

Ileostomy and Internal Pouch Support Group

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Urostomy Association

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General information for people with a Stoma

GHP512_04_09

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Review due: April 2012

trousers. Some companies make trousers with a 'higher waist' e.g. Chums Ltd., Unity Grove, Knowsley Business Park, Prescott, Lancs. L34 9AR Tel: 0151 5488088.

There are companies that make swimwear especially for people with stomas i.e. men's shorts higher waisted, women's costumes designed to conceal the appliance. Speak to your Stoma Care Nurse for details. These items are not available on prescription. However, it is possible to buy suitable swimwear on the high street. For the women it is probably better to go for a costume with a design/pattern than a plain one.

There are companies that make specially designed underwear for both men and women. Sometimes a 'pocket' is built in to support the appliance. Support garments are available. Many women find "Sloggi" pants (available on the High Street) comfortable and supportive. Also Lycra type 'bodies' are useful in giving a sleek appearance as well as being supportive (for those without a bag as well).

These two companies have a variety of products for people with stomas:

CUI Wear – Tel: 0800 279 2050 - www.cuiwear.com

White Rose Collection – Tel: 01202 854634 - www.whiterosecollection.com

National groups which you might find useful

The National support groups offer a range of literature and support to people with a stoma. If you are interested please discuss this with your stoma care nurse.

Colostomy Association

15 Station Road

Reading

Berkshire

RG1 1LG

Tel: 0118 939 1537

Fax: 0118 9569095 E-mail: sue@bcass.org.uk

Always ensure that the bag is emptied before your bath, to avoid it floating in the water.

Many people prefer to have a shower or bath without a bag on. This is perfectly safe. Some people worry about water entering the body. This is very unlikely to happen and certainly would not hurt you if it did.

Ileostomists may prefer to bath with a bag on, as it can be quite distressing if it acts and soils the water.

If your bag has a filter on it, then cover the filter with one of the sticky labels provided in the box to prevent water from clogging the filter. Remove the label after bathing.

Tiredness

You will be surprised at how very tired you will feel when you go home, this is normal.

Having had an operation, your body will need more energy to help the healing process. Eating little and often is advisable as it helps to refuel those energy requirements.

It is often helpful to plan your day so that you have time to rest and do the things you want to do most.

During the first couple of weeks family, friends, neighbours and social workers may be able to help you manage your everyday activities.

It is very important to increase doing things for yourself, set yourself aims each day to achieve, and soon you will be able to resume your previous activities as you wish.

Clothing

Many people with stomas find it unnecessary to change their style of dress. However, the following tips may be useful to some people.

When wearing trousers some people find it better to choose a style with pleats at the waistband to help conceal the appliance. Men may find it more comfortable to wear braces rather than a belt with their

How to get your supplies

When you are discharged from hospital you will be given approximately two weeks supply of pouches and your dispensing options will have been discussed with you by your Stoma Care Nurse. If you have decided which appliance to use, you may also have your equipment details (ordering codes). Usually this is not done until all the swelling in your stoma has settled and you are at home. Stoma care products are available on prescription which you get from your General Practitioner (GP). The prescription can be taken to either of the following:

Local Pharmacist - your supplies will be available upon receipt of your prescription.

Specialist Delivery Company - they will deliver your supplies directly to you free of charge. They also supply cleansing wipes, disposal sacks, curved scissors and a 'cutting service' for those that need it. Usually you send your prescription direct to them in a prepaid envelope, or in some instances you may telephone them on a free phone number.

Dispensing Surgery - some GPs are able to dispense directly from their surgery.

Are you entitled to free prescriptions?

If you have a permanent Stoma – YES.

If you are under 60 years, you will need to apply for an exemption certificate (FP11). The FP11 form can be obtained from your Stoma Care Nurse, GP Surgery or Post Office. This form must be signed by your GP who can then send it off to the FHSA for you. You will then receive your exemption certificate. Each time you get a prescription from your GP you will need to tick the box on the back of the prescription marked medical exemption and sign as normal. It is advisable to photocopy your certificate as you may need to send a copy to your Stoma Supplies Delivery Company if you receive your supplies from them.

If you have a temporary stoma and are under 60 it is ultimately at your GP's discretion as to whether you are exempt from prescription charges. Please discuss this with your Stoma Care Nurse.

Work, benefits and allowances

Can I return to work

YES when YOU feel ready.

As a very broad guide-line this is approximately 6-8 weeks after major surgery

If you have a medical officer or occupational health nurse at your place of employment, you may wish to discuss your operation and plans to return to work.

It is normal to feel very tired when you first return to work. If you work full-time you could discuss with your employer an option of returning to work on a part-time basis until you feel able to return to full-time employment.

Benefits and allowances

Having a stoma does not qualify you for benefits, but if you need help financially because you are having to take time off work, or need help with personal care or mobility as a result of your illness, you may be entitled to claim.

Benefit leaflets and advice is readily available from your local Social Security office, and we would strongly advise you contact them for further information.

Most importantly, if you anticipate you are going to have difficulties keeping up your repayments, for example mortgage, rent, bank loans, it is essential you notify the appropriate lenders as soon as possible and contact the Social Services for further advice.

Below is just a very brief guide to the benefits you may be entitled to.

Tel: 0207250 3222

E-mail: radar@radar.org.uk

Or you can order on line at www.radar.org.uk

Body image

It is important to realise that you are not immediately going to feel at ease and comfortable with your stoma. It is something completely new for you and takes time in coming to terms with the change in body image.

Some people feel very weepy after major surgery, as their body has been through a major event. This is quite normal, and as you get stronger, you will start feeling better.

If possible, have someone at home with you who can give you some support in the early days after your discharge.

If you have a partner, try and talk through your feelings and anxieties, as this often helps. Things do improve, but as with any major change, it takes time.

Body hair

It is essential to keep the area around the stoma hair free to ensure that the appliance sticks well. Men will probably need to shave once or twice a week. We do not advise that you use any shaving creams, as some people may develop a reaction to these, causing soreness around the stoma and difficulty in applying the bag.

Try and shave in the direction that the hairs are growing to avoid undue irritation to the skin. Some ostomists report that using a very good quality razor gives the best results and reduces skin irritation.

Bathing and showering

It is fine to have a bath or shower with your stoma bag on or off. Remember that the adhesive is designed to tighten up when exposed to water, so it may be an idea to change your bag beforehand for comfort.

supermarkets or chemists. It can be taken to help slow the gut down, so that it has a chance to absorb fluids and therefore reduce the diarrhoea.

If you have an ileostomy, in contrast to what it says on the Loperamide packet it is advisable to take the Loperamide ½ to 1 hour before a meal.

Also if you can get hold of the Loperamide tablets rather than capsules they will work quicker and more effectively for you.

Radar key

As an ostomist, you are entitled to acquire a “Radar” key. This National Key Scheme offers independent access to around 4,000 locked public toilets around the country. This key opens any disabled toilet in the country, and provides you with more privacy than other public toilets. It does not mean that you are considered to be disabled in any way, but is intended to make things a little easier for you, as you will find a wash basin and disposal facilities within the toilet.

Please note that the toilets are the property of the providers concerned, and as such, any queries or problems concerning a toilet should be directed to that provider, rather than RADAR.

RADAR makes no profit in supplying keys, but has to charge VAT for keys. In order to apply zero rate for keys, orders must state the name and address of the person with a declaration of disability (eg “I am an ostomist and I wish to buy a National Key Scheme Key”).

To acquire a Radar key, write to the address below, enclosing the statement: “I AM AN OSTOMIST” (or they can be obtained locally from the Municipal Offices in Cheltenham).

Please enclose a cheque or postal order for £3.50 payable to “Radar”

12 City Forum
250 City Road
London
EC1V 8AF

If you are employed

If you have been in employment with the same employer for a minimum of 3 months you will be entitled to and will receive statutory sick pay from your employer for up to 28 weeks.

Income support can also be considered, but this will be means tested.

After this, or should your employment contract be terminated earlier, you can then apply for incapacity benefit. The amount you will receive will be dependent on how long you have been and will be incapable of work.

If you are self employed

If you have paid your National Insurance contributions you will be entitled to claim Incapacity Benefit. If you are the main wage earner in your family, you may be considered for Income Support as well, but this will be means tested.

Even if you have not paid your National Insurance contributions, you will be entitled to Income Support, but once again the amount will be means tested.

If you are requiring help with your personal care because of your illness you may be entitled to apply for an Attendance Allowance. It will not usually affect savings or income support and can be claimed whether or not care is received. It does not include shopping and cleaning.

Holidays

When you have sufficiently recovered from the surgery, you may be considering a holiday to recharge your batteries. It is a good idea to go away for the odd weekend first before planning a world tour.

Top tips

1. Ensure that you have adequate holiday insurance that covers you for existing medical conditions. The Ileostomy Association has a list of insurers who offer competitive insurance.

They can be contacted on: 01724 720150.

2. If you are travelling abroad, ensure that you carry all your stoma supplies with you in your hand luggage, as it would be disastrous if your case went missing with all your supplies in it. Take twice the amount you would normally need.
3. In hot climates, ensure that you store all the equipment somewhere cool to avoid the adhesive from becoming tacky (for example take a cool bag as your hand luggage).
4. If you are travelling by air, avoid fizzy drinks and alcohol as these will increase the amount of wind and produce a ballooning effect in the pouch. Similarly, avoid foods that you know give you excessive wind (perhaps request an aisle seat so that you can easily get to the toilet).
5. If you are a "closed" pouch user, take a couple of drainable pouches with you, in case you suffer with diarrhoea while you are away. This will save your skin from getting sore from excessive changing of bags.
6. Remember to ask your stoma care nurse about mini closed pouches that are ideal for swimming (sorry these are for colostomists only).
7. If swimming a lot either in the sea or chlorinated pool, it may be necessary to change the flange/bag more frequently as it causes the adhesive to dry out.
8. Even if you do not have a stoma it is often advisable to take some Dioralyte, a rehydration solution, or similar mixture with you in case you suffer with an upset tummy. It is essential to drink plenty while you are away to avoid dehydration. In countries where tap water is not recommended for drinking, it is strongly recommended that you drink bottled water. Avoid ice cubes as you don't know how old they are or what has dripped onto them.
9. Some of the companies produce a travel certificate which explain in different languages what you have had done in case a medical emergency arose, or if you are stopped at customs. Your stoma care nurse will give you information on this, if interested.

10. Most importantly relax and enjoy your holiday.

Holiday tummy

When we go on holiday we are all susceptible to picking up an upset tummy. This advice is general for anybody whether you have a stoma or not.

It is very important to drink plenty to avoid becoming dehydrated (a minimum of 8 cups per day).

If you do experience diarrhoea it is advisable to avoid high fibre foods (fruit, salad, green vegetables) until the diarrhoea has settled. Eat more carbohydrates (potatoes, pasta, and rice) and protein (meat, fish, cheese, egg).

For ileostomists, dehydration can be more problematic because you have had your colon removed. Therefore it is imperative you maintain your fluid intake.

It is recommended that if you have diarrhoea or a watery output or losing extra fluid through sweating e.g. when the weather is hot or you are undertaking exercise, additional fluids must be drunk. Isotonic drinks are advised during these circumstances. Isotonic fluids are better for you because they have a higher sodium (salt) content and the combination of sugars; it encourages fluids to be absorbed into the gut, rather than passing straight through.

These types of drinks include dioralyte (can be bought from supermarkets and chemists) and Lucozade Sport, Powerade, Isostar or you can make up your own rehydration drink using:

- 1/2 flat teaspoon of salt
- 200mls of squash (not sugar free)
- Make up to 1 litre of tap water

This solution should be drunk over 24 hours. Some people have found eating bananas or jelly helps firm up the output.

Loperamide 2mg (usually found in the medication known as Immodium/Diarese. This anti-diarrhoeal medication can be bought at