Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

December 2014

Future dates

The following ME meetings are open to all members and carers.

15th January 2015 (Thursday) 12noon The White Hart
White Hart Lane, Wood Street Village, Guildford, Surrey, GU3 3DZ

Directions from Guildford - Join A323 towards Aldershot. Turn left at the roundabout just after The Rydes Hill Prep School, onto Broad Street, sign-posted to Wood Street. Drive through Wood Street until you get to the Village Green, then turn left immediately after the green and right onto White Hart Lane. The pub is 50 yards down on the right.

9th February 2015 (Monday) 7.30pm The Weyside
Millbrook, Guildford, Surrey, GU1 3XJ
www.theweyside.co.uk
Over the last few years the Weyside was called the Boatman.

11th March 2015 (Wednesday) 11am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

Roburin-rich oak wood extract for ME/CFS

Source (Full article): www.prohealth.com/me-cfs/library/showarticle.cfm?libid=19389
By Michael Franco 12th November 2014

Frustrated by a lack of treatment options for ME/CFS, an international team of researchers has focused their attention on a group of unique molecules called roburins, which are derived from oak wood.

Roburin-rich oak wood extract has shown tremendous promise in managing a cluster of the symptoms that define chronic fatigue syndrome.

Evidence suggests that roburins are responsible for improving the functioning of our cellular ribosomes. Located in nearly every cell in the body, ribosomes are the sites of protein production and are intimately involved in the function of every tissue, organ, and system.

The science of "*ribosomal biogenesis*" is now capturing the interest of scientists as a potential method for improving energy and biological function in the aging body.

Hope from the Oak
Determined scientists at several research centres have discovered unique compounds in oak wood that are proving to be an effective therapy in treating chronic fatigue.

Humans have been exposed to oak wood extracts for as long as they have been storing alcoholic beverages in aged oak barrels. This practice was originally adopted because of the preservative effects of fresh oak on new wines and spirits, but it has continued because of the unique flavour and character the oak provides to the aging liquor.

As the roburin molecules have been isolated and analysed in modern laboratories, they have become available for use in animal and human studies aimed at transferring some of the oak's resilience and stress resistance to humans.

Roburins in the human body
Two major human studies demonstrate the potential of roburins for mitigating chronic fatigue syndrome symptoms.

In the first study, researchers were interested in understanding how roburin molecules were distributed and absorbed, as well as their compatibility in the human body.[5] Following five days of oral supplementation with roburin-rich oak wood extract-three capsules of a proprietary, patented extract called Robuvit-the scientists found a 100% increase in plasma total phenols (a general measure of absorption of molecules in this class), as well as the presence of roburin breakdown products (metabolites) in urine of healthy volunteers.

Since roburins are found only in oak wood, the data demonstrated vigorous absorption and conversion of roburins into substances including *urolithins* and*ellagic acid*, which are known to have potent biological activities.

This study also revealed that the oak wood roburins trigger a complex set of biological events in the body. Using a sophisticated technology that measures changes in *gene expression*, the researchers were able to show that blood serum from supplemented people in the study may beneficially alter the expression of several genes in human cells in culture.

Among the most consistent changes in gene expression induced by the serum from oak wood extract in supplemented patients had to do with the activities of ribosomes, the ultramicroscopic cellular organelles that are responsible for the "translation" of genes in DNA into specific proteins.[5] Long regarded as simply tiny protein-manufacturing plants, ribosomes are now emerging as essential in the maintenance of normal cellular functions, and as key players in the science of "systemic aging" and disorders such as chronic fatigue syndrome.

Roburins and chronic fatigue
The clinical impact of roburin-rich oak wood extract was made evident by a second important human study, this one conducted among patients with known chronic fatigue syndrome. In the study, adults with at least five primary chronic fatigue syndrome symptoms were treated with 200 mg/day of Robuvit oak wood extract for a minimum of six months. A control group that did not use the supplement was also established among patients with the same chronic fatigue symptoms. The scientists found that oak wood extract was productive in alleviating many of the most troubling symptoms of chronic fatigue.

Among those who used the oak wood extract, there were significant reductions for a multitude of key symptoms of chronic fatigue, including:

- 18% reduction in weakness and exhaustion,
- 44% reduction in unrefreshing sleep,
- 29% reduction in short-term memory impairment,
- 63% reduction in muscle pain,
- 51% reduction in joint pain,
- 33% reduction in headaches, and
- 47% reduction in tender lymph nodes in the armpit and neck.

Additionally, impressive reductions from baseline were also found in most secondary symptoms of chronic fatigue syndrome, including:

- 51% reduction in sensitivity to noise, foods, medications, and chemicals,
- 38% reduction in dizziness,
- 58% reduction in depression,
- 49% reduction in mood swings,
- 40% reduction in weight fluctuation,
- 24% reduction in alcohol intolerance,
- 39% reduction in allergies, and
- 29% reduction in visual disturbances.

There were no significant changes from baseline in all of these parameters for the patient group not taking the oak wood extract. These weren't all of the changes, though. On a standardized mood scale, supplemented subjects had significant increases in their scores on positive items including feeling active, happy, peppy, caring, calm, and loving, along with significant reductions in negative items such as feeling gloomy, fed-up, grouchy, sad, or tired. In fact, the overall mood evaluation score in supplemented subjects rose from an average of -6.93 at baseline to +4.32 at six months. For controls, the average score at baseline was -6.5 and rose only to -3.4 at six months.

In those with chronic fatigue syndrome, scientists have found that oxidative stress levels are usually elevated. At the start of this study, 65% of supplemented and 70% of control patients showed elevated oxidative stress on blood tests. Following the supplementation period, control patients showed no decrease in oxidative stress, but supplemented subjects had 8 and 10% reductions at three and six months, respectively.

A third study demonstrated the impact of oak wood extract on the response to histamine in normal subjects. Histamine is a substance released in the face of allergic or inflammatory stimuli, and there is some evidence suggesting that chronic fatigue syndrome may be related to excessive release of, or sensitivity to, histamine in skin, intestines, or brain tissue.

In this study, female participants were randomly assigned to control or supplement groups (300 mg Robuvit/day) for three days, followed by an injection of pure histamine into the skin. A normal response to this injection produces a so-called "wheal and flare" response: a raised, itchy skin wheal associated with a red flare on the skin surface and with increased microcirculation in the immediate area. Compared with control subjects, those who had supplemented with Robuvit had a significantly smaller wheal area (28%), smaller area of redness (13%), and lower levels of circulation increase in the immediate area (49%). These results suggest an additional mechanism, blockade of histamine effects, for this novel roburin-rich oak wood extract's effects on chronic fatigue syndrome.

No side effects of the oak wood extract supplementation were reported in any of the participants in these studies.

For the full version of this article please refer to the source internet link provided under the title.

Buying example (Oak wood extract)

It would seem that given how new this supplement is that it is only currently available to order from America. The following example is from iherb, a company used by a few group members.

Life Extension, RiboGen French Oak Wood Extract
200 mg, 30 Veggie Caps, Take one capsule daily with or without food

$27 + shipping (about £17.30 + shipping)

Shipping is either via DHL or International Airmail as follows:
DHL = $8 + 20% import VAT + £8 admin fee. Arrives 2 to 4 days.
Airmail = $4.45 + 20% import VAT + £8 admin fee. Arrives 1 to 4 weeks.

The 20% import VAT applies to both the goods and shipping.
DHL is recommended. Royal Mail (Airmail) may apply 10% duty and require collection from the sorting office.

The following internet link will take you to the product on iherb:
www.iherb.com/Life-Extension-RiboGen-French-Oak-Wood-Extract-200-mg-30-Veggie-Caps/62213#p=1&oos=1&disc=0&lc=en-US&w=robuvit&rc=1&sr=null&ic=1

Plant derived trace minerals

Partial source: www.simplynaturals.com
Partial source: www.supremefulvic.com/documents/html/organic-inorganic.html

With the lack of a cure for ME/CFS it is common for sufferers to throttle down their activity, avoid stress and try to live as healthily as possible. Often a wide range of diets, medications and supplements are tried. A supplement that I believe is worth considering is 'plant derived trace minerals'. To explain such minerals I've used information from various suppliers and given purchasing examples below.

The following overview is provided by Simply Naturals. Their product is called 'Sizzling Minerals.'

Above by Newsletter Editor

Plant derived trace minerals

Approximately 99% of the body is comprised of minerals yet minerals are generally overlooked when nutrition is considered. Did your mother ever remind you to take your minerals? Probably not, but she did say don't forget to take your vitamins! Why do Doctors, Nutritionists and Health Practitioners constantly promote vitamins without mentioning minerals? Don't they know vitamins are basically useless in the absence of minerals? Gary Price Todd, M.D., says the human body needs at least 60 trace minerals in order to maintain a disease and ailment free state.

If this is true, it's easy to understand why sickness is so prevalent throughout the world. Foods that are raised or purchased today contain, on average, no more than 16 to 18 minerals. This small number of minerals in plants is due to a mineral deficiency of the soils around the world. Science has proven the soils of the earth did contain approximately 80 minerals in prehistoric times. However, millions of years of wind and rain erosion and centuries of unwise farming practices have drastically reduced the mineral content of the earth's surface where plants grow. According to Dr. Todd, minerally deficient soils produce sick plants, which produce sick animals and ultimately sick human beings. Dr. Linus Pauling, two times Nobel Laureate, said "one could trace every sickness, every disease and every ailment to a mineral deficiency".

If the preceding is true, it only makes sense people need to find a mineral source that provides 60 or more minerals. This is the reason the principals at Simply Naturals believe you should consider Sizzling Minerals. This product provides up to 75 trace minerals. It is also plant derived, containing the same kind of hydrophilic minerals that are found in fruits and vegetables. This type of mineral is unlike a metallic mineral obtained from ancient seabeds, soil or ground up rocks.

Metallic minerals have a positive electrical charge whereby plant minerals like those in Sizzling Minerals have a negative charge or what experts call a negative zeta potential. This makes a big difference in the body's ability to digest these minerals for the utmost benefit. Today's environment of polluted atmosphere, toxic chemicals, toxic emissions and contaminated water can alter the functions of one's body on a day-to-day basis. Plant derived minerals can help regulate these alterations.

Frequently asked questions:

What is the difference between Major minerals and Trace minerals?
There is no difference. All minerals are the same. However, those that the World Health Organization believes an adult needs in quantities of more than 100 MG per day are classified as major minerals. Those that are believed to be required in smaller quantities are called trace minerals.

Why do the well-known mineral supplements contain only about 12 minerals at best?
Most nationally advertised mineral supplements come from the earth and are classified as metallic minerals. They are usually available in capsule or tablet form. All metallic minerals come from soil, ground up rocks, salts or ancient seabeds etc. Due to the earths' mineral deficiency, there are not more than 12 or 15 minerals available to put into most nationally advertised brands.

If the earth is deficient in minerals, how can Sizzling Minerals claim to have 75 minerals?
The Sizzling Minerals come from a prehistoric deposit of plant humus that accumulated, according to scientists, around seventy million years ago. It is believed the plants that grew during that period contained 75 to 80 minerals because there were at least 80 minerals in the soil to feed the plants. This Humus, referred to as Humic Shale has been safely encapsulated far below the earths' surface for millions of years.

What is the difference between plant minerals and metallic minerals?
Metallic minerals are metals and are much more difficult to assimilate because they are harder for the human digestive system to dissolve. Minerals like those that come from tomatoes, carrots, apples or Sizzling Minerals were at one time metallic minerals. As the plants grew the metallic minerals passed through the plant roots and through a scientific process known as photosynthesis, the metallic minerals became water-soluble and were broken down in size. This is Mother Nature's way of converting metallic minerals into a more useable and effective form for human and animal consumption. According to the Colorado School of Mines, a plant mineral (depending on the specific mineral) is hundreds and even thousands of times smaller than a metallic mineral. It is understood that due to the solubility and small size, a plant derived mineral can be more easily assimilated than a metallic mineral.

Sizzling Minerals contain Aluminium. Can this be safe for humans to consume?
Few people are aware of this but nearly every food on earth contains a significant amount of aluminium because aluminium is the second most abundant mineral in our soils. Fortunately the aluminium in a tomato or carrot or Sizzling Minerals is attached to another molecule by Mother Nature. It is not raw aluminium like that used to make soup pans. The aluminium in a tomato and Sizzling Minerals is attached to a hydrogen molecule forming aluminium hydroxide. Aluminium hydroxide is approved for food and food processing throughout the world.

Aren't certain minerals toxic?
Did you know that an apple contains 3-5 mg of aluminium and trace amounts of lead, arsenic and mercury? Micro or trace minerals are essential for good health if they come from an organic or plant source. In contrast, if they come from an inorganic or metallic source, such as heavy metals, they are toxic. For example, iodine in an organic form is necessary for health. Non-organic or metallic iodine in the same amount can kill you.

Why are people frightened of these trace minerals? The reason is well understood.
There have been numerous deaths and birth defects caused by heavy metal poisoning from metals such as lead. People have used arsenic as a poison and pesticide for centuries. The news is filled with grim reports about these substances. However, little is said about the all-critical source. Is it organic or inorganic?

Organic trace minerals are not deposited in the body like inorganic forms of these elements. Research shows that organic plant-derived trace minerals will actually replace the heavy metals deposited in the body. The heavy metals are then flushed from the body.

Once a plant source utilises minerals from the ground, they are digested, making them ionic or electrical in nature. This makes it easier for the body to assimilate and use the minerals at a cellular level. Subsequently, they are not stored or deposited somewhere else in the body. Trace minerals in their inorganic form are not easy for the body to use. They are stored in the tissues and eventually large amounts build up and become extremely toxic.
In the late 1980s an interesting experiment was conducted by Gary Price Todd, MD, author of the book Nutrition, Health and Disease. The study involved individuals with heavy metal poisoning, specifically lead, mercury, cadmium and aluminium. Patients were placed on a program of full spectrum bio-available organic, micro trace minerals.

After 16 months the study demonstrated reduced levels of toxic metals in the patients. They concluded that organic, ionic minerals naturally chelate or remove the inorganic minerals from the body. Furthermore, ionic minerals cannot be stored in the body for longer than a few hours, they are much like the water soluble vitamins; therefore they cannot build up to toxic levels in the soft tissues. (Todd, Gary P. Unpublished Observations, The Institute of Nutritional Science Journal, June 1996, 1:1).

Another study on trace minerals and detoxification was conducted by Dr. Michael Zimmerman, Chief of Staff of the Specialized Clinic for Chronic Illnesses and Therapy Resistant Patients and Biophysicist, Dr. Fritz Albert Popp in Uberlingen, Germany. They concluded that trace minerals were not toxic, but rather assisted the cells' vital functions and enhanced detoxification as well as accelerated the healing process of chronic illness. (Popp, Fritz Albert. Bio-electronic Response of Cellular Stimulation).

Like lead, mercury and other metals, arsenic is toxic when it comes from an inorganic source. However, from an organic source it is an essential micro-mineral needed by the body in minute quantities (The Nutrition Bible, Joan Anderson and Barbara Deskins, 1995). In a recent study where organic arsenic was given to 12 patients with leukemia, 11 went into remission. The treatment apparently stops cancer cells from reproducing and then they self-destruct (New England Journal of Medicine, November 1998).

Buying examples
There are a number of available 'plant derived minerals' products. Following are two examples: Sizzling Minerals by Simply Naturals and ConcenTrace by Trace Minerals Research.

Sizzling Minerals, by Simply Naturals
Sizzling Minerals is available to buy from www.simplynaturals.com

It's £28.97 for 30 effervescent Wafers (tablets) which each containing 600 milligrams of 75 pure plant derived minerals.

It's £23.97 for 30 Wafers when bought on a regular monthly basis.

Dose: 1 to 2 wafers daily. Fully dissolve in a glass of drinking water.
Flavours available: Orange, Lemon Lime, Cherry Berry, or Natural.
Servings per tube: 15

ConcenTrace by Trace Minerals Research
ConcenTrace Trace Mineral Drops is an all-natural mineral concentrate that contains over 72 naturally occurring ionic trace minerals from the Great Salt Lake with 99% sodium removed.

For more information: www.traceminerals.com

Available, from America, via Amazon UK: £33.87 + £4 delivery for 8-Ounce Bottle.
Dose: Start at 10 drops per day, increasing up to 40 drops per day.

What is the current NHS service provision for severe ME/CFS patients?

Source: http://bmjopen.bmj.com/content/4/6/e005083.full.pdf+html
By: McDermott C, Al Haddabi A, Akagi H, et al. 19th November 2014
Article discovery: Will Marsden (Guildford ME group member)

The following article gives some insight into the current (2013) NHS service provision for severe ME/CFS patients. Although most of the article is reproduced here, please refer to the source link above for a full version of the article.

Above by Newsletter Editor

Abstract

Background
Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), in its most severe clinical presentation, can result in patients becoming housebound and bedbound so unable to access most available specialist services. This presents particular clinical risks and treatment needs for which the National Institute for Health and Care Excellence (NICE) advises specialist medical care and monitoring. The extent of National Health Service (NHS) specialist provision in England for severe CFS/ME is currently unknown.

Objectives
To establish the current NHS provision for patients with severe CFS/ME in England.
Setting and participants: All 49 English NHS specialist CFS/ME adult services in England, in 2013.

Method
Cross-sectional survey by email questionnaire.

Primary outcome measures
Adherence to NICE guidelines for severe CFS/ME.

Strengths and limitations of this study

- Our survey received a 100% response from the 49 chronic fatigue syndrome/myalgic encephalomyelitis specialist services in the National Health Service (NHS) in England and all data queries were resolved via telephone or email.
- The study collected data on adult specialist CFS/ME services only. Further research is needed to determine paediatric service provision.
- While this study collected data on service provision, it did not collect data on clinical outcomes for treated patients. This limitation should be addressed by further research.

Results
All 49 services replied (100%). 33% (16/49) of specialist CFS/ME services provided no service for housebound patients. 55% (27/49) services did treat patients with severe CFS/ME and their interventions followed the NICE guidelines. The remaining services (12%, 6/49) offered occasional or minimal support where funding allowed. There was one NHS unit providing specialist inpatient CFS/ME provision in England.

Conclusions
Study findings highlight substantial variation in access to specialist care for patients with severe presentation of CFS/ME. Where treatment was provided, this appeared to comply with NICE recommendations for this patient group.

Introduction
Chronic fatigue syndrome, also known as myalgic encephalomyelitis (CFS/ME), is an illness characterised by debilitating physical and mental fatigue, pain and other symptoms.

It is estimated to affect up to 250 000 people in the UK. At its most severe, CFS/ME can lead to individuals becoming housebound, wheelchair user or bedbound and dependent on carers for all basic activities of daily living.

The illness can last for decades, leaving many severely affected individuals profoundly disabled for many years, although others return to health within a much shorter time. There has been little research to establish the prevalence or prognosis of severe CFS/ME.

Severe CFS/ME presents particular clinical risks, as noted by the NICE guidelines. Patients who are bedridden for a long period may have associated medical risks, including postural hypotension, deep venous thrombosis, osteoporosis, pressure sores and deconditioning.

Symptoms including malaise and nausea, combined with impaired physical mobility for tasks of daily living have led to reported instances of patients becoming dehydrated or critically underweight, leading to emergency hospital admissions. The NICE guidelines recommend that all patients with severe CFS/ME receive specialist medical care to monitor clinical risks, and to advise on individually tailored treatment plans.

While significant progress has been made in researching and treating CFS/ME in mild-to-moderately affected individuals, housebound patients are generally too ill to travel to outpatient appointments for treatment. There has been little formal research conducted on this patient group, as highlighted by successive national reports on CFS/ME. Nevertheless, case reports, pilot studies and anecdotal evidence suggest that substantial improvement or recovery is possible for some patients given specialist intervention individualised to patient need. Within this context, what specialist care is currently provided by the National Health Service (NHS) in England for this patient group?

Our searches of published literature and consultation with national organisations indicated that no systematic data had been collected to date on this question. The aim of this scoping exercise was to ascertain current service provision within the NHS for severe CFS/ME within England. This study was conducted as part of a PhD doctoral fellowship funded by the National Institute for Health Research (NIHR) School for Primary Care Research. The team comprised independent researchers and representatives from the British Association for CFS/ME (BACME), which is the national 'umbrella organisation' representing specialist NHS CFS/ME services in the UK (http://www.bacme.info).

Box 1 NICE 2007 guidelines on severe chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) (extract, page number 305)

General principles of care

- Management of severe CFS/ME is difficult and complex and healthcare professionals should recognise that specialist expertise is needed when planning and providing care for people with severe CFS/ME.
- Diagnosis, investigations, management and follow-up care for people with severe CFS/ME should be supervised or supported by a specialist in CFS/ME.
- When making decisions about prolonged bed rest, healthcare professionals should seek advice from a specialist experienced in the care of people with severe CFS/ME. The significant physical and psychological risks associated with prolonged bed rest should be taken into account.
- Healthcare professionals working with people with severe CFS/ME who are in bed most (or all) of the time, should explain the associated risks (such as postural hypotension, deep venous thrombosis, osteoporosis, pressure sores and deconditioning) and monitor these.
- People with severe CFS/ME should be offered an individually tailored activity management programme as the core therapeutic strategy, which may be delivered at home, or using telephone or email if appropriate, drawing on the principles of cognitive–behavioural therapy (CBT) and graded exercise therapy (GET).

Background to study

In 2013, there were 49 specialist adult CFS/ME services in the NHS in England. While all specialist CFS/ME NHS services in the UK follow the 2007 National Institute for Health and Care Excellence (NICE) guidelines for diagnosing and treating CFS/ME, each service is autonomous in how they choose to implement this guidance in clinical practice. The 2007 NICE guidelines on CFS/ME offer 'general principles of care' for severe CFS/ME (summarised in box 1).

Method
This scoping exercise was a cross-sectional study conducted by an emailed questionnaire. Questionnaire design was guided by existing research literature, discussions with specialist health professionals and consultation with two patient support groups who provided Patient and Public Involvement (PPI) for the study (The Association of Young People with ME and the Dorset ME Support Group).

In this study, we defined 'severe CFS/ME' as patients who are predominantly housebound or bedridden, in accordance with the Cox and Findley severity categories for CFS/ME.

Data collection
Identification of services was conducted between January and February 2013 from a list provided by the British Association for CFS/ME cross-checked against lists of specialist CFS/ME services compiled by ME support groups. Initial contact with services was made by telephone or email between February and March 2013. We asked services to return the completed questionnaire and consent form by post, email or by telephone with a researcher.

All services replied giving a 100% response rate. We sent participants who completed the questionnaire by telephone a copy of their questionnaire answers to verify and return with consent form.

Results
All 49 specialist CFS/ME adult services in the NHS in England replied. Twenty-seven of 49 services (55%) regularly provided face-to-face therapy and support to severely affected CFS/ME patients. Of these, 26 provided home visits and 1 offered specialist inpatient CFS/ME treatment. Sixteen of 49 (33%) were not able to offer any service to housebound patients. The most commonly reported reason for this was lack of funding.

Three of 49 (6%) services provided neither home visits nor inpatient care, but did give advice/support by telephone or email to severely affected patients on a regular basis. These were defined as providing a 'regular but minimal service'.

Three of 49 (6%) services reported that they very occasionally provided help to severely affected patients.

The study identified only one NHS specialist inpatient unit in England providing treatment for patients with CFS/ME. This eight-bed unit accepts extra-contractual (i.e. 'out of area') referrals from across the UK. In addition, clinicians from four CFS/ME services reported contributing to the care of patients who had been admitted as inpatients to other hospital settings. Examples included a patient admitted to a general medical ward for comorbidities and another admitted for acute dehydration and weight loss.

Questionnaire data were analysed from the 30 CFS/ME services which provided a regular service to severely affected patients (27 services which provided inpatient or domiciliary care, +3 services which provided 'minimal' care by telephone or email). All services completed the questionnaire. Questionnaires were returned by post (n=15), email (n=9), telephone (n=5) or in person (n=1). All missing data or data queries were resolved by phone or email. This process was completed by August 2013.

Referral pathways
All 30 services accepted general practitioner (GP) referrals. In addition, 20/30 services accepted referrals from tertiary care (i.e hospital specialists) and 12/30 services accepted out of area or 'extracontractual' referrals, provided that these were funded by the patient's own Clinical Commissioning Group.

Diagnostic criteria
Twenty-three of 30 (77%) used the Centers for Disease (CDC) 1994 (Fukuda) criteria making this the most common case definition for diagnosis. Ten services used the CDC 1994 criteria and the recent NICE 2007 criteria.

Five services used the NICE 2007 criteria only. Three services offered no diagnostic service and only accepted referrals from patients with prior diagnosis.

Caseload

Twenty-six of 30 (87%) services provided caseload figures. Four services reported that they were unable to provide this information because their database or other data collection methods did not categorise according to illness severity.

The average (mean) caseload was 16 patients (median n=10, range 3–90). The largest caseload was approximately 90 patients, reported by a service commissioned with the specific remit of offering treatment to patients at the severe end of the CFS/ME spectrum. All reported figures were for total caseload. Discharge policy varied between services, with some allowing patients to remain registered with the service for many years after initial intervention, and others discharging patients after much shorter periods. In general, higher caseloads tended to be reported by services which allowed patients to remain registered for longer periods. The total sum of severely affected patients on caseloads reported by all the services in England combined was 408 patients. We also asked services how many severely affected patients were on their waiting list. However, most reported that this was difficult to determine, since illness severity tended to be categorised at first appointment.

Treatment approach

All 30 services reported that they used more than one treatment approach in combination. The most commonly reported treatment approaches were activity management which was used by 28/30 (93%) services; cognitive–behavioural therapy (CBT) used by 25/30 (83%) services and graded activity used by 24/30 (80%) services.

Participants reported tailoring treatment to individual patient need, drawing on a range of available therapies. Results are shown on next page in table 1.

Many respondents provided free-text comments that highlighted variations in how different services interpreted some of these therapeutic terms. For example, while 83% of services reported that they used ‘CBT’, some respondents annotated this answer to comment that they incorporated some CBT-based approaches on exploring beliefs and thinking patterns, but did not have a qualified CBT therapist on the clinical team. Similar variations in the use of terminology became apparent with the term ‘pacing’. Several participants commented that they used ‘pacing’ in the sense of balancing rest and activity within the context of other treatments (e.g. graded activity) but wished to emphasise that they did not use pacing as a ‘stand-alone therapy’.

Table 1 Therapeutic approaches used (in combination) by CFS/ME services for severely affected patients

Therapy	Number of services using this approach	Percentage of services using this approach
Activity management	28	93
CBT	25	83
Graded activity	24	80
Mindfulness therapy	22	73
Lifestyle management	22	73
Dietary advice	21	70
Pacing (within graded activity, not adaptive pacing)	17	57
Graded exercise therapy	13	43
Counselling	10	33

CBT, cognitive–behavioural therapy; CFS/ME, chronic fatigue syndrome/myalgic encephalomyelitis.

Dietary assessment and advice

Nineteen of 30 services (63%) reported that they gave basic dietary advice, 15/30 (50%) reported that they assessed patients for adequate nutrition and 24/30 services (80%) could refer patients to a dietician where necessary. No service recommended exclusion diets unless the patient had been assessed and advised by an immunologist or gastroenterologist. Where services did report giving advice on diet, this was related to basic healthy eating (e.g. drinking enough fluid, adequate fruit and vegetables, reducing caffeine intake).

Treatment duration
Sixteen of 30 (53%) services reported that duration of treatment and follow-up was based on individual patient need, which could range between a single visit to ongoing support. Since many services reported a high level of individualisation to patient need, we did not calculate mean duration or number of sessions.

Health professionals involved in delivering care
The smallest clinical care team consisted of one doctor and one clinical psychologist. All other services (29/30, 97%) reported multidisciplinary teams (MDTs) involving three or more different health professionals. Doctors were the most common MDT members; 27/30 (90%) services had either a consultant or a GP with special interests on the team.

The three services which did not have their own doctor (3/30, 10%), reported that they received medical input from doctors based in neighbouring teams.

Occupational therapists were the second most common MDT members. Table 2 shows results for this question.

Table 2 Health professionals on the multidisciplinary team among the 30 CFS/ME services which provide services for severely affected patients

Health professionals within multidisciplinary teams	Number of services	Percentage of services
Doctor	27	90
Occupational therapist	26	87
Physiotherapist	18	60
Clinical psychologist	15	50
Specialist nurse	6	20
Counsellor	3	10
Dietician	3	10
Clinical psychology assistant or mental health practitioner	3	10
Cognitive–behavioural therapist	3	10
Peer specialist (individuals with experience of getting better from CFS/ME	3	10

CFS/ME, chronic fatigue syndrome/myalgic encephalomyelitis.

Measurement of outcomes
Twenty of 30 services (66%) used some or all of the CFS/ME National Outcomes Database (NOD) questionnaires. These include patient-reported outcome measures on fatigue (Chalder Fatigue Scale),physical function (SF-36),mood (Hospital Anxiety and Depression Scale; HADS),pain (visual analogue pain rating scale), sleepiness (Epworth Sleepiness Scale) and quality of life (EQ-5D).14 Other services used one or more of the NOD outcome measures listed above, plus additional outcome measures including the Work and Social Adjustment Scale.

General practitioner information Twenty-five of 30 (83%) services reported that they had taken action to provide GPs with information about what their service provided, for example, by presentations at GP training events.
The questionnaire also included a free-text question on participants' views on barriers to service provision for severely affected patients. This data will be the subject of a separate qualitative paper.

Discussion
This study found from the responses to the questionnaire emailed between February and March 2013 that while 55% of adult CFS/ME services in the NHS in England treated severely affected patients, 33% did not, with the remaining services offering regular but minimal (by email or telephone) or occasional assistance to this patient group. This suggests that a substantial proportion of patients with severe CFS/ME lack access to face-to-face, local specialist care, even when they live in an area with a CFS/ME service.

How does this compare with access to treatment for patients with mild-to-moderate CFS/ME? In 2012, Collin et al collected data from 46/49 (93%) specialist CFS/ME services and found that while 85% of (former) primary care trusts provided a specialist CFS/ME service, 8% did not (7% services did not respond to survey). If the outcomes of the current scoping exercise are combined with those of Collin et al, it would appear that over a third of the population of patients with severe CFS/ME in England lack access to local specialist care for their condition.

The 2007 NICE guidelines on CFS/ME recommend referral of all severely affected patients for individualised therapeutic management and monitoring/management of clinical risk by health professionals with specialist expertise in CFS/ME. The findings of this study suggest that this recommendation is not currently being met.

However, results from those services that do provide help for severe CFS/ME suggest that treatment is being offered in accordance with 2007 NICE guidelines including the use of MDTs and treatment individualised to patients including activity management, CBT and graded activity.

Conclusion
This scoping exercise highlights a lack of access to specialist care for patients who are housebound and unable to access outpatient services due to severe CFS/ME. From the findings of this study we suggest that the development of clinical services for severely affected patients requires rigorous research to determine optimal practice, so that evidence-based interventions can be funded and offered to all patients with severe CFS/ME.

CMRC conference report

A UK CFS/ME Research Collaborative (CMRC) conference was held in September 2014. An associated report is now ready.

The following link provides access to parts of the report:

www.actionforme.org.uk/get-informed/research/our-research-related-activity/uk-cfsme-research-collaborative/cmrc-conference-report-september-2014/cmrc-conference-report-september-2014

The following link provides access to the entire report:

www.actionforme.org.uk/Resources/Action%20for%20ME/Documents/research/cmrc-report-final.pdf

An overview of the content of the report follows:

Plenary session one on inflammation

- Welcome by Prof Stephen Holgate, CMRC Chair
- Anne Faulkner Lecture: The neuroimmune basis of fatigue by Prof Robert Dantzer, University of Texas Anderson Cancer Centre
- Interferon-alpha rapidly changes brain microstructure by Dr Neil Harrison, University of Sussex
- Interferon-alpha induced persistent fatigue by Alice Russell, Kings College London
- Blood cytokine concentrations in CFS: a systematic review by Dr Lisa Blundell, Barts and the London School of Medicine and Dentistry
- Resveratrol treatment on TNF-α-induced cytokine release by Kate Earl, University of Liverpool

Associate Member/patient and researcher session

- Working together for more and better research that benefits people with CFS/ME, a workshop facilitated by Sally Crowe
- Panel discussion for researchers and Associate Members, chaired by Prof Stephen Holgate, CMRC Chair

Plenary session two on MRC-funded CFS/ME research

- Understanding the pathogenesis of autonomic dysfunction in chronic fatigue syndrome and its relationship with cognitive impairment by Dr Stuart Watson (for Prof Julia Newton), Newcastle University
- Biological fingerprints of fatigue by Prof Wan-Fai Ng, Newcastle University
- Inflammation and fatigue: is it different from depression? by Prof Carmine Pariante, King's College London
- Sleep and CFS/ME by Dr Sue Wilson (for Prof David Nutt), Imperial College London
- Mitochondrial function and cytokine production in skeletal muscle of patients with CFS/ME by Prof Anne McArdle, University of Liverpool
- The epidemiology of CFS/ME in adolescence by Dr Esther Crawley, University of Bristol
- PACE: a trial and tribulations by Prof Peter White, Barts and the London School of Medicine and Dentistry

Plenary session three on infection

- Acute infection & post-infective fatigue as a model for CFS by Andrew Lloyd, University of New South Wales
- Microbiology & immunology of CFS/ME and other challenging disorders by Prof Ian Lipkin, Columbia University

Plenary session four on pain, paediatric CFS/ME and epidemiology

- Understanding pain mechanism in children and adolescents by Prof Maria Fitzgerald, University College London
- The epidemiology of adolescent CFS and chronic widespread pain by Prof Jon Tobias, University of Bristol
- Recovery and persistence from CFS/ME in adolescents by Dr Roberto Nuevo, University of Bristol

Closing presentations

- Workshop feedback, chaired by Prof Stephen Holgate, CMRC Chair
- Taking collaboration forward: next steps by Prof Stephen Holgate, CMRC Chair
- End of conference summary by Prof Hugh Perry, University of Southampton

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