EMPOWER: PALLIATIVE & END OF LIFE CARE SIG

Palliative dementia care from diagnosis to end of life

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Funded by Alzheimer's Society

- **Funder:**
  Alzheimer's Society
  (grant number 704 / AS-PDF-25-052)

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THE PROBLEM

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Leading cause of death in the UK

(Office for National Statistics, 2022)

83%

will attend the emergency department in the last year of life

(Williamson *et al.*, JAMDA 2023)

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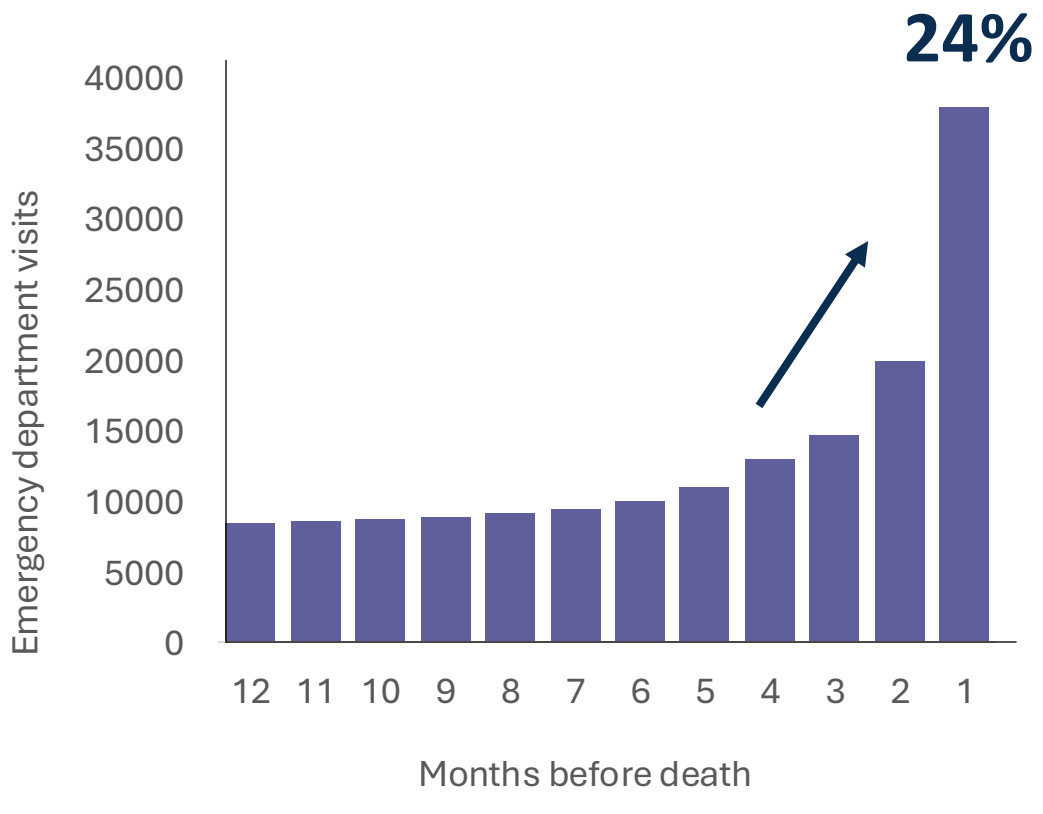

Fig 1. Number of emergency department visits in the last year of life among people with dementia (n=154,508 visits; Williamson *et al.,* JAMDA 2023)

20%

of the last six months of life in hospital

(Yorganci et al., Age Ageing 2023)

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“Hospital isn't any place for someone with dementia.
We need to be in our own environment.

...because you go in the hospital, you don't come out at the same level as you were when you went in. I have seen it with so, so many of my friends.

Just the noise, the lack of routine, lack of knowledge, lack of understanding, makes it just an alien environment.”

Person with dementia

(Williamson *et al.,* Int J Geriatr Psych 2023)

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Palliative care input
Care home residence

Minoritised ethnicity
Lower socioeconomic position
Greater multimorbidity
Neuropsychiatric symptoms

Factors associated with emergency department visits among people with dementia nearing the end of life

(Williamson *et al.,* J Am Med Dir Assoc. 2021)

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Palliative care

Active, person-centred care aiming to improve quality of life for people with life-limiting conditions and their families.

Palliative care can be of benefit:

- 40% will benefit, at **any stage** of dementia
  (Knaul *et al.,* Lancet Glob Health, 2018)
- Recommended from diagnosis
  (NICE Guideline 97)
- Palliative care needs not well recognised
  (Leniz *et al.,* Palliat Med, 2021)

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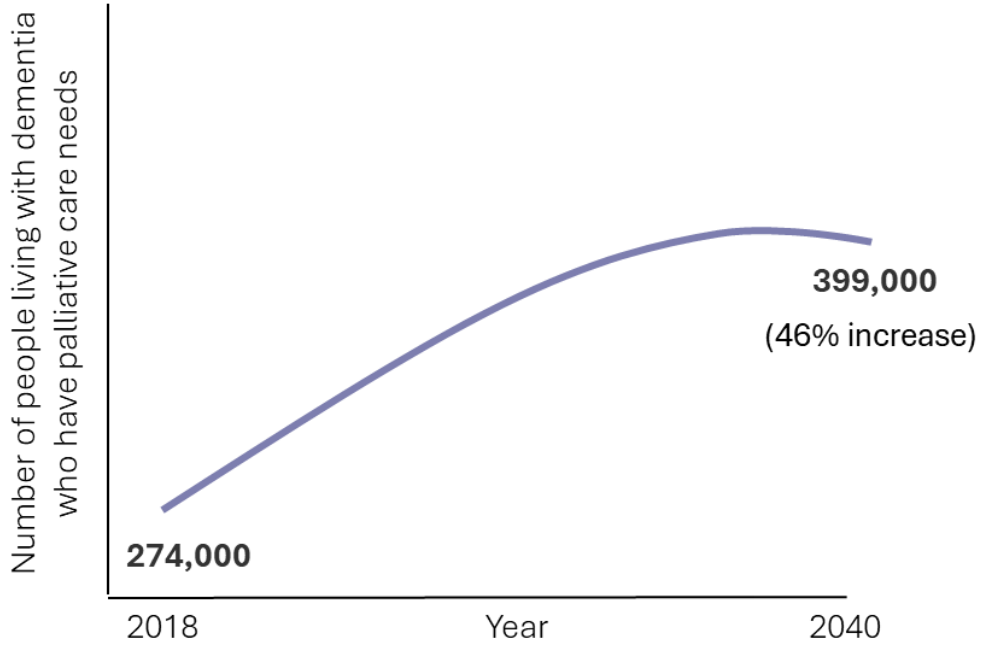
Palliative care

Active, person-centred care aiming to improve quality of life for people with life-limiting conditions and their families.



The projected number of people living with dementia who have palliative care need (Yorganci *et al.* Age Ageing 2024)

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THE PROJECT

PALLDEM

DIAGNOSIS TO END OF LIFE

To co-design and evaluate the implementation of IPOS-Dem in primary care

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Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem)

(Ellis-Smith *et al*., Pall Med 2017)

- Standardised, holistic assessment
- Identifies and monitors symptoms and concerns over time and in response to care
- Promotes best practice in providing person-centred care

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Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem)

(Ellis-Smith *et al*., Pall Med 2017)

- Identifies unknown needs
  (Kinley *et al*., Int J Palliat Nurs, 2019)
- Improves communication
  (Kinley *et al*., Int J Palliat Nurs, 2019)
- Promotes shared decision-making
  (Awordine *et al*., Health Expect, 2022)
- **Used by anyone**
  (Ellis-Smith *et al*., Plos One 2018)

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Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem)

(Ellis-Smith *et al*., Pall Med 2017)

- Developed in care home setting
  (Ellis-Smith *et al*., Pall Med 2017)
- Implemented in different settings:

EMBED-Care
Care homes and palliative care

PALLDEM-Homecare
Domiciliary care

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PALLDEM
DIAGNOSIS TO END OF LIFE

To co-design and evaluate the implementation of IPOS-Dem in primary care

Three parts

1. Implementation planning
2. Implementation and process evaluation
3. Community engagement and impact

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DIAGNOSIS TO END OF LIFE

1. Implementation planning

- Activities:
  - Literature review
  - Co-design workshops
- Outcome:
  - Preliminary blueprint and co-designed resources to implement IPOS-Dem in primary care

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DIAGNOSIS TO END OF LIFE

2. Implementation and evaluation

- Activities:
  - 12-week implementation trial
  - Mapping local services
  - Questionnaires and interviews
- Outcome:
  - Final blueprint to guide implementation of the IPOS-Dem in primary care

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DIAGNOSIS TO END OF LIFE

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3. Community engagement and impact

- Activities:
  - Engagement activities
  - Monitoring reach and impact
- Outcome:
  - Increased awareness of palliative care approach from diagnosis to end of life

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WHAT DIFFERENCE COULD THIS PROJECT MAKE?

"…the whole support for people with dementia it's much like, I suppose you could argue it's not a pull system, ***it's a push system****.*

…You have to get very pushy."

Current care partner

(Williamson *et al.,* Int J Geriatr Psych 2023)

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“I had eight phone call conversations expressing why I want [the GP] to come and see my dad.

***If this was another illness**; if I was saying, ‘Look, my dad's passing blood’, [they’d] be there.”*

Current care partner

(Williamson *et al.,* Int J Geriatr Psych 2023)

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“If I have any changes, and I’ve noticed a few changes… I don't have a consultant I can get in touch with…

…somebody who has cancer, there's a clear pathway to go on... But with dementia, ***there's nothing at all****.”*

Person with dementia

(Williamson *et al.,* Int J Geriatr Psych 2023)

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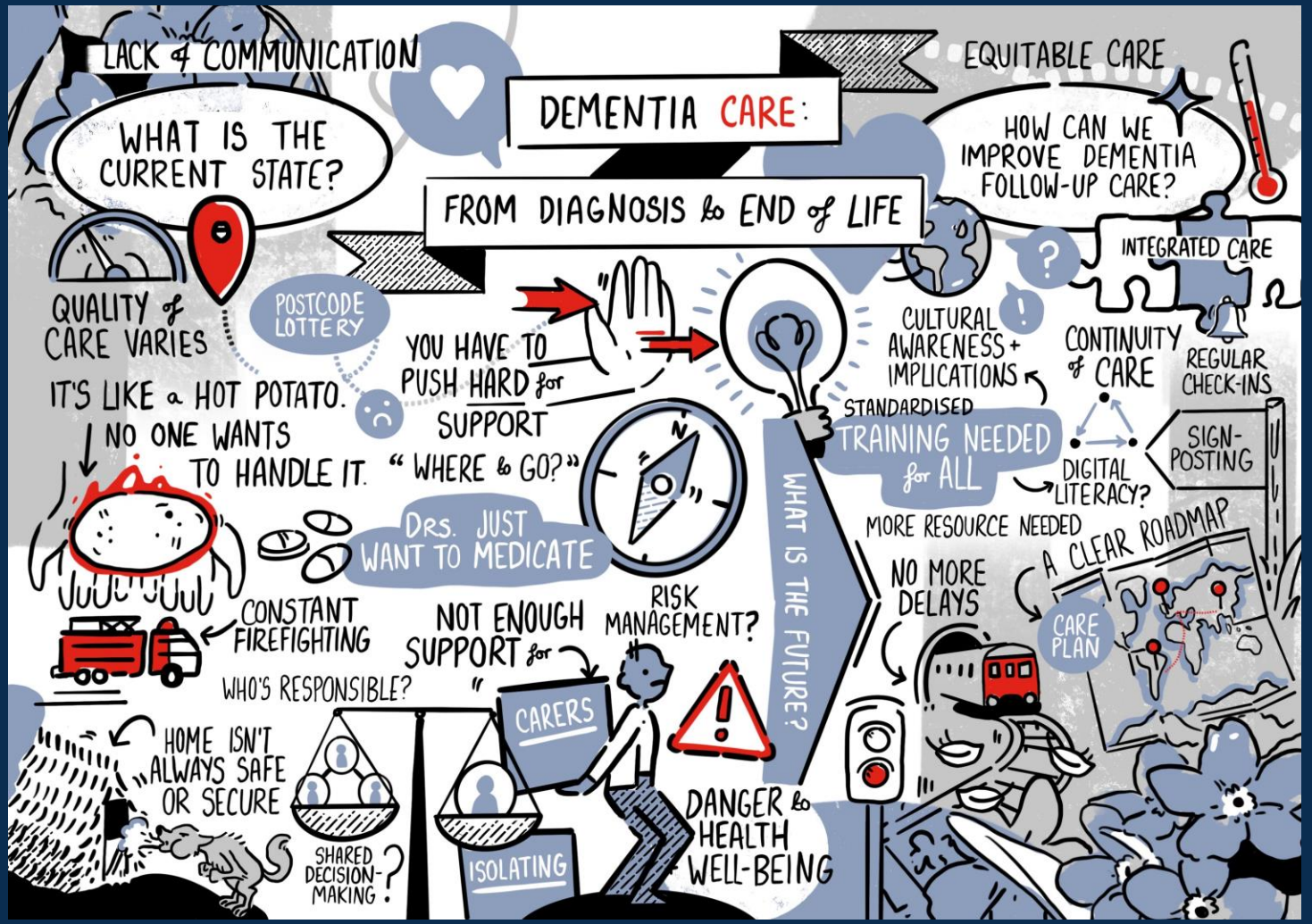

Current state:

- Isolating
- Postcode lottery
- Medication-focused
- Not enough support

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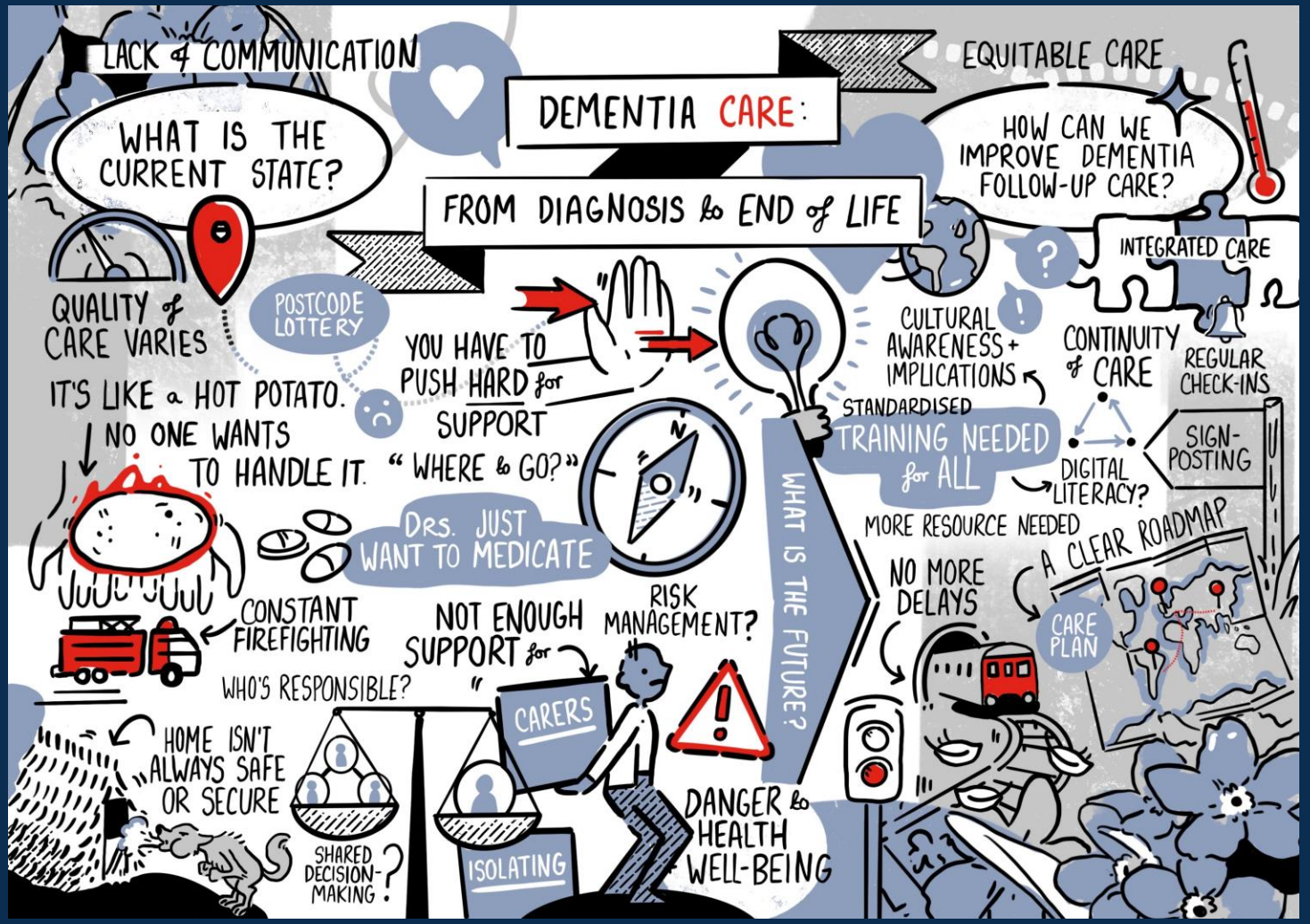

Future priorities:

- Integrated care
- Clear road map
- Regular check-ins
- Continuity of care

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Routine use of IPOS-Dem

- Standardised person-centred care
- Proactive, holistic care
- Continuity of care
- Reduces need to ‘push’ against system
- Potential to improve end of life care

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You’re invited…

- Drive action towards better palliative dementia care
- Opportunities to be involved
- Feel free to get in touch

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Thanks for listening.

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