UWWCF INSIGHTS

Identity: Who am I?

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 Identity.

Identity – what does it mean?

One thing that is key to living well with CF is identity. Identity (also known as self-identity or sense of self) is all about how you view yourself – what makes you, you? This includes characteristics, roles, strengths, weaknesses, likes, dislikes, behaviours, moral code, values, beliefs and what motivates you, in all areas of life. Identity includes self-esteem (how much you value yourself), social identities (e.g., your role as a father, big sister, soccer coach, manager) and self-efficacy (belief in your abilities). The unique genes you are born with, your personality, social and environmental factors (e.g., relationships, experiences, social circumstances, upbringing, health) all shape your sense of identity. Our identity can change throughout life depending on what happens. CF is part of your identity, but it is by no means the most important part. Everyone's experience of CF is unique and how they view CF in terms of their overall identity is individual.



Having CF in your life can have a positive impact on your identity. You may feel part of the CF community or feel that CF has helped you focus on what is important to you. CF can, however, create some identity challenges. Weaving CF into your identity in a positive way that does not allow it to dominant can be hard, especially when daily life requires CF treatment. CF treatment and medications are also changing and developing all the time and this too can create identity issues, as you may find yourself needing to rethink your life goals or how CF fits into your identity. The good news is there are SO many ways to foster and improve identity.

"I believe in social justice, advocacy, and giving people a voice who wouldn't have a voice. I believe in that. I think CF has helped shape that."

– Adult with CF

How do I foster a positive identity?

The following steps aim to support you in creating a positive identity. 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

When it comes to developing a positive sense of identity, you are in control. Your identity is about how YOU feel and not about other people's perception of you – so you get to determine it!

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

Most of us have busy lives and don't spend time intentionally thinking about our identity. The first step to improving identity is connecting with yourself, so take some time to self-reflect. Make a list or diagram of all the different parts of your life and components to your identity, then ask yourself: *How much do I value myself? How much do I believe in myself? How positively do I view who I am as a person?*

3. Make a plan

If you feel you need to make some changes to improve your sense of identity, it is time to make a plan! To do this, identify specific goals so you have something clear to work towards (e.g., speak up more at work if I have an opinion). Identify your motivations to improve your sense of identity (e.g., to make more friends) as this will help you persevere when things get tough. Then it's time to identify strategies. These may be things you have used before or new strategies. To help you get started see some of the suggestions below.

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 improving your sense of identity is a gradual process and it can take many months before you start to notice changes. 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 - don't give up!

"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 Foster Positive Identity

- **Talk to the people that love you.** If you are struggling to recognise all the great things about yourself, ask the people you're closest to, Get them to tell you the top 3 things they love about you and offer to do the same in return.
- **Connect.** Spend time and have fun with people that truly know and love you. This can remind you why you matter.
- Have fun getting to know yourself! We rarely take time to get to know ourselves like we would a friend. Be your own best friend and explore what you like, don't like and enjoy getting to know yourself better.
- **Try new things.** Consider exploring new things to get to know yourself better. This could involve exercise, cooking, joining a group or volunteering. Experiment and see what things you like best.
- **Own and talk about all parts of you.** Having a positive sense of self is not about seeing yourself as perfect, but accepting that having tendencies, weaknesses, challenges and quirks are all part of being human. It's important that you feel comfortable to truly be yourself around the people who love you, so talk to them about the many aspects of your identity to help them understand what makes you, you.
- Look after your mental health. If you are struggling with anxiety, low mood and negative selftalk (that annoying voice in your head that says you are not good enough), it is very difficult to have a strong and positive sense of identity. Sometimes we have very deep rooted and negative beliefs about ourselves that have been with us for a long time. These can be hard to shift and we may need support from a mental health professional to do so. If you need help, please ask for it.
- **Talk to a professional.** Even if you are not struggling with poor mental health, talking to a mental health professional can be a great way for you to explore and improve your sense of identity.
- 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 your identity, reach out so they can provide any information and support you need to *live well*.

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:

Bandura A. (2006). Toward a psychology of human agency. *Perspectives on Psychological Science*, 1(2), 164-80.
Baumeister RF (ed.). (1999). *The self in social psychology*. Psychology Press; 1999.
Borschuk AP, Everhart RS, Eakin MN, Rand-Giovannetti D, Borrelli B, Riekert KA. (2016). Disease disclosure in individuals with cystic fibrosis: Association with psychosocial and health outcomes. *Journal of Cystic Fibrosis*, 15(5), 696-702.
Havermans T, Duff AJ. (2020) Changing landscape: psychological care in the era of cystic fibrosis transmembrane conductance regulator modulators. *Current Opinion in Pulmonary Medicine*, 26(6), 696-701.
Knudsen KB, Pressler T, Mortensen LH, Jarden M, Boisen KA, Skov M, Quittner AL, Katzenstein TL. (2017). Coach to cope: Feasibility of a life coaching program for young adults with cystic fibrosis. *Patient Preference and Adherence*, 1(11), 1613.
Russell JK, Strodl E, Kavanagh DJ. (2021). Correlates of distress in young people with cystic fibrosis: The role of self-efficacy and metacognitive beliefs. *Psychology & Health*, 36(12), 1497-1513.

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