

# Returning home following your bowel cancer operation

An information guide



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Being discharged from hospital can be an anxious time and you may feel worried about what to do if you don't feel 'right'. Many people worry about how they will cope at home and are unsure of what to expect. Everyone recovers differently depending on their age, type of operation and previous level of fitness. It is normal to feel physically and emotionally exhausted following surgery and it can take several weeks, or even months to fully recover.

The information in this booklet aims to help you understand the changes in your body and how to find ways to manage them. It also explains what to expect in your colorectal cancer follow-up journey and how you will be supported in managing your own health.

**If you don't feel well or develop any of the following symptoms within the first 48 hours of going home, please contact your colorectal/stoma nurse specialist or ward staff**

- Increased abdominal pain not relieved by medication.
- Your wound looks red, warm to touch or develops a smell or discharge.
- Persistent diarrhoea nausea or vomiting.
- A high output of fluid from your stoma.
- A high temperature or feeling feverish.
- Unable to eat or drink.

Colorectal nurse specialist \_\_\_\_\_

Stoma nurse \_\_\_\_\_

Ward \_\_\_\_\_

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## **Information prescription**

The information needs of people with bowel cancer vary from person to person. An information prescription is an individualised way of providing relevant information tailored to your needs at the appropriate time.

It prevents you from being overwhelmed with too much information, much of which may not be of interest to you. If you would like any booklets, fact sheets or details of support groups please ask your specialist nurse.

## **Getting active**

### **The first few days**

For the first few days at home you should get plenty of rest. Keep to a routine, get out of bed and get dressed every day. Walking is an excellent form of exercise after your operation. Walking helps to reduce the risk of chest infections and blood clots, it improves strength and reduces anxiety.

Walk around the house and up and down the stairs. Remember that even gentle pottering about can leave you feeling tired. Returning to normal is a gradual process. Aim to have a short walk outside every day gradually increasing the speed and distance of your walk.

Avoid heavy lifting whenever possible for the first 6 weeks to allow your body to heal. As a guide do not lift anything heavier than a kettle full of water.

**The first 4 weeks** - Start with light activities such as washing up, dusting and preparing meals.

**After 4-6 weeks** - Increase your activity to include changing the bed, ironing and hanging out washing.

**After 6 weeks** - Resume your normal activities such as light gardening, low impact exercise, dancing, bowling and longer walks

**After 8 weeks** - If you feel up to it you can begin more strenuous exercises such as swimming, golf and most other sports.

## **Driving**

Don't drive until you feel fully confident you can perform a quick movement and an emergency stop. This is usually between 4 to 6 weeks after your operation. Do not drive if you are taking strong painkillers which may affect your concentration.

Check with your insurance company as some insurers will not provide cover for a period of time following major surgery.

## **Changes in bowel function**

In the early stages of recovery, your bowel or stoma will be sensitive.

Following surgery many people have changes in how their bowel works. Part of your large bowel has been removed, making it shorter than before, so stools pass through more quickly and can be loose and frequent.

It can take many months for the bowel to settle down but most people find that, with time, symptoms become manageable. Although your bowel habits may not go back to how they were before treatment most people establish a new pattern.

Try to eat small regular meals, chew food well and avoid skipping meals. Drink water frequently throughout the day and reduce the

amount of tea, coffee, fizzy drinks and alcohol. Common problems include:

- Going to the toilet several times a day (frequency).
- Rushing to the toilet when the urge to pass a stool comes on (urgency).
- Leakage of stool.
- Difficulty emptying the bowel completely.
- Excessive wind.
- Loose stools or diarrhoea.
- Constipation.

### **Slowing the bowel down**

If your stools are soft, and you are going to the toilet frequently, avoid foods high in fibre for the first few weeks. Too much fibre too quickly can cause diarrhoea, wind and bloating.

Slowing down the passage of stools through your bowel will help to reduce the frequency and firm them up, making it easier to control. Fibre is important to regulate how the bowel works. There are two types of fibre -insoluble which speeds up bowel motions and soluble which helps to firm up and slow down bowel motions.

### **Limit these foods if you have diarrhoea or soft frequent stools**

- Bran, seeds, wholegrain/wholemeal/multigrain cereals and bread.
- Some fruits - grapes, apricots, plums, peaches, prunes and berries.
- Vegetables - especially beans, broccoli, sprouts, peas, cabbage, onions, peppers, sweetcorn, spinach and garlic.
- Greasy or fried food.
- Spicy food- chilli, curry.

- Caffeine in coffee, tea, chocolate drinks, cola and energy drinks.
- Chocolate.
- Alcohol.

Introduce these foods back into your diet gradually as your bowel slows down.

### **Foods that can help firm up motions**

- Porridge oats.
- White bread, boiled white rice and pasta.
- Apples and pears (with skins removed) bananas, mashed potatoes.
- Chicken and fish.
- Yogurt, smooth peanut butter and marshmallows.

If changes to your diet are not enough to control the bowel you may also need anti- diarrhoeal tablets or soluble fibre supplements.

### **Loperamide or Imodium**

This is the most commonly used anti-diarrhoeal medication. It is safe to take over long periods of time and is non-addictive. It is useful to firm up the stools and reduce diarrhoea. Loperamide works by slowing down the passage of food through the gut and encouraging the body to absorb more water from the waste in the large bowel.

### **What dose should I take?**

Start on a low dose (1 tablet =2mgs loperamide) and build up slowly over a few days until your bowels are more manageable. The more you take the firmer your stools will become. If you take more than

you need you may feel constipated. Maximum dose 8 tablets in 24 hours.

It is best to take one tablet half an hour before a meal, as this will slow down gut activity stimulated by eating. If your bowel is most active in the morning take a tablet before breakfast. It will work within ½ hour and is effective for 8-12 hours. A further tablet at bedtime can help early morning frequency.

## **Fybogel**

This works by absorbing water, making the stool bulkier and easier to push out, so it helps with frequent bowel motions, leakage and incomplete bowel emptying. Sachets can be taken 1 or 2 times a day. Make sure you drink plenty of water and avoid if you are taking strong painkillers such as codeine, tramadol or morphine.

## **Faecal incontinence**

Having surgery that involves removing part of the rectum can damage the muscles wrapped around the anus (sphincters) so that you cannot squeeze enough to stop yourself passing a stool.

Surgery can also damage the nerve supply to the muscles, giving the brain the wrong signals. This makes it difficult to tell if you need to pass wind or stool. If you have had an accident and cannot control your bowels it is a natural reaction to tense all your muscles, hold your breath and rush to find a toilet when you get the urge. It is better to sit or stand still, breathe deeply and squeeze your anal sphincter until the urge passes.

Exercises to control your sphincter muscles can help strengthen them to improve bowel control and stop leakage of gas or stool. The more you do the exercises the stronger and more efficient the muscles will become. Ask your colorectal nurse specialist for details on sphincter exercises.



## **Controlling wind**

After your bowel operation you may produce more wind and feel bloated. Sitting still for long periods of time can cause discomfort. Try to move about or change position every 30 minutes. This will help to avoid a build-up of wind that can get trapped in the bowel.

You may have less control over when you pass wind if your rectal muscles are weaker or if you have a stoma. The amount of wind that certain foods can cause varies from person to person but it is usually foods high in fibre. Try experimenting with different foods to see what suits you.

Keeping a food diary can be helpful to eliminate the foods that cause excess wind. Try to eat slowly and chew food well. Eat little and often rather than one large meal.

## **Foods that may cause wind**

- Sprouts, broccoli, cabbage, beans, onions, spinach, sweetcorn, cauliflower and cucumber.
- Dairy products, rich fatty food.
- Nuts, lentils, bran, spicy food.
- Beer and fizzy drinks.
- Chewing gum.
- Sorbitol - a type of sugar found in some artificial sweeteners as well as apples pears and peaches.

## **Medicines which can make or increase wind**

Metformin, antibiotics, beta-blockers, magnesium in antacids, anti-inflammatory pain killers such as voltarol and ibuprofen, some anti-depressants such as venlafaxine and citalopram and also fybogel and lactulose.

## **Also try these tips**

- Peppermint oil capsules, peppermint water/tea, charcoal tablets.
- Live yoghurts and probiotic drinks can also be helpful.
- Eat regularly and sit down to eat.
- Drink water little and often.

## **Wound care**

Some discomfort around the wound is normal. Take painkillers regularly and continue to do so until you can breathe deeply, cough, sleep and move around without discomfort

Your wound will go through several stages of healing. To start with it may be tingling, itchy or numb. It may feel thick and lumpy as new tissue forms. You may also feel it pull as it heals. Rubbing a little baby oil around the area can help to soften the skin.

It is safe to have a bath or shower (unless you have been told not to) but avoid very hot water, bubble bath and antiseptic until the wound is fully healed. Remember if the wound is painful, discharging, smelly or red contact the district nurse, ward staff or specialist nurse for advice.

## **Tiredness (fatigue)**

This is the most common side effect of bowel cancer surgery. Think about what you have been through - worry and uncertainty about your cancer diagnosis, undergoing a major operation and being discharged from hospital after a very short time. You may lack energy and find even the smallest tasks exhausting. Rest often does not make it better. Fatigue can last for many months after treatment has finished. It can be linked to other problems such as depression, pain, disturbed sleep, anaemia or low levels of oestrogen, testosterone or thyroid hormones. It is important to

find out if there is another cause for your fatigue so that it can be treated. Speak to your GP, consultant or specialist nurse if your energy levels do not improve over time.

Fatigue can make it more difficult to do the things you enjoy and can affect your mood and relationships with other people.

## **Ways to help yourself**

Regular exercise can reduce fatigue and build energy levels. Start with short walks and increase the distance slowly. Exercise can help you sleep better and improve anxiety and depression

Complementary therapies can help to reduce stress and anxiety.

Keep to a routine. Try not to stay in bed too long after you have woken up and go to bed at the same time each evening.

Eat small light meals rather than large meals.

Accept all offers of help from family and friends with shopping, housework, gardening etc.

## **Lifestyle choices**

As they start to fully recover from their bowel cancer surgery most people want to improve their general health and do all they can to help reduce the risk of the cancer coming back. The government recommends :

- Giving up smoking.
- Avoiding drinking large amounts of alcohol at one time.
- Getting 30 minutes of exercise a day and avoiding sitting for long periods.
- Reducing the amount of processed foods high in sugar, fat, salt and preservatives when you eat.

- Increasing the amount of fresh food you eat including a wide range of fruit and vegetables.
- Eating small portions of high quality protein; fish, white meat, lean red meat, soya or tofu.
- Drinking plenty of water to help digestion and to avoid dehydration
- Taking gentle exercise to help relieve stress and anxiety and improve concentration, low energy and sleep.

## **Sex**

Many people lose interest in sex as a result of cancer and bowel surgery. The side effects of treatment can leave you feeling anxious about resuming sexual activity. Having a stoma or unpredictable bowel habits can have a big impact on the way you feel about your body or how you perceive your partner to feel. It is safe to resume sexual activity when you feel ready but you may want to start with cuddles and kisses to re-establish intimacy.

## **Going back to work**

After treatment for bowel cancer you may find it difficult to do the same type of work as you did before. Perhaps the workplace does not allow extra toilet breaks or you don't have the same amount of energy or confidence. Often, the side effects of bowel cancer do not end straight after treatment and it can take a long time to return to your old self and carry as before. If you would like help with getting back to work speak to your specialist nurse who can refer you to an employment specialist.

## **Your bowel cancer follow-up programme**

Soon after your operation the results of an examination of some of the tissues which has been removed (histology) will be discussed at the colorectal multi-disciplinary team meeting (MDT). This will help your team to decide if you need any further treatment and the level of monitoring you will require. You are usually given the opportunity to discuss this with your specialist nurse after the MDT meeting or at your first post-operative appointment with your consultant.

## **Treatment summary**

At your first outpatient appointment you will be given a copy of your treatment summary, which will include the stage of the cancer, the treatment you have received, side effects and signs of recurrence. It will also explain how you will be followed up in the future, depending on your diagnosis, general health and personal circumstances. A copy of the treatment summary will also be sent to your GP.

## **Health needs assessment**

The impact of bowel surgery can affect all areas of your life from changes in bowels, eating, mobility, emotions, relationships, work and finance. Having a health needs assessment (HNA) at the end of treatment can help you identify any concerns or needs. This will be discussed with you at your first outpatient appointment.

## Notes



**If English is not your first language and you need help, please contact the Interpretation and Translation Service**

Jeśli angielski nie jest twoim pierwszym językiem i potrzebujesz pomocy, skontaktuj się z działem tłumaczeń ustnych i pisemnych

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@ : interpretation@pat.nhs.uk

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