



Advocacy for Carers

Many people don't see themselves as carers, they see themselves as parents, partners, children or friends. As a carer of a person living with ME/CFS there may be times when you are called upon to provide support through advocacy.

Advocacy can be undertaken on the behalf of the person you provide care for with healthcare professionals, service providers, workplaces or even within your family or friendship circle.

This factsheet has been designed to support carers to advocate for fair and equitable treatment of people living with ME/CFS.

Taking a person-centred care approach

Person-centred care involves understanding and supporting the preferences and wishes of the person you provide care for when it comes to decision-making and accessing the best supports.

Being a person-centred carer means respecting the dignity, rights and autonomy of the person living with ME/CFS and supporting them to receive the most relevant care for their unique needs.

Sometimes you will find yourself needing to be the advocate for the person you provide care for. Advocacy simply means that you can speak up on their behalf to support the outcomes they would like. You may need to support the person living with ME/CFS to:

- ensure they get **access to the information they need** to be better informed
- ensure they can **connect with appropriate services** or resources for support
- protect their **rights, entitlements and special considerations**
- ensure they are **treated with respect and dignity** at all times
- ensure they are **not discriminated against** in any way.

Understanding the rights of the person you provide care for

It is very important to understand the rights of a person living with ME/CFS so you can effectively support them.

This includes the right to:

- make clear and informed decisions about their own care
- seek a second opinion or further information on a diagnosis or treatment plan
- be given a full explanation of medical options so that they can make an informed decision
- bring a support person to appointments to advocate on their behalf if needed
- have any concerns or complaints addressed by their healthcare team
- be treated with respect and dignity, with attention given to their medical wishes
- have their personal information kept private and confidential.

Learning about the rights of a person living with ME/CFS and being able to advocate for these rights empowers both of you, informs decision-making and assists you to set healthy and useful boundaries. Knowing what to expect ensures the person you provide care for can get the best from their healthcare team.

Conversation starters to better understand the wishes of the person you provide care for

It is important to have regular discussions with the person you provide care for about how you can further support them.

Here are some examples of how to start a conversation on advocacy:

“I’d like to find out more about how I can help you to be better supported by your medical team. Can you share with me examples of your best and worst experiences so far?”

“I noticed you seemed very quiet after your medical visit this week, can you tell me what bothered you at the time? I may be able to help.”

“What is your biggest challenge when it comes to dealing with doctors, nurses and healthcare staff? Perhaps there are some ways I can help you?”

Document their feedback, comments and experiences plus possible ways in which they have suggested or agreed that you could assist them. This will help you to form a plan, write an email or complete a complaint on their behalf which accurately reflects their thoughts, feelings and wishes plus preferred resolution options.

How to advocate for the person you provide care for with boundaries and respect

Advocating for a person living with ME/CFS may feel challenging at times. Standing up for fair and equitable treatment on their behalf requires respectful communication and an understanding of healthy boundaries.

Respect involves showing consideration for the feelings, views and opinions of another person. You can display respect by using appropriate language, patience and a polite tone. Listen actively and respond using calm and assertive communication.

Boundaries help you to maximise the effectiveness of your interactions, stay on track and understand when to escalate concerns further.

When setting boundaries, it may be helpful to consider the following:

- **What are the 'reasonable rights' in this situation?** Are these rights being overridden or ignored and how can I draw attention to this?
- **How is this situation impacting the person I provide care for?** How can I explain these impacts and seek a resolution that would best achieve the outcome they want?
- **What are the values of the person I provide care for?** What is most important to them? Is this situation or decision working against their values, and how can I help to address this?

Building a successful partnership with professionals

Partnering successfully with professionals brings better healthcare outcomes and experiences for the people living with ME/CFS. Trust, mutual respect and knowledge-sharing can be enhanced, leading to more successful person-centred care.

- **Be prepared** – speak with the person you provide care for about the healthcare provider prior to meeting with them. Familiarise yourselves on the provider's physical setting, staffing, specialisations, their background with ME/CFS and any other information that may assist to make that first visit successful.
- **Establish rapport** – be on time and bring notes, relevant records, medication history, past diagnoses, information and observations. Have the information well organised and easily accessible. Be ready to help them to quickly learn about the person you provide care for. Listen respectfully and take plenty of notes. If the person living with ME/CFS is unable to ask their own questions, ensure you cover the areas they are most curious about.



Carer Gateway

The Carer Gateway is an Australian Government initiative that delivers new, improved and expanded services to carers across Australia. Through the Gateway you can get the practical support and advice that you need including information, counselling, peer support and respite care.

Visit carergateway.gov.au or call 1800 422 737

- **Inform and educate** – for healthcare staff who may be unfamiliar with the health history of the person you provide care for, it may be useful to provide links to authoritative information (such as Emerge Australia's GP education modules) to help them to understand the situation more readily.
- **Facilitate a multi-disciplinary approach** – speak with the person you provide care for and ask them to consider the advantages of providing consent for each of the healthcare providers to consult each other, where relevant. This could help the providers to work together more effectively to assist the person you provide care for.

How to get support and help with advocacy

There are many organisations that provide support and information to assist with advocacy across a range of concerns. Use the links below to connect with the support offered in your state or territory.

- disabilitygateway.gov.au/legal/advocacy
- afdo.org.au/resource-disability-advocacy-organisations

Connecting with other ME/CFS carers

Join the Emerge Australia Online Community initiative to connect with other carers who just like you support someone living with ME/CFS. Visit the link below for further information and to learn how to get involved:

emerge.org.au/online-community



www.emerge.org.au
1800 865 321