

Cancer Caregiver Action Plan



Cancer caregivers are a vital part of the team who help and support their loved one diagnosed with cancer. Caregivers may be spouses, parents, extended family, friends, neighbors or co-workers. While helping someone during their time of need is a meaningful experience, in many instances, caregivers find themselves in the midst of the caregiving journey without any preparation or training, and often feel overwhelmed by the tasks required of them.

When caring for someone with cancer, it is important that the caregiver also takes care of their own emotional, mental and physical health. Despite the demands, many caregivers feel empowered by the support they are able to provide, and find that caring for their loved one is a humbling experience.

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The Cancer Caregiver Action Plan was developed based on conversations with fellow caregivers who asked for a way to 'pay it forward' — a way to help other caregivers by providing real world perspective and insight into the caregiver journey. Throughout the care plan you'll see their stories and words of encouragement illustrating practical advice to help make the caregiving experience a little easier.

The Cancer Caregiver Action Plan also serves as a workbook with numerous areas for personalized notes based on individual needs. The Action Plan is comprised of two separate chapters. The first chapter provides emotional support and information to help meet the needs of caregivers. The second chapter provides practical information regarding the patient experience, and ideas to help caregivers manage multiple tasks.

It is our hope that the information our Cancer Caregiver Action Plan provides will help make a meaningful difference and serve as a roadmap for cancer caregivers as they support their loved one throughout the cancer journey.







The Raymond Foundation's Cancer Caregiver Action Plan is made possible by the generous support of Taiho Oncology, Genentech and Bristol-Myers Squibb

Caring for the Caregiver

Depression

In order to provide the best care for someone with cancer, caregivers need to take care of their own emotional, mental and physical health.

Take a moment to evaluate your current feelings, understanding your feelings may change throughout the cancer caregiving journey.

Caregiver Emotional Concerns: Track symptoms by date and severity

Anxiety/Stress
Fear
Sadness
Family Concerns (Parenting, Relationships, etc.)
Withdrawn from People and Activities
Sleeping Concerns
Sexual Health Concerns
Fertility Preservation/Issues
Smoking Cessation
Substance Abuse
Additional side effects:

Caregiver Emotional Concerns continued

What type of support would help you manage these feelings?

Would speaking with a social worker or counselor help? If so, contact your oncology center or check for community resources in your area.

"Schedule your own 'alone time'. Find your joy – go for a walk, read or find a hobby that you enjoy. The main thing is to schedule time for yourself to relax, reflect and rejuvenate."

—Prostate cancer caregiver



Maintaining physical health and mental wellness: It may be helpful to track your exercise, personal alone time, nutritional supplements, medications, etc. so that you make a point to schedule time for self-care

Day/Time/Duration/Reflections

Notes:	
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"Walking my puppy and spending time at our local dog park brings me joy and a sense of calm. The pounding butterfly-feeling in the pit of my stomach goes away as soon as I hear the dogs' woof and greet each other with reckless abandon. It's the little things that can make a big difference."

—Skin cancer caregiver



Journaling is a popular hobby and a way to reflect on your feelings, creating an invaluable resource. Writing or drawing is also a known stress reliever, and provides an emotional outlet. Many caregivers find that a personal journal dedicated to their caregiving experience is a positive way to reflect and keep things in perspective.

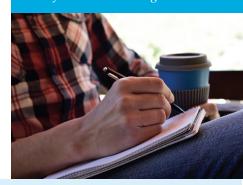
How would you begin today's journal?

I woke up today feeling	
I am grateful today because	
I am feeling stressed because	
I need	from my family
I need	from my friends
My goals for today include	
I will make time today for myself, and I will	
Personal reflections	

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"Spend time journaling - keep a diary, and be very honest with your current thoughts and emotions. I journal every day, and it is very powerful to go back and read through my thoughts. There were times I didn't think I could go on, but I did, and now I look back and feel strong and confident. I weathered bad times, but I got through it and I know you can too."

—Thyroid cancer caregiver



Build a support team and ask for help when needed. Accepting help is not always easy, but provides a way for friends and relatives to show their support.

Contact Information: Building Your Support Team

Family
Extended Family
Friends
Neighbors
Co-Workers
School Office
Teacher(s)
Guidance counselor
After school (coach, teacher, etc.)
Community Services
Faith-Based Services
Areas or tasks where you can use help (laundry, meal preparation, respite care, childcare, transportation to medical appointments or treatment, prescription pick-up, grocery shopping, etc.)

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"When someone asks 'what can I do?' - take a minute to really think about what you need, and then be specific. Ask them if they can mow the lawn on Saturday morning at 10:00 AM or pick up the kids from school on Friday afternoon at 2:00 PM. Friends and family want to help, but don't know what you may need. Accept help when offered, but be specific."

Breast cancer caregiver



You are not alone. Caregivers may feel isolated, but there are resources available to help.

Community resources:
Oncology center or hospital center support groups
Oncology center social worker or counselor
Local or regional community centers
Faith-based meetings or classes
Book clubs
Walking clubs (mall walkers, etc.)
Helplines or Call centers (advocacy groups offer free services)
Online support groups
Additional resources:

Notes:

"At first I was skeptical of attending a support group as I am a very private person. But, I realized after listening to others in the group, that I wasn't the only one experiencing sadness and anxiety. I don't speak up very much in the group, but it is helpful and I've met some good friends who understand."

Uterine cancer caregiver



Managing family life and daily responsibilities may become more difficult when caring for someone with cancer. Open communication, setting boundaries and expectations may help. Families often feel pulled in many different directions, leading to increased levels of stress. Families need to rely on each other more than ever during times of illness, so honest communication and understanding are vitally important.

Work with your family to create a 'to do' list that outlines everyone's responsibilities and care shifts. Working together will help ease the burden for everyone.

Weekly Planner: Who/What/When/Where MD appointments Prescription re-fills Grocery shopping Home cleaning Care shifts/hours including overnight Family pets/walking/feeding Additional tasks:

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"Our family was always a little dysfunctional even before our brother was diagnosed with cancer. On the surface we appeared pretty normal, but looking back we never discussed difficult topics or had honest conversations - everything was on *the surface – sports,* politics, and work. Now all of those things don't seem to matter very much. I think we all learned what is important and what isn't."

—Testicular cancer caregiver



Caregiving while also parenting children can be very stressful. It may be difficult to manage the demands on your time, and the need to provide a safe and secure atmosphere for your children. Ask your children how much they want to know, and let them ask you questions. It's positive for children to see their family member or family friend being loved and cared for, teaching them a positive lesson about compassion.

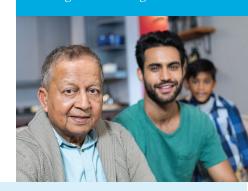
Weekly Planner: Who/What/When/Where

School bus drop-off/pick-up
After-school activities (pick-up)
Homework
Special school events (day)
Special school events (evening)
Doctor/Dentist appointments
Pet feeding/walking/exercise
Additional tasks:

N	otes:	

"While caring for my father I was away from our children for three months. It was very difficult for our family, and I felt very depressed that I wasn't with my husband and children. But, being with my father during his final days was so important to me. I will never regret spending this time with him, and I believe our family grew stronger knowing we were all supporting 'Papa' in our own way."

—Lung cancer caregiver



Caring for the Patient

Following are practical guidelines that may help to make the caregiver's work a little easier. Keeping all information organized in one place is extremely important, especially if other caregivers or respite helpers need to access important medical information.

Healthcare Providers (Name, Contact Information) Oncologist Surgeon Radiation Oncologist **Primary Care** Nurse/RN, NP Genetic Counselor Social Worker Nutritionist **Oncology Center** Hospital Network **Pharmacist** Palliative Care Team

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"Get organized. It's not necessarily fun, but will make you feel more in control. Keep all medical information together in a folder or a binder. Ask for copies of all scans (get the disk, too), ask for the doctor's notes, get copies of all biopsies and blood work. Keep everything together, have a list of questions ready, and take everything to each appointment."

—Brain cancer caregiver



Additional Contact Information

Co-Workers		
Human Resources		
Insurance Company		
Community Services		
Patient Physical Side Effects: Track symptoms by date and severity		
Weight loss		
Weight gain		
Bleeding		
Fatigue		
Infections/Fever		
Low White Blood Cell Count (Neutropenia)		
Low Red Blood Cell Count (Anemia)		
Allergic Reactions		
Diarrhea		
Constipation		
Mouth Sores		

Patient Physical Side Effects: Track symptoms by date and severity continued

Numbness/Tingling in Hands/Feet		
Skin Changes		
Trouble Thinking/Concentrating		
Urinary Symptoms		
Trouble Breathing		
Nausea/Vomiting		
Muscle/Bone Soreness		
Pain (Location, Degree)		
Hair Loss		
Heart Damage		
Ostomy Concerns		
Feeding Tube Concerns		
Sleep Disorders		
Sexual or Intimacy Concerns		
Lymphedema		
Early Menopause		
Additional side effects:		

Patient Emotional Side Effects or Concerns: Track symptoms by date and severity

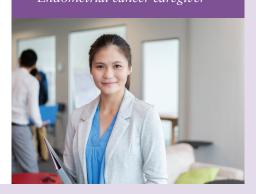
Depression
Anxiety
Fear
Sexual Health/Concerns
Fertility Preservation/Issues
Family Concerns (Parenting, Relationships, etc.)
Smoking Cessation
Substance Abuse
Guilt – Survivor's Guilt
Adjusting to a 'new normal'
Additional side effects:

Insurance/Work Place Concerns

Employment - Family and Medical Leave Act
Health Insurance
Life Insurance
Disability Insurance

"Call your insurance company and request a case manager. This will be very helpful when you need to speak with someone familiar with your case. Ask for a policy review to make sure you understand the policy benefits. Don't hesitate to ask questions – insurance is changing all the time and can be confusing."

—Endometrial cancer caregiver



Medications: For safety & maximum benefit, it is important that medication be taken exactly as instructed by prescriber.

Name of medication (brand name & generic)		
Dose		
When to take (time of day)		
Medication description		
Other information		

Schedule of Follow-Up MD Visits

Physician Name/Address	Frequency	Date			
Questions to ask Physician: (including new symptoms or concerns, persistent side effects, possible late or long-term side effects, etc.)					



Resources and Support Services

Please visit The Raymond Foundation website for updates to resources and support services.

TheRaymondFoundation.org

info@TheRaymondFoundation.org Twitter: @TheRaymondOrg

Notes:	

The Raymond Foundation was founded to honor the memory of Margaret and Patrick Raymond who both passed from colon cancer while in the prime of their lives. For over thirty years, the Raymond Foundation has worked in the cancer community developing resources, programs and initiatives for cancer caregivers, patients and survivors. We understand first-hand the challenges a cancer diagnosis brings. We are humbled and honored to be known as a leader in the cancer community, most importantly sharing the patient and caregiver voice and perspective.

Join us November 1

as we honor and celebrate cancer caregiversduring our

1st Annual Global Cancer Caregiver Day





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