A diagnosis of cancer of unknown primary can be overwhelming. The time ahead will be very important to you. This fact sheet gives advice on how to:

- Understand your diagnosis and treatment plan
- Communicate with your health care team
- Build a network of resources and support
- Care for yourself emotionally

What Is Cancer of Unknown Primary and How Is It Treated?

Cancer of unknown primary occurs when the cells found in the body begin to change and grow uncontrollably, forming a tumor (also called a nodule), which can be either cancerous or benign, but the source of the cancer cannot be found. The main types of cancer of unknown primary are carcinomas, squamous cell cancers and adenocarcinomas.

There are a wide range of treatments for cancer of unknown primary, including surgery, radiation therapy, hormone therapy, targeted therapy and chemotherapy. If treatment is necessary, ask your health care team to recommend reliable publications and websites to learn more. Knowing what to expect can help you feel more in control.

How Can I Stay Informed About My Cancer?

- **Communicate with your health care team.** Your doctors and nurses are the central part of your team. It also can include pharmacists, oncology social workers, counselors and more. They all help you make decisions about your care.

- **Keep your health care appointments.** Prepare your questions before your appointments and write down or record the answers to help you remember them. Think about bringing a friend or loved one for support.

- **Contact health care organizations.** CancerCare’s A Helping Hand is a listing of state and national organizations with advice and resources. This can be ordered in print or found online at www.cancercare.org/helpinghand.

- **Be aware of health care disparities.** Cancer of unknown primary is sometimes discovered later for certain groups, such as Black patients and the uninsured. This may affect the stage of cancer and resources needed for treatment.
What Are Some Resources That Can Help?

You do not need to cope with cancer on your own. There are local and national support services available to assist you.

Financial Assistance. Many organizations provide help with medical billing, insurance coverage and reimbursement issues. There are also financial assistance organizations for people who cannot afford the cost of their medications. Good places to start are the websites of the Cancer Financial Assistance Coalition (www.cancerfac.org) and the Medicine Assistance Tool (medicineassistancetool.org).

Benefits and Entitlements. Local and national government agencies can give you information on Social Security, Medicaid, disability issues, SNAP benefits and more. Check your local phone directory for listings or visit www.usa.gov/benefits.

Housing/Lodging. Lodging for families who need to travel for treatment may be found at The Hope Lodge of the American Cancer Society (www.cancer.org/support-programs-and-services/patient-lodging) and the National Association of Hospital Hospitality Houses (www.nahhh.org). Joe’s House offers an online database with lodging information across the U.S. (www.joeshouse.org).

How Do I Help Myself Emotionally?

Cancer may not just affect yourself, but everyone around you. It is important to take care of your feelings. You may find emotional support from friends, family and loved ones. There are also many organizations, such as CancerCare, that provide support services to help people affected by cancer. CancerCare provides one-on-one counseling and support groups to connect you with others in a safe and supportive environment. We can also help find other resources to help you in many ways.

CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include resource navigation, counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master’s-prepared oncology social workers and world-leading cancer experts.

To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

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