The Development of a Family-Focused Intervention for Parents of Adolescents with Cystic Fibrosis

Study 1: "I'm cured now!": Provider Perspectives in the development of a family-focused intervention for teenagers with cystic fibrosis – issues of adherence and family dynamics, in the era of modulator therapies.

Study 2: The Development, Evaluation and Feasibility of a Novel Family-Focused-intervention for parents of teenagers with cystic fibrosis

Thesis submitted by

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in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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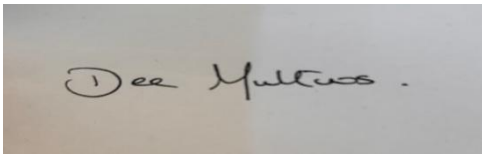
Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.



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Abstract

Cystic fibrosis (CF) is a lifelong genetic condition that requires intensive, family-centred management across childhood and adolescence. Parents play a central role in treatment adherence, emotional regulation, and the gradual transfer of responsibility as adolescents move towards greater autonomy. Although the introduction of CFTR modulator therapies has transformed physical health outcomes for many young people with CF, emerging evidence has suggested that psychosocial challenges for families have not been eliminated. Instead, adolescence in the modulator era is characterised by reconfigured uncertainty, shifting parental roles, and complex negotiations of autonomy, responsibility, and risk. Despite this, psychosocial research and intervention in CF has remained largely focused on early childhood, individual distress, or adherence behaviours, with limited attention to parents as ongoing recipients of structured psychological support during adolescence.

This thesis presents a programme of research examining family experiences of CF during adolescence in the modulator era and the development and preliminary evaluation of a family-focused psychological intervention for parents. The programme comprised two interlinked studies. First, a qualitative healthcare provider engagement study explored multidisciplinary perspectives on emerging family challenges in adolescent CF care and examined how these challenges might inform the development of a feasible, clinically relevant intervention. Second, a mixed-methods feasibility pilot evaluated the acceptability, practicality, and preliminary psychological impact of a newly developed one-day Family-Focused Intervention (FFI) for parents of adolescents with CF.

The provider engagement study identified heightened parental vigilance, emotional reactivity, uncertainty regarding treatment expectations, and difficulties negotiating adolescent autonomy as central challenges shaping family dynamics in the modulator era.

These findings informed the design of the FFI, which integrated principles from Acceptance and Commitment Therapy, narrative approaches, and structured problem-solving within a brief, service-compatible format. The feasibility pilot examined uptake, retention, acceptability, and early psychological change using qualitative interviews and standardised self-report measures targeting emotional distress, psychological flexibility, and perceived family functioning.

Findings indicate that the FFI was acceptable to participating parents and feasible within existing service constraints. Qualitative process data suggested shifts in parental awareness, emotional regulation, and meaning-making following the intervention, while quantitative outcomes provided preliminary evidence of change in psychological flexibility and emotional wellbeing. Short-term changes in perceived family functioning were interpreted within a systemic and process-oriented framework, highlighting the importance of examining early activation effects alongside outcome measures.

Taken together, this thesis contributes novel empirical insight into family life in adolescent CF during the modulator era and demonstrates the feasibility of a provider-informed, family-focused psychological intervention embedded within routine care. The findings underscore the value of integrating stakeholder perspectives, targeting parental psychological processes, and examining process alongside outcome in early-stage intervention development.

Chapter 1: Thesis Overview

Cystic fibrosis (CF) is a complex, lifelong genetic condition that has historically required intensive, family-centred management across childhood and adolescence. Parents play a central role in supporting treatment adherence, emotional adjustment, and the gradual transfer of responsibility during adolescence, a developmental period characterised by increasing autonomy, shifting family roles, and heightened relational strain. Although the introduction of CFTR modulator therapies has transformed physical health outcomes for many young people with CF, emerging evidence has suggested that these advances have not eliminated psychosocial burden for families. Instead, they have reconfigured experiences of uncertainty, responsibility, and parental role negotiation, underscoring the need for contemporary psychological interventions that are responsive to the realities of the modulator era.

Family-focused psychological interventions are increasingly recognised as important within paediatric chronic illness care, yet the evidence base remains equivocal, with mixed findings regarding effectiveness and limited clarity regarding active mechanisms of change. Within CF specifically, there is a relative absence of parent-focused interventions that are developmentally informed, theoretically coherent, and tailored to the evolving treatment landscape. Moreover, the perspectives of healthcare providers and families themselves have rarely been systematically incorporated into intervention development, despite their potential to enhance relevance, feasibility, and acceptability within routine clinical care.

This doctoral research programme aimed to address these gaps through the development and preliminary evaluation of a novel Family-Focused Intervention (FFI) for parents of adolescents with CF. The research adopted an iterative, multi-method approach

aligned with contemporary guidance for the development and evaluation of complex interventions. Across the thesis, quantitative and qualitative methods were integrated to inform intervention design, delivery, and early evaluation, with a particular emphasis on relational processes, parental psychological flexibility, and family functioning during adolescence.

Chapter 2 presents an extended review of the literature on family-focused psychological interventions in paediatric chronic illness, with specific attention to adolescence and parental adjustment. This chapter synthesises evidence relating to intervention content, theoretical models, and outcome measurement, and identifies key limitations and gaps in the existing literature. Particular emphasis is placed on uncertainty, family functioning, and process-based psychological constructs relevant to parents managing long-term illness in the context of CF.

Chapter 3 reports a qualitative provider engagement study exploring multidisciplinary healthcare professionals' perspectives on the psychosocial needs of parents and families of adolescents with CF. Using a focus group methodology, this chapter examines clinicians' views on family challenges, service gaps, and priorities for psychosocial support in the modulator era. Findings from this study directly informed the development and tailoring of the FFI.

Chapter 4 presents a supplementary chapter expanding on the provider engagement study. This chapter provides additional methodological detail, analytic transparency, and contextual information that could not be fully reported within the main empirical chapter. It further elaborates on the implications of provider perspectives for intervention development and service delivery.

Chapter 5 describes the development and initial feasibility evaluation of the Family-Focused Intervention. This chapter outlines the theoretical rationale underpinning the intervention, the integration of Acceptance and Commitment Therapy, narrative approaches, and problem-solving components, and reports quantitative and qualitative findings relating to feasibility, acceptability, and early change processes.

Chapter 6 provides a supplementary chapter for the FFI study. This chapter offers detailed intervention description, expanded consideration of outcome measures, explicit articulation of modulator-era adaptations, and guidance on facilitator stance, fidelity, and flexibility. It is intended to enhance transparency, replicability, and future implementation of the intervention.

Chapter 7 presents an integrative discussion and conclusion. This chapter draws together findings across the programme of research, situates them within relevant theoretical frameworks, and considers clinical and research implications. Strengths and limitations of the work are discussed, alongside priorities for future intervention refinement, evaluation, and integration within CF services.

Chapter 2: Toward the Development of a Family- Focused Intervention for Parents of Adolescents with Cystic Fibrosis: Evidence, Theory, and Context

This chapter critically reviews the empirical and theoretical literature on family functioning and psychosocial adaptation in paediatric chronic illness, with a particular focus on cystic fibrosis (CF). It situates CF within a broader body of family-focused health psychology research, recognising the condition not only as a biomedical illness but as one that places sustained emotional, relational, and developmental demands on families, particularly during adolescence.

Drawing on family systems theory and related psychological frameworks, the literature reviewed here examines how family interactions, parental wellbeing, and emotional regulation shape adjustment, health behaviours, and treatment engagement over time. Particular attention is given to adolescence as a developmentally sensitive period during which responsibilities shift, autonomy is negotiated, and family dynamics are renegotiated in the context of chronic illness.

The chapter also reviews evidence for family-focused and psychologically informed interventions across paediatric chronic illness contexts, with emphasis on cognitive-behavioural, problem-solving, and acceptance-based approaches that have demonstrated efficacy in supporting parental coping, family communication, and resilience (Eccleston et al., 2015; Law et al., 2019). Interventions such as the Congenital Heart Disease Intervention Program (CHIP), Family First, and Improving Outcomes for Children with Epilepsy (IOCE) are critically examined to identify transferable mechanisms relevant to families affected by CF.

Despite this growing evidence base, there remains a notable absence of CF-specific family-focused psychological interventions, particularly for families of adolescents. This gap provides the rationale for the present research, which seeks to integrate theoretical

insight, empirical evidence, and stakeholder perspectives in the development and preliminary evaluation of a family-focused intervention tailored to the CF context.

Cystic Fibrosis

Cystic Fibrosis (CF) is a progressive, life limiting genetic disorder. It impacts several organs and causes enduring lung infections which over time limits the ability to breathe (O'Connor et al., 2018). CF is caused by a mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene. This leads to the development of an abnormally thick and sticky mucus which primarily impacts the lungs, digestive tract, pancreas and reproductive systems (Bierlaagh et al., 2021). Ireland has the highest per capita incidence of cystic fibrosis (CF) globally, driven by a distinctive genetic profile that includes a high frequency of the F508del mutation associated with increased severity. Combined with Irelands relatively isolated population history, this has resulted in a greater number of gene carriers and a higher likelihood of severe clinical presentations compared to other regions with approximately 1,400 individuals affected and an estimated 33 new diagnoses each year. Owing to the implementation of newborn screening programmes, these diagnoses are typically made quickly (Cystic Fibrosis Ireland, n.d.). This biomedical understanding forms the foundation for exploring its profound psychosocial dimensions, which are equally consequential for families.

People with CF endure highly burdensome and laborious multimodal treatment regimens (Smith et al., 2016). CF significantly impacts on the physical, emotional and social well-being of people with CF, as well as their families (Bell et al., 2020; Burgel et al., 2024; Macdonald et al., 2019). Additionally, due to lowered immune capability to fight infection, people with CF are often subject to severe infection control guidelines, including being

forbidden from face-to-face contact with other people with CF. This leaves people with CF at higher risk of social isolation and psychological distress (Tickner et al., 2022). For families, cystic fibrosis has been described as one of the most challenging paediatric diseases to manage, given the strict treatment regime required across all systems the child/young person is embedded in.

While for adults with CF, the life expectancy was historically severely limited, the life expectancy of children and young people with Cystic Fibrosis has increased dramatically due to the advent of Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) modulators. CFTR modulators are a group of drugs which treat the underlying case of CF by targeting the faulty CFTR protein (*Cystic Fibrosis Trust*, n.d.). Such improvements in mortality have led to a shift in focus to Quality of Life and adjustment of people with CF. Despite this positive medical advancement, the management of the disease and coping with chronicity of the disease puts a burden on the child and the systems in which they live (Bell et al., 2020). This burden encompasses the physical demands of treatment as well as the psychological, social, and developmental challenges associated with lifelong condition management. Increased life expectancy has reshaped morbidity, with higher rates of cancers, cardiovascular conditions, and cystic fibrosis related diabetes now affecting more than half of adults in developed countries (Bell et al., 2020; Bierlaagh et al., 2021; Plant et al., 2013).

While modulators have transformed prognosis, they have also introduced new uncertainties regarding long term adjustment, identity, and expectations of treatment (Bierlaagh et al., 2021; Harrigan et al., 2025; Mayer-Hamblett et al., 2021). Although discussions about reducing treatment burden are emerging, pivotal modulator trials were

conducted alongside standard therapies, and evidence has suggested health decline is slowed but not eliminated (Bell et al., 2020; Bierlaagh et al., 2021).

Psychosocial burden of CF

The burden associated with cystic fibrosis encompasses the ongoing tasks, lifestyle adjustments, and disease management regimes required for daily life, and these demands may contribute to psychosocial outcomes such as increased depression, anxiety, and emotional distress. Evidence consistently indicates elevated levels of such distress among people with cystic fibrosis (Campagna et al., 2024; Graziano et al., 2020, 2023; Harrigan et al., 2025; Lord et al., 2023; Quittner et al., 2020a).

Further, physical health outcomes in CF are impacted by an intricate interplay of biological, social and psychological factors (Harrigan et al., 2025). Disease progression and treatment response are shaped not only by genetic and physiological mechanisms but also by family dynamics, socioeconomic conditions, access to specialist care, and the individual's coping resources. These interacting influences highlight the importance of viewing CF management through a biopsychosocial lens that recognises health as embedded within relationships, contexts, and lived experience.

The presence of untreated anxiety and depression has been linked to adverse effects on health-related quality of life, medical outcomes, and adherence to treatment regimens. Such mental health conditions can impair concentration, reduce motivation, and heighten avoidance, which may negatively affect adherence to complex self-management regimens that are central to CF care (Cronlyet al., 2019; Possidente et al., 2005) and are therefore of significance to the CF population (Barker & Quittner, 2016;

Fidika et al., 2015; Prieur et al., 2021; Quittner et al., 2020b; Riekert et al., 2007; Smith et al., 2010).

Additionally, chronic illness can disrupt self-esteem and identity formation, both central tasks of normative adolescent development, thereby heightening vulnerability to mental health difficulties during this critical developmental stage (Harrigan et al., 2025).

Adolescence

The developmental period of adolescence, characterised by identity formation and an increasing drive for autonomy (Beyers et al., 2025), is made more complex by the demanding nature of cystic fibrosis (CF). Normative psychosocial challenges, common to all adolescents, are often amplified in the context of chronic illness, which can undermine disease self-management and treatment adherence (DeLambo et al., 2004; Tuchman et al., 2010). Core developmental tasks such as establishing independence, developing self-care skills, and preparing for employment may be disrupted (Tuchman et al., 2010).

As CF progresses during adolescence, adherence to rigorous treatment routines becomes critical, coinciding with a developmental stage marked by significant social, biological, and cognitive transitions (Toprak et al., 2020; Tuchman et al., 2010). The cumulative burden of intensive treatment regimens, frequent hospitalisations, and lifestyle restrictions can limit adolescents' participation in educational, recreational, and social activities that are vital for psychosocial growth (Muther et al., 2018). Furthermore, infection control measures which are essential to preventing cross-infection among individuals with CF, can contribute to social isolation (Toth, 2016; Vines et al., 2018), disrupting normative experiences of friendship, belonging, and community engagement. .

This period also typically coincides with the transition from paediatric to adult-oriented healthcare services; an important developmental milestone that can significantly influence long-term health outcomes for individuals with CF (Tuchman et al., 2010). For adolescents managing CF, the task of achieving independence from parents coexists with the responsibility of maintaining complex treatment routines, both of which can adversely affect quality of life, a key predictor of overall health status (Tanja Besier et al., 2011). Further, tension and conflict between adolescents and parents may have negative effects on adolescents physical outcomes (Patterson et al., 2009; Smith et al., 2010). This interplay between developmental demands and medical adherence underscores the need for family-inclusive support during adolescence.

Adolescence, caregivers, their relationship and its impact on treatment adherence/CF

Within the intersecting contexts of treatment adherence, transition to adult healthcare services, and normative adolescent development, the parent–adolescent relationship assumes particular significance. Research indicated that reduced parental involvement is associated with poorer self-management behaviours among adolescents with chronic health conditions such as diabetes (King et al., 2014). Conversely, fostering collaborative problem-solving, facilitating knowledge transfer regarding disease management, and maintaining open, ongoing communication have been shown to mitigate conflict, prevent parental disengagement, and enhance adolescents' autonomy and self-efficacy in managing conditions such as sickle cell disease and diabetes (Kayle et al., 2016; Lerch & Thrane, 2019). Although tension between parents and adolescents is a well-recognised feature of this developmental stage, evidence has suggested that, somewhat counterintuitively, many adolescents continue to value and seek parental involvement at

key points along their journey toward autonomy (Lerch & Thrane, 2019). Further, CF specific research showed that adolescents whose families are experiencing unhappy and conflicted relationships may be at greater risk for poor adherence to treatments; thus, suggesting that family relationships are appropriate targets for interventions given the knock on impact on adherence (DeLambo et al., 2004).

Psychosocial Burden on Caregivers

Given the significance of parents and family functioning on outcomes for the young person with CF, impact on parents and families themselves is important to consider. The psychosocial impact of cystic fibrosis (CF), as with other chronic health conditions, extends across the entire family system. Parents must adapt to their child's diagnosis, manage intensive daily treatment regimens, and cope with ongoing uncertainty about their child's health, all of which place them at elevated risk for poor mental health outcomes (Daly et al., 2022). Empirical studies have shown that caregiver well-being often deteriorates during periods of disease exacerbation and that levels of psychological distress among caregivers can be comparable to, or even exceed, those reported by individuals with CF themselves (Graziano et al., 2023).

Rates of depression and anxiety among parents of children with CF are substantially higher than those observed in the general population. Parents are estimated to be approximately three times more likely to experience clinically significant depression than community samples (Quittner et al., 2020b; Smith et al., 2010). In Ireland, Cronly et al., (2019) found that 38% of parents reported clinically elevated anxiety and 21% exceeded cut offs for depressive symptoms. Data from over four thousand parents across the United Kingdom, United States, and Europe reflect similar patterns, with clinically elevated

depression in 37% of mothers and 31% percent of fathers, and anxiety present in 36 to 48% of parents, rates two to three times those observed in community samples.

Beyond emotional distress, parents of children with chronic illnesses frequently experience financial strain, increased parental stress, and disruptions to family functioning, including heightened conflict (Cousino & Hazen, 2013; Friedman et al., 2004). These cumulative pressures illustrate the close interdependence between caregiver wellbeing and the broader functioning of the family system, underscoring the need for approaches that recognise the reciprocal links between parental mental health and child outcomes. The psychosocial impact of cystic fibrosis (CF), as with other chronic health conditions, reverberates throughout the entire family system. Parents of children with CF face numerous additional challenges, including adapting to their child's diagnosis, managing a demanding treatment regimen, and coping with ongoing concerns regarding their child's health. Consequently, they are at increased risk of experiencing poor mental health outcomes (Daly et al., 2022). Although the caregiving role is central to the lives of individuals with CF and their families, research indicated that caregivers often experience significant declines in objective measures of quality of life during periods of disease exacerbation. Moreover, rates of psychological distress among caregivers have been found to be comparable to, or even higher than, those reported by individuals living with CF themselves (Graziano et al., 2023).

Family functioning within the Cystic Fibrosis Context

Extending this broader chronic illness literature, research in cystic fibrosis highlights family functioning as a central influence on adolescent psychosocial and health outcomes. Families characterised by cohesion, clear communication, and adaptability tend to provide

a protective environment that supports resilience, facilitates engagement with treatment routines, and promotes emotional regulation and wellbeing in young people (Psihogios et al., 2019). In contrast, patterns of conflict, disengagement, or limited emotional availability can exacerbate stress within the family system and undermine both caregiver wellbeing and child adjustment (Continisio et al., 2020). Although these associations are well established, most studies remain cross sectional, limiting conclusions about causal pathways.

Parental mental health represents one of the primary mechanisms through which family functioning influences child outcomes. Parents of children with chronic illnesses, including cystic fibrosis (CF), experience higher rates of psychological distress than parents in the general population, and this distress is associated with poorer emotional and behavioural adjustment in their children (Law et al., 2014; Wong & Heriot, 2008). These effects are particularly salient in CF, where daily care requires sustained parental involvement in medication management and physiotherapy. Elevated parental stress can reduce coping capacity, affect communication, and disrupt the consistency needed for effective disease management (Landi et al., 2021). Positive parent–child relationships and strong social support, by contrast, have been linked to more favourable psychosocial outcomes in children with CF (Ernst et al., 2010).

Parent–child interactions also play a central role in adherence to treatment, a critical component of CF care. Parental psychological distress not only affects caregivers' own wellbeing but can negatively influence the child's adherence to complex treatment regimens, with higher child depressive symptoms and poorer perceived parental relationships associated with lower adherence (Smith et al., 2010). Furthermore, maternal

coping styles and illness perceptions have been shown to predict behavioural outcomes more strongly than objective indicators of disease severity, illustrating the powerful influence of parental cognitive and emotional responses on child functioning (McCusker et al., 2012). Taken together, these findings highlight the interdependence between caregiver wellbeing, family functioning, and child disease management, underscoring the importance of psychosocial support interventions that address the needs of both parents and adolescents.

Although systematic research exploring family functioning specific to cystic fibrosis remains limited, available studies underscore its significance. Wilson et al. (1996) showed that the way a family functions can influence how a child's health problems impacts both their physical and emotional wellbeing. In other words, the child's health and the family's patterns of coping interact with each other, shaping the overall impact of cystic fibrosis (Wilson et al., 1996). Similarly, a study which examined the role of parental adaptation, found that parents who were unresolved regarding their child's diagnosis exhibited lower family functioning, with their children reporting more family conflict themes (Popp et al., 2014). These findings highlight the importance of illness narratives and parental meaning-making processes in shaping family adjustment. A systematic review investigating the impact of CF on unaffected siblings identified four central themes: family functioning, psychosocial impact, knowledge of CF, and condition-specific differences, emphasising the need for CF-specific research, as findings from broader chronic illness literature may not fully capture the unique demands of this condition (Chudleigh et al., 2019).

Collectively, this body of evidence demonstrates the intrinsic interrelatedness between parental psychological distress, family functioning, and adjustment, psychosocial,

health and adherence outcomes for individuals with CF. Specific variables, such as child age, appear to moderate these relationships. Although family functioning is a predictor of outcomes across the developmental spectrum, periods of transition, particularly middle childhood, and adolescence, pose distinctive challenges in managing the chronicity of CF and merit focused investigation.

Adolescence can intensify existing family tensions as parents navigate evolving roles, balancing the need to support their child alongside fostering autonomy (Lerch & Thrane, 2019). During this stage, decreasing parental control and challenges with treatment adherence often heightens parental worry and anxiety about their child's health (Besier et al., 2011). The quality of the parent–child relationship remains central to emotional wellbeing; for young people managing chronic illness, a secure relational foundation facilitates better disease management and psychosocial adjustment (Smith et al., 2010).

Supporting parents through this developmental transition may therefore promote positive outcomes for both parties. Providing parents with guidance on how to navigate shifting roles, foster autonomy, and manage their own emotional responses can strengthen family communication and reduce conflict at a time when treatment demands and identity development intersect. Enhancing parental coping and flexibility may also create conditions that support adolescents' psychological adjustment and engagement with self-management. In this way, developmental and family systems research identifies supporting parents as a modifiable target that can be translated into specific intervention components designed to improve both parent and adolescent

Underlying cognitive processes, including coping strategies, illness perceptions, and stress appraisal, represent key mechanisms linking parental distress and child outcomes, and they provide viable targets for psychosocial intervention (Cousino & Hazen, 2013; Lazarus & Folkman, 2006; McCusker et al., 2012; Thompson et al., 1992). These processes shape how parents interpret symptoms, respond to treatment demands, and engage with their child's emotional needs (Brosig et al., 2007; Smith et al., 2010). For example, parents who appraise situations as overwhelming or who hold negative illness beliefs may communicate heightened worry, offer less consistent support, or struggle to maintain treatment routines (Bellinger et al., 2009; Continisio et al., 2020; McCusker et al., 2006, 2012).

Despite recognition of the family's vital role in illness management, there remains a notable gap in high-quality intervention research addressing family functioning within CF populations. Specifically, adolescence represents a developmental period warranting greater empirical attention, given the simultaneous transition from paediatric to adult care and the growing expectation for self-management (Marciel et al., 2010; Sawicki et al., 2015). Together, this evidence underscores the need for integrated, family-centred approaches to care.

Conceptual Frameworks for Family Focused Interventions: Family Systems and Transactional Coping Models

A theoretical framework is a saliant quality assurance measure in intervention development because it provides an evidence based and coherent foundation for all intervention activities. It ensures that decisions about content and delivery are grounded in established principles rather than arbitrary judgement, thereby enhancing the

intervention's effectiveness, consistency, and ethical integrity (The Improved Clinical Effectiveness through Behavioural Research Group (ICEBeRG), 2006). Family Systems Theory (FST) provides a valuable framework for understanding the complex relational dynamics within families managing chronic illnesses such as cystic fibrosis (CF). The theory conceptualises the family as an interconnected emotional system in which the wellbeing of each member directly influences the overall functioning of the unit. From this perspective, individual and collective adjustment are inseparable; changes in one member's emotional state or behaviour reverberate across the family system. Empirical evidence supports this view, demonstrating that parental emotion regulation and empowerment operate as dynamic, system-level processes that shape caregiving behaviours, family interactions, and, ultimately, child outcomes (Asiegbu, 2024; Paley & Hajal, 2022). Together, Family Systems Theory and the Transactional Model offer complementary insights into relational and cognitive mechanisms underpinning adaptation.

Within this framework, parents who demonstrate a higher degree of differentiation of self-i.e., the ability to regulate emotions and maintain autonomous functioning while remaining connected in relationships; tend to provide more consistent and responsive care environments. Such environments support adolescents' self-management, treatment adherence, and psychosocial wellbeing (Bowen, 2015; Psihogios et al., 2019). Conversely, heightened caregiver stress or burnout may disrupt family cohesion, impair communication, and diminish adolescents' capacity for self-care and independence (Zehrung et al., 2024). Effective parental regulation thus not only facilitates stability in daily routines but also models adaptive coping strategies essential for navigating the ongoing demands of CF.

Complementing this systemic perspective, our new intervention is also underpinned by the Transactional Model of Stress and Coping (Lazarus & Folkman, 2006; Thompson et al., 1992). This model posits that the psychological impact of illness is mediated by the family's cognitive appraisal of stressors and their perceived ability to manage them. Stress arises not solely from the illness itself but from how individuals and families interpret and respond to illness-related challenges. Accordingly, coping is conceptualised as a multidimensional, dynamic process emerging from the ongoing interaction between person and environment. It encompasses both problem-focused strategies, aimed at altering the source of stress, and emotion-focused strategies, aimed at regulating emotional responses to stress (Lazarus & Folkman, 2006). Several established family-focused interventions draw explicitly on this model including interventions such as the *Congenital Heart Disease Intervention Programme (CHIP*), (McCusker et al., 2010), *CHIP – School* (McCusker et al., 2012). While others are extended its principals to different paediatric conditions such as such as *Improving Outcomes for Children with Epilepsy (IOCE)* (McCusker et al., 2025) *and* Family First (McCusker et al., 2024). Interventions informed by the Transactional Model focus on enhancing coping and adjustment capacities within families, recognising that fostering adaptive appraisal and flexible coping mechanisms can mitigate the stress associated with chronic illness.

Integrating Family Systems Theory and the Transactional Model of Stress and Coping thus provides a comprehensive conceptual foundation for understanding and supporting family functioning in the context of CF, where emotional regulation, communication, and collaborative coping are critical determinants of both psychosocial and health outcomes. While both frameworks are conceptually robust, their empirical

integration in CF-specific research remains limited, particularly in examining how family-level emotion regulation and appraisal processes jointly predict treatment adherence and psychosocial adjustment. Empirical testing of this integration in CF populations remains rare, underscoring the originality of applying these models in the current research.

Family-focused interventions in Paediatric Chronic Illness

A growing evidence base demonstrates the importance of family-centred psychological care across paediatric chronic illness contexts. Parental wellbeing is recognised as an important protective factor, and psychosocial interventions have shown promise in improving coping, reducing anxiety and stress, and strengthening communication, family cohesion and flexibility, although findings are mixed and not consistently observed across studies (Eccleston et al., 2015; Psihogios et al., 2019). In conditions such as cystic fibrosis (CF), where care responsibilities are shared between parents and adolescents, effective communication and flexible role-sharing are critical for fostering adolescent autonomy (Nicolais et al., 2019).

FFI are non-medical interventions which are socially, psychologically, or behaviourally orientated and involve the patient and their family or members of the patient's family (Knafl et al., 2017). Psychologically informed FFIs typically aim to improve parenting behaviour and mental health, enhance family functioning, and, indirectly, support child adjustment. While evidence for their impact on child outcomes is emerging, effects are often partial and variable across studies. Reviews of the literature suggest that the most commonly evaluated family-focused therapeutic approaches in paediatric chronic illness include cognitive behavioural therapy (CBT), problem-solving therapy (PST), family therapy (FT), motivational interviewing (MI), and multisystemic therapy (MST) (Eccleston et

al., 2012, 2015; Law et al., 2019; Mitchell et al., 2020). However, the strength and consistency of evidence vary across these approaches.

Cognitive Behavioural Therapy

Among these approaches, CBT represents the most extensively studied intervention for parents of children with chronic medical conditions, with over 20 trials conducted across a range of paediatric illness contexts (e.g., Kashikar-Zuck et al., 2012; Laffel et al., 2003; Palermo et al., 2009; Sanders et al., 1994; Westrupp et al., 2015). However, the methodological quality of this evidence base is mixed. Most studies employed active comparator conditions, with only a small minority using wait-list controls, limiting causal inference (Bonnert et al., 2017; Palermo et al., 2009). Meta-analytic evidence indicates that CBT is associated with small to moderate improvements in parenting behaviour at post-treatment, with smaller effects maintained at follow-up, but there is no consistent evidence of benefit for parental mental health (Law et al., 2019). Effects on child outcomes are similarly variable, with modest improvements in child behaviour or disability and short-term medical outcomes, but no reliable effects on child mental health or broader family functioning. Where benefits are observed, effect sizes are small, suggesting incremental rather than substantive change (Law et al., 2019; Palermo et al., 2009; Wade et al., 2017). Notably, alternative approaches such as PST have placed a greater emphasis on parental coping rather than cognitive restructuring.

Problem-Solving Therapy (PST)

Problem-Solving Therapy (PST) aims to strengthen individuals' capacity to manage stress and adversity by targeting both problem orientation (the individual's mindset toward challenges) and problem-solving skills (structured approaches to resolving difficulties)

(Cuijpers et al., 2018). Through systematic steps of problem identification, goal setting, and solution generation, PST seeks to reduce psychological distress and enhance adaptive coping. These structured strategies align closely with the DO ACT model used in prior family-focused interventions, supporting parents to define concerns, generate workable options, and translate plans into action (McCusker et al., 2025).

Problem-solving therapy has been evaluated in a smaller but comparatively more focused body of work, with twelve trials involving parents of children with chronic illness (Daniel et al., 2015; Greenley et al., 2015; Husted et al., 2014; Nansel et al., 2009, 2012; Palermo et al., 2016; Sahler et al., 2002, 2005, 2013; Seid et al., 2010; Wade et al., 2006, 2017). PST is distinctive in that it has often been delivered exclusively to parents and explicitly designed to reduce parental distress. Consistent with this focus, PST shows more reliable effects on parental coping and mental health than several other intervention types (Law et al., 2019). However, evidence for child-level and broader family-level outcomes remains limited, with insufficient data to draw firm conclusions regarding downstream effects. To date, PST has been evaluated predominantly with parents of children with cancer, with more limited application across other chronic illness populations.

PST-informed programmes including CHIP, Family First, and IOCE illustrate how structured problem-solving can be embedded within broader family resilience interventions, alongside psychoeducation and opportunities for peer support (McCusker et al., 2010, 2012, 2024, 2025). Such skills may be particularly valuable during adolescence, when shifting family roles and increasing autonomy can challenge established caregiving patterns (Lerch & Thrane, 2019; Nicolais et al., 2019). More broadly, group-delivered PST has demonstrated adaptability across diverse populations (Cuijpers et al., 2018), and

parent-targeted PST interventions for paediatric chronic health conditions have been associated with improvements in parental wellbeing and aspects of family functioning (Zhou et al., 2024). Together, these findings support PST as a relevant mechanism for supporting parents of adolescents with CF, where collaborative problem-solving and flexible role negotiation are central to effective disease management.

Family Therapy, Motivational Interviewing and Multisystemic Therapy

In contrast the evidence base for family therapy is both small and methodologically weak. Across four studies, only one employed a wait-list control condition, and data on key outcomes were frequently unavailable or insufficient for synthesis (Kazak et al., 2004; Wysocki, 2000; Wysocki et al., 2007; Yeh et al., 2016). Meta-analytic findings indicate no clear benefits for child symptoms or family functioning, with high heterogeneity and very low quality of evidence. While family therapy aligns strongly with systemic models of adjustment to chronic illness, current empirical support remains limited, highlighting a gap between theoretical appeal and demonstrated effectiveness.

Similarly, motivational interviewing and multisystemic therapy have been evaluated in a small number of studies, all using active comparator conditions and often conducted by the same research groups (Ellis et al., 2005, 2012, 2017; May et al., 2017; Mayer-Davis et al., 2015; Naar-King et al., 2014). Across both approaches, insufficient extractable data and small sample sizes preclude meaningful conclusions regarding effectiveness for parent, child, or family-level outcomes. The overall quality of evidence for both MI and MST have been rated as very low due to imprecision, heterogeneity, and risk of bias.

Taken together, the broader FFI literature suggests that parent-focused interventions are more likely to yield improvements in parental coping and distress than in child psychological outcomes or family functioning. Effects on children, when present, tend to be modest, delayed, and inconsistently observed. These patterns underscore the importance of clearly specifying mechanisms of change and aligning intervention targets with theoretically informed pathways of influence. Complementary synthesis and meta-analytic (Garcia Rodrigues et al., 2022) evidence demonstrated reliable gains in parental quality of life alongside more variable downstream child outcomes. Collectively, these findings show the importance of clearly identifying how an intervention is expected to work and ensuring that its targets are guided by theory, especially when benefits for children are likely to occur indirectly through improvements in parents' flexibility, coping skills, and family relationships.

Importantly, such findings highlighted that effective interventions attend not only to challenges common across chronic illness, such as providing space for families to express worries and share experiences, but also to disease-specific and developmentally contingent demands. For example, in cystic fibrosis, family interventions frequently centre on treatment adherence and shared responsibility across adolescence, while in acquired brain injury, supporting parental understanding of cognitive and behavioural changes becomes a central focus. The review further identified shared features across interventions including strategies to strengthen resilience, enhance coping and problem-solving capacity, and support families in adapting to evolving illness-related demands over time (Garcia Rodrigues et al., 2022).

The Congenital Heart Disease Intervention Program (CHIP) exemplifies this family centred, disease specific approach. Delivered through brief group workshops, CHIP strengthens parental mental health, parenting confidence, and family functioning—factors shown to predict child outcomes beyond illness severity alone McCusker et al., 2006). Grounded in transactional stress and coping theory (Thompson et al., 1992), CHIP provides psychoeducation, practical parenting skills, and the DO ACT structured problem-solving model, which guides parents to define concerns, generate solutions, and take action (McCusker et al., 2010). Trials of CHIP-Infant and CHIP-School report significant, sustained improvements in maternal mental health, reduced family strain, and enhanced perceptions of child wellbeing and school attendance (McCusker et al., 2010; 2012) demonstrating the lasting benefits of early, targeted psychological support that prioritises family functioning.

Building on CHIP's foundation, the Family First programme supported families affected by childhood acquired brain injury (ABI) by enhancing family resilience through multiple theory-driven approaches. Delivered over a series of group sessions in community settings, Family First combines psychoeducation, emotional support, skill development, and peer support to address the complex challenges families face following ABI (McCusker et al., 2024). Underpinned by transactional stress and coping theory and family systems theory, this intervention promoted open family communication, adaptive problem-solving, and emotional regulation. Early findings demonstrated feasibility, significant improvements in family communication and problem-solving abilities, enhanced parental emotional wellbeing, and reduced stress (McCusker et al., 2024).

Similarly, the Improving Outcomes for Children with Epilepsy (IOCE) programme, adapted from CHIP and congenital heart disease research (McCusker et al., 2006, 2010,

2012b) offers a structured, theory-driven family resilience approach tailored for paediatric epilepsy. Delivered as a one-day workshop with a follow-up session, IOCE normalises parental experiences and improves family communication. Through psychoeducation, narrative meaning making, and tailored problem-solving strategies, IOCE promotes adaptive coping among parents (McCusker et al., 2024). Key mechanisms include helping parents reframe worries, modelling coping through "expert by experience" input, and practising the DO ACT framework. Pilot results were promising; parents reported reduced maternal worry, improved family expressiveness, increased resilience, greater confidence in child independence, and enhanced social connectedness. Although child behavioural changes were less immediate, parents noted improved perceptions of quality of life, consistent with evidence that parental gains often precede child outcomes improvements (Kim et al., 2018).

Collectively, the evidence reviewed highlights the value of family-focused interventions in promoting parental wellbeing, adaptive coping, and family resilience across a range of paediatric chronic illness contexts, with potential downstream benefits for child outcomes. Interventions that prioritise parental mental health, strengthen communication, and support collaborative problem-solving appear particularly effective in addressing the relational and emotional demands of long-term illness management. However, despite demonstrated efficacy in several paediatric populations, a comparable, well-evaluated family-focused intervention has yet to be established for families affected by cystic fibrosis.

Reviews of psychosocial interventions in cystic fibrosis have consistently identified a limited and uneven evidence base, alongside ongoing uncertainty regarding optimal

approaches for supporting families (Glasscoe & Quittner, 2008; Goldbeck et al., 2014). Existing interventions have tended to focus on individual adherence, child behaviour, or symptom management, with less emphasis on parental psychological wellbeing and family-level processes, particularly during adolescence. The transferability of family-focused models developed in other paediatric conditions remains uncertain, given the unique and evolving demands of CF care.

Contextual and Developmental Challenges in Cystic Fibrosis

Cystic fibrosis presents a distinct constellation of challenges for families, including high daily treatment burden, infection control–related social restrictions, and the requirement for sustained parental involvement alongside the gradual transfer of responsibility to adolescents. These challenges have been further complicated in the modulator era, where improvements in physical health coexist with ongoing uncertainty regarding long-term outcomes, treatment expectations, and potential physical and psychological side effects. For many families, this ambiguity has altered caregiving roles and expectations without necessarily reducing emotional burden, underscoring the need for psychosocial support that is responsive to contemporary CF realities.

Adapting evidence-based family-focused intervention models to the CF context therefore represents a proposition that warrants empirical exploration rather than simple transfer. While programmes such as CHIP, Family First, and IOCE demonstrate the effectiveness of theory-driven, parent-focused approaches grounded in stress and coping and family systems frameworks, their application to CF requires careful theoretical refinement, attention to developmental stage, and sensitivity to disease-specific demands. This gap highlights the need for further empirical exploration of family-focused models that

are theoretically refined and sensitive to the developmental and disease-specific demands of CF.

Drawing on the broader FFI literature and evidence from disease-specific programmes, the current intervention integrates three complementary therapeutic approaches: Narrative Therapy, Acceptance and Commitment Therapy, and Problem-Solving Therapy.

Acceptance and Commitment Therapy (ACT)

Acceptance and Commitment Therapy (ACT) provides a useful framework for supporting individuals living with incurable or chronic conditions, where distress may not be fully resolved but rather accepted and channelled into meaningful action (Feliu Soler et al., 2018; Wynne et al., 2019). ACT emphasises the cultivation of psychological flexibility, defined as the capacity to remain present and engaged with difficult internal experiences while acting in alignment with one's values (Doorley et al., 2020; Hayes et al., 2006). This flexibility enables individuals to respond adaptively to distress rather than resorting to avoidance, promoting resilience and wellbeing over time.

Within family contexts, greater psychological flexibility among parents is associated with improved parenting practices, lower emotional burden, and more adaptive family interactions (Coyne et al., 2021; Daks et al., 2020; Wang & He, 2025). ACT-based family interventions, which integrate acceptance, mindfulness, and values-driven action, have been shown to enhance caregivers' capacity to manage distress, improve emotional regulation, and promote constructive family communication (Lobato et al., 2022; Parvin et al., 2024). Furthermore, ACT group interventions that focus on resilience, defined as the

ability to adapt and recover from adversity, have demonstrated significant improvements in wellbeing, underscoring the importance of relational empowerment and social support (Pinto et al., 2021).

A growing body of evidence supports ACT's transdiagnostic utility in chronic illness. Recent systematic reviews and meta-analyses have shown that ACT outperforms inactive controls and, in some cases, active treatment groups in improving quality of life, psychological flexibility, and symptom management (Konstantinou et al., 2023). Although the methodological quality of some studies remains low, consistent findings suggest ACT's potential relevance to families coping with chronic paediatric illness. Specifically, ACT interventions for parents of children with chronic health conditions have demonstrated reductions in psychological distress and improvements in parenting behaviour (Jin et al., 2021). Single-session ACT interventions have also shown feasibility and clinical benefit, offering an accessible, resource-efficient model that aligns well with the intensive demands of CF management (Dochat et al., 2021). Given ACT's emphasis on adaptive functioning and values-based action, it presents a promising framework for enhancing family resilience, promoting adherence, and improving quality of life among families managing CF. Future CF-focused adaptation of ACT could emphasise brief, group-based models feasible for family workshops. Further, ACT may be especially well suited to families managing cystic fibrosis, as it provides tools for responding flexibly to uncertainty related to treatment expectations, long-term outcomes, and evolving care demands.

Problem Solving Therapy

Building on its earlier discussion as an evidence-based intervention approach, Problem-Solving Therapy (PST) is also considered here as a core theoretical mechanism

underpinning the present intervention design. PST provides a structured, skills-based framework to support parents in managing the practical and emotional challenges associated with chronic illness. PST focuses on enhancing problem orientation, that is, how individuals perceive and approach difficulties, alongside teaching systematic problem-solving steps including problem definition, goal setting, solution generation, decision-making, and action planning (Cuijpers et al., 2018). Within family contexts, PST supports parents to respond to stressors in a more flexible, deliberate, and collaborative manner, reducing feelings of helplessness and emotional overload. These processes are particularly relevant for parents of adolescents with cystic fibrosis, who must navigate ongoing treatment demands, shifting responsibility, and recurrent decision-making under conditions of uncertainty. PST's emphasis on shared problem definition and solution-focused dialogue aligns closely with the DO ACT framework used in prior family-focused interventions, supporting adaptive role negotiation, effective communication, and sustained engagement with care tasks. When delivered in group-based formats, PST also facilitates normalisation and peer learning, further strengthening parental confidence and resilience. As such, PST represents a pragmatic and theoretically coherent mechanism for enhancing parental coping and family functioning within a CF-specific family-focused intervention.

Together, ACT and PST address complementary dimensions of parental adjustment, with ACT supporting flexible responses to internal experiences and PST equipping parents with practical strategies to address ongoing external challenges

Narrative Therapy (NT)

Narrative Therapy (NT) offers a complementary, strengths-based approach to psychosocial support in chronic illness. NT facilitates meaning-making by helping individuals and families re-author their personal narratives, positioning them as agents in their own stories rather than passive subjects of illness (Tadros et al., 2024). By externalising problems—viewing them as separate from the person—NT promotes empowerment, resilience, and self-efficacy.

Empirical evidence supports NT's efficacy in reducing emotional distress, improving quality of life, and enhancing coping among individuals and families facing chronic health challenges and psychosocial stressors (Ghavibazou et al., 2022; Hu et al., 2024; Shakeri et al., 2019). NT's adaptability to group and family-based interventions also makes it a valuable tool for improving communication and relational understanding (Dane et al., 2025; Menard et al., 2018). For parents of adolescents with CF, NT offers a meaningful avenue to explore and reframe the emotional and relational impacts of illness, strengthening family communication, promoting reflective processing, and supporting adaptive coping. Narrative reframing thus aligns closely with family meaning-making processes identified earlier, providing a coherent theoretical bridge to intervention design. Narrative Therapy complements ACT and PST by providing a relational and meaning-focused framework through which families can integrate emotional experiences and practical challenges into a coherent shared understanding

Taken together, ACT, PST, and Narrative Therapy offer a theoretically integrated and developmentally sensitive framework for a family-focused intervention that addresses

emotional regulation, practical coping, and meaning-making among parents of adolescents with cystic fibrosis.

Best practice guidance and identified research priorities

This section situates the proposed study within existing policy frameworks and consensus research priorities. The UK Medical Research Council (MRC) provides a comprehensive framework for the development, evaluation, and implementation of complex interventions, which are defined not by their specific content but by the dynamic interaction of components, behaviours, and systems (Skivington et al., 2024). The framework positions intervention development as an iterative and theory-informed process, shaped by evidence and context rather than a linear progression toward trial. In line with this approach, preliminary pilot and feasibility studies are strongly encouraged before undertaking large scale evaluations, so that acceptability, relevance, and deliverability in real world settings can be examined and refined. A central feature of the framework is the emphasis on process evaluation, which seeks to understand how and why an intervention may operate, for whom it might be beneficial, and under what conditions such effects could occur (Skivington et al., 2021). Within pilot research, process evaluation plays a critical role by informing the adaptation of intervention content and delivery, exploring implementation fidelity and participant engagement, and identifying contextual factors that influence feasibility. In this study, the MRC framework provided a structure through which the emerging intervention could be developed in a systematic, context aware, and evaluative manner**.**

The National Institute for Health and Care Excellence (NICE, 2017) recognises that people with cystic fibrosis (CF) and their families may require psychological support at

multiple points across the lifespan, including diagnosis, transitions between care stages, management of disease complications, fertility concerns, transplantation, and end-of-life care. Despite these recommendations, a recent scoping review identified that the psychological and mental health needs of individuals with CF remain inadequately addressed (Tickner et al., 2022). The review highlighted a limited evidence base for effective, high-quality interventions targeting mental health in CF populations. Most existing interventions have primarily focused on education, adherence, or behavioural modification; however, randomised controlled trials have shown little evidence of clinically meaningful improvement. Moreover, Tickner et al. (2022) cautioned that implementing widespread mental health screening in the absence of evidence-based interventions risks widening the mental health gap in this population.

The James Lind Alliance (JLA) has sought to align research priorities with the lived experiences of patients, families, and clinicians. Established to bridge the gap between academic research agendas and the practical needs of those affected by health conditions, the JLA methodology identifies unanswered questions that are most relevant to service users (The James Lind Alliance, 2023). In 2017, the Cystic Fibrosis Priority Setting Partnership (PSP) conducted by the JLA, identified the top research priorities for CF. While the ten highest-ranked questions focused primarily on physical health outcomes, psychological wellbeing was still recognised as a critical area of unmet need. Specifically, research questions ranked 13 and 14 addressed (13) *"What types of psychological and family support benefit people with cystic fibrosis in maintaining regular treatment and good quality of life?"* and (14) "*What is the most effective management of anxiety and depression in people with cystic fibrosis?"* (Question CF, 2023). These priorities underscore

the growing recognition that psychological and family-based interventions are essential components of comprehensive CF care.

In response to these identified gaps, the proposed doctoral project comprises two interrelated studies:

Study One: A provider engagement study designed to inform the development and design of a novel family-focused therapeutic intervention.

Study Two: Development, feasibility and pre–post pilot study evaluating the acceptability, accessibility, and preliminary effectiveness of the intervention for parents of adolescents with CF.

The overarching aims of the project are fourfold:

1. To develop an evidence based, family-focused intervention for parents of adolescents with Cystic Fibrosis
2. To assess the feasibility of a community-based, family-focused intervention in terms of engagement, accessibility, and acceptability.
3. To examine preliminary pre–post outcomes relating to parental psychological wellbeing and family functioning.
4. To explore participants' experiences of engaging in a family-focused intervention for CF.

Together, these priorities affirm the necessity of family-focused, theoretically grounded psychosocial interventions for CF—precisely the gap addressed by the present doctoral project.

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Chapter 3: Provider Engagement Study

"I'm cured now!": Provider Perspectives in the development of a family-focused intervention for teenagers with cystic fibrosis – issues of adherence and family dynamics, in the era of modulator therapies.

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"I'm cured now!": Provider Perspectives in the development of a family-focused intervention for teenagers with cystic fibrosis – issues of adherence and family dynamics, in the era of modulator therapies.

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Abstract

The rapidly transforming landscape of cystic fibrosis (CF) care, driven by widespread use of CFTR modulator therapies, has reshaped the clinical, developmental, and psychosocial experiences of young people with CF and their families. As treatment expectations shift, there is an urgent need for family-focused psychological support that reflects contemporary realities. Yet clinician perspectives, despite their frontline knowledge of emerging challenges have not been systematically incorporated into the development of parent-focused interventions. This study explores these perspectives to inform the design of a novel Family-Focused Intervention (FFI) for parents of adolescents with CF.

Hospital-based providers from medical, nursing, and allied health disciplines (n = 7) participated in a focus group to share their observations of family needs in the modulator era. Thematic analysis generated four interconnected themes: (1) shifting adherence and treatment practices, (2) family communication and emotional climate, (3) adolescent development, identity and social pressures and (4) the need for enhanced family-centred support. These interrelated themes emerged within the context of modulator therapies and a rapidly changing landscape for adolescents, parents and providers alike. This study directly shaped the FFI by informing its emphasis on autonomy-supportive communication, problem solving skills-building, emotional coping skills, and the integration of lived experience.

Plain English Summary

Cystic fibrosis (CF) care is changing quickly because of new treatments called CFTR modulators. These medicines have allowed many young people with CF to feel much healthier than before. While this is a very positive development, it also brings new challenges for families. Teenagers who feel well may be less motivated to keep up with daily treatments, and parents may find it difficult to know how much responsibility they have to hand over. Families and healthcare teams are now navigating a very different landscape compared to previous generations.

To create better support for parents during this time, we spoke to hospital-based providers who work closely with teenagers with CF and their families. Seven providers from medical, nursing, and allied health backgrounds took part in a focus group to share their experiences. We analysed their discussions and identified four main themes. These were: (1) changes in treatment routines and adherence because of modulator therapies; (2) the importance of family communication and the emotional impact of CF on parents; (3) the challenges of adolescence, including identity, independence, and peer pressure; and (4) the need for improved, family-centred support for parents.

These insights directly shaped the development of a new Family-Focused Intervention (FFI) designed for parents of adolescents with CF. Providers highlighted the importance of helping parents support their teenager's growing independence, manage difficult emotions, and solve problems together. They also emphasised the value of hearing from other parents with lived experience.

By listening to providers' frontline perspectives, this study provides a strong foundation for an intervention that reflects the realities of modern CF care and aims to support families through this period of change.

Keywords: Clinical/provider engagement, Cystic Fibrosis, Adolescence, Parenting

Background

Cystic fibrosis (CF) is a life-limiting genetic condition caused by mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene, resulting in the production of thick mucus that primarily affects the respiratory and digestive systems Cystic Fibrosis (Bierlaagh et al., 2021; Cystic Fibrosis Foundation, n.d.). CF causes enduring lung infections and over time limits the ability to breathe (Cystic Fibrosis Foundation, n.d.). Ireland has the highest prevalence of CF worldwide, alongside the most difficult to treat gene mutation. Around thirty new cases of CF are diagnosed in Ireland annually (Cystic Fibrosis Foundation, n.d.). Adolescents with CF typically manage demanding multimodal treatment regimens that can occupy several hours each day, creating substantial practical and emotional demands for both young people and their families (Nicolais et al., 2019; Smith et al., 2016). For families, cystic fibrosis has been described as one of the most challenging pediatric diseases to manage, given the strict treatment regime required across all systems the child/young person is embedded in. Historically, life expectancy for people with CF was severely limited; however, the introduction of CFTR modulator therapies, including elexacaftor/tezacaftor/ivacaftor, has led to marked improvements in physical health outcomes and quality of life for many individuals. These therapies target the underlying protein dysfunction and are effective across a wide range of CFTR variants, although not universally, and some individuals experience side effects that necessitate treatment modification. While these biomedical advances represent a significant shift in prognosis, they have also altered expectations of illness and care, introducing new patterns of adjustment for families navigating adolescence in the contemporary CF landscape.

Research to date has demonstrated that the management of CF and the burden of this disease places caregivers at high risk of developing psychosocial difficulties, mental

health difficulties and reduced quality of life (Fidika et al., 2015; Graziano et al., 2020). Given the additional demands which parents of children with CF face (e.g., adjustment to their child's diagnosis, a demanding treatment regime, and worry for their child's health), parents of children with CF are at risk of poor mental health (Graziano et al., 2023). The chronicity of constantly managing their child's illness, managing the treatment burden of CF and uncertainty about the future may lead to high levels of chronic stress and anxiety (Daly et al., 2022). Parents of children with chronic illnesses often report increased financial strain, family conflict and parental stress (Cousino & Hazen, 2013; Friedman et al., 2004). Parents of children with CF were found to be three times more likely to experience clinical depression than those in a community sample, and rates of depressive symptoms were elevated in both children with CF and parents (Quittner et al., 2014; Smith et al., 2010). Further, the prevalence of anxiety in parents was found to be high (Lord et al., 2023). These parental factors alongside the impact of the disease on the child can lead to a cumulative impact on family functioning.

CF complicates the already challenging developmental stage of adolescence. Adolescence is important for identity formation and a developing need for autonomy, however the burden of disease treatments, lifestyle restrictions and poor physical health can often limit an adolescents engagement with normal recreational, social and educational activities which are crucial to normative psychosocial development (Muther et al., 2018). Adolescents with CF are unable to socialize with others with CF due to infection control measures (Vines et al., 2018). This disrupts the normative adolescent experiences of community, friendship and social development, leading to increased levels of loneliness and social deprivation from being unable to interact with others who are just like them (Moola, 2018).

The impact of the disease on the wider family is doubly important as the way a family functions is an essential determinate of psychosocial and physical health outcomes for adolescents living with chronic illness (Whitehead et al., 2018). Parents play a significant role in their child's ability to adjust to living with a chronic illness, in terms of their child being able to participant in activities of daily life and their child's emotional functioning. As children with CF are dependent on their parents for support around the administration of medication and physical therapies at home, the links between family functioning, child adjustment and treatment adherence is especially relevant (DeLambo et al., 2004; Psihogios et al., 2019). Parental psychological distress is understood to be a risk factor for poorer outcomes in children with chronic health conditions, therefore having the potential to influence their child's adjustment to chronic illness (Law et al., 2014). A bidirectional relationship has been established whereby parents of children with disease are at risk of increased mental health difficulties, and these mental health difficulties in turn impact the outcomes of the child's disease (Landi et al., 2021; McCusker et al., 2012). While family functioning is a predictor of outcome across the developmental span, developmental transitions such as adolescence present unique challenges in managing the chronicity of cystic fibrosis and warrant research.

Psychologically informed, family-focused interventions have attracted growing research attention as a means of strengthening resilience and coping among families managing childhood chronic illness (Eccleston et al., 2015; Psihogios et al., 2019). Programmes that directly target parenting practices and family communication have demonstrated benefits for parental wellbeing and aspects of child adjustment across several paediatric conditions. Examples include the Congenital Heart Disease Intervention Program (CHIP), which reported sustained improvements in maternal mental health and

family strain (McCusker et al., 2006), the Family First programme for acquired brain injury, which showed early gains in family communication and parental coping (McCusker et al., 2024), and the Improving Outcomes for Children with Epilepsy (IOCE) workshop, which integrates psychoeducation, narrative approaches, and structured problem-solving (McCusker et al., 2006, 2010, 2012). Despite encouraging findings in other conditions, equivalent family-focused work remains limited in cystic fibrosis, indicating the need for models that are theoretically grounded yet tailored to the developmental and disease-specific demands of CF.

In response to this gap, the planned Family-Focused Intervention (FFI) was conceptualised as a brief, psychologically informed group workshop for parents of adolescents with CF. The proposed format centred on a one-day session combining psychoeducation, reflective discussion, and structured skills practice, drawing on established frameworks including Acceptance and Commitment Therapy, systemic and family-based principles, narrative approaches, and problem-solving strategies. The intended focus was to support parents in understanding adolescent development, communicating effectively, managing uncertainty and emotional strain, and promoting flexible autonomy while sustaining treatment engagement.

While this framework offered a theoretically coherent starting point, the rapidly evolving clinical context of CF, particularly in the modulator era, signaled the likelihood of emerging patterns of family adjustment and support needs. A professional focus group was therefore undertaken to ensure that the intervention's structure, emphasis, and delivery were aligned with contemporary clinical realities and service contexts. This positioned provider engagement as a developmental step aimed at refining the intervention and increasing its likely relevance, acceptability, and practical utility.

Patient and public involvement is increasingly recognised as central to producing clinically relevant and patient-centred research (Agyei-Manu et al., 2023; Harrison et al., 2019). Although clinician or provider engagement is typically conceptualised as broader stakeholder involvement rather than formal PPI, it has similarly been associated with improvements in healthcare performance and outcomes (Boaz et al., 2015, 2024). In paediatric chronic illness, where care is complex and condition-specific expertise is essential, collaboration with frontline providers offers a pragmatic route to ensuring that intervention development is both clinically grounded and responsive to the lived realities of families affected by cystic fibrosis.

Against this backdrop of changing clinical and psychosocial demands, the present study sought to explore multidisciplinary CF providers' perspectives to inform the development of a family-focused psychological workshop for parents of adolescents. The aim was to understand how clinicians' frontline insights into family dynamics, adolescent adjustment, and emerging challenges in the modulator era could shape the focus and delivery of a parent-centred intervention.

Methods

Design

This study used a qualitative approach, underpinned by a constructivist paradigm. We ran a focus group with MDT staff from the CF team to gain an understanding of their perspectives and thoughts about numerous aspects of the design and implementation of a one-day family-focused psychological intervention for parents of adolescents with CF. Further, the focus group aimed to elicit the team's perspectives on the psychosocial and clinical nuances of CF, including family dynamics, needs, and emerging challenges. A focus group was selected to gain individual and shared clinical experiences and perspectives

while encouraging multiple viewpoints within an interactive group setting (Krueger & Casey, 2000). Focus groups are well suited to capturing the subtleties of professional practice, interpersonal dynamics, and contextual influences that may be overlooked in quantitative surveys or individual interviews. Research indicated that clinician focus groups can enrich understanding of researcher–practitioner collaboration by highlighting shared perspectives rooted in everyday clinical contexts (Daniels et al., 2021). Moreover, involving a broad range of clinical stakeholders early in intervention planning has been shown to help researchers anticipate and mitigate common barriers to trial implementation (Tambor et al., 2021). Further, we were interested in understanding the participants' experiences as a clinical team, to allow space for participants to reflect on each other's experiences and ultimately to gain perspectives via differing clinician lens. However, a single focus group also constrained the breadth of accounts generated and may have amplified consensus, professional norms, or socially desirable accounts of service provision.

Participants, Recruitment and Setting

All members of the multidisciplinary team (MDT) within the tertiary-level CF service in Ireland were invited to participate in a focus group exploring the development of a Family-Focused Intervention (FFI) for parents of adolescents with CF. The MDT comprises medical, nursing, physiotherapy, occupational therapy, dietetics, and psychology professionals. Information sheets were displayed across clinical areas, and the Principal Specialist Psychologist distributed electronic invitations to the wider MDT (n = x). The final sample consisted of seven participants.

Participants represented a range of professional roles, reflecting the multidisciplinary nature of CF care. The sample included medical (n = 1), nursing (n = 2), dietetic (n = 1) physiotherapy (n = 2), and a clinical psychologist, providing a breadth of

clinical perspectives relevant to family functioning and adolescent care. Table 1 summarises the demographic and professional characteristics of the participants, including pseudonyms, professional role, and gender. This diversity strengthened the richness of the data by incorporating varied clinical lenses on adolescent wellbeing, parental adjustment, and emerging challenges in the modulator era. However, participation was self-selected, and those who chose to attend may have been particularly interested in psychosocial care, family work, or intervention development. As such, the findings may over-represent clinicians already attuned to the value of psychological and family-focused support.

Table 1

Participant characteristics

Pseudonym	Profession	Gender
Michael	Medic	Male
Peggy	Physiotherapist	Female
Anne	Clinical Nurse Specialist	Female
Paula	Clinical Nurse Specialist	Female
Mary	Dietitian	Female
Veronica	Physiotherapist	Female
Elaine	Clinical Psychologist	Female

Procedure

The focus group discussion was conducted at the CF service and lasted just under one hour. The group was facilitated by two of the authors (NL & DM). The focus group

discussions were structured around four core areas of inquiry that were directly relevant to the design of the Family-Focused Intervention:

- The main fears parents face
- The greatest challenges adolescents face,
- Practical suggestions for the workshop
- Perspectives around families who achieve positive psychological outcomes

such as improved parental coping, reduced distress and worry, improved communication, greater confidence in supporting adolescent independence, and improved family functioning.

The development of these questions was directly informed by the study's aims. Specifically, the schedule was designed to elicit providers' views on the current challenges faced by parents and adolescents, their perceptions of gaps in existing support, and their recommendations for the structure, content, and delivery of a brief Family-Focused Intervention. This ensured that the data generated would meaningfully inform the refinement and tailoring of the planned intervention, rather than simply providing descriptive commentary on practice.

The focus group was guided by a semi-structured interview schedule developed to balance open exploration with attention to key areas relevant to the planned intervention (see Appendix H). The schedule invited providers to reflect on parents' fears and concerns, the challenges faced by adolescents, practical considerations for workshop delivery, and examples of families who appeared to achieve positive psychological adjustment.

Development of the interview protocol was informed by two priorities. First, we aimed to ensure that the proposed intervention reflected the lived realities of families affected by CF, drawing on providers' experiential and tacit knowledge to enhance the

relevance, feasibility, and acceptability of the workshop. Second, we sought to align the questions with existing literature on stakeholder involvement in intervention development (e.g., Boaz et al., 2015, 2024; Daniels et al., 2021; Tambor et al., 2021), research on parental distress in chronic illness (Cousino & Hazen, 2013; Goldbeck et al., 2014) and evidence concerning adolescent adjustment and family resilience (Modi et al., 2008; Quittner et al., 2014; Walsh, 2016).

Data Analysis

Data was analyzed using thematic analysis. Thematic analysis (TA) is a method for developing, analyzing, and interpreting patterns within a qualitative dataset. This involves a systematic process of coding data to generate these patterns. An inductive data analysis approach was employed, meaning the coding and theme development were driven by the data rather than shaped by an existing theoretical lens; nonetheless, a deductive component was incorporated to ensure alignment with the family-focused framework guiding the intervention's design. The analysis was semantic in that it explored meaning at a surface or explicit level rather than at an implicit level. An experiential qualitative framework was adopted, with the analysis positioned within an essentialist or realist epistemological stance. This approach sought to privilege participants' own meanings and interpretations, treating their accounts as reflective of their lived experiences and the realities they encounter in clinical practice (Braun & Clarke, 2022).

A six-phase approach to thematic analysis was employed to systematically explore patterns within the dataset (Braun & Clarke, 2006; 2013; Terry et al., 2017). The familiarisation phase involved repeated listening to the focus group audio and multiple close readings of the transcript to develop an in-depth understanding of the breadth and nuance of the data. The dataset was then analysed systematically through an iterative

coding process, during which meaningful units of text were identified, labelled, and organised in relation to the study aim. Subsequent analytic phrases involved collating codes into preliminary themes, reviewing these against the dataset to ensure coherence, refining thematic boundaries and generating clearly defined and analytically robust themes that captured both shared patterns and areas of divergence within the data.

My positionality as a researcher was shaped by several intersecting influences. I had no prior clinical experience of working with CF families and therefore approached the research as an outsider, which supported openness to learning from providers' expertise (Braun & Clarke, 2022). At the same time, I was personally invested in the development of the intervention, which introduced a potential analytic stake in identifying themes that supported its relevance. My experiences as a parent, alongside a strong grounding in Acceptance and Commitment Therapy and systemic approaches, shaped the interpretive lens I brought to the data. As the focus group facilitator, I remained reflexively aware that my presence, the direction of my questioning, and my theoretical orientation could influence both the discussion and subsequent interpretation, and I sought to remain critically attentive to these dynamics throughout analysis.

The second facilitator (NL) brought extensive clinical experience with CF families, a strong grounding in ACT, and her own perspective as a parent, which informed her attunement to family-related issues raised in the discussion. Her prior familiarity with many participants likely supported rapport and ease of conversation. However, this also introduced the possibility of social desirability effects, which was considered during reflexive appraisal.

Quality assurance involved prolonged familiarisation with the dataset, including repeated listening to the audio recording and multiple close readings of the transcript.

Data were coded systematically and reflexively, with detailed documentation of coding decisions and iterative refinement of emerging patterns. Themes were developed through an ongoing, cyclical process of reviewing coded extracts, refining conceptual boundaries, and checking interpretations against the full dataset to ensure coherence and credibility. Initial themes were refined, defined, and named over several weeks. Emergent themes were also interrogated through structured supervisory meetings, during which preliminary analyses were reviewed, alternative interpretations considered, and analytic decisions critically examined to strengthen reflexivity and analytic rigor.

Results

The thematic analysis generated four interrelated themes that reflected providers interpretations of the changing realities of CF care, the evolving needs of families, and the implications for intervention design. These themes represent how clinicians understood the psychosocial and developmental context in which the families are currently navigating adolescence in the modulator era. Table 2 provides an overview of the superordinate and subordinate themes identified through the analytic process, illustrating their interconnections and the breadth of clinical insight they represent. The following sections present each theme in turn, supported by illustrative extracts that demonstrate how providers articulated these perspectives and experiences in their own words.

Table 2

RTA superordinate and subordinate themes

Superordinate theme	Subordinate theme
1. Navigating Adherence in the Era of Modulator Therapies	a. Changing perceptions of illness and adherence b. Autonomy–control tensions in treatment routines
2. Family Communication, Emotional Climate, and Psychological Adjustment	a. Impact of communication style on family functioning b. Emotional undercurrents: anxiety, grief, and psychological adaptation
3. Adolescent Development, Identity, and Social Pressures	a. Identity formation and striving for normality b. Social pressures and developmental transition
4. Support Systems, Collaborative Care, and Intervention Needs	a. Need for family-centred psychosocial supports b. Enhancing collaboration with clinical team

Theme One: Adherence and shifting treatment practices

Providers perceived adherence as one of the most significant challenges facing families, particularly since the introduction of CFTR modulator therapies. While modulators have dramatically improved physical health, providers reported they appear to have unintentionally reduced adolescents perceived need for treatments. As one clinician explained:

"It's hard to convince them to continue when they're feeling well."

(Mary)

Several providers described adolescents expressing a belief that they were "cured," which, in their view, complicated parental efforts to maintain adherence and reshaped family negotiations around treatment expectations with providers noting:

"Some of them have said, 'I'm fine now… I'm cured.' So, it's getting it back that you still have to do your treatments." (Anna)

Participants also felt that reduced hospital attendance and fewer acute health crises were changing the rhythm of clinical engagement, which they believed altered the relational and supportive function of clinic contact

"Because they're so well now… I haven't seen [them] in six months… you're trying to build that relationship." (Anna)

From the perspective of providers, as physical symptoms became less dominant in clinical encounters, psychological, relational, and developmental processes appeared to become more visible:

"All these other things are coming now. The emotional stuff is coming to the forefront." (Anna)

Theme two: Family Communication, Emotional Climate and Parenting Dynamics

Providers emphasised that, in their experience, family communication patterns strongly shaped how adolescents engaged with their treatment. In their experience, closed or authoritarian styles of parenting were linked to conflict and resistance:

> "A lot of families where communication is quite closed… quite authoritarian… there can be resistance and pushing back." (Elaine)

Providers perceived such authoritarian styles of parenting as being underpinned by parental anxiety, particularly fears about relinquishing control. One clinician recounted a parent stating:

> "I've kept them so well to now… if they give them control, they are not going to do it 100%." (Peggy)

Conversely, providers perceived that families who adopted balanced, open communication and who normalised CF within everyday life tended to achieve more adaptive outcomes. As one participant reflected,

> "CF isn't everything about the child… the children then just see the CF as another part of them… I don't know what way the parents do that, but you definitely see a difference that way they're a bit more laid back" (Paula)

Theme 3: Adolescent Development, Identity and Social Pressures

Providers framed adolescence as a developmental period in which normative developmental needs such as identity formation, autonomy, and peer belonging, intersect with CF in complex ways. Providers observed tensions between parents' long-term health concerns and adolescents' present-focused priorities:

> "They can't see the long-term outcomes… they're living in the moment." (Elaine)

Clinicians perceived the transition to adult services as a particularly vulnerable period, during which parents sometimes struggled to step back and adolescents negotiated

increasing responsibility. Providers felt that supporting both parents and adolescents during this transition was an aspect of care which required more structured guidance and intervention.

> "It's a real wrench for them… they're not quite ready, and we need to do more to help with that transition." (Elaine)

Participants also highlighted the influence of social pressures, including risk behaviours like vaping and drinking, were described as both normative and stressful for families. One clinician recounted a parent's reaction:

> "She caught him vaping… and was demanding a chest X-ray." (Anna)

Further, providers described adolescents navigating these challenges in the absence of peer solidarity further exacerbated these challenges:

> "Not having that sense of peer solidarity with others with CF makes it even harder." (Elaine)

Theme Four: The Need for Enhanced Family Centred Support

Across accounts, providers highlighted families' need for structured psychological and practical support during adolescence. They reported that parents frequently sought guidance:

> "We're getting phone calls… 'Can we speak to the psychologist to help us parent our teenager?" (Anna)

Providers felt parents would welcome help with communication, boundary-setting, managing emotional reactivity, and understanding developmental norms:

> "Coping mechanisms, skills for dealing with peer pressure, smoking, vaping, drinking… but having CF and being part of that peer group." (Anna)

Participants believed that opportunities to connect with other parents and access lived experience input would be particularly valuable in promoting reassurance, normalisation and hope.

> "Its important parents hear, 'They will come back.'" (Paula)

Providers strongly endorsed the value of a structured workshop to address these needs and provide reassurance, normalisation, and practical strategies.

Taken together, these themes suggest that providers perceived family challenges in the modulator era as increasingly psychosocial, relational, and developmental. However, these interpretations reflect clinician perspectives and require further exploration with parents and adolescents themselves. Providers' accounts suggested that adolescent autonomy, parental anxiety, communication patterns, and social pressures may interact in ways that create complex challenges for families, particularly where structured support is limited. Providers' insights point to a potential need for a family-centred psychological intervention that helps parents balance autonomy with safety, fosters open communication, supports identity and developmental transitions, and strengthens collaboration with clinical teams. These themes contributed to the conceptual foundation for the developing intervention.

Discussion

The clinician engagement phase contributed to the development of a Family-Focused Intervention (FFI) that was more closely aligned with providers' understandings of CF care. Drawing on providers' perspectives regarding family dynamics, adolescent development,

and the evolving treatment landscape enabled the design of an intervention that was both contextually relevant and clinically responsive. Insights generated through the focus group informed the refinement of the FFI by clarifying parental priorities, shaping the tone and framing of workshop content, and highlighting emerging challenges associated with CFTR modulators and shifting patterns of family life. Collectively, this input enhanced the intervention's clinical relevance, acceptability, and practical applicability within current service contexts.

Our analysis generated four interrelated themes that highlighted core challenges for families and pointed to clear opportunities for targeted intervention. Providers described how CFTR modulators have transformed adolescents' perceptions of their illness and reported that many young people feel well and therefore question the need for burdensome treatments. This shift has altered parent–adolescent dynamics and created uncertainty around treatment expectations. These insights informed the FFI's inclusion of values-based adherence discussions, autonomy-supportive communication strategies, and structured skill building based on Problem-Solving Therapy (PST). PST was incorporated to help parents identify barriers, generate options, and negotiate realistic challenges. To ensure these strategies felt authentic and relatable, the FFI also incorporates Experts by Experience (EBE) in the form of a parent and young adult with CF dyad.

Providers emphasised the emotional and relational strain associated with the transition toward adolescent independence. Parents were described as struggling to relinquish control due to fears about adherence and long-term outcomes, an issue well documented in the chronic illness literature (Neinstein, 2001; Russo, 2022). Our findings extend this work by highlighting the emotional toll on parents themselves. To address this, the FFI integrates Acceptance and Commitment Therapy (ACT) strategies for managing

parental anxiety and supporting emotional regulation, alongside Narrative Therapy (NT) practices that help parents reframe dominant family narratives, particularly those centred on fear, over-control, or catastrophic expectations (e.g., “If I don’t stay in control, something will go wrong”). EBE involvement further strengthens this narrative component, providing parents with alternative, hopeful real-world stories about raising adolescents with CF and demonstrating how families can navigate conflict, uncertainty, and shifting roles.

A further theme concerned the need for practical, tailored resources addressing communication, boundary-setting, peer pressure, and treatment resistance. Providers emphasised normalising developmental pushback and incorporating lived-experience perspectives. Their observations underscored the value of strengthening collaborative communication between families and the healthcare team. These priorities, combined with Narrative Therapy’s focus on meaning-making and PST’s focus on behavioural problem-solving, were embedded directly into the structure and sequencing of the FFI. To enhance relevance and relatability, EBEs were integrated to allow parents to ask real world questions and to anchor skill-based material within authentic family experiences. Although EBE involvement strengthened the intervention by incorporating lived experience, it was not equivalent to broader co-design. The EBE contribution reflected a small number of perspectives and may not capture the diversity of family experiences across gender, culture, socioeconomic position, ethnicity, Traveller identity, family structure, or illness trajectory.

Considered together, these themes illustrate a dynamic interplay rather than discrete challenges. Shifting adherence patterns in the modulator era appeared closely linked to parental anxiety and uncertainty, which in turn shaped communication styles and

the degree of autonomy afforded to adolescents. Difficulties relinquishing control frequently intersected with developmental pressures for independence and peer belonging, creating tension within family relationships and increasing the likelihood of conflict around treatment expectations. Providers' emphasis on practical resources, lived-experience input, and collaborative communication therefore reflected not separate needs but interconnected responses to a shared developmental and psychosocial transition. Viewed in combination, the themes suggest that effective support must address emotional regulation, relational patterns, and behavioural problem-solving simultaneously rather than in isolation.

Addressing the uncertainties raised by CFTR medications explicitly within the workshop allows for transparent discussion and supports parents in navigating evolving expectations. Reduced hospitalisations have limited opportunities for providers to build relationships with families and provide timely support. These insights informed the FFI's emphasis on offering up-to-date information on modulators, realistic expectations for adherence, and guidance for navigating reduced clinical contact. EBEs offer crucial support, helping parents understand shifting illness narratives and instilling hope that the turbulence of adolescence will eventually ease.

A key implication for the intervention was the clear need for structured, parent-focused psychological support; an area providers identified as notably underserved. Although psychological expertise is increasingly part of CF care, services remain largely oriented toward physical care. Providers described parents as often suppressing their own distress, consistent with evidence of elevated parental stress and depressive symptoms (Daly et al., 2022; Graziano et al., 2020; Lord et al., 2023; Quittner et al., 2014). The FFI was therefore designed to explicitly address parents' emotional needs, normalise their

experiences, and support both values-based coping (ACT) and meaning-making processes (NT), alongside practical behavioural strategies (PST). The integration of EBEs further strengthens this parent-centred focus, offering credibility, validation, and hope, elements uniquely shaped by lived experience and not replicable through professional input alone.

Providers also contributed concrete recommendations for workshop delivery, including peer-to-peer discussion, flexible participation formats, and the integration of lived experience. These suggestions align with best practice in patient and public involvement (Brett et al., 2014) and were incorporated to ensure that the workshop resonates with parents lived realities and fits within existing service structures. EBE participation directly operationalises these recommendations, grounding the intervention in authentic family perspectives and enhancing its acceptability.

Together, these insights provided an initial provider-informed basis for refining the FFI. They highlight that in the modulator era, family challenges are increasingly psychological, relational, and developmental rather than biomedical. The FFI was therefore designed to equip parents with the understanding, emotional flexibility, and problem-solving skills needed to support their adolescent's autonomy while maintaining treatment engagement. ACT, NT, PST, and EBE contributions work together to support emotional regulation, meaning-making, relational coherence, and practical behavioural planning. In doing so, the intervention directly addresses the real-world issues identified throughout the clinician engagement process and represents a preliminary step toward more family-centred psychological support in CF care.

Clinical and practical implications

The findings underscore the importance of developing new interventions that acknowledge parents as key partners in adolescent CF care which is in line with previous

research. Supporting parents' psychological flexibility may, in turn, facilitate smoother transitions of responsibility and more sustainable adherence for young people. Providers' emphasis on peer connection suggests that workshops should create space for shared storytelling, normalising parental struggles and fostering mutual support. In addition, practical elements such as problem-solving exercises around treatment routines may enhance parents' sense of competence and efficacy.

From a service-delivery perspective, providers noted that interventions must be adaptable to parents' time constraints and varied levels of engagement. Embedding the workshop within routine CF clinic schedules, or offering modular versions online, may maximise accessibility. However, the latter may impact on the relational aspect of a face-to-face environment. These considerations are especially pertinent as CF care is in a state of rapid flux and uncertainty given advent of CFTR modulators, which alter disease trajectories and may shift family experiences and expectations. Interventions will need to evolve in parallel with these changes to remain relevant and clinically meaningful.

Strengths and limitations

This study was enriched by the firsthand insights of experienced frontline providers, whose multidisciplinary backgrounds offered a comprehensive understanding of parent–adolescent dynamics in cystic fibrosis (CF). The use of a focus group format fostered dynamic exchange and collaborative reflection, enabling a deeper exploration of challenges and potential solutions that may have remained unarticulated in one-on-one interviews. This methodological approach represents an important and relatively underexplored contribution within CF research. While some literature captures provider or clinician perspectives in CF, it remains limited in scope, primarily addressing topics such as fertility (Corcoran, Campbell, et al., 2023) , telehealth use during the COVID-19 pandemic

(Corcoran, Marley Campbell, et al., 2023), conceptualisations of care partnerships (Tluczek et al., 2022), provider attitudes toward men's health in CF (Clarke et al., 2022; Kazmerski et al., 2023) barriers to adherence (Eaton et al., 2020), and adaptations of the CF care model (Tran et al., 2024). To date, however, no studies have integrated provider perspectives into the co-development of a family-focused psychological intervention. This represents a meaningful and underexplored contribution to both CF care and the broader intervention development literature.

Nonetheless, there were several limitations. The sample was drawn from a single clinical context (an acute Irish hospital setting), which may limit the transferability of findings to other settings with different service structures. Further, the perspectives represented were solely those of providers; while highly valuable, they do not capture parents' or adolescents own voices. Notably, we had hoped to run a similar focus group with parents however we were unable to recruit sufficient numbers within the specified timeframe.

The absence of adolescent voices is particularly important given that the intervention focuses on adolescence, autonomy, adherence, and family communication. Future work should involve adolescents not only as informants but as active contributors to intervention development, including decisions about content, language, delivery format, and how parent-focused work can support rather than undermine adolescent agency. Research that integrates both stakeholder groups would provide a more comprehensive understanding.

A further limitation concerns diversity and difference. The study did not systematically examine how family experiences of CF may vary according to gender, socioeconomic position, ethnicity, culture, Traveller identity, family structure, parental

education, rurality, or access to services. Using a framework such as Social GRACES (Burnham & Roper-Hall, 2017) in future work may help ensure that intervention development attends more explicitly to power, identity, privilege, and structural barriers. This is particularly important in CF care, where assumptions about treatment routines, parental availability, health literacy, and access to specialist services may not apply equally across families.

Finally, the focus group method may be subject to social desirability biases, where the providers may minimize challenges and/or gaps in service provision which directly impact families.

Next Steps

In line with the MRC framework for complex intervention development, the next phase should involve iterative refinement of the FFI through broader stakeholder engagement, including parents, adolescents, EBEs, and clinicians from diverse service contexts. This should include attention to intervention acceptability, feasibility, mechanisms of action, contextual barriers, and implementation within a rapidly changing CF landscape. Given the pace of change in CF care, future iterations should also consider how modulator access, treatment burden, reduced clinic contact, and changing illness identity may alter family needs over time.

Conclusions

This study provides a provider-informed account of the psychosocial and developmental challenges perceived to affect families of adolescents with CF in the modulator era. The findings contributed to refinement of the FFI by highlighting issues relating to adherence, autonomy, parental anxiety, communication, and the need for structured support.

However, the findings should be interpreted as clinician-derived and partial. Further development requires more systematic integration of parent, adolescent, and diverse lived-experience perspectives to ensure that the intervention remains clinically relevant, culturally sensitive, and responsive to the changing landscape of CF care.

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Chapter 4: Provider Engagement Study Supplementary Information

Provider Engagement in Intervention Development for Chronic Illness: Methodological Reflections, Quality Assurance, and Positionality

This supplementary chapter reflects on the clinician engagement phase underpinning development of the Family-Focused Intervention (FFI). It outlines the rationale for early provider involvement, methodological and reflexive considerations, and the contribution of clinician perspectives to intervention coherence and feasibility within contemporary cystic fibrosis (CF) care.

Rationale for sequencing stakeholder involvement

Stakeholder involvement was conceptualised as iterative and staged in line with MRC guidance (Craig et al., 2008; Skivington et al., 2024). Although parent and public involvement was initially planned alongside clinician engagement, recruitment of parents of adolescents with CF to a discrete PPI activity was unsuccessful within the study timeframe. This likely reflected the wider realities of CF care, including treatment burden, competing caregiving demands, and research fatigue (Faulkner & Thompson, 2023; Mitchell, 2024). Clinician engagement was therefore prioritised pragmatically to ensure intervention development remained grounded in current clinical and family contexts, while recognising that clinician perspectives could not substitute for lived experience. This approach is consistent with evidence from implementation and intervention research indicating that stakeholder involvement most commonly occurs during early preparatory phases (Arnahoutova et al., 2025).

Provider engagement in intervention development for chronic illness

Intervention development in paediatric chronic illness increasingly emphasises integration of clinical, experiential, and contextual knowledge alongside empirical evidence (Chalmers et al., 2023; Thomsen et al., 2022). In CF, multidisciplinary teams often maintain long-term relationships with families and are therefore well positioned to observe patterns of parental coping, adolescent adjustment, adherence, and family communication over time. Importantly, this study occurred during a period of rapid clinical transition following the introduction of CFTR modulators (Harrigan et al., 2025). Providers described uncertainty regarding adherence, autonomy, and changing parental roles, which informed intervention components targeting parental emotional regulation, values-based parenting, psychoeducation, and problem-solving. To our knowledge, this study was the first to incorporate provider perspectives in the design of a family-focused intervention for parents of adolescents with cystic fibrosis (CF).

Provider engagement as distinct from, and complementary to, PPI

Provider engagement and PPI serve related but distinct functions within intervention development. Whereas PPI foregrounds lived experience, provider engagement captures professional, organisational, and longitudinal perspectives derived from working across multiple families and systems. In the present study, clinicians were invited to reflect on perceived family needs and service-level realities while recognising the epistemic limitations of clinician-derived accounts. This distinction was considered particularly important given the absence of direct parent involvement at this stage (Arnahoutova et al., 2025).

Quality assurance

Rigour was supported through prolonged engagement with the dataset, repeated transcript review, systematic coding, reflexive note-taking, and regular supervisory discussion. Alternative interpretations and analytic assumptions were actively explored throughout analysis.

Focus groups enabled clinicians to collectively reflect on shared clinical challenges, although risks relating to conformity, dominance effects, and social desirability were acknowledged and considered during analysis. Consistent with reflexive qualitative approaches, the aim was not objectivity or consensus, but the development of a transparent and coherent account grounded in participants' accounts (Krueger & Casey, 2000).

To illustrate the analytic process underpinning theme development, Table 1 provides an example of how a brief extract from the focus group transcript was coded and refined through iterative analysis and supervisory discussion.

Table 1

Example of coding and process of theme development

Transcript extract (anonymised)	Initial code	Analytic refinement
"They don't even have their…masks with them…don't use it anymore… And especially since modulators, some of them have said 'sure I'm cured now, I'm fine now'	Reduced adherence following modulator initiation	Reconfiguring parental responsibility in the modulator era
"We're seeing a lot of families where communication is really problematic …parents maybe have been quite authoritarian…often because of their own anxieties…resistance to that understandably during adolescence"	Parenting style shaped by parental anxiety	Relational processes shaping family adjustment
"Hearing other parents say the same things is incredibly powerful, it normalizes their experience straight away"	Normalisation via shared experiences/Peer connection	Relational empowerment

Importantly, quality assurance was not conceptualised as achieving consensus or objectivity, but as enhancing transparency, coherence, and reflexive accountability. The analytic aim was not to establish definitive truths about CF families, but to produce a credible and well-supported account of how providers perceive and interpret the challenges facing parents and adolescents in current clinical contexts.

Reflexivity and researcher positionality

Reflexivity was considered throughout the clinician engagement process. The primary researcher entered the study without prior clinical experience in CF, positioning her as an outsider to the specialty. While this supported openness to provider expertise and reduced assumptions regarding CF care, the researcher's background in Acceptance and

Commitment Therapy and systemic approaches inevitably shaped aspects of data interpretation and intervention development.

The dual role of facilitator and analyst also required ongoing reflexive consideration. During data collection, discussion was guided toward areas relevant to intervention development while remaining open to unanticipated perspectives. During analysis, reflexive journaling and supervisory discussion were used to consider how prior theoretical interests and assumptions may have influenced interpretation.

The involvement of a second facilitator with extensive CF experience added both strength and complexity to the process. Her familiarity with participants supported rapport and contextual understanding, while also raising the possibility that certain shared assumptions remained implicit. Attention was therefore paid to both explicit discussions and potential areas taken for granted within the group context. This emphasis on reflexivity and the negotiation of insider–outsider positions align with broader qualitative research literature that highlights how researchers' positionalities influence participant access, context interpretation, and analytic outcomes (Wilson et al., 2022; Yip, 2024).

Provider engagement as a mechanism for intervention coherence

Provider engagement contributed to the coherence and contextual relevance of the FFI by informing how intervention components were prioritised, integrated, and delivered. Clinicians' observations regarding parental anxiety, control, and changing family roles within the modulator era informed the inclusion of emotional regulation, values-based parenting work, and structured problem-solving within the intervention. This is in line with previous work framing clinician engagement as more than consultation (Boaz et al., 2015).

Provider accounts of adolescent identity development, autonomy, and peer relationships also supported the inclusion of narrative and reflective exercises aimed at

helping parents adapt to evolving family dynamics during adolescence. In addition, clinicians highlighted the importance of avoiding overly prescriptive adherence messaging and instead supporting families to navigate uncertainty and flexibility within contemporary CF care. These perspectives informed both the tone and delivery of psychoeducational content within the workshop.

Ethical and relational considerations

Ethical considerations included confidentiality, psychological safety, and attention to professional power dynamics. The focus group was framed as reflective rather than evaluative, with emphasis placed on voluntary participation and respectful discussion. Consistent with wider literature on stakeholder engagement, consideration was also given to how professional perspectives may privilege particular forms of knowledge or service contexts (Boaz et al., 2015; Guillemin & Gillam, 2004).

Contribution to the overall intervention development programme

Within the broader thesis, the clinician engagement study occupies a critical intermediary position. It sits between the theoretical and empirical literature review and the feasibility testing of the FFI. By grounding intervention development in provider perspectives, this phase strengthened the ecological validity and clinical relevance of the intervention.

Diversity and Representation

The perspectives represented within the clinician engagement phase were shaped by the composition of the participating MDT and may not fully reflect the diversity of families affected by CF. Important considerations relating to gender, socioeconomic disadvantage, cultural background, family structure, and minority communities, including Traveller families, were therefore only indirectly represented through clinician accounts. This

highlights the importance of integrating broader lived experience perspectives, including adolescent voices, within future co-design and intervention development work.

Conclusion

This chapter has outlined the methodological and reflexive considerations underpinning the clinician engagement phase of intervention development. Clinician perspectives contributed to the coherence and contextual relevance of the FFI while also highlighting the limits of provider-derived knowledge and the need for broader lived experience involvement in future development phases.

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Chapter 5: Main Research Study

The Development, Evaluation and Feasibility of a Novel Family-Focused-intervention for parents of teenagers with cystic fibrosis

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The Development, Evaluation and Feasibility of a Novel Family-Focused-intervention for parents of teenagers with cystic fibrosis

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Abstract

Background: Advances in cystic fibrosis (CF) care have extended life expectancy and improved physical functioning, increasing attention to psychosocial outcomes and quality of life. Although family-focused interventions have demonstrated benefit in other paediatric chronic illness contexts, such approaches remain underdeveloped in CF, particularly for families of adolescents. Methods: As part of a staged research programme, a family-focused psychological intervention for parents of adolescents with CF was developed through adaptation of evidence-based approaches used in other chronic illness populations and informed by clinical consultation. The intervention comprised a one-day workshop with a single follow-up session and integrated problem-solving, acceptance and commitment, and narrative therapy principles. A mixed-methods feasibility pilot was conducted with five families. Uptake and retention rates were examined alongside qualitative process analysis of parent experiences and pre–post changes on standardised measures of psychological functioning and quality of life. Results: Uptake was limited, while retention and indicators of acceptability were high. Reflexive thematic analysis suggested participation was associated with intrapsychic and relational changes, with themes of *relational empowerment, transformative reflection, knowledge in context,* and *navigating the storm* identified. Quantitative findings showed a mixed pattern of change across individual questionnaire profiles, examined using exploratory and case-series approaches. Conclusions: This study describes the development and initial feasibility testing of a family-focused psychological intervention for parents of adolescents with CF within a broader research programme. Findings support the acceptability of the approach and the value of process-focused evaluation at early stages of intervention development. Further refinement and larger-scale evaluation are required.

Introduction

Since the discovery of the cystic fibrosis transmembrane conductance regulator (CFTR) gene in the 1980s, the management of cystic fibrosis (CF) has advanced dramatically (Poamaneagra et al., 2024). Once a life-limiting childhood disease, CF is now managed as a chronic condition, with substantial improvements in life expectancy. In 1999 the median age of death was 24 while in 2020 it was 37 years (Singh et al., 2023). Accordingly, the focus of care has shifted from survival to promoting quality of life and psychosocial wellbeing (Bell et al., 2020). Despite these gains, individuals with CF continue to face considerable treatment burden, symptom distress, and daily disruption, all of which contribute to reduced wellbeing (Harrigan et al., 2025).

It is now well established that CF outcomes are shaped not only by biomedical factors but also by psychological and social processes (Prieur et al., 2021). Rates of anxiety, depression, and emotional distress among people with CF remain significantly higher than in the general population (Campagna et al., 2024; Graziano et al., 2020; Quittner et al., 2020). Adolescence represents a particularly vulnerable period, as young people strive for autonomy and identity while balancing the demands of treatment and self-management (Harrigan et al., 2024; Modi et al., 2008; Moola, 2018; Tuchman et al., 2008, 2010).

Parents and caregivers also experience heightened distress, managing complex regimens, uncertainty, and the emotional demands of chronic illness. Studies consistently report elevated stress, reduced quality of life, and greater caregiving burden among parents of children with CF (Daly et al., 2022; Fidika et al., 2015; Lord et al., 2023). Family dynamics are particularly influential, with evidence showing that cohesive, communicative families promote better psychosocial adjustment and adherence in adolescents with chronic illness (Landi et al., 2021; McCusker et al., 2012; Van Der Mheen et al., 2019;

Whitehead et al., 2018). Conversely, conflict or dysfunction can heighten caregiver strain and adversely affect both parental and child wellbeing (Continisio et al., 2020).

Family-focused interventions (FFIs) are grounded in behavioural family systems frameworks, integrating family systems theory (Paley & Hajal, 2022) and the transactional model of stress and coping (Lazarus & Folkman, 2006). These models conceptualise adjustment as a systemic process in which communication, problem-solving, and emotional regulation within families collectively determine resilience or vulnerability (Law et al., 2019; McCusker et al., 2025).

Such interventions, including cognitive behavioural, problem solving and systemic approaches, have demonstrated efficacy across paediatric chronic conditions such as epilepsy, diabetes and congenital heart disease (Eccleston et al., 2012; Law et al., 2019). Findings consistently point to benefits at multiple levels of family functioning. At a parental level, they are associated with reduced distress, enhanced coping and improved confidence in managing the condition. At the dyadic level, they can strengthen communication and reduce conflict between parents and adolescents, supporting more collaborative disease management. At a broader systemic level, these interventions may improve family cohesion and shared problem solving, which can contribute to more adaptive patterns of interaction around treatment demands (Besani et al., 2018; Nicolais et al., 2019; Psihogios et al., 2019). Emerging evidence also suggests potential flow-on benefits for child outcomes, including quality of life, treatment engagement and emotional adjustment, when parental wellbeing and family communication improve (Eccleston et al., 2015; Landi et al., 2021; McCusker et al., 2006).

Previous family-focused interventions including CHIP, Family First, and IOCE have demonstrated improvements in parental wellbeing, family functioning, communication,

and coping across paediatric health conditions (McCusker et al., 2006; 2010; 2012; 2024). Collectively, these programmes provided the conceptual and practical foundation for the development of the current intervention.

Despite recognition of the importance of psychosocial support within CF care, few interventions have been tailored for families, particularly parents of adolescents navigating autonomy, adherence, and identity formation (Tickner et al., 2022). CF care has traditionally focused on medical management, yet evidence increasingly supports addressing family-level factors that influence both psychological and clinical outcomes (Prieur et al., 2021). Adapting proven FFI models to the CF context may therefore strengthen family functioning, reduce caregiver burden, and improve long-term wellbeing.

The current study extends this body of work by developing and evaluating a CF-specific, family-focused intervention designed to meet the needs of parents of adolescents. Drawing on existing FFI frameworks, this model integrates psychoeducation, narrative exploration, and structured problem-solving within a supportive, group-based format. The intervention was adapted to offer parents up to date and relevant psychoeducation specific to CF and the changing landscape of the disease alongside information on the adolescent phase of development and how these might intersect. Problem solving therapy was adapted to focus on disease specific problems and the narrative therapy arm focused on allowing parents to externalise and re author their stories as parents of children with CF.

Acceptance and Commitment Therapy (ACT) is a relatively new third wave therapy which has shown promise for parents of children with chronic health conditions (Konstantinou et al., 2023). ACT promotes psychological flexibility, defined as the capacity to engage with difficult thoughts and emotions while acting in accordance with personal

values (Doorley et al., 2020; Hayes et al., 2006). This approach supports adaptive coping and resilience in chronic illness, helping individuals acknowledge distress without avoidance and commit to meaningful action (Feliu Soler et al., 2018; Wynne et al., 2019). ACT-based family interventions have shown benefits in reducing parental distress, improving emotional regulation, and strengthening communication (Jin et al., 2021; Lobato et al., 2022; Parvin et al., 2024). Meta-analyses indicate ACT's effectiveness in improving quality of life and symptom management across chronic conditions (Konstantinou et al., 2023). Our FFI integrated ACT by introducing acceptance, diffusion and values-based action as practical tools for responding to uncertainty and treatment demands.

Problem-Solving Therapy (PST) complements ACT by providing structured methods for identifying and addressing challenges. It enhances goal setting, communication, and adaptive coping within families facing illness (Cuijpers et al., 2018; McCusker et al., 2012; Nicolais et al., 2019).

Narrative Therapy (NT) contributes a relational and meaning-focused dimension, enabling parents to reinterpret illness experiences and construct empowering family narratives (Dane et al., 2025; Menard et al., 2018). Storytelling and reflection promote perspective-taking, identity reconstruction, and hope, which are key mechanisms for resilience in chronic illness contexts. Integrating ACT, PST, and NT offers a comprehensive framework that addresses both intrapersonal and systemic change. Together, these approaches foster flexibility, problem-solving capacity, and shared meaning-making, all of which are foundational components of family resilience (Coyne et al., 2021; Daks et al., 2020; Hu et al., 2024).

This study describes the development and feasibility testing of a one-day, family-focused intervention designed for parents of adolescents with CF. The intervention was

adapted from the CHIP, IOCE, and Family First programmes developed by the second author (McCusker et al., 2010, 2024, 2025; Van Der Mheen et al., 2019). Consistent with prior models, it incorporated a “one-day workshop plus one” format, combining group-based learning with an individual follow-up session and a structured parent manual to facilitate maintenance and generalisation of gains.

The workshop was facilitated by Clinical Psychologists with input from Experts by Experience, including parents and adolescents with cystic fibrosis, to ensure relevance, authenticity and engagement. The format supported families in translating worries into manageable goals, strengthening the parent–adolescent relationship and developing a psychological understanding of behaviours within the context of CF. Through shared reflection, narrative exploration and values-based exercises, the workshop aimed to promote more flexible, compassionate responses to challenges while maintaining accessibility and therapeutic depth.

Specifically, the study aimed to (a) develop and describe a theoretically grounded, family-focused intervention for parents of adolescents with CF, and (b) assess its feasibility by exploring parent experiences, perceived acceptability, and preliminary quantitative outcomes on psychological distress, flexibility, and family functioning. This represents the first known attempt to develop and evaluate a brief, family-focused psychological intervention within CF care. By combining established therapeutic principles with a pragmatic, low-burden delivery model, the study aimed to inform the integration of psychosocial interventions into routine CF practice and lay the groundwork for a future controlled trial.

While Chapter 5 focuses on the development, feasibility, and preliminary evaluation of the Family-Focused Intervention, detailed intervention materials, expanded

measure descriptions, and implementation guidance are provided in Chapter 6 to support transparency, replicability, and future clinical use.

Methods

Study design

This study followed the Medical Research Council (MRC) framework for developing and evaluating complex interventions (Craig et al., 2008) and the updated guidance emphasising iterative, theory-driven, context-sensitive work (Skivington et al., 2021). Process-evaluation principles were integrated to examine implementation, mechanisms of impact, and contextual influences (Moore et al., 2015). Research questions focused on feasibility, specifically accessibility and acceptability, and on preliminary indications of effectiveness. A mixed-methods design combined a qualitative process-evaluation strand with a quantitative case-series strand.

The process evaluation was conducted to assess intervention feasibility, accessibility and overall effectiveness. Semi-structured online interviews were completed two weeks post-intervention and analysed using reflexive thematic analysis and content analysis. The quantitative strand examined change in parental emotional wellbeing, family functioning, and family quality of life using standardised measures at baseline and two weeks post-intervention.

Due to the small sample and absence of a control condition, a single-case series approach was adopted to complement the individual pre–post analyses and provide a clearer picture of change at the level of each participant. Group and individual pre–post change and effect sizes were calculated, and qualitative findings were used to contextualise quantitative results and guide refinement for future evaluation.

Participants

Parents were recruited from a regional tertiary CF service in Ireland. Inclusion criteria were being a parent or primary caregiver of an adolescent aged 12–17 years with CF, capacity to provide informed consent, and sufficient English to participate. Participation was open to one or both parents. As is shown in Table 1, Parents from 39 families were invited (via email and in-clinic contact) to a one-day workshop with an online follow-up session. Parents of 5 adolescents took park in the intervention.

Table 1

Participant Characteristics of sample

Parent pseudonym	Parent age	Employment status	Adolescent gender	Adolescent age	Adolescent education level	Parents at home
Anna	44	Full-time	Male	14	Secondary Level	2
Danny	57	Stay at home parent	Male	16	Secondary Level	2
Joanne	47	Part-time	Female	14	Secondary Level	2
Mairead	46	Full-time	Male	15	Secondary Level	2
Tracey	54	Part-time	Male	13	Secondary Level	1

Notes: Parent age = at time of workshop, Adolescent Age = at time of workshop

Baseline measures of psychological distress were collected prior to the intervention to characterise participants' psychosocial functioning. As shown in Table 2, pre-intervention *DASS*-21 scores indicated mild levels of depression and stress and anxiety scores within the non-clinical range. When compared with UK normative data (Henry & Crawford, 2005; Thiyagarajan et al., 2022), parents in the present sample demonstrated small elevations in overall distress and a moderate elevation in stress specifically. Standardised mean differences indicated a moderate effect size for stress relative to norms (d = 0.56), with small effect sizes observed for depression (d = 0.19) and total distress (d = 0.22). Anxiety scores were lower than normative values (d = −0.41).

Table 2

Pre-intervention DASS-21 scores compared with normative data

***DASS*-21 scale**	**Study sample M (SD)**	**Normative M (SD)**	**Effect size (Cohen's d)**
Depression	6.8 (4.32)	5.66 (7.17)	0.19
Anxiety	2.2 (1.92)	3.56 (4.06)	−0.43
Stress	9.2 (5.26)	6.14 (5.56)	0.57
Total *DASS*-21	18.2 (9.41)	15.36 (11.12)	0.28

Notes: Normative data derived from UK adult population samples (Henry & Crawford, 2005; Thiyagarajan et al., 2022).

This pattern suggests mild but clinically meaningful emotional strain, characterised primarily by elevated stress rather than broad affective disturbance, and is consistent with the ongoing demands associated with parenting an adolescent with cystic fibrosis.

Ethical approval was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals on 13 June 2024 (Ref: ECM 4 (i) 14/05/2024). All participants provided written informed consent.

Intervention

A one-day structured group workshop was delivered at the tertiary CF service. The workshop was facilitated by two senior Clinical Psychologists with paediatric expertise and one Clinical Psychologist in training. The intervention integrated principles of Acceptance and Commitment Therapy (ACT), Problem-Solving Therapy (PST), and Narrative Therapy (NT) within a family-centred framework. Delivery combined brief didactic input, small-group exercises, reflective discussion, and lived-experience narratives from a parent and an adolescent Expert by Experience. Session content is summarised in Table 3.

Table 3

Outline of the Family-Focused Intervention.

Intervention Content
1. Overview of challenges faced by adolescents with CF and their families; importance of family factors in predicting outcomes.
2. Paired discussions exploring worries; clustering of themes to identify common concerns.
3. Facilitated narrative with parent and child expert by experience (EBE); linking to group work themes; highlighting problem-solving strategies used.
4. Brief talk illustrating application of problem-solving therapy with real examples; small group practice on selected worries; large group reflection to share learning.
5. Topics including treatment adherence, parent-adolescent conflict, adolescent independence, communication, social / community supports and relationships with services.
6. Introduced ACT-based metaphors and exercises to help parents accept difficult emotions, clarify values and respond flexibly to parenting challenges.
How was the intervention delivered, tailored and modified?
Delivered as a one-day workshop integrating group discussion, facilitated storytelling, and practical skills exercises. Content shaped by parents identified concerns and challenges and further informed by input from an Expert by Experience (EBE) and themes emerging within the group. Flexibility was embedded throughout, enabling

facilitators to adapt discussions and problem-solving activities to reflect individual family contexts and priorities.

Who delivered the intervention?

Delivered by proficient facilitators experienced in CF and psychological interventions.

Additional Materials:

Parent e-manual covering relevant psychoeducation electronically sent to participants two weeks post-intervention.

Facilitators used group discussion, guided storytelling, and skills practice. Content was shaped by parent-identified concerns and by themes emerging in session. Flexibility allowed facilitators to tailor discussion and problem solving to family context and priorities. An electronic parent manual summarising psychoeducation and workshop-specific discussion points was provided approximately two weeks post-intervention and before the follow-up session.

A full description of the intervention content, session structure, and accompanying materials is provided in the Family-Focused Intervention manual (see Chapter 6 and Appendix H). This manual reflects how the intervention was delivered in practice and is intended to support replication and future implementation, outcome and process evaluations.

The outcome and process evaluations were shaped by the UK Medical Research Council framework, which provides guidance for the development, evaluation and implementation of complex interventions. Central to this framework is the recommendation that preliminary pilot studies are undertaken before advancing to large

randomised controlled trials. Within this structure, a process evaluation assesses feasibility, including accessibility and acceptability, while also exploring early signs of potential effectiveness (Moore et al., 2015; Skivington et al., 2021, 2024). As this study was designed to assess feasibility and pilot potential effectiveness, it did not specify definitive primary versus secondary outcome measures. Instead, a range of measures addressing both feasibility and effectiveness domains were included, as outlined below (Moore et al., 2015).

Accessibility

Demographic and clinical characteristics were recorded for parents and adolescents, including parent age, gender, employment, adolescent age and gender, education, CF clinical profile, treatments, and service contacts.

Acceptability

All workshop attendees were invited to an online follow-up session. Semi-structured interviews were conducted by the third author (COS) who attended but did not facilitate the workshop. Interviews were recorded and transcribed using Microsoft Teams. Questions were designed to elicit experiential accounts that informed reflexive thematic analysis, as well as outcome-focused insights relating to feasibility, accessibility and perceived impact, which were examined using reflexive content analysis. *The Friends and Family Test* (NHS England, 2020) was also administered to assess likelihood of recommending the intervention.

Effectiveness

Effectiveness was primarily explored through qualitative interviews. To supplement these findings, participants also completed standardised self-report measures assessing emotional distress, psychological flexibility, and family functioning. Measures were

selected to map directly onto the intervention's theoretical targets, namely reductions in general emotional distress, increases in parental psychological flexibility consistent with ACT principles, and potential downstream changes in perceived family functioning. This allowed preliminary exploration of whether shifts occurred in psychological processes explicitly targeted by the workshop, rather than formal evaluation of intervention efficacy. These were completed at baseline and two weeks post intervention. All measures have established reliability in both general and clinical populations.

- *Depression, Anxiety and Stress Scale* – 21 items (*DASS*-21; Lovibond & Lovibond, 1995) measures overall emotional distress, encompassing symptoms of depression, anxiety, and stress. Both the total score (reflecting global distress) and the individual subscales for Depression, Anxiety, and Stress were included in the present analyses. Internal consistency within the current sample was acceptable (α = .81, total scale), consistent with published normative data (α = .90, total scale).

- *The Comprehensive Assessment of Acceptance and Commitment Therapy Processes* – 10 items (*CompACT* 10; Francis et al., 2016) assesses psychological flexibility, representing key Acceptance and Commitment Therapy (ACT) processes of openness to experience, behavioural awareness, and values-based action. The current analyses included the total psychological flexibility score which aggregates the subscales of openness to experience, behavioural awareness and values-based action. Internal consistency was satisfactory (α = .84), aligning closely with established normative reliability (α = .91). In this measure, higher scores indicate better functioning.

- *Paediatric Quality of Life Inventory - Family Impact Module* (PedsQL-FIM; Varni et al., 2004) evaluates perceived family functioning and the psychosocial impact of a child's chronic illness on the parent and family system. Analyses utilized the Total Family

Functioning score, derived from the Parent Health-Related Quality of Life and Family Functioning Summary subscales, and the Family Functioning subscale. Internal consistency within the current sample was excellent (α = .95), comparable to published normative data (α = .97). In this measure, higher scores indicate better functioning. The total score assesses the impact of a paediatric chronic illness on parents and their family, while the Family Functioning subscale specifically considers the impact on family activities and relationships.

- *The friends and family test (FFT)* (NHS England, 2020) was administered to all participants. This is a feedback tool used to gather patient feedback on experiences with healthcare services.

Analysis

Accessibility data were summarised descriptively. Acceptability was examined using *Friends and Family Test* responses and qualitative feedback. Qualitative data were analysed using reflexive thematic analysis and reflexive content analysis, as each aligned with a distinct component of the research aim. Reflexive thematic analysis was used to address the question of how parents experienced the intervention. This approach supported an in-depth exploration of meaning, allowing patterns to be generated inductively from participants' narratives, capturing nuance, emotional tone and the personal significance of the workshop content. Reflexive content analysis was applied to questions focused on feasibility, accessibility and perceived impact. This supported the practical purpose of informing future optimisation and implementation of the intervention. Using both approaches allowed the study to explore the subjective, relational and developmental meaning of the workshop for families, while also systematically capturing feedback relevant to feasibility and effectiveness. The analytic process included iterative

reading and familiarisation, generation and refinement of codes, and development of coherent themes. The researcher who led the analysis was not a facilitator to reduce social desirability and support open disclosure. For credibility, one transcript was independently coded by the analyst and a supervisor, followed by discussion to enhance reflexivity and conceptual clarity.

Quantitative analyses were conducted in IBM SPSS 25. Statistical significance was set at $\alpha = .05$, and non-parametric tests were used given the small sample. Wilcoxon signed-rank tests examined pre–post change. Effect sizes (Cohen's d) were calculated to estimate magnitude and direction of change. Individual change was examined using a case-series approach. Reliable Change Indices (RCIs) and individual effect sizes were calculated for each participant across scales. RCIs used established internal consistency values, and change was considered reliable when the absolute RCI exceeded 1.96.

Results

Accessibility

Parents of 39 eligible adolescents were invited to participate (N = 39). Uptake was limited, with parents of eight adolescents expressing interest (21 percent) and six parents of five adolescents attending the workshop (15 percent). Same day withdrawals due to illness or childcare issues (N = 3), together with barriers such as scheduling conflicts (N = 5), involvement in other psychological supports (N = 7) and a preference to avoid groups (N = 1), indicate practical and contextual challenges to engagement. Five parents expressed interest in future sessions (N = 5), suggesting that demand may increase if accessibility barriers are addressed. The final workshop sample comprised five families (13 percent participation). Retention at post intervention follow up was 83%, as one of two parents in a dyad did not complete follow up.

Participant characteristics for responders and non-responders are summarised in Tables 1 and 4. As shown in Table 4, non-responders were broadly similar to responders in household structure and rates of co-existing conditions, but a higher proportion had previously engaged with paediatric psychology services. This pattern suggests that prior support context may have influenced perceived relevance or preferences for intervention format, rather than indicating clear demographic differences. Participants were self-selected and may have differed systematically from non-participants. Those who attended may have been particularly motivated to seek support, open to psychological approaches, comfortable with group-based discussion, or experiencing specific levels of distress. Consequently, the findings may not reflect the experiences of parents who declined participation, preferred individual support, or felt unable to engage with emotionally focused interventions.

Table 4

Comparison of responder and non-responder characteristics

Characteristic	Responders (n = 5)	Non – Responders (n = 26)
Two-parent Household	4 (80%)	25 (96%)
Separated Household	1 (20%)	1 (4%)
Prior Engagement with paediatric Psychology	2 (40%)	16 (62%)
Adolescent with co-existing condition	1 (20%)	6 (23%)

Note. Characteristics are presented as n (%). Co-existing conditions included neurodevelopmental or psychological diagnoses. Responders refer to families who participated in the feasibility pilot; non-responders refer to families who did not respond to the invitation. n (%)

Acceptability

All five participants completed an online follow-up interview two weeks after the workshop, and all indicated they would recommend the intervention, reflecting very high satisfaction according to the *Friends and Family* Test (NHS England, 2020). Although based on a very small sample, tThehis outcome compares favourably with the 88% satisfaction rate typically reported for NHS mental-health services, and the 94% satisfaction rate for NHS community health services from August 2025 (*Friends and Family* Test Data, n.d.)

Content analysis identified the most valued elements as in-person delivery, the facilitators' warm and relatable style, and the inclusion of lived-experience storytelling. Visual materials used during the workshop and the follow up manual (Appendix H) were also positively rated. Suggested improvements included greater father involvement, a brighter and more informal venue, and larger or mixed groups to increase openness. Parents recommended offering the workshop annually, extending breaks, adding practical scenarios, and having parents co – develop the workshop content.

Using Braun and Clarke's (Braun & Clarke, 2022) approach, RTA Analysis identified four interrelated main themes which captured parents' experiences of the intervention: *relational empowerment, transformative reflection, knowledge in context, and navigating the storm*. These themes and their subthemes are detailed in Table 5.

Table 5

RTA Superordinate and Subordinate themes.

Superordinate theme	Subordinate theme
1. Relational Empowerment	"The Power of the Group"
	"Human Connection Over Information"
	"You're Not Alone"
2. Transformative Reflection	"Shifting Perspectives"
	"Relinquish Control"
3. Knowledge in Context	"Clued into" Common Sense
	"Little Seeds" From Insight to Action
4. "Just Navigate the Storm Around It"	"Forced [to] the Front"
	"Holding the Weight"

Theme 1: Relational Empowerment

Parents consistently identified the in-person group interaction as the most therapeutic component of the workshop. The subtheme "the power of the group" captured how being physically present with others who "get it" transformed the session from an information event into a shared emotional experience that disrupted isolation and normalised uncertainty.

> "Even to know you're not alone in experiencing this… that made a huge difference." (Danny)

Because infection-control restrictions in cystic fibrosis (CF) often limit in-person contact, several parents described this as the first time they had spoken openly with others who genuinely understood their circumstances.

> "…even the importance of just coming together, alone, is significant." (Danny)

This rare sense of togetherness offered relief from the loneliness of caregiving. Hearing others' stories in person provided a depth of connection that virtual or information-based interventions could not.

> "What other situation would you go into… and start talking about your problems? I just don't think it would come as naturally to sit with a group of people you've never met before and speak to them like that." (Anna)

The subtheme "human connection over information" reflected parents' view that lived-experience storytelling was more powerful than didactic material. Listening to those who had "come out the other side" provided realism and hope:

> "…the projector for me wasn't really taking my attention… listening to [stories] are the things that stuck with me." (Anna)

Hearing shared struggles normalised parents' uncertainty:

> "…that was quite reassuring… that there are other people having the same type of struggles… and not having the answers." (Mairead)

Authentic, unfiltered exchanges created credibility and validation:

> "…when people are willing… to share the good, the bad and the ugly, then you know it's real." (Tracey)

Overall, *relational empowerment* arose through collective storytelling and emotional resonance rather than information exchange, offering parents reassurance, perspective, and renewed confidence in navigating the uncertainties of CF parenting.

Theme 2: Transformative Reflection

The workshop functioned as a rare restorative pause that legitimised emotional processing and encouraged reflection on long-standing coping habits. Parents often recognised a tendency to "push it down to keep going," acknowledging both its protective and costly nature:

> "I'm very good at, come on, get up now, work, do this, do that… let's just pretend everything is fine and let's not deal with that." (Anna)

Others described emotional distancing to preserve daily functioning:

> "…all you're thinking and talking about is her condition… when I need to think about it, I'll think about it." (Joanne)

The group helped parents see emotional engagement as constructive rather than threatening:

> "…maybe I do, for my own mental health, need to practise a little bit more of [ACT]." (Joanne)

This shift represented the emergence of self-awareness and reframing, consistent with Acceptance and Commitment Therapy (ACT) processes that encourage presence, acceptance, and value-driven action. A related subtheme, "relinquish control," described a growing understanding that caring for an adolescent with CF requires balancing responsibility with acceptance of uncertainty.

"It is a waiting game with teenagers… you can't control it; you just have to accept it." (Joanne)

"You get over it, it has to be done... This is part of our lives, but it's not the defining part." (Danny)

"Stop worrying about what you can't change… We're not happy with it—but we've accepted it." (Mairead)

Collectively, these reflections illustrated movement toward self-compassion and psychological flexibility—the ability to act with purpose despite distress—marking an adaptive shift in coping and identity.

Theme 3: Knowledge in Context

Parents frequently described the workshop content as familiar rather than novel, connecting it to previous counselling, CBT, or ACT experiences. While the material was viewed as "common sense," it was valued for reinforcing understanding and prompting reflection.

"I'm kind of clued into that stuff anyway… a lot of the stuff on the projector was kind of common sense." (Anna)

"There was nothing horrifically shocking… it was reiterating most of what we probably knew already." (Tracey)

Rather than seeking new information, parents appreciated the workshop as a space to consolidate prior learning within a supportive, CF-specific context.

"That acceptance… that whole pause, the Viktor Frankl… stay in the middle for a bit… that's crucial for everybody." (Mairead)

A few wanted deeper, more targeted discussion:

> "It starts out quite general… It basically scratched the surface and I'd like to have delved in a little bit more." (Danny)

Despite this, the psychoeducational content often seeded practical changes at home—such as allowing adolescents to lead conversations or adjusting communication style.

> "The whole fertility part… it will be something I'll have to bring to the fore with my daughter at some point." (Joanne)

> "…it just has prompted a lot more informed conversation." (Mairead)

> "I would keep doing the same thing that doesn't work… I've tried to be a bit more patient… speak to [my children] more in an adult way." (Tracey)

Overall, the workshop validated existing coping strategies while encouraging incremental adjustments that strengthened communication and parental confidence.

Theme 4: "Just Navigate the Storm Around It"

Alongside connection and reflection, parents described the persistent emotional weight of CF caregiving. The workshop surfaced feelings usually suppressed in daily life, creating both discomfort and relief.

> "It does immerse you in the possible negative side of CF… your survival instinct is to just push it to the back of your head—it's forced to the front." (Joanne)

Several participants described post-session emotional release as both painful and necessary:

> "The following day, I kind of broke down… I cried and cried and cried… but I still see that as a positive thing because I do think it's important to do that." (Anna)

The recurring subtheme "holding the weight" captured this ongoing psychological and practical burden. The workshop did not remove it but provided space for recognition and validation.

> "You're managing day-to-day on your own… and that's the reality of it." (Danny)

> "You can't really talk to anybody else in your life like that." (Anna)

Gendered caregiving patterns were prominent, with mothers describing disproportionate responsibility and emotional labour:

> "I think men just check out… even when my husband did live here, I went alone to every single event or anything to do with CF." (Tracey)

The sole father highlighted the expectation of stoicism:

> "You have to manage it rather than it managing you… you never get the luxury of being able to not worry." (Danny)

These accounts portray caregiving as relentless but also reveal how shared acknowledgment can transform isolation into solidarity. The workshop offered a brief but meaningful opportunity for emotional connection and mutual recognition—helping parents "navigate the storm" together rather than alone.

Effectiveness

Group-level analyses showed small but consistent trends in the expected direction. While no results reached statistical significance ($p < .05$), moderate effect sizes were observed for several outcomes (see Table 6).

Table 6

Parent outcomes pre and post intervention

Measure	Time Point	M	SD	Z score	P	Cohen's d
Total FIM Score	Pre	66.11	26.90	-1.04	.30	-.046
	Post	57.64	15.96			
Family Functioning	Pre	60.00	27.19	-1.00	.32	-.045
	Post	51.88	17.34			
DASS Stress	Pre	9.20	5.26	-1.84	.07	-0.82
	Post	6.60	4.16			
DASS Anxiety	Pre	2.20	1.92	-0.74	.46	-0.33
	Post	1.80	1.92			
DASS Depression	Pre	6.80	4.32	-0.38	.71	-0.17
	Post	6.20	5.89			
DASS-21 Total	Pre	18.20	9.45	-1.17	.24	-0.52
	Post	14.60	11.46			
Open to Experience	Pre	24.40	14.21	0.39	.69	0.18
	Post	26.20	8.61			
Behavioral Awareness	Pre	9.80	10.09	0.36	.72	0.16
	Post	11.00	8.75			
Valued Action	Pre	35.00	6.40	-0.47	.64	-0.21
	Post	33.60	9.42			
CompACT Score	Pre	66.60	23.71	.52	.60	0.23
	Post	70.80	22.88			

Notes: Reliability coefficients for calculations are drawn from published validation studies: *CompACT* – Francis et al. (2016); *DASS-21* – Lovibond and Lovibond (1995), Thiyagarajan et al. (2022); *PedsQL-FIM* – Varni et al. (2003), Lim et al. (2020).

Reductions were seen across all *DASS*-21 subscales, with the largest for stress (d = –0.82, p = .07) and total distress (d = –0.52). Smaller, non-significant decreases were observed in anxiety (d = –0.33) and depression (d = –0.17). Psychological flexibility (*CompACT*) showed small, non-significant increases (d = 0.16–0.23). PedsQL-FIM domains showed small-to-moderate declines (d = –0.45 to –0.47).

Case Series Analysis

To assess clinically meaningful change at the individual level, Reliable Change Indices (RCIs) and individual effect sizes (Cohen's d) were calculated for each participant across scales. RCIs were calculated using established internal consistency values (Cronbach's α), with change considered reliable if the RCI exceeded ±1.96. Individual case-series data (Table 7) showed heterogeneous change patterns across participants.

Table 7

Case-Series Summary of Pre–Post Change Across Outcome Measures (n = 5)

Participant	*DASS*-21 Δ (Post – Pre)	*CompACT* Δ (Post – Pre)	PedsQL-FIM Δ (Post – Pre)	Overall Direction	Summary of Pattern
Anna	-8	+17	-8	Mixed	Lower distress, greater flexibility, small decline in family functioning
Danny	-1	+6	-12	Mixed	Stable distress, higher acceptance, modest QoL decline
Joanne	-4	-7	-20	Deterioration	Decline across wellbeing and functioning domains
Mairead	-6	+12	-9	Mixed	Increased flexibility, temporary QoL reduction
Tracey	-3	+10	+6	Improvement	Reductions in distress and improvement in flexibility and QoL

Note. Δ = Post – Pre change score; arrows indicate direction (↑ = increase, ↓ = decrease, ↔ = minimal change). For *DASS*-21, lower scores reflect improvement; for *CompACT* and PedsQL-FIM, higher scores reflect improvement. Patterns summarize overall direction rather than statistical significance.

At the individual level, several participants demonstrated changes that exceeded the Reliable Change Index threshold (RCI ≥ 1.96).

- Anna showed small declines across PedsQL-FIM domains, none of which were reliable. A large reliable increase in anxiety was observed (d = 1.05), with smaller, unreliable increases in depression and overall distress. *CompACT* total and subscale scores indicated small-to-moderate dis-improvements, including a reliable decline on the total scale (d = 0.80).
- Danny demonstrated a moderate reliable decline on the PedsQL-FIM total score (d = 0.65), with unreliable reductions on subscales. No change occurred on the *DASS*-21. *CompACT* scores showed mixed, unreliable changes, including a moderate improvement in behavioural awareness and a decline in valued action.
- Joanne exhibited a large reliable decline in PedsQL-FIM total and HRQL scores (ds = 0.95–1.00) but a large reliable improvement in anxiety (d = 1.10). Moderate, unreliable improvements were seen in stress and total distress, and small, unreliable gains across all *CompACT* domains.
- Mairead showed small, unreliable declines on the PedsQL-FIM but reliable improvements in depression and stress on the *DASS*-21 (ds = 0.88–0.91). *CompACT* scores indicated generally stable functioning with modest, unreliable gains in valued action and total scale scores.
- Tracey demonstrated small-to-moderate, unreliable improvements in PedsQL-FIM domains, alongside a large reliable reduction in stress and

total distress (ds = 0.95–1.00). *CompACT* total and subscale scores showed consistent improvement, including a large reliable increase on the total scale (d = 1.03).

Discussion

This study provides preliminary evidence that a brief, family-focused workshop for parents of adolescents with cystic fibrosis (CF) is both feasible and acceptable, with relational processes emerging as a potentially important feature of participants' accounts of the intervention.

The workshop proved feasible in delivery and retention (83%), but recruitment was challenging, highlighting the need to understand barriers to participation. Constraints related to project timelines may have limited reach; future work could benefit from longer recruitment windows and multi-site collaboration. Common barriers included scheduling conflicts, childcare demands, and limited participation by fathers. These barriers are also consistent with wider literature on parental engagement in chronic illness research, which highlights that participation is often shaped not only by logistical constraints but by parents' perceptions of personal relevance, emotional readiness, and anticipated benefit (Cousino & Hazen, 2013; Mitchell et al., 2020). These findings suggest the value of flexible delivery models and strategies that explicitly enhance perceived relevance, such as integrating lived-experience testimonials, embedding recruitment within routine clinical contacts, and clearly signaling practical benefits for parents. Nonetheless, parents' strong preference for in-person sessions underscores the importance of preserving relational depth and peer connection, features consistently identified as therapeutic mechanisms in group-based interventions (Burlingame et al., 2018). Cohesion research (an important construct in the group therapy literature) indicated that groups led by facilitators with an

interpersonal orientation and a moderate sample size (5–8 members) achieve stronger outcomes (Burlingame et al., 2011), a configuration consistent with the present study, although further work is needed to examine cohesion processes within single-session interventions.

The feasibility and acceptability of a one-day workshop format have important implications for the delivery of psychosocial care within cystic fibrosis services. Parents described the condensed format as accessible and manageable, reducing common barriers related to time, fatigue, and competing caregiving demands, while still allowing emotionally meaningful work to occur. This finding is consistent with evidence from other brief psychological and psychoeducational interventions, which suggests that shorter, focused formats can promote engagement and reduce attrition without necessarily compromising perceived benefit (Besani et al., 2018; De Haan et al., 2013; Dindo, 2015). In high-burden clinical contexts such as CF, where infection-control requirements and service constraints limit opportunities for extended intervention, brief relationally focused models may therefore represent a pragmatic and scalable approach to embedding psychosocial support within routine care pathways. While parents generally valued the opportunity for emotional exploration, some accounts suggested that the workshop activated difficult emotions. For example, one participant described prolonged emotional distress following the intervention. Although she ultimately viewed this positively, it is also possible that a single intensive workshop format may not provide sufficient containment for all participants. Future iterations may benefit from additional follow-up sessions, staged delivery, or enhanced opportunities for emotional processing and support.

Additionally, the sample consisted primarily of mothers and did not adequately represent broader dimensions of diversity, including socioeconomic disadvantage,

ethnicity, Traveller identity, family structure, rurality, or differing levels of health literacy. As such, the acceptability and relevance of the intervention across diverse populations remains uncertain. Only one father participated, mirroring the wider underrepresentation of fathers in paediatric and family research (McCusker et al., 2010; McCusker & Raleigh, 2024; Phares et al., 2005). Limited paternal involvement, often shaped by gendered caregiving patterns (Sharma et al., 2016), may constrain opportunities for shared adaptation and reinforce maternal caregiving burdens. Addressing these imbalances through targeted recruitment of fathers and male Experts by Experience should be a priority in future iterations. Future research should also consider how differences in health literacy, cultural beliefs regarding illness, family structure, and access to specialist services may influence both intervention engagement and outcomes.

The findings broadly align with the intervention's intended focus on family resilience and functioning, although conclusions regarding effectiveness remain tentative. Four interconnected themes; *Relational Empowerment, Transformative Reflection, Knowledge in Context, and Just Navigate the Storm Around It*, captured parents' experiences, illustrating a dynamic process of connection, reframing, and adaptive flexibility. Participants frequently described relational empowerment and transformative reflection as meaningful aspects of their experience. Parents experienced the intervention as transformative due to the group- setting facilitating them to reframe who they were, in the presence of others who are in the same situation. *Relational empowerment* embodied validation via shared experiences, recognition of mutual struggles and the development of a shared identity as CF caregivers. These relational accounts point less to isolated benefits and more to a shared process of identity re-negotiation and emotional permission among parents. This sense of validation, shared understanding, and developing a collective

caregiver identity is consistent with evidence that group-based interventions promote change through relational processes and cohesion rather than information alone (Burlingame et al., 2011). While these findings suggest that relational processes, shared experience, and lived-experience storytelling may represent important features of participants' accounts of the intervention, the study design does not permit conclusions regarding mechanisms of change. It is therefore not possible to determine whether these elements directly contributed to observed outcomes or simply reflected aspects of the intervention that participants found most memorable or meaningful. Further process evaluation within larger controlled studies would be required to explore these relationships. Parents reported relief from isolation, increased self-awareness, and greater acceptance of uncertainty, processes that align with ACT-based models of psychological flexibility, which emphasise openness to internal experience and values-consistent responding under conditions of ongoing stress (Hayes et al., 2012). Lived-experience storytelling further enhanced engagement and credibility, supporting emerging evidence that incorporating experiential perspectives may strengthen acceptability and emotional impact in parent-focused interventions for paediatric chronic illness (Coyne et al., 2021). Although EBE contributions were highly valued, the perspectives represented a small number of individuals and may not reflect the diversity of experiences within the CF community. Care should therefore be taken not to assume that these narratives are representative of all families. Furthermore, EBE involvement occurred primarily during intervention delivery rather than throughout the research cycle and therefore should not be considered equivalent to full co-production.

Quantitative trends broadly mirrored these qualitative shifts, suggesting early directional change rather than definitive outcome improvement. The clearest directional

improvement was observed for stress (d = –0.82, RCI = –0.87), with a moderate reduction in overall psychological distress (d = –0.52, RCI = –0.85). Smaller, non-reliable decreases were seen in anxiety (d = –0.33) and depression (d = –0.17). Conversely, family impact (d = –0.46) and family functioning (d = –0.45) declined slightly. One possibility is that increased reflection and discussion of previously avoided concerns heightened awareness of family challenges in the short term. However, an equally plausible interpretation is that aspects of the intervention were experienced as emotionally challenging or insufficiently supportive, contributing to a temporary deterioration in perceived family functioning. Given the small sample, lack of a control group, and brief follow-up period, these competing explanations cannot be disentangled. Psychological flexibility scores showed small, non-significant improvements (d = 0.16–0.23). Although underpowered for statistical inference, the pattern is consistent with early indications toward reduced distress and greater reflection. Qualitative accounts of emotional release, renewed perspective, and acceptance echoed these small quantitative shifts, implying that subtle psychological change may precede longer-term adaptation. This pattern is consistent with process-oriented models of intervention, which emphasise that early changes in underlying psychological processes may precede, rather than coincide with, observable improvements in broader functional outcomes (Moore et al., 2015; Vowles & McCracken, 2008).

Strengths and Limitations

This study represents the first known development of a family-focused psychological intervention specifically designed for parents of adolescents with cystic fibrosis, addressing a notable gap in CF psychosocial care. Key strengths include the theoretically integrated design of the intervention, drawing on Acceptance and Commitment Therapy, narrative approaches, and problem-solving principles, as well as its development through an

iterative process informed by parent experiences and clinical insights. The mixed-methods approach further strengthened the study by allowing early outcome trends to be interpreted alongside rich qualitative process data, providing a nuanced understanding of acceptability, feasibility, and potential mechanisms of change. To complement the feasibility findings reported in this chapter, Chapter 6 provides supplementary detail on the intervention content, rationale for measure selection, modulator-era adaptations, and facilitator guidance, alongside the full intervention manual (Appendix H).

Several limitations should also be acknowledged. The small, self-selected sample, gender imbalance, and absence of a control group limit generalisability and preclude causal inference. In addition, the two-week follow-up interval may have been insufficient to capture measurable or sustained change, as shifts in psychological flexibility and family functioning are likely to evolve gradually over time. Longer follow-up periods and the inclusion of a comparator condition will therefore be important in future evaluations to assess durability of effects and refine outcome measurement.

Challenges in engaging parents in aspects of the research process, including limited uptake of planned parent and public involvement activities, represent a further limitation. This difficulty likely reflects the substantial emotional, cognitive, and practical burden experienced by parents of adolescents with chronic illness, for whom caregiving demands and heightened uncertainty can constrain capacity to engage in additional research activities beyond immediate clinical care (Cousino & Hazen, 2013; Mitchell et al., 2020). Emerging qualitative research also highlights the emotional labour associated with reflective research participation, suggesting that reluctance to engage may represent an adaptive prioritisation of coping resources rather than lack of interest (Faulkner & Thompson, 2023).

Future development may benefit from frameworks such as Social GRACES (Burnham, 2012), which encourage consideration of social difference, power, privilege, and marginalisation. Such frameworks may help ensure that intervention content, recruitment strategies, and implementation approaches are culturally responsive and inclusive. Although the intervention focused on supporting parents, adolescents themselves were not directly involved in evaluating the intervention. Future development should incorporate adolescent perspectives not only through EBE contributions but through direct involvement in intervention refinement, outcome selection, and evaluation.

Future research may benefit from integrating recruitment within routine clinical care, sharing participant testimonials to normalise engagement, and offering flexible, lower-burden modes of participation. Consistent with MRC guidance for complex interventions (Skivington et al., 2021), the present study should be viewed as an early-stage feasibility and optimisation study. Future work should focus on intervention refinement, larger-scale feasibility testing, and eventual controlled evaluation before conclusions regarding effectiveness can be drawn. Further adaptations should also explore active strategies to recruit fathers and male co-facilitators, alternative delivery formats, and longitudinal designs capable of capturing sustained individual- and family-level change. Ongoing advances in CFTR modulator therapies may continue to alter treatment burden, illness identity, family expectations, and patterns of healthcare engagement. Consequently, the intervention may require ongoing adaptation to remain responsive to the evolving realities of CF care. Embedding this relationally grounded, low-burden intervention within standard CF care pathways may provide an accessible means of supporting parental wellbeing and family resilience during adolescence.

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Chapter 6: Main Research Study Supplementary Information

Chapter 6 provides supplementary methodological and intervention detail to support the findings presented in Chapter 5 and enhance transparency, replicability, and future implementation of the Family-Focused Intervention (FFI).

Rationale for Measure Selection

The quantitative measures selected for this feasibility study were chosen to align with the intervention's theoretical targets and intended outcomes. Consistent with Medical Research Council (MRC) guidance on complex interventions, outcome selection was informed by theory, hypothesised change processes, and the exploratory nature of early intervention development (Moore et al., 2015; Skivington et al., 2021, 2024). The primary aim was therefore to examine potential signals of change in domains targeted by the intervention, rather than to evaluate efficacy.

The intervention sought to promote parental psychological flexibility, reduce emotional distress, and support adaptive family functioning during adolescence. Measures were selected to reflect these domains while remaining acceptable to participants and feasible for use within routine clinical settings.

Depression Anxiety Stress Scales (DASS 21)

The DASS-21 (Lovibond & Lovibond, 1995) was included as a measure of parental emotional distress. It has been widely used with parents of children with chronic health conditions, including cystic fibrosis, and provides a broad assessment of depression, anxiety, and stress symptoms (Cousino & Hazen, 2013; Daly et al., 2022). The measure was considered particularly relevant given evidence that parental distress and stress can

influence family functioning, parent-adolescent relationships, and adaptation to chronic illness (Psihogios et al., 2019; Thompson et al., 1992).

Comprehensive Assessment of ACT Processes (CompACT 10)

The CompACT (Francis et al., 2016) was selected to assess psychological flexibility, a central target of the intervention and a core process within Acceptance and Commitment Therapy (Hayes et al., 2006, 2012). ACT-informed content was integrated throughout the workshop, including acceptance of uncertainty, present-moment awareness, and values-based parenting. As psychological flexibility is conceptualised as a transdiagnostic process associated with adaptive coping under conditions of ongoing stress, the CompACT was considered an appropriate measure for exploring potential intervention-related change in parents of adolescents with cystic fibrosis (Whittingham et al., 2014, 2019).

Paediatric Quality of Life Inventory Family Impact Module (PedsQL FIM)

The PedsQL Family Impact Module (Varni et al., 2004) was included to explore perceived family functioning and the broader impact of cystic fibrosis on parents and family life. The measure has been used extensively in paediatric chronic illness populations and captures domains relevant to family adaptation, caregiver burden, and family relationships (Cousino & Hazen, 2013; Jastrowski Mano et al., 2011; Panepinto et al., 2009; Varni et al., 2004). It was selected to complement the individual-level measures by providing a broader assessment of family-level functioning and quality of life.

Detailed Intervention Description

The Family-Focused Intervention was delivered as a single, in-person, group-based workshop for parents of adolescents with cystic fibrosis, designed to integrate psychoeducation, experiential exercises, and facilitated peer discussion within a structured yet flexible format. This manual summarised the psychoeducational content, metaphors,

exercises, and examples discussed during the day and functioned as both a consolidation and fidelity support document. The description below aligns explicitly with the manual structure to enhance transparency and replicability.

Structure and Format

The FFI was delivered as a single in person group workshop, lasting approximately six hours including breaks, followed by an individual online follow up session two weeks later. The one-day format was chosen to balance accessibility with therapeutic depth, recognising the time pressures, fatigue, and infection control constraints faced by families affected by CF (Daly et al., 2022; Moore et al., 2015; Thompson et al., 1992).

The workshop was facilitated by two senior Clinical Psychologists with experience in paediatric chronic illness and group work, supported by a trainee Clinical Psychologist. An Expert by Experience (EBE) parent and their child, a young adult with CF contributed lived experience narratives at key points during the day. These EBE contributors were recruited by a senior Clinical Psychologist with longstanding experience working within the specialist cystic fibrosis multidisciplinary team, who was known to families through routine clinical care.

The day followed a structured but flexible flow, alternating between brief psychoeducation, reflective exercises, small group discussion, and whole group sharing. Facilitators actively responded to parent led themes, allowing content to be shaped by the concerns raised in the room. The section by section outline that follows maps directly onto the parent manual, demonstrating how core content was sequenced and delivered during the workshop.

Welcome and Orientation

The workshop commenced with an orientation to the day and establishment of group guidelines, framed by discussion of the challenges and resilience associated with living with cystic fibrosis as a family (Appendix H, pp. 1-4).

Understanding Adolescence in CF

This section drew directly on the manual's psychoeducation regarding adolescence and cystic fibrosis (Appendix H, pp. 5–12; 28–37). Facilitators explored normative adolescent developmental processes including identity formation, risk taking, emotional detachment, and neurological maturation, and explicitly linked these to CF specific challenges such as adherence, perceived difference, and future oriented uncertainty. Emphasis was placed on understanding adolescent behaviour as developmentally meaningful rather than oppositional, and on reframing conflict as a relational and developmental process.

Acceptance and Psychological Flexibility

Acceptance and Commitment Therapy processes were introduced experientially, consistent with the manual's ACT section (Appendix H, pp. 46–56). Short video clips illustrating ACT metaphors were used to support experiential learning, consistent with established ACT practice (Hayes et al., 2006). Facilitators used accessible ACT metaphors including the Chinese Finger Trap, Tug of War, Unwanted Party Guest, and Dropping Anchor to illustrate how struggling with thoughts and emotions can amplify distress. Exercises focused on noticing internal experiences, practising pause and presence, and shifting from control-based reactions to values guided responses in parenting contexts.

Problem Solving in Real Life

Problem Solving Therapy formed a core skills-based component of the workshop and followed the DO ACT structure outlined in the manual (Appendix H, pp. 14–27). Parents

worked with real concerns generated during the session, including adherence, school difficulties, family conflict, and sibling impact. Facilitators guided parents through defining problems, brainstorming options, weighing pros and cons, and selecting values consistent actions, with emphasis on flexibility and collaboration.

Modulator Era Adaptations to the FFI

The intervention was explicitly adapted to reflect the contemporary CF context. Rather than framing CF solely as a life limiting illness, facilitators acknowledged the coexistence of hope and uncertainty. Discussion included ambiguity around long term treatment expectations, adherence thresholds, fertility, and mental health side effects of modulators.

This adaptation required facilitators to resist overly reassuring narratives and instead model tolerance of uncertainty. Parents were supported to hold multiple truths simultaneously, including gratitude for medical advances and grief for ongoing unpredictability. This stance was central to maintaining credibility and relevance in the modulator era.

Intervention Fidelity and Facilitator Guidance

Facilitator guidance and fidelity strategies were informed by both the theoretical model underpinning the FFI and the structured content of the parent manual. Fidelity was conceptualised as adherence to core processes and stance rather than rigid script delivery, consistent with contemporary guidance on intervention fidelity and process evaluation (Bellg et al., 2004; Moore et al., 2015).

Core (Non-Negotiable) Intervention Components

Core elements required for fidelity included the group-based format, integration of narrative, ACT, and problem-solving components, explicit focus on uncertainty, and

inclusion of lived experience perspectives. Facilitator stance, characterised by validation, curiosity, and non-expertise, was considered essential.

Adaptable Intervention Elements

Flexibility was permitted in pacing, emphasis, and examples used. Facilitators were encouraged to follow parent led themes, adapt language to the group, and prioritise relational safety over content coverage when needed.

Fidelity Checklist

Fidelity was monitored at two levels: adherence to core intervention components and competence in therapeutic delivery.

- Adherence markers included coverage of key sections reflected in the manual: psychoeducation on CF and adolescence, narrative reflection and lived experience input, structured problem solving using DO ACT, experiential ACT metaphors, and values-based parenting integration.
- Competence markers focused on facilitator stance, including consistent validation of parental experience, modelling curiosity rather than expertise, avoidance of premature advice giving, explicit normalisation of uncertainty, and active facilitation of peer connection. These markers reflect the relational and process-oriented emphasis reinforced throughout the manual.

Conclusion

This supplementary chapter provides detailed intervention description and fidelity guidance to support future replication, refinement, and evaluation of the FFI. It highlights the importance of relational processes, facilitator stance, and contextual adaptation in delivering family-focused psychological support in contemporary CF care.

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Chapter 7: Integrative Discussion

Overview

This chapter offers an integrated interpretation of a programme of research examining family experiences of cystic fibrosis (CF) during adolescence in the modulator era and the development and preliminary evaluation of a family-focused psychological intervention. Rather than considering each study in isolation, findings are synthesised across the provider engagement study and the feasibility pilot to examine what they collectively contribute to understanding family processes, intervention development, and psychosocial support within contemporary CF care. Adopting a programme-level perspective allows these studies to be understood as interdependent components of a single line of enquiry, each informing and refining the other.

The overarching aim of this research programme was twofold. First, it sought to clarify emerging psychosocial challenges faced by families of adolescents with CF in the context of rapidly changing treatment expectations associated with CFTR modulator therapies, drawing on the perspectives of healthcare providers. Second, it aimed to translate these insights into the development and preliminary testing of a developmentally attuned, family-focused psychological intervention that could be feasibly delivered within routine CF services. The development of the Family-Focused Intervention (FFI) was therefore conceptualized as a central research outcome in its own right, reflecting a deliberate methodological choice to treat intervention development as a knowledge-generating process informed by stakeholder perspectives, theory, and empirical data.

The integration of a healthcare provider engagement study at the outset of the programme represents a key contribution of this work. Providers offered system-level

insight into recurrent patterns observed across families and services over time, including heightened parental vigilance, uncertainty regarding adherence expectations, and intensified negotiation of adolescent autonomy. These perspectives provided a structured account of pressures shaping family functioning in the modulator era and directly informed both the content and delivery of the intervention. The subsequent feasibility pilot extended this work by examining how parents engaged with the intervention, how they made sense of its components, and how early changes in psychological processes and wellbeing might be understood in context. Considered together, these studies enable triangulation of provider perspectives, parent experiences, and preliminary outcome data, offering a more nuanced account of family adaptation during adolescence than would be possible through a single methodological lens.

Situated within a literature that has historically prioritized biomedical outcomes, treatment adherence, and early childhood interventions, this programme addresses a notable gap in psychosocial research on CF. Adolescence has received comparatively limited attention as a distinct developmental period, and parents have rarely been conceptualised as ongoing recipients of structured psychological support. While family-focused interventions have demonstrated benefit in other pediatric chronic illness contexts, psychosocial interventions in CF have largely focused on individual distress, adherence behaviours, or early developmental stages. This research responds to a contemporary clinical landscape characterised by improved physical health outcomes alongside persistent uncertainty, shifting parental roles, and evolving expectations of independence, positioning family processes and parental psychological adaptation as central to understanding life with CF in the modulator era.

By integrating stakeholder-informed intervention development with mixed-methods evaluation, this chapter moves beyond descriptive reporting of individual findings to articulate how this programme of research advances understanding of family life in CF during adolescence. In doing so, it clarifies the contribution of developmentally sensitive, theoretically grounded, and clinically feasible psychosocial interventions to supporting families navigating the complexities of the modulator era.

Contribution to knowledge and Advancement of Family – Focused Interventions

This programme of research advances understanding of family adaptation in cystic fibrosis (CF) during adolescence by showing how psychosocial demands are reshaped, rather than resolved, in the CFTR modulator era. Across provider perspectives and parent reflections, adolescence was characterised by ongoing parental responsibility, heightened uncertainty, and complex negotiation of autonomy, despite improvements in physical health. This challenges assumptions that modulator therapies necessarily reduce psychosocial burden for families and extends CF psychosocial models that have primarily focused on adherence, education, or early developmental stages (Glasscoe & Quittner, 2008; Tickner et al., 2022).

A key contribution of this work lies in the prospective integration of healthcare provider perspectives into psychosocial intervention development. Providers offered system-level insight into recurring challenges observed across families and services, including intensified parental vigilance, ambiguity regarding adherence expectations, and uncertainty about appropriate parental involvement during adolescence. Embedding these perspectives at the outset of intervention design extends existing approaches in CF psychosocial research, which have more commonly relied on retrospective parent feedback or consultation focused on discrete aspects of care, and strengthens the clinical

relevance and feasibility of the resulting intervention (Boaz et al., 2015; Chalmers et al., 2023).

The development of the Family-Focused Intervention (FFI) represents a substantive contribution in its own right. The intervention integrates Acceptance and Commitment Therapy processes, narrative reflection, and structured problem-solving within a brief, developmentally targeted format designed for parents of adolescents with CF. Unlike many existing family-focused interventions, which emphasise behavioural management or psychoeducation, the FFI explicitly targets parental emotional and relational processes during adolescence, positioning psychological flexibility and meaning-making as potentially important processes associated with adaptive autonomy negotiation (Brown et al., 2014; Burke et al., 2014; Byrne et al., 2021; Law et al., 2019). The inclusion of parent and young adult Experts by Experience strengthened the relevance and credibility of intervention delivery. However, EBE involvement occurred primarily within intervention refinement and delivery rather than throughout the research cycle. Future work should seek greater co-production, involving parents and adolescents more consistently in research design, implementation, interpretation, and dissemination.

The feasibility pilot indicates that a brief, provider-informed, family-focused psychological intervention for parents of adolescents with CF is acceptable and deliverable within routine service constraints. While not designed to establish effectiveness, the findings suggest that parental psychological flexibility and emotional wellbeing may represent feasible and relevant targets for engagement within a structured intervention (Byrne et al., 2021; Hayes et al., 2012). This extends the CF psychosocial literature by shifting attention from adherence-focused outcomes toward relational and emotional processes experienced by parents during adolescence.

Finally, the mixed-methods design strengthens the contribution of this research by clarifying early change processes rather than privileging outcome evaluation. Qualitative process data illuminated how parents described increased awareness, emotional activation, and reflection following participation in the intervention, while quantitative measures provided preliminary signals relevant to psychological flexibility and wellbeing. Interpreted together, these data support a process-oriented understanding of early change, consistent with guidance on complex intervention development that emphasises examining mechanisms and context alongside outcomes, particularly at early stages (Greene et al., 1989; Moore et al., 2015; Skivington et al., 2021).

Integrated Interpretation of Findings Across the Research Programme

Consistent with Medical Research Council (MRC) guidance, intervention development was conceptualised as an iterative process of development, feasibility testing, refinement, and re-evaluation rather than a linear progression from design to effectiveness testing (Craig et al., 2008; Skivington et al., 2021). This approach recognises that intervention components, contextual influences, and potential change processes often require ongoing optimisation before large-scale evaluation.

Synthesising findings across the provider engagement study and feasibility pilot revealed a coherent pattern of emotional, relational, and meaning-making challenges shaping family adaptation during adolescence in the modulator era. Considered together, provider perspectives, parent experiences, and preliminary outcome data offer a more integrated understanding of potential intervention targets and how parents made sense of their experiences during and following participation.

Parental psychological flexibility and emotional regulation

Across both studies, parental emotional regulation emerged as a salient process shaping how parents described their experience of adolescence in cystic fibrosis (CF). Healthcare providers consistently highlighted heightened parental vigilance, anxiety, and emotional reactivity, particularly in the context of uncertainty regarding treatment expectations and adolescent independence. These observations are consistent with family systems and stress and coping frameworks, which emphasise the reciprocal influence of parental emotional responses on adolescent behaviour and the wider family climate (Lazarus & Folkman, 2006; Paley & Hajal, 2022). Provider perspectives therefore offer an important contextual backdrop for understanding how parents reflected on their experience of the Family-Focused Intervention.

Qualitative interviews in the feasibility pilot focused explicitly on parents' perceptions of what had shifted for them during or following participation in the programme. In this context, parents reflected on becoming more aware of their emotional reactions, particularly in situations involving perceived risk or conflict. Rather than describing unmet needs or changes in family functioning, parents spoke about changes in how they noticed and related to emotional responses that they recognised as longstanding. ACT-informed exercises were described as providing a shared language and framework through which parents could observe these reactions with greater distance, rather than responding automatically (Hayes et al., 2012; Byrne et al., 2021).

These accounts are best understood as parents' descriptions of increased awareness and reflective capacity, rather than as evidence of intervention impact or effectiveness. Preliminary quantitative findings indicating directional change in measures of psychological flexibility and emotional wellbeing are therefore interpreted cautiously

and used to contextualise the relevance of these processes, rather than to support evaluative claims (Byrne et al., 2021). This interpretive stance is consistent with guidance on early-stage intervention research, which emphasises the importance of examining process-level change alongside feasibility and acceptability, without over-extending conclusions regarding outcomes (Moore et al., 2015; Skivington et al., 2021).

Taken together, the convergence of provider perspectives and parent reflections suggests that parental psychological flexibility represents a meaningful lens through which parents themselves understood what had changed for them during the programme. This interpretation aligns with evidence from other paediatric chronic illness contexts linking parental psychological flexibility to coping and relational adjustment, while remaining consistent with the exploratory, process-focused aims of the present study (Coyne et al., 2021; Lappalainen et al., 2021).

Communication, autonomy negotiation, and parental sense-making

A second integrative theme concerned parental sense-making around communication and the renegotiation of autonomy during adolescence. Providers described recurring patterns of conflict, avoidance, and miscommunication within families, particularly in relation to treatment adherence and parental monitoring. These dynamics were understood as intensifying during adolescence, when developmental drives toward independence intersect with parental concerns about safety and health outcomes (Beyers et al., 2025; Modi et al., 2008). Provider perspectives therefore offer a developmental and systemic context for understanding the reflections reported by parents following participation in the intervention.

In qualitative interviews, parents reflected on how they made sense of these tensions in their own parenting during or following the programme. Many described

becoming more aware of feeling caught between supporting their adolescent's independence and maintaining a sense of responsibility for health and safety, often in the absence of clear guidance regarding appropriate levels of oversight in the modulator era. Importantly, these accounts are best understood as reflections on parents' own uncertainty, emotional responses, and habitual ways of engaging, rather than as descriptions of family-level functioning or relational difficulties.

Narrative and communication-focused components of the intervention were described as facilitating reflection on these experiences, rather than producing changes in family communication patterns. This reflective process enabled parents to recognise familiar interactional cycles and to consider alternative ways of responding to situations involving autonomy and risk. These accounts illustrate shifts in parental awareness and meaning -making, rather than changes in family communication patterns per se.

Short-term changes in parent-reported family functioning measures are therefore interpreted cautiously and remain secondary to the process-focused aims of the feasibility study. From a systemic perspective, increased awareness of relational dynamics can temporarily heighten perceptions of strain when previously implicit patterns are brought into focus (Greenberg, 2015; Teixeira De Melo & Alarcão, 2017). However, it is also possible that aspects of the intervention were experienced as emotionally challenging or insufficiently supportive for some participants. Given the exploratory design and small sample size, these competing interpretations cannot be disentangledf. In this context, qualitative accounts of insight and emotional activation are understood as reflecting early engagement with relational meaning-making, rather than deterioration or improvement in family functioning.

Meaning-making and uncertainty in the modulator era

Across both studies, parents described their experience of adolescence within the ongoing uncertainty associated with CFTR modulator therapies. Healthcare providers highlighted ongoing ambiguity regarding long-term prognosis, adherence expectations, and potential physical and mental health effects of modulators. These perspectives provide a contextual frame for understanding how parents reflected on their experience during and following participation in the Family-Focused Intervention, rather than introducing new or unmet needs.

In qualitative interviews, parents reflected on how they were making sense of this evolving treatment landscape. Parents described valuing opportunities to consider how cystic fibrosis had changed over time, how modulators had reshaped expectations for their adolescent's health and independence, and how their own identities and roles as parents were being renegotiated. Narrative elements of the intervention were described as offering space to articulate and organise these reflections, rather than as producing specific outcomes. These accounts are best understood as parents' descriptions of meaning-making and perspective-shifting, consistent with narrative approaches that emphasise the role of coherent illness narratives in psychological adjustment (Eeltink & Duffy, 2004; Jacobi & MacLeod, 2011).

This emphasis on parental meaning-making is particularly salient in the absence of clear clinical scripts for families navigating adolescence in the modulator era. Parents' reflections illustrate how uncertainty was experienced and interpreted, rather than resolved, and how values-based considerations informed ongoing parenting decisions in a context of ambiguity. These reflections align with broader commentary on the modulator era, which highlights improved physical health alongside persistent uncertainty regarding

long-term trajectories and psychosocial implications (Goetz et al., 2023; Southern et al., 2023).

Integrating qualitative process data and preliminary outcomes

The mixed-methods design of the research programme enabled early change processes to be interpreted through the integration of qualitative and quantitative data. Qualitative process data captured how parents described emotional activation, reflection, and increased awareness following participation in the programme, while quantitative measures provided preliminary signals regarding psychological flexibility and emotional wellbeing. Consistent with mixed-methods scholarship, this integration allowed experiential accounts to be considered alongside outcome data without privileging one form of evidence over the other (Greene et al., 1989; Johnson & Onwuegbuzie, 2004).

In keeping with the exploratory aims of the feasibility study, quantitative findings are interpreted cautiously and used to contextualise the relevance of psychological processes rather than to evaluate effectiveness. From a process-oriented and systemic perspective, early engagement with emotional and relational material may involve disruption of previously unexamined assumptions or habitual responses, particularly when interventions target entrenched emotional and interactional processes rather than surface behaviours alone (Paley & Hajal, 2022; Watzlawick et al., 2011). Longer follow-up periods and multi-informant assessment will therefore be essential in future research to examine how early process-level shifts are sustained and translated over time (Cox & Paley, 2003; Moore et al., 2015).

Implications for Routine Cystic Fibrosis Care

The integrated findings of this research programme have clear implications for how psychosocial care for families of adolescents with CF is conceptualised and delivered within

routine services. Taken together, provider and parent accounts indicate that adolescence in the modulator era remains a period of significant relational and emotional demand, with parents continuing to play an active role in treatment oversight, emotional containment, and autonomy negotiation

Parents as ongoing recipients of psychosocial support during adolescence

Providers consistently described parents as carrying responsibility for treatment oversight, emotional containment, and negotiation of autonomy, often in the absence of clear guidance about appropriate levels of involvement. Parents' accounts reinforced this picture, highlighting the emotional strain associated with balancing safety, independence, and family relationships during adolescence.

These findings support the inclusion of parents as ongoing recipients of structured psychosocial support during adolescence, rather than assuming a gradual withdrawal of parental involvement as adolescents age (Modi et al., 2008; Tuchman et al., 2008, 2010). Interventions that strengthen parental psychological flexibility and reflective capacity may help parents remain supportive without becoming over-controlling, thereby facilitating healthier autonomy negotiation and communication within families.

Uncertainty associated with CFTR modulator therapies further underscores the importance of this support. Both providers and parents described ambiguity regarding adherence expectations, long-term outcomes, and potential mental health effects of modulators. Rather than being resolved through prescriptive guidance alone, this uncertainty appears to require psychosocial approaches that support parents to tolerate ambiguity and engage in values-based decision-making alongside medical care (Goetz et al., 2023; Southern et al., 2023).

Embedding family-focused psychological interventions within MDT care

The feasibility of the one-day Family-Focused Intervention (FFI) has clear implications for multidisciplinary team (MDT) models of CF care. Providers highlighted persistent constraints related to time, staffing, and competing clinical priorities, which often limit opportunities for extended psychosocial intervention. Consistent with models of paediatric psychosocial care, these findings emphasise the importance of integrating structured psychological support within MDT pathways in ways that are responsive to service realities (Kazak, 2006; Kazak & Noll, 2015).

Within this context, the one-day format, supported by a follow-up manual, was experienced as a pragmatic and deliverable approach that aligned with existing MDT workflows while still allowing meaningful psychological work to take place. Rather than representing a comprehensive model of family support, the FFI can be understood as a feasible entry point for integrating family-focused psychological intervention within resource-constrained services. Brief, structured interventions of this kind may be incorporated as standalone workshops or as adjuncts to routine psychology input, consistent with psychosocial care guidance in CF that emphasises flexibility of delivery and interdisciplinary collaboration (Quittner et al., 2016).

The findings also highlight the importance of developmentally timed, prevention-oriented support. Providers and parents described difficulties that emerged gradually and became entrenched over time, suggesting that psychosocial input offered earlier in adolescence may be more effective than support triggered only at crisis points. Embedding family-focused psychological support as a routine component of adolescent CF care, rather than as an optional add-on, may therefore help families adapt more effectively to changing

expectations in the modulator era (Cox & Paley, 2003; Mrazek & Haggerty, 1994; Paley & Hajal, 2022).

Summary of clinical implications

Taken together, the findings suggest that adolescence in cystic fibrosis is characterised by ongoing parental responsibility and uncertainty, rather than a straightforward transition toward reduced involvement. While provider and parent accounts converged in identifying emotional and relational demands during this period, experiences varied considerably across families, limiting the extent to which uniform clinical conclusions can be drawn.

Within these bounds, the feasibility work indicates that brief, provider-informed family-focused psychological input can be delivered acceptably within multidisciplinary team care and may offer parents a structured space for reflection and sense-making at a developmentally sensitive point. The clinical implication is therefore not that specific intervention components should be implemented wholesale, but that psychosocial care pathways may need to better accommodate parents as ongoing participants in adolescent CF care, particularly in contexts characterised by uncertainty. Further evaluation is required to establish for whom, when, and under what conditions such approaches are most useful.

Diversity, inclusion and cultural responsiveness

An important consideration arising from this programme of research concerns whose voices were represented and whose may have been absent. Participants were predominantly mothers, and the studies did not systematically explore how experiences of adolescence in CF may vary according to gender, socioeconomic position, ethnicity, Traveller identity, family structure, rurality, health literacy, or access to specialist services.

These factors may shape not only family experiences of CF, but also the acceptability and accessibility of psychosocial interventions.

Future intervention development may benefit from frameworks such as Social GRACES (Burnham, 2012), which encourage explicit consideration of social difference, power, privilege, and marginalisation. Applying such frameworks could support greater cultural humility in both research and clinical practice and help ensure that future iterations of the intervention are responsive to the diverse realities of families living with CF.

Limitations and lessons learned across the research programme

As an early-stage programme of research, the findings must be interpreted in light of several methodological and contextual limitations. The feasibility pilot involved a small sample size and was not designed or powered to evaluate effectiveness. Quantitative findings were therefore interpreted cautiously and used to examine acceptability, feasibility, and early signals of change rather than to support conclusions regarding efficacy, consistent with guidance on pilot and feasibility studies (Eldridge et al., 2016; Skivington et al., 2024). Similarly, the provider engagement study reflected perspectives within a single national service context, and experiences of service delivery may differ across settings with varying resources, structures, and models of care. These contextual influences should be considered when assessing the transferability of the findings (Moore et al., 2015).

The short follow-up period represents a further limitation. Outcomes were assessed at baseline and two weeks post-intervention, which was appropriate for examining acceptability and early process-level change but unlikely to capture sustained or family-level effects. Family functioning is understood as a relational and systemic process

that typically unfolds over time and involves multiple family members (Bowen, 1992; Paley & Hajal, 2022). Longer-term follow-up is therefore required to examine whether early psychological shifts observed in parents are maintained and translate into broader relational change, as suggested by longitudinal family intervention research (Cox & Paley, 2003; Moore et al., 2015). The reliance on single-informant parent-report measures further limits interpretation of family-level outcomes, highlighting the need for future research to incorporate multi-informant and observational approaches to strengthen assessment of relational processes (Paley & Hajal, 2022).

Challenges encountered in parent and public involvement also offer important lessons for future work. Despite determined effort, parent participation in the PPI component could not be secured. Parents of adolescents with cystic fibrosis may experience high emotional and practical burden, which can limit capacity to engage in additional research activities, particularly during adolescence (Cousino & Hazen, 2013; Mitchell et al., 2020). Recruitment pathways relying on third-party organisations may have further reduced opportunities for personalised engagement and trust-building (Dudley et al., 2015; Harrison et al., 2018, 2019). Future research may benefit from more flexible and lower-burden approaches to involvement, such as brief individual consultations, asynchronous input, or staged engagement across the research lifecycle, particularly in high-burden illness contexts.

A further limitation concerns the relative absence of adolescent voices throughout the programme. While young adult EBEs contributed to intervention delivery, adolescents were not directly involved in the provider engagement study, feasibility evaluation, outcome selection, or intervention refinement. Future research should move beyond consultation and consider adolescents as active partners in intervention development,

implementation, and evaluation to ensure that psychosocial support remains aligned with their priorities and experiences.

The intervention itself also warrants critical consideration. While participants generally valued the one-day format, some accounts suggested that emotionally evocative material may have required greater containment and follow-up support. The brevity of the intervention may also have limited opportunities for consolidation, skills practice, and inclusion of broader family members. Future iterations should therefore examine whether additional follow-up sessions, booster contacts, or greater family involvement enhance acceptability and outcomes.

Taken together, these limitations underscore the importance of methodological flexibility and process-focused evaluation in early-stage intervention development. Engaging healthcare providers early proved valuable for ensuring feasibility and clinical relevance, but future work should aim to integrate parent perspectives. The findings also highlight the value of examining process alongside outcome, particularly where early emotional activation or increased awareness may precede observable functional change (Craig et al., 2008; Skivington et al., 2021). These lessons provide a clear foundation for subsequent research to refine the intervention, extend follow-up, and evaluate effectiveness across diverse service contexts.

Future Research and Intervention Development

Consistent with the Medical Research Council (MRC) framework for complex intervention development, the present programme of research should be viewed as an early-stage process of intervention development, feasibility testing, and refinement rather than an evaluation of effectiveness (Skivington et al., 2021, 2024). The findings provide

preliminary support for the acceptability and clinical relevance of a family-focused intervention for parents of adolescents with cystic fibrosis, while also identifying important areas for further optimisation. Future development should involve broader stakeholder engagement, including parents, adolescents, healthcare providers, and Experts by Experience, to refine intervention content, delivery methods, and outcome selection. Particular attention should be given to incorporating adolescent perspectives throughout the research process and ensuring that intervention development is informed by a diverse range of family experiences.

Subsequent phases of research should focus on larger-scale feasibility and pilot studies across multiple clinical sites to examine implementation challenges, recruitment strategies, intervention fidelity, and longer-term acceptability. This work should be accompanied by process evaluation to further explore how participants engage with the intervention and which aspects are perceived as most meaningful or relevant. Only following this iterative programme of refinement would a controlled evaluation of effectiveness be warranted. Importantly, intervention development in cystic fibrosis cannot be considered a static process. Ongoing advances in CFTR modulator therapies continue to reshape treatment burden, illness expectations, family roles, and experiences of adolescence. Future iterations of the intervention may therefore require ongoing adaptation to ensure that psychosocial support remains responsive to the evolving realities of contemporary cystic fibrosis care.

Conclusion

This thesis examined family experiences of cystic fibrosis during adolescence in the CFTR modulator era and developed and preliminarily evaluated a family-focused psychological

intervention informed by these experiences. By integrating a healthcare provider engagement study with a feasibility pilot of the Family-Focused Intervention (FFI), the research provides an empirically grounded account of how families navigate emotional, relational, and practical challenges during a period of rapid clinical and developmental change.

Taken together, the findings indicate that adolescence in the modulator era is characterised not by the resolution of psychosocial burden, but by a reconfiguration of uncertainty, parental responsibility, and relational negotiation. Providers and parents converged in identifying ongoing emotional strain, challenges in autonomy negotiation, and difficulty making sense of evolving treatment expectations, despite improvements in physical health outcomes associated with modulator therapies. These findings underscore the importance of psychosocial models of care that recognise the relational and emotional implications of biomedical advances for families.

This programme of research contributes to the cystic fibrosis psychosocial literature by demonstrating that a brief, provider-informed, family-focused psychological intervention for parents of adolescents is acceptable and feasible within routine care and designed to target key psychological processes. In particular, the findings suggest that parental psychological flexibility and meaning-making may represent salient targets for intervention during adolescence, extending existing CF psychosocial research that has largely focused on adherence, education, or behavioural management rather than relational and emotional mechanisms. The integration of qualitative process data with preliminary quantitative outcomes allowed early changes to be interpreted in context, supporting a cautious, process-focused understanding of change rather than outcome-based claim.

While conclusions regarding sustained or family-level change are necessarily limited by sample size, follow-up duration, and measurement scope, this thesis provides a clear foundation for future work. It demonstrates the value of integrating provider insight into intervention development, highlights the importance of developmentally timed and uncertainty-aware psychosocial support for parents during adolescence, and offers a feasible starting point for embedding family-focused psychological input within contemporary cystic fibrosis care pathways.

Overall, this programme of research advances understanding of family life in cystic fibrosis during adolescence and establishes a pragmatic, theoretically grounded basis for further evaluation of family-focused psychological interventions in the modulator era.

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Appendix A Staff Information Letter

| AUGUST

Information leaflet

Purpose of the study

The researchers in the School of Applied Psychology at University Colllege Cork (UC working with the Cystic Fibrosis team at Cork University Hospital and Cystic Fibrosis Ireland.

The title of our study is: *A public patient involvement study to inform the design of a methods family focused intervention for parents of adolescents with CF in Ireland.*

We want to listen to parents and professionals experience of cystic fibrosis to infc intervention. We are asking participants to take part in a focus group to explore this topic.

The research team

The research team is made up of four people
Ms. Dee Mullins, Psychologist in clinical training, UCC
Dr. Christopher McCusker, Clinical Psychologist, UCC
Dr. Nicola Lally, Principal Specialist Clinical Psychologist, CUH
Dr. Muireann N Chronin, Respiratory/Cystic Fibrosis specialist

Why have I been asked to take part?

You have been asked to take part because you are a parent of an adolescent witl fibrosis or a young adult with cystic fibrosis. Participation is completely voluntary and will nc your engagement with Cystic Fibrosis Ireland or CUH in any way.

Can I change my mind?

You can think about taking part and if you have any questions about the study y contact the research team. We will support you with any questions you may have. If you cor take part, and then decide before the focus group that you no longer wish to take part y withdraw. If you decide after the focus group that you wish to withdraw, you have two week us know and we will then remove your contribution from the focus group.

What will I have to do?

A focus group is where a small group of people come together to share their views and feelings on a topic.

If you take part in our study we will ask you attend a focus group. The focus group will take approximately 1-2 hours to complete. We will communicate a time with you beforehand.

While our intervention and manual has been devised in line with the evidence base, we intend to gain feedback and considerations from the PPI group on the proposed study and associated materials. This means that there may be some aspects of the research which we cannot alter as it does not reflect the current evidence base.

What kind of questions will I be asked?

An example of questions you might be asked are;

What issues do you feel might be important to know about when parenting an adolescent with CF?

Are there any specific circumstances you have been thinking about or encountering lately which you feel would be relevant?

What are your thoughts on having an expert by experience attend and speak at the Workshop?

And if there was an expert by experience present, would you prefer that expert by experience to be a parent of a young adult who has recently navigated adolescence or a young adult who has recently navigated adolescence?

What happens to the information I share at the focus group?

The focus group will be confidential. This means that any information you share will be kept private. The only time we would break this confidentiality is when there is a risk to you or another vulnerable person/child. This keeps everyone safe.

The information you share during the focus group will be audio recorded and analysed by the research team to inform the project. The written record will anonymise your information. That means we won't write your name or identifying information about you.

The research team will then analyse the information from the focus group and use this valuable information to guide our main project.

Will other people know I am taking part?

Your participation will be kept confidential. The only people who will know you are taking part are the research team, and the other members of the focus group. Any forms you give to us with your details on them will be password protected and kept in a shared folder, only accessible to the research team, on a secure laptop.

If you have a concern about how we have handled your personal data, you are entitled to this raise this with the Data Protection Commission.

https://www.dataprotection.ie/

SHOULD YOU BECOME AWARE OF A BREACH OF THE PERSONAL DATA OF PARTICIPANT(S), YOU MUST REPORT THIS TO THE DATA CONTROLLER.

"A personal data breach occurs when the data is accessed, disclosed, altered, lost or destroyed in contravention of an organisation's obligation to keep personal data in its possession safe and secure"

https://www.dataprotection.ie/

If you have any queries about this research, you can contact us at

Dee Mullins
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UCC'S Data Protection Officer (DPO) is Catriona O'Sullivan, Information Compliance Manager, University College Cork, 4 Carrigside, College Road, Cork, Ireland.

Telephone: +353 (0)21 4903949* Email: gdpr@ucc.ie

The Data Controller for this study is Dee Mullins 103543811@umail.ucc.ie

If you have a complaint about how this research was conducted, please contact in writing:

The Ethics Committee,
School of Applied Psychology,
University College Cork,
Cork

If you agree to take part in this study, please sign the consent form overleaf

Appendix B Staff Consent Form

Consent Form

- ❑ I……agree to participate in the research study by researchers: Dee Mullins, Dr. Christopher McCusker, Clinical Psychologist (UCC) and Dr. Nicola Lally, Principal Specialist Clinical Psychologist (CUH).
- ❑ The purpose and nature of the study has been explained to me in writing and I have had the opportunity to discuss it before deciding.
- ❑ I am participating voluntarily.
- ❑ I give permission for my contribution in the focus group to be audio-recorded.
- ❑ I understand that I can withdraw from the study, without repercussions, within 2 weeks of the focus group.
- ❑ I understand that I can withdraw permission to use the data within 2 weeks of the focus group in which case the material will be deleted.
- ❑ I understand that my data will be anonymised via redactions or by turning specific detail into generic detail. This include any reports, publications or research papers that will be completed.
- ❑ I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed: …….. OBJ Date: ……...

PRINT NAME: …….. OBJ

Appendix C Provider Engagement Focus Group Protocol

Pseudonym

Age

Gender

Years working with CF families

Role type

1. In your opinion, what are the main worries/fears facing parents of adolescents with cystic fibrosis?

2. From working with adolescents with cystic fibrosis, what do you feel are the greatest challenges they face? You might especially consider social or psychological challenges.

3. If you were to think about a developing a family focused psychological intervention for these families of adolescents with CF. What do you think that might look like?

4. Have you noticed anything specific about what is going on for families who have good psychological outcomes?

Appendix D Journal of Research Engagement and Involvement Author Guidance

Preparing main manuscript text
Quick points:

- Use double-line spacing
- Include line and page numbering
- Use SI units: Please ensure that all special characters used are embedded in the text, otherwise they will be lost during conversion to PDF
- Do not use page breaks in your manuscript

File formats

The following word processor file formats are acceptable for the main manuscript document:

- Microsoft word (DOC, DOCX)
- Rich text format (RTF)
- TeX/LaTeX

Please note: editable files are required for processing in production. If your manuscript contains any non-editable files (such as PDFs) you will be required to re-submit an editable file when you submit your revised manuscript, or after editorial acceptance in case no revision is necessary.

Additional information for TeX/LaTeX users

You are encouraged to use the Springer Nature LaTeX template when preparing a submission. A PDF of your manuscript files will be compiled during submission using pdfLaTeX and TexLive 2021.

All relevant editable source files must be uploaded during the submission process. Failing to submit these source files will cause unnecessary delays in the production process.

Data and materials

All BioMed Central journals strongly encourage or require authors to provide all datasets on which the conclusions of their manuscripts rely. You may either deposit datasets in publicly available repositories (where available and appropriate) or present them in the main paper or in additional supporting files. Please provide datasets in a machine-readable format (such as spreadsheets rather than PDFs). You will find data repository guidance in our editorial policies.

To find out if providing data is an absolute requirement for your submission, please read the relevant article-type information.

Where there is a widely established research community expectation for data archiving in public repositories, submission to a community-endorsed public repository is mandatory.

For all manuscripts, information about data availability should be detailed in an 'Availability of data and materials' section. For more information on the content of this section, please see the 'Declarations' section of the relevant journal's article type page in the submission guidelines. Read more about our policies on data availability.

Formatting the 'Availability of data and materials' section of your manuscript

The following format for the 'Availability of data and materials section of your manuscript should be used:

"The dataset(s) supporting the conclusions of this article is(are) available in the [repository name] repository, [unique persistent identifier and hyperlink to dataset(s) in https:// format]."

The following format is required when data are included as additional files:

"The dataset(s) supporting the conclusions of this article is(are) included within the article (and its additional file(s))."

BioMed Central endorses the Force 11 Data Citation Principles and requires that all publicly available datasets be fully referenced in the reference list with an accession number or unique identifier such as a DOI.

For databases, this section should state the web/ftp address at which the database is available and any restrictions to its use by non-academics.

For software, this section should include:

- Project name: e.g. My bioinformatics project
- Project home page: e.g. https://sourceforge.net/projects/mged/
- Archived version: DOI or unique identifier of archived software or code in repository (e.g. Zenodo)
- Operating system(s): e.g. Platform independent
- Programming language: e.g. Java
- Other requirements: e.g. Java 1.3.1 or higher, Tomcat 4.0 or higher
- License: e.g. GNU GPL, FreeBSD etc.
- Any restrictions to use by non-academics: e.g. licence needed

Information on available repositories for other types of scientific data, including clinical data, can be found in our editorial policies.

References

See our editorial policies for author guidance on good citation practice.

Please also check the submission guidelines for the relevant journal and article type.

What should be cited?

Only articles, clinical trial registration records and abstracts that have been published or are in press, or are available through public e-print/preprint servers, may be cited.

Unpublished abstracts, unpublished data and personal communications should not be included in the reference list, but may be included in the text and referred to as "unpublished observations" or "personal communications" giving the names of the involved researchers. Obtaining permission to quote personal communications and unpublished data from the cited colleagues is the responsibility of the author. Only footnotes are permitted. Journal abbreviations follow Index Medicus/MEDLINE.

Any in-press articles cited within the references and necessary for the reviewers' assessment of the manuscript should be made available if requested by the editorial office.

How to format your references

Please check the Instructions for Authors for the relevant journal and article type for examples of the relevant reference style.

Web links and URLs: All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, as well as the date the site was accessed, in the following format:

The Mouse Tumor Biology Database. https://tumor.informatics.jax.org/mtbwi/index.do. Accessed 20 May 2013.

If an author or group of authors can clearly be associated with a web link, such as for weblogs, then they should be included in the reference.

Authors may wish to make use of reference management software to ensure that reference lists are correctly formatted.

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Preparing illustrations and figures

When preparing figures, please follow the formatting instructions below.

- Figures should be numbered in the order they are first mentioned in the text, and uploaded in this order. Multi-panel figures (those with parts a, b, c, d etc.) should be submitted as a single composite file that contains all parts of the figure.
- Figures should be uploaded in the correct orientation.
- Figure titles (max 15 words) and legends (max 300 words) should be provided in the main manuscript, not in the graphic file.
- Figure keys should be incorporated into the graphic, not into the legend of the figure.
- Each figure should be closely cropped to minimise the amount of white space surrounding the illustration. Cropping figures improves accuracy when placing the figure in combination with other elements when the accepted manuscript is prepared for publication on our site. For more information on individual figure file formats, see our detailed instructions.
- Individual figure files should not exceed 10 MB. If a suitable format is chosen, this file size is adequate for extremely high-quality figures.
- Please note that it is the responsibility of the author(s) to obtain permission from the copyright holder to reproduce figures (or tables) that have previously been published elsewhere. In order for all figures to be open access, authors must have permission from the rights holder if they wish to include images that have been published elsewhere in non open access journals. Permission should be indicated in the figure legend, and the original source included in the reference list.

Figure file types

We accept the following file formats for figures:

- EPS (suitable for diagrams and/or images)
- PDF (suitable for diagrams and/or images)
- Microsoft Word (suitable for diagrams and/or images, figures must be a single page)
- PowerPoint (suitable for diagrams and/or images, figures must be a single page)
- TIFF (suitable for images)
- JPEG (suitable for photographic images, less suitable for graphical images)
- PNG (suitable for images)
- BMP (suitable for images)
- CDX (ChemDraw - suitable for molecular structures)

For information and suggestions of suitable file formats for specific figure types, read more about data presentation.

Figure size and resolution

Figures are resized during publication of the final full text and PDF versions to conform to the BioMed Central standard dimensions, which are detailed below.

Figures on the web:

- width of 600 pixels (standard), 1200 pixels (high resolution).

Figures in the final PDF version:

- width of 85 mm for half page width figure
- width of 170 mm for full page width figure
- maximum height of 225 mm for figure and legend
- image resolution of approximately 300 dpi (dots per inch) at the final size

Figures should be designed such that all information, including text, is legible at these dimensions. All lines should be wider than 0.25 pt when constrained to standard figure widths. All fonts must be embedded.

Figure file compression

- Vector figures should if possible be submitted as PDF files, which are usually more compact than EPS files.
- TIFF files should be saved with LZW compression, which is lossless (decreases file size without decreasing quality) in order to minimise upload time.
- JPEG files should be saved at maximum quality.
- Conversion of images between file types (especially lossy formats such as JPEG) should be kept to a minimum to avoid degradation of quality.

If you have any questions or are experiencing a problem with figures, please contact our customer service team at info@biomedcentral.com.

Preparing tables

When preparing tables, please follow the formatting instructions below.

- Tables should be numbered and cited in the text in sequence using Arabic numerals (i.e. Table 1, Table 2 etc.).
- Tables less than one A4 or Letter page in length can be placed in the appropriate location within the manuscript.

- Tables larger than one A4 or Letter page in length can be placed at the end of the document text file. Please cite and indicate where the table should appear at the relevant location in the text file so that the table can be added in the correct place during production.
- Larger datasets, or tables too wide for A4 or Letter landscape pages can be uploaded as additional files. Please see [below] for more information.
- Tabular data provided as additional files can be uploaded as an Excel spreadsheet (.xls) or comma-separated values (.csv). Please use the standard file extensions.
- Table titles (max 15 words) should be included above the table, and legends (max 300 words) should be included underneath the table.
- Tables should not be embedded as figures or spreadsheet files, but should be formatted using 'Table object' function in your word processing program.
- Color and shading may not be used. Parts of the table can be highlighted using superscript, numbering, lettering, symbols or bold text, the meaning of which should be explained in a table legend.
- Commas should not be used to indicate numerical values.

If you have any questions or are experiencing a problem with tables, please contact our customer service team at info@biomedcentral.com.

Preparing additional files

As the length and quantity of data is not restricted for many article types, authors can provide datasets, tables, movies, or other information as additional files.

All additional files will be published along with the accepted article. Do not include files such as patient consent forms, certificates of language editing, or revised versions of the main manuscript document with tracked changes. Such files, if requested, should be sent by email to the journal's editorial email address, quoting the manuscript reference number. Please do not send completed patient consent forms unless requested.

Results that would otherwise be indicated as "data not shown" should be included as additional files. Since many web links and URLs rapidly become broken, BioMed Central requires that supporting data are included as additional files, or deposited in a recognised repository. Please do not link to data on a personal/departmental website. Do not include any individual participant details. The maximum file size for additional files is 20 MB each, and files will be virus-scanned on submission. Each additional file should be cited in sequence within the main body of text.

If additional material is provided, please list the following information in a separate section of the manuscript text:

- File name (e.g. Additional file 1)
- File format including the correct file extension for example .pdf, .xls, .txt, .pptx (including name and a URL of an appropriate viewer if the format is unusual)
- Title of data
- Description of data

Additional files should be named "Additional file 1" and so on and should be referenced explicitly by file name within the body of the article, e.g. 'An additional movie file shows this in more detail [see Additional file 1]'.

For further guidance on how to use additional files or recommendations on how to present particular types of data or information, please see How to use additional files.

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Appendix E - Journal of Paediatric Psychology Author Guidance

Source - https://academic.oup.com/jpepsy/pages/author_instructions

Manuscript Preparation Instructions

The *Journal of the Pediatric Psychology* is an online only journal.

Cover Letter

The cover letter is an essential document and must be included with the submission of all new manuscript submissions and revisions. The cover letter should be addressed to the journal editor and include the following:

1. Manuscript title
2. Assurance that all authors agree with the content of the manuscript and order of authorship
3. Assurance the publication is not currently submitted to another journal
4. Information about duplicate and redundant publications
5. Notice of any conflicts of interest
6. Consideration for a special issue/series or if this is an invited commentary
7. Corresponding author contact information

Article Types

- Original research
- Review articles
- Invited commentaries (e.g., Student Journal Club Commentaries)

The *Journal of Pediatric Psychology* no longer accepts brief reports but will accept manuscripts that are shorter in length. Case studies and narrative reports of special cases that are more descriptive will not be considered for review.

Original Research

Original Research is the most common type of journal manuscript used to publish full reports of data from original research. Authors are also encouraged to visit the Equator Network for additional information on transparent reporting of all manuscript types.

See the following articles for detailed guidance concerning preparation of manuscripts:

- Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the *Journal of Pediatric Psychology*: How to Write a Convincing Introduction;
- Editorial: How to Report Methods in the *Journal of Pediatric Psychology*;
- Editorial: How to Write an Effective Results and Discussion Section for the *Journal of Pediatric Psychology*.

1. *Cohort and observational studies*. We welcome submission of the STROBE checklist; however, these are not required.
2. *Clinical Trials*
    - a. *Randomized controlled trials*: *JPP* is committed to enhancing the transparent reporting of all intervention studies. Please use the CONSORT checklist.
    - i. All Randomized Controlled Trials (RCTs) must be registered at or before the time of first patient enrollment in any primary registry of the WHO International Clinical Trials Registry Platform (ICTRP) or in ClinicalTrials.gov. Provide the registry name and registry number in the cover letter and methods section.
    - ii. If you are submitting a secondary data analysis from an RCT, please clearly indicate that it is a secondary data analysis in your manuscript and

refer readers to the primary publication of outcomes. Consult with the editorial office if there are questions about reporting.

- b. *Pilot and feasibility trials*: Feasibility studies investigate whether something can be done and if/how it should proceed with further testing, while pilot studies test some aspect(s) of a future trial on a smaller scale. For pilot feasibility trials, we encourage authors to refer to our 2021 Editorial (Hilliard et al. 2021), which provides guidance on the reporting of pilot feasibility trials. Please use the CONSORT extension checklist.
- c. *Non-randomized trials*. A non-randomized clinical trial involves participants who are not assigned to different treatment groups by chance.

3. *Single Subject Studies*: As a journal that encourages submission of intervention studies, the Journal does accept, and encourages submission of, well-conducted single subject studies (N-of-1 designs). It is important to note that rigorous single subject designs are considered logical equivalents of Randomized Controlled Trials and include control conditions that support conclusions of causality. Previously published examples can be found in this journal including: Bernard, Cohen, & Moffett (2009). Authors considering submissions of case reports adopting N-of-1 methodology should consult the following sources within this journal: Cohen, Feinstein, Masuda, & Vowles (2014); Cushing, Walters, & Hoffman (2014); Rapoff & Stark (2008).

Review articles

1. *Topical Reviews*: Topical reviews summarize contemporary findings, suggest new conceptual models, or highlight noteworthy or controversial issues in pediatric psychology. Topical reviews are not intended to provide short data summaries or

syntheses. Rather they are intended to foster new ways of thinking about a topic area and provide a direction for future research or practice.

2. *Systematic reviews and Meta-Analyses*: Systematic reviews provide a research synthesis of a body of literature using an explicit methodology to minimize bias and ensure conclusions are made from reliable findings. Authors of systematic reviews that do not include a meta-analysis must provide a clear justification in the manuscript explaining why such an analysis is not included for all or relevant portions of the report. Please note the PRISMA should be submitted with your manuscript.
3. *Scoping Reviews*: Scoping reviews determine the scope of a body of literature on a particular topic and identify the volume of the literature (i.e., available studies), and provide an overview of its focus. These are particularly helpful for emerging evidence. Please note the PRISMA-ScR should be submitted with your manuscript.

Please consult this editorial (New Guidelines for Publishing Review Articles in *JPP*) which further describes guidelines for review articles.

Invited commentaries

Commentaries are invited on all topics of interest in pediatric psychology, and the page length and scope should be discussed with the Editor. Un-invited commentaries will not be considered.

Reporting Guidelines

JPP requires that the relevant reporting guidelines be used for the following studies:

- Randomized trials: CONSORT
- Pilot and feasibility trials: CONSORT extension

- Non-randomized trials: TREND
- Scoping reviews: PRISMA-ScR
- Systematic reviews: PRISMA

Editable checklists for reporting guidelines may be found on the EQUATOR network site.

All intervention studies (RCTs and non-randomized trials) will undergo an additional review for transparent reporting conducted by the *JPP* Assistant Editor for Transparent Reporting. Review comments will be provided on the corresponding checklist. Authors will be required to address any identified reporting issues prior to publication.

Please clearly indicate the page numbers where each checklist item is reported in the manuscript. Please upload this checklist as supplementary material when you submit your manuscript for consideration. If a component of a checklist was not included in the manuscript, an explanation of the rationale for exclusion should be provided. Adherence to these reporting requirements provides standardization, ensures that important information has been included, and facilitates the peer review process.

We publish the final version of all required checklists as supplementary material. Thus, a final version of your CONSORT/TREND/PRISMA checklist will be requested as supplementary material prior to final acceptance of your manuscript. Please note the checklist should be reference in the methods section of your manuscript.

General Formatting

1. *File format*. Please save the main manuscript file as a .doc format.
2. *Font size and type*. Please use a standard font that is compatible with Windows, such as Times New Roman or Arial. Font size should be 12 pt.

3. *Double-spacing*. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch).
4. *Naming Files*. When naming your files, please use simple file names and avoid special characters and spaces. If you are a Macintosh user you must type the three-letter extension at the end of the file name you choose (e.g. .doc, .rtf, .tif).

Manuscript Formatting

The American Psychological Association Publication Manual (7th edition) should be used to guide manuscript formatting, with the exception of the title page and abstract as noted below. Authors MUST format their references per the American Psychological Association Publication Manual (7th edition) . Failure to do so will cause their manuscript to be unsubmitted until this is corrected.

Title Page

In addition to the APA Manual, the academic degrees of authors should be placed on the title page following their names.

Abstract

A structured double-spaced abstract of not more than 250 words should be included. The abstract should include the following parts:

- a. Objective (brief statement of the purpose of the study)
- b. Methods (summary of the participants, design, measures, procedure)
- c. Results (the primary findings of this work)
- d. Conclusions (statement of implications of these data)

Body of the Manuscript

- a. *Introduction*

- b. *Methods* - Informed consent and ethical treatment of study participants: Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s).
- c. *Results*
- d. *Discussion* - Clinical relevance of the research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Acknowledgements

Add appropriate acknowledgements, including information on the funding sources as noted below:

Funding

Details of all funding sources for the work in question should be given in a separate section entitled "Funding." The following rules should be followed:

- The sentence should begin: "This work was supported by . . ."
- The full official funding agency name should be given, i.e. "the National Cancer Institute at the National Institutes of Health" or simply "National Institutes of Health," not "NCI" or "NCI at NIH" (full RIN-approved list of UK funding agencies)
- Grant numbers should be complete and accurate and provided in parentheses as follows: "(grant number xxxx)."Multiple grant numbers should be separated by a comma as follows: "(grant numbers xxxx, yyyy)"
- Agencies should be separated by a semi-colon (plus 'and' before the last funding agency)

- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number "to [author initials]."

Oxford Journals will deposit all NIH-funded articles in PubMed Central. See the Complying with funder policies page for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above.

Tables and Figures

Tables

Tables should be included as separate pages using acceptable formats (e.g., .doc files).

Figures

Figure resolution should be no less than 300 dpi for halftone color (photo) images, 600 dpi for combination halftones, and 1200 dpi for line art. Most standard figure formats are acceptable, such as .jpg, .gif, .tif, or .eps format. Please follow this link for useful information on preparing your figures for publication.

Figure accessibility and alt text

Incorporating alt text (alternative text) when submitting your paper helps to foster inclusivity and accessibility. Good alt text ensures that individuals with visual impairments or those using screen readers can comprehend the content and context of your figures. The aim of alt text is to provide concise and informative descriptions of your figure so that all readers have access to the same level of information and understanding, and that all can engage with and benefit from the visual elements integral to scholarly content. Including alt text demonstrates a commitment to accessibility and enhances the overall impact and reach of your work.

Alt text is applicable to all images, figures, illustrations, and photographs.

Alt text is only accessible via e-reader and so it won't appear as part of the typeset article.

Detailed guidance on how to draft and submit alt text.

Permission for Illustrations and Figures

As an author, you must obtain permission for any material used within your manuscript for which you are not the rightsholder, including quotations, tables, figures, or images. In seeking permissions for published materials, first contact the publisher rather than the author. For unpublished materials, start by contacting the creator. Copies of each grant of permission should be provided to the editorial office. The permissions agreement must include the following:

- nonexclusive rights to reproduce the material in your paper in JPP
- rights for use in print and electronic format at a minimum, and preferably for use in any form or medium
- lifetime rights to use the material
- worldwide English-language rights

If you have chosen to publish under an open access license but have not obtained open access re-use permissions for third-party material contained within the manuscript, this must be stated clearly by supplying a credit line alongside the material with the following information:

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- Author, Original publication, year of original publication, by permission of [rightsholder]

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Our publisher, Oxford University Press, provides detailed Copyright and Permissions Guidelines, and a summary of the fundamental information.

Diversity, Equity, and Inclusion Considerations

The Journal of Pediatric Psychology (JPP) and Clinical Practice in Pediatric Psychology (CPPP) both identified enhancing reporting practices for diversity, equity, and inclusion (DEI) in pediatric psychology as a top priority (Duncan, 2023; Modi, 2023). Building upon a guidance for reporting on race and ethnicity in JPP articles (Palermo et al., 2021), we recently published an editorial focused on recommendations on inclusive language and transparent reporting relating to diversity dimensions. Our current efforts strive to address a broader set of diversity dimensions, using the ADDRESSING Framework (Hays, 2016) as guidance, with the goal of enhancing the rigor and inclusiveness of pediatric psychology science. Several important existing checklists and guidelines on inclusive language and transparent reporting relating to DEI exist (American Psychological Association, 2023b; Buchanan et al., 2021; Letzen et al., 2022; Matsui et al., 2020; Miller et al., 2019; Williford, Sweenie, et al., 2023). However, no comprehensive guidelines were available that captured the specific context of pediatric psychology (e.g., developmental/family considerations), while also being broadly applicable across the field (e.g., not focused on a specific condition or symptom).

Acknowledging that this is a rapidly evolving area of science, the updated guidelines represent a living document that will exist online within the Instructions for Authors of both journals, which will be updated yearly. Please find the first iteration as a guidance to

implement optimal DEI reporting practices (See Table 1), as well as examples of how these apply to the manuscript types published in our journals (see Table 2).

Table 1. Diversity Dimensions Checklist

Table 2. Application of Diversity Dimensions Checklist in Study Design and Manuscript Preparation

Please see full editorial.

Research Data Policy Statement

Where ethically feasible, *JPP* strongly encourages authors to make all data and software code on which the conclusions of the paper rely available to readers. Authors are required to include a data availability statement in their paper. When data and software underlying the research article are available in an online source, authors should include a full citation in their reference list. For details of the minimum information to be included in data and software citations see the OUP guidance on citing research data and software.

Whenever possible, data should be presented in the main manuscript or additional supporting files or deposited in a public repository. Visit OUP's Research data page for information on general repositories for all data types, and resources for selecting repositories by subject area.

OUP is a signatory to the Center for Open Science's Transparency and Openness Promotion (TOP) Guidelines which served as a framework for our overall data policy approach, as well as the policies implemented by individual titles. OUP also supports the Joint Declaration of Data Citation Principles and the recommendations of the FORCE11 Software Citation Implementation Group, which is reflected in our data and software citation practices.

The *Journal of Pediatric Psychology* adheres to LEVEL 2 reporting of data availability and is defined as follows: Level 2: The journal encourages all authors, where ethically possible, to publicly release all data underlying any published paper. Authors must include a Data Availability Statement in their published article.

Appendix F – Family Focused Intervention Study Consent Form

Consent Form

- ❑ I……agree to participate in the research study by researchers: Dee Mullins, Dr. Christopher McCusker, Clinical Psychologist (UCC) and Dr. Nicola Lally, Principal Specialist Clinical Psychologist (CUH).
- ❑ The purpose and nature of the study has been explained to me in writing and I have had the opportunity to discuss it before deciding.
- ❑ I am participating voluntarily.
- ❑ I give permission for my contribution in the focus group to be audio-recorded.
- ❑ I understand that I can withdraw from the study, without repercussions, within 2 weeks of the focus group.
- ❑ I understand that I can withdraw permission to use the data within 2 weeks of the focus group in which case the material will be deleted.
- ❑ I understand that my data will be anonymised via redactions or by turning specific detail into generic detail. This include any reports, publications or research papers that will be completed.
- ❑ I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed: …… Date: ……..

PRINT NAME: ……

Appendix G – Study Information Sheet

PARTICIPANT INFORMATION LEAFLET

Study Title: **Strengthening Resilience in Families of Teenagers with Cystic Fibrosis**

Dear Parent / Guardian,

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why we are doing this research and what is involved. You should understand enough about any risks and benefits to make an informed judgment. This process is known as informed consent. This Participant Information Leaflet gives detailed information about the research study. When you are sure you understand the study, and what will be expected of you, you may sign and return this form if you wish to participate. Please take time to read this leaflet, and if you want to, discuss it with your family or friends. Please feel free to ask us if anything is not clear, or if you would like more information. Thank you for taking the time to read this.

Principal Investigator Details:

Dr Muireann Ní Chróinín, Consultant Paediatrician in Respiratory Medicine, Cork University Hospital

Co-Investigator Details

Dr. Chris McCusker, Clinical Psychologist, Head of School of Applied Psychology, University College Cork

Dr. Nicola Lally, Principal Specialist Clinical Psychologist, Cork University Hospital

Ms Dee Mullins, Psychologist in Clinical Training, School of Applied Psychology, University College Cork

Ms Clodagh O'Sullivan, Masters Student in Applied Psychology, University College Cork

Purpose of the Study

Researchers and Psychologists in the School of Applied Psychology at *University College Cork* (UCC) are working with the Cystic Fibrosis team at *Cork University Hospital* (CUH) and *Cystic Fibrosis Ireland*. We are interested in exploring whether a new psychological intervention to strengthen the resilience of parents of teenagers with CF has a positive impact. Research with families of children with other chronic illnesses has shown this can produce benefits for the whole family including the child / young person with a chronic illness. We would like to look at the feasibility and effectiveness of this with families of teenagers with cystic fibrosis (CF).

Why have I been asked to take part?

You have been asked to take part because you are a parent of a teenager with cystic fibrosis attending CUH. Participation is completely voluntary and your decision will not affect your child's treatment at CUH in any way, or any engagement you may have with Cystic Fibrosis Ireland.

What will participation involve?

Should you choose to take part in our study we will ask you to first complete some questionnaires that asks you about aspects of yourself (e.g. psychological well-being) and your family (e.g. how your family normally relate to each other).

We will then invite you to you attend a one-day workshop with other parents, plus an individual follow up session with a Psychologist. The workshop will focus on psychological and other strategies that you as parent(s) / guardian (s) may consider in supporting your teenager with CF. It will be delivered by two Clinical Psychologists on the research team.

Following your participation in the workshop, you will be offered an individual follow-up session to review your experience of the workshop and to further help you implement the guidance discussed in the workshop. We will also ask you complete some of the same questionnaires you completed prior to participating in the group and you will be interviewed about your experiences and thoughts on this new programme. Each interview will be audio recorded and is expected to take about 60 minutes to complete. Interviews may be conducted in person or online as suits.

What happens to the information I share when taking part?

Discussions during the workshop will be confidential. This means that any information you share will be kept private. The only time we would break this confidentiality is when there is a risk to you, or another vulnerable person/child. This keeps everyone safe.

If you agree to participate, your consent form with your name / contact details will be securely stored in a locked cabinet, or on an encrypted computer, at the research centre. All participants are then allocated a code so that all subsequent information and data collected during the study is not linked to your specific identity, but rather an anonymous code. The questionnaires you complete will not ask for any personally identifiable information.

The information you share during the interview will be audio recorded and then transcribed by the research team. The audio recordings will be stored in a locked filing cabinet, or on an encrypted computer, and then destroyed after written transcription. Written transcriptions will be anonymized (extracting or masking any statements which could identify individuals). No names or identifying information will be associated with each transcription. These will be stored on the *University College Cork* OneDrive system. The anonymized data will be stored for 10 years.

The data you provide will be analysed and written up as part of a doctoral thesis. We also hope to publish the findings and present at conference. We would like to share findings with you at publication given your valued participation, and we will discuss how we might do this with you at the follow-up interviews.

Will other people know I am taking part?

Your participation will be kept confidential. The only people who will know you are taking part are the research team, your medical team at CUH and the other members of the workshop. Any forms you give to us with your details on them will be password protected and kept in a shared folder, only accessible to the research team, on a secure laptop.

What are the possible advantages and disadvantages of taking part?

We hope that participation in the workshop will benefit you and your family as outlined above. However, as this is a new psychological programme, the main purpose of the research is to explore this. We do not anticipate any negative consequences for you in taking part. If, however, you feel uncomfortable at any stage or have any concerns regarding your participation, you can talk with the Clinical Psychologist on the research team (contact details below) who will sign post you to appropriate help if required.

Can I change my mind?

You can think about taking part and if you have any questions about the study, you can contact any member of the research team by email. If you consent to take part, and then decide before participating that you no longer wish to take part, you can withdraw. If you decide after taking part that you wish to withdraw from the study, you can do so and also withdraw any data you provided as long as it is within two weeks of the end of your participation.

Who has reviewed this study?

Approval must be given by the Clinical Research Ethics Committee of the Cork Teaching Hospitals before studies like this can take place. This study was approved by the Clinical Research Ethics Committee of The Cork Teaching Hospitals on 13 June 2024.

Any further queries?

If you have any queries about this research, you can contact us at:

Dee Mullins 103543811@umail.ucc.ie
Dr. Christopher McCusker christopher.mccusker@ucc.ie
Dr. Nicola Lally Nicola.Lally@hse.ie

What do I do next?

If you would like to participate in this study, please complete the informed consent form enclosed and return it to the Principal Investigator muireann.nichroinin@hse.ie, or in the stamped addressed envelope enclosed. We would also ask that you read and sign the Data Protection Notice also Enclosed.

Appendix H – Family-Focused Intervention Follow up Manual

double click to open as PDF, this is best option in terms of layout/formatting.

Word Copy included in following pages.

CFParentsManualCorrectedVersion.pdf

PARENT WORKSHOP FOR ADOLESCENTS WITH CYSTIC FIBROSIS

Improving outcomes for children with CF Study

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Cystic Fibrosis Ireland

Thank you for attending our Parent Workshop. This booklet provides a summary and information presented and the topics discussed during the day.

An extended thanks to also to the Congenital Heart Disease Intervention Programme (CHIP) team, the Family Intervention for Siblings and Parents of Children with Cancer and the Improving Outcomes for Children with Epilepsy (IOCE) for allowing use to reproduce some of their materials in this booklet.

Our sincere thank you also to Nicola and Jen from Cystic Fibrosis Ireland who generously provided materials, guidance and support.

Cystic Fibrosis, like most childhood illnesses is a condition that impacts not only on the child but on the whole family. Ireland has the highest incidence of Cystic Fibrosis in the world with around 1400 people living with the condition and around 30 new cases of Cystic Fibrosis being diagnosed in Ireland each year, generally in the first few weeks due to newborn screening. Cystic Fibrosis is a challenging and difficult chronic illness to treat.

Due to lowered immune capability to fight infection, people with Cystic Fibrosis are often subject to severe infection control guidelines, including being forbidden from face-to-face contact with other people with Cystic Fibrosis. This leaves people with Cystic Fibrosis at higher risk of social isolation and psychological distress.

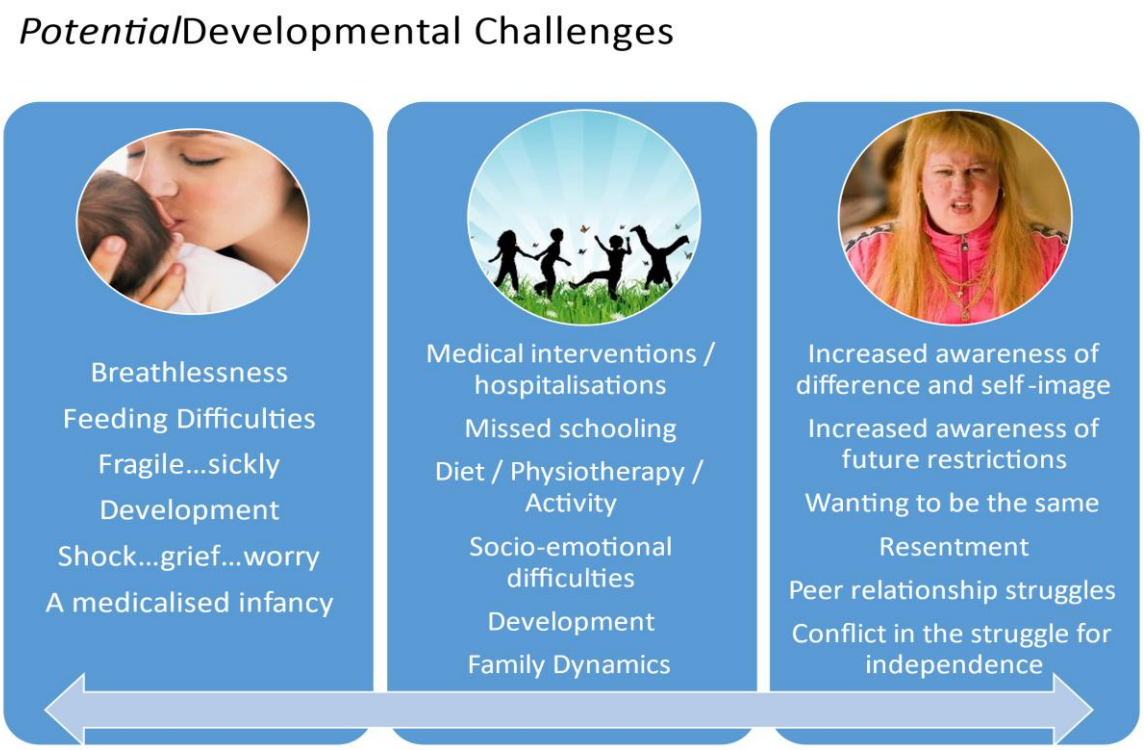
Adolescence is a significant time of physical, emotional and social change when young people develop their identities, gain independence and prepare for adulthood. Adolescence often brings challenges within families as

they navigate this period of adjustment. For families of adolescence with Cystic Fibrosis, supporting their adolescent through this stage while they begin to take control of their cystic fibrosis treatment plan can bring about specific challenges.

For adolescents with Cystic Fibrosis, family functioning can impact on disease management and has a relationship with treatment adherence in children and adolescence with Cystic Fibrosis. There has been limited research which specifically focuses on interventions to support families through adolescence.

We discussed at our workshop that in more recent years attention is increasingly being drawn to quality of life – to the psychological and social effects of the condition on the adolescent and their family. It is important to remember that many families cope very well, and the family can learn skills and gain resilience. Nonetheless, research and our clinical experience show there are some negative effects on the lives of the child and their family, which we think that together we can do something about.

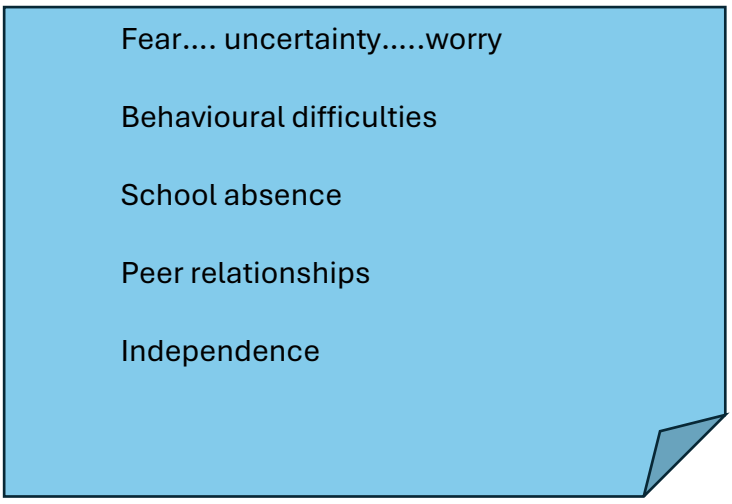
POTENTIAL IMPACT OF CYSTIC FIBROSIS ON THE ADOLESCENT



Life with Cystic Fibrosis can be uncertain and is not always easy. Having Cystic Fibrosis impacts adolescents as they navigate a critical developmental stage. Managing a chronic illness such as Cystic Fibrosis during adolescence presents unique challenges that may impact on the young persons overall well-being.

Physically, rigorous treatment regimens can feel overwhelming and interfere with their desire for independence and spontaneity. Energy levels and physical limitations can impact on sports, social activities, and school while Cystic Fibrosis -related physical changes can lead to self-consciousness and negative body image.

Emotionally, adolescents may struggle to balance their growing independence with the reliance on caregivers for treatment and decision-making. The stress of managing Cystic Fibrosis, coupled with concerns about the future, can lead to mental health challenges. Further, adolescents may experience frustration over the restrictions Cystic Fibrosis places on their lives, grieving the loss of a “normal” adolescence.



There is a social impact to Cystic Fibrosis with some adolescents feeling isolated due to frequent absences from school, social events, or activities. They may also worry about disclosing their condition to peers, fearing pity or stigma. To fit in, some may engage in behaviours like smoking or drinking, which can worsen their health.

There is also an impact on educational or vocational aspirations as frequent hospitalisations or treatment may disrupt school attendance leading to challenges with academic achievement and/or feelings of falling behind. Additionally, feelings of uncertainty around their future due to the unpredictable progression of Cystic Fibrosis can have an impact on motivation to strive towards educational goals.

POTENTIAL IMPACT OF CF ON THE FAMILY

Cystic Fibrosis not only impacts the person with the condition, but like all chronic illnesses, it impacts the entire family. The demands on the family's time, energy and emotions can shape the family dynamics, roles and relationships in significant ways. Parents often experience constant worry about their child's health, treatment adherence, and their future. The fear of disease progression or complications can lead to chronic stress. Families may grieve the loss of a "normal" life for their child or the family unit, particularly

when Cystic Fibrosis limits activities or opportunities. Siblings may be impacted as they may feel neglected as parents focus much of their time and attention on the child with Cystic Fibrosis. They might also worry about their sibling's health or feel guilty for being healthy themselves. Although unpleasant, these feelings are very normal reactions to the situation and adjusting to and mentally processing these feelings of is often the first stage of coping and adaptation. Some children and families cope very well and experience positive changes such as increased sensitivity to the needs of others, thoughtfulness, as well as more emotional maturity, empathy and compassion. However, other families can benefit from a little more guidance and support.

Financially, while insurance or the state may cover some expenses, the ongoing cost of medications, physiotherapy equipment, and travel for specialist appointments can strain family finances. A loss of household income may occur if a parent needs to reduce their working hours to manage a child's care. Families with Cystic Fibrosis are managing daily treatments, including medications, airway clearance, nutritional supplements, and appointments which time-consuming and can disrupt family routines. Additionally, treatment schedules and the need to avoid infections may limit family outings, holidays, and spontaneous activities.

Parents own relationships are also important as coping together with a child's condition can bring parents closer together. Nonetheless, it can also put enormous strain on a relationship, as parents may have little time for their own relationship when they devout all their time energy into the child.

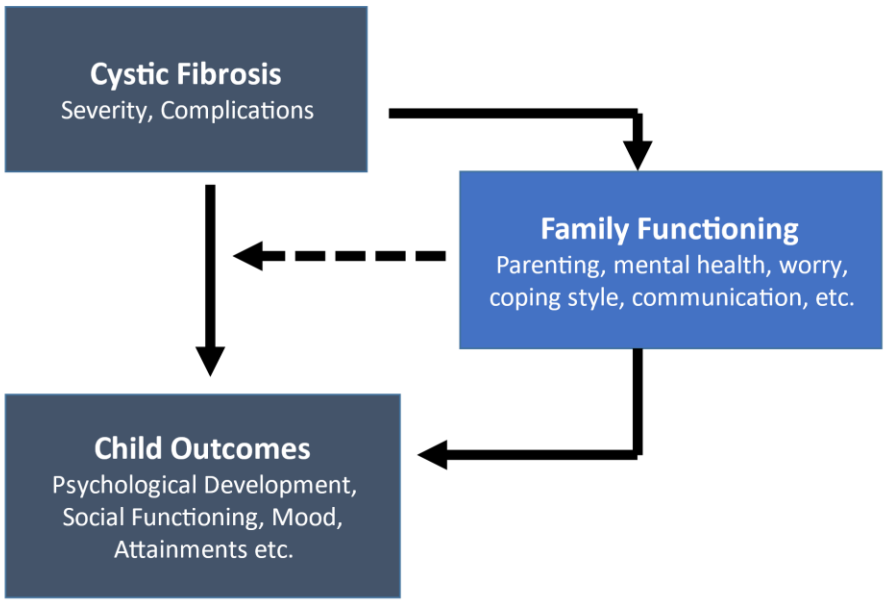
Finally, families can face a host of practical, emotional and social stresses. Some families may become socially isolated if, for example, they simply do not trust anyone to mind their child, or even if extended family or friends are themselves too scared to look after the child for the parents to have an evening out.

Considering all of the challenges, we might expect….

But we more often get….

Given all these challenges, across each developmental stage, we might expect most children with CF to have difficulties. In fact, the majority do not. Research tells us that many children who live with chronic illness do better in terms of adjustment than their healthy peers. Partly, this is because they have had to learn to cope with challenges their peers do not. They develop coping skills which serve them well in other aspects of their lives and they do not sweat the small stuff. This is an important message. Nevertheless, it does not take away from the fact that a significant group of children and young people with CF do have difficulties with mood, behaviour, and relationships, perhaps at least 30%

The Importance of Families – Amplify or Reduce Risk



Why and why focus on families…

- Despite improved medical outcomes, a significant proportion of children with CF at risk for developmental and psychosocial difficulties.
- Research suggests that **family factors** are often a greater predictor of outcome than disease severity

WHAT CAN WE DO TO HELP?

At the workshop we discussed how emerging paediatric research is beginning to report findings that the family, and not just the illness or the child's IQ and personal coping strategies, may be the biggest predictor of outcomes in children with chronic conditions. What does this mean? This means that family can act as a buffer - How well a family functions, communicates, faces challenges and adjusts to the child's condition, plays a powerful role in the child's social, emotional and behavioural development. We know from research and clinical experience that there are a number of things that affect

how well families overcome the challenges described earlier. Some of these factors such as the severity of the disease or the medical interventions required, we can do little about. However, we also know that there are some things, which affect how well children and families cope, which parents CAN do something about! These include parents "skilling" themselves up by:

- Becoming knowledgeable about the condition, about what it means and does not mean for your child https://www.cfireland.ie/
- Feeling confident and skilled enough to look after your child's own physical and medical needs as much as possible. This improves bonding and good attachment relationship
- Developing good problem-solving skills, which will allow you to find ways of overcoming the challenges posed by Cystic Fibrosis at different stages of development
- Developing effective parenting skills to promote independence and confidence in your child
- Ensuring good communication and relationships within families and between families and professionals involved in your child's life.

Our brief psychologically informed parent workshop aimed to tap into the resilience of parents to help them rediscover and enhance their own strengths. It aimed to help parents learn new coping strategies to help them

deal with their child's condition and hopefully help prevent problems developing in the future. The workshop also aimed to help different families to share their experiences and learn from each other. It is often the case that when people are overwhelmed by problems, they tend to think that they are alone.

IN CONVERSATION WITH AN ADULT WITH CF AND THEIR PARENT

We had two experts by experience attend the workshop. They were a mum and daughter who kindly shared their experiences. Some themes which came through this interview included:

- navigating the challenges of adherence in adolescence, age came a different perspective
- recognising the impact on siblings
- walking the middle path between wanting to protect her daughter and recognising her daughter's need to be a teenager
- how helping her daughter gain some independence actually helped their relationship and reduced conflict
- the benefit of having the diagnosis out there with friends
- the importance of a good support network
- realising that when you are ill you do need an adult to help with medications and treatments, that being ill affects your energy and organisational capacity
- the value of good relationships with staff, especially having one key person
- the perspective of an adult looking back is different to that of a teenager

INTERVIEW HIGHLIGHTS

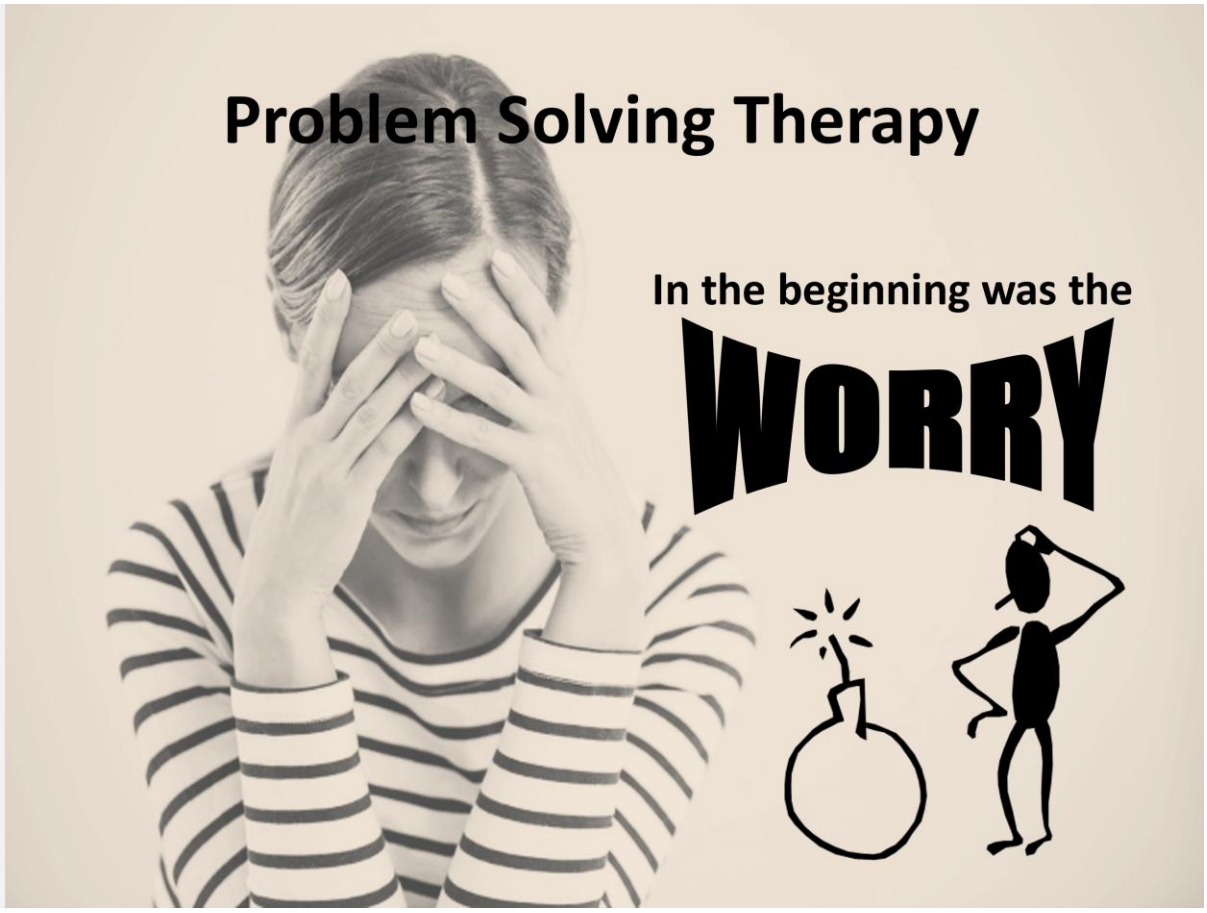
Focus on the relationship first, everything else will follow

Pick your battles

This too shall pass

Support is important

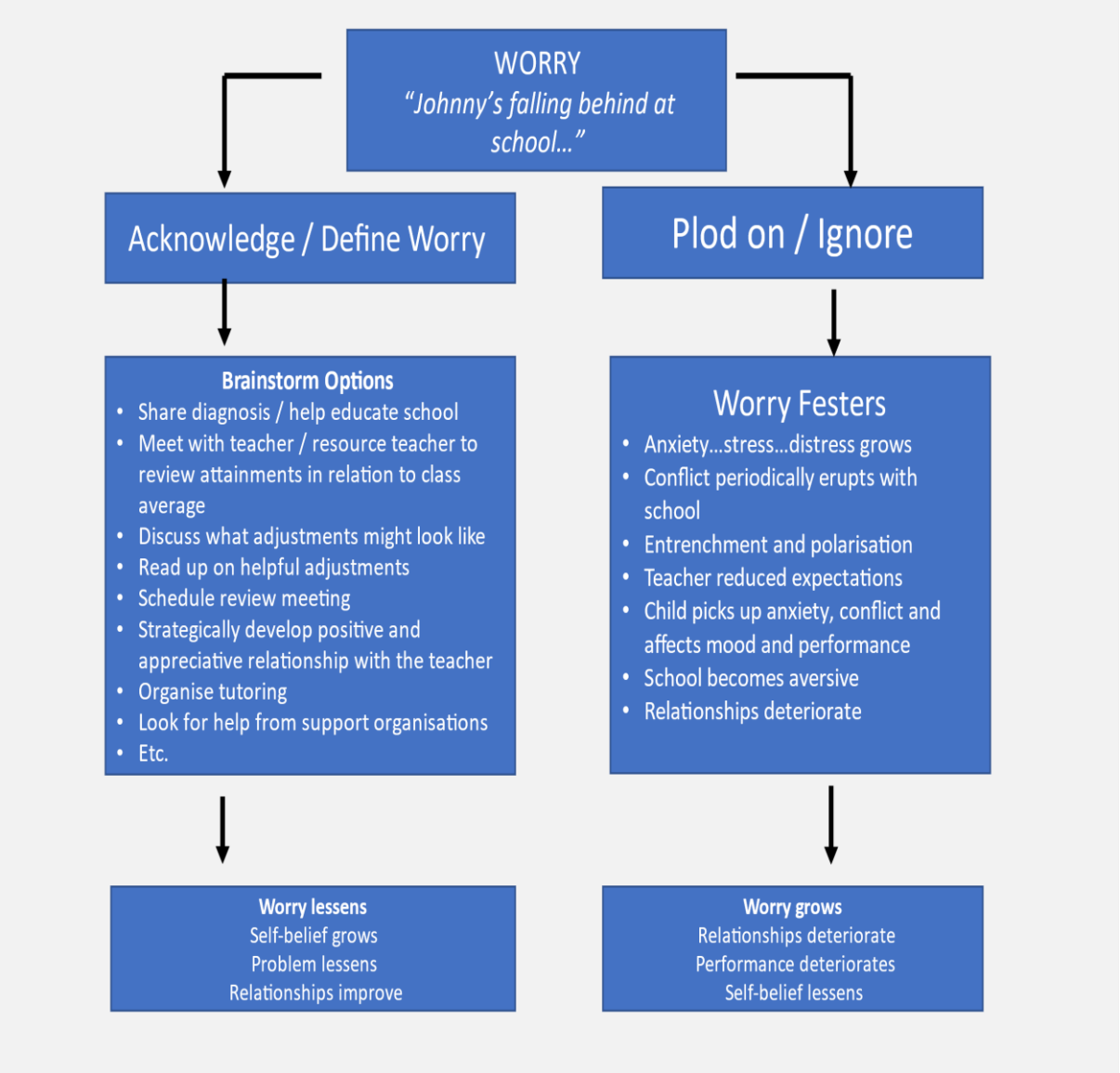
Foster a good relationship with your clinical team



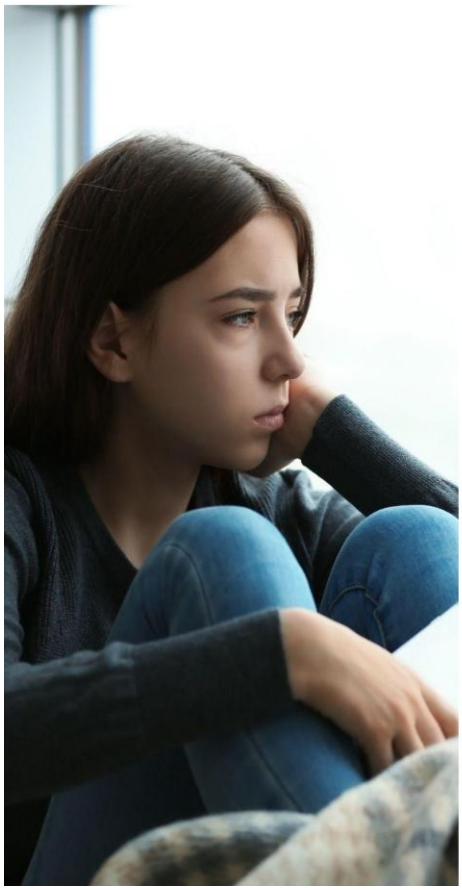
Research tells us that PST and ACT are two of the most promising psychological therapies in terms of promoting good adjustment to living with a chronic illness. In this session we are going to look at PST. Worry is not all bad. It becomes bad if we do not do something about it. However, our brain's way of telling us there is a problem to be solved, there is action to be taken.

One example which you might all have been familiar with in the past - we might be worried that our child will not settle well into school, something

we know is important for them to do - we talk about going to school with excitement, we emphasise all the positive, exciting things they will do there, we prepare them for what it will be like, we take them out and buy them special school shoes, a new schoolbag and pencil cases - we take their first day at school off work so we can go with them and collect them - we have a special treat waiting for them at home etc. etc. We are taking active steps here to prevent a problem occurring and it was our **WORRY** which prompted us into this action. **Worry** was the signal that some decisions had to made, some action taken. Now let's consider two alternative scenarios in this example.



Below were some of the common worries parents of teenagers / children with CF voice…some will ring bells with you more than others…many came out from our group work this morning.



Common Worries

"We are always fighting, I worry he actually hates me"

""I worry that she seems sad all the time"

"I worry he will develop Diabetes"

" Is he really sick, or just looking for the day off school…can I take the chance…?"

""I feel sad that so much of his life revolves around medical treatments and issues"

"She's falling behind at school…the teacher doesn't seem to care…why can't I get more help for her…why will no one listen…"

"I worry he will vape again or go drinking with friends"

" Do I spoil him…he's been through so much…why shouldn't I spoil him…does his sister feel left out ?"

"I worry if she doesn't exercise she'll get sick again"

"I fear for her future, what if she can't have kids"

It's important to know that worry has a function! We can often sense problems approaching and the mechanism by which we do this is called WORRY. Before the challenge becomes a full-scale problem, we "worry" about it. Although it may feel unpleasant, worry is not always a bad thing. Indeed, it is a natural defence mechanism which alerts us to potential problems which we may have to face. When worry is raised, we take steps to prevent, or minimise, the problem which we fear occurring and the worry is reduced. For example, we might be worried that our child is falling behind in

school – something we know is important. We might take steps to ease this worry by considering the following:

- Sharing your child's diagnosis and help educate the school
- Meeting with the teacher / resource teacher to review attainments in relation to the class average
- Reading up on helpful learning adjustments that could be made/ get
- cognitive assessment
- Scheduling a review meeting
- Strategically develop a good relationship with the teacher
- Organise tutoring
- Look for help from support organisations (E.g. Cystic Fibrosis Ireland Ireland)

In this scenario, we do our best and take active steps to address the problem which we are worrying about. Generally, the effect of this is that the worry lessens, you and your child's self-belief grows, and relationships improve. Now, consider another possible scenario. In this scenario, we do nothing. This may be because we feel powerless to address the worry or because we tend to deny or ignore our worries. What can happen?

- The worry then festers and grows. We feel more anxious and uncertain

- Conflict may periodically erupt with school
- The child picks up on this worry and fear and in turn becomes anxious and worried about falling behind in school. This effects mood and performance
- School becomes an aversive place for the child and blaming/cajoling creeps in
- Teachers may reduce expectations for the child and not push them academically
- Relationships deteriorate

In above scenario, we are not taking active steps to address the problem which we are worrying about. Generally, the effect of this is that the worry grows, you and your child's self-belief lessen, and performance deteriorates.

In our clinical experience, we have noticed that when families are facing extraordinary and challenging situations, it is more difficult to use their usual problem-solving skills. For this reason, we discussed Problem Prevention Therapy as part of our workshop.

PROBLEM PREVENTION THERAPY

Problem Prevention Therapy (PPT) is a strategy to help your family find ways of coping with potential problems. The aim of PPT is not to give parents answers for different problems. This would not be appropriate or possible because (a) every child and family are different and need to find their own answers and (b) challenges and worries will change as your child grows older and faces different issues.

PPT is a self-help strategy that you can apply to all problems and worries. During the workshop we looked together at how to apply PPT to current worries and difficulties. PPT is also a strategy that can help families to find a way to cope with potential or future worries and difficulties.

There are 5 steps to PPT. These are summarised below and can be remembered with the aid of the acronym: **DO ACT:**

1. **D**efine Problem/ Goal
2. **O**ption Brainstorm
3. **A**ssess Pros and Cons
4. **C**hoose a Strategy
5. **T**ake Action and Re-Evaluate

The PPT steps can be a useful tool for your family. It can help you to name and reframe worries and difficulties within your family. It can also help you to develop active problem-solving strategies in a flexible way. In this section we went through each step of the PPT and we also offered an examples.

STEP ONE: DEFINE THE PROBLEM/SET THE GOAL

This is, perhaps surprisingly, the most difficult but most important step of all. We know that if we recognise a worry or a problem early on, it can be easier to try to tackle the problem and find possible solutions. Solutions and strategies can sometimes easily follow when we acknowledge and clearly define the nature of our problems, rather than running away from or denying them. First of all, you need to know your worry signs. Many times, these are obvious – trouble sleeping, feeling uptight or tense much of the time, snapping, being irritable, not being able to concentrate or feeling tired and unwell. However, by the time these symptoms show up the problem has often become huge and can feel insurmountable. Watch for the first, sometimes small, signs of worries so you can intervene early and prevent things becoming too difficult.

Some problems are too vague or big to be solved. They need to be broken down into smaller, more concrete, units so that something can actually be done. We asked the parents in our group to be more specific and pick one main problem. We considered:

"I want my husband to be more supportive"

It is also often useful to turn problems into goals. Goals need to be:

- Relevant: choose goals which are important to you/your child.
- Specific: one way of helping to be even more specific is to imagine what the future would look like when you achieve the goal.
- Observable: define your goals in such way that they can be measured.
- Make them realistic: think about your own resources, time and ability.
- Set the limits: think about how long you can give for this goal.

Turning the above worry into a goal by breaking it down and turning it into a practical manageable change:

“I would like Jim to work with Joe on his exercise program”

Examples:

Instead of: "I want Jim to be more supportive."

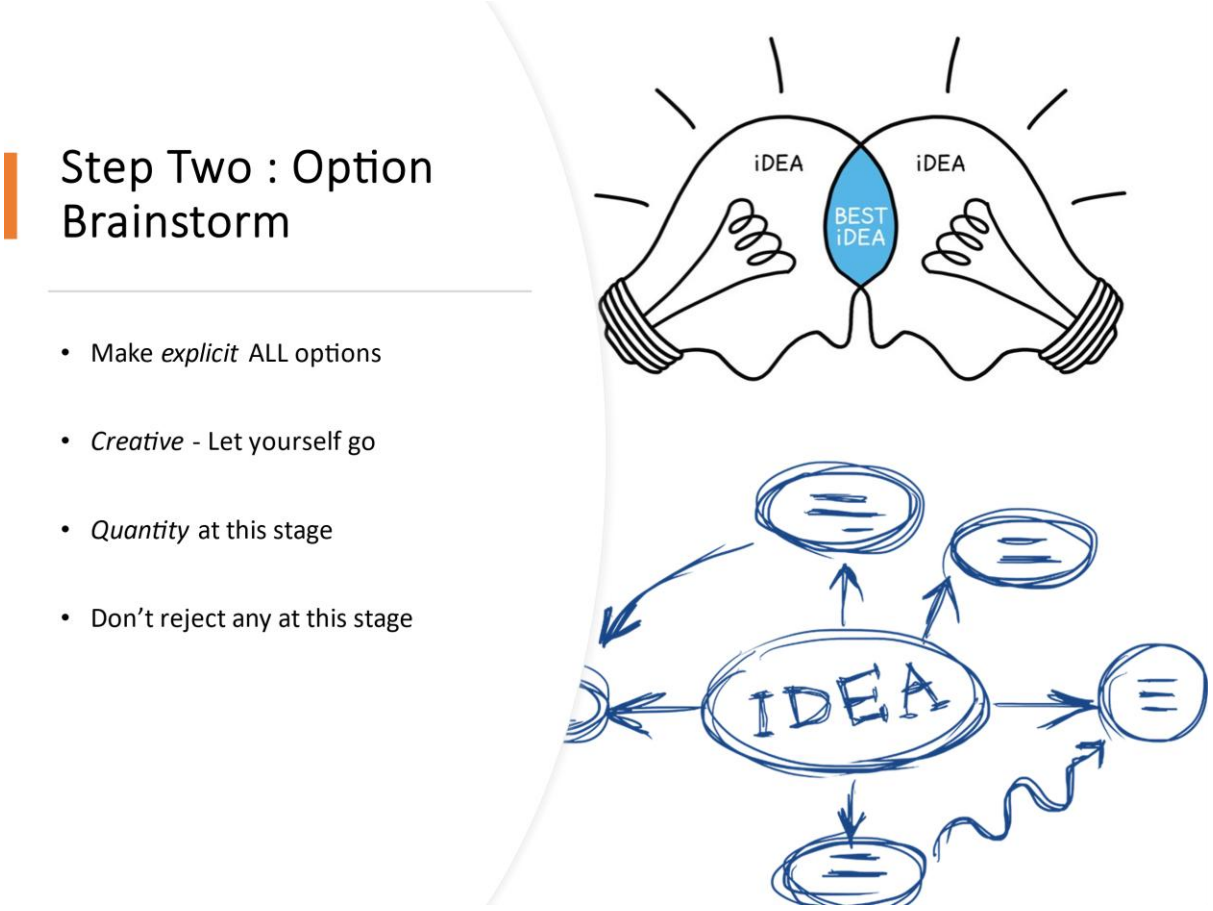
Try: "I want Jim to attend clinic reviews and put the kids to bed twice a week."

Instead of: "I want her to be happy."

Try: "I want Mary to feel comfortable discussing her feelings with me and to have a strong circle of friends."

STEP TWO: OPTION BRAINSTORM

Once you have acknowledged your worries and precisely defined your goals, you are ready to move onto the next step which is to, literally, brainstorm options. We encourage families and children to brainstorm as many possible options as possible.



We asked the parents in our group to think about possible options to try and get a child to exercise. The main point at this stage is simply to write down as

many options as possible – even if they sound silly or unwise. Here are some options from the parents in our group:

"I want her to exercise more"

- Don't let her see her friends until some exercise completed
- Confiscate her mobile phone until done some exercise
- Keep reminding her – nag nag nag and she will give in
- Get the CF nurse to talk to her about the importance of exercise
- Leave her to it and let her see the consequences
- Listen to her about the barriers to exercise for her after a clinic discussion. Show I understand.
- Join a gym and sign up for a programme together – build in girls time together
- Buy an exercise bike and get the whole family on a fun competitive programme
- Share Instagram page of that fit fitness instructor who has CF and shares life challenges
- Get her referred to the Psychologist to find out why she seems not to care
- Join an online support group for ideas

After you have completed the "option brainstorm ", then you are in the position to consider which option to employ. First you need to assess the pros and cons of each.

STEP 3 & 4: ASSESS PROS AND CONS AND CHOOSE A STRATEGY

First step, get rid of unacceptable or impossible. Once the unacceptable options have been eliminated, carefully assess the other options in terms of:

- How beneficial they are to meeting your goal
- The cost or disadvantages involved
- Whether you have the necessary resources to put the option into Action

Write down the pros and cons and discuss them with your family. These are possible pro's and cons about the goal.

Step Three: Assess Pros and Cons

- Discuss each option
- Pros and Cons of Each
  - how beneficial to goal?
  - What would the costs be?
  - Are the necessary resources there?
- Eliminate the unacceptable

Confiscate the mobile phone until she has done 10 mins on the new exercise bike	
PROS	**CONS**
• Will have made sure she does daily exercise • I'll have one less thing to worry about • She might start to enjoy it • It will become a routine	• Mary will resent me and feel treated like a child • She will become angry and upset • We will argue a lot • She won't talk with me about how she feels • She'll be difficult about other things to get back at me • Jim will disagree with me and there will be further family conflict

The final decisions about which strategies to follow will depend on the balance between the pros and cons of each option. Sometimes you may need help or advice to implement one of your options. It is possible that you may want to try a few options before choosing one in the long term.

Step Four: Choose a Strategy

- Make final decisions
  - balance of pros and cons
  - own values
  - clear and specific
  - realistic
  - time limited
- May be sequential or simultaneous combination of options

STEP 5: TAKE ACTION AND RE EVALUATE

Step Five: Take Action and Re-Evaluate

- Consider obstacles
  - need for information
  - need for skills
  - need for help
- Implement Action Plan
- Evaluate Outcome
  - how close to goal?
  - If successful what does it say about the problem, you, your child
  - if unsuccessful, why?
    - ?unanticipated problems, ? Correct implementation, ? Not like outcome...

As you take action and follow your chosen course of action, think about the following two points:

- Consider any obstacles you might meet along the way and think about how you might minimise these or deal with them.
- Look for support and help – from your partner, family, friends, professionals involved etc.

Having taken an action, it is very important to keep track of how successful the strategy is for your family. Ask yourself the following questions:

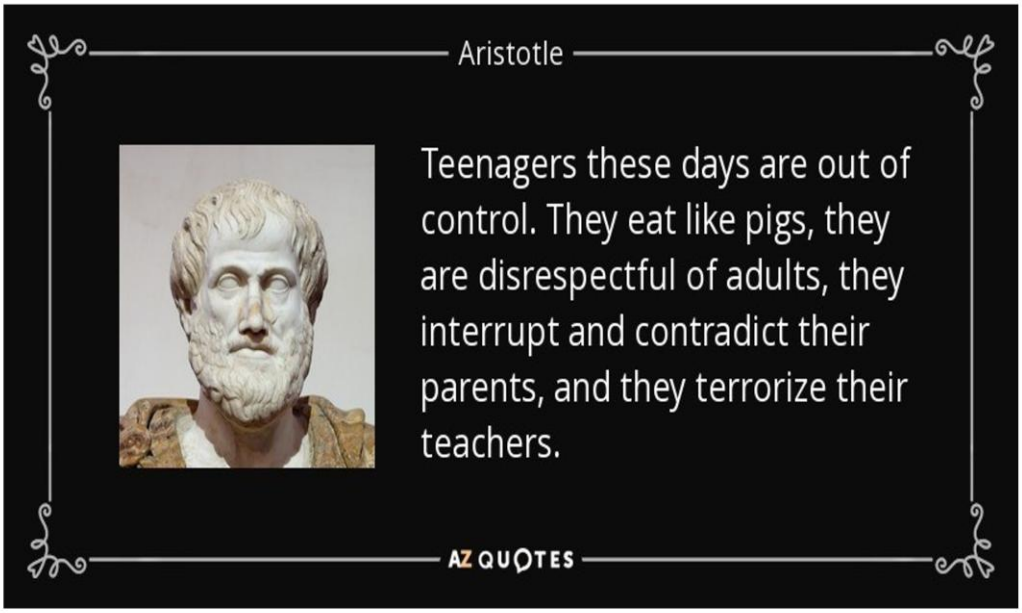
- How far has your goal being achieved?
- If it has been successful what does this tell you about the problem, about your child, about yourself? Success should not be taken for granted. You should look at what useful information it gives you relevant to other parts of your life and that of your child.
- If the chosen option has not been successful you need to understand why. What unforeseen obstacles occurred? Do you need to repeat the PPT stages around those obstacles?
- Have you reached the goal, but realised that it was the wrong one in the first place?

We can always go back and change a strategy or challenge it altogether! This would be a good time to model that humans are imperfect and make mistakes. Even parents 😊

ADOLESENCE AND CYSTIC FIBROSIS

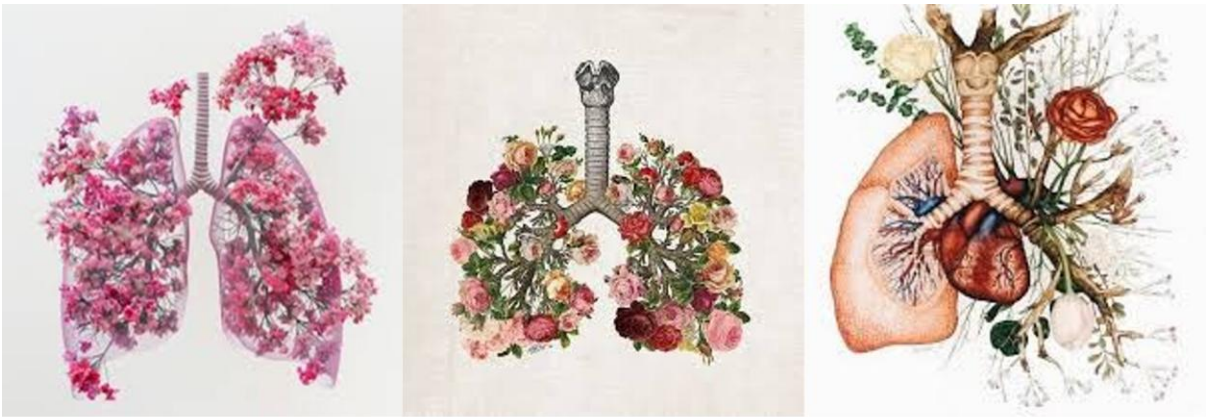
For this part of our workshop we spoke about adolescence as a developmental stage and what can be expected as you navigate parenting an adolescent with Cystic Fibrosis.

A quote from about 300 BC. Parenting remains the toughest job in the world. Added demands when there are medical needs add another layer and increases the risk of fatigue, burnout, stress, anxiety



Parenting is the Hardest Job in the World

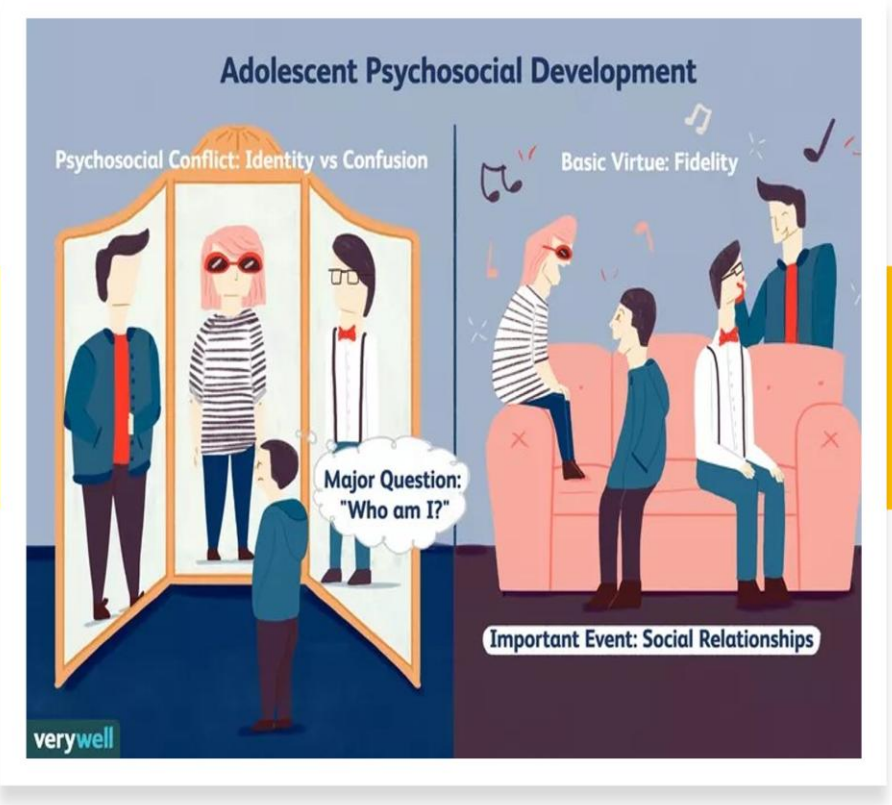
If you are not ok, your child likely won't. We lose sight of our own care in the midst of keeping our kids alive and this can be counterproductive.



Having a condition like CF can have its risks for adolescence .....

AND ..... there are so many
Protective factors

Adolescent
Development



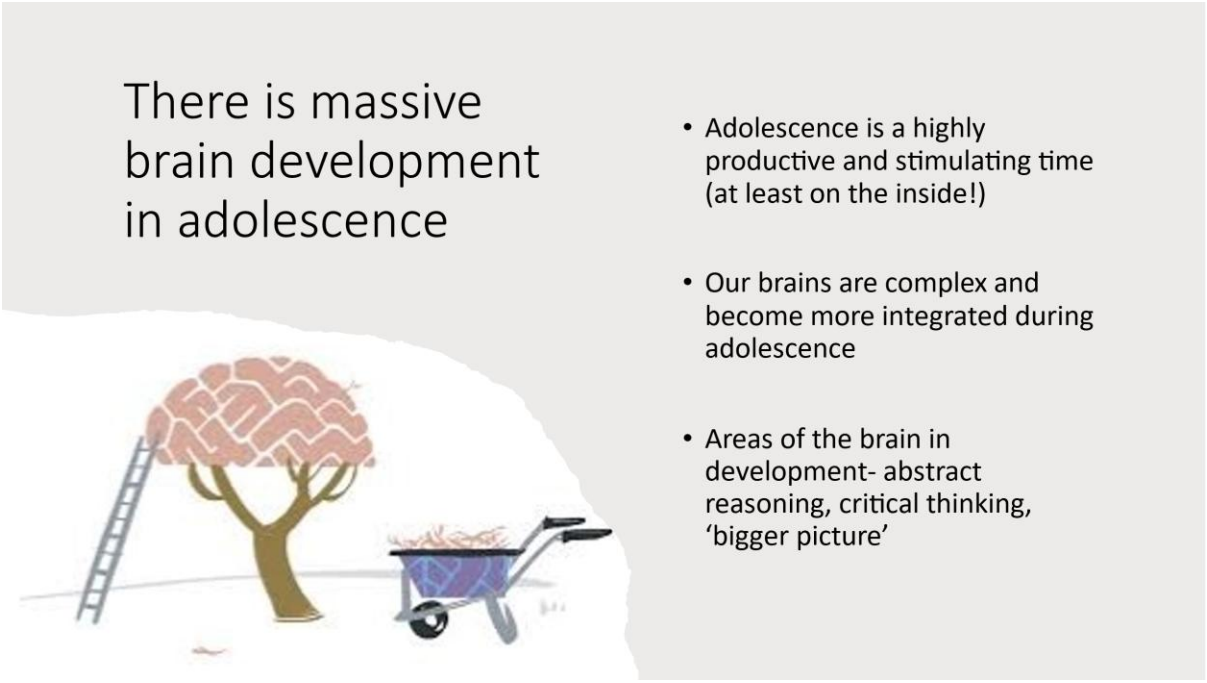
Adolescent Identity

We are all Ex-Teenagers and can probably recall what it was like for us at that stage. The focus is on “Who am I?” and therefore peer and social relationships are crucial. Teenagers camouflage themselves by belonging. They want to be Special AND they want to be the same as everyone else.

It is understandable that ‘restrictions’, perceived differences, perceived not achieving/ failure and similar can cause upset. And CF is a difference.

A More Complex Brain is Developing

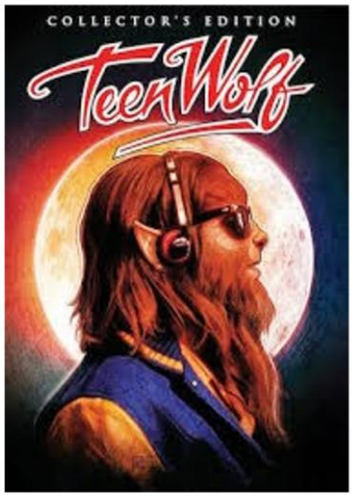
Adolescence is a period of significant social- emotional neurological development and transformation and these changes are still going on into your 20s.



Abstract thinking or 'bigger picture' thinking is only developing. Focus is on the here and now; imagining the future is very hard.

These changes mean that we can't assume that a child will have internal motivation to stick to the treatment plan or to fully get long term risks.

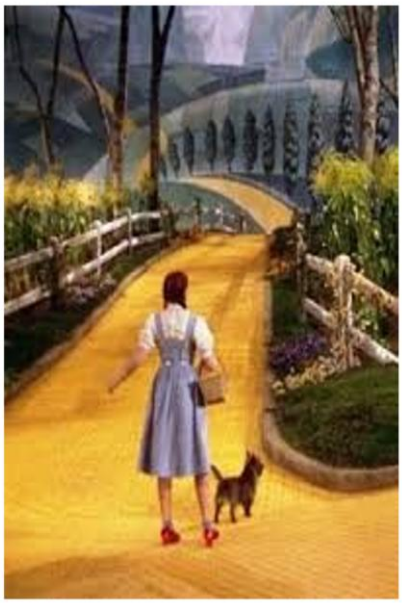
All of the frustrating symptoms of being a teenager are signs that this transformation is working!



Adolescent behaviour may seem strange but it has a purpose

- Teens need to develop a healthy emotional distance from parents to prepare for future 'fleeing the nest' and independence
- Teenagers' intense social engagement is a hardwired aspect of preparing to leave home (survival)
- Trying new things- helps to connect with peers and to work out what adult life will be like

Young children may be more unquestioning and admiring of their parents; teens may be more embarrassed, more critical. ‘Emotional detachment’ makes the transition to adulthood easier



Teenagers have Risk Needs

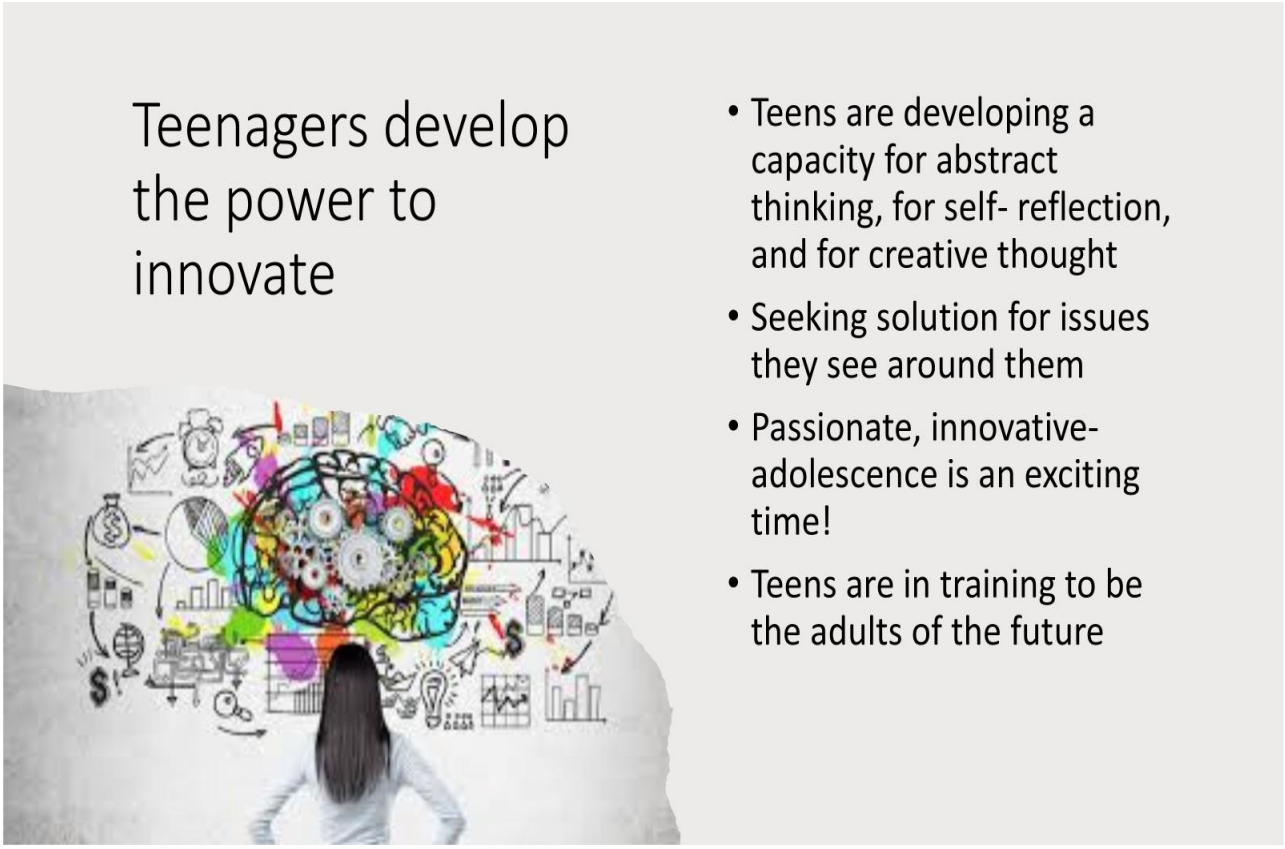
- Evolutionary benefits to increased social engagement
- Which does mean increasingly prone to peer pressure, increased likelihood of risky behaviours
- Helpful to go outside your comfort zone, to have more open attitudes, to become more adaptable, to increase opportunities
- Teens have Risk needs- how can these be safely met?

Adolescence is a time of newfound independence and new social bonding. When you're outside the family circle for the first time and exploring the unknown, it's programmed into teens to look for new support structures. Teens will also be driven to seek thrills. Post- thrill seeking- they can be calmer and more rested as neurological and physiological needs have been met. In saying all that, boundaries are still important. But there is a need to avoid strict control as well as avoiding a full laissez faire, 'you go it alone' approach.

Adolescents generally recognise risky behaviour but don't always know when to stop

- Seeking novelty, excitement is part of normal adolescent development
- Hormones attached to the pleasure centres in the brain and more intense in adolescence
- These hormones do tend to result in teens over- estimating their confidence and the likely positive outcome and overlooking the potential negative consequences

There is a difference between acceptable risk vs reckless risk. Teens need to take ‘risks’ to learn AND we need to help them reduce danger. Dopamine is the hormone which plays a role in novelty and excitement seeking. It attaches to pleasure receptors in the brain, and results in feelings of happiness, exhilaration, and pleasure. The intensity of dopamine is on average higher in adolescent’s brains than adults.



In adolescence there is a push for freedom, a desire to distinguish themselves from other generations. Adolescents are in training for being the adults of the future

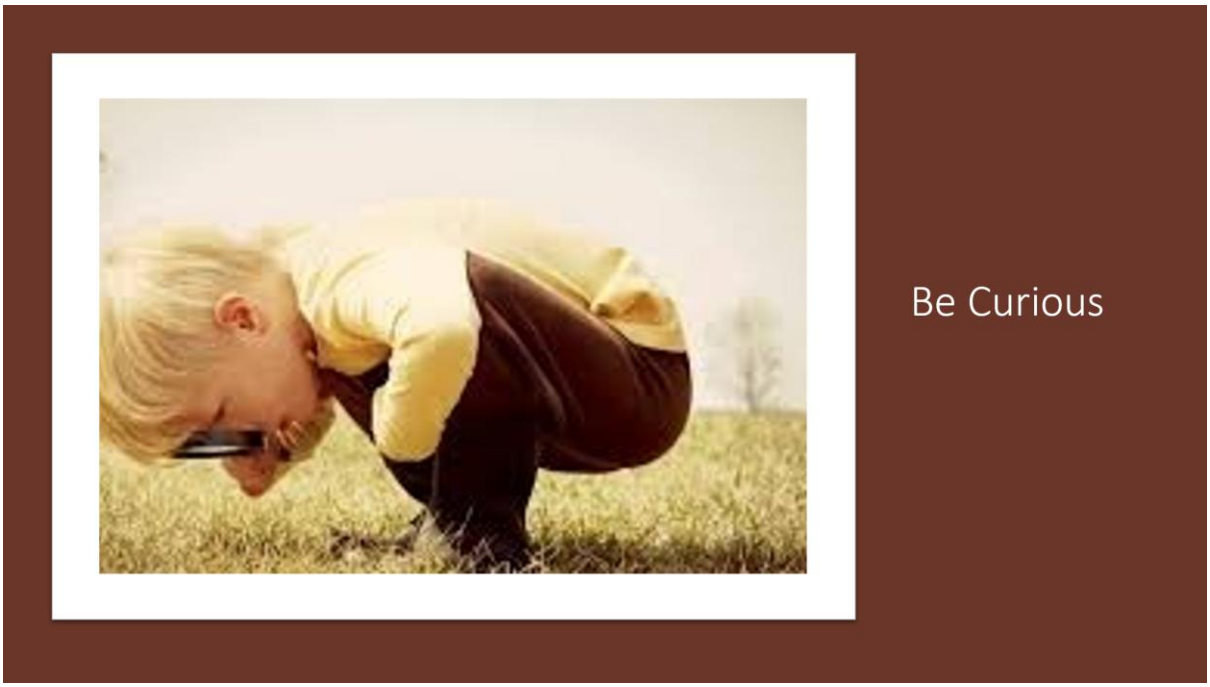
Some Tips

Adolescents should be encouraged to engage in reflective conversation

- Reflective conversations whether internalised or with others stimulates both the development and integration of the prefrontal cortex
- This is where planning and problem- solving takes place; it's also the part of the brain where we attune to others
- Helping teens to engage in reflective conversations, helps them develop empathy skills

Listening is not only an exercise in hearing but also in understanding the emotions behind words. It is important to create ‘emotional’ safety to communicate anything and everything, with no filter on emotions, thoughts, dreams or otherwise. Communicating feelings helps to create empathy.

It is both true that a parent is an expert on their own child AND we don’t always know best. Following your gut is important AND we also need to learn. This also means that you and your child can have two perspectives. Both can be valid. We have to walk the middle path. Rather than qualify with a ‘yes, but …..., replace with ‘and’. So for example, “This outing with your friends is really important to you AND I am worried about your health”. Two things can be true at once.



Be curious about their perspective. All behaviour is communication. Be curious about where a behaviour has come from, whether in your head or out loud. Even if our guesses are wrong, the fact that we are wondering and trying to understand, tells the young person that we are holding them in mind.

Tell me more

What was/is that like for you?

What did that make you think?

How did/does that make you feel?

How did/does that affect you?

What did/does that mean to you?

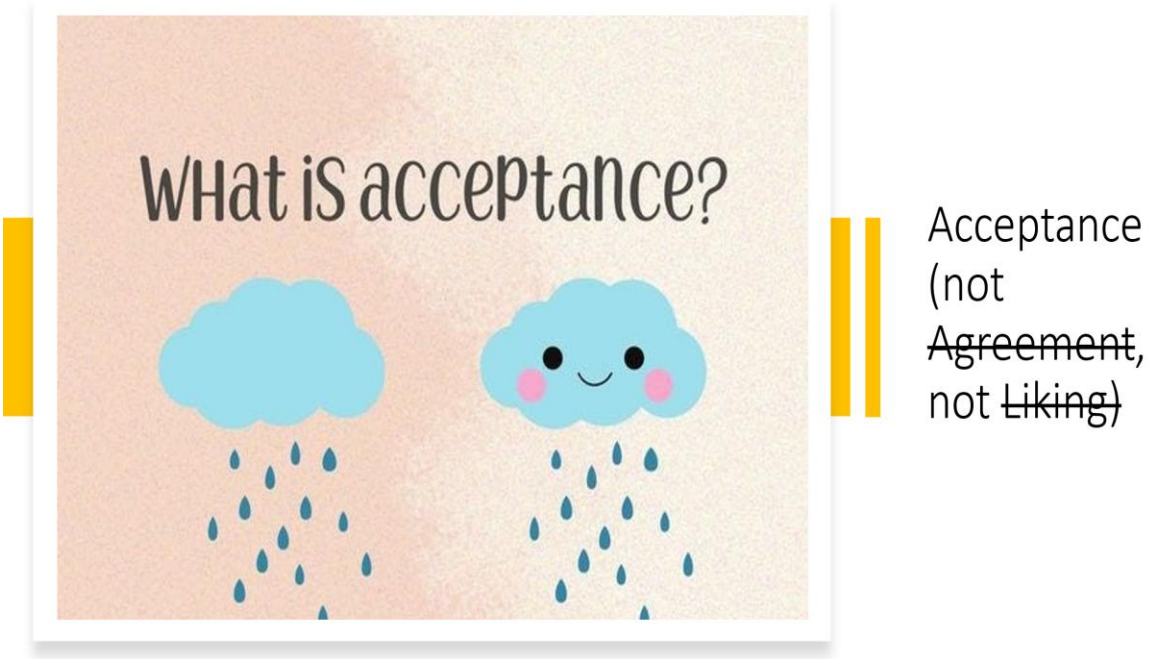
I wonder

Being With vs Doing

Parents are often very practical, active people who are often in Drive mode, striving to get things done. We're also quite often in Threat and Survival mode, especially if caring for a child with extra needs. Sometimes the hardest thing is not rushing to fix and just Pausing. Practise the Pause.

Connection first (problem solving can come later)

Connection is an intervention in of itself. Going to problem solving mode is often easier when we have taken a moment to connect and when we work on strengthening the relationship. The relationships with the medical team and the school are also important. Problem Solving together is often easier when we have a relationship.



Acceptance (or whatever word fits best for you) does not mean that you necessarily agree with something, nor that you like it. Rather it means that you accept someone's needs and emotions that drive a behaviour without judgement.

Empathy,
Empathy,
Empathy

Empathy- really connecting with how they are feeling and showing compassion. Validation- the process of learning about, understanding, and expressing acceptance of another person's emotional experience. Validation does not necessarily mean that you like or agree with what the other person is doing, saying, or feeling. It means that you understand where they are coming from. A good example of empathy is demonstrated in ‘Inside Out’ when Sadness sits with Bing Bong. offering empathy and validating Bing Bong’s experience helps to regulate Bing Bong and only then can they move on to problem solving and a solution.

The Importance of Repair

Repair after tricky moments is important. Apologise for your part. However repair shouldn't only be dependent on an apology from the young person. Sometimes it's helpful just to name it- "that was a really tough moment wasn't it".

ACCEPTANCE AND COMMITMENT THERAPY

Parenting adolescents can be challenging as they navigate emotions, identity, and independence. This workshop focused on strategies to support parents in managing their own responses while guiding their teens effectively. So far today we have discussed ways we can problem solve around certain challenges that occur when parenting a child with Cystic Fibrosis. And in considering some of these challenges it might also be worth thinking about some factors which we cannot control, even when we desperately want to. For example, we discussed how difficult it is living with the uncertainly, fear and worry that a child may develop diabetes. Letting go of struggling with our own thoughts, feelings and memories gives us the energy and focus to put into changing what we can change.

We did two experiential exercises. The Chinese Finger Trap is a powerful metaphor used in Acceptance and Commitment Therapy (ACT) to illustrate how struggling against difficult emotions or thoughts can actually make things worse.

How this helps with parenting:

- Struggling with a teen's emotions can make things worse. Trying to force them to feel happy or problem-free often leads to more resistance.
- Acceptance doesn't mean giving up—it means allowing difficult emotions to exist without letting them dictate reactions.

- Flexibility leads to better problem-solving—just as pushing into the trap releases you, engaging with emotions rather than fighting them helps foster connection and growth.

The Tug-of-War metaphor in Acceptance and Commitment Therapy (ACT) illustrates how struggling with difficult thoughts and emotions can keep us stuck, draining our energy and preventing us from living a meaningful life.

How This Helps in Parenting

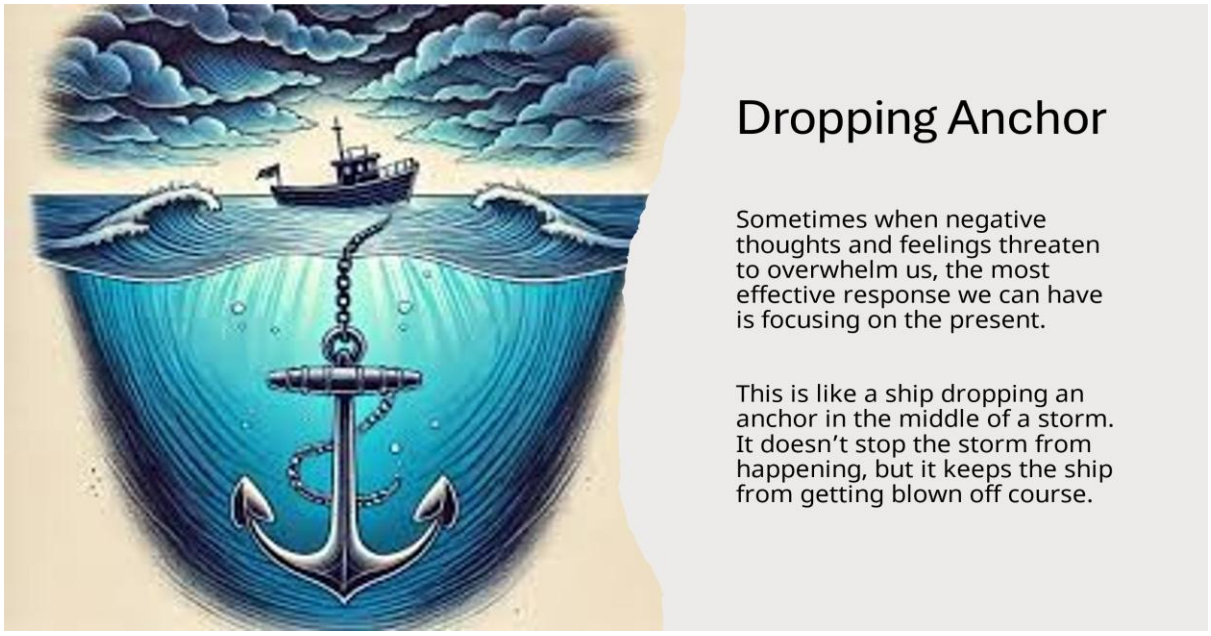
- Parents often engage in a tug-of-war with their own emotions (e.g., "I must be a perfect parent" or "I shouldn't feel frustrated").
- They may also get into a struggle with their teen (e.g., "I must get them to listen" or "They must stop talking back").
- Dropping the rope doesn't mean ignoring problems but choosing to focus on values like connection, patience, and support rather than getting stuck in power struggles.

We watched a video called 'The Unwanted Party Guest'. This metaphor is a powerful way to illustrate the idea of acceptance in Acceptance and Commitment Therapy (ACT). It helps explain how resisting difficult thoughts, emotions, or experiences often makes them more persistent, while accepting them allows us to focus on what truly matters.

- Difficult emotions are part of parenting. Stress, frustration, and guilt will sometimes show up, but fighting them only makes them stronger.
- Acceptance allows parents to focus on their values. Instead of trying to "fix" every negative feeling, parents can choose to focus on connection, patience, and support.
- Modelling acceptance for teens. When parents show that emotions are normal and manageable, teens learn to handle their own feelings more effectively.

Dropping Anchor

Imagine you're on a boat in the middle of the ocean, and suddenly, a storm hits. The waves get rough, the wind is strong, and you feel like you're being tossed around in every direction. Your natural instinct might be to fight the storm—to panic, shout, or try to steer against the massive waves. But no matter how much you struggle; you can't stop the storm. Instead, what you can do is drop an anchor. Dropping an anchor won't make the storm go away, but it will keep you steady. Your boat may still rock with the waves, but you won't be dragged miles away or completely lose control. You'll stay grounded until the storm passes.



How This Helps in Parenting

- Parenting can feel like **an emotional storm**, especially when dealing with a child's struggles, behaviour issues, or personal stress.
- Instead of **getting swept away by frustration, guilt, or anxiety**, parents can use **anchoring techniques** to stay calm and present.
- By modelling this for children and teens, parents **teach emotional regulation** and resilience.

So far, we have considered how difficult thoughts and emotions can get us stuck and impact on how we behave – and how we think and how we respond to our kids. And we briefly touched on the idea of dropping anchor or steadying the ship. Taking a moment. But how might this approach guide our parenting?

Parenting is full of challenges—moments of frustration, doubt, and emotional overwhelm. It’s easy to get caught up in daily struggles and lose sight of the bigger picture. **Identifying your core values** can help guide your parenting decisions, keeping you focused on what truly matters rather than just reacting to stressful situations.

What Are Parenting Values?

✅ Values are the guiding principles that shape your parenting.

✅ They describe how you want to parent and the kind of relationship you want with your child.

✅ Values are ongoing—you never fully "complete" them, but you keep striving to live by them.

Examples of Parenting Values:

- Patience – "I want to stay calm and listen, even in difficult moments."
- Connection – "I want to build a trusting relationship with my child."
- Respect – "I want to treat my child with the same respect I hope they show others."
- Support – "I want to be someone my child can turn to in tough times."

Values are like a compass—they guide your parenting decisions, but you never "finish" living by them.

What Are Parenting Goals?

✅ Goals are specific, measurable outcomes you want to achieve.

✅ They are short-term or long-term and have a clear endpoint.

✅ Goals help you track progress but are not as flexible as values.

Examples of Parenting Goals:

- "I want my child to finish their homework every night this week."

- “I want to have one family dinner together each night.”
- “I want my teen to reduce screen time to two hours a day.”
- “I want to stay calm and not raise my voice during conflicts.”

Goals are like destinations—you either reach them or adjust them.

How Values and Goals Work Together in Parenting

While values give you direction, goals give you milestones to check progress.

- Example:
  - Parenting Value: “I want to have a strong and open relationship with my child.”
  - Parenting Goal: “I will spend 15 minutes each day talking with my child about their day without distractions.”

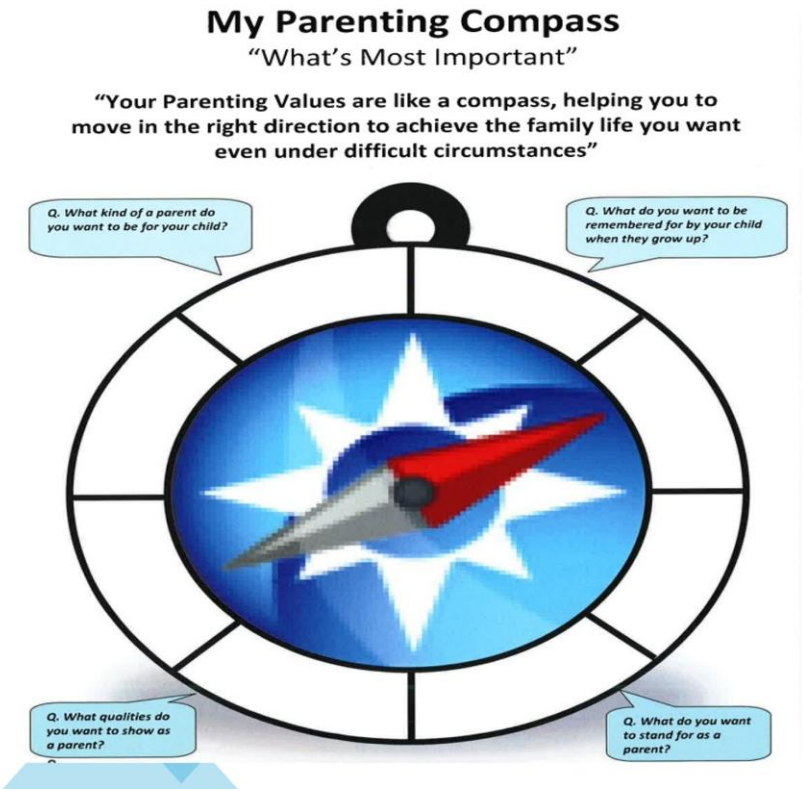
If you don’t meet a goal, that’s okay—your values remain constant, and you can adjust your approach.

How Values Help in Parenting

1. **They Provide Direction in Tough Moments**
   - When your teen talks back or refuses to listen, you might feel the urge to yell or punish harshly.
   - If you value **patience and understanding**, you can pause and respond in a way that aligns with those values rather than reacting in frustration.
2. **They Help You Stay Consistent**

- Parenting can feel overwhelming with so many decisions to make.
- When you base your actions on your values, your approach remains **consistent**, giving your child a sense of stability.

3. **They Shift Focus from Control to Influence**
    - Instead of focusing on controlling your child's behavior, values encourage you to **model the qualities** you hope to see in them.
    - Example: If you value **kindness**, consistently showing kindness in your interactions will teach your child to do the same.
4. **They Reduce Guilt and Self-Doubt**
    - No parent is perfect. There will be moments of frustration, mistakes, and difficult days.
    - Instead of dwelling on what went wrong, ask: *"Did I act in a way that reflects my values?"*
    - If the answer is no, use it as a learning opportunity and move forward with intention.



 What kind of parent do I want to be?

 What qualities do I want my child to learn from me?

 When I look back in 10 years, what do I want my child to remember about my parenting?

Final Thought

Your values won't prevent challenges, but they will anchor you when things get tough. By parenting with intention, you create a strong, loving, and resilient family environment.

Key Takeaways

- **Acceptance Over Control**: Parents learn to stop fighting emotions and instead allow them to exist while focusing on meaningful actions.
- **Values as a Compass**: By prioritizing values over goals, parents can adapt to changing circumstances and maintain a sense of purpose in their parenting journey.
- **Resilience Through ACT**: The principles of ACT offer a counterintuitive but effective approach to managing the unique stressors of parenting an adolescent with CF.

This workshop section helps parents reduce stress, strengthen their connection to their values, and approach parenting with greater compassion and clarity.

Books

1. **The Happiness Trap: How to Stop Struggling and Start Living** by Russ Harris
    - A highly accessible introduction to ACT principles, filled with practical exercises and relatable examples.
    - **Why it's great**: Written in a conversational tone, perfect for beginners.
2. **ACT Made Simple: An Easy-to-Read Primer on Acceptance and Commitment Therapy** by Russ Harris
    - While aimed at practitioners, this book is also valuable for clients due to its clear explanations and practical tools.
3. **Get Out of Your Mind and Into Your Life: The New Acceptance and Commitment Therapy** by Steven C. Hayes and Spencer Smith
    - Written by one of ACT's founders, this book provides step-by-step guidance on applying ACT to reduce suffering and live a meaningful life.
4. **A Liberated Mind: How to Pivot Toward What Matters** by Steven C. Hayes

- Explores ACT in the context of overcoming life challenges and building psychological flexibility.

5. **Stuff That Sucks: Accepting What You Can't Change and Committing to What You Can** by Ben Sedley
    - A short, engaging book for young people and adults dealing with tough emotions.

Videos and Online Resources

1. **The Happiness Trap Videos** by Russ Harris (YouTube)
    - A series of short, engaging videos explaining ACT concepts like defusion, acceptance, and values-based living.
2. **The ACT Matrix (YouTube)** by Kevin Polk
    - Explains the ACT Matrix, a simple, visual tool to apply ACT principles in everyday life.
3. **ACT Mindfully** (Website by Russ Harris)
    - Offers free ACT worksheets, exercises, and videos.
    - Website: www.actmindfully.com.au
4. **Association for Contextual Behavioral Science (ACBS)**
    - The official ACT organization's website, which provides free resources, videos, and community support.
    - Website: www.contextualscience.org

Podcasts

1. **The ACT in Context Podcast** by ACBS

- Offers insights and interviews with ACT practitioners and researchers, often covering real-life applications of ACT.

2. **The Mindful Kind Podcast** by Rachael Kable
    - Combines mindfulness and ACT principles in an accessible format.

NOT FORGETTING…..THE REST OF THE FAMILY

We emphasised at the workshop about the importance of not forgetting the rest of your family when it comes to caring for a child with Cystic Fibrosis. As we noted earlier, if families are the biggest predictors of outcome, then we need to think about the whole family when managing your child's needs. This means thinking about your other children too.

It can certainly be difficult to be a sibling of a child with a chronic illness. They can sometimes learn that they cannot put their own demands on parents as they see their parents rushing from appointment to appointment with their sibling, and so may not wish to further 'burden' their parent. Other times, the sibling can almost grow up too fast and adopt a parentified role in wanting to look after their sibling with chronic illness. This emphasises the need to have that open communication with siblings about Cystic Fibrosis too so as to prevent them imagining the worst-case scenario. They are children too – they also need special time with mom and dad. It can be understandably easy, and

importantly unintentional, to let their needs take a back seat when you are caring for another child with a chronic illness.

Even if you have already had this conversation with your other children, it may be beneficial to go back and refresh this conversation at appropriate times, for example if your child is in hospital, and explain to their sibling that none of it is their fault and they are not responsible for the child with Cystic Fibrosis's care. Creating a shared experience of Cystic Fibrosis as a family is so important.

Now, think about you! The importance of parental self-care cannot be understated. It is imperative for you as a parent to maintain your own relationships - with your partner, your wider family and your friends. You too need your own support network around you and to build up your own bank of positive experiences from which to draw on when perhaps your resources are depleted. As a couple – find time together! This 'me time' is NOT a luxury – it is a necessity. In looking after yourself, you are also modelling how to do this for your child and emphasising the importance of going out and enjoying the fun things in life! Think about the messages this is sending your child. If you aren't currently taking time for yourself- problem- solve how to!

RECAP

The other children

Living with someone ‘special’

Need their own special time/attention

Shared family activities

Partners

This booklet aimed to summarise the Parent Workshop you took part in. We hope that the workshop and this booklet will help you and your family to face and overcome the challenges which you may come to face with more confidence.

The research team

Chris, Nicola, Dee, Clodagh & Muireann