

Healthcare **Communication** Review

On Building Health Partnerships: Food-for-Thought, Practical Tips, Resources

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Nursing Homes and Home Care

Nursing homes and home care services generally provide care to people who are frail, chronically ill or functionally disabled and cannot live at home without assistance. When that assistance is largely non-medical – with things like bathing, preparing and eating meals, housecleaning and so on – it may continue indefinitely. In those instances, it is called long-term care.

Nursing homes and home care services are also in the forefront of providing temporary, short-term, mostly medical care that is expected to result in patients regaining their health or, at the least, becoming able to live at home without the same level of skilled medical care. Such care is typically arranged for hospital patients who are about to be discharged, yet have not recovered sufficiently to go home untended. For those who fall into this category, the gap between being a hospital patient and being able to live independently at home may be bridged by home- or nursing-home care. For example, some patients who are not quite ready to recover at home might be transferred to “beds” that have been set aside by nursing homes for “short-term” rehabilitation. Others may be discharged to the care of home care agencies, with continuing treatment provided at home by nurses and/or physical, speech, or occupational therapists.

The ‘Long’ and the ‘Short’ of... Nursing Home Care

Traditional nursing home care is long term care, where mostly non-medical support services are provided for people who need around-the-clock assistance or supervision and cannot be cared for at home or in the community. It is generally provided to Medicaid or private-pay (self-paying) patients. Medicaid will pay for long-term nursing home care, Medicare will not. Those patients who need such care and who do not qualify for Medicaid, might at first pay the nursing home either with their own money or have it paid by private insurance plans. When that coverage or their own money runs out and they need to remain in the nursing home, they may apply for Medicaid.

Sub-acute nursing home care is made possible by advances in medical technologies, which allow many types of care that once could only be provided in hospitals, to now be provided in settings such as nursing homes. The shifting of sub-acute care to these settings has been encouraged by the fact that nursing home care is less costly than hospital care. Sub-acute care (also called post-acute or transitional care) is short-term care. Types of sub-acute care include rehabilitation (from illnesses or injuries, for instance), intravenous therapy, wound care, respiratory care and cardiac or stroke rehabilitation. Medicare will pay for this level of care.

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From the Editor

While Long Term Care services can, and do, help people of any age, Medicare's administrators report that the numbers of elderly Americans needing some form of long-term care will grow from nine million this year to twelve million by the year 2020. Even if we, personally, will be fortunate enough to not require these services ourselves, chances are that someone we love will.

Some types of long-term care involve medical care. Many do not. Non-medical long-term-care services generally assist people who have lost the ability to dress or bathe themselves, to prepare their own meals, take their medications, or to carry out some other important function of living independently. For individuals who find themselves in this position, the question of what to do next is no small matter. Often their concern is whether ways can be found to allow them to keep living at home or whether it will be necessary for them to go to a nursing home – also called a skilled nursing facility.

Within these pages, readers will find a series of articles designed to help them understand and find the nursing home, home care agency and community-based support services that are 'right' for them or their loved ones. Resources for monitoring the level of care actually provided may also be found in these pages. And because home care services generally require the participation of family caregivers, we end with an article on caregiver resources.

In this issue, we have tried to provide as comprehensive an overview as our number of pages allow. The magnitude of the subject, however, limits us in what we can include here. Take questions to ask, for instance, (an important part of the process for finding and monitoring care). In place of providing them, we tell readers where they can be found. This and more information is on the Internet and we encourage the use of public libraries when home access is not possible. As always, we hope you find this issue useful. Be well. *Judith Greenfield*

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Home Care Agencies

Certified Home Health Agencies (CHHA)

CHHAs (pronounced, chahs) are agencies that have been certified by Medicare as having met its standards for providing, at home, much of the same sub-acute care that is provided in nursing homes. Medicare beneficiaries who are eligible for short-term, sub-acute care at home are required to use CHHAs to provide that care. As directed by patients' physicians, the services may include skilled nursing care and the support of home-health-aides when that support relates to the condition being treated by the nurses. Services might also include physical, speech and occupational therapy. Because the care is provided on a part time and intermittent (not continuous) basis, family caregivers often need to be part of the care team – assisting and monitoring their loved ones. Medicaid and some health insurance policies will pay for this care. Self-paying (private pay) patients are also accepted.

Homemaker and Home Care Aide Agencies

These agencies provide homemaker and home care aide services to meet the long-term needs of patients. In some, but not all, areas they may be allowed to provide nursing services. Some states, including New York State, require that these agencies be licensed. In New York State, they are called Licensed Home Care Agencies. Their services are available to private pay patients as well as to patients covered by private insurance. Upon entering into a contract with local departments of social services, these agencies may also provide care to Medicaid patients. Medicare will not pay for these long-term care services either.

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Other Types of Home Care

There are other, specialized types of home care or assistance, as well. To learn more, ask local health or social services departments or visit, for example, <http://www.cancer.org/>. Enter 'home care agencies' in the search box, then select 'Types of Home Care Agencies.'

Nursing Homes Without Walls

Federal rules guide states' implementation of Medicaid. Some of those rules have favored placing eligible patients in nursing homes. In the mid-1990s, the federal managers of Medicaid began promoting the use of home and community-based services (HCBS). They created a waiver that would allow states to provide care through HCBS instead of through nursing homes. As a result, some states now offer what has been called, 'Nursing Homes Without Walls.' New York has such a program, which is called Long Term Home Health Care. To find similar programs elsewhere, try searching for 'nursing homes without walls' on the Internet or ask your local health or social services departments.

Types of Services Provided

While a nursing home without walls may not be appropriate for all Medicaid patients, it may work well for those who are eligible for traditional nursing home care but who would rather stay home with the help of home care agencies and community support services (see page 6). Services provided in nursing homes without walls may vary from state to state. In New York State, regular Medicaid services are provided along with other services that may include: case management by nurses, home delivered meals, home visits by doctors, respiratory therapy, medical social services, respite care, social day care and social transportation. Because professional care is usually not provided around-the-clock, family and/or friends will need to share responsibility for assisting and supervising their love ones.

Eligibility Requirements

In addition to being medically and financially eligible for this program, a key monetary condition for participation must be met. That is, the costs of providing these services at home *must be less* than the costs of providing that care in nursing homes within the county in which the patient resides.

Other Waiver Programs

Other waiver programs include the Program for All-inclusive Care for the Elderly (PACE) and Social Managed Care Plans. For more information about these

programs, visit <http://www.medicare.gov/> and enter 'nursing home alternatives' in the search box. To find out what is available in your community, ask your local social services department.

Consumer Directed Personal Assistance Programs

Preserving personal choice and self-direction is another important goal of the Medicaid waiver programs. For those patients receiving care in their own homes, that goal has led to the establishment of the Consumer Directed Personal Assistance Program (CDPAP). Under this program, patients who meet the requirements for participation may choose someone, other than the aides sent by home care agencies, to provide their care. They can choose a family member, friend, or other person.

What CDPAP Aides May and May Not Do

When CDPAP aides are not licensed aides, as is often the case, they are able to provide care that licensed aides are not allowed to provide. In New York State, that means they are able to perform all services provided by personal care and home health care aides AND the services provided by registered and licensed practical nurses. It is important to note CDPAP aides *may not* evaluate patients and plan therapy programs, but may carry out programs that are planned by a licensed healthcare professional, when the patient directs them to do so.

Program Participation

The approval process for participation in this program begins with the submission of a physician's order for such services to local social services departments. The department then sends a nurse to assess the patient's social and nursing needs and to determine whether that individual has the capacity to direct his or her own care. If participation is approved, then the nurse will also recommend the amount, frequency and duration of services.

Patients' Responsibilities

Patients who participate in this program (or a designated adult friend or relative) must have the capacity to make informed choices, as they will be responsible for the management of provided services. In New York State, that means the patient or designated representative will be responsible for recruiting, hiring, training, and supervising the aide; for arranging for and coordinating with other services; for finding back-up coverage; and, if desired, for firing the aide. They will also be responsible for keeping payroll records. To find out about CDPAP programs in your state, contact your local social services department. □

Finding and Monitoring Nursing Homes & Home Care Agencies

Sometimes lack of available beds or insurance coverage may limit the number of facilities (nursing homes) or agencies (home care agencies) from which to choose. Sometimes they do not. Even when there is little or no choice, however, families can take steps to learn about the facility or agency that will be used so that they can better understand what to look for when monitoring that care. The following suggestions may therefore help when both time and circumstances permit a careful selection process *and* when they do not. Note that the online sources presented here and on page 6 can be accessed either from home or public libraries, and that librarians are available to help those who are new to these kinds of searches.

Finding Facilities and Agencies

Having determined the type of agency or facility that is needed, the next step is to find those that serve your area and, in the case of facilities, to find those that operate within a comfortable traveling distance for family and friends (whose visits are often essential for maintaining patients' physical and mental wellbeing). Talking with your doctor, social service professionals, friends and even the Yellow Pages directory can provide answers here.

Learning About Facilities

'A Consumer Guide to Choosing Nursing Homes,' published by the **National Citizens' Coalition for Nursing Home Reform**, includes links to various resources and tips for understanding the information they provide. It also offers guidelines for using visits to nursing homes as part of the information gathering process. For this they advise paying attention to sights, sounds, smell and touch, pointing out what you should look for. Lists of questions to ask staff, as well as residents and their families, are provided. For a copy, call **202-332-2275** or visit <http://nccnhr.newc.com/>. Click on 'fact sheets' then on the report title.

Comparison information for facilities throughout the U.S. is available and may include: numbers of beds; how many and what types of nurses and assistants they employ; characteristics of residents (percentages of patients with pressure sores, urinary incontinence and so on); and State inspection information. Quality of care and of life measures, nutrition and safety issues, summaries of complaints lodged against the facilities may also be included.

Safety information is also available and can be found at <http://www.memberofthefamily.net/>, which maintains

a national watch list of facilities with recently cited violations and/or complaints that patients have actually been harmed or are in danger of being harmed at any moment.

Questions to ask facility staff are also offered on the web. Visiting facilities gives you the opportunity to question staff, residents and residents' families as well as to gather information through your senses, as described above. Those looking for short-term, sub-acute care in a facility should take special note of a question that addresses the issue of what happens if residents complete their short-term care but need to stay on for long-term care. According to **Friends and Relatives of Institutionalized Aged (FRIA)**, the law that requires facilities to allow such residents to remain is often not enforced. As a result, many such patients are not allowed to stay – often because their change in status results in lower reimbursements for care provided. FRIA therefore suggests asking about this up front and offers guidance for dealing with this eventuality.

Learning About Agencies

Unless they are accredited, little comparison information is available for Non-Medicare-certified agencies. See page 6 to check agencies that are accredited by **JCAHO**, the Joint Commission on Accreditation of Healthcare Organizations. Comparison information on Medicare-certified agencies can be found on the **Medicare.gov** web site. It offers comparisons of quality measures such as percentages of patients: who improve their abilities to get around; who get better at caring for themselves; who are able to stay at home after their home care ends; and who need immediate, unexpected care or hospital admissions. Guidelines for using the comparison information are also provided.

Questions to ask agencies: Although it is often not possible to speak with different staff, patients and their families, it may be as important to find and question people who know the work of the agency – healthcare professionals who refer patients or friends who have used the agency – as it is to question agency staff. That's because agencies with similar results reported on comparison charts may, nevertheless, not be equally good. Questions that may be asked are found on many sites and include questions about certification, licensure, accreditation; employee hiring and supervising practices; scheduling of visits; accepted payment sources; emergency responses; written plans of care; and coordination of care.

See Finding, on pg. 5

Finding, continued from pg. 4

When hiring home care assistants, special care must be taken to screen applicants and plan for things like back up care. The federal **Administration on Aging (AOA)**, as part of its **National Family Caregiver Support Program**, offers guidance for this screening process. To access this information, visit <http://www.aoa.gov/>. Enter 'how hire home care aide' in the search box. Then click on the links whose address includes the words 'taking care of others.'

Monitoring Care

The involvement of family and friends does not end with placement in a facility or agency's care. When home care services are used, at least one family member or friend must share in caregiving tasks *and* monitor the care provided by homecare professionals. Guidance for this task can also be found from sites listed on page 6, as

well as in the AOA document on hiring employees.

Monitoring the care in facilities, while more difficult, is especially important. Family oversight can make a big difference in the health and well being of residents. Advice on how to do this is included in "[Comprehensive Care Planning: A Family guide to Effective Participation](#)," from the Friends and Family of Institutionalized Aged (FRIA), and in the book reviewed below. The FRIA site, offers fact sheets on what families need to know and do; on how to address culture and language concerns; on how to prevent and resolve problems through advocacy; and much more. Based in New York City, FRIA has a helpline to help with problems of care as well as with questions regarding selection of facilities and long term care questions. They may be reached at 212-732-4455, Tuesday – Friday, from 10 a.m. to 5 p.m.□

Book Review

Danger Zone: Unlock the Secrets of Nursing Home Medical Records and protect Your Loved Ones

By Dennis R. Steele and Edward C. Watters III, MD

Reviewed By Jeffrey Falk, RN, MS, CLTCCO

As a senior care manager, I strongly concur with the authors' thesis that to provide a safe environment in a long-term care facility, you must look, listen and ask questions. *Danger Zone* explains what a concerned friend or loved one must do in order to ensure the best possible care is given and maintained.

In 80 pages, plus templates for data recording, Steele and Watters explain what is needed to follow care provided at Long Term Care Facilities (LTC) – often referred to as nursing homes. Layman text allows the reader to follow without the confusion that is frequently befuddling even professional caregivers. Clear instructions are given on what to look for and what questions to ask.

They not only confirm that it is necessary and appropriate to be persistent, but say it is necessary to be firm, consistent, and self-assured. And while they state that being nice doesn't always work, they advise first trying to do so. These are good rules to guide the people who have the responsibility of looking after loved ones and friends who are confined to LTC facilities for any amount of time – a responsibility that calls for regular and ongoing attention.

The book finishes up with instructions for contacting officials of the LTC facilities, the state agencies, doctors and the HIPAA section of the Office for Civil Rights (OCR). Additionally, there are charts to help with monitoring bedsores and tips for photographing medical conditions for following improvement or deterioration. Finally, there are helpful charts for collecting and organizing the data observed.

On the other hand, it seemed to me that too much time was spent on blaming the medical community. And, because laypeople are likely to find it difficult to read medical records (even with the book's sample charts), the authors should have focused more on observing and reporting. I say this because, as a former Concurrent Review Nurse with a HMO, I found that reviewing charts was not an easy task. A better approach, in my view, is to observe and report. Let the professionals deal with the medical chart. After all, the goal is to obtain the best care possible. The first step is to identify the problems, and the obvious is a good first step.

There is no question in my mind that a constant vigil must be maintained to ensure the best possible care for those whose medical monitoring has been given to others. I believe that the *Danger Zone* is a useful tool to help family and friends do just that. The information contained in this short and easy to read manual can be a major influence on the outcomes and comfort of residents in LTC facilities.□

This book may be purchased through any book store or through the Member of the Family web site at www.memberofthefamily.net.

Community-Based Services

Several community-based services are available for seniors who can only stay at home with the assistance of others. Some of the services are local branches of federal programs. These programs are not offered in every community and, where they are offered, the agencies doing so may differ from one another. For instance, in two of New York's Mid-Hudson Valley **Senior Companion Programs** (see description below), Greene and northern Ulster County elders are served by the Community Action of Greene County (<http://www.cagcny/> or 518-943-9205) and Dutchess County residents are served by RSVP of Dutchess County (845-485-8170). To find a full list of services available in your community, contact your local Area Agency on Aging, which is called the Office for the Aging in most New York counties.

For those individuals who are not homebound, **Adult Day Care Centers** (ADC) can provide needed supervision along with the opportunity to socialize with others. There are two forms of ADCs: medical models and social models. Social models focus on enriching the lives of their clients through activities that are socially and mentally stimulating. Medical models may also provide activities but can, as well, provide medical, therapeutic and rehabilitation treatments. To learn more about adult day care, visit <http://www.helpguide.org/>. This site is a joint project of the Santa Monica, CA Rotary club and the Center for Healthy Aging. Once there, Click on 'Challenges of Aging', then on Adult Day Care. The site offers a lot of helpful information, including what questions to ask when checking out ADCs.

The **Senior Companion Program** offers companionship, friendship and more. Local seniors who volunteer to serve in this federally funded program might help with food shopping, paying bills, transportation, and other types of assistance. Their visits may also be timed to allow the primary family caregiver short periods of relief from their caregiving role (respite). This program is not available everywhere. In addition to asking your Area Agency on Aging if the program is available in your community, you can visit <http://www.nationalservice.gov/>. Click on 'Senior Corps' and then use the 'Senior Corps in Your State' search box to find state contact information. To find programs in New York, visit <http://www.ocfs.state.ny.us/>. Enter 'senior companion program' in the search box, click on 'senior corps information' and, finally, 'senior companion program.'

Meals on Wheels is a federal nutrition program for the homebound elderly. Generally speaking, a mid-day meal is delivered five days a week – from Monday to Friday. Some programs, such as **Citymeals-on-Wheels** in New York City, deliver on weekends as well. Others, such as the Austin, Texas **Meals on Wheels and More**, offer additional services. Recipients are asked for a donation to help defray the costs of the meals. Suggested donations vary from program to program, but are usually very modest amounts. □

Information Resources

Eldercare Locator • 800-677-1116

For phone numbers of local & state agencies that can tell you what services are in your area.

Joint Commission Accrediting Healthcare Organizations (JCAHO)

www.jointcommission.com

Click on 'quality check'

Medicare • 1-800-633-4227

Finding Facilities:

www.medicare.gov/Nursing/Overview.asp?

Finding Agencies:

www.medicare.gov/HHCompare/Home.asp?

National Aging Information & Referral Support Center

www.nasua.org • 202-898-2578

Offerings include tips for communicating effectively with difficult persons and in cases of dementia, hearing loss, stroke, and more.

National Coalition for Nursing Home Reform

www.nursinghomeaction.org • 202-332-2275

Links to fact sheets, locating state ombudsmen, states' citizen advocacy groups and more.

National Family Caregiver Association

www.thefamilycaregiver.org • 800-896-3650

Offers many helpful tip sheets and how-to guides on topics that include taking charge and effective communication with healthcare professionals.

US Administration on Aging

www.aoa.gov • 202-619-0274

Click on 'Press Room' then scroll down for links to current and archived fact sheets on a variety of helpful topics.

For Questions to Ask

American Cancer Society

www.cancer.org • 800-ACS-2345

Enter 'Home Care Agency' in search box.

JCAHO • www.jointcommission.org

Click on 'General Public' then 'Helping You Choose Guides'

Mayo Clinic • www.mayoclinic.com

Click on 'Healthy Living' then 'Senior Health'

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*A copy of our latest Annual Report may be obtained from the
Office of the Attorney General, Charities Bureau, 120 Broadway, NY, NY 10271.*

Promoting Health Partnerships

Resources for Family Caregivers

How can I make sure my mother is receiving the best care, when I live in a different state? How can I balance my caregiving, work and other responsibilities? Turning and shifting my bed-bound father is hurting my back. Is there an easier way to do this? How can I get some ‘time off?’ I just placed my husband in a nursing home. Does that mean I’m a bad wife? Who can I talk to about what’s going on? Where can I find help? Where can I find answers?

Fortunately for the more than 27 million family caregivers in America, help and answers can often be found. Long-distance family caregivers, for instance, can hire geriatric (senior) care managers to help. The roles they play may vary widely, ranging from one, specific task (such as helping to find a nursing home, home care agency, or home care aide) to a full range of responsibilities (such as assessing care needs; helping caregivers identify solutions and plan a care path; overseeing the care and, as needed, linking seniors and their caregivers with lawyers, doctors, social workers and a variety of other professionals). Visit <http://www.findacaremanager.org/> to find a geriatric care manager or ask your local professionals.

These professionals can help you find answers to many other questions, too, as can some very valuable web sites. <http://www.helpguide.org/> offers caregivers practical tips for caring for both themselves and their loved ones. They also provide information on respite care; support groups, eldercare services and much more. For a full listing of their information, scroll down to the bottom of the page and click on ‘site map.’ Another very valuable resource is <http://www.caregiver.org/>, the **Family Care Alliance** web site. It offers a free, 31-page *Handbook for Long-Distance Caregivers* as well as a wealth of information on: how to communicate and work with health care professionals; dealing with the strains on sibling relationships that caregiving can bring; strategies for dementia caregiving; how to advocate for loved ones; and how to take care of yourself, to name just a few of

the topics they cover.

For those caregivers whose loved ones reside in nursing homes, the New York City-based **Friends and Relatives of Institutionalized Aged (FRIA)** offers both information and support. While some of their programs, such as organizing and assisting family councils within nursing homes are limited to their service area, caregivers from all over can benefit from their telephone helpline, at **212-732-4455**, and web site, at <http://www.fria.org/>. In addition to the topics described on page 5, they offer an article that addresses the guilt felt by many caregivers, at having had to place their loved one in an institution. By calling their free helpline from Tuesday – Friday, between 10 a.m. and 5 p.m., callers can get either English or Spanish speaking assistance. FRIA helpline representatives can offer advice on long-term care options and financing as well as on evaluating & selecting nursing homes. For those whose loved ones are institutionalized within FRIA’s service area, they offer intervention with facilities and the Department of Health.

Finding information and support for the caregiving process is not an unimportant matter. To ensure that the best possible care is given, it is equally important for caregivers – who often become more susceptible to illnesses – to learn how to take care of themselves. Those who are caregivers, or have been caregivers, know the great difficulty in doing just that. Nevertheless, information in that regard is offered in **Helpguide’s [tip sheet on respite care](#)**. It offers a number of do-able suggestions that can be taken whether or not respite care is available. These include: taking time each day to call a friend or family member, especially if you can’t schedule a regular afternoon or evening outing for yourself; eating nutritious meals, limiting sweets and alcohol; joining a support group – on-line if you can’t get to a local group; and asking for help with caregiving or other responsibilities, such as housekeeping, shopping, home repair and the like. Remember, how well you care for others can depend upon how well you care for yourself.□