Module no. 14
Special issues in the elderly

Learning objectives:

By the end of the chapter, non-specialist medical officers should be able to:

- Understand what home-based care implies, it benefits, and challenges.
- Understand the concept of caregiver burden, strive to identify and offer solutions for it in all situations where elders are being cared for by both formal and informal caregivers.
- Understand and apply the principles of palliative care in the community-based setting, as it applies to the terminally ill patient.

HOME BASED CARE

1. Concept & Definition

A decline in health, physical and mental ability occurs with increasing age. This increases the dependency of elders on others for a variety of functions. This population also has one or more chronic illness, making their care more complex. As a majority of older adults prefer to stay at home for as long as possible, this support will need to be provided in a home-based setting. Home-based care can be defined as any form of assistance provided to a sick person referred to as the patient directly in the home by family, friends and members of the local community, cooperating with the advice and support from the trained health workers.

2. Magnitude and epidemiology

The demand of home based care is substantially increasing as the elderly population is increasing. It is estimated that for an average individual, 70% of health care needs can be met in the home environment. This can result in better health outcomes and lower medical costs for the patients. Home-based care includes health services, personal care, and support services to enable people to stay at home and live as independently as possible. These services may be short or long-term. This form of care is very useful for,

- Patients having neurodegenerative disorders (like dementia),
- Mobility problems
- Terminally ill patients
- Patients discharged from an acute care setting etc.

3. Some of the services that can be provided include (but are not limited to):

Service provider	Services
Doctors	• Evaluate clinical problems and advise management strategies.
Physiotherapy	• Strengthening exercises

	• Range of motion and balance exercises • Environment modification from safety point of view • Appropriate use of mobility devices
Nursing services	• Administration of medication • Feeding tubes • Changing of Urinary Catheters • Removal of Stitches / Staples • Wound and Stoma Care • Pain management
Care givers	• Companionship • Recreational activities • Escorting to the hospital • Grocery • Shopping malls or for entertainment, housekeeping (cleaning, dusting), • Meals preparation • Mentally stimulating activities

6. The advantages of Home-based care are:

1. Home care is an acceptable form of care for majority of elderly.
2. Homes are familiar and safe environments.
3. It can be personalized to the needs of the patient. The home environment provides the greatest comfort.
4. It is an economically better option

7. Problems in Home Based Care

When most of the care is provided by the family caregivers, it is essential to identify caregiver stress and provide support for the same **Training for Care-givers**

8. **Management of home-based care**

The 3 M's of home-based care are Man-power or Human Resources, Material and Money (Financial Resources)
Manpower: There needs to be availability of doctors, nurses, physiotherapists and supervised daily helpers in accordance to the patient's comfort.
Material: The home-environment may need to be converted into a mini-hospital and may need improvised or hospital beds, air-mattresses, bedside railings, dressing material and monitoring equipment.
Money (Finances): It needs to be evaluated based on the requirements of the patient's needs.

When caregivers are informal (family members or untrained hired help) they need to be sensitized to the common problems of the elderly and training the caregiver, very **often the spouse** or children who is an important link in the care of the older person is crucial for success of any home-based care.
They need to be educated on the following aspects of caretaking:

- Ageing process
- Home Safety
- Hygiene
- Falls Prevention

- Bed-sore prevention
- Safe transfer of Elderly
- Personal Hygiene and Grooming
- Dressing of wounds
- Pain relief
- Physiotherapy

One also needs to identify elder abuse, which is covered in different module.

9. Health education messages,

1. Home based care offers an economical and safe method of providing health care to patients especially with cognitive and mobility issues.
2. Nevertheless, home based care is time and energy consuming and finding health personnel who can offer home based care can be a daunting task.
3. Home based care needs multidisciplinary team effort and can be done well with dedicated health personnel, enthusiastic caregivers and necessary equipment.
4. Home based care is ideal for the majority of elderly who have chronic debilitating illnesses or terminal disease. However, it may not be an appropriate choice for acute, potentially reversible conditions.
5. It is acceptable by the elderly and can be personalized to the needs of the patient.

10. Myths and reality

Home care is only for very sick people

Untrue. Even though home care can certainly be helpful for terminally ill people, not all home care recipients are very ill. Non-medical care, on the other hand, offers help with activities of daily living (ADLs) like eating, bathing, personal care, and transportation.

Caregivers aren't trustworthy

Untrue. Even though there are instances about this issue, there are agencies which you can trust upon.

Seniors who need 24/7 care aren't qualified for home care

Untrue. Home care can be highly individualized. Home care agencies often put together 24/7 care teams and can work with you to ensure that you get exactly the services you need.

11. References were not given in the module, which were provided

1. Home care myths and misconceptions. (Internet, available from http://commhealthcare.com/15-crazy-home-care-myths-and-misconceptions/)

CARE GIVERS BURDEN

1. Concept & Definition

The act of care-giving is an essential part of caring for older persons, especially those with cognitive and functional impairment. While it is considered to be satisfying and culturally appropriate in the Indian context, the complexity of the situation brings in a form of stress on the caregiver, called caregiver burden. The caregiver becomes

an “invisible patient” and therefore doctors taking care of older people must enquire for caregiver burden on a regular basis.

Definition

A practical definition of caregiver burden is “extent to which care-givers perceive that care-giving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning.”

2. Magnitude and epidemiology

Caregiver distress and burden indicate prolonged consequences of poor physical and emotional health. Studies on caregivers in India suggest that caregiving is associated with more psychological complaints and a poor physical and psychological Quality of life, prevalence of depression among the caregivers was 10.6%.

Types of care-givers

1. Formal or
2. Informal.

Most of the care-givers are informal and include spouse, children, other family members and friends.

Care-giving includes,

- Assistance with basic and instrumental activities of daily living (bathing, toileting, moving)
- Medical support-buying and administering medicines
- Taking them for appointments
- Making treatment decisions
- Offering emotional support

75% of the caregivers of terminally ill patients are women i.e. wives, daughters, sisters and daughters-in-law. As women are widowed, they need to depend on paid professionals for care.

3. Risk factors effecting the condition

- Low educational attainment
- Female caregiver
- Residence with care recipient
- Depression
- Social isolation
- Financial stress
- Number of care-giving hours
- Not being a caregiver by choice

4. Diagnosis

The impact of caregiving on the caregiver is enormous as there is higher mortality among caregivers when compared to non-caregivers.

Symptoms of care givers stress and clinician assessment of care givers

Symptoms of caregiver stress	Clinician assessment of care givers
1. Symptoms of depression, poor coping ability and quality of life 2. More frequently seeking health care and using more medications 3. Caregivers report a lot of physical and psychological symptoms	1. Identify the primary and additional caregivers 2. Incorporate the needs and preferences of both the care recipient and the caregiver 3. Improve caregivers understanding of their role and teach them the skills 4. Recognize the need for periodic assessment of care outcomes for the care recipient and family caregiver

5. Management
This can be done by:

1. **Psychological measures** such as support groups, counseling and skills training can help mitigate burden.
2. **Including the caregiver** as a member of the treating team and encouraging them to bring out their difficulties at home while taking care, ensuring the caregivers maintain their own health can be useful.
3. **Providing respite care**: Talking to other family members and encouraging them to undertake temporary care-giving roles can provide necessary respite to the overburdened caregiver. Some Non-governmental agencies can be roped in to provide daily meals, assistance with basic and instrumental activities of daily living.
4. **Pharmacological measures** for underlying cause and prompt referral to psychiatrists in higher centres.

Indications for Referral

- Patient not responding to treatment
- Patients with multiple psychiatric issues
- Patient with recurrent suicidal ideas or attempts
- Patient with severely reduced activity, food intake, sleep or personal care
- Patient needing primarily psychological intervention which is not available
- Patients with comorbid dementia or neurologic issues

6. Myths and reality

I need to be perfect.
Untrue. Often the care givers feel that they should be perfect in par with skilled health workers; however they have to realise it’s part of learning and to be calm. The old saying "perfect is the enemy of good" is a good one for caregivers to remember.

I should have only positive thoughts about providing care for my loved one.
Untrue. Even though being strong is very much needed in few situation like patient with Alzheimer's disease, you may feel sad when they do not recognise you.

My needs need to take a back seat to those of the person I'm caring for.
Untrue. "Caring for the caregiver is an important part of caring for the patient."

9. Follow up and expected progress including referral
The health workers should also assess the status of caregivers and refer the care givers for appropriate diagnosis and treatment of the underlying conditions.

10. References (Not provided in previous modules)

1. Seven Myths That Lead to Caregiver Guilt. (Internet, available from http://www.caringnews.com/en/161/1/390/Seven-Myths-That-Lead-to-Caregiver-Guilt.htm)

ELDERLY ABUSE

1. Concept & Definition
Abuse of the older person is an important problem. Healthcare workers have an important role in suspecting abuse and protecting these victims. It is defined as any mistreatment of an older person (aged more than 60 years) by a person responsible for the care of the victim such as spouse, child or a caretaker. Abuse by strangers is not considered within the ambit of elder abuse.

2. Magnitude and epidemiology
Prevalence of elder abuse ranges from 2% to 60% in studies from different groups. It is likely to be underestimated due to underreporting. A survey conducted by Helpage India identified that nearly 20% of the elderly felt neglected, around 23% of them felt they were abused at some point of time with predominantly verbal abuse in the lower socioeconomic strata and neglect in the higher socioeconomic strata. Daughter-in-law was the perpetrator of abuse in many cities and most elders (98%) did not report their abuse to concerned authorities.

Types of elder abuse

Type	Examples
Physical abuse	Hitting, pinching, kicking an older person, withholding/overdose of medications
Psychological abuse	Deliberate emotional harm to the older person
Sexual abuse	Willful and non-consensual sexual contact
Neglect	Failure of a caregiver to provide for the needs and protection of a vulnerable elder person.
Self-neglect	Subcategory of neglect, is a failure of an older person to provide for their own care and protection
Abandonment	Caregiver abandons the older person

3. Objectives of the Modules

After reading this section we should be able to:-

- Identify elder abuse among the geriatric population
- Offer solutions for the same through the various agencies.

4. Risk factors effecting the condition

- Advanced age
- Female gender (single women)
- Inability in self-care
- Dementia
- Depression
- Stroke and hip fracture
- Social isolation
- Low socioeconomic status
- Inappropriate caregiver (reluctant to perform the tasks, temperamental, violent or anti-social, addictions, poor physical health, financial constraints and competing interests)
- Absence of immediate family member as a caregiver

5. Diagnosis

Warning signs of elder abuse

Findings	**Signs**
Skin	Skin tears, abrasions, lacerations, burns and bruises that are inadequately explained
Fractures	Spiral fractures of long bones and fractures in sites other than the wrist, hip or vertebrae especially in a non-alcoholic older person may be suspicious for physical abuse
Malnutrition/weight loss	May indicate neglect and financial exploitation where the older person's financial assets are taken away by the family member
Dehydration	Sign of elder neglect if the elder needs assistance to be able to take in sufficient fluids
Pressure ulcers	Nonhealing ulcers may suggest that the ulcer is not being nursed
Sexual abuse	Pain or soreness in the anal-genital area, evidence of venereal diseases in the oral or anal-genital regions, vaginal or rectal bleeding, bruises or lacerations on the vulva, abdomen, or breasts
Financial exploitation	Inability to pay bills or unpaid bills with disconnection of electricity or water supply

Screening and assessment for elder abuse

A short screening comprising of 3 questions to identify elder abuse is:

1. Do you feel safe where you live?
2. Who prepares your meals?
3. Who handles your finances?

Based on the clinical evaluation and results of the screening tools, clinicians assesses the executive capacity or function and if there is lack of executive capacity, a guardian either a family member or a guardian is appointed to take care of the older person's affairs.

6. Management

Medical measures:

1. Patients may need to be treated for wounds arising out of physical abuse, neglect or sexual abuse.
2. They may need treatment for depression, dementia or infections.
3. They may need shifting to a safer place such as old age homes if abuse is likely to be repeated or are unable to care for themselves due to self- neglect.
4. Interviews with caregivers may be required to understand the stress of care-giving that often leads to abuse. Measures to reduce caregiver stress can lead to better circumstances at home.

Legal measures

1. The government must create awareness about rights of older persons, advocacy of old age issues at all level of governance and ensure implementation of policies pertaining to protection of interests of older persons.
2. Mention the names of policies

Social measures

1. Asking friends to visit them at home if they have moved in with a relative or to a new address may be helpful. Even a brief visit insures observation of their well-being.
2. Accepting new opportunities for activities can bring in new friends. Some steps elders can take to prevent abuse include participating in community activities as long as they are able and staying sociable as they age, maintaining and increasing the network of friends and acquaintances.

Indications for Referral

- Grievous injuries
- Severe depression
- Suicidal tendencies
- Psychological intervention needed
- Behavioral problems

7. Myths and realities

If older people say they are not being abused, it didn't happen.

Untrue. Most of the elderly tend to not disclose about the abuse especially by their children due to family and social issues.

Elderly abuse means only physical

Untrue. They are many other types of abuse like neglect, verbal abuse, self-neglect, abandonment etc.

Most elder abuse occurs in nursing homes.

Untrue. Even though there is elder abuse in few nursing homes noted, most elder abuse occurs at home, with family members and other loved ones as the perpetrators.

8. Follow up and expected progress including referral

a) Expected progress and interval at which it is to be reviewed

9. References

1. Six Myths About Elder Abuse. (Internet, available from https://www.forbes.com/sites/nextavenue/2017/06/15/6-myths-about-elder-abuse/#58b38d4c5fd4)

PALLIATIVE CARE

1. Concept & Definition

Palliative care is an interdisciplinary medical specialty that focuses on preventing and relieving suffering as well as supporting the best possible quality of life for patients and their families facing serious illness. Many people prefer to die at home with greater family satisfaction, better desired patient outcomes, better perception of dying process by family members and lower financial burden to the family. Ability to recognize the last few days of a person's life can help the family and the clinician to make appropriate plans for death at the preferred place. Home based palliative care is sparsely available in our country and therefore palliative care is being provided in hospital settings. Identification of the signs of impending death is essential for clinicians.

2. Magnitude and epidemiology

At least 40 million people need palliative care each year, but only around half that number receive it, according to the Worldwide Hospice Palliative Care Alliance. India comes near the bottom of the global league in access to end-of-life care—ranked 67 out of 80 countries in 2015.

Physiological changes in the last few days of life which should be identified are:

Physiological changes	Causes
Weakness, fatigue and functional decline	The most significant issue is inability to transfer.
Decreased oral intake	Due to impaired swallowing, weakness, medications, or metabolic disturbances
Decreased blood perfusion	Identified by giddiness, reduced urine output, cold clammy hands
Neurological changes	Altered level of consciousness or terminal delirium, changes in breathing patterns
Loss of sphincter control	Incontinence of both urine and stools, Unnecessary catheterization should be avoided if urinary flow is reasonable.
Accumulation of upper airway secretions	Impaired swallow and cough reflex can lead to pooling of secretions
Inability to close eyelids fully	Due to loss of retro-orbital fat

3. Management

Respecting patient's autonomy/ cardiopulmonary resuscitation (CPR) issues

An important aspect of palliative care is breaking bad news and honoring the patient's wishes. Bad news and medical plans have to be conveyed compassionately yet adequately to the patient and their family. Ideally plans on CPR should be determined well in advance before the patients enter the active dying phase. CPR is futile and can be potentially harmful in actively dying patients but this has to be discussed in detail.

Management of symptoms and other issues

Pharmacological management of specific symptoms

Symptom	Primary level	Secondary level/Tertiary care
Pain management	**Mild pain:** Non-opioids like paracetamol, ibuprofen **Moderate pain:** Weak opioids such as tramadol	• Opioids are the mainstay of treatment in patients with moderate to severe pain. • Morphine 2.5 to 5 mg every 4 to 6 hours and titration of the dose is based on response. Concurrently, patients need to be started on laxatives and anti-emetics for a few days to avoid constipation and vomiting. • Fentanyl is safe in patients with renal failure • Radiotherapy (Prostrate cancer)
Breathlessness / dyspnoea	• Relaxation & psychosocial therapies can be helpful in allaying the distress / anxiety related to breathlessness. • Bronchodilators and Steroids may be used in obstructive airway disease and asthma • Antibiotics for pneumonia	• Oxygen therapy • Opioids based on the severity of the disease
Nausea/ Vomiting	• In patients with chemotherapy or radiotherapy induced vomiting, 5HT3 antagonists such as ondansetron or granisetron are the drugs of choice. • Prednisolone based on the condition	• Metoclopramide • In patients with malignant bowel obstruction, haloperidol is first line followed by steroids. • In patients with vomiting secondary to CNS lesions, steroids should be the first choice.

Dysphagia	• The risks and benefits of artificial feeding/ fluids should be discussed. • Intravenous route can be used to administer fluids if patients cannot swallow.	• In patients with esophageal obstruction, radiotherapy, esophageal stenting and esophageal dilatation can be tried to ameliorate the obstruction.
Delirium	• Treatment of delirium should include treating the underlying cause if any.	• Terminal delirium is best treated with antipsychotics such as haloperidol. • Benzodiazepines are of little benefit and in fact may be harmful and lead to paradoxical agitation.
Depression	• Psychotherapy may be helpful in some cases	• Palliative care guidelines suggest selective serotonin reuptake inhibitors (SSRI) /serotonin noradrenaline reuptake inhibitors (SNRI) or atypical antidepressants as first choice.

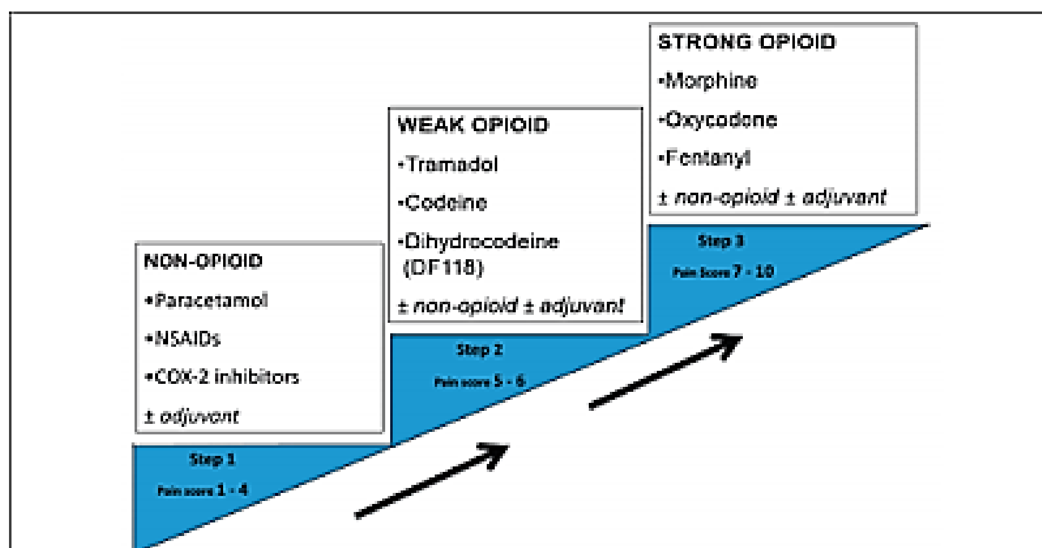

Figure 1. Three-step Analgesic Ladder

Source: Adapted from World Health Organization. Cancer pain relief (Second Edition) with a guide to opioid availability. Geneva: WHO; 1996

Adjuvants are drugs that are usually used in patients with neuropathic or other pain producing mechanisms.

Some of these measures mentioned below may be useful in managing a dying patient

- Try to shift to a single room- dim lighting with minimal disturbance
- Stop unnecessary observations and remove unnecessary lines and tubes
- Address the spiritual needs of the dying patient
- Antibiotics for pneumonia or aspiration should be given if symptoms suggest such involvement. Troublesome respiratory secretions can be managed with Hyoscine with possible side effects of dry mouth and urinary retention.
- Anxiety can be managed with lorazepam or midazolam
- Keep mouth moist with ice flakes or moist cotton.
- The caregiver needs a lot of support during the ordeal of managing a family member with a terminal illness. Adequate psychosocial and financial support, regular appraisal during the
- Dying process and contacting them after the patient passes away can be helpful to tide over the crisis.

4. Myths and realities

- **Palliative care hastens death.**
  Untrue. Palliative care does not hasten death. It provides comfort and the best quality of life from diagnosis of an advanced illness until end of life.

- **Palliative care is only for people dying of cancer.**
  Untrue. Palliative care can benefit patients and their families from the time of diagnosis of any illness that may shorten life.

- **Palliative care is only provided in a hospital.**
  Untrue. Palliative care can be provided wherever the patient lives – home, long-term care facility, hospice or hospital.

5. References

10 Myths about Palliative Care. (Internet, available from http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/What+Is+Palliative+Care_/10+Myths+about+Palliative+Care.aspx)