



**Elissa Baldwin:** Hello everyone and welcome to sexuality and young adult cancer what you need to know my name is Elissa Baldwin with the Patient Education Team at The Leukemia & Lymphoma Society, and I will be your moderator today. We will have a question answer session after the presentation, where our guests will answer questions that came into our LLS Information Resource Center and Online Community.

Special thanks to Dr. Anne Katz for sharing her time and expertise with us today, before we begin our President and CEO, Dr. Louis DeGennaro will make some remarks.

**Louis J. DeGennaro-VIDEO:** I'm Dr. Louis DeGennaro, President and CEO of The Leukemia & Lymphoma Society. I'd like to welcome all of the patients, caregivers, and healthcare professionals attending the program today.

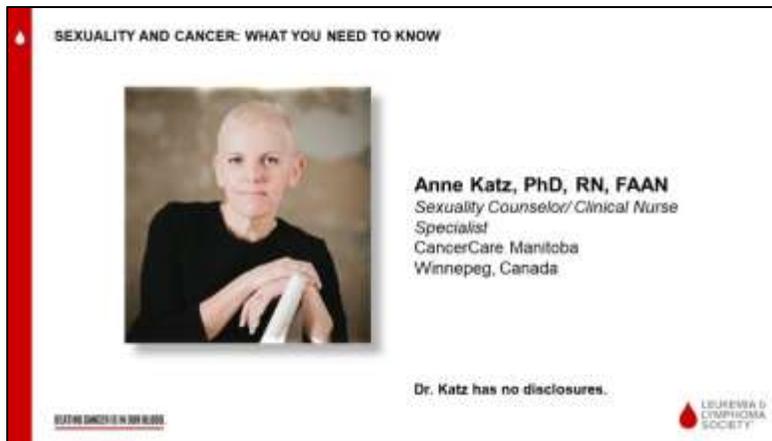
At The Leukemia & Lymphoma Society our vision is a world without blood cancers. Since we started in 1949, LLS has invested more than \$1.2 billion in breakthrough research to advance life-saving treatments and cures. We've played a pioneering role in funding many of today's most promising advances, including 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. 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 until we find a cure

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 today.

**Elissa Baldwin:** Thanks to Dr. Lou for his remarks and thank you for watching today, as you continue to face your blood cancer diagnosis during a pandemic and beyond.



I'm now pleased to introduce Dr. Anne Katz, a Certified Sexuality Counselor and Clinical Nurse Specialist at CancerCare Manitoba in Winnipeg, Canada. Dr. Katz was the past Editor of the premier research journal, *Oncology Nursing Forum*, and was inducted into the American Academy of Nursing in 2014. She is the author of 14 books on the topics of illness and sexuality, as well as cancer survivorship. Her latest book, the Second Edition of *Women Cancer Sex* was published in late 2020 and she is completing her latest book about sexuality and illness. On behalf of The Leukemia & Lymphoma Society, thank you for volunteering your time and expertise, Dr. Katz I am now privileged to turn the program over to you.

## Objectives

- Situate young adult sexuality in the trajectory of normal developmental milestones
- Describe potential changes for young adult men and women after hematologic cancer
- Provide some guidance on how to address these issues



**Dr. Katz:** So, thank you so much, Elissa. I'm really happy to be here to talk about a topic that really is something that caught my interest, some time ago, because I think, you know, young adult cancer in general, I don't think gets the attention that it deserves. And that's one of the reasons why I wrote the book for consumers called *This Should Not Be Happening: Young Adults With Cancer*. I also have an essential companion book for healthcare providers informing them about providing psychosocial care because that's so important.

Today I'm going to be talking about really, the development of young adult sexuality normal development of young adult sexuality.

And then really talk about how this has impacted in young adult men and women who have hematologic cancer or, quite frankly, any cancer, for that matter. And then interspersed with all of this is

really some tips and guidance on how to address these issues because I find, you know, that really is the thing that the young adults tell me is the most difficult thing to do. How do you talk about this? So as I move through my presentation today, I'm going to provide some really practical advice to young adults to help them.

## Developmental tasks of young adulthood

- Creating a sexual identity
- Establishing romantic and sexual relationships
- Exploring sexual preferences and practices

Morgan, Davies, Palmer & Plaster 2010



So at each stage of life, there are developmental tasks that we have to do so, for example, you know young children have to learn to play with others. They have to learn to well, you know, to talk, certainly, but they have to move through those stages of you know, individual play, playing with others and then moving into the teens forming that peer group that becomes so important.

In young adulthood, essentially, there are three major tasks that young adults have to address. The first is creating a sexual identity, establishing romantic and sexual relationships, as well as exploring sexual preferences and practices and I'm going to be talking about each of these, as well as how they're impacted by cancer.

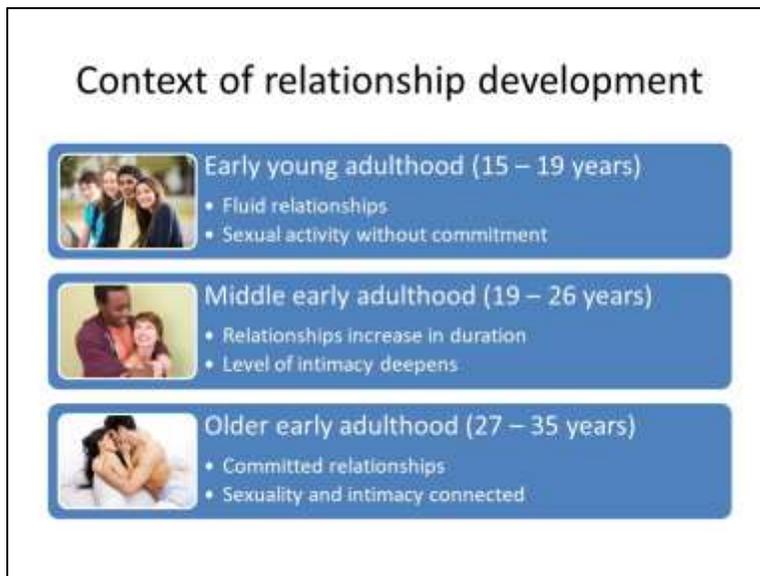
## Identity formation

- Who am I?
- Who do I want to be?
- Who do I want to be with?
- How do I want others to see me?



So identity formation is all about who am I, who do I want to be, who do I want to be with and how do I want others to see me.

And this is just so important because we carry this through from young adulthood into middle and older adulthood, and then into old age and really this is where our identity is cemented.



In terms of relationships, we really do see changes as we move from early young adulthood through middle early adulthood, and then to older early adulthood, and this really is, this 15 to 35 year span, is really what we call young adulthood, in terms of cancer. So we see in early young adulthood, so those sort of mid-to-late teen years - fluid relationships, you know girlfriends, boyfriends, perhaps a little bit of experimentation, our relationships really don't seem to last a long time. There's of course, a lot of heartbreak and heartache involved with us.

And any sexual activity that happens really doesn't have that commitment that we see in later adulthood or later early adulthood. So this might be experimentation with a young men, young women or both, but it really isn't what we would call an intimate relationship. An intimate relationship is not about sex in my world, it's about that an emotional connection that people have.

From the years of about 19 to 26, this is where relationships tend to last longer and that connection deepens. And this is often the age where people get together, where couples get together and stay together for a long period of time. So they might be engagements or living together or marriage in these years, typically.

I think this is kind of changing as well, people seem to be waiting longer to get married or move in together for a whole variety of reasons that I'm not going to go into. So in older early adulthood, from 27 to 35, this is where people tend to be in committed relationships and sexuality and intimacy that connection is really cemented.

## Establishing romantic and sexual relationships

- Cultural and social norms
  - Flirting
  - Asking someone out on a date
  - Appearance
  - Fitting in with peers



Establishing remote romantic and sexual relationships is really, really important, and this is enacted through flirting which really can start in those teenager years. Often it's, you know, the attempts of flirting are really quite clumsy and don't work that well. I recall, as a young teenager, the boys used to snap our bra straps. It's just a stupidest thing ever highly embarrassing for girls. But somehow this was flirtatious behavior on the part of boys. Certainly asking someone out on a date is a big deal and requires a great deal of practice, and this applies equally to young men and young women and there's no reason why you know, women have to sit around, young women have to sit around waiting for some guy to ask them out on a date.

People's appearance becomes really important here fitting in with peers. You know, wearing the same clothes, listening to the same music, watching the same movies, etc. Really, this is where the peer group really does supersede parents or older adults in terms of the importance and their influence.

## Cancer = interruption

- Gap in socialization → missed opportunities
- Missed experiences and diminished maturation
- Missed sex education at school
- Over-protective parents → lack of distancing, independence and sexual identity

(Evan, Kaufman, Cook, & Zeltzer, 2006)

So what happens when cancer comes along? Multiple, multiple interruptions in this these normal developmental milestones that really need to happen to solidify identity. So if someone is in hospital, for example, having a bone marrow or stem cell transplant, they may miss a big chunk of that socialization

that goes on within their peer group. So they may miss opportunities to practice that that flirting behavior, for example. These missed experiences can also mean that the young person kind of gets stuck at an earlier stage of development, while the peer group moves on, and so there perhaps is some immaturity. Miss sex education at school, and I know for some people sex ed. at school is not particularly helpful or useful, but any little bit may be missed completely.

And then of course there's the whole issue of overprotective parents, which we see a lot of. So parents tend to infantilize the young adults, treat them as much younger, don't allow them the freedom that they should be having. Really holding them close. In part, because you know I think for a parent the most terrifying thing is when their child gets ill, but this really does delay those normal developmental milestones that we want to see young adults going through.

**Disclosure**

- When?
- How?
- Conditions?



One of the biggest issues that I see and the questions that I get from young adults is how do I tell someone that I've had cancer. When do I tell them, you know first date, second date, third date, never? How do I get those words out without, you know, prompting someone to ghost me or without getting really emotional and embarrassing me? You know under what conditions should I do this? Is it better to do it by text or on the phone or, should I do it in person? So many questions about disclosure and quite honestly, I don't know the correct answers for anything. I can only provide some guidance based in part on my experience working with young adults and talking and, most importantly, listening to their experiences.

## So how do you tell?

- It all depends on what you are comfortable disclosing.
- A good place to start is to state simply: "I had cancer \_\_\_ months or years ago."
- Wait for a response. If they don't say anything immediately, don't try to fill the silence. (This is big stuff, and they may need to collect their thoughts for a few moments.)
- If they change the subject, it may mean that they aren't able to process this and you need to ask them at another time what they think or feel about your disclosure.
- If they ask you to tell them more about what happened, you can start simple and let their questions guide how much detail to give.

So how do you tell? It all depends on what you're comfortable disclosing you know you don't have to give your whole history, how you were diagnosed, what your treatment was like. Sometimes it's just some it's important to simply state I had cancer, two years ago. And then keep your mouth shut and don't say anything more. And that's often the most difficult thing at all, so you know, once you get going, you tend to blurt out the whole story. You know, and then just wait for the person's response. If they say nothing or appeared shocked, that really is a natural response and shouldn't have any huge meaning for you.

It doesn't mean that they don't want to see you again, it might just mean that they have never known anybody with cancer before. It may mean that a parent or beloved grandparent has had cancer. You don't know their story and the history that they bring to this moment.

They may just change the subject and move on. They may ask additional questions. Start simple. You know, nobody needs to perhaps know at this point about mouth sores or catheters. All the horrible, horrible details that you have endured. But you know you can say well you know, I was in hospital for about six weeks when I had my transplant. And then see if there's another question. It's not easy. It can take practice.

And you know, perhaps what's important or something that might be helpful, is to actually practice with a really good friend. Because they may think of questions that somebody else would ask, and that gives you an opportunity to really you know, create your story. So that when you do disclose to someone and they do start asking questions, you've got a little bit of practice.

## Altered body

- Scars
- Stretch marks
- Weight gain
- Weight loss



Certainly, an altered body has a huge impact on your identity, how you see yourself. And you know there can be all manner of alterations to the body. And certainly what we see with hematologic cancer is because of the steroids and the chemotherapy, people will often gain a lot of weight.

And then they lose it, but they have all these stretch marks which, for some people can be really, really embarrassing. It's also, you know, can be really difficult if you've lost a lot of weight.

And you may not, you know if you're hemoglobin is low, your color might be a little bit off, so there are all sorts of things that can change your body. And unfortunately, the certainly early parts of young adulthood, appearances are so important, and nobody wants to look different to their peers.

## What can you do about this?

- Think about what you like about your body instead of what is changed or different.
- Remind yourself that others will like those parts of you too .
- Ask a close friend to look at and describe your scars and your body; someone else's view may be quite different from your own.
- Talk to others with cancer and ask how they cope.
- We all have things that we don't like about our bodies—potential partners do, too.

So what can you do about dealing with this altered body? You know, I often see people who really focus a lot on the things that they don't like. And I will often say to patients who come and see me, hey you actually got here. You took the bus or you took an Uber or you drove yourself here, you found parking, you came into the building, you found my office.

That's a lot. Because when you were going through treatment, you probably couldn't do that and dreamed of doing that. So sometimes it's really thinking about what your body can do instead of what has been lost, or what is different.

The parts of you that you like, whatever it is, maybe it's your hands and others will like those parts of you, too. And it requires a little bit of self-confidence because others will pick up on that. Certainly, if you have a friend, a close friend, ask them, perhaps to maybe look at your stretch marks and see what they honestly say. We often don't see what other people see we see something way worse. Talk to other people who've gone through this and ask them how they dealt with us and how they cope with this. Nobody knows the walk that you have walked better than someone who's walked that same path.

And the reality is it's not often that you find someone who is really, really, really satisfied with their body. You know, even people who to us look like they're in fantastic shape, may have some issues with their body. And you know the media has a lot to do with this right? We see altered images and think that we have to achieve that and it's really not possible.

It does take some time to get used to what you look like and who you are and the maturation that you have gone through. Try wearing your clothes that are probably somewhere in the deep dark corners of your closet from before. Often you know when you're going through treatment you're wearing sweats all the time, kind of like most of us now during COVID, where sweats have become the uniform.

But when you wear something a little bit perhaps dressier, pair of jeans, a T shirt or sweatshirt, it can really help make you feel better and read us create that divide between being sick and not. For anybody, and this is not just for young women, makeup can make you feel better. It doesn't always. If you want to make the effort, why not? Perhaps a little bit of blush, perhaps some mascara if your eyelashes have grown back. Certainly without eyelashes, looking in the mirror and it can really make you feel worse.

You know I can't say enough about physical activity. We've got such good evidence that getting some physical activity in the day has huge benefits, particularly in how we feel, in our emotions and certainly moderate exercise is as effective as medication for depression. So working out and, you know, it doesn't mean going to the gym and putting on workout gear. Just getting some kind of activity can really make a difference.

You may need professional help and certainly you know cancer centers have social workers, sex therapist, sexuality counselors who can help you, and groups like Young Adult Cancer Canada, Stupid Cancer, Elephants And Tea, Lacuna Loft - really are there to support young adults and can provide you with much needed help and advice, because people know what you've been through.

## How do I ask for help about sex?

- Say what you mean. No beating about the bush!
- "When my partner touches my \_\_\_\_\_, it feels numb. Why is that?"
- "The last time I masturbated I noticed that \_\_\_\_\_. What can be done about this?"
- "How will I know when it's OK to have oral sex/go down on someone?"
- "What precautions does my partner need to know about if we want to \_\_\_\_\_?"

And don't worry if you blush; it can't be controlled. And if your oncology care provider blushes, the same applies.

So I'm a sexuality counselor and if these walls could talk they'd have great stories to tell, but you know I'm in this confidential bubble, so these walls do not talk at all. But how do you ask for help if you're having sexual problems? You know, this is a difficult topic for older adults as well. I sometimes think that young adults actually are much better at this than young adults certainly most of you have you know, seen videos and read books and because of the Internet have been exposed too much more that, for example, than people my age. The important thing is to just say what you mean.

If you hem and haw, your embarrassment will probably transfer to the health care provider that you're talking to. So it's just better to say it, as you think it. Don't worry about using the correct terms. You know healthcare providers often hide their embarrassment by talking in Latin. Like we use all kinds of Latin words and you don't have to do that. So you know something like when my partner touches my breast - genitals if you don't want to say penis or vulva or vagina, you know just say it. You could even say when my partner touches me "down there."

And if you have a healthcare provider who knows what they're doing, they're going to say what do you mean by "down there" and may offer you a diagram, for example, so that you can actually point at something, because we really need to know what "down there" means. I always tell my patients that when they say I'm dry down there or it's painful down there, I tell them that down there is like Australia, so really big place and in order to help you I need to know the difference between Sydney, Melbourne, and Perth. So accuracy is really important.

You know here's another statement, the last time I masturbated, I noticed that - whatever it is - what can be done about this? We will answer truthfully if you talk to us openly. Everybody masturbates. That's the beginning, middle, and end of it.

When I grew up my beloved grandmother told me that if I touched myself down there I would grow hair on the palms of my hand. It is absolutely not true, everybody masturbates. Let's get that out.

Certainly questions about oral sex are important ones, and you know rather ask them live in fear and anxiety. So and the next question which I really want to answer and give you some advice about is you know what precautions need to be taken, for example when you're on chemotherapy.

So the answer is, it depends. But essentially it depends on what the exact chemotherapy agent is. So we know that chemotherapy is broken down into the body into what is called metabolites and we know that the metabolites are present, for example in urine.

Do we know exactly how much of these metabolites are present in semen or vaginal fluid? The short answer is no, we don't. But just using logic, there is likely less in semen than there is in urine, just by volume, and less in vaginal fluids, as compared to semen. It's a question of volume. In order to be accurate about this, we really need to know what the half-life of the particular chemotherapy agent is. And, quite frankly, many of us don't, so we sort of issue a blanket statement. You know, you should have if you're going to have sex, it needs to be protected, and this includes oral sex, it needs to be protected. And that is for 36, 48, 72 hours, a week. It really is a ballpark and not particularly accurate. So if you really want to know, because you don't want to use condoms or dental dams or saran wrap, for oral sex, you need to say what is the half-life, of whatever, Adriamycin? But most healthcare providers would actually look to you and go, "I have no idea", but they can look it up.

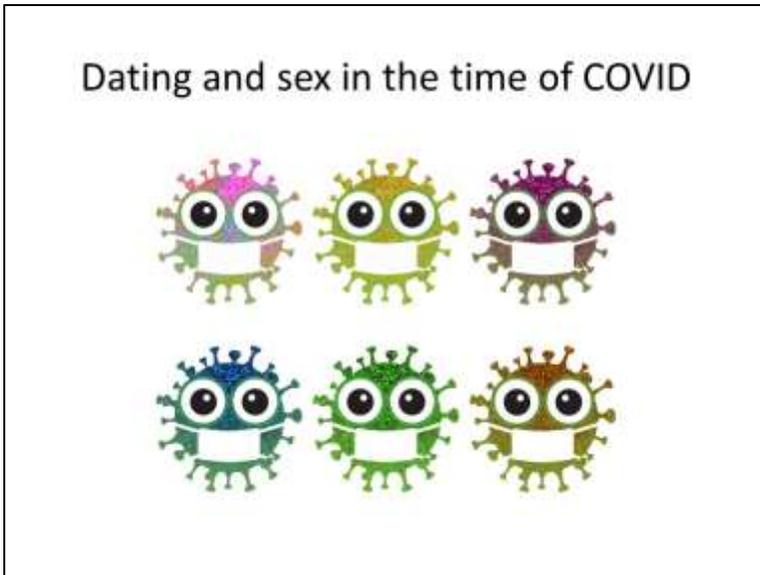
But we do know that, you know, we need to err on the side of caution. We don't want your sexual partner to be exposed to metabolites of these chemotherapy drugs because these drugs are really toxic. And so, you know, just ask if you want the exact number, otherwise you know I think 72 hours pretty much covers it. You know, don't worry about blushing. I sometimes blush and I pretty much heard everything. There really is nothing that you can do about that.

Gay, lesbian, bisexual, transgender,  
questioning YAs



You know, we really don't have a lot of information about sexual minority individuals with cancer, particularly in the young adult group.

The research that exists is mainly about breast cancer in sexual minority women and prostate cancer in sexual minority men. There has not been a lot of research in this area for a whole variety of reasons, none of them good, but that's as it, may be. But I think we are certainly seeing changes in how healthcare institutions, cancer institutions and the people who work in them really approach individuals of different sexual orientation, so I think that the use of gender neutral language is becoming much more common and certainly acceptance of same sex partners is becoming much more common, which is a good thing.



I want to talk a little bit about COVID because it's important because it's not going away anytime soon. And I think that, while there has certainly been some blame put on young adults for the spread of COVID, that actually is quite misplaced. But there certainly are some cautions around dating and sex in the time of COVID.

We know that, today, the majority of couples actually meet on the Internet, which I think provides some protection if you are living with cancer because you have some time to get over that getting to know you stage, gives you some distance of protection, perhaps. If you are disclosing, you know, you don't necessarily run the risk of somebody getting up to go to the restroom and not coming back. But certainly ghosting is an issue, and you know that hurts as much as any other kind of rejection. But certainly, you know, I think that just really being careful taking care about who you meet and what you're doing with them.



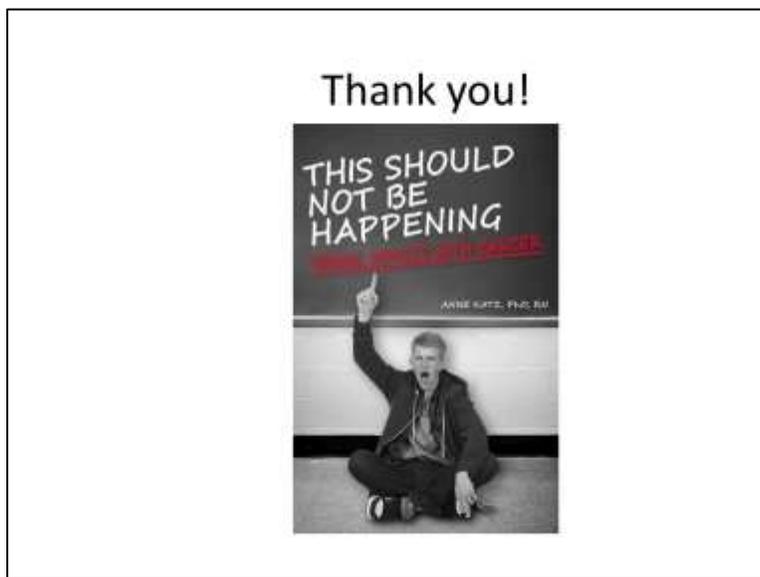
So here's a little cartoon that I actually found yesterday, as I was going over my presentation. You know, so start with a virtual date-get to know somebody. Perhaps don't spill all the beans initially, because maybe that first video chat with someone doesn't go anywhere because there isn't a spark.

Certainly, before you meet anybody, you actually need to ask them, like, are you being careful, what are you doing around precautions, Are you wearing a mask? Are you working at home?, or Are you working in an office with physical distancing? Here in Canada, we talk about physical distancing rather than social distancing because social distancing I think has overtones of isolation, so we prefer physical distancing two meters or six feet, so ask them, you know if you're working in the office or if you're working at a grocery store or you're a barista, what precautions are you taking?

And if you are going to meet somebody in person, really think about if this is a wise thing to do, or not and you know they suggest here that you check local transmission rates. You know, even if they're low, it does not mean that this is necessarily something safe to do.

Indoors is way worse than outdoors, so if you are going to meet somebody in person, think about meeting in a park or go for a walk together. And you know, you really should be separated by six foot. And you should be wearing a mask and boy, that doesn't sound very sexy to me. And then the suggestion is that if you are going to be sexual with them, you both need to be tested to make sure that you are negative COVID-19 negative. However, you got to be careful about this, because one test does not mean that you are protected. You can test negative today, you can be exposed tomorrow and on the weekend, you are able to transmit or a potential partner is as well. So you know I mean, really I would suggest hold off on getting naked with anyone that you don't know really well that you don't have an established relationship with.

Kissing is a frankly dangerous activity in the time of COVID because this is something that is spread with your breath and you know there's no better way to share breath than with kissing. During the summer, the Chief Medical Officer of Health in British Columbia, here in Canada, Dr. Bonnie Henry, issued a statement about sexual activity during the time of COVID. And she suggested the use of glory holes, which caused all kinds of excitement and titters and giggles and outright laughter. You know, I thought that that was a great thing that she actually talked about this. For those of you who don't know what glory hole is, Google it. But you know, she said that you've just got to be really careful about that face to face contact. So that's probably much of what I have to say.



For now, there are some interesting questions which I would be happy to answer. So I'm going to turn it back to Elissa now, who is going to read out some of the questions that I hopefully we'll be able to answer.



**Elissa Baldwin:** Thank you, Dr. Katz for your very informative presentation. It is time for the question and answer portion of our program. We will start with our first commonly asked question: “If I get my partner pregnant during treatment can cancer be transferred to our baby?”

**Dr. Katz:** that's a really great question and you know I think something that that really bothers people. The short answer is no. So, the baby or the fetus in the uterus in the woman's tummy, is protected from all kinds of things in the environment and when cancer is passed from a parent to a child, it's through genetics. It's not through actual transfer of anything to that fetus or baby. So just not to complicate things - no.

**Elissa Baldwin:** The next question is: “I am a gay male and want to date again, but worry about sexual dysfunction. I don't want to be embarrassed what should I do?”

**Dr. Katz:** Another great question. So, you know, I think this applies really to all men. You know, men don't want to be embarrassed. Particularly if they can't have an erection, you know, it tends to be really, really embarrassing. Remember that the brain is the biggest sex organ and if you are anxious about getting an erection or maintaining an erection, the exact opposite happens right, because you get what's what we call performance anxiety. I actually don't like the term “performance anxiety” because I'm not sure sex is a performance, but that's another discussion for another day.

It's important to masturbate frequently so that the tissues of the penis are well-nourished and well-oxygenated. You know, certainly some anxiety is to be expected, and if you find that it's really, really bad, certainly talk either to your oncology team or, even better, to your primary care provider and perhaps one of the oral agents to support erections might be something that that you can use, certainly initially, because it acts as a bit of a safety net. Remember that these pills do not cause an erection, they only help to maintain it, so you still need adequate penile stimulation to have an erection.

Perhaps the way to start there is perhaps with somebody who you've been sexual with before, so that they are understanding and understand what you've been through and that you are anxious or nervous and that will build your confidence, perhaps, if you are then with a new partner.

**Elissa Baldwin:** Our next question: “I'm non-binary and am in a cancer support group. I feel weird talking about sex when it comes up. How should I approach this?”

**Dr. Katz:** Be open and honest, you know. I think that, certainly, you have experience, perhaps, with both men and women, which is a huge advantage. Because you have understanding that perhaps other people in the support group don't have. I think people really today are much more accepting and

understand what being non-binary is. You know, you enjoy people for who they are not necessarily for what their genitals are. And you can really help other people who may be questioning, unsure of where their preferences lie and by speaking openly and honestly you really may provide somebody with the exact support that they need.

**Elissa Baldwin:** And our next question: “I lost my hair and gained a significant amount of weight during treatment. I want to date again but I really fear getting intimate with someone. I also wear a wig. So how do I address that?”

**Dr. Katz:** You know, I think, once again, you know fear can hold you back from all kinds of things. So, once again, be open, you know, “this is not my real hair, this is a wig”. I certainly think that being hairless is much more acceptable today than perhaps it was. We see certainly so many young men today who are shaving their head, because it just kind of looks cool or perhaps they are losing some of their hair.

So I think boldness is much more acceptable. But yeah it's really difficult, you know, not having a positive body image, is it can really hold you back. And that's I think one of the reasons why it's important to really get to know somebody. You know the other thing is that when you are in lust, people tend not to focus so much on physical things. It's almost as if they kind of have blinkers on. So you know being open about it, I lost my hair, I am wearing a wig is important. If you are not confident about how you look because of weight gain, you don't have to be naked.

If you are more comfortable wearing a T shirt or some other item of clothing, just so that you can feel comfortable, then go right ahead and do that. Because if you're uncomfortable, you're really not going to enjoy things and your partner may not either.

**Elissa Baldwin:** Our next question: “Are side effects like dryness and loss of libido normal? Is there anything to help?”

**Dr. Katz:** Those are entirely normal. So loss of libido or loss of sexual desire is not uncommon in both men and women. Women tend to complain about it more, however, and I think just from a hormonal perspective, men tend to have more libido. But libido is also impacted by how you feel about yourself. If you're not feeling well, if you're feeling anxious, it is natural for your desire to decrease. And perhaps even more important for women is that we know that for women our desire is often reactive rather than spontaneous. So what do I mean by that? Spontaneous desire is when you walk around, and you know you think constantly or every now and then about something related to sex. And that kind of thing turns you on. The turning on is arousal.

So spontaneous desire often goes away with how you're feeling, whether you're depressed, how you feel about your body, how you're feeling generally, how you feel about your partner. Right, if your partner doesn't have good hygiene, maybe your desire goes down. But reactive desire happens when women start with what I call kissing and canoodling. So you know, I don't know what young people today, they wouldn't call it heavy petting. But if you, you know get something started, that is often when desire- reactive desire happens for women.

There really are not any effective treatments for that other than understanding why this happens and not having that expectation that you need to be thinking about sex and ready for sex at any moment. In terms of dryness, there are lots of things that you can do. For people with hematologic cancer, certainly, women can use some local estrogen in cream, pill, or ring form. You need to talk to a gynecologist or your oncology care provider about that probably for a referral so vaginal estrogen is

really the only thing that helps with dryness. Everything else is really what I call a band-aid. So for external dryness, some vitamin E oil can be really, really soothing.

For internal dryness, they are a couple of non-hormonal treatments that can be very helpful. One of them is called Gynatrof, which is a gel. There's also something called Repagyn®, which is a suppository that goes into the vagina that contains a powerful moisturizer. And certainly for any kind of sexual activity, and that includes any kind of sexual touch, as well as penetration, if that's what you want, you have to use a good lube and I always recommend a silicone lube.

If you find some KY jelly in your mom's bathroom, do not use it. It's a terrible lubricant. There really are so many decent lubricants now. Go to a sex store, ask them for a silicone lubricant. You can certainly find them in most drugstores now as well.

**Elissa Baldwin:** And our next question: "I am scared of having sex. It hurts and I have no libido. How can I be intimate and feel close to my partner?"

**Dr. Katz:** So you know, just relating this back to my last answer, if something hurts, why would you want to do it? So you need to address the issue of sexual pain. That's really, really important. So when a woman experiences pain with sexual touch or the attempted penetration, the natural response of the body is to tighten all the muscles, including the muscles of the pelvic floor. And so penetration may not even be possible. Pain, you know, the response of the body to pain is protective.

So, you know, do what you can to really alleviate the pain and the issue of no libido is also related to pain. Why would you want to have sex if sex was painful? So you've got to get to the root cause of the problem. So certainly you know, vulva and vaginal moisturizers like that vitamin E oil on the outside, that I talked about, Gynatrof, and Repagyn inside, local estrogen if that's okay and lubricants. And also just take time.

Right, so when I often find is that when pain is involved, women try to hurry things along because they just want to get over it, and they want to get it over and done with. And that, in turn, can cause problems for the male partner's erections. So you've got to take time to be adequately aroused. If you know, looking at some porn helps, do that. Use a vibrator with your partner to really, really get turned on an adequately aroused and then your body produces natural lubricants as well.

**Elissa Baldwin:** And our next question: "I'm a transgender female and I'm attracted to men. Dating before cancer was difficult, and now I have the cancer label with chronic leukemia. I feel like nobody will ever want me now. How do I possibly date again?"

**Dr. Katz:** Just gotta get out there right? You know, I'm hearing a lot of assumptions in this question. I feel that nobody will want me. How do you know that nobody will want you? You still are the same person that you were before. You've just had an experience that not many other people have had, which, in many ways is maturing and makes you stronger. Because look what you have gone through and look what you are living with. So cancer should not define you, and it will, if you allow it to, so you know, get out there.

Start with friendship and see where it goes, but don't let the cancer hold you back. You know, I think people who've had cancer of everybody, know that life is so precious. And what I don't always agree that you got to live life to the fullest because as human beings, I think we're very future oriented.

And it's difficult, especially over a long time to always be in the moment, and live each day. You know, there are lots of platitudes about that. But certainly you know the personal growth and the appreciation for life that comes from having cancer, just makes you a stronger person and more aware of what's important so don't let the cancer hold you back.

**Elissa Baldwin:** Our next question: "I'm just not feeling like myself and not wanting to date anymore. What should I do?"

**Dr. Katz:** You know, listen to your body and listen to your heart. If you're not feeling yourself, what does that mean? Are you depressed? Are you fatigued all the time? Really look for what may be the cause. And sometimes you know going into some counseling can be really helpful because when we live in our heads we don't always get to answer the questions that we should be asking.

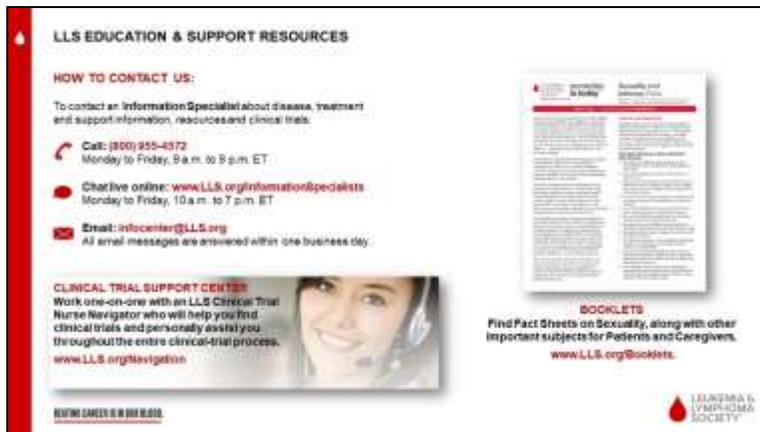
So you know not feeling yourself can be a whole bunch of things that can be poor body image, it could be lack of energy. It may have some physiological basis, in which case you know that needs to be fixed. So you know, think about talking to your primary care provider about this or a counselor and get to the root cause of it and then maybe it will you know you when you start feeling like yourself again dating will become something that you're interested in doing.

**Elissa Baldwin:** And now for our final question of the program: "I met my partner early on in treatment, how do we continue building on the relationship post cancer?"

**Dr. Katz:** Communication, communication, communication. And you know, I think that that often, this is something that people forget. We talk a lot at the start of a relationship. You talk about your hopes, your dreams, your feelings for each other and then often that talk stops and we begin to act like dolphins and whales. We communicate in grunts and squeaks if we communicate at all. You know, things may change. I think it's great that you, you know, met during that time.

But you know, really, you need to keep talking, because you have, in all likelihood, really grown through this experience. And maybe a changed person and I don't mean for the worst. I might mean you know I mean for the better, as well. So keep those lines of communication open. Now one of the things that I do as a sexuality counselor is get couples to talk and they resolve their own problems for the most part. I just help them along by asking questions and essentially making them talk. I don't have anything magic to offer, just encouragement, some probing questions and then I leave the rest to my patients.

**Elissa Baldwin:** A special thanks again to Dr. Anne Katz for sharing her expertise with us and for her continued dedication to cancer patients.



**LLS EDUCATION & SUPPORT RESOURCES**

**HOW TO CONTACT US:**

To contact an **Information Specialist** about disease, treatment and support information, resources and clinical trials:

- Call:** (800) 955-4572  
Monday to Friday, 9 a.m. to 8 p.m. ET
- Chat live online:** [www.LLS.org/informationSpecialists](http://www.LLS.org/informationSpecialists)  
Monday to Friday, 10 a.m. to 7 p.m. ET
- Email:** [infoCenter@LLS.org](mailto:infoCenter@LLS.org)  
All email messages are answered within one business day.

**CLINICAL TRIAL SUPPORT CENTER**  
Work one-on-one with an LLS Clinical Trial Nurse Navigator who will help you find clinical trials and personally assist you throughout the entire clinical-trial process.  
[www.LLS.org/navigatortn](http://www.LLS.org/navigatortn)

**BOOKLETS**  
Find Fact Sheets on Sexuality, along with other important subjects for Patients and Caregivers.  
[www.LLS.org/Booklets](http://www.LLS.org/Booklets)

KEEPING CANCER IN OUR BLOOD



If we were not able to answer your question during this program please contact an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572 from 9am to 9pm Eastern Time or reach us by email at [InfoCenter@LLS.org](mailto:InfoCenter@LLS.org).



**THANK YOU**

Please fill out Program Evaluation at  
[www.LLS.org/SexualityEval](http://www.LLS.org/SexualityEval)



SCAN ME

We have one goal: A world without blood cancers



We also encourage you to please complete the program evaluation, which can be found at [www.LLS.org/SexualityEval](http://www.LLS.org/SexualityEval) or by scanning the QR code on your screen with your smartphone. Completing the evaluation will help us to continue to provide the engaging and informative programming that would benefit you the most.

Dr. Katz, thank you again for volunteering your time with us today. And on behalf of The Leukemia & Lymphoma Society, thank you for watching this program. Please let us know what you need from us during this time. Take good care.