

Activities of Daily Living & Other Problems

Understanding & respecting the person with dementia

If you are caring for someone with dementia you will want to ensure that they are always treated with respect and dignity and as an individual person, however little they may seem to understand. They are a unique and valuable human being.

Someone with dementia, whose mental abilities are declining, will feel vulnerable and in need of reassurance and support. It is important that those around them do everything they can to help them retain their sense of identity and their feelings of self worth. Carers and family should remember that:

- Each person with dementia is a unique individual with their own very different experiences of life, their own needs and feelings and their own likes and dislikes.
- Each person will be affected by their dementia in a different way.
- Everyone reacts to the experience of dementia in a different way. The experience means different things to different people.

Those caring for people with dementia will need to take account of the abilities, interests and preferences they have at present, and the fact that these may change as the dementia progresses. They should be prepared to respond in a flexible and sensitive way.

Background information

The more background information you can give about the person's past, as well as their present situation, the easier it will be for others to see them as a whole person rather than simply as someone with dementia. They may then feel more confident about finding topics of conversation or suggesting activities that the person may enjoy.

You may need to remind others that:

- Dementia is nothing to be ashamed of and that it is no one's fault.

- Dementia may cause the person to behave in ways that others find irritating or upsetting but this is not deliberate behaviour.
- People with dementia often remember the past far more clearly than the recent present and are often happy to talk about their memories (unless these are painful).

A Caregiver's Diary is available from the Alzheimer Society of Ireland which can be used to record important details from a person's past, daily routines, likes and dislikes, names etc and once completed will always be there as a guide for whoever is caring for your loved one or filling in for you while you have a break.

Our names are important

Our sense of who we are is closely connected to the name or names we are known by. It is important to make sure that others address the person with dementia in a way they recognise and prefer.

Not everyone is happy for other people to call them by their first name or the name used by friends and family. Some may prefer younger people or those who do not know them well to use a courtesy title such as 'Mr' or 'Mrs'.

Culture and religion

Make sure that anyone caring for the person, however briefly, has appropriate details about any relevant cultural or religious customs or beliefs so that these can be respected. These may be anything from diet, clothing and the use of jewellery, for example, to ways of undressing, doing hair, washing or going to the toilet. Some forms of touch which are



taken for granted in some cultures may be thought disrespectful in others. You may need to explain any religious observances such as prayer and festivals as well as other traditions to those providing care from a different culture.

A person with dementia is still an adult

It is important that everyone continues to treat the person as an adult and with courtesy, however advanced their dementia.

- Be kind and reassuring without talking down to the person with dementia as though they are a small child.
- Never talk over the head of a person with dementia or across them as though they are not there.
- Do not talk about the person with dementia in front of them unless they are included in the conversation.
- Avoid scolding or criticising the person as this will make them feel small.
- Look for the meaning behind what they may be trying to communicate even if it seems not to make sense.

Focus on abilities

Help the person avoid situations in which they are bound to fail since this can be humiliating. Look for tasks they can still manage and activities they can still enjoy.

- Give them plenty of praise and encouragement and let them do things at their own pace and in their own way.
- Do things with the person, rather than for them, so they can maintain some independence.
- Break activities down into small steps so that the person has some feeling of achievement, even if they can only manage part of a task.
- Much of our self-respect is often bound up in the way we look. Encourage the person to take pride in their appearance and give them plenty of praise.

Respecting privacy

Try to make sure that the person's right to privacy is respected.

- Suggest that people knock on their bedroom door before entering, for example.
- If the person needs help with intimate activities such as washing or going to the toilet, this should be done in a sensitive way. Make sure that the bathroom door is kept closed if other people are around.

Offering choice

It is important that the person with dementia should be informed and wherever possible consulted about matters which concern them. They should also be given every opportunity to make appropriate choices.

- Even if you are unsure how much the person can understand, always explain what you are doing and why. You may then be able to judge their reaction from their expression or body language.
- Although too many choices can be confusing, you can continue to offer choice by phrasing questions that only need a 'yes' or 'no' answer such as 'Would you like to wear your blue jumper today?'

Expressing feelings

Dementia affects the thinking and reasoning part of the brain and memory. It does not mean that the person no longer has feelings.

People with dementia are likely to be sad or upset at times. They have the right to expect those caring from them to try and understand how they feel and to make time to offer support rather than ignoring them or jollyng them along.

In the earlier stages, people may want to talk about their anxieties and the problems they are experiencing. It is important that others do not brush these worries aside, however painful they may be, but listen and show that they are there for them and will be there for them.

Feeling 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. It helps if those caring:

- are flexible and tolerant
- can make time to listen and to chat and enjoy being with the person
- can show affection as appropriate.