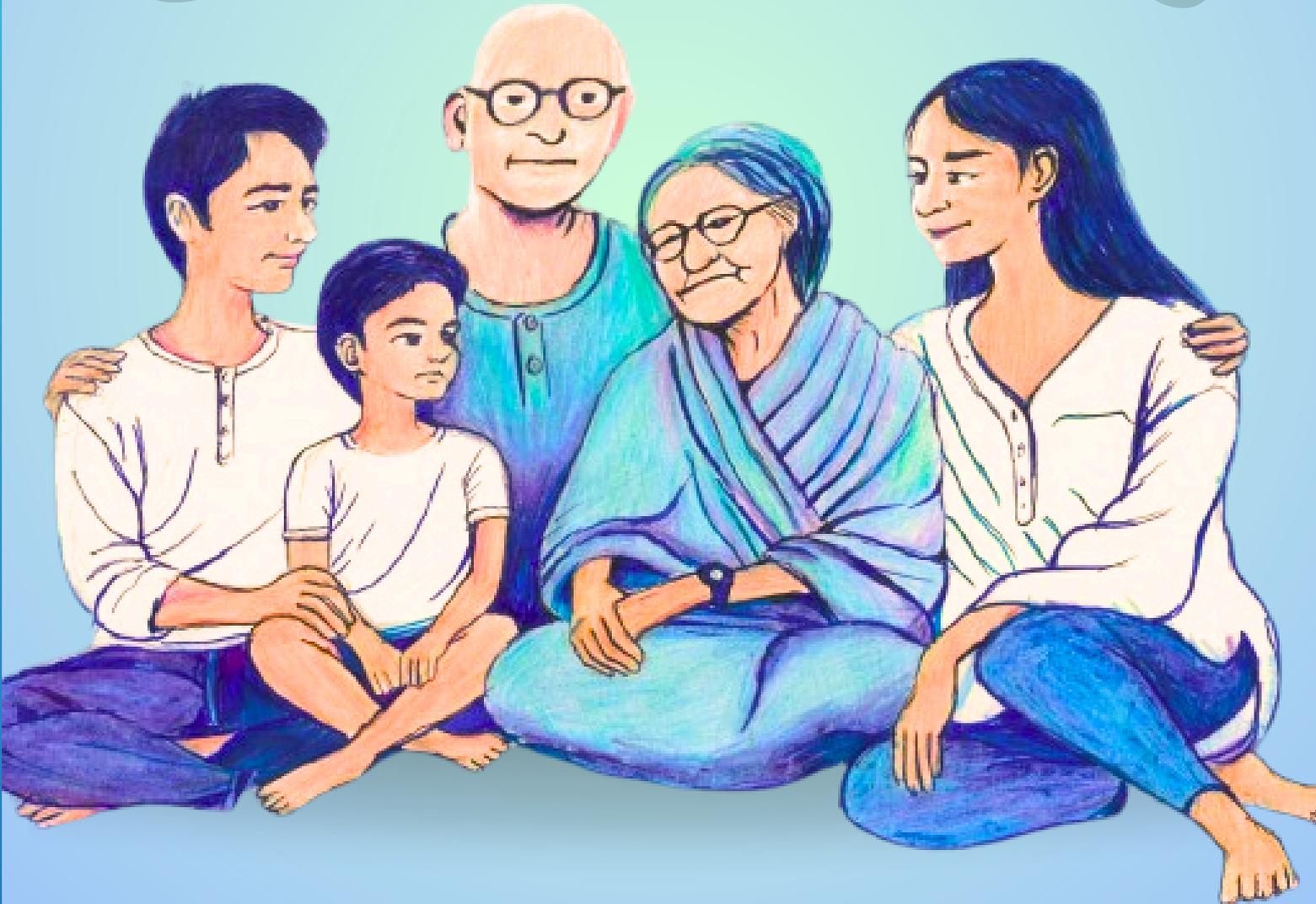




CAREGIVER

“Supporting your loved ones through their journey”

CANCER



Professional Insights ★ Community Voices ★ Upcoming Events

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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.

EMOTIONAL CHALLENGES AS A CANCER CAREGIVER AND HOW TO DEAL WITH IT

DR. S. ANAND KUMAR, CONSULTANT PSYCHIATRIST



At any stage of life, you might find yourself caring for a loved one with cancer. After a loved one is diagnosed with cancer, the dynamics of your relationship can change, and the way you support them could differ from before. Overall, caregiving can be intense, especially if you haven't had prior experience. This intensity often leads to a multitude of emotional challenges.

As caregivers are primarily family or close friends, it's

important to understand what motivates someone to take on this role. Love, a sense of duty and responsibility, or even guilt, often drives people to become caregivers. In some cases, financial incentives might also play a role.

Caregivers face various emotional challenges, including grief, mental health issues, loss of personal time, and financial burdens. Anxiety and depression are common among caregivers, with many experiencing burnout.

Burnout, a state of physical, emotional, and mental exhaustion, can significantly reduce a caregiver's quality of life and increase their burden, sometimes leading to severe depression. Identifying and managing these emotional hurdles is crucial to avoiding disastrous consequences.

Dealing with Emotional Challenges

Seek Help

Many caregivers, in hindsight, realize they took on too much alone. They often regret not seeking help from friends and family. It's important to set realistic expectations for what you can and cannot do. Decide what tasks you want to handle individually and what you're willing to delegate to others. For instance, you might choose to ask for help with household chores, taking care of children, or driving your loved one to appointments.

Accept Disappointment When Help Isn't Available

When someone is seriously ill, friends and family often offer to help. However, not everyone may be able to assist, which can be disappointing. Understand that some people might be too busy, dealing with

their own health issues, unaware of the situation's severity, or even afraid of dealing with cancer due to stigma or misconceptions. Clearly communicate your needs and be prepared for the possibility of rejection. If someone can't help, try to accept it and look for other avenues for support.

Take care of Yourself

As a cancer caregiver, you might prioritize the patient's health over your own, sometimes neglecting your needs. However, caring for yourself can give you the strength you need to continue. Make time for yourself, even if it's just an hour each day. Use this time for activities you enjoy, like exercising, gardening, or watching your favorite TV show. Socializing with friends and family can also provide a much-needed break from caregiving.

Analyze your feelings to understand what might lift your spirits. Learn about your loved one's cancer to gain clarity and better explain the situation to others. Share important moments with your loved one, as facing challenges together can strengthen your bond and provide hope for the future.

Joining a support group can also be very helpful. Whether in person, over the phone, or online, these groups allow you to vent your feelings to others facing similar challenges. Writing in a diary or journal can help you reflect on precious memories with your loved one, providing hope during difficult times. If you're struggling to cope, seek professional help from a counselor, psychologist, or spiritual leader. They can offer new perspectives and coping strategies.

Practice stress management

Promoting adaptive coping strategies helps resolve stress. By having realistic expectations and input from professionals, you can better handle what happens to your loved one with cancer. Taking things day by day allows you to stay in the present and avoid false hope.

Anticipate problems and have a backup plan in case Plan A doesn't work. Sometimes, a hopeful outlook can help you reframe your thoughts and gain a different perspective on life.

Relaxation techniques like prayer, meditation, deep breathing exercises, or other muscle relaxation methods are crucial for your mental health. Strong social support systems, as mentioned earlier, can also be highly beneficial.

*"You can't always control what goes on outside,
but you can always control what goes on inside."*

— Wayne Dyer

MAKING THE RIGHT CHOICE: A CAREGIVER'S GUIDE TO ORIGINAL Vs GENERIC MEDICINES IN CANCER TREATMENT

DR. ARUN SESHACHALAM, MEDICAL ONCOLOGIST



Navigating the complex world of medications is often a daunting task for cancer caregivers, who are already juggling numerous responsibilities. A common question that arises is whether to choose original (brand-name) medicines or their generic counterparts. Understanding the differences between these options is crucial to ensuring your loved one receives the best possible care without unnecessary financial strain.

Understanding Original Medicines

Original medicines, also known as brand-name drugs, are the first versions of a medication developed by pharmaceutical companies.

These drugs are the result of extensive research, clinical trials, and rigorous regulatory approvals. The high costs associated with their development and marketing are often reflected in the price of the medication. For many caregivers, the familiarity and perceived quality of these brand-name drugs provide a sense of comfort, even though they come with a hefty price tag.

The Case for Generic Medicines

On the other hand, generic medicines are essentially copies of original drugs produced after the original drug's patent expires. These generics contain the same active ingredients

and are designed to work in the same way, offering the same therapeutic benefits as the original medicines but at a significantly lower cost. The lower price is primarily due to the reduced development and marketing expenses that generic manufacturers face.

Despite the cost savings, some caregivers remain hesitant about switching to generics, often due to concerns about their effectiveness or the possibility of different side effects. However, it's important to know that regulatory agencies such as the FDA and CDSCO require generic medicines to meet strict standards, ensuring they are just as safe and effective as their brand-name counterparts.

Making informed Decisions

When deciding between original and generic medicines, it's essential to have an open conversation with your healthcare provider. Discuss the availability of generic alternatives and whether they are suitable for your loved one's treatment. Healthcare providers can offer valuable insights into the efficacy, safety, and cost-effectiveness of generics, helping you make a well-informed decision.

In some cases, your loved one might need the original medicine, especially if they have specific allergies to inactive ingredients found in the generic version. However, these instances are rare, and generics are generally a safe and effective option.

Financial Considerations

The cost of cancer treatment can be overwhelming, and medication is a significant part of that burden.

If generics are not available or suitable, financial assistance programs offered by pharmaceutical companies or non-profits can provide relief. These programs can make original medicines more affordable, ensuring that cost does not become a barrier to receiving the best care.

Key Takeaways for Caregivers

- **Generic medicines** are as effective and safe as original medicines, meeting the same regulatory standards.
- **The lower cost of generics** stems from reduced development and marketing expenses, not a difference in quality.
- **Differences in inactive ingredients** between original and generic medicines generally do not affect the drug's effectiveness.
- **Healthcare providers** are a valuable resource for making informed decisions

about medication choices.

- **Financial assistance programs** are available for original medicines if generics are not an option.

Conclusion

As a caregiver, your role in managing your loved one's medication is vital. By understanding the options and collaborating with healthcare providers, you can ensure that your loved one receives effective treatment without undue financial stress. Whether choosing between original or generic medicines, the key is to stay informed, ask the right questions, and advocate for the best possible care.

This knowledge not only empowers you as a caregiver but also contributes to the overall well-being of your loved one, making a challenging journey a bit more manageable.

UNDERSTANDING THE ROLE OF CAREGIVERS

DR. ARUN SESHACHALAM, MEDICAL ONCOLOGIST, DR. NIRAIMATHI, RESEARCH CONSULTANT
MS. SOUNDARYA, PSYCHOLOGIST & MS. RAMYA, ARCHITECT AND PRIMARY CAREGIVER

The session began with an introduction to the importance of caregiving. Caregiving is something everyone experiences at some stage in life, whether as a caregiver or someone who needs care.

This introduction set the stage for the first question for Dr. Niraimathi:

"How does it feel to be a caregiver?"

Dr. Niraimathi stated that being a caregiver is a complex emotional experience, characterized by a mix of fear, hope, and gratitude. She emphasized that the responsibility can feel overwhelming at times, as caregivers constantly balance their personal and professional lives while making critical decisions for their loved one's care. Reflecting on her own experience caring , she shared that while the journey was filled with worry, it was also driven by hope and a desire to give back to those who supported them. However, she acknowledged that the stress of managing work, family, and caregiving demands was intense and often challenging.

As a caregiver, how do you handle the practical challenges of balancing work-life responsibilities with caregiving duties?

Ramya explained that balancing work, life, and caregiving is indeed challenging, often requiring the eldest family member to take on the primary role.

She shared that, while the journey can be overwhelming, there's a sense of accomplishment in managing it all. Despite setbacks, such as the logistical challenges of traveling between the hospital and home, Ramya and her family developed a routine that made things more manageable.

They plan ahead for chemo days, preparing everything the day before and adapting as needed when plans change. This systematic approach, combined

with her dad's support, made a significant difference. Ramya emphasized that having a system in place is crucial, even in the face of financial constraints and other challenges. Trusting the doctors and following their advice also helped alleviate some of the mental stress. Despite the difficulties, Ramya's ability to prioritize, plan ahead, and rely on a strong support system proved essential in navigating the caregiving journey.



Communication with patients is key. There's often hesitation or awkwardness in being open with them, but it's really important. Question posed to Dr. Niraimathi;

How crucial is communication with patients during their treatment, and what role does it play in their overall care?

Dr. Niraimathi emphasized that communication with patients is crucial for effective care. While there may be hesitation or awkwardness about being fully transparent, it is essential to avoid hiding information, as this can leave patients unprepared and emotionally unsettled.

Addressing fears directly and providing clear, detailed information about the illness and treatment helps patients understand their situation and manage their expectations.

She noted that if the treatment process is not communicated clearly, patients are likely to have ongoing questions and fears. Explaining the treatment plan and its duration allows patients to feel more in control and confident throughout their journey.

Dr. Niraimathi emphasized the importance of involving the patients in decision-making, respecting their emotional capacity, and ensuring that they understand their illness.

Clear communication from the start helps to build trust and reduce anxiety.

In a home environment where discussing the illness may be uncomfortable, it's essential to have private and respectful conversations. By being open from the start and honoring the patient's preferences, caregivers can help make the treatment process more effective, build trust, and improve the patient's emotional well-being. In addition

Dr. Arun discussed the unique caregiver-patient relationship in India, emphasizing that patients often rely heavily on their caregivers for decision-making, placing significant responsibility on them. He noted that family dynamics and the amount of information shared can vary widely, as some patients are better equipped to handle difficult news than others. In India, the caregiver's role is particularly significant due to the close involvement of children in their parents' care, regardless of their age, which often results in caregivers shouldering substantial financial, emotional, and social responsibilities.

In this context, Dr. Arun also pointed out that while patients may initially be unaware of their cancer diagnosis, the reality eventually becomes evident, as cancer cannot be hidden like a common cold. The process of fully disclosing information to patients can take different amounts of time, from a few months to a year or more.

This evolving dynamic between patient and caregiver is crucial for effective treatment, and oncologists must pay close attention to it. Without the caregiver's full involvement, treatment compliance might suffer.

How can caregivers educate themselves about the specific needs and treatment options of their loved ones?

Ms. Soundarya, Psychologist, responded

"Educating both the patient and caregiver is essential when dealing with special needs or specific treatments. Many individuals come with preconceived notions from social media or Google searches, but it's important to verify this information with healthcare professionals when seeking guidance related to patients' diseases, treatment options, and any potential complications.

Balancing information can be challenging. Ensuring that the information shared is accurate helps prevent misunderstandings.

In this conversation, Dr. Arun also added

"It's common for patients to rely on Google for information, which is normal behavior. However, obtaining a second opinion from reputable sources is crucial. He advises patients to seek opinions from trusted centers,,

before finalizing a treatment plan. Treatment decisions should involve the doctor, patient, and caregiver and should be personalized based on the patient's age and health conditions. The healthcare system, includes nurses, Front desk personnel, and emergency.

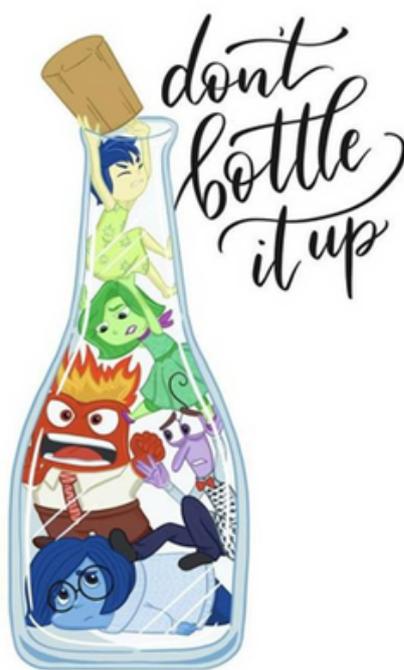
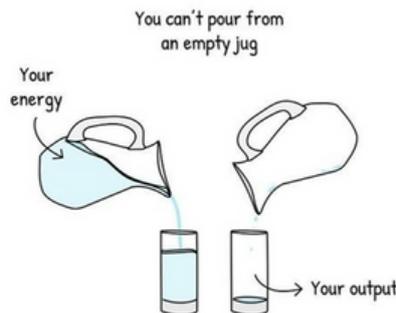
services, etc plays a significant role in patient care. It's important to choose a system that is affordable, flexible, and suits all your needs, especially for long-term care."

How can caregivers maintain their mental health, and why is seeking professional support important? When should caregivers consider doing so?

Ms. Soundarya, Psychologist, explained

"Caregivers often experience significant stress and feel overwhelmed, which can impact their mental health. It's crucial to recognize and express emotions rather than suppress them. Maintaining both physical and mental well-being involves regular replenishment of energy. She highlighted that today's caregivers are tomorrow's Hidden patients. Professional help with appropriate mental health support can enhance resilience, and coping skills and help caregivers navigate the emotional challenges of the caregiving journey.

Adjusting to a new normal takes time, and it's essential for caregivers to regularly replenish their physical and mental energy. Being in a good headspace is crucial for them to support the patient effectively.



In addition, Dr. Arun highlighted

"Families sometimes attach stigma to discussing serious issues like cancer, leading to hidden. Struggles and a lack of support. This can intensify the caregiver's burden, as they may

may face severe stress and even depression. Observing signs of burnout, such as changes in weight, sleep disturbances, or social withdrawal, is essential. Caregivers need to take breaks without guilt and seek support from counselors, friends, or family. Engaging in activities like listening to music, spending time with loved ones, and celebrating small victories can significantly benefit their mental health and overall well-being."



Key takeaway messages

Emotional Complexity of Caregiving

1. Caregiving is an intense emotional experience, marked by fear, hope, and gratitude.
2. Caregivers often feel overwhelmed as they balance personal and professional responsibilities.

The journey is motivated by a deep desire to support loved ones, yet managing stress along the way can be difficult. Practical Challenges in Caregiving:

- Balancing work-life and caregiving duties requires careful planning and routine.
- A strong support system, including family, and friends, is essential in managing the demands of caregiving.

- 3. Trusting healthcare professionals and being adaptable helps alleviate logistical and mental stress.

The Importance of Communication

- Open and clear communication with patients is crucial for their emotional well-being and treatment compliance.
- Hiding information can leave patients unprepared and emotionally unsettled.
- Involving patients in decision-making and respecting their emotional capacity fosters trust and reduces confusion.

Unique caregiver-patient Dynamics in India

- In India, patients often rely heavily on caregivers for decision-making, placing significant responsibility on them.
- The gradual disclosure of a cancer diagnosis is common, with the caregiver's involvement being crucial for treatment compliance.
- Caregivers bear substantial financial, emotional, and social responsibilities, especially in family-centric cultures.

Education and Support for Caregivers

- Educating both patients and caregivers about specific needs and treatment options is essential.
- It is important to verify information from social media or Google with healthcare professionals.
- Caregivers should seek guidance from a multidisciplinary healthcare team to ensure accurate information and support.

--CAREGIVER TIPS--

- *Avoid hiding information, as this can leave patients unprepared and emotionally unsettled.*
- *Open communication with patients is crucial for effective care.*
- *Explaining the treatment plan and its duration allows patients to feel more in control and confident throughout their journey.*
- *Trusting the doctors and following their advice also helped alleviate some of the mental stress.*
- *Developing a routine that made things more manageable.*

THE HUG DRUG THERAPY

CA.S.SRINIVASAN., FCA., DISA., CHARTERED ACCOUNTANT



In the western culture it is very usual to hug friends and families on every possible occasion. This practice has many health benefits. In the eastern culture, there is an advanced version of hug drug therapy. The seniors in the home will bless their children/grandchildren with their hands on the head/forehead of the children/grandchildren and the children/grandchildren will in-turn touch the feet of their parents and Grand parents on every special occasion. According to some spiritualists, this practice of blessing

the children and touching the feet was prevalent in India on a day to day basis (Not only on special occasions) Now it was reduced to only special occasions & festival days. They believe that the wisdom and intelligence of their family seniors will come to the juniors by touching their feet on daily basis and both feel connected to each other.

In the personal experience of the author of this blog, he was suffering from very severe insomnia due to withdrawal effects of antidepressant drugs for nearly 4 years. He used to cry literally in the

middle of every night watching the clock passing through. His parents used to wake up and console him.

Mother used to sit near his head and father near his feet. Both of them will give a gentle massage. One on his forehead and the other on his legs. This treatment or therapy did a greater wonder in healing this chronic insomnia and withdrawal effects. A brief period of anxiety disorders/OCD history was also there for the author of this blog and the gentle and warm massage from his parents dispersed the same.

Caregivers can take this hug drug therapy both as preventive therapy and also after diagnosis. Daily at fixed intervals, they shall hold the palms of their loved ones and discuss the happy moments they have spent together; the places they visited together; the festivals they celebrated together, and at the end the caregiver shall say to their loved one. "See, I want you in my life. Whatever the scientifically trained Doctor says, I want your presence in my life. know the greater intelligence of this universe

which created you and mine, can help you in healing your disease. I Also they shall say how deep they love them". Also they shall say to their loved ones (patients) that they love them unconditionally irrespective of any odds in the past and accept them as they are.

Dinner Family Meet - Informal

It was traditional Indian custom to have an informal meeting every night after dinner, where all the family members would gather

together. They will share whatever happened throughout the day (both the success stories and failure stories, the good and the bad) to the other members of their family.

Elders will give guidance and they wish good night to everyone before going to sleep. This therapy ensures good sleep for all the members of the family. Though this is preventive care, this can be undertaken post diagnosis also as this will reduce anxiety.

*"Every touch, every word, every shared moment
is a step towards healing and understanding"
-Anonymous*

--UPCOMING EVENTS--

“Are we Truly Meeting Patient Expectations “



“Raising child with Special Needs”



TIME

6.00pm - 7.00pm

ZOOM MEETING

Meeting ID: 863 4222 5932

Passcode: 524556

YOUTUBE LIVE

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

CaregiverAdvocacyGroup

--COLLABORATORS--



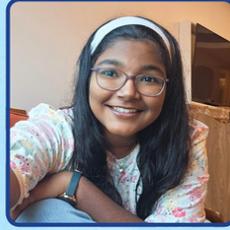
--ACKNOWLEDGEMENT--

We extend our deepest gratitude to Ms. Ramya, Architect and Primary Caregiver, 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.

--Core Members--



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