

# Dementia

# Session outline

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

# Activity 1: Person's story

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

# 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?

# 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.

# 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.

# Video

Show Alzheimer's video:

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

# 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 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.



# 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).

# 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.

# 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.

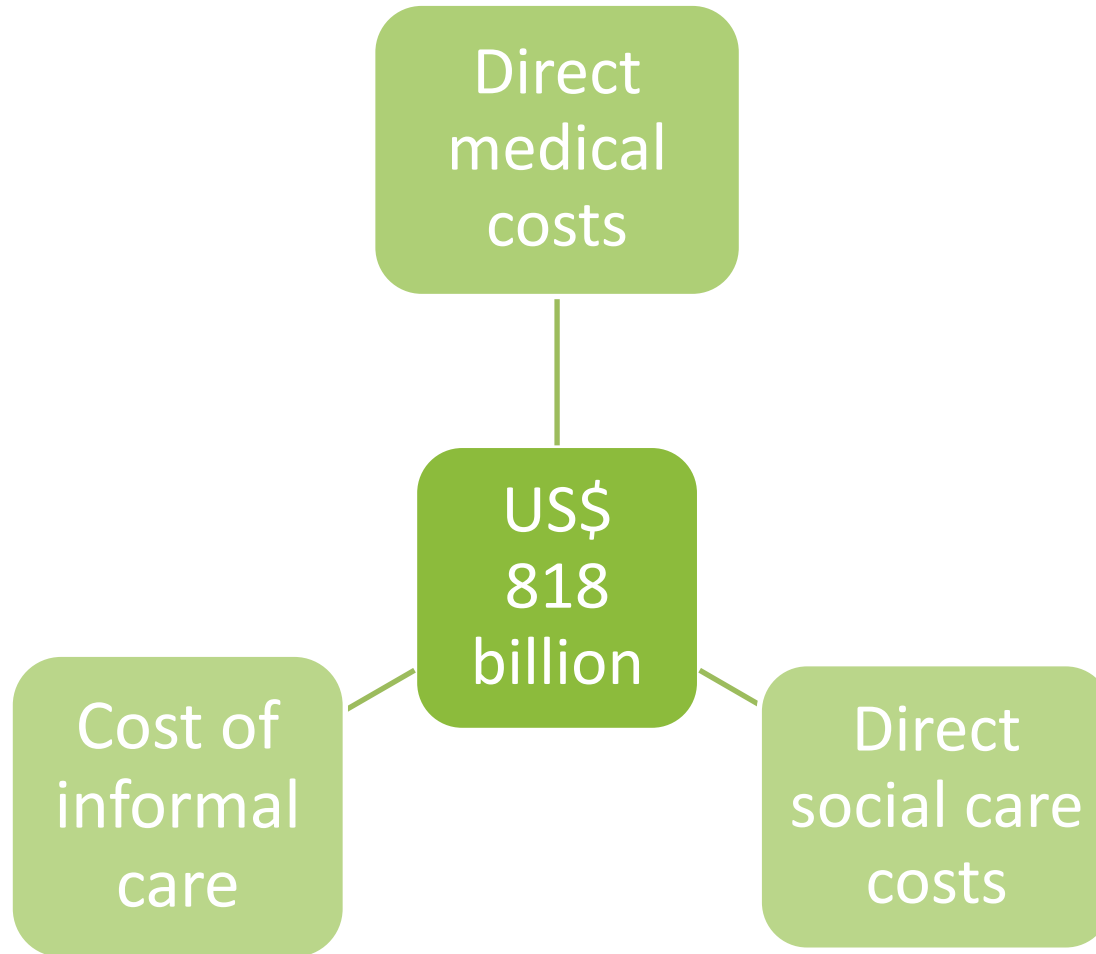
# Impact on families and carers

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.

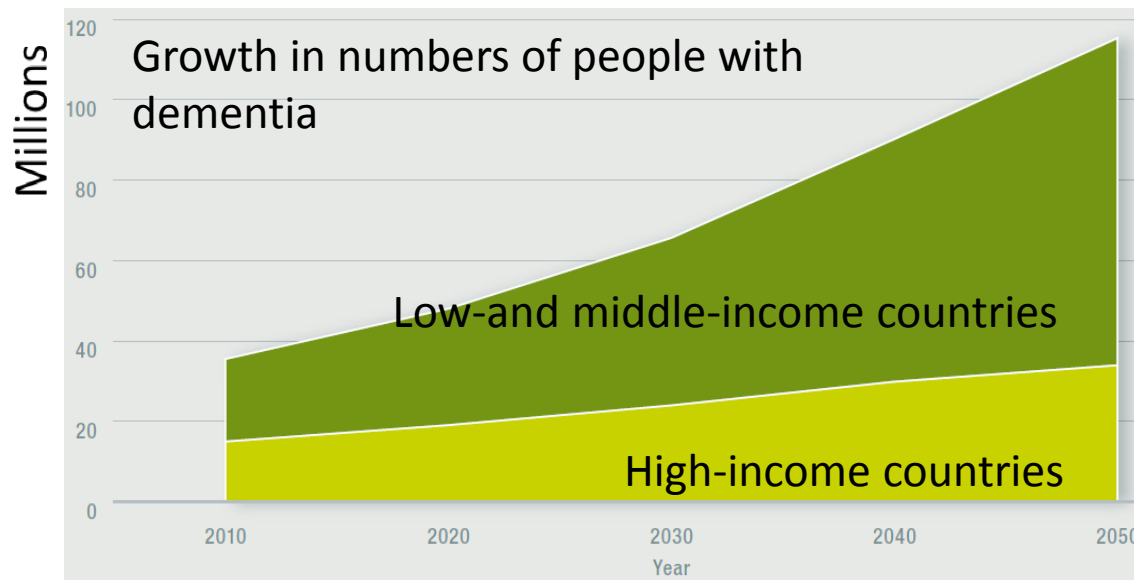
Support for families of people with dementia is required from the health, social, financial and legal systems.

# Socioeconomic impact of dementia



# 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.



# DEMENTIA

## A public health priority

### What are the symptoms?



### Who is affected?



Nearly 10 million new cases every year

One every 3 seconds

47 million people worldwide in 2015

Set to almost triple by 2050



### What is the cause?

Conditions that affect the brain, such as Alzheimer's disease, stroke or head injury



### What does it cost?

2015

US\$818 billion: estimated costs to society in 2015

2030

US\$2 trillion



Majority of people who will develop dementia will be in low- and middle-income countries



Families and friends provide most of the care

Carers experience physical, emotional and financial stress

# 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.



### **Child/adolescent being seen for physical complaints or a general health assessment who has:**

- » Problem with development, emotions or behaviour (e.g. inattention, over-activity, or repeated defiant, disobedient and aggressive behaviour)
- » Risk factors such as malnutrition, abuse and/or neglect, frequent illness, chronic diseases (e.g. HIV/AIDS or history of difficult birth)

### **Carer with concerns about the child/adolescent's:**

- » Difficulty keeping up with peers or carrying out daily activities considered normal for age

- » Behaviour (e.g. too active, aggressive, having frequent and/or severe tantrums, wanting to be alone too much, refusing to do regular activities or go to school)

### **Teacher with concerns about a child/adolescent**

- » e.g. easily distracted, disruptive in class, often getting into trouble, difficulty completing school work

### **Community health or social services worker with concerns about a child/adolescent**

- » e.g. rule- or law-breaking behaviour, physical aggression at home or in the community

## **CHILD & ADOLESCENT MENTAL & BEHAVIOURAL DISORDERS (CMH)**

*Common presentations of emotional, behavioral and developmental disorders vary by age in children and adolescents.*

- » Decline or problems with memory (severe forgetfulness) and orientation (awareness of time, place and person)
- » Mood or behavioural problems such as apathy (appearing uninterested) or irritability
- » Loss of emotional control (easily upset, irritable or tearful)
- » Difficulties in carrying out usual work, domestic or social activities

## **DEMENTIA (DEM)**

- » Appearing affected by alcohol or other substance (e.g. smell of alcohol, slurred speech, sedated, erratic behaviour)
- » Signs and symptoms of acute behavioural effects, withdrawal features or effects of prolonged use
- » Deterioration of social functioning (i.e. difficulties at work or home, unkempt appearance)
- » Signs of chronic liver disease (abnormal liver enzymes), jaundiced (yellow) skin and eyes, palpable and tender liver edge (in early liver disease), ascites (distended abdomen is filled with fluid), spider naevi (spider-like blood vessels visible on the surface of the skin), and altered mental status (hepatic encephalopathy)
- » Problems with balance, walking, coordinated movements, and nystagmus
- » Incidental findings: macrocytic anaemia, low platelet count, elevated mean corpuscular volume (MCV)
- » Emergency presentation due to substance withdrawal, overdose, or intoxication. Person may appear sedated, overstimulated, agitated, anxious or confused
- » Persons with disorders due to substance use may not report any problems with substance use. Look for:
  - Recurrent requests for psychoactive medications including analgesics
  - Injuries
  - Infections associated with intravenous drug use (HIV/AIDS, Hepatitis C)

## **DISORDERS DUE TO SUBSTANCE USE (SUB)**

*All persons presenting to health care facilities should be asked about their tobacco and alcohol use.*

- » Extreme hopelessness and despair
- » Current thoughts, plan or act of self-harm/ suicide, or history thereof
- » Any of the other priority conditions, chronic pain, or extreme emotional distress

## **SELF-HARM/SUICIDE (SUI)**

# 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.

# 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.

# 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.

# 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)?

# 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?

# 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?

# DEM » Quick Overview





## ASSESSMENT

- » Assess for signs of dementia
- » Are there any other explanations for the symptoms?
  - Rule out delirium
  - Rule out depression (pseudodementia)
- » Evaluate for other medical issues
- » Assess for behavioral or psychological symptoms
- » Rule out other MNS conditions
- » Evaluate the needs of carers



## MANAGEMENT

- » Management Protocols
  1. Dementia – without behavioural/psychological symptoms
  2. Dementia – with behavioural/psychological symptoms
- »  Psychosocial Interventions
- »  Pharmacological Interventions



## FOLLOW-UP



# Video demonstration: Assessing for dementia

Show mhGAP-IG video for dementia assessment.

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



# DEM 1 » Assessment



## CLINICAL TIP:

Interview the key informant (someone who knows the person well) and ask about recent changes in thinking and reasoning, memory and orientation. Occasional memory lapses are common in older people, whereas some problems can be significant even if infrequent.

Ask, for example, whether the person often forgets where they put things. Do they sometimes forget what happened the day before? Does the person sometimes forget where they are?

Ask the informant when these problems started and whether they have been getting worse over time.

## COMMON PRESENTATIONS OF DEMENTIA

- Decline or problems with memory (severe forgetfulness) and orientation (awareness of time, place, and person)
- Mood or behavioural problems such as apathy (appearing uninterested) or irritability
- Loss of emotional control—easily upset, irritable, or tearful
- Difficulties in carrying out usual work, domestic, or social activities

## CLINICAL TIP

Assess directly by testing memory, orientation, and language skills with a general neurologic assessment, utilizing culturally adapted tools if available. See Essential Care & Practice (» ECP).



1

Assess for signs of dementia

Are there problems with memory and/or orientation?

(e.g. forgetting what happened the previous day or not knowing where he or she is)

NO

YES

**DEMENTIA is unlikely.**

» Screen for other MNS conditions.

Does the person have difficulties in performing key roles/activities?

(e.g. with daily activities such as shopping, paying bills, cooking, etc.)

NO

YES

**DEMENTIA is unlikely.**

» Screen for other MNS conditions.

# 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?”



# DEM 1 » Assessment

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2

Are there any other explanations for the symptoms?

Have the symptoms been present and slowly progressing for at least 6 months?

YES

NO

» Ask for **ANY** of the following:

- Abrupt onset
- Short duration (days to weeks)
- Disturbance at night and associated with impairment of consciousness
- Disorientation of time and place

NO

YES

Does the person have moderate to severe **DEPRESSION**? Go to »DEP.

YES

NO

Suspect **DELIRIUM**

**CLINICAL TIP**  
Cognitive impairment may be the result of depression – "Pseudodementia"

» **Manage depression. Go to »DEP.**  
» Once treated for depression, review criteria for dementia. Go to STEP 1

Suspect **DEMENTIA**

» Evaluate for possible medical causes (toxic/metabolic/infectious).

- Obtain urinalysis to evaluate for infection
- Review medications, particularly those with significant anticholinergic side effects (such as antidepressants, many antihistamines, and antipsychotics)
- Evaluate for pain
- Evaluate nutritional status, consider vitamin deficiency or electrolyte abnormality

**CLINICAL TIP**  
*Delirium*: transient fluctuating mental state characterized by disturbed attention that develops over a short period of time and tends to fluctuate during the course of a day. It may result from acute organic causes such as infections, medication, metabolic abnormalities, substance intoxication, or substance withdrawal.



# 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).

# 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.

3

### Evaluate for other medical issues

Does the person have **ANY** of the following?

- » Less than 60 years old prior to symptom onset
- » Onset of symptoms associated with head injury, stroke, or altered or loss of consciousness
- » Clinical history of goitre, slow pulse, dry skin (hypothyroidism)
- » History of sexually transmitted infection (STI), including HIV/AIDS

YES

NO

**Unusual Features.**

» Refer to specialist. 

Does the person have poor dietary intake, malnutrition, or anaemia?

NO

YES

» Fortification of food and monitoring of weight is necessary.

Does the person have cardiovascular risk factors?

- Hypertension
- High cholesterol
- Diabetes
- Smoking
- Obesity
- Heart disease (chest pain, heart attack)
- Previous stroke or transient ischaemic attack (TIA)

NO

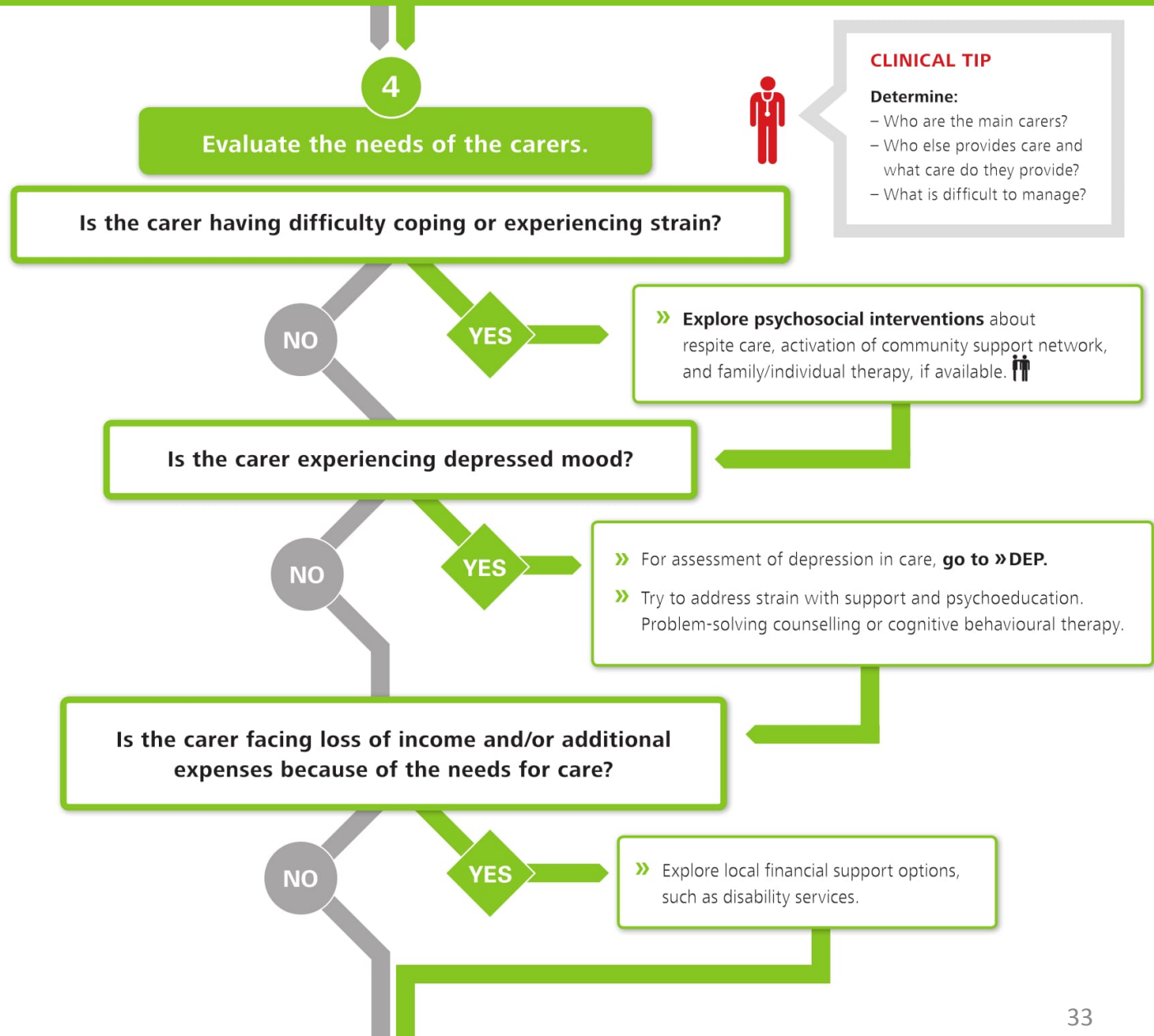
YES

» Refer to appropriate **SPECIALIST**. 

» Reduce cardiovascular risk factors:

- Advise person to stop smoking
- Advise weight-reducing diet for obesity
- Treat hypertension
- Treat diabetes





# 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.

5

Does the person have ANY of the following **BEHAVIOURAL** or **PSYCHOLOGICAL** symptoms of dementia?

**Behavioural symptoms, e.g.**

- » Wandering
- » Night-time disturbance
- » Agitation
- » Aggression

**Psychological symptoms, e.g.**

- » Hallucinations
- » Delusions
- » Anxiety
- » Uncontrollable emotional outbursts

YES

NO

» Go to **PROTOCOL 1**

» Go to **PROTOCOL 2**

**!** IF THERE IS IMMINENT RISK OF SUICIDE, ASSESS AND MANAGE before continuing to Protocol. Go to »SUI.

IF THE PERSON HAS OTHER CONCURRENT MNS CONDITIONS, ASSESS AND MANAGE before continuing to Protocol

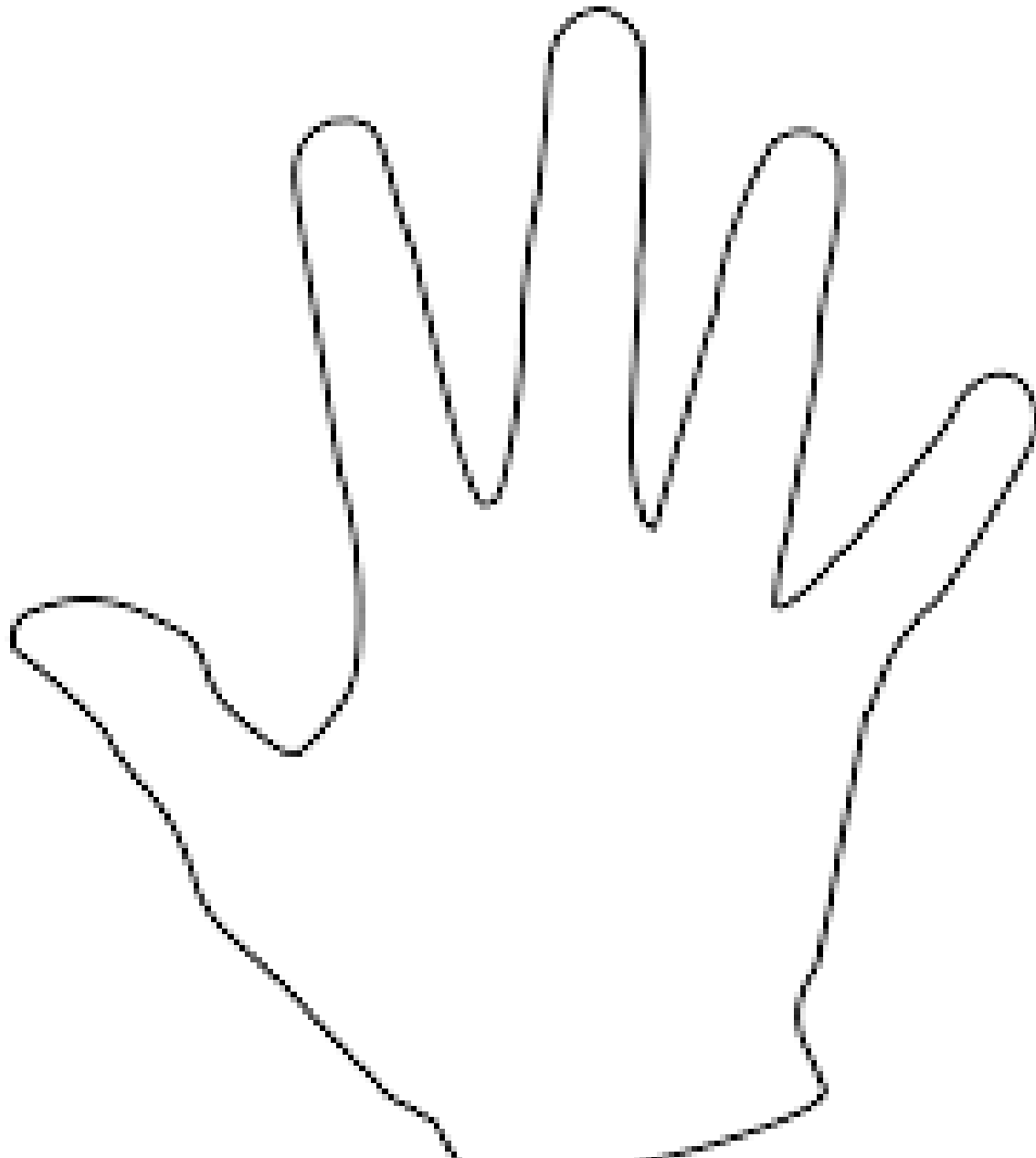


# Behavioural and psychological symptoms of dementia

- Apathy
- Aggression
- Wandering
- Restlessness
- Eating problems
- Agitation
- Disinhibition
- Pacing
- Screaming
- Hallucinations
- Delusions
- Anxiety
- Uncontrollable emotional outbursts
- These are not usually present at the beginning of dementia

# 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.



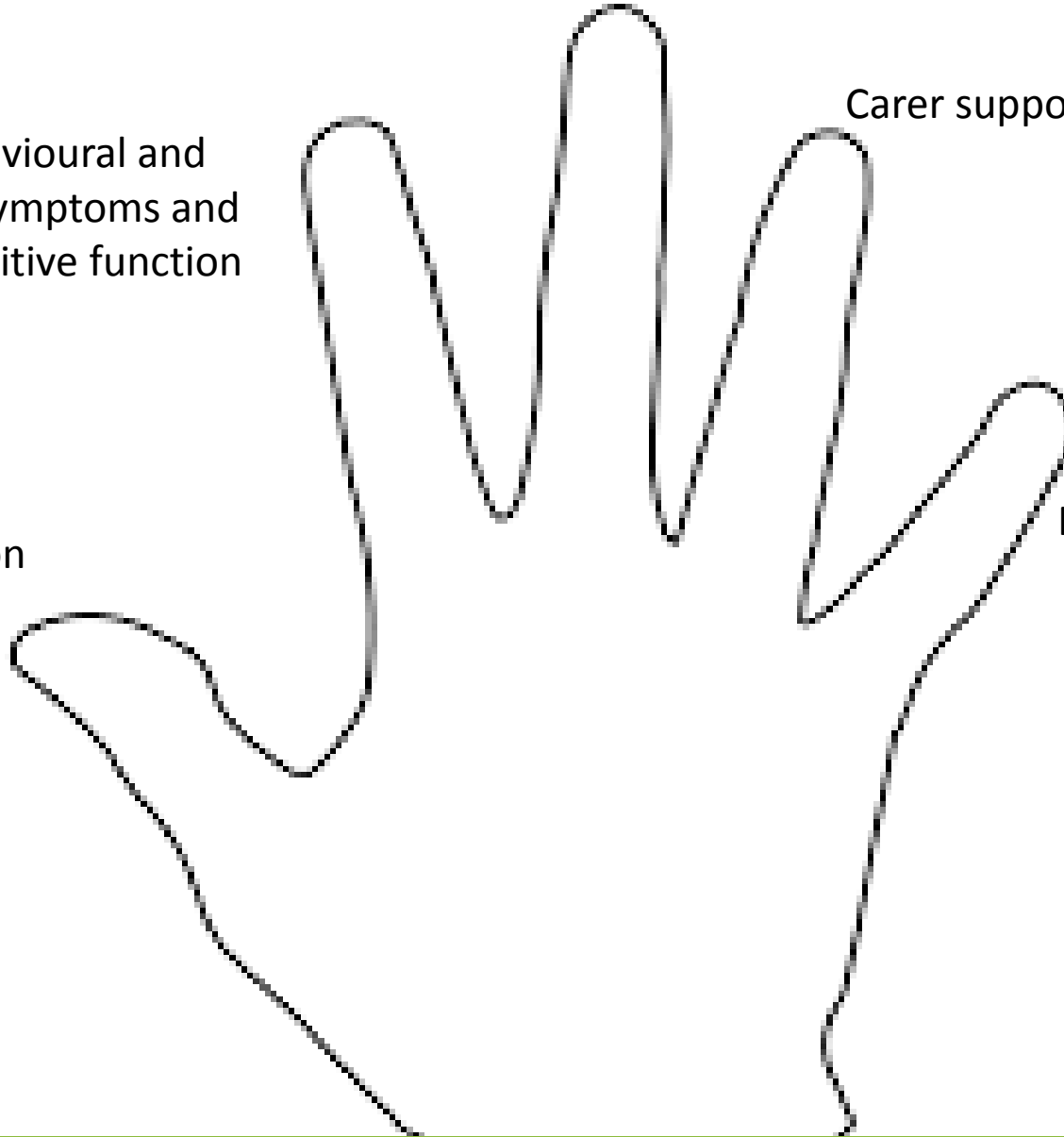
Promote activities for daily functioning

Carer support

Managing behavioural and psychological symptoms and improving cognitive function

Psychoeducation

Pharmacology






# DEM 2 » Management

## PROTOCOL

1

### DEMENTIA – without behavioural and/or psychological symptoms

- » Provide **Psychoeducation** to person and carers. (2.1) 
- » Encourage carers to conduct interventions to improve cognitive functioning. (2.4)
- » **Promote independence**, functioning, and mobility. (2.3)
- » **Provide carers with support.** (2.5)
- » Consider medications only in settings where 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. (2.6)

## PROTOCOL

2



### DEMENTIA – with behavioural and/or psychological symptoms

Follow PROTOCOL 1



- » Manage behavioral and psychological symptoms. (2.2)

#### If there is imminent risk to the person or carer:

- » Consider antipsychotic medications if symptoms persist or if there is imminent risk of harm. (2.7) 
- » **Refer to specialist** when available. 



# 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.

# 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.

# 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

# 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.

## 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 »DEM 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, elicit 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 (like 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 AND 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.

# Special populations

Note that interventions may differ for PSYCHOSES in these populations



## WOMEN WHO ARE PREGNANT OR BREASTFEEDING

- » Liaise 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

#### PSYCHOSIS

- » In women with psychosis who are planning a pregnancy or pregnant or breastfeeding, low-dose oral haloperidol, or chlorpromazine may be considered.
- » Anticholinergics 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 stabilizers, 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.

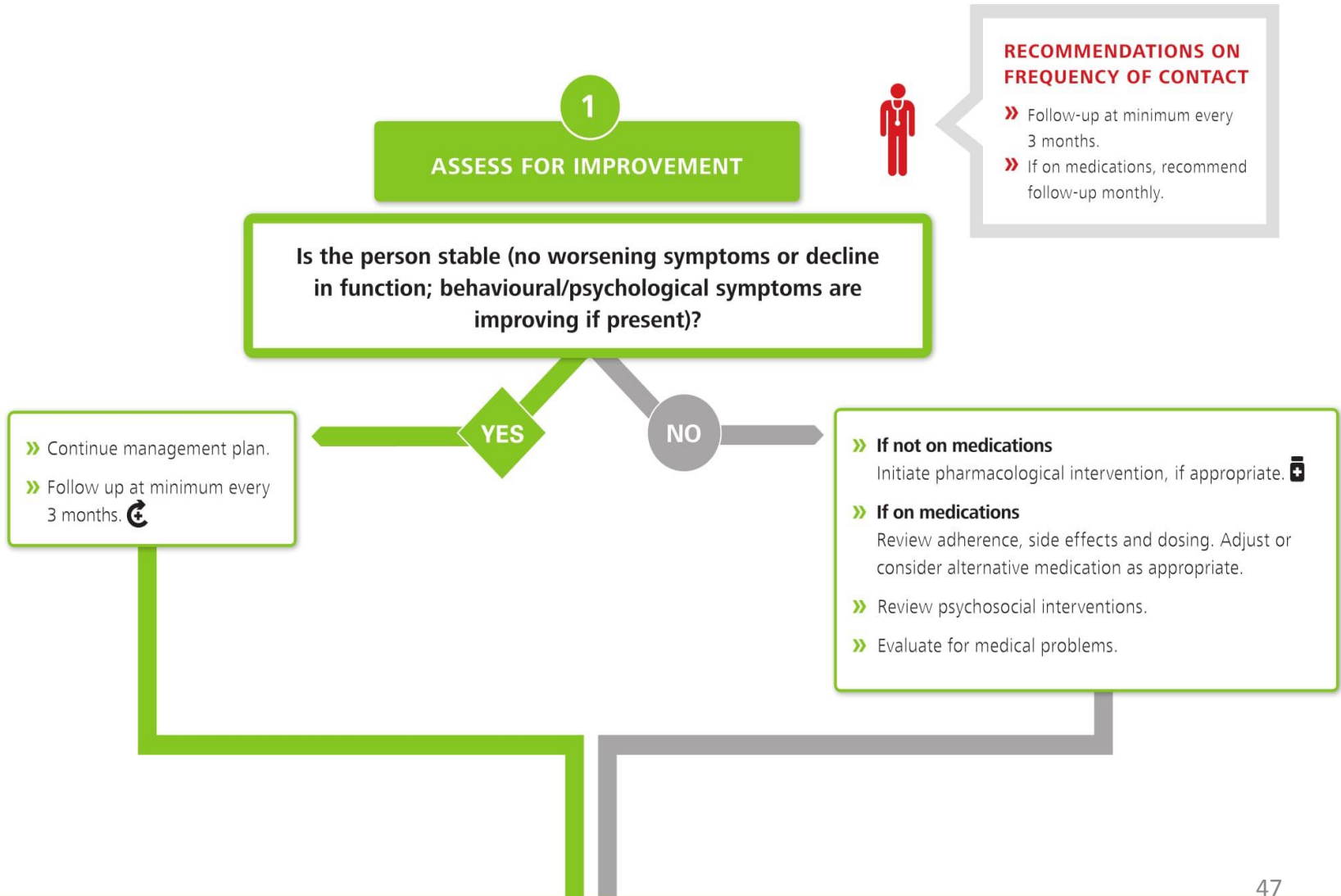


## OLDER ADULTS

- » 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.



# DEM 3 » Follow-up



2


**CONDUCT ROUTINE ASSESSMENTS**

**At each visit, routinely assess and address the following:**

- » **Medication side-effects**  
If on antipsychotics, check for extrapyramidal symptoms (Go to » **PSY**). Stop or reduce dose if present.
- » **Medical and MNS co-morbidities**
- » **Ability to participate in activities of daily living and any needs of care**
- » **Safety risks** and offer appropriate behaviour modification if disease has progressed (e.g. limit driving, cooking, etc.)
- » **New behavioural or psychological symptoms**
- » **Symptoms of depression** (Go to » **DEP**) or **imminent risk of self-harm/suicide** (Go to » **SUI**).
- » **Needs of the carers**

3

**PROVIDE PSYCHOSOCIAL INTERVENTIONS**

- » **Continue to promote functioning and provide psychosocial education.**   
See » **DEM 2.1-2.5** and » **ECP** for details.



# 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.

# Review