

## DEFINING SURVIVORSHIP

- Everyone's disease can be different, but the median overall survival is greater than 20 years for follicular lymphoma. So many patients live with this more like a chronic disease, according to Dr. Maddocks. This is a disease that many people live with for many years.
- Dr. Maddocks says, "Somebody with cancer is defined as a survivor from the time they're diagnosed moving forward," so take heart!
- If you have fear or anxiety about your survivorship, recognize those feelings and set up your milestones of follow-up appointments or seek out a survivorship clinic or psychosocial oncology.

**Question:** What is the difference between relapsed and refractory follicular lymphoma?

**Answer from Dr. Maddocks:** "When we think of relapsed disease, we think of a patient who's had therapy, gotten a response to that therapy, that response has lasted some time, and then their disease recurs. When we think of refractory, we think of that more as patients that have received a therapy, and they haven't responded."

**Question:** "I'm getting treatment every eight weeks, and I plan to travel to Europe via plane and cruise. I would like to know how to travel as safely as possible. Is it advisable to get certain vaccines for travel like yellow fever?"

**Answer from Dr. Maddocks:** "Consider looking at the CDC guidelines for recommendations for what should be received in the area you are traveling to as well as the time of year you're traveling. Ask your doctor to work with your pharmacy to decide what vaccines are recommended as it can depend on a patient, what treatments they've received or are receiving. Typically, we avoid live virus vaccines in our patients."

**Question:** What is the statistical likelihood of follicular lymphoma recurrence or transforming after 10 years of remission? Do you have any lifestyle recommendations to prevent recurrence?

**Answer from Dr. Maddocks:** "Unfortunately, there's nothing you can do that will prevent your lymphoma from coming back. Studies have shown that somewhere between 10 to 15 percent of patients diagnosed with follicular lymphoma will have a transformation in their lifetime. There is a risk of 1 to 2 percent per year that a patient will experience transformation."

## MANAGING SIDE EFFECTS OF FOLLICULAR LYMPHOMA TREATMENT

- Side effects or toxicities for bispecific antibodies and CAR T-cell therapies include cytokine release (CRS) or immune effector cell-associated neurologic toxicities (ICANS).
  - These side effects or toxicities can involve fever, a lower oxygen level, or a drop in blood pressure.
  - To manage side effects or toxicities, patients may be admitted to the hospital for an observation period, receive acetaminophen (Tylenol), antibiotics, fluids, oxygen, steroids like dexamethasone (Decadron), or cytokine blockers such as tocilizumab (Actemra).
- As a way to prevent and decrease severity of cytokine release, a lower dose of the bispecific antibody is given initially with increased dosing each week until maximum dose is reached.

## COPING WITH RELAPSED OR REFRACTORY FOLLICULAR LYMPHOMA

- When dealing with a relapse, ask your physician what symptoms to watch out for and keep an open line of communication with your healthcare team.
  - This helps if you are experiencing new symptoms, so you know which ones could be attributed to the follicular lymphoma and can reach out to your physician to be evaluated.
  - By reporting new symptoms promptly, they are more likely to be managed effectively.
- Continuously follow up with your physician. Write down all your questions and concerns on paper to help get them out of your mind and recorded to paper instead.
- Discuss with your healthcare team about available treatment options, including clinical trials.
- Gain emotional support through professional counseling or a support group.
  - It can be helpful to hear from others who are going through similar situations and coping strategies they have used, but remember that everyone's journey is a little bit different. Do not feel anxious if you hear a bad story.
- Lean on your support network of family and friends. Let them know how they can help you, whether it's through practical assistance or emotional support.
- Keep yourself physically healthy. Maintain a healthy diet, exercise regularly, and get enough rest. These can help improve your overall well-being and energy levels.
  - Ensure you regularly see your primary care physician for routine health maintenance including managing your blood pressure, glucose, and other routine cancer screenings.
- Manage your stress through meditation, yoga, and deep-breathing exercises.
- Stay informed by educating yourself about follicular lymphoma and treatment options. Reliable sources like the Lymphoma Research Foundation and other cancer organizations can provide valuable information.