

## **Stockport ME Group response to Greater Manchester Integrated Care review of ME/CFS services in Greater Manchester**

Stockport ME Group	1
Executive summary	1
Inconsistency of services across Greater Manchester	2
Diagnosis and support	3
Treatment	5
Reviews	7
Severe ME/CFS	7
Children and Young People	8
Ongoing experience of NHS and relationship with the NHS	9
Long Covid	11
Orthostatic Intolerance/Dysautonomia/POTS	12
Summary of recommendations	12
Looking to the future	14
Conclusion	15

### **Stockport ME Group**

Stockport ME Group has members with ME/CFS, Long COVID and related conditions across Greater Manchester and East Cheshire. We have been campaigning for better, safer and more consistent services for people with ME/CFS in our area for decades. The Stockport NHS ME/CFS service was originally set up and run by our charity with funding from the National Lottery before being taken over by the NHS.

### **Executive summary**

Stockport ME Group has broadly welcomed the new NICE Guidelines (published October 2021) and Implementation statement (published May 2022). For decades the NHS in Greater Manchester has given people with ME/CFS a disproportionately low allocation of resources.

As well as ME/CFS provision being under-resourced, patients have experienced gaslighting, dangerously bad advice and support, and had their needs neglected. The duty now falls to Greater Manchester NHS to act in accordance with the new guidelines, correct their previous failures and meet the needs of people across Greater Manchester with ME/CFS. We are pleased to be working with GMIC and to have the opportunity to provide recommendations for improving the care and support offered to people with ME/CFS in Greater Manchester.

At present, services are inconsistent and GPs are often left without a clear referral pathway for patients presenting symptoms of ME/CFS. This leaves patients without the opportunity to see a specialist clinician, which is leading to frequent misdiagnosis and a lack of treatment for comorbidities and controllable symptoms. ME/CFS is an incredibly debilitating and multi-system disease which leaves people feeling isolated, and can be worsened by a lack of appropriate advice and lifestyle changes. Below are a number of thematic sections, detailing on behalf of our group’s membership, the problems which they currently face with NHS services, along with recommendations for improvements which could be realistically implemented across the ten boroughs.

**Inconsistency of services across Greater Manchester**

Across the ten boroughs of Greater Manchester there is a huge inconsistency of services. We are aware that some services accept referral of patients from outside their borough, however there are instances of this being misadvertised<sup>1</sup>, applied inconsistently, or varied over time according to capacity.

Stockport	A specialist OT-led service but has no clinical expertise or support. This means many people cannot access the service and misdiagnoses are not corrected, comorbidities not identified and treatable elements of symptoms not attended to.
Manchester	A limited service of condition management with no clinical expertise. It is under-resourced and there is currently an excessively long waiting list.
Salford	A hospital-based service that in the past has used a dangerous and harmful treatment pathway (Graded Exercise Therapy and

<sup>1</sup> The Stockport NHS website claims “The Stockport ME/CFS Service is available to adults who have a diagnosis of ME/CFS and are registered with a GP in the Stockport and Tameside & Glossop areas.” We know this not to be available to patients in Tameside or Glossop. <https://www.stockport.nhs.uk/ServicesDetail.aspx?id=821#:~:text=The%20Stockport%20ME%2FCFS%20Service.treatment%20plan%20to%20individual%20needs>. [accessed 16 April 2023].

	CBT utilising that approach). At times the waiting list has exceeded a year.
Bury and Bolton	Has a service but with no domiciliary element resulting in patients with the most severe needs being effectively excluded.
Wigan	We understand Wigan has a service, but as we have no membership from that part of Greater Manchester we cannot comment on it. <sup>2</sup>
Tameside, Trafford, Oldham and Rochdale	All completely lacking in a service of their own. Occasionally people are able to access out of area services but this is not common, consistent or straightforward for patients.

### Recommendations

1. **Wherever someone lives in Greater Manchester they should have access to specialist support for ME/CFS. This should include:**
  - clinical expertise around diagnosis and comorbidities
  - specialist services for condition management
  - regular reviews with a clinician with adequate experience
2. **There should be choices for patients. For example, online/telephone appointments should be offered as this can minimise the overexertion which travelling to appointments can cause.**
3. **Access to domiciliary services, one-to-one support around condition management and group-based support should be available in every borough. Currently only the Stockport NHS ME/CFS service offers domiciliary visits.**

### **Diagnosis and support**

There are very high rates of people who are wrongly diagnosed with ME/CFS, in addition to those who have ME/CFS but have not received a diagnosis. A 2010 report from the Royal College of Physicians in Edinburgh showed that in one local clinic, almost half of the people who had been diagnosed with ME/CFS were wrongly diagnosed, with 47% having another medical disorder.<sup>3</sup> This is consistent with the experience of our Group's members and with other research<sup>4</sup>. Obviously, this is not good enough and highlights how specialist expertise

<sup>2</sup> <https://www.wvl.nhs.uk/our-departments?service=21> the Wigan service details are here

<sup>3</sup> Newton, J. L. *et al.* (2010) cited in ME Association (2022). "Diagnosis of ME/CFS" (online) Available at:

<https://meassociation.org.uk/wp-content/uploads/DIAGNOSIS-OF-MECFS-IMPORTANCE-OF-EARLY-AND-ACCURATE-DIAGNOSIS-APRIL-2022.pdf> [accessed 2 April 2023], p.14

<sup>4</sup> For instance: Hives L, Bradley A, Richards J, *et al.* "Can physical assessment techniques aid diagnosis in people with chronic fatigue syndrome/myalgic encephalomyelitis? A diagnostic accuracy

can improve the number of people getting diagnosed and treated correctly. In line with the NICE Guideline (2021), we call for Greater Manchester to have a specialist team including:

*"a range of healthcare professionals with training and experience in assessing, diagnosing, treating, and managing ME/CFS. They [should] have medically trained clinicians from a variety of specialisms (including rheumatology, rehabilitation medicine, endocrinology, infectious diseases, neurology, immunology, general practice, and paediatrics) as well as access to other healthcare professionals specialising in ME/CFS. These may include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists."*<sup>5</sup>

We have found that many people with ME/CFS or potentially with this diagnosis have reported that best practices are not being carried out. Often they have not been offered key tests, and in some cases practitioners have refused a diagnosis. This has happened for a wide range of reasons but worryingly include the perception among some clinicians that "it would stop the patient trying to get well if they were given a diagnosis". In Stockport a patient needs a diagnosis in order to access the ME/CFS service, and therefore without one they are denied any support in managing their symptoms.

If someone needs to rest and pace to effectively manage their ME/CFS, then the sooner they know this, the sooner they can make the lifestyle adjustments they need. Appropriate condition management can lead to a better chance of them making a fuller recovery. It is often taking people years to get a correct diagnosis of ME/CFS and this is harder to achieve given the current strain on NHS resources. On top of long waits to get diagnosed, over the last decade many patients have had no access to specialist services and many have had to wait in excess of a year for services. This simply is not good enough.

Peer support is invaluable to patients in learning about their condition and how to manage their symptoms. Whilst patients would ideally have access to one-to-one support in understanding how to pace, rest and manage their condition, group support potentially offers a cost-effective solution which will be suitable for many people. One of our strongest

---

study". *BMJ Open* 2017 doi:10.1136/ bmjopen-2017-017521 Available online: [https://www5.uclan.ac.uk/sites/ImageBank/Marketing\\_Image\\_Library/bmjopen-2017-017521.pdf](https://www5.uclan.ac.uk/sites/ImageBank/Marketing_Image_Library/bmjopen-2017-017521.pdf) [accessed 16 April 2023].

The physician who was probably more experienced than many only correctly diagnosed 70% of patients in this study.

<sup>5</sup> See Box 3, p.16, NICE guideline (2021) "Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management" Available online: <https://www.nice.org.uk/guidance/ng206/resources/myalgic-encephalomyelitis-or-encephalopathychronic-fatigue-syndrome-diagnosis-and-management-pdf-66143718094021> [accessed 16 April 2023].

recommendations for the support of people with ME/CFS or a suspected diagnosis is to establish a Greater Manchester group condition management peer support service. This could be provided as a nurse or OT led service, with a series being delivered at relatively little cost. Stockport ME Group would be pleased to advise on the content of sessions if required or to recommend practitioners. This could give patients options and ensure that people with a ME/CFS diagnosis could get some support quickly within a few weeks, not years after diagnosis.

### Recommendations

- 4. GPs require a standard referral pathway to a specialist ME/CFS service. Currently they often have no obvious place to refer people, leading to inappropriate referrals to departments without the required breadth of experience. Sometimes a diagnosis is made but nothing suitable is recommended for condition management or treatment of symptoms.**
- 5. GPs require education about ME/CFS services. Often even when specialist ME/CFS services are available, we know that patients are not referred to them.**
- 6. When ME/CFS is suspected, practitioners should explore interim diagnosis and early referral to specialist ME/CFS support. Timely diagnosis and early intervention is really important in giving patients the quickest and fullest chances of improvement in their health.**
- 7. Effective condition management support can be provided online, and in a group format. Group support will not be suitable for everyone but it can offer significant benefits to people in managing a potentially life-long health condition, and at a relatively low cost to the NHS.**
- 8. Establish a Greater Manchester group condition management/ peer support service, providing an efficient pathway for patients with confirmed or suspected ME/CFS to access support with pacing and lifestyle adjustments.**

### **Treatment**

We know that Salford Royal Hospital's ME/CFS service was treating adult patients with Graded Exercise Therapy (GET) without warning patients about the risks of this treatment. As people with ME/CFS, we knew this was not acceptable given the amount of harm to patients which had been reported, even when the practice was still within the NICE Guidelines. We do not know whether this 'treatment' is still being carried out by the hospital, but we suspect that while the same staff are in post, even if it is not recommended it will be

something that they promote. We have also heard of patients being prescribed less controlled activity based treatments than a GET programme, even after the new guidelines have been published. For people with ME/CFS, exercise comes with very high risks of triggering potentially permanent relapse so should not be recommended without significant expertise and incredible caution.

Whilst ME/CFS is not curable, there is often much which can be done to identify issues and symptoms that can be treated or managed. However, often this does not happen. ME/CFS rarely exists on its own and there are common comorbidities including orthostatic intolerance, fibromyalgia and sleep problems such as sleep apnoea. Often inadequate steps are taken to explore these issues, leaving patients struggling unnecessarily and getting in the way of their health, wellbeing and recovery. For example, many patients experience pain but are rarely given much support in managing that pain or referrals to pain management specialists. Many have sleep issues or find that their symptoms can become much worse when their sleep is disturbed, but few are referred for this to be explored.

Often people with ME/CFS go to their GPs for help with issues that may or not be ME/CFS related, but find that their problem is dismissed as part of their ME/CFS and told there is nothing that can be done. Sometimes this is a symptom that could be managed with existing knowledge e.g., pain. Sometimes new symptoms have nothing to do with ME/CFS. Patients' lives and well-being are constantly being put at risk due to misunderstanding and prejudice. We have members who believe that they are best off not mentioning their ME/CFS and hoping it is not obvious in their records so that a doctor will consider their issues without bias. In some cases, conditions such as Postural Tachycardia Syndrome (PoTS) have not been identified and patients have been left with this issue untreated. In other cases, patients are struggling with pain but it is not being explored, nor are they being supported because it is being written off as part of their ME/CFS.

Whilst this bias needs to be addressed and highlights a training need, it also demonstrates how important access to specialist ME/CFS expertise is, and to the importance of regular review. Specialist expertise could correct errors made in Primary Care and help patients access appropriate treatment or referrals where necessary.

#### Recommendations:

9. **Discontinuation of the recommendation of GET and other less controlled activity-based programmes across GM. This should come with a particularly close review of services at Salford Royal Hospital and the advice given by their ME/CFS team.**
10. **Education and training for GPs and practice nurses working in Primary Care which directly addresses commonly held biases and out of date explanations of ME/CFS, condition management, referral pathways and treatments available for common symptoms and comorbidities.**

## Reviews

We support the recommendation in the NICE Guideline (2021) that regular reviews should be available for people with a diagnosis of ME/CFS.<sup>6</sup> Although NICE makes the recommendation that this should be undertaken in Primary Care, we believe it is important that reviews are carried out by practitioners who have adequate expertise and are without the preconceived mindset that nothing more is likely to be available to support the patient.

With several common comorbidities such as PoTS, the medical understanding and treatments have developed significantly in recent years. For many of our members living in Greater Manchester, there may be far more known and understood about the conditions they live with than when they first received their diagnosis. If they have had previous negative experiences with NHS services including their GPs and are not offered review appointments with appropriate professionals, they may be suffering unnecessarily with symptoms which could be treated or managed effectively.

### Recommendations:

11. **Implementation of regular reviews with a suitable clinician for every patient with a diagnosis of ME/CFS.**

## Severe ME/CFS

Many people with ME/CFS are classed as being “severe” in the level of their condition,

---

<sup>6</sup> 1.15 Review in Primary Care, p.47, NICE guideline “Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management”, available online: <https://www.nice.org.uk/guidance/ng206/resources/myalgic-encephalomyelitis-or-encephalopathychronic-fatigue-syndrome-diagnosis-and-management-pdf-66143718094021> [accessed 16 April 2023].

where it becomes very difficult, if not impossible for them to leave their homes to attend any medical appointment. People with severe levels of illness generally have high support needs and a greatly reduced quality of life.

Although rare, it has been shown that people do die from ME/CFS. The condition does not generally cause patients to present test results which would indicate a danger to life, but this may obscure the urgency with which they require treatment. Often these patients are deemed a low priority for medical attention despite the severity of this disabling condition.

#### Recommendations:

- 12. Systems should be in place to meet the access needs for severe ME/CFS patients in Primary Care, and to refer for social service support where applicable.**
- 13. Greater appreciation is needed across NHS services for the urgency of treatment for severe ME/CFS patients, whose situation needs to be considered in times that they wait for receiving appropriate medical services.**

### **Children and Young People with ME/CFS**

Stockport ME Group does not currently support people under 18 years old but we are aware of many issues young people face in seeking diagnosis and treatment for ME/CFS. Despite Graded Exercise Therapy (GET) now being disproven and shown to be a harmful treatment for people with ME/CFS, we believe that rehabilitative treatment based on GET is still routinely being used by mental health teams treating children and young people. We have heard horror stories of children being forced into increasing activity when it is not safe for them to do so<sup>7</sup>. GET and interventions based on the assumption that patients need to address deconditioning and anxiety around activity should have no place in the treatment of children and young people with ME/CFS. Given their age and vulnerability there needs to be clear oversight and protections in place to make sure that these abhorrent and inappropriate treatments are a thing of the past. Other activity based interventions where a patient is not supported to establish their baseline can have even more damaging effects than GET.

We are also aware that children and young people, and their carers are put under considerable pressure from social services and schools in terms of school attendance and

---

<sup>7</sup> Tymes Trust a charity focussed on Children with ME/CFS references this here <https://www.tymestrust.org/pdfs/mrharleyletter2022.pdf>



other issues. In extreme cases parents are threatened with having their children removed from them if they do not take their very ill children to school. Parents are being accused of Munchausen by proxy rather than listening and believing what the children say. We call on the NHS to do more to support young people and their carers through working with other services and providing the necessary evidence to ensure that health needs are met. Children and young people should not be placed under undue pressure to attend school when this is not appropriate and jeopardises their chances of recovery. Parents doing their best to look after very ill children shouldn't be demonised. This review article provides a good overview of issues with children and young people with ME/CFS -

<https://www.frontiersin.org/articles/10.3389/fped.2017.00121/full>

#### Recommendations:

- 14. Treatment plans based on Graded Exercise Therapy (GET) must be removed immediately for children and young people diagnosed with, or suspected to have ME/CFS. This should also be the case with interventions based on increasing activity or where their illness is treated as a psychological issue.**
- 15. A system for child protection must be established to investigate cases of outdated or inappropriate treatments prescribed for children and young people.**
- 16. Establish a joined-up approach to working with social services and education providers on cases where a child has ME/CFS. Ensure that realistic condition management plans are created for children and young people with a proportional approach to school attendance. This would prevent them being threatened with exclusion when they are not well enough to attend school regularly.**

#### **On-going experience of NHS and relationship with NHS**

Many patients with ME/CFS have experienced considerable discrimination, bias and gaslighting from clinicians within the NHS. Some patients are told to do exercise when it is not safe or possible for them to do so; some are not given referrals that anyone else without an ME/CFS diagnosis would be given. Many have been told that their issues are entirely due to their deconditioning, mental health or health anxiety and they just need to be more active. These attitudes are at least partially due to out-of-date information and training from a time when the condition was understood as a psychiatric disorder. However Doctors with ME

refers to what has become a “normalised disregard for standards”<sup>8</sup>, and the experience of our members demonstrates a systemic failing in the responsibilities of the NHS to consider the Public Sector Equality Duty in regards to patients with ME/CFS.

Discrimination, bias, gaslighting and lack of the allocation of resources have become embedded within NHS practices. This needs to be acknowledged and serious steps need to be taken to rectify patients' experiences. There should be a clear complaint pathway for this type of discrimination where patients actually feel listened to. When complaints are made, they should be properly investigated and recommendations followed. Employees of the NHS need to know that discrimination is unacceptable and if they do not change their behaviours, they could face severe consequences. Individual perpetrators of abuse should face consequences and not receive protection from the NHS.

There have been instances when patients have been told that if they do not follow a protocol they have been given, even if it includes dangerous and inappropriate activities, that they will stop receiving any services. Patients should not be threatened with a withdrawal of support for declining to do one element that they are convinced is damaging their health. Members of our group had reported how dangerous and unhelpful aspects of the Salford service were, and how some of the services for young people were (through the use of GET). If the negative outcomes experienced by those members had been taken seriously and responded to through a review of services at Salford Royal, it could have prevented significant patient harm. ME/CFS is a very difficult and complex condition to understand and by involving patients in service development and delivery it gives the best chance of overcoming barriers that they could face to receiving services and increasing the chances of those services being appropriate to them. It can also minimise the chances of bias, ignorance and prejudice. Best practice in this area would include patient involvement in recruitment decisions.<sup>9</sup>

Many members of our group have got to a point where they feel that engagement with the NHS is harmful for them. They are not helped, are treated with contempt and bias and are not listened to. Many patients try to manage on their own. Due to the embedded nature of prejudice, it is important that proactive action is taken to minimise and help overcome the barriers that patients can face as a result of bias, discrimination and ignorance. These

---

<sup>8</sup> Doctors with ME (2022). “Normalised Medical Rule Breaking and the UK DHSC ME/CFS Review” (online) Available at: <https://doctorswith.me/normalised-medical-rule-breaking-and-the-uk-dhsc-me-cfs-review/> [accessed 2 April 2023].

<sup>9</sup> Integrating patients into recruitment decisions would be in line with the ambitions of NHS Trusts such as Pennine Care: <https://www.penninecare.nhs.uk/involvement> [accessed 16 April 2023].

include where possible allowing self-referral to services, and allowing patients choice in which services to access.

Recommendations:

- 17. Acknowledgement and development of a plan to address past failings and restore patient trust in NHS services and practitioners, including training and education for clinicians and serious treatment of complaints. When patients are being discriminated against or shown significant bias this should not be allowed to continue.**
- 18. Establishment of a system for patient involvement in important decisions including recruitment, procurement of NHS services and delivery of implementation plans.**
- 19. Establishment of a self-referral pathway, facilitating patient choice to specialist ME/CFS and other related services (e.g., pain management).**

## **Long Covid**

Many people currently diagnosed with Long Covid are experiencing symptoms consistent with ME/CFS. It is likely that if their initial infection had not been SARS-CoV-2, they would have been diagnosed with ME/CFS. A reasonable number of people with Long Covid do indeed get appropriately diagnosed with ME/CFS. Recent research from the Bateman Horne Centre suggested that almost all of their Long Covid patients experienced ME/CFS type symptoms, other studies suggest that up to 75% might have ME/CFS type issues. It is really important that these people get the support that they need in management of their symptoms and on-going health condition in a timely manner. Often appropriate support for PEM/PESE has not been put in place with inadequate support in diagnosing and identifying whether PEM is present or not and little support or advice in effective management of PEM/PESE issues.

Long Covid has put additional pressure on waiting lists for many NHS services. Long Covid and ME/CFS have enough commonalities that whilst they are treated through different pathways within Greater Manchester, there is the potential for sharing resources and expertise to assist the management of both conditions.

In the patient feedback sessions you will have heard how some of our members suffered

greatly with a decline in their health due to Graded Exercise Therapy or other activity based treatments. Yet these treatments are often being offered to patients with Long Covid presenting symptoms consistent with ME/CFS including PEM. This will cause patients considerable harm and is entirely preventable. We recognise that the NHS does not have the resources to offer certain treatments, but argue that the health service should not be proactively providing treatments that do patients harm.

### **Orthostatic Intolerance/POTS/Dysautonomia Issues**

About 50%<sup>10</sup> of people with ME/CFS and even more people with Long COVID have some form of dysautonomia. In the USA under the Institute of Medicine diagnostic criteria patients need either cognitive impairment or orthostatic intolerance<sup>11</sup> to be diagnosed with ME/CFS. Many of our members have had issues with orthostatic intolerance and the NHS has not been well placed to deal with them. Best practice guidelines are often not being followed and patients not being supported. At least 4 of our members within the last year have needed to go outside of the NHS for diagnosis and treatment. Dysautonomia is often missed at GP level and is usually managed in the NHS via a cardiology referral. There is no centre of excellence or coordinated pathway for orthostatic intolerance/dysautonomia despite its high prevalence. It is hard for cardiologists more used to dealing with other issues to manage these issues with dysautonomia patients. We firmly believe that a specialist dysautonomia referral to cardiologists who are used to and welcoming of such referrals could greatly improve patient outcomes and take pressure off other cardiology departments. As to why effective dealing of orthostatic intolerance is so important we could do no better than quote Dr Bateman:- *“So why is it important to assess and treat orthostatic intolerance? Well first of all it's reportable and observable. It's measurable and it's treatable and treatment can improve symptoms and function in ME/CFS and may lead to insight about the underlying disease processes.”*<sup>12</sup>

### **Summary of recommendations**

1. Wherever someone lives in Greater Manchester they should have access to specialist support for ME/CFS. This should include:

---

<sup>10</sup> Diagnosis is so fraught its hard to know for sure with studies suggesting ranges from 22% to over 90%<https://translational-medicine.biomedcentral.com/articles/10.1186/s12967-021-02819-0>

<sup>11</sup> <https://www.cdc.gov/me-cfs/healthcare-providers/diagnosis/iom-2015-diagnostic-criteria.html>

<sup>12</sup>

<https://batemanhornecenter.org/wp-content/uploads/filebase/education/Addressing-Orthostatic-Intolerance-in-MECFS-November-2021-Transcript.pdf>

- clinical expertise around diagnosis and comorbidities
  - specialist services for condition management
  - regular reviews with a clinician with adequate experience
2. There should be choices for patients. For example, online/telephone appointments should be offered as this can minimise the overexertion which travelling to appointments can cause.
  3. Access to domiciliary services, one-to-one support around condition management and group-based support should be available in every borough. Currently only the Stockport NHS ME/CFS service offers domiciliary visits.
  4. GPs require a standard referral pathway to a specialist ME/CFS service. Currently they often have no obvious place to refer people, leading to inappropriate referrals to departments without the required breadth of experience. Sometimes a diagnosis is made but nothing suitable is recommended for condition management or treatment of symptoms.
  5. GPs require education about ME/CFS services. Often even when specialist ME/CFS services are available, we know that patients are not referred to them.
  6. When ME/CFS is suspected, practitioners should explore interim diagnosis and early referral to specialist ME/CFS support. Timely diagnosis and early intervention is really important in giving patients the quickest and fullest chances of improvement in their health.
  7. Effective condition management support can be provided online, and in a group format. Group support will not be suitable for everyone but it can offer significant benefits to people in managing a potentially life-long health condition, and at a relatively low cost to the NHS.
  8. Establish a Greater Manchester group condition management/ peer support service, providing an efficient pathway for patients with confirmed or suspected ME/CFS to access support with pacing and lifestyle adjustments.
  9. Discontinuation of the recommendation of GET and other less controlled activity-based programmes across GM. This should come with a particularly close review of services at Salford Royal Hospital and the advice given by their ME/CFS team.
  10. Education and training for GPs and practice nurses working in Primary Care which directly addresses commonly held biases and out of date explanations of ME/CFS, condition management, referral pathways and treatments available for common symptoms and comorbidities.
  11. Implementation of regular reviews with a suitable clinician for every patient with a diagnosis of ME/CFS. .

12. Systems should be in place to meet the access needs for severe ME/CFS patients in Primary Care, and to refer for social service support where applicable.
13. Greater appreciation is needed across NHS services for the urgency of treatment for severe ME/CFS patients, whose situation needs to be considered in times that they wait for receiving appropriate medical services.
14. Treatment plans based on Graded Exercise Therapy (GET) must be removed immediately for children and young people diagnosed with, or suspected to have ME/CFS. This should also be the case with interventions based on increasing activity or where their illness is treated as a psychological issue.
15. A system for child protection must be established to investigate cases of outdated or inappropriate treatments prescribed for children and young people.
16. Establish a joined-up approach to working with social services and education providers on cases where a child has ME/CFS. Ensure that realistic condition management plans are created for children and young people with a proportional approach to school attendance. This would prevent them being threatened with exclusion when they are not well enough to attend school regularly.
17. Acknowledgement and development of a plan to address past failings and restore patient trust in NHS services and practitioners, including training and education for clinicians and serious treatment of complaints. When patients are being discriminated against or shown significant bias this should not be allowed to continue.
18. Establishment of a system for patient involvement in important decisions including recruitment, procurement of NHS services and delivery of implementation plans.
19. Establishment of a self-referral pathway, facilitating patient choice to specialist ME/CFS and other related services (e.g., pain management).
20. Establish a clinic in Greater Manchester to receive dysautonomia referrals from across Greater Manchester to better meet the specialist needs of patients as well as taking pressure off current cardiology departments. This wouldn't need extra resources necessarily as it could be met with existing staffing levels, just targeting referrals through practitioners best able to support issues these patients face.

## **Looking to the future**

This review is in response to the NICE guideline update from 2021. GMIC should not just be looking backward though but also looking forward to improving on the standard of care beyond the guidelines published two years ago.

Stockport ME Group has been running research along with The University of Liverpool, The Workwell Foundation, PhysiosforME and others into the uses of Heart Rate Monitoring and Heart Rate Variability in assisting with condition management. The research is still to be concluded but other research in these areas is already suggesting that use of Heart Rate Monitors can be very helpful in condition management both for patients to use on their own and in collaboration with healthcare professionals. Many people with ME/CFS struggle to use this effectively on their own and this is something where a small amount of support could yield large benefits.

ME/CFS research stalled for a long time with it being underfunded and with much of the funding being directed through GET/CBT type routes that are ultimately a dead end. The similarities with the presentation of symptoms in Long Covid means that there is now a lot of research that is directly correlative with ME/CFS even when it does not specifically include an ME/CFS cohort. There is research in Hyperbaric Oxygen Therapy in Israel that looks promising, as does some research using ADHD drugs that help with brain fog for people with Long COVID. Already more and more patients are getting access to Low Dose Naltrexone with reports of positive benefits. We hope that once these potentially inexpensive, safe medications pass the required research thresholds they will be offered to patients living with this devastating and life-altering condition. Patients will resort to untested and potentially dangerous alternative therapies if they cannot get the help they need from mainstream health care. Patients with ME/CFS in Greater Manchester deserve to benefit from research findings that are not yet represented in the NICE Guidelines.

## **Conclusion**

Stockport ME Group has welcomed the opportunity to present feedback to the GMIC and to facilitate and enable individual patients to share their experiences. We are encouraged by the review of ME/CFS services, but we do feel we have been here before and have been told wrongly by commissioners that adequate services were in place which we knew from member experiences that was not the case.

Patients not getting the right treatment will ultimately cost the NHS more than getting treatment and support in place. The NICE Guidelines and the Implementation statement make it clear that the NHS needs to find ways to meet the needs of patients. That means

correcting the historical imbalance in resources due to biases and underappreciating the needs of ME/CFS patients.

Patients deserve better, they deserve to be able to be honest with medical professionals within the NHS and not hide their ME/CFS for fear they will be adversely treated. They deserve to have the services and support recommended in the NICE guidelines and implementation statement regardless of where they are in Greater Manchester. Change needs to happen and patients and community groups need to be involved in that change so it best meets the needs of patients with ME/CFS in Greater Manchester.

This statement was prepared by the Stockport ME Group Committee on behalf of Stockport ME Group. It was submitted by email by Ben Wickens, co-chair of Stockport ME Group after working with the committee in the production of this statement.