Good Morning Everyone!

Thank you, - to Alzheimer's Australia for inviting me to join you in this Symposium, - to briefly share some of our experiences as a family of looking after someone with a dementia when they are admitted to hospital, and to reflect on what our experiences might tell us about dementia care in hospitals.

In sharing our experiences, - I know some people here today may have had similar experiences in hospital care. So, - our family experiences I know are not unique. But in briefly sharing them, - it will hopefully reflect some of the significant challenges for people with a dementia in hospital care, - and help us identify the THINGS THAT MUST CHANGE!

The person at the centre of this story, is my husband Michael, - a former Art Student; - then a Fitness Instructor in the British Air Force; - and later a Health Professional in the Rehabilitation of people with a disability. He was a man of versatile intelligence, an elite sportsman, - with a love of life and family. Michael's special and enduring personal qualities are perhaps exemplified in a story he would sometimes share from his time in the Air Force, - when on a Training Exercise once, he was pursued by 'the enemy' for over 24 hours, - and when finally tracked down, he was the last to be 'captured', - and was found collapsed but still ‘running’, in his semi-conscious state. These qualities of persistence, determination, strength of spirit and character, are qualities we each here today would admire. But, - as you will hear, – these were the very qualities which would work against him, when admitted to hospital as a person with dementia, - as someone with changing cognition and capacities, - struggling to understand and engage in his environment and the unfamiliar, sometimes ‘threatening’ people who were part of it.

It was in 2001, - after some five years of changing capacities, - that Michael was diagnosed with a Younger Onset Dementia. In the following ten years, we learned a lot about the huge shortcomings in care and services for people with a dementia. But, some of the most challenging experiences came during his last year of life in 2010, - when he had four acute hospital admissions spanning some 18 weeks, for medical co-morbidities.

These admissions should have been routine, - but with his co-existing cognitive impairments, - it became a nightmare, - for him, - and for our daughter, - our son, - and myself, - as his family. A lot
of things happened to Michael in these 18 weeks of hospitalisation, that were alarming – and even left us in disbelief on some occasions, - but I will briefly highlight a couple of experiences which perhaps inform us of what the experience of hospital care can be for some people with a dementia.

The first admission, following a short period in Residential Care, was with Acute Renal Failure. He was admitted via ED to a Respiratory bed, because no other beds were available. On his third night there, - he apparently tried to climb over the bed rails, - to follow us when we left after Visiting Hours. Michael was still relatively fit, strong and mobile at the beginning of 2010. Someone on duty made the judgement to give him five times his dose of Risperidone, - to ‘quieten him down’ ! He was rendered unconscious for the next five days. When he regained consciousness, a Security Guard was posted with him for a week, followed by a Special Nurse for subsequent weeks. He was finally discharged from the Aged Care Acute Unit after five weeks, with noticeably diminished capacities, - and he was doubly incontinent.

A second admission, again from Residential Care, about a month later, - involved a resection of his Prostate Gland. He was nursed post-operatively on the Urology Ward, - with both wrists and ankles tied to the bed rails for 48 hours, so he would not ‘pull his tubes out’! This was in the absence of consultation with us as his family. As I arrived on the first evening after surgery and walked into his room, - a nurse was sitting at the end of his bed writing notes. She glanced up at him, - picked up a roll of bandage, - threw it at him, - and said “Here, play with this”! The fear on Michael’s face – in that moment, - in his physically constrained and confused state – was palpable!

A third admission, following an apparent ‘unwitnessed fall’ in Residential Care, - which left him with four fractured ribs and other injuries, - was managed in acute care with significant doses of pain relief medications. His swallow reflex became unreliable; he was placed on a moderately thickened fluid diet; he was drowsy and unresponsive, - and couldn’t be mobilised by the two physiotherapists who came to see him once a day for about 15-20 minutes. Mobilising someone with a dementia, we learned, was not a priority in acute hospital care, - a resource issue it seemed! Michael never regained his mobility. After six weeks he was declared palliative. At our request, - he was discharged home. I left my job – and our only family income, - and our daughter, son and I cared for him at home. I looked after him full-time and our daughter and son helped at night after work and on the weekends.

With the one-to-one care we were able to give him at home, he actually picked up! He gradually regained his swallow reflex; gained weight again; the integrity of his skin returned; - and he became more responsive and engaging with his environment again. But after five months, with a return of his strength, came a return of his agitation. During a subsequent brief stay in the local hospital to review his medication, - he developed aspiration pneumonia. I might mention here, - that in the entire time Michael was at home with us, - he had never aspirated! Following treatment for this in hospital, he was discharged home, - but he died two days later.

So, - in conclusion, - what did some of our family experiences tell us about ‘Dementia Care in Hospitals’??
Each of us is an individual; and – each experience of the neuro-degeneration that is a dementia, is also different, - we know. No two people are the same – and no two dementias are identical. So, I urge you, - SEE THE PERSON, - look past the dementia, - and see the HUMAN BEING – with their UNIQUE QUALITIES – and their INDIVIDUAL needs!

Secondly, - we need to shake off the stereotypes of both dementia and of age! Yes, - dementia is a terminal condition, - but people with a dementia are not LESSER HUMAN BEINGS – or – LESS WORTHY of the best possible care, - than any one of us here today! People also deserve and have a right to the best care, - whether they are 55, 65, 75 – or older! Hospital care, - needs to reflect and demonstrate respect for older people, who are an important, unique and valuable part of our families and of our communities.

And – Thirdly, - we have a World Class Health and Hospital system in Australia. The National Safety and Quality in Health Care Standards and other regulations, guide and support excellence in care for everyone. But, - as we have heard with Michael's experience, - you can’t regulate for everything! HUMAN KINDNESS, - RESPECT, - and CONSIDERATION - are fundamental to - caring for our fellow man, - and - it COSTS NOTHING!! Perhaps change in our care for people with a dementia in hospitals starts right there!? Is it perhaps that simple?? Get this right, - as a fundamental necessity, - and we will have taken one giant step towards achieving EXCELLENCE IN CARE for PEOPLE WITH A DEMENTIA in our HOSPITALS!

CONGRATULATIONS – to Alzheimer's Australia for providing this opportunity today, for us to look together at these issues, - because we know that change starts with each of us who are here today!

Thank you for listening.

Joan Jackman

29th April 2014.