

PJ Pod transcript: 'We are all fighting something' — breaking the silence on hidden disabilities in pharmacy

Across the UK, there are pharmacists putting on a brave face and going to work, but behind the mask they are struggling to cope. In this podcast, opinion editor Abigail James uncovers the problem of 'hidden disabilities' in pharmacy and what can be done to make the profession more supportive for those with health conditions that may be hard to see.

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Abigail James:

I want to place you in someone else's shoes for a moment. It's still early in your career as a pharmacist. And you're so excited by the possibilities of your new job in hospital pharmacy: rushed off your feet, but loving every minute. And then two years in, you start to notice changes in your body. There's something wrong.

Nalwenga Mutambo:

The pharmacy was kind of like outside of the hospital. So, I used to run from outside of the hospital, doing the prescriptions and things. And then one day, I just started getting like this weird sensation of like pain coming running up my arm. And I had to stop because at that point, I became really dizzy. And then, I couldn't from that moment, it was like, I think that affected my balance. So I couldn't run. So I ended up trying to walk quickly. But then I noticed that I did start to trip more whilst I was trying to walk quickly, but because of I thought I was just stressed. And so yeah, and there was only when the burning came back that I thought oh my god, I should go and see the GP.

Abigail:

This is Nalwenga Mutambo. In 2015, she started working as a hospital pharmacist in the south east. But within just a few years, she would be diagnosed with multiple sclerosis (MS).

Nalwenga:

And then sometimes with MS. The symptoms are very difficult to really vocalise or like describe when you say burning sensations or I feel tired. And they're like, well, what why is this tiredness different from you just feeling exhausted, because you're stressed, it's like, well, it's like muscular tightness. So I can't, I can't walk far distances because I feel tired. And then I suffer from something called foot drop. And that's what causes this, like, you can't lift your foot high from the floor. So then I end up tripping. And but trying to describe that to someone, once again, it's very hard.

Abigail:

What Nalwenga is describing is a hidden disability. You wouldn't necessarily know she had one to look at her. And in fact, of the 11 million people with a disability across Great Britain, a third who have problems with stamina, and fatigue, and half will have problems with mobility. Many of these problems you wouldn't necessarily notice, they might put on a brave face, but behind it, they could be struggling, especially during the pandemic.

Aamer Safdar:

The mask one is hard, because everything is muffled anyway. And I rely so much on lip reading, that I can't obviously, the lip reading is not there. The mask is making everything muffled. And if somebody's speaking quietly, then I just genuinely can't hear them. So I will just be honest and say can you repeat that for me because I can't hear what you're saying.

Abigail:

This is Aamer Safdar, a pharmacist and education lead at Bart's health NHS Trust. He has hearing loss and tinnitus, but you wouldn't know it unless you spotted the small devices in his ears. What's interesting about Aamer is he found it difficult to admit that he has a disability even to himself.

Aamer:

When I started at Bart's health last year, we had the induction and we had somebody talking about disabilities. She said put your hand up if you've considered yourself as, as with having a disability. And I didn't. But then I talked to her about coffee break. What about hearing loss: where does that put me? Because if I'm wearing glasses, I don't see myself as disabled. But if I'm seeing wearing hearing aids, does that make me disabled? And she said, yes, you should tick that box for disability because things will need to be put in place for you.

That then made me think that I have to be adjusting myself by wearing hearing aids. So actually, I will tick that disability box.

Abigail:

And that's the problem with hidden disabilities. You may not even know that you have one. You may not realise that your condition means that you can tick that disability box and get the help that you need. Would you have ticked the box? How do you define disabled? When we think of someone with disability, we often imagine that it's present from birth. But like Nalwenga, 83% of people with a disability acquire it during their working lives. It could be hearing loss, MS and mental health condition, diabetes, cancer. And out of the blue, it can happen to any of us.

Aamer:

So in 2012, I was working obviously with it in the hospital, but also I was doing a really intense leadership course. And towards the end of the leadership course, as with any course you have lots of assignments. So I was under lots of pressure to do multiple assignments as well as doing the work.

My hearing went, I felt my hearing was being impaired, but I didn't know why. So I went to a GP to get my ears washed. And it was then that, I noticed that there's a continuous whistling sound in both of my ears. And I don't know what that is. At the time, I didn't think it was tinnitus wasn't even in my thinking. I then got referred to the hospital. And they also referred me to an MRI, which I'd never done an MRI before. So that was quite scary sitting in the MRI thing, because a small percentage of people who have tinnitus can have a brain tumour. So at the time, brain tumour was big in my thinking, you know, big in my head. I was still petrified when I went to see the doctor. So they made me do some balancing tests and things like that, close your eyes and walk, straightforward, walk back, clap your hands, those sorts of things. And then after that, he said, I think you've got tinnitus. So you need to have hearing aids.

Abigail:

So after five months, Aamer finally had an answer. But it would take Nalwenga a year and a half to get her diagnosis. And throughout that whole period, she carried on working with extreme tiredness, dizziness, and burning sensations, all the while her employer none the wiser.

Nalwenga:

I'm a very stubborn person, and what I want to do something I will do it. So I just went into work. And I just tried my best. Because I hadn't been diagnosed, I didn't really know what was going on. So it's hard for me to go to someone like and say I'm having this random array of symptoms, you know? And then can you do this and this and that, for me, I didn't want to be a bit of a burden, if you know what I mean, I just wanted to get on with my job and just try and do it the best that I can. Because you always think like with these kinds of symptoms, they're quite scary. And if I was telling someone else about it was like validating the seriousness of the symptom, so I would rather just, you know, put a bandage over the wound and just get on with it. Rather than talking to anyone about it.

Abigail:

Eventually, Nalwenga had to rip off that bandage. Her condition made it too difficult for her to keep up with the pace and stress of life on the ward. So she left her hospital job.

She's still making a difference for patients though. She's putting her pharmacy knowledge to use as a clinical writer at the RPS. She told her new employees about her condition, and she feels really supported there.

And a hidden disability hasn't stopped Aamer doing brilliant things either. In fact, he's quite a prominent figure in pharmacy. He sat on the RPS English pharmacy board for many years. He's now a council member of the GPhC. All on top of his role at Bart's.

But more importantly, his colleagues know exactly what he means when he says "he's just putting his ears in". But despite these very public roles, it wasn't until eight years after his diagnosis that he shared his disability with the rest of the pharmacy profession.

It all happened rather suddenly, in an online RPS inclusion and diversity meeting. And event he hadn't planned to speak at all.

Aamer:

And I was at the time, I was just curious as to what this group is about. And we heard from somebody who had had cancer, and she was telling her story. We had another person who had a physical disability, and was telling her story. And at the time, I thought, why can't I share my story? So on the chat function on the zoom, I messaged that I want to, you know, can you make some time for me, because I want to say a few things.

So I just shared a snippet of my experiences. And I could see that actually, it was resonating with people. And I thought, actually, I'm glad I did that as a big burden off my chest. It picked up so much traction that I just never expected it to pick up as much traction as it did. Because, you know, having hearing impairment is so common. Yet no one talks about it.

Abigail:

But Aamer is now initiating that conversation. He knows just what it means for other pharmacists to see a leader like him talk about having a disability.

Aamer:

Other people have now volunteered to write blogs or speaking a bit more openly about their disabilities or problems or situations because they've seen somebody like me, who is in the pharmacy world well known. If he's vulnerable and sharing, then other people should be able to do the same thing.

Abigail:

We're not yet at the point where any pharmacist can speak about their condition without fear. In January 2020, we published a piece by a pharmacist with hidden disabilities, who prefer to remain anonymous, who had an entirely different experience.

They said they'd never had a feeling of belonging while working in pharmacy. They'd spent years hiding their disability. And they even once heard a colleague suggest that pharmacists with disabilities should find employment better suited to them elsewhere.

Another point they made was that they thought pharmacy was oblivious to the Equality Act, and the social model of disability.

This social model says that it's barriers in society that stopped people with disabilities from engaging in everyday activities, not the disability itself. The model says workplaces must adapt to accommodate different abilities, and not the other way around.

Paul Day:

If there is a flight of stairs into a building and you're in a wheelchair. Yeah, the reason you can't get in the building is not because you're in a wheelchair. The reason you can't get in the building is because there's no ramp.

Abigail:

That's Paul, who you'll meet in just a moment. But just to say, as far as supporting patients goes, pharmacy is doing just fine. They can park their car in the accessible parking bay, and they can sit down on the chair while they wait for their prescription.

But what about pharmacists? They're expected to stand up all day, often in cramped dispensary's, where taking breaks can be frowned upon. And an RPS survey from November 2019 shows the profession has much more to do to make pharmacy a more welcoming place. 43% of pharmacists believe disability was the biggest barrier to inclusion and diversity within the pharmacy profession, above all other protected characteristics, such as ethnicity or gender. And over half felt that more should be done to support pharmacists with disabilities.

I wondered just how many people working in pharmacy had been affected by discrimination. So I caught up with an expert from the Pharmacists' Defence Association (PDA), a trade union for pharmacists in the UK.

Paul:

I'm Paul Day, and I'm the director of the PDA. We launched last year, a couple of networks based on equality. And one of those was what we're calling the ability network, which is for pharmacists with disabilities. And it's striking compared to other networks, how, you know, if the equality network is around gender, or about sexual orientation, or about ethnicity, people understand whether or not or where they fit in that. But often many people with disabilities don't appreciate that they've got a disability is classified as a disability.

Abigail:

This sounds just like Amer. He didn't see himself as disabled either. But if you don't recognise your own disability, how will your employer? Paul describes the discrimination this can leave people open to.

Paul:

The scale ranges from, you know, not really employing a locum from not promoting somebody from petty name calling. And just, you know, disrespectful treatment to actually just making someone's working life impossible. So they end up leaving, you know, a lot of this stuff is, is quite low key. And perhaps people don't even recognise that they're being discriminated against.

Abigail:

Of course, most firms employers want to get the best from their employees. But for those who think getting on the wrong side of discrimination case amounts to a mere slap wrist, you'd be wrong.

Paul:

In terms of the individual scale, one of the biggest cases we've had was, ultimately a payout from a hospital trust of over 200,000 pounds to one of our members. Basically, you had a pharmacist who was working at a hospital trust, had been working there for a while, got a new manager, they had a medical condition, they had Aspergers, the manager, then the way that they manage them was they set them up to fail.

Ultimately, they lost their job. They ended up having to do portering I think in the same hospital where they previously been the pharmacist. And, you know, through court process through court process, ultimately we've got that payout for them, but it should never have happened.

Abigail:

It's difficult to think just how much of this unfair treatment could be going unreported. And all because victims themselves aren't aware that this kind of treatment, legally, it's discrimination. But it's so important to speak up. And Paul tells me what pharmacists should do if they find themselves in this position.

Paul:

You know, if someone's not sure how to do it, and they say, you know what, I think some of the other team are sort of taking the mickey out of me because I get tired early. Let's just go with that example. And they come to us and we will say well, how does that manifest in you know, let us help you raise

that with your manager, empower someone to go back to their manager. The managers got their sense about them, they're going to talk to the other team. They'll have to explain their personal business and their personal condition or their diagnosis.

But you know, that person needs breaks. And hopefully that stops here. That's much cheaper for the employer, and better for everyone concerned than letting it go for a spiral of negativity, person who gets stressed, they're sick leave. Ultimately, there's a potential legal case, if there's a legal case, there's all the legal fees, there's the managerial and administrative cost that supports trying to defend yourself in a call.

And if it's a public settlement, and therefore what happened is in the public domain, we weren't hesitate to warn other people about what sort of employers are out there. So your reputation is going to be in shreds as well, if you treat people badly, because we want to make sure you don't do it to someone else.

So you know, it's much much better to talk about things early to talk about things, you know, listen, and to actually try and make sure that you're getting the best out of people. Because that's the other thing is if someone is being mistreated at work, it is unlikely that their work is going to be focused and have the best standard because they've got all this going on.

Abigail:

With our anonymous pharmacists never got to show their best. I thought about to what they told me. pharmacy is oblivious to the Equality Act, they said, did their employer break the law? For over 10 years now, the Equality Act has legally required employees to make what are known as reasonable adjustments for their employees.

Paul:

Changes to their environment, or their role that can make things easier for them, changes to targets, physical adjustments assays, a stall to lean against or breaks, it can be about hours, it can be about job content. If they say walking around the wards is something that causes someone a problem because they lose their mobility. Well, could you readjust the workload amongst the pharmacy team, so that person actually only ever works in the pharmacy. So the work still gets done. Others just do a bit more of a ward work and the individual does none of the ward work and therefore it doesn't affect their themselves in that sense.

So you know, you can you can go as far as you go, and the law requires the employer to be reasonable. This is not my opinion, this is the law. It's also good business sense. Because why do you want to distract your employees from doing the best job they can for you by mistreating them?

Abigail:

Exactly. That Paul tells me that there could be something else at play here.

Paul:

This is not an excuse. Ignorance is not an excuse. But I think some managers may not realise that when they mistreat people, because their disability, that they are discriminating against someone. Whereas I think there's a higher level awareness if I treat someone differently because of their skin colour, for example, you know, I would recognise it as racism, other people recognise it racism, whereas if I say, Mary keeps on needing a break, I can't have her on the counter because she's had three breaks during a shift the other day. Well, if that's due to a medical condition that fits in the

criteria for disability, she's got legal protection for that. So I think people managers and employers won't always recognise that what they're doing is wrong.

Abigail:

Just as Paul says, it can be hard as an employer to know exactly what reasonable adjustments you should be making for someone with a disability. So I spoke to Diane Lightfoot, chief executive of the Business Disability Forum, or BDF, a charity that supports businesses and organisations, such as the GPhC to get better at recruiting and retaining disabled employees. And she agreed with the sentiment, employees just aren't sure.

Diane Lightfoot:

I think they also worry about what they can practically do to support people and make adjustments. But for anyone who's had a condition or a disability, for any length of time, they are likely to know what they need, they are likely to be the expert in their own condition, if you ask them.

And if someone's acquired a disability, it can be a bit different, because they might be coming to terms with that, but just having conversation and doing things like making them making it public, that people work differently, or what adjustments are possible that then makes it feel like actually perhaps it's okay to ask is really, really massive. So I don't think it should be too difficult. I think it's just about having the conversation.

Abigail:

So these adjustments shouldn't be too hard to make. But Diane showed just how valuable they are.

Diane:

We did a survey the great big workplace adjustment survey two years ago, just what it says on the tin. And although 80% of the people that replied and it was a big sample, it was 1200 people 80% said their adjustments, help them stay in their job and be more productive. And 60% said they even enjoyed their job more because of their adjustments.

A third didn't ask for them at all, because they are worried about what their manager would think. And the same number, a third, were worried about what their colleagues would think if they were seen to have, say, preferential treatment.

Abigail:

Making reasonable adjustments isn't just the law. They change people's lives for the better. And they benefit businesses too.

And Diane told me that adjustments aren't just for retaining employees with disabilities. She even went on to say that pharmacy employees could be making adjustments to recruit more inclusively, too. She said, many people with autism, for example, may find it difficult to show you what they're made of in a traditional panel interview. But there are other ways they can show you their skills.

Diane:

Particularly where people are applying for, say, technical roles, or scientific roles, that don't actually require someone to be able to be being the external face of an organisation and presenting, arguably, a panel interview doesn't test the right skills at all.

So under the Equality Act, offering, say a work trial, as a reasonable adjustment instead of a panel interview is perfectly legal and acceptable. And it can be a much better way for someone to show you how they would do a job rather than having to tell you about it. Some of the other things that we're seeing as good practice include letting people see where they will be interviewed, or make the panel first or even have the questions first.

Abigail:

And with Diane's inclusive approach to recruiting pharmacists, we'll be able to support people with a range of disabilities to join the profession. And Diane told me just how important this is.

Diane:

I think diversity across the whole the workforce, but particularly at senior level, it makes them much better decision making, it makes for much better product and service creation and delivery, because it's actually reflecting a much wider breadth of the community that you want to serve. And people with different backgrounds have different life experiences. And this is true across the whole of diversity, not just disability, and they bring different perspectives will create better solutions, because they will have that much better breadth to be able to design out what doesn't work to know what does. And you know, numerous studies show that diverse teams are more productive.

So how can employers make sure that they're nurturing a workforce with different perspectives? They should look at their policies and their processes differently. And if they have an HR function, or if they're a small organisation, and it's just the manager, talk to the manager, and suggest they need to do something about it. Because lots of times, people sort of don't know what they don't know. And once it's pointed out to them, what's not there, then usually, hopefully, there is an appetite to get better.

But organisations are at different stages. And that's fine. Just want you to take the next step really, and get better and realise that there is loads of practical support out there. And it doesn't have to be difficult. I'm not suggesting that you should necessarily hire a disabled person. But why on earth would you want to have procedures or policies or processes that exclude someone who could be the best possible person for your job? That just doesn't make any sense. So talent comes in all forms. That's what I would say. And yeah, let's just be inclusive and embrace the widest possible talent pool and the widest and best possible workforce.

Abigail:

So employers, it's on you to think about how you can better support people with disabilities, including hidden ones. But of course, since these disabilities can't be seen, there's also a responsibility for people to speak up about them to their employers. After everything we've heard, it's hard not to wonder whether things would have gone differently for Nalwenga if she'd spoken up to her employers at the hospital.

Nalwenga:

I think so, because my biggest thing was just walking. So being on the wards and standing up because a lot of the time there wasn't anywhere to sit. So if there was somewhere for me to sit, then I think it would have made the job a lot easier. There can always be accommodations for people. People don't always realise that we're all fighting battles. And I think the whole thing is just to be kind to everyone. Yeah, I don't need a label for someone to be kind to you.

And just to be aware that, you know, sometimes people do look like as if nothing is wrong, but they are fighting something. And it doesn't always have to be like they're in a wheelchair, or they have a stick when you can't see it doesn't necessarily mean that everything is okay, so just to be kind to everyone.

Abigail:

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