

Rampe? Reicht! Season 2, Episode 4: ME/CFS & Millions Missing (Interview)

tier: ramp

Clara: enough

tier: a 20 minute podcast about

Clara: ME / CFS and millions missing

tier: i'm simo_tier and as you can hear today SchwarzRund is not present, but another person:

Clara: Clara! i'm here for the first time i'm (laughs) i'm a queer white woman, i'm cis, i'm from the middle class and i'm chronically ill and disabled, because i have ME.

tier: welcome Clara! really great that you are here and that it worked out today with our special episode. we wanted to try to make an episode on millions missing, so that this episode comes out on the day of millions missing, on may 12th. we will explain in a moment what that is. As Clara has already said: Clara has ME and as you already know if you've been listening to rampe?reicht! for a long time, I also have ME. And I think it's a nice thing that we have found each other, because ME is a somewhat rarer, but then again not, thing and this exchange about it is very important, because yes. I had thought about reading a short summary first, really very briefly, about ME, so that you know what it is. this is from the website millionsmissing.de. ME is the abbreviation of a very difficult word that took me several years to learn: myalgic encephalomyelitis (both laugh), also known as chronic fatigue syndrome, CFS, and this is often written together as ME/CFS. there is, for example, the hashtag #ME/CFS on twitter. "this is a serious neuro-immunological disease with involvement of the endocrine and metabolic system, which is often associated with a high degree of disability and can lead a person to become complete bedridden" So a few difficult words, but a few important words, I like the word neuro-immunological.

Clara: yes

tier: because that gets to the point what it is, so there is something in the brain, it is not quite clear what, but at the same time our immune system is very, very bad! (laughs) and that the degree of disability is very high, also very fluctuating: there are people who are completely bedridden, then there are people who can still move quite well, but have to struggle a lot with exhaustion and it is a spectrum: everything in between. exactly, would you like to tell a little bit what this chronic illness actually entails, Clara?

Clara: yes, I always find it very important to say that it can be very different for those affected, so the range of symptoms and also of the seriousness of the disease is very, very large. For me personally it means very strong restrictions in what I can do and how much I can do, because the energy that is available to me is very limited. so i can, for example i had a doctor's appointment yesterday and i went there, i waited, i had my appointment, i drove home and it was for me on that day! i come home and then i'm so exhausted that i have to go to bed.

tier: that sounds very familiar to me!

Clara: Exactly! so that's a very classic example of what ME means to me. What and how much I can do depends on my daily form, there are days when it is enough to brush my teeth in the morning so that I have to lie down for an hour and there are days when I can just do my studies and cook myself something to eat in the evening. it's very different. what is also somehow part of ME and what many people overlook a bit i think are cognitive limitations. because it's not just any kind of physical exhaustion, but it actually works with difficulties with thinking sometimes, so sometimes I have problems with getting a clear thought, formulating a sentence. this can be very limiting at times.

tier: I know that very well and I am always fascinated that you're going to university, because that must be very difficult! I've tried it a few times and I didn't make it because of these cognitive problems. that definitely plays a big role. also this, i call it this brain-fog, which sometimes just, to form a thought or to understand something, it's like there's a veil or like a fog in the head, so that it doesn't reach me or nothing can get out. yes, maybe we can also say about ME that it is very difficult to find out whether someone has it, because first of all there are hardly any doctors who are familiar with it, almost none!

Clara: yes!

tier: a big problem! Secondly, it is a disease that many deny that it even exists, it has a long history with so-called "feminine diseases", ie diseases that women often have, although with ME it is not necessarily that .. so there are probably more women who are diagnosed ... can you say something about that?

Clara: Well, I know that the proportion of women who have ME is higher, but I can't pinpoint a specific number. But I think there are definitely many diseases that are more extreme than ME in that regard.

tier: yes! but somehow ME is classified withing a group of illnesses that are afflicted with the "hysteria" term. also ME something that is not very clear, it is not possible to prove it in the laboratory, it is not, there are no clear parameters and it is also very difficult because it is then associated with a socially negative thing like this exhaustion / fatigue. I like to rather call it exhaustion, but in very many other diseases exhaustion is also a symptom. so first, to even find out if one has it .. yes, exactly, maybe we can go diagnostics. because with me it was so that I was ill for a very, very long time and was going to a lot of doctors, they didn't find out anything, and then I started looking myself, I also talked about this in our previous episode where we talk about diagnoses. I actually found out myself at some point on the internet that this disease exists and went through the list of symptoms where I could say at almost every one: "yes that's me, yes that's me or yes, I have that." and then I went looking to find doctors. But first it has to be said that there are no doctors who treat it, but there are immunologists in Berlin at the Charité who can do the diagnosing. we are of course lucky that we both live in Berlin! and that's how it was for me, so that I really had to find the illness myself and then go on to get a diagnosis. it was very complicated and it took several years. would you like to tell how it was for you?

Clara: yes, for me it was a little more compressed: I got sick quite young, so most people would say pretty young, I was 19 when I got sick and it took longer until my family doctor at the time even believed that I didn't just have a cold! I actually said from the beginning: "Okay, that's not a normal cold! I've had a cold before."

tier: you can feel it!

Clara: that's not normal! and ME is a disease where it is often said that it is a post viral disease, so you have some kind of virus and after that you develop ME. So you have a cold, for example, and you will simply never get well again.

tier: exactly!

Clara: and then a lot of tests were done that were all negative. I was lucky that I already knew ME, so I had already heard about it.

tier: ok?

Clara: and after about six months I said to myself: "ok, I kind of think I have it it." I naturally hoped that it would be different, because ME is not only not curable, but also not really treatable. So there is .. there is not even anything that would really gets the symptoms under control for most people and it actually took over two years until I finally managed to get a referral to this outpatient clinic at the Charité, the one you've already mentioned. it is also an exclusion diagnosis, so before you can go to this clinic you have to have a large amount of other tests done

tier: yes!

Clara: and I think I did them all

tier: (laughs)

Clara: I had MRIs, i had blood drawn, i had an operation ..

tier: wow!

Clara: Well I had a lot of tests done and at the end there I got this diagnosis ME/CFS. and on top of that I've also got POTS. From my point of view it mixes very badly (laughs) and then that's exactly what, then you end up with this diagnosis after an eternal marathon from doctors to doctors who are all either at a loss or don't believe you! and then you have a diagnosis that cannot be treated, and you should go back to your general practitioner with this doctor's letter from the Charité.

tier: (laughs) exactly!

Clara: and they should then continue to treat you! and they read the letter and don't understand

what's in it!

tier: (sighs deeply) exactly!

Clara: So the supply gap is very large. even in berlin, where we are lucky enough to be able to go to this outpatient clinic at the Charité. But they don't offer treatment!

tier: no, they are not even able to do that. it's not that they are somehow evil and mean, you have to look at the systematics: there is simply no money for research! and at the clinic they are actually doing research, which is great that more research is being done, but they are like only one point three people who do it, or so it feels like, and of course they don't have the capacity to do any treatment at all! And that's why every person here in Germany is really on their own, people are actually left alone with it and then they have to be lucky enough to find doctors who believe in them. For example, I have a very general practitioner who also did a little research, then gradually got a few more ME patients and, I think, also went to the training seminars, the Charité sometimes offers training courses for doctors. In any case, she kept herself informed, but she's still not able to treat me that much. she does believe in me, which is nice! and then I'm being treated at the pain center who are well versed in fibromyalgia, but they're always a bit at a loss with me, but at least through them my pain medication is taken care of. but yes, it's not easy! According to statistics, it is said that around 300,000 people in Germany have ME, certainly there are many, many, many more

Clara: yes

tier: because people don't know ME and it is so difficult to get the diagnosis. one thing, hmm ... right now I have to think about it .. do you have any aids or medication that are important to you or that you need to cope with your life with ME?

Clara: yes, i have a wheelchair, meanwhile also with an electric auxiliary drive

tier: so a manual wheelchair?

Clara: Yes, exactly, so one that you push yourself, that works quite well for me too, but with an electric auxiliary drive. it is like with an electric bike where you pedal a little and the electricity picks up the speed. This is how my wheelchair works too, only as a wheelchair (both laugh) that is what helps me to get from a to b on not so good days and, above all, gives me the security that I'll make it home again!

tier: oh yes!

Clara: because before I had my wheelchair, I was often just stranded somewhere. it's the greatest horror, even if the wheelchair breaks, simply the greatest horror!

tier: (laughs) we don't recommend that, it's not a good idea!

Clara: zero out of ten! would not recommend! I remember sitting in a hospital lobby for five hours because I was there for an MRI and just couldn't get home!

tier: that's terrible!

Clara: these are just things that happen with ME, because you, because sometimes you suddenly run out of energy and that's not like healthy-people-tiredness!

tier: no!

Clara: when I run out of energy I can't just say: "OK, I'm going home now and will have a cozy evening," but I sit there and don't get away!

tier: yes! i have a lot of issues with my legs, so when exhaustion comes, i'm like: "ok, i can't move at all!"

Clara: yes yes

tier: and then i can't walk either!

Clara: yes, it definitely is, this muscle weakness is definitely a big issue! that was also one of the first or one of the big shock moments for me in terms of health, when I really fell the first time! because that's so .. adult people who are healthy don't just fall while walking and that just happened to me and i am, well i was out in the city and i just really fell and that was a moment when i thought to myself got: "ok, this is kind of really serious!" (laughs)

tier: yes

Clara: well it suddenly feels very serious when your legs just give away under you! So with the wheelchair, I have to say, was one of my, is one of my greatest moments of liberation because it

gives me so much mobility back! and if I'm not doing so well, then I just sit down and if I have someone with me, then I can let myself be pushed and I can still do things!

tier: yes, the big word again: participation! yes, I know that too, it's the same with me! I also use a wheelchair, an electric wheelchair, because I have very big problems with my hands, sometimes I can't grip, my hands are very weak and my arms, and an electric wheelchair was the right thing for me and it gives really the possibility to take part in things for me and to still do something on bad days! I used to be a lot more at home, because i couldn't move so much and now, when the weather is good, I can just go out! that is wonderful! I thought maybe we could talk a little about the discussion "why ME and not CFS?"

Clara: oh yes!

tier: so why is there now the more difficult word and why are we not satisfied and do not find it good when someone says: "ah, you have this chronic fatigue syndrome!"

Clara: (laughs)

tier: what doesn't feel so great about it?

Clara: I recently had an argument with my neurologist about this subject (laughs)

tier: oh wow!

Clara: a real argument! usually i avoid discussing too much with doctors because it can really endanger the level of care that you get!

tier: yes!

Clara: But I find the term chronic fatigue syndrome very, very problematic, . and language is important, so the way we speak about things changes how we think about things! and this chronic fatigue syndrome, it's not just exhaustion! so it kind of reduces a really complex disease that comes with a lot of limitations! I have chronic pain, I have cognitive impairments, I have mobility problems, I am restricted in many ways by this disease and it reduces the whole thing to a symptom! and yes: i'm exhausted, it's true, but i have so many other symptoms and i often have the feeling that chronic fatigue syndrome, the moment the term comes up everyone in the room is like: "yes , I'm tired sometimes too! "

tier: exactly that, oh yes!

Clara: I think to myself: "yes, I know you get tired sometimes"

tier: it's not the same (laughs)

Clara: "and then you lie down and sleep for two hours and then you'll be fine!"

tier: exactly! that is the crucial difference, because when a abled person says: "I am exhausted and tired!" and goes to sleep and then maybe sleeps through the night, sleeps well and then notices the next morning: "oh, wow ok, sleep helped!" What also plays a big role for me: I sleep a lot, I need a lot of sleep and, for example, I woke up again today and I feel as if I hadn't slept for four days even though I slept ten hours! so sleep is not restful.

Clara: yes totally! so i had this conversation the other day with a friend, because we figured out we have very different rhythms in our lives, because when i say in the evening: "now i'm going to bed" he says: "I'm starting to cook dinner now!" and we get up at the same time! he gets up in the morning and he is full of energy, he starts his day like that and does things all day! and I get up and think to myself: "ah, no actually .. actually I could really sleep another ten hours now. (both laugh)

tier: yes, please another ten hours! If you meet a person with ME or others Disabilities where exhaustion plays a role, it is not a good idea to say. "Sometimes I am exhausted and tired too!"

There is this hashtag millions missing, that is a movement that was founded a few years ago. The day for millions missing is on May 12th, and I don't know how it will be this year, because of the pandemic and everything ..

SR: but I know that! this is SchwarzRund from the editing room! And it has meanwhile been announced: on millionsmissing.de you can find all the information about it and the idea is as follows: because of the corona pandemic, of course there cannot be actions on the streets, but there is a postcard action! it is actually before May 12th, but you can still do that. the idea is that you write to the presidents of the state parlements, there are also preprints, preprinted postcards, even an online postcard dispatch service on millionsmissing.de and the idea is that they will be flooded with

postcards! I would like to read briefly from the website why this is particularly important this year :
"Currently there are no drugs and no approved treatments for ME. Most doctors have either never heard of the disease or can neither diagnose nor treat it. those affected have been suffering for decades, disappearing from school and the world of work, their social environment and only in the rarest of cases can they manage to see a doctor. according to estimates by professor Scheibenbogen at the Charité university hospital berlin, around one to two percent of all infected with COVID 19 will as a result develop ME/CFS. Professor Anthony Komaroff from the Harvard Medical School assumes that ten percent of all SARS-CoV-2 infected people will develop a disease that is caused by NASEM, the US case definition of ME/CFS, and thus the number of American people suffering from ME/CFS will double. Worldwide around 17 million people are affected by ME/CFS. According to more conservative estimates, COVID19 is expected to increase this number by ten million. Based on this assumption, the number of affected people in Germany will increase from 250,000 to around 400,000 adults, children and adolescents. This year we ask the 16 state parliaments to address the following demands to their respective state governments: the initiative and implementation of targeted measures in each state to ensure the medical and social care of 250 to 400,000 chronically ill people with ME in Germany." and a copy of this text and everything else can be found on millionsmissing.de, so take part quickly!

tier: ..but that there are more or less rallies around the world where several people participate, and it is often described figuratively with shoes that are put there, that all of the people with ME who are not able to take part in events like this one are represented by these shoes. because ... yes, there are people with ME who actually cannot leave their house because it is too exhausting. i thought i would really like to take part in this event, but now because of the pandemic it won't work. it would be so nice to network, we will definitely put all of this in our shownotes with #millionsmissing and millionsmissing.de and there's also a ME/CFS hour on twitter! do you remember what the hashtag for this, Clara?

Clara: no

tier: I'll find out and it will be in the shownotes below, this is now a movement on twitter [#MEawarenesshour] if you want to get more information, I think we have already recommended that, but we'll recommend it again: there is a film by Jennifer Brea, she is a black woman with ME, she made a really great film that shows how ME is and also how it is in different countries and what the problems are at government level and at care level and what all goes wrong. this film is called Unrest. do you want to tell us, Clara, where to find you?

Clara: yes, I'm also on twitter at @clarakruemel. I'm only on twitter.

tier: okay! Thank you very much, Clara, for being here

Clara: gladly!

tier: that we could do an episode with only ME affected (laughs)

SR: on May 12th, 2021 is millions missing, #millionsmore you can find @simo_tier on instagram and twitter and on etsy. @rampereicht can be found on insta and patreon. and our paypal is: rampereicht@gmail.com. then you can also write us an email.