



# Caring for people with ME/CFS who are bedbound

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*Emerge Australia has put together this guide to help you care for a loved one who is severely impacted by ME/CFS and has become bedbound*

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People who are bedbound by ME/CFS live each day with limited energy and require a significant level of care to meet their basic daily needs.

Approximately 25% of people with ME/CFS are so severely impacted that they are housebound or bedbound. Every person with ME/CFS is different and understanding their limitations is critical.

## **People who are mostly or entirely bedbound by ME/CFS may need support with:**

- **activities of daily living**, such as food preparation and eating, showering or dressing
- **tasks that require cognitive energy** such as phone calls, emails, appointment or paying bills
- **mobilisation and use of mobility aids**, such as wheelchairs if they able to sit or transfer.

They may have limited capacity to sit upright. Even if they can move from the bed to the couch, they will still need to lie down after a brief period.

ME/CFS leaves some people so unwell that they are not able to manage any activities of daily living without help. They are often extremely sensitive to light, sound and touch, and need total care. They may not be able to speak or may only be able to speak in short bursts.

Caring for a person who is bedbound by ME/CFS can be complex. They can remain extremely unwell for many years, and some may not see any improvement. Losing this level of independence is physically and emotionally difficult, so it is important to give the person as much control over their care decisions as possible.

While there is no cure or effective treatment for ME/CFS, compassionate and high-quality care is crucial. It can help the person living with ME/CFS to manage their condition to the best of their capacity. It may also help reduce their overall symptom severity, prevent the condition getting worse and improve their quality of life.

## ***Lynne's Story - carer of an adult son who lives with very severe ME/CFS***

*"All care for my son needs to be administered in a very low-light room, silently and making sure that all personal care products, cleaning products are fragrance free.*

*He is unable to communicate and suffers from extreme noise, light and smell sensitivities. He can't tolerate being spoken to and wears an eye mask and ear plugs 24 hours a day. He needs help to lift the drink bottle to his lips, feeding, toileting, hygiene....and the list goes on.*

*Any disruption in his care will cause consequences that impact his health, not just at that immediate time, but can cause a crash that when he does 'recover', his baseline health is lower than before."*

## Symptoms of severe and very severe ME/CFS

***People who are bedbound with severe or very severe ME/CFS live with a broad range of symptoms and disabilities including:***

- profound weakness
- difficulty speaking or swallowing
- severe and often almost constant widespread pain and severe headaches
- sensitivity to stimulation of the senses (such as light, sound, touch and smells), which can trigger pain and other symptoms
- an extreme intolerance to any physical, mental or emotional activities (such as sitting, bathing, toileting, eating and speaking), which can trigger post-exertional malaise (PEM) and increased weakness
- severe cognitive impairment, which can limit their ability to communicate and understand written information
- severe gastrointestinal disturbances (such as nausea, abdominal pain, food intolerances, problems with swallowing and slow gastric transit), which can all contribute to poor nutrition
- orthostatic intolerance that can be serious enough to prevent them being able to be upright (even sitting partially upright in bed can be a problem)
- problems with sleep (such as unrefreshing sleep, shifted sleep cycles and broken sleep)
- complications from being homebound or bedbound (such as osteoporosis, constipation, pressure ulcers, aspiration pneumonia, depression and a loss of condition).

## Working with healthcare professionals

As the carer of a person who is bedbound with severe or very severe ME/CFS, you will have a very good understanding of their needs. However, finding the best ways of communicating together will make sure the person with ME/CFS is able to have as much input as possible into their care.

Not everyone who is bedbound with ME/CFS will require the same level of support to access healthcare. Some may need help booking appointments, or with arranging transport to and from appointments. Others may need more intensive support, and partial or complete advocacy during appointments with home visits or telehealth. It is important to let the person guide you in the level of support they need.

Make sure you are able to work well with their healthcare team, so the person is heard, and treated with compassion and respect.

At the bottom of this page, you will find links to help you advocate for the person and have practical information to provide to healthcare professionals.

***Some things to consider include:***

- **how well you communicate with the healthcare professionals who are looking after the person**, so they have a clear understanding of what the problems are and can provide appropriate treatment (review [Advocacy for Carers](#)).

- **being an advocate**, as this is a key role for the carer of a person who is unwell with ME/CFS. At times, people who live with ME/CFS may be referred to a healthcare professional who lacks up-to-date knowledge about ME/CFS or appropriate treatment. Some may not believe in ME/CFS, or insist the person participates in treatments that are beyond their capacity (energy limits). Having an advocate is crucial to prevent inappropriate treatment and management
- **organising healthcare professionals to visit** the person at home or setting up telehealth appointments. This could include:
  - doctors
  - occupational therapists
  - nurses
  - home care assistants
  - social workers or someone who provides emotional support
  - physical therapy for pain management, joint mobilisation or muscle relaxation. Any therapy should be symptom led, and not cause an increase in symptoms or further decline in function
- **controlling the number of appointments** with healthcare professionals, limiting the number of them on any one day, and booking them at the best time of day for the person, to protect their energy levels as much as possible
- **looking after your own needs** and being aware of your own health (physical and emotional). Community resources, respite care and local support groups can often help to support you.

## Changes to the person's condition

The health of a person who is bedbound with severe or very severe ME/CFS can change over time. Working with the person to develop a plan of their wishes is important. It is sometimes called an advanced care directive, which includes a summary of their health issues, treatment and medications.

As their carer, remember to update it regularly and when anything changes. This will be very useful whenever there is a change in the person's care circumstances (if you or someone else involved in their care becomes unwell or stops working, such as through illness or resignation), when they have a change of healthcare professional, or if they have a very severe relapse where they can no longer communicate their needs.

Emerge Australia's Telehealth Nurse Service can support you to create a summary of your health care needs and medications. This can be completed with the person who lives with ME/CFS, their carer or both of you. For more information on the Emerge Australia Telehealth Nurse Service, [click here](#).

It is a good idea to always have a bag packed with essential medication, clothes and supplies, in case of an emergency. For instance, a deterioration in the person's condition can happen quite rapidly and they might need to be admitted to hospital. You may need to visit regularly and be prepared to provide information and guidance to hospital staff (including the advanced care directive).

Being able to consent to medical treatment may be difficult if the person with ME/CFS has lost the capacity to speak or write, or if understanding and processing information is difficult. It is important that people with ME/CFS are allowed plenty of time to make a decision, and time to talk with their advocate/carer if they are able to. Healthcare professionals may need to break down information, ask yes/no questions, and give time for discussions and decisions to be made. Unless a decision is time critical (an emergency), it is okay to take time and to ask further questions.

If the person with ME/CFS loses the ability to give informed consent (due to cognitive processing issues or speech problems, for example), you may need to consider applying for enduring power of attorney. For more information [click here](#).

Make sure you understand what is required when the person is discharged home, so you can encourage them to follow the medical advice and help organise follow-up appointments.

*(For information on practical tips for supporting people with severe ME/CFS, we have created a guide which will follow on next page)*



## Recommendations to help with activities of daily living

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*Emerge Australia has put together these practical tips to assist you in supporting your loved one living with severe ME/CFS, with their daily activities*

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There are practical ways you can support the person you are caring for while performing activities of daily living with them. We have provided a list of recommendations that are set out under common daily tasks.

**The most important thing you can do while caring for a person with severe or very severe ME/CFS is to conserve their energy as much as possible.**

**Use this list as a guide only. Discuss things with the person you are caring for, to see what works best for them.**

### Tips for bathing include:

- Give them a sponge bath at their bedside or in bed to conserve energy.
- Wash different parts of their body at separate times (for example, face on one day, hair on another day).
- Use hypoallergenic soaps without fragrance.
- Use dry shampoo (be careful of chemicals and fragrance if the person you care for is sensitive) and suggest that the person considers having short hair (you need to gain consent if possible).
- Check their skin and look for any red areas or sores
- Make sure they rest immediately after washing and before dressing if needed. Wrap in blankets, a dry towel or robe, and return them to bed.
- Consider bathing them every few days (or once a week) instead of daily.
- Suggest getting the bathroom remodelled if it would improve accessibility.

For showering, use a shower chair and have grab bars installed. If using a bath, a transfer board can help when moving the person between the chair and bathtub. Use a pillow for neck support. Elevate their feet and start with a lukewarm water temperature.

### **Tips for toileting include:**

- Use a raised toilet seat and get handrails installed near the toilet. If needed, use a bedside commode to conserve energy for other activities.
- If the person is unable to transfer or be in an upright position, they may need to use adult diapers, a bedpan or a catheter. Try to plan toileting on a regular basis to help reduce urgent visits and accidents.

### **Tips for tooth brushing include:**

- Conserve the person's energy by having them brush their teeth in bed if needed.
- Use a mild-flavour toothpaste or just water.
- Use a soft-bristle brush. If an electric toothbrush is used, choose one with different levels of vibration and strength.

### **Tips for dressing include:**

- Help them to dress in bed to conserve energy, if required.
- Use fragrance-free and chemical-free laundry detergents to wash clothes. Keep an eye out for any sensitivity to clothes (such as contact dermatitis).
- Make sure they have loose-fitting clothing made of soft, lightweight, breathable material in plain colours, if patterns are too stimulating. Suggest clothes that slip on without fastenings or buttons, as these may be easier to put on and take off.
- If one side is more weak or painful for the person, put the garment on that side first, and take it off on that side last.
- Help them to dress in stages if they are not able to complete it all at once.
- Change clothes for comfort and cleanliness, rather than daily.

### **Tips for eating and drinking include:**

- If preparation of food is an issue, home delivery of meals or a supply of frozen or canned foods that require minimal preparation can be critical, particularly when the person experiences a bad day. Prepare large quantities of food when you are able and store it for future use.
- Provide foods that are highly nutritional and do not need much or any preparation, such as shakes, bars, soft or liquid foods. Referral to a nutritionist may be needed for the right dietary advice.
- Make sure the person can easily access a variety of snacks.
- Help them to eat or drink in bed, if needed, to conserve energy. Less severely ill people may prefer to eat with their family for social interaction where possible.
- Help with setting up the meal and support the person to eat if needed.
- Use lightweight bowls, plates and cutlery (such as plastic or bamboo).
- Use a non-spill water bottle or small, lightweight cup for drinking. Use a short straw as it requires less effort to suck. Be careful of re-useable straws as they require very careful cleaning. Paper disposable straws may be more appropriate.
- If the person's oral nutrition and hydration is not adequate, let their healthcare team know.
- Install a small bar fridge next to the bed for easy access to snacks.

**Tips for moving and better positioning to protect the person from pressure ulcers, contractures, skin and joint irritation, and poor alignment include:**

- Use foam wedges, bolsters and pillows for support and positioning, or consider getting a specialised, adjustable bed.
- Use a reclining chair with a footrest. Make sure the person's neck and lumbar area are well supported for proper alignment.
- Find out from the person's healthcare team about the importance of regular repositioning as tolerated, and how often it should be done.
- Where possible, use passive or active range-of-motion exercises to help avoid contractures and maintain some flexibility. This must be done in a way that does not trigger PEM.

**Tips for mobility and transfers to protect both the carer and person with ME/CFS from injury due to lifting and turning include:**

- Arrange transfer and mobility devices (such as a hoist lift or sling, slide boards, a wheelchair, cane or walker) for use as required.
- Make planned, slow and controlled changes of position, especially for people affected by orthostatic intolerance or who are hypersensitive to touch.
- Enquire about having a stairlift installed or moving the person to a more accessible room if necessary.
- Use a wheelchair to move the person between rooms if required and if it is possible.
- Ask for advice from healthcare professionals, such as the person's physiotherapist, on how to move and lift the person safely to protect both of you from injury.
- Ask about what transport options are available from private companies (such as National Patient Transport, taxis and ride-share), and public organisations (such as ambulance and non-emergency patient transport services), so you are prepared when this needs to be arranged.

**Tips for setting up the room to protect the person from unnecessary physical, cognitive or emotional exertion include:**

- Hang blackout shades and plain curtains (with no patterns).
- Keep the room temperature and humidity controlled as much as possible.
- Limit sounds from inside and outside the home when you can. Provide protection such as headphones or ear plugs to minimise sound.
- Do not use products that have a strong smell, such as cleaning supplies or perfumes.
- Arrange for assistive technology, such as call buttons, remote controls for lights, fan and TV, and smart light bulbs, and make sure the person knows how to use them.
- Set up a bedside table with adjustable height, tilt and a swivel top so the person can reach things on it easily.
- Attach hooks and other fasteners to the wall and headboard to use for baskets or containers so that supplies, snacks and tools are within the person's reach.
- Use a magnetic board or a board with symbols for common items or actions on it that the person can point to as a communication aid.
- Keep an eye on the person's balance, fall risk and hazards (such as stairs and rugs). Remove obstacles out of their way.
- Provide blankets, a fan, and other warming and cooling devices, if the person has poor temperature regulation.
- If the person can prepare their own meals, make sure the kitchen is set up for safety and energy conservation. For example, provide a stool or chair that is the correct height for the person, and put the most commonly used dishes and utensils within easy reach.

### Tips for support and socialising include:

- Support the person to socialise as much or as little as they wish, and where possible.
- Help them gain access to needed community resources.

Emerge Australia has a wealth of information that may support you when caring for a person with ME/CFS. We have put together a list of helpful webpages and resources below:

[Supporting friends and family members who live with ME/CFS by understanding the energy limits of ME/CFS and staying connected](#)

[Power of Attorney](#)

[Carers page](#)

[Carers gateway](#)

[Looking after yourself](#)

1 BMJ Best Practice. (2017). Chronic fatigue syndrome.



**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](http://emerge.org.au) or call 1800 865 321**