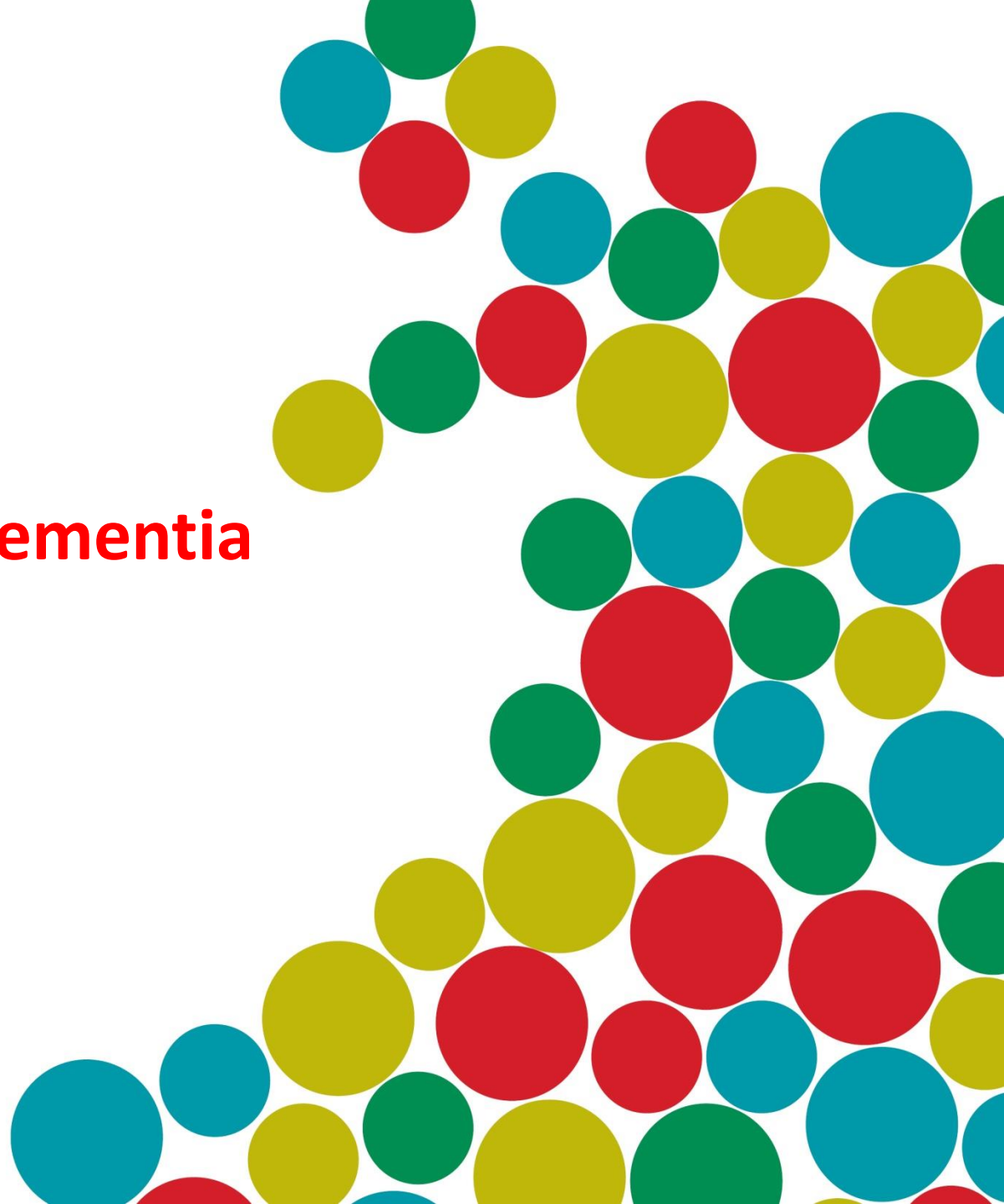




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Carer burden in dementia

*Dr Foteini Tseliou,
Dr Sunil Dolwani,
Dr Pauline Ashfield-Watt*



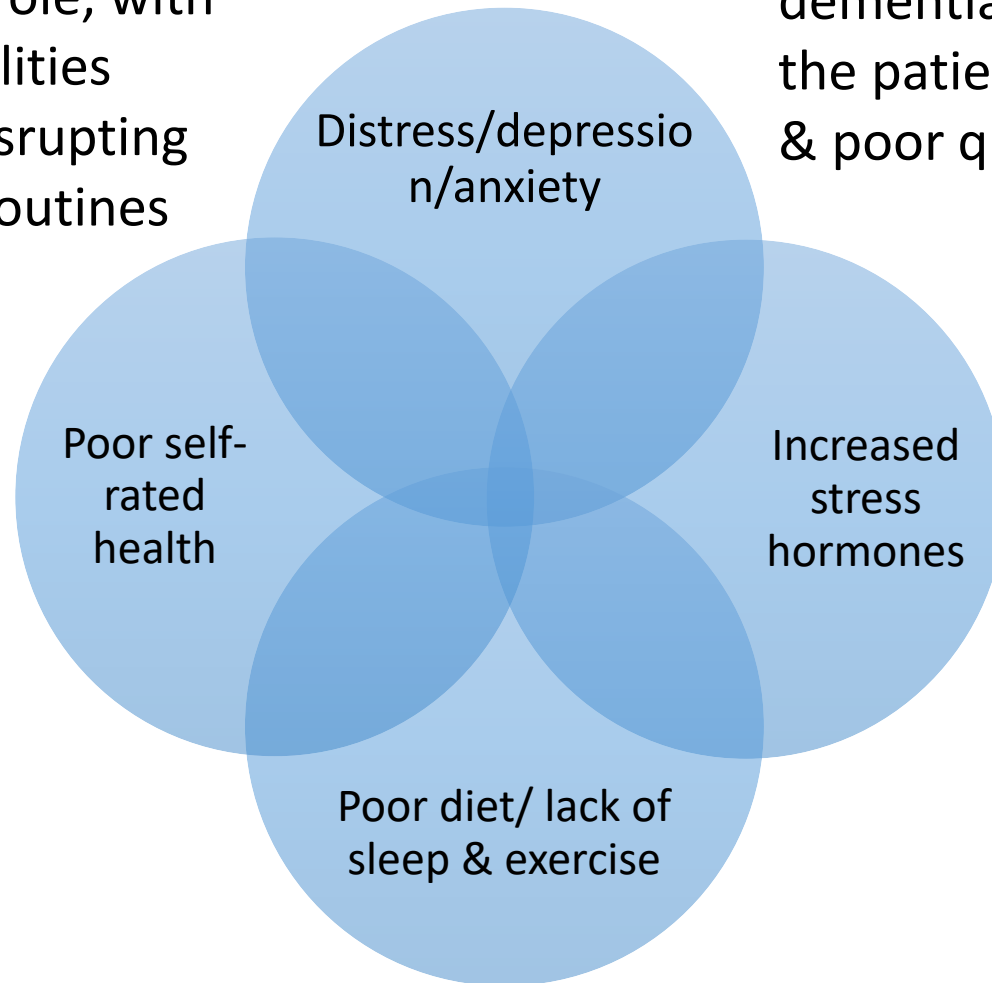
Being a carer

- Informal carer defined as a person who:
“provides some type of unpaid, ongoing assistance with activities of daily living to a person (such as family members, friends or neighbours) with a chronic illness or disability”
- Informal caregiving is an integral part of many societies, linked to an ageing population and increasing reliance on unpaid carers
- Care-related responsibilities may vary according to:
 - i. the care recipient’s condition and needs
 - ii. the extent of the carer’s contribution

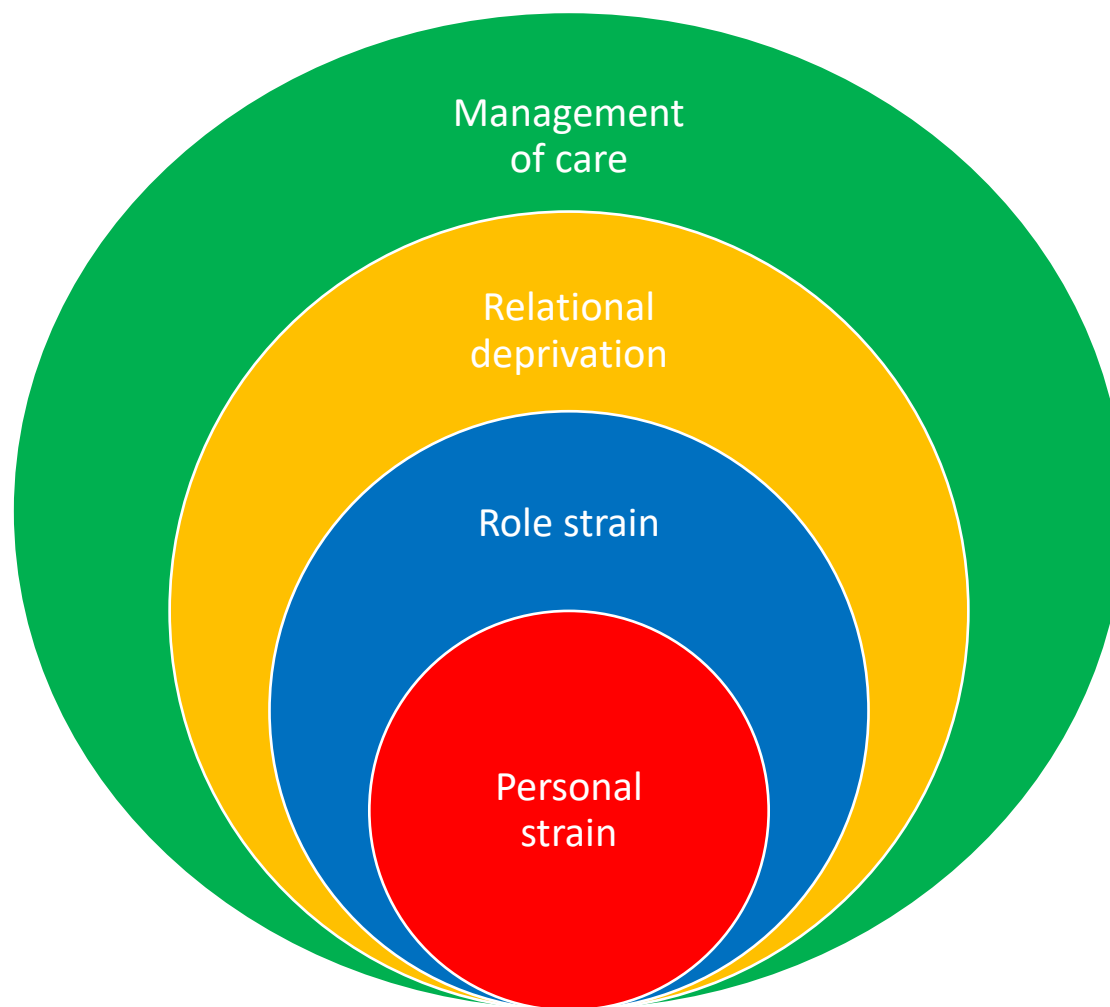
Carer burden in dementia

Caring for a loved one can be a demanding role, with lots of responsibilities increasing and disrupting one's own daily routines

Stress among carers of dementia patients linked to the patient's health decline & poor quality of life



Carer burden in dementia



HealthWise Wales



Together we can improve
healthcare in Wales

**REGISTER
TODAY**



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HealthWise Wales questionnaires

➤ Core questionnaires:

- Work
- Mood & mental health
- Physical activity
- Alcohol
- Smoking
- Pregnancy
- Height and weight
- Diet

➤ Researcher-led questionnaires:

- Medicines:
- Prescriptions and medicine wastage
- Managing prescribed medication
- Caring and prescribed medicines

HealthWise Wales & Great Minds

Get involved in dementia research today



How can you help?

If you are aged 40 or over, you can volunteer to take part in dementia studies by signing up to Great Minds and completing online tests. Researchers will use this information, along with the information you provide in your HealthWise Wales questionnaires, to make connections between lifestyle, environmental factors and brain function, which can help to understand and predict dementias.

What will this involve?

If you agree to register with Great Minds, you will be asked to create an online account and be presented with online cognitive tests, which you will be asked to repeat at intervals. As a member of Great Minds, you will also be notified of other research studies into dementia, which you may take part in, should you wish to.

Please note that the Great Minds questionnaires are external to HealthWise Wales and are only available in English.



[More information »](#)

[Take part in Great Minds »](#)



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**Dementias
Platform**^{UK}
Medical Research Council

GREATMINDS
>FAST-TRACKING DEMENTIA RESEARCH

HealthWise Wales & Great Minds

Why is HWW working with the Dementias Platform?

- Dementia research is important for HWW participants and their families constituting a research priority for HWW
- Link between lifestyle questionnaires and other HWW data to the cognitive questionnaires from the Great Minds project, will allow us to make connections between lifestyle, environmental factors and brain function



Dementias
Platform^{UK}
Medical Research Council

GREATMINDS
>FAST-TRACKING DEMENTIA RESEARCH

HealthWise Wales carers

- level of caring (0; 1-19; 20-49; 50+ hours per week)

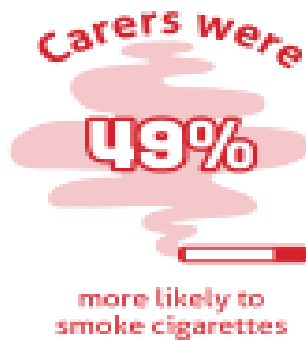
“Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term disability, mental health disability, problems related to old age?”

- whether they left employment due to their caring role

“Have you ever had to give up work to look after a family member, friend, or neighbour?”

HealthWise Wales carers

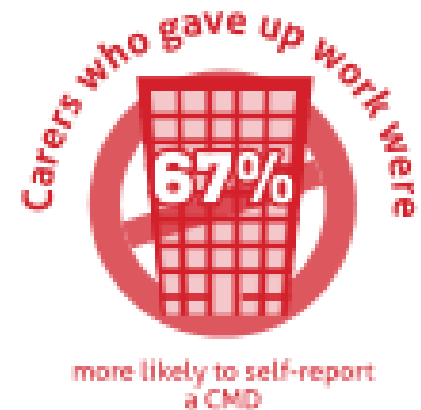
- How do carers' day-to-day health behaviours differ from non-carers?



- How might caring affect their physical and mental health?



more likely to report having been diagnosed with a mental health condition



HealthWise Wales carers

Giving voluntary carers a voice through research

- Study the experiences of long-term voluntary carers of people with mental illness in relation to:
 - caring demand
 - the social support they receive
 - their coping mechanisms
 - the link to psychological well-being
- 10 interviews have been completed through the advertisement and the analysis of these interview data is underway.



Cardiff
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Prifysgol
Metropolitan
Caerdydd

HealthWise Wales carers

- Caring for a family member or friend can have a negative effect on health and social activities, especially for young people
- Young carers (16-25 years) may have difficulty voicing their needs
- Music, e.g. Rhythm and Poetry (RAP), as a creative outlet for engaging with and acting upon research findings
- We aim to:
 - Help young people to communicate important health messages
- Project now evolving in a virtual setting due to COVID environment



Implications for research

- Additional analyses on carer burden by the health needs of the person they care for using data on caring and prescribed medicine
- Plans to analyse data collected through the collaboration with the Dementias Platform UK and Great Minds

GREATMINDS
->FAST-TRACKING DEMENTIA RESEARCH

- Share the music video and other outputs from the interactive activity to carers and across all HWW participants



- **Carers' Needs Ambassadors** - talk about their story or advising us on activities to involve and support carers through our research & outreach

Implications for policy

- Caring can affect every part of the carer's life, leading to carer's needs being overlooked
- As the carer's ability to cope effectively is linked to the patient's survival and well-being, the impact of dementia care should be considered by professionals
- Carer's physical and mental health needs should be considered as aspects of dementia care
- As primary care is the point of first contact, targeted interventions can decrease burden for carers of dementia patients

Key points

- Carers report more unhealthy lifestyle behaviours and worse mental health than non-carers
- This can be worse for carers of dementia patients who experience more unmet needs for help with different care activities due to:
 - Increased need for help with tasks
 - Lack of family support or family conflict on treatment
 - Inability to arrange for assistance from friends/neighbours
- Negativity and over-involvement may increase carer burden and the carer's personal experience of distress

Thank you for listening!

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Follow us on Twitter @HealthWiseWales
[#wearehealthwisewales](https://twitter.com/HealthWiseWales)

Acknowledgements

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