

Understanding and respecting the person with dementia

It's very important that people with dementia are treated with respect. It is important to remember that a person with dementia is still a unique and valuable human being, despite their illness. This factsheet looks at ways that you can help the person to feel valued and good about themselves.

When a person with dementia finds that their mental abilities are declining, they often feel vulnerable and in need of reassurance and support. The people closest to them – including their carers, health and social care professionals, friends and family – need to do everything they can to help the person to retain their sense of identity and feelings of self-worth.

Helping the person feel valued

The person with dementia needs to feel respected and valued for who they are now, as well as for who they were in the past. There are many things that the people around them can do to help, including:

- trying to be flexible and tolerant
- making time to listen, have regular chats, and enjoy being with the person

- showing affection in a way they both feel comfortable with
- finding things to do together, like creating a life history book.

What's in a name?

Our sense of who we are is closely connected to the names we call ourselves. It's important that people address the person with dementia in a way that the person recognises and prefers.

- Some people may be happy for anybody to call them by their first name or nickname.
- Others may prefer younger people, or those who do not know them very well, to address them formally and to use courtesy titles, such as Mr or Mrs.

Respecting cultural values

Make sure you explain the person's cultural or religious background, and any rules and customs, to anyone from a different background so that they can behave accordingly. These may include:

- respectful forms of address
- what they can eat
- religious observances, such as prayer and festivals
- particular clothing or jewellery that the person (or those in their presence) should or should not wear
- any forms of touch or gestures that are considered disrespectful
- ways of undressing
- ways of dressing the hair
- how the person washes or uses the toilet.

Acting with courtesy

Many people with dementia have a fragile sense of self-worth; it's especially important that people continue to treat them with courtesy, however advanced their dementia.

- Be kind and reassuring to the person you're caring for without talking down to them.
- Never talk over their head as if they are not there especially if you're talking about them. Include them in conversations.
- Avoid scolding or criticising them.
- Look for the meaning behind their words, even if they don't seem to be making much sense. Whatever the detail of what they are saying, the person is usually trying to communicate how they feel.
- Try to imagine how you would like to be spoken to if you were in their position.

Respecting privacy

- Try to make sure that the person's right to privacy is respected.
- Suggest to other people that they should always knock on the person's bedroom door before entering.
- If the person needs help with intimate personal activities, such as washing or using the toilet, do this sensitively and make sure the door is kept closed if other people are around.
- Everyone involved including the person's friends, family members, carers, and the person with dementia themselves reacts to the experience of dementia in their own way. Dementia means different things to different people.

Helping the person feel good about themselves

There are lots of things you can do to help the person with dementia feel good about themselves.

When you spend time with someone with dementia, it is important to take account of their abilities, interests and preferences. These may change as the dementia progresses. It's not always easy, but try to respond flexibly and sensitively.

Supporting the person to express their feelings

Dementia affects people's thinking, reasoning and memory, but the person's feelings remain intact. A person with dementia will probably be sad or upset at times. In the earlier stages, the person may want to talk about their anxieties and the problems they are experiencing.

- Try to understand how the person feels.
- Make time to offer them support, rather than ignoring them or 'jollying them along'.
- Don't brush their worries aside, however painful they may be, or however insignificant they may seem. Listen, and show the person that you are there for them.

Offering simple choices

- Make sure that, whenever possible, you inform and consult the person about matters that concern them. Give them every opportunity to make their own choices.
- When you are helping someone, always explain what you are doing and why. You may be able to judge the person's reaction from their expression and body language.
- People with dementia can find choice confusing, so keep it simple. Phrase questions so that they only need a 'yes' or 'no' answer, such as 'Would you like to wear your blue jumper today?' rather than 'Which jumper would you like to wear today?'

Tips: maintaining respect

- Avoid situations in which the person is bound to fail, as this can be humiliating. Look for tasks that they can still manage and activities they enjoy.
- Give plenty of encouragement. Let them do things at their own pace and in their own way.
- Do things with the person, rather than for them, to help them retain their independence.
- Break activities down into small steps so that they feel a sense of achievement, even if they can only manage part of a task.
- Our self-respect is often bound up with the way we look. Encourage the person to take pride in their appearance, and compliment them on how they look.
- Try not to correct what the person says to you, the accuracy of the information is not as important as what the person is trying to express.

Supporting other carers

Make sure that anyone involved in caring for the person has as much background information as possible, as well as information about their present situation. This will help them see the person they're caring for as a whole person rather than simply 'someone with dementia'. It may also help them to feel more confident about finding conversation topics or suggesting activities that the person may enjoy.

If someone is not used to being around people with dementia, it may help to emphasise the following points:

- Dementia is nothing to be ashamed of. It is no one's fault.
- If the person tends to behave in ways that other people find irritating or upsetting, this may be because of the dementia it's not deliberate.

• The person with dementia may remember the distant past more clearly than recent events. They are often happy to talk about their memories, but anyone listening needs to be aware that some of these memories may be painful.

Always try to remember

- Each person with dementia is a unique individual with their own individual experiences of life, their own needs and feelings, and their own likes and dislikes.
- Although some symptoms of dementia are common to everyone, dementia affects each person in different ways.
- We all need to feel valued and respected and it is important for a person with dementia to feel that they still have an important part to play in life. Give encouragement and reassurance and support other family members to understand the person's needs and concerns.

For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/localinfo

For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request. Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9am–5pm Monday–Friday 10am–4pm Saturday–Sunday

alzheimers.org.uk

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Leading the fight against dementia

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