

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

24 April, 2012

Dear Committee Secretary,

Senate Community Affairs Committees Inquiry into Palliative Care in Australia.

Thank you for the opportunity to make a submission to this Inquiry, and to participate in a Hearing before the Committee on the morning of 24 April, 2012.

The most valuable contribution I felt I could make to this Inquiry, is to briefly share some of the experiences of my husband Michael, - who was diagnosed in 2001, - after a few years of misdiagnosis, - as being in the Early Stage of a Younger Onset Left Frontotemporal Dementia. Michael had been a fit, healthy man, - who had formerly been a Fitness Instructor in the British Air Force, before later becoming a British Remedial Gymnast. He was an elite sportsman, with a love of life and family. Dementia was a devastating diagnosis. A progressive, terminal condition, with no treatment and no cure. We had two children still in high school; a mortgage; Michael was no longer able to work; - I was the full-time breadwinner. We determined to live the best possible life we could, - with Michael, - for as long as we could.

In 2001, - we were invited to participate in a clinical research trial of a new drug, - Galantamine, - being developed to slow the progress of AD. 1% of people on Galantamine develop an Arrhythmia. In 2003, - Michael developed an Arrhythmia and went into Atrial Fibrillation. He was given a successful Cardioversion. Six months later he developed AF again. The Cardiologist decided against a second Cardioversion because of his diagnosis of Dementia. He was instead placed on life-long Warfarin. His Cardio-respiratory fitness began a slow and steady decline, as did his capacity for and enjoyment of long walks in the bush and near the ocean.

We managed Michael's changing needs, as a result of the dementia, at home, until in 2009, - due to changes in Govt. funding, - we lost 2 of the five days of Community Respite Services, which provided outings and activities for Michael during the working week. In the absence of suitable, sufficient Respite Services in our area, we finally had to make the monumentally difficult decision of placing Michael in Residential Care. We visited him each evening after work and brought him home each Sunday.

Within 2 months, - due to what was labelled BPSD, - he was placed on Antipsychotic medication. He deteriorated. After 4 months there, - he tried to 'escape'. He was transferred to a High Level Care Unit for PWD and BPSD in the same Facility. He deteriorated further. A month later he was found collapsed. The staff advised us that it was a CVA. He was transferred to Hospital, - where in ED he was found to have Acute Renal Failure and severe Urinary Retention. There was no CVA. After 6 weeks in Hospital, he was discharged back to the Facility with an indwelling catheter. The Facility Manager explained to us about their expertise in Palliative Care for PWD. I was bewildered.

Within 2 months, - he was found in a collapsed state again, - in severe pain and unable to move. We were advised by the Facility staff that he was in a probable Kidney Failure and asked what Palliative arrangements did we want put into place. We requested he be immediately transferred to Hospital for investigation. In ED he was found to have severe Urinary Retention due to a blocked catheter. He was in AF. There was no Kidney Failure.

He survived the night, - despite this not being the expected medical outcome. He subsequently was found to have a Grade 7 enlarged Prostate Gland, with a small area of secondary cancer in his Illium. I was advised this was slow in development. As he was always trying to pull his catheter tube out, - causing increasing internal damage, - the Geriatrician referred him for a TURPS to enable the removal of the Catheter. The Urologists refused, - due to his diagnosis of dementia. With dogged determination and persistence, the Urologists were finally convinced this was worthwhile for the effective day-to-day management of Michael and his QUALITY OF LIFE! After 5 weeks, he was discharged temporarily back to the Facility, whilst I organised my finances to leave work and care for him full-time myself at home.

However, -within a month, - he was found collapsed again, unable to move and in severe pain. He had been in that state for over 24 hrs. No-one contacted us. We had him transferred to Hospital again, - where the examining Dr. in ED advised us to lodge a formal complaint with the Aged Care Complaints Unit. The attending Paramedic had also independently advised us similarly. Michael was found to have 4 fractured ribs, - and an acute inflammation of his Right Head of Femur and his right Knee. He was in AF. He never regained his mobility, - and after 6 wks. was discharged home as 'Palliative' with approx. 4 - 6 wks. to live.

There were no Palliative Care Services designated for dementia. The Community based Palliative Care Team (for cancer) was alerted to our needs and operated on the 'fringe' in an advisory role for our community. Nurse support, who attended fortnightly for Catheter care. We had been on the Waiting List for over 7 months for an Each-D Package, but with still none available on Michael's return home, we were given temporary support from the Regional Commonwealth Emergency Respite Service for the essential equipment of an Electronic Bed; Pressure Care Mattress; Electric Hoist; Recliner Wheelchair; Roho Cushion, - together with 1 hr. per day of Personal Care assistance, M. - F. It took 6 wks. to find a G.P. who was willing and available to do Home Visits for Michael; - a necessity I was informed in order that a Death Certificate could be issued when necessary.

Michael did not die in the first month as predicted. He gained weight; regained his swallow reflex, when we were able to reduce his 'pain' medication (hydromorphine); gained in alertness and ability to engage with us and his environment. After 5 months, - his agitation began to increase again. The Palliative Care Team agreed to admit him to the local hospital Palliative Care Unit for 1 wk. to review his medication. On admission to the 'gateway' of ED however, the ED Registrar indicated that Michael was in 'excellent condition' for someone with severe dementia, - that we were 'excellent carers', and that he was 'too good' for the Palliative Care Unit. He instead admitted Michael to the acute medical ward. Within 2 days, they put him on a significant dose of 'pain medication' to reduce his 'agitation'; he lost his swallow reflex; he developed Aspiration Pneumonia within 5 days of his admission to hospital (he NEVER aspirated in the entire 5 months he was at home in our care). This was treated. D/C home was planned. Within another 5 days however, - and on his arrival home, - he had developed Aspiration Pneumonia again. Michael died at home, - 2 days later.

This is not the experience or 'journey' of dementia anyone would want to have or that any of us would want for someone we love. Along the whole continuum-of-care there are huge gaps in effective and appropriate care and services for people with this Terminal condition. Most of all, - the

notion or concept of 'palliation' for the person with dementia is just about non-existent, - despite what staff at RACF's claim they are providing or in which they believed they are skilled; - and despite 'token' services being provided in the community, - particularly for the support of what this condition brings in the severe and the end-stage of the disease. For some, - it is a living nightmare.

This is a disease like no other. People with dementia deserve a carefully considered, planned and supported programme of care that ensures a QUALITY OF LIFE for the duration of the condition - and a death that is reached with dignity and with peace.

In conclusion, - I would like to acknowledge my husband Michael, who showed great courage through every stage of his condition - and what it brought to him. He continues to inspire us. Thank you.

Joan Jackman.
(Michael's wife of 35 years).

5 Barnett Avenue
Bundanoon, NSW, 2578