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ME/CFS

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Improving lives

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- What is ME/CFS?
- Latest research
- NICE guidelines
- Conditions to exclude
- Referral process
- Service structure
- Treatment programme

Improving lives

“tired all the time”

“It’s mostly in
their heads”

“same as fibromyalgia”

“laziness”

Common preconceptions….

What is ME/CFS?

Patients feel…….

“Frustrated”

“Overwhelmed”

“Hidden disability”

“Guilty”

- “ME/CFS is a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients.
- In its most severe form, this disease can consume the lives of those whom it afflicts.
- It is “real.”’

Institute of Medicine 2015 ‘Beyond ME/CFS: Redefining an illness’

- **"We estimate that at least 404,000 people in the UK have ME/CFS. In addition, 950,000 people unable to recover from a Covid infection could meet the diagnostic criteria for ME/CFS. This could mean that 1,350,000 adults and children in the UK are affected by ME/CFS. It represents a very real health crisis, and we are determined to improve the healthcare that people receive."**
- **Prevalence may be as high as 0.6% of the population (**Samms GL and Ponting CP, 2025)
- **Female preponderance approx. 3:1**

THE ME ASSOCIATION
me

M.E. can affect more than one family member – suggesting that genetic factors are involved.

M.E. is the commonest cause of long term sickness absence from school.

M.E. affects all social classes and ethnic groups.

M.E. has been estimated to cost the UK economy £3.3bn each year

ME Association, 2020

What’s in a name?

1956

The term “**Myalgic encephalomyelitis/ME**” originally introduced in 1956

Pathologically, encephalomyelitis indicates inflammation within the brain and spinal cord – a description for which there is currently no sound scientific evidence.

1969

WHO classification as a neurological disease

1980s

Renamed as ‘**chronic fatigue syndrome**’ by doctors in the 1980s:

this was felt to trivialise the level of suffering, ignores the multisystem symptomatology and can encompass all people with ‘chronic fatigue’ symptoms

1990s

Known as CFS/ME

2002

UK Chief Medical Officer (2002) – “A complex and debilitating, chronic neurological condition”

2021

Known as ME/CFS
Responding to patient concerns about the emphasis on ‘chronic fatigue’

Decode ME

The ME/CFS Study

Compared the DNA of 15,579 people with ME/CFS with the DNA of 259,909 people without ME/CFS, all of European descent

- People with ME/CFS are more likely to carry certain DNA differences in **eight** regions of their genome
- Three of the most likely genes produce proteins that respond to an **infection**
- Another likely gene is related to chronic **pain**
- None are related to depression or anxiety
- Nothing to explain why more females than males get ME/CFS

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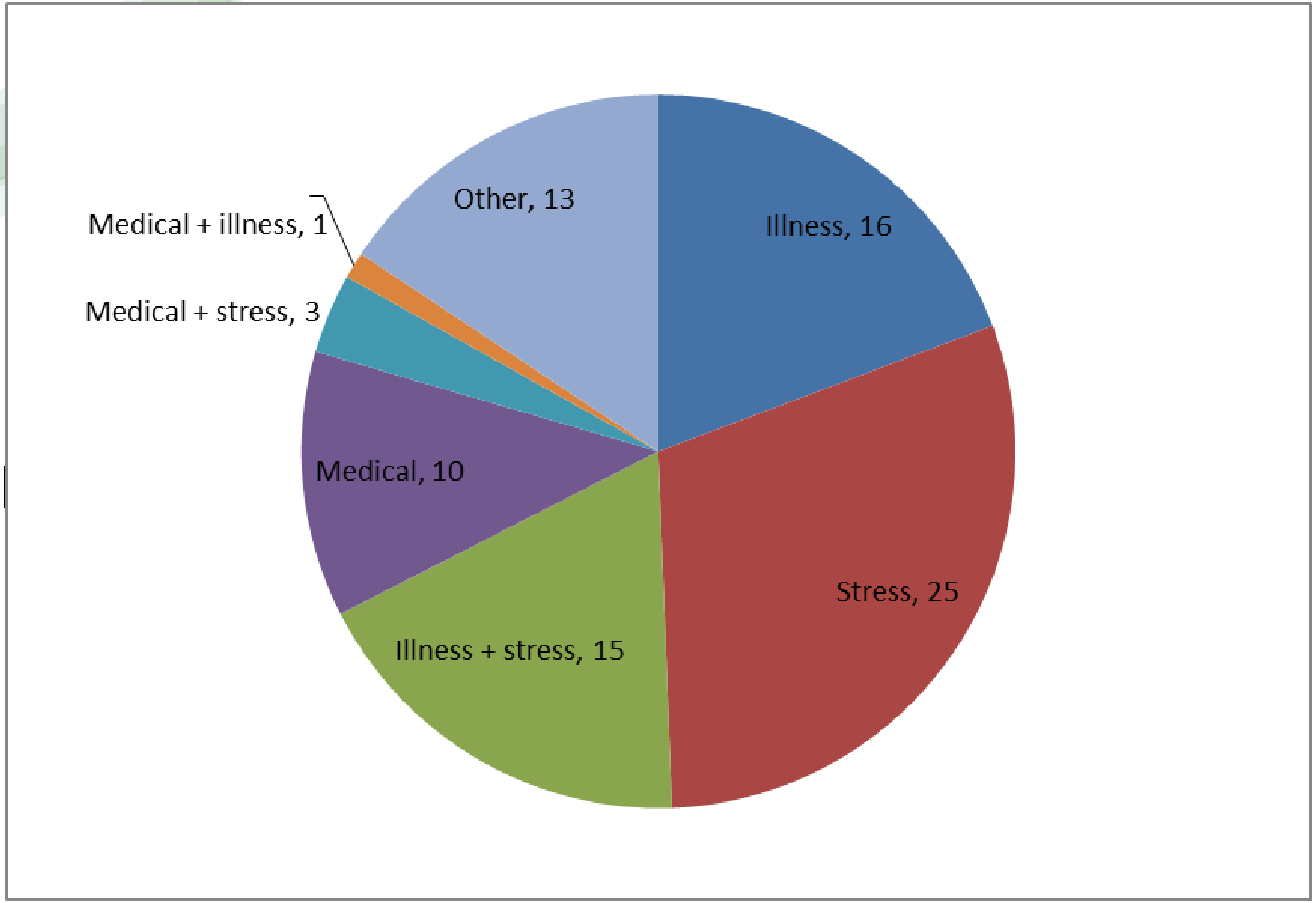

Links between conditions?

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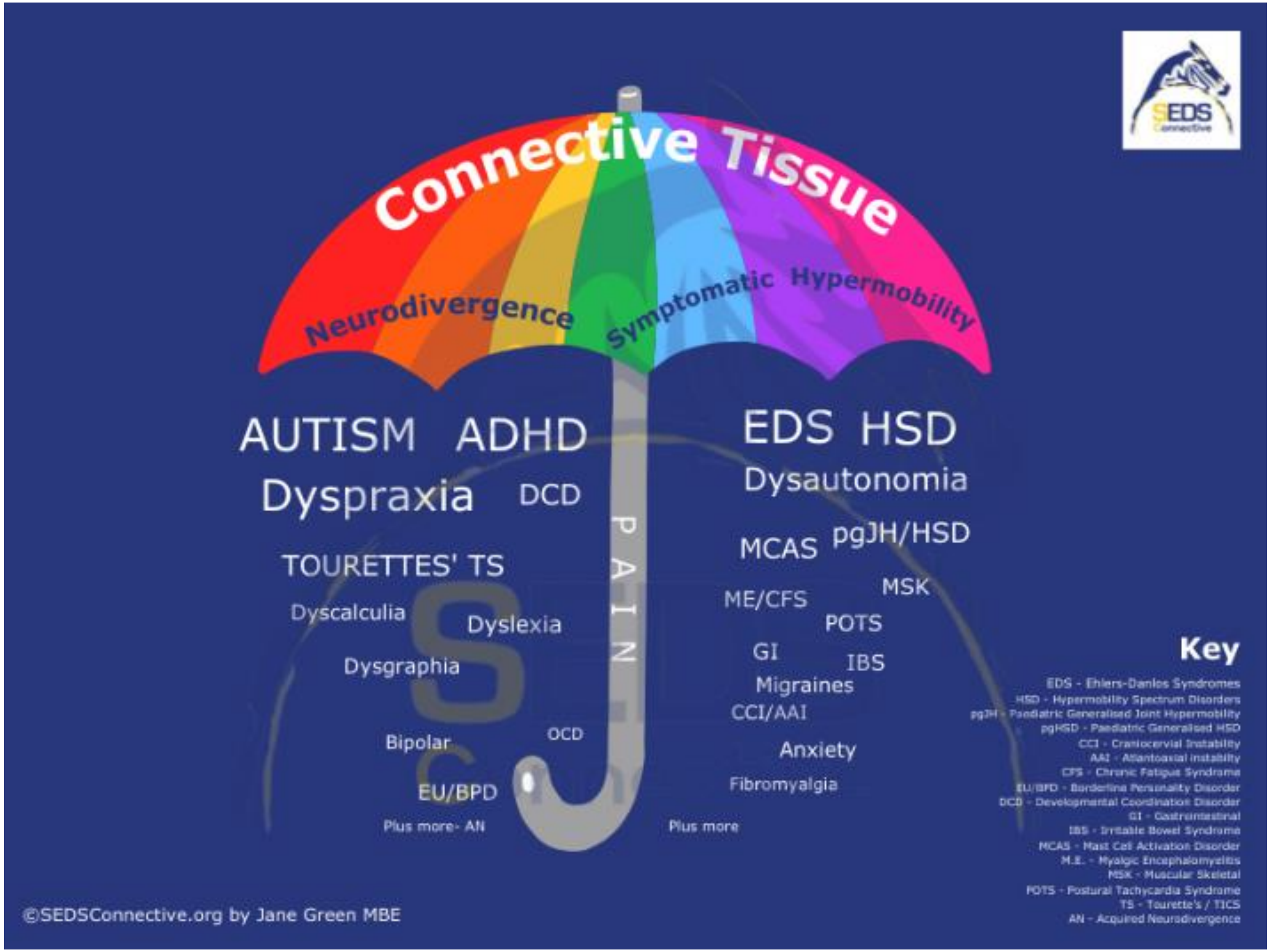
ND adults 4 times more likely to have hypermobility

J Csecs et al, Feb 2022, Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain



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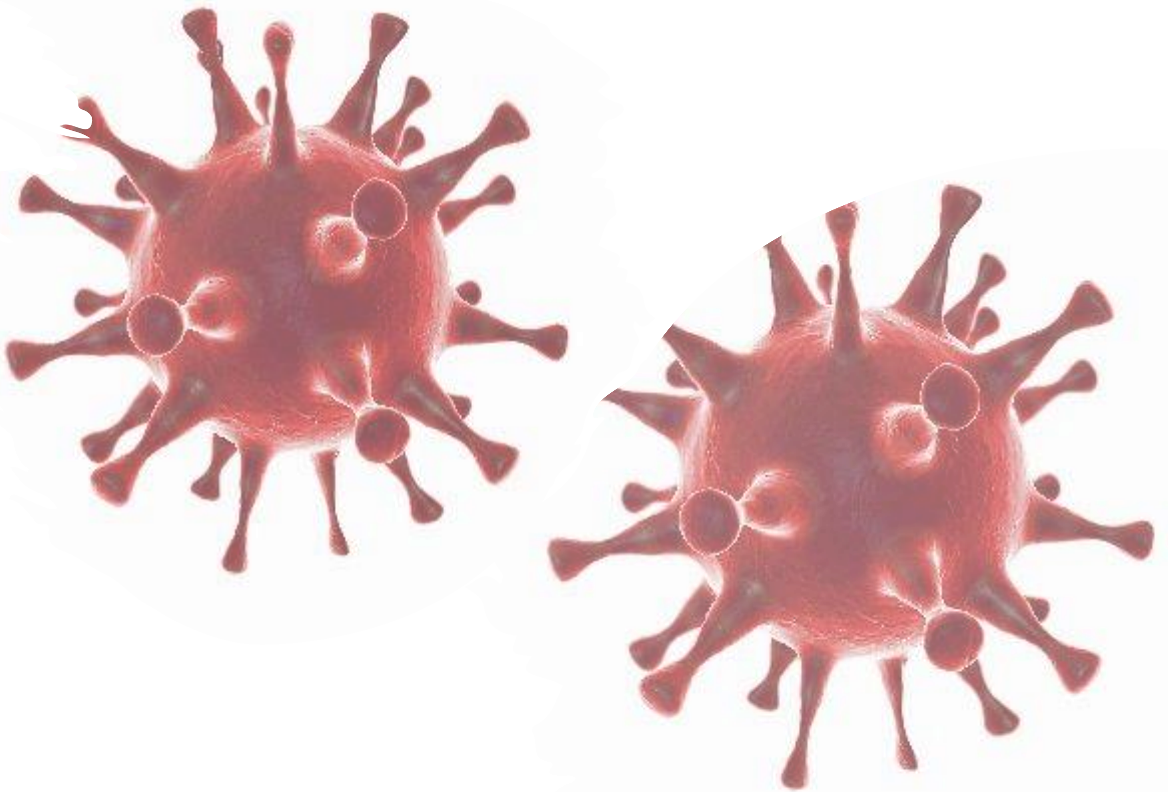
[The Ehlers-Danlos syndromes (EDS) GP Toolkit]

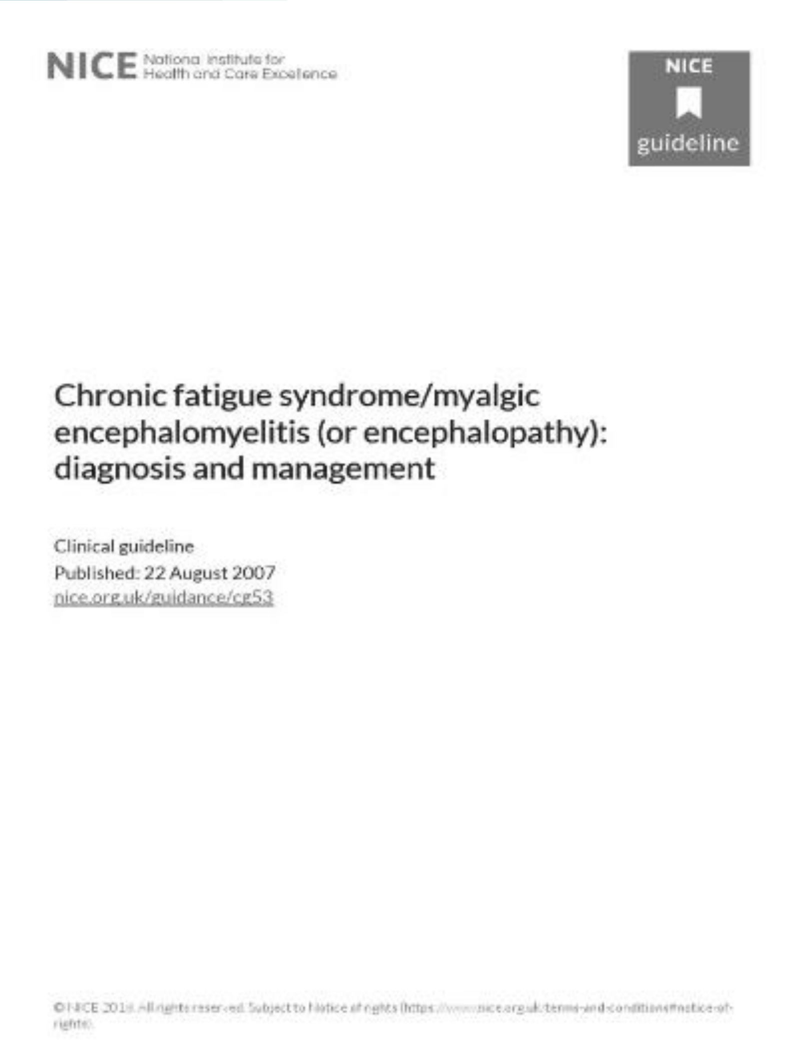
Potential pathophysiology:
ME/CFS research conference 2025



- **EBV as potential trigger of antoantibodies**
- **Muscle impairment – anaerobic metabolism, mitochondrial dysfunction, thickening of capillaries, lipofuscin accumulation ? defective autophagy**
- **Similar reduction in VO2 peak due to low cardiac output due to low filling pressures and/or poor systemic O2 extraction in both ME/CFS and long covid – study 2025**
- **Microvascular dysfunction: capillary lumen seems to be reduced, endothelial dysfunction, microclots**
- **Lactate excess and adrenergic stress affect the immune system**
- **Dysregulation of the immune system leads to chronic inflammatory response and overproduction of regulatory T cells**
- Common co-morbidities: hypermobility, MCAS, small fibre neuropathy, immune deficiencies

NICE Guidelines: 2021 update

- ME/CFS rather than CFS/ME
- Recognition of post-exertional malaise (PEM) as a key symptom of ME/CFS
- Graded-exercise therapy (GET) no longer considered effective for ME/CFS
- CBT to be used as supportive therapy rather than treatment for ME/CFS itself



NICE National Institute for Health and Care Excellence

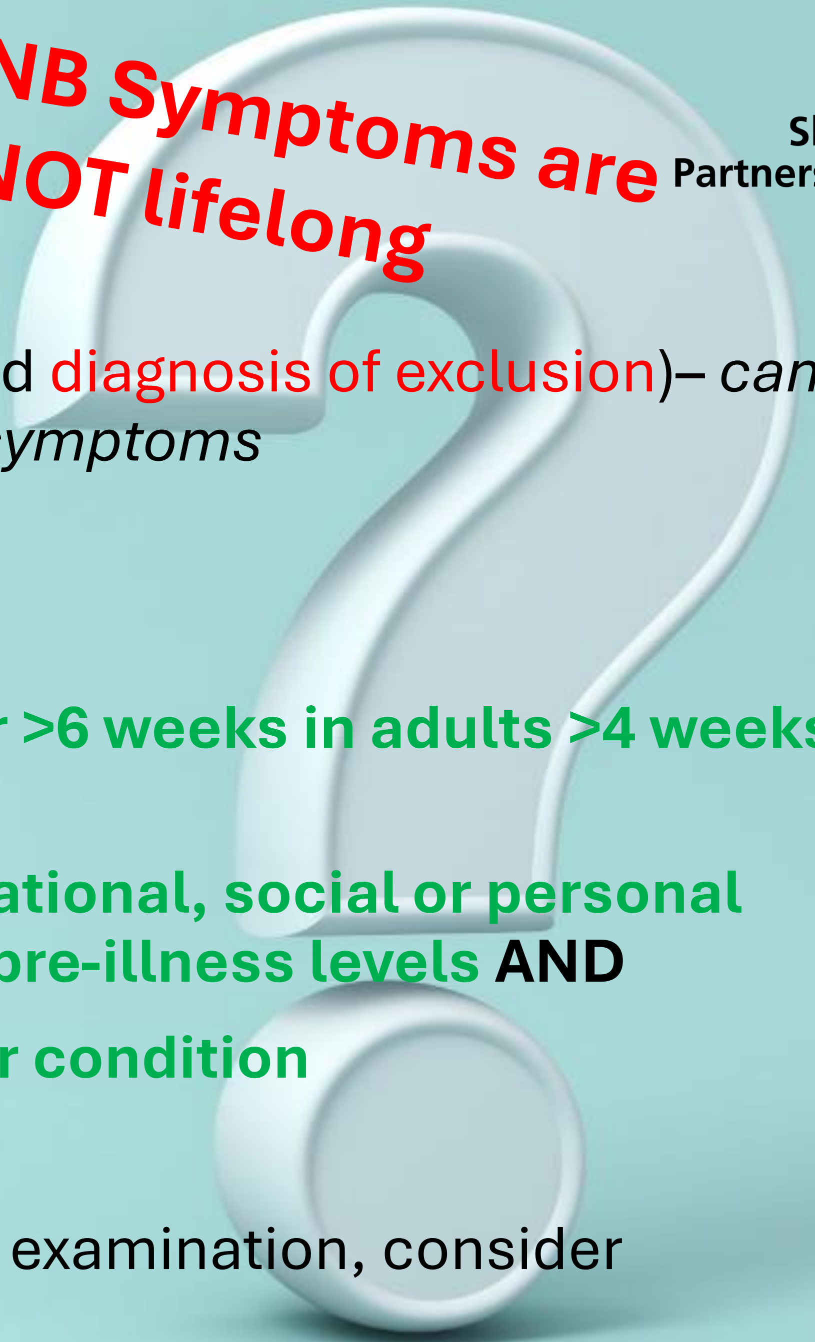
NICE guideline

Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management

Clinical guideline
Published: 22 August 2007
nice.org.uk/guidance/cg53

Suspected ME/CFS?

NB Symptoms are NOT lifelong



- No diagnostic test – clinical diagnosis (and diagnosis of exclusion)– *can only be confirmed after **3 months** of relevant symptoms*

- **Consider referral if:**
- **All of the main persistent symptoms for >6 weeks in adults >4 weeks in children AND**
- **Ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels AND**
- **Symptoms are not explained by another condition**

- Full medical assessment in primary care, examination, consider psychological well-being

Main symptoms (ALL should be present)

- **DEBILITATING FATIGUE with new or specific onset (NOT lifelong)**
  - **Worsened by activity**
  - **Not caused by excessive cognitive, physical, emotional or social exertion**
  - **Not significantly relieved by rest**

- **COGNITIVE DYSFUNCTION**

- **UNREFRESHING/DISTURBED SLEEP**

- **POST-EXERTIONAL MALAISE/SYMPTOM EXACERBATION after activity**
  - **Often delayed**
  - **Disproportionate to the activity**
  - **Prolonged recovery**

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Additional symptoms

Orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations

- fainting, nausea on standing or sitting upright from a reclining position

Temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold

Neuromuscular symptoms, including **twitching** and **myoclonic jerks**

Flu-like symptoms, including sore throat, tender glands, nausea, chills or muscle aches

Intolerance to alcohol, or to certain foods and chemicals

Heightened **sensory sensitivities**, including to light, sound, touch, taste and smell

Pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint

Not typical symptoms of ME/CFS…

- Cognitive symptoms without physical symptoms
- Pain is the main issue with symptom improvement on movement/exercise
- Mainly neurological symptoms e.g. tingling, numbness, other changes in sensation, pseudo-seizures
- Fatigue only at the beginning or end of the day, none otherwise
- Fatigue improves significantly/resolves with medication/supplements
- Lack of motivation/low mood preventing activity rather than fatigue

Exclude or treat:

- Adrenal insufficiency
- Anaemia (iron deficiency)
- Chronic infection e.g. Lyme disease
- Coeliac disease
- Eating disorders inc. obesity
- Fibromyalgia
- Consider ADHD-related fatigue, autistic burnout
- Immunodeficiency
- Malignancy
- Medication side effects
- Menopausal symptoms including perimenopause
- Neurological conditions

  e.g. multiple sclerosis or myasthenia gravis
- Psychiatric and mental health problems including anxiety and depression.
- Primary sleep disorder inc. obstructive sleep apnoea
- Rheumatic diseases
- Somatisation disorder
- Substance misuse inc. alcohol
- Thyroid disease
- Testosterone deficiency
- Travel and tropical diseases
- Neuro-fatigue: CVA, post-concussion syndrome, brain surgery etc

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Required screening tests

Within last 6 months

NICE guidance 2021

- Full blood count
- ESR
- CRP
- Urea and electrolytes
- Serum creatinine
- Creatine kinase
- Calcium profile
- Liver function tests

- Thyroid function tests
- Serum glucose / HbA1C
- Coeliac serology
- Urinalysis – blood, protein
- BMI
- Epworth sleep score
- Ferritin

Consider…. vitamin D, vitamin B12 and folate levels; serological tests, if there is a history of infection; and 9am cortisol for adrenal insufficiency

ME/CFS Diagnosis and Referral

SheffieldCCGPortal.co.uk

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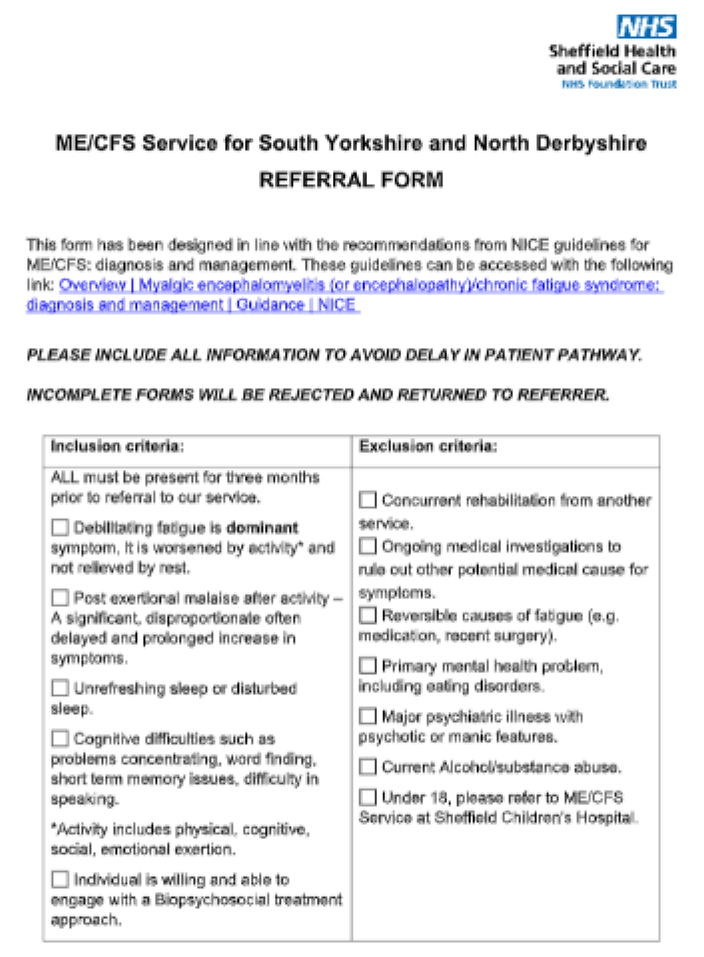

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ME/CFS Service for South Yorkshire and North Derbyshire

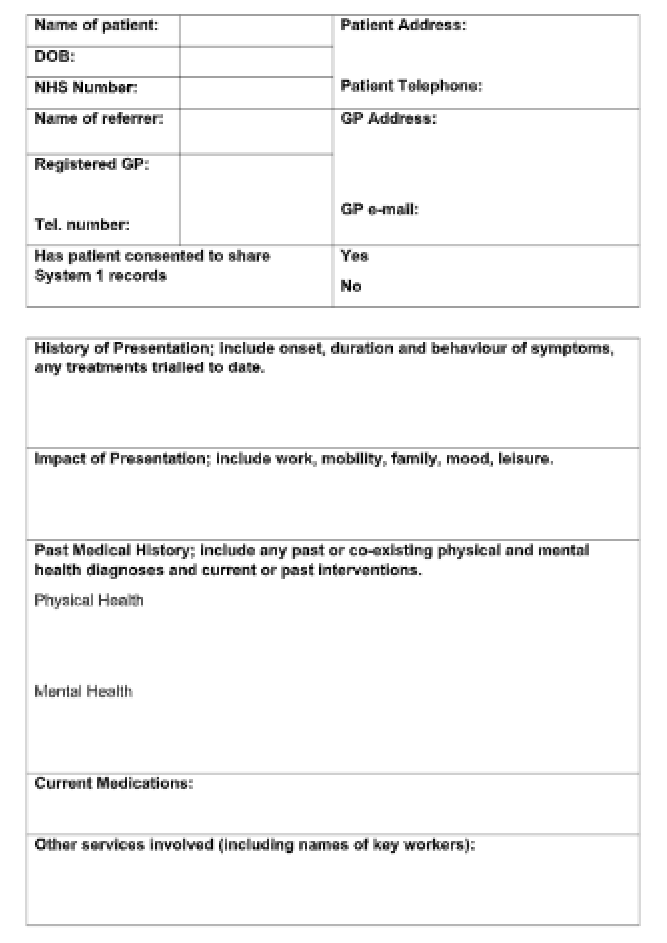
REFERRAL FORM

This form has been designed in line with the recommendations from NICE guidelines for ME/CFS: diagnosis and management. These guidelines can be accessed with the following link: Overview | Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE

PLEASE INCLUDE ALL INFORMATION TO AVOID DELAY IN PATIENT PATHWAY.

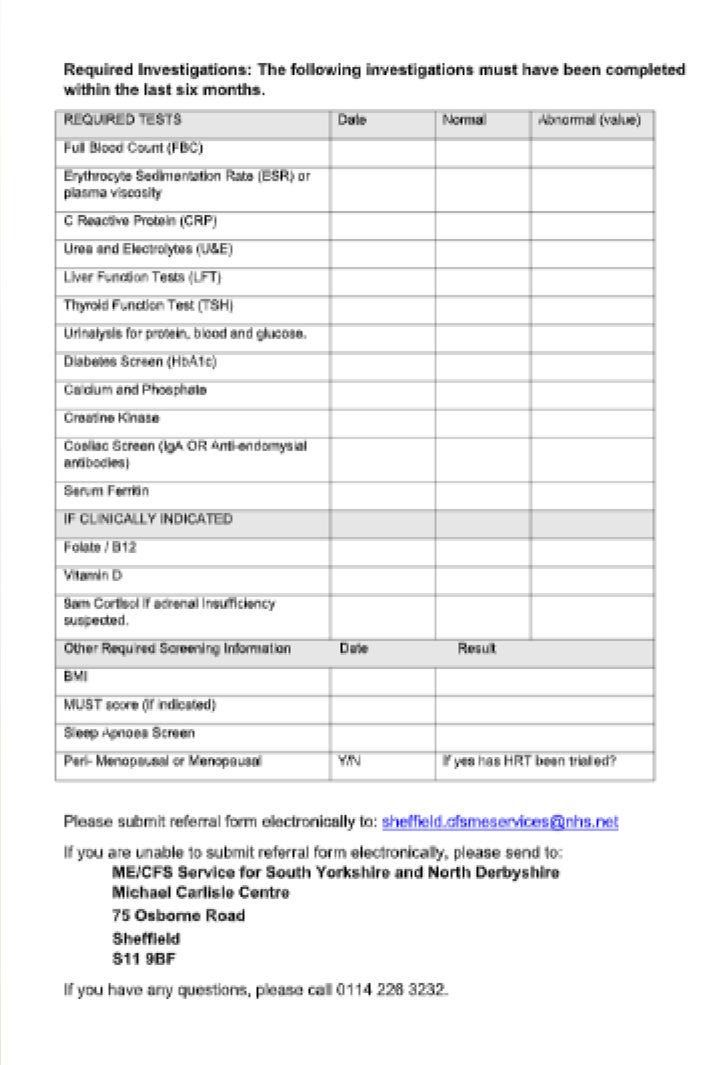
INCOMPLETE FORMS WILL BE REJECTED AND RETURNED TO REFERRER.

Inclusion criteria:	**Exclusion criteria:**
ALL must be present for three months prior to referral to our service. ☐ Debilitating fatigue is **dominant** symptom, It is worsened by activity* and not relieved by rest. ☐ Post exertional malaise after activity – A significant, disproportionate often delayed and prolonged increase in symptoms. ☐ Unrefreshing sleep or disturbed sleep. ☐ Cognitive difficulties such as problems concentrating, word finding, short term memory issues, difficulty in speaking. *Activity includes physical, cognitive, social, emotional exertion. ☐ Individual is willing and able to engage with a Biopsychosocial treatment approach.	☐ Concurrent rehabilitation from another service. ☐ Ongoing medical investigations to rule out other potential medical cause for symptoms. ☐ Reversible causes of fatigue (e.g. medication, recent surgery). ☐ Primary mental health problem, including eating disorders. ☐ Major psychiatric illness with psychotic or manic features. ☐ Current Alcohol/substance abuse. ☐ Under 18, please refer to ME/CFS Service at Sheffield Children's Hospital.



Name of patient:		**Patient Address:**
DOB:		
NHS Number:		**Patient Telephone:**
Name of referrer:		**GP Address:**
Registered GP: **Tel. number:**		**GP e-mail:**
Has patient consented to share System 1 records		**Yes** **No**

History of Presentation; include onset, duration and behaviour of symptoms, any treatments trialled to date.
Impact of Presentation; include work, mobility, family, mood, leisure.
Past Medical History; include any past or co-existing physical and mental health diagnoses and current or past interventions. Physical Health Mental Health
Current Medications:
Other services involved (including names of key workers):



Required Investigations: The following investigations must have been completed within the last six months.

REQUIRED TESTS	Date	Normal	Abnormal (value)
Full Blood Count (FBC)			
Erythrocyte Sedimentation Rate (ESR) or plasma viscosity			
C Reactive Protein (CRP)			
Urea and Electrolytes (U&E)			
Liver Function Tests (LFT)			
Thyroid Function Test (TSH)			
Urinalysis for protein, blood and glucose.			
Diabetes Screen (HbA1c)			
Calcium and Phosphate			
Creatine Kinase			
Coeliac Screen (IgA OR Anti-endomysial antibodies)			
Serum Ferritin			
IF CLINICALLY INDICATED			
Folate / B12			
Vitamin D			
9am Cortisol if adrenal insufficiency suspected.			
Other Required Screening Information	Date	Result	
BMI			
MUST score (if indicated)			
Sleep Apnoea Screen			
Peri- Menopausal or Menopausal	Y/N	If yes has HRT been trialled?	

Please submit referral form electronically to: sheffield.cfsmeservices@nhs.net

If you are unable to submit referral form electronically, please send to:
ME/CFS Service for South Yorkshire and North Derbyshire
Michael Carlisle Centre
75 Osborne Road
Sheffield
S11 9BF

If you have any questions, please call 0114 228 3232.

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What does the screening process involve?

Why can't I request my own investigations/make referrals?

Your assistance with this is much appreciated!

Initial screening band 7s team

All results supplied, no abnormalities/medical complexity – accept

Missing results or does not seem appropriate – reject and ask for results/further information

Abnormalities or medical complexity – forwarded to GPwER ME/CFS

Therapy-led service (in line with ME/CFS services nationally)

GPwER ME/CFS role:

- **3 sessions per week, no medical cover at other times**
- **Medical screening of referrals (>70/month), MDT with therapists, Medical review appointments for more complexity with detailed letters to GP if diagnosis not made, respond to queries, liaise with secondary care**
- ***NB not able to request investigations or make new referrals as part of this therapy-led service. Diagnose ME/CFS, not fibromyalgia***

Consultant Liaison Psychiatrist : 1 session/month – review any patients with complex mental health issues

Risks of diagnosis?

- Lifelong label

- Future non-specific symptoms attribute to ‘flare’ of ME/CFS leading to other conditions missed including malignancy, autoimmune diseases etc

- Caution re: coding

e.g. SystmOne has no code for ‘chronic fatigue symptoms’ (just ‘fatigue’) therefore can be coded as ‘chronic fatigue syndrome’ in notes and subsequently wrongly treated as a confirmed diagnosis

- *Newton et al. The Newcastle NHS Chronic Fatigue Syndrome Service: not all fatigue is the same.* 40% of referrals were eventually diagnosed with other conditions which could explain the clinical picture

- *Devasahayam A et al. Alternative diagnoses to chronic fatigue syndrome in referrals to a specialist service: service evaluation survey. JRSM Short Rep 2012*; diagnosis of “CFS” was eventually confirmed in only 54% of patients

Why ask for screening investigations if patient already has diagnosis of ME/CFS?

To exclude other conditions which may be causing symptoms which manifest as a flare of ME/CFS, for which our treatment approach would be inappropriate and which may lead to other potentially serious conditions being missed.

E.g.

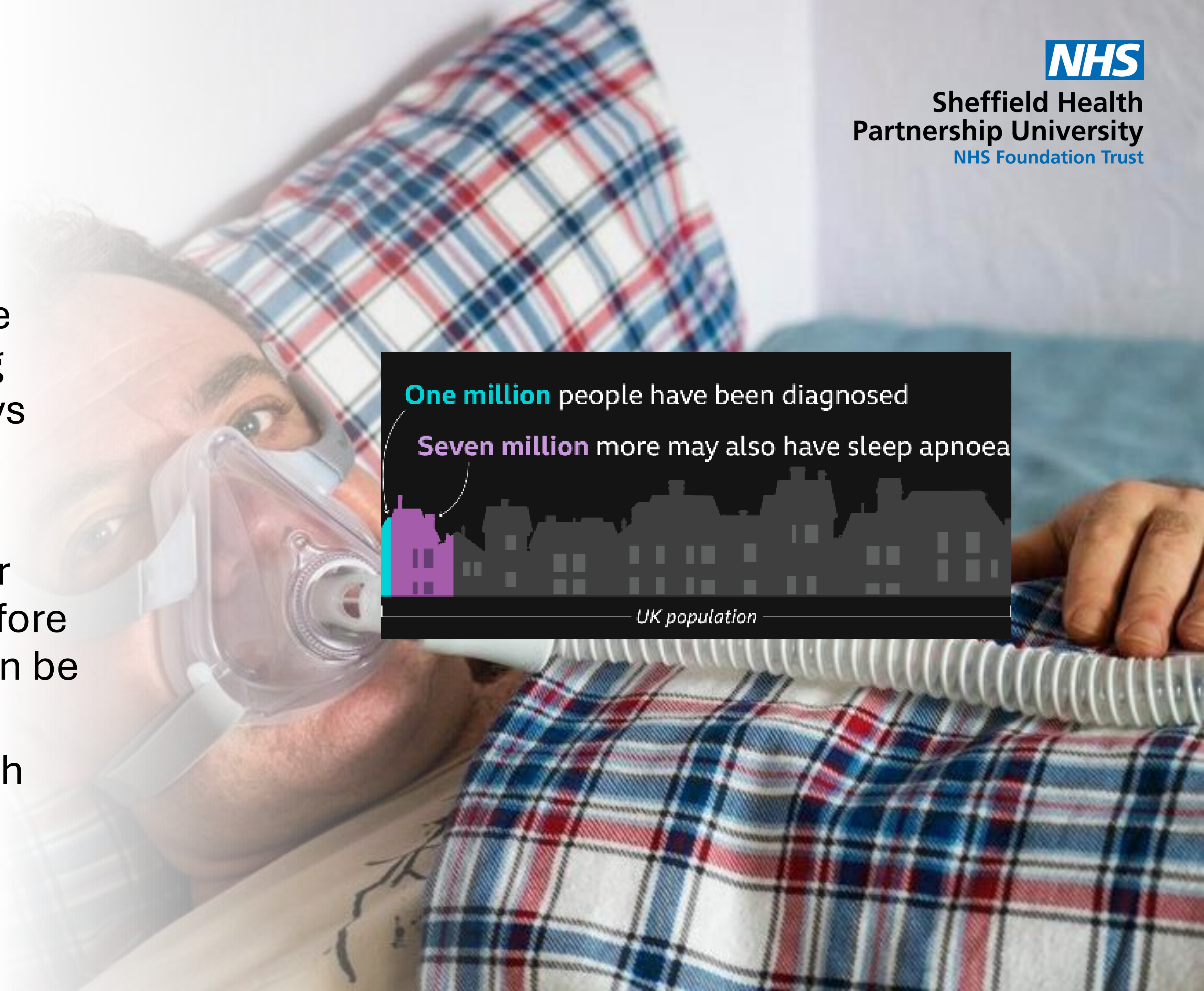
- Haemochromatosis
- Inflammatory bowel disease
- Coeliac disease
- Ovarian cancer
- Bowel cancer
- Sleep apnoea
- Primary hypoparathyroidism
- Autism burnout
- Thyroid disorders
- Liver disease

Case – previous diagnosis of ME/CFS

- 32 year old lady, recently had first child
- Previous diagnosis ME/CFS following EBV infection age 27
- Sept 2022 Increasing fatigue for 3 months. Attributed to ME/CFS flare
- Started with upper abdo pains. USS – gallstones – referred for surgery
- Fatigue progressively worse. Bloods checked – anaemic. Had blood and iron transfusion which seemed to help
- Subsequently had FIT – positive. Referred 2WW.
- Colonoscopy – adenocarcinoma. CT – multiple local and retroperitoneal LN with liver mets
- Referred for palliative chemo/immunotherapy

Sleep Apnoea

- Can experience daytime somnolence or morning headache but not always
- More common than previously thought
- Needs to be excluded or successfully treated before diagnosis of ME/CFS can be considered
- Risk assessment – if high refer for sleep studies



OSA risk assessment

NICE guidance:

“When assessing people with suspected OSAHS:

- **Use the Epworth Sleepiness Scale in the preliminary assessment of sleepiness.**
- **Consider using the STOP-Bang Questionnaire as well as the Epworth Sleepiness Scale.**
- **Do not use the Epworth Sleepiness Scale alone to determine if referral is needed, because not all people with OSAHS have excessive sleepiness."**

- **Local referral pathways: "Epworth > 11 *OR otherwise high level of suspicion*”**

- **ME/CFS service: use Epworth and STOP-bang**

  - **Epworth: 10-15 – excessive daytime sleepiness, >16 severe excessive daytime sleepiness NB r/o ?narcolepsy**

STOP-bang UK

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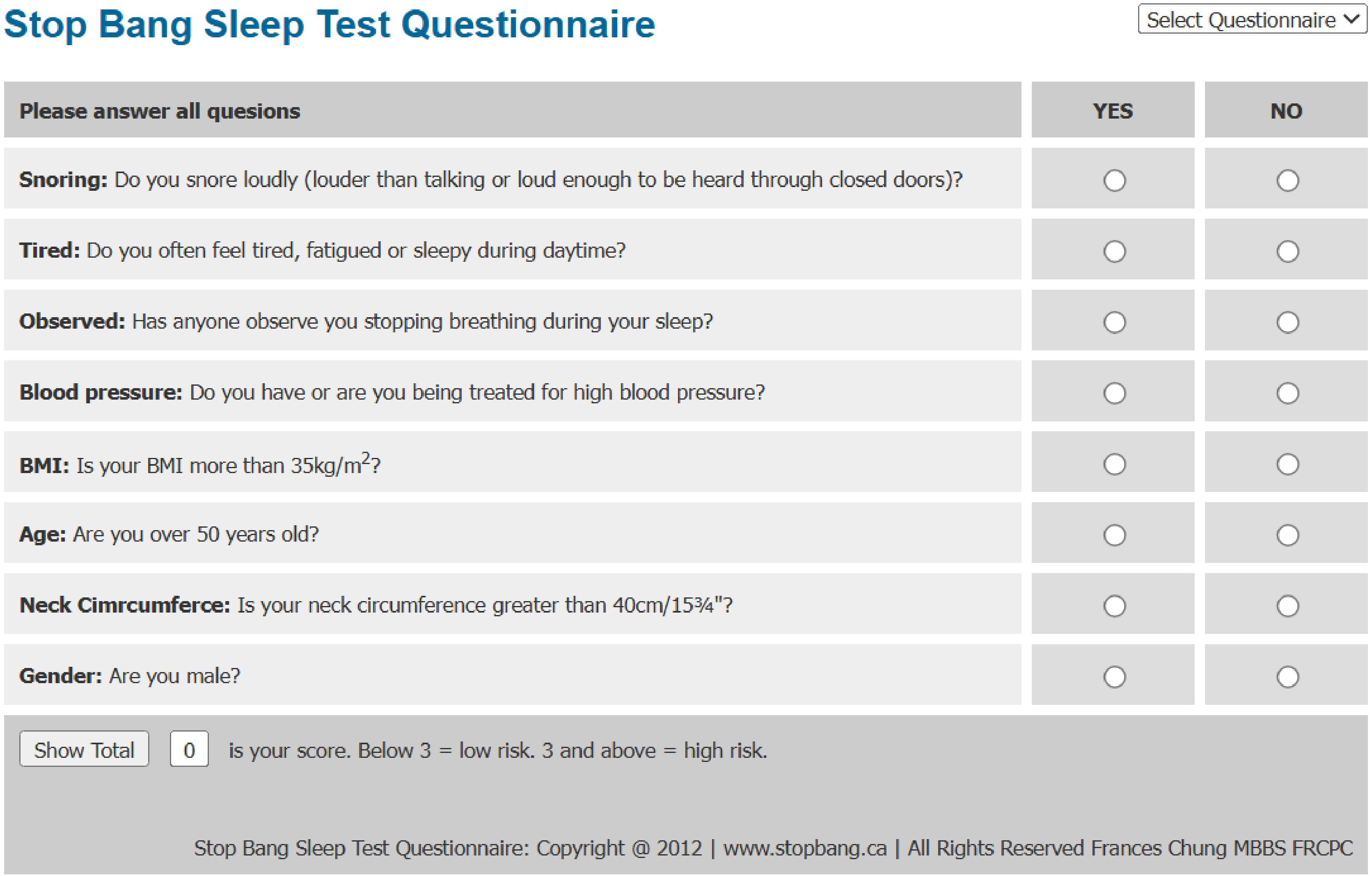

Stop Bang Sleep Test Questionnaire

Please answer all quesions	YES	NO
Snoring: Do you snore loudly (louder than talking or loud enough to be heard through closed doors)?	○	○
Tired: Do you often feel tired, fatigued or sleepy during daytime?	○	○
Observed: Has anyone observe you stopping breathing during your sleep?	○	○
Blood pressure: Do you have or are you being treated for high blood pressure?	○	○
BMI: Is your BMI more than 35kg/m^2?	○	○
Age: Are you over 50 years old?	○	○
Neck Cimrcumferce: Is your neck circumference greater than 40cm/15¾"?	○	○
Gender: Are you male?	○	○

0 is your score. Below 3 = low risk. 3 and above = high risk.

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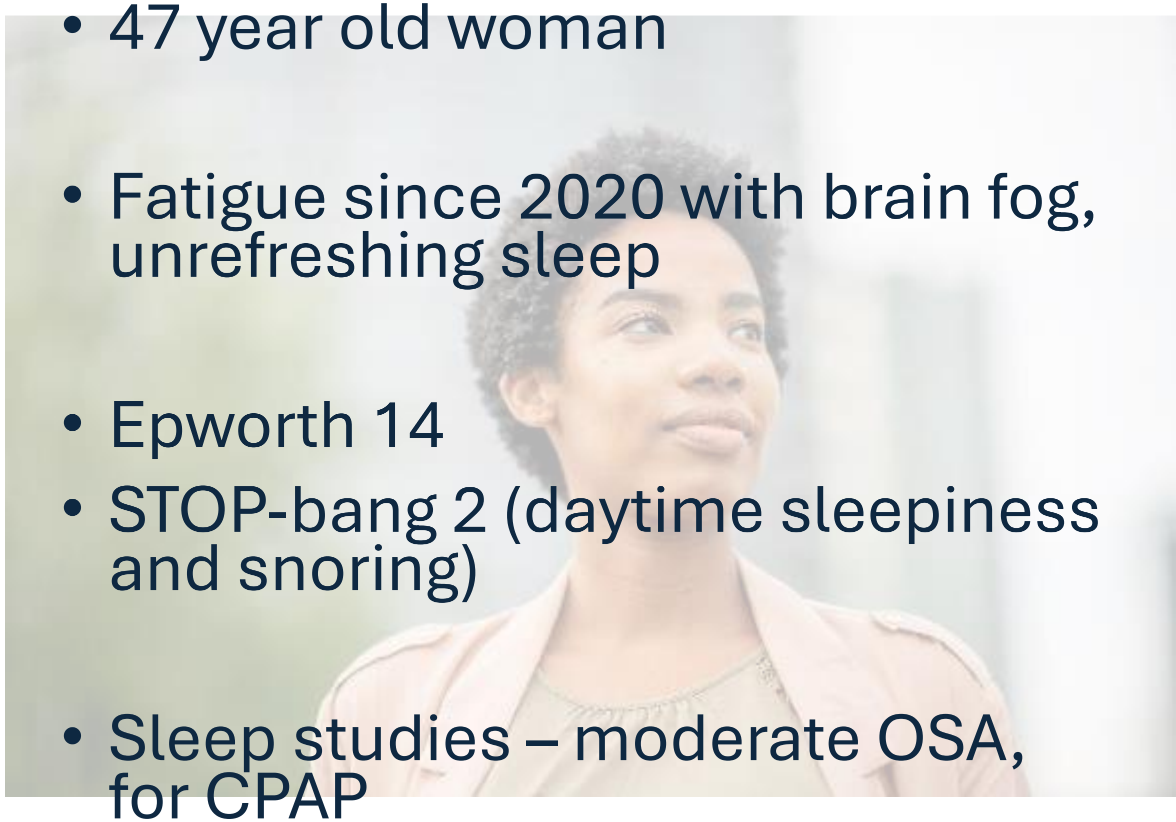
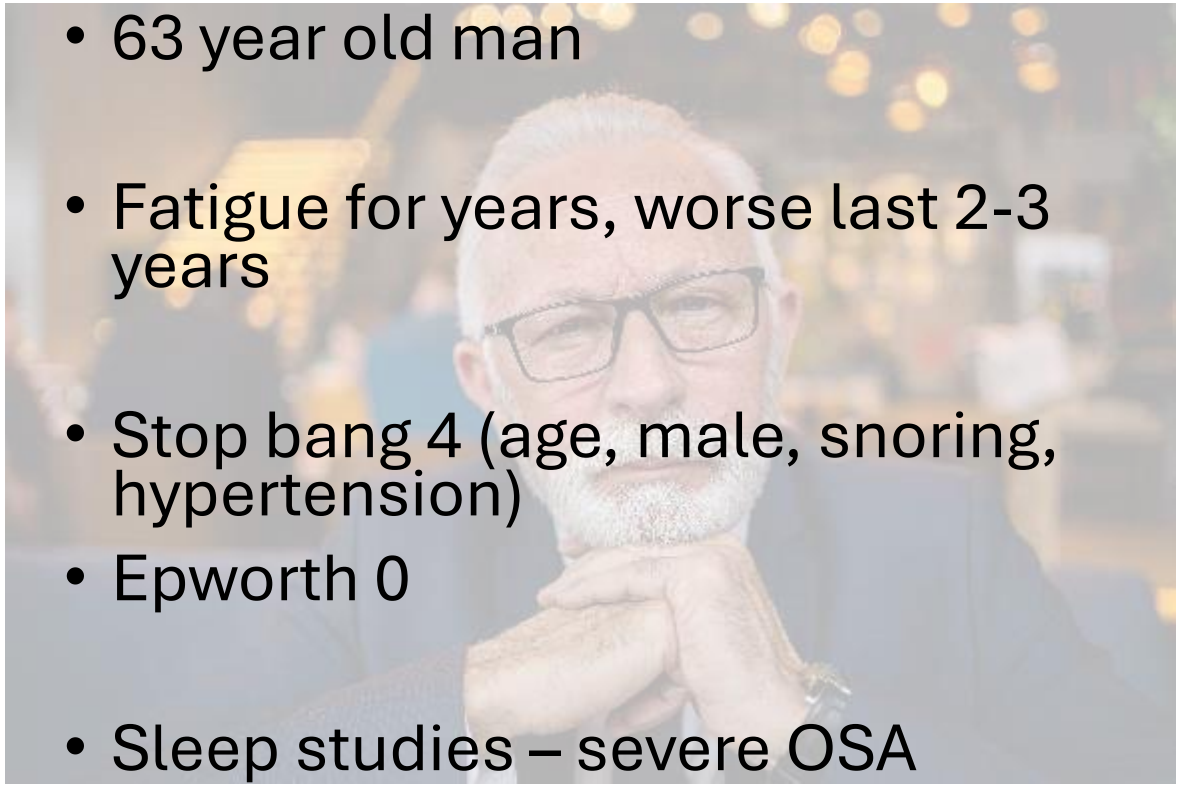


- 47 year old woman
- Fatigue since 2020 with brain fog, unrefreshing sleep
- Epworth 14
- STOP-bang 2 (daytime sleepiness and snoring)
- Sleep studies – moderate OSA, for CPAP



- 63 year old man
- Fatigue for years, worse last 2-3 years
- Stop bang 4 (age, male, snoring, hypertension)
- Epworth 0
- Sleep studies – severe OSA

Consider other sleep disorders: insomnia, narcolepsy, RLS, parasomnias etc

- 53 year old lady
- Fatigue symptoms started 2005 following birth of second child
- Some insomnia during pregnancy which persisted and was followed by fatigue symptoms
- Insomnia continued since then – can have as much as 4-5 hours some nights but often it is less than this. Often gets up for the day around 3.30 – 4.30am therefore already often tired by 8am. Mornings are best time for energy levels, crashes in evenings and can nap which refreshes her a little. GP has ruled out OSA.
- Lots of stress in personal life due to ongoing divorce process, previous psychological and emotional abuse. Often in sympathetic overdrive 'fright or flight'. Nightmares/night terrors.
- Imp – chronic fatigue symptoms linked to chronic insomnia and chronic stress/trauma ? PTSD
- Recommend assessment for PTSD with potential subsequent further sleep analysis as appropriate.
- Energy management advice session and d/c.

Can ME/CFS be diagnosed with other co-morbidities?

- If inflammatory condition – should be **inactive or fully controlled** on treatment with evidence of this e.g. normal calprotectin, inflammatory markers, normal endoscopy in letter from specialist
- IHD/COPD/other chronic conditions are controlled and minimally impacting on symptoms
- NAFLD/MASLD – check NILS r/o other causes abnormal LFTs, check **non-invasive fibrosis score** ? Needs referral to hepatology
- OSA on CPAP – completed **3 months with good compliance and CPAP review to confirm OSA is controlled**
- Cancer treatment completed, continued fatigue persisting beyond usual expected period of time
- *Timeline of symptom onset is important*

Iron deficiency

- Defined as **ferritin < 30** ug/L as per UK guidelines
- NICE: "In all people, a *serum ferritin level of less than 30 micrograms/L confirms a diagnosis of iron deficiency*. Low levels of ferritin can result in symptomatic and functional impairment even in those individuals with a normal haemoglobin, especially in women who are menstruating."
- Ferritin levels can be difficult to interpret if infection or inflammation is present, as levels can be high even in the presence of iron deficiency."

- Common – especially in menstruating women (this does not mean we should ignore it! **NB lab reference ranges not helpful in this respect**)
- Can cause or contribute towards chronic fatigue, cognitive difficulties

- Diagnosis – **ferritin (not FBC or iron profile) as it is the test which most reliably correlates with body iron stores**
- Treatment – identify cause and address, treat deficiency

- NB also vitamin D, B12, folate deficiencies should be treated as they can contribute to symptoms
- B12 < 350ng/L could be deficient (B12 updated NICE guidelines)

Iron overload

- 36 year old woman
- TATT, palpitations, gradual onset last 2 years
- Ferritin 342

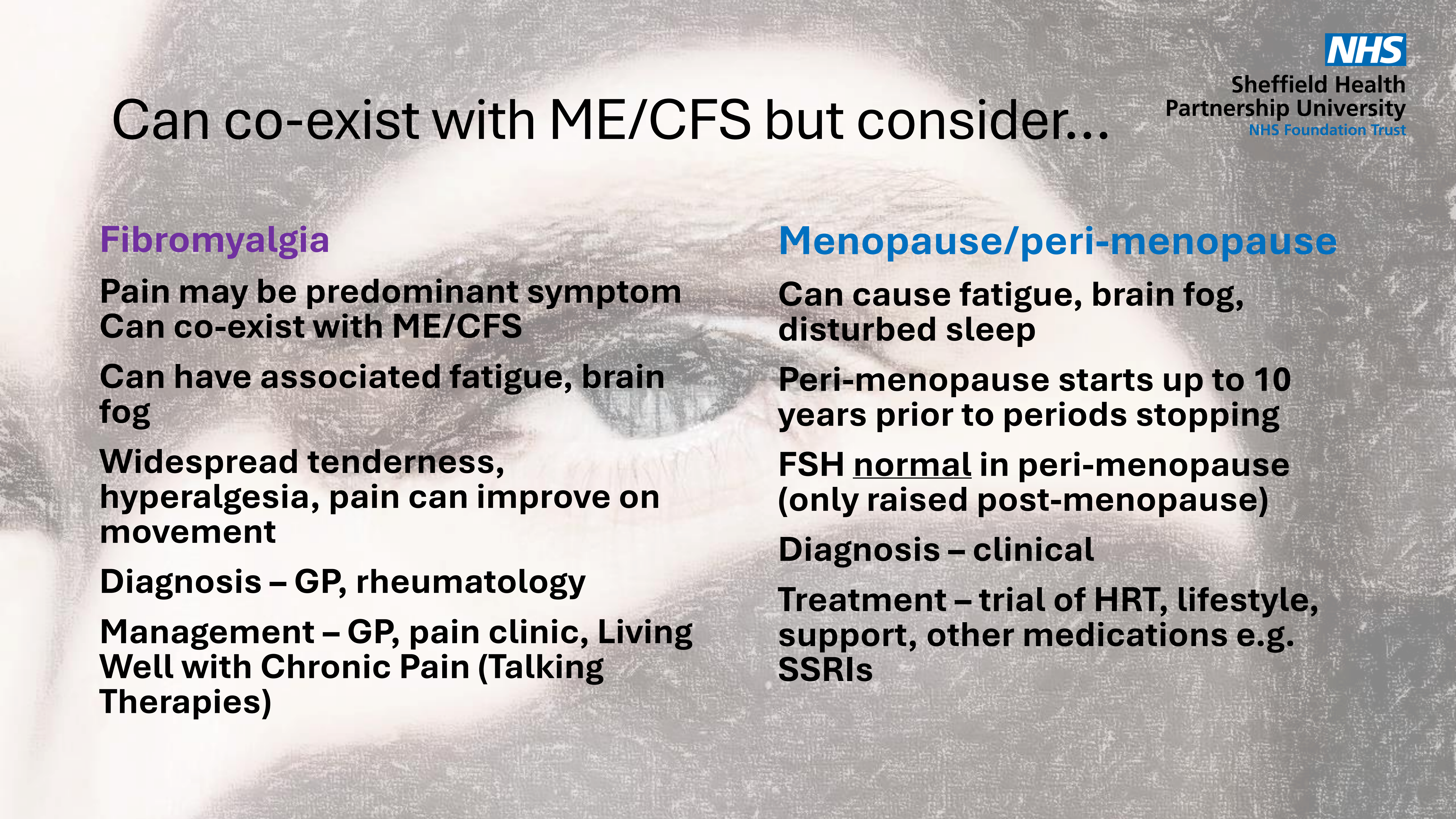
Requested iron profile:

Iron * 29.3 umol/L (6.6 – 26)
% IBC Saturation * 70% (15 – 45)
Total Iron Binding Capacity * 42

Need to exclude haemochromatosis (HFE genotyping, referral as appropriate)

- Haemochromatosis – most common inherited condition caused by single gene variant, affects up to 1 in 150 people in Northern Europe. Around 1 in 10 people in UK are carriers. Autosomal recessive
- Onset of symptoms is insidious and non-specific: fatigue/malaise, joint pains, abnormal LFTs
- If ferritin > 200 ug/L in pre-menopausal women or > 300 ug/L in men and transferrin saturation/%TIBC > 45% consider checking HFE genotype
- NB Acute phase reactant – can be raised in multiple acute and chronic inflammatory conditions

Can co-exist with ME/CFS but consider...



Fibromyalgia

Pain may be predominant symptom
Can co-exist with ME/CFS

Can have associated fatigue, brain fog

Widespread tenderness, hyperalgesia, pain can improve on movement

Diagnosis – GP, rheumatology

Management – GP, pain clinic, Living Well with Chronic Pain (Talking Therapies)

Menopause/peri-menopause

Can cause fatigue, brain fog, disturbed sleep

Peri-menopause starts up to 10 years prior to periods stopping

FSH <u>normal</u> in peri-menopause (only raised post-menopause)

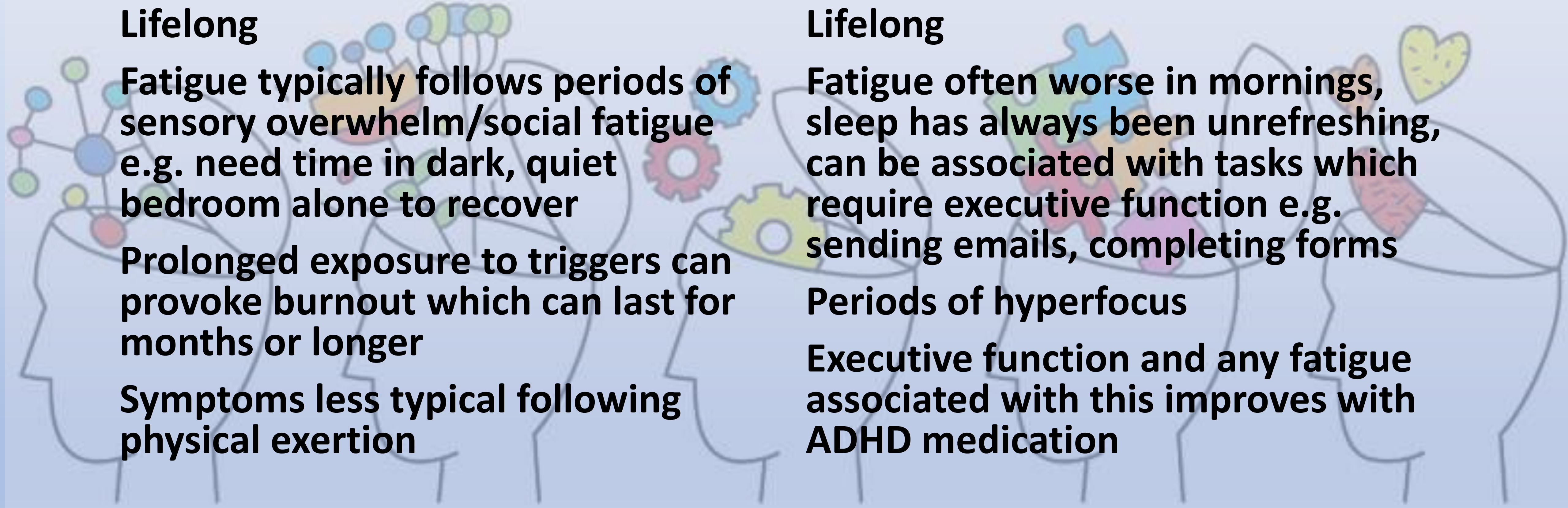
Diagnosis – clinical

Treatment – trial of HRT, lifestyle, support, other medications e.g. SSRIs

- 46 year old lady
- Fatigue, brain fog, aches and pains worsening since 2020
- Not tolerating iron supplements well
- Takes co-codamol, mirtazapine, gabapentin
- Sleep issues
- ?Perimenopause

- Ferritin 5 (13 in Jan 2022 earliest result on ICE)
- Hb 102
- Vitamin D 28.2

- Identify cause iron deficiency, try alternative oral iron, consider referral for iron infusion if appropriate
- Consider HRT trial
- Treat Vitamin D deficiency
- Review medications and address sleep issues



Autism

Lifelong

Fatigue typically follows periods of sensory overwhelm/social fatigue e.g. need time in dark, quiet bedroom alone to recover

Prolonged exposure to triggers can provoke burnout which can last for months or longer

Symptoms less typical following physical exertion

ADHD

Lifelong

Fatigue often worse in mornings, sleep has always been unrefreshing, can be associated with tasks which require executive function e.g. sending emails, completing forms

Periods of hyperfocus

Executive function and any fatigue associated with this improves with ADHD medication

Can co-exist with ME/CFS

- 49 year old female

- ‘burnout’ 15 years ago, very busy lifestyle little rest, lots of travel with work
- Rested and improved, commenced HRT for peri-menopause

- Worse since 2.5 years ago after had covid for third time – wiped out for months, not been the same since then, had to stop lots of activities
- Now has unrefreshing sleep, brain fog, PEM
- Has hypermobility, wonders about MCAS and takes quercetin for this. Symptoms of dysautonomia.

- Diagnosed with ADHD 6-7 months ago and commenced methylphenidate. This helps with executive function but does not improve the fatigue
- Perimenopause and ADHD have been addressed. Fits symptomatic criteria for ME/CFS.
- Diagnosed ME/CFS – for treatment programme.

- 57 year old female
- No specific time of onset for fatigue symptoms, gradually getting worse for years, pushes herself lots.
- Traumatic year in 2017 due to bereavement, ongoing grief trauma since then, anxiety - constantly thinks something bad is going to happen. Struggles to switch brain off, sleep initiation difficult.
- Diagnosed OSA, could not tolerate CPAP or mandibular advancement device.
- Thinks she could have ADHD/autism – high risk on questionnaires. Feels may explain why struggling to process trauma, struggles with focus/concentration
- Imp – Chronic fatigue of multifactorial origin: untreated OSA, bereavement reaction, possible PTSD, anxiety/depression, possible ADHD/ASD
- Recommend – referral ADHD/ASD assessment, Talking therapies and support with mental wellbeing
- Energy management session prior to d/c

Our improvements....

- Improved access to shared records (fewer requests to GP for information)
- Provide energy management advice booklet to patient waiting for referral to be accepted
- ICE CFS panel STH
- Referral form (not mandatory but hopefully helpful)
- Review letter templates
- Website improvement
- Refresher group offered quarterly for 12 months following completion of treatment

No current robust evidence to support recommendation for prescribing any medications. We are a non-prescribing service.

The future?

- ME/CFS delivery plan, July 2025
  - Research, Attitudes and education, Living with ME/CFS

- Trials targeting autoantibodies:
  - Plasma cell targeting by daratumubab - immune trigger can lead to long lasting B cells in people with ME/CFS which produce autoantibodies – they express CD38 – daratumumab binds to these receptors and reduces immunoglobulins. Pilot study 6/10 patients had clinically significant improvement in symptoms
  - Rituximab trial in Japan, Wakiro Sato

- Other potential treatments with ongoing trials:
  - IgG therapy
  - Hyperbaric oxygen therapy – increase oxygen delivery to the tissues; increase angiogenesis, improve mitochondrial activity, reduced inflammatory cytokines
  - Low-dose naltrexone (reduce natural killer cells/pro-inflammatory cytokines) with pyridostigmine (increases preload therefore improve vascular tone when upright)

  - Further exploring link between hypermobility and ME/CFS

References / Resources

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- ME Association The ME Association - The ME Association
- DeCODE ME DecodeME : The world's largest ME/CFS study | Institute of Genetics and Cancer
- BACME BACME - British Association of Clinicians in ME/CFS
- NICE guideline ME/CFS Overview | Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE
- NICE guideline OSA 1 Obstructive sleep apnoea/hypopnoea syndrome | Obstructive sleep apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s | Guidance | NICE
- NICE guidance iron deficiency Anaemia - iron deficiency | Health topics A to Z | CKS | NICE
- NICE guideline B12 Overview | Vitamin B12 deficiency in over 16s: diagnosis and management | Guidance | NICE
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Service | Sheffield Partnership University NHS Foundation Trust
- SEDSConnective SEDSConnective | Hypermobility, EDS & Neurodivergence Charity
- @BendyBrain Dr Jessica Eccles | Instagram, TikTok | Linktree
- J Csecs et al, Feb 2022, Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain
- The Ehlers-Danlos syndromes (EDS) GP Toolkit
- Circulatory Dysfunction in ME/CFS, David Systrom, ME/CFS Research Foundation Conference 2025
- Mechanisms of post-exertional malaise, Christian Puta, ME/CFS Research Foundation Conference 2025
- The Lancet, Jan 2020; Editorial: Time to wake the giant of obstructive sleep apnoea: 2019, Benjafield et al: Estimation of the global prevalence and burden of obstructive sleep apnoea: a literature-based analysis
- Plasma cell targeting by the anti-CD38 antibody daratumumab in ME/CFS, Prof Oystein Fluge University of Norway ME/CFS Research Foundation Conference 2025
- Rituximab trial in Japan, Wakiro Sato, ME/CFS Research Foundation Conference 2025

SYND ME/CFS Service: Who we are.....

NHS
Sheffield Health
Partnership University
NHS Foundation Trust

- Specialist, regional therapy service for adults affected by ME/CFS across South Yorkshire and North Derbyshire.
- Condition specific service NOT a general fatigue service.
- MDT: AHPs, 4 OTs & 1 PT (4.0 WTE), Clinical Psychologist (0.6WTE), GPwER (0.3 WTE), Consultant Liaison Psychiatrist (1 afternoon a month), 3 Administrators (1.6 WTE), Team Manager (PT) (0.4WTE).

Improving lives

SYND ME/CFS Service:
What we do ....

Sheffield Health
Partnership University
NHS Foundation Trust

- Provide individualised, trauma informed, patient centred care.
- Treatment Approach: evidence based informed by NICE guidelines (2021). Biopsychosocial treatment approach underpinned by ACT (Acceptance and Commitment Therapy).
- We do NOT offer a cure. Support development of self-management strategies to help individuals live well with their ME/CFS.

Improving lives

SYND ME/CFS Service
What we do …. Pathway

NHS
Sheffield Health
Partnership University
NHS Foundation Trust

- **Screen** referrals.
- Offer a one-hour biopsychosocial **assessment** with a therapist.
- **Confirmation of diagnosis** if appropriate is made in discussion with MDT GPwSI and Cons Psychiatrist. (If diagnosis not possible we offer 2 general fatigue management advice sessions and signpost to alternative services and discharge).
- Discuss treatment options and **agree management plan**.
- Potential assessment and sessions with psychologist if indicated either prior to or following treatment program.

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SYND ME/CFS Service offer
What we do……. Service Offer

Sheffield Health
Partnership University
NHS Foundation Trust

IF a diagnosis is confirmed…Treatment Manual provided, Care & Support Plan offered, **PLUS** option of:

> 6-8 **individual sessions** face to face, video or telephone
> **OR**
> 6wks 2hr **group programme** via Teams.
> Following completion of treatment program,1-year open appt and option to attend quarterly refresher group sessions.

If required, we liaise with and support relevant services, family and carers. Provide letters of support for employers, educational organisations and benefits applications if appropriate. Signpost to resources on reasonable adjustments.

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Sheffield Health
Partnership University
NHS Foundation Trust

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