

Caring for Someone with Dementia – An Information Meeting

(for registered patients of Baddow Village Surgery)

A presentation aimed at carers of partners or relatives diagnosed and in the early stages of dementia, or people waiting for, or anticipating a dementia diagnosis.

Areas of discussion will include:

Medical
Evaluation

Health
& Care
Plans

Legal &
Financial
Planning

Lifestyle
Changes

Support
Networks

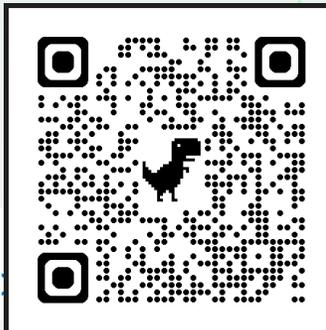
Carer's
Support



Where & When: Baddow Village Surgery – February 19, 1pm-2.30pm

Presented by: Baddow Village Surgery **Patient Participation Group** (the **PPG**) supported by Practice Staff, the Alzheimer's Society and Carers First

Visit the PPG website to access a copy of the Dementia Presentation Notes and our latest Newsletter >





Dementia - a carer's perspective

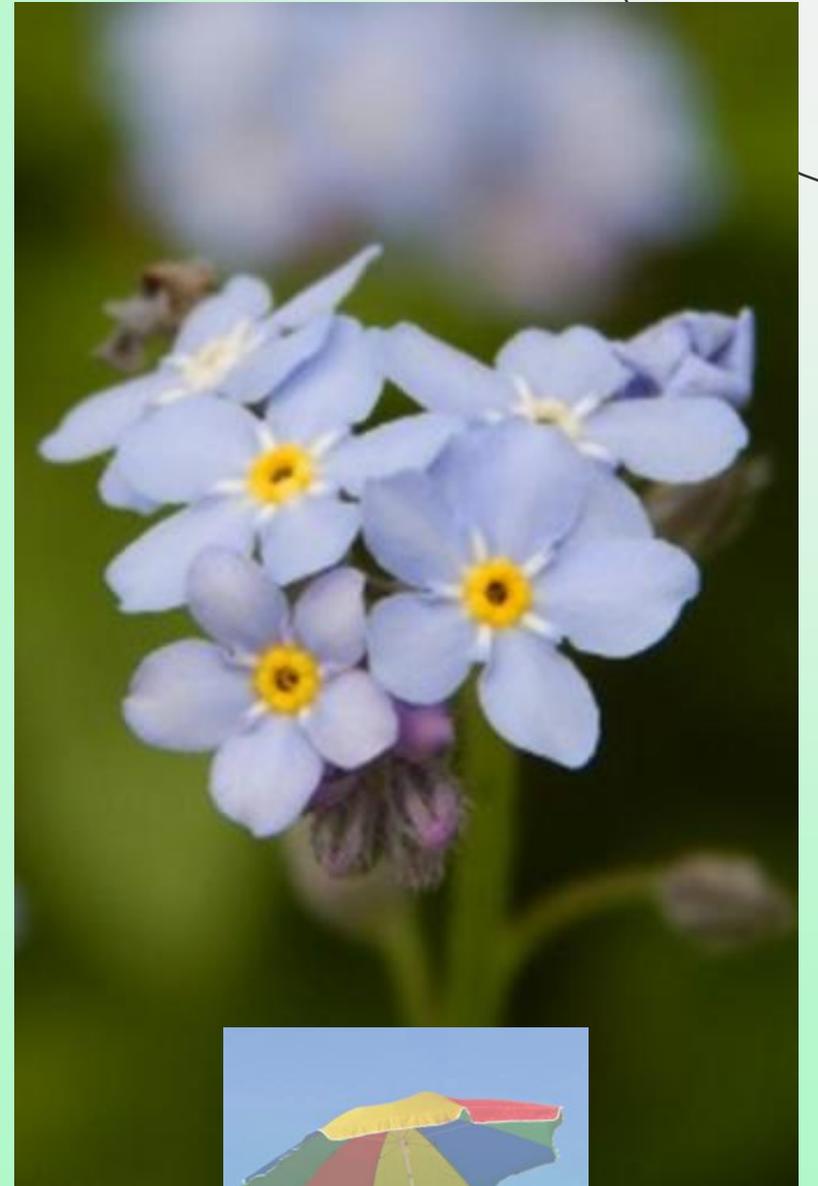
"People with dementia need support, respect and dignity. Simple and little things can make a lot of difference."

Learning to care well for someone with dementia is a challenge most carer's never planned for.

***"Living well with dementia"** - a short video where Dr.Jennifer Bute shares her day-to-day life with dementia - note her spirit shine through and her search for opportunity.*



<https://vimeo.com/40513833>



Early indications of dementia include behavioural changes:

- **Memory** – forgetting words, events or repeating stories, forgetting people
- **Communication** - frequent pauses, trouble forming sentences
- **Planning** - may miss appointments, struggle with finances, shows confusion, and has trouble with planning tasks
- **Mood changes**, anxiety, and behavioural shifts, hallucinations
- **Movement** changes like gait changes, coordination issues, unsteadiness, and limb stiffness
- **Vision** issues - affecting depth perception and shape recognition





Dementia - a carer's personal observations

Get an early diagnosis – go to the doctors together

.. Alzheimer's Society suggested a carer's course

Peer support groups - helpful advice /emotional support

Become a dementia friend (Alzheimer's Soc.)

Life can still go on after an early diagnosis

Wages, pension, attend-allowance - to separate accounts

Never refuse any help – you are going to need it

Register as a carer with your GP

Make Social Care aware of your situation

Set up Power of Attorney with trusted "attorney"

None of us is guaranteed a tomorrow – live for today

Make sure legal will in place (whilst mental capacity)

(Personal notes and suggestions from a local carer)



Supporting Identity

People with dementia may lose their memory and their skills - but they do not lose their feelings!

- People with dementia, whose mental abilities are declining, increasingly feel vulnerable and in need of reassurance and support
- It is important to do everything you can to help them retain their sense of identity and feeling of self worth
- Carers and family will need to make adjustments and plan to learn new skills to support the person with dementia



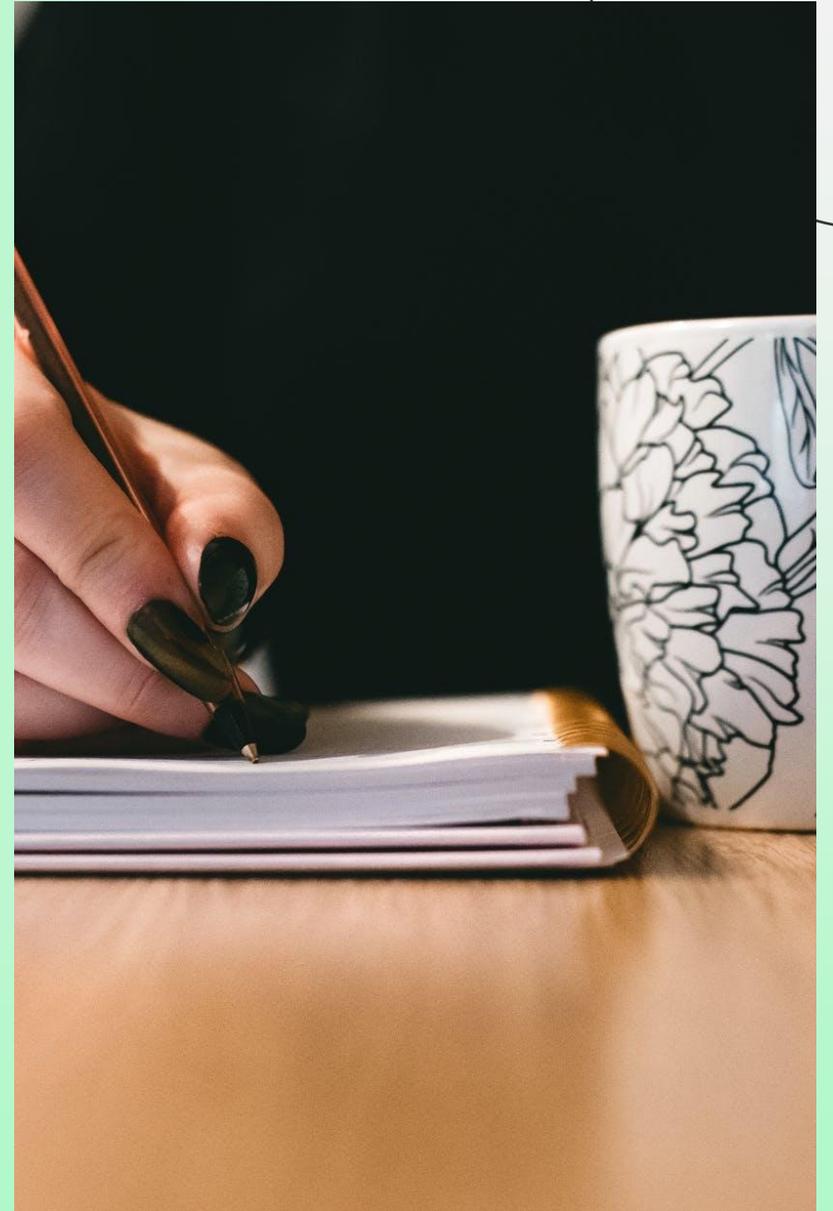
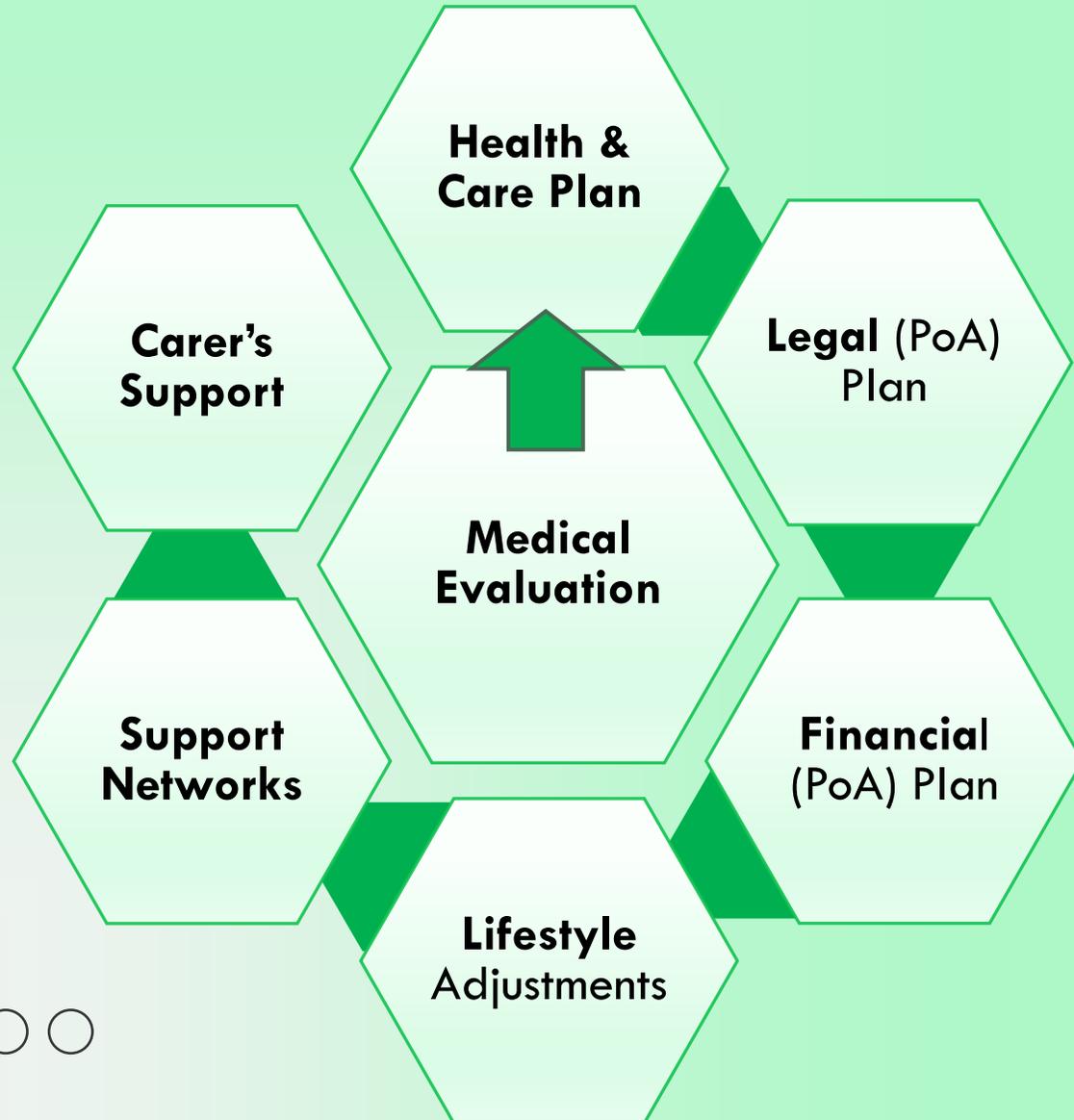
≡ Cognitive decline - a need to plan for a very different future:



NOTE: Early diagnosis of dementia helps individuals and their families make informed decisions about their future.

	Normal behaviours (i.e. before dementia)		Severe dementia behaviours (most likely case)
Memory function	No memory loss or slight inconsistent forgetfulness	➔	Severe memory loss; only fragments remain; finally mute
Personal Orientation	Fully oriented /aware and confident with surroundings and able to function normally	➔	Disoriented, especially related to time, date and place. Oriented to person only (withdrawn)
Judgment & problem solving	Solves everyday problems; handles work and finances well; reliable judgment in relation to past decision making	➔	Unable to make judgments or solve problems
Social activities	Independent, functions at usual level for activities such as shopping, volunteering and participating in social groups	➔	No independent function outside home; too ill to be taken to functions outside family home
Home and hobbies	Life at home, hobbies and intellectual interests well maintained	➔	No significant function in the home
Personal care and hygiene	Fully capable of maintaining own appearance and selfcare	➔	Dependency in basic activities of daily living; incontinent
Affect / Personality	Normal day to day personality	➔	Delusions; anxiety and agitation; repetitive obsessive behaviour, hallucinations

≡ Dementia - planning checklist





Medical Evaluation

Start with your GP – ask for an appointment for diagnosis and tests to confirm dementia. Accompany the patient and make notes to later recall the advice and information provided.

Diagnosis should lead to access to specialist care, information and be the start for key planning steps for the future of both the patient and their carer.

Expect introductions to other health and care services and determine who will coordinate care across services for both the patient and for the carer.





Health and Care Planning

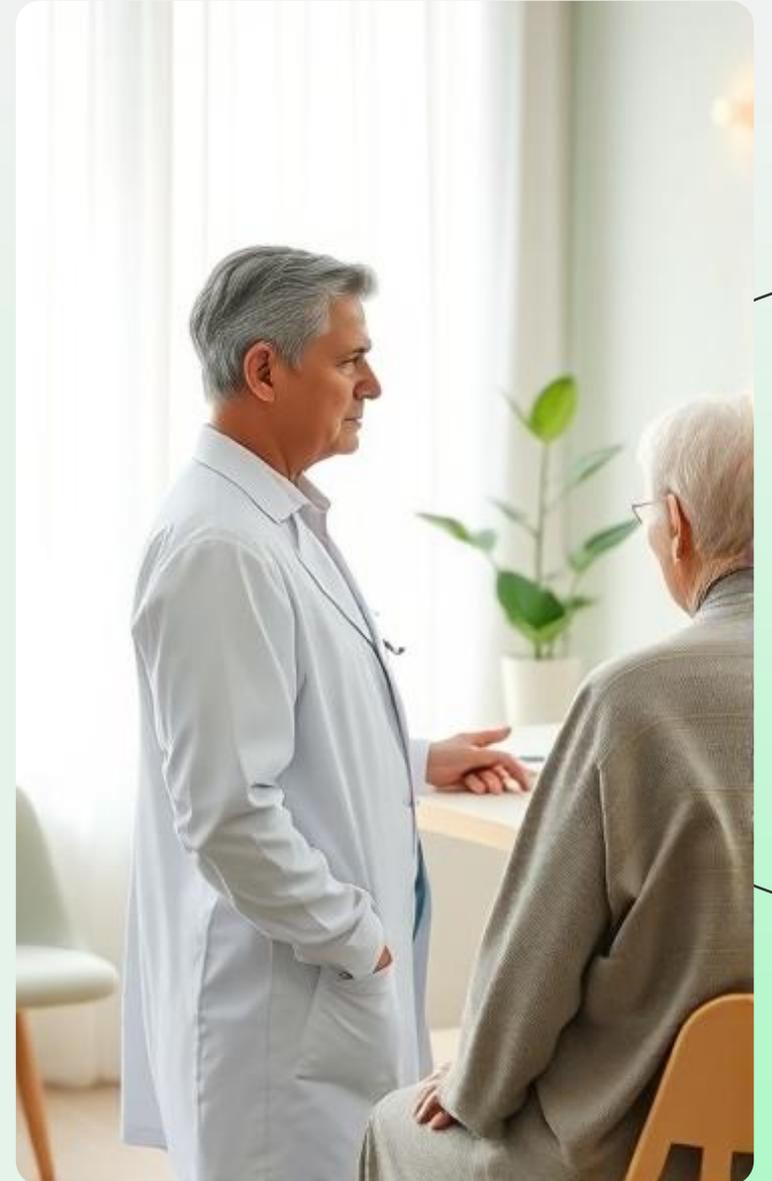
A confirmed diagnosis leads to identification of a lead coordinator for care and wellbeing of the patient and carer, and access to specialist help and support from medical and social care services, charities and other sources.

This GP Practice has a trained dementia nurse, and also aims to support carers' needs

- Your PCN has a social prescriber / care navigator who can signpost help and support for both carers and dementia patients
- Social services can assess and advise what help and support is available in this area for each stage of dementia, and for carers
- Charities can help with information and support groups for patient and carers, including free and paid-for services available locally and advice relating to all of the planning elements.



Plans should be reviewed and amended annually or when needed





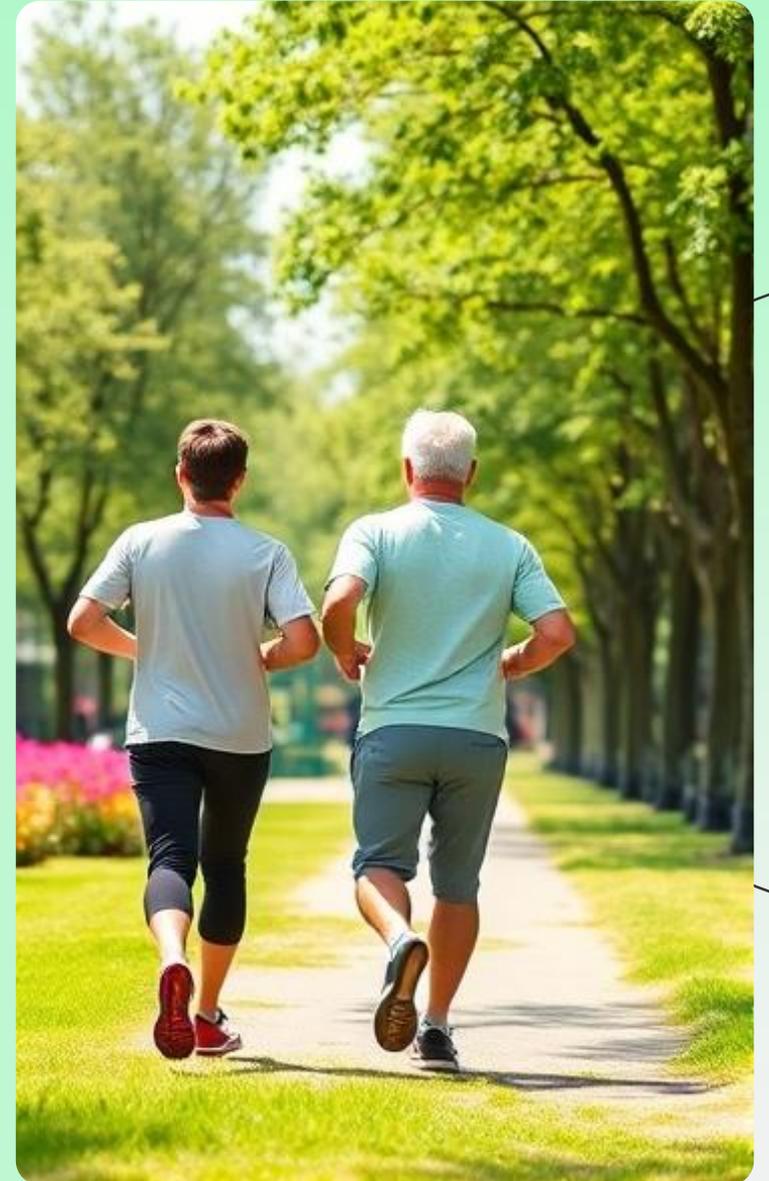
Legal and Financial Planning

- Early planning helps avoid difficulties later when the patient no longer has the capacity to make informed decisions or express preferences for themselves.
- Legal planning usually includes registering a lasting power of attorney (LPOA) to recognize that a carer can make health and wellbeing decisions on behalf of the person with dementia (daily care needs / medical care / care home choice)
- Financial planning LPOA's relate to the nominated carer(s) having authority to immediately manage a persons finances and property – including care home fees planning and sale of property

≡ Lifestyle Adjustments

Healthy Habits, Safe and Stimulating Environments

- Modify your **home environment** – make it a safe but stimulating environment. Consider labels (take your keys note at doorway), contrasting colours – don't have white plates and white table cloths, toilet bowl coloured water, digital clocks, pill taking boxes etc.
- Maintain a **healthy lifestyle** including regular **exercise** and adopting a healthy **diet** such as the Mediterranean or the MIND diet , reduce or **eliminate alcohol and smoking**.
- Maintain or increase **social circles** and events and hobbies to help with independence as long as possible Consider hobbies like music, choir, writing, reading out loud, allotment.
- Improve **your carer's skills** to recognize triggering incidents that raise anxiety or confusion and develop coping strategies that handle these circumstances effectively. Learn to pick up on non-verbal cues and to interpret miss-statements / confused words.
- **Memories** of "who I am". Build a scrapbook of places and things that were important parts of the patients life – this can become a source of engagement when some of these memories fade and will also help professional carers when the time come to transfer to a care home
- **New technologies** can help patients – smart speaker alarms, drug taking prompts, daily messaging. Using a tablet or smartphone to stay in touch with friends and family, quizzes, news sources, personal interest etc Check-out Alzheimer's Soc. aids



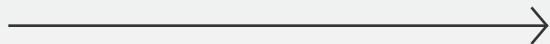


Support Networks

Encourage social activities, involve family and friends (Dementia Friends)

Consider:

- Memory Cafes
- Creative Workshops
- Specialist Support Groups – in touch with peers
- Maintenance Cognitive Stimulation Therapy (MCST) is a weekly one- to two-hour-long programme to help maintain memory and mental functioning
- Day Centres
- Carer's Courses and Respite Opportunities
- Travel/holidays with Dementia (*Dementia Adventure CIC*)





Carer's ...



- Dementia also effects the carers - *Can become exhausted and very depressed, and hide it well*
- Need a break from their responsibilities – *need to seek respite opportunities*
- Suffer great guilt if unable to cope - *This can add to their loss/grieving and may be hypersensitive*
- Younger people can find it more distressing - they may feel trapped and be fearful for their own future
- Some aren't able to make use of offered help – *empathise with them, encourage them*

≡ Carers support - finding help

Caring for someone with dementia is a profoundly challenging yet often rewarding responsibility that demands significant emotional, physical, and psychological effort from caregivers, who are frequently referred to as "the invisible second patients" due to the high levels of stress, burnout, anxiety, and depression they experience. While the journey is marked by difficulties such as managing behavioral and psychological symptoms, loss of memory and independence, and the emotional toll of watching a loved one decline, support systems and resources are increasingly available to help caregivers navigate this path.

Carers First & Carers UK support carers to with their own wellbeing, advocacy and caring advice

<https://www.carersfirst.org.uk/caring-for-someone-with/?selectedTags=Dementia>

<https://www.carersuk.org/help-and-advice/guides-and-tools/animated-information-guides-for-carers-practical-and-emotional-support/>

Dementia UK can provide early stage meetings with **Admiral Nurses** who specialize in dementia care can help raise awareness and help begin planning for the long and challenging journey ahead.

Alzheimer's UK provides extensive information and advice for carers and for people with dementia

Others – Age UK, Citizens Advice, Nationwide Building Society, Social Services, PCN Care Navigators





Carers' Adjustments

- in a world turned upside down:

Adjustments may be needed to the way carers **communicate** and engage with people with dementia (new carer's skills needed)

- Carers and families have to adapt and acquire new skills to communicate effectively and to manage the caring situation .

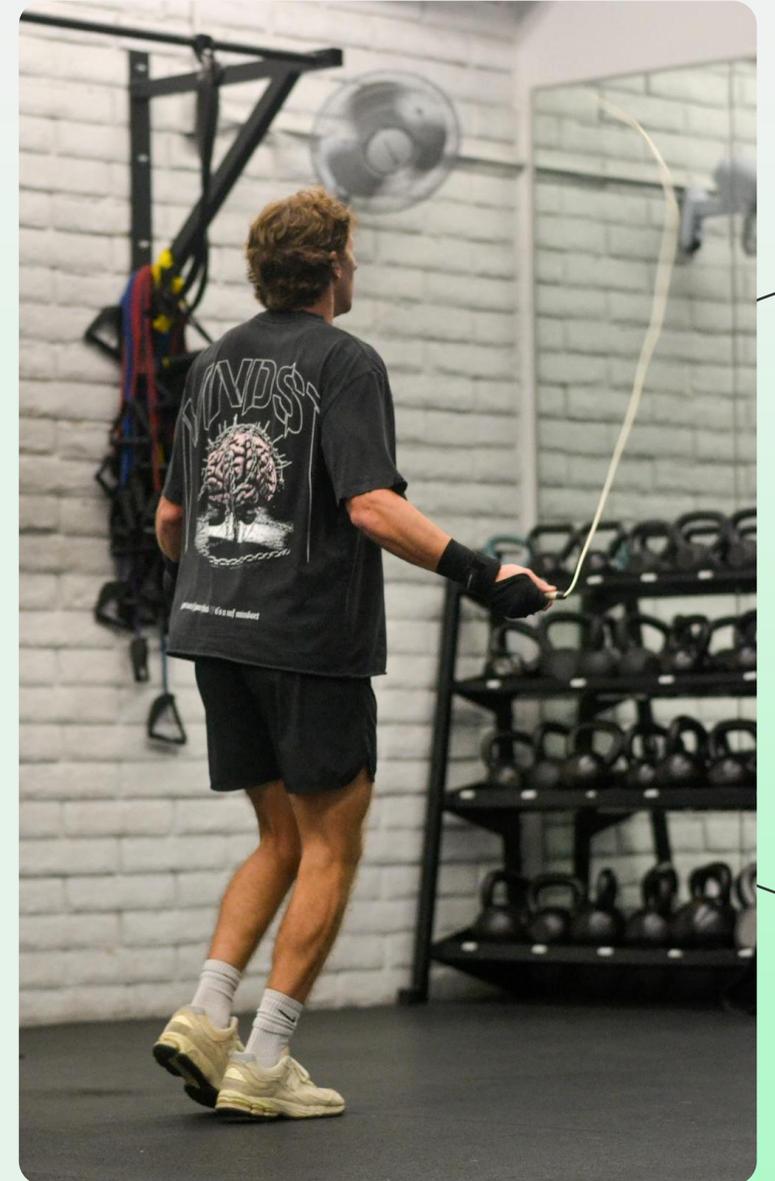
Favourable outcomes rely on what is communicated, and how.

Consider:

- why and how conversations can go badly or work well
- what helps to maintain good conversations

Watch: Exeter University's dementia communications play – **"The World Turned Upside Down"**

[https://www.youtube.com/watch?v= A255O5vAk](https://www.youtube.com/watch?v=A255O5vAk)



≡ PPG DEMENTIA EVENT -- Resources Appendix

Subject:	Hyperlinks (URL)
Understanding and supporting a person with dementia – Alzheimer’s Society	https://www.alzheimers.org.uk/get-support/help-dementia-care/understanding-supporting-person-dementia
Dr Jennifer Bute a former GP with Dementia shares some insights (see also her “GloriousOpportunity.org” charity site.)	https://vimeo.com/36906603 (39 minutes awareness video)
Advice and assistive products that may help at home	Alzheimer's Society - home assistive products
Information and support index and links – Dementia UK	https://www.dementiauk.org/information-and-support/resources/our-leaflets/
Activity ideas for people with dementia at home Alzheimer's Soc.	https://www.alzheimers.org.uk/get-support/living-with-dementia/activity-ideas-dementia
Carer’s health and support – Carer’s UK	https://www.carersuk.org/help-and-advice/your-health-and-wellbeing/
Local support organisation near me (Alz. Soc.- enter postcode)	https://www.alzheimers.org.uk/find-support-near-you
<p>Book recommendations:</p> <p>(1) Dementia From The Inside - a short book by Dr. Jennifer Bute – her story of contracting dementia as a GP and after caring for her father; - how she remained active and engaged and sharing her insights.</p> <p>(2) Contented Dementia – recommended by Dr Bute – a methodology for managing dementia and improving patient and carer’s communications, wellbeing and outcomes. A toolkit to help understand and avoid anxiety events for people as the condition worsens.</p> <p>(3) Keep Sharp: Build a Better Brain at Any Age – a science driven guide by Dr Sanjay Gupta to retain and improved cognitive health based on 5 pillars; exercise, mental engagement, sleep, nutrition, and social connections.</p>	

Try this short dementia knowledge game:

<https://games.focusgames.co.uk/dementiaawareness/>