

Monthly newsletter for people caring for those affected by Alzheimer's disease or another form of dementia.

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Raising Awareness of Incontinence and Dementia

By Amanda Quinn. Originally published by Alzheimer's Society UK

This month, we're featuring a story from across the pond. Amanda Quinn wasn't aware that incontinence could be a symptom of dementia when she was diagnosed at age 49. Read her story here and learn why taboos around the restroom must be broken.

At 49, I was diagnosed with rapidly progressive Alzheimer's Disease.

I couldn't believe it. Dementia at 49? I didn't know it was even possible to get dementia so young – I just couldn't comprehend it.

It was my family that first noticed my symptoms. They said my personality had changed. I was being forgetful, had terrible mood swings and was struggling to sleep.

I just put it down to menopause, but apparently it wasn't. I went to the doctor one day and she asked 'what can I do for you?' I had to say "I can't remember why I've come."

Although I was given some information about how dementia progresses, it's still a shock when new things happen.

I started noticing that every time I went out in the car I would mess myself. I never had any sign that I needed the toilet or anything.

Then it started happening in bed at night – so it became more and more. Sometimes you just don't know you need to go to the toilet before it's too late.

It was a huge shock - I just wanted to cry. Never in a million years did I think this was going to happen to me.

Now we can't go anywhere without a spare change of clothing. It can happen anywhere – in the shower, the car, or in the street. Anywhere. You don't get any warning. It happens, and you don't know it's happened until it's done.



Amanda (left) with her daughter Bethany

If I'd have known what was coming, that might have made it easier to deal with. When I first told the GP what was happening I didn't think they knew how to explain it. I think they need a bit more training on that. They just couldn't tell me why it was happening.

I had thought dementia meant memory loss and that it was for old age pensioners. It wasn't until the NHS continence team got involved that I was told unfortunately this can be part of dementia too. They sorted me out with incontinence pads and everything else.

There's not a lot of information out there about incontinence. You have to ask the right people for information. But who do you go to?

Because it is embarrassing, especially at a young age. You need to be able to pick something up to read that's easy to

Continued on next page

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understand. You don't want any of this medical jargon – you just want it straight to the point. For people with dementia, reading is a hard thing.

My family and husband were able to support me. But I didn't know who else to go to.

The Change Amanda Wants to See

There's nothing you can do to stop it from happening, but there needs to be more access to public toilets. Not a lot of shops have toilets you can use. A lot of them will just say you can't use our toilets – and then you're stuck.

There also needs to be changing facilities within the toilets, so that if you do have an accident there's a sink there and you can change. In a lot of public toilets the sinks are outside of the toilet area. That's no good if you need to clean yourself up. You might need help as well, so it needs to be a big enough cubicle for two of you.

Not all trains have toilets either, unless you're on a long journey. If you mess yourself on a train like that, you've got to sit in it until you get to wherever it is you're going.

Definitely more awareness of incontinence and dementia is needed. More help needs to be given.

Some of the products and incontinence pads need to be sorted out too, because they're not all suitable.

The sizes of some of them are ridiculous. It can go from stupidly thin—which does nothing—to ridiculously thick, to the point you're

walking around like John Wayne. I mean no disrespect - but we don't all go around wearing granny pants. They won't fit inside your knickers!

And they're so uncomfortable and bulky. There's nothing discreet about them – you can see when somebody is wearing them.

I know a lot of people with incontinence are farther on in their journey so they don't think about it. But for people like me who are just starting out on their journey – it does bother me. I don't like the fact that people can see it, so I have to wear long clothes.

A lot of things need to be changed.

Amanda's Advice for Others

Be prepared. Take extra clothing and wipes with you wherever you go.

If an accident happens, don't make a thing about it. Just go off to the toilet and do what you have to do in the best way possible.

Don't get upset or make a big song and dance about it – especially the [caregivers]. At the end of the day it's a medical condition. We cannot help it. It's an accident, so move on from it - and I know that's easier said than done.

I'd like to see a change in attitude across society. There needs to be more awareness as to what it's actually like to live with dementia. We're not a lost cause. People need to know that life can go on after a diagnosis.

I know it's upsetting and embarrassing, but if you experience incontinence you just have to hold your head up high.



TIPS

Accidents happen. Here are some tips for caregivers handling this common issue:

- ◆ Be matter-of-fact. Don't shame or scold the person after an accident.
- ◆ Encourage them to tell you when they need to use the restroom.
- ◆ Watch for nonverbal cues - restlessness, unusual expressions, pacing, etc.
- ◆ Establish a regular bathroom schedule, perhaps every 2 hours.
- ◆ Make it easy to find the bathroom by keeping the door open and light on.
- ◆ Make sure they stay hydrated, but limit fluid intake near bedtime.
- ◆ Choose clothing that is easy to remove and clean.
- ◆ Use waterproof mattress covers, pads, or both to keep fluids from soaking into their bed.

Find more tips at alz.org

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