



Having a Partner with CF

Having a partner with cystic fibrosis (CF) will no doubt have a big impact on your life. There will be many things that a couple with CF may face that others will not; health changes, financial impacts, effects on social life, medications, treatments and more. On the other hand, many couples dealing with CF report a greater appreciation for life and a stronger relationship because of these struggles.

Having a partner with CF means you probably take on some level of being a caregiver. The role you play is likely to change over time and throughout your relationship, depending on your partner's health. It may include anything ranging from assisting with medications, going to clinic appointments, helping with cleaning nebs and other devices, encouraging them to do their treatments and maintain a routine, helping with day-to-day life if they are experiencing low lung function as well as being a strong support system.

Although taking on a caregiver role is likely done from a place of love and care for your partner, it can take a toll on your health if you aren't taking the time to look after yourself as well.

Taking Care of You

As a caregiver, your role is to make sure that your loved one who has CF is healthy, supported, and cared for. But who cares for you?



It is vital for your emotional health and wellbeing that you have time to look after your own physical and emotional health to avoid caregiver burnout.

Warning signs of burnout include:

- Withdrawal from friends, family, and other loved ones.
- Loss of interest in activities previously enjoyed.
- Feeling blue, irritable, hopeless, and helpless.
- Changes in appetite, weight, or both.
- Changes in sleep patterns.
- Getting sick more often.
- Emotional and physical exhaustion.

Self-Care and Positive Thoughts

Ways that you can seek help and take care of your own health include:

- Accept support from family, friends and support organisations.
- Make connections with other carers who understand what you're going through.

- Take time for yourself e.g. exercise, hobbies, friends.
- Practice positive thinking.
- Stay connected with support systems.
- Eat well.
- Get plenty of sleep.

Read our <u>Self-Care for Carers</u> factsheet for more information on implementing self-care into your life.

Practicing self-care and learning how to create useful thoughts and actions in response to stressful events increases personal strength and resilience to 'bounce back' from challenging situations. Practicing positive thinking each day can have huge long-term benefits.

Some ways to do this include:

- Practice gratitude. Think of 3 things each day you are grateful for. You may even like to start a gratitude journal.
- Spend time with positive people.
- Practice positive self-talk e.g. "I really messed that up" vs "I'll try again in a different way".
- Start each day on a positive note
 e.g. tell yourself you're going to have
 a good day, listen to a happy song,
 exercise or do something you enjoy
 first thing.
- Find humour in each day, even in bad situations.

Seeking Support

CFWA can provide the following support to partners:

- Over-the-phone support and education.
- <u>Carer Support Events</u>- designed to help carers meet and develop ongoing support networks e.g. ladies high tea, carers dinner, posttransplant support dinner.

- <u>Counselling and General Support</u>-Centrelink help, counselling, referrals etc.
- Resources and Information- to learn more about different aspects of CF.
- <u>Financial Support</u>- Centrelink information and subsidies for your partner.
- <u>Transplant Support</u>- if your partner is pre or post-transplant, we can offer extra support in the home.
- Home Care Worker (HCW) Program-Encourage your partner to access our HCW program to give you a break. Our HCW can also provide a lot of support to you.

You can also receive support from <u>Carers</u> WA who offer various services to carers.

Useful Resources

- Partner Interviews (CFWA)
- <u>Taking Care of Yourself When Your</u> <u>Partner has CF</u> (CF Foundation)
- <u>Living with CF: A Partner's</u> <u>Perspective (CF Ireland)</u>
- An Interview with my CF Caregiver Husband (cysticfibrosis.com)

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