# Mindfulness Treatments for Parents of Children with Developmental Disabilities

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## Certificate of Original Authorship

I, Raphaella Osborn, declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Graduate School of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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## List of Original Publications and Manuscripts

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## List of Conference Presentations

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## Definition of Key Terms and Abbreviations

### Developmental Disability (DD)

Developmental disability is a broad, umbrella term to describe a group of conditions that begin in the developmental period, are typically lifelong, and characterised by impairment across multiple domains - including intellectual, behaviour, physical, learning, and/or language functioning. Examples of DD are autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), Down syndrome, cerebral palsy, and intellectual disability (ID; Centers for Disease Control and Prevention, 2020).

### Intellectual Disability (ID)

Intellectual disability is a type of DD that involves deficits in both intellectual and adaptive functioning. Adaptive functioning includes conceptual, social and practical functioning, with impairments presenting as reduced social participation, communication, and independent living. Intellectual disability is specified according to severity level, with mild, moderate, severe and profound diagnostic categories (American Psychiatric Association, 2013).

**Abstract**

*Background*. It is well documented that parents of children with developmental disabilities (DD) experience increased rates of psychological distress. Research into effective treatments for these families is important as parental distress can maintain or exacerbate behavioural problems in children with DD. There is emerging evidence that mindfulness-based treatments may offer benefits to these families. The present dissertation examines the efficacy of mindfulness treatments for reducing distress in parents of children with DD, including relevant adaptations to treatment.

*Method/Results*. Four independent studies were conducted. Study 1 involved a systematic review to examine the evidence-base for mindfulness treatments targeted to parents of children with DD. Data from eight randomised controlled trials, involving a pooled sample of 793 caregivers, confirmed that mindfulness treatments contributed to significant, medium to very large reductions in emotional distress. Study 2 used a case series design to investigate the efficacy of a mindfulness-based treatment not previously trialled in this population; Mindfulness-integrated Cognitive Behavioural Therapy (MiCBT). While the results of this case series suggested that a combination of CBT and mindfulness meditation may be beneficial, recruitment difficulties led to the hypothesis that parents of children with DD may experience barriers to accessing psychological treatment for themselves. Specific barriers to treatment were subsequently examined in the third study, a survey of 80 parents. Treatment cost, arranging childcare, and availability of service providers were identified as key barriers. The final study examined the feasibility and efficacy of a mindfulness treatment that countered accessibility issues by being brief in duration and delivered online. While recruitment was once again problematic, parents reported improvements in general mood as well as mindfulness gains which were maintained at 3-month follow-up. Moreover, the online treatment was deemed feasible.

*Conclusion*. In combination, the present findings indicate that mindfulness treatments can be beneficial to parents of children with DD, with reductions in anxiety, stress and depression symptoms identified, alongside improvements in mindfulness skills. Despite this evidence, significant barriers to accessing face-to-face psychological treatment were reported. Importantly, an adapted mindfulness treatment that required low time commitment and could be readily accessed via smartphone at a low cost, demonstrated potential to substantially reduce parental distress. Nonetheless, engaging parents' commitment to even this brief, adapted treatment was a significant challenge. Clinicians who work with families who have children with DD should be aware of the difficulties that parents may have in prioritising treatment for themselves, but also the potential benefits of engaging them in even brief treatments.

# Chapter 1: Introduction

## Developmental Disabilities

A functional family system is considered to be a vital contributor to the wellbeing of all of the individuals of a family (Thompson et al., 2013). Consequently, stressors which disrupt the ability of a family to function can have a significant impact on individual members. The diagnosis of a child's developmental disability (DD) has been described as a traumatic stressor for parents, requiring the processing of grief over loss of image of an ideal child (Schuengel et al., 2009).

DD is an umbrella term used to describe a group of conditions that begin in the developmental period, are often lifelong, and involve functional impairment in one or more domains - namely intellectual development, behaviour, physical ability, learning, and/or language. Commonly noted examples of DD are autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), intellectual disability (ID), and Down syndrome (Centers for Disease Control and Prevention, 2020). Autism spectrum disorder refers to a group of disorders characterised by persistent deficits in social communication and interaction, and restricted patterns of behaviour or interest. Attention deficit hyperactivity disorder, although not a spectrum disorder, can produce a range of disruptive symptoms similar to ASD including inattention and/or hyperactivity. In comparison, diagnosis of ID is based on the intelligent quotient of 70 or less and requires deficits in adaptive functioning (e.g., independent living, social communication), both of which must begin in the developmental period (American Psychiatric Association, 2013). Down syndrome, a genetic disorder which is often comorbid with ID, is caused by an extra copy of chromosome 21 (Centers for Disease Control and Prevention, 2020). The above DDs are either diagnosed before birth (e.g., Down syndrome, or other chromosomal abnormalities that can result in

DD) or are frequently diagnosed during early childhood (e.g., ASD, ADHD; Centers for Disease Control and Prevention, 2020).

The impairments associated with DD lead to ongoing and complex challenges for families resulting in high levels of carer burden, or an accumulation of stressors that present as reduced emotional and physical health (Nolan et al., 1990). The stress of diagnosis, is compounded by societal stigma and prejudice identified by these families – both of which can prolong distress, lower self-esteem, and induce anxiety when required to leave the house with their child (Ali et al., 2012). In addition, many children with DD have specialised day-to-day care needs, compared to typically developing peers (e.g., meal time cleaning, toileting, night time settling), as well as requiring continual parental advocacy to ensure their child receives the services they require (Plant & Sanders, 2007b). Financial stress can also result when one parent assumes a full-time carer role, leading to decreased family income and opportunity cost (Baker et al., 2005). In an Australian sample of families where a child had a mild ID, out of pocket expenses for families in a six month period was estimated to be AUD$7,689, and the opportunity cost of time spent caring for a child was estimated to be AUD$31,817. For parents of children with a mild ID, the national estimate of cost to families over a six month period was AUD$3B (Doran et al., 2012). Children with DDs are significantly more likely to have behaviour problems than typically developing peers (Matson, Wilkins & Macken, 2008). The high rates of behaviour problems seen in children of DD, particularly those with ASD, are especially challenging for parents (Abbeduto et al., 2004; Roper et al., 2014), with some researchers calling for a trauma-based conceptualisation of parental experience when a child has a DD, citing child behaviours that include biting and property destruction (Stewart et al., 2016). Behaviour problems appear to substantially contribute to parental stress, and are a significant predictor of parent stress when controlling for other factors such as adaptive behaviour and socioeconomic status (see Hastings, 2002 for

a literature review). Moreover, behaviour problems have high prevalence rates in children with DD, with research showing 94% of a sample of children with ASD to have challenging behaviours, as assessed by parent report. In this sample, 56% of parents reported their child would leave the supervision of the caregiver without permission, 38.1% reported their child had aggression towards others, and 27.4% reported their child had self harming behaviours (Jang et al., 2011).

**Models for Conceptualising Parental Distress**

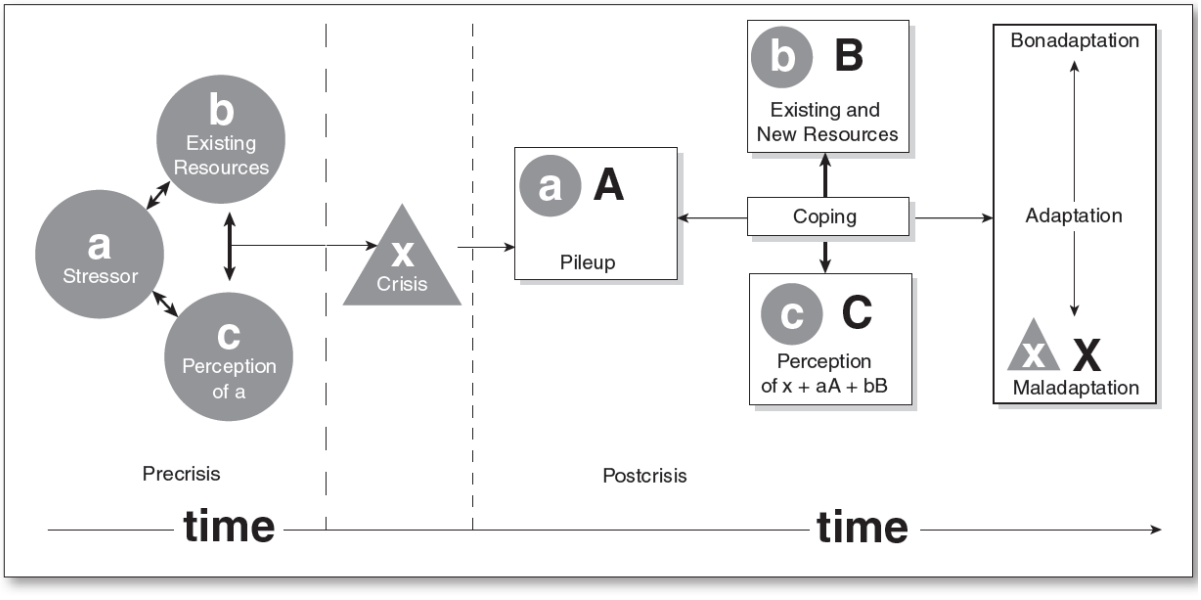
Several theoretical models have been proposed to conceptualise parental stress and stress among families where a child has a DD. The ABC-X model, originally developed in the 1940s and 50s by Hill (1958) to understand the impact of war and economic challenges on family systems, provides a framework for understanding families in crisis and coping. According to this model, a stressor (A), in combination with a family's available resources - including material resources such as wealth and individual resources such as self-esteem (B), interacts with an individual's perception of the triggering event (C), resulting in a response (X), where X represents the level of crisis which occurs as a result of the interactions between A, B and C (Rosino, 2016).

The ABC-X model was later adapted by McCubbin and Patterson (1983) to illustrate the enduring nature of DD, by acknowledging the impact of subsequent life stressors and ongoing development of coping strategies (see Figure 1). In the Double-ABCX model, families respond to a crisis (X) by continually adapting to the ongoing accumulation of stressors (aA) through the development and integration of new and existing resources (bB), which combined with perception of stressors and coping (cC) then leads to adaptation or maladaptation (xX; Jones & Passey, 2004; McCubbin & Patterson, 1983). For families of children affected by DD, stressors (aA) may include a child's behaviour problems in combination with symptom severity and competing parental demands which, in combination,

may result in poor mental health outcomes for individual family members (xX). However, available social supports (bB) and a parent's ability to make positive appraisals (cC), can ultimately influence whether an outcome (xX) is adaptive or maladaptive (McStay et al., 2014).

Figure 1.

*Double-ABCX Model*

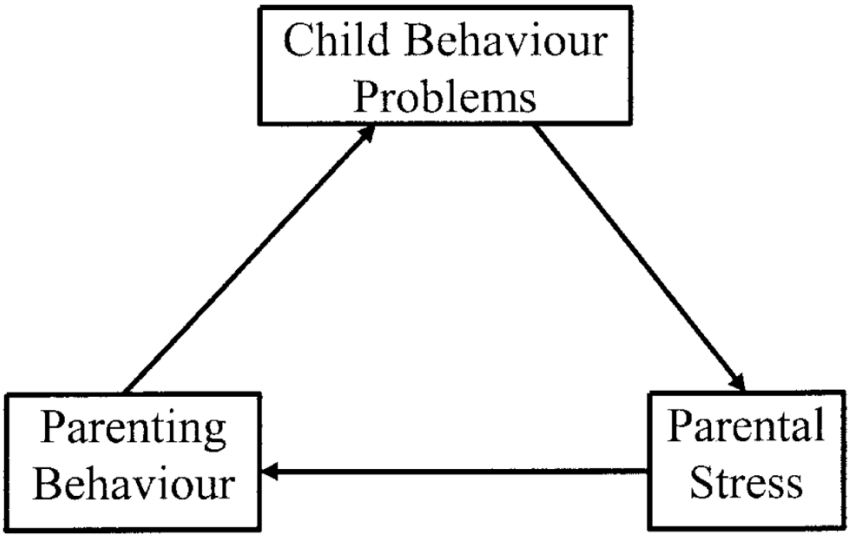



Note. From McCubbin, H. I., & Patterson, J. M. (1983). The family stress process. *Marriage & Family Review*, *6*(1-2), 7-37. https://doi.org/10.1300/j002v06n01_02

In consideration of the high rates of challenging behaviours associated with DD, a family systems model has also been proposed (see Figure 2). Accordingly, families of children with a DD are likely to experienced increased stress due to the high probability of child behaviour problems which, in turn, may influence parenting behaviour (e.g., an increase in authoritarian parenting practices). These changes in parent stress, with resulting changes in parenting practices, may further exacerbate child behaviour problems (Hastings, 2002).

Figure 2.

*Model of Parental Stress and Child Behaviour Problems*




Note. From Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability*, *27*(3), 149-160. https://doi.org/10.1080/136682502100000865

In support of the Family Systems model, longitudinal research has provided evidence of a transactional relationship over time, whereby parent stress contributes to child behaviour problems and child behaviour problems, in turn, demonstrate a positive and strong relationship with levels of parent stress (Neece et al., 2012; Woodman et al., 2015). However, to ensure a holistic understanding of parental distress it is arguably important to consider the multiple co-existing stressors that parents experience (e.g., social stigma, finances; Crnic et al., 2017), as represented in the Double-ABCX model. Indeed, a range of research has found the Double-ABCX model to have good utility for understanding families where children have a DD (McStay et al., 2014). The Double-ABCX model has been effectively used to provide insight into family quality of life and wellbeing (Pozo et al., 2014), as well as to explore how

factors such as racism, child behaviour problems, and parental ability to reframe can impact potential outcomes for families (Manning et al., 2011).

**Psychological Treatments for Parents**

Given the complex nature of parental distress, including the accumulation of stressors over time and subsequent impact on both parental and family wellbeing, it is important to have effective psychological treatments available for parents of children with DD. In the context of the Double-ABCX model, effective psychological interventions provide a new resource (bB) to help reduce parental distress by increasing the likelihood of adaptive coping (xX). Parent training, cognitive behavioural and mindfulness-based therapies, have shown promise in improving parent and child outcomes in families of children with DD.

**Parent Training**

When parenting stress occurs in the context of child behaviour problems, parent training programs such as Triple P-Positive Parenting Program are considered to be an evidence-based approach to improving parental outcomes (Plant & Sanders, 2007a; Sanders et al., 2014). These behavioural treatments change child behaviour through teaching new parenting practices, such as positive parenting skills. Parent training is effective at reducing child behaviour problems, and has been shown to improve parental outcomes (Sanders et al., 2014). In a sample of families where a child had ASD, Triple P has been shown to reduce reactive parenting behaviours, improve parental-self efficacy, and reduce parenting stress (Schrott et al., 2018). While child focused behavioural approaches may be beneficial for parents, targeting parental stress directly through parent focused psychological treatments is also important due to the wide range of stressors that parents experience (Crnic et al., 2017).

**Cognitive Behavioural Therapy**

Cognitive Behavioural Therapy (CBT) is widely considered to be a gold standard psychological treatment for a range of problems, including depression and anxiety (David et

al., 2018). CBT theory posits that psychological concerns are caused or exacerbated by unhelpful or dysfunctional beliefs, thoughts and behaviours in response to life events (Arch & Craske, 2009). CBT involves identifying, evaluating and modifying these unhelpful or dysfunctional behaviours and thinking styles, with the aim to improve mood (Beck, 2011). Commonly used treatment components of CBT include psychoeducation (i.e., empirically based explanation of psychological concerns), cognitive restructuring techniques to monitor, identify and change unhelpful thoughts, and exposure (systematic desensitisation to real or avoided stimuli; Arch & Craske, 2009).

Both treatment efficacy and treatment processes have been established for CBT, with a vast amount of research conducted across various clinical and non-clinical populations and age groups (Butler et al., 2006; David et al., 2018). There is some evidence that CBT is also effective for parents of children with DD, with significant reductions in distress observed (e.g., Wong & Poon, 2010). However, the evidence base for CBT for this population remains preliminary, with a small number of wait list controls studies, and small sample sizes (see Hastings & Beck, 2004, for a review). Further, it is worth considering the applicability of CBT for this population. CBT is categorised as a change focused treatment, due to its emphasis on labelling and changing "dysfunctional" thoughts. It is possible this approach may be considered invalidating for these parents – at times the distressing thoughts they experience (e.g., thoughts centred on the difficulty of parenting tasks and child behaviour) may well be proportionate to their circumstances.

**Mindfulness Treatments**

Mindfulness treatments have gained popularity in recent years as part of what has been described as a "third wave" of psychotherapies (Hayes & Hofman, 2017). Mindfulness is broadly conceptualised as an "acceptance-based treatment", in comparison to CBT's conceptualisation as a "change-based treatment". Mindfulness can be considered as both a

standalone treatment as well a treatment that could potentially be integrated with CBT-based strategies (Orsillo et al., 2003). In contrast to CBT's focus on content- evaluating and modifying thoughts, mindfulness treatments focus on the relationship with thoughts and involve cultivating a non-judgemental awareness and acceptance of thoughts - or being able to notice thoughts without judging them as "good or bad" and allowing thoughts to exist and to pass in their own time. This approach towards thoughts forms what is often referred to as a "third wave" in psychotherapy research. A further aim of mindfulness and other third wave treatments are to enhance one's awareness of internal and external experiences of thoughts, emotions and bodily sensations (Baer, 2003, Brown & Ryan, 2003; Nyklíček & Kuijpers, 2008; Hayes & Hofman, 2017).

Mindfulness skills of present moment awareness are often developed through meditation practice. An example of meditation practice is a structured time where an individual focuses their attention to present moment experience in a non-judgemental manner (Shapiro et al., 2006). Research suggests that meditation may act as a form of exposure, whereby individuals are able to form an increased tolerance towards discomfort experienced in day-to-day life by developing non-judgemental acceptance towards discomfort that arises during meditation practice (Baer, 2003). It has also been suggested that cultivating non-judgemental observation of thoughts may lead to understanding of thoughts as not necessarily reflecting reality, whereby thoughts then become less distressing (Baer, 2003).

In addition to improved attentional control, emotion regulation, and self-awareness, mindfulness practice has been associated with neural changes in associated brain regions. More specifically, regular mindfulness practice has been linked to increased white matter integrity and greater cortical thickness in the anterior cingulate cortex- an area of the brain implicated in executive attention and control, through its ability to form networks with far reaching brain areas (Tang et al., 2015). Research has also demonstrated reduced amygdala

response (an area of the brain involved in processing of emotions) in experienced meditators, in addition to stronger connections between areas of the brain involved in self-awareness - such as the posterior cingulate cortex, dorsal anterior cingulate cortex and dorsolateral prefrontal cortex (Tang et al., 2015).

A range of mindfulness-based interventions are currently utilised in psychotherapy. One example is Mindfulness-based Stress Reduction (MBSR). MBSR involves a structured eight week program with a primary focus on meditation practice and integrating mindfulness principles into daily life (Kabat-Zinn, 2013). In addition to 2.5 hour group meetings and a full day retreat, MBSR requires daily 45-minute body scan meditation and hatha yoga practice with gentle stretching (Praissman, 2008). Mindfulness Based Cognitive Therapy (MBCT; Segal at al., 2002) and Mindfulness-integrated CBT (MiCBT; Cayoun, 2011) offer the benefits of acceptance-based mindfulness and change-based CBT within a single treatment. Like MBSR, MBCT is a structured 8 week intervention incorporating mindfulness techniques, such as viewing thoughts nonjudgmentally, alongside a CBT informed understanding of the impact of negative thoughts on depression (Baer, 2003). Additional treatments incorporate mindfulness principles without an active meditation component, such as Acceptance and Commitment Therapy (ACT; Hayes et al., 2006), based on principles of behaviour therapy, and Dialectical Behaviour Therapy (DBT), which was designed to flexibly alternate between change (e.g., problem solving) and acceptance-based strategies (e.g., observation and acceptance of intense emotion; Neacsiu et al., 2012).

Research suggests that mindfulness-based treatments may be effective in treating a wide range of mood and anxiety disorders (Rodrigues et al., 2017), with broader benefits to quality of life and stress management (Grossman et al., 2004). For example, a systematic review of 17 randomised control trials found that MBSR improved mental health in a mixed sample including clinical and non-clinical populations, compared to wait list or treatment as

usual (Fjorback et al., 2011), and research comparing MBSR to CBT showed greater improvement in symptoms in the MBSR group compared to the CBT group, in a social anxiety disorder sample (Abbasi et al., 2018). There is also evidence to suggest that MBCT is effective at not only reducing depressive symptoms but also reducing risk of relapse in clinical samples, with rates of relapse appearing to be comparable to those who have had cognitive therapy (Chiesa & Serretti, 2011; Farb et al., 2018). MBCT has shown similar efficacy to CBT in treating major depressive disorder, in participants who had experienced less than four episodes of depression (Goldberg et al., 2019; Manicavasgar et al., 2011), and for individuals with generalised anxiety disorder, MBCT may be more effective than CBT in reducing anxiety in the short term (Jiang et al., 2021). The evidence base for MiCBT is less developed than MBCT and MBSR, with smaller sample sizes and study protocols ( Frances et al., 2020). Conversely, ACT has a developing evidence base over the last 20 years, with over 60 RCTs confirming its efficacy for depression, OCD, psychosis and anxiety (Öst, 2014). Finally, DBT has been shown to reduce suicidal and self-destructive behaviour (Panos et al., 2013).

Although mindfulness treatments, such as MBSR and ACT, have been trialled for parents of children with DD, available systematic reviews (see Cachia et al., 2015; Whittingham, 2013) have relied on quasi-experimental designs. Despite promising findings, and the importance of pilot studies (which often use quasi-experimental within subjects designs or case series) in early phase research (Craig et al., 2009), these also have the potential to introduce validity concerns due to lack of experimental control. Recently, a number of randomised controlled trials (RCTs) have been published which can add to this evidence base. These trials also demonstrate that mindfulness treatments such as MBSR or mindful parenting can effectively reduce distress for parents of children with DD compared to wait-list controls (Neece, 2013), or usual care (Behbahani et al., 2018). Moreover, traits

such as psychological acceptance and general mindfulness have been shown to mediate parental distress in parents of children with DD, providing further evidence that mindfulness treatments may help these parents by offering a means to develop acceptance and mindfulness skills (Jones et al., 2014)

**Research aims**

In light of the degree of distress experienced by parents of children with DD, and accumulating evidence that mindfulness-based treatments are beneficial for a variety of psychological concerns in the general and clinical population, investigating the potential of mindfulness-based treatments for parents of children with DD is indicated. An examination of the current evidence base of mindfulness treatments for parents of children with DD is a necessary preliminary step, in order to establish the strength of the evidence-base as well as identify any gaps in the literature and directions for future research (Craig et al., 2009). These research goals are addressed in the following chapter, which outlines a systematic review of RCTs for parents of children with DD. The findings of this review (Study 1) not only highlight the efficacy of existing mindfulness treatments but also the potential for novel treatment adaptations that address the specific needs and challenges experienced by this parent group.

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## Chapter 2

## Mindfulness Therapies for Improving Mental Health in Parents of Children with a Developmental Disability: a Systematic Review

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REVIEW ARTICLE

# Mindfulness Therapies for Improving Mental Health in Parents of Children with a Developmental Disability: a Systematic Review

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## Abstract

Mindfulness offers promise as a therapy approach for parents of children with developmental disabilities (DD), however its effectiveness in managing mental health symptoms remains unclear. This review quantitatively examines the comparative effectiveness of mindfulness-based and informed interventions, drawing on the evidence base from randomised controlled trials (RCTs). Eight RCTs were identified from the Embase, PsycINFO, PubMed and Scopus databases. Risk of bias was assessed using the Cochrane Collaboration tool and Hedges' *g* effect sizes, with associated 95% confidence intervals and *p* values calculated. Parents who completed Mindful Parenting or Mindfulness-Based Stress Reduction programs reported immediate and large to very large reductions in psychological distress ($g_w$ range: .39–1.94), with some improvements maintained up to 6 months post-treatment. A single study reported short-term benefits with Acceptance and Commitment Therapy. Evidence for the mental health benefits of mindfulness for parents of children with DD is still at an early stage. Controlled trials are needed to determine the differential effects of specific mindfulness techniques and how to best adapt this approach to best meet the unique needs of a vulnerable caregiver population.

**Keywords** Autism · Developmental disorders · Mindfulness · Parents · Meta-analysis

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# Chapter 3

## Research Directions: The Integration of Cognitive Behavioural Therapy with Mindfulness Treatments

The previous chapter outlined a systematic review that identified eight RCTs evaluating the effectiveness of mindfulness treatments for parents of children with DD, all published in the last 10 years (Study 1). Effect sizes for studies were calculated to measure pre- and post-treatment change, as well as changes between post treatment and follow up. The review adds to the current literature due to its focus on high-quality research in this area, in addition to its comprehensive consideration of different mindfulness treatments, including those where the primary strategy involved meditation practice (e.g., MBSR; Kabat-Zinn, 2013), but also mindfulness-integrated treatments which did not have a formal meditation component (e.g., ACT; Hayes et al., 2006). The review highlighted the heterogeneity of mindfulness research, which is characterised by a range of interventions involving varying approaches to developing and integrating mindfulness skills. In addition to different treatment types, adaptations to treatment were also incorporated for parents to improve accessibility, namely onsite childcare onsite (Dykens et al., 2014), and delivery of a brief (6 sessions, with ten minutes of daily meditation) treatment (Lo et al., 2017).

Mixed results were reported by the various mindfulness interventions examined in the review. In particular, studies that used MBSR (Chan & Neece, 2018; Dykens et al., 2014) reported large reductions in parenting stress, yet mixed results for depressive symptoms. Notably the MBSR studies included follow-up data that demonstrated significant, sustained treatment effects once treatment had ceased. ACT and mindful parenting, the latter based on a MBSR protocol, did, however produce large reductions in parenting stress, depression

and/or anxiety symptoms (Behbahani et al., 2018; Lo et al., 2017; Whittingham et al. , 2015), whilst Family Mindfulness resulted in significant reductions on the Parenting Stress Index (Lo et al., 2020). The benefits of combining yoga with meditation (MiYoga) were less clear, with a single study reporting non significant effects on the Depression Anxiety and Stress Scales (Mak et al., 2018).

The aforementioned findings are in keeping with the current evidence base for mindfulness treatments for the general population (see Khoury et al., 2015, for a review). The variability in outcomes may reflect differences in treatment components, an aspect which could not be investigated with subgroup analyses due to the small number of available RCTs, but one which certainly requires further research.

An additional research direction is to evaluate adapted treatments for this population. This includes the potential to integrate mindfulness strategies with change-based psychological treatments (i.e., cognitive therapy), as seen in "third wave" psychological treatments (Hayes et al., 2006). Importantly, integrating elements of acceptance and change in a single treatment offers a flexible rather than dogmatic approach, by providing the therapist an option to respond in an individual manner to client concerns (Neacsiu et al., 2012; Hayes et al., 2006). Indeed, integrated approaches, such as MBCT, ACT and DBT, have demonstrated efficacy for a range of psychiatric disorders – including comparative effectiveness with standard cognitive therapy (Chiesa & Serretti, 2011; Lau & McMain, 2005; Neacsiu et al., 2012; Öst, 2014).

**Mindfulness-integrated Cognitive Behavioural Therapy (MiCBT)**

An additional, yet less commonly researched treatment that integrates elements of CBT with mindfulness practice is Mindfulness-integrated Cognitive Behavioural Therapy (MiCBT; Cayoun, 2011). While a study protocol has been published (Frances et al., 2020), there remains limited empirical research to evaluate the efficacy of MiCBT.

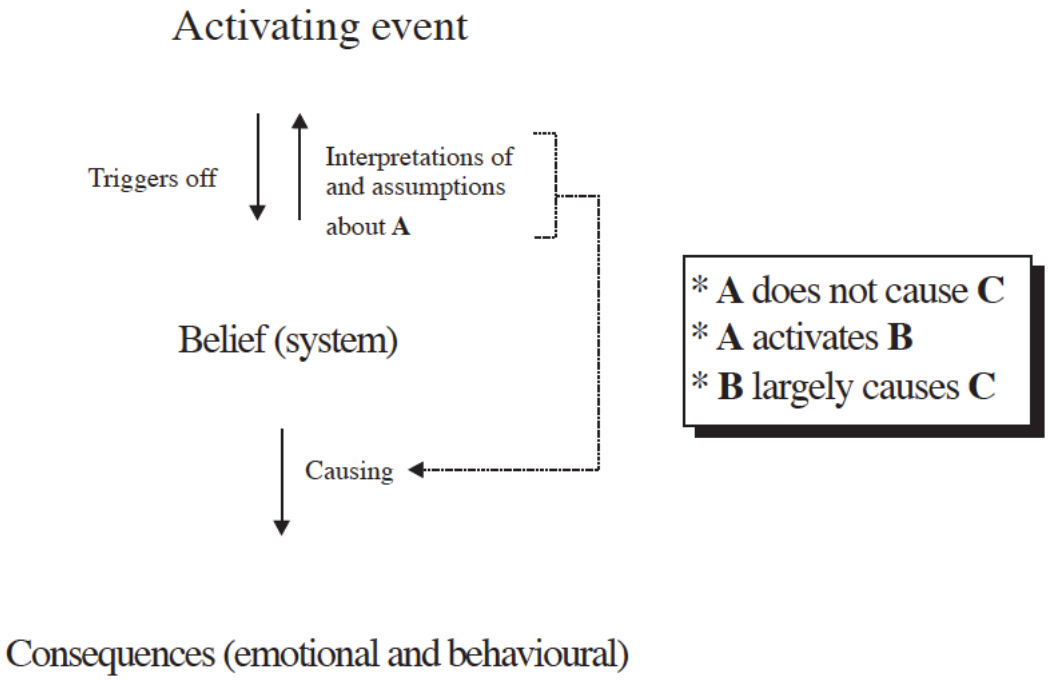
CBT principles present in MiCBT include structured exposure exercises (via mindfulness) to gradually desensitise the client to distressing thoughts and sensations that they are avoiding. The ultimate aim is to develop "equanimity", or calmness in response to thoughts and sensations. The individual can then generalise this 'equanimous' response to any distressing stimuli experienced in daily life (Baer, 2003). Another traditional CBT element used in MiCBT is Socratic questioning, or the use of open questions, to facilitate awareness of bodily sensations as well as understanding and changing reactive behaviour (Foa et al., 2003; Neenan, 2008).

In addition to utilisation of exposure exercises and socratic questioning, MiCBT expands the traditional ABC model used in CBT. The ABC model, seen in Figure 1 (Lam & Gale, 2000), is a theoretical model which depicts the role of dysfunctional thinking in psychological distress. The ABC model suggests that an A (Activating Event or antecedent) leads to a process of cognitive appraisal B (Belief) that results in either an emotional or behavioural C (Consequence). A key assumption of the ABC model is that one's emotional and behavioural consequences (C) are directly related to the interpretation (B) of an event (A), rather than resulting from the event itself. Accordingly, one's cognitive appraisal of an activating event (B) can be changed or reframed so that dysfunctional or unhelpful thoughts become less distressing (Lam & Gale, 2000). The ABC model is a foundational CBT framework and skill which is taught across many CBT treatment protocols (Lupu & Lupu, 2018; Paudel, 2020; Syrafryadin et al., 2017). In MiCBT, the ABC model is expanded so that in response to an event or situation ('A' –activating event), thoughts ('B'- beliefs) and bodily sensations (also referred to in mindfulness research as interoception), emerge simultaneously, or co-emerge (Figure 2). This co-emergence of thoughts and bodily sensation is thought to influence both the reaction to the situation, and how automatic the reaction is ('C' - consequence). The suggestion is that the automaticity of reaction helps to maintain a

cycle of distressing thoughts and reactive behaviour (Cayoun, 2011). According to the co-emergence model, developing equanimity in response to thoughts and sensations, and desensitisation towards distressing thoughts and sensations, offers benefits by allowing a chosen response to evaluation of a situation or thought and its co-emergent body sensations, rather than the automatic and reactive response which is considered to maintain distress. Indeed, research has found that for participants who have been shown neutral and unpleasant images, interoceptive awareness has been positively correlated with both trait anxiety and mean arousal scores for unpleasant images (Pollatos et al., 2007). Dysfunctional interoception has been identified in a range of mental health disorders, including eating disorders and PTSD, anxiety and depression, where it has been proposed that "noisy" interoceptive signals combined with unhelpful beliefs about these signals (i.e., lack of equanimity) can lead to and maintain distress and dysfunction (Khalsa et al., 2018; Paulus & Stein, 2009).

Figure 1.

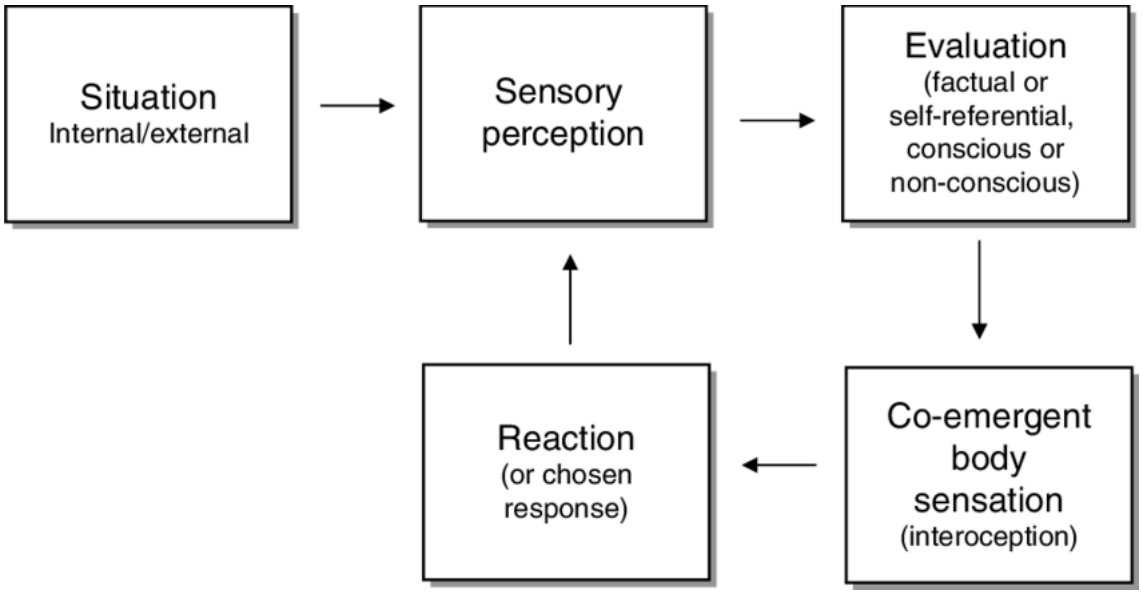
*The ABC Model in CBT*




Note. The ABC model in CBT shows an activating event (A) leads to interpretation and Beliefs (B) about the event, which leads to C, emotional and behavioural consequences. From Lam, D., & Gale, J. (2000). Cognitive behaviour therapy: Teaching a client the ABC model - the first step towards the process of change. *Journal of Advanced Nursing*, *31*(2), 444-451. https://doi.org/10.1046/j.1365-2648.2000.01280.x

Figure 2.

*The Co-emergence Model of Reinforcement*




Note. From Cayoun, B. A. (2011). *Mindfulness-integrated CBT: Principles and practice*. John Wiley & Sons.

As discussed in the Introduction chapter, integration of foundational, change-based elements of CBT with acceptance-based mindfulness elements may offer a flexible treatment approach for families of children with DD. Clinicians can focus treatment more on acceptance or change depending on the client's individual need. Development of equanimity through meditation practice, as per MiCBT, may also be beneficial for these parents, given this group may be at risk for dysfunctional responses to interoception (Khalsa et al., 2018). While MiCBT has gained clinician recognition following publication of an eight week protocol (Cayoun, 2011) empirical evidence is in early stages, including unpublished works (see Frances et al., 2020). To address this research gap, the following chapter examines the efficacy and acceptability of MiCBT for a subset of parents of children with ID, a subset of DD, in a case series study (Study 2).

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# Chapter 4

## Mindfulness-integrated CBT (MiCBT) for Reducing Distress in Parents of Children with Intellectual Disability (ID): a Case Series

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ORIGINAL ARTICLE

# Mindfulness-Integrated CBT (MiCBT) for Reducing Distress in Parents of Children with Intellectual Disability (ID): a Case Series

**Raphaella Osborn**[1] · **Mary Girgis**[1] · **Stephanie Morse**[1] · **Jovana Sladakovic**[1] · **Ian Kneebone**[1] · **Alice Shires**[1] · **Seeta Durvasula**[2] · **Lynette Roberts**[1]

Published online: 12 May 2018


**Abstract** Caring for a child with an intellectual disability (ID) is associated with significant psychological distress. Interventions include cognitive behavioural therapy (CBT) and Mindfulness-based Stress Reduction (MBSR). Mindfulness-integrated CBT (MiCBT) may offer a balance between CBT's change focus and MBSR's acceptance focus for these parents. Five participants were recruited and provided one to one MiCBT tailored to parental carers of children with ID. Four participants completed the Depression Anxiety Stress Scales 21 (DASS-21) pre-treatment and post-treatment. Reliable change analysis was used to identify clinically reliable change. One participant dropped out after four sessions, four completed eight of the available eight sessions. Two participants reported reductions in depressive and stress symptoms, and one of these, additionally reported a reduction in anxiety symptoms. All four participants who completed treatment rated the treatment as acceptable. MiCBT shows promise as an intervention to assist parental carers of children with ID.

**Keywords** Intellectual disability · Parent · Stress · Wellbeing · Mindfulness

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## Chapter 5

## Potential Barriers to Accessing Treatment, and Adapting Mindfulness Treatments for Parents of Children with Developmental Disabilities

The previous, published chapter involved a case series trialling MiCBT (Study 2) for parents of children with ID, and is the first trial reporting primary data for this treatment in this population. The findings, although preliminary, highlight the potential for MiCBT to offer a combination of acceptance and change based treatment in this context, particularly given the enduring nature of DD (Neacsiu et al., 2012). Significant reductions in depressive and stress symptoms were noted for participants who completed the intervention. Importantly, all participants rated MiCBT as acceptable, providing a basis for a future large-scale controlled trial.

The MiCBT intervention in Study 2 required parents to commit to 90 minute face-to-face treatment sessions, weekly, over 8 weeks, with masters candidate clinicians who had undertaken training and supervision in MiCBT (Cayoun, 2011; Crane et al., 2017). While preliminary findings were promising, with significant reductions in depressive and stress symptoms, as well as positive ratings of treatment acceptability, clinicians delivering the intervention noted the time commitment was extremely challenging for the participants. In addition, further anecdotal evidence indicated that participants had difficulty completing twice daily meditation practice for 30 minutes. Notably, the treatment requirements in this study were comparable to standard MBSR protocols (Baer, 2003). These observations suggest there may be a need to adapt existing evidence-based treatment protocols for this typically time-poor and stressed group (Crnic et al., 2017).

No recent research has specifically asked parents of children with DD what barriers they may experience in accessing mental health treatment for themselves. Before proceeding with future trials, our experience with recruitment and treatment adherence from Study 2

suggested it would be prudent to do this. Surveying parents also represents an important step in the early stages of research design by targeting population participants to understand how an intervention would fit with daily activities (Bowen et al., 2009). If parents identify barriers to accessing psychological treatment it may provide information on how to best design a feasibility trial of an adapted treatment for this group. Previous research has identified common stressors that parents of children with DD experience: financial (due to one parent often needing to care for their child full time); child behaviour problems (which can range from complex meal time needs to specialised appointments); availability of service providers; work scheduling; and distance to travel (Baker et al., 2005; Plant & Sanders, 2007). Each of these stressors could potentially also act as a barrier to accessing face-to-face treatment, by creating a paucity of time and emotional as well as environmental resources for accessing care. If parents experience difficulty in accessing treatment for themselves, a potential method for improving accessibility might be through e-treatment - or treatments that use information and communication technologies (e.g., the internet) for service delivery. E-treatments can help enhance treatment access for rural communities, in particular, at a substantially lower cost in comparison to in-person treatment (Catwell & Sheikh, 2009; Moffat & Eley, 2010). In addition, because use of information and communication technologies is rapidly increasing, in both older and younger generations, e-treatments are considered a beneficial means for improving mental health treatment accessibility (Lal, 2019). Importantly, small to moderate effects have been observed in available e-treatment studies among the general adult and student populations – including improvements in anxiety, depression, stress and wellbeing, as well as improvements in mindfulness (Spijkerman et al., 2016).

In the following chapter (Study 3), a survey was developed, with questions focused on potentially relevant barriers previously identified in research and clinical practice including

financial difficulties, child behaviour problems, availability of service providers; work scheduling, and distance to travel. In addition, on account of the potential benefits, the survey assessed interest in an e-treatment, and which aspects of an e-treatment (e.g., accessibility, cost) would be important. It was considered that if parents nominate barriers to treatment and express interest in an e-treatment, this would provide information about the unique needs of this population, as well as informing the development of treatments. The subsequent published chapter details the development and results of this survey (Study 3).

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# Chapter 6

## Barriers to Accessing Mental Health Treatment for Parents of Children with Intellectual Disabilities: a Preliminary Study

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# Barriers to accessing mental health treatment for parents of children with intellectual disabilities: a preliminary study

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RESEARCH PAPER



# Barriers to accessing mental health treatment for parents of children with intellectual disabilities: a preliminary study

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**ABSTRACT**

**Purpose:** Parents of children with intellectual disability often experience heightened levels of psychological distress compared to parents of typically developing children due to increased parenting demands. Given these demands, parents may also have difficulty accessing mental health treatment for themselves. This research investigated whether parents of children with intellectual disability experience barriers in accessing mental health treatment for themselves related to the increased parenting demands of having a child with an intellectual disability.

**Materials and methods:** 80 parents of children with intellectual disability were surveyed about barriers to accessing mental health treatment for themselves and interest in an e-treatment.

**Results:** Parents who experienced mental health difficulties were more likely to experience barriers in accessing treatment. For parents who had experienced mental health difficulties, cost, arranging childcare, and availability of providers were significant barriers to accessing treatment. Older participants were less likely to report cost as a barrier. Participants with higher incomes were less likely to report work scheduling as a barrier. Participants reported interest in an e-treatment, with younger participants more likely to express interest.

**Conclusions:** These preliminary findings suggest that parents of children with intellectual disability experience barriers to accessing treatment. Research directions include developing e-treatments for these carers.

**➤ IMPLICATIONS FOR REHABILITATION**

- Having a child with an intellectual disability is associated with increased parenting demands, and significant stress for parents
- The results of this survey suggest that for parents who are experiencing mental health difficulties, cost, arranging childcare and availability of providers may act as barriers to accessing treatment for their own mental health concerns
- Rehabilitation professionals can assist parents in addressing these barriers and encourage parents to seek treatment for themselves by offering flexibility in appointment times, reduced cost services and options for childcare
- Accessible and affordable treatment options, such as e-treatments may further assist these parents in accessing care for themselves

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# Chapter 7

## Adapting Treatment to Improve Accessibility for Parents of Children with DD

The survey in Chapter 6 (Study 3) found that parents of children with DD were likely to have experienced mental health difficulties in the year prior to being surveyed. A large proportion (68%) also reported barriers to accessing mental health treatment for themselves, including treatment cost, difficulty arranging childcare, and limited availability of providers. The survey results align with clinical experience, in that parents anecdotally report difficulty accessing and completing an intensive mindfulness protocol. Treatment adaptations adopted by other mindfulness studies with this parent group (for example, provision of onsite childcare, Dykens et al., 2014), support that researchers have encountered similar difficulty in engaging parents of children with DD in face-to-face treatment. Increasing treatment options and accessibility for these families is therefore critical (Plant & Sanders, 2007).

E-treatment, in terms of efficacy, accessibility and affordability (Catwell & Sheikh, 2009; Grandja et al., 2018; Moffat & Eley, 2009) could help to improve mental health care and cost for parents of children with DD. As identified in the systematic review (Study 1, Chapter 2), evidence-based mindfulness treatments appear to be effective in reducing distress for parents of children with DD. Creating an online mindfulness treatment may therefore offer a high quality treatment which is also low cost. As outlined in Studies 2 and 3 (Chapters 4 and 6), the time commitment involved in any mental health treatment is another important consideration. The efficacy of brief mindfulness treatments has been demonstrated, including a 4-week MBSR program which led to improvements in wellbeing among nurses (Mackenzie et al., 2006), and an 8 week, 13-minute a day mindfulness program to manage mood and anxiety symptoms among a nonclinical population (Basso et al., 2019). In parents of children with DD, a brief treatment, with 10 minutes of daily meditation over 6 weeks, resulted in significant reductions in parenting stress and depressive symptoms (Lo et al., 2017). A

randomised controlled trial of a brief online mindfulness treatment, involving 10 minutes of meditation a day for two weeks, was likewise associated with significant reductions in stress, anxiety and depression symptoms, in addition to improvements in mindfulness, compared to wait list controls, in a student sample (Cavanagh et al., 2013). Importantly, Cavanagh et al.'s (2013) research combined the two suggestions detailed above, of providing a brief mindfulness treatment, and delivering this treatment online. Their findings are not only promising, but offer an encouraging option for addressing treatment accessibility concerns for parents of children with DD.

To successfully adapt the online treatment trialled by Cavanagh et al., (2013) for parents of children with DD, a feasibility trial is initially required. Feasibility studies represent an early stage of research, helping to assess whether an intervention is relevant for a population (Bowen et al., 2009). Feasibility studies often test efficacy of a treatment in a limited way, for example with a smaller sample, and may offer future research directions for a larger scale trial. Feasibility trials also help to determine population interest in an intervention, acceptability of an intervention, and what adaptations may be required (Bowen et al., 2009). Study 3 (Chapter 6) surveyed parents' interest in an e-treatment – helping to confirm broad interest in this approach. The next step was to conduct a small trial of Cavanagh et al.'s (2013) treatment in a population of parents of children with DD. The subsequent chapter details a feasibility trial of a brief online mindfulness treatment for parents of children with DD (Study 4), to determine whether a larger scale controlled trial is warranted, through assessing efficacy and acceptability of treatment. If a brief online treatment appears feasible, this could serve to broaden treatment options for parents and potentially improve accessibility.

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Moffatt, J. J., & Eley, D. S. (2010). The reported benefits of Telehealth for rural Australians. *Australian Health Review*, *34*(3), 276. https://doi.org/10.1071/ah09794

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# Chapter 8

## Feasibility of a Brief Online Mindfulness Treatment for Parents of Children with Developmental Disabilities

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Feasibility of a Brief Online Mindfulness Treatment for Parents of Children with Developmental Disabilities

**Abstract**

Parents of children with developmental disabilities (DD) often experience increased levels of distress, alongside difficulty accessing face-to-face mental health treatment due to parenting demands. A brief, online mindfulness treatment was designed to improve accessibility for these families. Ten mothers of children with DD completed a 2-week treatment in addition to standardised measures of mood and mindfulness and feasibility assessment. Six participants provided 3-month follow-up data. Reductions in distress alongside improvements in mindfulness were reported, with gains maintained over time. Difficulties were identified in recruitment, however satisfaction ratings and user-end data suggested good engagement. Online mindfulness training may reduce distress for parents of children with DD. These promising findings require confirmation with an adequately powered randomised controlled trial.

*Key words:* Mindfulness, Parents, Developmental Disability, Feasibility, Online

## Introduction

A large body of research has documented high levels of psychological distress among parents of children with a developmental disability (DD) (Baker et al., 2005; Hayes & Watson, 2013). This distress has been associated with household financial stress, increased complexity of caregiving tasks, and child behaviour problems (e.g., Ali et al., 2012; Baker et al., 2005; Hastings, 2002; Dumas et al., 1991). Over time, psychological distress can negatively influence parenting practices and, in turn, the family system (Neece et al., 2012). Given the increased longevity of individuals with DD and movements away from institutionalised care, it is important for parents to be given the opportunity to develop skills to manage feelings of distress and improve psychological wellbeing (Cuskelly, 2006; Woodman et al., 2015).

Mindfulness treatments provide an approach to help parents cope with their own distress. Mindfulness focuses on the development of attentional capacity towards the present moment as well as a non-judgemental awareness of thoughts, emotions and bodily sensations (Black, 2011). These abilities are often developed through formal or informal meditation practice (Baer, 2003; Kabat Zinn, 2003). The suggestion is that mindfulness can promote wellbeing by enhancing executive attention and concentration which, in turn, may help self-regulation of emotionally reactive behaviours (Marchand, 2014; Chiesa & Serretti, 2010).

Mindfulness-based treatments are being increasingly used to treat parental depression, anxiety, stress for families of children with high needs due to a DD (Osborn et al., 2020). Recent trials suggest that mindfulness treatments have reciprocal benefits to parental wellbeing and child behaviour concerns – at least over the short to medium term (Bebhahani et al., 2018; Cachia et al., 2016; Dykens et al., 2014; Neece, 2013; Osborn et al., 2020; Ryan & Ahmed 2018). Further research is, however, needed to confirm these preliminary findings

There are, however, pertinent caveats to the effectiveness of mindfulness treatments. In particular, parents may find the substantial time commitment required by standard treatment protocols, such as Mindfulness-based Stress Reduction (MBSR), challenging to complete. MBSR typically involves daily mindfulness practice in addition to a full-day retreat, or approximately 1.5-2 hours a week of in-person therapy over an 8-week period (e.g., Chan & Neece, 2018; Parswani et al., 2013; Shaprio et al., 2005). However, due to time constraints, difficulties in arranging childcare, and cost of face to face treatment, many parents suspend or withdraw from psychological treatment (Osborn et al., 2019).

Given the reported benefits of mindfulness practice, coupled with difficulties in treatment engagement, adaptations to standard MBSR protocols have been considered. In particular, a brief low-intensity approach may be easier for parents to commit to. Mindfulness treatments with reduced daily meditation practice (i.e. 13 minutes daily) have demonstrated promising results in the general population (Basso et al., 2019). There is also evidence to suggest that treatments with larger doses of mindfulness do not necessarily lead to proportionate decreases in mood symptoms, with shorter treatments potentially as beneficial as those with a longer duration (Strohmaier, 2020). Treatment accessibility might also be improved through online delivery, available via smartphone or desktop computer (see Spijkerman et al., 2016; Jayawardene et al., 2017). Online treatments have the added benefit of cost-effectiveness, for both the service provider and recipient (Osborn et al., 2019).

Preliminary findings suggest that brief internet-based mindfulness programs can improve mental health. Cavanagh et al. (2013) trialled such a program with a student population and reported significant reductions in perceived stress, anxiety and depressive symptoms, alongside an increase in participants' ability to incorporate mindful practice in their day-to-day life after a 2-week period. The application of online mindfulness training for parents of children with a range of special needs (e.g., Attention Deficit Hyperactivity Disorder, ASD, Anxiety Disorder) has also been piloted, with promising reductions in stress and improvements in mindfulness (Shaffer et al., 2020). It follows that these findings may extend to parents of children with DD.

The current study extends the work of Cavanagh et al. (2013) to parents of children with DD. The aim was to determine whether a self-guided online mindfulness treatment was feasible and potentially beneficial to general wellbeing in a group prone to experiencing high levels of stress. We anticipated that parents would engage with an online treatment and, similar to Cavanagh's (2013) findings, would experience improvements in different facets of mindfulness alongside reductions in stress and distress (i.e., depression, anxiety).

## Method

### Study design and pre-registration

A pre-post design was used to pilot a brief meditation program designed to reduce distress in parents of children with a DD. The trial was prospectively registered on the Australian New Zealand Clinical Trials Registry (REGISTRATION NUMBER ACTRN12618001654246p). The initial design was a randomised control trial (RCT) however, due to low recruitment numbers and resource limitations, the trial proceeded as a single-group feasibility study.

### Eligibility criteria

Inclusion criteria required that participants be a parent (aged 18+ years) of a child (of any age) with a DD. Participants also had to self-report symptoms of current stress (>7 on Depression Anxiety and Stress Scales – Stress subscale; Lovibond & Lovibond, 1995). Those who reported clinically significant levels of depressive symptoms (>9 on the Patient Health Questionnaire 9; Kroenke & Spitzer, 2002), or suicidality (scores >2 on question 10 of the PHQ 9) were excluded and provided the contact details of relevant counselling and support services in the community.

**Materials**

**Demographic information**

Details relating to age, gender, income, relationships status, and the diagnosis of the child with the DD were collected.

**Depression Anxiety and Stress Scales 21 (DASS-21)**

The 21-item Depression Anxiety and Stress Scales was used to evaluate general distress and to discriminate between depression, anxiety and stress symptoms (DASS-21; Lovibond & Lovibond, 1995). Higher scores on the DASS-21 reflect greater distress. The reliability of the subscales has previously been determined (Cronbach's alpha = .73- .81; Lovibond and Lovibond, 1995).

**Patient Health Questionnaire 9 (PHQ-9)**

The 9-item PHQ was used as a depression severity measure, with higher scores indicate greater symptom severity. This scale is considered to have sound reliability and validity (Kroenke et al., 2001) and good internal consistency (Cronbach's alpha = .83; Cameron et al., 2008).

**Parenting Stress Index 4 Short Form (PSI-4 SF)**

The 36-item PSI-4 SF was used to determine degree of Parenting Stress, including perceptions of Parental Distress (i.e., parental competence, partner support, life impact of having a child), Parent-Child Dysfunctional Interaction (i.e., parent experience of the parent child relationship), and Difficult Child Behaviour. Higher scores on the PSI-4 SF are indicative of greater levels of stress. Cronbach's alpha for the total PSI-4 SF has been found to be high (alpha = .95; Abidin & Abidin, 1990).

**Five Facet Mindfulness Questionnaire (FFMQ)**

The 39-item FFMQ was used as a measure of mindfulness. In addition to providing a total score, there are five "sub-facets": Observing (noticing internal and external experiences), Describing (labelling of internal experiences), Acting with Awareness (mindful attention of activity moment to moment), Non-judging of Inner

Experience (a non-evaluative stance towards thoughts and feelings) and Non-reactivity to inner experience (letting thoughts and feelings come and go). Higher scores indicate greater degrees of mindfulness. Subscale alpha coefficients range from .75-.91, indicating good internal consistency (Baer et al., 2006; Baer et al, 2008).

**Feasibility**

Feasibility was evaluated by examining recruitment, drop-out rates, treatment adherence and user acceptability (Bowen et al., 2009; Tickle-Degnen, 2013). Treatment adherence specifically considered the number of times each participant accessed a meditation and length of time that each meditation was listened to. User satisfaction was evaluated with Net Promoter Scores (NPS). This involved a single question rated on a 10-point Likert scale, "*How likely is it that you would recommend our mindfulness program to a friend or colleague"*. Scores ranging from 0-6 are considered "detractors", 7-8 are considered "passives" and 9-10 are considered "promoters". A total score, ranging from -100 to 100, was subsequently calculated by subtracting the percentage of detractors from the percentage of promoters (Reichheld, 2004).

**Mindfulness Treatment**

*Learning mindfulness* is a 2-week online treatment adapted from Cavanagh et al. (2013). The purposely designed web-page included an opening page with general information on mindfulness and its benefits, ways to practice mindfulness (e.g., mindful walking), emotions and sensations that may occur when practising mindfulness or meditation, and advice regarding these experiences (e.g., noticing one's mind wandering while meditating). Alongside the opening page were three separate sections or 'tabs' - one devoted to each week of the treatment, in addition to a frequently asked questions (FAQ) section (e.g., questions related to experiencing restlessness while meditating and noticing judgemental thoughts about ones practice). Each week of the treatment included brief instructions on how to incorporate mindfulness principles into daily life: Week 1 focused on how to bring mindful awareness to routine activities (e.g., brushing teeth, having a shower), and Week 2 focused on how to bring mindfulness principles to walking. The website also provided two versions of a daily 10-minute meditation practice, with a male or a female voice (Cavanagh et al., 2013). Participants accessed the meditation by entering their unique study identification number.

In addition to this online written and audio material, participants received standardised email contact from the first author every three days (i.e., 4 emails in total over the two-week period). The emails provided mindfulness tips, including how to normalise busy thoughts when meditating and how to generalise mindfulness principles to stressful life events.

**Procedure**

Following ethics approval from the University of Technology Sydney Human Research Ethics Committee (REFERENCE NUMBER ETH-18-2523), 344 community-based disability services and schools around Australia were contacted, with 23 indicating a willingness to assist with recruitment. Study flyers were posted via e-newsletters, email list servs and social media platforms, with interested participants directed to contact the research team for further information. Participants who confirmed interest were then sent an online consent form and screening questions (i.e., DASS-21 stress subscale, PHQ-9) via REDCAP, a secure web-based software platform designed to support data capture for research studies (Harris et al, 2009; Harris et al., 2019). Eligible participants (i.e., DASS-21 stress score > 7, PHQ-9 score < 9) were subsequently emailed the baseline survey along with a personalised number to access the *Learning Mindfulness* website. The same survey was sent two-weeks after the first login and three and twelve months thereafter.

**Statistical Analyses**

Both short-term (i.e., pre- to immediately post-treatment) and longer-term (i.e., post- 3 month follow-up) change scores were examined for each repeated measure (DASS-21, PHQ-9, PSI-4 SF, FFMQ) using paired samples *t*-tests. A low response rate ($n = 3$) meant results at 12 month were not considered. Significance ($p$) value was set at ≤.05, two tailed. No adjustment for multiple comparisons was made given the intention of this early stage exploratory trial was to maximise identification of the potential benefits of the treatment (Li et al., 2017). The magnitude of change was additionally calculated using Hedges' $g$ effect size, which provides an unbiased population estimate for small $N$ samples (Hedges, 1982). Effect sizes were standardised so that positive values reflected improvement with the online treatment (i.e., reduced depression and stress, increased coping and mindfulness). Cohen's (1992) criteria were applied to interpret $g$, where .2, .5 and ≥ .8 represent small, medium and large to very large effects, respectively.

## Results

**Participants**

Of 58 parents who responded to online advertising, 12 completed screening measures and gave consent to participate. Two participants subsequently dropped out of treatment, and did not respond to follow up emails, leaving a final sample of 10. All participants were mothers and primary carers of children with a DD (see Table

1). Most (80%) were also married or in a de facto relationship and employed on a full or part-time basis (70%). Autism Spectrum Disorder (ASD) comprised the primary diagnosis among children (70%).

**Preliminary outcomes associated with online mindfulness**

As seen in Table 2, pre to post positive changes were reported across all psychological measures. This included a reduction in psychological distress and related symptoms of depression, anxiety and stress (DASS-21, PHQ-9). Perceptions of parental stress also improved at the 2-week assessment, particularly the amount of stress caused by the parent-child relationship (PSI-4 SF Difficult Child, Parent Child Dysfunctional Interaction subscales). These findings were associated with large to very large treatment effects. In addition, parents reported immediate, positive and large to very large impacts on most facets of the FFMQ (Describing mindfulness, Non-judgemental inner experience, Non-reactivity), aside for the Observing and Acting with Awareness subscales ($p > .05$).

Follow-up data at 3 months was provided by six participants. Changes in mood (DASS-21, PHQ), parenting stress and mindfulness from post-treatment to 3-month follow-up were not statistically significant, although associated with very large effects (Table 3). These results are graphically depicted in Figures 1 to 4. These support decreased distress symptoms and increased mindfulness during the 2-week treatment, with benefits maintained at 3-month follow up. The response rate at 12 months ($n = 3$) was deemed too small a sample to analyse.

**Feasibility of online mindfulness**

Recruitment efforts yielded 44 expressions of interest from potential participants, 12 participants completed baseline measures and were eligible for treatment. The online treatment was associated with a modest 17% drop-out rate. Reasons for withdrawal could not be determined as both participants were unable to be contacted. Six participants responded to 3-month follow up questionnaires, however, only three responded to 12-month follow up questionnaires.

Data recordings indicated that the online meditations were accessed by all participants who listened, on average, to 34.5 (SD=36.47) minutes of meditation, and accessed each meditation at least four times over the 2-week period (SD=3.61).

The total NPS of 30 was a positive integer, indicating that participants were, generally, willing to use the online treatment. Net promoter responses did, however, range from passive scorers (score 7 - 8; $n = 6$) - or those with neutral feelings about the website, to promoters (score 9-10, $n = 3$) - or those likely to recommend the website to others.

## Discussion

An accumulating body of evidence suggests that mindfulness treatments may be beneficial for reducing distress in parents of children with DD, a group that is at risk for experiencing chronic mood symptoms (Osborn et al., 2019). However, many mindfulness treatments, including those that have already been trialled in this population are relatively time intensive, and parents may experience barriers to accessing lengthy face to face treatments due to factors such as arranging childcare (Osborn et al., 2019). To improve accessibility of treatment, we designed a treatment that was both brief and entirely online, with no face-to-face contact required.

While recruitment and randomisation difficulties were experienced, promisingly, our results suggest that a very brief online treatment has potential to reduce general distress, anxiety, depression and stress, for parents of children with DD. Improvements in parental perceptions of stressors as well as mindfulness skills (e.g., nonjudging, nonreactivity) were also noted. Notably, there was a trend towards maintaining these gains at 3-month follow-up, suggesting treatment feasibility. Further, participants deemed treatment as acceptable, as noted by our NPS.

These findings are in keeping with Cavanagh et al.'s (2013) trial with a student population. The large reductions in mood symptoms noted in the present study are also comparable to results of more time intensive face-to-face mindfulness treatments for parents of children with DD (e.g., Neece, 2013 [*d* range: .7 to .9]; Dykens et al, 2014 [*d* range: .49 to .98]). If a brief treatment such as this can reduce or relieve mood symptoms, it may offer an alternative to parents who are unable to commit to a lengthy treatment.

The significant reductions noted in perceptions of parenting stressors, particularly the quality of the parent-child interaction and parents feeling less perturbed their child's behaviours, are also promising. Given that a bidirectional relationship has been noted between parent stress and child behaviour problems (Plant & Sanders, 2007; Hastings, 2002), a mindfulness treatment that reduces parenting stress and leads to positive parent perceptions and behaviours could potentially benefit the health of the broader family system (Neece et al., 2012). Mindfulness treatments could also be used as an adjunctive to child-focused behavioural treatments in the hopes of improving treatment potency, by helping parents manage their distress and, in turn, their ability to implement the treatment (Plant & Sanders, 2007; Whittingham et al., 2014).

The non-significant result associated with parenting distress may, in part, reflect the content of the parenting distress scale. This particular PSI-4 SF subscale captures impact of parenting tasks (e.g., an item about amount of time given towards parenting tasks) yet it is possible that parenting tasks may continue to be described objectively as challenging, even if parents are more accepting of challenges. However, this non-

significant result, in addition to the mixed findings on the FFMQ subscales may also reflect the brevity of the online treatment we examined. Whilst significant improvements in non-judging, non-reactivity and describing were noted, so too were non-significant changes on the observing and acting with awareness scales, it is possible that longer term practice of mindfulness principles would relate to further widespread improvements in these areas (Lykins & Baer, 2009).

Importantly, the positive NPS, with no detractors, suggests that parents found ten minutes a day of meditation manageable. However, there were also a substantial number of parents who reported indifference to the online treatment (the 'passives'). Future research might explore how to connect with this subgroup and, potentially, turn a 'passive' into a promoter, by offering them opportunity to provide feedback about the online program but also opportunity to connect in real-time with a therapist if the need requires.

Recruitment of the final sample of ten participants proved challenging, suggesting that despite adapting treatment for this population, parents of children with DD may still find difficulties in accessing treatments. Use of relevant services to promote research may be key. In addition to difficulties with recruitment, 40% of participants were lost to 3-month follow up, and 70% of participants were lost to 12-month follow up. The results from this feasibility trial offer promising early evidence that an adapted mindfulness may help parents of children with DD over the medium term. Feasibility factors such as similar drop-out rates to other mindfulness research in families with DD (Osborn et al., 2020), large effect sizes, evidence that meditations were accessed and listened to, and positive NPS suggest that a brief online mindfulness treatment is a worthwhile target for future research.

Adapted treatments may be particularly valuable in increasing treatment availability in this population. Previous face to face adaptations aimed at improving accessibility for these families have included provisions of childcare (Dykens et al., 2014; Neece, 2013), however providing childcare may not be a realistic option for many clinicians. Difficulty recruiting participants suggests that even a brief treatment may be challenging for parents of children with DD, however, Cavanagh et al., (2013) note that a brief online treatment may provide some relief to individuals who otherwise may not present to therapy at all. Given the chronic stressors that families of children with DD experience, a short online treatment may provide families with additional tools for reducing psychological distress at a low cost, and may help families who would otherwise not present for treatment. Future research directions could include a larger scale randomised control trial, or, given the relationship between parent stress and child behaviour concerns, as an add on to a child focused program.

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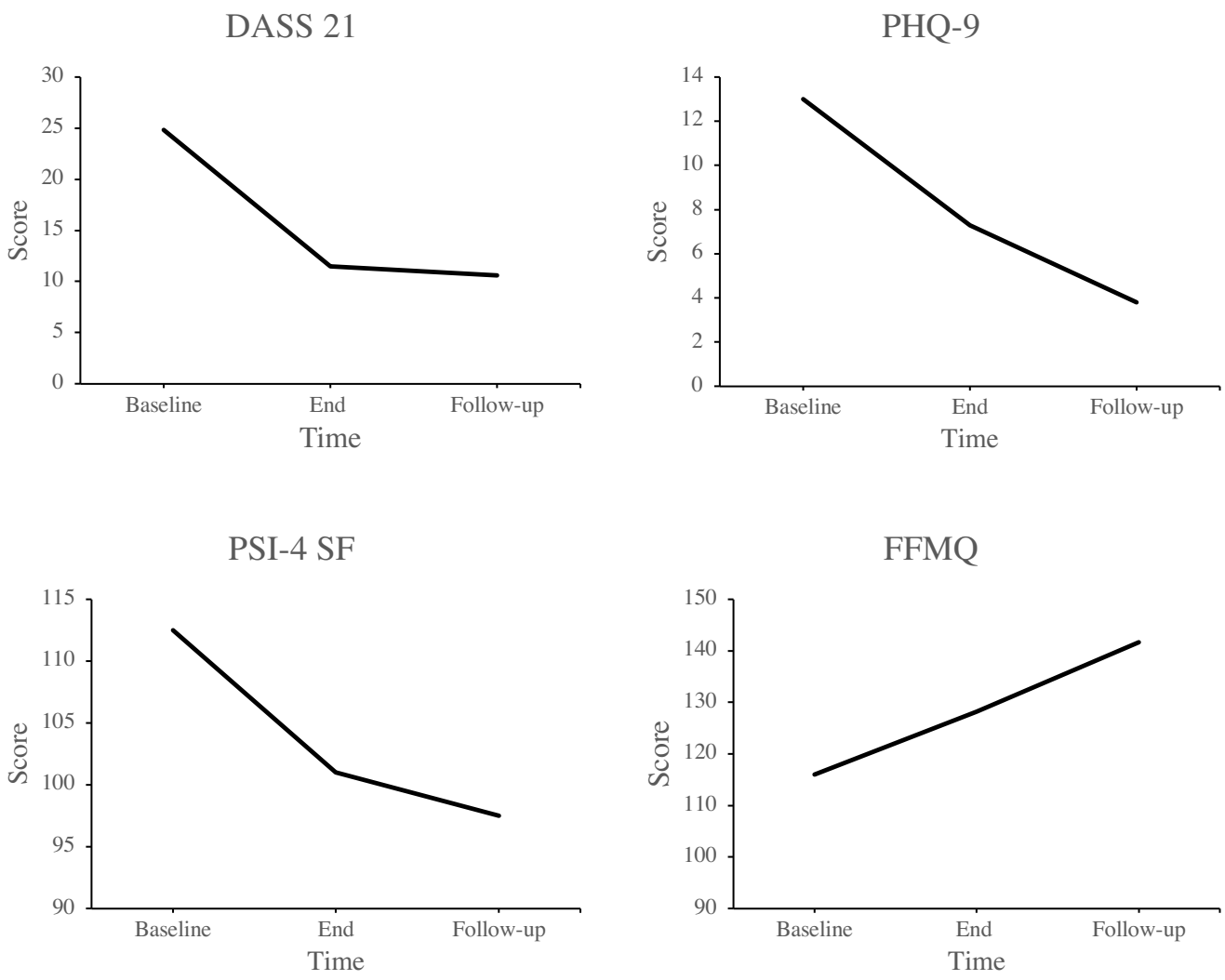


*Figures 1-4*. Trend showing DASS-21, PHQ-9, PSI-4 SF and FFMQ scores at baseline, post-treatment and 3-month follow-up

# Chapter 9

## Conclusions and Discussion

### *Overview*

Parents of children with DD are considered to be at risk for long term psychological distress and reduced wellbeing (Cuskelly, 2006). The overarching aim of this thesis was to examine the treatment potential of adapted mindfulness for this group. Providing efficacious and acceptable psychological treatment is a key factor for maintaining holistic family functioning and enhancing individual parent outcomes in this population (Crnic et al., 2017; Woodman et al., 2015). The project aim was achieved through four independent studies. Study 1 (Chapter 2) involved a systematic review of RCTs, which served to assess the strength of the current evidence base and identify future research directions. Study 2 (Chapter 4) used a case series design to evaluate MiCBT, a treatment that blends CBT and mindfulness elements, for parents of children with ID. Study 3 (Chapter 6) comprised a survey developed in response to participant recruitment and treatment adherence difficulties described in Chapter 5. The fourth and final study (Chapter 8) investigated the feasibility of an adapted, brief, online mindfulness treatment developed based on the basis of the treatment barriers that parents nominated in Study 3 (Chapter 6). In combination, these four studies indicate that while mindfulness treatments may be an effective treatment for parents of children with DD, difficulties may present in accessing face-to-face treatments. A brief online treatment may provide a means for improving treatment accessibility for parents of children with DD.

### *Study 1: Mindfulness Therapies for Improving Mental Health in Parents of Children with a Developmental Disability: a Systematic Review*

Study 1 (Chapter 2), a published systematic review, updated the existing evidence base of mindfulness treatments for parents of children with DD. Previous reviews in this area were published several years ago and relied heavily on studies with a quasi-experimental

design (e.g., Cachia et al., 2015), thereby introducing potential validity concerns and overestimation of treatment benefit. However, the last 10 years has seen much research development in this area, with a number of RCTs published (e.g., Dykens et al., 2014; Lo et al., 2017). This systematic review was comprehensive in its coverage, by separately examining a range of mindfulness-based treatments - those with a formal meditation requirement (e.g., MBSR) and those without (e.g., ACT). The results of the systematic review are in keeping with the current evidence base for mindfulness treatments in the general population; mindfulness appears to promote psychological health, by reducing emotional distress, for parents of children with DD (Cachia et al., 2015; Fjorback et al., 2011). However, variability in treatment results was evident – with MBSR associated with large reductions in stress, specifically, whilst ACT and Mindful Parenting studies reported significant changes across several outcomes including depression, anxiety and/or stress (Chan & Neece, 2018; Dykens et al., 2014; Lo et al., 2017; Whittingham et al., 2015). Research gaps were also highlighted, with further controlled trials needed to determine which components of treatment, or which forms of treatment delivery (i.e., face-to-face, group or online) may be most beneficial for families, or through evaluating novel treatments.

***Study 2: Mindfulness-integrated CBT (MiCBT) for Reducing Distress in Parents of Children with Intellectual Disability (ID): a Case Series***

Study 2 (Chapter 4) was a case series evaluating the efficacy of MiCBT for parents of children with ID. As identified in the systematic review (Chapter 2), evaluation of novel mindfulness treatments remains an important research direction. MiCBT's integration of CBT elements, alongside the development of mindfulness skill provides a theory-driven treatment that provides flexibility between change and acceptance strategies, which could be beneficial for these parents (Cayoun, 2011). This "third wave" psychotherapy acknowledges that when a stressor cannot be changed (i.e., a child's DD), acceptance-based practices, may

be particularly beneficial. Importantly, there is evidence to suggest that psychological constructs of mindfulness and acceptance may mediate parental distress (Hayes et al., 2006; Jones et al., 2014). While the case series highlighted reductions in depression, anxiety and stress symptoms, and while participants reported that MiCBT was acceptable, difficulties with recruitment and anecdotal reports of difficulties completing lengthy daily meditations led to the hypothesis that parents may still experience barriers to benefitting from psychological care. Despite adaptations seen in other research (Dykens et al., 2014), little is known about whether parents of children with DD experience difficulty accessing psychological treatment and what barriers, if any, they face when accessing professional mental health support.

***Study 3: Barriers to accessing mental health treatment for parents of children with intellectual disabilities: a preliminary study***

The systematic review in Chapter 2, and results of the case series in Chapter 4, show that mindfulness treatments, while beneficial for parents of children with DD, are time intensive. While substantial research shows that parents of children with DD experience high levels of psychological distress, causes of this distress (e.g., financial difficulties, paucity of time and resources due to parenting demands), are likely to make it difficult to present for face-to-face psychotherapy (Baker et al., 2005; Hastings, 2002; Plant & Sanders, 2007). Given these concerns, in conjunction with observed difficulties with recruitment and treatment adaptations implemented by other researchers (e.g., Dykens et al., 2014), it was hypothesised that parents of children with DD likely encounter barriers to accessing psychological treatments. The survey outlined in Study 3 was designed to evaluate potential treatment barriers for these parents, with the aim of developing the literature base and informing future research. Among a sample of 80 parents of children with DD, significant barriers to accessing psychological treatment were noted, including cost, availability of

providers, and difficulty arranging childcare. In addition, parents expressed interest in online or e-treatment solutions to address the aforementioned barriers. Providing treatment for this population is important for both the long term health of parents who often care for their children after they reach adulthood, as well as for their children who experience flow on effects from parental stress (Cuskelly, 2006; Orsmond et al., 2003; Woodman et al., 2015). Information gathered in the survey in Chapter 6, such as the nominated barriers to treatment and interest in an e-treatment can be used to guide treatment adaptations for parents of children with DD.

***Study 4 Feasibility of a Brief Online Mindfulness Treatment for Parents of Children with Developmental Disabilities***

E-treatments may help to address some of the difficulties in accessing face-to-face care that parents nominated in Study 3 (Chapter 6), such as cost and availability of providers. A treatment grounded in theory, and with a smaller time commitment than traditional mindfulness protocols, was therefore undertaken as the final study of this dissertation. The brief e-treatment was based on a protocol developed by Cavanagh et al., (2013). The initial research design was a pilot RCT, however difficulties with recruitment led to the need for a pre-post design. Twelve participants were recruited in total, with 10 completing treatment. Despite difficulties with recruitment, retention rates in this study were similar to those observed in mindfulness studies included in Study 1 (Chapter 2), where the average drop-out rate was 12%. Indeed, in comparison to attrition rates for other e-treatments, participant retention appeared satisfactory. For example, online use of smartphone apps for depressive symptoms have reported dropout rates as high as 50% (Torous et al., 2020). Importantly, from a brief, 2 week treatment with only ten minutes a day of meditation, significant and medium to large reductions across all measures of psychological distress were observed, from pre to immediately post-treatment. Significant improvements in mindfulness were also

observed during this timeframe. Moreover, these changes were maintained at 3 month follow up, suggesting that a brief treatment may be beneficial at least in the medium term. Parents also reported a high level of acceptability of the treatment. Future research directions from this study include a full scale RCT with longer follow-up period.

***Research Conclusions***

The high rates of psychological distress that parents of children with DD experience can be debilitating not only for parents, but the entire family unit – resulting in an escalating cycle of stress and challenging child behaviour (Cuskelly, 2006; Plant & Sanders, 2007; Orsmond et al., 2003; Woodman et al., 2015. While the current gold standard of psychological care for a range of mental health concerns is CBT (David et al., 2018), the evidence base for this therapy for parents of children with DD remains limited (Hastings & Beck, 2004). Moreover, as a change focussed treatment which prioritises identifying and adapting unhelpful or distorted thinking styles, CBT may be perceived as invalidating by parents who are undergoing genuine challenges in parenting and organising specialised, and often daily, care for their child. Mindfulness treatments offer an appealing alternative to CBT because of their focus on acceptance and observation of mental states (Orsillo et al., 2003). Mindfulness treatments may be particularly beneficial to parents of children with DD, where distressing cognitions may be reflective of how challenging their circumstances are. Moreover, there is evidence of a positive relationship between mindfulness and acceptance, resulting in beneficial flow on effects for parental distress and overall family functioning (Crnic et al., 2017; Jones et al., 2014). In context of the Double ABCX model (McCubbin & Patterson, 1983), mindfulness treatments present an additional coping resource for parents.

Despite the potential benefits of mindfulness, barriers to accessing this treatment were also identified by parents of children with DD. A brief, online mindfulness treatment was subsequently developed to address some of the identified physical and financial barriers in

the hopes of making treatment more accessible. E-treatments form part of a rapidly developing field that addresses concerns such as treatment cost and provider availability through use of information technologies (Moffat & Eley, 2010). E-treatments have been shown to be effective for a range of psychiatric disorders and populations, and are considered to represent an important future direction for the delivery of effective mental health care due to their advantages of accessibility, coupled with high rates of internet use, in both younger and older people (e.g., research in a Canadian sample found 58% of seniors who had access to internet had used it for health information, and research in an Australian sample of carers of disabled children showed 63% to be frequent internet users, and 91% to have access to the internet at home -Blackburn & Read, 2005; Lal, 2019; Naslund et al., 2015). It is important to note there are several potential criticisms of e-treatments; online or self-help treatment may not be appropriate for all individuals (e.g., those who are experiencing high levels of distress, or for those who are suicidal), and in addition risks have been identified in terms of privacy as well as governance (i.e., the potential for unregulated treatments to be available- Lal, 2019; Leavey & Hawkins, 2017). In regards to the current research, difficulties with recruiting parents of children with high needs for this feasibility trial were noted, even with a brief, accessible online treatment. In spite of these criticisms, e-treatments may still offer care to individuals who would otherwise not engage in treatment at all, and can be seen as a means for improving health access, rather than as a panacea (Cavanagh et al., 2013; Lal, 2019). Importantly, the noted reductions in depression, anxiety, stress, and parenting stress symptoms, as well as improvements in mindfulness, immediately following the 2-week online mindfulness treatment are very promising. Participants also commented that they would recommend the program to a friend, suggesting high levels of acceptability. The low (17%) attrition rate was also comparable to the attrition rate observed in the systematic review in Chapter 2 (Study 1). Given the brevity of treatment compared to traditional

mindfulness protocols, the low cost, the findings of the feasibility trial (Study 4) provide a promising basis for a future full-scale RCT, with the potential to offer care to individuals who would not otherwise present to treatment.

**Research strengths, limitations and future directions**

The initial three studies in this thesis; the systematic review, case series, and survey led to the development of an online mindfulness treatment for parents of children with DD in Chapter 8. In combination, these four independent studies add to the existing literature base by examining the strength of evidence for mindfulness treatments for parents of children with DD, by identifying barriers to accessing treatment, and by assessing feasibility of a time-limited, accessible treatment. The steps taken to developing the online mindfulness treatment (Study 4) followed current guidelines for developing interventions, by identifying the existing evidence (through systematic review, Study 1), developing treatment adaptations (through identification of barriers to treatment and interest in an e-treatment, Study 3) and through use of a preliminary feasibility study (Craig et al., 2008). The predominant strength of this thesis is that the research findings are highly translational to clinical practice. The case series in Study 2 identified anecdotally that parents may have difficulty in accessing treatment, and the survey in Study 3, found evidence for this hypothesis; that parents of children with DD do experience difficulty in prioritising and accessing care for themselves. The adapted treatment in Study 4, which was brief and online, showed significant reductions in distress from a treatment that is substantially shorter than standard mindfulness protocols. These findings can be translated to clinical practice by helping mental health care workers to identify and attune to parent stress levels, as well as offer a briefer mindfulness treatment than what may be typically offered.

However, this research is not without limitations. In particular, the four studies relied upon self-reported data. Future research may benefit from including objective measures of

distress, such as cortisol or galvanic skin response, or a clinician-based diagnostic interview. An additional limitation across all four studies was the relatively homogenous carer sample of mothers examined. As such, possible gender differences in response to treatment could not be captured by this research. Indeed, there is evidence that women report greater improvements from mindfulness treatments than males (Katz & Toner, 2013). It may be beneficial for future research to advertise family mindfulness treatments that encourage both parents to enrol in the study. In addition, the systematic review (Study 1) outlined in Chapter 2, comprised of a small number of studies, thereby precluding further subgroup analysis (i.e., direct comparison of the effectiveness of different mindfulness therapies). In Chapter 4 (Study 2), the case series evaluating MiCBT, there was no follow up period. Future research could consider whether MiCBT leads to longer term benefits. Several limitations were also observed in Study 3 (Chapter 6), the survey evaluating barriers to treatment. Although parents were asked about mental health difficulties experienced in the last year, no standardised self-report measure of assessing mental health was used. Likewise, parents nominated barriers to accessing treatment using an 8 point Likert scale. While there was an explanation for what zero and seven meant on the scale, there may have been individual differences in the interpretation of what each number within this range meant. Additionally, while interest in e-treatment was assessed, the survey was distributed in an online format, which may have led to sampling bias towards participants who were internet savvy and, therefore, more likely to express an interest in an online treatment. The final feasibility trial (Study 4, Chapter 8) was adapted from a pilot RCT to a pre-post design due to recruitment difficulties. While a larger scale trial would be beneficial to provide further evidence of efficacy of an online treatment, it is important to consider the recruitment difficulties encountered throughout this research. It may be beneficial when planning a larger scale RCT to consider partnering with existing services for DD with the aim of improving recruitment

results. Alternatively, if using a smaller sample size, a more stringent quasi experimental design, such as one with multiple baselines, could also develop the evidence base. An additional limitation of the feasibility trial is that changes in child behaviour and wellbeing were not evaluated; inclusion of a measure of child behaviour problems or child distress would help to evaluate any potential flow on effects resulting from improvements in parental mental health and increased mindfulness (Plant & Sanders, 2007).

***Conclusions***

The results of the research presented in this dissertation indicate that mindfulness treatments may be beneficial in reducing distress for parents of children with DD, and that the benefits of treatment may continue – at least in the short to medium term. However, it is important for clinicians to be aware of the challenges that parents of children with DD face in presenting to treatment. Parents reported some benefit from a brief, online mindfulness treatment, with significant reductions in distress and improvements in mindfulness maintained at 3 month follow-up1. It is however noteworthy that, despite the brevity of this treatment as well as the benefits that parents experienced, difficulties with initial engagement of participants was encountered. It is imperative that clinicians treating both children with DD and their parents are aware of the mental health challenges and treatment barriers that this group face as these barriers make it difficult for parents to engage with treatment even when they are experiencing high levels of distress. Clinicians need to actively engage parents in treatment, encouraging these parents to partake in even a brief daily meditation as an additional, beneficial coping resource.

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# Appendix 1

## Ethics Approval for Studies

### *Ethics Approval for MiCBT Case Series (Chapter 4, Study 2)*

**From:** Robert Brockman
**Sent:** Thursday, March 24, 2016 1:43 PM
**To:** Lynette Roberts
**Subject:** FW: Ethics Approval UTS HREC REF NO. 2015000482-25

24th March, 2016

Dear Applicant,

Thank you for submitting your research project for internal ethical review under the **"Program Approval: Low Risk Research MPsych (Clinical) Program Graduate School of Health"** which has been granted approval by the UTS Human Research Ethics Expedited Review Committee to review low risk research within the Discipline of Clinical Psychology. I am pleased to inform you that program ethics approval is now granted in full for your research titled **"Stress Reduction Treatments for Parents of Children with Intellectual Disabilities"** .

Your approval number is **UTS HREC REF NO. 2015000482-25.** Approval will be for a period of two (2) years from the date of this correspondence. After this period has lapsed, approval will automatically cease unless an extension has been sought and approved in writing.

You should consider this your official letter of approval. If you require a hardcopy please contact Robert Brockman (Robert.Brockman@uts.edu.au).

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact me at Robert.Brockman@uts.edu.au.

Yours sincerely,

**Dr Robert Brockman**
Lecturer & Clinic Supervisor
Graduate School of Health | **University of Technology, Sydney**

*Ethics Approval for Survey (Chapter 6, Study 3)*

**25/7/2016**

Dear Applicant/s,

Thank you for submitting your research project for internal ethical review under the **"Program Approval: Low Risk Research MPsych (Clinical) Program Graduate School of Health"** which has been granted approval by the UTS Human Research Ethics Expedited Review Committee to review low risk research within the Discipline of Clinical Psychology. I am pleased to inform you that program ethics approval is now granted for your research titled **"Acceptability and interest of an e-stress reduction treatment for parents of children with an intellectual disability"**.

The committee also suggests that you consider changing the name of the project away from "acceptability" as this may confuse some participants with thinking the project may be some kind of feasibility type trial of the treatment. If you make the change please let me know for my records.

Your approval number is **UTS HREC REF NO. 2015000482-27.** Approval will be for a period of two (2) years from the date of this correspondence. After this period has lapsed, approval will automatically cease unless an extension has been sought and approved in writing.

You should consider this your official letter of approval. If you require a hardcopy please contact Robert Brockman (Robert.Brockman@uts.edu.au).

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact me at Robert.Brockman@uts.edu.au.

Yours sincerely,

**Dr Robert Brockman**
Lecturer & Clinic Supervisor
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Think. Change. Do

***Ethics Approval for Online Mindfulness Feasibility Study (Chapter 8, Study 4)***

# HREC Approval Granted - ETH18-2523

R

Research.Ethics@uts.edu.au

Reply all

Wed 21/11, 2:03 PM

Ian Kneebone;
Raphaella Osborn;
Research Ethics

Dear Applicant

Thank you for your response to the Committee's comments for your project titled, "Online Mindfulness Treatment in Reducing Stress for Parents of Children with Developmental Disabilities (DD).". The Committee agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (http://www.gsu.uts.edu.au/policies/research-management-policy.html).

Your approval number is UTS HREC REF NO. ETH18-2523.

Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:

- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.

- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat (Research.Ethics@uts.edu.au).

- The Principal Investigator will notify the UTS HREC of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions can be found

at https://staff.uts.edu.au/topichub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/Post-approval/post-approval.aspx#tab2.

- The Principal Investigator will promptly report adverse events to the Ethics Secretariat (Research.Ethics@uts.edu.au). An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.

- The Principal Investigator will report to the UTS HREC annually and notify the HREC when the project is completed at all sites. The Principal Investigator will notify the UTS HREC of any plan to extend the duration of the project past the approval period listed above through the progress report.

- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).

- The Principal Investigator will notify the UTS HREC of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

Dr Tim Luckett
(Acting) Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology, Sydney
E: Research.Ethics@uts.edu.au

REF: E38

## Appendix 2

## Website Information Used in Online Feasibility Trial

***Website Copy, as provided to website developer***

### Welcome! (Landing Page)

Thank you for agreeing to participate in this study. You have now been given access to this website, where you will be able to learn about mindfulness, gain access to daily 10 minute meditation practice, and learn about how to bring mindfulness to your everyday activities.

Click on your week below for information on how to practice mindfulness for each week of the study.

Sections of the website (links to this from the landing page/scroll bar)

- **General Information on Mindfulness (START HERE!)**
- **Access Your Meditations**
- **Week 1**
- **Week 2**
- **Mindfulness FAQ**
- **Study Information**
- **Contact Details**
- **Privacy Statement**

### General Information on Mindfulness (Start Here)

#### What is mindfulness?

The term mindfulness comes from Eastern spiritual and religious traditions, but psychology has begun to find that mindfulness (without the religious and spiritual context) can be helpful for people in many ways. Regularly practicing mindfulness has been shown to have a number of benefits including:

- Improving our concentration
- Helping us to handle stress
- Fortifying our self-confidence
- Strengthening our resilience and ability to cope with change
- Enhancing the quality of our communications and relationships
- Enabling a deeper peace of mind and sense of flow

Mindfulness is paying attention in the present moment, with openness and curiosity, instead of judging experiences as good or bad or right or wrong. We often focus on things other than what is happening in the moment- worrying about the future, thinking about the past,

focusing on what is coming next rather than what is right in front of us. Sometimes it is useful that we can do a number of things without paying attention to them. However, sometimes it is helpful to bring our attention, particularly a curious and kind attention, to what we are doing in the moment.

Sometimes we do play close attention to what we are thinking and feeling, and we become very critical of our thoughts and feelings; we try to change them or distract ourselves because this critical awareness can be very painful. For example, we might notice while we are talking to someone new that our voice is shaky, or that we aren't speaking clearly, and think "I'm such an idiot! What is wrong with me? If I don't calm down, this person will never like me!"

We often find ourselves responding to unpleasant experiences by fighting against them, getting caught up with them or by trying to ignore them. Mindfulness is a 'middle way' of responding to unpleasant experiences. It allows us to notice experiences without getting drawn in to them, without fighting against them and without trying to push them away. Rather, mindfulness allows us to notice experiences in each moment, step back and 'watch' these experiences without judgement and allow them to fade and pass as new experiences come into awareness. For example, when talking to someone new, we might notice those same changes in our voice and take a moment to reflect, "This is how it is now, there go my thoughts again", and gently bring our attention back to the person and our conversation. This second part of mindfulness, holding our judgements loosely and not trying to change our thoughts or feelings, can be especially hard. In fact, often being mindful involves practicing not judging our tendency to have judgements.

Each of these aspects of mindfulness are worth taking a little time to consider:

- Mindfulness involves paying attention on purpose. We decide to pay attention.
- The object of our attention is the present moment. This includes whatever experiences we notice in each moment. We might notice sounds, sensations in our bodies, thoughts and feelings.
- Mindfulness encourages us to notice these experiences non-judgmentally. We try, as best we can to notice current experiences without judging them as right or wrong, or as good or bad.

Not judging our experiences takes a lot of practice. You might notice judging things about:

- Yourself (e.g. "I can't do this, I can't do anything")
- Thoughts (e.g. "I shouldn't be thinking this")
- Mindfulness practice (e.g "this is a waste of time")

The aim of mindfulness is to notice these judgments and to bring our attention back to the present moment.

**What can mindfulness do for me?**

Mindfulness will not get rid of unpleasant thoughts of feelings, but with practice we can learn to notice unpleasant experiences without getting caught up with them. Mindfulness is not a relaxation technique, although some people notice that they feel more relaxed after practicing mindfulness. Other people, particularly when they first start practicing mindfulness, might notice that they get drawn into unpleasant thoughts and feelings and that they get caught up in these experiences.

If this happens for you, try as best as you can to step back from these unpleasant experiences, watch them fade and pass as if you could see them on a screen, as clouds drifting in a summer sky, or leaves floating down a stream, and then gently bring your attention back to the present moment. If you are able to do this just once while practicing mindfulness you are beginning to find out that it is possible not to get caught up in unpleasant experiences and to let them go.

**How do I practice Mindfulness?**

*Mindfulness Meditation*

Mindfulness meditation can be a good way of developing our mindfulness ability. Our minds are very busy, and they will wander to thoughts about the past, worries about the future, to unpleasant feelings and sensations in our body. Each time this happens we try as best we can to notice where our mind has wandered to and then to gently bring our attention back to the practice. You are invited to engage in a mindfulness meditation practiced in the **daily practice** section on this site.

*Bringing mindfulness to everyday activities*

You are invited to explore bringing mindfulness to everyday activities on the **Every Day Mindfulness Activities** page on this site. This might mean focusing on a task such as the washing up and really noticing what is happening for you in each moment. As your mind wanders to thoughts, feelings, images and so on, just notice where your mind has wandered to ands gently bring your attention back to what is happening for you in the present moment.

**Access your daily mindfulness practice here!**

*Daily Mindfulness Practice*

For the next several minutes, you're going to be asked to explore a particular kind of awareness called mindfulness in the form of a daily practice. We invite you to do this practice daily for the next two weeks, though you are more than welcome to do the practice more than daily if you wish. Research has shown that the more you practice the more you are likely to benefit.

The best way to understand mindfulness is to practice it repeatedly, so let's do that now. We have provided an audio guided practice for you to follow, lasting around 10 minutes. You can choose a male or female voice from the links below. We recommend you undertake the practice in a quiet, calm area, or wear headphones.

*Everyday Mindfulness Activities*

For the next two weeks, you are invited to practice bringing a particular kind of awareness called mindfulness to some of your daily activities, in the first week, we invite you to try bringing mindfulness to one routine activity. In the second week, we invite you to practice bringing mindfulness to walk that you do regularly and to try bringing mindful awareness to pleasant moments in your day. You might also like to continue with activity from week one, perhaps experimenting with a different routine activity.

**Week One**

*Bringing awareness to routine activities*

A central tenet of mindfulness is learning how to bring awareness to everyday activities so that you can see life as it is, unfolding moment by moment. Mindfulness also involves not judging our experiences and cultivating an attitude of acceptance to whatever we notice.

Choose one of the following (or another of your own choosing), and each day for the next week, see if you can remember to pay non-judgmental attention while you are doing it. You do not have to slow it down, or even enjoy it. Simply do what you normally do, but see if you can be fully alive to it as you do it.

- Brushing your teeth
- Taking a shower
- Drinking tea, coffee, juice
- Taking out the rubbish
- Loading the washing machine or tumble drier

Try this as an experiment with the same chosen activity each day for a week. The idea is not to make you feel different, but simply to allow for a few more moments in the day when you are "awake". Go at your own pace when doing your chosen activity, for example:

Brushing your teeth: where is your mind at when you are brushing your teeth? Pay careful attention to all the sensations- the toothbrush in relation to the teeth, the flavour of the toothpaste, moisture building up in the mouth, all the movements required to spit, etc.

Showering: Pay attention to the sensations of the water on your body, the temperature, and the pressure. Notice the movements of the hand as you wash and the movements of the body as you turn and bend, etc. If you decide to take some of your showering time to plan or reflect, do so intentionally, with awareness that this is where you have decided to focus your attention.

Next week, feel free to continue this experiment with a different activity.

**Week Two**

*Going for a walk*

Over the next week, choose a five to thirty-minute walk that you do regularly. The aim is to walk as mindfully as you can, focusing your awareness on your feet as they land on the ground, ands feeling the fluid movement of all the muscles and tendons in your feet and legs. You might even notice that your whole body moves as you walk, not just your legs. Pay attention to all of the sights, sounds and smells. If you're in a city, you'll see and hear a surprising number of birds. Notice how they react when they realise that you've seen them.

See if it's possible to be open to all of your senses: smell the scent of flowers, the aroma of cut grass, the mustiness of winter leaves or, perhaps, the smell of exhaust fumes and fast food; see if you can feel the breeze on your face or the rain on your head or hands; listen to the air as it moves; see how the patterns of light and shade can shift unexpectedly. Every moment of every season has a host of sensory delights- regardless of where you live.

Try stopping and looking upwards too. If you are in a city, you'll be surprised by how many beautiful architectural features are just above natural eye level. You might also see tufts of grass or even trees growing out of roofs and guttering. If you are in a park or in the countryside, you'll see all manner of things from bird's nests to bees' nests hidden in trees and bushes.

Appreciation here and now

Happiness is looking at the same things with different eyes.

Life only happens here- at this very moment. Tomorrow and yesterday are no more than a thought. So make the best of it. You do not know how long you have got. This is a positive message, it helps to give appreciative attention to what is here and now. How much appreciative attention do you have for the here and now? Become still and look around. How is the 'now' for you?

We easily miss the beautiful things and give them little attention. Take time to pause for simple things, daily things. Maybe you can give a few of these activities or spontaneous events in your life extra attention.

Which activities, things or people in your life make you feel good? Can you give additional appreciative attention to these activities?

Can you pause for a moment when pleasant moments occur?

Help yourself pause by noticing:

- What body sensations do you feel at these moments?
- What thoughts are around?
- What feelings are here?

These materials are taken and adapted from Williams, M., Penman, D. (2011) *Mindfulness: A practical guide to finding peace in a frantic world.* London: Piatkus.

## Daily Practice and Mindfulness FAQ

As a result of the mindfulness meditation practice or of bringing mindfulness to everyday activities, you may experience a range of emotions and feelings, both good or bad. This FAQ page gives you some information as to how to deal with any of those feelings that arise.

*I felt restless*- This is very common and not a problem. We would encourage you to bring attention to the experience of tension or restlessness during the practice and, as best you can, greet that with gentleness and patience.

*I felt my mind wandering away from the present moment*- It is not a failure if our mind wanders. All of our minds wander; this is what minds do. Noticing our mind wandering is a valuable skill to develop. When we notice that our mind has wandered in the mindfulness practice, as best we can we acknowledge what the mind has wandered to, let go of any judgments about the fact that the mind as wandered, and then gently bring our attention back to the present moment.

*I think I haven't done the practice well, or can't do the practice, or that I haven't been very mindful of activities*- it can be helpful to remind ourselves that we are not aiming for a

particular state of mind when we practice mindfulness. Whatever we notice is a success. If we notice thoughts such as "I am not doing it right", it is great that we have noticed them. Perhaps we can take a few moments to watch the effect these thoughts are having on our moment-by-moment experience, before returning to following the practice's guidance.

*I felt I was daydreaming or getting lost in pleasant experiences*- Many of us get lost in pleasant thoughts or daydreams from time to time. When we notice this has happened during practice, the invitation is to let go of these and to gently return to following the guidance in the practice.

*I was feeling sleepy or falling asleep during the practice*- Any of us can feel sleepy during mindfulness practice at times. Feeling sleepy during practice can be a really valuable opportunity to explore the present-moment experience of feeling sleepy, including how the body feels when this happens. If you regularly feel sleepy during practice, you may want to reconsider the time of day that you practice and you may want to practice with your eyes open instead of closed. Sitting with an upright posture, with your back away from the chair if that is comfortable for you, can be helpful, as can practicing standing up.

*I felt relaxed or calm*- Feeling relaxed or calm can be a really interesting experience to explore and we'd encourage you to bring awareness to the body and to notice what body sensations come with feeling relaxed or calm, and whether there are any changes in these moment by moment.

*I felt focused or absorbed in the present moment*- Sometimes when practicing mindfulness, we can be very absorbed with our present moment experience and our minds may wander a little, which is great to notice. Also, it is important to remind ourselves that this experience is no better or worse than when the mind wanders, from the point of view of this practice.

*During the practice or mindful activity, I felt irritated or disturbed by an experience (e.g. a noise, people talking, an unwanted thought or feeling, a pain in the body)*- Very often there will be times in our experience while practicing mindfulness when feelings of frustration or irritation will arise. These are good opportunities to explore frustration and irritation in the present moment, including noticing what is happening in our body (e.g. maybe asking ourselves "where do I notice this most intensely in my body?") and what is happening in our mind. Feelings of frustration and irritation can also be a valuable opportunity to practice inviting in the possibility of bringing patience and gentleness to our experience.

*The practice or mindful activity made me feel more emotional or distressed*- Because practicing mindfulness involves intentionally bringing our awareness to our experiences, whatever they may be, it is quite common to get in touch with feelings that can be upsetting. It is important to know that we have a choice at such times. One choice open to us is to explore this experience in the present moment, particularly noticing any bodily sensations that are occurring. Another choice that is open to us is to return attention to the breath.

If these feelings are persistent and overwhelming, then please also remember that you are free to stop a practice and/or to end your participation in this study at any time. If you feel that you need help with these feelings, then please see the list of contacts on the help or assistance page, or email the researcher.

*I'm doubting whether the practice or mindful activity will help me*- If you are having such thoughts then we invite you to continue as best you can, acknowledging this doubt and maybe suspending our judgement until the end of the study.

*I'm becoming aware of bodily sensation that I haven't noticed before*- It's great that you are noticing more things about your experience. When we practice, it is not unusual to start to notice things that we were not previously aware of.

*I find memories arising during the practice or mindful activity*- It is very common to notice our minds wandering to memories. When you notice this has happened, we would invite you to acknowledge where your mind has wandered to and then gently bring your attention back to the present moment, as best you can.

**Study Information (copy of PIS will go here)**

**Help and Assistance**

If you are feeling distressed at any point during this study, you can contact the research team using the following emails:
Raphaella.osborn@student.uts.edu.au or ian.kneebone@uts.edu.au

You may also find it helpful to contact Life Line on the following phone number:
13 11 14

Alternatively, you may want to contact your GP for further guidance and support, we are able to provide a letter to your GP to assist with this.

***Meditation Script for audio recording on website, ten minute daily meditation***

**Guided Scan**

This guided sitting meditation will help you learn to simply be and to look within yourself with mindfulness and equanimity. Allow yourself to switch from the usual mode of doing to a mode of non-doing. Of simply being. As you allow your body to become still, bring your attention to the fact that you are breathing. And become aware of the movement of your breath as it comes into your body and as it leaves your body. Not manipulating the breath in any way or trying to change it. Simply being aware of it and of the feelings associated with breathing. And observing the breath deep down in your belly. Feeling the abdomen as it expands gently on the inbreath, and as it falls back towards your spine on the outbreath. Being totally here in each moment with each breath. Not trying to do anything, not trying to get any place, simply being with your breath.

You will find that from time to time your mind will wander off into thoughts, fantasies, anticipations of the future or the past, worrying, memories, whatever. When you notice that your attention is no longer here and no longer with your breathing, and without judging yourself, bring your attention back to your breathing and ride the waves of your breathing, fully conscious of the duration of each breath from moment to moment. Every time you find your mind wandering off the breath, gently bringing it back to the present, back to the moment-to-moment observing of the flow of your breathing. Using your breath to help you tune into a state of relaxed awareness and stillness.

Now as you observe your breathing, you may find from time to time that you are becoming aware of sensations in your body. As you maintain awareness of your breathing, see if it is possible to expand the field of your awareness so that it includes a sense of your body as a whole as you sit here. Feeling your body, from head to toe, and becoming aware of all the sensations in your body.

Being here with whatever feelings and sensations come up in any moment without judging them, without reacting to them, just being fully here, fully aware of whatever you're experiencing. And again whenever you notice that your mind wandered off, just bringing it back to your breathing and your body as you sit here not going anywhere, not doing anything just simply being, simply sitting. Moment to moment, being fully present, fully with yourself.

Now as you sit here once again allowing the field of your awareness to expand. This time, expanding your awareness to include thoughts as they move through your mind. So letting your breathing and sense of your body be in the background and allowing the thinking process itself to be the focus of your awareness. And rather than following individual thoughts and getting involved in the content and going from one thought to the next, simply seeing each thought as it comes up in your mind as a thought and letting the thoughts just come and go as you sit and dwell in stillness, witnessing them and observing them. Whatever they are…just observing them as events in the field of your consciousness…as they come into your awareness and they linger and as they dissolve.

If you find yourself at any point drawn into this stream of thinking and you notice that you are no longer observing them, just coming back to observing them as events and using your breathing and the sense of your body to anchor you and stabilize you in the present.

The thoughts can take any form, they can have any content and they can be either neutral or very highly charged. If thoughts come up that have fear in them, then just be aware of fear being here and letting these thoughts come and go. The same for worries, preoccupations, and so on. Regardless of the feeling that a thought might create for you, just observing it as simply a thought and letting it be here without pursuing it or without rejecting it. Noticing that from moment to moment, new thoughts will come and go.

As the meditation ends, you might give yourself credit for having spent this time nourishing yourself in a deep way by dwelling in this state of non-doing, in this state of being. For having intentionally made time for yourself to simply be who you are. And as you move back into the world, allow the benefits of this practice to expand into every aspect of your life.

**Awareness of Breath**

This guided meditation on the breath will help you learn to simply be and to look within yourself with mindfulness and equanimity. Allow yourself to switch from the usual mode of doing to a mode of non-doing. Of simply being. Sitting in an erect posture, either on a straight back chair or on a cushion. As you allow your body to become still, bring your attention to the fact that you are breathing. And become aware of the movement of your breath as it comes into your body and as it leaves your body. Not manipulating the breath in any way or trying to change it. Simply being aware of it and of the feelings associated with breathing. And observing the breath deep down in your belly. Feeling the abdomen as it expands gently on the inbreath, and as it falls back towards your spine on the outbreath. Being totally here in each moment with each breath. Not trying to do anything, not trying to get any place, simply being with your breath. Giving full care and attention to each inbreath and to each outbreath. As they follow one after the other in a never ending cycle and flow.

You will find that from time to time your mind will wander off into thoughts. When you notice that your attention is no longer here and no longer with your breathing, and without judging yourself, bring your attention back to your breathing and ride the waves of your breathing, fully conscious of the duration of each breath from moment to moment. Every time you find your mind wandering off the breath, gently bringing it back to the present, back to the moment-to-moment observing of the flow of your breathing. Using your breath as an anchor to focus your attention, to bring you back to the present whenever you notice that your mind is becoming absorbed or reactive. Using your breath to help you tune into a state of relaxed awareness and stillness.

Now as you observe your breathing, you may find from time to time that you are becoming aware of sensations in your body. As you maintain awareness of your breathing, see if it is possible to expand the field of your awareness so that it includes a sense of your body as a

whole as you sit here. Feeling your body, from head to toe, and becoming aware of all the sensations in your body. So that now you are observing not only the flow of breathing, but the sense of your body as a whole.

Being here with whatever feelings and sensations come up in any moment without judging them, without reacting to them, just being fully here, fully aware. Totally present with whatever your feelings are and with your breath and a sense of your body as a whole. And again whenever you notice that your mind wandering off, just bringing it back to your breathing and your body as you sit here not going anywhere, not doing anything just simply being, simply sitting. Moment to moment, being fully present, fully with yourself.

Reestablishing your awareness on the body as a whole and on the breath as it moves in and out of your body. Coming back to a sense of fullness of each inbreath, and the fullness of each outbreath. If you find yourself at any point drawn into a stream of thinking and you notice that you are no longer observing the breath, just using your breathing and the sense of your body to anchor you and stabilize you in the present.

Just being with your breathing from moment to moment, just sitting in stillness, looking for nothing and being present to all. Just as it is, just as it unfolds. Just being right here, right now. Complete. Human. Whole.

As the practice comes to an end, you might give yourself credit for having spent this time nourishing yourself in a deep way by dwelling in this state of non-doing, in this state of being. For having intentionally made time for yourself to simply be who you are. And as you move back into the world, allow the benefits of this practice to expand into every aspect of your life.