

INFORMATION SHEET 3.2

Stress, anxiety and chronic fatigue – isolation and getting support

Having a fatigue condition can be isolating. This can be due to the effort of social contact, or perhaps lack of understanding and support, amongst other reasons. If the condition was triggered by traumatic experiences, this can be further isolating, perhaps because the experience can be so intense it is hard to explain to someone who has not encountered anything similar. Humans are social animals: interdependence is essential to our survival and so isolation can be very stressful.

Support groups and helplines
Planning social situations
Getting professional support
Associations and helplines (contact details)
Further reading

- 1 It can be distressing if family, friends, or even doctors don't
 - 2 understand, and it can feel very lonely at times. However, illness
 - 2 and traumatic experiences are part of life – almost nobody
 - 3 goes through life without it. Chronic fatigue is hard to imagine
 - 3 and people may find it hard to directly relate to your
- experience, but they may be able to make a connection with times when they have been ill or down in their own life.

Support groups and helplines

Keep in touch with people who have been through similar things and who care about the same things as you. Anything that gives you a sense of being part of a community can be very helpful. Communities take on many different forms.

Support groups can be helpful, while the phone and the internet can mean your community can be international. The ME Association and Action for ME both have support groups, online and in person, as well as telephone helplines. Their details are included at the end of this sheet. ([Go to www.violasampson.com/Resources.html](http://www.violasampson.com/Resources.html) for links).

If you have a partner or carer, they are likely to need support at times too – but not from you! The helplines listed above are also for carers and families, and there are support groups specifically for them. At times, fatigue symptoms are so confusing that people can wonder if they are going mad. This is when it can help to have conversations with others who know

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even a little of what you are going through. If someone can't get adequate support from friends or family, it is important to get a referral to a counsellor from their GP, as anyone on their own would struggle to cope (also see below for more on getting professional support). While the Samaritans don't have a specialised helpline, they are supportive of anyone feeling lonely and isolated.

Planning social situations

While people are still recovering, they may find they are sensitive to bright lights or loud noises, or are easily startled. They may hate surprises and spontaneity and need to plan everything in detail. Because of all this, people may consciously or subconsciously avoid social situations, especially noisy ones like parties and pubs, and so increase their sense of isolation.

If this is true for you, think of things you can do that are social but gentle, like meeting one good friend for a walk in the nearby park, or a maybe a picnic by a river. Also explain to your friend that you may need to go home early, give yourself permission to do that, and pace yourself (see information sheet on pacing). You may not get it right first time, but with practice, socialising within your energy levels and comfort zone can become easier – so rather than it being depleting it can be supportive of your healing.

Getting well is more important than saving face or maintaining friendships that are unsupportive. Prioritise the relationships where you can be honest about your limits.

When you are tired, consider texts rather than phonecalls, or let people know in advance that sometimes you will need to keep phonecalls or visits brief. If you can, tell your friends how you are feeling, so that they can be supportive of the perhaps detailed plans or changes you need to make to ensure you can stay within your energy limits or stress levels. Your friends are likely to want to be able to support you, and it can help them to know this is one way they can.

It is natural to feel nervous if you are building up your social life after withdrawing for a while. Be patient with yourself, make a plan in which you set achievable goals (such as one meeting, or phone call, with a friend each week, for a month) and reward yourself afterwards. When you know you can usually manage this level of social activity, review your plan and set new goals.

Read the information sheet on *Pacing* and make sure new activities are properly balanced by restful time and activities that are resourcing for you.

Getting professional support

It is normal for people with long-term stress and anxiety, or for those who have experienced trauma, to need professional support. Both chronic fatigue and post-traumatic stress are increasingly recognised conditions, and mainstream medicine is taking stress in general more seriously now. If you haven't already, it is vital to give your doctor a full picture of all your symptoms, so that you can have any tests needed to rule out other medical conditions that have similar symptoms to chronic fatigue or ME. GPs may also be able to refer people to counsellors, particular complementary therapists, or specialist fatigue services at local hospitals, on the NHS, although this depends very much on your area and your GP.

Doctors now have more flexibility to be able to work with you to decide whether you need some extended time off work, or a gradual, or phased, return to work. They may offer you medication, like antidepressants or tranquilisers, as some people have found them helpful for some fatigue-related symptoms. Try and get clear how you feel about this kind of medication and write down any questions before you go to your appointment with your GP, so that you know what you need from any discussion about whether they may be helpful for you.

Importantly, if you don't find your GP supportive, shop around until you find one that is – you can research GP practices online and it can be useful to ask the receptionists about the doctors in that practice, and their approach to chronic fatigue, before you make an appointment.

Alternative or complementary therapies are often good at supporting the body's natural recovery processes. Do make sure any therapist you choose is registered with a professional association, which should mean they have had good training and are well-supported themselves. It is a good idea to speak with them before making an appointment and ask if they have training or experience of working chronic fatigue or ME, or post-traumatic stress. Perhaps due to increased sensitivities, fatigue conditions can respond to treatment in unusual ways, and it can be counterproductive to work with someone who doesn't have specialised knowledge. Practitioners who are trained to work with post-traumatic stress are likely to be able to work in ways that are gentle and helpful for fatigue conditions.

Once you have had your first appointment with a therapist, take your time to make a decision about whether you want to work with them. You don't have to go back if, on reflection, you feel their approach or their personality is not helpful to you. However, some resistance to working through difficult

experiences is natural and it takes time to build trust. If you decide not to stay with one therapist, then see if you are willing to find another. If you are not, it may be worth talking about your reluctance with the therapist themselves, if their manner helps you feel comfortable with that, as there may be things they can offer to support you to stay with the process of therapy. But you (or they) should never push through resistances – resistance is there to protect you. When it is safe enough, reluctance and resistances usually melt away.

Associations and helplines

Action for ME

As well as an extensive website, with information and self-help guides, Action for ME provide telephone information and support. They have campaigned for more research, better treatments and services since 1987. They run support groups for people with ME, their carers, family and friends. You don't need to be a member to use its helpline.

www.actionforme.org.uk

0845 123 2314 (11am-3pm, Monday - Friday)

The ME Association

The ME Association offers support and information to people with ME, their families and carers. Their website also has a lot of current information. They run a helpline, and an online discussion group on facebook. There are support and social groups in London (and across the UK) run by and for people with fatigue conditions, families and carers.

www.meassociation.org.uk

0844 576 5326 (10am-12noon, 2-4pm, 7-9pm every day)

The Samaritans

Samaritans provides confidential emotional support to those experiencing despair, distress or suicidal feelings – by telephone, email, letter and face to face.

www.samaritans.org

08457 90 90 90 (24hours a day, every day)

Further reading

The Body Remembers, by Babette Rothschild covers detailed post-traumatic stress theory and practice, and outlines what should be expected from a good therapist.

Another helpful book is *Overcoming Chronic Fatigue: A self help guide using Cognitive Behavioural Techniques*, by Mary Burgess and Trudie Chalder. This includes methods for setting targets and making plans to increase social activities as well as CBT techniques for managing stressful thinking patterns.