



CAREGIVER

“Supporting your loved ones through their journey”

CANCER



Professional Insights ★ Community Voices ★ Upcoming Events

SERIES-3

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DR. K. NIRAIMATHI
FOUNDER MEMBER,
CAREGIVER ADVOCACY GROUP

“TO CARE FOR THOSE WHO ONCE CARED FOR US IS ONE OF THE HIGHEST HONORS.”

- TIA WALKER, THE INSPIRED CAREGIVER: FINDING JOY WHILE CARING FOR THOSE YOU LOVE

As caregivers, we often find ourselves in a role that we didn't anticipate - a role that asks for endless strength, patience, and understanding. Whether it's waking up in the middle of the night to offer comfort, understanding the complex medical care, or balancing the emotional demands of caregiving with our own well-being, the journey is one that requires immense resilience. And yet, caregivers are often the ones who go unseen and unheard.

This is why we felt a deep need to create something more - a space where caregivers could not only receive support but also feel validated, connected, and empowered. The Caregiver Advisory Group was born out of this very need. At Evidentia Research Solutions, in partnership with KK Charitable Trust, our goal is to provide you with the tools, resources, and community that you deserve.

This newsletter, CAREGIVER, is just one part of our larger vision. We want it to be more than just an update or resource - it's a testament to the importance of your role, and a reminder that you are not alone in this journey. We hope it becomes a source of encouragement, inspiration, and practical guidance as you continue your caregiving efforts.

The decision to focus on caregivers, especially those caring for loved ones with cancer and autism, comes from a deep recognition of the unique challenges you face. For those caring for someone with cancer, the journey can be particularly heavy. You are often the backbone of support, managing everything from medical appointments to emotional reassurance. The toll it takes on your mental and emotional health is real, and we want to ensure you have the tools and support to take care of yourself as well.

Similarly, caregivers of individuals with autism face their own set of ongoing challenges. Autism is a lifelong condition that requires constant adaptation and understanding. Whether it's accessing educational resources, managing behavioral interventions, or simply finding time for self-care, the road can feel isolating. But through the Caregiver Advisory Group, we are committed to providing you with the guidance and community that can make this journey a little less lonely.

We invite you to be an active part of this community. Share your experiences, engage with the resources we provide, and know that we are here to listen and support you every step of the way. Together, we can build a stronger, more resilient caregiving network - one where caregivers are truly recognized for the vital role they play in the lives of their loved ones.

**MS. PRAJNA.A**FOUNDER MEMBER,
CAREGIVER ADVOCACY GROUP

“Will they be okay?” is the question that every caregiver ends up asking at some point in their lives. As a caregiver and a neurodiversity advocate, this is a question I’ve both asked myself and have had parents ask me, time and time again. While looking for ways to answer this question, I found myself asking more questions: “Why is this anxiety not being voiced out?” “How can we ensure that the caregivers are also cared for, seen, and heard in the long term?”

It was clear that the way to answer this question was not by temporary reassurance but by initiative. An initiative that would bring together caregivers from all over the state, who were asking themselves this question. An initiative that would give us a platform where we could voice out this question to experts and to other caregivers, and see our experiences reflected in others. This is how the seed for the caregivers’ sessions was planted, nurtured by a powerful need for community and change in the way we approach care. This initiative was born out of a culmination of all our individual experiences as caregivers for family members with stigmatizing illnesses, disorders, and disabilities. It is important to remember that what we hope to address through this initiative is a human right. We’re different in our own ways, but underneath our differences, we all want to be seen, heard, and supported something that most individuals with stigmatized disorders, disabilities, and illnesses, and their families are deprived of.

Progress is ultimately a process and not a destination. This initiative is only a small step towards a world that is accepting and inclusive of difference. We hope to watch this grow as a movement led by caregivers from all over the nation. Even if one caregiver walks away from these sessions feeling seen and heard - I count it as a step towards a better society and world.

Once again, the caregiver session could not be possible without the help of Dr. Niraimathi, co-founder, Ms. Soundarya.M, project co-ordinator and all the advisory board members, and last but not least, the caregivers themselves. You deserve to be cared for and supported, just as you do for the people in your life.

CREATING A SAFE & COMFORTABLE HOME ENVIRONMENT FOR PATIENTS

Mrs. Revathy Sudhakar

Assistant Professor, Department of Psycho-oncology Cancer Institute (WIA)

Researchers have stated that patients who stay or die in an Intensive Care Unit (ICU) or hospital experience more physical and psychological distress and worse quality of life at end-of-life.

More than 70% of patients prefer to be at home during their final days.

CREATING APPOINTMENT AND TREATMENT CALENDARS

Cancer treatment involves a complex mixture of treatment components with frequent appointment schedules and rigid medication schedule. As adherence to cancer treatment and follow up is vital, it is ideal to maintain an appointment and treatment calendar.

EXPLORE THE NEEDS OF PATIENTS AND TAILOR THE ENVIRONMENT

In order to maintain the patient's quality of life and ensure that their physical, emotional, and spiritual needs are met in a manner that aligns with their wishes, caregivers may explore the unmet needs and wants of the patient in terms of their physical needs, emotional needs and social needs and tailor the environment in line with the same.

RESPECTING AUTONOMY OF PATIENTS

Cancer journey involves numerous decision-making scenarios for the family caregivers. Recognizing and supporting patient's right to make decisions about their own treatment, care, and lifestyle. Autonomy is a fundamental principle in medical ethics, emphasizing that patients should be involved in the decision-making process regarding their care and that their personal values, preferences, and beliefs should guide treatment choices.

RESTRICT THE NUMBER OF VISITORS

As every modality of cancer treatment requires extensive care, due to the severity of its physical impact on health, patients require a safe and sterilized environment at home. In order to ensure this, it is ideal to control the number of visitors during the active recovery phase of the patients.

PROVIDING COMFORT TO PATIENTS

Providing a physical comfortable environment can eventually impact the psychological comfort and well-being of patients. This involves suitable bedding, clothing, and repositioning to prevent bedsores.

EMOTIONAL SUPPORT

Caregivers are the first source of information as well as the first point of catharsis for patients at home. In line with this, caregivers are expected to be compassionate listeners and encourage open communication of patients to express their feelings, acknowledge their concerns and validate their emotions.

PHYSICAL ACTIVITY

Caregiver can encourage mild physical activities that are advised as safe and appropriate for the patient's condition, by their primary physician / oncologist. This could help the patients feel they are in control of their body and promote feelings of independence.

CREATE AND PROVIDE A LIST OF EMERGENCY CONTACTS

Caregivers can create a list of emergency contacts which would include doctors, family members and neighbours who can be reached for help and assistance and make this list accessible for patients.

NUTRITIONAL CARE

One of the biggest concern of caregivers is the diet plan for cancer patients during and after their course of treatment. Caregivers can discuss with the nutritionist at the primary hospital to get the detailed diet care plan and prepare a schedule to ease the process. Sometimes during treatment, as a result of treatment, plan may develop loss of taste and lack of appetite and carers can structure small and frequent diet plan when they are at home.

HANDLING TREATMENT MODALITIES AND THEIR EFFECTS

DR. SOPHIA RAJESH, RADIATION ONCOLOGIST
DR. NIRAIMATHI, RESEARCH CONSULTANT
MS. SOUNDARYA, PSYCHOLOGIST
MRS. SELVI, CAREGIVER

Introduction

The Caregiver Advocacy Series is designed to empower caregivers with the knowledge and resources to support their loved ones through the challenges of cancer care. The third session, titled “Handling Treatment Modalities and Their Effects,” focused on equipping caregivers with strategies to navigate treatment processes and manage the physical, emotional, and practical demands associated with cancer care.

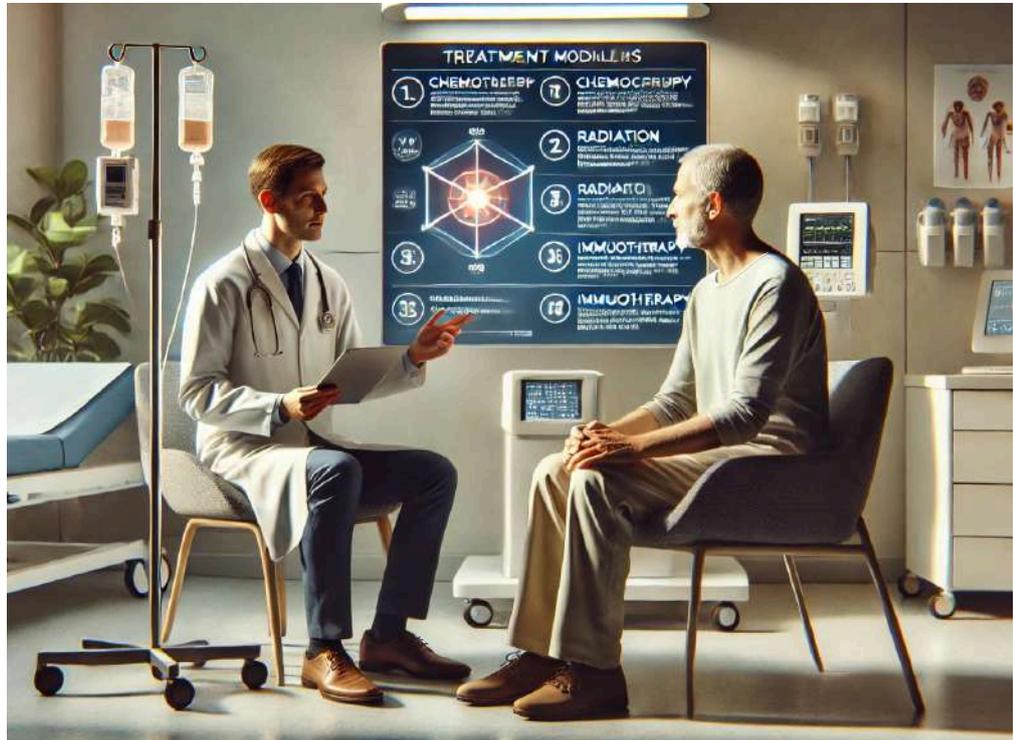
Session Highlights

Caregiver Insights: A Personal Journey

Mrs. Selvi shared her experience caring for her mother and mother-in-law, both cancer patients undergoing different treatment modalities. Her key challenges included:

- Convincing patients to cooperate with treatments like chemotherapy and surgery.
- Balancing caregiving responsibilities with household duties and caring for young children.
- Managing financial constraints alongside regular hospital visits and treatment side effects.

To address these challenges, Mrs. Selvi emphasized the importance of staying



informed about treatment processes, maintaining detailed records of medications and symptoms, and building emotional resilience to navigate the uncertainty of caregiving.

Treatment Modalities and Their Effects

Dr. Sophia Rajesh provided a comprehensive overview of cancer treatment modalities:

- **Surgery:** The primary step for solid tumors to remove cancerous growths.
- **Chemotherapy:** Administered orally or intravenously to target remaining cancer cells.
- **Radiation Therapy:** Advanced techniques with fewer side effects, such as mouth sores or throat irritation.

- **Emerging Therapies:** Immunotherapy, hormone therapy, and targeted therapy based on the cancer type and stage.

Impact on Patients and Caregivers:

- **Physical Effects:** Common side effects include nausea, vomiting, hair loss, and infections.
- **Emotional Strain:** The lengthy treatment process can lead to stress and anxiety for both patients and caregivers.
- **Role of Caregivers:** Dr. Sophia highlighted the caregiver’s role in ensuring proper hygiene, managing diet, and monitoring side effects.

Emotional and Psychological Support

Dr. Niraimathi and Ms. Soundarya emphasized the critical role of caregivers in addressing the emotional and psychological needs of patients:

- **Active Listening:** Providing empathy and reassurance to alleviate fear and uncertainty.
- **Positive Environment:** Maintaining a calm and supportive atmosphere at home.
- **Engagement:** Encouraging patients to participate in meaningful activities to reduce isolation.
- **Professional Support:** Seeking counseling for both patients and caregivers to manage stress and emotional turbulence.

Practical Caregiving Tips

Dr. Sophia offered practical advice for caregivers to manage treatment side effects and ensure patient comfort:

- **Hygiene:** Prevent infections by maintaining cleanliness during hospital visits.
- **Dietary Care:** Follow simple, nutritious meal plans tailored to the patient's condition.
- **Follow-Ups:** Regularly consult healthcare providers for ongoing care and adjustments.
- **Chronic Conditions:** Manage pre-existing health issues like diabetes or hypertension alongside cancer treatment.

Conclusion

The session highlighted the multifaceted role of caregivers in cancer care, emphasizing the importance of their mental and emotional well-being alongside that of the patients.

The discussion underscored the need for continuous learning, self-care, and support networks to navigate the challenges of caregiving effectively.

With gratitude to the panelists and participants, the session concluded on a collaborative and hopeful note, reinforcing the critical role of caregivers in the cancer care journey.

- *Caregivers play a vital role in ensuring treatment adherence and emotional well-being.*
- *Empathy and patience are crucial in managing the psychological impact of cancer treatment.*
- *Structured systems, such as detailed charts for medications and symptoms, enhance caregiving efficiency.*
- *Peer support groups and community resources provide valuable assistance for caregivers.*

BREAKING THE BAD NEWS

DR. PRADEEP, SURGICAL ONCOLOGIST
DR. ARUN SESHACHALAM, MEDICAL ONCOLOGIST
DR. NIRAIMATHI, RESEARCH CONSULTANT
MS. SOUNDARYA, PSYCHOLOGIST

Introduction

The session, Breaking the Bad News, explored the intricate process of communicating challenging diagnoses, particularly cancer, to patients and their families. The discussion emphasized empathy, clear communication, and patient-centered approaches, drawing on the personal and professional experiences of panelists.

Key Highlights

Personal Perspectives:

Dr. Niraimathi's Caregiving Journey

Dr. Niraimathi shared her personal experience of receiving her mother's cancer diagnosis, describing it as overwhelming and life-altering. Balancing the emotional strain of a cancer diagnosis with significant life events, such as her brother's wedding, was particularly challenging. Her mother's resilience provided clarity and strength to navigate the difficult journey.

Key Insights:

- The importance of involving patients in discussions, provided they are emotionally ready.
- The critical role of empathetic communication in guiding families through uncertainty.



Breaking the News: Professional Approaches

Dr. Pradeep emphasized tailoring communication to each patient's emotional and cultural context.

- **Transparency and Empathy:** Honest discussions about treatment options, prognosis, and potential outcomes foster trust.

Family Dynamics: Gradual involvement of both the patient and caregiver is vital for shared decision-making.

Dr. Arun Seshachalam highlighted how patients perceive different aspects of their diagnosis and treatment:

- **Emotional Impact:** Outcomes like hair loss, mastectomy, or a colostomy often carry more emotional

weight than the diagnosis itself.

- **Targeted Communication:** Understanding patient-specific concerns helps dispel myths and reduces anxiety.

Both panelists agreed that breaking bad news requires ongoing dialogue, empathy, and support, ensuring that patients feel informed and empowered.

Psychological and Emotional Support: Strategies for Caregivers

Ms. Soundarya elaborated on managing the psychological turbulence following a cancer diagnosis:

- **Active Listening and Empathy:** Address patients' fears and uncertainties with understanding.

- **Open Dialogue:** Encourage discussions that align medical goals with patient preferences.
- **Professional Support:** Psychologists can aid in fostering acceptance and readiness for treatment.

Conclusion

Breaking bad news is a continuous, nuanced process that significantly impacts patients and caregivers. The session highlighted the importance of empathetic communication, shared

decision-making, and robust support networks. By fostering trust and clarity, healthcare professionals can help patients and caregivers navigate the complexities of the cancer journey with resilience and hope.

- *Empathy in Communication: Healthcare professionals must balance honesty with sensitivity, addressing both emotional and informational needs.*
- *Patient-Centered Decision-Making: Involving patients in treatment discussions fosters trust and autonomy.*
- *Addressing Stigma and Misconceptions: Clear communication about treatment advances can alleviate fears.*
- *Support Systems: Building strong networks of emotional, informational, and practical support is crucial for patients and caregivers.*

FINDING COMFORT AGAIN

Her expression reveals deep insecurity.



THE STRUGGLE

Meera sits alone on her bed, gazing at her reflection in a handheld mirror. Her shoulders are slumped, and the scar from her Breast conservation surgery is visible.

But know that you are beautiful just as you are".

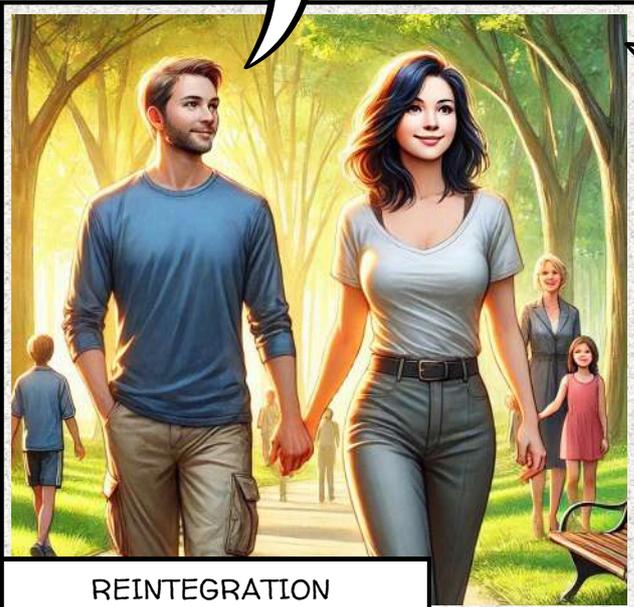
Raj, her husband sits beside Meera, holding her hand warmly. He speaks gently, looking into her eyes, "Your body has been through so much to keep you alive.



ENCOURAGEMENT

"With Raj's support, Meera began to see herself with confidence and strength, ready to take the first step.

Meera and Raj walk hand-in-hand through a lively park. Meera is smiling, her confidence radiating as she reconnects with the world around.



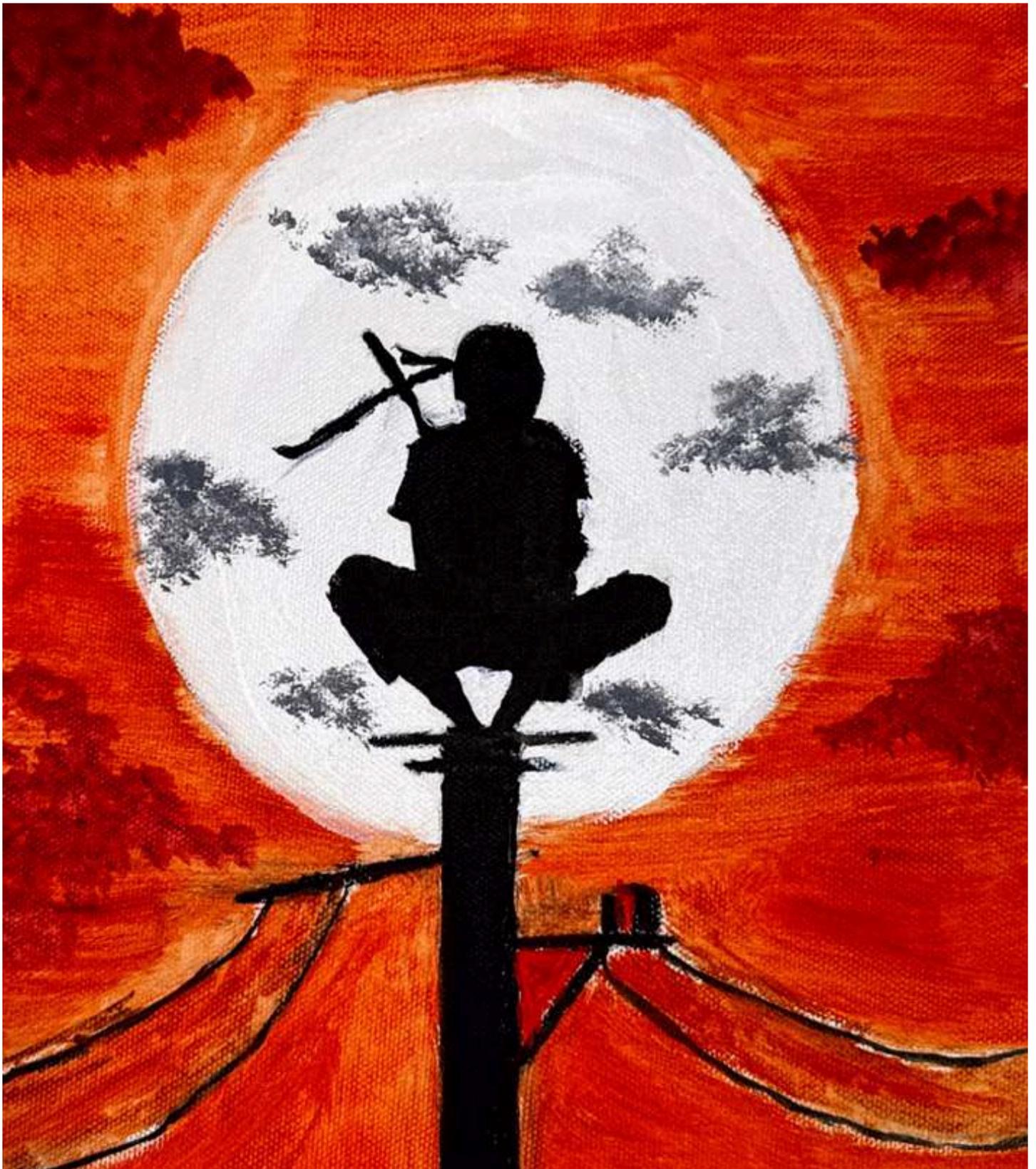
REINTEGRATION

Moral:

HEALING IS NOT JUST A PERSONAL JOURNEY BUT A SHARED ONE. WITH THE RIGHT SUPPORT, CONFIDENCE AND SELF-ACCEPTANCE CAN FLOURISH.

CREATIVE ARTS, CARING VOICES





Painting by

Master. Mithun Raj

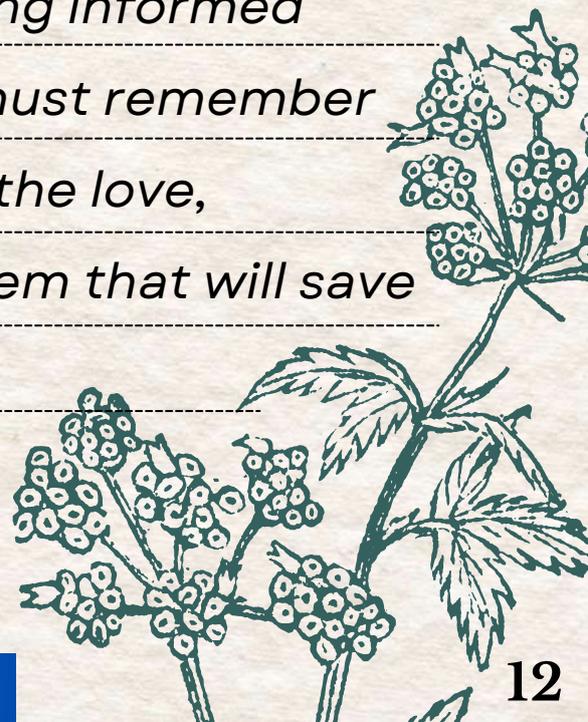


Those were difficult days for me. I was very shocked that this happened to my mother within a few months of my father's death.

First of all, we have to be confident. We need to treat them very carefully but also like everyone else. It is very important to treat them as if everything is normal.

It is also very important to ask questions and learn about the patient's care. Talking to the treating doctors, understanding the treatment process, and staying informed makes a big difference. We must remember that it's not just the pills, but the love, warmth, and hope we give them that will save them.

MS. KAVITHA, TEACHER
Caregiver of a Survivor

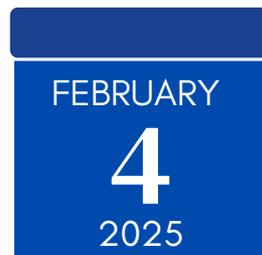


--UPCOMING EVENTS--

“Helping with activities of daily living: Personal Hygiene”



“Seeking a Second Opinion in Cancer Care :
Do’s and Don’t”



TIME

6.00pm - 7.00pm

ZOOM MEETING

Meeting ID: 863 4222 5932

Passcode: 524556

YOUTUBE LIVE

www.youtube.com/@

CaregiverAdvocacyGroup

--COLLABORATORS--



--ACKNOWLEDGEMENT--

We extend our deepest gratitude to **Mrs. Selvi, a caregiver**, for sharing her empowering journey as a guest speaker in our webinar. Her courage, resilience, and dedication have touched the hearts of many, offering hope and strength to those facing similar challenges. We are truly honored to have had her as part of our event and are thankful for her invaluable contribution.

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Newsletter Subscription

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