Understanding and respecting the person with dementia

If you are caring for a person with dementia you will want to ensure that they are always treated with respect and dignity. They are a unique and valuable human being.

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

- Each person with dementia is a unique individual with his/her own needs and feelings, likes and dislikes.
- Although there are symptoms of dementia which are common to everyone each person will be affected by their dementia in a different way.
- Everyone reacts to the experience of dementia in an individual way. The experience means different things to different people.

Those caring for a person with dementia will need to take account of their abilities, interests and preferences. They need to be aware that these things may change as the dementia progresses. They should be prepared to respond in a flexible and sensitive way.

The life story of the person

The more background information you can give other people who are involved in the care of the person, as well as their present situation, the better it will be. This information will make it easier for other people to see the person as an individual rather than simply as someone with dementia. People involved in care and support may then feel more confident about finding topics of conversation or suggesting activities that the person may enjoy.

You may need to remind other people that:

- Dementia is nothing to be ashamed of. and it is not caused by anything the person concerned might have said or done.
- Dementia may cause the person to behave in ways that other people may find irritating or upsetting but that this behaviour is not deliberate.
- A person with dementia may often remember the distant past more clearly than the recent past and the present. They are often happy to talk about their memories, but remember, past memories may be painful.
Our names are important
Our sense of who we are is closely connected to the name or names that we are known by. It is important to make sure that other people address the person with dementia in a way that they recognize and prefer.

- Some people may be happy for anybody to call them by their first name or the name used by friends and family who are close to them.
- Others may prefer younger people or those who do not know them formally and to use courtesy titles such as ‘Mr’ or ‘Mrs’.

You may come from a cultural background, which has its own particular way of using names and addressing people in order to show respect. If so, make sure that you explain this clearly to anyone in contact with the person with dementia who is from a different background so that they can use the appropriate name or title.

Culture and religion
Make sure that anyone caring for the person, however briefly, has appropriate details of any relevant cultural or religious customs or beliefs so that these can be respected. These may range from diet, clothing and the use of jewellery, for example, to ways of undressing, doing hair, washing or using the toilet.

Some forms of touch which are taken for granted in some cultures, may be thought disrespectful in others. You may also need to explain religious documents and artefacts (such as the Bible, the Koran, rosaries, and statues), observances such as prayers, fasting and festivals to those from a different culture and ensure that these are respected.

Treating the person with dementia as an adult
It is important that everyone continues to treat the person as an adult, with courtesy and dignity however advanced their dementia. Try to imagine how you would like to be spoken to if you were in their shoes.

- Be kind and reassuring – do not talk down to the person as though they were a child.
- Never talk across them or over their heads as if they are not there.
- Do not talk about the person with other people while the person is present. Always include them in the conversation.
- Avoid scolding or criticizing the person – this will make them feel small. All these things will attack the probable fragile sense of self-worth of the person.
- Look for the meaning behind the words even if, on the surface, they do not seem to make much sense. The person is almost certainly trying to communicate with you about how they feel.
Focus on the remaining person’s abilities
Avoid situations in which the person is 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 encouragement; let them do things at their own pace and in their own way.
- Do things with the person, rather than for them, so that they can preserve some 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 give them plenty of praise.

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

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

Offering choice
It is important that the person is informed and whenever possible consulted about matters, which concern them. They should 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 and 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?’ rather than ‘Which jumper would you like to wear today?’

Expressing feelings
Dementia affects the thinking and reasoning part of the brain and the memory. It does not mean that the person no longer has feelings. A person with dementia will probably be sad or upset at times.

They have the right to expect that those caring for them will try to understand how they feel and to offer support rather than ignoring them or ‘jollying ‘them along’.
In the earlier stages the person may want to talk about their anxieties and the problems they are experiencing. It is important that other people do not brush these worries aside, however painful they may be, listen and show them understanding.

**Feeling valued**
The person with dementia needs to feel respected and valued for what they are now, as well as for who they were in the past. It helps if those caring are:

- Flexible and tolerant
- Prepared to take time to listen, have a chat and enjoy their company
- Able to show appropriate affection.