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06:48

Autism and health - a thread while I wait for my car to be fixed (stuck at my parents house).

Autistic people have a lower life expectancy. The statistics are clear. There are many reasons for this, many of which are quite upsetting (mental health difficulties are an important factor.) /2

But a big factor has to be to do with access to medical care and the different ways that we autistic people can display symptoms and so on. /3

For a start, deciding to access medical care can be a real difficulty. Many autistic people have a default stance of not wishing to make a fuss, usually (it seems to me) based on traumatic experiences of not being listened to in the past, or feeling were not taken seriously. /4

A lot of us have chronic health conditions too, and one issue here is that doctors can be very impatient and unreasonable with us. It may be that we *did* get regular appointments before but were treated so badly we just give up. /5

I wonder whether doctors see 'autistic' on our records and automatically assume we're not able to rationally discuss our health - an ableist default setting. I've certainly felt this in appointments - like I'm just being humoured rather than properly heard. /6

And then you've got access issues generally. In the UK the standard means to get a GP appointment is to call your surgery first thing in the morning, hoping to get through and get given a slot.

If you're phone-phobic, like many of us are, this is a huge hurdle. /7

Some offer an online service but often applying for them is unnecessarily complex and involves making a call anyway. Others don't at all. But these hurdles add up and stop us getting early interventions for issues. /8

When we do get an appointment, they are rushed and hectic and often running late. For routine-focused autistics this is a nightmare, and I often feel the pressure to get the appointment finished (that empathy sponge effect where we can feel the doc's impatience) /9

The number of times I've failed to tell my doc about a second or third issue, due to a sensitivity to that feeling of being rushed, is extremely high. I can't be the only one. But

there's no acknowledgement of it. /10

And even if we *do* get as far as explaining symptoms to a doc, we seem to do it differently to neurotypicals and doctors aren't trained to spot that difference. /11

One big example is how we report pain. It seems autistic people tend to be quite conservative, attempting to be accurate as possible rather than exaggerate. So if asked 'scale of 1 to 10', we're less likely to say 9 or 10. /12

Which means, of course, we're not seen as urgent. It might be, and there's some evidence to support this, that we're actually dealing with extreme pain, but just haven't communicated it in the 'standard' way. /13

After all, all of the scripted questions that docs ask us are predicated to non-autistic people. So we're up against it from the start. /14

All of this adds up to autistic people being way less likely to get health issues spotted early and efficiently. This is bad for everything, but especially for cancer and similar life-threatening issues. /15

Doctors need to be more aware of how autistic people communicate their symptoms, and surgeries have to do an awful lot more to improve their accessibility for disabled people. /16

Maybe then we would see life expectancy start to rise, and quality of life improve. /17

Thanks for reading.



Peter Wharmby is creating as much awareness and understanding of autism as possible!

If you like my tweets and blogs, please give a thought to my insatiable caffeine need and throw a...

<https://www.buymeacoffee.com/UfTVnRY>

Still no one arrived to fix the car. Not great timing for a car based issue today in the UK. This is stressful.

It needs a new injector so goodbye money

The above link is no longer 'buy me a coffee' but 'help me with my massive bill to get home' btw...

Tivitiko - The most beautiful shape of tweets!

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