Counting The Cost

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

28th September 2017

Executive Summary

2020health.org

THE OPTIMUM HEALTH CLINIC FOUNDATION

The purpose of this report is to:

Support improved NHS and societal understanding of chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME);

Highlight current inequalities of care and support

Identify the economic implications of the condition – not just to the NHS, but also to UK society as a whole.

About this report

It is hoped that policy makers and commissioners will use this information to make decisions on the planning and funding of CFS/ME services and research.

For the sake of clarity and relevance to UK public health, we adopt the nomenclature of 'CFS/ME' throughout this report as a catch-all term, unless specifically quoting from sources that have used singular or other terminology.

The views expressed in this report are those of the authors alone. All facts have been checked for accuracy as far as possible.

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Julia Manning, Founding Director
2020health

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Foreword

David Butcher, Chairman

"As someone who has suffered from CFS/ME I understand how appalling this illness is, how it can devastate the lives of sufferers, their carers and their families."

For the past 20 years there has been extensive argument in the UK about the causes and diagnostic criteria for this illness. For some considerable time, the conventional wisdom was that this illness was purely psychological in origin.

The World Health Organisation has clearly classified CFS/ME as a neurological disease in its International Classification of Diseases (ICD), section G93.3.

Despite this clarity, there is still a lack of universal agreement about CFS/ME in the UK. This has led to a paralysis of research into both the bio-medical causes of and treatments for CFS/ME, and the research that has been done has focused primarily on the psychological side.

The time has come for a proper research strategy for CFS/ME, looking at both bio-medical causes and treatments. In order to commence a dialogue with government and other interested parties, it is essential for everyone to be on the same page. To achieve that degree of agreement will be a challenge, but I believe the first step in that process is to start a new public conversation about this horrible illness.

The purpose of this report by the health think tank 2020health, sponsored by the Optimum Health Clinic, is to do just that. Nothing concentrates the mind like money. This is the first cost of illness study of CFS/ME to the UK economy combining direct costs (including primary and secondary care contacts, prescription and over the counter medications, and complimentary treatments) and indirect costs (including work productivity losses, informal care and welfare payments). The results are staggering.

In commissioning this report, our hope is that we can:

- Demonstrate clearly all the costs of CFS/ME to the UK economy;
- Use this report to start a new public conversation about the illness;
- Start a dialogue with all interested parties to create a new strategy to research the bio-medical causes of and treatments for CFS/ME.

The Optimum Health Clinic Foundation
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Executive summary

> *Greater disability that those with type 2 diabetes, congestive heart failure, back pain/sciatica, lung disease, osteoarthritis, multiple sclerosis, and even most cancers.*

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is a complex, fluctuating condition characterised by emotional, mental and physical fatigue.

Accompanying symptoms typically include postexertional malaise or incapacitation, memory and concentration problems, musculoskeletal pain, headaches, sore throat, painful swollen lymph nodes and sleep disturbance (Fukuda, 1994; Carruthers, 2003). The National Institute of Health and Care Excellence (NICE) estimates the prevalence of CFS/ME to be 'at least' 0.2% to 0.4% of the UK population, implying up to 1 in 250 people affected, or 260,000 in total.

Quality of life research suggests that the well-characterised CFS/ME sufferer may experience on average greater disability than those with type 2 diabetes, congestive heart failure, back pain/sciatica, lung disease, osteoarthritis, multiple sclerosis and even most cancers (Nacul et al., 2011a). Severe sufferers are largely housebound, the very severe confined to a bed most of the time and reliant on carers for all their needs, day and night (ME Association, 2007). In prolonged severe illness, associated psychological

and physical health risks increase, including postural hypotension, deep venous thrombosis, osteoporosis, deconditioning and pressure sores (NICE, 2007).

The average length of the illness is around six years, though some people live with CFS/ME for decades (Nisenbaum et al., 2000). In addition to the significant and protracted suffering caused by CFS/ME, patients may experience further **psychological distress** resulting from clinical and public scepticism, even stigma, still common in the UK (Action for ME: Time to deliver survey, 2014). A 2008 patient-group survey suggested that **one third of GPs were not supportive in CFS/ME cases** (Gibson et al., 2011); another survey found GPs on the whole expressing 'little confidence in positively attributing the label of CFS/ME to a patient and their symptoms' (Chew-Graham et al., 2010). The causes of CFS/ME remain unknown – a frustration to patients and clinicians alike.

Calls for action

CFS/ME sufferers are probably among the most marginalised patients in the UK. NICE's Guideline Development Group noted 'anecdotal reports of people with severe CFS/ME not seeing medical practitioners for many years' (NICE, 2007). Even now, more than one third of specialist adult CFS/ME services in the NHS provide no support to severely affected patients (McDermott et al., 2014).

Our own investigations suggest that some 14,000 people are referred to publicly-funded specialist CFS/ME services each year in the UK, with NHS running costs at around £14 million.[1] Approximately three quarters of people referred are diagnosed with CFS/ME.

In England, we estimate the number diagnosed in specialist services to be in the region of 10,000. Though the number of services does not appear to have risen by much in recent years[2], services themselves appear to have expanded slightly. This is potentially good news for people with CFS/ME whose CCG, health board or trust is providing the service; our FOI responses however reveal often minimal

referrals 'out of area' for CFS/ME patients, meaning that inequalities of access remain significant.

If just a small minority of CFS/ME sufferers have access to full specialist services in any particular year, it should also be noted that the average time to assessment in specialised services is three years four months (NOD, 2011). This can hardly be described as timely access.

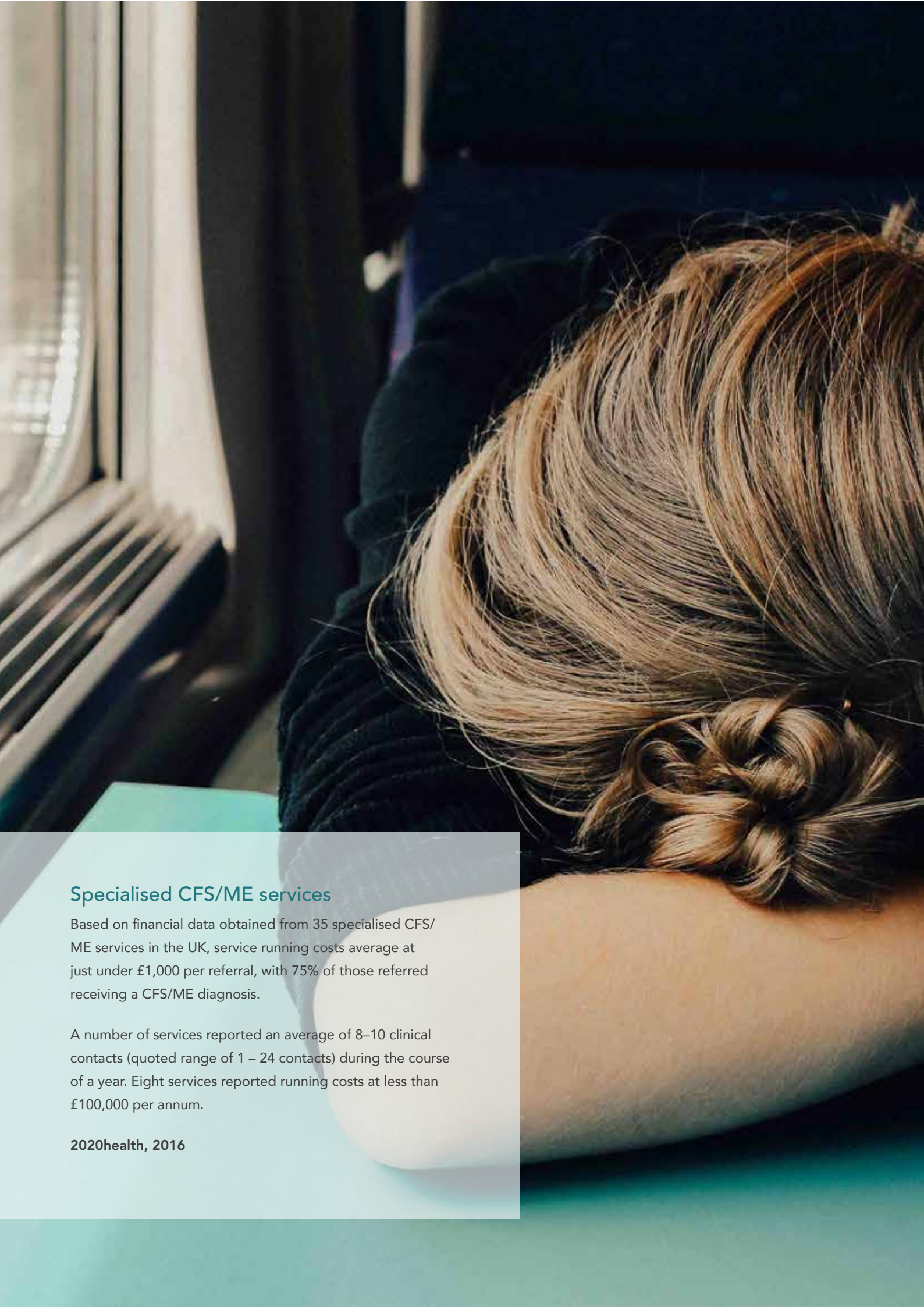
It is likely that a lack of clinical specialism in CFS/ME is attributable in part to the trend of under-investment in chronic conditions generally (Monitor, 2013), and also a lack of appreciation as to the costs and societal implications of CFS/ME to the UK.

Our study

We undertook a comprehensive UK cost-of-illness study on CFS/ME, based on recorded patient data from both specialised services and primary care. Data were found in (i) economic evaluations within clinical trials for CFS/ME, and (ii) cross-sectional economic studies of CFS/ME. Only (peer-review) papers from the UK were included due to significant differences between the UK and other countries in regards to health care system structure, employment, earnings and benefits. Papers from other countries were used to corroborate findings.

With little data on welfare payments received by recruited patients, we also contacted the Department of Work and Pensions for estimates on Employment and Support Allowance (ESA) and Disability Living Allowance (DLA) payments to people with CFS/ME as a primary disabling condition.

According to our weighted analysis, **the total cost to the UK economy of CFS/ME in 2014/15 was at least £3.3**



Specialised CFS/ME services

Based on financial data obtained from 35 specialised CFS/ME services in the UK, service running costs average at just under £1,000 per referral, with 75% of those referred receiving a CFS/ME diagnosis.

A number of services reported an average of 8–10 clinical contacts (quoted range of 1 – 24 contacts) during the course of a year. Eight services reported running costs at less than £100,000 per annum.

2020health, 2016

> *"The total cost to the UK economy of CFS/ME in 2014/15 was at least £3.3 billion*

billion, assuming a cautious estimate of 0.4% prevalence within the UK population.[3] In our unweighted analysis, we found an average cost per person with CFS/ME of £16,966. These figures account for health care costs, the majority of disability-related welfare payments, productivity losses and unpaid informal care. We were unable to capture all CFS/ME costs. Missing costs included productivity losses among carers themselves, through reduced hours in employment, and costs associated with 'presenteesim' (productivity losses due to working while unwell). The true costs of CFS/ME to the UK are therefore likely to be much higher.

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Implications for the NHS and wider society

Health boards, CCGs and trusts that have not invested in CFS/ME expertise may be running false economies. Our economic analysis revealed NHS spending on people with CFS/ME to be in the region of £542 million. Drawing on matched sample findings by Lin et al. (2011), this amounts to well over £300 million more than a 'non-fatigued' population.

Just 3% of the £542 million applies to the running of joined up, specialised services. Clinicians with CFS/ME specialism are not of course exclusive to such services, but it is highly probable that the NHS is spending substantial amounts of money on the non-specialised treatment of CFS/ME.

CFS/ME services

The specific advantages of a joined up, specialised CFS/ME service have not yet been systematically evaluated. However, there are strong reasons why commissioners need to consider investment in specialist CFS/ME care.

First is the economic reason. If a CCG, trust or health board has decided not to commission a specialist CFS/ME service they are still faced with potentially substantial expenditure on CFS/ME support, symptom management and treatment. Expenses associated with specialist care may not be much more than non-specialist care, and yet hold greater promise for return on investment, even in the short to medium term.

Second, we would not expect sufferers of (for example) MS, diabetes or heart failure to be advised, supported and treated by non-specialists. NICE claims that approximately half of all people with CFS/ME 'need input from specialist services' (NICE, 2007) – such is the complexity of the condition, especially among the moderately, severely and long-term affected.

Third, equality of access is a core value of the NHS. That many severely affected, housebound people with CFS/ME receive negligible or even no support from specialised services is no doubt distressing to both patients and their families. For sufferers across the range of CFS/ME severity, there is evidence that out of area referrals do not bring equality of access, running counter to NHS principles.

CFS/ME Research

The funding of CFS/ME research needs to be re-evaluated in light of the immense economic implications of the condition,

£14 million
UK NHS spend on dedicated, specialised CFS/ME services

£542 million
Total UK health service spend on people with CFS/ME

£3.3 billion
Annual cost of CFS/ME to the UK

which has greatest prevalence among the working-age population. The DWP alone pays out well in excess of £100 million annually in ESA and DLA payments to people with a primary disabling condition of CFS/ME; productivity losses (of patients and carers) mean lower revenues for businesses and government of a far greater order. Stronger research emphasis has the potential to diminish the economic impact of CFS/ME to wider society in the longer term.

Well-designed research is the best means by which new frontiers can be explored in CFS/ME care. It holds promise not just for patient outcomes, but could also resolve some of the disagreement between patient organisations and medical authorities on the nature of CFS/ME, which is confusing to patients and potentially steering some away from specific treatment options (Hossenbaccus & White 2013). In this respect, research needs to be designed in collaboration with CFS/ME patient organisations, drawing on patient insight and lived experience.

Conclusion

There is some outstanding work being done in support of CFS/ME sufferers across the UK, by local NHS and by patient-support charities, and also in the sphere of research. **But the picture in the UK as a whole is one of grossly unequal care, marginalised and sometimes forgotten patients, and in the light of our findings, probable false economies.**

Impact of greater access and quality of care may be discernible well within a funding cycle. Commissioners and central government need to reconsider funding decisions and organise CFS/ME services and research as appropriate to a treatable condition that has far-reaching societal and economic implications for the UK.

20-40 **The peak age of onset of CFS/ME.** (Capelli et al., 2010)

81% **Proportion of carers who are husbands, wives or partners.** *(Nacul et al., 2011)*

76% **Proportion of CFS / ME sufferers who are female** (Collin, 2011)

85% **Proportion of CFS/ME sufferers who have experienced some form of lost employment due to the illness.** *(PACE trial, 2012)*

[1] Information, mainly via Freedom of Information Requests, obtained from 54 (of 56 known) specialist CFS/ME services, run by trusts, health boards and community interest companies, throughout the UK. 53 services returned referral activity data, 35 of those including information on running costs. Average costs extrapolated according to estimated numbers referred across all 56 services. (2020health, 2016.)

[2] We found 51 services operating in England during the period 2013–15. According to Collin, S. et al., 2012, there were 49 in operation between 2008–10.

[3] Further studies on prevalence have been undertaken since NICE produced its estimates in 2007. A meta-analysis by Johnston et al. (2013), examining seven studies using clinical assessment, found adult prevalence at 0.76%.

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Matt is an Assistant Director and Senior Researcher at 2020health. He studied political history and sociology as an undergraduate before completing a Master's degree in bioethics and medical law. His wide-ranging portfolio of expertise spans the arenas of public policy, academia and third sector. Matt has co-authored reports on various topics including reviewing post-transplant care for bone marrow transplant patients and reviewing the quality of care and models of best practice for those living with ankylosing spondylitis (AS). Matt is a Fellow of the Higher Education Academy (HEA), an honorary research associate at University College London (UCL) and a Fellow of the RSA.

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Full Report

The full Counting The Cost Report is available for download at:

www.2020health.org/2020health/publications and

www.TheOptimumHealthClinic.com/research-overview/publications