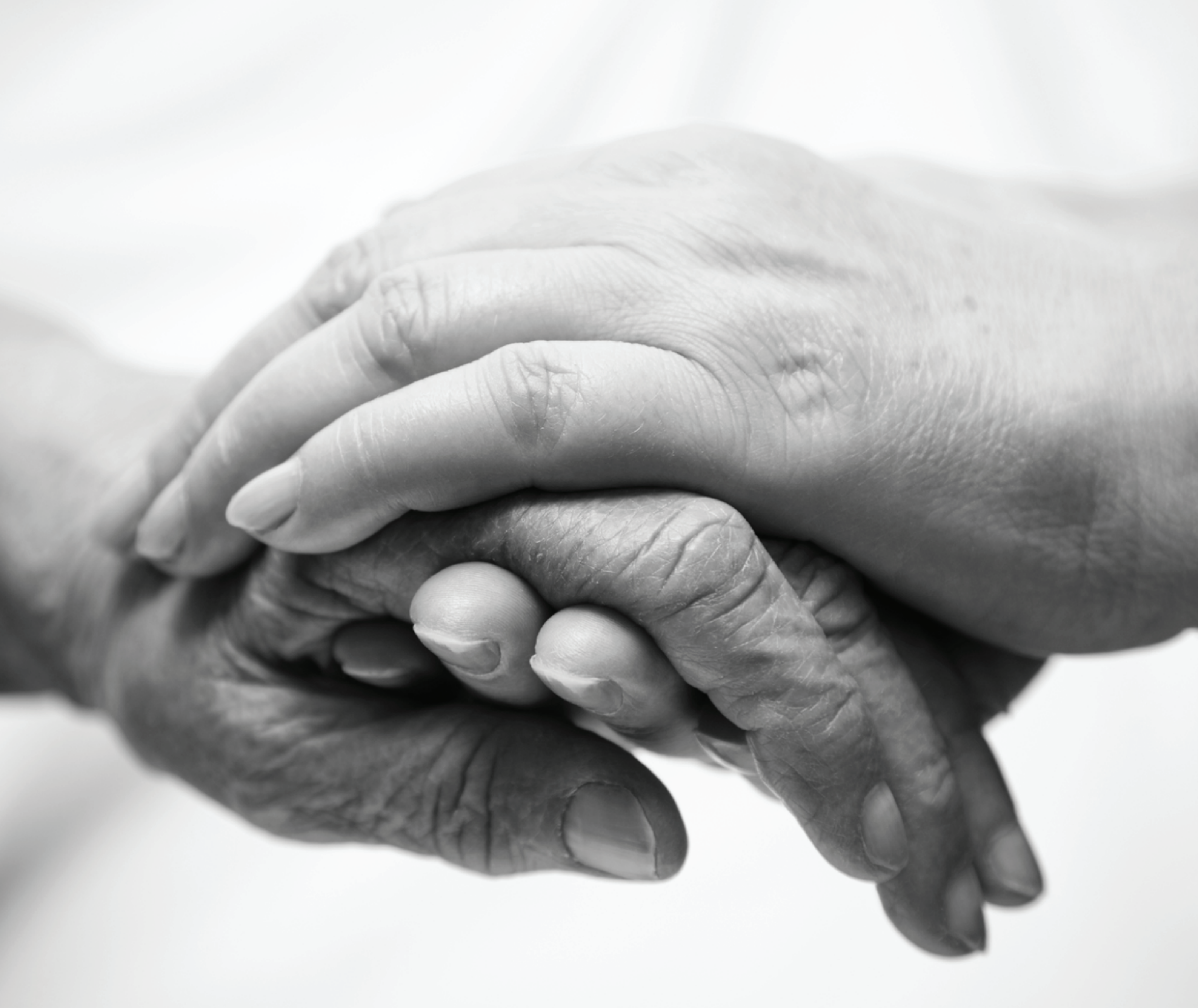
Alzheimer's Disease
International

10/66 Dementia Research Group

Helping Carers to Care

Training modules



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10/66 Dementia Research Group

Helping Carers to Care

Modules for use by community health workers in the intervention 'Helping Carers to Care'

Contents

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HELPING CARERS TO CARE

MODULE 1

Initial 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

How will I cover this module?

This module could be covered in the first session.

Who should attend this session?

You should gather this information from the main 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 main 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 is the content of this module?

There are four sections to this module:

1 Screening for dementia

Three simple questions to see whether it is likely at all that the person suffers from dementia. If the answer to all three questions is ‘no’ then if there is a problem, it may not be dementia.

2 Identifying dementia

Some more questions about the abilities and daily life of the older person. At the end of this section you simply add up the score from all of the questions (including the first three) and from this you will have a reasonably clear idea of whether or not the older person suffers from dementia. You can also use the caregiver’s answers to these questions to summarise the main problems that they are facing.

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?

SECTION 1 Screening for dementia

Ask these questions and tick the answers.
Add up the ticks in each column and multiply by
the score factor for that column to get the total scores.

	Score factors	
	0	1
	No	Yes
Have you seen a change in her daily activities in the past several years?	☐	☐

If Yes, please ask the carer for some examples and write them down here

	No	Yes
Has there been a general decline in her mental functioning?	☐	☐

If Yes, please ask the carer for some examples and write them down here

	No	Yes
We all have slight difficulties in remembering things as we get older, but has this been a particular problem for her?	☐	☐

Total ticks in each column	☐	☐
Multiply by the score factor	x 0 =	x 1 =
Total scores for this page	0	☐

These first three questions will give you an indication of whether dementia is likely to be a problem for the older person. Remember, though, that even if the carer answers 'no' to all three questions, they may be minimising the problem, or seeing it as a normal part of ageing. Carry on anyway, to ask the remaining questions. This should clarify whether dementia really is a problem, as well as identifying any difficulties that the older person has with carrying out important daily activities.

SECTION 2 Identifying dementia

Ask these questions and tick the answers.
Add up the ticks in each column and multiply by
the score factor for that column to get the total scores.

	Score factors		
	0	**½**	**1**
	No	Sometimes	Yes
Does she forget where she has put things?	☐	☐	☐
Does she forget where things are usually kept?	☐	☐	☐
Does she forget the names of friends?	☐	☐	☐
Does she forget the names of members of the family?	☐	☐	☐
Does she forget what she wanted to say in the middle of the conversation?	☐	☐	☐
When speaking does she have difficulty saying the right words?	☐	☐	☐
Does she use the wrong words?	☐	☐	☐
Does she tend to talk about what happened long ago rather than the present?	☐	☐	☐
Does she forget when she last saw you?	☐	☐	☐
Does she forget what happened the day before?	☐	☐	☐
Does she forget where she is?	☐	☐	☐
Does she get lost in the community?	☐	☐	☐
Does she get lost in her own home, for example, finding the toilet?	☐	☐	☐
Does she have difficulty performing household chores that she used to do, for example, preparing food or boiling a pot of tea?	☐	☐	☐
If Yes, was that mainly due to physical disability?	*If mainly due to physical disability, then tick 'No'*		
Total ticks in each column	☐	☐	☐
Multiply by the score factor	x 0 =	x ½ =	x 1 =
Total scores for this page	0	☐	☐

	Score factors			
	0	**1**	**2**	**3**
Does she have difficulty feeding herself?	Eats cleanly with proper utensils ☐	Eats messily with a spoon only ☐	Simple solids such as biscuits ☐	Has to be fed ☐
If Yes, was that mainly due to physical disability?	*If mainly due to physical disability (for example difficulty feeding because of a stroke causing a paralysis of one side of the body) tick 0: Eats cleanly with proper utensils*			
Does she have difficulty dressing?	Dresses herself ☐	Occasionally misplaces buttons etc ☐	Wrong sequence, commonly forgets items ☐	Unable to dress ☐
If Yes, was that mainly due to physical disability?	*If mainly due to physical disability (for example difficulty fastening buttons because of arthritis in the fingers) tick 0: Dresses herself*			
Does she have difficulty using the toilet? Does she wet or soil herself?	No problems ☐	Occasionally wets bed ☐	Frequently wets bed ☐	Doubly incontinent ☐
If Yes, was that mainly due to physical disability?	*If mainly due to physical disability (for example difficulty getting to the toilet because of difficulty walking) tick 0: No problems*			

Total ticks in each column	☐	☐	☐	☐
Multiply by the score factor	x 0 =	x 1 =	x 2 =	x 3 =
Totals for this page	**0**	☐	☐	☐

	Score factors		
	0	**1**	**2**
Has there been a loss of a special skill or hobby she could manage before?	No ☐	Yes ☐	
Have you noticed a change in her ability to think and reason?	No ☐	Yes ☐	
Has there been a change in his/ her sleeping pattern over the last year?	No ☐	Yes ☐	
Does she have difficulty in adjusting to a change in her daily routine?	No ☐	Yes ☐	
Has there been a change in her ability to handle money?	No difficulty ☐	Some difficulty ☐	Cannot handle money ☐
Total ticks in each column	☐	☐	☐
Multiply by the score factor	x 0 =	x 1 =	x 2 =
Totals for this page	0	☐	☐

Now add up the total score for all four pages, including the three questions that you asked at the beginning.

Total score page 3	☐
Total score page 4	☐
Total score page 5	☐
Total score page 6	☐
Total score	☐

- If the score is 5 or below then the person probably does not have dementia
- If the score is between 5½ and 8 then the person probably does have dementia, but you will also need to consider the possibility that depression may have led to reduced activity
- If the score is 8 or more then the person almost definitely does have dementia

List here all of the problems with thinking and memory, and all of the problems with daily activities that you have identified.

Problems with thinking and memory

Problems with daily activities

Now discuss your findings with the caregiver.

You will find the questions on the next page useful.

SECTION 3 Awareness of dementia

We have been talking about problems with thinking and memory, and also about problems with everyday activities. You have told me that she has recently developed problems with ………

(Read out the problems you have listed on the previous page)

What or who do you think is the cause of these problems?

Write the answer here. Give an account, as full as possible, of the answer that you are given.

Do you have any idea as to what is going to happen to her in the future? For instance are you hopeful that you will find a cure?

Do you think that things will in general, get better, get worse, or stay the same?

What do your family members think is the problem?
Are they sympathetic/ understanding/ supportive, or not?

What do neighbours and others in your community think is the problem?
Are they sympathetic/ understanding/ supportive, or not?

Ask the following questions if there is a local word commonly used by ordinary people to describe a dementia like syndrome.

	No	Yes
Have you heard of dementia?	☐	☐
Do you think that she may be suffering from dementia?	☐	☐
Have you considered that an illness of some kind affecting the brain may have caused her problems?	☐	☐
Have you heard of an illness called dementia, or Alzheimer's disease?	☐	☐

If Yes to any of these questions…

What do you understand by this?

Write the answer here. Give an account, as full as possible, of the answer that you are given.

At this point, explain to the carer that you feel, from the answers that she/he has given you, that it is probable that she suffers from dementia.

Give some brief information, using the materials that you have been given

- Although dementia mainly affects older people it is not the same as ageing, it is an illness
- Dementia is an illness, like any other, but affecting the brain
- The older person with dementia cannot help their behaviour
- There is no cure
- One can expect further deterioration over time
- However, there is much that can be done to help
- Support from the family is crucial

Other family members will need to have the problem explained to them.

SECTION 4 Caregiving arrangements in the home

Who lives in this house?

Write down their names and ages, their occupation, and their relationship to the person with dementia (for example, son, granddaughter, etc.)

Name	Relationship	Age	Occupation

Which of these persons is involved in providing care? What do they do?

Describe the household care arrangements here.

Which other family members or family friends have close links with the family?

Name	Relationship	Age	Occupation

Which of these people is involved in providing care? What do they do?

Describe these other care arrangements here.

For how long can she be left on her own? __________ hours

I am now going to ask you about some of the problems that families and others caring for people with dementia can experience. Which of them apply to you?

	No	Yes
Do you find it difficult to encourage her to wash and bathe herself properly and to keep clean, or do you have difficulties helping her to do this?	☐	☐

If Yes, describe here

	No	Yes
Does she find it difficult to get dressed, or does she not dress herself properly, or do you find it difficult sometimes to help her get dressed?	☐	☐

If Yes, describe here

	No	Yes
Is she sometimes incontinent, or does she sometimes find it difficult to find or use the toilet appropriately?	☐	☐

If Yes, describe here

	No	Yes
Does she tend to ask you the same question over and over, or call out repeatedly?	☐	☐

If Yes, describe here

	No	Yes
Does she follow you around everywhere and resist being left on her own, so that it is difficult for you to get things done?	☐	☐

If Yes, describe here

	No	Yes
Is she sometimes agitated and angry, does she shout, or even hit out at you or others?	☐	☐

If Yes, describe here

	No	Yes
Does she tend to wander off, so that you are worried that she will go outside of the house or get lost when you are both out together?	☐	☐

If Yes, describe here

	No	Yes
Does she show a lack of interest in things? Does she tend to just sit around? Do you think she is underactive?	☐	☐

Overall burden

Overall, how burdened do you feel caring for your relative?

Tick one option below

No burden ☐

Mild burden ☐

Moderate burden ☐

Severe burden ☐

Financial Issues

Many families lose money, or have to spend more money providing care for an older person. What are the extra costs which you have to meet ?

Write in the amounts below

	Amount spent or lost per month
Medicines	
Medical consultations	
Paid day time or night time care	
Laundry	
Have you or anyone else had to give up work, or cut back on work to provide care for them? If so, how much income have you lost?	
Any other costs of care	
TOTAL COSTS	

How much family income do you have to meet these extra costs?

How much financial strain are you under because of these extra costs?

Tick one option below

No strain ☐

Mild strain ☐

Moderate strain ☐

Severe strain ☐

Are you aware of any help available locally for older people?

This will vary according to what is available in the district where you are working. In general you should discuss, and provide appropriate information about:

1. Primary health care services
2. Any specialist health care services for people with dementia
3. Any voluntary organisations, such as the local branch of the Alzheimer association
4. Any day time or night time home care or home nursing
5. Any disability benefits, for which people with dementia might be eligible, and how to apply for them

For each of these services, if they exist, you should give some basic information about what they may be able to provide, how they can be accessed, and any costs that are likely to be involved.

2

HELPING CARERS TO CARE

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 meet the needs of the person with dementia, and for the adaptations and changes they will need to make in the future.

How will I cover this module?

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.

Who should attend these sessions?

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, and

b) Even if the other family members are not directly involved in providing care, it is important that they recognise and understand what it is that the principal caregiver is dealing with.

What is the content of this module?

There are four sections to this module:

1 Dementia

This is a general introduction to the illness.

2 Dementia – what can I expect?

This covers the typical course of the dementia syndrome, including the types of symptoms and problems that the caregiver might expect at different stages in the illness.

3 What causes dementia?

Little is known of the causes of dementia. This section gives some basic information, and can be used particularly to deal with any myths or misconceptions.

4 Care and treatment for people with dementia

The first part of this section considers the role of local formal services. Firstly it stresses the importance of diagnosis. Other than this, the content of the first part of the section will need to be carefully tailored to the availability of support services locally. The second part of the section stresses that much can be done by the family caregivers to improve the quality of life of the person with dementia, and to reduce their strain.

SECTION 1 Dementia

Explaining dementia

Dementia is an illness recognised by doctors all over the world. When someone is given a diagnosis of dementia, it is because that person shows clear signs of problems with memory, thinking and behaviour.

Dementia has several causes. Of these Alzheimer's disease is by far the most common, accounting for nearly three quarters of all cases.

Explaining Alzheimer's disease

Alzheimer's disease (sometimes shortened to AD) attacks the parts of the brain that control thought, memory and language. The disease comes on gradually and decline is usually slow. As yet, although we understand a lot about the process, the underlying cause of the disease – why one person should be affected and another should not – is unknown. Unfortunately there is no cure.

Alzheimer's disease is named after Dr Alois Alzheimer, who in 1906 described changes in the brain tissue of a woman who had died of an unusual mental illness. These changes are now recognised as the characteristic abnormal brain changes of Alzheimer's disease.

Alzheimer's disease affects all groups in society; men, women, rich people and poor people, and people in all countries of the world. Although Alzheimer's disease is more common among older people, it is an illness, and quite different from normal ageing. Younger people can also be affected.

SECTION 2 Dementia – what can I expect?

How are people with dementia affected by the illness?

Dementia affects each person in a different way. Its impact can depend on what the person was like before the disease; their personality, their lifestyle, their physical health.

The problems linked to dementia can be best understood in three stages:

1) **Early stage** – first year or two

2) **Middle stage** – second to fourth or fifth years

3) **Late stage** – fifth year and after

These times are given as guidelines only – sometimes people can deteriorate quicker, sometimes more slowly. Unfortunately, dementia reduces the lifespan of affected people. Somebody with dementia can expect to live for roughly 5-7 years after the beginning of the illness. Again, of course, some may live for longer, and some may live for shorter times because of some other serious health condition.

It is important that you explain to the caregiver that not all persons with dementia will display all of the symptoms listed in the next section. Nevertheless, going through the stages should help caregivers to be aware of potential problems and to allow them to think about future care needs.

The three stages of dementia

1 Early stage

The early stage is often overlooked. Relatives and friends (and sometimes professionals as well) see it as 'old age', just a normal part of the ageing process. Because the onset of the disease is gradual, it is difficult to be sure exactly when it begins. The person may:

- Have problems talking properly (language problems)
- Have significant memory loss, particularly for things that have just happened
- Not know the time of day or the day of the week
- Become lost in familiar places
- Have difficulty in making decisions
- Become inactive and unmotivated
- Show mood changes, depression or anxiety
- React unusually angrily or aggressively on occasion
- Show a loss of interest in hobbies and activities

2 Middle stage

As the disease progresses, problems become clearer and more restricting. The person with dementia has difficulty with day-to-day living and:

- May become very forgetful – especially of recent events and people's names
- Can no longer manage to live alone without problems
- Is unable to cook, clean or shop
- May become extremely dependent on their family and caregivers
- Needs help with personal hygiene, that is, toilet, washing and dressing
- Has increased difficulty with speech
- Shows problems with wandering and other behaviour problems such as repeated questioning and calling out, clinging, disturbed sleeping
- Becomes lost at home as well as outside
- May have hallucinations (seeing or hearing things which aren't really there)

3 Late stage

This stage is one of near total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious. The person may:

- Have difficulty eating
- Be incapable of communicating
- Not recognise relatives, friends and familiar objects
- Have difficulty understanding what is going on around them
- Be unable to find their way around in the home
- Have difficulty walking
- Have bladder and bowel incontinence
- Display inappropriate behaviour in public
- Be confined to a wheel chair or bed

SECTION 3 What causes dementia?

For any one person, it is not possible to answer the question, 'Why has this person developed dementia?'.

In general, there is no single cause.

- There is a slight tendency for dementia to run in families. However the extra risk if one of your family members is affected is very small, so you should not be too concerned about this. Lifestyle factors also certainly play a part. It is important to stress that there is no family link whatsoever to mental illnesses in earlier life.
- There is some evidence that health problems like high blood pressure and diabetes may be linked to dementia, so it is important to have these problems treated.
- Healthy lifestyles, not smoking, having a good diet and taking exercise may all play a role in preventing dementia, so this is another reason to keep healthy throughout your life.

There are some common myths about dementia.
It is not generally caused by or related to:

- Under-use or over-use of the brain
- Old age; it is not a normal part of the ageing process
- Mental illnesses
- Sexually transmitted diseases
- Other infections
- Aluminium or other metals

SECTION 4 Care and treatment for people with dementia

Local health and social care services

What services are available?
For each of the following services, if they exist, you should give some basic information about what they may be able to provide, how they can be accessed, and any costs that are likely to be involved.

1) Primary health care services
2) Any specialist health care services for people with dementia
3) Voluntary organisations, such as the local branch of the Alzheimer association
4) Any day time or night time home care or home nursing
5) Any disability benefits, for which people with dementia might be eligible, and how to apply for them

Why is a diagnosis so important?
Early diagnosis is helpful so that the caregiver can be better equipped to deal with the disease and to know what to expect. A diagnosis is the first step towards planning for the future.

There is no simple test to make a diagnosis. The diagnosis of Alzheimer's disease is made by taking a careful account of the person's problems from a close relative or friend, together with an examination of the person's physical and mental state. It is important to exclude other conditions or illnesses that can cause memory loss. Your doctor may be able to help with this. This might involve blood and urine tests, a physical examination, and testing for raised blood pressure.

Is there treatment?
At the moment there is no cure for dementia.

However there is a great deal that can be done for the person with dementia as well as things to ease the strain on you, the caregiver. Consult your doctor, social worker or other health professional for more information. See also the tips that we have provided on the next sheet.

There are now some drugs available in some countries for people with mild to moderate dementia. These drugs are not a cure but may help some people with some of the symptoms of dementia. Caregivers should contact their nearest Alzheimer association or physician for more information.

Useful tips for caregiving in the family home

Caregiving can be very difficult at times. However, there are ways to deal with the situation. Here are some general tips that have worked for other caregivers:

- Establish routines…
- …but keep things normal
- Keep it simple
- Encourage independence
- Maintain dignity
- Avoid confrontation
- Keep your sense of humour
- Make safety important
- Encourage fitness and health

Establish routines… A routine can decrease the decisions that need to be made, and bring order and structure into an otherwise confused daily life. A routine may help the person with dementia to feel secure.

…but keep things normal Although a routine can be helpful, it is important also to keep things as normal as possible. As much as the dementia will allow, try to treat the person as you did before the disease.

Keep it simple Try to make things simple for the person with dementia. Don't offer too many choices.

Encourage independence The person should stay as independent as possible for as long as possible. Encourage them to do as much for themselves as possible. It helps to maintain their self-respect and decreases the strain on you, the caregiver.

Maintain dignity Remember that the person you care for is an individual with feelings. What you and others say and do can be disturbing for them. So, for example, avoid discussing their condition in their presence.

Avoid confrontation Any type of conflict causes unnecessary stress for you and the person with dementia. Avoid drawing attention to things that go wrong and stay calm. Becoming upset can only make the situation worse. Remember it is the disease, it is not their fault.

Maintain a sense of humour Laugh with (but not at) the person with dementia. Humour can be a great stress reliever.

Make safety important Loss of memory increases the chance of injuries and accidents, so you should make your home as safe as possible.

Encourage fitness and health This should do no harm, and may well help well-being, morale and interest in life. The appropriate exercise depends on their state of health. Consult your physician for advice.

3

HELPING CARERS TO CARE

MODULE 3

Behavioural symptoms of dementia

What is the purpose of this module?
The purpose of this module is to educate family members about approaches to deal with commonly encountered behaviour problems related to dementia. The idea behind this module is that you will have identified in the assessment you carry out in the first session, and in your discussion with family caregivers in the two general education sessions, what are the particular problems with which the family is struggling to cope. You will then focus on these problems.

How will I cover this module?
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. Give them some simple tasks to try out before the next session. Leave them the written materials to read and think about before the second session.

Who should attend these sessions?
For this module it is mainly important that the principal caregivers and others 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 is the content of this module?
There are eight sections to this module:

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

SECTION 1 Personal hygiene

The amount of help a person with dementia needs in personal care varies with the extent of the brain damage. The person with dementia will be able to care for himself in the early stages of the disease, but may gradually begin to neglect himself and will eventually need total help.

Dressing and bathing are personal activities. We each have our own individual ways of doing things. Some change their clothes twice a day, some every other day – each of us is quite set in our habits. If a family member has to help he/she may overlook these personal habits. Taking a bath by oneself is a sign of independence, and it is a private activity, so suddenly if someone has to help the person to bath and change clothes it can be very upsetting.

People with dementia can become abusive and non-cooperative, unaware that the carer is only trying to keep them clean. Look for ways to simplify the number of decisions involved in bathing and dressing without taking away their independence.

Suggestions

- Try to find out how they like to take a bath (type of soap, warm or cold water, time of the day, etc.)
- While bathing allow them to do as much they can for themselves - pouring the water, applying soap, drying.
- If they are used to one method, try to do the same, and introduce any changes carefully – for example, don't suddenly expose them to a shower.
- If they refuse to bathe, try again a little later, when their mood has changed.
- If they feel shy keep their body covered during bathing.
- It will be better to encourage them to sit while giving a bath as it will cut down on their scope to make sudden movements, and reduce the risk of falling.

SECTION 2 Dressing

People with dementia often forget how to dress and may not recognise the need to change their clothes. They may sometimes appear in public with inappropriate clothing or no clothing. They may be unaware that they are not properly clothed; they may not realise that this may be very shocking for others. So be patient with them if they are not properly dressed. Being angry with them will make them feel more confused and scared.

Suggestions

- Consider their comfort and convenience, as well as their dignity. Too many layers of clothes can be difficult and confusing to put on correctly. Of course they still need to be kept warm if the weather ever gets cold. Loose fitting clothes are generally easier to put on, as well as more comfortable, particularly in hot weather.
- It may be very difficult for them to manage zips. It will be easier to wear skirts or trousers held up by elastic. Some of their clothes might be converted in this way.
- It will be difficult for them to manage buttons too, so a local tailor can convert the buttons into velcro which will be very easy to use both for the person with dementia, and their carer.
- Too many choices can be confusing. Try to select their clothes for them and lay them out the night before, so that they can find them easily when they need to dress in the morning.
- When you have the opportunity, take extra time to dress them in their best clothes. Brush their hair neatly, and make sure that they are very well presented. Like anyone else, they will be happy to look smart. They will appreciate the extra attention and will feel good about themselves. They may also be more cooperative with you.

SECTION 3 Toileting and incontinence

The person with dementia may lose the ability to recognise when to go to the toilet, where the toilet is, or what to do when in the toilet. People with dementia can pass urine or motions in their clothes. This is called urinary incontinence and bowel incontinence. The two are separate problems and one can occur without the other.

Medical problems can cause incontinence, so if this problem occurs for the first time, you should check with the doctor straight away. There may be a problem like bladder infection, diabetes or a problem with medication that can be corrected.

People sometimes suggest that you should give the person with dementia fewer drinks to reduce incontinence. However, be careful. Particularly in hot weather an older person can get dehydrated (dry out) very quickly, and this can make them seriously ill. Both too little and too much fluid can be bad.

People use different terms for passing urine, piss, take a leak, going to toilet, etc. Due to difficulty with language the person may be unable to say that they need to go to the toilet and use the wrong words.

Regularly taking the person to the toilet can avoid lot of embarrassment for the person and family.

Suggestions

- Make a schedule and assist the person in going to the toilet – ask them regularly if they need to go.
- Label the toilet door using bright colours and large letters.
- Easily removable clothing will help them not to pass urine in their pants.
- Always seat them in a chair from which they can get up easily.
- Cut down on drinks before bedtime.
- Provide a commode by the bedside so that they can avoid searching for the toilet in the night.

SECTION 4 Repeated questioning

A person with dementia may quickly forget what they asked us even before we answer. So they repeatedly ask the same question. This can be annoying and exhausting for family members. If they are repeatedly asking the same question it may be that they are worried about something else. If the family members can correctly guess and reassure them, they will stop asking questions.

Suggestions

- Repeated questioning, or calling out, is often a sign of anxiety and insecurity. Try to reassure them in their anxiety. Perhaps give them a hug, or tell them how much you care for them.
- Don’t keep on answering the question over and over if this seems to be getting you nowhere. This will only make you impatient; they will pick this up and get more anxious.
- Try to distract them, offering something else to see, hear or to do.
- Talk about the person’s favourite topics.
- You could try writing down the answer to commonly asked questions and referring to it when they start questioning.

SECTION 5 Clinging

The person with dementia can become very dependent on the carer or family member and may try to be with them all the time. This can be quite difficult for the family member as they will find it difficult to get on with their life. Also the person can become very restless or frightened if the caregiver disappears. The trusted caregiver becomes the only security for the patient.

It is vital to try to sort out this problem. No caregiver, however devoted can afford to spend 24 hours a day, seven days a week in constant care. You need time to yourself, to rest, to recharge your batteries, and to return to your caring role refreshed and energetic as before.

Suggestions

- As far as possible try to involve other trusted people as regular carers, so that the patient can identify with at least two people. When one person wants to take time off the other can care for the person with dementia.
- It is better to use a few regular caregivers rather than many people who will seem to be strangers to the person with dementia.
- From the beginning of the illness make it a point not to be with the person with dementia all the time.
- If you have to be away, first do it for a short time and slowly increase it, rather than being away for very long hours.
- If you can arrange for other family members to take over at home for a while, try to take a short break. Go to visit your friends, or go out to do something enjoyable. Don't feel badly about this. You will feel better for it, and the person with dementia will be better off with you refreshed rather than tired and irritable. Remember, it is good for them as well as for you!

SECTION 6 Aggression

Aggression may or may not be a problem. Generally, this is a problem that appears rather late in the course of the dementia illness, when the person with dementia may have deteriorated in many ways. It is, of course, very disturbing to the family. Aggression can have several causes:

1) The person with dementia may be in pain or discomfort. They may, for example, turn out to have a broken leg that has not been noticed. They should therefore always be checked over by a doctor.
2) People with dementia sometimes falsely believe that, for example, someone has been stealing their possessions. They genuinely believe this to be true, and so understandably can become aggressive.
3) In advanced cases of dementia sometimes people may no longer recognise family members. They may think that you are someone else who is threatening them in some way. Again, understandably this can lead them to be aggressive.
4) Aggression is often caused by extreme anxiety. Try to work out what it is that is making them so anxious.
5) Sometimes aggression is simply a result of severe brain damage to parts of the brain that control aggressive behaviour. Always remember, whatever the cause, it isn't the fault of the person with dementia. It is a result of the illness.

Suggestions

- Keep calm and try not to show fear.
- Try to find what provoked anger. Think back and see if there is a pattern of some kind. Try to avoid such situations in future.
- At all costs, do not become aggressive yourself. If you are losing your temper, remove yourself from the person with dementia until you cool down.
- Do not physically push, pull or restrain the person, unless it is necessary to do so for their own safety.
- If all other measures fail, your doctor may be able to help with medication to calm down the person if he becomes violent often.

SECTION 7 Wandering

The person with dementia can leave the house and may not know how to get back. This can be a major problem for the family, as they have to go in search for them. It becomes all the more difficult if it happens in the night time. Similarly, while taking them out they may wander off. If you are not careful, you can lose them.

Suggestions

- Keep restraint to a minimum. It may seem kind to strap the person with dementia in a chair, or lock them in a room to prevent them coming to harm, but this will be a horrible experience for them.
- Try using warning signs on key exits such as 'No Exit' 'Wet Paint' or 'Danger'.
- Try using physical obstacles which make it difficult for them to pass through a door.
- If you have a yard or garden then allow them access into this area. Provide objects of interest for them to look at, touch and feel. Encourage them to wander into this area.
- As a last resort, if all else fails then lock the front door.
- Keep an identification card with your address and telephone number in the person's pocket.
- Embroider their address in all their dresses.
- If the person gets lost, inform the police and give them a recent photograph.
- While taking the person out, hold their hand.
- When you find the person after they have been lost, try not to get angry. Remember they cannot help it. Just take their hand and lead them back. This will avoid a lot of embarrassment for both of you.

SECTION 8 Loss of interest and activity

For many caregivers, as the disease progresses, one of the most distressing things is the sense that the person with dementia has withdrawn from their family and the world. They communicate less and less, and can seem to take little interest in what goes on around them. It is very important to recognise that the person with dementia cannot help this change. They are not being lazy or difficult. It is just part of the illness. However, as with other aspects of the illness, there are things that you can do that may make a difference:

Many people with dementia get depressed. They may appear sad, anxious or tearful. They may talk in a despairing way. Often they lose interest in things, and sometimes go off their food and drink. This is not surprising. When people with dementia are aware of their limitations, this can be very frustrating and upsetting. Also they can misunderstand what is going on around them, and this will be bewildering and frightening. As many as half of all people with dementia may have some degree of depression.

Suggestions

- The ideas listed below may help with depression.
- Sometimes, when depression does not lift of its own accord, treatment with antidepressant medicines can help. These medicines are generally safe and easy to take. Your physician can advise.

Maintain Communication

- Make sure they can see and hear properly (e.g. spectacles may no longer be of the right prescription, or a hearing aid may not be working properly)
- Make sure you have their attention before speaking
- Speak clearly, slowly, face to face and at eye level
- Show love and warmth through hugs, if this is comfortable for them
- Pay attention to their body language - people whose language is impaired communicate through non-verbal means
- Be aware of your own body language
- Find out what combination of word reminders, or prompting words, guidance and demonstration is needed to communicate effectively with them

Keep up activities and interests

- Planned activities can enhance a person's sense of dignity and self worth by giving purpose and meaning to life
- Remember, however, that because dementia advances, their likes, dislikes and abilities will change over time. There is no point in trying to encourage

the person with dementia to do something that doesn't interest them, or that is now beyond them. You will need to try different things

- A person who was once a homemaker, gardener, trade person or business executive may gain satisfaction and reassurance from using some ability related to their job. Often some of these abilities are kept when, in other ways, they can do little for themselves
- In the later stages of the illness, consider how you may stimulate each of the senses in simple, interesting but reassuring ways
- Hearing: music, a radio programme, reading a book or poem out loud, singing
- Touch: interesting objects that can be squeezed, or bent, or are covered in soft material (make sure that they cannot come to any harm with them!)
- Sight: bright colours, painting, clearly labelled pictures of relatives, old photographs
- Smell: involve them in cooking, familiar smells of food and spices (remember again to keep things safe at all times!), perfumes

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