Manual

For physical activity specialists supporting people with a stoma.

IA®
The ileostomy & internal pouch
Support Group

Bowel & Cancer Research

1. Introduction

1

The physical activity specialist delivering this physical activity programme will ask at the first physical activity consultation what (if any) advice and guidance participants have had about physical activity from the bowel cancer care team and other sources.

The physical activity specialist can build on this advice and/or provide different advice.

This manual describes a physical activity programme for people living with a stoma.

The purpose of this manual is to provide information and instructions to facilitate the delivery of the 12 week physical activity programme.

Throughout this manual, we refer to the people who deliver the physical activity programme as **physical activity specialists.**

In order to use this manual, you need to have a Level 4 cancer and exercise qualification provided by for example Canrehab (canrehab.co.uk) and to have attended the training event about physical activity and stoma.

We refer to the people recovering from bowel cancer surgery, and people with inflammatory bowel disease (IBD) with a stoma who are participating in the physical activity programme as **participants.**

The physical activity programme described in this manual is based on the most recent research about:

- Health benefits of physical activity for people recovering from bowel cancer surgery, and for people with IBD
- Safe exercises for people with a stoma
- Theories of behaviour change to promote physical activity and compliance with the programme

This physical activity programme has been developed by a team of researchers led by Dr Gill Hubbard, University of the Highlands and Islands. The programme is being evaluated with funding from Bowel and Cancer Research (http://www.bowelcancerresearch.org), and the Ileostomy and Internal Pouch Support Group (IA) http://www.iasupport.org

The programme has two key components:

1. Physical activity consultations with a physical activity specialist
2. Community and home-based physical activity and exercises

Guidance for delivering these two key components is provided in this manual.

Who are the participants?

This physical activity programme has been developed for people recovering from bowel cancer, and people living with IBD who have a stoma.

The programme can start from **6** weeks after stoma surgery. Patients who have chemotherapy or radiotherapy after surgery can start the week after their last course of chemotherapy/ radiotherapy. When participants wish to start the programme may however, vary. Participants with IBD can start when they are fully recovered from surgery. A recommended time for this is also 6 weeks. If you are unsure, please discuss this with your medical team.

Participants should also follow advice and guidance from their medical team about physical
activities pre- and immediately post- surgery.

Definition of physical activity

Physical activity is any activity carried out throughout the day that involves movement, such as walking, housework, gardening and taking the stairs.

Exercise is a specific kind of physical activity, such as cycling, swimming or running. During the physical activity consultation and goal-setting, both physical activity and exercise may be included.

Ileostomy
Photograph: St Mark's Hospital

2. Snapshot of physical activity programme

2

The physical activity specialist will provide individual consultations and provide bespoke physical activity prescriptions for each participant.

Participants
People at least 6 weeks from bowel surgery who have a stoma.

Purpose
Promote physical activity to improve health and well-being.

Duration
12 weekly 30-60 minute physical activity consultations for 12 weeks.

If the physical activity specialist is on annual leave or off sick or if the participant is on holiday or unwell then a short break in the programme will happen and will resume straight after.

Procedure
Weekly physical activity consultation face-to-face or video conferencing (e.g. Skype, Cisco Spark) depending on participant preference and Internet facilities at home.

Location
Community and home-based physical activities or leisure centre depending on participant preference.

FITT principles
Frequency and **I**ntensity and **T**ime will increase gradually through the 12-week programme. **T**ype of physical activities will be based on participant preference.

Prescription
The prescription in this manual is generic, and broadly suggests working towards 5 sessions per week of:
• 30 minutes for aerobic activities,
• two sets of 12 repetitions for muscular strength and endurance, and
• flexibility and balance activities – each stretch held for up to 60 seconds

However, in practice weekly prescriptions for physical activity will vary from one participant to the next.

3. Condition overview

Bowel Cancer

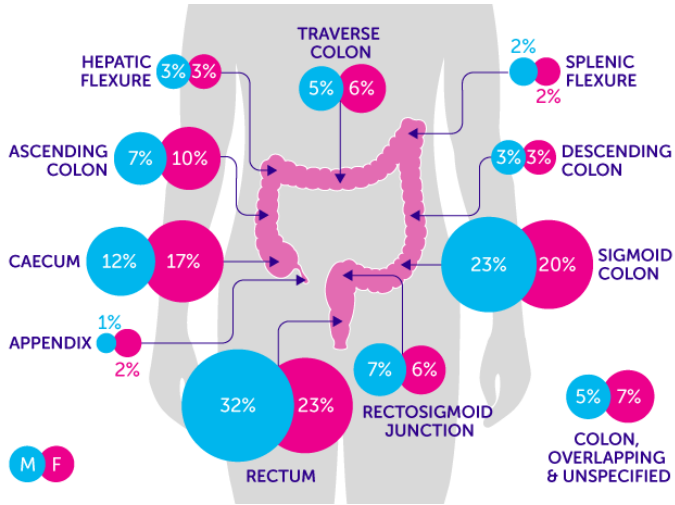
Bowel cancer is the second most frequently diagnosed cancer in women and the third most frequently diagnosed cancer in men, with approximately 40,000 new case registrations each year [(1)]. Almost three-quarters of cases occur in people aged 65 or over.

Bowel cancer means cancer that starts in the colon (large bowel) or ileum (small bowel) or back passage (rectum). Most bowel cancers occur in the rectum. It is also known as colorectal cancer.

When a person has a colostomy or ileostomy the end of his or her bowel is brought out into an opening on their abdomen. The opening is called a stoma. This is usually formed during the planned bowel resection operation to allow time for the bowel to heal.

Approximately 83 per cent of rectal cancer patients have a stoma formed at the time of surgery [(2)].

Distribution of cases diagnosed by anatomical site, UK



Cancer Research UK, http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer/incidence#heading-Four

Inflammatory Bowel Disease

3

The physical activity specialist delivering this physical activity programme should encourage participants to contact their stoma nurse if they have any specific questions about the stoma and stoma care. A stoma nurse can approach a physiotherapist to support participants to improve their physical functioning.

Crohn's Disease and Ulcerative Colitis (UC) are the two main forms of Inflammatory Bowel Disease, affecting more than 300,000 people in the UK. IBD is a chronic condition, and may be diagnosed as early as young adulthood. The symptoms experienced are very individual and range from mild to very severe.

A wide choice of medication are available to manage IBD, and to relieve the associated symptoms. Although the condition and its symptoms can change over time, with periods of well-managed disease, mixed with spells of more severe symptoms.

If symptoms become difficult to manage, and quality of life is being affected, then surgery is often discussed. It is estimated that 8 out of 10 people with Crohn's Disease will need surgery at some point in their lives, and up to 1 in 4 people with UC.

The stoma

The stoma does not hurt because it has no nerve supply.

The surgeon stitches the end of the large bowel (colon) to a hole cut in the abdomen. This is called a colostomy. The waste from a colostomy is usually more formed than from an ileostomy, as it has had some of the water removed on its way around the bowel. The waste passes out of the colostomy and is collected in an external pouch (generally known as a colostomy bag).

The small bowel is called the ileum. The surgeon stitches the end of the small bowel (ileum) to a hole cut in the abdomen. This is called an ileostomy. The food waste passes out of the ileostomy and is collected in an external pouch (generally known as an ileostomy bag).

There are different types of stoma (e.g., colostomy or ileostomy) which may be temporary or permanent. The person might have a temporary stoma. The patient will have another operation to close the stoma. This is called stoma reversal.

A bag stuck onto the skin over the stoma collects bowel liquid, semi solid stools and wind. This is usually called a stoma bag or an appliance.

Ileostomy
Photograph: St Mark's Hospital

Stoma nurse

Stoma care nurses are registered nurses who have acquired additional knowledge, skills and expertise in the speciality. They provide comprehensive holistic care to people who may require a bowel or urinary stoma.

They provide support and information to enable those with newly-formed stomas to achieve independence in managing their stoma after surgery.

Stoma care nurses counsel patients contemplating stoma surgery, preparing them for what life will be like having a stoma. They train individuals on how to care for their stoma and change their stoma appliance. They offer guidance on a range of issues including; nutrition, finances, work, relationships, and travel. Support is usually on-going through provision of telephone helplines and drop-in clinics.

What stoma should look like

A stoma should be red, warm, moist and the spout should be flush.

Colostomy
Photograph: St Mark's Hospital

4. Physical activity guidance

After Bowel Cancer

People treated for bowel cancer improve their chances of living a longer healthier life if they are physically active. An increasing body of evidence summarised in meta-analyses and systematic reviews [3-5] has linked physical activity during and/or following treatment for bowel cancer with improved survival.

People who are physically active have a better quality of life. There is insufficient evidence about the psychosocial benefits of physical activity for people treated for bowel cancer [6]. Nonetheless, meta-analyses and systematic reviews have summarised the large body of evidence about the psychosocial benefits of physical activity for people with different types of cancer [7].

Physical benefits of physical activity in people with cancer include improvements in cardiorespiratory fitness, body composition (i.e. muscle mass and bone health), immune function, strength and flexibility, and reduction in nausea, fatigue and pain. Psychological benefits include body image, self-esteem, mood, stress, depression and anxiety.

Accordingly, professional bodies in different countries, including the UK, have published detailed physical activity prescription guidelines for people with cancer [8-12]. For instance, the British Association of Sport and Exercise Sciences recommends that: 'Unless advised otherwise, cancer survivors should follow the health-related physical activity guidelines provided for the general UK population' [8].

These professional bodies concur that people recovering from any type of cancer – including bowel cancer – should, if possible, aim to meet national physical activity recommendations for the general public. However, most people recovering from cancer are not physically active [12,13].

The majority of people recovering from surgery for bowel cancer are 65 years of age and over. The next section presents physical activity guidelines for the older adult.

For IBD participants

Some people with Inflammatory Bowel Disease will have a stoma, along with on-going disease and its symptoms. Concerns and barriers such as low energy and fatigue, fear of stoma leakage, and fear of hernia can be a strong barrier to becoming physically active.

Exercise has benefits on the immune response, and a growing body of evidence suggests that exercise may improve disease activity, quality of life, and fatigue levels in patients with IBD (REF - Engels M, Cross RK, Long MD. 2018. Exercise in patients with inflammatory Bowel Diseases: Current perspectives. Clinical and Experimental Gastroenterology 11: 1-11)

Further evidence and research is needed to demonstrate the ideal types of exercise for this population.

Physical activity guidelines for older adults

4

The physical activity specialist delivering this physical activity programme will aim to have each participant meeting the UK physical activity guidance recommendations for older adults by the end of the 12 week physical activity programme. To meet this aim, progressive goals will be set on a weekly basis (see Section 6).

However, this may be an unrealistic aim for some participants, and a more appropriate end-point for the 12 weeks will be set accordingly.

Physical activity guidelines for older adults (aged 65 years and over) are particularly relevant to the target group (i.e., people recovering from bowel cancer who have a stoma) because the majority of people diagnosed with bowel cancer are older adults.

1. Older adults (aged 65 years and over) who participate in any amount of physical activity gain some health benefits, including maintenance of good physical and cognitive function. Some physical activity is better than none, and more physical activity provides greater health benefits.

2. Older adults should aim to be active daily. Over a week, activity should add up to at least 150 minutes (2 hours and 30 minutes) of moderate intensity activity in bouts of 10 minutes or more – one way to approach this is to do 30 minutes on at least 5 days a week.

3. For those who are already regularly active at moderate intensity, comparable benefits can be achieved through 75 minutes of vigorous intensity activity spread across the week or a combination of moderate and vigorous activity.

4. Older adults should also undertake physical activity to improve muscle strength on at least two days a week.

5. Older adults at risk of falls should incorporate physical activity to improve balance and co-ordination on at least two days a week.

6. All older adults should minimise the amount of time spent being sedentary (sitting) for extended periods.

Individual physical and mental capabilities should be considered when interpreting the guidelines.

Department of Health, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213741/dh_128146.pdf

5. Physical activity consultations

5

The physical activity specialist delivering this physical activity programme will deliver 1 physical activity consultation each week for 12 weeks face-to-face or by video conferencing.

Participants will receive one-to-one physical activity consultations with the physical activity specialist either face-to-face or by video-conferencing (e.g. Skype), depending on participant preference.

The idea of it being face-to-face or video conferencing is so that physical activities can be clearly demonstrated and participants can practice under the supervision of a physical activity specialist who will be able to advise on posture etc.

This level of supervision may be particularly important for participants who are anxious about being active (see section 16).

Consultation is a good delivery mode for the intervention because studies of physical activity preferences conducted in Canada and Norway of mixed cancer diagnostic groups suggest that counselling is a preferred mode of delivery of a physical activity programme. Evidence suggests that more than half of people recovering from cancer are interested in counselling for physical activity [15-17].

Participants will be given an individual weekly physical activity consultation at a time and place convenient for them.

The consultation length may vary from one week to the next and from one participant to the next but on average will be approximately 30 minutes.

The consultation will be conducted in accordance with self-determination theory (see Section 10).

6. Consultation conversations

6

Physical activity specialists will demonstrate how to perform physical activities safely, and observe participants performing activities.

The specialists will conduct a weekly review, to assess if the participant has progressed and support them to do so.

The physical activity programme incorporates core techniques recommended by the National Institute for Health and Care Excellence (NICE) for exercise referral for people who have a health condition or other health risk factors. This includes agreeing goals and actions plans, monitoring progress and providing feedback, and tailoring behaviour change techniques to individual circumstance and need.

The consultation also involves demonstrating how to perform particular activities safely – this is especially important for the abdominal exercises.

Each consultation will assess progression during the previous week and ascertain any presence or change in stoma- or bowel cancer- related difficulties and discuss issues relating to safely engaging in physical activity in the context of recovering from surgery for bowel cancer and having a stoma.

Physical activity achievements will be acknowledged, barriers discussed, and subsequent physical activity goals agreed upon. Continued self-monitoring of physical activity will be encouraged and supported by use of a weekly physical activity diary completed by participants and pedometer.

During the consultation, physical activity specialists should ask participants about their surgery and the stoma appliance. Where is it? Where does it sit? How will this affect the activities you choose? Are there any particular concerns about being active with the stoma?

Below, is a quick guide for a consultation conversation

Encourage participants to describe the physical activities they did the previous week. This will help determine current activity levels so you can support the participant to set appropriate activity goals and set the right pace for achieving them.

In particular, talk about the activities that they ENJOYED because they are more likely to do these again.

Discuss any stoma/health-related problems with a focus on safe engagement in activities.

Help them address their fears and concerns by assisting them to come up with solutions e.g. finding a walking route in their local area where they pass a toilet facility that they can use.

Anticipate any other general barriers for being physically active (e.g., lack of time, weather, lack of self-discipline).

Encourage them to set goals for the coming week ahead.

If they seek your advice about activities do not be afraid to give it because you are the expert in physical activity but also ask them what they think.

7. Physical activity prescription

7

Physical activity prescription will be progressive and will be unique to each participant. Physical activity specialists will teach participants about monitoring intensity and help them set SMART goals.

The physical activity specialist will complete the "Physical Activity Prescription" with the participant during the consultation which can be found in the participant's "Physical Activity Diary". The specialists should retain a copy (e.g., take a photo-shot) for their own records.

The physical activity specialist will not supervise participants when they are actually engaging in the prescribed physical activities.

Nonetheless, the physical activity specialist will ensure that participants know how to engage in physical activities safely and show them how to monitor intensity during activities using the Rate of Perceived Exertion (RPE) Scale (see below).

If the participant has wearable technology (e.g., fitbit/strava/ applewatch) which includes heart rate monitoring, the physical activity specialist will assist in setting the intensity zone at which the participant should be exercising.

The physical activity prescription (comprising aerobic, muscle strength and endurance, and flexibility activities) will be progressive with a view to participants moving towards achieving national recommendations for physical activity by the end of the 12-week programme (but please note, that goals will vary from one participant to the next).

Physical activity specialists work with the participant to create a programme of physical activity for each week. This is called the physical activity prescription. The weekly prescription is recorded in the 'Diary' (see section 13).

In terms of FITT principles (frequency, intensity, time and type), current recommendations concerning the adaptation/ progression of the physical activity prescription for patients state that the first component to be progressed is the duration for each component of the physical activity programme followed by frequency, and finally, intensity.

During the initial phase of the 12-week programme, an increase in duration of aerobic activities per session of five to 10 minutes from baseline every one to two weeks over the first four to six weeks of a physical activity training programme is reasonable for the average adult.

After the participant has been engaging in regular physical activity for a month or more, the frequency, intensity, and/or duration of activities can be gradually increased over the next four to eight weeks - or longer for older adults and very deconditioned persons - to meet the recommended quantity and quality of physical activity.

Therefore, founded on baseline physical activity levels, the participant will be given a programme which will increase incrementally in duration until:

- 30 minutes for aerobic activities most days of the week,
- two sets of 12 reps for muscular strength and endurance of the large muscles of the body e.g., quads, hamstrings, pectorais major, Latissium dorsi at least twice a week
- flexibility and balance activities most days of the week.

Borg Rate of Perceived Exertion Scale

6		**How you feel when lying in bed or sitting relaxed.**
7	**Very, very light**	
8		
9	**Very light**	
10		
11	**Fairly light**	
12		
13	Somewhat hard	How you should feel with exercise or activity
14		
15	Hard	
16		
17	Very hard	How you felt with the hardest work you have ever done
18		
19	Very, very hard	
20	Maximum exertion	Don't work this hard.

Goal Setting

A key component of the physical activity consultation is supporting participants to set their own goals.

It is important that the physical activity specialist does not tell the participant the goals. The role of the specialist is to provide advice and guidance (see section 10). Ask the participant for feedback, and suggestions. Work together.

SMART goals:

Specific - Ensure that any prescribed physical activity activity prescription is well defined.

Measurable - The goal must be clear for the period of time; for instance, increase steps by 1000 this week, or walk 5 extra minutes each day. Use numbers that are measurable.

Agreed upon - This is important, and should be controlled by the participant.

Realistic - Goals that are not achievable will be demotivating for participants. Conversely, goals that are too easy, will not provide a target to reach for.

Time-appropriate - Discuss short term goals for next week, but it is also worth looking at aims for the end of the 12 week programme.

Goals are identified in the weekly activity prescription you and the participant agree on.

8. Type of physical activity preferences

8

The physical activity specialist delivering this physical activity programme will prescribe weekly physical activities that will be unique to each participant.

We suspect that walking (e.g. from home to the shops and back) will be a key component of the aerobic element of the programme.

This is because participants are likely to be over 65 years of age, have multi-morbidities and the recent treatments for bowel cancer are likely to have exerted a negative impact on their confidence to engage in other forms of physical activity.

If so, appropriate warm-up activities will be included prior to the home-based aerobic component. The muscle strength and flexibility activities will also be incorporated into the home programme.

It is also likely that the IBD group will be in a younger age group, and potentially have the ability to increase the exercise load more than the bowel cancer patients. This will, of course, be assessed on an individual basis.

If preferred by the participant, he/she may attend community-based physical activity classes and be physically active as part of a group (e.g. circuit training or participation in a walking group). Otherwise, the participant will be physically active in their own home and local vicinity such as their local park.

Exactly which activities will be performed individually or in a group will be agreed during the physical activity consultation and will vary from one participant to the next.

9. Benefits of physical activity for people with a stoma

9

The physical activity specialist delivering this physical activity programme will recommend and plan aerobic and muscle strengthening and physical activities.

Section 4 outlined the benefits of physical activity for people with bowel cancer, and for inflammatory bowel disease. In this section, the benefits of people with a stoma are presented.

Aerobic

Aerobic training can help patients maintain a healthy weight.

This is important for people with a stoma because obesity causes undue strain on the rectus abdominis and according to the Association of Stoma Care Nurses is therefore a risk factor for parastomal hernia [18].

Colostomy UK recommends that patients avoid gaining weight to help avoid parastomal hernia [19].

Aerobic training improves cardiorespiratory function and has positive effects on the immune system and inflammatory markers - essential if people with bowel cancer are to experience the health benefits associated with activity post-bowel cancer diagnosis [5, 6, 20].

Muscle strengthening

There is currently a lack of robust research evidence about what kind of abdominal activities and at what intensity people with a stoma can do safely and how much this could reduce their risk of hernia formation.

Nonetheless, the UK Association of Stoma Care Nurses recommends core muscle exercises to strengthen the abdominis in order to prevent parastomal hernia formation [18].

The Association of Stoma Care Nurses and others including the Colostomy UK, advise against lifting heavy objects since this may cause a parastomal hernia.

We discuss stoma hernia in Section 15.

10. Motivating people to be physically active

10

The physical activity specialist delivering this physical activity programme will use these techniques during the physical activity consultations with the participant. The physical activity specialist should not feel the need to cover all of the techniques in every session, but try to use all of them across the 12-week programme. The physical activity specialist may find it helpful to think about which techniques they are going to use in each session in advance, to ensure all techniques are covered.

Self-determination theory (SDT) proposes that behaviour is dependent on motivation.

Conditions that support a person's basic psychological needs - their need for 'autonomy,' (feeling they are the origin of the behaviour), 'competence' (feeling they are effective) and 'relatedness' (feeling they are being understood and cared for by others) - are argued to foster the most volitional and intrinsic forms of motivation for initiation and long-term maintenance of health behaviours [21, 22].

The literature provides general guidance to create an environment that will foster motivation such as 'encouraging participants to make choices about how to behave, providing them with the information they need for making the choices, and respecting the choices they make' [23].

In addition, it is possible from the literature to identify specific techniques and methods used within autonomous supportive environments to foster motivation [24, 25]. The techniques that will be used by the physical activity specialists will be as follows:

Autonomy

- Offering clear reasons to become more physically active
- Giving information to support decisions on different types of physical activity
- Giving a choice, with various options for being more physically active
- Encouraging enjoyment of physical activity by choosing activities that participants like doing
- Avoiding coercion and persuasion
- Encouraging participants to make their own choices (e.g. avoid controlling language, rewards, threats, external evaluation, and deadlines)
- Using neutral language (e.g., "may" and "could", and avoiding "should" or "must")
- Recognising barriers and conflicting feelings about wanting to be physically active
- Encouraging self-monitoring through use of a pedometer (and other devices). Self-monitoring is a common evidenced-based behaviour change technique and, if applied in a non-authoritarian style, is believed to foster autonomy
- Encourage setting time aside to include physical activity, with back up plans if this doesn't happen

Competence

- Discussing issues around exercising safely
- Individualising goals for ability and health
- Providing non-judgmental and positive feedback on progress
- Focussing on participants' strengths and acknowledge all (including small) achievements
- Giving support on how best to achieve goals
- Assessing the pros and cons of being physically active
- Helping with ideas to overcome stoma-related barriers to being physically active
- Ensuring that failure to achieving a given goal is viewed as a prompt to explore barriers and/or concerns to help future improvement

Relatedness

- Valuing all opinions discussed. Not judging progress by being negative or positive
- Acknowledging participants' feelings and perspective
- Giving positive feedback. (Feedback should not make participants feel they are being ‘tested’)
- Helping participants indicate their reasons to change their physical activity levels
- Showing genuine appreciation and concern for participants by devoting time, energy and resources to support them.

11. Behaviour change techniques to increase physical activity in older adults

11

The physical activity specialist delivering this physical activity programme will use these 3 behaviour change techniques (BCTs) during each physical activity consultation with the participant.

Other BCTs may also be used. The specialist will use their own judgement regarding which BCTs will work best for each individual participant.

People with a stoma who are recovering from surgery for bowel cancer are likely to be 65 years of age and over.

The IBD group are likely to be a younger population.

A recent systematic review [26] in non-clinical community-dwelling older adults found that 3 behaviour change techniques (BCTs) were associated with higher physical activity in this age group:

- Barrier identification/problem solving

  The person is prompted to think about potential barriers and identify the ways of overcoming them. Examples of barriers may include behavioural, cognitive, emotional, environmental, social and/or physical barriers.

- Provide rewards contingent on successful behaviour

  This can include praise and encouragement as well as material rewards but the reward/incentive must be explicitly linked to the achievement of the specific target behaviour i.e. the person receives the reward if they perform the specified behaviour but not if they do not perform the behaviour. This can include self-reward.

- Model/demonstrate behaviour

  This involves showing the person how to perform a behaviour e.g. through physical or visual demonstrations of behavioural performance, in person or remotely.

The authors [26] suggest that older people may be more concerned with enjoyable and sociable activities than reaching a particular level of performance with regard to physical activity.

12. Pedometers

12

The physical activity specialist delivering this physical activity programme will encourage participants to use the pedometer and record daily steps in their 'Physical Activity Diary.'

The physical activity specialists will [27]:

- provide the participant with a pedometer (the research team will supply these)
- describe the many health benefits of walking
- explain the motivational benefits of using a pedometer
- demonstrate how to use the pedometer
- encourage the participant to progress towards 10,000 steps every day
- create a plan to help the participant increase steps per day

Participants will be asked to record their daily step count as recorded by the pedometer within their 'physical activity diaries'. This will help participants to get a better sense of what they are already achieving and help them to improve on this.

The physical activity specialists will use these diaries to review progress and to support achievable and progressive goal setting for daily steps.

Using pedometers to set goals can enhance participant motivation and increase activity [28]. Physical activity specialists will explain that even increasing by 1000 or 2000 steps can have a positive effect if activity levels are low (which often they are after being treated for cancer, and after having invasive abdominal surgery). As a guide it takes about 10 minutes to walk 1000 steps.

In line with SDT (see section 10), research has shown that pedometer use leads to:

- increased autonomy (through supporting tailoring of walking activity),
- increased competence to achieve goals for steps (through providing feedback), and
- relatedness (surveillance of participants' steps can help participants to feel observed, yet supported) [29].

13. Physical activity diaries

13

When reviewing diaries, physical activity specialists will ensure that monitoring efforts are praised regardless of what is written down. If participants have struggled to fill out the diary, help to problem solve how they could manage over the coming week and reinforce how useful it is.

The pedometers will be used in conjunction with the "Physical activity diary" that the participant completes each week.

The diary will support self-monitoring and provide a useful tool for the physical activity specialists to use within sessions for monitoring progress and goal setting. Self-monitoring has proven to be an effective behaviour change strategy within physical activity interventions [30].

The Physical activity specialist and participant will agree on a programme of physical activity for each week. This is called the physical activity prescription and is written in the diary:

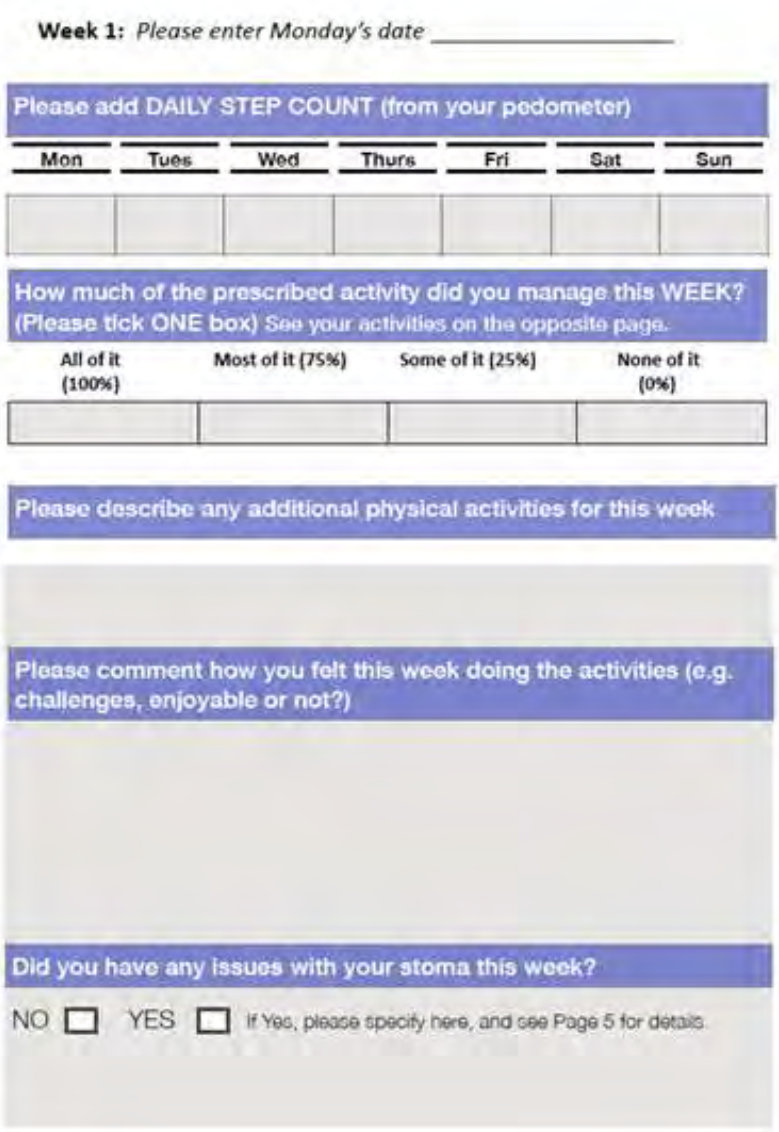
Physical activity prescription

Aerobic activities	Frequency and intensity

Muscle strengthening activities	Frequency and intensity

Flexibility activities	Frequency and intensity

Then, participants record in the diary if they managed to complete the prescribed programme for that week and record if they did any additional activities:



Week 1: *Please enter Monday's date* _____

Please add DAILY STEP COUNT (from your pedometer)

Mon	Tues	Wed	Thurs	Fri	Sat	Sun

How much of the prescribed activity did you manage this WEEK? (Please tick ONE box) See your activities on the opposite page.

All of it (100%)	Most of it (75%)	Some of it (25%)	None of it (0%)

Please describe any additional physical activities for this week

Please comment how you felt this week doing the activities (e.g. challenges, enjoyable or not?)

Did you have any issues with your stoma this week?

NO ☐ YES ☐ If Yes, please specify here, and see Page 5 for details

14. General precautions for physical activity in Bowel cancer patients

14

The physical activity specialist delivering this physical activity programme will discuss contra-indications for physical activity with the participant and prescribe each weekly physical activity goals accordingly.

Specialists should address multiple morbidities as they would if they were supporting a member of the general population to engage in physical activity.

Several contraindications for physical activity have been identified by the American Cancer Society, American College of Sports Medicine [11] and Exercise and Sport Science Australia [3]. This is applicable to participants who have likely had some treatments such as chemotherapy, and radiotherapy.

Precautions for physical activity that may apply to people recovering from bowel cancer are as follows:

- People with severe anaemia should delay exercise, other than activities of daily living, until the anaemia is improved.
- People with compromised immune function (e.g. low absolute neutrophil counts, when catheters or feeding tubes are being used, during wound recovery from surgery) are at increased risk of infection and should avoid public gyms and public pools until their white blood cell counts return to safe levels.
- People with ataxia, dizziness, or peripheral sensory neuropathy are recommended to avoid activities requiring balance and coordination (e.g. treadmill exercise, cycling) and specific resistance exercises such as those using free weights.
- When nausea, dyspnea (shortness of breath), fatigue and/or muscle weakness exist, exercise intensity and duration should be prescribed to tolerance.
- People with multiple or uncontrolled comorbidities need to consider modifications to their physical activity programme.

15. Precautions for stoma hernia

15

The physical activity specialist delivering this physical activity programme will discuss the importance of weight management and building core muscle strength to decrease the risk of stoma hernia formation.

The specialist will give participants the *Colostomy UK* booklet and/or the IA (The *Ileostomy and internal pouch support group)* booklet which illustrates safe exercises.

The specialist will discuss with participants the importance of avoiding **excessive** intra-abdominal pressure e.g. sit ups and abdominal crunches.

What causes a stoma hernia?

The hernia develops in an area of the abdominal wall adjacent to the stoma. When a stoma is brought out to the surface of the abdomen it must pass through the muscles of the abdominal wall, thus a potential site of weakness is immediately created. In the ideal situation the abdominal wall muscles form a snug fit around the stoma opening. However, sometimes the muscles come away from the edges of the stoma thus creating a hernia.

Factors that can contribute to causing a stoma hernia to occur include coughing, being overweight or having developed an infection in the wound at the time the stoma was made.

The development of a stoma hernia is often a gradual phenomenon, with the area next to the stoma stretching and becoming weaker with the passage of time. This weakness, or gap, means that every time one strains, coughs, sneezes or stands up, the area of the abdomen next to the stoma bulges, or the whole stoma itself protrudes as it is pushed forwards by the rest of the abdominal contents behind it.

British Hernia Association
https://www.hernia.org/types/stoma-hernia/

Physical activity recommendations

The Association of Stoma Care Nurses published Stoma Care Clinical Guidelines in 2016 [18]. These guidelines highlighted the following risk factor for hernia:

"Undue strain and force on rectus abdominis."

The guidelines also highlight the importance of regular physical activity and stressed that most people 12 weeks after surgery for a stoma can

"be as active as you wish to be."

The guidelines promoted pelvic floor and core muscle exercise regimes to decrease the incidence of stoma hernia formation.

The guidelines suggest avoiding sit ups or abdominal crunches.

The guidelines propose the following core muscle exercises as a minimal exercise regime which should start 2 to 3 days after surgery:

Abdominal Exercise (Lying)
With your hands gently resting on your tummy, breathe in through your nose and as you breathe out, gently pull your tummy button down towards your spine.
As you feel the muscles tighten, try to hold for 3 seconds and then breathe away normally.

Pelvic Tilt
Comfortably position your hands in the hollow of your back.
Tighten your tummy muscles as before, attend your lower back onto your hands and lift your bottom.
Hold for 3 seconds and then breathe away normally.

Knee Roll
Tighten your tummy muscles as before and gently lower both knees to one side as far as is comfortable.
Slowly bring them back to the middle and relax. When ready, repeat this movement to the other side.

Abdominal Exercise (Standing)
Stand with your back against a wall.
Tighten your tummy muscles and try to keep your back in contact with the wall.
Hold for 3 seconds and relax.

You should aim to do each of these exercises 5 times per day.
Do more repetitions as you feel able.

These exercises are illustrated in a booklet produced by **Colostomy UK** and a booklet by **IA** (*Ileostomy and internal pouch support group).* Physical activity specialists should give participants one or both publications. These are available for download or as hard copies from the charities (see section 18).

Currently, there is a lack of evidence about how a hernia can be prevented.

There have been a couple of research studies suggesting that a prevention programme can help people manage their risk of stoma hernia formation [31]. These prevention programmes had 3 key components:

- Awareness of potential for development of parastomal hernia
- Abdominal exercises to strengthen the abdominal muscles
- Using abdominal support belts while undertaking heavy lifting and heavy work for 1 year postoperatively.

Nevertheless, these are very small-scale non-randomised studies and so we currently do not know if any of this advice makes a difference or not.

Photographer:Aggie Banks

16. Solutions to address concerns about being active

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The physical activity specialist delivering this physical activity programme will discuss with the participants fears and concerns about being active with a stoma. Specialists will help participants develop plans to address their fears and concerns.

Participants may face a number of barriers to physical activity. Some participants may avoid public spaces because they think that other people will stare at the bag or they perceive that they smell bad.

These issues will need to be discussed in a sensitive manner and it may be worth helping participants develop a plan to address their fears and concerns.

These are some of the things that people with a stoma have found useful:

1. Wear a support garment, pouch belt or girdle or flange extenders. This can help keep the bag in place at all times, even if the adhesive starts to come away from the skin. This way may avoid embarrassment if the bag drops to the floor.
2. Wear a cotton pouch cover to help prevent any chaffing of the skin.
3. Take some spare supplies of bags and clothing with you in case of an emergency.
4. Consider getting specialised swimwear if you are concerned about the visibility of the bag.
5. Again, consider small pouches for use when swimming if you are worried about the visibility of the bag.

The stoma nurse should be able to help participants with pouch belts etc. and these can be on NHS prescription.

Some participants may find reading about the experiences of other people with a stoma being physically active helpful. There are Facebook groups, and websites founded and written by people with a stoma.

However, we also recommend that participants look at some of the resources listed in section 18.

17. Experiences of being active and useful tips

17

The physical activity specialist delivering this physical activity programme will discuss with participants people's 'top tips' for being active with a stoma.

Physical activity specialists must be able to support participants to be active with confidence. Participants need to know that their exercise specialist is aware of the kind of issues and concerns that they will have.

Many people who have a stoma are physically active. Below, are some of their experiences of being active and some useful tips.

Azmina Vejee was diagnosed with Crohn's disease when she was 10 years old and bowel cancer when she was aged 25. She has a permanent stoma. Here are her top tips:

1. The waistband of your shorts or leggings will need to be higher or lower to avoid restricting the stoma or bag. This is because effluent will 'pancake' (pancaking is when a vacuum occurs in the stoma bag and the bag sticks together, preventing the contents from dropping to the bottom) if there is too much pressure on the bag.
2. Activity triggers stoma activity and if you have a rectum in situ discharge of mucus and/or blood. This is normal and wearing a pad inside your underwear may help to catch any leakage.
3. Empty the bag before starting an activity.
4. Regular interruptions to physical activity may be needed to empty the bag or open the rectum to let discharge out. This is normal. After a visit to the toilet, just resume the activity. Remember that activity does not have to be continuous to be beneficial and these regular breaks to go to the toilet can help you enjoy your activity more and feel these stressed.
5. Before you plan an activity, you may want to take note of where the toilets are.
6. Sometimes an activity that generates a lot of sweat will cause the bag to unstick from the skin. If this happens then you might have a leak. Flange extenders may be useful to keep the bag in place.
7. i always wear dark coloured clothing when I am exercising so that if a little bit of liquid does escape from my bag, the stain doesn't immediately show. And I also carry wet wipes and a spare bag - just in case.

Photographer:Aggie Banks

Andrea Robson was diagnosed with Ulcerative Colitis aged 6 and with bowel cancer aged 37. She has an ileostomy and currently still has a rectum. Here are her top tips:

1. Ask the physical activity specialist to wear a pretend stoma bag for a day or while exercising (maybe at one point with a little water/gel inside to feel the weight a little) so they have a better understanding of what it feels like for participants.
2. Wear what makes you feel comfortable and confident. As Azmina says, take note of the waist line, make sure it fits over or under the stoma bag. You may be more confident in wearing support wear such as a waist support band or supported pants with a "stoma bag pocket". Your stoma nurse can advise where you can get these items from.
3. Add extenders to your stoma bag for extra sticking power if you are worried about your bag lifting/leakage - especially if swimming.
4. Always carry spare supplies with you: pants, wipes, hand sanitiser, a pre cut bag, disposal bag. I find it useful when walking to wear a small backpack/rucksack, so you don't have to hold a bag that gets in your way.
5. Empty/change your stoma bag before your activity/exercise.
6. It may be beneficial to speak to your instructor (if in a class situation) to let them know you have a stoma; that you may be restricted with some movements and you may have to leave during the class.
7. Always take water (with Dioralyte) on your activity/exercise to keep hydrated.
8. Know where the nearest toilets are in a gym/studio/your local area in case your bag takes you by surprise. Carry a "Can't Wait Card" & a "Radar Key" for extra reassurance.
9. Do things gradually, don't push or exert yourself too much, if you need a rest during exercise or an activity, even if it's just a walk to your local supermarket, do.
10. The more you move around or stretch etc. your tummy may make loud noises or squeak (mine does!) so know that's normal. If like me you still have a rectum you may need to release mucus. That's normal too.

Photographer:Aggie Banks

Susan Meer was diagnosed with bowel cancer and has a stoma.

I went to my first yoga class since having my stoma and completing chemo, and just thought it might be helpful to let you know a few of my thoughts.

I attended an easier class than the one I used to go to, following discussion with my yoga teacher. I think that if I had tried going to my usual class I would have come away feeling disappointed at what I was able to achieve, whereas in this class I felt a great sense of achievement and was surprised by how much I felt able to do. I think that if I had started to exercise sooner this might not have been the case. I was thinking that actually, the timing and the amount of exercise, are probably key to the success rate of your proposed plans. Walking my dog every day has certainly helped me to keep fit up to a point and so a small amount of daily exercise right the way through the treatment and operation must be beneficial.

The yoga class focused on core strength and balance, which was perfect for me! My yoga teacher is qualified with the British Wheel of Yoga and has done further training on teaching yoga to people going through cancer treatments. However, she was saying that she had been unable to find any information on specific exercise for people with a stoma.

I was also thinking that before attending a class you need to feel fairly confident with your 'bag'! It has taken a lot of time, trial and error for me to begin to understand it!! I also realised yesterday, the importance of good supportive underwear. I got mine via the NHS, so no added expense. Several companies do a range of support vests and pants which really do hold everything in place!

Andy Coogan is 75 years old and has a stoma.
I had prostate cancer diagnosed in 2007. The treatment included two years of female hormone therapy and 30 days of radiotherapy followed by brachytherapy.

About a year later, I had severe stomach pains which resulted in being taken into hospital for an emergency operation (Hartmann's operation). My weight had dropped to 46/47 Kg.

I was very lucky in only spending a week in hospital.
I took about 3 months to recover (6 weeks before driving).
Initially, to get active again, I waled from one room to another, up and down the garden, about a three quarter mile up to meet my wife returning from the dog walk.

I was advised not to go caravanning (we tow our caravan all over UK) for at least 4 to 5 months AND to wear a support garment. At first, this was the 'Boob Tube' type (that's how my Wife described it).

I soon realised I needed a stronger support and after seeing a manufacturer's representative demonstrate an elasticated Velcro belt type I changed to that and always use one for every activity - mowing the grass, hoovering, DIY, all lifting and playing with our grandchildren.

I firmly believe for their own protection, physical activity instructors should ask participants if they have a hernia and if they wear a support garment. Wearing a support garment is very, very important to me because I believe that is one of the main reasons why I do not have a hernia.

Barry Caplan is aged 73 and has a stoma.
I had my Ileostomy in 1957 that makes it 60 years ago, when l was only 13 years of age. l am now 73. At that time there was very little information passed on to me and of cause, no stoma nurses. Thanks to two wonderful parents we struggled through the early days. Going back to the beginning, l was admitted into hospital with severe stomach pains and the usual toilet problems that go with it. No one knew what my problem was so l was put into an isolation ward for 3 weeks. They still didn't understand what my illness was but I was moved into a normal ward but was restricted to bed only. This went on for many weeks until l was move to the old Middlesex Hospital where l had my first operation. During the time in bed my back and leg muscles got very weak and couldn't support me. When l was discharged and strong enough, my parent bought me a bike, which was one of the best things to build up my strength again. After several month of gentle cycling l returned to normality .l also took up swimming but had to be careful not to overtax myself as it was very easy to strain my stomach muscles.

l find now in my later years walking is a great way to keep fit. I retired from driving a London Black Cab after 51 years and with all my walking in the past 18 months I have lost a stone and a half. l am very happy about this. I try and keep my weight down to 11 and a half stone. I have in the last few years developed a small hernia and awaiting the delivery of a support belt. I think if you are sensible and listen to your body you know how far you can stretch yourself. I think l have been very lucky that l haven't too many problems.

18. Resources

18

The physical activity specialist can use these resources to inform their decision about physical activities to prescribe for participants. However, the main purpose of this list is so that the physical activity specialist can recommend resources for participants to obtain for their own use.

Four people who have a stoma looked at a range of resources that might be useful to hand to participants. They give information about physical activity with a stoma and present some exercises in pictorial format.

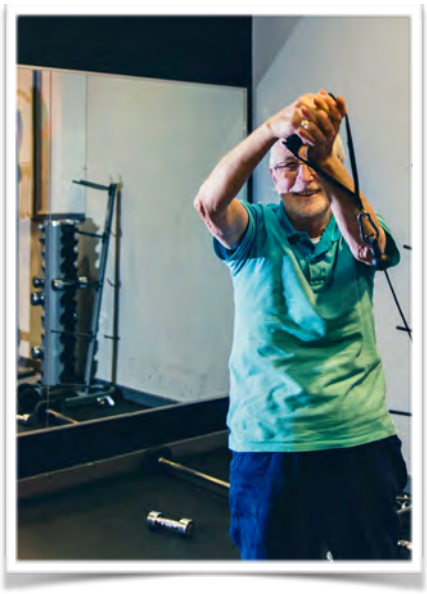
Colostomy UK – Registered Charity.
Website Information - Living with a Colostomy
Section - Sports and Exercise
http://www.colostomyuk.org/wp-content/uploads/2017/05/CA030-01v01r00-Sport-and-Fitness-after-stoma-surgery.pdf

IA (*The Ileostomy and internal pouch support group)* - Registered Charity.
Website Information - Exercises for Ostomates
http://www.iasupport.org/about/publications/factsheets/exercises-for-ostomates

ConvaTec me+™ recovery programme
Booklets available from the website that provide advice and support about the importance of movement and physical activity after stoma surgery
https://www.convatec.co.uk/stoma-care/living-with-a-stoma/meplus-recovery/

healthtalk.org provides free, reliable information about health issues, by sharing people's real-life experiences.
One man describes how he became an accomplished sportsman after his ileostomy
http://www.healthtalk.org/peoples-experiences/cancer/colorectal-cancer/daily-living-stoma

19. Frequently Asked Questions



Photographer:Aggie Banks

1. How much physical activity can someone do after abdominal surgery?

After abdominal surgery, it can take a few weeks to get back to fitness. It is likely that they will feel tired and may experience some pain or other symptoms of treatment.

Since the abdominal muscles can be weakened after an abdominal operation, it is important that care is taken when lifting and carrying objects for at least six weeks. General advice is not to pick up anything heavier than a full kettle of water during this time.

Week 1-2: It is reasonable for someone to try to walk each day after surgery, starting with 5-10 minutes and increasing this day by day.

Weeks 2-4: Once the individual starts to feel stronger, they can start doing daily activities such as dusting and making light meals. It is still important that they do keep active and start to walk further and/or for longer, but making sure that they pace themselves.

Weeks 4-6: Most people will feel comfortable to do more – provided their recovery has been uncomplicated. Activities may include light housework such as ironing and cooking whilst still not lifting any really heavy items. By week 6 they should be able to walk for 30 minutes comfortably.

Week 7+: Assuming that the person has not suffered any further complications then they should be able to be treated just like anyone else regarding physical activity prescription. The only exception is care in relation to stoma hernia (see section 15).

Key message: While someone may want to avoid strenuous activities during the first few weeks after surgery, having a stoma is no barrier to living a full or active life.

2. How much physical activity can someone with a stoma do?

Physical activity with a stoma is possible and can be achieved safely provided certain principles are followed.

People with stomas (ostomates) can essentially do anything provided they build up safely and slowly (just like everyone else). The level of activity achieved will depend on how active the individual was before their stoma was formed, the surgery they had and their post-operative recovery afterwards.

Walking is the easiest physical activity for people to start with. However, people with a stoma can undertake other forms of activity such as gym sessions, running, cycling and all ball sports. There are a few considerations for people with a stoma to take on board when undertaking high impact and combat activities.

We recommend people check out the 'Ostomy Lifestyle Athletes' Facebook group for support and inspiration.

3. Can people with a stoma go swimming?

Yes, a person with a stoma can go swimming. Most individuals need to know facts such as they do not need to wear a special appliance and if they have an appliance with a filter, this will need covering.

Self-consciousness may be a barrier for some people. If this is the case, the appliance itself can be covered to disguise the stoma and some people choose to wear a smaller appliance whilst they swim (participants can discuss with the stoma nurse about obtaining a small appliance).

In general, choosing what to wear when exercising can be a dilemma. The presence of the stoma should not require anyone to change their personal style. It is worth knowing about the range of specialist clothing for people with a stoma - including swim wear and casual wear. It is a case of trial and error to find what works for that individual.

Key message: With modern appliances, people are able to swim in the pool or the sea without the bag coming off and it won't be harmful to the stoma. In addition, the adhesive on a drainable bag is more adhesive when it gets wet especially just after being changed

4. How does someone know if they are overworking their intra-abdominal muscles?

This is a difficult question to answer. People need to strengthen the abdominal muscles to reduce the risk of a hernia but not put too much strain on the abdominal muscles. We advise the following:

- Build up training the abdominal muscles gradually
- Breathe out with exertion and breathe in with relaxation
- Make no jerky movements when reaching and stretching
- Listen to your body and stop if it hurts.

5. Can someone be physically active when having chemotherapy?

Yes. Evidence suggests that remaining active during treatment can help reduce fatigue and improve wellbeing.

Blood cells may be affected during chemotherapy treatment. Blood cells do return to normal at the end of the treatment

cycle. Low red blood cell count and can cause: dizziness, fatigue, feeling weak, short of breath. If a member of the cancer care team informs the that the patient that their red blood count is low then the individual may not feel up to exercising as much and may wish to ease off a bit.

Low white blood cell count can increase risk of infection. If a member of the cancer care team informs the that the patient that their white blood count is low then the individual may wish to avoid public places such as the gym to avoid catching a cold etc. from a member of the public.

Impact on the stoma
The combination of the chemotherapy medication and the supporting medication can cause some people to develop constipation and/or diarrhoea. Diarrhoea may require an individual to have a new appliance and use a drainable pouch during this time because it is easier to empty the pouch and will also reduce damage to skin tissue with frequent changes.

Many people notice a little bleeding from the stoma when removing and changing their pouch and this is not a cause for concern. Very gentle cleaning is required during pouch changes with a soft damp wipe. If bleeding persists, it may be stopped with gentle pressure from a soft wipe.

During chemotherapy treatment, a stoma may swell slightly and so it should be measured regularly to ensure the appliance still fits correctly to avoid leakage and unnecessary irritation / discomfort to the skin around the stoma (peristomal). If the peristomal skin does become irritated and sore, the stoma nurse can advise on products to help. Some people may also experience stomal sores on the actual stoma, these do not require any treatment and will heal on their own.

6. What are the drinking tips for people with ileostomies when undertaking physical activity?
Drink little and often. Always take a drink when you go out to exercise. Don't wait until you're thirsty - stay one step ahead and keep your body hydrated and healthy.

The best indicator of your hydration status is your urine colour. Aim for light straw coloured urine –this means you're probably drinking enough. If your urine is darker in colour you need to drink more fluid. If your urine is completely clear, you may actually be drinking too much and flushing electrolytes out of your body. Drink fluids which will rehydrate you such as Dioralyte. Avoid sports drinks with carbon dioxide because it will fill your bag with gas. This will not be harmful but can be uncomfortable or inconvenient when doing exercise.

The Manual was developed by: Drs Gill Hubbard, Rebecca Beeken, Gozde Ozakinci and Chloe Grimmett who are behavioural scientists; Ms Julie Munro, sports and exercise physiologist; Dr Claire Taylor, Macmillan colorectal cancer nurse consultant; Dr Anna Campbell, cancer and exercise consultant; Dr Jackie Gracey, senior physiotherapist and lecturer; Professor Angus Watson, colorectal consultant surgeon.

The following people who have a stoma contributed towards developing this Manual: Azmina Verjee, Andy Coogan, Andrea Robson, Barry Caplan, Susan Meer and Vanessa Denvir.

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This manual is a guide to support people who are recovering from bowel cancer surgery and have a stoma.

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