



Cystic fibrosis and mental health: what psychologists need to know

“This is not a short-term crisis - it is relentless”

What is cystic fibrosis

Cystic fibrosis (CF) is an inherited chronic medical condition that affects the lungs, airways and digestive system in which people develop excessive sticky mucus that requires daily treatment from birth.

CF is commonly diagnosed through newborn screening with parents receiving the news of diagnosis at around 3-6 weeks after their baby's birth. While CF is a life limiting chronic illness, new medications now mean eligible patients can have an improved and much longer quality of life.

Caring for a child with CF requires parents to attend regular PCH clinic appointments where they are seen by the multidisciplinary team. These appointments can be stressful and time consuming for the family.

Mental health and CF

It is well established that approximately 30-40% of parents of children with CF will be diagnosed with a mental health condition such as depression and anxiety. Parents and carers are likely to experience very high levels of stress and distress associated with the daily demands of caring for their child. Carer burnout is common, affecting the entire family.

Children with chronic medical conditions such as CF are 30-40% more at risk of developing depression and anxiety compared to their healthy peers. Some children will experience trauma from medical procedures. Access to mental health services can be difficult, often leaving children and parents isolated in managing psychological distress.

Impact of diagnosis on parents and family

A diagnosis of CF is a shock and parents can experience a range of complex emotions including significant grief, loss, and chronic sorrow.

Admissions to hospital can occur from a very young age, with some children having frequent admissions, while others may never have an admission throughout their childhood and adolescence. Admissions to hospital are very stressful for the child, their



parents and family. This gives rise to concerns about time away from home (especially for rural families) and from other children. Time in hospital can range from 3-4 days through to 2-3 weeks. Hospital admissions can have a significant impact on family relationships, parent wellbeing, social relationships and school engagement. Admission can either be planned, with parent's having time to prepare for their child's admission or may occur quite suddenly due to an acute health exacerbation.

Parents also need to manage the distress of their other children. It is not uncommon for siblings to experience a range of complex emotions due to not having CF.

Parents are required to juggle multiple demands on a daily basis incorporating CF care for their child as well as caring for other family members. Parents often report feeling mentally and emotionally exhausted.

Daily treatment gives rise to time pressures in the household, and can limit after school activities, and generally impacts the entire family system.

Parent-child relationship

Parenting a child with CF can result in unexpected changes in the parent-child relationship. At times parents struggle with normal parenting strategies such as limit setting, establishing normal routines, or incorporating a degree of flexibility in their parenting approach. Parents frequently lose trust in their own parenting knowledge, skills and abilities.

Conflict in the parent-child relationship often arises when children are unwilling or reluctant to participate with daily treatment. Many of the emotional challenges faced by parents are often due to underlying fears about the health and wellbeing of their child as well as their desire to protect the relationship with their child.

Common psychosocial challenges associated with the diagnosis

Following the diagnosis, parents often turn to the internet for information. Information from non-official websites is not helpful as it creates high levels of distress due to inaccurate and out of date information on some websites. These first "online" impressions can be difficult to shift psychologically due to the high emotional impact this has had on the parent during a vulnerable time in their lives.

Parents need to incorporate numerous roles when caring for their child with CF, such as advocacy in medical and educational settings, advocacy across other community services who support their child, and increase their role of carer when their child becomes unwell.

Children with CF will have medical procedures which are painful and frightening to them. Parents are at times required to physically hold their child during these procedures. This can cause distress in the parent and some will experience intrusive memories of these events.



Other common parenting challenges across the child's development include difficulties at mealtimes as some children with CF have a poor appetite. Mealtime challenges can give rise to anxiety in the parent due to the natural drive of wanting to nourish their child, and the known benefits which come with a good nutritional status for a child with CF.

Psychosocial pressures such as work demands, financial stress, physical and mental health problems in parents, conflict in the couple relationship, can further exacerbate the difficulties of caring for their child with CF.

Extended family support is not always available or helpful as extended family members may not always understand the complexities of caring for a child with CF. It is not uncommon for parents to seek emotional support from other parents in the CF community which can bring its own challenges.

For further information

Each family's experience of caring for a child, or children, with CF is unique. Take time to listen to your clients' individual experiences and seek their permission to speak with the clinical psychologist who is working with your client's family at Perth Children's hospital if you both agree this could be helpful.

The following websites are recommended for further information on CF

- Cystic Fibrosis Australia www.cysticfibrosis.org.au
- Cystic Fibrosis WA www.cfwa.org.au



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