

## How cancer quietly reshapes roles within families

When cancer enters a family, the first response is often immediate and instinctive. People step closer. They want to help and hold things together. In those early moments, care comes from a place that feels natural. It comes from love.

But over time, that care begins to take shape in ways no one fully prepares for. Daily routines shift. Conversations change. Responsibilities quietly move from one person to another. What once felt like helping slowly becomes something much larger, something that stretches across every part of life.

Care that begins to feel like an obligation can make it harder to stay connected to what the person is going through. Care, when rooted in love, allows patience, understanding, and presence to grow even during uncertainty. This does not make the journey easy, but it makes it more human.

At the same time, it is important to acknowledge that love does not remove the weight of responsibility. Families suddenly find themselves learning about treatments, managing hospital visits, adjusting finances, and holding emotional space for each other. It can feel overwhelming, especially when everything changes at once.

Across cancer care, research shows that families provide a large share of day-to-day support. Studies examining *caregiving in oncology*, including work published in *Psycho-Oncology* and palliative care research settings, show that caregivers take on responsibilities that go far beyond emotional support. A meta-analysis published in *JAMA Oncology* in 2021 further found that caregivers frequently experience anxiety and depression at clinically significant levels.

These patterns reflect something deeper. Cancer does not just affect the person diagnosed. It reshapes how families function. It redistributes roles, often quietly, but in ways that influence everyday life, relationships, and long-term well-being.

### When Care Becomes Everyday Responsibility

As treatment begins, family members step into roles that extend beyond what they expected. They start managing medications, keeping track of appointments, noticing changes in symptoms, and responding when something feels off. Many learn how to support physical care at home, often without prior experience.

Research in *advanced cancer care*, including qualitative studies in palliative settings and multisite caregiver research, shows that families gradually take on responsibilities that require attentiveness, decision-making, and coordination. These are not small tasks. They demand time, energy, and emotional presence.

Most caregivers do not receive formal preparation for this. They learn by observing doctors, asking questions during appointments, or figuring things out along the way. This process can

feel uncertain, especially when every cancer journey looks different. The type of cancer, stage, treatment plan, and side effects vary widely, which makes it difficult to have one fixed way of preparing caregivers.

Instead of rigid guidelines, what helps is ongoing, flexible support. Studies on *caregiver interventions* show that when caregivers receive simple, practical guidance, such as understanding how to respond to common side effects, how to manage medication schedules, or when to seek medical help, they feel more confident.

This guidance does not standardize care. It supports caregivers in adapting to their specific situation. This is not about replacing professional care. It is about recognizing that families are already deeply involved and making sure they are not left to manage everything on their own. When healthcare teams take a few moments to explain, guide, and check in, it can ease a significant part of the uncertainty caregivers carry.

### **Holding Emotional Weight Together**

Alongside physical care, families also hold a large emotional responsibility. People often try to stay strong for each other. One person reassures the patient, another keeps the household steady, and someone quietly absorbs the fear and uncertainty that comes with the illness.

Caregivers do not just respond to what is happening around them. They also manage their own emotions while trying not to let them affect others. Over time, this balancing act can become exhausting.

Research consistently shows that caregivers experience high levels of emotional strain. The *JAMA Oncology meta-analysis*, which reviewed multiple randomized clinical trials, looked at structured psychological support programs for caregivers. These trials included interventions such as counselling sessions, stress management techniques, guided conversations with trained professionals, and peer support groups. The findings showed that caregivers who received such support reported lower levels of anxiety and depression compared to those who did not.

This reduction reflects real changes in how caregivers cope. When people have a space to express what they are feeling, learn ways to manage stress, and connect with others in similar situations, it becomes easier to continue providing care without feeling overwhelmed.

Emotional strain in caregiving is not something people simply have to accept. It can be supported. Access to counselling, support groups, or even open conversations within the family can make a meaningful difference. When caregivers feel supported, the entire environment around the patient becomes more stable and less tense.

### **Balancing Care and Financial Reality**

Cancer places immediate financial pressure on families, and most are not prepared for how quickly these costs build. Treatment costs, travel, medications, and daily expenses can add up

quickly. At the same time, family members may need to reduce work hours or step away from their jobs to provide care.

This creates a difficult situation. Families are not choosing between work and caregiving because one is more important than the other. They need both. They need financial stability and to be present for their loved ones.

Research on *financial toxicity* in cancer care shows that many families experience long-term financial stress. Studies on work and caregiving show that many caregivers face reduced income, interrupted careers, and job insecurity.

In this context, workplaces play an important role. When employers offer flexibility, understanding, and support, it can significantly ease the pressure on caregivers. Simple steps such as flexible hours, remote work options, or compassionate leave policies can help people manage both responsibilities.

This is not just about productivity. It is about recognizing that employees are also people navigating deeply personal challenges. A supportive workplace does not remove the difficulty, but it makes it more manageable and allows caregivers to continue both their work and their role at home with less strain.

### **Making Decisions Together**

Cancer care often involves complex decisions. Treatment options, side effects, timelines, and uncertainties can feel overwhelming, especially when information comes quickly and emotions run high.

Caregivers frequently help navigate these decisions, but it is equally important to keep the person with cancer involved in these conversations. When patients understand what is happening and feel included, it reduces fear and helps them feel more in control of their situation.

Research in *palliative care* shows that structured communication between healthcare teams, patients, and families improves understanding and reduces distress. Studies on family meetings and shared decision-making highlight that when doctors take time to explain options clearly and allow space for questions, families feel more confident in their choices.

Communication creates space for people to process what they are going through. When families talk openly and include the patient in discussions, decisions become more shared and less overwhelming.

### **When Relationships Begin to Shift**

As roles shift, relationships within families also begin to change. A spouse may feel more like a caregiver than a partner. Children may take on responsibilities that change how they see themselves within the family. These changes can be subtle but deeply felt.

Family-centered care offers a way to respond to this. It is an approach that sees the family as part of the care process, not just as support on the side. In this model, healthcare providers include family members in discussions, listen to their concerns, and recognize their role in everyday care.

Research in *family systems and oncology care* shows that when families are included in this way, communication improves and emotional stress reduces. It also helps maintain a sense of connection between family members, even as roles evolve.

Family-centered care does not try to fix every challenge. It creates space for families to adapt together, with support from the healthcare system.

### **Where Current Support Falls Short**

Even with growing research, support systems are still developing. Many families continue to navigate responsibilities without consistent guidance, emotional support, or financial protection.

Studies from low- and middle-income countries, including India, highlight additional challenges such as travel for treatment, limited access to services, and reliance on informal care networks. At the same time, research in these regions remains limited compared to high-income countries.

There is also a lack of long-term research on how caregiving affects people over time. Many studies focus on immediate experiences but do not fully capture what happens months or years later.

These gaps show that while we understand the problem better today, there is still work to be done in building systems that respond to it fully.

### **Making Care More Supportive**

Improving support for families does not require completely new systems. It requires small but meaningful shifts in how care is delivered.

Healthcare providers can include caregivers more actively in conversations and offer simple, ongoing guidance rather than one-time instructions. Emotional support services can be made more accessible, not only for patients but for caregivers as well.

Workplaces can adopt policies that recognize caregiving as a reality many employees face. Flexibility and understanding can make a significant difference in how people manage both roles.

At a broader level, policies can begin to acknowledge caregiving as an essential part of healthcare. Financial support, access to services, and inclusion in care planning can help reduce the burden families carry.

## **The Human Side of Caregiving**

Caregiving often reflects deeper social patterns. Women frequently take on a larger share of responsibilities, and this can affect their work, financial independence, and long-term well-being.

At the same time, caregivers themselves need care. When they feel supported, they are better able to provide care that is patient, attentive, and sustainable.

This is not only about reducing burden. It is about dignity. Both patients and caregivers deserve to experience care that respects their emotional, physical, and social realities.

## **Sanjeevani: Holding families through changing roles**

When cancer enters a family, roles rarely stay the same. Responsibilities move quietly from one person to another. Someone who once led the household may begin to rely on others. A caregiver steps into decisions they were never prepared for. Families may not always speak about these shifts, but they shape how they experience the illness every day.

In the midst of these changes, support often needs to reach both the patient and those around them. Sanjeevani's in-hospital counselling creates space for these moments. Conversations happen during treatment, when emotions are still settling, and decisions feel immediate. Patients and caregivers are able to speak openly, ask questions, and make sense of what lies ahead. This shared understanding gives families more clarity and steadiness as they adjust to changing roles.

Many families feel this need for support deeply. Research conducted with the College of Social Work Nirmala Niketan echoes how important emotional and psychosocial care becomes during the cancer journey, not only for patients but also for those who care for them. Families often carry responsibilities that go unseen, and spaces where they can be heard make a real difference alongside medical care.

Support takes another form through the CanSahyogi initiative. Here, individuals who have lived through cancer, either as survivors or caregivers, become part of the care ecosystem. Their presence brings a different kind of reassurance. They help patients navigate treatment processes, manage practical concerns, and understand what to expect. Because they have experienced similar moments, their support feels familiar and easier to trust. At the same time, this initiative also creates a pathway for them to rebuild a sense of stability in their own lives, especially when cancer has already affected their financial situation.

Support also takes the form of helping caregivers learn how to care. Initiatives like Satori and Srjan support families in ways that go beyond immediate treatment. These spaces recognize that recovery does not end when treatment does. It continues in how people rebuild their daily lives, manage their health, and find steadiness again.

Satori brings attention to life after treatment, where many cancer victors continue to face physical side effects, emotional strain, and the quiet fear of recurrence. It creates a space where individuals learn how to support their well-being through meaningful practices. Guidance around nutrition, breathing, and mental health helps them rebuild strength and develop a more active relationship with their health. Over time, this shifts the experience of care. People are slowly understanding how to care for themselves.

Srjan continues to support families beyond the early stages of adjustment. It does not stop at one-time guidance. It gives patients and caregivers a space to keep learning over time. As they return, they begin to see how different parts of health connect. Food, breath, movement, and emotional well-being start to come together as part of everyday life.

As people return to these sessions, something shifts quietly. They begin to notice patterns in their bodies, respond to stress differently, and feel more aware of what helps them feel steady. Care begins to feel more manageable rather than something they are constantly trying to keep up with. They begin to understand what works for them. In this way, families move from reacting to the illness to finding a rhythm that supports them through it.

As families move through treatment, the need for connection continues beyond hospital settings. Sanjeevani's monthly support group meetings bring patients and caregivers together, where they openly share their experiences. These gatherings often include conversations with healthcare professionals, along with discussions on nutrition, movement, emotional well-being, and everyday challenges. When people listen to others who are going through similar situations, it becomes easier to process their experiences. These moments of shared understanding help reduce the sense of isolation that many families feel during treatment.

At the same time, caregiving often brings practical strain that is harder to speak about. When work is interrupted or income is reduced, the pressure on families increases in ways that go beyond treatment. CanSaarthi responds to this reality by recognising the value of lived experience and building on it. It helps family members and cancer survivors learn caregiving in a more structured way, based on what they have already been doing for their loved ones.

Over time, this begins to change how they see their role. Caregiving is no longer only managed within the family. It becomes something they feel more confident in. Many go on to support other patients as trained caregivers, while also bringing some financial stability to their own families. What they carry into this work is not just training but an understanding that comes from having lived through similar moments.

In this shift, the meaning of care expands. Caregiving may begin within the family, but it can grow into supporting others and helping people rebuild direction and dignity in their own lives.

Practical concerns also become part of how roles shift within a family. Managing finances, arranging treatment, and ensuring continuity of care often fall on caregivers who are already balancing emotional stress. Sanjeevani's resource teams work closely with patients to connect them with government schemes and financial support wherever possible. When gaps remain, they connect patients with donors to cover them. This reduces some of the uncertainty

around treatment and allows families to focus more on care rather than constant financial decision-making.

Beyond immediate care, support also grows into something more sustained through the Aham Sanjeevani initiative. Individuals who have experienced cancer train as community leaders and bring their understanding to spaces where awareness and guidance are needed. What begins as a personal journey gradually becomes a way to support others. Over time, people shift from receiving care to supporting others through similar experiences.

Across these efforts, one thing becomes clear. Cancer reshapes the rhythm of an entire family. When support acknowledges these shifts and responds to both emotional and practical needs, it helps families move through the experience with greater balance. Care then becomes something shared, understood, and held together more gently.

## **Conclusion**

Cancer changes the rhythm of everyday life. It shifts roles, reshapes relationships, and asks families to adapt in ways they may never have imagined.

Care holds everything together, not as a task, but as a way people stay connected to each other through uncertainty.

Research continues to show that families play a central role in cancer care. Recognizing this is the first step. Supporting it meaningfully is the next.

When families receive the support they need, they are better able to care, not just with effort but with presence and understanding. And in a journey as complex as cancer, that presence can make all the difference.

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