

Module: Dementia

Overview

Learning objectives

- Promote respect and dignity for people with dementia.
- Know common presentations of dementia.
- Know the assessment principles of dementia.
- Know the management principles of dementia.
- Perform an assessment for dementia.
- Use effective communication skills in interactions with people with dementia.
- Assess and manage physical health concerns in dementia.
- Provide psychosocial interventions to persons with dementia and their carers.
- Deliver pharmacological interventions as needed and where appropriate.
- Plan and perform follow up for dementia.
- Refer to specialists and link with outside agencies where appropriate and available.

Key messages

- Dementia is not a normal part of ageing.
- Dementia is usually progressive – it gets worse over time.
- Symptoms of depression and delirium in older adults can mimic symptoms of dementia, therefore, a thorough assessment and regular follow-up is essential.
- It is critical to assess the carer's stress and psychosocial well-being and provide psychosocial support.
- There is much that can be done to improve symptoms and the living situation of people with dementia and their carers.
- Psychosocial interventions are the first-line treatment options for people with dementia; pharmacological interventions should not be routinely considered.
- Behavioural and psychological symptoms of dementia can be very distressing for the person and carer; therefore, developing treatment plans that address these symptoms are essential.
- Follow-up should be planned, at minimum, every three months.

Session	Learning objectives	⌚ Duration	Training activities
1. Introduction to dementia	Promote respect and dignity for people with dementia	30 minutes	Activity 1: Person's story Tell the person's story to introduce participants to what it feels like to live with dementia
	Know the common presentations of dementia Understand how dementia can impact a person's life and the life of their carer and family Know why dementia is a public health concern and understand how it can be managed in non-specialized health settings	30 minutes	Presentation to supplement the person's story Use the PowerPoint presentation to facilitate a structured discussion on: • Symptoms of dementia • Causes of dementia • How dementia impacts on a person's life • Why it is a public health priority
2. Assessment of dementia	Know the assessment principles of dementia	60 minutes	Activity 2: Reflecting on caring for people with dementia Give participants the opportunity to use the mhGAP-IG master chart to reflect on times they have cared for people with dementia
	Perform an assessment for dementia Use effective communication skills in interactions with people with dementia Assess the needs of carers Assess and manage physical health concerns in dementia Refer to specialists and link with outside agencies where appropriate and available	30 minutes	Activity 3: Video demonstration: Assessing for dementia Use videos/demonstration role play to show an assessment and allow participants to note: • Principles of assessment (all aspects covered) • Effective communication skills (what and how this is done) Activity 4: Role play: Assessment Feedback and reflection
3. Management of dementia	Know the management principles of people with dementia	30 minutes	Presentation on management interventions
	Provide psychosocial interventions to persons with dementia and their carers	30 minutes	Activity 5: Case scenarios: Treatment planning In three groups, participants practise developing a psychosocial treatment plan for a person with dementia and their carer
	Deliver pharmacological interventions as needed and where appropriate	20 minutes	Presentation on pharmacological interventions
4. Follow-up	Plan and perform follow-up	30 minutes	Activity 6: Role play: Follow-up Feedback and reflection
5. Review		15 minutes	Multiple choice questions and discussion
Total duration (without breaks) = 4 hours 35 minutes			

Step-by-step facilitator's guide

Session 1. Introduction to dementia

 1 hour

Session outline

- Introduction to dementia
- Assessment of dementia
- Management of dementia
- Follow-up
- Review

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Begin the session by briefly listing the topics that will be covered.

Activity 1: Person's story

Activity 1: Person's story

- Present a person's story of what it feels like to live with epilepsy.
- First thoughts.

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How to use the person's story:

- Introduce the activity and ensure participants have access to pens and paper.
- Tell the person's story – be creative in how you tell the story to ensure the participants are engaged.
- First thoughts – give participants time to give their immediate reflections of the story. Have they cared for people with dementia in the past?

Local terms for people with dementia

- What are the names and local terms for dementia?
- How does the community understand dementia? What do they think causes it?
- How does the community treat people with dementia?

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Write a list of local terms and descriptions for dementia and compare those with the presentations described in the mhGAP-IG Version 2.0.

(Maximum five minutes.)

What is dementia?

- Dementia is a term used to describe a large group of conditions affecting the brain which cause a progressive decline in a person's ability to function.
- It is **not** a normal part of ageing.

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Explain the points on the slide.

Emphasize that dementia is **not** a normal part of ageing. Although it generally affects people over 65, people as young as 30, 40 or 50 can have dementia.

Explain that quite often people, and especially carers, think that their loved one's decline in functioning (i.e. starting to lose their memory and their ability to carry out daily tasks) is a normal part of ageing and so rarely seek care and support.

This can cause carers and family members a lot of stress as they often do not understand why their loved one is behaving the way they are and they do not know how to manage and help the person.

Therefore, it is important to stress from the beginning of the module that caring for someone with dementia requires that you care for the carer as well.

Common presentations

People with dementia can present with problems in:

- **Cognitive function:** Confusion, memory, problems planning.
- **Emotion control:** Mood swings, personality changes.
- **Behaviour:** Wandering, aggression.
- **Physical health:** Incontinence, weight loss
- **Difficulties in performing daily activities:** Ability to cook, clean dishes.

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Explain that dementia is caused by changes in the brain.

The changes are usually chronic and progressive.

People with dementia can present with problems in different aspects of functioning, as listed on the slide.

Video

Show Alzheimer's video:

<https://www.youtube.com/watch?v=9Wv9jrk-gXc>

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Explain that the most common type of dementia is **Alzheimer's disease**.

Play a short video on Alzheimer's disease (<https://www.youtube.com/watch?v=9Wv9jrk-gXc>). The video lasts three minutes.

At the end of the video, note that Alzheimer's is the most common type of dementia (60–70% of cases). Vascular dementia (reduced blood flow to the brain) is also common, as is dementia with Lewy bodies (tiny deposits of a protein that appear in nerve cells in the brain).

Stages of dementia: Early stage

- Becoming forgetful, especially of things that have just happened.
- Some difficulty with communication (e.g. difficulty in finding words).
- Becoming lost and confused in familiar places – may lose items by putting them in unusual places and be unable to find them.
- Losing track of the time, including time of day, month, year.
- Difficulty in making decisions and handling personal finances.
- Having difficulty carrying out familiar tasks at home or work – trouble driving or forgetting how to use appliances in the kitchen.
- Mood and behaviour:
 - Less active and motivated, loses interest in activities and hobbies.
 - May show mood changes, including depression or anxiety.
 - May react unusually angrily or aggressively on occasion.

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Explain that dementia can generally be described in stages.

Talk through the points on the slide. Emphasize that these are general descriptions and will vary from person to person, but in the early stages people may present with these symptoms.

At this stage, carers may notice these symptoms but minimize or ignore them, believing they are a normal part of ageing.

Therefore, in non-specialized health settings, you may not see people with dementia until they are already in the middle stages.

Ask participants to imagine how this early stage may impact on the person's life?

Stages of dementia: Middle stage

- Becoming very forgetful, especially of recent events and people's names.
- Having difficulty comprehending time, date, place and events.
- Increasing difficulty with communication.
- Need help with personal care (i.e. toileting, dressing).
- Unable to prepare food, cook, clean or shop.
- Unable to live alone safely without considerable support.
- Behaviour changes (e.g. wandering, repeated questioning, calling out, clinging, disturbed sleeping, hallucinations).
- Inappropriate behaviour (e.g. disinhibition, aggression).

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Talk through the points on the slides emphasizing that these are general descriptions, and behaviours may vary.

Explain that because the dementia is progressing, limitations and restrictions on what the person can and can't do are much clearer in the middle stage.

Ask participants to imagine how this stage may impact on the person's life?

Stages of dementia: Late stage

- Unaware of time and place.
- May not understand what is happening around them.
- Unable to recognize relatives and friends.
- Unable to eat without assistance.
- Increasing need for assisted self-care.
- May have bladder and bowel incontinence.
- May be unable to walk or be confined to a wheelchair or bed.
- Behaviour changes may escalate and include aggression towards carer (kicking, hitting, screaming or moaning).
- Unable to find their way around in the home.

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Talk through the points on the slide and briefly explain that the presentations in the late stage are of near total dependence and inactivity.

Memory disturbances and emotion regulation is not only distressing for the person but is challenging for family members.

By the later stages the physical impact of dementia becomes more obvious.

Ask participants to imagine how this may impact on the person's life?

Human rights abuses

- People with dementia are frequently denied their human rights and freedoms.
- In many countries physical and chemical restraints are used on people with dementia.
- This is an abuse of human rights.
- Chemical and physical restraints should not be used; instead people with dementia should be treated with dignity, and psychosocial interventions should be first-line treatment.

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Explain that people with dementia are frequently denied their basic human rights and the freedoms available to others.

In many countries, physical and chemical restraints are used extensively in care facilities for elderly people and in acute-care settings, even when regulations are in place to uphold the rights of people to freedom and choice.

Impact on families and carers

Dementia is overwhelming for the families of affected people and their carers.

Physical, emotional and economic pressures can cause great stress to families and carers, which has far reaching impacts on the wider society and community.

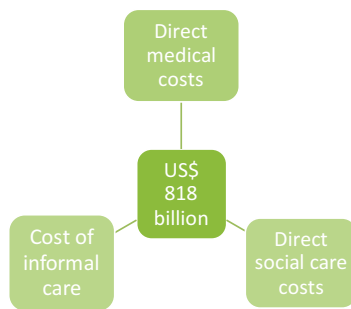
Support for families of people with dementia is required from the health, social, financial and legal systems.

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Impact on the carers

Explain that dementia is overwhelming for the person and their family and carers. Therefore, when treating individuals with dementia we have a responsibility to support the families and carers as well. The emotional and physical stress of looking after a person with dementia (especially in the middle and later stages) is difficult.

Socioeconomic impact of dementia



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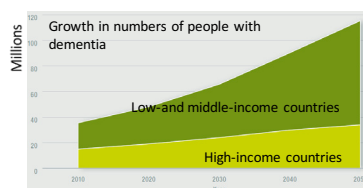
Explain that the socioeconomic impact of dementia is also overwhelming, including:

- direct medical costs
- direct social care costs
- costs of informal care (including carers having to take time off work etc.)

In 2015, the total global societal cost of dementia was estimated to be US\$ 818 billion.

Why is dementia important?

- Worldwide, around 47 million people have dementia with nearly 60% in low- and middle-income countries.
- Every year there are 9.9 million new cases.
- By 2030 there is projected to be 75 million people with dementia and 132 million by 2050.



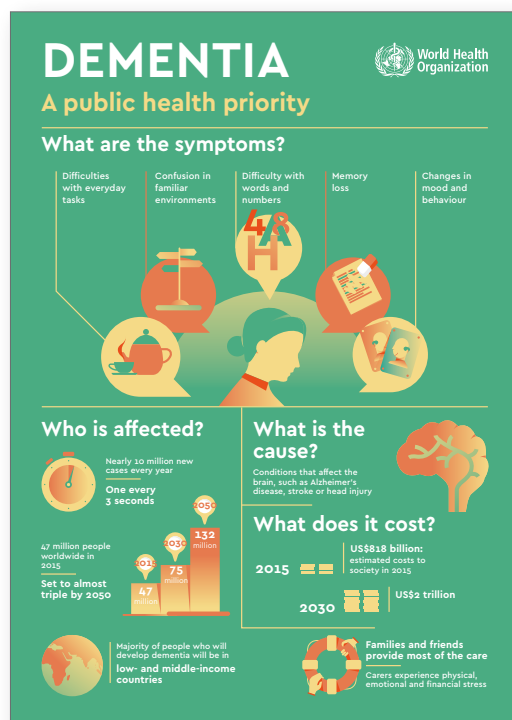
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Dementia as a public health concern

Worldwide around 47 million people have dementia. Every year there are 9.9 million new cases.

Explain that:

- Dementia is one of the major causes of disability in later life.
- Dementia is prevalent worldwide but is often misdiagnosed.
- 58% of all people with dementia worldwide live in low- and middle-income countries. By 2030, 75 million people will be living with dementia. By 2050 that number will rise to 132 million. Much of the increase is attributable to the rising number of people with dementia living in low- and-middle income countries.



Dementia in non-specialized health settings

Talk through the infographic and highlight the major findings.

Explain that although there is no cure, but with early recognition, especially in non-specialized health settings, and supportive treatment, the lives of people with dementia and their carers can be significantly improved. Physical health, cognition, activity and the well-being of the person with dementia can also be optimized.

Principles of dementia care

- Early diagnosis in order to promote early and optimal management.
- Optimizing health, cognition, activity and well-being.
- Identifying and treating accompanying physical illness.
- Detecting and treating behavioural and psychological symptoms.
- Providing information and long-term support to carers.

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Talk through the points on the slide.

Session 2.

Assessment of dementia

🕒 1 hour 30 minutes

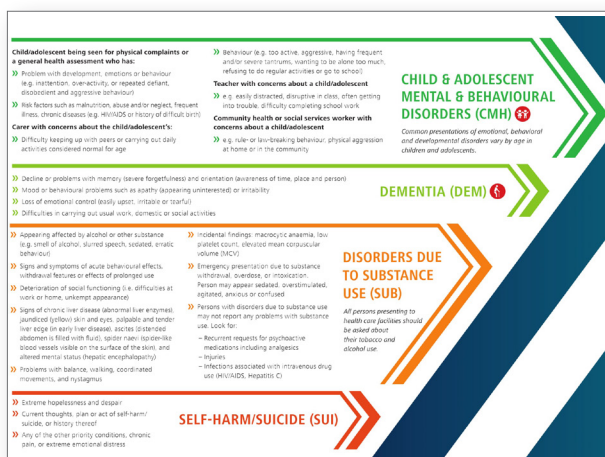
Activity 2: Reflecting on caring for people with dementia

Duration: 15 minutes.

Purpose: Have participants reflect on times when they may have cared for someone with dementia (even if they did not know it at the time).

Instructions:

- Individually ask participants to think about people they have seen in the past that they now suspect may have had symptoms of dementia.
- Ask them to quickly write down a description of the person and how they presented.
- After five minutes have them turn to the person next to them and discuss their cases.
- Direct them to the master chart in the mhGAP-IG Version 2.0 to compare the common presentations described with their cases.
- After five minutes' discussion bring the group together.
- In plenary, ask participants to evaluate how they managed to communicate with someone with dementia?
- Facilitate a discussion (five minutes).



Ask the participants to imagine they are in their clinic.

Communication during the assessment

- People with dementia may have cognitive impairments that will limit the communication they can have with you.
- Therefore, make an effort to communicate with the person **and** their carer.
- Make sure you sit in a way that the person can see and hear you properly.
- Speak clearly, slowly and with eye contact.
- Look at the body language and non-verbal cues.
- Give the caregiver and family a chance to talk and listen to their concerns. You may need to be flexible in how you do this.

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Communication during the assessment

Read out the description on the slides and explain that it may be hard for a person with dementia to follow a conversation, so you will need to talk to the carer and the person about the symptoms to gain a full understanding.

Communicating with the person with dementia

- The progressive nature of dementia means that over time the person may experience:
 - Problems finding the right words.
 - Their fluency when talking may deteriorate.
 - They may interrupt, not respond, ignore others, appear self-centred.
 - They may have trouble understanding the questions put to them. They may be confused when answering.
 - Their reading and writing skills may deteriorate.
 - The way they express their emotions will change.
 - They may have hearing and visual problems as well.

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Explain that as dementia progresses it will become harder to communicate. List the ways in which it is harder to communicate as stated on the slide.

Therefore, it is important to find other ways to build a relationship and communicate with the person with dementia.

This can be done by changing your verbal communication to non-verbal communication, e.g. being calm with the person, putting the person at ease wherever possible, and thinking about the environment in which you see the person (can it be familiar, somewhere where they feel safe).

Give the person time and do not make them feel rushed.

Ensure that you are visible and that they can see you clearly and hear you clearly. Spend time with the person or work with the carer to understand the person's facial expressions and body language.

When asking questions:

- Use closed questions.
- Give clear simple instructions.
- Give clues to try and help them find the words that they forget or allow them the time to find the words if they are forgetting them.

Establish communication and build trust with carers

- Provide the carer and family with opportunities to express their worries and concerns about the person's illness.
- Listen carefully to the concerns of the carer and family members.
- Highlight the positive aspects of the family:
 - Congratulate the family for taking such good care of the person, if appropriate.
- Be flexible in your approach with the carer and family. The family may come to you with needs you did not expect.

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Explain that listening to the concerns and experiences of the carer is an effective way of understanding the person's presentation and symptoms.

The carers may be overwhelmed and feel exhausted from caring for their loved ones.

Therefore, it is important to give them the time and space they need to explain the person's symptoms and explain what has been happening.

Talk through the points on the slide.

Ask participants to think of some assessment questions they could ask the carer to assess if a person has dementia? Allow five minutes maximum and make a note of their answers and feedback to the group.

Ask the carer

- Have you noticed a change in the person's ability to think and reason?
- Does the person often forget where they have put things?
- Does the person forget what happened the day before?
- Does the person forget where they are?
- Does the person get confused?
- Does the person have difficulty dressing (misplacing buttons, putting clothes on in the wrong way)?

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Talk through the questions on the slide and explain that the answers to these questions can help identify if the person's cognitive functioning has deteriorated.

How well are they performing their everyday activities (compared with a few years ago)?

Talk through the questions on the slides, asking for the group's views.

Get more information about the symptoms

Ask the carer:

- How has the person changed since having these symptoms (changed behaviours, ability to reason, changed personality, changed emotion control)?
- What does the person do in a typical day? How do they behave? Is this different from what they used to do?

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Ask the group to provide alternative, culturally appropriate, questions.

Make a note of their suggestions.

Get more information about the symptoms

Ask the person or their carer:

- When they first noticed the symptoms?
- How old was the person when they first noticed the symptoms?
- Did the symptoms start suddenly or gradually?
- How long have the symptoms been present for?
- Are the symptoms worse at night?
- Is there associated drowsiness, impairment of consciousness?

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Finally, talk through the final list of questions on the slide.

Ask the participants to give their opinions on what the answers may be.

Then explain the key information learned from these questions:

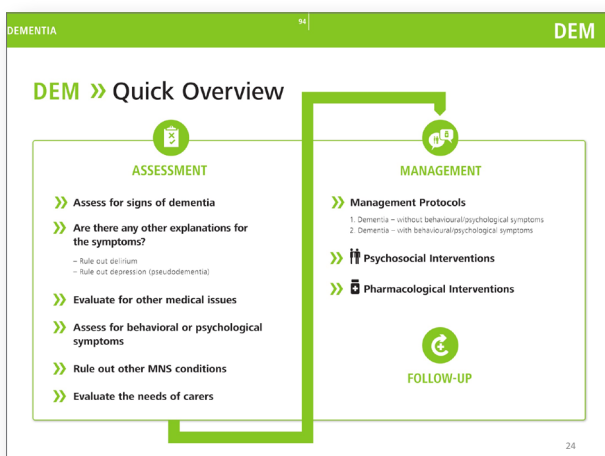
Dementia usually starts later in life (e.g. 60 and 70 years old) although people in their 30s, 40s and 50s can also develop dementia. So, it is important to know when it started.

Onset is gradual over months to years. So, again, it is important to know when they first noticed the symptoms and whether the onset has been slow or fast?

Dementia is progressive. Once it starts it continually deteriorates, although the decline may be slow.

Usually, consciousness is not impaired in people with dementia.

Explain that **impairment of consciousness** can mean a number of different presentations, including fluctuating attention, to coma with only primitive responses to stimuli. The important aspect of an impairment of consciousness is that it is a change from what is normal for that person.



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Instruct participants to turn to the assessment page 94 in the mhGAP-IG Version 2.0 and note the principles of assessment for dementia.

1. Assess for signs of dementia.
2. Are there any other explanations for the symptoms:
 - rule out delirium
 - rule out depression (pseudo -dementia).
3. Evaluate for other medical issues.
4. Assess for behavioural or psychological symptoms.
5. Rule out other MNS conditions.
6. Evaluate the needs of carers.

Re-emphasize that dementia is commonly misdiagnosed and therefore requires a thorough assessment.

Ask participants to reflect on why it is important to cover these steps in an assessment?

Activity 3: Video demonstration: Assessing for dementia

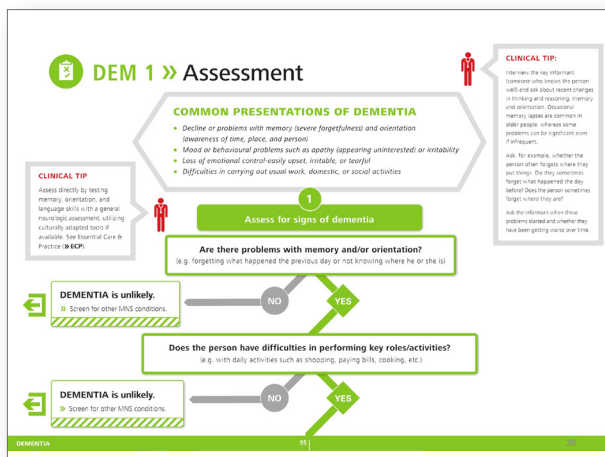
Video demonstration: Assessing for dementia

Show mhGAP video

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Explain that they are about to see a video of an assessment for someone with suspected dementia (<https://www.youtube.com/watch?v=fO9nwqF1OJE&index=11&list=PLU4ieskOli8GicaEnDweSQ6-yaGxhes5v>).

Ensure that whilst watching the video participants have a look through the assessment algorithm in mhGAP-IG Version 2.0 (page 95).



Remind participants of the stories they heard and explain that cognitive decline is a common symptom of dementia. Therefore, if you suspect dementia start by assessing for signs of dementia by testing memory and/or orientation.

Testing orientation, memory and language

Example of questions:

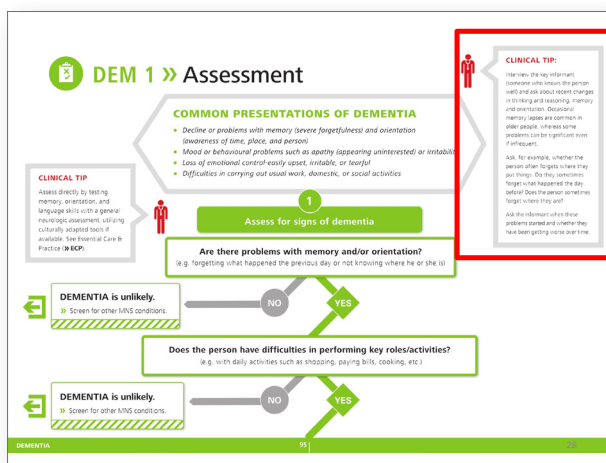
1. Tell them three words (e.g. boat, house, fish) and ask them to repeat after you.
2. Point to their elbow and ask, "What do we call this?"
3. Ask below questions:
 - What do you do with a hammer? (Acceptable answer: "Drive a nail into something").
 - Where is the local market/local store?
 - What day of the week is it?
 - What is the season?
 - Please point first to the window and then to the door.
4. Ask, "Do you remember the three words I told you a few minutes ago?"

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At the end of the video, show participants the short example on the slide of how they can formally test for orientation, memory and language.

Have a few participants volunteer to take the test.

Talk through the questions in the test and answer any questions participants may have.



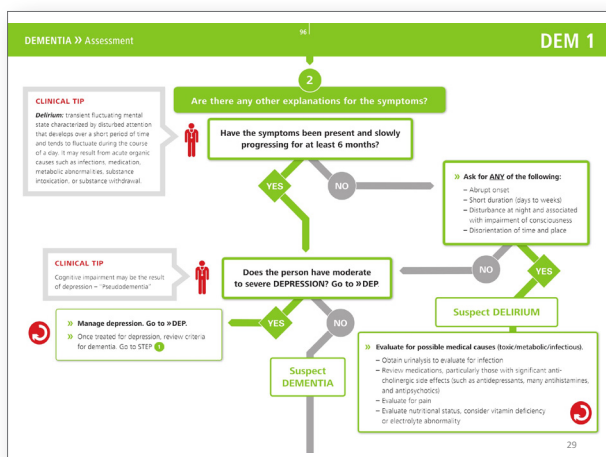
Start at the beginning of the assessment algorithm.

Draw the participants' attention to the clinical tip that advises clinicians to interview key informants.

Explain that we have looked at some questions that could be asked of carers in order to understand more about the person's symptoms.

Discuss how the health-care provider (in the video) asked/found out about any problems with memory and/or orientation?

How did the health-care provider find out if the man was having difficulties performing key roles/activities?



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How did the health-care provider examine if there are any other explanations for the symptoms?

Delirium resembling dementia

- Delirium is a state of mental confusion that develops quickly and usually fluctuates in intensity. It has many causes, including medications and infections.
- Delirium can be confused for dementia.
- Suspect delirium if it is acute onset, short duration and the person has impaired level of consciousness.
- If you think that a person has delirium;
 - Try to identify and manage underlying cause
 - Assess for dehydration and give fluid
 - Ensure that the person is safe and comfortable
 - Refer the person to a specialist (e.g. neurologist, psychiatrist, or internal medicine specialist).

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Delirium resembling dementia is a possible explanation for symptoms.

Talk through the points on the slide.

Emphasize that it is possible for someone with dementia to have delirium at the same time. In which case treat the delirium and continue to assess and monitor for symptoms of dementia.

Depression resembling dementia

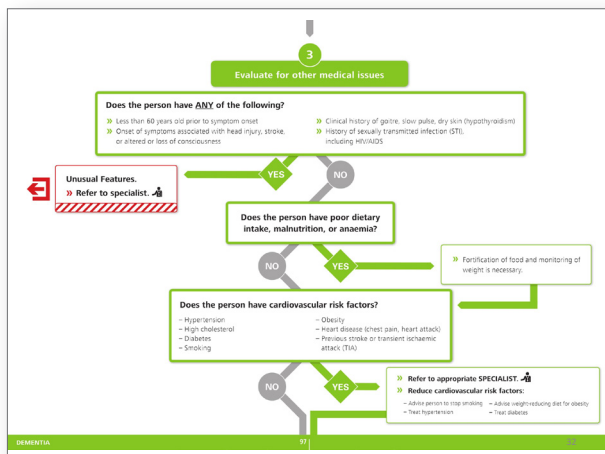
- In older people, depression can sometimes resemble dementia.
- Older people with depression can often be confused, irritable, lose interest and motivation, stop functioning well (be unkempt and neglect personal hygiene) and generally present in ways similar to dementia.
- If you suspect depression then go to the Module: Depression and manage the depression but the person should be re-assessed for dementia 12 weeks later.

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Ask group how depression can resemble dementia?

Give them a few minutes to answer and then reveal the explanation on the slide.

Explain that depression is common amongst the elderly but if they do not have depression they should also be screened for other priority MNS conditions such as psychoses.



Ask participants:

How did the health-care provider evaluate the person for other medical issues?

Instruct the participants to read through step 3 of the assessment for dementia.

Highlight that:

Looking for cardiovascular risk factors is very important considering that vascular dementia is the second most common cause of dementia.

You can take this opportunity to explore the risk factors for cardiovascular disease.

Explain that managing these risk factors as well as any other medical conditions is crucial for managing dementia.

Emphasize that:

- Signs of hypothyroidism can present as dementia.
- Head injury and stroke can cause dementia-like symptoms
- Syphilis and HIV can cause dementia
- Anaemia and B12 deficiency can cause dementia

Remind participants of their responsibility to assess stress in the carer.

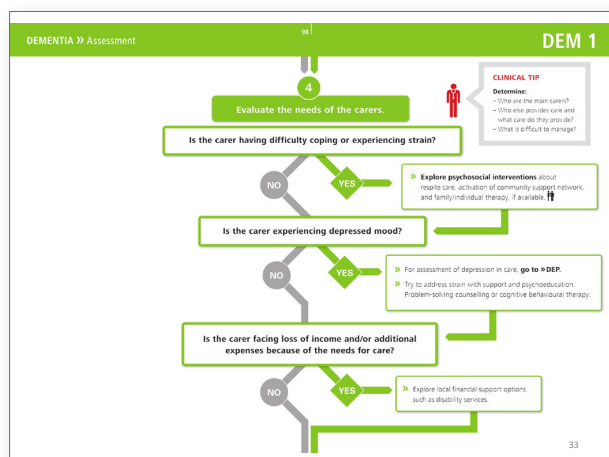
In fact, the well-being of the person will be influenced by the resilience of their family and carer, so it is essential to go through the following steps:

In order to allow the carer a chance to speak freely, find a time and space when you can speak alone.

Ask the carers the questions that are on the slide to establish how they are coping. Explain to participants that they need to emphasize to carers that even the best carers get frustrated. Some carers may get so frustrated that some may resort to physical and psychological abuse.

Give examples of what they should be looking for during the physical exam – bruises with different colours (black, green-yellow) or in unusual places (inner sides of arms and thighs, abdomen, eyes). It is important to protect the person, but also to support the carer to prevent this situation.

Link the carers with appropriate services to help them cope better with the situation.



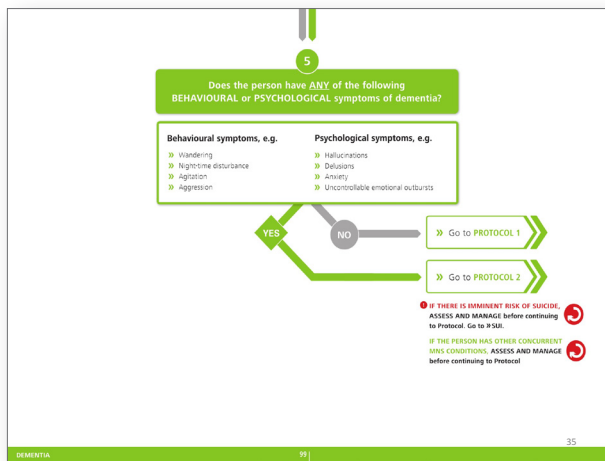
Assessing the carer

Assess:

- Who is the main carer?
- Who else provides care and what care do they provide?
- Is there anything they find particularly difficult to manage?
- Are the carers coping? Are they experiencing strain? Are they depressed?
- Are they facing loss of income and/or additional expenses because of the need for care?

It is important to make sure that the carer is coping because they will ensure the well-being of the person with dementia.

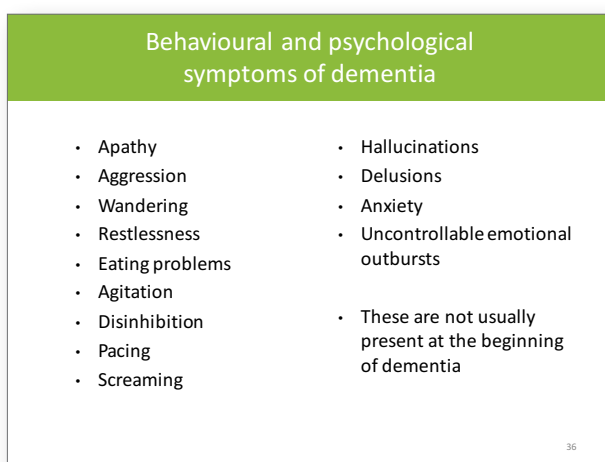
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Around 90% of people affected by dementia will experience behavioural and psychological symptoms.

Behaviours such as wandering, night-time disturbance, agitation and aggression can put the person at risk. They can also be very exhausting for carers to manage.

Try to learn as much as possible about these symptoms from the carers.



Work with the carers to help manage these behaviours and minimize any risks that the behaviour may cause.

Explain that in addition to the symptoms described in the mhGAP-IG, some people may experience apathy, eating problems, disinhibition, pacing and screaming.

Explain that these symptoms are usually seen in later stages of dementia.

Activity 4: Role play: Assessment

Activity 4: Role play: Assessment

- Farah, 45 years old, brings her mother Ingrid, 73 years old, to your clinic.
- Farah reports that her mother has been acting strangely over the last few months.
- Her mother has become increasingly forgetful and vague.
- Sometimes she doesn't seem to recognize people that she has known for years.
- Assess Ingrid for possible dementia.
- Also assess Farah's well-being.

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See DEM supporting material role play 1.

Print off the three different instruction sheets for the participants playing the different roles.

Ensure the person playing the role of the observer also has a competency assessment form (see ToHP training forms) in order to assess the participants.

Duration: 30 minutes.

Purpose: To practise using the mhGAP-IG algorithm to assess an older person for dementia and their carer.

Situation:

- Farah, 45 years old, brings her mother Ingrid, 73 years old, to your clinic.
- Farah reports that her mother has been acting strangely over the last few months.
- Her mother has become increasingly forgetful and vague.
- Sometimes she doesn't seem to recognize people that she has known for years.
- Assess Ingrid for possible dementia.
- Also assess Farah's well-being.

Instructions:

- Divide the participants into groups of four – one person to play the role of the health-care provider, one the role of Farah, one Ingrid and one the observer.
- Distribute the role play instructions to each person depending on their role.
- Ensure that the participants keep to the allotted time.

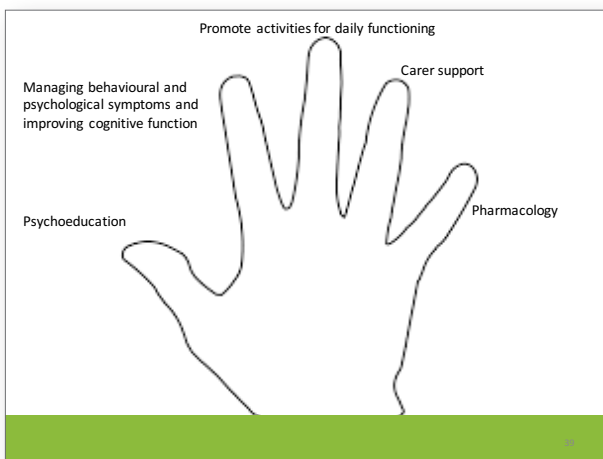
Session 3.

Management of dementia

🕒 1 hour 20 minutes

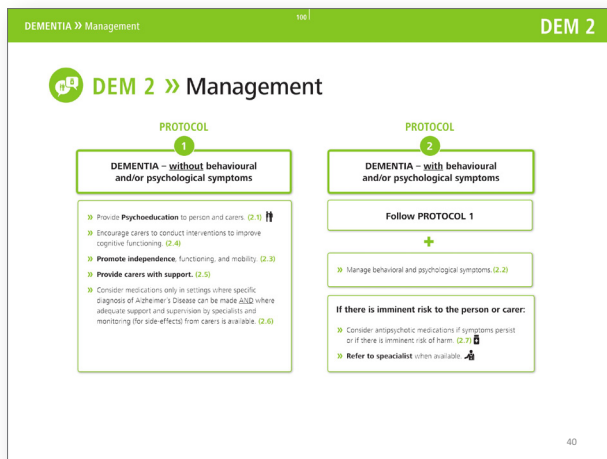


Ask the participants to name which management interventions they think could be used for people with dementia and their carers?



Explain that the management interventions for dementia differ slightly from other MNS conditions. Specifically, there is a focus on improving cognitive functioning; behavioural and psychological symptoms; and supporting the person to live well *with* their condition.

Management interventions should aim to enhance the person's independence as well as ensure that the carer's needs are supported.



Talk through the different protocols.

Emphasize the importance of delivering psychoeducation messages to the person and their carers.

Psychoeducation: Explain the need to tailor and adapt the language when talking to the person with dementia so that they understand and are not overwhelmed.

Carer support: Ensure when delivering management interventions, to focus on the individual with dementia and the carer.

Carer support

1. Empathize: Acknowledge how difficult and frustrating it is to care for someone with dementia:

- Remind them to keep calm and avoid hostility.
- Explain how scared the person with dementia may be feeling and the importance of treating them with respect and dignity and thinking of them as a person.

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Explain that participants should find the time to see the carer alone.
Offer them support.

Empathize: acknowledge their frustrations but remind them to respect the dignity of the person.

Support them to find ways to manage their frustrations such as relaxation strategies, taking a short break etc.

Carer support

2. **Encourage** carer to seek help and support.
3. **Provide information** to carers about dementia and the symptoms.
4. **Train** the carers and support them to learn to tackle difficult behaviours like wandering and aggression (use role plays).
5. If possible offer **respite care** for the carer.
6. Explore any **financial support** or benefits the carer and person may be entitled to.

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List the different ways in which the health-care provider can support carers.

Ensure that participants read through the interventions as you discuss them and that participants have their mhGAP-IG Version open to page 102.

Managing behavioural and psychological symptoms of dementia

Following are common problems faced by caregivers in managing care for older person with dementia:

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

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Explain that the list of behaviours on this slide are a common set of behaviours, psychological symptoms and difficulties with activities of daily living that many people with dementia experience.

Not paying attention to personal hygiene, dressing, having problems toileting and with incontinence can be embarrassing and undignified for the person with dementia and very distressing for the carer. However, there are psychosocial strategies that can help support a person with dementia take back some control in these areas.

Similarly, explain that repeated questioning, wandering, aggression etc. are very challenging behaviours and cause the person and the carer distress.

Research has shown that pharmacological interventions are largely ineffective or have serious side-effects for people with dementia. Therefore, psychosocial interventions must be used as first-line treatment options.

Explain that during the next activity participants will be given a set of handouts (see DEM supporting material case scenarios and handouts) with explanations of these behaviours and suggestions about how to manage them.

Activity 5: Case scenarios: Treatment planning

Activity 5: Case scenarios: Treatment planning

In small groups:

- Practise choosing different management interventions to help manage someone with dementia.
- Specifically focus on managing psychological and behavioural symptoms.

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Duration: 50 minutes.

Purpose: To allow participants to practise developing a treatment plan for people with dementia and their carers. The exercise will enable them to: practise choosing which management interventions to use; to decide whether to refer; and to think about how to follow-up.

Instructions:

- Divide participants into four groups.
- Give each group a different case scenario which describes an older adult and their carer's experience of dementia (see DEM supporting material).
- Ask the groups to develop a treatment plan.
- Instruct the groups to use the clinical tips and ideas given in the mhGAP-IG Version 2.0 Module: Essential care and practice as well as the management interventions in the dementia module and other relevant modules. Give the groups nine handouts on behavioural, psychological and daily activity symptoms.
- Give each group 10 minutes to start identifying if the person in the case study is experiencing any behavioural, psychological and daily activity symptoms. If so, which ones?
- After 10 minutes, give them the lists of suggestions for managing behavioural symptoms of a person with dementia. Then ask them to start developing a treatment plan for the person and their carer.
- After a further 15 minutes, come back together as a large group and have each group present their case scenario, the behavioural, psychological and daily activity symptoms identified and the treatment plan.

DEMENTIA » Management

DEM 2

PSYCHOSOCIAL (CONT.)

2.5 Carer support

- Assess the impact on the carer and the carer's needs to ensure necessary support and resources for their family life, employment, social activities, and health (see **PSY 1**).
- Acknowledge that it can be extremely frustrating and stressful to take care of people with dementia. **Carers need to be encouraged to respect the dignity of the person with dementia and avoid hostility towards, or neglect of, the person.**
- Encourage the carers to seek help if they are experiencing difficulty or strain in caring for their loved one.
- Provide information to the carer regarding dementia, keeping in mind the wishes of the person with dementia.
- Provide training and support in specific skills, e.g. managing difficult behaviour. If necessary, to be most effective, seek active participation, e.g. role play.
- Consider providing practical support when feasible, e.g. home-based respite care. Another family or suitable person can supervise and care for the person with dementia to provide the main carer with a period of relief to rest or carry out other activities.
- Explore whether the person qualifies for any disability benefits or other social/financial support (government or non-governmental).

PHARMACOLOGICAL INTERVENTIONS

2.6 For Dementia without behavioural and/or psychological symptoms

- Do not consider cholinesterase inhibitors (e.g. donepezil, galantamine and rivastigmine) or memantine routinely for all cases of dementia.
- Consider medications only in settings where specific diagnosis of Alzheimer's Disease can be made (NICE) where **adequate support and supervision by specialists** and monitoring for side-effects and response from carers is available.

If appropriate:

- For dementia with suspected Alzheimer's Disease, and with **CLOSE MONITORING**, consider cholinesterase inhibitors (e.g. donepezil, galantamine, rivastigmine) or memantine.
- For dementia with associated vascular disease, consider memantine.

2.7 Antipsychotic medication for behavioural and/or psychological symptoms

- Provide psychosocial interventions first.
- If there is imminent risk to person or carers, consider antipsychotic medication. Go to **PSY 2, Management** for details about antipsychotic medication.
- Follow the principles of:
 - "Start low, go slow" (titrate) and review the need regularly (at least monthly).
 - Use the lowest effective dose.
 - Monitor the person for extrapyramidal symptoms (EPS).
- Avoid i.v. haloperidol.
- Avoid diazepam.

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Pharmacological interventions

Emphasize that medication should **not** be routinely considered for all cases of dementia.

State that the participants should **not** consider acetylcholinesterase inhibitors (like donepezil, galantamine and rivastigmine) or memantine routinely for all cases of dementia.

Explain that they should only consider medications in settings where the specific diagnosis of Alzheimer's disease can be made **and** where adequate support and supervision by specialists and monitoring (for side-effects) from carers is available.

Emphasize that even if no medications are prescribed, there is much that can be done to improve the quality of life of the person with dementia and their carers.

Point out the three principles:

- "Start slow, go slow" (titrate) and review the need regularly.
- Use the lowest effective dose.
- Monitor the person for side-effects, such as extrapyramidal symptoms (EPS).

Avoid i.v. haloperidol.

Avoid diazepam.

Special populations

Note that interventions may differ for PSYCHOSES in these populations

WOMEN WHO ARE PREGNANT OR BREASTFEEDING

- Liase with maternal health specialists to organize care.
- Consider consultation with mental health specialist if available.
- Explain the risk of adverse consequences for the mother and her baby, including obstetric complications and psychotic relapses, particularly if medication stopped.
- Consider pharmacological intervention when appropriate and available. See below.

Pharmacological interventions

PSYCHOSES

- In women with psychosis who are planning a pregnancy or pregnant or breastfeeding, low-dose oral haloperidol, or chlorpromazine may be considered.
- Cholinesterase inhibitors should **NOT** be prescribed to women who are pregnant due to extrapyramidal side-effects of antipsychotic medications, except in cases of acute, short-term use.
- Depot antipsychotics should not be routinely prescribed to women with psychotic disorders who are planning a pregnancy, pregnant, or breastfeeding because there is relatively little information on their safety in this population.

MANIC EPISODE IN BIPOLAR DISORDER

- AVOID VALPROATE, LITHIUM and CARBAMAZEPINE** during pregnancy and breastfeeding due to the risk of birth defects.
- Consider **low-dose haloperidol** with caution and in consultation with a specialist, if available.
- Weigh the risks and benefits of medications in women of childbearing age.
- If a pregnant woman develops acute mania while taking mood stabilisers, consider switching to low-dose haloperidol.

ADOLESCENTS

- Consider consultation with mental health specialist.
- In adolescents with psychotic or bipolar disorder, **risperidone** can be offered as a treatment option only under supervision of a specialist.
- If treatment with risperidone is not feasible, **haloperidol** or **chlorpromazine** may be used only under supervision of a specialist.

OLDER ADULTS

- Use **lower** doses of medication.
- Anticipate an increased risk of drug-drug interactions.
- CAUTION**
Antipsychotics carry an increased risk of cerebrovascular events and death in older adults with dementia-related psychosis.

CHOS15 39 46

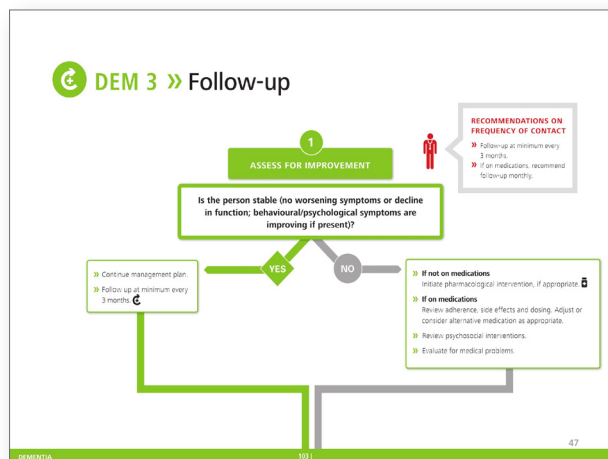
Explain that the behavioural and psychological symptoms can be very distressing for the person and the carer but that mhGAP recommends psychosocial interventions as the first-line treatment option, **not** pharmacological interventions.

Antipsychotics should only be considered if:

- Symptoms persist despite providing psychosocial interventions.
- You assess that there is imminent risk for the person and/or carer.

Session 4. Follow-up

 30 minutes



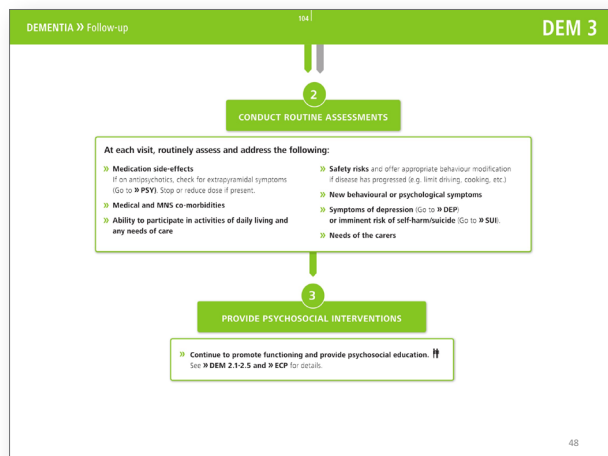
As a large group, discuss the follow-up algorithm

Ask volunteers to read out the first decision-making step and options.

Have them suggest questions they could use to find out this information out?

Emphasize that the person **MUST** be followed up regularly, every three months.

There is currently no cure for dementia, therefore long-term monitoring is the best form of treatment.



Have a different volunteer read out steps 2 and 3 of the follow-up algorithm.

Ask participants to suggest possible questions they could use to find this information out.

Emphasize that due to the progressive and degenerative nature of dementia, at each follow-up appointment the participants **must assess all the areas** as described on page 104 of mhGAP-IG Version 2.0. This way they can assess if there has been deterioration in the person's cognitive, emotional, behavioural and physical functioning and how well they are managing to carry out the activities of daily living.

Explain that they will be practising doing this in a role play.

Activity 6: Role play: Follow-up

Activity 6: Role play: Follow-up

- Farah and Ingrid return to your clinic three months later for a follow-up appointment.
- Ingrid explains that Farah's behaviour has deteriorated. She is now waking up at night and wandering around the house. One night last week she fell over a piece of furniture in the house and hurt her leg.
- Farah has also been going out of the house during the day and getting lost.
- One day it took Ingrid over 12 hours to find Farah and when she did Farah had not eaten or drunk anything all day and was weak and dizzy. Ingrid worries about what could have happened to her.

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See DEM supporting materials role play 2.

Print off three different instruction sheets for the participants playing the different roles.

Ensure the person playing the role of the observer also has a competency assessment form (see ToHP training forms) in order to assess the participants.

Duration: 30 minutes.

Purpose:

To practise using the mhGAP-IG follow-up algorithm to conduct a routine follow-up appointment including:

- Using effective communication skills.
- Offering routine follow-up assessments.
- Offering new psychosocial interventions to the person and their carer.

Situation:

- Farah and Ingrid return to your clinic three months later for a follow-up appointment.
- Ingrid explains that Farah's behavior has deteriorated. She is now waking up at night and wandering around the house. One night last week she fell over a piece of furniture in the house and hurt her leg.
- Farah has also been going out of the house during the day and getting lost.
- One day it took Ingrid over 12 hours to find Farah and when she did Farah had not eaten or drunk anything all day and was weak and dizzy. Ingrid worries about what could have happened to her.

Instructions:

- Divide the participants into groups of four; one person is to play the role of the health-care provider, one Farah, one Ingrid and one the role of the observer.
- Distribute the role play instructions to each person depending on their role.
- Ensure that the participants keep to the allotted time

Session 5.

Review



15 minutes

Duration: Minimum 15 minutes (depends on participants' questions).

Purpose: To review the knowledge and skills gained during this training session by delivering MCQs and facilitating a discussion.

Instructions:

- Administer the MCQs (see DEM supporting material) to participants.
- Discuss the answers as a group.
- Facilitate a brief discussion answering any queries or concerns the participants may have.

DEM PowerPoint slide presentation



PowerPoint slide presentation available online at:
http://www.who.int/mental_health/mhgap/dem_slides.pdf

DEM supporting material

- Person stories
- Role plays
- Case scenarios
- Treatment planning handouts
- Treatment planning suggestions
- Multiple choice questions
- Video link

Activity 3: mhGAP DEM module – assessment

<https://www.youtube.com/watch?v=fO9nwqF1OJE&index=11&list=PLU4ieskOli8GicaEnDweSQ6-yaGxhes5v>



Supporting material available online at:
www.who.int/mental_health/mhgap/dem_supporting_material.pdf