



Panelists:

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Ben S. and Brittney T.

Patient Advocates

Understanding the Medical Side of Young Adults with Bladder Cancer

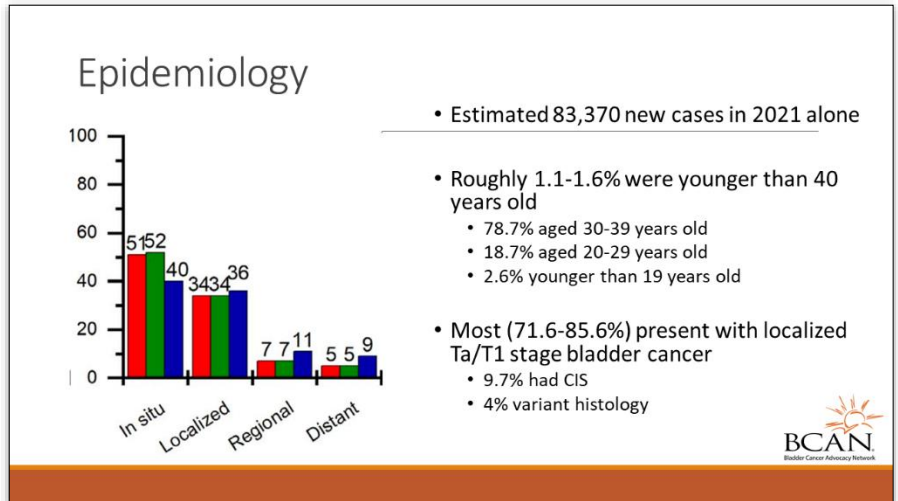
Stephanie Chisolm: So, Dr. Porten and Dr. Washington, have you had experience with a number of patients that are under 40, or is this also a very rare thing that comes through your practices?

Dr. Sima Porten: I would say overall it still is a rare thing, being at a tertiary academic medical center, when young patients are diagnosed we do see them in terms of referrals. So, I would say probably more represented than in other areas, but it does tend to be a more rare diagnosis, particularly when it presents aggressively. And we'll talk a little bit about how maybe some things can present differently. I think some of the experiences that you both shared with many people, it not being at the top of someone's mind when you come in to the ER or see your primary doctor, or see your gynecologist, and so I do hear that story a lot. And that people think it's stones for some of my patients, for men, and I had one who was a very active runner and they kept telling him it was because he was running, it was running induced hematuria. It was not, and so some of the heuristics that we use as physicians to be able to make diagnoses and follow down pathways, I would say age is part of that decision making process.

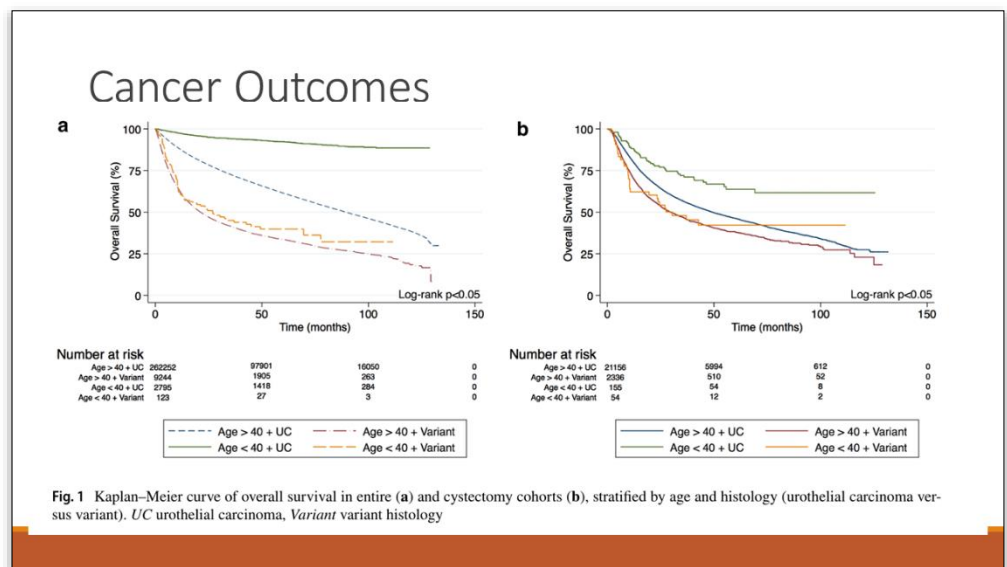
So, just like when women come to the ER with a typical chest pain, it doesn't get thought of, because that's not who you think of as being a person who could have bad coronary disease. I hear very similar stories from some of my patients who are young, and so when I say young I mean under 45 or under 40, is the technical definition for young. That doesn't mean you're not still young at heart when you're 80, but when you're looking at their age that's what we mean by young.

Dr. Sam Washington: Yeah, well I was going to say along the same lines it's uncommon that this happens, so I split my time between Mission Bay where we see a lot of referrals, and then the VA where we see people at the forefront when they have the hematuria workups. So, we see there more often it is young patients who may have seen blood in their urine and it gets discounted because of the same heuristics that we've talked about before, so it's always just us being mindful and cognizant that it can happen, particularly in that setting where we're the first people doing the evaluation.

So, I'll start here just going over the epidemiology of bladder cancer as a whole. Now, we know all comers within the United States, there's going to be an estimated about 83,000 cases in 2021 alone. We know the majority of those are, as we've discussed thus far, older cohort within the population. Prior studies have estimated about one to 2% of patients will present with bladder cancer while being under the age of 40, and within that group the majority of them are within the 30 to 39 year old age range with decreasing proportions as you get younger. We see there are a very small subset of patients who even present with it under the age of 19, we see that of those young patients who present with bladder cancer, the majority of them present with TA or T1, so low stage or non-muscle invasive disease. Though we still see a proportion of those having variant histology, so non-urothelial carcinoma. In other words, a non-common form of bladder cancer that we see in greater proportions in the older age groups as well.



Dr. Sam Washington: We're going to the next slide. Now, we know outcomes overall, here we stratify groups looking on the left side those that underwent cystectomy, and then on the other side those stratified by age and as well as histology. So, urothelial carcinoma, the more common type versus variant histology. And we see that within the cystectomy group on the left side, we see breakdowns, obviously, those who are less than 40, this green line at the very top, have the best outcomes up to 115 months, or about 125 months after cystectomy. And we see that those with variant histology, we see a different overall survival profile



compared to those with urothelial carcinoma, but we also see differences by age. If we were to go over to the graph on the right side, we again see a similar pattern where both age and variant histology are seemingly impacting survival outcomes.

Now, the big question is, from a population perspective, is this a different disease or a different approach, or different monster we have to deal with? Yes, but from a treatment perspective we treat all of these very similarly. Thankfully we know enough that we have protocols in place and understand the steps that we should do, would be the same regardless, and that's

because they rely on the principles of grade, stage, risk, and then discussions of treatment intensity as well as preservation of quality of life. These are the core domains when it comes to treatment decisions. Sorry, you may hear a contractor in the background. The key differences here, particularly in a younger cohort is, we have to consider whether or not this is the result of a hereditary or heritable disease, the impact on fertility and sexuality, particularly in patients who are at that part of their life course where they're thinking about family planning. And they may not have the financial support that they would have 30 years from now, a long life of career and savings and wealth building.

Dr. Sam Washington: And that leads directly into the financial toxicity, so the impact on work and family. Not that it's better or worse, but it's at a different place in a person's time course, and life course, so the financial toxicity that a retiree is facing may be different than someone who's in, say, their 30s and starting to build their career and their family.

Is it different?


From a population perspective: yes

From a treatment perspective: we approach similarly

- principles of grade, stage, risk, treatment intensity and preservation of quality of life are at the core of treatment decisions

Key Differences:

- Considerations for hereditary disease
- Impact on fertility (and sexuality)
- Financial Toxicity (Work and Family – not that is better or worse, just different as it is a different time in life)



Dr. Sima Porten: So, I'm going to take over for a little bit here. And so I wanted to pause and talk about, we'll go over the key differences, like Dr. Washington said, that we really use the same principles in terms of treatment we just might have some different considerations and different thought

processes. So, exposures predominate in terms of risk of bladder cancer, but there is some evidence to suggest inheritable causes. So where does this come from? This comes from very large European population studies, they are much better than we are at being able to track people and collect long, long-term outcomes, as well as a lot of the twin studies. And so, what they find from both

these types of research is that there's sometimes greater odds if you have a first degree relative with bladder cancer of you developing bladder cancer, and when they create like estimates of heritability you can attribute about 30% of bladder cancer that happens due to heritable cause.

One of the more well known syndromes with urothelial cancer is called Lynch syndrome. And so this is where there is a alteration in what we call our DNA mismatch repair genes. And so, those are the kind of housekeeping genes in ourselves that say that, "Oh wow, that DNA strand is not okay, we need to go there and fix it." If there is something wrong with those housekeeper genes, particularly if it is in your germline, and so that is your DNA not the cancer DNA but your DNA itself, that you are at a higher risk of getting many different cancers. So, for Lynch syndrome it's actually the most heritable cause of colon cancer and endometrial cancer.

In terms of urothelial cancer, it's more related to upper tract urothelial cancer not so much bladder cancer itself, however as we're studying this more and more, paying more attention to taking family histories, and investigating tumors both from the tumor from the genetic perspective but also sequencing people's germline from their blood or from the saliva. We're starting to see a little more of a relationship of Lynch syndrome to lower tract disease.

Hereditary syndromes

Exposures predominate but some evidence to suggest inheritable causes

- Twin studies/European population studies → approximately 2x odds if first degree relative, estimated 30% "heritability"

Lynch Syndrome

- Germline variants DNA mismatch repair genes (*MLH1*, *MSH2*, *MSH6*, *PMS2*)
- Colon cancer, endometrial cancer, upper tract UC



Dr. Sima Porten: Next slide. There have been some recent studies, particularly from Memorial Sloan Kettering, that germline alterations are actually seen in 10 to 22% of patients with bladder cancer regardless of family history. And so, this is when you take all comers of patients who are presenting with bladder cancer, and these patients tend to have more advanced disease in a lot of these studies. If you actually sequence their DNA mutations such as BRCA2, which is really common in prostate cancer, ovarian cancer and breast cancer, as well as ATM which is another DNA damage response gene pop up is really common germline alterations. And so, where does that put us now? Well, it puts us in the conversation of talking about, when should you refer for genetic counseling for patients with bladder cancer? And there is more of a interest in push in terms of using age as a criteria, so 45 or younger, family history, advanced disease, so stage three or four disease, family history, and this is key we're seeing this all across, even in prostate cancer about the importance of family history. So, taking a detailed family history so that you can actually figure out if someone is at increased risk, and send for genetic counseling.

And the more important thing is that, should we just recommend genetic counseling for all patients with bladder cancer? And I would say I don't know if we're there yet, because there's definitely an impact on financial and emotional health. So, how will you look at things like getting life insurance down the road, can you? What does this mean when you find out you have this alteration in your DNA, what does it mean for your family, for your siblings, for your parents, for your kids, for your other relatives? And so, although I'm a big proponent of referring for genetic counseling, I think that we definitely have to be mindful of it and use the data we have to figure out who would benefit the most. I think it definitely is a really good conversation to have with patients.

Hereditary syndromes

Recent studies have suggested that germline alterations are seen in 10-22% of patients with bladder cancer regardless of family history

- BRCA 2
- ATM

Consider referral to genetic counseling for patients with bladder cancer

- Younger age (45 or younger)
- Advanced disease
- Family history
- Impact on financial and emotional health



Dr. Sima Porten: So, dovetailing into sexuality and then fertility, so what's really interesting is when you look at studies of either survivors of childhood cancer or survivors of young adults who have been diagnosed and treated for cancer, you see that sexual dysfunction is present in greater than 50% of men and women treated for any of these pelvic malignancies. What's even more interesting is that in 33% of people who are treated for things like head

and neck malignancy, lymphomas, leukemias, sarcomas in other areas of the body, there's still a pretty high prevalence of sexual dysfunction. And there's many many reasons this can happen. What they found is that it's the greatest impact in those that are sexually active, and that happens to be associated with a younger age. So, it's not saying that if you're older that this is not important to you, but they have seen associations that have to do with age and time in someone's life when they are diagnosed with cancer. The distress from the impact of a cancer diagnosis, as well as the treatment and what that really means for someone's sexuality, also provides a really big impact on how someone views sexuality and with sexual dysfunction. So, there's not only the physical aspects of that but the emotional and mental aspects of it.

In terms of bladder cancer, what are some of the practical considerations? So, I've had a lot of my younger patients actually point out, and we've fixed our instructions for BCG, "Well, so what do I do about sex?" And so, "Is my partner going to catch the BCG that I have in my bladder? How do I protect myself, and also my partner, and what does this mean for me?" So, we've actually changed and revamped our instructions, and it's basically that you do have to protect yourself for about a week after having BCG installation because the bacteria does live in the urethra and around the introitus, so that's the urethra vaginal area for women for about a week. And so, you can't have sexual intercourse but you have to protect yourself. I didn't even realize that was missing from our instructions until a younger patient who's in her 30s pointed it out.

Dr. Sima Porten: The loss of desire is something that definitely should be acknowledged and addressed, I don't think that as physicians we pay that much attention to, somebody may just have a lack of desire for this because of all of the things going on, and they feel uncomfortable, acknowledging that lack of desire, and they feel bad about it. So, I have a lot of patients who feel really bad about this part of their life, having a change in that. And so sometimes just a conversation acknowledgement is enough to address this. For men specifically, erectile dysfunction (ED) is much of the time surgically induced. So, it's damage to nerves at the time of bladder removal surgery or even from radiation damage, and for women it seems to be a little more multifactorial. So, it can be damaged at the time of surgery from removal of the ovaries, from removal of the uterus, from damage to the nerves that are on the sides of the vagina, and that leads to a lot of dryness and pain, honestly. But it also can be from a loss of hormonal regulation.

Sexuality

Sexual dysfunction is present in >50% of men and women treated for pelvic malignancies

Greatest impact is in those that are sexually active (associated with younger age)

Distress from impact of cancer diagnosis and treatment is greater in younger patients

- Practical consideration (BCG)
- Loss of desire

Men: ED (surgically induced- damage to nerves)

Women: loss of hormonal regulation (ovarian damage from chemotherapy or surgery) which leads to vaginal dryness/pain



Dr. Sima Porten: So, when we give treatments like chemotherapy, immunotherapy, those types of things, particularly with chemotherapy, that you can have ovarian damage and then an imbalance in hormonal regulation. And that can also cause some of the same symptoms, lack of desire, dryness and pain, just because a lot of the hormones that your body naturally makes that support sexuality and desire are gone. Next slide.

So, when I look at this there's not that much in terms for younger patients specifically with bladder cancer, a lot of the data and things that we find and draw from come from other malignancies and survivors of childhood malignancies. But I think we need to have a greater emphasis on this overall, and I think it's really important to assess at baseline and talk to patients about what potential impact that this diagnosis can have from both the physical treatment and emotional perspective. Again, a multidisciplinary approach is the most effective if you have a team that you could send, you could talk to patients about and send for counseling for hormonal support for some patients, that's a really useful thing but I think awareness, education and resources are key in this area. And I wanted to pause a little bit, and if Brittney and Ben feel comfortable talking about this, what their thoughts were when they were diagnosed as it relates to this domain in their life, and their experiences were.

Brittney: Yeah, actually I'm comfortable with it. So, I didn't really think about it much at the time of diagnosis, there was too much going on, I was like, "Just taper bladder out, whatever makes me feel better." And when I went to my first follow up visit after surgery my doctor, he's fantastic, my surgeon is fantastic but he's also a guy and you could tell he felt uncomfortable, and he just said, "There's a little less space now." That's verbatim, he said, "There's a little less space now." And I didn't know what that meant until later when I had healed, and me and my husband wanted to be intimate and I realized I truly had a physical change down there. Just, where my tumor had invaded and everything that comes with connective tissue removing, my cervix, my uterus, my bladder. I truly physically was smaller. We were able to leave my ovaries, but just with everything that's happened down there, there some nerve damage, there's dryness, and I had to make this a concern for my medical team. No one was going to just out and ask me, "Hey, how's your sex life going?"

I had to come to my oncologist and say, "Hey, I am finding difficulty with this, what can I do?" And she gave me a variety of options from over the counter things I can try to procedures down the road if things still become a problem, that's really been the greatest thing that I've been working through over the year since my surgery. I was lucky and unlucky in the sense, I never had a desire for a family so the fertility part wasn't a concern at the time, but signing that paperwork that, "We're going to take everything out, that you will not be able to have your own biological children." When that choice is taken from you, even if you didn't want kids, that hurt so much. So, it is, it's something my medical team had never asked about how I felt about all of this and what I was going through, I had to make it a priority for them because it was a priority for me.

Stephanie Chisolm: That's really unfortunate that it was on you as the patient, but everyone is tapping themselves in the back saying, "Oh, we saved your life." And then the patient says, "But you took away some of the best parts." And that's a real challenge and unfortunately I think that probably many of the people that are on this call, and others, are experiencing that at any age, because as doctors you just are concerned with the problem and life expectancy. And sometimes it's on the back burner, these quality of life issues as well. Ben, did you want to add anything?

Ben: Yeah. Obviously, it was not to the point that Brittney had, also being a different sex. It was traumatic, when they actually removed the tumor. And the catheter, I don't think anyone likes a catheter, but especially myself, and waking up with a catheter the size of a fire hose was not, it was very traumatic for that area down there. And for the month, or month and a half or so, every time you have to urinate or anything it's... I used to bring in a mouth guard and just bite down on it, because there was pain there afterwards, it was a sensitive area and constant scopes going up there for a good amount of time. Yeah, there was a mental aspect to it, "Do I even want to do this? I'm afraid it's going to hurt, I'm afraid I'm going to... Anything sort of dysfunction or..." There's definitely that fear of it. Luckily it went away after a while, but sexuality was a big part of it because it's a sensitive area and there was a lot of trauma to it.

Stephanie Chisolm: So, Ben, did your doctor's talk to you about that at all or did you have to bring it up, or did you just not bring it up and you just coped on your own?

Ben: They said it would take some time. I mean, luckily it was, like I said, in the beginning it was just a tad bit muscle invasive. So, I mean, they got it really early, so there was no other procedures except getting the tumor out. So, they said it would take some time for the pain to go away, and with urinating and then sexual activity the pain just went away to the point where just you coped with it yourself.

Dr. Sima Porten: Thanks for both of you for sharing, I know it's not always the most comfortable subject to talk about, but it's one that's really important. And so, it took me a while even as an attending physician to be comfortable with talking about that, and now it's part of the list that we go down and we said, "Okay, now it's time to talk about sexuality." And if somebody's parent or kid or someone's on the line with them on these zoom meetings, and things like that, I usually preface it, "Hey, we're going to start talking about this, if you want to send anyone out of the room, or the Zoom Room or that, let me know." And so, it's taken a while for me to get comfortable with those conversations too as a physician.

So, moving to fertility, I think Brittney touched a little bit upon this too, is that treatments to bladder cancer can damage fertility by damaging the testis, ovaries, fallopian tubes, and uterus. And primarily this can happen with

chemotherapy and then also from surgery, and also from radiation depending upon if that's included in the treatment plan for your bladder cancer. Some good news is that when you look at large studies of children born to parents who were treated for cancer before conception, they have been largely reassuring. Even if somebody had chemotherapy and had their testes in place and didn't bank beforehand,


children conceived after that treatment seemed to do okay, which is wonderful because I have a lot of

Fertility

Treatments related to Bladder cancer can damage fertility (by damaging testes, ovaries, fallopian tubes, or uterus)

- Pelvic surgery
- Chemotherapy
- Radiation

Large studies of children born to parents who were treated for cancer (childhood survivors or young adults) before conception have largely been reassuring



patients who do ask me about that and I think sometimes we forget to address that fear or worry as well. Can you go to the next slide?

Stephanie Chisolm: Let me just ask a quick question. So, as physicians, if you have a young patient for whom the fertility issue was a big concern, would you be suggesting the fertility preservation by having sperm frozen or having Eggs frozen? Is that something that you would automatically suggest?

Dr. Sima Porten: Yes, and mainly from a urologist perspective many of those are, I would say for men who are looking at sperm banking, that those processes tend to be in place and can be activated rather quickly, although it is at a cost to the patient themselves, from experience with taking care of our patients with testicular cancer. And so, we do have a path forward quickly to sperm bank and to do the tests needed, and we can usually execute that within less than two weeks. I would say one of the bigger barriers is cost, there are some low cost options and some resources that are a little bit regionally specific but, I would say, for my patients who are men who had bladder cancer, and we're talking about needing fertility preservation ASAP. That is the pathway we go down as I utilize the pathway I've set up for the patients I take care of who have testicular cancer.

Doing egg retrieval is a little bit more difficult. It can be done, there's a contemporary technique to stimulate ovaries at any time in the cycle that can be accomplished in approximately two weeks, but sometimes that's even too much, depending upon the amount of bleeding and pain and symptoms of patient's having. And so, it is also probably four to five times that of sperm banking with egg retrieval and even less covered by insurance, and so this is a pretty big financial gap for patients who are young adults facing pretty intense treatment and potential loss of fertility.

About 50% of men sperm bank, but only 10 to 20 use it least. Only about 12% of females who are, this is all cancers, end up doing egg retrieval with only one to 2% using it later. So, we do have some resources here and it'll be also in the recording on different fertility toolkits, what to talk to your healthcare team about this, and also some information and resources about navigating dating, intimacy and sexuality, particularly when you're a young adult. And so, those resources are here and will be available also after it. Can go to the next slide, Stephanie? And so, I'm going to have Sam take over here to talk a little bit about financial toxicity and some considerations and resources.

Dr. Sam Washington: I think this is a good segue, because also in terms of fertility some of these costs are recurring, so it's not just a one time upfront fee but just this persistent need to pay to sustain, or to store your specimens, sperm or eggs long-term. And it becomes this aspect of financial toxicity that's not commonly measured or discussed, we noticed that overall about a quarter of patients endorse paying more for cancer care than they could afford. And we see that for

Financial Toxicity

Overall, 24% of patients endorsed paying more for cancer care than they could afford

- Bladder cancer remains most expensive cancer due to long surveillance and survival

Given life stage at diagnosis, young adults at great risk of negative effects of cancer treatment (ie financial toxicity) such as:

- Interrupted work and income loss, accumulated debt, avoidance of medical care, social isolation

Additional considerations

- Insurance status, family planning/obligations, ability to take time off from work, ability to afford general expenses

many patients with bladder cancer, due to the long time of surveillance, the intensity of surveillance and their overall survival, it becomes one of the most expensive cancers out there, particularly within our GU space. And, again, going back to this idea of this stage of life where you're placed within your life course, these young patients who have longevity, who have decades left in their life, are at much greater risk of the negative effects of treatment in terms of financial impact or cost.

Dr. Sam Washington: Now, a lot of studies have looked at costs in terms of monetary value and impact from insurance for the patient out of pocket, but there are also these indirect or unmeasured factors that fold into financial toxicity, like interrupted work and income loss, accumulated debt over time, avoidance of medical care due to anticipation of costs, and then social isolation that can come from just a lack of income, or a larger financial burden that impacts other aspects of your life. So, when we talk to these patients, oftentimes I think a lot of it stops adjusting insurance status, the type of insurance whether they have it or not, but this also impacts family planning, familial obligations. The ability to take time off of work is one of the subtle things that we all understand, and it's all part of the calculus but is rarely measured or discussed long-term, when we think of counseling patients about treatment for cancers. And then just broadly the ability to pay for general expenses, how cancer treatment and the incurred costs impact your ability to pay for anything else that you need during treatment.

So, here are three sites that go over financial resources, the Sam Fund, no relation or association with me, are grants for younger cancer survivors and education about financial wellness. There's also hope for young adults with cancer, these are, again, grants that are provided to help people for up to five years after diagnosis, as well as copay assistance and treatment related costs through cancercare.net, and those will be available on the website as well.

Financial Resources

The Sam Fund: Grants for cancer survivors ages 21-39, Financial Wellness and Education


- [Thesamfund.org](http://thesamfund.org)

Hope for Young Adults with Cancer: Provides grants for AYA from screening up through 5 years after diagnosis

- <http://www.hope4yawc.org/>

CancerCare.net: Co-pay assistance and treatment related costs.

- https://www.cancerCare.org/financial_assistance



- [Thesamfund.org](http://thesamfund.org)
- [Hope for Young Adults with Cancer](http://www.hope4yawc.org/)
- [Cancer Care](https://www.cancerCare.org/financial_assistance)

Dr. Sam Washington:

And then working after a cancer diagnosis. So, a lot of these things we talked a little bit about the ability to take time off of work, how occupation may impact financial toxicity, but there also need to be resources for people who are looking for a new job, managing a job after a diagnosis, anticipating what to inform your employer about, in terms of medical follow up after a procedure, after clinic appointments, after getting intravesical therapy. And then how to manage work plus cancer care, either looking for a job or holding on to the job that you have right now. So, here are a few other resources for that as well. [Cancer and Careers](#)


Working After A Cancer Diagnosis

Cancer and Careers: Resources for Workers and Managers, Resume Tips, Managing Work and Treatment

- www.cancerandcareers.org

Cancer.net Going To Work During and After Cancer: Helpful tips for continuing and returning to work after cancer, and looking for a job.

- <https://www.cancer.net/navigating-cancer-care/young-adults-and-teenagers/school-and-work-during-cancer/going-work-during-and-after-cancer>



And then lastly, I just want to point out mental health, this is another area that is, I would say, sometimes underappreciated as we focus on the tumor and less on the patient, which I think is the opposite way in which we should be doing things. But mental health becomes another aspect of care that is sometimes overshadowed by our need to follow the protocol and treatment, but coping with this is incredibly important, and all the other factors that we talked about impact mental health. So, here are two other resources as well from cancer care, and then stupid cancer, that provide resources, financial assistance, education as well, for mental health. [CancerCare: Counseling, Etc...](#), <http://www.stupidcancer.org>

Other Support Resources and Considerations


Mental Health and coping with this diagnosis is important!

CancerCare: Counseling, Case Management, Limited Financial Assistance, Information on Handling Issues Unique to Young Adults

- https://www.cancercares.org/adolescents_and_young_adults

Stupid Cancer: Support Community for Adolescent Young Adult (AYA) Cancer Community, Financial Resource List, AYA Webinars

- www.stupidcancer.org



Stephanie Chisolm: Can I just interrupt for one second, because this is really good information. And now, Brittney and Ben, you were both in relationships when you were diagnosed. And so dating was not an issue for you, but obviously talking to your friends to your families, your co-workers about having bladder cancer, how was that for you? What was that experience like, and do you have any tips for anybody who's listening to this webinar?

Brittney: So, I was out of work for six months, thankfully my company had a program where they put a call out where people were able to donate leave time for me to be out. When I came back it was interesting, I just had a set the tone as far as coworkers and managers, of, "Hey, I have this, and because

of my staging it's not going to go away, so I have regular appointments." My job is, I'm getting back into it solely now but before I went out I cover my entire state so I travel a lot, and with an ostomy there's a little bit of restriction there. If I'm by myself in the car I have things that help me get through it, but I'm not carpooling with anyone anywhere if it's going to be over an hour away. And just getting them to understand, "With an ostomy I need bathroom breaks, I have to say in the corner of a boardroom, I have..." There's no, "Brittney, can you hold it?" Mostly it's been getting people through the idea of my ostomy honestly more than my cancer, and it was the same thing with my friends and family.

Brittney: I think they're just now getting used to, I'm still the same Britney I just have a little bit of extra attached to me now. I was really lucky that everyone rallied around me, and a big part of that was, again, I set the tone for everyone. I was the one who told people when I had cancer, it wasn't my mom posting a Facebook post, my husband, it was me. And I was very adamant in my Facebook post, I was, "Look, I have cancer and you're not going to show up at my hospital room crying. Don't send me flowers." I set the tone, and I think that's what's made it easier starting to live with this like a chronic illness, and how people approach me, talk to me, support me, because I was the one to set that tone. I know not everyone has that opportunity in their cancer journey, things happen quickly, slowly, you don't really necessarily think ahead to take control like that, but I think [inaudible 00:43:42] taking control with my friends and family and taking control when I went back to work. That just made everything, "It's all good, she's back. She has some extra equipment but she's okay."

Stephanie Chisolm: Thanks for sharing that. Ben, did you have anything to add?

Ben: Yeah. Initially, people, friends, family, I don't think they knew what to expect. I think people, when they hear cancer they have a stigma of just the bald heads, which I already have, but just very frail. I mean, cancer has many different stories to it, there are people that get chemotherapy, there are people that take a pill, there are people that have all different types of things. So, that was a little... People didn't know what to expect. Normally I'm a pretty shy person, I was open with this full fledged because it was something that I never wanted anyone to go through, ever. Especially at my age, I mean, no age matters but I wanted to get the word out about this, that it could happen to anyone. From what they told me this the symptoms, not the symptoms, the causes for this cancer were, if you're a smoker, if you work around chemicals.

I work in a cubicle and I've never had a cigarette in my life, so I wanted to be open with it. For mentality I thought it was important because if you're open about it, you're talking about it, people might throw in interjection of a thought about it, where you're not bottling everything up. So, I thought that was very important on my part, and getting involved with BCAN or the hospital that does my procedures every year, with their cancer runs, and everything. I thought it was very important to just be open about it and to discuss it.

Dr. Sam Washington Yes, please. Great. This is a good segue into prevention of recurrence. Now, we're always trying to find ways to decrease the risk of recurrence, obviously, decrease the burden of all this testing and surveillance. There's no silver bullet yet, unfortunately, we know that as was mentioned before, smoking cessation is key, we see that smoking accounts for about 47% of all cases. Other exposures are more obvious, arsenic contamination, industrial chemicals, long term catheter use, are things that we think of or were taught as we go through our urology training. There's also additional resources of prior webinars, specifically on diet and exercise. A lot of these general recommendations

about dietary changes to more healthy lifestyle, maintaining exercise weight, strength training, impact the whole body in all patients, but also benefit those who are dealing with the diagnosis and treatment for cancer, including bladder cancer.

The key principles here are that physical activity overall has been shown across the board to improve quality of life,

as well as impact in a positive way other outcomes, in terms of recurrence, death for all stages of bladder cancer. This is something that we've seen in this pattern in prostate cancer and other diseases as well. Maintaining a healthy BMI, or body mass index, it goes along with physical activity, management and prevention of type 2 diabetes, which can impact not just when we think of just blood sugar levels but the cardiovascular impact, and impact to all the other tissues and parts of the body as well.

Dr. Sam Washington For non-muscle invasive disease lactobacillus supplementation may reduce recurrence. And it's a low cost intervention, in that standpoint. Again, going back to healthy diets, good foods like broccoli, avoiding fried foods, charred red meat, would be also things to work into the diet or low hanging fruit in terms of dietary changes that one couldn't make. I counsel patients, no matter what type of cancer I see them for, that there's no silver bullet supplement [inaudible 00:48:13] that you can get that's going to decrease recurrence. And I think for a lot of people that's almost reassuring because it's, again, when we go back to financial toxicity, not another cost that they need to anticipate, but just general overall lifestyle changes can help.

Dr. Sam Washington:

Surveillance is the key to timely detection of recurrence, but we're still working on what's the best method for prevention. So oftentimes when I see patients I let them know that, "We are going to check in, this is just going to be your urology blood pressure check. You're going to

Prevention of Recurrence

Risk reduction via lifestyle changes

- Smoking cessation → Smoking accounts for 47% of all cases
- Exposures: arsenic contamination in water, industrial chemicals, long-term urinary catheter use
- Previous BCAN Webinar on diet/exercise (Jill Hamilton-Reeves)

Key Principles:

- Physical activity: many studies showing improvement in quality of life and other relevant outcomes (recurrence/death) for all stages of bladder cancer
- Healthy BMI (body mass index)
- Type 2 diabetes prevention and treatment
- For Non muscle invasive disease: Lactobacillus casei probiotic supplementation may reduce recurrence
- Good Foods! (like broccoli, avoiding fried foods and red meat)
- No strong data re: individual supplements



Surveillance

Surveillance is key to timely detection of recurrence but no clear method of prevention

Duration of follow-up post-treatment – no one knows!

- Based on population data in older individuals
- NCCN guidelines suggest annually or as clinically indicated after 10 years



come in and see the urologist, we're going to check and make sure everything's okay." The key is that if there is a recurrence we identify it early and intervene early. Now, the duration of follow up, even if you look at our guidelines, the evidence and the recommendations get a little sparse the farther out you go from initial diagnosis and treatment. So, honestly, when we look at our national cancer guidelines, really they suggest annually or clinically indicated after 10 years.

Dr. Sam Washington: Now, if someone's diagnosed at the age of 30 or 40, the next 20 or 30 years we don't have a clear idea of what we should do for those patients, and that's why it's phrased that way. And a lot of that is, again, driven on a larger population of older patients for whom expected lifespan would be shorter. So, unfortunately we don't know yet, but we've got to figure it out.

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