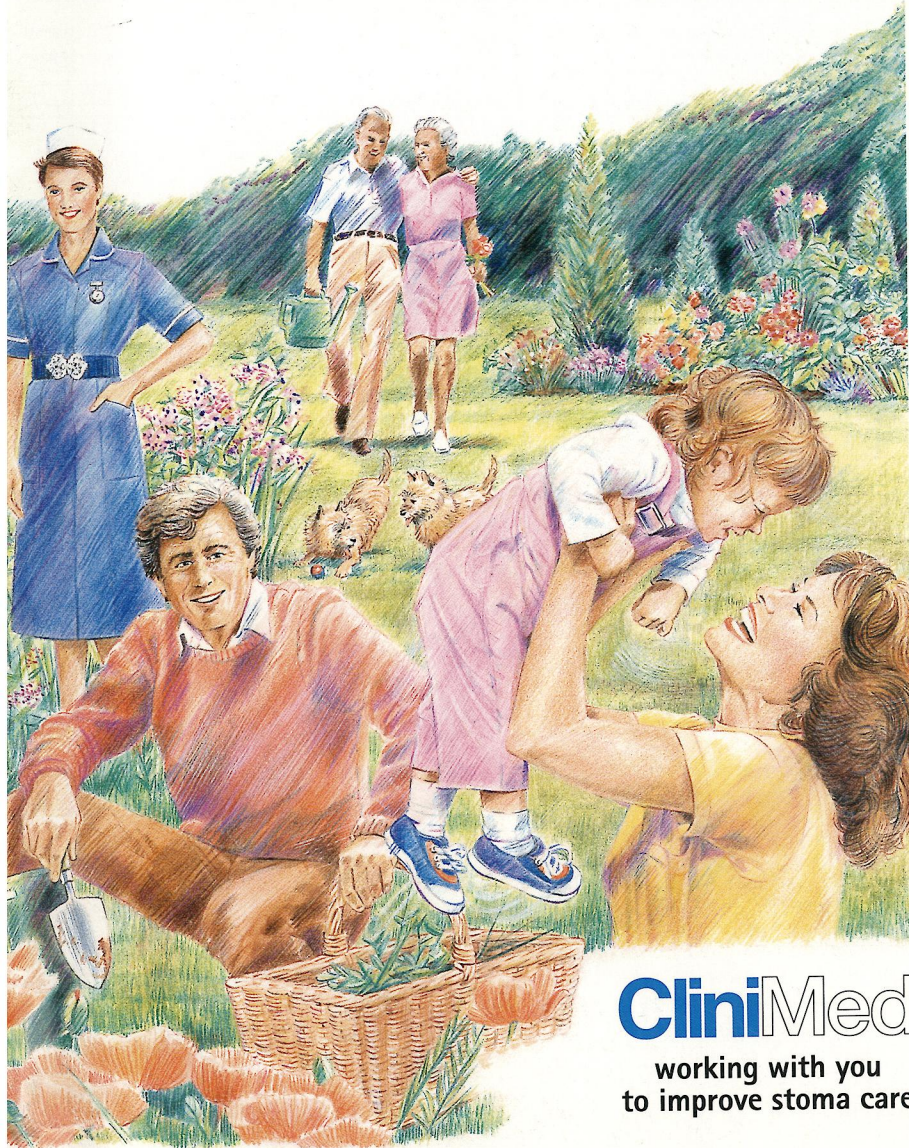


Ileostomy

A practical guide to stoma care

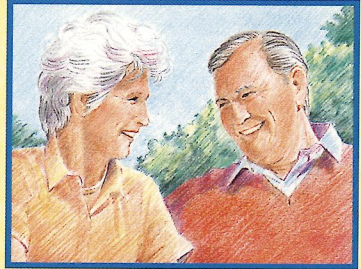


CliniMed[®]
working with you
to improve stoma care

Learning about the need for an ileostomy.

It is a worrying time when you learn that you need to undergo major surgery. It can be particularly traumatic when you learn that as a result of that surgery your bodily functions will not be the same – that you will have an 'ileostomy' and will not be able to pass motions in the normal way but will wear a 'pouch' on your abdomen.

You may not have heard of an ileostomy or a stoma before or have only a vague idea what one is. You may feel horrified and upset, or temporarily numb at the news. You may, on the other hand, feel relief that something is being done to relieve what may have been years of debilitating symptoms.



Whatever your reactions and feelings, you will find hospital staff very understanding and supportive. They have helped very many people through the same experience.

Very experienced nurses who specialise in stoma care will be there to care for you and help you with information, practical assistance, advice and reassurance about what having a stoma involves. A support organisation like the Ileostomy and Internal Pouch Support Group (ia) can help with advice and visits from other (happy, healthy) ileostomists. The creation of a stoma can not only be a life saving operation, but for many people (and there are thousands and thousands of people with ileostomies) it actually greatly improves the quality of their lives.

By the time you leave hospital you will be able to manage the pouches for your ileostomy. You will in your own way learn to cope and to come to terms with the change in your body and with your stoma. Caring support is also readily available within the community, so you won't feel alone. Soon, your stoma seems less important, and you will get back to normal life.

This booklet is intended to 'fill in' on some of the information you may have been unable to take in at the time of your surgery, to give you background information and practical advice about the day-to-day care of a stoma and to answer some of the queries that are bound to arise. It will also act as a reference source of other relevant organisations and of advice available.

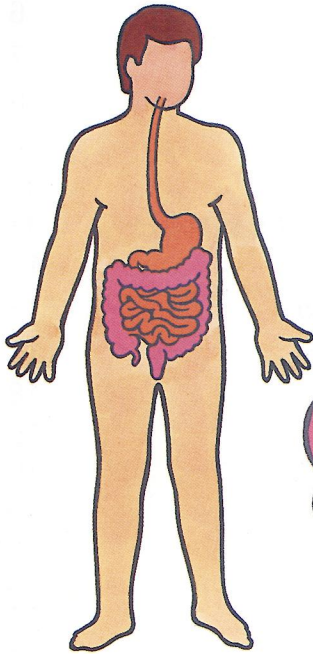
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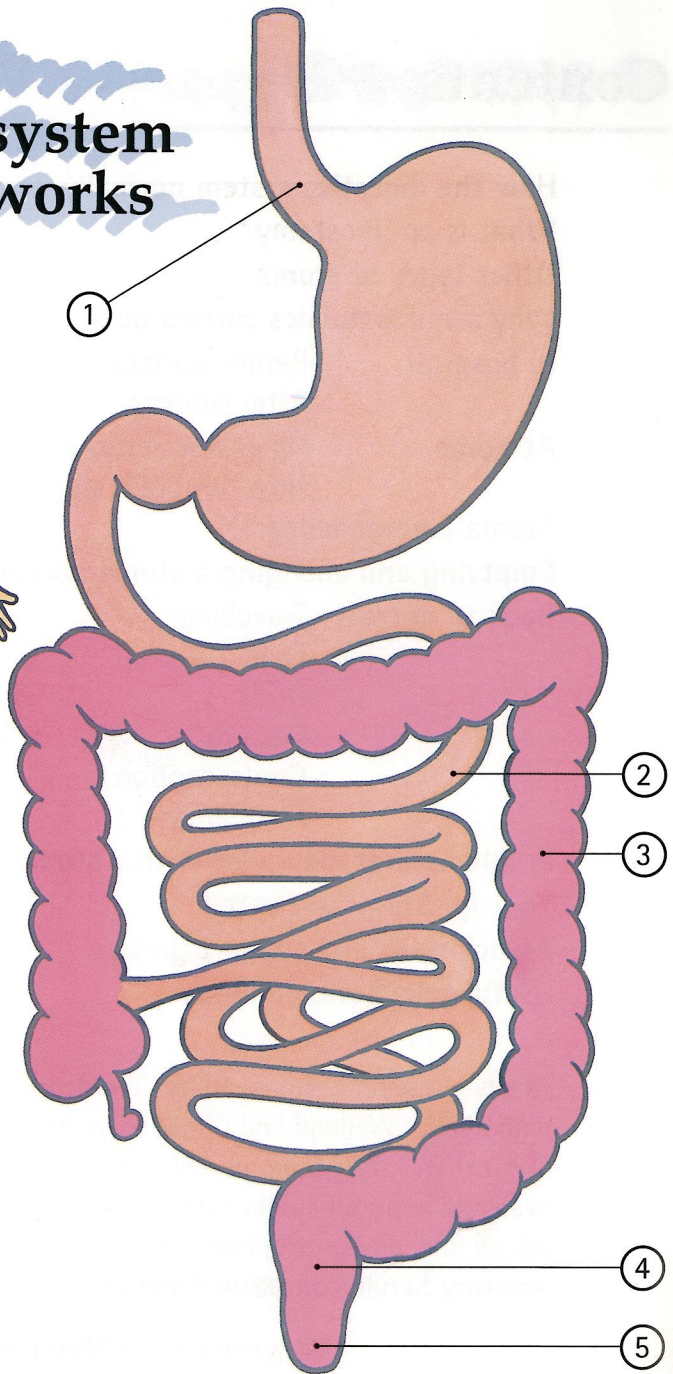
This publication is produced by CliniMed Limited – suppliers of high quality Welland and CliniMed stoma care items. If you would like further information or advice about the product ranges available or about stoma care in general, CliniMed have a special advice line. Please telephone free-of-charge, the **CliniMed Advisory Service on 0800 585125**.

Or write to CliniMed Limited.
FREEPOST.
High Wycombe HP10 8BR
(no stamp needed).

How the digestive system normally works



Simplified diagram



To allow waste matter (faeces) to leave the body, the surgeon makes a small opening on the outside of the patient's abdomen and brings through and attaches to the surface the end of the remaining small intestine or ileum (2). This is a stoma and because it is a stoma created using the ileum, it is called an ileostomy.

The words ostomy and stoma come from the Greek word meaning 'mouth' or 'opening'.

An ileostomy looks like a small spout, deep pink in colour similar to the inside of the mouth. Although it looks raw, it has no feeling. Waste matter (faeces) comes out of the stoma and is collected in a special stoma pouch attached around it.

Consistency of the waste matter.

Food from the stomach travels round the small intestine, where the nutrients the body needs are absorbed leaving just indigestible matter and water. This then leaves the body through the stoma. Because the waste matter has not travelled through the colon, much of the water in it will not have been absorbed. The waste material passed will therefore be runny and passed frequently. There is no control over this and a stoma pouch is usually worn at all times.

Sometimes, if the rectum has not been removed but is left in place, the cut end of that may also be brought to the surface to make a small opening called a mucous fistula. This usually needs little attention. You can contact your stoma care nurse for further advice on this procedure.

Ileostomies are sometimes created just as a temporary measure, to allow the remaining intestine a chance to rest and heal, and 'reconnection' takes place at a later date. Your surgeon will advise if the ileostomy is just a temporary measure. Day to day care of the stoma, however, remains the same.

Other types of stoma

Colostomy.

A similar type of procedure to an ileostomy is a colostomy. Here the opening is made into the colon (large intestine), rather than the ileum (small intestine). Because part of the colon remains and does its job of absorbing water from the gut contents, the faeces evacuated from a colostomy are often more solid than from an ileostomy (dependent on how far along the colon the stoma is created). A colostomist will usually pass (semi-solid) motions only once or twice a day and uses a different type of non-drainable, or 'closed', stoma pouch which is changed completely once or twice a day.

The average age range of people with colostomies tends to be older than those with ileostomies.

Urostomy.

A different type of stoma, the urostomy is nothing to do with the digestive system, but is an opening made to divert urine from the body.



Why are ileostomies carried out?

Like any other major surgery an ileostomy is not undertaken lightly and doctors will only recommend it where absolutely necessary.

Although there are a few other causes, the main conditions that may give rise to the need for an ileostomy are covered by the general term 'inflammatory bowel disease.' This includes ulcerative colitis and Crohn's disease.

Symptoms.

Inflammatory bowel disease varies tremendously in its degree of severity and can cause a variety of symptoms. These include (amongst others) diarrhoea, abdominal cramps or discomfort, weight loss and blood in the motions. Suffering from these symptoms does not necessarily mean inflammatory bowel disease and, similarly, having inflammatory bowel disease does not necessarily mean that an ileostomy will have to be carried out - symptoms can be mild or sporadic and even the more severe ones can often be controlled by medicine.

Only in the more serious cases, where adults or children have suffered from severe, debilitating symptoms for some time; where physical problems dictate; or where emergency surgery becomes necessary will an ileostomy be considered.

Whatever the reason for a stoma being created, many patients find that having an ileostomy, and thereby losing a badly diseased bowel, leads to a dramatic improvement in the quality of their lives and, for some, particular freedom in not having to plan their lives around the immediate availability of a WC!

An ileostomy will not in itself stop anyone from leading a full and active life.

In hospital

Before surgery.

Members of the medical team will help to prepare you and advise you about the coming operation and answer your queries. The procedure involved will be carefully explained to you, and the doctor will tell you whether your ileostomy is going to be a permanent one (and whether there is any chance of a reversal in the future) or if it is being created as a temporary measure and when you can expect further surgery.

It is quite likely that you will not be able to take in all the information at first - it may help to jot down any queries you have as you think of them, so that when you see the doctor you can remember what to ask.

In many hospitals specially trained senior staff called stoma care nurses will be available to help you and your family. These nurses will be closely involved in your care and will make sure you have continued support in the hospital and at home. It is often helpful to meet another person who has experienced living with an ileostomy and this can be arranged, usually through the Ileostomy and Internal Pouch Support Group (ia).

Where will the stoma be?

An ileostomy is usually sited on the right side of the abdomen but sometimes if previous operations have been performed, leaving scars, the stoma is put on the left. Usually a mark is made on your abdomen before the operation. You can help the staff by indicating what might suit you best, by sitting and standing and discussing what clothes you like to wear, and where the waistbands are likely to come.

You should also make sure you can see where the stoma will be, to make appliance changes more easy.

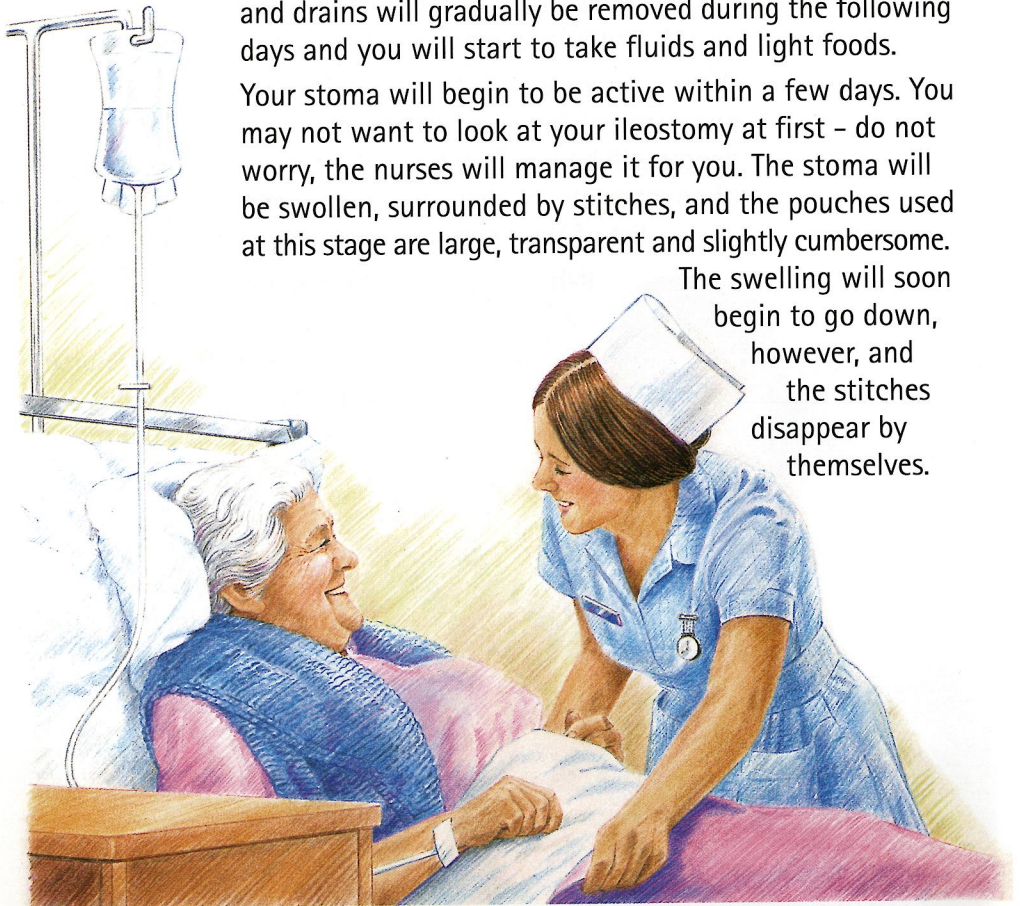
Before the operation you will probably have your bowels emptied and a washout given - medical staff will advise.

After surgery.

When you come round after surgery you will have a number of drips, tubes, catheters etc. attached to you and you will feel some discomfort and weakness. All the tubes and drains will gradually be removed during the following days and you will start to take fluids and light foods.

Your stoma will begin to be active within a few days. You may not want to look at your ileostomy at first - do not worry, the nurses will manage it for you. The stoma will be swollen, surrounded by stitches, and the pouches used at this stage are large, transparent and slightly cumbersome.

The swelling will soon begin to go down, however, and the stitches disappear by themselves.



In hospital

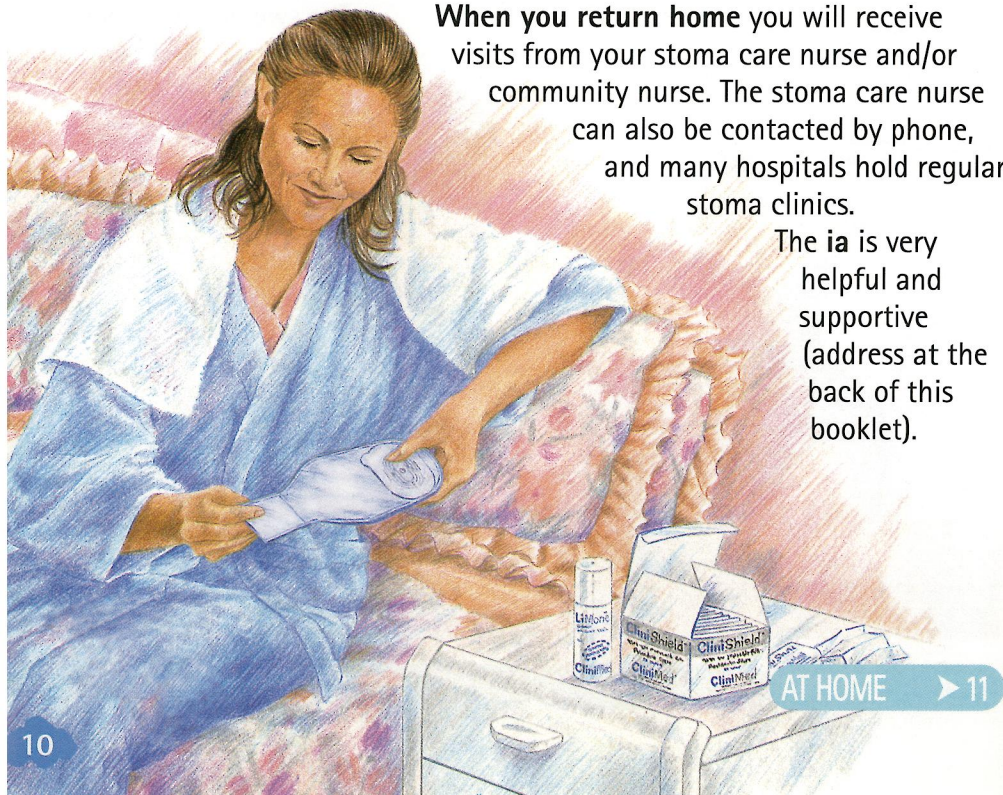
The stoma will become smaller and less obtrusive. (The stoma will continue to become smaller even after you are allowed home and you will need to check that your pouches are still a good fit.)

You are likely to be in hospital for somewhere between 1 and 3 weeks. The stoma care nurse will teach you how to change pouches, how to measure the stoma to see that the aperture of the stoma pouch is correct and how to care for your stoma generally. The stoma care nurse will also fit you with a more discreet type of pouch.

When you leave hospital you will be given an appointment for your first check-up and your family doctor will be notified. You will be given enough supplies of pouches etc. to keep you going for the time being. A list of the items you need will be given to you.

When you return home you will receive visits from your stoma care nurse and/or community nurse. The stoma care nurse can also be contacted by phone, and many hospitals hold regular stoma clinics.

The **ia** is very helpful and supportive (address at the back of this booklet).



At home

Ask your doctor to give you a prescription for the items on your list.

You are exempt from charges if you are over 60. People of any age are exempt from prescription charges if their ileostomies are permanent. Apply for exemption on the special P11 form which will either be given to you in hospital or is available from your doctor, local DSS office or ia.

How to obtain stoma care supplies.

Your doctor writes you a prescription. You can then have your prescription dispensed by your local retail chemist in the normal way. They may need a little time to obtain the items you need, so do not wait until supplies are too low.

In case of difficulty, supplies may usually be obtained direct from the manufacturer of the pouches you use, and also from general ostomy suppliers. You will need to send your prescription to these organisations.

Manufacturers are also very helpful if you need emergency supplies.



If you would like assistance, information about stoma care in general or about the wide range of Welland stoma care pouches and accessories supplied by CliniMed Limited, please contact the **CliniMed Advisory Service** on the free of charge telephone number **0800 585125**.

CliniMed are happy to make available free samples of their stoma pouches and accessories.

Stoma care pouches

Your stoma care nurse will be able to show you a selection of pouches and accessories available.

The waste passed out from an ileostomy is quite liquid and the volumes involved are around 300–700ml per day (roughly 1/2 to 1 pint). A drainable pouch clamped shut at the bottom is therefore used so that the pouch can be unclamped and emptied as often as necessary during the day. There are basically two types of drainable pouches - 'one-piece' and 'two-piece'.

One-piece pouches.

These simple pouches are very popular. They are fixed around the stoma by means of a self-adhesive wafer. The pouch may be unclipped at the bottom and emptied when necessary. When changing a pouch for a fresh one, the whole pouch is gently removed and a new one applied in its place.



Some drainable pouches offer the choice of having a filter. The existence of a filter helps wind to escape easily thus preventing ballooning under clothes.



The type of self-adhesive wafer and precise means of attaching the pouch vary with different types and makes, so it is worth experimenting to find one that suits you, your skin and your way of life. Welland pouches, for example, are affixed with a special thin and flexible 'skin protector' called Hyperflex Plus. This can help to avoid soreness around the stoma.

The material the pouches are made from also varies. The most modern ones are very fine, soft and discreet, with a backing that is very comfortable next to the skin.

Most manufacturers are only too happy to provide free samples for you to try (and you can also keep up with the latest developments this way).

Two-piece pouches.

These pouches have a flange (or baseplate) that fits round the stoma and stays in place for several days, with separate pouches that are attached to it.

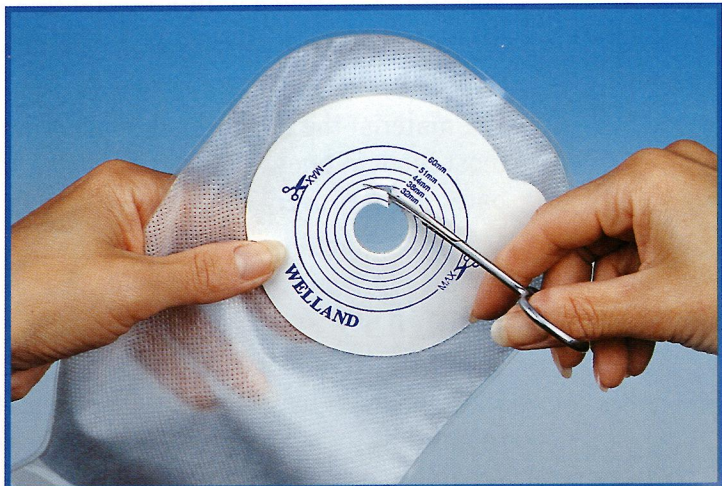
Stoma care pouches

The baseplate is left in position and a new pouch is fixed to it when required. The baseplate is usually changed once or twice a week.

Aperture sizes.

The size of a stoma varies in diameter and stoma pouches are available with different sized apertures or holes. Most appliance manufacturers supply a measuring device to check the size. Find the correct size measuring ring which fits comfortably and snugly round the stoma, without touching it or cutting in. If the stoma is irregularly shaped, it is best to cut your own pattern to fit, using the measuring device as a basis, or using the pouches which are available with cutting guides printed on.

In the months after surgery the stoma size usually reduces slightly while it is settling down. Check carefully to ensure a good fit - many problems with leakage or skin soreness are caused by using a pouch with the wrong-size aperture.



Other accessories.

The importance of cleaning carefully and gently and of taking care of the skin around the stoma to avoid soreness cannot be emphasised too much. The waste matter in the stoma pouch contains digestive juices which can harm the skin if they come into contact with it. If the skin becomes sore, it can be difficult to get it to heal and to get a good fit with the stoma pouch.

Various barrier preparations which help protect the skin are available on prescription. These include pastes, seals, powders, sprays, creams or liquids, and handy disposable wipes that can just be wiped around the area which when dry form an invisible protective skin.

Free disposal bags (to put used stoma pouches in), belts and deodorants are also among the many stoma care accessories available.



Back to normal

If you do have any problems, or if you are entering into a new relationship and would like advice, don't wait too long - help and counselling on the subject is readily available so contact your stoma care nurse or one of the support organisations like the **ia** or Relate National Marriage Guidance.

Contraception.

Having a stoma should not affect your fertility. However for women, the contraceptive pill may not be the best answer as it may be passed through the body before being fully absorbed. Discuss this with your medical adviser.

Pregnancy.

Many women with ileostomies have had successful pregnancies, reporting no more difficulty than that of seeing over their bumps to change their stoma pouches! If you want to try for a baby, discuss the matter with your doctor or stoma care nurse.



Problems that may arise

1. **Surface bleeding**-this can happen if you are too vigorous in your cleaning routine or suffer a slight knock. No cause for alarm.
2. **Bleeding from inside the stoma**-not normal. This or any change in stoma size should be reported to your doctor.
3. **Change in stoma colour**-if the stoma suddenly changes colour, e.g. becoming dark or blueish, check to see it is not being constricted in any way and inform your doctor.
4. **Constipation**-if the waste matter in your pouch seems too thick, drink extra fluids.
5. **Diarrhoea**-can cause dehydration. Drink plenty of fluids to replace that lost. If you think that a certain food has affected you, leave it out of your diet for a few weeks and then try again. Severe diarrhoea (or persistent vomiting) - seek medical attention.
6. **Skin soreness**-check aperture size of pouch is correct. Change appliance only when necessary, and do so slowly and carefully. Gently ensure surrounding skin is absolutely clean and dry. Barrier wipes and creams may help. Try a pouch with better skin protection. Allergies occasionally occur - consult your doctor or stoma care nurse.
7. **'Accidents'**-shouldn't happen! Check to make sure the appliance is applied properly and/or that you are using pouches with the correct size aperture. Pouches vary in the degree of security offered, so try other types if you continue to have problems.
8. **Flatulence or gas**-can be caused by certain foods and can't be controlled. Some say that eating yogurt can help. Experiment to see which foods cause it, e.g. cucumber, beans, fizzy drinks, nuts.
9. **No faeces** going through into the pouch, associated with severe pains - seek medical advice.

Your questions answered

Will people be able to tell I have an ileostomy?

The answer to that is NO - today's stoma pouches are very slim and discreet. Wear what you like and what's comfortable (see below for sportswear). Have you ever seen anyone who you thought looked as though they had an ileostomy?

What about sports?

No problem - the only sports you might prefer to avoid are the very rough physical contact ones. Patterned one-piece costumes disguise any slight bulges for female swimmers, while males might prefer fairly high-waisted boxer type shorts. Baggy T-shirts are great cover-ups at any time, but particularly over leotards for ladies keep-fit.

Whom should I tell?

It's entirely up to you and is a very personal decision. If you've been poorly with colitis for a while, however, your friends and relatives may wonder why you are suddenly so much better!

What about odour when I empty/change my pouch?

No more than anyone else's when they go to the loo (and may even be less)!

Baths and showers?

Yes, either with the pouch in place or, at times of relative inactivity of your stoma, without a pouch on.

Can I take medicine?

Yes, but remind your GP if necessary that you have a stoma - some tablets can go through and come out unchanged at the other end!

Will my life insurance be affected?

Your insurance company should be notified about your ileostomy. The **ia** can refer you for advice if there are any problems.

Associations/Support Groups

Ileostomy and Internal Pouch Support Group (ia)

Central Office,
Amblehurst House,
P O Box 23,
Mansfield,
Notts NG18 4TT
Telephone: 01623 28099

The **ia** is an excellent source of information and advice. **ia's** primary aim is to help others return to full, active lives after ileostomy surgery. It has over 10,000 members in local groups throughout the country and offers help, advice and personal visits to anyone who has, or is about to have, an ileostomy.

In addition the **ia** publishes a quarterly journal for members. Please telephone or write (enclosing s.a.e.) to Bruce McKenzie, National Secretary at the above address for information.

N.A.S.P.C.S.

The National Advisory Service for Parents of Children with a Stoma.
Mr. John Malcolm,
51 Anderson Drive, Darvell,
Ayrshire KA17 ODE
Telephone: 01560 322024

A support and advisory service for parents of children with disorders that lead to colostomies, ileostomies, urostomies and/or incontinence. Send s.a.e. for further information.

British Colostomy Association.

15 Station Road,
Reading,
Berkshire RG1 1LG
Telephone: 01734 391537

Urostomy Association.

Mrs. Angela Cook,
Buckland,
Beaumont Park,
Danbury,
Essex CM3 4DE.
Telephone: 01245 224294

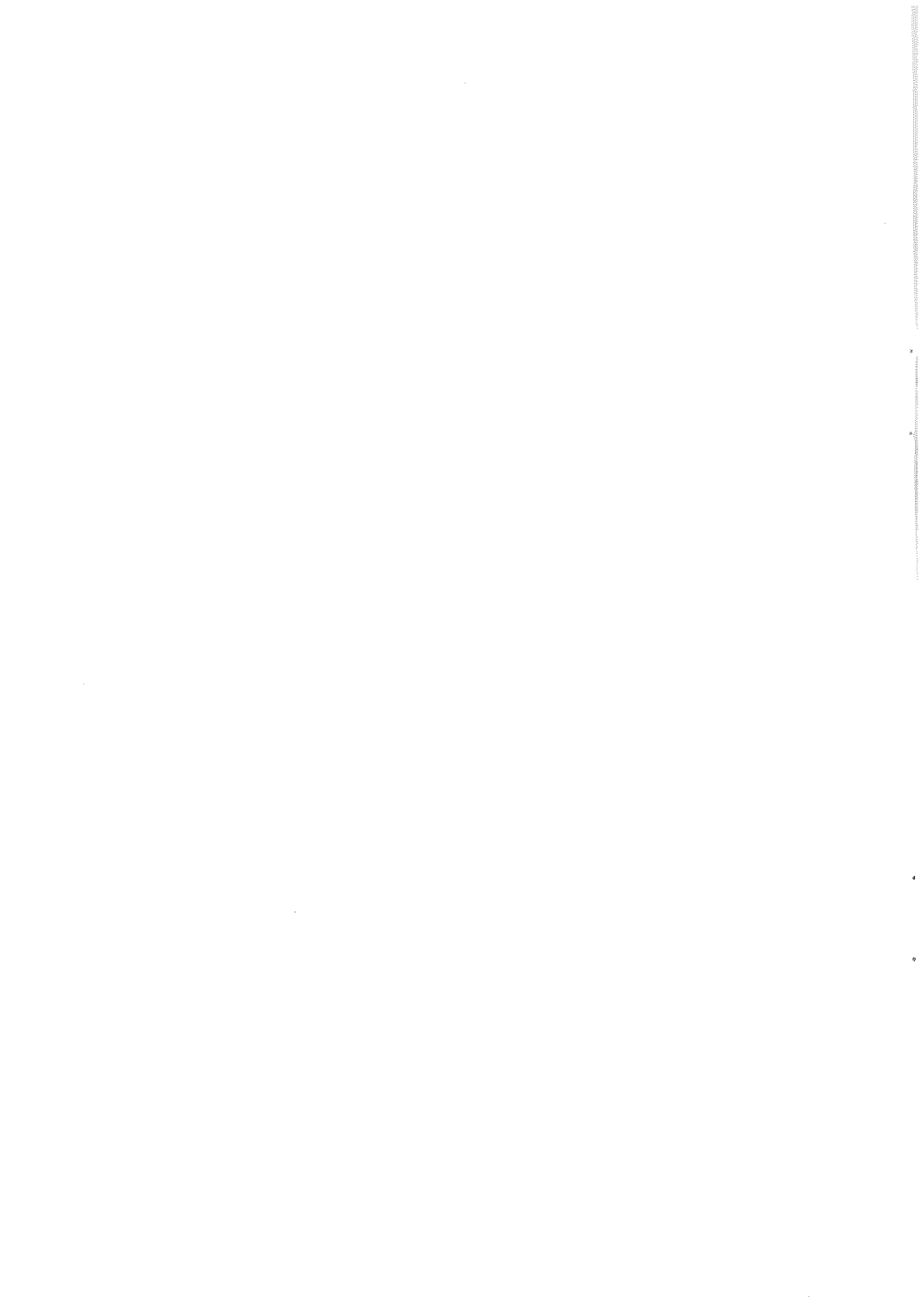
National Association for Colitis and Crohn's Disease.

4 Beaumont House, Sutton Road,
St. Albans,
Herts AL1 5HH
Telephone: 01727 830038

Royal Association for Disability and Rehabilitation (RADAR).

12 City Forum,
250 City Road,
London EC1V 8AF
Telephone: 0171 2053222

RADAR operates the National Key Scheme. This allows people access to toilets which are locked to avoid vandalism and misuse.



Welland stoma pouches from **CliniMed**[®]



▲TEAR▲

To: CliniMed Advisory Service. Please send me free samples of:

PLEASE TICK

- Welland Silhouette[®]
- Standard length
- or
- Shorter length
- Welland Silhouette[®] Plus* *
- (drainable with filter)
- Welland Ovation (drainable with an Oval skin protector)*
- PREFERRED COLOUR: BEIGE CLEAR
- LiMone[™] Ostomy Deodorant Spray
- CliniShield[®] Peristomal Wipes
- ClearPeel[®] Adhesive Remover

Current Product _____

I do not wish to be kept informed of any further developments.

* Not available in shorter length version

My stoma size is _____ mm diameter

Name _____

Address _____

_____ Post code _____

Please return this card (in an envelope if preferred) to:
 CliniMed Advisory Service
 FREEPOST CLINIMED
 HIGH WYCOMBE
 HP10 8BR

▲TEAR▲

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working with you to improve stoma care

The last word - from Bruce McKenzie, National Secretary of the IA, Ileostomy and Internal Pouch Support Group.

Stoma care in the U.K. has changed considerably since 1945 when Dr Lionel Hardy, a senior physician in Birmingham who was specially interested in ulcerative colitis, brought back from America a few samples of rubber pouches and some tubes of adhesive.

Dr. Hardy asked Mr. Bryan Brooke (later Professor) to carry out ileostomy operations on some of his patients in a way which would allow the new pouch to be used, and stoma pouches began to be manufactured in Birmingham.

Since then surgical techniques have been further developed and ileostomy equipment which would have been beyond the dreams of those who had their ileostomies in the 1950s is now freely available.

The aim of **ia** is to help people who have an ileostomy operation to return to a fully active and normal life as soon as possible. We and they are able to achieve this thanks to Lionel Hardy and Bryan Brooke, to all the physicians and surgeons who have followed their lead, to stoma care nurses, and to companies like CliniMed, who not only supply high quality stoma care products for ileostomists but also provide excellent literature such as this booklet.

Bruce McKenzie,
National Secretary.

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working with you to improve stoma care

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