

Developing Human & Social Capital to build a resurgent India



# **Palliative Care in collaboration with Mysore**

# **Medical College and Research Institute**



**Standard Operating Protocol for Palliative Care Volunteers** 

# **Table of Content:**

•	Introduction	. 2
•	Why should you volunteer?	. 3
•	Roles of Volunteers	. 4
•	Guidelines for Volunteers	6
•	Management	. 7
•	Application Form	. 8

#### **Introduction:**

Palliative care is specialized care to improve the quality of life from healthrelated suffering. In India, there is a greater need for palliative care than in the west as disease-specific treatment does not reach patients adequately or early enough. Palliative care is beyond just end-of-life care, is not limited to specific age groups, and care can be with or without curative intent. The care can vary based on what the patient or the family need. Palliative care is an increasing NCD burden in India with at least 40 million people needing palliative care each year. 1 in 5 suicides in India is committed by a person living with a progressive, chronic, or life-limiting condition. In Karnataka, less than 2% of patients who need palliative care receive it. In Mysore alone, many people need it, but only 600 people are reached. This is where SVYM comes in as they provide free access to palliative care throughout Mysore. SVYM is too small to get everyone, which is where volunteers come in.

Volunteering in palliative care is defined as "the time freely given by individuals, with no expectation of financial gain, within some form of organized structure other than the already existing social relations or familial ties, with a palliative approach, i.e. the intention of improving the quality of life" (Vanderstichelen et al). Palliative care's goal is to improve the quality of life and relieve the suffering of patients and their families as they navigate life-threatening illnesses. This can be done with help from volunteers. Volunteers are essential in

2

providing patients with the utmost positive care in palliative care. Volunteers can significantly affect the quality of care for patients and their families by helping them emotionally, socially, and spiritually whether it's through at-home care, outpatients, or patients. They offer companionship to both patients and family by offering guidance through engagement and compassion. Volunteers are a vital part of providing palliative care to patients by being a support system, which is why you should volunteer to significantly impact people's lives.

#### Why should you volunteer?

"Palliative care can be the trigger to build kinship in communities," said Dr. Balasubramanya, noting that nuclear families have become more prevalent in India. "It appeals to a larger context. Everyone feels isolated, a stranger within their community; what is better than health care for showing concern for a fellow human being?" You should volunteer because you would be helping people at their most vulnerable times. It can provide an opportunity for experiential learning of social reality and gratitude towards life. The critical role is to comfort the patients and improve their quality of life through different services. SVYM is made possible with the contribution from support from the community members, as they provide free palliative to those who need it, and by having more volunteers the services can reach more people. Palliative care can transform someone's life and you could be the one to bring that change. Whether you are a student interested in

3

Medicine, a high school student, retired person, anyone can become a volunteer and be part of the difference.

### **<u>Role of Volunteers</u>** -

Volunteering as part of the SVYM palliative care team means providing services to improve patients' quality of life and offering a support system. There are different roles for everyone, from medical to non-medical personnel. There are various roles you can fulfill and these are some examples you could participate in by becoming a volunteer.

Medical Staff:

- House Visits
- Checking the progress of caretaker/caregiver
- Monitoring progress, patients' health, and drug usage
- Routine check-ups
- Nutrition supports
- Counselings Supports
  - Counseling the patients, family, neighbors/community
  - $\circ~$  Open to social workers, counselors, psychology students, or any

passionate individual with training

Paramedical:



- Counseling
- Physiotherapy training
- Medical Aid
- Awareness session about palliative care
- Train with healthcare workers to learn about patients' illnesses to assess the situation and provide the best care the patient wants and needs

# Any Volunteer:

- Providing food/ food grains
- Providing transportation
- Recreational activities
- Give emotional and spiritual support
- Training personal hygiene, and nutritional education
- Can help out a neighbor
- Train caregiver if needed
- Can financially support to the patients directly
- Promote food pantry
- Connecting with hotels to get food/ food grains
- Link to potential business enterprises
- Reference to additional care i.e. old age care



### **Guidelines for volunteer**

- Must be 14 years of age to become a volunteer (with parental consent if under 18)
- Be open-minded and willing to learn
- MUST protect the confidentiality of patients
- Remember care is based on the need of patients and not their disease
- Offer compassion and be empathic
- Do not accept gifts or money from patients or family members
- Be patient when building relationship with patients and have open communication with both the patients and their family along with the coordinators
- Helps patients gain the strength to carry on with daily life
- Be respectful to the values of the organization and offer sincere service
- Communicate with coordinators about the patients to ensure relationships are being established
- Don't force a relationship if the patients don't wish to have one
- Do not forget that you are not there to cure them
- Stay within the boundary of volunteer placement description



#### Management

Volunteering can not only be beneficial to oneself but helpful to the programs by providing support to offer patients with the best services possible. However, for this work, it will require for the volunteer to cooperate with the organization's values and have open communication about their work with the patients. Volunteers are expected to communicate with the organization to ensure relationships with the patient within the first 3-4 visits. The organization is responsible for making sure that volunteers are treated well. In return, the organization benefits by getting the volunteer extra effort and good quality work. Volunteers can be recruited through individual approaches, universities and schools, and the community. Opening up for future engagement for all the future volunteers. With cooperation, there can be room for feedback and suggestion to improve the organization and ways to establish relationships with patients and family best. Providing evaluation will help assure patients are benefiting from the services being provided to them, and the volunteers are also comfortable and suitable for the assignment. Ensure the patients are aware that their data might be used as a teaching experience by getting consent or reinstating consent. Data is to be not to be shared with outsiders to protect the privacy of patients. Only share with those who are caring for the patients with permission from the patient. Fill out the Volunteer Application and join the SVYM palliative care team!!



# Personal Info

Name Of the Volunteer:

Address:

Date of Birth:	Sex:
Email:	Phone Number:

Education Qualification:

Occupation:

What is your area of expertise?

Any previous experience in palliative care?

What are your duration, start, and end date?

How did you hear about SVYM's Palliative care?

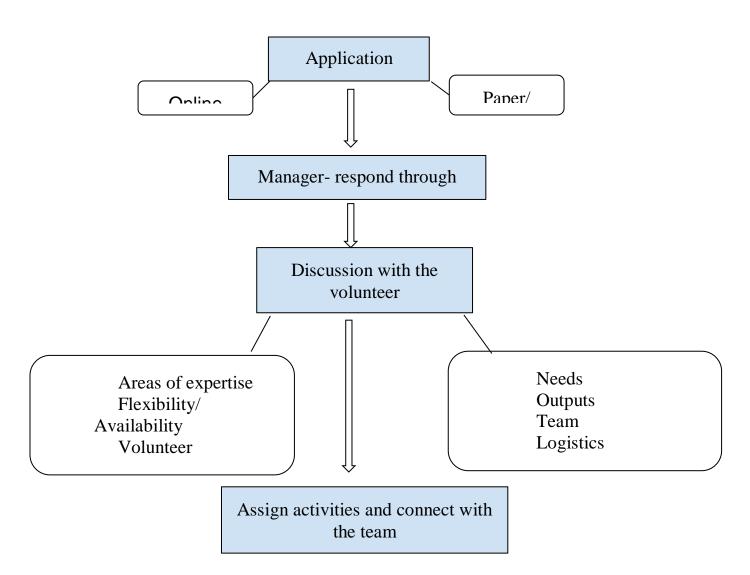
Languages known/ spoken/ writing:

Skills and Interests:

Patients have given consent, but reiterate the consent to ensure that they are aware that their data could be used as a learning experience.

I hereby state that I have gone through and understood the above guidelines for Volunteering. I
give my consent to abide by the stipulations mentioned and extend my commitment as per my
option indicated to volunteer for the period

Signature:	
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#### **Contact Info:**

Email: palliativecare@svym.org.in

Phone: +91 9686666155

Volunteer open services: 9:30 am- 4:30 pm

#### Feedback/ Suggestions: