

LOST IN SPACE

Alzheimer's Disease

Her dad was forever losing things: his glasses, his chequebook, his keys, the TV remote. When Sally would drop in unexpectedly, she'd often find him rummaging through drawers and cupboards, muttering under his breath. Of course, for as long as Sally could remember, her dad had misplaced things. But then her dad stopped remembering ...

Birthdays were first. Sally's. Carl's. Lynda's. Bruce's. His own. Very unlike the father who had never failed to send a card, or buy a little present.

Appointments were next. The doctor. The dentist. All were forgotten. Sally had calls from both of them one month asking where her father was.

Sally's dad had notes posted all over the house. "Memory joggers," he called them. But still he forgot.

And then there were the names. Odd, Sally had thought, that her father couldn't seem to remember the names of the



children one Sunday when he was over for dinner. He kept calling them June and Ron, the names of his own sister and brother. The children thought it was a game Grandpa was playing, but Sally wasn't so sure.

Then Sally's husband Carl stopped by one morning to get his father-in-law's grocery list and found him taking a nap in a smoke-filled house. He'd put some baked beans on the stove to heat, and gone to sleep. The smoke detector was working, but he'd removed his hearing aid and, as he told them later, forgotten where he'd put it.

The final straw came several weeks later when Sally got a phone call. Her father was at the Lotto shop having walked the three kilometres in the rain. He insisted he was in the bank, wanted to know the balance in his account, and demanded his money. Could Sally please come and get her father, asked the manager. Sally did.

Alzheimer's disease is a family affair. It affects people like Sally and her dad. People like our mothers, our fathers, husbands, wives and children. The cared-for and the caregivers. But whenever people talk about Alzheimer's, certain questions come up. Questions like:

- How can I tell if it's Alzheimer's?
- What are the signs and symptoms?
- What about the bizarre behaviours – how can I manage them?
- Is there a right time to put my loved one in a nursing home?
- What about my emotions – I'm feeling angry, guilty, depressed and resentful? Is that normal?
- What about my needs as a wife, husband, daughter, son?

My mother said her mind was all mixed up, like the tangled strand of purple wool she was trying to crochet into one of her famous afghan squares. Mixed up. Tangled. That's a fairly accurate picture of what's happening to someone with this disease.

Some facts about Alzheimer's

It was Alois Alzheimer who first noticed those tangles back in 1906. He was a German psychiatrist and a neuropathologist. And one of his patients was a middle-aged housewife who suffered from profound memory loss, confusion and depression, amongst other things.

When she died in a nursing home at age 55, he decided to conduct an autopsy. When Dr Alzheimer looked in his microscope at a slice of his patient's brain tissue, he discovered two startling abnormalities. The fine nerve fibres inside brain tissue were twisted around each other, and between the brain cells were plaques of burned out nerve endings.

Alzheimer's is not a result of normal ageing. It's related to a specific disease – a type of brain disorder or dementia that gets steadily worse. No-one has yet put a finger on the cause. There is no definite treatment and, to date, no foreseeable cure ... although drugs known as cholinesterase inhibitors (*Aricept and Donezil*) as well as memantine (*Ebixa*) seem to help some people retain memory, slowing down the disease and making it easier for them and their families to cope.

The word *dementia* literally means 'mind away' – and more than half of all dementia cases are due to Alzheimer's. However, reduced oxygen supply, strokes



or multiple mini-strokes can cause a mental and physical decline not unlike Alzheimer's. And other diseases, such as Parkinson's and Huntington's disease, can also produce Alzheimer-like symptoms.

Alzheimer's has been described as a terminal illness that results in a slow death of the mind. In past decades, Alzheimer's was one of New Zealand's most under-diagnosed diseases. But today, with the help of campaigns such as World Alzheimer's Day and promotions like the 'See it Sooner' message, people are being encouraged to go to their doctors for a proper and early diagnosis. That way, sufferers can get the care and support they need.

Downloading material from the internet or listening to friends can often be misleading.

A friend told me her mother had Alzheimer's because she had all the symptoms my mother has. She was confused and forgetful. She couldn't even remember her own name, and she was having a lot of personality changes. But it had only been happening for about a month and that didn't fit. I told her to take her mother to a doctor straight away. It turned out she didn't have Alzheimer's – she had a rapidly growing brain tumour!

Diagnosing Alzheimer's takes a lot more than one test or one visit to the doctor. And as caregivers, we might be the single most important diagnostic tool. Two key words are *change* and *onset*. What are the changes you have noticed over the past weeks, months or years? When did you first notice them? Have they crept up gradually or come on suddenly?

These changes might be noticed in attitude and behaviour. They will affect conversation and speech. The ability to make decisions and keep up with daily tasks might have lessened. And what about self-management, eating habits, and grooming? Even interest in hobbies and people may have changed. What about recent illnesses or falls? Drugs, too, are a vital factor. Many drugs, prescribed or otherwise, can cause confusion in older people.

Drug toxicity, depression, as well as heart and lung problems can all produce symptoms of dementia. But these can respond to treatment. So a visit to the doctor is an all-important step.

The doctor never actually saw my father's bizarre behaviour. He wondered if it was my mother's imagination. Until he could see the problem for himself, he wouldn't believe her.

He finally took Dad into a room and asked him some questions. Dad didn't know if he was married. He didn't know his religion. He didn't know the month or the day or the year. The doctor finally realised my mother had been telling the truth.

Tests will help the diagnosis. Blood tests can find out whether other problems are causing the symptoms. Even urine tests and spinal fluid tests can indicate if there are infections present that might produce the same sort of behaviours.

A CAT (computerised axial tomogram) scan gives a computer-drawn X-ray of the brain itself. An EEG (electroencephalogram) will measure electrical activity in the brain. And MRI (magnetic resonance imaging) gives an even more detailed picture of the brain.

However, no test will prove that it is Alzheimer's. Only a brain autopsy after death can do that. But tests will eliminate other causes of dementia. And they can detect tumours, clots and the like.

Blowing away the myths

With dementia and Alzheimer's in particular, myths abound. There's a lot of fiction mixed in with the facts, largely because of fear and lack of knowledge.

MYTH: All old people get senile

Not all people who age become confused. In fact, 85 percent of people over the age of 65 have minds that, intellectually speaking, function very well indeed. Isolated forgetfulness may simply be due to information-overload or the natural memory loss we face from time to time.

MYTH: Only certain types of people get the disease



Alzheimer's is no respecter of persons. Sex, race, social position or education – none of that matters. However keeping your brain active lessens your chance of getting dementia. And, although there are no guarantees, studies show that a healthy lifestyle, (including emotional and mental health), a good diet and regular exercise can help to ward it off.

MYTH: Alzheimer's is contagious.

You can't catch it like Aids or the flu. It's not contagious. It's a specific disease process.

MYTH: Alzheimer's has something to do with the amount of aluminium in the brain

Higher concentrations of aluminium have been found in the brains of Alzheimer's and other dementia sufferers. But most researchers think it is the result, not the cause, of Alzheimer's.

MYTH: There were just as many Alzheimer's sufferers around in the old days

Probably not. People are living longer, and age is the biggest factor in Alzheimer's. The illnesses and diseases that caused the deaths of our grandparents and great-grandparents are no longer major killers. But other diseases, like Alzheimer's, are becoming more apparent. About 41,000 New Zealanders had dementia in 2008 and, of these, 50–70% have Alzheimer's.

Statistics NZ suggests that, by 2030, 1,000,000 of us will be over 65 – and research indicates that by 2026 almost 75,000 New Zealanders will have some form of dementia.

Spotting the symptoms

It's often hard to see the signs of Alzheimer's because sufferers usually *look* healthy and alert. They may in fact have more energy than we do! And in the early stages, the changes are subtle and gradual. They creep up and take us unawares, surprising both us and our loved ones.

In the beginning we didn't know what was happening to Dad. When he started acting strange in front of other people, we felt embarrassed ...

People in the early stages of Alzheimer's disease need all the support they can get – from family, friends, relatives and the health-care community. They need to be assured they aren't going crazy, that life is not over for them, that they are still loved and accepted.

I tried to explain it to him so he would understand. I told him that having Alzheimer's was

like having a car with the wires disconnected. I told him they hadn't yet figured out a way to reconnect the wires in his brain. He seemed to accept that.

As time passes, the mental and physical decline becomes more and more pronounced. Recent events are forgotten. There is confusion about where they are. It's hard to follow directions, to understand what's been read or said. Moods change for no apparent reason. The simplest tasks become a frustration.

My husband forgot how to dress himself. He couldn't figure out how to button his shirt, tie his shoes or buckle his belt. He just couldn't seem to remember what went where.

Language changes. They may get out a few words of a sentence but not the complete thought. It may sound as if they are reading from a primary school book where all the words are nouns or verbs. Some sufferers go back to the language of their youth. Eventually, language may fail altogether.

Once in a while a word comes out I can understand, like "Christmas," or a phrase like "It's cold in here." But most of the time my husband just babbles. Sometimes we sit and babble together. I love to hear his voice. I dread the day when his babbling stops. Can you understand that?

The symptoms and behaviours vary in intensity. For many Alzheimer's sufferers the decline is slow and hard to track. But others behave in ways that are unpredictable and disturbing, even bizarre. Memory loss becomes more profound, and they

recognise nothing and no one – a painful experience for loved ones.

I remember one day my mother didn't know me. She complained to Dad, "Who is she? She wants me to sit down. Do you know who she is?" If there was anything left of my heart to break, it broke right there. I walked into our backyard and cried my eyes out.

Caring for your loved one

For most caregivers, the unrelenting demands of Alzheimer's disease are very real. The tough assignment they face has been described as 'the 36-hour day'. Bit by bit the responsibilities grow.

Like the whole problem of keeping your loved one – and others – safe.

I used to pray every day for other drivers, because my father was a maniac on the road! He had been an excellent mechanic and driver, but as his disease progressed he became careless and dangerous.

It's hard to restrict someone's independence – by taking the car keys off them, for example. One caregiver hid her husband's glasses, then the car keys. She even removed the distributor cap and disconnected the starter wire!

Sometimes, someone outside the family can help.

The doctor bailed me out, and it worked just fine. He took my husband into his office, sat him down and said, "George, how many years have you been driving? Don't you think it would be a good idea if you sat in the passenger seat for a while and let your wife

do the driving for you both?" I guess it must have been the voice of authority. I never had to speak to my husband about it again. He just quit driving.

As the disease progresses the risks grow. If you can't judge hot from cold you can be burnt by water, heaters, irons – anything! Knives and appliances can be hazards. Using gas or electrical stoves unsupervised is downright dangerous.

Falls are a problem for all elderly people – but with lessening co-ordination and muscle control, the dangers are even greater for Alzheimer sufferers. Trouble spots like slippery rugs, cords, stairs and railings need to be sorted out.

Then there are basic everyday things like eating, dressing and toileting. Sooner or later, tasks that were once automatic, simple, even trivial become a daily challenge. Everything needs someone else's help. The memory of how to go about it has faded.

My mother sits down at the table but then can't remember how to eat, what to do with her fork or spoon. I usually have to get her started, and then the old memory seems to come back and kick in. At other times it doesn't, and I have to feed her an entire meal.

How, when, where and what an Alzheimer's sufferer eats will often change. Your loved one may even forget how to swallow!

My brother can't always judge where his food is. We have to put it in his hand. He does a lot better with finger food, with things he can feel. He eats sandwiches, bananas, cheese – things like that.



And caregivers have to lose the notion that toileting is a very personal, very private affair. There's simply no place for embarrassment.

My mother had wet herself right there in the supermarket. I was at the check-out when I turned around and there she was, taking off her wet pants over by the window. I ran over, grabbed the pants, stuffed them into my bag and got her out of there. Fast! Just a week later I saw a two-year-old in a shop do just the same thing. And her mother reacted the same way I did. I think you need a sense of humour in this business.

But coming to terms with these sorts of things is difficult for most carers ...

The biggest problem I had was when my wife first became incontinent. She'd wet the bed at night and I decided, well, I'll just have to get her up. Often, before I could get her to the toilet, she'd urinate on the floor. It used to make me so mad because I didn't understand what was happening. Finally I decided there

was no sense in trying to get her up and me getting mad. It didn't do either of us any good. So I got some of those incontinence pants and pads, a rubber sheet, and some smaller sheets they call draw-sheets – and I put them on the bed. If she was swimming in the morning, that was all right. I just had extra washing to do.

There are many faces of memory loss with Alzheimer's disease. Caregivers have, firstly, to accept and acknowledge that it's happening. Then they have the task of helping their loved ones deal with it as the disease progresses.

It's never easy. And some of the behaviours are frustrating beyond words. Like the restlessness and wandering that affects people with Alzheimer's. They call it *sun-downing* – it usually happens late in the day, even through the night. And it can be very hard to calm someone down when they're this agitated.

The habit of taking things causes problems too. One experienced caregiver reckons people with Alzheimer's love to "rummage, pillage and hoard – a little like pirates!"

But the emotional fireworks are the hardest to cope with – wild outbursts that come from nowhere. This is the person you have lived with and loved, perhaps for all of your adult life. Yet suddenly, he or she is someone else.

One minute my wife seems to know who we are, and five minutes later she'll be yelling and calling us names. It's as if somebody turns a switch and another person appears. She gets violent and very abusive – just the opposite of what she used to be. She never swore. But since she's developed Alzheimer's, I've learned language from her I didn't know existed!

Caring for the carer

For some people, taking care of their loved-one throughout their dementia journey is a rewarding process – but for others the challenges can prove overwhelming. Here you are, swallowed up in the life of your loved one ... lost in the broken dreams of what might have been ... sucked dry in an empty barren wilderness.

Anger rages – you're angry with the disease, angry with the rest of the family who don't care enough, angry with your loved one for asking you the same question 10 times this morning. Angry at God.

And when that anger has no outlet it can turn inwards – where the result is depression.

And then there's the guilt. Especially when the time comes to put your loved one in an institution. No matter how necessary it is, making that decision is never easy. And nor is living with it.

I still feel guilty whenever I visit my wife. The other night I went to see her, and she hugged me and kissed me and seemed to know who I was. I cried. I couldn't help it. But when she's not good and doesn't know me, I'm glad she's where she is, So I'm up and I'm down.

No-one can face this battle alone and survive. Caregivers need some kind of lifeline to wider family and friends, to people who understand. And perhaps a belief that God will share this exhausting experience with them and support them through it.

Having someone who can listen, someone who understands how it feels, is vital.

I have this wonderful friend I can go to at any time. It started when she came home from hospital after a hip replacement. I'd go and help her with her shoes and stockings and we'd talk. Once she said she wanted to pay me. I told her she was crazy – psychiatrists cost big money! I should be paying her! She's wonderful. She simply listens.

Support groups are scattered all over the country. Most are linked to *Alzheimer's New Zealand*. They come in all shapes and sizes, but they're all made up of people who really understand the situation. People who can prop each other up when they're weary. People who can stand by each other and walk with each other.

The support group was the place where I could share my real feelings. Even the negative ones – my guilt and my pain. No one ever told me I shouldn't feel that way. They all knew exactly what I was feeling. And why.

Safety valves are essential – especially with the pressure of constant caregiving. Not just someone to talk things over with, but some way of letting off steam and doing something for you. Like time-out exercising – swimming, walking, whatever. When our large muscles are exercised, stress-locked parts of the body relax and we have more energy.

Neighbours and friends can help by sitting with your loved one for that time. And there is respite care available in most communities.

Keeping (or developing) a sense of humour is so important, because funny things do happen, and we shouldn't be afraid to enjoy them.



We have our jokes, our light moments. We laugh at the things Dad does. He's very funny sometimes. These moments may only last a split second, but when they do appear they're good. They're very good.

Children too, have a special place. And we need to make them part of our loved one's life. They seem to accept Grandma's behaviour and encourage that pat on the head, a gentle stroke, a hug. Grandma's life has purpose when they come to call.

One of my home-help aides has two children, aged seven and nine. They used to come with her over the summer and after school. Mum called them her "cute little fellas". Once I got home from work to find the three of them – Mum and the children – hard at work on a special project the children had organised. They were all colouring – with a book each.

While her colouring lasted it was a joy to watch her interact with the children and to see the children care about her.

The difficulties are real, but they're not the whole picture. Care-giving also means growth. It can make us more patient, more compassionate and more courageous.

Our assignment is one of the toughest. But we can discover untapped, unrecognised strengths in ourselves and in those around us. And that discovery can lift us and comfort us.

There's also hope for our loved ones. As we care for them to the best of our ability, through hard times and not-so-hard times, we have the chance each day to fan the embers of their hearts and spirits.

Alzheimer's is not just normal ageing. It's a disease, a deviation from the norm. And, no matter how strange or bewildering their behaviour, our loved ones are still precious people. If we've learned anything over the years, it's that all diseases are solvable biological puzzles that may one day reveal to us the reasons for their existence.

For the sake of our loved ones – and for future generations of Alzheimer's sufferers – let's hope and pray that day will come soon.



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