

Track 2: Treatment Options

[Narrator]

Many people with non-Hodgkin lymphoma have found an educational support group helpful. Support groups take many forms: some meet the needs of people with all kinds of cancers; others focus on one type. Some provide information while others offer emotional support. Some are led by nurses or social workers, others by peers – people who have lymphoma. This lymphoma group has been running for years and is open to family and friends. Some members have lived with lymphoma for a while, and then there are new members – people who have recently been diagnosed. Let’s listen in on a meeting.

[Carlotta (Social Worker)]

Hello, I’m Carlotta, an oncology social worker. Tonight, our focus is on how a lymphoma diagnosis is confirmed, and treatment. Dr. Griffin, a medical oncologist, is here to help us understand these issues.

[Dr Griffin]

Diagnosing lymphoma is not always simple. Symptoms that usually bring people to the doctor are a painless and swollen lymph gland, often in the neck area or under the arms; weight loss, fever, sweating at night or tiredness that won’t go away. Sometimes, a person has no symptoms and lymphoma is discovered by accident during a check-up. If the lymphoma is in the gastrointestinal tract, skin, or lung, there may be abdominal pain, skin lumps, or trouble breathing or chest pain.

[Carlos]

Is lymphoma contagious? Somebody told me lymphoma can be caused by a virus.

[Dr Griffin]

Some forms of non-Hodgkin lymphoma are linked to viruses and bacteria such as the Epstein-Barr virus and the H. pylori bacteria. However, these are not contagious, so you cannot get lymphoma from another person.

[Renee]

Why does it take so long to find out if it's cancer? I noticed a lump by my collarbone when I was showering. Other than a cold a couple weeks before, I'd been feeling great. The doctor said if the lump was still there in two weeks or got bigger, I should see him. After two weeks, when he examined me, he gave me antibiotics, but the lump didn't go away. Next was a biopsy. That was when lymphoma was found. I wonder why I had to wait. Treatment could have started sooner.

[Dr Griffin]

It's normal to wonder why it took so long, or to feel angry about the delay. Because symptoms are most often **not** due to cancer, doctors often treat for an infection first. If the doctor suspects lymphoma, a biopsy is needed to diagnose it and determine the type. There are more than 67 types of non-Hodgkin lymphoma. The most common type of aggressive lymphoma is diffuse large B-cell lymphoma. The most common type of indolent lymphoma is follicular lymphoma.

In addition to the biopsy, tests are needed to determine the stage or extent of lymphoma. CT scans of the neck, chest, abdomen, and pelvis can show if lymph nodes are enlarged. The scans also show if the lungs, liver, or other organs are affected. Another test is the PET scan, which involves an injection of radioactive glucose molecules into the bloodstream. Cancer cells pick up more of the glucose than normal cells. Even if lymph nodes are not enlarged, the PET scan can identify small areas of lymphoma. A bone marrow biopsy – marrow cells are removed, usually from the hipbone – is often done. Blood tests include counts of red cells, white cells and platelets, lactate dehydrogenase or LDH, beta 2-microglobulin and chemistry studies to check for kidney or liver damage. Results help determine the stage of the lymphoma. Tests are repeated occasionally to assess and monitor your disease. You can find more information about the stages of non-Hodgkin lymphoma in the booklet accompanying this CD, or on the Lymphoma Research Foundation website (<http://lymphoma.org/>) or Helpline (1-800-500-9976).

[Ari]

I was just diagnosed, so my doctor and I are deciding on treatment. He told me there are several factors in deciding which treatment is best. My heart problems will be important in our decisions. He also said because I have a slow-growing lymphoma and no symptoms, we might just watch and wait. I'm not sure I like the idea of doing nothing.

[Dr Griffin]

Let's talk about making treatment decisions. Besides the type and stage of lymphoma, other considerations include your age, general health, life-style and quality-of-life wishes, symptoms and *co-morbidities* – conditions or chronic illnesses that may limit treatment options. In general, patients are treated with chemotherapy and biotherapy medicines called “monoclonal antibodies.” Sometimes, radiation therapy is used alone to treat an isolated disease site; other times, it's used with chemotherapy or biotherapy. A new, promising treatment is “radioimmunotherapy” – where radioactive materials are combined with monoclonal antibodies. Depending on the type of lymphoma, some patients receive stem cell transplants – stem cells are removed from the patient's blood (or sometimes a donor's blood), treated, and returned to the patient. For others, a watch and wait approach may be a choice. Watch and wait is sometimes used on slow growing cancers that will require future treatment. Treatments are not usually given prior to cancer growth, but saved for when needed. This approach involves careful, regular monitoring. If you start having symptoms or CT scans show changes, your doctor may then recommend treatment. There are many treatments available, and we try to use medicines that work together to achieve the best results, and these are tailored for each patient.

[Carlos]

With diffuse large B cell lymphoma, an aggressive type, my doctor recommended chemotherapy. He also suggested I have an IV line — a catheter called a central line — inserted into a vein in my chest. The catheter's used to give chemotherapy and other medicines, fluids and blood, and to take blood samples. There are different types of catheters and vascular access devices, so ask your healthcare

team to explain them and how the choice for the best device for you is made. A vascular access nurse helped the surgeon choose the best access site for my catheter and helped me learn to take care of it.

My doctor ordered a combination of drugs called R-CHOP: rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone. Rituximab is a monoclonal antibody, a type of biotherapy that targets B-cell lymphomas. It worked. My lymphoma was in remission for three years, but then my CT scans showed it was back. The doctor suggested a different combination of drugs, then a stem cell transplant. That was two years ago – so far so good. I know it can come back, but my doctor says there are more treatment options. That’s reassuring.

[Renee]

My story’s different. I was diagnosed with lymphoma in my stomach, a mucosa-associated lymphoid tissue lymphoma or MALT lymphoma. It’s caused by an H. pylori bacterial infection. The doctor ordered antibiotics to get rid of the infection and lymphoma. It’s hard to believe my only treatment was antibiotics. However, I still have to be watched regularly.

[Dr Griffin]

Your stories are good examples of some of the different types of non-Hodgkin lymphoma and differences in treatment. Researchers continue to look for better treatments. There are many clinical trials in progress, a good sign that we’ll continue to see new treatments. We’re very hopeful.

[Sam]

When I was diagnosed, my doctor suggested I enroll in a clinical trial.

[Ari – interrupting]

What’s a clinical trial? It makes me nervous.

[Carlotta (Social Worker)]

Ari I’m glad you asked that question. Sam, would you describe your experience, and maybe Dr. Griffin can add some information.

[Sam]

On the clinical trial, I took a new drug and it worked great! The study was called a “blinded study” – neither my doctor nor I knew which drug I got – but it had to be at least standard therapy OR something at least as good as the current standard therapy. Either way you get good treatment. I found out after the study I was on the experimental drug and what it was. My doctor recently told me the drug I took has been approved by the Food and Drug Administration, which means the trials are finished and the drug was shown to be effective. It’s helped – my lymphoma’s in remission.

[Dr. Griffin]

There’s a lot of information about lymphoma clinical trials on websites for the National Cancer Institute (<http://www.cancer.gov>; 1-800-422-6237), the Lymphoma Research Foundation (www.lymphoma.org), and the Leukemia and Lymphoma Society (www.lls.org/clinicaltrials; 1-800-955-4572). Each has a Clinical Trial Information Service that will help you find trials for your type of lymphoma. The *Toolbox*[®] program, “First Steps for the Newly Diagnosed” provides additional information.

[Carlotta (Social Worker)]

Ari, you are still trying to understand your illness and make decisions about your treatment. Do you have questions or concerns that we can talk about tonight?

[Ari]

Well, yes, actually. I feel sort of funny about this. But, sometimes, I don’t think my doctor is being straight with me. My daughter thinks I ought to get a second opinion, but I don’t want my doctor to be offended either.

[Carlotta (Social Worker)]

It is important that you are able to talk to your doctor – whoever it is – openly and honestly. We can help you improve your communications skills – and again, one of the *Toolbox* programs focuses on communication. This could help you be more assertive about meeting your own needs for information, and your relationship with the doctor could work much better for you. As for a second opinion, it’s

almost always a good idea – even if the second opinion turns out to be exactly the same as the first. And, the *Toolbox's* “First Steps” program suggests ways to go about setting up second opinions. At least you may feel more comfortable with the treatment recommendations. Or, it may turn out that you could have a better relationship with another doctor, and that is very important, too.

[Renee]

I have another suggestion for you, Ari. I recently took part in a Lymphoma Education Series teleconference provided by the Leukemia and Lymphoma Society. Printed transcripts and audio recordings are also available. People from all over could ask lymphoma experts questions. I learned about current lymphoma research, the newest drug that was approved, and information that helps me be as healthy as I can be.

[Carlotta (Social Worker)]

Please know that there are people all around to help you through this – the people in this support group continually reach out to help each other. The oncology social workers and oncology nurses and doctors, too, are here to help you, along with other members of cancer care team. You only have to let someone know you need help.