Action Bladder Cancer UK

# Living with a Urostomy

## PATIENT TIPS

**These tips are from bladder cancer patients, both men and women, who have had a cystectomy and are living with a urostomy. These are in their own words and their comments apply to their own situation – they may be of direct help or you may find things are different for you – but it is all direct patient experience and provides practical tips and hints to help with everyday life**

### At first...

When you're first told you have cancer, and you may need to have your bladder removed, there is a lot to take in. It may seem too soon to worry about how to live with a stoma, but it can help to think about it early on and try to learn as much as you can.

Everyone is different, and each person finds their own tips and tricks for living with a stoma. However, it soon becomes part of everyday life, with rarely any need for anyone else to know that you have a stoma.

We've tried to give you a lot of tips based on our individual experiences of learning to live with a urostomy. But please don't despair when you read this - it doesn't mean you will experience never-ending issues and problems! It is just not like that in daily life - but from time to time issues do arise, and we feel that a reference of practical tips and advice like this would have been really helpful for us to turn to in the early days. But please remember - we don't all get every problem we've listed here and, once you've got used to things and got your own routine, life can go on much as before. It can be a bit daunting when your journey is starting. Be willing to try new things and be prepared for sometimes things going wrong.

Here are some tips from those who have already started their life with a urostomy.

## Before the op

- If you're lucky, you'll be offered the chance to try out a stoma pouch (the stick-on bag to replace your bladder) before you're admitted for your cystectomy (the operation to remove your bladder). If you're not - ask for one, as it is well worth the effort to try it out at home before your admission. Many hospitals provide a kit which even includes a (not very realistic) stoma. Or several pouch suppliers will give you one if you ask. It helps enormously for when you experience the real thing for the first time.
- It's unlikely that any of the doctors or nurses looking after you has a urostomy themselves, so their knowledge of living with one is somewhat limited. Try to find out as much as you can from sites such as this, from patient stories on the suppliers' websites, or attending any support groups you can find. If you pick up just one really good tip from those living with a urostomy each time you visit, it's worth it.
- You may find some gentle exercise to strengthen your core will help you recover from surgery and help to reduce the possibility of a hernia. You can find suitable ones from several pouch suppliers' websites.
- Prior to the op, a doctor or nurse will mark up where the stoma will sit on your stomach. It's usually on the right hand side, but could go on the left hand side if, for example, you're a right handed professional guitar player.
- Also, it's worth thinking about where your clothes normally sit on your waistline - you don't really want the stoma slap bang under your belt. It's usually better to have the stoma below your belt, even if that means abandoning hipsters, as then there's nothing to interrupt the flow of urine into the pouch. So don't be reluctant to ask where the pouch is being marked up, and why, once it's there it's not easily moved.

## Recovery and getting home

After surgery, it will take some time to get your strength back. A recovery nurse or physiotherapist will usually help you get back on your feet and walking (including stairs) as soon as possible. Your first shower could be exhausting (but worth it!), and you'll be shown how to change your pouch a few times. You'll be expected to change it successfully yourself before being discharged. And the stoma nurse looking after you in hospital will provide you with an initial kit for a few pouch changes, as well as setting up a delivery service for you. However, it's important to remember that, after your discharge, it's up to you to arrange future prescriptions through your GP.

Your hospital stoma team will also arrange a handover to the community stoma team for ongoing support, and you may well get a home visit quite soon after discharge to see how you are doing. If your local hospital is a cystectomy centre then the level of community care will usually be very good. If not, then it may well be worth asking for a stoma nurse who specialises in, or has a specific interest in, urostomies. This is because most stomas are colostomies (a colostomy bag collects waste from the bowel) and therefore many stoma nurses tend to be much more familiar with them. There are significant differences in caring for urostomies.

## Urostomy (stoma) supplies and prescriptions

It varies from place to place how you get your stoma supplies (pouches, night bags etc). The usual situation is that stoma nurses in hospital will help you get started whilst you are an inpatient and they'll provide you with a small stock of the items you need to take home. They will also link with the community stoma nurse team to set up a more regular ongoing supply for you.

Again, it can vary - but most stoma nurse teams have links with a whole range of product suppliers and have samples of different types of pouches (urine bags), leg and night bags and accessories for you to try, if necessary, as you - and they - work out exactly what works best for you. Everyone's stoma is unique - and shapes of body vary of course - as well as lifestyles and activities. They will help you to find which combination works best for your body and needs.

Stoma nurse teams usually have a strong link with firms that specialise in being able to supply and deliver your equipment, and they will set up your first delivery with them direct. They may also link with your GP practice and agree how you will be able to order subsequent deliveries of whatever equipment you need. You may need to order your monthly prescription for your equipment in your usual way (by phone or online). You might have to send your prescriptions yourself to your supplier or, if you are able to do so, it may be possible for your GP surgery to send your prescription electronically to the supplier without you having to do so. Sometimes, the supplier may deal directly with the GP practice and you just have to call the supplier to tell them exactly what you need.

Most of the suppliers will also offer you some additional 'free' items to make life easier. This usually includes dry and/or wet wipes and disposal bags but can include other helpful accessories such as mattress protectors, scissors, hand sanitisers etc.

Over time, your stoma, the skin around it and your body shape may change a little and you may need assistance from your stoma nurse to get the best fitting pouches and related pieces of equipment to keep things working well.

As with everything else, it does become routine and once established isn't too much of a problem. But it can be a little daunting at first. Make sure you ask for help from your stoma nurse or your GP practice if you need it.

## Going back to work

How quickly you can get back to work depends in part on your general level of fitness, the operation itself, and the type of work you do. If you have a relatively sedentary job, such as an office job, you could be back to work quite quickly. However, if you have a more active job it will take longer to build up sufficient strength. As you've had a hole made in the muscle wall of your tummy for the stoma, there is a risk of developing a hernia. Most clinicians will probably give you a lifetime weight restriction of between 5 and 10kg. This can affect a wide variety of surprising jobs, eg a chef could find it difficult to manage heavy professional pots and pans. It is important not to rush into lifting heavy objects too quickly, so no ironing or hoovering to start with, and be careful with heavy shopping or in the garden! You may find a special hernia belt for those with a stoma can help - ask your stoma nurse or pouch supplier for guidance.

If at all possible, explore the possibilities of varying your work with your employer to reduce the need for handling heavy objects as early as possible. If you think this may affect you, ask your GP or hospital team to point you at sources of advice, or try your local Citizens Advice Bureau for help, especially if you're concerned about the financial implications.

## Toilet breaks

- There are choices of pouch/urine bag size - small and large capacity. You may use one or the other all the time or might decide on which size to use according to what it is you plan to do. Perhaps if you're travelling, or need to attend a long work meeting or training event, you might decide to use a larger pouch/bag. You could also add a leg bag to your pouch if you're wearing trousers.
- Even if you always use the larger capacity bags, you're likely to need to empty it into a toilet more frequently than when you used to - when you had a bladder. If you're working, you need to make this clear to your employer who should be happy to ensure you can have more regular toilet breaks etc.
- Planning ahead and preparation will help you avoid most difficulties or potential embarrassments. Let people know that you may need to go to the toilet sooner or more often that might be usual for others. It's easier to explain your needs ahead of time rather than to have to rush out in the middle of a meeting or training event. It might be that you really don't want to miss anything important or you forget that you do need to empty before your urine bag gets too full - and then you may realise that you have a very full bag that needs emptying straight away.
  If you warn people beforehand, you might find it's easier to have to leave the room quickly rather than have a leak to deal with.
- The same applies out of work, when you are out and about. You will need to develop a discreet way of being able to check how full your urine bag is to ensure you do manage to empty it in time.
- It's always best to go to the toilet before any situation where you don't want to have to be disturbed, such as the doctor, a hospital appointment, a bus journey, etc. I personally never knowingly pass a toilet without going in!
- I plan journeys and (safely) adjust fluid consumption ahead of time – that is, I don't overdo the fluids if I know I will have a toilet free gap to deal with. And carry an emergency option - an empty bottle or night bag and attachment for those times when the best laid plans go astray - for example when stuck in traffic or when toilets are closed or occupied. It's worth asking to use staff toilets in shops or other public buildings before you feel desperate. You may want to carry a card showing that you need urgent access to a toilet, and you can get these from the *useful links* provided at the end. I carry one for reassurance but have never had to show it to anyone.
- It's always good to choose where you sit if you're going to be there for a while, such as in meetings or gigs and music events or the cinema. Opt for a seat near the door or at the back of the room or near an aisle close to the exit and the toilets. You can then excuse yourself without disturbing others - and get yourself first in the toilet queue whenever there is a break.

# Pouch management

## Why this section

How you manage your pouch is probably the most important way to ensure a comfortable day-to-day life without the embarrassment of unexpected leaks. We've divided this section into 3 parts:

- **when to change your pouch;**
- **how to change your pouch;**
- **which pouch to use.**

## When to change your pouch

- The usual timescale for changing your pouch is two days (i.e. change every other day). But some people are more comfortable changing it every day. A few manage to keep their pouch on (without any leaks) for longer. It may depend on how active you are, or how the weather has been (e.g. if the weather's warm or you're on holiday in a hot country or when you've been swimming in the sea every day etc). You'll work it out, with time and experience.
- Most people find that changing their pouch first thing in the morning works best. Your body should then have emptied itself of most of your urine which may help with avoiding unwanted 'spurts'.
- Shower or bath - before or after or even whilst in the shower or bath, sitting down at your bedside or standing up in your bathroom - it's a matter of personal preference, the practicalities of where you live and finding what works for yourself. And yes - you just might need to get up a bit earlier on the days when you change your pouch.
- You can adjust the changing day to fit in with your commitments. You may find that you prefer to change your pouch before travelling or when you plan to go out socially, to make sure you have a good attachment. As the days go by between changing your pouch there is probably more of a possibility of developing a leak – you will get to know how long you can go between changes without having a problem.
- You could, if you're really keen, have a look at **https://www.bladderbowelandstomahandbook.com/**, which lists all the stoma products approved by the NHS.
- Although it's usual that, once you have a successful combination of equipment and products in place and working well, you don't want to make changes – and that is fine.

## How to change your pouch

- Some people like to change their pouch with the aid of a mirror, which might mean standing in front of the bathroom mirror or using a portable mirror to be able to see what you're doing. In time, many of us are comfortable to change without a mirror judging the fit by eye. For those that are hairy in the abdominal area, you may need to shave around your stoma on a regular basis – perhaps once a week. This requires a slightly altered routine and extra caution when using a razor.
- Simple soap and water to aid shaving is preferable to using other shaving products. It's probably best to use a fragrance-free soap without too many extra ingredients. I use a non-skin drying soapless soap for sensitive skin, such as Hopes Relief Soap-Free Cleansing Bar.
- I used to be keen to replace my old pouch as quickly as possible, to try to avoid any unplanned spurts onto myself or any of my equipment. But now I tend to take more time. I find that an extra 5 to 10 minutes can make a big difference. First of all, I delay having anything to drink prior to changing my pouch, even if I'm desperate for a first cup of tea. And then I spend a little time moving about – cleaning teeth etc – to encourage any urine in my body to drain away before I change my pouch. A little cough or two also helps to extract any last urine. I use a barrier spray mostly and, again, after I've cleaned the area and dried it ready for the next pouch, I'll use the spray and wait for a few minutes to make sure it's really had a chance to fully dry – before I apply the replacement pouch. I find that the extra time taken is very worthwhile and helps to ensure a good bond and helps to avoid leaks.

## Pouch management (continued)

- It helps your pouch to adhere to your abdomen if the baseplate (the side with the hole in it for your stoma) is warmed up before you put it on. There are various options to do this effectively. You can hold the pouch against your body with the baseplate next to your skin, for example under your arm. Another option is to sit on it whilst you are removing the 'old' pouch. What I do is put the baseplate down under the small metal bowl that I fill with warm/ hot water to use to clean around the stoma once I've removed the old pouch. I also put my stoma paste into the water (cap on the tube) to warm up and wipe any mucus off with damp wipes that have been soaked in the water and wrung out. You'll find a method that suits yourself best – but warming it up does help.
- Another important thing to remember after you've put your new pouch on is to try to avoid too much bending over or physical exertion generally for a little while – perhaps half an hour – until your new pouch has had time to get firmly attached.

## Which pouch to use

- Over the years, I've changed the make and 'style' of pouch that I use on several occasions. Your stoma nurse will help you with getting a pouch that fits well to the individual shape of your abdomen. Some have a standard baseplate, others have a convex or concave baseplate, depending on whether your stoma is in a little 'depression' or on a little 'hill'. Your stoma will usually reduce in width within a short period (a month or two perhaps) after your operation so it may be necessary to change the size of the opening. Again, your stoma nurse can help you to ensure the right size and shape of the hole for your stoma. Body shapes can change over time as we put weight on or lose it and this can require a change of fit or style.
- Pouches come in different sizes (capacity) – some people prefer to use the smaller option as it has a slimmer profile under clothing. This may be helpful in a work situation, sporting activity or social outing for example. Others are happy with the larger versions – and prefer the greater capacity and less frequent emptying – which may be helpful when travelling. Again it's a matter of personal preference, lifestyle and practicality. And there is no reason why you can't use a mix of the two according to need.
- When it comes to pouch manufacturers, there is a problem with incompatibility of different manufacturers' equipment. For example, you may find that pouches made by Firm A do not connect easily with night bags made by Firm B. However, there is usually an adaptor that can make a suitable join between the two so that you can choose to use equipment from whomever you wish or are recommended. The firm making the pouches and/or the night bags will provide the right connector if you ask.

Like everything else, products do change over time and new models come out. It may be helpful for you to check this out periodically.

- Occasionally, you may find that the manufacturer has made changes to your usual equipment that means you want to look at alternatives. Most manufacturers will provide free samples of their products for you to test out if you want to. But it's probably best to check with your stoma nurse first before doing so. Some manufacturers will ask you who your stoma nurse is and contact them direct to check with them.
- You can also look at alternatives in magazines, such as the quarterly Urostomy Association journal, which has ads from most of the equipment manufacturers with their range of products, or anything new that has come out. You could also attend one of the promotional events organised by local stoma nurse teams or support groups, with a range of manufacturers displaying their product range.
- You could, if you're really keen, have a look at **the bladder, bowel and stoma handbook** which lists all the stoma products approved by the NHS. You can find it in the *useful links* section at the end.
- Although once you have a successful combination of equipment and products in place and working well, you won't want to make changes – and that is fine.

## Leaks

- Be prepared to have leaks. Some are inevitable, especially in the early days when you are still learning how best to look after your stoma and change your pouch. If you get into the habit of carrying the essentials you need to change a pouch, together with a change of clothes, you will feel far more confident to get out and about. I use a small rucksack with a minimal pouch changing kit, a lightweight pair of summer jeans, a shirt and spare underpants. Even though now I rarely need it, I find it immensely reassuring to have it with me, or close by in the car boot when I'm out.
- Most people experience a few leaks initially, as you develop your own routine and method for changing your pouch successfully. But you shouldn't have many leaks later on when you have your correct pouch and system in place.

Do seek advice from your stoma nurse if you are still having regular leaks after a month or two.

- If you have a large stoma (perhaps bigger than 35mm diameter), then the hole in the baseplate of the pouch will need to be quite large, thus reducing the area left to stick to your skin. Try ordering flanges with your pouches, which extend the area to stick down.
- Get to know where the public toilets and disabled toilets are in your area, including those in shops, pubs and restaurants. You may find a toilet card and a radar key invaluable in an emergency – see *useful links* at the end.

## Leaks at night

- The first leak I had in bed was devastating, and I was extremely upset for days. I had never previously wet the bed. Again, the best advice is to be prepared - make sure you have a pouch replacement kit to hand, in the bathroom perhaps, fresh bedding in the airing cupboard, and, if you have a partner who sleeps through everything, a torch! A big help is an effective but comfortable waterproof sheet. I use one from HippyChick, which has the huge advantages that I'm totally unaware it's there, and that you can tumble dry it. See *useful links* at the end.
- Night bags are not usually a problem with leaking, but what can happen is that you either forget to close the tap at the bottom or not quite fully closed it, and that can result in leakage out of the tap during the night. It isn't very nice to wake up to a little pool of urine at the side of your bed!! It usually only ever happens to you once - and you then always remember to double check each night when attaching the night bag. Some of us have our night bag resting in some sort of container, a bowl or small bucket, just in case. I use a highly absorbent pad under the night bag at home and when travelling, as that's easy to pack. Some people like to have their night bag attached to a stand to make it easy to carry but I prefer to let it just lie in the bowl that I use. I find that the lower the top of the night bag (where the tube enters) is below you (in bed) the better the drainage is likely to be.
- When you attach a night bag it's a good idea to ensure that there is some urine still in your pouch. When you attach the night bag, the urine from your pouch should rush into your night bag and will create a vacuum in your pouch which should mean that the urine passed overnight will be drawn into the night bag. Night bags are usually a lot bigger in capacity than your pouch (usually about 2 litres) and this should mean that you may be able to drink without a problem until late into the evening without the prospects of having to get up in the night - one of the benefits of having a stoma.

- I have found that night drainage bags fitted with non-kink tubing work much better than the standard options. These seem to be available only from Coloplast – you can find them in the *useful links* section at the end.
- You may want to explore a product called U-Drain which does away with the need for night bags by providing suitable tubing to connect your bag directly to the soil pipe. Both installation and supplies are free with an NHS prescription. It is not suitable for installation in every home. It works best if there's a very short length of pipe required, as the system has to clear mucus from your stoma as well as urine, which could block the pipe if its quite long. I found it excellent for four years, before it blocked up. As my installation needed long and complicated pipework, I now use nightbags. If it is successful for you, it does have the advantage that pretty much unlimited amounts of urine can be discharged without disturbance. Details are under *useful links* at the end.

## Looking after your stoma

- When you change your pouch, you may notice some slight bleeding from around the stoma. This is normal and is almost never cause for concern. The stoma is similar tissue to the inside of your mouth, so it can bleed quite easily. Treat it gently.
- If blood is discharged from the stoma outlet itself then that is potentially serious, and you should seek urgent help.
- Some people are trouble free so far as skin irritation or soreness is concerned. Others may experience ongoing or periodic issues. Contact your stoma nurse if you have skin problems; they can usually come up with some suggested actions to help. Checking the fit of your pouch around your stoma is the usual first step. There are some specialised creams that may help – but you need to seek advice rather than trying without guidance. On a rare occasion a change of pouch may actually be the solution. Pouch manufacturers advertise their pouches as having various skin-friendly ingredients incorporated into their pouch baseplate and just by changing the make of pouch and baseplate may be enough to let your skin recover.
- If you develop a crease or little 'moat' around your stoma it is possible to use one of a variety of pastes and seals that can fill the crease/dip and help make a good seal when you apply your bag. Your stoma nurse will be able to advise you as to what might work best.

## Going back in hospital

- If you're due to have a procedure of any significant length in hospital or another health setting, it may be worth asking if you can attach a night bag and having one available to hand. This could be especially helpful if you have been advised to drink fluids prior to the procedure. I have experience of not doing so and encountering a very full pouch. And I've also mistakenly not drunk before a procedure to avoid this issue, and then had problems afterwards ending up with a urinary tract infection (UTI).
- Most hospital nurses are not trained in stoma care, so it's best to take everything you need into hospital with you. I found that, even on the urology ward in my local hospital (not a cystectomy centre), the agency night staff had no idea what to do with night bags. On my first night a night bag was jammed into my pouch opening without an adapter, which meant that in the morning when the night bag was removed the closure would not work, necessitating a pouch change. Not great if you're ill and the only one around who knows how to do it.
- If this is a planned hospital visit, it is well worth while tracking down the hospital stoma team in advance (perhaps attached to the gastroenterology department) to let them know you're being admitted and may need help.

## Diet

- You don't need to change your diet in any way because you have a urostomy. ABC UK have an information sheet on Healthy Eating under *useful links*.
- However, it is essential to drink plenty of fluids every day, as this is the best possible protection against getting a urinary tract infection (UTI). These can be extremely serious and could require a hospital admission, so do drink plenty of water.
- Eating healthily is also a good idea to help with your general health and well-being.

## Leisure, exercise and sport

- I have not found any barriers from having a urostomy in enjoying the activities I did before. I started with weekly Pilates classes and now do a daily aerobics/conditioning circuit routine. I've completed a half marathon for Cancer Research UK. ABC UK have an information sheet on Exercise under *useful links* at the end.
- We have travelled extensively including snorkelling on the Great Barrier Reef, climbing up hundreds of steps out of the deeper tombs in Egypt's Valley of the Kings, and regular walks in our beautiful local countryside. I've never been into contact sports such as rugby or football, but even contact sports are possible with a stoma protector and a suitable stoma support belt, both available through urostomy suppliers - not for quite a few months after surgery, and not before checking with your GP or stoma nurse, obviously. Finally, I enjoy frequent socialising with friends, and have been known to enjoy a drink too...
- When eating out at a table, and especially if you are in a group and engaged in conversation, you may be bending forward more than is usual and this can restrict the normal flow of urine down into your pouch. Be aware of this and perhaps consider emptying your pouch more often than usual, or check and straighten up in your seat periodically to allow normal flow. You might even be able to discretely loosen your clothing at the waist to reduce constriction – but do make sure you remember to redo anything you have loosened before or immediately once you stand up.

## Clothing - what to wear

When you first get home, you may find that your normal clothes don't fit, but don't rush out to change your wardrobe – your normal clothes should soon fit when the initial swelling goes down.

### WOMEN

- Knickers with 'light control' can help to minimise the look of the bag under clothes as they hold the bag close to the body. Perhaps try to avoid the heavier control ones as you may find they constrict the bag.
- Try different kinds of knickers to find what works for you – some people may find higher waist ones that cover the bag more comfortable.
- It is useful to wear a slip under dresses as they help to hold the dress away from the urostomy bag
- Leggings are useful to roll up as a spare in handbags as they don't take up much room and are useful to have in an emergency in case a leak occurs.
- When wearing jeans or trousers, high waisted work better, as they don't then interfere with the stoma.
- In a fitted dress, buy a size bigger and have the top taken in, as this helps to stop the bag being visible across the middle as there is slightly more fabric there.
- Loose tunic or shirt style dresses work well
- A patterned fabric hides the bag better than a light plain colour, black also hides the bag well.
- Board shorts look good with a bikini or swimsuit to hide the bag without looking obvious. Sarongs also work well if you are not going into the pool.

### MEN

- Having a spare pair of underpants and a shirt or T-shirt as a minimum in case of emergencies may suffice. They roll up easily and you rarely end up with very wet trousers if you do have a leak – a loose top may be enough to cover any spoilage on your trousers until you can change. But do include some crease-resistant trousers, lightweight jeans or track suit bottoms if you can.

- Personally, I wear exactly what I've always worn with no changes at all, so don't think you will necessarily have to adapt in the ways we describe here. Some people wear their pouch inside their underwear. You may find this restrictive and that it also makes it more difficult to extract your tap when you need to empty, especially if you use a urinal in public toilets. If you use 'normal' underpants then you can just fold down the waistband so that it sits comfortably below your pouch and allow your pouch to hang unrestricted outside your underpants and inside your trousers/shorts.
- You can buy high waisted trousers/shorts for men, but you can manage with standard versions – perhaps with a waist size bigger than usual to allow a bit more room for your pouch. You can also buy elasticated waist trousers (including from M&S) which provide more 'give and take'. Or you may find you can manage with standard ones – but maybe leave the top fly fastening open or add an elastic fitting to make it more expandable.
- You may find some trouser belts restrictive, or you may be able to wear them looser than usual but enough to make sure your trousers/shorts stay up. Braces work for some people. It's very much a personal choice, but you may find that wearing your shirt outside your trousers is more comfortable – and provide some screening for your slight bulge caused by your pouch.
- Pyjama trousers present challenges when it comes to arranging night bag tubing and the connection to your pouch. It helps drainage through the night to have the pouch, connector and tubing as flat on the bed as possible. Old fashioned bottoms with a draw cord work well as you can leave the fly open, fold the relevant side down out of the way and the pouch and tube can lie much flatter to make draining of urine easier. To avoid the bottoms falling down when you get up you can tighten the waist by tying a knot in the cord at both sides. If you can't find that style, then making an adjustment to the fly arrangement of more modern pyjama bottoms can achieve the same result. Some come with a button fly and they work well; those without a fly can be adjusted with a bit of cutting and sewing (and perhaps adding of a button or two) to get the right fit. Or try pyjamas with a short sleeved top and shorts - works great, including in hospital.
- For swimming costumes or shorts, high waisted versions are available to buy but don't always look very good. It's increasingly possible (and acceptable socially) to use standard ones and just allow your pouch to show above the waistline. If you are worried about appearance then you can always wear a vest top or T-shirt over standard swimming trunks/shorts.

## Travel and insurance

- Always travel with a set of spare pouch requirements – pouch + wipes and anything else you might need – in some sort of bag or container. And, for any significant travel distances, it is advisable to have some basic replacement clothing (eg. some underwear and some sort of top and bottom garment). It's much easier, of course, to have a full change of clothing available if you are travelling in your own or someone else's car.
- Carry a wide necked sports drinks bottle in the car when travelling, in case you can't get to a toilet, as it is relatively easy to empty the pouch into a wide necked bottle. Alternatively attach a night drainage bag when travelling (provided it is out of the way of the pedals if driving). This is also useful when being transported on a coach from the airport to the hotel, or even when flying. It's easy to hide the nightbag inside a shopping bag.
- As someone with a urostomy, you are entitled to have a radar key to enable you to access public disabled toilets. They are available from Disability Rights UK, but they can also usually be obtained from your equipment supplier or the Urostomy Association. You may get some odd looks when you enter or come out as your 'disability' isn't obvious – but you are entitled and it is much easier to change your pouch and to manage a change of clothing if you need to. You could also carry a toilet card, although I've never had to use mine. Both can be found under *useful links* at the end.
- You could obtain a sunflower lanyard to signify a hidden disability. This will mean that you can ask not to queue in airports for example, or anywhere else, so that you are not worrying about needing the toilet. Again, see *useful links* at the end.

- It's usually suggested that you should take twice as much of your essential pouch and equipment requirements as is usual when on holiday or away from home for a period. This allows for accidents/ leaks and such issues as delayed flights, hot climates, holiday activities, frequent swimming etc. And it is also advised that in hot countries you store your pouches in a cool place if at all possible.
- Always pack medical supplies, including urostomy pouches, in your hand luggage when travelling, and have a copy of a current prescription with you in case you are stopped. Ring the airline's special assistance line when you have booked your flights and ask them to seat you near to the toilets if you'd find that useful. Some airlines charge for this, others don't. All airlines will allocate an extra 10kg of hand luggage for your medical supplies only, if required.
- Unless you have access to a toilet throughout your journey, it may be helpful to manage your fluid consumption by moderating your consumption of liquids in the hour or two prior to travelling, remembering to catch up with your hydration and fluid intake once you have arrived.
- Consider when you change your pouch before you travel. Is it best to have a newly attached pouch perhaps? This may depend on what time you are setting off but ensuring a good attachment that day may be helpful. And, if you have put a new pouch on, try to allow some time to let it properly attach before doing a lot of luggage lifting remembering to avoid lifting anything over 10kgs to avoid getting a parastomal hernia.
- Whilst you can purchase special safety belt additions for when you are driving, you may find that a small cushion in front of your stoma area is sufficient. And, if you are a passenger in someone else's car and don't have your usual arrangement– then you can improvise and perhaps use your coat or something else that's fairly soft as a substitute. Personally, I've never felt the need to add anything to a seat belt.
- When travelling on holiday you may find it helpful to purchase one or two collapsible camping type plastic bowls – a larger one to put your night bag in overnight or perhaps a smaller one to use for changing your pouch. They squash down and take up much less space. They are available from several outlets and online.
- Another option for your night bag is to use a thick plastic bag (duty free bags are good for this purpose) without any holes and attach it to the sheet at the side of your bed with a couple of large safety pins. Then safely pop your night bag in to avoid any potential for spillage.
- For international travel, get a multi-language travel certificate to show you have a stoma. Security staff in most countries recognise them and allow for the pouch showing up on x-rays or body searches. Despite extensive international travelling, I've only ever been searched once (in a private room), and on all other occasions have been waved through on showing the certificate. They are available from several suppliers, and I got mine from StomaWise UK – look under *useful links* at the end. You will need to get it stamped and signed by your GP, so plan ahead.
- In the very unlikely event that you get stuck or seriously delayed abroad, it's a good idea to take the local contact details of your stoma equipment supplier. Almost all of them distribute internationally, and they will be happy to give you details of how to obtain your usual supplies in an emergency whilst you're abroad. Don't forget to take a full copy of your regular order!
- Your usual travel insurance company may add additional cover for your urostomy for a reasonable charge. If not, there are a number of travel insurers worth trying who specialise in travelling with various illnesses – see under *More Information* at the end.
- Travel insurance with bladder cancer is available, but you must shop around. Some premiums are high or unobtainable in certain circumstances, for example if you are waiting for the results of key diagnostic tests, are waiting for surgery, or have been told that your illness is terminal. Even in these circumstances it is possible to find insurance tailored (and priced) according to your exact needs. You may find it harder to get cover if you are taking part in a trial. Do not, under any circumstances, travel abroad without adequate insurance - it is definitely not a risk worth taking.

  You could use an insurance broker who will shop around on your behalf. An advantage to this is that you only have to go through your medical history once, but there is no guarantee that any policy they suggest is the most suitable for you, or good value.

## FINALLY...

We've tried to list some things that we would have found helpful ourselves when we first had a urostomy or encountered a problem. Not all of these tips will apply to everyone – so please don't feel that you are bound to experience some of the issues mentioned here, you may not – we just wanted to list what we could and hope this can help others. You may also find your own best way of doing things.

Good luck and we hope you enjoy your new life to the full.

And remember: if you are experiencing problems or have questions do seek help – you shouldn't have to put up with discomfort or difficulties and there could well be a way to solve your problem or to improve things. You can always speak to your medical team in hospital, your community stoma nurse or your GP. We have listed some helpful links below.

Of course, you can always contact ABC UK if you have specific issues or questions – our contact details are at the bottom of this sheet.

**Disclaimer: Any reference to specific products are made by individual patients and are not directly endorsed by ABC UK.**

## Useful links

You may find the following links helpful:

Sunflower Lanyards: **https://hiddendisabilitiesstore.com/**

Radar Keys: **https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key**

Bladder & Bowel toilet card: **https://www.bladderandbowel.org/help-information/just-cant-wait-card/**

Macmillan Toilet Card from Macmillan at **https://be.macmillan.org.uk/be/p-24952-macmillan-toilet-card.aspx**

List of all Stoma Products (aimed at clinicians):

**https://www.bladderbowelandstomahandbook.com/**

Hippychick: **https://www.hippychick.com/categories/waterproof-bed-protectors/ waterproof-mattress-protector-flat-cotton-sheet**

U-Drain: **http://www.u-drain.co.uk/**

Anti-kink night bags: **https://products.coloplast.co.uk/coloplast/continence-care/simpla/simpla-profile/simpla-profile-bedside-drainage-bag/**

Travel Certificate: **http://www.stomawise.co.uk/stomawise-store/stomawise-travel-certificate**

## More information

As well as information about bladder cancer and treatments, you can also find your nearest bladder cancer patient support group on our website. We mentioned the following ABC UK information sheets – you can find them on our website, links below, or ask us for print copies:

### Cystectomy:

**http://actionbladdercanceruk.org/library/directory_listings/77/CYSTECTOMY%20AND%20 BLADDER%20SUBSTITUTES%202019.pdf**

### Healthy Eating:

**http://actionbladdercanceruk.org/library/directory_listings/83/HEALTHY%20EATING%202019.pdf**

### Exercise:

**http://actionbladdercanceruk.org/library/directory_listings/82/EXERCISE%202019.pdf**

### Other charities and organisations

have information about the operations and life afterwards that may be helpful, too.

- **The Urostomy Association** has information and a list of suppliers at **https://urostomy association.org.uk/**
- **Cancer Research UK** at **http://www.cancer- researchuk.org/about-cancer/bladder- cancer/ treatment/invasive/surgery**
- **Macmillan Cancer Support** at **www.macmillan.org.uk/information-and- support/bladder-cancer/invasive-bladder- cancer/treating/surgery/surgery-explained**
- **The British Association of Urological Surgeons (BAUS)** has produced some helpful leaflets – you can find them at **www.baus.org. uk/patients/information_leaflets/category/3/ bladder_procedures**. The leaflet called 'Living with a urostomy' lists some delivery companies
- **European Association of Urology Nurses (EAUN)** at **https://patients.uroweb.org/bladder-cancer/**

### Shops and Suppliers

- **Live Better With Cancer** at **https://livebetter with.com/** is an online shop that also has blogs and information.
- **SOS Talisman** at **www.sostalisman.co.uk** supplies medical information jewellery.
- **MedicAlert** at **www.medicalert.org.uk** is a charity that supplies medical alert items, such as bracelets
- **The following companies are examples of insurers offering travel insurance to those with cancer (we do not specifically recommend any of these):**
  All Clear Travel: **https://www.allcleartravel.co.uk/travel-insurance/cancer/**
  Free Spirit: **https://www.freespirittravelinsurance.com/medical-conditions/cancer/**
  Insure Cancer: **http://www.insurecancer.com/**
  MIA Travel: **https://www.miatravelinsurance.co.uk/**
  Staysure: **https://www.staysure.co.uk/medical-travel-insurance/**
  An example of a travel broker specialising in pre-medical conditions is **Orbis Insurance Services** (**https://www.orbisinsurance.co.uk**)