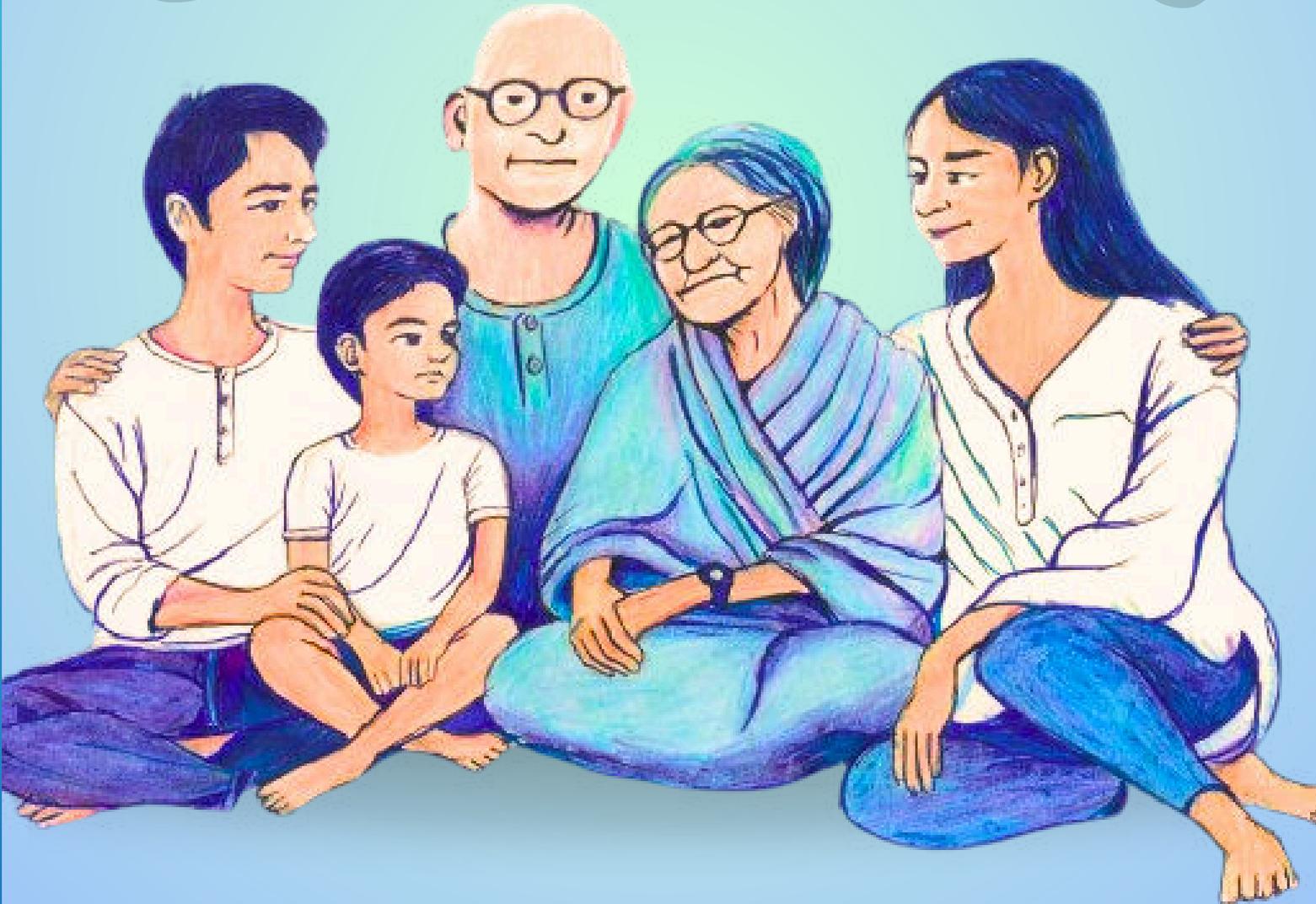


# CAREGIVER

“Supporting your loved ones through their journey”

# CANCER



Professional Insights ★ Community Voices ★ Upcoming Events

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**DR. K. NIRAIMATHI**  
FOUNDER MEMBER,  
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## **“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.

# GENETIC TESTING FOR CANCER CAREGIVERS

DR. ARUN SESHACHALAM, MEDICAL ONCOLOGIST



## Genetic Testing for Cancer Caregivers: What You Need to Know?

Genetic testing can be a valuable tool for cancer patients' caregivers. It involves analyzing DNA to understand a person's risk of developing certain cancers. Here, we explain genetic testing, how it works, and why it can help both patients and caregivers make informed decisions.

## What are genetics, genetic testing, and heredity?

Genetics is the study of genes, which are units of DNA inherited from our parents. Genes determine many things about us, from eye color to health risks. A molecular test analyzes small particles, like DNA, to look for mutations or changes that could increase the risk of diseases like cancer.

Genes determine many things about us, from eye color to health risks. A molecular test analyzes small particles, like DNA, to look for mutations or changes that could increase the risk of diseases like cancer. Heredity is the process of passing down genes from one generation to the next.

When cancer is hereditary, it means a mutation (changes in genes) linked to cancer can run in families, increasing the risk for relatives.

Genetic testing identifies if a cancer patient has inherited certain mutations. This knowledge can help guide treatment decisions, determine future risks, and alert family members who may also be at risk.

## Why Should Cancer Patients Consider Genetic Testing?

Genetic testing for cancer

patients helps identify if their cancer is caused by hereditary mutations. Most cancers are caused by lifestyle or environmental factors, but around 5-10% are linked to genetic mutations that run in families. By identifying these mutations, doctors can tailor treatments, predict cancer risks, and establish follow-up plans that best meet the patient's needs.

For example, breast cancer patients with **BRCA** gene mutations might respond well to specific treatments, like **PARP** inhibitors, which target cells with **BRCA** mutations. Testing also helps doctors determine which patients are at higher risk of recurrence, so they can recommend more frequent screenings or other preventive steps.

## Understanding Hereditary Cancer Testing:

Hereditary cancer testing looks for mutations (changes) in genes that increase cancer risk, such as BRCA1 and BRCA2 (related to breast and ovarian cancer) or genes linked to Lynch syndrome (associated with colorectal cancer). This testing involves taking a blood or saliva sample to see if someone has these mutations. For cancer caregivers, understanding hereditary cancer testing can be essential because test results don't only affect the patient they may reveal a risk for other family

members. Caregivers play a supportive role here, helping both the patient and family members process and act on test results

## Implications of Genetic Testing on Treatment and Follow-Up:

### • Personalized Treatment

Test results can reveal which treatments are most effective for the patient's unique genetic profile. For example, some patients with specific gene mutations may benefit from targeted drugs, while others might need regular screenings for related cancers. Genetic testing helps doctors create a treatment plan that is as personalized and effective as possible.

### • Risk-Reducing Options

Genetic testing sometimes leads to options like preventive surgeries. For example, women with a BRCA mutation might consider a preventive mastectomy to reduce breast cancer risk. Caregivers are often involved in these complex decisions, helping the patient weigh the benefits and emotional impact.

### • Long-Term Follow-Up

Patients with certain mutations may require more frequent follow-ups to catch early signs of recurrence. Caregivers help by organizing and keeping track of these

appointments, providing reminders, and ensuring the patient stays consistent with follow-up care.

## Impact on Family Members and Caregivers

Genetic testing results can affect the entire family, as mutations may also be present in siblings, parents, or children. For caregivers, this means supporting not only the patient but also family members who might want to consider testing themselves. This can bring families closer, but it may also require emotional and psychological support for everyone involved.

Caregivers often help family members understand what a positive result could mean, assist with managing anxiety around testing, and find resources for emotional support. In addition, they may guide the family through considerations like insurance and financial planning if more preventive care or treatments are needed.

## Role of Caregivers in Supporting Genetic Testing

- **Education and advocacy**  
Caregivers can educate themselves and the patient about genetic testing, advocating for consultations with genetic counsellors. Counsellors provide risk assessments and explain results in the context of family history, helping everyone involved understand what the results mean.

- Testing can be emotionally challenging. Caregivers provide a safe space for open conversations about potential impacts on family and future generations. This support is vital in helping patients feel confident and informed throughout the testing process.

- **Coordination of Care**  
Long-term follow-up can involve scheduling regular screenings, tracking appointments, and managing a structured plan for ongoing care. Caregivers often help coordinate these elements, ensuring patients stay consistent with care and preventive measures.

## Conclusion

For cancer patients, genetic testing opens the door to more personalized care and early interventions. For caregivers, understanding genetic testing and supporting patients in this journey is essential. It helps them provide well-informed care, handle the psychological impact, and support family members in understanding their risks. In this way, caregivers not only support the patient's current care but also contribute to safeguarding family health for the future. Genetic testing ultimately provides a deeper understanding of hereditary cancer risks, allowing caregivers and families to work together toward a proactive, supportive approach to managing health. For more information, resources like Cancer.net

# CAREGIVER ADVOCACY SERIES

## SESSION 2: MEETING PATIENT EXPECTATIONS

The second session of the Caregiver Advocacy Series explored how caregivers meet patient expectations while navigating the emotional, physical, and financial challenges of caregiving. Hosted by Ms Soundarya, a psychologist, the session highlighted the critical role caregivers play in shaping patient experiences, especially in India, where they are deeply involved in treatment decisions. The panel included Dr Niraimathi, a caregiving expert; Dr Arun Seshachalam, a medical expert; Ms Ammai Priya, a caregiver with 20 years of experience; and Mr Jayakumar, who cared for his wife during her cancer journey.

The discussion delved into the multifaceted aspects of caregiving, from understanding patient expectations to balancing emotional, physical, and financial demands, offering practical insights and personal stories that resonate with caregivers. The highlights of the discussion are given as follows.

### Understanding Patient Expectations

Caregivers face varying patient expectations, influenced by age and personality. Ms. Ammai Priya shared that “caregiving feels like a divine calling; it demands empathy, patience, and compassion,

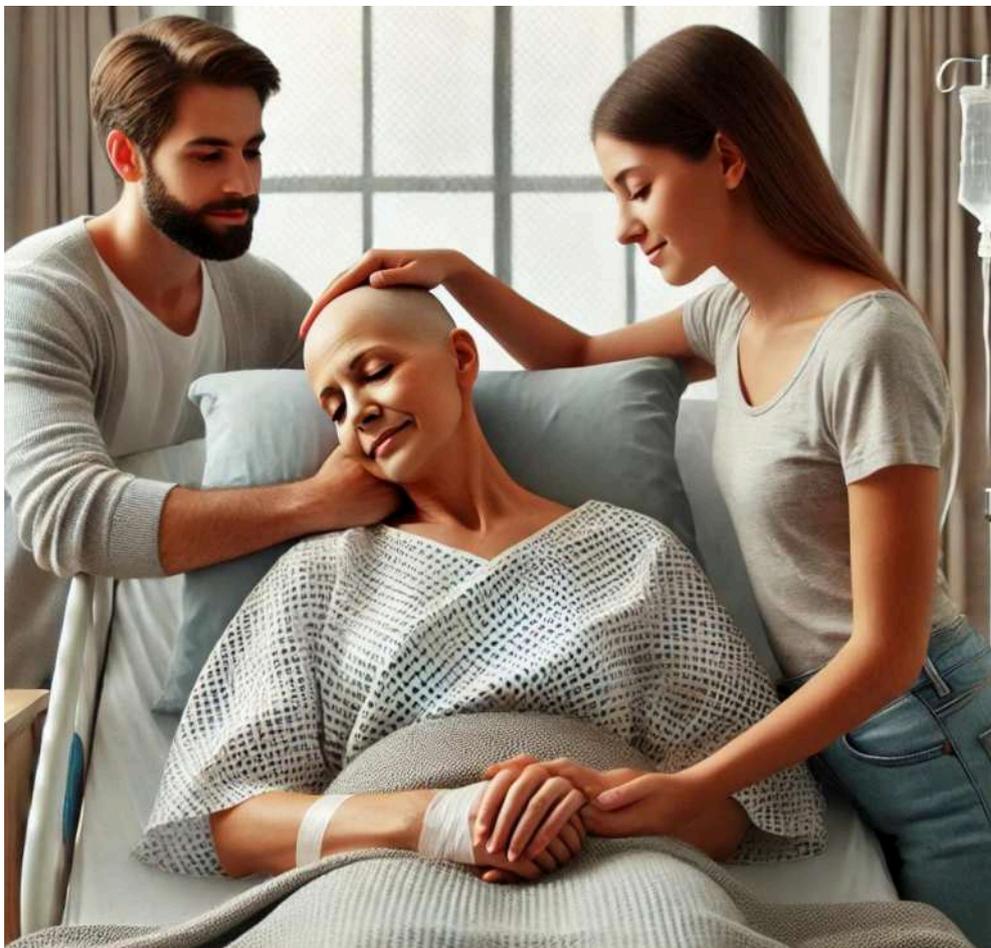
also be at risk. much like caring for a child.” However, managing demanding or uncooperative patients can be overwhelming. She stressed that setting a simple daily routine is essential to balancing caregiving duties and personal well-being, noting, “a simple daily routine can ease the overwhelming demands of caregiving while maintaining balance.”

### Caregiver Well-Being

The discussion emphasized that caregivers often experience burnout and stress. Dr. Niraimathi stated, “Self-care is not selfish; it’s essential. You can’t pour from an empty cup.” She highlighted the need for caregivers to set boundaries, delegate tasks, and seek emotional support through counselling or support groups. Caregiving, she added, is rarely a solo journey: “Caregiving is never a solo journey; emotional honesty and shared responsibilities strengthen families.” Including all family members in caregiving ensures better outcomes while reducing the burden on primary caregivers.

### Financial Challenges in Caregiving

Mr Jayakumar highlighted the unpredictable financial strain of caregiving, particularly for expensive treatments like chemotherapy. He recommended discussing cost-effective alternatives,



such as generic medications, with doctors, stressing that “proactive financial planning is critical. Even small steps like exploring affordable treatment options can ease the burden.” He also spoke about the emotional toll of caregiving, advising caregivers to “turn fear into faith, finding strength in the face of uncertainty.”

### **Managing Uncertain Treatment Outcomes**

Positivity and spiritual resilience emerged as key themes in addressing uncertain outcomes. Ms Ammai Priya shared that “spiritual resilience and positivity are transformative; they bring hope and strength

to patients and caregivers alike.” She recounted stories of families shifting focus from fear to love and laughter, emphasizing that involving loved ones emotionally uplifts patients. “Involving family and loved ones shifts focus from fear to love and laughter, making the caregiving journey more meaningful,” she remarked.

### **Conflicts in Treatment Decisions**

Conflicts in treatment decisions require clear communication and trust in healthcare providers. Dr. Arun Seshachalam noted, “Empowering patients with clear, accurate information

fosters trust and better decision-making.” He warned against relying on unverified sources, stating, “Misinformation is dangerous; always rely on trusted medical advice to guide treatment decisions.”

### **Conclusion**

The session concluded with a call for collective support in caregiving. The panellists underscored the transformative power of empathy, inclusivity, and faith in navigating caregiving challenges. By embracing these principles, caregivers and families can work together to provide meaningful care while preserving their well-being.

*The best way to find yourself is to lose yourself in the service of others*

*- Mahatma Gandhi*



**"I don't think I can handle another treatment."**

*"It's completely understandable to feel overwhelmed. You've shown so much strength to come this far. Let's focus on just one step at a time—I'm here with you every step."*




**"I'm a burden on everyone around me."**

*"It's completely natural to feel this way, but I want to reassure you that you're not a burden. Your presence is so important, and we all want to support you in any way possible. You're not alone in this journey, and it's okay to lean on others."*



**"TURNING TOUGH TALKS INTO MOMENTS OF SUPPORT"**



**"No one really understands how I feel."**

*"I may not fully understand, but I'm here to listen and be by your side, no matter what. I'll be with you, learning how best to support you through every moment."*




**"I feel so weak and tired all the time."**

*"Treatment takes a lot out of you, and it's natural to feel exhausted. Your body is doing its best to heal, and resting is part of that process. Each day you make it through is a step forward, and that's something to be proud of."*



# HANDS OF HOPE



Cancer Survivors Day is observed annually in the month of June, a special occasion dedicated to celebrating the strength, resilience, and triumph of individuals who have overcome cancer. It is a day not only to honor cancer survivors but also to offer support to those still battling the disease.

The Survivors Day 2024 event was initiated by GVN Riverside Hospital, Trichy, in partnership with KK Charitable Trust. This powerful event brought together survivors, caregivers, and supporters, creating a shared space of unity, support, and inspiration.

One of the most poignant moments of the day was the creation of the Handprint Wall of Hope, where survivors left their handprints in a spectrum of colors, each representing a unique emotion from their journey. Together, these handprints told a powerful story of personal strength, woven into a larger narrative of collective survival and boundless hope that shines through even in the most challenging times.



## --UPCOMING EVENTS--

### “Connecting with your Autistic Child”



### “Palliative Care and End-of-Life Matters”



#### TIME

6.00pm – 7.00pm

#### ZOOM MEETING

Meeting ID: 863 4222 5932

Passcode: 524556

#### YOUTUBE LIVE

[www.youtube.com/@](http://www.youtube.com/@CaregiverAdvocacyGroup)

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## --COLLABORATORS--



## --ACKNOWLEDGEMENT--

We extend our deepest gratitude to Ms. Ammai Priya and Mr. Jayakumar, 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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