

## Worcestershire M.E. Social Group Website Information

ME/CFS Local Services (BLOGS & INFORMATION): 2023.01.07 - 2023.04.15

### **NHS ME/CFS Specialist Services**

<https://worcsmegroup.weebly.com/about-me.html#6aWorcs-CFS-ME-LMDT>

For a new ME/CFS diagnosis request a referral through your GP. The nearest service to the centre of Worcestershire is at the Barbury, Edgbaston, Birmingham. There is information about the Barbury site location through here or here (with map). Other ME/CFS centres are in Bristol, Bath, Oxford and Brecon as listed on the ME Association website.

After you have received a diagnosis, request a referral through your GP to the Worcestershire ME/CFS Therapy Team who can be contacted through Malvern Community Hospital. (Contact Information: 01684 612671 [WHCNHS.chronicfatigue@nhs.net](mailto:WHCNHS.chronicfatigue@nhs.net) and their webpage NHS Worcestershire ME/CFS Specialist Services).

In April 2022 the Worcestershire M.E. Social Group received a copy of this notification (pdf) stating that the ME/CFS Service run by Infectious Diseases with Consultant input at Worcestershire Acute Hospital had been Decommissioned and they are now unable to take patients for ME/CFS or Fibromyalgia. Our blog Decommissioned - ME/CFS Service at Worcestershire Acute Hospital explains that this letter was sent from Dr Mirella Ling Consultant Physician in Infectious Diseases, Worcestershire Acute Hospitals NHS Trust, to Worcestershire GPs in April 2021.

## Worcestershire ME Social Group Website News Blogs

<https://worcsmegroup.weebly.com/blog>

### **Worcestershire NHS ME/CFS Local Services News**

<https://worcsmegroup.weebly.com/blog/worcestershire-nhs-mecfs-local-services-news398788415/4/2023>

The Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) Herefordshire & Worcestershire Health and Care NHS Trust webpage was updated in January, with information included on our ME/CFS Local Services webpage update blog.

This is a specialist part-time service that delivers support and treatment to people with ME/CFS within community settings across Herefordshire and Worcestershire.

At the end of March, we received further information from Marina Townend, Specialist Occupational Therapist/ Team Lead, of the Worcestershire & Herefordshire ME/ Chronic Fatigue Syndrome and Post-Covid Syndrome services, updating us on the situation at the Herefordshire and Worcestershire NHS ME/CFS Local Services, and responding to our queries. Marina hopes to be with us at our next Worcestershire M.E. Social Group Afternoon Café Meeting (*see end of this blog*).

### **Changes to the Worcestershire NHS Service, following the revised NICE (The National Institute for Health and Care Excellence) Guidelines, published in October 2021**

Marina informed us -

We have gone through the changes in the revised guidelines as a team, and developed an action plan to ensure that we are following them. Some of these actions are still work in progress as I'm sure you can appreciate that it is time-consuming, and we are already under a huge amount of pressure carrying out our day-to-day work. However, we check in each team meeting to make sure these have not been forgotten and are still progressing.

Actions included changing our language to ME/CFS from CFS/ME (in written format and when speaking), updating our referral protocol and service literature to ensure that they reflect new guidelines, developing a workshop for carers, and compiling a care and support plan. We are in on-going conversations with our commissioner about medical cover and also regarding how we work with people who are severely affected. We were not offering CBT or GET as a 'cure' for ME/CFS so our approach to therapy has not changed - we see these interventions as beneficial for some people, at the correct time, and if applied in an appropriate manner.

### **The Current Worcestershire NHS ME/CFS Specialist Services, -**

We recently mentioned to Marina -

On the [NHS ME/CFS Service webpage](#), it states - "we work as a multi-disciplinary team with Occupational Therapists, Physiotherapists and Psychologists".

Marina's response included -

We have Nikki Mills (Physiotherapist) working in the Post Covid team 1.5 days/week. She doesn't cover ME/CFS, but will offer guidance and resources to the team at times. We are very much hoping to recruit a physiotherapist still and are in the process of going to recruitment again. The PCS service also has access to Carrie Garrett, a Speech and Language Therapist, who offers us approximately 1 session/month.

### **Diagnosing Long Covid**

Marina informed us -

Diagnosing Long Covid is more straight forward than ME/CFS, and GPs seem to feel more comfortable with this as many people have had a positive Covid test, or recognise the symptoms of the Covid virus. If other possible causes of on-going symptoms have been ruled out, Long Covid is diagnosed by the GP.

This situation is likely to change, however, as testing is reduced, and new variants have different symptoms which are maybe less recognisable as Covid-19. We anticipate that there will be more referrals to the ME/CFS service, and hope that the distribution of funding will reflect this. It is one of the reasons why it has been decided that the PCS service should sit under the umbrella of the ME/CFS service, to allow some flexibility with this. Referral to the PCS service is mainly via GPs, but other clinicians sometimes refer as well.

[Previous news](#) from Marina Townsend is available from our blog last month.

### **Next Month**

Marina informed us -

I am hoping to come to the Social Group on 10th May. I look forward to seeing you again and will be very happy to answer any questions then.

Please join us, when we look forward to greeting Marina at our next [Afternoon Café Meeting](#). This will be held during ME Awareness Week on Wednesday, 10 May, from 2.00 - 3.30 pm, in the Next Café, above the Next store at the Elgar Retail Park, Blackpole, Worcester, **WR3 8HP**.

Our recent [Worcester Afternoon Café Meetings](#) blog, gives [future dates](#), and further information.

The new **Myalgic encephalomyelitis (or encephalopathy)/ chronic fatigue syndrome: diagnosis and management**. [NICE guideline \[NG206\]](#) was published in October 2021.

See also from our website -

[NICE ME/CFS: new Guideline \(New downloadable Publications\)](#).  
19/1/2022

[NICE ME/CFS: new Guideline \(Reactions\)](#).  
25/11/2021

[NICE ME/CFS: new Guideline now Published](#)  
29/10/2021

## **Worcestershire NHS ME/CFS Local Services News**

<https://worcsmegroup.weebly.com/blog/worcestershire-nhs-mecfs-local-services-news-9/3/2023>

The Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) Herefordshire & Worcestershire Health and Care NHS Trust [webpage](#) was updated in January, with information included on our ME/CFS Local Services [webpage update](#) [blog](#).

### **Worcestershire NHS ME/CFS Local Services News.**

The Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) Herefordshire & Worcestershire Health and Care NHS Trust [webpage](#) <https://www.hacw.nhs.uk/services/service/chronic-fatigue-syndrome-cfs-72/#service-about-the-service-tab> was updated in January, with information included on our ME/CFS Local Services [webpage update](#) <https://worcsmegroup.weebly.com/blog/worcestershire-mecfs-local-services-webpage-update> [blog](#).

This week, we've received further information from Marina Townend, Specialist Occupational Therapist/ Team Lead, of the Worcestershire & Herefordshire ME/ Chronic Fatigue Syndrome and Post-Covid Syndrome services, updating us on the situation at the [Worcestershire NHS ME/CFS Local Services](#). <https://www.hacw.nhs.uk/services/service/chronic-fatigue-syndrome-cfs-72/>, and responding to our queries.

### **Diagnosing ME/CFS,**

Marina informs us -

Unfortunately, we are still unable to confirm a diagnosis of ME/CFS within this service, despite our continued efforts to resolve this situation. Last year, a service level agreement was made with Birmingham and Solihull Trust whereby the Consultant in their ME/CFS service would assess 50 people within Herefordshire and Worcestershire who have a suspected diagnosis of ME/CFS. Once a diagnosis has been confirmed, we then provide a service to those patients. This temporary arrangement has worked well but there isn't capacity to continue so we need to find another solution.

We have been working closely with our commissioner to identify various options, and these are being discussed with GP's and at executive level within the Trust and ICB. I hope a model will be agreed soon and look forward to local people being able to receive a diagnosis (and therefore support and treatment) in a timely way.

In the meantime, GPs continue to refer to this service. We advise about other options for diagnosis ([as detailed on your website https://worcsmegroup.weebly.com/about-me.html#6aWorcs-CFS-ME-LMDT](#) ) and hold a list of the patients who are in this position. We have also told people about the (paying) Healthcare service that Action for ME offer, but appreciate this is not an option for everyone.

Action for ME's "[Healthcare Services for M.E.](https://www.actionforme.org.uk/get-support-now/our-healthcare-services/healthcare-services-for-me/)" <https://www.actionforme.org.uk/get-support-now/our-healthcare-services/healthcare-services-for-me/> (mentioned by Marina above).

Following our merger with The ME Trust in February 2022, we are now able to offer Healthcare Services alongside our [Information and Support](#), [Family Support](#) and [Advocacy](#) services.

Click on the menu for more information about each clinical service, including how to refer yourself and details of fees.

Action for ME give details of [bursary support](https://www.actionforme.org.uk/get-support-now/our-healthcare-services/bursary-support/) <https://www.actionforme.org.uk/get-support-now/our-healthcare-services/bursary-support/> on their website.

## **Covid-19,**

Marina informs us -

Since October 2021, the Post Covid Syndrome (PCS) service sits under the umbrella of the ME/CFS service. Sara Young (OT) has been seconded to the Clinical Lead post, and Helen Ayres (Psychologist) and I both work additional hours to staff the PCS service. Demand has been very high, and it has been difficult to recruit to the service due to the way that the government provides funding on an annual basis at present.

## **The Current Worcestershire NHS ME/CFS Specialist Services, -**

Marina informed us -

We have recently welcomed Ceri Howell, Therapy Assistant, to the team and she works full-time hours across both services. Mya Krishnan, Clinical Psychologist, also started with us last May, working 2 days/week.

I am currently covering all the Occupational Therapy input in the ME/CFS service. Unfortunately, the team has been without full admin support for the past 14 months, which has been difficult but will hopefully improve soon.

We continue to offer 1:1 and group interventions, mainly (but not exclusively) on-line as the feedback we have received suggests that this is generally helpful to manage fatigue. We are starting to get more referrals from Herefordshire GP's now, and still receive a steady stream of referrals for people with the condition who live in Worcestershire.

Marina also apologised for the time it has taken her to get back to us. She explained - - it has been an even busier couple of months as I have had two 3rd year students (OT and Physiotherapy) with me and the team, and new staff members to induct. All very positive but also time consuming...!

We are still making edits to our website, and any feedback is welcome as we are keen to improve it further, within the corporate constraints of design. I am aware there are various typos and some links that need updating, and I am still liaising with our Comms team about these so hopefully the website will be amended soon.

I was very sad to hear about Warwick but I'm pleased that you have resumed your meet-ups, and hope to come along to one of these in the next couple of months. It has been a challenging time for many over the past few years, and support from us all is valued and much needed.

The new **Myalgic encephalomyelitis (or encephalopathy)/ chronic fatigue syndrome: diagnosis and management**. [NICE guideline \[NG206\]](#) was published in October 2021.

See also from our website -

[NICE ME/CFS: new Guideline \(New downloadable Publications\)](#).  
19/1/2022

[NICE ME/CFS: new Guideline \(Reactions\)](#).  
25/11/2021

[NICE ME/CFS: new Guideline now Published](#)  
29/10/2021

## **Worcester Afternoon Café Meetings**

Our next Afternoon Café Meeting will be from **2.00 - 3.30 pm, on Wednesday 12 April**, in the Next Café, above the Next store at the Elgar Retail Park, Blackpole, Worcester, WR3 8HP. (There is a lift and escalator in the store, plus plenty of parking, including blue badge spaces near the main entrance.)

Our recent **Worcester Afternoon Café Meetings** blog, gives future dates <https://worcsmegroup.weebly.com/blog/worcester-afternoon-cafe-meetings>, and further information.

## **Worcestershire ME/CFS Local Services webpage update**

<https://worcsmegroup.weebly.com/blog/worcestershire-mecfs-local-services-webpage-update>

**7/1/2023**

### **Worcestershire ME/CFS Local Services**

The Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) Herefordshire & Worcestershire Health and Care NHS Trust [webpage](#)

<https://www.hacw.nhs.uk/services/service/chronic-fatigue-syndrome-cfs-72/> has recently been updated.

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS).

We are a specialist part-time service that delivers support and treatment to people with ME/CFS within community settings across Herefordshire and Worcestershire.

### **To contact the service:**

Address: Malvern Community Hospital 185 Worcester Road, Malvern, WR14 1EX

Reception phone number: 01684 612671 (an answerphone is available).

Email: [whcnhs.chronicfatigue@nhs.net](mailto:whcnhs.chronicfatigue@nhs.net)

This local NHS ME/CFS webpage includes sections on -

About the service

How to refer into the service

What we do

General information

Links and Resources

Following Discharge (*includes - Recovery And Management (RaM) group*)

Support for families and carers

Carers' Assessment

The '**How to refer into the service**' section states -

"Please see the referral "protocol or NICE guideline ng206 for details of symptomology and tests that should be done. in order to confirm a diagnosis of ME/CFS".

The new Myalgic encephalomyelitis (or encephalopathy)/ chronic fatigue syndrome: diagnosis and management. [NICE guideline \[NG206\]](#) was published in October 2021.

See also from our website -

[NICE ME/CFS: new Guideline \(New downloadable Publications\).](#)

19/1/2022

[NICE ME/CFS: new Guideline \(Reactions\).](#)

25/11/2021

[NICE ME/CFS: new Guideline now Published](#)

29/10/2021