

Lived stroke experience

Life after stroke

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Scan to
view Ray's
video



Before stroke - still working full time



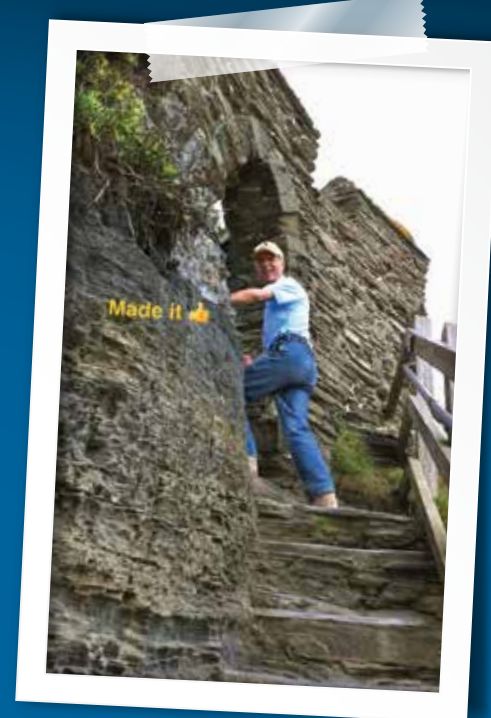
Suffers severe stroke, aged 68 (blockage left frontal lobe) paralyzed head to toe right side

- Admitted major public hospital - Melbourne
- Stroke treatment limited (clot retrieval unavailable 2008) rehabilitation able patients only.
- Fearful of future - Vision of wheel chair forever.
- Young intern said "Oh no, you can get up to 95% recovery".
First sign of hope & motivation.
- Started 8 weeks extremely demanding rehabilitation - with neuro trained therapists.
- Physiotherapy, Hydrotherapy, Occupational therapy and Speech therapy.
- Hardest task ever undertaken in life.
- Observed many stroke patients struck by **fear** - stroke a death sentence - waiting for God
- Realized that I had to accept the stroke before I could really begin recovery.
- Wife brought a book containing the following quote: **"Life is a journey, enjoy all the parts of the journey, the good parts and the not so good parts"**.
- These three points essential to the process of recovery.
- Identified Mirror therapy in UK - introduced this to Rehab therapy team.
- Indebted to all therapists for their dedicated and diligent work.
- Discharged home after 10 weeks, wife as carer - continued out-patient rehab further 6 months.



Major difficulties, barriers and successes to life after stroke

- Fingers lacking fine motor control - difficulties with buttons, eating / drinking / writing.
- Ecstatic when learned to tie shoe laces again.
- Climbing stairs okay - handrail on left - forced to descend backwards when only one rail.
- Driving with left foot accelerator (after license re-test) - wonderful new lease of mobility.
- Sexuality and intimacy issues - major barrier, often with frustrations.



Consumer advisor position at hospital and health services

- Offered to help motivate stroke in-patients toward recovery.
- In 2012 this was not permitted in Victorian hospitals.
- Appointed by Hospital as Consumer Advisor on key hospital committees.
- During next nine years served on Clinical Governance, Best Care, Person Centred Care and Quality & Safety Committees providing feedback & suggestions from a patient perspective.
- Gave numerous presentations to clinical and nursing staff with "stories" of my journey citing improvements to care that may assist current and future patients, especially stroke patients.

Person Centred Care (PCC)

- Research states - Person Centred Care patients recover quicker.
- Typically, Person Centred Care often absent in hospital care.
- As co-chair of PCC committee - helped bring this into focus at health service.
- Common claim from staff - "too busy to provide PCC"
- Director Nursing - "learn to manage busy - nurse primary responsibility - care for every patient"

Consumers on Health Committees

- **Partnering with Consumers** originated as a directive to health systems.
- **Health providers** initially placed consumers on committees to appease the directive.
- The consumer perspective is often afforded "lip service only" by clinicians.
- Value your consumers - they really do provide the patient perspective.

Consumers - want to be listened to.

- Sometimes tentative and afraid to speak out.
- Some speak out too forcefully thinking their view is always right.

This is not a war, it is a partnership looking for the best possible care for patients.

- After above service, appointed by Minister for Health to the Hospital Board.

"There is always a person inside each patient - find the person in the body."



Key recommendations

Health Service Professionals

- Please listen to and consider carefully, the consumer perspective.
- Please look for the person in the patient body.

Consumer Advocates

- Please contribute wisely & respectfully to committee discussion.
- Please accept the agreed outcomes for patients.

Now at 84 years - am fully retired but still retain interest in Life After Stroke.



Anyone interested
may contact me at:
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My greatest supporter is my wife of 60 years - thank you Lyn!