Community Palliative Dementia Service:

A new initiative from Silver Chain- Responding to a Community's Needs.

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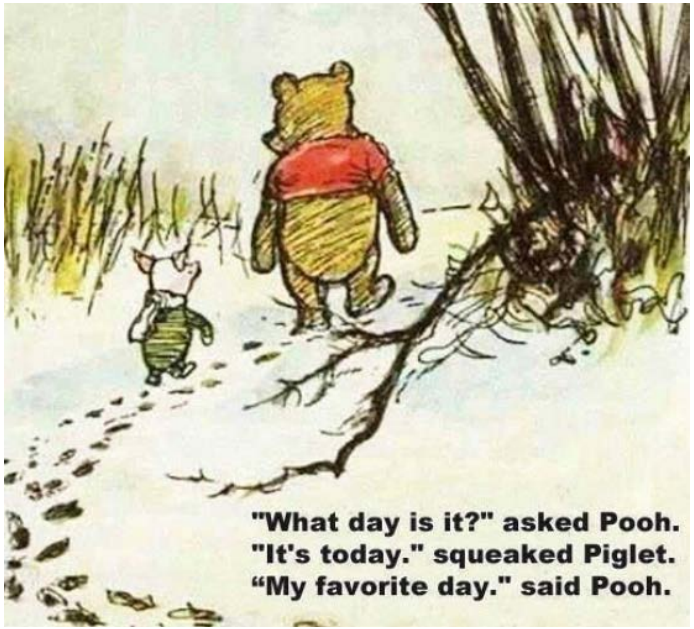
Silver Chain
Nurse Practitioners

Palliative Care- a broader concept

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

WHO, definition of Palliative Care accessed 7/2020

Dementia has a physical, psychological, social, and economic impact, not only on people with dementia, but also on their carers, families and society at large.



World Health Organisation, 2017. Global action plan on the public health response to dementia 2017-2025

https://www.who.int/news-room/fact-sheets/detail/dementia

Care is accessible to those living with cognitive impairment- Dementia, who are currently under-served.

- Care is person-centred;
- Carers are valued receiving support and information;
- Everyone has a role to play in palliative care;
- Care is high quality and evidence based

KEY PRIORITIES

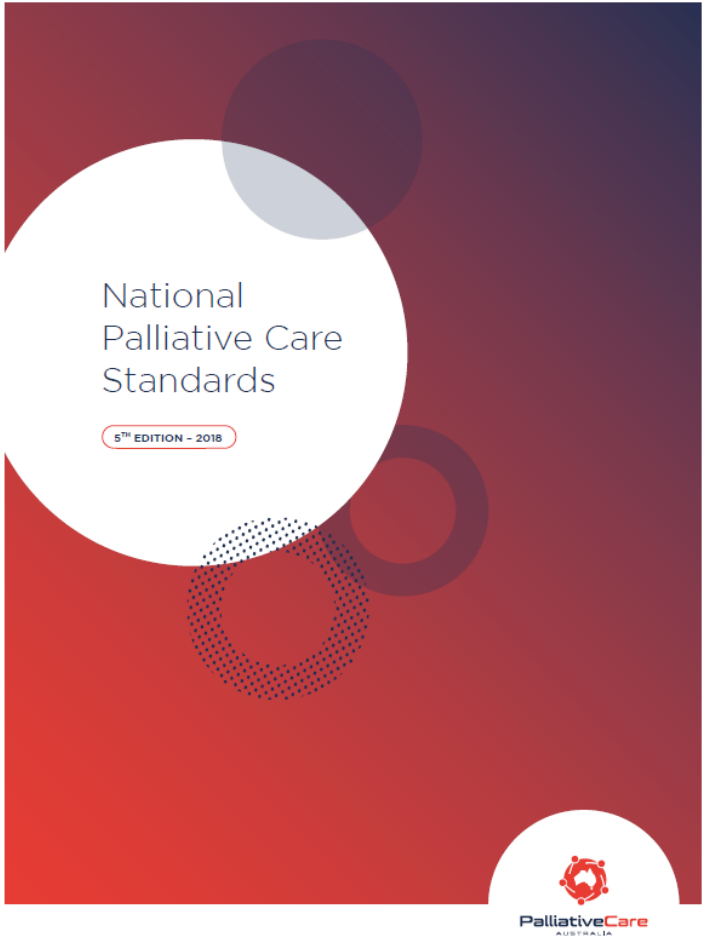
- **Care is accessible**
  - Improve access to care for all
- **Care is person-centred**
  - Seamless transitions/ communication & coordination/ access to information
- **Care is coordinated**
  - Right care/time/place/from the right people
- **Families and Carers supported**
  - Part of the treating team/ the outcome of the caring experience is positive.
- **Staff are prepared to care**
- **Community is aware and able to care**

Government of Western Australia
Department of Health

WA End-of-Life and Palliative Care Strategy 2018–2028

Recognising vulnerable populations

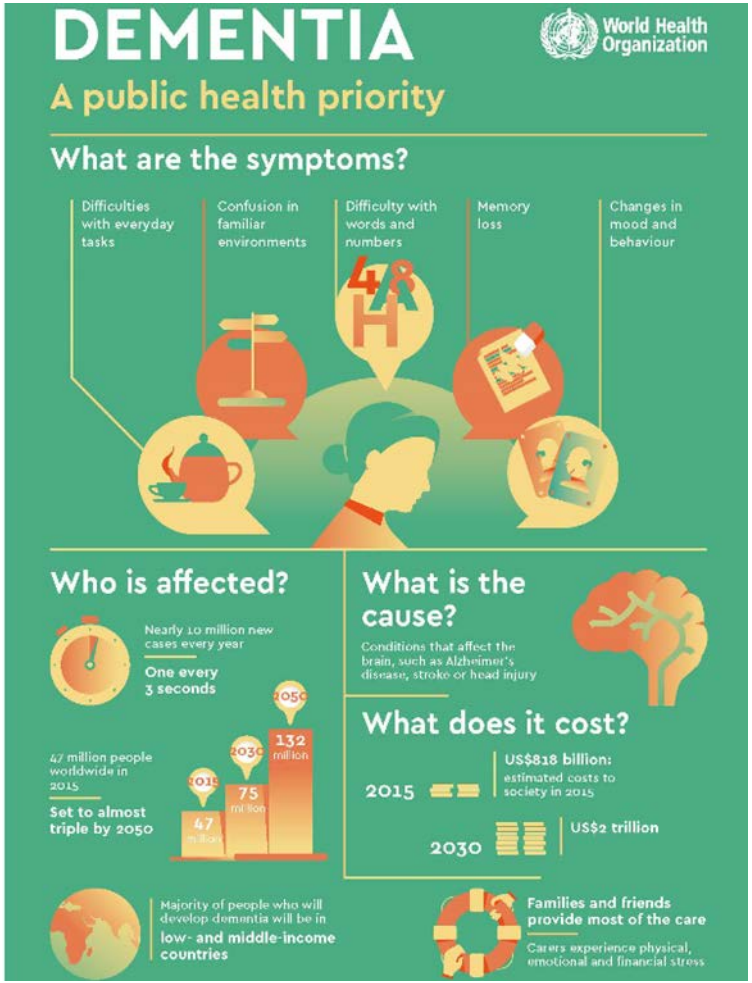
National Palliative Care Standards, 5th Edition



Worldwide Statistics

- **Worldwide, around 50 million people have dementia, and there are nearly 10 million new cases every year.**
- **Dementia is one of the major causes of disability and dependency among older people worldwide.**
- **Every three seconds someone in the world develops dementia**

https://www.who.int/news-room/fact-sheets/detail/dementia



Dementia in Australia

- Dementia is the second leading cause of death of Australians

- Estimated 459,00 Australians living with Dementia, without a medical breakthrough, estimates are likely to increase-
- 590,000 by 2028
- and 1,076,000 by 2058
    - (Dementia Australia 2020)

- 3:10 people over the age of 85 and almost 1:10 people over 65 have dementia

https://www.dementia.org.au/statistics

The beginning

‘Our service aims to partner with you to provide the best care’

- Winter Link Appeal success- local recognition of a need
- The Pilot- aims to support clients with Advanced Dementia and their carers to remain in their own homes.
- Based in the Perth Metropolitan area.
- Service provision is during week days, business hours with out of hours nursing telephone support.

Referrals

- The Referral Form
- Referral is to be made via a Palliative Dementia Service specific form

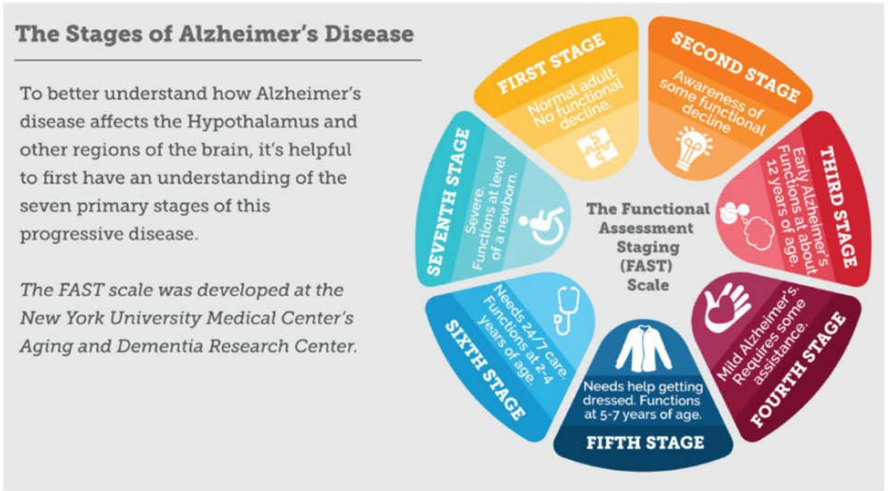
Referral Criteria

- Client/ Substitute decision maker agree to referral to Palliative Dementia Service
- A diagnosis of at least moderately severe dementia
- Living at home
- Functional Assessment Scale (FAST) from 6d level of disability (on reverse of referral form)

Understanding where we are…..

What is moderately severe dementia?

The FAST Tool



Recognising the impact…….

The Functional Assessment Staging Test (FAST Tool) Comparison

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	--	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0

Information and Contact

- Please provide additional information: recent medical letters; scans; blood results or Hospital Discharge Summary
- Please complete referral form in as much detail as possible.
- First Telephone contact next business day
- Telephone support/ advice available

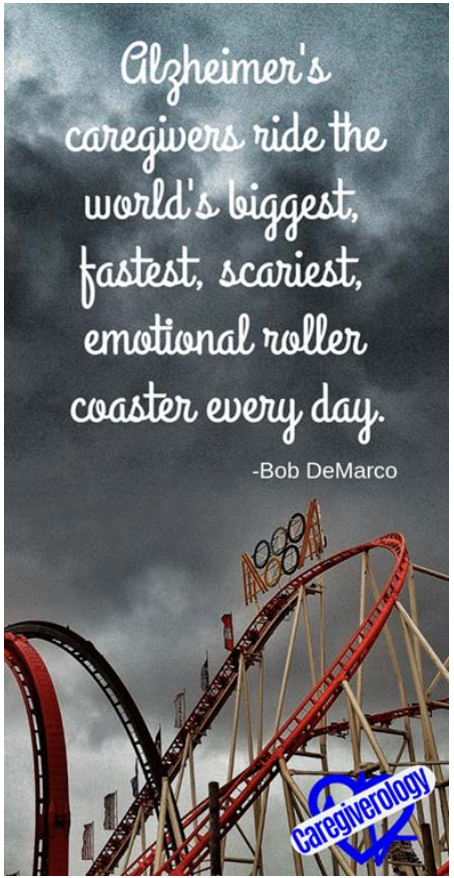
What the service provides

The Client

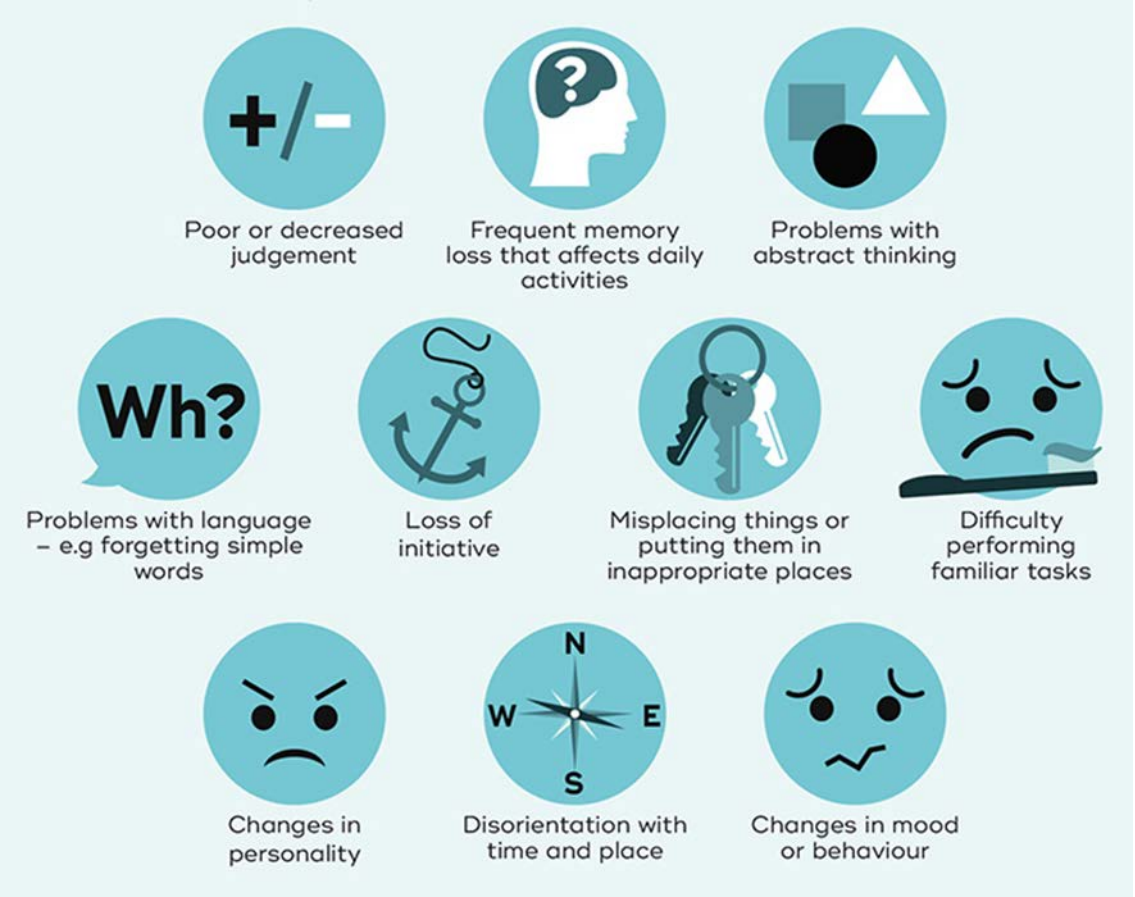
- Community Palliative Dementia Care support provided by Nurse Practitioners
- The service holistically addresses symptom management issues utilising a person centred approach
- Recognise increased care requirements, utilising optimal package use
- Advance Care Planning
- Aim to reduce hospital admission/ Length of stay
- Identification of deteriorating condition, referral to SCHCS

The Carer

- Identify carer strain and provide support
- Promote and support confidence and capability
- Optimise understanding through education and advance care planning
- Communication the lynchpin
- Identify deteriorating condition, support and referral to SCHCS
- Bereavement follow-up based on assessed risk of the bereaved and length of engagement with the service.
- Provide dementia and advance care planning resources



What are family seeing?



Communication

Talk with me

https://www.dementia.org.au/resources/talk-with-me

Talk with me! Good communication tips for talking to people with dementia

These are principles of communication that people living with dementia have told us would make a difference to their lives.

TALK WITH ME
Please talk with me, not my carer, family member or friend. Don't prejudge my level of understanding.

PLEASE SPEAK CLEARLY
Make eye contact and speak clearly. Use short sentences, with one idea at a time. Avoid jargon, as I might misunderstand.

PLEASE KEEP QUESTIONS SIMPLE
Make sure I am listening and use simple questions and/or repetition, offered with sensitivity. It's easier for me to answer direct questions, rather than open-ended questions, such as saying 'Wasn't it lovely when we went out to the park yesterday?' not just 'Wasn't it lovely yesterday?'.

TREAT ME WITH DIGNITY AND RESPECT
I am still a person, so don't patronise me. Respect and empathy are important to everyone. If I act differently it may be because I am having difficulty communicating or because of my disease.

DON'T QUESTION MY DIAGNOSIS
The symptoms of dementia are not always obvious. Listen to me and don't minimise my feelings.

DISTRACTIONS CAUSE DISRUPTIONS
Less noise and fewer distractions, such as bright lights, will help me to focus.

BE PATIENT AND UNDERSTANDING
Sometimes it takes a little longer for me to process information and find the right answer. Don't rush me. Give me more time to respond and compose my questions.

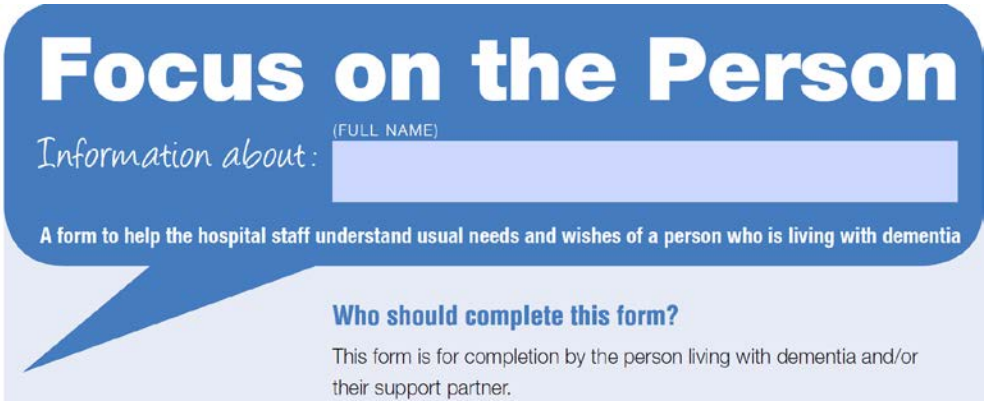
BREAK IT DOWN
Providing information in smaller chunks will really help me.

SIGNAGE
Please use clear and simple signage.

The Hospital and Community

- Collaborating with community services to ensure best person-centred care through the appropriate and efficient use of resources
  - General Practitioner
  - Care package provider
  - Medical specialists- Geriatricians,
- Focus on the Person Form– provides information on the views, needs and wishes of the client to support optimal informed care
- Aim to reduce hospital re-admissions, length of stay, facilitation of advance care planning discussions/ Goals of patient care, reduce carer strain- increased understanding

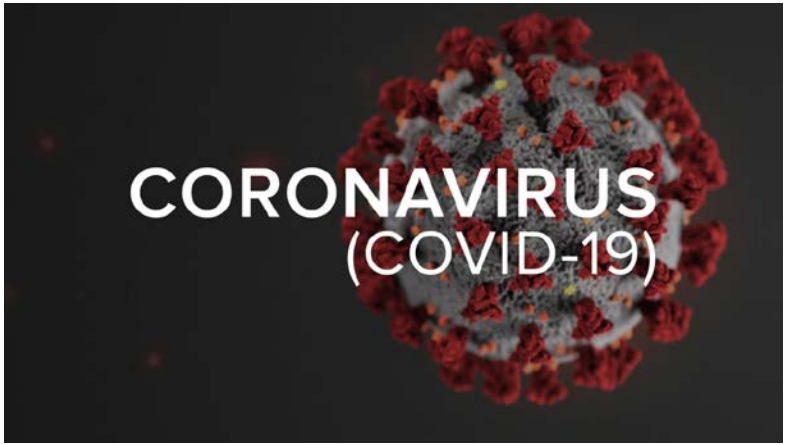
A Focus on the Person Form



Burton E, Slatyer S, Bronson M, et al. Development and pilot testing of the "focus on the person" form: Supporting care transitions for people with dementia. *Dementia (London)*. 2019;18(6):2018-2035. doi:10.1177/1471301217736594

COVID-19 Impact

How has Covid-19 impacted the Palliative Dementia Service



- Non- essential visits therefore only contact by phone- loss body language, communication subtleties, talk carer, not see client, verbal vs non verbal, impact of stress and fear.
- Families cancelling appts, carers in fear, burden in the home
- Not go to hospital- fear of if admitted increased stress- families unable to visit or only limited times
- Routine changes- day centres- carer burden, not able to go out- activity- loss of distraction
- GP visits- only phone
- Family visits/ family over EAST/ global- no break no assistance- grandchildren
- Groups and day centres cancelled
- Closure of Memory Clinics- reduced diagnoses
- Overall impact – Client, carer and the system

What have we learnt so far

- Building relationships and collaboration
- Increasing awareness
- Why do families want to keep their loved ones at home
- Enormous holistic complexity
- Small cohort- but growing
- Fear in a name- timing confusion
- Health literacy- what are you seeing, what do you understand
- Transitions to community Palliative Care services
- Acute setting issues- no dementia diagnosis; acutely unwell, family overwhelmed, terminal phase- some stabilise at home

NEXT STEPS:

Complexity in a case…..

CASE 1: Transitions

Mr D is a 62 year old man with Young Onset Alzheimer's Dementia.

BACKGROUND

He lives with his wife.

Referred from hospital – (admission for investigation of abdominal mass).

Issues during hospital admission with agitation, functional and cognitive decline.

Mrs D - Hospital admission was a disaster! Never want to go through that again.

COVID restrictions added to distress.

REFERRAL to PDS

Incontinent

Agitation, function and cognition improved after a few weeks at home.

Continence improved.

? do we discharge from service.

Decision made for surgery – PDS support through surgery.

Mrs D had many concerns and was very anxious about the surgery and admission.

Successful Transitions

PDNP SUPPORT

- Focus on the Person Form
- Contact with Dementia Coordinator in hospital.
- Many advanced care planning discussions.
- Feedback from carer.
- Carer felt supported and was confident in the ability of the hospital to cater for Mr D's needs.
- "The nurses couldn't have been more helpful"

Complexity in a case…..

CASE 2: Recognising the small things

Mrs B is a 91-year-old lady with Advanced Alzheimer's Dementia

BACKGROUND

She resides with her daughter and family having lived independently since her husband died 3 years ago.

Referred from hospital – (admission for abdominal pain- CT mild colitis and sigmoid diverticulitis, which causes much distress)

Issues during hospital admission- bed centred care- functional decline, incontinence, anxiety, poor nutritional intake. Colitis resolved.

Referral to PDS

Expecting further rapid decline potentially toward terminal phase, requirement for ACP considerations.

On waitlist for a level 4 Care package; currently assisted 3hrs/week

The following two months have been challenging- with distressing toileting behaviors, change to dietary requirements- sensory related, gradual reduction in engagement, wandering late pm, disturbed sleep- requiring assistance and further changes this week have seen increased sleeping, increased weakness and family realisation of ensuing deterioration and what that means……

Recognising the small things- building memories

FAMILY COMMENTS:

-Provision of many recourses and given much needed support and information

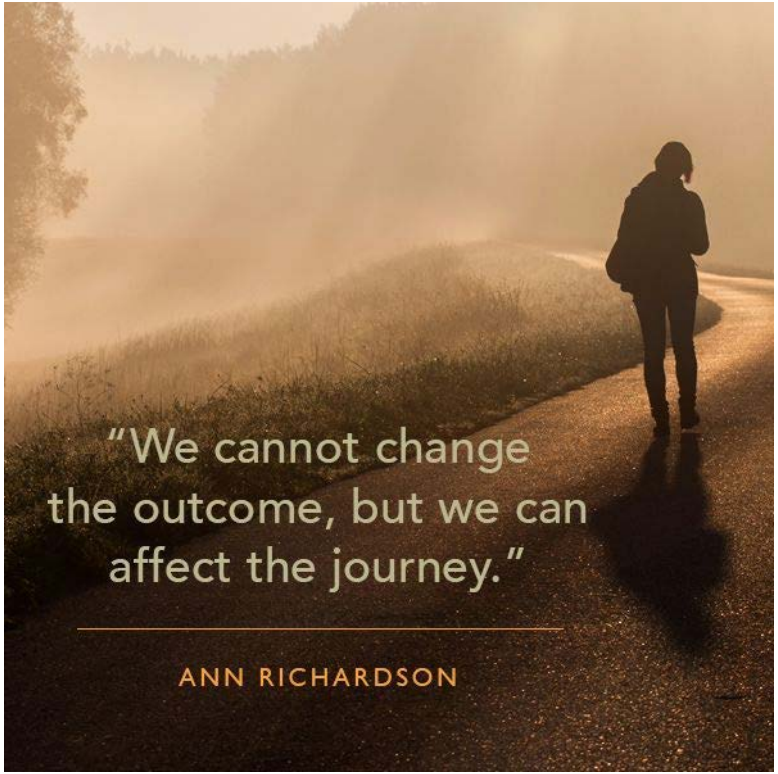
-Initially thorough history taking into consideration both the needs not only of Mum but also myself.

-Holistic review- considering all aspects of care and advance care planning

-Each review providing a plan to move forward

-‘Due to the nature of dementia and the constant changes as the illness progresses it is reassuring and comforting to know the service is there to support and guide’

- ‘It has been great to recognise and be reminded of those happy times- picnicking as a family in the park; playing snakes and ladders with the children; baking cakes and cooking; time spent remembering’.



"Sometimes
the smallest things
take up the most
room in your
HEART"

Winnie the Pooh

Questions

Questions