

Dementia and End of Life Care

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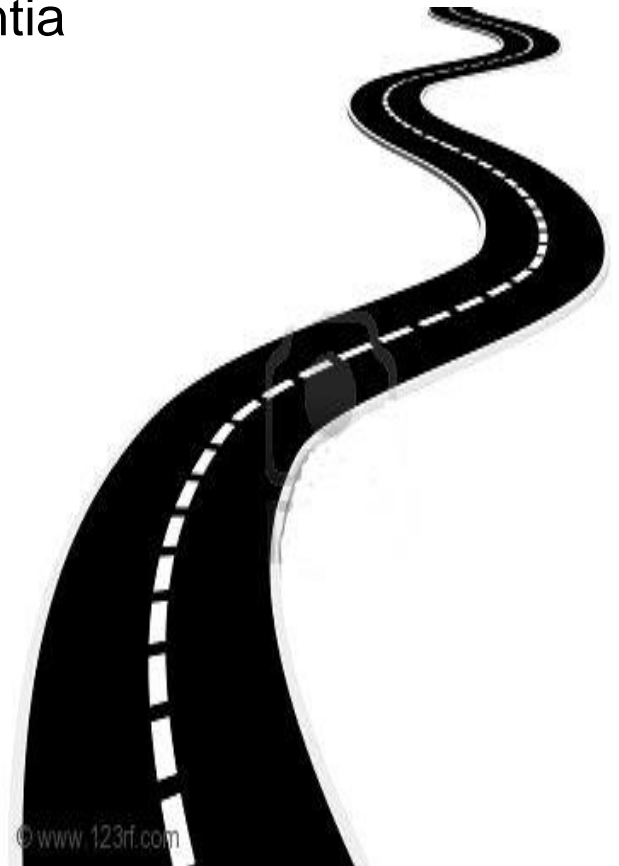
Dementia Clinical Specialist



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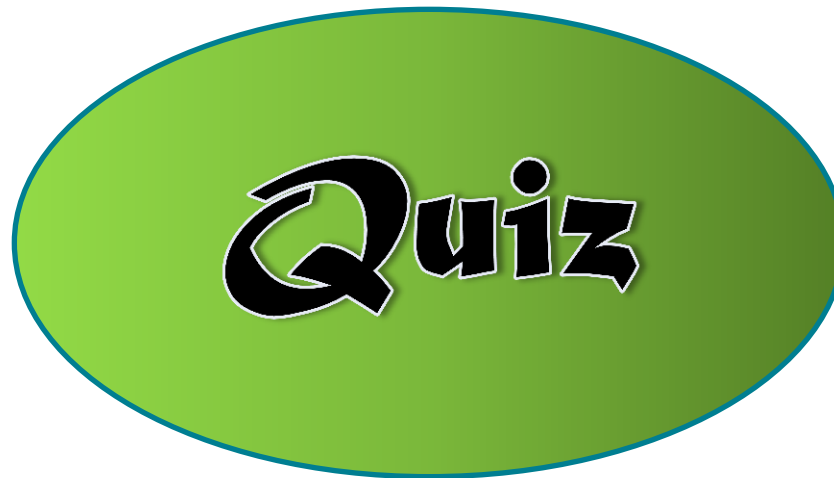
For the next hour

- What is Dementia
- Look at the signs of aging and signs of Dementia
- Dementia and Learning Disability
- Understand the prevalence of dementia
- Dementia and EOLC ... what we see
- Case study
- Carers perspective
- What we can do ... once chance to get it right



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Fact or Fiction



Definition



The term dementia describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease.

Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time.

These changes in ability include a reduction in the person's capacity to make decisions about major life events and circumstances as well as day-to-day decisions.

Eventually they will need help with all their daily activities, spanning health and social care.

Dementia is recognised as a terminal condition

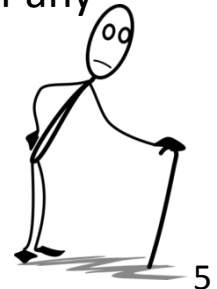
Usual sign of getting older VS Dementia

Normal Aging

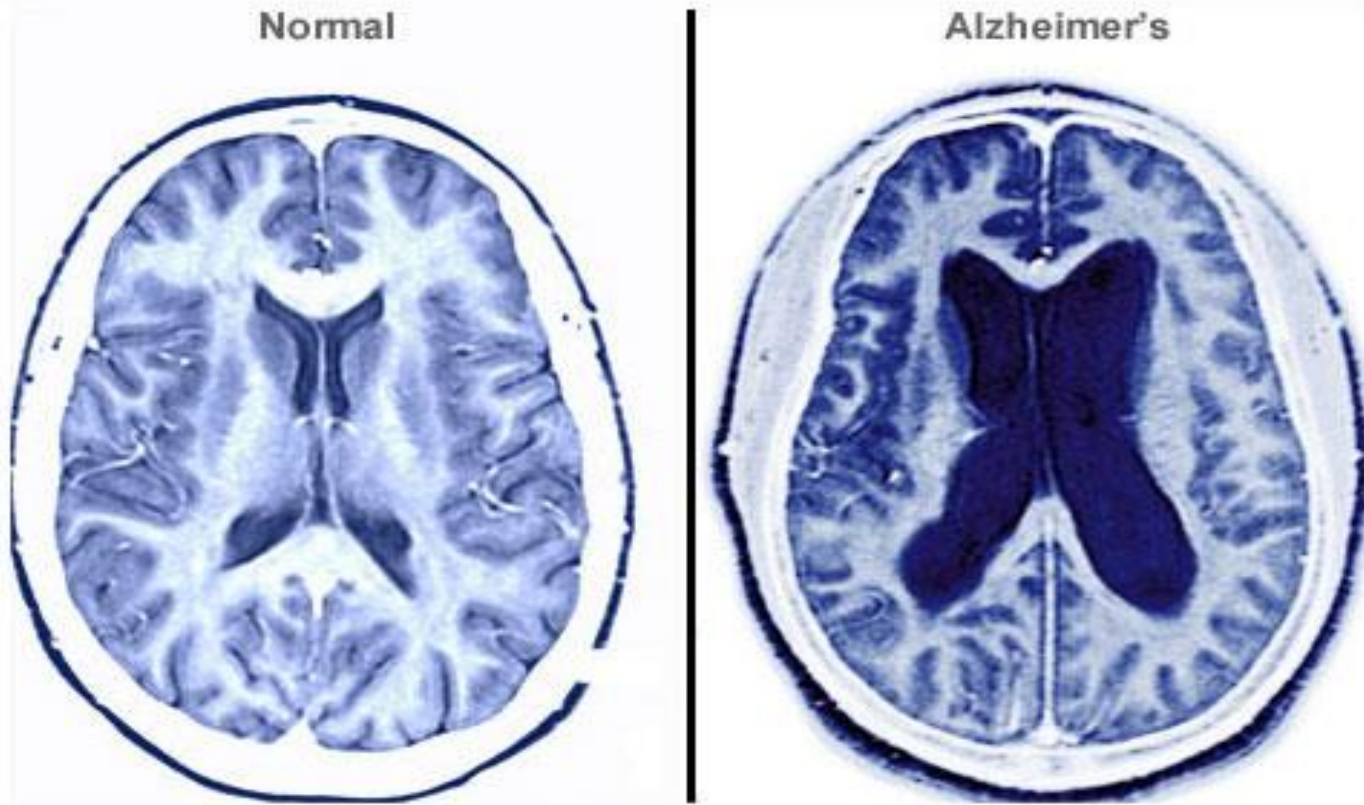
- Not being able to remember details of a conversation or event that took place a year ago
- Not being able to remember the name of an acquaintance
- Forgetting things and events occasionally
- Occasionally have difficulty finding words
- You are worried about your memory but your relatives are not

Dementia

- Not being able to recall details of recent events or conversations
- Not recognizing or knowing the names of family members
- Forgetting things or events more frequently
- Frequent pauses and substitutions when finding words
- Your relatives are worried about your memory, but you are not aware of any problems



Getting Older



Living life to the full



Dementia & EOLC

- Over 1.5 million people in the UK, including both people with dementia and their carers, would benefit from dementia treatments today; that's more than the combined populations of the cities of Bristol, Manchester and Sheffield.
- There are 850,000 people living with dementia in the UK today (1.3 per cent), including over 700,000 people in England, over 45,000 in Wales, nearly 20,000 in Northern Ireland and 70,000 people in Scotland. By 2025 the number is expected to rise to over one million and by 2050 it is projected to exceed 2 million.
- In the UK it is estimated that 62 per cent of people with dementia are female and 38 percent are male.
- Dementia is the leading cause of death among women in the UK with 12.2 per cent (31,850) of deaths per year attributed directly to the condition.
- In the UK over 40,000 people under the age of 65 have dementia.
- There are approximately 700,000 informal carers caring for their loved ones with dementia, this is expected to rise to 1.7 million by 2050.

Dementia & EOLC

- The Department of Health estimate that 59 per cent of people with dementia in England have a formal diagnosis.
- There are over 44 million people worldwide with dementia. This is predicted to increase to over 75 million by 2030 and over 135 million by 2050.
- In Europe the numbers of people with dementia is expected to increase by 90 per cent between 2013 and 2050, from 11 million to 21 million.
- The idea that illnesses like Alzheimer's are a disease of rich developed nations is a myth: 62 per cent of people with dementia live in low and middle income countries and 38 per cent live in high income countries.
- By 2050 it is estimated that the proportion of people with dementia living in G8 countries will have decreased to 21 per cent, while the proportion living in low and middle income countries will have increased to 71 per cent.

Stigma

Stereotypes or misinformation can intimidate friends and family. Some believe that nothing can be done, or dismiss symptoms as “just a normal part of old age.”

Negative language is often used to describe Alzheimer’s disease and other dementias.

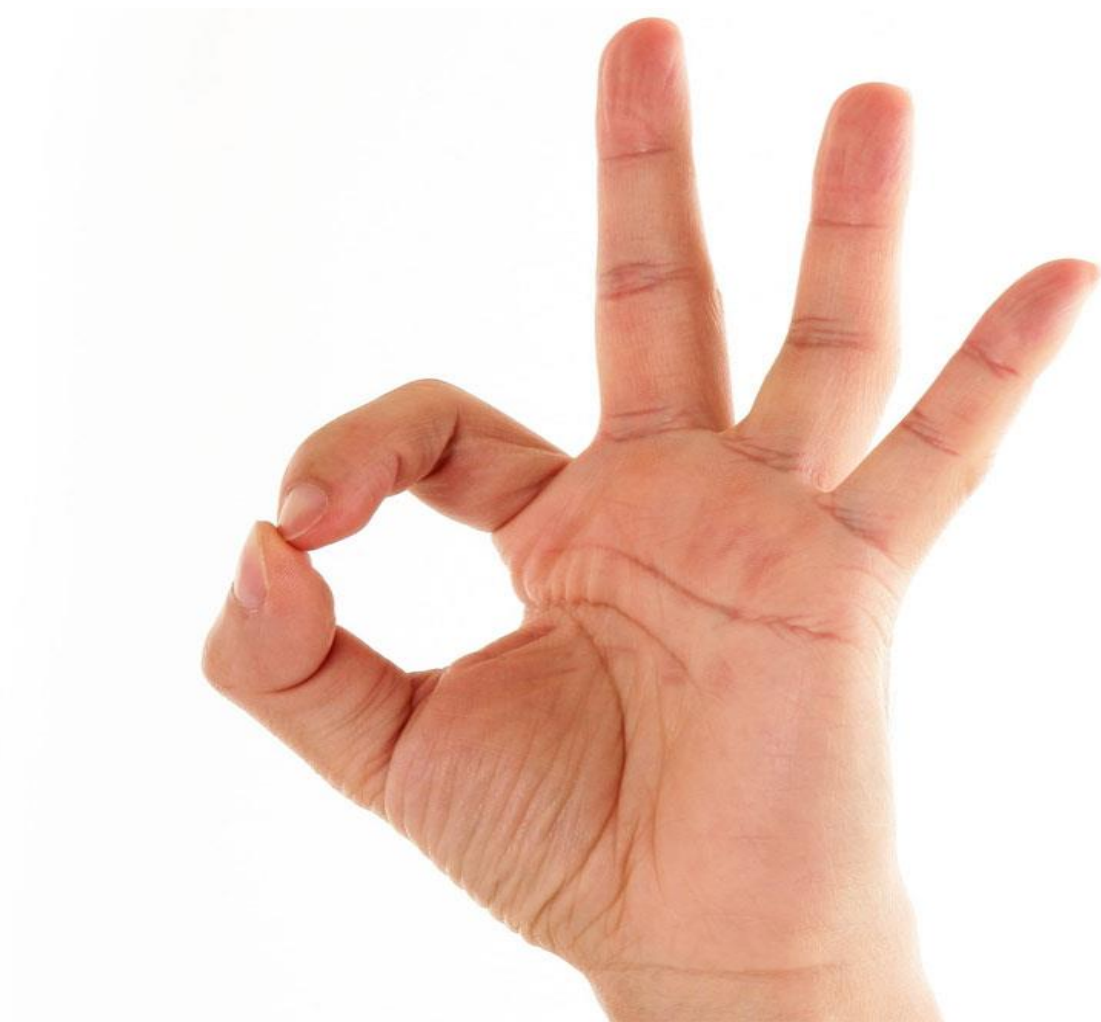
The wording tends to focus on the illness and reduces people with the disease to a series of labels, symptoms or medical terms.

It is important to be aware that negative reactions from friends, family and professionals can impact a person’s well-being and ability to manage the changes brought about by the disease.



People with LD and EOLC





Dementia Journey

Table 2: The dementia journey

Phase 1	When memory problems have prompted me, and/or my carer/family to seek help.
Phase 2	Learning that the condition is dementia.
Phase 3	Learning more about the disease, how to manage, options for treatment and care, and support for me and my carers/families.
Phase 4	Getting the right help at the right time to live well with dementia, prevent crises, and manage together.
Phase 5	Managing at more difficult times (including if it is not possible to manage at home).
Phase 6	Receiving care, compassion and support at the end of life.

Dementia Journey



Dementia a terminal illness

- ❖ Dementia shortens life expectancy, but it is very difficult to know how long someone with dementia will live for. If the person also has another life-limiting illness, their condition is likely to worsen in a more predictable way over a period of weeks or days. This may mean that the person dies from another condition (e.g. cancer) when their dementia is at a relatively early stage.
- ❖ But someone with later-stage dementia without another life-limiting illness often deteriorates slowly over many months. They gradually become more frail, have more frequent falls or infections, become less mobile, sleep more, and eat and talk less
- ❖ A person with later-stage dementia may have symptoms that suggest that they are close to death, but actually live with these symptoms for many months. This uncertainty makes planning for the end of someone's life difficult.

Dying and dementia

All of the people with dementia in the UK will face additional complications at the end of their lives, regardless of which disease causes their death.

The dementia itself causes problems in areas that are key to planning for and ensuring a good death:

- ❖ Diminishing mental capacity
- ❖ Difficulty with communication – (hunger, thirst, discomfort, pain or other needs)

There is also the problems of :

- ❖ Difficulty predicting prognosis
- ❖ Difficulty predicting dying phase
- ❖ The risk of over-intervening - e.g. hospitalisation

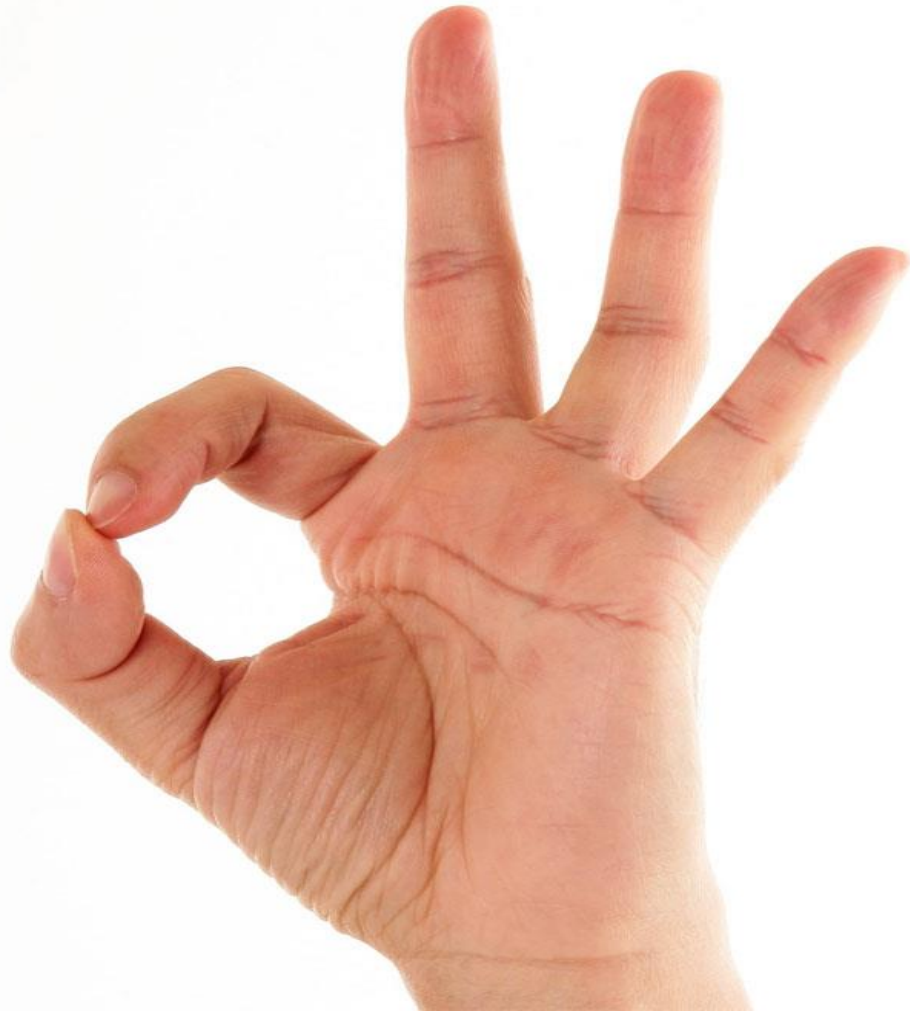
Dying and Dementia

There are three ways in which people with dementia die

- ❖ • People may die from the complications arising from end-stage dementia
- ❖ • People may be in the early stages of dementia and die from another illness (e.g. cancer)
- ❖ • People may die with a mix of problems

Dementia may not be the main cause of death, but it interacts with other conditions and can complicate and worsen them. Research has shown that people with dementia can often have problems swallowing and contract pneumonia along with fevers and seizures

Many people with dementia may also have long-standing medical conditions which will complicate their care, such as diabetes, arthritis, heart problems and trouble breathing.



Case Study

Joan, aged 81 years, living with dementia – final year of life

Dementia progressively worsening; dwindling physical state
No end of life care plan ...

Several crisis calls to GP over a period of 7 weeks – falls, resistance, poor sleep, confusion and weight loss

Admitted to hospital – dehydration ... Discharged after 9 days

Dementia markedly worsens

Readmitted with confusion and distress – dehydration

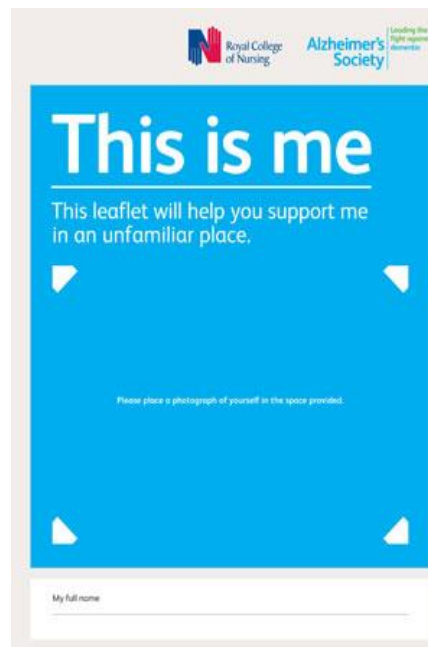
Discharged after 13 days

Readmitted 5 weeks later following a fall ... Dies soon after



Dementia and palliative care

- Public /Carer family awareness
- Dignity/respect
- Care planning and proxy decision making



Dementia and palliative care

- Pain management
- Withholding and withdrawing treatment
- Emotional and spiritual concerns
- Place of care and environment.

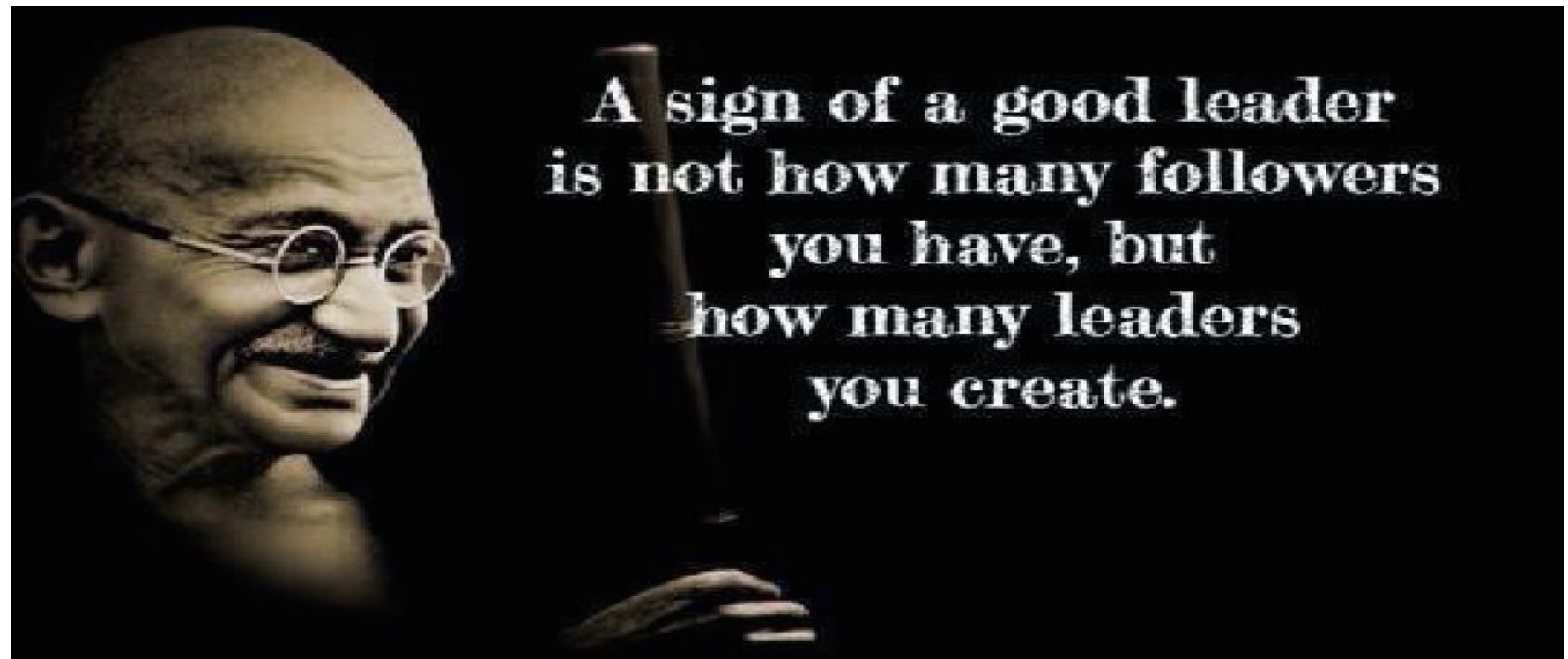
Carers Perspective

- the best bit!!

The message

- We NEED do all we can to ensure people with Dementia die with Dignity and Respect

- People with Dementia and their carers need you as **Leaders**





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