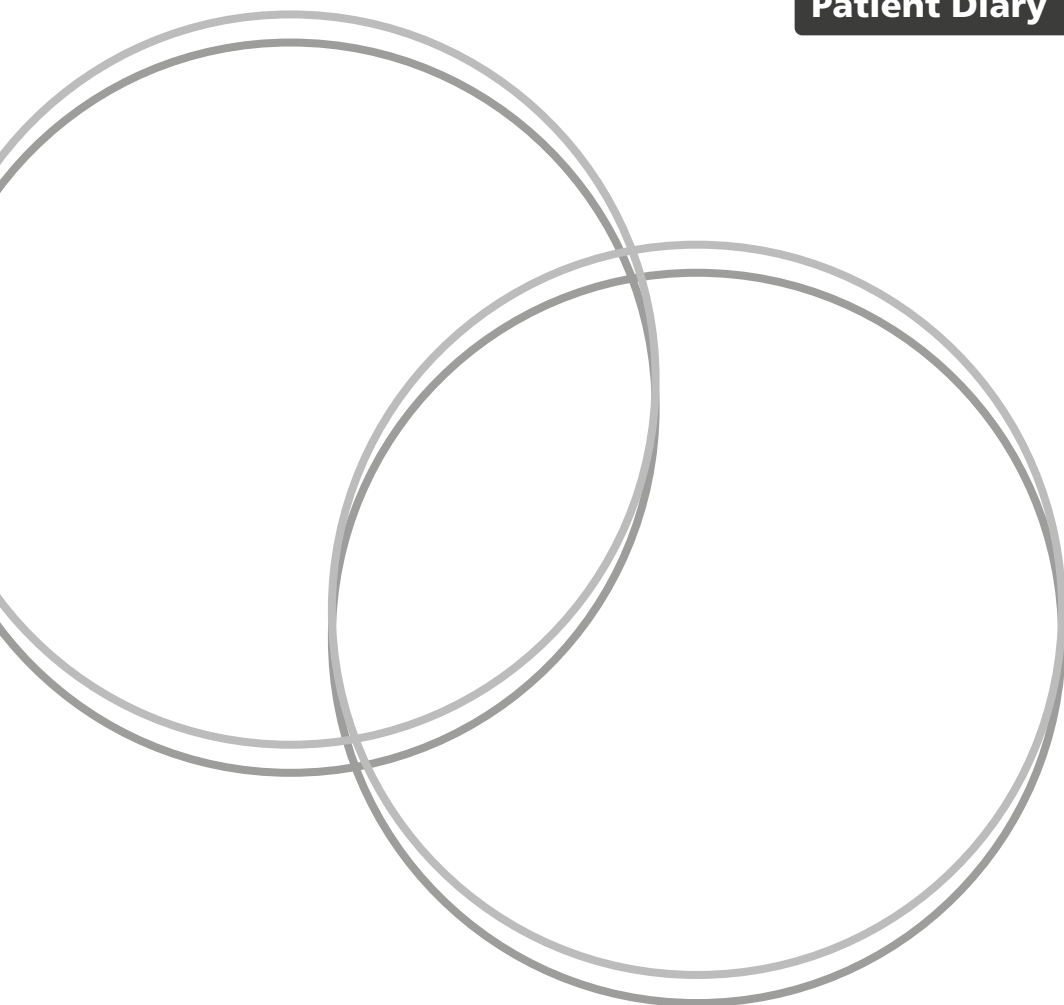


Enhanced Recovery After Surgery (ERAS) Cystectomy

Patient Diary



What is Enhanced Recovery?

Enhanced recovery is a way of improving the experience and wellbeing of people who need major surgery. The programme focuses on making sure that you are actively involved in your recovery, recover quicker, and aims to get you home sooner.

There are four main stages:

- planning and preparation before admission (including improving your nutrition and physical fitness before surgery)
- reducing the physical stress of the operation
- a structured approach to pre-operative (before surgery), intra-operative (during surgery), and post-operative (after surgery) management, including pain relief and early nutrition
- early mobilisation (getting you moving as soon as possible).

The purpose of this diary is for you to record your thoughts and feelings and to note down your progress during your time in hospital after your operation. We encourage relatives and friends to be involved in your recovery, they can help you recover by taking you for walks, provided the nurses agree it is safe to do so.

The diary is designed for you to complete, but your relatives, friends and members of the team looking after you (doctors and nurses) can help you to fill it in if you find this difficult. This diary sets out an example of what to expect in the first few days after your surgery. The programme may not be suitable for everyone. If this is the case for you, the team looking after you can make changes, making sure that the care you receive is not only of the highest quality, but is also designed around your specific needs.

This document is not legally binding and if your recovery is different to the programme set out, this is nothing to be worried about. We realise that every person is different, and everyone will achieve the goals at their own pace.

Whilst we hope that you will complete this diary, it will not affect your care if you choose not to.

Day of Surgery

Date/Day

Plan: After your surgery, your care will be managed in the Churchill Overnight Recovery Unit (CORU) after your surgery. You will be helped to sit up in bed and have something to drink. Pain effectively controlled with painkillers.

Mobility: *(tick if achieved)*

I was able to sit up in bed

☐

I was able to sit in the chair

☐

Nutrition: *(tick if achieved)*

I was able to have something to drink

Water ☐ Squash ☐ Tea/Coffee ☐

How I feel today:

Post-Operative Day One

Date/Day

Plan: You will be transferred to the Urology Ward to continue with your recovery. You will be helped to sit in the chair on two occasions, go for two walks with assistance and to have something to eat and drink.

Mobility: *(tick if achieved)*

I was able to sit in the chair for **1-2** hours (am and pm)

☐ ☐

I was able to go for **2** walks

☐ ☐

Distance walked (aim for walks each of 100 meters)

Chewing gum: *(tick if achieved)*

I was able to chew sugar-free gum for 20 minutes at:

10am

☐

3pm

☐

8pm

☐

Nutrition: *(tick if achieved)*

I was able to have something to drink

Water

☐

Squash

☐

Tea/Coffee

☐

I was able to have my nutritional supplement drinks

am

☐

pm

☐

I was able to have something to eat

Breakfast (e.g milky cereal, yoghurt)

☐

Soup and puddings (e.g. yoghurt, mousse, custard, jelly, creme caramel, ice-cream, stewed fruit' rice pudding)

☐

If you have a urostomy pouch/stoma: *(tick if achieved)*

I was supported with my urostomy pouch care

☐

If you have a neobladder: *(tick if achieved)*

I was shown how to flush my urinary catheter

am

☐

pm

☐

How do I feel today?

Post-Operative Day Two

Date/Day

Plan: Sit on the chair on two occasions. Go for walks with assistance. Have something to eat and drink.

Mobility: *(tick if achieved)*

I was able to sit in the chair for **1-2** hours (am and pm)

☐ ☐

I was able to go for **2** walks

☐ ☐

Distance walked (aim for walks each of 100 meters)

Chewing gum: *(tick if achieved)*

I was able to chew sugar-free gum for 20 minutes at:

10am ☐

3pm ☐

8pm ☐

Nutrition: *(tick if achieved)*

I was able to have something to drink

Water ☐

Squash ☐

Tea/Coffee ☐

I was able to have my nutritional supplement drinks

am ☐

pm ☐

I was able to have something light to eat
(e.g. cornflakes, Rice Krispies®, white bread or toast,
egg, chicken, mashed potato, fish, rice, cheese pasta)

☐

If you have a urostomy pouch/stoma: *(tick if achieved)*

I was supported with my urostomy pouch teaching

☐

If you have a neobladder: *(tick if achieved)*

I was shown how to flush my urinary catheter

am ☐

pm ☐

How do I feel today?

Post-Operative Day Three

Date/Day

Plan: Sit on the chair on two occasions. Go for walks with assistance. Have something to eat and drink.

Mobility: *(tick if achieved)*

I was able to sit in the chair for **2-3** hours (am and pm)

☐ ☐

I was able to go for **2** walks

☐ ☐

Distance walked (aim for 2 walks each of 200 meters)

Chewing gum: *(tick if achieved)*

I was able to chew sugar-free gum for 20 minutes at:

10am ☐

3pm ☐

8pm ☐

Nutrition: *(tick if achieved)*

I was able to have something to drink

Water ☐

Squash ☐

Tea/Coffee ☐

I was able to have my nutritional supplement drinks

am ☐

pm ☐

I was able to have something light to eat

(e.g. cornflakes, white bread or toast, egg, chicken, mashed potato, cheese)

☐

If you have a urostomy pouch/stoma: *(tick if achieved)*

☐

I was supported with my urostomy pouch teaching

If you have a neobladder: *(tick if achieved)*

I was shown how to flush my urinary catheter

am ☐

pm ☐

How do I feel today?

Post-Operative Day Four

Date/Day

Plan: Sit on the chair on two occasions. Go for 2 walks (ask for help if you need it). Have something to eat and drink.

Mobility: *(tick if achieved)*

I was able to sit in the chair for **2-3** hours (am and pm)

☐ ☐

I was able to go for **2** walks

☐ ☐

Distance walked (aim for 2 walks each of 200 meters)

Nutrition: *(tick if achieved)*

I was able to have something to drink

Water ☐ Squash ☐ Tea/Coffee ☐

I was able to have my nutritional supplement drinks

am ☐ pm ☐

I was able to have eat more than half of my light meals

☐

If you have a urostomy pouch/stoma: *(tick if achieved)*

I was supported with my urostomy pouch teaching

☐

If you have a neobladder: *(tick if achieved)*

I was shown how to flush my urinary catheter

am ☐ pm ☐

How do I feel today?

Care of my urostomy pouch/stoma

If you have a urostomy, the table below is for you to record the care of your urostomy pouch/stoma. You will need to be able to look after your urostomy pouch/stoma on your own before you leave hospital.

Please use the table below to record the day that you reached each goal. You will be supported by your stoma nurse and nursing team initially with the goals in the table and as you become more independent with you urostomy pouch/stoma care you can continue to use this table as a reference to allow you to see your progress.

Goal/Target	Post-operative day achieved
I was shown my urostomy pouch	
I was shown my urostomy pouch supplies	
I was shown how to disconnect and reconnect my night bag	
I was shown how to empty my urostomy pouch	
I was shown how to change my urostomy pouch	
I was able to disconnect and reconnect my night bag	
I was able to empty my urostomy pouch under supervision	
I was able to empty my urostomy pouch on my own	
I was able to change my urostomy pouch under supervision	
I was able to change my urostomy pouch on my own	
I have all my equipment ready for going home	
I know how to contact my stoma nurse	

Your stoma nurse will call you after you have been discharged from hospital and will arrange to see you in their clinic within two weeks of your discharge. If you live outside Oxfordshire, you will be referred to your local team.

The stoma nurse will organise all your stoma supplies shortly after you have been discharged.

Recovery goals and targets

The first few days of your recovery involve the removal of the various drips and drains that were put in during surgery. You will now start to feel more free and able to walk around, without the fear of pulling something out. It is from this time onwards that your recovery should really make a turning point and the team looking after you will work with you and your family/friends to prepare you for leaving hospital.

Below is a list of goals and targets we would like you to achieve to help your recovery and to get ready for leaving hospital. We realise that every person is different and everyone will achieve the goals at their own pace. This table is for you to make a note of the day you reached the goal for your own reference and to let you see your progress.

Goal/Target	Post-operative day achieved
Sit out of bed for the majority of the day	
Walk independently along the ward	
Get dressed into your own clothes (unaided)	
Managing your meals	
Managing your nutritional supplement drinks	
If you have a urostomy: Care for your urostomy pouch/stoma independently	
If you have a neobladder: Flush your urinary catheter independently	
Be assessed as competent to safely administer your blood thinning injections, if applicable (or have an alternative option in place if unable to self-administer)	

Leaving hospital

The Enhanced Recovery Programme is based on criteria-led discharge and when you have achieved all the criteria, it is time for you to leave hospital.

The criteria are listed below:

(Please tick when achieved – this is for your reference only)

Discharge criteria	Tick when achieved
Assessed as medically fit for discharge	
Effective pain control with oral analgesics (painkillers)	
Managing to eat and drink with no nausea or vomiting	
Independently mobile (able to get self out of bed and on/off toilet)	
If you have a urostomy: Independent with urostomy pouch/stoma care	
If you have a neobladder: Independent with flushing your urinary catheter	
Bowels opened	
Confident with blood thinning injection self-administration (if applicable), or have an alternative option in place	

Medications for going home

After your surgery you will need some new medications to take home. Please ask the Urology Ward team whether you need to continue taking the medications you were on before your surgery.

Please use the following list to check that you have everything you need. If you have any questions, speak to your ward nurse or doctor.

Medication	Tick if supplied	Explanation
Omeprazole		An antacid to help protect your stomach after your surgery. To be continued for 4 weeks after surgery. If you normally take antacid medication, this should continue during your stay in hospital and as normal after you leave, unless you are told otherwise.
Sodium bicarbonate (following neobladder surgery only)		To help neutralise extra acid that may be reabsorbed over time through the new bladder lining. You may be started on these tablets before leaving the hospital after your neobladder surgery . We will give you specific advice about how often to take them.
Enoxaparin		An injection to reduce your risk of blood clots. To be taken for 28 days after surgery. If you already take medication to thin your blood, you will be given this injection at a higher dose before resuming your blood thinning medication.

Paracetamol tablet		Mild painkiller. To be taken regularly for the first week and then continued as needed, to help you remain active and able to continue to achieve your recovery goals. Gradually reduce then stop this painkiller last.
Codeine tablet		Moderate painkiller. To be taken as needed, to help you remain active and able to continue to achieve your recovery goals. Gradually reduce then stop this painkiller first Managing constipation: Codeine may affect your normal bowel pattern and cause constipation. Please use the laxative provided whilst taking codeine, to help with constipation. It is important that you do not stop this painkiller too soon after leaving hospital, as this may affect you achieving your recovery goals.
Sodium docusate or Laxido		A laxative to help soften your stools. To be used whilst taking codeine, to help with constipation.

Recovery after discharge

You may be a little worried about returning home when you have been discharged from hospital after an operation. However, all the professionals involved in looking after you will have decided that you are well enough to leave hospital. It is important to continue with your recovery after discharge to help you to return to your normal activities sooner. It can take at least three months to recover from your cystectomy surgery.

We have answered some commonly asked questions over the next few pages to help aid your recovery. However, this is a general guide, for questions related to your specific needs please speak to a member of your clinic team.

How do I manage my pain after discharge?

You will be given painkillers to take home along with advice on how to take them and how long for when you are discharged from hospital. For most individuals, pain reduces over a short period of time, but you may need to continue to use pain killers when you return home. Most individuals do not need stronger painkillers after a week. The painkillers should be reduced and gradually stopped as your pain settles.

Do I follow a special diet after the surgery?

Eating regular meals and having a balanced and varied diet can help you to get the right nutrients to help you heal and recover after surgery. Including foods rich in protein in your meals can help towards wound healing. This includes foods such as eggs, meat, fish, pulses (such as beans, lentils, chickpeas), cheese, milk and milk puddings.

If your appetite is reduced or your portion sizes are smaller than normal you could try having five or six smaller meals, snacks or nourishing drinks during the day.

To avoid constipation, include foods rich in fibre such as fresh fruit, vegetables, beans and pulses, porridge, wholemeal bread and cereals.

Aim to drink 1.5 to 2 litres of a variety of fluids each day to help keep you well hydrated and prevent constipation. Fluids can include water, flavoured water or diluted squash, tea, herbal tea, coffee, malted drinks, hot chocolate and milk. Foods containing fluid can also help you to maintain your hydration and include soup, ice-lollies, jelly, yoghurt and milk puddings.

What do I do if I become constipated?

We will assess you have opened your bowels whilst in hospital. When you leave hospital, we will provide you with gentle laxatives in your discharge medication pack to use if you start to notice signs of constipation, such as straining when opening your bowels, passing hard stools, or opening your bowels less often than usual.

If you are taking stronger painkillers at home these can also make you more likely to be constipated. It is important to continue to move around and be gently active such as walking when you are home to help keep your gut working.

How do I manage my tiredness?

Cystectomy is a major operation, and recovery can take time. It is normal to feel tired or to need a midday nap to help balance your energy levels as you continue to recovery at home.

Try to build up your activity gradually, listen to your body and rest when needed. Most patients find their energy levels improve slowly over the weeks and months after surgery.

When can I start exercising again?

Please request the **'Physiotherapy advice after abdominal surgery'** leaflet from the ward which helps outline guidance on recovery and exercise after your surgery. We encourage light walking after your surgery and building up your activities goals each week as advised in the physiotherapy leaflet. From six weeks after your surgery, you may gradually return to more strenuous activities such as jogging, unless advised otherwise by your surgical team.

How do I care for my wounds after surgery?

We usually use skin glue to close your wounds, so you will not normally have dressings on your wounds other than your stoma bag. The stitches in your tummy are dissolvable and do not need to be removed.

Keep your wounds clean and dry and avoid rubbing or scratching them while they heal.

Can I shower or bath after my surgery?

We recommend showering rather than bathing after your surgery. You can use soap or shower gel to wash your body but avoid rubbing soap directly onto your wounds. Rinse thoroughly and gently pat your wounds dry with a clean towel.

We advise you to shower with your stoma pouch on while your stents are still in place. Once the stents have been removed, you can shower with the pouch off if you wish but be aware that urine may pass without warning. It can help to have your new pouch and stoma equipment ready before you get out of the shower.

Avoid bathing until at least six weeks after surgery, or until your wounds have fully healed. Please keep your stoma pouch on while bathing.

When can I drive?

You can drive when you are comfortable to do so and when you are able to confidently perform an emergency stop. This is generally at least six weeks after your surgery. Please also check with your insurance company before returning to driving.

When can I have sex again?

You should wait until you have recovered from your surgery and your wounds have healed before having sex again. Your surgical team can advise you when it is safe to resume sexual activity.

Most individuals will experience significant sexual dysfunction after a radical cystectomy surgery.

Men can experience difficulties getting or keeping an erection. Women can notice changes such as shortening of the vagina.

Your surgeon will discuss these changes with you at your first outpatient appointment after surgery. If you have any further queries around this before your discharge, please do speak to your surgical team.

When should I return to work?

Please allow time for recuperation before returning to work. The amount of time required will depend on the nature of your work and your surgical team can guide you on this. If you require a fit note (sick note) for your work or your work involves lifting, please speak to your doctor before leaving hospital.

How do I look after my drain at home?

After your cystectomy surgery, you will have a drain tube coming from your tummy. This helps remove and collect any extra fluid while your body heals and allow your doctors to monitor your recovery.

You may go home with the drain still in place. Before you leave hospital, your nurse will show you how to care for your drain safely at home. Please keep a daily record of how much fluid is coming out of your drain each day as this will help your surgical team to check your continued recovery and healing.

Before you go home, you will be given a follow-up appointment for the drain to be reviewed at Urology triage.

Ureteric Stents

Your two ureteric stents (small plastic tubes) will usually stay in place for 14 days after your surgery. Sometimes, they may need to stay in for longer, for example if you go home with a wound drain. Your consultant will tell you when your stents need to be removed.

You will be given a single dose of antibiotic in your discharge medication pack to help reduce the risk of infection. Please take this antibiotic one hour before your stent removal appointment.

What else should I look out for?

You should monitor the healing of your wounds, look out for any sudden changes in your overall recovery, for any signs of infection, a new cough, changes in the colour of your stoma or new swelling of the legs, particularly if only on one side.

Contact your GP or Urology triage if you:

- feel feverish or generally unwell
- have increased redness, throbbing pain or pus-like discharge from your wound(s)
- increasing abdominal and/or loin pain, not controlled with painkiller
- new productive cough that is not getting better
- develop significant blood through the stoma
- your stent(s) fall out.

Very occasionally, following surgery serious complications can develop. Please attend your nearest Emergency Department if you:

- start vomiting and are unable to keep fluids down
- have worsening shortness of breath
- develop chest pain or a painful swollen leg

Support after discharge

If you are unsure on any aspects of your care, please do not hesitate to contact us.

For advice during office hours, please contact your consultant surgeon's secretary or your specialist nurse on the telephone numbers listed below. If you are unable to contact a member of the team, please contact your GP or the Urology Ward.

Urology Ward

Tel: **01865 572 332** or **01865 572 333** (24 hours)

Urology Triage

Tel: **01865 227205** (24 hours)

Consultant Surgeon's Secretaries

Tel: **01865 227072**

(8.00am to 4.30pm, Monday to Friday)

Uro-oncology Specialist Nurse

Tel: **01865 572374**

(8.00am to 4.00pm, Monday to Friday)

Stoma Specialist Nurses

Tel: **01865 234390**

(8.00am to 3.30pm, Monday to Friday)

If the ward is unavailable, your question needs an urgent response or it is outside of office hours, please contact your GP's surgery or out-of-hours GP's service (including NHS 111 – call 111 free from any landline or mobile). They can assess you and decide what further action needs to be taken.

If you require an urgent review, you may be asked to visit Urology Triage at the Churchill (Level 2 of the Cancer Centre) for further tests and investigations. **In an emergency or life-threatening situation, call 999 or go to your nearest Emergency Department.**

Enhanced Recovery Team

My Consultant is

My Specialist Nurse is

My Dietitian is

My Enhanced Recovery Nurse is

My ERAS Physiotherapy Assistant is

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



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ERAS Patient Experience Questions

We would like to understand how you felt about your recent stay in hospital and would be grateful if you could answer the following questions. Your answers will be treated confidentially. We value your input in helping us look at ways of improving our service.

Thank you.

Do you feel the Enhanced Recovery After Surgery programme improved your recovery? (please **tick** one answer)

☐ Yes

☐ No

If no, what were the reasons?

Did you feel being on the Enhanced Recovery After Surgery programme allowed you to be involved in your recovery?

(please **tick** one answer)

☐ Yes

☐ No

☐ I did not need to be involved

☐ Don't Know

Were there any parts of the Enhanced Recovery After Surgery programme that you felt were not relevant for you?

(please **tick** one answer)

☐ No

☐ Yes

If yes, what parts did you feel were not relevant?

How well do you think your pain was managed after your surgery?

Poorly managed

Adequately managed

Very well managed

1

2

3

4

5

6

7

8

9

10

ERAS Patient Experience Questions

Did you find the Enhanced Recovery After Surgery patient information leaflet useful?

☐ Yes ☐ No

Did this make you feel – *(please **circle** the most appropriate words)*

well informed prepared in control confident happy
supported unclear unprepared out of control anxious
stressed unsupported frustrated

Did you find the Enhanced Recovery After Surgery Patient Diary useful?

☐ Yes ☐ No

Did this make you feel – *(please **circle** the most appropriate words)*

well informed prepared in control confident happy
supported unclear unprepared out of control anxious
stressed unsupported frustrated

Did your overall care experience make you feel –

*(please **circle** the most appropriate words)*

well informed prepared in control confident happy
supported unclear unprepared out of control anxious
stressed unsupported frustrated

If you could change one part of the Enhanced Recovery programme, what would it be?

Do you have any other comments?

After completion, tear this page out of the booklet and leave on the hospital ward before you are discharged home.

Thank you.

Cystectomy