

Self-Management

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 **Self-Management**.

Self-Management – what does it mean?

One thing that is key to living well with CF is self-management. This refers to how well we manage the things in life that we have to manage including our physical, mental and social health. Successful self-management requires that you have:

- Positive self-identity, self-belief, self-worth and a positive identity so you know you are worth it.
- Motivation to achieve what you want to do is key to keeping you going, especially when things get tough.
- Information and support so that you can identify what you need to do, why you need to do it and where you can access support to help achieve it.

- Skills, strategies and capabilities to drive at the life you want, know you are in control and can manage challenges and change as they arise.

“For me to manage my care and life in the best way, I have had to understand my health better, develop the skills I needed to manage my time and work more closely with my healthcare team. Once everyone was on the same page, and my team understood my priorities, it made life it so much easier!”

– Young adult with CF

How do I maximise self-management?

The following steps aim to support you in developing healthy self-management habits. These steps can be used to make change in any area of your life, or reach any goal you have, and most importantly help you 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 be in control of what you need to do, when it comes to managing your health and life, you are in control of your goals, priorities, choices and ensuring your needs are met.

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

It is important to understand what your self-management is like now. Ask yourself: *How is your health? What are your goals and priorities? What are your motivations? What are your needs? Do you have good self-belief and confidence? Do you have a positive identity? Do you have agency in your life? What are your strengths? What are the challenges you are facing? What do you want to change?*

3. Make a plan

If you feel you want to improve your self-management, it is time to make a plan! To do this, identify specific and clear goals so you have something to work towards. Identify your motivations behind wanting to improve self-management as this can help you persevere when things get tough. Finally, identify strategies that can help you improve your self-management. These may be things you have used before or new strategies. Look at the list of strategies below 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 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 have fun!

5. Review

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

“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

Strategies to Maximise Self-Management

- **Give yourself a break.** Managing CF treatment, care and life is hard. Developing the capabilities to self-manage effectively can take time. So, be patient with yourself and know it is okay not to be perfect; just try your best and take one step at a time.
- **Believe in yourself!** Think about the strengths you already have and remember that you are worth it. Positive reflection can help reinforce your belief in yourself that you can make change or improve your self-management.
- **Identify your motivations.** Knowing the motivation behind every goal you have or decision you make can help you better understand yourself and make it easier to communicate to others the reason behind your actions.
- **Information is power.** Being able to identify gaps in your knowledge and where to seek information can give you a greater sense of control over your life and the decisions you need to make. Whether it's finding the information yourself or asking for support from your friends, family or healthcare team, effective self-management means staying informed.
- **There is no such thing as a stupid question.** Make sure you don't have any unanswered questions about your health, care and life.
- **Identify your skills.** Identifying the skills you already have can help you recognise which skills you can use if you hit a speed hump or challenge. Identifying the skills you might want to develop lets plan how best to build these skills and decide whether you are able to do this yourself, or whether you will need support.
- **Use your support network.** No one is an island. Your support network can help you to set intentions, reflect on the things you need and celebrate successes with you too.
- **Your healthcare team are key!** Aside from your family and friends, your healthcare team are the people most invested in your health, wellbeing and self-management. If you are struggling to set intentions, think ahead, know what you need, or know what to do to make a change, talk to them. This way they can provide any information and support to help you to manage your life in the best

Hints and Tips

See the other Living Well with CF Insights resources for more 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. Algrante JP, Wells MT, Peterson JC. (2019). Interventions to support behavioral self-management of chronic diseases. *Annual Review of Public Health*, 40(1), 127–146.
2. Fisher WA., Fisher JD, Harman J. (2003). The information–motivation–behavioral skills model: A general social psychological approach to understanding and promoting health behavior. In Suls J & Wallston KA. (eds.), *Social psychological foundations of health and illness*. Blackwell Publishing.
3. Holland LR, Hilton J, Cookson K, Heinsch M, Gilligan C, Wark P. (2022). Understanding motivation for Australian adolescents and young adults with cystic fibrosis: Modifiable factors to support self-management. *Health and Social Care in the Community*, 30(5), e2712-e2723.
4. Lozano P, Houtrow A. (2018). Supporting self-management in children and adolescents with complex chronic conditions. *Pediatrics*, 141(Suppl 3), S233–S241.