

The UPMC-Magee GynOnc Family CARE Center: An Academic – Clinical Partnership to Support Family Caregivers

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GynOnc Family CARE Center at UPMC-Magee Family Caregiver Advocacy, Research & Education Center



The GynOnc Family CARE Center

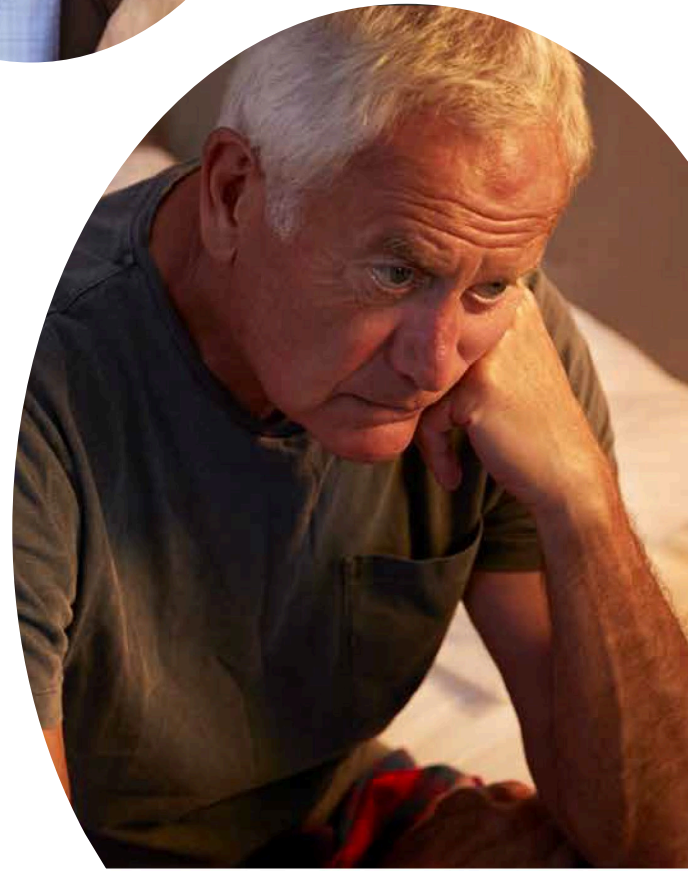
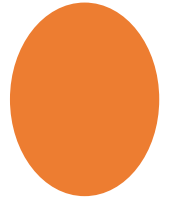


Cancer Reaches Beyond the Patient...
So Should Cancer Care

- Family CARE Center Proposal accepted June 2018
- Stakeholder driven Family CARE Center launched in March of 2019
- Staffed by one dedicated staff member, three nursing faculty and one retired RN volunteer

Our Guiding Principle

- CGs need (but rarely receive) training as valuable members of the healthcare team
- CGs need (but rarely receive) education and support to recognize and manage the emotional and physical stress of caregiving for a loved one.



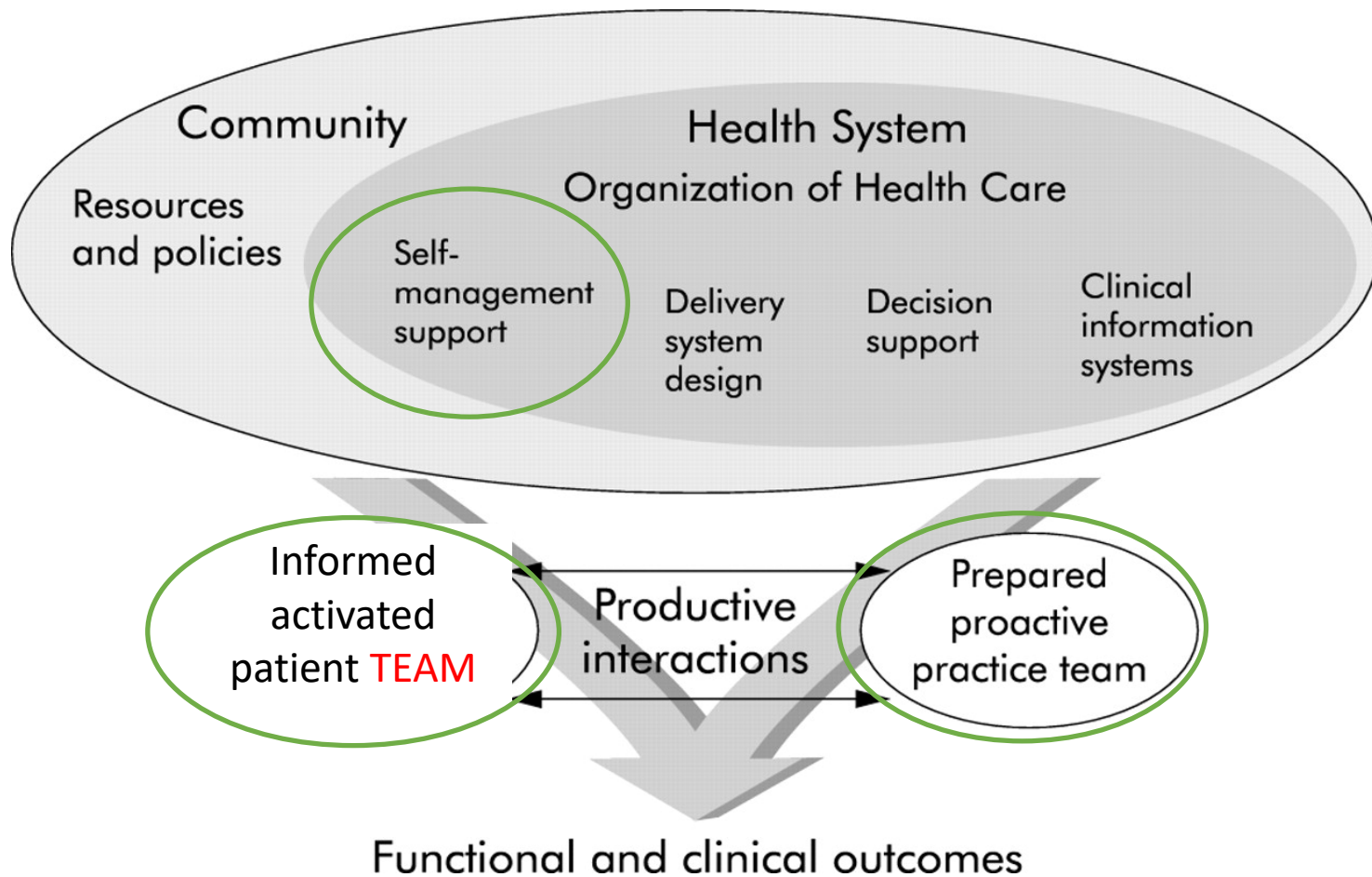
This is best
done through
provision of
“Self-
Management
Support”

Self-Management:

- The tasks of illness-related work for patients and families with cancer.
- “Awareness and active participation by the person **and their family** in their recovery, recuperation, and rehabilitation, to minimize the consequences of treatment, promote survival, health and well being **for the entire family**”.

Barlow et al. Patient Educ
Couns 2002

Self Management Support of Family Caregivers is ESSENTIAL to quality cancer care



Evidence Base for Family CARE Center

Theory: Representational Approach – Road Map
for all subsequent interventions

Donovan & Ward, 2001, Image J Nurs Sch
Donovan et al., 2007, Image J Nurs Sch

Ward/Donovan
Face-to-face pain
management
intervention

Donovan/Ward:
Gynecologic Cancer
Symptom Experience

Ward et al, 2009, Health Psychol
Donovan et al, 2008, J Pain Symptom Manage

Pilot Study of WRITE Symptoms Self-
Management Intervention
Donovan et al., 2014, J Pain Symptom Manage

Cancer Caregiving
Bill & Barb Givens

Alzheimers Caregiving
Rich Schulz - REACH

WRITE Symptoms 3-arm RCT (n=497)
Nurse Delivered vs Self-Directed vs Usual Care in
Recurrent Ovarian Cancer
Donovan et al, 2022, JCO

Sherwood
Distinct Trajectories of at Risk CGs
Most prevalent unmet CG needs
Choi et al., 2012, Ann Behav Med
Boele, 2018, Neuro Oncol

Implementation of Family Support into
Gynecologic Oncology
Campbell et al., 2019, J Oncol Pract


Sherwood & Donovan
SmartCare 3-arm RCT (n=120) of a CG self-
management intervention in neuro oncology
Boele et al., 2022, Support Care Cancer

SmartCare GO – adapting the SmartCare Intervention to an
mhealth intervention to Support Gynecologic Oncology
CGs(ACL/NIDILRR Funding – 2019-2024)
Targeting System-wide UPMC implementation


Self-management support in the Family Care Center is guided by the Representational Approach to patient/family education

Intervention elements	Description	Goal
1. Representational Assessment	In depth assessment of how CG views the problem/issue and its impact on patient and family	Shared understanding between CG and clinician. Motivate CG to make change
2. Identify and address concerns	Discover issues /misunderstandings that interfere with self-management	Reduce barriers successful self-management
4. Provide evidence-based information	Evidence-based CG guides: <ul style="list-style-type: none">• Caring for patient• Caring for self• Communication, support, resources	Promote confidence in ability to effect change
5.Problem solving:	Assist CG to identify realistic goals and strategies to meet goals.	Provide clear roadmap for action
6. Review	Follow up to evaluate progress toward goal; modify plan	Model ongoing iterative process; build relationship

Moving from research to implementation in clinical practice



Fidelity to theory-guided
intervention meets the reality
of a busy outpatient clinical
practice



The Family CARE Center aims to create systems to:

- Identify and document a primary family caregiver (defined and designated by the patient) for every patient seen in the clinic
- Assess and document level and sources of caregiver distress for caregivers of patients diagnosed with cancer receiving adjuvant treatment.
- Provide information, self-management and problem-solving support
- Facilitate referrals to specialty services

A white circle with a green border containing the text "ASCO Quality Training Program".

ASCO[®] Quality
Training Program

WHO IS YOUR CLOSEST SUPPORT PERSON?

The Family CARE Center is a family support program that provides patients and their support persons (caregivers) with information, resources, and supportive services.

For more information, you can call us at **412-641-5605**.

Please leave a message and we will call you back.

Or email us at carecenter@upmc.edu.

When you see us in the clinic, please stop by to talk, get some information and have a cup of coffee or tea.

Please let us know who your closest support person is by filling out this form.

We will put this person in your chart as your “caregiver” so that we know they are there for you.

CG Identification:

- Form now included in all New Patient Packets
- CG Information entered into EPIC with unique caregiver identifier for later use in analyses
- Information entered into CARE Center tracking system for confirmation of cancer diagnosis
- 1,547 Family CGs identified and documented since 2019.

PATIENT CAREGIVER FORM

Today's Date: _____

Patient Name: _____

Patient Birthdate: _____

My closest support person/caregiver is my: _____
(mother/father, sister/brother, husband/wife, partner, daughter/son, friend, relative)

Caregiver Name: _____

Caregiver Phone: _____

Caregiver Email: _____

Caregiver Address: _____

Caregiver Assessment



GynOnc Family CARE Center
Cancer Reaches Beyond the Patient; So Should Cancer Care

Dear Family Support Person,

The hospitalization of a family member or close friend is a stressful experience. In addition to the worry you may have about your loved one, you may also be learning new information or skills to help her as she goes home from the hospital. The Family CARE Center, located in the outpatient gynecologic oncology clinic at Magee, is here to support you. Please fill out this card (front and back) so that we can reach out to you about any of your questions or concerns. Also feel free to stop by our office in Suite 1750, or reach out by phone (412-641-5605) or email (CARECenter@upmc.edu).

Date: _____

Support Person's Name: _____ Age _____ Gender _____

Your phone: _____ Your email: _____

Please identify who you are supporting (mother, father, sister, wife, partner, son, daughter, friend, other) _____ who has cancer.

Do you live with your family member/friend with cancer? ____ Yes ____ No

Do you have children living in the home with you? ____ Yes ____ No

Name of patient with cancer: _____

Patient's Birthdate (MM/DD/YEAR): _____



GynOnc Family CARE Center
Cancer Reaches Beyond the Patient; So Should Cancer Care

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress

No distress

Check any of the following issues that are contributing to your overall distress:

- ☐ Need for information on the cancer
- ☐ Need for information about cancer treatment
- ☐ Managing patient symptoms
- ☐ Managing patient medications
- ☐ Maintaining your emotional health
- ☐ Maintaining your own physical health
- ☐ Finding time for yourself
- ☐ Spiritual Concerns
- ☐ Finances
- ☐ Legal Issues
- ☐ Transportation/Parking
- ☐ Work/Employment issues
- ☐ Self-Confidence as a caregiver
- ☐ Communicating with providers
- ☐ Talking with others about cancer
- ☐ Relationship with patient
- ☐ Family Dynamics

Multiple Approaches to Completing CG Assessment

Proactive Outreach by CARE Center

- In-person; telephone; email outreach to CGs identified through New Patient Form
- Student and staff rounds on inpatient unit

Referrals to CARE Center

- Clinician referral – MDs, APPs, RNs, SW/Navigators; Palliative Care
- Clinician integration of assessment card into daily practice

What We Have Learned from Caregiver Assessments (n=515)

Who are our Caregivers?

- Men (52.4%)
- 56.5 years old (SD=14.6)
- Supporting:
 - Spouse/partner: 41%
 - Mother: 30%
 - Sister: 13%
 - Living with patient (56%)

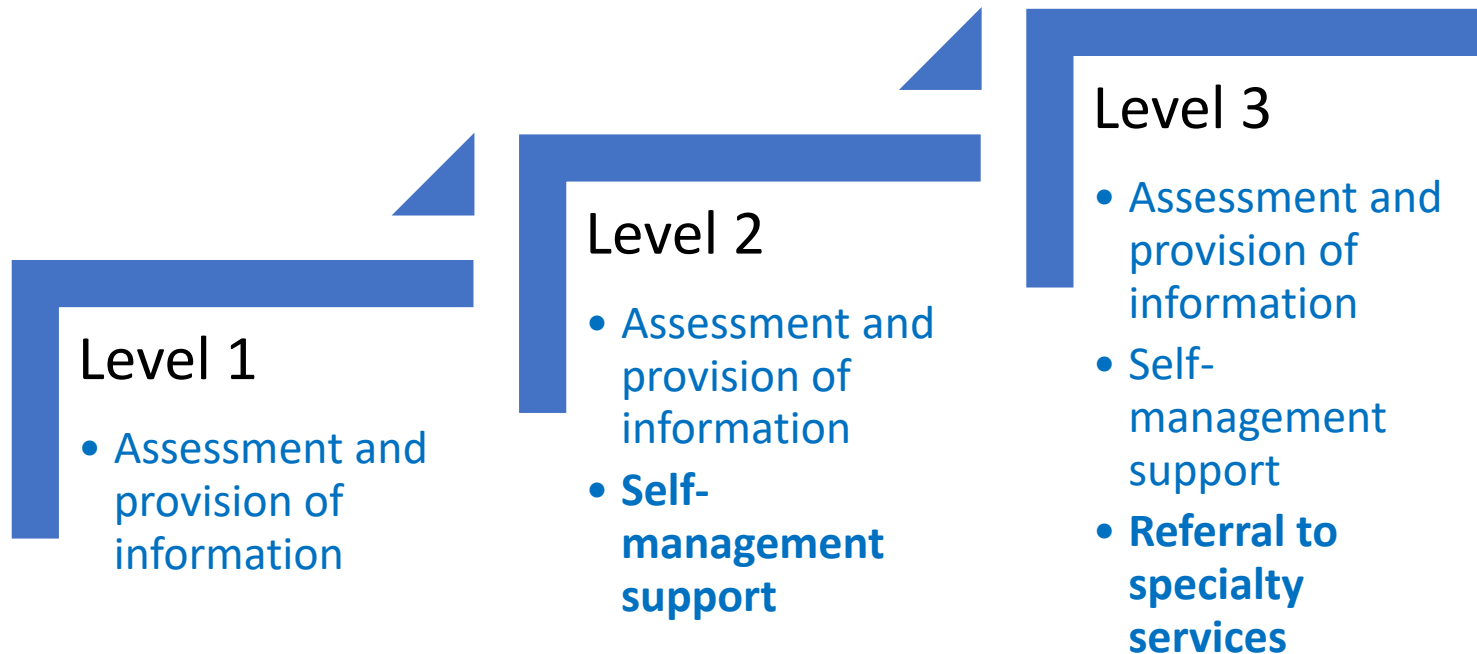
Mean CG distress = 4.3 (SD=3.3)

Needs related to providing care
Needs related to caring for self

Most frequently identified CG Needs:

- Managing patient symptoms (44%)
- Information about cancer treatment (40%)
- Maintaining your own emotional health (36%)
- Need for information on the cancer (31%)
- Financial issues (22%)
- Transportation/Parking (20%)
- Maintaining your own physical health (19%)
- Finding time for yourself (19%)
- Communicating with healthcare providers (18%)
- Managing patient medications (18%)
- Self-Confidence as a caregiver (17%)
- Family dynamics (17%)

Tiered Caregiver Support



Level 1 - Assessment and Provision of Information: 19 Self-Management Guides for Family Caregivers

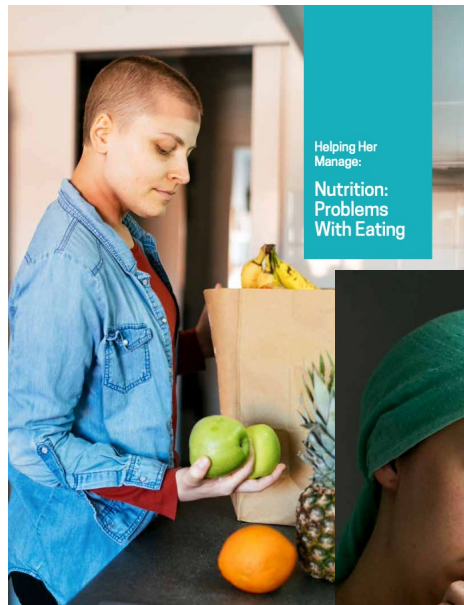
1. Caring for the Caregiver

- Healthy Lifestyle
- Emotional Health



2. Helping Her Manage

- Symptoms/Side Effects
- Nutrition
- Stress of Cancer



3. Finding Support

- Communication
- Employment/Legal



Individualized
Self-
Management
Support

Rep Approach philosophy – less
protocolized

Teaching/supporting CG to
maintain their own emotional
health

CG education about symptom
management

Proactive information, decision
making support

Referrals – with a warm hand-off

-
- Vetted online resources
 - Referrals to specialty services (behavioral oncology, palliative care navigation)
 - Connection and warm handoffs to community organizations resources



Integrating our Teaching/Training mission with the Center

- Undergrad research students: Expansion of CG assessment to in-patient unit
- Graduate Students (Nursing and Information Sciences)
 - Development of intervention manual and training videos for students
 - Implementation and evaluation of a CG orientation “bootcamp”
 - Development of searchable database of resources
 - Development of charting template to quantify process and outcomes
- GynOnc Fellow: Leadership and grant and manuscript writing

Barriers and Challenges

- Electronic Health Record (EHR) integration
 - If it wasn't charted, it wasn't done
 - Ethical/Legal implications of charting on CG in patient chart
- Data collection & management
 - Clinical care vs. research assessment.
 - What is the sweet spot?
 - Demonstrating outcomes – what counts?

Next Steps

- SmartCare G.O. – mhealth supported implementation project to begin in 2023
 - Campbell & Donovan
- Implementation package for dissemination
- Move toward further integration with clinic staff



NATIONAL CENTER
ON FAMILY SUPPORT

(ACL/NIDILRR 90RTGE0002).
Donovan, Beach and Parmanto

2:21

< Back Goals and Plans

Let's evaluate how her fatigue has affected both of you

In the past week, how distressed have you been about her Fatigue?

0	1	2	3	4	5
6	7	8	9	10	

How severe is her Fatigue?

0	1	2	3	4	5
6	7	8	9	10	

How much has Fatigue interfered with her daily activities?

0	1	2	3	4	5
6	7	8	9	10	

Previous Preview

2:22

< Back Goals and Plans

My Goal is to * [More Info](#)

Help her sleep more

With a timeframe of *

In 2 weeks

So that... *

- ☐ She can do the things she enjoys doing
- ☐ She can return to work
- ☐ She can help more around the house
- ☐ She feels better emotionally
- ☐ I could worry less
- ☒ We can spend more time together
- ☐ I feel less overwhelmed
- ☐ Other (describe)

Thank You

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**On behalf of the Women's Cancer
Research Group at Pitt &
Duquesne Schools of Nursing:**

Dr. Heidi Donovan

Dr. Grace Campbell

Dr. Teresa Thomas

Dr. Young Ji Lee

Mary Roberge

Patty Jo Murray

The National Rehabilitation Research and Training Center on Family Support
at the University of Pittsburgh presents:

Building Bridges: Advancing Family Caregiving Research Across the Lifespan

Second Biennial Conference on Caregiving Research

September 30 - October 1, 2022

<https://www.caregiving.pitt.edu/2nd-conference-caregiving-research>