



# Need for Home Based Palliative Care & Role of Volunteers

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- What is home based palliative care?
- Why this home based palliative care?
- Who needs this care?
- When to initiate home care?
- Why integrate with hospital or hospice?
- Volunteers as part of the TEAM
- Role of Volunteers

# What is home-based palliative care?



Matching CARE to changing needs for a person with an incurable illness, at his/her home .

- Care provided at home to support the family
- Care provided at home to improve quality of life and death
- Trying to meet the palliative care needs .
- Empowering the family to take care of the person till the end.
- Aim is to facilitate a good and peaceful death at home and help the family to cope



# Why home-based Palliative care?

**Home based palliative care is considered the backbone of palliative care services.**

1. Patients are cared for in their own home environment and are much more *comfortable* than in a hospital, which is alien to them and is usually associated with fear and anxiety.
2. The expenses incurred by the patient and his/her family are very less when home-based palliative care is provided to them than when they receive care from a hospital-based care setting.
3. The difficulties experienced by the patient and his/ her family during transportation to hospitals is completely avoided when care is provided at patients' own home.
4. Visit by a care provider to the patient's home provides an opportunity to assess a complete picture of the patient and the family, which is crucial to plan the care.
5. There is only minimal disturbance/disruption to family dynamics when the patient is cared for at home than in the hospital.
6. There is a possible financial gain to the family as expenditure in terms of transportation charges, In-patient charges are avoided when the patient is cared for at home.
7. The involvement and *empowering the family* in patient care is better when the care is provided at home.



# Why Home based Palliative care?

8. Networking of neighbours and their involvement in patient care can be effectively achieved through home-based palliative care.
9. The **quality of death and dying experience is very often better** when a patient receives home-based palliative care.
10. Home-based palliative care is **less expensive** and less demanding on health-care infrastructure than hospital-based care setting
11. A home-based approach provides advice and support to family members to help them as caregivers, and the home-care team is able to facilitate referral to additional services.
12. On the one hand, home-based care helps the patient and family maintain privacy and confidentiality, but on the other hand it helps to **increase community awareness** of palliative care.
13. Local resources and support networks can be mobilized and training can be provided by community health workers to others in the local area.
14. Bereavement care is better facilitated.
15. **Effective home care should be a component of integrated palliative care program.**



# To whom is home-based palliative care provided?

1. Long-term illnesses in both adults and children
2. Terminal illnesses
3. Old age-related illnesses and debilities
4. Economically challenged patients who cannot access conventional medical care
5. Patients who are terminally ill and bedridden who cannot be brought to the hospital



## When to initiate Palliative Home Care

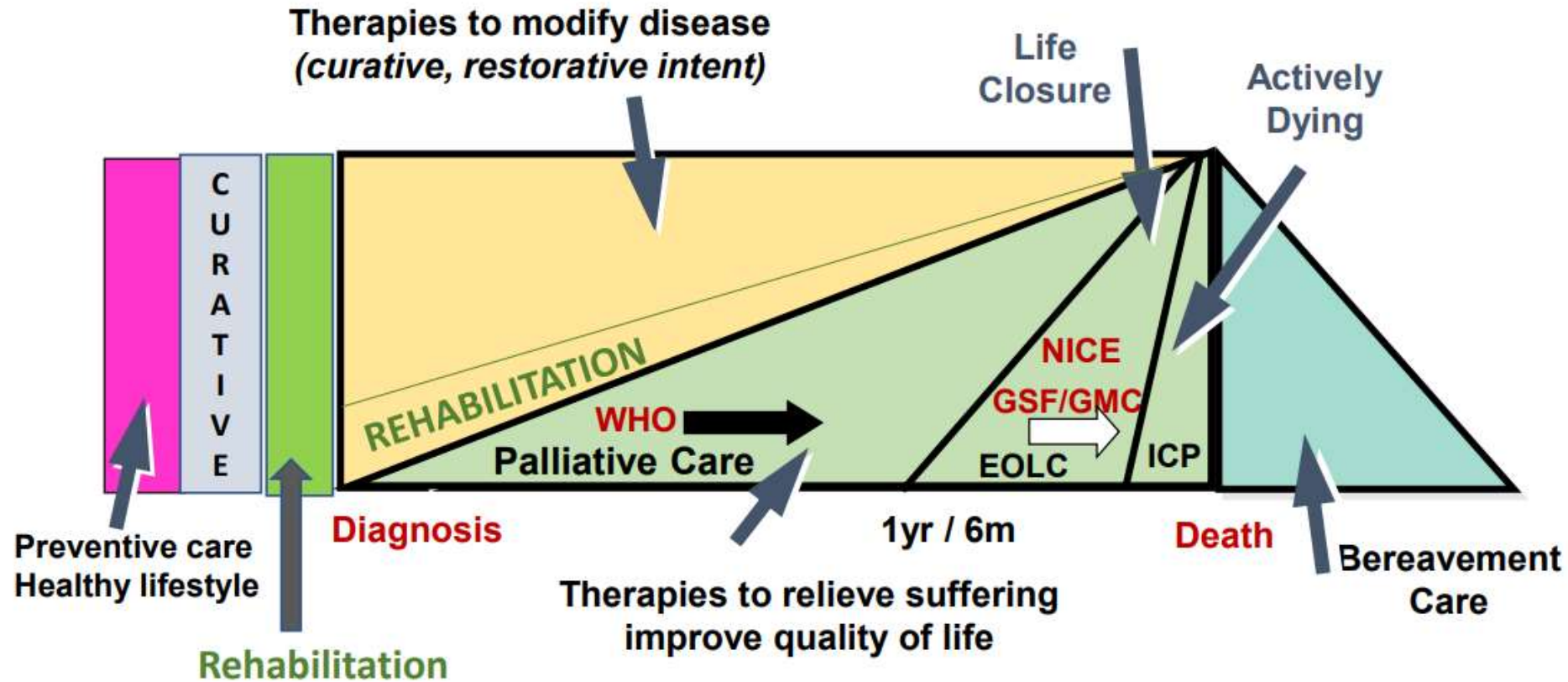
- When they become home bound, or bed bound
- When the person is approaching the end-of-life
- Start soon if referred late and entering the actively dying phase



# The continuum of (palliative) care

Modified from-

<http://depts.washington.edu/pallcare/training/ppt.shtml>





# Why multidisciplinary & multipronged approach?

- Culturally acceptable
- Very cost effective
- Facilitates good, rapid and effective communication
- Co-ordination of services easily done.
- Facilitates quick achievement of Pt goals
- Difficult ground realities tackled easily
- Facilitates discussion to understand the person & the Family
- Burn out is perhaps less as quick ventilation of feelings possible

# Who are the members of the Homecare team?

- The members of the homecare team can vary from place to place based on the availability and need for the professional caregivers and community caregivers.
- The homecare team can be a combination of any of the following members. Doctors, Staff Nurses, Community/Auxiliary Nurses, Palliative care assistants, Physiotherapist, Psychologist, Social worker, Community volunteer, Chaplain/Spiritual healer and Trainees.
- Home-based palliative care is mostly provided by the nurses (NHC- Nurses Home care), but as per the availability and requirement, other care professionals and non-professionals are also involved in providing home-based palliative care.

# Requirement for a home based palliative care

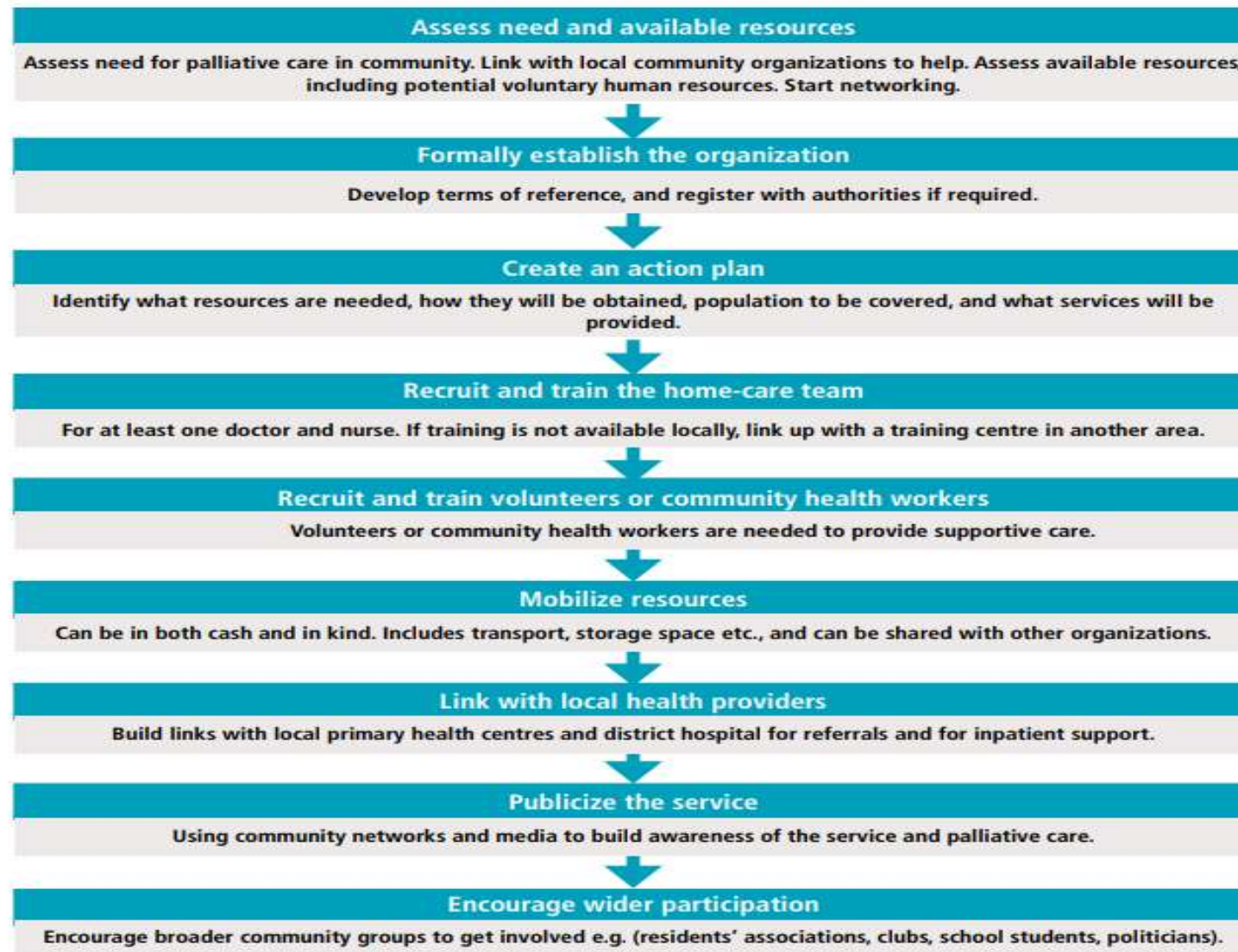


# Training requirements for PC Providers

	Basic	Mid-level	Advanced
Doctors	Foundation courses (3-10 days)	Residential course (6 weeks)	Fellowship/postgraduate qualification in palliative care (1-3 years)
Nurses	Foundation courses (3-10 days)	Residential course (6 weeks)	Certificate course (4 months), fellow- ship (1 year)
Community health workers	3-6 hours to supplement prior training	Basic course (3 months/400 hours)	Advanced communication skills/ lymphoedema management
Volunteers	Introductory course (3 hours)	16 hours theory + 4 clinical sessions,	Advanced communication skills and train-the-trainer course

<sup>1</sup> Note: Minimum requirements for home-care team depend greatly on the format of the health system. There are countries where nurses play a larger role, and others where home care is conducted more by doctors.

# Steps for establishing a home based palliative care service



## How to prepare for home care visits?

The homecare visit made by the home care team is of three types. Preparation for the home care visit is different for each type.

- 1. The first visit of a newly registered patient
- 2. Follow-up visit of an already registered patient a. Including Bereavement care visit
- 3. Emergency visit of an already registered patient

# General guidelines to be followed during a homecare visit

- Always seek patients'/family's consent before making a homecare visit
- Introduce all the members of the homecare team to the patient and the family caregivers
- Members of the homecare team should dress appropriately, in line with local cultural values
- Seek consent of the patient/family before performing any interventions during homecare visit. This includes explaining the benefits of the procedure and risks associated with the procedure and giving time for the patient and the family to make an informed decision.
- Taking photographs/videos should be done only after taking permission from the patient/family.
- Conversation between the team members that excludes the patient and the family should be avoided.
- Ensure that the home care vehicle is locked and the medications are secure during the home visits.
- When homecare visits for the days is complete, the medications and other equipment should be returned to the area allotted in the PC office. They should not be kept in the homecare vehicle.

## Possible limitations of homecare

1. The selection of patients for care under home-care services is very important as all patients and conditions may not be suited for home-care.
2. Running a homecare service of good quality requires the support of Outpatient and In-patient services in the nearby vicinity.
3. There may be an additional burden to the primary caregiver when the patient is cared for at home and may lead to burn-out.
4. Access to homecare at odd hours is a limitation if there no emergency homecare system
5. Some medical procedures that involve significant risk and continuous monitoring cannot be done at home.



## Who are the patients who should receive higher priority for regular homecare visits?

- **Accessibility:** Homecare priority is given to patients with limited accessibility. The limited accessibility could be due to physical constraints, financial constraints and geographic constraints.
- **Unsettled problems:** Patients with poor symptom control and End of life symptoms will require frequent homecare visits.
- **Patients who require procedures (like catheter change)**

## Identifying patients in need of palliative care in the community (Screening Tool)

Tool is developed based on the status of various patients enrolled for palliative care in Kerala. It is a non-disease specific tool and can be used by doctors, nurses and community volunteers.

The score ranges from 0 to 24. The tool contains 8 components. The total score is the sum of the scores of all 8 components. Any patient with a score above 10 should be clinically evaluated for palliative care. This tool is now being used by palliative care teams in Bangladesh and Kerala. Components included

1. Mobility Level
2. Activity Level
3. Ability to self-care
4. Eating and Drinking
5. Consciousness
6. Pain
7. Other symptoms
8. Anxious/ Depressed/ Worried

# Essential palliative medicines

S No	Drug name	Dosage
1	Alprazolam	0.25mg/0.50mg
2	Albendazole	400mg
3	Amitriptyline	10mg/25gm
4	Amlodipine	2.5mg/5mg
5	Amoxicillin	250mg/500mg
6	Amoxicillin and potassium clavulanate	625mg
7	Antacid Syrup	
8	Aspirin	75mg/150mg
9	Atenolol	50mg
10	Atorvastatin	10mg
11	Azithromycin	500mg
12	B-complex	
13	Baclofen	10mg
14	Bisacodyl	5mg/10mg
15	Calcium and Vitamin D3	500mg
16	Carbamazepine	200mg
17	Cetirizine	10mg
18	Chlorpheniramine maleate	4mg
19	Ciprofloxacin	500mg
20	Ciprofloxacin and Tinidazole (combination)	500mg and 600mg
21	Clopidogrel	75mg
22	Clonazepam	0.5mg
23	Cremaffin (Liquid Paraffin + Milk of Magnesia)	
24	Cough syrup	
25	Dexamethasone	4mg/8mg
26	Diazepam	5mg
27	Diclofenac	50mg
28	Dicyclomine	10mg

29	Domperidone	10mg
30	Enalapril	5mg
31	Enema (Sodium Phosphate)	
32	Etamsylate	250mg
33	Etophylline and Theophylline	100mg
34	Fluconazole	150mg
35	Fluoxetine	20mg
36	Folic acid	5mg
37	Furosemide	20mg/40mg
38	Glibenclamide	5mg
39	Glycopyrrolate	1mg
40	Haloperidol	5mg
41	Loperamide	2mg
42	Lorazepam	1mg/2mg
43	Meloxicam	15mg
44	Metformin	500mg
45	Metoclopramide	10mg
46	Metronidazole (Coated/uncoated)	400mg
47	Morphine**	10mg, 20mg, 50mg
48	Multi-vitamin	
49	Norfloxacin	400mg
50	Omeprazole	20mg
51	Ondansetron	4mg/8mg
52	ORS Sachets	
53	Pantoprazole	40mg
54	Paracetamol	500mg/650mg
55	Pheniramine maleate	25mg
56	Phenobarbitone	30mg/60mg
57	Phenytoin sodium	100mg
58	Ranitidine	150mg
59	Risperidone	2mg
60	Isosorbide dinitrate	10mg/20mg
61	Salbutamol	2mg

62	Sertraline	50mg
63	Sodium Valproate	200mg
64	Sucralfate	1mg
65	Sucralfate Syrup	
66	Terazosin	1mg
67	Telmisartan	20mg/40mg
68	Tramadol	50mg
69	Trihexyphenidyl	2mg
70	Turpentine Oil	

**\*\*According to the NDPS amendment act 2015, Morphine can be transported in the palliative homecare vehicle. The number of morphine tablets taken into the homecare vehicle should be recorded in the daily account register and the return of the same should be documented in the daily account register.**

#### Parenteral injections to be carried for home care

S.No	Drug name (Oral)	Dosage
1	Atropine	0.6mg/1mg
2	Adrenaline	1mg (1:1000)
3	Dexamethasone	8mg
4	Dextrose	5%,10%,25%, 50%
5	Diazepam	5mg
6	Etamsylate	125mg
7	Etophylline& Theophylline (Deriphylline)	100mg
8	Furosemide	20mg/40mg
9	Glycopyrrolate	0.2mg
10	Haloperidol	5mg
11	Ketamine	
12	Lignocaine	
13	Metoclopramide	10mg
14	Metronidazole	500mg
15	Midazolam	1mg/mL



16	Normal Saline	
17	Ondansetron	8mg
18	Paracetamol	1000mg
19	Phenytoin	50mg/mL
20	Ranitidine	50mg

# Essential Equipments for Home Care

## Essential equipment to be carried for home care

1. Sphygmomanometer
2. Stethoscope
3. Digital Thermometer
4. Flexible measuring tape
5. Glucometer and strips
6. Sterile tray
  - a. Wound dressing
  - b. Catheter change
  - c. Ascitic tapping
7. Sterile blade
8. Scissors
9. Disposable shaving set
10. Nail cutter
11. Crepe bandage (2-inch, 4-inch, 6-inch)
12. Surgical Spirit
13. Sterile Syringe
  - a. 2mL
  - b. 5mL
  - c. 10mL
  - d. 20mL
  - e. 50mL
14. Sterile needles (1 ½ inch)
  - a. 18G
  - b. 20G
  - c. 22G
  - d. 23G
  - e. 24G
15. Cotton pack
16. Foley's Catheter
  - a. 14F
  - b. 16F
  - c. 18F
17. Nel Cath
18. Urobag
19. Nasogastric tube
  - a. 14FG
  - b. 16FG
20. Micropore plaster
21. Elastoplast
22. IV cannula
  - a. 20FG
  - b. 22FG
  - c. 24FG
23. Scalp vein set
  - a. 21G
  - b. 23G
24. IV set
25. Mask
26. Apron
27. Goggles
28. Sterile gloves (6.5 and 7 size)
29. Clean gloves (6.5 and 7 size)
30. Liquid soap
31. Hand sanitizer
32. Povidone Iodine
33. Torchlight
34. Waste collection containers
  - a. For sharps (Puncture-proof container)
  - b. For soiled gauze and bandages
  - c. For soiled equipment

# VOLUNTEERS



Patient and Family



Healthcare Workers


- Improves Quality of Life
- Spreading Awareness
- Community Participation



# VOLUNTEERS IN PALLIATIVE CARE

Research article | [Open Access](#) | [Published: 14 March 2017](#)

## To be a trained and supported volunteer in palliative care – a phenomenological study

[Ulrika Söderhamn](#) , [Sylvi Flateland](#), [Marthe Fensli](#) & [Ragnhild Skaar](#)

*BMC Palliative Care* **16**, Article number: 18 (2017) | [Cite this article](#)

7110 Accesses | 20 Citations | 13 Altmetric | [Metrics](#)

### Abstract


#### Background

It has been found that including volunteers in palliative care is a positive contribution to seriously ill patients. It is, however, recommended that the volunteers are trained and supported. The aim of this study was to describe a group of trained and supported volunteers' lived experiences as volunteers in palliative care within the community health care services.

### Conclusions

The findings showed that trained and supported volunteers among seriously ill or dying people within the realm of community health care services play an independent and important role in the palliative care team. A coordinator in palliative care is especially suitable for training and supporting the volunteers.

## The role of volunteers in Palliative care

 [Blazenka Eror Matic](#)

Volunteers are recognized as the third resource for palliative patients alongside with professional care and family care. They do not replace them. Volunteers have their own special place and their specific role in that care. Besides the volunteers who will be directly with the patient and the family, volunteers who are involved in organizing, fundraising, promotion and various other roles are also important. In order to help volunteers to play their role and to make this assistance sustainable, it is important to have volunteer organizer (manager) that links all three care resources (family, professionals and volunteers).



*Palliat Med.* 2018 Jul; 32(7): 1233–1245.

Published online 2018 May 8. doi: [10.1177/0269218318772263](https://doi.org/10.1177/0269218318772263)

PMCID: [PMC6050945](#)

PMID: [29737245](#)

### Palliative care volunteerism across the healthcare system: A survey study

[Steven Vanderstichelen](#)<sup>1</sup>, [Dirk Houltelier](#)<sup>1</sup>, [Joachim Cohen](#)<sup>1</sup>, [Yanna Van Wesemael](#)<sup>2</sup>, [Luc Deliens](#)<sup>1,3</sup> and [Kenneth Chambaere](#)<sup>1</sup>

## Volunteers in Palliative Care Make A Difference

February 2009 · *Journal of Palliative Care* 25(1):30-9

DOI: [10.1177/082585970902500104](https://doi.org/10.1177/082585970902500104)

Source · [PubMed](#)

# Community participation

- Regular continuous emotional support for the patients and the family.
- Data collection/needs assessment
- Social support to the patient
- Wound care ,bed sore prevention, mobility
- Organisation and administration of palliative care services including fund raising





# Role of a volunteer

- Be a good listener
- Get to know the person & family
- Be a good observer
- Assess if person is being neglected and report to team.
- Keep in touch with the palliative care team
- Check if family is following instructions given by the team
- Encourage frank communication within family
- Ascertain wishes of the person and help family to meet them
- Facilitate completion of unfinished business
- Be a calming presence when situation is stressful.
- Become a friend of the person and family



# Role of Community Volunteer



***“You matter because you are you , and you matter to the end of your life .We will do all we can not only to help you die peacefully ,but also to live until you die.”***

*Dame Cicely Saunders*

***Thank you***

