At the end of January 2010 I underwent a radical prostatectomy (removal of the prostate), by robot, in the Royal Berks Hospital. I have nothing but praise for the place. I must admit, however, that a lot of the useful information I gathered along the way was not given me by the hospital.

So if you have decided to have the operation there too, here in case it helps you is my attempt to list as much of this information as possible, as if under the heading of Things I Wasn't Told (or not clearly, or not in advance, or only when I asked). Parts of it will apply only to the robot operation rather than open surgery, though I hope this will be obvious as you read through.

Having written everything down, I realize that no-one could reasonably be expected to digest all the information in one go, and it might even be discouraging to try to do so. Therefore it is separated into four sections, and I would suggest you read each one only when (or just before) it applies to you:

- 1) Approaching the operation
- 2) To hospital
- 3) Back home
- 4) Incontinence

Of course everyone reacts differently to things, so remember that this is only my personal collection of info. I'm afraid I can't be held responsible for the consequences of following any of the advice!

An Other

(1) APPROACHING THE OPERATION

GENERAL

Join the Reading Prostate Cancer Support Group at the earliest opportunity, for reassurance that you are not alone. If you can't get to the next monthly meeting (at St Andrew's Ch Hall, corner of Craven Rd & London Rd, normally 1st Friday of the month, between 6.30 and 8.30 pm)

Most importantly, don't hesitate to contact the Urology nurses, by email

(urologynurses@royalberkshire.nhs. org) or by phone (0118 322 7905: you will probably have to leave a message), with any questions that are in your mind, related to the operation — they are willing to answer even the most trivial of queries.

If you are a blood donor, the diagnosis will put a stop to it. This is a blanket rule by the National Blood Service for all cancer sufferers (except those with a certain type of skin cancer).

If you have a holiday already booked, plus insurance cover (whether an annual policy or just for this trip), you should advise the company of your situation. In my case, I was told I could either claim for cancelling the holiday, or else travel with full cover except for any problem that might arise because of the cancer. Then after the operation, I was advised that this restriction would continue from the next annual renewal but might be removed subsequently. And not surprisingly the restriction now applies to cancellation cover, because in the company's eyes the cancer has become a known risk factor.

RUN-UP TO THE OPERATION

You will receive a letter a few weeks in advance, giving you the date of admission (for me this was the day before the operation). It will ask for a phone call confirming whether the date is OK for you. You will also be told to attend a pre-admission clinic, a couple of weeks before the op.

At this clinic, they will ask many questions and check all sorts of bodily functions, to ensure you are fit & ready for the operation. You will be given a booklet covering general aspects of coming into hospital for an op, including information on anaesthetics.

You may read (eg, in leaflets from the Prostate Cancer Charity: <u>www.prostate-cancer.org.uk</u>) about 'nerve-sparing' techniques the surgeon can use in order to minimize the likelihood of impotence after the operation. If, however, you ask at the hospital about this before the op, you will probably be told (reasonably enough) that this is a cancer operation first & foremost, and that nerve-sparing is a secondary consideration. Better perhaps to ask what was actually achieved, when you see the surgeon again afterwards. Many experts and patients strongly recommend commencing pelvic-floor exercises well before the operation, and continuing them afterwards, in order to lower the chances of extended incontinence and/or impotence. You will soon notice a strengthening of the muscles (if nothing else!), as measured by the length of time you can hold them tight. The problem, I find, is remembering to do the exercises regularly.

STOCKING UP

It is worth getting hold of a pack of incontinence pads such as Tena for Men, Level 1, for your return from hospital even though you will have a catheter in place, as there may still be seepage. They are obtainable from any chemist or chemist's department in a store, often displayed under the heading of Bladder Weakness —

(2) TO HOSPITAL

DAY OF ADMISSION

I'm assuming that like me you will be asked to arrive the day before the operation. Your letter will ask you to phone the ward in the morning to confirm that there will be a bed available that night. The time they want you to appear will probably be late afternoon (though in my case this was delayed until mid-evening). There should be no reason not to eat/drink normally before arrival. If this is late afternoon, then (I was told) you are given a light supper later.

As for items to pack & take, from the list in the booklet I would emphasize: moist wipes (to clean your hands when meals arrive) and a stick (for helping you around the ward after the op and then when going home) — though don't hesitate to ask for a zimmer initially if you feel the need for maximum support.

I would recommend also: throat pastilles (not supplied on the ward), mobile phone (not frowned upon, as you might assume from hospital information), a small firm cushion (for clutching to your tummy when you need to cough), ear-plugs (in case the ward is noisy at night), radio, torch.

With the robot operation at least, you are unlikely to be in hospital long enough to need more than one set each of day & night clothing — you will be supplied with sufficient hospital wear (gowns & pyjama sets). And the ward will not be cold.

ARRIVAL AT HOSPITAL

From my experience, you will probably spend the first night in a separate room with en suite. But unpack your things only into/on the (moveable) bedside cupboard, because after the operation you will probably be in a ward (with the cupboard having followed you). though small shops may have to order men's pads in. More information in Section 4: Incontinence.

Another item that might be worth buying, for peace of mind later, is a mattress cover. John Lewis sell a Waterproof Towelling Mattress Protector, from £18 to £39 according to size of bed.

For a short time I found a raised loo seat (on legs, to fit over a standard loo) helpful, partly for the handles you can grip either side, and partly if you need to sit down for longer than usual. However, if your existing loo pan rises more than say 40 cm from the floor, the raised one may have to be adjusted too high to be comfortable. The seats are available on loan from the British Red Cross, 90 Eastern Av, Reading (tel 0844 412 2750). They suggest a donation of £20 for a month's loan — rather more than just spending a penny!

The reasons you need to be admitted the evening before the operation include: interview with a hospital doctor, injection with antibiotics and other things, consumption of 'energy drinks' in small packets (these I found quite palatable in spite of warnings from staff that they weren't), and making sure you have nothing further to eat. Plus an early start the next day.

OPERATION DAY

The day commences with more antibiotics and energy drinks ... and an enema: a slightly uncomfortable injection of liquid into the back passage. You then wait for as long as you can (it won't be more than 15 minutes) until the loo calls irresistibly — and within minutes your system will be empty.

With luck you will then have time for a shower, before visits for reassurance from the anaesthetist and the surgeon. The latter will also produce the consent form for you to sign.

At 8.30, in just my dressing-gown & slippers, I was walked across to the theatre block by the surgeon. In the outer room the anaesthetist painlessly inserted a tube (cannula) into the back of my hand, and then we chatted until ...

Much later in the day (the operation had taken rather longer than normal) I woke up in the recovery room, feeling fine. I have read that if you are in pain or feeling nauseous, you should immediately let the recovery staff know. The surgeon had already phoned home to report, I was told later.

After a while my bed & I were wheeled up to the ward. This was the only time really that I felt a bit nauseous, though nothing came of it. Later as the anaesthetic wore off, my tummy ached when I tried to change position, and later still (in the small hours) more

continuously — but after that, mainly only when I coughed (keep the hard cushion within reach!).

You should be able to cope with visitors once you have been 'installed' in the ward. Later that evening was the only time my brain felt not quite in control of itself. Through the night, nurses will be regularly checking all sorts of things, including (possibly) whether you are awake, when you would rather be asleep. But any time you do need them eg, for pain relief, press your buzzer. The loud gossiping between arriving and departing nurses when the shift changes is in fact a handing over of vital information on all the patients.

WHAT'S DIFFERENT?

You now have an oxygen supply clipped to your nose, and two cannulae in your hand. A drip-bag high up is feeding you paracetamol solution, and there's a button within reach to give yourself a shot of morphine if you feel you need pain relief. Press the button hard the first time, to get the feel of it! The supply is programmed not to allow overdosing. I took just one shot, but more might have served me better. On the other hand, I was told that taking the maximum dose might slow down the recovery (I'm not sure in what way).

There's also a drainage tube emerging from the side of your tummy, and a catheter from lower down, both attached to bags at the side of the bed. <u>Assuming</u> you had the robot operation, you will find several small cuts across the tummy plus one longer one above the navel, all closed off with staples. These cuts are surprisingly high up, yet most of your hair lower down will have been shaved off, for some reason.

Inside, the urethra tube will have been drawn up towards the bladder (across where the prostate was) and joined to it. It's while this join heals that you need the catheter passing through. More information on the catheter in Section 3: Back home. Be prepared for a little seepage around it.

Your tummy will be swollen (and may take some weeks to return fully to normal). Initially this is partly because of air that was pumped in to aid the operation. The air will tend to drift up through your body over the next day or two, and can cause pain in the chest & shoulder. The other reason for the swelling is fluid — this will tend to sink, and so you are warned to keep your legs raised whenever possible, in the early days at home.

You might possibly also have skin damage to your shoulder(s), from the tape that was used to keep you in position during the operation.

You will find yourself in a hospital gown, and your legs in elasticated stockings to minimize the risk of DVT (blood clots). You should try to reduce this further by regularly exercising your feet & legs while in bed (or anywhere). Your pre-op clothing will be in a bag brought with you up to the ward.

THE DAY AFTER

Your first doctors' round may well coincide with breakfast being served — a good thing, because you need to get their permission to start eating & drinking again. The more liquid the better, of course.

The aim (after a robot operation, at least) is to get you up and walking today before lunch. You will be feeling fragile, so ask for a zimmer initially. The best clothing to wear for the expedition is probably the gown still, plus hospital trousers. The catheter will be shortened to feed into a bag in a leg-bandage pocket above your knee. As for the drainage bag, this can be conveniently hung on the cord of the trousers.

You will be pointed to a wash-room for ablutions and for emptying your knee-bag. The basin will not have a plug (reason: to prevent cross-infection), but you can ask for a disposable cardboard bowl which will fit into it.

THE DAY AFTER THAT

With luck (and assuming it was a robot operation), the doctors will say you can go home today. If they do, the drain tube will of course be removed from your side first (with a curious sensation inside briefly as it departs). You will be given a pack of night-drainage bags for the catheter (see Section 3: Back home) and a frame to hang them on.

You will receive a Nursing Transfer Summary form (to be shown to anyone medical outside who might need to treat you), and an appointment to return to the ward in about a week for the catheter and staples to be removed. And you will be given a supply of pain-killers (see Section 3 again) — though you may have to wait some while for these to arrive from the hospital pharmacy.

With luck also, later today your bowel will start to resume action. The important thing is not to strain at all, as this will put pressure on the urethra and cause seepage: just sit patiently. I noticed a slight internal stinging when in this position — probably caused by the catheter and nothing to worry about, I was told.

If bowel action seems slow to restart, just be patient for a day or so. Use of a laxative such as Lactulose is not recommended by the doctors until you are sure you have an actual problem of constipation.

(3) AFTER YOU ARE HOME GENERAL

After you are home, don't hesitate to phone the ward with any post-operative questions or problems. Particular signs of trouble would be: a raised temperature, strong-smelling urine, large clots of blood in the urine, no urine flow, pain that the pain-killers can't relieve, signs of infection around the surgery wounds, and painful or swollen legs. External bruising here and there (eg, on the left hand & wrist from where the cannulae were) should be nothing to worry about.

It's quite OK to have showers (carefully patting your tummy dry), but you are advised not to sit down for a bath. Take as much gentle exercise as you can cope with, combined with as much rest as possible. Go very gently up & down stairs, we are told — I assume the lifting of the legs puts strain on the tummy muscles. Don't lift anything remotely heavy for a couple of weeks at least, even if you feel capable of it. I made the mistake of doing so, and for a day or two afterwards didn't feel nearly so comfortable!

THE CATHETER

I expected this to be uncomfortable, especially where it emerges, but it was not. Obviously it's important that the tube doesn't get pulled accidentally but it won't fall out. This is because it has a little water balloon at the top end, keeping it firmly inside the bladder. (The balloon was pumped up, and will later be deflated for removal, by means of an inner tube running down to a little fork that you can see in the tubing.) When walking out, or moving around much, don't rely on the leg-bandage pocket to support the knee-bag: fix the bag in place with the strap provided.

Initially the urine will appear cloudy, because of the blood within it. I found it then cleared, six days after the op.

It's important to wash around & under the foreskin, as this is a potential entry point for infection with a catheter present. Although all the urine is passing through the catheter, there is likely to be a seepage of fluid (including blood) out around it too. To catch this, it may be worth wearing a Tena for Men (Level 1) pad inside your pants.

Possibly for the first time in a long while, the catheter may allow you an uninterrupted night's sleep! You hang a night-bag on the frame, and connect it to the drain-tap of the knee-bag (not forgetting then to open the tap). The nearer the end of the bed the night-bag is, the better probably, to avoid entanglement and kinking of the tubes (this can happen above and below the knee-bag). It's a good idea to check a bit later that the night-bag is beginning to fill. If there is a blockage, though, your bladder will soon tell you.

You should have been given enough night-bags to last until your return visit to the RBH for catheter removal. If the bags are type P2000, however, they are in fact reusable (according to the manufacturer): the push-button drain-valve will push back afterwards. Just in case the return visit is postponed, it could be worth making some bags last a couple of nights (rinsing them out well in the morning). And when you do return to the ward, the staff might be glad to have any unused bags and the frame back.

PAIN-KILLERS

I was given quantities of Paracetamol, Ibuprofen and Tramadol to bring home, but no advice (apart from the standard leaflets with dosage information) on how best to make use of them.

As I understand it, they work independently of each other, but the above is their order of increasing strength — so while you are still having aches & pains, it might seem sensible to start with Paracetamol, then add Ibuprofen (always only with food) if needed, and then Tramadol if really needed. I decided to avoid Tramadol altogether (returning the box to the ward) because of its high strength and possible side-effects, and to cut out the others as soon as I could manage fairly comfortably without them, which was within a week of the operation. But maybe I was lucky.

DRIVING AND INSURANCE

It goes without saying that you should not risk driving while you are still taking pain-killers, while you still have the catheter in, or while you are still in any discomfort from the operation that might distract you, or prevent you from making an emergency stop.

The medical advice I encountered didn't go much further than this, except to say you should check with your insurance company, which also seems sensible: the small print always says you must inform them of anything that may be relevant. However, when I spoke to my insurer, the response was: you are covered as long as your specialist isn't telling you not to drive yet. This seems to put the responsibility back on you to decide when you are completely safe again at the wheel.

RETURN TO HOSPITAL: STAPLES & CATHETER

This could occupy up to six hours of the day, depending on how leisurely you are seen to. The staples will be extracted (painlessly) with a special tool. Doublecheck that they *have* all been removed (a few of mine were overlooked, being higher up!). The catheter too will be taken out, equally painlessly. You would be wise to bring at least one incontinence pad, in case of leaks afterwards.

Then comes the investigation: the staff will give you instructions to consume two jugs of water (and to note any other drinks you have), and will want to record how much you produce — for this purpose, you are given cardboard bottles to fill (in a washroom) and told where to leave them. The idea, of course, is to check that what goes in comes out again. They may also do a bladder scan (which you probably experienced before in pre-op testing) to measure how much is left in. When they are satisfied with how your water-works are working, they will let you go.

In my case, unfortunately, I found that with the catheter removed I was totally incontinent — at least when I was standing and moving around. Therefore much of my output ended up in the pads I was wearing (these will be replenished by the staff on request), and so was not being measured! Eventually I persuaded the staff that because of this they would never make their totals balance, and I was allowed to leave. If you find yourself in this situation, there is plenty of advice in Section 4: Incontinence.

BACK HOME AGAIN

You should find that you recover steadily in almost every way. I would say: wear an incontinence pad day & night until you are confident of your capability of bladder control — this could take weeks (or much longer) to return. Others say: try to manage without a pad as soon as possible. The simple advice I received from all directions was: be patient, and keep up the pelvic-floor exercising.

As for erectile & related functions, these you will have to reassess according to what you discover happening (or not). Recovery will take some time, and may well need 'supplementing'. In February (2010) Lorraine Grover, a 'Therapist in Sexual Well-Being', gave a frank & instructive talk to the Reading Prostate Cancer Support Group on what can be done to assist in this area. She emphasized people's rights to help & advice from the medical profession, and described many possible methods of treatment.

4) INCONTINENCE

INCONTINENCE PADS

These are obtainable from any chemist or chemist's department in a store, often displayed under the heading of Bladder Weakness — though small shops may have to order men's pads in. There are several makes, though I only know about Tena. Their website (www.tenadirect.co.uk) shows what's available. You can order pads online as well, but this won't I think be any cheaper than in the shops unless you order in bulk and go for 3 for the price of 2. Morrisons is sometimes mentioned as being cheaper than other local outlets.

Men's pads are triangular and come in Level 1 and Level 2 (thicker). They are highly effective at absorbing the liquid and keeping it behind the lining so that you yourself stay dry. But if you find you are having to buy a lot of pads, you could consider ladies' versions that are narrower (if you are happy with this) and longer — suitable therefore for cutting in two, and sealing off the cut ends with tape (then install the half-pad in your pants with the taped end uppermost). These half-pads

FOLLOW-UP VISITS

Within a couple of weeks of the operation, you will be sent an appointment for the first follow-up outpatients visit, about six weeks after the op, probably to see the surgeon who did it. There will also be a requestsheet for a PSA blood test, to be done just beforehand. You take this to your surgery, or to the Royal Berks, for the test. For simplicity, and to be sure the result would be ready for the follow-up, I was recommended to go to the hospital (Pathology/Phlebotomy Dept, South Block, Level 2, no appointment needed), five days before the follow-up — that's including the weekend.

At the follow-up, you will be told what condition your prostate was actually in when extracted, and what your PSA reading is now: very low, let's hope, indicating that all the cancer cells were removed with the prostate. Even if there is some doubt about this, the recommendation may be to wait for the next blood-test and follow-up (or two), to see if the PSA is rising again, before any consideration of radio-therapy to 'finish the job'.

Obviously, ask the surgeon any questions that may be on your mind. I enquired about the use of Cialis (similar in its general purpose to Viagra), as I had heard it could boost the blood supply to the pelvic-floor muscles & nerves, to assist recovery from incontinence. He agreed this was quite possible, and later wrote to my GP requesting a prescription for 20 mg of Cialis to be taken twice-weekly.

Then shortly afterwards you should receive the appointment letter for a second follow-up visit about three months later.

work out at about 1/3 the cost of men's pads. See the website for the range of ladies' pads and their different thickness. If and when your output is minimal, it's even possible to use triangular men's pads cut in two horizontally (the upper section when worn would then be rotated through 90°).

INCONTINENCE ADVICE

The rest of this section is mostly for the benefit of anyone with similar 'severe' incontinence problems to mine, At present I still seem to have no control — except briefly by actively tightening the muscles — whenever I am moving around. Sitting or lying down, however, I hardly leak at all. And at night, I find my bladder seems to wake me when it needs emptying, again with hardly a leak. Fortunately, one small pad is therefore sufficient safeguard all night, or even for more than one night.

But during the day, throughout February (ie, both before & after recovering full strength & activity) I was getting through several full-size pads a day, and was becoming desperate for help & advice. I consulted my GP, who merely referred me to the practice nurse. She then called on me, and referred me to the Continence Advisory Service at Wokingham Hospital. All this took two weeks, which I could easily have saved by phoning Wokingham myself in the first place!

Why was I referred to Wokingham? I'm not sure. West Berkshire Primary Care Trust runs C/A clinics at Wokingham, Thatcham, and the Royal Berks which would have been nearer for me. I understand (now) that you can get an appointment at any of these centres by phoning Wokingham, on 0118 949 5146. Similarly, East Berkshire runs clinics in Maidenhead, Bracknell and Langley: phone 01753 638489.

Before attending at Wokingham I had to fill in a 3-day chart of all liquid consumed & produced. Probably I took too much trouble over this — it is only needed for giving an approximate assessment of your incontinence.

I found Mrs Terri Dunbar at Wokingham to be most helpful with her advice and offerings of samples. She explained that my choice was really between trying to control the problem (using pads and the exercises alone) or solving it immediately with 'plumbing'. This usually means a thin condom-like sheath on the penis, coupled to a leg-bag, all available from the GP on repeat prescription. I said that this is what it would have to be, for now at least, and she gave me some samples from different manufacturers to take away.

Looking at these and trying some of them, I decided to investigate Manfred Sauer products further, and phoned for further information: their number is 01604 595696, and you ask for Phil. He was very helpful and sent more samples, plus catalogues and a 'tutorial' book — all available also on their website: www.manfred <u>sauer.co.uk</u>. The end result, after a few teething troubles which I shall describe, is that I now have a high confidence in their system, and it has given me complete freedom to go out and about. This isn't to say of course that other makes might not be equally good.

When you have worked out what items you need to get yourself plumbed in (see below), and the quantities to last you two months, say, take the list to your GP, who should give you a repeatable prescription for it all without argument. Obviously, you should aim to keep sufficient supplies of everything in reserve, and also in an emergency-pack.

Mrs Dunbar did say that she can set up a regular free supply of incontinence pads, provided your usage is two or more a day (so I wouldn't at present qualify for this, though she was able to find and send me some bags of pads unofficially). [All the while, I'm looking out for signs that my sphincter muscle is starting to work automatically again ... but if my problem lasts for approaching a year, I'm told, the hospital will then consider 'permanent' ways of dealing with it — there are several different options.]

LEG-BAGS & ACCESSORIES

Of the Manfred Sauer range of leg-bags, the standard one suitable for most purposes is the 600 ml Comfort bag. Even this comes in several variations. I guess the appropriate one for many people would be code '710.1345adj': non-sterile, with a lever-type draintap and a long inlet tube which you would probably want to shorten. This is even if you are going to wear the bag below the knee — which seems the most convenient place, if only for easy access to the drain-tap, above your ankle. When you absolutely certain of the surplus length of tube you *don't* need, cut this off with its fixed tapered connector, and push the spare connector (included with the bag) firmly on to the tube.

Before fitting the bag to your leg, you need to sort out the three different straps: code CS.01 is wide, with a detachable velcro strip, and goes round your thigh to support the top of the tubing (just below the connector), by means of an adhesive tab which you stick around the tubing and which is then held between the strap and the strip (this is the `p.grip' system).

The LB.W strap is wide, with an attached velcro strip which feeds through the slots in the top of the bag, to hold this just below the knee (if that's where you want it). The LB.N strap is narrow, and feeds through the slots at the bottom of the bag. The instruction sheet included with the bags makes this clearer.

Trial and error will tell you how tightly to fasten the straps. Just make sure that the hook-surface of the velcro doesn't come into contact with your skin. The legbag is of course meant to fitted with the soft side against your leg. A night-bag (if you need one) can be attached to the leg-bag just as you would have done when you had the catheter in.

The adhesive tabs come in a bag of ten: code CS.TABS. The leg-bags too arrive in packs of ten, each pack also containing an LB.W and an LB.N strap (but not the CS.01), and a connecting tube for a night-bag. A legbag should be discarded after 7 days at most. Curiously, Manfred Sauer do not permit themselves to give advice on rinsing out the bags daily. Apparently this is because of the risk that the user might not do this the sensible way, with clean mains water (poured slowly into the connector and down the tubing).

Try not to fold the bags sharply at any time. One of mine developed a pinhole leak after a couple of day's use, exactly on a fold that had been put in previously.

A problem I haven't solved yet is that after a couple of days, the tubing starts to work its way through the adhesive tab — upwards, defying gravity — and it's

impossible to pull it back to where it was. Soon you have to cut the tab away and apply a new one (so make sure you have some to spare).

SHEATHS & ACCESSORIES

Manfed Sauer offer a range of different sheaths to roll on to the penis and connect to the leg-bag tubing. I will cover only the 'p.sure' self-adhesive synthetic sheath, code 97.xx, where xx is the diameter in mm nominally equal to the diameter of the shaft of the penis. Among your samples received should be a marked paper tape for reading off the xx (by wrapping it round your circumference). Otherwise, you could measure the circumference and divide by 3.14 to calculate the diameter. You can then ask for samples of that size and maybe the adjacent ones, 2 mm different up & down, to experiment with (read the next page first!). In a prescription, the 97.xx code represents a box of 30 sheaths ie, a month's supply.

Another item you will need on prescription is adhesive remover — otherwise, over a day or two the residue from the sheaths builds up and becomes a nuisance. I was recommended, and would recommend, Clinimed Appeel spray which you can apply either direct or (better, I find) via a tissue, then you wipe & pick the adhesive residue off. Appeel is also supplied in the form of boxes of 30 wipes, but by my rough calculation these would actually work out at twice the cost (to the NHS) of using the spray — which itself has a price-tag of £10 or so! See www.clinimed.co.uk .

Both manufacturers also offer skin-protection barrier products, apparently quite different from each other in their make-up, which might be of use to some people. So far, luckily, I haven't had a need for them.

Another accessory from Manfred Sauer, for periods when you are only leaking small amounts, is a tap that can be attached to the sheath in place of wearing the leg-bag — see their literature.

ATTACHING THE SELF-ADHESIVE SHEATH

The sheath unrolls to reveal first a non-sticky section, then a sticky one, then another short non-sticky one. Manfred Sauer's instructions for applying it to the penis (much as you would a condom), and then connecting it up, come in several slightly different versions. This itself is confusing, but in my opinion they all omit certain things that I find essential for achieving a reliable result. I will therefore offer my own advice for attaching the sheath, which you can of course compare & combine with their instructions. (Warning: if you are circumcised, my advice may well not work.) Another thing is that I don't bother with the protective square cloth that's provided with the sheaths.

Initially the sheath unrolls naturally in 'steps'. Before applying it, unroll it just *two steps* — and then take note of how it looks. [The MS instructions say unroll three steps or even more, but if you do, there's a risk that when in place the sticky section will be too far forward: if the penis body later retracts (eg, when you are sitting down), the adhesive can make contact with itself in front of the loose foreskin, and block the flow this happened to me twice, before I realized why. I'll admit though that with a sheath whose diameter is slightly on the large side, relative to you, the sticky section might instead end up too far back for comfort, and so you might need to start with three steps. Trial & error may be unavoidable...]

Now close the 3rd & 4th fingers of one hand around the pipe of the sheath, placing your thumb and 1st & 2nd fingers ready to continue the unrolling. Apply the sheath to the tip of the penis, using your other hand to support this and to keep hair out of the way. Then carefully start unrolling the sheath over the skin *without allowing it to slip*. If it does slip, take the sheath off, roll it up to how it was when you looked at it after two steps, and start again (otherwise it could end up too far forward — see above).

Once the sticky section appears and starts to adhere to the skin, gently stretch the latter (between your hands) as you continue unrolling. Stop when you have reached the final non-sticky section.

CONNECTING UP

If you simply push the sheath pipe on to the conical connector (already strapped to your thigh), it will probably go about half-way down the tapered section. *This is not enough!* Twice, for me, the pipe fell off the connector (later in the day) from this position. I think it is essential to slide the pipe ³/₄ of the way down the connector. This requires a little moisture as well as a strong twist and push. Saliva seems the most effective lubricant (but find a hygienic way of transferring it from mouth to pipe). Obviously, do aim not to leave the loose central 'buffer' section of the sheath twisted up, after connecting.

Manfred Sauer do not tell us the purpose of the final non-sticky section of the sheath itself — indeed, they recommend (as I do) that you remove it: lift part of it away and, with great care, snip it with scissors diagonally towards the adhesive section. You should then be able to tear the end section off all the way round (snipping again if necessary).

Sometimes a line of adhesive becomes exposed later, around where you cut the end of the sheath away (not that this is the cause). If you find that your pants and the adjacent skin tend to stick to this, a simple remedy is to wrap a folded piece of toilet tissue around the end of the sheath.

With your pants now hitched up, make sure that the conical connector is strapped high enough to give the buffer section enough slack in all positions of your leg — and also that the pants don't pinch this section against your leg (if they do, you will have to change to a looser

style!). Once the flow into the bag has begun, it's quite normal for the buffer section to close in, under suction from the liquid flowing down. This may also cause the foreskin to adopt an unusual shape.

SHEATH REMOVAL

I don't find the sheath easier to remove in the bath or shower, as MS suggest. I've tried warming it with a hot flannel too. Now I simply remove it 'cold', inserting a finger and working round, rather than trying to roll the sheath straight off. Try to stretch the skin as little as possible, of course. If it sticks firmly to the sheath at any point, a small squirt of Appeel will release it. And then down at the other end of the sheath, a thumbnail against the pipe should enable you to roll it back and loosen it from the conical connector. Finally (or at least before you apply a new sheath the next time), use Appeel to remove any adhesive residue and stickiness.

Good luck! The plumbing does become easy to cope with, with a little practice.

TRAVELLING WITH CONFIDENCE

When it came to my first journey by air after the operation and after being plumbed in, I could see two problems looming: (1) getting through security with a bag strapped to my leg, possibly containing liquid, and (2) wanting to have my bag of spare plumbing in the cabin but without my space allowance for other items being reduced.

The solutions, I found, were (1) to request a letter from my GP stating that I had had a prostatectomy leaving me incontinent, that I was therefore obliged to wear drainage aids including a leg-bag and to carry spare items, and that I was otherwise (currently) in good health and fit to travel by air, and (2) to obtain from the airline (Ryanair in this case) an exemption letter allowing me to carry the bag of spares as extra hand luggage — stating its maximum weight — for the specific flights.

What actually happened was that (1) the plumbing was not detected at security, so I didn't have to produce the GP's letter, and (2) I managed to fit the bag of spares into my regulation hand-luggage anyway.

Certainly you should check the airline's small print regarding medical issues. And I suppose the letter from your GP could be useful backup even when travelling by Eurostar, which does make security checks.

POSTSCRIPT (August 2010)

Three months further on, nothing seemed to have changed: I could detect no sign (when I was moving around at all) that my system was recovering any automatic control, enabling my bladder to fill. It still suited me well to be wearing the plumbing during the day. I also continued the pelvic-floor exercises — when I remembered them.

Then one day, with nothing in the diary, I thought I would risk staying unplumbed just to see what happened. Well, I had to use a magnifying glass to see it (so to speak)! The small cut-in-half pad that I wore overnight as a precaution lasted me right on through to the end of the day, and even then it wasn't half-filled. And every day since has been the same. Evidently my system had already relearned its duty, and just needed reminding of it. Suddenly, in retrospect, the plumbing seemed an unnecessary encumberance. Out walking, I guess I now keep control partly automatically but also by continuous pelvic-floor exercising, in step with my step. The drawback, perhaps, is that I now need to find a loo regularly again like everyone else!

What advice would I now give to my six-monthyounger self, or anyone else in a similar situation? The problem is, of course, that I have no idea how quickly I would have noticed the recovery of control in the absence of the plumbing. So all I can say is: if you do get plumbed in like I did, leave it off regularly to assess progress. Was this improved by the pelvic-floor exercising — who knows? Anyway, I keep it up, as it probably is helping me now!

As for how to remember to exercise regularly, one trick I've found is to associate it in your mind with other things that do impinge on your consciousness: for example, I remember the exercising whenever I notice the perpetual high whistle of my mild tinnitus.

And only now have I discovered a surprising bonus of my prostate extraction: it has cured me of paruesis. That's the medical name for a 'shy bladder', or the inability to pee in the vicinity of others (which I have suffered from for as long as I can remember). Some people, I gather, get it to a much worse degree than I did. Anyway, it would seem that my surgeon removed either the nerve or the sphincter that was imposing it on me — so a double thank-you to him.