



# Healing Hands and Caring Hearts

Stories of the SVYM Palliative Care Center

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By: Sunitha Skanda and Samantha Ivey

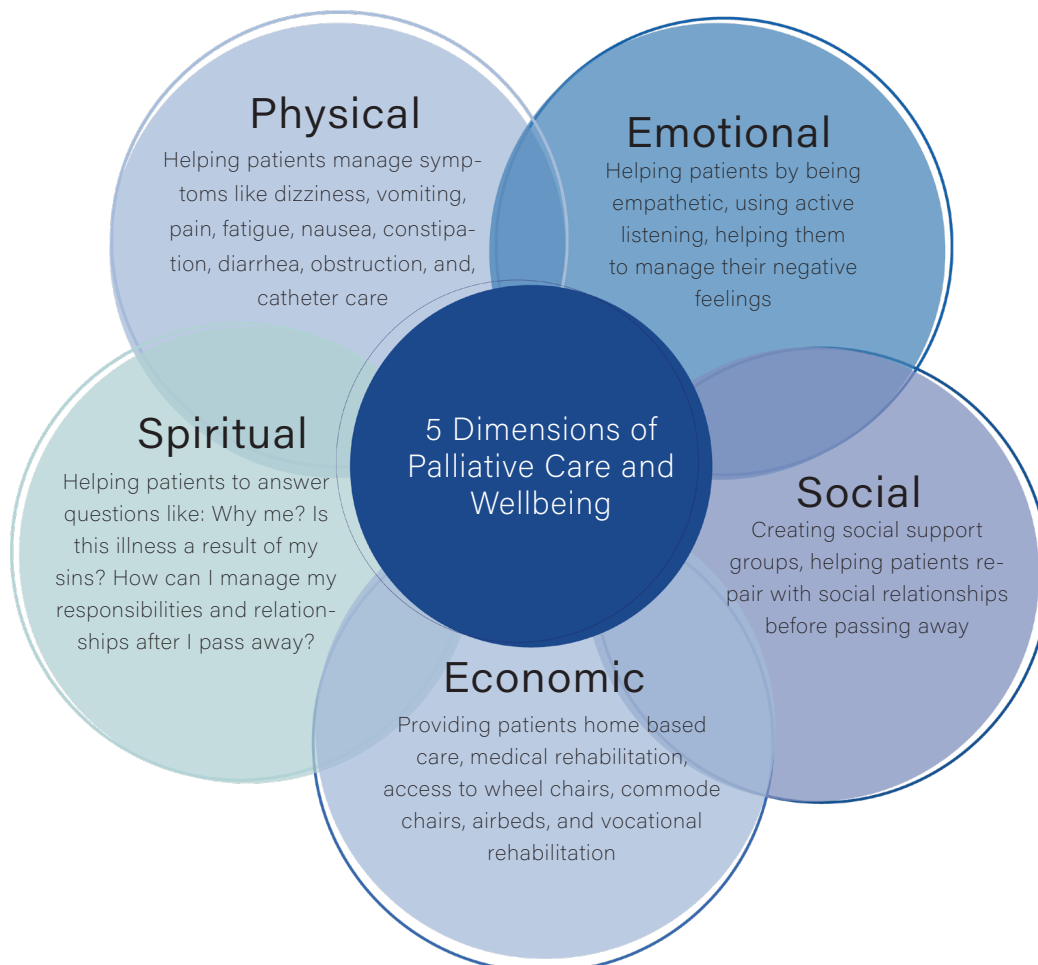
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# Introduction

## The 5 Dimensions of Palliative Care

Palliative care is a holistic approach to improving the quality of life of the patients and their families suffering from serious health-related illnesses where holistic care overrules the cure. Palliative care is delivered at different levels of the healthcare system and focuses on five dimensions of well-being for patients and their families: **physical, emotional, social, financial, and spiritual**. Palliative Care is not only end-of-life care; it can begin as soon as a patient is diagnosed with an illness in order to give them the best quality of life every step of the way. Each dimension of palliative care helps to make a person complete. When someone lacks a couple of them, life can become very difficult. Each story in this book shows different ways the SVYM Palliative Care Center helped fill the gaps in a person's wellbeing and do its best to show care, compassion and support.



# Turning Illness to Wellness

## *Kanya & Tanujamma's Story*



When you walk into the Swami Vivekananda Youth Movement building, you're guaranteed to find numerous quotes and words of wisdom from great thinkers from across the globe. One that SVYM's palliative care center embodies every day is, "When you replace 'I' with 'We' even Illness becomes Wellness." When a patient comes to stay at the palliative care center, they are also joined by their caregiver who can be anyone from a family member to a friend. Through support meetings at the center, caregivers and patients get to know each other and become a support system for each other.

One afternoon Kanya who was diagnosed with breast cancer was groaning with severe pain, despite being on pain medi-

cations. Her son was off to his work at that time and couldn't be there to provide any comfort. Another breast cancer patient, Tanujamma, who was beside her and under radiation therapy, heard Kanya's groaning of pain. Tanujamma quietly sat down next to her and began to gently massage her hand. Soon Kanya's groans began to quiet, the soft warmth and assurance of human touch was something that no pain medication could capture.

*Kanya & Tanujamma's story helps show that in Palliative Care we can all be of help to each other regardless of if you are a patient or caregiver. Kanya & Tanujamma help to show that we can share in each other's happy moments but we can also share each other's sad moments of pain.*

# Advice for Caregivers: The Power of Human Touch

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A hug. A handshake. A high five. Each form of human touch serves as communication to convey connection or compassion. Many studies have shown that human touch has a role in physical and mental wellbeing.

Touch can signal safety and trust and has the ability to soothe. Physical touch becomes even more important when other senses, like sight, hearing and speech, are no longer available for patients. Gentle touch gives the feeling of being cared for and can help ease pain, depression, and anxiety.

*Curran Parenteau, L., White, M. and Dalbec, K., 2009. Massage Therapy for Hospice and Palliative Care | AMTA. [online] American Massage Therapy Association. Available at: <<https://www.amtamassage.org/about/position-statements/massage-can-improve-quality-of-life-hospice-palliative-care/>>*

# Healing the Hidden Wounds

## *Thimayya's Story*

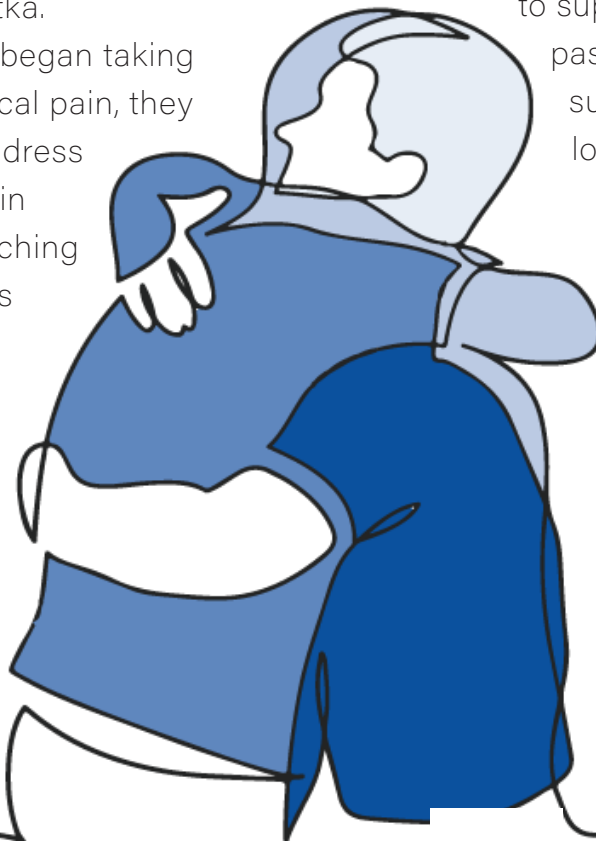
When Thimayya was brought to the palliative care center, he was in end-of-life care. He was diagnosed with metastatic squamous cell carcinoma and was suffering from severe physical and emotional pain. He had been living with his younger sister and was being cared for by his mother. It had been over five years since he had spoken to his wife or children and he felt guilty for not being able to take care of them. His family left him since throughout his life, he was an alcoholic and was addicted to smoking and gutka.

As SVYM began taking care of his physical pain, they also began to address his emotional pain starting with reaching out to Thimayya's

older son. After a few discussions over the phone with the counselor, SVYM convinced Thimayya's son to see his father in his last moments. When the two met the next day, the meeting was one full of bittersweet joy. His son was informed about his condition and he was asked to forgive his father for his mistakes since he was on his deathbed. His son held no vengeance or anger toward his father and forgave him for his shortcomings.

The next week, his son convinced the rest of his family to visit him. Over the next weeks, Thimayya's family came to support him. When Thimayya passed away at home, he was surrounded by everyone he loved.

*Thimayya's story highlights how important social care is within palliative care. Being able to resolve disputes before dying has a huge impact on someone's life and helps to relieve a lot of emotional pain and regret they carried throughout their life.*





# Caring Across Cultures

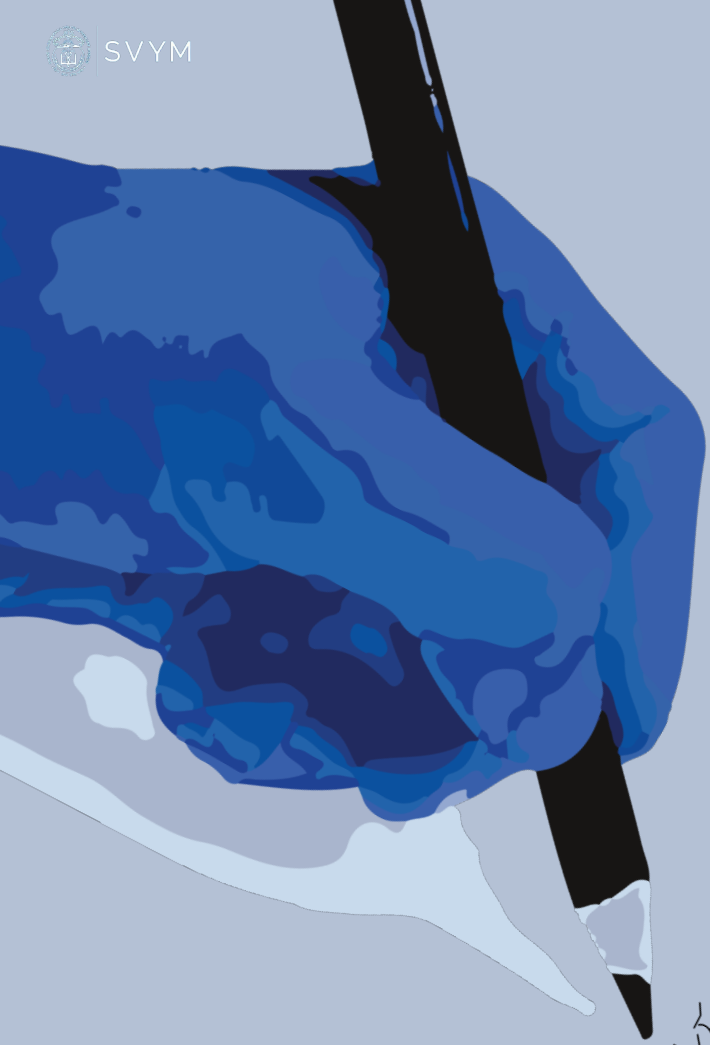
## Ganavi's Story



Ganavi came to the SVYM Palliative Care Center when doctors determined that curative care for her cervical cancer and chronic kidney disorder was no longer going to be effective, so she entered end-of-life care. Despite the prognosis, every person on the team saw her lightness, positivity, and joy. Ganavi was a loving wife and mother of three children. She worked at an NGO where she met her husband and fell in love. While she had met the love of her life, he was from a different caste which led to her and her husband losing the support of both their families. The isolation and lack of support from her and her husband's family would always impact her and would be the source of a lot of her feelings of guilt. Nevertheless, Ganavi's husband was her faithful caregiver and source of unwavering support.

While the couple had accepted her prognosis, her husband was struggling to accept that she would soon not be with him. With the help of counseling and many conversations between Ganavi, her husband, and the staff at the palliative care center, the family finally began to come to terms with her illness.

When Ganavi passed away a few months later at home, she was surrounded by her loved ones. After Ganavi's passing, her husband was in great emotional pain and missed his wife very much. When he came to palliative care a few days after her death, he shared with the counselor that both of their families still had different beliefs about Ganavi's burial rituals. He was overwhelmed with this decision on top of trying to take care of his children, especially his daughter who was pregnant. After speaking with the counselor he decided that Ganavi would go through burial rituals of both cultures.



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# You Need Not Speak To Communicate

## *Shyamanna's Story*

When Shyamanna came to the SVYM palliative care center at the beginning of the pandemic, he was suffering from buccal mucosa cancer and demyelinating neuropathy. While the condition prevented him from speaking, SVYM and Shyamanna's family discovered that he could continue to communicate through writing. Through writing, counselor and doctor could communicate with Shyamanna about how he was feeling which helped them provide better care. His ability to communicate with his family and those at the palliative care center allowed him to be empowered in his care and share his wishes and needs. In the words of the counselor, "Communication is one of the most important things in a patient's care as it results in the actual care which is required or truly needed by the patients. With patience and using different forms of communication, we will be able to communicate effectively with challenged patients. Observing non-verbal cues, sign language, using close-ended questions or putting down on paper may help the caregiver or health care professional to care better."

When it came to Shyamanna, his ability to communicate through writing helped bring him and his family closure before he passed away. One of the last things he wrote to his family was, "The symptoms of this disease are high. I don't blame myself for this cancer. All my friends and relatives are very friendly."

# Isolation



*Rehman's Story*

Although it was dark by the time Rehman's friends came to visit him at the palliative care center, the space was filled with light and joy. The five of them gathered and wheeled him around the swaying trees, laughing and joking like it was any other night they had spent together traveling the world. This was the first time they had seen each other since Rehman was diagnosed with leukemia. After the diagnosis, Rehman isolated himself from his friends and family. When he came to the Swami Vivekananda Youth Movement Palliative Care Center for end-of-life care, he was in great physical pain, unable to eat, sleep or walk, and he isolated himself from the medical team. It took a few days for Rehman to open up to the counselor to share that he was also in a great deal of emotional pain.

Before being diagnosed, Rehman was larger than life, an auto driver who loved to travel with his friends. He had

a wife and three young children that he knew he would never get to see grow up. The thought of dying was something he couldn't accept. After sharing this with the counselor, she suggested that he spend the last moments of his life with the people he loved. SVYM got in contact with his friends through his wife and they visited him the next night. When the counselor spoke to Rehman the morning after his friends visited, he shared that his friends were exactly what he needed. The next day, Rehman's friend returned with his barber, who gave him one last haircut. One by one, Rehman got in contact with each of his relatives and friends and began to feel happier and at peace with his life. Upon his death, Rehman was just as he was in life, surrounded by friends and family; love and joy.



# I Too Can Talk to You

## *Nandish's Story*



SVYM's Palliative Care team had been visiting Nandish for a while now and each monthly visit was the same. Nandish would lay silently while the team spoke to his caregivers about how he had been doing. But this time it was different. When the counselor began to interact with him, he started to communicate with her. In his own language, Nandish began to tell her about the things that brought him joy; his bracelet and his ring, all things given to him by his favorite person; his younger brother who he called 'Paapu'. While Nandish and his counselor may have spoken different languages, she was still able to understand him through her compassion and patience. It was a surprise to everyone, including the counselor and the health facilitator, that he could actually communicate.

When she spoke about the encounter later, the counselor spoke about how happy

she felt being able to speak with him for the first time. After an accident falling out of an autorickshaw at age 6, he suffered from a head injury that led to his Cerebral Palsy. Nandish's accident led to his father leaving his family and which led his mother to take care of her two sons. Since the accident, his mother took good care of Nandish and his brother. While she went to her job at a nearby school, Nandish was left in the care of his grandmother. Much like Nandish's family, adjusting to the circumstances of their life, SVYM adjusted to communicate with Nandish and provide the best care and support they could. Much like Nandish's family, adjusting to the circumstances of their life, SVYM adjusted to communicate with Nandish and provide the best care and support they could.

# Accepting the Inevitable

## *Alisha's Story*

Alisha came to the SVYM Palliative Care Center for supportive care and pain management for the symptoms she was experiencing from Breast Cancer. Her religious faith helped her and her family to accept her illness and to find peace. When Alisha was in any pain you could see her praying while holding her prayer beads. She would say that praying would help to relieve her pain. Her only concern was her children who were very supportive. Every time she spoke to the counselor she would say they were her strength and weakness.

Alisha's faith helped her to grow in her religion and also allowed her to help others in support group meetings to overcome pain. She would sit with other patients to try and help them by sharing her experiences. The counselor at the Palliative Care Center remembered how much Alisha always smiled despite the pain she was going through. Alisha's story and her presence helped to show much faith and spirituality could be a powerful source of healing and strength.

*Alisha's story highlights the importance of spiritual care. Regardless of the religion someone follows, faith is an important part of enhancing a patient's quality of life by helping them to feel the support and comfort of their belief system. Alisha's faith helped her to accept her illness but it also helped her to support and comfort other patients and caregivers during caregiver's support meetings at SVYM.*







# The Love of Family

## *Kanishka's Story*

Kanishka was 12 years old when she was admitted to the palliative care center for her severe pain. Before she was diagnosed with spinal cord cancer she was just like any other kid. She enjoyed going to school, playing with her friends, and watching cartoons. Her school friends used to visit her. But soon enough, their summer break ended, and her friends had to stop their visits while Kanishka stayed at home. But one friend remained, her younger brother Varun. Varun was 6 years old and would take very good care of his sister. While their mother would go to work as a tailor, Varun would care for Kanishka at home by giving her medication, feeding her food, and even massaging her legs. Varun was never taught how to be a caretaker but learned what to do himself by seeing his mother. The counselor of the palliative care center said that Varun is one of many examples of the empathy, compassion, and care that is present in all people. Varun's caretaking was truly important to Kanishka's medical care.

Their mother was under great stress working to support both her children. As a single parent, she was struggling and under stress after her husband passed away from a stroke a few years

before Kanishka's diagnosis. The pandemic caused a huge financial strain and it put the family in a tough position to figure out if it would be possible to support both kids. Kanishka's mother had to decide between food for the family or medicine for Kanishka. Often, her mother had to choose to support the entire family and wasn't able to take Kanishka to the hospital for treatment.

When Kanishka passed away in the center, her mother was too financially devastated to pay for Kanishka's final burial rituals. At that moment the SVYM Palliative Care Center helped to give her financial and bereavement support. When the counselor spoke to Kanishka's mother a few weeks after her death, she said that she missed her a lot but that she was also grateful that she passed away soon. The pain of seeing her child suffering was more than the pain of missing her. The pain of seeing her child suffering was more than the pain of missing her.

*Kanishka's story helps to explore emotional care through her relationship with her brother Varun. While he was a young child, he was still able to show great care and empathy for his sister. His care helps show that are each born with an ability to show empathy to those in need.*

# Reflections

## *Celebrating SVYM Palliative Care Workers*

*This section was inspired by Ms. Sunitha, a counselor at the Palliative Care center and a huge part of each of the stories in this book. When writing about her work at the center, she wrote, "Found my IKIGAI." Ikigai is a Japanese concept that expresses something that brings you joy and inspires you to get out of bed every day. Ikigai is about feeling your work makes a difference in people's lives and finding the purpose in your life. People like Ms. Sunitha and the many passionate workers of the SVYM Palliative Care center are what helps to keep the world running. Her reflections on the lessons she has learned since beginning her work are conclusions that I hope to come to myself one day. I hope you learn from her words as much as I have.*

**- Samantha Ivey**

### **Ms. Sunitha**

*Palliative Care Counselor*

The purpose of life is service. • Life is unpredictable and full of uncertainties. • Pain is inevitable and suffering is optional. • I am becoming spiritually stronger. • Live in the moment. Accept how life takes you and learn what teaches you. • The moment we leave this world, our responsibilities end, don't think beyond that. • Change is challenging. • If you can't change, accept it as it is. Don't blame or defend.

### **Ms. Samantha Ivey**

*Palliative Care Intern*

I have learned that helping someone heal can be listening to their story about their favorite memory with a loved one that just passed. Care can be giving someone cranberries through their feeding tube because it's their favorite food, regardless of if they can taste it. There are so many ways that we can show care and help others to heal simply through our compassion toward others. Each story and interaction I have had while creating this book has taught so much about myself and the world. I hope to bring all the lessons I have learned every person and place I come across throughout my life. Thank you SVYM!

## Dr. Vinutha Raman

Senior Manager

Dr. Vinutha Raman is an anesthesiologist that works as the Senior Manager at the Palliative Care Center. When speaking about her work at the center she said she was inspired to go into palliative care after the passing of her father where she felt that it was important to transform death into a good experience instead of one associated with just sadness and loss. As an anesthesiologist, she also feels that it is a patient's right to be pain-free.

*"When someone dies I feel like they are getting liberated, it is the end of their suffering. After we counsel the family and they accept the death of their loved one, it is a peaceful death. We can transform a bad death into a good death."*

## Ms. Mary Catherine

Palliative Care Nurse

Ms. Mary Catherine is a nurse in the Palliative Care center. When speaking about her job she said that she was inspired by the work of the Swami Vivekananda Youth Movement when she discovered them in 2014 and has been working there ever since. Since being here she was inspired by the depth of care and support the SVYM Palliative Care Center shows for their patients and their families. Being a part of the holistic care of SVYM is something she is inspired by every day and she is motivated by being able to support people when they most need it. Since being here she has learned more about learning how to be patient and communicate better with patients and how to take better care of herself and her family.

## Ms. Nandini

Program Manager

Ms. Nandini has been the Program Manager at the Palliative Care Center for the past 2 years but has worked with the Swami Vivekananda Youth Movement for the past 13 years. Before working at the center she worked in Health, Training, and Research for the Socio-Economic Empowerment Program (SEEP). Since coming to the Palliative Care Center she said that she is motivated by the team of people she works with that she feels have become her family.

## Mr. Ramakrishna Mudre

Palliative Care Counselor

Mr. Ramakrishna Mudre has been volunteering with SVYM for the past 10 years and has been working with the Palliative Care team for the past 8 years. When speaking about his experiences he says, "It is a small gesture of showing my gratitude to Nature that today I have the opportunity to share my abilities, this window may not be available to me for long. When we continue to serve people with pain, gradually, we transmute helping ourselves to evolve...a feeling that provides satisfaction that my abilities are being better utilized."

Mr. Ramakrishna Mudre says that while the work can be draining, what brings him back is that the work needs to be done for his fellow human beings. Palliative care is a way to show compassion where every one of us can participate. "We are given time by all powerful Nature, the duration being uncertain. Can we provide the best care possible to enhance the quality of life for the remaining time a patient has?"

*"When you massage a person's back who is suffering because of severe back pain and with difficulty when he raises his head and smiles at you, it is a small thing but it makes all the efforts worth it."*



SVYM

# Healing Hands and Caring Hearts

Stories of the SVYM Palliative Care Center

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Welcome to Healing Hands and Caring Hearts! This is a book sharing the experiences of patients and caregivers of the Swami Vivekananda Youth Movement's Palliative Care Center in Mysuru, Karnataka. The Palliative Care Center was created in 2009 and has since provided care to bedridden patients at the center, conducts hundreds of patient home care visits, and enrolls hundreds of new patients each year. The Center provides a number of different services like free home-based care, free Institution based care, pain and symptom management, caregiver training, and bereavement care and counseling.

