



Coping with dementia: Addressing the needs of everyone involved

Person-Centred Approach



**An interactive handbook for people recently diagnosed with
dementia, their family and professional caregivers**

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Introduction

Dementia: what it is and what it is not

Dementia ≠ Alzheimer's Disease

Dementia is *NOT* a disease: it is an umbrella term used to describe a set of symptoms which are caused by a damage in the brain. Alzheimer's disease is the most common cause of this damage, accounting for approximately 60-80% of dementia cases.¹

Dementia ≠ Just Memory Problems

Dementia is *NOT* just about memory loss. Although dementia is usually first manifested by short-term memory impairments, *other symptoms*, such as disorientation, mood changes or difficulty with finding words are also common in dementia.²

Dementia ≠ End of Active Life

Individuals diagnosed with dementia should *NOT* withdraw from their daily activities because of perceived limitations. On the contrary, involvement in various *activities* can *improve* the *quality of life and well-being* of people with dementia.^{3,4} Most importantly, it can help to *prevent the feelings of losing identity* that are very common in dementia.^{5,6}



The *AIM OF THIS HANDBOOK* is to introduce a person-centred approach to dealing with dementia. Whether you are a patient or a caregiver, it will give you strategies and tips for living meaningfully with this condition.

People with dementia

Dementia diagnosis – what next?

After being diagnosed with dementia I felt (tick what applies):

- relief
- embarrassment
- grief
- fear
- withdrawn
- frustration



Many people diagnosed with dementia experience some of these feelings, most of which are negative.⁷ Joining in with interventions that combine social support and educational elements can **improve well-being and quality of life**.⁸

Support Programmes

Provided by [Alzheimer Scotland](#)

Dementia Link Workers (one year's post-diagnostic support)

can give you an understanding of dementia and help you to **manage your symptoms**⁹ and thus improve your quality of life. Ask your doctor for more information or click [here](#).

Video 1: People with dementia and their caregivers talk about the impact Dementia Link Workers had on their lives. Also available here:

<https://youtu.be/bhcTCXGusIQ>



Dementia Cafés

are places where you and your relatives can **share your feelings** with others diagnosed with dementia. Such facilities can improve your social and emotional well-being.¹⁰



People with dementia

Everyday problems in dementia

Because of dementia I now experience difficulty with (tick what applies):

- handling money and shopping
- knowing where I am
- remembering recent events
- communication and self-expression
- mood or behavioural changes

If you ticked any of the above, **you are not alone**. People with dementia usually experience some or all of these symptoms.²

Shopping experience of Mr James McKillop

James would not be able to count money properly because of his dementia. Unknowingly, he would hand over an incorrect amount of money to a shop assistant. The shop assistant would follow this up and James would then need to admit that he couldn't count money which would be met with a disbelief and suspicion from others. To prevent this, James found a subtle way of informing others about his condition – the *Dementia Help Card*.¹¹

Most people seem to be understanding and **provide help** when they find that someone has dementia.¹² You can **use the Dementia Help Card** to discreetly inform others about your condition and ask for assistance. It can be downloaded [here](#).

How often do you go outdoors?

Even though dementia symptoms (disorientation, confusion, anxiety) can initially put you off going out, **outdoor activities** are **important for your well-being**.¹³ If you are worried about getting lost outside, have a look at some **adaptation strategies** that may help you.¹⁴

- Walk in areas that are well known to you.
- Pay attention to landmarks.
- Walk on paths that loop.
- Have a phone on you.



Family caregivers

How to preserve the sense of self when coping with dementia?

Memory loss goes hand in hand with a loss of identity.¹⁵ This is because people with dementia have to increasingly rely on others and they stop doing activities that they previously engaged in.¹⁶ It is therefore desirable to involve the person you care for in daily tasks to help them retain a sense of identity and provide meaning to their life.¹⁷

My relative with dementia continues to take part in these activities (tick what applies):

- favourite hobbies
- household chores
- social involvement

It is important for people with dementia to continue taking part in all of these tasks.¹⁷ For example, even though your relative may need to use different strategies to do household chores than before they were diagnosed with dementia, they may still be happy to **take part with your assistance**.¹⁷ Here is a list of **tips**¹⁸ that will guide you when engaging the person you care for in daily activities:

- **Be patient**

Allow them enough time to complete tasks.

- **Provide support**

*Write notes with instructions (e.g. how to use a microwave).
Provide schedules for the day.*

- **Encourage**

Acknowledge their efforts by praising them.



TIP: If you had to restrict your activities to care for your loved one, you may want to find out more information about [Day centres](#) provided by Alzheimer Scotland. While your relative can meet other peers with dementia and participate in a number of therapeutic activities nurturing their independence, you will have **time for yourself**. Use it to meet your friends or do your hobbies to bolster your **OWN** sense of identity and well-being.¹⁹

Family caregivers

Maintaining the connection with the person you care for

People with dementia often have **difficulty with following conversations** due to their memory problems.²⁰ This can negatively affect your relationship and cause **distress**.²¹ That is why developing communication skills that are suited for the needs of your loved one can improve well-being for you both.

Have you ever tried to change your communication behaviour to adjust to your relative with dementia?

- YES
- NO

Essentially, it is important to consider two aspects of your communication: the demands that you place on your relative's memory and the emotional side of your interaction.¹⁸ These **communication strategies**¹⁸ can help you to maintain meaningful interactions with the person you care for.

- **Ask about preferences and offer choices**
e.g. Would you like to listen to the radio or watch TV?
- **Use simple sentences with one idea at the time**
e.g. I put your coat back in the wardrobe.
- **Draw on shared history**
e.g. You loved the view from our first house, didn't you?
- **Guide and encourage**
e.g. Zip the jacket from the bottom to the top. Well done!



Video 2:

A number of communication tips illustrated with examples from everyday life.

Also available here:

<https://youtu.be/NTfZfhuZ2TI>

Initially it may be difficult for you to change long-lived habits of communication. However, using these strategies can have a positive effect on **the quality of the interaction** with the person you care for.¹⁸

Professional caregivers

Why do we need person-centred care?

I have observed these types of behaviour in the people I care for (tick what applies):

- aggression
- wandering
- agitation
- restlessness
- apathy



All of the above behaviours are common among people with dementia.²² In fact, the behavioural symptoms are a frequent reason why their relatives resort to professional care.²³ You might feel that they induce **feelings of stress and burnout** in yourself and that is completely normal.²⁴

Research suggests that the challenging behaviours of people with dementia are actually **poorly communicated needs**.²⁵ It is thus important to practise a person-centred approach to dementia care which emphasises meeting the needs of individuals.²²

The **VIPS** framework²⁶ describes four main principles of **person-centred care**:

- V** VALUING people with dementia and their family carers
- I** Treating people with dementia as **INDIVIDUALS**
- P** Seeing the world from the patients' **PERSPECTIVE**
- S** Providing supportive **SOCIAL** environment for the patients

Engaging in meaningful activities **improves** the **well-being** of people with dementia.²⁶ By getting to know the person better, you can develop a better understanding of their individual needs. This can enable you to design activities that would give them a sense of fulfilment and thus reduce their challenging behaviours.²⁸



Video 3: Impact of person-centred care on the lives of people with dementia.

Also available here:

https://youtu.be/OZXeXHJX_1A

Professional caregivers

Person-centred care in practice I

The key is to find out what the patients liked to do before their dementia diagnosis and identify their retained skills.²⁹ Family members and friends of the person with dementia can be a useful starting point.³⁰ If you happen to gather any material related to their past, you can use it to **reminisce** with them.

Have you ever practised reminiscence therapy?

- YES
 NO

REMINISCENCE

People with dementia usually have relatively spared long-term memory.³¹ Pictures, household items, music or newspapers can help to recall the memories which can enhance communication, increase the sense of one's identity and thus improve the well-being of people with dementia.³²

Case study: Phil³³

Characteristics upon admission to a care centre: grumpy, withdrawn, depressed.

Hobbies: Used to play the banjo.

Intervention: Music therapy group.

Did it work? Initially no.

Intervention 2: Individual music therapy.

Did it work? Yes.

Outcomes:

- He started to tell stories linked with songs.
- He tried to play his old banjo.
- He was happy to play for others and socialise with them.

→ **His well-being had improved.**



Quiz: What elements of the music therapy had improved Phil's well-being?

Professional caregivers

Person-centred care in practice II

Quiz Answers – the effects of person-centred therapy

- The caregivers gave Phil **individual attention** and he became more sociable and shared experiences from his past.³³
- They obtained his old banjo and **supported him** to play which increased his sense of identity as a musician.³³
- After that, he participated in music therapy **group sessions** where he could show others his retained skills and thus bolster his feelings of self-worth and mood. This also helped him to integrate himself into the community.³³

Overall, you can see that people with dementia can significantly benefit from a person-centred approach. Reminiscence will help you to get to know the patient better. This will enable you to offer them activities **tailored to their needs**.³⁴

Tip: Together with the patient you can create a **memory notebook** containing important facts about them.

- They provide reassurance that important events of the patients' lives will not be forgotten and thus improve their well-being.³⁵
- They can serve as a tool for you and other caregivers to find information about the patients in the future.³⁵



Video 4: Person-centred approach: a woman records information about herself in a book and a video so that herself and her caregivers can access it when her dementia progresses. Also available here: <https://youtu.be/jBIYYjXYp5U>

Conclusion

Key messages for people with dementia and their caregivers

People with dementia

- 1) Even though your dementia diagnosis may initially be overwhelming, support programmes can help you with adjusting your lifestyle to living with this condition.^{7,8}
- 2) You may have difficulty with carrying out a number of everyday tasks but there are strategies that can help you.^{2,14}



Family caregivers

- 1) Preserve the sense of your relative's identity by encouraging them to participate in tasks they can still do.¹⁷
- 2) Improve the quality of your interaction with the person you care for by adopting simple supportive strategies that do not place high demands on their memory.¹⁸



Professional caregivers

- 1) It is important to practise person-centred care because it can reduce the behavioural symptoms of dementia and improve the well-being of the patients.^{22,23,26}
- 2) Reminiscence can help you to find out more information about people with dementia which you can use to design meaningful activities for them.^{32,33,34}



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