



SIGN

Scottish Intercollegiate Guidelines Network
Part of NHS Quality Improvement Scotland



Cancer pain

Booklet for patients and carers



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purpose of implementation in NHSScotland

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What is this booklet about?

This booklet is for adults with cancer who experience pain. It is also for their carers. It is based on the recommendations from a national clinical guideline on how to look after patients with cancer who have pain. This booklet will tell you about:

- different types of pain;
- different treatments available from the NHS;
- side effects from treatment; and
- how pain is assessed.

It will not cover information on how pain in children under 12 is treated, the way medications act in your body or on medications not used in Scotland.

We have listed a number of support organisations, where you can get more information, on page 21.

We have explained the medical terms used in this booklet on page 28.

What is cancer pain?

Pain happens when tissues in the body are damaged. Pain may sometimes be more than a physical condition. It can affect your emotions, mindset, relationships and spirituality.

Do all patients with cancer experience pain?

Just because you have cancer doesn't mean that you will have pain. There are many people who have cancer and do not have any pain. If you have cancer and have pain, it may not be caused by the cancer itself. Pain can be caused by your cancer treatment, for example surgery, chemotherapy or radiotherapy.

Your pain may also be caused by other things or conditions other than the cancer. Pain associated with cancer can increase if the cancer gets worse. You should receive a full assessment from your health-care professional to help find out what is causing your pain (see page 7).

How can I talk about my pain?

If you have been diagnosed with cancer you should ask your health-care professional about the treatments that are available. If you are experiencing pain, you need to tell your health-care professional right away. The earlier you tell your health-care professional about the pain, the better they can help you.

It is important that you, your family and carers have good communication with your health-care professional. Your care and treatment is a partnership between yourself and your health-care professional. You must tell them about all of your pain and how it affects you. If you have questions about treatment you are having to treat your pain, you should ask your healthcare professional. You have the right to have your pain controlled in the best possible way.

Do not feel embarrassed or uncomfortable when you talk about your pain. The more details you can provide, the better your health-care professional can help.



What will happen?

Pain from cancer can affect your whole life. Your health-care professional will assess your pain and consider your physical and mental wellbeing.

For most patients, pain can be reduced effectively by using a range of treatments.

You should discuss your beliefs and understanding about your treatment with your health-care professional. They will monitor your progress and change your treatment when necessary. Your GP, specialist nurse or hospital doctors may change your medication.

Will how I feel affect my pain?

Your emotions and feelings can affect your pain.

Positive feelings can help you reduce your pain or help you to cope with it.

- If you have support from family and friends and you understand what is going on, your pain may not feel so bad. Having a member of your family or a friend to talk to and being able to talk with someone who understands your pain can help you cope with negative feelings such as anger, fear or being alone.
- Keeping mentally, physically and socially active (for example, reading, exercising and seeing friends), can help you feel better about yourself and you may feel less pain.
- It is important to get enough sleep. You may need to take time during the day to rest if you feel tired.
- If you are depressed or feel anxious, you may need to get help from a professional. Ask your health-care professional about therapies that may help you.



Do not feel that you have to cope with pain on your own. Support from family and friends can help, as well as support from support groups and professionals.

Why should pain be assessed?

Pain can affect every area of your life. If you are experiencing pain, it can limit your ability to care for yourself.

How will my pain be assessed?

Your health-care professional will find out what type of pain you have and the amount of pain you are experiencing by asking you questions and using assessment scales (these rate your pain, using words, numbers or pictures).

Your health-care professional will treat you as an individual and will listen to you.



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Questions

Your health-care professional will ask you questions to help identify the type of pain you are having. These questions help them to assess your pain and choose the best treatment for you.

These are some of the questions that you may be asked

- ⦿ What does the pain feel like?
- ⦿ Where is the pain or pains?
- ⦿ Is the pain there all the time?
- ⦿ How long have you had the pain?
- ⦿ Has the pain spread to other areas?
- ⦿ How bad is your pain? (You may use one of the pain assessment scales to answer the questions. This should be your assessment of the pain, not someone else's).
- ⦿ What makes the pain worse?
- ⦿ What makes the pain better?
- ⦿ Does the pain affect your relationships?
- ⦿ What are your spiritual beliefs about pain and treatment?
- ⦿ What are your fears about treating your pain?

Assessment scales

Your health-care professional will use pain assessment scales to help decide how bad your pain is. These are examples of the different types of scales.

- ① **Number scale** - this scale asks you to rate the pain using numbers, for example, from 0 to 10.
0 = 'no pain'
10 = 'severe pain' or 'the worst possible pain'
- ② **Word scale** - this scale asks you to rate your pain by using the words 'none', 'mild', 'moderate', or 'severe'.
- ③ **Visual scale** - you can use this scale if you are not able to use the two above. This scale shows a picture of a line usually marked 0 at one end and 10 at the other.
0 = 'no pain'
10 = 'severe pain' or 'the worst possible pain'

If you care for someone who has problems communicating, ask their health-care professional about other assessments you could use.

Pain is different for each person. This is why it is important for the health-care professional to find out about the pain from the person who has the pain.

When you are seeing a health-care professional for pain from cancer, you should take a list of all the medications you are taking. This is especially important on your first visit. This will help your health-care professional assess how best to treat your pain.

What treatments will I receive?

Your treatment will be based on the type of pain, the cause of the pain and the amount of pain you suffer. The World Health Organization (WHO) uses a diagram called the 'three-step ladder' to relate the level of pain to specific drug treatments. Once your pain has been assessed and your health-care professional has chosen a drug treatment, you will be monitored to see if the treatment is working. Your medication and the amount you will be given may change. If your pain increases then your treatment may change.

Ongoing pain

You have this type of pain most of the time, unless you take medication. You must take your medication regularly to keep the pain away. You will be told how often to take your medication and you should stick to this for the best results.

Breakthrough pain

Some people may experience 'breakthrough' pain – a type of pain that happens either 'out of the blue' or every time you move in a certain way. It can be sudden and severe pain and should be treated quickly. As soon as you feel a breakthrough pain starting, you should take the fast-acting medication prescribed to you (see page 13).



It is important to take medications to relieve pain exactly as they have been prescribed to you. Paracetamol is a simple medicine that relieves pain, but when used with other medications it can greatly reduce your pain. If your health-care professional prescribes paracetamol, you should take it as they tell you to. Often, one type of medication can work better when taken with another medication.

There are two types of pain medication.

Slow-acting pain medications are released gradually into your body. They take one to two hours to start reducing pain and they last a longer time (12 to 24 hours depending on the type of tablet or capsule you are prescribed). They help control your pain daily, so you must take them regularly (usually once or twice a day).

Fast-acting pain medications act quickly but wear off faster, usually within a few hours. They are taken when you have breakthrough pain or when you first start on strong pain medication. The pain should go within 30 to 60 minutes. If this doesn't happen, you should contact your health-care professional right away.

Medications may have more than one action or effect. For example, amitriptyline and imipramine were first used to treat depression. Gabapentin, carbamazepine and phenytoin are usually used to treat epilepsy, but are also prescribed to control pain.

If you know that one of your medicines is used for another condition and you are worried about this, talk to your health-care professional or pharmacist. The usual answer is that the medication can help with more than one condition, even though it does not say this in the information leaflet enclosed with your medication.

How can I manage my pain?

You should be involved in your treatment plan, if this is what you want. You should be given information about the type of pain you have and instructions on the best way to manage it. The more involved you are in managing your pain, the better your results are likely to be. Don't be frightened to ask questions about your pain or medications.

The more you know and understand about your treatment, the better you will be able to help yourself.

What are the common side effects of treatment?

Some treatments have common side effects and it is helpful to know about these. If you start to have any side effects, you should talk to your health-care professional. This is a list of the most common side effects.

- **Constipation** - Almost all patients taking medication for moderate to severe pain will develop constipation. Constipation is when you have trouble opening your bowels. Your health-care professional will usually prescribe a laxative (a drug used to help you go to the toilet) as well as your medication to relieve pain. If they do not, then you should ask for a laxative.
- **Nausea (feeling sick) and vomiting** - When you are first prescribed a strong medication to relieve your pain, you may feel sick, and some people vomit. These symptoms should stop within two to three days. You may need to take a pill to stop you from feeling sick. If you still feel sick after three days, despite taking a pill to stop you from feeling sick, contact your health-care professional.
- **Gastrointestinal bleeding** - This is bleeding in your digestive system. You may have a higher risk of getting swelling, ulcers or bleeding in your digestive system if:
 - you smoke;
 - you have another illness as well as your cancer; or
 - you use certain medicines to relieve pain over a long period of time.

If you do smoke, you should consider stopping. Your health-care professional may prescribe you another medication to take, as well as medicines to relieve pain, which will help to prevent damage in your digestive system.

Can I become addicted to pain medication?

It is possible for you to develop a physical need for the medication. If you suddenly stop taking strong pain medication, you may get withdrawal symptoms such as chills, stomach pain, or diarrhoea. Talk to your health-care professional before you stop taking your medication.

It is very unlikely that you will become psychologically addicted to pain medication, and you should not refuse medication because you are scared of becoming addicted. You should discuss any worries you have with your health-care professional.

What are my other options for treatment?

Cognitive behavioural therapy (CBT)

This therapy focuses on the relationship between your thoughts (cognitive) and your actions (behaviour). The idea behind CBT is that the way you think about pain may affect the way you handle it. CBT allows you to talk about this with a health-care professional, either on your own or in a group session.



Complementary therapies

There are many other options available to treat pain. Often it is not clear if these therapies really relieve pain. There is either no scientific proof or very little proof to say that the following treatments are effective at reducing pain.

- Massage and aromatherapy - Using aromatic oils and rubbing the body to improve circulation, reduce a build-up of fluid, reduce muscle spasms and improve muscle tone.
- Music therapy - Using music to help you relax.
- Acupuncture - A Chinese medicine which involves having needles placed into your skin to help you relax.
- Transcutaneous electrical nerve stimulation (TENS) - A treatment that uses pulses of low-voltage electricity to relieve pain.
- Reflexology - Where firm pressure is applied to reflex points using the thumb or fingers.
- Hypnotherapy - A person is put into a sleeplike state, when the mind is said to be more open to suggestions and past memories than usual.
- Reiki - A therapist can channel energy into you, through touch.

Some people do find complementary therapies helpful. If you try one of these therapies, you should continue to take your prescribed pain medication. Do not change or stop taking your medication without first discussing it with your health-care professional. Many of these treatments are relaxing and this can make pain easier to cope with.

How can I help myself?

Here are a few ideas that may help you control and cope with your pain.

- **Keep a diary of your pain** - This should include the details of your pain and how much medication you are taking. You should write down how bad your pain is each day using the assessment scales (see page 9), how many times you have taken your breakthrough medication and the amount of medication you take each day. It is also a good idea to list all of the medications you take every day. This will help your health-care professional understand the pain you are having and help them make any changes to your treatment.

PAIN DIARY Note perception of pain on scale 1-10 each day at different times of the day and note any comments
e.g. extra painkillers taken, specific activity e.g. gardening

0 = no pain **1-3 = occasional mild pain. I can live with symptoms** **4-5 = Moderate pain which limits some activities** **6-10 = Severe pain present. Activities and concentration markedly affected**

			MON	TUE	WED	THU	FRI	SAT	SUN
Week 1	Pain level	Morning							
		Evening							
	Comments								
Week 2	Pain level	Morning							
		Evening							
	Comments								
Week 3	Pain level	Morning							
		Evening							
	Comments								
Week 4	Pain level	Morning							
		Evening							
	Comments								

- **Talk to other patients** - You and your family may find it helpful to talk to people who have been through a similar experience. Many organisations offer information and support groups for people who are experiencing cancer pain (and their families). Contact details for some of the organisations providing help are also listed on page 21.
- **Monitored dosage system** - If you have problems remembering to take your medication or don't know which medication to take on what day, a monitored dosage system may help. An example of this is a dosette box which your community pharmacist or health-care professional will give you. A monitored dosage system helps you keep track of your daily medicine.



Ask your health-care professional if you would like more information on any of these options.

You and your health-care professional must work together to treat your pain. Communication is important. If your pain has not improved and you want to see a pain specialist, ask your health-care professional to arrange this.

You also need to know about the financial and care benefits that are available to you. There is help available for you to carry out everyday tasks and to help you claim any benefits you are entitled to. Your local social work department and citizens advice bureau will give you advice and help with these arrangements. Some other organisations which provide this help are listed on page 21.



Where can I find more information?

Cancer Help UK

Website: www.cancerhelp.org.uk

CancerHelp UK is the patient information website of Cancer Research UK. It provides free information about cancer and care for people with cancer and their families. It includes information on cancer and how to control pain.

Cancer in Scotland

Scottish Executive Health Department

St Andrew's House, Regent Road

Edinburgh, EH1 3DG • Fax: 0131 244 2989

Website: www.cancerinScotland.scot.nhs.uk/

E-mail: cancer@scotland.gsi.gov.uk

Cancer in Scotland identifies the wide range of actions needed to prevent, detect and improve treatment and care for people with cancer in Scotland.

Carers Scotland

The Cottage, 21 Pearce Street

Glasgow, G51 3UT

Phone: 0141 445 3070

Website: www.carerscotland.org

E-mail: info@carerscotland.org

Carers Scotland aim to improve support for carers, by giving policy makers and professionals working with carers relevant information.

CLAN Cancer Support

Clan House, Caroline Place

Aberdeen, AB25 2TH

Phone: 01224 647000 • Fax: 01224 640802

Website: www.clanhouse.org

E-mail: enquiries@clanhouse.org

Provides information and support to people with cancer and their families. Covers Grampian, Orkney, and Shetlands.

Crossroads Caring Scotland

24 George Square

Glasgow, G2 1EG

Phone: 0141 226 3793 • Fax: 0141 221 3793

Advice line: 0141 353 6504

Website: www.crossroads-scotland.co.uk

E-mail: info@crossroads-scotland.co.uk

Crossroads is Scotland's largest provider of short breaks and practical support for carers. They represent 46 local services throughout the country that provide opportunities for carers to take time for themselves. Their services are available to all carers whatever their age, disability or the illness the person they are caring for has.

Macmillan Cancer Support (Scotland)

132 Rose Street

Edinburgh EH2 3JD

Phone: 0131 260 3720 • Fax: 0131 260 3750

Website: www.macmillan.org.uk

E-mail: agow@macmillan.org.uk

The Scottish office of the UK charity, which supports people with cancer and their families with specialist information, treatment and care.

Maggie's Centres Scotland

Website: www.maggiescentres.org

E-mail: enquiries@maggiescentres.org

The aim of Maggie's Centres is to help people with cancer to have as healthy minds and bodies as possible and help them be involved in their medical treatment and recovery.

Maggie's Dundee

Ninewells Hospital, Tom McDonald Avenue

Dundee, DD2 1NH

Phone: 01382 632999 • Fax: 01382 632998

E-mail: dundee@maggiescentres.org

Maggie's Edinburgh

The Stables, Western General Hospital

Crewe Road

Edinburgh, EH4 2XU

Phone: 0131 537 3131 • Fax: 0131 537 3130

E-mail: edinburgh@maggiescentres.org

Maggie's Fife

Victoria Hospital

Hayfield Road

Kirkcaldy, KY2 5AH

Phone: 01592 647997 • Fax: 01592 207579

E-mail: fife@maggiescentres.org

Maggie's Glasgow

The Gatehouse, Western Infirmary

10 Dumbarton Road

Glasgow, G11 6PA

Phone: 0141 330 3311 • Fax: 0141 330 3363

E-mail: glasgow@maggiescentres.org

Maggie's Highlands

Raigmore Hospital, Old Perth Road

Inverness, IV2 3UJ

Phone: 01463 706306 • Fax: 01463 706305

E-mail: highlands@maggiescentres.org

Maggie's Lanarkshire

Flat 78, residential accommodation

Wishaw General Hospital

50 Netherton Road

Wishaw, ML2 0DP

Phone: 01698 358392 • Fax: 01698 366943

E-mail: lanarkshire@maggiescentres.org

Marie Curie Cancer Care (Scotland)

29 Albany Street, Edinburgh, EH1 3QN

Phone: 0131 456 3728 • Fax: 0131 456 3711

Website: www.mariecurie.org.uk

Marie Curie Cancer Care, a care charity, provides practical nursing care at home and specialist care across its 10 Marie Curie Centres.

Pain Association Scotland

Cramond House, Cramond Glebe Road

Edinburgh, EH4 6NS

Phone: 0131 312 7955 • Fax: 0131 312 6007

Freephone: 0800 783 6059

Website: www.painassociation.com

The Pain Association Scotland is for all cancer patients suffering from pain. They offer patients and their carers the chance to join support groups.

Princess Royal Trust for Carers

Charles Oakley House, 125 West Regent Street

Glasgow, G2 2SD

Phone: 0141 221 5066 • Fax: 0141 221 4623

Website: www.carers.org.uk

E-mail: infoscotland@carers.org

The Princess Royal Trust for Carers is the largest provider of support services for carers in the UK. They currently provide quality information, advice and support services to almost 310,000 carers, including over 15,500 young carers.

Samaritans

The Upper Mill, Kingston Road

Ewell, Surrey, KT17 2AF

Phone: 020 8394 8300 • Fax: 020 8394 8301

Website: www.samaritans.org.uk

E-mail: admin@samaritans.org

Helpline: 08457 90 90 90

E-mail: jo@samaritans.org

Write to:

Chris, PO Box 9090

Stirling, FK8 2SA.

Samaritans is available 24 hours a day to provide confidential and emotional support for people who are feeling despair and distress and may be thinking about suicide.

Tak Tent Support (Scotland)

Flat 5, 30 Shelley Court

Gartnavel Complex

Glasgow, G12 0YN

Phone: 0141 211 3398 • 0141 211 0010

Website: www.taktent.org

E-mail: taktent4u@gmail.com

Offer information, support, education and care for people with cancer, their families and friends and professionals. They have support groups throughout Scotland.

Useful websites

www.healthtalkonline.org/

Healthtalkonline is the website of the DIPEX charity and replaces the website formerly at dipex.org. Healthtalkonline lets you share in other people's experiences of health and illness. You can watch or listen to videos of the interviews, read about people's experiences and find reliable information about conditions, treatment choices and support.

Department for Work and Pensions (DWP)

www.dwp.gov.uk

The DWP website can give you details on benefits you may be entitled to.

Definitions

Acupuncture – a therapy where fine needles are inserted into the skin at specific points on the body.

Amitriptyline – a drug used for treating depression that also relieves pain.

Carbamazepine – a drug used to treat epilepsy that also relieves pain.

Cognitive behavioral therapy (CBT) – a therapy that focuses on your thoughts and beliefs and how they affect your actions and behaviour.

Complementary therapies – various forms of therapy that can be used alongside traditional medicines.

Constipation – a condition in which a person has difficulty opening their bowels.

Digestive system – the system in the body that processes your food.

Gabapentin – a drug used to treat epilepsy that also relieves pain.

Health-care professional – a person who has contact with patients and provides them with medical treatment (for example a doctor, nurse or therapist).

Hypnotherapy – a form of psychotherapy that puts a person into a sleeplike state, where the mind is more than usually open to suggestions and past memories.

Imipramine – a drug used to treat depression that also relieves pain.

Laxative – a drug used to increase bowel movements.

Massage and aromatherapy – a complementary therapy using aromatic oils to rub your body to improve circulation, reduce a build-up of fluid, reduce muscle spasms and improve muscle tone.

Music therapy – a complementary therapy which uses music to help patients to relax.

Paracetamol – a drug used to treat mild and moderate pain and reduce fever.

Phenytoin – a drug used to treat epilepsy that also relieves pain.

Physical pain – an unpleasant sensation in the body

Reflexology – a therapy based on the theory that reflex points on the feet connect with all parts of the body. Firm pressure is put onto the points using the thumb or fingers.

Reiki – a therapy which involves a therapist putting their hands on or very close to you to boost your natural and invisible energy.

Relaxation therapy – treatment that teaches you to become less anxious by relaxing your muscles.

Spirituality – a sense of meaning to life which gives a person identity, belief systems and a place in the world.

Transcutaneous electrical nerve stimulation (TENS) – a treatment that introduces pulses of low-voltage electricity to relieve pain.

Ulcer – a break in the skin, or in a thin layer of tissue lining the area inside the body that digests your food, that does not heal and often swells.

Notes

Notes

What is SIGN?

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice to doctors, nurses, surgeons, physiotherapists, dentists, occupational therapists and patients about the best treatments that are available. We write these guidelines by working with doctors, nurses and other NHS staff and with patients, carers and members of the public. The guidelines are based on the most up-to-date evidence.

Other formats

If you would like a copy of this booklet in another language or format (such as large print), please phone Karen Graham, Patient Involvement Officer, on 0131 623 4740, or e-mail her at karen.graham2@nhs.net.



This booklet is based on a clinical guideline given to all NHS staff.

The guideline was developed by the Scottish Intercollegiate Guidelines Network (SIGN). It is based on the most up-to-date medical evidence.

You can download the full clinical guideline from the SIGN website at www.sign.ac.uk/pdf/SIGN106.pdf

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