Preparing for Your Doctor's Visit

A worksheet for people considering immunotherapy

Immunotherapy is a type of cancer treatment. It works with the body's natural defenses or the immune system. Immunotherapy helps the immune system identify, attack, and kill cancer cells. There are many kinds of immunotherapy treatments. Some immunotherapies can help fight against cancer by boosting the immune system or "marking" cancer cells so they can be easily found. Other immunotherapies help the immune system find cancer cells so that treatments, like chemotherapy, can be delivered directly.

If immunotherapy might be an option for your cancer care, this guide can help you take control and have better discussions with your health care team. It provides a quick overview of this treatment option, questions to ask your health care team, a worksheet to help you set your own goals, and resources for information and support.

After a cancer diagnosis, things may happen quickly. It is normal to feel anxious and overwhelmed. You can learn more about coping and details on this treatment in our *Frankly Speaking About Cancer: Immunotherapy* booklet (**www.CancerSupportCommunity.org/Immunotherapy**) or call our Cancer Support Helpline at 888-793-9355 for support.

GETTING TO KNOW YOUR HEALTH CARE TEAM

Cancer treatment is complicated and can change with new discoveries. You need a health care team you can trust to take the best care of you. This team should treat you as a partner in your care and encourage you to ask questions Your team may include a number of health care professionals who work together, including:

Physicians: You may see a **medical oncologist, surgical oncologist** or **hematologist,** a **radiation oncologist.** Look for doctors who have experience treating your specific type of cancer, if possible.

Nurses/Physician Assistants (PAs): Your oncologist or physician may work with **oncology nurses, oncology nurse practitioners,** or **physician assistants.** They may be the people you talk with the most, who help you manage the side effects of treatment.

Clinical Social worker: This health care professional can help you and your family find resources to cope with cancer, cope with treatment, and pay for care.

Patient or nurse navigator/advocate: Some cancer centers use patient navigators or nurse navigators. They help patients through the care system, from diagnosis through treatment and follow-up care.

Nutritionist/Dietician: A registered dietician can recommend foods to help you eat comfortably and get the nutrients you need throughout your cancer experience.

Palliative care specialist: This person helps patients manage difficult symptoms, pain, and side effects. They focus on improving patients' quality of life during their cancer treatment.

Financial Navigator: This team member provides information and resources to help you and your family manage cancer related costs. They can offer referrals and help you enroll in financial assistance programs if available.

Psychologist/Therapist/Cancer Counselor/Clergy: Cancer is a lot to deal with. Having someone to talk to can affect how you look at things. It may help you find or maintain the energy you need to get through treatment and take the best possible care of yourself. It is a good idea to seek support early on so that you have somewhere to turn when you need it.

TALKING ABOUT IMMUNOTHERAPY TREATMENT

You will hear many words used to describe immunotherapy. However, there are some terms that you should become familiar with as you discuss this treatment option with your health care team. Some key ones to know are:

IMMUNE SYSTEM: The immune system is a network of cells, tissues, and organs that work together. It protects the body from bacteria, viruses, parasites, fungi, and unhealthy cells like cancer cells.

T CELLS: T cells are a type of white blood cell. They are the immune system's "soldiers." They help protect the body from infection and help fight cancer. T cells are also called T lymphocytes.

ANTIBODY: Antibodies are proteins made by your body's immune cells. They help the body by finding and attaching to an invader. These invaders can be bacteria, viruses, or cancer cells.

TUMOR ANTIGEN: A tumor antigen is a substance made by a tumor cell. This substance can cause the body to create a specific immune response.

BIOMARKER: A biomarker is a molecule in your body that your doctors can measure. Biomarkers give your doctor specific information about your cancer. Testing for biomarkers can let your doctors know if your tumor has a good chance of responding to a certain treatment. Ask your doctor about biomarker testing if it is not mentioned.

IMMUNOTHERAPY: Immunotherapy uses the body's natural defenses to find, attack, and kill cancer cells. It may help to think about it as boosting the immune system's response.

CLINICAL TRIALS: Clinical trials are research studies that test new treatments or new treatment combinations. These studies can also help us learn how to use existing treatments better. Ask your doctor if a clinical trial may be right for you as an initial treatment option.

ASK YOUR HEALTH CARE TEAM

- Ask about the next steps in your treatment and what tests you will need.
- Ask your health care team about the best way to contact them after hours or on the weekend.
- Ask about symptoms and side effects and which ones you need to know about and report to your team. Ask about side effect management and who you should contact if you have questions or don't feel well.
- Ask questions until you understand what is being said. You can ask for information in a different language or a drawing if you need it.
- Talk to your health care team about how you are feeling. Ask about a counselor or mental health services if you are feeling depressed, overwhelmed, or anxious.
- Ask about the latest information on clinical trials and if a clinical trial may be an option for you.

TIPS FOR TAKING CONTROL

- Talk with your doctor and confirm that the specialists on your health care team have experience with immunotherapy for your type of cancer.
- Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, bring a recorder or use a cell phone to record your conversation with your doctor. Be sure to ask your doctor if it is OK to record.
- Be proactive. Talk to your health care team or financial navigator about ways to manage treatment costs before you start treatment.
- Write down your questions before each doctor's visit. Keep a journal to take notes or use this worksheet to track your progress over time. This can include information about tests, lab works, and the symptoms and side effects you may be experiencing.
- Be your own advocate. If you don't feel your health care team is addressing your concerns, consider getting a second opinion. Don't worry about hurt feelings!
- Learn the words that doctors use to talk about immunotherapy. This can help you better understand your diagnosis and treatment options.

Below are some symptoms and side effects people experience during immunotherapy treatment, as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how best to manage them.

	Rarely	Sometimes	All the Time
Fatigue or feeling very tired			
Cough or shortness of breath			
Pain or soreness			
Muscle or joint pain			
Diarrhea, unintended weight loss, trouble eating			
Nausea and vomiting			
Flu-like symptoms (fever, chills, headache)			
Skin problems (rashes, redness, or itching)			
Feeling anxious, overwhelmed, or depressed			
Others:			

In rare cases, immunotherapy can cause serious side effects. Think about if you have developed any of the following side effects. Talk to your health care team right away if you notice any changes in side effects or symptoms.

- Stomach or intestinal problems (nausea, vomiting, and diarrhea)
- Problems with the thyroid, liver, kidneys, and heart - Your doctor may perform blood tests and heart function tests to check for this.
- Lung problems (cough, shortness of breath)
- Diabetes or autoimmune disorders - Your doctor may perform blood tests to check for this.

How often are cancer or side effects interfering with your life?	Rarely	Sometimes	All the Time
Work/school/home (unable to go to work/school or do daily tasks)			
Unable to do activities I normally enjoy, such as traveling			
Low Confidence/self-image			
Difficulty thinking/brain fog/chemo brain			
Problems in social relationships			
Health insurance or other financial worries			
Loss of appetite/decrease in eating and/or unable to exercise/ be active			
Difficulty sleeping/insomnia			
Others:			

THINK ABOUT TREATMENT AND YOUR PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of each treatment and how each treatment might affect the goals that you have for your life. Possible goals may be to: live as long and as well as possible, contribute to progress in science by taking part in research, make it to a special event/ milestone, or find cutting edge treatments. Let your health care team know about your treatment and personal goals. Remember that your goals may change over time.

SETTING YOUR PERSONAL GOALS FOR TREATMENT

Physical Health and Well-Being	*What do you want to be able to do?*
Family and Social Relationships	*What's going on in the lives of others that is important to you?*
Work/School	*Do you want to continue working? Can you adjust your schedule or responsiblities?*
Community Involvement	*Are you getting the support you need from your loved ones and your community? Are you able to stay active/ involved in your community?*
Other:	*What else is important to you?*

PREPARING FOR YOUR NEXT HEALTH CARE VISIT

If you are feeling either better or worse today than at your last appointment, let your health care team know.

Write down your questions before each doctor's visit. Below are some suggested questions and discussion points. Concentrate on the issues that are most important to you.

Do you recommend immunotherapy treatment for me? If so, what type?

When should I start treatment? What happens if I don't start treatment now?

Are there any genetic risk factors I should be aware of?

Have I been tested for biomarkers? If so, how will the results impact my treatment?

How long will I be on the treatment?

What side effects should I expect (short and long term and side effects that may appear later)?

Will treatment impact my fertility? Should I see a fertility specialist before I start treatment?

Should I or my partner use birth control when on this treatment? What kind is best?

What can I do to prepare for immunotherapy treatment?

How often will I have treatments and how much time will each treatment take?

Will I need someone to drive me home after treatment?

The symptoms and side effects that are affecting me the most are: [discuss your answers from page 4].

My symptoms and side effects are interfering with my life in these ways: [discuss your answers from page 4].

What can we do to manage my symptoms and side effects?

My top goals for treatment are: [fill in your answers from page 5].

Is the treatment that I am currently on the best treatment for me to meet these goals?

What other treatments are available to me? What are the pros and cons of each option?

Are there any clinical trials for immunotherapy that may be right for me? How do I find out more about them?

Do you have a suggestion for where to go to seek a second opinion?

How can I manage treatment costs? Is there a financial navigator that I can talk with?

GETTING SUPPORT

Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).

- Make a list of things you need (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need.
- Ask your health care team about in-person or online resources for social, emotional, and practical support.
- You can also ask for a mentor or to be matched with someone who has a similar cancer experience.
- If you search for information online, make sure that you are using trusted websites.
- Turn to the back page of this publication to see a listing of trusted organizations. CSC and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from other people living with cancer.

FINANCIAL RESOURCES

Even with a health care plan, treatment can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your health care team and your pharmacist about the cost of your treatment.
- Ask your doctor to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for help managing financial issues and costs.
- Reach out to your health care plan to find out what resources they have that could help you.
- Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment center is far away, ask if there are assistance programs that can help cover your travel costs.

The more you learn, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, visit: **www.CancerSupportCommunity.org/Cost**

FINANCIAL SUPPORT RESOURCES

Cancer and Careers (CAC) · **www.CancerandCareers.org**
CancerCare · 800-813-4673 · **www.CancerCare.org/financial_assistance**
Partnership for Prescription Assistance · **www.pparx.org**
Patient Access Network Foundation · 866-316-7263 · **www.panfoundation.org/get-help**
Patient Advocate Foundation · 800-532-5274 · **www.patientadvocate.org**

CANCER INFORMATION AND SUPPORT

Cancer Support Community · 1-888-793-9355 · **www.CancerSupportCommunity.org**
American Cancer Society · 800-227-2345 · **www.Cancer.org**
Cancer.net · 888-651-3038 · **www.Cancer.net**
National Cancer Institute (NCI) · 800-422-6237 · **www.Cancer.gov**
NCI Clinical Trial Information · 800-422-6237 · **www.Cancer.gov/ClinicalTrials**
Patient Empowerment Network · **www.PowerfulPatients.org**

CANCER SUPPORT COMMUNITY RESOURCES

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 9am-8pm ET and Sat 9am–5pm 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.

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**.

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

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. 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**.

This publication was made possible through generous support from: Bristol Myers Squibb

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