



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. It's almost essential to have some that can help you through the process.

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 serve as a crucial bridge, helping people manage the complexities of healthcare while ensuring their questions are heard and their worries are resolved. 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 resource
- Information about complementary treatments
- Support in lifestyle changes

WHAT DOES A PATIENT ADVOCATE DO? (CONTINUED)

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. You should also ask questions if there is anything you don't understand about your diagnosis or treatment plan.

WHERE DO PROFESSIONAL PATIENT ADVOCATES WORK?

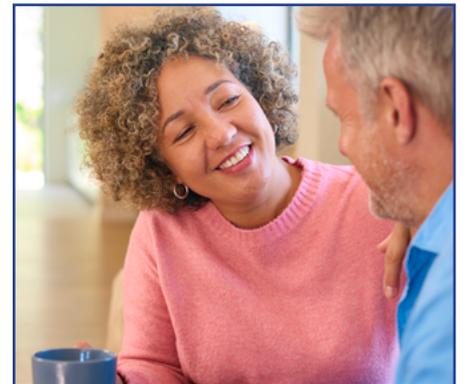
Professional patient advocates are sometimes called patient navigators. Cancer centers and hospitals usually have patient navigators. Sometimes, patient advocates are also called healthcare advocates. Local and national nonprofit organizations, Federally Qualified Health Centers, government agencies, 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. 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. 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, organizations like American Society of Clinical Oncology, the American Association of Cancer Research, Patient Power, and other organizations engage in patient advocacy.

RESOURCE LIST

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

- [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.

- [Resource Navigation](#), CancerCare: Free telephone resource navigation 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.



RESOURCES (CONTINUED)

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.
- [Help Paying for Prescription Drugs](#), American Cancer Society: Public and private programs that help with the cost of medicines.
- [Cancer Finances tool](#), Triage Cancer.
- [Co-Pay Relief Program, Financial Aid Funds and Scholarships](#), Patient Advocate Foundation: financial assistance to insured patients who meet certain qualifications to help them pay for the prescriptions and/or treatments; small grants to patients who meet financial and medical criteria and for patients living with a serious or chronic health condition; and scholarships for college students with cancer or another chronic illness.
- [National Financial Resource Directory](#), Patient Advocate Foundation: National and regional resources dedicated to improving access to quality care and decreasing the financial burden of medical treatment.

Transportation

- [American Cancer Society Road To Recovery® program](#): Trained volunteers that drive patients and families to hospitals and clinics for treatment. This is available in some areas.

Housing during treatment

- [Hope Lodge® program](#), American Cancer Society: A free place to stay if cancer treatment is far from home.
- [Health care Hospitality Network](#): Free or low-cost housing for families getting medical treatment far from home.

Integrative Cancer Care

- [The Center for Mind-Body Medicine](#), programs that support those who have been through psychological trauma through a model of self-care, social support and community building.
- [Commonweal](#), integrative healing programs for patients and health care workers.
- [Beyond Conventional Cancer Therapies](#), a database of evidence-based integrative practices that can support patients going through cancer treatment.

Legal services

- [Advance Directives](#), American Cancer Society: Information about advance directives and how to develop one.
- [Putting Your Health Care Wishes in Writing](#), American Society of Clinical Oncology: Advance directives and decisions for urgent or emergency care. Health Insurance
- [Health Insurance Options](#), American Cancer Society: Information about types of health insurance and where to find it.
- [Medicare Resource Center](#), Patient Advocate Foundation: A hub for updates to Medicare for beneficiaries.

Other

- [Advocacy Curriculum](#), Patient Advocate Foundation: Empowers learners to champion equitable and patient-centered healthcare.
- [Managing Your Care](#), American Society of Clinical Oncology.
- [Work and Employment](#), Cancer and Careers: Guides and other resources.
- [Dating, Sex, and Reproduction](#), American Society of Clinical Oncology: Information on dating and intimacy, sexual health, fertility, pregnancy, and more.
- [Cancer Survivorship Checklist](#), Cancer Survival Toolbox and more, National Coalition of Cancer Survivorship.
- [Imerman Angels](#), Peer Support: Patients can be matched with another patient according to age, gender, cancer type, and experience.

