

Couple reveal all about the

Like many married couples, Steve and Nikola Voce enjoy eating out at restaurants, weekend strolls in the city's parks, shopping together and watching TV. But their run-of-the-mill routine belies a unique and cast-iron partnership that is overcoming the test of Steve's early onset dementia. The pair, from Carlton, told **JO ROBERTS** about the difficult future they are facing in a brave and honest joint interview

WHEN Nikola and Steve Voce vowed 'for better or worse' eight years ago, they had no idea the promise would become so pivotal.

In 2006, a neurologist at Queen's Medical Centre broke the news to Steve – then just 53 – that he was one of only 18,000 people with 'younger dementia' in the UK, and one of just 189 in Notts.

It refers to those diagnosed with dementia under the age of 65, and Steve's particular variety – Fronto-temporal dementia – damages parts of the brain that control behaviour, emotions and language.

Since then Nikola, herself only 34, has dedicated herself to taking care of every element of Steve's needs as well as working part-time, running their home and bringing up their daughter Rebecca, 14.

"The first big restriction was that he couldn't drive, but Steve now needs help putting clothes on, he can't make any meals, he can't read well or write at all, and can't operate any technology like a TV remote control," said Nikola, a charity administrator from Carlton.

"Just in the past few days I've had to start helping him in the shower too."

"It is very challenging but at the outset I made a deliberate decision that I would look after Steve for as long as I could. There was no discussion about whether or not I would be willing to care for him; it was the natural assumption for both of us."

"We are very close and, despite the fact that Steve's got this illness, in some ways we are lucky because we can still converse and he has the ability to empathise, which, while impaired, at least is still there."

"I can cope with anything while we can still connect on an emotional level, but I fear losing that, and how I would cope then."

Steve cannot be left alone for more than about four hours at a time now, but the former radio DJ – who worked for GEM and Saga stations – and IT trainer for South Notts College is still able to talk about his condition, though with some difficulty remembering the detail and forming flowing sentences.

"For me it wasn't some big change occurring, it was more like a gradual, 'I can't remember that'," said Steve, who had previously been signed off work by a doctor on the assumption he was suffering with depression.

"We first acknowledged something else was wrong in 2005 after spending time with friends, one of whom was a nurse. She sussed out that something wasn't right, and raised it with Nikola – I certainly hadn't noticed anything wrong."

LOVING FAMILY: Steve and Nikola now (main picture) and (inset) with their daughter Rebecca

It was, then Nikola admitted dementia had already crossed her mind; Steve's 'strange' behaviour included forgetting her birthday and Rebecca's birthday, struggling to recognise the value of coins, putting butter on toast with a fork, and difficulty signing his name.

Steve agreed to go to his doctor and then on to the hospital for further investigation, a process that took months of tests, including CAT, MRI and ECG scans,

before younger dementia was confirmed.

"We were shocked and I did feel quite tearful," remembered Steve.

But Nikola added: "Although I was very sad I also felt relieved – it was just confirmation of what I already knew, and hearing it didn't change what I'd been experiencing anyway."

Nikola had been working full time hours split between two ad-

Support on hand for 'young dementia' sufferers

IN NOTTS there are 189 people with younger dementia, which is a lower number than would normally be expected for the population.

"However, our Working Age Dementia Strategy is just being implemented and with improved screening, this number may well go up," explained Nottinghamshire Healthcare NHS Trust

spokesman Julie Grant. "We offer support through our consultants, Community Psychiatric Nurses and Occupational Therapists and day services, as well as the Alzheimer's Society and Carers support forums. There is also a specialist social worker in the south of the county. Referrals are through GPs."

ups and downs of early dementia

Why marriage is for better – or worse



NORMAL LIFE: Steve and Nikola Voce before Steve began to suffer from dementia

points where we argue out of frustration, but day to day we remain quite upbeat."

Steve took the opportunity to credit Nikola, saying: "She's spot on. I don't know what I would do without her. We are best friends and always have been."

To which Nikola added: "It will certainly stay that way."

While Nikola accepts Steve's condition is rare, she wants others to be more aware of the issues surrounding younger dementia.

"It does require you to be more patient with sufferers – Steve often feels people aren't giving him time to speak, or to keep up with their conversation."

"But we are fortunate that we realised what was happening to Steve fairly early on – it could have been very distressing and caused tension between us if we hadn't been aware that it might be dementia causing the changes in his behaviour," said Nikola.

"When people think 'dementia' they tend to think of very elderly people shuffling around in a corner in the late stages, but in the early stages, you can still have a good quality of life and live as normally as possible, which is what we're trying to do."

Nikola found there is very little in the way of support for younger dementia carers in the area so has founded her own group, which she is urging anyone in a similar position to join.

"It can feel lonely at times, so I find talking to others usually helps. It's hard to find people in similar situations so I hope this website will put me in touch with more people in my boat," she said.

For more details, go to her website at www.youngerdementianottingham.co.uk

Diagnosis of dementia in young people

● Most people think of dementia as a condition affecting only older people but it can affect anyone, at any age.

● People also use the terms 'early onset dementia', 'young onset dementia', or 'working age dementia' to refer to those diagnosed with dementia under the age of 65.

● Only around one-third of younger people with dementia have Alzheimer's disease. More

common forms of younger dementia include Fronto-temporal dementia, which Steve has – this is caused by damage to parts of the brain that control behaviour, emotions and language.

● Vascular dementia occurs when the blood vessels in the brain are deprived of oxygen; and Dementia with Lewy bodies is caused by the build-up of tiny protein deposits in the brain.

● Getting an accurate diagnosis of dementia can take a very long time for younger people, due to lack of awareness of dementia in people under 65.

● The Alzheimer's Society can provide information on specialist support available to younger people with dementia and their families. Go to www.alzheimers.org.uk/ypwd for more information.

'It is very challenging but at the outset I made a deliberate decision that I would look after Steve myself for as long as I could'

min jobs at St Andrew's Church in Mansfield Road – where the couple are members – and the women's charity YWCA.

Gradually, as Steve's care needs have grown, Nikola's hours have shrunk to 12 a week.

One small mercy is that they haven't felt a big impact on their financial circumstances, as their former fairly modest wages have been met by alternative state benefits.

But, despite their Christian faith, it is difficult to face the

bigger picture and what the future will mean for their lifestyle as a family.

"I still find joy in everyday life and enjoy it, but I have down days," said Steve. "My close friends understand what has happened, and I enjoy going out for meals or for walks with Nikola and Rebecca."

"But little things can put me in a bad mood and I get frustrated. I feel very down after going to the hospital for tests. They always come back with lower results."

Fortunately Rebecca is a teenager with a busy social life, which allows her to lead a fairly normal existence for her age, but Nikola is aware that things at home may become harder.

"From my own reading, it seems the life expectancy from diagnosis ranges from three to ten years, and I believe Steve will fall into the ten-plus category since he was diagnosed promptly and doesn't appear to have an aggressive progression."

"I'm expecting to perform increasing care at home as long as possible, with a view to hopefully never needing a nursing or care home, but I accept that if certain things happen – if he became aggressive or doubly incontinent, was wandering uncontrollably and putting himself in danger – I would seriously consider it."

"But it's hard to imagine the future while he is still himself. There are occasional flash