

Tool 7: Understanding and Enhancing the Role of Family Caregivers in the Re-Engineered Discharge¹

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Purpose of This Tool

Patients who benefit from the Re-Engineered Discharge (RED) frequently rely on family members or friends to help them manage their health at home. While families are mentioned in other tools, this tool is different; it targets family caregivers as a critical element in the success of the discharge plan. This tool systematically reviews the challenges they face and the support and training they need from staff in the hospital and beyond.

It is often assumed that the person at the bedside is the family caregiver. But that may not be the case. Identifying the family caregiver—or caregivers, if there is more than one—is an important first step.

We use the term “family caregivers” to refer to individuals who are related by:

- Birth, marriage, or commitment

AND

- Who take on responsibilities for providing various kinds of assistance to the patient. In addition to the emotional support that is the mainstay of family life, family caregivers manage medications, coordinate care, take care of financial matters, and provide personal care, skilled medical and nursing care, and household tasks.

This tool is intended to highlight the roles and needs of family caregivers in the hospital so that they are partners in improving transitions and reducing readmissions. Along with Tool 4, which addresses the special circumstances of delivering RED to diverse populations, this tool broadens the RED perspective to include the skills, potential, and care-related needs of family caregivers.

Understanding the Role of Family and Community

Many discharge plans assume a considerable amount of family care.

- The patients most at risk of hospital readmission are often too sick, cognitively impaired, or otherwise unable to “self-manage.”

¹ This tool was developed by the United Hospital Fund (UHF) in collaboration with **Project Re-Engineered Discharge (Project RED)**. *Authors:* Carol Levine and Jennifer Rutberg, United Hospital Fund; Brian Jack, MD, and Ramon Cancino, MD, Project RED. UHF is a nonprofit health services research and philanthropic organization in New York City. Its Families and Health Care Project stimulates the development of partnerships between family caregivers and health care providers. Project RED is a research group at Boston University Medical Center that develops and tests strategies to improve the hospital discharge process in a way that promotes patient safety and reduces re-hospitalization rates. This toolkit was originally funded by the Agency for Healthcare Research and Quality.

- The best discharge plan may fall apart if one key partner—the family caregiver—cannot do the job.
- If family caregivers are not involved in planning, they may not understand what is expected of them. They also have no opportunity to discuss problems or issues in the care plan or to express their unwillingness or inability to participate in some or all aspects of care.

Five Steps to Integrating Family Caregivers into the Discharge Plan

Step 1: Identify the Family Caregiver

You will need to think about:

- Who in the care team will identify the family caregiver and the role that caregiver plays in the patient's care.
- How that information will be gathered. This includes the most appropriate and feasible time during the hospitalization and what tools and skills will be used.
- Where that information will be recorded so that hospital staff can always easily know who the family caregiver is and, in cases of multiple caregivers, what each caregiver's role is (such as managing medications or assisting with mobility).

Some hospitals begin the identification at the initial nursing assessment on the hospital unit. Other hospitals include family caregiver identification as part of a social service or care management assessment. As with other RED components, it might make sense to try several scenarios to discover what works best in your hospital, with staff, and processes.

Points to consider:

- **About the family caregiver:** Anyone who provides care or coordinates care is a family caregiver. This could be a member of the patient's biological family, a partner, or a friend. The family caregiver can live with the patient, nearby, or in another region. Sometimes there are several family caregivers with different roles and responsibilities. Clarifying these distinctions can help you identify specific areas of need.
- **Finding the family caregiver:** Assess each situation independently. You should not assume that whoever surrounds the patient's bed are his or her family caregivers. They may be "covering" for the family caregiver, who may have other duties (job, child care) during your visit with the patient. In addition, many patients do not identify the family caregiver as a "caregiver." If possible, ask the patient who assists him or her at home. Who do they call in case of emergency? Who helps with medication, food preparation, coordinating or travel to doctor appointments, and other daily tasks? The idea of someone "helping" may be difficult for some patients; "goes with you" to doctor appointments or "deals with" medication may be phrases that elicit more information.
- **Multiple family caregivers:** Try and identify the person most likely to assume responsibility for care after discharge. Who lives in closest proximity to the patient? Who seems to be more knowledgeable about the patient and his or her condition? Who seems to have more capacity

for care or care coordination? Be aware and sensitive to personal, family, and community dynamics (see Tool 4: How To Deliver the Re-Engineered Discharge to Diverse Populations).

- **Documenting and sharing:** Record the family caregivers' names, contact numbers, and roles in care. Store this information so that it can be easily accessed by all care team members and use this information to coordinate the care plans and address educational and training needs.
- **Communication:** As discussed in Tools 3 and 4, ask the family caregiver which language is preferred and use your hospital's language interpreter services to ensure high-quality communication. Often a person at the patient's bedside is the family member or friend who is most fluent in English. The actual family caregiver may be at home or work, or even be listening quietly in the background due to low English proficiency.

Sometimes a patient is unable to name a family caregiver, often due to reluctance to burden a family member or confusion from delirium or dementia. In such cases, a "next of kin," emergency contact, or a person at the bedside can be asked. Here is a suggested script for opening that discussion:

Hello, I am (*your name*). I am the (*your job title*) for (*patient's name*). We start planning for discharge early on, and it is important that we work together with the people who help (*patient's name*). Do you know who those people are and how I could contact them, or do you know who I could ask?

Step 2: Assessing the Family Caregiver's Needs

A caregiver needs assessment is a tool to help identify strengths and limitations and to develop a realistic plan for the next stage of care. The goal is two-fold:

1. Ensure that the patient's health and well-being are maintained and enhanced; and
2. Ensure that the caregiver's capacities and needs are considered and addressed in a care plan.

Introduction to the Guided Caregiver Self-Assessment of Needs

There are **four critical concepts** in caregiver needs assessment:

1. **Structured assessment.** The needs assessment is a structured method for eliciting the family caregiver's assessment of his or her own abilities and limitations (*guided self-assessment*). The assessment tool is a guide for nonjudgmental discussion about what the family caregiver feels he/she can do, could do with training, and cannot realistically do, as well as the caregiver's other responsibilities, which can significantly reduce the caregiver's ability to provide consistent care. There is wide variation in caregiving; some caregivers provide only emotional support, some coordinate care, others provide certain types of hands-on care, and still other perform skilled tasks such as wound care and intravenous therapies. The assessment is the basis for the After Hospital Care Plan (AHCP), a smooth discharge from the hospital, and successful integration of the patient's care back to community providers.
2. **Unique caregiver needs.** The caregiver needs assessment is not simply a mirror image of the patient's needs. The family caregiver is a unique individual, with separate responsibilities, health, stressors, and abilities. The family caregiver may see the caregiving situation in a completely different way from the patient and identify different barriers or risk factors. The patient and the caregiver may even have different goals: one may want the patient to move to

another setting or home while the other feels that the current home is still appropriate, or they may disagree on how much time the family caregiver should spend caregiving.

3. **Dialogue.** A caregiver needs assessment is a conversation, not as a task or form for the caregiver to do alone and “hand in” to staff, nor is it a checklist for staff to “fill in.”
4. **Integration.** Results from the caregiver needs assessment must be integrated along with assessments of the patient into the care team’s understanding of the patient’s situation at home and into the RED process. If the family caregiver’s self-assessment of caregiving needs is not incorporated, the AHCP may fail.

Many different professional perspectives can be important in guiding caregivers in assessing their own needs. Some hospitals find it effective to have the guided self-assessment of needs divided among various disciplines; other hospitals find that it combines naturally with one particular discipline’s workflow. Your hospital might test several options before making one method the new standard practice.

A Task- and Time-Oriented Needs Assessment

There are several caregiver self-assessment tools available. Most, such as the American Medical Association’s instrument, focus on long-term stress and burden. These can be most helpful if your hospital is in a position to provide matching services. A needs assessment is different; while incorporating the basics of stress and burden, a needs assessment is task- and time-oriented. It elicits issues, including caregiver burden, which can put a patient at risk for rehospitalization or other negative outcomes. For a guided self-assessment of the family caregiver’s needs, developed by United Hospital Fund, see *Next Step in Care’s* “What Do You Need as a Family Caregiver?” (http://nextstepincare.org/Provider_Home/What_Do_I_Need/)

The results of the needs assessment should include:

- Availability, other responsibilities, and relevant health status of the family caregiver.
- Breakdown by task of what the family caregiver feels he/she currently does, could do with training, and cannot do.
- Overarching concerns and questions. Deep-seated worries about the caregiving situation may hamper a family caregiver from engaging in education and discharge planning.
- Perception of the patient’s health and functional status.
- Values and preferences about caregiving (“do it all myself,”; “can’t deal with needles or incontinence,”; “I can’t take Mom to my home because there just isn’t room for another person”).
- Impact of caregiving on emotional status, finances, and other family members.
- Community resources used by the patient or the family caregiver, or resources they are interested in accessing.

Documentation of the Needs Assessment

Documentation of the results of the needs assessment is critical. All members of the care team should be aware of the results, and the results should be in a location easily accessed by all team members on all shifts. The results should be integrated into the inpatient plan of care. This allows staff time to be used more efficiently; for example, for the patient who requires heavy lifting who has a family caregiver with a back injury, the discharge plan should direct education to the family caregiver on safe use of lift

aids and equipment instead of unassisted lifting, and may include time for the patient in subacute rehabilitation if there is a reasonable expectation that, with physical therapy, the patient will require less assistance. Physical therapy can also teach the family caregiver how to safely assist with transfers, ambulation, bathing, and more, given the patient's needs and the caregiver's back injury.

The AHCP includes orders and delivery information for the needed aids and equipment and follow up by home care with the equipment in place. As always, Teach Back is recommended to ensure that the family caregiver understands and recalls the education as well as the supplemental services arranged.

Potential Barriers

Staff sometimes feel discomfort with the concept of family caregivers assessing their own needs. They may feel that professionals "know best" what the family caregiver needs, and that family caregivers don't even know what to ask for. It is true that professionals have expertise that family caregivers do not have, but family caregivers have the most intimate knowledge of the home situation and the realities they and their family members will face post-discharge. That is why a self-assessment guided by a health care professional is recommended. Both participants can learn from each other and keep the assessment focused on areas critical to creating a safe discharge plan.

Sometimes, family caregivers are reluctant to engage in a needs assessment. They may fear that expressing concerns about providing care will reflect negatively on them and that staff will see them as uninvolved or unloving. They may not trust health care professionals to have their interests at heart and may fear that whatever they say will result in fewer services for the patient. Staff should be sensitive to these fears and create a friendly, nonjudgmental atmosphere to reassure the caregiver.

It is important to prioritize the caregiver's needs according to what could have the biggest impact on the patient's post-discharge safety and well-being. Some needs can be addressed through longer-term supports, such as community-based organizations. For guidance, refer to the *Next Step in Care* guide, "Referring Patients and Family Caregivers to Community-Based Services" (http://nextstepincare.org/Provider_Home/Community_Based_Services/). It can be helpful to remember that our overall aim is the patient's safe discharge home, and that the caregiver can best address changes (and even improvements) over time.

For family caregivers, a guided needs self-assessment is an opportunity to talk about their own lives for perhaps the first time in any encounter with the patient's health care team. They may express fears or concerns about their own abilities to provide certain kinds of care, and the realities of their own situations. In health care settings, needs assessments will necessarily be brief but can raise important questions that the family caregiver can further discuss with others and can suggest types of resources that may be available and helpful.

Some professionals are reluctant to ask questions about the kinds of help that a caregiver may need, because they cannot fill those gaps. But most caregivers are grateful for any suggestions and for the attention being paid to them.

Presenting the Guided Family Caregiver Self-Assessment

As stated earlier, a needs assessment is best done as a guided self-assessment, with conversation between the identified family caregiver and the health care professional. For many professionals, this

may be different from the usual mode of question-answer. The strength of a guided self-assessment is in facilitating the family caregiver’s own decisions about what is realistic.

This is a suggestion for starting the conversation and keeping on topic:

I would like to talk about (*patient*)’s situation at home, so we can make a plan that will keep (*him/her*) healthy and hopefully help you, too. Is this a good time? (*If not, when? This may be outside of traditional working hours, so arrangements with a colleague or supervisor may need to be made.*)

Thank you! I have spoken with (*patient*), and it would be helpful if you could share some other details. We want going home to be as smooth as possible. Let me double-check – you are the person who usually (*caregiving task, such as takes patient to the doctor or prepares meals*)? Is there anyone else who helps with this? I am sure you have a lot of other responsibilities. What are they? Children, other people you take care of? Do you have any issues that could keep you from being able to do (*caregiving task*)? Thank you for letting me know.

I will do a little research, and we should talk again about what we might be able to arrange to help out. What time tomorrow works for you?

For more guidance, see “Assessing Family Caregivers” by *Next Step in Care* (http://nextstepincare.org/Provider_Home/What_Do_I_Need/).

Sample Training Agenda

Time	Title of Session	Presenter
9:00 – 9:05	Introductions	
9:05 – 9:25	Review of Guided Family Caregiver Self-Assessment Tool	
	Objectives: <ul style="list-style-type: none"> • Understand the purpose of the guided family caregiver needs self-assessment • Understand the components of the guided family caregiver needs self-assessment • Understand how the guided family caregiver needs self-assessment builds on Step 1: Identification of the Family Caregiver 	
9:25 – 9:50	Practice Conducting the Guided Family Caregiver Self-Assessment Tool	
	Objectives: <ul style="list-style-type: none"> • Gain experience introducing the Guided Family Caregiver Self-Assessment Tool • Increase skill and comfort level in purposeful interaction with family caregivers • Understand what information can be obtained through a Guided Family Caregiver Self-Assessment Tool of needs and how that can be used to strengthen the discharge plan 	
9:50 – 10:00	Review and Conclusion	
	Objectives:	

	<ul style="list-style-type: none"> • Identify areas for follow-up training • Begin thinking about opportunities for integration into workflow 	
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Time	Title of Session	Presenter
9:00 – 9:05	Introductions	
9:05 – 9:50	How Will Your Team/Department Incorporate the Guided Family Caregiver Self-Assessment Tool into Daily Workflow?	
	Objective: <ul style="list-style-type: none"> • Discuss and decide first method for trying this in your setting <ul style="list-style-type: none"> – Which team member/discipline(s) – At what point in the hospitalization – Method of documentation, information sharing with the team, and integration into the RED 	
10:50 – 11:00	Review and Conclusion	
	Objectives: <ul style="list-style-type: none"> • Finalize new process plan • Establish start date and date to reassess new process 	

Step 3: Integrating the Family Caregiver’s Needs into the After Hospital Care Plan

You and your team have identified the patient’s family caregivers, what their roles in care have been up to now, and what parts of the patient’s post-discharge care they can coordinate or perform. Now it is time to put this into operation: integrating this information into the After Hospital Care Plan (AHCP).

Discharge options

Given the patient’s care needs and the assessed abilities of the family caregiver, realistic discharge options can be developed.

Realistic options for discharge cannot be developed without a thorough understanding of both the patient’s situation (care needs, home setup) and the family caregiver’s abilities, training needs, and other responsibilities. After eliciting this information, you can advise the patient and caregiver of options that have a higher chance of success, and counsel them regarding ideas that are less likely to work.

For example, a patient may need physical therapy, hands-on assistance with walking and toileting, and medication administration. The patient lives with a family caregiver who demonstrates through Teach Back an understanding of the medication regimen and is learning how to help with walking and toileting. But who can provide care during the daytime, while the family caregiver is at work? Home care could provide the physical therapy. However, insurance benefits will only pay for 6 hours of an aide per week, making this a potentially unsafe discharge. An alternative choice, although not the first choice, may be transfer to sub-acute care to restore the patient’s abilities to walk and toilet independently, if that is a

reasonable expectation. Caregivers' assessments of their own needs can enlighten everyone as to what is an AHCP that will truly benefit a patient's transition. The clinician's acceptance, without judgment or criticism, of the caregiver's own needs assessment can build the trust necessary for discussion of a discharge to a subacute setting.

Medication

An important part of post-discharge safety is a thorough and accurate medication reconciliation. Reconciliation can be more complete when staff elicit the input of the family caregiver who assists with or manages the patient's medications, or picks up prescriptions or attends doctor visits. Additional insight can also be gained from the family caregiver regarding the patient's tolerance and reactions to medications and past or potential barriers to obtaining or taking medications.

For short-term or ongoing medication management, the family caregiver may require training. When the patient returns home, the family caregiver may need to dispose of old/changed medications and OTCs, and adjust to further changes made during follow-up medical appointments. Caregivers report uncertainty and fear of dealing with medications. One tool you can use is the *Next Step in Care* guide to preparing family caregivers to manage medications

(http://nextstepincare.org/Provider_Home/Medication_Management_Guide/). As always, confirmation of understanding of the medication regimen should be made via Teach Back (*see Tool 3*).

Postdischarge appointments

As discussed in Tool 3, the AHCP should include follow-up appointments with the patient's health care providers and for tests. In making those appointments, it is important to elicit information from the family caregiver who may travel with the patient to medical appointments. Important information may include: best time to schedule an appointment, how much time to allow for travel, transportation availability, and other factors that may make it more likely that the appointment will be kept. The health care providers should receive a discharge summary in a timely manner so that they are aware of the reason for the follow-up visit (*see Tool 3, "Transmit the Discharge Summary to the Postdischarge Clinician"*). The family caregiver should receive a copy of the AHCP and also be prepared to arrange (or rearrange) follow-up appointments. This can be challenging for caregivers; provider offices may not realize the necessity of a quick appointment. "Getting a Post-Discharge Appointment in 7 Days" (http://nextstepincare.org/Caregiver_Home/Post_Discharge_Appointment/) can provide guidance to the family caregiver in advocating for those appointments.

Identifying and eliminating gaps in care

Now that you have an AHCP based on comprehensive information on the patient's post-discharge needs and the abilities and constraints of the family caregiver, you can identify potential gaps in care. A gap may be short-term, such as until home care begins, or it may develop after a couple of days when the family caregiver returns to work.

Many gaps in the AHCP can be met through social service and community-based agency services. Referrals to social service programs for follow-up case management, respite services, congregate or at-home meals, transportation, minor home repair, adult day services, caregiver support, and more may have specific eligibility criteria and wait lists. If the referral is to meet a patient safety issue, then you should confirm with the providing agency when the service will start, and make alternate plans if there is a delay. Some hospitals have relationships with local agencies (such as the Area Agency on Aging) to be the lead on social service assessments and referrals.

The Postdischarge Followup Phone Call (*see Tool 5*) can be used to identify and rectify previously undiscovered gaps in the AHCP. Gaps can usually be found during the sections regarding the medication regimen and coordination of postdischarge home services.

Identification of gaps in the AHCP can become a meaningful measure in the evaluation of your hospital's implementation of the RED. See the section in Tool 6 on "Is Appropriate Followup Care Being Arranged?" for ideas.

Training

This is an area which can have great positive effect on the patient's postdischarge care. If done incorrectly, training can be a cause for patient and caregiver confusion and frustration, and a waste of staff time.

The first step is to ensure that the right person is being trained. Is the patient going to be independently responsible for the new medication regimen, or will a family caregiver assist, even if temporarily? Is a family member responsible for all medications, and if so, which family member? Check the caregiver identification to be certain, and confirm when you speak with that person. Without this step, you may be training the wrong person.

The next step is to ensure that you are meeting the patient's and caregiver's needs for training. Refer back to the patient assessments and the caregiver needs assessment. If the patient and caregiver reported that they were familiar with a topic, such as blood sugar testing, then ask for a demonstration and use mentoring and Teach Back skills to correct any errors in technique or understanding. If they reported that they needed education, then arrange a mutually convenient time to meet, or even talk over the telephone if necessary.

Make the time for education according to the caregiver's schedule for best participation and retention. In the morning, a caregiver may only be at the hospital to speak with the physician before hurrying to work or other responsibilities. In the daytime, the caregiver may only be available over the telephone, or only during lunch. A caregiver may work evenings or nights and have daytime child care duties, making trips to the hospital difficult. Flexibility with timing and method for training may be required.

Guidance on what and how to teach can be found in Tool 3 in the sections "Teach the Content of a Written Discharge Plan in a Way the Patient Can Understand" and "Assess the Degree of Patient Understanding." Materials and training should always be in the person's chosen language. This may be

different depending on the person being trained; for example, an older patient may need materials and verbal training in Spanish, while a younger daughter who will be assisting may prefer training in English. Materials, examples, and equipment should also be tailored to match the home situation and the patient's specific conditions. This reduces confusion after discharge. Information about who was trained and in what manner (was there a curriculum or best practice used?) should be shared with the next care providers, such as home care, medical providers, and social service agencies as appropriate.

Hospital training is only the beginning. Some caregivers will require reinforcement and adaptation, for example, to different kinds of equipment supplied at home. A referral to home care services may be part of the AHCP.

Step 4: Share Family Caregiver Information with the Next Setting of Care

"Transmit the Discharge Summary to the Postdischarge Clinician" in Tool 3 describes an essential part of transition work: communication with the clinicians who will carry on the care of your patient after discharge. Sharing the information gathered about the family caregiver is also important; this allows the clinician to understand the role of the family caregiver in care and the caregiver's other responsibilities which could impact care. Information about what training was done with the caregiver and areas that likely need reinforcement (based on Teach Back) can also be very helpful to the clinician. This enables the clinician to target issues of best benefit to the patient's postdischarge care and to support the AHCP.

Step 5: Provide Telephone Reinforcement of the Discharge Plan

Postdischarge telephone calls should be directed to the people responsible for each part of the AHCP. That may require phone calls to both the patient and to a family caregiver, or even to multiple family caregivers, depending on the patient's situation. The sections of the AHCP in which each person participates should be the focus of the call. For example, a call to the family caregiver who deals with medications and medical appointments should review and reinforce those areas of the AHCP. Further guidance on postdischarge calls can be found in Tool 5, "How to Conduct a Postdischarge Followup Phone Call."

Measuring Effectiveness

Your team can measure the effectiveness of your efforts to meaningfully engage family caregivers in care planning. Monitoring the methods used and the outcomes can reveal successes as well as areas for improvement, as discussed in Tool 6, "How to Monitor Re-Engineered Discharge Implementation and Outcomes."

As always, select and specify the measures you will use. Those measures should be meaningful, credible, feasible, and timely to give you accurate, helpful, and consistently collected data.

Implementation Measures

Two measures to think about are:

- Chart review of interactions with family caregivers
- Chart review of assessed needs accounted for in AHCP

Reviewing charts for documentation of substantive interactions with family caregivers can show if staff are aware of who the identified family caregiver is and what that means for after-hospital care. If your hospital has an electronic medical record, this may be an opportunity to improve documentation of this important information within the given fields. This information may highlight opportunities for working together with family caregivers. It also reflects on staff perception of family caregivers: do staff view their conversations and education with family caregivers as important enough to document?

A chart review to see if all of the family caregiver's needs that were identified in the assessment (*see Step 2: Assess the Family Caregiver's Needs*) were incorporated into the AHCP can indicate where additional resources need to be found or developed in the community. It can show if all of the needs that the hospital should reasonably meet, such as for training, were accomplished. If not, a root cause analysis can be used. Trends can also be identified, including staffing issues, communication lags, and other items for study and improvement.

Impact Measures

Your team can measure the impact of changes involving the family caregiver in RED activities through readmission and other standard measures. Those are largely measures of impact on the patient or on the hospital. But what impact did your interventions have on the family caregiver? How did these interventions, and the sharing of family caregiver information, affect the work of the next settings of care, such as the primary care provider or the home care agency? How did that reflect on the patient's care in the community?

One way to measure these impacts is through postdischarge surveys. Surveys can be long and complex, or short and less formal. Many hospitals have found that patients and family caregivers are overwhelmed by numerous postdischarge surveys – from the hospital, from the insurance provider, from the hospitalist group, from various accreditation bodies, and even from hospital meal services. In your hospital, you can examine the various surveys, look for opportunities to consolidate them, and consider to whom they are targeted. Is the survey directed toward the patient, when an identified family caregiver would be a more appropriate respondent? The nature of the surveys should be considered as well; is satisfaction an appropriate measure, or would a review of the medications or AHCP demonstrating the effectiveness of training be more informative?

Another area for postdischarge surveying is the next setting of care. You are spending time and effort providing tests, assessments, and more to the clinicians who will be continuing the patient's care in the community. Is this information what they find useful? Is there something different that would be of more utility, especially regarding the family caregiver and areas for follow-up?

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