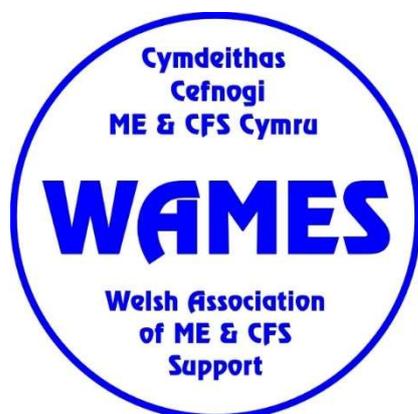


A Patchwork of Progress, Regional Variations and Gaps

Report of ME/CFS Services in Wales Survey 2025-6



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Introduction

In September 2025 WAMES sent a questionnaire to all 7 Health Boards in Wales wanting to find out:

- what stage the development of Services for people with ME/CFS had reached
- which ages and illness severity was being catered for
- how the Services operate and can be accessed
- whether the management recommendations from the 2021 NICE guideline for ME/CFS were being implemented

All Health Boards replied to the survey between October 2025 and January 2026. This report presents an analysis of responses.

Background

In March 2023 the Welsh Government announced an increase in funding for NHS Long COVID services to widen access *‘to people with other post-viral associated conditions.’*

The Health Minister at the time, Eluned Morgan MS said:

“We know many people with other, long-term conditions have reported feeling ‘misunderstood’ and ‘invisible’. I hope by widening access to Adferiad (Recovery) services we can better support people with conditions such as ME/CFS and fibromyalgia to get a diagnosis, manage their symptoms and access rehabilitation services, which are vital in helping improve physical and mental health and wellbeing.” [1]

Each Health Board was responsible for expanding services separately. This was the first time in WAMES’ 25 years of advocacy that people with ME/CFS had been named as potential recipients of Welsh Government funded services. It is important to note that ME/CFS was one of 6 possible medical conditions that the Welsh Government suggested expanding Long COVID services to include.

A Welsh Government paper on Long COVID in 2024 links to the Community pathway on Long COVID and notes that *“Long COVID services therefore, may have elements that are appropriate to guide management for ME/CFS type conditions, but the assessment and management for both may vary in some respects, depending on presentation and systems affected.” [2]*

Before the pandemic there were an estimated 13,000 people with ME/CFS in Wales but by 2025 researchers suggested that figure could have increased to 19,122. An additional 47,950 are thought to have developed the condition after experiencing a COVID infection. [3] This makes a combined total of ME/CFS plus Long Covid

patients who meet the criteria for ME/CFS in Wales as 67,072. This is not an insignificant number of patients needing care and support.

Health Boards	Population of Health Board	People with ME/CFS	Severe /very severe	Children <16	Long Covid meeting criteria for ME/CFS
Prevalence estimates	→	0.6%	25%	10%	3%
Betsi Cadwaladr UHB	688,741	4,132	1,033	413	10,538
Powys THB	132,719	796	199	80	2,031
Hywel Dda UHB	382,641	2,296	574	230	5,854
Swansea Bay UHB	378,330	2,270	568	227	5,789
Cwm Taf Morgannwg UHB	434,515	2,607	652	261	6,648
Aneurin Bevan UHB	577,672	3,466	867	347	8,838
Cardiff & Vale UHB	476,440	2,859	715	286	7,289

In Oct 2021 revised NICE guidelines were published, retaining a recommendation to establish specialist services for ME/CFS, but removing the focus on fatigue, CBT and GET. Instead, the emphasis was placed on the key roles of Post Exertional Malaise/ Post Exertional Symptom Exacerbation (PEM/PESE) and Energy Management. [4].

Welsh Government and the NHS have both repeated a commitment to implementing the NICE guidelines in Wales unless it can be shown there is a good reason not to do so. [5]

Guides from the professional association the British Association of Clinicians in ME/CFS (BACME) have influenced past services for ME/CFS in Wales and are still considered a resource for therapists. This charity is however increasingly being criticised for inconsistent application of the 2021 NICE guideline for ME/CFS and therapy approaches based on lack of evidence e.g. [6]

Key findings:

- **Service development is uneven** across the 7 Health Boards in Wales. 1 service opened and closed within 1 year, 6 remain operational, only 3 have fully launched by early 2026.
- **People who are severely affected by ME/CFS, plus children and young people (CYP)** can't access specialist services in every part of Wales. Only 3 Health Boards support adults who are severely affected. 3 support mild-moderately affected CYP, and only 2 support CYP who are severely affected.
- **Access to diagnosis and confirmation of diagnosis varies.** Only 3 services can diagnose or confirm diagnosis.
- **Referral routes into the services vary.** Only 2 services so far accept self-referrals and the others accept referral from a varying range of health professionals
- **Multidisciplinary teams with varying ranges of specialisms** cater for multiple conditions, not just ME/CFS.
- **Services vary in their ability to implement all the NICE guideline management recommendations**
- **There is under-use of ME specific assessment tools** and no standardisation in which other tools are used across services
- **Availability of information and communication methods vary.** Web pages, leaflets and virtual courses are in different stages of development, affecting the sharing of information about: the illness; management of ME/CFS; and Service publicity.
- **Clarification is needed on whether co-production and service co-design has taken place** – though all Services 'engage' with service users, and some with ME/CFS 3rd sector.

Comment

While the Welsh Government's funding for expansion of Long COVID services created new opportunities, the result is a **patchwork** of provision which is currently **fragmented, inconsistent, and incomplete**. This report highlights **progress**, but also **significant gaps** that leave many people with ME/CFS without equitable, evidence-based care.

Many Health Boards have faced significant challenges during the development process and are aware that there is more work to be done. Some services are still to fully launch and others prepare to assess their progress. Details about the services could therefore change. WAMES hopes the findings of this survey will provide a new perspective and be a useful resource.

WAMES calls for

1. **A national ME/CFS service specification** aligned with NICE NG206.
2. **Guaranteed diagnostic pathways** in every Health Board.
3. **Specialist multidisciplinary teams** with ME/CFS-specific training.
4. **Equitable provision** for children, young people, and the severely affected.
5. **Consistent use of assessment tools**, including PEM/PESE measurement.
6. **Clear access routes**, with relevant training for professionals, and self-referral options.
7. **Commitment to co-production** to ensure services meet users' needs
8. **Monitoring and accountability** to ensure Health Boards deliver safe, equitable, evidence-based care.
9. **Consistent recording** of the code for ME/CFS in primary care, so that accurate prevalence figures can be collected, and can shape the provision of specialist services.

Bottom Line

Welsh services have made progress, but ME/CFS services remain a **patchwork**. Without medical national leadership and consistent standards, tens of thousands of people will continue to fall through the gaps. This isn't just variation. It's **inequality**.

Who is developing expanded services?

All Health Boards have been offering specialist services for Long COVID since 2021 and 2 were also separately offering some form of service aimed at people with ME/CFS prior to that - in Powys and Betsi Cadwaladr Health Board areas.

Development of expanded services are progressing at varying speeds in different parts of Wales. 3 of the 7 services were fully launched by the start of 2026 and 1 was soft launched and then closed down. 6 services remain operational, but with many differences.

Health Board	Service Name	Launch Status
Powys THB	Powys Living Well Service / Gwasanaeth Byw'n Dda Powys	Soft launch 2008 Fully launched
Cardiff and Vale UHB	Keeping me well: Living well / Cadw'n fi'n iach: adferiad	Soft launch Jan 2024 Fully launched
Cwm Taf Morgannwg UHB	Primary Fatigue Service / Gwasanaeth Blinder Cyntaf	Soft launch Oct 2023 Closed early 2025
Betsi Cadwaladr UHB	Living Well Service / Gwasanaeth Byw'n Dda	Soft launch 2024
Swansea Bay UHB	Golau Adferiad Adult and CYP Service	Soft launch Nov 2024 adults Soft launch Jan 2025 CYP
Aneurin Bevan UHB	Symptom Management Service / Gwasanaeth Rheoli Symptomau	Soft launch Oct 2024 Full launch April 2025
Hywel Dda UHB	Long Covid and ME/CFS Service / Gwasanaeth Covid Hir a ME/CFS	Soft launch April 2025

THB = Teaching Health Board

UHB = University Health Board

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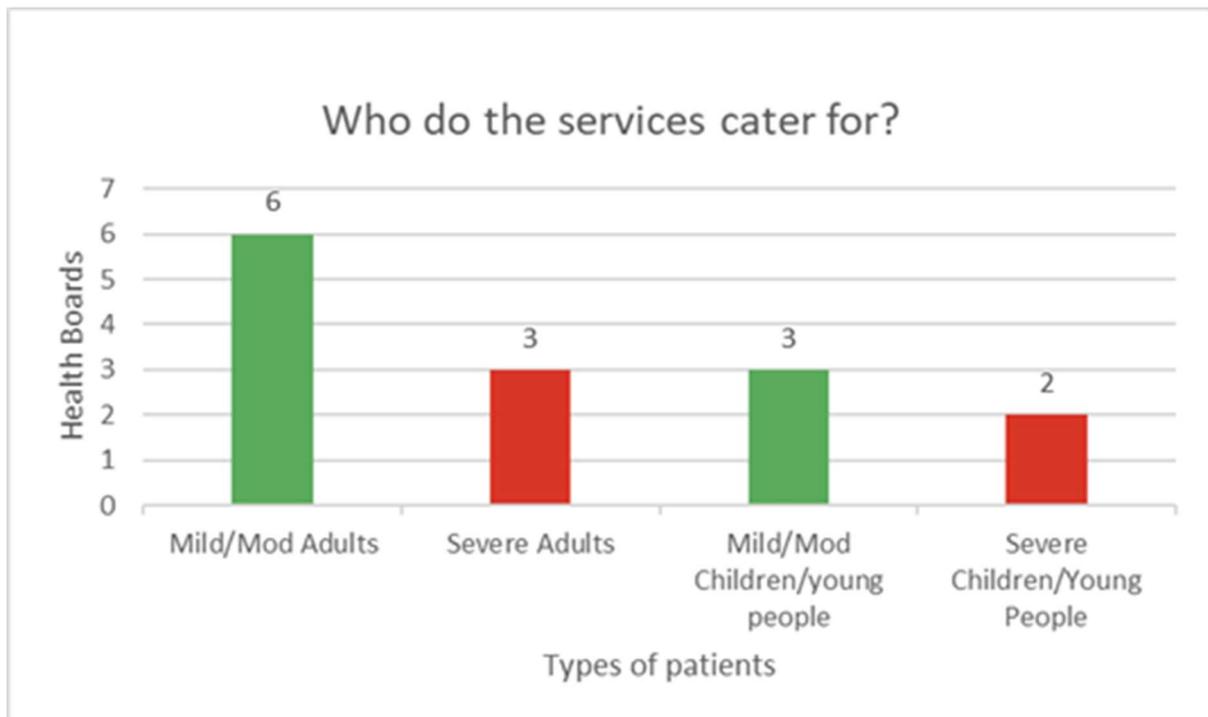
Organisation of and access to services

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We asked several questions about the way the services were being delivered and how they could be accessed.

Who do the services cater for?

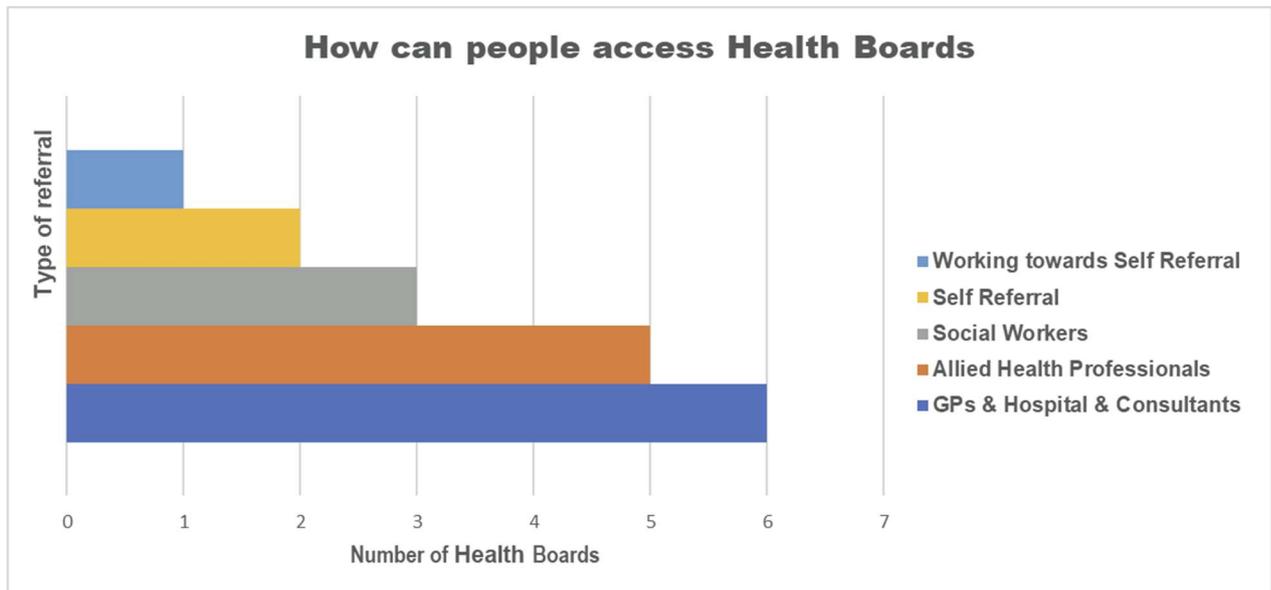
- **All 6 services** cater for **adults with mild-moderate ME/CFS**. However, provision for other patient groups is limited:
 - **3 services** say they support **mild-moderate children and young people** – Hywel Dda, Swansea Bay, Aneurin Bevan, although Hywel Dda so far work largely with young people.
 - **2 services** say they support **severely affected children and young people** – Hywel Dda, Aneurin Bevan. As mentioned above, Hywel Dda works largely with young people.
 - **3 services** support severely affected adults – Betsi Cadwaladr, Hywel Dda, Aneurin Bevan



How can people access the services?

- **All 6 services** accept referrals into their services from **GPs** and **hospital consultants**.
 - All except Swansea Bay also accept referrals from **Allied Health Professionals** (the umbrella term for a wide range of therapists).
 - Cardiff, Aneurin Bevan and Betsi also accept referrals from **Social Workers**.

Patients can **self-refer** into [Aneurin Bevan](#) and [Betsi Cadwaladr](#), and Cardiff is working towards accepting self-referrals.



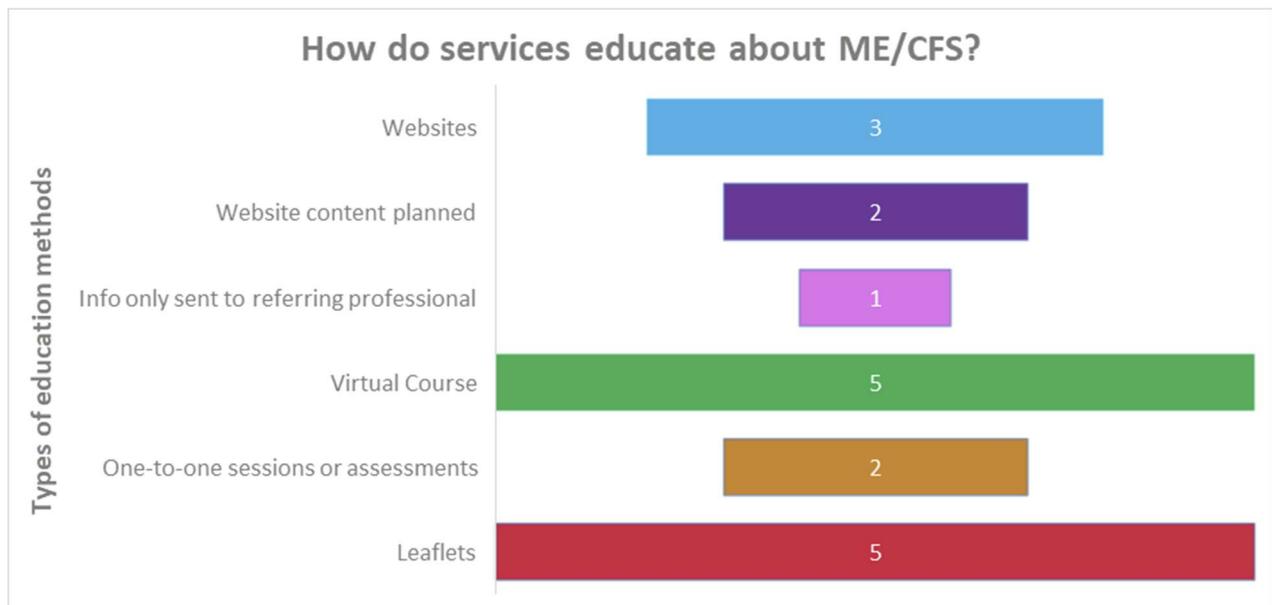
How long can people access a service for?

- **All 6 services** allow users to access them for as long as they need. Some will officially discharge them once their services are no longer necessary, but all permit people to refer themselves back in to the service if necessary. This could be a 'patient initiated follow up', 'time specific' or 'see on symptoms' approach.

How do services educate about the illness ME/CFS?

- **There is considerable variation** in the way that Services say that information about ME/CFS is communicated. [We did not ask about communication about self-management strategies.]
 - [Cardiff](#), [Aneurin Bevan](#) and [Betsi](#) Cadwaladr have information on their websites
 - Swansea sends information to the health professional who refers the patient. They and Hywel Dda are planning website content.
 - All except Swansea say they run a virtual course.
 - Hywel Dda and Aneurin Bevan share information during one-to one assessments and/or sessions.
 - All except Swansea share leaflets about ME/CFS

NB From the answers it was not clear whether the virtual courses and leaflets were dedicated to describing/explaining the illness or whether this information was combined with management information or service information. We did not ask about the depth of information shared about the research, clinical characteristics and experiences of ME/CFS.



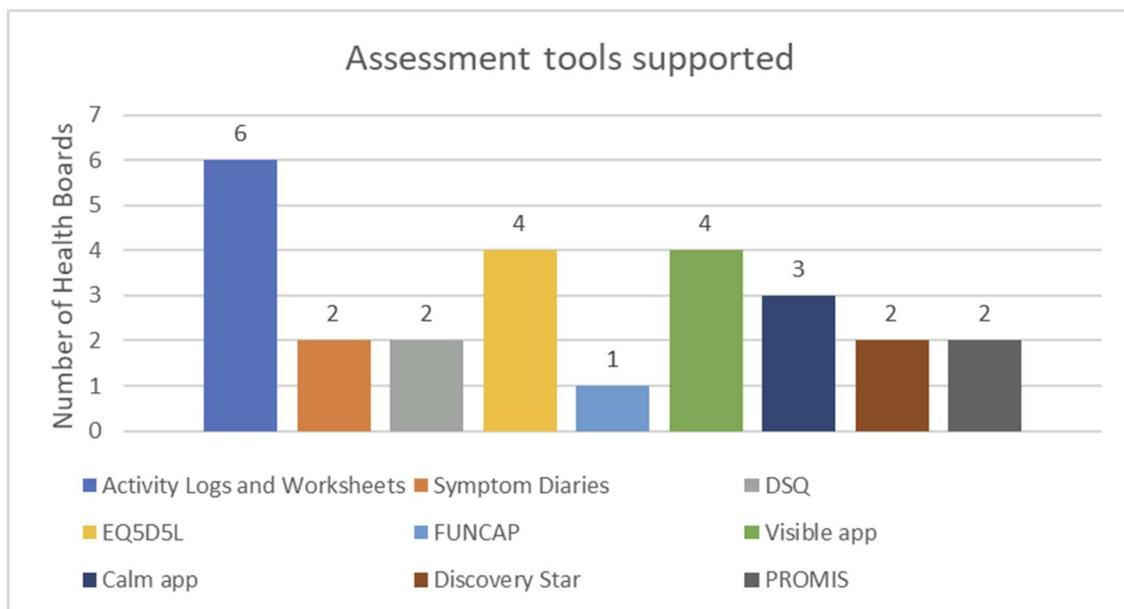
Which assessment tools do services use/support?

We asked Health Boards if they recommend **Symptom assessment tools and activity logs** to enable people with ME/CFS to record which symptoms they have and to measure the severity and impact of them, which can be difficult to quantify. These tools also help patients and healthcare professionals to decide which management strategies might be helpful. Additionally, they can be used to track changes in the variety of symptoms experienced and their severity over time, which can help when assessing the usefulness of management strategies.

- **All 6 services** recommend using Activity logs and worksheets and Betsi mentioned Symptom diaries
- **2 services** are happy to help users with the **DePaul Symptom Questionnaire (DSQ)** with service users, which was designed specifically to measure ME/CFS symptoms, plus their frequency and severity over time. These were Betsi and Aneurin Bevan.
- **4 services**, Swansea, Betsi, Powys and Hywel Dda use **EQ5D5L**, which is a questionnaire designed to measure general health-related quality of life and is often used to compare experiences in different services or areas.
- **0 services** use **FUNCAP**, which is a questionnaire designed to assess functional capacity, taking into account post-exertional malaise etc. in ME/CFS.
- **4 services**, Cardiff, Betsi, Powys and Aneurin Bevan are happy to help patients use the **Visible app** which is a commercial app and armband designed to monitor heart rate and activity to aid pacing. NB Visible uses FUNCAP.
- **3 services**, Cardiff, Powys and Aneurin Bevan are happy to help patients use the **Calm app**, which is a commercial app designed to help reduce stress, improve sleep, and practice mindfulness through guided meditations, Sleep Stories, and breathing exercises.

Additional comments:

- Betsi also makes use of: **Symptom diaries**, **Discovery Star/ Outcomes Star** and **PROMIS**. Discovery star is a tool designed to help people who live with long-lasting physical symptoms, like fatigue, breathlessness, pain, or palpitations. It aims to help them understand their experiences and track their progress over time.
PROMIS (Patient-Reported Outcomes Measurement Information System) is a questionnaire designed to evaluate and monitor physical, mental, and social health in both adults and children.
- Aneurin Bevan will work with people to utilise any tools they feel comfortable with to self-assess the development of symptoms and function; this will vary dependent on individual capacity and affordability. They also aim to pilot, on behalf of similar services across Wales, patient reported outcome measures to support assessment of the effectiveness of the service delivery.
- Cardiff noted that they also have service users where English/Welsh are not their first Language. This will inevitably limit the ability of participants to make use of assessment tools.



How do Health Boards assess the effectiveness of their services?

- **All services** conduct service user questionnaires and share knowledge amongst the other services throughout Wales

We also asked whether they **co-produced** with service users and 3rd sector, and received positive responses from all, but we hadn't explained what we meant, so may not have received the answers we expected. We wanted to know if there had been, and continued to be, co-production of services. Co-production is defined as:

‘Co-production is an asset-based approach to public services that enables people providing and people receiving services to share power and responsibility, and to work together in equal, reciprocal, and caring relationships. [7]

In practice Services appear to have used ‘engagement practices’ or ‘focus groups’ to listen to users or potential users and carers, but we have not clarified if all stakeholders or interested parties are equal partners in decision making.

The Role of NICE guidelines

We asked a number of questions to find out the extent to which the service model in each Health Board is being shaped by NICE recommendations. NICE has laid down guidelines for Assessment and ‘care and support’ planning by a multidisciplinary ME/CFS specialist team, highlighting the importance of the ability to confirm a diagnosis, help develop a personalised management plan for energy management, symptom treatment, and flare/relapse management. [8]

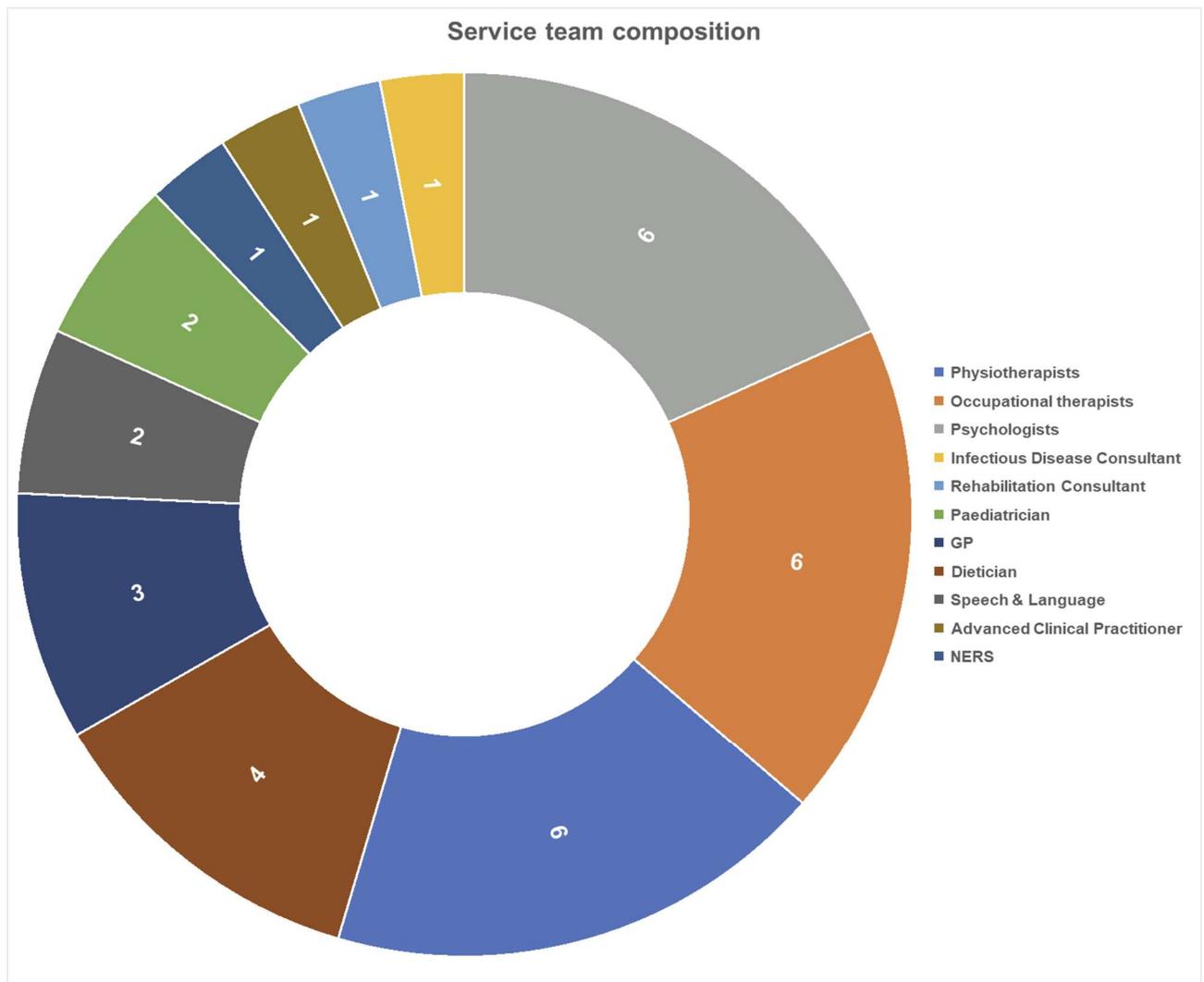
Who are the staff on the specialist teams?

- **All 6 services** employ multi-disciplinary teams to provide support to multiple conditions, not just ME/CFS. All contain **physiotherapists, occupational therapists** and **psychologists**.

Some services employ additional professionals, many in a part-time capacity.

- **Consultants** - Aneurin Bevan can access support from an **Infectious Diseases Consultant** and Cardiff from a **Rehabilitation consultant**.
- **Paediatrician** – is part of the team in **2 services** - Aneurin Bevan and Swansea.
- **GP** – **3 services** include GPs on their team: Swansea Bay, Betsi and Powys
- **Dietician** – **4 service** teams include dietitians: Swansea, Cardiff, Betsi and Powys
- **Speech and language therapist**– **2 services** include speech and language therapists on the team: Cardiff, Betsi
- An **Advanced Clinical Practitioner** can be found on the Betsi team (ACPs are trained to independently assess, diagnose, treat, and manage complex cases.
- **Exercise professionals**, including the **National Exercise Referral Scheme (NERS)** can be found in the Aneurin Bevan team.

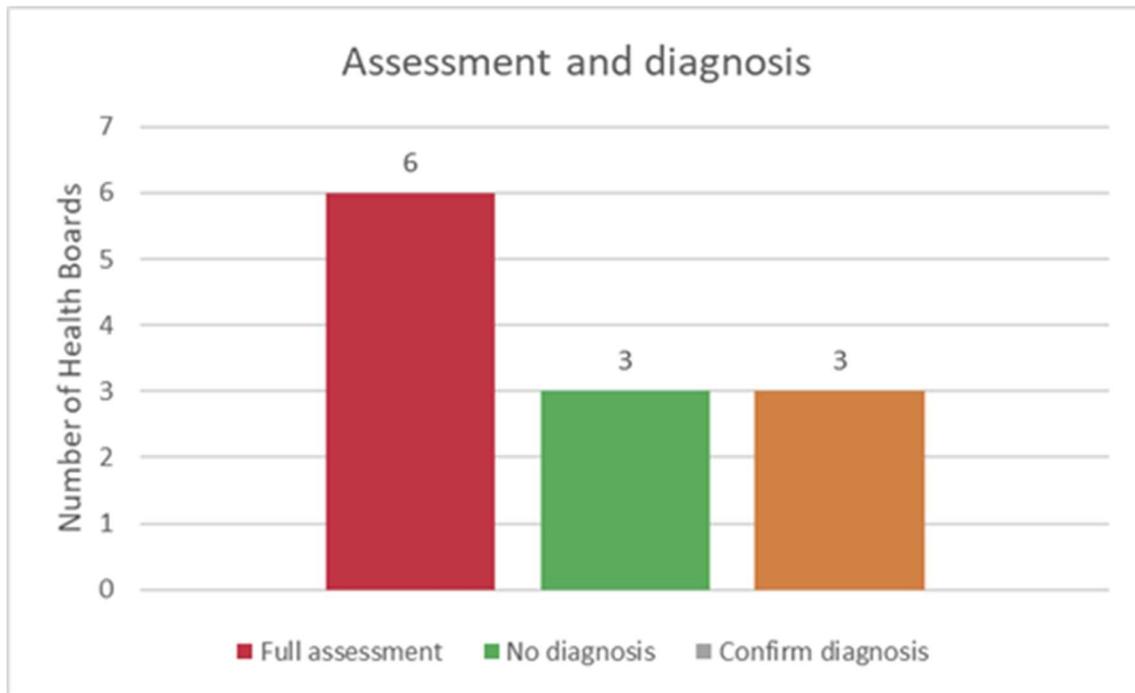
chart below...



Do services offer a holistic assessment & confirm diagnosis of ME/CFS?

- **3 services** say they offer full assessment and confirmation of diagnosis: Betsi, Hywel Dda and Powys.
- **3 services** say they provide assessment of needs as required, but diagnosis should be obtained before referral – Swansea Bay, Cardiff and Aneurin Bevan.

Chart below...



Do Services offer help developing a Care and Support Plan?

NICE describes a Care and Support Plan as a plan devised by the service user following a holistic or wide-ranging assessment. It gives an overview of other assessments and plans, made or to be made, in areas such as ‘social care, energy management, physical activity, physical functioning and mobility, cognitive behavioural therapy and dietary management.’ [9]

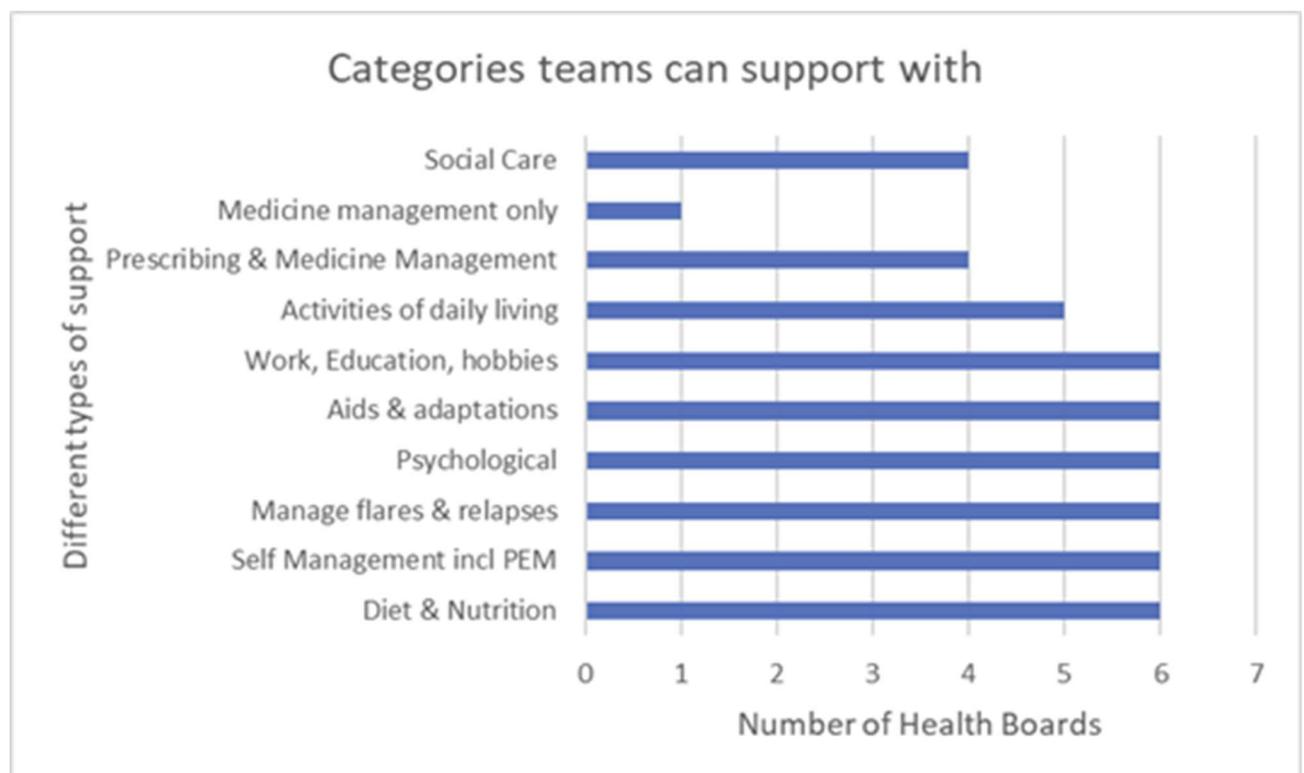
It is recommended because it brings together key information in one place, which can help if something like brain fog is a problem, and can be used to share that information with others such as healthcare practitioners, families, friends, employers and care workers.

- **5 services**, all except Powys, will provide support with devising a plan if asked, though some mentioned that it might not be appropriate for, or desired by, every service user.
- **BCUHB** is the only service who will provide a named contact within the specialist team for adults (& carers) to coordinate their care and support plan, and help them access services and support them during periods of relapse.

Do Services offer help with all aspects of a Care and Support Plan?

ME/CFS can affect all areas of a person’s life but not all people with ME will need to make a plan to manage everything. NICE suggests a wide range of areas people might need help from a specialist team to manage. We asked services which areas they had expertise to cover as listed in the guideline. [10]

- **All 6 services** replied to say their staff were able to help with:
 - **Self-management strategies, including energy management for PEM/PESE**
 - **Management of flare-ups and relapses**
 - **Psychological, emotional and social wellbeing**, including family and sexual health
 - **Diet and nutrition**
 - **Mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services**
 - **Support to engage in work, education, social activities and hobbies**
- **5 services**, all except for Powys, **said they could help with:**
 - **Activities of daily living**, including dental health
- **4 Services** – Betsi, Swansea, Hywel Dda and Aneurin Bevan are able to help with:
 - **Symptom management, including prescribing and medicines management** - Powys can help with medicines management but not prescribe
- **4 Services** – Betsi, Hywel Dda, Powys and Aneurin Bevan - are able to help with:
 - **Social care and support**



Cwm Taf University Health Board

Cwm Taf UHB launched a Primary Fatigue Service in 2023 but closed it in 2025 due to a shortfall in referrals. In spite of this the HB say it is possible for people with ME/CFS to receive healthcare and support:

“CTMUHB continues to support patients affected by ME/CFS on a needs-led basis.

CTMUHB services will continue to support people to access a framework of quality information and education for self-management, with assessment and advice according to the needs of our patients.”

It is unclear how this might be accessed, other than by getting a diagnosis from a GP and requesting a referral to general services. Hospital consultants and Allied Health Professionals can also refer patients. They say they can offer help for **mild-moderately affected adults** with:

- Information and support needs
- Development of personalised care and support plans
- Self-management strategies including energy management for PEM/PESE
- Guidance on managing flare-ups and relapses;
- Physical functioning and mobility
- Support for activities of daily living
- Mobility and daily living aids and adaptations to increase or maintain independence, avoiding falls and problems from loss of dexterity,
- A copy of the plan for the person and their family or carers (as appropriate) and their GP
- Social care and support

They supply information about ME/CFS from a variety of perceptions of the illness on their website, explaining the theory of dysregulation and proposing the management of ME/CFS as achieving homeostasis by balancing body systems.

[What is ME/CFS? - Cwm Taf Morgannwg University Health Board](#)

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