

Helen Walker

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A short note that needs little explanation I was diagnosed in 1990 after 50 years of searching for reasons as to why I never could compete in strength or ability in sport , why I could never sing in a church choir even though I loved music and came from a musical family.

My symptoms are a carbon copy of many already written in so many testimonials.

In 1958 my first serious illness that could not be diagnosed other than maybe it was acute rheumatism. Then 4 unusual surgery of a Putti Platt on my right shoulder and removal of bone from both scapulars.



Weakness in legs , dislocating left hip unable to get out of a chair, short of breath, not able to walk any distance these all progressed slowly for years but in 1991 breathing became a huge issue.

Such frightening experience , living 300 km from a major city I suffered severe headaches and discomfort for 4 months until I managed to get an appointment with a lung specialist in Melbourne.

After prescribing a Bi Pap (a machine that helps breathing) I was sent back to the country town where my GP took over again even though she knew nothing about the breathing problems to do with Pompe.



Helen receives the Medal of the Order of Australia (OAM) from the governor of Victoria for her work for the Australian Pompe Association (APA).

But the worst issue was the complete lack of knowledge by the medical profession on an obvious neuromuscular disease. Surgery performed to experiment on muscle weakness for joints that were dislocating. A term of 30 years of not knowing what I had wrong and trying to convince myself that it wasn't in my head.

After diagnosis still no help as I was simply told "you have Pompe Disease — good luck — we know nothing about it ".

So much searching 12 months later I had a contact with another person in the UK who had Pompe Disease.

So started a new era of access to knowledge and an opportunity to join in and contribute to the future of a treatment for Pompe disease.

I was fortunate to be granted ICAP (free) treatment 4 years ago , my well being improved ,the progression stopped and I had improved mobility I have slowed up somewhat now but I attribute that to age.

I am able to walk with the aid of 2 crutches inside my house I care for myself I use a wheelchair for outside.

I suggest to all who have this disability to join in and make a difference in trying to make the future brighter for newly diagnosed Pompe patients so that they enjoy life.

There is so much that can be done in this new electronic world, education is the chance to give your history to those who may learn from it. We are the trail blazers we need to open our book of knowledge to the medical world and our fellow travelers.

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