**QUESTIONS I WISH I’D ASKED BEFORE MY MITROFANOFF SURGERY**

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| **QUESTION** | **REPLY/COMMENTS** |
| How long is the wait-list? (How long before I can get my surgery?) |  |
| What are the main complications with this surgery? |  |
| How likely is it that I will have to have this surgery re-done at some time in the future? |  |
| What is the revision rate? |  |
| If the surgery doesn’t work, what are my options? |  |
| Will I have to do bowel prep? |  |
| If so, what does this entail and when do I start? |  |
| How big will my scar be? |  |
| What pain medication will be available when I wake-up? |  |
| Can I have a PCA? |  |
| Will I have to go into ICU/HDU after surgery? |  |
| If so, how long on average, are people there? |  |
| How long will I be in hospital for? |  |
| What tubes will I have in when I wake-up? |  |
| Will I have to have an NJ tube? |  |
| How long before I can eat? |  |
| How long before I can drink? |  |
| How long is the recovery for this surgery? |  |
| Will I need blood thinning medication? |  |
| If so, will I continue to need these when I get home? |  |
| Who can do the blood thinning injections for me? Can you teach my caregiver to administer them? |  |
| How long will the SPC be in for? |  |
| What are bladder spasm and am I likely to get them after surgery? |  |
| If so, what can I take to stop them/ease the pain? |  |
| What happens if my SPC comes out when I’m at home? |  |
| How long will the Mitrofanoff catheter be in for? |  |
| What happens if my Mitrofanoff catheter comes out when I’m at home? |  |
| When do my stitches come out? |  |
| What happens if my stitches come out before my appointment? |  |
| How long before I can resume intimate relations with my partner? |  |
| How long before I can drive? |  |
| How long before I can go back to work/school/university? |  |
| How long before I can play sports/go to the gym again? |  |
| What happens if I change my mind?  If I decide I don’t want this surgery, what other options have I got? |  |
| How often will I have to come back for follow-up appointments in the future? |  |
| Who do I contact if I have any other questions before my surgery? |  |

**QUESTIONS/THOUGHTS IF YOU ARE IN A WHEELCHAIR**

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| **QUESTION** | **REPLY/COMMENT** |
| Where will my Mitrofanoff stoma be? I want to be able to reach it easily when I’m sitting in my wheelchair. |  |
| Should I get a different sling for my hoist? Mine has a band that crosses over my abdomen and I’m worried it might hurt after my surgery? | Speak to your OT as soon as you can to discuss your fears and concerns. It might be you need to use a bucket style sling which won’t do up across your abdomen, for a few weeks after your surgery.  If you are advised you need the hospital to do an assessment – speak to them ASAP after you arrive. It can take several days to arrange and then several days to order and receive any new equipment so plan ahead for these types of delays.  If you have a caregiver and change the style of sling you plan to use, check that you don’t need an additional (if you currently use one) caregiver to safely use a new sling. |
| How long will it be before I can safely do transfers? I’m worried that I might fall, or it might hurt or pull on the catheters or cause bleeding. |  |
| How easy is it to catheterise from a wheelchair? Are there any special catheters I can try? | You can insert a catheter from a seated position and either have the liquid empty straight into the toilet or into a jug/urine collection container or other suitable container. Then simply empty into the toilet.  There are many different catheters including ones which have their own urine collection bag attached meaning you can empty your bladder almost anywhere – the car, any room in your home, aeroplane, doctor’s office, hospital etc. All without needing to find a toilet. Speak to your healthcare professionals and/or ask your home delivery service for samples. |

**QUESTIONS I WISHED I’D KNOWN THE ANSWERS TO, ONCE I’D HAD MY MITROFANOFF SURGERY**

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| **QUESTION** | **REPLY/COMMENT** |
| How long will my suprapubic (SPC) catheter be in? |  |
| What happens if my SPC comes out when I’m at home/work etc.? |  |
| How long will my Mitrofanoff catheter be in? |  |
| What happens if my Mitrofanoff catheter comes out when I’m at home/work etc.? |  |
| How long will the stitches around my surgery wound be in?  Are they dissolvable or will I need to come back in to have them removed? |  |
| What happens if the stitches holding my Mitrofanoff catheter in place come out before my follow-up appointment? |  |
| What should I do if my scar or any of my catheter sites starts to bleed? |  |
| What should I do if I get a discharge from any of my wounds or the catheter sites? |  |
| Will I have to do a bladder wash/flush? |  |
| How will I get more supplies of day bags, night bags and the things I need for bladder washes etc.? |  |
| How long do I have to continue the blood thinning injections for? (not everyone will need these). |  |
| What if I can’t do the injections myself? |  |
| What happens (once I’m using my Mitrofanoff) if I can’t get a catheter in? |  |
| There’s blood in my urine what do I do? |  |
| My urine is cloudy and smells what do I do? |  |
| I’m feeling unwell and feverish, does this mean I’ve got a bladder infection? |  |
| What do I do at night time? Do I have to wake up every few hours to empty my bladder using my Mitrofanoff catheters? |  |
| Where do I dispose of my used catheters, can I dispose of them in the household waste? |  |
| It really hurts when I try to get my catheter in, there seems to be some resistance, what do I do? |  |
| Do I have to do a dip test with test papers every day to see if I’ve got an infection? |  |
| Who do I contact if I have any questions after I am discharged? |  |