Gail podcast episode transcript

Jim: [00:00:00] Welcome to My Life with Dementia, a podcast from Dementia UK. I'm Jim Broadbent. I'm an ambassador for the charity. In this series, you'll hear from people whose lives have been impacted by dementia. Gail was diagnosed with young onset Alzheimer's disease when she was just 54 years old. She has good days and bad days, but she's found ways to see the positives in how her life has changed, discovering new passions and appreciating the small things in life that used to pass her by.

Gail: I grew up in a little town called Nelson, which is very near to Burnley. Everybody seems to know Burnley because of the football club, but I lived in Nelson with my parents in a little terrace property. It's only a little town, round Pendle, but yeah, it's great. [00:01:00] My parents would say I was an annoying child. Um, a needy child. My parents would most probably say. I was an only one and most probably got bored quite easily. I can remember the ones told me that they'd gone to Butlins or Pontins for a holiday, and I was the child that screamed all the time. That kept coming up over the telly, child crying in Shelley, whatever, and I was that child.

I live in Lancashire, near to Blackpool in a little bungalow, and I'm joined by my husband John, who I call 'Hubby' and my two dogs. Toby, who's, I think, eight or nine, and Sooty, who is eight months old. Toby has been my best pal for years, and through my dementia journey, he's meant quite a lot to me. He's always by my side, and he seems to know when I'm having a bad day.[00:02:00]

He'll come and sit next to me and he presses his body up against my legs as he's acting like a little bit of security, I think.

Jim: Twenty three years ago, Gail's now husband, John, had a crush.

Gail: I used to go out occasionally with my mum on a Saturday night. I didn't go out much, I was a single parent with two children.

My dad used to sit in and look after the girls and me and my mum would just go for a quiet drink to the local pub. And we'd go on one Saturday night. A lady who I knew approached me and said, my cousin's interested in finding out more about you. And I said, "No." Basically, no. I don't want a relationship.

I've had enough of men, that's it. And that was it. Anyway, a couple of days later, I went to visit a friend who lived next door but one to this lady. And my friend said, oh, I believe that somebody called John Gregory's been interested in you. I said, he's [00:03:00] married. She said, he isn't, he's divorced now. And I said, oh.

And I think it were, is there a little glimmer of interest there? The next week when I went out, we met in the local pub. And, yeah, just chatted all night, talking and talking. We met the week after and we've never been apart. We always say that we're a good team. We work together quite well. I'm not saying it's perfect all the time, because it's not, but since dementia I think we've got more of a special bond now.

Jim: Gail was diagnosed with dementia in 2019. At the time, she was running a business selling personalised teddy bears.

Gail: My mum used to make the clothing for the bears, and then I would embroider onto the bear's top a message for that person. Happy birthday, happy anniversary. [00:04:00] My recall memory was beginning to fail me, and I'd noticed people were ringing up giving me orders over the telephone and I was writing things down, putting the phone down and then thinking, was that right? I can't remember. Was it right? I realized that I couldn't retain the messages that was being said to me. So I started letting the answering machine kick in. John realized that I was doing this.

And he had questioned me on, on why the answering machine was always on. I just kept saying, it's cause I'm busy. I'm busy, John. I'm busy. And it was because I couldn't retain the information. John noticed changes, but John, being a man, sometimes tries to put them to one side and won't accept that there's changes, and makes an excuse for something, which he did quite regularly, until we [00:05:00] went to the doctors and he did the simple test of just, can you draw me a clock face?

And I couldn't do it. And I'd never even thought about that at the time, but I just couldn't get the numbers in the right place. And they said an address to me and I couldn't repeat the whole address. I were only getting odd bits because I wasn't retaining. And I could see John's face at the side of me and he knew then that there was something wrong.

We went to the memory clinic. They asked me to name an animal. They gave me a letter and said name an animal. And I named one or two animals and then that were it. And I could see him willing me carry on repeating the names of all these animals. It's quite scary at first. Reality hits you that there is something wrong, there's something happening somewhere and um, I think that's when it hit John that he [00:06:00] knew then that there was something more than just stress.

We were pushing it to one side. People will say well I forget this and I forget that and you know I lose my keys and I, yeah I lose my keys all the time but all I'd say is do you lose yourself? Because I lose myself quite regularly. Walk into a place, go to the toilet, come out of that toilet door, and not have a clue where I am. And I'm lost. Totally lost. That's the difference.

I think it was around seven or eight months of to’ing and fro’ing to hospitals, to memory clinics. I had blood tests, I had MRI scans, I had written tests, verbal tests, and they came to the conclusion because of the scoring on my [00:07:00] tests and everything that it was Alzheimer's. It's a bit of a shock when you actually get that diagnosis.

I know a lot more now about dementia but at the time I'd never heard of anybody getting dementia at 54 and yet there's people a lot younger than me that have dementia. We walked out of that clinic quite numb, really. What people don't understand as well when you get early onset dementia, you still have working age, and John had come out of work to come to the clinic with me, and then we both walked out and went his separate ways, because John had to go back to work, and I was coming back home alone.

Thinking about what's just gone on. I can remember him ringing up a couple of hours after to ask if I was alright. And me being me, yeah, I'm fine, I'm fine. And I wasn't fine. [00:08:00] I think I was in shock, really. Feeling quite numb and empty. And that was when I realised that once you've got your diagnosis, You're into a new chapter.

It's like entering onto a new motorway not knowing where you're going.

Jim: The early days after Gail's diagnosis were very tough.

Gail: I suffered really badly with anxiety. And travelling, going anywhere, for some reason anxiety just took over. A new thing for me, I had people coming round to the house. Telling me that I was doing okay.

They didn't know anything about me, but because the house was clean, um, they never asked how I was.

Jim: A support worker recommended a local dementia support group.

Gail: I was reluctant to go to the group and she said, “No, no, no, it will do you world a good if you go.” [00:09:00] So I went and within 20 minutes of me being in that room with the people…

They were lovely people, please don't get me wrong. They were absolutely lovely people. But they was all, I'd say, 15, 20 years older than me. They was in the later stages of dementia. Some couldn't even remember the name. They didn't know why they were there. And I was sat in this room. I'd been diagnosed about three weeks.

And it was terrifying. And I went to the toilet in tears. and said, come and pick me up because I don't think I can cope with this. I can't do this. I can't have a life like this now. This is going to be me. And it was terrifying. And I was really down about that for a couple of months. It really hit me hard thinking that I wasn't going [00:10:00] to know who I was or who my husband was.

And it was scary. It took me quite a few weeks to get over that. And then I was invited to go to another group. And what a difference! I walked in and I could hear laughter. And I could hear people joking and talking. And there were people around my age. And it was wonderful! We sat and we had a drink and we talked and we discussed things.

And I think that was the turning point for me. Because I realised that just because I have dementia, I don't have to sit there all serious and sad. I can still have fun, and I can still enjoy myself. The thing is, when you get your diagnosis, Imagine your life suddenly comes to a standstill. Everything is taken away from you.

Even my [00:11:00] identity. I just become a dementia statistic. It's not like me to sit back and do nothing. I have to do something. And you're given two choices. You can sit back and do nothing. Or you can find another way through it. And for me, I was looking for that way through. So the peer support groups helped me.

Immensely, because I was seeing that there was people out there that was living well with a dementia diagnosis. It wasn't just sitting there and deteriorating. I've met many, many, many people that have been so inspirational that have helped me along my journey. Because this is my next chapter. This is my dementia chapter.

Jim: Gail even started referring to Alzheimer's as her ‘sidekick’.

Gail: It's an accepting thing, I think. I have accepted my diagnosis now. It's taken me quite some time. And I suppose I'm still accepting it [00:12:00] and still growing and learning. But it's an easy thing for me to say that, Oh, it's my sidekick that's causing trouble today.

Jim: So Gail and her husband began adjusting to life with Gail's new sidekick together.

Gail: We had a few moments where the understanding of the disease and what I was going through I think was difficult for John. I think it's all about communication. That's what we do, we communicate. So if I'm having a bad day and John thinks I can just carry on, we sort of talk about it and I'll say, you know, and tell him how it feels.

Because nobody knows how it feels until you actually tell them. It is adjusting and it's accepting as well that things aren't the same. It's not just you adjust for that moment, it might be a couple of weeks down the line and then you're adjusting something else because something else has changed. One of the, the [00:13:00] main adjustments was I don't sleep very well.

So now we have separate bedrooms. And at first, if you say that you're a married couple and you have separate bedrooms, a lot of people go, Oh, but it works and we still love one another. And we can still be together. It's just that we sleep separately. You know, it was difficult at first. Do we do it? Don't we do it?

But why not? If you're comfortable. I think we've become closer, um, and I, I also think John listens more. He has to do.

Jim: When Gail decided she wasn't going to sit there and do nothing, that she wanted to live well with dementia, she turned to something brand new.

Gail: I'd never done art before. I was told at school I was useless.

So there you go, I've learnt how to paint and to draw. While living with dementia.

Jim: Art and [00:14:00] photography have become central to Gail's life now.

Gail: We're sitting right now in my craft room. And my craft room is my haven, my sanctuary, my safe place. I spend lots of time in this room. Around me we have my artwork.

We have crafts. We've got boxes and we've got containers which are all neatly labelled. So that I can find everything. There's lots of things for my card making, and there's files, and there's scissors, and rulers, and tapes, paintbrushes, my watercolours. It's just quiet, peaceful, and I can be me in here.

Jim: Of course, there are still bad days.

Gail: When you wake up, and you've no idea where you are, and you're in your own home. [00:15:00] Things smell the same, but it doesn't feel the same, if that makes sense. I get up and I open the bedroom door and, and I'll bump into the, the door frame and my balance is a little bit wonky.

and I'll look at the cup of tea that John's prepared for me the night before. There's always a cup with a teabag and the sugar in and all I've got to do is put the water in. But getting the water in the kettle sometimes, getting the lid off the kettle, is a task to be able to figure out how to do it.

That's a really bad day. And the feeling in your head is a heavy feeling. It's a jumbled up feeling. I hate that feeling. There's like something inside my head that I can't control. It's horrible. It really is [00:16:00] horrible. I hate those days. But we don't dwell on the bad days now. We think about the things that I can do and where I can go.

And the thing is, people think that once you've got that diagnosis that there's nothing left for you. They're wrong, because I'm living with dementia. And I've tried lots of new things. And I like to try new things. I like to see if I can do it. If I can't do it, fair enough, but I've tried.

Jim: Gail continued going to dementia support groups, and it was at one of these that she first met an Admiral Nurse.

These are specialist dementia nurses supported and developed by Dementia UK. They give free advice and support to people living with dementia, as well as their families and carers.

Gail: I think I'd had one or two changes with my dementia and it sort of throws you back a little bit. I just said to her, yeah, I haven't been coping very well.

And she said, well, I'm going to give you my [00:17:00] phone number. And if you feel that you're not coping, ring that number and we'll come round. I said, but I don't ask for help. I said, I don't do help. I'm not very good. I said, but I'll put the number in my diary and I put it in the back of my diary. Normally, I would have come home and thrown that number away.

Because I do things like that. Because I don't need help. And I didn't. And it was a couple of weeks down the line and I was really, really struggling. I'd had a very bad encounter with a healthcare professional and I'd hit rock bottom. My husband couldn't sort me out and I couldn't sort me out and everything was getting on top of me.

And I was quite depressed actually. And I went to the back of my diary, and I phoned the number, which took me to the Dementia UK Helpline. She said, please [00:18:00] don't worry, I will get somebody to contact you. And within minutes, the phone rang, and it was this Admiral Nurse called Maxine. She came round and we chatted, and she had time for me.

And this is the difference, if you go and see your doctor, you're in and out in five minutes. The Admiral Nurse had time, and she sat and listened to every single word I had to say. She didn't judge me, she hugged me, and it was just wonderful.

I do think about the future, but I tend not to sort of dwell on the future, because I live more for the here and now. That's what's important to me now. I do have a death folder, which everybody's sort of, oh what? It's a death folder. It's also, I suppose, a living folder, because it's got things in there [00:19:00] so that if I do get to a stage where I lose capacity and I can't speak, in that folder, tells people the things I like and the things I don't like.

Because if you put peas on my plate, I'm just going to throw that plate at you. Something so simple. Like, I don't want to drink out of a plastic mug. I want to drink out of my China mug. When you get to that stage where you might not be able to communicate, some people might not know these things.

And it's very important for that person to be comfortable. If you have to go into a care home, I want to have my favourite blanket and I want to have my favourite mug. And I don't want people feeding me things that I don't like to eat. And my death folder, of course, well, that's got things in that can help people navigate what to do.

And I do talk about it. I never used to do, but we talk about it now. [00:20:00] I've told my daughters, who were horrified when I said to them at first, let's talk about death. Mum, mum, no, you're morbid. No, we don't want to talk about it. Yes, but how do you know what tunes I want playing at my funeral? And there was silence, and I said, because I want tragedy.

And there was laughter. Tragedy by steps means a lot to me and my girls because we once went on a holiday to Turkey and we did that dance quite regularly. And so I said, yes, that's what I want playing at my funeral. So you can sort of talk about things like that and make it a light hearted subject.

After I'd sort of picked myself up from the depression of getting the diagnosis, [00:21:00] I started looking on life more positively, and I'm never used to be a positive person. So dementia has changed my whole attitude to life, which I'm thankful for. Now I see the good in everything and the positive, and I can walk outside with nature whenever I want now.

And I can stand and take in the smells and the sounds and just be Gayle. I'm just in the moment, not dementia. Dementia's forgotten. Because I'm just focusing on the beautiful sounds of the birds and the smells. Lifting a camera and taking a photograph because that way I've got my memories.

Before dementia I would have never in a million years gone for a walk and stood and [00:22:00] listened to nature. So I'm thankful for that because it's given me a different outlook on life. It's given me a calmer approach to life. I like to go to the nature reserve, which is only a 5, 10 minute drive from here.

And if you go early in the morning like I do, at 5, 6 o'clock in the morning, there is nobody around. And I can sit, and I can look over the river wire, and I can listen to the seabirds that come in and out of there, the oyster catchers, the herons. And then I can walk around and go to the pond. I can feed the ducks and the geese.

I have a little robin that at certain times of the year comes out of a tree. And I hand feed him. And we have a little conversation and then off he flies.[00:23:00]

I don't know what it is with dementia. People automatically think that when you've got dementia that that's it. And it's not. I am still that same person. When I got that diagnosis, I didn't instantly just deteriorate and go to the end stages. People forget that you had a life before dementia. Nobody's interested in what you've done before.

And I've had lots of jobs and I've done lots of things. And there's lots of people that live with dementia which are very clever people. Actors, actresses, poets, writers. And people don't realise this. I mean, I trained as a hairdresser. I've worked as a weaver. I've done packing. I've done cleaning. I've done management. I've worked with asylum seekers. And I had a life before, and I think that's important as well, because we are still people. I'm still Gail.[00:24:00]

Jim: Thank you to Gail for sharing how she's embracing life after getting her diagnosis of young onset Alzheimer's disease. You, or someone you know, might be experiencing something similar right now. So two of Dementia UK's Admiral

Nurses, Hilda and Vic, are here to expand on some of the themes that Gail brought up.

Vic: Hi, my name's Vic Lyons. I'm one of the Senior Admiral Nurses at Dementia UK.

Hilda: I'm Hilda Hayo and I'm the CEO and the Chief Admiral Nurse of Dementia UK. We've heard from Gail about how she's living well with dementia. So frequently, people are not living as well with the diagnosis because other people are telling them they can't live as well.

They're telling them what they can't do anymore. They're focusing on the negative aspects of dementia. For some families, it needs some sort of specialist support in order for them to be able [00:25:00] to kind of tap into their inner reserves that they will need to live as well as possible. If people are able to think positively after they get their diagnosis of dementia, usually it's because they have an ability to be able to see what they can still do, rather than be defined by the term dementia.

So, for instance, with Gail, she likes a lot of arts and crafts. She actually gets fulfillment in her self esteem and self worth. For some people, because of the changes that have occurred, they might not be able to engage in the hobbies that they once had. And so they, they need to find something that's different that they can still do.

So it's about exploring the person's strengths. It's about exploring their interests.

Vic: One of the things that Gayle talked about as well is sort of viewing dementia as her sidekick. And I think that, that helps her to, to live happily and to live well with this diagnosis, because actually [00:26:00] it's, viewing it as your sidekick is her kind of taking control in a way, because it's, it's there, it's her sidekick, it's with her, but it's not.

All of her and that kind of mindset is really helpful. But I think for some people, that's really difficult. It's very difficult to do that. And to actually sort of almost step outside and look at yourself and look at the situation and do that is really challenging.

Hilda: I think you can live as well as possible with dementia, but you do need support to be able to do that, right at the time of diagnosis, because if you don't get that support, it can go either way.

So for some people, they will, they will take it and the diagnosis will become them, and for other people, like Gail, it'll be something that's, you know what, I can still get on and I can still enjoy my life.

Vic: The other thing that I liked about Gail is that kind of planning that she's done that that's amazing, you know, to to to actively plan and decide what you what do you want?

What's how do [00:27:00] you want your life to be and have those conversations with your nearest and dearest to say to them? This is what I want. And that that's does so much to alleviate anxiety, to alleviate confusion, um, you know, and allowing it's so you to live well in the present because you kind of know what's coming to a degree or you've, you've tried to control it as much as possible, um, going forward.

Hilda: And I think that's the key thing. This is about control. It's about control over the person's own life. That gives you a sense of, of wellbeing yourself because you are making the decisions that you might not be able to make later on in the process. And then. Family can and friends can actually follow what your wishes are rather than making an assumption about what your wishes may or may not be.

Vic: Yeah, I think you're right. And I think then as well, it's also making sure that you document those wishes and that, you know, your loved ones are involved so that because you could have these wishes and thoughts yourself. If you don't tell anybody, it's like, how do they respect that? We all know, don't we, that having a [00:28:00] positive attitude to life is, is a good thing.

That's generally good advice to have a positive attitude. It gives you quality of life if you've got positive attitudes to things. And I guess one of the things I'm definitely going to take is that, that view that Gail had about her dementia as a sidekick. Because I think that's, that's a really good way of taking that identity and not letting the dementia own you.

Jim: This has been an episode of My Life with Dementia, a podcast from Dementia UK. Please do subscribe in your podcast app, and you'll get new episodes as soon as they come out. You can find lots more information about the things we've talked about in this episode by visiting the Dementia UK website. It's dementiauk.org. You'll also find links to the website and other resources in the show notes for this episode.

Thank you so much for [00:29:00] listening.