

## Living with a stoma

Information for ostomates and their carers

www.ColostomyUK.org



### Contact us

Write to: Colostomy UK 100 Berkshire Place Winnersh Wokingham Berkshire **RG415RD** 

#### Adminline:

Tel: 0118 939 1537

Stoma helpline: 0800 328 4257

#### E-mail

hello@ColostomyUK.org

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www.ColostomyUK.org













### Contents

Colostomy UK	4
How we can help you	6
After the operation	7
Stoma bags	8
Obtaining supplies	10
Changing a stoma bag	11
Early days at home	13
The road to recovery	14
Getting back to normal	15
Coping away from home	18
Different approaches	20
Exercise following stoma surgery	21
What should I eat?	22
The Eat Well Plate	23
Common concerns about eating	24
Often it's not what you eat	25
Other concerns	26
Colostomy UK support literature and factsheets	28
Support organisations	30

### Colostomy UK

We are Colostomy UK. Here if you have questions, need support or just want to talk to someone who lives with a stoma.

Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you; building communities to support you.

#### We provide:

- A stoma helpline: 0800 328 4257.
- Support literature and factsheets about all aspects of Living with a stoma.
- Tidings, a quarterly magazine full of the latest news, articles by stoma care professionals, product information and real–life stories from other ostomates.
- A closed Facebook group for supporting each other and exchanging hints and tips.
- A website that provides practical information, details of open days and a directory of organisations, support groups, products and services.



In addition to our office team we have volunteers throughout the UK who all have stomas. They are fully trained and adhere to guidelines set out by Colostomy UK.

#### **Our volunteers:**

- Attend open days arranged by: hospital stoma care nurses; manufacturers and suppliers of stoma bags.
- Visit ostomates in hospital and at home.
- Answer the helpline.



### How we can help you

All medical queries (such as sore skin, leakage from a stoma bag or changes in bowel function) should be directed to your stoma care nurse, GP or surgeon.

We have a wealth of knowledge to share about the experience of living with a stoma and can give guidance on a wide range of issues. For example, you could contact us:

- Prior to surgery and discuss any concerns you might have about the practical aspects of life with a stoma.
- In the early days after surgery, if you would like to share your feelings with someone who understands what you've been through and knows what it's like to have a stoma.
- Later on if you have concerns about issues such as going back to work, taking up sport again or going on holiday etc.





### After the operation

When you come round from your surgery you will be wearing your first bag over your stoma. Don't panic, this bag is often much larger and different to the ones you will eventually use at home. It is transparent and drainable sometimes with a clip or clamp at the bottom. This allows the nurse to examine the stoma, and for the contents to be drained away without removing the bag and disturbing the skin.

Each individual NHS Trust will have its own protocol for when you will start to eat and drink. Some may use the Enhanced Recovery Programme and you will be informed about this by the nursing staff/Enhanced Recovery Nurse. Eventually you will be able to return to a normal diet (see page 22 for more advice about food).

At first you will pass wind through your stoma and then, usually within two or three days, you will pass a motion. This is likely to be fairly liquid at first, but will gradually become more formed and solid.

The stoma care nurse will visit to show you how to change your bag. S/he will also measure your stoma to make sure that the bag fits snugly round the stoma to avoid leakage and sore skin.



### Stoma bags

#### How do I decide which stoma bag suits me?

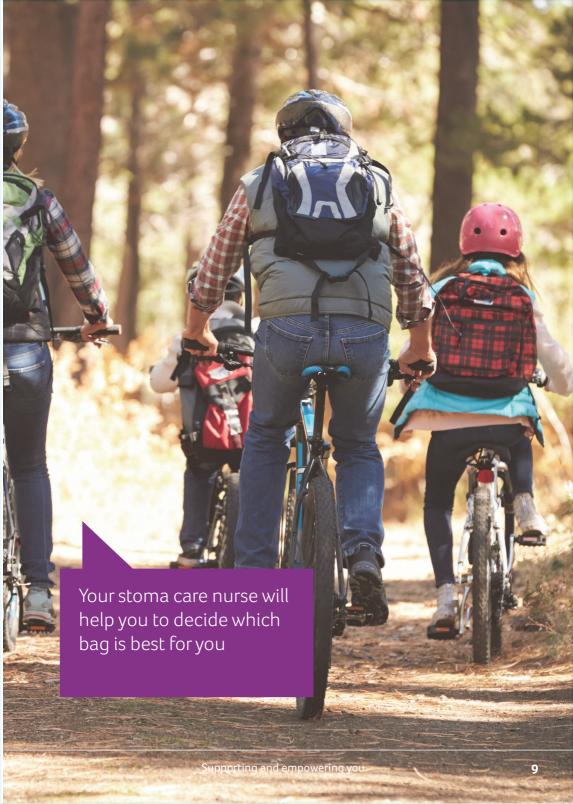
There are many different stoma bags. They are made by a number of different manufacturers. Your stoma care nurse will help you to decide which one is best for you. Immediately after your operation this is likely to be a drainable bag.

#### Different types of bags...

- **One-piece system** where the adhesive flange is attached to the bag and after use the complete bag is removed and replaced with a new one.
- **Two-piece system** which consists of an adhesive base-plate that is fitted snugly round the stoma and a bag that either sticks or clips onto the base-plate. The bags can be changed quickly, without removing the base-plate, thus avoiding disturbing the skin.
- Closed bags. These are mainly used for coping with formed motions. They
  are usually changed two or three times a day. Closed bags with a special liner
  that can be flushed down the toilet are also available.
- Drainable bags. These are mainly used for coping with liquid motions. They
  can be worn for two or three days as they can be emptied through an outlet
  at the bottom and then resealed afterwards (using an integral Velcro seal or a
  clip).
- **Mini-bags and stoma caps.** These have a limited capacity and are designed for wearing for a short time, when the stoma is likely to be less active (or in conjunction with irrigation see page 20).

#### What else might I need?

- **Adhesive remover** (spray or wipes) to protect the skin when removing the bag.
- Spray, wipes or lotion to form a protective barrier between the adhesive and the skin.
- Deodorizing drops or capsules for inside the bag if there is a problem with odour.



### Obtaining supplies

When you leave hospital you will be given some stoma bags and a prescription for more. Your GP will then give you prescriptions for further supplies. Your stoma care nurse will explain how the system works.

You can give your prescription to your specialist supplier or local chemist. You can choose where you get your bags from and which make of stoma bag you want to use. You need to feel as comfortable as possible when you're wearing the bags, so it is important to choose the ones that suit you best.

#### Will there be any costs?

If you live in England, are under the age of 60 and have a permanent stoma you will need to apply for a prescription exemption certificate. You do this by completing form FP92A (obtained from your GP surgery) and returning it to your doctor. Once you have this certificate your prescriptions will be free of charge. You will need to renew this certificate every five years.

You will not be entitled to free prescriptions if you have temporary stoma and live in England (unless you have been diagnosed with cancer). If you think you will have to pay for three or more prescriptions in three months, or 13 or more items in 12 months, you may find it cheaper to buy a prescription prepayment certificate (PPC). If you have been told that your stoma may be temporary, please discuss this with your surgeon, stoma care nurse or GP.

Prescriptions in Scotland, Wales and Northern Ireland are free of charge.

Your GP will give you prescriptions for further supplies





### Changing a stoma bag

Your stoma care nurse will show you how to change your bag while you are in hospital. S/he will also teach you how to use a stoma guide to check if the hole in the adhesive flange or base—plate is the correct size. If necessary your nurse will show you how to cut the right size and shape using a template.

#### Here is a simple guide to the changing routine:

- Check you have everything you need: water, soft wipes, a new bag, adhesive remover and any other accessories you use, and a plastic disposal bag.
- If you are using a drainable bag open the closure at the bottom and drain
  the contents into the toilet before removing it. To do this sit well back on
  the toilet seat, although some people find it easier to kneel or bend over
  the toilet.
- Remove the old bag, working slowly and gently from the top to the bottom using adhesive remover if necessary.
- Wash the stoma and surrounding skin with warm water using dry—wipes (provided free by suppliers) or kitchen roll. Don't use harsh solvents, soaps or disinfectants. Remember the stoma bleeds easily if it is rubbed a bit too hard, but the bleeding should stop quite quickly. (Contact your stoma care nurse if the blood is coming from inside the stoma).
- Dry the area around the stoma thoroughly using dry—wipes or soft kitchen roll
- Fit the new bag (or the base—plate), making sure that it is secure all the way round. When fitting a one—piece bag, it helps to bend the top half of the flange away from your body, so you can see to fit the bottom half accurately around the stoma. Then with the flat of your hand press the remainder of the flange in position. The warmth of your hand will ensure it adheres snugly.
- If using a two-piece bag, then attach the bag to the base-plate.

#### Living with a stoma

#### Disposal of used bags

There are a number of options.

- Empty the used bag and seal it inside a disposal bag (provided free by suppliers) and discard with your normal household waste.
- If it is not practical/acceptable to empty the used bag, contact the environmental department at the local council to enquire if they operate a domestic clinical waste collection service.
- Bags with liners that contain the waste and can be flushed down the toilet are now available.
- Some ostomates keep a bin designed for nappy disposal in the bathroom. These systems seal each used bag individually within a polythene film and control odour until the bin can be emptied.





### Early days at home

When you first get home from hospital you may feel emotional and need to gain confidence before mixing with others. Your stoma may behave erratically or make noises. This is perfectly normal in the early days; the bowel takes time to settle down after surgery. Your abdomen may be tender to touch, which can make changing your bag difficult. All of this will improve with time.

It is a good idea to establish a routine. As you get used to your stoma you may find that at certain times of the day it is more active than others and you will be able to choose the best time to change your bag.

In the first few months a stoma tends to shrink so use the stoma guide which you will find in your box of supplies to check the size and make sure that the hole in the flange isn't too large.

#### **Bathing and showering**

The bag can be left in place or taken off while in the bath or shower. Water cannot get into the bag or the stoma.

If leaving the bag in place it is a good idea to cover the outside of the filter with one of the sticky patches that come with your supplies. This will prevent the filter getting wet and becoming less effective.

If bathing or showering without a bag, choose a time when the stoma is less active i.e. before rather than after a meal.

Bath preparations with oil in them are best avoided as they can leave oily residue on the skin and prevent the adhesive from sticking properly. Make sure your skin is completely dry before fitting the bag.

### The road to recovery

Your recovery will take at least three months. There are no fixed rules, everyone is different. Tiredness is one of the after effects of surgery, so take the opportunity to rest whenever you can. Exercise is important too. Initially, just taking short walks out in the fresh air will help you to build up your strength. Avoid over—exertion.

Remember, you have had major surgery and your abdominal muscles are weaker. For at least three months avoid lifting anything heavy and support your abdomen when coughing and sneezing. It may be advisable to wear a support belt or girdle. Your stoma care nurse or surgeon will be able to advise.

One step at a time is the rule. Keep your mind active and don't hide away. Stay in contact with your family and friends but don't feel guilty excusing yourself if you feel tired. Having a stoma isn't a disability unless you let it become one; you can still live a full and active life.

It may help to talk things over with someone who has a stoma. We have more than 100 volunteers who have a stoma and they would be happy to speak to you on the phone. Just call our free helpline (0800 328 4257) and we will be happy to arrange this.





Alternatively, you could go along to a stoma support group. You may find that just a couple of visits help you to come to terms with your stoma. Equally, you might make friends and decide to continue attending meetings and perhaps go on to help others. Details of groups in your area can be found on our website and in our quarterly magazine. You can also join our closed Facebook support group.

### Getting back to normal

#### Making a decision to talk about your stoma

Only you can decide who you should tell. Some people prefer only their close friends to know. Others are happy telling everyone. The decision is up to you.

Remember, having a stoma has not changed who you are. You are still the same person you were before surgery. It may take some time to come to terms with your altered body image. If you would like to talk to somebody who has a stoma call our stoma helpline or send us an e-mail.

#### Do I need different clothes?

Most ostomates are able to find suitable clothing in ordinary retail outlets and high street stores. There are also companies that manufacture specialist clothing.

#### These include:

- High-waisted trousers for people who have a stoma at waist level.
- Underwear which is high-waisted or with an internal security pocket.
- Support garments to prevent or control a parastomal hernia.

Factsheets listing suppliers of these products can be downloaded from our website or obtained by giving us a call.

#### Living with a stoma

#### Will I be able to return to my job?

Once you have fully recovered, there is no reason why should not return to work. Your doctor will advise you when you are fit enough to consider returning. It is very important to listen to his or her advice. They will also be able to talk to you about any adjustments that you might need to make. For example, if your work is strenuous, involves heavy lifting, or puts a strain on your abdominal muscles they might suggest that you wear a support garment to lessen the risk of a parastomal hernia. They can also liaise with your employer's occupational health department.

#### Will my driving be affected?

You should wait until at least six weeks after your surgery before you start driving again. Having a stoma will not affect your driving ability, but it is wise to check with your motor insurer as policy conditions vary. If you find the seat belt is uncomfortable across your stoma try fitting a 'Klunk clip' device. These can be readily obtained online or from most car accessory stores. The clip is attached to the inertia reel of the seat belt and reduces pressure on your stoma. Forward movement releases the clip allowing the restraint system to operate normally.

#### Can I travel at home and abroad?

Having a stoma shouldn't prevent you from travelling. At first it is natural to feel a little apprehensive about this. The important thing is to plan ahead and be prepared. If you are planning your first trip abroad and have had surgery in the last six weeks, check with your surgeon or GP prior to booking in order to make sure you are able to travel. Also, seek medical approval if you have been in hospital during the last six months.

We produce a comprehensive travel guide covering travel in the UK and abroad. You can download this from our website or obtain a free copy by giving us a call.



#### Will it affect my sex life?

Most people with a stoma can enjoy a healthy sex life.

Some ostomates feel more comfortable wearing attractive underwear, use a cummerbund to conceal/ support the bag or use a bag cover.

Mini-bags and stoma caps are also available (see page 8)

If the rectum is removed during stoma surgery:

- Some women may experience a different sensation, pain or dryness in the vagina during intercourse. This can be helped by using a lubricant.
- Some men may experience difficulty in getting an erection. This can be successfully treated in 90% of cases.

Should you experience any such problems do not be embarrassed to discuss them with your surgeon or stoma care nurse. Colostomy UK has a number of male and female volunteers who are willing to talk in confidence about any concerns.

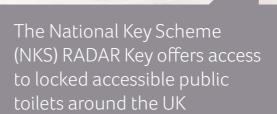
See our factsheets for further information.



### Coping away from home

Initially you may be hesitant about going out. Take short trips at first. Then as you become more confident increase the distance you travel and the time you are away from home. Remember to take a spare bag, wipes, disposal bag and any other equipment you use just in case you need to change your bag while you are out. It is useful to also take wet—wipes or cleansing gel (available from stoma manufacturers and suppliers) in case you need to change your bag in a toilet cubicle where water is not available.

People with stomas are entitled to use accessible toilets. These always have a wash basin and a bin to dispose of used bags. The National Key Scheme (NKS) RADAR Key offers access to locked accessible public toilets around the UK. Toilets fitted with NKS locks can be found in shopping centres, pubs, cafes, department stores, bus and train stations and many other locations across the country. If you are out and about in the UK a RADAR key can open the door to 9,000 accessible toilets. You can obtain a RADAR key from Colostomy UK for £3.50 including p&p. Alternatively you can get one from Disability Rights UK for £4.50 including p&p. \* They also produce guides that list the accessible facilities by region. You may also be able to obtain a RADAR key from your local council.



\*prices correct at time of publication



### Different approaches

#### Irrigation

Irrigation is an alternative to wearing a bag. It is a means of controlling the output from a colostomy and involves using specialist equipment to introduce a measured amount of water into the bowel. The water then causes muscular contractions which leads to the bowel expelling its contents.

Irrigation allows you to decide when you wish to evacuate the bowel, thus restoring control. A small bag or a stoma cap or plug is all that is needed to cover the stoma in–between irrigations.

We have volunteers who are willing to discuss their own experience of irrigation if you want to consider this method of stoma management.

If you have an ileostomy, then irrigation is not possible. If you have a colostomy, then you might be able to irrigate, but consent will need to be obtained first from your stoma care nurse or surgeon.

#### **Continence control devices**

**Conseal Plug** – a lubricated, soft foam plug which is inserted into the stoma and held in place with an adhesive flange.

**Vitala** – a non–invasive stoma device that clips onto a base plate and rests gently but snugly against the stoma. It allows the body to temporarily store the motion inside the colon.

Both these devices are only suitable if motions are formed and passed on two or three occasions a day.

The consent of your surgeon, or stoma care nurse, must be obtained prior to using these devices, since they are not suitable for all types of stoma. Their use needs to be taught and the first attempts supervised by a stoma care nurse.



### Exercise following stoma surgery

Gentle exercise is an important aspect of getting better after an operation. In hospital you will be encouraged to do more and more each day until you are fit to go home. Once home, it's important to keep exercising.

#### Why is exercise important?

Exercise improves the circulation and so helps the healing process. Appetite is stimulated too. There are also wider benefits. It can make you stronger and help you to do more without feeling weak and breathless. In turn this has positive consequences for both your physical and mental wellbeing. For more information, download or request a copy of our booklet 'Active Ostomates'. This contains useful advice on sport and exercise and includes details of exercises you can do at home.



### What should I eat?

By the time food reaches the colon, it has been almost completely digested, so having a stoma does not mean you will have to change what you eat.

It is not necessary to follow a special diet (unless you have been advised to do so by your doctor for another specific medical condition).

Try, as far as possible, to eat a diet containing a variety of items from all the food groups illustrated in the diagram opposite.

This will ensure that your body receives all the essential nutrients (protein, carbohydrate, fat, vitamins and minerals) it needs.

#### Are there any foods colostomates should avoid?

We are all different. Some ostomates can eat anything. Others have found, by experience, that it is best to avoid certain foods. If you have persistent problems try keeping a food diary you may find it helps.

If you suspect a food causes problems, try it at least three times, separated by an interval of at least a week, before eliminating it altogether.

If you find you are cutting out most of the items in any one of the food groups shown in the diagram, then it is advisable to seek dietary advice. Your GP can refer you to a dietitian.

#### Should I eat more fibre and less fat?

Bear in mind that, although current advice is to eat more fibre and less fat:

- Too much fibre (e.g. pulses and bran based cereals) may cause wind or loose motions.
- If you are trying to regain lost weight, it may be better to use full fat milk and cheese, rather than semi–skimmed or skimmed alternatives.

### The Eat Well Plate



Source: Department of Health in association with the Welsh Government, the Scottish Government and the Food Standards Agency in Northern Ireland. Crown Copyright 2007.

### Common concerns about eating

#### Wind

Beans, peas, onions, leeks, unripe banana, potato which is cooked then cooled (e.g. potato salad and shepherd's pie) contain a type of sugar and starch that can escape digestion and enter the colon, where they are fermented to produce gas. It may also help to avoid foods which are high in fibre or contain unmilled grains and seeds. Beer and fizzy drinks may also increase the amount of wind.

#### Diarrhoea

Very spicy foods and large amounts of lager and beer can irritate the lining of the digestive system and cause frequent loose motions. These effects can be reduced by eating spicy dishes in small quantities with plenty of rice, pasta or potatoes and never drinking alcohol on an empty stomach. Pure fruit juices and some fruits and vegetables may cause diarrhoea in some people.

#### Constipation

Eating more foods containing fibre can help to prevent constipation. Try to increase the amount of fibre by choosing wholemeal (rather than white) bread or pasta, wholegrain cereals and more fruit and vegetables. It is best to make these changes gradually to avoid problems with wind. Fibre acts by absorbing water to make motions softer, so it is very important to drink plenty of fluids, at least six to eight glasses a day.



### Often it's not what you eat

The consistency of your stoma output doesn't only depend on the type of food you eat. Water is absorbed from undigested food as it passes along the colon. If a large section of the colon has been removed, then your stoma is likely to work more often and the output to be fairly liquid, or of a toothpaste consistency. If most of the colon is still intact, then motions will be more formed and less frequent.

Don't assume that food is to blame for the way your stoma behaves. There may be some other reason.

#### Wind may be due to:

- eating in a hurry
- · meals at irregular times
- · going for long periods without food

#### Diarrhoea may be the result of:

- a stomach bug
- stress or an emotional upset
- antibiotics

#### Constipation may be due to:

- not drinking enough fluid
- not getting enough exercise
- some medicines e.g. certain painkillers or antidepressants (check with your doctor or pharmacist)

This information is intended as a general guide. You should seek medical advice if you experience persistent alteration in your stoma functioning, or if you develop new digestive symptoms.

### Other concerns

#### Odour

There should only be odour when emptying or changing your bag. This can be reduced by spraying a deodorant. Odour while the bag is in place might indicate a leakage or a faulty bag. Drops, gels, capsules and sachets are available to neutralize any odour inside the bag. For more information, download or telephone for a copy of our factsheet on deodorants.

#### Leakage

A stoma bag may leak occasionally. If this occurs regularly consult your stoma care nurse who will be able to identify the cause and suggest a different bag or accessories e.g. barrier rings or paste to solve the problem.

#### **Ballooning**

This occurs when gas expelled through the colon collects inside the bag causing it to inflate. Most bags have a filter which allows this gas to escape. Occasionally the filter will block and the bag needs to be changed. If this happens to you regularly, it may be worth trying a different bag. When in the bath or shower, ensure the filter does not get wet and become ineffective; cover it with a sticky patch supplied in your box of stoma bags.

#### **Pancaking**

This occurs when, instead of dropping to the bottom of the bag, the motion collects around the stoma and may seep between the flange/baseplate and the skin. This can happen because there is not enough air in the bag and so the two sides stick together. It may help to cover the filter with a sticky patch to prevent gas escaping from the bag. Alternatively, you could place a small piece of crumpled tissue inside the bag to keep the sides apart. Lubricating the inside of the bag with baby oil or a special gel may help the motion to drop to the bottom of the bag. For further advice, speak to your stoma care nurse.



#### Sore skin

Red and inflamed skin around the stoma can be due to damage caused when removing the flange/base-plate. Using an adhesive remover may help to prevent this. With a two-piece or drainable bag, the flange/base-plate remains in place for several days which reduces skin damage. We produce a factsheet listing medical adhesive removers which you can download from our website or obtain by calling us.

Sore skin can also result from contact between the bag contents and your skin. Stomas can change in size and shape. You should check the size of your stoma every few months in order to ensure that the hole in the flange/base—plate fits snugly and your skin is not exposed. If the problem continues, consult your stoma care nurse who can advise on special products that can heal the skin and do not interfere with the adhesion of the bag.

#### Rectal discharge and discomfort

It is normal for ostomates who still have their rectum in place to pass clear or putty—coloured mucus from their anus. Even though motions now pass out through the stoma, the rectum continues to produce the mucus that was previously used as a lubricant to assist the passage of food and waste. Over time, the amount of mucus produced will decrease.

Following stoma surgery some people continue to experience the sensation of rectal fullness and feel as if they need to pass a motion in the normal way. Sitting on the toilet may provide some relief.

Further information download or call for a copy of our booklet on Rectal Discharge.

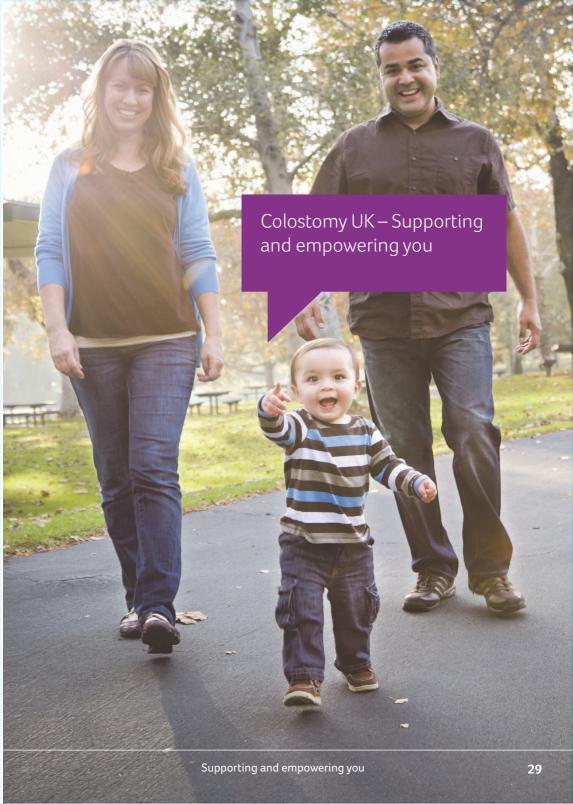
# Colostomy UK support literature and factsheets

### Our range of Support literature includes:

- · Active ostomates
- An introduction to irrigation
- · Campaign and projects
- Caring for a person with a stoma and dementia
- Colonoscopy through the stoma
- Healthy eating
- · Ovarian cancer and stomas
- Pain and discomfort.
- Parastomal hernias
- Rectal discharge
- Stoma reversal
- Travel advice and travel certificate

#### **Factsheets:**

- Clothing suppliers:
  - High-waisted trousers
  - Bag covers
  - Support garments
  - Swimwear
  - Underwear
- Manufacturers of stoma bags
- Stoma accessories:
  - Deodorants
  - Products which may help to reduce pancaking
  - Products which may help to prevent leakage
  - Medical adhesive removers
  - Solidifying agents
- Suppliers of stoma bags
- Travel insurance



### Support organisations

Below are a list of organisations providing information and support for associated medical conditions.

#### The Ostomy Support Organisations

• IA – The Ileostomy & Internal Pouch Support Group

Freephone: 0800 0184724 E-mail: info@iasupport.org Website: www.iasupport.org

#### Urostomy Association

Tel: 01386 430 140 E-Mail: info@urostomyassociation.org.uk Website: www.urostomyassociation.org.uk

#### Breakaway Foundation

Tel: 01283 240 253

E-mail

info@breakawayfoundation.org.uk

Website:

www.breakawayfoundation.org.uk

# Organisations providing advice on practical aspects of living with a stoma

#### Benefits Enquiry Line

Freephone: 0845 7123 456

E-mail:

dcpu.customer-services@dwp.gsi.gov.uk

Website:

www.nidirect.gov.uk/information-andservices/money-tax-and-benefits

#### Carers UK

Advice line: 0808 808 7777 E-mail: advice@carersuk.org Website: www.carersuk.org



#### **Organisations** providing information and support for associated medical conditions

#### Cancer

Bowel Cancer UK

Website: https://www.bbuk.org.uk Helpline: 0161 214 4591 Email: bbuk@disabledliving.co.uk

**Macmillan Cancer Support** Helpline: 0808 808 0000

Website: www.macmillan.org.uk

#### Crohn's Disease & Ulcerative Colitis

Crohn's and Colitis UK (formerly NACC) Information line: 0845 130 2233 Support line: 0845 130 3344 E-mail: infoaCrohnsandColitis.org.uk Website: www.Crohnsand Colitis.org.uk

#### Incontinence

Bladder and Bowel Foundation

Helpline: 0845 345 0165

E-mail:

info@bladderandbowelfoundation.org

Website: www.bladderandbowelfoundation.org

Bladder and Bowel Community

Website: https://www.bladderandbowel.org

Email: help@bladderandbowel.org

#### Information on other bowel conditions

e.g. Diverticular disease, Hirschprung's disease available from:

**Guts UK** 

Website: https://gutscharity.org.uk Helpline: 0300 102 4887

This booklet is intended for general information and guidance only. Colostomy UK would like to take this opportunity to thank:

Wendy Osborne – Association of Stoma Care Nurses (ASCN) UK, Education Officer, Jo Sica – Clinical Nurse Specialist – Stoma Care and Laura Swanton – Colorectal Physiotherapist

for their assistance in the production of this booklet.

**Colostomy UK's** flagship magazine *Tidings*, is hailed by ostomates and healthcare professionals alike for the support and information that it provides readers with on a quarterly basis.

Visit our website or call us to sign up for your free copy.

### How to contact us

**Write to:** Colostomy UK,100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD

**Adminline:** 0118 939 1537 **Stoma helpline:** 0800 328 4257

**E-mail:** hello@ColostomyUK.org **Website:** www.ColostomyUK.org













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