



Siblings & Offspring

Having a sibling or parent with cystic fibrosis (CF) can be hard. These children are considered young carers due to the demands and stressors of having someone with a chronic illness in their family. This can have a significant impact on the young person's wellbeing, education, relationships and connection to the community.

The impact of CF on a healthy sibling/ offspring may be affected by several factors, including severity of CF, family support and more. Many young carers experience a range of concerns:

Common Concerns

Guilt

Feeling they might have caused the illness through something they did wrong, about being the healthy one, or guilt about their feelings towards their sibling or parents.

Worry

About whether they will become ill like their sibling/parent, whether their loved one may die or return to hospital, concern about the family's financial situation, their parents' emotional wellbeing, or pressure to be the 'good', 'easy' or 'able' child.

Resentment

Feelings of unfairness or disappointment about the extra attention and time devoted to their sibling/parent, the limitations imposed on the family due to CF.



Sense of loss and Isolation

Feeling different from peers who have healthy siblings/parents, sad that they cannot have the same type of relationships with their family member as their peers or isolated when they have a hospital admission.

Embarrassment

About their sibling/parent coughing, having a PICC line etc.

Responsibility

Such as increased independence due to parents' preoccupation with caring, or their own caregiving responsibilities, more chores etc.

Signs Your Child May Be Stressed

- Being anxious, withdrawn or angry
- Losing interest in friends or favourite activities
- Reverting to a former level of immaturity

- Performing poorly in school
- Pushing too hard to achieve or be a perfect child
- Rebelling in negative ways (staying out too late, smoking, drinking)

How Parents Can Help

Information

Give your child information about CF at their level of understanding, increasing the detail as they age or ask questions. Let them know it is ok to ask questions.

Prepare them

Help prepare your child for how to cope with difficult situations. For example, you might practice what they can say if someone says upsetting things about their sibling /parent.

Communication

Have regular conversations with your child and help them to voice any concerns or worries they may be experiencing. They can learn that it is ok to have both positive and negative emotions.

Coping Strategies

Identify and share strategies for coping with difficult feelings and situations. Help them find activities that help them to destress such as physical activity or music.

Involvement

Keep your child involved in family life, such as discussions about family routines, the changes that might occur because of CF, and the role each family member plays in creating a strong, caring family. This can add to their sense of value as a contributing member of the family.

Feel Important

Most children will understand the extra attention given to a child with CF if they are helped to feel important too. Parents, professionals or extended family/friends

can all show interest in the healthy child and help them to feel special.

Engaged

Encourage your child to engage with and find support from other young carers through support organisations.

CFWA Support

CFWA support siblings and offspring through a variety of events and resources:

- <u>Support events</u> including annual Sibling and Offspring Camp and Sibs Day Out event.
- Sibling and Offspring Webinars
- CFWA social workers can provide <u>psychosocial support</u> including short term counselling and strategies for coping with their feelings around CF.
- Annual magazine, <u>Rozee</u>, produced for children with CF, siblings and offspring with a range of CF related articles and interviews.

Useful Resources

- Parents & Other Carers page (CFWA)
- Sibling & Offspring Member Stories (CFWA)
- Young Carers Program (Carers WA)
- What About Siblings? (CF Foundation)
- Helping Siblings Cope (Baby Steps CF)
- 'Growing up with a Sibling who Has CF' Blog (CF Foundation)

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