

# Managing Treatment and Care (Adherence)

*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 **Adherence**, or **managing treatment and care**.

## *Adherence - what does it mean?*

One thing that is key to living well with CF is **adherence**. Many people living with CF prefer the terms “managing treatment” or “managing daily care” but the term “adherence” is most commonly used by your health care team. Adherence essentially means how well we stick to something. In the context of living with CF, it describes how well we stick to the treatments we are recommended by our healthcare team (including medication, physiotherapy, dietary treatments, exercise, etc.) and follow-up appointments.

*“Having my questions about my treatment answered by my CF team helped me to understand what I need to do and why.”*

- Young adult with CF

Adherence is important because the more you stick to your prescribed treatments and care:

- The better your treatment works
- The better your health is now and will be in the future
- The better you will feel, both physically and about yourself
- The better you can support changes to your health and wellbeing
- The more you are able to do in life and achieve the things you want to!

Although adherence is really important, we know that adhering to all CF treatments can be really hard, especially when you feel well, treatments are complicated or have side effects, or when life gets busy and other priorities take over. Knowing how best to support adherence can be really challenging for carers and family too. The good news is there are loads of ways you can maximise your adherence and live your best life.

## *How do I maximise adherence?*

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 be in control of what treatments you need to do, you are in control of your choices, goals, behaviours and actions in terms of your adherence, or managing daily care, and how you *Live Well* with CF.

### **2. Identify what your adherence is like now**

It is important to understand what your adherence is like now if you want to see what changes you can make to *Live Well*. Ask yourself: *Do you understand what treatments you need to do, and why? How much treatment are you managing now? What is helping you? What are your needs? What do you want to change?*

### **3. Make a plan**

If you feel you want to improve your adherence, or managing daily care, it is time to make a plan! To do this, identify specific and clear goals for your treatments, care and adherence so you have something to work towards. Identify your motivations to improve adherence (this helps you to keep going when things get tough). Finally, identify strategies that can help you to improve adherence. 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 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.

#### *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 Maximise Adherence*

- **Give yourself a break.** Managing CF treatment is hard. It is ok not to be perfect, you just need to do your best and know that you are worth it!
- **Know your treatment plan.** Ask your healthcare team for a written treatment plan, or write one down yourself, so you know what you need to do and when you need to do it.
- **Information is power.** There is no such thing as a stupid question. Make sure you don't have any unanswered questions about your treatment or adherence so you know what you are doing and why.
- **Use your strengths and strategies you have worked for you before.** Think about previous times that you have overcome challenges to successfully manage treatment so you believe that you can do it!
- **Create routine.** Do treatment at the same time each day so you don't have to think about it, and it becomes a part of everyday life.
- **Make it less hard.** It is almost impossible to make treatment fun, but you can do something that you enjoy while you are doing treatment to make it less hard (e.g. watch your favourite show or connect with friends).
- **Monitor the challenges.** Record any challenges that stop you from doing treatment (e.g. not understanding what you need to do, lack of time, not feeling well, managing other commitments, etc) so you can work out how to address these.
- **Monitor the wins.** Record the treatment you do every day and goals you achieve to keep you motivated. Every treatment you do is a win.
- **Celebrate.** Reward yourself regularly for the treatments you do (for example, say yes to that pair of shoes or game you've wanted for ages) and celebrate with others too. Why not throw yourself an adherence party?!
- **Use your support network.** No one is an island – you are surrounded by people who are there to help. Family and friends can play a huge role in reminding you about treatment, supporting you and helping to identify and address challenges you encounter – and by celebrating with you too!
- **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, including your adherence and how you manage daily care. Have regular conversations with them about your health, treatment, care, and any questions you have, as well as your needs, goals and priorities. This way they can provide any information and support to help you to manage your treatment, care and life in the way that works for you best.

### *Hints and Tips*

*See the LWWCF Insights resource on [Defining Living Well with CF](#) for more strategies about Living Well with CF in general.*

### **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.

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

1. Faint, N. R., Staton, J. M., Stick, S. M., Foster, J. M., & 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.
2. Gardner, A. J., Gray, A. L., Self, S., & Wagener, J. S. (2017). Strengthening care teams to improve adherence in cystic fibrosis: A qualitative practice assessment and quality improvement initiative. *Patient Prefer Adherence*, 11, 761-767. <https://doi.org/10.2147/ppa.S130439>.
3. Holland, L. R., Hilton, J., Cookson, K., Heinsch, M., Gilligan, & Wark, P. (2022). Understanding motivation for Australian adolescents and young adults with cystic fibrosis: modifyable factors to support self-management. *Health and Social Care in the Community*, e2712-e2723.
4. Nicolais, C. J., Bernstein, R., Saez-Flores, E., McLean, K. A., Riekert, K. A., & Quittner, A. L. (2019). Identifying factors that facilitate treatment adherence in cystic fibrosis: qualitative analyses of interviews with parents and adolescents. *Journal of clinical psychology in medical settings*, 26, 530-540.