

Going Home

For all round support
for an ileostomy



Ileostomy & Internal Pouch
Association



Royal College
of Nursing

- Providing support and guidance
- Helping you with your concerns
- Local support

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Introduction

Taking each day one at a time with support from IA means that you will never be alone or without support at this time of change.

Now you are leaving hospital and family and home life moves forward this excellent booklet is there to help you by providing answers and advice to some of the questions you may have.

This booklet has been produced in association with the RCN Gastrointestinal Nursing Forum and IA (Ileostomy and Internal Pouch Association).

Using their extensive knowledge and experience, these two groups work together in many ways to ensure that you are supported and given the best advice available to try and make the coming months as easy and comfortable as possible.

This is the third 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 care nurse and pharmacy on page 38 of the booklet for ease of reference.

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Ileostomy & Internal Pouch
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Listen • Inform • Support

Introducing You to Your Ileostomy

There are many reasons why an ileostomy operation is performed. This may be because of inflammatory bowel disease, for example, ulcerative colitis or Crohn's disease or because of bowel cancer.

Ileostomies can be temporary or permanent depending on the surgery performed.

The main function of your colon was to re-absorb water from your body's natural waste products and to produce a dry, firm, compact stool; you may have been familiar with diarrhoea and other symptoms which occurred when you were unwell.

Digestion of food and the absorption of the nutrients in the food takes place before the waste products are passed on to the colon. Your digestive tract above your new outlet is just the same as it was before your operation, and the part of your ileum (small intestine) that now forms the outlet has always been a natural part of you, even though you could not see it. The outlet is known as a stoma, from the Greek word for mouth or opening.

There will be two main differences in your everyday life now that you have an ileostomy.

The ileum produces waste products in semi-fluid form and this will be quite normal for you. You may find that your body compensates by making you feel thirstier to increase your body fluid intake.

Your stoma does not have any muscle, so you will not be able to control it. You will not be able to retain your bowel motion until a socially convenient time.

Your stoma may work at irregular intervals, particularly in the early days while your body is readjusting after your operation, so you will need to wear an ileostomy bag.

Ileostomy bags

... are usually held on to the skin of the abdomen by an adhesive patch (flange) of about 75mm to 100mm, which may be square or circular but shapes can differ as new products are developed. The bag fits over the stoma and the output goes into it. The bags are

usually drainable, which means that they have an outlet which can be opened and securely re-sealed as often as necessary to allow emptying without having to change the bag each time.

You will have to change the bag, though the interval between these changes will vary; experience will show the best period between changes for you. As time passes and you return to regular eating habits, you will begin to know when your stoma is likely to be least active so you can judge when to change bags, or to shower/bath without wearing a bag if you wish.

The future

Thanks to the latest surgical techniques, medical aftercare, modern stoma equipment and the collective experience of others, an ileostomy is not a handicap. Depending upon your reason for surgery you may have exchanged the misery and pain of uncontrollable illness and diarrhoea for better health with only a minor, but controllable, inconvenience.

Temporary ileostomy

This is often referred to as a 'loop' ileostomy, as it is formed by bringing a loop of small intestine out onto the abdominal wall. A temporary ileostomy may be formed to enable an ileo-anal pouch to heal, or to allow a join between two ends of large intestine (colon) to heal, when a section of colon has been removed, most commonly for bowel cancer. Some time later, the bowel may be rejoined and the stoma closed (reversed).

Prescriptions

England

If you have a permanent stoma you can apply for a certificate exempting you from payment of prescription charges by obtaining form FP92A from your doctor's surgery. You need to complete the required sections of the form and your doctor (or an authorised member of the practice staff) will sign to confirm the information you've given is correct and that you have a permanent fistula which requires continuous surgical dressing or an appliance.

The surgery sends the form to the NHS Business Services Authority who will issue you with an exemption certificate. You can claim refunds for prescription charges, after you've applied for your exemption, by asking the pharmacist for the official NHS receipt. Once you have this certificate you are permitted to sign the declaration on the back of the prescription forms issued to you by your doctor.

Certificates do expire so please remember to keep your certificate current otherwise you may be liable for charges.

Where you are not exempt from prescription charges because your stoma is temporary, it may be cheaper to apply for a prescription prepayment certificate (PPC). Once your application has been processed you will receive a card entitling you to free prescriptions for either three or twelve months, depending upon the time period you apply for.

Cards can be ordered online, over the phone or by obtaining a form from your pharmacy or GP surgery (where stocked). While you are waiting for the card and need to pay a prescription charge, you should obtain an official NHS receipt otherwise you will not be able to obtain a refund.

For further information please refer to:

<http://www.nhs.uk>

Scotland and Wales

Prescriptions issued and dispensed in Scotland or Wales are free of charge. Where you are registered with a GP in England but live in Scotland or Wales, you may need to obtain and present an entitlement card to avoid payment; application for an entitlement card can be made through your GP surgery.

For further information please refer to:
<http://www.scot.nhs.uk>
<http://www.nhsdirect.wales.nhs.uk>

Northern Ireland

Prescriptions issued in Northern Ireland are dispensed free of charge.

For further information please refer to:
<http://www.nidirect.gov.uk>

Ireland

Different schemes operate in Ireland and your current circumstances may decide which one applies to you.

Where you qualify for a medical card prescribed medicines and appliances are charged per item up to the monthly maximum set at the time per family. If you do not qualify for a medical card and are required to pay the full cost for your medicines and appliances a higher monthly maximum amount per family will apply.

If you use different pharmacies during the month you may exceed the monthly maximum charge for your medicines and appliances. Please contact your Local Health Office for further guidance.

For further information please refer to:
<http://www.hse.ie>



Supplies

Stoma bags and accessories are available on prescription. You will need to obtain your prescription from your doctor and take it to your local pharmacy. They will order your equipment for collection, usually in 24-48 hours time, or may deliver it if required.

Most pharmacies will keep a small stock of your supplies if you use the same shop regularly. (There are so many different stoma care products available that the pharmacist cannot keep everything in stock).

Alternatively, you can send your prescription in a pre-paid envelope to one of the many dispensing

appliance contractors (DACs), who will deliver to your home on receipt of your prescription. If you use a DAC, speak to them about the different services that they can offer. Pharmacies and DACs also supply complimentary wipes and disposal bags as part of dispensing your prescription which you can use when changing your bag, although this does not apply to GP surgeries offering a dispensing service in rural areas.

Some pharmacies and DACs will also customise your bags where requested; you will need to supply them with a template beforehand (it is recommended you do this with your stoma care nurse to



avoid incorrect sizing). This is a handy service where you are unable to cut your bags or have an irregular shaped stoma but the service is available to everyone.

In the early days post surgery, your stoma size is likely to change so it may be best to avoid using the customisation service until your stoma size has settled.

Some GP surgeries in rural areas have a licence to dispense stoma equipment and medicines to their patients. Information about these services can be obtained from your stoma care nurse or GP surgery.

When you leave hospital, your stoma care nurse will ensure that you have sufficient supplies available until you can obtain a prescription.

Remember...

- To order new equipment well before you run out – about half way down your last box.
- That you will need a new prescription for all subsequent orders.

- To order your supplies regularly and give your doctor time to supply your prescription.
- To order your supplies well in advance of Christmas and Bank Holidays.
- That many of the dispensing appliance contractors supply you with a freephone number to use in cases of emergency.
- That stoma equipment is expensive and will deteriorate if not stored under the right conditions.
- That your equipment should be kept in a cool, dry place.
- Not to over order or stockpile.

Tips

- **You can use kitchen roll to clean around your stoma.**
- **Any unused stoma care equipment can be sent to one of the charitable associations which send unwanted medical equipment to countries where supplies are limited (details available from IA National Office).**

Disposal

Used stoma bags should be disposed of safely. It is sufficient to empty the contents of your stoma bag into the lavatory then tie it up in a plastic bag before placing it in the dustbin. Some choose to wrap the soiled bag in newspaper before placing it into the plastic bag.

There are also disposal units, originally designed for the disposal of babies' nappies, which can be bought at some retail pharmacies or retail stores selling baby products. The units seal used stoma bags into a plastic bag which can then be placed into your dustbin.

Do not attempt to flush your used ileostomy bag down the lavatory. It will become stuck in the S bend and cause a blockage to the drainage system.

When travelling, used stoma bags can be disposed of in a manner similar to that used at home. Women can use certain sanitary towel disposal units in public lavatories, but this is not recommended.

You may also wish to purchase a special key which opens many disabled toilets around the country. These toilets are also equipped with washing and disposal facilities. There is usually a small charge for the key and booklet listing all the sites although some local authorities supply keys free of charge to people with long term conditions; please contact your local authority to check.

Further information is available from Disability Rights UK.

www.disabilityrightsuk.org.



Common Concerns

Sore Skin

Possible causes:

- Leakage from the bag.
- Allergy to the adhesive.
- Too frequent changing of the bag.
- Excessive cleaning of the skin.
- Too large an opening in the adhesive flange.
- Pre-existing skin conditions.

Leakage

Possible causes:

- Too large an opening in the adhesive flange.
- Change in body shape.
- Change in body size.
- Inappropriate use of creams and powders.
- Forgetting to remove the backing paper from the flange.

If you have leakage, change the bag as soon as possible.

Bleeding

Possible causes:

- Too small an opening in the adhesive flange causing friction and bleeding: check your stoma size.

- The stoma may bleed for a short while if it is knocked.
- Anticoagulants and aspirin could be the cause.

It is normal for specks of blood to be seen on the tissue when you clean your stoma. If bleeding persists, you should contact your stoma care nurse or doctor, but if the blood comes from inside the stoma, you should contact your doctor.

If you eat beetroot, it will turn your output red.

Blockage

If you get a blockage, you will notice that either the output from your stoma has stopped for longer than is usual or that your bag contains excessive amounts of watery fluid.

If your output changes significantly in consistency, colour or quantity and you feel unwell with stomach pains and/or nausea or vomiting, you should contact your doctor or stoma care nurse.

If you feel that you have a blockage, you should stop taking

solid food, but continue drinking water in small quantities until you have been seen by your stoma care nurse or doctor.

If blockage occurs, your stoma may temporarily change in size or colour.

Possible causes:

- May be related to your surgery.
- Plug of food: for example nuts, citrus fruits, sweetcorn, coconut or other high fibre foods.
- Drugs – some pain killers may slow down the output.

Blockages are usually remedied easily, but may require medical attention.

Rectal discomfort or pain

Sometimes referred to as 'Phantom Rectum', this can occur in a small number of patients when their rectum has been removed. While pain or discomfort usually resolves spontaneously when the wound has healed this may take as long as six months. If it continues, you should mention it at your hospital clinic visit.



There may be discharge from the rectal wound. You should ask your community nurse or stoma care nurse to check this condition if you are concerned.

Rectal discharge

If your rectum has not been removed, you may have the urge to open your bowels. This commonly occurs and is a normal feeling. You may pass mucus (jelly/slime), which is a normal bowel secretion.

If you have a loop ileostomy, the discharge may be coloured brown. If soreness of the skin around the anus occurs, wash the area when possible and pat dry with a soft cloth or toilet tissue.

If soreness becomes troublesome, contact your stoma care nurse, who will give you further advice.

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. Some people benefit from quiet times when they reflect alone.

If you have not yet talked to someone with personal experience of living with, and managing, a stoma and now feel that you would like to do so, please contact your stoma care nurse or we can connect you with an IA visitor; somebody who has been through similar surgery and is now living with an ileostomy or an internal pouch. An IA visitor is trained to listen and offer support.

IA aims to closely match visitor to patient in terms of age, gender and lifestyle wherever possible, and based on our experience, can be of great comfort to someone either considering or who is new to surgery. IA can also put families, friends and carers of anyone going through surgery in touch with others who have been through a similar experience.

Bathing

You can bathe or shower, as usual, with your bag on. When your wounds have healed, and you feel confident, you may wish to bathe or shower without your bag on.

Tips

- **Warm water may stimulate your bowel.**
- **Water cannot get into your stoma.**
- **If you use bath oils or talcum powder, make sure you have removed the oil and powder from your skin and dry your skin well.**
- **You may find it easier to change your bag before you bathe.**

Clothing

You should be able to wear your existing clothes without needing to change the style or type.

Men may choose high-waisted trousers, or braces, to position their trouser waistband above their stoma.

Ladies may continue to wear comfortable and attractive support garments (girdles or corsets) with adjustments made to incorporate the stoma appliance.

Tips

- **Some ladies may find stockings more comfortable to wear than tights.**
- **You should ensure that your beltline does not restrict your stoma output.**
- **Leisure wear may be comfortable to wear immediately after your operation.**



Dietary Considerations

Having an ileostomy should not affect your digestive process, so try to 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.

- Blockages can be caused by food such as nuts, coconut, some vegetables and fruit. A blockage may cause colicky pain, which is usually of a temporary nature (see page 12).



- Some foods, for example baked beans or cabbage, may cause more wind, so you may wish to limit or avoid these items.
- Certain foods may colour output. For example, the output after eating beetroot may be mistaken for bleeding. Don't be alarmed.
- Beer, lager, chocolate and some fruits may have a laxative effect, in which case you may have to empty your bag more frequently.
- Highly-spiced foods may give you diarrhoea. You may want to try milder spices to monitor the effect.
- Certain foods may cause strong odours. Eggs and fish are two examples.
- 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 which you may have avoided previously.

Remember

Do not try to regulate your ileostomy output by cutting down on fluids as you may become dehydrated.

Tips

- **Marshmallows or ripe bananas may alleviate diarrhoea.**
- **Fennel or peppermint tea may reduce wind.**
- **Natural yoghurts may reduce both odour and wind.**
- **Extra salt may be required, especially during hot weather or if you have diarrhoea.**
- **Beef extract and crisps will help replace some salt.**
- **You can continue drinking alcohol, but this may cause dehydration and you may find beer and red wine increase your stoma output.**
- **Fizzy drinks may also increase the amount of wind entering your bag.**

For more information about staying hydrated, please obtain a copy of IA's 'Staying Hydrated' leaflet available from IA national office.

Self Image

If you have recently gone through the trauma of having an ileostomy, it would be natural to be concerned about the effect it may have on your present and future relationships with other people. You may well try to hide the fact that you have an ileostomy but be worried that everyone will find out because you think you look different. It is quite common for new ileostomists to feel this way.

Broadly speaking, there are two ways you can deal with this – firstly, you can look at the practical matter of appliances and other services available and, secondly, you can do something about how you view yourself.

There is available a wide range of stoma equipment and other associated products, such as swimwear, backed up with advice from manufacturers' representatives. Full details can be obtained from your stoma care nurse or from the IA Journal.

Anyone, through their local IA member organisation, can make contact with other ileostomists and find out what others do. You will soon realise that there are no

constraints on where you go, who you meet, how you travel, what pursuits you take up, how you look, what you wear, what you eat – in fact there is really no need for your appearance or behaviour to change at all.

Apart from gathering all of this valuable information and finding stoma equipment that suits you, you may also need to deal with the not so straightforward matter of how you feel about it all. In considering how you see yourself, first of all don't pretend that your ileostomy and bag aren't there.

They are – it's a fact. However, it is important to get this into perspective – it's a small part of your life and who you are. Secondly, think of all of the people you see – at work, friends, in shops and so on. Do you know someone who has an ileostomy or, for that matter, a colostomy or urostomy? Do you?

Well, the chances are that you do know someone who wears a bag, yet you don't know they wear a bag, because how would you? You are not inspecting everyone to see if they have a stoma, any

more than others will be looking at you.

Self-perception

Consider this – possibly the biggest factor which affects how others see you is the way you see yourself. Some people who don't have ileostomies lack self-confidence and are too ready to stress their perceived faults and failures rather than their many good points.

When you have an ileostomy, it can be taken as an invitation for these characteristics to be

exaggerated. You might think the ileostomy is the most important thing about you and you can see it as meaning you are less, rather than different. If you find it difficult to see yourself as good as everyone else or to think of yourself in a positive way, this is not surprising, but it is possible to do something about it.

There are a number of books available which focus on self-image and help you think well of yourself. Also, a number of excellent counsellors and counselling services exist, not necessarily specialising in dealing



with ileostomists or altered body image. These provide an opportunity to talk over the non-medical aspects of living with an ileostomy and help you become more confident and think better of yourself.

A list of the different counselling services in your area can be obtained from 'The British Association for Counselling and Psychotherapy' (telephone 01455 883300 or visit www.bacp.co.uk).

Remember, however, that it is likely to take some time to become adjusted to your new self. Having your body visibly altered by surgery is a significant transition in life. It is well known that at times of significant transition, for instance bereavement, redundancy, leaving the parental home, there are certain stages people go through. It is normal, and perhaps necessary, to experience emotions like shock, denial (making light of it) and depression, before becoming positive about the change and accepting your new circumstances.

Ileostomists entering a new relationship often ask, How will

I tell him/her? When? What will he/she think? Most ileostomists in this situation have found that their worries are unfounded and that the person who truly cares for you accepts all of you as you are. Equally, the person whose view of you changes on discovering that you have an ileostomy may not be the person with whom you should consider embarking on a long-term relationship.

Physical difficulties

Occasionally, physical difficulties with having sex can result from having an ileostomy. Sometimes it may not be possible to continue in the same way as before your operation. Your stoma care nurse will be happy to discuss this with you and your partner.

As time goes by, you may find yourself telling more and more people about your ileostomy and, curiously, once you have accepted it yourself, you may find any problems you do have are with helping others with their feelings as they are not sure what to make of it.

Social Activities

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

Sports

- Provided that your wound has properly 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 contact/strenuous sports.

Tips

- **Stoma protectors are available to wear (with a belt attachment) over your stoma.**
- **You can continue swimming as normal once your wound has healed.**
- **Small activity pouches, which cannot be detected under your swimwear, are available.**
- **For added security, you may wish to seal your stoma bag with adhesive tape.**
- **Special swimwear and sportswear are available if required. However, patterned**

swimwear (swimsuit or trunks) is often quite suitable.

Driving

You may resume driving when your wound has healed and when you are comfortable in sitting positions. This is usually at least six weeks after your surgery. You should check the terms of your policy with your motor insurance company beforehand. Please remember that you are not exempt from wearing a seat belt.



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.

Male ostomists

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

Female ostomists

Following surgery to remove the rectum, some women may find sexual intercourse painful. This can be due to the perineal scarring. 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. The use of the coil may be inadvisable and there are other methods of contraception that ostomists can use. If you are sexually active, you should discuss these methods with your doctor or family planning clinic.

While many ostomists do conceive and have successful pregnancies, you may need to discuss the method of delivery with your obstetrician.



Making love

- Check that your stoma bag is secure and empty.
- Use a stoma bag cover of some sort.
- Secure your stoma bag against your skin with tape.
- The stoma itself should not be used for sexual activity.

Conclusion

Some ileostomists are concerned about how their partners may react to their stoma and misunderstanding can lead to sexual difficulties. Talk to each other about how you feel. Remember, sex is only a part of life and is as individual as the ostomist.

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

Work

You are likely to 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. Having an ileostomy should not bar you from any employment. If you encounter any problems at work because your employer doesn't understand the nature of your operation, help and support can be obtained from your surgeon, doctor, stoma care nurse or IA.

You may wish to discuss your operation with the medical officer or occupational health nurse at your place of employment.

Tip

- **Remember to keep a full set of stoma equipment at work in case of accidents or emergencies.**

Travel Advice

Having an ileostomy should not stop you travelling wherever you want to go. Perhaps a short trip should be undertaken first to give you some experience and confidence before you consider adventures further afield.

When planning travel, consider the following points.

Travel insurance

It is recommended that you should:

- Check the small print of the policy to satisfy yourself that 'pre-existing medical conditions' are not excluded, as stomas come into this category.
- Make sure you are not travelling 'against medical advice' – you may require a letter from your doctor.
- Shop around for travel insurance to ensure you get the policy that suits your requirements. Policies can differ greatly in terms of cover and cost between providers. IA can provide a list of travel insurance providers as a starting point but this list is not exhaustive.

- Familiarise yourself with 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 - see '*European Health Insurance Card*'.

European Health Insurance Card (EHIC)

If you are travelling within the EU, consider applying for an EHIC in plenty of time before you travel. These cards allow access to the same state-provided healthcare, which becomes medically necessary during your holiday, as is available to a resident of the country you are visiting.

Most importantly this should not be seen as a replacement for travel insurance.

Remember, in addition to health, travel insurance typically covers you for cancellation, repatriation back to the UK and loss of items and personal possessions to name a few. This will of course depend on your policy.

Please be aware of the following points:

- Managing the symptoms of pre-existing or chronic conditions that arise while abroad are all covered by the EHIC.
- You may be expected to make a financial contribution towards treatment costs even with an EHIC. If you cannot claim those costs back at the time, they may be recoverable in the UK. Obtain receipts as evidence, wherever possible.
- EHICs are valid for up to five years and can be renewed up to six months before expiry.

For more information or to apply for a card, visit www.ehic.org.uk.

Tips

- **Take at least double the amount of bags you would normally require for the period of your trip. This will allow for extra bag changes due to the heat, perhaps any changes in bowel habit due to a change in diet or any delays you may encounter**
- **Small stoma bags may be useful when you go**

swimming.

- **Store your stoma equipment in a cool bag.**
- **Carry a small travel kit in a pocket or handbag, when out and about.**
- **Obtain a travel certificate which explains, in several different languages, what a stoma is and why you are carrying appliances (travel certificates are available from IA). A certificate could be useful if your baggage is checked by customs officials.**
- **In an emergency, you may be able to buy some stoma products whilst you are abroad – check before you travel.**
- **Bags can be delivered abroad by international carrier.**
- **Some delivery companies offer an emergency holiday service when abroad. Check with your delivery company to understand what services it offers.**
- **Consider using the Hidden Disability Lanyard scheme at your airport (where available), if flying, to get extra support if required.**

Food and Drink

A change of environment may alter your stoma output and exotic and highly-spiced foods may increase your output.

It is recommended that you should:

- Increase your fluid and salt intake in hot climates*.
- Check with your travel agent about levels of hygiene within the country you are visiting.
- If advised, use bottled water for drinking and cleaning your stoma.
- Avoid ice cubes, ice cream and salad washed in local water.
- Stop eating and drink plenty of fluids if diarrhoea occurs*.
- Take a supply of anti-diarrhoea tablets with you. Loperamide can be obtained over the counter at your local pharmacy without prescription.
- Take rehydration solutions*, which are available from your local pharmacy.

Tips

- **When you travel by air, a change in air pressure and different food may make your stoma produce more wind.**
- **Use a towel or plastic sheet to protect the bed or order an absorbent bed pad; available from selected retail outlets and chemists or from your DAC.**
- **Take a list of emergency telephone numbers. Your stoma care nurse can provide you with details of the local stoma care nurse in the area to which you are travelling, both in this country and abroad.**
- **For tips about swimming and swimwear refer to the section on social activities (see page 21).**

* A copy of IA's leaflet 'Staying Hydrated' is available from IA national office.



Exercises

The exercises described in this booklet should not be followed without first consulting your doctor. All guidelines and warnings should be read carefully, and IA cannot accept responsibility for injuries or damage arising out of failure to comply with the same.

Here are some simple exercises designed to help anyone who has had surgery leading to the formation of ileostomy, colostomy, urostomy, or internal pouch. These exercises may also prove useful for people with low back problems.



If in any doubt about any of these exercises, seek the advice of a state registered physiotherapist, your GP or consultant. If there is any difficulty contacting any of these professionals, your stoma care nurse can refer you to them.

These exercises can be progressed by-

- (i) Adding more movements to each exercise every few days, starting with 4 movements, say, but don't go beyond 10. Start by doing these exercises twice a day, and then increase the number of sessions.
- (ii) Build up the 'holding' part of the exercise to a **maximum of 7 seconds**.

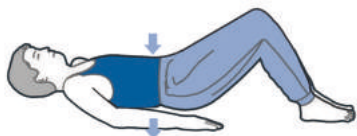
For those too busy to do the exercises as often as you should, those marked *Group 2* can be slipped into your daily routine. Try to do the first group of exercises twice a day.

Group 1

1. Lying on the bed or floor, with a pillow under your head if needed, knees bent up:

(i) Flatten your lower back onto the bed, hold for a slow count of 3, then relax. Progress this by

(ii) Raising your head and shoulders, holding then relaxing.



2. In the same position, follow (i) and (ii) by then taking one hand across to touch the opposite knee, holding and relaxing. Repeat to the opposite side.



3. Lying, with one knee bent, shorten the straight leg by hitching the hip up towards your shoulder, then slide it towards the foot of the bed. Keep the weight of the leg on the bed at the time. Repeat 5 more times.

Change to the other leg and repeat the exercise.



4. Position as in (i), lift your bottom as high as you can, hold for a count of 3, then lower.



5. On your hands and knees, keep your back flat while you pull your tummy up towards your spine, count 3, and then let go slowly. This can be progressed by gently rocking forward and backward, but keep your back flat!



6. This exercise can be started within three days after surgery, or at any time in the future, to strengthen the pelvic floor.

Exercise “6” should be avoided by internal pouch patients unless recommended by their consultant.

Lying with your knees bent, sitting or standing, with your legs apart, tighten up the opening to the back passage (or where it was) as though you are trying to prevent yourself passing anything from the back passage; hold for a few seconds and then let go slowly. Repeat 4 times. Then tighten up at the front as though you were trying not to pass urine, hold and let go as before. Repeat 4 times.

You will find that all the pelvic floor works at the same time but you will get more benefit from the exercise if you concentrate first on one and then the other. This exercise should be carried out as many times in the day as you can. You can do it anywhere, any time. After all no-one knows that you are doing it.

Group 2

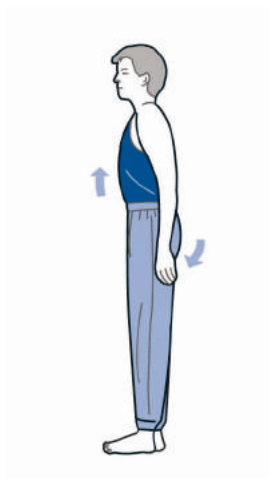
These exercises are designed to be done in the upright position, so they are useful both for the busy person, as a progression after you get home from hospital, or for the person with a low back problem.

1. Standing, leaning against a wall with your heels at least 12 inches (30.5 cm) away from it and your hands tucked in behind your lower back, press that part of your back against your hands, on to the wall. Hold that position for at least 5 seconds, then relax. Do this 1 – 5 times.

This strengthens the tummy muscles, and is very good for relieving low back pain.



2. If there is no wall handy, simply tuck your bottom in and hold for 3 to 5 seconds. You will find that the bottom of your tummy moves upwards towards your ribs, shortening and strengthening the tummy muscles.



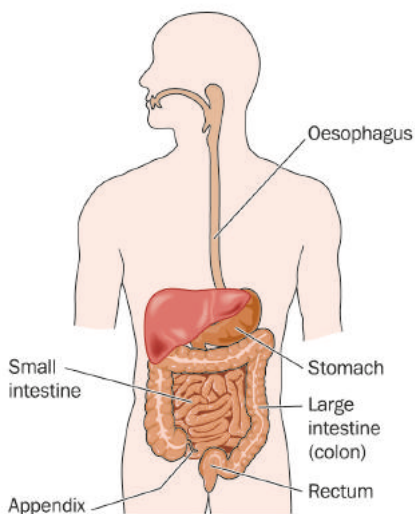
Some general advice...

- Double leg raise and sit-ups are not recommended for people who have had abdominal or pelvic floor surgery.
- Sit well with your lumbar spine (the hollow area behind your belt line) supported. A small cushion or rolled towel will do.
- Develop a 'roll out of bed' habit. This protects your back as well as your tummy muscles.
- Walking is the best exercise for maintenance of general fitness.
- When you can, swim or do exercises in water.



Medication Issues

Before considering how drugs are absorbed into the bloodstream so they can reach their site of action, it is useful to understand how the body deals with food and drink. It is then easier to appreciate why ileostomists particularly need to adhere to advice given by their healthcare professionals.



Layout of the Digestive Tract

Most of the food we eat needs to be digested by enzymes into smaller molecules before it can be absorbed. Chewing food and the grinding action of the stomach breaks the food into smaller pieces so that the enzymes can digest it faster.

Enzymes are found in the saliva (for carbohydrates) and stomach (for carbohydrates, fats and proteins).

Glucose (from sugar and carbohydrates) is absorbed in the mouth, the stomach and the upper small intestine (duodenum and jejunum which also absorb fats and fat-soluble vitamins A & D).

Amino acids (from proteins) are absorbed in the middle small intestine (jejunum and ileum). Water soluble vitamins (vitamins B & C) and electrolytes including sodium and some potassium, are also absorbed in this region.

Vitamin B12 is only absorbed in the last part of the ileum (the terminal ileum) and if you have had approximately 30cm (1ft) of this removed, it is likely that you will need vitamin B12 injections to prevent anaemia.

Water is absorbed throughout the bowel when other nutrients are absorbed, but the large intestine (colon) extracts the excess fluid from the gut contents, thereby solidifying the stool.

Potassium is primarily absorbed

here, along with Vitamin K. Ileostomists therefore have a fluid output though their fluidity depends on how much of the bowel has been removed – as a general rule: the shorter the remaining bowel, the faster the gut contents move through it and the more fluid the output.

Medication

Tablets are absorbed in different regions of the digestive tract and many require mechanical breakdown into smaller pieces prior to absorption which takes time and can result in incomplete uptake into the body.

For this reason, some ileostomists may find that breaking their tablets into smaller pieces prior to taking them, may make them more effective although some people may require their medicines in liquid formulations or larger doses to achieve the desired effect. Syrups should be avoided as a rule because their high sugar content can prevent water absorption and increase stoma output.

Slow-release formulations (signified by MR, SR or XL) should generally be avoided as they release the active medicine over a longer period of time than it is likely to be in the gut. Similarly enteric-coated (EC) tablets have a coating that only allows the tablet to dissolve in the small bowel and this is likely to result in incomplete absorption of the drug into the body. Such medication may include Prednisolone, iron tablets, potassium and salt tablets.

Glyceryl trinitrate tablets for angina should be allowed to dissolve in the mouth, since this substance can be absorbed through the mucous membrane of the mouth into the blood. This medicine acts very quickly. However, most drugs are absorbed through the lining of the upper small intestine.

Some drugs have an irritant effect on the lining of the stomach and should be taken with or just after food. For example, many of the anti-arthritis drugs have this property. Other drugs can become chemically bound to certain foods and will, therefore, not reach the blood in sufficient quantity to exert their proper action.

The Tetracycline antibiotics combine with milk and should be taken with water. Some antibiotics should be taken on an empty stomach so that they can be absorbed quickly and completely, for example Penicillin V and Ampicillin.

The drugs already mentioned are absorbed by ileostomists just as well as other patients, but some drugs are formulated into medicines in such a way that the drug is released slowly to exert a prolonged effect.

If an ileostomist has a very rapid movement of food through the small intestine (intestinal hurry), the tablet may be collected in the stoma bag and not reach the bloodstream. If you have intestinal hurry, do remind your doctor and mention it to your pharmacist to ensure that you receive a preparation suitable for you.

It is thought that ileostomists lose electrolytes faster than others and should take care to replenish them if they perspire heavily or have diarrhoea and vomiting. Rehydration sachets, obtainable on or off prescription, when made

up with water as instructed on the label will provide a balanced replacement of electrolytes in a readily available form.

Drugs effecting change in the colour of your output:

Some medicines colour the faeces or urine and can cause alarm if not expected. Often labels will warn of this effect. Examples include:

Iron	Black
Charcoal	Black
Antibiotics	Green or grey red
Aspirin*	Pink, red or black
Antacids	White, grey or speckled

* See Common Concerns, page 12.

Drugs affecting output

Constipating effect: morphine, codeine, iron tablets, some anti-depressants.

Diarrhoea: antibiotics, iron tablets, some antacids containing magnesium, laxatives.

Some diuretics (drugs used to remove excess fluid from the body) act by increasing the amount of electrolytes excreted in the urine taking water with them. These diuretics are best avoided by ileostomists. There are other diuretics available, so do remind your doctor of your ileostomy.

Most medicines, either purchased or dispensed, bear labels stating the dose and its frequency, and also special instructions or precautions. Please read them carefully and follow them. If in any doubt ask the pharmacist, and tell or remind him that you have an ileostomy, and ask if your lack of large intestine will affect your medication.

Contraceptive pill: see page 22.

Remember

- You should not stop taking any prescribed tablets or medicines without consulting your doctor.
- When you obtain a prescription, remind your doctor that you have a stoma.
- If you are unsure of the effects of the medication, please consult your doctor, pharmacist or stoma care nurse.



About IA

IA (Ileostomy and Internal Pouch Association) is a support group which has the primary aim of helping people who are living with an ileostomy or an internal pouch; their family, friends and carers.

It was started in 1956 by ileostomy patients and members of the medical profession. It was the first ostomy association in the UK and is a registered charity.

Certain inflammatory bowel diseases, such as ulcerative colitis and Crohn's disease sometimes cause such damage to the patient's large intestine (colon) that it is necessary for the surgeon to remove it entirely.

With a Brooke ileostomy, the lower end of the small intestine (ileum) is brought out through the abdominal wall and the body's waste matter is collected in an externally attached bag. Alternatively, the patient, depending on the reason for surgery, may be able to choose to have an internal pouch, which involves the construction of a reservoir from a section of the ileum. Someone who has an internal pouch does not need an external bag.

It is estimated that there are more than 9,000 new ileostomy operations carried out in England alone each year (source: NHS 2018) and around 400 internal pouch surgeries (source: Ileoanal Pouch Registry 2017). This means that you will almost certainly have met someone who has an ileostomy or internal pouch, as they lead perfectly normal lives.

What are IA's aims?

Any serious illness will disrupt a person's normal lifestyle, especially if it has lasted many years and has led to major surgery resulting in a change of body function and body image.

IA aims to help anyone living with, or supporting somebody with, an ileostomy or an internal pouch to return to a fully active and normal life as soon as possible.

IA aims to help them with all aspects of their rehabilitation including social activities, and relationships with their families, friends, employers, colleagues and members of the general public.

IA aims to work in close co-operation with the medical authorities as part of a team whose primary aim is the complete rehabilitation of every ileostomy or internal pouch patient.

IA aims to promote and co-ordinate research – not only into ways of improving the quality of life with an ileostomy or internal pouch, but also into the illnesses which lead to these operations.

IA aims to improve knowledge about the management of ileostomies or internal pouches and encourage development of new stoma equipment and skin care preparations.

IA Activities

Hospital and home visiting to give confidence and encouragement, by example, and practical help in living with an ileostomy or an internal pouch.

Members' meetings are arranged throughout the country by IA's local member organisations. A medical adviser or stoma care nurse may be present to give advice if necessary and there may

be a guest speaker, either on a medical subject or one of general interest.

Equipment exhibitions are often held at members' meetings, with manufacturers' representatives present to give advice and answer questions. Members have the opportunity to examine and compare all the alternative brands to find the ones best suited to their individual needs.

The **IA Journal** is published quarterly and is sent to every member free of charge. It is full of articles of interest, news and views, exchanges of correspondence, and advertisements by equipment manufacturers of their latest products. Other literature is also available from national office.

Medical research is carried out into the illnesses which lead to ileostomy or pouch operations, and into many aspects of life without a colon.

Lectures and demonstrations are often given by IA members to groups of doctors, surgeons and nurses, to assist them in gaining

more knowledge about ileostomies or internal pouches for the benefit of future patients who need such operations.

IA Organisation

IA is represented by a network of local member organisations across the UK and Ireland.

Each group offers support to its members, prospective members and other interested parties on a local level

IA Membership

IA membership is open to anyone living with, or due to have, an ileostomy or an internal pouch; to family, friends and carers or anyone who may be living with any other type of stoma or is interested in the work of IA.

To join IA visit www.iasupport.org or contact us for an application form using our contact details on the back of this booklet.



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