minnesota cancer alliance summit

2026 | *the power of collaboration*

February 26, 2026

McNamara Alumni Center

Minneapolis, MN

Breakout Session #2

Thomas Swain

February 25, 2026

McNamara Alumni Center

Practices in Integrating Caregiver Support into Health System Practice

Allison Breininger, MA

Ellen LaFontaine, MSW, LICSW

Pamela Mason, MS

Financial Disclosure Statement

- There are no relevant financial disclosures for this session.

Breakout Objectives

- Identify how community collaboration can positively impact care delivery & project implementation for caregivers on the macro and micro scale.

- List the benefits of caregiver support on patients, health systems, and caregivers

- Describe the models being implemented by these two projects and their intended outcomes


UNWAVERING
STRONG
ENERGETIC
TENACIOUS
EXCEPTIONAL
COMMITED
SELFLESS
CHALLENGING
COURAGEOUS
RESILIENT
PIONEERS
STEADFAST
FORTITUDE
POWERFUL
COMPASSIONATE
INTEGRITY
SINCERE
UNDERPAID
ACCOMPLISHED
INDEFATIGABLE
EFFECTIVE
CREATIVE
HELPFUL
RESOURCEFUL
DEDICATED
QUINTESSENCE
DEVOTED
ACCOMODATING
DYNAMIC
GENEROUS
INSPIRATIONAL
IMPACTFUL
WISE
RESILIENCE
RESPONSIVE
PATIENT
STRENGTH
SAINTS
PERSERVERING
DETERMINED
PASSIONATE
CARING
HEROIC
REMARKABLE
VITAL
PERSEVERING
MAGNIFICENT
GENUINE
EMBRACING
COMMITTED
ENTHUSAISTIC
AWESOME
INSPIRING
INDIPENDENT
COMMITMENT
PERSERVANCE
AMAZING
LEADERS
PHENOMENAL
EMPOWERING
ENTHUSIASTIC
INFLUENTIAL

Cancer Plan Minnesota

Caregiver Support and Inclusion is a Now a Stand-Alone Objective

Under Goal 4: Diagnosis, Treatment and Survivorship

Objective 4:5: “Increase access to appropriate caregiver support services.”

Strategies:

- Conduct outreach and education for cancer care partners on the importance of maintaining healthy behaviors and available support services.

- Train healthcare providers to facilitate culturally responsive conversations about the importance of caregiver well-being and available resources that promote caregiver mental, emotional, spiritual, and logistical support.

How We Got Here

Minnesota Cancer Alliance + American Cancer Society® + ACS CoC Commission on Cancer American College of Surgeons

↓

COMMISSION ON CANCER (CoC) NETWORK

The Alliance's Commission on Cancer (CoC) Network brings together representatives of Minnesota's Commission on Cancer hospitals and clinics; the American Cancer Society; and the Alliance to facilitate achievement of shared objectives around quality cancer care. CoC facilities treat a large percentage of newly-diagnosed cancer patients, making them ideal partners to improve cancer prevention, treatment, research, education, support services, survivorship and end of life care.

The MN Commission on Cancer Network
presents

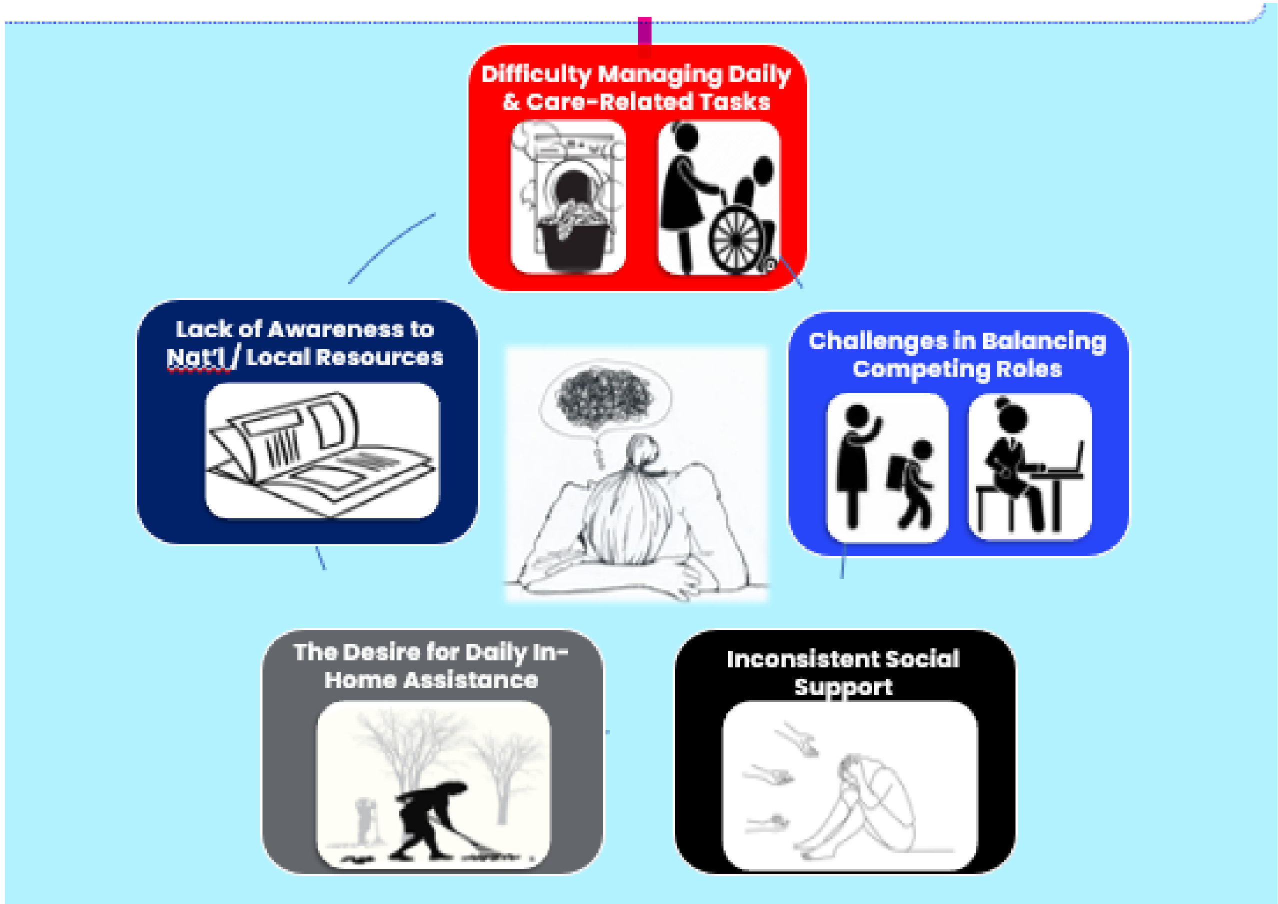
Caring for Caregivers: How We Can Put Compassion into Action

Featuring Guest Speaker
Allison Breininger, Founder of The Negative Space

October 2023

Why Cancer Caregivers?

- The Population Is Growing
- Caregivers Are Overwhelmed With Psychological and Physical Demands
- Support Is Critical Now More Than Ever



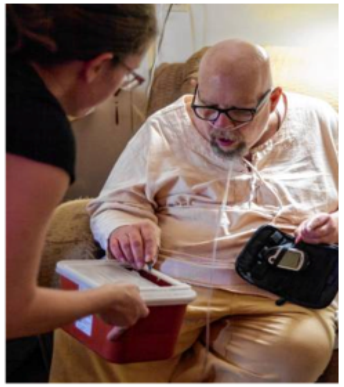
American Cancer Society (2024). *Developing Caregiver Clinical Services: A Tool Kit for Cancer Centers and Staff*.

https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/caregivers-clinic-toolkit-v24.pdf

Trends Continue to Impact Cancer Caregivers

- Increased time patients live with advanced cancer
- Increased % of advanced cancer patients with major co-morbidities (e.g. dementia, heart failure)
- Increased cost of medical care
- Increased complexity of home medical management

- Pressure to decrease hospital length of stay
- Increased complexity of care coordination between primary and specialty providers
- Increased sociodemographic diversity of the caregiving population
- Increased remote / distance caregiving



Jacobs & Shulman, 2017; National Academy of Medicine, 2020 (Workforce), 2019 (Oncology Workforce); 2018 Survivorship, 2016 (Digital Strategies); Alfano, 2019; National Alliance for Caregiving, 2020

American Cancer Society

As a result…

90%

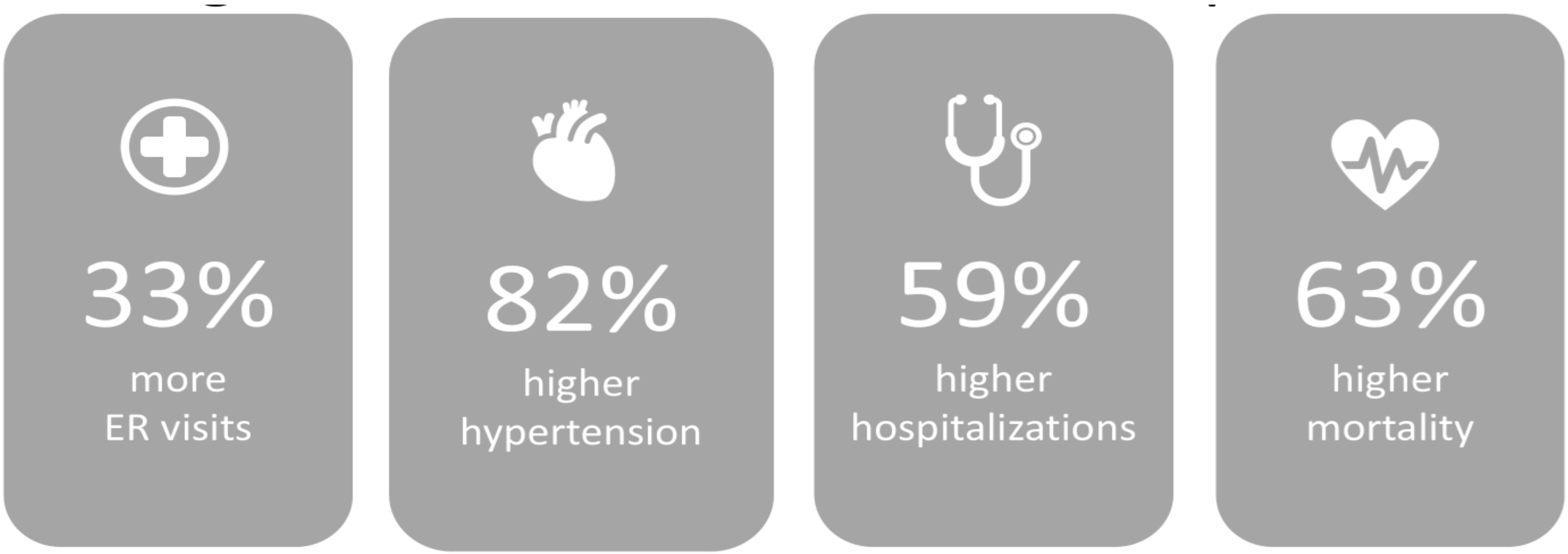
more likely than their peers to experience anxiety daily

70%

show signs of clinical depression

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9989224/#:~:text=The%20literature%20demonstrates%20significant%20anxiety,health%20needs%20among%20HNC%20caregivers.
https://parade.com/health/caregiving-mental-health-survey

Without support, caregivers often become the next patient.



33%
more
ER visits

82%
higher
hypertension

59%
higher
hospitalizations

63%
higher
mortality

https://www.caregiver.org/resource/caregiver-health/
https://www.bcbs.com/the-health-of-america/reports/the-impact-of-caregiving-on-mental-and-physical-health

The Impact of Effective Caregiver Support

On Patients

- ↑ Quality of Life[33–41]
- ↑ Health Care Savings[42]
- ↓ Potentially Inappropriate and Unnecessary Treatments[33-41]
- ↓ Social Isolation[33–41]

On Health Systems

- ↓ Hospital Readmission Rates[32]
- ↓ Medicare Expenditures[31]
- ↓ Emergency Department Use[31]
- ↓ ICU Use[31]

American Cancer Society (2024). *Developing Caregiver Clinical Services: A Tool Kit for Cancer Centers and Staff*.

https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/caregivers-clinic-toolkit-v24.pdf

“Caring for Caregivers: Putting Compassion into Action”

MN CoC Caregiver Coalition
January Kick-Off Meeting

January 8, 2024

Embedding Caregiver Recognition and Support into Health Care Spaces

Allison Breininger, Founder and Executive Director of The Negative Space

MCA Strategy Action Grant 2025-26

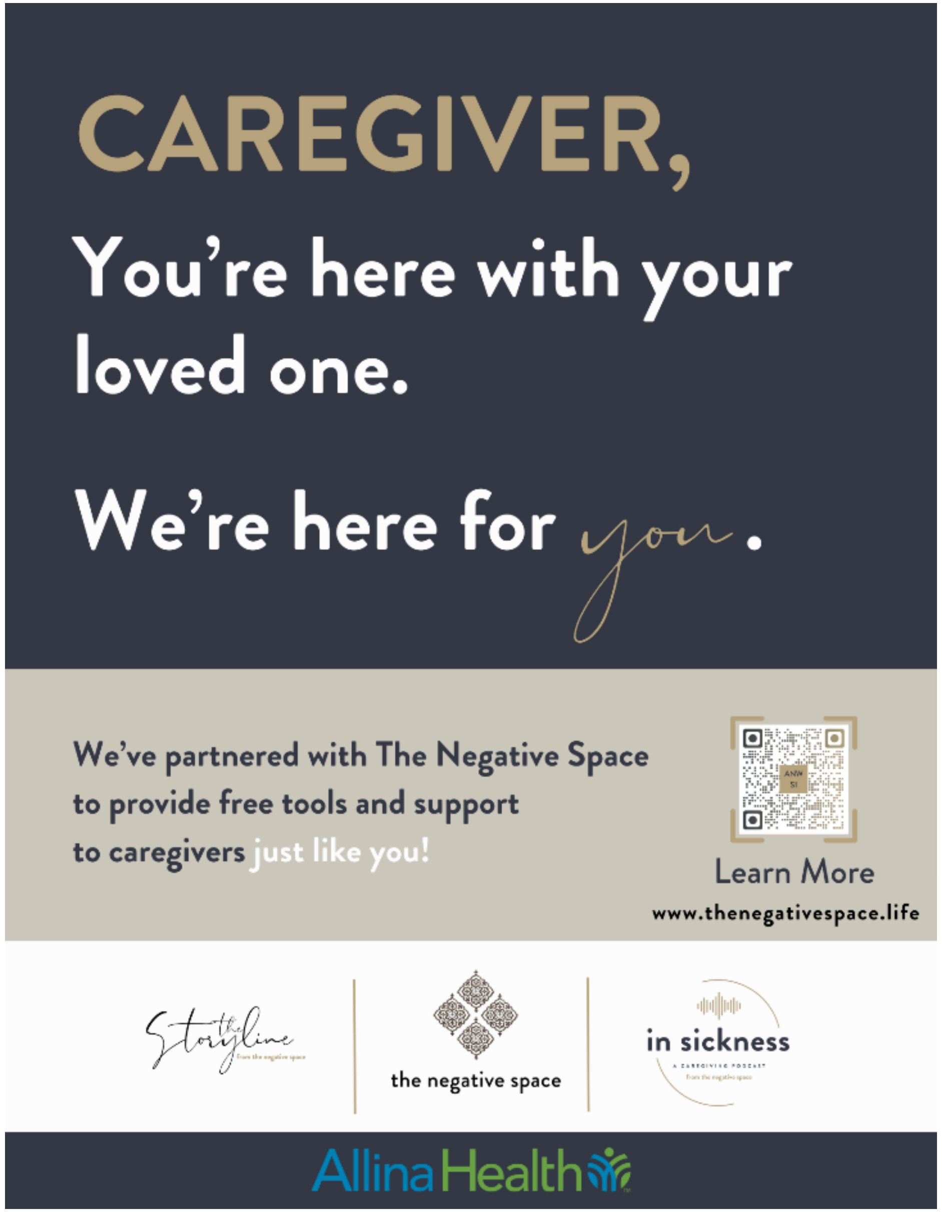
“***Embedding Caregiver Recognition and Support into Health Care Spaces***”

Partners:

- The Negative Space
- Allina Health
- HealthPartners
- M Health Fairview

Timeline:

- Began work in November 2025
- Launched 2/20/26 - National Caregivers Day



CAREGIVER,

You're here with your loved one.

We're here for *you*.

We've partnered with The Negative Space to provide free tools and support to caregivers just like you!

Learn More

www.thenegativespace.life

the storyline

the negative space

in sickness

Allina Health

CAREGIVER,

Thank you

for all you do on appointment days like this and all the days in between.

We know days like today can be hard, so we've partnered with The Negative Space to provide free tools and support to caregivers just like you!

the negative space

LEARN MORE

www.thenegativespace.life

YOU ARE PART OF THE STORY AND WE ARE HERE FOR YOU.

Allina Health

CAREGIVER,
YOU'RE HERE WITH YOUR LOVED ONE.
WE'RE HERE FOR YOU.

HAS YOUR LOVED ONE RECENTLY RECEIVED A NEW DIAGNOSIS?

THIS IS HARD ON YOU TOO.

We've partnered with The Negative Space to offer free tools and support for caregivers processing a new diagnosis and beyond. Just like your loved one, you need and deserve help every step of the way.

the negative space
Allina Health

LEARN MORE

ANW S4

CAREGIVER,
YOU'RE HERE WITH YOUR LOVED ONE.
WE'RE HERE FOR YOU.

DID YOU HAVE TO ADJUST YOUR WORK SCHEDULE TO BE HERE TODAY?

BALANCING WORK AND CAREGIVING IS HARD.

We've partnered with The Negative Space to offer free tools for working caregivers just like you. Like your loved one, you need and deserve help every step of the way.

the negative space
Allina Health

LEARN MORE

ANW S5

CAREGIVER,

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We're here for *you.*

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HealthPartners

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HealthPartners

YOU ARE PART OF THE STORY AND WE ARE HERE FOR YOU.

CAREGIVER,

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We are here for you.

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You are part of the story & you deserve support.

www.thenegativespace.life/fairview

LEARN MORE


Park Nicollet Methodist Hos
Hours 8:30 a.m.
Services for p
and family mem
2022 Impact of Giving
Know Your Cost
1-844-997-COST
CAREGIVER,
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HealthPartners


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Cranes of Hope Cards

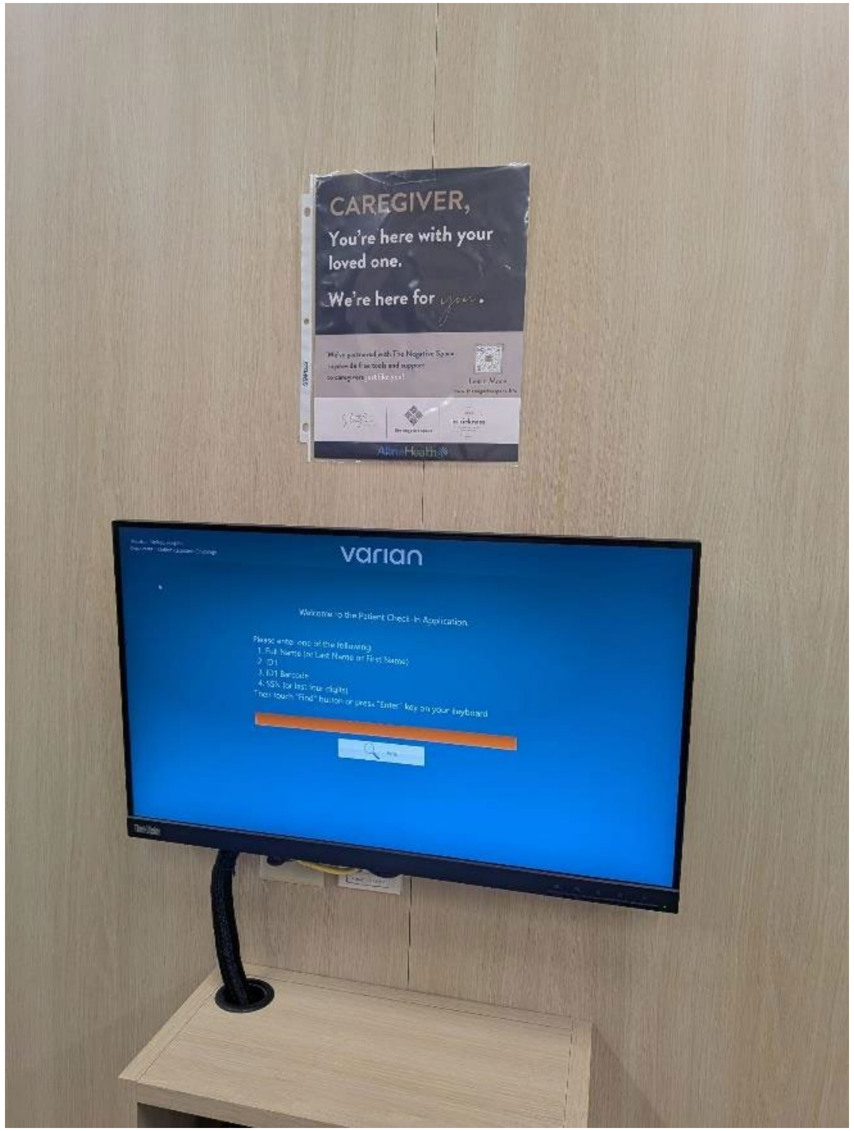
CAREGIVER,
You're here with your loved one.
We're here for you.

We've partnered with The Negative Space to provide free tools and support to caregivers just like you!

Learn More
www.thenegativespace.life

the negative space
in sickness
Allina Health


CAREGIVER,
You're here with your loved one.
We're here for you.
We've partnered with The Negative Space to provide free tools and support to caregivers just like you!
Learn More
in sickness
the negative space
AllinaHealth
Welcome!
RN:
NA: Steph / Cliff
Purell
HAND SANITIZER


CAREGIVER,
You're here with your loved one.
We're here for you.
AllinaHealth
varian
Welcome to the Patient Check-In Application.
Find

THANK YOU CAREGIVER,

for all you do on appointment days like this and all the days in between.

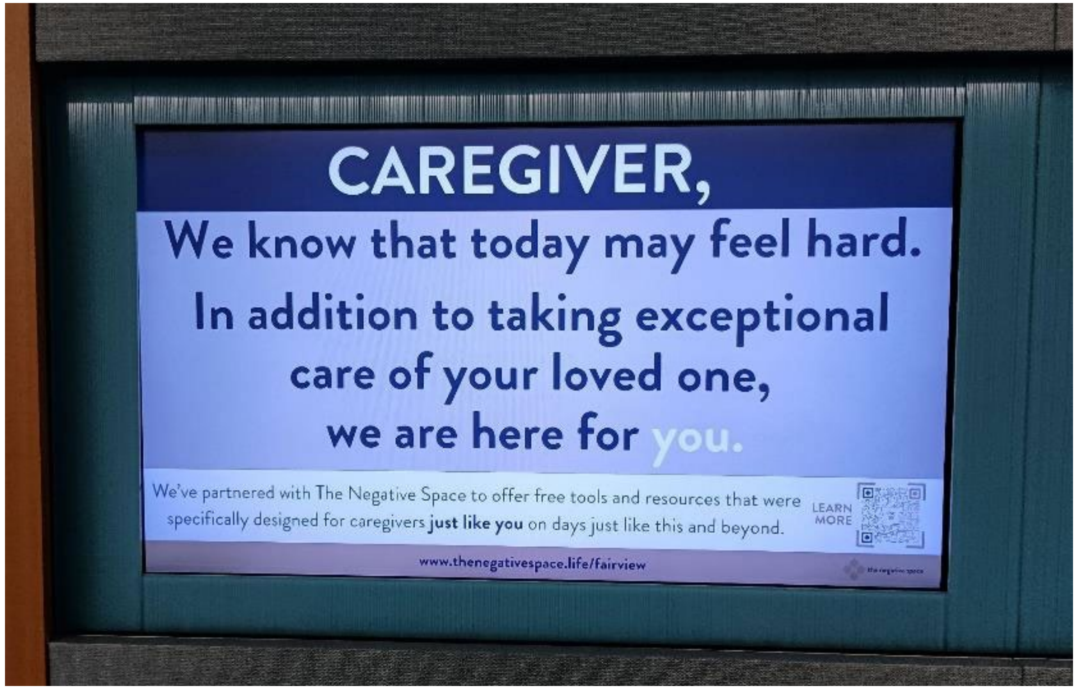
We know days like today can be hard, so we've partnered with The Negative Space to provide free tools and support to caregivers just like you!

the negative space

LEARN MORE

www.thenegativespace.life/fairview

YOU ARE PART OF THE STORY AND WE ARE HERE FOR YOU.



CAREGIVER,

We know that today may feel hard.

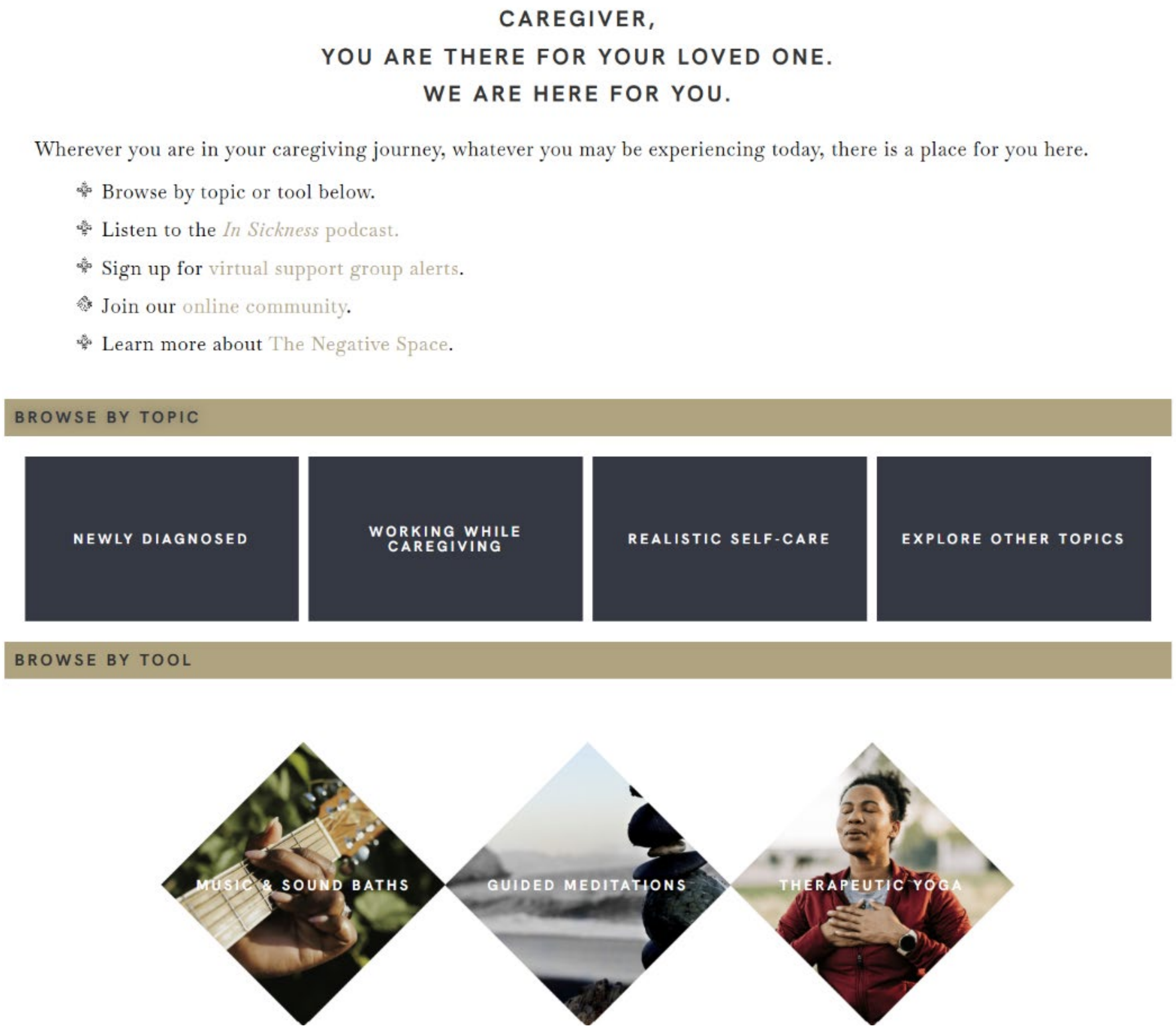
In addition to taking exceptional care of your loved one, we are here for you.

We've partnered with The Negative Space to offer free tools and resources that were specifically designed for caregivers **just like you** on days just like this and beyond.

LEARN MORE

www.thenegativespace.life/fairview

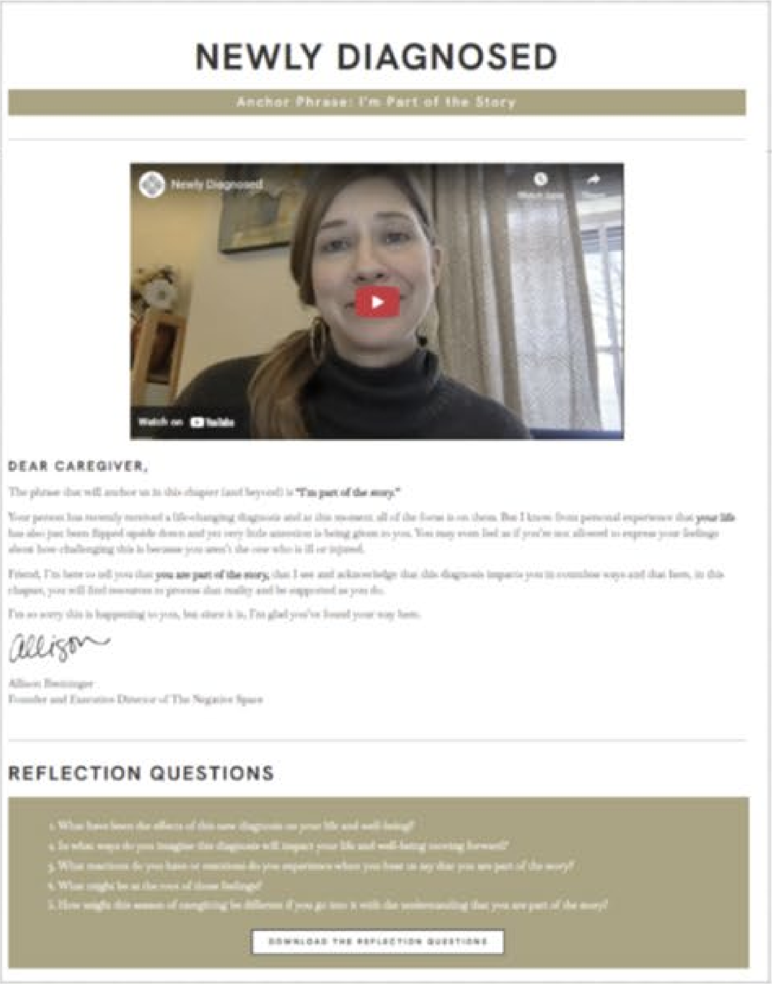
Allina Health



CAREGIVER,
YOU ARE THERE FOR YOUR LOVED ONE.
WE ARE HERE FOR YOU.

Wherever you are in your caregiving journey, whatever you may be experiencing today, there is a place for you here.

- Browse by topic or tool below.
- Listen to the *In Sickness* podcast.
- Sign up for virtual support group alerts.
- Join our online community.
- Learn more about The Negative Space.



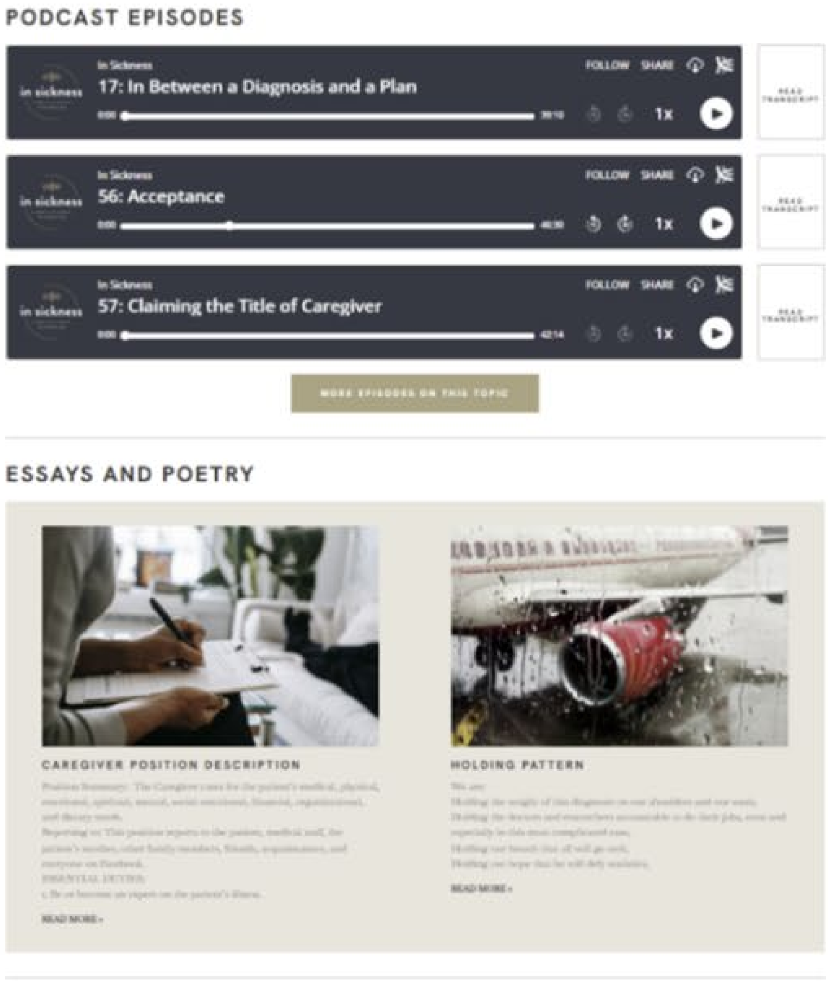
NEWLY DIAGNOSED

Anchor Phrase: I'm Part of the Story

DEAR CAREGIVER,

Allison

REFLECTION QUESTIONS



PODCAST EPISODES

In Sickness
17: In Between a Diagnosis and a Plan

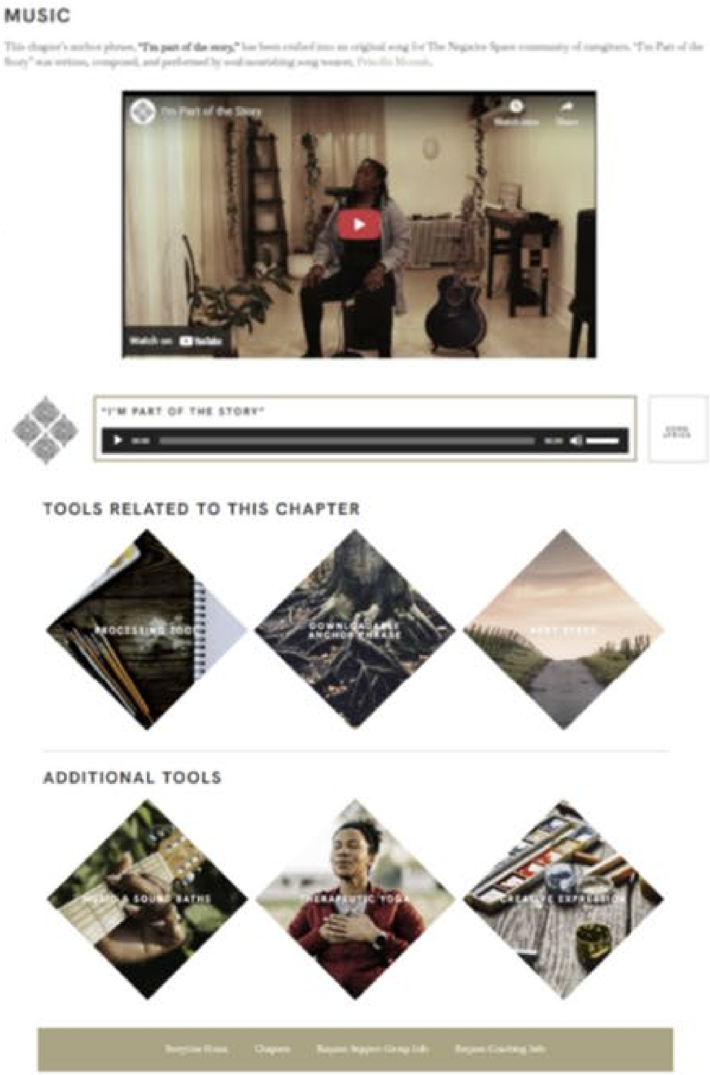
In Sickness
56: Acceptance

In Sickness
57: Claiming the Title of Caregiver

ESSAYS AND POETRY

CAREGIVER POSITION DESCRIPTION

HOLDING PATTERN



MUSIC

TOOLS RELATED TO THIS CHAPTER

ADDITIONAL TOOLS

Request Support Group Info　　Request Coaching Info

the negative space

	HealthPartners	Allina Health	M Health Fairview	TOTALS
Number of sites	12	3	1	16
Number of spaces	20	51	35	106
Estimated number of caregivers/day	410	370	800	1580

These ideas are:

- **Easy to implement** in existing clinical workflows
- **Sustainable** beyond grant funding
- **Measurable** in terms of impact and outcomes
- **Scalable** across departments and facilities

The Impact

Caregivers:

- recognize themselves as caregivers
- feel seen
- are directly connected to evidence-based tools and resources that support their emotional, mental, physical and logistical health
- feel like the health systems cares about and appreciates them
- are more loyal to the health system
- are better able to care for their person
- are less likely to become the next patient

All because of a well-placed sign with a QR code.

How will we measure success?

Next Steps

- Study data
- Make adjustments as indicated
- Work towards wider implementation within current health systems
- Work towards adoption of this initiative within new health systems and with other types of partners
- Patient as caregiver version with Herself Health

Not Alone:
Centering the Experience of Brain Tumor Caregivers

Ellen LaFontaine, MSW, LICSW, OSW-C

Pilot Project Timeline

Grant Approval
2/19/2025

Approval of MCA's SGA grant (awarded $2,500)

Pre-Intervention Surveys
2/25- 3/12/2025

Surveyed current caregivers & care team members about gaps in care delivery for caregivers

Packet Material Preparation
3/15/25- 4/30/25

Creation of Caregiver Toolkit, 2-week APP visit & Caregiver Concerns document, Procurement of both internal and external materials

Caregiver Intervention
5/1/25- 8/31/25

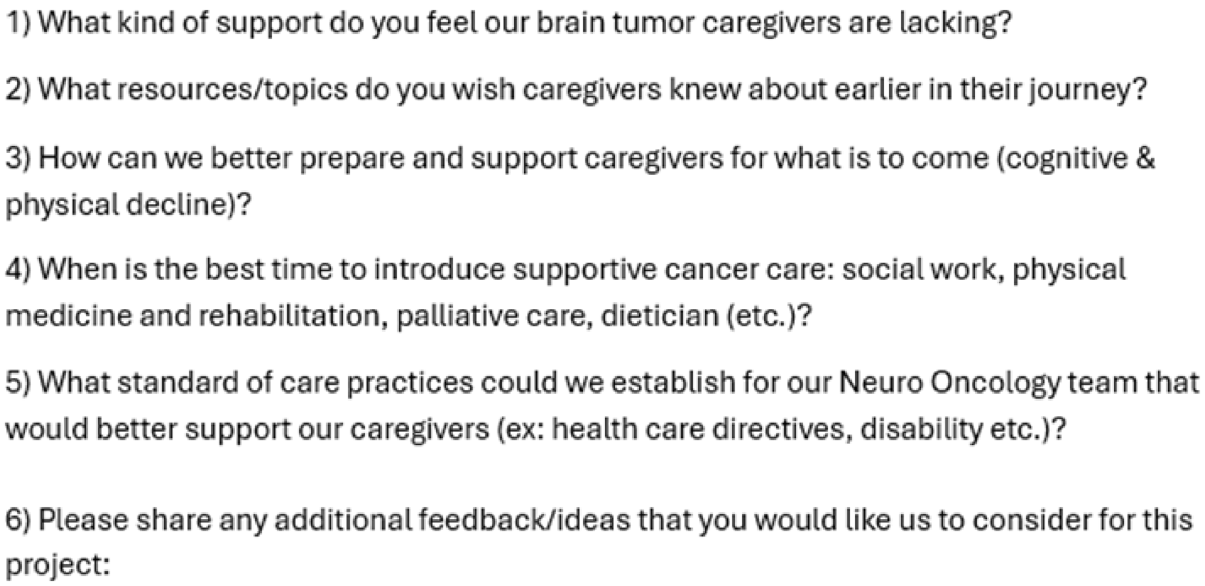
Caregiver Packet Distribution, 2-week APP provider f/u appts, Caregiver Concern document review & continued care team caregiver check-ins

Post-Intervention Analysis
9/1/2025 -10/3/2025

Post-Intervention Surveys of Caregivers & Care Team and Chart Audits of workflow adherence

Survey

Care Team	Caregiver



1) What kind of support do you feel our brain tumor caregivers are lacking?

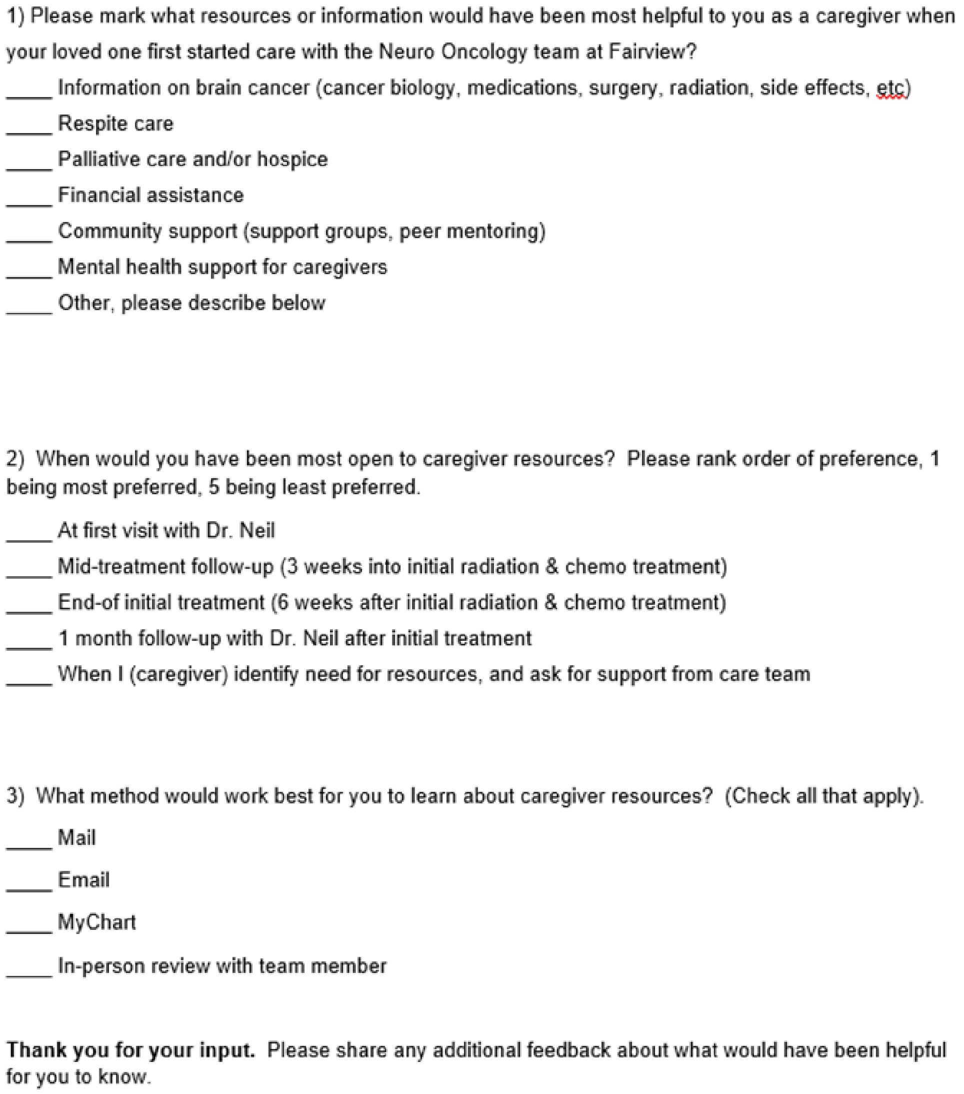
2) What resources/topics do you wish caregivers knew about earlier in their journey?

3) How can we better prepare and support caregivers for what is to come (cognitive & physical decline)?

4) When is the best time to introduce supportive cancer care: social work, physical medicine and rehabilitation, palliative care, dietician (etc.)?

5) What standard of care practices could we establish for our Neuro Oncology team that would better support our caregivers (ex: health care directives, disability etc.)?

6) Please share any additional feedback/ideas that you would like us to consider for this project:



1) Please mark what resources or information would have been most helpful to you as a caregiver when your loved one first started care with the Neuro Oncology team at Fairview?

____ Information on brain cancer (cancer biology, medications, surgery, radiation, side effects, etc)
____ Respite care
____ Palliative care and/or hospice
____ Financial assistance
____ Community support (support groups, peer mentoring)
____ Mental health support for caregivers
____ Other, please describe below

2) When would you have been most open to caregiver resources? Please rank order of preference, 1 being most preferred, 5 being least preferred.

____ At first visit with Dr. Neil
____ Mid-treatment follow-up (3 weeks into initial radiation & chemo treatment)
____ End-of initial treatment (6 weeks after initial radiation & chemo treatment)
____ 1 month follow-up with Dr. Neil after initial treatment
____ When I (caregiver) identify need for resources, and ask for support from care team

3) What method would work best for you to learn about caregiver resources? (Check all that apply).

____ Mail
____ Email
____ MyChart
____ In-person review with team member

Thank you for your input. Please share any additional feedback about what would have been helpful for you to know.

Outcomes of survey led to creation of:

1) Caregiver Toolkit
2) Adding earlier visit with APP (at 2 weeks)
3) Common Caregiver Concerns

Caregiver Toolkit

To be given to all new brain tumor caregivers at first meeting with Dr. Neil

Intro Materials	Resources	Caregiver Specific
- Welcome Letter - Frequently Asked Questions - Health Care Directive (HCD) - Physician Order for Life Sustaining Treatment (POLST)	- M Health Fairview Supportive Care Services - Palliative Care M Health Fairview - Cancer Legal Care - Triage Cancer - New Onset Seizure in Adults - Brain Function and Deficits	- American Brain Tumor Association Caregiver Handbook - American Cancer Society Caregiver Resource Guide - Common Caregiver Concerns - Community Resource List

Created Documents

Welcome to the Care Team

Dear Caregiver,

First, you need to be commended for all that you do. Being a caregiver is challenging, but it is already clear to us that your actions and advocacy show your commitment, concern, and love.

We can only imagine the level of stress and anxiety that you have undergone as you navigated to this point in time, but please know that from now on, the M Health Fairview Brain Cancer Comprehensive Care Team has your back! Your team is comprised of your healthcare doctors and advanced care providers, cancer clinic nurse coordinator, clinical pharmacists, and oncology social worker. Together, we are here to answer your questions, build your confidence, and partner with you and your loved one on this journey.

In preparation for the road ahead, please review the Caregiver Toolkit that has been specifically created with you, the caregiver, in mind. While the medical therapy that your loved one will receive is a top priority, we recognize that we cannot comprehensively provide treatment and care for your loved one without you. For this reason, we believe it is of critical importance that you have the support you need.

Included in this packet are resources to help you prepare for the path ahead as a caregiver and to help you maintain your mental and emotional wellbeing. This Caregiver Toolkit is a starting point for our conversations; you are an important part of our team, so please let us know if you have any concerns. Additional questions you may be asking yourself include things like managing leave from work, supporting children/grandchildren, navigating impacts to home life and finances, and connecting to local and national resources. Please know that we are here to help you every step of the way.

On behalf of your whole M Health Fairview Brain Cancer Comprehensive Care Team, it is an honor to take part in your loved one's care. Thank you for partnering with us, and we look forward to building a strong and supportive relationship in which you are seen and valued.

Sincerely,

Elizabeth C. Neil, MD

Cara Leuchtenberger, APRN

Amber Scheierl, CNP

Laura Kveene, BSN, RN

Kathy Clausen, BSN, RN, OCN

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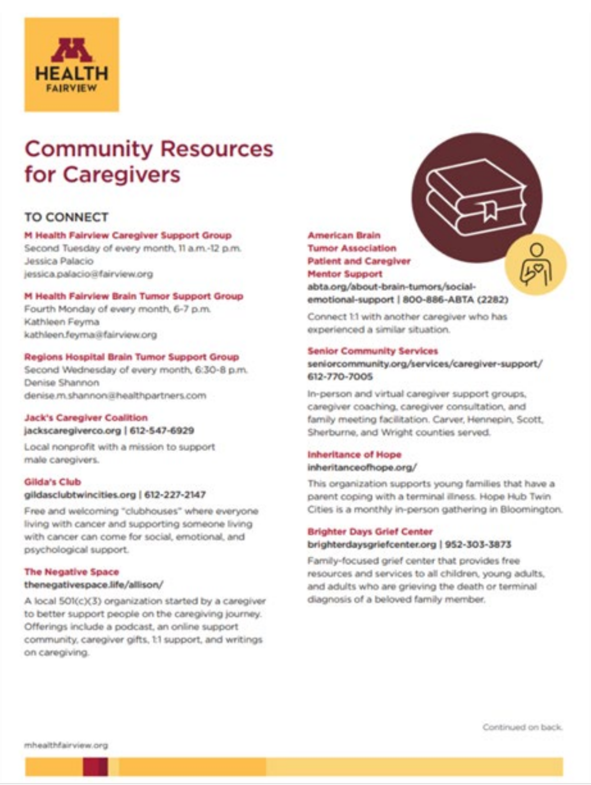

Community Resources for Caregivers

TO CONNECT

M Health Fairview Caregiver Support Group
Second Tuesday of every month, 11 a.m.-12 p.m.
Jessica Palacio
jessica.palacio@fairview.org

M Health Fairview Brain Tumor Support Group
Fourth Monday of every month, 6-7 p.m.
Kathleen Feyma
kathleen.feyma@fairview.org

Regions Hospital Brain Tumor Support Group
Second Wednesday of every month, 6:30-8 p.m.
Denise Shannon
denise.m.shannon@healthpartners.com

Jack's Caregiver Coalition
jackscaregiverco.org | 612-547-6929

Local nonprofit with a mission to support male caregivers.

Gilda's Club
gildasclubtwincities.org | 612-227-2147

Free and welcoming "clubhouses" where everyone living with cancer and supporting someone living with cancer can come for social, emotional, and psychological support.

The Negative Space
thenegativespace.life/allison/

A local 501(c)(3) organization started by a caregiver to better support people on the caregiving journey. Offerings include a podcast, an online support community, caregiver gifts, 1:1 support, and writings on caregiving.

American Brain Tumor Association Patient and Caregiver Mentor Support
abta.org/about-brain-tumors/social-emotional-support | 800-886-ABTA (2282)

Connect 1:1 with another caregiver who has experienced a similar situation.

Senior Community Services
seniorcommunity.org/services/caregiver-support/
612-770-7005

In-person and virtual caregiver support groups, caregiver coaching, caregiver consultation, and family meeting facilitation. Carver, Hennepin, Scott, Sherburne, and Wright counties served.

Inheritance of Hope
inheritanceofhope.org/

This organization supports young families that have a parent coping with a terminal illness. Hope Hub Twin Cities is a monthly in-person gathering in Bloomington.

Brighter Days Grief Center
brighterdaysgriefcenter.org | 952-303-3873

Family-focused grief center that provides free resources and services to all children, young adults, and adults who are grieving the death or terminal diagnosis of a beloved family member.

Continued on back.

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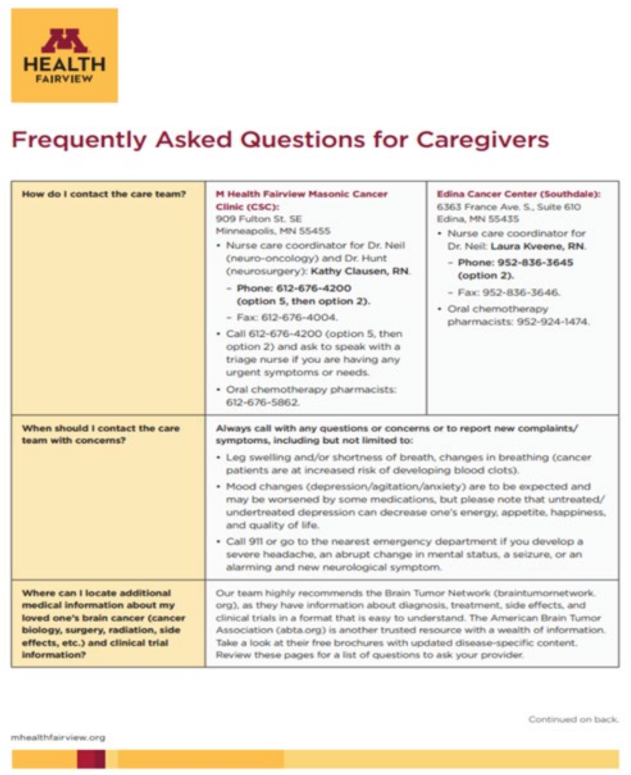
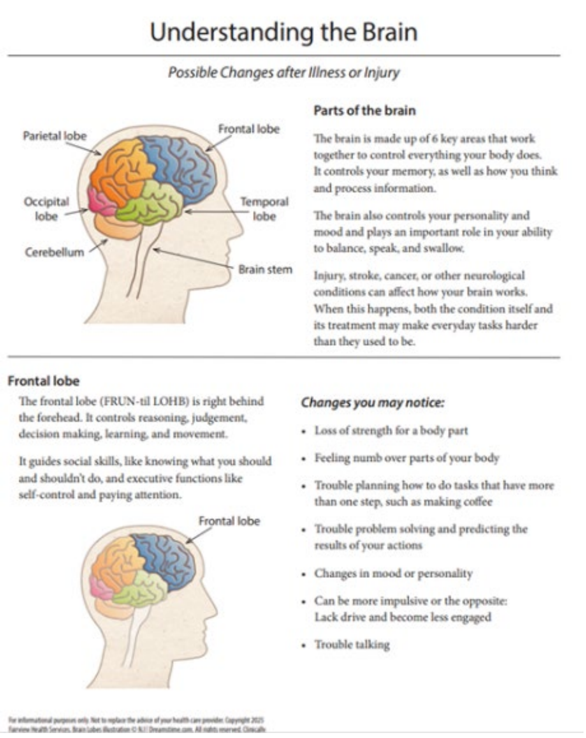


Frequently Asked Questions for Caregivers

How do I contact the care team?	**M Health Fairview Masonic Cancer Clinic (CSC):** 909 Fulton St. SE Minneapolis, MN 55455 • Nurse care coordinator for Dr. Neil (neuro-oncology) and Dr. Hunt (neurosurgery): **Kathy Clausen, RN.** – **Phone: 612-676-4200 (option 5, then option 2).** – Fax: 612-676-4004. • Call 612-676-4200 (option 5, then option 2) and ask to speak with a triage nurse if you are having any urgent symptoms or needs. • Oral chemotherapy pharmacists: 612-676-5862.	**Edina Cancer Center (Southdale):** 6363 France Ave. S., Suite 610 Edina, MN 55435 • Nurse care coordinator for Dr. Neil: **Laura Kveene, RN.** – **Phone: 952-836-3645 (option 2).** – Fax: 952-836-3646. • Oral chemotherapy pharmacists: 952-924-1474.
When should I contact the care team with concerns?	**Always call with any questions or concerns or to report new complaints/symptoms, including but not limited to:** • Leg swelling and/or shortness of breath, changes in breathing (cancer patients are at increased risk of developing blood clots). • Mood changes (depression/agitation/anxiety) are to be expected and may be worsened by some medications, but please note that untreated/undertreated depression can decrease one's energy, appetite, happiness, and quality of life. • Call 911 or go to the nearest emergency department if you develop a severe headache, an abrupt change in mental status, a seizure, or an alarming and new neurological symptom.	
Where can I locate additional medical information about my loved one's brain cancer (cancer biology, surgery, radiation, side effects, etc.) and clinical trial information?	Our team highly recommends the Brain Tumor Network (braintumornetwork.org), as they have information about diagnosis, treatment, side effects, and clinical trials in a format that is easy to understand. The American Brain Tumor Association (abta.org) is another trusted resource with a wealth of information. Take a look at their free brochures with updated disease-specific content. Review these pages for a list of questions to ask your provider.	

Continued on back.

mhealthfairview.org



Understanding the Brain

Possible Changes after Illness or Injury

Parts of the brain

The brain is made up of 6 key areas that work together to control everything your body does. It controls your memory, as well as how you think and process information.

The brain also controls your personality and mood and plays an important role in your ability to balance, speak, and swallow.

Injury, stroke, cancer, or other neurological conditions can affect how your brain works. When this happens, both the condition itself and its treatment may make everyday tasks harder than they used to be.

Frontal lobe

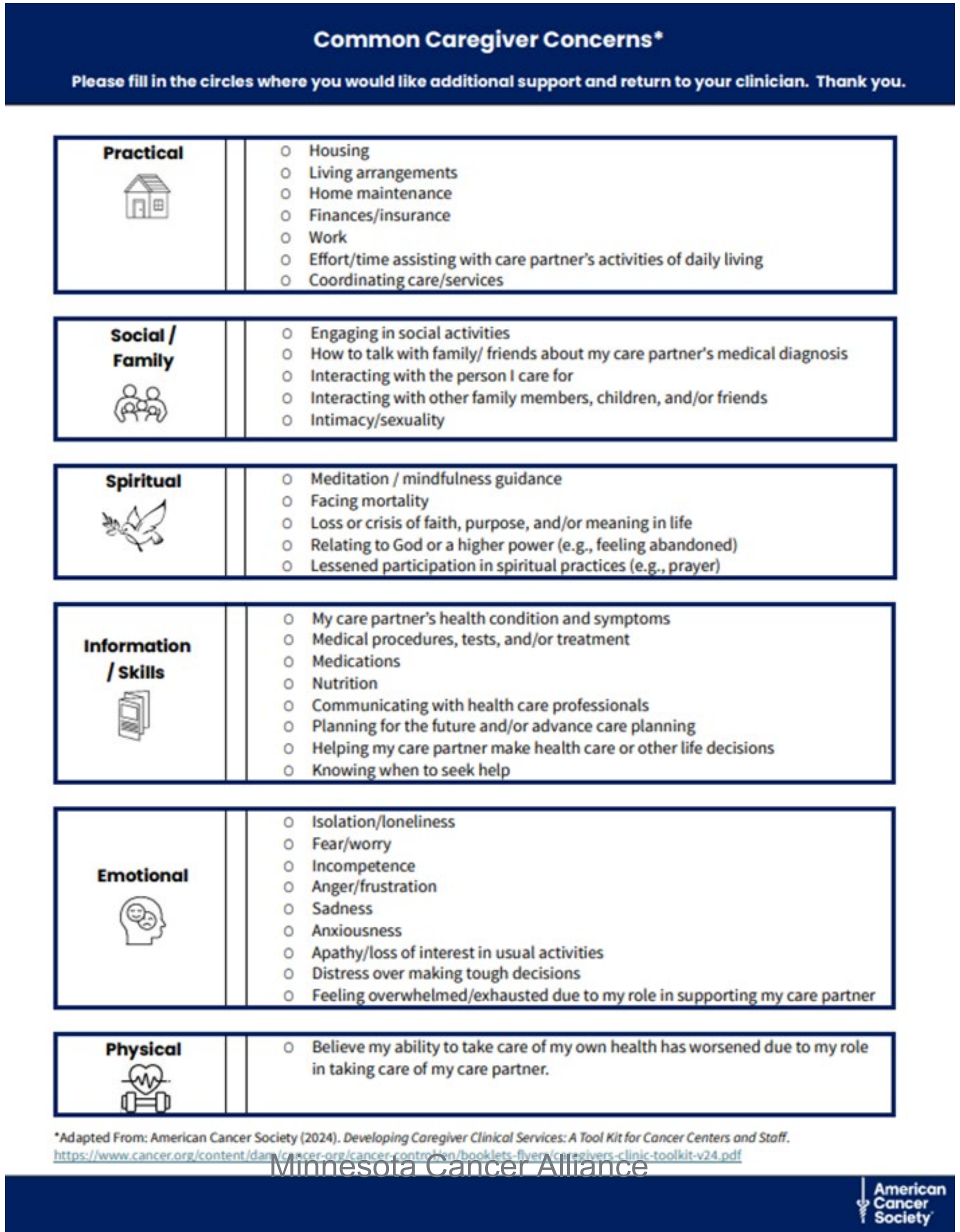
The frontal lobe (FRUN-til LOHB) is right behind the forehead. It controls reasoning, judgement, decision making, learning, and movement.

It guides social skills, like knowing what you should and shouldn't do, and executive functions like self-control and paying attention.

Changes you may notice:

- Loss of strength for a body part
- Feeling numb over parts of your body
- Trouble planning how to do tasks that have more than one step, such as making coffee
- Trouble problem solving and predicting the results of your actions
- Changes in mood or personality
- Can be more impulsive or the opposite: Lack drive and become less engaged
- Trouble talking

Common Caregiver Concerns



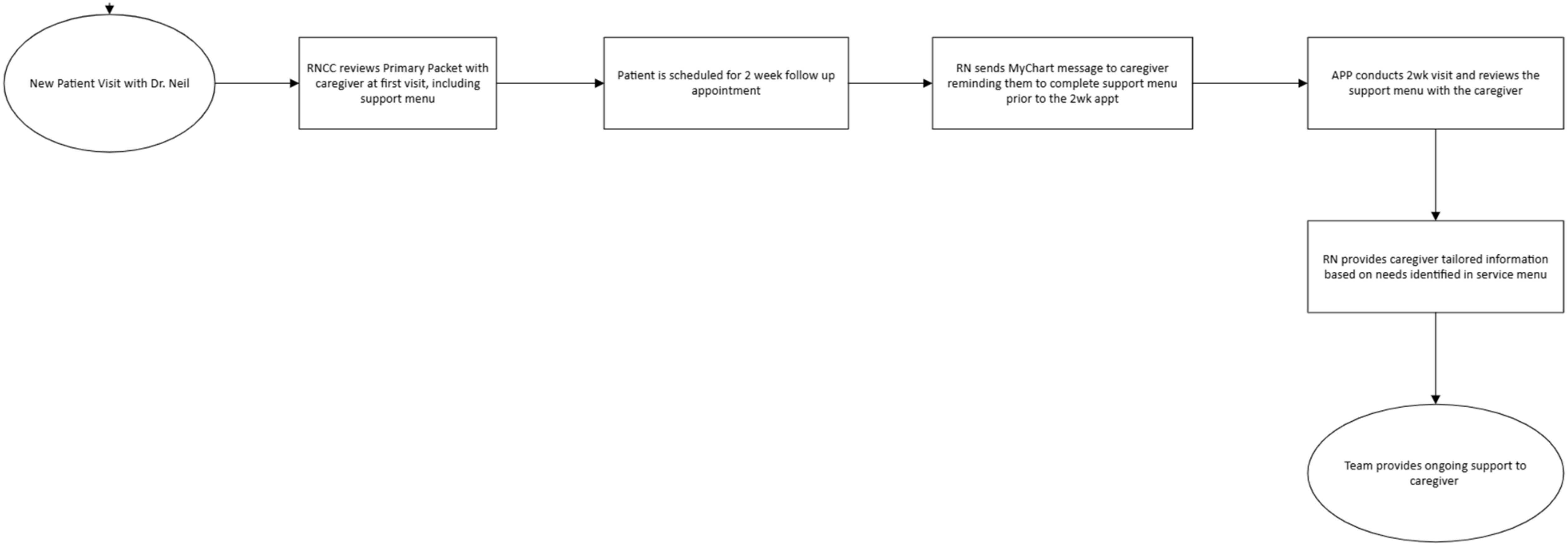
Common Caregiver Concerns*

Please fill in the circles where you would like additional support and return to your clinician. Thank you.

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 ○ How to talk with family/ friends about my care partner's medical diagnosis ○ Interacting with the person I care for ○ Interacting with other family members, children, and/or friends ○ Intimacy/sexuality
Spiritual	○ Meditation / mindfulness guidance ○ Facing mortality ○ Loss or crisis of faith, purpose, and/or meaning in life ○ Relating to God or a higher power (e.g., feeling abandoned) ○ Lessened participation in spiritual practices (e.g., prayer)
Information / Skills	○ 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	○ 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.

*Adapted From: American Cancer Society (2024). *Developing Caregiver Clinical Services: A Tool Kit for Cancer Centers and Staff*.
https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/caregivers-clinic-toolkit-v24.pdf

Caregiver Packet Intervention Workflow



New Patient Visit with Dr. Neil

RNCC reviews Primary Packet with caregiver at first visit, including support menu

Patient is scheduled for 2 week follow up appointment

RN sends MyChart message to caregiver reminding them to complete support menu prior to the 2wk appt

APP conducts 2wk visit and reviews the support menu with the caregiver

RN provides caregiver tailored information based on needs identified in service menu

Team provides ongoing support to caregiver

Project Outcomes

As told by the data

Primary Objectives

- **Increased satisfaction with care**
  - Increase in Dr. Neil's customer experience scores
- **Increased knowledge of caregivers re: available services**
  - 16/16 caregiver survey respondents indicated they either agreed (8) or strongly agreed (8) that as a result of the packet materials they have a good understanding of where and/or how to access caregiver support if needed.

  - 10/16 caregiver survey respondents indicated they either agreed (8) or strongly agreed (2) that as a result of the packet materials, they experienced an increase in knowledge about their role as a caregiver.

Provider Survey Highlights (n=5)

4.20

Average Rating

① ② ③ ④ ⑤

Workflow Adherence

4.60

Average Rating

★ ★ ★ ★ ★

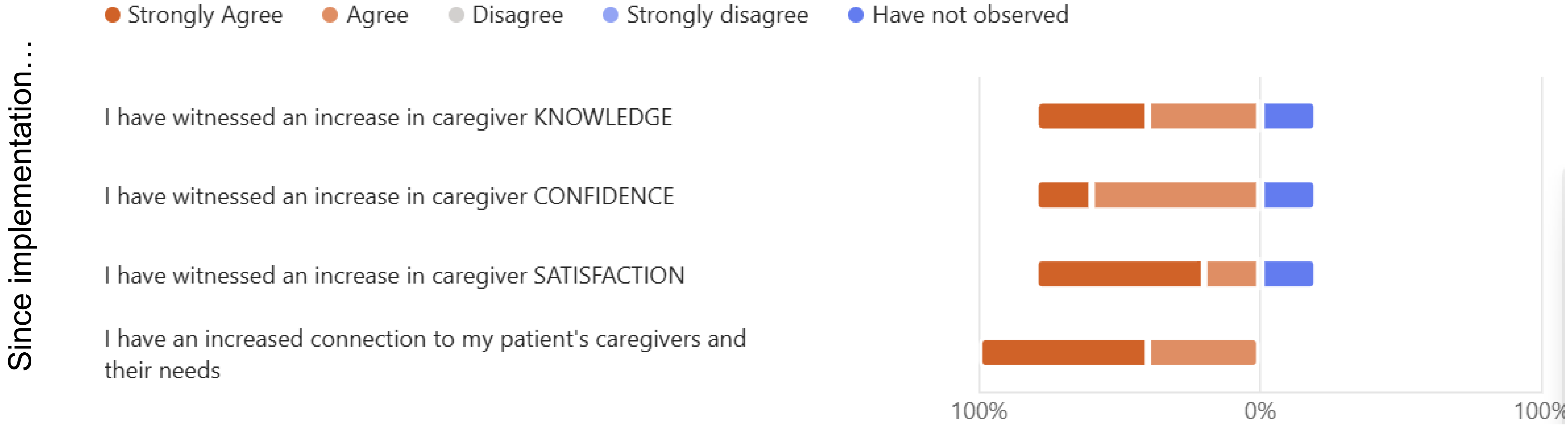
Project Outcome Achievement Rating

4.80

Average Rating

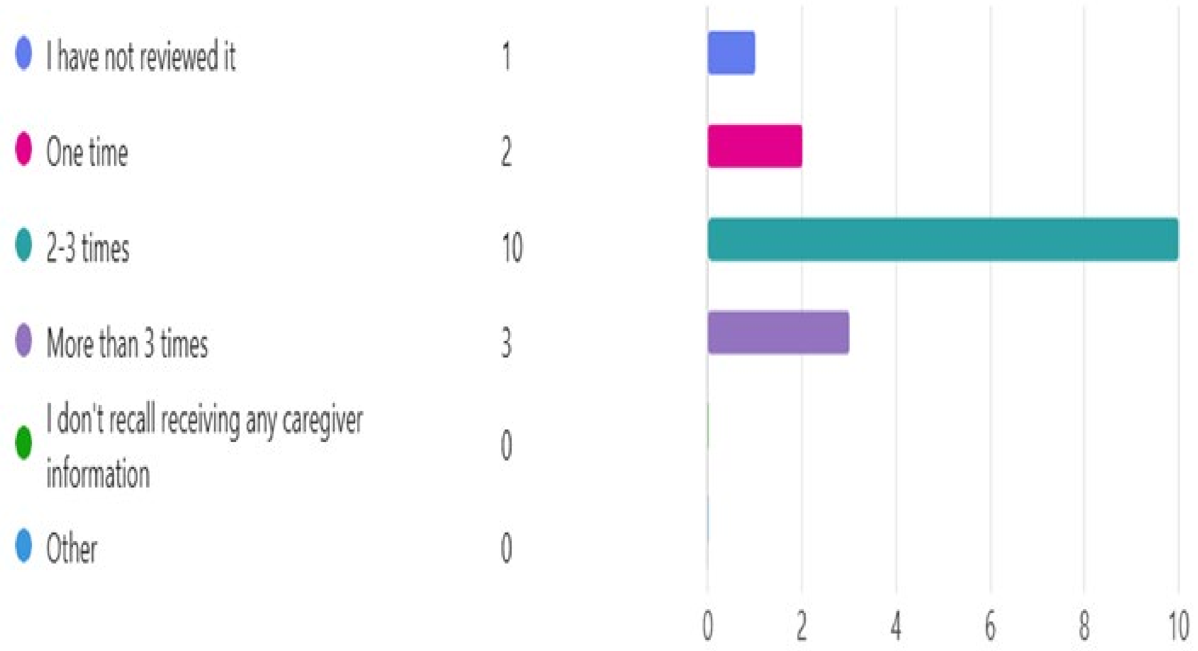
★ ★ ★ ★ ★

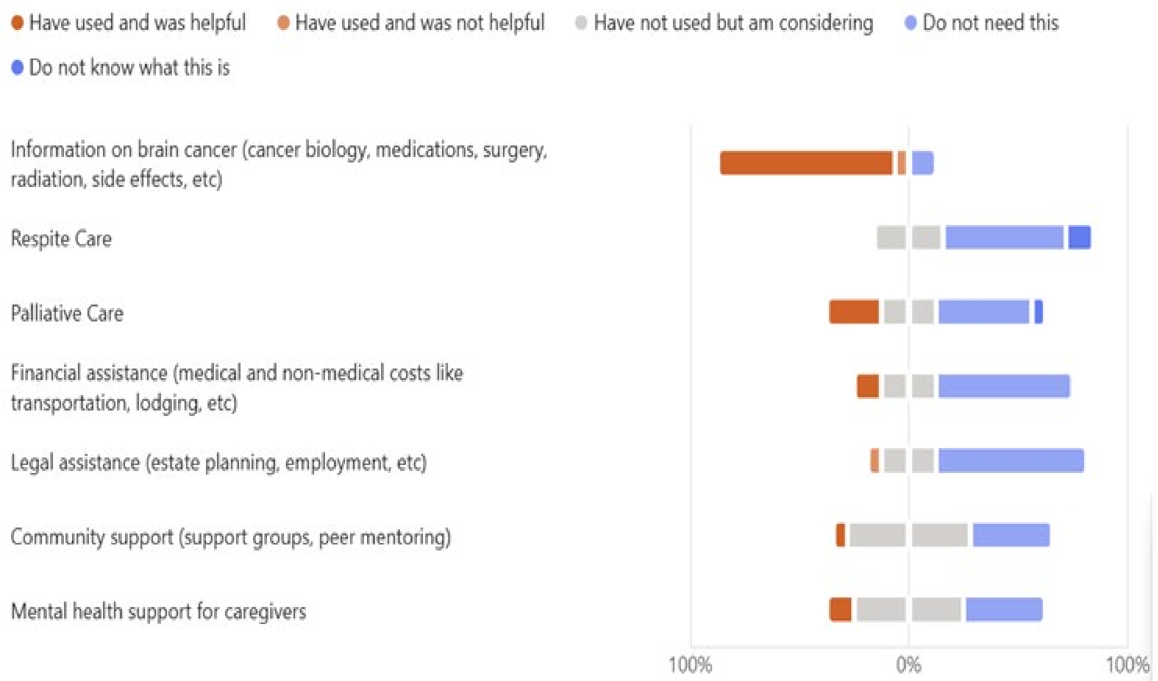
Project Sustainability Rating



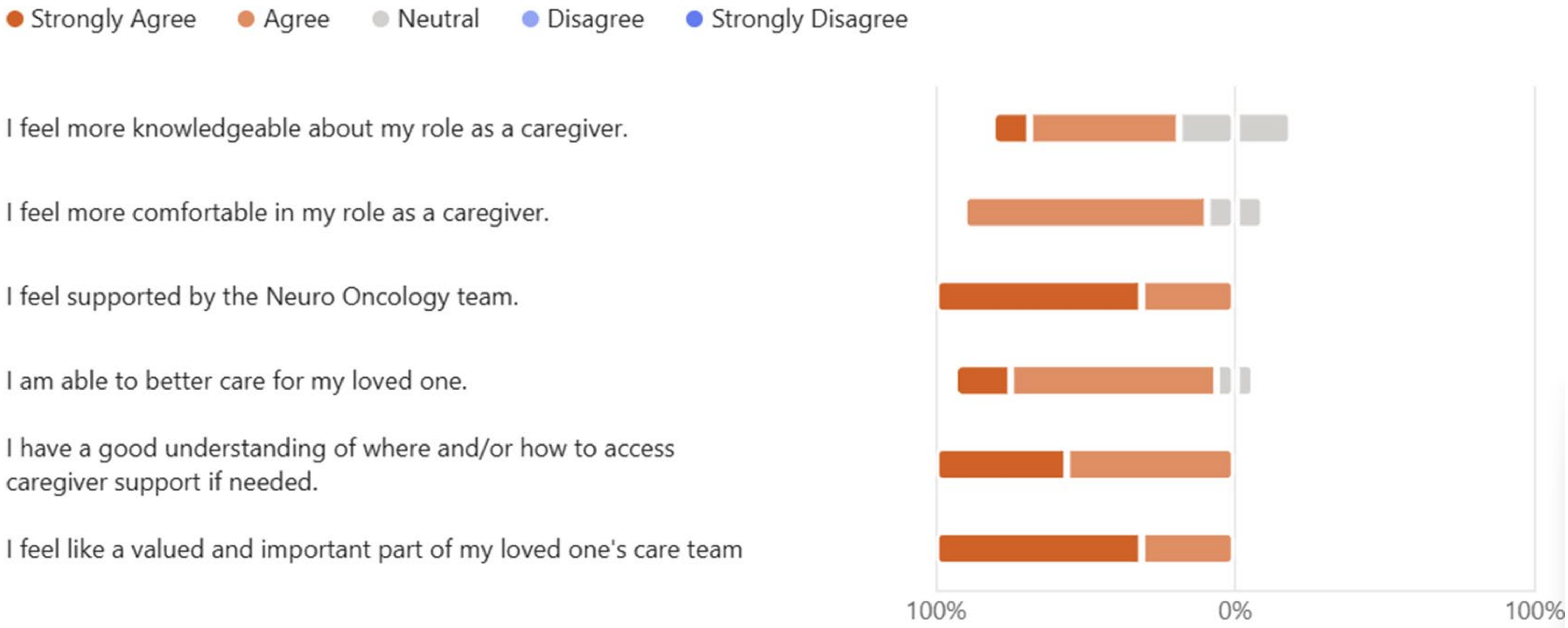
Caregiver Survey Highlights (n= 16)

Number of Times Reviewed	Packet Material Experience





Caregiver Survey Highlights (n=16)



Project Success or Wins

As told by the participants: caregivers & providers

Comments on Packet Material Helpfulness

- “Information about brain cancer” x7 (basic info and treatments)
- “Availability of support and services” x3
- “All of it” x3
- “The support groups and organizations that are available for the caregivers”
- “Websites with real information about treatment, etc”
- “Frequently Asked Questions for Caregivers”
- “The financial help with the chemo medication”
- “conversations with caregivers and pharmacy via myChart and phone calls”
- “I am VERY appreciative of all the information, but the Financial stuff esp. The medical team is amazing at explaining the tumor, side effects etc but for me, the financial weighs very heavy so will definitely be using those resources”

Provider Survey Comments

Successes

Caregivers being surprised and appreciative of having a packet of information that honors who they are as a caregiver,

Group effort in building the project, project tailored to the care needs identified by this specific patient population

Helpful to have a shared documents that all can look back to, ensure that all are getting the same information up front.

Caregivers feeling seen. Understand that our care team is partnering with them as well.

Challenges

Time for providers to complete.

Follow up is challenging when it gets busy.

It took such a long time to complete the "Brain Function" document, that it was not included in Caregiver Toolkit for this project (but will be added in when complete).

RNCC and APP time in adding in this additional teaching.

Possible Revisions

I haven't been very diligent in reminding the caregivers to bring the "caregiver concern" sheet to the APP meeting.

This might be challenging to implement with larger care teams requiring coordination among many different providers.

Providing team with a laminated… Caregiver Concerns copy so we can prompt asking about it…baking it into our process more explicitly.

Reflections

Impressed by the success and positive feedback. Truly admire the care team's dedication to supporting care givers.

I feel that I have more confidence and pride in the way I care for my patients living with brain cancer. I feel that I support them better and can acknowledge issues ahead of time

I am more cognizant of asking about the caregiver's experience when working with my families (whether the caregiver is present in the visit, or not).

Very important initiative. Workflow is straightforward. The process is streamline and very doable within the current workflow.

Suggestions for Care Team

- *“We are still in the first phases, and it is going well. There will be more need for help in the future, I am sure.”*
- *“A web site with all the information condensed. I have some of all over the place. This may exist already but cannot remember.”*
- *“I wish there were a way for a caregiver to ask a question "in secret" so to speak for those few instances where you want to know something that perhaps the patient isn't ready to hear.”*
- *“Having the availability to talk with Dr. Neil one on one without my spouse present would be valuable.”*

Suggestions for Care Team Continued

- *“Maps of hospitals and clinics we are using. Where to park and rates. Which appointments validate parking.”*
- *“More conversations on next steps, what the future plans may look like for the patient so we can have a better understanding of what to expect.”*
- *“Need help to understand how this will progress and when we will need to provide more support.”*
- *“Maybe occasional texts to check in.”*

Next Steps

- Phase II of Project
    - Updating website
    - Further discussion with Neuro Onc team regarding Caregiver Concern screening
- Consider engagement with other disease teams
- We pick up the threads and continue doing the good work

Questions?

Thank You!