

Skills guide:

For friends, family and carers

Supporting someone with functional somatic symptoms

Overview

You might be reading this guide because someone you care about is struggling with Functional Somatic Symptoms. Maybe they've been diagnosed with one or more functional somatic syndrome, or they're dealing with unexplained chronic symptoms.

Supporting people with functional symptoms can be a difficult balance. Relationships themselves can be healing, but symptoms can also create challenges in relationships. It can be hard to find good advice.

This guide shares some insights from others who have been in a similar situation. Healthcare professionals, caregivers, and people who have had difficulties with functional somatic symptoms have all contributed to this guide.

We hope you find it useful.

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Supporting someone functional somatic symptoms

Supporting someone with these kinds of illnesses brings up some unique challenges:

- **The causes of functional symptoms are often invisible on medical tests. This means they are easily misunderstood, and can fall between the gaps in healthcare.**
- **As a general rule 'magic bullet' cures, in the form of medication or surgical treatment, don't exist for functional disorders.**

This means, in the early stages of supporting someone with symptoms, there may be some confusion and uncertainty around what the symptoms mean, and what can be done about them.

The first part of this guide provides advice on supporting someone through this process, especially in the early stages.

In summary, you can support by:

- **Taking the time to listen to the person's story and build a shared understanding.**
- **Recognizing that symptoms are real and disabling.**
- **Helping the person believe that change is possible.**
- **Supporting a balanced routine**
- **Not jumping in to help with practical tasks too quickly. Let the person with try first – then you can help and support afterwards.**
- **Thinking carefully about introducing aids or equipment.**
- **Making a plan together to manage specific symptoms.**

Caroline's Experience

My husband Chris has struggled with fatigue and other symptoms for many years. We also have 2 children, age 11 and 8. I am not an official carer and though when Chris and I first met he was unable to work, he is now able to work full-time hours, though he takes Fridays off each week to rest.

At his worst, Chris was bed-bound, having to drop out of his PHD programme and move home with his parents. To paint a picture, he had to use all-fours to get up and down the stairs, and his mother would place food on a plate for him on the floor as he couldn't sit up at the table. He has come such a long way since then, but fatigue still dictates many things about the way we live our lives and what we can and cannot do. It is a largely private and invisible struggle to have a spouse who has this sort of misunderstood illness – and the struggles are so unique that I often don't think to share it with others which can be isolating.



Listen to understand

Research has shown that having a better understanding about functional symptoms helps recovery. It is helpful if you find a shared understanding about what causes and maintains symptoms with the person you are trying to support.

You might want to ask:

- What have you learnt about your condition?
- Have you noticed any patterns in your symptoms?
- What seems to make your symptoms better or worse?
- What do you think is going on in the body when you are experiencing symptom X?
- Why do you think X developed?
- What do you think stops your symptoms from going away?
- What do you say to other people when they ask about your health?

However, when someone has symptoms, advice comes from all directions, and **it can be overwhelming.**

You might be bursting with good advice to give. **Don't jump ahead.** It is best to spend time really trying to **understand the situation**, and all its nuances, **before you jump in with advice.**

Everyone who struggles with functional symptoms needs to find a way to work with and through a unique bodily condition.

An approach you heard worked for someone else, might not have the same results for the person you are supporting.

Caroline's Experience

Usually this comes in the form of advice from friends, family and acquaintances who think they are being helpful by suggesting healing through oils, teas, special diets, etc... the advice can get tiresome.



Validate

People suffering from functional somatic symptoms often feel misunderstood and have the experience that other people don't see their illness as legitimate.

It is hard to move forward without feeling that, despite normal tests, those around you take your bodily complaints and worries as real.

The person you support might need to hear from you, that you believe them when they talk about their symptoms, and you see that they are not well and need time to recover.

Empower

One of the most important steps in recovering from FSS is feeling like it is possible to make positive changes. It is easy to lose this confidence when you have symptoms. You can empower the person you support by helping them remember their strengths and that change is possible.

Strengths and Resources: Remind the person you support of their strengths and resources.

Positive Opportunities: Help them explore new and positive opportunities to take risks, try out changes, and do things differently.

Consistent Routines: Help create structures that allow the person you support to establish consistent routines, make time for themselves, and stay committed to the changes they want to make.

You might want to ask:

- What are the most helpful management strategies that you have learnt?
- What can you do if you notice that your symptoms or function are getting worse?
- What is important for you in recovering?
- What holds you back from believing recovery is possible?
- What are your goals for the next 3, 6, 9 and 12 months?
- How can I support you with these goals?

Caroline's Experience

Being positive is really important, but also, allowing a person to feel ill without pressure to 'will' themselves better is vital. During some seasons, improvement may not be possible. Making peace with these difficult times brought Chris some peace of mind.



Supporting balance

Many people with functional symptoms are extra susceptible to stress, which maintains and intensifies many functional symptoms.

If this is the case for the person you support, they might benefit from help reduce stressful circumstances that help maintain symptoms and stabilize their daily life.

At the same time, it is helpful to encourage the person you care for to keep up with hobbies or interests. You don't need to put pressure on them, but checking in occasionally will give them the opportunity to get involved when they feel able to.

If you live together, it can be helpful to sit down and plan the week ahead. In this way, you clarify expectations for each other, and can plan time to work on recovery.

You might want to ask:

- **What activities or responsibilities in your life might be pushing your body out of balance?**
- **In your daily life, when can you set aside time to enter a relaxed state in the body (physiological rest)?**
- **How can I support you to find the time to take care of your body?**
- **In your daily life, when can you set aside time to work on recovery?**

Supporting with practical tasks

When someone gets sick, you might want to help by doing things for them. While this comes from a good place, it's important to know that the body quickly becomes weaker when it's not active every day. So, the tasks you take over for the person you're looking after might be things they'll need to learn to do again later.

So, even though it can be good to help with some things when the person is overwhelmed, it's better to be cautious about taking over daily tasks like personal care, or mobility. If you want to help with a practical job, it's better to encourage the person to try it themselves first, even if it takes a bit more time.

For example cooking a meal might involve:

- Breaking the task down into manageable steps,
- Allowing enough time to take plenty of rests,
- Sitting down while chopping,
- Replacing some ingredients for example use a shop brought sauce instead of a homemade one etc.

It is helpful if these solutions come first from the person you are supporting.

You might want to ask:

- **How could you break down (task X) so you are able to do it at a manageable pace?**

Aids and equipment

It might be tempting to look for aids and equipment that can help reduce the impact of symptoms. However, the general advice is that using these aids and equipment might be unhelpful when it comes to recovering from functional symptoms, especially if you've recently developed these symptoms and your goal is to fully recover.

The reason for this is that using aids and equipment can sometimes create new problems. For example, if you start using crutches, you might end up with shoulder pain. Mobility aids also interfere with the body's natural patterns of moving and make it more likely the body adapts in dysfunctional ways.

A similar principle applies to things like sunglasses indoors for light sensitivity or headphones for noise sensitivity. Using these aids full-time can prevent the brain learning to tolerate those stimuli and can exacerbate hypersensitivity over time.

Despite this general advice, there are times when adaptive equipment is appropriate and/or necessary. For example, for people with long term symptoms, aids and equipment may help the person be more independent, or get around in their community, which on balance is the more important goal.

Because functional symptoms can come and go, keep the mindset that aids and equipment are not forever. If you really need to use something, remember three things:

- 1. Think of it as a short-term solution,**
- 2. Use as little equipment as possible, and**
- 3. Have a plan to use it less over time.**

If you have any doubts or questions about how aids and equipment in your situation, an occupational therapist may be able to advise.

Having a plan to manage specific symptoms

Having a plan for managing symptoms can make everyone feel more comfortable and the person with the symptoms feel safer. This can sometimes prevent the symptoms from getting worse and make them go away faster.

It is difficult to give specific advice on how to help people with particular symptoms. A good starting point is to ask the person how they'd like to be supported when they're experiencing these symptoms. They might have a plan made with their healthcare team that you can follow. If not, you can ask this question at their next healthcare appointment.

Caroline's Experience

Asking these sorts of questions when a person is feeling better is probably more useful. If I was to ask Chris what sort of support he needs during a time of relapse, he was say 'I don't know,' and feel overwhelmed by the question.



Quite often, the **automatic responses** or coping strategies a person might have to their symptoms, can actually be unhelpful. If you recognize this in the person you are supporting, it's helpful to gently challenge these things and suggest different ways to deal with them.

An example plan to support someone with Dissociative Seizures:

If you are having a seizure, I will support you to a safe space where you are unlikely to injure yourself.

When you are in a safe place I will step back and encourage others not to touch you.

I will speak to you gently and reassuringly during the seizure but understand you will be unable to respond.

If other people are around, I will ask them to behave as they would if someone is having a panic attack (i.e. gentle, reassuring, give you space, not to call an ambulance etc.)

You might want to ask:

- **Have you noticed any triggers or warning signs that happen before symptom X starts?**
- **What do you normally think or do when you get symptom X?**
- **In what way is your current coping strategy helpful (in the short and long term)?**
- **Can you think of any other reactions you could try?**
- **What can I do to support you when X happens? (X=specific symptom etc.)**

Symptoms in relationship

When any one of us is sick, it's difficult to recover by ourselves. Getting better often happens with the help of the people around us. This is especially true with illnesses that involve complex physical, emotional, and social factors, like functional syndromes and disorders.

Having strong and positive social connections is linked to better outcomes for people with these symptoms. Even if it doesn't always seem like it, your relationship and support really matter to the person you're helping.

However, no relationship is perfect. Symptoms don't just impact the person experiencing them directly; they also affect those close to them, often putting relationships to the test.

Caroline's Experience

In the case of friends who wish to visit the ill person, it can be important to establish an understanding that visits may need to be short. Chris often had to ask his friends to leave after about 20 minutes of a visit as socialising was exhausting for him.



Healing relationships

Relationships best support healing when:

- **There is a joint intention for healing and well-being to occur**
- **The relationship is grounded in trust,**
- **You have good times together as well as sharing more difficult aspects**
- **The relationship benefits both parties**
- **The relationship feels safe, like being home and being known**

Shifting roles

Roles in a relationship can shift when someone becomes ill. The healthy person in the relationship may take on the role of the “helper” and feel they must always be strong. This can be manageable for a short time, but the pressure can build when symptoms persist. An imbalanced relationship isn’t beneficial for either party.

Balanced communication

Every one of us has limitations and needs. You, as the caregiver, also have tough days and require support, care, or time for yourself. To help keep a balance in a relationship it is important to make time to talk about your own vulnerabilities and needs with the person you are supporting.

Sometimes we avoid these discussions because it feels like an exercise in finding someone to blame for difficulties in a relationship. This can lead to defensiveness. It can be more helpful to frame imbalances in the relationship as a challenge that affects both of you. This shifts the perspective away from assigning blame to one person and makes it a joint effort to find solutions together.

Think about your own relationship. How does it feel to discuss your needs and expectations of each other?

Make time for yourself

Research shows that partners of individuals with chronic conditions are at greater risk of developing depression, anxiety, stress, and chronic pain themselves. This underscores the importance of taking care of yourself when someone close to you has longer-term symptoms.

Making time for yourself is a vital aspect of care. Put regular time aside for activities that give you a sense of enjoyment or satisfaction, such as seeing friends, and getting exercise.

You may feel guilty doing things for yourself, while the person you support may not be able to enjoy the same activities. But remember that nurturing your own interests and enjoyment in life is not selfish. It's the only way to sustain your ability to care for others.

Caroline's Experience

I had to accept the fact that I would have to go out and do things without Chris and have my own social life that didn't usually include him. This was really hard, but I had to do this.



Advice for parents:

Functional somatic symptoms effect the whole family. Children are often aware of problems in the family and may worry if their parent is unwell. Although it is hard to know how much information to share with children, if things are not discussed openly, children often fill in the gaps. For example, they might worry the illness is their fault, or that their parent has a life-threatening disease that is being kept from them.

Therefore it is important to keep an open communication with your children, where you can explain what functional symptoms are in age appropriate language. Let them know clearly it is not their fault. Let them know what they can do to help (for example to respect the need for peace and quiet at particular times of the day). Allow them to express any worries or concerns they might have.

If your child shows signs of symptoms themselves, it is normal to become worried. However it is good to know that functional symptoms are actually very common in childhood and adolescence.

There may be some factors in the genes which predispose people to FSS. However, in the main, FSS are not inherited illnesses.

Despite this, evidence shows that:

- **Children of chronic pain patients go to the doctor more often, use more painkillers and are hospitalized more often than children of healthy parents**
- **Children and young people of chronic pain patients have a higher risk of developing anxiety and depression than children of healthy parents.**

The above facts can be explained through social learning processes. We all inherit our core beliefs about the body from our parents. Children look to their parents' behavior to know how to respond to symptoms and manage illness.

Therefore it is important to model constructive behaviors around illness to your children.

It is also important that your worry about your children does not lead you to take over control of their life. As a young person it is especially important to develop independence, and symptoms (the parents or the child's) should not get in the way of this.

Advocate

If you care for someone, you will probably know a lot about their diagnosis, treatment and care. You will probably also know a lot about their likes and dislikes, and their personal history. Therefore you can play an important role in sharing information and advocating for them during interactions with the wider world.

Supporting someone around work and education

Supporting someone to manage their symptoms in the context of work and study needs to take into account many individual factors, but here's some general advice:

Sustaining Employment or Study: It's usually a good idea for people with Functional Somatic Symptoms to continue working or studying. If the level of pressure or stress can be managed, maintaining continuity and engagement with the wider world is beneficial.

Communicating with Employers and Educators: It can be helpful if employers and educators understand that the person has a condition with symptoms that can vary in severity. There might be times when the symptoms are not as bad (remission), and times when they worsen (exacerbation).

Gradual Return After Sick Leave: If the person has been on sick leave, it's often a good idea to return to work or study gradually. This allows the body time to adjust to the new routine. Occupational health services can assist in planning this and finding reasonable adjustments to improve work or study performance. These adjustments might include changes in the job role, reduced work hours, regular breaks, and flexible working arrangements.

Consider Alternative Roles: If, even after adjustments have been tried, it's not possible for the person to continue in their current job or studies, you might want to explore alternative roles, whether paid or unpaid. This might involve difficult decisions. It can help to have an open discussion with the person you support about what is best for their well-being overall.

Advocating for an optimal healing environment

In order to heal from functional somatic symptoms, a person needs to feel calm and relaxed in their surroundings. Unfortunately this is not always the case. An inadequate or unsafe housing situation, or financial insecurity, may act as a trigger or maintaining factor for symptoms. The person you support may benefit from your support as an advocate in these parts of life (housing, debt relief etc.).

When someone is living in a situation that does not allow them to feel calm and relaxed, it can take time to work out an alternative. During this time, you can support by inviting them out to spend time together in calm and pleasant public places. For example, visiting an art gallery or a park together.

Supporting someone through the healthcare system

Navigating health and social services when you have FSS is challenging for many complex reasons. This next section of the guide offers some general advice for carers.

Rules around sharing information

As a carer, you can share information with healthcare professionals that you think will be helpful. Unless the person you support has asked healthcare professionals not to talk to you, they should listen to the information you have to share. They should also consider how it might help with care and treatment.

Usually, the person you care for will give permission for their information to be shared with you. If this is the case, healthcare professionals should share information with you that will benefit the person you care for.



Professionals will often want to hear things in the patient's own words first.

Confidentiality

In some cases, the person you care for might not want you to be involved. When this happens, healthcare professionals won't be able to share information with you, except in specific circumstances.

This can be frustrating, however, it is important to respect these boundaries. If you are especially worried, this doesn't stop you contacting the emergency services or sharing information with health professionals when you feel this is necessary.

Sometimes medical professionals won't want to share information with carers, even if the person they are caring for has given consent. This can feel very disheartening, but it isn't a reflection on you or the person you care for. Try to speak to the health-care professional to find out why this is. If you think they do not have a good reason, you can make a complaint.

Before a healthcare appointment

Preparing for a medical appointment will make sure that you both get the best care and support.

Try to work with the person you care for as much as possible to understand:

- **How much they want you to be involved in their care**
- **Which areas of their care they want you to be involved in.**
- **What they are hoping to get out of the healthcare appointment**
- **What they might want to mention or ask**
- **If they have any worries or concerns about the appointment**
- **Encourage them to share their wishes with the people who are treating them.**

It can be helpful to write down information or keep a list of questions. You might want to write down together your top three concerns to make sure that you discuss these.

Attending healthcare appointments

If the person you support agrees, it can be helpful to attend healthcare appointments with them. You can help by:

- **Keeping track of what is explained and advised, and asking questions when things are unclear.**
- **Providing useful information to professionals when this is needed.**
- **Ask questions to ensure the care is focused on the person you support as an individual. For example, being a good advocate may sometimes involve questioning the need for interventions (investigations/medications). More healthcare is not always better healthcare.**
- **Helping build trust between the person you care for and the professionals treating them.**
- **At the end of the appointment, it might help to ask the person you care for:**
 - **If they have understood everything that has been said**
 - **If they have any questions**

Advocating for better services

In most European countries, there is currently inadequate provision of multi-disciplinary treatment for functional disorders. If you have the time and capacity, you could think about working with a patient organization to advocate for better services where you live.

Don't struggle on alone

As a carer, you might experience a lot of different challenges and difficult feelings including:

- **Stress from the pressures of caring for someone all the time**
- **Anger about your own life being 'put on hold'**
- **Guilt, shame or sadness about the fact the person you care about is ill**
- **Frustration with the way they act or the things they do**
- **Feeling isolated from family and friends who don't understand what you are experiencing.**
- **Challenges with coping and asking for help**
- **Concerns about money, housing, family or other things happening in your own life**
- **Losing your sense of 'self' or burning out**

If you are finding your role as a carer challenging, help and support are available.

Consider how you can ask others in your network of family and friends to support you in your caregiving role and help alleviate some of the pressure you may be facing.

It is a good idea to let your doctor know that you have caring responsibilities, especially if you notice your own physical and mental health is being affected. You might feel as though asking for help for yourself isn't a priority, but you are just as important as the person you are caring for. Don't neglect your own need to share difficult things in your life and seek support.

You might want to join a **local carers' support group**. Sharing experiences, practical advice and information with other carers can provide social and emotional support and reduce isolation. There are both online and in-person voluntary organizations, support groups and networks focused on mutual support for carers, friends and families.

Financial and practical support

Carers can be entitled to financial and practical support.

Depending on where you live, you will have a slightly different situation regarding the rights you have as a carer and the support available to you.

You might have questions about

- **What financial support is available to you as a carer**
- **Access to respite care or local carers support**
- **Specific advice for communicating with social care services**
- **Advice on workplace support like flexible or hybrid working**

Because there are significant differences in local legislation and social care systems, these resources can help explain what support you can access where you live:

United Kingdom:

<https://www.carersuk.org/help-and-advice/guides-and-tools/>

<https://carers.org/>