



**The Transition Network's
Caring Collaborative
2011**

WHAT YOU NEED TO KNOW WHEN YOU GO TO THE HOSPITAL

BEFORE.....DURING.....AFTER

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FORWARD

The Transition Network (TTN) is a national non-profit organization that helps women over 50 explore their next steps by using the TTN community to support each other as they move forward. It is a groundbreaking organization for these women as they face new challenges in health, finances, family and friendship bonds, and second careers. Living and aging in community is a priority of TTN. See our website at www.thetransitionnetwork.org.

In 2009, TTN created a successful program called the **Caring Collaborative (CC)** that demonstrates how reciprocal care-giving in the community can benefit members, especially those not covered by a family network. Many TTN members are now in their 60s and 70s and are beginning to wrestle with health and care-coordination concerns brought about by age-related illness and disability. The Caring Collaborative is relevant for a wide range of community organizations, whether they be churches, alumni associations, book clubs, or high-rise buildings

What You Need To Know When You Go To The Hospital is one component of the Caring Collaborative. In addition to this manual, TTN offers two other manuals: *Creating a Caring Collaborative in Your Community*, for community organizations and their members, and *Creating a Vertical Village in a High-Rise Building*, for creating a health case support network in apartment buildings or neighborhoods. The Caring Collaborative is managed by a dedicated team of TTN members who are professionals in medicine, law, government, business, social work and journalism, and who have put together these manuals.

All of these manuals are available free of charge to organizations interested in offering a version of this program suited to their needs. The manuals are written in Word and use Word's standard Table of Contents. As such, they can be modified and customized to community needs. We do ask that if you use these manuals, you respect our copyright and credit The Transition Network by keeping the copyright statement in the document. And, please let us know at www.thetransitionnetwork.org/ContactUs how use of these materials helped improve life for your community.

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Hospitalization – Plan for the Best Outcome

Anyone who has recently been hospitalized knows that the days of being a trusting patient are long gone. For many, the hospital experience is fraught with fear, confusion and frustration. Care is fragmented among multiple health care providers. Medications can be erroneously added or changed. And, far too many people are sent home before they are ready, with scant instruction about handling their own care.

This lack of communication and poor coordination has harmful consequences. Studies show that nearly 40% of patients over age 65 make medication errors after leaving the hospital. Emergency room patients fare no better with 75% of patients admitting they do not understand important aspects of their medical condition when they leave the ER. Not surprisingly, these problems often lead to more emergency room visits, hospital re-admissions and poor health outcomes. It's bad medicine and bad business.

This guide speaks to the importance of having the right information and the right team of people to help you. It tells you what to expect when going to the hospital and offers tips and strategies on preparing for hospitalization and ways to help make your hospital stay more comfortable. It suggests ways to ensure all the pieces are in place when you enter the hospital and when you are discharged. Finally, the guide provides Resources for researching medical providers, hospitals, medical aids and devices, and offers sample forms that spell out the medical information you should keep handy in case of an emergency or medical incident.

Preparation for Admission

A bit of simple, straightforward planning can improve your odds for a successful hospital experience. These tips were developed by savvy patients who learned to minimize the emotional trauma and confusion that is typically a part of being hospitalized.

Select a friend or family member to be your health advocate or buddy

This individual will be the liaison between you and your community of friends and relatives as well as the person you may want to have at your side when talking with your health care providers. You may need to sign a HIPAA (Health Insurance Portability and Accountability Act) waiver indicating that you give the hospital permission to share your health information with this point person. Every hospital has its own policies, so it's wise to check in advance. The HIPAA Privacy Authorization Form can be downloaded from HIPAA websites.

Get as much information as you can about your procedure – before, during, and after

Ask a friend or relative, or better yet, your designated health advocate, to accompany you to consultations with physicians. Your advocate can listen carefully, take notes and ask questions you may not have the presence of mind to ask. The National Institute on Aging (NIA) has a useful guide, *Talking to Your Doctor: A Guide for Older People*, with sections such as, *What Can I Say, What Can I Ask*. Download at, www.nia.nih.gov/HealthInformation/Publications/TalkingWithYourDoctor.

Keep your primary care provider in the loop

Talk to her/him about coordinating your overall care. Make sure she/he is copied on pre-admission tests and visits with specialists. It's a good idea to keep all your pre-admission test results with you -- just in case.

More tests are not always better

If your physician or surgeon orders extra tests or treatments, don't be afraid to ask why and how they can help you. There's potential for a lot of duplication in pre-admission testing -- lab work, x-rays and CT scans -- which are not always in your best interest. Pay attention to what is being ordered and feel free to ask for explanations.

Complete a Health Care Proxy and share it with your health advocate

With a Health Proxy you appoint a health care agent who is empowered to make medical decisions when and if you are impaired and unable to make them yourself. The Health Care Proxy form, along with instructions and answers to some frequently asked questions can be downloaded at the NYS Department of Health website in New York or in a state health department website in most states. Also informative is the following website: <https://community.compassionandchoices.org>.

Evaluate home care services in your area

Ask for recommendations from friends and those with personal experiences. Call a few agencies in advance to learn their policies, such as if they take your insurance, and how much lead time is needed for scheduling. If you wait until the day you leave the hospital to call for a home health aide or nursing help, you may have to wait a day or two for services to begin. It could leave a dangerous gap in care.

Evaluate skilled care and rehabilitation facilities in your area

If you need skilled care following your hospitalization, know your options. Talk with family and friends about their experiences as patients, caregivers or volunteers. Ideally, after you've identified several good facilities, make appointments to visit them.

Call your insurance company to find out what is and is not covered

Ask questions about sub-acute care, homecare and criteria for coverage. Ask, "What else do you cover besides nursing and physical therapy?" Similarly, find out if your insurance covers ambulance or ambulette service from hospital to home. Take notes and record contact information. Share it with others involved in your care and bring the information, including phone numbers, with you to the hospital.

Assess your physical living environment

Will you need special supplies or equipment for the bathroom or bedroom? Do you have throw rugs that should be secured? Is the lighting adequate? Is the telephone within easy reach? Do you have sturdy chairs? Make a list of needed repairs or supplies and take care of them before going to the hospital.

Ask your physician/surgeon about medical devices/aids/supplies you will need during your recovery

Make a list and visit a hospital supply store in advance to see what works best for you. The Resources section lists websites offering helpful products, aids and devices.

Develop a support network for reporting on your progress and to help you when you return home

Develop a list of email addresses for friends and family who will want to know your progress and give it to your designated helper to send out as you move forward. You will probably need help with neighborhood errands -- getting prescriptions filled, food brought in -- and help getting to and from doctor or physical therapy appointments. Don't be afraid to ask friends and relatives to help during the recovery process.

CaringBridge.org is a free patient website that helps family and friends share information during a significant health challenge. It offers a private space where those who are close to the patient can share health updates and leave messages of support. This website is a way to communicate with a wide circle of people without disturbing the patient or placing additional demands on hospital or home care staff.

Cook meals in advance and freeze them

Then, you won't have to think about meal preparation during your post-hospital recovery. Similarly, stock up on non-perishable food items and throw out perishables before you go to the hospital. Keep a list of food delivery services by your phone.

Pack a comfortable outfit for your return home

Look in your wardrobe for loose, comfortable and sort of stylish clothes for the return home.

Hire a home cleaning service before you return home

Ask them to put on fresh sheets. Sometimes, small touches make all the difference.

Check out websites

Refer to the Resources section for useful websites.

Hospital Survival Kit – What You Should Take to the Hospital

Consider items on this list to make your stay more comfortable:

- Eye mask for sleeping
- Travel toothbrush and travel toothpaste
- Dental floss
- Comb
- Hand sanitizer (a few individually-wrapped and a travel size bottle)
- Sunglasses (some rooms are very sunny)
- Eyeglasses instead of contacts
- Cell phone and charger, with important numbers in the contact list
- Baseball cap to shield eyes from harsh overhead light
- Telephone number for your doctor
- Copies of pre-admission medical tests
- Information on insurance coverage, with contact numbers
- Comfortable clothes for the day of discharge and rehab if you will proceed to a facility directly from surgery

Making your Hospital Stay More Comfortable

The health care system today doesn't afford you the luxury of being a trusting, carefree patient. You need to be vigilant about your care. Since most people who are hospitalized will have temporarily reduced capacity, you need someone by your side who is watching out for your best interests.

Identify a point person for your health care team.

Before entering the hospital, you should select a point person who should be introduced as your "spokesperson" to the health care team. You may need to sign a HIPAA waiver to allow this person access to your medical information and medical providers.

Relate to hospital staff

You will interact with a number of hospital professionals and support staff. Most will be courteous and attentive. You may enhance your relationships if you are courteous and polite in return. Everyone likes to be thanked for good service. However, hospital staff are often busy and may be abrupt, rude and unresponsive. You should not suffer bad service. Instead, discuss the service with your physician or the head nurse and ask, politely, how necessary service like help getting to the bathroom, or increased pain medication can be improved.

Consider your hospital discharge plan right away

Identify who is in charge of discharge planning and ask to meet with her/him. Don't wait until the day you are leaving! Ask the floor nurse for the name of the person in charge of planning your discharge and his/her contact information. When you meet with the discharge planner, be sure to share helpful information, such as insurance details, medications, physician names and contact information as well as your concerns about your home environment.

Get the name of the hospital's patient advocate or patient relations representative

They are the hospitals' point persons who handle problems that patients encounter when in the hospital. It's good to have a name and contact information -- before you need it.

Keep a journal or diary

Record daily doctor visits; changes in diet or medications; suggestions from the physical or occupational therapist; conversations about problems you may be experiencing. If you are sharing a room, you might also get helpful tips from your roommate -- remember to jot them down.

Be inquisitive

When a new test is being ordered or medication changed, ask why. If you don't understand medical terms being used, ask for an explanation. Don't be afraid or embarrassed to ask questions -- and make sure you understand the answers.

Check the medications that are being administered

Keep track so you can avoid having medication or a dosage incorrectly administered.

Trust your instincts

If you think something is wrong, don't back down. This is not the time to be compliant and trusting. Tell the doctor or nurse. If this tactic doesn't work, ask to see the patient representative or administrator on duty.

Be sure people coming in and out of the room are washing their hands

This means family, friends and health professionals. Hospital-acquired infections are common and can be a serious setback to your recovery.

Preparing for your Discharge from the Hospital

Put home care services in place before you leave the hospital

Speak to your discharge planner about the types of home care services you will need -- skilled and/or custodial, such as home health aides -- and what you are eligible for. If you've looked into home health care agencies before entering the hospital, you can make the call and reserve appropriate staff members. If not, the discharge planner can provide a list of home care agencies (they cannot, however, make a recommendation.) Having a home care agency in place while you are still in the hospital will improve the odds of a smooth transition home.

Schedule an appointment with your primary care doctor

This should be done before you leave the hospital. The visit, typically, takes place within a week of your discharge.

Ask about a timeline for your hospital discharge

The hospital is required to notify you 24-hours in advance of your discharge. If they do not, you have the right to remain in the hospital -- at their expense.

Insist on a departure time

Hospitals are notoriously bad about making and adhering to scheduled departure times, which makes coordinating transportation home virtually impossible. You need to be insistent, perhaps, telling them you must leave at 11:00 am because a friend is picking you up. Be confident and persistent. Speak up if you have a concern or a problem.

Ask the discharge planner about transportation options

Ask if any supplies will be going home with you. Patients are sometimes surprised to find they need a large box of supplies or bulky medical equipment that they cannot transport by car or cab. If you are weak and debilitated by surgery or illness, Medicare may cover the cost of an ambulance or ambulette service from hospital to home or another care facility. If this service is not covered, be prepared to pay. In New York City, an ambulance will cost around \$250; an ambulette, approximately \$100. Place a request for this service with the discharge planner or on-duty nurse. Other options include a car service or cab and ParaTransit services.

Insist on a written list from the discharge planner of all post-hospital medications, with instructions on dosage and timing, and a review of all medications

Medications you were taking before you were hospitalized should be compared with the post-discharge list to ensure there are no duplications, omissions or harmful side effects. Ask if new medications are covered by your insurance. If not, ask if there is an equivalent drug that is. Don't be afraid to ask questions. And, ask whom to contact if questions or problems arise.

If you're frightened about going home, say so

Express your reservations to your doctor and/or the discharge planner. They may be able to help you pinpoint the reason and come up with a plan to address your concerns. *If you feel you are not ready to go home, you have the right to appeal the hospital discharge.* Tell the nurse or discharge planner about your concern, and that you want the decision reviewed. If they are not responsive, contact the patient representative or administrator on call. You can remain in the hospital until the case is reviewed and decided – generally, three days. But, be forewarned -- appeals are rarely successful. If your appeal is denied, you will be financially responsible for costs incurred for the extended stay.

Be sure you receive and understand the hospital discharge plan

It is generally a two-page summary describing your hospital care and instructions for follow-up care. It should include your diagnosis, results of hospital procedures and tests, medical consultants involved in your care by type and name, your condition at discharge, medications prescribed and dosage instructions, a follow-up care plan and contact information. This is a major part of your hospital experience, so ask questions and keep asking until you or your caregiver feel confident about the instructions. Make sure you receive copies of lab tests, blood work ups and procedures so you can provide them to your primary physician.

Be aware of possible adverse signs and symptoms that might occur and require medical attention

Be clear about whom you should contact should problems arise; for instance, the hospital physician, your internal medicine physician, the surgeon, home care provider or emergency department. Review a variety of scenarios and make notes of appropriate contacts.

Settling in Back Home

The transition to home is a major part of the hospital experience and a juncture where things can go wrong. Chances are you will be tired, woozy, sore and possibly, in pain. Here are some helpful tips to prevent complications and adverse events and to speed your overall recovery.

Ask a friend or family member to stay with you for the first 24 to 36 hours

She/he can help you readjust to being home -- perhaps changing some of the furniture around, providing medication reminders, getting you squared away with home care services, or preparing a home-cooked meal. It will be a comfort to you and to your friend to know you are safe and well cared for.

Keep emergency contact information with you or near the phone

Accept help from family, neighbors, and friends

You will likely need a lot of rest during the immediate post-hospital period. Even if your illness or injury is fairly minor, chances are you won't be able to do everything you used to do around your home. For example, a woman with a broken elbow had her routine disturbed more than she had expected because she couldn't sleep well, she couldn't pick up objects, and she was in pain. Don't be stoic and try to go it alone.

Take your medicines as prescribed

If you have problems with side effects, contact your physician or pharmacist.

Keep track of your home care providers

Medicare and private insurers may cover some or all of your skilled home-care (nurses and physical therapists.) But custodial care -- home health aides who help with personal care and activities of daily living -- will likely come out of your own pocket. Monitor who is coming, the service being provided, how long they stay, and, importantly, whether or not you like them, and if they're doing a good job.

Keep a journal on how you're feeling

Record unusual symptoms or pain, problems you didn't anticipate, or concerns for your well-being. Share this information with your physician at your follow-up appointment or even before if they are serious.

Follow through on medical appointments

Keep appointments that were made when you were in the hospital, not just with your primary care physician but other specialists such as your surgeon, cardiologist or physical therapist.

Take It Easy

Recovery from any illness or injury takes time. Be patient with yourself. Eat well and rest.

Navigating a Hospital Emergency Room

Few people report having a good experience in hospital emergency rooms. The waits are long, staff is abrupt, and there's a sense that no one cares about you -- unless you are in danger of dying. Prevention is, of course the best strategy -- taking extra time and care so you don't risk an injury or fall. But even when care is taken, accidents happen and illness strikes without warning. Here are some tested strategies for navigating the emergency room and planning your escape.

Put emergency contact information in your cell phone

Phones are programmed with an ICE (In Case of Emergency) button. Emergency personnel are trained to look for ICE numbers. This provides immediate contact information for your physician and close family members.

Provide medical information to emergency room staff

It's useful to keep information about medications, chronic diseases, allergies and insurance in your wallet so it's available at all times.

Be prepared for a long wait

If you are alone, call your health advocate or a friend and ask that she bring water, food and reading material -- anything that might make you more comfortable.

Consider whether emergency care is needed

If your illness or injury is not life-threatening, consider whether you need the emergency department. Call your primary care provider for advice. Perhaps an office visit the next day can offer the help you need.

Be the squeaky wheel

In a busy, crowded emergency room, you have to make some noise or you will be forgotten. Ask questions -- it's a good way to engage staff and get them to pay attention to you.

Have your discharge plan in hand before leaving the emergency room

Your discharge plan should include written instructions about the treatment you received and any needed follow-up care. It should describe medications prescribed, care for wounds or injuries, and any specialists who should be contacted, such as an orthopedist or plastic surgeon.

Be careful

Pay attention to traffic signals; watch out for street potholes, hold onto handrails; install a grab bar in your shower; take your time when the phone or door bell rings -- quick starts are the most common reason for falls.

Useful Resources

Websites with Information on Doctors – Recommendations and Ratings

This is by no means a complete listing. It is meant as a starting point for your research.

- drscore.com. A site where patients rate their physicians. Free, easy to use. It links to patient advocacy groups, books and media, patient resources, and prescription savings.
- healthgrades.com. Information on disciplinary actions, board certification, education/training, patient opinions. You can research physicians, hospitals and nursing homes. Some information is free. There is a charge for extensive information. The site is slow.
- insiderpages.com. Lists over 9,000 doctors and more than 300 doctor referral services in Manhattan. Some are rated by stars, but it's not clear who produced the ratings. The site is a bit overwhelming, but seems to be free and possibly useful.
- Nymag.com/bestdoctors. Doctors selected on the basis of a peer review survey. It links to the castleconnolly.com/membership site where there are a number of membership choices as well as an opportunity to purchase *America's Top Doctors*.
- rateMDs.com. A free site that rates doctors on the basis of patients' opinions. It links to nydoctorprofile.com that has profiles for all licensed medical doctors who are registered to practice in New York State.
- extapps.ama-assn.org/doctorfinder/. Comprehensive information on individual physicians, including more than 690,000 medical doctors.
- ZocDoc.com. Reviews by patients of doctors and dentists, organized by neighborhood.

Websites with Information on Hospitals in your Area

- healthfinder.gov. Site is considered a gateway to reliable consumer health information from the federal government and other organizations.
- qualitycheck.org. Comprehensive listing of health care organizations and reports on their quality from the Joint Commission on Accredited Health Care Organizations.
- hospitalcompare.hhs.gov. Compares the quality of care at hospitals according to medical conditions and surgical procedures.

Websites On Hospital Discharge Planning and After

- health.state.ny.us/professionals/patients/discharge_planning. A discharge-planning guide prepared by the NYS Department of Health.
- nextstepincare.org. Guides for transitioning out of the hospital.
- caregiver.org/caregiver/jsp/content. Services and support for families and caregivers

Websites that Offer Products, Aids, and Devices for Mobility and Safety

- activeforever.com
- aidsforarthritis.com
- arthritissupplies.com
- dynamic-living.com
- goldviolin.com
- lifesolutionsplus.com
- rehabmart.com

Sample Health Profile Form

You can download this form, fill it out, and keep it handy for instant reference and for passing along to your health advocate:

INSURANCE INFORMATION & HOSPITAL/PHARMACY

Medicare Number:

Medicare Supplemental Insurer and policy number:

Drug Insurer:

Medicare HotLine: 1-800-633-4227

Hospital:

Pharmacy

LIST OF MEDICAL DOCTORS & DENTISTS

Primary Care Doctor

Allergist

Audiologist

Cardiologist

Dentist and Periodontist

Dermatologist

Endocrinologist

Gastroenterologist

Gynecologist

Internist

Ophthalmologist

Orthopedist

Podiatrist

Radiologist

Rheumatologist

MEDICAL TESTING

Bone Density (date)

Mammogram (date)

Other

OTHER HEALTH PRACTITIONERS

Acupuncturist

Chiropractor

Physical Therapist

Other

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