



Living alone with dementia

Managing without
informal support to
contact and
navigate services

Disclaimer

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Definitions

People with dementia who **live alone**

and who are managing **without informal support**

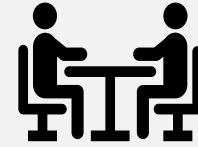
to **contact and navigate services***

* For brevity, we will refer to this population as living on their own without an informal carer.

Work packages



Rapid service
audit in 2 regions



Hearing from people
with dementia



4 case studies of
services that support
people with dementia



2 workshops to co-
create resources

Findings

Findings - Audit



Awareness of this population was limited



Only two local authorities had services/pathways for this group



These services offered additional support and/or different pathways



Some dementia services excluded people who did not have a carer - or stopped

Characteristic	Range of participants
Age	59-89
Time since diagnosis	<1 year – 10 years
Living situation	Own home (owned/rented), sheltered housing, extra care facility,
Family situation	No children, estranged, other responsibilities, own health issues, far away
Diagnosis	Alzheimer's, PCA, vascular dementia, young onset, Parkinson's dementia
Social care	Regular carers, dementia adviser, assessment but refused care because of cost, no social care contact



1. Finding the right support

Not everyone is ready for support
Not always obvious where to go
Finding the right group takes time

Implications

- **Regular contact, even if not needed straight away**
- **Variety of services**
- **Ongoing and widespread communication**

2. Access to support

Travel and timing can
make groups inaccessible
Some groups require carers

Implications

- **Practical issues create inequalities**
- **Requirement for carers excludes this group**



3. Emotional support is important

Range of support

Emotional support is really important

Other people with dementia are a good source of support

Implications

- Emotional support is rarely provided by services
- But services can facilitate good relationships





4. Building networks

People had different sizes of network

Building networks isn't easy for everyone

Providers sometimes facilitated relationship-building

Implications

- **Networks aren't always obvious or visible**
- **Services can support and encourage people to build networks**

5. Networks can be fragile and precarious

Support can stop for many reasons
Lack of continuity of groups and services
Networks are often disconnected

Implications

- Contingency planning if a service ends
- Lack of secure, continuous supporter



Resources

Guides for:

- People with dementia who live alone without carers
- General public
- Practitioners
- Commissioners

Six short videos

<https://livingalonenewithdementia.co.uk/>

LIVING ALONE WITH DEMENTIA



**Guide for people
living alone with
dementia who don't have
family and friends nearby**

Next steps

New project: Personalised care and support planning for people with dementia without informal carers

Jenni – j.brooks@shu.ac.uk

<https://livingalonenewwithdementia.co.uk/>

Please let us know if you use any of our resources.

Important questions

- Where can I get **information** about living alone successfully with dementia?
- What **peer support** is available from other people with dementia?
- Who can I **contact** if I need a bit of help or things change?
- Can you help me build a **network** of people or organisations that I can get support from?
- What **technology** might be available and useful for me, and what support can you provide to ensure I know how to use it?

- How will you **notice** if something is going wrong for me?
- How will you **check in** with me and make sure I am not just left on my own to manage?
- Who can I **trust** to know that I live on my own and do not have family nearby?
- How can you help me to **plan ahead** and make sure my choices are respected?
- How can you make sure that I can **attend** appointments or services on my own?
- How can I get involved in **volunteering** and making changes within my community?