Dementia, the real story

Introducing Jack and Freda

- **Jack** is 82yrs, **Freda** is 78 yrs old. They have been married for 58 years. They have one son, Jonathan, who lives in Australia

Introducing Jack

- **Jack** was a builder, he is an ardent rugby fan, and a ‘quiet man of few words’
- Jack had a successful hip replacement 3 years ago
- His health is mostly good, but lately he tends to high blood pressure

Introducing Freda

- **Freda** is a social butterfly, with lots of friends, and is very involved with the local community
- She has been noticing problems with her memory for a year or two.
- She recently got lost in Queensgate shopping mall which frightened her

Freda has not told anyone about these symptoms and is hoping no one is noticing

Why is Freda not telling anyone?

Jack has noticed!

He thinks the changes are

due to old age

Son Jonathan comes home for Christmas

Jonathan's perspective

Notices a big change in his mother

- Is very concerned at Mum's poor memory
- Is surprised to see she is no longer cooking meals – (just heats premade ones in the microwave)

How could Jonathan broach the subject of getting Freda assessed by her GP?

Being prepared for GP's consult

- **Where possible choose an appointment for the time of day where the person of concern is at their best**

- **Information from families** – Discuss and write down what has changed ie how is this person functioning now compared to 5 or 10 years ago
  *may need to phone/email this info ahead of time

- **Take along a urine specimen**

I am sorry to tell you

You have Alzheimers disease

What word describes how you would feel if you were diagnosed with a dementia today?

The Practice Nurse refers Jack, Freda and Jonathan to

Alzheimers Wellington

What do you think Jack and Freda and Jonathan might want to know?

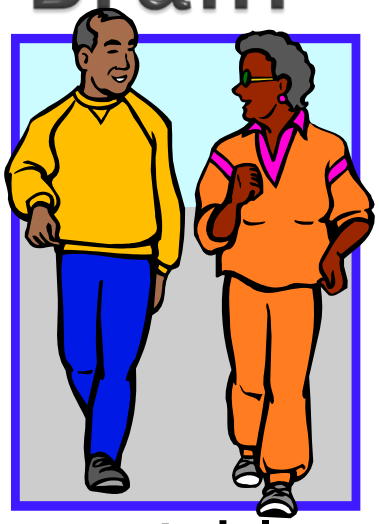
Information/support ...

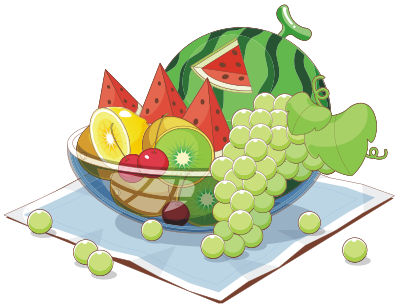
- Alzheimers Wgtn Community Worker
- Alzheimers Wgtn Workshops
- Social Groups
- Supporter Groups

Initial NASC involvement

- Good to have person ‘in the system’ even if no service required at this point
- Encourage EPOA, Advance Care Planning and Health Passport completion
- Liaise with Alzheimers organisation

Healthy Brain





Top five factors

- Eat and drink well
- Move daily
- Attend to signs of illness quickly
- Have an active social life
- Keep your mind stimulated

One year later...

- Freda is not leaving the house as she is frightened of getting lost
- She has become apathetic, and low in mood
- She says Jack is grumpy all of the time
- Jack looks tired

Support is increased from…

- Care Coordination
- Alzheimer's Wgtn

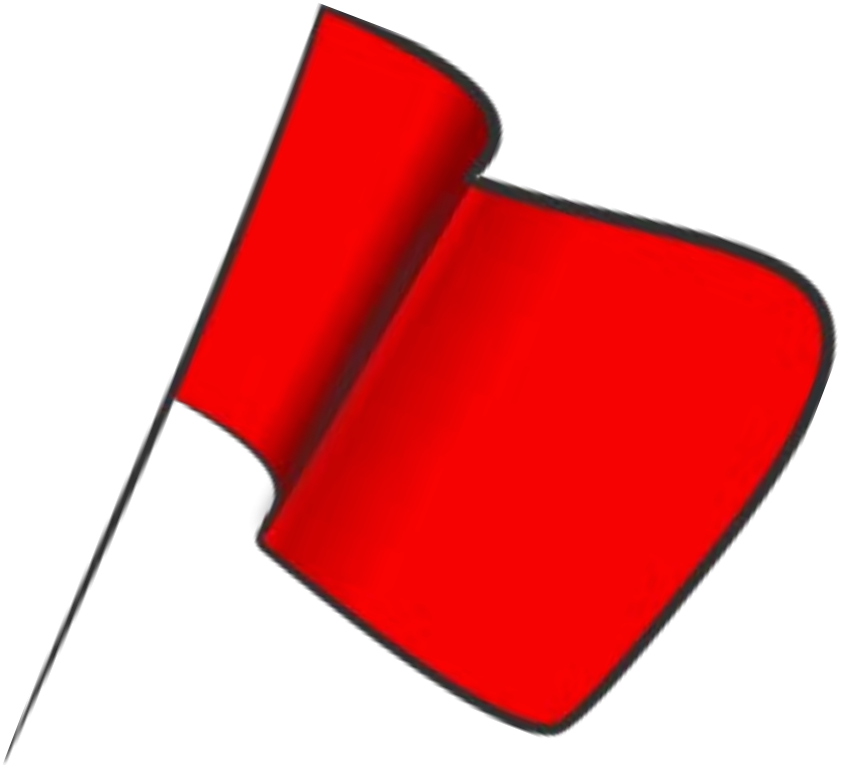
Another year passes… life is harder for Jack and Freda

- Freda waking 2 to 3 times a night
- Occasional incontinence
- Having difficulty expressing herself
- Appears sad

And Jack ?

- Maintains a stoic attitude to caring for Freda
- Tending to downplay any difficulties
- Some repetitiveness evident during conversation. ? Jack has some cognitive problems too, or is this related to stress?
- **Jack looks very tired**

Red flag time



Or is it, was the flag flying earlier and we missed it?

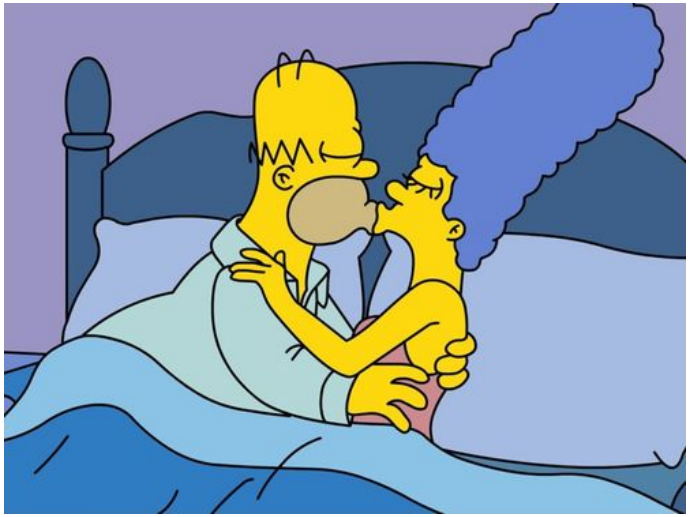
What options are there for Jack and Freda now

- Increased public funded support
- Support from Private Care Provider
- Respite care in facility
- Long term placement in facility
- Stay as is and hope for the best

Sadly……

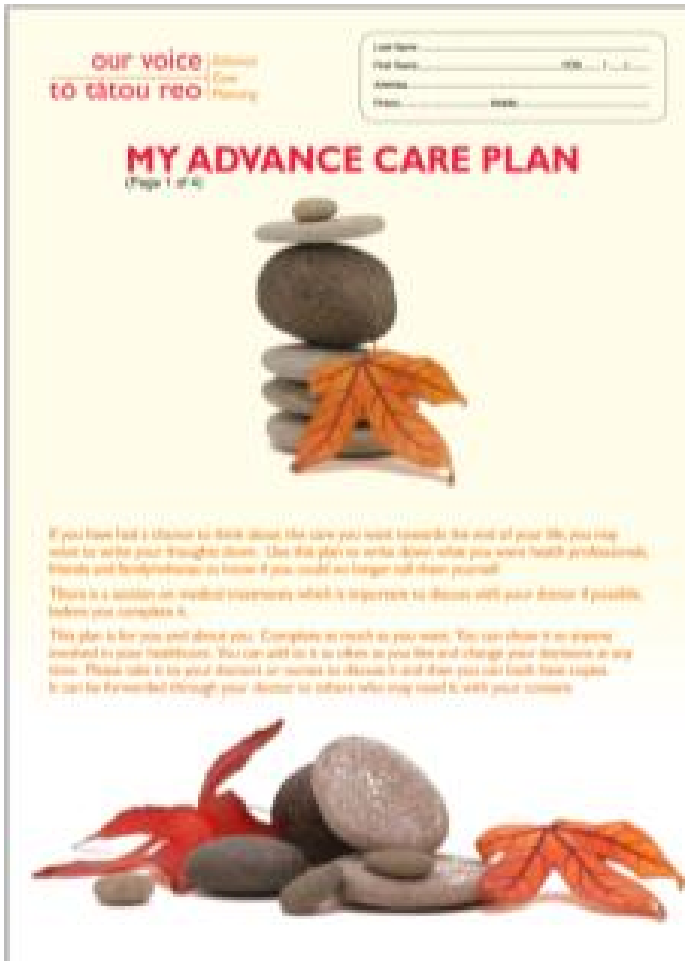
For Jack – these options may be too late

What Jack wants



What does Freda want?

No one knows and she can't say



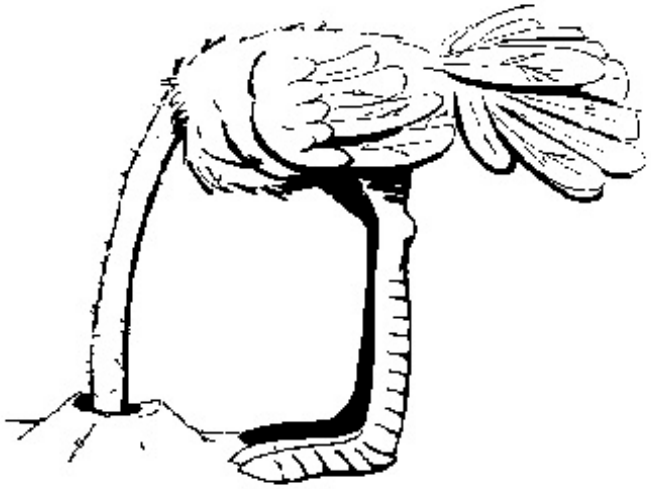
our voice
to tātou reo

MY ADVANCE CARE PLAN

What would you want if you were Freda?

What happened next?

- Jack chose the option ‘stay as is and hope for the best’



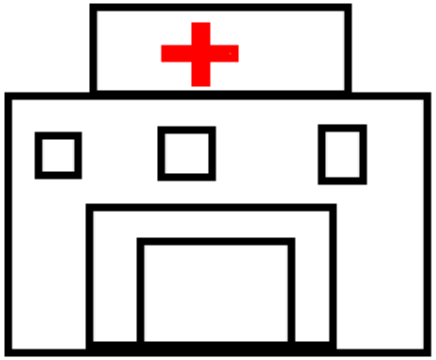
What every HP in the room can now predict .....

A crisis happened –

Jack collapsed

And so …

- Freda was admitted to a hospital ward, via ED, where she was assessed as needing dementia level care



But…

- Jack was the **only** named EPOA and he is incapacitated…

Effect on Freda

- She is extremely distressed at being in hospital
- Required admission to Psychogeriatric inpatient unit
- Then had long wait before being placed in a care facility

A health passport may have helped

Six months later...

- Freda's condition had progressed to end stage dementia
- Freda endured yet another move into hospital level care

It is anticipated that she is likely to die within the next six months

Some learning from this…

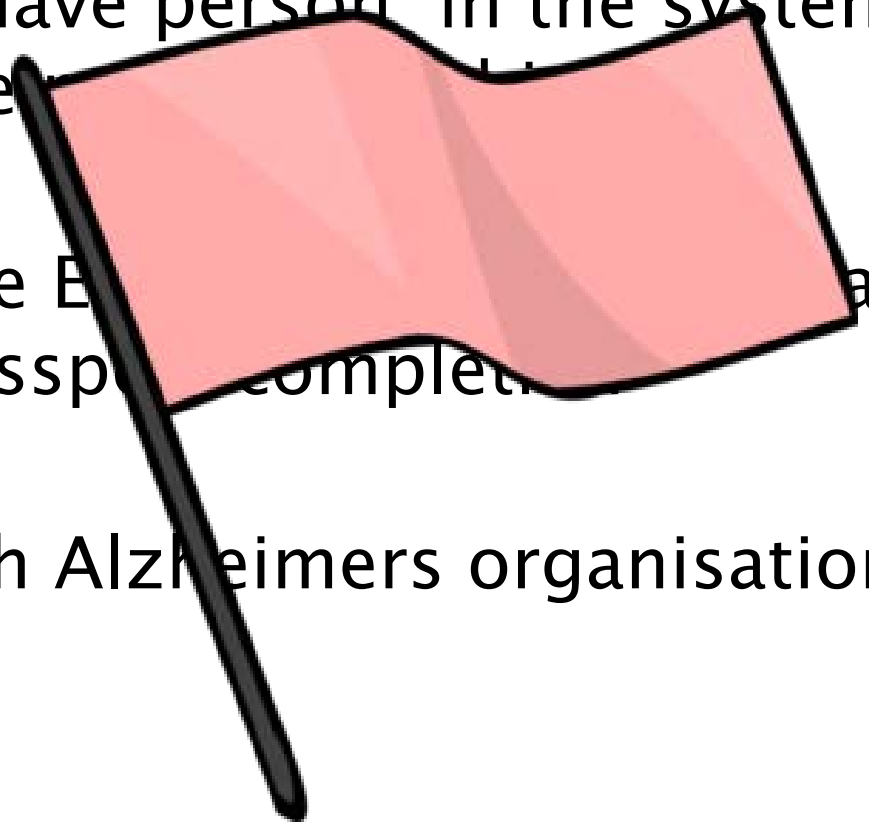
The two top areas of concern when supporting a person with a dementia liviing at home are

- Safety

- Carer stress

Initial NASC involvement

- Good to have person 'in the system' even if no service
- Encourage E anning and Health Passp ompleti
- Liaise with Alzheimers organisation



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Another year passes… life is harder for Jack and Freda

- Freda
- Occas
- Havin
- Appea

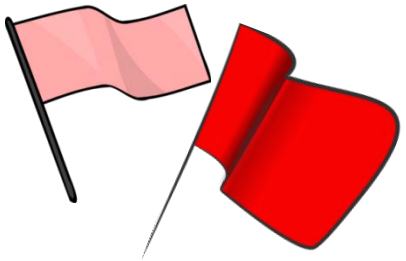
ight

erself

3 Key areas to reflect on...

1. Actively promote EPOA, Advance Care Plans and Health Passports

2.Respond creatively before the going gets tough – ie spot the pink and red flags



3. Build strong networks with the key people/organisations that specialise in dementia support

New Zealand Dementia Cooperative

Recommended Resources

- Alzheimers New Zealand 0800 004 001
- Dementia, what you need to know by Chris Perkins
- www. Alzheimers.org.nz
- ndc.hiirc.org.nz (National Dementia Cooperative)
- www.advancecareplanning.org.nz
- http://www.lawsociety.org.nz/news-and-communications/guides-to-the-law/powers-of-attorney