

MACMILLAN
CANCER SUPPORT

A GUIDE FOR PRISONERS AT THE END OF LIFE



About this leaflet

This leaflet is for you if you may die in prison from a serious illness.

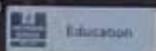
It explains what might happen, how you may feel and what support is there to help you. There is some information about what will happen after your death and the support available for any family members and friends.

If you would like to talk about this information, tell the prison staff. They can arrange for you to speak to a prison officer, someone from the healthcare team or a chaplain.

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Coping with the news

Finding out that your illness cannot be cured can be very hard. You may have lots of different feelings. You may find it hard to believe that you are going to die.

You may feel angry that your illness cannot be cured. You may think that what is happening is not fair. You may feel frightened about the future. It is also common to feel upset and depressed.

It may help to talk about your feelings with another prisoner. Or you could talk to a member of the prison staff, the prison healthcare team, or the prison chaplain.

You may also find it helpful to contact the Samaritans (see page 37).

How long will you live for?

This is a difficult question to answer. Your healthcare team may be able to give you some idea of how many weeks or months you might live for. But they cannot be sure. You may live longer than they say or, unfortunately, you may live for less time.

What care will you get?

You should get high-quality care wherever you are, including prison. This means you should be treated with dignity and respect. Any symptoms you get, such as pain or sickness, should be managed well. You should also be in a safe and comfortable place.

There are many people who can help you.

Prison officers

The prison officers will help you get the best care possible. Tell them if there is something you need. They will be able to contact the right people to help you. In some prisons, each person has a key worker. You may want to talk to your personal officer or key worker about your illness, or anything else you are worried about.

Prison healthcare team

Prison healthcare teams will help you stay well for as long as you can. They will check what care you need and help control any symptoms you have.

Many teams work closely with doctors and nurses outside of the prison who are experts in controlling symptoms and giving emotional support. This is called palliative care.

Palliative care doctors and nurses can come to the prison to support you. They can help control your symptoms. Sometimes you can go to a hospice for this help (see pages 10 to 12).

Family liaison officer (FLO) or family contact officer (FCO)

If you cannot see your family regularly, the family liaison officer (family contact officer in Scotland) can tell them what is happening with your health. They will only do this if you say this is okay with you. It is fine if you do not want them to talk to your family.

Your FLO or FCO can arrange more regular family visits. Sometimes they may be able to arrange for your family to be with you when you die.

Ask your FLO or FCO what they can do to help you and your family.

Prison chaplain

Many people think more about religion or spiritual feelings when they know they are dying. All prisons have a spiritual adviser. This person is usually called the prison chaplain. They may be able to help you find some peace of mind. You can ask to talk to them.

Personal officer or offender supervisor

Your personal officer or offender supervisor will help make decisions about your care and where you are looked after.

Other prisoners

Other prisoners may be able to help you when you do not have much energy. They can also listen to your worries. Talking to them may help distract you from what is happening.

Family and friends on the outside

If you stay in prison when you are nearing the end of your life, you may be able to have more visits or phone calls from your family and friends. Sometimes, they may be able to stay with you when you are dying. The FLO or FCO will tell you if this is possible.

It may be hard for your family and friends to support you as you become more ill. You may find it hard to know what to say to them. It can help to talk openly with each other about your illness. Talking about your feelings may help all of you when you are sad and worried.



Where will you be cared for when you are dying?

This will depend on:

- the care you need
- where you would like to be cared for when you are dying
- any security needs, to make sure that you and others are safe
- what healthcare services are available
- whether you will be allowed to leave the prison if you want to die at home or at a family member's home (this is called compassionate release).

Your healthcare team will talk to you about where you can be looked after. They will make sure that other health services have all the information they need. You will need to say it is okay for this to happen.

You should be treated with dignity and respect, wherever you are cared for.

Care in the residential area

Many prisoners want to be cared for in their own cell for as long as possible. If possible, the prison healthcare team and staff will do their best to make sure this happens.

Another prisoner may want to help so you can stay in your cell for longer. If you would like this to happen, talk to your healthcare team or personal officer.

When you need more nursing care, you will usually be moved somewhere else to get the right help.

Care in a prison inpatient unit

You may go to a prison inpatient unit if you need nursing care. This often means you need to be transferred to another prison. This can be unsettling. The nurses and doctors in the unit often work closely with palliative care nurses and doctors (see pages 5 to 6).

If there is no prison inpatient unit, you will be moved to have care outside the prison.

Care in a hospital

If you have had treatment in a local hospital, you may go back there when you need full-time care. Hospitals have palliative care nurses and doctors who will help look after you. You will be escorted by prison officers or a security escort service.

Care in a hospice

Hospices specialise in caring for people who are dying. They can help with symptoms and give emotional support. You may be able to go to a hospice if you wish to die there.

Care at home (compassionate release)

If you want to be looked after at home, and you have someone who can care for you, you have the right to apply for compassionate release.

You can apply for this when a consultant in the healthcare team thinks you may only have three months to live. If your application is refused, you may be able to apply again when you become more ill. Only a few people are given compassionate release.

If you are allowed to go home, you need to have someone who can care for you there. Your care will be moved to a community healthcare team. Before you go home, the prison healthcare team will talk to the community team to plan your care.

Some prisoners may be granted a licence for a temporary release.

Being involved in your care

You may be feeling unwell or unsure at times. There are things you can do to help yourself.

If you have a job, you might have days when you cannot work your normal hours. Talk to the prison healthcare team to see if you can do fewer hours.

You may want to write letters to family and friends, or keep a diary. If you do not have much energy, you may just want to watch TV.

Your prison may have groups you could join, such as a chaplaincy group or an educational group. If you have a bit more energy, you may even want to join a group at the gym. Talk to your personal officer about any groups that might be helpful for you.

Information about your illness

You may want to know more about your illness. The prison staff can arrange for you to talk to someone from your healthcare team. They can answer your questions and help you find more information.

Get help with symptoms

You may have different symptoms as you become more unwell (see pages 19 to 21). Most symptoms can be controlled well with medicines.

If you do not feel like eating or if food does not taste the same, tell the prison staff. They can talk to the kitchen manager about what you need.

Planning ahead

You may want to plan ahead for your care. You can talk about this with the prison staff and your healthcare team. They will be able to tell you what is possible for you. You might want to:

- think about where you would like to be cared for (see pages 10 to 12)
- make or update a will
- choose any treatments you do not want to have if you become unwell and cannot tell the healthcare team yourself (see page 16)
- sort out an issue – for example, if you have not spoken to someone for many years for some reason
- make plans for your funeral (see page 17)
- talk with the prison chaplain about any spiritual or religious practices that are important to you before and when you die (see page 7).

Making a will

A will says who you would like your property, personal items and any money to go to after you die.

Before you die, you may want to make, or change, a will. If you would like to do this, speak to your family liaison officer, family contact officer or a lawyer.

Your wishes for your care

You can write down what you would like for your future care. For example, you could write down where you would like to be cared for. It is important to talk to someone from your healthcare team first, to make sure your choices can actually happen.

There are different forms used in different parts of the UK. Your healthcare team can tell you more.

Decisions to refuse treatment

As you become more unwell your healthcare team may ask you to decide about treatments and care. But sometimes you can be too unwell to make decisions or communicate – for example, if you become unconscious. It can help to plan ahead in case you are not able to make decisions yourself.

There may be certain treatments you do not want to have. It is important to tell your healthcare team about these. They may suggest you write down your choices. They will be able to help you do this. In England, Wales and Northern Ireland this is called an advance decision to refuse treatment. In Scotland it is called an advance directive.

Organ or tissue donation

You may want to think about donating an organ, such as a kidney. Or you may want to donate body tissue, such as the clear part at the front of your eye (cornea). Not everyone can donate an organ or tissue. Your healthcare team can tell you more.

Planning your funeral

Although this can be a hard thing to do, you may want to think about planning your funeral.

You may know how you would like your funeral to be. For example, you may know whether you want a cremation or burial. Or there may be something you want someone to read at your funeral.

You may be worried about paying for your funeral. Your family liaison officer, family contact officer, personal officer or healthcare team can talk about this with you.



Managing symptoms

Pain

Not everyone has pain as their illness gets worse. But if you do, it can usually be well controlled. Your healthcare team can give you medicine to help. They can also tell you about other things you can do to feel better.

Painkillers

It is important to tell your healthcare team:

- where your pain is
- how it feels
- how it affects you.

If you have pain all the time, you will need to take painkillers regularly. The prison healthcare team can give you strong painkillers if your pain is very bad.

Tell the prison staff and your healthcare team if you are still in pain. They can change the dose of painkiller or change your medicines. It can sometimes take a few days to get this right.

Some painkillers cause side effects. These include feeling sleepy, feeling sick and being constipated.

Ways to relax

Learning to relax can help with pain. Tightening and then relaxing different groups of muscles around your body can help you relax. Taking deep breaths may also help. Your healthcare team may be able to give you a relaxation CD to help. Some prisons have relaxation courses you can go on. You may also find listening to music or watching a film helps to distract you from the pain.

Sickness and constipation

If you feel sick or are sick, your healthcare team can prescribe anti-sickness medicine. Taking this regularly will help stop sickness from coming back.

Some people get constipated. You may need medicine to help you go to the toilet. This may be laxatives or enemas.

Eating problems

You might lose your appetite, especially if you feel sick. You may only want small meals. The kitchen team may be able to work with your healthcare team to help you have the food that is best for you.

As you become more unwell, you may find it harder to eat. Sometimes, you may need to have food as a liquid meal that you can drink. When you are very unwell, you may only need fluids such as water, squash or tea. This is normal.

If your mouth feels dry, talk to your healthcare team. They can give you something to help, for example an artificial saliva spray.

Tiredness and weakness

Feeling very tired all or most of the time is common when you become more unwell. This may be because of your illness. Or it may be because of symptoms such as pain.

If you feel tired, do things slowly. Save your energy to do things that are important to you.

Other side effects and symptoms

You may have other symptoms, depending on your illness. Your healthcare team can help you manage these.

The last weeks of life

Usually you slowly get weaker and more tired over a few weeks or months. But sometimes people become more ill and die more quickly than expected.

In the last weeks of life, many changes can happen in your body. You may feel very tired and weak. You may lose weight and not be hungry anymore. Once a person stops eating, they usually only live for a couple of weeks.

As you become weaker, doing normal activities, such as getting up, can make you feel very tired. As you become more tired, you will need to rest or sleep more during the day. At this stage, you may lose interest in things that used to be important to you. This is normal.

Spiritual needs

If you have religious or spiritual beliefs and would like to see a spiritual or religious adviser, talk to the prison, hospital or hospice staff.

If you would like any special practices to happen when you die, talk to your personal or family liaison officer (see page 7). It may not be possible to do some practices. This is because as soon as you die, your body becomes the responsibility of a coroner (or procurator fiscal in Scotland). This means certain processes have to be followed.



The last few days of life

In the last few days of your life, you usually need more physical help and support from your healthcare team.

If you are in a hospice or hospital, your family or friends can spend more time with you. Usually a member of the prison staff or security escort service stays with you. You may just want to lie still and have people sitting quietly nearby.

You may keep waking up and going to sleep again. You might be confused and may not recognise people you know. You may hear or see things that are not there. Or you may become distressed and restless. All these things are normal when someone is dying. A nurse or doctor can give you medicines to help.

Your feet and hands may feel cold. Or your skin may feel very sensitive to touch. The people looking after you may need to be very gentle when moving or touching you.

Unconsciousness

Usually people become more and more sleepy, and then become unconscious. This means you cannot respond to anything around you. You may be very peaceful. Or you may move, twitch or grimace sometimes, like you are dreaming.

Even when you are unconscious, you will probably be aware that people are with you. You may be able to hear them if they talk to you. This may only last a few hours, or it can continue for a few days.

You will not need food and drink. When someone who is near the end of their life stops drinking, they usually only live for a few days.

Breathing

Your breathing may change and you may make a groaning (rattling) noise. This is because of fluid in your air passages. The healthcare team can give you medicines to help with this. You may also have long gaps between breaths.

The final moments of life

For most people, the final moments of life are very peaceful. Your breathing may become even slower and more irregular, with very long pauses between each breath.

Finally, you stop breathing altogether. Sometimes it can be difficult to know exactly when someone dies. Often, the person's body relaxes completely and they may look very peaceful.

After you have died

This section is about what happens after you have died.

What happens to your body after you die?

Your body will be taken to a mortuary. This may be at a local hospital, hospice or a funeral director's (undertaker).

When someone dies in prison, or under the care of the prison service (in custody), the death is always referred to the coroner. In Scotland, the death is referred to the procurator fiscal. They will order a post-mortem to find out or confirm the cause of death. After the post-mortem, your death will be registered and your body can be released for your funeral.

If you die at home after being given compassionate release (see page 15), there may not need to be a post-mortem. The coroner or procurator fiscal makes this decision. The prison team will have contacted the coroner or procurator fiscal before your release.

Who will tell your next of kin?

If you die in prison and your family does not know, the family liaison officer will tell them about your death. If you are in Scotland, the police will tell your family.

If you die in a hospital or a hospice, the prison officer or security escort service will tell the prison staff. They can arrange to tell your family.

After your family has been told about your death, the governor will tell the prison staff and other prisoners.

Your funeral

As far as possible, your funeral will happen in the way you want. Your family will be given advice about how to pay for the funeral. The family liaison officer or chaplain may be able to help support your family.

An inquest

An inquest looks into how someone died. In Scotland it is called a Fatal Accident Inquiry (FAI). It is normal for this to happen when a person has died in prison or under the care of the prison service (in custody). It may happen some time after your death.

An inquest is held in a Coroner's Court and there may be a jury. The inquest aims to make sure that you were given the best possible care. An FAI happens in front of a sheriff.

In England and Wales, an independent investigation by the Prisons and Probation Ombudsman also happens when someone has died in custody. The results of this investigation are passed to the coroner in charge of the inquest. In Scotland, every death in custody has a Death in Prison Learning and Audit Review (DIPLAR).

When someone close to you dies in prison

This information is for you if someone close to you has died in prison or under the care of the prison service (in custody) It has information about how you may feel and the help that you can get.

How grief might affect you

Grief is a word for some of the feelings you may have after someone close to you dies. Grief is different for everyone. Straight after the death of your loved one, and for some time afterwards, it is normal to feel different emotions, including:

- numbness
- denial
- anger
- guilt
- longing or yearning
- depression
- acceptance.

Emotional effects

After the person has died, you may feel numb. You might find it hard to believe. You may feel angry at what has happened. You may direct your anger at other people for not being able to stop the person from dying.

Many people continue to 'see' or 'hear' the person who has died, or feel their presence. Other people have vivid dreams where they see the person. These are normal experiences, but they can be shocking and upsetting.

You may have times where you feel very anxious and distressed, and you might cry. This usually happens less often after the first couple of weeks. But seeing or doing something that holds strong memories can cause distress, even months or years afterwards.

It is natural to cry when you are thinking and talking about the person who has died. Tears can help, although long periods of crying can be exhausting.

Physical effects

Some people feel physically ill and have some of the following:

- headaches
- dizziness
- a dry mouth
- a feeling of weakness
- breathlessness
- a feeling of tightness in the chest and throat
- a feeling of sickness.

These feelings are normal and do not mean you have a serious illness.

Support for you

There are different people and organisations that can help you get the support you need.

Practical support

You may need help with practical tasks. The family liaison officer or family contact officer (see page 6) can support you with some things. For example, they can help you arrange a funeral and cope with visitors. In Scotland there are family centres who support families of people in prison.

You may also need to spend some time on your own, to come to terms with what has happened.

Financial support

You may be able to claim bereavement benefits, such as:

- a bereavement payment
- a widowed parent's allowance
- a bereavement allowance.

You can find out more about these from your local Citizens Advice. You can also visit the Department for Work and Pensions website at **dwp.gov.uk** or call the Macmillan Support Line on **0808 808 00 00**.

Emotional support

You may find it helpful to talk about how you are feeling. There are lots of organisations that can help. You can find details for Cruse Bereavement Care and the Samaritans on pages 37 to 38.

There is more information in our booklet **After someone dies – coping with bereavement**. You can order a copy by calling the Macmillan Support Line on **0808 808 00 00** or by visiting **be.macmillan.org.uk**



If you are another prisoner

If you were involved in caring for the person or they were your good friend, you may have some of the feelings we talk about on pages 30 to 32.

If you need help to cope with the person's death, you could talk to:

- your personal officer
- a member of the healthcare team
- the prison chaplain.

They will be able to tell you about the different types of grief support services you can get. The chaplain may also organise a separate memorial service at the prison. This will give you the chance to remember your friend and say goodbye.



Other useful organisations

There are lots of organisations that can give you information or support

General health information

Macmillan Cancer Support

Tel 0808 808 00 00

(Mon to Fri, 8am to 8pm)

www.macmillan.org.uk

Call the free Macmillan Support Line to talk to one of our cancer support specialists, who can give support to anyone affected by cancer.

NHS.UK

www.nhs.uk

The UK's biggest health information website.

Samaritans

Tel 116 123

Email jo@samaritans.org

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Support for family and friends

Cruse Bereavement Care

Helpline 0808 808 1677

(Mon and Fri, 9.30am to 5pm, and Tue to Thu, 9.30am to 8pm)

Email info@cruse.org.uk

www.cruse.org.uk

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Winston's Wish

Helpline 0808 802 0021

(Mon to Fri, 9am to 5pm)

Email

ask@winstonswish.org

www.winstonswish.org.uk

Helps bereaved children and young people throughout the UK re-adjust to life after the death of a parent or sibling.

Disclaimer

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Thanks

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We welcome feedback on our information. If you have any, please contact [**cancerinformationteam@macmillan.org.uk**](mailto:cancerinformationteam@macmillan.org.uk)

Sources

We have listed a sample of the sources used in the booklet below.

If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Department of Health and Social Care. Guidance on choice in end of life care: Government progress: How the national end of life care programme board is delivering personalisation and choice in care for people at or near the end of life. 2017. Available from www.gov.uk/government/publications/choice-in-end-of-life-care-government-progress (accessed June 2019).

NHS Improving quality. The route to success in end of life care – achieving quality in prisons and for prisoners. 2014. Available from <http://endoflifecareambitions.org.uk/wp-content/uploads/2016/09/Route-to-Success-End-of-Life-Care-in-prisons.pdf> (accessed June 2019).

Prison and probation ombudsman for England and Wales. Learning from PPO investigations. Older prisoner: Palliative and end of life care. p19. 2017. Available from www.ppo.gov.uk/app/uploads/2017/06/6-3460_PPO_Older-Prisoners_WEB.pdf (accessed June 2019).

This booklet is for you if you may die in prison from a serious illness.

It explains what might happen, how you may feel and what support is there to help you. There is some information about what will happen after your death and the support available for any family members and friends.

Questions about living with cancer?

Call free on **0808 808 00 00** (7 days a week, 8am to 8pm).

Hard of hearing? Use textphone

0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.

**MACMILLAN
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