

# R.E.A.C.H. for Caregivers

RESOURCES • EDUCATION • ASSISTANCE • COUNSELING • HEALING



Memorial Sloan-Kettering  
Cancer Center

The role of the caregiver is a complex one and the challenges facing the caregiver often go unrecognized. If you are a caregiver, please know that resources and support are available. Memorial Sloan-Kettering offers a multidisciplinary team approach that recognizes the complex and demanding responsibilities that come with caring for a loved one with cancer.

## Why REACH?

By Annamma Abraham-Kaba

As a licensed clinical social worker on various medical services throughout my career, I have seen first-hand the challenges that caregivers face. On the Bone Marrow Transplant Service, I witnessed caregivers managing the demands of immunocompromised patients for three months to a year, and sometimes longer, as these patients could not be left alone. Similarly, on the Geriatric Service, older adults facing cancer often rely on their caregivers to help them navigate the myriad practical and emotional issues that can arise when coping with a cancer diagnosis. These two vulnerable caregiving populations made me think deeply about the pivotal role they play in patient care. In collaboration with my colleague Linda Mathew, a program was developed that



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provides caregivers with an opportunity to discuss their issues, fears, concerns, and feelings of isolation.

The program's most successful component to date is the virtual caregivers support group. Caregivers are frequently too busy to commute or take time from work and other family demands to receive the support they need. When the face-to-face caregiver support group shifted to a virtual space, the numbers of interested caregivers

let us know that we were serving an unmet need. The feedback we have received suggests that the virtual group is a space where caregivers can be vulnerable, feel recognized, and experience the support of others who are willing to assume the role of caring for their loved ones with cancer. Caregivers offer their inspiration and honesty, and help each other manage the complexities of this challenging role. The virtual group enables caregivers to go through their own poignant emotional struggles without leaving their home or workplace.

What caregivers are saying in the Virtual Group:

*“Caregiving can be described as utter drudgery and boredom interspersed with moments of panic and terror.”*

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## Recognizing the Caregiver

### Who is a caregiver?

The National Cancer Institute estimates that approximately 1.6 million new cases of cancer are expected to be diagnosed in the United States in 2013. Generally speaking, more women than men become caregivers, most caregivers are related to the person who has cancer, and most caregivers are aged 55 years or older. Many patients diagnosed with cancer will eventually require support from a family caregiver. In fact, non-professional caregivers form the foundation of the healthcare system in the United States, supporting advances in treatment such as

multimodality treatment protocols given in outpatient and home settings.

### What is the caregiver's role?

The role of a caregiver can be an extremely rewarding experience, but simultaneously, a stressful and difficult one. Non-professional caregivers, defined here as family and friends, often assume this role with minimal preparation, no guidance or support from the community, and a lack of empathy from the healthcare system. Caregivers are often balancing work and family demands, along with emotional, physical, financial, and

spiritual distress as they help patients cope with a life-threatening illness.

### What is the impact of caregiving on the caregiver?

Caregivers have their own emotional responses to patients' diagnoses and prognoses, and they may require education and emotional support separate from that offered to patients.

Caregiver roles and caregiver burden are deeply affected by a patient's prognosis, stage of illness, and goals of care. Shorter

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## Caregiver Story

My husband, Sam, was officially diagnosed with stage IV non-Hodgkin lymphoma the day before the birth of our first child. It's funny how, in an instant, life can change so dramatically. We were catapulted into the new world of cancer, all the while trying to learn how to be new parents. I spent many sleepless nights during those first few months nursing our son while googling treatment options and survival rates.

It was a very isolating experience, and looking back I was clearly operating in survival mode. Friends and family would constantly tell me, "Make sure you take care of yourself," and though I would smile and respond appropriately I secretly wondered what on earth that would even look like. Back then, it was a successful day if I got to take a shower and eat a bite of a sandwich.

Thankfully, life settled down and we got our footing as parents. I finally learned



the importance of taking time for myself, and came to realize the complexities of caregiving, which extend far beyond cooking healthy meals and keeping track of medication and doctor's appointments. This was especially important when Sam was undergoing his allogeneic stem cell transplant at MSK.

The odds of survival were not in our favor, but we put our full trust in our expert

medical team. Sam didn't need me to be his "caregiver." He already had enough of those hovering about around the clock. He needed me to be his wife. He spent 28 days in the transplant unit, and I spent each of them by his side, keeping hope alive and his spirits high. We planned home improvement projects, family vacations, and even went ahead and named all of our future children.

Hope is a very powerful thing. Sam is now one and a half years post transplant and in full remission. He's had some complications, but for the most part, he's thriving. I continue to navigate my way through life as a wife, mother, and caregiver. Some days are triumphant and others a complete failure, but I thank God every day for being given the chance to live this life alongside the man I love. We're expecting our second child in February, and look forward to this new and exciting chapter. ■

### Upcoming Programs

#### Virtual Caregivers Support Group

This group creates a space for caregivers to discuss the unique challenges facing them. Caregivers encourage one another through their complex roles and emotionally support each other. The group meets every fourth Wednesday, 1:00–2:00 PM. E-mail [virtualgroups@mskcc.org](mailto:virtualgroups@mskcc.org) for more details

#### Psychosocial Support and Counseling

Ask your physician for your social worker's contact information or contact the Social Work Department at 212-639-7020.

#### Inpatient Bone Marrow Transplant Caregiver Support Group

Connect with other caregivers of patients currently hospitalized for a stem cell transplant. This group, led by a social worker, provides an opportunity to ask questions, share experiences, and gain

support around the unique role of being a transplant caregiver. The group meets every Thursday, 3:00–4:00 PM, Room M-8, at the main campus, 1275 York Avenue location. Call Natalie Ishak, LMSW, at 212-639-7150 or Chelsea Chin, LCSW, at 212-639-6096 for more details.

#### Online Writing Group for Caregivers

During this eight-session weekly workshop for caregivers, we will be reading and discussing short stories, excerpts from novels and memoirs, personal essays, and poems, as well as creating and sharing our own work. This workshop is a collaboration between the Department of Social Work and Memorial Sloan-Kettering's Visible Ink writing program. All writing abilities are welcome. Consultation is necessary for this program. E-mail [forcaregivers@mskcc.org](mailto:forcaregivers@mskcc.org) or call Annamma Abraham Kaba, LCSW, at 212-639-2460.

#### Caregivers Clinic

The clinic, which is part of Memorial Sloan-Kettering's Counseling Center, provides psychosocial support to family members and friends who are caring for MSK patients. Led by Dr. Allison Applebaum, the clinic offers group and individual therapy, as well as family and couples consultations. For more information, or to make an appointment with Dr. Applebaum or another counselor, please call the Counseling Center at 646-888-0200.

#### Caregiver-to-Caregiver Support Program

Consider volunteering your time to support another caregiver. To be considered for the Caregiver-to-Caregiver Support Program, you must no longer be caring for a patient in active treatment. For more information, contact Jennifer Wang at 212-639-5007 or [patient2patient@mskcc.org](mailto:patient2patient@mskcc.org).

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## Why REACH?

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***“This support allows me to plug in and plug out.”***

***“I like that this space is independent of my husband and my kids.”***

The Social Work Department’s R.E.A.C.H. for Caregivers Program aims to highlight and organize interdisciplinary services for caregivers both at MSK and within the community. R.E.A.C.H. for Caregivers stands for Resources, Education, Assistance, Counseling, Healing. This new initiative is geared toward bringing awareness and streamlining vital information and services to MSK caregivers. Our objective is that this newsletter will also help ease the feelings of isolation some caregivers may experience and help make support easier to find. ■

## Resources in the Community

### Next Step in Care

[www.NextStepinCare.org](http://www.NextStepinCare.org)

Provides practical information to help family caregivers before, during, and after care transitions.

### Caring Bridge

[www.caringbridge.org](http://www.caringbridge.org)

Online community where you can connect, share news, and receive support.

### American Cancer Society

<http://www.cancer.org/treatment/caregivers/index>

Comprehensive information on caring for a loved one with cancer.

### Cancer Care

[www.cancercares.org](http://www.cancercares.org)

Cancer Care offers a Caregiver and Loved one Support Group. This is a 12-week telephone group for people who have a loved one diagnosed with cancer. Information about in-person groups and educational podcasts is also available on their website.

**November is National Caregiver Month!**

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## Recognizing the Caregiver

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hospital stays and fewer community resources have increased the burden from previous generations. The physical and emotional demands of caregiving reach their peak as the disease progresses to the terminal phase. In the context of recurrent illness, terminal illness, or the dying process, the caregiver must meet a new set of challenges in dealing with increasing functional limitations, increasing dependence of the patient, and greater symptom burden. If treatment is prolonged, the ability of caregivers to meet the daily needs of patients is severely strained.

Here are a few other challenges common among caregivers, which we offer to help caregivers have a better understanding of their experiences:

**Physical Effects:** Cumulative sleep disruption and fatigue are common among caregivers who are on duty 24 hours a day or only during nighttime hours. Not getting enough rest or exercise and neglecting their own health can mimic depression in caregivers, but can also contribute to the impairment of their health and quality of life.

**Social Changes:** The nature and quality of the prior patient-caregiver relationship is an important consideration in the assessment of caregiver need. The social impact of cancer and pain can be ameliorated by social support, financial security, and stability at work. Given the increasingly chronic nature of cancer, caregivers may find that even strong social and practical support can erode over time.

**Financial Concerns:** Families can incur financial burden from insurance deductibles, copayments, uncovered services such as transportation and home

care, and lost salaries. Additional areas of concern are: medication expenses; missing work; preparing for surgery and medical procedures; and neglecting their usual activities and relationships.

**Spiritual Aspects:** Patients and caregivers have parallel spiritual tasks when dealing with cancer, such as finding meaning and hope in the disease process while also confronting existential questions about the meaning of life.

We would be remiss if we did not point out that there are many positive aspects to caregiving: discovery of personal strength through adversity; improved sense of self-worth; deepening of the relationship with the cancer patient; a sense of personal growth. The positive aspects of caregiving can be strengthened by healthcare professionals through group and individual support as well as practical assistance with problem solving. ■