ASSOCIATION
OF CANCER
CARE CENTERS

IMMUNO-
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A GUIDE FOR THE
CANCER CARE TEAM

Talking to Those Undergoing Immuno-Oncology Treatment: Planning for Survivorship

CANCER SURVIVORSHIP refers to the period starting with a cancer diagnosis through the rest of a person's life, regardless of the outcome of treatment. In the context of survivorship care planning, survivorship generally means that the person is no longer in treatment and has no evidence of active disease. But there is a growing population of people treated with immuno-oncology (IO) therapies who are living with cancer while continuing IO treatment for extended periods of time.

This guide can help you work with your patients treated with IO therapies so they can maintain a high quality of life both physically and emotionally, whether they have stopped treatment or will remain on it.

Set Appropriate Goals and Expectations

Starting early, make sure you and the person who will be treated with IO therapies are on the same page with treatment goals. Whether this is their first line of treatment or third, some may not have a clear understanding of their prognosis and may assume the goal of IO therapy is to cure, when it may not be.

ASK:

- *What is your understanding of your situation?*
- *How much information do you want to receive?*
- *How do you prefer to receive information?*
- *What are you hoping for?*
- *What are your concerns going forward?*

ACT:

- Make use of your team—especially social workers and or psychologists—to meet during transition points. Have someone who is not the person giving patients medical news check in with them.
- *Consider goals*-of-care conversations where appropriate.

Symptom and Side Effect Management

Effectively managing symptoms and side effects of IO therapies can enable people to remain on treatment longer, decrease future adverse outcomes, and may even increase overall survival. Regardless of whether the person is still receiving treatment, IO therapies can have long-lasting effects, and managing them will improve a patient's quality of life. Ask about issues preemptively; patients may not openly tell you if they are struggling.

ASK:

- *Do you currently have any physical symptoms that bother you, like pain, fatigue, nausea, shortness of breath, or gastrointestinal distress?*
- *How are you sleeping?*
- *How is your mood?*

ACT:

- Use a symptom assessment tool at each visit. Some examples are available at **accc-cancer.org/projects/io-survivorship/resources**
- Refer patients to palliative care as soon possible if you identify any issue that could negatively impact quality of life and that you are not able to manage effectively. If your institution does not have palliative care specialists, utilize the resources available to manage pain, fatigue, anxiety, and other symptoms and side effects associ-ated with cancer treatment.

Psychosocial Well-Being

People who have gone through cancer treatment are dealing with a changing sense of self and are living with what may or may not be a terminal disease. Especially for those who continue long-term on IO therapy, it can be a struggle to figure out their identity as a survivor when they are still being treated. Living with a chronic disease over time can be demoralizing and cause burnout. Even those who end treatment may still deal with feelings of uncertainty or last-ing effects of treatment toxicities.

ASK:

- *How are you coping?*
- *What concerns do you have about the future?*

ACT:

- Help your survivor plan for the future as best you can. This may mean connecting them with someone in a supportive role who can help them address future-oriented concerns.
- Screen for distress at regular intervals. Circumstances and emotions change over time. Some distress screen-ing resources are available at **accc-cancer.org/projects/supportive-care-resource-hub/distress-screening-resources**
- Identify psychosocial support for the survivor, or connect them with someone else who can, such as a social worker or psychologist. Support comes in many forms, including groups, individual counseling, online message boards, and cancer center programs.

Physical Well-Being

When people live longer with the help of IO therapies, they may benefit from general wellness goal-setting conversations as part of the care plan, rather than just focusing on cancer treatment-related wellness. This applies whether they have completed treatment or will stay on IO therapies long-term.

ACT:

- If your program has guidance on restarting exercise or healthy nutrition, share it with the patient.
- Be sure to include health screenings in follow-up care plans.

Sexual Health

Sexual health may be impacted by treatment-related side effects and by psychosocial responses to these effects or the experience of cancer diagnosis and treatment itself. Care planning for survivors should address short- and long-term health issues, including sexual health. Addressing sexual concerns should be guided by the goals of the survivor and their partner, with appropriate evaluation, counseling, and discussion of options.

ASK:

- *Is there anything else you want to talk about?*
- *Sometimes people in this situation experience problems with intimacy/romantic relationships. I wonder if that is something you are experiencing?*
- *Do you have any concerns about sexual activity?*
- *Are you having any pain with sexual activity?*

ACT:

- Create generic intake office forms and use inclusive language regarding gender and sexual orientation.
- Include questions related to sexual health on a general intake form to offer the opportunity for survivors to bring up these related topics.

Financial Distress

Survivors who have received multiple lines of treatment may be at increased risk of financial burden. Asking them about financial strain should not be a one-time conversation. It is useful to ask each time you see a patient because financial situations can change. Keep in mind that financial distress is not only about cancer treatment, but also includes related costs such as childcare, transportation, and caregiver absence from work.

ASK:

- *Are you having difficulty or concerns about paying for your care?*
- *Are you having difficulty or concerns about keeping up with other costs, like childcare or travel?*
- *How stable is your employment situation?*
- *How stable is your insurance situation?*

ACT:

- Have this conversation with all patients to avoid making incorrect assumptions and to decrease any stigma related to financial need. Ask at regular intervals, not just once, because the answers may change over time.
- Make use of social workers and financial counselors to help provide support for survivors dealing with financial distress.

Transition of Care

Survivors on IO therapies may remain under your care for the duration of treatment, however long, but there may be times when it is appropriate to transition their care and/or update their other healthcare providers about the treatment they are receiving. Because IO therapies have immune-related adverse events (irAEs) that can appear years after treatment, the care team for people who are no longer receiving IO therapy would benefit from this information.

ASK:

- *Who else is involved in your medical care? (For example, does the person have a primary care provider or spe-cialists like a cardiologist, pulmonologist, or endocrinol-ogist who might benefit from knowing the details of the survivor's IO treatment for future irAE monitoring?)*

ACT:

- Set up a warm handoff and provide basic information from the patient's files to any other current providers. Don't rely on what's in the electronic health record to get transferred, as it often gets lost. With the patient's permission, call the relevant provider to let them know that the person has been treated with IO therapy, and there are some potential late effects of treatment that they should be aware of. Then send the **Care Transition Summary** for their files.
- If the patient does not have a primary care provider who can support their ongoing care, help them find someone.

Endnotes

1. Shin JA, El-Jawahri A, Parkes A, et al. J. Palliat. Med. 2016;8(9):863-869.
2. Basch E, Deal AM, Dueck AC, et al. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA. 2017;318(2):197–198.

The **ACCC Immuno-Oncology Institute** is the leader in optimizing the delivery of cancer immunotherapies for patients by providing clinical education, advocacy, research, and practice management solutions for cancer care teams across all healthcare settings. Access survivorship resources for patients on cancer immunotherapies at accc-cancer.org/immunotherapy-survivorship

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