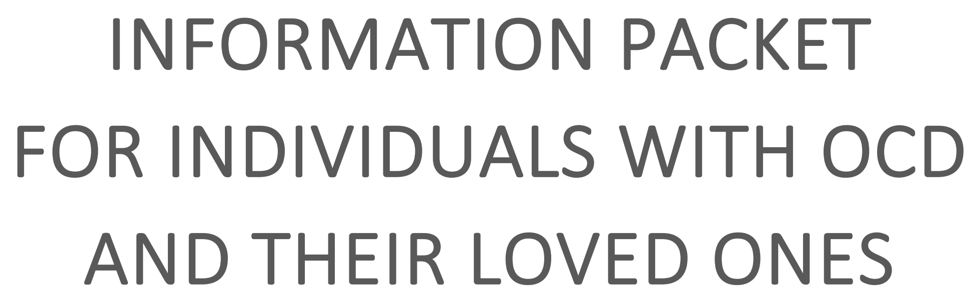

INFORMATION PACKET FOR INDIVIDUALS WITH OCD AND THEIR LOVED ONES

Compiled by Dr. Caitlin Claggett Woods, C.Psych

This packet contains a compilation of information from various resources, including the International OCD Foundation (IOCDF), the Anxiety and Depression Association of America (ADAA), and AnxietyBC.
See page 20 for a full list of resources and references.

This packet is to provide you with information. The content is not a substitute for professional psychological advice, diagnosis, or treatment. Always seek the advice of your physician or a licensed mental health provider with any questions you may have regarding a psychological condition. Information enclosed is subject to change without notification.

OBSESSIVE COMPULSIVE DISORDER

INFORMATION ON OBSESSIVE COMPULSIVE DISORDER

WHAT IS OBSESSIVE COMPULSIVE DISORDER?

Obsessive-compulsive disorder, commonly called OCD, appears in different ways, and not every person has the same symptoms; many people have combinations of various OCD symptoms. In general, those who have OCD suffer from unwanted and intrusive thoughts that they can't seem to get out of their heads (obsessions), often compelling them to repeatedly perform ritualistic behaviours and routines (compulsions) to try and ease their anxiety.

Most adults who have OCD are aware that their obsessions and compulsions are irrational, yet they feel powerless to stop them. They may spend several hours every day focusing on obsessive thoughts and performing seemingly senseless rituals to ward off persistent, unwelcome thoughts, feelings, or images. These can interfere with a person's normal routine, schoolwork, job, family, or social activities. Trying to concentrate on daily activities may be difficult.[1]

OCD occurs in approximately 2.3% of the population. That is, between 2 and 3 individuals out of every 100 people meets criteria for OCD in their lifetime. Research indicates that in any given 12-month period, approximately 1.2% of individuals – between 3 and 4 million adults in the United States – currently have OCD. Although OCD can occur at any age, there are two age ranges at which OCD tends to first appear: 1) Between the ages of 8 and 12, and 2) Between the late teens and early 20s.[2]

WHAT ARE OBSESSIONS?

Obsessions are recurrent and persistent thoughts, urges, or images that are experienced as outside the person's control. Individuals with OCD do not want these thoughts, and experience them as highly disturbing and/or distressing. Because obsessions are unwanted and distressing, people try to resist them, get rid of them, or reduce their distress in some way.

WHAT ARE COMPULSIONS?

Compulsions (commonly called rituals) are repetitive behaviours or mental acts that the person with OCD feels driven to perform in response to an obsession, and/or in accordance with rigid rules. Compulsions in OCD are performed with the intention of neutralizing, counteracting, and/or eliminating anxiety. Compulsions can also include avoidance of situations that trigger obsessions. Compulsions are time consuming and get in the way of important activities the person values. In most cases, individuals with OCD feel driven to engage in compulsive behaviour and *would rather not have to do* these time consuming (and in many cases, torturous) acts. In OCD, compulsive behaviour is done with the intention of trying to escape or reduce anxiety or the presence of obsessions.[2]

WHAT CAUSES OCD?

While the exact cause remains unknown, research suggests that both genetic predisposition and environmental stress play a role in the onset of OCD. According to the Diathesis-Stress model, individuals have varying levels of predisposition to the development of psychological disorders, based on a combination of biological and genetic traits. Specific to OCD, research suggests that genetic predisposition accounts for 27% to 47% of adult-onset OCD. In combination with genetic predisposition, stressful life events and other environmental factors appear to be implicated in the development and onset of OCD. While stress alone does not cause OCD, when an individual is genetically predisposed or has a subclinical case of the disorder, stressful events may precipitate symptoms.[2,5]

COMMON OBSESSIONS IN OCD[2]:

CONTAMINATION

- Body fluids (e.g., urine, feces)
- Germs/disease (e.g., herpes, HIV)
- Environmental contaminants (e.g., radiation)
- Household chemicals (e.g., cleaners, solvents)

LOSING CONTROL

- Fear of acting on an impulse to harm oneself
- Fear of acting on an impulse to harm others
- Fear of violent or horrific images in one's mind
- Fear of blurting out obscenities or insults
- Fear of stealing things

RELIGIOUS OBSESSIONS (SCRUPULOSITY)

- Concern with offending God or blasphemy
- Excessive concern with right/wrong or morality

OBSESSIONS RELATED TO PERFECTIONISM

- Concern about evenness or exactness
- Concern with a need to know or remember
- Fear of losing or forgetting important information when throwing something out
- Fear of losing things

UNWANTED SEXUAL THOUGHTS

- Forbidden or perverse sexual thoughts/images
- Forbidden or perverse sexual impulses
- Obsessions about homosexuality
- Sexual obsessions that involve children or incest
- Obsessions about aggressive sexual behaviour towards others

HARM

- Fear of being responsible for something terrible happening (e.g., fire, burglary)
- Fear of harming others because of not being careful enough (e.g., dropping something on the ground that might cause someone to slip and hurt him/herself)

OTHER OBSESSIONS

- Concern with getting a physical illness or disease (not by contamination, e.g. cancer)
- Superstitious ideas about lucky/unlucky numbers certain colors
- Doubt about having OCD

COMMON COMPULSIONS IN OCD[2]:

WASHING AND CLEANING

- Washing hands excessively or in a certain way
- Excessive showering, bathing, tooth-brushing, grooming, or toilet routines
- Cleaning household items/objects excessively
- Doing other things to prevent or remove contact with contaminants

CHECKING

- Checking that you did not/will not harm others
- Checking that you did not/will not harm yourself
- Checking that nothing terrible happened
- Checking that you did not make a mistake
- Checking your physical condition or body

OTHER COMPULSIONS

- Arranging/ordering things until it "feels right"
- Telling asking or confessing to get reassurance
- Avoiding situations that might trigger obsessions

MENTAL COMPULSIONS

- Mental review of events to prevent harm (to oneself/others, to prevent terrible consequences)
- Praying to prevent harm (to oneself/others, to prevent terrible consequences)
- Counting while performing a task to end on a "good," "right," or "safe" number
- "Cancelling" or "Undoing" (e.g., replacing a "bad" word with a "good" word to cancel it out)

REPEATING

- Rereading or rewriting
- Repeating routine activities (e.g., going in or out doors, getting up or down from chairs)
- Repeating body movements (e.g., tapping, blinking)
- Repeating activities in "multiples" (e.g., doing a task three times because three is a "good," "right," "safe" number)

EXPOSURE AND RESPONSE PREVENTION

INFORMATION ON THE TREATMENT OF OCD

WHAT IS EXPOSURE AND RESPONSE PREVENTION (ERP)?

You may have heard of Cognitive Behaviour Therapy (CBT). CBT refers to a group of similar types of therapies used by mental health therapists for treating psychological disorders. The most important type of CBT for OCD is Exposure and Response Prevention (ERP).

Exposure is the process whereby an individual systematically confronts the thoughts, images, objects, and situations that cause anxiety and/or trigger obsessions. For example, an individual might touch a common-use doorknob (contamination obsessions), hold a sharp knife (fear of harming obsessions), or read religious scripture about going to Hell (religious obsessions).

Response prevention refers to making a choice not to do a compulsive behaviour once the anxiety or obsessions have been "triggered," but to instead allow oneself to feel the anxiety and experience habituation. *Habituation* refers to the decrease in anxiety with nothing but the passage of time.

HOW DOES ERP WORK?

In a typical OCD scenario (see Figure 1 below), an individual encounters an object or situation that evokes anxiety. To alleviate this anxiety, they engage in a compulsive ritual. While the ritual provides short-term relief from the anxiety, the long-term consequences are that the individual will 1) always feel anxious in that particular situation, 2) likely need to engage in more and more rituals to experience relief, and 3) avoid more situations/objects to avoid feeling anxious, which often reduces quality of life.

With ERP (see Figure 2 below), individuals learn to approach their feared situations through exposures, and practice preventing the rituals that they have used previously to reduce their anxiety. Instead of engaging in rituals, individuals are instead taught to fully experience their anxiety. Then, over time, they will experience a reduction in their anxiety through the process of habituation. By approaching their fears in this way, individuals learn that 1) the situations that they fear are not actually dangerous, 2) their anxiety will reduce on its own over time without the use of rituals, and 3) they are able to experience and tolerate feelings of anxiety. As a result, individuals experience reduced anxiety to the same stimulus over time and are able to approach more and more of their previously-feared situations, which often significantly improves overall quality of life.

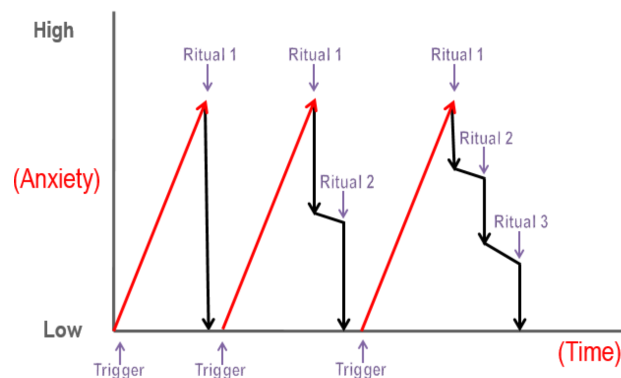

Figure 1. Typical OCD scenario

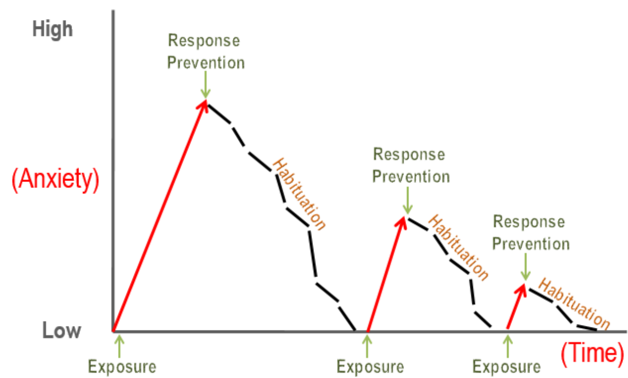

Figure 2. Exposure and Response Prevention

HOW IS TREATMENT IMPLEMENTED?

With ERP, we collaboratively develop a treatment plan with an individual that serves as the roadmap for recovery from OCD. The treatment plan consists of two main components: the exposure hierarchy and identification/elimination of rituals.

The *exposure hierarchy* is a document that lists possible exposure exercises that an individual may engage in during treatment. It includes a wide range of activities that would elicit low anxiety to extreme anxiety if approached without using any compulsive rituals. Exposure exercises are assigned if they would cause *challenging* but *manageable* levels of anxiety. This range is chosen to ensure that an individual is experiencing enough anxiety to benefit from the exposure, but not so much that they are likely to avoid their assignments or engage in rituals. Individuals are typically assigned 3-5 exposure exercises at a time and are asked to complete exposure exercises each day. When conducting exposure, individuals engage in the anxiety-provoking activity (e.g., hold on to a knife), resist engaging in any compulsive rituals (e.g., checking, mental reassurance), and stay in the situation until *either* anxiety decreases by at least 50% (e.g., until anxiety reaches a ‘4’ if the peak anxiety was an ‘8’) *or* the expectancy of a feared outcome has been violated (e.g., expecting that holding a knife for 5 minutes would result in aggressive behaviour, then engaging in a knife-holding exposure for 6 minutes). Exposures are discontinued (and new ones are initiated) once the individual is willing to experience the anxiety without using compulsions.

While in treatment, we strive for our clients to adhere to 100% ritual prevention. However, we recognize that individuals may be unable to fully adhere to “complete” ritual prevention. As a result, an individual’s therapist may ask them to keep track of their rituals in a small notebook to increase awareness on how frequently their urges to ritualize are occurring, and to monitor how frequently they are engaging in (versus resisting) their urge to ritualize. Individuals are asked to eliminate their rituals as quickly as possible, and to practice ritual prevention throughout the day (i.e., not just during exposure trials). If an individual submits to completing a compulsive ritual, they are asked to ‘spoil’ or ‘undo’ it in some way (e.g., touch a contaminated object after hand washing).

ADDITIONAL TREATMENT COMPONENTS

Depending on an individual’s specific needs, several adjunct treatment components may be prescribed.

MEDICATION

Medication treatment of anxiety is often used in conjunction with therapy. Medication may be a short-term or long-term treatment option, depending on severity of symptoms, other medical conditions, and individual circumstances.[1] Medications are recommended and prescribed by psychiatrists.

BEHAVIOURAL ACTIVATION

When people experience low mood and depression, they may increasingly disengage from their routines and withdraw from their environment. Over time, this avoidance exacerbates low mood as individuals lose opportunities to be positively reinforced through experiences of mastery, pleasant experiences, or social activity. Behavioural activation seeks to increase the patient’s contact with sources of reward by helping them get more active and connect with their values and, in so doing, improve one’s life context.[5]

OBSESSIVE COMPULSIVE RELATED DISORDERS

INFORMATION ON OBSESSIVE COMPULSIVE RELATED DISORDERS

WHAT ARE OBSESSIVE COMPULSIVE RELATED DISORDERS?

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is a resource that mental health clinicians use to diagnose mental health disorders. In 2013, a new edition of the DSM was published. In the fifth edition of this manual (DSM-5), a new chapter was created that clusters disorders together that involve obsessional thoughts and/or compulsive behaviours. These include OCD, body dysmorphic disorder (BDD), hoarding disorder, and two body-focused repetitive behaviour (BFRB) disorders: trichotillomania (hair-pulling disorder), and excoriation (skin-picking) disorder.

WHAT IS BODY DYSMORPHIC DISORDER (BDD)?

BDD is a body-image disorder characterized by persistent and intrusive preoccupations with an imagined or slight defect in one's appearance. While everyone has some aspect of their body or appearance that they don't like, individuals with BDD think about their real or perceived flaws for hours each day. They can't control their negative thoughts and don't believe people who tell them that they look fine. Their thoughts may cause severe emotional distress and interfere with their daily functioning. They may miss work or school, avoid social situations and isolate themselves, even from family and friends, because they fear others will notice their flaws.[1]

SYMPTOMS OF BDD

People with BDD suffer from obsessions about their appearance that can last for hours or up to an entire day. Hard to resist or control, these obsessions make it difficult for people with BDD to focus on anything but their imperfections. This can lead to low self-esteem, avoidance of social situations, and problems at work or school. People with severe BDD may avoid leaving their homes altogether and may even have thoughts of suicide or make a suicide attempt.

BDD sufferers may perform some type of compulsive or repetitive behaviour to try to hide or improve their flaws although these behaviours usually give only temporary relief. Examples include camouflaging their perceived flaw (with a body position, clothing, makeup, hair, hats, etc.), comparing their body part to other peoples' appearance, seeking cosmetic surgery, checking their body repeatedly in the mirror, avoiding mirrors altogether, skin picking, excessive grooming, excessive exercise, and changing clothes excessively.[1]

HOW IS BDD TREATED?

Treatment for BDD has significant overlap with best-practice treatment for OCD, with some minor modifications. In general, cognitive behavioural therapy for adults with BDD is effective in improving BDD symptoms and has also been shown to improve related symptoms, such as depression, insight, body image, self-esteem and social anxiety. The category of medications called serotonin reuptake inhibitors are also effective for BDD and related symptoms.

WHAT IS HOARDING DISORDER?

Hoarding disorder is characterized by persistent difficulty discarding or parting with possessions, regardless of their actual value. Attempting to get rid of their things causes individuals with hoarding disorder to feel significant distress, due to perceived need to save their items. The accumulation of possessions that congest and clutter the living areas of someone's home/property substantially compromise their ability to use these spaces for their intended purpose (e.g., use a kitchen for cooking).

HOW IS HOARDING DIFFERENT FROM CLUTTER, COLLECTING, OR SQUALOR?

	TYPES OF ITEMS	METHOD OF ACQUIRING	APPEARANCE OF HOME	LIFE IMPACT
Hoarding	Items do not have a specific theme. Many different types of items.	Items are not acquired in a planned fashion. Acquisition is often excessive.	Disorganized clutter takes over living spaces and prevents them from being used as intended.	•Efforts to get rid of the items and/or not acquire items causes distress. • Spending to acquire items may be excessive, causing financial distress. •Can cause conflict in social/family relationships, in addition to general withdrawal from society. •State of home may have a broader impact on surrounding homes (e.g. sanitation concerns, structural issues)
Normal Clutter	Items may or may not have a specific theme.	Items are not acquired in a planned fashion. Acquisition is not excessive.	Disorganized, generally located in storage spaces. Does not prevent living spaces being used as intended.	•Items may cause mild distress, but generally do not have broad or lasting impact on finances, work, social life. •The thought of getting rid of items or not acquiring any more does not cause distress.
Collecting	Items center around specific theme, (e.g. stamps).	Items are acquired through planned searches.	Items are arranged, stored, and/or displayed in an organized fashion. Items do not take over living spaces.	•Items usually have a positive or pleasurable impact. •Collecting usually does not cause financial distress, impairment in work, social life.
Squalor	No intentional saving/acquiring of items.	Build-up is due to neglect or inability to remove items.	Home is generally in a state of disrepair, may look unclean/unkempt.	•State of home may or may not cause distress. State of home has a negative impact on the health and wellbeing of all inhabitants, and may have broader impact on surrounding homes.

HOW IS HOARDING DISORDER TREATED?

Helpful treatment options include cognitive behavioural therapy, motivational interviewing (a technique that seeks to increase one's motivation to make positive changes in their behaviour), skills training (teaching organizational, problem solving, and decision-making skills), and medication. Often people find the most benefit from using a combination these methods. Ongoing in-home treatment work is particularly important following discharge.

TRICHOTILLOMANIA

Trichotillomania, also known as hair pulling disorder, is characterized by the repetitive pulling out of one's hair. There are times when pulling occurs in a goal-directed manner, and also times when hair is pulled in an automatic manner in which the individual is less aware. Although the severity of hair pulling varies widely, many people with trichotillomania have noticeable hair loss, which they attempt to hide.

EXCORIATION DISORDER

Excoriation Disorder, also known as Skin Picking Disorder or dermatillomania, is characterized by the repetitive picking of one's own skin. Individuals who struggle with this disorder touch, rub, scratch, pick at, or dig into their skin in an attempt to improve perceived imperfections, often resulting in tissue damage, discoloration, or scarring. Occasional picking at cuticles, acne, scabs, calluses or other skin irregularities is a very common human behaviour; however, research indicates that 2% - 5% of the population picks their skin to the extent that it causes noticeable tissue damage and marked distress or impairment in daily functioning.[3]

WHAT ARE BODY FOCUSED REPETITIVE BEHAVIOUR DISORDERS (BFRBs)?

BFRB is a general term that refers to any repetitive self-grooming behaviour (e.g., pulling, picking, biting or scraping of the hair, skin, or nails) that results in damage to the body. The difference between normal grooming behaviours and a BFRB arises when the behaviour causes substantial personal distress and/or interferes with daily functioning. The two most common BFRBs are trichotillomania (hair pulling disorder) and excoriation (skin picking) disorder.[3]

HOW ARE BFRBs TREATED?

Habit Reversal Training (HRT) is the approach most frequently used for the treatment of trichotillomania, excoriation disorder, and other BFRBs. HRT is the method that has been examined most in research studies, and is particularly indicated to achieve rapid, short-term improvement. HRT includes 3 critical treatment components:

- **Awareness training:** Aims to help the person identify the circumstances under which pulling/picking is most likely to occur. The goal of this component is to increase awareness of the likelihood that pulling/picking will occur so that the individual may engage in an alternative, therapeutic technique.
- **Competing response training:** Teaches the individual to substitute another response for the pulling or picking behaviour. For example, when an individual experiences an urge to pull or pick, he/she would sit on their hands so as to make pulling or picking impossible at that moment. This response is to be repeated each time 1) that individual experiences an urge to pull or pick, or 2) when faced with a situation where pulling or picking is likely to occur.
- **Social support:** involves bringing loved ones and family members into the therapy process in order to provide positive feedback when the individual engages in competing responses. They may also cue the person to employ these strategies and provide encouragement and reminders when the individual is in a trigger situation.

ANXIETY RELATED DISORDERS

INFORMATION ON OTHER ANXIETY RELATED DISORDERS

WHAT ARE ANXIETY RELATED DISORDERS?

OCD and Obsessive-Compulsive Related Disorders are closely related to other anxiety disorders – such that intense anxiety is one of the symptoms. The term "anxiety related disorders" refers to a group of disorders characterized by intense anxiety. These are grouped together in the DSM-5, and include social anxiety disorder, panic disorder and agoraphobia, and generalized anxiety disorder. Each disorder has specific symptoms, which will be described below.

WHAT IS SOCIAL ANXIETY DISORDER?

OCD and Obsessive-Compulsive Related Disorders are closely related to other anxiety disorders – such that intense anxiety is one of the symptoms. The term "anxiety related disorders" refers to a group of disorders characterized by intense anxiety. These are grouped together in the
Social anxiety disorder is the extreme fear of being scrutinized and judged by others in social or performance situations. The anxiety can interfere significantly with daily routines, occupational performance, or social life, making it difficult to complete school, interview and get a job, and have friendships and romantic relationships. People with social anxiety disorder often have strong physical symptoms before or during social situations, which may include blushing, sweating, trembling, nausea, heart palpitations, chest discomfort, shortness of breath, dizziness, or headaches.[1] People with social anxiety will often try to avoid or escape social situations. If they do go into social situations, they tend to do things to feel less anxious or to protect themselves from embarrassment or negative evaluation (e.g., staying quiet, avoiding eye contact). It is not uncommon for people to fear some social situations and feel quite comfortable in others. For example, some people are comfortable interacting socially, but are very fearful of performance situations such as participating in business meetings or giving formal speeches. Also, some people fear only a single situation (such as public speaking), while others fear and avoid a wide range of social situations.[4]

WHAT IS GENERALIZED ANXIETY DISORDER?

Everybody worries from time to time. But for about 3% to 4% of Americans, worry goes beyond the normal degree experienced by most people and manifests as Generalized Anxiety Disorder (GAD). Worry functions differently for individuals with GAD when compared to the general population. In GAD, worry is excessive, chronic, and interferes with someone's ability to work or socialize. Individuals with GAD don't know how to stop the worry cycle, which they feel is beyond their control. It is also accompanied by physical symptoms such as muscle aches and pains, sleeping difficulties, restlessness, being easily fatigued, difficulty concentrating, and stomach distress. People with GAD are highly intolerant of experiencing uncertainty. That is, they don't like it when they are not 100% sure of themselves, others, their actions and decisions, or the future. As a result, they will often engage in tiring and time-consuming behaviours designed to make them feel more certain, including:[4]

- Excessive reassurance-seeking (e.g. asking for several peoples' opinion before making a minor decision)
- Checking (e.g. calling a loved one's cell phone several times a day to make sure that they are OK)
- Information seeking (e.g. having to read every review on a product before making a purchase)
- Delegating decision making to others (to avoid the uncertainty of making decisions)

WHAT ARE PANIC DISORDER AND AGOROPHOBIA?

A panic attack is the abrupt onset of intense fear or discomfort that reaches a peak within minutes and includes at least four of the following symptoms:

- racing or pounding heart
- sweating
- shaking or trembling
- shortness of breath
- feeling of choking
- chest pain or discomfort
- chills or hot flashes
- nausea or upset stomach
- dizziness or light-headedness
- feeling detached from oneself (derealisation)
- numbness or tingling sensations
- fear of losing control
- fear of dying

Panic attacks are fairly common, experienced by many healthy children and adults in the general population. However, people with panic disorder experience *unexpected* and *repeated* panic attacks. They become terrified that they may have more attacks and fear that something bad will happen because of the panic attack. As a result, individuals with panic disorder will change their behaviour to feel safer and try to prevent future panic attacks or panic symptoms – carrying items such as medication or water, having a companion accompany them to places, avoiding activities (e.g., exercise, sex), avoiding certain foods or beverages (e.g., spicy food, caffeine), or sitting near exits.[4]

A diagnosis of agoraphobia is assigned when a person fears and avoids specific places or circumstances where they expect panic attacks or panic-like symptoms to occur. Often these are public places where immediate escape would be difficult, such as shopping malls or sports arenas, as well as public transportation, stores, theaters, and similarly enclosed places.

HOW ARE ANXIETY RELATED DISORDERS TREATED?

Treatment for anxiety related disorders has significant overlap with best-practice treatment for OCD, with some minor modifications. In general, adults with the above-described disorders will also engage in exposure-based treatment. An exposure hierarchy that targets an individual's specific fears is created, and anxiety-driven behaviours (or "bans") are identified. In the same way as was described above for OCD (see 'How is Treatment Implemented?' on page 6), exposure exercises are assigned that cause *challenging* but *manageable* levels of anxiety and individuals are asked to resist their anxiety-driven behaviours. In addition, the following interventions are also likely to be implemented:

- **Imaginal Exposures:** Individuals create a story or script of the "worst case scenario" including as much detail and sensory information as possible. Individuals then create an audio recording of their script and listen to it repeatedly, until the story no longer creates anxiety.
- **Interoceptive Exposures:** Most commonly associated with the treatment of panic disorder, interoceptive exposures are exercises that are desired to deliberately elicit – and ultimately decatastrophize – the physical symptoms of a panic attack. For example, an individual may breathe through a cocktail straw for 30 seconds to simulate shortness of breath, allowing themselves to experience and habituate to the uncomfortable sensations.
- **Cognitive Restructuring:** This technique aims to help people identify and correct errors in thinking patterns. For example, an individual with social anxiety disorder may believe that everyone is judging them because it *feels* that way. By identifying their error in thinking and by examining the evidence that does/does not support their belief, we are able to practice taking a more balanced, realistic perspective of feared situations.

SYMPTOM ACCOMMODATION

INFORMATION ON WHAT SYMPTOM ACCOMMODATION IS, WHY IT'S IMPORTANT TO REDUCE SYMPTOM ACCOMMODATION, AND TIPS FOR HOW TO DO SO

WHAT IS SYMPTOM ACCOMMODATION?

Symptom accommodation refers to specific behaviours of support persons to:

- Modify family expectations, responsibilities, and functioning because of OCD and anxiety-related disorder symptoms, and/or
- Participate in OCD rituals or other anxiety-driven behaviours to reduce in-the-moment anxiety

WHAT ARE SOME EXAMPLES OF SYMPTOM ACCOMMODATION?

GENERAL FAMILY ACCOMMODATIONS

- Changing the family member's or family's daily routines due to anxiety (e.g. Parent changes work schedule to be available to anxious child during high anxiety portions of the day)
- Driving separately to events due to the family member's symptoms causing them to be late
- No/few household chores or responsibilities outside of the home (e.g., work, school)

OBSESSIVE-COMPULSIVE DISORDER

- Cleaning yourself and/or objects to reduce family member's contamination anxiety
- Performing tasks for a family member (e.g., opening doors, plating food, meal prep) due to anxiety-related fears (e.g., contamination, fear of harm to others).
- Saying phrases/prayers or repeating yourself to reduce a family member's anxiety
- Waiting for family member to finish rituals before speaking so as not to disrupt the ritual

SOCIAL ANXIETY DISORDER

- Making phone calls for your family member
- Speaking for your family member to reduce/avoid his/her anxiety (e.g., ordering at a restaurant)
- Accompanying your family member to social events when unnecessary (i.e., for anxiety reduction of the family member) and/or it interferes with your own schedule

GENERALIZED ANXIETY DISORDER

- Frequently checking in with your family member to reassure them that you are safe
- Making decisions for your family member
- Doing things for your family member due to fears that they will not do them well (e.g., doing their housework, paying the bills)

PANIC DISORDER

- Accompanying your family member to places where they fear they could have a panic attack
- Providing extra supplies for them to feel safer in the event of a panic attack (e.g., a cell phone if they would otherwise not have one, medications, first aid kits, etc.).

ACCOMMODATION OF AGRESSION

- Not providing consequences to your family member when they are aggressive
- Expecting yourself or other family members to endure verbal or physical aggression

Symptom accommodation is most often discussed regarding parents and spouses accommodating their anxious family members/partners, but can also apply to non-family members (e.g., teachers, friends).

WHY IS SYMPTOM ACCOMMODATION A PROBLEM?[6]

When you love someone that struggles with anxiety, you believe that your role is to provide comfort, reassurance, and a sense of safety. Above all, you want to support your loved one and alleviate his or her suffering. However, when your family member has OCD or another anxiety-related disorder, shielding them from the things that trigger their fears is actually counterproductive to their recovery. Research consistently demonstrates that symptom accommodation is associated with increased symptom severity. Instead of decreasing distress, doing what comes naturally to comfort a loved one inadvertently strengthens their disorder.

Symptom accommodation also tends to escalate over time. What seems like a small and easy adjustment to make at first (e.g., providing hand sanitizer), evolves into more elaborate and difficult accommodations (e.g., repeated sanitization of household objects, helping with washing rituals). Caregivers are often left asking themselves, "How did we get here?"

IMPACT OF SYMPTOM ACCOMMODATION ON TREATMENT OUTCOMES:

- Reduces the opportunity for an individual to learn that their feared outcomes don't actually occur (e.g., that saying a specific phrase keeps them from harming someone).
- Prevents an individual from experiencing a reduction in anxiety after facing their feared situation without avoidance or rituals – that is, it interferes with the process of habituation.
- Limits an individual's opportunity to learn to cope with distress, instead sending a message that difficult emotions (such as fear and doubt) need to be avoided and cannot be tolerated.
- Prevents an individual from building a sense of mastery and increasing their ability to cope with stressful situations.
- Leads to decreased motivation to change. If an individual is protected from the negative consequences of their symptoms through symptom accommodation, they are less likely to engage in treatment and work towards recovery.

IMPACT OF SYMPTOM ACCOMMODATION ON CAREGIVERS:

- Linked to more frustration and stress. Symptom accommodation consumes increasing amounts of time and attention, leading to unintended increases in distress.
- Increases conflict between the individual with OCD and the caregiver. Increased conflict is especially pronounced among those who disagree on the accommodations being given.

HOW COMMON IS SYMPTOM ACCOMMODATION?[6]

Symptom accommodation is VERY COMMON. Here are some specific research findings about accommodation of anxiety disorders:

- 97.3% of parents reported providing at least some accommodation of a child with anxiety.
- 76% of parents reported that they both participated in their family member's symptoms and changed family routines due to their family member's symptoms.
- 89% of adult patients diagnosed with OCD and their relatives reported receiving or providing anxiety accommodation within the past week

WHAT IS REASSURANCE SEEKING?

One of the ways in which your family member might seek to reduce their anxiety is through reassurance seeking. This is one of the most common expressions of symptom accommodation, and involves asking you lots of questions, asking the same question repeatedly, or seeking physical comfort (e.g., hugs). Reassurance seeking serves to reduce anxiety through increasing certainty about a feared situation by gaining perspective from a trusted source. It may also work to reduce anxiety by transferring perceived responsibility of a feared outcome to another person. Although providing answers to (often simple!) questions may seem harmless, providing reassurance serves to maintain the anxiety disorder cycle.

It can be difficult to tell which questions are appropriate to answer, and which questions are attempts at gaining reassurance. Below is a list to help determine whether a question is appropriate to answer and when to encourage the family member to resist a ritual:

Information Gathering	***Reassurance Seeking***
Asks a question once	Repeatedly asks the same question
Asks a question to be informed	Asks a question to feel less anxious
Asks people who are qualified to answer the question	Often asks people who are unqualified to answer the question
Asks questions that are answerable (e.g., what time are we going out today?)	Often asks questions that are unanswerable (e.g., will this give me cancer?)
Seeks the truth	Seeks a desired answer
Accepts relative, qualified, or uncertain answers when appropriate	Insists on absolute, definitive answers whether appropriate or not
Pursues only the information necessary to form a conclusion or make a decision	Indefinitely pursues information without ever forming a conclusion or making a decision

Adapted from the Anxiety Disorders Center, St. Louis Behavioural Medicine Institute

Becoming familiar with these differences is important, however it is imperative to remember that even questions that appear to be information gathering can serve as reassurance! Exploring the function *behind* the question with your family member may serve as a more effective method of identifying – and ultimately reducing – reassurance seeking. To help determine the function of a question:

- Ask: Why? For example, "*Why do you want me to answer that question?*"
- Ask: What? For example, "*What will an answer do for your anxiety?*"

After some education, your family member should be able to identify his/her reason for asking as either satisfying curiosity (i.e., information gathering) or for anxiety reduction (i.e., reassurance seeking). If they are not able to identify the function of the question they are asking:

- Wait. Give yourself some time before you answer. All questions do not need to be answered immediately; you are allowed some time. If the purpose of the question was to reduce anxiety, then a period without an answer would likely increase anxiety. If simply curiosity, not providing an answer is not likely to cause any change in emotion. Sometimes the question may even be forgotten. An important aspect of waiting is encouraging the family member to reflect on why he or she is asking the question and to build awareness of reassurance seeking behaviours.

HOW CAN FAMILY MEMBERS REDUCE SYMPTOM ACCOMMODATION?

Reducing accommodation is a gradual process that should be done collaboratively with the individual in treatment, their family members, and the treatment team. It is important for everyone to work together in the fight against anxiety, placing everyone on the same team against the anxiety symptoms.

Below are some examples for ways to start reducing accommodations and/or support treatment progress. Talk with your family member and their treatment team to determine specific strategies for your household

- While your family member is in treatment, initiate a new family routine that is not dictated by anxiety. How would life be different in your home if your time wasn't spent on accommodating?
- Provide praise and encouragement to your family member for engaging in treatment and working to reduce rituals/anxiety-driven behaviours.
- Practice the accommodation reduction strategies that you have discussed with your family member and the treatment team. When you notice your family member engaging in anxiety-driven behaviours that are assigned to be monitored, calmly encourage them to record and attempt to resist this.
- Have a plan if your family member becomes upset or overwhelmed. This could include reminders that your family member can cope with anxiety, reminders of their treatment goals, and/or timely disengagement if your family member is having only anxiety-driven conversations.
- Reduce outright avoidance by *shaping* behaviour. For example, if the thought of going into a restaurant is too overwhelming, take smaller, more manageable steps – driving to the restaurant, sitting in the parking lot, sitting in the waiting area, sitting in a quiet section of the restaurant, etc. – and allow habituation to occur.
- Process any behavioural incidents (including arguments in response to reduced accommodations) when everyone is calm.
- Remember that feelings cannot always be controlled, but the way in which feelings are managed can. Natural consequences for anxiety-driven behaviours/rituals should be in place – for example, missing an event due to engaging in time-consuming rituals.
- You should prepare your family member for accommodation reduction through good communication. Discuss the changes that will be made at home while they are in treatment.

Always remember that consistency is key when reducing accommodations. Many family members will "break down" and provide accommodations if their family member has had a particularly challenging day, if they are emotionally upset, or if they are in a hurry or late for a task that needs to get done (e.g., opening the door for a family member so they can get to work or class on time). This is understandable, as it can be very difficult for family members to hold firm when faced with their loved one's distress. Nevertheless, it is necessary to remain consistent with the plan that has been established with your family member and the treatment team so as to help them fight back against OCD/anxiety. In particular, once an accommodation has been removed, it should not be re-introduced. If the reduced accommodations are consistently overwhelming, talk with your family member and the treatment team about how to make the accommodation reduction process more manageable.

HOW CAN FAMILY MEMBERS REDUCE REASSURANCE SEEKING?

Reducing reassurance seeking is crucial to treatment success, and should include as many family members and support persons as possible. When your family member comes to you for reassurance, you can try responding with "*What do you think?*" in order to give your family member the opportunity to answer the question themselves. Other options include:

- Asking: "*Have I already answered that?*"
- Saying: "Maybe, maybe not" or "It's possible"
- Saying: "I don't have an answer for that"
- Or simply pointing out that they are seeking reassurance, and therefore, it would not be helpful for you to provide an answer

Most importantly, make a plan with the treatment team and your family member while they are in treatment to determine how reassurance seeking will be handled going forward.

REASSURANCE AND ACCOMMODATION VERSUS VALIDATION

Not providing your family member with reassurance or accommodation when they are in distress can feel mean. However, it is important to remember that one can be empathic without being accommodating. The use of *validation* can especially helpful when your loved one is struggling.

Reassurance and accommodation serve to remove doubt, fear, or distress. They are verbal and non-verbal actions that are done in an attempt to artificially reduce anxiety, or to offer certainty when certainty is not available.

Validation, instead, refers to the provision of acceptance, support, and confirmation. It is communication to another person that his or her emotions, thoughts, and behaviours have causes and are understandable in the current context. Validation takes the individual's emotional and behavioural response seriously, without discounting or trivializing their experience. Validation is non-judgmental; it acknowledges someone else's point of view, conveying understanding and empathy without trying to fix things or disregard their experience. The act of providing validation includes three important steps:

- *Active observing:* First, gather information about what is happening in the moment. Listen to what your family member is thinking and feeling; observe what they are doing.
- *Reflection:* Check in with them about what they are experiencing. For example, "I want to make sure I understand. You're feeling anxious and worried because you are scared about offending God, is that right?"
- *Direct validation*: Try to understand the situation from your family member's point of view, even if it doesn't make sense to you. Respond with caring. For example, "I'm not surprised that you want to give up; every day is a huge challenge for you to make it through with all of the anxiety you've been experiencing. I know you can do this. I'm here to support you."

By responding with validation instead of reassurance or accommodation, you can continue to support and care for your family member while simultaneously helping them to move forward in breaking free from OCD and anxiety.

LEARNING TO TOLERATE YOUR FAMILY MEMBER'S ANXIETY

It is understandable that you may struggle with this new approach to dealing with anxiety. It can be VERY difficult to see your family member struggling, and it makes perfect sense that you want to do whatever you can in the moment to help alleviate their distress. Unfortunately, as described throughout this packet, symptom accommodation from family members contributes to *worsened symptoms*, *lack of treatment progress*, and even *premature dropout from treatment*. Remember that the ultimate goal is to decrease anxiety and anxiety-driven behaviours in the long-term, and that you all are working together towards this goal! Like any goal worth having, this includes feeling *some discomfort now for less discomfort later*.

Here are some tips when witnessing your family member's distress:

- Practice empathy and validation without accommodating. Reflect the emotion that you see without offering advice or distraction (e.g., "I can see how hard this is for you" and "I'm here to help you fight against your OCD")
- Be aware of your body language and tone of voice when your family member is anxious. Keep a calm demeanor (resist pacing, tensing up, etc.) and calm, even speech (instead of using a rapid, high pitched, or frustrated tone). Practice your poker face!
- Challenge your own thoughts about anxiety. Remember that anxiety is NOT dangerous, even though your family member *feels* that it is. Remind yourself that the presence of your loved one's anxiety in a given situation is not an accurate indicator to the *actual safety* of the situation
- Tolerating your family member's anxiety is especially challenging when you struggle with anxiety yourself. It's important to be aware of your own worries and anxiety-driven behaviours/rituals, and to seek professional help as needed. In addition to supporting treatment principles, seeing family members address their own mental health needs can be a highly motivating factor in increasing an individual's willingness to engage in treatment.

THE IMPORTANCE OF SELF CARE

Dealing with anxiety can be very challenging, both for the individual in treatment as well as for the family as a whole. During this stressful time, it is important for everyone involved to take care of themselves. Not only will this help to reduce your own levels of stress and anxiety, but engaging in regular self-care can serve as a powerful method of modelling healthy choices to your family member with OCD/anxiety.

Ask yourself: When is the last time you…

- Exercised routinely?
- Went on a date with your spouse?
- Spent time with friends?
- Been 'unplugged' from technology (including being available 24/7 by phone)?
- Read a book (that has nothing to do with anxiety/OCD/treatment)?
- Took some time just for yourself?

Take time while your family member is in treatment to reset your routine and to care for yourself!

QUESTIONS FOR FAMILY MEMBER/PARTNERS

How has anxiety changed your family routines and dynamics?

Do you feel as though you are “walking on eggshells” with your anxious family member? What would life look like if you were not doing that?

How would your time be spent if you weren’t providing accommodations (including giving reassurance)?

What are some accommodations that are being made for your family member?

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Do you have any questions for your family member's treatment team?

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GUIDELINES/SUGGESTIONS PROVIDED BY THE TREATMENT TEAM FOR REDUCING ACCOMMODATION OF YOUR FAMILY MEMBER’S ANXIETY

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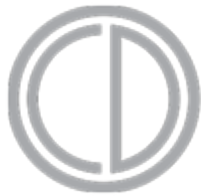
RESOURCES

FIND OUT MORE INFORMATION FROM THESE ORGANIZATIONS

ANXIETY AND DEPRESSION ASSOCIATION OF AMERICA

[1]Founded in 1979, The Anxiety and Depression Association of America (ADAA) is an international nonprofit organization and a leader in education, training, and research for anxiety, OCD, PTSD, depression, and related disorders.



International OCD Foundation

[2]The mission of the International OCD Foundation is to help everyone affected by obsessive compulsive disorder (OCD) and related disorders to live full and productive lives. Our aim is to increase access to effective treatment, end the stigma associated with mental health issues, and foster a community for those affected by OCD and the professionals who treat them.

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[3]The TLC Foundation for BFRBs provides treatment information, education, and support for anyone affected by trichotillomania, skin picking disorder, and related body-focused repetitive behaviour disorders.

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[4]The Anxiety Disorders Association of British Columbia (AnxietyBC™) is a non-profit organization established in 1999 by a group of concerned individuals, family members, and health professionals. The association's mission is to promote awareness of anxiety disorders and support access to evidence-based resources and treatment.

AMERICAN PSYCHOLOGICAL ASSOCIATION

[5]APA is the leading scientific and professional organization representing psychology in the United States, with more than 115,700 researchers, educators, clinicians, consultants and students as its members.

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[6]For a review on the impact of symptom accommodation, see: Kagan, E., Frank, H., & Kendall, P. (2017). Accommodation in youth with OCD and anxiety. *Clinical Psychology: Science and Practice, 24*(1), 78-98.