Caregiver
ADVOCACY GROUP
Caring your loved ones

# CAREGIVER

“Supporting your loved ones through their journey”

# CANCER

Professional Insights ★ Community Voices ★ Upcoming Events

SERIES-4

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# DIRECTOR'S NOTE

**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.

# EDITOR'S NOTE

**MS. PRAJNA.A**
FOUNDER MEMBER,
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“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?”

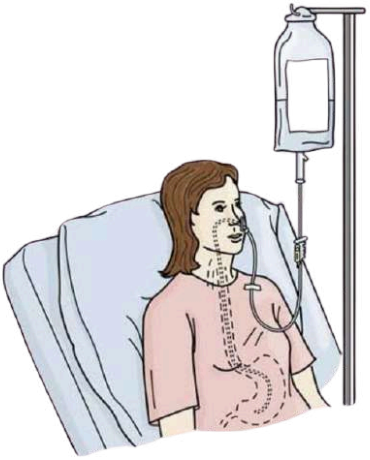
It was clear that the way to answer this question was not by temporary reassurance but by initiative. An initiative that would bring together caregivers from all over the state, who were asking themselves this question. An initiative that would give us a platform where we could voice out this question 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.

# RYLES TUBE FEEDING OR NASOGASTRIC TUBE FEEDING

DR. SOPHIA RAJESH
RADIATION ONCOLOGIST



Ryles tube feeding is recommended for patients who have difficulty swallowing food or face obstruction in the food passage due to a tumor. A small tube is inserted through the nostril to reach the stomach. This is usually a temporary solution and will be removed once the tumor subsides. While the initial response from both the patient and caregivers may be a strong "NO" to the suggestion of a Ryles tube, it’s important to understand that this tube serves as a nutritional lifeline for already emaciated patients, helping them undergo critical therapies like radiation and chemotherapy. After a round of thorough counseling, most patients can understand the importance of maintaining an uninterrupted nutritional supply.

A common concern arises about what to feed through the Ryles tube. The answer is simple: continue feeding the patient their normal daily diet in liquid form. Our regular diet consists of rice (carbohydrates), dal (proteins), vegetables (fiber), and fruits. These can be given as broth (kanji), vegetable soup, or fruit juices. However, people often make the mistake of switching to health mixes or different cereals, which can lead to bloating and slow digestion, ultimately causing the patient to lose their appetite, reduce their intake, and decrease the number of feeds. Therefore, it’s always best to stick to the normal daily diet in liquid form.

To put it simply, it's similar to feeding a child. A growing infant is fed liquid or semi-solid food, yet still receives the necessary nutrients for development. So, don’t worry about the adequacy of the nutrition. You can feed 100ml every hour or 200ml every two hours, depending on the patient’s stomach capacity. After feeding, help the patient move around a bit to assist with digestion. Keep the Ryles tube clean by flushing it with a small amount of water after each feed. Avoid introducing new dietary supplements—just the regular balanced diet is sufficient.

# PALLIATIVE CARE AND END-OF-LIFE MATTERS

DR. VIDHUBALA, PSYCHO-ONCOLOGIST
DR. NIRAIMATHI, RESEARCH CONSULTANT
MS. SOUNDARYA, PSYCHOLOGIST

Caregiving is one of the most selfless and challenging roles, especially when it comes to palliative and end-of-life care. Many caregivers struggle with understanding what palliative care really means, making difficult medical decisions, and dealing with emotional exhaustion.

During this session, Dr. Vidhubala shared valuable insights on breaking the stigma around palliative care, supporting caregivers through emotional and mental health challenges, and addressing the realities of caregiving at the end-of-life stage.

## Key Insights from the Discussion

### 1) Understanding Palliative vs. End-of-Life Care

Palliative care is not just for the dying. It is about ensuring quality of life for those with serious illnesses. Unfortunately, many associate palliative care with death, leading to fear and stigma. End-of-life care, on the other hand, is a part of palliative care focused on the final stages of life.

She emphasized that early integration of palliative care leads to better patient comfort and reduced caregiver stress.

- Hospice care vs. Palliative care – Hospice care is provided when curative treatment is stopped, whereas palliative care can exist alongside active treatment.
- Dr. Vidhubala emphasized that early integration of palliative care leads to better patient comfort and reduced caregiver stress.

**Q&A Insight:** Does hospice care speed up death ?

- Hospice care is often misunderstood as "hastening death," but its purpose is to ensure comfort and dignity in a patient's final days. While some paid hospice facilities can be expensive, home-based palliative care offers a cost-effective alternative. Kerala's community-driven palliative care model was highlighted as an example of affordability and caregiver empowerment.

### 2) The Caregiver's Silent Struggle

Caregivers often suffer more stress than the patient. Juggling medical responsibilities, work, family, and social expectations can lead to burnout, guilt, and emotional distress.

"Many caregivers feel judged by society–'Did I do enough? Did I give up too soon?' These questions haunt them," said Dr. Vidhubala.

- Family conflicts often arise, especially when distant relatives have different opinions on treatment.

- Many caregivers struggle to prioritize their own health, leading to chronic conditions like hypertension, diabetes, and depression.
- Rotational caregiving (sharing duties with other family members) and seeking emotional support are crucial for a caregiver's well-being.

## 3) Challenges in Breaking Bad News

One of the toughest parts of caregiving is communicating difficult news. Often, doctors disclose a diagnosis only to caregivers, leaving the patient unaware. Cultural beliefs prevent families from openly discussing death and end-of-life wishes.

"Many patients already know their condition, even if their family doesn't tell them," Dr. Vidhubala shared. Encouraging open, compassionate discussions can ease anxiety for both patients and caregivers.

**Q&A Insight:** How can caregivers ensure a peaceful end-of-life experience?

- Talk about spiritual and emotional needs.
- Understand and respect the patient's final wishes.
- Encourage family members to share good memories.

## 4) The Dangers of Late Diagnosis

One of the biggest struggles struggles families Face is families face is getting a timely diagnosis. Many patients go through months or even years of alternative treatments before seeing an oncologist.

**Why does this happen?**

- Symptom misinterpretation – Early cancer symptoms are often mistaken for minor health issues.
- Preference for traditional medicine – Many patients try Ayurveda, Siddha, or homeopathy first before seeking modern treatment.
- Financial constraints – Costly treatments often delay medical intervention.

The result? – Many families are forced into palliative care without preparation, leaving caregivers overwhelmed.

## 5) The Caregiver's Role in Decision-Making

Despite being on the front lines, caregivers often don't have full decision-making power.

- Who makes the decisions? – Often, extended family members, particularly those living abroad, try to intervene. This creates conflict and emotional strain.
- What can caregivers do? – Being well-informed and having a support system of doctors and counselors can help caregivers assert their role and advocate for the patient's best interests.

**Q&A Insight:** How can nurses help caregivers accept palliative care?

- Listen patiently and answer repeated questions.
- Be empathetic– understanding emotions takes time.
- Encourage caregivers to seek counseling if needed.

## 6) Breaking the Stigma Around Cancer

Cancer still carries a heavy stigma in society. Unlike diabetes or hypertension, it is seen as a death sentence, discouraging people from getting tested early.

- Many refuse to say 'cancer' aloud, associating it with death.
- Survivors rarely talk about their experiences, while deaths from cancer reinforce fear.
- The lack of open conversations discourages proactive screening and early treatment.

## 7) Caregiver Self-Care: A Non-Negotiable

- Caregivers are often called 'hidden patients' because they ignore their own health while caring for a loved one. But caregivers can only provide the best care if they take care of themselves first.
- Simple self-care rules for caregivers:

- Eat on time – Skipping meals weakens immunity and mental clarity.
- Prioritize sleep – Lack of sleep leads to burnout and poor decision-making.
- Hydrate & take breaks – Even a 10-minute walk can reduce stress.
- Rotational caregiving – Share responsibilities among family members.

“Self-care isn’t selfish. Caregivers need to take care of themselves like they would for a loved one.”

## Final Thoughts

Palliative care is about quality of life, not giving up. Families need support, awareness, and an open dialogue to navigate this difficult journey. Caregivers play a pivotal role, and their mental, emotional, and physical health matters just as much as the patient’s.

## Dr. Vidhubala’s Message

“We need to start talking about cancer the way we talk about any other disease. Fear and stigma only push people further away from timely treatment.”

# SEEKING A SECOND OPINION IN CANCER CARE: DO'S & DONT'S

DR.KRISHNAKUMAR RATHNAM, MEDICAL ONCOLOGIST,
DR. NIRAIMATHI, RESEARCH CONSULTANT
MS. SOUNDARYA, PSYCHOLOGIST

**In light of World Cancer Day and its theme 'United by Unique', Dr. Krishnakumar, a highly experienced Medical oncologist with over 20 years of practice, provided insights into the challenges faced by both patients and caregivers on navigating treatment decisions in cancer care . The overarching message of the session is that cancer is a unique and complex disease, but with collaboration, early detection, proper treatment, and the support of caregivers, it can be managed effectively. The role of second opinions in confirming the right course of treatment is essential, but patients should also trust the guidance of reputable doctors and seek clarity without overthinking.**

## 01

### TIMING OF THE SECOND OPINION

It's generally advisable to seek a second opinion before starting treatment. This ensures that patients are confident in the treatment plan and are aware of all available options as it gives broader understanding of the condition and potential approaches. Sometimes, treatment plans can vary significantly, and getting another perspective can help confirm the best course of action.

## 02

### RESEARCH BEFORE AND AFTER CONSULTATION

Nowadays, patients often come to doctors having done their own research, using tools like Google or AI platforms such as ChatGPT. While this is not inherently wrong, it's important that once a doctor is chosen, the patient trusts the professional advice and guidance provided. However, questions about the treatment's effectiveness, possible side effects, or expected outcomes often arise once the doctor explains the details. In such cases, it's perfectly reasonable to seek a second opinion, particularly if there are uncertainties or concerns about the proposed treatment plan.

## 03

### COMMUNICATION WITH DOCTORS

Open and transparent communication is important. If a patient decides to get a second opinion, they should inform their primary doctor. Ethical medical practice emphasizes the importance of maintaining trust and transparency between patients and doctors. A responsible doctor will not feel threatened by a patient seeking additional advice but rather will appreciate the patient's desire to make informed decisions. Some doctors might even encourage seeking a second opinion to ensure that the chosen treatment is the best fit for the patient's needs.

## 04

### ROLE OF SPECIALISTS AND INSTITUTIONS

In some cases, patients may want to consult specialists or institutions different from their current healthcare provider. A second opinion from another doctor or institution can sometimes offer new insights into the condition and possible treatments. The expertise available at various hospitals or clinics may vary, and sometimes a different perspective can be invaluable. However, it's crucial to select a reputable institution or doctor for the second opinion to ensure accurate and reliable guidance.

## 05

### THE IMPORTANCE OF THE RIGHT PLACE

Whether the second opinion is sought online, through a family physician, or at another medical institution, it's crucial to ensure that the second opinion comes from a reliable, trustworthy source. Sometimes patients may travel to other cities or consult different hospitals for better options, and that's perfectly acceptable as long as the chosen place adheres to ethical standards and offers the appropriate expertise.

## 06

### EASE OF ACCESS AND COMMUNICATION FOR SECOND OPINIONS

When seeking a second opinion, especially from doctors in different locations, it's important to ensure easy communication and access to all necessary medical documents. This includes sending test results, medical records, and a complete patient history ahead of time, so the second doctor can review everything and avoid redundant tests or delays. Often, the original doctor helps by sending a summary of a pastient case or key observations to ensure the second opinion is based on accurate and complete information. This preparation allows the second doctor to provide the most informed advice, especially in complex cases like cancer treatment.

**07**

### POTENTIAL PITFALLS OF SEEKING A SECOND OPINION

While second opinions can be helpful, they may create confusion, especially when doctors provide conflicting advice. This can leave patients uncertain about which direction to take and add stress. It's important to consult specialists with expertise in the specific condition to avoid misguidance, particularly for complex or rare diseases.

**08**

### COST AND PRACTICALITY OF INTERNATIONAL SECOND OPINIONS

Seeking second opinions from international experts can be expensive and may not always be practical, especially for patients with limited financial resources. Importing medications from abroad can be costly and may not be suitable for the patient's specific demographic. Additionally, international treatment regimens may be more aggressive than necessary for the patient's age or condition. Doctors must carefully guide patients through the logistical and financial challenges of following international advice.

**09**

### PATIENT AUTONOMY, SATISFACTION, AND ONGOING CARE

Doctors emphasize the importance of respecting a patient's autonomy in seeking a second opinion, as it allows them to make informed decisions about their health. Whether the patient stays with the current treatment or adopts a new approach, the doctor must support their choice. After receiving the second opinion, it is essential for the original doctor to follow up, understand its impact on the treatment plan, and ensure both doctors are aligned. This helps the patient feel confident and comfortable with the chosen path.

**10**

### FULL DISCLOSURE AND ACCURATE REPORTING

It's crucial for patients to provide all relevant medical information, including previous tests and treatment history, to ensure an informed second opinion. Incomplete disclosure can result in misdiagnosis or inappropriate treatment.

**11**

### CONFLICTING OPINIONS

Discrepancies between the initial and second opinions can lead to confusion. Patients should ask for clarity on treatment recommendations and consider the advice based on their unique condition and health.

**12**

### CRITICAL CASES AND TIMELINESS

In urgent cases, such as leukemia, delaying treatment for a second opinion can be life-threatening. Doctors advise that treatment should not be postponed when immediate care is needed.

**13**

### COORDINATION OF CARE

It's best to complete treatment in one healthcare facility to ensure continuity and avoid potential gaps or delays in care due to differing protocols at multiple institutions.

**14**

### REASSURANCE OR ALTERNATIVE TREATMENT

A second opinion may either confirm the original treatment plan or suggest adjustments. For example, second opinions can offer access to clinical trials or treatment options not previously considered.

**15**

### HANDLING CONFLICTING REPORTS

Discrepancies in test results from different labs can create confusion. Sending samples to specialized centers for verification ensures accurate diagnosis and appropriate treatment decisions.

**16**

### DOCTOR-PATIENT RELATIONSHIP AND TRUST

Trust between doctors and patients is essential. Patients should feel comfortable discussing concerns and seeking second opinions without fear of judgment, fostering better outcomes.

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## AVOIDING OVERTHINKING AND TREATMENT DELAYS

Seeking multiple opinions can lead to unnecessary delays. Once a second opinion is obtained, patients should make timely decisions based on all available information.

18

## PRACTICAL DECISION-MAKING

Patients should consider all opinions and medical expertise to make the best decision. It's important to take into account personal health factors and treatment preferences when choosing a path.

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## THE ROLE OF CAREGIVERS

Caregivers should be mindful of their own mental and physical health, as they cannot properly care for the patient if they are not healthy themselves.Psychologists and counselors are recognized as being particularly helpful in providing emotional support not only to patients but also to caregivers. The speaker advocates for mental health support for caregivers and stresses that it is essential for them to prioritize their own well-being.

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## CANCER AWARENESS AND EARLY DETECTION:

Early detection significantly improves treatment outcomes. Regular screenings, such as mammograms for breast cancer or oral cancer checks for smokers, are crucial for early intervention. Government guidelines suggest regular screenings for women over 40, and the cost of such screenings has become more affordable. Early screening can help detect cancer even before symptoms appear, which can save lives

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## LEGAL AND ETHICAL CONSIDERATIONS IN MEDICAL ADVICE

- The legal aspect of medical treatment and second opinions, explaining that the advice and treatment prescribed by a doctor are often formalized as service contracts. This means the doctor is legally bound to provide a professional and well-documented opinion that can be used in a court of law if needed.

- The importance of honesty between patients and doctors is highlighted. Patients should never hide information about their condition, as withholding details can lead to misdiagnosis or inappropriate treatment. A case of a patient who didn't disclose their history of chronic renal failure and diabetes is shared to show how this can negatively impact the treatment process.

> *"Every cancer case is unique, with patients experiencing different symptoms, treatments, and outcomes. Despite the uniqueness of each case, the common goal is to unite against cancer and fight together for better treatment outcomes."*

# CREATIVE ARTS

Drawing by

**Rithika**

# RISING STRONG

SAMPOORNAM

## BREAST CANCER SURVIVOR

When I was first diagnosed with breast cancer, I was completely filled with fear. There was no one to guide me through the uncertainty, and I felt completely alone. But my sister stood by my side, offering the support I desperately needed.

Eight years have passed since I completed my treatment, and today I stand with confidence, knowing that I can overcome anything. The fear I once felt is no longer a part of me. My greatest source of strength throughout this journey has been my children, who gave me the courage to keep going.

Today, I am a proud member of Magalir Suya Udhavikuzhu, and I dedicate my time to educating women about cancer awareness and prevention. Even today, I get goosebumps when I recall my journey and feel privileged to share my story with current patients and caregivers, with the hope that they, too, can emerge stronger.

I would like to conclude with a note that;

***"WOMEN CAN DO ANYTHING. THERE IS NOTHING BEYOND OUR REACH, NOTHING WE CANNOT ACHIEVE."***

# --UPCOMING EVENTS--

## ADL dental care: brushing

**ZOOM MEETING**
Meeting ID: 858 5714 1348
Passcode: 387170

MARCH
25
2025

**YOUTUBE LIVE**
www.youtube.com/@CaregiverAdvocacyGroup

**TIME**
7.00pm – 7.40pm

## April 2025 Exclusive!

### A SPECIAL EDITION NEWSLETTER

### On Cancer Nutrition

It's caring with dignity – providing comfort for cancer patients at home

**ZOOM MEETING**
Meeting ID: 874 5762 0345
Passcode: 495923

APRIL
1
2025

**YOUTUBE LIVE**
www.youtube.com/@CaregiverAdvocacyGroup

**TIME**
6.00pm – 7.00pm

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We sincerely thank **Mrs. Sampoornam and Ms. Rithika** , for their heartfelt contributions to this newsletter. Your beautiful paintings, messages, and support have added meaning and warmth to our initiative. We truly appreciate your effort and creativity in making this edition special.

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