

# Working with dementia



*A handbook for care staff*

by Margaret MacKinlay

This project has been made possible through funding from the Millennium Commission's "After Dementia Millennium Award" scheme. It highlights how carers, relatives, friends, care staff and nursing staff can work alongside each other for the benefit of the person in care.

© Margaret MacKinlay, 2004

This is dedicated to my sister-in-law Mary.

# Booklet for care staff

This handbook is for you if you work in a long stay care setting that is home to people with dementia. It may be a hospital, residential or nursing home. It has been produced by a carer who has the experience of having a relative with dementia moving from home into a residential setting and then on to nursing home care.

The booklet aims to be a simple, easy to read, resource for staff and covers the basics of:

- What is dementia? pages 1–3
- The time around admission into care pages 4–7
- How you can help pages 7–8
- Challenging behaviour and communication pages 8–12

The following information is intended to assist you in your day to day work.

## What is dementia?

Many of the people that you help to care for each day will have dementia. This could mean that your work will be very challenging and stressful but it should hopefully also be rewarding and enjoyable.

Dementia is what happens to a person if they have any of the following illnesses:

- Alzheimer's Disease
- Vascular dementia
- Lewy Body dementia
- Others such as frontal lobe dementia and Picks disease

These illnesses cause brain cells to die off far more rapidly than is normal. How the illness affects someone will depend on which area of the brain is damaged. It is a progressive illness for which there is no cure, unlike damaged skin, brain cells cannot regrow. Nevertheless, a great deal of medical research is ongoing into causes and cures. In the people you care for you will notice many symptoms, one of the main ones being memory loss.

### **Short-Term Memory Loss**

The most common type of memory loss will be *short-term memory* loss, where people can sometimes literally not remember from one hour or minute to the next. You will no doubt see the people you are caring for not remembering that they have just eaten, not remembering where they are, perhaps not remembering where the toilet is, not remembering that they have just asked the same question several times, therefore, not remembering the answer. This is because there has been damage to the temporal lobes of the brain (located at each side of the temples) these lobes are responsible for short-term memory.

### **Long-Term Memory Loss**

Some people will surprise you at having no recollection for something that happened a moment ago but can talk at great length about things that happened as far back as childhood. This *long-term memory* usually lasts much longer than short-term memory as it is held in a different part of the brain and may not be affected until the later stages of the illness.

Memory loss is not only about remembering events; it is about being able to remember how to do things for “you”. Remembering that you need to get up in the morning, wash and dress, eat and drink, keep cool/warm, go to the toilet. All the daily tasks; cleaning the house, shopping and cooking. It also forms your identity; remembering your family, your role in your family, your likes and dislikes, your attitudes, hobbies, fears; it encompasses everything that makes you a unique individual.

## Communication

People with dementia lose the ability to communicate as effectively as before, and as they lose these abilities, behaviour will replace conventional means of communication (speaking and having a conversation).

People with dementia can become withdrawn and seem to have “no get up and go”. They may lack insight into their abilities and believe that they are fine, believe that they are still able to do most of things they could do before having dementia.

## Difficulties

The person with dementia will have been experiencing difficulties (or their family will have been experiencing difficulties looking after them) over a period of time, and the time has come when they could no longer stay in their family home or in their own home by themselves. Some of the difficulties will have been:

- Confusing days of the week
- Forgetting to turn up for appointments
- Unable to handle money
- Constantly using the phone
- Neglecting personal care
- Becoming isolated
- Frightened in their own home
- Becoming increasingly vulnerable
- Unable to go out on their own
- Forgetting the time of day and night
- Changes in behaviour

They have now come into your care (in partnership with their family and friends), as they need constant assistance.

# The time around admission into care

The time leading up to moving into care will have been extremely difficult for the person with dementia and their family members.

## **Imagine what they must feel like!**

**Think about yourself.** You can no longer stay in your own home but maybe do not fully understand why you cannot stay. You leave your familiar environment where you feel safe and comfortable and move to a place that is really frightening and confusing. Lots of



strange faces, strange smells, corridors and passageways and doors that lead to other places that you do not recognise. The routine is completely different from the one you had before. You ask to go home or say that you are going to leave but do not seem to be able to do this, plus you have these feelings that you cannot describe.

**How would you feel in this situation?**

**How would you behave?**

## **Imagine how the carer/relative must feel!**

**Put yourself in their position.** You have looked after your mother for years and she has lived with you for some time now. It has become increasingly difficult for you to meet her needs and the time comes when you admit that you can no longer cope with the demands of looking after her, yourself and perhaps your family.

**How would you feel in this situation?**

**How would you behave?**

The guilt that a carer may experience can be overwhelming. The worry that your mum will not be cared for properly makes you tense, angry and frustrated. When your mum goes into the Care Home you dread visiting because you do not know what the daily routine is, and all the fears come rushing back that she will not be cared for in the way that you cared.

One carer's feelings:

*"I had been so involved in caring for mum that when she went into a nursing home I found letting go very difficult. I could not stop thinking about her, there was no sense of relief only a large void in my life"*

Care assistant feelings in a Nursing Home:

*"Some of the relatives come in looking angry and suspicious as though they want to catch us out. It makes it difficult to approach them therefore I dread their visits"*

By "putting yourself in their shoes" you may be able to understand relatives' behaviour and through understanding be more confident in getting to know them and to deal with any questions they may ask.

How would you feel if it was your husband, wife, mum, dad, brother, sister or grand parents that have had to go into care? If you have children think of their first day away in nursery care or their first day at school – think back ; what emotions did you go through?

It is only through time that the void and the feelings of guilt pass. This is where care staff can assist the relative to be confident that their relative is in good caring hands.

## **The feelings of the person with dementia and the carer**

**How can you, as staff, help the person with dementia and their relatives in the initial settling in period?**

When you are informed that a new resident is coming to live in the “home” try to find out as much as you can about the new resident beforehand. Ask the person in charge for the “Personal Profile” to familiarise yourself with the person’s life up to that point in time. *(These forms should be available in your establishment and contain information about the person’s previous life along with any relevant medical care required.)*

If a “Personal Profile” has not been completed for various reasons, encourage the relatives to complete this. If the person has no family or friends request to take on a “Personal Profile” as a “project”. Get as much information as you can from working with the person by asking them about themselves. Many people, with encouragement, will have something to offer, to enable you to get to know their likes and dislikes and share in past memories.

**Think about yourself and ask yourself what kind of things would you want care staff to know about you to assist in your care?**

Remember this is the person’s new “home” and think back to how you felt when you moved to a new home. It takes time to settle in to a new house and the person with dementia is no different from any other person moving house, only that they may not be able to communicate how they really feel about this new “home” and continually ask to go home.

**Moving in to their new home**

- If the new resident arrives at a meal time make sure that someone is dedicated to welcoming them and their carer.
- Explain to the carer and particularly the person with dementia, the daily routine and layout of the Care Home.
- See the carer as your “partner” in caring for the person as they have the experience, knowledge and understanding of the person.
- Ask the carer “How are you today?”

- Work with them by asking if there are any aspects of the person's care that they would still like to be involved with, such as taking them out for a walk, going shopping, out for a meal, visiting friends, doing their hair, nails etc.
- Encourage the carer to still be involved in the care as this will assist the carer to adapt to their new way of life.
- Encourage the carer to visit on a regular basis and welcome help at meal times if assistance is required.
- Try to understand carers' feelings and the reasons behind them perhaps appearing "angry and suspicious".



## How you can help

- Encourage the person with dementia to continue to do things for themselves, such as, washing, dressing, tying shoe laces, eating at the dinner table with others, walking about and being active as much as possible.
- Make sure the person knows where their room is by putting their name on the door or a symbol on their room door to enable them to recognise their room.
- Include the person in the conversation and let them put their thoughts over even if it is not in relation to the conversation.
- Listen to what they are saying and talking about.
- Encourage them to be involved in social events.
- Encourage them in their hobbies and other interests.



- Offer positive information to carers about their relative by sharing news of an event or activity that they enjoyed, such as, sitting in the garden, eating ice cream, listening to music. No detail is too small.
- It is good for carers to have feedback and it helps them to realise that being “in care” means that there is still enjoyment in the life of their relative.
- Remember there will be down days as well as up days and that is part of getting to know the person and the person getting to know you.

## Challenging behaviour and communication

Some of the behaviour that people with dementia exhibit can be hard to understand and difficult to handle. Nevertheless, there are lots of ideas to assist you to manage behaviour. For example;

- Bear in mind that as the person’s ability to communicate deteriorates over time their behaviour will replace the normal means of communication.
- Look for the emotion underneath the words, facial expression and body language. What do you hear and see? Expressions of fear, happiness, anger or sadness? Always acknowledge the emotion.
  - If fear then you could say “You look frightened, may I help you?”
  - If they are happy then make a comment, “ It is so nice to see you happy today.”
  - If angry you could say, “What has upset you so much?” in a quiet calm voice. You may be told to go away but let the person calm down and try distracting them and take them away from the situation that caused the anger.

- If they are sad then say “Why are you feeling sad? Would you like to talk about how you are feeling?”
- Always remember to approach the person face to face. If seated get down to their level and speak in a normal voice
- Remember a smile goes a very long way.
- Always remember to ask the person if you may help them.
- Never shout back at them as this could lead to an aggressive outburst.

### **Constantly moving around**

- Reluctant to “settle” or sit down. People with dementia are often unable to just sit in a chair all day unless they are at the final stage of the illness. At certain times in the day they may just want to be on the move. Ask yourself is this a problem? A problem for you? People will move around for many different reasons. For example, looking for the toilet, looking for their room, boredom, need for exercise, wishing to find their way home. Discuss this “moving around” with other members of staff and the relative when they visit. It may be that it is okay for the person to be on the move. It might actually be a positive thing to keep them mobile. Trying to keep them in one place may be creating other problems, such as agitation and physical problems such as immobility, leading to urinary and chest infections.

### **Repetition**

- Remember that people with dementia cannot remember asking the same question or the answer. Try distracting them from the topic by giving them something purposeful to do, for example, folding tea towels, dusting and polishing.
- Asking for “mother” can be a common occurrence and usually indicates feelings of insecurity and fear. Try answering this with “Oh, do you miss your mother? Tell me about her.” Or acknowledge the insecurity and say “Do not worry, you are quite safe here” and try moving off the subject to another subject or activity.

## Searching and Hoarding

- Constantly looking for handbag, wallet, keys, scarf or hiding things. Understand and recognise that the person has left most of their belongings behind when they came into your care, therefore, a handbag, a wallet, keys or scarf can offer great comfort and security. You know what it is like if you lose those items yourself – absolute panic! Allow the person to keep their handbag, wallet, keys or scarf on their person along with a small amount of money in the handbag or wallet – no-one likes to be penniless. Hiding things such as glasses, food or other personal objects could be for any reason. It takes time to



understand the reasons behind the “hiding”. A favourite place to hide things or objects is a tissue box. Ask the relative if this occurred at home and how did they cope with the problem.

- Wanting to tidy up, setting or clearing the dinner table, or emptying the waste bin – let the person help. Tidying up can be very therapeutic to them. Being able to be active in setting or clearing the dinner table is comforting in that it is a task that we learn from early childhood. To someone with dementia it is a skill, like riding a bicycle, that stays in the long-term memory, encourage them to continue to help as long as possible. Supply waste bins with old newspapers, to prevent a mess, and you might find they are happy transferring the newspapers from one bin to the other.

Remember people with dementia have a lot to give and it is up to all of us to give them the dignity, respect and security they so richly deserve.

## Summary of behaviour and communication

### Behaviour

Questions to ask.

- Is the behaviour really a problem?

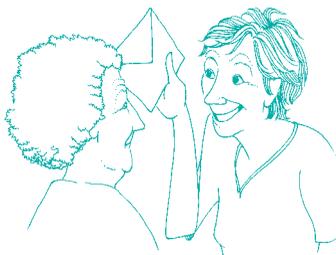
- If so, why?
- Who is it a problem for?
- How did the behaviour start?
- What was the person like before?
- If an incident occurred, did something or someone “trigger” it?
- What happened afterwards?
- How did you help resolve the problem?

By breaking down behaviour, you can often begin to know what to do about it should it occur again.

Ask the relative how did they cope with the behaviour at home? They may have tips that will work for you too. Ask if this behaviour is new, is it something that could be caused by another illness, for example, urine infection, chest infection, anaemia or thyroid problem. All of these will increase confusion and challenging behaviour. Check with the person in charge if they know of any illness. Talk to other members of staff, they may also have tips on how to resolve the problem.

## Communication

- Remember that the person can still communicate but that they will increasingly use behaviour to do this.
- Use prompts such as photographs, symbols and gestures.
- Try and keep eye contact, calm voice and body language friendly. Check your facial expression, is it matching the words that you are saying? Happy expression for good news, concerned expression for worry about someone, sad expression for sad news.
- Avoid asking too many questions.
- Talk about things that you know that the person with dementia can remember (think about short-term memory and long-term memory).



- Always include them in the conversation. Allow them to have their say.
- Do not talk over them. People with dementia may still understand what is being said but they may have lost the ability to form the words that are in their mind. This is very frustrating for them, be patient with them and encourage them to speak. Do not speak for them.
- Keep communication open with relatives and visitors.
- Remember that the relatives have a wealth of knowledge about the person that you are helping to care for now.

## “ME”

*There are still many things I can do like, walking, smiling, crying, laughing, speaking my way. I am here and I hear you speak. I have not yet gone.*

*My mind might be slowly ebbing away but deep down I know I am still Mary. You see the changes in me I do not. I have not yet gone.*

*I know the time will come when I will not remember your name but please remind me even if only for a few seconds I can say it back to you. I have not yet gone.*

*When words fail me I strike out. I do not mean to hurt you. I still have feelings but these feelings I cannot put into words. I have not yet gone.*

*Actions speak louder than words. Your help keeps me going. I have not yet gone.*

*Where have you gone? I know not where. When I call you, you do not answer. Where am I? I am not sure but in my world I feel secure. I have not yet gone.*

*I love your smile, your name is gone. I know your face and feel at peace. I have not yet gone.*

Margaret MacKinlay (compiled from Mary's words)

# Acknowledgements

It is with special thanks to the Millennium Commission's "After Dementia Millennium Award" scheme that enabled me to produce this booklet. Also a very special thanks to my husband Bill, my daughters Fiona and Alison for their encouragement. To my sister-in-law Mary, who has dementia, Mary is the light and voice behind this booklet. To Julie Miller, for being my mentor and guide whose in-depth knowledge has given me a better insight and understanding of how to help people with dementia. To The Glasgow Carers Panel who listen to me and helped us with hints and tips when looking after Mary. To my friend Rosemary Fraser who also encouraged me with this booklet. To Anne Burnside, who helped with the layout of this booklet and the illustrator, Merrill MacWilliam. Thank you all.



[www.alzscot.org](http://www.alzscot.org)

ISBN 0 948897 42 2

May 2004

Single copies free to care staff.



AN AFTER DEMENTIA MILLENNIUM AWARD PROJECT



**CARERS UK**



The After Dementia Millennium Awards are run by the Alzheimer's Society in partnership with Alzheimer Scotland and Carers UK, and are funded by the Millennium Commission with money from the National Lottery.