



**Alzheimer's Disease
International**

10/66 Dementia Research Group

Helping Carers to Care

Trainers manual



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Helping Carers to Care

**Manual for training community health workers
in the use of the intervention 'Helping Carers to Care'**

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Curriculum

Training community health workers for the 10/66 caregiver intervention 'Helping Carers to Care'.

The aim is to enable the trainee to acquire knowledge and skill to work with the family in the following areas:

- 1) Generic counselling skills
- 2) By simple assessment to identify dementia cases in the community
- 3) To identify the resources and problems experienced by the patient's family in caring for the person with dementia
- 4) To educate the family members about dementia, its causes, typical course, and possibilities for treatment
- 5) To educate the family members about general caregiving strategies
- 6) To teach simple strategies to caregivers to better manage specific troublesome symptoms
- 7) To maximize the function of the family as a united caregiving unit

The training is delivered over two days.

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

At the end of the training, each trainee should practice the intervention in the field on a real family under the direct supervision of the trainer with detailed feedback on their performance.

Day one: morning

Notes on counselling

General principles for the intervention

The trainer should first go over this material, and then get the trainees to practice what they have learnt in a context with which they are familiar. For example, if they work primarily in the area of child and maternal health, the trainer could role play the part of a mother whose baby will not stop crying, or whose husband will not allow her to use contraception. Make sure, as a minimum, that the trainee learns to listen first, to empathise, and to tailor his or her advice to the particular situation of the mother.

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 had planned 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

Now try the role playing activities.

You will play, for example:

- The mother with a crying baby
- The wife with a husband who will not use contraception
- The husband who drinks too much

Ask the health care worker trainee to find out about the problem and then counsel you. Make sure that they:

- a) Ask about the problem first
- b) Listen
- c) Empathise
- d) Don't contradict
- e) Only make suggestions at the end, and that they base these on what has emerged during the session

Get their fellow trainees to say what they thought was good and bad about the health care workers approach. Get them to make alternative suggestions. Then give your feedback to the health care worker. If they have done it badly then ask them to repeat the exercise taking into account the feedback from you and their colleagues.

You could watch the trainer's video for hints as to how to run this session.

Day one: afternoon**MODULE 1 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 about the disease.

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?

Review the assessment in detail

The three screening questions and the subsequent assessment have to be explained in detail. The trainer must explain to the trainees what each item assesses and its significance for the diagnosis of dementia. The trainer must explain to the trainees not to 'explain away' symptoms and not to skip questions under any circumstance.

Watch the video

Now show 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. Ask the trainees to score the interview as it is played, and afterwards go through the scoring with them to check that they have done it properly and that they understand the significance of Rosie's responses.

Practice session

The trainer should now facilitate 'mock interviews' for the trainees. The mock exercises develop the trainees' interview and assessment skills. One trainee can be the interviewer and the trainer can 'play' the caregiver. All of the trainees should participate as interviewers. While one is interviewing the others should watch and comment on their performance. At the end of the interview the interviewee and the others should summarise what has been learnt from the assessment.

- Does the older person suffer from dementia, and why?
- What are the functional impairments?
- What are the behavioural problems?
- How much does the caregiver understand about the problem?
- What are the sources of strain for the caregiver?
- What help is available?
- What strains exist within the family?

The most demanding part of this assessment for the health care worker is likely to be the section that addresses family supports and family responses to the condition. The trainer should go over the following scenarios with the trainees.

Family supports

Many affected families gradually become isolated from their 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 aside 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?

Review the video

Review the final stage of the assessment section of the training video (first module) in which Rosie tells Betty about the difficult relationships with her two sisters Cleusa and Isobel. Ask trainees to comment on the family dynamics, and also how they think they should deal with this in subsequent sessions.

Next session

You can explain to the trainees that at the beginning of the next section of the training video (second module) they will see how Betty deals with these issues when she meets Rosie with her sister Isobel.

Day two: morning**MODULE 2 Information about dementia**

The purpose of this module is to educate family members, in general terms, about dementia. The trainees need to use the materials provided but should tailor this information a little to the family's needs.

What is dementia?

In order to educate caregivers about 'what is dementia', clearly the health care workers need to have a working knowledge of this area themselves. All of the trainees should first have gone through the training for health care workers as 'casefinders'. Therefore they should already have a basic understanding of what dementia is. However, it is useful now to revise this material, which focuses on the presenting symptoms of dementia, and to extend this to include the typical course of dementia.

We would suggest that a useful way to do this would be to get the trainees to talk about their experience of contact with people with dementia. This could come from the casefinding exercise, from older people that they have encountered in their work, or possibly, neighbours, friends or family. Ask any trainees who have direct experience to describe how the problem started, and how it developed. Use this to identify typical symptoms and course.

Review of the intervention material

Now go over the material that is provided for the health care workers, to educate the caregiver. Make sure that they understand that this is a fairly comprehensive list of symptoms which may occur. All cases are different, there is no 'typical' case. The course may vary considerably. The typical duration, to death, is 6 to 7 years, but individuals may survive for shorter, or much longer periods than this.

Indicate to them that they should present the material interactively, trying to ascertain which of the problems described apply, and which do not apply, to the older person looked after by the caregiver.

They should also attempt to work out, with the caregiver, which of the stages of dementia, early, middle and late, most closely fits the situation of the older person.

Stress that when an older person suffers from early dementia, it may be counterproductive (that is, frightening and alarming) to discuss the symptoms of the late stage. These may be some years off, and of course the older person may die of other causes before they reach this stage.

Modelling

Play the second module section of the training video (30 minutes), showing Betty giving information about dementia to Betty and Isobel.

The trainer should now discuss how this information might be delivered to a real caregiver. Consider in particular the needs of caregivers with differing levels of education, and with different baseline knowledge and understanding of the problem.

Practice

Trainees should then split into pairs and administer this section of the intervention to each other, under the trainer's supervision.

Day two: afternoon**MODULE 3 Behavioural symptoms of dementia**

The third module covers simple behavioural strategies to overcome distressing symptoms. Carers 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.

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

Modelling

The trainer should go over each of the behaviours in turn, describing the nature of the behavioural problems and their origins, together with general tips that may be helpful to the family.

Now show the third section (module 3) of the training video, in which Betty counsels Rosie about three behaviour problems – problems with bathing, repeated questioning, and incontinence.

Practice

The trainees can do a role-play to practice this part of the intervention. The trainer role plays the part of the caregiver in each of the following scenarios. Each trainee in turn plays the part of the intervention worker. At the end of each role play, the trainer and the other trainees comment on the efforts of the trainee, seeking to identify useful tips that might have been offered. In each of these examples, the trainees should be encouraged to think not only of the main caregiver, but also how the rest of the family and other significant persons could be made more aware of the problem and more supportive.

You may consult the trainer's video for hints as to how to run these practice sessions.

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 5 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.

Consolidation

After the two day training, each trainee should be directly supervised by the trainer in delivering the intervention on a trial basis to a 'dummy' family; a real caregiver not to be included in the Randomised Controlled Trial (RCT).

The trainer should give detailed feedback on the performance of the trainee at the end of each session.

You should not allow any trainee to participate in the Randomised Controlled Trial until you are satisfied with their performance in these dummy sessions. If their performance is inadequate then go over some of the basic training with them again, and try them out under supervision with another 'dummy' family.



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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