

Karen

Well hello fellow RCN people. This is one of the maddest nurses around my name is Karen, I'm 49 and I've been a nurse since I was seventeen and a half, a qualified nurse since 1998. I've always had a disability and that's not just the craziness in my life, that is a movement disorder which I started with since birth called Dystonia and I've collected them along the way cos I've got a head injury, Ehlers Danlos Syndrome, I've had cancer this year along with the Covid lockdown. Amongst everything else my body is powder- but hey, who cares.

Having said that I'm still working. I work from home, I am a band 6 sister who works for a rehab service called hospital discharge service. In the backend of London which is London borough of Essex and I actually work for NELFT. And I can say NELFT because along with the RCN they've allowed me, they've enabled me is the word, to be able to work and to be able to help others as I've been helped as well.

Disability doesn't mean you can't do it. You may have to work a bit harder to do things hence you have to learn a bit quicker and a bit faster but with the right help and the right equipment you too can do it. I mean who wants to stay at home and go made with 4 walls? I can stay at home and go mad with my doggy whose fast asleep behind me and do a bit of work and spread a little craziness everywhere else.

Don't tell you its easy. I've been through health and safety departments, we've had major problems with getting understanding, I mean I am old, with getting understanding that you can't just take bits off your adjustments; you need them all. And unfortunately yes, you do. But people can't read minds and people do need to learn.

I have a lot of invisible disabilities which means that I have to be, I'm not bothered, I've been with this problem a long time, but I am vocal. because other than my tremor which makes me look as if I have the DTs (and I don't drink alcohol) you can't see what's going on. Yet if I put it down on paper its bigger than my shop list.

I am not restricted; I have a full life. I am a nurse, but also I am a group exercise instructor and through lockdown with cancer I learnt to teach combat (yeah I know!) and cycling to music, Les Mills RPM. I also teach pump which is weights to music. And whatever you do, you put your mind to it.

I also trampoline, I am doing my badges . And every single thing I do in life has a reasonable adjustment behind it. The main thing you as nurses, or as healthcare professionals, whatever your title is because we're all in this together and we can't work without each other and I'm very much respectful of everybody from the people who clean the hospital, to the people who feed the patients, to the postman, I love you all. But the main thing is that you work together as a team, colleague care. If you think if some is looking a bit grumpy, I'm a grumpy old devil, is that you ask them because there might be a reason why.

It's about supporting each other. About signposting, Occupational Health, use them. And don't be afraid, where you get knocked back, dust yourself down, stick your boxing gloves on. And come out fighting. If you really want something go out and get it. alright it might be a hassle for everyone else, who cares? you know you can do it you keep going until you get it. Driving- I can't drive a manual car. I'd be on the sideways on the major routes but with an automatic and a few exceptions and a medical license ,I drive. Short distances but that means that again I've got a life.

People, don't forget people with long term stroke disabilities, you're the best because you're not just reading things from the text book you're living it every day. So you should be in the NHS or wherever you're working community, homes wherever, you're the best experienced people to be here. You can give back, you can understand, you can empathise. And what from my point of view is you should be at the top on your game but all I want to say through this podcast is never give up. I've never given up and I never will even with the cancer side of it I'm coming back fighting and so should you. If one thing I can do today by talking the hindlegs off everybody is we're here, the RCN is here, they will guide people if they don't know so your NHS or wherever you work.

I am NHS so forgive me but wherever you work if you are a member of the RCN they are your best signpost because they will help guide your local workplace environment. Also don't forget Access to Work, you can find them online. I get transport everyday and they can also do a work based assessment.

All I would say as it gets to 6 mins is take care, be safe and it's a big hug for everybody, I know you can't do it in person, and take care from me and Benji the dog.

Sylvia

Hi, I'm Sylvia I'm an adult nurse on a ward in a small hospital, a community hospital based, as it says on the tin, that is local to where I live and shop and do all those sorts of things and it's great. But I came to nursing really late. I'm dyslexic I discovered when I finally trained. I always knew the wiring was wrong somewhere, somehow, I wasn't really sure quite how. So when I started training I decided; if I want to do this properly I've got to get the assessment that will allow me to learn properly. Which I did. And it was transformative. It meant that I was able to study, and learn, and discover my learning style and really, really succeed. For the first time in my life I actually did well in exams. Its quite soul destroying to discover that however hard you try exams just don't turn out right. And other people would say to me "well, you've passed what are you worried about?" But I knew that I had pulled out all the stops that I could and actually when it comes to doing the exam just couldn't pull it off, not properly. As you can perhaps imagine that kind of, well I perceived it as failure, is a very disheartening thing. Which is another reason that I was quite determined that I was going to turn it round if I could when I got to uni. And I did. I really succeeded and not just a scrape of a pass I got a 1st and I got published and I won a university prize. I was astonished. Completely bowled over. Did not see that one coming. But what a validation.

So anyway, I got on to the wards. I went to the community hospital, in fact I'd been a HCA before. And everything went wrong. I just couldn't seem to find my feet. It was bizarre; every other placement I'd done really well at. Every bit of academic work I'd done really well at. Why on earth was I coming here now and finding it so difficult?

I think one the problem is that neurodiversity, which is the label I prefer to use, just isn't recognised in the nursing profession. Particularly if the management style as where I happened to be, is very structured and systems based, at least that's my perception, and I feel that often people have to serve the system rather than the system serving the ppl ; I think that is quite the disadvantage.

Anyway, I struggled on and was finally assigned a mentor who, bless her heart, stuck with me. She said later that "I've never come across anyone quite like you. You're obviously very bright and able to do a lot of things but something just wasn't clicking". So she stuck with it and racked her brains until she came up with what she called a priorities pyramid. I was having trouble prioritising, couldn't see the wood for the trees. So she said right, lets sit down and look at todays tasks and prioritise them. And it transformed the way I looked at the day's work. And better still the way I succeeded at the day's work. I was really grateful to her for having stuck with me and really taken the effort to find something that she thought would work.

Anyway, that's kind of history now that was a couple of years ago, not very long, I'm now much more confident. But it's given me some interesting time to think. What I have discovered from it is, as an organisation within the NHS we don't expect neurodiversity. We expect conformity. We expect typical behaviour.

To start with the application form says “do you want to declare a disability?” Well actually no, I really don’t want to declare a disability. Neurodiversity, different. But the perception that we are disabled, less abled, not perfect, something to be cured, something to be managed, is really destructive. So I would like it if at all possible if we could change our perception of neurodiversity and see it as an asset. See the strengths, see the empathy see the soft skills that so often go with the neurodiverse. And given that probably 1 in 7 of the population has some form of neurodiversity, and that that is even more strongly rep in the caring profession, I think it I s high time we had more mentors like mine who take the time and trouble to look at learning styles and to look at what would really make the difference and start to see ability not disability.

Garth

Hi my name is Garth Ravenhill I am 49 years old. I've worked for the NHS for nearly 20 odd years. I am a stroke nurse by trade and training if you like, I've done ten years working in stroke services working everywhere from A and E, TIA clinics, to the ward, to stroke research and stroke education.

Unfortunately, I have had Parkinson's for 13 years. I currently work, luckily and thankfully, in respiratory research.

So how has your experience been as a nurse with Parkinson's in the NHS?

I was very open about my diagnosis and I think I let my management know pretty early on in my disease process. At first there was no issue; there was no issue with me physically or mentally, obviously I had the anxiety of the diagnosis. Unfortunately a couple of years ago I was told I was too disabled to continue my work in neurosciences. I suggested multiple things that I could do which would benefit patients and the service itself but was not allowed to due to my disability.

How do you think your experience could have been improved?

I think it could have been improved by talking to me face to face. Unfortunately, there were a lot of emails going each way and this way and that way. It sounded or it felt as if I had no way of fighting through, although I did fight through it and if I hadn't got my current role I would probably be out of work.

Communication is the key to this and also knowing your staff member. Managers have to be brave enough to broach the subject and talk to us on an even keel basically. I was very honest in what I could do and what I couldn't do. I agreed with Occupational Health when they said that I couldn't do this or couldn't do that. But I also gave suggestions of things that I could do for example, a Parkinson's nurse but was told that because I couldn't do injections I couldn't apply for the role. So communication is vital and knowing what your staff member can or can't do.

What are you doing now in the NHS around disability?

At the moment I am a member of the workforce disability team in respect of the NHS directive for improving disability equality standards in the NHS. We are a small group of people, forever trying to grow in size, of staff members discussing disability activities in the Trust. We all have a history of good and bad treatment and it has been interesting listening to others tell their tales and stories as well as trying to improve what we are doing for our disabled colleagues and those who may unfortunately become disabled in the future in the hospital where I work.

What would you like to see change in your Trust?

I would like to see more openness from managers. I would like to see tougher restrictions if you like on those who break disability law. I think its ok saying don't do this, don't do that, but we have known about the Equality Act for a good many years

and we work in health and maybe we should already know that we should be fair to people.

I also feel that disabled staff nurses, and nurses of any grade, have a great deal to offer their profession and their patients and they should be seriously listened to so that we can share their experiences and relate it to our current patients.

What are your fears for the future?

My fears for myself are what am I going to do when my career comes to an end. I don't think we're far from that to be honest with you. I have some important decisions to make and to look in to early next year. My fear for nursing is that now the retirement age is 67, potentially we're going to see a lot more disabled staff and we have to learn to accept these people with these life changing experiences and make sure that they are a useful part of the workforce. We may have to look outside of the box, but we have to grow and realise the asset that a diverse workforce can have for our patients and for our profession.