St Christopher’s
Community Palliative Care and Outpatient Services
Information for patients and their carers at home

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St Christopher’s Community Palliative Care and Outpatient Services

St Christopher’s Community Team

This booklet has been put together for people who are unwell at home and for those caring for them.

St Christopher’s Community Palliative Care and Outpatient Services began in 1969 so that, whenever possible, people who are seriously ill can be supported to remain in the comfort and familiarity of their own homes. It was the first service of its kind in the world and today is setting the highest standards of care for people at home. In 2008 St Christopher’s merged with Harris HospisCare (renamed St Christopher’s Bromley in October 2013) and we now have two sites. At the Sydenham site you will find the Anniversary Centre, Inpatient Unit, Rehabilitation Gym, Candle child bereavement service and our Education Centre. Our Bromley site incorporates the Caritas Centre, the Community Palliative Care and Outpatient Service and the Bromley Lymphoedema Service.

St Christopher’s Community Palliative Care and Outpatient Services consists of teams of nurses, known as clinical nurse specialists (CNS), as well as doctors and social workers for each of the areas we cover (the London boroughs of Bromley and Croydon and parts of Lambeth, Lewisham and Southwark). A St Christopher’s Nurse Manager oversees the service to help you get the best quality of care.

Other members of the St Christopher’s team you may come across are welfare officers, physiotherapists, an occupational therapist, a chaplain, complementary therapists, a dietitian, speech therapist, psychiatrists and bereavement support volunteers. Please ask your St Christopher’s nurse for more information.

After you have been referred, one of our nurses will see you at either our Sydenham or Bromley site to assess your needs. If you are not able to manage the journey your nurse will see you at home.

We look forward to welcoming you to the Anniversary Centre or the Caritas Centre where you can enjoy the relaxed and friendly atmosphere and see first-hand the wide range of individual and group activities and therapies on offer.

Our services are aimed at supporting you and your close friends and family throughout your illness with whatever is important to you. This can be the physical aspects of your illness, or its emotional, social or spiritual impact on your life, and on those close to you.

Your St Christopher’s nurse will coordinate your care working closely with your GP and will arrange for other members of the St Christopher’s Community Team to become involved in your care if needed. You may also receive the services of district nurses and personal carers, some of whom are employed by the local authority and some by St Christopher’s Personal Care Services, depending on the borough.

Outside normal working hours (evenings, nights and weekends) a telephone and visiting service is available for urgent problems that cannot wait until the next working day.

If your condition stabilises and specialist palliative care services are no longer appropriate you may need to be discharged from our care. This will be discussed with you in advance. It is, however, very easy for us to become involved again if your condition changes. Your GP or district nurse should contact us on 020 8768 4500 (Sydenham site) or 01689 825755 (Bromley site).

The Anniversary Centre and Caritas Centre: outpatient and day services

The centres have been designed around the needs of patients and their families so that you can access the services you need as easily as possible. They are staffed by a Clinical Nurse Manager, health care assistants and volunteers. Patients who regularly attend the centres will have their care delivered by a team of nurses who are based in the centre. Your nurse will work with you to develop a personalised care plan to meet your needs. Appointments with your nurse or other members of the team take place in clinic rooms on site and you are welcome to spend all or part of the day with us with a family member or close friend if you wish.

In the centres you will find:

• a spacious social area
• consultation rooms for outpatient clinics
• group rooms
• bathing facilities (Sydenham)
• a rehabilitation gym
• a hairdressing salon
• an information area with PCs and internet access.

Medication
If you are spending the day with us, please bring any medication with you and feel free to discuss any issues you may have with your St Christopher’s nurse.

Café
While you wait for your clinic appointment or group session, relax and enjoy a cup of coffee, tea, or some café-style food.

Rehabilitation Gym (Sydenham)
This purpose-built gym aims to help people maintain their strength through gentle exercise. Groups available include Breathlessness Management Service, Pilates and Circuits. All groups are supervised by a physiotherapist.

Creative and complementary therapies
Both centres have a range of music and arts therapies available for one-to-one appointments and group programmes. Massage and relaxation therapy is available. All our therapists are registered to practice with the Complementary and Natural Healthcare Council.

Emotional and psychological care
Being diagnosed with a serious illness can affect many aspects of your life, including how you feel about yourself and your relationships with other people. It can affect your relationships and also revive problems from the past. Both the person who has the illness and those caring for them can find that it helps to talk to each other about how they feel about the changes in their lives. Sometimes you need to talk about your sadness, anger or worries about what has happened to you.

However, you may find it difficult to talk as openly with each other as you would like to because you are concerned about upsetting each other. You may find yourself feeling alone with your experiences of the illness. There are various different ways in which St Christopher’s can help you with your concerns.

What emotional and psychological care does St Christopher’s provide?
Your St Christopher’s nurse will give you time to talk about how you feel about what has happened and can refer you to any of our services, including:

Social workers
St Christopher’s social workers have particular expertise in helping with emotional or family difficulties. It can be helpful to talk to someone who is not personally close to you. The social worker can see you on your own or with anyone you chose; carers, family members or friends. They can help you say things to those close to you that you want or need to say. They can also help you to talk about practical planning.

Cognitive behavioural therapy (CBT)
CBT is brief problem-focused therapy that can help people regain a sense of control as well as identifying ways of coping with their difficulties. The average course of CBT lasts for between four to six sessions and is provided by a qualified CBT therapist at the Sydenham site.

Psychiatry
St Christopher’s has a Psychiatry Team which has expertise in helping people to manage particularly difficult emotional problems arising from living with a serious illness.

Art and music therapy and group programmes
Both of our centres have various therapies and activities that many people find helps them to feel less alone with their illness, including relaxation and support groups.

Children and young people
Children and young people also need help in understanding the illness and its effects. Adults may not talk to children because they are concerned about protecting them. However, even very young children find it helpful to talk about their own questions, worries and fears. The St Christopher’s social workers can help you and your children or grandchildren in
having these conversations and give you information about booklets and activities to support you. The St Christopher’s social workers can also help with planning for the future care of children.

**Spiritual and religious care**

St Christopher’s welcomes everyone – whatever their beliefs – and encourages people to feel free to express their spirituality or practise their religion in their own way.

St Christopher’s is committed to ‘total care.’ This means that whatever is important for each individual person matters to us. You and those close to you may have questions or concerns which are just as distressing as the physical symptoms of the illness. If you would find it helpful we can arrange for the hospice chaplain to contact you and arrange a visit.

The chaplain and his team work with clergy and leaders from many faiths, denominations and religious communities in the area. They can, if you wish, arrange to visit you and your family at home informally to meet any particular religious needs.

If you are visiting the Sydenham site, you will find the Pilgrim Room provides a quiet space to think, meditate or pray. There are books of poetry and photographs and faith texts you may wish to use. You may light a candle or record your thoughts in the large Memory Book on the table. At the Bromley site a similar space is provided in the Quiet Room where a candle can also be lit.

**Information for patients and carers**

The following information leaflets are available at either centre and can also be downloaded from our website:
- Additional information on medicines used in symptom control
- Advance care planning
- Barrier nursing
- Bereavement
- Breathlessness
- Candle: Someone close has died
- Candle: Someone has died suddenly
- Caring for someone with advanced dementia
- Choosing and moving to a care home
- Circuit classes group
- Clostridium difficile (C. diff)
- Coming to St Christopher’s Hospice as an inpatient
- Community support volunteers
- Complementary therapies
- Consent – what you have a right to expect
- Coping with breathlessness
- Coping with dying
- Cornea and tissue donation
- Difficulty sleeping
- Fatigue and breathlessness group
- Fluids and the use of artificial hydration
- Frequently asked questions about blood transfusions
- Frequently asked questions about cardio-pulmonary resuscitation (CPR)
- Frequently asked questions about morphine
- Frequently asked questions about ‘next of kin’ and power of attorney
- Frequently asked questions about the Supportive Care Programme
- Healthcare associated infection – how you can help reduce it
- Help during your bereavement
- How to complain or comment about our services
- Information for carers of St Christopher’s patients
- Methicillin Resistant Staphylococcus Aureus (MRSA)
- Pilates mat/ chair work group
- Preparing for a funeral
- Social work and welfare for the St Christopher’s Group
- The Anniversary Centre
- The bathing and hairdressing service at St Christopher’s Hospice
- The Caritas Centre
- Transport and St Christopher’s Anniversary Centre
- Why won’t they eat?
- Your bereavement: claiming welfare benefits
- Your information: how we use and keep it.

**NHS continuing care**

St Christopher’s patients are sometimes eligible for ‘NHS continuing care.’ NHS continuing care is the name given to a package of care which is arranged...
and funded solely by the NHS. You can receive continuing healthcare in any setting, including your own home or a care home. NHS continuing healthcare is free, unlike help from social services for which a financial charge may be made depending on your income and savings.

In your own home, continuing care means that the NHS will pay for healthcare and personal care, for example, help with bathing, dressing and some night nursing care. In a care home, the NHS also pays for your care home fees, including board and accommodation.

Eligibility for continuing care is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. If your overall care needs show that your primary need is health-related and includes a rapidly progressing condition, you should qualify for NHS continuing healthcare. Funding decisions are made by your local clinical commissioning group. This is subject to review, and should your care needs change the funding arrangements may also change.

To assess whether your primary need is health related, all of your care needs are looked at and then related to four key indicators – the nature of your needs, their complexity, their intensity and unpredictability.

Applications for NHS continuing care can be made by your St Christopher’s nurse.

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**Coordinate My Care**

**What is Coordinate My Care?**

As a patient you may well have views about your care: what you would like to happen, where you want to receive care, and even things you would like to avoid.

Coordinate My Care is a free service, which supports you to record this information. A doctor or a nurse will talk to you about your illness and wishes and create a care plan that is available to help you. All these details will be entered onto Coordinate My Care, which is an electronic record. It can be accessed by your GP, community nurses, hospital team, out-of-hours doctors, specialist nurses, London Ambulance Service and NHS 111 (NHS 111 is the unscheduled emergency telephone number that operates day and night).

If you need help, the doctors and nurses caring for you either in the community or in the hospital will be able to access the information about you and know what care they should deliver to you.

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**Do you need my permission to include my details on Coordinate My Care?**

Your Coordinate My Care plan is set up only with your consent and is flexible so you can alter your wishes at any point should they change.

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**What are the possible benefits of Coordinate My Care?**

Coordinate My Care will give you an opportunity to have your decisions and expressed wishes about your care recorded. This information will be available to all professionals who are looking after you. The fact that everyone can see your care plan and wishes will help to ensure that any care you receive is in line with what you’ve decided. You have complete choice whether or not to participate.

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**How can I access the information about me on Coordinate My Care?**

When your entry is created you will be offered a paper copy. It is up to you whether you take a copy or not. You can request this at any time. You just need to ask the nurse or doctor who discusses the Coordinate My Care record with you to print you off a copy.

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**What are the possible disadvantages of taking part?**

Some of the questions the care professional may need to ask you could be sensitive. The nurse/doctor will make every effort to discuss your care and wishes in a sensitive manner, however if you find any of the questions upsetting, you do not need to answer.
What happens if I agree to have my details put on Coordinate My Care?

Coordinate My Care works like this:

One of your care professionals (such as your GP, doctor, specialist nurse or community nurse) will:

- have a discussion with you about your condition, and whether you have any particular views on your future care
- ask you if you wish to have your details placed on Coordinate My Care
- if you say yes, they will input your details, including your age, address, next of kin, diagnosis, medications and your specific wishes onto Coordinate My Care.
- create a personalised care plan to let other doctors and nurses know about your condition and the treatment plans in place to care for you.

The Coordinate My Care system will:

- send an alert to London Ambulance Service, NHS 111 and the out-of-hours GP service in your area telling them that information about you is available if needed
- give care professionals access to your record (but only where they have a legitimate professional relationship with you)
- offer you a paper copy of your Coordinate My Care record to check and keep.

Is Coordinate My Care confidential?

Yes, your record is confidential. Only professionals involved in your care and issued with a secure user name and password will be able to see your details on Coordinate My Care. Your record will be accessed when you need help or advice.

In addition, it is a good idea to let your carers and next of kin know that you have a Coordinate My Care record so that everyone knows your wishes about your care. That way everyone can work together to help you.

From time to time, information held on Coordinate My Care may be used to look at trends in services in different areas. However, your name will not be disclosed. You will not be identified in any report or publication that is produced about Coordinate My Care.

If there are any specific queries relating to your record we may need to include your details in the report.

To ensure that the information on Coordinate My Care is of high quality, care and data managers employed by Coordinate My Care will be able to view your record for monitoring purposes only. They will have secure user names and passwords.

What happens if I do not wish to take part in Coordinate My Care?

You will never be included without being asked first. You can change your mind at any time. All you have to do is let one of your care professionals know.

Should you decide to leave Coordinate My Care, your record will be closed down, so that professionals can no longer access your record.

Whatever you decide, everyone will still give you the best care possible with the information they have.

What should I do if I want to update my record, for example, if I move or if my wishes change?

Your healthcare team will regularly discuss your health issues with you. If your wishes change at any time they will update your Coordinate My Care record. Please inform your GP or District Nurse if you change GP or move to a new address.

Please contact the Coordinate My Care team on 020 7811 8513 or email coordinatemycare@nhs.net if you have any questions about how Coordinate My Care works. If you need medical or nursing care advice please contact your GP/district nurse/clinician.

www.coordinatemycare.co.uk

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St Christopher’s and your personal information

We receive personal information about you from you, your family and other services. We need this information so that we can provide you with proper care and treatment.

Members of the St Christopher’s Community Team looking after you may share your personal information
with each other. This team may include nurses, doctors, therapists, social workers, pharmacists and clerical support staff plus students and trainees in medicine or other health and social care professionals who are looking after you.

Often it is necessary to share your information with professionals in other services who may be directly involved with your care or if you need treatment elsewhere. Your information will only be made available if there is a genuine need to do so. Such professionals might, for example, include GPs, ambulance services, social care services.

We will not share information about you with your family or friends without your consent.

Access to your medical records – the ‘right of access to personal data’

If you would like to have access to your medical records, please talk to one of the hospice nurses or doctors responsible for your care. Most of our records are electronic and one of our staff can help see your notes on a hospice computer or we can arrange for a paper record, but this may take a few days.

Financial help when you are sick

The Welfare Department is available to help you get the financial help to which you are entitled.

Below is a list of benefits you could be entitled to as a patient of St Christopher’s. These benefits are not charity – they are your right.

We hope that the following information is clear, but if you have any questions or you need help getting any claim forms, please telephone the hospice and ask to speak to the welfare officers who will be happy to advise you further. You can contact them between 9am and 5pm, Monday to Friday on 020 8768 4500 (Sydenham) or 01689 825755 (Bromley).

Attendance Allowance (AA)
Personal Independence Payment (PIP)
Disability Living Allowance (DLA)

Attendance Allowance is paid to people aged 65 and over who need help with personal care (i.e. help with washing, dressing etc).

Personal Independence Payment (PIP) is paid to people under 65 when they first claim and who need help with the tasks of daily living. There is also an additional mobility component of PIP if you have difficulty getting around. PIP will continue to be paid after age 65 if you get it before your 65th birthday.

PIP replaced Disability Living Allowance (DLA) in 2013 for new claimants. Some people already claiming DLA may continue to get it instead of PIP. However, a gradual transfer to PIP for these claimants is planned for the future. These benefits are tax-free and paid on top of any other benefits, sick pay or pensions you may be getting. They can also be paid if you are still working. Getting either AA, PIP or DLA may mean that you are automatically entitled to other benefits.

Special rules for claiming Attendance Allowance (AA), Personal Independence Payment (PIP) and Disability Living Allowance (DLA)

There are special rules for people who have an uncertain future because of their illness and people referred for hospice care, whether as an outpatient or an inpatient. These mean that you may have an automatic right to be paid the highest rate of AA or enhanced rate for daily living of PIP or the highest rate of the care component of DLA. If you are not already getting the highest rates, let your St Christopher’s nurse know and he/she will help make the claim if the special rules apply or refer you to the Welfare Office if you need to make a claim under the usual rules.

Benefits paid if unable to work through sickness

Statutory Sick Pay

If you are employed but off sick you will be paid Statutory Sick Pay as part of your wages/salary for the first 28 weeks you are off work. You may also be
entitled to Income Support to top this up if you have a low income and savings under £16,000. When the Statutory Sick Pay ends you should claim Employment and Support Allowance from the Department for Work and Pensions.

**Employment and Support Allowance**

Employment and Support Allowance (ESA) is paid if you are under pension age and unable to work because of illness and your Statutory Sick Pay has ended or you are not entitled to it. ESA replaced Incapacity Benefit in 2008. There may be a few people still getting Incapacity Benefit who have not been moved to ESA.

You may get extra work sick pay or superannuation on top of any Statutory Sick Pay or Employment and Support Allowance, depending on your employer.

If you are self employed or unemployed you should claim ESA straight away.

If you have paid enough National Insurance contributions in the three years before your claim you are entitled to a basic amount of contributory ESA which is not affected by any savings you have or the income of any other members of your family. The amount you receive may be affected by any work pension you get.

In addition to the above, you may qualify for income-based Employment and Support Allowance if your income is low and you have savings under £16,000. The amount you get depends on your family circumstances and any other income and savings.

Getting income-based Employment and Support Allowance (or Income Support) may also entitle you to other types of help, such as free prescriptions, dental treatment and home improvement grants.

You can claim by ringing the Jobcentre Plus new claims call centre on 0800 055 6688 or contact one of St Christopher’s welfare officers who have claim forms available.

**Industrial Injuries Disablement Benefit and compensation**

If you have mesothelioma or another illness caused by contact with asbestos, you may be entitled to Industrial Injuries Disablement Benefit and compensation, paid in addition to some of the benefits above. Please contact one of our welfare officers.

**Working Tax Credit**

If you (or your partner if you have one) are working for 16 hours a week or more or getting Statutory Sick Pay and you are on a low income you may be able to claim Working Tax Credit to help top up your wages. The amount you get depends on your income (as well as that of your partner, if you have one). Your entitlement should increase as a result of your illness. Contact the Tax Credit Helpline for a claim form.

**Child Tax Credit**

If you have a dependent child or children you may be able to get Child Tax Credit. Some families will already be claiming this, but if the family income has dropped as a result of your illness you may be entitled to more Child Tax Credit. Contact the Tax Credit Helpline to make a claim or to inform them of a change in circumstances.

**Pension Credit**

If you are of pensionable age, you may be entitled to Pension Credit to top up their income. Even if you have savings or an occupational pension, you might still qualify for some Pension Credit if your income is low enough.

Getting Pension Credit may also entitle you to other types of help, such as help with mortgage interest payment or housing service charges.

The amount you get depends on your income including other benefits. Contact the Pension Credit application line on 0800 991234 to make a claim.

**Housing Benefit**

If you are finding it hard to pay your rent, you may be eligible for Housing Benefit. You can apply online or your housing officer or local council offices will be able to send you the relevant application form. Anyone on a low income can apply for Housing Benefit as long as their savings/capital are less than £16,000 or they are getting Pension Credit.
**Universal Credit**

In some areas, Universal Credit has replaced Employment and Support Allowance, Income Support, Housing Benefit and Tax Credits as one amalgamated benefit. Check [www.gov.uk](http://www.gov.uk) to find out if you are in one of these areas.

**Council Tax**

If you are on a low income with savings under £16,000, you can apply for Council Tax reduction to help with Council Tax payments. In circumstances where particular alterations have been made to the home Council Tax discounts may be available – check these out with St Christopher’s welfare officers.

If you are living permanently in a hospital, nursing care home, residential home, private hospital or hostel, are receiving care or treatment there, and have no other home, then you do not have to pay Council Tax.

**Free prescriptions**

If you are claiming income-based Employment and Support Allowance, Income Support, income-based Jobseeker’s Allowance, or in certain circumstances Working Tax Credit or Child Tax Credit, or if you are aged over 60, you can get free prescriptions by ticking the appropriate box on the back of the prescription forms.

If you are under age 60 and do not qualify for free prescriptions through one of these routes, you may qualify for exemption from charges on medical grounds. This includes any cancer diagnosis. You will need to claim an exemption certificate.

If none of the above applies, but you have a low income, you and other dependent members of your family may also qualify for free prescriptions under the low income scheme. You will need to apply for an HC2 certificate on an HC1 form. You can get these by ringing the NHS costs helpline on 0300 330 1343 or contact one of our welfare officers who have forms available.

**Blue badge parking concessions**

You will qualify for a blue badge if you get the enhanced mobility component of PIP or the higher rate of the mobility component of Disability Living Allowance, are blind or deaf, and/or have difficulty walking outdoors and your GP confirms this.

Applications are made through your local authority disability services or you can ask your St Christopher’s nurse for an application form. Some local authorities make a charge of £10 for the badge.

If you display a blue badge in a car you are driving or being driven in this means that you are entitled to parking concessions. You can park in places reserved for disabled people and may be eligible for free or reduced parking charges where these are shown to be available to blue badge holders.

If you are a blue badge holder you may also apply for an exemption from the London Congestion Charge. This costs an initial £10, but is free on renewal. You can apply for exemption by calling 0845 900 1234 or apply online at [www.cclondon.com](http://www.cclondon.com)

**Freedom Pass – free travel on buses and trains in London**

All London councils run a scheme for people with disabilities in their borough to get a free pass which covers all London transport. People over pension age will be entitled to the older person’s pass.

You will qualify for a disabled person’s pass if you get the enhanced mobility component of PIP or the higher rate of the mobility component of Disability Living Allowance or if your GP confirms that you have difficulty walking outdoors.

Contact your local authority disability services for an application form. It can take a few weeks for the claim to be processed especially if you are not getting the higher rate of the mobility component of Disability Living Allowance and the authority then needs to get a report from your GP.

**Taxicard**

People who live in London and get the enhanced mobility component of PIP or the higher rate of the mobility component of Disability Living Allowance or whose GP confirms that they have difficulty walking out of doors and/or using public transport will also qualify for a Taxicard.

With Taxicard you can get a taxi and pay a flat fare (on average about £2.50 a journey) as long as the
meter charge for the journey is less than a certain amount. If the meter charge for the journey is above the set limits, the additional amount will be charged. There is a set number of journeys allowed under the scheme.

Applications can be made through your local authority disability services or by contacting 020 7934 9791 or by visiting their website at www.londoncouncilsgov.uk/services/taxicard or you can ask your St Christopher’s nurse for an application form.

Dial-a-Ride

You can join the London door-to-door Dial-a-Ride scheme if you get the higher rate of the enhanced mobility component of PIP or the mobility component of Disability Living Allowance or if your GP confirms that you have substantial difficulty walking outdoors.

You usually have to book in advance so it cannot be used for emergencies. The fare will depend on the distance travelled. You may be travelling with other people so your journey may take longer so that they can be picked up or dropped off.

Some local authorities have their own extra schemes as well as Dial-a-Ride.

Help with NHS costs

You can claim a full refund on your travel costs to get NHS treatment if you are claiming income-related Employment and Support Allowance, Income Support, income-based Jobseeker’s Allowance, Pension Credit (guarantee credit) or have a Tax Credit exemption certificate because you are claiming high levels of Tax Credits.

The amount refunded will be the costs of the cheapest means of travel available to you. In order to have taxi fares paid, you will need proof from your GP that you cannot travel by public transport if this is the case. They will also pay the cost of an escort if your doctor confirms this is necessary. You should be able to find out how to apply for a refund at the hospital where you are receiving treatment. This scheme does not apply to treatment received at the hospice.

If you are getting the relevant benefits you will also be entitled to help with other NHS costs such as NHS dental treatment, eye tests, vouchers for glasses and NHS wigs and supports.

You may also get some help with these costs if you hold an HC2 or HC3 certificate because you have applied under the low income scheme. You can apply using form HC1 (see section on free prescriptions on page 13).

Useful telephone numbers

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<th>Service</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tax Credit Helpline</td>
<td>0345 300 3900</td>
</tr>
<tr>
<td>Disability Living Allowance and Attendance Allowance Helpline</td>
<td>0845 712 3456</td>
</tr>
<tr>
<td>Pension Credit Application Line (freephone)</td>
<td>0800 99 1234</td>
</tr>
<tr>
<td>New claims (Income Support, Employment and Support Allowance and Jobseeker’s Allowance)</td>
<td>0800 055 66 88</td>
</tr>
<tr>
<td>NHS Costs customer enquiry line</td>
<td>0300 330 1343</td>
</tr>
<tr>
<td>Personal Independence Payment (PIP) application line</td>
<td>0800 917 2222</td>
</tr>
</tbody>
</table>

Financial help when you are caring for someone

Carer’s Allowance

You may be able to get Carer’s Allowance if you are:

- spending at least 35 hours a week looking after someone getting either Personal Independence Payment (PIP) at either rate of the daily living component or DLA for personal care at the higher or middle rate or Attendance Allowance at either rate
- over the age of 16
- not working or if working you earn less than a prescribed amount and
- not a full time student.

It does not matter if you live with the person you care for, but if the person you care for lives alone check before you claim Carer’s Allowance because they may
lose entitlement to some of their benefit. You can get Carer’s Allowance if you have a partner who is working.

If you are already getting State Retirement Pension, contributory Employment and Support Allowance, Incapacity Benefit or Bereavement Benefit you will not get Carer’s Allowance. However, it may still be worth claiming because you may qualify for extra Income Support, Pension Credit, income-related Employment and Support Allowance, Housing Benefit or Council Tax Benefit because you have an underlying entitlement to Carer’s Allowance.

**Child Tax Credit**

If you have a dependent child or children you may be able to get Child Tax Credit. Many families are claiming this already but if the family income has dropped as a result of your extra caring commitments you may be entitled to more Child Tax Credit. If you get more than the basic amount you will become entitled to free school meals and some health benefits.

Contact the Tax Credit Helpline to make a claim or to inform them of a change in circumstances.

**Housing Benefit**

If you are finding it hard to pay your rent, apply for Housing Benefit. Your housing officer or local Council offices will be able to send you the relevant application form. Anyone on a low income can apply for Housing Benefit as long as your capital/savings are less than £16,000 or you are getting Pension Credit (guarantee credit).

**Universal Credit**

In some areas, Universal Credit has replaced Employment and Support Allowance, Income Support, Housing Benefit and Tax Credits as one amalgamated benefit. Check [www.gov.uk](http://www.gov.uk) to find out if you are in one of these areas.

**Council Tax**

If you are on a low income you can apply for Council Tax reduction to help with your Council Tax payments. In certain circumstances there are also discounts on Council Tax available to carers and disabled people – check these out with the hospice welfare officers.

**Health care benefits**

If you get Pension Credit, Income Support, income-related Employment and Support Allowance or high levels of Child Tax Credit you will become entitled to free prescriptions, free dental treatment, free optician’s services and fares to hospital.

You may also be entitled to some help with the above if you do not get these benefits but you have a low income. You need to make a separate claim on a form.
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' which are treated separately.

CPR can include:
• ‘mouth-to-mouth’ or ‘mask-to-mouth’ breathing and
• 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.

What CPR facilities are available on site?

At the Anniversary Centre and the Caritas Centre we do not have defibrillators and breathing machines because they are very unlikely to help our patients. Our staff are trained in chest compressions (and ‘mask-to-mouth’ if appropriate) to cover the very rare situations when patients might benefit from an attempt at CPR. In this situation a ‘999’ ambulance will also be called.

Sudden stoppage of the heart and breathing requiring CPR is very unusual in hospice patients: more commonly the person becomes sleepier and the heart and breathing slow down gradually over a period of hours or days.

How successful is CPR?

Sometimes the media present CPR as being very successful. 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.
How are decisions recorded?
Following discussion with you and/or your family, if the decision is that an attempt at CPR would not be clinically appropriate, a form called the ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR) may be completed and left in the home. The form is completed and signed by a senior nurse and/or doctor (usually your GP). Neither you nor your family need to sign the form. Decisions about resuscitation can also be documented on the Coordinate My Care (CMC) record – ask your nurse for more information about CMC. If you attend our outpatient services or are admitted to the hospice, it may also be appropriate to record the decision in your medical records.

What happens if I am unhappy with the decision?
We recognise that these situations are potentially very stressful for you and those close to you. You have a right to a second opinion if you are 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. And if we feel that antibiotics or ‘drips’ may help you, we will discuss these with you in the usual way.

Who can I talk to about CPR?
If you do not have a current, valid Not for Resuscitation form, we will discuss your views about CPR with you, unless it appears that to do so would be harmful. A senior nurse or doctor 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 are 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.

Who is responsible for the decision?
The ultimate responsibility for the decision generally rests with the senior doctor caring for you.

At home this will usually be your GP. On hospice premises, 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. For most patients, CPR is inappropriate but the team will have considered the matter carefully for every patient.

Decisions are reviewed by the clinical team looking after you. Although you, your family and/or ‘healthcare proxy’ may be consulted as appropriate, the ultimate decision about whether to offer CPR as a medical treatment is a clinical one.

Admission to the Inpatient Unit in Sydenham
Not everyone we look after is admitted to the Inpatient Unit. However, admission can be very useful sometimes and may be suggested or requested for:

Only one in eight people (with all kinds of illness) who receive CPR in a hospital with all the available facilities will recover enough to leave hospital.

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.
• **symptom control** — you may be admitted at any stage for help with difficult symptoms. The aim would be for you to go home once things have settled
• **end of life care** — if, for whatever reason, this cannot happen at home or in a local nursing home
• **rehabilitation** — short admissions will be considered for people who require rehabilitation where it is felt that the hospice can assist in the improvement of health or independence.

### Accommodation for family or friends
Family members or friends are welcome to stay at the bedside of patients who are very ill. We have a riser/recliner chair at each bedside. Please discuss this with the nurse.

### Travelling to us
After you have been referred to St Christopher’s Community Palliative Care and Outpatient Services, one of our St Christopher’s nurses will contact you and arrange to come and see you at home for an assessment visit. For future appointments they will invite you and any important family members to come and see your nurse in one of our consultation rooms in the Anniversary Centre or Caritas Centre.

If at any stage you find you are unable to make the journey we will visit you at home again. Your St Christopher’s nurse will discuss with you the most appropriate location for your appointment.

### Private arrangements
If you are able to make your own arrangements to get there, you may find it useful to know that there are drop-off facilities immediately in front of the main entrance. We keep wheelchairs at reception and staff can help you into the building. There is some free parking at both sites and unrestricted parking in the roads around St Christopher’s in Sydenham.

### Taxicard
Most of our patients are entitled to a Taxicard as part of the London Taxicard Scheme that offers subsidised travel via the black taxi service. The scheme will give you a greatly reduced fare for regular planned journeys to see the St Christopher’s team.

Your St Christopher’s nurse can provide you with more information about the scheme that operates in your borough.

### Minibus
Our transport resources are limited and are intended for those most in need, so we do ask that if possible you make your own travel arrangements to see us.

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**Admissions procedure**
All admissions are discussed in our weekday admissions meeting at 10am on Monday to Friday. The requests are prioritised and dates for admission suggested. You will be informed at the earliest possible time of the decision made. If required and if possible an admission can be arranged for the same day.

**What to bring**
You should bring with you:
• the tablets or medicines you are taking at present
• night and day clothes
• toiletries and
• a small amount of money (for newspapers, telephone calls, etc).

**What is provided**
St Christopher’s provides:
• towels and
• food (please let staff know of any special requirements – for example, if you want vegetarian food, have religious dietary obligations or need a diabetic diet).

**Bed/room allocation**
Our accommodation is in single rooms and four bedded bays. Occasionally a patient in a single room may be asked to move to a bay if we need to admit someone else to a single room because of their particular care needs.

**Telephone and TV**
Each bed has a telephone and can receive calls directly. The cost of outgoing calls are the same as BT national payphone rates. Each bed also has a TV with Freeview channels and there is no charge for this facility. We also have free wifi access.
However, if you are not able to get to us, our minibus can pick you up even if you are in a wheelchair. Please bear in mind that the minibus is likely to be collecting other patients as well and we therefore cannot give you an exact ‘pick up’ time.

We ask for a voluntary contribution if you regularly use our minibus service.

Public transport at the Sydenham site

Our Sydenham site is well served by public transport. Bus routes 176 and 197 stop outside the hospice in Lawrie Park Road. Routes 122, 202 and 227 stop at either end of Lawrie Park Road. Routes 3, 75, 194 and 306 stop a 10 to 15 minute walk away.

A map is available on our website.

Public transport at the Bromley site

Our Bromley site is well served by public transport. Bus routes R5, R8, R10, R11 and 358 go via Orpington High Street and stop near Caritas House.

If you are coming from Orpington train station, bus route 654 stops near Caritas House.

A map is available on our website.

Carers

This section is for anyone who is providing care or practical, emotional or social support for a partner, relative, or friend with advanced illness living at home.

Many carers find that taking care of someone is an important and fulfilling time in their lives where bonds between people are strengthened. Nonetheless there can be strains and worries, and the following information aims to offer useful advice and sources of support.

As a carer you will probably still be coming to terms with the illness and the effects it is having on everyone in the family. Each situation is different and every person has their own way of coping. Illness brings many changes to everyday life and relationships. This can bring you closer to the person you are helping, but it can also be worrying and tiring and you may not know what help is available or who to call.

You may be involved in giving help yourself or arranging for other people to provide help with a wide variety of tasks such as:

• washing and dressing
• getting to bed and to the toilet
• housework, laundry or cooking
• spending more time with the person needing care
• responsibility for paperwork, bills and financial matters
• attending medical or hospital appointments or
• monitoring care being given at home by professional caregivers.

Most carers need help and support at some point so that the best care can continue to be given.

Having good information about the illness of the person you are caring for and about their treatment can help. Your St Christopher’s nurse, in consultation with the hospice doctors, can provide information, as can the specialist team at your local hospital and your GP. At its best, caring is a partnership between patient, carer(s), and the St Christopher’s team.

Good quality written information is available free from Macmillan Cancer Support and from our centres in Sydenham and Bromley (see page 8).

Your St Christopher’s nurse or social worker can help you contact the various agencies offering personal care and domestic tasks.

Looking after yourself

In concentrating on looking after others we can sometimes start to neglect ourselves. Your health is very important so try to eat well and ask for help if you are having problems sleeping.

A physiotherapist can offer advice about the safest way to help the person you are caring for move and get about. Sometimes special aids and equipment provided by community services can bring much physical relief for you and the person you are looking after. Your St Christopher’s nurse can advise you as to whom to contact.

Looking after someone is not always easy and often frustrating. There are times when it will help to talk to someone about how the cared-for person’s illness and treatment are affecting you and your life. Having someone you can trust to share some of your thoughts and feelings can lessen your worries and feelings of anxiety. Some conversations can be
difficult for families. You may have a relative or good friend whom you can trust or you might find it more helpful to talk to someone outside the family circle. This could be the St Christopher's social worker. The hospice also offers the services of a consultant psychiatrist if you need to have more specialist advice.

It is important to continue doing things which give you pleasure and help you to relax. Try to make time for maintaining friendships and social contacts.

Leaflets and activity booklets are available to help parents or grandparents talk to any children in the family about what it is like for someone close to them to be ill, and about dying.

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**Eating and drinking**

**Basic information**

Following a healthy, nutritious diet is something we all try to do. However, this may change when people are unwell due to:
- decreasing appetite
- changes in body needs
- the effect of any treatment (including oral medications, radiotherapy, chemotherapy) or
- other symptoms.

This can be very difficult for people and their carers as food plays such an important part in our lives normally.

**Notes for carers – how you can help**

Despite all of your efforts the food you prepare may not be eaten. This is nothing personal – it is very common with people who are ill. Try not to worry if the meals that you are used to preparing are no longer desired. Smaller meals are often more acceptable.

There is a wide range of food supplements (available on prescription via your GP). These provide extra nutrition and can be used as a meal replacement or taken between meals to increase intake. Ensure™, Enlive™, Fortisip™ and Fortijuice™ are some of the ones available.

**Useful tips**
- Encourage the patient to sit upright if possible
- ensure a relaxed environment
- alcohol can act as an appetite stimulant
- use a small plate
- offer small snacks or meals frequently and
- prepare what is wanted, when it is wanted if possible.

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**Washing and skincare**

**Basic information**

Maintaining good personal hygiene and keeping the skin in good condition is important for several reasons such as:
- a sense of well being and comfort
- prevention of infection and
- prevention of pressure sores.

**Notes for carers**

- Check the person's skin every day – observe pressure points carefully (spine, elbow, hips, heels and ears)
- keep bed sheets dry and free of wrinkles
- use a mild soap
- pat skin dry, do not rub
- use a moisturiser
- encourage a change in position every two hours if possible and
- if the person's skin becomes red or sore, inform your district nurse as soon as possible.

As someone gets weaker they will need more help. Emotionally this may be very difficult for them as it signifies a loss of independence. They may need professional help or special equipment.

In order to make things easier some equipment may need to be organised to help you, e.g. for bathing or managing the toilet. The St Christopher's nurse or district nurse may make a referral for an occupational therapist's assessment. The occupational therapist will be able to advise on managing activities of daily living and will organise specialist equipment if needed. Ask your St Christopher's nurse for further information.

If someone needs more help than you can provide, this can be arranged. A district nurse will make an assessment as to the most appropriate arrangements. At first, this care will usually be provided by Social Service carers who, depending on need, can visit up to seven days a week. As someone becomes more ill more
specialised help may be needed and the district nurse may be able to help.

Mouthcare

Basic information
Mouthcare is an important part of daily care as it:
• increases comfort
• prevents mouth sores and
• may improve appetite.

Notes for carers – how can you help?
• Assist with regular denture or teeth cleaning (using a soft toothbrush)
• encourage regular mouthwashes
• encourage fluids, ice cubes, gum or pineapple to keep the mouth moist
• look out for white patchy areas on the mouth – they may indicate oral thrush that requires special treatment
• apply petroleum jelly to the lips and
• report any problems to the nurse or doctor.

Common problems
For dry mouth:
• encourage use of sugar-free gum
• encourage fluid intake, sucking ice cubes or pineapple
• apply petroleum jelly to the lips (unless the person is on oxygen).

For oral thrush (white patchy areas in the mouth):
• clean teeth and dentures with toothbrush and toothpaste and
• treat dentures with thrush treatment.

If either dry mouth or thrush persist, discuss with your nurse or GP.

Mobility

Basic information
As people become less well, they may find it becomes more difficult to move around. This may be due to a number of factors such as weakness, fatigue, pain, breathlessness or a combination of things that just make it seem like too much effort.

While rest is important, it is also helpful to continue to move around independently for as long as possible, safely and comfortably.

Notes for carers – safety in the home
Try to arrange the areas where your friend or relative will be, so that pathways are as uncluttered as possible:
• make sure doorways are not blocked by things jutting out
• make sure the floor is clear of hazards such as flexes or cables and
• make sure the flooring is secured, e.g. no loose rugs to trip over, no carpet edges or tiles lifting.

This will make it much easier to move about safely.

Useful tips
• Encourage your friend or relative to change their position frequently and take short walks, even just around the room.

• A simple walking aid, such as a stick or frame, may help to maintain mobility and improve confidence. It is much safer to use an aid than to clutch on to furniture (or people). A physiotherapist can advise on this (your St Christopher’s nurse can arrange an appointment, if this will help).

• Make sure clothing is not hindering mobility or safety. Clothing needs to be loose and comfortable, but not too long or it may cause someone to trip (this can be a problem with nightwear or dressing gowns).

• Footwear needs to be comfortable but secure. Avoid ‘sloppy’ footwear without backs. A slipper that encloses the whole foot is much safer than a mule-type. Make sure that the sole of the shoe or slipper is not shiny or slippery.

• It is much easier to get up and down from a firm base than a very soft one. Try to ensure that the bed has a firm base and the mattress does not sag, and that a firm and comfortable armchair is available (not too low or soft).

• Further advice can be obtained from the St Christopher’s physiotherapist or occupational
therapist, or from the NHS community physiotherapy or occupational therapist.

Helping someone to move
Do not try to physically help someone to do things they can manage unaided. It is safer, both for you and for them, to be as independent as possible. If a manoeuvre seems very difficult, or you are in any doubt, don’t attempt it – seek help.

Make sure you or your friend or relative knows what you are trying to do and how you will go about it.

Using a good technique will often help with manoeuvres and enable someone to retain their independence for as long as possible.

To stand from sitting
Ask your friend or relative to carry out the following steps with you:

1. Bring their bottom forward to the front of the chair, bed or toilet.
2. Place their hands firmly on arms of chair. If there are no arms, place their hands on the edge of the seat.
3. Tuck feet well back under them, a little way apart.
4. Lean forward from hips (nose over toes!).
5. Push through arms to stand. If help is needed, assist by giving gentle forward pressure on back, between shoulders. Say “Ready, steady, up!” so you work together. Never try to lift someone from under the armpit or by pulling their arms.
6. If a walking aid is used, they should now take hold of it.
7. Make sure their knees are straight and they are well balanced before they start to move or walk away.

To help someone turn in bed from flat on their back

1. Remove tight or heavy bedclothes (you can keep them covered with a small light blanket).
2. If possible have only one pillow whilst moving.
3. Ask your friend or relative to bend up both their knees and put feet flat on the bed (you can do this gently, one at a time, if they are unable to do it for themselves).
4. Stand at the side of the bed they are to face.
5. Bring their far arm towards you across their body.
6. Facing your friend or relative, place one hand behind their shoulder and one behind their hip.
7. Ask them to roll towards you. You can give assistance.
8. Use pillows behind to support them, if necessary, and ensure they are comfortable.

It is much easier to nurse someone in a hospital bed than a domestic one. The district nurse can usually provide these and instruct you in their use.

Our occupational therapist may also be of assistance with advice on technique or equipment.
If someone falls

Try not to panic. Don’t rush to get them up quickly – you may injure them or yourself. Try to stay calm and reassure them. Let them sit on the floor for a few minutes to get their breath and see if they have hurt themselves.

If they are unhurt and have no pain, and are able to get up on their own, then let them do so. Putting a firm chair next to them may help, or encourage them to move across the floor on their bottom to a solid armchair.

If they appear hurt or in pain, or are too frail to get up without assistance, phone 999 and ask for the ambulance service. They will come and take the appropriate action. Keep your friend or relative as warm and as comfortable as possible on the floor while waiting.

Anxiety and depression

What is anxiety?

Anxiety is a mixture of feelings. Such feelings include fear, worry, being ‘on edge’ or being ‘panicky’.

Why does it happen?

It is often not easy to find out why some people get anxious but it commonly happens when people are feeling very ill. One problem when we get ill is that there is a lot of uncertainty and this may make people feel especially anxious. Sometimes people try to ‘bottle it all up’ and this can make them feel worse.

What are the symptoms?

There are a mixture of symptoms, including:
• tension, worry, fear or dread
• difficulty sleeping (especially getting off to sleep at night)
• restlessness, agitation, irritability and
• shortness of breath, tingling fingers, feeling the heart racing, frequent need to go to the toilet.

What is depression?

Everyone has bad days when they feel low and people with a serious illness can expect to feel emotionally overwhelmed at times. However, in some people these normal reactions may become more severe and persistent. If the person you are caring for has strong feelings of depression, do take them seriously. They are not a sign of weakness, but they may need to get some help.

What is it like to have depression?

One of the difficulties about diagnosing depression is that many patients with serious physical illnesses lose their appetite or sleep badly and may feel low or sad some of the time. This is not necessarily a sign of depression. Other signs may be:
• feeling restless and find it hard to relax
• worrying more than is usual for them
• wanting to avoid people
• feeling snappy or irritable
• losing confidence in themselves
• feeling useless or a burden to others
• noticing that they can’t concentrate properly or not being able to enjoy the things they usually do
• feeling panicky
• losing their sexual feelings
• depression, worry and anxiety can affect memory and make people feel confused
• feeling bad or guilty, dwelling on things from the past and perhaps getting things out of proportion or thinking about suicide.

Why does it happen?

Depression can come out of the blue. More often it is triggered by something; some of us are more likely to get depressed when faced with a difficult or painful situation.

Any physical illness can trigger depression, especially if there are physical symptoms; or the patient is taking some drugs or having treatments with side effects that are hard to put up with; or there are family difficulties or worries. Although this makes the depression more ‘understandable’ it does not mean that it cannot be helped. This type of depression often responds well to treatment.
What can a carer do?

The most important thing is to recognise the problem and to try and talk about it, if possible (without forcing them). Talk to a member of the team at St Christopher’s or encourage the patient to do so.

What can St Christopher’s do?

- It can help to talk to a good listener. Our nurses may be able to offer help, and our social work team is very experienced in helping people with depression.

- Helping with pain and other symptoms often makes a difference.

- Visits to the Anniversary Centre or Caritas Centre provide support, a chance to meet others who understand how you feel, and a change of scenery.

- We have a CBT therapist who may be able to offer some sessions to help the person regain a sense of control (see page 7).

- Antidepressants can be very effective – about 50 to 60 per cent of people who take these tablets will find they help. They are safe and not addictive. We can ask your GP to organise a prescription, or we may suggest that you meet one of our psychiatrists as they have the expertise that is sometimes required.

- We can provide practical support to manage difficulties which cause depression such as housing difficulties or problems with benefits.

- Distraction may help too, for example trying to keep busy when you feel anxious.

- Complementary therapies such as aromatherapy or hypnotherapy may help. These therapies are available at the hospice – ask your St Christopher’s nurse for details.

- Exercises to help you control your breathing and your anxiety can be taught by our physiotherapists.

Pain

What is pain?

This is difficult to define. Everybody experiences pain differently so pain is what the person experiencing it says it is.

What causes it?

- Physical causes, these may or may not be related to the illness, and

- emotional, spiritual or social causes – these non-physical aspects may cause physical pain to increase. For example, people who are anxious or depressed may experience greater pain than people who are not.

What can you do?

- Ensure that painkillers are taken regularly (see following pages). It is better to keep the pain at bay, so encourage the taking of regular painkillers, even if there is no pain when they are due.

- Ensure that ‘when needed’ painkillers are taken for breakthrough pain.

- Monitor the pain in terms of:
  - Patterns of pain – Where is the pain? How far does it extend? What makes it worse? What makes it better?
  - Types of pain – Is it an aching, stabbing, burning or shooting pain?
  - Effect of painkillers – Do they help? How much? How long for?
  - How many extra painkillers are being taken? Do they help?

- Keep a diary of what does and does not help so that your nurse can look at it with you and work out a pain plan.

- Use other methods such as gentle massage, heat pads, encourage relaxation. These things can help.

What to do if your pain plan is not working

Contact your St Christopher’s nurse:

• Exercises to help you control your breathing and your anxiety can be taught by our physiotherapists.
• when there is a new pain or a worsening of an old pain
• when sleep is disturbed by pain
• when the painkillers do not seem to be working very well or for very long or
• when the painkillers are causing troubling side-effects, e.g. sickness, constipation, drowsiness or confusion.

We sometimes find it helpful to refer people for massage, aromatherapy, physiotherapy or an appointment with one of our doctors. We will review your pain plan regularly and discuss it with the multi-professional team.

Medicine safety

Many hospice patients have a lot of medicines to take. Some of these will be prescribed to take regularly, others just when they are required and some may be given just in case they are needed in the future.

Where should medicines be stored?

All medicines must be stored in a practical way so that they can be taken when needed but they should be kept out of the reach of children. Most medicines can be stored at room temperature but make sure that they are not kept too close to a heat source, such as next to a radiator or in direct sunlight.

If a medicine needs to be kept in the fridge, this will be printed on the package. It is OK for most of those medicines to be out of the fridge for a while – e.g. if you need to take them out for a day. If in doubt, please check with the pharmacist who provided them.

What about medicines that are no longer being used?

Please do not put any unused medicines into your domestic rubbish. Liquids should not be poured down the sink or flushed away in the toilet as they can contaminate the water supply. Please take them back to your local pharmacy.

Morphine

What is morphine?

Morphine is a strong painkilling drug. It works very well on many types of pain, although it is most commonly associated with cancer pain. It is also sometimes used to control feelings of breathlessness.

How is morphine taken?

Morphine can be given in several ways. It’s available as a simple tablet or liquid which work for about four hours but as well as these, there are slow-release tablets or capsules that last for 12 or even 24 hours, so that you might only have to take one or two a day. For people with swallowing difficulties, slow-release morphine is also available in granules.

Morphine is available as an injection too if needed although most patients take morphine in tablet form.

Morphine and addiction

Taking morphine for pain will not make you an addict. It is quite normal for the dose to increase over time, although many people remain on a stable dose for long periods. As with other medicines, you should not stop taking morphine suddenly without discussing this with your doctor or nurse, as your body needs time to adjust.

We always start with the lowest possible dose to allow the body to get used to it. The pain should improve very quickly, although it may take a little while to find the right dose and so it may have to be increased if it is not enough to stop the pain.

What are the main side effects to look out for?

Morphine tends to cause constipation and most people who take it need laxatives. Morphine can also make you feel sick when you first take it. Your doctor may give something to stop this feeling, but it usually only lasts a few days.

Morphine can make you feel sleepy for the first few days while you are getting used to it or when the dose is increased but our bodies can usually adapt gradually. However, in people who are already taking pain killers
they can often be equal in effect to a low dose of morphine, so changing to morphine should not feel especially different.

What about day-to-day activities if taking morphine?

It should be possible to carry on doing things when taking morphine. In fact many of our patients find they can do more because their pain is better controlled.

Driving may be possible but there are many factors to consider and St Christopher’s doctor or nurse will be able to advise. Please remember that as in any other situation people should only drive if they feel it is completely safe for them to do so.

How long does one take morphine for?

All medication, including morphine, will be reviewed regularly with the doctor or nurse. Later on there may be less pain or we may try a different treatment for pain. If that happens, the doctor or nurse can gradually reduce or even stop the morphine. However if the cause of the pain is still there most people find they need to carry on taking it.

Is there a maximum dose?

No – morphine is unusual in that there is no maximum dose. If it is taken for pain as prescribed, the dose can be increased gradually to match the pain. Often, people can be on very large doses of morphine for a long time, with no significant problems.

Why might other painkillers be needed as well as morphine?

Although morphine works well on many types of pain, some sorts of pain need different painkillers to manage the pain.

Morphine belongs to a group of painkillers called opioids. Morphine is the most commonly used opioid, but there are also several others, for example codeine, oxycodone or fentanyl. These can be as effective as morphine but occasionally one may suit a particular pain or patient more than another.

We can also give painkillers in a number of different ways. For example, some can be supplied as a patch that sticks to the skin or as a dissolvable tablet or spray to use in the mouth.

What about morphine for breathlessness?

If there is no obvious treatable cause of breathlessness there are several ways in which breathing can be made easier, such as a low dose of morphine. There are also other medicines which may help.

For more information

If you have any further questions about morphine or other medicines, please ask the nurse, doctor or pharmacist.

Breathlessness

What is breathlessness?

Breathlessness (dyspnoea) is the sensation of not being able to get enough air. It can be a very frightening feeling and limits even simple activities. Knowing how to help someone who is breathless can bring confidence in the ability to cope with this distressing symptom.

The important thing to remember, if breathlessness makes you panicky, is that you will continue to breathe.

What causes it?

• The illness itself
• secondary problems related to the illness, e.g. anaemia
• chest infections
• general weakness
• anxiety or stress or
• chronic lung or heart disease.

What carers can do

• Try to stay calm to help give reassurance.
• Find a relaxed, supportive, resting position.
• Encourage slow breaths out... this is more helpful and effective than emphasising taking breaths in, and it’s easier to do.
• Sometimes distraction can help – try the TV or music.
• Ensure the room is well ventilated, eg open window or use a fan.
• Observe for signs of infection, eg high temperature or coughing up green or yellow phlegm.
• Check that prescribed medication is taken regularly.
• Give medicines in between for bad attacks.

Additional helpful advice
• A referral to one of our physiotherapists may be helpful for breathing exercises, breathing control and coping strategies.
• Ask your nurse or physiotherapist for our breathlessness leaflet which gives helpful advice on strategies to help you manage breathlessness. We run a regular Breathlessness Management Service gym group at the Sydenham site.

When to call for help
If there are signs of infection your GP needs to know as antibiotics may be required.
If the symptom of breathlessness persists and you are concerned then ring the hospice.

Nausea and vomiting

What are nausea and vomiting?
Nausea is the unpleasant sensation of feeling sick. Vomiting is the mechanical action of being sick. They are very common in people who are seriously ill.

What causes them?
• The illness itself
• the cancer treatment
• other medications, e.g. painkillers
• constipation or
• emotional distress.

What carers can do
• Make sure anti-sickness medications are taken.
• Monitor the severity of the problem and report it to your St Christopher’s nurse.

• Keep the room cool – a fan may help.
• A cool flannel on the forehead may soothe.
• Give small sips of fluid or ice cubes to suck.
• Avoid giving acidic foods and fluids.
• Ensure regular laxatives if necessary.

When to call for help
Persistent vomiting may mean that drugs need to be given by an alternative route (e.g. suppositories or medication via a syringe driver – see page 28 about syringe drivers). These need to be organised by a nurse or doctor.

Persistent nausea and vomiting are very unpleasant. If you are concerned, ring your St Christopher’s nurse.

Constipation

What is constipation?
Constipation means difficulty opening the bowels regularly.

It is important to remember that it is necessary for us to open our bowels regularly even if we are not eating much. Constipation causes a lot of problems such as discomfort, nausea, vomiting, reduced appetite and, in severe cases, confusion and bowel obstruction.

What causes it?
• General debility, i.e. not moving around much
• reduced fluid intake
• diseases of the gut or
• medications, e.g. painkillers, some anti-sickness drugs and iron supplements.

What carers can do
• Monitor bowel habit in terms of frequency of actions and consistency and amount of motion.
• Ensure as much fluid is taken as possible.
• Ensure laxatives are taken as prescribed and monitor their effect.
Syringe driver

What is a syringe driver?

A syringe driver is a lightweight battery-operated pump that is used to deliver continuous medication under the skin over a 24 hour period. It is easy to carry around and should not hinder most everyday activities.

A syringe driver may be used for several reasons, for example:
• difficulty in swallowing tablets or reduced absorption from the stomach
• persistent nausea or vomiting that cannot be controlled with oral medication or
• symptoms needing more control.

In these circumstances a syringe driver is used to achieve a constant level of medication and gain control of symptoms. When a syringe driver is used the medication is delivered continuously. The nurse will calculate the correct dose of medication based on what you were taking previously. Additional injections can be given if symptoms break through and the dosages in the syringe driver will be adjusted accordingly.

A needle or a very thin plastic tube will be inserted under the skin, usually in the upper arm, thigh, stomach or chest. The syringe driver is connected to this by an infusion set (long thin tube). The plastic tube will be held in place with a small clear dressing. A small light above the on/off button will flash green regularly. The alarm beeps when the syringe driver is due to be changed or when there is a problem with the syringe driver. In these cases you should contact your nurse as soon as possible.

• Remember that everybody is different and will need different amounts of laxatives. The dose can be increased as long as it does not cause problems of colic or diarrhoea.
• If the patient feels they are becoming constipated, discuss this with the nurse.

When to call for help

• If bowels have not opened for two to three days
• if there is any discomfort or other symptoms of constipation or
• if you are not sure what to do.

In a majority of cases by taking enough oral laxatives the problem will be solved. However on occasions suppositories or enemas may be needed. Your GP will prescribe them and your district nurse will administer them and help monitor the situation. Your St Christopher’s nurse can organise this help if it is necessary.

What to expect as death approaches

How to recognise the approach of death

As death approaches you will notice a day to day (even hour to hour) deterioration. People normally lose their appetite, become more weary, weaker and increasingly drowsy over a period of time until they become bedbound and perhaps semi-conscious. There
is normally a period of unconsciousness (lasting hours to days) before someone dies.

As death approaches, swallowing will become difficult, so taking medication by mouth will become impossible. Drugs may need to be administered via a syringe driver to ensure that pain and other symptoms are controlled as well as possible.

When death is very close (within minutes or hours) the breathing pattern may change again. Sometimes there are long pauses between breaths, or the abdominal muscles (tummy) will take over the work – the abdomen rises and falls instead of the chest.

If breathing appears laboured, remember that this is more distressing to you than it is to the person dying.

Some people may become more restless as death approaches. If this is the case, contact your St Christopher’s nurse who will ensure that pain and other symptoms are controlled with the right medication.

Involuntary movements may occur; these are normal and not necessarily a sign of distress. Other things you may notice include change in skin colour, a change in body temperature and levels of consciousness.

Most people do not rouse from sleep, but die peacefully, comfortably and quietly.

**What carers can do**

- Talk and comfort – speaking normally, as it is thought that hearing is the last sense to be lost
- touch
- use foam swabs to moisten and cleanse the mouth – keep lips moist with petroleum jelly – and
- provide regular re-positioning (if you are able).

Call the district nurse or St Christopher’s nurse if you are worried about anything.

Just sitting with someone helps, but you also need to look after yourself, so do not feel guilty if the person you care for dies while you are out of the room.

**What to do after the death**

Take your time to gather your thoughts; there is no need to do anything in a hurry. You may be feeling upset. If you are very distressed you may find it helpful for a nurse to visit.

Soon after the death you can close the person’s mouth and eyes, if you wish.

**Practical concerns**

You will need to contact your GP, who has to visit to certify the death. If it is out of hours, contact the on call doctor service. The doctor will issue you with a medical certificate that you need to take with you when you register the death.

If organ donation has previously been discussed, contact your St Christopher’s nurse.

Your nurse will arrange to pick up any equipment that is no longer needed.

You will need to register the death in the borough in which it has occurred and make an appointment with the registrar to do this. The person who goes to register the death should be prepared to give the following information:

- the date and place of death with the usual address of the person who has died
- the full name of the person who has died with a maiden name if she is a married woman
- their date and place of birth giving a town and country
- the occupation or the name and occupation of the husband if the person who has died is a married person or widow
- whether the person who has died received a state pension of any kind, such as a disability or war pension and
- if the person who has died was married, the age of the surviving widow or widower.

Once the death is registered the registrar will issue the following:

- The disposal certificate – this form is the authority for the funeral director to go ahead with the arrangements. It must be given to him as soon as possible.
- A death certificate – this is a copy of the official registration of the death. You must ask for this and a charge is made. You may buy more copies if you need them for claiming insurance.

If you haven’t already contacted a funeral director you should do this as soon as possible. Take the disposal certificate with you or ask him to visit you at home.
Not all funeral directors charge the same so it is worth getting more than one quotation.

When you can, please return any medicines to your local pharmacy where they can safely dispose of them. Medicines cannot be reused so please do not return these to the hospice.

Bereavement support

Many people cope with bereavement and grief with the support of family and friends. Some people, however, may need extra help for a while to help them deal with their loss. Your St Christopher’s nurse will make contact with you after the death of the person you cared for to assess how are you are coping and tell you about the support we offer, but you can ring and ask for the bereavement service at any time if you feel you need to.

What is bereavement support?

Bereavement support is the opportunity to talk about your loss, in confidence, with someone who will be able to listen to your experience of grief. Usually one of the Bereavement Service volunteers will contact you by letter or telephone and can arrange to meet you at the hospice or visit you at home.

How can bereavement support help?

Every loss is a very personal experience and no two people experience loss in the same way. It is impossible to say how long the pain will last or how you will feel but some people find that it helps to talk with someone who is not part of their family or close circle of friends.

Grief is a natural response to death but may cause powerful feelings. It may also bring many changes as we adjust to life without the person who has meant so much to us.

Children grieve too. We can help you to support them in their bereavement. The Candle Child Bereavement Service offers bereavement support to children and families of patients. Candle provides individual and group support to children and young people aged up to 18 years, and group support for parents and carers. Families can make contact with Candle directly by phoning St Christopher’s, or through their St Christopher’s nurse or social worker.

Sometimes people find that at first they do not want support but then later change their mind. If this happens to you, please contact St Christopher’s.

Who would I see?

The Bereavement Service volunteers bring a variety of experience to their work for the hospice. They are carefully selected and follow a comprehensive training programme. Their work is regularly supervised by qualified hospice staff.

How long will I need support?

This will depend largely on you. You may want to see your volunteer regularly. Usually the volunteer will meet with you for about an hour once or twice a month.

Bereavement evening

All families will receive an invitation to this evening meeting which is organised approximately three months after bereavement. It offers you a chance to meet with other people in a similar situation and talk together in a small group.

Members of the Bereavement Service and other hospice staff attend the meeting and lead the groups. Anyone over the age of 15 years is very welcome, but our experience has shown that the evening is generally not suitable for younger children.

Bereavement groups

We hold some groups which bereaved relatives and friends can find helpful. They run for eight weeks and focus on different topics each week. This is also an opportunity to meet with others in a similar situation and to share experiences.

Thanksgiving and memorial service

As close as possible to the anniversary of the death, an invitation to a service will be sent to the person whose name we have been given to contact. Family and friends are also welcome to attend. This occasion provides an opportunity to remember the person who died.
Remembering with St Christopher’s

Just before Christmas each year we hold a service around a remembrance tree in the grounds of our Sydenham and Bromley sites. You can dedicate a tree light to remember the person who has died. The illumination of the tree is a special part of these events.

Welfare benefits advice

Advice about welfare benefits is available to the main carer for up to six months after the death. If you need welfare advice, please ask your nurse or social worker to refer you to the welfare service.

Your feedback on our services

Your views are very important and will help us improve care for future patients and their families. We usually send out a survey questionnaire called VOICES - HOSPICES SCH to carers after the death of a patient asking for your views on the care we provide. We would be very grateful if you could complete this and return it in the pre-paid envelope provided.

How to make a complaint

Complaints are a way for us to improve our service. We want to make sure the care we give is as helpful as possible, both for patients and those close to them. If there is any part of our service with which you are dissatisfied or where you can suggest improvements we would like to know.

You may want to comment informally to a member of the clinical team or in writing to:

The Joint Chief Executives, St Christopher’s, 51-59 Lawrie Park Road, Sydenham, London SE26 6DZ

We investigate and respond promptly to all complaints.

If you would like a copy of our complaints leaflet then please ring the PA to the Joint Chief Executives on 020 8768 4500 and ask for one to be sent to you.

Your experience of our care

We assess the quality of our care through regular monitoring and evaluation. One of the most valuable ways of finding out how well we are doing is to ask you, our patients and their families. Your feedback and comments help us know whether the care we are giving is as good as it can be, and to improve care for future patients and their families.

We encourage you to let us have your comments or suggestions verbally or in writing. Some of the other ways in which we may seek your views include:

SKIPP

You may be asked to complete a very short questionnaire called SKIPP (St Christopher’s Index of Patient Priorities) which asks about how well we have dealt with your main concerns.

User Forum

We may invite you to meet with us at the User Forum, which is a meeting of patients and carers during which we discuss people’s experiences of the services at St Christopher’s and look at ways they could be improved. Your care will not be affected by taking part. We need your honest views, comments and criticism about St Christopher’s and the services we provide.

Regular meetings take place at both sites. You are welcome to bring a family member or carer. The meetings are fairly informal. We will be asking for your comments, observations and suggestions about the way we support you.

What happens after the User Forum?

We take your comments to a meeting of all the heads of departments and decisions are made there about any changes that need to be made. Your comments are presented anonymously; we don’t put your name to any comments. After that meeting we publicise in the Anniversary Centre and Caritas Centre any changes we make as a result.

If you are not able to come to one of the User Forums but would like to make comments or suggestions about our services, please write to:
Head of Quality, St Christopher’s, 51-59 Lawrie Park Road, Sydenham, London SE26 6DZ

Or you can put a note into our suggestions boxes in either of our centres.

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**Supporting diversity**

St Christopher’s serves five boroughs in south London, one of the most diverse cities in the world. We value the different backgrounds, cultures, faiths and life experiences of every individual. Please treat our staff and everyone you meet with consideration, courtesy and respect – whatever our physical, social and spiritual differences.

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**Support St Christopher’s**

St Christopher’s is a local charity. Every year it costs £19 million to deliver our services, of which approximately £13 million must be fundraised. St Christopher’s strengths and achievements are a direct result of the generosity of people in our community. We are extremely grateful to our patients, family and friends and the trusts, foundations and companies that support us that enable us to deliver our specialist palliative care and family care services free of charge.

If you would like to make a contribution, it will help us continue our care for others. A donation form is included opposite. If you are a tax payer we can also claim Gift Aid on your donation.

If you are interested in finding out more about activities to support the work of St Christopher’s, further information is available at the back of this booklet, or you may like to contact the Fundraising Team by telephoning 020 8768 4575 or by emailing fundraising@stchristophers.org.uk
I would like to support St Christopher’s with my gift

If you are a UK tax payer it makes it worth 25% more to use at no extra cost to you. To enable us to claim Gift Aid please tick the following box and ensure you have completed all the details marked * on this form.

☐ Please treat as Gift Aid donations all qualifying gifts of money made in the last four years, this gift and all future gifts

I am a UK taxpayer and understand if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that year it is my responsibility to pay any difference. Gift Aid is reclaimed by the charity from the tax you pay for the current year. Your home address is needed to identify you as a current UK taxpayer. Please notify the charity if you want to cancel this declaration, change your name or address or no longer pay sufficient tax on your income and/or capital gains.

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Data protection We value your support and promise to respect your privacy. The data we hold is managed in accordance with the Data Protection Act (1998). We will not disclose or share your details with any third party. We would like to keep you informed by post, email or telephone, about the vital work we do. If you would prefer not to receive this information please let us know by ticking this box. [ ] St Christopher’s is registered charity 210667.

My donation is of ☐ £10 ☐ £25 ☐ £50 ☐ £100 ☐ £500 ☐ Other £ ____

My donation is in memory of

☐ I would like to make this a monthly donation WE WILL CONTACT YOU SHORTLY
☐ I do not need my gift acknowledged
☐ I enclose a cheque made payable to St Christopher’s or
☐ Please debit my ☐ Visa ☐ Mastercard ☐ Maestro ☐ CAF account

Card no _______________ _______________ _______________ _______________ _______________ _______________ _______________ _______________ Start date ______ / ______ / ______ Expiry date ______ / ______ / ______ Issue ______ MAESTRO ONLY

If you are donating via debit or credit card, please ensure you provide a telephone number below as we may call you to clarify the three security digits on the reverse of your card.

Signature* Date*

Forename(s)*

Surname*

Address*

Postcode*

Email

Telephone

PLEASE INCLUDE YOUR EMAIL ADDRESS IF YOU WOULD LIKE US TO CONTACT YOU IN THIS COST-EFFECTIVE WAY.

I’d like more information about ☐ making a regular donation ☐ leaving a gift in my Will ☐ organising a fundraising event ☐ supporting St Christopher’s as a group or company

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