Talking to others about ME

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Explaining ME to others

ME is a “non-visible” condition, so other people won’t necessarily be able to tell how you are feeling, or what you can manage physically and emotionally.

It is also a condition that has been poorly understood in the past, so you may need to communicate about your condition to another person who isn’t well educated about ME.

Good communication skills are an important part of self-management.

Three important areas of communication

There are three important areas of communication, and it can help to keep them separate, so that any messages you are trying to communicate are as clear as possible.

What is ME?

It can be simpler to offer a quick explanation of what ME is, rather than trying to get into the complexity of the research findings.

It can help to have a simple, one-line answer that you have prepared, when people ask you what it is.

For example, some people say:

> *“It’s a neurological condition that causes extreme fatigue and pain.”*

That way, people who have a real interest can read more, and you can save your energy for other conversations.

What does ME feel like?

Some people also want to know how you feel, and what your symptoms are.

However, the symptoms can be difficult for other people to understand, particularly because there can be so many.

We have heard people describe ME in the following ways:

> *"It's like having terrible flu that doesn't go away."*

The Spoon Theory might also be a useful tool here (you may have seen references to spoonies online).

Christine Miserandino, an American woman living with lupus, wrote it to convey what it's like to live with a chronic health condition.

It is even harder to explain how you feel to somebody who has never had a significant health problem.

To complicate matters further, even if other people are able to understand a little of how you feel, that won't tell them anything about what you can manage, or how you go about living your life.

To do that, you need to talk to them about your self-management approach.

How do you manage ME?

This kind of conversation can sometimes be more straightforward.

If somebody doesn't understand the medical explanation of ME, or how you are feeling today, they may understand it if you explain how long you might be able to walk for before needing to rest.

A good understanding of your baseline (i.e. the level of activity that you can sustain on a regular basis.

If you know that your baseline for using a computer is 20 minutes, then you can tell somebody else what you can typically manage.

If you know that you need to rest for three half-hour periods of the day, then you can explain your needs if you have a visitor, or if you go away somewhere.

Other people are more likely to understand if you are able to communicate clearly. Sometimes you may need to be assertive when you are explaining this to people. There are many books and online resources about assertiveness.

Writing in Action for ME's membership magazine, InterAction, counselling psychologist Joan Crawford says:

> *"Being assertive is about being able to communicate how we are feeling confidently and non-aggressively and reasserting the boundaries with those around us – boundaries which may have been violated by someone else's disbelief or misunderstanding. It may well be necessary to express ourselves assertively because not doing so may lead to increased anxiety due to our own needs not being met."*

Disclosing your illness at work

Some people with ME will not be able to work at all and will have to rely on savings, welfare benefits, insurance or private income.

Some will be well enough to do an hour or two of voluntary work, at home or in the community, which will need to accommodate the fluctuations of their illness.

Some people with mild to moderate ME are able to work part-time or even full time as they move into recovery.

If you are in work or considering employment, it's important to know that having a long-term fluctuating illness which adversely affects daily life – like ME – may be regarded as a disability under the Equality Act 2010.

The Act aims to protect people who have a disability from discrimination (both direct and indirect) in the workplace. Potential employers are not allowed to ask health-related questions, except in specific circumstances.

Disclosing a disability lets employers know they need to make reasonable adjustments to the recruitment process and/or to support a disabled person in work.

You do not need a formal diagnosis for this to be the case.

Disabled people and their employers are entitled to apply for help from the government through Access to Work (Tel: 0800 121 7479).

They are also entitled to apply for disability benefits.

You don't have to disclose a health problem or disability to an employer, unless it could cause health and safety problems e.g. if your ME causes cognitive problems, there would be an issue if you couldn't concentrate and your safety or someone else's might be at risk as a result.

You may be worried in case disclosing your ME will put you at a disadvantage, label or stigmatise you, especially if bullying is a problem at work. You may be concerned about what will happen to the information you will provide.

The Equality Act 2010 exists to protect you in these circumstances.

ACAS also provide useful information on the law on disability discrimination.

If you tell your boss or employer about your illness, you can ask them to treat the information as confidential.

The Data Protection Act 2018 says employers must ensure confidential and appropriate handling of 'sensitive personal data,' which includes information about a person's health.

This means that information about your ME should not be shared with any other person, inside or outside the organisation, without your prior, expressed consent. Some colleagues may need to know about any adjustments to hours, work practices or environment that are agreed.

However, they do not need to know the precise medical reason why, unless you want them to.

Dealing with disbelief

This is a difficult subject and, sadly, impacts many in the ME community.

Doubt and lack of understanding in any situation is hard. When it comes from loved ones, it causes extra hurt. It can be hard to explain your ME to people.

It may be best to stick with some key phrases which you can repeat when needed, for example:

"I need to manage my energy to help me be as well as possible, so I'm going to rest now but I look forward to seeing you later."

"I need to rest somewhere quiet, so I'm going to spend some time in my room."

"My earplugs help me when I'm finding the television too loud. I'm happy for you to watch a film whilst I sit here, they just filter some of the sound to prevent me feeling unwell."

"Don't worry that I'm missing out. I'm very glad of the time I'm getting to spend with you by putting things in place to help me do so."

"When you dismiss my ME, I find it really hard. It's a real illness. I didn't choose it and it's very hard to live with. I hope that you respect me enough to try and accept this."

It's important to remember you are not responsible for other people's behaviour. Other people's lack of belief is not a reflection of your truth.

If you don't have energy to explain, don't feel compelled to do so. You are allowed to prioritise your health and wellbeing. Put yourself first as best you can.

ME is real. You live it every day and you are an expert in your own condition.

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