Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

September 2015

Future dates

Open to all members and carers.

15th September 2015 (Tuesday) 7.30pm The Weyside
Millbrook, Guildford, Surrey, GU1 3XJ
www.theweyside.co.uk

14th October 2015 (Wednesday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

5th November 2015 (Thursday) 7.30pm The Weyside

27th November 2015 (Friday) 11.15am The Seahorse

Christmas Dinner ! 16th December 2015 (Wednesday) 7.30pm The Weyside

We automatically reserve 10 seats for the Christmas Dinner and places are taken on a first come, first served basis. If we receive more than 10 requests we will attempt to book additional seating. Please let Andy know as soon as possible if you intend to come.

If you would like to come to the Christmas Dinner please text message or call Andy, our Treasurer, If you send a text please clearly state your name.

Important !

There are two possible menu options for the Christmas meal. The everyday menu is available on the day and does not require any pre-ordering. There is also a **Christmas menu which does require pre-ordering**. (included at the rear of this newsletter).

If you wish to pre-order from the Christmas menu this must be done before 1st December by telling Andy your food choices. The disadvantage of pre-ordering, however, is that if you are unable to attend on the night you will be liable for the cost of the meal ordered.

We look forward to seeing you there. The Christmas Dinner is our most popular event.

Respite breaks to unpaid Carers

Source: www.crossroadscaresurrey.org.uk

'Crossroads Care Surrey' is a charity that offers a level of assistance for unpaid carers in Surrey.

We provide high-quality, bespoke care for your loved one in their own home. Our highly trained Carer Support Staff take over a Carers responsibility for a few hours each week. This "me-time" contributes to the Carer's physical and mental well-being, enabling them to have some time to themselves, to meet with friends, participate in leisure activities, go shopping or simply relax. The key factor is that they can spend their time with complete peace of mind, knowing that the Crossroads Care staff member is a qualified professional working to a detailed care plan.

There is increasing recognition that society depends heavily upon unpaid Carers, who can find themselves on call '24/7' for years on end – a burden that often takes a toll on their own health. A Carer is someone who looks after a family member, friend or neighbour who is frail due to old age, has a long-term disability or illness. This ranges from a child with cerebral palsy, to an elderly person with dementia.

Crossroads Care Surrey is a leading, registered Charity that has been providing vital respite breaks to unpaid Carers in the County for over 30 years. Our core purpose is to improve the quality of life of unpaid Carers and the people for whom they care and to foster their physical and mental well-being. We support Surrey Carers by enabling them to take a break from their caring responsibilities, with the peace of mind that comes from the knowledge that the person with care needs is in the good, reliable and professionally trained hands of our Carer Support Workers.

Our services operate throughout Surrey and include; three hours a week respite care; Social Clubs that give Carers an extended break and a variety of self-funded respite packages that offer extended time away from their caring responsibility. In partnership with the NHS we also provide a unlimited End of Life service for those caring for someone in the last twelve months of their life.

Together, we can help more Carers make a life of their own outside of caring.

Respite care service

Our respite care service, which is primarily funded by Surrey County Council and the NHS, provides Carers with a 3 hour weekly respite break. This usually takes place on the same day and at the same time each week. We try to ensure that the same Carer Support Worker (CSW) attends each visit so that the family gets to know them and in turn the CSW has a clear understanding of the family's needs.

One-to-one care is provided at home. If appropriate, we may take the person who is cared for out into the Community whilst the Carer takes a break. This might be to go shopping, to feed the swans or to enjoy one of their favourite leisure pass times. Our Carer Support Workers undertake activities which improve the quality of the cared for person's life such as:

- Outings where appropriate, based on an individual's choice.
- Meal, drink preparation and light domestic duties.
- Chatting, reading to the cared for person & playing games.
- Personal care such as washing, dressing & toileting.
- Health care procedures such as wound care, continence management.

All of our CSW's work to a detailed care plan constructed by a Care Co-ordinator. This document is regularly updated to ensure a tailored service is provided and a standard of excellence is maintained.

As the number of Carers needing our support increases, we rely on vital donations from our generous supporters to provide essential short breaks. At the moment, demand for these specialised services, exceeds supply so there is a waiting list for this service.

For more information on our respite care service or to put your name on the waiting list please contact a Care Co-ordinator in the location nearest you.

Where
Crossroads Care Surrey covers most of the county and parts of Middlesex. We operate out of the 3 main locations show in the map below. To find out more about how we can help you, or a Carer you know, simply contact the appropriate office below.

Crossroads Care Surrey – North
Room 255, Community Link, Knowle Green, Staines, Middlesex TW18 1XB
t: 01784 446294 and 01784 448578
e: enquiries.north@crossroadscaresurrey.org.uk
In case of emergency or late cancellation please call 07784 938697

Crossroads Care Surrey – East
Oxted Community Hall, Church Lane, Oxted, Surrey RH8 9NB
t: 01883 714641 and 01883 732284
e: enquiries.east@crossroadscaresurrey.org.uk
In case of emergency or late cancellation please call 07770 742377

Crossroads Care Surrey – West
1st Floor Suite, Park Barn Centre, Park Barn Drive, Guildford, Surrey GU2 8EN
t: 01483 447771 and 01483 447772
e: enquiries.west@crossroadscaresurrey.org.uk
In case of emergency or late cancellation please call 07914 186162.

Self-funded packages
Respondents to our 2013 Annual Carers Research asked us to introduce a variety of respite packages. We listened and responded by launching a variety of flexible, affordable 'Packages of Care'. In order to keep the cost of our packages to a minimum, we only offer these packages in blocks which must be taken on the same day.

Many Carers struggle on without help until they themselves reach breaking point. Yet, as a Carer it is important that your own health and well-being is maintained so you can continue to care.We can offer you extended respite breaks to give you a day or an evening away from your caring responsibilities in a block of:

3 Hours – At a time that suits you to allow you the flexible short break that you need.
10 Hours – This gives you the option of day, sleeping or waking night respite care.
24 Hours – This includes 24 hours sleeping or waking care.
48 Hours – This allows you to have a weekend away, safe in the knowledge that the person you care for is receiving the highest standard of care.

Our overnight packages provide the option of waking nights, where our CSW will not go to bed at all, or sleeping nights where a bed is available for our CSW.

All of our Care Packages are flexible and can be tailored around you and the specific needs of the person for whom you care. Call us now to find out more.

The process:

1. Contact our Crossroads Choices Care Coordinator, Elaine McKee now for more information, to discuss your requirements or to ask for a price list. Call 01483 447770/ 07481 810981 or email elaine.mckee@crossroadscaresurrey.org.uk.
2. Allow time for a comprehensive assessment to take place prior to receiving your package. This will enable us to fully understand your care needs and write a comprehensive, structured care plan.
3. You will then be matched with a Carer Support Worker who will be introduced to your family before your Care Package takes place. This is to ensure that both you and your loved one feels comfortable, cared for and there is continuity of care.

Please note different rates apply for weekends (Friday, Saturday & Sunday) and bank holidays.

ME/CFS overview by Dr Amolak Bansal

Source: www.prohealth.com/library/showarticle.cfm?libid=20739

The 10th Invest in ME International ME Conference 2015 - IIMEC10 - took place on 29th May 2015 in London and attracted delegates from seventeen different countries - from Europe, North America, Middle East and Australasia.

An overview of the conference can be seen at the source link above.

Dr Amolak Bansal (immunologist) was one of the speakers. He leads the 'Chronic Fatigue Service' in Surrey at Sutton hospitals, with clinics at St Helier Hospital. The service provides management and support for people with CFS.

Dr Amolak Bansal gave an overview of the diagnosis and differential diagnosis on ME. He explained how fatigue occurs in many illnesses, but is the cardinal feature of ME/CFS. He said the post-exertional malaise is hard to explain. He then went through the various criteria being used to diagnose the illness. He discussed the differences between the criteria (CDC, ICC etc.).

He thinks that the term SEID may be too simple. He talked of exclusion criteria, including temporary exclusion criteria, such as hypothyroidism and morbid obesity leading to sleep apnoea; and psychiatric exclusion criteria. He mentioned comparisons which are made between the terms CFS and ME.

He then went through the Sutton scoring system developed at his clinic. The main symptoms have a “loaded” score: e.g. PEM scores 3 points, sleep problems 2 and all other symptoms 1 point. 8 or more points out of 13 points is needed for a diagnosis. All patients must have post exertional malaise. For subjects involved in research he uses a score of 10+ from 13 to ensure a critically well-defined population. Subjects with a significant depression or anxiety are excluded from research but can still be diagnosed with ME/CFS for management purposes if they have sufficient points and the depression and anxiety is secondary to the ME/CFS. Treating the depression, anxiety and ME/CFS are all critical to improvement in these people. It is important to note that sensitivity to medication, and alcohol intolerance are very common in ME/CFS. Fewer than 10% patients can tolerate alcohol. Another unusual sign in 60 % patients is altered pupillary reflexes (alternating dilatation and contraction while a light is shined) and sighing respirations. Other physical signs include: joint hypermobility (20%), increased respiratory rate (80%), coldness of peripheries (70%).

Conditions that can cause symptoms similar to ME/CFS include: hypothyroidism, Addison’s disease, pituitary dysfunction, Sjogren’s syndrome, gluten sensitivity, persistent anxiety, primary sleep disorder, Ehlers Danlos Syndrome joint/hypermobility type, cardiac dysfunction, Parkinson’s disease and temporo-mandibular joint disorder.

He then compared ME/CFS with depression and anxiety. The sleep disturbance in ME/CFS is different to that in depression and the former are also markedly hypersensitive to psychoactive medications. Functionally those with ME/CFS can start a task, but then trend downwards while those with depression cannot start a task as they have reduced motivation, but once started they can often manage to complete it. Those with ME/CFS rarely resort to alcohol, while those with depression do frequently. However chronic anxiety associated with ME/CFS will deplete energy further, contribute to faintness, cognitive difficulties and increased respiration.

He then talked about appropriate investigations. The basic blood workup should be done as for all fatiguing illnesses and these are sufficient to exclude other causes for chronic fatigue in the majority of patients. Things to add in depending on history and symptoms may be: ANA, CK, calcium, magnesium, tests for Addisons and on rare occasions infection serology (Lyme, viral) and neurological abnormalities (MRI, fMRI, PET scans). Other tests that are occasionally considered include tilt table, ECG monitoring and neuropsychological tests. Unfortunately in the UK searching for triggering infections, such as viral, bacterial (incl spirochaetes), protozoa and fungi (no evidence for involvement of candida) is rarely rewarding in terms of offering specific therapeutic options. History of immunisations on rare occasions may suggest a possible trigger and there is recent controversy about the HPV vaccine.

Quite often it is a difficult question of how far to delve into issues such as life events, stress, physical injuries, environmental toxins and childhood trauma as there is at least some evidence that they may all play a cofactor role in precipitating ME/CFS. He then discussed the importance of the control population in ongoing ME/CFS research. Although the ideal control group would be family members this is often difficult and perhaps monitoring people with ME/CFS through several periods of relapse and remission would be best way forward.

Riding the chronic illness roller coaster

Source: www.prohealth.com/library/showarticle.cfm?libid=20834
By Suzan L. Jackson 25th July 2015

The song "Helter Skelter" (originally by The Beatles) often goes through my mind when I go from feeling fine one day to being badly crashed the next. It resonates with my sense of climbing up only to find myself on a ride back down again. For those of us with ME/CFS and fibromyalgia, life is like a roller coaster. Not everyone with ME/CFS or fibromyalgia experiences physical ups and downs – some people feel about the same every day – but all of us living with chronic illness deal live with an emotional roller coaster. Kubler-Ross famously identified five stages of grief: denial, anger, bargaining, depression, acceptance. What many people don't realize is that these stages don't occur linearly and aspects that you think you are done with (like anger or depression) can recur over time.

I have found this to be very true in my own life. I certainly experienced all of those stages of grief at the beginning of my illness and even got stuck in depression for a while. For the most part, I feel that I am fully in acceptance mode now, 13 years later. However, once in a while, those other emotions still appear and surprise me.

I am generally a very happy, optimistic person. That's just my natural temperament, and I am usually content with my life, even with chronic illness. I've made peace with my new normal and accept my limitations; I've learned to find joy within my restricted life. Every once in a while, though, even after 13 years, despair will just hit me with the force of a tidal wave. I'll suddenly feel depressed, abandoned, and like a failure. I'll cry and grieve over all the things I can no longer do. This dark state of mind might last for a day or two and then I gradually come back to my normal, happy self – riding the emotional roller coaster.

I've learned over the years that these sudden storms of despair often accompany a physical worsening of symptoms or a crash. That tells me it is tied to the biochemistry in my brain. It helps a bit to understand this, though it is hard to be logical in the midst of that darkness.

So, what helps when I hit bottom? The first key is to recognize that what you are feeling is normal and natural and will eventually pass. This is easier said than done! Those feelings are very real when you are in the midst of them, and it can be hard to remind yourself that you are at the mercy of changing biochemicals. However, reminding myself that these are transient feelings that will pass, just as they have before, can help immensely. I think of it as riding the wave – allowing myself to feel what I am feeling, while acknowledging that it is temporary.

Over the years I have developed some other coping mechanisms when despair hits:

- Think about/write down what you are grateful for. It helps to remind yourself that things aren't as black as they seem, that you still have some positive things in your life – family, friends, good books, birds singing outside your window. I wrote previously here about keeping a Joy Journal ("Finding Joy in Every Day") – writing down each day the little things that brought you joy – and that can help now, too.

- Reach out to others. These illnesses are isolating anyway and even more so when you are feeling emotionally low. If you have understanding friends or family, tell them you are feeling down. Just sharing those feelings with a loved one can help. (Make sure it is someone who can be empathetic and not make things worse.) You can also share your feelings online with others who you know will understand, in discussion groups or Facebook groups for your illness. For me, that often means writing a blog post, and I am always comforted by the outpouring of support and understanding when I do admit to feeling down.

- Take care of yourself. Focus on your own needs and do things that you enjoy: read a good book, watch a favourite TV show or movie (a funny one is even better!), take a nap, listen to an audiobook. Do whatever brings you comfort.

- Be kind to yourself. If you are going through a bad period emotionally (or physically), don't try to be productive and get things done or push yourself in any way. Indulge in comforting rituals, like a favourite herbal tea, a piece of dark chocolate, staying in bed. Don't berate yourself for feeling down. Let others take care of you.

- Help others. It may sound counter-intuitive, but helping other people can be a great way to help yourself. It feels good to be of use or to know that you helped someone. Reach out through your social media networks, chronic illness groups, or to close friends or family. Helping others has been one of the biggest unforeseen benefits of our illnesses in my family.

If none of these kinds of things work or you are stuck in a serious depression that lasts more than a few days, seek professional help. Start with a local referral service or search online. Look for a therapist who has experience with chronic illness. (Call the office and ask that question before you book an appointment.) If you are too sick to leave the house or can't find anyone locally, look online – there are therapists specialising in chronic illness who will work with you via Skype. In my first few years of chronic illness, I struggled to adjust to my new life of limitations; when my two sons also got sick, I sunk even deeper into despair. I found a wonderful local psychologist (through my husband's workplace referral service) who had a grown son with ME/CFS. She understood what I was going through and helped me immensely.

Most of all, I have learned to focus on one day at a time. Considering a lifetime with this illness is too overwhelming. Thinking about all that I want to do with my life in light of my current restrictions is just too depressing. It's better to focus on small goals, on getting through each day, even each hour, and taking care of myself now. Those black feelings will come sometimes, but I know they will also pass.

Suzan Jackson is a freelance writer who has had ME/CFS for 13 years. Both of her sons also got ME/CFS, but one is now fully recovered after 10 years of illness and the other is in college. She writes two blogs: Learning to Live with ME/CFS(with an emphasis on LIVE!) at http://livewithcfs.blogspot.comand Book By Book at http://bookbybook.blogspot.com.

'Fit for work' deaths

Source: www.huffingtonpost.co.uk/2015/08/27/benefits-death-claimants-welfare-ids_n_8047424.html

More than 4,000 died within six weeks of being deemed 'Fit for work', reveal government

More than 4,000 people died within six weeks of being found "fit for work", the Department for Work and Pensions (DWP) has revealed.

Figures released today show that between December 2011 to February 2014, 4,010 people died after being told they should find work following a "Work Capability Assessment".
Of that figure, 1,360 died after losing an appeal against the decision.
Labour branded the figures a "wake-up call" for the Government, who has faced criticism for the way the assessment tests are carried out.

The figures have only been released after the Information Commission overruled a Government decision to block the statistics being made public.

TUC General Secretary Frances O'Grady called for an urgent enquiry into the figures, and said: "We urgently need an enquiry into the government's back-to-work regime. These disturbing findings cannot be swept under the carpet.

“The fact that more than 80 people are dying each month shortly after being declared ‘fit for work’ should concern us all. These deaths relate to just one benefit – Employment Support Allowance (ESA).

“We need a welfare system that supports people to find decent jobs not one that causes stress and ill health.”

The figures show that of the 4,010 who died after being told they were "fit for work", 3,720 were in receipt of ESA, while 290 were on either Incapacity Benefit or its replacement, Severe Disablement Allowance.

The DWP were keen to stress throughout its "Mortality Statistics" report that: “Any causal effect between benefits and mortality cannot be assumed from these statistics."

More than 50 charities, acting as the Disability Benefits Consortium Members, called on the Government to reform the way they assess welfare claimants.

Mencap's Rob Holland, co-chair of the consortium, said: “These tragic figures are concerning and warrant further investigation. We know the fit for work test is failing disabled people, with devastating consequences. Wrong decisions can mean people are left with little or no support at all, in some cases struggling to pay for their homes and basic essentials like food and heating.

He added: "These figures should act as a stark warning to the Government to improve the fit for work test and ensure disabled people get the level of support they need.”
Mike Sivier, a campaigner who requested the statistics under Freedom of Information law, welcomed their release and suggested he might now push for details of the causes of death in each case - including cases of suicide.

Labour called the delay in their publication a "disgrace", and Shadow Minister for Work and Pensions Kate Green said: “These figures should be a wake-up call for the Government. Ministers need to focus on sorting out the assessment process so that everyone can have confidence in it, and providing support for disabled people who can work in order to help them do so."

Labour leadership candidate Andy Burnham called for a "national debate" in light of the revelations.

He said: "These are shocking figures that for the first time show the human cost of this Government's punishing benefits regime.

"It raises serious questions about this Government's punitive approach to people on benefits.

"We now need an urgent national debate about these figures, and if elected Leader I would call a full-day debate in Parliament at the first available opportunity.

"This Tory Government has been playing politics with the lives of vulnerable people."
The DWP said the figures showed death rates had remained in line with trends in the wider population for a decade.

A spokesman said: "The mortality rate for people who have died while claiming an out-of-work benefit has fallen over a 10-year period. This is in line with the mortality rate for the general working-age population.

"The Government continues to support millions of people on benefits with an £80 billion working-age welfare safety net in place."

Rituximab – an update

Source: http://phoenixrising.me/archives/26930

It's out! Dr Øystein Fluge and Professor Olav Mella have published their new study in PLoS ONE. And though the study was not a blinded, placebo-controlled trial, the results are further evidence that rituximab is beneficial in some ME/CFS patients, and potentially life-changing for a substantial minority. The findings also give important new insights into the optimum dosing schedule to maintain those benefits in the long run.

We all know the story that led up to this study: cancer specialists Fluge and Mella treated an ME patient for cancer with the immune-system drug rituximab. The patient's ME symptoms improved markedly. The effect was confirmed in two additional patients and so Fluge and Mella set up a 30-patient, double-blind, randomised, placebo-controlled trial of rituximab in ME/CFS.
The results, when published in October 2011, were striking: although there were no differences between the two groups at the pre-defined endpoint of three months, 67% of patients receiving rituximab had moderate to major improvement during follow-up, compared to only 13% of placebo patients (p=0.003).

And not only that: there was a tell-tale delay of several months in the improvement. This time-lag suggested that it was rituximab's B-cell destroying capabilities that were responsible. That, in turn suggested that rituximab was switching off an autoimmune process (some B-cells produce antibodies that attack the body's own tissues).

The findings took the ME/CFS world by storm and started a sea-change in attitudes to the disease. The Norwegian Health Directorate apologised for how ME patients had been treated. Researchers and clinicians outside the ME/CFS community began to focus on autoimmunity as a hypothesis rather than psychology. Fundraising efforts for more rituximab trials started up all over the world, includingMEandYou's successful crowdfund in Norway and the ongoing fundraising for Invest in ME's UK rituximab trial and B-cell studies.

Meanwhile, Fluge and Mella set up a small study – this newly published study – to inform the design of a larger trial. In their original placebo-controlled study, most of the patients who benefited from rituximab had a transient response and then relapsed. Fluge and Mella needed to investigate the best dosing schedule, and other aspects of rituximab's use.

The large multi-centre rituximab trial is now underway in Norway, led by Fluge and Mella and funded by MEandYou, the Norwegian government, and others. It's another double-blind, placebo-controlled, randomised study and has 152 patients, who will be followed up for 24 months post-treatment: results won't be available until 2017 or 2018.

Meanwhile, this new study has much to tell us. Over to Simon, to take a look at it.

The study findings are very encouraging. 64% of patients showed a clinical response, similar to the 67% seen in the original trial. Half were classed as major responders. And at the end of the study a quarter of patients were doing exceptionally well: in my opinion the data suggests they were close to recovery.

How the study worked

All patients met both Fukuda and Canadian consensus criteria. The average age of patients was 40, and 69% were women. They'd been ill for an average of nine years, and 20 (two-thirds) were at least housebound, including three who were mainly bedbound.

The main measure of success was change in fatigue from baseline (see box below). For clinical response, patients needed six consecutive weeks of improvement, and to average at least a slight-to-moderate improvement, including at least one week better than moderate (so at least one of the fatigue symptoms had to be rated as a major improvement). This could be at any time during the 36 months of the study.

Patients received an initial two doses of rituximab two weeks apart and then maintenance infusions at 3, 6, 10 and 15 months. They were followed up for a total 36 months.

Results

"Eleven of the 18 responders were still in remission three years after beginning the treatment, and some have now had no symptoms for five years," says Fluge. "Suddenly, their limbs started to work again and their hands were no longer cold or sweaty." (From an interview in the New Scientist)

Of the 28 patients who received any maintenance doses, 18 (64%) showed a clinical response, similar to the 67% seen in the initial trial. 14 were classed as major responders and four as 'moderate responders'.

Thus, half of the patients showed a 'major' response, with an average response period of 105 weeks (out of 156 weeks in the study). Typically, patients didn't start improving until 23 weeks after the first dose of rituximab.

Peak response, and relapse for some

The results for patients overall peaked at 20 to 24 months, which was 5 to 9 months after most patients had had their final dose. (Some patients who were responding slowly received more, but these additional doses didn't seem to make much difference.)

During this peak response time, the average SF-36 scores for major responders matched average population scores (though some were well below average, at levels typically seen in people who have long-term illness). That's a big improvement from baseline when the scores showed they were all well and truly sick.

However, some patients declined after this peak period, including four major responders who, after doing extremely well, relapsed severely – almost back to baseline levels.
Even so, nine out of 14 major responders (32% of patients) were still showing a clinical response, of various levels, at the end of the study. Including moderate responders, eleven were still in response at the end of the study, showing that repeated rituximab dosing had given a sustained response, right to the end of the study for some.

Mega-responders?

However, for me, the big story of this study is the substantial group who did exceptionally well, though I should stress this is my interpretation of the data in the paper rather than anything the authors have claimed. There is a wealth of data in the paper, down to the level of individual patients. Seven patients – a quarter of those who had maintenance rituximab doses – showed a response that looks close to recovery at the end of the trial, that is, at 32 to 36 months, which is the final data point on the graph of outcomes. Fatigue, SF-36 Physical Function and self-rated daily functioning scores all look very impressive:

- Seven patients reported the maximum possible fatigue improvement from baseline, that is, major improvement in all four fatigue symptoms. One patient was actually just shy of the maximum, scoring approximately 5.9 out of 6.0 (Fig 2A).
- Seven had an SF-36 Physical Function score of 85 or more, which is equal to or better than the population average (Fig 5A).
- Seven had function levels of 80% or higher (someone at 80%-90% is defined as having "slight restrictions in physical or social functioning, who may perform all activities almost as a completely healthy person, but at a reduced pace or duration"), with two scoring 100% (Fig 6B).

All of the patients in the study started with low scores in each of these three areas, so those highs represent huge progress. There is no guarantee that the same seven patients have top scores in each of those three areas, but it seems very plausible.

While the placebo effect and response-bias may occur, they are relatively modest effects. And with ME/CFS, natural recovery rates are low. So these 'mega-responder' results strike me as very impressive, and important. Such life-changing improvements are not a common feature of ME/CFS clinical trials.

ME/CFS found worse than Diabetes, Multiple Sclerosis, Cancer, etc...

Source: www.cortjohnson.org/blog/2015/08/05/chronic-fatigue-syndrome-worse-mulitple-sclerosis-cancer

Let's put aside questions of whether a disease is going to kill you or not and concentrate on what happens if it doesn't kill you. Let's say God said you had to have a chronic illness but he/she would allow you to choose which one to have. On what basis would you make that choice? My guess is that most people would pick the disease that allows them the highest quality of life and the most functionality.

If a disease doesn't affect quality of life – how much does it need to be addressed? If it does significantly affect QOL – how much more urgently should it be? A disease that doesn't impact our ability to function or to be productive in society or our quality of life, may be a disease that doesn't need a lot of attention.

A disease on the other hand, that significantly restricts our functioning is a disease that our society, purely from a pragmatic viewpoint, should pay a great deal of attention to. A disease that significantly impacts our quality of life is a disease that we as human beings would dread, most of all, of having.

People with ME/CFS often assert their disease is not taken seriously enough at their doctors office, by the public, by their families or by the federal government. A Danish research group put the impact of chronic fatigue syndrome to the test recently. They compared the quality of life scores of people with ME/CFS with people who had serious medical disorders. It was put up or shut up time. For ME/CFS to be considered a serious disease it had to pull its weight against diseases like multiple sclerosis, cancer, rheumatoid arthritis and stroke. Could it? Let's find out.

The study

> The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Michael Falk Hvidberg,1,* Louise Schouborg Brinth,#2 Anne V. Olesen,#1 Karin D. Petersen,#1 andLars Ehlers PLoS One. 2015; 10(7): e0132421.Published online 2015 Jul 6. doi: 10.1371/journal.pone.0132421

The data for the ME/CFS part of the study came from 112 people associated with the National ME/CFS Danish Association. Except for some questions specifically targeted at ME/CFS patients, the same standardised survey was used in this survey and in a 23,000 person Danish survey. The bigger study examined the quality of life in chronic illness.

Let's get one thing out of the way first. The big question overhanging this survey was how representative the 112 people coming from the Danish ME/CFS Association were of ME/CFS patients in general. The demographic results indicated that with regards to age, gender, and socio-economic status the Danish patients looked much like ME/CFS patients surveyed in other countries. The authors agreed, though, that patients joining a group like the Danish Association probably tended to be less satisfied with their health care, more severely ill and more resourceful than patients not joining organisations like that.

They argued, though, that sampling support groups may actually produce a more realistic assessment than sampling patients from clinics, because clinic studies usually miss the more severely ill patients. Since high percentages of ME/CFS patients (relative to other diseases) are severely ill, the authors proposed that their sampling protocol may more accurately reflect the chronic fatigue syndrome community. The authors also reported that because they 'extracted' the effect of the QOL (HRQoL) of ME/CFS from other conditions that might have been present, the study only estimated the impact of ME/CFS. That was an advance over most QOL studies.

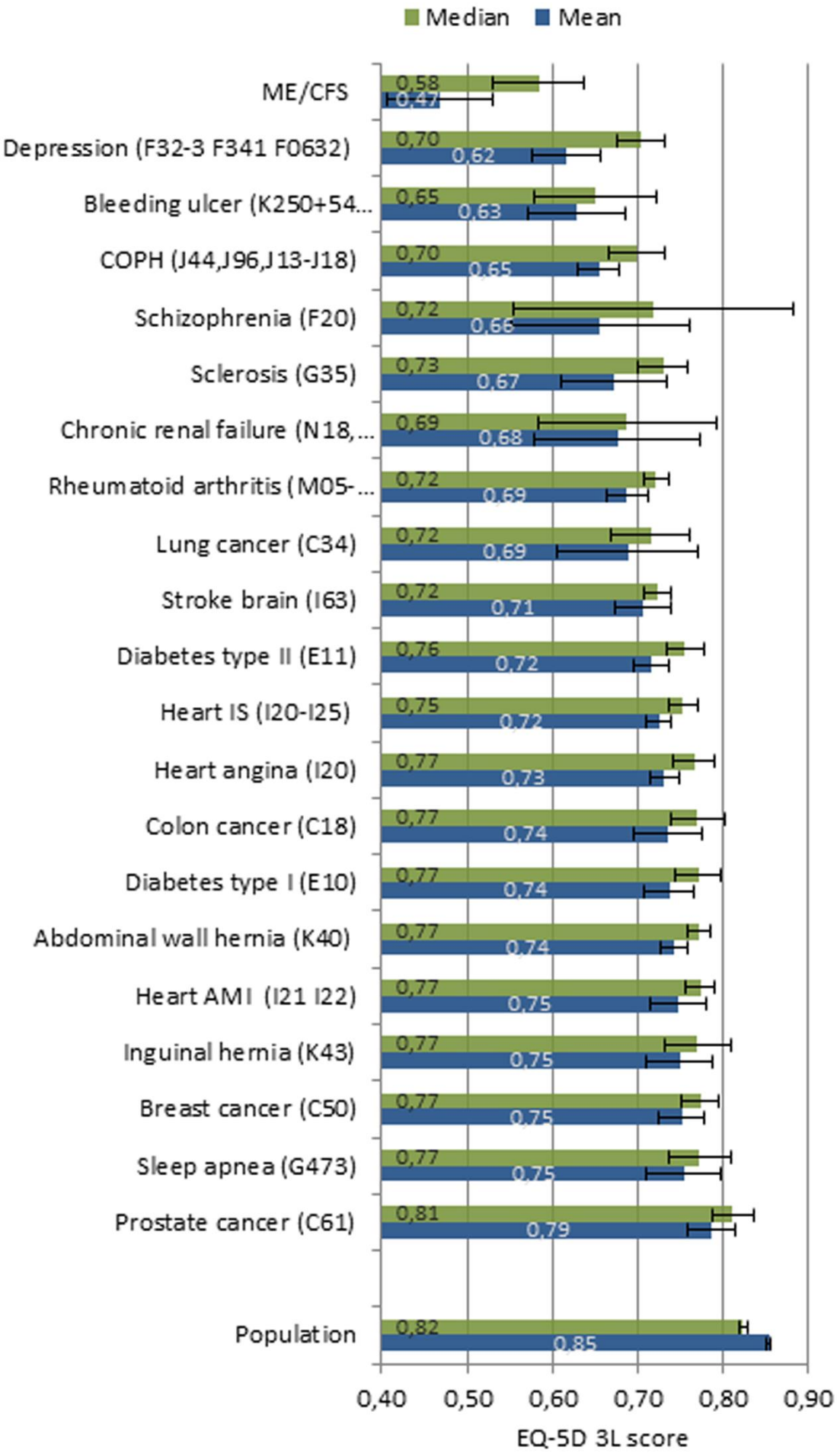
Results

The authors looked at median and mean quality of life scores. The median scores are a more accurate measurement of a community because they're not skewed by people with really high or low scores. How did the quality of the lives of people with ME/CFS stack up next to those of people with cancer, multiple sclerosis, heart attack or stroke? They were worse – significantly worse.

Median scores

People with ME/CFS had the lowest median quality of life (QOL) scores of any disease tested. The next highest QOL score was 12% higher (bleeding ulcer). Next came people with chronic kidney failure with 15% higher scores. People with ME/CFS had lower quality of life scores than people with other major illnesses People with the big, scary diseases (the ones people think – "Please, Lord not me!") all had consistently higher quality of life scores than people with ME/CFS. Schizophrenia is one of the last diseases I would wish on anyone, but people with schizophrenia scored 21% higher in their QOL scores than people with ME/CFS. The same was true for people with stroke, multiple sclerosis and rheumatoid arthritis.

Please refer to the chart overleaf for more information.


Median
Mean
ME/CFS
0,58
0,47
Depression (F32-3 F341 F0632)
0,70
0,62
Bleeding ulcer (K250+54...
0,65
0,63
COPH (J44,J96,J13-J18)
0,70
0,65
Schizophrenia (F20)
0,72
0,66
Sclerosis (G35)
0,73
0,67
Chronic renal failure (N18,...
0,69
0,68
Rheumatoid arthritis (M05-...
0,72
0,69
Lung cancer (C34)
0,72
0,69
Stroke brain (I63)
0,72
0,71
Diabetes type II (E11)
0,76
0,72
Heart IS (I20-I25)
0,75
0,72
Heart angina (I20)
0,77
0,73
Colon cancer (C18)
0,77
0,74
Diabetes type I (E10)
0,77
0,74
Abdominal wall hernia (K40)
0,77
0,74
Heart AMI (I21 I22)
0,77
0,75
Inguinal hernia (K43)
0,77
0,75
Breast cancer (C50)
0,77
0,75
Sleep apnea (G473)
0,77
0,75
Prostate cancer (C61)
0,81
0,79
Population
0,82
0,85
0,40
0,50
0,60
0,70
0,80
0,90
EQ-5D 3L score

Christmas Dinner Menu - Weyside

Starters

Butternut squash, orange & chestnut soup (v)
Quinoa, avocado, mizuna, beetroot & pumpkin seed salad (v)
Chicken liver parfait, caramelised onions, winter pickles, sourdough toast
Whisky oak smoked salmon, orange, pomegranate & mizuna salad

Mains

All served with goose fat roasted potatoes, honey roasted carrots & parsnips, spiced red cabbage
Crown of English Rose turkey, pigs in blankets, stuffing, bread sauce, winter greens & chestnuts
Butternut squash & spinach pithivier, celeriac purée, winter greens, root vegetable mash (v)
Gressingham duck leg, haricot beans, lentils & smoked bacon
Pan fried sea bass, celeriac, smoked bacon, chicory & shallots

Pudding

Figgy pudding, salted caramel ice cream
Pear, fig, honey & cinnamon tart, crème fraîche ice cream
Chocolate & orange brioche bread & butter pudding, vanilla ice cream
Oxford Blue cheese, quince jelly, seeded crackers
2 courses £23.50 3 courses £28.50

Children's portions are available for most dishes. Please ask for more details.
A discretionary 10% service charge will be added to your bill.

(V) suitable for vegetarians. Fish dishes may contain small bones.
If you require further information on ingredients which may cause allergy or intolerance, please speak to your server before you order your
meal. If you do have a food allergy, it will be helpful to us if you could inform staff so we can ensure that the dish you select is not at risk of
cross contamination by other foods during its preparation and service.