

Royal Prince Alfred Hospital



Health
Sydney
Local Health District



Pelvic Exenteration

Patient Information

Patient information

This information booklet is for patients who will have pelvic exenteration surgery at Royal Prince Alfred Hospital (RPAH). Your family members or carers may also find it helpful to read.

It includes information about the surgery and information about the hospital. This information should be used as a guide to help you prepare for surgery and for your recovery afterwards. You will be given extra information by hospital staff about your individual needs.

There is some medical terminology in this book. Please ask your treating team if you have any questions about this information.

Your care is important to us, if you have any questions or concerns please speak to your doctor, nurse, or clinical care coordinator.



Consumer reviewed

This booklet has been reviewed by patients and consumers through the Sydney Local Health District Community Participation team.

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What is Pelvic Exenteration?

Pelvic exenteration is a surgery performed at Royal Prince Alfred Hospital for patients with extensive primary or locally recurrent pelvic malignancy, most frequently associated with rectal or gynaecological cancer. A pelvic exenteration is performed to remove cancer that has involved part, or all of, the contents of the pelvis. Surgery can differ depending on the position and involvement of the disease and so it is important to ask questions and remember what your surgeon has explained to you.

Total Pelvic Exenteration:

A Total Pelvic Exenteration removes the bladder, urethra, reproductive organs, rectum, anus, and supporting muscles and ligaments. If bone is involved, a sacrectomy (taking part of sacrum) will also be performed. A Vertical Rectus Abdominis Muscolocutaneous (VRAM) flap is sometimes used to fill in the cavity of the perineum. This is done by taking a part of the rectus muscle and transposing it, to allow the skin island to exit the area of the anorectal resection. The flap is then tailored to fill in the perineal deficit and stitched to the surrounding skin. A total pelvic exenteration can leave you with two permanent stomas, a colostomy and a urostomy.

Anterior Exenteration:

An Anterior Exenteration removes part or all of the organs towards the front of the pelvic cavity. In females this includes the vagina, uterus, ovaries, bladder and urethra. In males this includes the prostate, bladder and urethra. Usually the rectum and anus are spared. The operation leaves you with a permanent urostomy.

Posterior Exenteration:

A Posterior Exenteration removes part or all of the organs located towards the back of the pelvic cavity. In females this includes the vagina, uterus, ovaries, rectum and anus. In males this includes the rectum and anus. Usually the bladder and urethra can be spared. This operation leaves you with a permanent colostomy.

Lateral Exenteration (left or right)

A Lateral Exenteration removes structures that are involved along the side wall of the pelvis – this can include the ilium and ischium bones as well as important vessels, muscles and nerves. Sometimes vascular teams assist with reconstruction of veins and vessels that are involved during surgery.

Central Exenteration

A Central Exenteration removes part of or all of the organs situated in the middle of the pelvic cavity. This can include bowel, bladder, connective tissue, gynaecological organs and pelvic floor. This operation can leave you with a permanent colostomy, a temporary ileostomy or a permanent urostomy.

Meet the team

You will be meeting a number of health professionals during your hospital stay. The following information will help you understand the role of each staff member.

Medical Team:

- Colorectal Consultants (Surgeons)
- Other Consultants (this may include Urology-oncologist, Upper plastics Surgeon)
- Surgical Fellows
- Surgical Registrars
- Senior Resident Medical Officers
- Interns

A member of your medical team will visit you daily – Monday to Friday. Weekends are covered by an on-call consultant.

Please note that although all these health professionals may be involved, your lead surgeon ultimately makes decisions about your medical care.

If you, or a family member or carer, has any concerns, arrangements can be made for the medical team to answer your questions at an agreed time.

If you have questions about your day to day care, please ask your nurse on duty, Nurse Unit Manager or the Pelvic Exenteration Care Co-ordinators.

Nursing Team:

Nursing staff work four shifts:

Morning	Mid-Shift	Afternoon	Night
7am - 3.30pm	9am - 5.30pm	1.45pm - 10.30pm	9.45pm - 7.45am

The nursing team includes:

Nurse Unit Manager (NUM): is in charge of the running of the ward

Pelvic Exenteration Clinical Nurse Consultant: will work with you to coordinate your care before & after your surgery and can answer questions you may have.

Pelvic Exenteration Nurse: Will work with you to co-ordinate your care from the Preadmission Clinic, through your admission and assist in discharge planning.

Clinical Nurse Specialists (CNS): are experienced nurses who have specialised in colorectal nursing.

Registered Nurses (RN)/Enrolled Nurses (EN): provide your daily nursing care

Stomal Therapy Nurses: work with you to assist in managing your stoma (colostomy/ileostomy/urostomy)

Nurses wear the NSW Health uniform which consists of navy pants / skirts and different coloured tops, according to their role:

Role	Uniform
Nursing Unit Manager:	White with blue and black stripes
Clinical Nurse Consultants:	Light blue and dark blue stripes / navy blue scrubs
Clinical Nurse Specialists:	Navy blue scrubs
Registered Nurses:	Navy blue scrubs
Enrolled Nurses:	Navy blue scrubs with a light blue edging on sleeve
Assistant in Nursing:	Royal blue scrubs

Allied Health Team:

The allied health team includes:

Clinical Psychologist: will discuss your cancer journey, past and current coping strategies and utilising supports to aid your recovery

Dietitian: will help you optimise your nutrition before your surgery and provide nutrition support after surgery to assist with your recovery

Physiotherapist: will work with you towards your goals of moving around again after surgery, which may include sitting exercises and walking

Social Worker: will provide you, your family and friends with emotional support, and will also organise practical support if extra assistance is required upon leaving the hospital. The Social Worker may also be able to assist with concerns regarding immigration, welfare, housing and transport.

Depending on your individual needs, you may also see:

- Aboriginal Liaison Officer
- Adolescent or Youth worker
- Drug & Alcohol worker
- Interpreter
- Hospital Volunteers
- Ministers of Religion
- Occupational Therapist
- Palliative Care Services
- Pharmacist
- Speech Therapist
- Private patient liaison officer

Royal Prince Alfred Hospital acknowledges the importance of your cultural and religious needs and will take this into consideration wherever possible regarding your care.

If you require further assistance from one of these staff members please let your nurse know.

Support Staff

You may also see these staff around the ward:

Position	Role	Uniform colour
Ward Clerk:	Carries out administrative duties for the smooth running of the ward	Purple
Clinical Support Officer:	Administration for NUM and Colorectal Unit	Purple
Ward Assistant:	Assists with general ward daily tasks	Green
Porters:	Transfer patients through the hospital	Green and navy
Cleaning staff:	General cleaning around ward areas	Green and navy
Dietitian assistants:	Assist with choosing food menu	Navy and white
Kitchen staff:	Deliver your meals	Green and navy

Planning to come to Hospital

You have met some of the team at your appointment with the surgeon and are thinking about coming in to hospital for your admission. Here are some ideas to help you prepare.

- Book/magazines — you may not feel like reading in the first few days after surgery, but you might find you need some entertainment
- Ipad/headphones — if you are travelling to Sydney to get to Royal Prince Alfred, valuables can be locked away while you are in surgery and ICU. If you are local, consider asking someone to bring these things in for you during your ward stay
- Phone — have you got credit for your phone
- Small amount of money for newspaper or something from the café
- Toiletries and pyjamas
- Cushion/pillow — a favourite item from home can be a comfort
- Photos/soft toy — small reminders of home you may want on your bedside
- Eye mask/earplugs — sometimes it can be difficult to fall asleep in a shared room. Eye mask or earplugs may help

Pre-Admission Clinics

1. Pelvic Exenteration Clinic, Suite 410, Level 4 at RPA Medical Centre.

You will be provided an appointment at the pelvic exenteration clinic prior to surgery. It may be a few weeks before surgery, or less, depending on your appointment date with the surgeon.

Here you will meet with more staff on the pelvic exenteration team for specific information and an assessment of your current situation.

- Clinical Nurse Consultant
- Clinical Psychologist
- Dietitian
- Physiotherapist
- Research officer
- Stomal Therapy Nurse (if applicable)
- Pain Specialist (if applicable)

2. RPA Pre-admission clinic: Level 2: RPA Medical Centre

You will also be required to attend a *general* pre-admission clinic at Royal Prince Alfred Medical Centre prior to surgery. At this clinic, you will meet:

Anaesthetist: the anaesthetist will assess your overall health to ensure that you are fit to undergo major surgery. They will also provide you with information about your pain management options.

Resident Medical Officer (RMO): the RMO will ask about your medical history. Please bring a list of all your medications, x-rays and relevant letters as it will help us understand your previous medical problems and provide you the best possible care.

Chronic medical conditions

If you have a chronic medical condition such as **asthma** or **diabetes**, these will need to be managed as best as possible prior to surgery. You may be required to see your specialist in these areas before your surgery can go ahead.

Smoking

Smoking **increases the risk of post-operative lung infection** and impairs wound healing. We encourage you to **consider quitting**. Please speak to your GP about the role of nicotine patches.

Pelvic Exenteration CNC: you will meet with the CNC and have a chance to discuss your upcoming surgery and hospital stay.

Stomal Therapy Nurse: the stomal therapy nurse will discuss managing a stoma (colostomy/ileostomy/urostomy) - if relevant to your situation.

Clinic Nurse: the nurse will check your blood pressure, heart rate, oxygen saturation and height and weight. They will also organise a routine ECG, chest x-ray and blood tests.



IF YOU ARE ON BLOOD THINNING MEDICATIONS SUCH AS ASPIRIN, WARFARIN OR PLAVIX, THEY WILL NEED TO BE STOPPED PRIOR TO SURGERY; THIS IS USUALLY THE WEEK BEFORE.

Please allow 3-4 hours to be spent at the clinic. We suggest that you have something to eat and drink before you come and bring something to keep you entertained!

Day before your operation

Bowel Preparation: A bowel preparation is a medicated drink that allows the bowel to be cleansed and emptied. Whether you are required to have the bowel preparation depends on your surgeon and the type of surgery you are having. If you do need a bowel preparation, information how to take it should be given to you by your surgeon.

All bowel preparations are to be taken the day before surgery. We recommend that once you have taken the preparation you remain at home and near a toilet. If you are required to have a bowel preparation you may only drink clear fluids the day before your operation.

Fasting: All patients are required to fast before an operation to reduce the chance of food inadvertently entering their lungs, which may cause lung infections.

Strictly **NO FOOD AFTER 12AM (midnight)** the night before your operation. You can have clear fluids up until 6am the day of the operation

Skin preparation: Patients, who are hairy, will have their hair clipped by their surgical team on the day of the surgery. Please do not attempt to shave this area at home yourself as this may lead to minor abrasions which could increase the risk of post-operative wound infection. A liquid soap called Avagard is used as an antiseptic pre-operative wash.

You need to wash yourself in this soap from head to toe the night before, or morning of surgery. This will be provided to you at the Pre Admission Clinic.



Confirmation

You need to contact the Peri-Operative Unit on:

(02) 9515 4603

or

(02) 9515 4604

Between **3pm - 7pm** on the afternoon before surgery, (or on Friday if your surgery is scheduled for a Monday) to confirm what time you need to come into hospital. You can expect this to be around **6am - 7am**.

Day of your operation

At home: Before leaving home we suggest you shower. After your shower do not apply any creams, powders, deodorant or makeup.

Admission: On arrival to the Peri-operative Unit (level 3) you need to check in with the clerical staff. A nurse will complete your nursing admission. You will then be asked to wait in the waiting area. Please be aware things can feel like they move quite quickly once you are called.

When the surgeon calls for you, the nurse will take you to change and prepare for surgery. Operating times are only approximate and it is difficult to give you the exact time for the operation.



Operating theatre: From admissions you will be transferred to the anaesthetic bay of your operating theatre where you will receive anaesthetic via a cannula. Once you are asleep under anaesthesia, calf compressors (foam pads or compression stockings) will be applied to help prevent blood clots in your legs. Surgery will then be performed. When the operation is finished, you will be transferred to Intensive Care Unit (ICU) where you will be closely monitored while you wake up from the anaesthetic. The Pelvic Exenteration CNC will call to during the afternoon to provide an update of how surgery is going.



ICU: You will need to be 'intubated' which means having a tube to assist you breathe for the first little while in ICU. You will be kept asleep over the first night following surgery, giving your body a chance to rest and allowing the doctors to get any pain under control. The tube will usually be taken out the next morning.

Once awake after your surgery, you will have a "**PCA**" – Patient Controlled Analgesia. This is pain relief that is delivered intravenously which you can control by pressing a button, to assist in controlling any pain. Your pain level will be reviewed daily and medication adjusted appropriately.

It is not uncommon for people to experience some confusion, delirium, unusual thoughts or visions or nightmares while in ICU. This can be due to the combination of pain medications and an unfamiliar and stressful environment. If any of these things distress you, it is important you speak to your nurse. They are there to help you.

To give your bowel a chance to recover, and to make sure you get all the nutrition you need, you will be started on "**TPN**" – total parenteral nutrition. This is a complete liquid nutrition that is delivered to you intravenously. This will keep you nourished until you are eating and drinking again. Your diet will be slowly upgraded – starting with clear fluids and progressing once your doctor is happy with your progress.

ICU can be overwhelming with lots of staff moving around, equipment you may not have seen before, noise and lights. If you feel worried or anxious please ask staff any questions you may have, they are there to help. Your stay in ICU will usually be 2-3 days.

ICT visiting hours are:

8:30am–1pm

3pm–8pm

Thursdays only unit closed 11am –12:30pm



Ward: When stable, and a bed is available, you will be transferred to 7E2 – the colorectal ward. This is where you will continue your recovery with the help of the Pelvic Exenteration team. This includes the Dietitian, Clinical Psychologist, Social Worker and Physiotherapist and the specialised nursing team who will attend to all your requirements from dressings to administering medications and assisting you with personal hygiene, and moving around. You will start to become more active in your recovery in setting goals towards going home.

Because you will have been lying down, often in the same position, for a long time in surgery and in ICU, there is a risk of developing pressure sores. To decrease this risk, you will be transferred onto a special air mattress. This relieves pressure to vulnerable points on your body- e.g. the sacrum, heels and shoulders. The nursing staff will also help with pressure sore prevention by helping you re-position frequently. If you have a VRAM flap, you will be required to lie side to side and will not be able to sit for the first 7 days after surgery. Once the team are happy, you can mobilise with the help of the physiotherapist.

As this is a complex surgery there may be the chance of complications post-operatively. This could be developing a fever, wound infection or blood clots. If you develop a more serious complication, your surgeon will discuss a management plan with you.

Discharge process

Your care team will ensure you have everything you need in planning for your discharge. They will be discussing your needs from very early on to make sure your discharge is well organised.

The Pelvic Exenteration Co-ordinators will discuss your transport needs, including flights if you are travelling from interstate. Based on your recovery, you may be recommended to have further medical support such as physiotherapy in a rehabilitation facility or community nurses to come to your home.

On the day that you are discharged you will be given:

- An appointment with your specialist, and with other specialists as required
- 5 days' supply of any new medications that may have been started during your stay
- Specific instructions for home
- A letter for your GP detailing your hospital stay. **This should be taken to your local GP within one week of discharge.**
- If necessary, a letter for the community nurses
- Medical Certificate if required
- Any private x-rays that you brought into hospital
- Any valuables that have been stored in security
- The Pelvic Exenteration CNC will organise times to call and check in with you

Please feel free to discuss, any services you usually need at home or may need after discharge. The **discharge time is 10am** and you may be required to go to the *discharge lounge*.

Discharge Lounge

If the person taking you home cannot pick you up before discharge time, or your discharge paperwork and medications are not ready, you will be guided to the Discharge Lounge. This is located on Level 5, near the main entrance. If you are unable to sit for long periods, you will not be moved to the discharge lounge.

This occurs because your bed may be needed for another patient coming into the ward. There is a nurse in the Discharge Lounge who will go through your discharge paperwork, appointments and medications. If needed, medications can be given to you in the Discharge Lounge and meals will be provided.

The discharge lounge is open between:

Monday – Friday

8am–6:30pm

After discharge

It may be helpful to prepare for your return home before you are admitted to the hospital. This may mean cooking extra meals or organising a family member or friend to assist with housework and perhaps to stay with you for a few days. Your physical and psychological recovery will continue after you go home.

Diet: Immediately after a major bowel operation, you should refrain from eating too much raw fruit, raw and leafy vegetables for at least 2 weeks. These foods can be re-introduced slowly as you recover from your operation. It is also important to drink lots of fluid, aiming for 2 litres a day.

Physical activity: You should continue walking and non-strenuous physical activity. You may feel tired and need an afternoon nap. This is normal after a major operation and you should regain your strength over 3 months.

You should refrain from heavy lifting (more than 5 kg) for the first 6 weeks as this will increase your chance of developing an incisional hernia. Depending on whether or not you had laparoscopic or open surgery, you may have to refrain from driving for 4-6 weeks after surgery. Your Clinical Nurse Consultant can help advise you on this.

Appointments: All your follow up appointments will be organised by the Pelvic Exenteration Co-ordinators and the team looking after you.

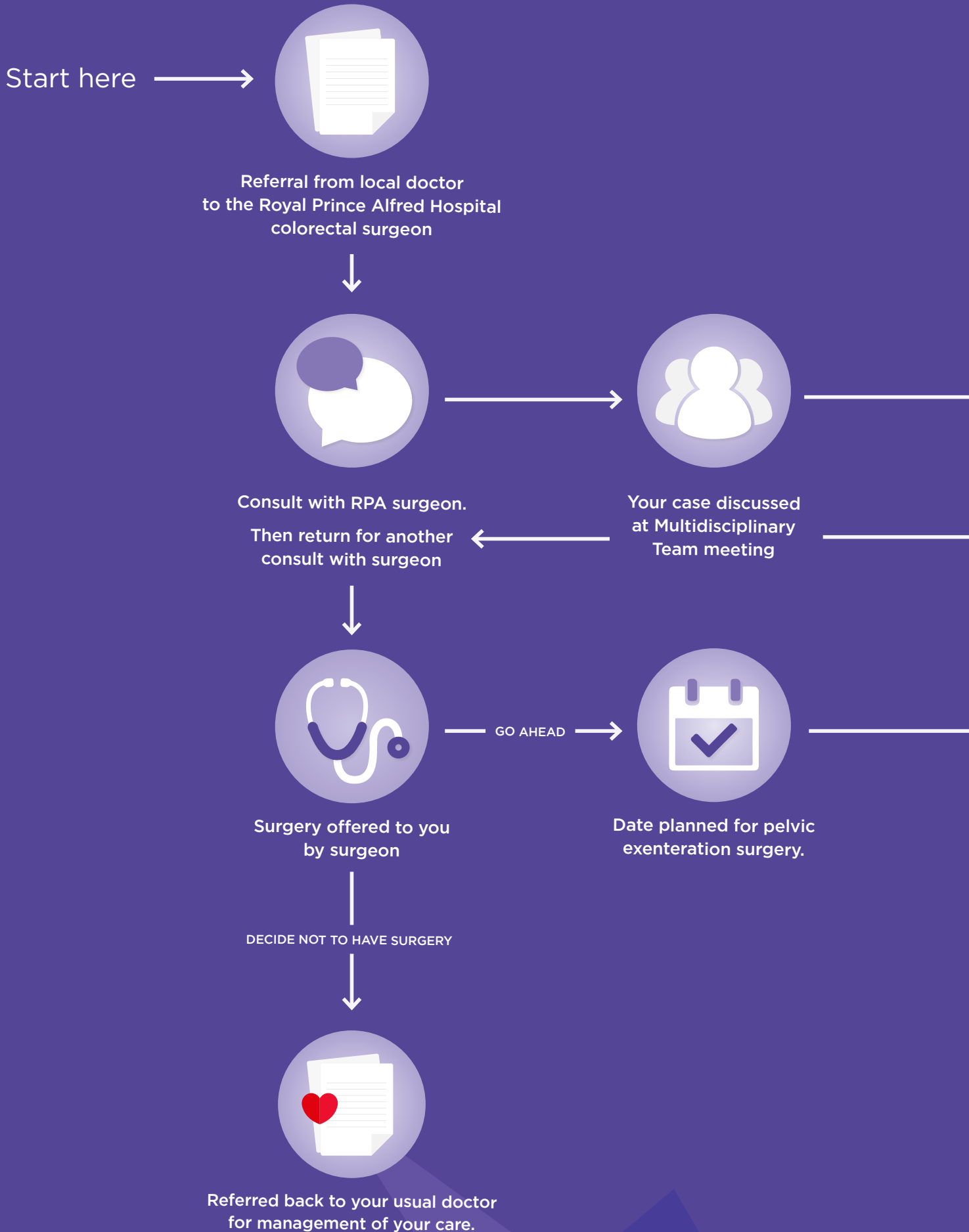
These will include appointments with your surgeon six weeks post-surgery and if necessary the radiation oncology (radiotherapy) and medical oncology (chemotherapy) departments.

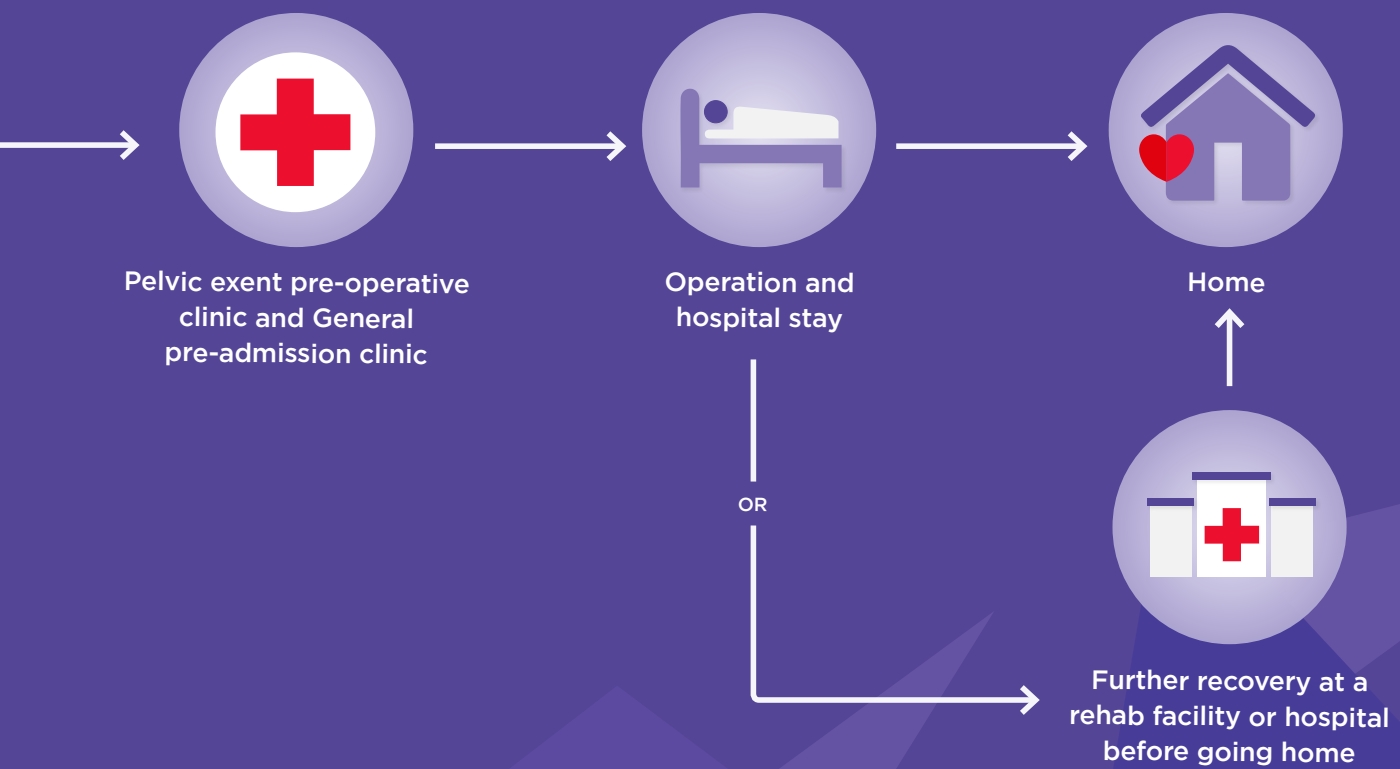
Once home, important things to look out for include:

- Bleeding
- Redness
- Swelling or discharge from a wound,
- Excessive pain or bloating of your abdomen
- Nausea and vomiting
- Difficulty in passing urine
- Faeces and fever or chills.

If you develop any of these symptoms or have concerns, depending on the degree of urgency, you should either get in touch with the Pelvic Exenteration CNC or see your GP. If it is after hours you should present to your local emergency department.

Patient Flow Chart





About Your Hospital Stay WARD 7 EAST 2 (7E2)

Ward 7 East 2 (7E2) is a 30 bed ward for male and female patients. Ward 7E2 specialises in patients needing treatment for diseases of their small and large bowel.

7E2 has single rooms and four bed rooms. Please note single rooms are NOT private rooms. The room you are given is based on medical and nursing requirements. The Nurse Unit Manager is in charge of bed allocation.



7E2 Ward visiting times

10am – 1:30pm

2:30pm – 8pm

Please note we ask you to only have **2 visitors in the room at a time** during visiting hours.

No visitors will be allowed into the ward **during rest period (1:30-2:30pm)**. However, you are welcome to leave the ward and enjoy the lounge area on level 7 with your visitors if you are well enough to do so.

Food & Beverages

Kitchen Facilities

There is a patient kitchen on the ward for you and your visitors to use. You may make tea and coffee, and use the microwave and refrigerator. Friends and family are welcome to bring in food or drinks for you to have, if approved by your medical team. Please label all items you put into the fridge. Unfortunately the ward staff cannot take responsibility for any food placed in the fridge.

Please note that any meals that the hospital kitchen provides are not to be heated up in the microwave. If the meal you have received is too cold please tell your nurse.

Ward meal times:

Meals will be delivered to your bedside at the following times (approximate times):

Breakfast	7:45am
Morning tea	10am
Lunch	12.30pm
Afternoon tea	3.30pm
Dinner	5.15pm
Supper	7pm

Hospital Services

Hospital Chapel

The Hospital Chapel and multi-faith prayer room is available for patients and visitors. Please ask staff for directions.

Shop

The shop is located inside level 5, Monday-Friday 8:30am-6pm Saturday-Sunday: 9am-6pm

Newsagency & Post Office

The newsagency & post office is located on Missenden Road next to 7/11.

Parking:

Parking around Royal Prince Alfred can be difficult due to limited space. There is some metered parking on Missenden Road in surrounding streets. Please allow extra time to find suitable parking if needed.

Disabled parking spaces are available outside the main entrance to Royal Prince Alfred on Missenden Road, the KGV Executive Building opposite the Main Entrance, the Women & Babies entrance on Johns Hopkins Drive and at the Gloucester Drive Entrance.

Concession parking is available at RPAH — please see attached flyer to see if you are eligible. Patients can be dropped off or picked up at any of the timed drop off zones outside the main entrance points to the hospital. See maps which also include wheelchair access spots.

NSW Health Sydney Local Health District
Sydney... it's your local health district

Concessions

Who is eligible for concession car parking ?

The following lists those categories of people who are eligible to obtain concession rates when parked in a designated hospital campus parking area.

1. Holders of a RMS issued Mobility Parking Scheme Permit.
2. Holders of a Blue Pensioner Concession Card.
3. Holders of a Gold Veterans Affairs Card.
4. Holders of a Health Care Card.
5. Ongoing cancer treatment patients.
6. Patients and their carers who are required to attend the hospital / facility for a course of treatment over a period of time greater than one week.
7. Patients and their carers attending more frequently than twice weekly, including carers of long term patients who visit frequently.
8. Cardiac rehabilitation education and exercise class attendees.
9. Daily dressing outpatients.
10. Health promotion education class attendees.

How do you claim your concession rate ?

Eligible patients, their carers, and holders of concession cards are required to present their parking ticket / photo identification / concession card or request for concession rates, for validation prior to exiting the car park at:

RPA Security Office
Level 5 Main Hospital Entrance

People without a valid concession card but who meet one of the criteria above (5-10) will be required to complete
"Concession Parking Ticket Authorisation Form"
 and have it authorised by clinical staff at the ward where you are being treated.

Concession parking is available for ELIGIBLE patients / carers / visitors in MARKED BAYS ONLY	
0 - 3 Hours	FREE
1 Exit Only <small>Single visit tickets are valid for one entry and one exit only.</small>	\$ 5.40
3 Day Access Card* <small>Frequent use allowing multiple entries and exits in a 3 day period.</small>	\$ 10.90
7 Day Access Card* <small>Frequent use allowing multiple entries and exits in a 7 day period.</small>	\$ 21.70

* "Parking spaces subject to availability" and that "no refund will be issued"








For more information: RPA Security Office - Level 5 Main Hospital Entrance - 9515 8409
 or visit www.parking.health.nsw.gov.au
 or download Mobile App NSW Health - hospital parking and directions

Patient Services

- 64 Administration Building - Main Hospital Entrance
- 63 Albert Pavilion (A Block)
- 89 Clinical Services Building (East Wing) - Main Hospital
- 77 Day Procedure Unit (TPU)
- 75 Edinburgh Building (E Block - West Wing) - Main Hospital
- 63 Emergency Department
- 88 Gloucester House
- 10 Institute of Rheumatology and Orthopaedics (IRO)
- 89 Intensive Care Services
- 77 Pathology / Laboratory Services
- 13 Population Health, Drug Health and Community Services
- 11 Professor Marie Bashir Centre
- 10 Queen Elizabeth II Building
- 27 Radiation Oncology Department
- 95 RPA Chapel
- 68 RPAH Medical Centre
- 12 Statewide Satellite Renal Dialysis Service
- 94 Tissue Pathology and Diagnostic Oncology
- 65 Victoria Pavilion (Vic Block)
- 89 Women and Babies Services

14 Chris O'Brien Lifehouse

Hospital Administration





- 13 King George V Building

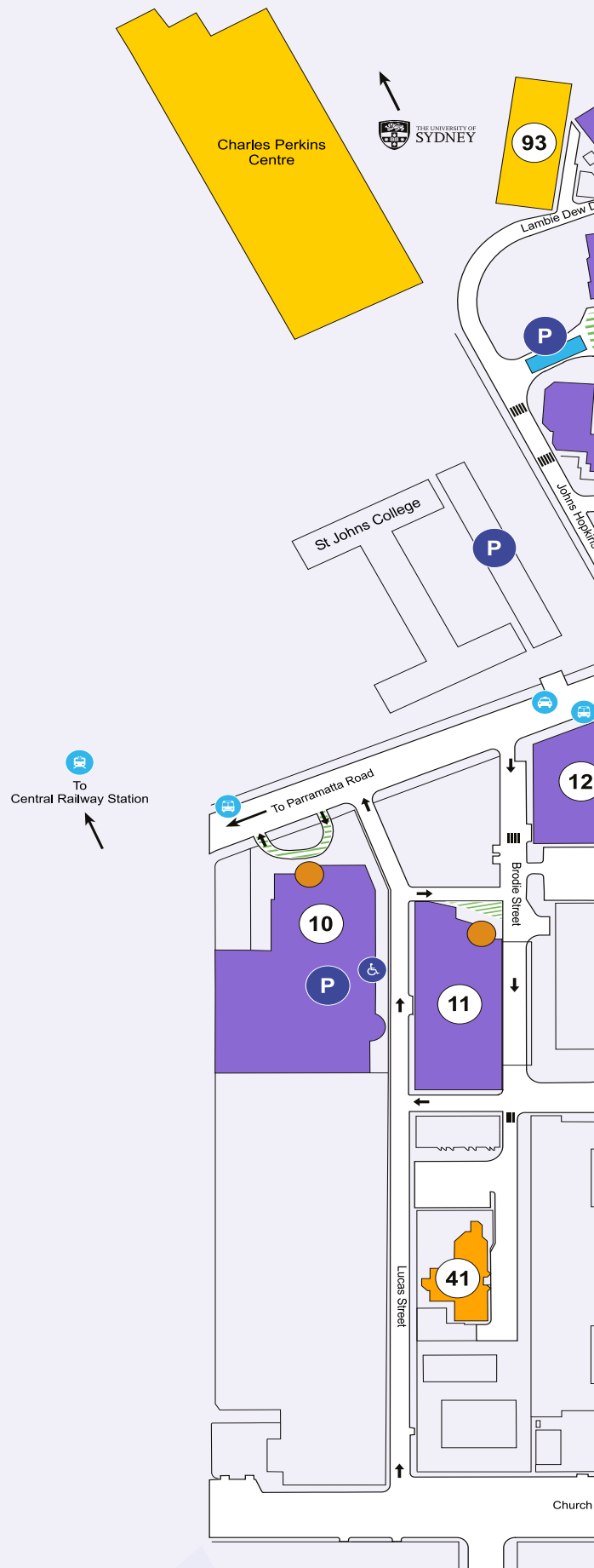
Education and Research Services

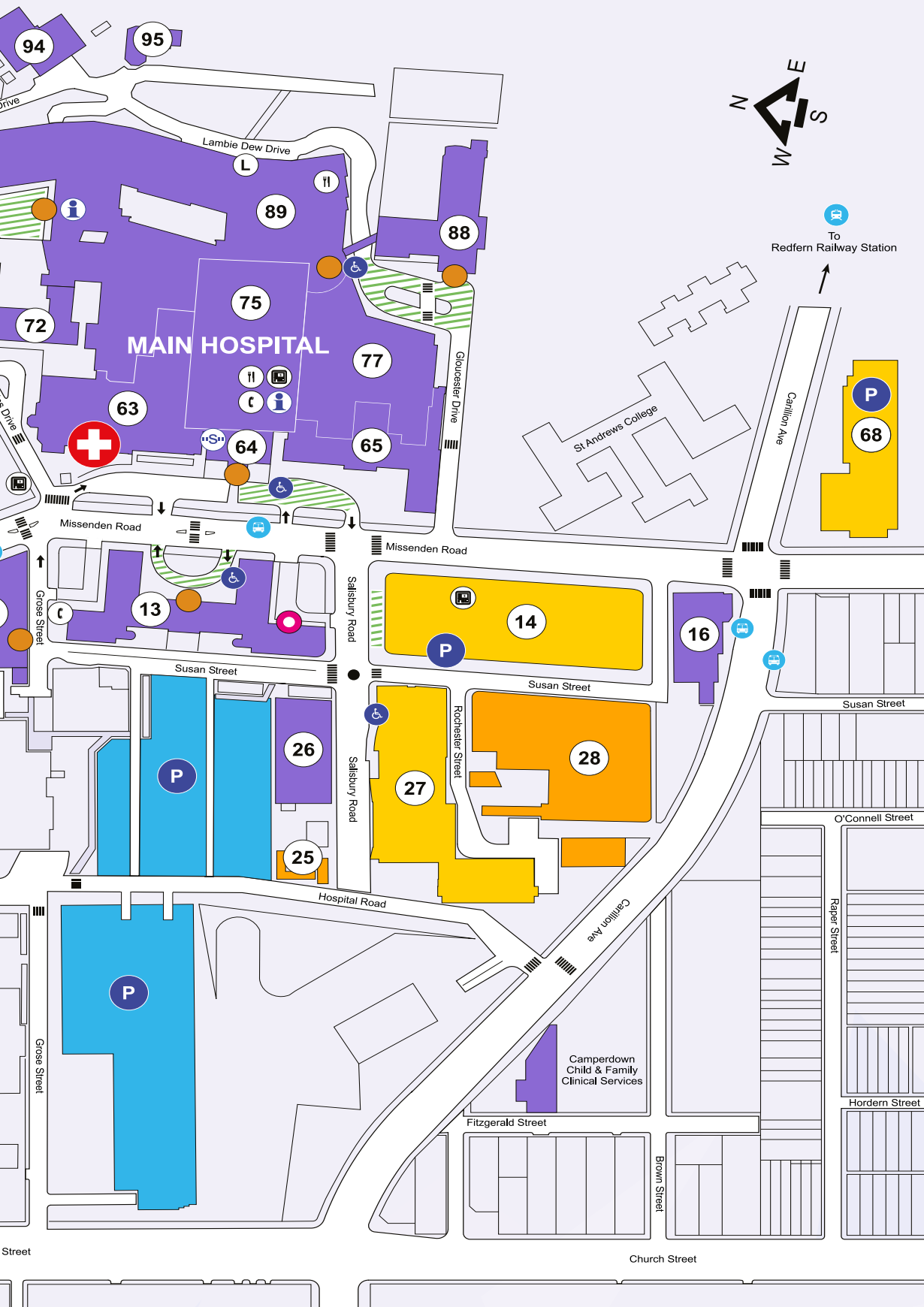
- 93 Centenary Institute
- 72 Kerry Packer Education Centre (KPEC)
- 16 RPA Institute of Academic Surgery
- 16 RPA Transplant Institute
- 13 The George Institute

Support Services

- 26 Audio Visual Services
- 28 Engineering Services
- 25 Fire Service
- 41 Lucas Street Child Care Centre
- 64 Security Services

- | | | |
|--|--|---|
|  INFORMATION |  TRAIN STATION |  ACCESSIBILITY PARKING |
|  EMERGENCY DEPARTMENT |  TAXI |  PATIENT DROP OFF / PICKUP |
|  MAIN ENTRANCES |  BUS STOP |  FOOD |
|  SECURITY |  ATM | |
|  PUBLIC + STAFF CAR PARK |  LOADING DOCK | |
|  CAR PARK PAY STATION |  PUBLIC TELEPHONE | |





Television

All beds have a television, which is available for hire. The rental services representative visits the ward twice a day to organise rentals. If you would like to hire the television, please speak to the ward staff and they will give you the rental form to complete. Hire costs are about \$9/day but there are special long term rates available. Discounted rates apply for pensioners. Certain Private Health Insurance companies may cover this fee.

The hospital has its' own TV Channel (25) for your information and interest.

Telephones

There is a public telephone on level 9 located near the lounge area. There are also public telephones located on level 5, near the enquiry counter. You can use both coins and telephone cards in these telephones.

All bedsides have a telephone for you to receive incoming calls. The direct number is above your bed. These incoming calls are free; however, if you would like to make outgoing calls from your bedside telephone you will need to purchase a phone card at the cashier's office which is located on level 5.

Mobile phones may be required to be switched off whilst near certain medical equipment.

Security

It is recommended you leave all valuables e.g. jewellery, computers, wallets at home. You are responsible for all items that you bring into hospital. Cash of more than \$20 cannot be kept on the ward. The ward staff will contact security to come and collect additional cash or valuables. A receipt will be given to you and your valuables will be taken away and locked up in the security department. Other items can be temporarily locked away on the ward when you need to go for a procedure. Please inform the staff as soon as possible if you would like to have any of your valuables locked on the ward or sent to security.

The security office is opened 24hrs and is located on level 5. You are allowed access to your valuables anytime.

Accommodation

If you live out of Sydney and need a place for you or your relatives to stay, the Pelvic Exenteration Co-ordinators or the RPAH accommodation coordinator can offer information on the different types of accommodation close by at varying costs. The accommodation coordinator at RPAH will be able to offer you the best advice on this — you can contact her on: (02) 9515 9901

Cafés

The Terrace by Zouki:

Located on level 4. There is seating outside.

Monday–Friday: 7am–2:30pm

Saturday–Sunday: Closed

Alfredo Deli Café:

Located on Level 5. There is no outside seating.

Monday–Friday: 7am–11pm

Saturday–Sunday: 8am–10pm

Internet

How to access the guest internet

1. Go to 'Wi-Fi settings' on your mobile device
2. Select SLHD-Guest
3. In your browser, review and agree to the terms and conditions

Please note, limits apply. Please do not download movies or apps. Users can connect for up to twelve hours per session. Guest Wi-Fi is suitable for web browsing, email and social networking as speed limits apply.

IPTAAS

If you live more than 100km out of Sydney, you are entitled to receive a small reimbursement for your accommodation and transport from the Government. This is called the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS). Social worker can help you with this.

The next section includes more about aspects of your recovery from members of the Pelvic Exenteration Service Team

Keep reading...

Managing your pain

Before the operation

Persistent pain has been a feature of Pelvic Exenteration Surgery. The Pain Management team at Royal Prince Alfred Hospital is dedicated to managing your pain. Successful pain control requires your dedication as well. This starts before your operation.

The book *Rewire your Pain*, by Stephanie Davies gives some great tips for managing your pain in the short and long term. It is highly recommended that you consider purchasing this by going to www.painaustralia.org.au and typing in "Rewire your Pain" in the search field. The book is \$30 to order.

Managing pain medications

You may be taking pain medications already. Try not to make major changes to these before surgery unless guided by your General Practitioner or Specialist.

For those people taking opiates such as Targin, Endone, MS Contin or Oxycontin, discontinuing them, or reducing them will cause a withdrawal syndrome. This can occur before, during or after your hospital stay.

You will notice:

1. More pain than you had before
2. Feeling grumpy and anxious
3. Sweating *and*;
4. Loose motions

If you are taking medications for pain, your perioperative physician should review them before surgery. This is usually an anaesthetist who you meet in the preadmission clinic. Always take your pain medications on the day of surgery so you are comfortable before your anaesthesia begins.

Fitness Program

This will help you to sleep better and therefore manage your pain better. It will also give you the opportunity to develop more physical and mental stamina to manage pain around the time of surgery.

The program should be within your abilities especially if you have conditions such as heart or lung disease that can make exercise dangerous. You may already have an alternate activity which you enjoy. The aim is to spend more time exercising intensively in the short time you have before surgery.

Some examples of a daily routine that you may choose include:

- Walking briskly for 30 minutes. You may wish to build up to this over a number of weeks
- Attending a Pilates class 2-3 times per week. If you are a beginner, try 1 on 1 with an instructor before attending a group class
- Yoga classes 2-3 per week, with close supervision if this is the first time.
- Cycling 30 minutes or more
- Swimming laps for up to 30 minutes
- Aqua-aerobic classes
- Tai Chi classes

Mood and Tension

You may be feeling happy that you are about to have a curative operation. Some may be feeling less so in the context that the cancer has recurred. Major surgery is to others a great threat to their ability to cope. In this situation you may feel tense, anxious, tearful and less able to tolerate difficulty.

When this situation persists for long enough some people become depressed. You may have one or more of these signs below. There are other signs that are more subtle.

- Feeling down or sad most of the time
- Losing interest or pleasure in things

You may also have one or more of these signs below:

- Altered sleep pattern. That is, less sleep than you would normally enjoy. You may be waking frequently with pain.
- When you wake in the morning you do not feel refreshed.
- A change in your appetite- more or less hungry with a change in your weight.
- Feeling more agitated restless or wound up than usual
- A change in the way you perceive the future. For example, less anticipation of happy events.
- Thoughts of not wanting to live longer.

These suggest a major depression and require treatment before surgery. Consultation with your General Practitioner is required. A medication is recommended because this will help you to cope with your pain after the operation.

Other people may just feel anxious and not sad. Again, managing the anxiety effectively is important because, anxiety makes pain worse. Mindfulness and Meditation are important tools to manage anxiety and pain.

Mindfulness:

This is a technique aimed at staying in the present and sitting comfortably with unwanted thoughts. This is worth practicing for those moments in hospital when you are feeling overwhelmed. There are a number of helpful 'Apps' to get you started:



1. 5 Minute Meditations-Easy to follow 28 day mindfulness course
2. The Mindfulness App.

Planning Happy Moments

For the many days you spend in hospital, plan 1 happy event every day. For example-a favourite friend visiting on day 1, a hand massage, being out in a chair, carbonated water, or a new magazine.

On the day of surgery

Make sure that you continue to take your prescribed medications and analgesics with water. Your surgeon and anaesthetist may alter which medications you take on the day.

Day one post-op

Your pain will be managed with medications that run straight into your veins. You will have an opiate medication such as Fentanyl, Morphine or Hydromorphone.

The side effects of these are:

- Sleepiness
- Nausea
- Vomiting
- Itchiness

A pain-relieving drug like Ketamine may be used. This can have side effects of sleepiness, bad dreams and seeing strange things. Make sure that you report any bad effects from your drugs so that they can be reduced or discontinued.

If your surgeon allows, you may get out of bed into a chair. This will be uncomfortable but is a good goal. Movement encourages blood flow to the wound, which enhances healing. Also, being out of bed helps to limit loss of muscle, which is required for walking.

Subsequent days

As your bowel starts to work, passing wind, your doctors will give you tablets for pain instead of injections. It's important that you are out of bed in a chair or walking as much as possible. This will help your mood because you can change your view and develop hope that you will get out of hospital. Your pain will also be better controlled when you are walking.

Dark days

After a number of days in hospital you will have received many visits by doctors, nurses and other staff. You will have had many nights with limited sleep. Your day will be endlessly interrupted with recordings, washing, dressing, stoma changes and trips to investigations.

Your pain control will not always be perfect.

In these moments, drawing on the preparation that you have made before surgery will be useful. For example, reminding yourself of your goals in the short and long term will be helpful. What are the special things that you have chosen to break up and enhance your day?

Reconnect with your mindfulness and meditation techniques.

Your team understands how tough things can get. Make sure that you tell them if you are feeling sad or flat. They may be able to adjust your care to give you more 'me' time. For example planning investigations or creating a 1-hour 'no go zone' in your room.

Nerve Pain

In order to achieve a cure, your surgeon may have cut large nerves. This can result in pain in a very specific area such as your leg. You may feel burning, electric shock sensations tenderness to touch in your leg.

This type of pain indicates that there have been changes in the brain. This does not have to be a permanent change because you can rewire your brain. This is called 'Neuropathic Pain'. It requires a special management plan.

Morphine-like drugs will not be helpful for your nerve pain in the long term. This is because the drugs cause your nerves to become tolerant. Rather, you will be given other nerve treatment medications. These may include:

- Tapentadol
- Pregabalin
- Gabapentin
- Amitriptyline
- Catapres.

All of these medications have side effects. Make sure you understand what you have been prescribed and that the person prescribing them has described the side effects.

Your nerve pain will get better. This depends upon how much you 'retrain' your brain and the pain.

- Walking and putting weight through your leg is an important way you can retrain your brain.
- Maintaining a positive mood and attitude is very helpful.
- Reducing anxiety will help you to 'inhibit' the pain. Mindfulness can help here.
- Actively working towards your goals will help to change your brain.
- Ask your pain team to explain why you have pain.

Going Home

When you go home you should be avoiding taking opiate (morphine-like) medication. You should be taking only the medications that are essential for your pain management.

Attendance at a rehabilitation facility is highly recommended. This will give you a head start in terms of redeveloping a physical and mental stamina that is difficult to do on your own.

To maintain your mental and physical health you will need to adhere to a health plan for a minimum of 6 months. This should include an exercise regimen — your physiotherapist will advise you and will link you into a physiotherapist close to your home.

Your diet will be assessed and planned for the future by your dietician.

Pain management long term will be arranged before discharge from hospital. Ideally, a Pain Medicine Specialist reviews you in your local area. We can advise and refer you before you leave hospital.

Alternatively, you can arrange to see a Pain Specialist in rooms around the time you see your surgeon.

Over the next 3 months your pain will gradually improve. There will be days and weeks when your pain is more intense but it should improve overall. Your General Practitioner or Surgeon should investigate an increase in your pain that does not go away.

All the best for a pain free future.

The Pain Management Service at The Royal Prince Alfred Hospital welcomes your feedback about your pain management.

Dr Charlotte Johnstone

MBChB, FANZCA, FFPMANZCA, FIPP
Staff Specialist Anaesthetist and Pain Medicine Specialist
Royal Prince Alfred Hospital, Missenden Road NSW 2050

Physiotherapy

The physiotherapist will see you on the day after your operation. It is very important to start walking as early as possible after your operation. This would usually start with the assistance of the physiotherapist and the nurse using a forearm support frame to assist with balance and support. Progression to a smaller frame or walking stick can be used if required with the aim to return to your normal walking. Your walking will improve your ability to breathe and ventilate your lungs by moving air in and out of your lungs thus preventing respiratory complications such as lung collapse and pneumonia.

It further helps to re-expand all areas of your lungs especially the lower zones through the downward movement of the diaphragm (a large breathing muscle). Adding breathing exercises while walking improves the volume and flow of air in your lungs. This will help you to have a strong and effective cough so that you may expel any secretions your airways which are common after an anaesthetic.

You may perform your deep breathing exercises when you are sitting in a chair as regularly as possible. Your walking will be reviewed and progressed by the physiotherapist during your hospital stay. This should be practiced regularly with nursing staff, family, or independently as directed by your physiotherapist.

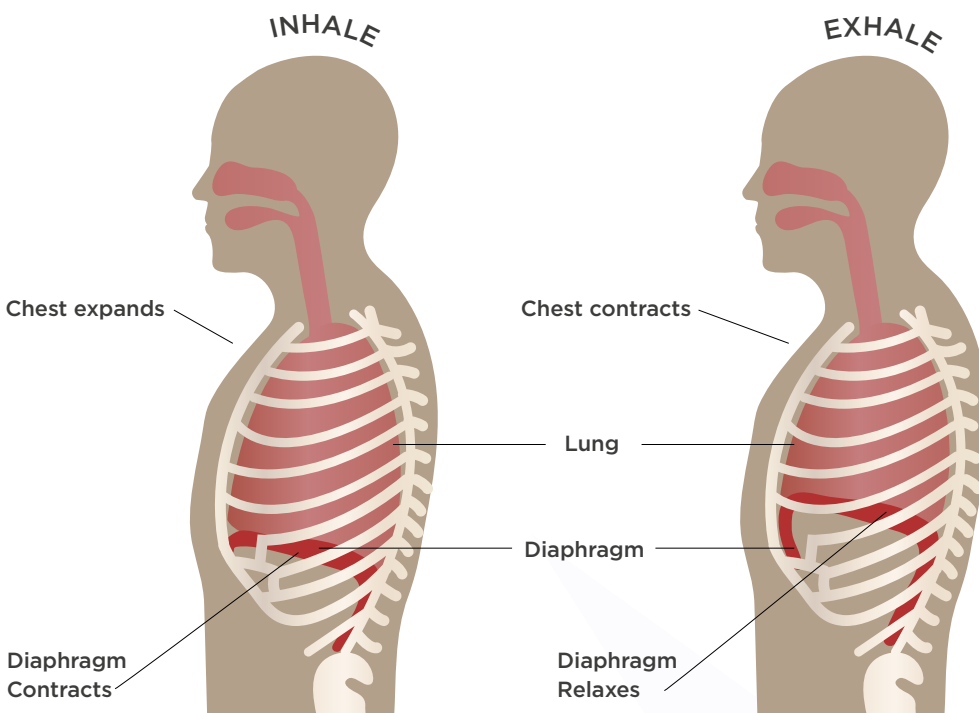
If you continue to have problems with walking, the physiotherapy will arrange follow-up interventions. Depending on which is most appropriate, follow-up physiotherapy can take place in a rehabilitation hospital, or at an outpatient clinic.

How to perform Breathing Exercises

1. Deep breathing exercises

Can be done when you are walking or sitting

- Take a deep breath in, inhaling deep so that your stomach walls move outwards.
- Hold the breath for 3 seconds
- Breath out , exhaling in a relaxed manner
- Do this 5 times



2. HUFF

Huff helps you to move secretions (phlegm) closer to your upper airways so that you can cough more effectively. To correctly perform a huff:

- Take a low volume /short breath
- Keep your mouth open
- Breath out a forceful breath “huff” sound as if you were fogging up your glasses or a mirror.

3. Cough

It is important to cough and clear the secretions from your lungs to prevent respiratory complications. Performing a cough will not open your incisions. You may place a clean folded towel across your abdomen to provide added support.

- Take a deep breath in
- Cough strongly to clear secretions
- Do not keep coughing multiple times
- Take a deep breath in / exhale after your cough.

This cycle is repeated until the huff is dry sounding and does not appear that there are any secretions (phlegm) in your airways.

DIET

Your nutrition is very important before and after your operation to help you recover from your surgery. It is common for your nutrition status to decrease during your hospital stay and soon after your discharge. For these reasons we must try and ensure you are eating well, before your surgery.

Why is nutrition important?

Prior to surgery you may experience symptoms such as nausea, vomiting or diarrhoea which can impact on your appetite. This can cause you to lose weight and put you at risk of malnutrition. After your surgery you have increased energy and protein requirements for wound healing and possible infection. The dietitian will work with you before, during and after your hospital admission to help meet your nutrition requirements which can help decrease post-operative complications and length of hospital stay.

How can I improve my nutrition?

When you first meet with the dietitian they will assess you to determine if you require nutrition support. Prior to surgery this might include:

1. Strategies to manage symptoms, such as nausea, poor appetite or vomiting
2. Tips and ideas on how to increase the energy and protein content of the food you are currently eating
3. Recommending the use of high energy and protein nutrition supplement drinks

Straight after your surgery the medical team will rest your gut and commence TPN. TPN is made up of carbohydrates, protein and fats and together with trace elements and vitamins, will meet all of your nutritional needs.

Once the medical team start you on a diet and you are eating adequate amount of food the TPN will be weaned. The dietitian may also recommend high protein and energy snacks or nutrition supplement drinks during this time to help meet your nutrition requirements.

What happens after discharge?

Once you leave hospital the dietitian will review you if necessary. They will ask you to monitor your weight and continue to follow any dietary advice they have given you during your hospital stay.

If you have any questions about your nutrition, please call the Royal Prince Alfred **Hospital Nutrition and Dietetics Department** on **(02) 9515 8053** and *ask to speak with your dietitian.*

Stomal therapy

Having any operation can be an emotional experience but being well prepared can help you to know what to expect. If, as part of your Pelvic Exenteration surgery you will require a stoma or stomas, you will be seen by a stomal therapy nurse who will provide help and advice both before and after your operation. A stoma is an opening on the abdomen (tummy) that acts as an exit for body waste.

There are 3 main types of stomas: colostomy, ileostomy and urostomy

The colostomy and ileostomy are both bowel stomas and will pass stool (faeces). The urostomy is a urinary stoma and will pass urine. All stomas require you to wear a pouch (this may also be called a bag or appliance) to collect the output.

Before your operation you will be seen by the stomal therapy nurse who will discuss the type of stoma/s you will be having and aspects of managing and living with a stoma/s. The stomal therapy nurse will also select a suitable position (site) on your abdomen (tummy) for your surgeon to consider when bringing the stoma out onto the skin. Ideally, we like to have the site on a flat skin surface that is free from abdominal creases and also visible to you so that you can manage your own stoma.

When selecting the appropriate site, the stomal therapy nurse will take into consideration a number of aspects including; the type of stoma/s you are having, where you may have skin creases and folds on your abdomen, or scars from previous abdominal surgery. Your abdomen is usually viewed whilst you are laying, sitting and standing. To help with the siting you may be asked a number of questions including any recent changes you may have experienced with your weight, what type of activities you do and the type of clothing you wear.

At the time of your operation, a post-operative pouch will be applied over the stoma/s. As you progress in your recovery you will be seen regularly by the stomal therapy nurse who will teach you how to manage your stoma/s. There are a large variety of stoma pouches available in Australia - you will be guided as to what is appropriate to meet your needs.

In Australia, residents are able to access free stoma supplies through the Stoma Appliance Scheme which is subsidised by the Australian Department of Health. To access these stoma supplies you are required to join a Stoma Association. Each state of Australia has these associations. There is a small membership fee charged to join the association. Whilst you are in hospital we will assist you with joining the association and where possible collect your first order for you to take home.

We are happy to also include your family members or support persons in any of the discussion or education sessions. Following discharge from hospital, the RPAH Stomal Therapy Department has an outpatient clinic which is available should you be experiencing any problems with managing your stoma/s or if you would like to have your stoma periodically checked. You will be provided with details on how to access this clinic. If you are not from the Sydney region we will try, if possible, to refer you to a stomal therapy nurse closer to where you live.

For further information, please do not hesitate to call the RPAH Stomal Therapy Department on (02) 9515 7280.

Psychology and your Recovery

You can expect to have a range of emotions about your cancer journey and surgery. All these emotions are natural reactions to a significant life event:

Fear: receiving a cancer diagnosis and preparing for surgery can be frightening. Most people cope better when they know what to expect.

Worry: when things are uncertain, worry is a natural thing for us to do. However, worrying a lot about the future can make you feel more distressed. Try to focus on one thing at a time or discuss your worries with someone.

Anger: you may feel angry at others around you, or just at your situation. This is a normal part of dealing with something as challenging as going through surgery.

Sadness: it is natural to feel some sadness about the changes you are going through, like not being as active as you used to be. Many people feel sad at times.

Depression: Many people feel low leading up to, or after major surgery. There is a difference between feeling low and being depressed. You may be clinically depressed if you are in a low mood most of the time, not enjoying things you used to for 2 weeks or more. Tackling depression early can mean that you can deal with it quickly. There are different treatments available including medication and non-medication options.

Loneliness: you may feel lonely if you feel that nobody else understands what you're going through. Communicating this with someone may help you feel less isolated.

Disbelief: you may have trouble believing you have cancer, particularly if you had been feeling otherwise well, or not realising the extent of the surgery needed. It is natural for people to wonder 'why' these things have happened.

What to do about worries?

You may have worries about being in hospital, caring for children, accommodation for family members, sick leave; as well as pain, body image or sexuality.

If you are having trouble managing your worries please consider speaking to family and friends, a counsellor, or psychologist, or joining a support group. Remember it will take time to adjust to life after surgery.

A clinical psychologist can work with you to identify problems you are having and increase ways of coping. It might include practical strategies for communicating with others, focussing on the present, relaxation techniques, recognizing and challenging unhelpful thoughts.

Call Cancer Council 13 11 20 to request information, or someone to talk to.

Adapted from 'Emotions and Cancer' — Cancer Council Australia

Physical appearance/body image

You will likely face changes to your physical appearance, or the way you feel about your appearance due to cancer treatment or surgery.

This could include – scarring, weight gain or weight loss, hair loss, or permanent stomas. It is normal to find these changes difficult to adapt to physically and mentally. Please consider speaking to a mental health professional or nurse if it is interfering with the way you want to lead your life. For example:

- Being too embarrassed to leave home
- Withdrawing from social activities
- Avoiding intimacy with a partner
- Low mood

You may find it helpful to:

- Speak to your psychologist during your stay, or another mental health professional after you return home
- Speak to your stomal therapy nurse for information and resources
- Consider an ostomy support group

Sexuality:

You will experience some changes in sexuality after your operation. Sexuality refers to sexual desire, preferences, arousal and function. Depending on the nature of your operation and psychological factors, such as the way you feel about your physical changes, there may be changes in any of these areas.

This is applicable to both male and female patients experience changes in their libido (desire) and sexual function.

It is important to speak to your doctor about what changes you will experience. There may be treatments available for you in your recovery.

You may also find it helpful to:

- If you have a partner, speak to them about what you are experiencing
- Speak to your psychologist on the Pelvic Exenteration team, or another mental health professional. You may be seeking emotional support, information or a referral to a specialist counsellor in this area
- Speak to other cancer survivors through the 'Cancer Council' NSW on 131120

Useful links

Hospital Information

Royal Prince Alfred Hospital

Website: www.slhd.nsw.gov.au/rpa/

Pain

NSW Health pain resources and information

Website: www.aci.health.nsw.gov.au/chronic-pain

Australian Pain Management Association

Website: www.painmanagement.org.au

Well-being and support

Stomal therapy support

Website: www.stomaltherapy.com/Ostomy_support_groups.php

Mental health information and resources

Website: www.beyondblue.org.au

Cancer information and support

Website: www.cancercouncil.org.au

Access to online psychological assessment and treatment programs

Website: www.mindspot.org.au

Mindfulness information and exercises

Website: www.mindfulness.org

Contact Numbers

Hospital Department	Phone
Royal Prince Alfred Hospital	(02) 9515 6111
7 East 2 (Colorectal Ward) Call to speak to physiotherapist, psychologist or stomal therapy nurse	(02) 9515 7708 (02) 9515 7709
Colorectal Fellow / Registrar	(02) 9515 6111
Nutrition and Dietetics Department	(02) 9515 8053
Pelvic Exenteration Clinical Nurse Consultant	(02) 9515 3247 0475 974 559
Pelvic Exenteration Nurse (CNS)	(02) 9515 4567 (02) 9515 6111
Green Intensive Care Unit	(02) 9515 7790
Blue Intensive Care Unit	(02) 9515 7786



Royal Prince Alfred Hospital
50 Missenden Road. Camperdown

(02) 9515 6111



Created: October 2017
Review by: October 2019
AVS 82620