Chronically FATIGUED

An insight into living with Chronic Fatigue Syndrome (CFS) + self-management resources

BY SIMONE CONLY

“*Discover what ignites your passion. Let it light you up. Then find a way to share that spark with others*

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ABOUT ME

About Me

Hi! I'm Simone.

I am an Accredited Exercise Physiologist (AEP) and Exercise Scientist with a passion for spreading awareness and helping those suffering from Chronic Fatigue Syndrome (CFS).

When I was 14 and in year 8 at high school, I came across an exercise physiology brochure and instantly knew what I wanted to become. I spent the remaining years of high school studying hard with a goal of one day studying exercise physiology, becoming an exercise physiologist and opening my own business.

At the same time, I was a keen soccer player. I played representative soccer multiple days of the week and had plans on moving to the USA to play collegiate soccer after high school. Unfortunately at the time, this pathway meant that becoming an exercise physiologist would be a much longer process and as I wanted to be an AEP rather than a professional soccer player, I decided to shift my focus and set my goal on completing exercise physiology at the University of New South Wales (UNSW). At this stage, I was 17 and in year 11.

As luck would have it, a few months later, after months of feeling exhausted, an inability to properly concentrate and unexplainable body aches and pains, I was diagnosed with Chronic Fatigue Syndrome (CFS).

For me this was just a diagnosis on a piece of paper that explained my unexplainable symptoms. I made no changes to my day-day and continued playing representative soccer and studying hard for the Higher School Certificate (HSC) to ensure I got into UNSW.

2012 for me was a blur. My symptoms were evident. I was very unwell and was experiencing a continuous boom-bust phase. Naively, I assumed this would pass as soon as the HSC finished, so I kept pushing through. I finished high school with the marks I was after and successfully made it into the exercise physiology degree at UNSW.

I began my dream degree at university in 2013. It was everything I had worked so hard for. I was studying hard and enjoyed learning, though I was still neglecting my numerous CFS symptoms. Right before the first semester finished, my health took an extreme turn and I was diagnosed with an autoimmune condition called alopecia. With this condition, your body basically decides to kill off all of your hair follicles. For me, it started as a small sized 20c piece bald patch on the top of my head and constant clumps of hair falling out. I then spent the last week of my first semester holding back tears, with handfuls of my hair, and unclogging my shower wondering what on earth was happening. One week later and I was completely bald.

You know its extreme when every medical specialist exclaims "wow I have never seen alopecia progress this quickly before". (Usually complete baldness happens over a much longer duration - not 1 week!). Now, if you're reading this with CFS stressing about also getting alopecia.... Rest assured it is not linked! Unmanaged CFS will not mean you develop alopecia. For me, it was an unlucky situation.

To cut a VERY long story short, at 18, I was severely unwell, bald, boom-busting like crazy and had to take leave from university to get my health on track. Less than 12 months later, after months of seeing numerous specialists to help with my CFS and alopecia, I bought a wig and headed back to uni.

What this experience taught me, was that I was taking my health for granted. I neglected my CFS symptoms and had pushed my body through so much that unfortunately triggered other health conditions. So at 19, with my wig intact, I made it my mission to get through my studies so that I could one day help others to manage their numerous medical conditions or even prevent the onset of others.

During my time at university, my hair began growing back and I learnt to manage my CFS symptoms. I taught myself pacing strategies and practiced by trial and error. In hindsight, this was not the best strategy, though at the time, there were not many services or information around on how to manage CFS.

6 years later and I graduated from university with a Bachelor of Exercise Physiology in 2019. I then spent the next three years working at UNSW Fatigue Clinic working with hundreds of patients who suffered from fatigue states (CFS, post-cancer fatigue, post-viral fatigue etc). To supplement this, I began exercise physiology services out of headspace at the Brain and Mind Centre at Sydney University and worked with young clients suffering from chronic mental health illnesses such as depression, anxiety, bipolar, PTSD, eating disorders and substance abuse disorders.

Fast track to now, 5 years later. I now own a successful exercise physiology business where I help others daily to manage their chronic illnesses, disabilities and injuries. What started as a dream in 2008, is now my reality and every experience along the way has made me into the clinician I am today. I am incredibly passionate about using exercise as medicine and helping others to better understand what it is that they are going through. Whilst my business sees clients with a range of conditions, my passion is helping those with CFS.

My goal is to provide the service I wish I had when I was 18.

> *"It is the commitment to the process that will determine your progress"*

WHAT I HAVE LEARNT

Everyone's journey starts somewhere. My fatigue journey started when I was 17 and has stuck around for the last 14 years. It has been a constant journey of ups and downs, managing then increasing, crashing then recovering, and learning plenty about my symptoms in the process.

Some people have CFS and recover, others may be left with symptoms for a longer period. Some people have greater functional capacity and can do more in their day, some people are left bedbound for long periods. Everyone's journey is different. So rather than diving into all the intricate details of my journey and to avoid any comparison, here are some things I have learnt over 14 years of managing CFS:

Things I have learnt over the years:

1. CFS management requires constant fine-tuning.

No matter how great I think my CFS management is, it always needs fine-tuning. Circumstances and routines change and this needs to be constantly factored into the management strategies. Something that may have worked previously, may no longer work. Specific thresholds may have changed because something else was added into a routine and this may require a huge structure shift.

2. Having CFS is a consistent journey of ups and downs

I have a relapsing remitting form of CFS and constantly follow a cycle of manage --> crash --> recover --> repeat. I have come to terms knowing crashes for me are somewhat inevitable. I can reduce their likelihood and minimise their intensity via specific pacing and management strategies, but given my current life circumstances, they are hard to completely eliminate.

3. Getting back on track is important

Learning how to pick myself up after large crashes has become a talent in itself. I have learnt patience and to be persistent with whatever I want to accomplish.

4. To roll with the punches

Things get bad, but they come good again eventually. On those days when I am unable to move in bed, knowing the moment always passes makes the crash itself slightly more manageable.

5. It is ok to feel frustrated sometimes

I used to ignore any feelings of frustration and would constantly try to be positive even when things got really tough. CFS can be incredibly frustrating sometimes. On days when the "fatigue hits" and when my aches and pains are through the roof, it's hard to feel 100%. It's frustrating to have to cancel things last minute or miss out altogether. It's frustrating to feel limited by sticking to thresholds and still have symptoms flare-up. BUT feeling frustrated is ok occasionally.

6. I appreciate everything that I am able to do both mentally and physically.

I have a new appreciation for activities I once did with ease.

7. Never judge a book by its cover

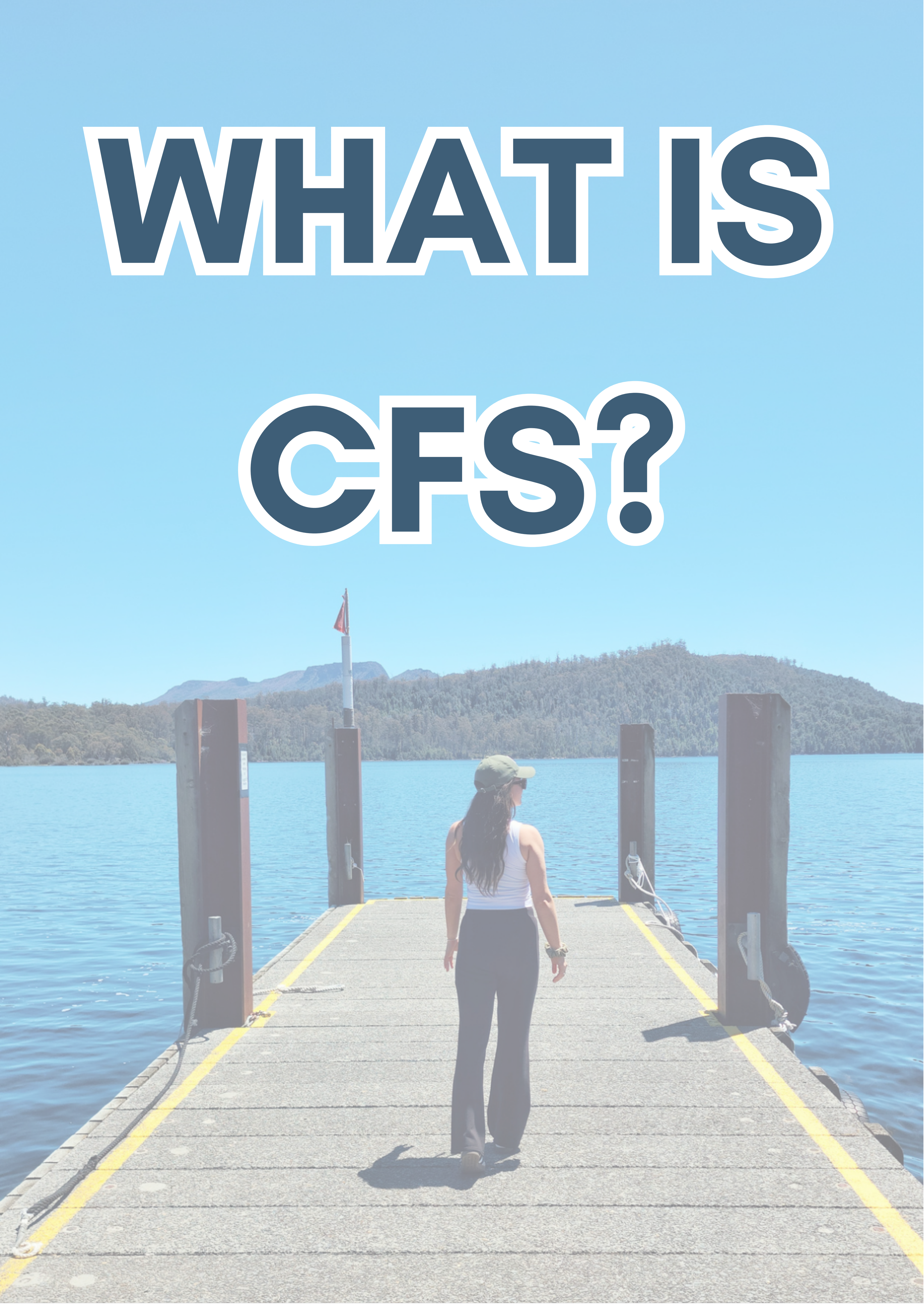
You can't always tell what someone is going through purely via observation or with what they choose to share publicly. You never know what the person next to you is going through.

8. Mindset is key

Instead of focussing on what you CAN'T do, focus on what you CAN do, whatever that may be. It is important to acknowledge your progress and being proud of any wins, no matter how small.

Don't compare your chapter 1 to someone else's chapter 20

WHAT IS CFS?



What is CFS?

Chronic Fatigue Syndrome (CFS) is a complex medical condition that has no known cure. Symptoms can vary on a day to day basis and can range from manageable to debilitating. A diagnosis of CFS is given when all other medically explained reasons for fatigue have been dismissed and when this fatigue has lasted longer than 6 months.

Symptoms Include:

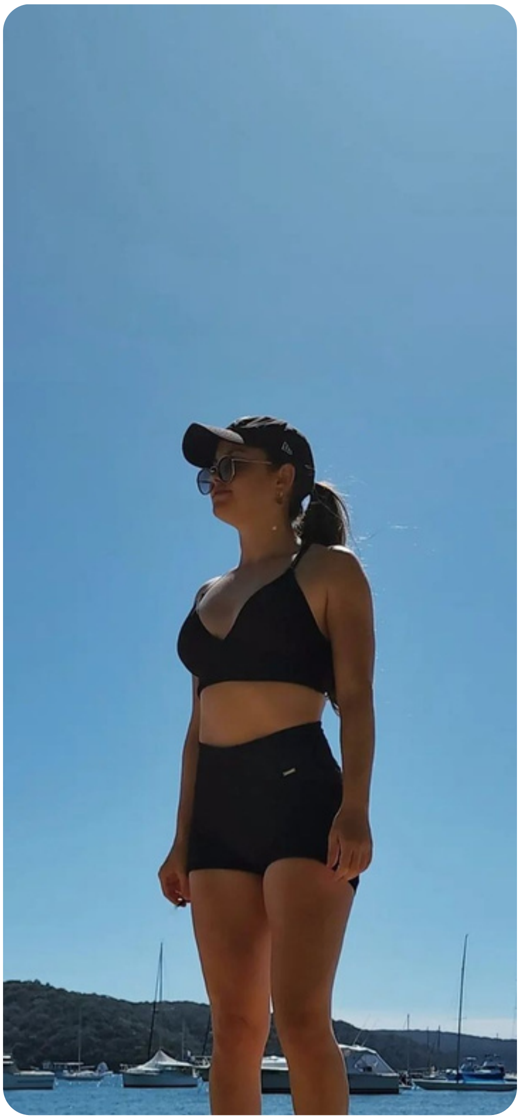
- Extreme exhaustion
- Widespread musculoskeletal pain
- Post-exertional malaise
- Difficulties with memory and concentration
- Brain fog/cognitive difficulties
- "Flu-like" symptoms i.e. sore throat, headache, dizziness etc.

With CFS, fatigue will worsen with physical or cognitive activity, but is not "cured" by rest.

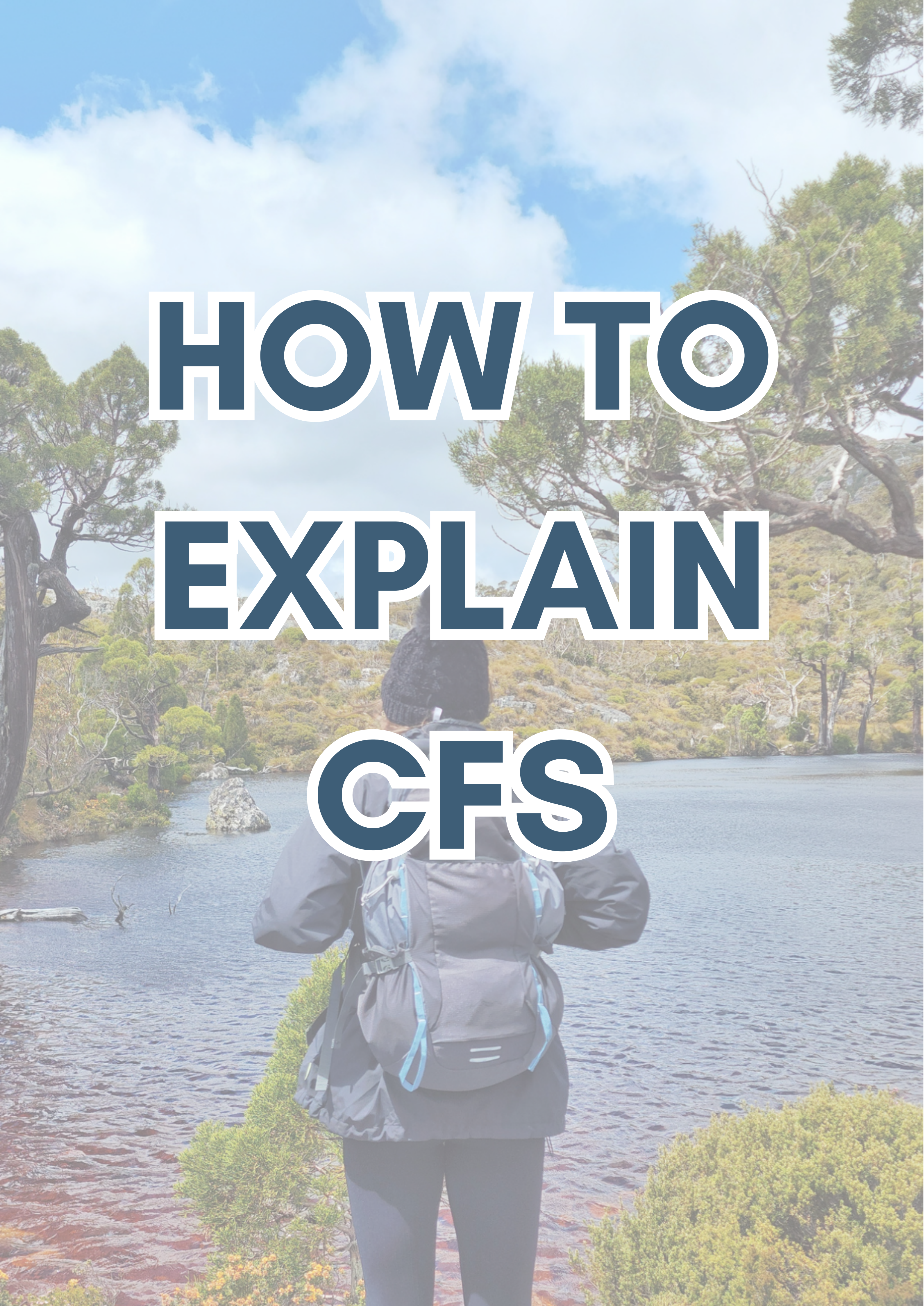
Important to note:

- CFS is often referred to as an "invisible illness" as those suffering may look healthy on the outside whilst suffering numerous aspects of the illness.

- CFS does not look the same for everyone. Functional capacity may vary. Those with CFS may range from bed- or house-bound, to working full-time and completing structured physical activity. No two patients with CFS experience the condition the same!



Fatigue ≠ Tiredness



HOW TO EXPLAIN CFS

How to

Explain CFS to those around you

Explaining and engaging in conversations with those around you on what it is you are going through is one of the most important first steps. Unfortunately it is much easier said than done and as CFS is very misunderstood, this may be one of the most challenging aspects. Patience here is key!

Start here:

"Chronic Fatigue Syndrome is a chronic illness that I have suffered with for ____. It is very difficult to explain, but CFS has no known cause or cure. I think my CFS may have started ____. The name is a bit misleading, because CFS does not just mean extreme tiredness. Whilst this is one of the symptoms, some of my other symptoms include ____. My symptoms can vary in intensity on a daily or weekly basis and can sometimes leave me ____. The treatment for CFS involves self-managing symptoms and I am currently in the process of understanding my patterns more so that I can minimise how often my symptoms flareup. It is a difficult process but the more we can both understand about what CFS is, the more this will be helpful for my management.

Let's Break this down:

1. Discuss how CFS affects you.

Everyone experiences CFS differently and symptoms vary in intensity and differ from person to person. Start with discussing your symptoms and your overall level of functional capacity.

- What are your symptoms daily?
- What are your symptoms when you experience a crash?
- What do your crashes look like?
- How often do you have crashes?
- How does CFS affect you daily?

2. Discuss your management strategies

- If you have strategies, what are they?
- How do you manage on a daily basis to ensure your fatigue stays within your threshold limits?
- How do you pace your activities?
- How do you plan your schedule to minimise crash risk?
- You may have your individual strategies sorted, but do you need assistance from others? If so, what do you need help with?

Communication is key with CFS and if you have people around you willing to support your CFS journey, discussing what you are going through, where you have been and what has worked for you, is going to be the best place to start in educating others about your condition.

You never know what someone is going through. Be kind always.

HOW TO EXPLAIN A CRASH

How To

Explain A Crash

The hard thing about an invisible illness is exactly that. The fact it is invisible. You can see a broken bone and you can see an injured knee. You can't see CFS.

You may be able to see or tell certain symptoms like extreme exhaustion, but you can't see the illness.

With CFS, a baseline level of fatigue is almost always present daily. A crash is determined when these symptoms are elevated.

Crashes may:

- Vary in intensity
- Be sometimes hard to predict
- Change in frequency and duration
- Be hard to manage because of the multiple variables causing them

Crashes **signify an increase in fatigue symptoms**. These vary from person to person. Everyone experiences CFS differently and everyone has different thresholds for activities. This means that whilst someone may have a higher threshold of activity than another, doesn't mean that the crash symptoms from exceeding a threshold are any less severe. Thresholds for activities can change overtime depending on multiple fatiguing variables.

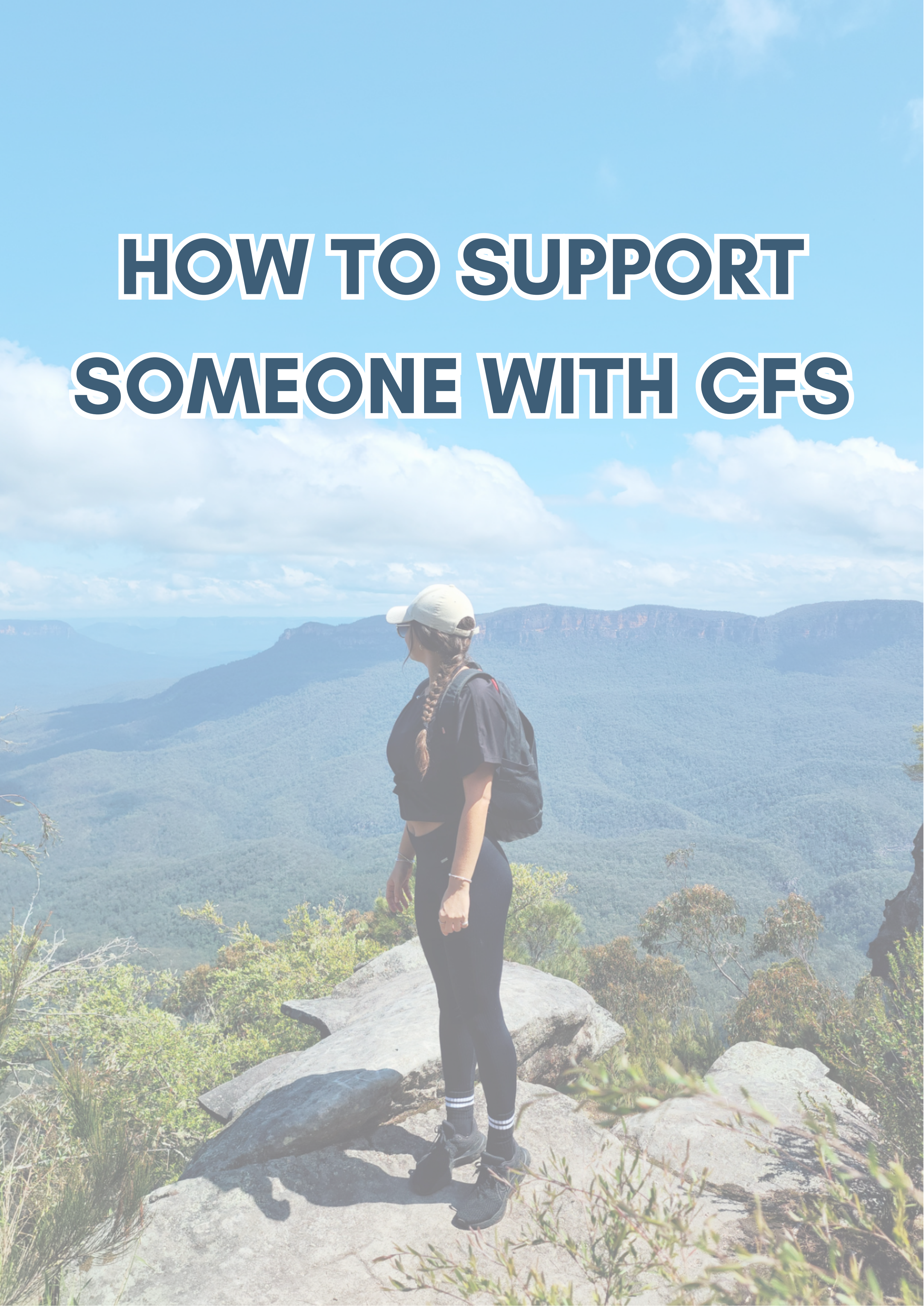
Management is not always a linear or stable process. Crashes are normal and may look like:

- Hitting a wall in the afternoon and needing to have a large nap for 2+hrs
- Having elevated symptoms and struggling to get through the day
- Having to adjust plans or change routine to cope with increased symptoms
- Needing to stay in bed for long periods (indicates a big crash - should be less frequent with better CFS management)

The best way to explain a crash, is to explain what a crash looks like for you, your crash management strategies and communicate anything you might need support with during these periods.

Remember to take a step back and to acknowledge your progress; to focus less on the distance you still have to go and more on the distance you've come.

HOW TO SUPPORT SOMEONE WITH CFS



How To

Support Someone with CFS

The best way to support someone through CFS or with their fatigue journey is to educate yourself as much as possible on what CFS is. The more you can understand about what the condition is and what the condition is NOT will be helpful when discussing some of the more challenging aspects of CFS. Read information from multiple sources, chat to the person suffering from CFS and ask them if they can explain what CFS means to them etc. The more you can learn and understand, the better.

If you are unsure how you can support, just ask! Having open conversations is an excellent step in knowing what you can do to assist. Common topics of discussing:

1. **How to provide assistance when suffering from a crash**
2. **Understanding last minute cancellations or plan changes**
3. **Discussing thresholds/pacing and any help they may need from your end on sticking to these etc.**

Try to avoid:

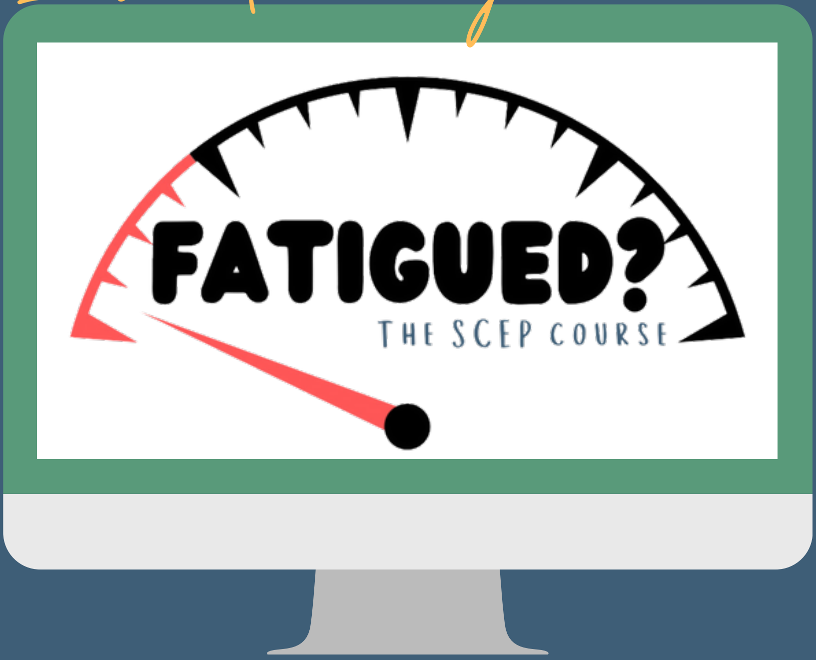
- Saying " I feel tired too" - fatigue does not equal tiredness. Whilst saying this may come from the best place, understanding that "feeling tired" is only one very minor aspect of CFS. Thinking fatigue = tiredness, leads to general misunderstanding of the condition and downplays the intensity of fatigue struggles

CFS is an invisible illness. Whilst some symptoms may be visible i.e. extreme exhaustion, others may be less obvious i.e. widespread body aches and pains. Just because something is not visible, doesn't mean it is non-existent. Understanding is key.

Instead of focusing on what you CAN'T do, focus on what you CAN do

Do you need help managing your fatigue symptoms?

Introducing...



SCEP's new course has all of the tools necessary to learn about fatigue management via self-paced learning.

Take control of your fatigue.

Coming soon!