

Pair join fight against life-altering disease

By Cameron Lucadou-Wells

SOMETHING had seriously changed for Oakleigh's Daryl Mooney, but for eight years doctors couldn't work out what.

Mr Mooney has been afflicted with progressive supranuclear palsy, a rare degenerative neurological illness that afflicts about five in 100,000 Australians.

The illness is similar to Parkinson's disease and notoriously hard to diagnose, being often mistaken for other diseases.

For eight years, Mr Mooney had unexplained and frequent tumbles, including a serious fall from a ladder, and his personality had soured unaccountably.

His wife and carer Anne said he couldn't accept anything was the matter until he received a definitive diagnosis.

"His personality changed from being a gentle soul to quite gruff and harsh. It was quite upsetting after being married to someone for 34 years."

Mr Mooney was diagnosed variously with Parkinson's disease, Alzheimer's and depression before being told he was healthy.

Three years ago, a Monash Medical Centre ophthalmologist noticed Mr Mooney had lost eye movement and made the correct diagnosis, which

PSP CLINICAL SIGNS

- Slowness of movement.
- Unsteady walking and frequent unexplained falls.
- Stiffness of the neck and limbs.
- Visual problems.
- Slow, slurred, muted speech.
- Difficulty swallowing.

was something of a relief for him and his wife.

But since the diagnosis, the disease has gradually torn Mr Mooney from most of his interests and pleasures. Once an active tennis player, swimmer and lawn bowler, he can no longer read the paper, shuffle cards, tend the garden or do his woodwork.

His greatest joys are his five grandchildren and the chance to sing along with a music therapist each fortnight.

"When absolutely everything is taken away from him, there's nothing for him to do because he's limited in movement," Mrs Mooney said.

"At the same time, there's nothing wrong with his memory or brain."

Mrs Mooney convenes Victoria's only PSP support group, based at Malvern East.

The 10-member group meets bi-monthly and is helped with advice on support agencies and given tips such as wearing satin boxer shorts to help

the patient move in bed. Most of all, there's a feeling of solidarity between patients and carers.

"It's like going into a room and everyone's been through it. You realise you're not alone in it at all," Mrs Mooney said.

Although the disease was not directly life-threatening, it led to many setbacks, such as serious falls or choking on food.

The degenerative illness gradually steals visual ability, slows movement and slurs speech.

Most people survive two to five years after diagnosis.

With no known cure, no genetic basis or specific medication, the race is on to find treatment for the disease.

For the past 18 months, Mr Mooney has been involved in clinical trials with movement disorder expert David Williams at The Alfred hospital in a bid to make a breakthrough.

He has been punctured with a lumbar needle to extract spinal fluid for doctors to do research, and will soon be trialling medication.

"If they find something, we want to be part of it," Mrs Mooney said.

The PSP group is hosting a fund-raiser, Pat a Paca Day, at Freshfield alpaca farm in Somerville next month. All money raised goes directly to The Alfred's movement disorder clinic. Details: 9568 7748 or 9551 1122.



Fighting on: Daryl and Anne Mooney battle together against a rare illness.

Picture: Ted Kloszynski