After a number of her family died from early-onset Alzheimer's disease, Chontell Johnson is worried that she will soon succumb to the illness, too.

"I watched dementia kill my mum at 47 – and I know I could be next"

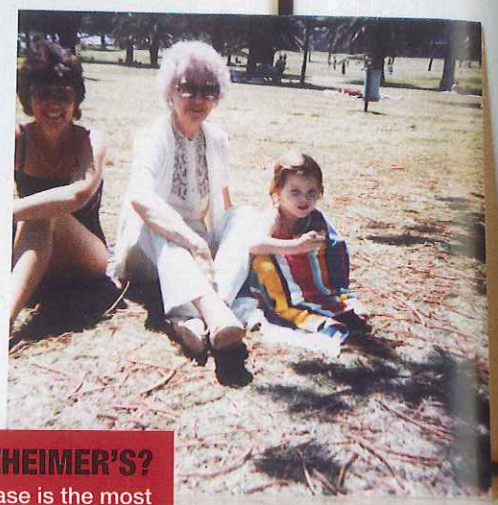
At 33, Chontell Johnson has a 98 per cent chance of developing Alzheimer's disease in the next 10 years, but, as she tells Ash Anand, she's 100 per cent committed to beating the odds and living life to the full

JOSH MORRIS

Mum slept peacefully as I lay beside her, gently brushing her long hair with my fingers. The first signs of grey were showing through the scarlet. I was reminded of how she'd looked when I was little, a good-looking woman who would throw back a mane of thick, red curls that were the envy of many. Now she woke with a start, snapping me out of my daydream with a scream. Her eyes darted around the room, bewildered. "Shh, Mum," I whispered. Taking her into my arms, I rocked her tiny, frail body. "I'm here. You're safe. It's OK." It was 2008. My mother, Shelly, was 47.

It had been like that for 10 days, although Mum had been steadily declining for months. She was scared and suffering moments of extreme anxiety; it was as if a thought would claw its way through the muddle of her mind, then suddenly surface and terrify her.

The early-onset Alzheimer's disease that had gradually taken her mind was now taking her body, too, as her muscles wasted away. She struggled to walk, and fell often and easily. Eventually she ▶



Chontell has a strong support network around her, including her dad's dog, Coco. Above right: aged five on a family outing.

WHAT IS ALZHEIMER'S?

Alzheimer's disease is the most common type of dementia in Australia, accounting for 50–70 per cent of all dementias. In the early stages it is characterised by short-term memory loss, confusion and depression. Onset is gradual and decline is progressive, causing physical symptoms like muscle wasting.

Early-onset Alzheimer's, in which symptoms develop before the age of 65, affects about five per cent of sufferers. The condition can develop through a genetic predisposition, but can also occur in people with no family history.

couldn't eat. "It's just a matter of time," the nurses told me. For two more weeks, I held her close and told her I loved her. Day by day, I watched my beautiful, precious mother slip away.

People who know my story often ask me about the signs of early-onset Alzheimer's. Had I noticed differences in Mum? What were they? How did she change? It's hard for me to talk dispassionately about what she went through because the disease didn't take only my mother. As I would discover, it may have taken six generations of my family, including my maternal aunt and grandmother. It means there is another awful truth to face: it's likely to strike me, too.

Mum's symptoms crept up slowly and she was undiagnosed for years. She'd always suffered bouts of depression, but when I was a teenager she became moody and aggressive – a far cry from the thoughtful and empathetic person I'd known. By the time I was in my 20s, she was often at a loss for words and unable to express herself clearly. Alzheimer's is a degenerative brain condition, but as the brain shrinks, it affects the body, too, hence the muscle wasting.

At 33, I'm just two years away from when those symptoms, like the mood swings and aggression, started showing in Mum. Every time I forget my keys or, mid conversation, can't think of a word I need, the thought crosses my mind: "Is this it? Is it starting? Will what happened to Mum happen to me?"

When I was little, Mum had an electric personality. Lively, curious, she was always engaged in the life going on around her. Our house in Brisbane would be filled with music – her favourites were Billy Joel and Barbra Streisand – and friends regularly dropped in for dinner or barbecues. It didn't matter that Mum was a petite 157cm; she was always the centre of attention. With her hair done and face made up, she was a striking woman whose beautiful green eyes reeled you in.

We were always close. She knew instinctively if I was happy, sad, or needing advice. Yet for all that, Mum had a fiery temper and could fall prey to those waves of despondency. She split with my father when I was three and I have an older sister from Mum's previous relationship. I remained close to my dad, Ian, but "normal" family life was alien to me.

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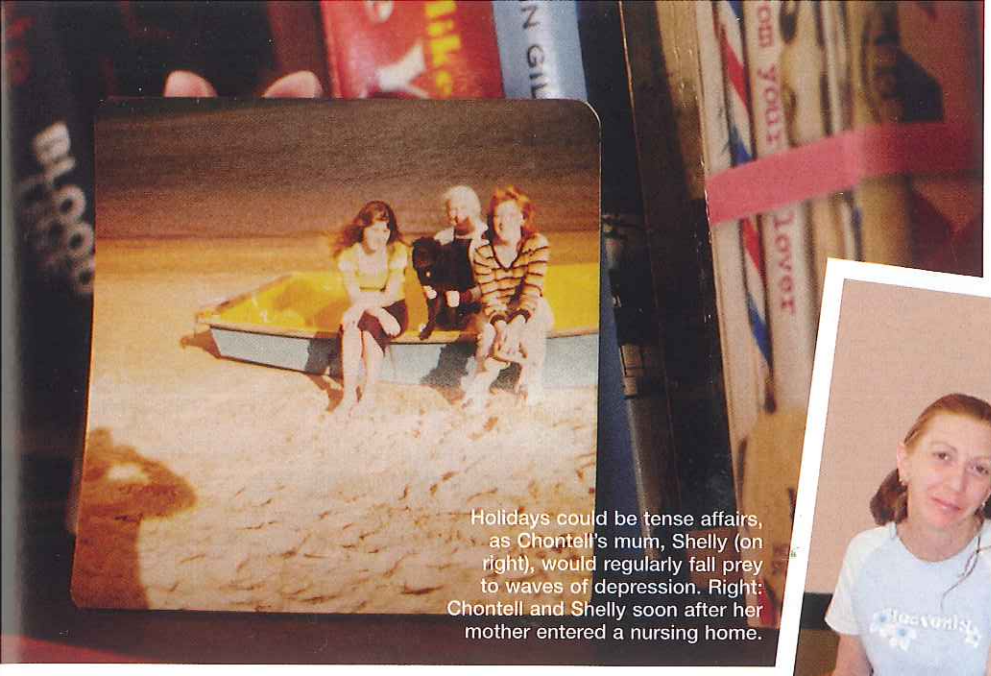
When I was in my mid teens, Mum grew more distant. She would hide in her room, refusing to communicate. Doctors said she had depression and friends agreed, but no-one really knew what was wrong. She became increasingly temperamental and would pick fights with me. In time, her aggression became physical: once, she spat in a friend's face mid argument; another time she punched a young guy in the face for taking her parking spot at the supermarket. By the time I was 18, my older sister had moved out. Mum became so unreasonable and erratic that I soon left and moved to Sydney.

It was like a breath of fresh air. It might sound selfish but, instead of having to take care of Mum, I could finally focus on myself. I enrolled in a beauty therapy course and got a job in customer service at a bank. Life was fun; I was making new friends and, before I knew it, I'd fallen for someone. Sam was the bank's security guard and he caught my eye on my first day there. One day he offered me a lift home and our relationship grew from there. He was handsome and goofy; the perfect antidote to everything I'd been through with Mum.

We fell in love quickly and moved in together. I couldn't have been happier, except for one thing: the shadows that were increasingly darkening my mother's life. I kept in regular phone contact with her, but she was having trouble communicating. Within months, it reached the point where she'd call and just babble, making no sense at all. Her inflection was up-beat and energetic, as if she thought we were chatting normally.

Mum left Brisbane and took to staying with friends all over the country. She was often confused when I spoke to her and her friends were anxious. It was clear Mum couldn't look after herself, so I suggested she come to live with Sam and me.

She was my mum and I loved her, but I wasn't prepared for what it would be like, given the state she was in. She'd sit in the same clothes for days, looking lost. Her once immaculate hair grew unkempt, and she'd smoke cigarette after cigarette.



Holidays could be tense affairs, as Chontell's mum, Shelly (on right), would regularly fall prey to waves of depression. Right: Chontell and Shelly soon after her mother entered a nursing home.

She was locked in a terrible spiral that I was powerless to stop, but we still didn't know what was wrong with her. Over the next four years her health deteriorated; she grew more insular, depressed, forgetful and confused. When I could no longer take care of her, my sister made the difficult decision to put Mum into care and I supported it. She was 43.

Visiting her in the nursing home was heartbreaking. Deep lines had etched themselves into her face, she was visibly distressed and even her gait had changed. Doctors still couldn't pinpoint the problem. "She's just very depressed," they kept saying. I was convinced there was something they were missing.

No-one in my family had ever been diagnosed with early-onset Alzheimer's. Doctors had suspected we had a history of Huntington's disease (a neurological condition), later found to be a misdiagnosis. Mum was eventually diagnosed with dementia, but doctors couldn't be specific about why she'd got it or what type she had.

By now she couldn't speak, but we found other ways to communicate. She loved having her hands touched, so I'd sit with her for hours, her hands clasped in mine. On her good days, I'd put on Billy Joel and we'd dance up and down the corridors. I could tell by her smile that she was happy. Each time it came time for me to leave, however, she'd scream over and over – a haunting, devastating cry. I can't begin to explain what it was like, at 23, to have to walk away from Mum like that.

A year later, in 2005, Mum was transferred to the Garrawarra Centre, a dementia facility 50km south of Sydney. It was there that we met Dr Bill Brooks, from Neuroscience Research Australia (NeuRA). He examined Mum and, while he said he'd need to do more testing, he believed she had early-onset Alzheimer's. Far from being devastated, I was relieved that after all these years of not knowing what was wrong, we might finally get some answers.

But, it turned out, Dr Brooks had another bombshell for us. As he read over our family history, he recognised my great-grandfather's name. Through his research, Dr Brooks had come across references to my great-grandfather and others in my family who, throughout the generations, had tested positive for a genetic mutation of Alzheimer's. He'd been unable to find their descendants, so the news had never filtered down to us – nor had it ever been mentioned within the family lore.

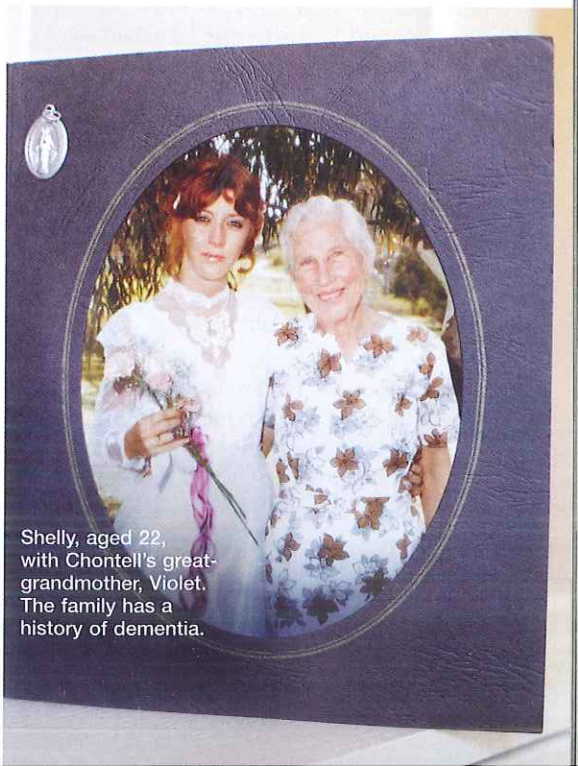
I tried to take in the implications. If Mum tested positive, did that mean I had the gene, too? As I confided in Sam, who had been like a rock through all of this: "I have to know if what's happening to Mum is going to happen to me." I was very calm and collected; at that stage the idea didn't consume me – I just really strongly believed I had a responsibility to find out because I was a part of a bigger family. Someone had to be the first to be tested, and my family deserved to know and not be kept in the dark. On the other hand, I worried about how Sam and Dad would cope if my results were what we all feared.

I decided to continue living as normally as possible while we awaited Mum's results, but fate had other plans. I was spending time with family and friends, and I'd even applied for a job managing the opening of new spas. On the day of my interview, I got a call from Sam, who was always so supportive. "Good luck, Chon," he said. I was nervous but excited. "Thanks," I replied. "I'll tell you all about it when I'm done. Oh, and hey, I love you." It wouldn't be much consolation, but later I would be so very glad I'd said that to him. Within hours of exchanging those few words with the man I adored, my world would fall apart.

I'd left the job interview and was on my way home when my phone rang. I answered quickly, thinking it was Sam. "Chon?" a voice said unsteadily at the other end. It was Sam's aunt. "You've got to come home, Chonny babe. Straightaway." She wouldn't tell me any more, but I knew. Tears were already streaming down my face as I stepped, trembling, into my living room, where Sam's aunt hugged me. The news was brief and devastating: Sam had left for a ride on his motorbike that morning. There had been an accident. He was gone.

The next few days were a blur. I couldn't believe I'd lost Sam. We'd been in love for eight years and I couldn't imagine life without him. In his absence, I clung to his family, who treated me like their own daughter.

Soon after the funeral and in the midst of my grieving, Mum's gene test came back positive for familial ▶



Shelly, aged 22, with Chontell's great-grandmother, Violet. The family has a history of dementia.

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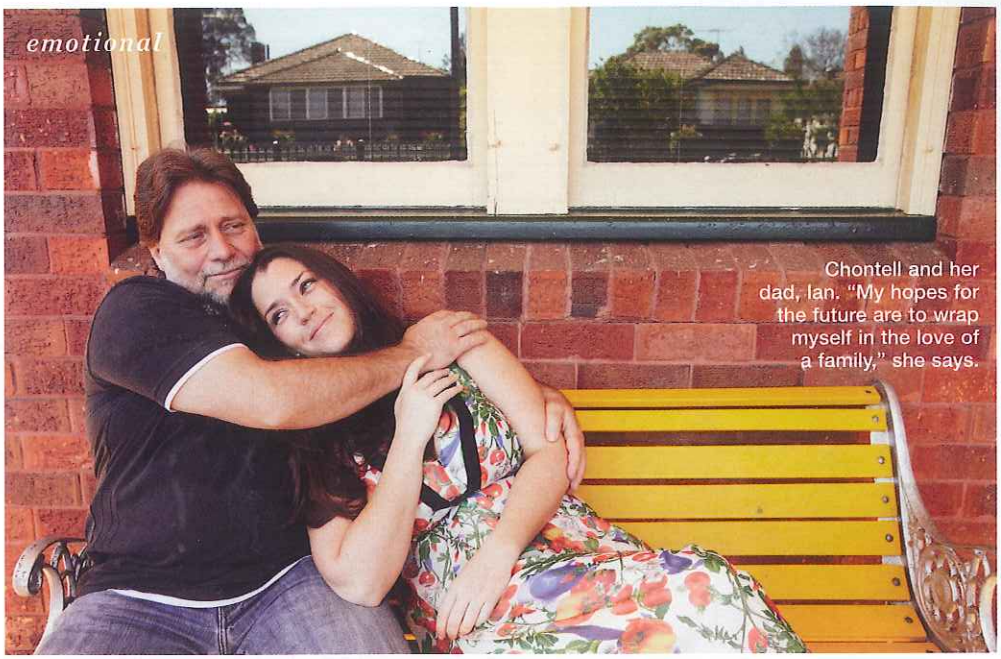

Chontell and her dad, Ian. "My hopes for the future are to wrap myself in the love of a family," she says.

Alzheimer's – she had the family mutation. For the first time, we had a name for the condition that was destroying her.

It was my turn next. I had to wait four weeks for the gene test result and at any other time it would have preoccupied me, but as it was, I barely thought about it.

Life doesn't go away, however. In late 2006, I took Dad with me to get my results. He was nervous – his grandfather had died of Alzheimer's (the usual late-onset type, for which there is no gene test) and his father was now afflicted. Dad's biggest fear was that he'd develop it, too, and, if my results were positive, there'd be no-one to look after me.

I held his hand as the specialist went through my blood and cognitive tests in detail. In my head I was shouting, "Just shut up and tell me!" and all of a sudden I heard the words I'd been dreading: "I'm very sorry, you've tested positive." Having the gene meant I had a 98 per cent chance of developing the condition in middle age (in my 30s to 50s). Dad and I sat silently. I'd asked so many questions during the testing that there was nothing left to say. I felt no physical sensation or sense of disassociation; all I felt was worry for my family – for my nieces, nephews and cousins. Would any of them be spared this disease?

By now, Mum was in the final stages of Alzheimer's and I had to stay strong for her. By December 2008, she was rail thin, frail and incredibly weak – a husk of the person she used to be. Her last days were plagued by anxiety and panic. Every day I tried to calm her, cuddling her and wondering how much longer she'd have to live this way. Towards the end, holding her close, I whispered, "It's OK, Mum, you can go. This isn't the place for you anymore." A few days later, she died.

Knowing what I knew, it was impossible not to dread leaving this world the same way Mum had. I tried to ward it off by throwing myself into work, regularly spending 70–80 hours a week project-managing and spending any free time with friends. I chose to get on with living and determinedly focused on making the most of every minute of every day.

Inevitably, last year I fell apart. I'd lost Sam, then Mum and, despite all my attempts to ward it off, I was worried about losing myself to this horrible disease. Waiting for Alzheimer's to take control of me was emotionally exhausting. I mourned for everything and at one point the tears just kept flowing. Ironically, it was Mum's no-nonsense resolve from my childhood that finally helped me pull myself together. "If there's something to be faced, just do it head-on," she used to say. I picked myself up again and realised I have so much support around me – great friends, family, and a job I absolutely love.

> "I make the most of every minute I have with friends and family. I'm a people collector"

I now have a plan for the worst-case scenario; it's mostly practical, but it wouldn't feel right without a touch of humour. I've given a list of demands to my friends and family: first, make sure my hair is always done up nicely. And see to it that someone's moisturising me – I can't get by with dry skin! If I end up in a care home, I've catalogued my favourite bands that I want blaring out of my room. I've also listed the special trinkets and pictures I want near me.

I'm hoping it won't come to that. I'm taking part in the Dominantly Inherited Alzheimer Network international study at NeuRA and hoping to take part in a clinical trial. As part of the trial, three experimental drugs will be given to participants like me as a preventive measure to Alzheimer's – basically, halting damage to brain cells before any symptoms can begin. Given my high chance of developing the disease, this trial means everything to me. If one of the drugs works, it could save me from suffering a fate like Mum's.

My hopes for the future are still similar to those I held as a little girl – to wrap myself in the love of a family. I don't think of myself as checking out in the next 10 years. The terrible things I've seen make me appreciate every single minute so much more than I otherwise would have. I make the most of every minute I have with friends and family; I go to dinner with friends, love drinking nice wine and being social. I'm a people collector, like Mum used to be, so my life is filled with valued friends and a loving family.

I'd still like to fall in love again and start a family, and I'm astounded at how accepting people are when they hear the news about me and this disease. After receiving my test results I was with an amazing man, Paul, for four years and he never once flinched or put me in the too-hard basket. We're still great friends; I've found that being open about it with someone you care about creates a closeness rather than scares them away. I'll always be hopeful about the future, unknown to every one of us, and like to look on the bright side of things. And every day I remind myself of one important thought: it's just possible that everything will be OK and I'll get to grow old one day. ■

GETTING HELP

- If you think you or someone you know might be affected by Alzheimer's disease, you should discuss your concerns with your GP.
- To contact or donate to Neuroscience Research Australia (NeuRA), visit www.neura.edu.au or call 1300 888 019.
- For further information on dementia, visit www.fightdementia.org.au or call the National Dementia Helpline on 1800 100 500.

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