

THE IDEA STUDY

MANUAL FOR TRAINING OF PRIMARY CAREGIVERS OF PEOPLE WITH DEMENTIA

OVERALL AIM

To improve quality of life for people with dementia and their caregivers in sub-Saharan Africa.

PRINCIPAL ELEMENTS OF THIS MANUAL

This manual contains an educational section, designed for primary caregivers and other relatives of people with dementia, designed to increase knowledge of the condition and address negative attitudes and stigma. The manual also contains a supportive, mental health promotion section designed to reduce caregiver burden in the primary caregivers of people with dementia.

This carer intervention is designed to run over five sessions over a three week period, in order to allow time for new skills to be practised and consolidated and to allow time for feedback to course organisers from carers.

EXPLANATORY NOTE

Our aims in producing this manual are to pilot an intervention for caregivers of people with dementia which will be delivered by trained specialist nurses and occupational therapists, through our dementia research project, and we aim to make this sustainable by enabling and empowering the carers themselves to continue to support each other with ongoing support from the specialist team delivered through a mobile health intervention.

Our manual is therefore aimed at the carers themselves rather than healthcare workers, and we have attempted to address cultural differences and resource implications in our setting.

Some materials utilised are based on existing primary healthcare worker training resources such as 'where there is no psychiatrist' by Vikram Patel and Alzheimers disease International online resources, but these have been adapted for training caregivers rather than primary healthcare workers. This has been acknowledged in the appropriate sections.

OUTLINE AND OVERVIEW OF TRAINING PACKAGE

Session	TITLE OF SESSION	CONTENT
1 WEEK 1	Introduction to dementia.	<p>Brief introduction to dementia.</p> <p>Beliefs and stigma about dementia</p> <p>Difficult or problem behaviours noticed by the group</p>
2 WEEK 1	Symptoms of dementia	<p>How to manage dementia symptoms and difficult behaviour.</p> <p>Discussion of case vignettes.</p> <p>Videos and role play about difficult behaviour</p>
3 WEEK 2	<p>Impact of dementia on carers and family members</p> <p>Carers mental health</p>	<p>Economic and health impact of caring.</p> <p>Psychological effect of stigma</p> <p>Principles of stress management.</p>
4 WEEK 2	Management – focussing on Cognitive stimulation therapy (CST)	Principles of CST
5 WEEK 3	<p>Summary and revision of sessions.</p> <p>Feedback and evaluation of training</p>	<p>Outcome of sessions</p> <p>Complications(economic and health-related)</p> <p>Feedback</p> <p>Opinion of carers on how best to help others.</p> <p>Discussion and plan for continuing self-managed support group to help others.</p>

TRAINING MANUAL FOR TRAINERS.

SESSION STRUCTURE AND GENERAL PRINCIPLES

Each session should follow a similar structure. The focus of the sessions is on discussion and talking together. For each session, start with an open discussion in order to find out existing knowledge and beliefs. Facilitators may then give a brief talk to explain the issues, taking into account the knowledge and beliefs already shared by the group. Address and include both knowledge and beliefs when giving information. Following each talk, use a video clip or role play to reinforce what has been said. Finish each session by further discussion and make a summary of important points raised.

Please also remember that these sessions are not primarily a training course. The aim is to support carers to feel able to start and continue their own support group in order to help each other and other carers with similar problems in their local communities. Remember also that the carers themselves have a lot of experience of management of difficult behaviour and may have experiences and advice which they can share with others and which the facilitators do not have.

The course will be organised over three weeks. There will be two sessions the first week, two sessions the second week and the final session will be organised a week later in order to allow time for practice of skills learnt and feedback on home activities and on the course in general. It is also recognised that a week-long course will be difficult for carers to attend due to other household responsibilities and other important tasks such as planting and harvesting crops and attending market days which cannot be delayed. Where possible negotiate the training days with the group in order to avoid the market days in the local area and other important activities such as Friday prayers if there are Muslim participants in the group.

DAY 1 – WEEK 1

This session is a simple introduction to dementia and an opportunity for the group to meet each other. Do not use written materials or powerpoint presentations – the focus is on talking together. Also be aware that the educational level amongst the carers may be very variable, so use of written materials may embarrass those who find reading difficult.

For this session you will need a projector in order to project or play short videos to illustrate the points you have discussed with the group.

INTRODUCTION – GUIDE FOR FACILITATORS. (GUIDE TIME 30 MINUTES)

Introduce this session by welcoming the carers, explaining that they have all been invited because they have a family member with dementia, and we want to provide support and education to help with their caring responsibilities.

Please also explain that the carers will have amongst them relatives with dementia with very different problems, some will have more severe dementia than others, and some will have very different care needs. Some will need little care at the moment because the dementia is mild, and some will be experiencing great challenges in looking after their relative already.

Explain that we want to discuss dementia for two reasons. Firstly, because understanding what is happening to a family member and why a relative is acting differently is likely to reduce stress on the family. The family can be taught about the illness and that it is likely to get worse and also what to expect in the future so that they can make plans. It will also help the caregiver to care for the person with dementia more effectively, whilst looking after their own mental health.

Also explain, from the beginning, that we are making this group for not only for education and support by trained experts in dementia, but to allow the carers to be able to support each other and also advise others in their local area on how to manage with caring responsibilities.

For this reason, we would like the caregivers here to consider carefully and share their ideas on what help, support and advice might help their families and other families the most.

Ask the carers to introduce each other to the group, and if they wish, to say which relative they are caring for.

SESSION 1 - WHAT IS DEMENTIA?

Suggested time for this session – 1 hour

BRAINSTORMING AND DISCUSSION.

Please start this session with a brainstorming session to determine the caregivers thoughts and beliefs on dementia. Take note of any traditional beliefs such as curses and witchcraft which might be shared because you will need to address these later.

This part of the session is very important because it will allow you to know the current level of knowledge of the participants/carers so that you know the correct level at which to explain about dementia.

SYMPTOMS AND SIGNS OF DEMENTIA

BRAINSTORMING AND DISCUSSION

What changes have the caregivers noticed in their relative?

After brainstorming, you may wish to summarise the following symptoms.

SYMPTOMS CAN INCLUDE

Memory problem, depression or sadness, less interest in activities, personality change (becoming very quiet and withdrawn, or instead becoming aggressive or shouting). Sometime people see or hear things which are not there

People may eat more than before, change in the food that they like, or refuse to eat. This is because the part of the brain that controls hunger has been damaged

As dementia becomes more severe, it usually interferes with activities of daily living, such as shopping, cooking, washing, dressing, eating, personal hygiene and toilet activities.

INFORMATION-GIVING SECTION FROM FACILITATORS

Include the following information

Dementia is not part of normal ageing. Dementia is an illness of the brain. It usually gets worse over time. The conditions that cause dementia produce changes in a person's mental ability, personality and behaviour. People with dementia commonly experience problems with memory and the skills needed to carry out everyday activities.

This is an illness – the changes in the person are not their fault and is not the fault of the family. It is not caused by witchcraft or a curse. It is a disease of the brain.

DEMONSTRATION (OPTIONAL – DEPENDS UPON THE PRIOR KNOWLEDGE AND

EDUCATIONAL LEVEL OF THE GROUP)

The purpose of this section is to demonstrate that dementia is an illness or disease. For this section you may wish to use a toy inflatable brain for demonstration. This is a very simple and large model of the brain, and can be passed around by the group members to understand and reinforce that this is a disease of the brain and not any form of curse or witchcraft.

Use this model to explain how dementia damages different parts of the brain. When a part of the brain is damaged, the person loses the ability associated with that part of the brain.

The brain has the four lobes of the brain marked on it for demonstration. Explain that the brain has brain cells inside that carry messages and allow the brain to function. If the brain cells are damaged, signals cannot pass and the function of that part of the brain will be lost.

Damage to the temporal lobe (lower left and right side) – can affect memory and the ability to learn new things. An example of this would be that the old person with dementia can remember how to cook ugali, because they learnt this a long time ago, but they cannot learn to use a mobile phone properly because it is a new thing.

Damage to the parietal lobe (upper left and right side) can cause problems in carrying out tasks such as washing and dressing properly, and people may put their clothes on incorrectly.

Damage to the frontal lobe (front part) of the brain causes problems in judgement, meaning that people behave differently and may change in personality. This can be difficult to deal with. This can also cause the person to have difficult behaviour, or to simply sit and not take part in activities when they are physically able to do the activities.

TIME FOR DISCUSSION AND CLARIFICATION.

VIDEO AND/OR ROLE PLAY FOR REINFORCEMENT.

Reinforce this discussion with a short video, or if no video is available, a role play.

FINAL DISCUSSION

Are there any points that the carers would like to add, or any areas of clarification?

BREAK

SESSION 2 - DEMENTIA AND STIGMA

Guide time for this session 1-2 hours

BRAINSTORMING AND DISCUSSION

Has anyone in the group come across stigma or negative attitudes about dementia from others?
Would they like to share this experience?

VIDEOS ON STIGMA AND DEMENTIA

For this section you may wish to show the video on stigma and dementia featuring Sarah Mkenda, and news videos on suspected witchcraft from other areas of Tanzania.

DISCUSSION

Allow a few minutes discussion on the issues raised in the video. Have participants come across these attitudes?

How might it be best to address these issues?

How might carers counsel others encountering stigma or beliefs about curses or witchcraft.

In relation to reduction of stigma, do the group have any suggestions on how others might best be helped? How would they advise other carers? What help from health workers would be most useful or effective for the group?

DAY 2 – WEEK 1 MANAGEMENT DAY

SESSION 1 - HOW TO MANAGE SYMPTOMS OF DEMENTIA – 1 HOUR

GENERAL DISCUSSION.

Ask the group to recap the main points and issues raised during day 1.

Ask group members if they would like to share experiences about difficult behaviour from their relatives. Examples might include not eating, not sleeping, repeating the same question again and again, not taking a bath or washing their clothes or accusing family members of doing things which they have not done.

Please remind the group that these problems are all caused by the dementia disease and are not the fault of the carer or of the person with dementia.

VIDEO OR ROLE PLAY

Please play a video or show a role play to illustrate the problems discussed.

SESSION 2 - DISCUSSION OF DIFFICULT BEHAVIOUR – 1 HOUR

What behavioural symptoms have carers encountered, how have they tried to manage them. Which symptoms are most problematic for them, which are not so much of a problem?

OPTIONAL CASE VIGNETTES

These are examples of people with dementia who have difficult behaviour. You do not have to use these if the group are able or willing to describe or explain the problems that they are having at home with their relatives. If they do not feel able to share their experience however you can use these examples. (These are available online as part of the Alzheimers Disease International primary healthcare workers intervention)

Please use as many of these as you feel necessary.

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 attending prayer meetings and singing.

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.

HOW TO DEAL WITH DIFFICULT BEHAVIOUR – GENERAL TIPS – 1 HOUR

Trainers can use the following summary to guide the session.

People with dementia often remember emotions rather than events – so they continue to feel happy, angry or upset depending on what has happened to them earlier in the day, but may not remember why. So if they have had a good day and enjoyed spending time with family they will feel happy even if they don't remember seeing their family. Likewise if you quarrel with them, they will feel sad or angry for some time but not remember that you have quarrelled.

Do not get angry with the person – they may not understand or remember why you are angry and it will make things worse.

If they repeat questions or forget what has been said – repeat it without telling them that they have forgotten – this will make them worry.

If they are not sure who someone is, or what is happening then simply remind them.

Continue to treat them as a wise person and involve them in family activities even if they cannot

give advice properly. Encourage them to take part in small works in the home. This will help them to remember what is happening.

If the person accuses you of stealing or other bad things remember this is because of their memory problem – they have simply forgotten where they have put their things, or cannot understand what is happening in the home or who family members are. Do not argue with them, remind them what is happening and try to talk to them about something else so that they forget.

Remember that they may not understand instructions – keep instructions simple. Speak slowly and clearly. If they do not understand, use simpler words and shorter sentences.

If they are uncooperative this is often because they do not understand that they need help – remind them and stay calm. You can distract them by talking about something else if necessary.

Show them love and affection – this will reassure them. To lose memory is frightening.

Involve them in the family routine

Feeding and eating

People with dementia often lose weight – encourage them to eat and remind or help them if necessary. Be careful with hot food as they may burn themselves. If they do not swallow well or cough when they swallow refer to a doctor – this may give them pneumonia if the food goes to their lungs. In this case always eat small amounts sitting up, and stiffer foods are best such as maize porridge.

Toileting problems

This can be a sign of severe dementia. It is part of the illness – the person has forgotten how to use the toilet or to know that they need the toilet. It is important to remind them and assist them to do this. It can help to take them to the toilet at regular times to make a routine, especially before bed. They should not have wet clothes because this can damage the skin. Special pads can be bought which can help with this problem.

Getting lost

If the person cannot find their way back to the home it is best to have someone nearby who can watch for them leaving the house and either walk with them or encourage them to come back. It can also help to tell the neighbours that this might happen so they can help the person with dementia go back home.

Changes in routine

If a person with dementia is moved to another environment that is not familiar to them they often become more confused. They may be unable to remember that they are not in their usual home and this may frighten them. For this reason it can help to maintain them in the same environment and not to frequently move them between households, unless they were previously accustomed to this before they got dementia

RISK FACTORS FOR DEMENTIA – BRIEF SUMMARY – 20-30 MINUTES

BRAINSTORMING SECTION

What risk factors for dementia are the group aware of? Can you always predict dementia?

SUMMARY

Trainers can use the following summary to give information on dementia risk factors.

If people get dementia it is not their fault. It becomes more and more common with age, so the older people are, the more likely they are to get it.

Certain risk factors can make dementia more likely to happen, but often it cannot be predicted. So people with dementia should not be blamed for their condition.

The risk factors we know can increase the risk of dementia are as follows.

High blood pressure, especially in middle age (age 40-60), especially not treated. Previous strokes, diabetes. Relevance to Tanzania – a recent study in Hai found that two out of three older people had high blood pressure that was not treated. Strokes are also very common in Tanzania. Therefore many people are at increased risk of dementia.

OTHER RISK FACTORS

Family history of dementia.

Excessive alcohol.

Low level of school education. Not being able to read and write.

Vitamin deficiency from not eating enough

HIV/AIDS causes dementia, and the prevalence of HIV/AIDS is rising in older people as well. This should always be considered as a cause.

CAN DEMENTIA BE PREVENTED?

The answer is no, but we can reduce the chance of getting dementia.

It is important to encourage a healthy diet, encourage children to go to school as long as possible, control HIV/AIDS and take treatment for blood pressure if recommended by a doctor in order to reduce risk of dementia.

If your relative has dementia, encourage them to eat well, and check their blood pressure. If the doctor says that they should have treatment for high blood pressure or diabetes, you should follow their advice.

DAY 3 – WEEK 2 CARERS MENTAL HEALTH

SESSION 1- CAREGIVER BURDEN AND EFFECT ON MENTAL HEALTH

DISCUSSION AND BRAINSTORMING SESSION – 30 MINUTES

In this section we will discuss the issues associated with being a carer and the need to consider your own health.

CAREGIVER BURDEN AND EFFECT ON MENTAL HEALTH- SUMMARY

It can be difficult to look after a person with dementia. You must remember to look after your own health. Ask others for help if necessary.

AREAS FOR DISCUSSION

How can caregiving responsibilities affect the carer?

Are there difficulties in carrying out other daily activities?

Effect of tiredness, stress.

What are the major challenges experienced by the carers in the group?

How have they managed these challenges?

What care do they currently provide for their relative, if any?

ECONOMIC BURDEN ON CARERS - 30 MINUTES

DISCUSSION SECTION

Effect on employment and ability to earn money, or to cultivate crops and food.

What are the major challenges experienced by the carers in the group?

Are there any strategies which they have found very helpful that they can share?

Are there good things about being a carer? What do you find rewarding?

VIDEO OR ROLE PLAY – CAREGIVER BURDEN

Please show the group a video or role play about carers issues.

DISCUSSION AND REINFORCEMENT

Time for further discussion

BREAK

SESSION 3 PROBLEM SOLVING

PROBLEM SOLVING SESSION – STRESS MANAGEMENT PRINCIPLES

PROBLEM SOLVING SESSION- MANAGEMENT OF CARE RESPONSIBILITIES IN THE HOME.

The aim of this session is to encourage the group to think about practical solutions to the challenges they face which might reduce their overall level of stress.

DISCUSSION

Who carries out the majority of care in the home?

What are their responsibilities?

Do carers have resources which help – other family members to assist, people to talk to?

Are there any suggestions from the carers for sharing the burden with others, or making caregiving easier?

In relation to management of responsibilities, do the group have any suggestions on how others might best be helped? How would they advise other carers? What help from health workers would be most useful or effective?

DAY 4 – WEEK 2. PRINCIPLES OF CST

BRIEF INTRODUCTION FROM FACILITATORS. EXPLAIN THE FOLLOWING (30 MINUTES)

Principles of CST

The dementia illness cannot be cured, but there are things that can help.

It is important maintain existing brain function – you need to exercise the brain in the same way that you need to exercise the body.

Even though the person has a problem with their brain, it is important to encourage them to use and exercise their brain and remain active. They are still able to do some things, but it may take them more effort than previously and they may need help. Some ability to do things can be regained.

Brief introduction to CST

GROUP DISCUSSION – 30 MINUTES

Ask the group to identify – which activities did their relative enjoy previously, and which do they no longer do? Could they be helped to do these activities again?

Introduce Cognitive Stimulation Therapy (CST) and explain that even if a group is not currently running in their village, they can utilise the principles of CST at home with their relative.

VIDEO SESSION

Show the group a video of a carer explaining how CST has helped their relative.

DISCUSSION

Time for discussion – what are the carers views on CST. Have they experienced CST? Did it help their relative?

SUMMARY

Trainers may wish to share these summarised advice points

General principles of CST that can be used or practised in the home.

Involve the person in what is happening in the home. Inform them of what is happening and current affairs. This is likely to reduce their confusion and make them feel calmer and happier.

Encourage them to take part in small works in the home and to keep active.

Encourage the person to remain independent – if they are able to feed and wash themselves – ensure that they do so.

Remember which activities they used to enjoy and encourage them to continue this if possible, such as making banana mats, pruning coffee trees etc. Maybe they previously enjoyed singing or taking part in prayer groups.

Often skills learnt early in life are retained, especially if they have been practiced a lot. The person may remember old songs for example.

If they simply stay inside and are not involved in the family they will become more confused.

HOMEWORK

Try to practice these principles and activities with your relatives at home. We will discuss this together as a group next week and share experiences.

DAY 5- WEEK 3 – SUMMARY AND FEEDBACK

FEEDBACK ON HOMEWORK – 30 MINUTES TO ONE HOUR

Ask the group to share experiences of trying to implement CST principles at home. What worked well? What were the challenges?

SUMMARY

In this session, the trainers should summarise the issues discussed so far, and also lead feedback and evaluation of the training programme.

They should encourage the participants to identify the most helpful parts of the course and to make suggestions how other carers might best be helped.

Are there ways in which they can support each other if the specialist trainers are not available?

FEEDBACK FROM CARERS

If the specialists were available from time to time, what aspects of education or support should they focus on, what are the current greatest challenges faced by the group, and how would they best like support for these problems?

OVERALL SUMMARY OF THE PROGRAMME

What is dementia?

Difficulties faced by carers, including increased responsibilities, and behavioural and psychological symptoms

Strategies for managing your own mental health and reducing stress

How to counsel others with the same problems

When to seek help – how to recognise delirium and what action to take.

In the future, what help would they find most useful

What do they think would help themselves and others in their caring role.

What do they think would help them and their relatives the most?

PLANS FOR ONGOING SUPPORTIVE GROUP

Refreshments and thanks to everyone taking part

