

Belonging & Connection

LWWCF Insights have been developed based on the experience of those living with CF as patients, carers, families and informed by health professionals.

Why is Living Well Important?

Living Well with CF is important because you are! You are the only one who can determine the kind of life you want to live. Making time to understand yourself, your strengths, needs, goals and priorities means that you can drive your life in the direction you want it to go. Recognising the positives and challenges that come with CF and life, plus maximising your physical health, mental health, emotional wellbeing and social health are essential to supporting you to live your best life.

People living with CF as patients, carers or family tell us that:

“Living well with CF means that you have the agency, sense of control, resilience and confidence to live the life you want to live. It means being able to live a life with CF but that is not defined only by CF. It means having access to appropriate resources and supports to empower you to live the life you want to live.”

Living Well with CF Insights

These *Living Well with CF (LWWCF) Insights* have been created as sources of information and inspiration. They have been developed based on the experience of those living with CF as patients, carers and families, and informed by health professionals. Whether you are a person with CF, a carer or a family member, these resources cover topics to help you to maximise the belief you have in yourself, your skills and your capabilities so you can optimise your physical, mental, and social health and wellbeing.

In this *LWWCF Insights* resource, we take a look at **Belonging and connection**.

Belonging and connection – what does it mean?

One thing that is key to living well with CF is belonging and connection. Human beings have an in-built need for emotional connections and to feel like they belong, in order to function well in all areas of life. This means having people in your life (not necessarily lots of people, maybe just a handful) who you feel bonded and close to and have a deep relationship with. These people are likely to be family or a close inner circle of friends who ‘get you’ – your perspectives, priorities, values and humour. Connection doesn’t mean that people are the same as us, or even agree with us, but that they make us feel like we belong and are valued. We can also have a sense of belonging and connection with bigger systems, like school, work, the community we live in and with the CF team.

Having CF in your life can create a great sense of belonging and connection to the wonderful CF community or people who support you. It is also common however for CF to make belonging and connection more challenging e.g., people not understanding what CF is and the impact it has on your life, having to cancel social plans at the last minute if you are unwell, struggling to balance CF treatment demands with making time for friends. The good news is there are SO many ways to foster and improve a sense of belonging and connection.

“Realising that I may not be in control of what happens to me, but I am always in control of how I respond and my choices, has changed my life.”

– Young adult with CF

How do I foster belonging and connection?

The following steps aim to support you to make change in any area of your life, or reach any goal you have, and most importantly to *live well*. You can use the **Living Well Worksheet** to help guide you as you work through these steps.

1. Know you are in control

The good news is that when it comes to belonging and connection, you have control! This doesn't mean you can control how other people think, act or respond to you, but you can believe in your own worth as a person and choose who you trust and open up to.

2. Identify how you are living now, and what you want to change

Think about how connected you feel at the moment. Ask yourself: *Do I currently have people in my life that I feel bonded with? Do I have a sense of belonging? Do I need to deepen existing connections or make some new ones?*

3. Make a plan

If you feel you want to improve your sense of belonging and connection, it is time to make a plan! To do this, identify specific and clear goals, so you have something to work towards e.g., open up more to my close friends about how I am feeling. Identify your motivations to improve your connection (e.g., to feel less lonely) as this can help you persevere when things get tough. Finally, identify strategies that can help. These may be things you have used before or new strategies. Take a look at the list of strategies below for some suggestions to help you get started.

4. Put your plan into action

Set yourself a timeframe so you know how long you will try your plan before reviewing how it's going. Remember that connection takes time, so set a realistic timeframe of at least a few months. Then just go for it, do what you have planned to do and have fun!

5. Review

Review what is working well, what you need to change and try again – don't give up, you will get there!

Hints and Tips

See the other LWWCF Insights resources for more topics and strategies to help you to manage treatment and care and live well. You can use the Living Well Worksheet in partnership with any of these.

Strategies to Foster Belonging and Connection

- **Open up.** It can be hard to be vulnerable and open about our needs and challenges, but if you practice talking about them with people you trust, this often leads to them being more open with you in return and building a sense of connection. Try asking your loved ones how they feel and really listen to their answer.
- **Talk about CF.** If you feel that lack of understanding around CF is getting in the way of forming a deeper bond, why not tell them a bit about it and tell them it's okay to ask you questions. It's hard for people to understand what it's like to live with CF unless you tell them. Try to be patient with people and focus on their intent when asking questions: to get a better understanding of you.
- **Kindness is infectious.** Consider going out of your way to be kind to someone. Try smiling at a stranger or sending a text to a friend you've lost touch with to let them know you are thinking of them.
- **Join a group.** Find a group that's focused on something you're interested in or enjoy doing e.g., a book club, a walking group, a community art group. Consider online groups too – there are lots of CF ones!
- **Consider volunteering.** You are probably thinking: “when do I have the time?”, but even just a little volunteering can help foster belonging and connection, both with the new people you meet and the community you are helping.
- **Step outside your comfort zone.** Say yes to social invitations, even if it makes you feel nervous. This can be difficult especially if you are introverted, but it can build confidence and connection.
- **Start talking.** Strike up conversations with people when out and about, at work, in the coffee shop queue, in the supermarket. This can help you practice social skills, build confidence and maybe even make a friend.
- **Be proactive and prioritise connection.** Schedule regular catchups with the people you care about, even if you feel you are too busy. The emotional energy you gain will make it worthwhile.
- **Your healthcare team are key!** Aside from your family and friends, your healthcare team are the people most invested in your health and wellbeing. It's really important to have regular conversations with them about your social supports and connections as well as your health, treatment, goals and priorities. This way they can provide any information and support you may need to help you feel connected and live well.

“Humans are pack animals...if you don't have a place to belong, it can be depressing...I think that part of the social connectedness is the key thing for me, having a group where I feel comfortable that I belong”

– Young adult with CF

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The resources in the LWWCF website and resource directory should be used in consultation with your healthcare practitioner or mental health professional.

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