

Frequently Asked Questions about Guided Care

1. What is Guided Care?

Guided Care is a practical, interdisciplinary model of health care designed to improve the quality of life and efficiency of resource use for persons with medically complex health conditions. A Guided Care Nurse works in partnership with several primary care physicians to provide coordinated, patient-centered, cost-effective care to 50-60 of their chronically ill patients.

2. What is the role of a Guided Care Nurse?

The Guided Care Nurse uses an Electronic Health Record and works closely with the patient, the family, and the primary care physician in conducting eight clinical processes:

- Assessing the patient and primary caregiver at home.
- Creating an evidence-based comprehensive “Care Guide” and “Action Plan.”
- Promoting patient self-management.
- Monitoring the patient’s conditions monthly.
- Coordinating the efforts of all the patient’s health care providers.
- Smoothing the patient’s transitions between sites and providers of care.
- Educating and supporting family caregivers.
- Facilitating access to community resources.

3. What is unique about Guided Care?

Guided Care integrates several previously successful innovations (see bullets in #2) with primary care to make evidence-based, state-of-the-art, chronic care available continuously from professionals the patient trusts. Guided Care is easily adopted by primary care practices.

4. What are the fundamental elements of Guided Care?

- Patients with complex chronic conditions.
- A rigorous curriculum for ensuring that registered nurses possess the skills necessary to practice Guided Care (see #13).
- A Guided Care Nurse co-located with several primary care physicians.
- Eight clinical processes (see #2).
- An electronic health record.

5. How does Guided Care differ from care/case management?

Guided Care includes Care/Case Management – and several other important processes. Unlike most care/case managers, the Guided Care Nurse:

- Is based in the primary care physician’s office.
- Works with the patient long-term, usually for life.
- Provides intensive transitional care.
- Uses motivational interviewing to help patients manage their conditions.
- Provides continuing education, resources, and support for family caregivers.

6. How does Guided Care differ from disease management?

Like disease management, Guided Care provides patients with periodic health education, reminders, and encouragement to adhere to evidence-based guidelines. In addition, the Guided Care Nurse also:

- Establishes a close personal relationship with the patient by conducting an initial comprehensive assessment in the patient’s home; by meeting face-to-face with the patient in

the physician's office, hospitals, and rehabilitation facilities; and by making follow-up home visits.

- Provides comprehensive care for *all* of the patient's conditions.
- Works closely with the patient's family caregivers.
- Works closely with the patient's primary care physician and office staff.
- Facilitates the patient's access to community services.

7. What is the status of Guided Care?

A multidisciplinary team of investigators at Johns Hopkins University and experts from across the nation has:

- Conducted a one-year pilot study of Guided Care that suggested Guided Care improves the quality and efficiency of care, and is feasible and acceptable to physician, patients, and family caregivers.
- Completed a 32-month cluster-randomized controlled trial of Guided Care at eight urban and suburban community primary care practices in the Baltimore-Washington, DC area. This study assesses the effects of Guided Care on a patient's quality of life, insurers' costs, family caregivers' strain, primary care office function, and physicians' and nurses' job satisfaction. Six-month data from the RCT show that Guided Care improves the quality of care, reduces health care costs, reduces family caregiver strain, and produces high job satisfaction among physicians and nurses. Outcomes data from 18 and 32 months is currently being analyzed.
- Based on early RCT results, two of the managed care organizations that participated in the trial have decided to pay for the costs of Guided Care for an additional year.

8. What are patients and family caregivers saying about Guided Care?

Feedback from patients and family caregivers in the Guided Care randomized controlled trial has been very positive. Anecdotal comments include: "It is like having a nurse in the family!" "I think I can do this, now that I have you." "Thank you for all of your help. Since you've been working with me, I'm feeling better." "It is about time someone put together a program like this!" "It is hard to put into words a way to thank you for all you did for my mom and me – you made a significant difference in our lives!"

9. What are primary care physicians saying about Guided Care?

Initial comments from the primary care physicians who have worked with Guided Care Nurses in the pilot study and the randomized controlled trial have been uniformly complimentary. They appreciate the role that the Guided Care Nurse serves in providing coordinated care and improving the health of their patients. Anecdotal comments include: "Guided Care gives you eyes and ears outside the office." "It's like having the hand of the doctor in the patient's home." "I developed a closer relationship with my patients through the Guided Care Nurse." "The Guided Care Nurse saved me time, and made my practice more efficient." "Because of her [the Guided Care Nurse's] coordination, I was better able to care for my patients." "What a wonderful, collaborative boon to patient care!" "I have had patients tell me (without my asking) how exciting they are about the self-management classes, and how attending the sessions has motivated them to make positive changes in their lives."

10. What are Guided Care Nurses saying about Guided Care?

Feedback from the Guided Care Nurses in the randomized controlled trial has been extremely favorable. Anecdotal comments include: "I'm practicing nursing the way it was originally envisioned – holistic patient care." "Patients appreciate immediate access to me and how I assist them through all parts of the system." "I like the patients and the direct access to the physicians. It is great to be in the primary care practice, working in partnership with the doctor."

11. What does a Guided Care Nurse actually do, day-to-day?

Each day in the life of a Guided Care Nurse (GCN) is different, but may include a combination of:

- Assessing a new patient. The GCN conducts an initial in-home assessment of a new patient. The GCN begins by asking the patient to identify his/her highest priorities for optimizing health and quality of life. The GCN then evaluates the patient's medical, functional, cognitive, affective, psychosocial, nutritional, and environmental status.
- Drafting a new patient's "Care Guide." Back at the office, the GCN enters extensive assessment information into the Guided Care Electronic Health Record (EHR). The GCN then prints an evidence-based "Care Guide," which will become a blueprint for the patient's health care for rest of his/her life.
- Completing a new patient's Care Guide. The GCN meets with the primary care physician to personalize the Care Guide (see #15) according to the unique circumstances of the individual patient. Later the GCN discusses the Care Guide with the patient and family caregiver and modifies it further for consistency with their preferences, priorities, and intentions. The completed Care Guide provides a concise, comprehensive summary of the patient's status and plans. The GCN then converts the information contained in final Care Guide into a patient-friendly "Action Plan" (see #16), which is written in lay language and displayed prominently in the patient's home to remind the patient to take medicines on time, eat proper foods, engage in healthy physical activity, self-monitor, keep appointments with health care providers, and call for help when needed.
- Monitoring patients' conditions. With reminders from the EHR, the GCN monitors each patient at least monthly by phone. The GCN also meets with patients during their regular office visits with their primary care physicians. The GCN is accessible by cell phone to patients and caregivers for problems that emerge between monitoring calls and office visits. The GCN discusses the patients with their primary care physicians, implements appropriate action, and updates Care Guides and Action Plans.
- Promoting self management. The GCN promotes patients' self-efficacy in managing chronic conditions by referring them to a free, local 15-hour (6 sessions) chronic disease self-management (CDSM) course. The course, developed at Stanford University, is led by trained lay persons and supported by the GCN. In the course, patients learn to refine and implement action plans.
- Coaching. In conjunction with the monthly monitoring calls, the GCN uses motivational interviewing to facilitate the patient's participation in care and to reinforce adherence to the Action Plan.
- Coordinating transitions between sites and providers of care. The GCN coordinates the efforts of all health care professionals as a patient enters an emergency department, hospital, rehabilitation facility, or nursing home. The GCN does not usurp the duties of other professionals, but instead provides each with current information (the patient's Care Guide), explains the GCN role, visits the patient, helps plan and execute discharge and follow up, and meets with the patient after the transition to ensure that care is proceeding as planned.
- Smoothing the patient's transitions between sites of care. The GCN smoothes the patient's path between all sites and providers of care, focusing most intensively on transitions through hospitals. The GCN keeps the primary care physician informed of the patient's status and updates the Care Guide and Action Plan.
- Educating and supporting family caregivers. For the family or other unpaid caregivers, the GCN offers individual and group assistance in the form of an initial assessment, information about resources, quarterly monitoring calls, workshop sessions, and ad-hoc telephone consultation to address family caregivers' questions and concerns as they arise.

- Facilitating access to community resources. The GCN facilitates access to community resources to meet the needs of a patient or family caregiver. For example, the GCN may suggest that a patient or family caregiver contact a transportation service, Meals-on-Wheels, the Area Agency on Aging, a senior center or adult day care center, or the Alzheimer's Association for additional supportive services.

12. What are the requirements for becoming a Guided Care Nurse?

The ideal candidate is a licensed registered nurse with at least three years of home care, case management, community health and/or equivalent gerontologic nursing. The nurse must have an affinity for working with chronically ill older patients and their caregivers, good communication skills, and flexible problem solving skills. The nurse must also be comfortable using electronic health records. All candidates must complete the Guided Care Nurse curriculum and pass an exam to receive a Certificate in Guided Care Nursing from the American Nurses Credentialing Center (ANCC). *Please note that the ANCC Certificate is not a certification, but rather a one-time recognition of professional achievement.*

13. What is unique about the Guided Care Nurse curriculum?

Many of the skills needed for Guided Care are already possessed by many nurses. Other skills may need refreshing:

- Motivational interviewing for behavior change.
- Working with Care Guides (see #15) and Action Plans (see #16).
- Promoting self-management.
- Educating and supporting family caregivers.
- Coordinating transitional care.
- Facilitating access to community resources.
- Operating the Electronic Health Record (see #17).

14. When is the Guided Care Nurse course offered?

For more information or to register for the course, go to <http://www.ijhn.jhmi.edu>. If you have specific questions about the course, please send an email to GuidedCare@son.jhmi.edu.

15. What is a Care Guide and how is it used by health professionals?

The Guided Care Nurse generates the Care Guide from information in the patient's electronic health record (see #17). The Care Guide summarizes the patient's conditions, medications, allergies, diet, physical activity, monitoring reports, care providers, family members, and other important data in a succinct, professional format. It is provided to physicians and other health professionals during scheduled appointments and upon admission to emergency departments, hospitals, home care, rehabilitation, and other venues of care.

16. What is an Action Plan and how is it used by Guided Care patients?

From the Care Guide (see #15), the Guided Care Nurse generates a personalized Action Plan. The Action Plan is written in lay language and displayed prominently in the home to remind the patient to take medicines on time, eat proper foods, engage in healthy physical activity, self-monitor, keep appointments with health care providers, and call for help when needed.

17. Describe the Electronic Health Record used in Guided Care.

The Guided Care Nurse uses an Electronic Health Record (EHR) that incorporates evidence-based guidelines for 15 chronic conditions and is secure (the information is not stored on the computer). The nurse uses the EHR to:

- Check a patient's medications for possible adverse interactions.
- Generate new and revised Care Guides (see #15).

- Document Guided Care Nurse contacts with patients, families, and providers.
- Check for reminders about scheduled events or actions.

18. What data will be available about Guided Care?

- In 2003-2004, the pilot test measured the effects of Guided Care on:
 - Quality of Care. *Boyd CM et al. A Pilot Test of the Effect of Guided Care on the Quality of Primary Care Experiences for Multimorbid Older Adults. J Gen Intern Med. 2008;23(5):536-42.*
 - Effect on healthcare costs. *Sylvia M et al. Guided Care: Costs and Utilization Outcomes in a Pilot Study. Dis Manag. 2008;11(1):29-36.*
- In 2008-2010, the randomized controlled trial will report the effects of Guided Care on:
 - Quality of Care. *Boult C et al. Early Effects of “Guided Care” on the Quality of Health Care for Multimorbid Older Persons: A Cluster-Randomized Controlled Trial. J Gerontol Med Sci 2008;63A(3):321-327. Boyd CM et al. The Effects of Guided Care on the Perceived Quality of Health Care for Multi-morbid Older Persons: 18-month Outcomes from a Cluster-Randomized Controlled Trial. J Gen Intern Med 2010;25(3):235-242.*
 - Quality of Life.
 - Patient satisfaction with health care.
 - Health care utilization. *Leff et al. Guided Care and the Cost of Complex Health Care. Am J Manag Care 2009;15(8):555-559.*
 - Family caregiver strain. *Wolff JL et al. Caregiving and Chronic Care: the Guided Care Program for Families and Friends. J Gerontol Med Sci 2009;64A(7):785-791. Wolff JL et al. Effects of Guided Care on Family Caregivers. Gerontologist 2010;50(4):459-470.*
 - Practice environment. *Marsteller J et al. Physician Satisfaction with Chronic Care Processes: A Cluster-Randomized Trial of Guided Care. Ann Fam Med 2010;8(4):308-315.*

Visit <http://www.guidedcare.org/publications.asp> for full citations or contact Tracy Novak at tnovak@jhsph.edu for copies of articles or for more information.

19. What are the costs of implementing Guided Care?

The costs of implementing Guided Care are the Guided Care Nurse salary and benefits, office space and equipment (laptop computer and cell phone), monthly internet and phone fees, and travel expenses (to patient homes and hospitals). Contact Tracy Novak at novak@jhsph.edu for more information.

20. How can I implement Guided Care in my community?

Read the book “Guided Care: A New Nurse-Physician Partnership in Chronic Care” (Springer Publishing Company 2009) which is an implementation manual for practices that want to adopt Guided Care. Go to www.springerpub.com/guidedcare for more information and to order.

21. Where can I get more information about Guided Care?

Visit the website at www.GuidedCare.org, or contact Tracy Novak at tnovak@jhsph.edu for more information.

22. What are the employment opportunities for a nurse who successfully completes the Guided Care Nursing course?

A nurse who successfully completes the Guided Care Nursing course will be well positioned to work in many “medical homes,” health care organizations that provide comprehensive, coordinated, continuous care to their patients, including those with chronic conditions who require complex services. Two

national Medicare Medical Home Demonstrations will soon begin, plus other demonstrations are underway in more than 30 states. For details, please visit <http://www.cms.hhs.gov/demoprojectsevalrpts/md/list.asp> (scroll down to list to Medicare Medical Home Demonstration) and <http://pcpcc.net/pilot-guide> for activity in the private sector.

23. What is the Guided Care Program for Families and Friends (GCPFF)?

The GCPFF, a component of Guided Care, supports caregivers of adults with complex health needs. The goals of the program are to improve patients' health and improve the well-being of their families and friends. In the trial, the Guided Care nurse managed the following for families of their patients:

- An initial one-on-one caregiver assessment.
- Education and referrals to community resources.
- Ongoing caregiver “coaching” and support.
- Six 90-minute group caregiver workshop sessions.
- Unstructured monthly support group meetings.

Anecdotal comments from families and nurses suggest that families' ready and direct access to nurses so that they can pose emerging questions and troubleshoot concerns is a tremendous comfort to them. The fact that the nurses' job explicitly includes both patients and their involved families, and that nurses roles' include care coordination may simplify some of the challenges of chronic care for patients' family members. In fact, after 18 months in the trial, families of Guided Care patients judged patients' quality of chronic illness care to be significantly better than did family members of patients in the control group. Among employed caregivers, we also observed a trend at 18 months toward greater work productivity (e.g., less distraction while at work) by Guided Care caregivers.

For more information, please visit <http://www.guidedcare.org/caregiver.asp>.