

Living Well with Dementia – Thank heavens for Carers!

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Objective 7: Implementing the Carers' Strategy

'Family carers are the most Important resource available for people with dementia'.



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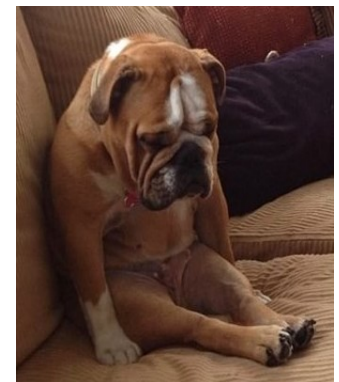
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Bleak Picture

‘Dementia not only has a devastating impact on those with the disorder, but also has **profound negative effects on family members...** (They) are **often old and frail themselves** and have **high levels of carer burden, depression and physical illness** and **decreased quality of life**’.

Does this ring a bell?

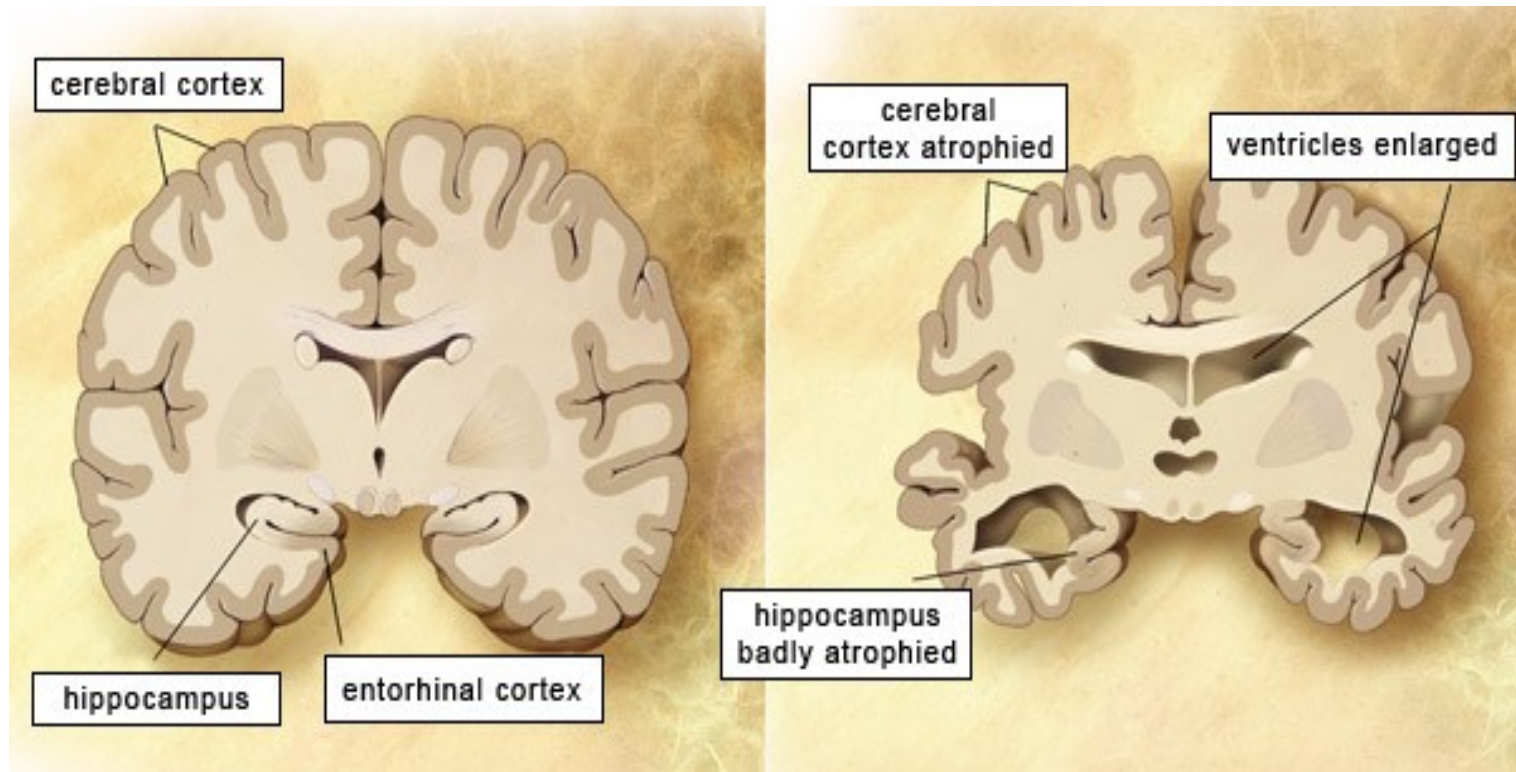


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Increasing loss of brain cells



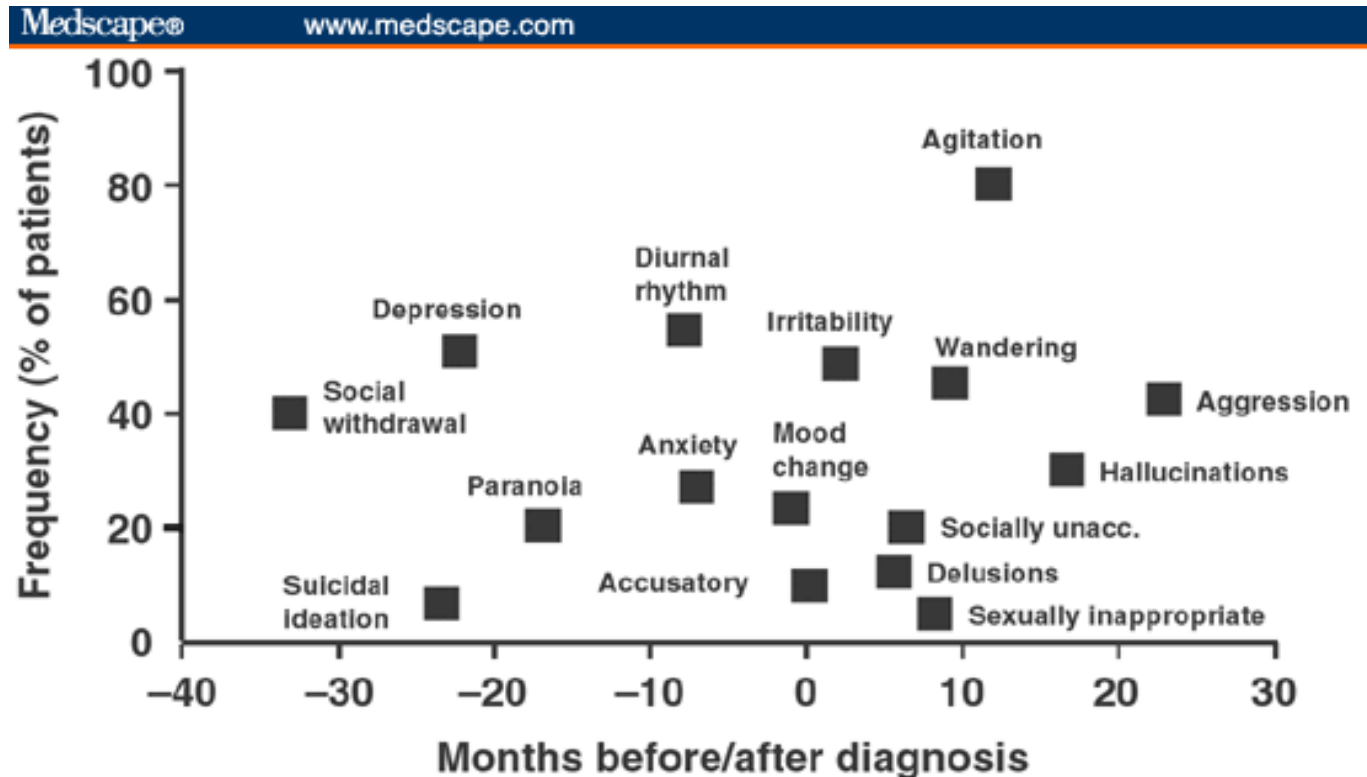
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Increasing BPSD

Behavioural and Psychological Symptoms of Dementia (BPSD)



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A Day in the life of a Carer

- Using the ‘eyes at the back of your head’
- Checking...checking...checking
- Wary about leaving loved ones alone
- Dealing with multiple ‘anxiety’ telephone calls
- Dread of ‘sundowning’
- Maintaining Personal Care standards
- Avoiding arguments
- Dealing with suspiciousness
- Putting up with repetitive questions



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'Dementia Tax'

- Cost of dementia to UK is £26 billion/year
- Average cost of £32,250 pp to PwD
- Two-thirds of cost is being paid by PwD and their families
- Unpaid care (£11.6 billion) or paying private social care
- Typical person's bill would take 125 years to save for

www.alzheimers.org.uk/info/20091/what_we_think/146/dementia_tax

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'Living well with dementia' made awkward!!!

Carer deals with:

- PwD living alone
- Living far from PwD
- Self neglect, wandering, complaints from neighbours
- Refusing outside help
- Own lives (home and family)
- Wage earner
- Depression or other mental health issues
- Unused to being a carer (not practical, short-fused)



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Profound Admiration for Carers

- *Diversity* of:
 - Relationships
 - age
 - abilities
- *Humanity* shines through
- Little or no *qualification*
- *Walking that extra mile*



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Pointers to being successful

Understanding dementia

- Symptoms – e.g.. short term memory
- Diagnosis – how was diagnosis made
- Behaviour that challenges – e.g. disinhibition
- ‘Recognition that I am a Carer’



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Pointers to being successful

Daily life

- How to communicate
- Washing and dressing
- Safety
- ‘Coping with my reactions’



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Pointers to being successful

Who can help

- Dementia Nurse Specialist
- GP Surgery
- Psychiatric Liaison Service (A+E Department)
- Alzheimer's Society
- Age Concern
- Social Services Personal Care options
- Social Care Attendance Allowance
- Faith Groups



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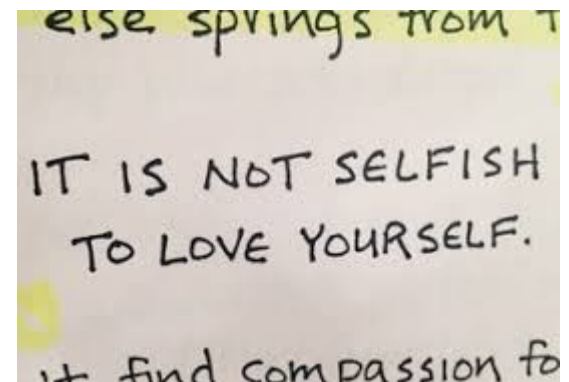
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Pointers to being successful

Looking after myself

- Looking after my own physical and mental health
- Having a laugh
- Dealing with frustration (develop strategies)
- Staying positive
- Set aside 'Me time'
- Being assured of adequate Sleep
- Someone to talk to



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Pointers to being successful

My relationship

- Seeing the person
- Power and control
- Maintaining independence
- Maintaining a relationship
- Arguing
- Deciding things together
- Doing things together



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Anticipatory Grieving (AG)

- Process of experiencing phases of normal bereavement in advance of loss of a significant person.
- Includes mourning, coping, planning (past, present, and future)
- May extend over many years while family members witness deterioration in the affected person's cognitive, social, and physical functioning
- Carers face changes in their roles and level of personal freedom



<https://www.ncbi.nlm.nih.gov/entrez/eutils/elink.fcgi?dbfrom=pubmed&retmode=ref&cmd=prlinks&id=21946013>

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How to deal with this AG?

- Review the pointers we have already looked at:
 - Understanding dementia
 - Daily life
 - Who can help
 - Looking after myself
 - My relationship
- Don't bottle up the emotions – ***Let rip!***
- Share...share...share (don't allow it to become a skeleton in a cupboard)



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How to deal with this?

- Talking Therapy
- Consider Cruse
- Cultivate a new interest
 - study, exercise, hobby, social group
- ‘Buddy’ Circle/Group
- Explore how religion could help
- Join Self-help Group, Action Group, Campaign Group



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Gille's Survival guide

Some days can be like being lost in the fog but above the clouds the sun is shining. Watch your steps, look after yourself and with care you won't plummet over the cliff.



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Thank you, and are there questions?

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