

28th July 2022

Dear Dr Shepherd

Thank you for your email to South Coast Fatigue which was received on the 11th July 2022 explaining that the ME Association is monitoring the way the new Nice Guidelines are being implemented by specialist teams.

South Coast Fatigue is an independent therapy practice that has been commissioned by Hampshire, Southampton and IOW CCG (now ICB) to provide a therapy led intervention for patients with mild to moderate ME/CFS, since 2015.

We hope the answers below provide an explanation.

(1) Why is South Coast Fatigue currently unable to provide the multidisciplinary specialist team that is recommended in the new NICE guideline?

SCF provide a service according to the service spec of the contract. Funding has remained at the similar level for the duration of the contract (7 years)

(2) In particular, why is there no physician involved who can:

(a) confirm that the primary care diagnosis is correct - as recommended in section 1.4.3 of the new NICE guideline - as there is a significant rate of misdiagnosis of ME/CFS in primary care

(b) provide medical assessment and management for key symptoms such as pain relief and dysautonomia

(c) provide medicines management - as recommended in 1.5.2

The service spec does not include provision for a physician and therefore it is not funded. In addition, it has been our experience that service users are not expecting SCF to review medication and are content for this to remain with their GP who holds access to their full NHS clinical records.

(3) Why (in the GP referral protocol) is South Coast Fatigue using a different diagnostic criteria for ME/CFS in relation to both the timeline (i.e. 4 months of symptoms) and diagnostic symptom profile to the one that is recommended in the new NICE guideline?

South Coast Fatigue is a non-diagnostic service. The referral form does require an update and is something we are working on. We are also removing the referral form and all reference to it, from the website. We will be asking our commissioners to issue a communication to all surgeries, with the revised referral form once it is complete.

(4) Why does South Coast Fatigue only help people with mild or moderate ME/CFS when the NICE guideline sets out (in section 1.17) a very clear and detailed clinical care pathway for the care and management of people with severe and very severe ME/CFS and one that is going to require meaningful input from a specialist referral service?

SCF is not commissioned and does not have a contract to provide a service for people who have severe or very severe ME/CFS.

Historically, SCF did accept a small number of people severely affected by ME/CFS, funded on an individual basis by IFR. At the time the SCF team included other disciplines employed on an associate basis. These clinicians are no longer working for SCF so we are therefore, unable to offer this service.

And what happens to people with severe and very severe ME/CFS in the geographical area that you cover?

We have not received any referrals for people with severe or very severe ME/CFS in the last 18 months.

Is there anywhere that they can receive specialist care and support?

In the past, we have suggested that GPs refer to Leeds and these referrals have been approved.

(5) If the list of 'fatigue symptoms' on the website is meant to refer to diagnostic symptoms of ME/CFS (which I assume it does) why does it contain symptoms that are not diagnostic of ME/CFS (ie loss of motivation) and omit others that are very characteristic of ME/CFS (ie dysautonomia)

SCF is an independent practice and its NHS contract for ME/CFS is only a small part of the work we do. We work with clients who have fatigue from a wide range of conditions and the list on the website does not refer to ME/CFS. There is a separate tab on the website for the NHS ME/CFS contract.

(6) As it is now accepted that CBT cannot be used to treat or cure the underlying disease process in ME/CFS why is a 'History of a failed rehabilitation specific to ME/CFS (eg specialist CBT programme)..' placed in the exclusion criteria for being referred to the service?

This will be removed as part of the updating of the referral form.

(7) What happens to children and young people in the area that you cover?

SCF is commissioned to provide a service for people aged 16 years plus with mild/moderate ME/CFS and in full time education.

Please refer to Children's and young people's commissioners regarding under 16s with ME/CFS or those who are no longer in full time education.

Is there any form of specialist referral service in place, or being planned?

As above

Finally, it would obviously be helpful to know if you are planning to make any changes to the service you provide, especially in relation to care and management of people who are housebound with severe or very severe ME/CFS, so that it provides the full range of diagnostic and management services that are referred to in the new NICE guideline.

Unfortunately, this is not something that SCF would be able to provide for the reasons outlined and is a wider commissioning question.

We hope this is helpful in explaining a bit more about the service South Coast Fatigue provides.

Yours Sincerely

A handwritten signature in black ink, consisting of a large, stylized 'C' shape followed by a horizontal line and a small upward tick.

Fran Hill
Director
Advanced Practitioner Occupational Therapist
South Coast Fatigue