Andy and Christine podcast episode transcript

Jim: [00:00:00] Just a note, this episode includes a reference to suicidal ideation.

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.

When Andy found out he had young onset dementia in his early 50s, it felt like a door was suddenly slammed shut. The life he had imagined with his partner Christine was never going to be the same. But with support from friends, family and professionals, he found a way forward.

Andy: I'm Andy Moxon. I'm 53 now. I was diagnosed with [00:01:00] dementia at 52, so March last year, so coming up to 18 months now. Still undergoing tests to try and define which type of dementia it is exactly. I was born and raised in St. Anne's or Luton St. Anne's I should say. which is not too far away from Blackpool. I live with Christine, my partner, my missus, and Alfie, my dog, in Bolton, which is sort of my adopted town now, isn't it.

I love Bolton. For me, it's like the perfect place to live. Everyone slags it off, but I just think Bolton's really friendly. It's multicultural. Everyone just seems to get on really well with everybody.

Jim: Andy's great passion in life is sports.

Andy: God, from being 16, I was [00:02:00] bike racing, training, doing events all over the country.

I was quite a good cyclist when I was younger. I then stumbled across triathlon, and I thought, yeah, that looks hard. I think I'll have a go at that. I do Ironman, which is 2. 4 mile swim, 112 mile bike, and a 26. 2 mile run. And marathons, I do. Marathons, I don't just do one marathon, I do three marathons a week apart.

I like to push my body and my mind to see how far I can actually go.

Jim: There's a wall of medals in the house from dozens of marathons and triathlons. Most of them are Andy's. But his partner Christine has also earned her fair share. Christine and Andy were friends for years before they got together.

Andy: We were both instructors [00:03:00] with the army cadets.

I was with Lancashire ACF and Christine was with Manchester. We were just really good friends, like, from the first time we met, really, wasn't we?

Christine: I was meant to be having a bit of a gathering of different people from Cadets and I think he paid them all off not to come.

Andy: It cost me a fortune.

Christine: And then it just sort of went from there.

Jim: They've now been together for nine years.

Andy: I'm glad you gave me a chance. Or are giving me a chance.

Christine: I'm going to say I’m giving you a chance.

Jim: Christine was the one who first noticed something was happening to Andy, back in 2021.

Andy: Christine asked me to go to see the doctors because I was getting forgetful and I just laughed it off and went, Oh, you're all right.

I don't need to go. And she [00:04:00] carried on and on and on. Then I noticed that I was forgetting things, like important things. I thought, you know what, I'm going to go to the doctors just to shut her up. So I made an appointment. I saw the nurse first who did some blood tests. Within about 10 days I got another phone call, can you come and see me again?

And we did some verbal tests, if I remember.

Christine: That you thought you'd smashed.

Andy: Yeah, and failed miserably.

Jim: Andy didn't see a dementia diagnosis coming.

Andy: I was going to be told by the doctor that I was just forgetful, or I needed to take multivitamins, or just go away and stop being an idiot, basically.[00:05:00]

Christine: I'm a nurse, so I do come across patients with dementia who work in end of life care. My initial thoughts were for something else coming on. As the forgetfulness got a bit worse and some other symptoms like becoming more clumsy and things, then I was thinking, no, he probably, quite possibly could be. Um, obviously hoping that you're wrong and it is something reversible, but I wasn't surprised when he failed the initial test at the doctor's and then when he was referred on to the memory assessment team.

I wasn't overly shocked when she'd said her thinking was dementia. Whereas you were just…

Andy: It devastated me. I didn't accept it at first, did I?

Christine: No.

Andy: I went back into work the next day and told my boss. Just carried [00:06:00] on. And slowly, it started sinking in. That's when I then needed time off.

Christine: You were angry.

Andy: Anger doesn't cover it.

Drink was my friend. I could sleep on the days I had a good drink and didn't sleep the days I didn't drink. So you drink, and then you wake up with a hangover and you drink. Um, being perfectly honest, I don't think you'll like hearing this.

I used to just walk out into the road without looking. It wasn't that I wanted to commit suicide, I just wanted to die. I [00:07:00] was too young. I was 52. I was fit and healthy. I ate well. I didn't smoke.

What had I done to deserve it? Was it my fault? Why now? Finally happy. In a good strong relationship. Good job. Nice house. Just,

I didn't know anything about dementia. I didn't have a clue. Like I've said, I was just overcome with anger, with rage.

Christine: I think you just couldn't see how you could move on from that point of diagnosis. And what hadn't helped at that point was the initial diagnosis and then nothing.

Andy: They said I've got dementia, they put me on medication.[00:08:00]

Christine: And then we were waiting for this ongoing testing but from that point there was just no contact with anybody. There wasn't like a little package with some leaflets of local support groups or anything like that, there was nothing. That, knowing where to go for support, very difficult. And knowing where to go for support for somebody who's 52.

We felt very alone and very lost. Through doing some research ourselves, we reached out to several nurses. And that was a big change point for you, wasn't it?

Jim: Admiral Nurses are specialist dementia nurses, supported and developed by Dementia UK. They give free advice and support to people caring for loved ones with dementia, and people like Andy, who are living with dementia themselves.

Andy: I saw an [00:09:00] advert on Facebook for Admiral Nurses. I'd never heard of Admiral Nurses or anything, it was all new to me. And, I can't remember her name, I wish I could, because she was amazing. She explained everything, what dementia is, how dementia works.

Christine: It was very useful that, as much as I'd tried to explain things to him, it coming from somebody else, who purely deals in, that area. The specialist nurse in that area, made a huge difference.

Andy: But it wasn't just about the dementia that she helped. I remember, and this sticks in my mind, even more so now because I am forgetting people's names. And it scares me, it still scares me, that I will forget people. And she just looked at me and said, yeah, you might forget who they are.[00:10:00]

But you'll never forget the feelings you get off that person.

So I know the day that I forget who Christine is, that I'll still know that she's only with me for the money.

Christine: Good job, I love you.

Andy: No, I'll always know the love that I get off Christine. And the other people around me who, have a big part of my life. But yeah, her and the GP, my GP, just basically told me off, told me how it was, didn't sugar coat anything. But then, explained to me, [00:11:00] which Helen, Helen, there, knew it would come!

Christine: That's a bit of a surprise.

Andy: Both Helen and my GP both said the same thing, that negativity will feed the dementia, where positivity will push against the dementia, so hopefully slow things down. And I remember coming out of the meeting with the admiral nurse, sitting on that little bench on the corner, and just burst into tears.

And we cried for, it seemed, forever. That was sort of like day one of me accepting it. Me not giving in to it.

Christine: She normalised the fact that he was angry. That was [00:12:00] completely normal, part of a grieving process.

Andy: Yes, she did, didn't she?

Christine: The life that you expected you'd have, to the life that you're going to lead.

Andy: Yeah.

Christine: Which helped.

Andy: Yeah, because I'd never thought of it that way. I was just angry. And I didn't know why I was angry. My mum had terminal cancer and she just faced it head on. There was no depression, there was no Sorrow. There was no pity. Yeah, that seemed to be all I had. Self pity. Anger.

And she did. She explained everything, didn't she? So I sat down and just thought to myself, I've got to just try and make a good life with what I've got left. The first thing I did, basically, was tell people. [00:13:00]

Jim: Andy let his friends and community into what was happening. And that has been critical, not just for his mental health, but in holding on to his independence too.

Christine: We've set up things with a couple of local places, local bar. If Andy gets disorientated or doesn't see quite himself, they know our address. Taxi home.

Andy: Your phone number.

Christine: They've got my number. At the local supermarket, the staff there are fantastic with you and there's been a couple of times where you've been a little bit not yourself.

They're really understanding. So yeah, little things in place. I think that being open and honest about things is helpful.

Andy: Recently somebody did say to me that they don't know how I can be so open. I want people to realise that they're not alone.

Jim: And he also took himself to a local dementia support group. [00:14:00]

Andy: Seeing somebody who's obviously in the later stages of dementia, hearing a song, getting up and dancing with a big beaming smile on their face, for me, was just like, there is still enjoyment in their mind. And then Dementia UK put a badge out saying the sun still shines in their muddled mind.

And On the Wednesday, I'd seen this old fella just, who was literally just sat there, not speaking, suddenly jumping up and just dancing and beaming a smile on his face. And then suddenly I see this badge, and it's like, oh my God. This last few days has just, the world telling me, you're better than where you are.

You deserve better than where you are. You're stronger. Yeah. Where you are.[00:15:00]

We just then carried on, didn't we? I went back to work with some changes.

Christine: I covered some of the practical things of looking at lasting power of attorney, horrible thought that most people don't like to think of, advanced care planning, of what will things look like for Andy in the future, what does he want.

Andy: We sat down and planned him a funeral.

Christine: Yeah.

Andy: Paid for it.

Christine: And did those things because the difficult conversations to have with anybody but the importance of doing these things while people have the capacity to express their wishes Whether it is a funeral, whether it's a will, but particularly for the advanced care planning and how they want to be cared for rather than a loved one having to guess up what is the right thing for their loved one.

So I dealt with lots of the practicality side of things.

Jim: There was another huge thing that Andy needed to get back [00:16:00] when he decided he was going to keep living his life. The triathlons. The marathons, the Ironman events. When Andy was diagnosed, he thought that part of his life was over.

Andy: Christine, my GP, and an admiral nurse, sort of made me realise that you can carry on with things.

Jim: So now Andy's back to training, but with guides. Christine, friends or even people from the local running club will join him to help spot potholes or speed bumps to make sure he remembers to eat. With their help, Andy's been able to carry on competing in some of the most challenging athletic events out there.

Andy: We had some T shirts made up. Andy's adventures with dementia. Just for a bit of, bit of a laugh, you know, just

Christine: Makes a bit of awareness. Yeah.

Andy: I've raised money for dementia in the UK, [00:17:00] yeah. And people came up to us and were like, Oh, who's Andy? I am. No, not really, who's Andy? Yeah, I am. And then they'd speak to us about their husband, their wife, their mum, their dad, their grandad.

Oh my God, they've just been diagnosed with dementia. Yeah. It then suddenly, very quickly, just became this whole new aspect and it wasn't me just running for me, it was me running

to prove a point that I am Andy with dementia. I'm not dementia. I'm still me. I'm still Andy.

Sport has become[00:18:00]

a big release for me. Especially swimming, and I cannot believe I'm saying this, because I used to hate swimming. Swimming is now the only sport I can do without a guide. I can just get in the water, I can't trip over anything. I can get away from everything. And I love my guides, and I love my friends.

And it's nice just to get in the water and just swim.

I used to sing to myself as I was swimming. Now I don't, I don't even count my strokes. I just, I literally, I just shut off. And I can get out of the water after having a bad day and it's like I'm a new me.

Jim: As his dementia progresses, there are new things [00:19:00] all the time that challenge Andy's resilience.

Andy: Some adjustments I deal with really well. Other things I find really hard. Choking on my food. For God's sake, it's like, Chewing is just, you don't think about it. But I've lost count of the amount of times you've had to give me back blows.

It's a good job I'm good at it.

Well, not really, cos if you was bad at him, you'd be living in a nice posh house in Lanzarote, cos you'd have got the life insurance.

Sometimes I feel weak and pathetic if I get emotional, especially when it comes out of the blue. You know? So, yeah, maybe someone hearing that I get emotional might make them feel better if they get emotional, cos, you know, every day's a good day. [00:20:00] Even though my mates do my head in, all they see is the strong, determined, never say die, Andy.

No one sees the emotional wreck. You know, the guy that just shouts at Christine because I couldn't remember the name.

Yeah, sometimes I need a cry. A good cry. But me and Christine have made a bit of a pact that we won't hide the tears and anger from each other.

Honestly, and I say it all the time, my friends, And my family are [00:21:00] amazing, absolutely amazing. I couldn't do anything that I do now without my support and I know that. I, you know, I try, I dig my heels in some days and I'll kick back and push.

Because I'm just so angry.

But then, at the end of the day, when I'm sat at home, I just think, yeah, stop being an idiot. Just accept that I'm lucky, that I have got the support and the friends, and people queuing up almost to do things with me, aren't they?

How many people tell their partners that they love them every day? Cuddle up when they go to bed at night. Probably not every day. [00:22:00] And now we do.

Christine: It makes you re evaluate things and prioritise things that are important that you might not be able to do in the future.

Andy: Yeah. We do things now rather than wait. We do things.

Jim: An enormous thank you to Andy and Christine for sharing their stories so far. You or someone you know might be experiencing something very similar right now. Two of Dementia UK's Admiral Nurses, Hilda and Vic, are here now to offer a bit more knowledge from their many years experience supporting people like Andy.

Vic: My name is Vic Lyons, I'm one of the Senior Admiral Nurses at Dementia UK.

Hilda: I'm Hilda [00:23:00] Hayo and I'm the CEO and the Chief Admiral Nurse of Dementia UK. So we've just listened to the podcast from Andy and Christine talking about the emotional impact of a diagnosis. And in particular, Andy talked about the feelings of grief and how he felt depressed and anxious after that diagnosis and felt like his life had been turned upside down.

That's a common feeling from experience. People under the age of 65 do not expect to have dementia. People are more likely to think of people with dementia over the age of 80. When a person is still working, when the person has got a young family, when the person is in kind of an everyday relationship with their partner, and this hits, it can hit right to the core of the person's soul.

It's difficult to be able to have any sort of hope at all. It's difficult to be able to plan what to do next, particularly if [00:24:00] you don't get specialist support at the time of diagnosis. I've come across families that either wrap the person in cotton wool and don't want them to do anything at all just in case that person's in danger, and other families that totally deny what's going on and are probably taking unnecessary risks at times.

People tend to see you then as a diagnosis. So they will see you the diagnosis first and they'll see Andy second. So the response that Andy had is not at all unusual. I always remember working with a family and this gentleman was in his forties. He'd got the diagnosis and he went into deep depression.

His family thought he was going to die. Their response to him had changed, and they were the wrapping in cotton wool sort of family. He felt that his self esteem had dropped, his self worth had dropped, he had to give up his job. And when we were sitting down, I was saying, well, what strengths have you got?

What things are you good at? And he kept saying, He was saying, well, I [00:25:00] was good at my job, and all of the things that he'd now lost, through no fault of his own, this is what he felt he was good at. I said, well, what do you like to do? And he said, I've always wanted to take photos and to do watercolors. And I said, well, why don't you register with your local college?

And what, can I? Yes, of course you can. He did that, and the watercolors and the pictures that he produced were absolutely fantastic. His esteem went up, and his esteem within that family went up too. So it's important. The same as Andy has found things that really, really matter to him and that he can enjoy and do, I think that's the most important message for anybody that's living with young onset dementia.

Vic: Yeah, I think for me, I'm just going to build a little bit thinking about those kind of positive affirmations and that holding on to the sense of self because they're, they're bits for me that are really important. We do, we tend to sort of have this thing where we see someone's dementia so big and so huge that we stop seeing the person.[00:26:00]

The dementia is too big and we kind of can't see over it and, and then what people also do is that they stop taking risks and, you know, and life's full of risks. You kind of need to take risks to allow somebody to do what they want to do, be that riding a bike, running a marathon or baking a cake. It's, you know, it, why not?

It's, it's about taking managed risks in a safe way. When I talk about that holding on to the sense of self, we all like different things. We've all got different interests and hobbies and, and things that we're passionate about. Making sure you maintain them and you kind of have them as a golden thread through someone's life.

So, you know, I remember working with somebody who, who really liked certain type of music. And I won't mention the artist because there's one sure way to upset people if you mention an artist, but there's this particular artist, there's this gentleman really liked and, and whenever he was exposed, Experiencing distress due to his dementia because we knew this about him, we could put on this artist, we would do some dancing and some [00:27:00] singing, and his mood would lift and, and within no sense time at all, he'd be telling you stories about when this artist performed in the Savoy and he met them and, and these kind of key stories that made him feel a real sense of who he was and the things that were important to him.

And, and I think that's the kind of steps towards acceptance that you can take. You keep who you are. Yes, you've got this diagnosis now, and yes, it's difficult to live with, but actually, this will help you to accept it if you keep the other bits of you too, and don't kind of let them kind of go by the wayside.

I also talk about people setting small goals. So, you know, if somebody was somebody who used to make a full Sunday dinner, and their Sunday dinner was cracking, and people used to come and flock around the table, you might go, well, okay, they can't do that anymore, perhaps. But they can peel the carrots, they can do the parsnips, they can be there to kind of tell me over my shoulder that I'm not cutting the turkey right or whatever it is that's going on.

So they're still involved, [00:28:00] um, which just doing it in a way that that's managed rather than in this kind of sense of, Oh, it's too risky. We've got this diagnosis now.

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. This story contained particularly heavy themes, so we've provided some additional mental health resources in the show notes. Thank you so much for [00:29:00] listening.