Interview: author Wendy Mitchell on how to live with Alzheimer’s and vascular dementia

The former NHS manager shares life-affirming insights on how to cope with the incurable diseases

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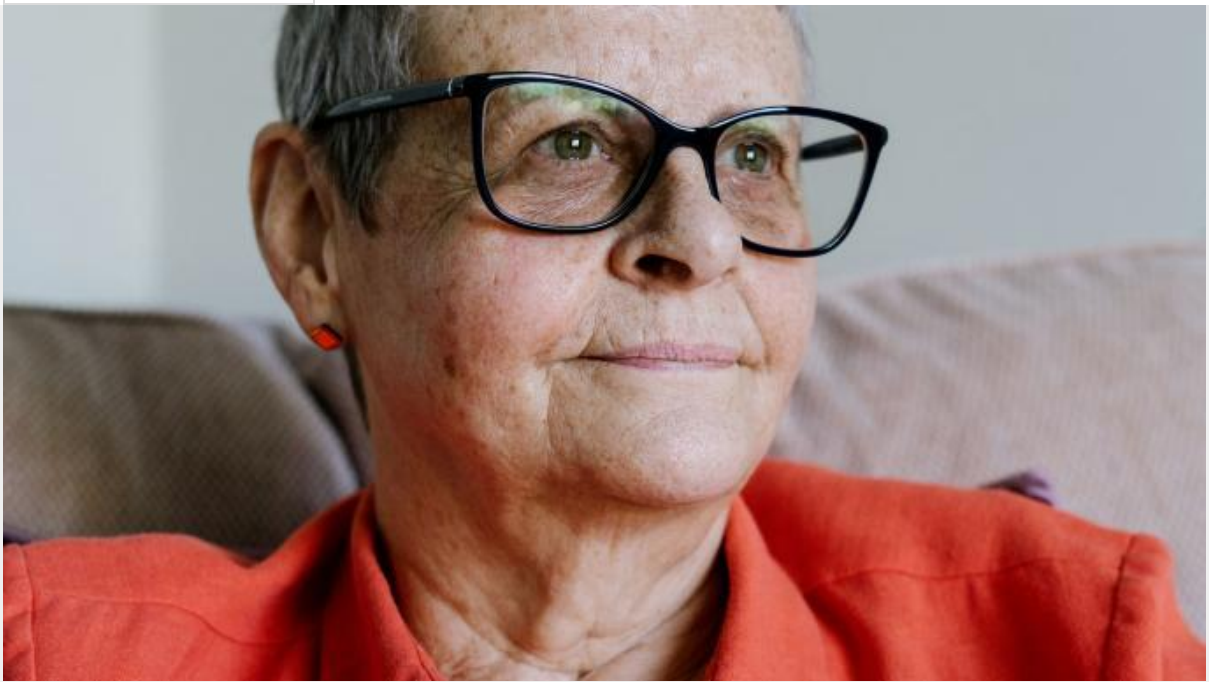

Wendy Mitchell PORTRAITS BY CHRISTOPHER NUNN

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The first time I met Wendy Mitchell, almost a year ago, we were on stage together at the Hay literature festival. Hundreds of fans had come to hear the author talk about her bestselling memoir, and she held the packed house spellbound, dissolving her audience into occasional gales of laughter with flawless comic timing. Even more unforgettable than the standing ovation, though, was the ripple of stunned silence when I asked Mitchell how much of the evening she would remember the next day. “Oh,” she replied airily, “barely a thing. Maybe nothing at all.”

This time, before my visit to her home in East Yorkshire, Mitchell has to find a photograph of me on the internet so that she will recognise this total stranger on her doorstep.

“I couldn’t remember what you looked like, or anything we did. I just remember we had a nice time, and it made me feel nice,” she says, welcoming me into the tidiest house I have ever seen. “Everything has to be in its place,” she explains, as I admire the immaculate cottage where she lives alone. “Otherwise, it doesn’t exist. And I have to have a routine, so I always clean on a Sunday morning. What day is it today?” It’s Monday, I tell her. “Ah, so I probably cleaned yesterday.”

Only five years ago, Mitchell was the type of person who knew what time and day it was to the nearest minute. A dauntlessly capable NHS manager, she had raised her two daughters alone on precarious finances, expertly navigating life’s relentless demands. Roofs were refelted, bedrooms decorated, cakes baked; departmental budgets were balanced, performance targets met. And then, out running one day, she fell over. The unexplained falls kept coming, along with a mysterious and sinister mental fog. One day at work, while chairing a meeting, she found herself searching in vain for a simple word. Hours later it came to her: “and”.

Baffled doctors initially misdiagnosed a stroke. When a neurologist eventually diagnosed early-onset Alzheimer’s and vascular dementia, Mitchell was just 58 years old. The disease was incurable, her plight hopeless. Her employers said how sorry they were, but promptly pensioned her off; friends melted away, fearful of awkward embarrassment. Had Mitchell conformed to all their expectations of an Alzheimer’s patient, we would never have heard of her. But when she discovered that the disease had spared the part of her brain that could type, she began a blog about her new life, Which Me Am I Today? She was soon as busy as she’d ever been, volunteering for Alzheimer’s support groups, campaigning for greater public understanding, educating the medical profession. A journalist, Anna Wharton, saw the blog and offered to ghost-write a memoir.

“All her friends who were ghost writers said, ‘You must be mad, trying to write a memoir with someone who has no memory,’” chuckles Mitchell, 62 — and they had a point. “I used to confuse Anna like hell for getting everything in the wrong order, and then the next day I’d tell her a different order.”

Undeterred, the pair created an accurate timeline from medical letters. They corresponded by WhatsApp and email, and the memoir about Mitchell’s life with Alzheimer’s, Somebody I Used to Know, became an instant bestseller, lauded in the media as “revelatory”. “The world could do,” the Sunday Times reviewer wrote, “with more Wendy Mitchells.”

Tucked into her armchair with a cup of tea, the author beams with guileless delight at all this success. “But it’s very weird,” she admits, “because I don’t know what's in the book. I can't read my book, because as soon as I turn the page, I forget what I've just read."

Stand by me: Mitchell with her daughter, Sarah, who keeps an eye on her via a GPS tracker CHRISTOPHER NUNN FOR THE SUNDAY TIMES MAGAZINE

I spend the next two hours in Mitchell's company continually startled and wrong-footed by the mysteries of the human brain. Most of the time she is eloquent, seemingly in full command of her mind, but then a word will escape her and she is suddenly silenced. The fingers of her right hand strum the air constantly, as though summoning the words by typing them, and her reedy voice seems much weaker than her body. But she can be funny, insightful and intently engaged, so much so that it's hard to believe she needs to paste pictures of the contents of her kitchen cupboards onto the cabinet doors, or that some days she can look out of the window and believe her garden shed has vanished. The fitted wardrobe doors in her bedroom are indiscernible to her gaze; when she moved into the cottage a couple of years ago, she kept laundering the same outfit every day, oblivious to the clothes hanging in her closet. Reconciling this with the alert, self-aware woman opposite me is endlessly confounding, but she says that she doesn't like people to see her on the bad days when "the fog descends", swallowing her up in confusion.

"I look at it like a game, and I don't like losing, so I'm continually trying to fight it and win. Some days I don't win, but the next day I might. I've always been a glass-half-full person, and I'm very lucky to be like that, because the glass-half-empty people, if they're having a bad day, they think every day will be a bad day, whereas I think tomorrow will be better.

I can't do lots of things, but if I concentrated on all those things I'd feel really fed up, so I just knew that I wasn't going to fit into the stereotype of giving up."

Calendars and planners in her kitchen map out a schedule of speaking engagements all over the country. No longer able to drive, she makes elaborate preparations for every journey, downloading and printing photos of each stage from her front door to her destination. "I make myself do things I have to be doing to stimulate my brain. If I'm not exposed to different environments then dementia starts to win, because it lulls you into that false sense of security that doing nothing is good. But it's not. Sometimes people say, 'Why don't you just live your life and enjoy not doing anything?' But that will make me progress far quicker. When I'm not doing anything for days and days and days, I can feel dementia just taking over, and I know that if I don't get out and do something that's challenging, I'll just decline quicker."

I tell her I'd had no idea the progression of Alzheimer's could be influenced by an effort of will. Had her doctors been aware? "No, that's the sad thing. When you get diagnosed, often the language that physicians use is very negative, and very down, and they'll give you a sad look. Whereas, if only they used positive language. You know, it's a bummer of a diagnosis and there's no getting away from it. But if they then said, 'But dementia doesn't mean the end, it's simply the beginning of a new life, a different life and one you might not have expected, but a life of adapting to all the challenges that come your way, so concentrate on what you can do, not what you can't do,' well, that would make you feel as though there was hope. With dementia you know there's no cure, so that's why people fall into this despair. Because no one gives them the hope of anything. We need hope, but clinicians give you the medicalised view. They tell us there's nothing they can do. They don't talk about what I can do."

What Mitchell can do has been transformed by technology, the impact of which she thinks the medical profession hasn't yet grasped. Had she been diagnosed before the internet was invented, she says, "I'd probably be dead now" — and she isn't joking. Before dementia, "I could never do anything technical", but an iPad is now her constant companion, programmed with a complex series of alarms to remind her of everything from brushing her teeth to getting off a train. She plays online Scrabble every morning, "to get my brain working", and although phone conversations are now too confusing, she can communicate by WhatsApp ("You can have whole conversations just using emojis!"). Her daughters persuaded her to carry a GPS tracking device, "which means they're happy, so I'm happy. Also, it means that if I don't know where I am," she laughs, "they'll know where I am."

The biggest game-changer for Mitchell, however, has been social media. "Now you no longer need to be isolated. I just love Twitter. For me it's a silent world of conversation, because I can never speak to lots of different people all at once in a room, but on Twitter I can, because there's no noise, and my fingers do the talking. They're far more eloquent than I am."

Mitchell may well be the only person active on Twitter I've ever met who says, "Everyone on it is lovely," but in her experience they really are. She does, however, mention a psychiatrist who has tweeted sceptically about the diagnosis of "high profile" individuals living busy lives with dementia. He is publicly doubtful that anyone living as actively as Mitchell could really have Alzheimer's — and for the first and only time, I see her look unhappy. "He's an old-age psychiatrist, so he sees people who are naturally in the later stages, so in his professional capacity he hasn't seen anybody like us. But that doesn't give a reason to doubt it when we have the medical proof that that's how it is. It just seems so unethical, because how does he think it makes us feel, seeing what he writes?"

What Mitchell cannot feel, though, is angry. "Things either make me sad, happy or content. Those are the only emotions I have. I don't have anything else. The disease has actually taken away the ability to feel anger, so I never feel it any more." Does she consider that a loss or a blessing? "Oh, a blessing. Yes, I do, because I don't get upset or angry like I used to." What about fear? She chuckles. "I used to be afraid of lots of things. But I lost all fear, because I've faced my biggest fear facing dementia, and I'm happy, so what's the point of being afraid of anything?"

In place of cognitive competence and emotional range, what Alzheimer's has given her is heightened intuition. "I immediately know whether I like someone or not. I feel when you have dementia, your brain is so empty of so much that things like intuition take over, because there's now more room for it." Has her heightened intuition ever let her down? "No, I don't think so." Likewise, while she can no longer remember factual details, her memory can still retain feelings. "We don't lose those, because that's a different part of the brain. So I won't remember any of the details about today when you've gone, but I'll remember how happy I am."

In her book, she poses an arresting question: "If you can still enjoy gazing at the moon, does it matter if you can't remember what it's called?" The longer I spend in Mitchell’s company, the more challenging the question of happiness becomes, for the striking impression I’m getting is one of an uncommonly contented person. I wonder whether Alzheimer’s has made her revise her assumptions about what constitutes a good life, and ask if she’s as happy now as she was before dementia set in.

“Oh, yes, I’m sure I’m more content now. Because I’ve realised the value of time. Yes, because time is a strange concept, isn’t it? Because when you’re working you spend all your time wishing for the weekend, wishing for your holiday, wishing for next year when something might happen. But time is now, today. You suddenly realise how next year might not happen, next year you may be in the end stages. You can’t put a time on it, and you never know what’s going to help and what won’t, so that’s why it’s important to enjoy today. Tomorrow might be a rubbish day, but I’m happy today, so I’ll enjoy today.” We laugh about the lengths the rest of us go to to achieve this state of mind, throwing money at mindfulness courses and apps and whatnot. “I know!” she agrees. “So of course it sounds like a cliché. But it really is just about enjoying the now.”

One of the overlooked upsides of her condition, she points out, is that a piece of good news brings fresh delight each time she hears it. Likewise, she can be relied upon to keep friends’ secrets. “Your secret’s safe with me,” she tells them. “I’ll have forgotten by the time we walk out of the room.” She takes the firm view that it is pointlessly cruel to remind people with dementia of bad news — that their parents are dead, for example. She has experienced vivid hallucinations in which her parents are there in front of her, alive, and writes, “I don’t need to be told over and over that Mum and Dad are dead; what difference does my fantasy make to anyone else? The helpful response is probably to ‘go along’ with our experience, rather than trying to pull us back into the present day.” But when I ask if she approves of care homes installing fake bus stops in their grounds, where residents can sit for hours, waiting for buses that will never come, she frowns.

“Is that kind or not? I think it’s terrible. That would just confuse the hell out of me. Why not take them to a real bus stop? And they have these fake pubs in some homes. But why not just take them to a real pub? Why does it have to be fake? Why are you trying to trick them into thinking they’re somewhere where they’re not, instead of going to the trouble of taking them there? I’ve never liked that.” In particular, she hates the roller blinds installed in some care home windows, decorated with pleasing but fake views — for example, of the seaside. “Why not just take them to the seaside?”

Paper trail: Mitchell uses photographs as a reminder of places visited, and as an aid to help her plan journeys CHRISTOPHER NUNN

Mitchell has no domestic support — she manages by herself, with the help of her daughters — and is clear that she will never move into a home. “I don’t like them. The whole system either needs a total rethink or more money. We knew the ageing population was going to come years and years ago, so why are we still talking about — surprise, surprise. We’re here, you know?

It seems that one government after the other is just leaving it for the next one to sort." Above all, she want us to change the narrative around care homes for people with dementia, which seem to focus on residents' "challenging behaviour". The assumption that "challenging behaviour" is an inevitable symptom of the condition is, Mitchell says, wrong; it's a symptom of people with dementia being cared for by those lacking the skills and training to understand their needs.

"I always turn that phrase round and say the 'challenging staff', because behaviour comes about from an unmet need, so there's something that a patient needs and isn't getting properly that's making them anxious, angry, uncooperative or the challenging bit. So it's about finding why that person is behaving as they do — and it's usually an unmet need." But not an unmeetable need? "No, no. I mean, if they've lost the verbal ability, you know, and somebody's pressing on their arm that hurts, trying to lift them up — well, they're going to hit them to get off their arm, aren't they?" The solution isn't to brand the patient "challenging", but to work out a way for them to communicate.

When Mitchell was diagnosed, one of her daughters, Sarah, was already training to be a nurse and was astonished to discover that her entire course included just one three-hour lecture on how to care for patients with dementia. She and her mother lobbied the lecturer, who duly redesigned the course to correct this inexplicable curriculum oversight — but, as Mitchell points out: "That's just one university. And really, all of them need to change. And with doctors it's more or less the same for them." Alzheimer's patients aren't admitted to hospital because of their dementia, she goes on, but with unrelated conditions, or health problems created by the dementia, so they are treated by doctors with virtually no specialist training in their needs. When Mitchell visited her eye clinic recently, she offers as an example, "Three different people asked me for my medical history!" What did she tell them? "I say, 'Well, I've got dementia, so I haven't got the most reliable memory, so it might not be a good idea to trust everything I say,'" she laughs. "But it's on my notes, so why would they ask me in the first place? It's just that they're following a process, instead of thinking."

Mitchell was hurt by the speed with which her NHS bosses got rid of her when she was diagnosed, but it strikes me that she's probably done more for the health service since leaving it — through her work to raise awareness of the potential for people living with Alzheimer's to lead fulfilling lives, which has been an eye-opener to the medical profession — than she could have done as a manager. Later this spring she will receive an honorary doctorate from Bradford University; and in a few weeks she will do a sponsored skydive. As her daughter Sarah puts it: “I feel like she’s fulfilled her potential now. She did an amazing job where she worked, but this has opened up her world so much.”

Somebody I Used to Know by Wendy Mitchell is out now in paperback (Bloomsbury £8.99)

Ten things Wendy Mitchell says about dementia

1 “I immediately know whether I like someone or not. The brain is so empty, intuition takes over”

2 “If you can still enjoy gazing at the moon, does it matter if you can’t remember what it’s called?”

3 “Dementia doesn’t mean the end, it’s simply the beginning of a new life, a different life, a life of adapting to challenges”

4 “Things either make me sad, happy or content. Those are the only emotions I have. I don’t have anything else”

5 “I lost all fear, because I’ve faced my biggest fear facing dementia, and I’m happy, so what’s the point of being afraid of anything?”

6 “I look at dementia like a game, and I don’t like losing, so I’m continually trying to win”

7 “When I’m not doing anything for days, I can feel dementia just taking over, and I know that if I don’t get out and do something that’s challenging, I’ll just decline quicker”

8 “You suddenly realise next year might not happen. That’s why it’s important to enjoy today”

9 “I don’t need to be told over and over that Mum and Dad are dead; what difference does my fantasy make to anyone else?”

10 “You no longer need to be isolated. I just love Twitter. For me it’s a silent world of conversation — my fingers do the talking”