

‘Every day we have together is precious’

We’ve all heard about the ‘sandwich generation’, but for Kelly Fraser, 40, from Kent, it’s particularly challenging, as she nurtures her son Tommy, seven, while caring for her husband Ian, 49, who has early onset dementia

‘There is a sign in my house that says “This kitchen is made for dancing” and sometimes, when the radio is on, my husband Ian and I will have a little boogie, just like we always have.

It breaks my heart to know those special times are being slowly unpicked by the relentless progression of his illness.

Ian and I married in 2009, a few months after our son Tommy was born. On the 16th of every month, to mark the day we met, we’d tell each other ‘Happy anniversary’, and share a kiss. But now it’s only me who says it – Ian doesn’t remember the day at all.

The two of us met on a night shift at Bromley Royal Mail sorting office. Away from work, sitting in a restaurant, listening to his passion for Italy, art and the great outdoors, it suddenly hit me: “Oh my god, I’m in love with you!” And from that day, 16 April 2004, we were inseparable.

A few years later, on a trip to Italy, we sat on the steps of the Duomo



Kelly and Ian treasure every moment they have together

in Florence and Ian wept as he told me about his mum who’d died of dementia when she was 50. As I comforted him, I asked if it ran in the family, but he reassured me that she was the only one to have the cruel illness.

Sadly, he was wrong. Since then, his brother and sister have both developed dementia and passed away. In October 2013, the same year Tommy started school, doctors confirmed that my gorgeous husband – a man who was always wowing me with the sheer volume of stuff he knew – also had the early-onset form of the illness.

Ian was just 47 when he received the devastating diagnosis and became one of the 40,000 people under 65 living with the disease. But the doctors were simply confirming something I’d guessed. Although I didn’t know it at the time, it was 10 years since the first signs of Ian’s illness emerged, when he started tripping up on his speech. A few years later, I had a conversation with him about my niece and half an hour later he couldn’t remember it. I knew then that it was only a matter of time.

STAYING POSITIVE

I try not to think about the limited time we may have left and instead focus on making sure today is as good as we can make it. Like any carer, I find it tiring, lonely and frustrating at times, but I keep it together for all our sakes and we try to have as much fun as we can. Ian’s childhood was clouded by his mum’s dementia and I know he wouldn’t want Tommy’s to be the same.

Tommy has never really known any different, although he sees the changes in Ian. I tell him: “Daddy has an illness in his brain that makes him forgetful”. Tommy has asked if he will remember again when he is better, and I’ve told him the truth: he isn’t going to get better.

The hardest thing for me is watching my future unravel before my eyes, grieving for my husband as I see him



Kelly with her husband Ian and their son Tommy

slipping further away. Sometimes I wish it was me that had this horrific disease, then I wouldn’t have to hurt this much.

‘The hardest thing is watching my future unravel before my eyes’

Ian was my partner and my friend. He would listen to my troubles or laugh at my stories. Now he can’t comfort me, hold me and make me feel loved.

I just want us to have as many happy times as possible while Ian is still with us. We can’t go away for weekends anymore but, every day, Ian comes with me to pick Tommy up from school. In the evenings, they watch a film or play Xbox together. There is a special bond between them that Tommy will always remember. Dementia can’t take that away.

My relationship with Ian has changed – in many ways I feel like a single parent of two children. I haven’t stopped adoring him, but it can be lonely. Fortunately, Ian has no real awareness he has dementia and can enjoy life in the moment, which is a good thing. But it means he doesn’t realise how important it is to treasure every moment – I wish he could write letters to Tommy, or play with him more.

There are lots of people who help me keep smiling – especially my friends and

family. Another lifeline has been Jody, my Admiral Nurse. Specially trained to help the families of people with dementia, she’s a friend, counsellor and nurse rolled into one. Thanks to her, Tommy is having therapy to help him process all the different feelings he has. He’s a kind, sweet boy, and talking with an expert has helped him to express any anger he has.

Jody has also encouraged me to carve out some space for myself. She helped me convert a big cupboard in our house into a craft room. In that tiny space, I can make jewellery or do some felting and totally switch off.

I don’t take anything for granted and get so much pleasure out of seeing Ian laugh or having him sing along with me to our favourite tunes by David Bowie or Damien Rice. Just having him here is precious.

Our house is filled with photos of the happy times we’ve had together. Those pictures aren’t just something beautiful to look at – they’re a reminder of what we had and have done, from flying over New York in a helicopter to trips to the park. Above all, they’re a celebration of our family who will always love each other.’

SPOT THE EARLY SIGNS OF DEMENTIA

MEMORY PROBLEMS

Forgetting recent events, familiar tasks or people and repeating conversations.

COMMUNICATION Struggling to recall words; using language that is out of character.

CHANGES IN MOOD Different responses and behaviour to everyday situations.

● Memory loss can be a result of other medical conditions, so discuss concerns with your GP.

For more information and support, visit dementiauk.org

Feature: Mel Hunter Photos: Leonie Morse

● Dementia UK offers support and advice for families living with dementia through Admiral Nurses like Jody. The charity’s Time for a Cuppa fundraising campaign is from 1 to 8 March. Register at timeforacuppa.org or call 020 7697 4052. If you’ve been affected by dementia, contact Admiral Nursing Direct on 0800 888 6678 or email direct@dementiauk.org.