

# THE POCKET GUIDE TO PATIENT ADVOCACY IN CANCER

## FAST FACTS

- Patient advocates are personal guides who help you get the right care at the right time during your cancer journey. They can take the form of a friend or family member, a social worker, nurse navigator, a former cancer patient, or yourself.
- A patient advocate can help you find ways to pay for treatment and living expenses, access health insurance, get transportation to visits, access to community resources, and more.

## HOW PATIENT ADVOCATES CAN MAKE YOUR CANCER JOURNEY EASIER

Having cancer or any serious life-changing disease is overwhelming. At a time when you're anxious and afraid, you are faced with navigating the complicated health care system to get the treatment you need. You and your family also face practical challenges, including paying for and getting to treatment. "Getting told you have cancer is like getting hit by a bus," says cancer survivor Lou Lanza. It's almost essential to have some that can help you get back on your feet.

You don't have to—and you shouldn't try to—do this all on your own. A patient advocate can help make your cancer journey easier.

## What is a patient advocate?

A patient advocate is someone who helps you get the care and support you need. This can be a professional patient advocate, a support group, a family member, or a friend. Get the best care and support by working with both a professional patient advocate and a family member or friend. Also, you can advocate for yourself.

## What does a patient advocate do?

"Patient advocates are very important in providing support, navigating the complex health care system, asking questions, and clarifying concerns," says Celeste Vaughan-Briggs, LCSW, manager, Breast and Cervical Cancer Screening Program and oncology social worker at the Sidney Kimmel Cancer Center at Jefferson University in Philadelphia, PA. .

A professional patient advocate can help you with:

- Getting access to health care, including coordinating your care and communicating with your care team.
- Getting practical information about your disease and treatment.
- Paying for treatment, including financial aid and health insurance.
- Paying for living expenses.
- Getting transportation to and from medical appointments.
- Referrals to community resources.
- Information about complementary treatments
- Support in lifestyle changes

A family member or friend who knows you well can listen during appointments, write down and organize what the care team says, and ask questions. They can let your care team know about things you might not mention, such as your symptoms and how you're feeling. "A family member or friend can be a connecting bridge for the care team, providing crucial information," says Vaughan- Briggs.

You should also ask questions. "There is no stupid question. Everybody has different questions, needs, and requirements," says Lanza. When Lanza was being treated for non-Hodgkin's lymphoma at the Sidney Kimmel Cancer Center in 2005, professional patient advocates weren't common. But he got help from his wife and friends who drove him to treatments, gave his kids rides, made meals, and helped in other ways. Now Lanza helps other cancer patients, including by being part of the Sidney Kimmel Cancer Center's Buddy Program, where he supports newly diagnosed cancer patients.

## Where do professional patient advocates work?

Professional patient advocates are sometimes called patient navigators. Cancer centers and hospitals usually have patient navigators. Sometimes, patient advocates are also called health care advocates.

Local and national nonprofit organizations, Federally Qualified Health Centers, government agencies, insurance companies, and for-profit patient advocacy firms also have patient advocates. Some patient advocates are self-employed.

## What qualities and skills should a patient advocate have?

Compassion is a key quality in a professional patient advocate, say both Lanza and Vaughan-Briggs. Other qualities and skills to look for are:

- Knowledge of your disease and the health care system.
- Ability to communicate effectively.
- Empathy.
- Good time management.
- Ability to do research to solve problems.
- Patience.

Also, if possible, look for a professional patient advocate who is like you: someone of the same race, ethnicity, age, gender, and setting (urban, suburban, or rural) who speaks your primary language, recommends Vaughan-Briggs. The patient advocate will understand your life and be able to make your care team aware of any barriers to care based on your life.

A family member or friend who serves as your patient advocate should know you well, be comfortable asking questions, and be organized and assertive.

## How do I find a patient advocate?

If your cancer center doesn't assign a patient navigator or advocate to you, ask for one. Your care team can help you find a patient navigator or advocate if the cancer center doesn't have any on their staff. You can also use a directory of patient advocates (see the Resources at the end of this guide).

## As my needs change, how can the patient advocate help me?

A professional patient advocate understands your needs during your cancer journey and can provide support and resources tailored to where you are. For example, when you're newly diagnosed, your patient advocate will focus on relieving your anxiety, working with you and your care team to develop a care plan so you know what to expect, and helping you navigate the health care system.

During treatment, your patient advocate will continue to provide support, can help coordinate your appointments, and help you communicate with your care team. After treatment, your patient advocate will work with you and your care team to develop a follow-up care plan and continue to help with your emotional, financial, and other needs.

If you need end-of-life care, your patient advocate will support you and your family and continue to coordinate your care. They will work with your care team to ease your pain and help you organize practical matters while respecting your advance directive and your wishes.

## Is a patient advocate different than patient advocacy?

Patient advocacy organizations and some patient advocates don't work directly with patients. Instead, they promote policies to help people with cancer, raise awareness of cancer, advance cancer research, and improve the quality of cancer care at the local, state, and national levels.

For example, the American Cancer Society's Cancer Action Network<sup>SM</sup> works with elected and appointed officials, policymakers, and candidates to ensure that cancer remains a top priority. Lanza provides his perspective as a cancer survivor for patient advocacy work at the American Society of Clinical Oncology, the American Association of Cancer Research, Patient Power, and other organizations.

## Resource list

Use these resources to make your cancer journey easier.

### Education

- [Cancer A–Z](#), American Cancer Society: Information on specific types of cancer along with cancer basics.
- [Guides for more than 120 types of cancer](#), American Society of Clinical Oncology
- [Guidelines for different types of cancer](#), National Comprehensive Cancer Network

### Patient navigation, case management, and patient advocates

- [Patient Navigation programs](#), Susan G. Komen Foundation Helpline: For breast cancer patients: 1-877-465-6636 or [helpline@komen.org](mailto:helpline@komen.org).
- [Case Management](#), Patient Advocate Foundation: Free help, including access to care, paying for treatment and living expenses, and employment for patients and families living with a serious or chronic health condition.
- [Case Management](#), *CancerCare*: Free telephone case management from oncology social workers.
- [AdvoConnection Directory](#): A directory of private patient advocates you can pay to help you. They are all members of the Alliance of Professional Health Advocates.
- [Advocate Directory](#), National Association of Health Care Advocacy: A directory of private patient advocates you can pay to help you.

### Financial Resources

- [ASCO Financial Resources](#), American Society of Clinical Oncology: Links to organizations that provide financial support to people with cancer. Types of support include financial aid, grants, and help with specific services or products, such as travel or medications.
- [Programs and Resources to Help With Cancer-related Expenses](#), American Cancer Society: Includes information on housing needs or mortgage payments, transportation, food costs, and other expenses.



## References

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