

You may find yourself in an unfamiliar role when caring for a loved one with cancer: care coordinator. You may find yourself managing schedules, medications, appointments, contacts, resources, insurance, bills, and more. This new coordinator role can be challenging. However, it is a vital part of being a caregiver.

COORDINATING CARE

The new role of care coordinator sometimes comes naturally. For others, this is a new world to navigate. Starting the process can be overwhelming. You may manage these responsibilities alone, or with the help of others.

- **Medical research.** You may find yourself researching to better understand your loved one's diagnosis, treatment, side effects, and care plan. You may even research doctors or hospitals online. If you are not computer savvy, ask someone in your family (i.e. adult child/grandchild) to look for you. Then have them report back to you.
- **Scheduling doctor's appointments.** There will be many appointments with the health care team, potentially daily radiation or chemotherapy, or physical therapy. Keep a notebook (or online spreadsheet) with names, contact numbers, and a calendar of appointments. This will help things run smoothly. And you will have easy access in times of emergency or questions.
- **Meeting with the health care team.** It can be important that either you, or someone you and your loved one choose, be at doctor's appointments. Caregivers can take notes, ask questions, and be a sounding board. Preparing a list of questions ahead of time and taking good notes will help.
- **Medication management.** Your loved one will likely have many medications that change frequently. Coordinating, filling, and administering prescriptions can be a job in itself. Work with your pharmacist or doctor to understand instructions, refills, and dosing. A pill box or chart may help you keep track of what medication is given when. Pharmacists sometimes will package medicines together in



www.CancerSupportCommunity.org
1-888-793-9355



MyLifeLine is CSC's private, online community where patients and caregivers are able to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond.

You can use this website to:

- Keep friends and family informed and involved through a personalized blog. You can ask for help with rides, meals, etc. in the Helping Center on your page. As a caregiver, your loved one can give you access as an Assigned Care Coordinator to run their page.
- Connect with other caregivers by joining the Caregiver Support online discussion board. Discussion boards are available 24/7 and are monitored by a licensed professional.
- Learn more about cancer through **Frankly Speaking About Cancer®** resources.

Sign up at **MyLifeLine.org**.

packets for daily use, which can be helpful. A home health care agency can also come in to organize medications a couple times a week. Many insurances cover the cost of this for people with serious illnesses, like cancer. Have your health care team look into this if you are interested.

- **Engage others.** It is okay to ask for help with some of the practical aspects of coordinating care. For example, family/friends could drive to appointments, make meals, or research information. Also, there are professional services that can help. These include home care agencies or other community services. Being a coordinator doesn't mean you have to do it all yourself. Your health care team can also help you find local agencies, resources, or online apps.

AVOID CAREGIVER BURNOUT

As a caregiver, you may be focused on balancing the new roles and demands in your life. You may forget to take care of yourself or feel out of control. It is okay to know your own strengths and limitations. Recognize when you need help and ask for it. There may be care tasks that others can help with, to leave you some time for yourself. Taking care of you is an important part of being a caregiver.

General Cancer Information, Survivorship & Support

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org

American Cancer Society • 800-227-2345 • www.cancer.org

CancerCare • 800-813-4673 • www.cancercare.org

Cancer.net • 888-651-3038 • www.cancer.net

Caregiver Action Network • 855-227-3640 • www.caregiveraction.org

Healthcare.gov • www.healthcare.gov

Livestrong Foundation • 866-673-7205 • www.livestrong.org

National Cancer Institute • 800-422-6237 • www.cancer.gov

National Center for Complementary and Alternative Medicine • 888-644-6226 • www.nccam.nih.gov

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

Cancer Support Community Resources

Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon–Fri, 9 am–9 pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Connect with other caregivers by joining the Caregiver Support online discussion board. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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