

LOCAL SUPPORT

ME/CFS Service for South Yorkshire & North Derbyshire

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75 Osborne Road

Michael Carlisle Centre

Sheffield

S11 9BF

We are open Monday to Friday, 9am to 5pm.

www.shsc.nhs.uk/services/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-service

Sheffield Yoga for ME/CFS

www.sheffieldyogaforme.org.uk

NATIONAL SUPPORT

NHS

www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/

Action for ME

For both children and adults with the condition.

www.actionforme.org.uk

The ME Association

www.meassociation.org.uk

Tymes Trust

Charity dedicated to children and young people with the condition.

www.tymestrust.org

For more local and national support check out our website.

ME/CFS INFORMATION BOOKLET

For people with ME/CFS/Long Covid/Post-Viral Fatigue Syndrome



The following booklet information can also be found on our website.



Scan me for our website

 Find us online & on Facebook

www.dawnofthenightingales.com

www.facebook.com/groups/dawnofthenightingales

dawnofthenightingales@hotmail.com

WHAT IS ME/CFS

ME/CFS stands for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. It is a long-term condition with a wide range of symptoms, the most common being extreme fatigue.

Long Covid is being recognised as a 'Post-viral Fatigue Syndrome' similar/the same as ME/CFS that is triggered by the Covid-19 virus.

It is called Post-viral Fatigue for usually the first sixth months before it is chronic and then called either ME/CFS.

The condition affects each person differently, while one person may struggle with a particular symptom, another might not suffer from it at all. The severity of ME/CFS can also vary, with some being able to work and lead a somewhat active life. At the same time, others are housebound or even bedridden.

Since this is a long-term condition it can affect many areas of a person's life. they will face many challenges and find themselves having to make adjustments. From using mobility aids, working less or giving up their job completely and having to rely on benefits and more.

May 12 is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) International Awareness Day. This day coincides with the birthday of Florence Nightingale, British nurse, statistician, and founder of modern nursing. She became chronically ill from a bacterial infection and was often bedridden later in life. Many believe she herself had the condition.

Dawn Of The Nightingales takes its name of 'Nightingales' from Florence. The lantern in our logo is a folded Turkish lantern, or fanoos which is what Nightingale relied on to illuminate her patients.

ADDITIONAL HELP

OTHER MOBILITY AIDS

If you get PIP, Motability scheme (www.motability.co.uk) can exchange your qualifying mobility allowance for a brand-new car, wheelchair-accessible vehicle, scooter or powered wheelchair.

Better Mobility has a list of charities that can help you with funding your mobility equipment. There are many charities that specialise in providing funding for children, and while it can be more difficult to find funding for adults, it is available. (www.bettermobility.co.uk/charity_funding_options.php)

CARER/HOME HELP

It can be difficult to take care of yourself and your home with a chronic condition, so you might need help from a carer at some point. Getting loved ones to help out is ideal if they are willing to come over to give your home a quick Hoover or change your bedsheets but sometimes we don't have someone who can help us.

If you want to get help from a paid carer your local council can arrange homecare for you if you're eligible for it or you can arrange your own.

Home help is slightly different and means day-to-day domestic tasks you might need help with. Great if you are able to care for yourself but struggle with your home. You Can contact a charity such as the Royal Voluntary Service, the British Red Cross, or a local Age UK to see whether they can help (it may not be free).

<https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/homecare/>
(above link is all one line or search 'help at home from a paid carer NHS' and it should be the first NHS link in the search results)

www.royalvoluntaryservice.org.uk/our-services/supporting-people/
www.redcross.org.uk/get-help/get-support-at-home
www.ageuk.org.uk/services/in-your-area/home-help/
www.gov.uk/apply-needs-assessment-social-services

ADDITIONAL HELP

Apart from Nightingales, there are many resources out there that can help you. From benefits, travel, websites and other resources. We have many of these listed on our website or/and forum. Below and on the next page are just some of the resources that could help you.

BENEFITS

Whether you can work or not, you could be entitled to one or more benefits. The most common one is PIP (Personal Independence Payment), which took over from (DLA) Disability Living Allowance.

Another is ESA (Employment and Support Allowance) or even a benefit/s to help if you're on a low income. This can help with heating, housing and other living costs.

For more information, visit : www.gov.uk/browse/benefits

TRAVEL

If you are unable to drive, getting around can be difficult. Especially if you struggle to get to bus stops or can not afford a taxi. Door-2-Door is a great alternative. Phone up to book, it's cheaper than a taxi and comes straight to your door. It's fully accessible and allows you to get out and about without having to rely on friends and family.

Barnsley - 01226 732096 | Doncaster - 01302 342400
Rotherham - 01709 517100 | Sheffield - 0114 285 9906

NHS MOBILITY AIDS

The NHS will let you borrow aids (walking sticks, walking frames, wheelchairs) and you can ask your GP for help in getting an NHS wheelchair. They will refer you to your local wheelchair service for an assessment and they will decide if you need a wheelchair and, if so, what type. You might be able to get a voucher, helping you pay towards the cost of a different type of wheelchair.

CAUSES OF ME/CFS

The cause of ME/CFS is not well understood and is still being studied. It is mostly triggered by infections, the person developing the condition after getting better from a viral or bacterial infection. Other ways include :

Genetics. The condition appears to run in some families, so some people may be born with a higher chance of developing the condition.

Physical or emotional trauma. There have been cases of people who have experienced an injury, surgery or high emotional stress shortly before their symptoms started.

Problems with energy usage. Some people with the condition have problems converting the body's fuel, primarily fats and sugars, into energy.

DIAGNOSIS

There is currently no specific test for ME/CFS. Diagnosis is based on your symptoms and ruling out all other conditions that could be causing the symptoms. Due to this diagnosing the condition can be difficult even time consuming.

Your GP is mostly likely to do a thorough medical examination and testing to rule out possibly conditions. These may include fibromyalgia, thyroid problems, anemia, Lyme disease, lupus, MS and more.

Usually a diagnosis of ME/CFS will be considered once other conditions have been ruled out or if you do not get better as quickly as expected.

There is also the case that you could have ME/CFS plus another condition/s. Many people with ME/CFS have multiple conditions. For example, both that of fibromyalgia and depression can be commonly found in people who have ME/CFS.

SYMPTOMS

ME/CFS affects multiple body systems, so it would probably be quicker to say what symptoms you can not have. People usually experience several symptoms, the severity can vary over time alongside what symptoms they suffer with. They can find themselves going years without ever having a particular symptom for it to start appearing later on. Or even one disappearing. The most common symptoms are fatigue, pain, sleep and cognitive problems.

Fatigue - Fatigue is a deep exhaustion that can not be lessened with sleep or rest. The severity of the fatigue can vary from person to person and also from one minute to the next. Activity, whether low-level or not, can worsen the fatigue. Doing too much can cause a setback making one's energy levels even lower and worsening symptoms for anywhere from 12 to 48 hours or longer.

Aches & Pains - This can be anywhere on the body from the joints or more commonly as an overall body ache/pain. This can be intensified by overactivity, lack of sleep/rest, anxiety, stress or even changes in the weather.

Sleep Problems - There are many problems a person with ME/CFS can have with sleep. Not only can it be nonrefreshing but the person could struggle with falling asleep, waking up through the night or/and getting up the next day.

Cognitive Problems - Most people with this condition experience cognitive difficulties, often called 'brain fog'. This can include feeling confused, difficulty concentrating, struggling with words/speaking and memory problems. To help with brain fog try reducing your activity, getting more rest/sleep, managing stress and limiting sensory input.

Other Symptoms - Headaches, sore throats, dizziness, sensitivity, sinus/nasal problems, abnormal temperature sensations, weight changes, depression, allergies and more.

TREATMENT

Unfortunately, there is no cure or effective treatment for this condition and full recovery is very rare. Due to this treatment is more the case of trying to control the symptoms and improving energy levels.

Symptoms can stabilize and/or improve over time with careful management of balancing activity and rest. Some people find particular things help them in improving their condition whilst others find the same thing can worsen their symptoms.

Since there is no common thing/medication that helps each and every person, there are many experiments to find out what works for each individual. There is also the case that over time something that once helped no longer works.

The best thing for ME/CFS is to manage the condition as best as you possibly can. Try to get into a routine with your sleep, having daily rest periods, make sure not to do too much at one time. Overtime once you find a nice balance and feel like you could do more, try to make some tiny changes by either increasing your activity or shortening a rest period.

ME/CFS is a juggling act and there will be periods when your condition could become worse due to stress, getting a cold/bug etc. Some find keeping a diary of their activity and rest periods helps them. If you have a setback a diary can show you where you might have done too much or too little.

You could use a notebook to track, an app of some kind or even search online for 'ME/CFS diary sheet', doing so brings up an collection of different types of printable sheets you can use to track your day to day, symptoms, sleep and more.

Nightingales also has some diary sheets on our website that are free to download/print yourself. www.dawnofthenightingales.com/downloads/