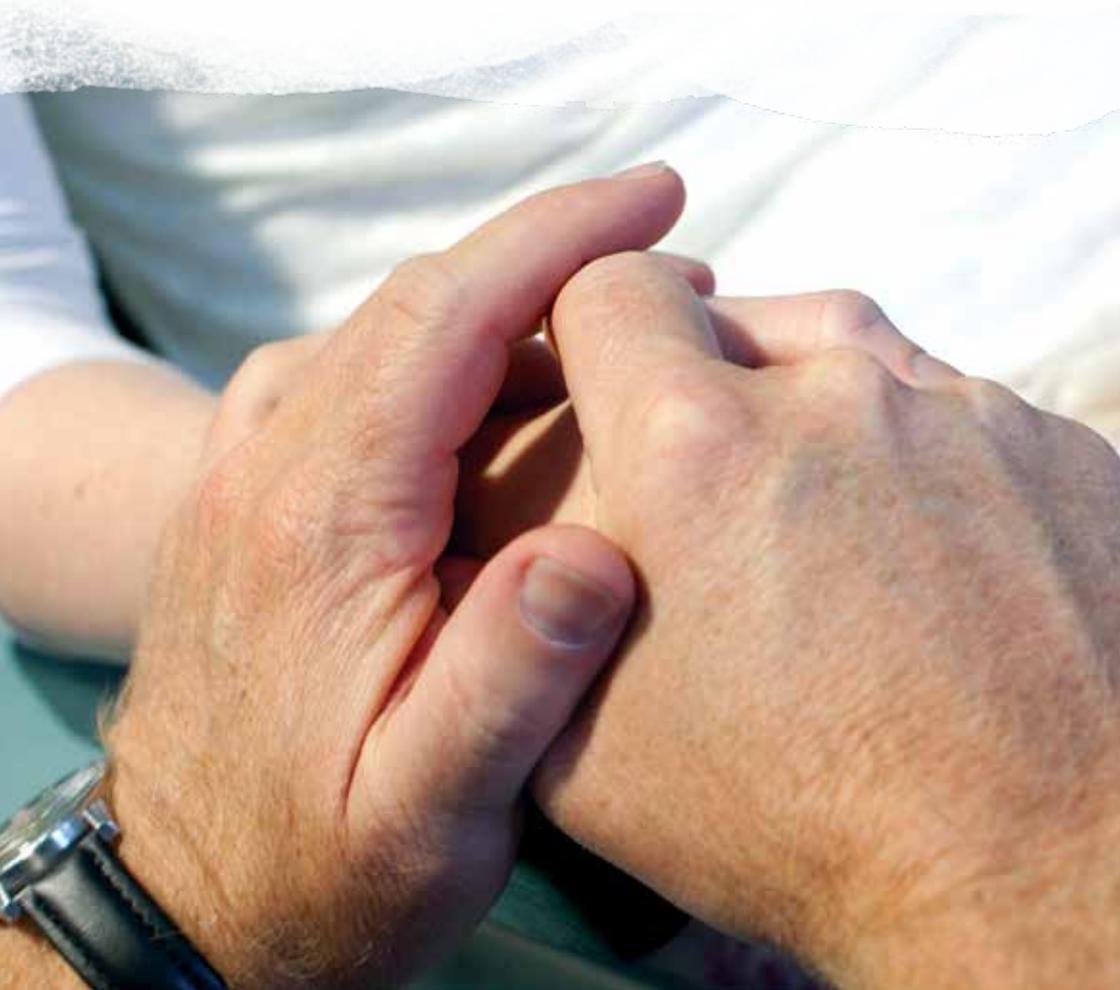


WE ARE  
MACMILLAN.  
CANCER SUPPORT

End of life series

# DYING: A GUIDE FOR PRISONERS IN ENGLAND AND WALES



# About this booklet

This booklet is for you if you are a prisoner with cancer and it's likely that you will die within the next few months. It also includes information for people close to you, so they may find it helpful to read this booklet too.

Although this information is aimed at prisoners who have cancer, it may also help prisoners who are dying from other illnesses. It explains what's likely to happen, how you may feel and what support you may need. There's also information about what happens after death and the support that's available for partners, relatives and friends.

There are some differences between prisons and their healthcare services across the UK. This booklet is for prisoners in **England and Wales**. If you'd like to know more about prison services in Scotland or Northern Ireland, and the care they provide for prisoners who are dying, please speak to the prison staff or a healthcare professional in that country.

Throughout the booklet are some quotes from prisoners, which we hope you'll find helpful.

If you'd like to discuss this information in more detail, let the prison staff know. They can arrange for you to speak to an officer or see someone from the healthcare team. You can use the notes pages at the back of this booklet to write down any questions you have (see page 79).



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# BEING DIAGNOSED AND COPING WITH UNCERTAINTY

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# Being diagnosed with cancer

You will see the prison GP or healthcare team. They will refer you to see a specialist team of doctors and nurses at a hospital. The hospital doctors will check your symptoms and arrange any tests you need.

You may have:

- x-rays
- scans
- a biopsy (when a small piece of tissue is taken from a suspicious area or lump).

When the doctors have your test results, they will arrange to see you. They will tell you the results and which treatments you may need.

# Cancer treatment

Cancer is usually treated with:

- surgery
- chemotherapy (treatment using drugs)
- radiotherapy (treatment using high-energy x-rays).

You may have more than one of these treatments. This depends on the type of cancer you have, its size and whether it has spread to other parts of your body.

For many people, treatment works well and the cancer can be cured. For some people, treatment may only be able to control the cancer for a while before it starts to grow again. Sometimes the cancer can come back after it has been treated.

You may worry that you won't be able to have treatment in the same way that other people do on the outside. You may also worry that you won't be given information about your cancer, or told the truth. This is not the case. You have access to the same treatment and the same information as everyone else.

The prison service and the healthcare team will arrange for you to have the treatment you need. You may need to spend time in hospital or on the prison healthcare unit during or after your treatment. Your healthcare team will discuss this with you.



# When cancer can't be treated

There may come a time when treatment can't control your illness anymore. This may happen if your cancer comes back or spreads.

Usually, we don't know when we will die and don't think about it very much. When you are told that treatment can't control your illness any more, you may start to think about death. This can be very frightening.

In this booklet, we explain what happens towards the end of life and how to plan for it. It's important to remember that everyone is different. Some people may get ill very slowly over many months. Other people may get ill more quickly within a few weeks.

## Coping with the news

Hearing the news that your cancer can't be cured is difficult. You may be feeling lots of emotions. You may know that your cancer is getting worse, but you might find it hard to believe what you're hearing. This may feel like a nightmare to you, and that you will wake up and find it's not true.

The shock and disbelief you first feel may change into other emotions. You may feel very angry that your cancer can't be cured. This may be because you think more could have been done to treat your cancer. Or you might feel you could have got better treatment if you weren't in prison. You may even feel angry with the healthcare team who told you the bad news. These feelings can make it difficult for you to think clearly.

Some people feel that what's happening to them isn't fair. They may feel frightened about the future. It's common to feel upset and depressed too.

Most people have some, or all, of these emotions. You may not know how to cope with them. As time passes, people often find that these emotions get less intense. They find they are able to think more clearly and cope better.

You may find it helpful to talk about how you're feeling with another prisoner, a member of the prison staff or the prison healthcare team. If you're not sure who to ask for support, let the prison staff know. They will be able to get you the support you need.

# Facing an uncertain future

Many people with advanced cancer want to know how long they will live. This can be a difficult question to answer and your healthcare team may not be able to give you a definite amount of time. If one of your doctors does give you some guidance, it's important to remember that this is just an estimate. You may live longer or, unfortunately, you may live for less time. What's important is that you are able to live well in the time you have left.

You'll probably have good days when you feel well and bad days when your energy is lower. It's important to plan for this. When you feel better and have more energy, make time to do some of the things you want to do. When you feel less well, try to balance rest with some gentle activity.



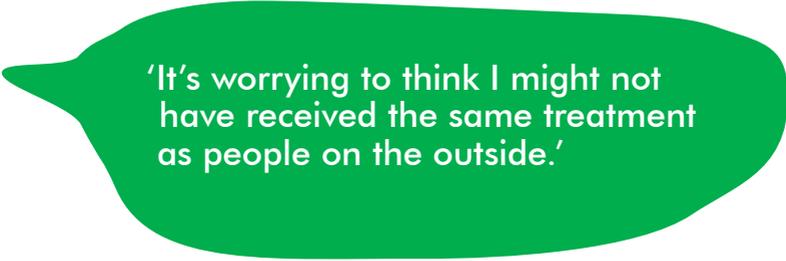
**'I would hope to be  
treated with respect,  
compassion and dignity.'**

# CARE IN PRISONS

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## What to expect



'It's worrying to think I might not have received the same treatment as people on the outside.'

Many prisoners worry that they may not be well cared for towards the end of their life. But you should expect good care, whether you're cared for in prison or somewhere else.

Standards of healthcare in prisons have improved a lot over the last few years. The NHS has produced a practical guide for prison staff and healthcare teams who are involved in caring for prisoners reaching the end of their lives.

The NHS guide describes the care you should expect to get:

- Healthcare staff should talk honestly and openly with you about your wishes as you near the end of your life. Together you will talk about the care you need and agree a plan of care.
- All the services involved in your care (inside and outside prison) should work together, so that your care is coordinated.
- You should get high-quality care, wherever you are.
- If you stay in prison, the healthcare staff there should know about your illness and that you are dying. They should find out what physical and emotional support you need. Other prisoners who are close to you should be given support too.
- After you have died, your family and other prisoners will be told. They should also get support and care to help them cope with their loss.



**'It's good to know there are people who can help, because once someone who is dying leaves the wing, you don't really know what happens to them.'**

# Who will help you get the care you need?

There are many people who can help you get the care you need. This may include:

- prison officers
- the prison healthcare team
- a family liaison officer
- a prison chaplain
- your offender supervisor
- other prisoners
- your family and friends outside the prison.

## Prison officers

The prison officers will help support you so that you get the best care possible. Let them know if there is something you need. They will be able to contact the right people to help you. You may want to talk to your personal officer about your illness, or anything else that's troubling you.

## Prison healthcare team

Prison healthcare teams are made up of different professionals and vary from prison to prison. The healthcare team will be involved in your care. They will help you stay as well as possible, for as long as possible. They will be involved in checking what care you need and helping control any symptoms you have.

When you're not able to look after yourself, the prison healthcare team will talk with you about the best place for your care. They will also help make sure you get all the information you need.

All prisons have their own nurses and doctors. Some prisons also have inpatient units open 24 hours a day (see page 26). Prisons that don't have an inpatient unit have nurses and doctors who can visit you on your residential wing during the day. They can help you with any healthcare problems you have. At night, out-of-hours healthcare services can be contacted if you need medical care. If your prison has an inpatient unit, you will go there when you're unwell and need nursing care. Sometimes you may need to be transferred to another prison with an inpatient unit.

Many prison healthcare teams work very closely with outside doctors and nurses who specialise in **palliative care**. This means they specialise in controlling symptoms and providing emotional support.

Palliative care specialists are sometimes known as Macmillan doctors and nurses, or Marie Curie nurses. They are usually based in hospices. A hospice is a place where people can be cared for if they need to have their symptoms controlled or if they are dying (see page 27). Doctors and nurses who specialise in palliative care can come to the prison to support you and help control your symptoms. They do not provide nursing care, so you will go to a prison inpatient unit if you need this.

Some prisons have special arrangements with a local hospice. This means that prisoners may sometimes go to a hospice if they need to have their symptoms controlled or if they wish to die there. This will only happen after the prison team, hospice team and appropriate authorities have all talked about it.

## Family liaison officer

If you're not able to see your family regularly, the family liaison officer will let your family know about what is happening with your health.

Family liaison officers can arrange more regular family visits. They may be able to organise for your family to be there when you die. After your death, they will keep in touch with your family and help support them with funeral arrangements and costs, if needed.

The role of the family liaison officer may vary in different prisons. So it's best to ask your family liaison officer to tell you more about what they can do to help you and your family.

## Prison chaplain

Many people find they become more aware of religious beliefs or spiritual feelings when they know they are dying. People with a strong religious faith often find this helps them during their illness. All prisons have a spiritual adviser, usually known as the prison chaplain. They are involved in supporting people with different faiths.

If you'd like to talk to a prison chaplain, let the prison staff know so they can organise this. The chaplain is used to dealing with uncertainty and people who are distressed. They may be able to help you find some peace of mind.

## Offender supervisor

Your offender supervisor (inside and outside the prison) will also be involved in making decisions about your care and where you are looked after.

## Other prisoners

Other prisoners can be a big source of support to you. They may be able to help you with practical things when you don't have much energy. They may support you by listening to your worries, or by helping to take your mind off things.

**'As a human being, I wouldn't have any worries about supporting someone. I would offer my support and shoulder no matter who that person was.'**

## Family and friends on the outside

It can be hard for family and friends to support you as you become more ill, particularly if you haven't seen or spoken to them much. When you do see them, you may find it hard to know what to say. It often helps to talk openly with each other about your illness. Talking about your feelings may help you support each other through the sadness, worry and uncertainty.

If you're in prison when you're nearing the end of your life, you may be able to have more visits or phone calls from your family and friends. They may also be able to stay with you when you are dying. The family liaison officer will let you know whether this will be possible.



# Where will you be cared for when you are dying?

Many prisoners want to know where they will be cared for when they are dying. This will depend on a number of things, including:

- the care you need
- where you would like to be cared for when you are dying, it's important to remember that this may not be the place where you are allowed to die
- what issues need to be thought about to guarantee your security and the security of others
- what healthcare services are available in the prison or outside in the local community
- whether you can be allowed to leave the prison if you want to die at home or at a family member's home, which is called **compassionate release**.

Any decisions about where you'll be cared for will be discussed with you first. The most important thing is that you get the care you need and that your symptoms are controlled well.

The prison healthcare team will make sure that all the information about the care you need is shared with the other health services involved. You will need to give your permission for this to happen. This will help make sure you get all the care you need without any problems or delays.

You should be able to expect the same high level of care wherever you are, and be treated with dignity and respect.

## Care on the residential wing

'Would I be allowed to stay in my cell, with staff and people I know?'

Many prisoners say they would like to be cared for in their own cell for as long as possible. This can be because they have been in prison for a long time and their cell has become their home. If possible, the prison healthcare team will do their best to make sure this happens.

## 'Can another prisoner be my carer?'

Another prisoner may want to give you some extra support so that you can stay in your cell for longer. If you would like this to happen, you will need to talk to your healthcare team or personal officer.

When you cannot look after yourself, or you have symptoms that are troubling you, you'll usually be transferred somewhere with more nursing and medical support. This may be the prison inpatient unit, a hospital or a hospice. Your healthcare team will talk to you about this before you are transferred from the residential wing.

### **Care in the prison inpatient unit**

If you've had treatment for your cancer, you may have been in and out of the prison inpatient unit. You may go back there if you need nursing care. The nurses and doctors in the unit will give you the care you need.

Inpatient units often work closely with palliative care nurses and doctors who work in the community. They can visit you while you are in the unit and give you advice about controlling any symptoms you have (see pages 41–47).

## Care in hospital

If you've had treatment in a local hospital over the last few months and your prison doesn't have an inpatient unit, you may go back to the same hospital when you need full-time care. Hospitals have palliative care nurses and doctors who will care for you. They can talk to you about controlling any symptoms you have and offer you emotional support.

## Care in a hospice

Some prisons can use the services of local hospices. Hospices specialise in managing symptoms and caring for people who are dying. They can offer a wide range of services, such as counselling and spiritual care.

You may be able to go into a hospice for a short period of time to have your symptoms controlled, or to die. A prison officer or officers will go with you. You can find out more about your local hospice from your healthcare team.

## Care at home

If you want to be cared for at home, and you have someone to care for you, it's your right to apply for compassionate release (see page 24). This is stated in the PSO 6000 Parole Manual.

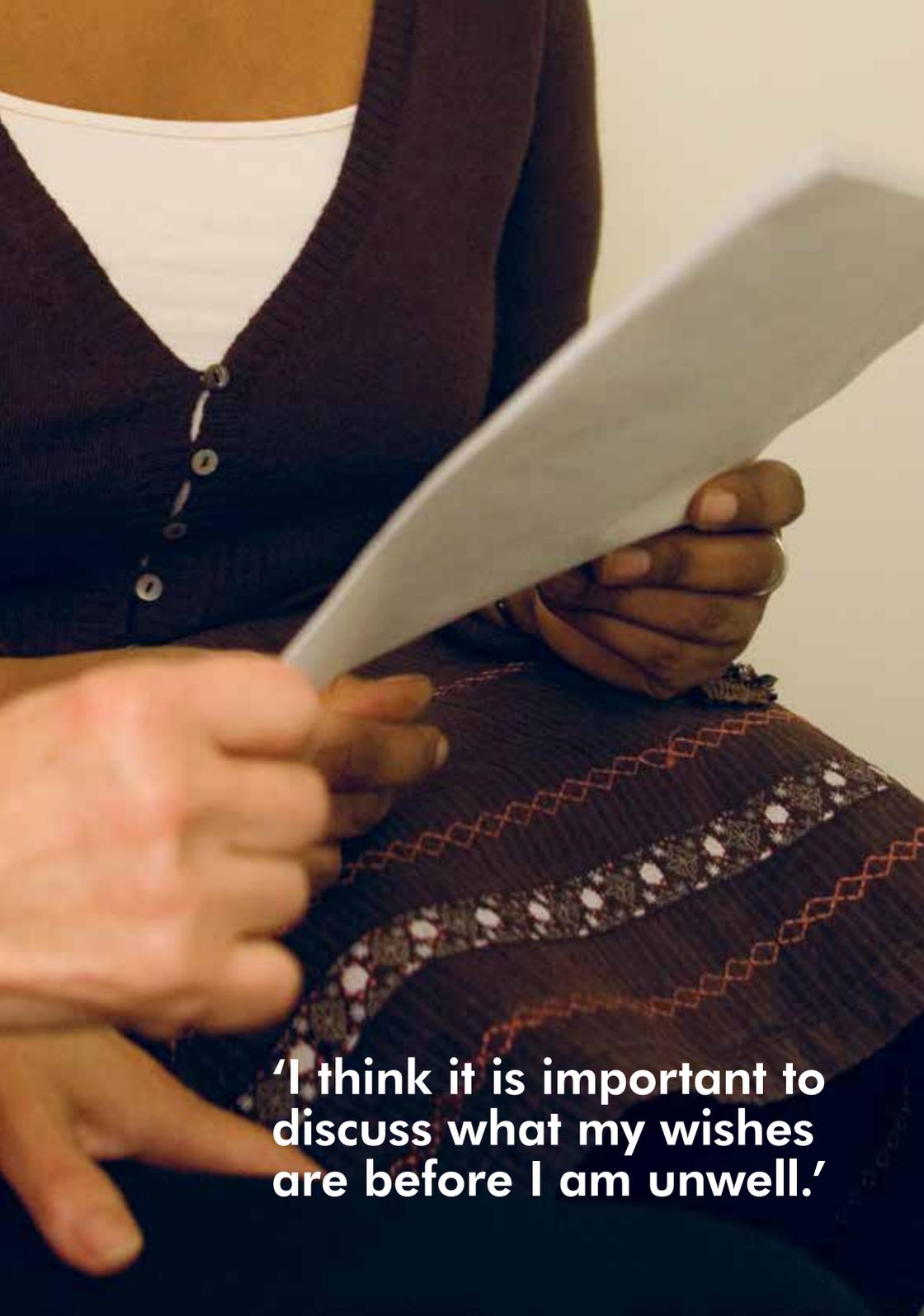
**'Do we get released when we only have three months left to live?'**

Applications for compassionate release are usually made when someone is thought to be reaching the last three months of their life. If you make an application, this doesn't mean you will get released. This may be because there are security issues that need to be carefully thought about by the prison authorities. If the application for your release is refused, you may be able to make another application when you become more ill.

'I would like to be able to go home to be with my mam and not die in prison.'

If you are allowed to go home, you'll need to have someone who can care for you there. This may be a family member or a close friend. Your care will be transferred to a community healthcare team. This team usually includes a GP, community nurses and a specialist palliative care team (from the local hospice or trust). They will be able to tell you more about the support they can give you. This may include nursing care, advice about controlling your symptoms, emotional support, and details of telephone helplines and homecare services.

Before you go home, your prison healthcare team will contact the community team to organise your care at home.



**'I think it is important to discuss what my wishes are before I am unwell.'**

# BEING INVOLVED IN YOUR CARE

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# How you can help yourself

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

## Keep your mind and body active

If you have a job, you might have days when you can't manage your normal hours. Speak to the prison healthcare team to see whether you can still work but do fewer hours.

Think of ways to keep your mind active. You may want to write letters to family and friends, or keep a diary. If you don't have much energy, you may just want to watch TV. Your prison may also 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.

Different prisons have different facilities, so you may want to talk to your personal officer about what's available and suitable for you.

## **Eat well if you can**

If you don't feel like eating much or if food just doesn't taste the same (see pages 45), let the prison staff know. They can contact the prison kitchen manager to discuss what you need.

## **Get information about your illness**

If you don't understand your illness and want to know more, let the prison staff know. They can put you in touch with someone from your healthcare team who can answer your questions and help you find more information. If you find reading difficult or don't have the energy to read, they may be able to give you information in different formats.

## **Get help with symptoms**

Your healthcare team will be able to help control any symptoms you have (see pages 41–47). Most symptoms can be controlled well with medicines.

## Plan ahead

You may want to make important choices about how and where you'd like to die. You can talk about these with the prison staff and your healthcare team. They will be able to let you know what's possible for you.

- Think about where you'd like to be cared for when you're dying (see pages 24–29).
- Choose any treatments you don't want to have if you become unwell and are unable to tell the healthcare team yourself (see pages 36–37).
- Make a will, or update it if you've already made one (see page 35).
- You may want to sort out an issue before you die. For example, if you have something to sort out with a family member or old friend.
- If you have children or grandchildren, arrange to leave them something special. This could be a letter, a photo or something that's special to you both.
- Think about who you'd like to be with when you're dying.
- Make plans for your funeral. For example, you may want to think about whether you'd prefer a cremation or burial (see page 39).
- Talk with the prison chaplain about any spiritual or religious practices that are important to you before and when you die (see page 57).

# Making a will

Before you die, you may want to make a will or make changes to one that you've already written. This makes sure that people close to you will be looked after, and that your wishes will be carried out after you die. A will states who you would like your property, personal items and any money to go to after you die. It may also include who you would like to look after any dependants you have. And it can include any specific funeral arrangements you want.

If you would like to make or change a will, the family liaison officer can help you or let you know who else can help. What you write in your will is confidential, so it won't be seen by any prison staff except the person who helps you write it.

# Making choices about your treatment and care

You may need to make important decisions about your treatment and care in the later stages of your illness. However, there may come a time when you can't make decisions or communicate easily, for example if you become unconscious.

## Advance Decisions to Refuse Treatment

If there are treatments you do not want to have, let your healthcare team know. They may suggest you make a written record of your choices, and they will be able to help you do this. These are known as Advance Decisions to Refuse Treatment.

For example, you may decide that if your condition gets worse and your breathing stops, you do not want people to try to bring you round (resuscitate you). Or you may decide that if you are very ill and have an infection, you don't want to be given antibiotics.

An Advance Decision to Refuse Treatment must meet certain instructions in the prison service's PSI 64/2011 document. To be legally binding, it must also meet the requirements of the Mental Capacity Act (2005). Your healthcare team will be able to tell you more about this.

## Preferred Priorities for Care

You can also use a document called a Preferred Priorities for Care to record your wishes. This document might include information about what is important to you for your future care, and where you'd like to be cared for. Before you write down your choices, it's important to talk about them with someone from your healthcare team. They can let you know whether your choices are realistic.

If you'd like more information about Advance Decisions to Refuse Treatment and Preferred Priorities for Care, your healthcare team will be able to help.

## Organ or tissue donation

You may want to think about donating organs (such as a kidney) or tissue (such as the cornea of the eye). Having cancer and being a prisoner does not mean you can't donate, but certain things have to be taken into account.

These include:

- your medical history – if you have CJD (Creutzfeldt-Jakob disease) or HIV (human immunodeficiency virus), you can't donate your organs
- whether your organs or tissues are suitable for donation
- whether the coroner agrees to the donation at the time of your death (see page 60 for more information about why a coroner is involved).

If you'd like to be an organ or tissue donor, talk to your healthcare team. They will tell you more about it and can help you join the donor register if this is appropriate. Remember that even if you join the register, this doesn't mean your organs or tissue will automatically be donated when you die. The decision about whether they are suitable, or whether the coroner agrees to the donation, will be made after you have died.

# 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'd like your funeral to be arranged, for example whether you want a cremation or burial, or specific things said. Your family liaison officer or personal officer will be able to discuss this with you.



# CONTROLLING SIDE EFFECTS AND SYMPTOMS

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# Pain

Not everyone has pain as their illness gets worse. But if you do, it can usually be well controlled. There are medicines you can take and other things you can do to help you feel better.

## Painkillers

Some commonly used painkillers include paracetamol, codeine, ibuprofen, diclofenac, tramadol and morphine. The type of painkiller you'll be given will depend on how bad your pain is. It's important to tell your healthcare team exactly where your pain is, how it feels and how it affects you.

'Would I get pain control on time or be left to suffer unnecessarily?'

If you have pain all the time, you'll need to take painkillers regularly. Each dose should be enough to control your pain until the next dose is due. If you're taking strong painkillers, they'll need to be given to you by the prison healthcare staff. They will give them to you at regular times (usually every 12 hours) so that your pain is kept under control.

If the pain comes back before your next dose is due, let the prison staff and your healthcare team know. They can review your pain and give you a more effective dose or a different drug. It can sometimes take a few days to get this right.

Some painkillers can cause side effects, such as feeling sleepy, feeling sick and constipation. Your healthcare team will let you know if the type of painkiller you're having is likely to cause any of these effects. Sickness and constipation can be helped by taking other medicines too (see page 44).

If you can't swallow, you may be given painkillers through a small, portable pump called a syringe pump. This gives you a continuous dose of the drug over 24 hours. If you need a syringe pump, you'll usually need to be cared for in the prison inpatient unit, or in a hospital or hospice.

## Relaxation techniques

Learning to relax can help with pain. Using relaxation techniques, even for short periods of time each day, can help release some of the fears that can make your pain feel worse.

You can relax by becoming aware of different groups of muscles around your body and learning to relax them. Practising deep breathing may also help to relax you. Your healthcare team may be able to give you a relaxation CD to help you learn how to do this. Some prisons have relaxation courses you can go on.

You may also find it helps to distract yourself by listening to music or watching a film.

## Sickness and constipation

If you feel sick or have trouble keeping food down, your healthcare team can prescribe anti-sickness medicine to help. This should be taken regularly to help stop the sickness from coming back.

You may get constipated because you're not eating enough, or because you're not moving around much.

Painkillers can also cause constipation. If you are taking them regularly, you may need medicine to help you go to the toilet (laxatives or enemas).



# Eating problems

Many people lose their appetite, especially if they feel sick. You may be put off even by the sight and smell of food. Small, frequent, simple meals using your favourite foods are likely to be the most tempting. The prison kitchen team may be able to work with your healthcare team to help with this.

However, as you become more ill, you may find it harder to eat. If this happens, let your healthcare team know. They can tell you about the different liquid meals available and give you them.

There may come a time when you don't want liquid meals. Fluids such as water, squash or tea may be all that you need to feel comfortable.

You may notice that your mouth feels very dry. If this is stopping you from being able to eat or talk, let your healthcare team know. They can arrange for you to have an artificial saliva spray or other medicines to help.

# Tiredness and weakness

Feeling extremely tired all or most of the time is a common and difficult problem for people with advanced cancer. It can be caused either by the illness or by symptoms such as pain.

If you feel tired, it's important to pace yourself and save your energy for the things that matter to you.

Tiredness and weakness can make it harder for you to concentrate or take part in what is going on around you. If you have important things to do, it's best to do them at a time of day when you have more energy.

# Other side effects and symptoms

Cancer may sometimes cause other symptoms. Your healthcare team can suggest things to treat these.

## Problems emptying your bladder

If you have problems emptying your bladder, this can be treated by putting a thin, flexible tube (catheter) into the bladder to drain your urine. Having a catheter will mean you don't have to use a bedpan or bottle if you can't get out of bed.

## Difficulty sleeping

If you feel agitated or confused, or have difficulty sleeping, tell your doctor. They will check these symptoms. They may give you medicines to help you relax and sleep.

## Feeling breathless

If you're breathless, your doctor will check your breathing. They may give you medicines to help.



# AT THE END OF LIFE

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# The last weeks of life

It's normal to gradually get weaker and more tired over several weeks or months if you're dying from cancer. However, there's always a small risk that you may die suddenly.

In the last weeks of life there are a number of changes that can happen in your body. These will depend on the type of cancer you have and where it is in your body. Most cancers affect the body's ability to use food to make energy. This can lead to you feeling exhausted and weak. Cancer cells can stop the body from working normally. They may change the chemical balance in the body and cause a build-up of waste chemicals (toxins).

These changes often make people lose weight, no matter how much they eat. You will gradually lose your appetite. You may start to look more tired and your muscles may waste away. Once a person stops eating, they usually only live for a couple of weeks.

As you become weaker and less able to do things, doing normal daily activities, such as getting up, can make you feel exhausted. You will gradually feel more tired and will need to rest or sleep more during the day. At this stage, people often lose interest in things that used to be important to them.

# The last few days of life

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

If you're in a hospice or hospital and reaching the last few days of life, your family will be able to spend more time with you, if you'd like them to. You will usually have a member of the prison staff in your room at all times. A lot of the time you may just want to lie still and have people sitting nearby, without necessarily talking to you.

'Will I have an open door when I am very ill?'

If you're being cared for in the prison inpatient unit, the staff will request an open cell door policy. This means you will have access to nursing and medical staff at all times, which will be monitored by a prison officer. After talking with the prison team, your family should be able to spend more time with you, if that's what you want.

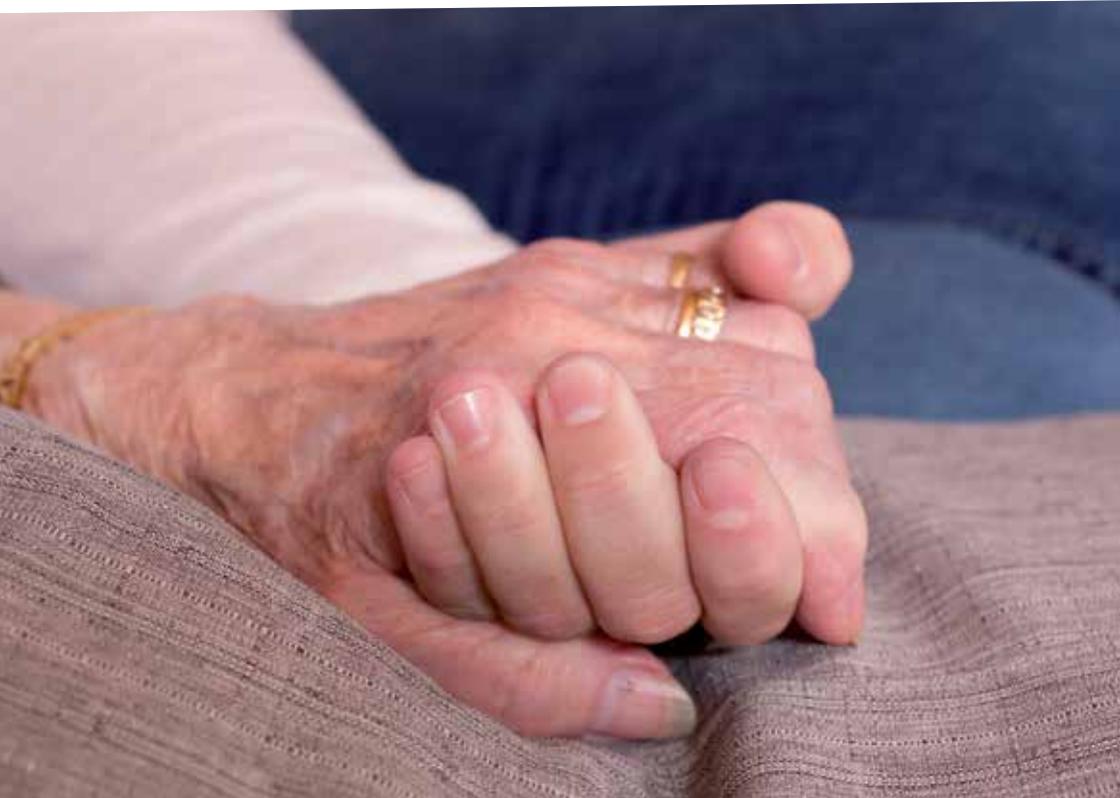
After needing to sleep and rest a lot, most people find they are not able to get out of bed. Then they become more and more drowsy, and then unconscious.

You may drift in and out of consciousness before becoming unconscious. At this time you may become confused and not recognise people you know. You may also hear or see things that aren't there (hallucinations). Some people may have thoughts or experiences that are like dreams, where they're not sure what's real or not. This confusion can be due to chemical changes in the body and the build-up of waste chemicals (toxins).

You may become distressed and restless. If this is the case, a nurse or doctor will be able to give you medicines to help you relax.

# Sensations

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

Feeling drowsy and sleepy usually leads to someone becoming unconscious and unable to respond to anything around them. You may seem to be peacefully asleep. Or you may move, twitch or grimace sometimes, as though you're dreaming.

Although you won't be able to respond to the people around you, you'll probably be aware that they are there and 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.

At this stage, you don't need food and drink because your body is no longer able to use them. Someone may moisten your lips or mouth to help you be more comfortable. When someone who is near the end of their life stops drinking, they usually only live for a few days.

# Breathing

If a person isn't moving around, the fluid normally produced by their lungs is not able to drain away and may collect in the air passages. This means that when they breathe, they make a slight groaning (rattling) noise. Medicines can be given to help with this.

Although noisy breathing can be upsetting for family and friends to hear, it doesn't seem to be uncomfortable for the person dying. Your breathing may also become irregular, with long gaps between breaths.

# The final moments of life

For most people, their final moments are very peaceful. Their breathing may become even slower and more irregular, with very long pauses between each breath. Their tummy (abdominal) muscles may take over control of the breathing from the chest muscles, so that their tummy rises and falls with each breath.

Finally, they will stop breathing altogether. This may seem to take a long time for some people. For others, it will only be a few minutes. Sometimes it can be difficult to pinpoint the exact moment of death. Often, the person's body will relax completely and they may look very peaceful. Some people feel they can sense when the person has died.

In some cultures, there's a belief that the person's consciousness (mind or soul) stays around the body for some time after death. Other people feel that their consciousness moves on quickly to another place. Some people believe that life just ends and nothing is left of the person's mind or consciousness.

# Spiritual needs

If you have different religious or spiritual beliefs, the prison, hospital or hospice staff will try to find out what is most appropriate for you in your final hours. But it's best if you make the staff aware of what you need. They can then make arrangements for your spiritual or religious adviser to visit.

If you'd like any special practices to be carried out at the time of your death, you will need to talk to your personal and family liaison officers beforehand. They will be able to let you know whether these are possible. You may find that it won't be possible to carry out some practices. This is because immediately after you have died, your body becomes the responsibility of the coroner, and specific prison procedures have to be followed.



# AFTER YOUR DEATH

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# What happens to your body after you die?

Many prisoners wonder what happens to their body after they have died. Whether you die in prison, at home, or in a hospice or hospital, your body will be taken to a mortuary. The mortuary may be at a local hospital, hospice or undertakers.

When someone dies in prison or under the care of the prison service (in custody), the death is always referred to the coroner. The coroner carries out a postmortem to find out or confirm the cause of death. After the postmortem, your death will be registered and your body can be released from the mortuary for your funeral.

If you die at home after being officially compassionately released (see page 24), a postmortem may not be needed. This decision will be made by the coroner, who will have been contacted by the prison team before your release.

# Telling your next of kin

If you die in prison, the family liaison officer will be involved in telling your family about your death, if they don't already know. If you die in a hospital or a hospice, the prison officer with you will contact the family liaison officer and duty governor so that arrangements can be made to tell your next of kin.

After your next of kin 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 how you want it to. The prison service can help with some of the cost of your funeral. The family liaison officer can also help your family arrange the funeral. They may be able to go to your funeral to support your family, depending on the circumstances.



# An inquest

It's normal for there to be an inquest when a person has died in prison or under the care of the prison service (in custody). This often happens some time after your death and is held in a coroner's court, in front of a jury. The purpose of the inquest is to make sure that you were given the best possible care. If it's found that your care could have been better, the prison staff can learn from this and make changes to improve care for other prisoners in future.

An independent investigation by the Prisons and Probation Ombudsman also needs to happen after a death in custody. This is to make sure the prison has looked after you properly during your time in prison and during your illness. The results of this investigation will be given to the coroner in charge of the inquest.



# IF YOU ARE A PARTNER, RELATIVE OR FRIEND

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# Information and support

Many people worry about what support and help is available after their death, for those close to them. This might be a partner, relative or friend on the outside, or another prisoner.

This section of the booklet 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's available to you.

# How grief might affect you

Grief is a normal response to the death of someone close to you. It's usually felt as a yearning for the other person. At times, the yearning can be so strong that it feels like very real, physical pain.

Everyone experiences grief in a different way, but most people move through some or all of the stages listed here. People often move backwards and forwards between these stages:

- numbness
- denial
- anger
- guilt
- pining or yearning
- depression
- gradual recovery and acceptance.

## Emotional effects

Immediately after the death, and for some time afterwards, you may feel numb. You might find it hard to believe that the person has died. It's common to feel angry. You may direct your anger at other people, such as family members, prison staff or healthcare professionals, for not being able to stop them from dying.

Many people continue to 'see' or 'hear' the person who has died, or have a sense of their presence. For example, some people walk into a room and have an experience of 'seeing' the person sitting in their favourite armchair. Other people have vivid dreams where they see the person who has died as fit and well. These are perfectly normal experiences, but they can be shocking and upsetting.

You may have times of severe anxiety and distress, where you miss the person and sob or cry aloud. This tends to happen less often after the first couple of weeks. But finding a photograph or visiting a place that holds strong memories can trigger the distress, even months or years afterwards.

It's important not to be afraid of showing your emotions. It's perfectly natural to cry when you're 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
- feeling weak
- breathlessness
- a feeling of tightness in the chest and throat
- feeling sick.

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



# Support if you're another prisoner

If you were involved in caring for the person or they were your good friend, you may experience the emotional and physical effects listed on pages 67–69.

It's important that you can get help and support to cope with the person's death if you need it. If you need more support or someone to talk to, you can speak to your personal officer, a member of the healthcare team or the prison chaplain. They will be able to tell you about the different types of bereavement support services available at the prison.

The chaplain may also organise a separate memorial service at the prison so that you have the chance to remember your friend and say goodbye.

# Support if you're on the outside

## Practical support

On the first day or so after the death, you will probably need help with practical tasks. You may feel overwhelmed by all the things you have to do, such as arranging the funeral and coping with visitors. The family liaison officer (see page 20) will be able to support you with some of these practical things. You may also need to spend some time on your own, to come to terms with what has happened.

## Financial support

You may be entitled to bereavement benefits, such as a bereavement payment, widowed parent's allowance or a bereavement allowance. You can find out more about any benefits you may be entitled to from the prison family liaison officer, or from your local Citizens Advice. You can also visit the Department for Work and Pensions website at **[dwp.gov.uk](https://www.dwp.gov.uk)** or call the Macmillan Support Line on **0808 808 00 00**.

Any instructions left in the person's will for who their property or money should go to are usually carried out by the next of kin.

## Emotional support

You may find it helpful to talk through your feelings with someone else. There are lots of organisations there to help, such as Cruse Bereavement Care (see page 78), which runs groups for people who are grieving.

Your GP can also put you in touch with a local bereavement counsellor if you would like one-to-one counselling. You can also contact one of Macmillan's cancer support specialists on **0808 808 00 00** for support and further information about counselling services.

Winston's Wish is a bereavement charity specifically for children (see page 78). It gives advice about caring for children who have lost someone close to them. It also has a website for children where they can write blogs and chat to other children who have lost a parent, grandparent or sibling.

## After the funeral

This can be the hardest time. Everyone has gone home and you're expected to get on with your own life. It's a good idea to try not to do too much too soon. If you make decisions in a hurry, you may find you regret them later. It's also important that you take time to look after yourself.

Some cultures have specific practices to follow, which can help to mark each phase after a person's death.

## Delayed grief

The grieving process is different for everyone and very personal. Sometimes, it can be hard to tell whether your feelings and emotions are normal. You may find that you get stuck at one stage of the grieving process, for example feeling very angry. If this happens, you can talk to your GP, who may recommend counselling.

Soon after the person has died, you may feel that you'll never be able to live your life normally again. These feelings usually get better over time, although this can take a year or longer. You will never forget the person and will always have memories of them. It's normal for you to be able to get on with life again after a while, and to be able to enjoy activities and make plans for the future.

If you feel you can't get on with your life after a year or so, you can ask for help and advice from your GP. You may need more support to help you through the grieving process.

A very small number of people develop suicidal thoughts as part of the grieving process. This might be because they feel unable to face life without the person who has died, or because they feel their own death might bring them closer to the person again. If you have suicidal thoughts, it's important you discuss them with your GP or someone close to you. You may need counselling and possibly medicines to help you feel better.

## Remembering your loved one

It's common for feelings of grief to be brought up again at particular times. This may happen on the anniversary of the person's death or on birthdays and other anniversaries. At these times, you may feel many conflicting emotions.

You may like to do something to remember them, such as go to the place where they are buried, or somewhere that meant a lot to you both. You may want to have a gathering of relatives and friends to share your memories and celebrate their life. You'll know the best way to remember them.



# FURTHER INFORMATION

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Other useful organisations

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Your notes and questions

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## Other useful organisations

### **Cruse Bereavement Care**

PO Box 800,  
Richmond TW9 1RG

**Tel** 0844 477 9400

(Mon–Fri, 9.30am–5pm)

**Email** [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

**www.crusebereavement  
care.org.uk**

Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website, at **www.cruse.org.uk/cruse-areas-and-branches**

### **Macmillan Cancer Support**

89 Albert Embankment,  
London SE1 7UQ

**Tel** 0808 808 00 00

(Mon–Fri, 9am–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.

### **Samaritans**

Freepost RSRB-KKBY-CYJK,  
Chris, PO Box 9090,  
Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** [jo@samaritans.org](mailto: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.

### **Winston's Wish**

3<sup>rd</sup> Floor, Cheltenham House,  
Clarence Street,  
Cheltenham GL50 3JR

**Tel** 08452 03 04 05

**Email**

[info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

**www.winstonswish.org.uk**

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



## Disclaimer

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## Thanks

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Questions about living with cancer?  
Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)

Hard of hearing? Use textphone  
0808 808 0121, or Text Relay.  
Non-English speaker? Interpreters available.

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