



Lifestyle and Mental and Emotional Health

So there are a number of lifestyle changes that you will find. But what I think is helpful that patients have told me is that they experienced fear of cancer recurrence, they might be anxious or depressed. There are oftentimes patients feel that they are discontent with the appearance of their body. They also don't like that, at least at the beginning, there is limited mobility, and they don't feel that they can retire more frequently, they cannot walk as fast anymore.

Lifestyle Factors- Patients

- Patient and caregivers may face numerous lifestyle changes as they transition to life after bladder cancer treatment.
- In addition to physical effects of surgery, patients may experience
 - Fear of cancer recurrence
 - Anxiety or depression
 - Discontent with the appearance of their body
 - Limited mobility

A small photograph of a woman from behind, looking into a mirror. She has her hair in a bun and is wearing a light-colored top. The mirror is ornate and white.

The logo for the Feinstein Institute for Medical Research at Northwell Health, featuring a colorful geometric design.

Dr. Diefenbach: And maybe they're worried that people will notice that their body has changed, and that people might detect that they're wearing something. These are all valid concerns. And the best way of doing this is that, they're dealing with them and talking with other people about it. And during those initial weeks caregivers are really, really important.

And the caregivers are a great help to the patients. They take lots of new responsibilities, and they also might face have their own challenges to deal with. So most commonly what caregivers are doing is that they're managing their loved ones medications, they're driving them to doctor's appointments, they organized a urinary diversion supplies, they deal with insurance companies, which can be a rabbit hole that you might find in there. And they are the eyes and ears of the medical team. Medical Doctors, the health care providers really rely on oftentimes rely on the reports of the caregivers. And the caregivers also report or document the symptoms are changes in how the patients are doing. And they're doing all of these things while they're dealing with their own responsibilities. They might have families, they might have jobs. So we will talk about this a little bit later.

So initially, when you go through major surgery, you might lose some weight. You feel that you had don't have enough appetite, you might experience some changes in taste and whether you feel whether you're eating enough. Things might not really work as well for you anymore as they were before. But what is really important is that you

have a healthy, well-balanced diet that will help. So that means that right from the hospital when you're being discharged, you start out with some soft foods and liquids. And as we said, water is very important. And the patient might feel much better when you eat smaller meals and more frequently, rather than three large ones. So if you're used to have a large breakfast, lunch, and dinner, so then maybe you will feel better if you have smaller and more frequent kinds of meals.

Lifestyle Factors- Caregivers



- Caregivers taken on many new responsibilities face many challenges.
- Caregivers' tasks include:
 - Managing their loved one's medications, doctor appointments, and urinary diversion supplies.
 - They are the eyes and ears of the medical team,
 - Report symptoms or changes in coping or physical care.
- While doing all of this, they are dealing with their own responsibilities in their life and at home.



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Diet

- Patients may experience weight loss, decreased appetite and changes in taste and satiety. A healthy, well-balanced diet will help with healing.
- Discharged from the hospital:
 - start with soft foods and liquids.
 - patients often feel better eating five to six smaller meals rather than three large ones.
- Digestive issues are often common:
 - bloating,
 - constipation,
 - diarrhea
 - and nausea



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Dr. Diefenbach: There

are a number of digestive issues that are common. So there's bloating, there could be constipation, there's diarrhea, and there could be nausea. So some of this could be the after-effects from right after surgery. And those will change and you will recover after that's over after some time. But there are also foods that you might want to avoid. And those foods are, limit spicy and greasy food. And high fiber foods, they prevent

bloating. Limit liquids during mealtime, as they can stretch your stomach and make you feel full, and then you don't eat enough, because you need to have enough protein and calories to maintain your weight. But again, there is this risk of dehydration and urinary tract infections. So again, drink plenty of water. Don't drink sugary drinks. But tea, for example, is very nice. And preferably tea that is decaffeinated or herbal tea, mint tea, camomile, and things like that. They really help with diarrhea, constipation, and some of those issues that we've talked about before.

A big issue that patients often ask is bathing and hygiene. So you will receive instructions when you come out from the hospital what you will do with all of those tubes and drains and incisions. And most of the time you will need help with bathing and showering. What you can do in preparation, for example, is if you don't have it already install a shower bar, install a shower bar either in the shower, or when you get into the bathtub try to find a chair or a stool made out of

wood that can get wet but doesn't rust that you can place into the shower. Showers are recommended anyways because it's very hard to get into bathtub in and out. And you shouldn't take a bath or so for at least the first month. So even though it can be very comforting to soak in a bath, it's not good for you at that time. So showers are fine. And this shower bar is really helpful for if you're showering.

Diet

- Eating sufficient protein and calories can help maintain weight.
 - Limiting spicy, greasy, and high-fiber foods prevents bloating.
 - Limit liquids during mealtimes as they can stretch the stomach and make you feel full.
- BUT: As patients recover, they are at an increased risk of dehydration, urinary tract infections and other complications.
 - Drink plenty of water,
 - avoid drinks with sugar,
 - Sip on warm beverages prevents diarrhea, constipation, gas and discomfort, and decreases odors.

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Bathing & Hygiene

- Upon discharge from the hospital, you will receive instructions on
 - how to protect incisions, tubes and drains (if any). Oftentimes, this means covering the affected area.
- Bathing and hygiene can be very challenging for patients
- Patients should not take a bath, swim, or use a hot tub until their wounds have completely healed and their doctor says it's fine- at least for 30 days after surgery.
- Install a shower bar,
 - A chair or stool might be helpful.
 - Sitting or holding onto something will help if patients get tired or lightheaded while showering.

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Dr. Diefenbach: If you have a pouching system, you can shower just as you have. There are some types of bags, and you will figure this all out, they are covered with some fabric because it's nicer to have them on the skin. They might absorb small amounts of water, that's not a problem. But you can also cover them with some saran wrap or something like that. And then once you're done with that, you should just change your bag, and then you're totally done for the day. You can shower if you have an Indiana pouch, you can shower after all of the drains are removed. But again, don't soak until the incision is healed and you can cover up your stoma with some covering, and then you can just take a shower just as you usually do.

Getting dressed. Well, it's as I said, a lot of people feel self-conscious about one's appearance. And body image problems are quite common. Well, we can accommodate this by just wearing more loose fitting clothes are made out of a breathable fabric. At the beginning I would avoid wearing belts or tight clothing. And after you're fully healed, dress whatever is comfortable. Some of the tips that our patients have given us is that dark colors may conceal better than lighter colors. Patterns will draw attention away from solid cultures, especially from some bulges that you might have when you have a bag hanging on the side. You know wear loose t-shirts or comfortable pants. You can wear light jackets or sweatshirts, pleated trousers also help for men, same for women. So again, you will be able to figure this out. And you can make these changes fairly easily, I would say. And some experimenting will be necessary.

So sleeping is another issue that a lot of patients talk about and are worried about. And especially when you come home at the beginning, it's can be quite uncomfortable. After 14 days in the hospital, you had a hospital bed, or 10 days you had a hospital bed that was adjustable and all of these things, and now you come home and you are happy that you're home, when you're sleeping in your own bed. But then you don't feel quite as comfortable all of a sudden anymore. Because you still deal with soreness. You

Bathing & Hygiene

- Patients with pouching systems can shower just as they always have.
- Some types of bags, particularly those with fabric coverings, absorb small amounts of water. This isn't a problem, but it does mean the bag might take longer to dry after a shower. Patients should get in the habit of changing their bag once fully dry after showering.
- For those with an Indiana pouch, they can shower when all the drains are removed, but they shouldn't soak in a bath or hot tub until the incision is healed.



Getting Dressed

- Feeling self-conscious about one's appearance and body-image is common..
- Dress comfortably by wearing loose-fitting clothing with breathable fabric
- Avoid wearing belts or tight clothing.
- After being fully healed, dress whatever is comfortable
- Dark colors may conceal better than lighter colors and patterns will draw attention away from any bulges.
- Wear loose T-shirts, high-waisted pants, light jackets or loose sweatshirts, and pleated trousers. These will help cover up the area and make the bag less noticeable if it starts to fill up.



have these tubes and drains coming out. So there's a lot of things that might interfere with sleeping. So lots of pillows help. You can even place a pillow over your stomach to feel comfortable. You might also use a heating pad, especially in the winter. Heating helps a little bit with pain. And that might make you feel more comfortable.

If you have urostomy bag, empty it right before you go to sleep. And there are even some night pouch systems that have longer tubes, and that there are bigger bags. And you place the bag on the floor next to your bed. (A helpful tip from patients, you can set your night bag on an upside down trashcan). And the tubes are long enough that they don't this large when you're sleeping. If you have an Indiana pouch, you might still have to empty it every three to four hours. So that can lead to disrupted sleep, especially at the beginning. Once it has its regular size and you can go for six hours or so, your sleep quality might improve. And with the neobladder, it's the same thing, every three to four hours. And again, those plasticized rubberized sheets are really, really helpful here.

Pain management. I know that a lot of patients are really worried about pain. That you are in pain after bladder cancer surgery is very, very common. That doesn't help you when you're in pain. But there is pain medication. So you don't need to suffer from pain. But then there is also the worry that if you use opioids, and they are much more restricted now in case taking them out, is that

Sleeping

- Sleeping can be quite uncomfortable and challenging, especially in the first days at home after surgery.
- A sore stomach and tubes, drains or bags might interfere with sleeping.
- This might help with sleeping:
 - Prop yourself up on pillows,
 - Place a pillow over their stomach to get comfortable
 - Use a heating pad set on low and place it over the stomach



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Sleeping

- Patients with a urostomy bag:
 - Empty the bag right before going to sleep.
 - The Night Pouch System has a bigger bag and longer tubes and makes it easier to move around.
- In the weeks after surgery, patients with an Indiana pouch may need to empty it every 3 to 4 hours.
- Patients with a neobladder:
 - Try to urinate before going to sleep.
 - Some leakage, especially at night, is normal during the first few weeks.
 - Use plastic or rubberized sheets



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Pain Management

- Pain after bladder cancer surgery and during recovery is common
 - Opioids may be prescribed to help with pain relief
 - When used as instructed & under guidance of medical team, opioids are helpful way to treat cancer-related pain
- Effective pain management requires more than a prescription
 - You should be monitoring your pain and your feelings
 - Keep medical team advised of changes
 - Keep a diary about pain
- If you are worried about addiction, you should talk to your doctor. Especially, if you-
 - Find yourself wanting to take medicine because it changes how you feel
 - Feel you are losing control over usage
 - Want to continue taking the medicine even when pain is completely gone



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people have some worries about getting addicted from them. So just use them when it is really, really, really uncomfortable. Monitor your pain and your feelings. Communicate them with your caregiver, communicate them with your medical team. Also write down in a diary, write down on a scale from zero to 10, with 10 being the worst pain imaginable, write down what your pain is. And it's very helpful for you to also notice that your pain will become less over over time. If you're worried about addiction to painkillers, definitely talk to your doctor, and especially talk to them if you feel like you want to take the medicine because it makes you feel better, or when you feel like you're or when your caregiver thinks that you're losing control over usage. And when you want to take the medicine even weeks after when the pain should be should be gone. So here again, the caregiver has a very important job to do to monitor your medication intake as a patient.

Dr. Diefenbach: I hope it's common knowledge that you shouldn't drink alcohol when you're on opioids or that you shouldn't combine opioids with sleeping pills. Anti-depressants or anti-histamines, they can really mess you up. And that's not a good thing. Also if you've been on opiates for quite some time, talk to your doctor how to slowly get you off it. Just stopping it from one time to and another is also not very good. So the common example is that once you're at home so try to facilitate your well being and your physical, your mental and your physical well being, try to stay active, try to exercise, even if it is really really hard and even if it is uncomfortable at the beginning, I urge everybody to start to walk as soon as possible. Start out slow. There is no rush. Nobody expects that you run a marathon. But try to be active. And once you're fully recovered, you will be able to do most almost any of those physical activities that you have been used to. And you will feel better. You will experience increased energy. It will prevent infection. You will be stronger. And overall, you will recover faster. Start with some slow walks, maybe with your caregiver or with a neighbor or a friend.


And what is also fun is, write it down and say, "Today I walked to the mailbox back and forth, and tomorrow I walk to the mailbox twice," or something like that. So that is really helpful and documents your process and your recovery. You shouldn't lift anything. I mean so you're happy to see your grandchild and the grandchild wants to jump up on you. That's not such a good idea right now. Just wait a little bit, and you will feel when you get better pretty soon. But that also means shopping bags and things like that,

Pain Management


- You should not take opioids while drinking alcohol or taking medicines that make you sleepy, such as:
 - Sleeping pills
 - Antidepressants
 - Antihistamines
- This can lead to overdose and side effects, including weakness, trouble breathing, confusion or anxiety.
- You should not suddenly stop taking opioid medication
 - Your body adjusts to these medications and will need time to adjust to their absence
 - Doctors will prescribe a schedule to slowly wind down the use of pain medicine

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Recreation & Exercise



- As life begins to return to normal, patients can start to engage in activities and exercise
 - Exercise enhances mood and rebuilds strength
 - You should take it slow at first, but after you've fully recovered, you should be able to resume almost any type of physical activity
- Daily activities has many benefits, such as:
 - Increasing energy
 - Preventing infections
 - Speeding up recovery process
- Start with slow walks and slowly make them longer as you heal

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it's not the best idea to really engage in that. And if you are a swimmer, you will be able to swim again. Even though you have a bag or you can wear as a female, it's might be a little bit easier to conceal it, if you have a one piece bathing suit. But men also can we have one of those t shirts, those swimming t shirts, and that should be fine.


Swimming will not harm the stoma, and they are waterproof stoma covering is available that will keep everything inside,

nothing goes outside that shouldn't go outside and nothing comes in that shouldn't come in. So I think that works pretty well. And if you are not a swimmer, then you might do something else. Not everybody has the opportunity to swim, but swimming is a great exercise.

Recreation & Exercise

- Because patients just had abdominal surgery, it's much easier to get hernias
 - In the early days after surgery, do not lift anything heavier than 5-10 pounds
- Overtime patients will be able to start swimming again
 - Patients with urostomy bag or Indiana pouch may be nervous about their stoma or leakage
 - Swimming will not harm the stoma
 - Waterproof stoma covering will keep mucus from getting in water and keep stoma covering dry & secure







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A lot of patients are worried about traveling. And what can you... And especially in this day and age with air travel and then you have to wait to enter security checks and things like that. There are a card so let us about your medical condition available so that you don't have problems with your, that you can tell them at the security check. Create a checklist of what you need while you are away.

Travel

- Patients who are travelling after fully recovered:
 - Create a checklist of what's needed while away
 - Pack at least twice the amount of supplies
 - Organize and pack all medications in carry-on bag
 - Bring a card/letter about medical condition
- Air Travel:
 - Check with airline to identify items not allowed
 - Reserve seat ahead of time
 - Travel communication card- details medical condition and can help ease communication at checkpoints
 - Restroom communication card- helps with getting access to restroom right away





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Always pack at least twice the amount of supplies. If you are traveling within the United States, it's much much easier to get the supplies that you needed, you can even send them to your destination where via UPS or FedEx. If you travel transatlantic, that might be a little bit more difficult. Not that you can't get the same supplies if you need it, but they might not necessarily fit or they might not have necessarily the stuff that you really are comfortable using. So it's much better to bring everything that you know that you will need and put it in a carry on. And check with the airline to see what you can bring and what you cannot bring.

Here are a couple of tips that again we have collected from patients who have done this many times successfully. If you are on the road and you plan a road trip. And many people prefer road trips because they feel like then they can take rests, they can use the bathroom much more frequently. And since they have more luggage, that might be easier for them to do. So one of the things that people are doing is


that they pack an emergency kit of supplies, which is much easy to learn, they also pack extra home... One of our patients says he always has an extra travel bag that he has in his car. He doesn't even take it out. And this travel bag contains what he needs medically. So he has one of everything to change, he also has a change of clothes, and he has a changed of underwear and things like that, and it just stays in the car. And that's then you don't even need to worry about it. And I think that was really such a wonderful idea. You might also consider for your bag, because it's more comfortable to use it if you're using a leg bag rather than a bag that is closer to your abdomen, because that might interfere with your seatbelt, and you want to be safe, of course.


Dr. Diefenbach: So let's talk a little bit about emotional health. I talked about it a little bit earlier. But for a lot of people it takes a while to adjust to this new normal. Life as you've known it is, it's different. And you might get frustrated, you might get sad, depressed about the things that you're now experiencing. And you might be frustrated, for example, that you don't recover as fast as you think that you might do. Or you might be very worried about

that the cancer might bite come back. So there is a lot going on. And as I said before, when there is a lot going on, the best thing to do is to communicate it, talk to your family, talk to your medical team. If you don't want to talk to your family, maybe you have a friend who you can talk to and that's fine, too. There is no one person who is... What I wanted to say is, regardless of who that person is, you will

Travel

- Road Trips:
 - Rest seat belt across hip bone and pelvis
 - Pack emergency kit of supplies
 - Avoid extreme temperatures when storing medication in car (can decrease longevity)
 - Consider using a leg bag







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Emotional Health

- After completing bladder cancer treatment and during recovery, patients experience many life changes and transitions.
- This might be a difficult time for patients as they are dealing with physical changes, challenges and emotions
- Coping might be challenging
 - Bodies are different and they may now even see themselves differently
 - May experience anxiety, fear of recurrence, anger, sadness, frustration or insecurity
- Be honest about how you are feeling
- Talk with family, medical team, friends,





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probably have one person who you might be able to talk to, and that person and talking about it is really helpful.

There are a number of coping strategies that our patients have been using. One of it is patience. I'm not a very patient person. I'm always getting frustrated if things are taking too long. But remind yourself that recovery takes time. And I find it particularly difficult when you're sort of in those middle stages of recovery, where you're saying, "I feel much, much better right now," and then all of a sudden, you're not. And then

that's when you get frustrated or sad about it. So be patient. Join a support group, I think BCAN that you here shows that you're interested in. And there are support groups around. Ask your hospital, ask your medical provider, the social workers there. This really helps. I also suggest that people are talking to other people right at the beginning, before something, before they have problems to anticipate the problems.

I mean, you're listening to me right now. I'm talking about these different kinds of things. I don't know some people might be newly diagnosed, others might be pros in it. But whatever it is, it is important to get as much information and to have the opportunity to exchange. As for help when needed, try something new if you want. And again keep active just as we said before. Eating well and get plenty of rest. We talked about that, too. And just take breaks which is again, it's a normal thing to do. You just had major, major surgery. So it will take time.

Intimacy is another issue that is coming up. Your partner might have different kinds of feelings right now about being together. And one of the things and it's actually on my next slide, but I want to tell you right now, is that you don't have to have sex to feel intimate. It is, again, open and honest communication, is key. And if you're interested in having sex, that's great. If your

Emotional Health


- Coping strategies:
 - Be patient and remind yourself that recovery takes time
 - Join a support group
 - Ask for help when needed
 - Try a new hobby
 - Keep active
 - Eat well and get plenty of rest
 - Take breaks






Intimacy

- After surgery, you may have different feelings about intimacy and relationships. Partners may also have different feelings and feel cautious about intimate contact.
 - Open and honest communication is key
- You should talk to your doctor about when it's safe to have sex
 - Usually 6 to 8 weeks after surgery
- Feeling anxious and self-conscious about changes to body is common
 - Talk to partner about physical limitations, pain, fears, expectations and emotions





partner's interested in having sex, that's wonderful too. And it takes usually two weeks or so after surgery to do this. And feeling anxious and self conscious about changes in your body is, especially if you can cover it up, it certainly is quite common. Talk to your partner about your physical limitations, talk about what you expect, your pain and so on. Talk

about your emotions, and that will create feelings of intimacy. You can cover things up while you're having sex, for example, of course, try to empty your bag beforehand. And if you want to, again, connect with others as to a care team, your doctors and your nurses, to social workers who have lots of experiences and they have heard everything. So there is nothing new to them. And keep an open mind to know what you feel is what you would like to need or what you'd like to receive and what you'd like to give. There are many, many different ways that you can feel intimate with your partner.

Dr. Diefenbach: Dating is another issue that can be quite difficult. If you're single, you may be afraid of rejection because of your history of cancer, there is the questions when do you introduce this to somebody who you've just met. Some people might just take this, take the dating out of the equation. Totally. I think it's a process. There is no right or wrong way. But again, talking to others who have been in this situation might be very, very helpful to see what their experiences were. And if you're single, you can build a network of close friends, casual friends and family. There might be more effort from your side too, by calling friends and planning visits. There are hobbies that you might be able to engage in, there are church communities. There are other groups or classes that you might take to meet others. So there are a number of things. You are not a pariah. And you are not any different than anybody else who is single.

Dr. Diefenbach: Let's talk a little bit about finances. Because cancer is very expensive, and it might bring unexpected costs. There are co-payments, there are medications, there's supplies, for example, that seem to be very expensive. You have to talk to, and this is really really painful, you have to talk to

Intimacy

- You don't need to have sex to feel intimate!
- Certain accessories, such as wraps and bands, small pouches or caps, and pouch covers can help make sex more comfortable
- Empty bag, pouch, or neobladder before engaging in sexual activities
- Bring up intimacy/sexual concerns to doctors or nurses
 - Whether concerns are physical, emotional or psychological, healthcare professionals can offer solutions or advice
- Keep an open mind about ways to feel sexual pleasure
 - Lubricants, pelvic floor exercises, and pelvic physical therapy or rehabilitation can help relax muscles and manage pain during sex



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Advice For Those Who Are Dating

- Patients who are single may be afraid of rejection because of history of cancer or the changes it has brought into their life.
- Some single people with cancer limit themselves by not even trying to date.
- Meeting new people or starting to date is a learning process.
 - Practicing how to approach the subject and asking friends for feedback may help
- Single people can also avoid feeling alone by:
 - Building a network of close friends, casual friends, and family
 - Calling friends and planning visits
 - Getting involved in hobbies, special interest groups or classes



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insurance to ask, what is allowed and what your deductibles are. Try to be as much as an informed consumer as you can. Be organized about it. Either keep a folder or an Excel spreadsheet to keep track of the things that are necessary, from co-payments to authorizations to contact information, all of these kinds of things. Your caregiver can help you too with these kinds of things.

And the good thing is that many manufacturers who are providing supplies are letting you use or provide samples for free, which you can then try out a number of times and then stick with the one that is most comfortable for you.

Finances



- Cancer is expensive and may bring about unexpected costs
 - Treatment, medications and medical appointments
 - Travel, childcare, elderly care or other specialized needs
- To avoid unexpected costs and bills, and manage expenses:
 - Check with insurance providers and ask how to get supplies and medications
 - Start a folder that keeps track of insurance information, including co-payments, required authorizations and contact information
- Finding which supplies and products work best may take some time. Most manufacturers let you sample their products for free, which will allow you to explore the many different products available



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