LOOK BEHIND YOUR SYMPTOMS
by Lynn Faulds Wood

HOW TO TEST IF YOUR SYMPTOMS MIGHT BE SERIOUS

BOWEL CANCER and other bowel problems

Includes hints and tips on controlling constipation, diarrhoea and rectal bleeding.
Twenty years ago, I was co-presenter of the BBC’s Watchdog programme with my husband John Stapleton. We had a three year old son. Life could not have been better. Then, out of the blue, after nearly a year of medical delay, I was diagnosed with advanced bowel cancer. I had never even heard of the disease, did not know that it is the second commonest cancer which kills people in this country, after lung cancer.

I was lucky to survive and pledged to spend most of my time investigating how to help save the thousands of people who die unnecessarily of bowel cancer every year.

So far, I have helped to come up with a new, research-based guide to symptoms, now officially adopted by the Department of Health, helped to set up better diagnostic training schemes and centres for doctors and nurses, helped to create patient feedback events so we can have our say in improving cancer services.

Bowel cancer is curable and preventable - if only we can find it early enough. Most people need early reassurance that they do not have cancer. We should not spread fear and worry.

People with symptoms don’t have to dash off to their doctor - there is time to test symptoms safely to see if they will go away. That’s what this leaflet is all about.

I hope you find it helpful.

*Lynn*
Suffering from any of these?

Feelings of discomfort, bloating, sickness, pain, wind, grumbling guts, bleeding from the bottom, diarrhoea, constipation, mucus with stools, losing weight, fatigue, off your food?

If you’ve never had problems with your insides, you’re lucky.

Most of us have them.

But how can you tell if they’re serious or not?

Can you safely test your symptoms?

When should you go to the doctor?

This leaflet is designed to look behind your symptoms, to help you decide with confidence what to do next.

One in five of us has bleeding from the bottom at some time every year - yet over 99% of people with bleeding do not have cancer. Even more millions suffer short-lasting bowel upsets and abdominal pain.

For most of us, these are common, non-serious symptoms and we don’t need to do much about them.

But how can you tell?

**FACT:**

Most people with seemingly worrying symptoms do not have cancer, do NOT have something seriously wrong with them.
People experience all sorts of vague symptoms, like general discomfort ‘down below.’ But these usually come and go within 3-4 weeks. If the symptoms are not severe, do not stop you from doing your work, eating or sleeping, it is safe to ‘watch-and-wait’ for a few weeks.

But consider this. Behind the vague feelings, you might be missing underlying symptoms which could be even more important.

Try asking yourself these questions:

Has there been a change in my bowel habits recently? Say going to the loo - or trying to go more often with nothing happening (some people call this constipation) Do these changes continue day after day with no complete return to normal?

Has the consistency of my ‘poo’ changed? Is it looser, softer, more diarrhoea-like without returning to normal?

Is there bleeding? In the pan or on the toilet paper and it keeps happening for no reason? A torch may help you see.

Could I be anaemic? Severe anaemia can produce symptoms of tiredness, breathlessness and lack of energy. These symptoms are common and not usually caused by anaemia.

Have I persisting pain in my tummy which comes on almost always after eating, putting me off my food and I’m losing weight? Pain in the tummy without this pattern of symptoms is almost always not serious.

If I have symptoms, is there a history of bowel cancer in my family? Most people with a family history are not at a seriously increased lifetime risk (see page 12) but if you have persisting symptoms and a genetic risk, see your doctor.

If I have ulcerative colitis? Extensive colitis for more than 10 years - you should be under special review at a hospital. Shorter length of time - no extra risk.
Some GPs won’t offer a rectal exam with a gloved finger - we need to encourage more to do it.

The commonest symptoms of bowel cancer are:

CHANGE OF BOWEL HABIT, RECTAL BLEEDING and ABDOMINAL PAIN, but these are very common in people who do not have cancer.

These are the HIGHER RISK symptoms to look out for, behind any other symptoms you might have:

Change of bowel habit
WITH bleeding
a recent persistent change which lasts for a few weeks without returning to normal.
• To looser, more diarrhoea-like motions
• To going to the loo several more times a day than normal or trying to go People with these symptoms should be referred to hospital for investigation AT ANY AGE.

Change of bowel habit WITHOUT bleeding
• Looser, more frequent - people should be referred to hospital if in an older age group.

Rectal Bleeding - bleeding from the bottom
• Over 55 - everyone should be investigated just in case.

Rectal Bleeding under 55
If there is no good reason for the bleeding (no straining, piles, pain etc) and it keeps coming and going, you should probably be referred for investigation.

Other higher risk symptoms include:
• Unexplained iron deficient anaemia found by your GP
• A lump or mass in your tummy felt by your GP
• Persistently colicky severe abdominal pain, which has come on recently for the first time, if you are in an older age group.
A stool sample may be useful

FACT:

Bowel cancer - also known as colorectal and colon cancer - is common. After lung cancer, it is the second commonest cancer killer in this country. It usually affects older people, over 60.

How to test your symptoms

If you can make your symptoms go away or improve a lot, then it is highly unlikely you have bowel cancer.

Here’s how to test them:

**Diet** - try different things, like fibre: eating more (if you’re constipated) or less (for more diarrhoea-like symptoms).

Fibre includes wholemeal bread and cereals, fruit and vegetables.

Try drinking more fluids.

**Change your lifestyle** - if you’re a couch potato, try taking more exercise, like brisk walking for half an hour a day. Exercise gets the guts moving.

Give up smoking and heavy beer consumption.

**Talk to your pharmacist** - about remedies you can buy or changing your diet. Symptoms may go away while you are taking these remedies - if they come back once you stop, or if symptoms persist for up to four weeks, see your GP.

**Get advice from your GP** - the average patient gets eight minutes with their GP so get straight to the point. GPs are used to talking about intimate subjects and will not be embarrassed to talk about your symptoms.

**Bleeding from the bottom?**

Ask your GP if you should have a ‘PR’, stands for ‘per rectum’ - a gentle, quick examination with a gloved finger to feel for any suspicious lumps which might be cancer.
Our stories

Lynn’s story: I looked down the loo one day and thought I spotted traces of blood. The next time I went, I shone a torch down and definitely saw traces - quite subtle but definitely a bit of bleeding. I mentioned it to the GP next visit and he said “nothing to worry about at your age, probably piles,” but at least he gave me a digital examination.

The bleeding - still subtle - came and went with no reason for it, so five months later (I’ll never know why as I had no suspicions it might be serious) I went to see the wisest GP at the practice and asked to be referred to a specialist. Because no one was worried, I wasn’t fast tracked. Finally, nearly a year after I went to the first GP, I was diagnosed with advanced bowel cancer in the lymph nodes. My son was just three - it was a terrible shock. I had no chemo - it was twenty years ago - today I am still here and cured.

* Anybody with persistant bleeding without any obvious reason may need hospital investigation at any age.

Norman’s story: Norman Gordon was colourblind - 1 in 12 men are colourblind - usually having problems with the red end of the colour spectrum. That can make it difficult to spot bleeding from the bottom. Norman didn’t know that he had rectal bleeding until it was too late and he died at 53 of bowel cancer. His wife Brigette says: “Norman was very colourblind. He used to wear odd combinations of colours. One day he asked me to look in the toilet to see if there was anything wrong and I was shocked to see blood, a lot of it. He couldn’t see it and he had had the symptom for some time.”

Colourblindness tends to run in families. So does bowel cancer. Norman’s father was diagnosed two years before Norman, his uncle 18 months after Norman died. If your family is affected by colourblindness (it almost always affects men) and bowel cancer, ask your GP about screening and genetic advice in your area.

Norman and Brigette Gordon

John, Lynn and Nick
What does the bowel do?

**Gut, bowel, large bowel, intestine, colon and rectum.** We use many words to describe our guts but basically this leaflet is referring to the long tube of muscle running from the appendix through the colon and down to the rectum.

**When we eat,** food passes down into our stomach then nutrients are absorbed through the bowel lining and into our bodies. The leftovers progress into the large bowel - a sort of fermenting storage area - which can produce gas. In some people, this may be the cause of their bloating, discomfort, even abdominal pain, if the bowel isn’t dealing with this smoothly. Reasons for this can include not enough - or too much - roughage or fibre in our diet.

**The remaining food matter** (motions) is mostly stored on the right side of the bowel then once or twice a day in a mass movement, moves to the left when we get an urge to go to the loo. The motions can be held in the rectum or back passage until we can get to a loo.

**The bowel secretes mucus** to help move the waste along, which is why people may spot mucus in their stools. Water is removed along the way and, if you don’t go to the loo every day or most days, more water can be absorbed, making your motions firmer and more difficult to pass. That’s why going to the loo when you feel the need is a good idea and why it’s important for the young to develop good bowel habits.
Constipated?

**Try:**

- A higher fibre diet with more fruit and vegetables, more wholemeal bread and cereals - prunes and figs may help to soften the stool.

- Not drinking enough? Increase fluid intake (water, tea, juice and coffee).

- Don’t delay going to the loo when you have the urge.

- Exercise can stimulate the muscles in the gut to work more effectively - joggers often find they go more frequently. Brisk walking works wonders!

- Remedies recommended by your pharmacist, like Lactulose (which makes the motions softer), Fybogel (which adds bulk to the motion), Sennakot (which stimulates the bowel to work).

- Don’t use laxatives for months without consulting your doctor. If they work, stop taking them after a few weeks or couple of months and, if your bowel action doesn’t stay normal, see your GP.

- It’s ok to strain a bit to stimulate the bowel to work but too much straining isn’t helpful - waiting till you get a stronger urge to go should do no harm.

*Chatting through your symptoms with a pharmacist to test them before you see your GP is a good-idea.*
Common Symptoms in detail and what to do with them

**FACT**
The chances of developing bowel cancer increase as you get older - 90% of people affected are over 50.

**BLEEDING FROM THE BOTTOM**
Five million of us have bleeding from the bottom every year, especially in our 20s and 30s - it's pretty normal. Most of the time, we're good at deciding if it might be serious - and so are our GPs.

**So when should you take bleeding more seriously?**

**Over 50** - don't assume piles. Most people will not have cancer but persistent bleeding for weeks/months should be checked with your GP.

**At any age**

- **No obvious reason for your bleeding**, no itching, no irritation, no pain and the bleeding persists for more than two or three months - see your GP.

- **Sudden large amounts of bleeding** after going to the toilet looks frightening and worries us - yet, paradoxically, it usually means we don't have cancer. If it stops immediately, this is usually caused by conditions like piles, rarely by cancer.

- In patients who have **cancers which bleed** a lot, the bleeding will not stop. It is also not usually fresh blood (the colour of a cut finger) but changed in colour.

- People with both **bleeding and persistent changes** in their bowels to more frequent and/or looser should be referred for investigation at any age.

**If you are worried about bleeding and can’t get it off your mind, see your GP. It’s a perfectly good reason for going. You may need hospital investigation, to reassure you, even though you have little risk of bowel cancer.**

**PILES - OR CUSHIONS?**
The good news - bleeding from the bottom is common and natural for most of us - especially younger people - and most diagnoses of 'piles' probably aren't piles at all!

If we do go to the doctor/specialist with bleeding from the bottom, we're often told 'it's probably your piles'. Doctors think this reassures us but many people don't like the thought of having 'piles', believing they must have done something wrong (bad diet, bad habits, straining etc) to get them. Bleeding affects one in five of us in any year and can continue on and off throughout our lives.

The bleeding, usually short bursts for a few days at a time, comes from 'cushions' around the anus - natural spongy bulges of tissue and blood vessels which close the anal canal to hold in gases. Pass a hard motion or strain and they can bleed easily, especially when we're younger.
Are you sure it's piles, Doc?

It means different things to different folks: not going frequently, passing hard stools, bloating. Passing hard stools is less likely to be serious - it's persistently looser stools which need watching.

CONSTIPATION FACTS:

Bleeding for no reason is uncommon.
It mostly goes away with no treatment. Perhaps the word 'piles' should be kept for patients whose 'cushions' are so large they come through the anal canal and the patient has to push them back (prolapsed piles). These may need surgical treatment.
If you are straining and grape like little lumps appear around the anus, disappearing when you stop straining, they're normal too. Occasionally a painful clot can form in one of them - that's known as a thrombosed pile.

What can be done to control bleeding?
- Change your diet to more fibre/more fluids so that the motions are softer and easier to pass.
- Straining a lot is an important cause of bleeding or piles - some straining to start the bowels working is normal but try to avoid excessive straining.
- Try buying products at the chemists but, as bleeding tends to come and go, it can be hard to know if the product has worked.
- If bleeding is a nuisance and you are referred to hospital, injections or rubber banding can control it in the short term.

Many patients get bleeding on and off in early adult life, whatever is done to them. All hospital treatments involve some discomfort but this usually settles down quickly.

Larger piles - banding with a rubber band to shrivel them. Quick but does not always work.
Really large piles - usually surgery the only option but last resort. Recovery can be painful for a couple of weeks, especially when going to the toilet. Laser, infra-red and cryotherapy treatments have been tried in the past but are not usual treatments at the moment.
Common Symptoms in detail and what to do with them cont’d

CHANGE OF BOWEL HABIT

So common that most of us have these, usually with an obvious cause like overeating, drinking, foreign travel. What’s not generally known - changes can happen spontaneously, without a reason. Very few people have regular bowel habits all their lives.

• Not serious changes - they usually go away in 4 weeks.
• Longer changes should probably be investigated in hospital though most will not be cancer.

If you are taking laxatives, they can make you more frequent and looser. Only way to tell if you have a problem - come off the laxatives and see if your bowel habit goes back to normal. If you have noticed a recent change in your bowels, which won’t go away, especially if there is bleeding, go to your doctor.

Shape of poo

People get worried by the shape, especially if motions are long and thin, imagining this must be due to a narrowing of the bowel higher up, perhaps due to cancer. Don’t be alarmed. Shape is determined by the anal canal, the last bit of the bowel. If this doesn’t relax completely when you go to the loo for some reason, motions get long and thin.

FACT:

Scientists have categorised shape of "poo" in the Bristol Stool Chart - go to Google to find out more.
What to do if it’s in your family?

Bowel cancer affects one in ten families.

But that doesn’t mean you’re going to get it, if it is in your family. Rough rule of thumb: the closer the relatives are to you (brother, sister, mother, father, child) and the younger they were when diagnosed, the more you need to do something about it.

- One close relative under 45 affected (brother, sister, parent or child) talk to your GP about screening possibilities in your area.

- Two or more older close relatives from the same side of the family. The younger your relatives, the more need for you to discuss screening with your GP.

- Usual yardstick for screening - around 10 years before the age at which your youngest close relative developed the disease.

- If you have a less strong family history, say one grandparent who died in their 60s or 70s, you have very little life time increased risk and screening is no more appropriate for you than patients with no family history at all.

TV presenter Matthew Wright has the bowel cancer gene Lynch Syndrome (HNPCC) in his family. Lynn pushed him to be tested and luckily Matthew is the first male not to have the gene.

Talk to your GP if you are worried.

Talk about bowel cancer. You could help save your life or the life of someone in your family just by chatting about it and sharing this leaflet with them.
Women between 20-40 are most likely to have bleeding from the bottom, usually after having a baby. Young men also commonly bleed, but this decreases as we all get older.

**What other conditions could cause your symptoms?**

**Fissures** - split or tear in the lining of last tiny bit of the anal canal, sometimes caused by constipation - may cause bleeding which drips into the toilet bowl. Nearly always associated with severe pain when going to the toilet. Can be itchy, especially in women.

**Irritable bowel syndrome (IBS)** - this diagnosis should only safely be made after referral to hospital for examination. Very common - over one third of us will have irritable bowel symptoms each year and not be referred. Symptoms similar to bowel cancer but don’t persist, they come and go, with long stretches where the gut goes back to normal. Many IBS patients have recurring symptoms which need investigation at some time to make sure it is not more serious.

**Polyps** - warty like growths on the bowel lining. Most don’t have symptoms, don’t cause cancer and are not usually discovered unless you are having other tests. Larger polyps can cause bleeding and around 3 per cent are thought more likely to turn cancerous. Removing these can usually be done by an internal flexible probe (endoscope) without the need for an operation. By screening people over 50 for important polyps, it is thought most bowel cancers could be prevented in the future.

**Crohn’s disease** - painful inflammation of the gut. No one knows the cause - may be life long. More common in smokers. Long time sufferers may have a slightly increased risk of bowel cancer.

**Ulcerative Colitis** - where the bowel becomes red and inflamed. May be life long. Tends to come and go with symptoms like bleeding and mucus, less often pain (often after a ‘poo’) Long time sufferers, over 10 years, at increased risk.

**Diverticular disease** - becomes increasingly common as we get older. Half of us over 60 have some it. Most people have no symptoms, occasionally causes changes in bowel habits, abdominal pain and more rarely, severe inflammation, which occasionally needs major surgery to correct. It doesn’t predispose you to cancer.
What to do about them

**Abscess** - doctors need to be consulted and will either try a course of antibiotics or refer you to hospital for surgical treatment to cut the abscess and let out the pus.

**Piles** - as most symptoms go away, most people don't treat them. However, if symptoms persist, ask a good pharmacist/chemist for self-treatments like cream or suppositories. Some bleeding from piles is a nuisance and needs hospital treatment (injections, banding) or advice about changing your diet.

**IBS** - Fortunately for most people the symptoms tend to be mild, pass and need little or no treatment. If diarrhoea is the symptom - try a low fibre diet with or without constipating drugs like Lomotil and Imodium. Constipation - high fibre diet. Abdominal pain and bloating - major symptoms which are extremely difficult to treat - most settle by themselves or come and go so you get periods of relief. If symptoms persist, go to your doctor to exclude anything more serious. For some, IBS is a severe problem in their work and home lives, very difficult to cope with.

**Polyps** - can be removed by colonoscopy with a tiny electric snare and tested (biopsied) to make sure they are benign (safe). Some bleed but most will never turn to cancer.

**Crohn's disease and Colitis** - contact the National Association For Colitis and Crohn's Disease for booklets - details at the back.

**Fissures** - mostly treated by special creams which relax the muscles, or injections with Botox. Most people don't need surgery but, if they do, it's a very simple operation. Unfortunately it can leave some people, especially women, with leakage problems (mucus, even small amounts of stool.) In over 90 per cent of patients, the operation is excellent, has few complications and is a permanent cure.

**Diverticular disease** - major symptoms can be controlled by changes in the diet. Going to the loo more frequently? Unlike other bowel conditions, try reducing the amount of fibre you eat - try white bread and rice, avoid cereals with wheat fibres, reduce fruit, take normal amounts of veg. Loose stools - do the same but if changing the diet doesn't work, try anti-diarrhoea medication from the chemist. Only rarely should surgery be needed.

**Constipation** - change to a high fibre diet, more fluids.
Smoking, heavy beer drinking and eating lots of red meat increase the risk of bowel cancer.

FACT:

Some questions you might like to ask:

How quickly will I be seen?
Is it an urgent or a routine referral?
‘Urgent’ doesn’t mean you have cancer!
People with higher risk symptoms should be seen within two weeks of referral for investigation.
Most people with these symptoms do not have cancer but it should be ruled out.

How long is the waiting list for routine referral?
This varies around the country but it could mean several months. If lists are long and you are worried, say so.

What kind of investigation are you recommending?
Resources vary around the country and, depending on your symptoms, some tests may be better than others.

Am I seeing a specialist?
Ask if your GP knows the doctor to whom you are being sent, is he/she experienced in dealing with bowel cancer and what does your GP think of them.
Many people are now sent to diagnostic clinics run by specialist nurses or doctors.

Is the specialist part of a team?
If you do have cancer, research shows that patients treated by the team approach do better. That is, treated by a doctor or surgeon who is part of a multi-disciplinary team, where all the professionals involved in your care work together and hold meetings to discuss your care.
First another bit of reassurance: most people referred for investigation don’t turn out to have cancer. How you are investigated depends on what’s available at your hospital.

**Rigid sigmoidoscope (20 cm)**
Most patients probably get a quick look inside with one of these, like a thin short telescope. It takes a few minutes.

**Flexible sigmoidoscope**
A thin flexible tube, with a camera or light on the end. It can look inside the first 60-70 cms of the bowel. You may be given a treatment to clear the end of your insides to use at home that day or invited to hospital a little earlier. “Flexi sig” is safe, takes only a few minutes and gets further round the bowel than a rigid one, good for investigating most symptoms.

**Colonoscope**
A longer version of the sigmoidoscope, a long flexible tube which can look inside the whole colon. You take laxatives beforehand and stop eating sometime the day before, to clear out your insides.

Advice varies between hospitals but you can usually drink liquids like tea/coffee and a form of sedative is given for the procedure.

**Barium enema**
An X-ray examination with laxatives taken the day before to clear out the bowel. On the day, the colon is filled with a thick white liquid (barium sulphate) and X-rays taken from several angles. Problems with the bowel show up black against the white liquid.

**Virtual Colonoscopy**
Virtual colonoscopy is a bit like a computer game, using scanners and computers to look inside the bowel for polyps and signs of cancer. The scanner uses X-rays to produce two-dimensional and three-dimensional images of the colon and rectum. Lynn has made a DVD with St Mark’s Hospital of her own virtual colonoscopy.

See our videos on flexi sig and colonoscopy on www.bowelcancer.tv
St Mark’s hospital has made a training DVD with Lynn.
Medical professionals can baffle you with language. Here’s what the words they commonly use mean:

Anal canal - last bit of back passage
Anus - the very end of the rectum, on the surface of the bottom.
Clinician - a hospital (or bed) doctor, it comes from the Greek word.
Colectomy - surgery to remove part or all of the colon.
Colic - really severe abdominal or tummy pain which comes and goes.
Colorectal - of the colon and rectum, as in colorectal cancer.
Defaecation - poo.
Faeces - poo.
Flatus - wind (or a fart).
Haemorrhoids - piles, from the Greek for bleeding.

Hemicolecotomy - removal of half of the colon.
Incontinence - inability to hold in stools or urine (wee).
Laxative - medicine to soften constipated stools.
Motions - poo.
Oncologist - cancer doctor, from the Greek word for a 'mass' or lump, usually refers in the UK to chemotherapy/radiotherapy specialists.
Proctitis - inflammation of the rectum.
Rectum - storage area above back passage, contains sphincter muscle to hold back poo till we are ready.
Sigmoid - last bit of the colon, above the rectum.
Sphincter - ring of muscle in anal canal. from the Greek to ‘bind tight’.
Stools - poo.
Waste - poo.

Whatever you call it we’ve got to talk about it.

POO-POO!
No 2
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www.bowelcancer.tv

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www.haveigotbowelcancer.com

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Bowel Cancer symptoms?

Do you know the main symptoms? Try the traffic light test to find out what to do:

**RED - Highest risk symptoms:**
- Rectal bleeding with change of bowel habit to looser stools/going more frequently.
- Lump in tummy or rectum felt by doctor.
- Unexplained iron deficient anaemia.

**STOP** wondering what to do. If your symptoms persist for a few weeks see your GP - you’re likely to be referred to hospital for investigation at any age but 5 out of 6 people will NOT have cancer.

**AMBER - Higher risk symptoms which might need investigating:**
- Recent persistent change of bowel habit with no bleeding.
- Bleeding without any reason.

**WATCH & WAIT** - take up to four weeks to test your symptoms.
- try changing your diet and lifestyle, buy remedies from the chemist.
- if symptoms persist for four weeks whatever you try go to your GP.

**GREEN - A wide range of bowel symptoms which come and go without getting worse:**
- Bloating.
- Bleeding with a reason like straining.
- Change of habit to going less frequently.
- Harder stools or changed shape.
- Mild tummy pain which doesn’t affect your life.

**GO** on with your life reassured you do not have serious cancer symptoms but if they worry you or last for more than a few months, see your GP.

[www.bowelcancer.tv](http://www.bowelcancer.tv)