



Planning ahead:

what you need

to know

Practical help and guidance towards the end of life

StChristopher's
More than just a hospice

Planning ahead: what you need to know

We hope the contents of this booklet will be helpful to you and your family and friends.

Serious illness and ageing bring challenges many of us prefer to avoid thinking about. At the same time many of us fear loss of control about decisions relating to our futures.

It may be helpful to use this booklet for reference, so there are regular contents pages to allow you to dip in to the parts that are most helpful to you when you need them.

The last section is about coping with dying, which may feel very hard to read. This includes advice and guidance for family members and carers on what dying can be like.

We can also recommend the following TED Talk at bit.ly/3y8NPHH which describes what happens as we die. You can watch the talk by visiting the link above or by scanning this QR code with your mobile device.



Please be aware that this booklet may feel quite overwhelming at first glance because it contains a lot of information and guidance on difficult and sensitive issues.

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Advance care planning

Why does planning ahead matter?

Thinking ahead and writing down what matters to you can help you maintain control amidst uncertainty. It can be really helpful for your loved ones to know what you want in advance and this can help them make sure your wishes are followed if you're not able to express them in the future.

It may be difficult to talk together as a family and you may not always agree, but having these conversations can help direct decisions that sometimes need to be made in an emergency. You may like to talk to a healthcare professional as well.

Where can I write down my preferences?

The most important thing you can do is to make your wishes known to others. Writing down your preferences

and choices can help you to influence what happens to you in the future.

It gives you the opportunity to think about what you would and wouldn't like to happen. It'll also help us, and other healthcare professionals, know what's important to you if you're ever unable to tell them yourself.

We have a booklet which can guide you through a series of questions and ideas for you to think about. This is called an Advanced Care Plan booklet. It is yours and you can show it to whoever you decide needs to see it. You can download the booklet at <https://bit.ly/4lw7rly> or by scanning the QR code below with your device. You can also ask a member of staff for a booklet as we have printed versions at St Christopher's. Alternatively, you can use an online tool to help you such as 'Planning Ahead: What matters most to you'.



Your wishes can also be recorded electronically on the 'Urgent Care Plan' – an online database containing your care and support wishes which is accessed by all relevant healthcare professionals and is accessible 24 hours a day.

What is advance care planning (ACP)?

Advance care planning helps you to make known your wishes, feelings, beliefs and values, and to make choices that reflect these. For example, where you want to be cared for, who you want to be involved in decision making, how you want practical things like pets to be cared for.

It is an ongoing process of conversations between a person, those important to them and those providing care, support or treatment. Advance care planning

should be an important part of life for all adults.

What is a treatment escalation plan (TEP)?

A treatment escalation plan is part of advance care planning and relates only to medical care and treatment. For example, whether or not going to hospital if you were acutely unwell would benefit you. It's important, although sometimes difficult, to think of the care and treatments we would or would not like to receive if we became ill.

In an emergency, health or care professionals may have to make rapid decisions regarding your treatment when you may not be well enough to discuss and make choices. A TEP empowers you to guide them on the treatments you would or wouldn't want to be considered for. It records those treatments that could be

important, or those that would not work for you. Many treatments that can prolong life for some people carry a risk of causing harm, discomfort, or loss of dignity. People can choose not to accept that risk if the likelihood of benefit from treatment is small. This plan is to record your preferences and agreed realistic recommendations for emergency situations, at whatever stage of life you're at.

A TEP is advisory. The team treating you will need to make decisions based on your clinical condition at the time, but knowing your wishes will be extremely helpful. The TEP cannot be used to ask for treatments that are not likely to be of benefit to you or be offered to you.

What is an Advance Decision to Refuse Treatment (ADRT)?

Even if a medical treatment might benefit you, you can refuse this both

at the time and in advance. If you wish to refuse a treatment that is life-prolonging, then this needs to be written down in advance and signed and dated by you and a witness. This document is called an Advance Decision to Refuse Treatment (ADRT).

ADRTs only become valid if you've lost the ability (known as mental capacity) to be involved in treatment decisions. It's important you discuss the different treatments you may wish to refuse with a health professional who can support you in completing this document. You do not need a solicitor to complete ADRT. You need to be over 18 and to have mental capacity to consent to or refuse the treatment that is being discussed.

It's important that all healthcare organisations including the GP, hospital and also your family have copies so that in an emergency it can be accessed quickly. ADRTs are legally

binding unless the treating team feel that the circumstances have changed since you signed it. It is important to note that an ADRT only allows you to refuse treatment not to request it.

You can also make a statement of wishes about treatments that you would and would not wish to receive but this is not legally binding.

Useful websites

- My Decisions is a free and simple website to help you plan ahead for your future treatment and care **mydecisions.org.uk**
- The ReSPECT process creates a personalised recommendation for your clinical care in emergency situations where you're not able to make decisions or express your wishes **resus.org.uk**
- Planning Ahead is an online tool to encourage conversations

about advance care planning
advancecareplanning.org.uk

- Digital Legacy Association: if you use the internet and connected devices it's important you make plans for the items that you own and for those you care about in the digital world.
digitallegacyassociation.org

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Frequently asked questions about CPR

What is cardiopulmonary resuscitation (CPR)?

CPR is an emergency treatment which tries to restart a person's heart or breathing when these suddenly stop ('cardiac and/or respiratory arrest'). CPR does NOT refer to other treatments such as antibiotics or 'drips' (see **What is a Treatment Escalation Plan (TEP)?** on page 4).

CPR can include:

- 'Mouth-to-mouth' or 'mask-to-mouth' breathing
- Pushing down firmly on the chest repeatedly ('chest compressions')
- In hospitals, a tube may be put in the windpipe and a bag or a machine is used to pump oxygen into the lungs
- Special machines known as defibrillators may also be used to deliver electric shocks to the heart

– only certain types of cardiac arrest respond to defibrillators.

How successful is CPR?

Sometimes the media present CPR as being very successful. But, unfortunately, the success rate in real life is much lower.

CPR usually only works in certain situations: people who were previously well and who have specific types of cardiac arrest are much more likely to respond to treatment.

Even in a hospital with all the available facilities, only one in five to six people (with all kinds of illness) who receive CPR will recover enough to leave hospital.

Outside hospital, this figure drops to one in ten people who survive to leave hospital. Even if people survive a cardiac arrest they may be left severely brain damaged.

In people with very serious, advanced illnesses (for example advanced cancer or severe heart or lung disease) only about one person in a hundred who receives CPR will recover enough to leave hospital.

Sudden stoppage of the heart and breathing requiring CPR is unusual. More commonly, people die naturally of their terminal illness. As it progresses, they'll become sleepier and the heart and breathing will slow down gradually over a period of hours or days.

What facilities for CPR are available at St Christopher's?

There's an automated external defibrillator (AED) outside the front of the hospice (Sydenham site) for public use in emergency situations, primarily intended for visitors and staff.

In the rare situation when a patient may benefit from an attempt at CPR, the AED may be used and a 999 ambulance will be called simultaneously whilst staff commence basic life support. The hospice doesn't have the facilities for advanced life support, such as breathing tubes/ machines and relevant medications, so a person would need transfer to hospital for these treatments.

Are there side effects or complications after CPR?

CPR often causes broken ribs and internal bleeding. Even if people survive after CPR, they may be left with additional medical complications such as brain damage.

Who is responsible for the decision?

Ultimately this is a medical decision. Whilst your views are taken into

consideration, you and your family are not expected to take responsibility for the final decision. The decision rests with the professionals caring for you. At home this will usually be your GP. In the hospice ward, this will usually be the consultant responsible for your care, but occasionally it may be a senior nurse. The medical and nursing team will always consider whether CPR is appropriate for people under the care of St Christopher's. Like any medical treatment, CPR will not be attempted if it won't work or if the harms are greater than the benefits.

Decisions are reviewed by the clinical team looking after you. Our aim is to emphasise your comfort and provide you with dignity at all stages of life.

Will CPR be discussed with me?

If you do not have a current, valid Do Not Attempt CPR (DNACPR)

form, we will discuss your views about CPR with you, unless it appears that to do so would be too overwhelming or upsetting to discuss. The doctor in charge of your care will tell you if they think you may benefit from it.

Should you require inpatient care and CPR is particularly relevant to your needs, or you're concerned to have full CPR facilities available, it may on rare occasions be more appropriate for you to be cared for in hospital rather than at St Christopher's.

If I'm too ill to discuss CPR can my family or friends decide for me?

It's the doctor's legal responsibility to decide what will be best for you medically if you're too sick to make your own decisions, and to

inform your family or friend of their decision. However:

- If possible, the team will ask your family and/or close friends if they know about treatments, including CPR, that you wouldn't want
- If there's a valid Lasting Power of Attorney for health, the person acting for you will be consulted but it's important to know they cannot insist on CPR being tried if it will not work.
- If there are particular people who you do (or do not) want to be consulted, let your doctor or nurse know.

What if I don't feel ready to talk about CPR?

You don't have to talk about CPR. If you want family or friends involved in conversations, remember that they can say what they think

you would prefer, but cannot decide for you or insist on CPR being tried.

If there's no CPR decision recorded and my heart and breathing stop, what will happen?

In the hospice, the clinical team in charge of your care will make a judgement at the time and will perform CPR if they think it will be successful. They will not attempt CPR if it will not work. The final decision rests with a senior doctor or nurse.

If you're at home and an ambulance is called, the paramedics will attempt to restart your heart and breathing unless there is a Do Not Attempt CPR (DNACPR) form or it's clear that it will not work. They may consult a senior doctor for advice.

What happens if I am unhappy with the decision?

We recognise these situations are potentially very stressful for you and those close to you. You have the right to a second opinion if you're unhappy with a CPR decision.

I've heard of people who are 'not for resuscitation' who are just abandoned and not given any treatment at all. Will this happen to me?

Definitely not. Our emphasis at all times will be on ensuring your comfort and dignity. If we feel that there is a problem which could be reversed or treated such as an infection and that antibiotics or a 'drip' may help you, we'll discuss these with you in the usual way.

How are decisions recorded?

CPR decisions are recorded on the electronic notes. With your consent, decisions can also be shared with other professionals via the Urgent Care Plan: this can be accessed by out of hours services and London Ambulance Service. If CPR will not work when your heart and breathing stops, a paper form called a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order is used to alert hospice staff, ambulance crews and other professionals in an emergency. A doctor or nurse signs this. Once the form has been discussed and agreed with you and/or your family, we recommend that you keep it safe and carry it with you if you're admitted to hospital or hospice. You may wish to refuse CPR in advance even if it may benefit you. This usually needs to be recorded

in an Advance Decision to Refuse Treatment which you'll need to sign and have your signature witnessed (see page 5 to find out more about an ADRT).

This information is in accordance with the 2016 joint guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing publication *Decisions relating to cardiopulmonary resuscitation*.

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Vulnerability and planning ahead

Living with a life-limiting condition can cause your level of independence to change. Your care and support needs may increase and you might need support from others, whether this be from family, friends or a care agency. Increased dependency on others can cause you to feel and be more vulnerable to abuse and exploitation. It is possible that a person living with certain types of life-limiting conditions could experience problems with communication, memory or confusion.

Therefore, it is important to be aware of your rights and of the help available. Planning ahead could enable you to protect yourself as far as reasonably possible; thinking about the following may help you plan.

Access to your home

If you couldn't answer the door how would the person or people caring for you gain access? Someone

you know well and trust could be a key holder. It's important to have a contingency plan if this person is not always available. For example, a keysafe could be installed – your key would be locked away safely outside your home and only family, friends and key professionals would have access to the pin number. It's important not to leave your front door unlocked and do not give a spare key to people you do not know.

A pendant alarm could be useful if you needed urgent help, such as if you had a fall. When you press the call button, a nominated person or agency visits your home to help you in a crisis. You can usually go to your local authority for a key safe and/or pendant alarm

Care and support

If you couldn't look after yourself due to loss of physical and/or

cognitive function, who would you want to look after you? This could be a family member, friend or a care agency. You may need personal and nutritional care, so it's important you feel safe and respected whilst this is carried out.

Who would you call if you're concerned about the care you're receiving? This could be the local authority, the care provider manager or the police (if you're in immediate danger or you think a crime has been committed).

Who would you want to advocate for you if you could not express your own views and wishes? This could be family, friends or an independent advocate.

If your care and support needs meant you were at risk in your own home, where would you want to be cared for? A hospice admission

can only be offered for pain management, symptom control or end of life care; other options could be a family member's home, sheltered accommodation or a care home.

Finances and valuables

If you could no longer manage your financial assets, who could help and protect you?

Who would do your shopping? It's helpful to obtain receipts for all items bought on your behalf.

Who would buy your personal items? Think about people who know what is important to you.

How would you know if you were being financially exploited, or if someone is stealing from you?

Who would look out for you if you couldn't protect yourself? If you feel unable to answer these questions then please do reach out to

St Christopher's for support. We can help you and signpost you to the right places.

Do you have a safe place to keep your valuables secure? Many new people may come into your home, so locking away your valuables could help keep them safe.

Have you made a Will? Are there specific items you want to leave to someone in particular?

Social inclusion

Maintaining relationships, meaningful activities and social interaction can be really important when planning ahead.

Who would you want in your life and how would keep in contact with them? It's helpful to notify professionals of the important people in your life, and of those you do not want contact with.

What do you like doing and how will you make sure you can keep doing it for as long as possible? Think about your quality of life and what is important to you.

How could you maintain social interaction with others? Decreased independence can lead to increased isolation. Our hospice staff could help you think about this.

Your home

How will you make sure you can remain living as independently as possible for as long as possible?

How will you manage the stairs if you have them? If you cannot manage the stairs, perhaps you have a room downstairs that you could rearrange into a safe living space.

Is your home suitable for adaptations? If you rent your home, this may not be possible; the

decision would be the landlord's to make.

Is your home suitable for specialist equipment? There's equipment available to help you adapt your everyday living needs. However, some of it can be quite large, e.g. you may need a hospital bed to enable the carers to look after you safely.

Children and adult dependents

Who else are you responsible for other than yourself?

Who can look after those dependent on you when you're not able to?

If you do not have an appropriate person within the context of UK legislation, the local authority will need to be involved in planning.

What support will the person you care for need and from whom? This could be physical, psychological or

mental health support. Our Social Work Team can help you and your dependent(s) plan if you need support.

How will you protect the people you care for from becoming your carer?

This is a complex situation and you may need support from our Social Work Team.

How will you prepare those dependent on you for times when you're not able to look after them or meet their needs?

This is likely to evoke all sorts of challenging emotions; our social work team can help you plan if you need support.

How will you prepare them and yourself for endings?

We have a range of support available at the hospice so please let your needs be known to one of our team members.

Useful websites

There's a range of options to consider when choosing the right care for you. We're happy to signpost you to advice and information to support your decision. Here are some useful websites which can help in making decisions about your care.

- Find care homes
www.nhs.uk/service-search/other-services/care-homes-and-care-at-home
- Housing Care
housingcare.org
- Extra care housing
www.housinglin.org.uk/topics/browse/housingextracare/
- You can also contact your local authority to ask about sheltered accommodation and other care support.

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Next of kin and Power of Attorney

When you're referred to St Christopher's, we ask about your 'next of kin'. This is someone you nominate to receive information about the care we provide, or any decisions we need to make. In identifying a next of kin, you're giving consent for us to keep the person or people most important to you informed.

You can choose whomever you like; it should be someone you trust and feel close to. It's often a spouse or civil partner, or someone you live with. It doesn't have to be a blood relative; it can be a good friend. You can give the name of more than one next of kin.

Whether or not you wish to name anyone as next of kin, we'll always continue to keep you informed about your care.

The term next of kin is in common use, however a next of kin has no legal powers, rights or responsibilities.

In particular, they cannot give consent for providing or withholding any treatment or care.

A next of kin is not the same as appointing a Lasting Power of Attorney (LPA). LPA is a legal process whereby someone can be appointed to act on your behalf, to make decisions about your health and welfare and/or your property and financial affairs.

Decisions about providing or withholding treatment or care are usually made by you. However, if you're no longer able to do this for yourself, treatment and care decisions are legally left in the hands of the relevant professional (doctor, nurse, social worker) acting in your best interests, unless someone has been given LPA for health and welfare matters.

This LPA is used to give an attorney of your choice the power to make decisions about things like:

- your daily routine, e.g. washing, dressing and eating
- medical care
- moving into a care home
- life-sustaining treatment

It can only be used when you're unable to make your own decisions.

If you do not have an appointed attorney and you're unable to make decisions about providing or withholding treatment or care, your next of kin is not given any legal right or responsibility to make such decisions on your behalf, although those important to you will of course be consulted.

For more information about setting up an LPA, please visit www.gov.uk/power-of-attorney.

A nominated next of kin has no legal rights and responsibilities in the event

of your death. If you've made a Will, your executor(s) will be responsible for arranging your affairs according to your wishes. Your executor may appoint another person to act on their behalf.

If you've not made a Will, the law sets out who has the right to deal with your affairs after you've died and who can inherit according to their legal or blood relationship to you. Your spouse or civil partner comes first and then the closest degrees of blood (or adoptive) relative in this order: children, parents, siblings, and so on. The law gives these groups of people priority over common law partnerships, step children and long-term friendships.

Your named next of kin will not have the right to deal with your affairs after you've died, unless they have the relevant legal or blood

relationship to you, or you write a Will appointing them as an executor.

For more information about the rules of intestacy, please visit www.gov.uk/inherits-someone-dies-without-will.

Your nominated next of kin can register your death if they:

- are a relative
- were there at the time of death
- are in charge of making funeral arrangements.

For more information about registering a death, please visit www.gov.uk/register-a-death.

For further help or advice in relation to any of these matters please ask to speak to a member of staff.

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Do I need to make a Will?

This is general guidance only and we suggest you obtain legal advice if you've any doubt about the meaning of anything in this section. Some of the legal terms used are explained below:

Crown The state

Beneficiary The person (persons) nominated in the Will to receive property, personal possessions and/ or money from the estate

Estate All the net assets owned by a person, especially at death. Assets include property, money and possessions

Executor The person responsible for arranging the funeral and then carrying out the terms of the Will. An executor can be a beneficiary in your Will but must not sign the Will

Intestate Dying intestate is the legal term for someone who has died without making a Will

Joint tenants Where tenants jointly own the whole of the property

Life interest Where a person is given an interest in a property or other assets for life, or for a shorter period of time

Tenants in common Where each tenant owns a set share of the property, this can either be half each or a defined percentage.

Do I need to make a Will?

You do not always need to make a Will.

A Will helps you to decide what happens to your property, money and possessions (your 'estate') after your death. Making a Will ensures your wishes will be carried out when the time comes.

However, if your affairs are straightforward it may not be necessary to make a Will. For example,

if the person who has died has just enough money to cover the cost of their own funeral, then a Will may not be necessary as most building societies and banks will issue payment to the funeral director on production of the final bill and a copy of the death certificate.

If you're uncertain, then please seek further advice.

What if I die without making a Will?

If a person dies without leaving a valid Will, this is known as 'dying intestate'. The state has rules which apply if a person dies intestate. These rules are called the rules of intestacy and they dictate how the estate is distributed.

Married/civil partners with children

If the estate is valued at more than £270,000 the married/civil partner will inherit:

- all personal property and belongings of the person who has died, and
- the first £270,000 of the estate, and
- half of the remaining estate

The remainder of the estate is divided equally between the surviving children. If a son or daughter has already died, their children will inherit in their place.

If the estate is valued at less than £270,000, the surviving married/civil partner will inherit the whole estate.

Married/civil partners with no children

The whole estate goes to the surviving married/civil partner.

Unmarried people with children

The children of a person who has died without leaving a Will will inherit the whole estate. This applies however much the estate is worth. If there are

two or more children, the estate will be divided equally between them.

If a son or daughter has already died, their children will inherit in their place.

Unmarried people with no children

The estate goes to the deceased's blood relatives in the following order:

- parents
- brothers or sisters, or their descendants
- half siblings or their descendants
- grandparents
- uncles and/or aunts or their descendants
- half uncles and/or aunts or their descendants.

It's important to remember that cohabiting partners (sometimes wrongly called 'common-law' partners) who were neither married nor in a civil

partnership cannot inherit under the rules of intestacy.

The rules of intestacy also make no provision for step-children, relations by marriage or close friends. Having a valid Will ensures you make the decisions about what happens to the property and money you own, rather than the state.

How do I make a Will?

For your Will to be legally valid, you must:

- be 18 or over
- make it voluntarily
- be of sound mind
- make it in writing
- sign it in the presence of two witnesses who are both over 18
- have it signed by your two witnesses, in your presence.

It's not always necessary to use a solicitor when making a Will, and it's possible to make your own Will without the help of a solicitor. However, you should only consider doing this if the Will is going to be straightforward. Standard Will kits are available to buy online or from some stationery shops and larger supermarkets.

If you want to be completely confident that your Will conveys your wishes, you should take legal advice from a solicitor. This is particularly important if your estate is complicated, for example if you own property abroad, you own a business or where inheritance tax is relevant. Solicitors and other professional advisors will charge for their services.

Other help with making a Will

Some charities offer free or reduced services from solicitors in return for

a donation to the charity. If you're a member of a trade union, you may find the union offers a free Will-writing service. Some banks also offer Will-writing services to their customers.

Support with preparing a Will from St Christopher's

St. Christopher's works with local solicitors to provide 'Will Week'. During Will Week, the solicitors we have teamed up with waive their usual fee in return for a donation to St Christopher's. For more information on Will Week and other support in preparing a Will please see our website.

St Christopher's staff and volunteers are unable to assist you with writing and witnessing your Will. However, we are able to give general guidance as to whether it is advisable for you to make a Will or not.

Important points to remember

- All Wills need to be witnessed by two independent individuals, whether you've written your own Will, used a solicitor or completed a standard Will template
- Anyone whose Will was made before their present marriage or civil partnership needs to make a new Will, unless it includes a clause which ensures it will continue to be valid
- Divorce changes but does not revoke your Will. However, the former spouse can no longer be a beneficiary, although can still be an executor. Consider whether this may cause problems
- Many couples own property as 'joint tenants'. This means that if one of the couple dies, the surviving person

automatically inherits the whole property

- If the property is held as ‘tenants in common’ the person who has died could leave their share of the property to whomever they want
- It’s worth checking how your property is held. If you change it to a joint tenancy this can mean you don’t need to make a Will as the property will transfer automatically to the surviving person.

For more information on current inheritance tax legislation, please visit www.gov.uk/inheritance-tax.

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Welfare benefits and financial support

Please note that these benefits usually only apply if you have no restrictions on your right to remain in the UK. If you have an uncertain immigration status, please seek further advice.

Welfare benefits for people over pension age

Attendance Allowance (AA)

Attendance Allowance is paid to people who need help with their personal care (e.g. help with washing, dressing etc) and who are over pension age when making a new claim.

Some people who claimed Disability Living Allowance (DLA) or Personal Independence Payment (PIP) before they reached pension age may continue to get DLA/PIP instead.

These benefits are paid on top of any other benefits or pensions you may be

receiving and can also be paid if you're still working. It is a tax-free benefit.

Receiving Attendance Allowance (or DLA/PIP) may mean that you're automatically entitled to other benefits.

There are special rules for people who have been diagnosed with a terminal illness. Claiming under special rules means:

- You'll receive the highest rate of Attendance Allowance
- Your claim will be dealt with quickly
- You won't need to complete all of the claim form
- Someone else can make the claim on your behalf
- You'll be paid Attendance Allowance weekly
- You do not need to have had problems looking after yourself for the last six months.

If you're eligible to claim under special rules your doctor or nurse will provide a medical report which is known as a DS1500 report.

If you're not already receiving Attendance Allowance you can request a form from the Department of Work and Pensions by calling **0800 731 0122** or visiting www.gov.uk/attendance-allowance/how-to-claim.

If you're already receiving a lower rate of Attendance Allowance or standard or lower rates of PIP or DLA ask your St Christopher's nurse if they can send a DS1500 medical report to increase your benefit to the higher amount.

Pension Credit

If you're over pension age and have a low income you may be entitled to Pension Credit to top up your income. An award of Pension Credit may also entitle you to other types of help, such as help with service charges for

home owners, free dental treatment, optician services and travel to hospital.

The amount of Pension Credit you can receive is dependent on your income including pensions and other benefits. Pension Credit can include additional amounts for any dependent children you're responsible for.

If your partner is under pension age you'll need to claim Universal Credit instead.

Contact the Pension Credit application line on **0800 99 1234** to make a claim or claim online at www.gov.uk/pension-credit/how-to-claim.

Help with rent payments

If you're over pension age and have a low income you can claim Housing Benefit for help with rent payments. Housing Benefit is dependent on the level of savings you may have. If you're already receiving some Housing

Benefit you may be entitled to a higher amount because of your illness.

You can claim Housing Benefit from your local council.

Welfare benefits for people under pension age

Personal Independence Payment (PIP) or Disability Living Allowance (DLA)

If you're under pension age and need help with personal care/daily living you can claim PIP. PIP replaced DLA for new claims for people aged 16 and over from June 2013. If you're already receiving DLA you can continue to receive it. However, you may be entitled to a higher amount if you instead apply for PIP. The rates are paid at the same amount for both benefits.

PIP (or DLA) is paid on top of any other benefits you may be receiving and can also be paid if you're still

working. It is a tax-free benefit. Being awarded PIP (or DLA) may mean that you're automatically entitled to other benefits.

There are special rules for people who have been diagnosed with a terminal illness. Claiming under special rules means:

- You'll receive the enhanced rate of the daily living component
- Your claim will be dealt with quickly
- You do not need a face-to-face consultation
- You won't need to complete all of the claim form
- Someone else can make the claim on your behalf
- You'll be paid PIP weekly
- You may also be able to apply for the mobility component, depending on your needs

- You do not need to have had daily living or mobility problems for the last three months.

If you're eligible to claim under special rules your doctor or nurse will provide a medical report which is known as a DS1500 report.

You can also be paid a mobility component of PIP and DLA if you have difficulty getting around. This will be assessed at the same time as the daily living component.

If you're not already receiving PIP or DLA you can start your claim by calling the 'PIP new claims' line on **0800 917 2222**. You'll be asked for personal details for the claim and will then be sent a questionnaire (PIP2) for details about your daily care needs and mobility issues.

You won't need to complete the questionnaire if you're eligible to claim under special rules and a DS1500

medical report is sent in support of your claim.

If you're already receiving a lower/standard or lower rate of PIP or DLA, ask your St Christopher's nurse if they can send a DS1500 medical report to increase your benefit to the higher amount.

New Style/Contributory Employment and Support Allowance (ESA)

If you've paid enough National Insurance contributions in the three years before your claim, you're entitled to a basic amount of New Style/Contributory Employment and Support Allowance (ESA) when the Statutory Sick Pay entitlement ends. ESA is paid from the Department of Work and Pensions.

ESA is not affected by any savings you have or the income of any other members of your family. The amount

you're paid may be affected by any work pension you receive.

You can claim New Style Employment and Support Allowance online by visiting **www.gov.uk**.

You can also claim ESA by calling the Universal Credit helpline on **0800 328 5644** (choose option **3**).

Universal Credit

If you've not paid enough National Insurance to qualify for ESA, you may be eligible for Universal Credit to top up your income. Universal Credit is dependant on your income, savings and family circumstances.

You can claim Universal Credit for help towards rent costs and for any dependent children you're responsible for.

An award of Universal Credit may also entitle you to other types of help,

such as help with free prescriptions and dental treatment.

If you're already receiving other benefits such as Income Support, income-related ESA, Jobseekers Allowance, Housing Benefit or Tax Credits these will stop and be replaced by Universal Credit. Please seek advice if this is your situation.

Universal Credit is claimed and managed online at **www.gov.uk**.

If you have difficulties accessing Universal Credit online, you can call the Universal Credit helpline on **0800 328 5644**.

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Preparing for a funeral

Planning a funeral can be helpful for those who are approaching the end of life and for their family and friends. It is one way of ensuring that a person's wishes are respected.

This section aims to help you consider some of the important things involved.

Making the arrangements and advance care planning

You can ask friends or family to help plan a funeral. It does not have to be a named next of kin. you can include instructions for your funeral in your Will or advance care plan.

What sort of funeral?

Religious beliefs and personal wishes may play an important part in funeral decisions. If you're familiar with your local place of worship, the faith leader will be able to discuss with you

readings from holy books, hymns or prayers. If you're not in contact with your local faith centre and would like to meet a religious leader from your faith, the St Christopher's Chaplain can arrange for you to talk to someone.

A non-religious service can take place, led by a Humanist Celebrant. A list of celebrants can be found at www.humanists.uk or our chaplain can give you the contact details.

What can be included?

Funerals are often a mixture of music, readings, hymns and addresses (or tributes). You can think about what you might want other people to say about you – either write it down or talk to them. A range of books with collections of poems and prose readings suitable for a funeral service are available from the chaplain for you to read or please visit www.uk-funerals.co.uk/funeral-poems.html.

If you want to include music, the choice of pieces is entirely up to you, from songs you've enjoyed to your favourite pieces of music. It is traditional to have music played as people enter and leave, and sometimes music during the service allows time for everyone present to reflect quietly. For help with choosing music or hymns for a funeral, please search '**funeral music**' online. Funeral directors hold lists of musicians you can hire to sing or play at the funeral.

Our chaplain is available to talk to you about planning your funeral and recording your choices.

Funeral directors

If you decide to use a funeral director, Funeral Directors Associations have listings. Please visit www.nafd.org.uk or www.saif.org.uk.

Unless you have a particular firm that you know well, it's advisable to

visit two or three and ask for written itemised quotes. This will help you to know what each aspect of the funeral might cost and to keep to your budget.

Burials are more expensive than cremations and if you wish to be buried outside your borough you could be charged for the grave.

If a funeral director is not involved, you'll need to liaise directly with the cemetery or crematorium office where the funeral is to take place. There are guidelines to help with this and the web link is listed.

'Green' funerals

You may wish to consider an ecologically friendly funeral where the body or ashes are buried in a wood land setting and a wicker or other sustainably sourced coffin used. You may find that the nearest green burial

site is some distance away, so it could be less easy for family or friends to visit the gravesite. The Natural Death Centre website at www.naturaldeath.org.uk gives information about alternative choices for funerals and natural (green) burial grounds.

Scattering ashes

Ashes can be scattered or buried in a place which has significance to you. You'll need permission from the landowner, the rivers authority or other legal body before or scattering takes place.

Leaving your body to medical science

If you wish to leave your body to medical science, speak to your nurse or doctor who can give you information about this. It means there will be no funeral, but a memorial service can be organised and you

may want to consider what should be included in this type of service. For more information please visit www.rcseng.ac.uk/about-the-rcs/support-our-work/donate/donate-your-body-to-medical-science.

Paying for a funeral

Funerals can be expensive. Often, the cost of a funeral is taken from the estate of a deceased person. Arranging for funds to be available may take some time and the funeral director will ask for part payment when arrangements are made. Always ask for a breakdown of costs before signing paperwork. You may want to talk with your family about how a funeral will be paid for and what aspects of the funeral are most important to you.

Normally the person who registers the death is involved in the arrangements made with funeral directors. However, whoever signs any

papers relating to this at the funeral directors is responsible for payment. It is advisable to make sure that these matters have been discussed and agreed in advance.

There are many 'pre-paid' funeral plans which are a form of insurance and guarantee that the cost is fixed. You can choose what level of service you wish to have. Grants are available in certain circumstances – if you need advice about this, ask one of our welfare officers.

Where there are no relatives or friends who can arrange the funeral, it may be organised by the local authority. In this event, the service will be basic, but will respect the religious belief of the deceased person.

Further help

If you would like to talk with someone about your funeral, or that of a family

member, please speak to a member of staff who will be glad to listen to your thoughts and concerns.

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Coping with dying

The last days and hours of life

What happens in the last days and hours of life is different for everyone. It can be helpful for those caring for someone to know a little about what to expect. For the vast majority of people, dying is a very gentle process, but for a few people death may be sudden. If you have any concerns about this, please talk to your team.

Syringe pumps are often used in the last few weeks and days of life as a safe and effective way to manage symptoms. Using a syringe pump won't cause a person to die sooner; commencing one often coincides with deterioration.

Knowing that a person is close to dying can be very difficult for everyone involved. What follows has been written for you, as well as for your carers, relatives and friends, as

they may worry they won't be able to cope or know what to do.

We know people deal with these issues differently, and no two situations are the same. However, we can give you some general information about what may happen and what can be done to support someone through the last days and hours before death.

CARERS The information shown in this style provides specific advice and practical tips for carers.

Letting go

Even if the physical body is ready to shut down, the mind may remain active. There might still be unresolved issues or relationships to put right.

CARERS Let the person you're caring for know that you're there for them and will help them with any of these issues. Allow them to share

any memories or feelings they have. Reassure them that it's all right to let go and die whenever they are ready. Some people will hold on until they have heard these words from the people they love. So, letting them go can be one of the most important and loving things you can do for them.

Physical changes

As the end of life draws closer, the body begins its natural process of slowing down all its functions. How long this takes varies from person to person. It might take hours or days.

When death is very near, you might notice some physical changes such as changes in breathing, loss of bladder and bowel control and reducing consciousness.

CARERS It can be emotionally very difficult to watch someone go through these physical changes.

But they are part of a natural dying process. It doesn't mean the person is uncomfortable or in distress. If you're looking after someone at home while they are dying, the Community Team from St Christopher's will be working with your GP, district nurses, and carers. For urgent problems or concerns, you can call St Christopher's on 020 8768 4500 for support.

Sleepiness and difficulty waking

As people get closer to the end of their life, they can sleep a lot and become more unresponsive. This doesn't mean they can't hear what is going on. Hearing may be one of the last senses to be lost.

CARERS If you would like to, do continue to talk to them and comfort them. You can sit close to them and hold their hand. In the same way as

when the person was in good health, it's important not to say anything that you wouldn't want them to hear. So, this may mean having difficult conversations in a different room. It's also a good idea to tell them when you enter or leave their room.

Difficulty swallowing or not wanting to eat or drink

As the body begins to slow down, the person's need for food and drink also slows down. There will come a time when the dying person may not want to eat or drink anything. They may also have difficulties swallowing. Food and drinks through a tube won't normally help at this stage, however the team will suggest it if they think that it will help. If the person wants to eat or drink but has difficulty swallowing, the team can also advise on what will be more comfortable.

CARERS Don't try and force them to eat or drink. This could make them uncomfortable. Sometimes it can be helpful to give them small pieces of ice to suck or sips of fluid, if they are still awake. This will keep their mouth moist. However, if the person has swallowing difficulties, please seek advice before doing this. You can also put lip balm on their lips to help stop them getting dry and sore. Even if they can't take anything into their mouth, you can moisten their lips and mouth regularly with swabs, or a soft toothbrush dipped in water or a drink they enjoy. Speak to your Care Team if you need mouth swabs.

Loss of bladder and bowel control

The dying person might lose control of their bladder and bowels. This happens because the muscles in these areas relax and don't work as they

did. This can be distressing to see and might cause embarrassment.

CARERS If you're caring for the person at home, the district nurses can arrange for you to have protective sheets or pads for the bed. They might also arrange for a special bed which can help to protect their skin, and make moving them in the bed a little easier. As people become very close to death and are not eating or drinking, the amount of urine and stools they produce gets less and less.

Pain

Many people who are dying, and the people around them, worry that they will be in pain. Many people will not have pain. However, if a person is in pain, it can usually be well controlled and people can be kept very comfortable. The St Christopher's team, the GP and the district nurses looking after the

dying person will do all they can to keep them as comfortable as possible.

CARERS It's important to tell the team looking after the dying person if you think they are in pain. Sometimes restlessness is a sign of being in pain. The St Christopher's team, GP and the district nurses will want to know so that they can plan the best way to control the pain.

Changes in breathing

When someone is dying their breathing often changes. It might look different or get noisy and irregular. There may be times when breathing stops for a few seconds. This is called Cheyne Stoke breathing. They may breathe with their mouth open and use their chest muscles to help them catch a breath.

Noisy breathing like gurgling or rattling can occur as someone

approaches death. This is coming from the chest or the back of their throat and is caused by a build-up of mucous and saliva. As the person is much weaker, they may not have a strong enough cough reflex to cough it up.

A doctor or nurse might suggest giving medications such as morphine or midazolam for difficulty breathing, even if they are not otherwise in pain. Morphine and midazolam are medicines which can help to make breathing easier.

CARERS It can help to raise the head of the bed with pillows or cushions. Just sitting with them, speaking gently and holding their hand can be very reassuring for them. Raising the head and turning it to the side can help gravity to drain the secretions. Let the team know if your loved one has noisy breathing like this. They

can sometimes use certain drugs to help dry up these secretions. Hearing the gurgling sounds can be concerning, but they don't usually seem to cause distress to the dying person due to them being much more sleepy.

Cold extremities

The dying person's hands, arms, feet and legs often become very cool to touch. Their skin might also become pale and look blotchy or mottled. This happens because the body is prioritising blood flow to the essential organs.

CARERS Keep them warm with blankets, but don't use an electric blanket as this could become too uncomfortable. Thick socks can help to keep their feet warm. Don't overheat the room, as this can make it stuffy. Just keep it at a comfortable temperature.

Confusion and disorientation (terminal delirium)

The person may say things which make no sense. They may not know what day it is or may not seem to know familiar faces. They could even say things that are totally out of character. For example, they might shout or physically push people away. This can be very hurtful and upsetting.

CARERS Try to understand that they don't mean it. They are not aware that they are doing these things. It happens partly because of the chemical changes going on inside their body, which affect the way the brain makes sense of information. Once again, let the team know if your loved one appears distressed by their confusion or disorientation. Sometimes certain drugs can be used

to help reduce these concerns, and help the person to feel calmer.

Death

At the end of life, the dying person will slip into unconsciousness. This is often a few hours or days before death.

The person's breathing may become irregular and/or noisy. You won't be able to wake them at all. Finally, their breathing will stop completely and they will not have a pulse.

How you might feel

CARERS You're likely to feel some very strong emotions during the time your relative or friend is dying. You might feel that you want to try and change what is happening. Giving them support and comfort during this difficult time is invaluable. Try not to worry that you're going to do something wrong. Just being with your loved one and letting them

know you love and care for them is the most important thing. You might need support and help yourself when someone close to you is dying. It could help to speak to:

- close friends and relatives
- any of the team at St Christopher's
- a religious leader or counsellor.

Further support

This booklet has provided a lot of information on some quite difficult topics. We hope you've found it useful and informative. If you need to talk it through, our staff are always happy to help and support you.

You can contact us at **info@stchristophers.org.uk** or call us on **020 8768 4500**.

Feedback

We really value your views. Please tell us what we do well and where we could improve.

There are lots of ways that you can provide feedback about your experience of St Christopher's. Email us at **feedback@stchristophers.org.uk**, call us on **020 8768 4500** or fill in a feedback form which can be found at both hospice sites.

Recording of calls

At St Christopher's we record our calls to allow us to support you as well as we can, in addition to using some recordings for training purposes.

When you call there is a series of numbered options available for you to select the service you require and to allow us to manage your call most effectively.

If you would like this information in a different format, such as audio tape, braille or large print, or in another language, please speak to the Communications Team on **020 8768 4500** or email communications@stchristophers.org.uk.

St Christopher's

More than just a hospice

Sydenham site

51-59 Lawrie Park Road, Sydenham, London SE26 6DZ

Bromley site

Caritas House, Tregony Road, Orpington BR6 9XA

Telephone **020 8768 4500**

Email info@stchristophers.org.uk

www.stchristophers.org.uk

   [stchrishospice](https://www.stchristophers.org.uk)

Registered charity 210667 registered with the Fundraising Regulator
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At St Christopher's Hospice our vision is of a world in which all dying people and those close to them have access to care and support, whenever and wherever they need it.

Each person is unique and we tailor our care to meet social, emotional and spiritual needs, as well as manage physical symptoms. Our goal is to help people live well until they die and support those affected by the loss of a friend or relative. Last year we provided care and support to nearly 5,000 patients, more than 2,000 carers and almost 2,000 bereaved people, across south east London, both at home and in the hospice.

We strongly believe that everyone should have access to the best care at the end of their lives, and through a blend of expert practice, education and research, we work with people across the world, to improve and develop hospice care.

We were founded in 1967 by Dame Cicely Saunders and, more than 50 years later, her words still remain at the heart of everything we do: "You matter because you are you and you matter until the last moment of your life."

As a registered charity we need to raise £15 million every year to continue to care for people when it matters most. Without the support of our local communities this wouldn't be possible.

Thank you, from us all, for your support.