

**Sheffield
Hallam
University**

Ageing without children and dementia

AWOC event
28th Sept 2023

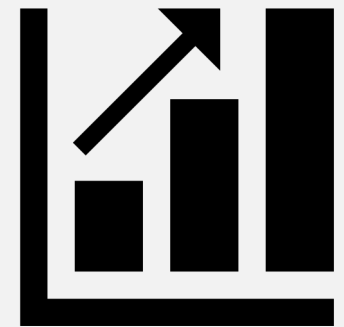


Dementia

Leading cause of death in England & Wales in 2022

Over **944,000** people in the UK

1.6 million by 2040





Dementia

?

Ageing
without
children

Definitions

People with dementia who **live alone**

and who are managing **without
informal support**

to **contact and navigate services**

Unpaid
carers
provide
a lot of
support



People with dementia who live alone

More likely to

have **unmet needs**

be **admitted to hospital**

only come into contact with formal services **in a crisis**

Even if they have a carer.



The pros cons and particular needs of those living alone with dementia and those living with a care partner

There are **many benefits** to living alone when you have dementia.

Many people do this successfully for a **long time**.

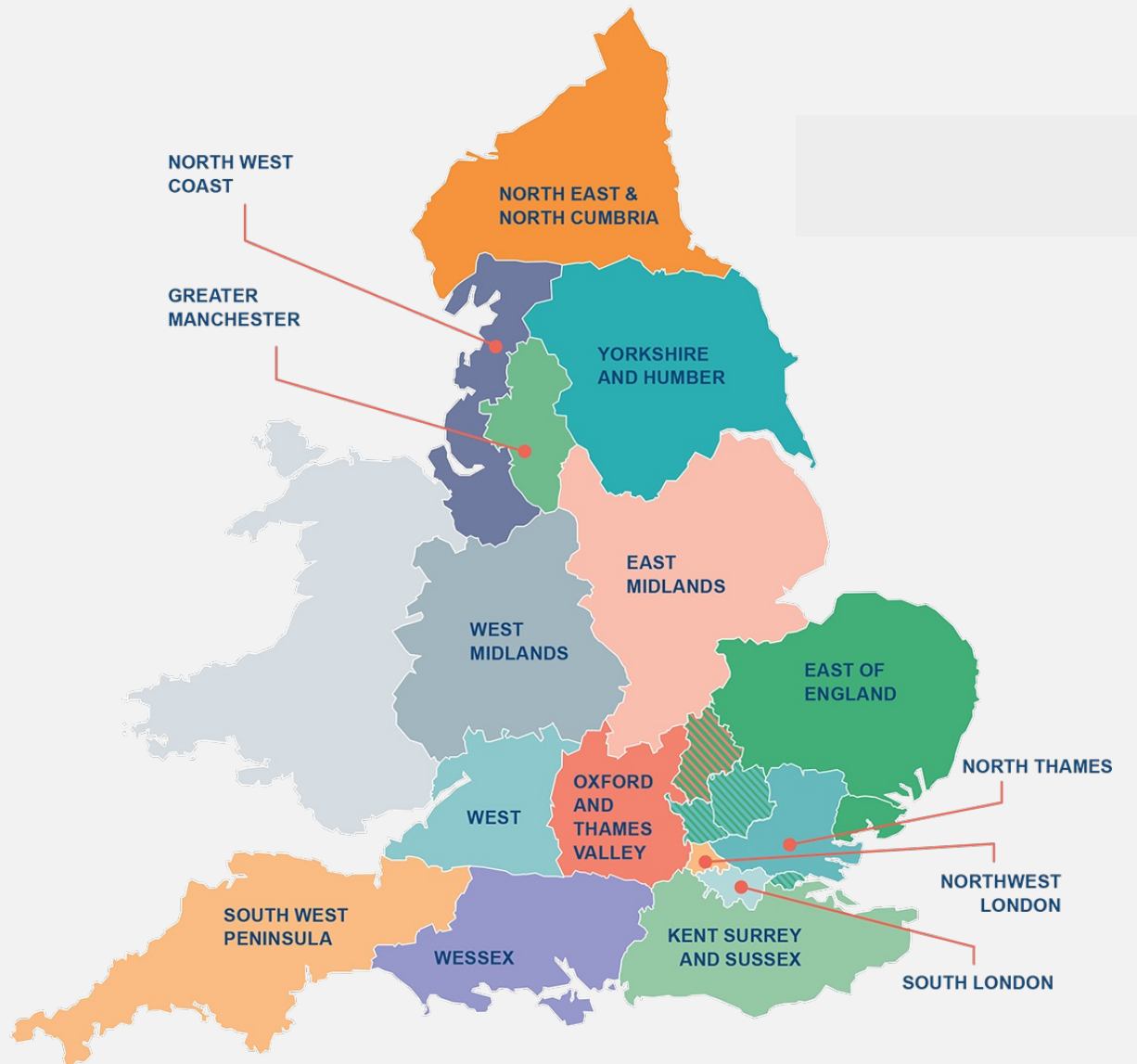
Search 'Dementia Enquirers York' for this report

Navigating
complex and
messy systems
by yourself
when you have
dementia is
hard work.



Service audit

Two regions



Yorkshire & Humber

Barnsley
Bradford
Calderdale
Doncaster
East Riding of Yorkshire
Kingston-upon-Hull
Kirklees
Leeds
North Yorkshire
Rotherham
Sheffield
Wakefield
York

13 local councils

North Thames

London Boroughs of
Barking & Dagenham,
Barnet, Camden, Enfield,
Hackney, Haringey,
Havering, Islington,
Newham, Redbridge,
Tower Hamlets, Waltham
Forest

Central Bedfordshire
Southend
Thurrock
Hertfordshire
Luton

17 local councils

Range of council types, socio-economic and demographic characteristics, rural-urban classifications

10/13

Ten local authorities had estimates of the **number of people with dementia** in their area.

0/13

None knew how many people with dementia **lived alone or had no informal carer**.

Only **four** had specific arrangements to support people living alone without carers.

Specific service

Pathway

Ongoing phone calls and reviews

Assisting with travel

Facilitating access to other services

Some day/leisure services were generic, and some specifically for people with dementia.

Many, especially the latter, **excluded people without carers.**



Including people with dementia

Damian Murphy

Findings – learning from people
with dementia themselves

1. Strategies and tips



'I realise I'm quite dangerous cooking, so I try to work round being dangerous and **not have to have people do it for me.**

I work round it by **getting things organised as much as I can manage**, like, meals coming and they all go in the microwave, so that's not a problem.'

2. Planning for the future

'It's all about **protecting my independence** now but also trying to give it as much **longevity** as possible.

The more things I can put in place that **it's my life that I'm going to be continuing**, as opposed to somebody else's impression of my life.'



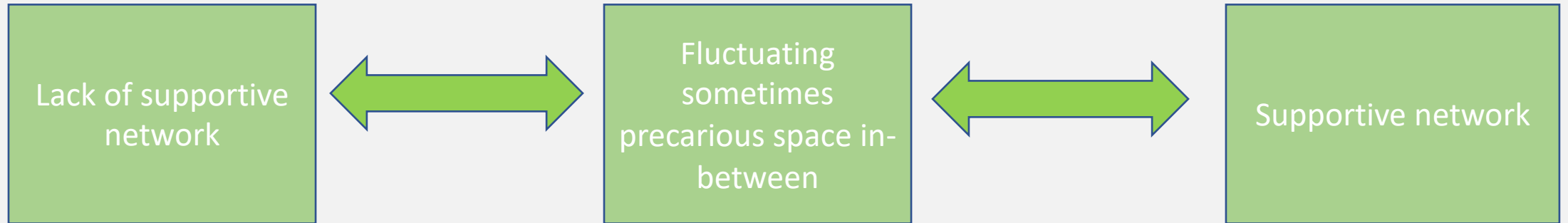
3. The importance (and precarity) of networks



‘If I wasn’t involved in activism, it would be tempting for all my thoughts and feelings to turn inwards.

It gives structure to my week’

NETWORKS



Lack of supportive network

Fluctuating
sometimes
precarious space in-
between

Supportive network

- Fragile, all eggs in one basket
- Fear of people making decisions for you
- Can't rely on one thing
- Need a back-up, a safety net

- Services should be proactive with transport
- Services should have responsibility for maintaining momentum of groups
- Precarity of services
- No services are perfect for everyone
- Got to find the right support for me
- Precarity of services
- Reaching out for and to help

- Trust
- Supportive not support
- Someone to rely on when I need it
- Peer support
- Making allowances, no judgement
- Connections
- Caring but not taking over

Summary

Little knowledge about this group

Very few specific services

Assumption that there will be a carer

People have **good strategies** – we can learn from them

Many people want to **plan for their future**

Networks are important, but can be **precarious**



What can **you** do...

- to prepare for the possibility that you might be in this situation yourself?
- to improve your life or share your tips if you already are?
- to acknowledge or support this group in your organisation or service?

Webinar for social care providers

Thursday 26th October 4-6pm - online

Workshops to co-design resources

Monday 6th November - Sheffield

Wednesday 15th November - London

Contact: j.brooks@shu.ac.uk

Disclaimer

This project is funded by the National Institute for Health and Care Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR202965). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

This project is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) North Thames.