

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.

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.

When caring for someone with cancer, it is important that the caregiver also takes care of their own emotional, mental and physical health.



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

Caring for the Caregiver

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

Depression

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

Nutritional supplements

Dietary needs

Exercise (walking, yoga, cycling, etc.)

Alone time

Meditation

Reiki

Hobbies

Medications

Additional wellness activities

Notes:

“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

Notes:

“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.)

Notes:

“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:

Notes:

“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:

Notes:

“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

Notes:

“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

Notes:

“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.)



*“We are in
this together.
Hold on, I’ve
got you.”*

—Cancer caregiver



Resources and Support Services

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

TheRaymondFoundation.org

info@TheRaymondFoundation.org

Twitter: [@TheRaymondOrg](https://twitter.com/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
caregivers during our

Annual Global Cancer
Caregiver Day



Copyright © 2018 by The Raymond Foundation

All rights reserved. No part of this publication may be reproduced, distributed, or transmitted in any form or by any means, including photocopying, recording, or other electronic or mechanical methods, without prior written permission.

RAYMOND
FOUNDATION

www.TheRaymondFoundation.org

info@TheRaymondFoundation.org

Twitter: @TheRaymondOrg