

Best supportive care for people with cancer - a palliative care approach

This leaflet is for people who are terminally ill and their friends and family. We hope you will find this information helpful in planning ahead and helping you to feel more in control. You may find some of the sections difficult to read and talk about so it can be helpful to dip in and out when you feel able.

A diagnosis of cancer can be life-changing for you and for the people close to you. Cancers that are diagnosed at an advanced stage may mean that treatment to cure the cancer is not possible. Hearing this news can be difficult. Treatments such as chemotherapy can be helpful at slowing down the growth and spread of cancer for some people. Radiotherapy can be helpful for managing a specific pain or managing other symptoms. As these treatments do not cure the cancer you may hear them called palliative treatments.

However, sometimes these treatments may not help, are no longer effective, or there are no further treatments available. Sometimes cancer treatments may not be safe, for example, if the person with cancer has other medical problems or is unwell or frail. Some people with cancer may choose not to have treatment, especially if their doctor does not feel it is likely to be very effective at making their life longer or better. Sometimes patients will want to try cancer treatments to see if they will help, but there is a risk that cancer symptoms may get worse rather than better, and after a time, many cancer treatments lose their effect. In these situations, there are other ways we can help manage your symptoms and ensure support is available to you. You might hear this called palliative care or best supportive care.

Best supportive care is important, whether you are on treatment or not. Some patients will remain well with no cancer symptoms for a long time and other patients will have a lot of cancer symptoms from the start of their diagnosis.

Best supportive care aims to:

- Help with managing symptoms such as pain, sickness or problems eating
- Help you and the people you care about come to terms with a diagnosis of cancer and what it means
- Help you to talk and plan for the future. This can be hard to do but it can also help you feel more prepared and in control
- Support you and your family to manage at home, if that is what you wish.

Best supportive care is provided by a combination of people and services, including general practitioners (GPs), district nurses (DN), cancer nurse specialists (CNS), hospital doctors and specialist palliative care teams. For people living at home, their GP and district nurses are usually their main point of contact.

Managing Symptoms

You may experience a range of symptoms due to your cancer. For example, tiredness, reduced appetite, breathlessness, or pain. For most people at home, the GP should be the first point of contact to assess and manage any symptoms. Your cancer nursing team, district nurse and sometimes the specialist palliative care team may also be involved. It is important that you tell your healthcare team if you have symptoms which are not controlled. They may suggest referring you to other healthcare professionals, for example a dietician if you need specialist advice and support.

Planning ahead (anticipatory care planning, sometimes called 'ACP')

What is important to you?

Many people want to plan ahead, even although the future may be uncertain. It is often helpful to think about what is important to you and talk about your wishes with the people close to you.

Thinking about your answers to the following questions can help you when we talk to you about your care:

- What do you know about your illness?
- What really matters to you when you think about your health?
- What matters to you the most when thinking about your future?

People find it reassuring to make plans and know they have sorted things out for the future, for example putting your affairs in order, considering life insurance/pension policies and thinking about funeral plans. If you have not already done so, it is helpful to write a will which ensures your wishes are followed. You may also want to consider appointing a Power of Attorney (POA), allowing a chosen person to make decisions for you, if you are no longer able.

This can be emotional but knowing your wishes can make it easier for your family or loved ones to know how and where you would like to be cared for at the end of your life. We know that people who are able to plan ahead are more likely to have the kind of care they would choose when they become less well. For many people, this involves spending less time in hospital and more time at home.

The Scottish Government and Health Improvement Scotland have developed a useful online document on planning ahead, which you might find helpful, called My Anticipatory Care Plan:

www.ihub.scot/media/1982/my-acp.pdf



Talking with your GP

You can talk through your wishes with your GP and other health care professionals who may be involved in your care. Having a discussion with your GP can help with the following:

- Avoiding unplanned admissions to hospital, by managing symptoms at home
- Stopping any unnecessary medicines
- Cancelling any routine hospital appointments which are no longer likely to be helpful
- Updating an electronic Key Information Summary (eKIS) which holds important information about your wishes and is available to health professionals when the GP surgery is closed
- Arranging anticipatory, or ‘just in case’ medications for you to have at home. These are medications including painkillers that can be given by injection if necessary. If your usual oral medications do not help or you are unable to take them, you can contact the district nursing team and they can visit to give you an injection
- Talking to you about ‘DNACPR’- a phrase we use to allow people to record their wishes about resuscitation. Scottish Government/NHS Scotland Decisions about cardiopulmonary resuscitation is a useful website which explains more:[Cardiopulmonary resuscitation decisions: information for patients, relatives and carers - gov.scot \(www.gov.scot\)](https://www.gov.scot/resources/publications/dnacrpd/decisions-about-cardiopulmonary-resuscitation-information-for-patients-relatives-and-carers.pdf)



Predicting your prognosis

Cancer does not always cause symptoms immediately, and some people live with cancer for some time before it affects their life. Cancer symptoms can change over time. Patients often ask how long we think they may live. This is always a very difficult thing to predict but we use our knowledge of your cancer as well as how you are feeling, and your symptoms, as a guide. If your life is fairly normal for you and you have few cancer symptoms then it might be measured in many months, or even sometimes years. If symptoms are changing or getting worse month by month then your life expectancy could be measured in months. If you are spending much more time resting and lying down and your symptoms are getting worse week by week then it might be measured in weeks. If the cancer is affecting you so badly that you cannot get out of bed and things are getting worse each day then it might be measured in days. If this is something that you would want to discuss more, your GP or district nurse, or another health care professional involved in your care, should offer this.

Grief and Bereavement

The experience of losing someone you love can be devastating. It is normal for you to feel a range of emotions and physical symptoms which may change from day to day. Grief and loss can feel overwhelming. There is no right or wrong way to feel. There are services available to help support you during this difficult time. Bereavement support is offered by your GP and both hospices. You can also seek support from other agencies.

More information on planning ahead, support and counselling can be found at:

NHS inform website: Planning for the Future www.nhsinform.scot/care-support-and-rights/decisions-about-care	
Macmillan Cancer Support: Planning Ahead for the End of Life www.macmillan.org.uk	
Caring for someone with a terminal illness (mariecurie.org.uk) www.mariecurie.org.uk/help/support/being-there	
Good Life, Good Death, Good Grief www.goodlifedeathgrief.org.uk	
Macmillan Cancer Support: Coping with Advanced Cancer www.macmillan.org.uk	
Cancer Research UK https://www.cancerresearch.org	
Cruse Bereavement Support www.cruse.org.uk	
Samaritans www.samaritans.org.uk	
Macmillan Cancer Support www.macmillan.org.uk/talktous (counselling service)	
Maggie's Centre www.maggiescentres.org	

Services available in the community

Some of the services listed below can help support you to manage at home.

District Nurses

The District Nursing team provides holistic, personalised nursing care in the community, including end of life care at home. This service is provided over 24 hours, 7 days a week. District Nurses can provide both practical and emotional support to you and those who are supporting you through a combination of telephone and home visits. They can assess your own personal needs and if needed, can order equipment, such as hospital beds and can help with giving you 'just in case' medications for any symptoms you have. They work with other

Health Care Professionals to maximize your quality of life at home, if this is where you would like to be cared for. Your GP or nurse specialist can refer you to the District Nursing team, or you and your family can self-refer.

Specialist Palliative Care

Throughout Edinburgh and the Lothians there are specialist palliative care teams based in the hospitals and the community who support patients with complex symptoms and needs. There are two hospices in Edinburgh with a few inpatient hospice beds, but most patients are cared for in their own homes by the district nurses with support and advice from palliative care teams.

St Columba's Hospice

St Columba's Hospice Care provides palliative care support to people living with a life limiting illness in the north of Edinburgh and East Lothian. The website has a huge amount of information: www.stcolumbashospice.org.uk

The Access team is available by telephone (0131 551 7751), Monday to Friday 9am-5pm (excluding bank holidays). They respond to requests for advice, undertake first assessments over the phone and aim to get you to the most appropriate service as quickly as possible.

The hospice has in patient unit beds for complex symptom management and end of life care. In the community we have our Hospice@Home Team which includes our Care@Home Team, our Community Hospice which has specialist nurses, nurses, specialty doctors, Occupational Therapy/Physiotherapy and the Family Support Team.



Marie Curie Hospice Edinburgh

Marie Curie services help people living with any terminal illness, and their families, to make the most of the time they have left. They have a wide range of resources and sources of support available – access their website at: www.mariecurie.org.uk/help to find out what might help you.

You might be referred to the Marie Curie specialist community team if you live in West Lothian, South Edinburgh or Midlothian. Their multidisciplinary team includes clinical nurse specialists, occupational therapists, physiotherapists, a patient and family support team, a day therapies team and a medical team. Admission to the Edinburgh Hospice can be arranged for short term assessment as well as end of life care. The Marie Curie Nursing service provides hands on care in your own home anywhere in Lothian, Fife and Borders and you can be referred by your district nurse or another healthcare professional.



Social Care

Social care services are there to help support you at home, to work out what your needs are and identify what is available to you within your local area. This may include support to help you with jobs such as cleaning and cooking. It may also be to help support you with some personal tasks such as washing and dressing. Your GP or District Nurse can refer you or you can refer yourself by contacting your local social work department.

Edinburgh Social Care Direct: Tel 0131 200 2324

Midlothian- Adult and Social Care: Tel 0131 271 3900

West Lothian Adult Social Care Enquiry Team: Tel 01506 284848

East Lothian Social Work: Tel 01875 824309

Occupational Therapy and Physiotherapy Services

These services can help you when the effects of your illness stop you doing the activities that you need or want to do. They will consider what is important to you, your strengths, abilities, health care needs and home environment. This might involve looking at ways to help you cope with self-care, household chores, getting out and about, or taking part in social and leisure activities. In some cases, equipment such as a toilet frame or a bath seat may help to make daily tasks less tiring. They can also give advice to your family on practical aspects of supporting your care. You can self-refer through your local social work department or your GP or district nurse can refer you. If you have been referred to the specialist palliative care team, they may refer you to their own occupational therapy and physiotherapy teams.

Financial Help and Benefits Advice

When you have a diagnosis of advanced cancer you might need help with extra costs, for example travel costs, clothing costs or heating bills. You may also need financial support if you have stopped working. You may be entitled to additional benefits or grants and the team caring for you will be able to refer you to the benefits team. You can contact the benefits team yourself, but they will often need to ask your medical team for information about your cancer. The benefits team can also discuss applying for a Blue Badge which you and your family might find helpful.

West Lothian Macmillan Advice Team

Tel 01506 283000 (option 2) or email: Macmillan@westlothian.gov.uk

City of Edinburgh Macmillan Advice Shop

Tel 0131 200 2360 or email: Macmillan@edinburgh.gov.uk

Midlothian Macmillan Welfare Benefits Service

Tel 0131 271 3910

East Lothian Macmillan Welfare Rights Team

Tel 0131 653 5231 or email: macmillanreferrals@eastlothian.gov.uk

Citizens Advice Scotland

Tel 0808 8009060 or email: www.citizensadvice.org.uk/scotland

Wider Support Available

There are several charities that can provide information and support for you and your family, these include:

Maggie's Centre

Maggie's Centre is there to help support you to take control when cancer turns life upside down. It provides professional support for anything from the cancer itself to money worries. All support is free. Maggie's Centre is based in the grounds of the Western General Hospital, and you do not need an appointment, you can just drop in, Monday to Friday 9am to 5pm. Tel: 0131 537 3131 or visit: www.maggiescentres.org



Macmillan Cancer Information and Support Centre

This centre aims to offer practical and emotional support. It is staffed by specialist staff and experienced volunteers who will work with you and offer time to talk in a relaxed atmosphere. Services include general and specialist information with guidance, complementary therapies, benefits/financial advice as well as end of life and bereavement support. The Centre is based in the Western General Hospital off the main corridor, and you can just drop in or make an appointment. We are open Monday to Friday.
Tel: 0131 537 3907

Macmillan – Improving the Cancer Journey (ICJ) Service

Being diagnosed with cancer can be overwhelming and many people don't know where to go for support. NHS Lothian and Macmillan Cancer Support want to offer everyone affected with cancer (including families and carers) time with a Link Worker to think about 'what matters to them' and access to the support they need.

This service is for anyone affected by cancer at any point on their cancer journey and is based in the community.



Some of the things they can offer support with:

- Money or housing worries
- Work
- Caring responsibilities
- Physical concerns
- Emotional Concerns
- Other types of support

Anyone can refer into this service. This includes people affected by cancer, or anyone working with people affected by cancer.

Tel: 0131 537 1500 or email: loth.icj@nhslothian.scot.nhs.uk

General support for carers can be found at:

VOCAL Support for Carers Edinburgh and Midlothian www.vocal.org.uk	
Carers of East Lothian www.coel.org.uk	
Carers of West Lothian www.carers-westlothian.com	