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A quick guide for health professionals

Background

Most cancer survivors will not have any long-term lower GI consequences of their cancer or its treatment. However, some will develop problems including chronic diarrhoea, faecal incontinence, urgency, pain, bleeding and excessive flatulence, particularly following pelvic radiotherapy and surgery^[1]. For these people quality of life can be severely affected.

Chronic GI symptoms often affect those who have been treated with pelvic radiotherapy for urological cancers (30% have chronic GI symptoms affecting quality of life), gynaecological cancers (40%) and colorectal cancers (up to 66%)^[1]. These symptoms may arise as new symptoms several years after cancer treatment has ended.

The content of this Quick Guide is based on '<u>The Practical Management of the Gastrointestinal Symptoms</u> <u>of Pelvic Radiation Disease'</u>^[2], by Andreyev et al, (often referred to as the 'bowel algorithm' found to be effective in the <u>ORBIT</u> study^[3], a randomised controlled trial) which can be downloaded at: <u>www.macmillan.org.uk/prdgastroguidance</u>

For further information, please refer to the British Society of Gastroenterology '<u>Practice guidance on the management</u> of acute and chronic gastrointestinal problems arising as <u>a result of treatment for cancer'.</u>^[4]

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Step 2

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Step 3

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Identify patients experiencing chronic GI problems

- If recurrent disease is suspected refer urgently to the oncology team
- If the patient is **currently undergoing cancer treatment** refer to cancer treatment unit or acute oncology team.
- Acute GI side-effects due to infection, perforation, haemorrhage or bowel obstruction are **oncological emergencies and require immediate attention**.

Trigger questions:

The following questions should be asked regularly to any patient who has had pelvic radiotherapy. If a person answers "**yes**" to any of the following proceed immediately to **Basic assessment** below.

- 1 Are you woken up at night to have a bowel movement?
- 2 Do you need to rush to the toilet to have a bowel movement?
- 3 Do you ever have bowel leakage, soiling or a loss of control over your bowels?
- 4 Do you have any bowel symptoms preventing you from living a full life?

Basic assessment

Rectal bleeding?

Yes? go immediately to or straight to Step 3 Step 2 (if you are in a position to follow the algorithm)

Rectal bleeding following radiotherapy is common, although it is usually mild and often does not need significant treatment, it should always be investigated to determine the cause and contributing factors. This should include at least a flexible sigmoidoscopy.

Medical History

A drug history can help to identify and rule out any possible drug-induced GI sideeffects caused by opioids, ondansetron, anti-muscarinic drugs, loperamide, iron supplements, PPIs, laxatives, beta-blockers, metformin and selenium.

Recommend keeping a bowel and/or food diary

This can help to identify whether certain foods trigger GI symptoms. A food and symptoms diary template is available from Macmillan (**www.macmillan.org.uk/symptomdiary**).

Provide basic advice and treatment

Information to support self-management

Further information for people experiencing GI problems following cancer treatment is available to order or download for free from be.macmillan

- <u>Managing the late effects of pelvic radiotherapy in men</u> (Order Code: MAC13825)
- <u>Managing the late effects of pelvic radiotherapy in women</u> (Order Code: MAC13826)
- Managing the late effects of bowel cancer treatment (Order Code: MAC12162)

Promoting health and wellbeing

- Physical activity: Information and advice during and following cancer treatment is provided <u>here</u> and in the Macmillan Cancer Support booklet <u>Move More</u> (order code MAC13314).
- **Alcohol consumption**: Patients should be encouraged to limit alcohol intake and include one or two alcohol-free days each week.
- **Stress**: can worsen GI symptoms, consider relaxation classes, counselling, psychological support or complementary therapies. Information about local cancer information and support centres can be found <u>here</u>.

Dietary advice:

After treatment, cancer survivors should follow the recommendations for cancer prevention as set out in the <u>World Cancer Research Fund UK Recommendations</u> (2013).

If dietary changes are made, they should be done in a systematic way and should initially always be for a trial period. If symptoms do not improve dramatically, the dietary change may not provide any benefit and may actually restrict the person's nutritional intake. If you are making long term dietary changes referral to a dietitian may be beneficial.

Specific dietary advice can be found below:

- Excessive fibre is a common cause of GI problems, especially following pelvic radiotherapy. A reduction in fibre may be beneficial.
- Inadequate fibre intake can also exacerbate GI symptoms. Patients should be advised that if they plan to increase the amount of fibre in their diet, they should also increase their fluid intake.
- High fat, caffeine and alcohol intake, artificial sweeteners and carbonated drinks can contribute to bloating, excessive flatulence and diarrhoea.
- Patients may develop carbohydrate intolerances including lactose or fructose intolerances. If a suspected food intolerance has been confirmed, referral to a dietitian is advised.
- Skipping meals may make bowel habits unpredictable. So patients may be advised to eat at regular times. If patients are losing weight as a result of their GI problems, referral to a dietitian should be considered.

Stool bulking agents or anti-diarrhoeal medications

- **Stool bulking agents** Fibre supplements are useful in relieving constipation or tenesmus. For excessive flatulence, a non-fermentable fibre supplement such as **Normacol (sterculia)** is recommended, as this is less likely to cause flatulence that may occur with other forms of fibre supplements or dietary fibre.
- Anti-diarrhoeal medications Loperamide can be used in cases of chronic diarrhoea after all reasonable measures have been taken to address the underlying causes. For adults, an appropriate initial dose is 1-2mg once or twice a day, subsequently adjusted according to response and given in up to 4 divided doses a day for maintenance; up to a maximum of 16mg daily.
 - Using smaller doses of Loperamide liquid (0.5 1mg) half an hour before meals can be helpful as it reduces the gastrocolic reflex triggered by eating. An additional dose before bed time or half an hour before leaving home may also be useful.

Access to toilet facilities

Patients suffering from urgency or bowel incontinence often feel anxious about going out and should be advised on toilet accessibility including:

- local authority websites and toilet apps,
- toilet cards to help them gain access to a toilet not normally accessible,
- purchasing a <u>Radar NKS key</u> from Disability Rights UK offering access to locked public toilets across the UK.

Practical advice

Bowel training

Patients can be advised to go to the toilet at regular times each day (such as after meals). Adopting the correct position on the lavatory may help to trigger bowel movements^[2].

- 1 Sitting on the toilet, lean forward with your forearms resting on your thighs and use a low footrest to raise your feet off the floor.
- 2 Relax and lower the shoulders. Breathe slowly, regularly and gently – do not hold your breath as this will encourage straining. Try and stay as relaxed as possible.
- 3 Try and brace your abdominal muscles. This is best done by putting your hands on your waist. Expand your waist and feel your hands being pushed out sideways. Concentrate on relaxing your anus to allow the stool to pass. Only push down from above once your anus is relaxed.
- 4 Relax very slightly for 1 second maintaining pressure but without the push.
- 5 Then brace outwards and push down once again.
- 6 Repeat steps 1-5

The brace position

- 1 Knees higher than hips
- 2 Lean forward and put elbows on your knees
- 3 Relax shoulders
- 4 Bulge out your abdomen



Pelvic floor exercises

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Cancer treatments such as pelvic radiotherapy or hormone treatment may weaken pelvic floor muscles. Exercises that strengthen muscles around the rectum, anus and anterior pelvic floor can help with reducing faecal urgency, leakage and incontinence. Detailed instructions are available in <u>Managing the Late Effects of Pelvic Radiotherapy</u> <u>in Men/Women</u> (MAC13825/13826).

- 1 Sit, stand or lie with your knees slightly apart. Tighten and pull up your bottom muscles as tightly as you can. Hold for at least five seconds and then relax for at least ten seconds. Repeat at least five times. This will work on the strength of your muscles.
- 2 Next, pull the muscles up to about half of their maximum squeeze. See how long you can hold this for. Then relax for at least ten seconds. Repeat at least five times. This will work on the endurance or staying power of your muscles and will improve their coordination.
- 3 Pull up the muscles as quickly and tightly as you can and then relax and then pull up again, and see how many times you can do this before you get tired. Try at least five quick pull-ups.
- 4 Repeat exercises 1, 2, and 3 at least ten times every day.
- 5 As the muscles get stronger, you will find that you can hold for longer than five seconds, and that you can do more pull-ups each time without the muscle getting tired.

Further Investigation and management

If the advice and basic interventions in **Step 1** do not improve symptoms, the following investigations and treatments may be necessary. If it is not possible to undertake/ request the suggested tests and interventions please go straight to **Step 3**.

A) Rectal bleeding

Blood tests required	Abnormal result	Action
 Haemoglobin RBC indices Platelets If heavy bleeding has occured, check clotting and haematinics 	lf Hb ≺80g/l	 Check ferritin, transferrin saturation, RBC folate and vitamin B12 levels and consider referring patient for blood transfusion where clinically appropriate. If iron deficient, consider iron supplements. If unexplained, refer patient for upper GI endoscopy and colonoscopy.
	Anaemic but Hb >80g/l	 Check ferritin, transferrin saturation, RBC folate and vitamin B12 levels. Replace if necessary and monitor response. If unexplained, refer patients for upper GI endoscopy and colonoscopy/ CT pneumocolon.
	Other abnormal results	• Follow routine treatment for abnormal blood results. (For more information, refer to full algorithm ^[2])

Consider the following investigations or referrals:

- Flexible sigmoidoscopy
- Colonoscopy
- Optimise bowel function and stool consistency

If it is dark bleeding consider the following investigations or referrals:

- Colonoscopy
- Upper GI endoscopy

(for more information, refer to the full bowel algorithm^[2] which can be downloaded at **www.macmillan.org.uk/prdgastroguidance**)

B) Faecal incontinence/leakage and urgency (without diarrhoea)

Tests required	Abnormal result	Action
 Routine blood tests Full blood count Electrolytes Urea and Liver function tests Glucose Calcium Additional blood tests Erythrocyte sedimentation C-reactive protein (CRP) RBC folate Iron studies Vitamin B12 Thyroid function tests Coeliac serology (TTG, IgA) Magnesium 	Abnormal haemoglobin levels/ anaemia	See table A
	Abnormal liver function tests	 Refer patient for liver ultrasound and liver screening, including Hepatitis B and C serology, ferritin, alpha feta protein, alpha 1 antitrypsin, liver auto-antibodies, total cholesterol and triglycerides, immunoglobulins. If unexplained refer to gastroenterology.
	Elevated ESR/CRP	 Consider the following: Infection, including small intestinal bacterial overgrowth (SIBO) Inflammation, including IBD; refer to gastroenterology for diagnosis. Recurrent malignancy; refer to oncology Non-GI causes (e.g. rheumatoid arthritis, vasculitis, connective tissue disorders).
	RBC folate deficiency	• Consider referring patient to a dietitian for specialist dietetic advice/supplementation.
	Abnormal coeliac serology	 If IgA deficient, request IgG coeliac screen. If TTG elevated, refer to gastroenterology to confirm with duodenal biopsy. Refer patient to a dietitian for specialist dietetic advice.
Other tests • Rectal examination • Anoscopy • Flexible simoidoscopy	Pelvic floor dysfunction with radiation protopathy and faecal incontinence OR anal sphincter defect	 Recommend pelvic floor and toileting exercises Prescribe a stool bulking agent ± anti-diarrhoeal medication Prescribe anti-diarrhoeal medication ± stimulant laxative suppositories/enemas. Consider the use of a topical sympathomimetic agent (e.g. phenylephrine). Advise patient on perianal skin care. Refer patient for biofeedback services (if available).
	Presence of other contributing factors	 If cause is unrelated to radiotherapy (e.g. childbirth, previous sphincter surgery), refer to specialist team for management of faecal incontinence.
	Presence of other mucus discharge	 Refer patient to a dietitian for a detailed dietary review. Recommend pelvic floor and toileting exercises. If due to haemorrhoids, consider local treatment If newly diagnosed neoplasm, refer urgently to oncology, requesting appointment within 2 weeks. If due to rectal mucosal prolapse, ulceration or if cause unknown, refer to gastroenterology.

Consider the following investigations or referrals if you are in a position to do so (for more information, refer to the <u>full algorithm^[2]</u>):

- Endo anal ultrasound AND
- Anorectal physiology
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C) Diarrhoea (type 6-7 stool – <u>Bristol Stool Chart)^[2]</u>

Tests required	Abnormal result	Action
Routine and additional blood tests		See table B
Stool sample for microscopy, culture and Clostridium Difficile toxin	Stools contain pathogen	 Treat as recommended by microbiologists and local protocols.
Stool sample for faecal elastase	Exocrine pancreatic insufficiency (EPI)	 Initiate pancreatic enzyme replacement therapy. Consider long-term multivitamin and trace element supplementation. Refer patient to a dietitian (Step 3) if dietary advice necessary. Refer to gastroenterology (Step 3) if symptoms do not improve.

Consider the following investigations or referrals if you are in a position to do so (for more information, refer to <u>the full algorithm^[2]</u>):

- Upper GI endoscopy with duodenal aspirate and biopsies
- AND/OR Glucose hydrogen/methane breath test
- Carbohydrate challenge
- SeHCAT scan
- Flexible sigmoidoscopy with biopsies from non-irradiated bowel (avoid biopsies from areas irradiated in sigmoid and rectum)

If all tests are negative but symptoms persist, consider the following:

- Symptomatic treatment with anti-diarrhoeal medication
- Trial of low-dose tricyclic antidepressants
- Biofeedback

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D) Constipation (type 1-2 stool – <u>Bristol Stool Chart)^[2]</u>

Tests required	Abnormal result	Action
Rectal examination	Anal fissure	 Initially, treat with a topical healing agent such as GTN or diltiazem gel for 8 weeks. Prescribe a stool bulking/softening agent ± short term topical local anaesthesic. If recurrent, consider referral for botulinum toxin treatment. If fissure has not healed after two months, refer to gastroenterology.
Routine and additional blood tests		See table B
Abdominal x-ray	Faecal loading/faecal impaction	 Full bowel clearance e.g. <i>Picolax, Klean-Prep.</i> Prescribe maintenance bulk laxative. Recommend pelvic floor and toileting exercises

Consider the following investigations or referrals if you are in a position to do so (for more information, refer to <u>the full algorithm ^[2]</u>):

- Colonoscopy CT pneumocolon if new onset
- Flexible sigmoidoscopy for long standing problems

E) Abdominal pain^[2]

Tests required	Abnormal result	Action
Routine blood tests and calcium, ESR and CRP		See table B
Abdominal x-ray	Faecal loading/ faecal impaction	 Full bowel clearance e.g. <i>Picolax, Klean-Prep.</i> Prescribe maintenance bulk laxative. Recommend toileting exercises

Consider the following investigations or referrals if you are in a position to do so (for more information, refer to the full algorithm^[2]):

- Upper GI endoscopy with duodenal aspirate and biopsies
- ± Glucose hydrogen/methane breath test
- Flexible sigmoidoscopy
- Ultrasound of biliary tree and small bowel (if no recent CT scan of abdomen and pelvis)

F) Painful bowel movements

Tests required	Abnormal result	Action
Medication assessment	Patient on nicorandil	Consider alternative medication
Visual assessment	Haemorrhoids	 Prescribe a stool bulking/softening agent ± short term topical local anaesthesic. Consider referral to gastroenterology for surgical review of grade 3 or 4 haemorrhoids.
Anoscopy and flexible sigmoidoscopy	Anal fissure	 Initially, treat with a topical healing agent such as GTN or diltiazem gel for 8 weeks. Prescribe a stool bulking/ softening agent ± short term topical local anaesthesic. If recurrent, consider referral for botulinum toxin treatment. If fissure has not healed after two months, refer to gastroenterology.
	Anorectal fistula	 Refer patient for Pelvic MRI Refer to gastroenterology.
	Anorectal abscess or ulcer	Refer urgently to gastroenterology
	Mucosal prolapse/ solitary rectal ulcer	Refer to gastroenterology
	Neoplastic ulcer	 Refer urgently to oncology, requesting appointment within 2 weeks.
	Radiation-related ulceration	 Do NOT biopsy. Sucralfate enemas. Consider stool bulking/softening agents Antibiotics. Refer to gastroenterology

Consider the following investigations or referrals if you are in a position to do so (for more information, refer to <u>the full algorithm^[2]</u>):

MRI

If all tests are negative but symptoms persist, consider the following:

- 1 Investigation under anaesthesia
- 2 Pelvic floor and toileting exercises
- 3 Stool bulking agent ± laxative
- 4 Referral for acupuncture
- 5 Referral to specialist pain team for further assessment
- 6 Low-dose anti-depressant
- 7 Agent for neuropathic pain
- 8 Referral for a urological/gynaecological opinion

Referral to a gastroenterologist or other specialist

If the symptoms do not improve following **Step 1** and **Step 2** patients will require referral to gastroenterology or other specialist departments. For guidance on where to refer see below:



Information to include in the referral

- Reports and results for tests that have been carried out in Step 2 such as endoscopy and histology reports if biopsies were carried out.
- Details of GI symptoms leading to the referral.
- Previous tumour type/location.
- Oncology treatment, including treatment type, duration and date at which treatment ended.

Be aware

A patient may believe that "nothing can be done" and may therefore need reassurance that there are specialist treatments that can help to manage their symptoms. **Consider further referrals to continence services, physiotherapy and psychology to manage the impact of these symptoms**.

Useful organisations

Bladder and Bowel Foundation www.bladderandbowelfoundation.org

Bowel Cancer UK www.bowelcanceruk.org.uk

British Association for Counselling and Psychotherapy **www.bacp.co.uk**

Crohn's and Colitis UK www.crohnsandcolitis.org.uk

Disability Rights UK www.disabilityalliance.org

Jo's Cervical Cancer Trust www.jostrust.org.uk Macmillan Cancer Support www.macmillan.org.uk/selfhelpandsupport

Maggie's Cancer Caring Centres www.maggiescentres.org

Pelvic Radiation Disease Association **www.prda.org.uk**

Prostate Cancer UK www.prostatecanceruk.org

Relate <u>www.relate.org.uk</u>

References

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- ^[1] Macmillan Cancer Support. <u>'Throwing Light on the Consequences of Cancer</u> <u>and its Treatment'</u>. 2013
- ^[2] Andreyev et al. <u>'The practical management of the gastrointestinal symptoms</u> <u>of pelvic radiation disease'</u>. Frontline Gastroenterology 2015;6(1):53–72.
- ^[3] Andreyev HJ et al. <u>'Algorithm-based management of patients with gastrointestinal</u> <u>symptoms in patients after pelvic radiation treatment (ORBIT): a randomised</u> <u>controlled trial'</u>, The Lancet 2013; , 382: 2084 - 2092
- [4] Andreyev HJ, Davidson S, Gillespie C, et al. <u>'Practice guidance on the management</u> of acute and chronic gastrointestinal problems arising as a result of treatment for <u>cancer'</u> Gut 2012; 61: 179–192

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As a healthcare professional, you know cancer doesn't just affect your patients physically. It can affect everything – their relationships, finances, work. But maybe you feel like there aren't enough hours in the day to spend as long as you'd like with them, or to answer all their questions.

That's where we come in. We're here to provide extra support to your patients with cancer, and their loved ones. Whether it's offering benefits advice, help returning to work, or support with getting active again – we're here to help you give your patients the energy and inspiration they need to feel more in control of their lives. Right from the moment they're diagnosed, through treatment and beyond.

To find out more about how we can help, visit **macmillan.org.uk**. And please let your patients know they can contact us on **0808 808 00 00** if they need support.