



Caregiver
ADVOCACY GROUP
Caring your loved ones

CAREGIVER

“Supporting your loved ones through their journey”

CANCER



Professional Insights ★ Community Voices ★ Upcoming Events

SERIES-5

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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.

Caring for the Caregivers: The Missing Link in Cancer Care

Dr. E. Vidhubala, Psycho-oncologist

Cancer Is a Family Crisis

Cancer is never a solitary struggle. While the patient endures the physical and emotional toll of the disease and its treatment, the burden silently extends to the family—particularly the caregivers. These caregivers, often immediate family members, become the backbone of the cancer journey, yet remain largely invisible in the healthcare narrative.



Unseen and Unsupported

In India, and in many parts of the world, cancer caregiving is typically shouldered by spouses, children, or close relatives. They are the ones navigating hospital corridors, managing medications, juggling finances, and offering emotional support—often at the cost of their own health and well-being. Despite this, the existing oncology care systems remain predominantly patient-centered, overlooking the profound impact the disease has on those who care for the patient.

The Dual Burden of Caregiving

Caregivers experience a unique kind of suffering. Financial strain is among the most common challenges—cancer treatment is expensive, and caregivers often have to reduce or quit their jobs to provide full-time care. This disrupts household income, children's education, and long-term financial stability. For many in their midlife, this caregiving phase overlaps with critical responsibilities like supporting children's education or elderly parents. A cancer diagnosis in the family can collapse these parallel life paths, creating an emotional and economic crisis.





Elderly Caregivers and Isolation

In families where children have moved away, aging spouses become primary caregivers. These elderly caregivers often suffer from chronic illnesses themselves—diabetes, hypertension, arthritis—and face their own physical limitations. When one partner is diagnosed with cancer, the other is left to navigate a complex care process alone, often with limited mobility, resources, and social support. The emotional toll is staggering, and yet, their needs go unrecognized.

The Impact on Patient Outcomes

The absence of a structured caregiver support system contributes to delayed diagnosis, poor treatment compliance, and increased patient distress. A patient without a consistent caregiver often misses follow-ups, struggles with medication schedules, and faces emotional isolation. On the other hand, empowered caregivers can positively influence treatment outcomes, enhance patient morale, and ensure continuity of care.



A Call for Policy Change

It is high time we reframe the cancer care continuum to include caregivers as active participants in the treatment journey. Policies must mandate psychosocial screening for caregivers, financial counseling, respite care services, and caregiver education modules in every oncology setting. Caregiver distress should not be seen as peripheral—it is central to the patient's healing process



Conclusion:

A Shared Journey

Supporting caregivers is not charity; it is a strategic and compassionate investment in better health outcomes. Caregivers are not accessories to the patient's journey—they are co-travelers who need just as much care and consideration. By making space for their voices, acknowledging their struggles, and institutionalizing their support, we can begin to offer truly holistic cancer care.



TOBACCO AND CANCER TREATMENT : WHAT EVERY PATIENT & CAREGIVER NEEDS TO KNOW



MRS. S. DEEPIKA, PSYCHOLOGIST
CANCER INSTITUTE (WIA) ADAYAR, CHENNAI

Tobacco use remains a major public health concern not only because of its direct health consequences, but also due to the lingering misconceptions around it. While most people associate tobacco with smoking, it comes in many forms: vaping, chewing, snuff, and more. All carry significant health risks, and surprisingly, many users still don't realize just how far-reaching the effects are—including on those around them.



01



Cancer risks aren't just limited to smokers.

Secondhand smoke exposure is a silent threat especially in indoor or enclosed spaces. Harmful chemicals can linger in the air and on surfaces, affecting non-smokers who may not realize the risks. Children, pregnant women, and people with respiratory conditions are especially vulnerable. It increases the risk of asthma, respiratory infections, complications in pregnancy, and even lung cancer.

Unveiling the Hidden Risks

Tobacco and cancer go hand-in-hand, but many don't realize just how damaging it can be. Tobacco smoke contains over 4,000 chemicals, and with vaping, around 3,000. Among these are over 70 known carcinogens substances that can lead to cell mutations and cause cancer. In fact, tobacco is one of the top cancer-causing agents, with smoking responsible for about 90% of lung cancer cases. And it's not just lung cancer we're talking about, oral cancers are also strongly tied to tobacco use. It's a common misconception that oral cancer is only caused by smoking, but it can happen with chewing tobacco, snuff, and even from secondhand smoke. These cancer risks aren't just limited to smokers.

02



The Psychological Struggle to Quit

For many tobacco users, quitting isn't as simple as it might seem. Nicotine is highly addictive, and the physical and psychological dependence it creates is tough to overcome. Many users continue smoking even after a cancer diagnosis, some out of denial, others out of psychological dependence. Nicotine triggers dopamine release, creating temporary feelings of pleasure or relief, which reinforces the habit.

Withdrawal can cause headaches, irritability, anxiety, and intense cravings, but the emotional dependence often poses the bigger challenge. It's not just a habit; it's a deeply ingrained psychological and physical dependence. Understanding these barriers

03



Keys to Quitting: Counseling, Support, and Relapse Prevention

Tobacco cessation isn't just about stopping a habit, it's about reclaiming health and improving recovery outcomes, especially for patients undergoing cancer treatment. Supportive strategies include:

- Counseling (individual or group) for emotional support
- Managing withdrawal symptoms
- Creating action plans to avoid relapse
- Identifying triggers that lead to tobacco use

Hospitals can play a unique role here. While routine disruption may increase cravings, hospitalization can also be a fresh opportunity to begin quitting, away from usual environmental cues.



05

Patient Education and Awareness

For many patients, especially those recently diagnosed with a serious illness like cancer, the link between tobacco use and disease isn't always obvious. Education is essential:

- **Tailored programs** can help patients understand the urgency of quitting.
- **Self-help strategies** like breathing exercises, hydration, and distractions can use during moments of intense craving, helping them manage withdrawal in the moment.
- **Trigger identification** (times of day, situations, or emotions—that lead them to crave tobacco.) helps patients recognize and avoid high-risk moments for relapse.



07

04



Challenges of Quitting During Hospitalization

Routine Disruption: For patients in the hospital, there's a break from their regular routine. While this could be seen as a challenge in terms of dealing with cravings, it also offers a chance to break the cycle of daily tobacco use. The hospital setting can, in some ways, serve as an opportunity to begin the process of tobacco cessation by helping patients detach from their usual smoking environment.

Hospital Rules and Addiction: Hospital protocols prevent patients from stepping outside for smoking, which can cause feelings of frustration and helplessness. This is compounded by the mental struggle between the knowledge of tobacco's harmful effects (like cancer) and the immediate psychological need for nicotine relief. It's not uncommon for these patients to feel trapped in this internal conflict, which can lead to stress or anxiety.

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Addressing Tobacco Use Holistically: From Psychological Triggers to Community Action

Tobacco addiction is more than a physical dependence on nicotine it's deeply rooted in psychological, social, and cultural behaviors. To effectively support tobacco users in quitting, we must address the emotional triggers, normalize support structures, and engage healthcare professionals and public health systems.

Psychological Dependence and Relapse Risk

Quitting tobacco is not just about willpower it's about untangling emotional and behavioral ties that often go unnoticed:

- **Emotional Triggers:** Smoking is frequently linked to specific emotional states like stress, boredom, anxiety and rituals like smoking after meals or during social gatherings. These associations can create powerful psychological barriers to quitting.
- **Coping with Stress:** Without healthy alternatives, many users relapse during stressful moments. Encouraging new coping strategies like mindfulness, breathing exercises, or physical activity is key to long-term success.
- **Relapse is Part of Recovery:** Relapse shouldn't be seen as failure. It's an opportunity to reassess triggers, strengthen coping mechanisms, and adjust the cessation plan. Support groups and consistent counseling can reinforce motivation and accountability.
- **Motivational Counseling:** Patients often feel defeated or helpless when told to quit after years of use. Counseling helps reframe quitting not as an end, but as a step toward healing and empowerment, especially after a cancer diagnosis.

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Cultural and Social Dynamics

- **Social Norms and Peer Pressure:** Smoking is often woven into social rituals in workplaces, tea shops, or casual gatherings. This normalization can undermine quitting efforts.
- **Alternative Social Supports:** Offering non-tobacco-related ways to socialize and providing emotional reinforcement through friends and family helps reduce this cultural reinforcement.
- **Community Involvement:** Involving caregivers, community leaders, and peer in counseling sessions and support groups reinforces the message at home. In Tamil Nadu and similar cultural contexts, this communal support is crucial to long-term success.

Online Meetings and Digital Support

- **Accessibility and Inclusivity:** Online support meetings like Nicotine Anonymous are more accessible, especially for patients who are geographically remote or recovering in hospital wards. These virtual communities provide comfort without the need for in-person presence
- **Peer Support and Shared Stories:** Hearing from others who have quit successfully builds hope and gives practical advice. These shared experiences are often more impactful than professional advice alone.
- **Mobile Apps and Digital Tools:** Tools for tracking cravings, delivering motivational messages, and providing guided quit plans help users stay on track, offering support at any hour.

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Healthcare System and Professional Involvement

- Integrated Support in Hospitals:** Nurses, doctors, and psychologists play key roles in cessation, offering personalized interventions based on the level of dependence. High-dependence users often need nicotine replacement therapy (NRT) in addition to psychological support
- Dentists as Frontline Advocates:** Dental health is directly impacted by tobacco. Dentists can educate and refer patients to cessation resources during routine checkups, making every visit a teachable moment. Regular dental visits are an excellent opportunity to screen for tobacco use, offer brief interventions, and refer patients to cessation support.
- Government Initiatives:** Tamil Nadu's expanding network of cessation clinics, mandates for tobacco screening in public health settings, and focus on professional training ensure that tobacco support reaches even the most underserved areas. Government also mandates now require dental clinics to include tobacco cessation services, ensuring widespread access and reinforcing the interdisciplinary approach needed for long-term impact.

Support Groups and Community-Based Healing

- Ongoing Group Counseling:** Groups like those run in cancer institutes or modeled on Nicotine Anonymous provide a space for shared recovery. Patients find strength in hearing from peers who've faced similar struggles and succeeded.
- Real Impact of Peer Mentorship:** Former users share their journeys—how they managed cravings, dealt with setbacks, and maintained recovery. This encourages new participants to stick with their goals and resist relapse.
- Inclusivity and Simplicity:** These support systems are open to all—no prerequisites, just a willingness to quit. They offer continuity, belonging, and real-time encouragement.

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Structure of Tobacco Cessation Clinics

- Tamil Nadu has 21 such clinics, though initially there was a misconception about there being only one.
- Clinics are supported by the WHO Tobacco Control Resource Center and various dental/public health institutions.
- Dentists, especially from public health departments, are trained and mapped for tobacco cessation services.

Multidisciplinary Team of Cessation Includes

Holistic, Multi-Layered Care: Combining behavioral, psychological, pharmacological, and digital tools is the future of cessation. No single method fits all, so flexibility and personalization are key.

- Psychologists – for behavioral therapy and addiction support.
- Social Workers – community outreach and patient referral.
- Dentists – conduct oral screenings and educate about oral health risks.
- Doctors & Nurses – medical care and withdrawal management. Public Health Dentists are specially trained and mapped for cessation services.
- Building Tobacco-Free Environments: Schools, workplaces, hospitals, and homes must reinforce a smoke-free culture. Public celebration of quitting, workplace rewards, and social encouragement help normalize non-use.

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Importance of Social Support

- Social and psychological support is essential, especially from caregivers.
- Patients often face guilt, stress, and relapse risks, which need compassionate handling.
- Caregivers should avoid pressure tactics and offer emotional encouragement instead.

Real life case study

A middle-aged patient diagnosed with oral cancer decided to quit tobacco immediately after his diagnosis, influenced strongly by his family and young children. During the course of his treatment, he experienced cravings but did not suffer from major withdrawal symptoms, likely due to the structured hospital environment and constant monitoring. However, after completing chemotherapy and radiation therapy, he relapsed once back at home. Despite this setback, with ongoing support and follow-up from his care team, he managed to stay tobacco-free for six to eight months. His case highlights both the challenges of maintaining cessation post-treatment and the importance of consistent support in preventing relapse.



மகளிரின் வலிமை

”வெண்ணை நீ
கருவறையில் உதித்து
இந்த உலகத்திற்கு வந்து
மல சோதனைகளைத் தாண்டி
சாதனைகள் மல மடைத்து
மாரதி கண்ட புதுமை வெண்ணாய்,

மல தியாகங்களை செய்யு
மகளாய், சகோதரியாய்
தாரமாய், தாயாய், சேயாய்
சேவைகள் மல செய்யு,

தனக்காக வாழாமல்
பிறருக்காக
தன்னுடைய உணர்வுகளை
அற்பணிக்கும் தியாகிகளுக்கு
உலக மகளிர் தின நல் வாழ்த்துக்கள்.”

– திருமதி. தமிழ் செல்வி

--UPCOMING EVENTS--

ADL - Dental care Sub Series : Sub series: Treatment Challenges in Dental Care

ZOOM MEETING

Meeting ID: 858 5714 1348
Passcode: 387170



YOUTUBE LIVE

*www.youtube.com/@
CaregiverAdvocacyGroup*

TIME

7.00pm - 7.40pm

Head and neck cancer : what you must know as patient and caregiver

ZOOM MEETING

Meeting ID: 874 5762 0345
Passcode: 495923



YOUTUBE LIVE

*www.youtube.com/@
CaregiverAdvocacyGroup*

TIME

6.00pm - 7.00pm

--COLLABORATORS--



--ACKNOWLEDGEMENT--

We sincerely thank Mrs. Tamil Selvi, 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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