



# Developing Caregiver Clinical Services: A Toolkit for Cancer Centers and Staff

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# Our Commitment to Caregivers

The Mission of the American Cancer Society (ACS) is to improve the lives of people with cancer and their families through advocacy, research, and patient support, to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer. Through the work of the ACS Patient Support pillar, we provide expert-level, patient-centric assistance to solve important problems across the cancer continuum for patients, families and caregivers, and health care professionals and communities.

ACS is uniquely positioned to develop and deliver resources for caregivers and the health care professionals who care for them. This Toolkit provides a comprehensive set of tools and resources that oncology leaders, clinicians, and staff members can use to implement a new or upgraded service line for psychosocial services for family caregivers. It's the first of its kind to manualize the documentation of caregivers within a cancer center so that they may receive the critical, mental health support they need.

ACS is committed to ending cancer as we know it, for everyone – including caregivers. Information about our caregiver resources can be found in the Appendix and they are also available at [cancer.org/caregiver](https://cancer.org/caregiver).



# Acknowledgments

We would like to acknowledge, with deep gratitude, the efforts of the primary authors of this Toolkit, **Allison J. Applebaum, PhD** and **J. Nicholas Odom, PhD, RN, ACHPN, FAAN**. As leading, international champions for caregivers, Drs. Applebaum and Odom contributed their subject-matter expertise, lived experience, and time to the development of this resource. Their invaluable role of clinician scientists has changed the way care is delivered to caregivers.

We want to thank the ACS Patient Support team, including **Rachel Cannady** and **Laura Makaroff, DO**, for providing vision, leadership, strategic guidance, and editorial review and direction. Additionally, we would like to acknowledge the ACS Medical and Health Content team, including **Christopher Peña, PhD** and **Brittany Lovely** for providing editorial support and staff expertise. Lastly, we want to thank **Ohlander Consulting Services** for the design and publication efforts.

## About the Authors

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# Background and Introduction

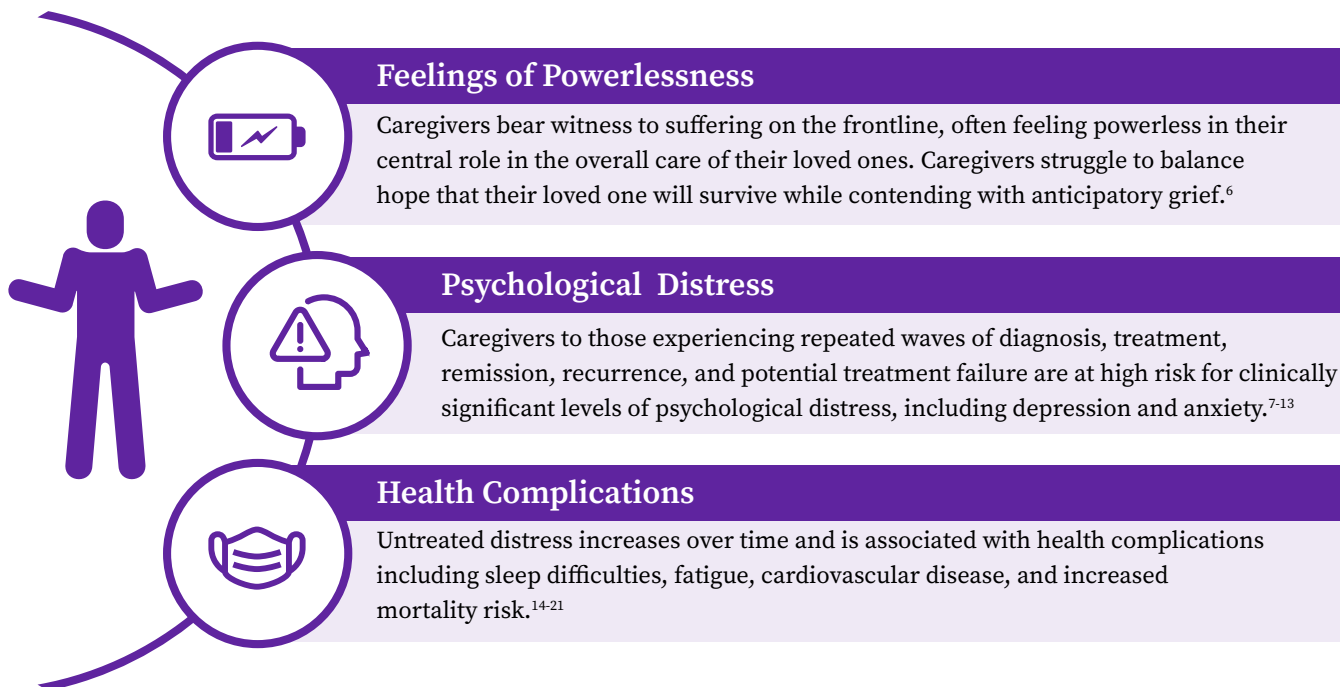
## The Population of Cancer Caregivers Is Growing



Caregivers are defined as family members and friends who provide unpaid care to patients with chronic or life-threatening, incurable illnesses.<sup>1</sup> In the United States, at least 5 million people are providing unpaid care to loved ones living with cancer.<sup>2</sup> These numbers will continue to grow due to rising health care costs, shorter hospital stays, preference for outpatient care models, and overall advances in oncologic care.<sup>3-5</sup>

## Caregivers Are Overwhelmed With Psychological and Physical Demands

In comparison to caregiving for other illnesses, the cancer caregiving trajectory is uniquely intense and episodic.<sup>2</sup> Whether their loved ones are undergoing cancer diagnosis, treatment, or remission, caregivers often experience protracted, multifaceted challenges, including:



Caregivers are also at risk for poor bereavement outcomes.<sup>22-25</sup> Subsets of bereaved caregivers can develop more severe and persistent bereavement-related mental health concerns, including prolonged grief disorder, major depressive disorder, post-traumatic stress disorder (PTSD), and substance abuse.<sup>26-29</sup>

## Caregiver Support Is Critical Now More Than Ever

Providing support to cancer caregivers that targets their emotional and mental health needs is necessary to help optimize outcomes for patients and assist caregivers in fulfilling their roles as critical members of the health care team.<sup>30</sup> Caregiver support can also impact health systems.<sup>31,32</sup>

### Impact of Effective Caregiver Support



#### On Patients

- ↑ Quality of Life<sup>33-41</sup>
- ↑ Health Care Savings<sup>42</sup>
- ↓ Potentially Inappropriate and Unnecessary Treatments<sup>33-41</sup>
- ↓ Social Isolation<sup>33-41</sup>



#### On Health Systems

- ↓ Hospital Readmission Rates<sup>32</sup>
- ↓ Medicare Expenditures<sup>31</sup>
- ↓ Emergency Department Use<sup>31</sup>
- ↓ ICU Use<sup>31</sup>

**The responsibilities taken on by cancer family caregivers is expected to increase, hence it is imperative to provide them support.<sup>44</sup>**

For more details on the state of caregivers in the U.S., please [see Appendix A](#).



## An Exemplar Caregiver Support Program

In response to a clear need for psychosocial support focused on addressing the profound and historically unmet psychosocial needs of cancer caregivers, Dr. Allison Applebaum founded the Caregivers Clinic at Memorial Sloan Kettering Cancer Center (MSK) in 2011. The Clinic was the first of its kind in any cancer center in the United States to provide targeted evidence-based, reimbursed psychosocial care to family and friend caregivers of patients with cancer across the illness and caregiving trajectory, from a patient's diagnosis through bereavement.



### 10-Year Operational Metrics of the MSK Caregivers Clinic (2011-2021)\*

**418**

caregivers received  
psychodiagnostic  
visits

**4,057**

total psychotherapy  
sessions for  
caregivers

**98**

psychotherapy  
sessions that included  
the patient and were  
conducted as either  
a couples or family  
therapy session

**244**

caregivers  
requested  
or required  
psychiatric  
medications

**~95%**

of caregivers had  
private insurance  
that covered the  
cost of care in part  
or in its entirety

\*Numbers are based on the effort of one part-time clinical psychologist, giving approximately 40% effort to the clinic over a decade.

In advance of the Clinic's launch, Dr. Applebaum canvassed the landscape of psychosocial support for caregivers in comprehensive cancer centers and found that support offered nationally mirrored practices at MSK: the primary source of support came from drop-in support groups that were often time limited and met monthly. Caregivers were also offered support individually with social workers when their care partners were in receipt of inpatient care. At MSK specifically, caregivers were also seen for ad hoc visits in the Counseling Center in the context of episodes of psychiatric care provided to patients with cancer. There was no formalized mechanism for family caregivers to receive ongoing support that focused exclusively on addressing their unique psychosocial needs, separate from support aimed at helping them to provide care to their care recipients.

**In 2011, Dr. Applebaum began seeing caregivers in her clinical practice. This started with four hours a week in the Counseling Center and advertisement limited to the Department of Psychiatry and Behavioral Sciences. That four-hour block quickly became booked for several months. The need for targeted care for caregivers was clear and the Caregivers Clinic was officially recognized.<sup>45</sup>**

From 2011 to 2021, Dr. Applebaum was the primary clinical psychologist in the service, complemented by several additional MD and PhD attendings who contributed a range of effort over the decade. During this time, **418** caregivers received psychodiagnostic visits in the Caregivers Clinic with Dr. Applebaum, or, a postdoctoral fellow or clinical psychology intern supervised by Dr. Applebaum. These caregivers went on to collectively receive **4,057** psychotherapy sessions, **98** of which included the patient with cancer and were conducted as either a couples or family therapy session.

Of the **418** caregivers who enrolled in the Clinic, **244** requested or required psychiatric medications and were subsequently referred to a psychiatrist or psychiatric nurse practitioner. At all times, at least one prescriber was available to see caregivers from the Clinic. At most times, one psychiatrist and one psychiatric nurse practitioner were available to provide support as needed. Approximately **95%** of caregivers had private insurance that covered the cost of care in the Clinic in part or in its entirety.



# How to Use This Toolkit

The Caregivers Clinic Toolkit is a comprehensive set of tools and resources that oncology leaders, clinicians, and staff members can use to implement a new or upgraded service line for psychosocial services for family caregivers. The Toolkit addresses key areas of Clinic development, including referral sources and triage processes, billing codes, and staffing. It also provides a road map based upon the history, experiences, and design of the MSK Caregivers Clinic and other services that have been developed to support cancer caregivers nationally.

The Toolkit is organized into the following sections:

1 Identifying Caregiver Champions and Gaining Leadership Support

2 Foundational Step: Medical Records for Caregivers

3 Staffing

4 Referral Sources

5 Scope of Practice

6 Screening and Triage Processes

7 Services Offered and Correlate Billing Codes

8 Diagnoses and Billing Considerations

9 Opportunities for Training

10 Approaches to Care and Pacing of Sessions

11 Marketing

12 Evaluation

13 Common Pitfalls and Resolution Strategies

14 Appendix A: The State of Caregivers in the U.S.

15 Appendix B: Caregiver Support Resources

# Identifying Caregiver Champions and Gaining Leadership Support

Gaining leadership buy-in and support is crucial for the successful implementation of psychosocial services for family caregivers. Engaging administrative, clinical, and staff leaders provides a strong foundation and necessary resources, and also sets a tone of importance and accountability for the initiative. The following graphic shows 10 key strategies and steps for effectively gaining leadership buy-in and support.

## Key Ways to Gain Leadership Support



## 1 Understand the Leadership Landscape

It is essential to have a clear understanding of your cancer center's formal (and informal) leadership structure, how decisions are made about clinical processes, and who the key constituents are. Be sure to identify individuals and groups responsible for approving and allocating resources for new programs and services.

## 2 Identify Champions

Champions are individuals who commit themselves to supporting, marketing, and overseeing implementation efforts. Champions should strongly believe in caregiver services. You may want to recruit an interdisciplinary group of champions to help with different tasks. Effective champions tend to be passionate, persistent, politically savvy, and able to solve problems using managerial and interpersonal skills.

## 3 Build a Compelling Case

Highlighting the potential benefits and impact on patients, caregivers, and the overall cancer center helps demonstrate the need for a family caregiver support service. Be resourceful in thinking about what motivates leaders in your cancer center. Use evidence-based research and real-life stories to illustrate the significance of supporting caregivers in improving patient outcomes and satisfaction.

## 4 Tailor the Message

Craft your message to resonate with the specific interests and priorities of different leaders. Emphasize how the family caregiver support service aligns with the cancer center's mission, strategic goals, and values. Frame the initiative in a way that showcases how it addresses key challenges, such as improving patient experience and reducing health care costs.

## 5 Engage Early and Communicate Effectively

Initiate early communication with leaders, providing regular updates and progress reports to maintain their interest and involvement. Articulate the purpose, goals, and expected outcomes of new psychosocial services for family caregivers. Use a combination of written materials and presentations to convey the importance and potential impact of the initiative.

## 6 Collaborate and Involve Leaders

Involve leaders in the planning and decision-making processes. Seek their input and incorporate their suggestions to foster a sense of ownership and shared responsibility. Demonstrate that their involvement is essential for the successful implementation and sustainability of the family caregiver support service.

## 7 Address Concerns and Mitigate Risks

Generate strategies to mitigate risks, such as developing a comprehensive implementation plan, addressing budgetary implications, and providing evidence of feasibility and potential return on investment.

## 8 Showcase Success Stories

Highlight success stories and examples from other cancer centers or similar initiatives. Present evidence of positive outcomes and demonstrate how these services have made a difference for patients, caregivers, and the overall health care system.

## 9 Establish Accountability and Evaluation Measures

Clearly define the roles and responsibilities of leaders in supporting and promoting the family caregiver support service. Develop mechanisms to monitor and evaluate the effectiveness of services, including regular reporting on key metrics, feedback from caregivers and staff, and continuous quality improvement initiatives. This helps leaders see the tangible impact of their support and encourages ongoing commitment.

## 10 Highlight Palliative Care Services to Fulfill Commission on Cancer Standards

The Commission on Cancer Standard 4.5 (Palliative Care Services)<sup>46</sup> states, “Palliative care refers to patient- and family-centered care that optimizes quality of life” and “[is] available to cancer patients and their families or caregivers.” It can be beneficial to highlight that Palliative Care Services in the Caregivers Clinic are “an essential component of cancer care and should be offered throughout treatment and surveillance and, when applicable, during bereavement.”

**Leadership buy-in and support is essential and helps facilitate acceptance, adoption, and engagement by others. By following the steps outlined, cancer centers can effectively secure leadership support for the implementation and sustainability of the family caregiver support service.**



# Foundational Step: Medical Records for Caregivers

In order to establish a Caregivers Clinic that can generate revenue and engage in ethical and legal billing practices, it is necessary that family caregivers become registered patients of your cancer center. The benefits of such documentation practices have been previously discussed.<sup>47</sup> A summary of several key points regarding the risks of including caregiver data in the records of patients and the benefits of creating separate records for caregivers is included here. These can be used to advocate for the creation of such records with your hospital administrators.

## Benefits of Creating Separate Medical Records for Family Caregivers<sup>47</sup>

Benefit	Rationale
Allows for protection of caregiver privacy and confidentiality	Privacy and confidentiality of caregivers are potentially compromised if their data are included in the medical record of patients
Promotes ethical billing practices	Instances when the patient, and not the caregiver, is billed for the services of the provider (e.g., clinical psychologists) can be avoided
Facilitates the identification and documentation of caregiver data	Locating caregiver-specific data within a large medical record is challenging, as patient records do not routinely have a specific section or tab devoted to caregivers
Facilitates ongoing care throughout bereavement	Caregiver records can assist with outreach, screening, and support during bereavement. Additionally, emotional distress during bereavement (i.e., suicidal ideation) can be documented

## Caregiver Advise, Record, Enable (CARE) Act

### Separate medical records for family caregivers also demonstrates compliance with the CARE Act

The CARE Act has passed in most states and has the following provisions:

1. Hospitals must document the name and contact information of caregivers in the record of the patient at the time of hospital admission.
2. Caregivers must be notified when the patient is to be transferred or discharged.
3. Hospitals must provide education and training to caregivers in the medical and nursing tasks they need to complete at home once the patient is discharged.

It is encouraged that you meet with a representative from your institution's informatics department to determine whether there are any unique steps that need to be taken to create caregiver records and a representative from your institution's legal department to ensure all legal and compliance standards are being met.

The medical record created for caregivers will be identical to those created for patients receiving care. To distinguish these records, you might consider opening your description of the patient in the History of Present Illness (HPI) section using a version of the following statement:

*[insert name of caregiver] is the [insert role, such as wife or father or child or sibling or friend] and primary caregiver of patient [insert patient's name and MRN (medical records number)], being treated for [insert primary diagnosis].*

**You might consider also including the patient's MRN, though it will be important to meet with members of your institution's legal and compliance departments.**










In the HPI section, consider the following domains for documentation:

- Context (e.g., caregiver/patient relationship, duration of caregiving, prior caregiving experiences)
- Caregiver's perception of recipient's health and functional status
- Caregiver's values and preferences
- Caregiver well-being
- Perceived challenges and benefits
- Needed skills, abilities, and knowledge to provide care

# Staffing

Before beginning to offer services, it is important to establish a staffing model. Staffing opportunities will vary across sites, and not all cancer centers will have the capacity to hire the same type and number of clinicians (e.g., licensed clinical psychologists, psychiatrists, psychiatric nurse practitioners, social workers).

Therefore, it is encouraged to consider a staffing model for starting your Caregivers Clinic and an ideal model to work toward.

Who	Start-Up Staffing Model	Ideal Staffing Model
 <p>Clinical psychologist or other mental health professional who can bill for services</p>	 <p>Conduct psychodiagnostic interviews and follow-up psychotherapy sessions to referred caregivers</p>	 <p>80% clinical care 10% training &amp; clinical supervision 10% administration</p>
 <p>Prescribing professional (psychiatrist or psychiatric nurse practitioner)</p>	 <p>Provide medication management to caregivers</p>	 <p>Conduct psychodiagnostic and follow-up medication management sessions at a higher frequency</p>
 <p>Clinic administrator</p>	 <p>Perform screening, scheduling, referral coordination, and other administrative tasks</p>	 <p>Perform screening, scheduling, referral coordination, and other administrative tasks</p>

FTE = full-time employee.

## Start-Up Phase

- One clinical psychologist or correlate mental health professional who has the capacity to make psychiatric diagnoses and bill for services. To start, this individual should be able to provide at the least 0.5 FTE to conduct psychodiagnostic interviews and follow-up psychotherapy sessions with caregivers referred to your Clinic. For example, at 0.5 FTE, this Clinic staff member should be able to accommodate up to 4 psychodiagnostic sessions and 15 follow-up psychotherapy sessions weekly.
- One prescribing professional, such as a psychiatrist or psychiatric nurse practitioner (dependent on state rules), who provides medication management to caregivers who need medications. To start, this individual should be able to provide at least 0.25 FTE to conduct initial and follow-up medication management sessions with caregivers. For example, at 0.25 FTE, this Clinic staff member should be able to accommodate up to 3 psychodiagnostic sessions and 9 follow-up medication management sessions weekly.

- One Clinic administrator, providing at least 0.25 FTE. This individual is tasked with screening caregivers referred to your Caregivers Clinic (see [Screening and Triage Processes](#)), scheduling them for initial and follow-up sessions, and assisting with referral to the community in the case that caregivers will not be seen in your Clinic. While it may be beneficial for this individual to hold a Master's Degree or equivalent in psychology or mental health counseling so that they are able to knowledgeably handle the screening and triage process, as well as facilitate targeted community referrals based on caregivers' needs, such prior training is not a requirement and could be provided on the job if necessary.

## Ideal Staffing Model

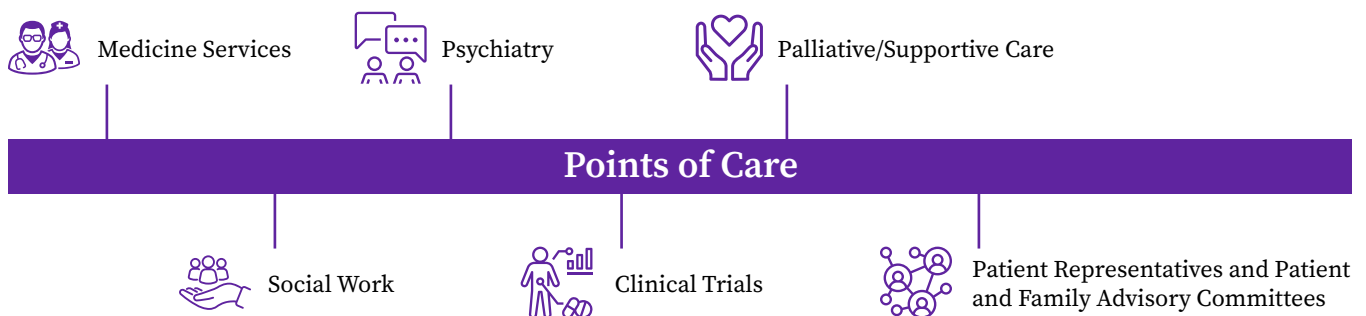
Once this initial infrastructure has been established and once you have demonstrated initial success in billing for services to generate revenue for your institution, your team might consider advocating for the following – or equivalent – staffing structure. This will help to ensure your capacity to accommodate a steady volume of caregivers referred to your Clinic. This structure does not include the effort of trainees and students who may also contribute to care in your Clinic (see [Opportunities for Training](#)).

- One full-time (1.0 FTE) clinical psychologist or correlate mental health professional, who is able to devote approximately 80% effort to clinical care, 10% to training and clinical supervision, and 10% to administrative tasks (e.g., documentation, billing). At 1.0 FTE, for example, this Clinic staff member should be able to accommodate up to 8 psychodiagnostic sessions and 30 follow-up psychotherapy sessions weekly. **Diagnostic visits are typically one hour, and follow-up psychotherapy sessions are typically 45 minutes.**
- One half-time (0.5 FTE) prescribing professional, such as a psychiatrist or psychiatric nurse practitioner, who can provide medication management to caregivers as appropriate. At 0.5 FTE, for example, this Clinic staff member should be able to accommodate up to 6 psychodiagnostic sessions and 18 follow-up medication management sessions weekly.
- One full-time (1.0 FTE) social worker, who can provide individual, group, family, and couple therapy sessions to caregivers in the Clinic. In some settings, social workers are unable to bill for services, and if this is the case in your institution, you can refer caregivers whose insurance does not cover mental health care to social work staff for follow-up care (i.e., sessions following the psychodiagnostics interview).
- One half-time (0.5 FTE) Clinic administrator who oversees screening and scheduling of caregivers in your Clinic and referral to the community.



# Referral Sources

Referral of caregivers to the Caregivers Clinic may occur through several mechanisms. Important referral sources include those who interact with caregivers across points of care for patients with cancer (see below). Staff in these areas may recognize those in distress and should be made aware of the Caregivers Clinic.



## Medicine Services

Distressed caregivers can present across lines of care. Keep leadership across medicine services informed of the Caregivers Clinic.

## Social Work

Social work staff can be advocates for the Caregivers Clinic following group support sessions or first encounters in inpatient settings.

## Psychiatry

Psychiatry care teams may have exposure to caregivers in need of support through psychosocial care sessions for patients with cancer.

## Clinical Trials

Clinical trials are increasingly being offered to caregivers. Inform research staff support offered through the Caregivers Clinic for those who need resources before, during, or after enrollment.

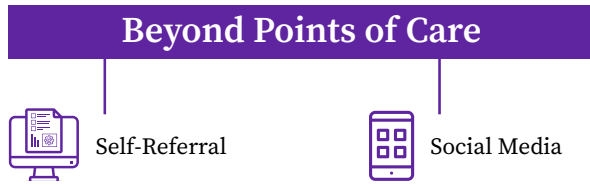
## Palliative/Supportive Care

In light of the integral role of caregiver support to the provision of high-quality palliative care and the Commission on Cancer Standard 4.5 regarding the provision of palliative care services that include caregiver support, the Palliative Care/Supportive Care services and teams at your cancer center will be an important referral source for caregivers to your Clinic.

## Patient Representatives and Patient and Family Advisory Committees

Outreach to Patient Representatives may be made by distressed caregivers. Staff should be aware of services and suggest support there when appropriate. Members of a Patient and Family Advisory Committee can also serve as advocates for caregivers.

Referral can also happen outside the patient and clinician setting, including:



## Self-Referral

Facilitated by advertisement on your cancer center's website and signage.

## Social Media

Advertisements of the Caregivers Clinic through your cancer center's social media platforms can raise awareness of the services you will be offering.



# Scope of Practice

Before opening and advertising your Caregivers Clinic, it will be important to specify who will be eligible to receive services. To begin, your Clinic Administrator can screen potential caregivers using the following initial question to determine appropriateness:

**Are you a family member or close friend who provides support and care for a patient receiving cancer care at *[insert name of your institution here]*?**

Individuals who identify as the primary caregiver – that is, the person most involved in patient care – need support. However, **all** caregivers can benefit and should be eligible to receive care in your Caregivers Clinic.

**Caregivers are individuals involved in providing care to a patient with cancer, no matter the stage of illness.**

## Who Qualifies as a Caregiver?



Family member (biologic or chosen)



Friend



Does not need to live with the patient



Financially uncompensated for caregiving

## What Type of Care Do They Provide?



Physical



Emotional



Financial



Logistical

The patient need not be receiving active treatment for their caregiver to receive services, though they should be registered as a patient at your cancer center and have received some type of care in the past (i.e., not just a second opinion).

***What do we do for caregivers interested in services whose patients do not have cancer?*** It is important to have defined processes and referral pathways for caregivers of patients with other serious illnesses to receive support. These parameters are necessary to address the inevitable capacity challenges that are experienced once the Clinic is up and running. It is also helpful to have a list of community referrals to give to caregivers who are not eligible for care in your Clinic.

# Screening and Triage Processes

To maximize resources available for caregivers in need, it will be necessary to implement a screening and triage process to ensure that only those caregivers who require your level of care are enrolled. The following suggestions can assist in implementing a screening and triage process tailored to your cancer center.

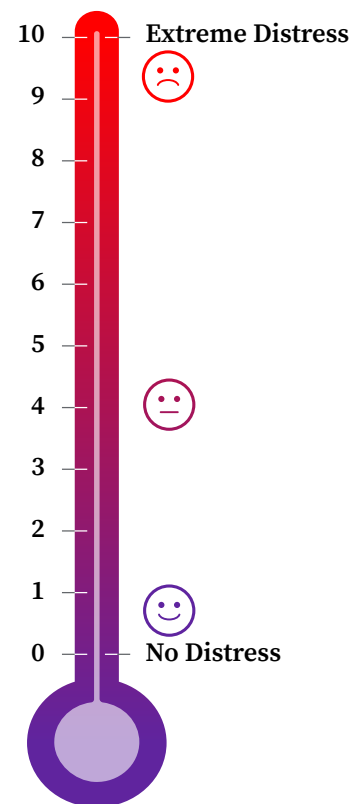
## Distress Thermometer

One way to quickly screen caregivers and triage them for services is by using a distress thermometer (DT) and problem list. Based on work by Dr. Odom and colleagues,<sup>48-50</sup> you can use a caregiver-specific DT based on NCCN\* Distress Management,<sup>51-53</sup> with 0 indicating no distress and 10 indicating extreme distress. If caregivers endorse  $\geq 4$ , it is encouraged that you ask them to identify what problems from a caregiver-specific problem list...

- 1) ...have been bothering them the most and
- 2) ...what problems they would like assistance with

\*National Comprehensive Cancer Network

For further reading on the results of using a Distress Thermometer in the clinical setting, please refer to [Dionne-Odom JN, et al](#); and [Hendricks BA, et al](#).



## High Distress

If a distress score is  $\geq 4$  and a problem is identified that the caregiver wants assistance with, a clear description and *brief* summary of the problem can be elicited by asking:

- |  |  |
|--|--|
| <input type="checkbox"/> What happens that makes this a problem? | <input type="checkbox"/> How does the problem happen?                      |
| <input type="checkbox"/> When does the problem happen?           | <input type="checkbox"/> Who does the problem involve?                     |
| <input type="checkbox"/> Where does it happen?                   | <input type="checkbox"/> What have you already tried to solve the problem? |

## Domains of Caregiver Support

In general and after considering the caregiver's brief description of the problem, caregivers who endorse wanting assistance with practical, social/family, spiritual, information and skills, and emotional problems may benefit from the targeted support available in your Caregivers Clinic. Consider offering the following types of caregiver support in your Clinic. Caregivers who endorse the items below in bold may particularly benefit from support in your Caregivers Clinic.



### Practical

- Housing
- Living arrangements
- Home maintenance
- Finances/insurance
- Work
- Effort/time assisting with care partner's activities of daily living
- Coordinating care/services



### Social/Family

- **Engaging in social activities**
- **Interacting with the person I care for**
- **Interacting with other family members, children, and/or friends**
- **Intimacy/sexuality**



### Spiritual

- **Facing mortality**
- **Loss or crisis of faith, purpose, and/or meaning in life**
- **Relating to God or a higher power (e.g., feeling abandoned)**
- **Spiritual shame or guilt**
- **Feeling isolated from faith community**
- **Lessened participation in spiritual practices (e.g., prayer)**

Importantly, while spiritual concerns have historically been addressed by chaplaincy, many caregivers find it beneficial to discuss spiritual and religious concerns with mental health professionals.



### Information and Skills

(Lack of information and/or skills concerning \_\_\_\_\_)

- My care partner's health condition and symptoms
- Medical procedures, tests, and/or treatment
- Medications
- Nutrition
- **Communicating with health care professionals**
- **Planning for the future and/or advance care planning**
- **Helping my care partner make health care or other life decisions**
- **Knowing when to seek help**



### Emotional

(I have been bothered by feelings of \_\_\_\_\_)

- **Isolation/loneliness**
- **Fear/worry**
- **Incompetence**
- **Anger/frustration**
- **Sadness**
- **Anxiousness**
- **Apathy/loss of interest in usual activities**
- **Distress over making tough decisions**
- **Feeling overwhelmed/exhausted due to my role in supporting my care partner**



### Physical

Believe my ability to take care of my own health has worsened due to my role in taking care of my care partner.

## Additional Tools

In addition to the DT, there are other screening tools, such as the CancerSupportSource-Caregiver™ (CSS-CG),<sup>54</sup> that can quickly evaluate caregivers' unmet needs and assist with identifying targeted referrals.

## Diagnostic Visit

At entry to the Caregivers Clinic, all caregivers should receive a diagnostic visit (see next two sections). During this visit, the caregiver's need for psychiatric medications should be evaluated and, if necessary, they should be referred for evaluation by a psychiatrist or psychiatric nurse practitioner.

## Maximize Resources

To facilitate triage and maximize resource use, create a comprehensive list of all resources available to caregivers in your cancer center outside of the Caregivers Clinic, such as integrative medicine services. Consider using the Distress Thermometer's Domains of Caregiver Support to help map on existing services. This will assist with the referral of caregivers to services other than support through the Clinic, like Pastoral Care.



# Services Offered and Correlate Billing Codes

## Without Medication Management

The following are common services, rendered by licensed clinical psychologists and other mental health professionals who bill for services\*, **for caregivers who do not require medication management:**

### Service Offered: Psychiatric diagnostic evaluation (often 60 minutes)

**Correlate CPT® Billing Code: 90791**

Must include an assessment of history, mental status, and treatment recommendations. The history taken should include both mental health history, including past psychiatric diagnoses, engagement in psychiatric care, and psychotropic medication use, as well as a caregiving-specific history, including an overview of caregiving responsibilities and milestones, and specific ways the caregiving role is impacting the caregiver's mental health. In this visit a diagnosis needs to be given (see discussion in next section on diagnoses). Consider mirroring the procedures used for psychodiagnostics visits conducted with patients with cancer in your cancer center for caregivers. For example, if certain diagnostic (e.g., Structured Clinical Interview for DSM-5 Disorders [SCID]<sup>55</sup>) or symptom (e.g., Hospital Anxiety and Depression Scale [HADS]<sup>56</sup>) assessments are used in the evaluation of patients, these too can be extended to the evaluations of caregivers in your Clinic.

### Service Offered: Psychotherapy, 45 minutes with \*\*patient and/or family

**Correlate CPT® Billing Code: 90834**

This is the most common billing code for individual psychotherapy provided to a caregiver who has already completed a psychiatric diagnostic visit. Sessions last for approximately 45 minutes.

### Service Offered: Psychotherapy, 30 minutes with \*\*patient and/or family

**Correlate CPT® Billing Code: 90832**

This billing code is most frequently used when caregivers have a specific concern that needs to be addressed but does not require a full 45-minute psychotherapy session.

\*Provider billing privileges vary by state and setting.

\*\*The patient here refers to the caregiver who has registered to become a patient of your health system and has been assigned their own medical record number.



### Service Offered: Family psychotherapy, with patient present

**Correlate CPT® Billing Code: 90847**

This billing code should be used when you conduct a psychotherapy session that includes the caregiver (your primary patient) and one or more members of their family/caregiving network. Most frequently, these sessions are conducted with the caregiver and the patient for whom they are providing care.

### Service Offered: Group psychotherapy

**Correlate CPT® Billing Code: 90853**

This billing code should be used when conducting group psychotherapy for caregivers. Often, groups are co-led by a clinical psychologist and a psychology doctoral student or social worker, but one leader must be able to bill in order to use this code.

## With Medication Management

The following are common services provided by prescribing clinicians rendered **for caregivers who require medication management**:

### Service Offered: Psychiatric diagnostic evaluation with medical services (often 60 minutes)

**Correlate CPT® Billing Code: 90792**

Must include an assessment of history, mental status, and treatment recommendations, as well as one or more medical services, such as writing a prescription or modifying a psychiatric treatment. Even though a caregiver referred for medication management will have previously undergone a psychiatric diagnostic evaluation with a licensed clinical psychologist upon entrance to the Clinic, the prescriber will need to conduct a complete psychiatric diagnostic evaluation in advance of prescribing psychotropic medications, when warranted.\*

\*In some cases, insurance carriers will not reimburse for two diagnostic visits (i.e., 90791 and 90792), one with a psychologist and one with a prescribing professional, within a short period of time. If a caregiver is referred immediately for medication management after meeting with a clinical psychologist, it's important for your Clinic Coordinator to check the caregiver's insurance to insure that the second evaluation will be reimbursed, or if a certain period of time is needed before billing code 90792 can be reimbursed.

**Service Offered: Established patient outpatient visit, 20-29 minutes****Correlate CPT® Billing Code: 99213**

This visit is for the evaluation and management (E/M) of an established patient and requires a medically appropriate history and/or examination and low level of medical decision making. This is most commonly used for periodic medication management sessions, where medications are being renewed or only slight changes are being made.

**Service Offered: Established patient outpatient visit, 30-39 minutes****Correlate CPT® Billing Code: 99214**

This visit is for the evaluation and management of an established patient, and requires a medically appropriate history and/or examination and moderate level of medical decision making. This is most commonly used for medication management sessions where there is a need for adjustment to the treatment plan and medications prescribed.

**Service Offered: E/M with psychotherapy, 17-37 minutes****Correlate CPT® Billing Code: 90833**

This visit combines medication management with the provision of psychotherapy, up to 37 minutes with the patient.

**Service Offered: E/M with psychotherapy, 38-53 minutes****Correlate CPT® Billing Code: 90836**

This visit combines medication management with the provision of psychotherapy, up to 53 minutes with the patient.

As a complement to these billing codes, providers in your Caregivers Clinic should be familiar with additional CPT codes that can be used for additional types of visits involving family caregivers. A list of these codes is found in Appendix A of the following report from the National Alliance for Caregiving: <https://bit.ly/3sZ3Sca>.

In 2024, the Centers for Medicare and Medicaid will begin paying practitioners to train caregivers to support patients with certain diseases or illnesses. Medicare will pay for these services when furnished by a physician, non-physician practitioner, or therapist as part of the patient's individualized treatment plan or therapy plan of care. For more information, visit: <https://bit.ly/3T2cgll>.

# Diagnoses and Billing Considerations

The psychiatric diagnoses used for documentation in the Caregivers Clinic are the same as those Although a diagnosis will be given for billing purposes, it is important to emphasize from the first Psychiatric Diagnostic Evaluation that the Caregivers Clinic does not exist because all caregivers experience mental health challenges. Instead, the Clinic exists because being a caregiver is a profound responsibility and can deeply impact caregivers' psychosocial well-being. Moreover, there is currently no ICD code/diagnosis for caregiver burden. In the absence of more pronounced and defined symptoms and syndromes, caregivers frequently receive an initial diagnosis of an adjustment disorder, such as one of the following:

## Diagnosis: Adjustment Disorder

**Correlate ICD-10-CM Code<sup>57</sup>: F43.20**

A category of psychiatric disorder characterized by emotional or behavioral symptoms that develop within 3 months of a stressor (i.e., beginning of caregiving) and do not persist for more than an additional 6 months after the stressor is no longer present. This diagnosis is given when social, psychological, or emotional difficulties in adapting to the life changes/stressors brought on by caregiving occur, but do not meet criteria for a major mood or anxiety disorder.

## Diagnosis: Adjustment Disorder With Depressed Mood

**Correlate ICD-10-CM Code<sup>57</sup>: F43.21**

Same description as Adjustment Disorder, but symptoms are marked by low mood, tearfulness, or feelings of hopelessness.

## Diagnosis: Adjustment Disorder With Anxiety

**Correlate ICD-10-CM Code<sup>57</sup>: F43.22**

Same description as Adjustment Disorder, but symptoms are marked by nervousness, worry, jitteriness, or separation anxiety.

## Diagnosis: Adjustment Disorder With Mixed Anxiety and Depressed Mood

**Correlate ICD-10-CM Code<sup>57</sup>: F43.23**

Same description as Adjustment Disorder, but symptoms are marked by a combination of anxious and depressive symptomatology.

**In addition to the Adjustment Disorders, common diagnoses used when working with caregivers include the following (though this list is not exhaustive):**

## Diagnosis: Generalized Anxiety Disorder (GAD)

**Correlate ICD-10-CM Code: F41.1**

Excessive anxiety and worry occurring more days than not for at least 6 months, about a number of events or activities (e.g., caregiving). The person finds it difficult to control the worry. Caregivers with GAD may be restless or feel keyed up or on edge; be easily fatigued (not better explained by an insomnia diagnosis); have difficulty concentrating; be more irritable than usual; experience muscle tension; and experience a sleep disturbance (e.g., difficulty falling or staying asleep, or restless unsatisfying sleep). Caregivers who have no histories of anxiety disorders may present with GAD as a result of the multidimensional worries that arise in the setting of caregiving.

## Diagnosis: Major Depressive Disorder (MDD), single episode/recurrent episode

**Correlate ICD-10-CM Code: F32.0/F33.0** (mild), **F32.1/F33.1** (moderate), **F32.3/F33.2** (severe without psychotic features)

Five or more of the symptoms listed below must be present during the same 2-week period and represent changes in functioning. At least one symptom is either a depressed mood or loss of interest.

- Depressed mood most of the day, nearly every day, as indicated in the subjective report or in observation made by others
- Markedly diminished interest or pleasure in all, or almost all, activities most of the day and nearly every day
- Significant weight loss when not dieting or weight gain, for example, more than 5 percent of body weight in a month or changes in appetite nearly every day
- Insomnia or hypersomnia nearly every day
- Psychomotor agitation or retardation nearly every day
- Fatigue or loss of energy nearly every day
- Feelings of worthlessness or excessive or inappropriate guilt
- Diminished ability to think or concentrate, or indecisiveness nearly every day
- Recurrent thoughts of death

For **mild depressive episodes** two or three symptoms from the following are usually present:

- The general criteria for depressive episode are met.
- At least two of the following:
  - Depressed mood to a degree that is abnormal to the individual, present for most of the day and almost every day, largely uninfluenced by circumstances\*, and sustained for at least two weeks
  - Loss of interest or pleasure in activities that are normally pleasurable
  - Decreased energy or increased fatigability
- An additional symptom or symptoms from the following list should be present to give a total of at least four:
  - Loss of confidence or self-esteem
  - Unreasonable feelings of self-reproach or excessive and inappropriate guilt
  - Recurrent thoughts of death or any suicidal behavior
  - Complaints or evidence of diminished ability to think or concentrate
  - Change in psychomotor activity, with agitation or retardation
  - Sleep disturbance of any type
  - Change in appetite with corresponding weight change

For **moderate depressive episodes** four or more of the symptoms noted above are usually present and the patient is likely to have great difficulty in continuing with ordinary activities.

For **severe depressive episodes**, the current episode is severe and there are no delusions or hallucinations during the episode. Many or most symptoms of a Depressive Episode are present to a marked degree, or a smaller number of symptoms are present and manifest to an intense degree. The individual has serious difficulty continuing to function in most domains (personal, family, social, educational, occupational, or other important areas).

Diagnoses are coded as recurrent when there are repeated episodes of depression without any history of independent episodes of mood elevation and increased energy or mania. There has been at least one previous depressive episode lasting a minimum of two weeks and separated by the current episode by at least two months.

\*In cases where caregivers are experiencing the physical decline of their loved one, or other caregiving-related situations in which sadness and anticipatory grief are appropriate, a Major Depressive Episode (MDE) diagnosis is likely not appropriate.

## Diagnosis: Post-traumatic Stress Disorder (PTSD)

### Correlate ICD-10-CM Code:

**F43.10** (Unspecified; criteria are met but onset and duration cannot be clearly delineated); **F43.11** (Acute; duration of symptoms is between 1 and 3 months); **F43.12** (Chronic; symptoms last more than 3 months)

- For caregivers, includes exposure to actual or threatened death, serious injury, or medical event in the patient for whom they provide care, and the presence of one or more of the following beginning after the event(s) occurred:
  - Recurrent, involuntary, and intrusive distressing memories of the traumatic event(s)
  - Recurrent distressing dreams in which the content and/or affect of the dreams are related to the traumatic event(s)
  - Dissociative reactions (e.g., flashbacks) in which the individual feels or acts as if the traumatic event(s) were recurring
  - Intense or prolonged psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event(s)
  - Marked physiological reactions to internal or external cues that symbolize or resemble an aspect of the traumatic event(s)
- Persistent avoidance of stimuli associated with the traumatic event(s), beginning after the traumatic event(s) occurred, as evidenced by one or both of the following:
  - Avoidance of or efforts to avoid distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s)
  - Avoidance of or efforts to avoid external reminders (people, places, conversations, activities, objects, situations) that arouse distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s)
- Negative alterations in cognition and mood associated with the traumatic event(s), beginning or worsening after the traumatic event(s) occurred, as evidenced by two (or more) of the following:
  - Inability to remember an important aspect of the traumatic event(s)
  - Persistent and exaggerated negative beliefs or expectations about oneself, others, or the world
  - Persistent, distorted cognitions about the cause or consequences of the traumatic event(s) that lead the individual to blame himself/herself or others
  - Persistent negative emotional state (e.g., fear, horror, anger, guilt, or shame)
  - Markedly diminished interest or participation in significant activities
  - Feelings of detachment or estrangement from others
  - Persistent inability to experience positive emotions (e.g., inability to experience happiness, satisfaction, or loving feelings)

- Marked alterations in arousal and reactivity associated with the traumatic event(s), beginning or worsening after the traumatic event(s) occurred, as evidenced by two (or more) of the following:
  - Irritable behavior and angry outbursts, typically expressed as verbal or physical aggression toward people or objects
  - Reckless or self-destructive behavior
  - Hypervigilance
  - Exaggerated startle response
  - Problems with concentration
  - Sleep disturbance (e.g., difficulty falling or staying asleep or restless sleep)
- Duration of the disturbance is more than 1 month
- The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning
- The disturbance is not attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition

## Diagnosis: Insomnia Disorder

**Correlate ICD-10-CM Code: G47.0**

Characterized by difficulty in initiating sleep, staying asleep, and/or by waking early in the morning and being unable to get back to sleep. The sleep disturbance causes significant distress or impairment in functioning, including difficulty carrying out caregiving-related responsibilities. Difficulty sleeping occurs at least three times a week and is present for at least three months. The problem occurs despite ample opportunity to sleep.\*

\*This last criterion is an important consideration when evaluating the appropriateness of this diagnosis in caregivers, who may not have ample opportunity to sleep. Additional considerations should be given to insomnia secondary to anxiety or other disorders.

## Telehealth Billing Consideration

For most cancer centers, the COVID-19 pandemic led to a shift in the delivery of psychosocial care through telemedicine platforms, and in many cases, this switch has become the norm. For sessions conducted over telemedicine platforms that include both audio and video components, the GT modifier should be used. The GT modifier indicates to the insurance company that the services took place via an interactive audio and video telecommunications system. For more information on telehealth billing considerations, please visit <https://bit.ly/3GnNkxm>.

# Opportunities for Training

To supplement the services provided by staff, and to provide unique training opportunities to students and other learners, your Caregivers Clinic can serve as a training clinic for externs, interns, and pre- and post-doctoral fellows, residents and attendings across disciplines to learn about how to best address the needs of family caregivers.

Keep in mind the following when integrating training opportunities into your Caregivers Clinic:



**Psychodiagnostic Visit**

Trainee initiates sessions.  
Licensed professional concludes sessions.

The psychodiagnostic visit should be shared by a licensed health care professional (i.e., clinical psychologist) and a trainee. In the Caregivers Clinic at MSK, trainees typically conduct the psychiatric interview for 45-60 minutes and then the licensed professional joins the session, at which point the trainee presents the case and discusses an appropriate plan of care.



**Group Supervision Sessions**

Multiple trainees discuss cases together with the licensed professional.

Each student should receive clinical supervision with a licensed mental health staff member from the Caregivers Clinic weekly. If more than one student is receiving training in your Clinic, consider a group supervision model. In the Caregivers Clinic at MSK, group supervision sessions are rich opportunities for students to learn from one another and from the cases for which they are not serving as the primary therapist.



**Co-therapy Sessions**

Trainee and licensed professional work together during a session.

Group psychotherapy sessions for caregivers provide a rich opportunity for students and trainees to develop their skills using a co-therapy model in which a student is paired with a seasoned mental health professional (e.g., clinical psychologist, social worker).





# Approaches to Care and Pacing of Sessions

There is no one-size-fits all care plan and it's important to tailor care to meet caregivers' unique needs. At all times possible, staff should deliver empirically supported interventions when supporting caregivers. To date, approximately 75 interventions for family caregivers have been tested in clinical trials.<sup>58,59</sup>

Many interventions have effectively improved a wide range of outcomes for both caregivers and patients including quality of life, physical health, burden, anxiety, and depressive symptoms.<sup>60-62</sup>

## Developing a Treatment Plan

A treatment plan should be established at the initial diagnostic visit. This should include a plan for the number and pacing of sessions, goals of care, and approaches to be used. Treatment plans should be periodically re-evaluated and revised as illness and caregiving-related events unfold.



### Pacing of Sessions

- Often dictated by staffing capacity
- Should be discussed with caregivers during the initial visit and tailored to their needs



### Examples of Care Goals

- Improve caregiver capacity to manage uncertainty
- Encourage caregiver to engage in advance care planning discussions with care partner and members of the health care team.

## Types of Treatment



### Family and Couples Therapy

Can be a powerful adjunct to one-on-one therapy and may be offered as needed to address specific concerns (e.g., communication with a loved one about treatment planning)



### Telemedicine

Mitigates the time and financial cost associated with traveling to and from treatment centers for care



### Support Groups

Provides a social circle for caregivers and a set number of sessions

At the Caregivers Clinic at MSK, one model frequently used is delivering an initial course of 4-8 sessions every other week, and then conducting booster sessions monthly. This model is particularly helpful for caregivers who require support around specific caregiving-related events but may not need the same level of support for an extended period.



# Marketing

Once you have established initial staffing for your Caregivers Clinic, you may consider marketing your Clinic to hospital staff as well as patients and caregivers.

## Sharing With Staff

Consider the following recommendations to share information about the Caregivers Clinic with staff at your cancer center:



Circulate hospital-wide email blasts



Deliver brief presentations to various hospital services (e.g., Social Work, Medicine, Patient Representatives) about support offered, who is eligible for care, and how to generate referrals



Include a description of the Clinic and referral information in hospital newsletters

## Sharing With Caregivers

To share information about the Caregivers Clinic to those interested in receiving care, consider the following recommendations:



Work with the marketing and communications department to update website and key word searches for 'caregiver'



Use electronic signage at the cancer center to promote the Caregivers Clinic



Advertise the Caregivers Clinic via social media feeds of the cancer center (i.e., Twitter/X, Instagram)



If available, advertise the Caregivers Clinic within the Counseling Center's physical space and on Counseling Center's web page

# Evaluation

Evaluation plays an essential role in assessing the effectiveness and impact of your Caregivers Clinic. By systematically collecting process and outcome measures, cancer centers can demonstrate the success of their program and make informed decisions about improving the quality of the service. It is essential to adapt and customize the evaluation measures and processes to align with the specific context, goals, and resources of each cancer center.

Below are guidelines for evaluation, including recommended measures and evaluation processes.

## Process Measures

Process measures help gauge the extent to which the services are being delivered as intended and provide insights into the overall program implementation. Some key process measures to consider include:

Process Measure	Description	Tracking
<b>Service Utilization</b>	Tracks number of family caregivers accessing the psychosocial services, the frequency of their engagement, and types of services utilized	Document in electronic medical record
<b>Reach and Diversity</b>	Evaluates diversity of family caregivers reached to identify potential gaps in service provision	Include factors such as age, race, gender identity, sex assigned at birth, sexual orientation, and socioeconomic status
<b>Referral Patterns</b>	Helps understand how caregivers are being connected to the program and identifies effective strategies for increasing referrals from sources	Monitor sources and methods of referral to psychosocial services
<b>Service Satisfaction</b>	Collects feedback from family caregivers on usefulness, accessibility, and overall quality of the program	Utilize surveys, interviews, or focus groups

## Outcome Measures

Outcome measures focus on the impact of psychosocial services on family caregivers' well-being, coping abilities, and overall quality of life. Here are some commonly used outcome measures:

Outcome Measure	Description	Tracking
<b>Caregiver Distress</b>	Assesses levels of psychological distress, anxiety, and depressive symptoms among family caregivers	Hospital Anxiety and Depression Scale (HADS), Patient Health Questionnaire-9, General Anxiety Disorder-7, Distress Thermometer*
<b>Caregiver Burden</b>	Evaluates the extent of burden experienced by caregivers, including physical, emotional, and financial burden	Zarit Burden Interview (ZBI), Caregiver Strain Index (CSI)
<b>Coping and Resilience</b>	Measures caregiver's coping strategies, resilience, and ability to adapt to the caregiving role	Connor-Davidson Resilience Scale (CD-RISC)
<b>Health-Related Quality of Life (HRQoL)</b>	Provides insights into the physical and emotional well-being of caregivers	Short Form Health Survey (SF-12 or SF-36), PROMIS Global Health 10
<b>Caregiver Skills and Knowledge</b>	Assesses the acquisition of skills and knowledge relevant to caregiving tasks, symptom management, and communication with health care providers	Self-report measures, objective assessments

\*It should be noted that some of these instruments are specific to anxiety and depressed mood, but not both.

## Evaluation Process

To ensure a comprehensive evaluation, consider the following:

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**Pre- and Post-Assessment**

Conduct initial assessments to establish baseline measurements before caregivers engage in psychosocial services. Follow up with post-assessments at regular intervals to track changes and improvements.

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**Data Collection Methods**

Determine the most appropriate data collection methods. This may include self-report surveys, interviews, focus groups, or even electronic data capture systems for certain measures. Work alongside your hospital's informatics team to determine if changes to the medical record are needed to formally capture such data.

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**Reporting and Dissemination**

Summarize the evaluation findings in a comprehensive report, including both process and outcome measures. Share the results with key constituents, such as your cancer center's leadership and administration, clinicians, staff, and community, to demonstrate the program's effectiveness and foster transparency.

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# Common Pitfalls and Resolution Strategies

Issue	Resolution
<b>Insufficient screening and needs assessment, and inefficient triage</b>	<ul style="list-style-type: none"> <li>• Implement a screening and evaluation plan for <i>potential</i> patients</li> <li>• Designate a staff person to conduct screenings and triage processes</li> </ul>
<b>Poorly structured clinical objectives, goals, and expectation setting</b>	<ul style="list-style-type: none"> <li>• Clinicians and patients establish treatment goals early during diagnostic visit</li> <li>• Revisit goals periodically to ensure focused sessions</li> </ul>
<b>Inadequate leadership and administrative buy-in</b>	<ul style="list-style-type: none"> <li>• Present Clinic data annually or semi-annually to leadership to help garner support and recognition of the benefits of your clinical service</li> </ul>
<b>Inadequate clinician and staff buy-in and understanding of service scope</b>	<ul style="list-style-type: none"> <li>• Conduct in-service trainings for hospital staff across disciplines and departments to discuss services offered and their impact</li> </ul>
<b>Lack of strategic planning</b>	<ul style="list-style-type: none"> <li>• Establish a strategic plan before opening Caregivers Clinic</li> <li>• Revisit strategic plan annually</li> </ul>
<b>Inadequate financial planning</b>	<ul style="list-style-type: none"> <li>• Work with staff from your institution's finance team to develop a business model before the Clinic's opening</li> </ul>
<b>Regulatory and compliance issues</b>	<ul style="list-style-type: none"> <li>• Before the Clinic's opening, work with a compliance officer to ensure that all of your procedures and processes adhere to hospital policy</li> </ul>

Issue	Resolution
<b>Under or over-marketing</b>	<ul style="list-style-type: none"><li>• Begin marketing internally, such as through your cancer center’s website and via internal signage, as you begin to set up your program</li><li>• Market via social media channels once staff and infrastructure are in place</li></ul>
<b>Overly ambitious expectations of service performance over the short term</b>	<ul style="list-style-type: none"><li>• Set SMARTIE (Specific, Measurable, Achievable, Realistic, Time Bound, Inclusive and Equitable) goals for your Clinic</li><li>• Evaluate progress every three months</li></ul>
<b>Failure to gather or ignoring caregiver feedback</b>	<ul style="list-style-type: none"><li>• Conduct one-on-one interviews or focus groups with caregivers who sit on your institution’s Patient and Family Advisory Committee to ensure specific needs are met before the Clinic opens</li><li>• Perform ongoing solicitation of feedback from caregivers who have received care</li></ul>





# Appendix A: The State of Caregivers in the U.S.

At least 53 million people in the United States (U.S.) serve as family caregivers, defined as family members and friends who provide unpaid care to patients with chronic or life-threatening, incurable illnesses.<sup>1</sup> The number of family caregivers in the U.S. has grown by over 20% since 2015,<sup>2</sup> owing to rising health care costs, shorter hospital stays, patient preference for these treatment settings, and expansion of ambulatory and telehealth services that continue to rely on family caregiver support.<sup>3-5</sup>

At least 5 million of these caregivers currently provide care to patients with cancer.<sup>2</sup> Due to advances in oncologic care, including sophisticated diagnostic tools and innovations in drug treatment and immunotherapies, our ability to extend lives and enhance survival has improved. With patients living longer – including those with advanced and life-limiting illnesses – the role of caregivers has expanded to include ongoing responsibilities once performed by health care professionals.<sup>6,3</sup>



Today's shorter hospital stays and push to outpatient models of care have placed a significant burden of complex health care on caregivers, many of whom have little or no preparation for this role. Undoubtedly, success of patient outcomes throughout the illness trajectory is shaped by the availability and well-being of caregivers.<sup>30</sup>

The profound, negative effects of these responsibilities on cancer caregivers are clear. In comparison to caregiving for other illnesses, the cancer caregiving trajectory is uniquely intense and episodic, marked by protracted, multifaceted challenges.<sup>2</sup>

Unlike patients, caregivers bear witness to suffering on the sidelines, often feel powerless in their role in the overall health care of patients, and struggle to balance hope that their loved one will survive while contending with anticipatory grief.<sup>8</sup> They live with the fear of cancer recurrence during times when the disease is controlled or in remission, and fear of disease progression when cancer is first diagnosed.<sup>7,9,10</sup> Those experiencing repeated waves of diagnosis, treatment, remission, recurrence, and potential treatment failure are at high risk for clinically significant levels of psychological distress.

## Caregivers Typically Struggle With Numerous Challenges That Can Change Over Time



**Approximately half of all cancer caregivers report clinically significant symptoms of depression and anxiety, with diagnostic rates higher among caregivers than the patients for whom they provide care.<sup>11-14</sup>**



Longitudinal studies show untreated distress increases over time,<sup>6,15</sup> and is associated with health complications including sleep difficulties,<sup>16-18</sup> fatigue,<sup>16</sup> cardiovascular disease,<sup>19</sup> and increased mortality risk.<sup>19-21</sup> As such, without support and attention to this distress, cancer caregivers are at risk for becoming the next generation of patients with chronic and life-limiting illnesses.

Caregivers are also at risk for poor bereavement outcomes.<sup>22-25</sup> While the intensity of psychological symptoms tends to decrease over time in bereavement for most,<sup>64</sup> a small subset of bereaved caregivers<sup>26</sup> develop more severe and persistent bereavement-related mental health concerns,<sup>27-29</sup> including prolonged grief disorder, major depressive disorder, post-traumatic stress disorder (PTSD), and substance abuse. For example, one study reported a high risk of prolonged grief disorder in over a quarter of caregivers of patients with terminal cancer.<sup>65</sup>

Caregivers who experience high levels of emotional distress or stressful events during active caregiving are particularly vulnerable to mental health challenges in bereavement,<sup>66,67</sup> as are caregivers of patients with greater cancer symptom severity and poor quality of life toward the end of life,<sup>68,69</sup> and caregivers who experience challenges implementing advance care directives.<sup>70</sup>

The intensity of pre-loss grief has also been found to predict outcomes in bereavement, including depression<sup>71</sup> and prolonged grief disorder.<sup>72,73</sup> Pre-loss grief includes both future-oriented anticipatory grief (i.e., worry and sadness about a future without the patient) and present-oriented illness-related grief (i.e., grief related to current losses, such as observing diminishing patient physical functioning).

Additionally, when caregivers witness intensive medical interventions or perceive the conditions of the death as traumatic or unexpected (e.g., medical interventions that result in disfigurement, uncontrolled pain, seizing, or bleeding at the time of death), they are at greater risk for post-traumatic stress symptoms in bereavement.<sup>74-76</sup> Finally, lack of emotional preparedness for the death<sup>77,78</sup> and low social support<sup>79,80</sup> can place caregivers at greater risk for these mental health challenges in bereavement.

In addition to significant benefits for caregivers, the benefits of caregiver support programs extend to patients and health care systems. Supportive caregivers are crucial to cancer care outcomes for patients.<sup>30</sup> Poor caregiver functioning during cancer treatment has implications for patients' psychosocial outcomes as well: higher distress among caregivers, including anxiety and depression, predicts inferior quality of care and patient health outcomes,<sup>33-37,63</sup> such as increased use of aggressive and unnecessary treatments as part of patients' end-of-life care.<sup>38-41</sup> Moreover, the financial and health-systems benefits of caregiver well-being are profound. For example, poor caregiver well-being has been associated with higher care recipient Medicare expenditures and emergency department use,<sup>31</sup> whereas the receipt of psychosocial support and education by caregivers has been associated with lower hospital readmission rates for patients<sup>32</sup> and lower overall health care costs.<sup>42,43</sup>



**Providing support to cancer caregivers that targets their emotional and mental health needs is necessary to help prevent poor outcomes and assist them in fulfilling their roles as critical members of the health care team.**

**As the burden of care responsibilities on family cancer caregivers is expected to continue to increase, it is imperative to support them in their role and to protect them from the negative downstream effects of caregiving.<sup>44</sup>**

# Appendix B: Caregiver Support Resources

The American Cancer Society has developed a suite of evidence-informed resources for caregivers that are aimed at:



**Building confidence in the caregiver role**



**Training in medical tasks, like drain care and symptom management**



**Assisting in the management of caregiver mental health and wellness**

Resources are available in English and Spanish.

Please distribute the following one-page fliers throughout your hospital to spread awareness of support opportunities for caregivers.



## Caregiver Resource Guide

# We Care for People Who Care for Others.

Caregivers play a critical role on every cancer care team. Since your loved one was diagnosed with cancer, you have likely been the one person who has been there at every step of their journey. You have probably coordinated their care and served as the primary communicator to family, friends, and medical staff – all while trying to balance your own daily responsibilities.

With this in mind, we created the Cancer Resource Guide that includes information about:

- **Cancer caregiving** – overview of what caregivers do and how your role is important in the cancer journey; also includes tips for being an effective caregiver
- **Caregiver self-care** – information about healthy lifestyle choices with guidelines to support physical activity and nutrition
- **Communication** – tools to help you better express thoughts and feelings about cancer to your loved one and to the cancer care team
- **Cancer information** – the basics about cancer: what it is, how it develops, and common cancer myths
- **Cancer treatment** – briefly describes surgery, chemotherapy, and radiation and their respective side effects; also provides resources in the event treatment stops working
- **Patient nutrition** – how eating the right kinds of foods before, during, and after treatment can help patients feel better and stay stronger
- **Coping** – the most common mental health concerns around cancer (e.g., anxiety, fear, and depression) and how caregivers can help their loved one cope with them
- **Caregiver resources** – a list of support resources available through the American Cancer Society and other organizations



Visit [cancer.org/caregiverguide](https://cancer.org/caregiverguide) to download a copy.

For more information about caregiving, visit [cancer.org/caregivers](https://cancer.org/caregivers).



## Caregiver Support Video Series

# We're here for you.

When you're caring for a loved one with cancer, you will likely face new challenges, including dealing with a wide range of emotions and learning how to provide at-home care.

The American Cancer Society and biopharmaceutical innovator EMD Serono are working together to help you meet these challenges. We encourage you to check out our **Caregiver Support Video Series**, which provides resources and training for caregivers.

This video series offers psychosocial and educational support for people caring for a loved one with cancer. It also provides self-care techniques, so you can maintain or improve your own quality of life as you go through the caregiver experience.

This is an evidence-informed video series. That means we've listened to caregivers – lots of them – who have shared what would help them in their role, and we used their feedback to create this video series.

### Video topics include the following:



#### **Physical Care Training –**

Drain care, lifting, pain management, medication management, symptom/side effect management, and identifying signs of infection



#### **Caregiver Self-Care –**

Nutrition, physical activity, stress management and coping, dealing with fear of recurrence, and deep breathing/relaxation



#### **Advocacy –**

Ways to effectively communicate the patient's needs to the cancer care team

Visit [cancer.org/caregivervideos](https://cancer.org/caregivervideos) and choose the videos that speak to your needs. Also, please share this information with others in your caregiver community. We want all caregivers to know that they are not alone, and that we are here to help.



**embracing carers**

Embracing Carers™ is an initiative led by EMD Serono, in collaboration with leading caregiver organizations around the world, to increase awareness and action about the often-overlooked needs of caregivers. Visit [embracingcarers.com](https://embracingcarers.com) to learn more.



Guía de recursos para cuidadores

# Cuidamos a las personas que cuidan a otros.

Los cuidadores juegan un rol importante en cada equipo de atención médica contra el cáncer. Desde que su ser querido fue diagnosticado con cáncer, probablemente usted es la persona que ha estado ahí acompañándole en cada paso del camino. Probablemente usted ha coordinado el cuidado y servido como el principal punto de contacto para la familia, amigos y personal médico, todo esto mientras intenta continuar con sus responsabilidades diarias.

Por esta razón, creamos la Guía de recursos para cuidadores que incluye información sobre:

- **Cuidadores de pacientes con cáncer** – resumen de la labor de los cuidadores y cómo su rol es importante en la experiencia con el cáncer; incluye también consejos para ser un cuidador eficaz
- **Cuidado personal del cuidador** – información sobre elecciones de estilo de vida saludables para apoyar la actividad física y nutrición
- **Comunicación** – herramientas para ayudarle a expresar de manera más eficaz sus pensamientos y sentimientos sobre el cáncer a su ser querido y al equipo de atención médica contra el cáncer
- **Información sobre el cáncer** – información básica sobre el cáncer: qué es, cómo se desarrolla y los mitos comunes sobre el cáncer
- **Tratamiento contra el cáncer** – descripción breve de la cirugía, quimioterapia y radiación y los efectos secundarios correspondientes; asimismo brinda recursos en caso que el tratamiento deje de funcionar
- **Nutrición del paciente** – cómo ingerir los tipos de alimentos adecuados antes, durante y después del tratamiento puede ayudar a los pacientes a sentirse mejor y mantenerse más fuertes
- **Sobrellevar** – las problemas de salud mental más comunes respecto del cáncer (p.ej. ansiedad, temor y depresión) y cómo los cuidadores pueden ayudar a sus seres queridos a sobrellevar estas situaciones
- **Recursos para el cuidador** – una lista de recursos de apoyo disponibles por medio de la Sociedad Americana Contra El Cáncer y otras organizaciones



Para obtener más información sobre el cuidado del paciente y para descargar una copia de la Guía, visite [cancer.org/cuidadores](https://cancer.org/cuidadores).





Serie de videos de apoyo para cuidadores

# Estamos aquí para usted.

Cuando cuida a su ser querido con cáncer, es posible que afronte desafíos nuevos, incluyendo experimentar un gran rango de emociones y aprender cómo brindar el cuidado en casa.

La Sociedad Americana Contra El Cáncer y la biofarmacéutica innovadora EMD Serono están trabajando juntos para ayudarle a afrontar estos desafíos. Le animamos a revisar nuestra **Serie de videos de apoyo para cuidadores**, que proporciona recursos y capacitación para cuidadores.

Esta serie de videos ofrece apoyo psicosocial y educativo para las personas que cuidan a un ser querido con cáncer. Además muestra técnicas de cuidado personal, para que usted pueda mantener o mejorar su propia calidad de vida, mientras vive la experiencia de cuidador.

Esta serie de videos está basada en evidencia. Esto significa que hemos escuchado a cuidadores, un gran número, quienes compartieron lo que les ayudaría en este rol, y usamos sus comentarios para crear esta serie de videos.

## Los temas de los videos incluyen lo siguiente:



### Capacitación En Cuidado Físico -

cuidado del drenaje, levantamiento del paciente, control del dolor, administración de medicamentos, control de síntomas/efectos secundarios, e identificar las señales de infección



### Cuidado Personal Para Los Cuidadores -

Nutrición, actividad física, control del estrés, y sobrellevar, lidiar con el temor a la recurrencia, y respiración profunda/relajación



### Lucha Por Los Derechos -

Cómo comunicar eficazmente las necesidades del paciente al equipo de atención de atención médica contra el cáncer

Visite [cancer.org/videoseriecuidadores](https://cancer.org/videoseriecuidadores) y seleccione los videos que aborden sus necesidades.

Asimismo, por favor comparta esta información con su comunidad de cuidadores. Deseamos que todos los cuidadores sepan que no están solos y que estamos aquí para ayudarles.



**embracing carers**

Embracing Carers™ es una iniciativa liderada por EMD Serono, en colaboración con las principales organizaciones de cuidadores de todo el mundo, para aumentar la conciencia y la acción sobre las necesidades, a menudo ignoradas, de los cuidadores. Visite <https://www.embracingcarers.com/us-en-home/> para obtener más información.

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