

# LIVING ALONE WITH DEMENTIA



**Guide for commissioners  
about how to support people  
living alone with dementia who  
don't have family and friends nearby**

### **Introduction**

**People can and do live on their own with dementia and without informal support. However, there are important considerations about how people in this situation can best be supported. This guide provides information about what's different for this group of people, and what you can do as a commissioner to support them.**

There are approximately 1 million people with dementia or memory problems in the UK. Not everyone uses the term dementia and not everyone has a diagnosis. In this guide, we mean people with a diagnosis and without. Although around 85% of people have a relative or friend to look out for them, 15% (around 150,000 people) do not. There will be an 80% increase in the number of single, childless older people needing care by 2032.

People can live successfully on their own with dementia. However, people who have no informal support from families and friends are more at risk of not having their needs met and of hitting a crisis where they may end up in hospital or in a care home.

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**If you have a population of 100,000 in your local authority or Integrated Care Board area, then approximately 20,000 will be over 65 years old.**

**Of these seven per cent will have dementia (1400 people).**

**Fifteen per cent of these (approximately 200) will not have a carer and may live alone.**

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### **About this guide**

**This guide provides Golden Rules about how commissioners can help ensure good support to people living alone with dementia and without family and friends nearby. There is information for each golden rule about why it matters and what's needed. The guide then has a pathway to help you think through how to support people, followed by examples of how this is being done.**

The guide was developed by the Living Alone with Dementia research project team. To develop it, researchers carried out an audit of services and interviews with people living alone with dementia; shared the research with stakeholders - including people with dementia, providers, practitioners and commissioners - and co-developed key messages; produced draft resources and gathered feedback from stakeholders before finalising this resource.



## Golden Rules

These Golden Rules cover how commissioners can help ensure good support to people living alone with dementia and without family and friends nearby.

**The overarching Platinum Rule is: If you get it right for people with dementia, who live alone and don't have informal support, you will get it right for others.**

### 1. Recognise this group

Work with partners to gather data about who in your area lives alone and without informal support.

#	Number of people in the Local Authority/ Integrated Care Board area
#	Number from above group living with dementia - including those with symptoms but without a diagnosis (expected 7%)
#	Number from above group living alone (expected 14%)
#	Number from above group with no informal support to contact and navigate services (estimate 10%)
#	Number from above group that is known to NHS and social care services

Identify how this group can access support to have an early diagnosis and what follow up they could have if they are diagnosed.

Consider if there is a way for social care, health and other services to flag people who are in this group.

### 2. Listen to people

Identify if you or your partners can contact local people living alone with dementia and without informal support, and have conversations about what works for them and what support might be helpful.

Consider how people with dementia who live alone without informal support can input to service development.

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### **3. Work with others**

You don't have to do it alone. Work with colleagues who might have other data, knowledge or expertise, and learn together. Listen to stories from other areas, and from other commissioners and stakeholders as well.

Work with existing services including navigation services, voluntary services e.g. befriending, care providers, faith groups and universal services e.g. libraries to expand provision so that it meets the needs of this group.

### **4. Make information accessible**

Review your and others' information and communication to see how easy it is to find and navigate for people with dementia who don't have family or friends to help.

Consider whether the information reflects the diversity of experiences of living with dementia, including acknowledging that someone may not have informal care.

Check that links to other organisations and services are up to date.

Include language about and depiction of dementia that includes people who live alone and without informal support.

### **5. Be inclusive**

Work with partners to understand how people access services and to ensure that there is a proactive offer of support for people who live alone without informal support. Provide a variety of options for them to seek support with no wrong point of contact.

Consider not commissioning services that exclude people without carers, unless the services are willing to evolve in a reasonable, specified timescale.

Check if the services you are commissioning can be flexible in meeting the needs of people who live alone and don't have informal support e.g. staying involved for longer, checking in proactively or visiting at home.

### **6. Develop a pathway**

Think about what additional information and advice, preventative support, and services focused on wellbeing are needed for this group.

Develop a service 'pathway' that helps people access appropriate services and support throughout their journey and recognises what is different (see pathway below).

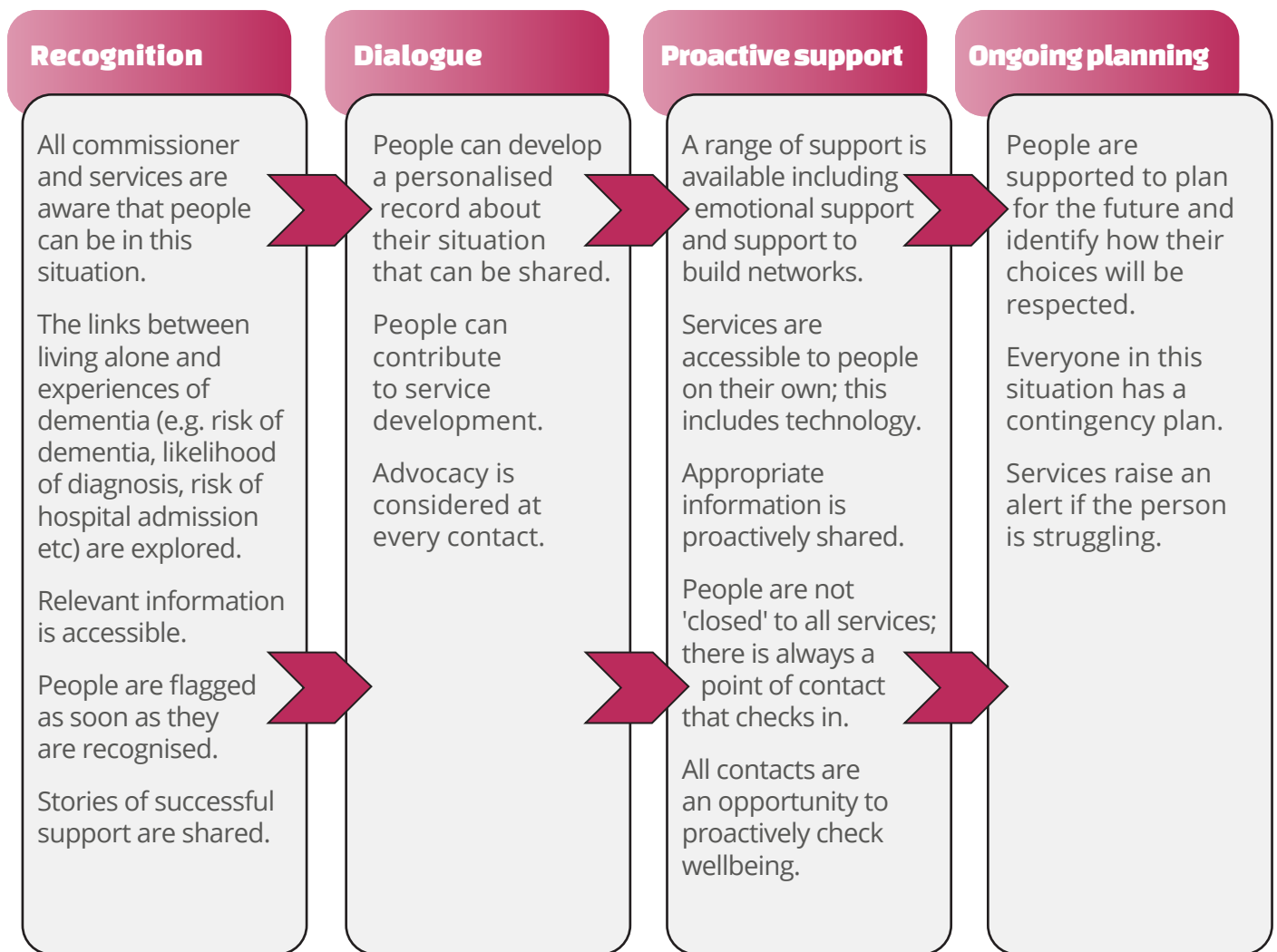
Work with partners to ensure that they make the most of planned contacts e.g. post-diagnostic dementia checks or social care reviews, and personalise these so that they work for people living alone and without informal support e.g. by making them more frequent or visiting people at home.

Support an integrated system where 'every contact matters' - no matter how, where or with whom it occurs, so that changing circumstances and needs can be identified and responded to.



## Pathway for people living alone with dementia and without informal support

This Pathway shows what is different for people living alone with dementia and without informal support. It covers recognition, dialogue, proactive support and ongoing planning.



This pathway is adapted from the [Well Pathway for Dementia](#).

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### **Good Examples**

These examples are adapted from real-life examples of how commissioners and services are supporting people who live alone with dementia and without informal support.

#### **Named commissioner**

One Local Authority and NHS partner have a joint commissioner with dementia in their job title, whose role is to lead on dementia provision.

#### **Prevalence information**

Local Authorities do not routinely collect this information, but one Local Authority used generic statistics and information on the number of people with dementia with carers in order to estimate the local population of people with dementia without carers. This was used to support service development.

#### **Planning ahead**

A commissioner in one local authority recognised that there are likely to be changing needs for services for people living with dementia because 40% of the local population is from minoritised ethnic groups. This population is now ageing and culture is changing so there is less reliance on family care and community support. The commissioner is aware that the demographics and expectations of this group are changing, so is planning for services that will be needed in the near future.

#### **Tailored service design**

A dementia advice service has a home visit path for certain groups including people living alone without family support. This means that the person with dementia is visited in their own environment and support needs can be clearly identified.

The dementia advice service has a named contact who stays with a person with dementia throughout their journey. This can be particularly useful for people living alone without family support.

*'It's about the fact that it's very tailored, very person centred because we get to know the people. So, we know what their needs are.'*

**(Quote from a service provider)**

## Life-time post diagnosis support

A step-up step-down service does not discharge people with dementia. Levels of support differ depending on changing needs. Telephone check-ins are carried out at agreed intervals typically 3-6 monthly. When someone lives alone without family support the telephone check-ins are more frequent, typically weekly or fortnightly.

*'But we also know that without regular contact, things can deteriorate quite significantly, and that regular contact enables us to keep people stable for a longer period of time.'*

(Quote from a service provider)

## Supported referrals not signposting

One service supports people with dementia living alone without informal carers to make referrals and then checks that services have got back to them and that the support requested is in place.

*'We needed to be able to have the time to support them in the way they needed to be supported. And that doesn't mean that we would step in and do everything for them...But somebody needs to organise those things and we need to recognise that that is a key thing when it comes to supporting people who are living on their own.'*

(Quote from a service provider).



### **About the research**

**The research methodology and key implications for commissioners are summarised below.**

The research was led by Sheffield Hallam University, NIHR Applied Research Collaborative North Thames/University College London, Leeds City Council/West Yorkshire Integrated Care Board and Innovations in Dementia funded by the National Institute for Health and Care Research. It ran from April 2022 to May 2024.

**The research focused on people with dementia who live alone and who are managing without informal support to contact and navigate services. It included:**

- An audit of services available for this group in two English regions
- Interviews with this group of people with dementia
- Case studies in four areas to explore the support available, what works, and what does not work
- Workshops with people with dementia, commissioners, providers and practitioners to share early findings and co-develop these resources.

**Key implications for commissioners are:**

- Awareness of this population was limited; no Local Authority in the audit knew who was living alone and had no carer
- Only two local authorities that were audited had services 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 if someone ceased to have informal support
- Travel and timing can make groups inaccessible
- Not everyone is ready for support immediately after diagnosis
- Finding the right support can be difficult for people on their own
- People had different sizes of network and building networks isn't easy for everyone
- Support and networks could break down e.g. services discontinued or people moved away
- Emotional support is important and other people with dementia can be a good source of support
- Services can be proactive in building wider networks
- Planning ahead and contingency planning are essential
- Proactive information and support are needed.







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All photos are from the Centre for Ageing Better's Age Positive Image Library

**With thanks to members of the Advisory Group and all who took part in the research**

### Find out more

Visit

[www.livingalonewithdementia.co.uk](http://www.livingalonewithdementia.co.uk)

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