Self-help series fact sheet 13

Managing relationships

Serious illness has profound effects on not just the person who is ill but also their family and friends. And just as each person with a debilitating fatigue condition (such as ME/CFS or long COVID) is different and needs to develop an individualised self-management plan, so, too, do you need to tailor your responses to dealing with family and friends.

It's important to be aware that whilst you are dealing with a new 'normal', your family and friends also need to make changes but may not always understand how debilitating fatigue affects you.

Of course, there are several factors that will determine how impacted your illness will have on them.

Probably the most important factor is the amount of disruption to your life and the amount of adaptation required of you.

A second important factor is your circumstances (age and health) and the life stage of your family. If you have young children then your partner (or other family members) may need to increase parenting responsibilities, compared to someone later in life whose children have grown and may be in turn be additional sources of help.

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A third significant aspect of your situation is your finances. This will impact every family in different ways and may result in an impact on housing, being able to meet medical costs and participating fully in the community.

The final factor is your family and friend’s ability to understand the condition. It is sometimes hard for family and friends to understand the effect of a debilitating fatigue condition as it is considered an ‘invisible’ condition. Many sufferers may have good days and bad days, allowing them to look and act well to those around them.

Living well with a debilitating fatigue condition requires a level of management like that for other serious, long-term conditions. Your family and friends need to understand that their attitude towards you will have a huge impact on your ability to function on a day to day basis.

Several ways in which you can help yourself (and in turn your family and friends) include:

1. Being honest about your condition and how this affects you ie. I can only go shopping for 30mins and then I need to go home.
2. Rethinking your expectations particularly regarding household chores.
3. Asking family members to help. Create a weekly roster with everyone doing more chores, or a weekly meal plan to help with meals.
4. Take advantage of home delivery or click and collect for groceries and meals.
5. Saying NO to hosting events or guests at your house.
6. Explaining that you may need to cancel social events at the last minute if you are too fatigued to attend.
7. Look at other ways in which you can socialise ie. Ask friends to meet you at a local café for 30mins.
8. Communicate to family and friends via short texts or email rather than phone calls.

When dealing with relationships the important thing is to not try and do the things you used to do before getting ill. This will heighten emotions such as guilt, frustration and resentment, which in turn will increase symptoms.

If you need further information or support please have a look at our website at www.arthritisact.org.au.