

Caregiver Navigation Toolkit

July 2019

A guide for hospital administrators, providers, and staff

Acknowledgments

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Purpose of Toolkit

How can this toolkit be used?

There are three main purposes for this toolkit:

1. Identify the basic components of a Caregiver Navigation Project
2. Describe how to launch a Caregiver Navigation Project in your hospital
3. Know where to go for more information

How was this toolkit developed?

This toolkit was developed by reviewing Caregiver Navigation Program materials from Dignity Health Home Care and interviewing staff and others who are knowledgeable about caregiver navigation programming. We organized this toolkit based on concepts from principles-based design and developmental evaluation (Patton, 2018). This approach is ideal for adapting programs to new settings once a basic program structure has been delineated. The following toolkit provides guidance on key program components and principles of effective implementation while allowing space for adaptation and innovation. Thus, this toolkit aims to assist other hospitals in understanding the key ingredients (or components) of a Caregiver Navigation Program while balancing the need for appropriate adaptation. It is intended to provide a starting place for others to build upon. We wish you luck in your program implementation adventure!

We attempted to land in the perfect, in between place of:

No Guidance

“Do whatever you want!”

Just the right amount



This Toolkit

Too Much Guidance

“Do EXACTLY what we did!”

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- 4. Appendix:** Please note that additional materials are available online [here](#).
The online Appendix includes the following (and additional materials):

Getting Started

[Caregiver Support Program Description](#)
[Caregiver Support Program PowerPoint](#)
[Caregiver Support Program Setup Checklist](#)
[Example of Caregiver Support Program Flyer](#)

Assessment Tools

[Example of Psychosocial Assessment for Caregiver/Care Recipient](#)
[Example of Referral Tracking](#)
[Patient Health Questionnaire](#)
[Zarit Burden Interview Instructions \(English, Spanish\)](#)
[Zarit Burden Interview Scoring](#)

Staff

[Example Job Description for Licensed Clinical Social Worker](#)
[Example Job Description for Support Clerk](#)

Referrals

[Atlas of Caregiving CareMap \(English, Spanish\)](#)
[Powerful Tools for Family Caregivers Flyer](#)
[Example Flyer for Caregiver Support Meeting](#)

Community Partner Identification

[Example of Program Volunteer Brochure \(English, Spanish\)](#)
[Onboarding Resources for Volunteers PowerPoint](#)

Budget

[Example Spreadsheet to Track Funding Sources](#)

Evaluation

[Evaluation Overview](#)
[Hospital Roles in Evaluation Data Collection](#)

Program Overview

A Caregiver Navigation Program is:

...a hospital-based program to support caregivers of medically fragile Medicare-eligible adults after an acute care hospitalization.

The program goals are to:

1. Support caregivers to manage complex medical care at home after an acute care hospitalization
2. Improve the health, well-being, and quality of life of caregivers and care recipients
3. Support hospitals in treating families as the unit of care
4. Reduce hospital re-admissions
5. Improve health outcomes and provision of value-based services

Return on Investment

“By and large, we are discharging patients into the care of family members...if they are not trained, aware, and educated, patients are likely to end up back in the hospital.”

- University of Pittsburgh Medical Center Researchers

What’s the ROI on Caregiver Navigation?

Caregiver Navigation Programs have the ability to:

1. Reduce unnecessary hospital readmission rates and penalties
2. Bolster a hospital’s ability to bill for value-based services
3. Improve health care quality scores

How do we know that programs can do this?

Promising Research and Evaluation Findings

- ✓ Data from the Caregiver Support Program implemented at Marian Regional Medical Center showed favorable findings related to **reducing caregiver burden and lowering hospital readmission rates**. Specifically, program data indicated that emergency room admissions were trending to an annualized 55% reduction and hospital admissions were trending to an annualized 35% reduction.
- ✓ According to research from the University of Pittsburgh Medical Center, healthcare organizations that practice meaningful family caregiver engagement and integrate caregivers into the patient discharge process can **reduce hospital readmissions by one-quarter**. The study found that the chance of 90-day readmission was reduced by 25 percent and 180-day readmission by 24 percent when providers integrated caregivers into the discharge process.
 - “With proper training and support, caregivers are more likely to be able to fulfill these responsibilities and keep their loved ones from having to return to the hospital.”
 - “Properly engaging family caregivers can help mitigate potential Hospital Readmissions Reduction Program (HRRP) penalties.”
- ✓ Research by the National Bureau of Economic Research found that **family caregiving can substantially reduce hospital costs and improve the health status** of people with disabilities. They found that family caregiving at home could replace some amount of hospital care.
 - When family caregivers were supported (with financial and other support), patients were a **third less likely** to use the emergency room and only **half as likely** to be admitted to the hospital when compared to those getting standard care. Those who were admitted stayed 13 days less and overall Medicaid spending fell.

Program Components

Figure 1. The 8 Components of a Caregiver Navigation Program



Please note that these are examples for each component. More detailed descriptions are included in the next section of this toolkit.

Principles

What effectiveness principles guide our work?

“An effectiveness principle is a statement that provides guidance about how to think or behave towards some desired result... based on norms, values, beliefs, experience, and knowledge.”

“A principle is prescriptive. It provides advice and guidance on what to do, how to think, what to value, and how to act to be effective. The wording is imperative: Do THIS!”

- Michael Q. Patton

Administrators and program staff should use principles to inform and guide programmatic choices and decisions. Thus, principles need to be regularly reviewed, thoughtfully considered, and applied – in planning meetings, staff meetings, trainings, and evaluation – to inform decisions relating to program activities. The following principles are offered for each component of the Caregiver Patient Navigation Program.

1. **Staff:** Ensure the Caregiver Navigation Program staff are trained to identify and engage family caregivers, have excellent skills to develop rapport and trust, are culturally competent and able to engage in other languages, and believe in the value of integrating caregivers into the health care team. Support staff to work both independently and as a team.
2. **Caregiver assessments:** Conduct assessments – with caregivers and care recipients in the home, if possible – to understand and focus on caregivers’ needs using standardized assessments. Make sure the assessment process is positive and supportive, not burdensome. Reassess to identify and track changing needs.
3. **Care planning:** Identify and work to address the unique needs of each caregiver and provide them with ongoing support.
4. **Community Partner Identification:** Work both within and outside the hospital walls to educate others about services offered by the Caregiver Navigation Program.
5. **Referrals:** Facilitate start-to-finish “active referrals” to comprehensive services in ways that make it easy for caregivers to access needed services. “Warmly hand-off” caregivers and then make sure services have been received. Continue to monitor and offer repeat or new referrals, if needed.
6. **Education:** Provide high-quality, convenient, training and educational opportunities for caregivers, health care providers, and other hospital staff to achieve desired program outcomes and system changes. Use evidence-based curricula – such as “Powerful Tools for Caregivers” – when possible.
7. **Integration into Health Systems:** Identify a hospital administrator/leader who will champion and support the program with resources, vision, enthusiasm, and commitment. Develop, support, and monitor systems to ensure consistent referrals and fully integrate caregivers and the Caregiver Patient Navigators (CGPN) into health care teams. Build the cultural norm that caregivers will be included in care planning and other aspects of health care delivery. Be a catalyst for the organizational and cultural shift to prioritize care and treatment of “the family unit”.
8. **Program Monitoring, Evaluation, and Learning:** Prioritize ongoing learning and program improvement as the work unfolds. Discuss program successes and challenges in structured, regular venues and evaluate the effectiveness of the program.

Principles

What else shall we consider?

The following section provides additional details about the eight effectiveness principles and offers suggestions to guide day-to-day program implementation. The following pages include “things to consider” as each program will need to adapt to their context in order to best meet program goals.



1 - STAFF

Things to consider when staffing a Caregiver Navigation Program. Staff need:

1. High levels of internal motivation to be able to work independently, without direct ongoing supervision, and the ability to work well with a team.
2. Well-honed cultural competence skills and the ability to engage caregivers in other languages using a Promotora or language line and be willing to work closely with others who support culturally diverse populations.
3. Experience and/or training in assisting caregivers and families with caregiving responsibilities (for example, a person who is a Licensed Clinical Social Worker or similar license).
4. Expert skills in developing rapport and trust with caregivers, care recipients, and others.
5. The ability to “get things done quickly” in complex health care settings and know how to creatively integrate the program into current hospital operations.
6. The skills to be able to influence the culture of a hospital by supporting how caregivers interact with the health care team.
7. The ability to maintain or develop strong professional relationships across the organization at every level.

Example job descriptions are included in Appendix.



2 – CAREGIVER ASSESSMENTS

Things to consider when conducting assessments to help caregivers and their families include:

1. Focus on deducing the primary needs of the caregiver and conduct ongoing assessments at the beginning, middle, and end of work.
2. Determine caregiver needs by using commonly used assessments that measure things such as caregiver burden, caregiver coping skills, and depression levels.
3. Gather information from caregivers in a respectful, kind manner, preferably in the home.
4. Collect a reasonable amount of assessment data to not overly burden or stress caregivers.
5. Incorporate the clinical judgement of program staff and others into the assessment process.

Commonly used assessments are included in the Appendix.

Principles



3 – COMMUNITY PARTNER IDENTIFICATION

Things to consider in identifying community partners include:

1. Program staff work outside the hospital walls to identify available services and high-quality programming for caregivers.
2. This work can include bringing caregivers who need support into the hospital's program.
3. Partner identification also includes relationship building and identifying the right person to contact in order to link caregivers and care receivers to needed services.

Documents to assist with partner identification are included in the Appendix.



4 – CARE PLANNING

Things to consider in creating and implementing a care plan include:

1. The care planning process is unique in that it focuses on the caregiver and the ways in which supporting a caregiver leads to supporting the care recipient.
2. The implementation of the care plan includes meaningful, ongoing support for the caregiver lasting at least 90 days.



5 - REFERRALS

Things to consider in the referral process include:

1. Caregiver Patient Navigators (CGPNs) connect caregivers and care receivers to needed services that were identified during the assessment process.
2. Referrals need to be done in a manner that allows caregivers and care receivers to easily and seamlessly access support and needed services.
3. Warm handoffs (in-person introductions, etc.) can ensure caregivers and care receivers are actively connected to needed services with minimal effort on their part.

Documents to assist with the referral are included in the Appendix.



6 – EDUCATION

Things to consider in the process of educating caregivers, health care providers, and others include:

1. Use evidence-based curricula for caregivers (which typically have multiple sessions) such as "[Powerful Tools for Caregivers](#)" or similar classes.
2. Focus on educating caregivers primarily, but also educate health care providers and others who interact with caregivers.
3. Provide both formal and informal education for health care providers (for example, training combined with hallway conversations and/or role modeling ways to meaningfully engage caregivers in a health care team)
4. Consider having a variety of community service providers, not just program staff, provide a variety of education and training.

Principles



7 - INTEGRATION INTO HEALTH SYSTEMS

Things to consider in ensuring the program is integrated into the health system:

1. Identify a champion in hospital administration who will support the program with resources and spread positive information about the work.
2. Work to ensure the Caregiver Navigation Program is known and respected by most hospital staff.
3. Formally document and consistently implement standard workflows to ensure consistent referrals of caregivers to program.
4. Train health care providers how to specifically include caregivers as part of health care team.
5. Make it the cultural norm to include caregivers in various aspects of health care delivery.



8 – PROGRAM MONITORING, EVALUATION, AND LEARNING

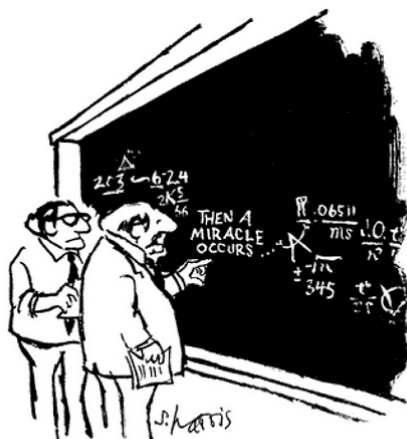
Things to consider in this area:

1. Conduct ongoing program monitoring to describe the type and amount of work done (including the number of individuals served, referrals made, and services provided, etc.).
2. Conduct evaluation activities that focus on how well the program met its intended goals and program effectiveness.
3. Engage in ongoing learning. Use intentional and structured practices to reflect on and change day-to-day work based on feedback and data to produce better outcomes.

Documents to assist with the program monitoring, evaluation, and learning are included in the Appendix.

Logic Model

How and why your program leads to what you want!






"I think you should be more explicit here in step two."

Image: Sidney Harris

Logic Model: Making EXPLICIT how what you are doing leads to what you want.

In order to understand how the activities implemented in your program will likely lead to the changes you would like to see in your context, it is important to create a logic model. A logic model is simply your theory of how changes happen in your hospital. The logic model on the next page describes how we (the authors) envision the Caregiver Navigation Program leads to specific outcomes. This logic model can be adapted to fit the details of your program and your intended goals.

Logic Model

| <p><i>If these activities happen,</i></p> <p>Program Activities</p> | <p><i>then, in the first year, we will see...</i></p> <p>Short-term outputs/outcomes</p> | <p><i>within 2 to 3 years...</i></p> <p>Long-term outcomes</p> | <p><i>after 3 years...</i></p> <p>Impacts</p> |
|---|--|---|--|
| <p>Caregiver (CG) and Care Recipient (CR) Focused:</p> | | | |
|  <p>Caregiver Patient Navigator (CGPN):</p> <ul style="list-style-type: none"> • Conducts outreach to CG, home visit, and assessments • Tracks progress of CR and CG from intake to 3 years • Provides CG gift basket and folio/satchel • Helps CG complete care map • Meets with hospital staff, groups, to explain program • Meets with community organizations to establish referral systems | <p>Caregiver Patient Navigator:</p> <ul style="list-style-type: none"> • Creates evidence-based plan of care for caregiver • Makes and tracks referrals, as appropriate • Provides CG in-depth support and case management <p>Caregiver:</p> <ul style="list-style-type: none"> • Offered/attends Powerful Tools for Caregivers class • Accepts recommendations provided | <p>Caregiver Reports:</p> <ul style="list-style-type: none"> • Increased confidence, skills, coping • Ability to provide higher quality care to care recipient • Being treated as a valued care team member • Reduced caregiving burden <p>Caregiver and Care Recipient Report:</p> <ul style="list-style-type: none"> • Improved satisfaction with providers and hospital • Supported in language, culture | <p>Caregiver and Care Recipient:</p> <ul style="list-style-type: none"> • Supported and able to manage complex medical care at home after acute care hospitalization • Improved health/well-being/quality of life |
| <p>Healthcare Provider Focused: (Physicians, Nurses, Medical Assistants, and other Hospital Staff)</p> | | | |
|  <p>Caregiver Patient Navigators (CGPN):</p> <ul style="list-style-type: none"> • Hired/trained for CGPN role <p>Healthcare Providers:</p> <ul style="list-style-type: none"> • Identify patients who fit criteria for referral to CGPN • Refer CG to CGPN • Welcome CR and acknowledges CG • Engage and asks questions of CG | <p>Healthcare Providers:</p> <ul style="list-style-type: none"> • Know when and how to engage CGPN • Talk with both CR and CG about any help needed when leaving hospital • Understand medical role of caregiver • Update CG info in all medical records | <p>Healthcare Providers Report:</p> <ul style="list-style-type: none"> • Engaging CG as care team member • Increased satisfaction with CR/CG interactions • Increased job satisfaction | <p>Healthcare Providers:</p> <ul style="list-style-type: none"> • Treat families as the unit of care • Attribute better patient outcomes to caregiver program • Spend more time working to the highest level/scope of their practice |
| <p>Hospital System Focused:</p> | | | |
|  <p>Hospital:</p> <ul style="list-style-type: none"> • Establishes effective referral system to CGPN • Integrates CGPN and CG into appropriate clinical workflows • Develops workflows so CGPN can make referrals to outside resources • Creates/enhances data tracking systems/EMR to integrate caregiver | <p>Hospital:</p> <ul style="list-style-type: none"> • Integrates CGPN and CG into hospital systems • Provides every patient an opportunity to designate a caregiver upon admission to hospital • Obtains signed consent for release of information and places in medical record • Ensures patients have advanced care directives in medical record • Trains Providers/Residents in CGPN protocol | <p>Hospital Reports:</p> <ul style="list-style-type: none"> • Reduced CR ER and hospital re-admissions • CG support program is embedded into health system • CGs are integrated across the continuum of care • Greater adherence to the California Hospital and Family Caregiver Law | <p>Hospital Return on Investment:</p> <ul style="list-style-type: none"> • Reduced acute care hospitalizations • Reduced hospital re-admissions • Reduced re-admission penalties • Increased value-based services • Increased health care quality scores |
| <p>Community focused activities: Strengthened integration with CG services/support network, Community outreach/engagement, Strengthened integration with other community-based organizations</p> | | | |

Implementation

What are key steps in program implementation?

Have a bias toward action - let's see something happen now. You can break that big plan into small steps and take the first step right away. – Indira Gandhi

The following table outlines key steps in program launch and implementation for approximately 3 years. While the program is sustainable well beyond 3 years, this table summarizes key milestones from program launch through three years. Additional materials are available in the Appendix.

| Timeframe | Key Milestones |
|---|---|
| Months 1 to 3 – Program Launch | <ul style="list-style-type: none">⇒ Staff hired⇒ Program tracking mechanisms established⇒ Referral sources identified |
| Months 4 to 6 – Program Partial Implementation | <ul style="list-style-type: none">⇒ Staff trained⇒ Data tracking systems established⇒ Key organizational partners identified⇒ About 4 of the 8 program components launched⇒ Staff trained in Powerful Tools curricula |
| Months 7 to 12 – Program Full Implementation | <ul style="list-style-type: none">⇒ All 8 program components launched⇒ Data tracking systems utilized consistently⇒ Learning practices begun |
| Year 2 – Program Full implementation and Program Adaptation | <ul style="list-style-type: none">⇒ Key metrics tracked consistently⇒ Adaptations are being made to improve program⇒ Program partially integrated into hospital systems |
| Year 3 – Program Maturation and Sustainability Planning | <ul style="list-style-type: none">⇒ Program fully integrated into hospital systems (workflows fully implemented)⇒ Sustainability plan implemented |

Implementation

What does the program cost to implement?

While program costs will range from hospital to hospital, the following table summarizes typical costs for a caregiver patient navigation program serving about 60 caregivers/family units at a time. Budget based on staff salaries in Ventura County, California.

| <i>Budget Item</i> | <i>Approximate Cost</i> | <i>Notes</i> |
|--|-------------------------|---|
| <i>Staff</i> 1 FTE Caregiver Patient Navigator (Social worker or similar license) .10 FTE Part-time supervisor .50 FTE Part-time Program coordinator | \$90,000/year | CGPN carries a caseload of approximately 60 caregivers at any one time. |
| <i>Supplies</i> | \$6,000/year | Gift baskets, folios, office supplies, program marketing materials |
| Travel costs for transportation to caregiver homes | \$4,000/year | |
| Travel costs for transportation to community providers | \$1,000 year | |
| Office space/overhead | \$10,000/year | Could be provided pro bono by hospital |
| Misc. expenses (staff trainings, other expenses) | \$1,500/year | |
| Total approximate yearly cost | \$112,500/year | |

Monitoring, Evaluation & Learning

Program Monitoring – What was implemented?

Program monitoring is used to describe the types of activities that were done and answer the question of, “What was implemented?” Below are examples of the types of information and activities that can be tracked.

- Demographics of caregiver (age/gender/ethnicity, etc.)
- Demographics of care receiver/patient (age/gender/ethnicity, etc.)
- Number and type of referrals to program
- Number of admissions to programs
- Number of initial home visits
- Number and type of staff encounters/visits with caregiver
- Number of participants in education classes (or # of participants who completed more than half of classes)
- Number of care map workshops offered
- Number of community presentations given
- Number of volunteers recruited
- Number of new community partners
- Length of caregiver engagement in program (# of days)
- Number and type of healthcare providers trained

See additional program monitoring materials in the Appendix.

Program Evaluation – How well did the program work or meet its goals?

Below are examples of potential evaluation questions. These questions can be answered with a variety of data collection methods (such as surveys, electronic medical record data, interviews, etc.).

1. Did caregivers’ quality of life, coping, and related skills improve after program participation?
2. Did patients with caregivers in the program have lower hospital readmission rates after program participation?
3. How impactful was the program to health care providers’ ability to meet patient needs?
4. In what ways and how well did hospitals integrate caregivers/family units into the health care system after 3 years?

See additional evaluation materials in the Appendix.

Learning Practices – How can we do our work better right now?

While learning has many definitions, we define “learning” as practices that bolster a program’s ability to make changes that produce better results. Typically, “learning questions” inform the delivery of a program as it unfolds. Learning questions tend to be answered in shorter timeframes and often include a rapid-cycle feedback process. Below are examples of potential learning questions you may want to explore:

1. What does it take to ensure the right staff are hired for the program to meet program needs?
2. How can we recruit more caregivers in a short period of time?
3. How can we engage more health care providers in education about the caregiver program?
4. How can the program overcome the challenge of limited budget and time?

See additional materials related to learning practices in the Appendix.

Resources

Curricula for Caregivers

Powerful Tools for Caregivers www.powerfultoolsforcaregivers.org

Information on Caregiving

Family Caregiver Alliance www.caregiver.org

National Alliance for Caregiving www.caregiving.org

Health Care Professional Working with Caregivers www.nextstepincare.org

Resources in California

[The Family Caregiving Institute at University of California Davis](#)

[Picking Up the Pace of Change for California's Family Caregivers: Report from Task Force on Family Caregiving](#)

Research on Caregiving

[Home Alone Revisited](#)

[Caregiving in the United States](#)

Citations

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