FAMILIES AND CARERS AS PARTNERS IN DEMENTIA CARE.

Integrated Admiral Nurse Service

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- *"A carer is anyone… who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or addiction and cannot cope without their support. The care they give is unpaid…"*

(NHS England, 2022)

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WHAT IS A CARER?

UNDERSTANDING THE WORD… "CARER"

- The majority of care for people with dementia is undertaken by their family as carers.
- The label 'carer' seems to imply that the person has willingly chosen this role; what often happens is that people fall into the role without choosing it.

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CARER STATISTICS

- One in two of us will be affected by dementia – either through caring for a loved one with the condition, developing it ourselves, or both
- There are estimated to be nearly one million people living with dementia in the UK today
- 52 percent of people in the UK know someone who has dementia

Stats about carers

- There are around 540,000 carers of people with dementia in England
- It is estimated that one in three people will care for a person with dementia in their lifetime
- 1.1 billion hours are spent each year on unpaid care for people living with dementia
- Two thirds of unpaid carers for those with dementia are women

Dementia Uk

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VALUING CARERS

Carers can be a valuable source of information. They will be able to fill you in on information from a person's past: this may be a critical piece of the puzzle in coming to understand a person's behaviour and their needs much better.

Through your communication you can demonstrate compassion, show carers that you respect their knowledge, and that you want to listen to their views. Working together, will give you more satisfaction and will also be of comfort to the carer.

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WHERE CAN I FIND WHAT SUPPORT IS AVAILABLE?

- What support is out there?
- Where can you find out if you don't know?

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SUPPORTING CARERS TO ACCESS INFORMATION



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SUPPORTING CARERS TO PROMOTE THEIR RIGHTS, CHOICES AND WELLBEING OF PEOPLE LIVING WITH DEMENTIA

Ensuring that carers and the person living with dementia's rights and choices are heard. Awareness of Person-centred care

Provide information on Lasting Power of Attorney (LPA) . Appropriate use of Advocacy service

It is important to recognise a carers own needs, such as their need for carers assessment, respite care, carers breaks, community carers support services

Support family members in making informed decisions for people living with dementia, including future care options/transitions/crisis & Advanced Care Plans (ACP) end of life care

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SCENARIO:

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SCENARIO:

A family member talks to you in confidence that they are struggling because they have noticed that their loved one who has advanced Alzheimer's disease is becoming more confused and agitated, particularly during the evening hours. The carer also disclosed she is feeling overwhelmed and exhausted and she has locked her husband in a room during this time so she could get away from it all

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DISCUSS

Think about the triadic relationship between the carer, the patient with dementia, and the healthcare professionals; why is this so important?

- Group 1: The patients views and feelings- Why is he presenting this way, what support do you think he needs?
- Group 2: In your role - views and feelings- How would you manage this situation, what actions might you take for the carer and patient; what other priorities might affect this?
- Group 3: The carers views and feelings- How may they feel at this time? How can the carer be supported in this situation? Why is it important to think about the carer at this time?

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CARING AND CULTURAL DIFFERENCES

Like any condition, dementia does not discriminate and will affect people from all cultures and backgrounds, social-cultural differences

Carers opinion's & values may not always align with the person living with dementia

Issues of diversity may have an impact on how people experience dementia.

This is including the acceptance of the condition within their family or community.

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BE AWARE OF THE IMPACT ON YOUNGER CARERS AND THEIR CONCERNS

- Many younger people have caring responsibilities for someone with dementia. This may be for a grandparent or for a parent who may have young onset dementia.

There is an estimated 7.5% or 70,800 of the estimated 944,000 people living with dementia in the UK living with young onset dementia where symptoms occurred under the age of 65. ***Statistics taken from Dementia UK***

- It is important to consider the impact of caring responsibilities on the whole family and understand the needs and concerns that younger carers or members of a household with caring responsibilities may have, including emotional impact

The 2021 census found there were about 120,000 young unpaid carers aged 5-17yrs in England (1.4% of 17yr old) and 8,200 in Wales (1.8% of 5-17yr olds)

Statistics taken from Carer UK

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THANK YOU FOR LISTENING.

- For more information about how to make a referral to our service please email: RCHT.admiralnurse@nhs.net or call: 01872 255741
- Dementia UK Helpline: 0800 888 6678.
- Department of health & social care – Dementia Training Standards Framework (Feb 2026)

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01872 255741

THANK YOU! ANY QUESTIONS?



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