

Resilience

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 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 the **importance of Resilience**.

Resilience – what does it mean?

Life inevitably throws challenges our way whether it be losing a job, the death of a loved one, the end of a relationship, or physical health difficulties. Resilience is all about how you adapt and cope with these events. It refers to your acceptance, adaptability and the flexibility of your feelings and behaviours, which help you to cope well with difficult situations. Resilience is a skill that you build over time. It requires that you tap into your strengths, but also know when you need to ask for help.

People living with CF are often very resilient because CF can present challenges from a young age. It is also common for CF to test your resilience by presenting new complexities e.g., a new diagnosis, drops in lung function, heavy treatment demands, other health difficulties, anxiety and mood issues, and financial stressors. The good news is there are SO many ways to foster resilience so you can feel confident to manage whatever comes your way!

“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 resilience?

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

You may not be in control of what stressful events happen in your life, but you are in control of building your own personal resilience, which can shape how you respond to these events.

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

It is important to understand how resilient you are at the moment. Start to reflect on this by asking yourself: *How do I cope with crisis, uncertainty, change or unexpected stressful life events? Do I identify strengths, positives and actions to take even during hard times? Do I adapt how I mentally view things and behave to help me cope with a difficult situation?*

3. Make a plan

If you feel you need to improve your resilience, it is time to make a plan! To do this, identify specific goals so you have something to work towards e.g., make 5 minutes each day to write down 3 positives or things to be grateful for. Identify why you're motivated to improve your resilience (e.g., to feel more confident at managing change) as this will help you persevere when things get tough. Finally, identify strategies that can help you achieve your goals. 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 building resilience takes time and practice. It is not an overnight process, so give yourself at least a few months before expecting noticeable changes. 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!

“Resilience is huge...I have a theory that the people with CF who do well are the ones who are resilient...a friend of mine who also has CF has been through so much, but he's still here...Things are tough, but let's keep going.”

– Adult with CF

Strategies to Foster Resilience

- **Reward and acknowledge your strengths and achievements.** Celebrate the wins but also be kind to yourself if you have setbacks.
- **Work on your sense of identity.** Having a positive sense of self provides a great foundation for resilience. Spend time reflecting on what makes you unique. Value yourself and enlist the help of those you love to remind you how great you are!
- **Set achievable goals each day.** This will add to your sense of purpose and accomplishment and help you practice being proactive and decisive.
- **Draw on your strengths and strategies you have used before.** Think about previous times that you have been able to cope well with bumps in the road. This will help you learn from these experiences and feel more confidence.
- **Know your coping mechanisms.** Identify what you do to cope with stressful events and reflect on whether you have healthy coping mechanisms or need to develop new ones.
- **Develop a mantra for when you feel overwhelmed.** A mantra is a sentence you say repeatedly to yourself when you are experiencing high levels of stress. Be creative with something that works for you, to help calm you down and remind you that you can do it (e.g., I am enough, this feeling will pass, I am safe).
- **Build your connections.** People who love and support you will boost you and provide care when things get tough so nurture those relationships. If you need new or more connections, seek them out – you could join a group, volunteer, or reach out to old friends. Check out the LWWCF Insights resource addressing the topic of Belonging and Connection for some more ideas.
- **Your healthcare team are key!** Aside from your family and friends, your healthcare team are the people most invested in your health and wellbeing. If you are struggling with resilience, reach out so they can provide any information and support you need to live well. Remember asking for help is a resilient thing to do!

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.

Acknowledgement:

This resource was funded and facilitated by Vertex Pharmaceuticals (Australia) and developed by The Med Collective through collaboration with members of the LWWCF initiative Steering Group. We wish to acknowledge the content contribution and intellectual property of Dr Lucy Holland and Maggie Harrigan, and most importantly, the consumer and health professional experts who shared their experience and expertise to develop this work.

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

References used to develop this *LWWCF Insights* Resource:

1. Mitmansgruber H, Smrekar U, Rabanser B, Beck T, Eder J, Ellemunter H. (2016). Psychological resilience and intolerance of uncertainty in coping with cystic fibrosis. *Journal of Cystic Fibrosis*, 15(5), 689-695.
2. Muther EF, Polineni D, Sawicki GS. (2018). Overcoming psychosocial challenges in cystic fibrosis: Promoting resilience. *Paediatric Pulmonology*, 53(S3), S86-S92.
3. Toprak D, Nay L, McNamara S, Rosenberg A R, Rosenfeld M, Yi-Frazier JP. (2020). Resilience in adolescents and young adults with cystic fibrosis: a pilot feasibility study of the promoting resilience in stress management intervention. *Pediatric Pulmonology*, 55(3), 638-645.