

Family Caregivers and Medicare Payment Models, including GUIDE

Speakers:

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- Tonya L Saffer, MPH, Director, Division of Healthcare Payment Models, Patient Care Models Group, Center for Medicare & Medicaid Innovation
- Laura Makaroff, DO, Senior Vice President of Prevention and Early Detection, American Cancer Society
- Steven Lee, Co-founder and CEO, Ianacare



Guiding an Improved Dementia Experience (GUIDE)

Presentation for CTAC October 2024

Overview | CMS Innovation Center Statute

“The purpose of the [Center] is to test innovative payment and service delivery models to reduce program expenditures...while preserving or enhancing the quality of care furnished to individuals under such titles”



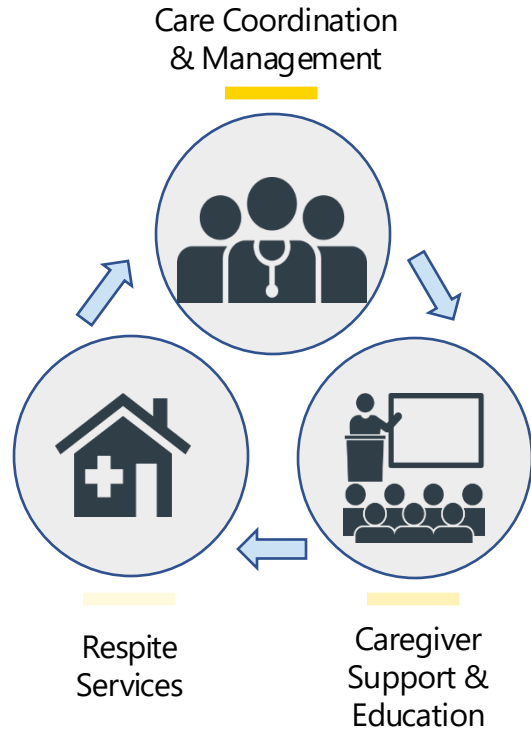
Three scenarios for success:

1. Quality improves; cost neutral
2. Quality neutral; cost reduced
3. Quality improves; cost reduced (best case)

A model that meets one of these three criteria (and other statutory prerequisites), can be expanded in duration and scope through rulemaking

Model Purpose and Overview

The GUIDE Model will test whether a comprehensive package of care coordination and management, caregiver support and education, and respite services can **improve quality of life for people with dementia and their caregivers** while **delaying avoidable long-term nursing home care** and **enabling more people to remain at home** through end of life.



Care Coordination & Management

Beneficiaries will receive care from an **interdisciplinary team** that will develop and implement a comprehensive, person-centered care plan for **managing the beneficiary's dementia and co-occurring conditions** and provide **ongoing monitoring and support**.

Caregiver Support & Education

GUIDE participants will provide a **caregiver support program**, which must include caregiver skills training, dementia diagnosis education, support groups, and access to a personal care navigator who can help problem solve and connect the caregiver to services and supports.

Respite Services

A subset of beneficiaries in the model will be eligible to receive payment for respite services with no cost sharing, up to a cap of **\$2,500 per year**. These services may be provided to beneficiaries in a variety of settings, including **their personal home, an adult day center, and facilities that can provide 24-hour care** to give the caregiver a break from caring for the beneficiary.

Snapshot of Medicare Beneficiaries with Dementia



10-20%

of Medicare beneficiaries over-65 have some form of dementia; 60-80% of cases are Alzheimer's



57-76%

of beneficiaries with dementia (BWD) have **incomes below 200% of the federal poverty line**



25%

of BWD are **dually eligible** for Medicaid (compared to 16% of all Medicare beneficiaries)



65%

of BWD **live in the community** (compared to 98% of beneficiaries without dementia); 24% reside in a nursing home (compared with 1% of beneficiaries without dementia)



92%

of BWD have a family member or friend acting as a **caregiver**; only 25.5% received **paid care**



95%

of BWD have 1 or more **chronic conditions**

Key Health Disparities in the Dementia Space



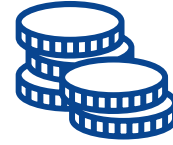
Gender

2/3 of Americans who live with Alzheimer's disease and of those who provide care for individuals with Alzheimer's disease are **women**



Race/Ethnicity

Compared to white individuals, **Black & Hispanic** individuals are **2x more likely to be underdiagnosed**, and **American Indian & Alaska Native** individuals have **2x the rate of dementia diagnosis**



Income/Neighborhood

Individuals with **high area-level deprivation** and individuals with **high individual-level deprivation** were more than **3x more likely to be diagnosed with dementia** than their low-deprivation counterparts



Geographic Region

Dementia accounts for up to **30% of the difference in non-metro area reduced life expectancy** (compared to metro area), and **rural areas** are more likely to have **underdiagnosis and delayed diagnoses**

Scope and Duration

The GUIDE Model is an 8-year voluntary model offered in all states, D.C., and U.S. territories. The Model Performance Period will begin on July 1, 2024, and end on June 30, 2032.



Established Program Track and New Program* Track

The purpose of the two tracks is to allow established programs to begin their performance in the model on July 1, 2024, while giving organizations that do not currently offer a comprehensive community-based dementia care program, including safety net organizations, time and support to develop their program.

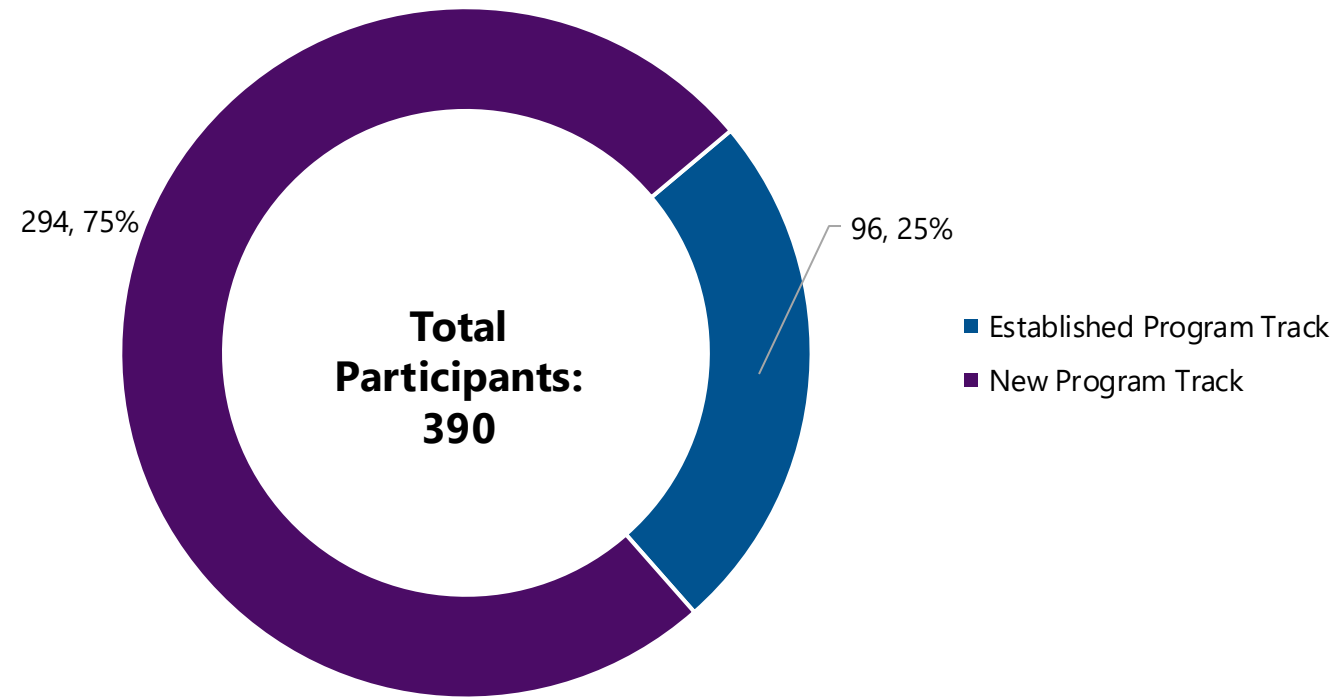
Model Timeline

	Nov. 15 2023 - Jan. 30 2024	July 2024- June 2025	July '25- June '26	July '26- June '27	July '27- June '28	July '28- June '29	July '29- June '30	July '30- June '31	July '31- June '32
Established Program Track	Application Period	Performance Year (PY) 1	PY 2	PY 3	PY 4	PY 5	PY 6	PY 7	PY 8
New Program Track	Application Period	Pre-Implementation (PI) Period	PY 1	PY 2	PY 3	PY 4	PY 5	PY 6	PY 7

*New program development is intended to help increase beneficiary access to specialty dementia care, particularly in underserved communities.

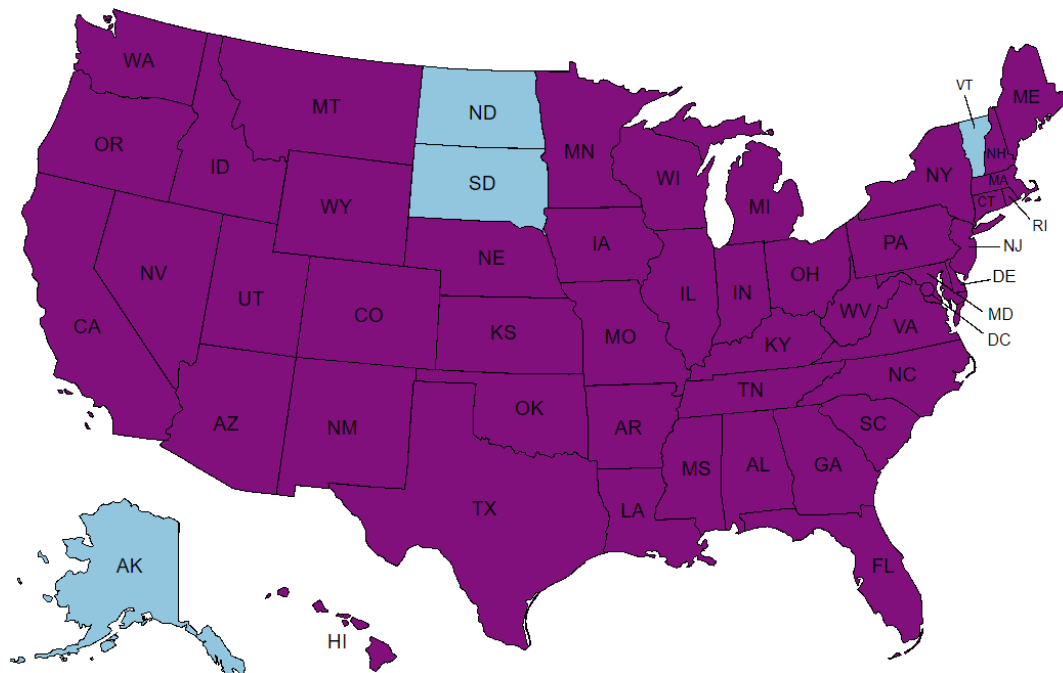
GUIDE Participants by Track

- 96 established program track participants who began their first Performance Year on July 1, 2024
- 294 new program track participants who will begin their first Performance Year on July 1, 2025



GUIDE Participants will Serve Beneficiaries in All 50 States

Geographic Distribution of GUIDE Participants

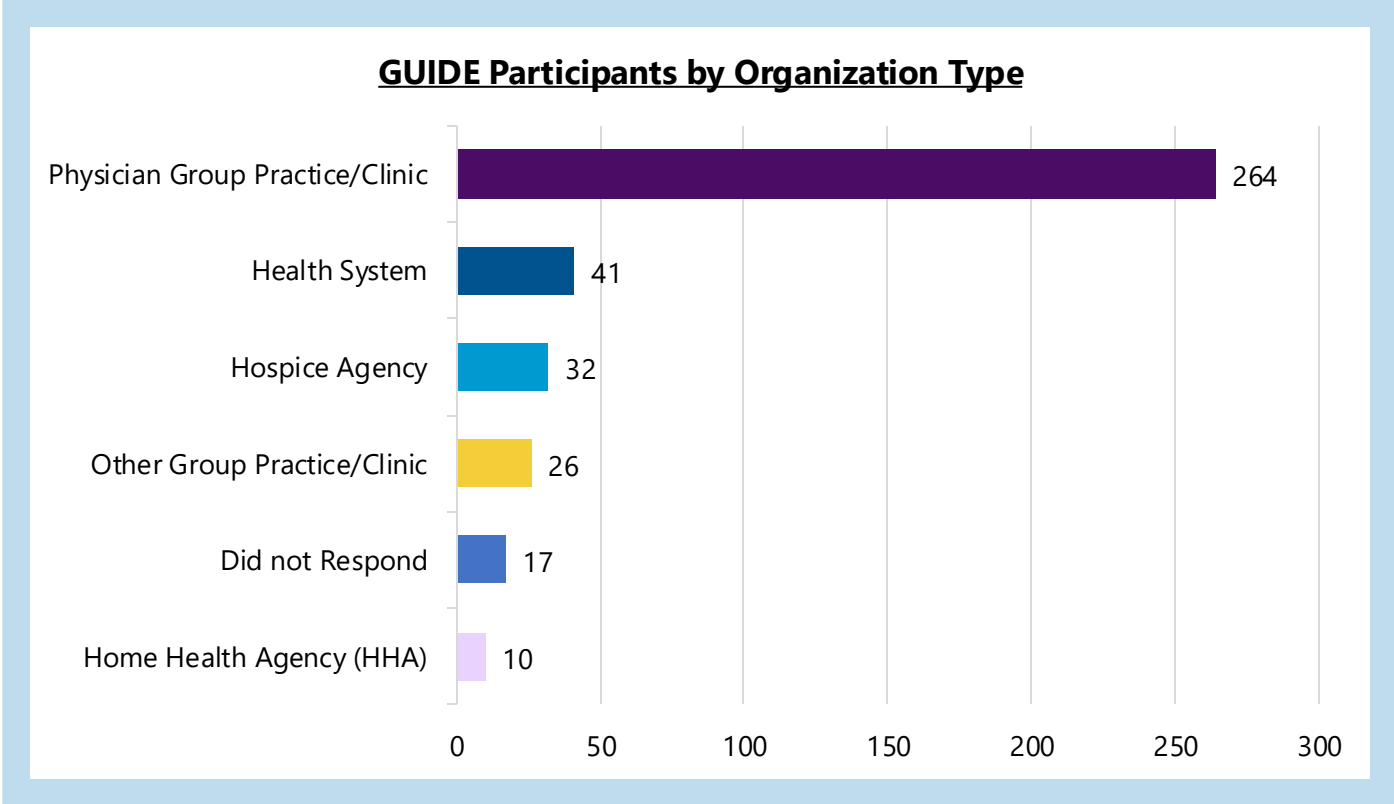


- GUIDE Participant site located within state
- GUIDE Participant site not located within state

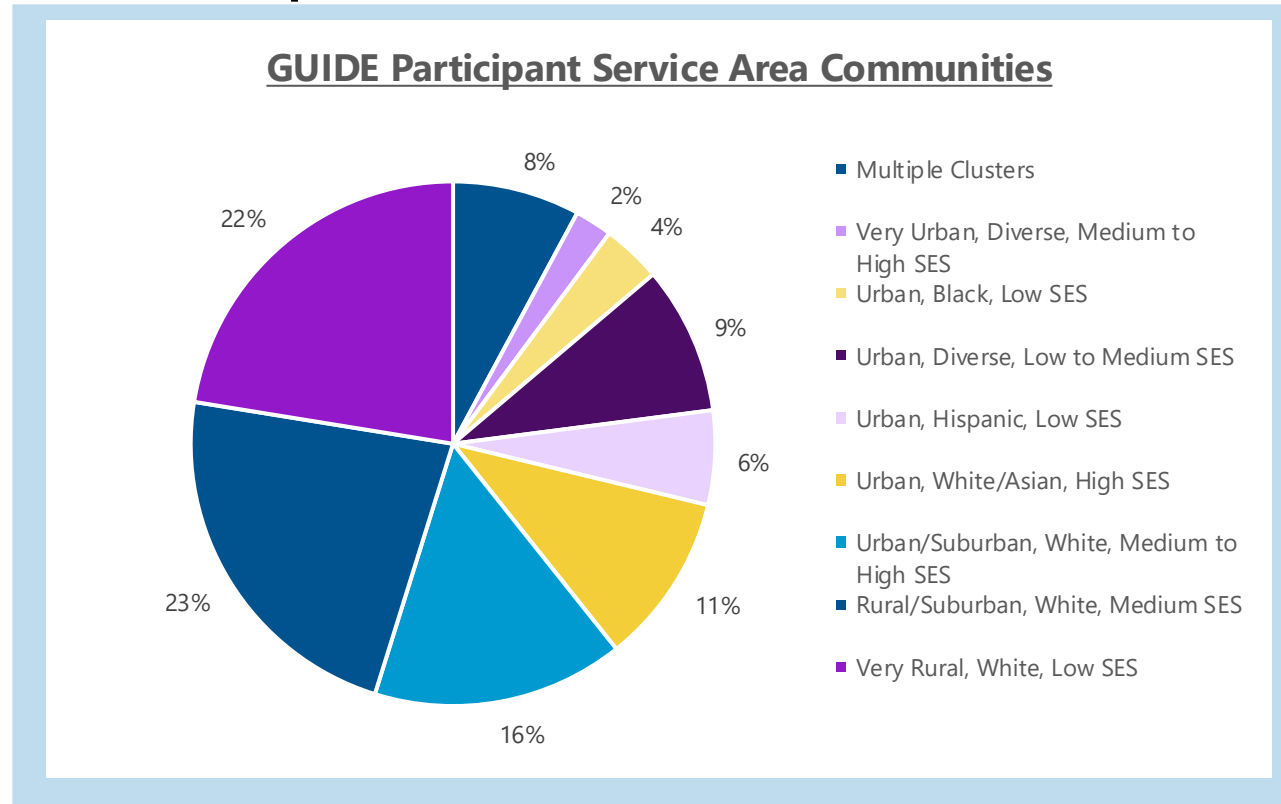
Key Insights & Considerations

- GUIDE Participants reported to CMS their service areas by zip code. GUIDE Participants' service areas reach all 50 states, plus Washington, D.C.
- 30,000+ zip codes served.
- The highest number of GUIDE Participants come from California, Florida and Texas.

GUIDE Participants: Organization Types



GUIDE Participants: Populations Served



Key Insights & Considerations

- 32% of service areas (by zip code) represent rural and urban low socio-economic status (SES) communities.
- GUIDE Participants can modify their service area reach over the life of the model, potentially expanding to more rural and remote areas.

CMS Participant Support

Technical Assistance

- Helps GUIDE Participants fulfill their responsibilities **to CMS**
- Active assistance: Webinars, Office Hours, Helpdesk
- Reference Materials: User manuals, policy methodology papers, fact sheets, tip sheets, checklists and FAQs

Learning Systems

- Helps GUIDE Participants fulfill their responsibilities to **Medicare beneficiaries and their caregivers**
- Peer to Peer: Connect site*, peer-led webinars and case study sharing
- Expert led: Care Delivery Webinars, Toolkits

*CMS provides a single platform for participants to access both technical assistance materials and expert created learning systems content through the Connect site.

Model Resources Publicly Available

The GUIDE Model team has a host of resources to support interested organizations. To see the latest resources, visit the [Model's website](https://innovation.cms.gov/innovation-models/guide) at <https://innovation.cms.gov/innovation-models/guide>.



Frequently Asked Questions

Please reference the [list of FAQs](#) on the Model's website for answers to common questions.



Model Factsheets

[Model Overview Factsheet](#), [Dementia Pathways Infographic](#), [Strength in Partnerships Factsheet](#), and [Participant Incentives Factsheet](#) may be found on the Model's website.



Find Participants

Visit the Model's web site to identify participating dementia care programs



Model Overview Factsheet



Dementia Pathways Infographic



Engaging family caregivers to improve care



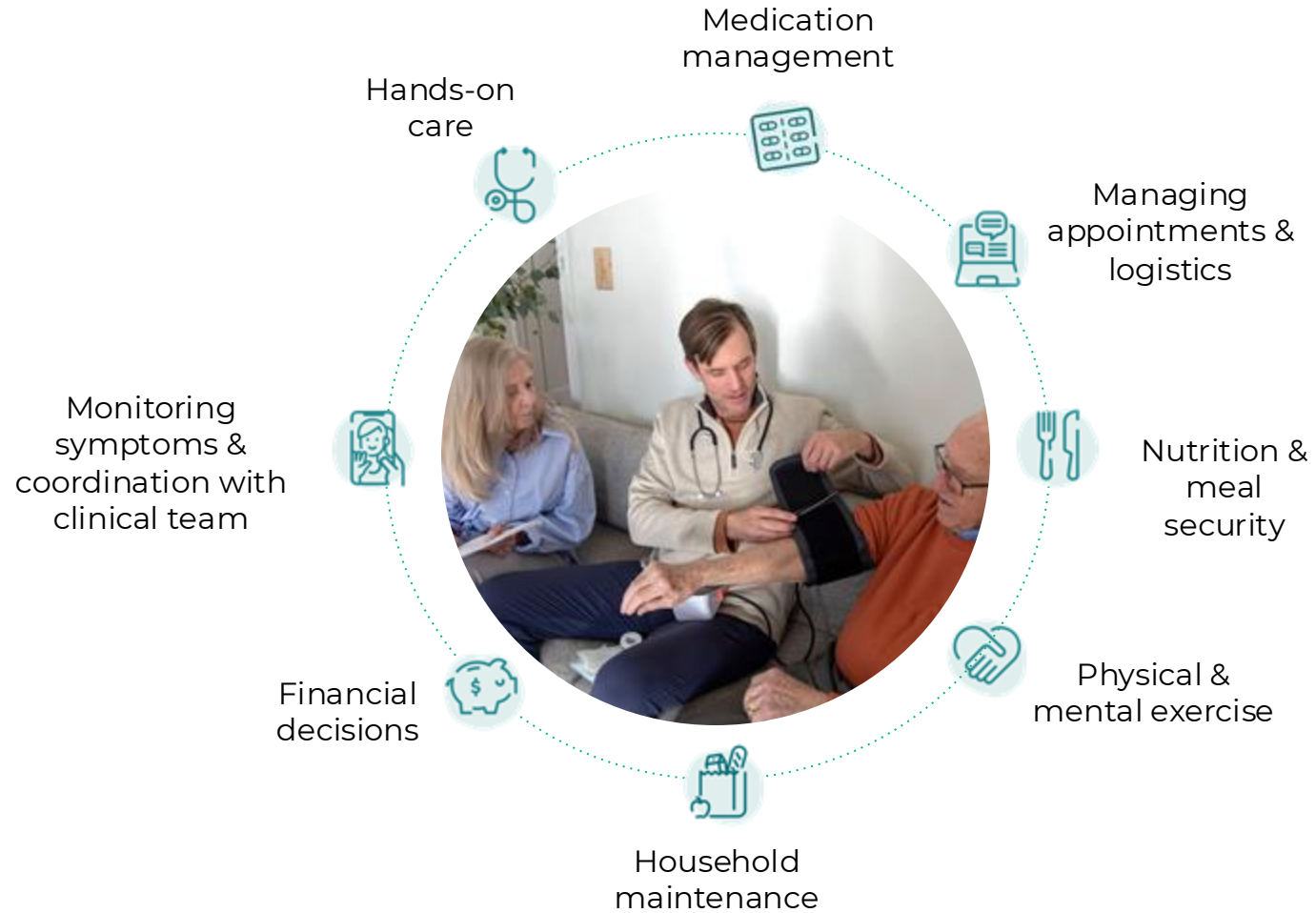
GUIDE Model

The GUIDE Model is designed to enhance quality of care by improving quality of life for people with dementia and *reducing burden and strain on their caregivers.*

CMS, 2023

OUR THESIS

Family Caregivers are at the Center of Care



WHAT WE DO

Engaging Family Caregivers to Deliver Better Outcomes

47k members served

21
avg touchpoints

our platform has coordinated:

- 15,000 rides
- 30,000 meals
- 50,000 medication reminders
- 11,000 appointments
- 48,000 posts
- 295,000 hugs

ianacare is the go-to source of information & support for caregivers

Just knowing there is **a place to ask questions as they come up is reassuring.**

Situations constantly change and I appreciate that I have a place to call that will support me during this difficult time.

Our Navigator provides additional physical, emotional, mental support to my daughter and myself, which is **very helpful and stress-reducing**

in and of itself.

I have **recommended it to several others**

who have expressed they are struggling with caregiving.



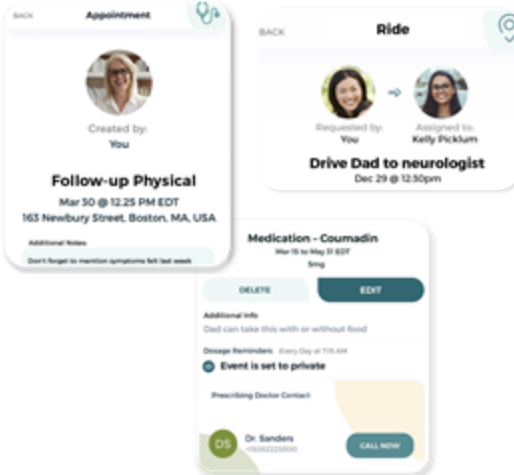
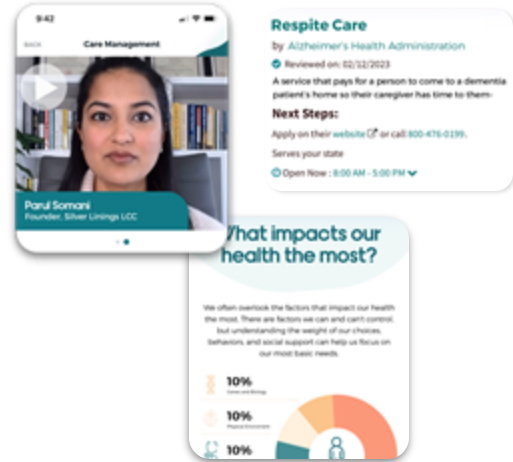
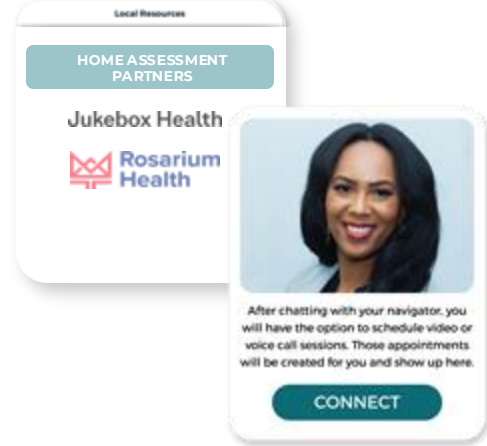
My navigator was the best.
She was like family

We just started with the service.... However, I am already happy with the research the team is doing, **legwork that I would normally have to do myself.**

My loved one is remote and has little need for assistance at this time but ianacare is **equipping me with useful information, so I am prepared** when they do need more from me as a caregiver.

It's helpful to know there are others going through the same thing. It also is nice to have **one place for care information or help** between multiple caregivers.

The front-door to unlocking support aligned with GUIDE requirements

 <p>GUIDE REQUIREMENT</p>	<p><u>PROJECT MANAGEMENT TOOLS</u></p> <ul style="list-style-type: none">Community Care CoordinationMedication Management	<p><u>SELF-SERVICE RESOURCES</u></p> <ul style="list-style-type: none">Caregiver Education & SupportCoordination of Support & ServicesRespite	<p><u>NAVIGATORS</u></p> <ul style="list-style-type: none">Comprehensive AssessmentOngoing Monitoring & SupportCare Plan & Coordination24/7 Access <p>+ Navigator-guided Education, Resources, Respite</p>
			

Addressing Caregiver Challenges



Social Determinants of Health



Training & Education



Appointment Completion



Caregiver Burnout/Fatigue





OUR DATA

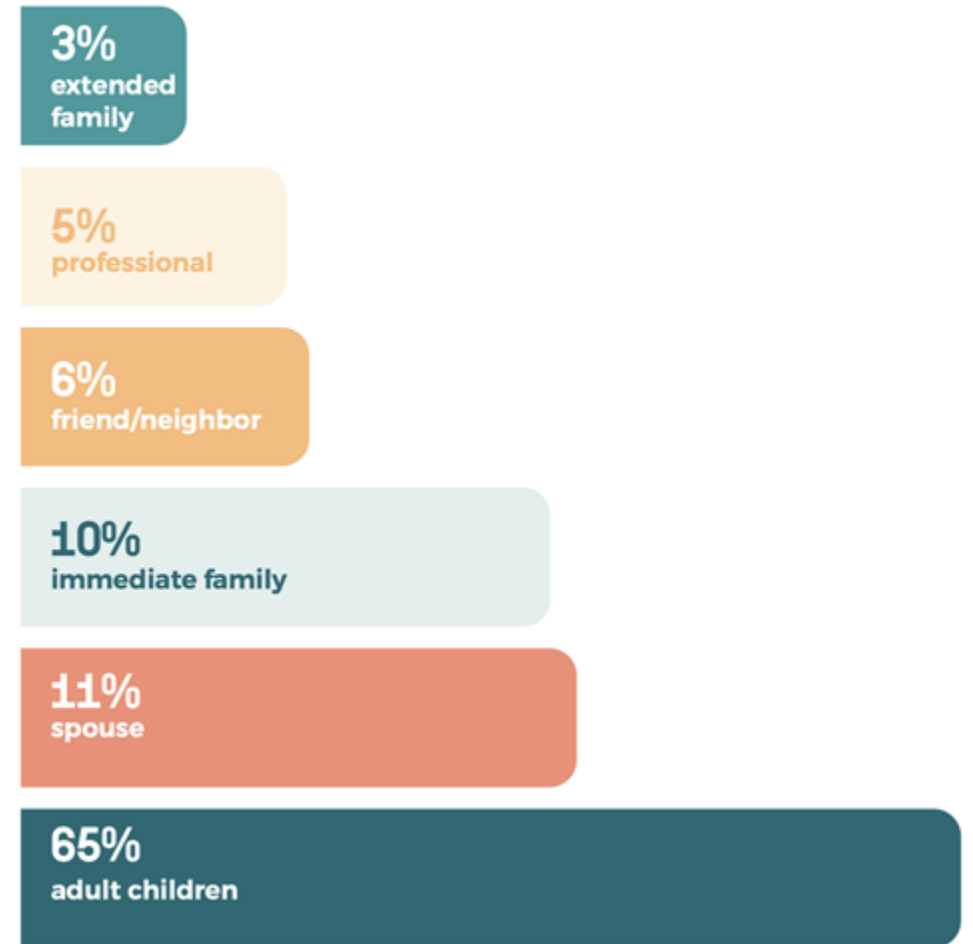
Appointments

Appointments

69% of appointments facilitated by ianacare were **non-urgent clinician visits**

These are most commonly missed vs. procedures, treatments, and more urgent appointments.

Caregiver Handling Appointment Logistics

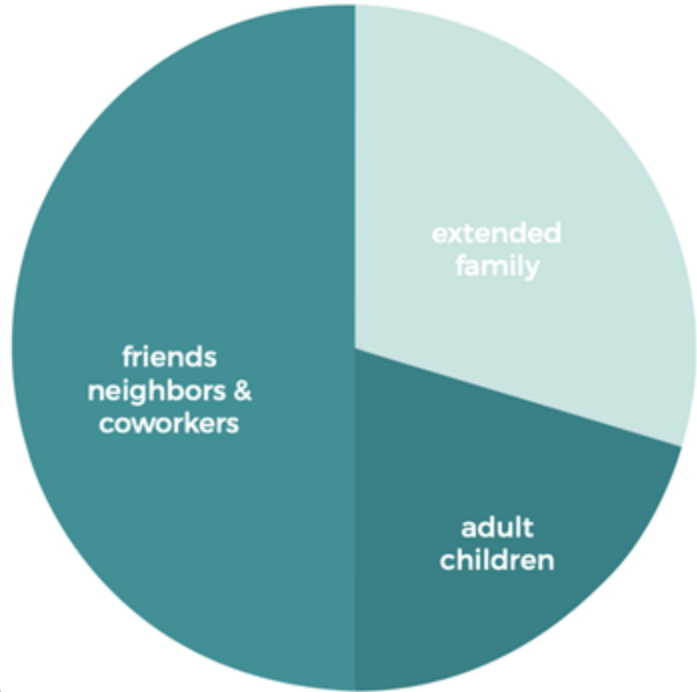


OUR DATA

Respite



Who offered respite



- 50% friends, neighbors, & coworkers
- 28% extended family
- 22% adult children



of respite offers came from **non-familial supporters**, showing the importance of community & informal care

Kinds of respite offered



82%
visitations &
check-ins



15%
meals with care
recipient



2%
other

Patients whose caregivers are burnt out or fatigued experience:

73%

increase in ER utilization ⁴

\$1,937

increased spend on medical costs ⁴

Respite services resulted in:

88%

delay in moving care out of
the home ⁵

98%

of individuals feeling like
better caregivers ⁵

Real examples of offers on the ianacare platform:



- *“Visit with Fred - allow Kelly to grocery shop/run errands”*
- *“Break for Stephanie to attend church”*
- *“Go out with Mary for lunch and a fun activity”*



OUR DATA

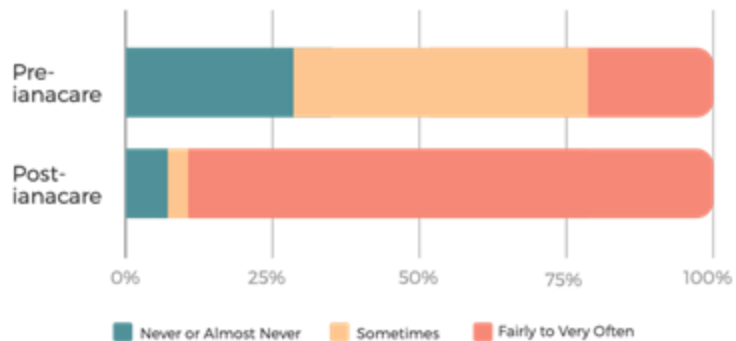
Navigator Use

Navigator Use



over 90% of members **highly recommend** their Care Navigation Experience

Are you able to access and maximize the benefits available to you and your loved one?



Support Caregivers Receive From Navigators

CARE MANAGEMENT & PLANNING

- Hands-on care planning
- Decisions and tasks like home mods.
- Facility searches
- Clinical advocacy

MENTAL/EMOTIONAL COPING

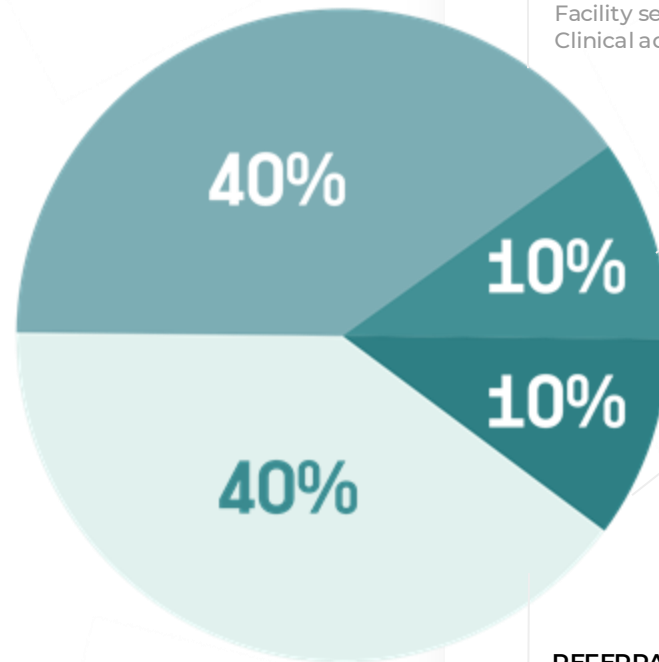
- Managing family dynamics
- Support for burnout & depression
- Practical advice

FINANCE & LEGAL

- Advanced care planning
- Preparing documents
- Budgeting
- Understanding insurance

REFERRALS TO COMMUNITY RESOURCES

- Access to a proprietary database
- Vetted local resources
- Take on legwork to find right resource





OUR DATA

Training & Education

Training and Education

Most popular topics in 2023:

- Sandwich Generation Caregiving
- Redefining Self-Care for Caregivers
- Alzheimer's/Dementia Caregivers
- Eldercare
- Understanding Medicare

5,708 Total Registrations

In 2023, ianacare conducted **9,120 hours** of training

On-Demand Recordings

Expert Content

Live Trainings



What Impacts our Health Most?

We often overlook the factors that impact our health the most. There are factors we can and can't control, but understanding the weight of our choices, behaviors, and social support can help us focus on our most basic needs.

10% Care and Support

10% Physical Environment

Finance/Legal

MONICA BRYANT
Cancer Rights Attorney

Work/Life/Home Balance FAQ

"I like I'm working two jobs between my actual job"

Physical Health

BRIAN SMITH
Caregiver to Wife

Checklist: Getting Organized

- **Personal & Family Records**
 - Social Security card, driver's license or state ID, passport, & military discharge papers (DD-214)
 - Birth certificates for yourself, spouse, and children
 - Marriage license and/or proof of divorce, if applicable
 - Contact information for your current employer and/or supervisor

Work/Life Balance

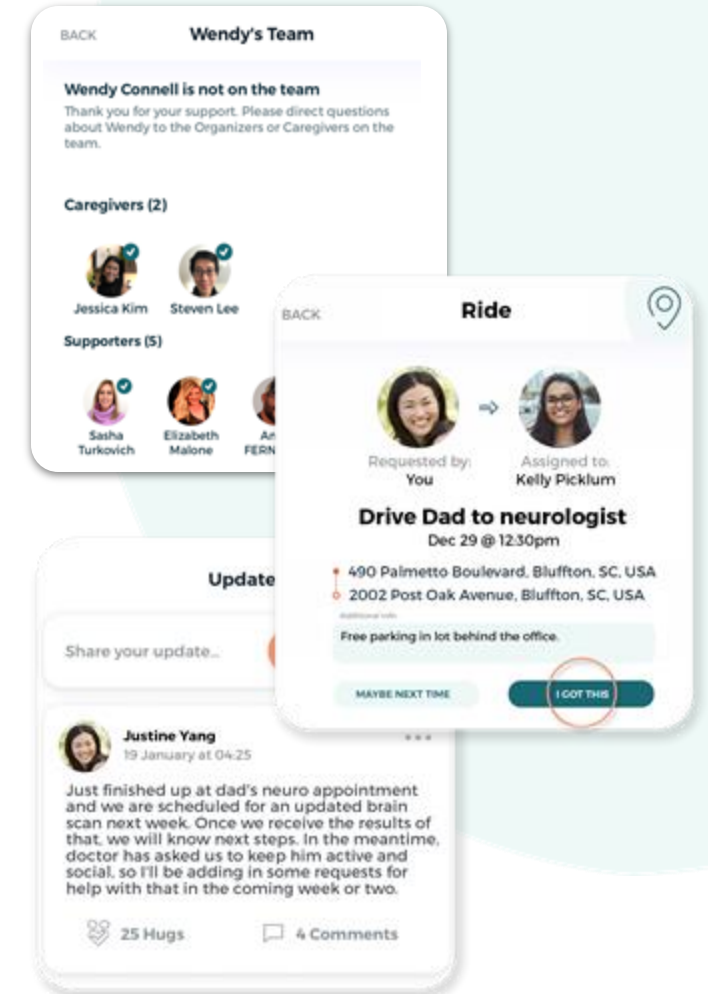
LIZ O'DONNELL
Founder, Working Daughter



GUIDE Performance-Based Adjustments are Tied to Engaging Family Caregivers

Domain	Domain Weight	Measure Name	Percent of total domain	Percent of total PBA	Associated PBA Potential
Care coordination and management	10%	Use of High-Risk Medications in Older Adults	100%	10%	-0.5% – +1%
Beneficiary quality of life	30%	Quality of Life Outcome for People with Neurological Conditions	100%	30%	-1% – +3%
Caregiver support	30%	New: Caregiver Burden Measure	100%	30%	-1% – +3%
Utilization	30%	Total Per Capita Cost	50%	15%	-0.5% – +1.5%
		Rate of beneficiaries entering a long-term nursing home	50%	15%	-0.5% – +1.5%
Total PBA Potential					-3.5% to +10%

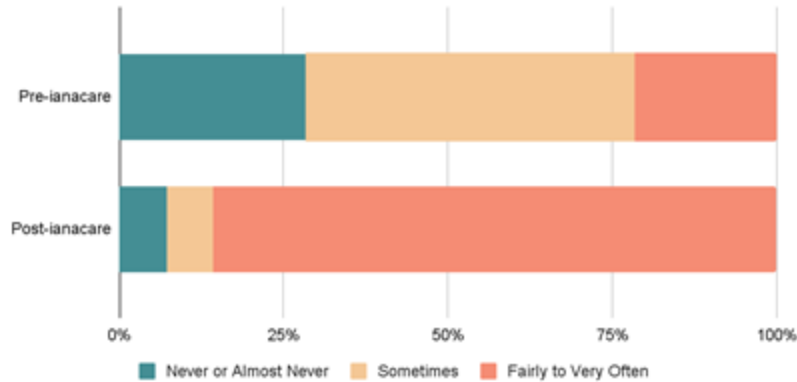
CMS, 2023



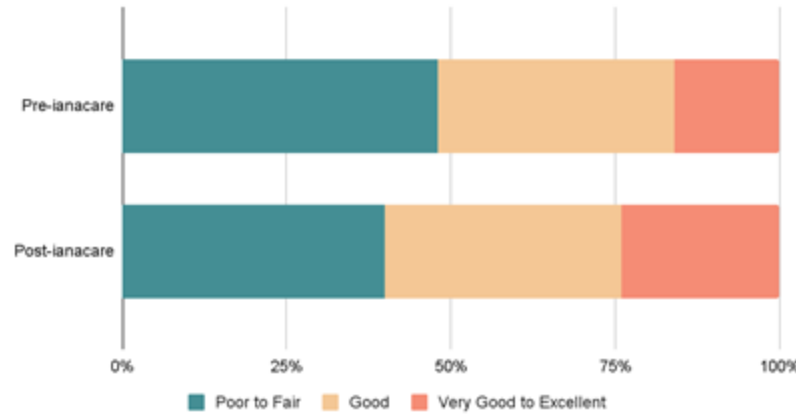
IMPACT

ianacare connect patients to the right benefits at the right time & drives improvement in care recipient health

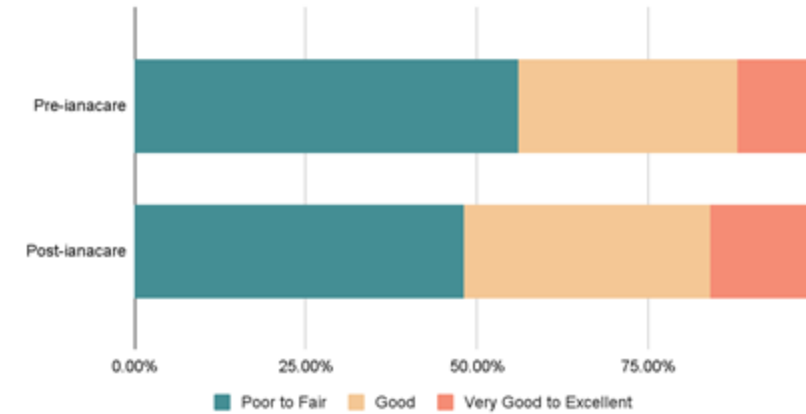
Are you able to access and maximize the benefits available to you and your loved one?



How would you rate your loved one's overall health?



How would you rate your loved one's mental/emotional health?



↑ benefit navigation



↑ care recipient overall health



↑ care recipient mental health

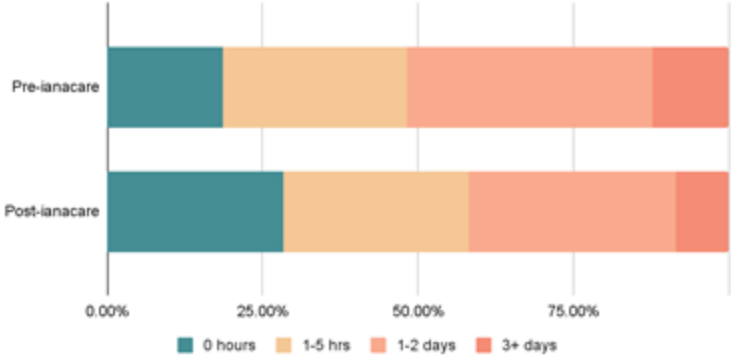


↑ Beneficiary quality of life

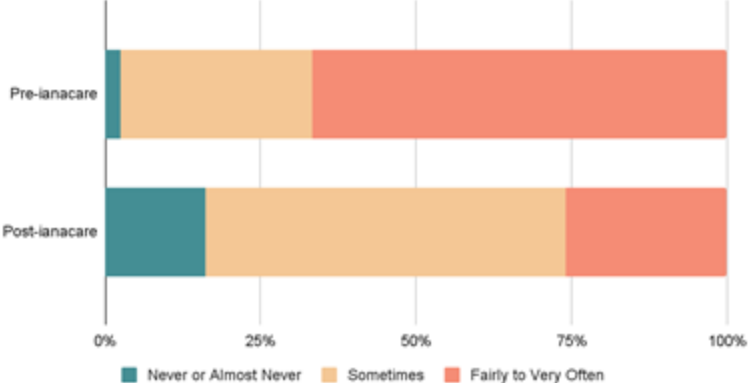
IMPACT

ianacare decreases time off, stress, and positively impacts caregivers' own health

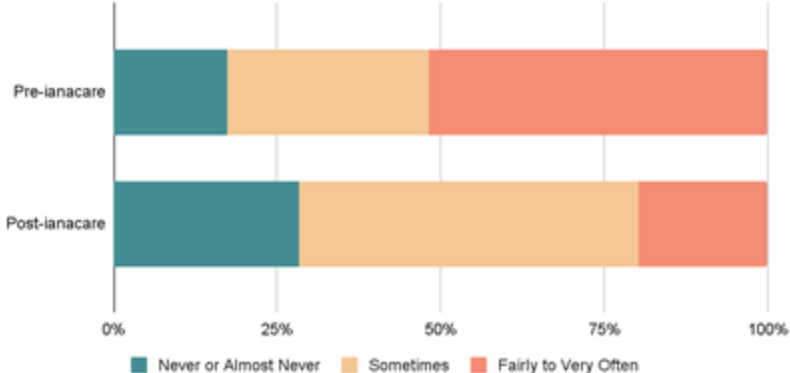
How many hours in a given month do you take off work due to caregiving related tasks?



How often do you feel overwhelmed by your caregiving tasks?



How often have you felt like your role as a caregiver negatively impacted your own health?



↑ caregiver productivity



↓ caregiver feeling overwhelmed



↑ caregiver overall health



↓ Caregiver burden

ianacare

partnerships@ianacare.com

Cancer Caregiver Support



Laura Makaroff, DO
Sr. Vice President, Prevention & Survivorship
laura.makaroff@cancer.org

October 21, 2024

The American Cancer Society exists because the burden of cancer is unacceptably high.



Our Vision:

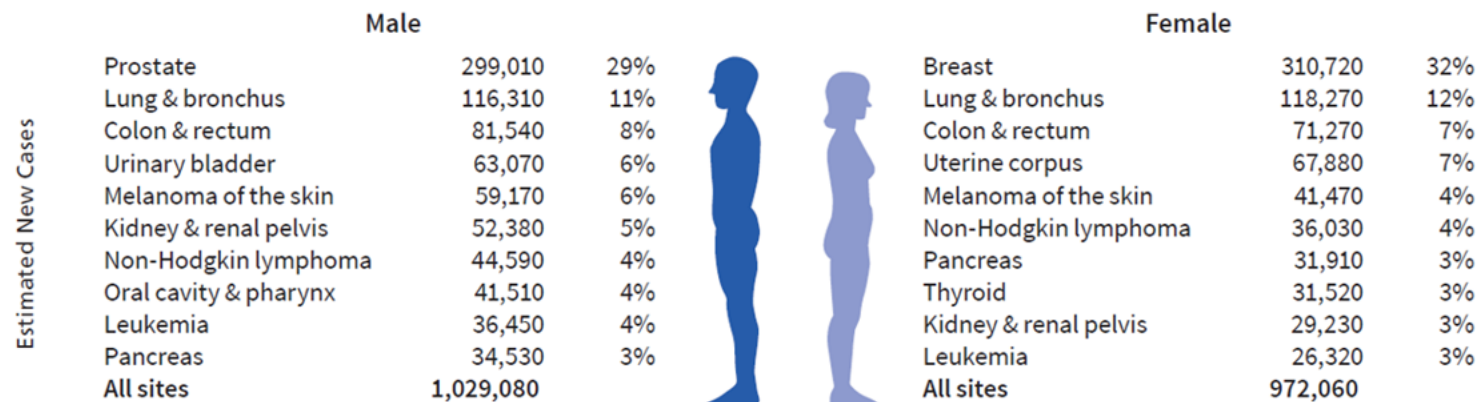
End cancer as we know it, for everyone.

Our Mission:

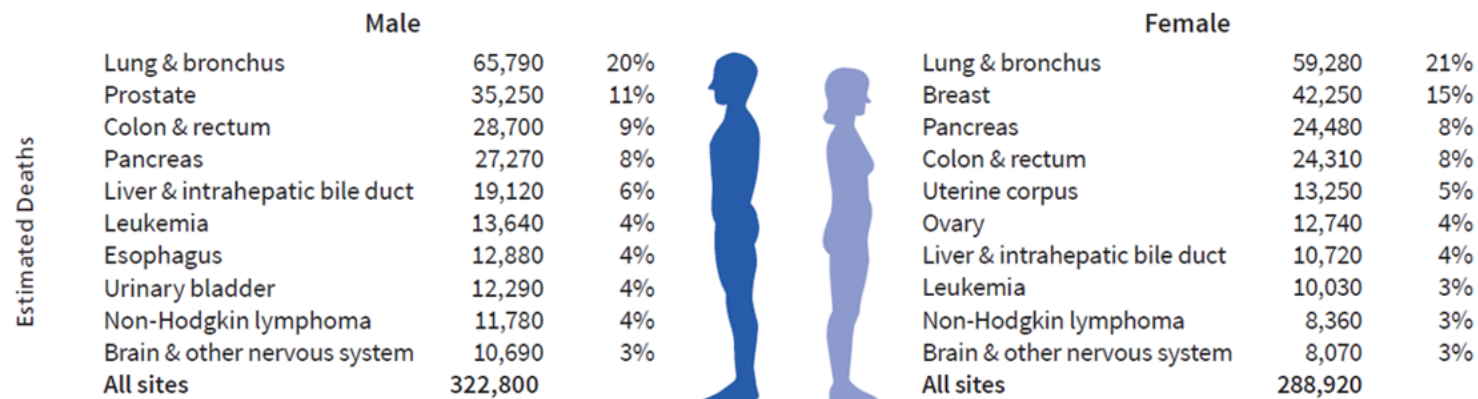
To improve the lives of people with cancer and their families through advocacy, research, and patient support to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer.

The National Burden of Cancer (USA)

Estimated new cases:
>2M new cases/year



Estimated deaths:
>610,000 new deaths/year



2024 ACS Cancer Statistics Report

Excludes basal cell and squamous cell skin cancers and in situ carcinoma except urinary bladder.
 Source: American Cancer Society, 2024.
 ©2024, American Cancer Society, Inc., Surveillance and Health Equity Science

Caregiver Support

- Cancer caregiving can be intense, episodic, and challenging
- Approximately 40% of caregivers reported finding caregiving emotionally difficult and 12% reported experiencing depression.
- Social support programs to improve coping skills can diminish the negative impact
- More information and understanding about the cancer diagnosis and treatment plan, support to reduce psychosocial stress, assistance with time off work, and assistance with daily household tasks are common caregiver needs



CANCER CAREGIVING IN THE U.S.

An Intense, Episodic, and Challenging Care Experience



ACKNOWLEDGEMENTS

Gail Gibson Hunt, *National Alliance for Caregiving*
 Margaret L. Longacre, Ph.D., *Cancer Support Community*
 Erin E. Kent, Ph.D., *National Cancer Institute*
 Lisa Weber-Raley, *Greenwald & Associates*



IN PARTNERSHIP WITH



Figure 4: Burden of Care Index

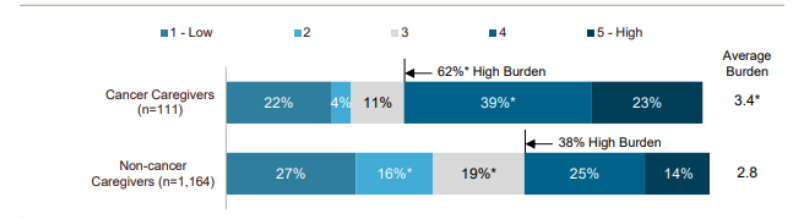
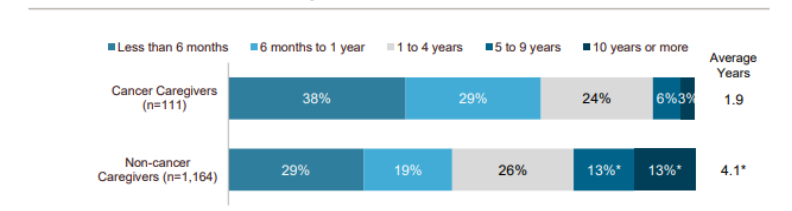


Figure 3: Duration of Care



Survivor Views

on Medical Debt



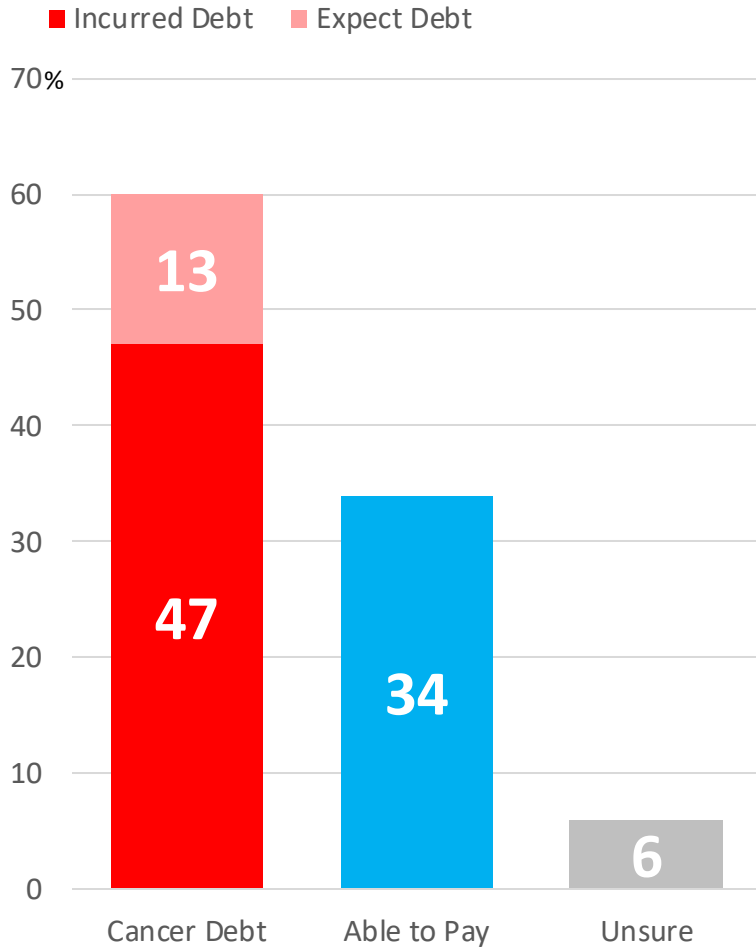
April 2024

Methodology

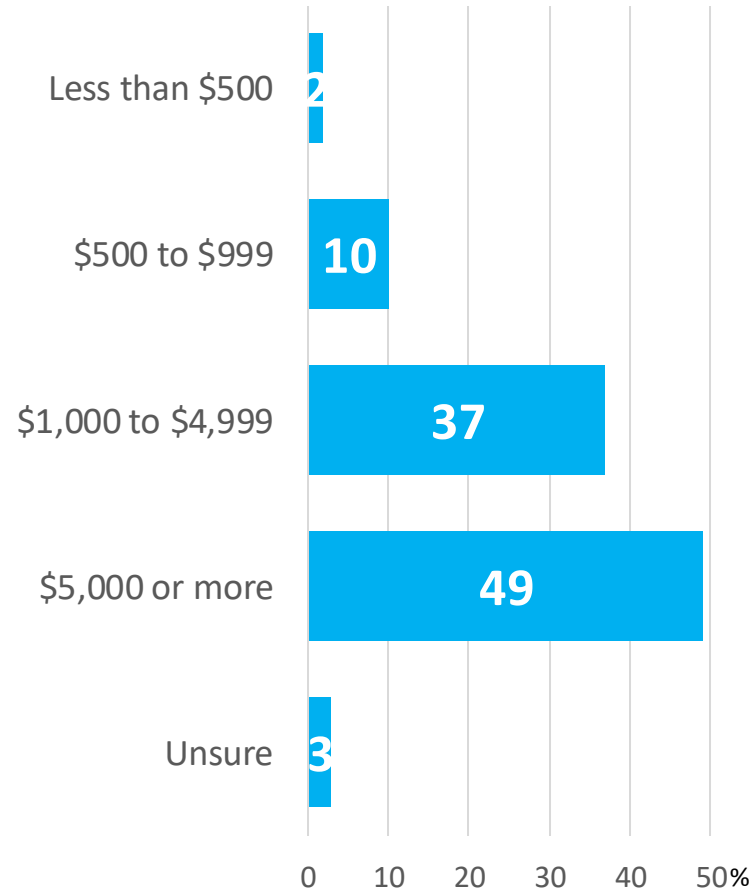
Sample	1,284n Cancer patients and survivors nationwide
Mode	Web-based interviews
Field dates	March 18 – April 14, 2024

Survivor Views surveys are conducted among a cohort of cancer patients and survivors who have been treated for or diagnosed with cancer within the past seven years. This population includes survivors who may still be carrying medical debt they acquired years ago as well as newly diagnosed cancer patients who are only just beginning to incur expenses related to their cancer.

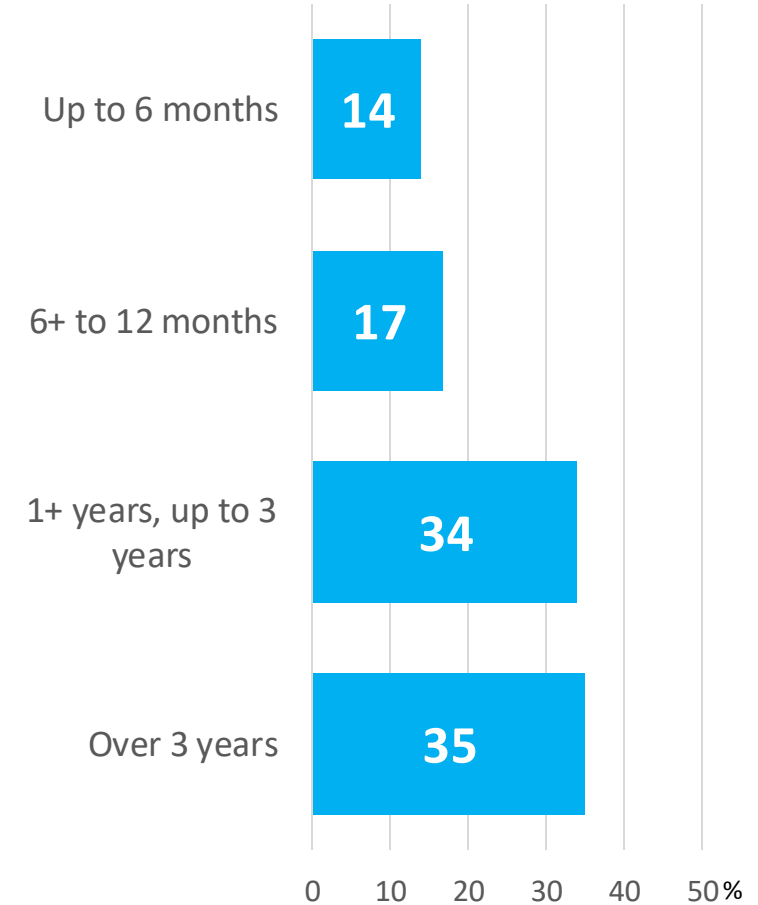
More than half have or expect to have medical debt; most often more than \$1,000 carried for over a year



Incidence of Debt
(N=1,2840)

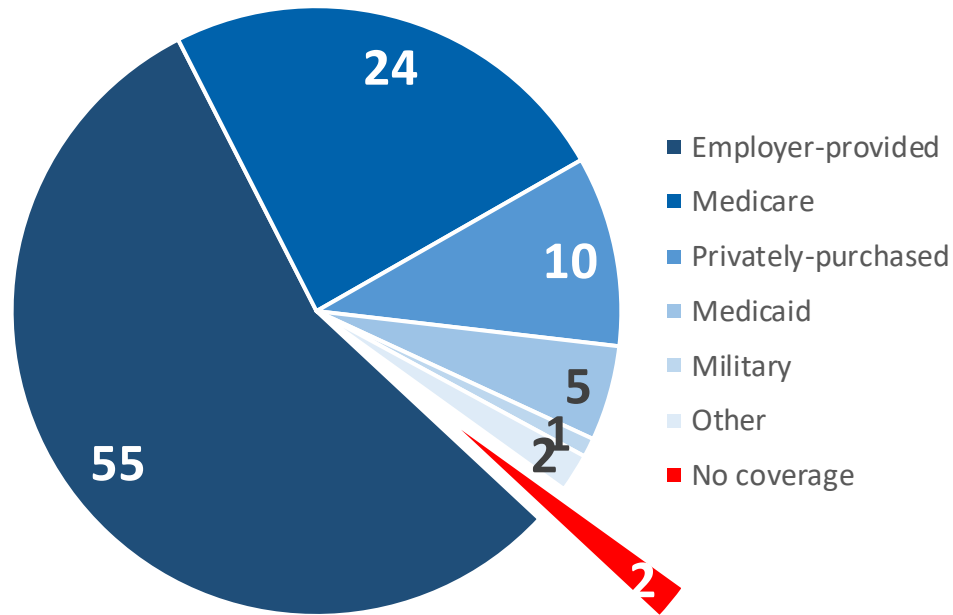


Amount of Debt
(N=599)

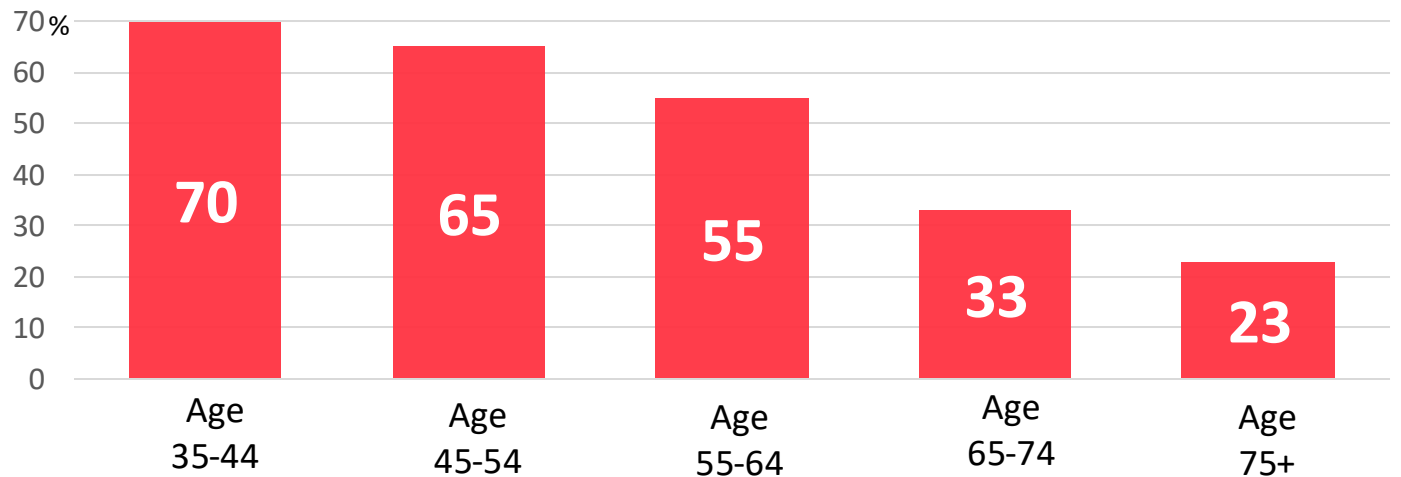
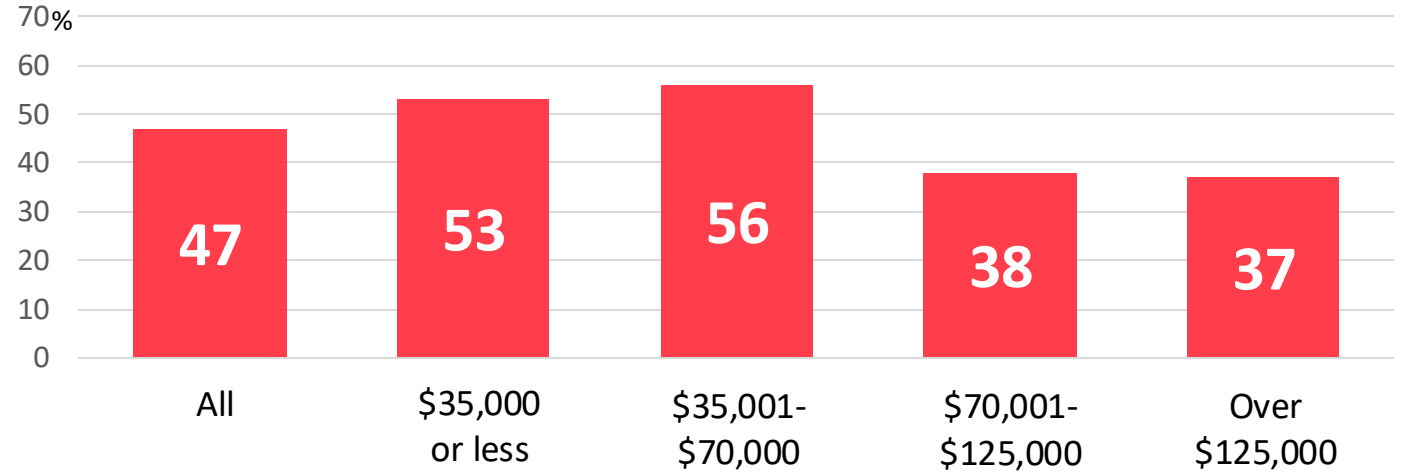


Duration of Debt
(N=599)

Most had coverage at the time and all income levels are impacted

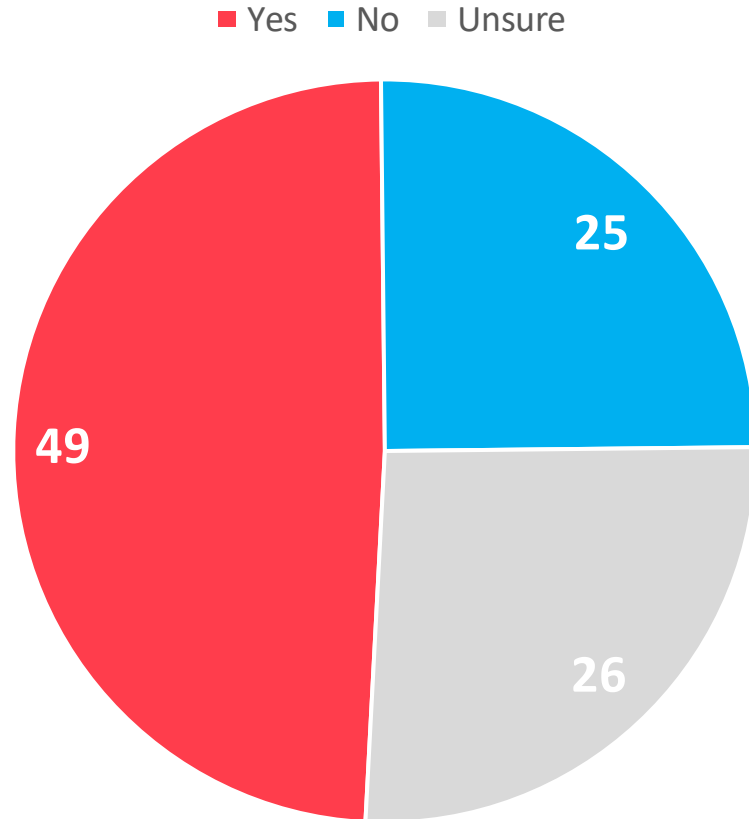


Coverage Type When Debt Incurred
(N=599)



Cancer Debt by Age & Income
(N=599)

More than half saw their credit score affected, with cascading impacts



**Credit score impacted
(N=599)**

	%
Unable to put money into savings	60
Mental health was negatively impacted	47
Felt pressured into a medical debt loan product	31
Credit problems and difficulty qualifying for loans	30
Went without adequate healthy food at any point	27
Delayed or skipped medical care to avoid further debt	25
Required to sign up for plan/loan before being treated	21
Considered filing for bankruptcy	18
Were required to pay debt in full before receiving care	14
Avoided provider you owed debt to	12
Became ill because of not seeking care due to debt	10

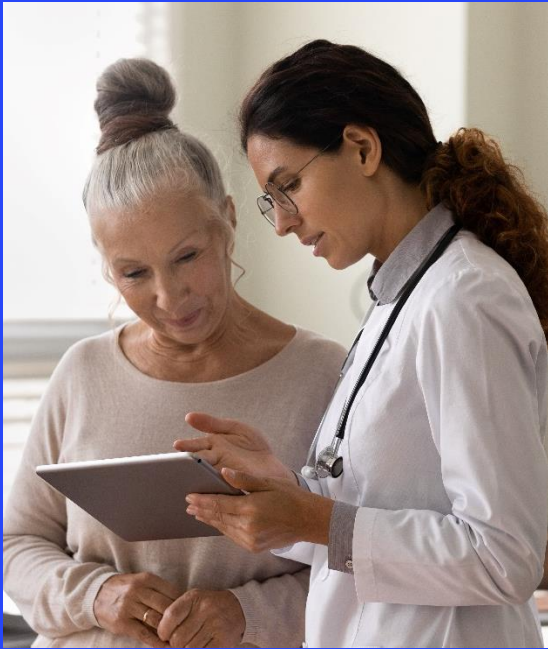
**Impacts of medical debt
(N=599)**

Resources





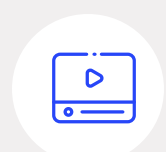


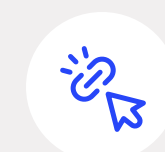


Most trusted source for cancer information next to a patient's physician

50+ million annual users



Cancer.org

	Comprehensive information across the continuum		1000's of downloadable patient education pieces
	Content is curated and maintained by oncology physicians and certified nurses		Directs patients to their health care team
	Includes videos, quizzes, 3-D animations and illustrations		Provides tools and resources for medical professionals
	Information in English and 13 other languages		Links patients to our access to care programs (i.e., lodging and transportation)



Introducing ACS CARES, the mobile app that provides you, your family, and your caregivers with the resources to navigate your cancer journey with confidence.

[Download the App](#)

**Cancer information, answers, and hope.
Available every minute of every day.
1-800-227-2345**

Whether it's the middle of the afternoon or the middle of the night, our cancer information specialists are here to help. Have questions about treatment options or potential side effects? We have you covered. Need a ride to chemo or a place to stay when treatment is far away? We can help. Even if you just need a friendly ear, we're here to help and can assist in more than 200 languages (via a language line) – 24 hours a day, 7 days a week.

Caregiver Support Video Series

Caregivers are a crucial part of any cancer care team. The goal of this video series is to provide educational support to caregivers as they meet with the everyday needs of cancer patients and provide self-care techniques to improve their quality of life.

- Physical Care Training:** skin 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 meditation.
- Advocacy:** how to effectively communicate your loved one's needs to the cancer care team.
- Caregiver Stories:** caregivers share their experiences through the ups and downs of their journey.

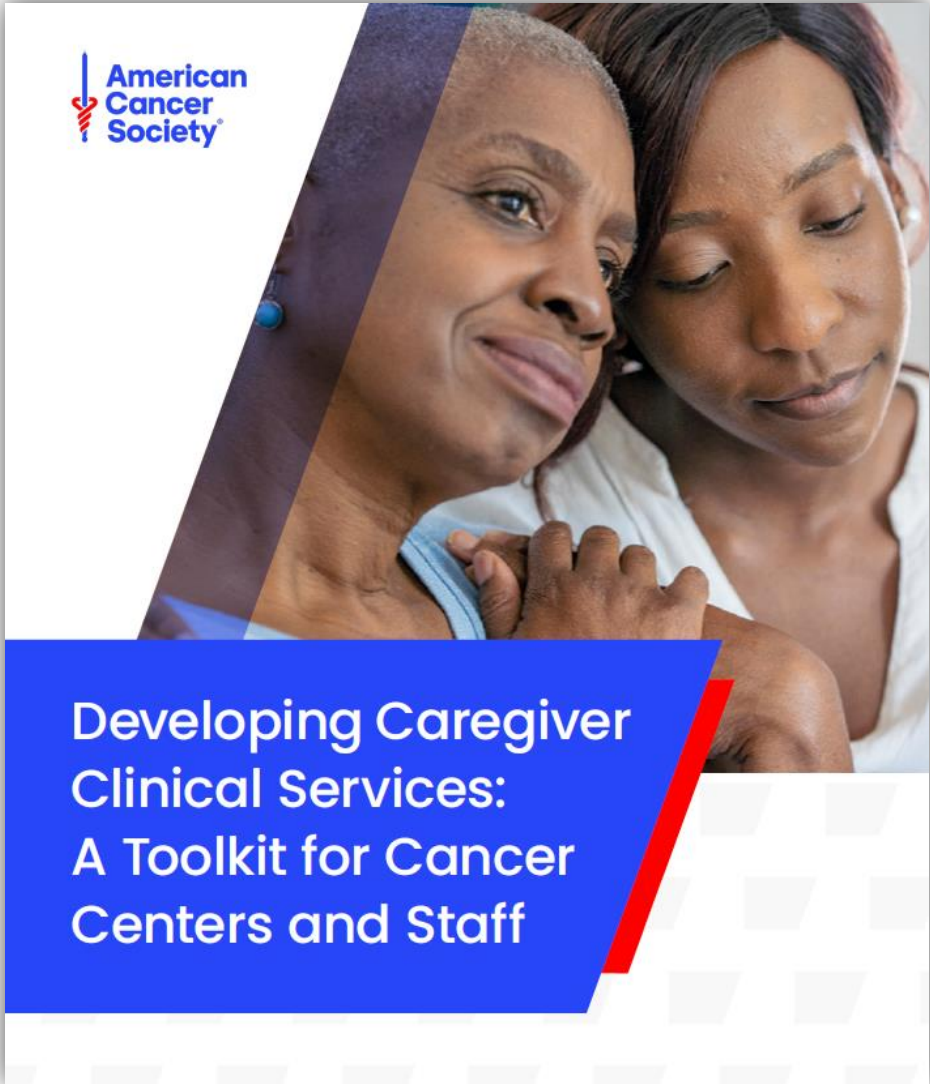
Physical Care Training

Caregiver Resource Guide

The American Cancer Society Caregiver Resource Guide is a tool for people who are caring for someone with cancer. It can help you learn how to care for yourself as a caregiver, better understand what your loved one is going through, develop skills for coping and caring, and take steps to help protect your health and well-being.

[Download the Guide](#)

Caregivers Clinic Toolkit



cancer.org/hcp

Thank You