

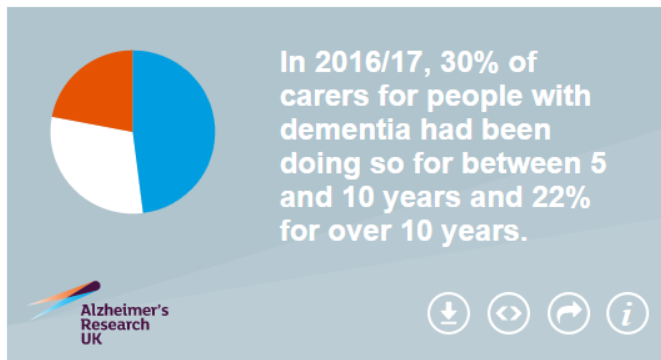
Case Study: Supporting and Working with Unpaid Carers to Provide Respite and Ease Pressure

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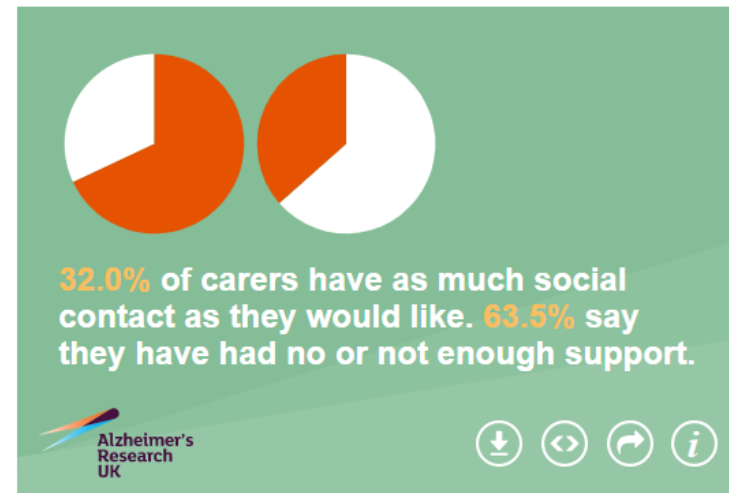
Pride in our older people's and adult
community services



Source: Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital; Question 18



Source: Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital



Source: Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital



Source: Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital Question 19



Source: Luengo-Fernandez, R. & Landeiro, F. (in preparation). The Economic Burden of Dementia in the UK.

Dementia in the Family – The Impact on carers (2019)

Touches the lives of millions of people:

there are currently 850,000 people in the UK living with dementia and 700,000 friends and family members caring for a person with the condition. Over 24 million people know a family member or friend with dementia

[Dementia-in-the-Family-The-impact-on-carers1.pdf \(alzheimersresearchuk.org\)](#)

Summary

- Is challenging: carers manage difficult changes in their loved ones' behaviour and personality, including aggression in some cases. Caring full-time can leave family members feeling socially isolated and having to meet hidden costs.
- Is rewarding: caring is often a very rewarding experience that can strengthen family bonds through the close and intimate relationship shared.
- Can change family relationships: changes in behaviour and personality can cause family carers to treat their loved one in a different way. Carers' relationships with siblings can also become strained as the amount of care increases.
- Impacts psychological and physical health: the negative health consequences of looking after a family member with dementia are well documented

State of caring report - 2022

With the health and social care system under intense pressure, many carers have experienced delays in accessing healthcare appointments and services.

- 19% of carers who had requested a GP appointment said they had had to wait over a month for this,
- and over a third (34%) of carers who were waiting for specialist treatment or assessment had been waiting for over a year.
- This has caused additional stress and anxiety and resulted in many carers feeling isolated and forgotten about.
- 67% of carers waiting for specialist treatment or assessment said that waiting was having a negative impact on their mental or physical health, with 38% of those strongly agreeing.

State of caring report - 2022

- Over a third of carers (36%) said that not knowing what services were available was a barrier to accessing support.
- With many services being reduced or cut completely, carers are extremely worried about the future: 61% said they were uncertain about what practical support they might be able to access in the next 12 months.
- This year, only a quarter (25%) of carers said they had undertaken a Carer's Assessment in England and, of those who had, many were concerned that the assessment has not led to any improvements in the support provided to them.

The Fog of Support – 2020



The support available for carers

- Carers are often expected to be proactive in seeking an assessment of their needs and subsequent support.
- The post-diagnostic support pathway - the onus is on people with dementia and carers to identify appropriate support services.
- The need for carers to identify themselves and actively seek support is a barrier to local areas fully supporting their carer populations.
- Post-diagnostic support is often provided by a diverse range of service providers with different levels of funding.

The Fog of Support - 2020



Findings

There is a reported lack of available services that enable carers of people living with dementia to take a break from caring.

Positive support is reported by some (such as that provided by local charities, and the use of community resources); however both professionals and carers report difficulty in finding care provision which suits the needs of people living with dementia, and this in turn prevents carers from arranging breaks for themselves.

The Fog of Support - 2020



Findings

The experience of carer assessments reported by carers is mixed; however this research confirms findings in the wider literature that only a minority of carers have received an assessment of their needs.

Furthermore, these assessments were not always experienced positively, with negative experiences being linked to assessments that were conducted over the telephone and/or did not seem personalised to the individual circumstances of the carer.

Case Study - John

- 65 year old married gentleman, diagnosed with Alzheimers disease in November 2021.
- Retired secondary school teacher, left employment in 2012 due to stress. Occasional memory lapses noticed by wife put down to stress at the time employment was terminated.
- Moved home in 2018 to be nearer their daughter, difficulty working new kitchen equipment, getting lost. Difficulty interacting with others. Requiring supervision.
- At time of diagnosis MMSE 15/30 – significant speech impairment, not able to draw complex figure or write a sentence, not able to recall daughter age or DOB, need help to take off shirt.
- Evidence of progressive decline over 4 years.

Case Study - John

- Referred to Dementia Intensive Support Team by FRS in October 2022.
- Unsettled, agitated, paranoid thoughts, worried about dying and wife struggling to cope. Not leaving wife's side.
- In the two weeks prior had been on holiday to Spain and on returning stayed with daughter. Chaotic environment as building work taking place.
- Wife suffered from her own mental health issues – Obsessive compulsive disorder.
- GP previously ruled out physical health issue.
- Prescribed PRN lorazepam by GP.

Education, training and techniques to manage the stress and responsibility of caregiving

Assessment identified:

- Lack of understanding of stage of disease
- Lack of understanding of cause of behaviours
- Difficulty adapting or changing routine, reluctance to change
- Self awareness and understanding of own limitations/impact of OCD on caring role
- Concerns that in a different environment, behaviours would not be problematic and would not need pharmacological interventions.

Plan: Intensive support to address the above and seek respite

The 10 Absolutes of Caregiving for Patients

Never **ARGUE** instead **AGREE**

Never **REASON** instead **DIVERT**

Never **SHAME** instead **DISTRACT**

Never say **YOU CAN'T** instead **DO WHAT YOU CAN**

Never **COMMAND** or **DEMAND** instead **ASK** or **MODEL**

Never say **REMEMBER** instead **REMINISCE**

Never say **I TOLD YOU** instead **REPEAT**

Never **LECTURE** instead **REASSURE**

Never **FORCE** instead **REINFORCE**

Incorporating carers and relatives into the decision-making process on care and treatment:

Top Tips:

1. Listening
2. Time, review and repeat.
3. Both verbal and written information.
4. Information tailored to the amount of detail the person wanted.

Outcome:

1. Referral to mental health social workers due to complexity of John's wife's OCD and level of support required.
2. Respite day care commenced
3. Medications optimised.
4. Whole family engagement
5. Referral on to CPN for long term support.

Thank you, any Questions?