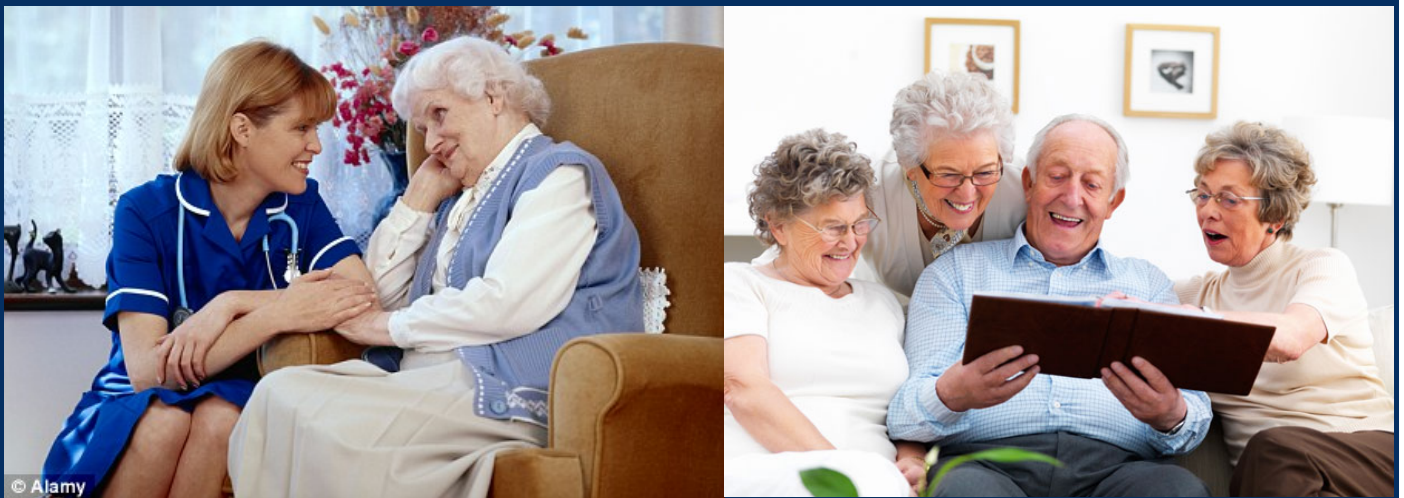




DEALING WITH DEMENTIA: SEEING THE PERSON OVER THE SYMPTOMS



A manual for improving sense of self and person-centred care in dementia: for the individual with dementia, family members and professional caregivers

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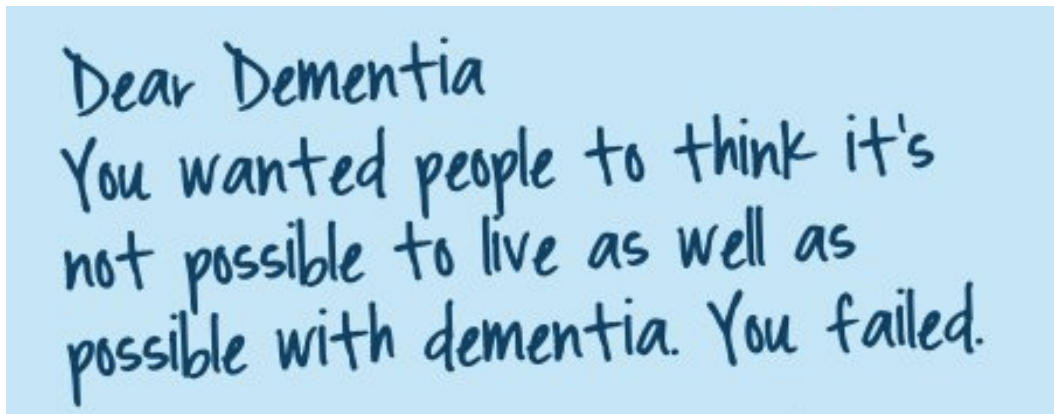
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Sense of self and dementia...

The symptoms of Alzheimer's disease are progressive and currently have no cure, although there are many ways to ensure people with dementia maintain a happy and fulfilled lifestyle - reflective of their personality. Whilst individuals experience symptoms in different ways, theory suggests that the management of dementia in order to keep the individual's personality at the forefront⁴ is the most effective way of limiting physical and psychological consequences for the person with dementia, family and professional caregivers.



Unfortunately, the term dementia can be used as a label – invoking negative connotations and contributing to a culture of poor treatment from family members and caregivers. This ‘culture’ has negative implications for all parties involved with dementia⁵. The goal of this handbook is to move away from viewing dementia as a ‘syndrome’ based on the symptoms – but rather to focus on the personhood of the individual with dementia so they can maintain their sense of identity and feel a valued part of our community. Information, including tips and case studies, is presented in the handbook in three sections for:

1. Individuals with dementia
2. Family members caring for people with dementia
3. Professional Caregivers

Quick Quiz: True or false?

1. Independence is lost with a dementia diagnosis.

2. Most people with dementia have a formal diagnosis.

3. People with dementia are able to communicate even in the most advanced stages.



4. There is no link between dementia and depression.



5. Memory for distant events is often well preserved in Alzheimer's disease.

Quick Quiz: Answers

1. False – Independence is not lost with a diagnosis and people with dementia should be encouraged to do things where they can throughout the progression of their symptoms⁶.
2. False – It is estimated only 20-50% of people with dementia symptoms have a formal diagnosis in developed countries. More people live without a diagnosis in developing countries⁷.
3. True – Comprehension and production of language becomes more difficult with symptoms, although people with dementia are able to communicate with others right up to the final stages⁸.
4. False – Significant numbers of people with dementia suffer from depression. Dementia and depression can cause similar symptoms, often making it difficult to identify but carers should look out for signs⁹.
5. True – Memory for recent events are disrupted early on, although people with dementia are often able to recall memories from their distant past¹⁰.



Information for the person with dementia: Focussing on you!



“ Brian’s story...”

Brian had an inquisitive interest in technology, although lost confidence in his ability to work simple things such as the TV remote after his diagnosis of dementia. As his confidence declined, Brian opted to take part in the COBALT project in order to try and improve his ability with technology. With this project, Brian re-kindled his enthusiasm through a regular blog and his confidence grew to the extent that he was able to learn new techniques such as downloading and using apps on his iPhone. The one-to-one contact and cooperation focussed on Brian’s interests and renewed the confidence in his ability - giving him a positive outlook on life and the reassurance that he could live well with dementia¹¹.

Many people with dementia can relate to Brian’s loss of confidence¹².

It is important to try and not to let the diagnosis of dementia impact your confidence. Instead, hold onto your passions now more than ever. Whether they are sports, reading, technology, gaming or socialising - these things help us maintain our identity and give us the required boost and reassurance that there are many ways to live well with dementia¹³.

What can you do?



- Get support – there's lots of it available! Whether its 1-1 support like in Brian's case or joining a support group to talk about experiences with others - get your personality out there.
- Use reminders and prompts to help you through daily activities¹⁴. Everyone needs a little help from time to time so don't let this affect your confidence.
- Decide what is important to you and what you enjoy doing. Dementia won't stop you enjoying new experiences and family and friends can help plan your day so you can achieve everything you want to.
- Take care of yourself. Maintain a healthy lifestyle by resting and eating well. Stay positive and focus on your retained skills, interests and opportunities¹⁴.



Getting to know YOU

We know you've got a great story to tell so let's hear all about it. Firstly, smile for the camera – upload your selfie here!!

<Click link to upload a photo here>

My name is and I am from...

Tell us about your family...

My favourite things to do are...

If I could be anywhere I would be...

Sense of self and dementia: For family caregivers...

The aim of this section of the handbook is to provide information for family members so care can be provided that maintains the identity of the person with dementia following a diagnosis.



After the shock of a diagnosis, people with dementia often feel a sense of loss, and a blow to their confidence as they begin to experience reduced ability to carry out tasks¹⁵. This is where your job as a family caregiver is vitally important. Providing the best care by focussing on retained skills and making an effort with meaningful communication will give your loved one the best chance of dealing with the symptoms and living well with dementia¹⁶.

The symptoms of dementia are hard and at times will put a strain on the relationship with the person with dementia¹⁷. However, using the tips and

advice in this handbook you can maintain a healthy relationship with your family member and not let dementia disrupt your life any more than it has to.

Tips and Advice



It is important to involve the person with dementia as much as possible. Explain to them the tasks in hand and allow them to help with chores. Make decisions as a team in order to enhance their feeling of involvement. (Tip: try not to talk about them with others when they are in the room)⁵.

Always allow more time than normal.

This gives you time for meaningful interactions and will avoid stress from falling behind a schedule. Always try to be patient and calm.



Try to maintain a routine and accommodate their difficulties.

Maintaining a routine can enhance confidence and sense of self in your family member. For example, arrange the house in an easier way for them to understand and leave instructions where possible (switching on the TV).

Involve other family members. Being the direct caregiver can become stressful and tiring. Give yourself a break by involving other family

members in the care process¹⁸. The result is you'll come back refreshed and ready to provide the best care possible again.

Engage with professional caregivers. Give professionals as much personal information about your loved one as possible¹⁹. This means they can plan personalised activities suiting their personality.

Set aside time for reminiscing and memory tasks. Looking at photos together and reminiscing can be a rewarding task for both involved²⁰. (Tip: go slowly and never become frustrated with your family member).



Support for Family Caregivers

It is important to look after your own health and wellbeing throughout the care process. Being a caregiver can be a difficult task and it is likely you still have a few worries or questions. If so there are plenty of sources of support available to you:

Talking Point - an online discussion forum for anyone affected by dementia where you can share information, seek advice and feel supported.

<https://www.alzheimers.org.uk/onlineforum>

Local Council Social Services – You are eligible for a needs assessment and help may be available with healthcare, help in the home, equipment or respite care. Contact your local council to find out.

Providing care that enhances sense of self: For professional caregivers...

The aim of this section of the handbook is to give information to professional caregivers in order to improve person-centred care and enhance the individual's identity throughout their symptoms.



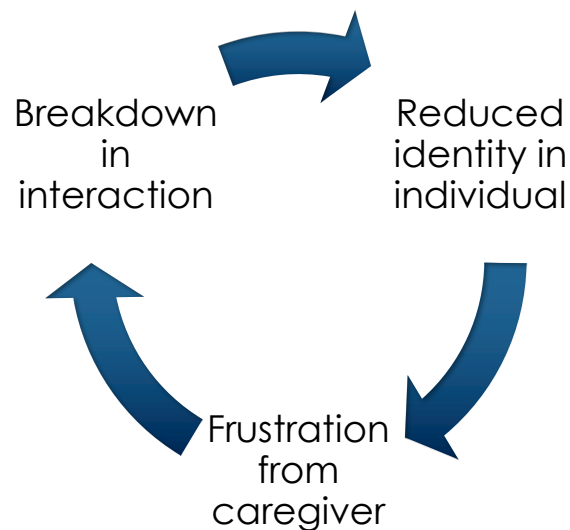
Your role as a professional caregiver is to assist with the daily needs and maintain the wellbeing of people with dementia who are progressing through the deteriorating symptoms. It is important to realise that your interactions have an impact on those you care for⁵ - there is much more to your job than completing daily tasks²¹.

Clink the link below to watch an engaging TEDx talk about providing care from an empathetic, patient and interactive approach in order to help find joy in dementia:

<https://www.youtube.com/watch?v=SxZqoIbnVis>

Impact of Social Interaction

Social interaction between the professional caregiver and person with dementia can significantly influence their sense of self and response to symptoms¹⁶. For example, a lack of interaction can be damaging to the identity and confidence of someone with dementia, which can make completing daily tasks more difficult and frustrating for the caregiver²² (this vicious circle is visualised below).



Instead, positively enhancing interactions can restore identity to individuals with dementia helping them to deal better with the symptoms experienced¹⁶. By focussing on the personality retained by the person rather a set of generic symptoms²³, you can attend to their specific needs as a person and improve their confidence. This has benefits for everyone involved.

Examples of Person-centred Care

Getting to know those that you care for is the first step in personalising their care. Make an effort with information about their past and address them by their preferred name in order to reinforce a sense of self²⁴.



Working with the rest of the care team to build a positive ‘family-like’ environment helps to improve wellbeing for caregivers and those with dementia.

Using the knowledge of their life experience, engaging activities can be planned, such as:

- Reminiscing with them using old photographs and making personalised memory boxes²⁵. Adding photographs from significant life events and treasured possessions helps you develop a relationship with them.
- Understanding their hobbies brings joy and enhances sense of self for the residents. Personalising activities encourage the most engagement. With some you could enjoy their favourite music, watch old sports games, help them with jigsaws or build models²⁶.

Remember:

The most important (and rewarding) part of your job is not assisting with everyday tasks but instead seeing the individual’s personality over the symptoms and renewing bonds with every interaction!

Useful Information and Contacts

Websites:

<https://www.alz.co.uk/finding-help>

<http://www.alzheimersresearchuk.org>

<http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-help-and-support.aspx>

<https://www.dementiauk.org>

<https://www.dementiafriends.org.uk/>

Helpline Numbers:

Alzheimer's Society 0300 222 1122

Alzheimer Scotland 0808 808 3000

Carers UK 0808 808 7777

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