

Tamsin's patient perspective leaflet – information for patients

This booklet has been provided to give you some information about gender reassignment surgery from a patient's personal perspective. Please note that not every patient's experience is the same and the timings of some aspects of your stay may differ from those detailed here.

Tamsin's patient perspective

As a brief introduction, I had my GRS at Charing Cross in January 2004. This guide will explain your stay and also give some 'Top Tips' to help you through the process.

Things to do before you come into hospital

Sort out home things such as someone to look after the cat/dog/budgie/goldfish, leave your keys with someone so that they can check up on your home, ask your neighbours to keep an eye out for burglary/fire/flood/acts-of-god(dess).

Make sure you have plenty of books and magazines to read while you are in hospital (and also for when you are recovering at home). Also, stock up on videos/DVDs to watch.

Arrange for someone to do your shopping for you, or sign up for Internet shopping/home delivery with a supermarket.

Things to buy to use at home after your operation

Lots of aqueous lubricant for dilation.

Lots of tissues (for cleaning up after dilation).

Wet Ones' or baby wipes (for use as above)

Disinfectant wipes (optional)

Panty liners

Senna tablets or similar in case of constipation.

Suggested list of what to bring with you to into hospitals

Books, magazines, personal stereo and headphones (plus tapes and CDs), Diary or notebook (for that autobiography you'll write one day).

Clothes – not too many, as you'll be confined to bed for most of the time. What you do bring should be loose-fitting and comfortable. Night clothes, dressing gown and slippers.

Wash Kit and towel, tissues, hand cream (if you wish).

Panty liners (for the last day or two – they're more comfortable than the hospital dressings).

Cash – for phone cards, newspapers and other little bits.

Tamsin's Top Tip 1 – How to make your stay more comfortable

Buy some fruit squash. This will give some flavour to the water and also supply a few calories to sustain you while you are on clear fluids only.

Buy some Jaffa cakes or something similarly easy to digest. These are for when you come round from the anaesthetic after the surgery and feel the need to start eating.

Buy some 'wet ones' or baby wipes to use to clean yourself after going to the toilet for the next 2 days and for cleaning up after dilation at the end of your stay.

Day 1 – Arrival

Once you have booked in at Admissions, you should go to the ward. You will be taken to your bay on the ward, shown to your bed and may also be introduced to any other GRS patients on the ward. They will be worth talking to, as they will be further down the line and can give you hints about what to expect, alongside horror stories of pain and Picolax. After sitting around for a while (or you could spend time unpacking), a nurse will come to admit you to the ward. Someone will also weigh you and take first observations (pulse, blood pressure, blood oxygen, temperature).

You are free to do what you want for the next few hours. This is probably a good time to visit the shop on the ground floor to purchase various items to make your stay more pleasant.

Early evening, the nursing staff will do the medicines round, at this point, you will be given your first dose of Picolax. It doesn't taste too disgusting (sort of like an artificial lemon flavour). The effect starts an hour or so after taking it. You will be visiting the toilet very regularly for the next few hours, after which the frequency will reduce.

Get as much sleep as the Picolax will allow you tonight.

(Please note that Picolax is now given on the morning of day 2 only).

Day 2

By the morning, the effects of the Picolax should have worn off enough for you to consider going for a walkabout. There's very little else for you to do today, so you might as well take the opportunity.

Alternatives to a walkabout:

Sleep, read, listen to CD's/tapes/radio, chat with peoples or solve Fermat's Last Theorem from first principles.

At some point, probably late morning or during the afternoon, you will be visited by the Clinical Nurse Specialist (CNS) and your surgeon. They will go through the procedure and you will be asked to sign the consent forms.

Early evening medicines round will see your second dose of Picolax (believe me, you'll be surprised at how much is still in there) and your first injection of anti-coagulant (heparin). Then it's toilet and sleep.

Day 3

These notes assume surgery in the afternoon.

You will be very hungry by now. While the other patients in the bay are having breakfast, avert your eyes by going for a bath or shower. Make sure you wash your hair – this is the last time you will be able to do so for several days. Also, ensure that you give the surgical area a good, close shave.

You will be given menus for lunch and dinner tomorrow. Fill these in – you can eat tomorrow. Choose 'small' meals (although I'm not sure there's any difference between 'small' and 'standard') and don't choose too much.

The CNS will pop in to see how you are doing at some point this morning and one of the nurses will measure your calves so that they can give you the right size TED stockings (to

help prevent deep vein thrombosis). The stockings are very chic and look so good you won't believe it (Not!!!). You will also be given a hospital gown to wear.

Sometime around 11.00am, change into gown and stockings and remove your jewellery, cosmetics (including nail polish) and your knickers. Hand over your valuables (jewellery, cash, mobile phones etc) to the nursing staff for safekeeping.

You will probably be visited by the anaesthetist at lunchtime, who will explain about the anaesthetics, measure you for the tracheal tube they will use (to give you the anaesthetic gases that keep you asleep during the operation), ask a few questions and discuss the painkillers you will have after the operation.

At some point between 1.30pm and 2pm a theatre porter will come to take you up to the theatre. You will be wheeled into the anaesthetics room, where they will prep you for the operation, putting in lines and inducing the anaesthesia. The last thing you will remember is chatting to the anaesthetist, until you wake up in the recovery room.

At this point, you will probably scream with pain and ask the time (I seem to recall my language at that time would have been enough to make a very world-wise merchant seaman blush). You may also by sheer instinct find the morphine self-doser (if you have been given a PCA machine) and give yourself a few shots. You will promptly pass out again and will be taken back to the ward. An hour or so later, you will come round again, this time on the ward. Hopefully, you will have the friendly faces of visitors. If not, sack your friends and family.

Tamsin's Top Tip 2

When you come round on the ward, you will be very thirsty. Don't gulp down lots of water (like I did) – you will only see it reappear through the same orifice very shortly afterwards. This is due to the level of dehydration in your gut and also perhaps to the morphine's natural ability to induce nausea. Instead, take small sips at intervals, to slowly rehydrate.

After several hours, you may be able to take larger sips, or even small gulps. At this stage, you might also be able to try eating. Take a Jaffa cake (or whatever else you brought in) and have a small bite. If you are able to keep it down, then try eating a some more.

By now, you will have noticed the sumo-wrestler's belt they have given you as a dressing. This is tight and quite uncomfortable. You will also have spotted the 3 tubes poking out through this and going over the side of the bed. One of these is your urinary catheter, which you will live with for the next few days. The other two are drains from the surgery site to take away any bleeding from inside. You will be pleased to hear that these come out tomorrow.

For the first few hours after you are brought back from the ward, you will have observations taken every hour to make sure that a) you are still alive and b) you are recovering. You will sleep between these and probably won't be too happy about being woken up when they do them.

Day 4

You will probably wake up in the wee-small-hours of the morning (3.00 – 4.00am) and be unable to get back to sleep. This day is probably the most variable of the whole stay, as patients' recovery times differ so much.

When you wake up, try raising the head-end of the bed gradually to a point where you are comfortable. Repeat this over the next few hours (or as long as it takes) until you are sitting upright.

You may find that you are now able to eat a little (if you didn't manage to last night).

Around 8.00 or 9.00am you will be offered breakfast. Try some cereal, but not too much. Later in the morning, you will be visited by the CNS and your surgeon, to change the dressings and look at the immediate results. The sumo-belt and drains will be removed and you will get some smaller dressings (of a sensible size) and a dressing which could well be a panty-liner for a horse. These will be held in place by some very loose mesh hospital knickers. Lovely!

A bit later, they will bring lunch round. Try to eat something – you will be quite weak from not eating for 3 days and need to regain your strength.

During the morning or afternoon, a nurse from the Pain Team will come and talk about pain relief. You may still be using the morphine self-doser (PCA), in which case they will ask you to try weaning yourself off it. The pain should be tolerable by now for you to do this (some people will come off it very quickly, mostly because they find the nausea induced by the morphine worse than the pain). The nurse will tell you about the pain relief tablets that you will be given over the rest of your stay.

After all of this, you will probably feel tired. Have a sleep in the afternoon (if the hordes of visitors allow) and then have dinner. If you haven't eaten yet, you should be very hungry by now. In the evening, if you haven't managed to get to sitting upright, try sitting with your legs over the edge of the bed. If you feel okay, try standing up and providing you still feel fine, try walking a few steps.

After all of this, you should sleep quite well tonight.

Tamsin's Top Tip 3

When sitting on the edge of the bed, do so on the side with the catheter bag. This will avoid the embarrassment (not to mention pain) of pulling your catheter out. For the same reason pick up the urine bag when walking.

Day 5

Carry on with the eating, sleeping, reading, getting bored. Towards the end of the day, you may find that bowel movements resume.

If you are able to walk about, ask the nurses to switch you to a leg bag for your catheter. This will mean you are able to wander a bit further abroad and also to sleep on your side, although you will have to be careful doing the latter – if you roll over onto the bag or raise it above your bladder, you may get a back pressure (where the urine is forced along

the tube back into your bladder) which is quite uncomfortable. You will also have to remember to empty the bag frequently, as it only holds about a pint and you will be producing 4 – 6 pints of urine a day.

Day 6

Eat, sleep, read, get bored.

Bowel movements should resume today if they haven't already. After passing motions they become resolutions, ermmm wrong subject. After passing motions, remember to wipe backwards and upwards. This prevents getting nasty gut bugs onto the fine work of the surgeon and reduces the likelihood of infection.

Try going for walkabouts today.

Day 7

Most boring day of the lot. Nothing really happens today. Eat, sleep, drink, read, walk about, get thoroughly bored.

Day 8 – probably the best day of the lot

Today you will have your catheter removed (freedom to pee!) and the packing in your vagina will also be taken out. Removing the catheter is a short, very sharp pain (a bit like razor blades coated in sandpaper being pulled out) and it will sting for a while afterwards. Removing the vaginal packing is a very different sensation, which is slightly uncomfortable but strangely thrilling. I haven't conducted the experiment yet, but I imagine it is similar to having several long strings of Thai love beads removed in rapid succession.

After removing the packing the CNS will clean up the area and then introduce you to your 2 new Perspex pals. Yep, you're going to start dilating now. She will introduce the smaller (2.5cm diameter) one first, with plenty of lube. You will keep this inside for 5 minutes, then remove it. Juices will run out as it is removed. These are a mix of liquefied lube, some of the iodine-based disinfectant from the packing and a load of red stuff (blood). **DON'T PANIC**

The blood is to be expected for a few days, as it takes a while for the internal bleeding to stop. The actual amount of blood is very small anyway.

The CNS will then introduce the larger (3cm diameter) and then when it is part way in, will let you take over. This is kept for 10 minutes before removal. The nurse will clean you up, put on a new dressing and give you hospital knickers, which are much better fitting than the previous ones. Make sure that you are left a tube of the lube, as you will need it from now on. If you forget, you can always ask the nurses for some later on. You are now committed to dilating 3 times a day, as described opposite. It will take a while to get used to inserting them, particularly the larger one.

Once your first dilation is out of the way, you will be able to have your first bath or shower since the day of your op. You will find that this feels heavenly. You can also wear your own clothes for now if you want to.

In the evening you will need to do your second dilation, this time on your own. Use plenty of lube for now; there is no such thing as too much!.

Day 9

Eat, sleep, read, dilate, go for walks. Think about packing your stuff away, ready for tomorrow.

Tamsin's Top Tip 4

Dilate after breakfast, lunch and dinner (visitors allowing). Wait until after your first dilation before having a bath or shower.

Before I forget, you can dump those wonderful fashion accessories (the TED stockings) today.

Day 10 – going home day

Assuming all is well, you should be discharged today. The booklet sent to by Charing Cross says that you must vacate your bed by 10am. Ignore this. You can stay on the ward until you have received your discharge kit (Betadine douches and pessaries, painkillers, lube, sick notes) and have been told what to do with it by the CNS. This will not happen until they come up to the ward from Pharmacy and could be even mid-afternoon.

Tamsin's Top Tip 5

Cards and/or chocolates as a 'thank you' are generally warmly received by the staff who have been looking after you. Visit the shops on the ground floor and get some.

Once you have been discharged you can leave.

Things to buy before you leave –

Thank you cards

Chocolates (if you haven't received an excess from your visitors).

Post-op care at home.

Personal hygiene

Have a bath or shower at least once a day, taking special care to ensure that the surgical site is kept thoroughly (but gently) cleaned.

Use the Betadine douches and pessaries as directed

Change panty-liners twice a day, or more frequently if needed.

You will notice some bleeding and a creamy discharge the suture line (stitches). This is perfectly normal and nothing to worry about. Just keep the area clean and dry.

Dilation

Set aside specific times of day for this. You will need to allow about half an hour each time. Every session, you will need 4- 5 tissues, wet ones or baby wipes, a mirror, lube,

both your Perspex pals (dilators), plus a mat to absorb the leakage which comes out after the dilators are removed. Ask the nurse for a couple of 'incopads' to take home with you. Set things out on your bed, so that they are readily to hand. Lie back (keeping your shoulders flat), lubricate the small one and insert it. Dilate as you have done in hospital. Afterwards, wipe yourself with a tissue, then clean up with a wet one or baby wipe, then dry off with another tissue. Put your knickers back on and clean up the dilators. Wipe off the excess lube with a tissue, clean off with a wet one or baby wipe, then dry with another tissue. Put the dilators back into their plastic bags and into the packets.

Place all the used tissues and wipes in a small plastic bag (freezer bags are good). After 2 or 3 dilations, tie the bag off and place it in your rubbish bin.

You might find that dilation (particularly with the larger dilator) is slightly painful for the first few days, particularly when the suture lines are inflamed. This will ease as the general swelling reduces and the inflammation disappears.

You might also find that it helps to go to the toilet (number 2s) a short while before dilating, as this will reduce the pressure inside that can make it awkward to insert the dilators.

Other bits and pieces

Almost as soon as you get home, you will find that the suture lines become very inflamed and sore. This indicates that they are healing, but unfortunately, makes it difficult to sleep or sit down.

Try placing a pillow or cushion between your legs when sleeping – this will take some of the pressure and make it easier to sleep.

If you are having difficulty sitting down, try putting extra cushions on your seat to raise it up.

Take painkillers as and when you need them.

You might find that the change in diet causes you to become a bit blocked up (constipated). If this happens, take a mild laxative (such as Senna) in the evening before you go to bed.