CARE AND SUPPORT PLANS

RECOMMENDATIONS FROM THE 2021 NICE CLINICAL GUIDELINE ON ME/CFS

JUNE 2022

THE ME ASSOCIATION

INTRODUCTION

A key recommendation from the NICE Clinical Guideline is that NHS specialist services should be primarily responsible for creating and co-ordinating a care and support plan - although this can also be done in primary care by a GP. This plan would be written in agreement with the patient or their representative and be regularly reviewed. It would form part of the ongoing care a patient should expect to receive from their specialist service and their GP and would be tailored to the individual. It would also be shared and reviewed with social care services should they be involved.

In this booklet we have provided all the Guideline's references to care and support plans and detailed the responsibilities of NHS primary and secondary care and social care services. We hope you can use it to explain to your healthcare providers what is required and that once a suitable care and support plan is established you will receive ongoing care and support.

Being able to regularly review progress and medications is important. Too many people with ME/CFS are not in regular contact with their GPs or specialist services and have no care and support plan in place. It may seem that, without an effective treatment for this condition and because of historic stigma, regular contact with a GP isn't worthwhile or is too much of a challenge.

But the NICE Guideline is changing the way your health needs are recognised. You should try and ensure progress is monitored regularly, so that your GP, specialist, or social care service can better understand your requirements and provide appropriate care and support when you need it most.

Janet Hassall who has ME/CFS wasn't making much progress when she tried to get her GP to recognise that people should have regular reviews and care and support plans in place. She didn't receive a satisfactory response to her first letter so she sent a follow-up which we have included below. You might like to use extracts together with the NICE Guideline recommendations should you experience similar difficulties.

Janet's full story was reproduced in ME Essential magazine (Summer 2022). We featured the recommendations for care and support plans and outlined primary and secondary care responsibilities in MEE Medical (Summer 2022) - the magazine for healthcare professionals.

How receptive were the NHS and social care to implementing these particular recommendations from the Guideline? Please email your experiences to: Feedback@meassociation.org.uk

You can nominate your healthcare professional to receive ME Medical magazine by completing a sign-up form on the ME Association website: **https://meassociation.org.uk/health-care-professionals**

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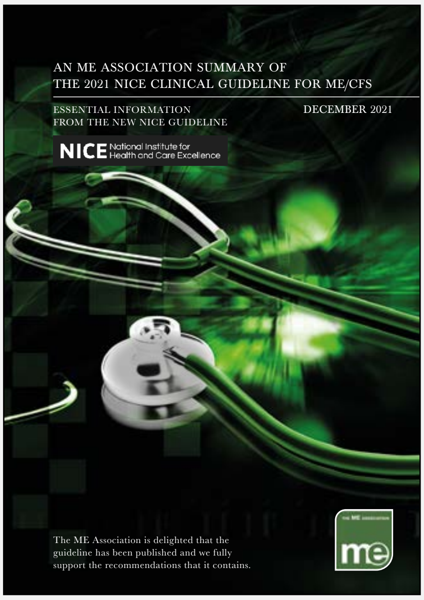

AN ME ASSOCIATION SUMMARY OF
THE 2021 NICE CLINICAL GUIDELINE FOR ME/CFS

ESSENTIAL INFORMATION
FROM THE NEW NICE GUIDELINE

DECEMBER 2021

NICE National Institute for Health and Care Excellence

The ME Association is delighted that the guideline has been published and we fully support the recommendations that it contains.

Please also refer to our free-to-download booklet, NICE Guideline for ME/CFS: An ME Association Summary:

https://meassociation.org.uk/9d0l

THE LETTER

Dear Doctor

Thank you for finding the time in your hectic schedule to send me feedback from the discussion at the Practice Meeting with regard to ME/CFS and for the kindly tone of your letter.

It was very helpful to understand better the nature of some of the annual reviews for chronic conditions and how they are often done to an established template by nurses. A template for a doctor-led review of ME/CFS could easily be formed based on a list of the main symptoms of ME/CFS.

However I did wonder if a differentiation between “management” and “treatment” of ME/CFS would be helpful. In your letter you imply that the decision not to institute an automatic annual review for people with ME/CFS was made at your meeting on the basis of there being no effective management for ME/CFS. Whilst it is true that there’s no direct treatment for ME/CFS, there are many things that can be done in terms of the management of symptoms and ameliorating the effects of this devastating illness.

Primary care can initiate and monitor medications to manage many of the symptoms of ME/CFS such as pain, sleep issues and associated comorbities such as digestive tract problems. Throughout the new NICE guidelines there is repeated emphasis on the importance of a management plan for ME/CFS, and there is a section about primary care which I sent to you. I’m sure the authors of the Guidelines were aware that there is no direct treatment for the condition and part of what they were repeatedly emphasizing when they talk about regular review was symptom management.

You say that anyone on medication will have an annual or more frequent review. In my experience that isn’t what has happened. I’m on the maximum dose of Pregabalin to treat pain associated with ME/CFS. At my last annual nurse-led review I asked about seeing a doctor to discuss a review of medication. I gained the impression that the nurse was unaware of this protocol and that I might be doubting her competence, and so it didn’t happen. I simply didn’t have the energy to oppose yet another healthcare professional saying that they couldn’t help me.

You say that patients can request a review at any time. To take an example, someone who is in great pain because of ME/CFS and struggles to find the energy to make a cup of tea, not to mention the cognitive difficulties associated with ME/CFS, may find it beyond their capacities to request help at all, let alone a review. I spend some time on the Facebook discussion group of the local ME and Fibromyalgia Group. People talk a lot about their unwillingness to see doctors because repeatedly being told by healthcare professionals that they cannot help is damaging to their mental health. Offering a supportive appointment annually could really help with this. To be honest, medication apart, just having someone listen would constitute a very good treatment.

In this booklet we hear from from **Janet Hassall** who experienced difficulties in gaining ongoing care and support from her GP surgery.

NICE GUIDELINE RECOMMENDATIONS FOR CARE AND SUPPORT PLANS

I'd like to raise the ethos associated with this issue. Particularly as I pointed out above this is a group of often seriously ill, vulnerable patients who may be averse to visiting doctors. In the past they have been offered inappropriate treatments and the new NICE guidelines give some hope that they may now be able to get some support. An ethos amongst GPs that they can now offer support would be a lifeline for those people.

Until these latest guidelines the illness has been viewed with unhelpful scepticism by many medical professionals. It was discussed on Woman's Hour recently and Dr. Shepherd, the medical advisor to the national ME Association, said that when he trained as a GP in the 1970s he was told that ME/CFS was a form of mass hysteria and should be ignored.

Whilst I am not suggesting that your practice takes this view or that your doctors still believe ME/CFS is a psychiatric illness, I do feel that there is a need for GP practices to consider their role in a more proactive approach to their patients with ME/CFS. For many years the treatment of this illness, which Dr Shepherd said can often have a bigger impact on people's lives than cancer or MS, has been left in the hands of patients. Self-help and self-management has been the only option. And whilst I'm sure you are happy to treat the symptoms of your patients with ME who have the emotional and physical strength to request treatment, I feel a more proactive approach would be supportive and in line with the ethos of your practice with regard to vulnerable people.

I've always admired the way your practice, having a high proportion of the more vulnerable and excluded within its cachement area, meets their needs, and in my case has supported me greatly in dealing with an unfair benefits system. One of your doctors offered many supportive appointments when there was little she could do in the form of treatment other than to listen. People with ME are a group of very vulnerable patients who could benefit from this ethos. Even Sajid Javid has acknowledged that something needs to be done about people with ME/CFS. Being proactive in the management of the symptoms of people with ME/CFS would go a small way to doing something. At the very least it would help their mental health to know that once a year there would be one appointment that they can look forward to, where somebody listens to their experience of an often serious and worsening illness, and reviews symptom management options.

I'm going to send a copy of this letter to the other partners in the hope that they'll understand that, far from there being nothing your practice can do, one supportive appointment a year would offer an anchor for patients struggling mentally and physically with a serious neurological immunological illness.

Sorry if this letter's a bit strong but I've nothing to lose really, and the whole issue of the treatment of people with ME/CFS is a national scandal that really needs a new approach from medical professionals in the light of the new NICE guidelines.

Regards, Janet Hassall

> "You say that anyone on medication will have an annual or more frequent review. In my experience that isn't what has happened. I'm on the maximum dose of Pregabalin to treat pain associated with ME/CFS"
>
> Janet Hassall

THE 2021 NICE CLINICAL GUIDELINE ON ME/CFS

The recommendations contained in the NICE Guideline make the development and review of care and support plans as well as ongoing care a key consideration for NHS primary and secondary care services. The following information has been taken directly from the NICE Guideline. We hope you'll find it useful when trying to get your GP or specialist service to establish and monitor a tailored care and support plan.

WHAT IS A CARE AND SUPPORT PLAN?

NICE Guideline Definition: The personalised collaborative care and support plan is developed by the ME/CFS specialist team based on a holistic assessment. It is the basis for other assessments and plans in areas such as social care, energy management, physical activity, physical functioning and mobility, cognitive behavioural therapy, and dietary management.

> "For many years the treatment of this illness, which Dr Shepherd said can often has a bigger impact on people's lives than cancer or MS, has been left in the hands of patients"
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Please note: The information on the pages that follow are extracts taken from the clinical guideline and may not entirely reflect the ME Association's position on certain issues.

NICE GUIDELINE RECOMMENDATIONS FOR CARE AND SUPPORT PLANS

1.15 REVIEW IN PRIMARY CARE

1.15.1 Offer adults with ME/CFS a review of their care and support plan in primary care at least once a year.

1.15.2 Offer children and young people with ME/CFS a review of their care and support plan at least every 6 months.

1.15.3 Arrange more frequent primary care reviews for children, young people, and adults with ME/CFS as needed, depending on the severity and complexity of their symptoms, and the effectiveness of any symptom management.

1.15.4 When carrying out a review in primary care, ensure you have access to the person's care and support plan and any clinical communications from the ME/ CFS specialist team (including their discharge letter, if relevant).

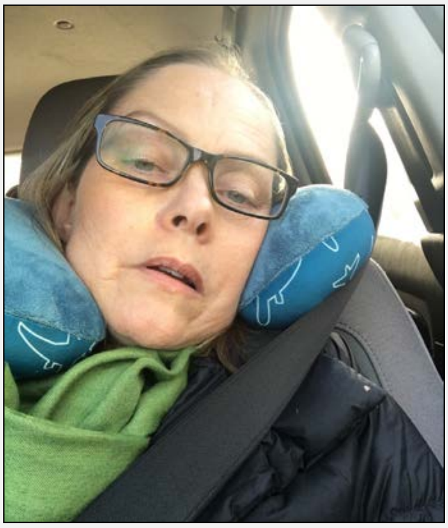
1.15.5 As part of the review, discuss with the person with ME/CFS (and their family or carers, as appropriate) and record as a minimum:

- their condition, including any changes in their illness and the impact of this,
- symptoms, including whether they have experienced new symptoms,
- self-management,
- ask about their energy management plan and (if relevant) their physical activity or exercise programme,
- who is helping them and how they provide support,
- psychological, emotional, and social wellbeing,
- any future plans,
- ask if the person is considering any changes or if they have any challenges ahead.

1.15.6 Refer the person with ME/CFS to their named contact in the ME/CFS specialist team if there are any new or deteriorating aspects of their condition.

1.15.7 Consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether a referral is needed.

1.15.8 Evaluate and investigate whether new symptoms, or a change in symptoms, are due to the person's ME/CFS or whether they are due to another condition.



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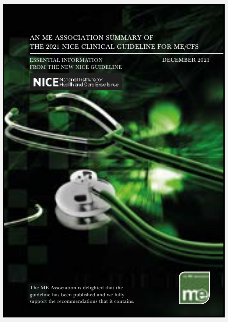

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The ME Association is delighted that the guideline has been published and we fully support the recommendations that it contains.

The ME Association has produced a free-to-download booklet, NICE Guideline for ME/CFS: An ME Association Summary. It lets you know what to expect from the NHS and social care services with regard to symptom recognition, diagnosis, management, referral, and ongoing care and support.

https://meassociation.org.uk/9d0l

1.4 DIAGNOSIS

1.4.3 Refer adults directly to an ME/CFS specialist team to confirm their diagnosis and develop a care and support plan.

1.4.4 Refer children and young people who have been diagnosed with ME/CFS after assessment by a paediatrician (based on the criteria in recommendation 1.2.2) directly to a paediatric ME/CFS specialist team to confirm their diagnosis and develop a care and support plan.

1.5 ASSESSMENT AND CARE AND SUPPORT PLANNING BY AN ME/CFS SPECIALIST TEAM

(Also see the section on care for people with severe or very severe ME/CFS)

1.5.1 Carry out and record a holistic assessment to confirm the person's diagnosis of ME/CFS and inform their care and support plan. This should include:

- a medical assessment (including relevant symptoms and history, comorbidities, overall physical and mental health, anything that is known to exacerbate or alleviate symptoms, and sleep quality),
- physical functioning,
- the impact of symptoms on psychological, emotional, and social wellbeing,
- current and past experiences of medicines (including tolerance and sensitivities), vitamins and mineral supplements,
- dietary assessment (including weight history before and after their diagnosis of ME/ CFS, use of restrictive and alternative diets, and access to shopping and cooking).

1.5.2 Develop and agree a personalised care and support plan with the person with ME/CFS and their family or carers (as appropriate) informed by their holistic assessment. Include the following, depending on the person's needs:

- information and support needs (see the section on information and support),
- support for activities of daily living (see the section on access to care and support and recommendation 1.6.8 on accessing social care),
- mobility and daily living aids and adaptations to increase or maintain independence (see the recommendations on aids and adaptations),
- education, training, or employment support needs (see the section on supporting people with ME/CFS in work, education, and training),
- self-management strategies, including energy management (see the recommendations on energy management),
- physical functioning and mobility (see the recommendations on physical functioning and mobility),

> "Give adults, children, and young people with ME/CFS and their family or carers (as appropriate) a named contact in their primary care and/or ME/CFS specialist team to coordinate their care and support plan, help them access services, and support them during periods of relapse."
>
> 1.10.3

- managing ME/CFS and symptom management, including medicines management (see recommendations 1.12.1 to 1.12.26 on managing symptoms),
- guidance on managing flare-ups and relapses (see the section on managing flare-ups in symptoms and relapses),
- details of the health and social care professionals involved in the person’s care, and who to contact (see recommendation 1.10.3).

1.5.3 Recognise that the person with ME/CFS is in charge of the aims of their care and support plan.

1.5.4 Give the person and their family or carers (as appropriate) a copy of their care and support plan. and share a copy with their GP.

1.7 SAFEGUARDING

1.7.6 Offer children and young people with ME/CFS a review of their care and support plan at least every 6 months, and more frequently if needed, depending on the severity and complexity of their symptoms.

1.8 Access to care and support

AIDS AND ADAPTATIONS

1.8.8 For people with moderate ME/CFS or severe or very severe ME/CFS, consider providing or recommending aids and adaptations (such as a wheelchair, blue badge or stairlift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits. Include these in the person’s care and support plan.

1.9 Supporting people with ME/CFS in work, education, and training.

1.9.1 Offer to liaise on the person’s behalf (with their informed consent) with employers, education providers and support services. Give them information about ME/CFS and discuss the person’s care and support plan and any adjustments needed.

1.9.4 Health and social care professionals should work with training and education services to:

- provide information about ME/CFS and the needs and impairments of children and young people with ME/CFS, including the need for a balance of activities in their life,
- discuss the child or young person’s care and support plan so that everyone has a common understanding of their priorities, hopes and plans,

Develop and agree a personalised care and support plan with the person with ME/CFS and their family or carers, informed by their holistic assessment

- discuss a flexible approach to training and education – this could include adjustments to the school day, online learning or education at home and using assistive equipment.

1.10 MULTIDISCIPLINARY CARE

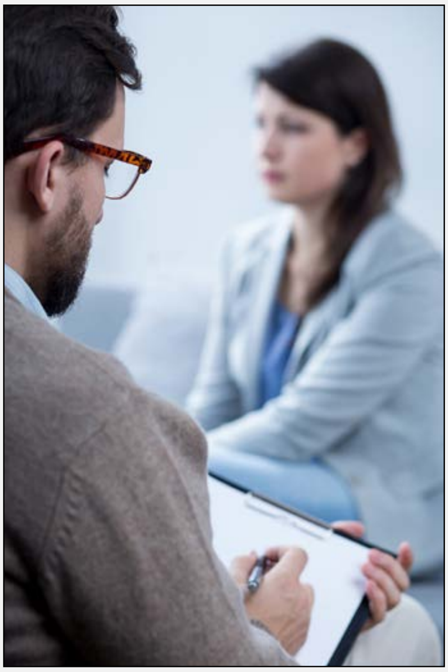
1.10.1 Provide care for people with ME/CFS using a coordinated multidisciplinary approach. Based on the person's needs, include access to health and social care professionals with expertise in the following as a minimum, with additional expertise depending on symptoms:

- medical assessment and diagnosis,
- developing personalised care and support plans,
- self-management strategies, including energy management,
- symptom management, including prescribing and medicines management,
- managing flare-ups and relapses,
- activities of daily living, including dental health,
- psychological, emotional, and social wellbeing, including family and sexual relationships,
- diet and nutrition,
- mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services,
- social care and support,
- support to engage in work, education, social activities, and hobbies.

1.10.3 Give adults, children, and young people with ME/CFS and their family or carers (as appropriate) a named contact in their primary care and/or ME/CFS specialist team to coordinate their care and support plan, help them access services and support them during periods of relapse.

1.11.3 Help people with ME/CFS develop a plan for energy management as part of their care and support plan. Support them to establish realistic expectations and develop goals that are meaningful to them. Discuss and record the following in the plan along with anything else that is important to the person:

- cognitive activity,
- mobility and other physical activity,
- ability to undertake activities of daily living,
- psychological, emotional, and social demands, including family and sexual relationships,



Provide care for people with ME/CFS using a coordinated multidisciplinary approach including access to health and social care professionals

- rest and relaxation (both quality and duration),
- sleep quality and duration,
- effect of environmental factors, including sensory stimulation.

1.12.4 Review the use of rest periods and sleep management strategies regularly as part of the person's care and support plan.

PHYSICAL FUNCTIONING AND MOBILITY

1.12.5 Include strategies to maintain and prevent deterioration of physical functioning and mobility in the care and support plans of people with ME/CFS. These strategies may need to be carried out in small amounts and spread out throughout the day. Think about including the following:

- joint mobility,
- muscle flexibility,
- balance,
- postural and positional support,
- muscle function,
- bone health,
- cardiovascular health.

1.12.8 Give families and carers information, advice, and support on how to help people with ME/CFS follow their care and support plan in relation to physical functioning and mobility. This may include:

- bed mobility,
- moving from lying to sitting to standing,
- transferring from bed to chair,
- using mobility aids,
- walking,
- joint mobility,
- muscle stretching,
- muscle strength,
- balance,
- going up and down stairs.

1.14.3 Include guidance on managing flare-ups and relapses in the person's care and support plan.

Include strategies to maintain and prevent deterioration of physical functioning and mobility in the care and support plans of people with ME/CFS

NICE GUIDELINE RECOMMENDATIONS FOR CARE AND SUPPORT PLANS

1.14.5 Discuss and agree self-management strategies with the person with ME/CFS to help them respond promptly if they have a flare-up or relapse, and record these in their care and support plan. This should include:

- For a flare-up:
  - identifying possible triggers, such as acute illness or over-exertion (in some cases, there may be no clear trigger),
  - temporarily reducing their activity levels
  - monitoring symptoms, recognising that although flare-ups are transient, some will develop into a relapse,
  - not returning to usual activity levels until the flare-up has resolved.
- For a relapse:
  - reducing, or even stopping, some activities,
  - increasing the frequency or duration of rest periods,
  - reassessing energy limits to stabilise symptoms.

1.14.6 If a flare-up or relapse cannot be managed using the person's self-management strategies outlined in their care and support plan, or they are worried about new symptoms or a change in symptoms, advise the person to contact their named contact in primary care or the ME/CFS specialist team.

1.14.7 When a person with ME/CFS has a relapse, review their care and support plan with them (if needed), and discuss and agree a course of action, taking into account:

- possible causes of the relapse, if known,
- the nature of the symptoms,
- the severity and duration of the relapse (bearing in mind this can be years).

1.14.8 Once a flare-up or relapse has resolved or stabilised, discuss with the person:

- whether their care and support plan needs to be reviewed and adjusted to reflect their current symptoms and energy limit if this is different from before the flare-up or relapse (for people participating in physical activity or exercise programmes, see recommendations 1.11.15 and 1.11.16),
- their experience of the flare-up or relapse to determine whether strategies can be put in place to manage potential triggers in the future.

When a person with ME/CFS has a relapse, review their care and support plan with them (if needed), and discuss and agree a course of action

1.17 CARE FOR PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

Assessment and care and support planning by an ME/CFS specialist team (Also see the main section on assessment and care and support planning by an ME/CFS specialist team.)

1.17.5 Offer home visits to people with severe or very severe ME/CFS to carry out their holistic assessment and develop their care and support plan.

ACCESS TO CARE AND SUPPORT

HOSPITAL CARE

1.17.7 When planning hospital care for people with severe or very severe ME/CFS:

- discuss with the person (and their family or carers, as appropriate) what to expect when they come into hospital,
- aim to minimise discomfort and post-exertional malaise during transfer to hospital, for example by planning the route in advance, avoiding noisy areas, and admitting them straight to the ward on arrival,
- discuss the person’s care and support plan with them, including information on comorbidities, intolerances, and sensitivities, to plan any reasonable adjustments that are needed,
    - aim to provide a single room, if possible,
    - keep stimuli to a minimum, for example by:
    - seeing them one-to-one,
    - using calm movements and gestures,
    - not duplicating assessments,
    - being cautious about the pressure of touch,
    - keeping lights dimmed,
    - reducing sound,
    - keeping a stable temperature
    - minimising smells.

WHY THE NICE GUIDELINE COMMITTEE MADE THE RECOMMENDATIONS

The NICE Guideline committee agreed that the key to managing ME/CFS symptoms successfully is having a collaborative personalised

Offer home visits to people with severe or very severe ME/CFS to carry out their holistic assessment and develop their care and support plan care and support plan. This should be developed based on a holistic assessment as soon as the person's diagnosis is confirmed.

The committee agreed that a medical assessment should be part of this assessment, typically requiring access to a medically trained clinician. A copy of the care and support plan can be shared with primary care and a copy held by the person themselves, and it can be referred to in situations such as planning an admission to hospital.

In the committee's experience, this approach to assessment and planning is common in ME/CFS specialist teams. The committee outlined key areas to assess what support might be needed, based on their experience. The committee noted that the key areas to assess and the support needed will depend on the person's severity of ME/CFS, the impact of their symptoms and their needs.

Once the care and support plan is agreed, it then provides a basis for the more detailed assessments and plans outlined in specific interventions in the guideline, such as social care needs assessments, energy management, physical functioning and mobility, cognitive behavioural therapy (CBT) and dietary management.

HOW THE RECOMMENDATIONS MIGHT AFFECT PRACTICE

Carrying out a holistic assessment and developing a care and support plan is already current practice in ME/CFS specialist services, although there may be more referrals to the specialist service resulting from these recommendations.

However, having a care and support plan will facilitate people's care and may lead to better outcomes. If assessment is carried out early and a care plan is implemented, it could reduce resource use in the longer term by preventing progression of disease.

MULTIDISCIPLINARY CARE

WHY THE COMMITTEE MADE THE RECOMMENDATIONS

Extract:

In the committee's experience, care for most people with ME/CFS can be managed in primary care after their diagnosis is confirmed and they have a care and support plan agreed.

However, the committee acknowledged the lack of confidence that non-specialists can have in managing ME/CFS and they recommended support from an ME/CFS specialist team.

The qualitative evidence showed that people with ME/CFS valued continuity of care and the committee agreed that having a single point of contact in their care team would avoid needing to have contact and appointments with multiple professionals which, for some people, could worsen their health.

HOW THE RECOMMENDATIONS MIGHT AFFECT PRACTICE

The recommendations on the ME/CFS specialist multidisciplinary team, providing a named contact and giving support to primary care services may need resources.

Current provision of ME/CFS specialist teams is very uneven across the country and increased staffing may be needed in some areas if there are more referrals. The specialist team will need to cover different areas of expertise, but most people will only need access to some elements and only at specific times.

However, faster access to diagnosis and appropriate care should lead to better symptom management and to substantially better outcomes for people with ME/CFS and so might reduce health and care costs in the longer term.

Allocating a single point of contact to people with ME/CFS is not routine practice across the NHS. This could be implemented differently in different regions according to local service structures and may not necessarily need the addition of new staff. It could improve the efficiency of care for people with ME/CFS by reducing the burden of repeated appointments.

ISSUE 162 ■ SUMMER 2022

THE ME ASSOCIATION

ME Essential

NEWS
Sajid Javid promises radical action for those debiitated with ME/CFS. MEA grants additional £175K to Uk ME/CFS Biobank. Launch of new MEA online resource. DeCodeME test phase is launched.

ME AWARENESS WEEK 2022
Anna Redshaw's Blue Sunday Tea Party smashes the records, and Sarah Elsby achieves 1,000 burpees in just three hours.

MENTAL HEALTH
Mental health and disability. The long-term effects of bullying. Trauma, grief and understanding.

FUNDRAISING
Garden in Gorseinon to raise money for the MEA. Gordon Jackson completes his 500-mile Scottish walk.

BECOME A MEMBER OF THE MEA

We have an excellent members' magazine and all we ask in return is a very reasonable subscription.

We rely on the support on our members and put their interests at the heart of everything we do.

We have kept subscriptions affordable because we know how much of a lifeline ME Essential magazine can be.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is also available to carers, family-members, and anyone with a professional interest in the condition.

Annual membership costs:
- £18.00 (UK residents and BFPO)
- £24.00 (Mainland Europe including Republic of Ireland)
- £30.00 (Rest of the World)

https://meassociation.org.uk/8cjm

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THE ME ASSOCIATION

ME CONNECT

The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect

Contact ME Connect
3 WAYS TO GET IN TOUCH:
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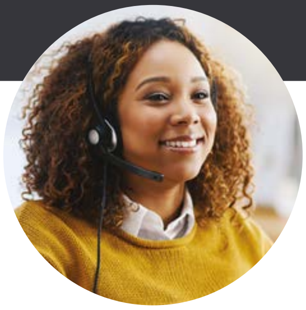

HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.

VITAL SUPPORT

We are here to help you reach an informed decision.

SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!

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