



## Treating Bladder Cancer Bladder Removal Surgery

Part 2: managing the psycho-social impact of radical cystectomy

With Michael Diefenbach, PhD, from Northwell Health

### For Caregivers

So, let's talk a little bit about caregivers and what their roles are. We've talked a little bit about that. But there is this really important bond between the patient and the caregivers. The caregivers take on new responsibilities and routines. They might all of a sudden, be in a role of support that they're not used to. They might experience anxiety, fear, depression, and the same range of emotions that the patient feels, they might feel very overwhelmed by all of these things,

especially if they have a family also to take care of. So the good thing is to figure these things out beforehand, before surgery. Planning is great. Planning is your friend, and try to set up a schedule. And you might have not only one caregiver, or you might need not only one caregiver, but you might actually need more people who rotate, and help you help the patients through this time. Again, a plan is a great thing.

So organization here. Your caregivers keep track of the medications, the appointments, the daily care and supply needs. And it's very easy to get lost in all of this, and get overwhelmed. And here are some of the things that we have heard from caregivers, successful caregivers are things that they have done before. Also from a caregiver perspective, what it helps, sometimes it helps to be less... There are

#### Caregivers: After Surgery

- Caregivers are greatly affected by their loved one's surgery
  - Take on new responsibilities and routines
  - Face many emotions
  - Overwhelmed
- In the first few days after returning home from surgery, caregivers may need to make significant changes to their home to accommodate the patient's new needs
  - Patients may be confined to the first floor and need an adjustable bed to be comfortable
- Changes may impact other family members and can change the family dynamic
  - Families may need to figure out new schedules to coordinate follow-up appointments and care for the patient



people who are these take charge people who are trying to take control of the situation, and this might not go too well with the patient, especially if they're also have a strong personality. So there might be some conflict in the making. So, there needs to be some negotiations. And this can be done by also giving some tasks to the patients as well.

Managing medication, there is medication list. There are a lot of places where you can download these kinds of templates. You all have seen these pill organizers, those are great. So this is something that you can ask your care team also to help you with to figure out and to reconcile the medication that you have. That is actually something that is quite important. After bladder cancer and after surgery, if you're on medications beforehand, you will be on medications afterwards, and there will be a lot more of it. So talking to your physician or talking to a pharmacist to reconcile those medications, is really, really important. Once a medication is no longer needed, it's important that you just safely dispose of it. Don't flush it down the toilet. You can return it to your pharmacy or in your doctor's office.

## Caregivers: Getting Organized

- Caregivers are learning to accommodate to new life changes and tasks
  - Managing medications, appointments, daily care and supplies
- With these new responsibilities, it's easy to get lost in all of the details and keep track of everything.
- Caregivers can stay organized by:
  - Making a list of the tasks they need to do and people who can help out
  - Giving little tasks to the patient
  - Taking notes during appointments
  - Keeping a running list of questions to ask the medical team
  - Keeping all important documents in one place
  - Asking questions and asking for help



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## Caregivers: Managing Medications

- People with cancer often take many medications for symptoms and managing them can be complicated.
- A medication schedule is key to successful adherence. To help caregivers keep track of all medications:
  - Medication List Worksheet
  - Pill organizer with different slots for morning, noon, evening and bedtime
- When a medication is no longer needed, it's important to safely dispose of it. Many pharmacy chains and law enforcement stations have disposal boxes for unused medicines.



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### Medication List

Use this page to keep track of all the medications your loved one is taking. Be sure to list prescriptions, as well as over-the-counter medicines, vitamins, and other supplements.

Some caregivers post a chart or spreadsheet on the refrigerator or bulletin board so it is easy to find when someone else comes to help. It is also helpful to bring this list to each doctor's appointment so you can update it with any changes.

Prescriptions are filled at:

Name of medication	Dose	What it looks like	Prescribing doctor	When to take	Other directions
Brand name:					
Generic name:					
Brand name:					
Generic name:					
Brand name:					
Generic name:					
Brand name:					



**Dr. Diefenbach:** There is really... I mean we all have to be aware, as a caregiver, of our limitations that we feel. As I said, it can be quite overwhelming. The caregivers might as much experience sadness and anger or loneliness, that the patient feels. They might feel guilty for the things that they can't do or that they might miss out. They can't take care of other things. So it's really, it can be a stressful time. And one of the most important things, and I've stressed this a number of times is that, talking openly about one's feelings and talking with other friends or family, is really important. And if necessary, also seek help. And you need a break. So as a caregiver, if you feel that you are really distressed, then signs of that is that you feel exhausted, rundown, or irritated, that you don't sleep well, that you do not enjoy the things that you used to enjoy, that you don't even want to talk to us or to your friends so that you withdraw from them. And again, address these things before your own health suffers. The caregiver might need also a caregiver, and things that help the patient also help you. Exercise, eating right, taking breaks, talk to others, joining caregiver support group.

And you can do things. These conversations can really be quite nice for you too, so that you can... If you open up, you will see that your patient might open up as well. And you can do fun things like playing cards. And the more support that the caregiver has, the better the outcomes are for the caregiver as well as for the patients. There are programs that allow you to take off from

## Caregivers: Emotional Awareness

- Stressful time for caregivers as they are not only caring for their loved one but also for themselves and their families.
- Anxiety and depression are common.
  - May have other duties that go beyond taking care of the patient
  - Experience sadness, anger, loneliness, guilt and fear
  - May feel guilty when they do things for themselves or feel guilty for the fact that they are healthy and their loved one is not
  - Afraid of doing something wrong, worried that the cancer will come back, or anxious about finances
- Caregivers should remember that taking care of themselves is just as important as taking care of their loved one.
  - Recognize and openly talk about feelings
  - Talk with friends, family, or the medical team
  - Seek help when needed



## Caregivers: Coping Skills

- Caregivers may suffer from stress.
  - Exhausted, run down, irritated and impatient
  - Restless sleep
  - Do not enjoy the things they used to
  - Withdraw from friends and family
- Address issues before feeling overwhelmed and putting own health at risk
- Principles and activities:
  - Exercise can boost mood and energy
  - Eat right and get enough sleep
  - Take breaks
  - Do not do too much and ask others for help
  - Keep a journal
  - Talk to a professional
  - Join a support group



## Caregivers: Talking About Cancer

- Talking about your loved one's cancer, how it's affecting your lives and how others can help is not easy.
- Conversations with friends and family can create a sense of support and togetherness and make everyone's life a bit easier.
- Helpful tips:
  - Listen to your loved one and be encouraging
  - Laugh and talk about other things to distract the patient
  - Do activities with the patient, such as card games or walks



work. There is the Family and Medical Leave Act that entitles you up to 12 weeks of unpaid time off, if you can afford it. And I have listed some of those requirements there. So the employer or your employer must have at least 50 employees there. You must have worked 12 months at this place, and you must have worked for about 1250 hours. But you can talk to your HR department to figure these things out.

And here is the list of some additional resources that I've put together for you. Of course this BCAN, there is the American Cancer Society, Urology Care Foundation, there's the Cancer Support Community, the National Cancer Institute, United Ostomy of America Association. And for caregivers, Help For Cancer Caregivers, My Cancer Circle, American Cancer Society Caregivers Resource Guide, and the Family Caregiver Alliance. I want to thank you for your attention. I will be

available to answer some of your questions. If you want to contact me, you can reach me at MDiefenbach@Northwell.edu. We have a current study going on that tests out the crisp platform that is for newly diagnosed and newly treated patients. And if you're interested in contributing to evaluating this program, then please contact me at this email. And thank you again.

## Caregivers: Time Off From Work

- In the weeks immediately following surgery, being a caregiver can be a full-time job.
- Caregivers are not only juggling their own work and responsibilities at home, but also the demands of caring for their loved one.
- If your employer qualifies for the Family and Medical Leave Act, you are entitled to up to 12 weeks of unpaid time off each year to care for seriously ill family members. Your employer can ask for proof of your relationship with the person and for proof of the illness.
- To be eligible, caregivers must meet these requirements:
  - They work for an eligible employer at a location with at least 50 employees
  - They have worked a minimum of 12 months for the employer
  - They have worked at least 1,250 hours in the past year, or about 25 hours a week



## Additional Resources

- Some resources that may help support patients include:
  - Bladder Cancer Advocacy Network
  - Urology Care Foundation
  - American Cancer Society
  - National Cancer Institute
  - The Cancer Support Community
  - United Ostomy of America Association
- Some resources that may help caregivers include:
  - Help for Cancer Caregivers
  - My Cancer Circle
  - American Cancer Society's Caregiver Resource Guide
  - The Family Caregiver Alliance



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