The Prostate Centre Guide to:

ROBOT-ASSISTED LAPAROSCOPIC RADICAL PROSTATECTOMY M6192

You have been given this information pack because you have decided, after considering other possible options, to be treated for your prostate cancer with a surgical procedure known as Robot-assisted Laparoscopic Radical Prostatectomy.

The Prostate Centre team is on hand to answer any questions you may have about your preparation, hospital stay and follow-up. But there is a great deal to remember, so we have produced this pack as an *aide-mémoire* which we hope you will find useful. It is arranged in sections for ease of reference.

We always welcome feedback, so if you can think of any way we could improve this information pack, or indeed any aspect of your care, please do tell us.

PLEASE BRING THIS BOOKLET IN TO HOSPITAL WITH YOU

CONTENTS

1.	ABOUT YOUR OPERATION a) Why is it necessary?	3 4 5 8 1
2.	COPING WITH YOUR CATHETER a) How to use and care for your catheter b) General guidelines c) Problems you may encounter	14 15 16
3.	CATHETER REMOVAL DAY	18
4.	PELVIC FLOOR EXERCISES	19
5.	YOUR HISTOLOGY (PATHOLOGY) REPORT	20
6.	SEXUAL FUNCTION	21
7.	FEES INFORMATION	24
8.	STAYING IN LONDON	25
9.	SUPPORT SYSTEMS: OUR "BUDDY" SCHEME	26
10.	FOLLOW-UP: CONTINUING CARE	27
11.	CONTACT INFORMATION	28

1. ABOUT YOUR OPERATION

a) Why is it necessary?

The prostate gland lies just underneath the bladder neck, surrounding the urethra (the tube through which urine passes). Its function is to produce the liquefying component of semen. As men grow older, their prostate gland almost invariably enlarges and can cause difficulties with urination. It can also become cancerous.

The fluid in the prostate gland contains a substance known as prostate-specific antigen (PSA), and this tends to be significantly increased when cancer is present in the prostate. The PSA passes into the blood stream and can be measured in a blood test. It is likely that this is how you were first alerted to the possibility that you might have prostate cancer: raised PSA levels normally prompt further investigation such as a biopsy.

Recent studies have shown that surgical removal of the prostate gland and seminal vesicles offers the best chance of cure in those men who are suitable. As with any operation, it does carry some risks and side-effects but these have to be weighed against the potential for complete cure.

b) What is done during surgery?

Up until quite recently, the **traditional or "open" surgical technique** was used to remove the prostate. This is still in common use throughout the UK and involves a 10cm incision through the abdominal wall. The surgeon detaches the prostate from the bladder and urethra, carefully dissecting it away from the nerves that control erections, and removes the seminal vesicles. A catheter (soft silicone tube) is then inserted up the urethra and into the bladder, where it is held in place by an inflated balloon, and the open end of the urethra is sutured to the bladder opening, around the catheter. The catheter is left in place to drain the urine and remains there for 2-3 weeks, allowing the anastomosis (join) to heal over it. Another tube (the "drain" through which any excess fluid is removed) is placed deep into the pelvic area before the abdominal wound is closed with stitches (sutures).

With **robotic surgery**, a "keyhole" technique, this process is made much more precise and less invasive. Six small 1cm incisions are made in the abdomen, and slim steel arms (called "ports"), with tiny instruments and a camera on the ends. are placed inside. The abdominal cavity is distended with carbon dioxide, creating space so that the organs can be viewed more clearly; the pressure from this gas on the blood vessels means that virtually no bleeding occurs.

While a trained surgical assistant sits next to the patient and ensures that the ports are accurately placed, the surgeon sits at a console across the room and looks into a screen where the operating site is displayed in 3-dimensional vision and magnified 10 times.

The instruments are manipulated remotely by the surgeon, who although unable to "feel" the tissues has a vastly improved view and can control the tiny instruments with far greater precision than is possible with the human hand. An additional benefit is that all tremor is eliminated from the instruments.

The superior vision enables a more accurate dissection as well as a more watertight join at the anastomosis. For this reason, the catheter has to remain in place for only a week or so and recovery is faster; the patient's small wounds normally heal quickly, soon becoming insignificant.

The NeuroSAFE procedure

This procedure can be incorporated into a radical prostatectomy if the surgeon has concerns that sparing the nerves by dissecting very close to the capsule of the prostate, may uncover the cancer. The procedure involves the prostate being examined carefully by a pathologist during the operation (this is called a frozen section) so that if, having spared the nerves, cancer cells are seen at the edge of the prostate, the nerve can be resected on the side in question. The operation duration is increased slightly meaning that the cost of the operation may be higher (although the insurance companies will cover most of this cost, they will not cover it all).

Retzius surgery

Retzius sparing refers to preservation of the structures anterior to the prostate itself. These structures include the ligaments which support the bladder neck promoting urinary incontinence. What data is available on this technique suggests that, whilst patients leak urine for less time after radical prostatectomy, in the longer term the degree of return of continence is similar. One concern that has been raised by the people who evaluated this technique in clinical trials is the increased rate at which cancer is found at the edge of the resected prostate, a so called positive surgical margin, which is linked to a decreased chance of cure (16.7 with Retzius sparing versus 7.7 % with a standard technique for cancer confined to the prostate and 31.8% vs 14.3% once the cancer had started to invade through the capsule of the prostate). As such the technique is only really appropriate for small, low grade cancers, the sort of cancers which are not usually treated surgically nowadays. For this reason we do not advocate a Retzius sparing approach as we believe that cancer control should not be jeopardised.

c) What are the risks and side-effects?

Even with the most experienced surgical team, this procedure carries certain risks and potential side-effects. A list of these can be daunting but it is important for you to understand that such complications may occur, even though many of them are very rare.

Your consultant and/or the nursing team will answer any questions you may have about this, as it is important for you to feel confident that you have been fully informed before giving your consent to the operation.

Risks (approximate percentage incidence throughout our series of cases)

- **Bleeding** blood loss should be minimal but is nevertheless a potential risk when any surgery is performed
- Damage to structures inside the abdomen (eg bowel) when the instruments are inserted (less than 0.5%)
- Wound Infection or hernia at the incision site (1-3%)
- Leakage of carbon dioxide gas into tissues which can cause some temporary shoulder/abdominal pain (3-5%)
- **Numbness** due to the position on the operating table; this usually resolves within a few hours or days (1%)
- **Haematoma** (external or internal bruising) (1-5%)
- Testicular swelling/bruising (1-2%)
- Problems relating to general anaesthetic such as chest infection, deep vein thrombosis (DVT), stroke, pulmonary embolus, irregular heart beat (1-2%)
- Conversion to open surgery If for any reason it is not possible to complete the operation with robot assistance, it would be necessary to "convert" to standard open surgery (less than 0.2%)

Side-effects

- Incontinence Some incontinence after removal of the catheter is almost inevitable, and you may need to wear pads for protection for a while. Most men achieve good control within one to three months; some may take longer, but virtually all will be back to normal within 6-12 months.
- Erectile dysfunction Radical prostatectomy, like all treatments for prostate cancer, tends to effect some degree of damage on the nerves which control erections, although this should be temporary. Even though with the use of the robot these nerves can be seen very clearly and the surgeon is able to "spare" them, they may still suffer from some disturbance due to traction injury and localised heat generated during the operation. Most men will recover their sexual function in time, aided if necessary with medication or other therapies. In fact, the ability to achieve orgasm normally returns very quickly, but erections sufficient for penetration can take much longer a year or more.
- Infertility Because the Vas Deferens (the tracts which link the testes with the
 urethra) are tied off, and because the prostate is no longer there to produce the
 seminal fluid, there is no semen to ejaculate and orgasm is "dry". Therefore men
 cannot have children following this operation. If there is a possibility that you
 might still like to father children afterwards, you should consider having frozen
 semen samples stored. We can advise you on providers of such services at your
 request.

d) Preparation

Once you have a date booked, you can focus on getting yourself as fit as possible for your operation. This may mean stepping up or embarking on an exercise programme; cutting down on alcohol, tea and coffee; increasing your water intake and even giving up

smoking! Anything you can do to increase your level of general health and fitness, even if the time available is limited, will help you to tackle the physical stress of an operation and speed your recovery.

Any questions?

If you have not already had a discussion with our Lead Nurse Vicky Clarete (for example when you were going through the decision-making process), this is a good time to make contact with her. Vicky is enormously experienced in looking after radical prostatectomy patients and will spend time explaining any issues you may have missed or forgotten to ask during your discussions with your urologist. She can give advice on practicalities and go into more detail about what to expect post-operatively. You can either make an appointment to see her, or speak to her on the telephone.

Diet

With or without the objective of weight reduction, you should address your diet in order to optimise your health in preparation for your procedure. The following are some general guidelines; but should you require more detailed recommendations we can refer you to a nutritionist with a particular interest in diet and cancer.

GENERAL GUIDELINES

- Drink at least 2 litres of water every day
- Eat small amounts of a diverse range of foods
- Always chew food well and slowly. You will reach satiety (a feeling of fullness) sooner and this will reduce your calorie intake
- Eat most in the beginning and middle of the day, less in the evening

DO EAT:

- organic food wherever possible
- plenty of raw food: fresh fruit and vegetables
- cruciferous vegetables (broccoli, Brussels sprouts, cabbage, cauliflower)
- fresh vegetable and fruit juices, especially cranberry
- wholemeal/wholegrain foods
- lean white meat and fish (grilled or poached)
- beans and pulses
- seeds and nuts

AVOID OR REDUCE:

- caffeine
- alcohol
- sugar
- all fried and processed refined foods
- white bread and white rice
- dairy products (especially cheese/cream/butter etc)
- red meat and meat products
- saturated and hydrogenated fats

Exercise

No matter what your current level of fitness, we would like you to improve this in the run-up to your operation. Those who already exercise regularly will know what to do to improve their lung function and overall fitness; anyone who does not exercise should

take the opportunity to begin now. A brisk walk for at least one hour a day is recommended.

Pelvic floor exercises

It is a very good idea to learn how to do pelvic floor exercises (see page 19) and begin them now. You want to build up as much strength as possible in your pelvic area, as this will help you to recover urinary control more quickly after the catheter is removed.

Pants and pads

It is essential to have a small supply of continence pants and pads ready for when you have your catheter removed, so it's a good idea to buy some before you go into hospital. You may not feel like going out to find some in the days immediately after you leave hospital.

An initial supply of one pack each (10 to a pack) of Tena Pants Plus (small, medium or large) and Tena For Men Pads is our recommendation. These should be available from your local pharmacy, although they may be on special order. John Bell & Croyden in Wigmore Street is a good source and is near to The Prostate Centre. Alternatively, you can contact Tena Direct (0800 393 431 or online at www.tenadirect.co.uk) and purchase with a credit or debit card. For further advice contact our nursing team.

Consent

At some stage prior to your operation, you will need to sign a **consent form**. This gives your surgeon permission to perform the procedure and states that you have understood the risks and benefits of the surgery. Ideally, you should sign the form well in advance – maybe at the time of a consultation with your urologist; you will be given a copy and it is a good idea to revisit it shortly before the day in case you need to ask any further questions. Please bring it with you to hospital; you will be asked to confirm your consent on the day of surgery.

Pre-operative tests and assessments

All patients undergoing robot-assisted radical prostatectomy will be required to follow our pre-operative protocol and have some blood tests (including a clotting profile) and a resting ECG (heart trace) not more than three months in advance of the planned surgery. A urine culture (to check for infection) and swabs for MRSA will also need to be carried out within 2 weeks of the surgery. These should be booked at The Prostate Centre as soon as you have decided to have the operation. Based on our assessment of the results, we may suggest further investigations (eg review by a cardiologist). This is in order to identify any problems with your general health and to help ensure your safety during the surgery and anaesthetic.

Blood-thinning tablets

If you are on any medications to thin the blood, you must let us know as you will have to stop taking them before the procedure and may need an interim coagulation bridging plan.

.

- Warfarin: stop five days beforehand. We will need to re-check your clotting profile the day before the procedure
- Dabigatran (Pradaxa), Apixaban (Eliquis), Rivaroxoban (Xarelto) and Edoxaban (Lixinia): stop two days beforehand
- Antiplatelet medication clopidogrel (Plavix) and/or high dose aspirin: stop seven to ten days beforehand following the advice of your urologist/cardiologist.

PLEASE MAKE SURE YOU CHECK WITH YOUR CARDIOLOGIST, GP OR OTHER PRESCRIBING DOCTOR THAT IT IS SAFE FOR YOU TO STOP TAKING YOUR MEDICATION.

NB. Post-operative anticoagulation should also be discussed at this time. The information on post-operative anticoagulation outlined on page 9 of this booklet may not be relevant in your case

Other regular medication

- You can continue taking all your other medications.
- Please make sure you tell us if you are allergic to any medicines.

e) What to expect in hospital

Your Robot-Assisted Laparoscopic Radical Prostatectomy will take place at a premier private hospital nearby, and you will be asked to attend on the morning of the operation. If it is scheduled for the afternoon, you should arrive at 10am; if in the morning, you will need to be there between 6.30am and 8am. The exact time will be stated in your Letter of Confirmation. You can expect to stay for three (sometimes four) nights.

Eating and drinking

The day before your operation, you may continue to eat and drink normally, making sure you keep your fluid intake high to ensure good hydration. We recommend you buy a bottle of Lactulose, which is a **mild laxative**, to take at around 10pm the night before (2 dessertspoons, or 20ml) and which you should bring with you to the hospital as it may be useful for a couple of weeks thereafter.

In preparation for the anaesthetic you must remain "nil by mouth" (nothing to eat or drink) for at least **six hours** before the operation. The exception to this is water, which you should continue to drink up until the time you are admitted to hospital, or at least **two hours** before your operation time.

In practical terms this means that if your operation is scheduled for the morning, you should stop eating and drinking by midnight the night before. If you have an afternoon operation booked, you may have a light breakfast, which should be consumed by 6am, but then have nothing but water until you reach the hospital. You will find your personal instructions in your Letter of Confirmation.

What to bring with you

Please bring with you to the hospital all medications you are currently taking (if you are on anticoagulants such as Warfarin, Plavix or aspirin it is very important to stop these tablets prior to surgery – see p7).

Otherwise, you need to bring only those personal effects which you will use for a threenight stay (toiletries, glasses/contact lenses and solutions, reading materials, loosefitting pyjamas with elasticated waist or a nightshirt if preferred, and snug-fitting underpants which are best for holding the catheter in place).

Arrangements for paying the hospital, surgeon and anaesthetist should already be in place. Please see page 24.

Before the operation

You will go through the admissions process and be shown to your room, where you will have a shower and put on a surgical gown. A nurse will run some final checks and you can expect some further tests at this stage; you will probably be given an enema. Anti-thrombus compression stockings will be fitted; these reduce the risk of blood clots forming in the legs and will remain on after you leave hospital for the next 4 weeks, although they may be removed at shower times. Your anaesthetist will come to see you and you will also have the opportunity to see your surgeon; you will need to confirm your consent by signing the Consent form, even if you have signed this initially at The Prostate Centre.

The operation

When you are ready to go to theatre you will be escorted down to the anaesthetics room on foot, as usually patients prefer this to being wheeled on a trolley! You will have a drip line inserted into your arm or neck for intravenous access; a spinal anaesthetic may be given to help with post-operative pain relief; and finally the general anaesthetic.

Recovery

The actual operating time is typically around 1½ hours; however you will be in the operating theatre for a period of time both before and after the surgery and can expect to be taken to the recovery room after about 2-3 hours. Some time later in the day you will be returned to your room.

When you are fully awake, you may be allowed to start drinking; alternatively, you will receive intravenous fluids until you are ready. However, you will not be given much food until you have passed flatus (wind), usually the next day. You should feel little or no pain; but if you do, please let the nurses know so that they can arrange for it to be managed.

You will find a catheter tube has been inserted in your bladder via the penis, draining urine into a bag. The urine is often blood-stained at this stage: although it will turn to yellow after a few days, it is not unusual to find blood in the urine intermittently for some weeks after the operation. The catheter will stay in place for another week or so, as will the clips that are used to secure the small incisions in your abdomen. The wound drain

that has been placed in the abdomen to prevent build-up of pressure from any oozing wound will remain there for one or two days.

Once you are able to mobilise, you will be allowed to shower and you will be taught how to take care of your catheter, so that you can manage yourself once you have been discharged. You may go home once you feel safe, confident about catheter care, your bowels are functioning and your pain is well controlled with tablets taken by mouth.

Anti-coagulation medication

Major surgery to the pelvis can occasionally cause a blood clot to form in the veins of the leg. The medical name for this is deep vein thrombosis (or DVT for short). These clots can be problematic and become very dangerous if they break free and travel through the bloodstream into the lung. To reduce the risk of this occurring you will be given a daily injection of a blood thinning medication called "Clexane" (enoxaparin) at a dose of 40mg. This medication is started 24 hours after your surgery and should be continued for 28 days. The injection is given in to the fatty tissue under the skin of your lower abdomen.

Whilst you are in hospital the nurses will administer the injections for you, but prior to leaving hospital, you or your partner will be taught how to inject yourself. The hospital may supply you with the medication you need for the full 28 days at the time of discharge, or alternatively provide you with a private prescription so that you can purchase the medication elsewhere. It is also possible that the hospital might be able to arrange for your NHS GP to supply the medication.

Companions and visitors

Your wife or partner will naturally be anxious to hear that the operation has gone well, and may want to come with you to hospital and wait for the news to be given personally by the surgeon. Alternatively, a telephone number can be left for the surgeon to call and this will be done as soon as possible after the procedure.

There are "open access" visiting hours for family members but please ask other visitors to check with the nurse in charge of your floor before coming to see you, as there will be times when you should not be disturbed. Sometimes we are asked if a wife or partner can stay in the hospital room overnight. This is often possible, depending on availability of companion beds, but it is costly, and discouraged by the nurses, whose job it is to make sure their patient is well rested and that nothing hinders his medical care. We can supply you with a short list of hotels which are within a few minutes' walk (see page 25).

Your surgeon and/or one of their Prostate Centre surgical colleagues will normally visit once or twice per day.

Going home

The doctor in charge will decide when you are ready to leave hospital. Please remember to take all medicines which you have brought with you or been prescribed to take home. Make sure you arrange for someone to collect you from hospital.

f) What to expect when you get home

General recovery

You should not forget that although you may feel comfortable and have no large wounds, you have still had major surgery and will need a period of time to recover before returning to normal activities. You may feel bloated and your clothes may feel tighter than usual; to help with this, wear loose clothing and try to be active around your home.

Do not "overdo it" by attempting to lift shopping or suitcases, mow the lawn etc; you could put a strain on your stitches and delay recovery.

We recommend that you have a rest, lying down, for 1-2 hours after lunch every day until at least a week after your catheter is removed. This will take some of the pressure off your pelvic floor and help you to regain continence.

During the first four weeks after surgery avoid sitting uright in a firm chair for more than 1 hour. It is better to sit in a reclining chair, sofa or comfortable chair with a foot stool.

Will I need nursing care?

You should not need a nurse at home. You will have been taught how to care for your catheter and will not be immobile. Obviously it is reassuring to have your partner looking after you, or otherwise to put friends on standby who can stay with you or on whom you can call if necessary.

Can I shower or take a bath?

You can shower (but not take a bath) as you usually would, making sure you rinse soap thoroughly from your body and pat yourself completely dry, especially around the umbilicus (belly button). Do not use lotions or creams on your wounds while they are healing, as this may cause irritation and increase the possibility of infection. It does not matter if your wound dressings get wet: just remove them and dry yourself carefully with a towel to prevent moisture sitting on the wound. Once the dressings are removed, it is not uncommon to see a small amount of oozing from a wound site. You can replace dressings that become soggy with new ones if you have any; otherwise use a large plaster to cover the wound and change it daily after showering.

When should I start taking my medications again?

If a course of antibiotics has been prescribed, please complete the course, even if you are feeling well. Resume your regular medications as soon as you are discharged from the hospital, unless otherwise advised. Please check with the medical team before you leave, if you are in any doubt.

When can I start exercising?

Light walking is encouraged right after the procedure. Take several short walks during the day and night and rest when you get tired. After about four weeks you can begin jogging and aerobic exercise, though nothing too strenuous. Heavy lifting or strenuous exercise must wait until at least six weeks after surgery.

It takes at least 6 weeks for a firm scar tissue to develop in both your wound and in the areas where you had surgery. If you over-do things before that time you may disrupt the delicate connection between your bladder and urethra. This could lead to long term problems with urinary control or a hernia in the incision.

When can I start driving?

Do not attempt to drive until you feel comfortable to do so – probably around 3-4 weeks. A good rule of thumb is to wait until you can comfortably twist to look behind you, or perform an emergency stop, bearing in mind that the seat belt may pull tightly across your stomach. It is wise to check with your insurance company whether you are covered in this post-operative period.

When can I have sex again?

You may resume sexual activity as soon as you feel able and comfortable enough to do so. You may not be able to achieve an erection to begin with, but arousal and orgasm are possible even without an erection. Regeneration of the nerves may take several months and can continue for a few years after the operation, but it is strongly recommended that you begin a **rehabilitation programme** (see page 21) at an early stage, in order to prevent permanent loss of erectile smooth muscle tissue. We advise you to book your first appointment with **Mrs Lorraine Grover** at some stage prior to your operation, or alternatively at or shortly after the time of catheter removal.

When can I go back to work?

If you have a sedentary job and assuming normal recovery, you could be ready to return to work after two weeks. Usually however, it is wise to allow time for a complete recovery and not go back to work too soon. Starting work after 4 weeks, perhaps part-time to begin with, is realistic and sensible. Heavy or manual work should not be attempted until at least four weeks after the operation.

When can I fly, go on holiday or return overseas?

Many patients like to book a holiday as a means of continued recuperation, and many overseas patients want to return home as early as possible. It is advisable to wait until at least a week after catheter removal before leaving. You should also bear in mind that the destination is an important factor: travelling to a seaside resort in France or visiting family in New York, where you can expect excellent medical care in the event of any problem, is not the same as going on safari in the African bush. Please ask the advice of our medical team if in doubt.

g) Problems you may encounter

Bruising around the incision sites and abdomen

This is not uncommon and should not alarm you. It will resolve over time.

Leaking or oozing at a wound or drain site

Change your dressings daily or as necessary. Wash the wound in the shower, then pat dry with a clean pad or towel before applying a clean dressing.

Abdominal bloating or constipation

Any bloating should settle quickly after your bowels start returning to normal; you may find your bowel movements are loose initially. Try to avoid becoming constipated: make sure you use your stool softener (Lactulose) and gradually increase the fibre in your diet by eating lots of fruit and vegetables and drink lots of water.

Weight gain

This is temporary and due to gas and fluid. Your weight should be back to your preoperative level within a week.

Leaking urine around the catheter

This is fairly common, especially if you strain. You may need to wear a small pad inside your underwear for protection.

Blood in the urine

You may find this happens after increased activity or following a bowel movement. Resting for a short period usually improves the colour of the urine; drinking more fluids helps to help keep it dilute.

Bladder spasms

Strong bladder contractions can be caused by irritation from the catheter, presenting as mild to severe pain or cramping, with the sudden need to urinate. This is perfectly normal but if you are troubled by it, let your consulting team know as the symptoms can often be relieved with tablets.

Perineal pain

Sometimes, after a radical prostatectomy, the testicles or perineum (the area between the scrotum and the anus) may be uncomfortable or painful. This is where your prostate gland was located, and is therefore the site of surgery. The discomfort may last for several weeks after surgery, but it will resolve. Simple pain medications such as paracetomol or ibuprofen should give relief, and sitting on a soft pillow or lying down may help. Please let us know if these measures are not enough.

Genital swelling and bruising

Scrotal or penile swelling and bruising may appear immediately after surgery but is not common after robotic prostatectomy. It should resolve in 7-14 days. You can reduce the swelling by elevating the scrotum on a small rolled-up towel when you are sitting or lying down. It is recommended that you wear supportive underwear such as Jockeys, even with the catheter in place.

Lower leg or ankle swelling

This can occur in both legs and should resolve in 7-14 days. Elevating your legs when sitting will help.

CONTACT US IMMEDIATELY (see page 25) IF YOU ARE EXPERIENCING ANY OF THE FOLLOWING:-

- Any pain that medication does not relieve
- Large amounts of clot in the urine that are blocking the catheter tube and preventing it from draining
- Bladder spasms that are not relieved by pain medication
- Nausea or vomiting
- High temperature or sweats
- Sudden breathlessness, dizziness or chest pain
- Uneven swelling of the legs, with redness or pain

Do not worry about "bothering the doctor" – this is all part of your postoperative care and we would rather know about any problems you may have.

2. COPING WITH YOUR CATHETER

The catheter is a soft, hollow silicone tube that drains urine directly from the inside of your bladder. It passes up the urethra into the bladder, and is held in place by a small inflatable balloon near the tip that is filled with sterile water.

You will find the catheter in place when you wake after your surgery, and it needs to remain there while the new join that has been created between your bladder and urethra is allowed to heal. This takes about a week, so you will go home with the catheter after three nights in hospital. You will come to The Prostate Centre approximately eight days after the operation to have it removed.

While at home, you will need to care for the catheter and drainage system. The components of this are:

- the catheter
- the leg bag for daytime use
- the leg bag support
- the G-strap
- the night drainage bag

Everything you need will be given to you when you leave hospital. However you will need to buy your own supplies of pants and pads for use after the catheter is removed (see pages 6 and 18).

a) How to use and care for your catheter

The catheter tube

You need do nothing to the catheter itself, other than to keep it clean from the outside. Having first washed your hands, wash the area around the catheter at the tip of the penis with soapy water at least twice a day; debris and mucous will collect there. If you have a foreskin, make sure you wash under it, replacing the foreskin over the head of the penis afterwards. Rinse and dry well. Never use any creams or talcum powder near the catheter.

The leg bag

This is attached directly to the catheter and will collect urine during the day. It will be secured to your leg, so that as it fills you will feel it getting heavier. You should not let it get too full. To drain it, simply open the tap at its base to allow urine to flow into the toilet. Always wash your hands before and after doing this.

The leg bag support

This is rather like a sock and is used to keep your leg bag securely attached to your leg.

The G-strap

This prevents the catheter from pulling down on the penis. It is a Velcro strap which fits around the catheter and your upper thigh, holding the catheter firmly in position.

The night bag

The larger night bag is connected directly on to your leg bag at night. To attach it, please carry out the following steps:

- Remove the leg bag support
- Attach the night bag to the base of the leg bag, and open the tap so that urine can flow directly into the night bag.
- The night bag is then attached to a stand (you will be shown how to do this)
- In the morning, close the tap at the base of your leg bag and disconnect the night bag. Empty the urine out of the night bag into the toilet and discard the bag. Use a new bag the following night.

b) General guidelines

Positioning of bags

- Keep the bag attached to the catheter at all times, even when showering
- Keep the catheter strapped to your thigh for comfort
- Keep the drainage bags and tube free of kinks and loops
- Always keep the drainage bags below the level of the bladder

Changing of bags

You will be sent home with a small supply of night bags (enough to last until catheter removal) and a spare leg bag. The leg bag should not need to be changed unless you have a problem or unless your catheter needs to remain in place for more than 7 days, in which case you should ask us if you need to replace it.

Always wash your hands before and after changing or emptying the bags.

Disposal

If you have to change your leg bag, first empty it of urine and then rinse it out. Leg and night bags should be disposed of in a plastic bag with your household waste.

Fluid intake

You need to ensure that you are drinking two litres (8-10 large glasses) of fluids per day. Try to include plenty of water. Above all, it is important that you include cranberry juice, 200ml twice daily in your fluid intake.

Bowels

After the anaesthetic, the operation, and the drugs you have had, the bowels can take some time to return to normal function. You will have brought home your bottle of Lactulose when you left hospital; this is a stool softener and you will be taking it every day. It is important that you keep your bowels regular, but equally important not to strain on the toilet. If the Lactulose alone is not working, obtain some SENNA from your chemist and take this as well. Remember also that your diet is important, so include plenty of fresh fruit and vegetables; prunes, prune juice and All-Bran can also be helpful.

c) Problems you may encounter

Bladder spasms

Bladder spasms (which feel like abdominal cramps) are quite common when you have a catheter. The bladder may try to squeeze out the balloon, which results in a muscle spasm. This may feel somewhat uncomfortable, but is not a cause for concern.

Soreness

The tip of the penis may become sore as a result of the catheter rubbing on this sensitive area; so it follows that any soreness will lessen after the catheter is removed. If you have this problem while you are still in hospital, you will be given some local anaesthetic gel to apply, and some to take home with you. If you start to feel sore for the first time after you have returned home, the gel (eg INSTILLAGEL) can be bought over the counter from your local chemist.

Urine leakage

Urine leakage around the outside of the catheter is called "bypassing". It is sometimes the result of a bladder spasm, or it can take place when you are opening your bowels. When it happens, check to ensure that the catheter is still draining into the bag. If no urine is draining, please contact the nurses at the hospital for advice (see page 28).

Blood in the urine

This is not uncommon after radical prostatectomy. When you go home and become more mobile, the catheter can cause inflammation in the bladder and this can lead to blood staining in the urine. You may also see blood in the urine when opening your bowels. The best thing to do is drink plenty of extra fluids, and the problem should resolve in time. The bloodstaining is of concern only if you can see large clots or solid pieces of debris passing down the catheter, because they can cause a blockage. If this happens, contact the nurses at the hosptial immediately for advice on what to do.

Airlock

Occasionally when the bag is emptied, an airlock may form. This is caused by all the air emptying out of the drainage system and can cause urine to stop draining, but is easily fixed. If the sides of the bag look sucked hard together and no urine has drained, just allow a small amount of air back into the system after emptying your bag by pulling the front and back of the bag slightly apart while the tap is open.

Infection

A urine infection can cause any of the following symptoms. If you notice one or more of these, contact The Prostate Centre, your surgeon or the nurses at the hospital as you will probably need some antibiotics:

- cloudiness of the urine
- cystitis (a burning sensation)
- strong smell
- high temperature (fever) and/or shaking attacks

IMPORTANT: If you notice that the catheter is not draining at all:

Check that:

- the drainage bag is below the level of your bladder
- the catheter has no kinks or twists in it
- · you are drinking enough fluid
- you are not constipated

If 1-2 hours pass without <u>any</u> drainage of urine taking place, the catheter may be blocked and therefore need either unblocking or changing. If this happens, you must contact the nurses at the hospital (see page 28) without delay as the problem will have to be dealt with in a hospital by flushing out the catheter.

3. CATHETER REMOVAL DAY

The day the catheter is to be removed (known as "Trial Without Catheter", or "TWOC") is usually eagerly anticipated by patients. The date for this will be fixed while you are still in hospital, to take account of your general progress, logistical issues, availability of staff and your own convenience. It generally takes place 7-9 days after the operation.

What you will need

Please make sure that you have a small supply of heavy-duty pads and either continence pants or closely fitting underpants to secure the pads, and bring some with you on the day. (See page 6 for information on where to get these products.)

The procedure for TWOC day

You will need to come to The Prostate Centre in the morning, having had plenty to drink at breakfast time, and should count on being either with us or somewhere nearby for several hours. This is because, after the nurses have removed your catheter and abdominal clips and have checked your wounds, you will need to wait until your bladder fills enough for you to want to pass water. Once urination is established we will perform an ultrasound scan of your bladder to make sure you have been able to empty it efficiently. We will run further checks on your blood and urine.

If all is satisfactory you are encouraged to go out and have lunch, and perhaps a very gentle walk; there are many places to eat nearby in Marylebone High Street. At some point you will feel that your bladder is full again and we will want you to come back to The Prostate Centre for a further ultrasound scan. After that, you are free to go.

What to expect when the catheter is removed

You should bear in mind that your bladder has not been filled with urine for a while, and that the outlet has been kept open artificially. The tissues at the site of the surgery are affected by swelling and lose their elasticity temporarily. In addition, because the bladder neck has been traumatised during the separation of the prostate, until it heals the sphincter tends to be less competent than before. This means that many patients will experience difficulty with urinary control initially. Unaccustomed leakiness can be upsetting but if you know what to expect, you can focus on the fact that this will certainly improve with time.

When the catheter is first removed, it is likely that you will leak urine and find yourself unable to control the flow: it will most probably happen on coughing, laughing, standing up and other similar actions, and tends to be worse in the evenings. It is possible that all the urine may leak out and you may feel that you have no control at all.

Gradually, as the swelling of the tissues subsides and the normal elasticity and bladder capacity return, things will improve. The time it takes to become fully continent varies from person to person and is unpredictable. One third of patients regain continence on removal of the catheter; a further third do so within three months of the surgery, and almost all the remainder become continent after a further three to six months.

You should continue to wear small incontinence pads for a few weeks or until you are confident you no longer need them.

As before, if you notice any signs of infection (eg burning on passing water, cloudiness of urine, strong smell, high temperature) make sure you contact us.

4. PELVIC FLOOR EXERCISES

An important factor in regaining your urinary control is to ensure that the relevant muscles recover their tone and strength. This can be achieved by performing special exercises for the pelvic floor. You cannot do them effectively while your catheter is in place but once it is removed, you should start straight away.

The pelvic floor is a strong sling, or hammock, of muscles that help to support the bladder and the bowel. The muscles stretch across the inside of the pelvis and are attached to the pubic bone at the front and the coccyx (tail bone) at the back. These muscles naturally relax when you pass urine, to let the flow through, then tighten again at the end of the flow to prevent leakage.

There is a knack to doing pelvic floor exercises and you will need to learn it. Ideally you should have been performing the exercises regularly in the lead-up to the operation. If you have not been doing so or have not yet learnt how to do them, you will be taught before you leave hospital.

To locate the correct muscles

- When passing urine, try to stop the flow by contracting your muscles up and inwards; then let go. Don't worry if the flow did not stop altogether.
- Pretend you are controlling an attack of diarrhoea and pull up the muscles around the back passage.

To perform the exercises

- Sit comfortably on a chair with your legs apart and your feet flat on the floor.
 Lean forward and rest your forearms on your thighs.
- Draw up both sets of muscles (as above) at the same time. Hold for a count of five, then let go slowly.
- Pause for a count of five. Then repeat this until you have done a total of five contractions.
- Aim to keep your stomach, thigh and buttock muscles relaxed and use only your pelvic floor muscles. Using other muscles will defeat the purpose of the exercise.

Getting into the habit

You need to build strength and endurance of your muscles and this requires regular exercise, just like an athlete in training. To achieve best results, perform the set of five contractions once per hour every day. In addition, you should perform one set of 20 short sharp pelvic floor contractions each day.

It is likely that several weeks of regular exercise will be necessary before an improvement is apparent. However you should persevere, and continue the exercises even after you start to notice the improvement. To help you remember, try to make the exercise a part of your daily routine, for example by scheduling each set of contractions to accompany a certain daily task.

5. YOUR HISTOLOGY (PATHOLOGY) REPORT

The question on every patient's mind, once the operation is over, is: "Have I got rid of the cancer?"

Surgical removal of the prostate offers the only definitive means of finding out the extent of the tumour. All other therapies have to rely on PSA monitoring over time, and sometimes repeat biopsy, to give an indication as to whether or not they have been effective.

In order to do this, the entire prostate, together with the seminal vesicles, and lymph nodes if these have been removed, are sent by courier to our specialist urological pathologists at St George's Hospital in South London. Here the specimens are "fixed" with formalin and sliced, then examined carefully under the microscope so that the extent and exact location of the tumour may be identified. Often, more than one is found.

It takes about 4-8 days for the pathologist to prepare, examine and report on the specimens. The report is faxed to The Prostate Centre and should be ready by the time you come for catheter removal.

The report will describe the "Gleason" pattern, which is made up by adding the score of the two main/significant tumour types, and varies from 4 (the least aggressive) to 10 (the most aggressive). The tumour volume will be assessed, as will the location of the cancer: it is important for your follow-up management that we know whether it has invaded or penetrated the capsule of the prostate or whether it is contained within it. The report will note whether tumour is present at any of the "margins" (edges) of the specimen to any significant degree (not all positive margins are important); also whether there is seminal vesicle or lymph node involvement.

A report that demonstrates a well contained, "well differentiated" tumour with a low Gleason score is cause for celebration since you can consider yourself cured. On the other hand, a less than perfect result is not necessarily a cause for despondency, since it may still mean that you are effectively cured. And if there is any potential need for further treatment in the future such as a course of radiotherapy, we have the information on which to base it and an opportunity to plan it at an appropriate stage for optimum results.

The terminology in a histology report obviously requires careful explanation. Your consultant will go through your results in detail with you and your partner, and discuss the implications. You can also, if you wish, contact the pathologist by telephone or e-mail for a more detailed interpretation of your results.

6. SEXUAL FUNCTION

(also referred to as Erectile Dysfunction, or ED)

<u>All</u> forms of treatment for prostate cancer are likely to affect sexual function, and most patients will need help in restoring their erections afterwards. Temporary use of drug therapy and mechanical aids can be helpful, and men can regain normal function over time – although some may need to continue with their preferred therapy in the long-term. In addition, the emotional impact of your diagnosis and treatment on both you and your partner, if you are in a relationship, should not be underestimated. So it is good idea to be aware of the changes that may occur, to manage your expectations and to understand what can be done to help you and your partner overcome any problems.

The effects of surgery

Ejaculation ceases completely after surgery. However, this does not normally affect a couple's sexual satisfaction: orgasm (climax) is usually possible, even during the period when the erections are not sufficient for penetration. In the early stages, some men can lose a small quantity of urine at orgasm (climacturia); this generally resolves over time.

"Nerve-sparing" surgery aims to reduce the damage done to the nerves which control erections. The robot-assisted procedure gives the best possible opportunity to do this as the 3D image and 10X magnification give the surgeon a superb view of the nerves. However, there is inevitably some disturbance to them, caused both by the stretching and displacement involved when accessing the prostate gland and by the heat generated by the cauterisation which prevents bleeding.

The effects of surgery on erections can vary from nil or minimal, at the bottom end of the scale, to severe and prolonged, at the worst end of the scale. Most men's experience lies somewhere between these two extremes and you should be prepared to be affected in some way. We find that most men are able to get reasonable erections, whether naturally or with the help of medication or mechanical aids, within six months of their operation. The remainder find that recovery can take up to 4 years, and perhaps around one-fifth will need to use other treatments, such as injection therapy, long-term.

Why you should start thinking about this NOW

Studies have shown that men who completely lose their erectile function and night-time erections straight after radical prostatectomy may go on to experience a gradual and permanent loss of smooth muscle in their penis over time, reducing their capacity to get erections in the future. But research has also shown that working to restore erections during the first six months after a radical prostatectomy may improve the recovery rate of normal erections. In other words, "if you don't use it, you lose it".

So if penile length and function is important to you, we would strongly urge you to begin a rehabilitation programme as soon as possible, to keep the smooth-muscle fibres healthy, functional and responsive while waiting for the nerves to grow back.

How you can help yourself

We take your sexual wellbeing very seriously at The Prostate Centre, because we know what a difference good advice and appropriate guidance can make. We are very fortunate to have on our team one of the most dedicated and knowledgeable therapists

in the UK: Mrs Lorraine Grover has unparalleled experience in helping men with their rehabilitation to overcome post-operative sexual problems, both physically and emotionally, having specialised in this area for over a decade.

Lorraine has devised a unique and comprehensive **ED management plan** for Prostate Centre patients, tailored to each individual, which may include:

- in-depth consultation sessions for assessment, explanation, instruction, guidance and counselling (we encourage your partner to attend with you)
- medications (Cialis, Viagra, Levitra) to use as continuous and ad hoc treatment
 provided that you have no contraindications to these
- a vacuum pump (mechanical aid to help re-establish correct blood flow)
- prostaglandin pellets (MUSE) as an alternative or add-on to tablets
- trial session of injectable prostaglandin medication (Caverject)

(NB: these services must be paid for on the day of attendance.)

Can't I just get all this on the NHS, or on my insurance?

Unfortunately this depth and quality of care is simply not available on the NHS. Your GP may be prepared to prescribe a very limited amount of medication or mechanical aids – indeed there is provision within the NHS guidelines for radical prostatectomy patients to receive a small number of tablets – but he/she will not have the time, expertise or resources to take you through the range of treatments available, let alone optimise your regime or tailor it to your own personal circumstances and requirements.

Unfortunately, too, health insurance companies will not pay for ED, even though it may be a consequence of surgery. They view it as a "lifestyle" rather than a medical problem.

While dealing with the cancer may be uppermost in your mind at this time, we do strongly advise all patients that to give yourself the best possible chance of sexual recovery, you should address these issues early and consult Lorraine before your operation – maybe even while you are still weighing up your treatment options. We like to include your partner, but it is important even if you are not currently in a relationship.

First things first

In order to be able to help you to the best of our ability, we need to know something about your "normal" sexual function. As part of this process we ask that you fill in and return the **questionnaire** in this pack before the date of your surgery. If you already have some erectile problems, for example, it is particularly important for you to start treatment prior to the operation. It is equally important to have realistic expectations, and this will help us to advise you.

The International Index of Erectile Function (IIEF) questionnaire is a widely used and well validated questionnaire to assess male sexual function in clinical practice. Please be assured that your responses will be treated in the **strictest confidence**; they will not be disclosed to anyone outside The Prostate Centre without your consent.

- Place the questionnaire in the envelope, seal it, and return it to a member of staff or send it to us by post
- Please ensure that your name and date of birth are recorded on the questionnaire, together with the date of completion

 If you do not wish to complete the questionnaire, please write "Declined" across the form

Should you have any questions about this questionnaire, about your current sexual health or about the potential impact of treatment on your sexual function, please don't hesitate to ask any member of our medical or nursing team for more information.

7. FEES INFORMATION

We do not want you to have any unpleasant surprises when it comes to the cost of this operation. Therefore you will need to know about any financial implications and how to proceed, whether you have insurance, are sponsored by a third party or are funding your treatment yourself. Please read this section carefully.

The first thing to remember is that fees are not billed as one single "package" but fall into four separate categories: the hospital; the surgeon; the anaesthetist; and any pre- or post-operative outpatient consultations, tests or other services (eg imaging/ laboratory fees, involvement of other specialists, etc). These parties will send their invoices individually, on their own account.

The second thing to remember is that whether or not you have any insurance cover, the responsibility for payment lies ultimately with you. The "contract" when you undergo treatment is between the patient and the provider (eg the surgeon, the anaesthetist etc): if you have insurance, then the extent of your cover is a matter between yourself and your insurer. So when bills are sent direct to an insurance company or other third-party sponsor, you can expect them to be paid according to your agreement with them; however, in the event of any non-payment or shortfall, you become liable for clearing the account.

The fees should have been discussed with you while you were deciding on your treatment, because they are not always paid in full by insurers and you may be faced with a shortfall – sometimes a significant one, depending on your insurer's agreements with hospitals and/or benefit levels for robotic surgery. Every insurer is different and cover levels vary. We strongly suggest that you speak to your claims team about this.

We are of course happy to help you find out exactly what your liability, if any, might be. Drawing on our considerable experience in dealing with the insurance companies, we can guide you through the process and advise on how to proceed.

If you are paying for your own treatment it is important for you to go through with us all the various costs and payment processes.

It is in everybody's interests to be clear about financial issues in advance, so please do speak to one of our Patient Liaison team at your earliest convenience.

8. STAYING IN LONDON

You will need to decide where you will stay during the few days after you are discharged from hospital and before you come back to The Prostate Centre to have your catheter removed.

If you live nearby or within easy reach of London, it is best to stay at home; if you live more than one hour's drive away, you should find an alternative (eg with a relative, or in an apartment or hotel). This is because in the event of any problem, such as a blocked catheter, it is important to be near the hospital, and the team, that is experienced in this type of surgery and its consequences.

The following is a list of hotels very close to The Prostate Centre and the hospital:

- La Suite Hotel, Nottingham Place, London W1 (some self-catering facilities, breakfast only provided by hotel) www.lasuitehotel.com
- The Marylebone Hotel, Welbeck Street, London W1. www.doylecollection.com
- Durrants Hotel, George Street, London W1 <u>www.durrantshotel.co.uk</u>
- The White House Hotel, Albany Street, London W1 www.meliawhitehouse.com
- Holiday Inn, Welbeck Street London W1 www.holidayinn.co.uk (search: London – Oxford Circus)
- The Landmark London, Marylebone Road, London W1 www.landmarklondon.co.uk

Our patients from Greece and Cyprus may be interested in the following small, family-run hotel in Bayswater (20 minutes' walk from The Prostate Centre and the hospitals) which is owned by a lovely Cypriot patient of ours and his wife. The rooms are not large and the facilities not as extensive as in the big chain hotels; but of course they speak Greek - and perhaps more importantly, have been through the whole process of George's prostate operation and care under our team at The Prostate Centre!

 St David's Hotel, 16-20 Norfolk Square, London W2 1RS www.stdavidshotels.com

9. SUPPORT SYSTEMS

You may already know how disruptive prostate problems can be to your life, and you may be prepared for some of the practical issues you'll face after prostate cancer treatment. But along with the physical difficulties come a number of emotional challenges which may affect not only yourself, but your wife or partner and family too.

While our primary concern for you as our patient is to help you overcome your condition, we see it as fundamental to a successful outcome that support is available as and when you need it.

That means support from those at home as well as from us. It means everything from encouraging your partner to be present during your visits and to take an active part in helping you reach a decision on treatment, right through to offering professional help when one or both of you feel the need.

It means helping you work through some of the many anxieties you may have – the sort of anxieties you might have been reluctant to raise with your consultant but which have remained as nagging questions ever since:

- Am I going to survive this?
- What should I say to other people?
- When should I tell our children?
- How is life going to change for me and my family?

Many stages in your "patient journey" can be potentially stressful and it is often helpful for you and your partner to share your concerns about them with others. These are some examples:

- Anxieties about procedures and side effects
- Waiting for results
- Organisation and planning
- Facing the future

The Prostate Centre has a range of facilities available to support you through various periods of your diagnosis and treatment:

- We have many previous and current patients we can put you in touch with who will be happy to talk over the issues with you, in confidence.
- Our highly trained nurses will spend time with you to explain practical matters and help you cope with physical and emotional difficulties
- For those who need further professional help, advice and counselling can be arranged with a specialist with a special interest in patients and families suffering the emotional consequence of life-threatening illnesses and surgical procedures. Most insurance companies will cover these consultation fees if you have been referred by your consultant; however you should check the terms of your policy beforehand. Call our Patient Liaison team if you would like to be referred.

10. FOLLOW-UP/CONTINUING CARE

We will want to monitor your progress in the weeks, months and years following your radical prostatectomy. This is very important.

Regular PSA checks

You should have regular PSA checks according to the following schedule:

- One month after TWOC
- After that, every three months for the first year
- Six-monthly (twice a year) for the second year
- Annually thereafter.

Ideally, you should come to The Prostate Centre for follow-up. Not only does this provide continuity for you, with the same consulting team, it also provides us with valuable data with which to monitor the success of the robotic prostatectomy and helps us to build improvements in to our patient care.

You will need to have a PSA test prior to each appointment, allowing at least 5 hours for the laboratory to process your blood sample (the test can be done several days in advance if you wish).

Other help and advice

You will also be able to discuss any problems you may be having, including continence and sexual issues. If you think you need specialist help in either of these areas you can make an appointment through our Patient Liaison team.

Do not hesitate to make a follow-up appointment at any time if you have any concerns or problems.

Please note that it may not be possible on these routine follow-up sessions always to see your surgeon in person. You will know by now that The Prostate Centre works as an integrated team, and will have shared knowledge of your case (having most probably discussed you in our multi-disciplinary team meetings as part of your care pathway). Depending on availability, you may therefore be asked to see another of our specialists.

11. CONTACT INFORMATION

The Prostate Centre is open 9am-5pm Monday-Friday

Phone (020) 7935 9720 Fax (020) 7224 5706

e-mail: info@theprostatecentre.com

There is a urology nurse specialist available during working hours at The Prostate Centre. Please call if you have any concerns regarding your health or progress.

Please call to speak to our booking or accounts staff if you would like to make or change an appointment or have any queries regarding payments.

For any URGENT medical problems out of office hours please contact:

•	Hospital	(020) 7
	Direct number for the ward (ask for the nurse in charge)	(020) 7
•	Surgeon	

CONTACT US IMMEDIATELY IF YOU ARE EXPERIENCING:-

- any pain that medication does not relieve
- bladder spasms that are not relieved with pain medication
- nausea or vomiting
- high temperature or sweats
- breathlessness, faintness or chest pain
- large amounts of clot in the urine that are blocking the catheter tube and preventing it from draining