

I'M STILL HERE

Caring for People with Dementia

INTRODUCTION

Welcome to I'M STILL HERE, an educational package about caring for people with dementia. Our aim in producing this package is to provide you with useful and practical information about caring for people with dementia. We also hope that you will draw on your own expertise and experience to discuss the issues raised and that you will share this with others in your group.

Many people suffering from dementia are slowly losing themselves—they are losing their abilities, their language and their memories. The more we can understand about what is actually happening to them, the better we can help them to do the things they still can. If we see them as individual people, we can enable them to keep their memories alive longer and to live with the dignity every person deserves.

“They’re special people, these people. They’re someone special. They’re someone’s Mum, Aunt, Grandpop...every one of them belongs to someone.”—Patricia, Assistant in Nursing

Presented by Georgie Parker

Starring Colleen Clifford (Mrs Oakes), Pat Thompson (Rose), Angela Toohey (Wendy)

Writers Helen Bowden, Susan MacKinnon, Penny Mulligan

Director Susan MacKinnon

Producer Helen Bowden

Executive Producer Janet Bell

Duration 57 minutes

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TO THE INSTRUCTOR

A FEW POINTS ON RUNNING THE SESSION

- For the exercises, sit the group in a circle so that everyone has eye contact.
- A blackboard, whiteboard or butcher's paper should be available.
- Familiarize yourself with the questions and exercises before starting each session.
- The more examples you take from your workplace, the more interesting and relevant the session will be.
- If during the session an issue about your workplace arises and you feel it needs to be discussed thoroughly, do so. If you run out of time, start the next session by replacing the video and starting the questions where you left off.
- The answers provided act as guides only. Your group may come up with many more pertinent answers. These should be recognized and included in discussion.
- We have tried to cover a wide range of work situations, so some of the questions may not apply to your group. If you find this is the case, drop them and move on.
- Always make sure you have time to ask each person how they feel after the exercises. Do this so that people can express how they felt during the exercise and so they can "sign off" from the game before going back to work.
- Make sure the counter of your video player is set at zero before you begin.

Your role as session leader:

- Guide the group but do not do all the work for it.
- Encourage all members of the group to interact as much as possible.
- Intervene if there are any personal attacks. If necessary arrange a time to resolve the problem outside the group.

TO THE PARTICIPANTS

Hello and welcome to I'M STILL HERE, an educational package for nursing and personal care staff. We hope you will find it both interesting and fun.

The package consists of six sessions. Each session has a video program of 8-12 minutes and some guidelines for discussion. We anticipate that you will watch the video first and then work through the questions and exercises.

PROGRAM ONE looks at the pros and cons of your job and provides some background facts about dementia.

PROGRAM TWO looks at what is actually happening in the brain of someone who has dementia.

PROGRAM THREE discusses how best to communicate with people who are confused or suffering from memory loss.

PROGRAM FOUR is about wandering and delusions and ways of dealing with these behaviours.

PROGRAM FIVE is about agitation and aggression and shows some ways in which you can prevent them. We also look at staff burnout, why it happens and ways to reduce it.

PROGRAM SIX looks at total nursing care and staff communication.

We hope that you will:

- review the information in the video through questions
- discuss similar situation in your nursing home
- look at new ways of working with residents and other staff

PROGRAM ONE: INTRODUCING DEMENTIA

LET'S LOOK AT

- A basic understanding of dementia
- Communicating with relatives
- Improving self esteem

EXERCISE

I'm Okay, You're Okay

Aim: To feel comfortable when talking about yourself and when getting positive feedback from others.

Divide the group into pairs. Tell everyone to carry on a conversation for five minutes, each person telling the other as much as possible about themselves. Ask the participants to pick those things about themselves that they think are important to share. (Participants might need some encouragement to talk positively about themselves.)

After each person has had a turn, ask the pairs to come back together again as one large group (preferably in a circle). Then ask each person to introduce their partner by stating their name and the one special thing that impressed them as most important about the person.

It is a good idea to end the discussion by asking the group to talk about what it was like to talk to the other person and what it was like to be talked about in the group.

UNDERSTANDING THE TERMS

1. What does dementia mean?
Loss of mental functioning
2. What are some of the causes of dementia?
Alzheimer's Disease
Multi-infarcts or little strokes in the brain
Alcoholism
Parkinson's Disease
3. What are some of the effects of dementia?
Loss of memory
Loss of judgement
Loss of thinking
Loss of concentration
Eventual change in personality and behaviour

NURSING STAFF AND RESIDENTS' RELATIVES—A TWO-WAY STREET

1. What are some of the feelings you've seen in relatives when they've placed a loved one into your nursing home?
Guilt
Sadness
Relief
2. How did this affect you?
Guilt can lead to relatives being overly critical, overly sensitive and overly suspicious
Sadness can mean that relatives cry a great deal or need a lot of comfort
Relief can mean that relatives don't visit very much

3. How can you help relatives deal with their feelings?
Make time to listen to what the relative has to say
Be reassuring
Involve relatives in decision-making and care of the resident
Be friendly, open and non-judgmental
Don't take excessive criticism personally
Talk to someone in charge if you feel attacked

4. How can talking to relatives make your job easier?
Give you information about the resident's likes and dislikes
Give you important information about their care
Help you understand them as a person
You can share some of the caring with them eg. Meals, walks, etc

OPTIONAL EXTRA EXERCISE

Tangle

For groups larger than four

Aims:

- Group development
- Trust
- Working as a team

The whole group links hands into a human chain. First person leads chain through itself, over and under arms, between legs, etc. Extra care must be taken not to break the chain. Move slowly and be gentle. TANGLE ends when group is too tightly packed to move. One person then untangles the group, giving people directions without touching them.

Save time by writing the number of the video counter here. That way you'll know whereabouts on the tape to find Program Two.

PROGRAM TWO: THE CHANGING BRAIN

PREPARATION

Make sure that the videotape is in the right place with the counter on the same number as at the end of the last session.

Photocopy the Nursing Care Plan in this booklet for each of your participants.

LET'S LOOK AT

- Maximising remaining abilities
- Passing information on to other staff
- The organic origins of problem behaviours

DOWN MEMORY LANE

1. Can you identify anyone in your nursing home whose long-term memory is good but whose short term memory is bad? Encourage the group to give specific examples of things residents can and can't remember.

2. Why do you think it is important to encourage people with short term memory loss to keep their long term memories as active as possible?
 - Reduces isolation*
 - Retains self esteem*
 - Retains identity*
 - The carer knows the resident as a person*
 - Reduces anxiety*
 - Reduces problem behaviour*

3. How can you go about encouraging residents to use their remaining memories?
 - Attentive listening*
 - Ask about past life experiences*
 - Encourage social interaction with those of the same age and cultural origin*
 - Consistent routines*
 - Organise interesting activities eg. musical sessions*
 - Call the residents by their preferred name all the time*

MAKING THE MOST OF WHAT SOMEONE CAN DO

1. Can you think of anyone in your nursing home who shows examples of apraxia—the inability to carry out tasks purposefully?

2. How does this kind of behaviour make you feel?

3. What are the four assessment steps Georgie talks about which help isolate the parts of an action someone can do?
 - Can the person start the task?*
 - Can the person copy your action?*
 - Can the person continue the action?*
 - Can the person stop the action?*

4. Once you know what the person can't do, what should you do then?
 - Let the resident do the rest for themselves*

5. Letting the residents do things for themselves can disrupt your routine. How can you change your routines to cope better with this?
 - Focus on the group's attitudes. Is getting things done seen as more important than giving the resident self esteem and self respect?*

6. Although sometimes it seems quicker to dress someone fully yourself, what are the benefits of letting the person do as much as they can?
 - Encourages independence*
 - Promotes self esteem*
 - Promotes reality orientation*
 - Reduces frustration*
 - Reduces agitation*
 - Promotes memory*

EXERCISE

Aim: To understand the importance of trust

Duration: Up to 5 minutes.

Ask a group member to volunteer to be blindfolded. The blindfolded person is turned around several times. The other members of the group give the person directions, beginning with simple and specific directions. They gradually become faster and more complicated eg. open the door, turn around, sit down. The group members can use touch as part of their directions. Once the exercise is over ask the blindfolded person how they felt.

This exercise can also be done in pairs, each member can have a turn at guiding and being guided. Always ask how the participant felt in the role.

EXERCISE

Hand out the photocopies of the following Nursing Care Plan and read through it together. Ask participants to access one resident with dementia in relation to one task before the next session.

Nursing Care Plan

Name of the resident: _____

The task eg. dressing, showering, eating _____

Assessment Yes/No:

Can the person start the task? _____

Can the person copy your action? _____

Can the person continue the action? _____

Can the person stop the action? _____

Any other difficulties: _____

Plan: What action can you take to maximise your resident's remaining abilities?

Evaluation: How is your new approach working?

Save time by writing the number of the video counter here. That way you'll know whereabouts on the tape to find Program Three.

PROGRAM THREE: COMMUNICATION

PREPARATION

Collect and discuss last week's written exercise. Make sure that the videotape is in the right place with the counter on the same number as at the end of the last session.

LET'S LOOK AT

- Concentrating on what residents can still do
- Maintaining individuality and self esteem
- Getting to know the resident as a person

DIFFERENT APPROACHES GET DIFFERENT OUTCOMES

1. What were the differences between the approaches of Wendy and Rose?
Wendy's priority was to get Mrs Oakes through the shower as quickly as possible
Rose's priority was to get to know Mrs Oakes as a person and to assess what she can still do
2. How might Mrs Oakes have been feeling on her first morning at Kambah?
Enthusiastic, relieved, positive, afraid, threatened, lost, unconfident
3. How do you think she felt after her first bath?
Confused, defeated, uncomfortable, angry, demoralized
4. What effect did Rose's approach have on Mrs Oakes?
Confidence, sense of independence, reduced confusion, greater feelings of self worth, satisfaction and pleasure found in what she can still do
5. Could Mrs Oakes have a bath just before going to bed in your nursing home?

ASSESSMENTS—BETTER FOR EVERYONE

1. What are the advantages of doing a careful assessment of a resident's capabilities?
Provides information for other staff
Enables consistent nursing
Maintains the resident's individuality
Happier residents
Reduces workload in the future
2. If Mrs Oakes is not treated as an individual what will happen to her?
Over dependence
Increased confusion/agitation
Depression
Apathy
Bitterness

LISTENING AND TALKING

- What were some of Georgie's suggestions for communication with confused people?
- Simple*
 - Slow*
 - Specific*
 - Show*

BECOMING A BETTER LISTENER

Either the instructor or a volunteer from the group plays the part of the interviewer. Another volunteer plays the interviewee. The interviewer asks the questions below. A time limit is set eg. two minutes. All questions have to be answered within the time limit. Ask the interviewer not to make any eye contact with the interviewee or use any encouraging body language.

Questions: How long have you been in your job?
 What do you like about it?
 What don't you like about it?
 If you were the Director of Nursing what would you change?
 How would you feel about living here as a resident?
 What would you want to change if you were a resident?

Ask both participants how they felt about doing the exercise.

Repeat the exercise this time with eye contact and encouragement from the interviewer and without a time constraint.

Note: if you feel that your group is confident enough, this exercise can be done in pairs. Always ask participants how they felt about their roles.

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PROGRAM FOUR: WANDERING

PREPARATION

Make sure that the videotape is in the right place with the counter on the same number as at the end of the last session.

LET'S LOOKS AT

- The importance of documentation
- Better ways of dealing with a confused, wandering person
- Preventative nursing

WHEN INFORMATION ISN'T PASSED ON

1. In the morning handover Ralph said "Mrs Oakes had a quiet night" when in fact she didn't.

How could this have happened?

Information not passed on to Ralph.

Ralph forgot to document information in nursing notes

Not enough time for a thorough handover

2. What you didn't see was that Mrs Oakes was unusually irritable and tired all the next day and no one knew why. What repercussions could this have on the day shift's management of her?

Her sleepiness could be misinterpreted as sickness or over medication and treated accordingly

Her irritability could be misinterpreted as increased confusion, transient strokes or just plain bad tempered and treated accordingly

3. What are the positive effects when information is passed on?

Staff have valuable information about what works and what doesn't

A consistent approach always gets a quicker response

4. How do you pass information on in your nursing home? Is this always consistent?

DEALING WITH DELUSIONS

1. Mrs Oakes' wandering leads her to the kitchen where she becomes quite confused and delusional. She thinks she is in the kitchen of her own restaurant. Why did Rose's attempt to get her back to bed only make matters worse?

Forceful without clear explanation

Communicated her level of impatience and frustration

Tried to talk Mrs Oakes out of her delusion about the restaurant

2. What was Mrs Oakes' reaction to Rose's approach?

Fright, anger, resistance, frustration, increased confusion, felt threatened

3. What techniques did Wendy use to soothe and re-orientate Mrs Oakes to time and place?

Reassurance

Didn't argue

Encouraged Mrs Oakes to re-orientate herself

Didn't hurry her back to bed

Allowed her to reminisce about her past

Listened in an interested and attentive manner

4. What was the outcome of this approach?

No loss of self-esteem

Less confusion

A more settled resident

IDENTIFY THE CAUSE IF YOU CAN

1. Is there anyone in your nursing home who seems to wander aimlessly? Why might they be wandering?

Physical discomfort

Loneliness

Boredom or restlessness

Searching for something or someone

Disorientation

Agitation

Stress

Separation anxiety/looking for a lost loved one

Night-time wandering due to low stimuli and few orientating symbols

2. How does it make you feel?

FREEDOM OF MOVEMENT

1. How do you feel about letting someone just wander?

The pros and cons of letting people wander include: reducing aggression and frustration, providing physical exercise, inducing natural tiredness; risking the patient's safety, disrupting other residents

EXERCISE

“Don’t Box Me In”

Aim: Empathy with residents who are restricted in their wandering.

Someone from the group volunteers to be blindfolded and is placed in a circle surrounded by the rest of the group. Each person in the circle should be able to just touch hands with the person on either side but they do not need to maintain the circle.

The blindfolded person is told to start wandering.

Members of the group give instructions eg. try over there, or no you can’t come here, go away. The blindfolded person should not be allowed outside the circle and can be stopped by touch.

Once the exercise is completed, ask the blindfolded person how he/she felt.

If you have time you can repeat the exercise, but always allow for time to ask the person how he/she felt.

Save time by writing the number of the video counter here. That way you’ll know whereabouts on the tape to find Program Five.

PROGRAM FIVE: AGITATION AND AGGRESSION

PREPARATION

Make sure that the videotape is in the right place with the counter on the same number as at the end of the last session.

LET’S LOOK AT

- Causes of agitation and aggression
- Reducing environmental causes of aggression
- Ways to minimize burn-out

BURN-OUT: WHAT’S IT ALL ABOUT?

1. Have you ever felt fed-up with your job like Wendy?

2. What can you do for yourself when feeling this way?

Be confident enough to let someone know you are not coping

Let someone take over and walk away

Let off steam in a safe place

3. Unfortunately the situation Wendy found herself in is common. It’s like the domino effect, one person’s agitation and distress can rub off on others, including the nurse. Sometimes you feel you have to cope with it all on your own. The risk of abusing your residents when under this kind of stress is very high. Think about it, have you ever:

(a) Brushed someone’s hair roughly?

(b) Dressed someone roughly?

(c) Got angry with someone for being incontinent?

(d) Shoveled food into someone’s mouth?

4. Do you think this counts as abuse?

5. What do you think could be some of the reasons behind this kind of abuse?

Heavy workload – as discussed in question 3.

Inability to ventilate your angry feelings to the right person (it's easier to take your angry feelings out on someone who isn't going to get angry back)

Blunted sensitivity eg thinking that the resident is too demented to notice

DOING SOMETHING ABOUT BURN-OUT

1. What can you do in your nursing home to protect yourselves from burn-out?

Use appropriate channels of communication eg hand over

Identify a staff member you respect, who is able to listen to feelings and problems as they arise

Let someone in charge know if your team isn't working well, or if someone isn't pulling their weight

Let someone in charge know if you are feeling unhappy or wish to work in a different area

Be assertive without being aggressive. Tell the appropriate person how you are feeling and why

2. Who is it in your nursing home staff can talk to when they are having problems?

Discuss the responsibilities of this role – time to listen, find out the facts, think about follow-up etc.

3. Do you think the management in your nursing home needs to allocate more time for staff communication?

DEALING WITH AGITATION AND AGGRESSION

1. Is there anyone in your nursing home who becomes aggressive or extremely agitated?

2. Why do you think this might be?

Frustration

Boredom

Feeling crowded

Noise and alarm

No privacy

Staff changes

Discomfort

Physical changes

Brain damage

3. How does it make you feel?

4. When does it usually occur?

Bath time, bed time or during interactions with others

5. As a group, can you think of any new problem solving approaches or nursing care plans for your agitated resident?

6. Allocate someone to document outcomes.

EXERCISE

Please Listen to Me

Aim: To help you avoid burn-out. Being able to ask for help and get your request heard can reduce stress.

The group sits on the floor in a circle. Someone volunteers to sit in the middle. Ask the volunteer to imagine that they've had a bad week—their home life is in a mess and their workload is particularly heavy at the moment.

The person sitting in the middle asks each group member for help with something. As she asks for help the members turn their backs on her so they are facing away from the centre of the circle. Finally everyone has turned their backs on her and all her requests have been denied.

Then everyone turns around again and the exercise is repeated, but this time no backs are turned. The volunteer asks for help and is given support.

Once completed, ask how the volunteer felt during both phases of the exercise. Also ask for feedback from the rest of the group.

Save time by writing the number of the video counter here.

PROGRAM SIX: TOTAL NURSING CARE

PREPARATION

Make sure that the videotape is in the right place with the counter on the same number as at the end of the last session.

LET'S LOOK AT

- Minimising workload by passing on information
- The importance of observation
- Exploring the repercussions of emotional involvement with residents

HOW WOULD YOU HANDLE IT?

1. The situation Wendy and Maria found themselves in was a difficult one, but most of us will have been in one like it at some time in our careers. Have you ever been in Wendy's position? How did it feel?

2. Have you ever been in Maria's position? How did it feel?

3. Why do you think Wendy acted as she did?

Emotional over-involvement with Mrs Oakes

Guilt about being away from Mrs Oakes for a week

4. What would have been a more appropriate way of handling the situation?

Attend to Mrs Oakes

Leave the room and find a quiet place to talk

If you cannot resolve the conflict, inform a third person

5. What did Wendy do that put Maria on the defensive?

She didn't listen to Maria

She made assumptions and judgements of Maria's nursing capabilities

She was on the attack

6. What were Maria's key responsibilities in caring for Mrs Oakes?

To make sure she was as comfortable as possible

To pass on any change in her condition

To ensure that any problems were being attended to

7. Why do you think Mrs Oakes got pressure sores in the first place?

Breakdown in communication

8. How could this be prevented in the future?

Careful documentation

Reading of the nursing-care-plans

Careful rostering

9. Although Wendy had Mrs Oakes' best interests at heart, she made matters worse by talking over Mrs Oakes in an angry manner but not explaining to her what was actually going on. Why is this bad nursing practice?

10. What are the dangers of emotional over-involvement with your residents?

11. Why do you think some people get a lot of attention while others get little?

12. Is this a problem in your nursing home?

EXERCISE

Replay at Kambah

Aim: Being assertive not aggressive.

Ask three volunteers to play the parts of Wendy, Maria and Mrs Oakes. Re-enact the scene where Wendy finds Mrs Oakes wet and with a pressure sore.

WENDY walks into MRS OAKES' room. She immediately notices a change in MRS OAKES' condition – MRS OAKES is very agitated, pulling at her sheets and at her nightie. WENDY turns to the new nurse who has been covering her shift.

WENDY: Hi – What's been happening to MRS OAKES?

MARIA: What do you mean?

WENDY: Well she's not usually so agitated.

MARIA: Isn't she?

WENDY: No

WENDY moves toward the bed and looks at her

WENDY: She's saturated.

MARIA: I know that's why I'm here...I'm just about to change her, OK?

WENDY: I'll give you a hand.

They pull back the sheets. As they roll MRS OAKES over WENDY gasps.

WENDY: Oh my god.

She is looking at nasty pressure sores.

MARIA: Hmmm...they've got worse since yesterday.

WENDY starts stroking MRS OAKES

WENDY: You poor old thing, they must be so painful, what have they done to you?

MRS OAKES looks up at WENDY and makes a softer less agitated noise.

WENDY: Have you told the RN about this?

MARIA: Hey look, it's not my fault. I've only been here since yesterday...

WENDY: Well does he know?

MARIA: I don't know.

WENDY: Hadn't you better go and find out?

MARIA: Look, if you're so worried why don't you go and tell him.

WENDY: Do you realise how painful this is for her?

MARIA: Look, I'm trying to tell you it's not my fault!

WENDY leaves

Key events:

Wendy and Maria introduce themselves to each other.

They don't talk over resident.

They separate the problem from the person ie the problem is not "Maria", it is the "pressure sore"; what can be done about it?