

# Service Provision for People with ME/CFS (Myalgic encephalomyelitis / encephalopathy / Chronic Fatigue Syndrome

Derby CFS/ME Service

- What is ME/CFS
- Number of people suffering
- Current situation with service provision for ME/CFS
- Nature of treatment
- Outcome of treatment
- Response to NICE and All Party Parliamentary Group Report

# What is ME/CFS

- ME/CFS is a complex, multi-system, chronic medical condition that has considerable personal, social and economic consequences and a significant impact on a person's quality of life, including their psychological, emotional and social wellbeing.
- Degrees of severity from mild -self caring, in work and education, to very severe- fully dependent, bedbound, needing help with all aspects of care.
- Severe / very severe affects approximately 25% people with ME
- People with ME require targeted service provision, including health and social care. Research by 2020 health has shown that, when lost taxes, welfare benefits, and health and social care costs are considered, the total cost to the UK economy of ME in 2014/15 was at least £3.3 billion (All Party Parliamentary Group (APPG) Report 2022)

# Number of People Affected

NICE 2021:

Recent data from the UK Biobank suggest that there are over 250,000 people in England and Wales with ME/CFS, with about 2.4 times as many women affected as men. ME/CFS can affect people of all ages.

# Service Provision at Derby

- Service established 2004 for adults aged 16 and over
- Based in Specialist Rehabilitation at Florence Nightingale Community Hospital
- Referrals received from any area
- No geographical boundaries but encourage nearer services if available
- Advice and guidance available to GPs
- Training to other disciplines

# Multidisciplinary Team:

- Consultants in Rehabilitation Medicine
- 3.5 Whole time equivalent:
  - Occupational Therapy
  - Physiotherapy
  - Cognitive Behavioural Therapist
- 0.8 Admin

# Additional staffing in response to pandemic

- Additional staffing for long covid impact:

- |                        |         |                           |
|------------------------|---------|---------------------------|
| • Occupational Therapy | 2 staff | 1.2 Whole Time Equivalent |
| • Admin                | 1 staff | 1 Whole Time Equivalent   |

# Referral Numbers

- 2018 – 2019 256
  - 2019 - 2020 236
  - 2020 – 2021 117 (+ 14 long covid)
  - 2021 – 2022 210 (+ 200 long covid)
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- Long Covid referrals now minimal

# ME/CFS Therapy

- Follows NICE Guidance 206 2021 for ME/CFS
- Holistic therapy assessment
- Therapy - Person Centred approach providing self management strategies to help the person to self manage their condition, aiming to reduce severity of symptoms, improve symptom management, and improve quality of life, including support with engagement in social, leisure, education and employment.
- Provision of reports to support employment, education, welfare applications
- Number of sessions depends on individual need
- No cure

# Medical Assessment / Management

- Initial assessment to establish the diagnosis of ME/CFS
- Further investigation if necessary
- Symptom management – treating pain, disturbed sleep
- Follow up from therapist
- Person requests
- Referral on
- GP advice
- Provision of medical reports

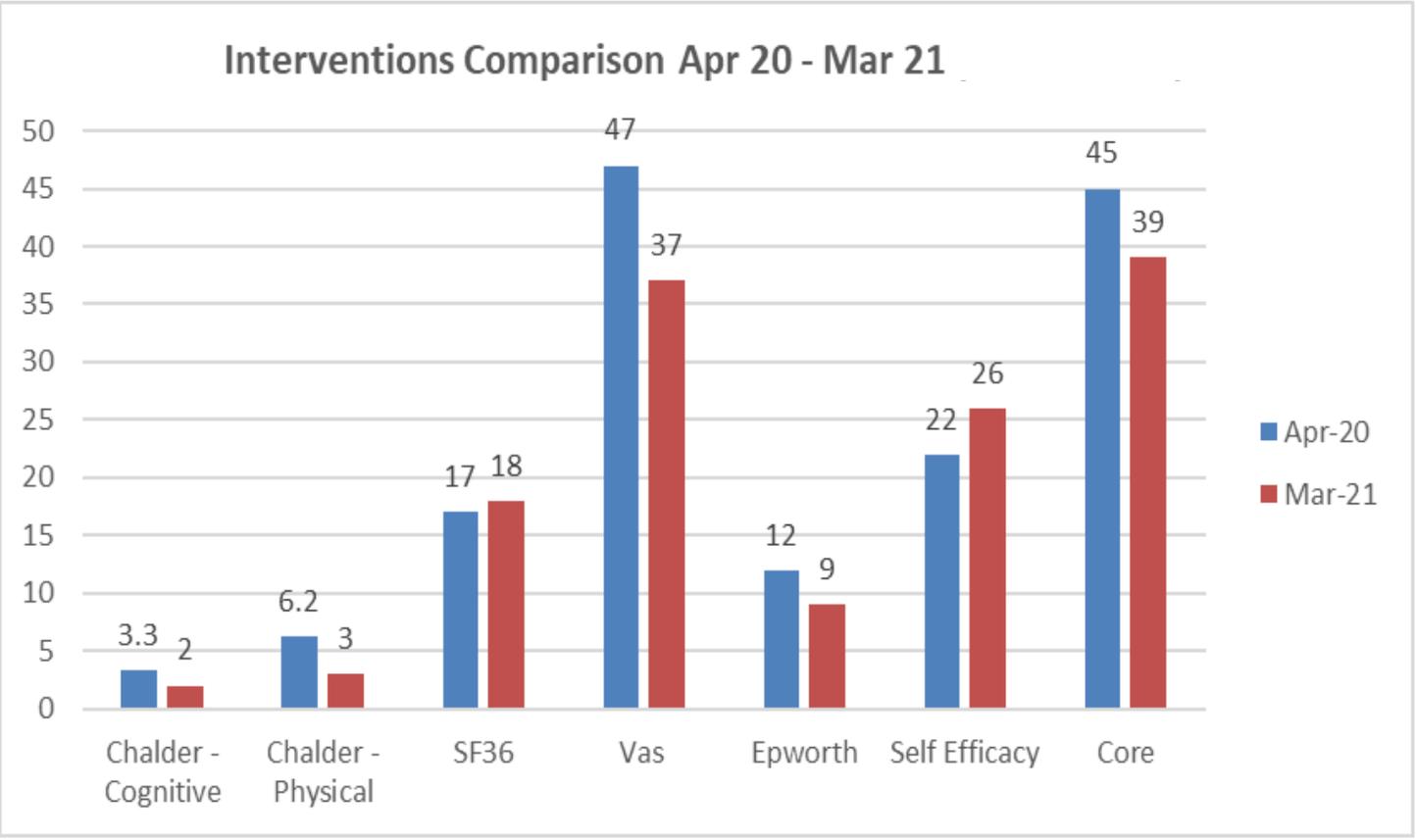
# Treatment medium

- Face to face
- Telemedicine
- Telephone
- Group
- Virtual group
- Home visits within local area

# Outcomes

- Measured through outcome questionnaires at initial appointment and 12 months:
- Epworth Sleepiness Score
- VAS (pain) scale
- CORE (Anxiety and depression)
- SF36 (Physical function)
- Self Efficacy
- Chalder Fatigue

# Outcomes 2020 - 2021



# Clinical performance Indicator

- A minimum of 80 % of respondents to CFS/ME Service evaluation questionnaire will report being more confident in self managing their condition.
- 2018 – 19 95%
- 2019 – 20 94%
- 2020 – 21 100% of respondents more confident

# Response to new NICE Guidance

- Baseline assessment tool completed against recommendations, service working well within these guidelines and will continue to monitor against guidelines and ensure best practice.
- Graded Exercise Therapy (GET) – potential harm in GET and where the person wishes to increase activity / exercise levels this is person led, done safely with careful timing, regular reviews and adjustments as required.
- Cognitive Behavioural Therapy – offered as an adjunct to therapy, not as a cure for ME.

# All Party Parliamentary Group Recommendations

- Greater spending on biomedical research
- Diagnosis, symptom Management and Services
- Children and Young People
- Welfare and Health Insurance based benefits
- Covid 19 and ME Community