Patient information

CFS – What is CFS?

What is Chronic Fatigue Syndrome? (CFS)

Chronic fatigue syndrome (CFS) can also be called post viral fatigue or Myalgic Encephalomyelitis (ME). It is a complex condition and how and why it happens is still being investigated. We also don’t fully understand why people get CFS, but we know that it usually occurs following an episode of being unwell or following a virus. It is an unpredictable and changeable condition that can affect different systems of the body. The severity and impact of CFS also varies between people.

There is no test for chronic fatigue syndrome. Your GP or paediatrician may have carried out blood tests and or other investigations. A diagnosis of CFS is made based on your reported symptoms, how long they have been present, and by ruling out other conditions as a cause.

With the right support and following the advice given to you, people can recover within a few months but with some people it does take longer. We do know that children and young people make quicker and better recoveries from chronic fatigue syndrome than adults do.

Introducing your team

Your care team is made up of a paediatrician, a physiotherapist, and a psychologist. They each focus on a slightly different aspect of your treatment using NICE guidelines.

The paediatrician checks that there is no other reason for the symptoms you are having, will carry out investigations if needed, and will usually be the team member who makes the diagnosis of CFS.

The physiotherapist will help you to establish a daily routine and work out how much you can do without worsening your symptoms. They will work with you, and your family to establish a baseline level of activity and problem solve ways to increase your activity so that you can return to doing the things you previously enjoyed. They will also work with your school in planning a suitable timetable.

The psychologist will help you develop coping strategies for managing how you are currently feeling. They will support you and your family and help you deal with any upsetting thoughts or feelings you might be having. The psychologist and the physiotherapist will work with you on issues of motivation and helping you overcome the barriers to sticking to your treatment plan.

You may not see all the members of the team; it depends on the difficulties you are having. The team will share information and ideas on how to help you so you can access the right support to move forwards.

What are the symptoms of CFS?

Children and young people diagnosed with CFS report common complaints and symptoms such as

- Constant tiredness that gets worse with physical and mental activity and does not improve with sleep
- Unrefreshing sleep and or sleep disturbance
- Nausea
- Headaches
- Dizziness
- Loss or change in appetite
- Cognitive difficulties such as poor concentration, difficulty finding words, unable to multitask and forgetfulness
- Pain and joint and muscle aches
- Low mood

What you can expect from your team, and what your role is

It is important that you and your family fully understand the diagnosis of CFS. The team can help you identify what is important to you and help set your goals for treatment. This will involve discussing what makes you feel better or worse, what the most important areas of your life are, and what you want to prioritise.

An agreed daily routine needs to be established avoiding a “boom and bust” pattern of behaviour. The team will also discuss what symptoms are affecting you the most and help you to find ways of coping with these. They will liaise with school and your family to help them understand your condition and your treatment plan. You will help set realistic goals together.

What is asked of you is that you try your best to meet your goals. Sometimes you will not want to stick to your routine, you may want to stay in bed or get up and do more than what was in your plan. Either of these can worsen your symptoms, it is therefore really important that you take part in the day as planned. We know that this is hard, so please be honest about what you have been able to manage and how you really feel about the treatment plan.

If you are struggling to comply with the plan it is important you talk to your team and your family. The psychologist can explore ways that would help you to continue with the plan and your recovery and discuss what else you might find helpful to support you.

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