Supporting a loved one through Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

By Melissa Searle

When a person is diagnosed with Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS) it can be a difficult and scary time, but it can be made easier when they have support. Although most people associate ME/CFS with physical symptoms such as fatigue, the emotional and psychological symptoms are just as taxing on peoples bodies. ME/CFS sufferers deal with hidden symptoms such as anxiety, panic attacks, social anxiety, brain fog and insomnia. Supporting someone through ME/CFS, although hard on the caregiver, can also help in the ME/CFS sufferer's recovery.

There are a few basic things about ME/CFS that loved ones need to know to understand what the sufferer is going through. There are also a few things that loved ones can do to make the sufferer's journey through their illness that little bit easier. Firstly, ME/CFS is a physical, psychological, emotional and psychosocial illness... it affects every part of a person's life. A person suffering from Myalgic Encephalomyelitis or Chronic Fatigue Syndrome may not talk about their illness, but they will be suffering from various symptoms every day. ME/CFS sufferer's can go through periods where their symptoms' improve, and they can also go through periods where their symptoms relapse. ME/CFS affects every sufferer differently, and every sufferer will have a different journey through their illness.

Flexibility of family and loved ones helps ME/CFS sufferers out a lot when they are feeling unwell. Some sufferers are housebound, and don't have the physical energy to be able to see visitors. If that is the case, then just contacting them and making them feel like they are cared about can help. If the person does not have the energy to come out for coffee but can see visitors, suggest coming to them. Allowing them to conserve energy will help them with their recovery.

When someone is going through ME/CFS, they may need a little bit of help from time to time, especially if they have been badly affected. Being helpful in this case doesn't necessarily mean picking up groceries for someone. It could just mean helping them by listening when they need someone to talk to, or arranging to meet for a social gathering at a more suitable location.

It is better to have a supportive attitude when talking to someone who has ME/CFS, as they often feel that support helps them recover. If they have a breakthrough moment when they feel that they are recovering, tell them how happy you are that they achieved that breakthrough. If they have a bad day, just the simple act of listening to the person can help them, even if it's just momentarily.

If you know someone who has ME/CFS, and they seem to be recovering slowly, do not judge them, as their recovery will take time. You do not know what they are going through on a day to day basis physically and emotionally. Judgemental things that you say to a person with ME/CFS will also affect them long after you have said them. Others judging how quickly a ME/CFS sufferer should recover will often cause a setback in symptoms for the sufferer. A setback in ME/CFS symptoms occurs when a sufferer deals with excess physical exertion, mental exertion, excess emotions or stress.

Providing support to someone with ME/CFS can help them feel like they are not so isolated from the outside world. Whether it is direct or indirect, any form of support will be appreciated by the sufferer. ME/CFS can be very socially isolating, so just knowing that there is someone there to go to for support, or a good laugh can be very comforting. Reaching out to a person with ME/CFS can be more helpful than you might think. Send a letter, leave a phone message, and contact them though various technology sources that are available. Even if they are not well enough to reply straight away, they can always listen or look later. Sometimes just knowing that someone is around can be the best thing for ME/CFS sufferers. It can also be emotionally uplifting for someone with ME/CFS to receive contact from loved ones.

Utilising technology can be a great way to keep in touch with someone who has ME/CFS. It can also help the sufferer to feel like they are still in touch with the outside world and the ones they love. Use Skype, email or social media to keep in contact with the ME/CFS sufferer. Using these contact methods still allows the sufferer to feel like they are connected to their loved ones. If the sufferer is housebound, it also allows them to feel like they are connected to the outside world.

Even if the ME/CFS sufferer does not say it, your support is appreciated by them. They are going through a tough time with their health and having someone in their corner is helpful. Whether it is emotional support, physical support or even just being there for them, any support that is given is appreciated.

The author of this article has given their permission for their work to be published by ME/CFS Australia (SA) Inc.