

Liisa Mikkonen – Why chronic pain is a disease in its own right from a patients´ point of view

The following text is a transcription of the presentation Liisa Mikkonen held during Workshop 1 which took place on the 30th of May during the SIP 2012 “Societal Impact of Pain” Symposium at the Bella Center in Copenhagen, Denmark. She has presented the patients´ reasoning; why chronic pain is a disease in its own right.

If chronic pain, which I feel 24/7, is just a symptom from the slipped disc operated in 2000 which should be ok after that, I really like to know when this pain, symptom of nothing, ends. And, I have been pain patient now for two years. Approximately for two years. Two operations with slipped disc and then some operations with knees, and so on and so on and so on. My operating doctor in 2000 told me that, after two months of the operation that, believe me or not but, you will suffer chronic pain after rest of your life, or rest of your life. And I couldn´t believe it. And that´s really, who would, I was 30 years old, just graduated from university. But because he was a good doctor and he told me the situation and he really, put me, understand the situation, I also get a good pain treatment, from the beginning and I got neurostimulator for the pain, painkillers which means that my muscles from my leg are not be disappeared as they should be disappear, so ehm..

Most of my doctors have been really good one, they have listened they have treated and they have made access to different medicines and different treatments. But still because of continuous pain I have lost my work opportunity, I just to be eh, working, working, working.. working, working working, and I just to enjoy to.. things and logics feel about 24 hours a day so.. I really liked to work.. Perhaps this is the reason why I now don´t have to do anything. I lost my benefit of the education so university, here you go, there´s nothing, nothing use for that. I lost my income so, which should be the master´s income as now retired income. I lost my possibility to have children and normal family. I lost my possibility of hobbies. I used to ride, that´s what I did before studies when I had some money and I saw that I am going to continue that after the studies. And dancing, that was another object. But more or less I lost the possibility of travel, and more as I want to and yeah, I can move, I can walk, I can even dance if I want but then, that´s what I do, for that day, I don´t do anything else. Long days, long walks, like in here, I have to sit in a wheelchair, but, I walk, that´s the most important thing.

Overall, my life is really good. I have to use different pain treatments, and more or less, pain, painkillers. I don´t want to talk about pain killers, because I have to use a lot of them, and strong ones, but I always tell myself when I have to start a new one or or I have to do something changes, well this is the way how I walk, and if it demands it, then let´s try a new one and so on. I have access for medicine but I don´t have access for rehabilitation. Public sites, insurance company, I had this way, have one, just one rehab course for chronic pain patients, and that´s mostly for mental issues, so they have set really strict rules that you can give that, you can give that, mostly, it´s mental issues. I got my first physical rehab course in 2008, 10 years after the accident. I would say that today I won´t be here, I would be working if I had rehab on the right time. There´s no reason to give rehab for me, just because there´s

nothing wrong with me anymore, or that's how they say, they have some pictures, scans, from head to toe, and nothing should be wrong. But still I have the pain, and because the pain is not a disease, I don't have right for rehabilitation.

If the pain gets the status of disease, naturally we thought, we as a patient would get the possibility for better treatment. And better treatment, because, if a disease, also the doctors want to study it more, they want to serve it more and they want more education, and so we got more doctors, and that's one way to get better treatments. What's more important, *demolish the stick* of chronic pain, because that's you get when you get chronic pain. You can't say that at school, you can't say that at work, you can't say it anywhere. If you say that, today I can't live this up because I have chronic pain or my back is broken or something like that, you are just lazy, that is. Pain is invisible, it can't be measured as we have seen today, there's a lot of different measurements, but no one of them are exactly. Patients must be trusted by their family and more important, by their doctors and by their nurses if they want to have a good treatment.

If the pain is a disease, and if the doctor believed you, if there, if we would find some kind of measurements that you can measure, yeah, the pain level is really 8, the doctor would give you a positive stamp, and I would say positive stamp in that way that, you can go home and say to your folks that, hey, the doctor says I have chronic pain, it's not me who says that I feel pain all the time, it is the doctor who said that I have chronic pain, and then you can discuss with your family and and debate that if that, am I or, is the doctor right or not, or should I go and see another doctor because, this kind of horrible disease he find or she find.. Early learning, that's something also which is important. If the pain is recognized as a disease, there's no sense to look something else, something which doesn't exist. You can put you through and see that there's nothing there shouldn't be anything wrong with your head, and spinal and so on, but something is wrong because you feel pain, and then, when you go through all the things you need to go through, then you can realize, okay that's chronic pain and that's the disease, that's acceptable, and that's it. You don't have to go through and through and through different doctors, different variations, today you have slipped disc and tomorrow you have slipped toe and so on, because if the doctor doesn't know what's wrong with you, he or she has to find out something, that's the doctor way to do, you have to find out something's wrong, whatever. Your eyelash is wrong, that's the reason you feel pain..

And, as I said, if it's real disease, doctors will get more treatment..more training. Yeah doctors will get more treatment to... But doctors will get more training, and more training for doctors, for nurses; better treatment for patients. And also, as we talk about Grünenthal here, we can talk about other medical companies, they will give money for researches, universities would like to research more about the real disease, not just the symptom. But if we decide that it's a disease, it's even more to ask the question: what kind of disease? In Finland we have a diagnose number 45 45, that's chronical pain centrum. But it's not a physical disease, it's a mental disease. It says that, these symptoms that the patient feels are not right, and they are not, and they shouldn't be treated with pain killers. They should be treated with antidepressants, or other mental medication. And that's something, I don't want to have that kind of stamp on my forehead, that I'm a chronic pain patient, pain patient, I have problems here and there and there, but still, nothing of them are right. If you have that stamp, then it means that, you just you just want, nothing is right, nothing is

real, something is right but nothing is real.. But disease or not, we patients know that recognizing pain as a disease, it doesn't make any difference for that, that every pain, is not healed. You can't, even doctors want to be superhuman that want to make miracles and so on, and every pain patient can't be healed. You can reduce the pain, but you can't heal it.

Thank you.