my body that was "dirty", as if a swarm of ants was running all over it, and my head would fill with white noise until all I could hear were the negative thoughts.

If it was my hand that was the focus, I'd clench it tight so as not to contaminate any other part of my body or anyone else. If it was an object, 99% of my attention would be focussed on that and I would notice where it was, what it touched, what needed cleaned, my mind consumed with how I could limit the damage.

I thought I'd hidden it. I learnt years later that my friends had nicknamed me Lady Macbeth and joked about my constant bleaching the toilet. I don't blame them – OCD is little understood, that's why even Stephen Fry made jokes about it.

#### How do you treat OCD?

It isn't easy, but one of the best ways of treating OCD is through exposure response prevention (ERP). To borrow from the suffragettes, it's about deeds, not words, taking action to overcome negative thoughts and beat the cycle of despair.

I said it wasn't easy because it involves confronting the situation that raises your anxiety level. Your therapist will only take it to a level that's bearable, however. This then shows your mind that you can deal with the anxiety without needing the ritual, so next time you're faced with that situation, your anxiety doesn't spike as high. You move on to more difficult situations, building on the confidence you've gained. It's not always a linear movement and there can be hiccups, but small stepping stones will lead you to the summit.

You can also overcome OCD through cognitive behavioural therapy (CBT), which is what most GPs in the UK will recommend.

Working with a therapist, you break down a big problem into smaller pieces and then look at whether your doubts and fears are realistic or not, as well as "It took a long time to overcome everything, but I can now go to a public loo and sit down without fear – even on the train.."

how responsible you are (I was always petrified that I would be the cause of damage to my loved ones).

Facing your fears can seem overwhelming, but your therapist knows and understands this and will help every step of the way.

#### What happened to me?

I'm afraid I was too full of shame and embarrassment to go and see the doctor. I mean, how perverted was my mind to think those thoughts? And washing my hands with bleach? What a bloody nutter...

Of course, I was neither perverted nor a "nutter". I was ill.

So instead, I read about OCD and did my own form of ERP – cold turkey, basically. There had always been that little voice in my head telling me how irrational I was, so I forced myself to listen to it more and started small (not looking at the ground as I walked so I couldn't see the dirt). I'd also moved to a new city and felt as if I could start afresh. It took a long time to overcome everything, but I can now go to a public loo and sit down without fear – even on the train.

Menopause has been a little bugger throwing a spanner in the works, it's true. Instead of Aunty Flo, I now have Regina George sneakily pummelling away at emotions and fears and my thoughts sometimes drift to dark places. But forewarned is forearmed and I have added CBT to my arsenal of weapons. They're just as powerful as a bus, Regina...

But of course, I'm only human. It is scary sharing my story – Mr 50Sense is the only one who has heard it all – but I hope it helps others in a similar situation.

Finally, I highly recommend **Overcoming Anxiety** by Helen Kennerley as a general self-help guide. It has highly relatable examples and a clear guide to CBT and how to use it in your everyday life. ■







SELF-HELP, NOVELS, FIRST-HAND EXPERIENCES

6

 $\langle$ 



#### By Jo Daniels

Senior Lecturer of Psychology, University of Bath

s the coronavirus proliferates on a global scale, worry and panic is on the rise. And it is no wonder when we are constantly being told how to best protect ourselves from being infected. But how do you stay safe in this climate and simultaneously make sure that the fear doesn't take over your life, developing into obsessive compulsive disorder or panic?

Fear is a normal, necessary evolutionary response to threat - ultimately designed to keep us safe. Whether the threat is emotional, social or physical, this response is dependent on a complex interaction between our primitive "animal brain" (the limbic system) and our sophisticated cognitive brain (the neo-cortex). These work busily in concert to assess and respond to threats to survival.

Once a threat has been identified, a "fight or flight" response can be triggered. This is the body's biological response to fear and involves flooding us with adrenaline in a bid to ensure that we are able to escape or defeat

any threat, such as a dangerous animal attacking. The response produces a range of intense physical symptoms palpitations, perspiration, dizziness and difficulty breathing - which are designed to make us run faster and fight harder.

However, this system can be prone to glitches, sometimes responding disproportionately to threats that aren't actually that serious or imminent. Worrying about health conditions such as heart attacks, stroke and even COVID-19 (the disease caused by the coronavirus) can therefore also trigger a fight-or-flight response.

That's despite the fact that there is no role for a primitive biological response to COVID-19 – no running or fighting is necessary. Instead, it is our high-level, cognitive neocortex that is required here, a rational and measured approach to infectious disease, without the messy complications of panic.

Sadly, this is easier said than done. Once the fear has kicked in, it can be hard to stop it.

#### **Vulnerable groups**

It is highly unlikely that a viral outbreak, even at pandemic levels, will trigger mental health problems in people who don't already have them or are

in the process of developing them. Research shows that most mental health problems start between early adolescence and the mid-20s, with complex factors being involved.

Around 10% of the global population experience clinical levels of anxiety at any one time, although some estimates are higher.

People who are chronically and physically unwell - the ones who are the most vulnerable to the coronavirus - are at particular risk of spiralling anxiety. This should not be ignored. Their concern is warranted and is vital in motivating them to take up precautionary measures. But it is important that these individuals have the support they need in dealing with their emotions.

People with health anxiety, preoccupied with health-related information or physical symptoms, are also at risk of worsening mental health as the virus spreads. So are individuals who are prone to frequent or increased "checking", such as constantly making sure that the oven is off or that the front door is locked. Those at the extreme end of the scale when it comes to such behaviour may be displaying signs of obsessive compulsive disorder.

People who have a lot of background anxiety, and are not easily reassured, may also benefit from assessment and support in the shadow of the coronavirus outbreak. This may include people with generalised anxiety disorder or panic disorder, which have strong physiological features.

#### Ways to manage the stress

If you find yourself excessively worrying about the coronavirus, this doesn't necessarily mean that you have a psychological disorder. But high levels of emotional distress, whatever the source, should be appropriately and compassionately attended to, particularly if it is interfering with normal day to day activities.

At times of stress and anxiety, we are often prone to using strategies that are designed to help but prove counter-productive. For example, you may Google symptoms to try to calm yourself down, even though it is unlikely to ever make you feel better. When our strategies for de-stressing instead increase our anxiety, it is time to take a step back and ask if there is anything more helpful we can do.

There are actually ways to dampen down the physical and emotional symptoms associated with anxiety. One is to stop checking. For example, avoid looking for signs of illness. You are likely to find unfamiliar physical sensations that are harmless but make you feel anxious. Normal physical changes and sensations pass in time, so if you feel your chest tighten, shift your focus onto pleasurable activities and adopt "watchful waiting" in the meantime.

In the case of COVID-19, checking may also include constant monitoring of news updates and social media feeds, which significantly increases anxiety only serving to reassure us momentarily, if at all. So if you are feeling anxious, consider tuning off automatic notifications and updates on COVID-19.

Instead, do less frequent checks of reliable, impartial sources of information on COVID-19. This might include national health websites rather than alarmist news or social media feeds that exacerbate worry unnecessarily. Information can be reassuring if it is rooted in facts. It is often the intolerance of uncertainty that perpetuates anxiety rather than fear of illness itself.

At times of stress and anxiety, hyperventilation and shallow breathing is common. Purposeful, regular breathing can therefore work to reset the fight or flight response and prevent the onset

of panic and the unpleasant physical symptoms associated with anxiety. This is also true for exercise, which can help reduce the excess adrenaline build-up associated with anxiety. It can also give much needed perspective.

Perhaps most importantly, don't isolate yourself. Personal relationships are crucial in maintaining perspective, elevating mood and allowing distraction away from concerns that trouble us.

Even in imposed isolation, it is important to combat loneliness and keep talking for example, via video chats.

We are globally united in living with a very real yet uncertain health threat. Vigilance and precautionary measures are essential. But psychological distress and widespread panic does not have to be part of this experience.

Continuing normal daily activities, maintaining perspective and reducing unnecessary stress is key to psychological survival. In other words, where possible, keep calm and carry on.

If you continue to feel anxious or distressed despite trying these techniques, do talk to your GP or refer to a psychologist for evidence-based treatment such as cognitive behavioural therapy.



ജ

Join a community of supportive individuals helping and advising each other on our discussion forums at: **www.ocdforums.org** 

#### PODCAST OF THE WEEK

What a fantastic podcast to kick off our recommended *Podcast of the Week* series with an interview with one of our favourite people, **Sorcha McCaffrey**. It's an interview that is both beautifully uplifting and inspirational, made possible through the open and personable interview style of Beth from *On Repeat (the OCD podcast)*. Grab yourself a cuppa and wander over to our website at: www.ocduk.org/category/podcast/

#### **CO-FOUNDER IN WAR CRY**

OCD-UK co-founder **Steve Sharpe** shared his story in our last magazine, and in March (14th) was raising awareness with a feature in the *Salvation Army's 'War Cry'* magazine. You can access the War Cry at: www.salvationarmy.org.uk/warcry

#### SKY

In March, Sky were running a social media video that we felt trivialised what OCD means, by using the words 'Obsessive Compulsive Drama'. We did contact Sky who subsequently took the video down. ■



#### **NEW OCD TRAINING** ↑

OCD-UK have been supporting health professionals and third sector organisations understanding of Obsessive-Compulsive Disorder for 15 years and we now also deliver training workshops specifically for employers. We can offer (post lockdown) bespoke training for third sector, NHS and organisations of all sizes. All of our training is designed to be informative, inspirational and empowering to improve outcomes when your teams are engaging with customers, clients or colleagues affected by OCD. Last year we successfully delivered the first of our revamped employers' OCD workshops in the north east and the company were so impressed they have commissioned us to provide additional workshops.

If you're interested in booking the workshop or to request a quote please email *office@ocduk.org.* 

Please include details about where and which dates you would like the workshop and how many people you think will attend. ■



#### **FREE OPEN UNIVERSITY COURSES ↑**

It can be helpful during difficult times, where possible, to have an alternative focus. For some that can be work, others fun with family/friends online, but we were also made aware that those wonderful people at *The Open University* have 1000+ free courses, with courses starting from just a couple of hours of studying. Check them out and enroll at: https://open.edu/openlearn/free-courses/full-catalogue



#### NATASHA'S OCD ILLUSTRATION

Our February theme for the young ambassador project was to represent what it can be like to have OCD through illustration. This amazing and creative illustration was kindly shared with us by OCD-UK Young Ambassador **Natasha**. You can check out other young ambassador's illustrations on the link to the right. ■



Our new Children, Young People and Parents lead.





GP ICE BREAKER

Several years ago we created a GP Ice Breaker printout to help people approach their GP and to ask for help to tackle OCD. Last year we updated the Ice Breaker which can be found at:

www.ocduk.org/gp-ice-breaker/

#### **CHILDREN IN NEED PROJECT EXTENSION**

In 2018 *Children in Need* funded a three year project specifically for young people with Obsessive-Compulsive Disorder. Children in Need are happy with the work we are doing and have confirmed they will fund the final year of the project. This ensures we can continue to offer the opportunity for young people (between the ages of 13-18) to join our team of *OCD-UK Young Ambassadors*.

Our young ambassadors are role models, they inspire other young people who suffer from OCD and they use their platform to raise awareness and break stigma. Our different creative themes allow our young ambassadors to use their experiences to express their journey. So far, we've had poetry, illustrations, artwork and photography. We are so impressed with the enthusiasm, hard work and creativity in our team and we are looking forward to what year three brings to the project.

The wonderful **Sue Millichap** did a great job of starting the project and following her departure last year, **Zoë Wilson** (read more about Zoë below) took over to follow in her footsteps. For more information about the project, or if you would like to become an OCD-UK Young Ambassador, please visit the link below.

# ۲ www.ocduk.org/ocdukya

..

y name is Zoë, I am 26 years old and I have OCD. I was diagnosed in my early 20s after many years of letting it control my life. This project is important to me as I know how disabling the disorder can be.

I want to expand the platform for young people to express their feelings and feel connected to others who have a personal understanding of OCD. I am also a creative person and can't wait to use some creativity to promote a positive outlook. Recovery is 100% possible and together we are much stronger than OCD. zoe@ocduk.org



f you're like us, the last thing you want to do is read yet another article or social media post about the coronavirus outbreak (or to give it the official name, COVID-19), but the ongoing public health concerns around the outbreak have left many people with OCD extremely anxious and distressed.

Because of the increased media coverage, much of which is unhelpful, we wanted to share some practical suggestions to help you cope and survive the ongoing situation.

Our survival tips, first published in March, are to help you differentiate between the recommended public health advice for this virus and OCD induced behaviours, but also to help you combine therapeutic steps whilst engaging in these recommended behaviours.



#### 20 SECONDS AND NOT A SECOND LONGER!

The advice from health professionals is to be careful not to touch our face and regularly wash our hands for 20 seconds. We know that this gives the OCD monster the perfect motive to come crashing in and try to disrupt all the hard work you have put in during recovery. So here's where you can still stay in control of the bully. You must ONLY wash your hands as frequently as the health professionals tell you to, and only for 20 seconds. We know all too well how it feels to hear that bully voice in your brain saying, 'just one more time' or 'just a few seconds longer'. Before we know it, it's escalated to five times. 5 minutes per time.

Remember the limits and stick to them... you CAN do this.



3

taken a diversion, so it's important to be mindful of other ways we can keep on top of things.

If there are other behavioural exercises you can be working on, which stay in line with health advice on COVID-19. do them.



#### **BE KIND TO YOURSELF**

Despite our suggestion above, there will be times when OCD gets the better of us. So if 20 seconds does become 30 or even 60 seconds occasionally, or if you do send a text to a loved one for reassurance, it's ok, don't beat yourself up. It's vitally important that we remember to be kind to ourselves by showing ourselves the same compassion we show to others. Be honest with yourself (about the OCD work needed), but be compassionate. Have your targets (I.e., 20 seconds), aim for them, but don't beat yourself up for the occasional miss.

#### DON'T ALLOW OCD TO SELF-DIAGNOSE

This is where it gets tricky for OCD sufferers, because as we know all too well OCD likes to play tricks on us. It is no secret that when someone with OCD is fixating on an obsession, it can cause physical sensations in the body.

You might notice harmless physical sensations, worry what they are and before we know it, we are panicked. That inevitably causes shortness of breath which convinces us we have coronavirus. Remember your therapy techniques!





#### YOU CAN STILL...

Social media and the newspapers are full of what you can't do, so it may be helpful to remember what is still possible, even if you have to self-isolate.

- You can still: Listen to your favourite music
- You can still: Talk and Skype family and friends
- You can still: Read your favourite book/s
- You can still: Enjoy the outdoors, even if it's your own garden in the short term
- You can still: Sing or dance at home (even if both are best behind closed doors!)
- You can still: Watch your favourite TV or films (we recommend the fun, laugh out loud variety!)



#### LIMIT YOUR TIME SPENT ON SOCIAL MEDIA

We are all guilty of it. Whenever you get a spare second you flick through Facebook, Twitter and Instagram. However, at the moment there's more scaremongering than ever. The mainstream media are also not helping, they are desperately relying on click-bait to sell headlines and it's working. Limit yourself on how long you spend on social media, delete notifications if you need to and focus on the real facts.

Information can be (non-OCD) reassuring provided it's rooted in facts. Educate yourselves with real factual evidence and ignore articles with fake news. Good examples for factual information are gov.uk and NHS.uk.



I have coronavirus, I have coronavirus, I have coronavirus, I have coronavirus. Be your own therapist, think about exercises that you can do, like getting used to the thought. Put a sign on your door; 'I have coronavirus' and help your OCD get used to the thought. We don't have to like the thought, we don't want the thought to become a reality, we just have to accept the thought without reaching for the soap or repeatedly checking for symptoms.



Don't be afraid to mute / unfollow / block / unfriend!

Even during normal times it's important when challenging OCD that we surround ourselves with positivity and limit the amount of negative influences in our lives. This is so important, now more than ever! Don't be afraid to mute or unfollow news outlets or people that push more negativity than positivity into your timeline. Unfollowing someone is not always easy to do, but do what is right for your mental well-being.

You can still: Smile and laugh (Don't let OCD stop you! It will try, we don't have to let it stop us smiling or laughing) You can still: Have HOPE for a life without OCD (even if that comes after this public health crisis)

# Global Pandemic vs OCD

#### By Hannah Possart

CD is a well known mental health disorder, but not always for the right reasons. For people who don't suffer from the condition, their first thoughts might gravitate from sufferers wanting to have things in a particular place to constant cleaning.

Now I'm not saying that they aren't part of it or they don't belong in the "OCD category", I'm saying there can be darker sides to it and I should know

My Obsessive Compulsive Disorder started off when I was a child. little things that nobody really picked up on and brushed away as just childhood habits.

Unfortunately it couldn't have escalated more. My day to day life can feel swallowed by my OCD, I feel like that's the only thing about me, it consumes so much time. Excessive hand washing, to the point where I scream out in pain but have to carry on as I know the intrusive thoughts will be worse. Not being satisfied unless I've cleaned my teeth in an order of threes, bleaching my skin until it bleeds just so I can feel safe. Feel relaxed.

The chemical burns have scarred my body. Having a drawer in my bedroom dedicated to bleach, antibacterial sprays and wipes like a shrine to them, living for them. Not being able to even touch my bed until I have bleached every surface in my room, bleached myself then washed my hands 87 times. Am I saying bleach too much? That's how my head feels, the thing is constantly on my mind like a love affair.

We all know what we're meant to do in this global pandemic, wash your hands, stay indoors. It's constantly on the TV, on social media, on news channels, magazines, newspapers and any other place you could imagine, the government constantly drilling into us; wash your hands, wash your hands, wash your hands. You could say I was built for this pandemic, always washing and bleaching things anyway. But after never being able to escape the instruction, my OCD took over and became stronger than I even thought possible. The monster I've been learning to fight is suddenly multiplying with a vengeance.

Everybody around me was panic buying soap, I went to do my normal shop - I buy 7 bottles of soap a week, they never usually last 7 days – and I went to get my soap, and then it hit me... gone. The bare minimum left. I grabbed what I could, 4, and was stopped by a middle-aged woman shouting at me for being selfish and for stock piling, that I didn't need that many. I didn't need that many, she was right, I needed more. My head went into overdrive, what if I ran out of soap? Someone I know will die, and it'll be my fault? I'll get ill, right? My hygiene will become so low that I'll catch anything and that'll be it. These are just some of the tamer thoughts consuming me.

Suddenly my OCD didn't feel valid. The sleepless nights turned into sleepless weeks, torturing myself that I'd exaggerated things in my head, there was no OCD at all and everyone did the same things I did. Everybody had these thoughts.

New compulsions started arising, I became restless until I turned the light switches on and off three times, cleaning the door handles several times a day and even then not being able to touch them with my bare hands. Entering my bedroom, having to open and close the door three times, again not using my hands. Elbows are more useful than we think. The thoughts got darker, I tried to stop doing this new order

of rituals, they'd never affected me before and like a tsunami they were taking over my whole body. One night, I didn't do them. I got into bed. I could feel my heart beating as if it was ready to burst through my chest, picking at my hands and knowing they were bleeding. I couldn't take it. It made me throw up. This keeps happening.

When I do manage to get back to bed and, if I'm lucky, fall asleep. The night terrors take that away from me. The thoughts and the nightmares include horrific things, convincing me people I love will leave, either through choice or injury/illness. Telling me that I should never leave the house, sexual assault is on the rise, it'll happen to me and it'll be my fault because I didn't want to bleach my legs for one night.

I can feel myself longing for my old routines, how easy and simple they seemed looking back to how my OCD has fuelled. I feel like this pandemic is feeding on me, making me submissive to its demands. Making me fear everybody, even the people I live with, in case one of us catches the virus. I agree with what the government are doing, the advice they are giving.

However, my OCD has spiralled so far that even when this is over, I don't think my "normal" compulsions will go back to being how they were before, breaking away from the new ones. The advice for many people will only stick around for a short period, but I can't see a way back.

#### -EDITOR:

The COVID-19 pandemic and the lockdown will ease in the weeks ahead. but OCD-UK know only too well that for some of us this is just the start of a long, mentally challenging journey.

Rest assured that whilst things are a challenge right now, we remain steadfast in the belief that recovery is possible.

We want to assure Hannah and all our readers that we are OCD-UK and we are here for you! We will do all we can to offer advice and support to anybody else struggling in the days and weeks ahead.

I feel like this pandemic is feeding on me.

3.0.071 Martines) 10.010010 in the stand of the (distance) No. Contraction NAMERAL **FERRITA** F STATISTICS ACT Manual and Long Street **Line of the color** Manager Braisida inst I Representation of Stapsonerse internet Page an excision PRESS BRANN

Denen's H



Northampton, November 2019



Sorcha and Laura during a breakout session for voung people.



OCD-UK's Ashley and Kylie



OCD-UK volunteers and speakers post conference Larry, Dr Josie Millar, Megan and Monica.



Professor Paul Salkovski

# **#OCDUKYA**

For March our Young Ambassadors were given a theme to educate, offer advice or show how OCD made them feel using the medium of photography.







"The darkness is the OCD but the flowers represent me blooming even though I have all these thoughts around me." - **Mia** 



I refused to let OCD stop me. Little by little, I got through each battle, and it was all worth it. - Millie-Grace Read the full story behind this photo at: www.ocduk.org/millie-grace-photography

"With this photo I wanted to convey that OCD may damage parts of your life but as long as you're still standing nothing can stop you from recovery." - Theo



my favourite photo just to remind myself." - Grace



<complex-block>

Being around nature always makes me feel relaxed and calm. I also forget about my ocd rituals." - Natasha

I'm so impressed with the enthusiasm, creativity and commitment of the OCD-UK Young Ambassadors.

1

Zoë Wilson, OCD-UK Children and Young People's Lead

# Small steps

OCD-UK Young Ambassador **Millie-Grace** shared her story for the website, a story that will inspire and offer hope for others struggling with OCD.



I first began to suffer from OCD when I was in year eight (I'm in year ten now). When someone turned a pen the wrong way round in my pencil case, I had my first ever panic attack.

For a long time, I blamed these panic attacks on asthma. After I visited the GP, he explained that I was suffering from anxiety and I was referred for Cognitive Behavioural Therapy and my OCD was diagnosed.

I began to work through my thoughts and some of them began to go away. For me the thoughts I have had never seemed necessary. Any kind of achievement I had didn't seem good enough, because any 'normal' person could do the same thing easily. For example, I used to have anxiety when touching certain things such as taking clean cutlery out of the dishwasher, and when I got over that fear I didn't allow myself to be proud because it should never have been a fear in the first place.

When I look back on these thoughts, I now realise how much of an achievement it was and I wish I had given myself credit at the time.

At this time OCD still controlled me. After I started appreciating my progress, I began to regain control. A lot of my OCD thoughts may not have seemed necessary to me but they were still there, the only way to beat OCD is to fight it and fighting can feel slow but allowing yourself to be proud of your progress can help a lot.

I have washed my hands so many times I made myself bleed, I ran out of countless lessons, I have had panic attacks when feeling my hands were dirty, or when things are out of order in my bedroom and even if all those things seem ridiculous, it was my reality for two years.

Even though I still wash my hands more than other people, even though I'm still overly tidy, I am on my way to recovery. Accept your reality, so you can learn to fight it. I am <u>fighting</u> my OCD and I am <u>winning</u>.

**#OCDUKYA** 

When I look back on these thoughts, I now realise how much of an achievement it was and I wish I had given myself credit at the time, - Millie-Grace

# WALKING FOR MOOD

Inspired by **Ruth Clarke's** well-being tweets in June 2017 we ran this feature about walking, a physically low impact activity that can really boost our mental well-being.

Spring and summer is the perfect time to get up, get out and go walking, and it's still possible to do that, provided right now you stay local and walk for no more than an hour.





#Wellbeing walk through Bluebell paths @nationaltrust @AshridgeNT Dockey Wood. Simply #beautiful & one of Hertfordshires gems @hertslife



11:20 PM - 10 May 2017

# UALKING FOR MOOD

There are numerous well-being and exercise activities, including running and cycling as our fantastic fundraisers demonstrate on a regular basis, but...

## Did you know that a good walk can do wonders for your mental well-being?

Even a short 10 minute burst of brisk walking increases our mental alertness, energy and positive mood. Walking boosts circulation, triggers endorphins, decreases stress hormones and increases oxygen supply to every cell in your body, helping you to feel more alert and alive.

Participation in regular physical activity can increase our self-esteem and can reduce stress and anxiety. It also plays a role in improving the quality of life for people experiencing mental health problems.

And if you can increase your walking to an hour a day then you'll be performing an incredible service and tune-up on your body, and more importantly, a significant boost to your mental well-being.

#### Some advantages of walking...

#### Stress Buster

Rough day? One of the most common mental benefits of walking and exercise is stress relief, we more than anyone need that!

• **Brain Boosting Chemicals** Exercise releases endorphins, which create feelings of happiness and euphoria. Studies have shown that exercise can even alleviate symptoms of depression and

anxiety. Let's be clear though, we are not saying it will alleviate OCD, but anything that improves our stress and mood levels can only be a good thing!

Improve Self-Confidence

Walking and exercise can boost self-esteem and improve positive self-image.

#### Improves Sleep

For some, exercise can lead to a good night's quality sleep, something many of us with OCD often struggle to achieve. So why not try it out, this weekend go for a nice moderate walk and see if you sleep better.

#### • The Beauty of the Great Outdoors

Exercising in the great outdoors can increase selfesteem even more, not to mention all the Vitamin D you'll soak up from a walk in the sun (Great British weather allowing!). If you happen to live near a local beauty spot don't forget water, sunscreen and shades, and if you don't, there are always walks you can start making plans towards for when lockdown ends.

#### Socially Interactive

Getting out of the house, even during lockdown, can still be an opportunity to socialize, be that a smile or wave at a passing neighbour or a chance for members of your household to step away from the news and computer just to chat and relax. After lockdown many mental health trusts will still offer group walks for people affected by mental health issues, with some councils offering group walks too. Sometimes walking with others allows you to experience and push yourself more, even to include an exposure exercise during your walk. So after lockdown, make sure to check out your local

walking groups.

#### Suggested Walking Kit

- Water and snacks.
- Sunscreen.
- Map (you know, those things before phones).
- Insect repellent.
- Suitable clothing and shoes, including hat.
  - (If you really get into walking it could be worth buying specialist clothing, Go Outdoors have an annual club discount card for £5 which offers discount on all future purchases within that year).

Please do send us your walking kit tips for the next magazine, email them to office@ocduk.org

#### Post Lockdown Resources:

- The Mental Health Foundation have a booklet
- 'Look after your mental health using exercise'.
  Magazines like BBC Countryfile, The Great
- Magazines like BBC Countrylile, The Great Outdoors or Country Walking often have lots of great walking routes.
- www.nationaltrust.org.uk/walking
- www.walkingforhealth.org.uk/walkfinder
- www.mentalhealthmates.co.uk

-----







Ruth Clarke @RooseClarke

Following

Replying to @OCDUK

Photography helps distract from the obsessive intrusive thoughts & refocus on beautiful surroundings. It calms my mind & brings some peace.



Compulsive Reading Flashback: Published in Compulsive Reading (June 2017). tograph Credit: Ruth Clarke. Showing Poppy the dog in Dockey Wo

# Coronavirus

Feeling anxious? Struggling to cope with the challenges coronavirus is throwing at you?

OCD-UK member, Vicki Goodwin shares some of her top coping strategies.



OCD

et's face it, even if you don't have OCD right now everyone is feeling some form of stress and/ or anxiety. It's natural given the situation. Perhaps then, this is the perfect time for us to recognise how important our mental health is and to implement a few techniques to improve our well-being – at least we all have a bit more time to do it!

I am by no means an expert on stress and anxiety, however, I have some experience personally and 20 odd years experience coping with OCD.

So when I was asked to run a virtual session on mental health and well-being for my team I thought, why not? The session was completely optional and I was surprised at just how many people showed up. It just goes to show that a lot of us are struggling right now.

So here goes, my top tips for dealing with stress and anxiety in a coronavirus world:

#### 1. Look after your body - Exercise

It seems obvious, but now more than ever we need to be making the time to exercise. It's far too easy to sit in front of the TV and binge watch Netflix.

But when our stress levels are high we produce a lot more adrenalin; this makes it hard for us to focus and stay calm - it's the fight or flight reaction from our caveman days. Exercise helps you to release some of the adrenalin and gives you a feel good feeling after. So schedule it in and get your blood pumping.

When you feel overwhelmed and the anxiety kicks in, have a go at a short quick burst of exercise. It will really help

#### 2. Stick to a routine

Get up at the same time each day and have a clear pattern you follow; this helps you to feel like it is a normal working day. Incorporate some 'you time' within that routine where you relax (further ideas on relaxation techniques to come below...). You need to prioritise time for you so that you are then in a good place to support others.

#### 3. Sleep

Make sure you are getting enough sleep. Try not using a screen for an hour before bed - not only will this keep you away from the bombardment of updates on coronavirus, but removing yourself from the unnatural light will help your body to understand that it is time for sleep. Not to mention the fact that the quality of your sleep will be so much better.

#### 4. Cut back on screen time

Right now, we are inundated with coronavirus updates on the news, Facebook, Instagram etc. How many of us reach for our phone to scroll through Instagram first thing in the morning or last thing at night? How many times are you news? It will be adding to your stress levels.

4. Cut back on screen time continued...

There is a lot of positive action and a real sense of community building on social media right now but how many posts have you found that aren't about coronavirus in some form? So limit your exposure: only read the news twice per day. Limit how often you go on social media. I have at least an hour when I wake up and before bed when I don't go near my phone.

#### 5. Adjust your mindset and reframe things

How we think about things and how we react contributes to our mental health. Our bodies naturally notice the negatives. Even when there are 20 positive posts on your social media picture, who doesn't get drawn to the one bitchy comment? When you feel particularly stressed, negative or anxious about a situation; for example, "I hate being stuck in doors all day, it sucks". Think about why you are actually doing it. Ultimately I am staving indoors a lot because I want to reduce the strain on the NHS. I want to save lives. It turns out I am a superhero contributing to saving people's lives. It's a much better way of thinking about the situation. You can apply this to anything, just ask yourself ultimately why you are doing it.

#### 6. Enjoy the simple things

We are allowed out once a day for some form of walk or exercise. I can't believe how many people I have spoken to that haven't been doing this (and they weren't in the complete isolation category). Get some fresh air, find a green space and appreciate nature. Actually stop and be mindful of your surroundings and take pleasure in small things, like the flowers starting to bloom or the leaves rustling in the trees. It sounds like poetic nonsense but it genuinely does help you to feel calmer.

#### 7. Feel gratitude

Find the small things in life to be grateful for, it changes your outlook. Every day I try and think of three things I am grateful for that day. One is the person I am grateful for. It doesn't have to be a huge reason although it could be! It can be something as simple as the neighbour waving at you on a walk. There is always someone to be grateful to. The second is an action from the day. It could be the walk you went on, taking the time to do a workout or even a soak in the bath. Acknowledge the small things and feel gratitude. Finally think of what you are looking forward to. This one can feel harder right now, but again, you can look forward to little things; the video call you have scheduled with a sibling, starting a new jigsaw puzzle, playing a board game.

#### 8. Meditate

I won't wax lyrical on meditation as most people know the value of taking the time to just breath and feel calm. There are apps to guide you through meditation that are great. Just five minutes of meditation today can really help you to cope with stress. It takes time to get used to and generally the first time you do it you feel daft but it gets easier. Simple meditations to try...

- Box meditation breathe in for 4 seconds, hold your breath for 4 seconds, breathe out 4 seconds, and hold for 4 seconds. Repeat for as long as you want
- Use a positive statement/ affirmation as a mantra. Think of what's bothering you at present and turn into a positive. For example if you feel lonely change this to 'I am strong and choose to enjoy time with myself'. Repeat the mantra in time with your breathing.

#### 9. Learn something new

Use this opportunity to learn something new. Right now we have all gained some 'free time', whether that is your usual commuting time or you have the whole day. It's an opportunity to try something new. Not only does this provide a distraction from loneliness or anxiety but you genuinely feel great when you learn new skills. So try something, it could be a jigsaw, a new workout, learning sign language, knitting, reading, learning a musical instrument...

#### 10. Be kind & support each other

If you are feeling stressed, anxious or lonely you can be 100% sure others are too. So let's be kind to each other. Implement acts of kindness; diarize time to chat to your friends, wave at people as you walk past them (2 metres apart of course), chat about your worries with your friends (sharing is caring).

Right now, we are all craving human contact. You may think your super empowered single friend is fine but unless you ask you won't know. So let's support each other and create the sense of community that

we need to fight coronavirus.

#### Final word from Vicki...

I'd love to claim that these are all my ideas but alas, they are not. Dr Rangan Chatterjee's 'The Stress Solution' was massively helpful for me and a lot of the ideas come from him. I definitely recommend reading it.

# "It just goes to show that a lot of us are struggling right now."

### **OCD-UK RESOURCE**

# Getting the most out of remote CBT

With the delivery of CBT online now the new norm, we have prepared a guide to help you get the most out of your remote therapy.

For those of us that suffer from OCD. treatment comes in the form of a talking and doing therapy called Cognitive Behavioural Therapy (CBT).

This involves sitting down face-to-face with a therapist and on occasions going somewhere together to do a behavioural exercise.

Current lockdown rules mean for the time being therapy can not happen in this format, so across the country NHS services are rolling out remote therapy through the use of video-to-video services

The key initial therapy tasks will be the same as traditional face-to-face therapy:

1. The therapist and patient getting to know each other;



- 2. Gaining a shared understanding of the problem (our OCD) and how it affects us:
  - 3. Generating a less threatening alternative belief that makes sense of the difficulties.

Then there are creative ways behavioural experiments can be adapted for remote therapy, for example, those with religious concerns, undertaking a remote tour of a religious building to provoke unwanted blasphemous thoughts or for those with concerns regarding attraction to children, watching a children's film.

But the practicalities of attending remote therapy do need some preplanning to get the most out of this new approach. So in response, we have prepared a guide to help you.

### **REMOTE THERAPY GUIDE FOR** SERVICE USERS

#### Serious

Treat the therapy session the same as you would a face-to-face meeting, with the same level of importance.

#### **Technology Test**

If it is your first time using the technology, get a friend to help you by arranging a test call a few days before, and get comfortable chatting that way. This might involve repositioning the furniture so you are at an angle or position you're comfortable with. Ensure the lighting is right, not too dark or light that the therapist can't see you and of course ensure the microphone is set at the right level so you can be heard.

If you live in a very rural area with a slow internet connection, it may not be possible for you to do video therapy. That is why it's important to test it out to ensure video/audio is smooth and not badly buffering because of a poor connection.

#### Tablet or Laptop

If available to you video calling is best delivered through a tablet or laptop/PC rather than a mobile.

#### **Data Allowance**

•

If you're on an unlimited data package with your service provider then no worries. But if you are limited to a particular amount of data per month you need to keep an eye on your usage.

Ensure you know how to check how much you are using daily and review the day before and after each session to ensure you're not exceeding your allowance and incurring large data fees. If it's within your budget, consider updating to an unlimited package.

#### Location Location Location •

If at all possible try and choose a location which doesn't have a distracting background, the same applies for the therapist. It may be boring, but a plain wall background can be the best.

#### Attire

•

If it helps you feel more comfortable, prepare how you would if it was a face-to-face session, shave, do your make-up or put on your favourite outfit.

#### Quiet / No Go Zone •

Therapy will not work if there are interruptions or background distractions. So ensure the TV/radio is off and laptop/phone notifications are muted (ideally off). If there are other household members, ensure they know to remain out of the room (make an 'occupied/busy' sign if you need to).

If you have toddlers and there are no other household members to look after them, you may need to prepare your therapist for this and ask if you can have two 30 minute sessions, instead of one 60 minute session, which may help with child management.

### Headset

If you do have toddlers that you need to keep an eye on, you may want to consider buying a noise cancelling headset to allow you to focus on the audio from your therapist (if safe to do so). Although bear in mind toddler noise from your end, may still be problematic for the therapist.

Have a Secure Folder Account Some exercises may require you to write down your intrusive thoughts in a Word document and share with your therapist. If you prefer you can use password protected shared file services like Dropbox or Google Drive.

Pre Session Notes Just like face-to-face sessions, prepare notes in advance for what you want out of therapy, what you want to tell your therapist and what's happened OCD wise between sessions. Don't worry, the therapist will expect you to have notes.

Water In case your throat dries up from talking, it can help to have a bottle of water or a cup of tea

ready. Tissues Talking is emotional, tears can and will happen, so be sure to

have some tissues at the ready.

#### **Record the Session**

Just like with face-to-face, it's still helpful to audio record the session. Depending on which technology you use that may be done automatically (both therapist and patient need to agree to this).

#### Pen and Paper (or camera phone) During the early stages of therapy, a therapist may want to work with you on collaborative formulation to create your unique 'vicious flower' diagram. Depending which technology is used it is possible for the therapist to share their screen which would allow you to draw out the vicious flower. So be sure to have pen and paper at the ready, or use your phone to take a screenshot to draw out later.

Homework

If it's set by your therapist, do it (or at least try) and be ready to give feedback to your therapist at the next session. If your therapist doesn't ask about previously set homework, that's their bad, so remind them!

### Session Summary

Ask your therapist to prepare a summary of the session and email it to you. Then be sure to review it!

This is the first draft of the guidance that we have prepared during this ongoing crisis. As we learn more in the weeks ahead we will continue to add to this and update via our website to allow you to get the most of your online therapy.

Subsequent updates will appear on our website at: www.ocduk.org/remotetherapy-guidance

#### GUIDE FOR THERAPISTS

Oxford Health Specialist Psychological Interventions Centre will shortly be publishing a guide for therapists about treating patients with OCD remotely. Once that guide is available we will link to it from the above page on our website.



### THE OCD-UK VIEW

The charity's view about the need for technology to deliver therapy both short and long term.

Remote therapy has become more accessible as advancements in technology have developed, and in some respect the NHS have been slow to utilise the undoubted benefits of remote technology.

COVID-19 is now accelerating the speed of remote therapy integration across NHS psychological services and will probably be a long-term beneficial consequence of this devastating pandemic.

Time will tell if this type of intervention proves to be as effective as traditional face-to-face therapy, where in-person support in tackling behavioural exercises has proven to be invaluable to so many of us. But until life returns to normal, this is the new therapy norm! Services must evaluate patient experiences and monitor recovery rate comparisons.

We suspect that for each patient (unless they happen to live close to the clinic), a combination of remote therapy some weeks and in person other weeks will become the most practical and timesaving way to access long term therapy in the future.

Once lockdown is a distant memory, we hope that the NHS will continue to offer remote therapy provision to those living in the very remotest of geographical locations and also for those whose mental or physical health actually prevents them attending therapy clinics.

#### CONCERNS

It's important that long term diligence is paid to ensure both clinicians and service users don't fall into the trap of over-using remote therapy interventions because of laziness or avoidance purposes.

There is also the question of how much data an average video therapy session might use. Many people, especially those on low income, will be on restricted data usage contracts with their service provider and therefore limited in accessing remote therapy.

It may also exclude many older people who simply don't have the understanding or equipment to make use of this kind of therapy provision.

#### **SUMMARY**

There are undoubtedly many advantages to remote video therapy interventions, but psychological services must carefully consider the limitations and review patient experiences when the time is right. The future is here, the future is now, but we must ensure no one is left behind.

OCD-UK Young Ambassador **Emma** shares her thoughts about coping with lockdown.



i everyone, my name is Emma and I am an eighteen year old from Edinburgh. I was diagnosed with anxiety and OCD (mostly intrusive thoughts based) when I was five. I wanted to share some tips and tricks and also just share my experience of the current lockdown situation.

Being told to stay in the house is my biggest fear. The thought of being stuck with my own brain with minimal distractions for days on end is my thought of hell. When Boris announced the three week lockdown I was sat with my boyfriend and I immediately burst into tears and had a panic attack. I wish I could go back in time to that moment and tell myself everything was going to be OK. It is now over the half way point of the initial three week lockdown and time has gone extremely fast and my OCD has been really good.

Yes, I have had multiple moments of weakness and a couple of breakdowns on the phone to my boyfriend but overall this has not been half as bad as my brain made me think it was going to be.



For people suffering with mental health problems, even getting out of bed in the morning should be an achievement at a time like this. Most people will have lots of unused energy right now due to doing nothing but sitting and watching television etc, but if anything, I am more exhausted now than I am usually. I have to constantly fight my brain so the fact I have nearly made it two weeks is amazing.

The lack of distractions is difficult but I have some tips to try and help others with mental health problems during this time.

1) Do not feel bad if you are not productive. Even staying sane takes work and effort during this time so do not put too much pressure on yourself to "get stuff done". You are doing enough!

2) Do not stay in bed all day (I know, this is very tempting) but getting dressed, showering, making your bed and other basic activities like this make you feel a sense of normality and like you have achieved something.

3) Be social online but don't overdo it. Yes, using video chatting services is amazing during times like this to stay entertained and in contact with your friends and family, but you do not want to become too dependent on other people. You need to train yourself to be comfortable in your own head sometimes, even if it's just for an hour a day.

Hopefully these tips help somebody and just know that we are all in this together! Emma.

Emma's Twitter account is: "ObsessiveCompulsiveDiscussion" (@ocdiscussion)

#### ournal of Obsessive-Compulsive and Related Disorders

1

# Journal of Obsessive-Compulsive and Related Disorders

# OCD Research Roundup

A summary of the recent OCD journal research papers...

For those with access to academic research articles here are a list of the papers featured. Those marked  $\stackrel{\bullet}{\square}$  are open access papers.

## JOURNAL PAPERS

#### www.sciencedirect.com/journal/journal-of-obsessive-compulsive-and-related-disorders/

Volume (23) of the *Journal of Obsessive-Compulsive and Related Disorders* was published in October 2019.

Poor insight in obsessive-compulsive disorder: Examining the role of cognitive and metacognitive variables

Heather K. Hood, Gillian A. Wilson, Naomi Koerner, Randi E. McCabe, Martin M. Antony

Real-world and clinical trial efficacy of selective serotonin-reuptake inhibitors in the treatment of obsessive-compulsive disorder measured by survey and meta-analysis

Erich W. Miller, David S. Shoup, Eric W. Recktenwald Help-seeking attitudes and experiences in individuals affected by skin picking Christina Gallinat, Markus Moessner, Holger A.

Haenssle, Julia K. Winkler, Stephanie Bauer A review of tech-based self-help treatment programs for

Obsessive-Compulsive Disorder Eric B. Lee, Cherie Hoepfl, Cali Werner, Elizabeth McIngvale

Positive affect and imaginal exposure processes in patients with taboo obsessions Noah Chase Berman, Berta J. Summers, Hilary Weingarden, Sabine Wilhelm

Body checking in pediatric eating and obsessivecompulsive disorders Jennifer S. Coelho, Shannon L. Zaitsoff, Rachelle

Pullmer, Diana Franco Yamin, S. Evelyn Stewart An examination of Continuum Beliefs Versus Biogenetic

beliefs in reducing stigma to ward violent intrusive thoughts in OCD Jennifer L. Cole, Debbie M. Warman

Comparing neuropsychological performance in adults with OCD, attention-deficit hyperactivity disorder and healthy controls: An online study Olivia Winkworth, Susan J. Thomas

The prevalence and clinical correlates of body-focused repetitive behaviors in pediatric Tourette Syndrome Tracy Bhikram, Mai El Banna, Elia Abi-Jaoude, Paul Sandor

Cognitive training for neurocognitive and functional impairments in OCD: A case report Himani Kashyap, Puneeth Reddy, Surekha Mandadi,

Janardhanan C. Narayanaswamy, Y.C. Janardhan Reddy Augmentation therapy of N-acetylcysteine for OCD: A

meta-analysis of double-blind, randomized, placebocontrolled trials Eliska Noskova, Pavla Stopkova, Jiri Horacek, Antonin

Sebela

Insomnia and obsessive-compulsive symptom dimensions: The mediating role of anxiety and depression

Samantha N. Hellberg, Jennifer L. Buchholz, Jonathan S. Abramowitz

The effects of obsession type and diagnostic label on OCD stigma Zoe Homonoff. Mark J. Sciutto

Perceived decision-making styles among individuals

with obsessive-compulsive and hoarding disorders Jedidiah Siev, Keith Lit, Yan Leykin

Is sensory processing sensitivity related to treatment outcome in concentrated exposure and response prevention treatment for obsessive-compulsive disorder?

Silje Elisabeth Hasmo Holm, Bjarne Hansen, Gerd Kvale, Thomas Eilertsen, Stian Solem

Special section on Research Domain Criteria in the Obsessive Compulsive Related Disorders; Edited by Dean Mckay

Don't tell me what to think: Comparing self- and othergenerated distraction methods for controlling intrusive thinking

Joshua C. Magee, Sarah E. Dreyer-Oren, Laurel D. Sarfan, Bethany A. Teachman, Elise M. Clerkin

Pediatric OCD in the era of RDoC Sarah L. Garnaat, Christine A. Conelea, Nicole C.R. McLaughlin, Kristen Benito

Animal models of OCD-relevant processes: An RDoC perspective

Christopher Pittenger, Helen Pushkarskaya, Patricia Gruner

Empirically supported treatments for obsessivecompulsive related disorders in the age of the Research Domain Criteria (RDoC)

Ana Rabasco, Miriam Ambrosino, Dean McKay Special section on Hoarding, Acquiring, and OCD;

Edited by Randy O. Frost To save or not to save: The use of cognitive bias modification in a high-hoarding sample Jonathan David, Peter A. Baldwin, Jessica R. Grisham

Predictors of treatment outcome and attrition in adults

with hoarding disorder Catherine R. Ayers, James O.E. Pittman, Eliza J. Davidson, Mary E. Dozier, Erin Almklov

Innovations in CBT treatment for hoarding: Transcending office walls

Jordana Muroff, Suzanne Otte

Disseminating Cognitive-Behavioral Therapy for obsessive compulsive disorder: Comparing in person vs. online training modalities

Ryan J. Jacoby, Noah C. Berman, Hannah E. Reese, Jin Shin, Sabine Wilhelm

Volume (24) of the *Journal of Obsessive-Compulsive and Related Disorders* was published in January 2020.

Emotional attachment to objects mediates the relationship between loneliness and hoarding symptoms Keong Yap, Jan Eppingstall, Catherine Brennan, Brandon Le, Jessica R. Grisham  $\stackrel{\circ}{\hookrightarrow}$ 

Test-based versus parent ratings of executive function in pediatric Obsessive-Compulsive Disorder  $\mathring{\mathbb{H}}$  Juliana Negreiros, John R. Best, Diana Franco Yamin, Laura Belschner, S. Evelyn Stewart

Moderators and processes of change in traditional exposure and response prevention (ERP) versus acceptance and commitment therapy-informed ERP for obsessive-compulsive disorder  $\stackrel{\circ}{\boxplus}$ Clarissa W. Ong, Shannon M. Blakey, Brooke M. Smith, Kate L. Morrison, Michael P. Twohig

"I just can't trust my partner": Evaluating associations between untrustworthiness obsessions, relationship obsessions and couples violence & Or Brandes, Avital Stern, Guy Doron

A preliminary investigation of excessive reassurance-seeking and attachment-related behaviours in adolescents with OCD  $\frac{1}{20}$ 

Sasha L. Walters, Paul M. Salkovskis, Brynjar Halldorsson, Sarah Elgie

"Not just right experiences" in children and adolescents: Phenomenology and relation to OCD symptoms 🛱 Ariel Ravid, Lindsey Collins, Meredith E Coles

Excessive acquisition of information during simple judgments in individuals with hoarding disorder Helen Pushkarskaya, Elisa Stern, David F. Tolin, Christopher Pittenger

Clinician-reported barriers to using exposure with response prevention in the treatment of paediatric OCD Julia Keleher, Amita Jassi, Georgina Krebs  $\mathring{\mathbb{C}}$ 

Corrigendum to "Family accommodation and empathic responses to persons with obsessive-compulsive symptoms: The moderating effect of consideration of future consequences" [Journal of Obsessive-Compulsive and Related Disorders 21 (2019) 138–143] Yusuke Kataoka, Ryu Takizawa

Introduction to a special series on hoarding, acquiring, and OCD honoring the career of Dr. Gail Steketee  $\stackrel{\circ}{\boxplus}$  Edited by Randy O. Frost

What's so complicated about hoarding? A view from the nexus of psychology and social work 🛱 Christiana Bratiotis, Sheila R. Woody

Feared possible selves in cognitive-behavioral theory: An analysis of its historical and empirical context, and introduction of a working model ☆ Frederick Aardema, Shiu F. Wong

#### ACCESS TO RESEARCH

Some of these research articles may be viewable through *Access to Research* which gives free access to over 10-million academic articles in participating public libraries across the UK.

You can search their website for your chosen paper, but to view you must access via a participating library. *www.accesstoresearch.org.uk* 



#### The coronavirus outbreak means that life is changing for all of us for a while. It may cause you to feel anxious, stressed, worried, sad, bored, lonely or frustrated.

It's important to remember it is OK to feel this way. There are some simple things you can do to help you take care of your mental health and well-being during times of uncertainty. Here are 10 ways that the NHS Every Mind Matters website have collated to help us improve your mental health and well-being if you are worried or anxious about the coronavirus outbreak.

#### Stay connected Maintaining healthy relationships with people we trust is important for our mental well-being, so think about how you can stay in touch with friends and family while needing to stay at home. You could try phone calls, video calls or social media instead of

meeting in person - whether it's with people you normally see often or connecting with old friends.



## Talk about worries

It's normal to feel a bit worried, scared or helpless about the current situation. Remember: it is OK to share your concerns with others you trust and doing so may help them too.

If you cannot speak to someone you know or if doing so has not helped, there are plenty of helplines you can trv instead.

## Support and help others

Helping someone else can benefit you as well as them, so try to be a little more understanding of other people's concerns, worries or behaviours at this time.

Try to think of things you can do to help those around you. Is there a friend or family member nearby you could message?

Remember, it is important to do this in line with official coronavirus guidance to keep evervone safe.

## Feel prepared

Working through the implications of staying at home should help you feel more prepared and less concerned. Think through a normal week: how will it be affected and what do you need to do to solve any problems? If you have not already, you might want to talk with your employer, understand your sick pay and benefits rights, and get hold of some essentials for while you are

at home. You could also think about who

you can get help from locally - as well as people you know, lots of local and community help groups are being set up.

## Stick to facts

6 Find a credible source you can trust - such as GOV.UK or the NHS website - and fact-check information you get from newsfeeds,

social media or other people. Think about how possibly inaccurate information could affect others too. Try not to share information without factchecking against credible sources.

You might also want to consider limiting the time you spend watching, reading or listening to coverage of the outbreak, including on social media, and think about turning off breaking-news alerts on your phone.

You could set yourself a specific time to read updates or limit yourself to a couple of checks a day.

#### Do things you eniov

If we are feeling worried, anxious or low, we might stop doing things we usually enjoy. Focusing on your favourite hobby, relaxing indoors or connecting with others can help with anxious thoughts and feelings.

If you cannot do the things you normally enjoy because you are staying at home, think about how you could adapt them, or try something new.

There are lots of free tutorials and courses online, and people are coming up with inventive new ways to do things, like hosting online pub guizzes and music concerts.

can follow from home.



## Focus on the present

Focusing on the present, rather than worrying about the future, can help with difficult emotions and improve our well-being. Relaxation techniques can also help some people deal with feelings of anxiety, or you could try our mindful breathing video.



### Look after your body

Our physical health has a big impact on how we feel. At times like these, it can be easy to fall into unhealthy patterns of behaviour that end up making you feel worse.

Try to eat healthy, well-balanced meals, drink enough water and exercise regularly. Avoid smoking or drugs, and try not to drink too much alcohol.

You can leave your house, alone or with members of your household, for 1 form of exercise a day – like a walk, run or bike ride. Or you could try home workouts, lots of personal trainers are live streaming workouts you

### Stay on top of difficult feelings

Concern about the coronavirus outbreak is perfectly normal. However, some people may experience intense anxiety that can affect their daily life.

- Try to focus on the things you can control, such as your behaviour, who you speak to, and where and how often you get information.
- It's fine to acknowledge that some things are outside of your control, but if constant thoughts about coronavirus are making you feel anxious or overwhelmed, try some ideas to help manage your anxiety or listen to an audio guide.

## Look after vour sleep

Good-quality sleep makes a big difference to how we feel mentally and physically, so it is important to get enough.

Try to maintain regular sleeping patterns and keep up good sleep hygiene practices - like avoiding screens before bed, cutting back on caffeine and creating a restful environment.

See the Every Mind Matters sleep page for more advice.

Source: The NHS Every Mind Matters website: www.nhs.uk/oneyou/every-mind-matters/ also see: www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-staying-at-home-tips/

# Please Stop Using OCD as an Adjective

OCD-UK member **Naomi Caplan**, 22, blogs for everyone whose life is destroyed by OCD.

**O**CD (Obsessive-Compulsive Disorder) is a mental illness which ruins lives. That's why I think it's about time people stopped using OCD as a quirky adjective...

With the recent news of the coronavirus pandemic polluting social media, my argument becomes more relevant than ever.

My frustration stems from countless occasions I've seen people share posts on social media, perhaps of pencils in an untidy arrangement, saying 'my OCD is going crazy!!' or people proclaiming that because they frequently hoover their house, they have OCD.

Honestly, all you need to do is a quick 'OCD memes' search and you will find page upon page of ridiculous posts highlighting the blissful ignorance around OCD. The classic 'memes' tend to be drawings of incomplete circles or wonky floor tiles... very original, hilarious.

The use of OCD being thrown around inappropriately has increased

considerably as a result of the mass hysteria surrounding coronavirus.

Whilst people are putting extra (and necessary) precautions in place to prevent a wider spread of the virus, this is simply common sense, and something which has been advised by health professionals. It's not OCD, it's basic hygiene practice in an uncertain time.

It's estimated that around 12 in 1,000 people (1.2% of the UK population) suffer from clinical OCD. The illness targets all demographics, from children to adults, regardless of gender, social or cultural background.

It's a debilitating illness, that takes over every aspect of the sufferer's life.

Washing your hands regularly or antibaccing your surfaces more so than usual, to avoid a rapidly spreading and potentially fatal virus, is not OCD. Likewise, basic tidying and cleaning is kind of standard.

Unsurprisingly, this new pandemic



The use of OCD being thrown around inappropriately has increased considerably as a result of the mass hysteria surrounding coronavirus.

has unleashed unimaginable panic in many OCD sufferers, who feel more vulnerable and out of control than ever before.

The problem with using 'quirky traits' to describe pretty normal feelings about cleanliness or tidiness, is that it totally makes a mockery of those who suffer with clinical mental illnesses on a daily basis.

Having suffered hideously from severe OCD since I was nine years old, it's no wonder that comments like 'I'm soo OCD' **really** get under my skin.

Part of the problem, I feel, stems from the lack of mental health education in schools and university. You can't blame people for not understanding when they haven't been taught. Where there is mental health education, it is often in the form of lack lustre leaflets and workshops on 'how to help your mental health', where someone drones on about the importance of exercise and eating right.

Boring, unhelpful, can we *please* stop that.

It's really no surprise that the majority of the population seem totally uneducated about the devastating effects of OCD on the sufferer.



OCD can present itself in many ways; these include extremely graphic, upsetting images or thoughts which occur throughout the day, constantly. To get rid of these thoughts, the sufferer develops compulsions which only increases the trauma of experiencing them. Given the sensitive nature of sufferer's thoughts, it means many are too upset or embarrassed to seek treatment.

... and this is why using OCD as an adjective really doesn't help the situation. It makes sufferers feel as though their illness is being made a total joke of and appears to be completely misunderstood by anyone who is lucky enough to not suffer from this awful disorder.

OCD specific mental health organisations such as the fantastic **OCD-UK**, of which I'm a member, or *The International OCD Foundation*, aim to educate people about OCD and ensure that sufferers feel supported and part of a community who truly understand.

My experience with OCD has been a complete and utter living nightmare. I've been tortured by OCD on a daily basis for over thirteen years now (OCD-UK suggests that most sufferers wait an average of 10-15 years between first developing symptoms and seeking treatment). When symptoms first developed as a young child, I remember feeling incredibly scared and confused. I wondered if everyone was experiencing what I was.

Having been passed around various mental health services throughout my lifetime, psychologists would recommend that I tried CBT. Being a hellish combination of young, confused, embarrassed and extremely stubborn, I declined, each and every time.

Thirteen terrible years later, I decided enough was enough. Its roots had wormed its way into every possible part of my life; relationships, education, work, my social life, eating habits, family life and general physical well-being. I'd become a rundown empty shell of the person I thought I was. Every part of life became second place to OCD.

Feeling uncertain and fairly uncomfortable, I made the first step towards treatment. Having seen a wonderful GP, who listened calmly whilst I broke down in her room, I was referred for an assessment with the local adult mental health services. As my therapy is in its earliest stages, I'm not strong enough to discuss intimate details. I will however, vouch for it being the most tiring, frustrating and relentless inner demon, destroying any avenue of life it can get its hands on. It doesn't rest and it doesn't stop.

Although I have accepted my illness, having been inseparable from it for most of my life, and on the right path for treatment, I can't help feeling an enormous wave of anger and upset come over me when I see it being used as an adjective.

#### It has to stop.

I'm sure my annoyances will be received with mixed views; no doubt many will see this as another cry from a 'millennial snowflake', but that's a risk I'm willing to take.

This decade has been an era of revolutionary thinking, in terms of mental health and the promotion of talking about feelings. People are encouraged to speak up for what they believe in, in an attempt to change the world... even just a little bit.

OCD is a serious mental illness which should be taken very seriously. Sufficient and effective mental health education is needed in schools and the workplace, to support sufferers and give silent sufferers the confidence to talk about their experience.

Please remember this the next time you hashtag OCD.

"I can't help feeling an enormous wave of anger and upset come over me when I see OCD being used as an adjective."



Take a look at our secure online shop for self-help books and OCD-UK gifts. The OCD-UK members 10% shop discount code is: **THANKU10** 

## THE CURIOUS CASE OF THE SPECIALIST ANXIETY CLINIC NOT SEEING LOCAL PATIENTS

In April (2019) we reported on the launch of a brand new NHS treatment clinic in Oxford for people with OCD and anxiety. The Oxford Health Specialist Psychological Intervention Centre (OHSPIC) based at Warneford Hospital in Oxford began accepting referrals from across the country from late April 2019.

5

Whilst the clinic has seen patients from various parts of the country, there remains the curious case of why the clinic is yet to see a single person from within its own region, anywhere across Oxfordshire.

In figures obtained by OCD-UK at the time of writing, there have been 35 requests for referral to the Oxford Health NHS Foundation Trust (OHFT) from across Oxfordshire and Buckinghamshire (the regions served by this local mental health trust). There have also been six referral requests to the Oxfordshire Clinical Commissioning Group (CCG). Both the OHFT and the CCG have confirmed that they did not approve any of those requests.

To summarise, at this time, no one from across Oxfordshire or Buckinghamshire has received treatment at the Oxford Health Specialist Psychological Intervention Centre (OHSPIC).

To further compound this, when we asked what the formal pathway for referral is, as of March we were informed that the OHFT were still working on that pathway, which is almost a year after the clinic opened and almost 6 months since OCD-UK started asking questions about this.

To read our full statement on the situation please visit our website: www.ocduk.org/curious-case-of-why-specialist-clinic-yet-to-see-patients-from-from-within-own-region/



#### NEW CARD RANGE ↑ and →

Now is a great time to send a note to tell a family member or friend that you are thinking about them. Don't forget we have a huge range of quality greeting cards, something for every occasion!

Check out them out on our secure online shop at: http://www.ocduk.org/shop/ ■



## WHAT DO ALL THE ABBREVIATIONS MEAN?

#### What does it mean?

We realised we used acronyms or abbreviations that sometimes people new to OCD may not recognise, so here is a glossary of terms. If we use an acronym you don't recognise, no worries, shoot us an email.

**BDD** – Body Dysmorphic Disorder

**CAMHS** – Child and Adolescent Mental Health Services

**CBT** – Cognitive Behavioural Therapy

**CMHT** – Community Mental Health Team

CCG - Clinical Commissioning Group (previously local NHS Trust)

**ERP** – Exposure Response Prevention

**GP** – General Practitioner (Doctor)

NHS - National Health Service

NICE - National Institute for Health and Care Excellence

**OCD** – Obsessive-Compulsive Disorder (we assume you know this one!)

SENCO – Special Educational Needs Coordinator SSRI – Selective Serotonin Reuptake Inhibitor



#### **BOOK REVIEW COMMENT**

OCD-UK member Christine sent us this note: "Thank you for telling us about the new book 'One of us has to go' by Katja Schulz. I have just started reading it and it's an amazing book. One of the best about OCD that I have read that wouldn't become monotonous to somebody not suffering from this disorder. It's especially meaningful to me as it's close to my own experiences."





#### PURE ON NETFLIX ↑

The 2019 comedy drama *Pure* which was based on *Rose Cartwright's* book of the same name will not be returning for a second series Channel 4 has confirmed. But the good news is that all six episodes of *Pure* are now available through *Netflix. Pure* starring Charly Clive tells the story of a 24-year-old who living with 'Pure O'.

Channel 4, told the Radio Times "Pure is a ground-breaking, taboo-busting and unabashed series which brilliantly illuminates a previously little-known, and even more little-understood, topic. Though it will not be returning for a second series for Channel 4, we are incredibly proud of the show and the immensely talented creative team, in front of and behind the camera, who created it." ■

#### SUPPORT GROUP NEWS

As expected we have cancelled all our facilitated support groups until at least the end of May.

We are experimenting in hosting facilitated support sessions for each group via our discussion forums during April and with Zoom audio/video meetings in May for the following OCD-UK funded groups:

- Liverpool
- Nottingham
- Swindon
- Worthing

#### Belfast

Earlier this year the Belfast support group closed its doors for the time being. We thank Laura for her amazing efforts in running the group in recent years and we wish her well in her future career opportunity. Thank you Laura!

#### Stay updated

Updated information for all groups can be found on our website at: <a href="http://www.ocduk.org/support-groups/">www.ocduk.org/support-groups/</a>

#### London, Oxford, Eastleigh and Worthing

Stephen, the facilitator of these groups is continuing to run meetings on a new online / phone meeting system. Details of these can be found on the support group link above.



#### WALL STREET JOURNAL ARTICLE

We've seen some horrendous journalism about OCD over the years, but an article published by The Wall Street Journal (WSJ) on Tuesday 31st March is arguably the worst we have come across in 15-years of OCD-UK's existence.

When the headline 'We all need OCD now' popped up on our screens we became instantly sceptical, however we reserved judgement for a few seconds because we know that sometimes great articles can be ruined by uneducated sub-editors who come up with a classless headline for click-bait. So we stumped up the £1 to get beyond the paywall, more in hope than expectation.

The frustration we felt from the headline turned into anger as we read the full article. You see the work of the OCD-UK team is not just a job for us, it's a commitment, it's a passion, it's life because we have all been where most of you reading this are, we have suffered with Obsessive-Compulsive Disorder.

We have reached out to the WSJ to ask them to review the content, we will update this page should they reply.

At the time of writing they have not responded to our requests for their complaints procedure.

Read our full response on the website at: www.ocduk.org/response-to-wall-street-journal/



# MY BRAIN IS NOT THE ISSUE HERE

by Clare Griffin

A s the novel coronavirus COVID-19 outbreak has progressed into a pandemic, people have had a lot of feelings about OCD. There have been any number of newspaper articles on this, as well as statements by government officials and comments by individuals on social media. Why? What possible link could there be between a respiratory illness and an anxiety disorder? The answer, as is annoyingly often the case with popular discussions of OCD, is hand washing.

Some people have written articles about how hard it is to have OCD right now, what a major impact a pandemic is having on OCD sufferers. And it is. For people who suffer from certain specific variations of OCD.

Hand washing, along with excessive concern over cleanliness and germs, are OCD symptoms associated with one kind of OCD, contamination OCD. And in fact, not everyone with contamination OCD necessarily compulsively washes their hands. That subset of the condition is bigger than one symptom, just as OCD itself is more than one manifestation of the disorder.

Other people, inexplicably, have decided that OCD is the solution to life's problems. Both the New Zealand Health Minister and an OCD specialist based at Stanford in the US, \*recommended\* OCD as a response to COVID-19, claiming that OCD compulsions around hand washing and distancing yourselves

Journalists, I do not need yet another pity party about OCD. I send back your invitation, unopened. from others are what is needed to combat the current outbreak.

I have read all the guidance provided by major public health organisations like the WHO and the CDC. And you know, none of them tell people to develop a disabling anxiety condition that might compulsively force you to stay away from others and wash your hands repeatedly. The public health advice is to wash your hands in specific situations, once, for 20 seconds each time. That is not OCD.

The second group of people, those \*recommending\* OCD are worse, but, honestly, I am tired of both kinds of people. I am tired of people claiming my chronic anxiety disorder is a magical cure for COVID-19. And I am also tired of people rubber-necking the pain of people with OCD.

When the outbreak started, highlighting that it would be hard on people with contamination OCD in particular was a legitimate point. But that point has been made <sup>1</sup>. And made again <sup>2</sup>. And again <sup>3</sup>. And again <sup>4</sup>.

What, now, is the point of writing such an article? What will people do after they have read it? Will they do something to support people with anxiety conditions? Or is it just voyeurism, an opportunity for people who do not have OCD to cry about how sad they imagine our lives must be, then go right back to what they were doing before?

Journalists, I do not need yet another pity party about OCD. I send back your invitation, unopened.

There are articles that should be written right now about COVID-19 and OCD. Because alongside the well-publicised cases of mental health professionals and government ministers making bizarre claims about the "benefits" of OCD during the present crisis, there are also the usual jerks, who on any day of the week would proclaim themselves "sooo OCD" for tidying their closet once a year. Except now they have been told to wash their hands, and they have heard that OCD means washing your hands. So there is a wave of comments, on every social media platform out there, of all the ignorant people misusing OCD to mean they kept their distance from people and washed their hands once in a while. And that's also been great to read.

Why not write that article, journalists? Why not discuss how ignorance of a major mental health condition has been further fuelled by the present crisis? Why not take people to task for claiming that an anxiety condition would help people survive a pandemic? Why not ask OCD sufferers how other people's oblivious comments are affecting them? Why not discuss how conflating public health advice with the symptoms of an anxiety condition is irresponsible, especially during a global pandemic? Why is no one writing about how ignorance of OCD hurts both sufferers of OCD and everyone trying to cope with the COVID-19 crisis?

Any number of people want to write about how our brains are a problem, and isn't that sad. No one seems to want to write about how ableist comments on our condition are a problem, not just for us, but for everyone.

My brain is not the issue here.

Now go wash your hands like the WHO told you to.

#### **References:**

1. www.nytimes.com/2020/04/03/style/ocd-coronavirus-challenges.html

- 2. www.nbcnews.com/news/us-news/coronavirus-person-
- al-nightmare-people-ocd-anxiety-disorders-n1164066 3. www.theguardian.com/society/2020/mar/13/why-regu-

lar-handwashing-can-be-bad-advice-for-patients

4. www.thehill.com/changing-america/well-being/mental-health/491814-will-coronavirus-give-us-all-ocd



In 2015 we launched a project aimed at engaging the public in conversations about OCD, with a view to changing perceptions.

The project funded by Time to Change saw OCD-UK volunteers supported by then project lead **Beth Hemus** host 'OCD discussions' at public gatherings, such as carnivals and festivals across the East Midlands. We simply chatted about OCD to anybody that engaged with us.

The misuse of OCD is prevalent at the moment, in part due to government advice to frequently wash our hands. So changing perceptions is harder now than ever.
"There are no hard and fast rules for talking about your mental health" wrote project coordinator, Beth Hemus in 2015.

s project coordinator for OCD-UK's mental health anti-stigma campaign I have observed and contributed to hundreds of mental health-themed conversations with the general public. And I have to agree with our funder: there are no hard and fast rules, and this is probably why it can feel like such a minefield at times.

It's painfully obvious that OCD is still shrouded in a veil of misconception, trivialisation and poor taste jibes. "OCD is the poor cousin of mental health in that people tend to joke about it and trivialise the suffering of those living with it," says Ashley Fulwood, Chief Executive of OCD-UK. "But it is a serious illness and it can lead to tragic consequences."

The pioneering "Stigma Shout" survey carried out by Rethink on behalf of Time to Change, was an information-gathering exercise that would steer a 3-year mental health anti-stigma campaign, of which OCD-UK are an affiliate partner. It involved more than 3,000 people with mental health problems, and starkly illustrated the volume and impacts of mental health stigma and discrimination nationwide. A startling 9 out of 10 sufferers consulted experienced stigma and discrimination that had a negative impact on their life and, in some instances, proved more difficult to deal with than their illness. Immediate and wider family, friends, neighbours, employers and GPs were identified as the most prolific discriminators. And stigma and discrimination were evidenced to lock people in a cycle of illness, with the effects of stigma and discrimination being contributing factors to mental illness. For example, barriers to employment are a common impact of stigma in the workplace and low income is a recognised contributing factor to mental illness. The full 'Stigma Shout' survey report can be found at: www.time-to-change.org.uk/sites/default/files/ Stigma%20Shout.pdf

When examining these facts, I am left with no doubt that mental health stigma and discrimination are very real and serious issues that we all have a responsibility to challenge and eradicate. At the end of this *Time to Change*'s 3-year anti-stigma project, thousands of volunteers with lived experience of mental health issues have been engaging the general public in anti-stigma themed discussions. I live in hope that these brave and important efforts have made a significant impact on this retrograde problem.

During the course of our project, my volunteer team and I have engaged people with every imaginable attitude towards OCD and mental health at large. Having been tasked with the responsibility of shifting negative or inaccurate attitudes towards OCD, we are consistently making efforts to engage people who present as 'cold' to mental health issues; that is to say that they are openly stigmatic or discriminatory.

This can involve crossing the road to avoid us at events, making jokes in poor taste about OCD to a member of our volunteer team, and everything in between. Poisonous reactions are in the minority and we generally receive empathic attitudes from our audience, with most people expressing gratitude for the opportunity to learn more about what they come to understand as a serious issue. The wilfully ignorant and unsympathetic are far outnumbered by the curious and the kind.

> The wilfully ignorant and unsympathetic are far outnumbered by the curious and the **k**ind.





### By: BETH HEMUS

But negative responses we have had. Most commonly, people exhibit a trivialised and inaccurate perspective of the illness, with the vast majority of people claiming to have 'a bit of OCD' as they approach our stand. In this way, OCD-UK's provocative choice of project title ('Are you a little bit OCD?') has served as a conversational bridge time and time again. This type of conversation can and does result in a positive shift of attitude in our audience members, usually because we share our personal stories and information about the illness in a digestible, clear and confident manner. With this experience in mind, I have been asked to write an article about 'talking OCD' for the magazine, with a particular focus on how to manage negative and challenging reactions. The advice below has been generated by myself and my volunteer team and is based on our personal experiences as well as our experiences during OCD-UK's anti-stigma project:

#### Make sure you are ready

You are not under pressure to share information about your OCD with anyone if you don't want to. Before you disclose anything to the individual or group in question, make sure that you feel comfortable with the idea of talking about your mental health issues with them and are prepared for the different reactions you might receive. My team and I all agreed that talking about your experiences in the right context can make you feel better and can be very cathartic as it liberates you from the need to hide your illness. Make sure that you have your conversation at a time and environment to suit both you and your listener.

#### Be empathic

Fear of using clumsy language, or of reacting unhelpfully and making your situation worse, can often barrier people from talking to you about your OCD. Try to remember this when sharing information and be as patient and understanding as you can. You can signpost friends, relatives and colleagues to the following link, a guide developed by Time to Change to support talking about mental illness with sufferers: www.time-to-change.org.uk/talk-about-mental-health/tellingsomeone-about-your-mental-health-problem.

#### Beware your own projections

Evidence indicates that the level of stigma sufferers expect at the point of disclosure vastly exceeds the actual stigma experienced. Indeed this is something that everyone I spoke to about this article resonated with. We have all hidden our illness from friends, family and employers at some point for fear of judgement and/or rejection. Sometimes you will experience a negative initial reaction, but these usually shift over time. And if this is not the case, heed the piece of advice below.

## • Share information about your mental health unconditionally

When unpacking this piece of advice, my volunteer team and I identified the inherent contradiction in the statement;



i.e. expectation will surround every disclosure made to those that play an important role in our life. But managing expectations and an unconditional approach will minimise the hurt and disappointment that a negative reaction can incur. We cannot control the thoughts and actions of others and we should not, in turn, be controlled by them. Being honest about our mental illness and talking about it openly is an important step in everybody's recovery journey. If someone close to you reacts to your sharing in a toxic way then do not mirror their fear-based, intolerant reaction. Try to remember that being honest about your illness will ultimately serve you and everyone around you.

#### Be informed

People will probably ask you a lot of questions about your OCD as they try to reconcile their perception of you with their (sometimes stigmatic) perception of your illness. The more information you can give them about your OCD, how it impacts on you, and how they can support your treatment and recovery, the better equipped they will be to react in a helpful way.

## • Stand up to stigma and discrimination in a constructive way

Winston Churchill is quoted as saying 'You have enemies? Good. That means you've stood up for something, sometime in your life.' For whatever reason, some people may respond to OCD in a stigmatic or discriminatory way. Try not to react in a way that clouds the issue. This is sometimes easier said than done, but reacting with clarity instead of anger will keep the situation on point. Make it clear that this kind of reaction is evidenced to lock people in a cycle of illness and explain why you have a problem with what has been said or done.

OCD-UK's provocative choice of project title ('Are you a little bit OCD?') has served as a conversational bridge time and time again. This type of conversation can and does result in a **p**ositive shift of attitude in our audience members. Through talking to the general public we have identified that the majority of misunderstanding about the illness has its origins in something watched on TV, read in the newspaper or heard on the radio. Don't be afraid to respond to examples of stigma and discrimination in public forums or the media; by sending a constructive letter or email you are helping to challenge the issue and it will give you an enormous sense of empowerment. Standing up to stigma in a productive way ultimately strips it of its power.

#### Ignore the trolls

Rise above thoughtless negative comments and do not waste your energy engaging in conversation with people who are seeking to rile or provoke a reaction. Let's be honest; if reacting to this kind of wilful ignorance in a negative way solved anything, the problem wouldn't exist anymore. As the famous prayer goes 'God, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.'

#### Know your rights

The Equality Act 2010 makes it illegal to discriminate directly or indirectly against people with mental health problems in public services and functions, access to premises, work, education, associations and transport. Advice on how to manage unfair discrimination can be found at: *www.gov.uk/discrimination-your-rights/what-you-can-do*.

#### SUMMARY

In summary, communicating honestly about OCD may not be easy but it will support your recovery, it can shift perceptions and is absolutely vital if we are to eradicate the misrepresentation that surrounds this illness. Every conversation matters. Even conversations that feel ineffective at the time can go on to shift personal, and eventually public attitudes. As someone who has been openly disclosing their mental health history to complete strangers for several months now, I cannot extol the virtues enough. The personal catharsis is beneficial, but knowing that I am doing my bit to end the stigma and discrimination that surrounds OCD and other mental illnesses is incredibly rewarding.

Wishing you the very best mental health and happy talking. Beth  $\blacksquare$ 

Even conversations that feel ineffective at the time can go on to **s**hift personal, and eventually public, attitudes.

#### 2020 OCD-UK CONFERENCE

With everything that is going on right now this announcement may seem a little strange timing wise and we did deliberate over whether to announce it.

However, we know that many of the people we serve look to us for help at times of crisis (for those of us with OCD, every day feels like our own personal crisis long before lockdown) and part of our job is to offer that help and even more importantly, HOPE.

Therefore, we are making tentative plans to host our annual conference in Chester on the North Wales / England border on Saturday 17th October with reserve dates of Saturday 7th or 14th November.

Until we know it is absolutely safe for people to gather as a group again we will not be taking bookings, but we know from experience that simply having a date to look forward to will prove comforting to many of our members.

Once we know it is safe to do so we will open bookings and very much hope that many of you will be able to join us for a day of mutual understanding, support and hope that will promote belief that life free from OCD is possible.

You can stay informed at: www.ocduk.org/conference/





LDL

JEW LI

Submitted by Audrey G, Canada

As anyone with OCD knows, daily life feels onerous at times. The burdens of anxiety and contamination are heavy, and can sometimes leave room for little else. I have dealt with OCD for over thirty five years. I've written two previous articles for this publication, detailing my struggles and successes in coping with OCD.

Recently, I commented to my therapist that I was managing okay. Frankly, I was feeling satisfied with my state of mind. Years of worry have habituated me to the dull, nagging feeling of things not being alright. My therapist, however, saw the situation differently. He reminded me that people do not need to accept OCD as a lifelong companion. I was rather annoyed at his suggestion that managing was not good enough. To me, getting through a day without excessive washing of my hands, clothes or purse feels like a success. If I can move through my waking hours without persistent ruminations about safety, that feels like an even greater success.

I don't think I've ever expected much more than managing, with brief interludes of "much better" than managing. However, maybe my therapist is right. Maybe those expectations are too low.

My therapist described my emotional life as a continuum. On one end, there are the times when I am sinking under

the burdens of OCD. Those days are experienced through the curtain of anxiety and persistent worry. Ruminations about safety are running through my mind frequently, and the day feels dutiful and tiring. On the other end of the continuum exists the GOOD days. These are days where the background sounds of OCD have faded to a dull, quiet whisper. My experience of the day is fuller. There are long stretches of engagement in my activities and moments of joy.

Most of the time I am somewhere in the middle of these two extremes. That is my state of "managing". Ideally I would like to have more GOOD days. Lately I've been asking myself how to get to GOOD from managing. My conclusion? It's not about getting there, it's about moving in the right direction.

Choosing the right direction is tricky. The wise mind tells me that ruminations about safety are not talismans against accidents, but old habits and beliefs are difficult to surrender.



The ruminations are demanding thieves, causing a brain fog and pulling me in the wrong direction on the emotional continuum, towards the sinking mood of depression.

To move towards GOOD days, I find it helpful to prepare a list of activities that have personal importance and which feed the spirit. I find that it's not enough to just run away from the ruminations, but to run towards an activity that engages. I'm trying to remember to choose to do this, and to choose well.

I've only started to think about OCD recovery in this way very recently. I am hoping that the happiness of engagement will make the pull of ruminations weaken. Those of us with OCD know that there is no single approach that works to weaken the obsessions. Hopefully this way of thinking about daily choices will be helpful to myself and others. ■

My conclusion? It's not about getting there, it's about moving in the right direction.



# "It's okay not to be okay"

That was **COMPULSIVE READING** by **CCD**ик