

# Going Home

For all-round support  
with an internal pouch



Ileostomy & Internal Pouch  
Association



Royal College  
of Nursing

- Providing support and advice
- Helping you with your concerns
- Local organisations
- Contact information

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## Introduction

Taking each day at a time, never alone.

Now that you are leaving hospital and you are on the way back home, looking forward to being back with family and friends, you may be wondering how life will be in years to come. We hope that it is going to be all that you would like it to be in the future.

This booklet is designed to help you and has been produced with the RCN Gastroenterology and Stoma Care Nursing Forum and IA (Ileostomy and Internal Pouch Association).

Using their extensive knowledge and experience, these two groups work together in this way to ensure that you are given the best advice available and that the coming months are made as easy and comfortable as possible.

This is the sixth edition of the booklet and we know that it has helped many people to enjoy a good quality of life. Therefore, please keep it handy so that you can refer to it at any time.

Remember, there are many healthcare professionals and others within IA, dedicated to your wellbeing. It may be worth making a note of the contact telephone number of your Doctor, Stoma Nurse and Pharmacy on page 8 of the booklet for ease of reference. If anything troubles you, please contact them for support and advice.

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Ileostomy & Internal Pouch  
Association

Listen • Inform • Support



## Foreword

If you suffer from ulcerative colitis or familial adenomatous polyposis (FAP), the ileo-anal internal pouch is an alternative to a permanent ileostomy.

The pouch operation will not restore your bowel function to the way it was before you became ill, but many people find it an acceptable alternative to having a permanent ileostomy.

It can take several months before you feel the full benefit of having your pouch operation and it may take six to twelve months before the pouch settles into a routine. However, at the end of this time most people go to the toilet four to six times during the day and possibly once or more at night. You should also be able to distinguish between wind or stool in your pouch.

You may experience some incontinence at first, particularly at night, and it can take time to get this under control. Remember that your pouch function continues to improve for up to eighteen months following surgery. Recovery from this procedure is individual and is usually straightforward, although you may feel very tired at times. Because the pouch surgery is often carried out in two or even three stages, it may take more than a year to complete and you will need the support of your family, friends and employers.



## Dietary Considerations

Having a pouch should not affect your digestive process, so try and eat as normally as possible. There may be some restrictions or some items you prefer to avoid. There is no need for a special diet unless you are so advised by your doctor.

It may take several weeks before your appetite returns, especially if you have been unwell for a time. You are advised initially to try eating small, appetising meals at regular intervals and gradually to introduce new food items into your diet. If you feel an item has upset you, you are advised to try it again after a week or so and on further occasions before you finally decide you cannot tolerate it.

It is worth bearing in mind the following:

- Anal irritation may be caused by coconut, spicy food, nuts, some fruit and food with pips. They may also cause colicky pain, which is usually of a temporary nature.
- Some foods may cause more wind, for example baked beans, cabbage and other green vegetables, so you may wish to limit or avoid these items.
- Fizzy drinks may also increase the amount of wind.
- Certain other foods may colour output, for example, beetroot, tomato, or red wine can make your output appear blood-stained.
- Some foods may be passed whole, for example sweetcorn, beans.



- Beers, lager, chocolate and some fruit may have a laxative effect.
- You can continue to drink alcohol, but this may cause dehydration (if taken to excess) and you may find beer and red wine increase your pouch output.
- Some drugs (see page 11) can affect the colour of your output.
- Your stoma care nurse can give you dietary advice, but you will soon learn what is best for you. We suggest that you experiment with foods that you may have previously avoided due to your colitis.

Further dietary suggestions can be found on the IA website at:  
[www.iasupport.org/pouch\\_faq.aspx](http://www.iasupport.org/pouch_faq.aspx)

### Remember

- Do not try to regulate your output by cutting down on fluids as you may become dehydrated. It is important to use a rehydration solution when necessary.

### Tips

- **Marshmallows, ripe bananas, apple sauce, potatoes, white rice or pasta may help to decrease pouch output.**
- **You may wish to avoid eating and drinking at the same time to cut down pouch activity.**
- **Experiment with main meal times to regulate pouch activity.**
- **Chew food well.**



## Concerns

### Leakage

This may be motion or mucus and, can happen in the early post-operative period, mainly at night. As you get stronger, leakage should cease. If it persists, see your doctor or stoma care nurse. Leakage may also occur if you take strenuous exercise. Regular Kegel (pelvic floor) exercises can also help reduce problems with leakage.

#### Tip

- **Wearing a small pad or panty liner will enable you to overcome soiling and give you confidence.**

### Sore skin

This sometimes occurs around the anus. When possible, wash around the area after opening your bowels, using a soft cloth for 'patting' dry. Moist toilet paper is useful on these occasions.

#### Tip

- **Soothing cream or barrier cream used sparingly after washing can prevent sore skin. Portable bidets for use on your toilet are available at moderate cost.**

### Frequent motions

Usually, the frequency reduces as you recover and regain strength. If it continues, contact your doctor or stoma care nurse. The problem is usually remedied easily with diet or medication.

### Wind

Due to an accumulation of wind, your bowel action may, at times, be explosive. This can be influenced by your dietary intake or delaying opening your bowels.







## Bleeding

This is not common, but may occur in the early days, or if you are taking anticoagulant medication, e.g. aspirin or warfarin. Contact your doctor or stoma care nurse.

## Feelings

Whilst you are recovering after your operation, you may experience mixed emotions - sometimes relief, sometimes apprehension and you may, at times, feel tearful and angry. There may be feelings of not being able to cope or being out of control; these are normal reactions for some people. Talking it through with your partner, a family member or close friend may help. Your stoma care nurse is also available to support you. If you have not yet talked to an established pouch patient and now feel that you would like to do so, please contact your stoma care nurse or IA.

## Complications

Sometimes the join between the pouch and anal sphincter becomes narrowed (stenosed), which in turn leads to increased pouch function. Your surgeon may decide that you need an anal stretch to improve pouch function; this may necessitate a day in hospital to have the stenosis dilated under a light anaesthetic. Another complication of surgery is 'pouchitis', which gives you similar symptoms to colitis with increased pouch activity. You will also feel tired and unwell and will probably need a course of antibiotics such as metronidazole to treat the inflammation in the pouch. A few people may need to be treated in hospital with intravenous fluids. However, many people never experience pouchitis. For further information and additional concerns please see the FAQ pages of the IA website at [www.iasupport.org/pouch\\_faq.aspx](http://www.iasupport.org/pouch_faq.aspx)



## Drugs

### Remember

You should not stop taking any prescribed tablets or medicines without consulting the doctor. Any drug may have some effect on your pouch output and colour. Some drugs may not be absorbed properly, especially if they are:

**Enteric coated (not absorbed in the stomach):** Prednisolone, iron tablets, potassium and salt tablets may be excreted whole before proper absorption has taken place.

**Modified release tablets (slow release):** some angina medicines and cold remedies may be difficult to absorb.

**Contraceptive pill: (see page 13)**

### Drugs affecting output

**Constipating effect:** morphine, codeine, iron tablets, some anti-depressants decrease pouch output.

**Increased pouch output:** this can be caused by taking antibiotics, iron tablets, some antacids containing magnesium or laxatives.

### Drugs effecting change in colour of your output

Iron	<b>Black</b>
Charcoal	<b>Black</b>
Antibiotics	<b>Green</b>
Anticoagulants	<b>Red</b>
Aspirin	<b>Red</b>

### Diuretics (water tablets)

These should be used with caution, as they may cause dehydration and your body salts become depleted.

### Remember

- You are not entitled to exemption from prescription charges when you have an ileo-anal pouch.
- When you obtain a prescription, remind your doctor that you have a pouch.
- If you are unsure of the effects of the medication, please consult your doctor, pharmacist or stoma care nurse.

## Daily Living and Social Activities

Given time, you will be able to resume previous activities as you wish.

### Work

You will need a suitable period of convalescence before returning to work. Some people prefer to go back to work on a part-time basis at first. Individual advice is available from your surgeon, doctor or stoma care nurse. You may wish to discuss your operation with the medical officer or occupational health nurse at your place of employment. To start with, avoid strenuous household activities such as:

- vacuum cleaning
- lawn mowing
- window cleaning
- picking up the children
- heavy shopping

### Driving

Following any major operation, you need to allow yourself time to feel comfortable to drive again. Seek advice from your doctor and check the terms of your policy with your motor insurance company.

### Sport

Provided that your wound has healed, there is no reason why you should not return to sport, but don't rush back too soon; you may require a few months' break. It is advisable to seek advice from your surgeon, doctor or stoma care nurse before resuming sporting activities. With very strenuous sports, you may experience some leakage from your pouch. You can return to swimming once your wound has healed satisfactorily.



## Sex and Pregnancy

Sex can be resumed at any time but remember that, having experienced major surgery, you will need time to recover. While sexual difficulties can be due to surgery, they can also be linked to anxiety, fear of failure or concern about your partner's feelings.

### Men

Following surgery to remove the rectum, some men may have sexual difficulties, such as failure to get an erection or problems with ejaculation. In most cases, these problems are temporary.

### Women

Following surgery to remove the rectum, some women may find sexual intercourse painful. Trying different sexual positions may help. Vaginal dryness may occur as a result of surgery or anxiety. The use of lubricating gel can help.

### Contraception and pregnancy

Oral contraceptives may not be fully effective as they may not be absorbed completely and the use of the coil may not be advised. There are other methods of contraception which can be used. If you are sexually active, you should discuss these methods with your doctor or family planning clinic. It is best to discuss childbirth

with your surgeon and obstetrician as a Caesarean section is usually advocated.

### Remember

If you are experiencing sexual difficulties, you may wish to discuss them with your stoma care nurse, doctor or surgeon.







## Travel Advice

Like all other activities, holidays and travel can be resumed when you feel that you are ready. When planning travel consider the following points.

### Food and Drink

- A change in environment may alter your pouch output.
- Exotic and highly-spiced foods may cause anal irritation and increase your output.
- It is important to increase your fluid and salt intake in hot climates.
- If advised, you should use bottled water for drinking.
- You should avoid ice cubes, ice cream and salad washed in local water.
- Remember you are just as likely as everyone else to suffer from traveller's diarrhoea. If this happens, take plenty of fluids (not milk) and seek medical help

if the diarrhoea continues for more than 24 hours.

- Take your supply of anti-diarrhoeal tablets and other medication with you, as these may help relieve the symptoms.
- Consider taking a rehydration solution, which is available from your local pharmacy.

### Tips

- **It may be useful to take a list of emergency telephone numbers.**
- **If you are taking medication, it is advisable to carry it in your hand luggage.**
- **IA produces a travel certificate which explains about an ileo-anal pouch in multiple languages. This can be obtained from IA national office.**

## Travel Insurance

It is recommended that you should:

- Make sure you are not travelling 'against medical advice' - you may require a letter from your GP.
- Check the policy to satisfy yourself that 'pre-existing medical conditions' are not excluded, as pouches come into this category.
- Consult your travel agent if you have any doubts about the policy.
- Be aware of the procedure for obtaining medical treatment or making an insurance claim. EU countries have a reciprocal health agreement entitling you to free emergency medical treatment. In the UK, obtain a European Health Insurance Card (EHIC). You can obtain an application form from your local post office or alternatively, you can apply online at [www.ehic.org.uk](http://www.ehic.org.uk).
- Advice leaflets on travel within the European Community can be obtained from your local post office. Anyone travelling outside the European Community can find advice and information on the IA website at [www.iasupport.org](http://www.iasupport.org).



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