



LLS Resources for Patients and Caregivers

Ms. Lizette Figueroa-Rivera

Hello, everyone. On behalf of The Leukemia & Lymphoma Society, a warm welcome to all of you. Special thanks to Dr. Daniel C. McFarland for sharing his time and expertise with us today. Before we begin, our president and CEO, Louis J. DeGennaro, will make some remarks.

Dr. Louis J. DeGennaro

I'm Dr. Louis DeGennaro, president and CEO of The Leukemia & Lymphoma Society. I'd like to welcome all of the patients, caregivers, and health care professionals attending the program today. At The Leukemia & Lymphoma Society, our vision is a world without blood cancers. Since we started in 1949, LLS has invested more than \$1.2 billion in breakthrough research to advance lifesaving treatments and cures.

We've played a pioneering role in funding many of today's most promising advances, including targeted therapies and immunotherapies that have led to increased survival rates and improved the quality of life for many blood cancer patients. Though LLS is known for funding groundbreaking research, we do so much more. As this program demonstrates, we are the leading source of free blood cancer information, education, and support for patients, survivors, caregivers, families, and health care professionals.

We also support blood cancer patients in their local communities through our chapters across the country, and we advocate at the state and federal level for policies to ensure that patients have access to quality, affordable, and coordinated care. We're committed to working tirelessly toward our mission every single day.

Today, you'll have the opportunity to learn from esteemed key opinion leaders. They each have volunteered their time, and we appreciate their dedication to supporting our mission—their commitment to caring for patients living with blood cancers. Thank you for joining us.

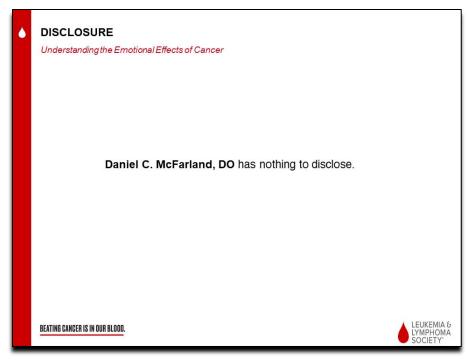




Understanding the Emotional Effects of Cancer

Ms. Lizette Figueroa-Rivera

Thank you. I am now pleased to introduce Dr. Daniel C. McFarland, Medical Oncologist, Psychiatrist, Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center in New York, New York. On behalf of The Leukemia & Lymphoma Society, thank you for volunteering your time with us today. Dr. McFarland, I am now privileged to turn the program over to you.



Disclosure Slide





Understanding the Emotional Effects of Cancer

Daniel McFarland, DO Memorial Sloan Kettering Cancer Center 1/29/2020

Understanding the Emotional Effects of Cancer

Daniel C. McFarland, DO

Wonderful. Thank you to LLS and everyone who is online and listening—delighted to be here and to share what I know about this topic and to take some questions.



Overview

- Emotions at diagnosis/recurrence
- Understanding emotional symptoms (distress, anxiety, depression)
- Spirituality
- Body Image
- Post-traumatic stress
- Fear of recurrence
- Survival Guilt
- · Recommendations

Overview

We're going to spend about half an hour going over a presentation that will introduce various topics that I have up on the slide now. These, of course, are not an exhaustive list of the emotional effects of



cancer, but they are some of the things that are generally highlighted. And then we'll have a period of time where we can go through some questions, and that is actually what I'm very excited to do.



Diagnosis

- · Coming to a diagnosis...-the waiting game
 - trail of doctors, nurses, hospitals, (invasive tests), and receiving information
- Pathology
 - Molecular data
- Treatment considerations-recommended treatment best treatment trial options? etc...
- · Cancer 'education'
- · Lifestyle changes

Diagnosis

So, I'm going to start at the beginning: the diagnosis period. And coming to a diagnosis is a traumatic experience for almost everybody. And it is a waiting game, generally. So, people have many stories about how they were diagnosed, how long they had to wait, the different doctors and nurses that were involved, how information was delivered, and different tests that they all undergo and how they receive that information. And oftentimes there are many different hospitals, even, that are involved.

And so, this just begins the experience. The experience is not just having cancer. It's also then understanding the molecular data behind that cancer diagnosis and then how that translates into different treatment options, which are incredibly varied. And people come to find out that there is not just one option, and that can in, and of itself be very stressful. So, all of this leads to a certain kind of education that nobody really asked to have. Although it's an expensive education as well, which is a whole other issue, of course. And these require lifestyle changes. And so, everyone is adapting in some way to the diagnosis.





Diagnosis-figuring it out...

- Information handling: "big picture versus need details"
 - 'I want to know everything'
 - 'need to know basis'
- Managing sources of information
- Disclosing, 'circle of trust'
- · Irony of needing to support family and friends
- · Living with constant uncertainty

Diagnosis-figuring it out...

There is an onslaught of information, as I alluded to. And for someone who has never interfaced with the medical community or had a diagnosis before, you'll find out that people want information in different ways. Some people like kind of just a big-picture overview, "Just tell me what I need to know," and other people very much want to know all of the details involved.

And sort of figuring out what kind—how you like to receive information is very important. And that lends itself to basically advocating for what you need in dealing with the diagnosis. Similarly, there are many sources of information. And so, that's something that we see often is the struggle of managing, "Which source do I believe? Which source is credible? Which source can I trust?" And so, that's something that I'd encourage people to talk to their hematologist about. And similarly with understanding, "Who am I going to tell about the diagnosis?"

And I put up this second-to-last bullet point because I've found that there is a certain irony that people are diagnosed—and of course, a diagnosis affects the whole family and people's social networks. And there's this sort of irony of almost needing to support family and friends when the patient actually has to do more work to do that. We generally think of family and friends supporting the patient, and so there can be a little bit of this irony.

And so, it's just so much that is required and requested of a patient. And so, people quickly find out that there is this living with uncertainty that's almost constant. And it's sort of always there, this uncertainty.

And so, that's all part of figuring out the diagnosis and then moving forward with treatment, which in a sense can be relieving in a way because you're finally there. You're finally getting the treatment that you need, even if it is a watch-and-wait kind of treatment. And so, that's sort of where people kind of land. It might feel a little bit better.





Emotional Effects of Cancer

- · What's a 'normal' reaction?
- Coping reserve and resiliency
 - Stress, appraisal, and coping
- Usual 'go to' coping mechanisms?
- Loss/gain of function

Lazarus & Folkman 1984

Emotional Effects of Cancer

There's not one normal reaction. "Normal" is sort of a term with some baggage to it. And I just highlight that because normal would really mean, "What is normal for yourself?" And so, that might be actually a guidepost as to, "Is this too much? Something else going on that would require some help?

We as human beings are very adaptable. We're very resilient. And if you think back to your life, most people have gone through other traumatic things—maybe not as traumatic—but people learn skills and become resilient. And that actually can be kind of called upon as you move through the diagnosis and further trials and tribulations dealing with cancer.

And so, those are just sort of go-to coping mechanisms. What has worked for you in the past? Where we start to become concerned is that, "Is there an issue with functioning, things that you need to do, your relationships, getting to a doctor's appointment, taking the medications or treatments that are required?"

And so, we can either see kind of a loss of function, or we can see a gain of function. Like I mentioned, this is a traumatic experience, and it can sometimes put people in a sort of survival mode where they are moving forward. And maybe they are really kind of having a gain of function. And that is normal as well.





NIH-Feelings and Cancer

So again, many different feelings are involved. These are some that the National Institutes of Health (NIH) have let us know are part of the package. So, feeling overwhelmed, having some level of denial, actually is normal—being angry, having some fear and worry, stress and anxiety, sadness, depression, guilt, and loneliness. This can be a very lonely experience.

And organizations like LLS, friends and family, and knowing other people who were going through this let us know that you are actually not alone in dealing with this. But one's personal experience can make one feel that way. And I put up here hope and gratitude. So, the feelings are, of course, not all negative, and the positive feelings can actually be abundant and can be very, very helpful. Of course, identifying feelings is the first task at hand.





Emotional Effects of Cancer-Distress

- The National Comprehensive Cancer Network 'Distress Screening'
- Definition of Distress in Cancer
 - "Distress is a multifactorial unpleasant experience of a psychological
 (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical
 nature that may interfere with one's ability to cope effectively with
 cancer, its physical symptoms, and its treatment. Distress extends along
 a continuum, ranging from common normal feelings of vulnerability,
 sadness, and fears to problems that become disabling, such as
 depression, anxiety, panic, social isolation, and existential and spiritual
 crisis"
- The practical, familial, emotional, spiritual, and physical

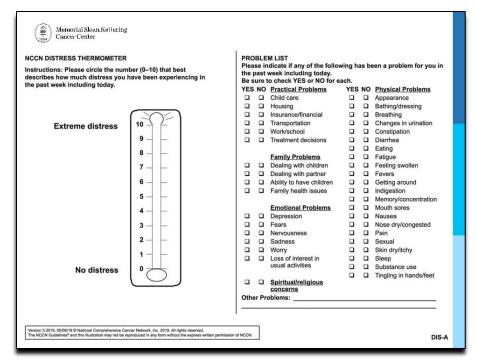
Emotional Effects of Cancer-Distress

The way that we get to that point of identifying, well, what is going on, is through this initiative that was through the National Comprehensive Cancer Network (NCCN) that looks at distress. And distress is a term that is sort of used very intentionally because it is not sort of stigmatized.

And when we think about cancer and emotional issues, I had a previous mentor who had highlighted what she called the double stigma of cancer and having an emotional issue. Cancer in itself used to be stigmatized. Now it's hopefully much less stigmatized. Mental health issues unfortunately have stigma to them that can be very real for people—and unfortunate. And so, this is a way as clinicians that we can help people kind of move through that.

Now, people are in distress for a whole multitude of reasons, which I put down on the bottom. That's certainly not comprehensive—just going to read the actual definition because I think it's important. "Distress is a multifactorial unpleasant experience of a psychological, cognitive, behavioral, emotional, social, spiritual, and/or physical nature that may interfere with one's ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears to problems that become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis." So, it is kind of an allencompassing definition.





NCCN Distress Thermometer

And many of you might have seen the Distress Thermometer. This is taken from kind of like the pain scale of zero to 10. It's a very similar idea, very straightforward.

So, you see the problem list again—not exhaustive necessarily—but it helps medical teams figure out where you might be best served. If it's a lot of practical issues, maybe having a social worker onboard would be helpful. If it's a lot of depression and fears, maybe having a therapist involved—chaplaincy. If it's physical problems, maybe working with the hematologist to address those issues.





Consequences-Emotional Effects of Cancer

- · Quality of Life
- Interference with cancer treatment (treatments, delays, communication)
- Impacts the ability to cope with cancer
- Relationships:
 - Primary, familiar, friends, acquaintances
 - Interpersonal styles and values
 - Stressor
 - Can strengthen, strain, or weaken relationships
 - Transformation
 - Relationship with self (self image/identity/roles)

Consequences-Emotional Effects of Cancer

What are the consequences of emotional effects of cancer? Well, there are many consequences. Namely, quality of life is the very first one. It's very important as you move through the cancer trajectory to maintain a good quality of life as much as possible. That is extremely important. We actually know that using what people write down on a questionnaire is actually the best indicator of how they're feeling, even more than going to the doctor and telling them. And so, research is moving in that direction.

The emotional effects of cancer can interfere with cancer treatment, ability to cope with cancer. It can affect relationships. It can be a stressor on your relationship. It can strain, it can weaken relationships, or it can actually strengthen relationships. Many people find that relationships change with a diagnosis of cancer. There's a certain transformation, and relationships that you didn't think were so important become more important.

And I also included relationship with the self: the idea that we have a self-image, our roles and identity. And as we take on new roles with cancer, that can change. For example, someone who is a caretaker of other people may not feel comfortable being taken care of—having someone else taking care of them. And there can be a little bit of work in switching this identity around.





What Does Anxiety or Depression Feel Like?

Anxiety

- Extra worry, can't relax and feel tense
- · May notice
 - Fast heartbeat
 - Headaches, muscle aches
 - Appetite disturbance or diarrhea
 - Shaky, weak, dizzy
 - Tight feeling in throat/chest
 - Sleep disturbance
 - Hard to concentrate

Depression

- · Sadness that doesn't go away
- · Emotionally numb
- Sense of guilt or feeling unworthy
- Helpless or hopeless (loss of meaning)
- · Moody, short tempter, irritable
- Crying (long periods of time or many times per day)
- Focused on worries and problems
- Little or no interest, enjoyment
- Thinking about self harm

NCI 2020.

What Does Anxiety or Depression Feel Like?

What does anxiety and depression feel like? Anxiety and depression are the two symptoms that we worry about. Now, I would just highlight that emotions are sort of a much more personal experience, right? No two emotions are exactly the same. We talk about anxiety and depression. These are symptoms which obviously sound much more clinical.

The issue with the symptom part is that we want to look at the symptoms because dealing with, "What is the meaning behind cancer? What role does it play, and what are your emotions?" can be undermined by symptoms like depression and anxiety that are too much. And so again, both are obviously very important. But this has a little bit more of a clinical feel.

Anxiety is that feeling of just not being able to relax, feeling tense. It can manifest itself in the body as muscle aches, a fast heart rate, changes in appetite, feeling weak, dizzy, problems with sleeping, and problems with concentrating.

Depression, believe it or not, can actually be a very hard thing to diagnose because people suddenly feel emotionally numb. They can't really identify how they are feeling. The two main signs of depression are the feeling of not being able to obtain enjoyment from things that you normally enjoy. That is a highlight and is kind of a red flag.

The other thing is your sense of self starts to change. You feel unworthy, or you start to feel guilty about things that you wouldn't normally feel guilty about. And other indicators might be just irritability, not acting like yourself. And certainly this idea of self-harm is very concerning and should require help. And so, that's something to be aware of.





Emotional Symptoms: Distress, Anxiety, Depression

Symptoms like depression, anxiety, and distress are common—very common. And they commonly cooccur, meaning that you can have both of them at the same time. And they are also very treatable. And that's the key point is that these are things that can be addressed. Now, red flags to look for would be, again, that sort of functional loss. Are you doing the things that you normally do that you need to do that make you sort of do your life, right? Are you doing those things?

Also, physical symptoms. So, not sleeping, changes in appetite, physical ailments are also red flags. Substance abuse certainly a red flag. Are you abusing or using a substance more than you would have in the past? Or is there a history of using a substance too much? These are things that should be red flags. And of course, like I said, any suicidal thoughts should be addressed with a professional.





(Post)Traumatic Stress

- Disorder versus symptoms
- Core symptoms of PTSD
 - Intrusive persistent negative thoughts
 - Avoidance type of behavior
 - Hyper-arousal and reactivity (vigilant)
- Cancer is considered a traumatic event (Diagnostic Statistical Manual-V)
- Associated with distress, depression, other anxiety disorders
- Cancer related PTSD is 12.6% while up to 20% may have symptoms
- Risk factors
 - prior trauma, pre-existing psychiatric conditions, poor social support, limited financial resources
 - advanced disease, invasive treatments, not remembering during key cancer experiences, persistent intrusive re-experiencing

Cordova et al. Lancet Psychiatry 2017.

(Post) Traumatic Stress

One of the topics that I heard about that was of interest was this idea of traumatic stress. And I put the post in parenthesis here because posttraumatic stress disorder—PTSD—is a specific psychiatric diagnosis. And it is based on a core of three symptoms: invasive or persistent negative thoughts, this kind of hyperarousal of reactivity.

We call it being vigilant or hypervigilant, looking over one's shoulder, sort of waiting for something bad to happen—and avoidance. So, if the triggering trauma might be going to the doctor's or might be another thing, if you find yourself avoiding doing that, this might be some sort of traumatic stress kind of behavior.

Now, the actual diagnosis of cancer is included as one of the traumatic events that can lead to PTSD. And in fact, it does in about 12% of everybody that has had cancer, while up to 20% of people can have these symptoms that are reminiscent of PTSD. Again, this is something that is very treatable—and very important to get treatment because it can interfere drastically with moving forward, living life to the fullest that's possible.

And so, there's a whole host of risk factors for these kinds of symptoms. But again, I would just reinforce that this is something very treatable and to get help with that if some of these symptoms are noted.





(Post)Traumatic Stress

- What aspect of the cancer experience might constitute a traumatic stressor?
 - Period of heightened anxiety following abnormal finding on self, laboratory test, screening procedure, routine imaging, clinical exam
 - Undermines assumptions of invulnerability, predictability, and control
 - Series of acute and chronic challenges (e.g., medical complications)
 - Life threatening
 - Diagnosis versus other time points
 - "Diagnosis and treatment of cancer pose a cascade of physical, emotional, practical, and social demands on the individual and their support network"
- Treatment

Cordova et al. Lancet Psychiatry 2017

(Post) Traumatic Stress

And again, the whole experience of becoming diagnosed with cancer and in dealing with cancer—we could look at any part of it as traumatic, in fact. So, just like I mentioned at the beginning, the waiting game is traumatic. It undermines our sense of invulnerability, the predictability and control that we like to have in life in general. It sort of turns that upside down. And again, it's a series of kind of acute and chronic challenges, even with treatment, right? So, things can happen with treatment that are sort of an ongoing challenge. You have to deal with a symptom over and over and over again. And it may come to the point where it's just too much to deal with, and that's why I just put treatment down here.





(Post)Traumatic Growth (PTG)

- Cancer has potential for both negative and positive psychological outcomes
- Positive relationship between growth and stress
- Refers to the cognitive process through which those who've encountered
 a traumatic event positively re-interpret and find meaning in the event
- Mildly correlated with PTSD in cancer, perhaps to a certain point (curvilinear relationship)

Tedeschi RG, Calhoun LG. J Trauma Stress. 1996.

(Post) Traumatic Growth (PTG)

On the flip side, there is this idea of posttraumatic growth and that is that cancer has the potential for both negative and positive psychological outcomes. People find that the stress of cancer can make them look at things in a different way. It certainly makes people question many of their assumptions about many different things. And so, you can find meaning in different aspects that you hadn't thought about before. And so, that's the ability to kind of reinterpret and find meaning.

There is a mild correlation between folks who have had PTSD in the cancer experience and having posttraumatic growth. But like I said before, of course if the symptoms of PTSD are great, then it's going to limit that. And that's the problem because this is something that if it is possible to find new meaning, it's very important and helps people move forward and cope to the best of their abilities.





Body Image Discomfort

- Body Image: An image of one's own body created in the mind
- · Changes throughout treatment and recovery
- Physical changes versus perceptual changes
- · Negative feelings about one's body affects:
 - Selfimage
 - betrayal'
 - Confidence (self esteem)
 - Relationships
 - Intimacy
 - Role
- · Cancer and treatment specific issues
 - Can persist
- Impedes post traumatic growth

Muzzatti et al. Support Care Cancer 2017.

Body Image Discomfort

Another issue is body changes. And so, this is something called body image discomfort. We all have a mental image in our minds of what our body looks like, and cancer can change what your body actually looks like. And so, this can change throughout treatment and throughout recovery.

That perception that we have in our mind may not be exactly accurate with how our body looks at the time, and that can kind of go either way. But the problem is when it affects really how we feel about ourselves. And people have described this sense of betrayal. Their body is betraying them. And it can affect self-esteem, confidence—it can affect intimacy and primary relationships and affect the role.

And these are things that can persist over time. And it certainly impedes this idea of posttraumatic growth as well. So, this is something that, again, can be addressed mostly through therapy and also with sort of changing the kind of frame of reference and acceptance.





Fear of Cancer Recurrence (FCR)

- The most prevalent unmet supportive care need in cancer is help with FCR
- Almost all patients experience some FCR;
 - 'scanitis'
- · Studies have shown even higher rates in caregivers
- Does not always decrease with time, even when the risk is low
- Intrusive thinking and preoccupation with checking (for cancer)
- Negative impact on QOL, psychological adjustment, ability to establish goals
- Interventions –few validated approaches
 - Risk perception modification
 - Self regulation of illness model -focuses on adaptive coping
 - Acceptance and Commitment Therapy (ACT)-cognitive flexibility

Thewes et al. Support Care Cancer. 2012.

Fear of Cancer Recurrence (FCR)

Another diagnosis that is important—it's not a kind of a psychiatric diagnosis. But we think about it a lot for folks that are working in cancer—is this idea of fear of recurrence, fear of cancer recurrence. Fear is specific. You're afraid of something specifically. Anxiety is more of a free-floating worry about sort of things that are more general or can kind of go from one thing to the other thing.

And so, if you think about it, we are very fine-tuned to look for danger. Danger, if we find it, keeps us safe. And so, this can be used to an extent where it's really not helping people anymore. Everybody has some fear of recurrence, and that's prior to a scan or a bone marrow biopsy. It's very normal to get nervous, maybe have a little bit of trouble sleeping, etc. But this fear of recurrence is something that can be ongoing, even when there is not a test involved. And it can become a preoccupation with checking the body and certainly can have negative consequences.

There are certain therapies that can help people with the fear of recurrence to kind of lessen that fear as much as possible. And so actually they have documented that this is the most prevalent unmet need, and so there is active research in this area.





Survivor Guilt

- Connection and identification with a community and surviving a situation that others have not
- · Comparing ones' life to the lives of others who have died
- Struggle to justify existence (fairness)
- · Deep sense of injustice
- · Majority endorse survivor guilt
 - Distinct from depression (self esteem)
- · Five themes:
 - Mentioning death of others
 - Questioning 'why not me?'
 - Role of passage of time on emotions experienced
 - Demographic and clinical characteristics
 - Strategies for managing

Perloff et al. J Psychosoc Oncol. 2019.

Survivor Guilt

Survivor guilt. So, if you think about the experience of having cancer, just like any other experience where you're suddenly doing something else or having a new role. Say it's becoming a parent or taking on a new job, it's very normal to identify with that new thing and to sort of feel empathy with other people who are kind of in the same boat.

And that's something that happens with the survivor guilt, in that on the one hand it's very good to identify and connect with other people who are going through the same thing. But when they don't do as well, there can be this very deep sense of injustice and feelings of, "Why not me?" And so, this is really another sort of source of stress that can be very much dealt with.





Dealing with Emotional Effects from cancer – Susan's Story

- Susan is a 75 year old retired school high school teacher. She lives alone but has
 several friends close by with whom she plays Bridge and two adult children who live
 out of the state. She underwent a stressful divorce 10 years ago but is financially
 secure through retirement/savings. Does not drink or use any drugs.
- She was diagnosed with CLL at age 65 and then diagnosed with Diffuse Large B Cell Lymphoma (DLBCL) 8 years later and underwent 6 cycles of R-CHOP.
- Initially, she was nervous but could garner the support she needed to get through her months of treatment. She had difficulty sleeping, eating, concentrating at times, and always felt 'on edge'. Treatment left her with fatigue and neuropathy.
- She used to only get nervous before her scans (all NED) but is now nervous and irritable most of the time. She is having trouble sleeping again but doesn't want medication or to see her doctors/nurses. She no longer enjoys playing cards, seeing friends or family and prefers solitude. Interests have diminished.

Dealing with Emotional Effects from Cancer – Susan's Story

I'm going to highlight just a story that will kind of tie some of these things together. So, Susan—obviously this is not a real person, but this is my example—she's a 75-year-old retired schoolteacher, lives alone but has several friends close by with whom she plays cards, two adult children that live out of state.

She underwent a stressful divorce 10 years ago but is financially secure through her retirement and savings. She does not drink, nor does she use any drugs. She was diagnosed with chronic lymphocytic leukemia at age 65, and then was diagnosed with diffuse large B-cell lymphoma 8 years later. And she underwent six cycles of R-CHOP chemotherapy. So, that would be 2 years ago.

So, initially she was very nervous about the diagnosis, but she was able to garner the support she needed to get through her months of treatment. She had some difficulty sleeping, eating, and concentrating at that time and always felt on edge. Treatment left her with fatigue and neuropathy.

She says she only used to get nervous before scans, which have all been, "No evidence of disease," but is now nervous and irritable most of the time. She is having trouble sleeping again but does not want medication or to see her doctors or nurses. She no longer enjoys playing cards, seeing friends, family, and prefers solitude. Her interests have diminished.





Susan's Story

Red Flags?

- Change in pace and tenor of her anxiety symptoms
- · Social withdrawal
- Not engaged with medical team (Avoiding?)
- Physical symptoms
- · Previous stressors
- Protective: finances

Possible Reasons?

- Anxiety
- Fear of recurrence
- Depression
- · Post traumatic stress

Susan's Story

So, some red flags in Susan's story. I noted that at the beginning she had some anxiety symptoms, but they were lessened with the support that she had around her. But now, the pace and tenor of those anxiety symptoms has changed. They are sort of coming out of the blue. That's a bit of a red flag.

There is some social withdrawal. She's not engaging with the medical team. Perhaps she is avoiding. She has some physical symptoms. She has noted some previous stressors, and some of the protective things might be that she has finances that can be protective. So, some possible issues: of course, she could be having fear of recurrence. She could be having anxiety. This could be depression, it could be posttraumatic stress. And we need to find out more information.





Susan's Story

- She needs a medical assessment along with a thorough/comprehensive evaluation into her recent psychological symptoms.
- Susan's medical work up is fine.
- On further discussion, she says that this time of year is difficult for her due to a previous loss. She is unsure of how to cope with the added stress of worrying about cancer and feels overwhelmed.

Susan's Story

The other thing is that she very much needs to have a medical workup. This could be a low thyroid issue, or it could be some other physical manifestation. And so, it's very important, again, to see the doctor to have a comprehensive evaluation.

So, let's say that her medical workup is fine, thankfully. Well, after discussion she says that this time of year is actually very difficult for her due to a previous loss that she had, and it brings up a lot of feelings. She's unsure of how to cope with the added stress of worrying about cancer and feels overwhelmed. This is something we see frequently called the anniversary reaction. And so, these kinds of emotions can couple together to the point of becoming overwhelming.





Dealing with Emotional Effects from Cancer

- · Alignment with medical team
 - Addressing physical symptoms (e.g., sleep)
- Familial/relationship stressors may add to cancer stress
- Psychologically stressful times in the past -what helped? What didn't?

Dealing with Emotional Effects from Cancer

So, she was able to align with her medical team, which is very important. That team, let's say, was able to address physical symptoms like sleep. If you don't get good sleep, it's hard to do much else. So that's kind of the first step. We noted that some of these familial and relationship stressors may be adding to the stress that she feels about cancer, in and of itself, and she is able to recall on some psychologically stressful times in the past—what helped, what didn't help to help her with this period of time.





Susan's Story

- Susan starts getting better sleep with the help of Cognitive Behavioral Therapy-Insomnia in addition to as needed lorazepam
- She finds a therapist through LLS in her area and benefits from obtaining another perspective on her cancer journey. She discovers that she feels constrained about her emotions. Everyone wanted her to act 'positive' and she never had a chance to express how she was truly feeling after her diagnosis and through treatment. She harbors anger at those around her who indicated (nonverbally) that they weren't willing to listen to her feelings even though they had been present.

Susan's Story

Now, she also notes that doing some cognitive behavioral therapy for insomnia has helped her sleep with the addition of some as-needed lorazepam (Ativan®).

She finds a therapist through LLS in her area and benefits from obtaining another perspective on her cancer journey. She discovers that she felt constrained about her emotions. She said that everyone wanted her to act positive, and she never really had a chance to express how she was truly feeling after her diagnosis and through treatment. She harbored some anger at those around her who indicated, albeit nonverbally, that they weren't willing to listen to her feelings, even though they had been present.





Coping with Emotion and Cancer

- Express your feelings
- Look for the Positive
- Don't blame yourself for cancer
- Don't try to be upbeat if you're not
- YOU choose when to talk about your cancer
- Be as active as you can
- Look for things you enjoy
- Look at what you can control
- Find ways to help yourself relax

NCI 2020

Coping with Emotion and Cancer

And so, what this story highlights is that this is a person who 2 years later is having some feelings about what had happened previously. And these are the ways that dealing with emotions around cancer can be. They can be sort of insidious and can come up at random times.

So, some of the tools. Moving through coping with emotions and cancers, it's always good to try to express your feelings, to sort of work on understanding what it is that you're feeling. Most things in life are not black and white, so there is a benefit of looking at some of the good things that might also be happening in that moment. It's really kind of an attitudinal thing. Not blaming yourself for cancer is very, very important.

And don't try to be upbeat if you're not. Just try to be real about the feelings you're having. It's very important that you as a patient are choosing when and how you are going to talk about the cancer. Try to be as active as possible and look for those things that you can enjoy and what you can control. And actually just finding downtime to relax is extremely important.





Spirituality

- Religion: viewed as specific set of beliefs and practices associated with organized religion or denomination
- Spirituality: recognized as encompassing experiential aspects, whether related to engaging in religious practices or a sense of peace/connectedness.
 - >go% express belief in God
 - >70% identify religion as important

- 77% think physicians should take spiritual needs into consideration
- 37% wanted religious beliefs addressed more frequently
 - Spiritual/religious needs not met by medical system
- Intensity of spiritual distress correlates with depression but not pain or perceived severity of illness
- · Affects coping and quality of life
 - Less distress
- Praver

Spirituality

The idea of spirituality: So, spirituality includes religion, of course. And 90% of folks actually express a belief in God, and 70% say that religion is important. And so, this is something that the medical team should very much encourage because it's very helpful. And that's what patients think.

They say 70% of physicians should take spiritual needs into consideration—if that's asking about it, asking what has been helpful and if the person is religious or spiritual—so that the doctor knows that about the patient. Thirty-seven percent said that they wanted religious beliefs addressed more frequently, and that's something that most facilities have access to.





Hope and Gratitude

- Maintain as much normalcy as possible (routine)
- Don't limit things you like to do
- Look for reasons to have hope. If it helps, write them down or talk to others about them
- Spend time in nature
- Reflect on personal beliefs
- Listen to stories about people with cancer who are leading active lives
- · The surprising solace in simplicity

Hope and Gratitude

About to wrap up the slide portion here--hope and gratitude, two very important emotions that can come from this experience and maintaining as much normality as possible. Routine is very good. Don't limit things that you like to do. Do those things that you like to do, of course. Look for reasons to have hope. Spending time in nature. There's actually a lot of research that shows that when we spend time in nature, it kind of resets and gives us a sense of balance. That can be extremely important when dealing with stress.

Reflecting on your own personal beliefs and values, listening to stories of people who have gone through cancer can be very helpful. And actually the surprising solace in simplicity. Again, these are just little bullet points. This isn't the whole story but just something to kind of take away.





Conclusion

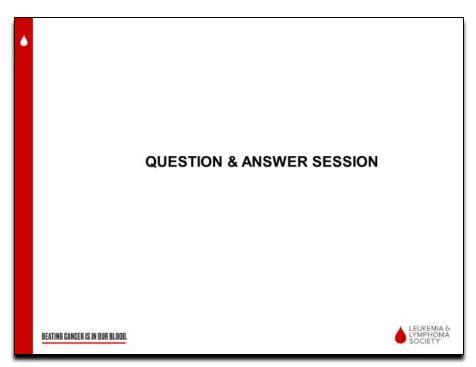
- Unique interface of cancer meaning and life trajectory
- Enormous task and complexity
- Capacity for coping and resilience
- Attention to symptoms and functioning
- Support and perspective go a long way

Conclusion

In conclusion, I'd say that cancer creates a kind of unique interface with one's meaning and purpose in life and that this can actually be leveraged to sort of find a way that cancer can actually even help us grow. It's an enormous task, and it's very complicated. But we are resilient. People are adaptable. And in order to do those sorts of things, we really need to pay attention to the symptoms and ways in which we're functioning well and ways in which our functioning may not be going as well as we want it to be. A little bit of support and some perspective can go a very long way.

Okay, thank you very much for your time and I'm happy to take questions.





Q&A Session

Ms. Lizette Figueroa-Rivera

Thank you, Dr. McFarland, for your very informative presentation. It's now time for the question-and-answer portion of our program. And we'll start with a question from our web audience. Doctor, Ross is asking, "I can't tell. When should I seek counseling since I'm on a lonely road and really don't know how it's affecting me?"

Daniel C. McFarland, DO

Right, so very good question. Counseling can be beneficial in multiple ways. I think there, it's really never too early to seek counseling—whether it's something that you're going to benefit from. It might be that you might need a couple sessions. You might need something a little bit longer term. But certainly the things that I've gone over in terms of those red flags—if any of those things are coming up. And there's a very individualistic kind of thing to this.

So I would encourage you, almost since--because you're asking the question, it's probably not a bad idea to give it a shot and to seek—if nothing else, you'll know that that resource is there. And sometimes it takes meeting a couple different therapists to find the one that you might click with. So, I would certainly encourage you to start that process.

Ms. Lizette Figueroa-Rivera

Thank you. And we'll take the next question from our telephone audience, please.

Operator

Our question comes from Alan, calling from New York. Please state your question.

Alan

Yes. Thank you, Dr. McFarland. I had after my follicular lymphoma treatments that were quite successful, I experienced the, "Oh, my God, what have I gone through?" which I characterize as PTSD. I was never formally diagnosed by it, but in the literature and of course talking to other cancer patients, this pretty much is a common occurrence.



A two-fold question, Doctor. First, the whole idea of having oncologists really understanding survivorship from the outset as mandated by the NIH and of course the oncological associations, and two, what can I do—and others—dealing with this time lag—this long time lag—until I was able to really engage and understand truly what had happened to me.

Daniel C. McFarland, DO

Right. So, the first question about survivorship, I think that the oncologic community is paying much more attention. But I think you're absolutely right, that the ways in which the medical community puts treatment together for folks who are in long-term kind of remission, etc., is really a work in progress.

There are a lot of key issues to survivorship. And right now, I think it tends to feel disjointed because we have many different disciplines that are involved. And so, for example, that's something that is being worked on here extensively. So, I think it's a work in progress, in other words.

The second question about the time lag. I would just say that similar to the story that I presented, actually, and what you're sort of bringing up is it's sort of attributed to like the way that our minds are. It just takes time to really process what has happened, as you're saying. And that is kind of how the mind works.

Sometimes our minds sort of protect us from things that we sort of unconsciously think, "Okay, I don't really want to deal with that right now." You're at a point where maybe you're starting to deal with those emotions. And so, emotions are tricky because while you're dealing with it, it's probably a good thing that those things are coming out. Ultimately, that is a good thing because it indicates that you do need to deal with those emotions.

So, I don't know exactly what those emotions are, but I would encourage you to not only talk with other people but even to seek professional help. It wouldn't hurt to do that, in other words. So, I hope that has answered your question.

Ms. Lizette Figueroa-Rivera

Thank you. And our next question comes from our web. Marla asks, "Can you please define psychosocial and how it differs from psychological and psychiatric."

Daniel C. McFarland, DO

Oh okay, very good question. So, yeah, these things obviously overlap tremendously. But the psychosocial part of it, of course, includes social. And that is the context in which we as individuals live: our society, our culture, the norms and mores of our culture. And so, these things certainly have an effect on how we feel as individuals. And so, the psychosocial is kind of like putting the person in the context of their community.

The psychological part is the psycho of the psychosocial, but it's more just dealing with those dynamics of your thoughts and behaviors without focusing on the sociological context as much. Now, the difference between psychological and psychiatric is somewhat arbitrary. I would say that the psychiatric tends to be where we start including the biological realm of how actually having emotions may be because of some biological process that's going on—not emotions but like symptoms, having certain symptoms. And so, the psychiatric is focusing on that. So, that's how I would define them.

Ms. Lizette Figueroa-Rivera

Thank you. And the next question from our web audience. Dawn asks, "As a spouse and a caregiver, would it be appropriate for me to give emotional support or would it best come from an outside source?"



Daniel C. McFarland, DO

Right. I mean, I think that's what we do as caregivers is to give emotional support. It's hard because by the nature of the relationship, it's a two-way street. And so, it really--I think it's something that should always be offered and available, but it very much depends on the patient.

Similarly, these types of diagnoses can affect the family. And so, what therapy really does is it offers an outside perspective that can be extremely helpful. And so, it's something to think about and consider. And again, I think it doesn't hurt to try. But yeah, so I hope that answers your question.

Ms. Lizette Figueroa-Rivera

Doctor, the next question from our web audience. Mary is asking, "Because of my residual complications, which mean lifestyle restrictions, I'm discouraged. I need to avoid crowds like church or movies, etc., and certain dietary restrictions due to the excess iron. Do you have suggestions for the social isolation many of us experience?"

Daniel C. McFarland, DO

Yeah, that is a tough one. It certainly is. The first thing I would say is just to be very specific with your doctors about what you can do because sometimes people can kind of overinterpret how much they need to be isolated. The other part is that if it is full isolation at home, etc., using technology to connect with people. And we have all kinds of technology that we can use these days. That's another one.

Finding other ways that can be helpful to pass the time, simply to pass the time in this period can be helpful. But I hear you. That is a very common one, and I wish there were a better answer. It's very trying to deal with the isolation part of it. But anything you can do to not feel as isolated—what has helped in the past and really kind of go with that.

Ms. Lizette Figueroa-Rivera

Thank you, Doctor. And the next question from our web audience. Doreen states, "I'm considering treatment cessation due to side effects impacting my quality of life. Can you address the emotional effects of the impact of quality of life from taking cancer treatment?"

Daniel C. McFarland, DO

Right. So, this is a very big deal. And so basically, it's a trial-and-error kind of process of treating the symptoms—maybe changing the treatments around. And there's kind of an interplay there. There is a lot that can be done in terms of the anticancer treatment that might really help with symptoms. So, of course, the oncologist or the hematologist is the one to do that. Even if it's seeking a second opinion—not a bad idea.

Thirdly, just addressing the symptoms, sometimes there can be a magic bullet. There can be one medication that really does the trick, and people can then move on and get the treatments that they need or desire. So, it's just basically trying one thing after another.

Then lastly is the idea of stopping treatment. And that's a very individualistic decision, but I would say really work with the hematologist on it to see if that's the right thing for you. And I think what you're pointing out is just the way that treatments can affect quality of life and maybe--maybe pointing out which aspect of quality of life is the most difficult to deal with in terms of the side effects. Or is it other things that are--that are bothersome? This may be a surprise that there is a treatment that can be helpful.

Ms. Lizette Figueroa-Rivera

Thank you. And the next question comes from Diane. Diane is asking, "How do you handle close family members who can't cope and pretend it isn't really happening?" Doesn't give any support?



Daniel C. McFarland, DO

Right. No, that's a great question and something that I really see very often: that the folks who--patients are much further along in terms of understanding what's going on than the family members. And I think that it just takes some time, that they will most likely get there. Or they may get there in their own way or they may understand it in a way that maybe we don't. We want them to understand more fully. But I would say, one, just give it some time.

Two, I'd say have an earnest conversation with them in terms of, "Look, this is very important to me. I really want you to understand what I'm going through and see what the issue is." There may besometimes what happens—or a lot of times what happens is that there's something that this person is thinking about that is some information that could be corrected. There may be one worry, in particular.

Now, it may not be your job as the patient to figure that out. But I would encourage them to either seek professional help or just to talk about it with you is fine, too. But if it's something that they need to address on an individual level, then definitely professional help.

Ms. Lizette Figueroa-Rivera

Thank you. And Kevin is asking, "How do people deal with the daily thought that, 'I have leukemia even though I'm in remission?"

Daniel C. McFarland, DO

Yes, so that is dealing with uncertainty. There's not one way to deal with it. And so again, it is a personal thing. I think what we end up telling people is that these are thoughts that--they should be kind of coming and going. When it becomes problematic is when that thought is there all the time.

So, a little bit of sort of distraction is okay, getting involved. And that's what I was saying in the slide deck about doing your sort of normal activity as much as you can. That is okay. And actually using a little bit of distraction is also okay. So, that would be the main thing. And is it affecting sleep? Do you need to find a way to enhance sleep or other symptoms—so, addressing the symptoms around it.

But that's how our brains work is that we try to find solutions to problems. And the cancer experience, just you're not going to have all the information right at hand. And so, that's why I'm saying it's usually encouraged and it's okay to kind of distract yourself. And you'll get more information as you move along. But dealing with uncertainty is what everyone is dealing with who has cancer.

Ms. Lizette Figueroa-Rivera

Thank you. And on the web, we have John making a point that most of these discussions seem to overlook the added stress of managing the expenses and the insurance of all the financial issues that come along with your cancer diagnosis.

Daniel C. McFarland, DO

Yes. So, I agree wholeheartedly. And I think it's another realm. What I would encourage you to do is that most cancer centers have financial resources where--and just get involved with them early on. It may be an insurance thing. Sometimes there's ways that these treatments can get covered. But these are generally expensive treatments and it becomes--it can be very burdensome.

And so, just work with the financial people and tell the doctor. The doctor really should be asking questions about it, but it doesn't always come up. And so, that's another way of just kind of advocating for yourself, "Hey, this treatment is costing this amount of money." And I think that any caring physician will work with you as much as possible.

Ms. Lizette Figueroa-Rivera

Yeah, I think that's a very important point. And Aaron is asking, "Can excessive stress or anger cause the cancer to reappear?"



Daniel C. McFarland, DO

So, this is a good question. And it's something that, looking back in the literature, has come up for a long time. The bottom line is the answer is no, thankfully—that it is not something that causes cancer to start or to recur. And so, now it's important for other reasons, too. It's uncomfortable to have a lot of stress, etc. And it can lead to like not following through on the treatment as well as you would otherwise. So, there's other ramifications, of course, and other reasons to mitigate the stress. The answer to your question is no.

Ms. Lizette Figueroa-Rivera

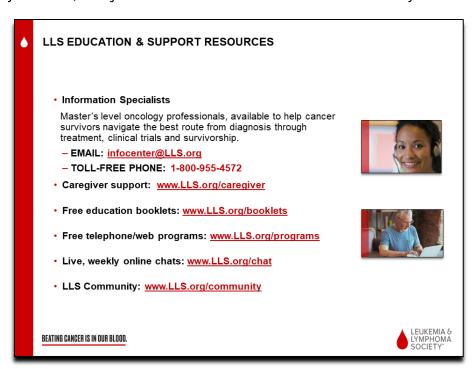
Thank you. And Fred is stating that after treatment, we are literally sent home to deal with the after-effects of treatment and remission, leaving a sort of emptiness. Is there any counseling that could be offered to help cope? He was treated 10 years ago and is still feeling it now while trying to work his way back into the workforce.

Daniel C. McFarland, DO

Yeah. No, that's a great question, and many people feel that way—that there's this intense experience with the cancer center, with the doctors, with the nurses. And then suddenly you kind of graduate and that those connections fade away. They don't fade necessarily. I think it's something where, for example, if the doctor says, "Well, come back in a year," you may not be ready to go that long.

And so, sort of more gradually disconnecting is something to discuss with the hematologist. And I think, as we were talking about survivorship before, many centers are looking into ways to help with survivorship, so that people don't go through exactly what you're saying—that there's sort of this drop-off period because these effects from treatment and from having cancer can last a long time.

And so, I would reach out to your hematologist. Just say you want to come in for a check, if that's what you need, and just discuss it with them because there may be some local resources available.



LLS Education & Support Resources



Ms. Lizette Figueroa-Rivera

Thank you. And thank you, Fred, for our last question today. And a special thanks to Dr. McFarland for sharing your expertise with us and your continued dedication and support that you provide to our cancer patients and their families.

If you weren't able to get your question in today, please contact an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572. And we're available from 9 a.m. to 9 p.m. Eastern time. Or you could reach us by e-mail at infocenter@LLS.org. So, Information Specialists are available to answer your questions about your diagnosis, about treatment, including clinical trials, or answer any questions that you might have about support. So, as Dr. McFarland mentioned, finding emotional support in your area—you can contact us. We have several chapters across the United States that would be able to assist you in your local area as well as Information Specialists that can help you.



LLS Education & Support Resources

Also, we have a First Connection program that allows you to speak to another person that has gone through the same or similar diagnosis or the same or similar treatment, just so you can talk to someone else who has gone through what you may be going through or what you may go through. Everyone is different, but sometimes it's nice to talk to another fellow patient or another fellow caregiver.





LLS Education & Support Resources



Thank You

Ms. Lizette Figueroa-Rivera

Dr. McFarland, thank you again for volunteering your time with us today. On behalf of The Leukemia & Lymphoma Society, thank you all for joining us for this program, and we hope to be able to bring you programs like this in the future, as we strive to assist patients and caregivers in maintaining a better quality of life during your cancer journey. Take good care.