

PATIENT INFORMATION

CYSTECTOMY AND BLADDER RECONSTRUCTION (FEMALE)



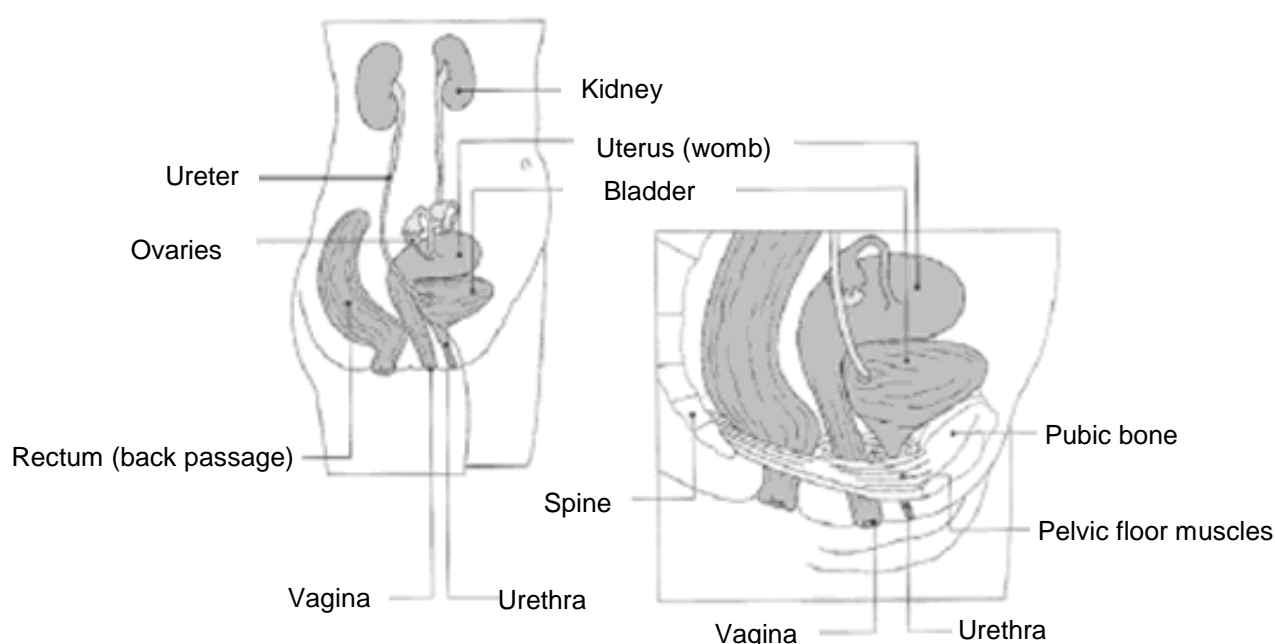
Department of Urology

It has been recommended that you have a cystectomy (removal of the bladder) and a new bladder reconstructed out of bowel tissue (neo-bladder or orthotopic reconstruction).

The advantage of this operation is that, in the long term, you will not need to wear a bag on your abdomen to collect urine. Instead, the neo (new) bladder is connected onto the urethra (the water pipe) and urine is passed naturally. Some people may need to use a small disposable catheter once or twice a day to empty the neo bladder.

This leaflet explains some of the benefits, risks and alternatives to the operation. We want you to have all the information you need to make the right decision. Please ask your surgical team about anything you do not fully understand or want to be explained in more detail.

We recommend that you read this leaflet carefully. You and your doctor (or other appropriate health professional) will also need to record that you agree to have the procedure by signing a consent form, which your health professional will give you.



About the procedure

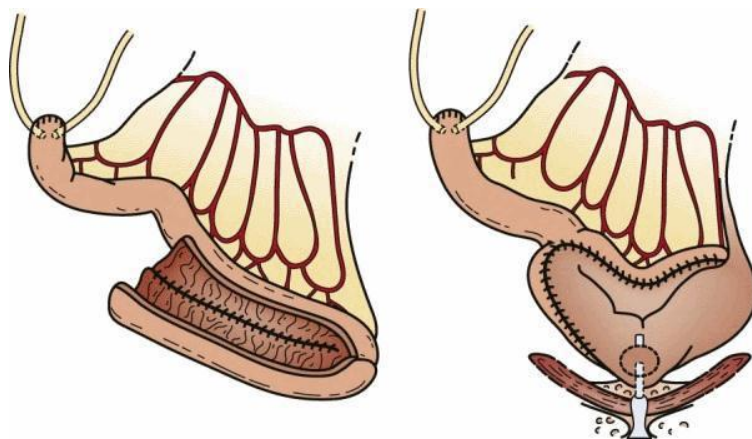
To remove your urinary bladder we usually make a vertical incision (cut) in your abdominal wall (tummy). Through this, we can see the exact nature of the disease in your pelvis and we can assess other parts of your abdomen – including the liver, small and large intestines.

The next step of the operation is to take out your bladder (cystectomy) along with the surrounding fatty tissue that carries the blood vessels, local lymph glands, uterus and a cuff of vagina. If you have not been through the menopause, it may be possible to leave the ovaries to provide normal hormonal balance. Your consultant will discuss this with you if appropriate.

The next step is to reconstruct a section of your bowel (normally between 45 – 60 cms long) into a new bladder. This piece of bowel is used to make the new reservoir (or pouch) that replaces your existing bladder. The tubes from your kidneys (ureters) are implanted into the new reservoir. This is then attached to your urethra (the tube that urine passes down from your bladder). A catheter is placed into your new bladder through your urethra and left in place for four weeks after surgery. You will then be admitted to remove the catheter.

Occasionally we are unable to proceed with orthotopic bladder substitutions due to anatomical variations in some people. In this case, the end of your bowel opens on to your abdomen (known as a stoma or a urostomy). Your urine then empties through this stoma into a small bag.

Occasionally the pouch will not reach the urethra, in which case a continent stoma may be formed onto the abdominal wall for intermittent self-catheterisation (known as a continent catheterizable pouch).



How will this affect me?

Permanent changes will be made to your body by this surgery. These changes affect urinary, sexual and reproductive function, and to some extent, bowel function.

Passing urine

After surgery, your kidneys will produce urine in the normal way, and the ureters (tubes from the kidneys) will drain urine into your new bladder.

Your new bladder will store urine until you decide to empty it. The sensation of your bladder being full is different from the usual feeling. Some people say that they get a full sensation in the abdomen; others say that it feels a bit like having “wind”. Another way of knowing when to empty your new bladder is by keeping an eye on the time and emptying your bladder at regular intervals.

To pass urine, you may have to relax your pelvis and use some abdominal pressure or straining to empty your new bladder. The capacity of your new bladder will increase over time.

After about three to six months, it should hold around a pint of urine (similar to a normal bladder capacity). At first, you will need to empty your bladder every one to three hours until you are able to build up the time in between as the bladder reaches its full capacity.

At night we recommend that you get up at least once or twice to empty your new bladder before it is full. This is important, as control may be difficult when you are asleep if the bladder is full. About 10% of people who have undergone this surgery may have some leakage at night. As the new bladder stretches, and is able to hold more urine, you will not need to empty it as often.

Sexual and reproductive function

As mentioned earlier, the aim of your surgery is to remove your bladder, along with all the bladder cancer cells. Therefore, other tissues that touch or lie close to your bladder are removed at the time of your operation. These other organs and tissues affect sexual function.

There is an area of tissue between a small area of your bladder and vagina, which has shared blood supply. This means that when this tissue is removed, a strip of the front wall of the vagina is removed along with the uterus (womb). The result of this is that there may be some shortening of the vagina, and full intercourse may not be possible in some patients.

You should wait for at least six weeks after surgery before attempting intercourse and we advise you to use a lubricant such as KY jelly.

This aspect of recovery is usually discussed at follow up clinics.

Bowel function

Following surgery some patients notice a change in bowel habit. You may go to the toilet more frequently or notice that your bowel movements are more “loose” than

before. This is due to the shortening the bowel when a section is removed to make your new bladder.

You must tell your consultant in advance if you have had ulcerative colitis or Crohns disease in the past.

Benefits of the procedure

The aim of your surgery is to remove the diseased urinary bladder and reconstruct a new bladder. For most patients this will provide a cure or a significant improvement in their bladder problems.

If you have been told that you have (or may have) cancer, surgery gives the best chance of a cure, although treatment may need to be combined with chemotherapy.

Serious or frequent risks

- Everything we do in life has risks. Surgery to remove (and reconstruct) your bladder is a major operation and there are some risks associated with it. The general risks of surgery include problems with:
 - the wound (for example, infection);
 - breathing (for example, a chest infection);
 - the heart (for example, abnormal rhythm or, occasionally, a heart attack); and
 - blood clots (for example, in the legs or occasionally in the lung).
 - increased risk of a stroke
 - bleeding requiring a blood transfusion (or occasionally repeat surgery)

Those specifically related to radical cystectomy and bladder reconstruction can include problems with:

- tissue or organs next to the bladder (for example, the ureter or rectum);
- Paralytic ileus (failure of your bowel to work) for several days causing nausea, bloating, vomiting requiring intravenous drip, stomach drainage (10-50%)
- the seal where the ureters and new bladder have been joined;
- problems with blood chemistry
- Discomfort or difficulties with sexual intercourse due to narrowing or shortening of vagina (nearly 100%)
- in event of ovary removal menopause may occur
- need to self-catheterise if new bladder fails to fully empty

- Occasionally (between 1 in 10 to 1 in 50) :
 - cancer may not be cured with removal of bladder alone
 - Incontinence of urine in early weeks and improves in most women but can persist, esp at night (15-30%)
 - Wound pain, hernia or infection/abscess requiring further treatment (2-10%)
- Rarely (Less than 1 in 50):
 - decrease renal function with time
 - Failure to performed neobladder and revert to ileal conduit
 - vaginal fistula requiring corrective surgery
- Very rarely:
 - diarrhoea due to shortened bowel / vitamin deficiency requiring treatment
 - bowel and urine leakage from anastomosis requiring re-operation
 - scarring to bowel or ureters requiring operation in future
 - urethral recurrence of the cancer
 - Spontaneous rupture of neobladder with urinary leakage requiring further surgery (0.4%-2%)
 - Numbness & weakness due to nerve compression caused by position during surgery, vascular damage or nerve damage while remove cancer (<0.1%)
 - intraoperative rectal injury requiring colostomy

Sometimes, more surgery is needed to put right these types of complications.

- Most people will not experience any serious complications from their surgery. The risks increase for elderly people, those who are overweight and people who already have heart, chest or other medical conditions such as diabetes or kidney failure. As with all surgery, there is a risk that you may die.
- You will be cared for by a skilled team of doctors, nurses and other health-care workers who are involved in this type of surgery every day. If problems arise, we will be able to assess them and deal with them appropriately.

Other procedures that are available if you have cancer

- External beam or radiotherapy to the bladder:
This is where x-rays are delivered through the skin from the outside to kill cancer cells.
- Chemotherapy (using drugs to treat cancer) can be used prior to removal of the urinary bladder or before radiotherapy.

Your oncologist will discuss this with you if appropriate.

Your pre-surgery assessment visit

We will ask you to go to a pre-surgery assessment clinic where you will be seen by members of the medical and nursing teams of the urology unit. The aim of this visit is to record your current symptoms and past medical history, including any medication you are taking. Your heart and lungs will be examined to check that you are well enough for surgery. Blood tests and x-rays will usually be taken or arranged during this clinic.

The members of the urology team will check that you agree to have the planned surgery. Please bring your operation consent form (which you were given in Outpatients), making sure that you have read and understood the form before you visit the clinic. If you have not understood any part of the information, you will be able to ask any questions you may have about your planned surgery.

Being admitted to the ward

You will usually be admitted on the day of surgery. We will welcome you to the ward and check your details. We will fasten an armband containing your hospital information to your wrist.

To reduce your risk of blood clots in your legs after surgery, we will usually give you clexane injections and ask you to wear support stockings before and after your surgery. You may also have a drip inserted to give you fluids straight into your veins before your operation. We will usually ask you to continue with your normal medication during your stay in hospital, so please bring it with you.

Before you come into hospital

There are some things you can do to prepare yourself for your operation and reduce the chance of difficulties with the anaesthetic.

- If you smoke, consider giving up for several weeks before the operation. Smoking reduces the amount of oxygen in your blood and increases the risks of breathing problems during and after an operation.
- If you are overweight, many of the risks of anaesthesia are increased. Reducing your weight will help.
- If you have loose or broken teeth or crowns that are not secure, you may want to visit your dentist for treatment. The anaesthetist will usually want to put a tube in your throat to help you breathe. If your teeth are not secure, they may be damaged.
- If you have long-standing medical problems, such as diabetes, hypertension (high blood pressure), asthma or epilepsy, you should consider asking your GP to give you a check-up.

Your anaesthetic

We will carry out your surgery under a general anaesthetic. This means that you will be asleep during your operation and you will feel nothing.

Your pre-surgery visit by the anaesthetist

- After you go into hospital, the anaesthetist will come to see you and ask you questions about:
 - your general health and fitness;
 - any serious illnesses you have had;
 - any problems with previous anaesthetics;
 - medicines you are taking;
 - allergies you have;
 - chest pain;
 - shortness of breath;
 - heartburn;
 - problems with moving your neck or opening your mouth; and
 - any loose teeth, caps, crowns or bridges.
- Your anaesthetist will discuss with you the different methods of anaesthesia they can use. After talking about the benefits, risks and your preferences, you can then decide together what is best for you.

- Also, before your operation a member of the theatre nursing staff may visit you. He or she will be able to answer any questions you may have about what to expect when you go to theatre.

The day before surgery

You may also be visited by the Stoma Nurse, who will mark the site of a stoma, as a precautionary measure. At the time of surgery it may not be possible to create a new bladder and you will therefore have a stoma formed.

On the day of your operation

Nothing to eat and drink (nil by mouth)

It is important that you follow the instructions we give you about eating and drinking. We will ask you not to eat or drink anything (including chewing gum or sucking sweets) for six hours before your operation. This is because any food or liquid in your stomach could come up into the back of your throat and go into your lungs while you are being anaesthetised. You may take a few sips of plain water up to two hours before your operation so you can take any medication tablets.

Your normal medicines

Continue to take your normal medicines up to and including the day of your surgery. If we do not want you to take your normal medication, your surgeon or anaesthetist will explain what you should do. It is important to let us know, before you are admitted, if you are taking anticoagulant drugs (for example, warfarin, aspirin, dipyridamole, dabigatran, apixaban or clopidogrel).

We will need to know if you do not feel well and have a cough, a cold or any other illness when you are due to come into hospital for your operation. Depending on your illness, and how urgent your surgery is, we may need to delay your operation as it may be better for you to recover from this illness before your surgery.

Your anaesthetic

When it is time for your operation, a member of staff will take you from the ward to the operating theatre. They will take you into the anaesthetic room and the anaesthetist will make you ready for your anaesthetic.

To monitor you during your operation, your anaesthetist will attach you to a machine to watch your heart, your blood pressure and the oxygen level in your blood. General anaesthesia usually starts with an injection of medicine into a vein. A fine tube (venflon) will be placed in a vein in your arm or hand and the medicines will be injected through the tube. Sometimes you will be asked to breathe a mixture of gases and oxygen through a mask to give the same effect.

Once you are anaesthetised, the anaesthetist will place a tube down your airway and use a machine to 'breathe' for you. You will be unconscious for the whole of the operation and we will continuously monitor you. Your anaesthetist will give you painkilling drugs and fluids during your operation. At the end of the operation, the anaesthetist will stop giving you the anaesthetic drugs. Once you are waking up normally, they will take you to the recovery room.

Pain relief after surgery

Pain relief is important as it stops suffering and helps you recover more quickly. Your anaesthetist may suggest that you have an epidural. The nerves from your spine to your lower body pass through an area in your back close to your spine called the 'epidural space'. An epidural injects local anaesthetic drugs into the epidural space using a fine plastic tube placed between the bones of the lower spine. This means that the nerve messages are blocked. This causes numbness and removes the pain. Epidurals may be used during and after surgery for pain relief. They can be inserted when you are conscious, sedated or during your general anaesthetic. The benefits of an epidural are:

- better pain relief than other methods;
- reduced complications of major surgery; and
- you may recover more quickly.

Following an epidural, you may experience some side effects. Side effects are common but are normally minor and easy to treat. Serious complications are rare.

Common side effects include itching from the drugs used and headache. There is a small risk of having a bad headache (one in 100) and of temporary nerve damage (1 in 10,000). Permanent nerve damage and paralysis are very rare indeed. Your anaesthetist will discuss these issues with you.

Another alternative for pain relief is to have a PCA (patient-controlled analgesia). This allows you to control your pain relief yourself. Morphine is the drug normally used, and the PCA machine allows you to press a button and give yourself a small amount of pain medication.

Some side effects are sickness, constipation and drowsiness. Larger doses can cause breathing problems and low blood pressure. However, you can never give yourself too much medicine by this method.

We may also give you tablets or injections to make sure you have enough pain relief. Once you are comfortable and have recovered safely from your anaesthetic, we will

take you back to the ward. The ward staff will continue to monitor you and assess your pain relief. They will ask you to describe any pain you have using the following scale.

- 0 = No pain
- 1 = Mild pain
- 2 = Moderate pain
- 3 = Severe pain

It is important that you report any pain you have as soon as you experience it.

What are the risks of anaesthetic?

Your anaesthetist will care for all aspects of your health and safety over the period of your operation and immediately afterwards. Risks depend on your overall health, the nature of your operation and how serious it is. Anaesthesia is safer than it has ever been. If you are normally fit and well, your risk of dying from any cause related to the anaesthetic is very small. Side effects of having an anaesthetic include drowsiness, nausea (feeling sick), muscle pain, sore throat and headache. We will discuss with you the risks of your anaesthetic.

After your surgery

- Once the medical team are happy with your progress, we will usually take you from the recovery room to the intensive care unit. You will need to rest until the effects of the anaesthetic have passed. You will have a drip in your arm to keep you well hydrated.
- You will usually have a tube (catheter) to drain urine from your neo-bladder into a bag next to your bed.
- You may also have a fine tube in your neck (a central venous pressure line – CVP) to help measure accurately the amount of fluids that you are being given. We will remove it when you no longer need it.
- Your anaesthetist will arrange for you to have painkillers for the first few days after the operation, as we mentioned earlier.
- We will encourage you to get out of bed and move around as soon as possible, as this helps prevent chest infections and blood clots. Usually, the physiotherapy or nursing team will help you with this.

Leaving hospital

❖ Length of stay

How long you will be in hospital varies from patient to patient and depends on how quickly you recover from the operation and the anaesthetic. Most patients having this type of surgery will be in hospital for 10 to 20 days.

❖ Medication when you leave hospital

Before you leave hospital, the pharmacy will give you any extra medication that you need to take when you are at home.

❖ Convalescence

How long it takes you to recover from your surgery varies from person to person. It can take up to three months. You should consider who is going to look after you during the early part of this time. You may have family or close friends nearby who are able to support you or care for you in your home during the early part of your recovery period. You might consider going to stay with relatives or you may want to make your own arrangements to stay in a convalescent home while you recover. After you return home, you will need to take it easy and should expect to get tired to begin with.

❖ Stitches

We will take out any clips or non-dissolving stitches that seal the wound after about 10 days. If you have left hospital before this time, we will arrange for a community nurse to do this.

❖ Heparin Injections

During your stay, you will have had daily injection into your abdomen. You will need to continue these for four weeks. We will give you instructions on how to do the injections, but should you not feel comfortable we can arrange a district nurse to see you.

❖ Personal hygiene

You will normally bathe or shower while you are in hospital, and this can continue as normal after you leave hospital.

❖ Diet

You do not usually need to follow a special diet. If you need to change what you eat, we will give you advice before you go home.

❖ Exercise

We recommend that you avoid strenuous exercise and heavy lifting for up to six weeks. You should do lighter exercise, such as walking and light housework, as soon as you feel well enough.

❖ Sex

As mentioned above this type of surgery has an effect on your sexual and reproductive organs. We recommend you do not attempt sexual intercourse for at least six weeks after surgery.

This will then be discussed with you at your post-operative appointment.

❖ Driving

You should not drive for at least six weeks after surgery. After this time you may drive if you feel confident that you could perform an emergency stop without discomfort. It is your responsibility to check with your insurance company.

❖ Work

How long you will need to be away from work varies depending on:

- how serious the surgery is;
- how quickly you recover;
- whether or not your work is physical; and
- whether you need any extra treatment after surgery.

Most people will not be fully back to work for three months. Please ask us if you need a medical sick note for the time you are in hospital and for the first three to four weeks after you leave.

❖ Trial without your catheter

Your new bladder takes around four weeks to heal, during which time you will have a catheter in the bladder to drain the urine. After this you will be readmitted to the ward for a cystogram – this involves putting dye into the catheter to ensure that there are no leaks from the neo bladder. Once the test confirms this you will have your catheter removed on the ward.

Immediately after the catheter is removed you will need to empty your bladder very frequently and may find you leak urine. In the following days and weeks, as the bladder stretches and its capacity increases, you should be able to manage two to three hours in between emptying your bladder.

At this time it is important to be doing the pelvic floor exercises as taught to you before the operation (you may have been given some instruction about these pre-operatively or been given some written information about them).

You will normally be in hospital for about 24 hours after removal of the catheter until you get used to emptying your new bladder.

❖ **Outpatient appointment**

Before you leave hospital we may give you a follow-up appointment to come to the outpatient department, or we will send it to you in the post. This appointment is normally 10-12 weeks following your surgery.

We ask that you have your bloods tested one week before you attend your clinic appointment (a blood request card is normally sent in the post to you).

Contact details

If you have any specific concerns that you feel have not been answered and need explaining, please contact the following.

- Urology Nurse Specialist Helpline 01905760809
(Monday - Thursday 08.30 - 16.30 and Friday 08.30 - 13.00)
- Alexandra Hospital:
 - Secretaries: 01527 512155
 - Ward 17 Nursing Staff: 01527 512045 or 01527 503030 ext: 44045 or 44046
 - Ward 14 Nursing Staff: 01527 507967 or 01527 503030 ext: 44032 or 47967
 - Sharon Banyard, Laura Grazier Urology Nurse Specialist
 - Jackie Askew, Uro-oncology Macmillan Nurse Specialist
- Kidderminster Hospital and Treatment Centre:
 - Secretaries: 01562 513097
 - Penny Templey, Aimee England, Urology Nurse Specialist
 - Sarah Holloway and Kerry Holden, Nurse Specialist – Survivorship Programme: 01562 512328
- Worcestershire Royal Hospital:
 - Secretaries: 01905 760766
 - Helen Worth, Emma Hurton, Lisa Hammond, Urology Nurse Specialists

Bladder Cancer Support group:

Jackie Askew, Uro-oncology Macmillan Nurse Specialist: 01527 503030 ext: 44150

Stoma Care Nurse Specialists:

Worcester Royal Hospital (phone 01905 760735)

Alexandra Hospital: Sandra Chambers

Other information

The following internet websites contain information that you may find useful.

- www.patient.co.uk
Information fact sheets on health and disease
- www.rcoa.ac.uk
Information leaflets by the Royal College of Anaesthetists about 'Having an anaesthetic'
- www.nhsdirect.nhs.uk
On-line health encyclopaedia
- www.worcestershirehealth.nhs.uk/acute_trust
Worcestershire Acute Hospitals NHS Trust

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PET@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.