Long-term pelvic pain:
information for you

Royal College of Obstetricians and Gynaecologists
Setting standards to improve women's health

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Contents

Key points

- Pelvic pain is any pain in the lower abdomen or pelvis. Long-term pelvic pain is pain that persists for at least six months.
- Long-term pelvic pain is common. It affects around one in six women.
- Long-term pelvic pain is a symptom, not a diagnosis.
- It is often due to a combination of physical, psychological and/or social factors and should be managed or treated 'as a whole', rather than as a single underlying condition.
- If a cause for long-term pelvic pain cannot be found, women may have fears that people will say it is 'all in the mind'.
- Whether or not a cause for long-term pelvic pain is found, doctors work in partnership with women to discuss a treatment and management plan.

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About this information

This information is intended to help you if you have long-term pelvic pain. It is based on the Royal College of Obstetricians and Gynaecologists (RCOG) guideline **The Initial Management of Chronic Pelvic Pain** (published by the RCOG in April 2005).

This information tells you about:

- the main factors that may contribute to long-term pelvic pain
- what your doctors can do to investigate and identify the cause of your pain
- the most effective methods recommended in the UK for managing long-term pelvic pain.

This information tells you about the recommendations the RCOG guideline makes and aims to help you and your healthcare team make the best decisions about your care. It is not meant to replace advice from a doctor or nurse about your own situation. This information does not tell you about what can be done for women whose initial treatment has not been successful. It does not tell you in detail about conditions that may be the cause of long-term pelvic pain, or about treatments for those conditions. For further information about these conditions see the section on **Other organisations**.

➢ Some of the recommendations here may not apply to you. This could be because of some other illness you have, your general health, your wishes, or some or all of these things. If you think the treatment or care you get does not match what we describe here, talk about it with your doctor, nurse or another member of your healthcare team.

What is long-term pelvic pain?

Pelvic pain is any pain you feel in the lower abdomen or pelvis. Healthcare professionals consider pelvic pain to be long-term if:

- you experience it either constantly or intermittently for at least six months
- it happens at times other than when you have your period or sexual intercourse.

Long-term pelvic pain is common. It affects around one in six women. Long-term pelvic pain is not a diagnosis in itself but a description of a symptom.

What could long-term pelvic pain mean for me?

How we experience pain is an individual matter and may depend upon any number of factors. Long-term pain can be very difficult to live with. It may cause you emotional, social and even economic difficulties. You may experience depression, difficulties in

sleeping and a disruption to your daily routine. Your may fear the worst about your pain, believing that it means you have cancer or you have a serious problem that may affect you having a baby. You may have fears that people will say your pain is 'all in the mind'. The pain is not 'all in your mind'.

The reasons for long-term pelvic pain are not always easy to diagnose. It is not always possible to treat. Women may need support in managing and coping with their pain.

Even if no reason can be found for the pain, many women find that the quality of their lives improves when they get a better understanding of what is involved.

What causes long-term pelvic pain?

In many cases, your healthcare professional will not be able to identify an underlying problem or give a clear diagnosis and he or she will only be able to assure you that there is no serious medical problem.

Long-term pelvic pain is often caused by a combination of physical, psychological and/or social factors, rather than a single underlying condition.

These factors include:

- endometriosis (a condition where cells of the lining of the womb (the endometrium) are found elsewhere in the body, usually in the pelvis)
- adenomyosis (a condition where the endometrium is in pockets within the muscle wall of the womb)
- pelvic inflammatory disease (PID) (an infection of the womb, fallopian tubes and/or pelvis)
- interstitial cystitis (bladder inflammation)
- musculoskeletal pain (pain in your joints, muscles, ligaments and bones)
- irritable bowel syndrome (IBS)
- depression, including postnatal depression
- previous or ongoing traumatic experiences such as sexual abuse in some women
- adhesions (areas of scarred tissue that may be a result of a previous infection, endometriosis or surgery) – although these are common, they do not always cause pain
- trapped or damaged nerves in the pelvic area.

For some women with long-term pelvic pain none of these factors may be found.

What happens when I first see the doctor?

At your first appointment, you should have the chance to 'tell your story', describe the pain you have experienced and discuss your anxieties. Your doctor will take your concerns seriously and listen. By working in partnership with you, he or she will aim to identify the cause(s) of your pain. Although at times you may feel you are repeating yourself, your story is important. The way you describe your symptoms is crucial in making a diagnosis. Your doctor will probably ask you a number of questions about:

- the pattern of your pain
- what makes your pain better or worse
  (certain sorts of movement, for example)
- whether you have noticed other problems that might be linked to the pain (intercourse, bladder, bowel or psychological symptoms, for instance).

You may be asked about aspects of your everyday life including your sleep patterns, appetite and general wellbeing. You may also be asked about how you are feeling and whether you are feeling depressed or tearful. This is because long-term pain is known to cause depression, which in turn may make your pain worse. If your healthcare professional knows how your pain is affecting you personally, this can be taken into account with your treatment.

Your doctor should explain the various factors that can lead to long-term pelvic pain (see section 'What causes long-term pelvic pain?').

What types of tests might I be offered?

Tests do not always involve getting a report from a laboratory. Your own history and the way you describe the pattern of your pain can provide much more valuable information or results. Because of this, you may be asked to keep a 'pain diary'. This involves noting down when your pain occurs, how severe it is, how long it lasts and the things that seem to affect it. A pain diary will also help you to describe your pain and to become more aware of the ways in which it affects you.
Then depending upon your own situation, you may be offered any of the following types of tests:

- You will probably be offered an ultrasound scan.
- You may be offered screening tests for sexually transmitted infections.
- If your pain is related to psychological, bladder or bowel symptoms, your consultant may refer you to a specialist or suggest you see your GP. If you have bowel symptoms, for example, you may be referred to a gastro-enterologist who may offer you tests for irritable bowel syndrome (IBS).

- If your pain occurs on a regular basis at a specific time in your menstrual cycle, then you may be offered drugs to suppress your periods for a few months. This may help your doctor in making a diagnosis.
- You may be offered a diagnostic laparoscopy. This is a procedure carried out under general anaesthetic. It involves a small cut in the abdomen to examine your reproductive organs and look for any abnormality, problems or damage. The surgeon will insert a tiny telescope (called a laparoscope) so that your reproductive organs can be seen more clearly. As with any surgical procedure, there are risks and benefits and these will be explained fully to you when you are offered the test.
- If your health professional thinks that your pain is due to a particular cause, you may be offered treatment on a 'try it and see' basis. Such treatment could help you to avoid a diagnostic laparoscopy, which carries small but significant risks.

What treatment may help?

Whatever your situation, you may be offered painkillers. If these do not help to control your pain, you may be referred to a pain management team or a specialist pelvic pain clinic. Depending on the type of your pain you may also be offered other treatment.

You should be offered treatment and advice if:

- your pain is related to your menstrual cycle and you have heavy periods
- your pain varies with movement
- you have symptoms suggestive of irritable bowel syndrome
- you may have symptoms suggestive of a sexually transmitted infection or PID.

Your doctor will provide you with full information about all treatment options.

Are there any risks?

Your doctor or specialist practitioner should give you full detailed information about the risks and benefits of any investigation, surgical procedure and treatment suggested. There are no risks associated with having an ultrasound scan.

Are there any alternatives?

Depending on your circumstances, you may have a range of possible options. You may be offered a combination of two or more types of treatment, such as medical treatments with tablets or injections (for example, pain relief or hormone treatment), surgery or pain management strategies. Some people find that complementary therapies can help to manage the pain.

What might happen if I don't have treatment?

Your doctor may not be able to predict what might happen for you as an individual. For many women the pain gets better with time. Most women have no serious or life-threatening problem underlying the pain. Many women find that they can cope better with their pain after they have been given a thorough explanation of the nature of the pain, including previous test results and possible causes of the pain. They can also cope better when they feel reassured that there is no serious or life-threatening disease present.

Is there anything else I should know?

- You should visit your doctor if you experience any of the following:
  - bleeding from your rectum
  - a change in your bowel habits which has lasted for more than six weeks
  - new pain after you have passed the menopause
  - any unusual swelling in your abdomen
  - suicidal thoughts
  - excessive weight loss
  - irregular vaginal bleeding, such as bleeding between periods, or vaginal bleeding after the menopause or vaginal bleeding during or after sex.
- No treatment can be guaranteed to work all the time for everyone.
- You have the right to be fully informed about your health care and have the opportunity to share in making decisions about it. Your healthcare team should respect and take account of your wishes.
- If you are not comfortable with the final diagnosis, you can ask for a second opinion.

Sources and acknowledgements

This information is based on the Royal College of Obstetricians and Gynaecologists (RCOG) guideline **The Initial Management of Chronic Pelvic Pain** (published by the RCOG in April 2005). The guideline contains a full list of the sources of evidence we have used. You can find it online at: **www.rcog.org.uk/index.asp?PageID=1124**.

Clinical guidelines are intended to improve care for patients. They are drawn up by teams of medical professionals and consumers' representatives, who look at the best research evidence there is about care for a particular condition or treatment. The guidelines make recommendations based on this evidence.

This information has been developed by the Patient Information Subgroup of the RCOG Guidelines and Audit Committee, with input from the Consumers' Forum and the authors of the clinical guideline. It was reviewed before we published it by women attending clinics in London, Oxford and Southampton. The final version is the responsibility of the Guidelines and Audit Committee of the RCOG.

Other organisations

IBS Network
Unit 5
53 Mowbray Street
Sheffield S3 8EN
Helpline: 0114 272 3253
(Mon-Fri, 6-8pm; Sat 10am-noon)
Email: info@ibsnetwork.org.uk
Web: www.ibsnetwork.org.uk
Web: www.ibsnetwork.org.uk/JuniorNetwork

Women's Health
52 Featherstone Street
London EC1Y 8RT
Helpline: 0845 125 5254
(Mon-Fri, 9.30am to 1.30pm)
Minicom: 0207 490 5489
Web: www.womenshealthlondon.org.uk

National Endometriosis Society
50 Westminster Palace Gardens
Artillery Row
London SW1P 1RR
Helpline: 0808 808 2227
Email: nes@endo.org.uk
Web: www.endo.org.uk