



Home Care Plan for Severe-Very Severe ME/CFS and long COVID

and associated conditions e.g. dysautonomia

Introduction: Holding Space for Care

Caring for someone you love who is living with severe or very severe ME/CFS can feel at once deeply instinctive and utterly overwhelming. This is not the kind of caregiving most people are prepared for. It asks more than practical tasks. It asks for patience without visible progress, presence in silence, and faith in the value of small mercies.

This guide was created for loved ones who are stepping into this role, not as professionals, but as whānau. You may be a parent, sibling, partner, or friend - someone who never imagined life would take this turn, yet here you are, showing up with courage, care, and a willingness to learn. You don't need to have all the answers. What matters most is that your loved one knows they are not alone and that their needs are understood.

The realities of this illness may be confronting - the extreme physical limitations, the isolation, the invisibility of pain. But you are not powerless. With the right knowledge, tools, and support, you can ease suffering, protect dignity, and help create a space of calm and connection - even in the stillness. This guide will equip you with essential strategies and resources to navigate the challenges of home care for severe ME/CFS.

This isn't just a care plan. It's an invitation to honour your loved one's reality with compassion and to care for yourself with the same tenderness. You are doing something incredibly important, and you deserve support every step of the way.

Understanding Your Loved One's Illness

Your loved one with severe ME/CFS may experience a wide range of challenging symptoms. Being aware of these can help you provide more effective and compassionate care:

- **Extreme Sensitivities:** They may be highly sensitive to light, sound, touch, smells, movement, temperature changes, and certain chemicals, medications, or foods.
- **Profound Weakness:** Expect severely reduced and limited movement due to extreme weakness.
- **Severe and Constant Pain:** They might experience severe and ongoing pain, including muscular, joint, and nerve pain, as well as headaches or migraines. Even light touch can sometimes cause pain.
- **Eating and Digestion Issues:** They may have a reduced ability or be unable to chew and swallow foods, alongside sensitivities to certain foods and impaired digestion.
- **Gastrointestinal Problems:** Be aware of issues like irritable bowel syndrome, nausea, constipation, bloating, incontinence, or slowed gastric motility.
- **Cognitive Difficulties:** You might observe cognitive impairment, such as difficulty processing information, communicating, brain fog, or memory issues. Some may even become non-verbal due to a lack of energy.
- **Sleep Disturbances:** They can have trouble falling or staying asleep, experience excessive sleepiness, altered sleep patterns, and sleep that isn't refreshing. Sleep apnea and delayed circadian rhythm are also possible.
- **Visual Disturbances:** Neurological visual issues, such as double vision, blurred vision, dizziness, or vertigo, may occur.
- **Autonomic Dysfunction:** They may experience symptoms of dizziness or lightheadedness upon standing, or simply when the head is turned.
- **Heart and Chest Symptoms:** They might experience palpitations, irregular or rapid heartbeats, or non-cardiac chest pain.
- **Shortness of Breath:** Difficulty breathing or a feeling of breathlessness can be present.
- **Temperature Dysregulation:** They may feel excessively hot or cold, experience sweating, and chills.
- **Persistent Fatigue:** A cardinal symptom is persistent, unexplained fatigue that is not alleviated by rest. For those with Severe ME/CFS this is profound exhaustion.

Post-Exertional Malaise (PEM):

The cardinal characteristic of ME/CFS and long COVID is Post-Exertional Malaise (PEM), also known as Post-Exertional Symptom Exacerbation (PESE) or Post-Exertional NeuroImmune Exhaustion (PENE). PEM/PESE/PENE is a debilitating response to normal, every-day activities. For loved ones with severe-very severe ME/CFS or long COVID, this can be triggered by sensory overload, such as exposure to light or even simple conversations, and can occur immediately.

Be prepared for significant day-to-day, or even hour-to-hour changes in your loved one's symptoms and abilities. What they can manage one moment might be impossible the next. For some PEM may be delayed 48-72 hours after the exertion. Repeated or rolling episodes of PEM can exacerbate these already severe symptoms, and even minimal exertion can lead to significant setbacks for your loved ones health and wellbeing.

Recognise the signs of a PEM "crash" and how to prevent it by carefully pacing all activities. Pacing is a vital strategy for carefully balancing activity and rest, helping your loved one stay within their fluctuating energy limits. Work together to recognise and learn your loved one's individual capacity for physical, mental, and sensory activity without triggering a crash.

Coexisting Conditions

The most common comorbidities associated with ME/CFS is orthostatic intolerance or other forms of dysautonomia (POTS, NMH, IST, etc).¹ Be aware that your loved one may also experience other conditions like dizziness or fainting upon standing (orthostatic intolerance), extreme sensitivities to light, sound, or touch, and various digestive issues. These can significantly impact their well-being and require careful management.

Comprehensive Resource for Severe ME/CFS and Long COVID: Best Practice Guidance and Care Plans

This comprehensive [resource list](#) provides essential guidance, best practices, and clinical tools for healthcare professionals and patients dealing with severe ME/CFS and Long COVID, covering critical topics such as home collection services, hospital admissions, nutritional management, the biomedical basis of the illness, disability definitions, and related co-conditions like POTS, MCAS, Fibromyalgia, and Hypermobility. It compiles a range of expert-backed documents, research articles, and practical toolkits to improve understanding, diagnosis, and management of these complex, debilitating conditions.

Helpful Resources:

- The [ME/CFS Crash Survival Guide](#) is designed for the patient, their support network, and care team to:
 - Understand ME/CFS and its defining characteristic of post-exertional malaise (PEM).
 - Help the individual prepare in advance for a crash/PEM episode, ensuring their critical needs are met.

¹ <https://www.medicalnewstoday.com/articles/fibromyalgia-chronic-fatigue-syndrome#diagnosis>

- Offer adaptive guidance in carrying out everyday living activities that support energy conservation with ME/CFS.
- Bateman Horne Centre resources with helpful info:
 - [Clinical Care Guide for ME/CFS, long COVID & Infection-Associated Chronic Conditions](#)
 - [Patient Resources page](#)
 - [Care Partners Resources page](#)

Set Up At Home:

Creating a Supportive Environment & Mindful Interaction

- **Setting Up a Calming Space:** Create a low-stimulation environment by ensuring the room is quiet and darkened, using blackout curtains and noise-cancelling measures, and keeping scents to a minimum.
- **Aiding Communication:** If verbal communication is challenging, utilise communication aids such as whiteboards, gesture cards, or text-to-speech applications.
- **Managing Temperature:** Maintain a consistent and comfortable temperature, as many patients with ME/CFS experience difficulties with temperature regulation.
- **Respecting Boundaries and Autonomy:** Always seek consent before touching, moving, or speaking to your loved one, even if they seem unresponsive, as they may still be aware.
- **Providing Calm Presence:** Offer calm and non-intrusive companionship. Remember that your quiet presence and silence can also be very supportive.
- **Cultural safety:** Honour the person's identity, whakapapa, and spiritual needs. This is especially important for Māori and Pasifika whānau.
- The [Complex Chronic Illness Support Care Kete](#) is designed to provide extra support for individuals with limited energy and functionality. It contains practical items such as bed bath wipes, shampoo caps, eye masks, heat and cool packs, and hydrating products. The kete, available to their members, also includes communication aids like a pen and notebook, lanyard, adapted New Zealand Crash Care Manual, and Bateman Horne communication cards.

How To Manage and Support Your Loved One's Daily Needs

Energy Conservation: Help your loved one save their energy by using tools like bedpans, shower chairs, and recumbent wheelchairs. These can significantly reduce the effort needed for daily tasks.

Medication Management: Keep medication routines as simple as possible. Be vigilant for any sensitivities or unwanted reactions to medications. Titration of medication should start slow and low.

Preventing Pressure Sores and Supporting Movement: Your loved one's profound weakness, constant pain, and severe limitations in movement make it difficult or impossible for them to reposition themselves independently. This significantly increases their risk of developing pressure sores (bed sores). You may need to help with regular repositioning to prevent these sores, especially if they are bedbound or have limited mobility. Gentle movement can also help maintain range of motion, prevent stiffness, and avoid muscle contractures. When assisting, always be careful and gentle, recognising the critical need to stay within your loved one's energy envelope to prevent worsening symptoms. Consider using pressure-relieving mattresses or underlays to further reduce risk. If tolerated, passive range-of-motion exercises and gentle stretching can also be beneficial.

Addressing Malnutrition and Feeding Challenges: Individuals with severe or very severe ME/CFS are at a significant risk of malnutrition or unintentional weight loss. Your loved one may be too weak to eat enough, or unable to chew and swallow sufficiently. In such cases, medical nutritional support, which might include gastric (NG) tube feeding or intravenous (IV) fluids, may be necessary to ensure adequate nutrition, hydration, and to avoid critical electrolyte imbalances. There can sometimes be an unnecessary delay by health professionals in starting feeding support due to a lack of recognition that these difficulties are a direct consequence of severe ME/CFS. It's vital to understand that there is no reliable evidence to justify refusing nutritional support based on speculated psychological theories.

Helpful Resources:

- [CDC Clinical Care Guide](#) offers practical strategies for severe ME/CFS patients.
- [CCI Support NZ](#) is an excellent local resource for caregivers and professionals.

Your Self-Care As a Caregiver

- **Clear routines:** Establish predictable patterns to reduce cognitive load for both you and the patient.
- **Recognise Warning Signs:** You are not a machine! Pay attention to your own physical and emotional health, noting signs of stress like headaches, sleep disturbances, digestive problems, persistent sadness, anxiety, irritability, or feelings of being overwhelmed or isolated. Early recognition is crucial to prevent these from escalating into more serious health issues, burnout or negligent care.
- **Prioritise Your Own Health:** Just as you prioritise the person you're caring for, make your own mental and physical health a priority such as sleep, healthy eating, regular medical check ups and physical activity. Access counselling for both you and the patient if possible.

- **Peer support:** Connect with other caregivers through online forums or local groups. See helpful links below to support groups and online communities.
- **Stay Informed and Utilise Educational Resources:** Actively seek out and engage with various forms of information, including educational materials, articles, videos, and newsletters from reputable sources. This continuous learning will deepen your understanding of the condition, empower you in care decisions, and provide ongoing tips and support.
- **Be Kind to Yourself:** Caregiving is demanding work. Allow yourself to feel emotions like sadness, frustration, or guilt without judgment. Practice self-compassion and give yourself credit for everything you do.

Helpful Links For Your Support and Guidance:

- [ME/CFS/Long COVID Caregiver Support Groups](#) offers crowdsourced wisdom from global caregivers, and a variety of support and resources for caregivers of individuals with ME/CFS, long COVID, and other chronic illnesses.
- [Carers Alliance NZ](#) offers practical advice, tools, and support to those in caregiver roles.
- <https://www.disabilitysupport.govt.nz/carers> for various support options for carers of disabled people, including information on connecting with support networks, accessing the Carer Support subsidy for respite, and more.

Community Support Available

Caring for someone with severe ME/CFS is a long-term commitment that can be emotionally, physically, and logistically demanding. It's important to remember that asking for help is not only okay, but often necessary. Bringing in outside support doesn't mean you're giving up; rather, it signifies that you are building a sustainable and resilient circle of care for your loved one and yourself.

You should consider additional support if you're experiencing caregiver fatigue, feeling overwhelmed, emotionally depleted, or physically unwell. It's also necessary when complex care tasks like feeding, toileting, or repositioning become too difficult to manage alone, or if you have safety concerns about falls, pressure sores, or medication errors. Finally, seek additional support if caregiving responsibilities begin to significantly impact your ability to work, parent, or maintain your own health.

NASC Assessment: Your Gateway to Support for Your Loved One

Needs Assessment and Service Coordination (NASC) is the entry point for publicly funded disability support in Aotearoa. Through a NASC assessment, you may be eligible for funded home help, including personal care, household tasks, and overnight support.

What NASC can help with:

- Assessing your loved one's care needs and eligibility for support
- Coordinating services like home help (3 hours per day), equipment, and respite.
- Supporting the family/whānau to continue caregiving safely

How to access:

- Ask your GP for a referral, or contact your local NASC directly
- You'll need to provide documentation of the diagnosis and functional limitations
- The assessment can take place at home, by phone, or online - and should include the voice of the person with ME/CFS if possible

Tips for a successful NASC process:

- Be specific about what daily tasks are difficult or impossible for your loved one.
- Emphasise the unpredictability and severity of their symptoms.

Connecting with GPs, Specialists, and Allied Health

- **GP & Specialist Coordination:** Advocate for home visits or telehealth appointments with your loved one's GP and specialists, as many patients with severe ME/CFS cannot attend clinics in person. ANZMES provides a document that advocates for home collection services for patients with severe to very severe ME/CFS, emphasising why home visits are a critical medical necessity, not merely a convenience.
- **Registered Nurse Service:** [ME/CFS Canterbury and West Coast](#) offers clinical support, symptom management, diagnosis assistance, and advocacy for individuals of all ages with or suspected of having ME/CFS or Long Covid in the Canterbury and West Coast regions. The service, delivered via home visits, Zoom, and other interactions, also provides referrals to other supportive services and a short-term loan of a wearable activity tracker to aid with pacing. Access to the service requires signing up as a member, and there is currently a waiting list.
- **Allied Health:** Allied Health are specialised healthcare professionals who offer diagnostic, technical, therapeutic, and direct health services. Professionals like occupational therapists can assist with adaptive tools to make daily living easier. Dietitians can provide crucial nutritional support, especially if there are swallowing difficulties or specific dietary needs.

Other Care Options

- **Private Carers:** Some families choose to hire carers directly. It's important to ensure they understand ME/CFS and are trained in low-stimulation, patient-led care.
- **Carer Support Subsidy:** If eligible, this reimburses some costs of hiring a support person so the primary carer can take a break. It's flexible and can be used creatively for a trusted friend or extended whānau member.
- **In-Home Respite:** A support worker comes to your loved one's home to provide care while you rest or attend to other needs.
- **Facility-Based Respite:** Rarely suitable for severe ME/CFS due to sensory overload and lack of understanding but may be an option in crisis with careful planning.
- **Peer Respite:** Some organisations (like ME Respite) are working toward ME/CFS-specific respite models that honour the unique needs of this community.

Helpful Links:

- Get a Needs Assessment: [Get a needs assessment | New Zealand Government](#)
- ANZMES Justification for Home Visits [The Critical Need for Home Collection Services for Patients with Severe - Very Severe ME - Google Docs](#)
- Carer Support & Respite: [Carer support and respite | Disability Support Services](#)
- ME Respite: [Home - ME Respite](#)

Communicating with Health Professionals:

Advocating for Your Loved One

Navigating the healthcare system when caring for someone with severe ME/CFS can be challenging. Many health professionals may not be familiar with the complexities of this illness, and miscommunication can unfortunately lead to harmful outcomes. This section provides guidance to help you effectively advocate for your loved one and protect their well-being.

Key Principles for Effective Communication

- **Be Clear and Specific:** Use concise, direct language. For example, say, "They experience post-exertional malaise after minimal activity" instead of "They get tired easily."
- **Provide Documentation:** Always bring a brief summary of your loved one's condition, sensitivities, and care needs. Include your hospital care plan and any relevant letters from specialists.
- **Establish Boundaries Early:** Clearly explain that certain interventions, such as graded exercise (GET) or unnecessary stimulation, can worsen their symptoms. Be firm but respectful in setting these boundaries.

- **Utilise Written Communication:** If verbal communication is too taxing for the person with ME/CFS, provide written notes or speak on their behalf, always with their consent.
- **Request Continuity of Care:** Ask to see the same GP or nurse whenever possible. Repeating your loved one's story can be exhausting and re-traumatising for them.

Helpful Phrases to Use

- "They are extremely sensitive to light, sound, and touch. Please speak softly and avoid sudden movements."
- "They may appear unresponsive, but they are often aware. Please speak to them as you would anyone else."
- "We have a care plan for hospital stays that outlines their needs. Would you like a copy?"

Resources You Can Provide to Healthcare Professionals:

- [Severe ME Day 2025 – 8 August 2025 – ANZMES](#) for all the relevant resources
- ANZMES Medical Professionals Hub: [Medical Professionals – ANZMES](#)
- CCI Support NZ Health Professionals: [Complex Chronic Illness Support | Empowering People Towards Wellness](#)
- NICE Guideline NG206 – this includes specific recommendations for severe ME/CFS: [Overview | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#)

Helpful Links

- Bateman Horne Centre:
 - [How to Communicate With Your Healthcare Provider](#)
 - [Working with your Medical Team page](#)

Preparing for Emergencies: Ensuring Safety and Respect For Your Loved One

Emergencies, whether they are medical, environmental, or related to your caregiving, pose a significant risk to your loved one with severe ME/CFS. Being prepared can help reduce panic and ensure your loved one's unique needs are understood and respected during a crisis.

Essentials to Prepare at Home:

- **Emergency Information Sheet:** Create a clear sheet detailing your loved one's diagnosis, key symptoms, medications, allergies, specific sensory needs, and important emergency contacts.

- **Crash Care Kit:** Assemble a kit with essential items like earplugs, an eye mask, electrolyte sachets, necessary medications, communication aids, and any comfort items that help them.
- **Power Backup:** If your loved one relies on electric beds, feeding pumps, or temperature control, consider having a battery backup or generator ready.
- **Evacuation Plan:** Develop a plan for safe evacuation, identifying accessible transport and secure locations. This should include a strategy for safely lifting or moving your loved one if needed.
- **Caregiver Backup:** Maintain a list of trusted individuals who can step in to provide care if you, as the primary caregiver, become unwell or are unavailable.

In Case of Hospitalisation

- **Utilise Your Hospital Care Plan:** Always refer to your existing Hospital Care Plan. Carry a printed copy of the Hospital Care Plan and advocate strongly for a low-stimulation environment for your loved one. You play an important role as your loved one's support person to help interpret their needs and prevent them from overexerting themselves. Refer to [ME Respite and ANZMES Care Plan](#) for more info on hospital stays:

Helpful Resources

- The [ME/CFS Crash Survival Guide](#) is an excellent resource for understanding Post-Exertional Malaise (PEM) and preparing for acute episodes.
- ANZMES [Secondary Care: Hospital Stays for Severe Patients Resource](#)