INSTRUCTIONS FOR PATIENTS WITH NEOBLADDERS

Once your catheter has been removed you will start to notice leakage of urine (incontinence). This is normal after your surgery and proper urinary function/control will develop by performing two separate activities. You must now learn how to train your bladder to regain control over urination. This is because your new bladder does not have the same feelings of fullness or the automatic control of your original bladder. You may experience some incontinence (involuntary flow of urine) for up to a year after your surgery.

1. Kegel (pelvic floor) exercises:
The first activity in retraining your bladder is to strengthen the muscles at your bladder outlet. These are exercises you can easily perform called Kegel exercises. When performed correctly, these exercises help to strengthen the pelvic floor muscles. This improves support for the neobladder. With regular exercise, you can build strength and endurance to help regain, improve and maintain bladder and bowel control.

- How to find and recognize the muscles:
  Imagine you need to stop the normal flow of urine or hold back gas. Squeeze and lift the rectal area (for women this includes the vaginal area) without tightening your buttocks or abdomen.
  Keep your thighs, buttocks, abdomen, and any other muscles relaxed as you do the squeezing.
  At first, check yourself frequently by placing your hands on your abdomen and buttocks to ensure that you do not feel your belly, thighs or buttocks move. Continue to experiment until you have found the correct muscles of the pelvic floor.

- Squeeze for 5 seconds then relax for 5 seconds
- Perform a set of 10 squeezes/relaxations
- Do 3-4 sets a day
- These can be performed sitting down, lying down or standing

2. Developing the new urinating action:
The second activity is to retrain your bladder to begin to urinate at times you desire. Your new bladder has an entirely different nerve supply than your original bladder so you will need to train yourself to empty it.

- At first you will need to urinate at short intervals. You can gradually increase the time between urinating by following the schedule below. This allows your new bladder to gradually hold larger and larger volumes of urine. You will be urinating “by the clock” as you progress to remind yourself of the need to urinate according to the schedule.

<table>
<thead>
<tr>
<th></th>
<th>DAY TIME</th>
<th>NIGHT TIME</th>
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<tbody>
<tr>
<td>WEEK 1</td>
<td>Every 1-1 ½ hours</td>
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<td>WEEK 2</td>
<td>Every 1-1 ½ hours</td>
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<td>WEEK 3</td>
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<td>WEEK 5</td>
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<td>WEEK 6</td>
<td>Every 2-2 ½ hours</td>
<td>Every 3 hours</td>
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- At night you will need to set an alarm to keep your toileting schedule

- Sitting down to urinate and pressing gently on your abdomen may help you pass urine easier. At first it is going to feel like a trap-door opening. Relax, bear down and let it flow.

- If you feel like you have not emptied your new bladder completely, stand up and sit down again. Try emptying again. This is called “double voiding”

- Early on, while you are leaking more significantly, you may not produce a good flow of urine.

- As your sphincter gets stronger you will be able to retain more urine and will notice a better flow when performing the urinating action.

- When you notice that you are developing a flow gradually start increasing the time between visits to the bathroom.

- Your goal is to be able to hold your urine during the day for 3 hours with good control. You may continue to have small amounts of leakage when coughing, sneezing, laughing or getting up from sitting or lying.

- Never go more than 4 hours during the day, between bathroom visits

3. **Moving forward to normal function:**

- Wear incontinent pads if needed (eg. Liners, pads, pull-ups)

- Use barrier creams(skin protection products) as needed if the skin in your perineum/groin becomes irritated and sore

- You will have leakage at night in the beginning because while sleeping your muscles relax

- Put a protective pad or mattress cover on your bed to protect your linen and mattress

- Monitor your fluid intake and watch how it affects your urination

- Limit fluids before going to bed at night. This will help decrease the amount of urine leakage you may experience

- After approximately a year after your surgery you will need to get up 1-2 times per night and otherwise should be dry with little to no urine leakage

**Be patient**

Think of your neobladder in the same way you would think of your bladder. Regardless of your schedule, empty your neobladder before such activities as going out, travelling, having sex, playing sports etc. This could save you both time and aggravation by avoiding the need to empty when it is less convenient.

Early on, this schedule may seem intimidating but following these instructions will be rewarding as the vast majority of patients achieve excellent long-term bladder control.