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Meeting the Challenge of Care Coordination

When Lisa Jones gave birth to daughter Emily, she not only became a parent, she became a family caregiver. Emily was born with spina bifida and other difficult-to-manage conditions. In order to keep her daughter as healthy as possible, and provide her with a satisfying and meaningful life, Lisa often finds herself doing research; tracking records; interacting with doctors, therapists, insurance companies and the school system; and documenting it all in anticipation of future needs. Some might say Lisa is doing what all mothers do for their children, but, in actuality, she is doing so much more. Every day, Lisa is applying a systematic approach to address the needs of her child with special needs. She is, in essence, acting like a care coordinator. For Lisa, who has the best understanding of her daughter's needs, this is the role that only she can fill on behalf of her family.

What Is Care Coordination?

Care coordination (sometimes called care management) applies professional skills to the caregiving situation. Since care coordination involves both medical and social issues, bridging the gap between the two is often one of the biggest challenges a coordinator will address. This individual must be knowledgeable about all aspects of caregiving, providing services as needed. These services include assessments; identification of available benefits; referral to financial, legal or medical specialists and programs; coordination with the medical team; crisis intervention; family counseling; long-distance care management; assistance with moving someone into a nursing home or other facility; consumer education and advocacy; long-range planning; and help with accessing information and resources. Some care coordinators also provide guardianship or conservatorship services. While the field originally focused on geriatric care, care coordination services work just as well for chronic illness or special needs situations.

Wilma Schmitz provides care coordination for a 150-bed geriatric facility in St. Louis, Missouri, and maintains a private practice. She holds a master's degree in gerontology, and has been in the business for 20 years. Asked why people hire a

care coordinator, Wilma replies, "The hardest thing is understanding the system as a whole. When I start trying to explain the ins and outs of government programs, I usually give someone a Hershey's kiss and tell them to hang on, it's going to be a bumpy ride. I also help caregivers take some care of themselves - I am big on bubble baths. People have to find some kind of support for themselves to stay healthy and give care."

Wilma fits her services to her clients as they need her, stays in touch with them and is always available - including online and by telephone - for help. Eric Land is a client of Wilma's. He cares for an aunt and brother in nursing homes, and watches over his 90-year-old mother, still living on her own. Wilma's services have changed as Eric's needs have changed. "I was not aware of what was available, especially programs that could help," he says. "Wilma helped me find out these things, and went with me to get my aunt qualified for assistance to be in the nursing home. She's taught me a lot." When Eric's mother resisted having help in her house, Wilma was able to convince her to try it.

From the medical point of view, care coordination can lead to better medical outcomes for the patient and substantial cost savings. Dr. Alan Lazeroff is responsible for geriatric medicine at Centura Senior Life Center, part of Centura Health, the largest health care system in Colorado. Lazeroff believes that care coordination helps doctors do what they want to do: deliver what medical science promises.

Lazeroff has run experiments using a care coordination team that includes a social worker, a doctor and a nurse working with a patient and his/her family to make better medical decisions. He is convinced that not only is this better for patients, but it leads to a better use of resources. He explains, "A team approach can reduce the rate of ER usage and hospital visits, keep patients more in control of their condition by using 'upstream' interventions, and make the whole system more effective. Patients and families who understand their condition, know the alternatives, and have a sense of being cared for will do better in the long run. This saves money for the system because there are fewer costly medical procedures and more preventive care. Patients with this type of coherent, informed care are less sick, less upset and anxious, and avoid inappropriate inpatient procedures."

What Does a Care Coordinator Do?

Working with a care coordinator usually begins with an assessment of the current situation. This includes a thorough identification of the medical/psychological issues facing the care recipient, a discussion of financial resources and preferences, an identification of family and friends who are part of the caregiving network, and a discussion of the needs the family has identified. Following the assessment, the care coordinator will provide a written report on problems, possible services, and options. Initial assessments range in price, usually between \$250 and \$400.

After the initial assessment, the caregiver can decide to request any number of services from the care coordinator. If the family has a good grasp of their financial situation, for example, they may not need help in planning for future costs, managing expenses, or applying for benefits. Some people ask for substantial help at first, and then call on the care coordinator as needed. Others choose periodic monitoring and checkups as conditions and opportunities change. Care coordinators will provide a written list of fees, normally based on hourly charges. Fees vary, depending largely on where one is located around the country. Ask the care coordinator the hourly cost. Each bill should contain a detailed statement of exact services provided.

Some financial assistance may be available to cover the costs associated with care coordination. More and more corporate and government employee assistance programs cover care coordination because the employer gains a more productive employee. Some forms of long-term care insurance also cover care coordination, as it keeps total costs down and works to put the most appropriate services in place. Your local Area Agency on Aging may be helpful in locating financial assistance or a less expensive coordinator.

As more and more families enter the caregiving environment, and as programs and treatment options become more complex, a flexible approach is better for consumers and providers. You may need just a little advice on occasion today, but full support if a crisis develops. If/when a crisis does develop, you want help from someone you know, and who knows your situation.

What Are the Benefits of Using a Care Coordinator?

Why should you bother with the time and expense of professional help? First, as a caregiver, you are facing many difficult decisions, and you need help. Having an expert on your side can save you time, energy and frustration when finding

resources. Just hiring someone to help in the home can be a struggle; a care coordinator will know the agencies and their staffs personally and can cut through the red tape quickly. Next, there may well be monetary savings, as a care coordinator helps you utilize your resources wisely. This individual can help you think ahead, identify resources and educational opportunities, and take a broader view of the situation.

An additional factor to consider is the value of having a "third party" to consult. Wilma Schmitz points out that baby boomers caring for their parents almost always encounter resistance. She explains, "We are used to talking about everything; our parents' generation is much more private. And our parents don't usually respect our judgment. But if someone outside the family says it, it's gospel."

Wilma, herself, experienced this recently when she appeared on television to discuss Missouri's innovative statute allowing family members to request a driving assessment. "When I got home my own father, who hadn't wanted to discuss his driving, finally talked to me about it. Because he saw it on television, suddenly it became okay."

Families benefit from care coordination as well. The presence of a third party helps families separate (or at least identify) what is emotional from what is factual. Family conferences that take place with a clear statement of the current situation, a presentation of options, and some independent advice are much different from family conferences where anxiety, jealousy and lack of information drive the discussion. This type of informed discussion also makes it easier for the loved one to participate as an equal, thus preserving his/her independence. In fact, the care coordinator is a valuable asset to the person needing care; he/she can be directly involved, and informed, rather than being the "object" of family decisions and actions.

Being Your Own Care Coordinator

In defining how you can best be an effective family caregiver and stay healthy yourself, thinking like a pro can help. If you examine what care coordinators do, you will likely find two things: The first is that they have a structure for objectively analyzing what you are facing. The second is that they know how to "work the system." Here are some concrete things you can do to begin to gain some of these care coordination skills yourself.

Care Management Techniques You Can Use:

- **Educate yourself.** Learn about the disease or condition you are managing. Use Internet sites provided by well-known institutions and agencies, contact the local branch of the organization associated with the condition, and read to gain the core medical knowledge you need.
- **Do your own initial assessment.** What is your loved one's ability to function, how has it changed over time, who is available to help, and what is the physical environment like? What are your financial resources? What are your other responsibilities and needs? Write this down.
- **Hold a family conference.** Using your assessment, talk with immediate and extended family about the present situation and future prospects. You may be able to divide responsibilities, anticipate problems, and clarify resources, including money, time and energy. (The participation of an objective third party in the conference makes a big difference. If you do not use a professional, consider a trusted family friend or advisor.)
- **Keep good records.** If you do nothing else, create a system for managing emergency numbers, doctors, medications, treatments, special requirements, insurance, and other information. A computerized record will make updating simpler, and it can be shared immediately with family members or the medical team in any location.
- **Identify local services.** Find out about respite care, special needs services, transportation, volunteer programs, home care providers, and government assistance programs. Look for resources for the care recipient and for yourself.
- **Plan ahead for difficult decisions.** When a crisis hits, it's too late to think rationally or prepare necessary documents. Your wishes as a caregiver, and the wishes of your loved one, will be respected if you have wills, advance directives and powers of attorney in place. No one likes to think about this, so do it now and cross it off your to-do list. You will rest more easily.
- **Develop a care team.** Take advantage of people who offer to help, assign them a task on a continuing basis (maybe they can come by once a week to let

you leave the house), or put them down for emergency help. This will back you up, and remind you to ask for help when you need it. Defining these people as a care team gives everyone a job, and makes the relationships clear.

You may have already incorporated some or all of these suggestions into your caregiving routine. If not, start with the ones you feel most comfortable with and build from there. Like Lisa Jones, you have the best understanding of your loved one's needs, as well as your own. You have the power to define your role of family caregiver, and to change the dynamics of that role as your family's needs change over time. Go for it!

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