

Care agencies employ carers who provide personal care such as dressing and washing, and domestic help for people in their own homes. Some social services departments also provide home care. There is a charge for these services and depending on your financial circumstances you/the patient may have to contribute to the costs.

In the last days of life services such as **Marie Curie nurses**, or the St Christopher's **Hospice at Home** service, may be helpful. These services give carers a chance to catch up on sleep, or take a break. Talk to your St Christopher's nurse if you would like to find out more.

5 St Christopher's services for carers

In addition to the St Christopher's services described above, you can obtain the following:

Advice out of hours

A St Christopher's nurse is available between 5.00 pm and 9.00 am for advice on any aspect of the patient's care. You can speak to a nurse out of hours by calling 020 8768 4500.

Complementary therapies

Complementary therapies such as massage, aromatherapy, relaxation, can help you cope with some of the stresses that come with being the main carer, or just give you a bit of time for yourself. Ask a St Christopher's nurse about whether this is available.

Spiritual care

Serious illness can make some people question their beliefs about the purpose and meaning of life, whether or not they have a faith. The Spiritual

Care Team, as well as other members of the multi-professional team, can listen and talk with you, and help you explore these sorts of questions and anxieties about the future.

Bereavement support

Bereavement is something that most people experience at some time in their lives, and people react to it in different ways. Grief can be very painful and it is impossible to say how long the pain will last or how you will feel, but many people find it is helpful to talk to someone who is not part of their family or close circle of friends. The St Christopher's bereavement service is free. It offers an opportunity to talk about the consequences of your loss, in confidence, with someone who will be able to listen. You can contact us at any time following the death of your relative or friend, via the Bereavement Service Administrator by calling 020 8768 4599 (Monday to Friday 9am to 5pm).

6 Other sources of help

There are many national and local organisations that offer different kinds of help and advice to carers. Please ask a St Christopher's nurse for more information about these.

It is really important for your care that the information you give us is as full and accurate as possible.

INFORMATION FOR CARERS AND PATIENTS

Information for carers of St Christopher's patients



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This leaflet aims to answer questions that you may have about caring and St Christopher's. We hope to answer your concerns by concentrating on the most commonly asked questions. If you have any more questions please ask your doctor or nurse.

1 Are you a carer?

If you look after a friend or family member who is unable to look after themselves, you are a carer. There is no standard picture of a carer and caring can last for a few weeks, or several years; it can occupy a few hours each week, or 24 hours a day.

You might help someone wash or dress themselves. You might drive them to hospital appointments or do their shopping. You may also provide company and emotional support. Being a carer does not change who you are – you are still a wife, husband, son, parent or friend – but it usually means making changes to your life.

2 Help and support

Caring can be very rewarding, but it can also be hard work and stressful. It is often a confusing time, with lots of information to take in and unexpected changes to deal with.

This leaflet

- summarises some of the ways in which St Christopher's tries to help carers of patients with terminal or life threatening illnesses
- describes briefly the services that are available to our patients at home, in care homes and on our wards – for a much fuller account, ask one of our nurses for our *St Christopher's At Home*

folder which has a section for carers as well as young carers under 18

- describes some of the other professionals you may come into contact with while you are caring for your friend or relative.

3 Palliative and hospice care

St Christopher's provides specialist palliative care for people with serious and life-threatening illnesses. This means that the focus of care is good symptom control and support with emotional, social and spiritual aspects of illness so as to maximise the quality of life of the patient and their family. In order to deliver the care, St Christopher's staff work in multi-professional teams. Not every patient will come into contact with each of these professionals, but their expertise is available to whoever needs it.

All our services are free of charge.

Our day care service takes place in the new Anniversary Centre. Patients can be referred by their St Christopher's nurse or another specialist palliative care team and are able to attend a wide variety of groups such as creative arts groups, support groups, practical information groups about a range of subjects such as managing finances, healthy eating etc, and relaxation groups. Some of these groups are specifically for carers. If you're interested, ask your St Christopher's nurse for more information.

4 A guide to who's who

It can sometimes be difficult to know who is responsible for what. The list that follows explains who's who at St Christopher's and in the community.

Clinical nurse specialists (CNS or specialist palliative care nurses) are nurses who have had extra training in palliative care to give emotional support and practical advice to patients and their families and provide pain and symptom control. They do not usually provide hands-on care, but give advice to the primary healthcare team (see below) and link into the hospice or hospital. If your friend or relative is being cared for at home, then the St Christopher's nurse who visits them is a clinical nurse specialist.

If the patient is living in a care home, the St Christopher's specialist nurse will advise the care home staff on symptom control and good palliative care. She can also refer the patient to other St Christopher's services.

The **primary healthcare team** usually includes the GP, district/community nurse, practice nurse, practice manager, receptionists, health visitors and other associated professionals.

The **GP** (general practitioner, or family doctor) is responsible for all aspects of medical care at home, and can arrange help from other professionals or services. St Christopher's at Home nurses work closely with GP practices.

District nurses provide hands-on nursing care and practical advice in the home. In some boroughs district nurses are available 23 or 24 hours a day. They can usually be contacted through a GP's surgery or directly at their office.

The St Christopher's **occupational therapist** gives advice on and provides equipment to help make daily life easier, e.g. with bathing, stairs or lavatory.

The St Christopher's **physiotherapists** help people maintain or improve their strength and mobility

through exercises. They treat swollen limbs, help with pain relief, breathlessness and anxiety/panic attacks.

The St Christopher's **social workers** specialise in helping people to cope with the emotional and practical stresses that serious illness can bring. They can help you think about concerns about the future, or with talking to other members of the family, including children, to understand, for example, the illness and the changes it has caused. St Christopher's social workers can tell you about support groups for carers where you live.

Social workers employed specifically by social services undertake carers' assessments, i.e. assessments of your needs as a carer. This should take account of your work and any other responsibilities you may have in order to support you and the person you are looking after. Ask your social services department to arrange for you to have a carer's assessment.

St Christopher's **welfare officers** can help with some of the financial and practical issues that may arise as a result of the illness. They can help with benefit claims, grant applications, housing problems, sorting out debts and other practical matters. They can advise on the need for legal advice (in making a will, or applying for power of attorney).

Caring for someone can be expensive. For example, you might have higher heating bills, extra travel costs, have to cut the hours you work, or leave your job altogether. There are many benefits that may be available to you or the person you care for, and it is important to get advice on these as soon as possible.