



**Alzheimer's Disease
International**

10/66 Dementia Research Group

Helping Carers to Care **Trainees manual**



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Helping Carers to Care

**Manual for trainees in the use of the intervention
'Helping Carers to Care'**

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About the intervention

Dementia is an illness, affecting the brain, leading to problems with memory and every aspect of thinking. It mainly affects older people. There is no cure, and sufferers become more and more disabled, eventually needing help with most basic activities. We have found that families generally do not understand what is happening to their affected relatives. Often they think that this is a normal part of ageing, and so do not seek medical help. Sometimes they are determined to try to find a cure, spending a lot of money seeing different doctors.

Their lack of knowledge and understanding about the problem leads to difficulties. Caregivers do not understand why the older person is behaving the way that they do. They do not know what the future holds. Sometimes, other family members do not understand all the difficulties they face and, far from supporting them, criticise them or blame them.

Our hope is that giving the caregivers some simple information about dementia and some useful advice on how to manage problems at home will be very helpful. This will be your role, and the purpose of this training is to enable you to carry out this task to the best of your ability.

The intervention has three modules delivered over five sessions with the family, each lasting between 30 minutes and one hour.

Session one

Module 1: Initial assessment of dementia

Sessions two and three

Module 2: Education about dementia

Sessions four and five

Module 3: Training to manage behaviour problems

Session five will also include a summary of the material covered in the programme and feedback from the family

What you will learn

You will gain knowledge and skill to work with the family in the following areas:

1 Counselling skills

How to talk to families, listen to their problems, and give advice

2 Assessment

Identifying the symptoms of dementia, and the strengths and weaknesses of the patient's family in caring for the person with dementia

3 Education

Telling the family members about dementia, its causes, typical course, and possibilities for treatment

4 Advice

Hints to the family about how to care for people with dementia

5 Training

Teaching simple ways to manage behaviour problems

6 Family counselling

Helping to heal family divisions, getting the family to work together

Course outline

The training will take two days. You will watch a training video, showing Betty, a health care worker, going through the three modules of the intervention with Rosie, a caregiver, and her sister Isobel. Your trainer will explain each of the modules of the intervention in detail. You will then practice each section of the intervention with your trainer and with your fellow trainees.

Timetable

Day one – morning	General counselling skills
Day one – afternoon	Module 1: Initial assessment of dementia
Day two – morning	Module 2: Education about dementia
Day two – afternoon	Module 3: Training to manage behaviour problems

What happens next?

At the end of the training, you will practice the intervention with a real family under the direct supervision of your trainer. Your trainer will give you detailed feedback on your performance, and will make sure that you are completely confident before you start to give the intervention on your own.

Day one: morning

General counselling skills

In your daily work, you will have had experience of talking to patients, listening to their problems and giving advice. This is 'counselling'. You probably have not given too much thought about this part of your work. However experienced, all of us can benefit from proper training in counselling skills. This is the purpose of this first morning session.

What you will learn

By the end of this session you should feel more confident about talking to caregivers. You should know how to engage the family into the intervention, and how to keep them attending the sessions. You should understand the importance of:

- listening
- understanding, supporting and sympathising
- not contradicting
- only offering advice when you have properly understood the problem

This is a very important session. What you learn here, you will apply in all the other parts of the training and, of course, when you start to use the intervention 'in real life'.

Agenda for the session

First it may be useful for each of you to talk about your experiences of counselling patients in your everyday work, what you think are your strengths and weaknesses. It may be useful to talk about your experiences (good and bad) in more detail to see what can be learnt.

Next the trainer will go over with you some key basic principles of good counselling practice. The notes on pages 5 and 6 will be useful.

Finally, in the first of several practical exercises, the trainer will get you to practice counselling him or her in an imaginary situation – probably one taken from your usual work experience.

Notes on counselling

Engaging with the family

- 1 If your intervention is to be effective, you need to first get the trust and confidence of the family. This is achieved over a number of sessions. You will need to pay attention to and listen to the concerns of the family members carefully. You should show an understanding of the family's problems. The family knows the patient and the resulting problems better than you. Do not lecture the family. Try to speak in simple and clear language.
- 2 In each family, there is usually one member who makes most of the decisions. There are families where the father may be considered the leader, but the mother may actually be making all the decisions for the family. Your intervention may prove more effective if you work with or through the leader.
- 3 Look for positive things about the family, though it may be difficult to do this. Highlight these to congratulate them on their achievement. This increases their confidence and sense of improvement. If the family does not acknowledge any positive changes, do not argue. Instead, you should repeat that changes are slow.
- 4 Provide them with opportunities to express their worries and concerns about the patient's illness. Family members feel relieved after disclosing these concerns. It also strengthens the bond between you and the family. You do not need to provide quick solutions or suggestions to their problems.
- 5 Listen to what all the family members have to say before guiding them as to how they could resolve the issue. You have to remain neutral and not take sides as this can have an adverse effect.
- 6 You will need to be flexible in your approach with the family. The family may come to you with needs different from what you may plan to approach in that session.

Counselling skills

1 Listening

Accurate listening is important for developing an effective working relationship, helping the family members to talk, and helping the family members to talk and to experience and express their feelings. You will need to show your interest and attention by:

- a) Leaning forward slightly: this indicates your involvement and encourages the person to speak.

- b) Maintaining good eye contact: do not stare, as the family member may feel dominated. Looking down or away too often may indicate tension and boredom.
- c) Appropriate facial expression: a friendly, relaxed expression, including a smile, usually demonstrates interest.
- d) Use of head nods: each head nod can be viewed as a reward to the family, giving the message that you are paying attention.
- e) Relaxed body posture: a relaxed body posture, without slumping or slouching, shows that you are listening. A stiff body posture, finger drumming, fidgeting, may indicate tension.

2 Empathy

This involves showing that you have understood the caregiver's feelings. For example, you could say:

'That must have been very upsetting for you'

or

'If that was me I would also have been very angry'

3 Reflecting back

Confirm and summarise what it is that the caregiver has told you, in slightly different words, for example:

'Just to check that I have understood you properly, you are not happy with the support you get from your brother in looking after your mother, and think that he does not understand how difficult it is for you'

or

'Am I right in thinking that your father's accusations are one of the most difficult things for you to cope with?'

4 Using silence

If you speak too much, this stops the family member talking. Keeping silent gives them space and encouragement to get more deeply in touch with their thoughts and feelings. A long silence can mean any of the following:

- a) The family member is uncommunicative
- b) They are upset
- c) They are afraid to disclose more
- d) They have finished what they want to say

Maintaining the family in treatment

Once the family attends the first session, the main task is to encourage them to continue with the sessions. Reasons for stopping include:

- a) Previous bad experiences with offers of help
- b) Conflicting or unrealistic expectations of intervention
- c) Pessimism about the outcome
- d) Family members feel blamed for the illness

If the family does not continue with the intervention they will not benefit.

It is important to find out:

- a) The family's past experience with professional help
- b) What they expect from you
- c) Any negative feelings about what can be achieved

You will have to try to give hope and explain what can be realistically expected from your intervention.

Practice session

At the end of this session, your trainer will ask you to play the role of a counsellor. Imagine a situation with which you are familiar in your everyday work, for example:

- the mother with a crying baby
- the wife with a husband who does not want to use contraception
- the husband who drinks too much

You could suggest an idea to the trainer and he or she will play the part of the patient. Show the trainer how you would approach this situation, how you would find out about the problem and what advice you would give the patient. Treat this like a real situation in your everyday work.

At the end, the trainer will ask your fellow trainees to comment on how you did, and perhaps to make suggestions. Then the trainer will give you some feedback. After this, perhaps you might like to try again to see if you can improve.

Day one: afternoon**MODULE 1 Assessment****What is the purpose of this module?**

- a) To establish whether or not the older person is likely to be suffering from dementia
- b) To find out what are the main difficulties experienced by the caregiver
- c) To see which of the modules of the intervention might benefit the caregiver

This module will be covered in the first of the five sessions with the family. You should gather this information from the principal caregiver, that is the person who is most involved with providing care for the person with dementia and who is best informed about the daily life of that person. Remember that while the principal caregiver is usually one of the family members living with the person with dementia, it may turn out to be a family member or a neighbour or friend who is living elsewhere.

What you will learn

At the end of this session you will understand the content of the assessment, and be familiar with all of the questions. You will understand the purpose of the questions; what information you are gathering, and why. In particular you will be able to:

- a) Make a basic assessment to check that the older person is suffering from dementia, and be able to identify the particular problems that the older person has
- b) Assess the type and amount of care that the caregiver is needing to provide
- c) Assess what the caregiver knows and understands about the problem
- d) Assess the role of the family as a whole; are they working together to support the caregiver or is there conflict or criticism?

Agenda for the session

First of all the trainer will go over the full assessment with you, explaining all of the questions.

Next you will watch the first section of the training video to see an example of the assessment being carried out by a health care worker.

After this you will practice the assessment and the trainer will give you feedback on your performance.

Finally the trainer will discuss with you how you might assess the role of the family, and how you might advise the family to work together more effectively.

Notes on the assessment

There are four sections in this module:

1) Screening for dementia

Three simple screening questions to identify dementia.

2) Assessing dementia

Identifying problems in performing activities of daily living, and presence of behavioural symptoms of dementia.

3) Awareness of dementia

Some questions about the caregiver's awareness and understanding of what is happening to the older person.

4) Caregiving arrangements in the home

Some questions to discover:

- a) Who are the family members?
- b) Who lives at home with the person with dementia?
- c) In what ways do they help out the principal caregiver?
- d) What behavioural problems are the family caregivers having to cope with?
- e) How burdened do they feel by caring for the person with dementia?

Going over the assessment

In the first part of the assessment, you will ask the caregiver questions about the older person to check that they really are suffering from dementia, and to get an idea of the types of problems that they have. It is very important that you:

- a) Understand all of the questions, and what it is that is being assessed. This means understanding more about the typical symptoms of dementia
- b) Understand how to ask the questions – you must ask them all, without missing anything out
- c) Understand how to score the questions

First the trainer will go over the assessment with you, explaining each of the questions. You have the assessment in your intervention pack. Make sure that you ask questions, if there is anything that you do not understand.

Watching the video

You will now watch the first section of the training video (approximately 30 minutes), in which Betty, the health care worker, goes through the assessment module with Rosie the caregiver. As you watch the video, try to score the assessment in your intervention pack according to Rosie's answers to Betty's questions. At the end of the first stage of the assessment, your trainer will stop the video to go over these scores with you to make sure that you have done this correctly.

You will now watch the end of the assessment in which Betty asks Rosie:

- a) what she understands about dementia
- b) about other members of her family, and who else helps her to care for her mother
- c) about any problems with behaviour that her mother may have

Practice session

Your trainer will now pretend to be a caregiver of someone with dementia and you will be the counsellor making the assessment. Your fellow trainees will watch and comment on how you do. At the end of the assessment try to summarise what you have learnt:

- Does the older person suffer from dementia, and why?
- What kind of help does the older person need, and why?
- What are the behaviour problems?
- How much does the caregiver understand about the problem?
- Is the caregiver under strain, and if so why?
- What help is available?
- How does the family react to the problem?
- Is the family working together well, or are there conflicts?

The most difficult part of this assessment is the role of the family. Your trainer will go over the following helpful hints with you.

Family supports

Many affected families gradually become isolated from their wider families and friends. You can ask the family members what they each do to distract themselves from the problems of living with the patient:

- Do they have contacts outside of the family whom they spend time with outside of working hours?
- Does the family approach anyone outside the immediate family at crisis times?
- What are the difficulties experienced by the family in caring?
- Are the contacts able to provide support?
- What kind of support do they provide?
- Do they offer to supervise the patient while the family goes out?
- Do they offer financial support?
- Do they advise the family as to what they should do?
- Do they listen to the problems of the family and help them emotionally to cope?

Family responses

You will need to ask the family members about how they feel about the problem:

- They may deny or have difficulties accepting that the relative has a problem
- They may get angry about the problem
- They may feel envious of others
- They may think 'why did this happen to me?'
- They make promises to cure the illness, such as 'I promise to pray everyday if he is cured of this illness'
- They feel depressed when they are no longer able to cope. The financial burdens, the older person's inability to work, stigma, etc increase these feelings.
- They continue to hope for a cure, the discovery of new medication that will improve the symptoms. This helps them to cope with their problems.

Who does what?

In every family, each member contributes in different ways. You will need to ask them questions like:

- 'Which members help in the household chores?'
- 'Who are the breadwinners?'
- 'When the family members are upset, which member do they approach to discuss their problems?'
- 'Who is the head of the family?'
- Are they meeting the expectations of other family members?

Some members may be stressed by having too many roles to play. For example, the mother may be the breadwinner, the housekeeper, the mother to the children, and the caregiver of the older person with dementia.

How do family members communicate?

- Do family members show sympathy and understanding, or do they tend to argue and criticise each other?
- Can they work through problems together, or do things tend to break down into arguments?

- Do family members feel comfortable to speak openly with each other and say what they feel?
- Are the family members extremely anxious or worried about the patient or his welfare? For example, do they make statements like; 'I worry about him all the time', 'I do not know what to do', 'I cannot cope', 'I've been so depressed since he got ill'?

Does the family work together?

- Based on your observations of the family, you should be able to assess whether the members of a family work together; have a 'we' feeling.
- The members could be emotionally over-involved or they may be uninterested and have no involvement at all. Both can be counterproductive.
- Rituals, such as eating meals together or other joint family activities, strengthen the family and marital bonds.

How does the family cope?

Ask family members how they handled crises in the past. This indicates their ability to solve problems and will hint at how they will cope with the person with dementia. Ask each family member what his or her individual contribution was.

- Who took the initiative to solve the problem?
- How did they solve the problem?
- Were they able to effectively solve the problem or did it recur?
- Was the family confused and unable to solve the problem?
- Were they able to cope?

Reviewing the video

You might now want to watch again the end of Betty's assessment of Rosie, in which Rosie tells Betty about the difficult relationships with her two sisters Cleusa and Isobel. What do you think about the family relationships, and how do you think that you might deal with these problems in future sessions?

Next session

Tomorrow morning, you will watch the second module of the video, in which you can see how Betty deals with these issues when she meets Rosie with her sister Isobel.

Day two: morning**MODULE 2 Information about dementia****What is the purpose of this module?**

The purpose of this module is to educate family members about dementia. This will make them better prepared to look after the person with dementia, and for the changes they will need to make in the future. Four areas are covered in the module:

- 1) Dementia (a general introduction to the illness)
- 2) Dementia – what can I expect? (the typical course of the dementia syndrome)
- 3) What causes dementia?
- 4) Care and treatment for people with dementia (general tips for caregivers)

This module could be covered in two sessions. The first session could include sections 1 to 3. The fourth section could be covered in the second session. It is important that as many as possible of the family members involved attend these opening sessions, not just the principal caregiver. This is because:

- a) Sharing the caregiving roles will ease the strain on the principal caregiver.
- b) Even if the other family members are not directly involved in providing care, it is important that they recognise what it is that the caregiver is dealing with.

What you will learn

You will need to understand some basic information about dementia, both the typical symptoms, and the course – that is how the illness begins and then how it develops as the symptoms become more severe. Of course, no two cases are the same, and so you will need to learn how to fit the information that you give to suit the situation of the particular caregiver and family that you are educating. The information that you give will change according to:

- The stage of dementia (early, middle or late)
- What the family knows already, in particular any misconceptions that they may have
- The educational level of the caregiver

You need to understand that the material in this module is a guide only – you should not simply read the information out, but instead you need to react to the family's responses.

Agenda for the session

First of all the trainer will talk to you about dementia, how the illness starts and how it develops. It will be helpful if you think about older people that you know

who may have been suffering from dementia. Talk about these cases with the trainer and with the others in the group, and see if you can understand what the key symptoms were for these patients.

Next the trainer will go over the content of this module in more detail, explaining each of the sections, in particular the three stages of dementia, and the general tips provided for caregivers.

Next you will watch the second section of the training video in which the health care worker gives information to a caregiver and her sister.

Finally you will practice this module in pairs. One of your colleagues will pretend to be a caregiver of an older person with dementia and you will practice educating them about the problem. The trainer will give you feedback.

Notes

The notes for this section are in the materials for this module, which you will present to the caregiver in the intervention. If your trainer has prepared a series of picture-based stories (cartoons) in addition to the written material, then you should go over these as well, and discuss the particular challenges of educating family caregivers who may not be able to read.

Day two: afternoon**MODULE 3 Behavioural symptoms of dementia****What is the purpose of this module?**

The purpose of this module is to educate family members about ways of dealing with behaviour problems linked to dementia. The idea is that you will already have identified what are the particular problems with which the family is struggling to cope. You will then focus on these problems.

This module could be covered in one or two sessions, depending on the number of problems identified. Try not to load too much information on the family in each session. For this module it is mainly important that those directly involved in providing care should attend. It may also be useful for other family members to attend, again so that they can understand better what goes on at home.

What you will learn

At the end of this session you will understand:

- What are the typical behaviour problems that can be linked to dementia
- How and why these can be a particular problem for caregivers and their families
- How to make a careful assessment of the behaviour problems before making suggestions
- Different strategies that can be suggested to caregivers to manage these problem behaviours
- The need to fit your suggestions to the particular problems, and to the home and family circumstances. Again the suggestions in the intervention module are a guide only; not all of these suggestions will be suitable for every family
- The need to respect the family and the tactics that they have come up with to deal with the problem. They are the experts; they have been dealing with the problem day in day out, and you are new to the situation

Agenda for the session

First the trainer will go over the different types of behaviour problems commonly linked to dementia, and will discuss with you the suggestions for managing them, which are included in the intervention module.

Next, you will watch the third section of the training video and see the healthcare worker assess three behaviour problems and make suggestions to the caregiver.

Finally you will practice counselling the caregiver. The trainer will play the part of the caregiver, and will explain to you the background to the case; information about the person with dementia and the behaviour problems that the caregiver is having to manage.

Notes on the third module

The third module covers simple behavioural strategies to overcome distressing symptoms. Caregivers in distress may sometimes not think of simple solutions to problems. Providing behavioural strategies can help them to overcome distressing symptoms. The third module gives information in bullet points and this can be given to the family. Only relevant information sheets are given to the family.

It is most important that you do not simply read out the suggestions provided. You need:

- First to listen to the caregiver talk about the problems, and find out about their techniques for managing them
- To sympathise with the caregiver; show that you understand how difficult this is for them, and give them praise for the good job that they are doing
- To come up with suggestions that may suit their particular circumstances

Behavioural strategies for the following symptoms are discussed in Module 3:

- 1 Personal hygiene
- 2 Dressing
- 3 Toileting and incontinence
- 4 Repeated questioning
- 5 Clinging
- 6 Aggression
- 7 Wandering
- 8 Loss of interest and activity

Watching the video

In the third section (module 3) of the training video, Betty counsels Rosie about three behaviour problems – problems with bathing, repeated questioning, and incontinence. Pay careful attention to what it is that Betty is doing:

- She assesses the problem:
 - How often does it occur?
 - When does it occur; is there a pattern?
 - What happens before, during and after?
- She shows sympathy and understanding
- She doesn't contradict the caregiver, or tell her she is doing things wrong

- She doesn't pretend to have all the answers
- She tries to come up with simple, helpful suggestions, only at the end of this process

Practice session

The trainer will play the part of the caregiver and will introduce the problem to you. You will play the part of the health care worker. Watch carefully when your fellow trainees are doing this. Try to note what they are doing well, and to make suggestions about how they could do better. What do you think of the suggestions that they have come up with? Can you think of some better suggestions? Think not only about the main caregiver, but also how the rest of the family and other significant persons could be made more aware of the problem and be more supportive.

The following are some examples of scenarios that the trainer may suggest that you use in this practice session.

Vignette 1

Mrs X is 75 years old and has been showing signs of dementia for the last three years. The main problem experienced by her family at the moment is that she gets aggressive from time to time. This happens in two main contexts; when her daughter is trying to persuade her to take a bath, and at nighttime when she tends to get up from her bed and to wander about the house and (occasionally) out into the street. When her family members try to persuade her back into the house or back to bed she insists that she is going to find her babies and gets aggressive and violent if pressured to return.

Vignette 2

Mr Y is 83 years old. He is widowed and lives with his son, daughter-in-law and their three children. The son's two brothers and daughters live near by. He is incontinent, wanders anxiously around the house and needs near constant supervision. The daughter-in-law complains that she gets no help from other family members. One brother insists that she mistreats her father-in-law. The daughter-in-law has had to give up her part-time work at a local factory to care for Mr Y. She says she feels desperate and sees no way out of their current difficulties. She would rather be dead than continue as things are.

Vignette 3

Mrs Z is 78 years old. She has suffered from dementia for five years. For the last year she has seemed very apathetic and withdrawn. She sits in a

chair or lies in bed, and needs to be prompted to wash, eat and go to the toilet. She scarcely speaks and it is almost impossible to engage her in conversation. She used to enjoy ... [*insert here some typical local pastime or activity*].

Vignette 4

Mr A is 73 years old. He lives with his wife, daughter and son-in-law. He began having memory problems three years ago. Now, he loudly accuses his wife of having an affair with his son-in-law to the outrage of his family and the embarrassment of their neighbours. He also insists that his son-in-law wants him dead and is trying to poison him. Meal times are therefore very problematic. The accusations get worse when, frequently, he drinks heavily.

Vignette 5

Mrs B is 78 years old. She lives with her husband and her two daughters live nearby and help when they can. She cannot bear to be parted from her husband, and cries and screams when she is left alone. When she is with him she follows him around the house, constantly asking him questions: 'Are the children ready for school?', 'Have you had your lunch?', 'Have we got the shopping, I must go to the market?'. He always tries to answer her, but she keeps on asking the same questions over and over again. It drives him crazy; he yearns for time on his own and feels that he cannot cope any longer.

What happens next?

After the two day training, you should be much more confident about carrying out the intervention in real life. However, it is important that you practice the intervention with the trainer overseeing what you do. The trainer will accompany you, and will, at the end of each session, offer advice on how you have done and some suggestions for improvement.

Only when you and your trainer are fully confident that you are properly trained should you attempt to work with caregivers and their families on your own. Even then you may well need to speak with the trainer to get further advice on dealing with difficult problems.



**Alzheimer's Disease
International**

Alzheimer's Disease International
64 Great Suffolk Street
London SE1 0BL
UK
Tel: +44 (0)20 7981 0880
Fax: +44 (0)20 7928 2357
Email: info@alz.co.uk
Web: www.alz.co.uk