

SVYM Palliative Care Locations:
Bengaluru, Dharwad, Hassan,
Mysuru, Saragur



SVYM PALLIATIVE CARE

MENTORS: DR. VEENA TA AND DR. VIDYA N.

Hosting a
Caregiver's
Meeting Manual

Created by:
Eunice Abigail Kang





Purpose of Manual:

In India, caregivers are more commonly family members. Empowering caregivers to cope with common mental and physical barriers will progress SVYM's movement towards a sustainable palliative care model.

The purpose of this manual is to provide a guideline for those hosting a caregivers meeting. The host should be able to explain the expected roles, responsibilities, and healthy habits of a caregiver. Explaining these factors is integral in being a reliable source of information and support for both patients and caregivers.

When caregivers come to our SVYM Palliative Care Centers, they arrive in a vulnerable emotional state, and sometimes a vulnerable physical state. Being able to provide the proper information as well as an environment of compassion and support is of utmost importance. The caregivers are who the patients fall back on. Thus, making sure that the caregivers are well educated resultantly would create a stronger environment for the patient as well.

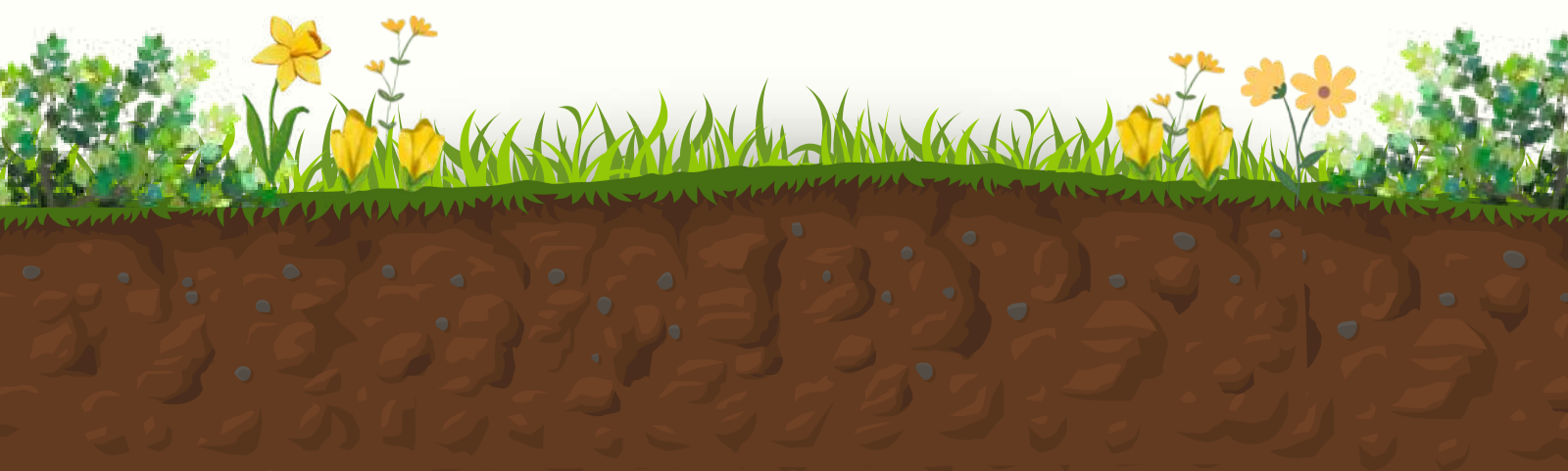




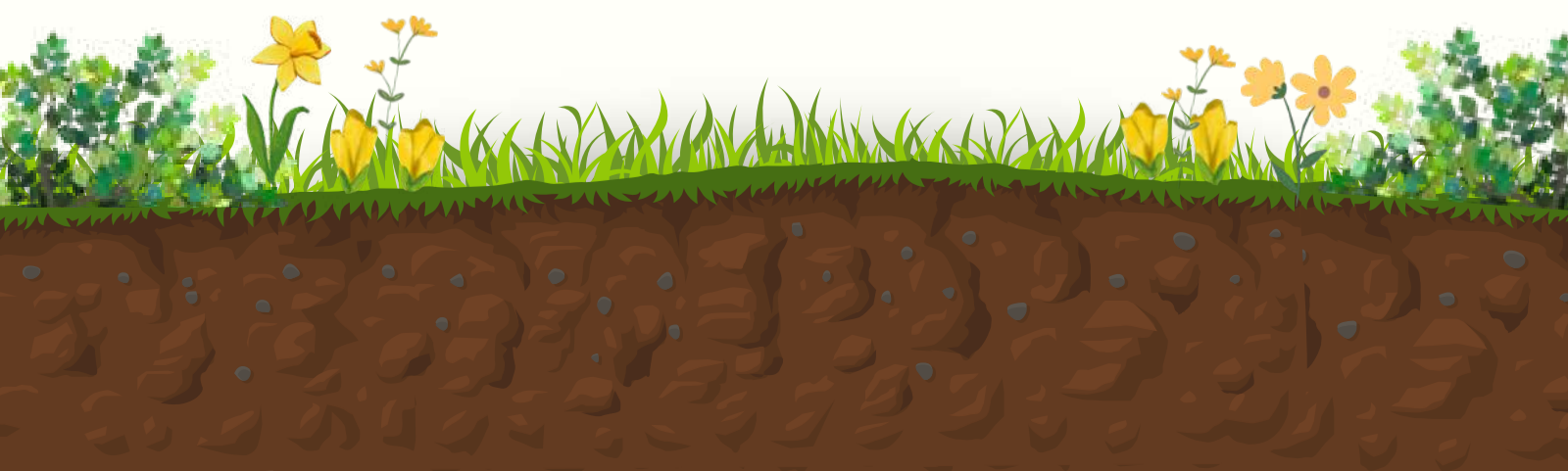
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WHO CAN CONDUCT CAREGIVER MEETINGS?



PALLIATIVE CARE TEAM:

DOCTORS



NURSES



COUNSELORS



VOLUNTEERS



HEALTHCARE
FACILITATORS



PREPARING FOR A CAREGIVER'S MEETING

MINDFUL OF ENVIRONMENT

Be mindful of choosing a location that is open, comfortable, and conducive to having this meeting.



THINK ABOUT NUMBERS

Each meeting should ideally have no less than 5 caregivers and no more than 15 caregivers.



HOW AUDIBLE ARE YOU?

When speaking, is your voice audible to all participants? Are you speaking slowly, clearly, and confidently? If audio is not clear, equipment may be needed.



EMOTIONALLY PREPARE YOURSELF

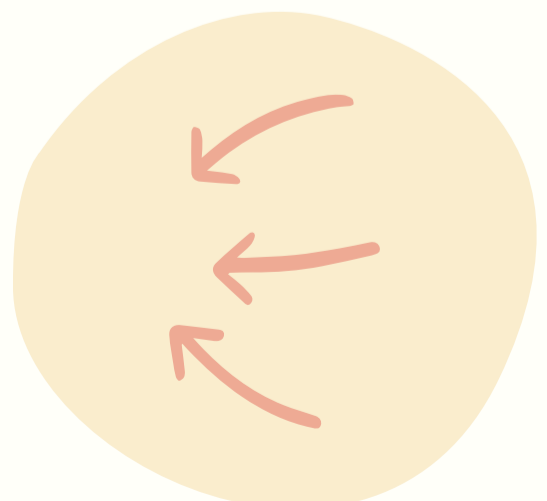
When speaking to a vulnerable group, it is important to settle your mind and prepare to be a comforting advocate for them. One should be mindful of tone and creating a space of trust and empathy.



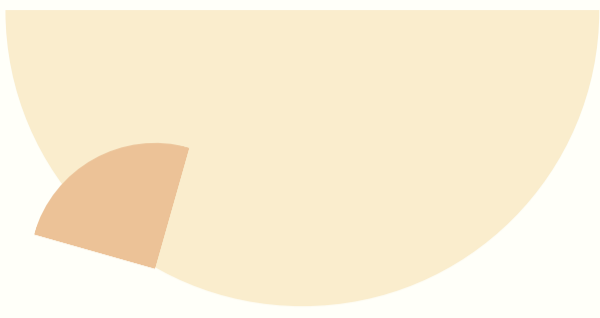
PREPARE TO DISCUSS

These arrows on the manual represent discussion reminders!

This meeting is not meant to be a lecture for the caregivers. Make sure to engage with the audience by asking questions and leading them into the topics.

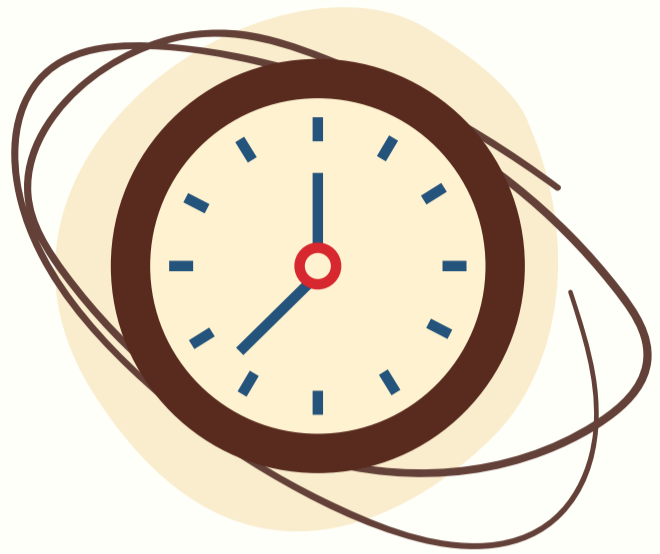


TIMING EACH MEETING SECTION



TIMING

Each section should be explained in a concise yet informative manner



~ 15 min

Passing Out
Caregiver Assessment Form

~ 5 min

Staff and Caregiver
Introductions

~ 10 min

What is Palliative Care?

~ 15 min

5 Aspects of
Palliative Care

~ 10 min

Who is a Caregiver?

~ 20 min

Caregiver Roles and
Responsibilities

~ 5 min

Questions? Feedback?

~ 5 min

Recreational Time

60 min ~ 70 min



~15 min

Now, Let's Begin!



PASS OUT CAREGIVER ASSESSMENT FORM

First, allot 10-15 minutes for all caregivers to fill out the mandatory form. Answer any questions they may have.

SVYM Palliative Care Center: Caregiver Assessment Form

Date: _____

Caregiver Name:		Age:																									
Contact Number:		Gender: Male / Female / Other																									
Patient Name:		Age:																									
Diagnosis:		Gender: Male / Female / Other																									
1) Relationship to individual receiving care <input type="radio"/> Self <input type="radio"/> Family <input type="radio"/> Extended Family <input type="radio"/> Other: _____		2) Are you new to the SVYM Palliative Care Center? Yes / No Have you been previously oriented as a caregiver? If yes, by whom, when, and where? _____																									
3) Are you the main caregiver? Yes / No	4) Do you live with the patient? Yes / No	5) Do you receive extra help for care? Yes / No If yes, who? _____																									
6) How long have you been the caregiver? <input type="radio"/> Less than one month <input type="radio"/> Less than one year <input type="radio"/> More than one year		7) How many days per week do you provide care? 1 2 3 4 5 6 7																									
8) Do both the caregiver and the patient understand these topics? <table border="1"> <thead> <tr> <th>Topic</th> <th>Caregiver</th> <th>Patient</th> </tr> </thead> <tbody> <tr><td>Nutrition</td><td>Yes / No</td><td>Yes / No</td></tr> <tr><td>Physical Care (Hygiene)</td><td>Yes / No</td><td>Yes / No</td></tr> <tr><td>Emotional Care</td><td>Yes / No</td><td>Yes / No</td></tr> <tr><td>Social Support</td><td>Yes / No</td><td>Yes / No</td></tr> <tr><td>Diagnosis Understanding</td><td>Yes / No</td><td>Yes / No</td></tr> <tr><td>Patient's Medication (How and When)</td><td>Yes / No</td><td>Yes / No</td></tr> <tr><td>Household Financial Stability</td><td>Yes / No</td><td>Yes / No</td></tr> </tbody> </table>				Topic	Caregiver	Patient	Nutrition	Yes / No	Yes / No	Physical Care (Hygiene)	Yes / No	Yes / No	Emotional Care	Yes / No	Yes / No	Social Support	Yes / No	Yes / No	Diagnosis Understanding	Yes / No	Yes / No	Patient's Medication (How and When)	Yes / No	Yes / No	Household Financial Stability	Yes / No	Yes / No
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Household Financial Stability	Yes / No	Yes / No																									
9) How stressed are you regarding financial care for both the patient and yourself? Low 1 2 3 4 5 High		10) Does anyone else provide financial support in the household? Yes / No																									
11) Are you currently employed? Yes / No	12) Do you have personal healthcare finances? Yes / No	13) Do you have any out of pocket expenditure? Yes / No																									

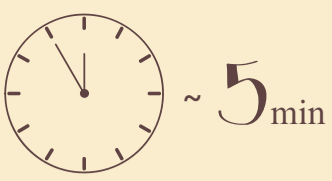


SVYM Palliative Care Center: Caregiver Assessment Form

14) How would you rate your relationship status with the patient? Poor 1 2 3 4 5 Excellent	15) "I give care out of _____." *Select all that apply <input type="checkbox"/> Love <input type="checkbox"/> Respect <input type="checkbox"/> Duty <input type="checkbox"/> Having no other alternative for care (unwillingly)
16) Is your relationship with the patient negatively affected due to any of the factors listed below? *Select all that apply <input type="checkbox"/> Prior relationship conflict <input type="checkbox"/> Inability for patient to trust <input type="checkbox"/> Patient unwilling to receive help <input type="checkbox"/> Other: _____	
17) What are the conditions of self cleanliness, patient cleanliness, and home cleanliness in your daily life? Poor 1 2 3 4 5 Excellent	18) If scale is 1-2, please explain: _____ _____
19) What are the patient's conditions regarding eating healthy and nutritious foods? Poor 1 2 3 4 5 Excellent	20) If scale is 1-2, please explain: _____ _____
21) What is your personal condition regarding eating healthy and nutritious foods? Poor 1 2 3 4 5 Excellent	22) If scale is 1-2, please explain: _____ _____
23) After providing care how do you feel? Poor 1 2 3 4 5 Excellent	26) What do you do to relax? *Select all the apply <input type="checkbox"/> Yoga <input type="checkbox"/> Meditation <input type="checkbox"/> Time in nature <input type="checkbox"/> Practicing gratitude and awe <input type="checkbox"/> Social time with friends or family <input type="checkbox"/> Hobbies: baking, cooking, music, dance <input type="checkbox"/> NA (I do not practice any relaxation techniques) <input type="checkbox"/> Other: _____
24) While providing care, what is your quality of sleep? Poor 1 2 3 4 5 Excellent	
25) Do you practice self care or relaxation techniques? Yes / Sometimes / No	



Please collect finished forms.



STAFF AND CAREGIVER INTRODUCTIONS

DOCTORS:

Background, years of work,
reason they are in palliative care



NURSES:

Background, years of work,
reason they are in palliative care

HEALTHCARE FACILITATORS/ VOLUNTEERS:

Background, years of work, reason
they are in palliative care



CAREGIVERS

Have them introduce their names
and how long they have been
caregivers



~ 10 min

WHAT IS PALLIATIVE CARE?



"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness."

SVYM's Palliative Care model includes both home based and institutionalized care



Quality of Life



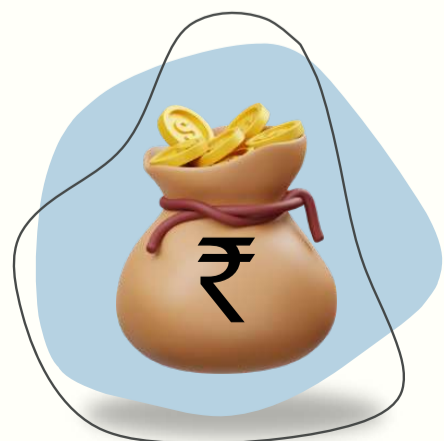
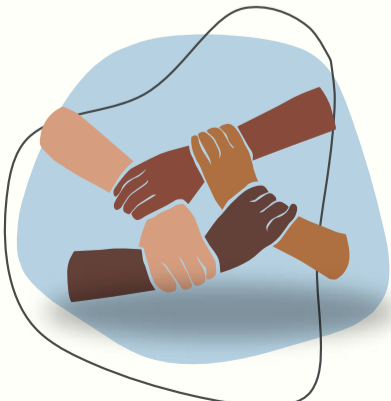
No Cure → Care

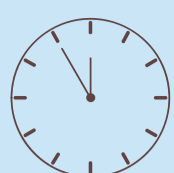


Dignity at Death



"It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual."



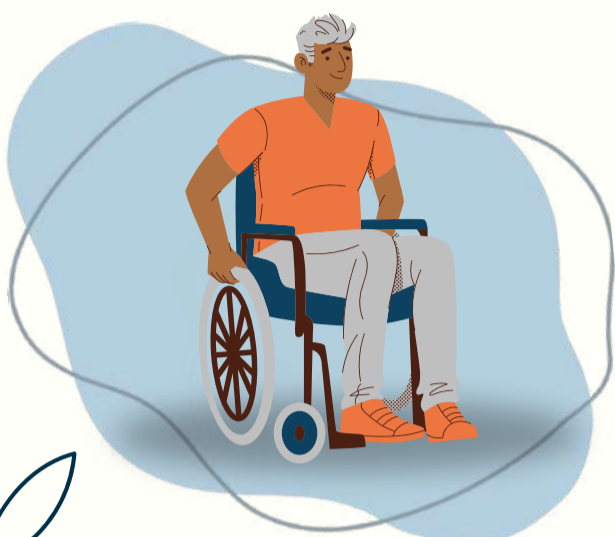


~15_{min}

5 ASPECTS OF PALLIATIVE CARE



First engage in discussion by asking the caregivers what they think the 5 aspects of SVYM's palliative care model are.



PHYSICAL SERVICES

Palliative care attends to patient pain management, symptom management, and patient medical equipment.

FINANCIAL SUPPORT

Nurses and doctors prioritize understanding the financial background and needs of each family, caregiver, and patient.



SOCIAL WELLBEING

Staff strive to create a supportive environment that serves a patient's and caregiver's social needs. This is done through recreational time and learning about the caregivers and patients.



MENTAL WELLBEING

SVYM provides counseling in order for caregivers and patients to feel better understood and to have an outlet to speak of both physical and emotional struggles.



SPIRITUALITY

Spiritual needs and desires of both the patient and the caregivers are prioritized. A holistic approach includes noting religious and spiritual backgrounds.



~ 10 min



NATIONAL
CANCER
INSTITUTE



🔍 WHO IS A CAREGIVER? ✕



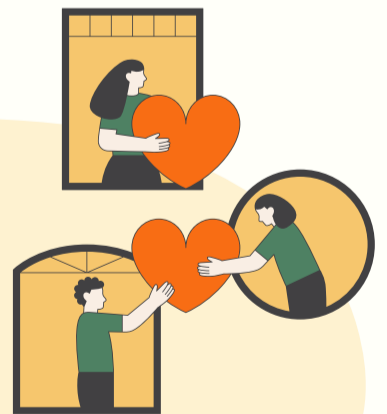
"A person who gives care to people who need help taking care of themselves."



"Examples include children, the elderly, or patients who have chronic illnesses or are disabled."



"Caregivers may be health professionals, family members, friends, or social workers."



~ anybody can be a caregiver ~



~ 20 min

CAREGIVER

ROLES AND RESPONSIBILITIES



Engage in discussion by asking the caregivers what they think basic caregiver responsibilities are.

1

Patient Physical Care

2

Patient Emotional Care

3

Caregiver Physical Care

4

Caregiver Emotional Care

PATIENT PHYSICAL CARE

PATIENT HYGIENE:



Oral Hygiene



Hair Hygiene



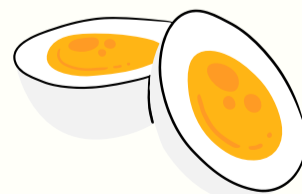
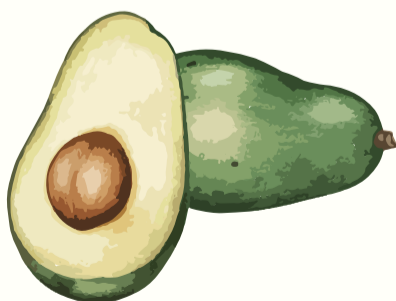
Body Hygiene



Excreta Hygiene/Aid

PATIENT NUTRITION

Having patients eat a healthy nutritious diet is important. Nutrient dense foods such as beans, yogurt, corn, fruits, and vegetables. SVYM Palliative Care also provides patients with nutrition kits if needed. Please ask nurses or doctors for further nutrition information if needed.



PATIENT PHYSICAL CARE

PATIENT FOOD CONSUMPTION ~ demonstrations can be done here ~



More abled patient:

- Prepare meal and encourage patient to independently eat.

Less abled patient:

- Prepare meal and feed patient.
- Make sure bed is between 30 to 90 degrees.

PATIENT MEDICATION



- If caregivers are unsure about what, how, and when medication should be administered to the patient, they should confide in the doctor or nurse.
- They should follow directions as told

- Remind of the importance of turning to medical professionals if they are confused.
- If they have concerns, again, they should discuss with the doctors or nurses.

First ask caregivers what they think patient emotional encompasses.

2



PATIENT EMOTIONAL CARE



EMPOWER THE PATIENT

- Encourage the patient to grow positive coping mechanisms.
- Reassure they are capable of doing their routine and activities.

GRADUALLY IMPLEMENT PATIENT AUTONOMY UNDER YOUR SUPERVISION

Gradually, patients can:

- Perform some parts of daily routine independently
- Take medication themselves at given time of day
- Feed themselves



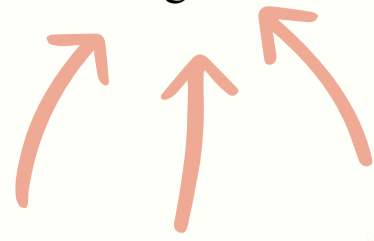
ACKNOWLEDGE PATIENT FEELINGS

- Understanding that at certain times, patient's will be frustrated, scared, and upset too.
- Acknowledging their emotions and giving them the space and support to express what they need is important.
- "Talk less and Listen More"

Ask caregivers what they currently feel regarding the topic of death. Give them a moment to connect on the shared feelings.

2

PATIENT EMOTIONAL CARE



IMPLEMENT DEATH LITERACY

“The knowledge and skills that make it possible to gain access to, understand and act upon end-of-life and death care options” - Canberra Health Literacy

CAREGIVER AND DEATH

- The topic of death can be very scary for both the patient and the caregiver.
- Introduce the topic of death and how palliative care serves to lessen the fear around it.



FEAR OF UNKNOWN ANTICIPATORY GRIEF

- Make it clear that death is something that can be talked about.
- Dealing with emotions such as anxiety, irritability, guilt, depression, and isolation is common for patients and caregivers.
- Clarify that SVYM is here to have those conversations and emotionally attend to both caregivers and patient grief needs.

COMMON CAREGIVER STRUGGLES.

3 and 4

AND

CAREGIVER PHYSICAL AND EMOTIONAL CARE



Ask caregivers to share their common daily struggles, if they are comfortable, and what they do to reduce these struggles

Stigma: Social Isolation and Loneliness

When dealing with a sick patient, there can be social stigma.

The stigma may bring one to self isolate as well as isolating the patient.



Turn to a Trusted Circle of Friends

Make time to see those who support you and holistically see you. Having a support system that listens and does not judge you is important.

Overwhelmed

When caring for a patient, it can be hard to ask for help. There can be difficulties adjusting to the routine needed to prevent burnout



Allow Yourself to Ask for Help

Allowing yourself to accept help from others is crucial to finding time for yourself and having your own needs met. This may also allow the patient to have a larger social circle as well.



Feeling Scared, Angry, Hopeless

When dealing with caring for an individual struggling with a chronic illness, the lack of solutions can build anger, frustration, and hopelessness.



Physical Activity

Physical activity is important for reducing disease, improving mood, reducing anxiety, and having better sleep. Prioritize 20-30 minutes of stretching, yoga, walking, or running everyday to reduce stress on the mind and body.



Prioritize Hobbies

Whether it is dancing, baking, cooking, listening to music, drawing, painting, or watching movies, make free time for yourself!



Eat a Balanced Diet

It is important to be physically healthy, not only for yourself but for the patient too. Nutrient-dense foods including vegetables, grains, fruits, and protein is important to incorporate in your daily meals.



Practice Gratitude and Awe

Many studies show the importance of practicing gratitude or awe. Examples include going for a walk, spending time in nature, sharing kindness with strangers and those you love, or even listening to music you enjoy





~ 5 min

QUESTIONS? FEEDBACK?





~ 5 min

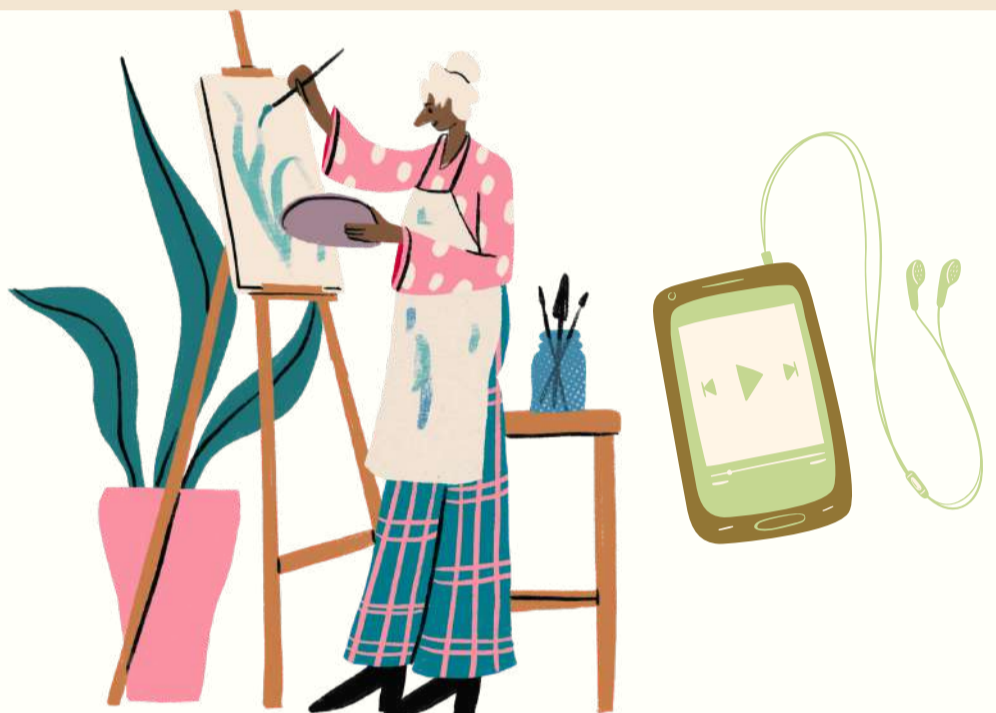
RECREATIONAL TIME

Begin recreational time and remind caregivers the importance of physical and emotional self care.



MUSICAL CHAIRS

MUSIC
OR
PAINTING



RELIGIOUS OUTINGS
OR
PRAYER TIME

GROUP MOVIE
TIME



GROUP NATURE WALK
OR
MEDITATION



WORKS CITED



“Caregiver Assessment Questionnaire - Texas Health and Human Services.” Caregiver Assessment Questionnaire, 15 Aug. 2020, www.hhs.texas.gov/sites/default/files/documents/doin-g-business-with-hhs/provider-portal/long-term-care/aaa/caregiverassessment-form.pdf.

“Death Literacy.” Canberra Health Literacy, 8 Mar. 2023, cbrhl.org.au/what-is-health-literacy/death-literacy/#:~:text=Death%20Literacy%20is%20%E2%80%9Cthe%20knowledge,people%20that%20you%20care%20for.

“NCI Dictionary of Cancer Terms.” National Cancer Institute, www.cancer.gov/publications/dictionaries/cancer-terms/def/caregiver. Accessed 30 June 2023.

“Palliative Care.” World Health Organization, www.who.int/news-room/fact-sheets/detail/palliative-care. Accessed 30 June 2023.

Patient Health Questionnaire (PHQ-9), med.stanford.edu/fastlab/research/imapp/msrs/_jcr_content/main/accordion/accordion_content3/download_256324296/file.res/PHQ9%20id%20date%2008.03.pdf. Accessed 30 June 2023.

Rajanala, Alekya et al. “Conflicts Experienced by Caregivers of Older Adults With the Health-Care System.” *Journal of patient experience* vol. 7,6 (2020): 1130-1135. doi:10.1177/2374373520921688

“Uba Household Survey Form 1.” Scribd, www.scribd.com/document/362440422/UBA-Household-Survey-Form-1. Accessed 30 June 2023.



ACKNOWLEDGEMENTS



I am deeply grateful to have been able to meet and work with each individual listed below. SVYM's Palliative Care Team has cultivated an environment of kindness, compassion, and selflessness. This process has been rich and filled with many lessons, wisdom, and human connection. Thank you to everyone who aided in process of making this manual.

I would like to express a special thanks to Dr. Veena TA and Dr. Vidya N. Both mentors have been extremely insightful, supportive, and inspiring to work with. I will forever hold the lessons, wisdom, and kindness that have been shared with me throughout my stay in Mysuru. Dr. Veena and Dr. Vidya, you both have been role models with unbreakable morals and values that I will emulate in my future pursuits in medicine and global health work.

-Eunice Kang

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“All power is within you; you can do anything and everything. Believe in that, do not believe that you are weak. You can do anything and everything, without even the guidance of anyone. Stand up and express the divinity within you.”

- Swami Vivekananda