



Employer guide for an employee with ME/CFS and/or Long COVID returning to work

As an employer, it is important to understand and recognise that returning to work will be important for the person living with ME/CFS and/or Long COVID, on their pathway to a better quality of life.

When an employee with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and/or Long COVID is employed or returns to work, it is normal for an employer to have some questions about how the employee can fulfil their role in the company, and how they can be supported to achieve the most out of their day.

Emerge Australia understands that this can be a challenging time. We have designed this fact sheet to help employers and employees to work together to create a work environment that is supportive for the employee, while ensuring that the employer still achieves the desired results required for their position in the company.

This fact sheet provides general information and employers will need to rely on their own policies and processes when supporting people with disabilities, employees returning to work, the advice provided by the employee and (sometimes) their health practitioner about their specific circumstances. Emerge Australia also provides advice to employers through our patient support line, see below.

What is ME/CFS and its connection to Long COVID?

ME/CFS is a serious, complex and debilitating biomedical disease that affects many systems in the body. These include, but are not limited to, the brain, muscles, digestive, immune and cardiac systems. ME is classified as a neurological disorder by the World Health Organization.

While the cause is not yet known, researchers have found evidence of problems with energy production, immune response, the nervous system and gastrointestinal system, as well as many other areas in the body.

While COVID-19 is a new illness, recent research has reported that at least 45% of Long COVID patients with ongoing symptoms, will meet the diagnostic criteria for ME/CFS six months after contracting COVID-19.

People with ME/CFS and/or Long COVID experience post-exertional malaise (PEM) This is the body's inability to recover after using even small amounts of energy, leading to a flare up in symptoms and reduced functional capacity.

A lack of understanding and awareness about ME/CFS and Long COVID means people can experience disbelief, and even discrimination, from friends, family, health and social care professionals, and employers. It also means some people can experience distressing symptoms for years before it is diagnosed, and this is usually difficult in an employment context. Employers can play a significant role in supporting their employees to live their best life and can empower people with ME/CFS and/or Long COVID to participate in a meaningful way.

Severity of ME/CFS and/or Long COVID

Each person with ME/CFS and/or Long COVID will have their own set of symptoms, and the severity of the condition can vary from person to person. Some people will be able to carry on normal activity and experience minor symptoms of disease, some will be in bed more than 50% of the time and some will be totally bedfast.

A person may begin with one level of disability, then move to another. For some people, symptoms can worsen significantly, with no known cause. Others can recover to a level that is less severe. Some have a 'fluctuating disease,' where they have better and worse times. It is unclear why this occurs, and it makes managing the condition difficult in an employment context.

Understanding your employee

The most important part of understanding your employee is understanding that **they want** to return to work. Each person living with ME/CFS and/or Long COVID is different and has their own pathway in managing themselves for a better quality of life. As an employer, it is important to understand and recognise that returning to work will be important for the person living with ME/CFS and/or Long COVID, on their pathway to a better quality of life.

Many people with ME/CFS and/or Long COVID experience a lack of understanding from others, including biased views based on stigma or discrimination. Acceptance and understanding are the keys to successful employment of persons who live with ME/CFS and/or Long COVID. For your employee to be most productive in your organisation, it has been found that communicating in an open and direct manner about the workplace will help create a supportive organisational culture.

Staff and colleagues understanding your employee

Some people living with ME/CFS and/or Long COVID can return to work with the right support in place. At times, with the agreement of the employee, it may be beneficial for other staff and colleagues to understand what reasonable adjustments have been put in place, and how they can support their colleague on return. Some changes may include, but are not limited to;

- changes to their working environment
- their workload
- flexible hours and time keeping
- regular review meetings.

Have the 'returning to work' conversation

Before your employee returns to work, it has been found useful to have a conversation with them. This will help you understand what you should expect when they return and helps the employee to understand what you expect too.

No one knows your employee's needs better than them, so it is helpful to develop a work plan collaboratively before they return. You may want to discuss the symptoms your employee is experiencing, and what reasonable adjustments you can make in the workplace to assist them.

Discussing symptoms

Not every person who lives with ME/CFS and/or Long COVID experiences the same symptoms, so it is best to discuss them with your employee to get an understanding of what they live with.

Some symptoms may include:

- post-exertional malaise (PEM)
- widespread pain and headaches
- cognitive difficulties
- balance problems and dizziness

- difficulties regulating body temperature and weight
- orthostatic intolerance (difficulty being upright)
- gastrointestinal problems
- sensitivities to food, medications, odours or certain chemicals
- recurrent flu-like symptoms

Discussing reasonable adjustments

As an employer, you want to find a way for your employee to be both productive and efficient. One effective way of achieving this is to make any reasonable adjustments that suit both your organisation and your employee living with ME/CFS and/or Long COVID.

When having a conversation about adjustments, understand that you can review these at any time and amend them if required. An adjustment shouldn't be made if it is not reasonably possible, will cause disruption to your operations, or if excessive costs are involved.

If agreed adjustments involve a change to your employee's contract, such as full-time to part time, ensure the employee is aware of what this means financially and for ongoing job security, including whether the agreed change is temporary or permanent. Allow plenty of time for the employee to seek independent advice before changing their contract to ensure that these changes are of mutual benefit.

Some adjustments to consider include:

- flexible hours – to suit when the employee is most productive during their day. Starting your employee on reduced agreed hours that suit you both may eliminate some stress that can occur with expectations of long days or full working week.
- agreeing to a change of their role in the organisation,
- work duties – deciding how and where they are carried out with working from home options added into the week where possible, to reduce energy required for travel
- how colleagues work with the employee
- aspects of the workplace environment, such as allowing the employee to wear earplugs, earbuds or headphones to reduce ambient noise
- providing extra support or equipment to enable the employee to carry out their job
- offer parking that is close the office (if possible) or an office space that is close to the tearoom or restroom

Remember, these adjustments are designed to help the employee to be as productive as possible. If they are not achieving the desired outcome, the employer should conduct a review.

When this employee is looking to return to work, the positive is that you are already familiar with this person. You understand what they can offer your organisation, as they have worked for you previously. The only difference is that their energy might not be the same as before and hours may be limited.

Advertising and trying to employ new people can be expensive and time consuming, so having a familiar person rejoin your company can be a great solution, which can also help improve organisational culture and team morale.

Managing Performance

In common with other disabilities, it is a mistake to ignore performance issues that the staff member may need to correct. It is also not usually helpful to “take work away” from staff members, as opposed to having a reasonable adjustment plan in place.

Staff members with ME/CFS and/or Long COVID, like all employees, need to know where they stand with respect to performance matters so that they can develop and improve their performance in line with expectations, as adjusted for their condition. "Taking work away" to make the job "easier" is different from reasonable adjustment, and over time jobs can shrink away as duties are removed to eventually become jobs that are less and less useful to both the organisation and to the staff member.

In line with normal performance management processes, that are normally set down in employment policies or agreements, employers should be clear about expectations and actual performance within the context of the agreed reasonable adjustments.

It is to be expected that both the reasonable adjustment and the performance expectations will change over time, including to take account of the employer's needs and the needs and circumstances of the staff member with ME/CFS and/or Long COVID.

Resources for employers

While Emerge Australia primarily provides support and education for people living with ME/CFS and/or Long COVID, it is also a support network for employers. We understand that having someone return to work who lives with ME/CFS and/or Long COVID might be challenging. This is why we offer free services for employers to use, which will help their employees with ME/CFS and/or Long COVID to successfully return to work.

Emerge Australia's ME/CFS and Long COVID Support Line

This service is available during business hours from Monday to Friday and can provide information about ME/CFS and Long COVID. It also provides advice to employers who employ a person living with ME/CFS and/or Long COVID.

To contact Emerge Australia's Information Line, please call 1800 865 321 or email information@emerge.org.au

Useful links

Employees with a disability: <https://www.fairwork.gov.au/find-help-for/employees-with-disability>

Discrimination: <https://www.fairwork.gov.au/employment-conditions/protections-at-work/protection-from-discrimination-at-work> and <https://www.fairwork.gov.au/tools-and-resources/fact-sheets/rights-and-obligations/workplace-discrimination>

Adverse action: <https://www.fairwork.gov.au/employment-conditions/protections-at-work#adverse-action>

Employer templates for managing performance: <https://www.fairwork.gov.au/employment-conditions/performance-in-the-workplace#templates-to-help-manage-performance>



**www.emerge.org.au
1800 865 321**

Patient Support and Information Service

Speak with our friendly team during business hours, Monday to Friday. Our team can provide you with information on ME/CFS and Long COVID and support you in navigating general health and community services. We can also answer common queries related to the programs and services provided by Emerge Australia.

Visit emerge.org.au or call 1800 865 321