

BREAKING BARRIERS FOR CYSTIC FIBROSIS

TODAY'S DEDICATION

DAY 18: MONDAY 18th SEPTEMBER 2023



Glenys

Glenys Kandelaars has Cystic Fibrosis but was only diagnosed in September 2016 aged 61 years. This is extraordinary given that very few CF sufferers of her generation survived beyond their teens. Up until recently the average age for a CF sufferer was around 35 years. The majority of people with Cystic Fibrosis (CF) are diagnosed very early in life through newborn screening in conjunction with the Guthrie heel prick test.

Apart from regular chest infections and heaps of coughing, her life growing up in the country was pretty normal and she played sports for school and the local community. Glenys lived a very “normal” life until her diagnosis, then within 7 months she had a double lung transplant.

Her weight dropped to 43 kg and her lung capacity was only 18%. At one stage it dropped to 15%. She couldn't breathe and eat at the same time so subconsciously she chose to breathe. Glenys required home oxygen 24 hours a day via a concentrator. Oxygen was also supplied via small cylinders when away from home.

Glenys was in Royal Adelaide Hospital every 2 – 3 weeks ranging from a couple of days to a couple of weeks. Between January 2016 and May 2017, she was hospitalised for 127 days, including 13 days for the transplant in Melbourne.

Between hospitalisations, she was on the ‘Hospital in the Home’ program where she administered her own IV medications 3 times a day.

At times there were more drugs in the fridge than food.

On February 28th, 2017, she received news that she was on the official waiting list for a double lung transplant. She was on the list for just 11 weeks.

Gerry, Glenys's husband, resigned from his position as a State MLC (Member of the Legislative Council) to care for her.

At 4 am on 17th May 2017, Glenys received a call from the Transplant Coordinator in Melbourne which changed her life.

New lungs were available!!!

Glenys and Gerry were flown via the RFDS (Royal Flying Doctors Service) to Essendon Airport and transported to The Alfred Hospital in Melbourne, early that same day.

Glenys was very fortunate in that everything went very smoothly. The surgery took around 4 hours instead of the 8 hours+, which she was told to expect, and she spent less than 48 hours in Intensive Care.

Glenys spent less than 2 weeks on the ward before being discharged to an apartment close to The Alfred.

In the six years since Transplant, Glenys, and Gerry, continue to share her story with community groups to promote awareness of Cystic Fibrosis and Organ / Tissue Donation.

Gerry is a current Board member of Cystic Fibrosis Australia.

