N&S OCD, BDD & Related Disorders Team
Working with young people with OCD during COVID-19
(June 2020, Version 2)

Aim of this resource

This resource is a guide for clinicians who are working with young people with Obsessive-Compulsive Disorder (OCD) during COVID-19. It highlights key points to consider when determining the appropriateness of commencing or continuing with OCD treatment at this time, and some practical guidelines to enhance efficacy during remote working.

Important considerations for young people with OCD during COVID-19

The COVID-19 pandemic is an uncertain and anxiety provoking time for all, but for young people who have OCD it can be particularly distressing for a range of different reasons:

Baseline anxiety is heightened making OCD worse generally: At times of stress, OCD sufferers are likely to ritualise more in an effort to manage anxiety and reduce perceived harm as well as to find it harder to resist their obsessions and compulsions.

Current situation may be exacerbating specific OCD fears: (re-triggering previous fears, or introducing new fears) and their associated compulsions:

- Fear of contamination (washing, cleaning, avoidance)
- Fear of harm coming to self, family, friends (checking, reassurance seeking)
- Fear of harming others through spreading contamination
- Fear of illness, death, dying
- Fear of bad things happening
- Fear (intolerance) of uncertainty

Reduced levels of activity due to lockdown: When young people are less busy and have less structure to their day it is common for OCD to extend to fill the extra time. Without usual routines in place young people may ritualise more, affecting their sleeping and eating patterns which will have a detrimental affect on their mental health generally. Conversely, for some, the reduction in demands may have reduced their overall anxiety and as lockdown eases there may be an increase in anxiety and in OCD rituals. Spending more time around others, and the academic, social and time pressures of returning to school could all be very challenging for young people with OCD.

High levels of OCD & ASD comorbidity: Young people with Autism Spectrum Disorder (ASD) often require routine and predictability to manage anxiety. This may be especially pronounced where there is co-morbid OCD. The current climate is likely to increase anxiety for these young people through

- Sudden and continuing disruption to daily routine without opportunity to prepare
- Parents are also under great deal of stress so maybe not as able to contain YP's anxiety
- Ongoing uncertainty about plans for the future.

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1) OCD treatment – can it be offered remotely?

Evidence-based treatment for OCD typically includes face to face weekly CBT with **a strong emphasis on the behavioural element of the intervention, "in vivo" exposure and response prevention (ERP)** (ref: NICE guidelines CG31)**.**
At the national specialist OCD clinic, there is a manualised treatment protocol that uses a workbook for young people with a manual for therapists
(ref: https://www.amazon.co.uk/OCD-Tools-Fight-Workbook-People/dp/1849054029;
https://www.amazon.co.uk/OCD-Tools-Help-Young-People-Fight/dp/1849054037)

The phases of treatment that are covered in this protocol are:
- Psychoeducation of anxiety and OCD
- Graded exposure and response prevention in session and for homework
- Relapse prevention

The clinic has also trialled carrying out this treatment over the telephone, using the same workbook and manual. The results showed that telephone treatment was as effective as face to face treatment for the majority of young people
(ref:https://www.sciencedirect.com/science/article/pii/S0890856714006649). This study illustrates how in-vivo exposure does not have to mean sitting in the room with the young person (although this is the ideal). It simply means completing the exposure supported by the therapist and this can be achieved over the telephone or on an online platform. Since this trial, there have been many developments in the availability of online platforms to deliver remote working and evidence to support their efficacy
(ref:(https://www.sciencedirect.com/science/article/pii/S0890856716318573).

In summary, whilst moving to remote methods of working poses a unique set of challenges to delivering the behavioural element of therapy (ERP) the evidence suggests that it can be done and can also be just as effective as face to face treatment.

2) Should OCD treatment continue or be started at this time?

Remotely or face to face, **CBT for OCD is a challenging and demanding treatment. However, working in the context of heightened general anxiety and uncertainty alongside the distance and technical challenges that can accompany remote working can make it more demanding. Therefore, it is especially important to consider the following areas before offering treatment:**
Risk:
- At this time more than ever, careful care planning is vital. CAMHS and emergency services are under enormous pressure therefore it is a priority not to work in a way that is likely to increase risk. Therefore, if it is felt that carrying out OCD treatment at this time is likely to increase risk then this may not be the time to start or continue this treatment.
- While young people are at home, in closer proximity with family members, and without access to respite or support, it is important to ensure that tasks are well planned out to be manageable for the whole family.
- It is also necessary to establish a contract early on to review risk and have an agreed plan of how to share such information, perhaps with parents or outside agencies, to support safety.
Family context:
- Many families are under enormous pressures currently: parents may have lost employment or be on reduced income; school and childcare arrangements may have ceased making it very hard for parents to continue with their work whether at home or outside of the home; parents may also be caring for, or worrying about, elderly relatives and their health at this time.
- Consider stresses that the whole family are under and discuss whether this is the right time to be working in this way with the young person. Ask whether the family can offer the support that the young person needs in order to do effective OCD treatment, and whether parents feel able to manage changes to anxiety in their current circumstances.

3) If OCD treatment is not to continue:

If after consideration **it is agreed not to continue with or embark upon CBT for OCD at this time** then the approach we would suggest would include 'active holding'. That is, to provide support and general stress management strategies to the young person and their family but also to use this as an opportunity to prepare for engaging in therapy as lock-down eases. This may include:

i. Continuing to offer the young person and their family remote sessions
ii. Agree regularity of these sessions that work for your service and the family
iii. Focus on how to keep the home situation as calm as possible in current circumstances by:
  ➢ Maintaining gains made in treatment where possible through continued discussion around daily opportunities to challenge OCD in a manageable way
  ➢ Completing or revisiting the psychoeducation ensuring a good understanding of anxiety, habituation and ERP so that they are in the best place possible to resume active treatment after lockdown.
  ➢ Using an activity scheduling approach to help maintain routine and structure and minimise worsening of symptoms or deterioration in mood
  ➢ Providing the message that current levels of accommodation of OCD can be maintained if needed to make life manageable for whole family
  ➢ In extreme circumstances, relaxing some OCD rules if needed but always with a clear message that '*accommodating OCD will lead to a worsening of symptoms and so post-lockdown fighting OCD will resume, and gains will be (re)-achieved*'

This final message is extremely important – COVID-19 is an exceptional situation and we don't want young people and their families who are really struggling at this time to lose hope of the possibility of freeing themselves from OCD in the future.

4) If OCD treatment is to continue:

For those where risk is low, families are managing well, and the young person is willing to continue with/start treatment then proceed to weekly remote therapy sessions.

i. General guidelines for remote working
Several helpful resources have been produced to offer general guidance on the process of setting up and carrying out remotely delivered therapy (see references and links below). These guidelines cover suggestions about software, equipment, environment, pre-session practice, and contingency planning for poor connection.

ii. Specific considerations for young people
In addition to this, there are specific considerations for conducting sessions with children and young people, and those with OCD. Some of these ideas may be especially helpful for young people with ASD who may struggle more with remote working.

Setting up remote sessions
  ➢ With young people it is especially important to set clear boundaries and expectations for remote sessions stressing that these sessions are just as important as face to face therapy and require a safe, quiet, confidential space.
  ➢ Agree with the young person about how to communicate and respond to distress. Due to the challenges of working over a screen, it is not always possible to see or recognize heightened emotion in the way you would in face to face working. It may help to encourage the use of a signal or agree the best way for the young person to communicate distress
  ➢ Sessions may end abruptly for any number of reasons. Prior to beginning treatment, agree a plan that covers how to check back in and share information with parents if needed.

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Sharing materials

- Treatment using a workbook relies on shared materials for psychoeducation, setting up ERP tasks, reviewing homework records; many online platforms (e.g. Microsoft Teams) offer the facility of "sharing a screen" which can aid learning and enhance efficacy
- If screen sharing is not possible, consider emailing materials ahead of the session and requesting homework to be emailed to you

iii. Ensure effective learning of session material

Not being present in the room and technical glitches or poor internet connection can make it more challenging to ensure that key messages are effectively communicated and understood. As such, ensure that there is an agreed plan for reviewing understanding at the end of each session.

- Some platforms offer the facility to record remote sessions which could be helpful for young people/family members to watch between sessions to enhance learning
- If not possible, consider emailing the key learning points of the session.

iv. Parental involvement

- If parents are not already involved then consider, with the young person, whether their help is needed during remote working e.g. they may be able to offer practical support during sessions such as holding a device whilst the young person completes their ERP task, or emotional support should the young person become distressed
- Separate phone calls may need to be offered to parents if young people would prefer to complete the session alone, to support parents to feel confident in acting as co-therapists between sessions.

v. For younger children, or those with neurodevelopmental conditions such as ASD and ADHD

Young people with neurodevelopmental conditions may struggle to stare at a screen for a sustained period of time or may feel uncomfortable looking at the therapist through the screen. Consider the following modifications to delivery to help sustain concentration and enhance learning:

- Agree on the use of helpful items such as a fiddle toy, phone or drawing materials. It is important that the item enhances concentration rather than detracts from learning. Agree this plan with parents to ensure that they understand that it is a therapeutic aid
- Consider using audio only or agreeing that the young person can look away from the screen whilst speaking with you.
- Be creative and make use of online resources and interactive games to engage them in remote working
- Consider shorter, more frequent sessions, regular breaks making use of the breakout rooms platforms such as Zoom offer to help sustain attention

General anxiety management

Strategies to manage general anxiety, such as relaxation, breathing exercises and mindfulness, can be helpful at a time like this. However, it is important to be clear that, **when doing ERP,** the young person must be encouraged to sit with, and tolerate the anxiety rather than distracting from it or trying to reduce it in any way. Keep a close eye on anxiety management techniques that could become a new compulsion or safety behaviour.

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Guidelines for exposure and response prevention tasks during COVID-19

NHS
South London
and Maudsley
NHS Foundation Trust

- If **OCD is <u>not</u> related to or particularly triggered by COVID-19** then continue treatment offering this remotely and considering how to do exposure within current lifestyle restrictions e.g. using more imaginal exposure and online resources as suggested in the table below.
- If **OCD <u>is</u> being particularly triggered by COVID-19 concerns** then the table below offers some suggestion for how to approach ERP tasks.

Compulsion	ERP during COVID-19
Excessive washing (COVID or non-COVID related)	• Handwashing and hygiene guidelines should still be observed Public Health England Guidelines: https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control • Where items or people are being touched, due to COVID, ERP tasks would not include a "no-hand wash" response prevention e.g. task could be to touch food packaging/shopping and then complete a PHE recommended hand wash only • Imaginal exposure to contamination and resisting any hand washing
Checking (of COVID-related information)	• If anxiety is leading to excessive checking of COVID-19 information then: • Practice watching only one or no news reports per day • Resist the urge to engage in repeated checking of multiple sources • If resisting completely is too difficult than perhaps just agree a limit on the number of checks or time spent checking
Reassurance seeking (about COVID)	• Develop a clear boundary between appropriate COVID-related reassurance and excessive reassurance • Once reassurance has been given about the current COVID situation this should not need to be repeated • Support parents/family members to practice resisting giving reassurance, using stock phrases such as 'that sounds like OCD and we have to resist OCD, even at this difficult time' • Support parents/family members not to go over and above recommended guidelines in order to accommodate the young person with OCD "I am not going to wash my hands a second time – that is what OCD wants"
Avoidance	• If anxiety is leading to clear avoidance of all things COVID-related then a task could be to actively approach COVID-related information (news broadcasts, images, online reports) and resist neutralizing or de-contaminating • For other non-COVID-related OCD avoidance, consider using imaginal exposure and online resources to access exposure stimuli that is unavailable due to lock down e.g. imaginal exposure to people, places or unpleasant thoughts through verbalizing, writing and recording and then repeatedly listening/reading back to experience habituation of anxiety • Replace physical exposure to avoided places with virtual exposure to schools, hospitals, deprived areas etc. in the local area via Google earth/Google maps, reading articles about feared scenarios and completing online image searches. Consider screening material in the first instance. • Invite a stooge to join a session remotely to have a conversation that would trigger OCD worries e.g. fear of upsetting people

References:

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Considerations for psychologists working with children and young people using online video platforms Division of Clinical Psychology, British Psychological Society

www.babcp.com/Therapists/Remote-Therapy-Provision.aspx

www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control

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