Large print version

St George's University Hospitals NHS Foundation Trust

A Guide to Support Pelvic Health and Abdominal Related Cancer Concerns

This map will be a resource for you to refer to before, during, and after your cancer treatment.

It is designed for any type of cancer diagnosis or treatment.

Consultant:

Cancer Clinical Nurse Specialist (CNS):

Macmillan Support Worker:

How to use this roadmap

Your needs are important to us and we understand that everyone's roadmap will look different, as we are all individuals and are so much more than a cancer diagnosis.

This guide will give you an overview of symptoms and some tips to help you. If you need further information, please access the videos and additional resources we have developed that complement the roadmap.

You are not on your own. There is a range of support available so you do not have to struggle in silence. Sometimes it is hard to know when to ask for help. If you are worried about anything, please seek advice from your cancer team or GP.

Scanning this QR Code will take you to a series of links dedicated to each section of the roadmap.

Each link will give you more information, resources and guidance for each topic.

Accessing QR codes

To use a QR code on your phone to access the resources in this leaflet please follow these steps:

- Open your camera app like you normally would for taking a photo.
- Point the camera at the QR code.
- A yellow link will pop up, click on this link to access the website or content associated with the QR code.

If you are unable to access the QR codes and would like paper copies, please visit the Macmillan information and support centre.

020 8725 2677 cancer.information@stgeorges.nhs.uk

Glossary

These are some terms that you might hear health professionals using. The Macmillan website is also a good place to look, to make sense of medical terms.

www.macmillan.org.uk

The pelvic area. The pelvis is the region of the body in between the hip bones. It contains the sex organs, the bladder, parts of the bowel, muscles, bones, nerve blood vessels and lymph nodes.

Pelvic floor muscles. These are muscles that span the bottom of your pelvis, running from your tailbone to your pubic bone. They support your pelvic organs. Both male and female these muscles.

Incontinence. This is the term used to describe difficulty controlling when they open their bowels (poo) and empty their bladder (have a wee). There are different types of incontinence.

Stress incontinence is when you leak when your bladder or bowel is put under sudden extra pressure, for example when coughing.

Urge incontinence is when you feel a sudden and very intense need to go to the toilet.

Sexual activity. This can include caressing, foreplay, masturbation (solo sex or partnered), oral sex and intercourse.

Sexual intercourse. Usually referring to the penetration (entry) of the vagina or anus.

Sexual stimulation. This includes situations like foreplay with a partner, self-stimulation (masturbation), sexual fantasy or any activity that increases arousal.

How and when to ask for help

Concerns about continence, pain or intimacy are no less valid than any other health concern.

We understand that it can be difficult to talk to your medical team about these concerns, and we appreciate that.

To help you to see your GP without revealing all your sensitive details to your practice reception team, you might find this phrasing helpful:

> "I'd like to see the GP to help me manage the pelvic consequences of my cancer treatment"

To open up the conversation with your healthcare professional, this approach might help:

> "I was reading an article about how people with cancer sometimes have concerns about sex. Is there anyone I could talk to more about that? Do you know of any resources that could help?"

Or you could take this guide to your appointment and use it as a prompt.

Please remember this won't be the first time someone has asked us these questions and we want to help you. There is no judgement. These conversations are private.

For more information about getting the most out of appointments:

www.patients-association.org.uk/getting-the-most-out-of-your-appointment

Psychological Wellbeing

It is normal to feel a range of emotions at diagnosis, during and after cancer treatment. If your cancer affects your pelvic or abdominal area you may experience distress related to this such as feelings of embarrassment, concerns around incontinence, or the impact it might have on your sex life or relationship.

Caring for your emotional wellbeing, alongside physical wellbeing is very important.

Try these tips to help:

- Make room for your emotions. It is normal to need time to adjust and you do not have to remain positive all the time
- Talk to others about how you are feeling
- Consider mindfulness, relaxation and breathing exercises to help manage anxiety and to ground you in the present moment
- Focus on elements of your life you can control
- Think about what is important to you and how you can continue to engage with these activities

If you need more support you can:

- Speak to your cancer team for a referral for psychological support with the Cancer Psychological Support Team (if you are within 2 years of active cancer treatment)
- Self-refer (or ask your GP to refer) to NHS Talking Therapies
- Or you can consider peer support options, charities that offer psychological support including Maggie's or use the Macmillan Support Line 0808 808 0000

Hear more about psychological wellbeing from our specialists by following this link

Sometimes people can have thoughts of harming themselves or ending their lives. If you feel this way please seek immediate support via the Samaritans (116 123), your GP, by calling 111 or by visiting A&E.

You are not alone.

Pelvic Health

This is the overall wellbeing of the organs, muscles, and connective tissue of the pelvis. Try these tips for good pelvic health:

✓ **Hydration** - aim for 5-8 cups of fluid daily

✓ **Avoid irritants** e.g. caffeine, hot chocolate, citrus, fizzy drinks, alcohol, and spicy or heavily seasoned food can all irritate your bladder and bowel

✓ **Avoid constipation**: stay hydrated, introduce fibre gradually with 5-7 portions of fruit and vegetables daily, aim for regular mealtimes, and put your feet on a stool when opening your bowels

✓ **Speak to a pharmacist** about whether your medications are interfering with your pelvic health

✓ **Pelvic floor muscle exercises** - try to complete the below 3-4 times daily:

- Long Holds – Hold for 10 seconds and repeat 10 times
- Fast Squeezes – Repeat 20 times

For pelvic floor muscle exercises, some people find it helpful to think about:

"Sucking up something through a straw into your vagina"

"Pull your tailbone up toward your tummy"

"Squeeze and lift your scrotum up"

Hear from our specialists:

Follow this link to find the pelvic floor resource best suited to your body

Understanding Your Anatomy

To learn more about abdominal and pelvic anatomy, scan this QR code to visit our anatomy guide that will explain it in more detail.

Living with a Stoma

Some people may require a stoma formation (colostomy, ileostomy or urostomy) as part of their cancer treatment. There is specific guidance available from your stoma nurses to support you to care for your stoma and we have included some specific information within this resource.

It is normal to feel uncertain as you get used to living with a stoma, talking about your feelings and setting small goals can help you regain your confidence.

Gradually resume every day activities at your own pace. Developing core strength, which includes your pelvic and abdominal muscles is essential after stoma surgery.

Contact your team if you notice bulging around the stoma, pain, pouch issues or changes in bladder/bowel habits.

Physical Activity

Being active can help you to tolerate your treatment better and deal with side effects that people sometimes experience. It can also help you to recover quicker after treatment. There are many different ways to be active - try and find something you enjoy!

Aim for:

- 30 minutes of aerobic activity 5 times a week
- 2 sessions of strengthening exercises each week
- Specifically finding exercises to strengthen the tummy, bottom, and leg muscles can help with overall pelvic health
- Start slowly and progress up to these recommended levels of activity - listen to your body and energy levels!

Healthy Eating

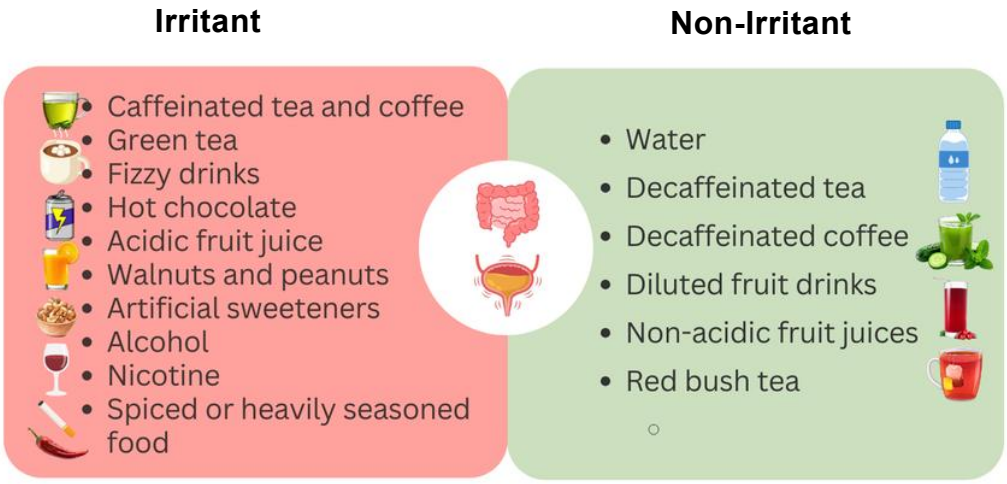
Cancer treatments can impact on appetite and weight. Try and keep a healthy and balanced diet during and after cancer treatment.

Aim for a healthy BMI and a balanced diet

Look out for:

- Clothes that no longer fit
- Changes in appetite/eating habits

Certain foods and drinks can irritate your bladder and bowel



If you are losing or gaining weight unintentionally or struggling with your appetite then ask your GP or cancer team for a referral to a dietitian.

Peer Support

Talking to others that have experienced cancer can be incredibly helpful. You can explore local support groups by accessing our local directory through the main QR code (see how to use this roadmap),or visit the St George's Macmillan centre or your local Maggies centre.

020 3982 3141

royalmarsden@maggiescentres.org

Bladder

Below are all very common bladder symptoms from cancer treatments and can often improve with some simple lifestyle changes and exercises!

- Frequency (going more than 7 times in the day)
- Nocturia (going more than once overnight)
- Urgency (feeling like you might not make it in time)
- Incontinence (leaking urine from urgency or from stress e.g. exercise or coughing

Hear more about bladder management tips from our specialists by following this link

Bowel

Below are all very common bowel symptoms from cancer treatments and can often improve with some simple lifestyle changes and exercises!

- Constipation (difficulty pooing)
- Loose stools or leakage of stool or wind
- Difficulty emptying your bowels fully
- Difficulty getting clean
- Fissures and bleeding

Hear more about bowel management tips from our specialists by following this link

If you suffer from any of these symptoms make sure you have read our ‘Pelvic Health’ and ‘Continence Tips’ section

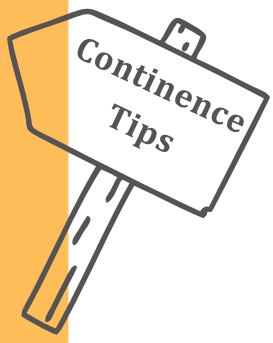
If you need more support with this, ask your GP to refer you to a community continence nurse

If you suffer from bladder or bowel urgency:

- Stay calm!
- Squeeze your pelvic floor muscles (see Pelvic Health section)
- Try and distract yourself e.g. count back from 120 in 7's
- Sit on a hard seat, cross your legs, curl your toes, or stand on tiptoes

To feel more in control, you can also plan ahead and pack a bag including:

- Just in case card
- Toilet map
- Radar key
- Wet wipes
- Change of underwear and clothes
- Fresh pads and scented disposal bags
- Oil free barrier cream



Continence products can be purchased from supermarkets or chemists, consider trying:

- Sanitary style stick on pads - these can be quick and easy to use in the day
- Underwear style pull on pads are often more comfortable overnight
- Absorbent underwear can also now be used for smaller leaks

If you need more support with this, ask your GP to refer you to a community continence nurse

To dispose of continence products:

- Never flush these products down the toilet
- Wrap the used product to minimise leaks or odours, using a scented or unscented plastic bag if necessary
- Dispose of the sealed bag in a regular or sanitary bin

Prolapse

This is when one or more of the pelvic organs sits lower in the pelvis and might cause feelings of:

- a bulge or heaviness in the vagina
- a bulge or protrusion of the anus
- urinary or bowel symptoms e.g. urgency or difficulty emptying your bladder or bowel
- pain or discomfort during intercourse

Weak pelvic floor muscles, hormonal changes, constipation, and surgery can all increase the risk of prolapse after cancer treatment. It is not life threatening and can improve with the correct management.

To help with these symptoms, consider trying:

- Follow our good pelvic health tips
- Maintain good pelvic floor muscle function
- Reduce or modify heavy lifting
- Reduce long periods of standing
- Avoid constipation

If you don't notice an improvement from following the above advice after 8-12 weeks then seek help from a pelvic health physiotherapist

Pelvic Pain

Pain can be complicated and stressful, below are some strategies you can use to help to manage some of your pelvic pain:

- Pacing - plan to take break from activities before pain or tiredness become too much
- Relaxation and Mindfulness - this can include activities such as belly breathing, progressive muscle relaxation, listening to some relaxing music
- Stretches and Movement - yoga, Tai Chi and Pilates are gentle forms of exercises to relax and move the body
- Massage can help with relaxation and reducing pain
- Heat, ice, and tens
- Pain can impact our sleep, and sleep can impact our pain - consider Sleepio app

If you need more support with managing persistent pain, speak to your GP or cancer team.

Fertility

Some cancer treatments can impact fertility. We would recommend you:

- Ask your cancer team about risk to fertility and options available for preservation
- Consider what contraception you should be using
- Communication is key. Speak with others (partner, family, cancer team)
- Remember it is normal to experience a range of emotions or to feel overwhelmed with the decision making process
- Find further information at the Fertility Network UK website https://fertilitynetworkuk.org/

Speak with your GP or cancer team for referral to a fertility specialist if needed

Sex & Intimacy

Sex and intimacy can be an important part of people's lives, and mean different things to everyone. We know that sexual consequences following cancer treatments are common, such as:

- Erection difficulties
- Vaginal dryness
- Low desire (lack of libido)
- Pain
- Changes to your sexual organs
- Concerns about incontinence
- Concerns about stoma(s)
- Body image concerns

Some of the above concerns may be temporary or permanent. You can ask your cancer team about what to expect, please follow their advice about when to have sex following surgery or treatment.

Top tips to consider:

- Allow yourself the time to understand and adjust to the changes
- Get to know what works for you now
- Speak with your partner
- Try new positions, lubrication, or different ways to be intimate

Although these issues can be difficult, there is a lot that can be done to help both medically and psychologically. If you are worried or if your sex and intimate life has been impacted then seek help.

Hear more about sex and intimacy from our specialists by following this link

Hormones

Androgen Deprivation Therapy (ADT), also called hormone therapy, is a common treatment for prostate cancer. Lowering testosterone levels can affect people in different ways, some may experience side effects and others might not. Common side effects include hot flushes, skin and hair changes, weight gain, changes in bone and muscle strength, as well as possible impacts on sexual function and mood.

A free monthly class run by Prostate UK: “ADT: The Low Down” led by a specialist nurse, will talk you through how to manage side effects and provide an opportunity to hear some top tips and ask questions.

www.prostatecanceruk.org

If you are need more support with hormonal symptoms, speak to your GP or cancer team

- Consider lifestyle factors e.g. sleep, balanced diet, exercise, limit caffeine and alcohol, stopping smoking
- Reduce stress and prioritise emotional wellbeing e.g. mindfulness, relaxation strategies, or CBT
- Try complementary and natural therapies e.g. acupuncture, aromatherapy, reflexology, or reiki
- Speak to your GP about non-hormonal medications or supplements

You may already be experiencing **menopause** symptoms, or these symptoms can be triggered by a range of cancer treatments. Menopause is where hormone production (mainly oestrogen) reduces or stops, which means people may experience a range of symptoms such as hot flushes, fatigue, vaginal dryness, or changes in mood and concentration.

Hear more about cancer and menopause from our specialists by following this link

Erection Difficulties

If you have noticed difficulty gaining or maintaining an erection this may be temporary or permanent. It can be caused by a variety of factors including surgery, radiotherapy, or hormone therapy and can also be impacted by anxiety or low mood.

Try these tips below to help:

- Masturbation helps keep the penile tissue healthy
- Practicing pelvic floor exercises
- Communicating with your partner
- Speak to your cancer team or GP about medical interventions that can help you gain an erection, such as tablets, creams, a pump, or injections. It is important to find the right approach for you
- If you are generally feeling anxious or low, consider accessing psychological support

Vaginal Dryness

The vagina produces a natural fluid which helps to keep the skin hydrated and healthy. Vaginal dryness can happen as a result of fluctuating hormone levels. This might be due to menopause, breastfeeding, or some cancer treatments. This may cause vaginal irritation or soreness, which can make sex uncomfortable or less pleasurable.

Try these tips to help:

- Use lubricants before and during sex - be sure to check the ingredients and find one that suits your needs
- Speak to your cancer team or GP about vaginal moisturisers, vaginal oestrogen, or HRT
- Speak with your partner about what you are experiencing
- Give your body time to feel aroused before vaginal penetration, feeling tired or stressed can reduce natural lubrication
- Consider intimate activities that don’t involve vaginal touch or penetration whilst you allow time for the skin health to improve

Low Desire

When diagnosed with cancer or undergoing treatment, people often find that desire for sex decreases and they describe having a reduced or no libido. This may be because of hormonal treatments impacting levels of testosterone or oestrogen, your focus being predominately on the cancer and treatment, fatigue, stress, or changes to your body confidence.

Try these tips to help:

- Spend time with your partner being intimate and affectionate in ways that do not involve or lead to sex
- Talk with your partner about this
- Try mindfulness exercises to help learn how to re-focus your attention during sex, to try and be more in the moment

If you need support in thinking about sex and intimacy:

- Speak with your cancer team to discuss medical support or a referral to the Cancer Psychological Support Team Speak to your GP for support or an onward referral
- Visit an NHS sexual health (GUM) clinic Consider accessing a psychosexual therapist (or sex therapist)
- Ask your GP if this is available via the NHS or you can consider private options at The College of Sexual and Relationship Therapists (COSRT) www.cosrt.org.uk/