

Referring Patients and Family Caregivers to Community-Based Services: A Provider's Guide

This guide is intended to help health care providers and care team members make referrals to the different types of community-based services and supports that may be available to patients and family caregivers experiencing transitions in care. This may be the responsibility of the social service, discharge planning, or other departments.

Referral to community-based services is an important but often overlooked component of the discharge process. It can be a vital complement to a successful transition — as important as an updated medication list and a follow-up doctor's appointment. Many services that support the patient and family caregiver through those critical post-discharge weeks and beyond are available through community-based agencies. However, patients and family caregivers often do not know how to find them on their own. Making the connection to services, or encouraging the patient and family caregiver to connect on their own, may help people with illness and disability better manage day-to-day, live longer in the community, and possibly avoid a rehospitalization or delay a move to an institutional setting.

Making effective referrals to community-based organizations is different from making referrals to health care services. It requires the family caregiver's **and** the patient's assessments of their needs. The patient and family caregiver may have differing ideas of what is needed. It may be a challenge to find the appropriate services for this particular patient. There may be wait lists.

This is where the skill and the art of working with family systems comes in. It may help to remember that while health care professionals and care teams cannot make patients and their family caregivers accept services, it is their responsibility to safely discharge the patient. To do this, a care team should carefully consider whether any support services offered are realistic, that they are fully understood by the patient and family caregiver, and that the patient and family caregiver are able to access those services and comfortable doing so.

The following scenario suggests the range of challenges that community-based services might resolve:

Mrs. Jones is 83 years old. She fell at home. When she did not answer the telephone, her daughter Teresa came home from work early and found her mother on the floor. Mrs. Jones was admitted to the hospital with a mild concussion and a bruised hip. Through conversations

with Mrs. Jones and her daughter, you learn that Mrs. Jones lives with Teresa due to a history of orthostatic hypotension and risk for falls. Teresa has never considered herself a family caregiver, despite her caregiving activities, such as managing her mother's medications and taking her to doctor appointments.

Mrs. Jones tells you that she has felt "unsteady on her feet" for some time and is afraid of falling. While Teresa is at work, Mrs. Jones sits in a chair and avoids standing and walking except to go to the bathroom. Teresa suspects she is not drinking much, so she can avoid having to walk to the bathroom and risking a fall. Mrs. Jones stayed overnight in the hospital. Since she is now medically stable, she is being discharged shortly.

You've covered all of the primary items with both Mrs. Jones and Teresa: changes in medications, a water pitcher and glass next to Mrs. Jones' favorite chair, and instructions to Mrs. Jones to stand slowly and steady herself before taking a step. Teresa will take her to her doctor within a week. Is there anything else? How can Mrs. Jones be kept safe and out of the hospital? How can Teresa, her family caregiver, get some relief from worry and guilt over her mother's isolation and fear of walking?

Organizations and program offerings vary widely from one community to the next, but generally provide the following kinds of services for patients and family caregivers:

- Adult social or medical day care
- Bath service
- Caregiver respite
- Caregiver training
- Congregate meals
- Elder abuse programs
- Exercise and physical fitness
- Friendly companion
- Home-delivered meals
- Home health aides
- Hotlines
- Legal services
- Light housekeeping
- Minor home repair
- Nutrition counseling
- Support groups
- Telephone reassurance
- Transportation

How to make community-based service referrals a standard part of the patient and caregiver assessment and discharge discussions

- ✓ Determine who on the care team will be primarily responsible for the assessment, discussion, and referral of patients and family caregivers. Depending on the setting and responsibilities for each team member, the referral might be made by a nurse, social worker, case manager, physician, or discharge planner.

- ✓ Maintain a current list of local resources and make it a standard part of the information available to patients and their family caregivers during transition planning.
- ✓ Document community-based service referrals or discussions of any support suggestions in the discharge summary so that patients and caregivers have a reminder of the organizations and services discussed. Communicate those referrals to the next care setting or the community physician.
- ✓ Follow up with patients and family caregivers to determine if they were able to access the services suggested, and whether the services are meeting the patient and caregiver's needs.

Guidelines for Identifying Community-Based Resources for Patients and Family Caregivers

Develop a list of available services. Gather information on available programs and services from a variety of sources; some health care facilities and agencies may already have such a list, often maintained by the social work or case management departments. If no such list exists, consider creating one, and keep it up to date.

Support programs may be administered by the Area Agency on Aging or a County Office for the Aging, or by an organization such as a YMCA, municipal health department, religious federation, or social service agency. Also include local not-for-profit and private-pay organizations, senior and recreation centers, settlement houses, mutual aid societies, and religious communities. In addition, there may be a NORC SSP (naturally occurring retirement community supportive services program) that older patients or their caregivers may be eligible for. Some disease-specific organizations, such as the Alzheimer's Association, have local chapters with opportunities for patients and caregivers to receive education and training. There are also national, web-based resources, such as the U.S. Department of Health and Human Services' *Eldercare Locator* (www.eldercare.gov) and the Family Caregiver Alliance's *Family Care Navigator* (www.caregiver.org) to assist with finding location specific resources.

Note eligibility requirements. Gather some basic information on eligibility requirements for services. For example, many services called "home and community-based services" are limited to people eligible for certain types of Medicaid. Other eligibility requirements may be based on age, diagnosis, service area, income, and assets, or on some combination of these. Keep in mind that eligibility rules may change over time.

Stay up to date. No single list may capture all of the agencies and organizations that serve a community. For example, a list from the municipal office on aging may only include services/agencies with which it contracts, or a list of home care agencies may include those that only take private pay. Contact information and eligibility criteria can change frequently; keep the list updated or it will be more of a barrier than a help to patients and family caregivers.

Consider need, eligibility, and service capacity before making referrals

Determine the patient's and caregiver's need for services. Have a conversation with the patient and family caregiver about the patient's care needs—and, if needed, speak alone with the caregiver about his or her own care. Help them figure out what it will take to meet those needs. If patients and family caregivers are actively identifying their own needs, they may be more likely to act upon referrals or accept services when needed. To guide the conversation, try a caregiver assessment tool like Next Step in Care's "[What Do I Need as a Family Caregiver?](#)" If there are multiple family caregivers, include them all as much as possible when discussing the need for services.

Identify the patient's or family caregiver's eligibility for the specific services needed. Before making a referral, review the agency's eligibility requirements to make sure the patient and family caregiver are eligible. If not, the service provider may have ideas for an appropriate alternative referral if necessary.

Be aware of the capacity of an organization or program to provide services. Be realistic about an organization's ability to deliver services. Does the organization have the capacity to serve this patient and/or caregiver right now? Find out what services are available and when they can begin. Also consider whether an agency and its staff will be able to communicate clearly and meaningfully with the patient and family caregiver in a language they are comfortable with and in a culturally sensitive manner.

Consider patient and family caregiver's interest, address financial concerns, and protect patient health information

Gauge patient and caregiver interest and willingness to accept services. In some cases, patients or family caregivers may accept services in an attempt to speed up the discharge home, only to refuse services later. There can be many reasons for this: patients and family caregivers may feel they can (or should) handle it all, be wary of strangers, uncomfortable about coming to the attention of social services, or concerned about cost or hassle involved in applying for a service. Sometimes patients and caregivers accept services only after multiple offers and exposure to the benefits of such assistance.

Is the patient or family caregiver able to pay for services? Costs, whether real or perceived, may determine whether a patient and family caregiver will accept a service. Find out if financial assistance is available and what documentation is required.

Safeguard protected health information. While investigating resources for the patient, be cautious when sharing patient information. HIPAA (Health Insurance Portability and Accountability Act) rules allow for the sharing of protected health information for the purposes of care coordination, and some information will likely have to be shared in order to determine eligibility. However, do not use identifying information until the patient, family caregiver, or other decision-maker agrees to the service. For example, an initial call to the local respite program may involve disclosing diagnosis, age, and income to determine if the service is a possible fit for the patient, but there is no need to share names, addresses, dates of birth,

or other protected health information. Specific permission to share protected health information can be made for the individual service providers chosen.

Conclusion

Careful and thoughtful attention to patients and family caregivers, with a practical awareness of what community-based resources are appropriate and available, can help resolve many issues after discharge from the hospital. The scenario of Mrs. Jones and her daughter Teresa provide a good example of such resolution:

In conversation, Mrs. Jones admits that her “life stops” when Teresa is at work. She has no one to talk with, and finds no joy in eating alone. Teresa finds this pressure to constantly be with her mother very stressful, especially when she has to work late. To potentially meet both Mrs. Jones’ social need (companionship) and medical need (eating and drinking and taking her medications on time), you find two local senior centers and a social day center for which Mrs. Jones is financially eligible. Typically both settings offer opportunities for congregate meals and supervised exercise, both of which may help improve Mrs. Jones’s confidence in walking. Some organizations may have transportation available to help Mrs. Jones get to and from the center, or even help get her to and from medical appointments. Through involvement at such centers, her daughter may also feel some relief—if Mrs. Jones is at the senior or adult day center, she is alone less. There may even be caregiver support programming that Teresa could use.

Teresa is hesitant about having her mother go out to a senior center. What if something happens? What if she doesn’t make friends? In the course of conversation, you realize that Teresa is speaking out of her own guilt at not being able to do everything her mother needs. Together, you can discuss how having her mother go out during the daytime to a safe and supportive place can be a positive thing she can do for her mother. Reframing the issue from a perceived “failure” by the family caregiver to a positive step forward can lead to a better chance of referral success.

For more information and assistance with finding community-based supports, visit:

Next Step in Care’s webpage of links and resources for family caregivers
http://nextstepincare.org/Links_and_Resources/

US Department of Health and Human Services Eldercare Locator
www.eldercare.gov

The Family Caregiver Alliance's Family Care Navigator

http://www.caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083

NORC Blueprint (Naturally Occurring Retirement Communities)

<http://www.uhfnyc.org/initiatives/aging-in-place/norc-blueprint>

Alzheimer's Association

www.alz.org

American Heart Association

www.americanheart.org

American Stroke Association (a division of the American Heart Association)

www.strokeassociation.org

American Cancer Society

www.cancer.org

Facing Disability: for families facing spinal cord injuries

www.FacingDisability.com

Lighthouse International (vision impairment or loss)

www.lighthouse.org

For a more comprehensive list of disease-specific organizations, visit www.nextstepincare.org.