

LIVING ALONE WITH DEMENTIA



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

Introduction

People can and do live on their own with dementia and without family and friends nearby. 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 in your profession, service or organisation 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 crisis where they may end up in hospital or in a care home.

About this guide

This guide provides key principles about how to offer good support to people living alone with dementia and without family and friends nearby. There is information for each principle about why it matters and what's needed. The guide then has an approach, based on NICE guidance, 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.

The quotes in the guide are all from people living alone with dementia and without informal support.

Principles

These principles cover how to offer good support to people living alone with dementia and without family and friends nearby. There is information for each principle about why it matters and what's needed.



1. Recognise that there is a whole different set of priorities and issues for people living alone with dementia and without informal support.

"Make sure everyone is aware of this group and always thinks about it whenever someone accesses a service."

What is important?

People can face a range of barriers to seeking and engaging with support, related to being on their own, including: accessibility issues; reluctance to engage with services due to stigma or concern about loss of freedom; and language that is not inclusive.

The word 'dementia' can be off-putting or even taboo e.g. for people from particular cultures. People may not necessarily have a diagnosis. Young-onset dementia is not well understood.

Practitioners and providers may not have a good understanding of dementia or might think it is just about memory.

What can you do?

- Listen to and learn from people's experiences.
- Recognise that people can and do live alone with dementia.
- Build understanding of the particular needs of people in this situation and educate others.

2. Be proactive and responsive.

"Asking for help can be hard."

What is important?

People can fall through the cracks between services if it is assumed that someone is helping them to access support.

People who live alone and don't have informal support are likely to have different needs so support needs to be tailored.

Small regular interactions or inputs can make a big difference.

What can you do?

- Don't make assumptions about how the person is managing. Listen to the person.
- Consider where and how people can get good information and make contact with someone when they need it.
- Make every contact count.
- Consider face-to-face support and home visits, as these allow you to get a clearer picture of what is happening.
- Give sufficient time for a good check-in so you can build up trust and explore what someone is telling you. If the time isn't right, try again.
- Don't close involvement unless it is clear how the person will be checked in on in the future.



3. Any support that you offer should be accessible for people on their own.

“When you go to a service they assume that there is input from families in the background.”

What is important?

Services can exclude people who are on their own. Transport is often an issue. When services work for people who are living alone and without informal support, they work for everyone.

Assistive technology can be useful. However, it isn't enough to just provide the technology. Thought needs to be put into how to support people to access and use the technology effectively.

Some technology, such as an alarm, requires a named person and so needs careful consideration. It is important to introduce technology in a timely manner when there is time to get used to it, rather than when it is urgent or in response to a crisis.

What can you do?

- Consider how technology could support someone, taking account of their strengths and barriers to using it. Tailor technology to the particular situation and include support to set up, use the technology and respond to any difficulties that arise.
- Involve people with dementia in planning any service or support so that you can be sure it is accessible.
- Ask these questions about a service or the service that you provide:
 - How do people living alone without a carer find out about the service?
 - Are people welcome at the service on their own?
 - Is the service at a convenient time and in an accessible place?
 - How can people get to and from the service easily and safely?
 - How affordable are the service and transport?
 - How are people on their own made welcome when they arrive at the service?
 - How does the service make sure people can navigate things like getting refreshments, using the toilet, etc?
 - How does the service make sure it communicates appropriately with people?

4. Help people to build networks.

“Society insists you have to be capable, but everyone needs a bit of help.”

What is important?

People may not be ready for support when they first develop dementia. It is not always obvious where to go for information and finding the right support can take time.

People's networks can be hard to build and to sustain. If something changes in the network, other people would not necessarily know and an important element of support could be lost. Professionals and the third sector can help with building networks.

What can you do?

- Map out who is in someone's network – e.g. distant family and friends, neighbours, NHS, social care, housing, neighbourhood services, and local services such as shops. You can then consider who else could join the network.
- With consent, let people in the network know who the others are, and identify who to communicate with about what, and who is the emergency contact. Identify how you will monitor how this is working.

An **ecomap** can be a useful tool. This allows you to draw a diagram of who is in a network and how they link together.

The Alzheimer's Society This is Me record captures a lot of useful information. This can be a starting point for capturing and sharing essential information about the person.

5. Recognise the importance of emotional support.

"It's good to talk to somebody going through this at the same time."

What is important?

Emotional support is really important and can be overlooked. When there is nobody at home or around to support with emotions, this can become a big issue.

Other people with dementia are a good source of support. This is a way of gaining emotional support through a sense of belonging to a non-stigmatising group. It is important to have a place to meet up with others.

What can you do?

- Talk with people about how they feel.
- Explore what support is available in your area. Find out about peer support groups, or help to develop these. Link people into support that works for them.
- It can help to have different ways to express what is happening e.g. you can encourage someone to write poetry or to keep a diary.



6. Plan with people for change and contingencies.

"I don't know what I don't know."

What is important?

Both networks and services are precarious; support can stop for many reasons. Back-up for when things change or for occasional issues is important.

Advocacy can make a huge difference. Anyone acting as an advocate needs to understand the particular needs of this group and of the specific person. The person should be in control of what happens.

What can you do?

- Co-produce care plans that work for the person and include future planning, particularly about decision making.
- Keep having proactive conversations about what is important to the person, and keep information about wishes and choices up to date.
- Recognise people's strengths and ability to problem solve, and build on these.
- Think about risk management and the importance of taking risks for positive outcomes, rather than being risk averse.

It can be helpful to complete the **Herbert Protocol**. This is a form where you put together essential information that can then be given to the Police if someone goes missing and is at risk. This helps the Police to find them as quickly as possible.

Approach to working with people living alone with dementia and without informal support

This Approach shows what is different for people living alone with dementia and without informal support. It is based on the [NICE Guideline on dementia](#).

Involving people in decisions about their care

Identify how to involve people who live alone and don't have informal support.

Proactively consider advocacy at every contact.

Providing information

Provide information in ways that the person can take in without support, and also arrange any support they need to understand and act on information.

Make sure that the person can get information when they need it.

Ask the person if you can flag up their situation and share information proactively with others.

Ensure that there is ongoing contact with the person to identify changing needs for information.

Follow up after diagnosis

Ensure that there is follow up after diagnosis and that it is known that this person lives alone without informal support.

Enable people to access health appointments on their own.

Do not discharge someone from post-diagnosis support without something in place to follow up.

Planning

Be proactive in offering support to help people plan ahead, particularly to identify who will support them with decision making.

Ensure that everyone has a contingency plan.

Make every contact count as an opportunity to review how things are going.

Sharing information

Agree with the person how you will share appropriate information to support them.

Ensure there is a way of raising an alert between services if a problem occurs.

Making services accessible

Check that any service you suggest is accessible to someone on their own or make adjustments so they can use it.

Be proactive in ensuring people can get to health appointments.

Care coordination

Ensure that there is a named person or service responsible for checking in with the person and/ or coordinating their care.

Consider specific areas in care planning that are particularly tricky for people in this situation including:

- Preventative support to avoid small issues becoming big issues
- Day-to-day emotional support
- Advice for day-to-day queries
- Prompts and orientation for day-to-day activities e.g. medication
- Minor practical support e.g. DIY or changing the clocks
- Accessing appointments
- Safe management of finances and life administration
- Safety in the home
- Emergency response in case of a problem.

Ensure that the care plan is proactively monitored. Do not end involvement without ongoing contact in place.

Staff training and education

Raise awareness of people in this situation, learn from them and share learning with others.

Be aware of the action to take if you are concerned about someone living alone with dementia and without informal support.



Good Examples

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

Occupational therapy support

One memory clinic provides ongoing support from a named occupational therapist. The occupational therapist checks in with the person with dementia every few months at home to see how they are managing and to problem solve any issues that arise. They are also the contact for any questions that the person has.

Extra-care support

One of the residents in extra-care housing does not have any next of kin or emergency contact. However, he has a support worker who visits three times a week. The support worker can ensure the provider and other services know what the resident's wishes are day-to-day.

Befriending

An at-home befriending service run by a charity includes befriending for people with dementia who live alone. They have a consistent long-term befriender, who has an ongoing relationship with them. The befriender refers back to the charity when additional support is needed. The charity will ensure a thoughtful handover to whatever service is best placed to support them and the befriender facilitates the input from the new service.

Opening up a support group

One voluntary sector group for people living with dementia was initially set up so that people would come along with a relative, friend or carer. Once the group was established, the facilitators realised that they could open this up to people who live alone. People who live alone are warmly encouraged to attend and supported to get to the group. Some sessions are now just for people living with dementia, and carers can attend a session at the same time in a different room or use this as an opportunity to have a break.



About the research

The research methodology and key implications for practitioners and providers 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 people working with people who live alone with dementia and without informal support are:

- 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
- Regular contact, a variety of services, ongoing and widespread communication, practical help, planning ahead and facilitating access to other services all help
- Practitioners and providers can be proactive in building support around people.



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

Find out more

Visit

www.livingalonewithdementia.co.uk

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