Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

December 2016

Future dates

Open to all members and carers.

23rd January 2017 (Monday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

22nd February 2017 (Wednesday) 7.30pm The Weyside
Millbrook, Guildford, Surrey, GU1 3XJ
www.theweyside.co.uk

9th March 2017 (Thursday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

United Nations: 'Grave' disability rights violations under UK reforms

Source: www.bbc.co.uk/news/uk-37899305
7th November 2016

UK welfare reforms have led to "grave and systematic violations" of disabled people's rights, a UN inquiry has said. Changes to benefits "disproportionately affected" disabled people, the UN Committee on the Rights of Disabled Persons (CRPD) found.

The UK was the first to be investigated under a UN convention it has been signed up to since 2007. But the government said it "strongly refuted" the committee's findings and its "offensive" view of disability.

The committee launched an investigation in 2012 after receiving evidence from disability organisations about an "alleged adverse impact" of government reforms on disabled people. Two UN committee members visited London, Manchester, Birmingham, Cardiff, Edinburgh and Belfast in October 2015 to identify any gaps in human rights protection for disabled people.

As part of its inquiry, the CRPD also looked at a range of recent welfare reforms and legislation including the Welfare Reform Act 2012, Care Act 2014, and Welfare Reform and Work Act 2016.

The inquiry concluded that changes to housing benefits and criteria for parts of the Personal Independence Payment, along with a narrowing of social care criteria and the closure of the Independent Living Fund, all "hindered disabled people's right to live independently and be included in the community".

Other findings:

- Disabled people were regularly portrayed negatively as "dependent or making a living out of benefits, committing fraud as benefit claimants, being lazy or putting a burden on taxpayers"
- Sanctions for some Employment and Support Allowance claimants "increased significantly" from 2012-2014 and had been "disproportionately applied"
- The so-called "bedroom tax" and social housing size criteria "failed to recognise the specific living arrangements" disabled people require
- Assessments did not take into account the "support persons with disabilities need to perform a job or the complex nature of some impairments and conditions"
- Some work schemes "had no visible impact in decreasing unemployment" among disabled people, and some who accessed other programmes experienced reductions in support or "loss of employment"

The inquiry also said welfare assessors displayed a "lack of awareness and limited knowledge of disability rights and specific needs", and disabled people experienced "anxiety and psychological strain" due to uncertainty about assessment results.

"The committee observes that measures have caused financial hardship to persons with disabilities resulting in... arrears, debts, evictions and cuts to essentials such as housing and food," the report said.

'Patronising and offensive'

The committee made 11 recommendations to the UK government, including calling for a complete impact assessment of reforms introduced since 2010, and introducing measures to fight "negative and discriminatory stereotypes".

However, Work and Pensions Secretary Damian Green rejected the report's findings and said the document demonstrated "an outdated view of disability which is patronising and offensive". "The UN measures success as the amount of money poured into the system, rather than the work and health outcomes for disabled people," he said.

"The UK is a recognised world leader in disabled rights and equality. Not only do we spend about £50bn a year to support sick and disabled people, but we also offer a wide range of tailored and effective support, which this report fails to recognise."

He added: "Our work and health Green Paper marks a turning point in our action to confront the attitudes, prejudices and misunderstandings within the minds of employers and across wider society."

Shadow work and pensions secretary Debbie Abrahams said: "The UN report confirms that, despite Theresa May's warm words, this government is failing sick and disabled people."

The 2016 International Association for CFS/ME conference: a focus on energy

Source: www.healthrising.org/blog/2016/11/17/iacfs-me-energy-exercise-metabolomics-chronic-fatigue-syndrome

On October 27-30th 2016 the 12th IACFS/ME Conference was held in Fort Lauderdale, Florida, USA. The following are insights from the conference. For a more thorough overview, please refer to the source above.

The conferences are attended by hundreds of scientists, physicians, other professionals, and patients interested in ME/CFS, fibromyalgia, and co-morbid illnesses (e.g. orthostatic intolerance, insomnia, irritable bowel syndrome, hypothyrodisim) as well as other medical conditions/ circumstances (e.g. cancer, multiple sclerosis, rheumatologic diseases, aging, overwork) associated with acute or chronic fatigue. Attendees come from all over the United States and over 25 countries.

Dr Fluge

Doctor's Fluge and Mella shocked the ME/CFS world with their 2009 case series and the 29-person 2011 study which found that about 2/3rds of ME/CFS patients had a significant and positive response to the chemotherapy and autoimmune drug Rituximab.

Dr Fluge, it turns out, was onto the metabolomic (study of the unique chemical fingerprints that specific cellular processes leave behind) connection in ME/CFS well before most of us were. Struck by the McGregor/Armstrong group's past work in Australia, he initiated a metabolomics study sometime in the past year. Then he appears to have initiated another study (a gene expression study) based on that study. Plus, he's been examining the effects of ME/CFS patients' serum on the energy production in their muscle cells. The man is nothing if not busy.

Fluge stated that symptoms in ME/CFS could easily be caused by defects in the energy production process, and cited both the anaerobic exercise work done by Workwell and Naviaux's metabolomics work. Like Naviaux, Fluge asserts there's nothing wrong with the mitochondria; they're not broken or damaged – they're simply turned off. That's probably good news given how complex the mitochondria are.

But how does the success with Rituximab fit into this energy breakdown? Very easily it turns out. It simply requires an immune attack on the mitochondria. Rituximab could, by knocking down B-cell activity, be stopping the production of the antibodies that are whacking the mitochondria in ME/CFS.

How did Fluge figure out that the mitochondria are not to blame? The same way Ron Davis did. Both exposed cells from healthy controls to the serum from ill ME/CFS patients – and watched those healthy cells poop out. Then when they put ME/CFS cells into healthy people's serum, they turned into healthy cells. Something in the serum of ME/CFS patients is knocking the heck out of their cells.

Ron Davis will begin bombarding those cells with different factors to see if he can figure out what in their own serum is causing their energy production to poop out.

Neither Fluge nor Davis knows what that is. It could be autoantibodies or it could be something else. Fluge suggested that a subset of aberrant B-cells producing these antibodies could do the trick. Fluge and Mella have apparently been searching for autoantibodies for quite a while, but Davis isn't surprised that they haven't found them yet; it's not that easy to do.

The key may be something called the pyruvate dehydrogenase complex (PDH). Both the Davis Open Medicine Foundation and the Fluge/Mella groups appear to be looking intently at the process of pyruvate metabolism.

The end product of glycolysis is pyruvate which then gets used by acetyl CoA in the citric acid cycle and aerobic energy production. It's essentially the bridge between anaerobic energy production and aerobic energy production.

Glycolysis is the part of the energy production process the Australian 2015 metabolomics study suggested was broken in ME/CFS. If pyruvate doesn't get produced or isn't broken down properly, aerobic energy production gets stuck in first gear; it's simply won't have the resources to get moving. Looking at a diagram, Christopher Snell of Workwell poked a finger at the point where energy production makes its rather momentous shift from anaerobic to aerobic energy production, and said that's where we always thought the problem occurred.

If I have this right (hopefully), then problems with glycolysis then – not aerobic energy production per se – but the part of the energy production cycle that provides the resources for aerobic energy production may be a key in ME/CFS. It's possible that the aerobic part of the energy production process is not damaged in ME/CFS; it's just starved for resources.

Pyruvate dehydrogenase is a main player in carbohydrate metabolism; if carbs aren't available or something is wrong with PDH, it gets down-regulated and fatty acids are used as an energy source. That's what the Australians' data suggest is happening in ME/CFS.

It's also, as the Aussies pointed out, similar to what happens in starvation. In starvation, the level of PDK enzymes increase as the PDH complex stops muscles from using glucose as a fuel and shifts towards using fats and amino acids. Fluge and Mella's unpublished gene expression study suggests a similar pattern is happening in ME/CFS. It also found that men were more likely to grab amino acids from their muscles to fuel glycolysis but women had more trouble breaking down pyruvate to acetyl-CoA.

Genetic problems with pyruvate dehydrogenase do suggest that something like ME/CFS can occur. They are associated with an abnormal build-up of lactate, low energy and severe lethargy. Pyruvate dehydrogenase has also been pegged as a possible factor in primary biliary cirrhosis – a disease Julia Newton has studied extensively – which shares similar fatigue characteristics with ME/CFS.

Fluge warned that the results are preliminary. We certainly have to be careful. We've had several instances of very promising work not pan out recently. Some of Dr. Newton's very promising work was apparently recently upended, and ten years of Dr. Natelson's work went down the drain as well. Both published several studies with positive findings until a larger study indicated the work was all for naught.

It's encouraging that both Fluge and Davis, the Aussies, Hanson and Naviaux are finding similar broad patterns of hypometabolism. Much more is to clearly to come. "We're just scratching the surface", Fluge said. "Give us a year…" and we'll know much more.

#MEAction denounces CBT treatment for CFS

Source: www.meaction.net
2nd November 2016

According to reports in The Guardian and BBC yesterday (1st November), hundreds of young patients in the UK suffering from myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) are set to receive online psychological therapy. FITNET will cost £1million, to be funded by British taxpayers — yet the Dutch study on which the trial is based found no difference in patients at long-term follow-up.

#MEAction, an international network of ME patients, along with other patient groups and scientists from around the world, condemn the waste of resources on such inherently flawed studies. Arguing that an intervention that consistently shows null results at long-term follow-up is not worth pursuing further.

The proposed study – known as 'FITNET' – shares many flaws with the debunked PACE trial, which was described as "the height of clinical trial amateurism" by Dr. Bruce Levin of Columbia University. It was subsequently discovered that scientists misrepresented the efficacy of cognitive behaviour therapy and graded exercise therapy in ME patients — but only after a protracted battle to obtain the open-sourced data.

It's "more meaningless research based on flawed assumptions and bad studies," said David Tuller, of University of California, Berkeley. "What a huge waste of time and money! When will these people let go of their dysfunctional and delusional belief that CBT is the pathway to 'recovery' from this disease? It's complete nonsense."

"Time and again, research has shown that graded exercise and cognitive behavioural therapy are not effective treatments for those suffering from ME," said L.A. Cooper of #MEAction Network UK. "To state that it is curative would be misleading, and ultimately very damaging."

Meanwhile, researchers worldwide continue to forge ahead with ground-breaking discoveries in ME/CFS: Fluge and Mella of Haukeland University have shown that an anti-cancer drug causes remission in a significant percentage of patients; Ian Lipkin and Mady Hornig of Columbia University have shown disturbed cytokine production patterns that differ early versus late in the illness; and numerous researchers in the US and UK have identified metabolic abnormalities in patients that differ vastly from controls, including Naviaux, who memorably stated that patients' cells appear to be in a form of metabolic hibernation. Last year's US Institute of Medicine Report unequivocally stated that ME/CFS is not a psychological illness after critically reviewing over 9000 pieces of scientific literature. The US Agency for Healthcare Research and Quality downgraded its recommendations for CBT and GET, stating that there was not enough evidence to label them effective treatments for ME/CFS.

"We can't continue to feign ignorance and pretend other countries aren't speeding ahead. The concept that ME can be improved with solely behavioural techniques is decades old, and frankly, an embarrassment to the nation's scientific and patient community," added Cooper.

Further information
The Countess of Mar (House of Lords) made an official complaint to the BBC:
http://www.margaretwilliams.me/2016/bbc-complaint-mar-nov16.pdf

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Coping statements for anxiety

Source: http://anxietynetwork.com/content/coping-statements-anxiety
By Thomas A. Richards, Ph.D., Psychologist

Often ME suffers have to contend with situations that they don't know if they are functional/robust enough to deal with. Understandably, that may lead to anxiety. The supplements Taurine and/or Magnesium may help to calm the mind. The following may also prove helpful.

Purpose: to put a stop to the thoughts that lead to anxiety, and to replace those thoughts with realistic, rational thoughts. When these rational self-statements are practiced and learned, your brain takes over and they automatically occur. This is a form of gentle conditioning, meaning that your brain chemistry (neurotransmission) actually changes as a result of your new thinking habits.

First, use thought stoppage. Be gentle but firm about it.

"STOP! These thoughts are not good for me. They are not healthy or helpful thoughts, and I have decided to move in a better direction and learn to think differently." (You are reminding and reinforcing your brain each and every time you make this rational and realistic statement.)

Then, pick two or three statements from the list below that seem to help you, and repeat them to yourself OUT LOUD each day. (You don't have to believe them fully yet – that will happen later).

Statements to use when anxiety is near:

1. I'm going to be all right. My feelings are not always rational. I'm just going to relax, calm down, and everything will be all right.
2. Anxiety is not dangerous -- it's just uncomfortable. I am fine; I'll just continue with what I'm doing or find something more active to do.
3. Right now I have some feelings I don't like. They are really just phantoms, however, because they are disappearing. I will be fine.
4. Right now I have feelings I don't like. They will be over with soon and I'll be fine. For now, I am going to focus on doing something else around me.
5. That picture (image) in my head is not a healthy or rational picture. Instead, I'm going to focus on something healthy like _________________________.
6. I've stopped my negative thoughts before and I'm going to do it again now. I am becoming better and better at deflecting these automatic negative thoughts (ANTs) and that makes me happy.
7. So I feel a little anxiety now, SO WHAT? It's not like it's the first time. I am going to take some nice deep breaths and keep on going. This will help me continue to get better.

Statements to use when preparing for a stressful situation:

1. I've done this before so I know I can do it again.
2. When this is over, I'll be glad that I did it.
3. The feeling I have about this event doesn't make much sense. This anxiety is like a mirage in the desert. I'll just continue to "walk" forward until I pass right through it.
4. This may seem hard now, but it will become easier and easier over time.
5. I think I have more control over these thoughts and feelings than I once imagined. I am very gently going to turn away from my old feelings and move in a new, better direction.

Statements to use when I feel overwhelmed:

1. I can be anxious and still focus on the task at hand. As I focus on the task, my anxiety will go down.
2. Anxiety is a old habit pattern that my body responds to. I am going to calmly and nicely change this old habit. I feel a little bit of peace, despite my anxiety, and this peace is going to grow and grow. As my peace and security grow, then anxiety and panic will have to shrink.
3. At first, my anxiety was powerful and scary, but as time goes by it doesn't have the hold on me that I once thought it had. I am moving forward gently and nicely all the time.
4. I don't need to fight my feelings. I realise that these feelings won't be allowed to stay around very much longer. I just accept my new feelings of peace, contentment, security, and confidence.
5. All these things that are happening to me seem overwhelming. But I've caught myself this time and I refuse to focus on these things. Instead, I'm going to talk slowly to myself, focus away from my problem, and continue with what I have to do. In this way, my anxiety will have to shrink away and disappear.

Panic attacks - what you fear the most cannot happen

Source: http://anxietynetwork.com/content/what-you-fear-most-cannot-happen
By Thomas A. Richards, Ph.D., Psychologist

Although it would probably be fair to say that most people with ME experience associated anxiety at one time or another during the illness, not everyone will escalate fear to the point of a panic attack. However, the following insights may prove useful to know.

As shown by #MEAction's statement on page 4 earlier, CBT is generally rejected as a meaningful treatment for the biological illness ME/CFS. However, this article about panic attacks goes on to mention CBT as potentially useful for Panic Attacks.

A panic attack is a horrible and terrifying experience, but it is not in any sense "dangerous". Panic disorder is actually a natural bodily reaction that is occurring OUT OF CONTEXT.

For example, when we feel our survival is somehow threatened, all mammals have an instinctual response to either fight or flee. This response produces a sudden surge of adrenaline, accompanied by strong feelings of anxiety and panic, and a very intense urge to flee or escape the fearful situation or circumstance.

It is interesting that the intensity of the reaction and the strong urge to flee are things that would ensure your survival if you were truly in danger.

The flow of adrenaline and the resulting extra blood flow increases your strength and awareness of the danger. This extra "awareness" of the perceived danger may cause all sorts of feelings, such as dizziness, nausea, hyperventilation, heart palpitations, confusion, lack of control, unreality, being dazed, shaking, trembling, and sweaty palms, among others.

During a panic attack, your body goes through the same physical processes as it would if you were in real danger. The DIFFERENCE, of course, is that although you feel you are in danger, you really ARE NOT. That you undergo panic attacks -- without knowing why -- only makes the situation much more frightening.

Because of these feelings of panic, it's very common to "invent" or attribute danger to the accompanying bodily symptoms. Remember, though, that NO ONE has ever had these things happen to them as a result of a panic attack:

> **"I'm going crazy"**
> No one with panic attacks and anxiety has ever gone "crazy". In fact, because you realize that you have panic attacks, this is just another indication that you are not going crazy. People that "go crazy" lose contact with reality. Anxiety people are TOO much in contact with reality. Thus, people with panic and anxiety problems NEVER "go crazy". It simply cannot happen.
>
> **"I'm going to pass out"**
> Temporary dizziness leads people with panic to feel that they may pass out. This is not possible because, during panic, your heart beats faster, and your blood pressure rises. As the blood pressure rises, it becomes impossible for you to "pass out". When people faint or "pass out", it's because of a sudden DROP or lowering in blood pressure.
>
> **"I'm having a heart attack"**
> When the heart begins to beat quickly and people experience "palpitations", they sometimes feel a heart attack is occurring. In the first place, the heart can beat quickly and continuously for a long period of time without causing any damage. Although heart palpitations seem to occur in the left side of the chest, there are many DIFFERENCES between panic attack and a real heart attack. During a real heart attack, the primary symptom is a crushing sensation inside the chest and a pain that is continuous.

During a panic attack, the attention is focused on the quick and rapid beating of the heart itself. ("I can hear my heart beating even in my ears!") People having panic attacks are NOT experiencing heart problems. A real heart attacks produces crushing internal pain that doubles people up and drops them to the floor. They DO NOT hear their heart beating nor do they care. The intense, crushing pain is the only thing they can pay attention to.

“I will stop breathing and suffocate”

Sometimes panic people feel that because they can't catch their breath (and are hyperventilating), they will suffocate. This is impossible because you cannot pass out and suffocate. It feels like you can, because the mixture of oxygen and carbon dioxide in your bloodstream is out of proportion. That is why people feel weak, dizzy, lightheaded, and faint. Suffocation is not a possibility during a panic attack. In a few moments, as the body gradually calms down, breathing returns to normal, and the other symptoms gradually go away.

“I’m losing control”

Experiencing many anxiety symptoms all at once can cause a person to feel that they are "losing control" of themselves. Sometimes the fear is of acting nervous and foolish in public where others will be able to notice. Sometimes the fear is of being rushed to the hospital in an emergency vehicle. For other people, it is the fear that losing all control proves they are crazy and may have to be institutionalised. Actually, the fact that you think you could "lose control" guarantees that this is not really possible. The only people who really "lose control" are people who are not aware of this and are not ever concerned or bothered by "losing control".

Although the thoughts and feelings of anxiety and panic are all too real, the brain is being tricked into thinking that you are somehow in danger -- when actually you are not. Part of effective therapy includes realising this, and slowly changing ingrained thought patterns. Another part of therapy is in actually tapping the emotional side itself -- to quiet and relax the mind so that anxiety and panic will have no choice but to eventually disappear.

Active, cognitive/behavioural therapy has been shown by research to be the most effective therapy in dealing with the anxiety problems. Usually, there is no reason to rehash the past and analyse it to death. In fact, the more you think and analyse your problems, the worse you make your condition. (Analysis = paralysis). Instead, a focus on making the present better so that the future is anxiety-free is the best and most permanent course of action to take.

Today, panic is being successfully treated in the vast majority of cases. Active cognitive-behavioural therapy plus a strong motivation and persistence on the part of the client are the essential ingredients in overcoming this major anxiety disorder.

Further reading

If panic attacks are part of your illness experience seeking associated psychotherapy and medication can have powerful results. The following link offers a number of ‘steps’ to work through to improve your coping strategy.

www.anxieties.com/6/panic#.WECdkFzw-30

MEGA research

Source: www.megaresearch.me.uk

I usually avoid articles that are simply about future research. Instead preferring insights that might be useful now. However, the following article introduces upcoming research of a very large scale.

Even in its mildest form, ME/CFS (within the NHS, a diagnosis of chronic fatigue syndrome or ME/CFS is often given) can have a significant impact on an individual's life, and not just on their health. A lack of understanding and awareness about ME/CFS means patients can experience disbelief, and even discrimination, from friends, family, health and social care professionals, and employers.

The ME/CFS Epidemiology and Genomics Alliance (MEGA) has been set up to try and change this by improving our scientific understanding of ME/CFS. We are a group of 15 UK scientists and four patient charities (Action for M.E., the Association of Young People with ME, the ME Association and ME Research UK, with Action for M.E. taking a representative role) who have come together to establish a big data research study of over 10,000 adults and 2,000 children and young people.

Our core aim is to investigate the biology of ME/CFS. This exciting, highly ambitious project is the first of its kind in the UK, and a potential game-changer. It will have to pass through rigorous peer-review in order to secure funding, and requires a multidisciplinary team of some of the UK's most distinguished scientists, with direct input from people with ME/CFS and their carers.

We are recruiting a Patient Advisory Group of 12 to 15 adults with ME/CFS, their primary carers and others with an interest in ME/CFS. Additionally, there will be a children and young people's advisory group, which is an existing group working with the University of Bristol.

MEGA will apply for funding to set up a Bioresource that will be available for all researchers to use. Using samples and data from participants, we will apply a range of biological tests. Analysing this with cutting edge technology, we can then begin to create a picture of the biological process involved in ME/CFS. This will provide the foundation for better diagnosis and targeted biological treatment in the future.

"Knowing more about how biological and environmental factors affect ME/CFS symptoms could show us what we might be able to do to change the course of ME/CFS over time, or even how to change the likelihood of the onset of ME/CFS symptoms in the first place," says MEGA team member, Prof George Davey-Smith. "Additional data in the related fields of epigenetics and metabolomics can tell us about pathways which might be involved, which can also be useful for considering how to alleviate symptoms. At the very least, a large scale study will give proof of principle about the degree to which these -omics approaches are applicable to advancing ME/CFS research."

The problem

What we call a single syndrome (or two if you separate ME and CFS in the way some do) may be a number of illnesses caused by different mechanisms but end up with very similar sets of symptoms. Equally, in common with other common chronic disorders, the problems that cause the initial symptoms may not be the same as those that cause them to persist or cause relapses, such as activation of microglia in the brain causing ongoing symptoms following an initial, triggering, infection. Additionally, the cause/s and ways in which the illness/es manifest in children may be very different.

The scientific community has generally tried to understand what is causing the illness by gathering information to test whether proposed causes deserve further attention or can be ruled out; this is known as hypothesis-driven research. Often, this has been done through small studies using a variety of different methodologies testing so that repeatability is low. It is essential that research findings are validated through replication of studies so the general inability to do this in the ME/CFS causes a significant challenge.

As a result of this scattergun approach, there have emerged a myriad of possible causes that, at different times, have had their supporters. Unfortunately, none, so far, has stood the test of time to provide definitive underlying causes that lead to objective diagnostic tests and treatments. Interesting findings continue to emerge, such as those shared at the recent IACFS conference in the US relating to exercise issues, abnormal biology post exercise and metabolomics, but still need validation. The number of false starts has been demoralising for those suffering from the illness as they search for ways to overcome their debilitating symptoms.

A further problem could well be the existence of subgroups, in which many of the proposed mechanisms may be operative in different individuals, with but with no single mechanism that can explain the disorder in all patients. Small studies are unable to detect subgroups, and if different individual patients have different pathologies, small studies may fail to find anything at all.

So far, no definitive diagnostic tests have emerged and little scientific basis for treating the underlying disease exists. Instead, effort has been made to alleviate symptoms but with varying success.

So, the problem we are faced with is a syndrome which may consist of different diseases with different causes, different factors leading to persistence and relapses, different clinical manifestations and differing natural history or effects over time. This represents a real challenge, but not an insurmountable one.

One solution

Against the sheer complexity of ME/CFS the harnessing of modern technologies offers real promise of finding a solution. The ‘Grand Challenge’ is how to make inroads into this puzzle. There are immensely complex biological processes responsible for how the disorder(s) expresses itself in people. By understanding these, we can use the information to identify cellular and molecular pathways that are involved in the cause of this illness.

This will enable to us to first devise diagnostic tests that use these pathways and then go on to develop effective treatments for them. In order to do this, the technology must be able to reveal the biological processes responsible for the different symptoms experienced by patients and to identify how these differ between individual patients.

To put this more simply: one size will not fit all. The challenge is to work out causation by stratifying (splitting out) ME/CFS into subgroups and then to create a personalised and precise approach to diagnosis and treatment.

The need for a large sample size to discover new molecular pathways

In other complex diseases such as cancers, diabetes, arthritis, asthma, inflammatory bowel disease etc. this approach of starting by looking at all the possible biological mechanisms is uncovering entirely new cellular and molecular pathways and leading to diagnostic tests and potential targets for novel treatments. This broad approach requires large numbers (thousands) of affected individuals with varying disease severity and ‘controls’ (participants without the illness). All of these people need to have their specific symptoms characterised, given physical examinations and laboratory tests using standardised approaches (standard operating procedures) so that this can be replicated.

It is important to emphasise here that in order to compare tiny differences, any study will require very large numbers of volunteers (over 10,000), with a range of severities. Additionally, it will need to include people who do not fit one of the commonly used closely defined definitions, so that the science can determine the definition of the key subgroups. If clinical and routine laboratory information has been collected from each patient using standardised procedures, then powerful statistical approaches can be used to identify separate clusters of people each with their own characteristic features.

For further information please refer to the ‘source’ listed at the beginning of the article.

I won't apologise for having fun while chronically ill

Source: https://themighty.com/2016/08/why-i-wont-apologize-for-having-fun-while-sick/

When I was six, I was hospitalised with Rocky Mountain spotted fever. At the hospital, I was encouraged to get out of bed, get dressed and spend as much time as possible in the playroom. I brought magazines and books back to my room to read and played with other kids who were up and about on the paediatric floor. There was a girl in the next room with leukaemia, and we made faces and waved to each other through our shared window. The fact that I was able to play didn't mean I wasn't sick enough to be hospitalised. It meant that regardless of my illness, I was a child with the same needs and wants as other children.

Yet, with adults, the same concept doesn't seem to hold true. Whenever ill people do — well, anything — it's taken as "proof" that we're bluffing about our condition. Many of us are confronted by complete strangers on a regular basis when we go out in public, on everything from using parking placards to requesting ADA accommodation at events. We're challenged more by people we know, who should really know better.

After I became ill, I decided to go to my favourite theme park one day. I didn't do much; it was a very sedentary experience. I posted a photo of myself on one of the rides on Facebook with my germ mask on backward, slept for days to recover from my adventure, and didn't think much of it. A few days later, my Mom called me about it. A "family friend" had seen the photo and was furious about it. She'd apparently complained to several people that if I was at a theme park, I was obviously well enough to be working and was pulling some sort of scam. It had gotten back to my mother.

I promptly unfriended and blocked the person, but their actions stayed with me. For most of the next year or so, whenever I posted a photo of myself doing anything fun, I looked over my shoulder. I always made a point of describing how sick I was and how I'd needed to rest, and how tired I was afterward. I felt the need to qualify what I was doing; to verify that I was still ill, and to remind everyone that there was more to the truth than what was visible in the photo. Someone's ignorance and unkind judgments had made me feel guilty about enjoying my life to the best of my ability and upset my mom, and that was unconscionable.

It often seems that there's no real way for chronically ill people to win this battle. Hostile individuals who don't want to believe that you're really ill will find fault with anything you do. There's no way to appease them, regardless of how you live your life.

Some chronically ill people are able to exercise, some are not. Some of us are encouraged to be physically active in some way to help us maintain function (I have a series of physical therapy exercises to do every day to help with some specific orthopaedic issues, for instance). Yet, if you're seen being physically active in any way, it's taken as a sign that you're not sick after all. Society likes to applaud those Olympic athletes who fight through their illness or disability to compete. If you fight through your illness or disability to do something physical sometimes, such as a 5K or dance performance, it may be seen as proof that you're a fraud.

It's widely accepted that having a strong, supportive network of friends and family is helpful to those who have chronic illness. We're told that for our own well-being, we should get out of the house once in a while. However, if we dare to go out in public with friends or do something fun occasionally, again, some will believe we're not sick. And if we spend one afternoon at the movies now and again, it somehow equates to being able to spend 40 hours a week, 50 weeks a year, at work.

If you live alone or don't have a lot of support, you still have to take care of daily tasks, but something as simple as buying your own groceries might actually be seen as proof you're able-bodied.

If you are too exhausted or hurting too much to shower, do your hair or dress up you've let yourself go; if you go out with makeup and styled hair, well, you're obviously not sick because you don't look sick.

If you post photos on social media where you're looking well people will think you're not ill; if you post photos of yourself undergoing treatment, you'll be accused of being an attention seeker.

If you tell someone about the progressive course of your illness, you're faking it because your Aunt Edna's son's niece had the same condition and she's fine now.

Social media photos and observations of chronically ill people smiling and looking "normal" or doing errands have even been used to deny or remove disability benefits, which is quite possibly the most troubling thing of all. It's hard to understand that disability determination specialists, doctors and government benefits administrators — people who supposedly are knowledgeable about a wide range of health conditions — don't accept the concepts of good days, payback and invisible illnesses that do not always have linear trajectories.

Nobody ever seems to consider what's happening outside and around that Facebook photo they're snarking about. The fact that it might have been the first time in weeks that chronically ill patient got to do something really fun eludes them. They don't realise how much those activities cost in terms of pain, fatigue and reduced function. They look at one photo or one Facebook status about one day and think they're an expert on your life.

I'm not sure what these people think we're supposed to do every day. We have incurable chronic illnesses. We often spend most of our time either at home or in treatment as it is. We're often exhausted and in a lot of pain. If we're not able to work full time, are we supposed to forgo any and all moments of joy, distraction, social interaction or enjoyment? Will that help us in any way? Being sick is extremely hard for many of us. It's even harder when hurtful, judgmental types decide that illness should invalidate the fact that we have the same needs as anyone else. Instead of telling chronically ill individuals to shake off comments and accusations, maybe the onus should be on these hecklers to refrain from making them and mind their business. Is it really that hard to leave other people alone?

Eleanor Roosevelt once said: "Do what you feel in your heart to be right — for you'll be criticised anyway." I've taken those words to heart when it comes to interacting with others about my chronic illness. I am no longer particularly nice when I'm confronted by impromptu judges. Every once in a while someone honestly doesn't understand, and politely and succinctly explaining a few things helps them. More often, though, they've already come to their own conclusions and nothing I say is going to put a dent in their hostility. I won't waste my time trying to justify myself to random strangers and mean-spirited acquaintances who have appointed themselves judge and jury of my life.

I can't stop others from thinking whatever they want about me. However, I can and do refuse to comply when someone demands apologies, guilt or justifications from me for getting out of the house once in a while. Anyone who decides that chronic illness somehow invalidates my needs as a person — including my needs for happiness and socialization — isn't getting an iota of my concern.

The Guildford & West Surrey ME/CFS Group newsletters aim to inform members of relevant news and treatment options. Use of the treatments is done at your own risk.