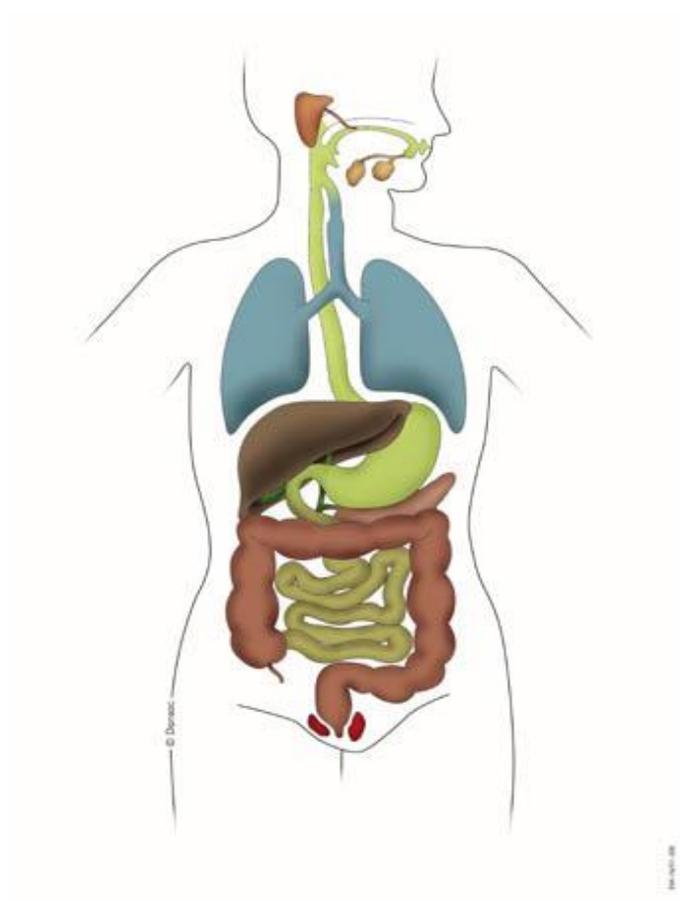


Going home after colostomy surgery

Information for patients



Name:

Operation:

Recovery

It can take between three and six months to recover following your stoma surgery. It is important to rest and slowly build up your strength and stamina.

Before you leave hospital you should be independent with your stoma care, but it may take time to get used to the stoma. You may experience mixed emotions, for example relief, apprehension, tearfulness, anger, or maybe feelings of not being able to cope or being out of control. These are all normal reactions. Talking about your feelings with someone you are comfortable with may help. It may also help to speak to someone who has a stoma; your stoma care nurse can organise this.

Supplies

When leaving the hospital, you will be given a two-week supply of stoma pouches to take home with you. The stoma care nurses will also arrange for a home delivery company called Medilink (tel: 0800 626 388) to, who will deliver all your supplies to your home address a few days after discharge.

After your first delivery you will be responsible for ordering further supplies. Please order supplies two weeks in advance, as Medilink will need to get a prescription from your GP. The stoma nurses will give you a Medilink file with all the details of the products you are using.

Prescriptions

If you have a permanent stoma or have been diagnosed with cancer, you can apply for a certificate exempting you from prescription charges by obtaining a form from your GP surgery. If you are not exempt from prescription charges, it may be cheaper to apply for a prescription prepayment certificate, available from your GP or pharmacist.

Support after you leave hospital

If you live in the London Borough of Camden

If you live in the London Borough of Camden you will see the stoma care nurses at the Royal Free Hospital. An appointment will be made before you leave hospital so you can be seen about two weeks after your discharge. This appointment is to ensure you are managing your stoma well.

You will also be asked to come and see the stoma care nurses at regular intervals so we can check on your stoma and discuss any concerns you may have.

If you are having problems with your stoma you can call the stoma care department for advice. The stoma care nurses may ask you to come into the hospital to see them. If no one answers the phone, please leave a message on our answering service and we will contact you as soon as possible.

At your out-patient appointments we will provide you with:

- practical help and advice
- advice on hernia prevention and relevant support garments
- ongoing support
- psychological and sexual advice
- up-to-date information on new products

If you have problems with your mobility we will organise for you to be seen by a community stoma care nurse at home. We will give you their contact details before you leave hospital.

If you don't live in the London Borough of Camden

We will talk to your local stoma care nurse to tell them about your surgery and how you are managing with your stoma before you leave hospital. They will contact you after you've gone home. We will also give you their contact details so you can contact them.

General advice

Disposing of stoma pouches

Used stoma pouches should be disposed of safely. You can empty the contents of your stoma pouch into the toilet and then put the pouch in a tied rubbish bag (included in your supplies) before placing in the bin. Don't flush your used stoma pouch down the toilet as it could get stuck and cause a blockage.

Going out

Please remember, having a stoma is just a different way of going to the toilet and you should continue to go out and do the things you enjoy. If you would like support, please speak to your stoma nurse.

When you leave the hospital, you will be given a toilet card that can be used in an emergency. This may help you avoid toilet queues when you go out.

You can also obtain a free Radar key from your delivery company Medilink. This key will give you fast access to all locked disabled toilets in case of an emergency, but please remember having a stoma is not a disability.

Diet

You should eat a normal, well-balanced diet. It may take several weeks before your appetite returns. Eating smaller meals more often and snacking can help. If you feel a particular food is causing problems with your stoma, try it again at a later date or in smaller quantities before you decide you can't tolerate it. Your stoma nurse can give you dietary advice, but you will soon learn what is best for you.

If you have ongoing dietary concerns, please ask your GP for a referral to a dietitian.

Ballooning

Sometimes the stoma pouch can fill with wind and this may cause it to balloon. Most pouches have a filter to release wind automatically, but some filters need to be uncovered. Your stoma care nurse can advise on the type of pouch you have.

Adjusting your diet to eat fewer foods that cause wind, for example onions, beans, eggs, salad and fizzy drinks, may help to control this. Peppermint tea or peppermint capsules can help as well.

Bathing

The main part of your stoma pouch is waterproof and will not fall off. The outer cover is water-resistant and may get damp, but you can dry it with a towel or hair dryer, or replace

the pouch after bathing or showering. You can bathe and shower as normal with or without your stoma pouch in place, but remember you don't have control over when your stoma may function.

You may need to remove the hair around your stoma to ensure the pouch stays attached properly. Shave the hair in the direction of growth. It may be useful to cover your stoma with an empty toilet roll to protect it when doing this.

Clothes

You may feel more comfortable wearing looser clothes while your wounds are healing. Eventually, you should be able to wear your usual clothes. Men may prefer to wear braces instead of a belt. Make sure your beltline doesn't restrict your stoma.

Exercise

Following your surgery, walking is the best exercise and may be all you can manage in the first few months. Strenuous exercise such as going to the gym and swimming should be re-introduced slowly. There is no reason why having a stoma should stop you swimming and there are companies that make different types of swimwear to make you feel more comfortable. Ask your stoma care nurse for more information. If you play any contact sports where you could damage your stoma, you should wear a stoma shield for protection. Please ask your stoma care nurse about this.

Driving

You will not be able to drive after surgery until your GP or consultant tells you it is safe to do so. This will usually be after about six weeks. Please also check with your car insurance company before driving to make sure you're still covered.

Work

When you return to work depends on your surgery and the type of work you do. You should talk to your stoma care nurse or consultant before you return to work to make sure you're fit to do so. Your GP can provide you a sickness certificate after you leave hospital. You may wish to start off by working part-time or shorter hours to ease yourself back in.

Sex

Sex may be more difficult after surgery. This can be due to the surgery itself, or can be linked to anxiety or concern about your partner's feelings. Men may experience problems with erections and ejaculation. This is normally only temporary. Women may find intercourse painful or have trouble with vaginal dryness, but this is also temporary. If you continue to experience problems after eight weeks, please talk to your stoma care nurse, GP or consultant.

You can have sex any time after your surgery, but you should check with your consultant before having anal sex if you've had surgery in your lower rectum or anus. The stoma itself should not be used for sexual activity.

Contraception and pregnancy

You can still get pregnant and have a normal pregnancy with a stoma. You should discuss methods of contraception with your GP or family planning clinic.

Travel

Having a stoma should not stop you from travelling, but there are a few things to consider:

- Check with your travel insurer to make sure you're covered. The Ileostomy/Colostomy Associations have a list of companies who can cover you.
- Make sure you take adequate supplies, including imodium and drainable pouches. It's a good idea to pack some in your hand luggage and some in another suitcase.
- Your stoma care nurse can provide you with a travel certificate.
- Follow precautions with regards to drinking water and foods
- In hot climates, increase your fluid and salt intake to avoid dehydration

Medication

Your surgery may affect how you digest and absorb your medication. If you notice tablets in your stoma pouch please speak with your pharmacist or GP as you may not be absorbing the medication. Some medication may also change how your stoma works. Speak to your GP if you have any concerns.

Common concerns

The following are common concerns experienced by patients. Please contact your community stoma care nurse for further advice and support.

Sore skin

It is not unusual to experience sore skin around your stoma. This may be due to:

- leakages
- allergy
- frequent pouch changes
- template size
- pre-existing skin conditions

Leaks

Possible causes of leaks include:

- change in body shape or size
- forgetting to remove the backing paper from the baseplate
- Too large a template
- If you have a leak, change the pouch as soon as possible. If this happens frequently, please contact your stoma nurse for a review.

Diarrhoea

You can still get an upset stomach from food, medication or viruses. You should treat this in the same way you did prior to surgery, and it may help to wear a drainable pouch. If this happens frequently, please speak to your GP.

Constipation

You can still become constipated with a colostomy. To help relieve this you can increase your fluid intake. You could also slowly increase the amount of fibre you have in your diet, for example fruit, vegetables, wholemeal bread and wholegrain cereal. Gentle exercise can also help.

Bleeding

It is normal for specks of blood to be seen on wipes when cleaning your stoma. If bleeding persists, please contact your stoma care nurse or GP. If blood comes from inside your stoma, please contact your GP or visit your local emergency department.

Possible causes of bleeding include:

- template too small and causing friction
- use of anticoagulants (blood thinning medication) and aspirin
- granuloma – looks like a red skin tag
- knocking or scratching your stoma

Blockage

If you get a blockage, your stoma may stop working or your pouch may contain excessive amounts of watery fluid. If the output changes significantly in consistency, colour or quantity or you are feeling unwell with stomach pain and/or nausea or vomiting, you should contact your stoma care nurse or GP.

Prolapse

Your stoma may increase in size or protrude further. This is quite rare. If your stoma is working and a normal colour, and your stoma pouches still fit, then you do not need to worry. If your stoma changes colour, stops working or becomes too big for your pouch, please visit your local emergency department. Contact your stoma care nurse if you have any concerns.

Lifting and parastomal hernia

A parastomal hernia is a bump, bulge or swelling around your stoma. This usually occurs gradually and it may get bigger over time. To prevent this from forming, it may help to wear a support garment. This can be obtained through your stoma care nurse. You can start wearing one eight weeks after surgery when post-operation swelling has settled.

You should also try to avoid activities that put pressure on your abdominal muscles, and be particularly careful for three months after surgery when coughing or sneezing. You may need assistance with cleaning, using a vacuum and shopping. Lifting small children may also put strain on the abdomen. Heavy lifting is classed as anything heavier than a kettle full of water. Be aware of this and support your abdominal muscles.

If you develop a parastomal hernia, please make an appointment with your stoma care nurse. Most parastomal hernias do not require any surgery and can be managed well with support garments.

Rectal discomfort or pain

This is sometimes referred to as a “phantom rectum” and can feel as if you want to open your bowels through your back passage, even when your rectum/anus has been removed. This normally resolves as your body heals and can take as long as six months. You may want to sit on the toilet to relieve this feeling, but it’s important not to strain. If this feeling continues, please mention it at your next hospital visit.

Rectal discharge

If your rectum has not been removed, you may experience some discharge from your back passage. This is usually mucus and is normal. It can appear sticky and cloudy in colour.

Shortly after surgery it may be brown or dark red in colour. You may even pass motion. This should settle over time, but if it continues, please let your GP or consultant know.

Pelvic floor exercises and reversal

Your consultant will advise you whether your stoma can be reversed and when a reversal will take place. While waiting for a reversal, it is helpful to start performing pelvic floor exercises daily. This builds up muscle strength and can help you control your bowel movements following reversal. Speak with your stoma care nurse and consultant to discuss pelvic floor exercises and expected bowel function following reversal.

Alternatives to wearing a pouch

There are alternatives to wearing a pouch over your stoma, for example colostomy irrigation and colostomy plugs. These methods take some time to learn and adjust to and are not suitable for everyone. If you would like further information please discuss this with your community stoma care nurse. Approval would be required from your consultant.

Notes

Further information on the following is available from the stoma care nurses should you need it:

- diet
- exercise
- sex and relationships
- pelvic floor exercises
- travel
- rectal discomfort
- rectal discharge
- parastomal hernia
- swimwear
- support garments

Contact us

For Royal Free London stoma care nurses, please call: 020 7830 2693

Other useful contacts

Ileostomy Association

Tel: 0800 018 4724

Website: www.iasupport.org

Colostomy Association

Tel: 0800 328 4257

Website: www.colostomyassociation.org.uk

Crohn's Colitis UK

Tel: 0845 130 3344

Website: www.crohnsandcolitis.org.uk/home

Macmillan Cancer Support

Tel: 0808 808 0000

Website: www.macmillan.org.uk

Beating Bowel Cancer

Tel: 020 8973 0011

Website: www.beatingbowelcancer.org

Acknowledgements

Front page image kindly provided by Dansac Ltd.

More information

For more information about the colorectal service at the Royal Free London, please visit our website: www.royalfree.nhs.uk/services/services-a-z/gastroenterology/colorectal-surgery.

Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: rf.communications@nhs.net.

Alternative formats

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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Service: Colorectal and stoma care service

Version number: 1

Approval date: November 2019

Review date: November 2021

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