THE AUSTRALIAN

Alzheimer's sufferers search for a ray of hope

Old woman with cane. Istock

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On a blustery October morning, three years ago, Allen Wilson walked into the kitchen of the beachside Surfers Paradise apartment he shared with his partner, Miriam Taylor*. With fondness he watched as she stood at the sink, slicing pears for their breakfast.

"Good morning," he said.

He waited for her enthusiastic "Happy Birthday". Despite his age, he couldn't help but feel some vestigial childlike anticipation for the card, the gift, and the cake with a phalanx of candles.

But instead, Taylor remained silent, staring out the window.

Not one to make a fuss Wilson, who had just turned 75, sat down to their usual breakfast of Weet-Bix and chopped fruit. He wondered if he was in trouble for something. And he consoled himself with the thought that perhaps a surprise was waiting for him later on in the day.

Wilson and Taylor went about their usual routine: a swim in the ocean, a walk on the beach, running errands in the afternoon. At no stage was there any acknowledgment from Taylor, who had always previously made a big fuss about his birthdays, that there was anything special about this day.

It was merely a simple slip of the mind, perhaps, but as they got ready for bed Wilson couldn't shake the sense of foreboding that something more sinister was at play.

Lately he had been picking up subtle changes in Taylor's behaviour. "Her short-term memory wasn't as good and she had been experiencing increased anxiety," he said.

Over the following months there were other moments of memory lapses: the stove left on, going out to get milk but not getting any, the tendency to forget other people's names.

Eventually, with increasing concern, Wilson persuaded Taylor, who was 65 at the time, to visit their GP, Dr Mark Jeffery, a Gold Coast-based clinician.

A CAT scan of Taylor's brain showed some classic features — hippocampal atrophy, dilation of the Sylvian fissures and shrinkage of the temporal lobes — consistent with Alzheimer's disease.

A subsequent visit to a geriatrician confirmed the dreaded diagnosis. "It was terrible," Taylor said. "I felt so sad and embarrassed. I said to Allen, 'I can't do this'. I felt like I should run away because it would be too hard for him."

Alzheimer's disease — first described by German physician Alois Alzheimer in 1906 — is a neurodegenerative brain disorder of unknown cause that results in memory impairment, increased difficulty in performing day-to-day tasks, and behavioural and psychological changes. As the disease progresses sufferers tend to become increasingly confused, disengaged and irritable, and reliant on others for their personal care.

Dementia, of which Alzheimer's disease comprises around 70 per cent of cases, is the second leading underlying cause of death in Australia. It is estimated to affect more than 420,000 Australians, with 250 people diagnosed with it every day. The average life expectancy after symptoms begin is eight years, with sufferers usually succumbing to complications of advanced debilitation, such as infection and malnutrition.

Many treatments have been tried for Alzheimer's disease including antioxidant therapy, dietary supplementation, hormone replacement, and cognitive rehabilitation, none of which have been proven to delay the eventual progression of the disease.

Many specialists recommend an initial trial of cholinesterase inhibitor medication for newly diagnosed patients.

This class of drug reduces breakdown of the neurotransmitter acetylcholine thereby partly compensating for the loss of cholinergic neurons in the brain. These medications have been shown to cause a small but measurable improvement in cognition, neuropsychiatric symptoms and activities of daily living in up to 50 per cent of patients with mild to moderate Alzheimer's dementia. They do not, however, appear to affect the progression of disability and they can be associated with significant side-effects including nausea, diarrhoea, weight loss, fainting and poor sleep.

When Taylor learned about these possible side-effects she refused to take the medications. Instead, with Wilson's support, she went to a holistic wellness centre and undertook sessions of hyperbaric oxygen therapy. She also took supplements to help remove heavy metal contaminants from her system and had all her amalgam tooth fillings removed.

Despite these measures, there was no noticeable improvement in Taylor's dementia and Dr Jeffery recommended she try another alternative treatment: red-light therapy. It has been known for some time that controlled exposure to red and near-infra-red light can improve wound healing and reduce inflammation through a process known as photobiomodulation — the term for light's ability to affect key biological processes at a cellular or genetic level.

To date, almost all studies on the effects of near-infra-red light for Alzheimer's disease have been performed on animals. The only human trial that has been reported in a peer-reviewed journal is a small study where five volunteers with Alzheimer's-consistent dementia received daily light therapy to their head. All subsequently reported an improvement in their symptoms.

Feeling she had nothing to lose, Taylor bought a mobile infra-red light device produced and marketed by Vielight, a company based in Canada. This device delivers 810nm wavelength infra-red light via something that looks like a futuristic cross between a light bicycle helmet and a cumbersome set of headphones.

Taylor has used it for 20 minutes per day, six days a week, for the past 18 months and Dr Jeffery's clinical impression is that it is helping. 'She is doing well,' he said. 'Her short-term memory loss is stable.'

Both Taylor and Wilson are even more impressed with the results. "The light is stalling her decline and giving her confidence," Wilson said. "Both her short-term memory and confusion have improved."

Taylor agrees. "I have more moments where it feels like everything has come good again and I remember things," she said. "My writing and piano playing have both improved and I am less anxious and confused when we go shopping."

Vielight founder Lew Lim, who has a background in engineering and medical neuroscience, says it is encouraging that some Alzheimer's sufferers have observed positive effects, though he agrees that more research is needed. "We are mobilising a gold-standard clinical trial involving a few hundred participants assessed in North American medical research institutions," he said.

Many people, however, feel they cannot afford to wait. Retired cabinet-maker David Ryder, 69, who has been using red-light therapy for his own Parkinson's disease, encouraged his wife, Faye*, 65, to give it a try after she was diagnosed in 2016 by a clinical psychologist as having Alzheimer's type dementia.

After two months of using red-light therapy Ryder says he noticed improvements in his wife's cognition and mood. "She was talking more, smiling again, and her self-awareness and emotions came back," Ryder said. "She even began to recontact old friends."

In addition to red-light therapy Faye has also adapted dietary changes and vitamin supplementation, and Ryder believes that this combination has maintained the improvements in his wife's dementia.

Dr Daniel Johnstone, 36, medical scientist and lecturer at the University of Sydney's medical research centre the Bosch Institute, has been involved in a number of animal experiments on the use of photobiomodulation for Alzheimer's disease and believes red and near-infra-red light therapy can also provide benefit in humans.

"If you can get the correct wavelength and intensity of light to vulnerable cells then you can afford them some level of protection against degeneration, whatever the underlying cause," he said. "Red light is a mild stress which can stimulate cells to up-regulate their in-built defence systems to protect themselves against more severe subsequent insults."

His supervisor at the Bosch Institute, executive director Professor Jonathan Stone, says there is growing evidence that photobiomodulation can potentially help in the cognitive aspects of Alzheimer's disease.

"When red light is directed at the brain, it impacts both the nerve cells and the blood vessels," said Stone, who is a proponent of the theory that Alzheimer's is at least partially due to microvascular disease. "When sufficient silent microbleeds occur, the individual begins to experience some noticeable loss of function. But we can delay this breakdown by things that help our heart and blood vessels, such as controlling our blood pressure and diabetes, and keeping our cholesterol down, as well as lifestyle measures including exercise, controlling our weight, eating a vegetable-rich diet, and interventions like red-light therapy."

Dr Ann Liebert, director of photomolecular research at the Australasian Research Institute and senior lecturer at the University of Sydney's department of medicine, noticed that patients in her physiotherapy practice who had been treated with laser before major surgery generally recovered more rapidly and experienced less delirium and post-operative cognitive dysfunction compared to those who did not.

As a result, Liebert, who is also vice-president of the Australian Medical Laser Association, began to administer laser to some of her patients with cognitive decline. Encouragingly, she says, four out of five of her patients who have Alzheimer's disease have experienced benefits.

This experience has prompted Liebert, in collaboration with geriatrician Dr Gregory Bennett, to apply for ethics approval to begin a clinical trial investigating the benefits of light therapy for Alzheimer's patients.

Bennett, who consults at the Sydney Adventist Hospital, agrees. He has been administering laser to some of his dementia patients since 2015 and has noticed some positive results.

"There seems to be general improvement in their engagement in life," he said. "They seem happier and more energetic and show more initiative in doing little chores around the house."

Bennett advises, however, that randomised, blinded, controlled trials are needed.

"The difficulty is, we can't really be sure that their improvements are not the effects of just the social stimulation of getting out and coming into the clinic," he said.

Professor Simon Lewis, dementia fellow and consultant neurologist at the Royal Prince Alfred Hospital in Sydney, is even more cautious. "I have not seen any clinical studies that would support this [red-light therapy for Alzheimer's disease] approach," he said.

"The major concern is that hype and hope can often collide with disappointing consequences. Clearly, the advice would be to wait for the outcome of properly conducted clinical trials and in the meantime invest in strategies that have an evidence base, such as minimising cardiovascular risk, healthy diet, good sleep patterns and exercise."

* Patient names have been changed for privacy