



Autonomy, Dignity & Independence

Your role as a carer of a person living with ME/CFS has no doubt changed over time. As you have continued to learn more about their needs and preferences, the importance of ensuring their autonomy, dignity and independence may become a priority for you.

This factsheet has been designed to support you to talk with the person you provide care for about how to maintain or increase their autonomy, dignity and independence.

Defining key terms

- **Autonomy** is commonly understood to refer to the capacity of a person to choose and act on their own preferences regarding their life and their body. As a carer, you might enhance personal autonomy by encouraging the person you provide care for to choose activities that they love and support them to access these in a way that is helpful for them.
- **Dignity** is the right of a person to be valued and respected for their own sake, and to be treated ethically. You might honour the dignity of the person living ME/CFS by advocating for others to treat them with respect, non-judgement and acceptance.
- **Independence** means freedom from outside control and being able to direct one's own affairs without interference. You can support the independence of the person living with ME/CFS by encouraging them to make their own decisions and to take ownership of activities, projects and tasks.

Talking with the person you provide care for about what these terms mean for them

It is very useful to speak with them about these terms and the ways in which their autonomy, dignity and independence could be enhanced.

- **'Person-centred' conversations** assist them to negotiate how you can better support their decision making, respect their wishes, and enable them to make informed choices - even if these choices differ from your own.
- **Speaking about autonomy, dignity and independence** invites and empowers the person living with ME/CFS to explore areas in which they would like to have more say or influence. This may be in relation to their daily routines, family life, healthcare and other personal priorities.
- **Discussing these issues** in an open and honest way assists them to feel more genuinely seen and heard, which strengthens your bonds and deepens your caring relationship.

Autonomy, dignity and independence in action

Discuss ways in which you can work together to support their unique needs with regards to further independence, autonomy and dignity.

Examples may be changes to personal hygiene preferences, practical assistance with mobility or daily tasks, communication between family members, household noise and light levels, food preferences, medical decision-making, recreational options, social connection and privacy issues.

Together with the person you provide care for:

- identify their personal 'wish list' of needs and preferences, and seek to understand why these things are important to them
- list the steps, tasks and/or resources that may be needed to address these requirements
- consider any barriers that may exist and how requirements may be adapted or negotiated around these
- write some simple notes together to record any agreed changes or approaches
- monitor and check in frequently to ensure agreement of any change.

Enhancing resilience

Resilience is the ability to "bounce back" emotionally under challenging circumstances. When the resilience of the person you provide care for increases, their confidence in their own capability may also be enhanced.

Here are some techniques to enhance resilience:

- **Get perspective:** Is this really as important as it seems?
- **Take a break:** Get a drink, rest for a moment, collect your thoughts in privacy
- **Embrace acceptance and forgiveness:** Yes, that thing really did just happen...now what?
- **Reflect on it:** What went well and what could I have done differently?
- **Reframe it:** Is there a different way to look at this that will help me more?
- **Get support:** Who may be able to help me navigate this best?

Plan ahead for times when autonomy, dignity and independence may be challenged and consider how you and the person living with ME/CFS can best handle these situations. Consider role-playing scenarios in advance to maximise confidence and resolve.



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

Setting goals, priorities, and personal boundaries

Encourage the person living with ME/CFS to consider setting some goals in relation to outcomes they would like to achieve ahead of time. Goal setting should be SMART (specific, measurable, achievable, realistic and time-bound).

Check in with them afterwards to review the outcomes – did they reach their goal, if not, what are their reflections on this and how can they try again next time? Boundary setting can help them to maximise their emotional energy and remain true to their values.

When setting boundaries, it may be useful for them to consider:

- **What are my reasonable rights in this situation?** For example, the right to be treated with respect, to say “no”, to negotiate with your needs in mind, to change your mind or not accept the unreasonable expectations of others.
- **What is my gut feeling?** Am I feeling a negative physical response right now? This will indicate to you when a boundary needs to be created.
- **What are my values?** What is most important to me? Is this situation or decision working against my values, and how can I express this clearly?

Validating negative experiences and moving forward

It is helpful to be able to recognise and accept the feeling of the person living with ME/CFS in relation to negative, hurtful or offensive interactions or outcomes. An example may be if their dignity or autonomy is impacted by a negative conversation or attitude from a medical professional, or other person.

To validate their feelings:

- **Listen:** Be open and curious about how the situation makes them feel. Suspend your own thoughts or feelings on the issue.
- **Seek clarification:** Ask “person-centred” questions that allow you to really understand the meaning they make of it.
- **Reflect back:** Summarise what they’ve said using simple language. “What I heard you say was...” This will help you to show that you see and hear them.
- **Normalise:** Let them know that what they’re feeling makes sense based on their experience or perspective - and that others in a similar situation might also feel the same.

Working together, you can assist them to identify and express their feelings, understand how to set boundaries and reflect on ways to ensure their dignity, independence and autonomy are protected and honoured.

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