

A Family Caregiver's Guide to Care Coordination

You have many responsibilities as a family caregiver for someone with a serious chronic illness or disability. You may do personal care such as bathing and dressing. You may make sure the person takes the right medications at the right time and operate medical equipment. You may shop and cook and keep track of bills. You may watch out for and report signs of medical problems, go to doctor visits with your family member, and much, much more.

These responsibilities may be yours alone, or you may share them with others. You may also get help from a professional care coordinator. It is good to know about ways to work together. This guide is designed to help. It has four sections:



See the Next Step in Care companion guide for professional care coordinators (http://nextstepincare.org/Provider_Home/care_coordination/) to help understand their perspectives on effectively working together.

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Professional Care Coordinators

Who are professional care coordinators? They are either health professionals (such as nurses or social workers) or office staff who help schedule, arrange, and oversee services needed to maintain the health and well-being of someone with a serious or chronic illness. The role of professional care coordinators can vary. Some may focus on medical care while others help with insurance, medication, or community services.

Professional care coordinators may be called discharge planners, benefit managers, case managers, private geriatric care managers, or some other title. They may work in a:

- ▶ Health care facility such as a hospital, outpatient clinic, medical practice, VA hospital or clinic, or primary care doctor's office
- ▶ Health plan, private insurance company, managed long-term care plan (MLTC), or pharmacy benefit plan
- ▶ Medicaid program, or a program for people who get both Medicare and Medicaid
- ▶ Home care agency, Area Agency on Aging, senior center, or other community-based service

How do professional care coordinators help? Their job is to help get needed services in a way that does not waste anyone's time or energy and does not create extra costs. Professional care coordinators can often access services that are hard, if not impossible, for patients and family caregivers to connect with on their own.

A doctor, nurse, social worker, or other health professional should work with you and your family member to determine what services your family member needs. This discussion is called an "assessment." Services may focus solely on medical care or help your family member live at home and take part in community activities. For instance, a care coordinator might arrange for doctor visits, make referrals for home care, order medical supplies, get the health plan to approve payment for certain services, and communicate with others on your family member's care team.

There are limits to what care coordinators can do, often depending on where they work. For example, a care coordinator from a health plan or medical practice may refer your family



Care coordination is not the same as disease management. Care coordination is about a patient's overall health. Disease management is a way to teach about a certain health problem, such as diabetes.

member to services and providers within their network but not know about more convenient options. A care coordinator from a community-based agency might have good local contacts but not be able to refer your family member for medical care. A care coordinator from a pharmacy benefits plan may coordinate prescriptions, refills, and delivery of medications but not manage other health care services.

How long do care coordinators work with patients and family caregivers? Most professional care coordinators work with patients and family caregivers for a specific period of time. For example, this might be for 30 days after leaving the hospital or just while your family member is getting a certain treatment. Some care coordinators are part of a long-term care plan and work with families for as long as that plan is in place.

In addition to care coordinators, other professionals may be involved in your family member's care. They may include:

- ▶ **Coaches** (such as nurses or other professionals), who teach patients and family caregivers how to take the lead in coordinating care and communicating with health care professionals.
- ▶ **Community health workers**, who live in the area and are trained in some aspects of basic primary care. They can help patients and family caregivers prevent disease and manage chronic conditions.
- ▶ **Navigators**, who can provide names and contact information for doctors, hospitals, health care staff, and community services. They usually do not arrange for, or schedule, appointments.

Family Caregivers and Care Coordination

It can be hard to coordinate care for someone with a serious or chronic illness. It takes a lot of time and skill for family caregivers to balance family resources, relationships, work, health care system requirements, and community resources like transportation, adult day care, and home-delivered meals.

Your caregiving responsibilities may vary depending on your

family member's needs at any given time. You may need to coordinate care only when your family member is discharged from a hospital or rehabilitation program, when caregiving plans fall apart, or when your family member just needs extra help. Or family caregiving may be a daily part of your life and take a lot of time and energy.

Even when working with a professional care coordinator, you have many responsibilities. Here are examples of how you might work together:



A professional care coordinator's job is to coordinate services. A family caregiver's job is to coordinate life.

- ▶ Your family member has a heart problem and needs to see a specialist very soon. But the specialist has a two-month wait list for new patients. A professional care coordinator may be able to get you an appointment for next week and even arrange transportation. It is your responsibility to get your family member ready for this appointment and perhaps leave work early so you can go, too. During the appointment, you need to speak with the doctor and take notes about what's next. Everything must go smoothly or the appointment could be missed and your family member's medical problems could get worse.
- ▶ Caregiving can be expensive, with the need to pay for special food, medicine, supplies, and insurance co-pays. You might need help paying some of these costs. A professional care coordinator may be able to talk with your family member's doctor about less expensive medicine, ask insurance to pay for certain supplies, or find help paying other bills.
- ▶ The hospital discharge planner ordered a shower chair, but it is too big to fit in your family member's bathroom. A professional care coordinator may be able to find a smaller chair and even arrange for someone to install the chair at home and teach you how to use it safely.
- ▶ You care for grandchildren, one of whom is disabled. Now you are not feeling well and need to go to the doctor. How can you find time to take care of yourself? A professional care coordinator may be able to work with you and your grandchildren's care providers so that you both can get needed care and services.

Questions to Ask a Professional Care Coordinator

It is good to ask a lot of questions. Asking questions helps you and the professional care coordinator work as a team. Find out ahead of time what tasks each of you will do. Speak up if you do not understand what a care coordinator says or you think there are problems. You as the family caregiver are responsible for making sure this works out. Don't leave it to chance. Here are some questions you might want to ask.

Questions about working together:

- ▶ What parts of my family member's care are you going to coordinate?
- ▶ What parts of care are you not going to coordinate? For instance, will you:
 - ▶ arrange transportation to the doctor,
 - ▶ find community resources,
 - ▶ get home care services,
 - ▶ order equipment and supplies, or
 - ▶ help me fill, refill, pay for, and arrange delivery of medication?
- ▶ How long will you help us with care coordination? Are your services ongoing or just for a while? If so, when will your services end?

Questions about my role as a family caregiver:

- ▶ What do you see as my role in care coordination? What if I cannot do some or all of the things you expect from me? Let's discuss this.
- ▶ Can I work with you to schedule appointments and other activities? I know it helps if I can go to appointments, too, and I want to fit them into my schedule.

Questions about communication:

- ▶ How will you communicate with me? Will it be by phone, e-mail, Skype, in person, or through an online patient portal?
- ▶ Are there certain times to call you with my questions?



Speak up if you are having problems with a professional care coordinator. Perhaps he or she is not following through on plans. Or you are not working well together as a team. If you are having problems, speak with a supervisor or request a different care coordinator.

- ▶ If my family member goes to a specialist, will that doctor tell you or me what happens next?
- ▶ Who gets my family member's test results? If it is someone other than me, who will tell me the results? Who will tell me if there is anything new or different we need to do?

Your family member may have two or more care coordinators, each working at different agencies (such as one from a doctor's office and another from a managed long-term care plan). Ask how they will communicate with you and each other. Good communication might not happen without a plan.

Tips for Staying Organized

It's hard to arrange a system of care that works for you and your family member. You have to include everything from doctor appointments to home care, from medication schedules to transportation. You may also need to coordinate services arranged by different professional care coordinators. And you need to know what to do when something goes wrong. This can be quite a challenge, even for the most organized person.

Here are some tips for staying organized.

- ▶ **Set up a notebook, computer folder, caregiver app, or patient portal.** Your records should include names, phone numbers, e-mail addresses, and other ways to contact services, doctors, and others involved in your family member's care. It should include what to do when there is a problem or emergency (such as calling the primary care doctor, specialist, care coordinator, family members, and pharmacy). It also should include information about transportation, food delivery, and other needed services.
- ▶ **Keep notes each time you contact a health care and other professional.** Include the date, name and title of each person you speak or email with, and what was discussed. You can save e-mails in a computer folder or print them out and add to your notebook. A reality of care coordination is that you may hear different things from different people. It helps to have notes showing who told you what.

- ▶ **Make a weekly chart of appointments, home care visits, family and friend visits, and other scheduled activities.** See the Next Step in Care guide, *A Family Caregiver's Planner for Care at Home* (http://www.nextstepincare.org/Caregiver_Home/Care_Planne_r/) for an example about how to set this up. Some caregiver apps have calendars that you can connect with your own app calendar. These apps may let others see the schedule and add their own visits.
- ▶ **Have an up-to-date list of all medications, including over-the-counter and herbal medicines. Bring this list to every doctor appointment or medical test.** It is best to use just one pharmacy for all your family member's prescriptions. This way, the pharmacist has a complete record of all medications and can alert you to any problems. If you need to use more than one pharmacy, tell each pharmacist about all other medications. If you use mail-order pharmacy services, you can talk to a pharmacist by phone.
- ▶ **Arrange for regular delivery of disposable supplies and other items.** These deliveries help make sure that you always have enough. You can arrange delivery through a catalog or online supplier. Ask the care coordinator at your family member's insurance company if certain suppliers offer a discount.
- ▶ **Ask other family members or friends to help.** They might pick up prescriptions, shop, do laundry, organize bills, prepare or deliver meals, spend time with your family member, drive your family member to the doctor, or do other tasks that help relieve you from some care coordination responsibilities.

Care coordination is like a jigsaw puzzle. There are many pieces. Just like a jigsaw puzzle, care coordination can be easier when several people work on different parts. It helps to always think of the big picture of tasks and appointments. That way, you can work on your own part of the puzzle while also being part of a team.

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