National
Alliance for
Caregiving

Cancer
Caregiving
COLLABORATIVE

Trends in Innovation: Implementing and Refining Caregiving Training Services in Medicare

June 2025

nac
National Alliance for Caregiving

Acknowledgments

The Cancer Caregiving Collaborative, an initiative of the National Alliance for Caregiving (NAC), is proud to present *Trends in Innovation: Implementing and Refining Caregiving Training Services in Medicare.* The work of the Collaborative, including this brief, is supported by EMD Serono, Kite, a Gilead Company, Bristol Myers Squibb, Exelixis, Merck, Pfizer, and Sanofi. The content and opinions expressed in this material are solely those of the National Alliance for Caregiving.

National Alliance for Caregiving

Leadership

Jason Resendez, President and CEO

Yadira Montoya, MSPH, Director of Programs

Project Authors

C. Grace Whiting, JD, CEO, Whiting Communications

Tara Anglim, EdD, LCSW-R, ACHP, SW, Associate Executive Director, Culture and Experience, Northwell Health

Diane Mariani, LCSW, CADC, Program Manager, Rush University Medical Center

Yadira Montoya, MSPH, Director of Programs, National Alliance for Caregiving

Cancer Caregiving Collaborative Executive Committee Members

Tara Anglim, EdD, LCSW-R, ACHP, SW, Associate Executive Director, Culture and Experience, Northwell Health

Allison J. Applebaum, PhD, Icahn School of Medicine at Mount Sinai

Abena Apau Buckley, MBA, Empowered Potential International*

Elizabeth Franklin, PhD, MSW, Sanofi

Erin E. Kent, PhD, University of North Carolina at Chapel Hill

Laura Makaroff, DO, American Cancer Society

Jason Resendez, National Alliance for Caregiving

Alexandra Zaleta, PhD, Cancer*Care*

Suggested Citation

National Alliance for Caregiving. (2025). *Trends in Innovation: Implementing and Refining Caregiving Training Services in Medicare*. June 2025.

Cancer Caregiving Collaborative Steering Committee Members

Aminah Abdullah, University of Illinois Cancer Center

Anneliese Barron, One Family Foundation

Laura Blessing, PhD, Georgetown University

Tamryn Gray, PhD, RN, MSN, MPH, University of North Carolina at Chapel Hill

Jasmine Greenmyer, MPH, Bristol Myers Squibb

Cathy Ferrone, Kite, a Gilead Company

Sharon Hamill, PhD, CSU Shiley Haynes Institute for Palliative Care

Theresa A. Hastert, PhD, MPP, Wayne State University, Karmanos Cancer Institute

Shelley Fuld Nasso, National Coalition for Cancer Survivorship

Randy A. Jones, PhD, RN, FAAN, University of Virginia

Youngmee Kim, PhD, University of Miami

Bellinda King-Kallimanis, PhD, LUNGevity Foundation

Parvathy Krishnan, Krishnan Family Foundation

Michael J. LaMonte, PhD, MPH, University at Buffalo - SUNY

Kristin Litzelman, PhD, University of Wisconsin-Madison

Candice Roth, MSN, RN, CENP, Academy of Oncology Nurse & Patient Navigators

Sherri May-Rogers, Pfizer

Hazel Moran, EMD Serono

Chandylen Nightingale, PhD, MPH, Wake Forest University School of Medicine

J. Nicholas Odom, PhD, RN, ACHPN, University of Alabama at Birmingham

Kristen Santiago, MS, Caregiver Advocate

Katie Schoeppner, MSW, LICSW, NMDP

Daneen Sekoni, Cancer Support Community

Allison Silvers, Center to Advance Palliative Care

Caroline Sloan, MD, PHD, Duke University School of Medicine

Brian Smith, Merck

Nicole Stout, DPT, CLT-LANA, FAPTA, American Cancer Society

Rachel Solomon, Sanofi

Lindsay Treadway, Exelixis

Ranak Trivedi, PhD, Stanford University

Madhavi Vemireddy, MD, Cleo

Background

About the Cancer Caregiving Collaborative

The Cancer Caregiving Collaborative, powered by the National Alliance for Caregiving (NAC), is a cross-sector initiative addressing the unmet needs of cancer caregivers through research, policy, and practice change. The Collaborative focuses on two core priorities: integrating family caregivers into healthcare teams and the financial impact of cancer caregiving. Its core strategies include peer learning and resource sharing, policy and education, and storytelling. The Collaborative hosted a workshop on November 19, 2024, in Washington, D.C., to explore Medicare reimbursement codes for Caregiver Training Services (CTS), a critical step toward formally acknowledging—and a step toward integrating—family caregivers into the care team.

About this Brief

Focused on Medicare, this brief aims to provide an overview of the Calendar Year (CY) 2025 Medicare Physician Fee Schedule (PFS) Caregiver Training Services (CTS) reimbursement for direct care activities necessary to support cancer patients in adhering to their treatment plans. The brief also provides two case studies from Northwell Health and RUSH University Medical Center who are at different stages of the process in implementing CTS, an example workflow, sample checklists for integration, and a set of recommendations for those interested in exploring CTS implementation in their systems or practices. Together, this information aims to provide insight from the cutting edge of innovation, drawing on new programs under Medicare and current knowledge of caregiver integration into healthcare systems.

By sharing information about recent innovations in CTS, NAC's goal is to foster a growing knowledge base of how to include family caregivers as partners and key decision-makers on the care team. **Consider these insights as guideposts for health systems and providers seeking to integrate caregiver training and support codes and expand assistance for family caregivers navigating complex conditions, such as cancer.**

Focus on Cancer Caregiving

While some healthcare models involve family caregivers to a small extent, they typically fail to reimburse the coaching, education, and training provided to friends and family members supporting the patient. In other cases, these models may overlook family caregivers entirely, leaving them to rely on informal workarounds to participate in the patient's treatment plan. As awareness of the family caregiver's role in supporting patients with serious illnesses continues to evolve, the introduction of Medicare reimbursement for CTS formally recognizes family caregivers as essential participants in a patient's care and a critical step toward integrating them into the care team.

Robust caregiver support and training can significantly reduce unplanned acute care utilization[1] and overall costs for cancer patients,[2] alleviate financial toxicity for cancer patients and caregivers,[3] and drive substantial cost savings through targeted psychosocial interventions.[4] **The Collaborative focuses on assessing and optimizing caregiver training and supporting implementation in oncology settings due to both the high burden cancer places on patients and their families, and the potential to improve patient outcomes by actively including family caregivers in the care process.** This brief highlights general considerations and opportunities for success, as well as elements specific to oncology practices and patient experiences.

Getting Involved and Sharing Feedback

To learn more about getting involved with the Cancer Caregiving Collaborative or to provide feedback on this brief, please email cancercarecollab@caregiving.org.

Not Legal or Compliance Guidance

This brief is provided for informational purposes only and is not intended to offer legal or compliance guidance within the Medicare program. When implementing recommendations suggested in the brief, please consult your organization's legal counsel to ensure compliance with all appropriate Medicare regulations and other federal, state, or local laws.

---

[1] *Burgdorf, J. G., Arbaje, A. I., Stuart, E. A., & Wolff, J. L. (2021). Unmet family caregiver training needs associated with acute care utilization during home health care. Journal of the American Geriatrics Society, 69(7), 1887. https://doi.org/10.1111/jgs.17138*

[2] *Poco, L. C., & Malhotra, C. (2024). More competent informal caregivers reduce advanced cancer patients' unplanned healthcare use and costs. Cancer Medicine, 13(11), e7366. https://doi.org/10.1002/cam4.7366*

[3] *Edward, J. S., McLouth, L.E., Rayens, M. K., Eisele, L. P., Davis, T. S., & Hildebrandt, G. (2023). Coverage and cost-of-care links: Addressing financial toxicity among patients with hematologic cancer and their caregivers. JCO Oncology Practice, 19(5), e696–e705. https://doi.org/10.1200/OP.22.00665*

[4] *Badger, T. A., Sikorskii, A., Segrin, C., Given, C. W. (2021) Supportive health education reduces health care utilization and costs in Latinas with breast cancer and their caregivers. Supportive Care in Cancer, 29(3), 1225–1233. https://doi.org/10.1007/s00520-020-05593-9*

Family Caregivers: Partners in Diagnosis, Treatment, and Planning

> *"Caregiving for someone diagnosed with cancer can easily become a full-time job. Patients and their caregivers are people before they walk through that door and enter into a world of illness. They have commitments and responsibilities—families, jobs, school, bills, hobbies—everything that makes up our lives. When cancer enters those lives, it can throw their lives into turmoil. Caregivers are inherently a critical member of the patient's team and should be treated as such. They should also have support to navigate the financial and logistical burdens that many families may face."*
>
> *Elizabeth Franklin, PhD, MSW, Sanofi*

Key Takeaways

- Cancer caregiving is particularly demanding, with caregivers providing an average of 33 hours weekly of unpaid care, including complex medical tasks and crucial support for treatment decision-making.
- Despite their essential role, caregiver needs remain underrecognized—25% of Commission on Cancer-accredited US cancer centers offer no caregiver support programs, and only about 20% provide training for medical tasks or self-care.
- The CY 2024 Medicare Physician Fee Schedule represented a significant policy shift by implementing Caregiver Training Services (CTS) codes that allow reimbursement for training caregivers separate from patients—recognizing caregivers as essential members of a patient's care team.
- The Centers for Medicare and Medicaid Services (CMS) will recognize and pay for five Current Procedural Terminology (CPT®) codes for caregiver training that require patient consent, sessions outside patient presence, and substantial training by physicians and other qualified healthcare professionals (minimum 30 minutes individual/60 minutes group)—creating financial incentives for health systems to develop sustainable caregiver support programs.

CANCER INSIGHTS

33 hours weekly of unpaid care: Cancer caregivers devote an average of 33 hours each week to both routine and complex medical tasks

Limited institutional support: 25% of Commission on Cancer-accredited cancer centers have no programs to support family caregivers (2023 survey)

Training has proven benefits: Evidence suggests effective interventions improve treatment delivery and patient outcomes, enhancing patient quality of life

Despite relying on caregivers' unpaid work, their needs are under-recognized, and they experience inconsistent support from the healthcare system and society at large.

Providing care to someone living with cancer is "an episodic and intense experience."[5] Cancer caregivers often help with medical and nursing tasks and other activities of daily living, giving an average of 33 hours each week of unpaid care to someone living with cancer. These activities include support that would take place in a healthcare setting, such as administering injections, tube feedings, catheter and colostomy care, and other at-home nursing needs (72% cancer caregivers vs. 56% non-cancer caregivers), as well as practical and emotional support.

Family caregivers also play key roles in decision-making around treatment decisions for cancer patients, including where to receive treatment, the treatment plan, second opinions, and when to start or stop treatment.[6] As technology advances and cancer treatment moves from in-patient facilities to outpatient settings, the work of managing cancer treatment will continue to shift to the patient and their caregiver in home and community-based settings.[7]

Despite relying on caregivers' unpaid work, their needs are under-recognized, and they experience inconsistent support from the healthcare system and society at large. A 2023 survey of Commission on Cancer-accredited US cancer centers found that one in four had no programs to support family caregivers. Only roughly one in five had training on helping with medical nursing tasks (22%) or on caregiver self-care (20%).[8] While more research is needed on the impact and cost-effectiveness of caregiver interventions within healthcare systems,[9] supporting family caregivers of cancer patients offers public health benefits for the caregiver and the person living with cancer.[10] Effective interventions can help alleviate the impacts of caregiving activities, improve the delivery of cancer treatment and patient outcomes, and ultimately, improve the quality of life for the cancer patient.

---

[5] *Hunt, G. G., Longacre, M. L., Kent, E. E., & Weber-Raley, L. (2016). Cancer caregiving in the U.S. Retrieved from https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf*

[6] *Dionne-Odom, J. N., Kent, E. E., Rocque, G. B., Azuero, A., Harrell, E. R., Gazaway, S., Reed, R. D., Bratches, R. W., Bechthold, A. C., Lee, K., Puga, F., Miller-Sonet, E., & Ornstein, K. A . (2023). Family caregiver roles and challenges in assisting patients with cancer treatment decision-making: Analysis of data from a national survey. Health Expectations, 26(5), 1965–1976. https://doi.org/10.1111/hex.13805*

[7] *Adashek, J. J., & Subbiah, I. M.. (2020). Caring for the caregiver: A systematic review characterizing the experience of caregivers of older adults with advanced cancers. ESMO Open, 5(5), e000862. https://doi.org/10.1136/esmoopen-2020-000862*

[8] *Odom, N. J., Applebaum, A., Bakitas, M. A., Bryant, T., Currie, E., Curry, K., Donovan, H., Fernandez, M. E., Ferrell, B., Azuero, A., Gray, T. F., Hendricks, B. A., Meier, D., Nightingale, C., Reinhard, S., Sannes, T. S., Sterba, K., & Young, H. M. (2023). Availability of family caregiver programs in US cancer centers. JAMA Network Open, 6(10), e2337250. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2810486*

[9] *Piil, K., & Boele, F. (2023). Paving the way to evidence-based clinical practice: Establishing effective caregiver and family support interventions. Neuro-Oncology Practice, 10(6), 504–505. https://doi.org/10.1093/nop/npad041*

[10] *The term "cancer patient" is used here to mirror the language of the Medicare program and to provide clarity with respect to the roles of the individual with cancer and their caregiver within a formal healthcare system. We recognize that cancer is just one part of the individual's identity and experience and terms such as "cancer survivor" or "person with cancer" are more appropriate in conversations outside of the regulatory landscape.*

Medicare Caregiver Training Services

Medicare providers have begun to recognize that a "whole-person model of care" requires strong partnerships with the friends and family who provide unpaid care to cancer patients. Traditionally, Medicare Part B has only reimbursed services delivered directly to the beneficiary. The CY 2024 Physician Fee Schedule (PFS) was the first major Medicare policy update to implement Caregiver Training Services (CTS), a change long advocated by the American Medical Association (AMA) and the National Alliance for Caregiving. By allowing payment for training provided to someone other than the patient—and crucially, outside the patient's presence—these new CTS codes represent a substantial shift toward valuing and addressing non-medical drivers of health and person-centered care.

Typically, healthcare providers may offer two types of services for family caregivers: services that improve patient care and focus on patient needs, and services that focus on the caregiver's needs, such as interventions that address the caregiver's mental and physical health.

In many health systems, support for caregivers meets both needs, recognizing that caregiver well-being allows the caregiver to be better prepared to care.[11] For example, in CY 2024, CMS recognized that unmet health-related social needs (HRSNs) may worsen health outcomes and increase the total cost of care. To combat this, CMS finalized new reimbursement codes for community health integration (CHI), social determinants of health (SDOH) risk assessment, and principal illness navigation.[12] CMS also offered new codes specific to caregivers to provide CTS and expanded psychosocial supports for family caregivers, such as group therapy.

Notably, CMS's CY 2024 final rule cites the "extensive empirical support" demonstrating that adequate caregiver training as part of a person-centered care plan promotes improved patient outcomes.

The five billing codes approved by CMS in CY 2024 for CTS are tied to the needs and treatment plan of the patient. As described by the American Academy of Professional Coders (AAPC),[13] CMS designated three "sometimes therapy" CTS codes for therapists to use with caregivers. The codes cover therapy, strategies, and techniques to help the patient adhere to their care plan, from those that support activities of daily living (such as eating, getting dressed, and bathing) to more medically complex tasks such as transfers, mobility, communication, and safety practices. The American Physical Therapy Association (APTA)

Typically, healthcare providers may offer two types of services for family caregivers: services that improve patient care and focus on patient needs, and services that focus on the caregiver's needs, such as interventions that address the caregiver's mental and physical health.

---

[11] *Gallagher-Thompson D., Bilbrey A., & St. Pierre L. R. (Eds). (2021). Caring for the caregiver: Incentivizing medical providers to include caregivers as part of the treatment team. National Alliance for Caregiving. Retrieved from https://www.caregiving.org/wp-content/uploads/2021/12/NAC_CaringForCaregiver_Paper_121221.pdf*

[12] *National Alliance for Caregiving and Act on RAISE. (2023). Policy brief: How the 2024 Medicare physician fee schedule advances supports for family caregivers. Retrieved from https://www.actonraise.org/wp-content/uploads/2023/12/NAC_Physician-Fee-Rule-Briefing_120723.pdf*

[13] *Dick, M. (2024). Get claims paid for caregiver training services. AAPC. Retrieved from https://www.aapc.com/blog/90634-get-claims-paid-for-caregiver-training-services/*

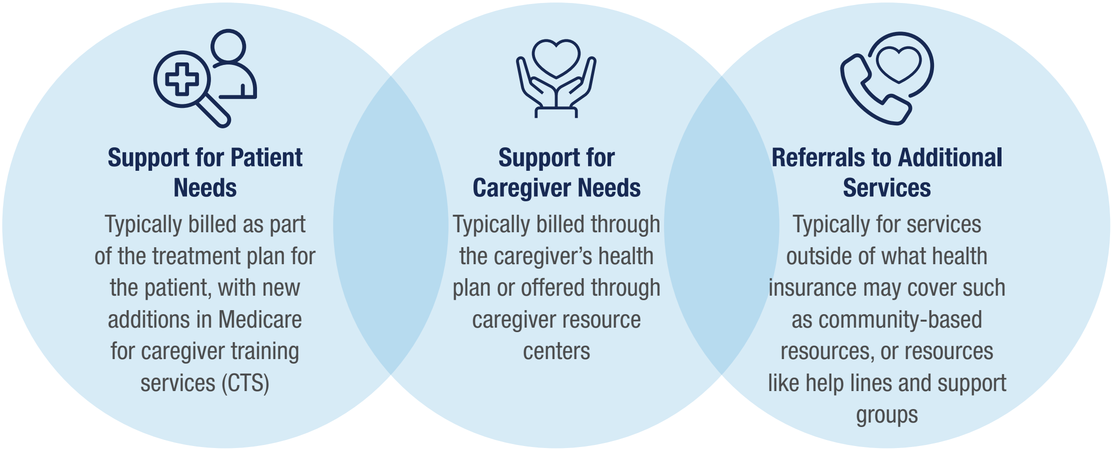
notes that physical therapists, occupational therapists, and speech-language pathologists are among the providers who can use these codes.

The 2024 reimbursement codes also pushed for a change in standard practice by requiring caregiver training done with the patient's consent but outside of the patient's presence. As AAPC notes, this approach differs from most practice models that offer caregiver and patient training at the same time. Finally, the billing codes require more extensive training than may be currently offered in existing workflows, with caregiver training of at least 30 minutes and group training of at least 60 minutes.

By formally recognizing and reimbursing caregiver training, CMS has not only validated caregivers as essential members of the care team but has also created financial incentives that encourage health systems to build robust, sustainable CTS programs.

As described in the two case studies at the end of this brief, health systems that currently provide caregiver support tend to blend support services for caregivers. Caregiver support may be available through charitable or philanthropic programs or billed directly to the caregiver's healthcare plans. Training on care activities may be billed to the patient's insurance program. Both approaches may include referrals to other specialists, community-based organizations, and resources to help with the treatment plan.

Three-Pronged Approach to Billing Medicare for Caregiver Training Services



Support for Patient Needs
Typically billed as part of the treatment plan for the patient, with new additions in Medicare for caregiver training services (CTS)

Support for Caregiver Needs
Typically billed through the caregiver's health plan or offered through caregiver resource centers

Referrals to Additional Services
Typically for services outside of what health insurance may cover such as community-based resources, or resources like help lines and support groups

> *"There could have been more attempts made through this healthcare process of folks [healthcare providers] checking in on me, and frankly seeing how I was doing, and what I needed... I wish caregiving [support] had been integrated into Tyrone's care. That those things had not been seen as separate—that Tyrone's wellness was my wellness too. That for him to be happy, healthy, and thriving his primary support system needed to be that way as well."*
>
> *Beth, Family Caregiver*

CANCER INSIGHTS

In addition, those seeking to develop CTS in oncology should consider:

- Leveraging interdisciplinary medical professionals, such as nurse navigators and social workers, who have experience and knowledge of how to work within family units to design pilot programs for CTS.
- Identifying natural "touchpoints" in care where caregiver training could be most helpful, including changes in treatment (e.g., switching to second-line therapies), increased medical intervention, or progression of disease.
- Reviewing the cancer-specific academic literature and implementation guides referenced in this brief.
- Connecting with networks such as the Cancer Caregiving Collaborative and RUSH University's C4C program, among others, to identify program mentors and additional implementation resources.

Suggestions for Operationalizing Caregiver Training Services to Strengthen Person-Centered Care Models

Key Takeaways

- Executive leadership buy-in is essential for sustainable caregiver support programs, requiring commitment from oncology departments, finance teams, and patient navigation services to allocate necessary resources and integrate caregiver support into organizational culture.
- Including family caregivers in shared decision-making requires continuous reaffirmation of patient consent, particularly in cancer care where the caregiving relationship fluctuates as the disease relapses and remits.
- Medicare requires documented verbal patient consent for caregivers to receive training services, with optional caregiver-focused health risk assessments (CPT® code 96161) to identify specific skills and knowledge gaps.
- Effective caregiver training should target common challenges in oncology settings, including performing medical tasks at home, managing nutrition, and handling changes in patient mood, behavior, and cognition.
- Documentation in the patient's medical record must identify the caregiver, patient consent, training activities performed, and timestamps—ideally designed for interoperability across healthcare systems.
- CMS has expanded CTS codes for CY 2025 to include both in-person and telehealth caregiver training services, with potential quality measures focusing on pre/post evaluations of caregiver skills and health status of both patient and caregiver.

As health systems look to formally integrate CTS into person-centered care models, a clear set of implementation guidelines can help guide the planning, piloting, and scaling of these programs.

As health systems look to formally integrate CTS into person-centered care models, a clear set of implementation guidelines can help guide the planning, piloting, and scaling of these programs. Strategies informed by evidence can provide a roadmap for operationalizing CTS in clinical practice to more effectively partner with family caregivers, enhance care quality, and improve outcomes.

The following are recommendations for health systems and practices to consider as they move forward with the implementation of family caregiver training services programs.

I. Gain Support for Caregiver Engagement from Leadership

Effective caregiver support programs require robust training, clear procedures, strong endorsement, and active participation of organizational leadership. Executive buy-in is a foundational requirement and should include leaders across care departments like oncology, finance, and operations teams, as well as patient navigators or other service groups.

Recommendations elsewhere in this brief assume that a baseline level of resources and a commitment to caregiver support are already in place at an organization considering CTS implementation. That type of support is also likely already in place at institutions discussed, such as the case studies featuring Rush University Medical Center and Northwell Health. Importantly, leadership buy-in is essential for creating a framework that broadly supports caregivers, and CTS implementation could operate as an expansion of current support. The aim is to leverage an established culture where caregiver needs and value are already recognized, ensuring a CTS program receives the necessary backing to expand and offer meaningful training.

For CTS to succeed, leadership must actively integrate caregiver support into the organizational culture. This means recognizing caregivers as vital partners in patient care.

Prioritization and Resource Allocation:

When executives champion these programs, they facilitate the allocation of necessary resources—both financial and operational—to build a robust framework for caregiver support. This underlying formation provides the structural base that allows CTS programs to develop, expand, and continuously evolve. Buy-in from finance teams, for example, help ensure CTS programs are built in a sustainable way that allows oncologists to rely on them as a pillar of care regimens when a family caregiver is available.

Cultural Integration and Ongoing Support:

For CTS to succeed, leadership must actively integrate caregiver support into the organizational culture. This means recognizing caregivers as vital partners in patient care and ensuring that the foundational support remains dynamic and responsive to caregiver needs and billing code acceptance. Ongoing leadership commitment is crucial for maintaining and enhancing CTS programs, ensuring they adapt to emerging needs and deliver useful, practical training that improves caregiver competence and patient outcomes.

Without a solid, leadership-driven foundation supporting caregivers, CTS programs cannot achieve the scale and effectiveness needed to truly enhance the quality of care. Efforts should note areas of existing success, such as the rich history of family support in oncology. It is also worth researching the potential return on investment (ROI) through new revenue from CTS codes, again leaning on oncology's history of being a complex, challenging area that involves emotional and physical changes or behavioral changes in areas like glioblastomas.

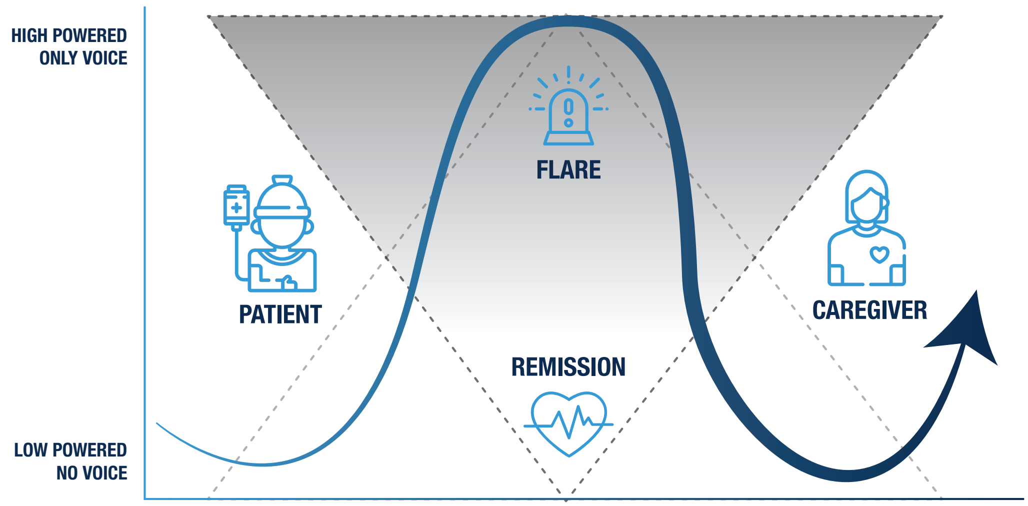
Pilot programs can help executives dip their toe in the waters of caregiving support. Consider areas with a narrow scope, such as supporting older adult Medicare beneficiaries, or something similar, based on what's most relevant to their clinical setting. Oncology clinics are often large, and the volume of patients may indicate the potential for supporting many caregivers.

II. Include Family Caregivers in Shared Decision-Making

The National Institutes of Health (NIH) describes shared decision-making (SDM) as "a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care." This is a common practice in oncology where people often must make very substantive, regular decisions about their care. It is also growing in frequency in many other care settings and situations.

The SDM process includes patient education about the disease, course of treatment options, and risks and benefits. It also encompasses the patient's values, goals, and concerns. Patient and caregiver support organizations such as Cancer*Care* have recognized that caregivers are another stakeholder in the SDM process, given their role in advocating for the cancer patient's wishes and preferred treatment.[14]

An important area of note is when a disease relapses and remits, often the case in cancer, the caregiving relationship is continually negotiated.[15] This contrasts with disease scenarios where the relationship between someone who needs care, and their caregiver may be clearer. For example, in pediatric disease, parents and legal guardians retain decision-making authority over the child even when the child is old enough to assent to treatment. In aging populations, caregivers of adults may "step into the shoes" of the person who needs care but are often restrained by the formal authority of a healthcare power of attorney or similar legal instrument.



Lappin, 2018. Remitting & Relapsing Mental Health and Chronic Condition Model, Paving the Path, n.15

Regulatory Guidance

Under the CY 2025 Medicare PFS,[16] Medicare reiterates that the beneficiary's consent is a prerequisite to delivering caregiver training services. As described in the Final Rule:[17]

- The treating practitioner must obtain the patient's (or the patient's representative's) verbal consent for a specific caregiver to receive CTS; and
- The patient's (or their representative's) verbal consent for one or more specific caregivers to receive CTS and the identified need for the CTS must be documented in the patient's medical record.

CANCER INSIGHTS

The roles in cancer caregiving are not always as clear. Ideally, the person with cancer will meet their survivorship goals and regain the independence that they may have lost during the disease or treatment. Because of this, the SDM authority granted to the caregiver to speak on behalf of a patient is constantly in flux. **Providers should continually reaffirm the patient's consent to have the caregiver involved in potential healthcare decisions or treatment.**

---

[14] *CancerCare. (2024). Shared decision making for caregivers. Retrieved from https://www.cancercare.org/publications/479-shared_decision_making_for_caregivers*

[15] *McCleary, K. K. (2019). Paving the path for family-centered design: A national report on family caregivers' roles in medical product development. National Alliance for Caregiving in Partnership with Leaders Engaged on Alzheimer's Disease. Retrieved from https://www.caregiving.org/wp-content/uploads/2020/05/NAC_LEAD-Coalition_Paving-the-Path_Report_May-2019.pdf*

[16] *Centers for Medicare & Medicaid Services. (2024). Final rule: CY 2025 payment policies under the physician fee schedule and other changes to part B payment and coverage policies (Reg. CMS-1807-F). Retrieved from https://www.cms.gov/medicare/payment/fee-schedules/physician/federal-regulation-notices/cms-1807-f*

[17] *Medicare and Medicaid Programs; CY 2025 Payment Polices Under the Physician Fee Schedule and Other Changes to Part B Payment and Coverage Policies; Medicare Shared Savings Program Requirements; Medicare Prescription Drug Inflation Rebate Program; and Medicare Overpayments, 89 F.R. 97710 (proposed December 9, 2024) (to be codified at 42 C.F.R.). Retrieved from https://www.federalregister.gov/d/2024-25382/p-1069*

> *"In cancer, caregivers service a critical patient and family support role before, during, and after treatment. Caregivers are already often key members of the cancer care team without any formal recognition of this role by our healthcare system, even though the well-being of people with cancer is often dependent on having caregiver support. Formalizing the involvement of, and support for, caregivers into the care team will both enhance the well-being and outcomes of people with cancer and also reduce undue burden and stress on caregivers."*
>
> *Alexandra Zaleta, PhD, CancerCare*

III. Assess the Caregiver's Skill and Knowledge

After receiving verbal consent from the cancer patient, the provider should assess the caregiver's knowledge of the activities of care that they will be providing. Family caregivers typically help with medical and nursing tasks such as administering injections, tube feedings, catheter and colostomy care, and other at-home nursing needs (72% of cancer caregivers vs. 56% of non-cancer caregivers).[18] Education and instruction on how to support activities of care can help alleviate tension between the patient and caregiver and ensure adherence to the treatment plan.

Regulatory Guidance

As described in the Final Rule:[19]

- When "reasonable and necessary," CMS clarified in the CY 2025 PFS that assessing the caregiver's skills and knowledge for the purposes of caregiver training services could be included in the service described by CPT® code 96161.
    - Note that caregivers are not required to have a caregiver-focused health risk assessment to participate in caregiver training services.
    - If offered, the assessment must focus on the ability of caregiver to support the patient's treatment plan and adherence and may be billed CPT® code 96161. This code was implemented in 2017 for the administration of a caregiver-focused health risk assessment instrument (e.g., depression inventory) for the benefit of the patient, with scoring and documentation, per standardized instrument.
- Verbal consent is required for caregiver assessment. The treating practitioner must obtain the patient's (or their representative's) verbal consent to receive the assessment because the caregiver-focused health risk assessment can be conducted outside of the patient's presence. This is a change from CY 2024, and aligns CPT® codes with other services, such as certain care management services, that are furnished without the patient present.

CANCER INSIGHTS

Caregiver Training Resources Examples

Caregiver Support Video Series, American Cancer Society
https://www.cancer.org/cancer/caregivers/caregiver-support-videos.html

Family Caregiving How-To Video Series, AARP, Home Alone Alliance
https://www.aarp.org/pri/initiatives/home-alone-alliance/family-caregiving-videos/

---

[18] *See Footnote 5.*

[19] *Medicare and Medicaid Programs; CY 2025 Payment Polices Under the Physician Fee Schedule and Other Changes to Part B Payment and Coverage Policies; Medicare Shared Savings Program Requirements; Medicare Prescription Drug Inflation Rebate Program; and Medicare Overpayments, 89 F.R. 97710 (proposed December 9, 2024) (to be codified at 42 C.F.R.). Retrieved from https://www.federalregister.gov/d/2024-25382/p-1007*

> *“So many of the psychological, physical, and financial challenges experienced by cancer caregivers can be addressed—and even prevented—when caregivers are identified early and integrated into the cancer care team. Too often, caregivers feel isolated and invisible, in addition to unsupported. Integrating caregivers onto healthcare teams and ideally, identifying and addressing their unmet needs, will address these issues and have a significant and positive impact on the experience of caregivers and ultimately, on the experience of the patients for whom they provide care.”*
>
> *Allison Applebaum, PhD, Icahn School of Medicine at Mount Sinai*

IV. Provide Caregiver Training to Support Patient and Caregiver Needs

Research shows that caregiver training programs can improve cancer caregivers’ efficacy, preparedness, and psychological well-being.[20] While interventions are still being developed, patient advocacy organizations and healthcare researchers have developed caregiver-focused interventions to help cancer caregivers effectively partner in care.

Providers should consider:

- Developing CTS programs that support caregivers facing common issues within oncology settings, such as
    - Conducting medical and nursing tasks at home and in the community.
    - Nutrition and meal preparation.
    - Managing financial strain and avoiding financial toxicity.
    - Managing changes in mood, behavior, mental health, and cognition.
- Identifying whether existing training programs can be modified or incorporated into CTS.

Regulatory Guidance

As described in the Final Rule:[21]

- CTS are “reasonable and necessary” when they are “integral to a patient’s overall treatment” and “furnished after the treatment plan is established.”
- Medical or direct care CTS should align with the patient’s treatment plan and help “effectuate the desired patient outcomes.”
- In general, CTS should focus on medical treatment scenarios where assistance from a caregiver is necessary and/or the patient cannot follow through with the treatment plan for themselves.
- Each training activity should be clearly identified and documented in the treatment plan.
- Caregiver training activities that are already provided through other programs, such as under the Medicare Home Health plan of care, at-home therapy, or DME services for medical equipment and supplies, are not also reimbursable as CTS codes to avoid duplicative payments.

---

[20] *Hendrix, C. C., Bailey, D. E., Jr, Steinhauser, K. E., Olsen, M. K., Stechuchak, K. M., Lowman, S. G., Schwartz, A. J., Riedel, R. F., Keefe, F. J., Porter, L. S., & Tulsky, J. A. (2016). Effects of enhanced caregiver training program on cancer caregiver’s self-efficacy, preparedness, and psychological well-being. Supportive Care in Cancer, 24(1), 327–336. https://doi.org/10.1007/s00520-015-2797-3*

[21] *Medicare and Medicaid Programs; CY 2025 Payment Polices Under the Physician Fee Schedule and Other Changes to Part B Payment and Coverage Policies; Medicare Shared Savings Program Requirements; Medicare Prescription Drug Inflation Rebate Program; and Medicare Overpayments, 89 F.R. 97710 (proposed December 9, 2024) (to be codified at 42 C.F.R.). Retrieved from https://www.federalregister.gov/documents/2024/12/09/2024-25382/medicare-and-medicaid-programs-cy-2025-payment-policies-under-the-physician-fee-schedule-and-other#p-1015*

- Physicians, nurse practitioners (NPs), clinical nurse specialists (CNSs), certified nurse midwives (CNMs), physician assistants (PAs), and clinical psychologists (CPs) can provide caregiver training services if they "personally perform" the training or if other personnel provide it as "an incident to their professional services."
- Mental and behavioral health providers—such as clinical social workers (LCSWs), marriage and family therapists, and mental health counselors—can bill Medicare for CTS that they "personally perform for the diagnosis or treatment of mental illness," assuming all other Medicare billing requirements are met. However, under existing Medicare rules, they cannot bill for services provided by auxiliary personnel.

Mental and behavioral health providers—such as clinical social workers (LCSWs), marriage and family therapists, and mental health counselors—can bill Medicare for CTS that they "personally perform for the diagnosis or treatment of mental illness."

> *"I had to basically learn how to take care of my spouse who was dying... The help you think you are going to get from hospice is really limited... You basically have to turn into a nurse, or you have to expend your own money to hire a nurse... They [hospice staff] would tell us how to turn him over in bed when he was bed bound and again that was at the very end... They taught me how to give him medication once he couldn't take it via mouth anymore... Other than that, no, they didn't give me any training."*
>
> *Whitney, Family Caregiver*

V. Document the Caregiver's Role in the Patient's Medical Record

While each health system may have different methods of recording caregiver roles and family education in the medical record, providers seeking reimbursement for CTS should document the following if seeking Medicare reimbursement:

- The patient's (or their representative's) **verbal consent** for a specific caregiver to receive CTS.
- Verification of the caregiver's consent, identification, and contact information.
- The **caregiver's role** in supporting the patient's treatment plan.
- That the appropriate medical professional "personally performed" the training.
- The **date of the training and length of time** (including timestamps).

If a provider has included a caregiver assessment and intends to seek reimbursement for the assessment under CPT® code 96161, providers may also wish to document the following to support billing claims and future research efforts:

- Confirm that a caregiver assessment was conducted to evaluate the caregiver's skills and knowledge, and the assessment found that caregiver training services are reasonable and necessary to achieve the patient's treatment plan.
- Provide a brief description of each training activity conducted, and any pre- and post-evaluation findings related to the caregiver's skill and knowledge.

CANCER INSIGHTS

Documentation Example

The American Cancer Society (ACS) toolkit, Developing Caregiver Clinical Services,[22] offers guidance on developing and implementing caregiver services into cancer care models. In their section on complying with the state CARE Act (in force in 44 states and the District of Columbia), ACS notes that there is a benefit to documenting caregiver services provided in both the patient's medical record and the caregiver's medical record.

One approach for documenting the caregiver in the patient's medical record is to note the following in the section for the History of Present Illness:

[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 record number)], being treated for [insert primary diagnosis].

Documentation may also include:

- 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's well-being
- Perceived challenges and benefits
- Needed skills, abilities, and knowledge to provide care

Electronic Health Records Improve Communication Across Settings

Data is not always fully standardized between and across electronic health record (EHR) systems. Recording the family caregiver in the medical record may be a data point that is not fully harmonized with other healthcare systems. Healthcare organizations should consider the following when implementing methods of recording caregiver information in the EHR:

- Alignment with other reporting requirements under other programs or billing codes that require a record of caregiver identification, assessment, and training, such as post-acute services like home health;
- Interoperability of data when sharing the data with other health systems, specialists, and providers;
- Accessibility of electronic data for rural and small practice providers and their patients; and
- Ability to record the patient's consent, the caregiver assessment, and designated training for compliance and future research.

Data is not always fully standardized between and across electronic health record (EHR) systems. Recording the family caregiver in the medical record may be a data point that is not fully harmonized with other healthcare systems.

---

[22] *Applebaum, A. J., & Odom, J. N. (n.d.). Developing caregiver clinical services: A toolkit for cancer centers and staff. American Cancer Society. Retrieved from https://www.cancer.org/content/dam/cancer-org/cancer-control/en/toolkits/caregiver-clinic-toolkit.pdf*

VI. Bill Medicare for CTS

In 2025, CMS expanded the list of CPT® codes to allow physicians and other qualified healthcare professionals to provide training for caregivers of patients as reasonable and necessary, determined by the practitioner and according to the volume and frequency required by the patient's care plan.

Previously approved codes included 96202 and 96203 for group CTS in behavior management/modification activities, and codes 97550, 97551, and 97552 for individual and group caregiver training services to facilitate a patient's functional performance in their home and community relating to activities of daily living (ADL).

In 2025, CMS finalized Healthcare Common Procedure Coding System (HCPCS) codes (G0541–G0543) for direct care caregiver training services and codes to add caregiver training services (CPT® codes 97550, 97551, 97552, 96202, 96203 and HCPCS codes G0541–G0543 and G0539–G0540) to the Medicare Telehealth Services list for CY 2025 on a provisional basis.

Appendix C contains the full list of Medicare billing codes describing caregiver training services as well as a flowchart format to support implementation of CTS codes into existing workflows.

With respect to supporting family caregivers with training on how to conduct activities of care, CMS recognized there is evidence that this will improve the lives of people living with cancer and other Medicare patients.

VII. Evaluate Quality and Track Quality Measures for Program Improvement

Identifying and tracking quality measures is a time-honored way to tell whether a new program works. As CMS describes, quality measures allow healthcare providers to gain insights and improve outcomes through benchmarking.[23] CMS offers two key principles to improving the quality of healthcare provided: first, that the new behavior is made systematic, and second, that the new behavior is aligned with evidence on sound practices (such as guidelines or systematic reviews).

With respect to supporting family caregivers with training on how to conduct activities of care, CMS recognized there is evidence that this will improve the lives of people living with cancer and other Medicare patients. Using these new Medicare billing codes will allow CMS and other researchers to evaluate the effectiveness of the CTS training.

Currently, there are no required quality measures for the CTS program. Some potential measures to track include:

- Pre- and post-training evaluation of caregiver skills and training.
- Pre- and post-training health status of the patient.
- Pre- and post-training health status of the caregiver.

---

[23] *Centers for Medicare & Medicaid Services. (n.d.). Quality measurement and quality improvement. Retrieved from https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Quality-Measure-and-Quality-Improvement-*

Knowledge Gaps and Advocacy Opportunities

As Medicare CTS codes continue to evolve, health systems can look to existing health plan initiatives that already recognize the value of caregiver support beyond direct reimbursement structures. These emerging partnerships between providers, plans, and regulators highlight both opportunities and challenges in implementing sustainable caregiver support programs.

Key Takeaways

- Some healthcare organizations managing population risk already offer caregiver training and support without requiring direct reimbursement, with major insurers like Elevance Health and UnitedHealthcare providing caregiver tools as an added value for members.
- Provider associations have developed implementation tools for family caregiver support aligned with the 2022 National Strategy to Support Family Caregivers, suggesting a unified approach to whole-person model of care support offers benefits beyond baseline reimbursement.
- The Office of Inspector General has indicated that while unpaid services to caregivers may potentially implicate federal fraud and abuse laws, the risk is generally low—though clear documentation remains essential as the Medicare CTS codes are newly implemented.
- Caregiver and patient advocate organizations can shape CTS implementation by advocating for expanded billing options that include services delivered by trained auxiliary personnel and ensuring caregiver training enhances—rather than replaces—existing Medicare home health benefits.
- Current Medicare reimbursement rates for CTS may be too low to incentivize widespread adoption, requiring health systems to consider how to meet the 30-minute threshold requirement while balancing provider time constraints.

For some healthcare organizations, particularly those managing population risk, the use case for offering caregiver training and support may exist without the need for reimbursement.

Health Plans Offer Insights to Caregiver Support and Training Programs

As health systems begin to implement CTS, knowledge gaps have emerged with respect to how these payment systems will work within existing Medicare and long-term services and supports frameworks. For some healthcare organizations, particularly those managing population risk, the use case for offering caregiver training and support may exist without the need for reimbursement. Companies such as Elevance Health (formerly known as Anthem)[24] and UnitedHealthcare[25] provide caregiver tools to offer more value to their members.

---

[24] *Anthem. (n.d.). Caregiver guide. Retrieved from https://www.anthem.com/caregiver*

Provider associations, such as the Long-Term Quality Alliance (LTQA) and the National MLTSS Health Plan Association (MLTSS Association) have even developed tools to support the implementation of family caregiver supports for managed care plans, in line with the 2022 National Strategy to Support Family Caregivers.[26] This interest indicates that supporting caregivers offers value to health systems outside of baseline reimbursement, and that a unified, holistic strategy toward whole-family support may offer the best approach to supporting caregivers.

Regulators Are Still Evaluating Caregiver Support Services

The Office of Inspector General (OIG), the government oversight office for the US Department of Health and Human Services (HHS), ensures that programs managed under HHS do not violate fraud and abuse protections. This includes an evaluation of whether an offered program would violate the federal anti-kickback statute and whether a program's services may be offering prohibited renumeration under the Beneficiary Inducements Civil Monetary Penalties provisions.[27] Recent advisory opinions from the OIG have indicated that although unpaid services offered to caregivers may implicate these federal fraud and abuse laws, if intent were present, the risk of fraud and abuse for offering caregiver supports is low.[28] Given that Medicare's CTS codes have only recently been implemented, providers may want to evaluate how proposed programs comply with existing fraud and abuse protections under the Medicare program.

Notably, the OIG opinions to date are in reference to unpaid services being offered to a beneficiary's caregivers, whereas the Medicare CTS codes will offer reimbursable services to the beneficiary's caregiver. Some providers may also treat the caregiver as a patient within the same system, offering support and the ability to receive reimbursement through billing codes related to care management, care coordination, or psychosocial supports. Clear documentation of any caregiver interventions, the rationale and need for support services, and the outcome of such interventions may be helpful in articulating that a program complies with all necessary laws and regulations.

As regulators continue to refine guidance for CTS and other caregiver services, advocates through the Act on RAISE Coalition have requested additional clarifications in the program. In public comments to CMS on the CY 2025 Medicare Physician Fee Schedule, Act on RAISE recommended:

- Change the CTS benefit and the proposed direct CTS benefit to allow a qualified healthcare provider to bill for all caregiver training services when rendered by trained auxiliary personnel as an incident to benefit, under general supervision;
- Provide clarification on CTS standards, or reference existing leading caregiver training programs, to ensure high-quality training;
- Clarify and confirm that CTS will not serve as a substitute for Medicare-covered home health aide benefits under the law, but rather as additional Medicare benefits to increase a willing and able caregiver's knowledge; and
- Ensure payment rates for CTS are adequate to incentivize implementation among providers and consider implications of co-pay requirements on widespread adoption.

In their current iteration, reimbursement rates for CTS under the Medicare program may be too low to allow for extensive implementation.

Reimbursement Rates May Need Adjustment

In their current iteration, reimbursement rates for CTS under the Medicare program may be too low to allow for extensive implementation. Health systems will also need to consider how a training program for caregivers can meet the required 30-minute threshold and still allow overtaxed providers to serve and care for other high-need patients and procedures. For some, implementing CTS into workflows that already contain caregiver education and training may be an elegant solution. Others may also want to identify whether interdisciplinary professionals, such as medical social workers or registered nurses, may be able to partner with providers to offer CTS, and bill "incident to."

---

[25] *UnitedHealthcare. (n.d.). Resources for caregivers. Retrieved from https://www.uhc.com/health-and-wellness/caregiver-resources*

[26] *Support Caregiving, Long-Term Quality Assurance (LTQA), National MLTSS Health Plan Association, National Academy for State Health Policy (NASHP), and the John A. Hartford Foundation. (2023). Family caregiver strategy action guide for MLTSS plans. Retrieved from https://supportcaregiving.org/managed-care-plans/*

[27] *See §§ 1128(A)-(B) of the Social Security Act (provisions relating to the Federal anti-kickback statute and the civil monetary penalty provisions). https://www.ssa.gov/OP_Home/ssact/title11/1128.htm*

[28] *See, e.g., OIG Advisory Opinion No. 24-13 (Favorable) (Dec. 26, 2024), https://oig.hhs.gov/documents/advisory-opinions/10148/AO-24-13.pdf (finding that a pharma company may offer travel support to caregivers of patients in a clinical trial), and OIG Advisory Opinion No.24-05 (Favorable in Part and Unfavorable in Part) (July 17 2024), https://oig.hhs.gov/documents/advisory-opinions/9936/AO-24-05.pdf (finding that travel support to caregivers would be permissible).*

Conclusion

> *“Integrating caregivers into the cancer care team would be beneficial because they are at the center of the patient’s daily care. As such, the caregiver’s perspective is critical to ensure that the patient’s overall needs are accounted for and that the family’s ecosystem (e.g., relational, financial, psychological, etc.) is a healthy one. A healthy family ecosystem increases care outcomes.”*
>
> *Abena, Family Caregiver*

Changes in the Medicare Physician Fee Schedule have the potential to dramatically shift caregiver integration and inclusion in settings like cancer care by supporting and reimbursing CTS. This is a long-awaited shift that publicly recognizes caregivers as essential members of the care team and encourages providers to do the same.

From the CY 2024 launch of individual and group CTS codes to the CY 2025 expansion for telehealth and interdisciplinary “incident-to” billing, these innovative payment pathways empower health systems to build sustainable, person-centered models that honor both patient and caregiver needs.

The Northwell and RUSH case studies illustrate how flexible reimbursement strategies—whether embedding CTS within existing speech-therapy workflows, leveraging philanthropic support, or billing through caregiver health plans—can catalyze scalable training programs and advance patient-friendly, equity-driven cancer care. As organizations explore blended funding approaches, quality measures and ROI analyses will offer concrete evidence of CTS’s impact on treatment adherence, acute-care utilization, and caregiver well-being.

Continued policy evolution, interdisciplinary collaboration, and EHR integration promise to deepen caregiver engagement across oncology settings. The Collaborative is excited to see how these pioneering reimbursement models will fuel innovation in cancer care, turning today’s pilot programs into tomorrow’s best practices and strengthening the landscape of person-centered healthcare for patients and those who support them.

The Cancer Caregiving Collaborative is excited to see how these pioneering reimbursement models will fuel innovation in cancer care... strengthening the landscape of person-centered healthcare for patients and those who support them.