

Defining Living Well with CF

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.

The following LWWCF Insights topics are available now (with more coming soon). We encourage you to explore these topics and resources as you take your next steps towards *Living Well* with CF.

- The **Living Well Worksheet** has been developed as a practical tool you can use to help you work through any of the *LWWCF Insights* topics below, or other area of life where you want to make a positive change.
- **Adherence** refers to how well you manage your daily care, stick to recommended treatments and attend follow-up appointments. This is crucial for your health and wellbeing so you can maximise your ability to achieve what you want to in your life.
- **Agency** is having the capacity to fulfil your potential. It relates to the beliefs, intentions, skills and behaviours that help you to act intentionally to influence your own wellbeing and life.
- **Belonging and connection** is essential for us all, for support and care, to keep you motivated and give greater meaning to your life.

- **Identity** includes and influences your self-esteem, social identities, and self-efficacy. A positive identity is crucial for self-belief!
- **Resilience** is your capacity to deal with challenges and the ‘tough stuff’. It is essential for your wellbeing and self-belief that you know you can deal with whatever comes your way.
- **Self-Management** refers to how well you manage everything in life (not just CF). It requires that you have a positive self-concept, motivation, enough information and skills, and the strategies and capabilities you need to successfully self-manage all parts of your life.
- **Social support** is crucial, not only to help you navigate life’s challenges, but also to help you celebrate the wins along the way.

How do I Live Well?

The following steps aim to support you to make change in any area of 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

While you may not always be in control of what happens in your life, remember that you are in control of your choices, goals, behaviours and actions.

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

It is important to understand how you are living now if you want to see what changes you can make to live your best life. Ask yourself: *What is your self-belief like? What is your identity like – is this positive? How much agency and control do you feel you have in life? Are you clear about your goals and motivations? What is your physical health, mental health and social wellbeing like at the moment? What are your strengths? What information, support or other needs do you have? Who are your supports?*

3. Make a plan

If you want to improve how well you are living, it is time to make a plan! To do this, identify specific and clear goals so you have something to work towards. Understand your motivations to make change (this helps you to keep going if things get tough). Finally, identify strategies that can help you along the way. These may be things you have used before or new strategies. Take a look at the list of Living Well Strategies below for some suggestions to get started.

Hints and Tips

See the other LWWCF Insights resources for more topics and strategies to help you to Live Well. You can use the Living Well worksheet in partnership with any of these.

4. Put your plan into action

Set yourself a time frame so you know how long you will try your plan before reviewing it. Remember that change doesn’t happen overnight, so give yourself time. Then just go for it, do what you have planned to do and enjoy the ride!

5. Review

Review and evaluate what is working well, what you need to change and try again.

Living Well Strategies

- **Prioritise you.** You are the only one that can determine the life you want to live. Prioritising you is key so you can be your best self and live your best life. This is how you can give the most to others too.
- **Believe in yourself.** If you are struggling to make a change, just think about previous times that you have successfully achieved something or reached a goal. Doing so can help boost your confidence and belief that you can do it.
- **Create space, get to know yourself.** Creating space in your life for you is important so you can have fun getting to know yourself. Regularly check in to identify your strengths, needs, goals and priorities as things change. Hint: You can use the Living Well worksheet to help you do this.
- **Watch your thoughts.** Your thoughts can be sneaky and sometimes very self-critical! Monitor your thoughts to minimise negative self-talk. Speak to yourself like you would your own best friend.
- **Maximise your health and wellbeing.** To *Live Well*, we need to maximise our physical health, mental health and social wellbeing. It can be difficult to make any change if you are struggling with physical health (e.g. CF-related, general health, not sleeping, poor appetite, etc.), mental health (e.g. worry, anxiety or low mood) and social challenges (e.g. relationships, study or work, finances, etc.). Making sure these are met helps you to live your best life.
- **Be kind to yourself and celebrate the wins.** Managing life can be hard at times and it's ok not to be perfect, to face challenges and stumble. You just need to do your best and be kind to yourself. Remember to celebrate your successes too - you are worth it!
- **Connection is key - build your support network.** No one is an island and we all need quality, meaningful connections to navigate life. Build a support network around you of people you care about and trust. The best support networks include your family and friends, your (or your loved one's) healthcare team and others with whom you have positive connections.
- **Aim for quality not quantity.** When it comes to connection and support it is all about quality, not quantity. It is those few people who really know you and who you trust that are crucial to your sense of connection, self-confidence and wellbeing.
- **Open communication is key.** It can be hard to be vulnerable about our needs and challenges, but remember that everyone has them. Practice talking about these with people you trust so you can ensure you receive the support you need.
- **If you need help, ask for it.** We all need a little help sometimes so reach out and ask for help when you need it.
- **Information is power.** There is also no such thing as a stupid question so make sure you don't have any unanswered questions about your health, care and life.
- **Your healthcare team are key.** Aside from your family and friends, your (or your loved one's) healthcare team are the people most invested in your health and wellbeing. Having regular conversations with them about your health, treatment, care, needs, goals and priorities means they can provide any information and support you need to enable you to live your best life.

“Realizing 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

Acknowledgement:

This resource was funded and facilitated by Vertex Pharmaceuticals (Australia) and developed independently 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 health care practitioner or mental health professional.

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