

Common Questions

What is the Yorkshire Fatigue Clinic?

We are a clinical assessment and rehabilitation service for people experiencing persistent fatigue. We specialise in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) but we also see people with fatigue related to other medical disorders. Our team has over 26 years' experience working in this area within the National Health Service (NHS), having set up one of the first specialist NHS services for CFS/ME in 1990. The Yorkshire Fatigue Clinic is an independent service based in York.

Who do we see?

Yorkshire Fatigue Clinic will provide assessment and intervention to adults aged 18 years old and over; and also to young people aged 13 -17 years old if they are under the care of a paediatrician. An initial assessment should always be made by the GP who can do standard investigations to exclude underlying medical problems that can be treated. For people with chronic fatigue often all of the routine test results will be within normal ranges. If you have had symptoms for over three months then specialist assessment and treatment needs to then be considered (as specified in the NICE Guidelines for CFS/ME).

What happens at the Yorkshire Fatigue Clinic?

The Yorkshire Fatigue Clinic offers a range of options to meet the needs of people with CFS/ME and other fatigue conditions. First, everyone will need an assessment which is normally done by a specialist therapist. If there are issues related to other possible medical diagnoses then we would suggest an assessment with a Consultant Immunologist, through the Nuffield Hospital in York. At the end of the assessment the diagnosis and options for therapy can then be discussed. It is important to understand what the diagnosis means and what therapy will involve. To help people to understand this further the clinic holds monthly Introductory Workshops and anyone undertaking therapy from the service, and the people who support them, attend the workshop before starting a therapy programme.

What does therapy involve?

The therapy interventions are based on over 26 years' experience of developing treatment programmes for people with CFS/ME. Therapy is individualised to each persons' needs and utilises evidence around how to change the way that energy is used on a daily basis to help regulate internal physiological processes. The therapy follows stages that aim to stabilise symptoms, then increase tolerance of activity and re-integrate daily life roles, such as going to work or school.

Therapy can be provided through a group programme, which provides support from other's with similar problems, or on an individual basis, depending on each persons' needs. For people who find it difficult to travel to York then sessions can be offered using telephone or telemedia, such as Skype.

If you are not funded through the NHS then the cost of sessions depends upon the type provided and prices are available on application.

How many therapy sessions are needed?

This will vary depending on the problem. We can be flexible to meet different needs, so some people may want occasional follow up sessions to support on-going progress whilst others may want a few sessions to learn the principle strategies and then manage their rehabilitation programme themselves. The average number of therapy sessions is eight, and people come for a session anywhere from every 2 weeks up to every few months.

Are staff suitably qualified and regulated?

The service is provided by appropriately qualified health professionals who are registered with the relevant professional body, such as Health and Care Professions Council. Current staffing includes:

Sue Pemberton, PhD, Specialist Occupational Therapist.

Sue is the former Clinical Lead and Consultant Occupational Therapist with the Leeds & West Yorkshire CFS/ME Service, working clinically in that service over a 22 year period. Sue then established the Yorkshire Fatigue Clinic in 2012.

Kelly Morgan, Specialist Occupational Therapist

Kelly worked previously as a Senior Occupational Therapist at the Leeds & West Yorkshire CFS/ME Service and in the past did voluntary work for the Association of Young People with ME. She contributed to a guide for the severely affected.

Joseph Bradley, Specialist Occupational Therapist

Joe previously worked as a Senior Occupational Therapist at the Leeds & West Yorkshire CFS/ME service, and has past experience working in rheumatology, chronic pain, and rehabilitation.

Stacey Maughan, Specialist Physiotherapist

Stacey works as a physiotherapist at York Hospital and has specialist experience working with children and young people working with CFS/ME.

All clinicians are members of the British Association of Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (BACME). The interventions provided are in accordance with national guidelines and practice, such as the NICE Guidelines. The service will not offer investigations or treatments which are not evidence based, which staff are not appropriately trained or qualified to provide, or for which the service does not have the appropriate equipment or resources.

Can carers be involved?

The people who support those suffering with fatigue disorders play an important role. We encourage carers or significant others to come to the assessment and workshop sessions. We normally see young people for a part of each session on their own and then do some joint work with

the parents included. Adults can choose how to involve others in their sessions, but group treatment sessions are for patients only. We can not accommodate dogs, except disability assistance dogs.

How do I consent to treatment?

There must always be voluntary and informed consent to treatment. This can be given by agreeing to the care plan discussed with the professional and requesting or attending further treatment sessions. Consent to treatment can be withdrawn at any time and therapy ended.

Is information confidential and protected?

Following your assessment, care plan, and at other key stages of your treatment we will write detailed letters as part of a collaborative approach to care. If you are referred by your GP, these will be addressed to the GP. For individuals who are self-funding, letters will be addressed to you, and you can decide if copies of correspondence are sent to your GP. You will automatically be sent a copy of letters about you unless you state you do not wish to receive these. Anything you discuss within your assessment and subsequent session may be reported within correspondence, and therefore please make the therapist aware of any issues you discuss which you do not wish to be disclosed. However, we have a duty of care to disclose anything that relates to a risk to your wellbeing or the wellbeing of others. If there are any areas of concern the therapist will discuss this with you and make you aware we are disclosing this information. If you have any concerns about letters being written about you, please discuss this with your therapist.

The service keeps electronic records on a secure, hosted system called *e-clinic* and uses Knowhow Business for letters and reports. These records enable the service to give the best possible care. They are kept in confidence and will be accessed by the professionals involved in the patient's care. For patients funded by the NHS we may need to share a minimal amount of personal information to facilitate commissioning and payment, we exclude name and address. In rare circumstances the service may need to share information about a patient with other organisations or authorities. This will be done to benefit their well-being or to comply with the law. If this is necessary, it will be done in a secure and confidential manner. The service will normally ask for the patient's consent to share any information with others. Exceptions to this would be in an emergency, where it is in the public interest, where there is danger to the patient or others or when required to by a court order or by law.

The service adheres to the Data Protection Act 1998. The service is registered as a Data Controller with the Information Commissioner's Office. The patient has the right to see the information that is held about them and what it is used for. Any requests should be made in writing to the service. The service may withhold data that contains reference to other clients or that may cause harm or distress. The service takes steps to ensure the security of personal data. If the patient gives consent to receive information about the service, this will only be used by the service and will not be passed on to any other body to use for marketing purposes.

We recognise that email can be a practical and accessible method of communication, and we will routinely confirm appointments via email. However, as we cannot guarantee recipients email is encrypted, we would remind you that email traffic could theoretically be intercepted and read by people without your permission. Also, any email we send can be accessed by anyone who has access

to your email account. Sending of personal information such as reports via email will only be done with your consent and acknowledgement of the risks detailed above. Emails containing information about your care will be considered to be part of your health record and copies stored accordingly.

How are outcomes measured?

Standardised clinical outcomes are collected at assessment and 12 months and/or discharge. The service also has an on-line patient satisfaction survey to collect feedback on patient experience. All outcome data collection is anonymous and the content may be shared with others as part of demonstrating the outcomes of the service.

What about complaints?

The service views feedback as a way of improving the care provided. Therefore, if there are any complaints about the care received these can be addressed informally with the service, through discussion or in writing. However, if we are unable to resolve the complaint then options for making a formal complaint are available. Clients whose care is funded by the NHS can also make formal complaints through their commissioning body or using the NHS Complaints Advocacy Service. In York this is provided through York Advocacy, Tang Hall Community Centre, Fifth Avenue, York YO31 0UG, Tel: 01904 414 357 or e-mail office@yorkadvocacy.org.uk. Patients can also share their opinions of the care they received through the Patient Opinion website.

Can assessment and treatment be funded through the NHS?

The Yorkshire Fatigue Clinic accepts NHS referrals from a GP. GPs within the Vale of York, Scarborough & Ryedale and Hambleton, Richmondshire & Whitby areas have an NHS contract with our service. The GP needs to send us a written referral with copies of all relevant medical investigations and a CFS/ME Pathway Form (available from the service). If the referral does not meet the criteria for our contract then we can still request NHS funding through the Individual Funding Panel. It can take a few weeks to get their decision on authorisation of NHS funding. However, for other areas NHS funding needs to be agreed prior to the referral being made. This would need to be discussed with the GP who would need to apply to the local Clinical Commissioning Group for funding approval. The NHS may place conditions upon the treatment offered, such as the number of sessions that will be funded or type of care to be provided.

If I want to self-fund then what about payment?

Each session is charged for individually and if you are self-funding sessions attended must be paid for prior to further sessions being provided. There are a variety of ways to pay and information is available upon application on prices and payment methods.

Can assessment and treatment be funded by Health Insurance?

We advise that this is clarified with the individual company in relation to the terms of the policy and whether assessment and / or treatment would be covered prior to referral to the Yorkshire Fatigue Clinic. Some insurance companies only cover acute conditions and treatment for these or will only fund a medical assessment, so please check the terms of your policy.

What if I can't come to my appointment?

Wherever possible we endeavour to make appointments that are convenient, however if you are unable to attend an appointment, please let us know by phone or email as soon as possible so that the appointment can be offered to others. If you do not attend an appointment without letting us know, we will send out a letter inviting you to arrange a further appointment. If we have no contact within 2 weeks of the date of the letter, we will discharge you. If you have been referred by your GP we will inform them of your discharge. If you are self-funding you will still be charged for the missed appointment. If you cancel three times, further sessions will only be offered at your therapist's discretion and we may discuss with you whether consistent engagement with therapy is possible at present.

Attending your appointment

When attending the service for the first time we suggest reading the information about parking and directions available on the Contact Us page of our website. If you cannot access this, please contact us for a paper copy. Please be aware there are parking restrictions at York Eco Business Centre that are outside of our control and fines may be implemented for parking within the Centre Car Park. Visitor parking is opposite the gates or available in unrestricted areas on the surrounding streets. If you can't attend the clinic due to the impact on your health contact us for other options, such as telephone or Skype.

If you have any individual questions, then please get in touch and we will help with your queries.

You can e-mail on sue@yorkshirefatigueclinic.co.uk or call 01904 479922.