

*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 **building Agency**.

***“A daily practice I find really useful is reflecting on my strengths and achievements. It lifts me up and reminds me that when things get tough, I have managed before”***

–Adult with CF

## ***Agency – what does it mean?***

One thing that is key to living well with CF is agency. Agency refers to the capacity you have 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.

Agency has four key components. These are:

- **Having intention** and acting intentionally to drive your life in the direction you want it to go.
- **Thinking ahead** about plans, goals, likely outcomes and the actions needed to make things happen.
- **Understanding and self-regulation** of your emotions and behaviours (e.g., noticing and naming how you feel; identifying what triggers negative emotions; practicing positive and compassionate self-talk; and actively making plans, choices, and setting goals and making changes as needed).
- **Having self-efficacy**; that is, the self-belief and confidence that you can complete the steps necessary to get where you want to in life.

To act with agency means you must believe in yourself and your capabilities and know that your actions can lead to the outcomes you want. It also means having access to the information, resources and the support you need to manage your health and life and achieve your goals.

## *How do I maximise agency?*

The following steps aim to support you in maximising agency. 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 life throws your way, you can control your actions, behaviours and decisions!

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

It is important to understand how strong your sense of agency is now, what is working well, and what you want to change. Ask yourself: *Do I have clear intentions? Do I think ahead? How well do I self-regulate and what is my self-efficacy like?*

### 3. Make a plan

If you feel you want to improve your agency, it is time to make a plan! To do this:

- Start by identifying specific and clear goals so you have something to work towards (e.g., catchup with friends weekly, apply for a work promotion, improve nutritional intake).
- Identify your motivations to improve your agency as this can help you persevere when things get tough (e.g., feel more socially connected, gain more job satisfaction, improve my physical health management).
- Finally, identify strategies that can help you. These may be things you have used before or new strategies. Take a look at the list 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 need to change and 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 Agency*

- **Give yourself a break and take your time.** Building a skill like agency is hard and doesn't happen overnight. Like strengthening a muscle, it requires practice and repetition. Be patient with yourself and try your best. Remember, it's okay to not be perfect.
- **Start small every day.** Agency is a skill that you develop, you don't have to decide on the big things, or set all your life goals at once. Start small to build your confidence and become familiar with the process. You can practice by taking five minutes in the morning every day to reflect on your goals, strengths and needs; set a clear intention for the day; think ahead about what you need to do to achieve your goal.
- **Pause.** Having agency means taking the time you need to determine your intentions, actions, what you need and decisions that need to be made. There is no rush. Push pause and take the time you need to think or talk to others if you need to.
- **Use your support network.** No one is an island. Your support network can help you maximise agency by offering advice and outside insight. They can help you set intentions and reflect on the tools, resources and supports you might need to build your confidence and agency. They are also great cheerleaders and will 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 agency. If you are struggling to set intentions, think ahead, know what you need, or know what to do to improve something or 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 way.

### *Hints and Tips*

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

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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.

## References used to develop this *LWWCF Insights* Resource:

1. Bandura A. (1989). Human Agency in Social Cognitive Theory. *American Psychologist*, 44(9), 1175–1184.
2. Code J. (2020). Agency for learning: Intention, motivation, self-efficacy and self-regulation. *Frontiers in Education*, 5, doi: <https://doi.org/10.3389/feduc.2020.00019>.
3. Cronly JA., Savage E. (2019). Developing agency in the transition to self-management of cystic fibrosis in young people. *Journal of Adolescence*, 75, 130–137.
4. Faint NR, Staton JM, Stick SM, Foster JM, Schultz A. (2017). Investigating self-efficacy, disease knowledge and adherence to treatment in adolescents with cystic fibrosis. *Journal of Paediatrics and Child Health*, 53(5), 488-493.
5. 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.