

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Stakeholder and Communication Conference Call

June 3, 2019

3:00 pm EST

Coordinator:

Welcome and thank you for standing by. At this time, all participants are in a listen-only mode for the duration of today's call. Today's conference is also being recorded. If you have any objections, you may disconnect at this time. I would now like to hand the meeting over to Dana Brimmer. You may begin.

Dr. Dana Brimmer:

Thank you. Good afternoon, everyone. My name is Dana Brimmer and I am a contractor working with the ME/CFS program at the Centers for Disease Control and Prevention. On behalf of the program, I am pleased to welcome you to today's Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, ME/CFS, Stakeholder Engagement and Communication Conference Call, also known as SEC.

Our primary purpose here is to share information with a large number of people who have interest in ME/CFS as part of our regular outreach and communication activities. Before we get started, I want to review how the SEC call works. As a reminder, there is no need to register or RSVP for the call. For today's call, we'll have a Webinar format in addition to the option of the telephone lines.

We have added this option in response to several requests we have received and as a way to make the information more accessible. Participants can still dial in using the 800 number and use the participant code provided in the SEC announcement email or also

found on the CDC ME/CFS website. To participate using the webinar format, click on the link that can also be found in the SEC announcement email or on the CDC website.

Please note that if you do participate using the Webinar format, you will need to use headphones plugged into your computer to hear the audio portion or you can use the 800 number, which is audio only, and then use the Webinar to see the slides.

Notification of calls will be sent by email and information is also posted on the CDC ME/CFS Web site. Due to the large number of call participants, we are unable to have call lines available in speak mode.

Therefore, we take questions via email using the ME/CFS SEC email. Note that this email address is used solely for these calls and is not monitored at other times. Please note that due to time constraints, CDC staff and the guest speaker will not be able to answer all questions, but the CDC ME/CFS program looks forward to reading all of the questions.

Our guest presentation today is entitled, "Pacing in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia" by Alison Bested. Before Dr. Bested begins, let's first hear from Dr. Elizabeth Unger, chief of the Chronic Viral Diseases Branch at CDC. She will provide updates about CDC's ME/CFS program. After Dr. Unger and our guest speaker finish, we will answer questions submitted via email. I will read the questions out loud and then our speakers will answer each one.

Before we begin, I need to read a short disclaimer. These calls are open to the public. Please exercise discretion in sharing sensitive content and material as confidentiality during these calls or items submitted via email cannot be guaranteed. Today's call is being recorded by the CDC and transcripts will be made available at a later date on the CDC Web site.

The views of non-CDC presenters expressed during this conference call are their own and do not necessarily represent the views of the US Department of Health and Human Services or the Centers for Disease Control and Prevention. I'd now like to ask Dr. Unger to start the call. Welcome.

Dr. Elizabeth Unger:

Thank you, Dr. Brimmer, and welcome all. Just as a reminder, we began these calls to have a forum for regular communication and engagement with the ME/CFS community about CDC's activities and to provide a forum for external experts to share information about their work related to ME/CFS. We are extremely appreciative of our speaker's willingness to accept our invitation to participate. Our outside speakers volunteer and independently prepare their remarks. The speaker's findings and conclusions are their own and do not represent CDC's official position.

If you have suggestions for speakers or for topics for future calls, please send them to the SEC call email and that is ME/CFSSEC@CDC.gov. This is also the address to use if you'd like to be added to the listserv to receive email notification about upcoming calls. A list of prior calls is available on CDC's ME/CFS Web site under the meetings tab. You can also find transcripts for calls that you may have missed.

Our plan is to have four SEC calls a year. Today is our second. And I'm happy to be able to announce that our third call will be on September 16th and will feature ME/CFS expert and Harvard Medical School professional, Dr. Anthony Komaroff. This presentation will be entitled, "The Biology of ME/CFS Emerging Models."

I'll now like to shift to give you an update on some of CDC's activities starting with ME/CFS Awareness Day activities.

May 12, 2019, marked the 27th annual observation of the International Awareness Day for ME/CFS and Fibromyalgia. CDC, once again, participated in this observation in a

variety of ways including four tweets posted on May 11th and 12th that promoted information on CDC's ME/CFS Web site. Tweet - three were tweeted through the Twitter handle of our center and that is @CDC_NCEZID. And one was tweeted by our national center director @DrKhabbazCDC. Our most accessed tweet used the image (called) faces of ME/CFS, which was contributed by the Solve ME/CFS organization. Also, in support of ME/CFS Awareness Day, we relaunched the video entitled, "Missing my life," in both English and Spanish. It was a public service announcement that we updated. Within two weeks of its launch, it had about 2,300 views. The video is also available from CDC-TV Web site.

Additionally, we posted an article on CDC's feature page to raise awareness about ME/CFS and lend support to those who have been affected by this illness. This page is hosted on the main CDC site and reaches a wide audience. This year, the feature piece drew attention to how families, schools, healthcare providers, and the general public can help those suffering with ME/CFS.

We also updated the previous Public Health Matters blog entitled, "ME/CFS, making strides to enhance the lives of those living with ME/CFS." Lastly, CDC's ME/CFS program staff showed their support for Awareness Day by wearing the international ME/CFS color blue and taking a group photo.

Now I'm going to shift to provide information about our educational activities. Continuing our partnership with Medscape in late February, we launched a new continuing education course entitled, "Diagnosing ME/CFS, the Experts Weigh In." This features expert panelists, Drs. Lucinda Bateman, Natalie Azar, Nancy Klimas and Jose Montoya. Within two months of launch, about 5,600 learners accessed the course. Of these, about 1,900 learners took and 1,850 passed the test to earn continuing education credits. Medscape also hosts the CDC expert commentary series. That series recently featured my commentary on ME/CFS that emphasized the problems patients

face and challenge healthcare providers to learn how to diagnose and manage this illness.

We are also collaborating with Medscape to develop two more ME/CFS courses using the methods of clinical practice assessment and test and teach. We will update you on progress in the upcoming calls.

During our March call, I updated you about our collaborative projects with the Georgia Chapter of the American Academy of Pediatrics and the National Association of School Nurses. I'm excited to share the progress related to the educational component of these projects. Through Georgia AAP, Dr. Robert Pendergrast, professor of pediatrics at the Medical College of Georgia, educated pediatric nurses about ME/CFS through his May 17th presentation to the Georgia Pediatric Nurses Association entitled, "ME/CFS in youth, impact on kids and families."

Also sponsored through the Georgia AAP collaboration, Dr. Peter Rowe will speak on "Update on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in Children and Adolescents" at the Pediatrics by the Sea and Pediatric Coding Conference, June 14, 2019. The preliminary program agenda for this conference can be found at the Georgia AAP Web site, GAAP.org.

We also have another continuing education event planned through the National Association of School Nurses. Dr. Kenneth Freedman, Beth Mattie, Dr. Faith Newton and Michael Newton will speak on ME/CFS, school nurses, improving student outcomes, at the 51st annual conference of the nurses in - June 27th in Denver, Colorado.

Now I will shift to the update on the multisite clinical assessment of ME/CFS studies, also referred to as MCAM. In the interest of time, I'm only going to touch briefly on a few items. As a quick review, the study design required the use of a standardized approach

for collecting information on patients participating in the study at their respective sites. The MCAM study information can be found on CDC's ME/CFS Web site under the programs tab.

In early April, we closed out the enrollment and data collection for four areas of the study - the ME/CFS longitudinal adult cohorts with homebound and (incident) cases and (healthy) controls, cognition and exercise testing and the (natural killer) cell function assessment. Over the past few weeks, we have received a final beta delivery from sites and our data management team is currently conducting checks on the quality of data collection and entering the remaining portion of the hardcopy data. We will begin cleaning, processing and merging the data in the next few months. While we still need time to look over everything, we have an analysis plan to help us prioritize the results for dissemination.

We are committed to publishing in peer review journals and will be sharing study information at conferences. The MCAM publications will communicate and educate readers about ME/CFS and the clinical findings of ME/CFS experts. This approach to bringing about improved clinical care is made possible by the MCAM study participants and we are deeply grateful for their help.

The MCAM extension study, focusing on children and adolescents with ME/CFS and adults with other chronic conditions showing some similarities with ME/CFS, referred to as the ill comparison groups, are ongoing. We will update you on the progress for this part of the MCAM study in upcoming calls.

I'd now like to shift to our surveillance activities.

During our last call, I mentioned the behavioral risk factor surveillance system, BRFSS, and the inclusion of ME/CFS specific questions in the survey. The ME/CFS module includes the following three questions –

1. Have you ever been told by a doctor or other healthcare professional that you have Chronic Fatigue Syndrome, CFS, or ME, Myalgic Encephalomyelitis?
2. Do you still have CFS/ME?
3. And thinking about your CFS or ME during the past six months, how many hours a week on average have you been able to work at a job or business for pay?

Leveraging BRFSS is a cost-effective way to track ME/CFS over time. It provides an opportunity for long-term sustainability and monitoring ME/CFS at state health departments. In April 2019, our program participated in the BRFSS closeout meeting for grantees and promoted the use of ME/CFS module. This meeting with public health epidemiologists and representatives from state health departments, also included a poster session that allowed us to share some of the results from analysis of data from the 2014 and 2016 state-added ME/CFS questions.

The first poster showed how BRFSS provides data for tracking ME/CFS prevalence and risk factors. The second poster shared the information on the burden of multiple chronic conditions in people with ME/CFS.

In the interest of allowing more time for our speaker, I will close with noting that we are continuing to work on developing ME/CFS educational materials and on enlisting partner organizations to educate their members about ME/CFS through their regular activities. This concludes our updates. And thank you so much for your attention and participation. At this point, I would like to turn the call over to Dr. Brimmer so she can introduce our guest speaker.

[Dr. Dana Brimmer:](#)

Thank you, Dr. Unger. I'd now like to introduce our guest speaker. Dr. Alison Bested is chair of integrated medicine at Nova Southeastern University and the clinical director of the Institute for Neuroimmune Medicine Clinic. She's also director of student research, Nova Southeastern University in Miami, Florida. Before coming to Florida, Dr. Bested

worked at the Environmental Health Clinic and the Complex Chronic Disease Program at BC Women's Hospital Clinic, both in Canada. She's the author of several books and numerous publications. Welcome, Dr. Basted.

[Dr. Alison Basted:](#)

It's a pleasure to be here. Thank you so much, Drs. Unger and Brimmer, for having me today on the session. And if it's okay with you, I'll begin now.

[Dr. Dana Brimmer:](#)

Great. Thank you.

[Dr. Alison Basted:](#)

Today, my topic is about pacing. And the reason I chose pacing is because I have found, as a clinician in seeing patients for the last 26 years, that pacing is one of the fundamental learning skills that, if learned, really helps patients to conserve their energy and to heal their bodies and improve over time.

So, today my talk is about pacing, how to learn to stop crashing, and increase your energy in Myalgic Encephalomyelitis or Chronic Fatigue Syndrome and fibromyalgia. I have no disclosures. I like to acknowledge my mentors, Drs. Marshal, Bray, Kerr, Melott, McClenon and Stine. These are the Canadian clinicians that I worked with for many, many years who helped to support me as I learned about patients with ME and FM.

And also where I'm working now, at the Institute for Neuro Immune Medicine Nova Southeastern University, both Dean Wallace, who has a vision of an integrated medicine program and Dr. Nancy Klimas, who I've known for many, many years, and our clinicians on staff, Dr. Vera, nurse practitioners, Violetta and Irena, and in particular, to my patients who continue to amaze me with their grace under pressure and who continue to be my teachers and who inspire me to continue to learn.

The goals of today's talk are basically looking at ME, fibromyalgia and basically chronic physical illness to basically try to improve the current symptoms that patients have, including their functionality and quality of life. And secondary, to prevent worsening of the presenting chronic complex medical conditions over time, which can happen if these conditions are not dealt with consistently and properly.

So, as a beginning, I'll look at a couple of examples of made-up patients but have sort of the criteria. Judy, aged 52, she started after a fourth whiplash injury in her car when she was rear-ended. She was driving her car and then, six months later, she developed pathological severe fatigue. Her energy was only four out of ten with nine to ten out of ten being normal on the function of the PACE scale, and she had post-exertional fatigue. Her sleep was non-restorative. She went to bed tired and woke up tired. She had pain in her muscles all over her body. She had a brain fog and poor memory and she felt dizzy when she stood up.

Contrast this with Noelle, who was age 56. Her problems started with when she developed a flu at the Christmas party where everybody got sick. There were ten of them in there. Nine of them got there better and she continued to get sick. Six months later, she had severe pathological fatigue with her energy of four out of ten and post-exertional malaise, which is the feeling of the flu and severe fatigue together, nonrestorative sleep, pain in her muscles and joints, brain fog, poor memory, and she also felt dizzy when standing up.

So to begin with, the first lady, she had fibromyalgia. She satisfied the criteria. She had widespread pain, pain above and below her waist. She had 11 out of 18 positive tender points. (Those are the old criteria). There are newer criteria out, but to simplify it for this talk, I'll just stay with the old criteria.

She also had fatigue, sleep dysfunction, neurological manifestations, which meant she had difficulty remembering, difficulty concentrating and she had autonomic and neuroendocrine symptoms, which included difficulty feeling dizzy when she stood up, and she had morning stiffness.

And these satisfied one of the definitions of fibromyalgia which was written by (Jane) in 2003. And there are numerous other criteria for fibromyalgia, as I mentioned previously. But for this purpose, we'll have this particular definition. And these are the particular locations of the fibromyalgia tender points. And this lady had 11 out of 18 which satisfied the criteria for making the diagnosis of fibromyalgia.

Just to be knowledgeable about the fibromyalgia tender points, so they can be present all over the body, from the top of the head to the bottom of the feet. So these were the common 18 that they found most prevalent in people when they came up with the (initial) criteria for fibromyalgia.

And in looking at the ME/CFS clinical criteria, the second lady satisfied these criteria, clinical criteria. She had severe fatigue, both severe physical and mental, and post-exertional fatigue and she had also malaise. She has sleep dysfunction. She had problems waking up in the morning. She didn't feel rested. She had pain. She had the neurological symptoms again of the brain fog, difficulty thinking, concentrating. She had some of the autonomic and neural immune symptoms. And she had the symptoms for greater than six months. She was an adult. If it was a child, that would have been for three months. So she satisfied the criteria for ME or CFS. And then there's the newer criteria by, which - or by the Institute of Medicine, which is called SEID or Systemic Exertion and Intolerance Disease.

This is another clinical criteria that's a bit shortens and it basically - the criteria for that are impaired ability to maintain pre-illness levels of occupational or personal activities, lasts more than six months, not improve with rest, post-exertional malaise, which is the

flu-like feeling that you have, and unrefreshing sleep, plus one of cognitive impairment and orthostatic intolerance. So she satisfied these criteria also.

So what are the commonalities between ME and FM? They both have fatigue. They both have nonrestorative sleep. They can have pain in the muscles and joints. These are often fleeting. There is not redness or swelling but there is pain from the patient's perspective. There is cognitive dysfunction, brain fog, and poor memory. And [there] is also a parasympathetic or sympathetic nervous system imbalance.

This is noted when the patients stand up. They feel dizzy. This is called the HPA axis problem, which stands for the hypothalamus pituitary adrenal problem. So there's a problem with the brain maintaining the blood pressure when a person stands up. Normally your blood pressure goes up when you stand up, but in patients with ME, this does not happen and this can be called orthostatic hypotension.

And some people have what's called POTS, which is postural orthostatic hyper/hypotension as well. And they might have also with it, tachycardia syndrome, which is what the TS stands for. So just a quick overview, physically, this is a physical disease, ME. So this is to show you physically where your symptoms are located, where they come from. So your brain dysfunction, so you have cognitive problems, difficulty with memory, sleeping, anxiety. The HPA dysregulation, which comes from your pituitary into your other endocrine glands. You have pain that can be a new headache or migratory muscle and joint pain. You have autonomic dysfunction with problems with maintaining your blood pressure. And there is also problems with low blood volume and low red cell mass.

There is immune dysfunction. I'm pointing here at the hips where in adults, where that's where your bone marrow is very active. And we know physiologically there's decreased natural killer cell activity and a host of other problems which I'm sure Dr. Komaroff will go into great detail about. And then there's post-exertional fatigue. There is abnormal

metabolism and this is - this arrow is pointing to the muscles here, showing that the mitochondria do not work properly and that there's difficulty producing normal energy and often the aerobic metabolism is impaired as shown by the two-day bicycle (ergometry) testing.

And in patients with fibromyalgia they, again, have the cognitive problems, sleep. There might be anxiety present as well. And there might be anxiety present in ME as a result of illness. There's widespread pain we know in FM, in the muscles. There also might be autonomic dysfunction where you get irritable bowel syndrome. There might possibly be the presence of autoantibodies.

This is being explored currently and we'll have more information, I'm sure, over the next couple of years. And we know there's post-exertional fatigue in patients and they have morning muscle stiffness as well. So there's a lot of commonalities.

So I just want to draw this to your attention. This is the link to, "Unrest," a documentary. In this particular snippet shows Jennifer's birthday party. I won't show this in the interest of time, but if you have not seen the documentary, this is about a collection of people and their families and their loved ones and how their journey has been dealing with ME. And I think it's a very touching story. If we have parents or family members or friends that don't understand ME, I think this is an excellent movie for you to watch with them and they'll get a much better idea of how profound the ME can be.

So, the key for making - helping patients, is basically making the diagnosis for ME. ME and CFS are both - and fibromyalgia - are all physical illnesses and it really helps if the physician that you're seeing has a concept of these things and what can help.

So today, we're going to be looking at supportive symptomatic care. As you know, there is not one drug for this illness, either ME or FM. However, patients can be helped with ongoing supportive care. And the management strategies including - include improving

symptoms, functionality, and quality of life, secondary prevention of the worsening symptoms or of the complex chronic condition and also supporting the family and the patient's family because they are the caretakers and they also can get burned out as well.

So the approach that we take in dealing with these patients is the holistic approach. This is the multiple determinants of health and the source is from the World Healthcare Organization. And it's basically looking at the person as a whole, so look at the person in terms of their social network. What income do they have? What gender are they? What kind of healthy environment do they have? Do they have problems in their physical environment?

So looking at the patient as a whole is absolutely essential in treating both of these illnesses. Adaptation is the process in which the body attempts to sustain the balance within. And in both these illnesses, and the balance is unbalanced. So, it's time to get the patient's body rebalanced over time and through supportive measures.

So, this is looking at homeostasis of the body in general. Then looking at what's called the SEEDS of health. And the SEEDS of health look at, again, the entire body. So "S" is the support the person has, either dealing with a sick child or being a teen in school. One of the "E's" stands for exercise. Is the person sedentary, deconditioned? Are they overtraining on the other hand? The other "E" stands for the environment, what kind of an environment is the patient in? Is it a polluted environment? Is there food and water available and is it healthy? Are there any other infections that are ongoing that the person has? The "D" stands for diet. Is the person, getting food on the table, having access to food. We know that 25% of patients do not have access to food when they have ME and FM. And the "S" stands for sleep. We know that there's a sleep disturbance with this, so is it basically also insomnia, basically unrestful sleep and is there an upset in circadian rhythm?

So, this is called the SEEDS approach of health. We call it the weeding out known aggravators or stressors, planting the seeds of health which looks at, again, the sleep, “E” stands for exercise, and this is where pacing fits in. “E” is also the environment or diet and drugs. And “E” is also the support for the family and socially, and occupationally and spiritually. So the idea is to feed the seeds and nurture whatever can help the person.

So, today we’re looking at the exercise part of this or the pacing treatment. So basically there is impaired function or fatigue, post-exertional fatigue or malaise, which is PEM. And this is what happens when patients with both ME and FM push themselves beyond their available energy. So the way to begin to correct this is use activity logs, possibly Fitbits, looking at their steps, learning to alternate activity with rest periods, and learn to stop pushing yourselves and stop the crashing.

And how you do that is to learn your body’s limits. And as you basically learn your limits, your limits slowly expand if you stop crashing and also the idea is to keep your heart rate low so you do not want to be pushing like you used to and get into that aerobic threshold. You want to avoid that. And you want to avoid aerobic exercise because your body’s muscles do not work well anymore and they do not have the capacity to exercise at that high heart rate level.

So that’s why you need to keep your heart rate level low so that you keep within your body’s energy availability. So this is using Dr. (Lenny Jason)’s envelope idea and applying it clinically to patients. So the pathophysiology in ME and CFS, we know that there is impaired aerobic metabolism, as shown by the two-day bicycle ergometry testing.

And in fibromyalgia, we know there’s abnormal small nerve fibers and abnormal pain pathways. So this is the essence of the physiology behind why you’re having difficulty moving and exercising.

So I want to introduce you to the idea of the activity logs and the functional capacity scale. The idea is to incorporate an energy rating, look at activities and also look at your symptoms or emotions on the reverse side of the also find it helpful. So it's a way to look at what you're doing and to record it to figure out what's working and what's not working and try something else.

This is an activity log. It's blank, as you can see. On the top, it shows the days of the week, Monday through Sunday. It also asks you to write in sleeping, the number of hours you slept so it could be zero to ten or even more and also the quality of your sleep. So gives you an idea, a record of your quality of sleep. And then going vertically are the hours in the day and these can be adjusted if you're not particularly on the daytime schedule. If you're on the afternoon schedule, you can change this.

These are available on our Web site and the reference is at the end of the slides. But this basically, on these slides you'll see in a second, you fill in every box with a one-word activity and also number from the activity from the energy capacity scale.

So this is a typical normal person, so normal energy is nine or ten out of ten. This person has energy, as you can see, every day in the morning, nine out of ten, and every day in the evening, nine out of ten. They have excellent sleep. The numbers put up here, were only the quality of sleep. They had five across the board which means you wake up in the morning and you feel restored and you feel ready to go again.

And this person was capable of exercising whenever they wanted, so they were basically doing 60 minutes, four times a week. So in this time, I just gave an example, so they went and they had energy - energy was nine out of ten, which is yellow, and they could go do things all day long. And the blue represented the sleep. So, this person had normal ongoing energy all day long and had no problems doing whatever they

wanted whenever they wanted to. So, that's what normal energy looks like in case you've forgotten, so in case it's been a while.

This is a functional capacity scale. Myself and Dr. Lynn Marshall came up with this because we found that patients said that they were feeling better and we thought they were better and they wanted to go back to work.

And we sent them back to work and after about three months, when they were sent back to work, they came back to the office and they said, "I crashed." And I went - so then I very sheepishly looked at my notes and I said, "Gee, I thought you said you were better and you were doing all of these things," and definitely they were doing all of these things.

But they did not have the energy to sustain them to go to work. So we came up with this capacity scale that's basically, based on an occupational health capacity scale, describing physically what you can do and mentally also what you're capable of doing.

So what we discovered was that we were sending people back to work and energy level of six which meant they could basically - had good concentration, 45 minutes at a time, and they could walk 20 to 30 minutes a day. But when they were sent back to work, they crashed because, when you go back to work, you literally need an energy level of at least an eight in order to sustain full-time work.

So we did this looking back at our patients and trying to figure out what they could do and what they couldn't do. And the scale has since been validated against several different scales and it's found to be the most specific in terms of being able to distinguish good days from bad days in people. And we compared it to the short form 36 and the other (cronoscopy) scales and it's much more sensitive, so we are tending to use this on an ongoing basis here in the clinic.

So, you have limited energy and the energy you have you can spend it in three different ways. You can spend it physically, for example, by going for a walk, or walking within your house or going grocery shopping. You can use it mentally by paying your bills or being on the computer, doing emails, facetime. Or you can spend it emotionally, if you fight with your mother or husband, or kids, whoever.

But because your energy is so limited, once you've spent it, it's gone. So, this just brings to your attention that, once you spend your energy once, you cannot spend it again because it is so limited. So, what happens in - over time, is if you continue to push yourself and you crash, because when you push yourself, as you know, you spend the next hours to days to weeks in bed to recover.

So what happens if you continue on that pattern, over time, you're pushing and crashing. Over time, your energy gets worse and worse and worse. Whereas, if you pace yourself and you learn not to use up all your available energy and you learn not to crash, you still do have some good days and bad days, which is signified here, but overall, your recovery pattern looks like this and you improve over time. So in order to do pacing, I want to introduce you to a new concept for some of you, which is called rest. Even though you're lying down, I know you're not resting. So rest for this purpose means lying down with your eyes shut, either meditating or sleeping.

Why is this important? Because we know with ME/CFS that you tend to basically push yourselves until you crash. And when you do that, what happens is you reactivate your viruses that are normally kept in check by your immune system and they reactivate and that's part of the crashing, that's part of that malaise that you feel, that flu-like feeling, because your viruses have been reactivated.

And it takes time for your immune system to put those viruses back in check and it takes time for your body to recover. So this is why it's so essential for you to avoid crashing. So in order to help you to relax, it really is helpful if you learn the relaxation

response, which was initially brought to our attention by a doctor in Harvard, Herbert Benson.

He went over to Tibet and he studied the Tibetan monks and tried to discover how they could manage to keep their heart rates so low that sometimes, and other times they raise their body temperature so high that they could literally dry themselves using their physical energy while they were lying in the snow to dry their robes.

And that was the initiation and that was how they passed their test to become Tibetan priests. So these people have mastered it and we can learn how to do what we need in this response, basically help ourselves.

And why is this important? Because when we meditate or when we have the relaxation response, there are two elements to it. We basically have controlled breathing and we give our brains a break. And by doing that, we rebalance. We have a homeostatic rebalance so we go from adrenaline overdrive, which is what most patients are in all the time. They're pushing themselves and they're using their adrenaline to get every little thing done.

And instead, this basically helps to put the body more into the parasympathetic, which is the rest and digest mode to help the body. That's the healing mode because the pushing mode is the adrenaline overdrive mode. And this is the fight or flight mode. And this is what too many people in our society and patients, in particular, are in all the time. So in order to heal, you have to give your body more time to rest, digest, and heal itself.

And basically, some of you out there got to the state because you basically were adrenaline junkies in the first place. You liked that feeling of pushing yourself all the time. And I'm sure if I had a show of hands, a fair number would have raised your hands if I could see you in person.

So again, just to remind you, your energies can be used once and it goes either physically, mentally, or emotionally. So take control of your energy. Use the tool. Learn to pace. This is the pacing tool. So, again, this is what normal used to look like. And this is what a patient of mine looked like when he was basically about halfway through the time with me. So this is filled out. I'm just going to go through the days of the week. So you can see the rest is in blue and the white are actually what he is doing throughout the day.

And as you can see, this is Monday, so he had rest throughout the day. Tuesday he had rest throughout the day. Wednesday he's missing some rests in the afternoon. And it puts - and you can read and hear it says movie and a dinner. And he circled at the end and he said "too much." And then Thursday he had some rest throughout the day. And then he said, "I don't remember what I did on Thursday." And I said, "I know what you did on Thursday. You crashed in your bed."

And he goes, "You're right. I did." So this is just to show you that sometimes you don't crash immediately the day after you've overdone it for your energy level, which his energy level was four or five, and some days he was a six. But sometimes you can have delayed crash by a couple of days, so he crashed the second day afterwards.

So this is what the crashing pattern can look like in a symbolic way. So, the blue represents sleeping or rest. The yellow represents the person's normal energy level for them, which is down to four or five. And the orange represents the lower energy level, so this person, as you can see, on Monday, they had activity, rest, activity, rest. The next day they rested a bit more as you can see here, at 1:00, rest.

And the Wednesday they went, oh, I'm back. I'm feeling so much better. So they missed one rest period here. That's one hour. They missed another rest period here, two hours. They continued on here, three hours, and they had an extra hour here, four hours. So for an extra four hours of activity, they had three days that they crashed in bed.

So you can see this is the lower-level of energy with resting most of the day. So this is what happens with most people. On a better day, they basically use up more energy and they don't continue - they stop pacing and then they crash for three days. So the key is, on the better days, to keep having the rest periods throughout the day to avoid these three days of crashing periods. And that way your body basically has to pay back what you've overspent.

So it's like having money in the bank. So, on a good day, you pay your loan, your energy loan back. Otherwise, if you push yourself, your energy loan gets bigger and bigger over time. And this is what a recovery pattern can look like. You can see this person's energy is continuously six out of ten on the functional capacity scale. They rest throughout the morning and they rest throughout the afternoon.

So their energy goes from a six in the morning to a five at night. And they can - by doing that, they're able to walk consistently daily. And this is what is so essential. You need to basically have some time to start to slowly rebuild your muscles for whatever - at whatever level you're at.

So, the energy, ideally, some of the energy that you're spending here should be spent time walking or whatever you're doing. If you're in bed, doing range of motion exercises or whatever is appropriate for your energy level.

But it just shows that over time, this person was able to plan activities in the morning, lower-level of activity in the afternoon which would be a five, but they were able to get their walking in every day. So this shows a person whose energy level was lower. The energy level was one to two, occasionally four to three, and they were resting mostly throughout the day.

But over time, this person managed to improve and became more threes and fours and then fours and fives. This person started off with an energy level of three to four. And her reds are in pink. And as you can see, her energy levels were six to seven out of ten. But she managed to basically get in walking throughout the day, up to 45 to 60 minutes. So her energy level had improved dramatically from the time that she initially saw me.

So how do you do this? It's awareness, is number one. You record your activities hourly. You can't put it off until the end of the day because, by that time, you'll have forgotten what you've done. So, you need to keep your activity log either on a piece of paper next to you or on your iPhone or iPad and you need to record it throughout the day as you go.

By doing this initially you'll find your best time of day and your worst time of day. And you need to ideally listen to your body and stop before you crash and plan for health. So how do you do this? This is basically my addition to the ideas on pacing, and I call this the Bested pacing method because it's really mind, body, medicine.

And what you need to do as a patient, if you need to close your eyes and ask yourself out loud - you need to say it out loud – “Body, in this moment, what I need?” And your answers will be either activity or rest.

And then basically, you need to scroll through the timetables. How many minutes can I go for walk - one, two, three, four, five? How many minutes do I need to rest - 10, 20, 30, 40? And then ideally you need to set a timer either on your phone or a mini timer you can buy at the dollar store and you need to basically honor that. And that's the hardest part, as basically saying, yes, I'm going to listen to what my body needs for it to do.

Because most of us have lists in our brain. We want to just get things done. But this basically honors your body and says, yes, there's a problem with my body. I'm going to

help it to heal. And then the next thing you do is basically you say how many times can I do this? And you do this throughout the day, so - and particularly on your good days.

It's not only on your bad days but it's on your good days because that's when you have a little bit more energy to spend. So you need to really be mindful of what your body is saying to it when it rings. So I'm going to ask you all, even though I can't see you physically, just close your eyes for a minute and do this with me. Say, body, in this moment, what do I need? And for many of you, it'll be rest.

And the next question I want to say is, body, in this moment, how many minutes of rest do I need? And scroll through the ten times table - 10, 20. Take a couple seconds to figure out how much time your body needs right now. And then what you would do, you would write that down in your activity log and you would go down and you would lie down and you would put your feet up to help your blood return to your head and you would hopefully learn to meditate during that time.

So that's how, in essence, of how this pacing method works. So what I'm asking you to do is to do a symbolic shift from the pilot who basically - you think of the pilot is usually the brain, and the copilot.

This slide got mixed up a bit, but the copilot is on the right. She's the blonde. And the pilot is the brunette on the left. So usually the brain has the idea to send the brain says, "Let's go for a trip to Fort Lauderdale, from Fort Lauderdale to Toronto today." And she talks to the copilot who is on the right, and the copilot says, "Yes, no problem. We've got lots of gas. All of the electricals have been fixed. Let's go." And that's it.

So, when basically - this is how normal people function. So basically, I'm asking you to do a symbolic shift here. So I'm asking you to put your brain in the copilot's seat, which is on the right side. We'll have to change the slides a bit because they're not quite - they've shifted a bit. So basically the brain is on the right-hand side and she's now a

copilot. And the copilot who was on the left, the blonde, is now basically in the pilot's seat.

So, the brunette still has the idea, let's basically go shopping at the mall today. That's what normal people do. And normal people say, "Yeah, no problem. I'll grab my wallet. I'll go to the bathroom, and away I go." Well, what happens now is when she asks the pilot - the copilot, whose now sitting in the pilot's seat, she asks, "Can we go to the mall today?" And she says, "Well, we've already gone to the doctor's office. I think we should go home because we've done enough."

So, what you're doing is you're giving your body the final say as opposed to your brain, which is a real paradigm shift for many people. So, the idea is using your activity log to help you with this. So you stay as active as possible without crashing. And another way of looking at this is staying within your glass box.

If you think of yourself surrounded by a plate glass window, so when you basically go up to the plate glass window that's in front of you, it's beside you, it's on top of you. So normally on a bad day, your glass box is very small because you have very limited energy. On a good day, it expands. So the trick is to find out where are my limits on my good days?

Otherwise, if you don't find your limits, it's like physically running through plate glass window. And what happens when you run through plate glass? You get caught up and you bleed all over and it takes a long time for your body to heal.

In the meantime, your energy levels drop back. So you if you think of that plate glass window, that's really helpful as well. So the idea is, as you improve physically, you need to improve. So you improve using the 10% rule. So most people think, you know, they remember when they were well and so they think, oh, well, you know, I can normally walk ten minutes and I'm having a good day today. I'll just walk 20 minutes.

Well, 10 to 20 minutes is a huge increase for your body to manage and most times it can't. So if you're not sure how to improve and you're not sure what your body is telling you in that moment, I usually suggest use the 10% rule. So, if you can walk for ten minutes, 10% of ten minutes is an additional one minute. So on a good day, you can walk eleven minutes. If you're doing range of motion exercises in bed and you can do - you can walk - or, you know, you can basically walk to the bathroom and back, maybe you can even walk to the bathroom and back twice?

Can you do some perimeter walking inside your house? So if you do one lap and one lap of your house or apartment is say, maybe, 15 steps, could you do, you know, 10% of that is an additional few steps, right. So, basically it's not much more. So the idea is to slowly improve. And ideally, you know, if you need to warm up and stretch after your exercises or do it when you're in the bathtub, especially fibromyalgia patients who have a lot of pain really do well in their bathtubs.

So you can have a hot shower and you are so tired, get a bathroom chair so you can sit in the chair. Or if you happen to have access to other nearby pools or things like that, that's a great way to basically learn to slowly exercise. But again, when you're first starting, if you're not sure, you're better off to check in with someone who is an expert, either a physiotherapist or an exercise therapist who understands your illness because the worst thing you can do is push yourself and do too much.

Ideally, over time, as you're improving, you need to strength train because there's a real risk of osteoporosis with both of these illnesses if you are not physically active. You need to learn to trust your perceptions and you need to learn to say no when you need to say no. But on good days, you can build gradually.

And there's a book that I like, "Strong women stay young," by Miriam Nelson, which shows some range of exercises and ideas for those of you who are mobile and able to

go shopping. So, for example, walking, for example, ten minutes a day is fine. And on a good day, you increase by 10% which means increasing by one minute, so you're increasing to a total of eleven minutes.

Most bedridden patients are able to walk to the commode at the bedside. On a good day, you might increase your walking by either pushing your commode a little bit further out or possibly walking twice to the commode before getting back to bed.

And again, I recommend a physiotherapist if you're in bed and you need to learn range of motion exercises. Passively, these can be done by teaching the family members and then slowly increasing over time.

So, what are the results look like in my patients? So this is what we're looking for - homeostasis, to try to get support for the patient and, in particular, today we're looking at exercise or pacing, but also all of the other components need to be looked at as well as the environment, diet, sleep, et cetera. And this is what - we're looking to rebalance the body. So, the other important roles of the functional capacity scale and the activity logs is it helps your clinician to understand where you are at physically.

For example, it would help the doctor explain why you either could not work or why you could work part-time or full-time because you've got your daily activities and what you're able to do available for your clinician to look at. So it's really helpful when they're filling out the insurance claims for disability forms for them to document your activities.

And again, this is to show you that crashing pattern over time, if you continue to crash, you basically get worse over time. Whereas, if you stop the crashing, this is the recovery pattern and that's what happens slowly over time. So, ideally again, you want - you can look at your energy. You're having a loan when you have ME and fibromyalgia and ideally you want to pay back your energy loan to your body on your good days. And that's why pacing on your good days is so important.

And these slides are little bit skewed, so on the left-hand side, you can see my patient Dorothy. She - that's what she looked like when she first came to me at age 55. She was extremely exhausted and very sick looking. And you can see her years later at age 72. And she recovered to the point where she could - she was retired at this point in time but she was able to work part-time.

So, my message today to you is never give up. I think we've come a long way in the last 25 years since I've started doing this kind of work. And I think that we have certainly a long ways to go in getting people diagnosed early. And I think that's a keynote in getting the support that they need over time. So this is the song that I wanted to sing with you. I'll see I can get this up on my thing.

And this is basically - I'm dedicating this to the patients and I would like you to sing along with me, if you can, because I think you'd get more out of it if you do. It's just taking a minute to warm up here. There we go.

"Do-do-do-do-do, do-do-do-do-do-doo, do-do-do-do-do. Boundaries are so wonderful to set. When I say no to you, I say yes to myself.

Scattered pictures of the life I left behind. Now I'm lying in bed crashing from pushing myself on my good days. Could it be that if I start to pace, and write in my activity log, if I persist with keeping it, tell me could I improve my energy.

Boundaries are so wonderful to set using my cell phone timer I can choose to (stop) before I crash. I help my body to heal whenever I remember the way to pace, the way to pace. Do-do-do-do, do-do-do-do, do."

So there we go, that's your song. Sing along and it'll remind you. I've - I wrote this song with the lyrics from Marvin Hamlisch because I really felt that you needed another way to hear it from me and I hope that helps you.

So, the resources (view), I'm on staff, as was mentioned, I know at Nova Southeastern University's Institute for the Neuroimmune Medicine. The Web site here is for you and it has on it both the activity log and functional capacity scale, which I would love for you and any of your physicians to use in any of their patients.

That's why we wrote them. So please use them. I've written a couple of books for patients to help them. And I hope they're helpful for you and the pacing is also interviewed in there as long as - as well as particularly nutrition, because I think that's absolutely key for patients and also getting the support you need.

And these are other online resources that are available. The first article I wrote as a review of ME to help clinicians to understand this illness. There's also the primer. That's another collection of information that's written for clinicians of any kind to help their patients.

And these are the definitions. The Carruthers definition is the currently - the research definition that we use here and the DePaul definition is based on this. And then there's the more current Institute of Medicine's clinical definition as well.

So, this finishes my chat for today and I'd be happy to entertain any questions from Dr. Brimmer at this time.

[Dr. Dana Brimmer:](#)

Thank you, Dr. Bested. We are actually nearing the end of our call but I want to say a huge thanks to you. That was a wonderful song. And we are - just to let everybody know, we're going to, not only have the transcript available on our Web site. We will also get a copy of the slides posted on the Web site so people can go back and refer to that song.

I want to thank everybody who called in today, and again, thank you to Dr. Bested for taking the time to be with us today. To submit questions or ideas for future topics, please email us at ME/CFSSEC@CDC.gov. And also more information can always be found on the CDC ME/CFS Web site. Thank you, again, everybody, and we look forward to having you join us on the next call.

Coordinator:

This now concludes today's conference. Callers may disconnect at this time.

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