PUSH THE PAUSE BUTTON
Supports for Caregivers
We are a relentless ally for anyone who is striving to manage the realities of this disruptive disease. No one can, or should, face cancer alone. While we have witnessed many advances in treating cancer, nothing takes the place of the power, inspiration, companionship, and connection that comes from community because

**Community is Stronger than Cancer.**
Overview

1. Becoming a Caregiver
2. Common Worries and Concerns
3. Mental Health and Cancer
4. Role Changes
5. Benefits of Caregiving
6. Balancing Caregiving and Work
7. Emotional Well-Being
8. Push Pause
"There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."

Rosalynn Carter
How Do You Identify?

caregiver

caretaker

carer

co-survivor
“Cancer caregivers have diverse backgrounds and characteristics. Cancer caregivers tend to be women (58%), and most have less than a college degree (60%). They are 53 years old on average (4 years older than non-cancer caregivers). Most cancer caregivers provide care to a relative (88%); six out of ten cancer caregivers provide care to someone age 65 or older.”

Becoming a Caregiver

*Cancer Support Community’s Cancer Experience Registry®* found:

- **98%** provided emotional support
- **96%** went with their loved one to medical appointments
- **82%** helped with decision-making
- **79%** coordinated medical care
- **80%** provided transportation
- **74%** helped manage finances
## Common Worries

<table>
<thead>
<tr>
<th>Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thrust into this role unexpectedly with little preparation</td>
</tr>
<tr>
<td>Performing caregiver tasks alone</td>
</tr>
<tr>
<td>Fear of losing someone you love</td>
</tr>
<tr>
<td>Juggling caregiving duties with other daily activities</td>
</tr>
<tr>
<td>Feelings of inadequacy</td>
</tr>
</tbody>
</table>
Top Concerns

71% Their patient’s cancer progressing or coming back

67% Worrying about the future and what lies ahead
## Top Concerns

### CAREGIVER REGISTRY: 2020 KEY FINDINGS

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>89%</td>
<td>were quite a bit/very much involved in providing emotional support</td>
</tr>
<tr>
<td>80%</td>
<td>were quite a bit/very much involved in going to medical appointments with the patient</td>
</tr>
<tr>
<td>16%</td>
<td>reported having received formal caregiving training</td>
</tr>
<tr>
<td>20%</td>
<td>spent more than 100 hours per week caregiving</td>
</tr>
<tr>
<td>41%</td>
<td>of those trained wanted additional training</td>
</tr>
</tbody>
</table>
### Top Concerns

#### CAREGIVER REGISTRY: 2020 KEY FINDINGS

| 39% reported making decisions together with the patient | 2 out of 3 were quite a bit/very much involved in patients’ treatment decisions | 29% reported that patients make decisions after considering their opinion |
## Top Concerns

### CAREGIVER REGISTRY: 2020 KEY FINDINGS

<table>
<thead>
<tr>
<th></th>
<th>58% did not feel prepared to care for patient’s emotional needs</th>
<th>68% did not feel prepared to handle caregiving stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>PREPAREDNESS</td>
<td>&gt; 1 out of 2 fell at least pretty well prepared to respond to and handle patient emergencies (60%) and care for physical needs (58%)</td>
<td></td>
</tr>
</tbody>
</table>
### Top Concerns

**CAREGIVER REGISTRY: 2020 KEY FINDINGS**

<table>
<thead>
<tr>
<th>Concern</th>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>QUALITY OF LIFE AND DISTRESS</td>
<td>49%</td>
<td>reported substantially worse anxiety than the national average</td>
</tr>
<tr>
<td></td>
<td>34%</td>
<td>reported substantially worse fatigue than the national average</td>
</tr>
<tr>
<td></td>
<td>39%</td>
<td>said their health was somewhat or much worse than before they began their caregiver role</td>
</tr>
</tbody>
</table>
## Top Concerns

**CAREGIVER REGISTRY: 2020 KEY FINDINGS**

| CAREGIVER NEEDS                  | 3 out of 4 wanted help with understanding the patient’s medical condition and treatment | > 1 out of 2 wanted help managing health benefits and financial services | Nearly 1 out of 2 reported at least sometimes experiencing a sense of loss of control over their own life |
Role Changes
Role Changes

Caregiving Encompasses a Variety of Duties

- Multi-Dimensional Job
- Time Consuming
What Caregivers Do

Physical Caregiving

Practical Caregiving

Emotional Caregiving
What Caregivers Do

Physical  |  Practical  |  Emotional

- Patient-Health Care Team Liaison
- Coordinate Care
- Personal Shopper
- Give physical care
- Offer emotional support
- Provide Companionship
- Driver
- Housekeeper
- Order and pick up medications
- Handle practical and financial matters
- Insurance advocate
- Other duties as assigned
Caregiving Resistance

Understand and acknowledge:

- Loss of independence
- Loss of control
- Change and uncertainty
Caregiving Benefits

Sense of **Purpose and Pride**

Enjoyment of **Role**

Inspired **Advocate**
Caregiving Benefits

<table>
<thead>
<tr>
<th>Sentiments About Their Caregiving Duties</th>
<th>Volunteered</th>
<th>Didn’t Volunteer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s important for me to provide a good quality of life for the care recipient</td>
<td>95%</td>
<td>90%</td>
</tr>
<tr>
<td>I like helping the care recipient</td>
<td>93%</td>
<td>76%</td>
</tr>
<tr>
<td>I enjoy spending time with the care recipient</td>
<td>93%</td>
<td>75%</td>
</tr>
<tr>
<td>Being a caregiver gives me a strong sense of purpose</td>
<td>86%</td>
<td>63%</td>
</tr>
<tr>
<td>Being a caregiver has led me to take better care of my own health</td>
<td>73%</td>
<td>55%</td>
</tr>
<tr>
<td>Being a caregiver has inspired me to document my own health and legal wishes</td>
<td>68%</td>
<td>61%</td>
</tr>
<tr>
<td><strong>Negative</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My own health takes a backseat to the health of my care recipient</td>
<td>53%</td>
<td>66%</td>
</tr>
<tr>
<td>My caregiving duties leave me feeling physically exhausted</td>
<td>52%</td>
<td>72%</td>
</tr>
<tr>
<td>My caregiving duties leave me feeling emotionally exhausted</td>
<td>51%</td>
<td>70%</td>
</tr>
<tr>
<td>I need more help with my caregiving duties</td>
<td>46%</td>
<td>61%</td>
</tr>
<tr>
<td>With all of my caregiving duties, I barely have time for anything else</td>
<td>43%</td>
<td>64%</td>
</tr>
<tr>
<td>My caregiving duties leave me feeling completely overwhelmed</td>
<td>40%</td>
<td>64%</td>
</tr>
</tbody>
</table>
Balancing Caregiving and Work

• 52% of caregivers are employed
• Inform your employer
• Know your legal rights
• Get help and support
Who is a long-distance care partner?
Care-supporting from afar
Staying connected
A partner in hope
Long-Distance Caregiving: 5 Key Steps to Providing Care From Afar

Steady communication and building a trusted team are crucial.

AARP, Updated May 15, 2020

1. Establish Access
2. Build a Team
3. Find a Local Coordinator
4. Stay in the Loop
5. Make the Most of Visits

5 Key Steps: https://www.aarp.org/caregiving/basics/info-2019/long-distance-care.html
Uncertainty

WHAT

IF

?
Emotional Stress
Mental Health and Cancer
Mental Health

DISTRESS

ANXIETY

DEPRESSION
Mental Health

The 6th VITAL SIGN

“If a caregiver experiences high levels of psychological distress, then likely so will the patient (ONS VOICE, 2019)”
Mental Health

CONSEQUENCES OF STRESS FOR CAREGIVERS

- Quality of Life
- Sadness (depressive symptoms)
- Worry (anxiety symptoms)
- Acute illness
- Chronic Illness
- Social Issues
- Weight Gain
- Sleep Issues
ANXIETY

49% of caregivers reported anxiety levels substantially worse than the national average.

- Cancer Experience Registry Report
Mental Health

Cancer Experience Registry Report

34% of caregivers reported fatigue and depression levels that were substantially worse than national average.

- Cancer Experience Registry Report
Mental Health

DEPRESSION

SEVERE WORRY AND SADNESS

Contact your health care provider for a referral to a trained psychologist or licensed mental health counselor if you notice:

• Your worry/sadness is getting in the way of doing the things you need and want to do
• You are worrying or sad most of the day for most days of the week
Emotional First Aid

- Relaxation Training
- Active Coping
- Setting An Intention For Self-Care
- Acceptance & Mindfulness
- Reframing Thoughts
- Maximizing Social Support
Push The Pause Button

ASSESS NEEDS AND VALUES
CREATE SIMPLE GOALS
IDENTIFY ACTIVITIES
EVALUATE
Setting Intentions

<p>| | |</p>
<table>
<thead>
<tr>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong> What is something I used to like to do?</td>
<td></td>
</tr>
<tr>
<td><strong>2.</strong> Can I incorporate it back into my life?</td>
<td></td>
</tr>
<tr>
<td><strong>3.</strong> Do I need to do it differently? Be creative.</td>
<td></td>
</tr>
<tr>
<td><strong>4.</strong> What might get in the way?</td>
<td></td>
</tr>
<tr>
<td><strong>5.</strong> How will I overcome that obstacle?</td>
<td></td>
</tr>
<tr>
<td><strong>6.</strong> Make a plan.</td>
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</tbody>
</table>
The 2 D’s

deleaters
and DERAILERS
A Little R&R

REFUEL

REPLENISH
Summary

**Make plans** for the future

- Make changes that are important to you or your loved one
- Start a new hobby
- Keep moving ahead one step at a time

**Set new goals** and/or priorities

- Spend more time with family/friends
- Focus on what really matters
- Complete a project (i.e. house project, scrapbook)
Reach Out

- Trusted Friend/Family
- Clergy Person
- Mental Health Professional
- Doctor
- Nurse
- Oncology Social Worker
CONNECT TO THE LLS’ INFORMATION SPECIALISTS

Information specialists assist patients and their families with financial and social challenges, and give accurate, up-to-date disease, treatment and support information at every stage of the cancer trajectory.

- **Call:** (800) 955-4572
  Monday to Friday, 9 a.m. to 9 p.m. ET

- **Email:** infocenter@LLS.org

- **Leave a message 24/7 and we’ll call back.**
  Call (800) 955-4572 to use the automated response system 24 hours a day, seven days a week.
A step-by-step guide for adult CAR T cell therapy patients and their caregivers from referral through treatment and follow-up.

To best support yourself and your caregivers, contact the Cancer Support Community. We can help.
Caring for a Loved One

Family members, spouses, partners and friends who take on a caregiving role have a unique relationship to cancer. Caregivers are often asked to provide care and make critical decisions for patients. It is important to understand the impact of these decisions on your loved one and on your own mental and physical health.

Helping Your Loved One Make Treatment Decisions

Family members, spouses, partners, and friends who take on a caregiving role for a loved one with cancer will find this section helpful. It provides guidance on how to support your loved one through the treatment process, including information on symptom management, nutrition, and emotional support. It also offers tips on how to communicate with healthcare providers and other important stakeholders in the cancer care team.

Support from a Distance

People who care about someone with cancer can become active participants in enhancing the health and well-being of their loved ones and nurturing their own emotional and physical health. This section provides guidance on how to support your loved one remotely, including tips on communication, virtual visits, and ways to stay connected.

When a Woman You Care About has Breast Cancer

This section offers support and guidance for caregivers of women with breast cancer. It provides information on the diagnosis, treatment, and support options available to women with breast cancer. It also offers tips on how to communicate with healthcare providers and other important stakeholders in the cancer care team.
References


- CancerCare (n.d.). *What is a living will*. Retrieved September 14, 2021 from https://www.cancercare.org/publications/260-what_is_a_living_will


