Partners in caring

Information and advice if you are seriously ill and being cared for at home
About this booklet

This booklet is intended to give practical information and advice to people who are seriously ill at home - and their carers. Although the information in this booklet has an emphasis on people with cancer, most of the information is relevant to patients with other terminal conditions. We hope it will help you in the time ahead, particularly between visits from your District Nurse, Marie Curie Nurse and other service providers.

It is also intended to point you towards other organisations which may be able to provide further advice, information and practical assistance.

Marie Curie Cancer Care - Nursing
Marie Curie Cancer Care provides high-quality nursing, totally free, to give people with terminal cancer and other illnesses the choice of dying at home, supported by their families.

Marie Curie Cancer Care - Hospices
Marie Curie Hospices actively promote quality of life for people with cancer and other illnesses and provide support for their families, completely free.

Disclaimer
Although every effort has been made to ensure accuracy, Marie Curie Cancer Care and their advisers cannot accept any liability in relation to the information in this booklet or any advice that our Marie Curie Nurses or Senior Healthcare Assistants provide in the home. It is not a substitute for professional medical or other advice. Readers are strongly advised to discuss the information provided and seek personalised advice from their doctor, specialist cancer nurse or other appropriate professional.
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About Marie Curie Cancer Care
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Introduction
If a person is very ill with a progressive incurable disease and the condition cannot be cured, their comfort and quality of life will take priority. Care of this kind is called palliative care.

Respite care can give a break to a person who is caring for someone at home who is ill.

Many people reading this booklet will be receiving palliative care (or will be caring for someone who is receiving palliative care). However, some readers will be receiving active treatment which aims to cure their illness so some of the information will not be applicable to them – please don’t be distressed if you read something that doesn’t apply to you.

The Marie Curie Nursing Service may provide nursing or respite care to both sets of people.

Your care plan
The District Nurse (or in a few cases another specialist nurse) coordinates your care at home. The District Nurse will discuss your care with you and your carer, and will talk to you about different services and options that may be suitable for you. Tell them what your wishes are in relation to your care and what support you think you need.

If appropriate, do also talk to them about where you would like to be cared for at the end of your life, and where you would like to die. For instance, do you hope to stay at home? Or would you prefer to go to a hospice, or hospital?

The District Nurse can then put together a care plan for you which reflects your wishes. Don’t worry about what will happen if you change your mind about anything, or if your needs change later. The care plan will be reviewed regularly – with your input, if you wish – and amended if necessary.

The care plan should be left in your home. It tells all the healthcare professionals
involved with your care what treatment and care you have already received, what is planned and what your wishes are.

Every healthcare professional should record any care they give you and any discussions you have with them about what you want.

You are entitled to see your care plan and to discuss it with the District Nurse and any other healthcare professionals involved with your care. If you have any problems – for instance, if you don’t have a care plan in your home or if you feel it doesn’t reflect your wishes or discussions you have had with anyone – talk to the District Nurse or the relevant healthcare professional, or to your GP if necessary.

If you have a living will or advance directive (please see the Planning for the future: Making a living will section on page 43 for further information), discuss it with the District Nurse. Ask for a copy to be added to the care plan, and make sure that the care plan reflects your wishes as expressed in your living will. If you don’t have a living will but would like one, ask if they can help you with this.

As well as discussing your care with you beforehand, healthcare professionals require your informed consent before they undertake any procedure. It is a legal requirement that they explain every procedure to you – what they will do, what the risks are (if any) and why they are doing it - before they go ahead with it. They should explain that it is your right to refuse any treatment or procedure offered, and they need to be sure that they have your consent before they start any treatment or procedure. It doesn’t need to be as formal as this may sound – a good nurse or healthcare worker will talk you through what they are doing anyway.
The Marie Curie Nursing Service

Marie Curie Registered Nurses and Senior Healthcare Assistants
For simplicity and clarity, we have used the terms ‘Marie Curie Nurse’ and ‘nurse’ throughout this booklet. Unless we state otherwise, these terms refer to both Marie Curie Nurses (who are Registered Nurses) and Marie Curie Senior Healthcare Assistants. (See Registered Nurses and Senior Healthcare Assistants section on page 12 for the difference between the two roles).

Many people who are seriously ill wish to remain at home as long as possible. The Marie Curie Nursing Service helps to make this possible through a nationwide network of Marie Curie Nurses who provide nursing care at home.

The service is free to patients and the people who care for them.

Requesting a Marie Curie Nurse
When discussing your care plan, the District Nurse may mention the Marie Curie Nursing Service and discuss with you whether it would be appropriate to request a Marie Curie Nurse. If so, they will also discuss what visits would be best (eg overnight or daytime) and what number/frequency of visits would be appropriate.

They will also consider whether your nursing needs require a Registered Nurse or Senior Healthcare Assistant (please see the Registered Nurses and Senior Healthcare Assistants section on page 12 for more information on this).

The District Nurse will review your care regularly and decide whether to change the amount of visits they are requesting from the Marie Curie Nursing Service or the grade of nursing staff, depending on whether your condition has changed. Sometimes they may decide not to request any more visits for a while if, for example, your condition has improved.
The District Nurse will supply any equipment needed for the Marie Curie Nurse to care for you at home.

We do our utmost to fulfil every request for a Marie Curie Nurse. However, sometimes no nurse may be available for the specific visit that has been requested. We will try to offer a different day or time to the District Nurse if possible. The District Nurse may discuss this with you.

Marie Curie Nurses are not permitted to make arrangements for visits directly with you or your carer. Visits must be arranged through the District Nurse.

**How the Marie Curie Nurse can help you**

Marie Curie Nurses recognise their role as a guest in your home. They are used to working in people's homes during difficult times, and will work with you to make sure that this arrangement is as comfortable as possible for you.

Your District Nurse has arranged for a Marie Curie Nurse to visit for a particular reason, for example to monitor the effects of a change in your medication or to provide a period of nursing care and allow your carer to get some rest.

Your Marie Curie Nurse will phone you before setting out for your home in order to introduce themselves and to confirm that they are on their way.

The Marie Curie Nurse provides the nursing care you need. They can provide practical and emotional advice and support to you and your carer/family, and also have the time to listen to any concerns about your illness or treatment.

The Marie Curie Nurse monitors your condition and deals with any changes that occur during the visit. To help plan future care, the Marie Curie Nurse will tell the District Nurse about any changes in your condition.

Your carer can still be involved in caring for you while the Marie Curie Nurse is in your home. For example, if they would like to be woken up during the night if there is a change in your condition, please tell the nurse. Please also tell the nurse whether your carer would like to be woken before the nurse leaves in the morning, and
whether you need any personal care before they leave.

**Hours of duty**
Marie Curie Nurses provide care for at least three hours and generally for a shift of eight to 10 hours. They usually visit overnight, but can also work during the day or in the evening. In consultation with you and your carer, the District Nurse will decide what hours of care are needed. A night shift is usually from 10pm to 7am but it may be possible to negotiate different times via your District Nurse.

**What you can expect**
Marie Curie Nurses have up to date experience of working in hospital or the community, and looking after patients at home on a one-to-one basis. They are offered regular updates in caring for patients. Marie Curie Nurses are trained in safely moving and handling patients at home.

We aim to ensure continuity of care by providing as few different Marie Curie Nurses as possible to you.

Marie Curie Nurses are not allowed to smoke or sleep while on duty. We want to make sure that you receive the care you need. In doing so, we must also make sure that our nurses work in a safe environment. You can help us by creating a smoke-free environment in the rooms where our nurse is caring for you. We cannot insist that nurses work in conditions where there is a risk of passive smoking. By providing a smoke-free environment you can make it easier for us to provide you with as much help and support as possible.

Marie Curie Nurses are not permitted to watch TV, videos or DVDs unless you have them on in your room.

**Registered Nurses and Senior Healthcare Assistants**
Marie Curie Cancer Care employs both Registered Nurses and Senior Healthcare Assistants to care for cancer patients and other patients in their own homes.

Marie Curie Cancer Care uses the job title Marie Curie Nurse for Registered Nurses and Marie Curie SHCA for Senior Healthcare Assistants, but in this booklet
we generally use the term Marie Curie Nurse for both.

The District Nurse assesses whether a Registered Nurse (Marie Curie Nurse) or Senior Healthcare Assistant (Marie Curie SHCA) is appropriate, depending on your nursing needs, the availability of other services and the needs of your carer or family.

All Marie Curie Nurses and Marie Curie SHCAs provide practical nursing care for patients and support for carers in their homes, but there are differences in their qualifications and in the work they are permitted to do.

Some of the most significant are listed below:

**Registered Nurses**
- Registered Nurses can administer medicines to a patient and give injections.
- All Registered Nurses are registered with the UK Nursing and Midwifery Council, and will have a nursing qualification. Marie Curie Registered Nurses also have palliative care experience and have completed a specialist course in palliative care.

**Senior Healthcare Assistants**
- Marie Curie SHCAs have experience and training in providing care for patients with palliative care needs.
- Marie Curie SHCAs are not allowed to administer any medication. They may help a patient who is not confused to take their medicine themselves. They cannot give injections.

**Things to do before the Marie Curie Nurse’s arrival**
There are a few things you can do to prepare for the Marie Curie Nurse's arrival.

It would be very helpful if you could put a reasonably comfortable chair in the room where the nurse will be working. If your room has an intercom, the nurse can be based in another room. If not, the nurse should remain in your room if possible (which is preferable even if an intercom is available).

The nurse will need a light so that they can monitor you during the visit.
You are not expected to provide food for the nurse. However, nurses do appreciate being able to make themselves a hot drink during the shift. Suitable heating is also appreciated, especially during the colder months and at night.

Please ensure the following are handy:

• District Nurse care plan with the prescription for medication to be given;

• emergency drug box if the District Nurse or specialist nurse has provided one;

• clean bed linen and night clothes for you in case a change is needed during the night;

• any equipment that has been left by the District Nurse to help with moving you;

• telephone numbers of doctor or other healthcare professionals and details of when to call them (if your condition changes, in an emergency, etc.);

• telephone numbers of family/carers and information about when they should be contacted, if appropriate.

When the Marie Curie Nurse arrives

We understand it can be confusing to have many strangers visiting your home to provide care and assistance. Marie Curie Nurses must always show their ID card when they arrive; wear their uniform and name badge; and leave a visiting card with their name after every visit. If they do not, please ask them to do so.

It is helpful for the nurse to be introduced to you and any other people they may need to be in contact with during the shift. The introduction also helps the nurse know how you and your carer like to be addressed eg Mrs Jones or Barbara.

The nurse should also be told if you have any likes and dislikes, and if you have any special names for things (especially if you sometimes feel confused).

Please show the nurse where they can wash their hands and where the bathroom is.

When our nurse arrives at your home, they need to contact CommuniCare, our lone
worker system, to say they have arrived safely. (They will need to do the same when they leave your home.) Some nurses use their mobile phone to do so but for technical reasons some may ask to use your phone. We very much appreciate your agreement to this. It is a freephone number so you will not be charged for the call.
Who else can help you?

Healthcare professionals

District Nurses
The District Nurse (sometimes called the community nurse) organises and coordinates home care. They carry out an assessment of your needs in consultation with you and your carer, and can arrange for a range of services to be provided to you. These vary from area to area but can include Marie Curie Nurses, Macmillan Nurses, social services, sitters or meals on wheels.

The District Nurse can also provide you with information about local services such as carers' groups, your local hospice, drop-in centres, organisations offering grants, complementary therapy practitioners, interpreting services and other relevant services and benefits.

GP and Primary Health Care Team
The Primary Health Care Team is a team of healthcare professionals and is usually based in a health centre or surgery. Your GP will liaise with the District Nurse, who is part of the team, regarding your care if you are being cared for at home. The GP is in charge of your medical care such as writing prescriptions and changing the dosage of drugs.

Macmillan Nurses
Macmillan Nurses are specialist nurses in cancer treatment and care, supporting people with cancer from the time they are diagnosed. They offer emotional support and practical advice to people with cancer and their families in the UK. They are highly trained in managing pain and other symptoms. Macmillan Nurses work with and advise the District Nurse or Primary Care Team.

A Macmillan Nurse usually spends up to an hour with each patient, and does not generally provide physical or nursing care unless the need arises during a visit.

The difference between Marie Curie Nurses and Macmillan or other specialist nurses
Marie Curie Nurses care for people who are seriously ill with cancer and other life threatening conditions, usually in the last few months or weeks of their lives.
Macmillan Nurses care for people with cancer from when they are first diagnosed.

Marie Curie Nurses will generally spend several hours at a time in a patient's home providing practical nursing care, often overnight. Macmillan Nurses will usually spend up to an hour with each patient providing practical advice and emotional support.

In some areas of the UK, Marie Curie Cancer Care employs specialist nurses who work in a similar way to Macmillan Nurses.

**Physiotherapists and occupational therapists**
A physiotherapist or occupational therapist can help with mobility problems or breathing problems and can provide walking frames and other equipment. Equipment can also be borrowed from the Red Cross via the therapist, or you can approach the Red Cross directly.

**Hospices**
Hospices provide expert palliative and respite care. Many hospices (both Marie Curie Hospices and those run by others) offer not only in-patient care but also day centres where you can go for recreation or rehabilitation. Staff are experts at caring for people with cancer and other life-limiting conditions, and specialist nurses are often available to give advice and support in your home.

Ask your GP or District Nurse if there is a Marie Curie Hospice or other hospice near you, and whether they think a referral would help.

The charity, Hospice Information, can tell you where your nearest hospice is and provide you with other general hospice information. Please see the Further information: Hospices and care centres section on page 46 for contact details.
Other support

Caring for the carers
Your carer should try not to do everything themselves. It is important to look after their own health and get enough rest for their own sake as well as yours.

Ask for help from friends and relatives as well as health professionals. Your carer’s energies are best spent on the things they really want to do with you or for themselves, and the things that nobody else can do for them.

The Marie Curie Nurse is there for your carer as well as for you, and your carer is welcome to talk to the Marie Curie Nurse about their feelings and any difficulties they are experiencing.

Social services
The District Nurse can ask social services to make an assessment of your carer’s and your needs. Your carer’s needs are as important as yours and the services offered will depend on both of your needs. The services available can vary from area to area, but may include such services as meals on wheels or assistance with shopping.

Carers' organisations
A number of carers' organisations provide a range of services for carers, including care in the home. Please see the Further information: Carers' organisations and information section on page 47 for contact details.

Support groups
Support groups exist for both patients and carers. These groups are usually made up of people who have had cancer or who are relatives of people with cancer. Someone may be able to make a home visit if you cannot leave the house. They also hold informal meetings where experiences and ideas can be shared. Many patients and carers find it a great help to meet with other people in a similar situation.

To find a support group for either patients or carers in your area:

- Ask your District Nurse or GP.
- Phone Macmillan Cancer Support’s CancerLine (see the Further information:...
Cancer charities section on page 45 for contact details and further information).

- If you are in contact with a Marie Curie Hospice or another local hospice, ask if they have a social worker who could advise you on local sources of support for carers.

Counselling
- Cancerbackup runs a helpline staffed by trained cancer nurses who can provide emotional support as well as practical advice.

- Macmillan Cancer Support’s CancerLine can provide emotional support.

- The British Association for Counselling and Psychotherapy can provide information on counsellors, including those with specialist training in cancer. See the Further information: Counselling section on page 49 for contact details and further information on these organisations.

Spiritual support
You may wish to contact a local minister or religious leader for spiritual support.

They are usually happy to help, even if you were not previously actively involved with your local place of worship.

If you are in contact with a Marie Curie Hospice or other local hospice, the hospice chaplain or director of pastoral care can offer advice and recommend a local person whom you could contact.

Marie Curie Nurses are trained in supporting families of all faiths or none in respect of their spiritual needs.

Family and friends
Family and friends may often want to be involved and to help, but may be embarrassed to ask or offer. It is very helpful to them if you make a specific request, in an open way so they feel free to refuse if they feel they cannot manage it. Or you could instead make a couple of suggestions so they can choose which they feel able to do.

Such requests could include:

- help with cooking a meal
- companionship
• shopping for the household

• visiting for a few hours to allow your carer to go out, perhaps for a coffee or a haircut. It can help you and the carer if they try to keep up at least some of their regular routine and do things that give them a break.

What can I do to help? by Deborah Hutton is a book written by a woman with cancer for the family and friends of people who have cancer. It gives advice on how to communicate sensitively and how to help in practical and supportive ways.

Visitors
You can find it stimulating to have visitors, and company can boost your morale as well as your carer’s.

However, sometimes you may be too tired for visitors or the time of the visit may not be convenient. In addition, some well-intended behaviour may be upsetting to you or your carer.

You or your carer may find it useful to mention some of the following to potential visitors if appropriate:

• Mealtimes may be best avoided.

• Certain times may not be convenient – for instance, if a professional carer will be with you.

• Visitors may sap your strength – it is often recommended that visits be limited to say half an hour, or to a couple of visitors at a time.

• While it is a natural human reaction to try to comfort you or your carer, some advice and anecdotes are not always helpful or supportive. Generally, comments on the lines of ‘everything will be alright’ or ‘I know someone who was given three months and lived for three years’ are best avoided.

• Information from newspapers or the internet about breakthroughs in treatment, or about treatments which are only available privately, is not usually helpful. For reported breakthroughs, the practical benefits for patients are
generally several years away. Private or experimental treatments are usually very costly (this is particularly the case for treatment in the USA).

If a relative or friend seems reluctant to visit, do bear in mind that some people may feel uncomfortable about visiting but would be very happy to provide practical help.

However, it may be possible to alleviate their concerns about visiting. They may well be afraid of seeing you or worried that they will become upset in front of you, or concerned that they will say or do ‘the wrong thing’ or upset you. The more explanations and openness you and your carer can offer, the easier it will be for them, and perhaps the more satisfying for you.
Practical assistance and advice

Moving and handling
The following section on moving and handling is addressed to your carer, but it should also help you to understand what they are doing and why.

Mobility
It is important to encourage the patient's independence for as long as possible. This helps to keep up morale and helps physical comfort. Before you help someone move in bed, or from bed to a chair, please note:

• Clear the floor of shoes, rugs or other items on which you might trip or which might prevent you getting into the correct position.

• If you are helping the patient to a chair or commode, remember to position it near to the bed.

• Explain exactly what you plan to do so that your patient understands and can cooperate with you.

• Remember to be as gentle as possible when moving the patient.
Important disclaimer
Whilst every care has been taken to give clear and accurate guidance regarding moving and handling patients, these guidelines are for information purposes only in order to show how someone who has received adequate and proper training and is proficient in moving and handling patients may carry out the relevant operations. The guidelines should not be regarded as a substitute for training. The guidelines may not be suitable for every situation, or every patient or carer, and we therefore recommend that if you are not fully trained you should seek advice from your District Nurse before undertaking any operation involving the moving and handling of patients. All moving and handling operations carry an element of risk. Also, moving and handling tasks are complex and require each situation to be assessed upon its own merits.

Marie Curie Cancer Care, its employees, consultants and agents shall not be liable whether in tort (including negligence), strict or any other form of legal liability for any loss or damage or injury caused by following the guidelines contained in this booklet or any advice that our Marie Curie Nurses or Senior Healthcare Assistants provide in the home.
Safer handling
Before carrying out any techniques, please read the following tips. These should help reduce the likelihood of injury.

• Make a good stable base with your feet, one foot in front of the other, hip width apart.

• Bend your knees, and use your legs to power the manoeuvre.

• Keep your back in a comfortable upright position.

• Keep your head up when carrying out a manoeuvre as this promotes good posture.

• Do use any equipment that you may have been given, ensuring that you have been instructed in and understand how to use it.

• If in doubt about moving the patient, ask the District Nurse or Marie Curie Nurse for advice.

Safety
The following pictures and text are designed to help you to roll a patient in bed, or move them from bed to a chair at home. Ask the District Nurse or the Marie Curie Nurse to demonstrate the movements before carrying them out yourself.

Due to the risk of injury, either to yourself or to the person you are assisting, you must NOT bear all or even most of the weight of another person. These techniques should only be carried out with patients who are able to help you with the movement and who can follow instructions.
**Rolling a patient over in bed**

To change the patient’s position in bed for comfort or to wash them:

**Step 1**
Remove bedclothes and all but one pillow. Cross one leg over the other leg towards you.

**Step 2**
Move their arm over their chest towards you.

**Step 3**
With one hand on their hips and the other behind their shoulders, roll them towards you onto their side. You can make your patient comfortable like this or wash their back.
Helping to move a patient from bed to chair

Before you can help the patient sit in a chair or commode, you need to get them to sit on the side of the bed. The patient should need very little help.

Step 1
With the patient already on their side, ask them to drop the lower part of their legs over the side of the bed.

Step 2
Have the patient gently push themselves into a sitting position. Now you need to help the patient stand.

Step 3
Sit alongside them and hold one hand (palm to palm) whilst placing the other around their waist. Do not interlock your thumb with theirs as this is potentially dangerous. Both of you should place one foot slightly in front of the other.
Step 4
On the command *ready, steady, stand* – help them to stand. They can help by pushing against the bed with their other hand.

Step 5
Using small steps, gently help them to the chair. If it has arms they should feel for one with their free hand. Once they feel the back of the chair against their legs they can lower themselves into position.

To help the patient back into bed, simply use the same techniques in reverse.

This manoeuvre is only appropriate if the carer is providing minimal assistance, and the patient is doing most of the work. If this is not possible, it may not be safe to help the patient to stand.
Personal care

Equipment to assist the carer
Various items of equipment may be available to help the carer care for you at home, such as a pressure-relieving mattress or commode. Your physiotherapist, occupational therapist, District Nurse or GP should be able to advise what equipment is available, how to obtain it and how to use it. The Red Cross provides a short-term loan of some items of equipment – if a healthcare professional has not made a referral to them, you can approach them directly. See the Further information: Equipment section on page 49 in this booklet.

Some families find a baby monitor or video baby monitor helpful so they can keep an eye on you while getting on with chores or activities elsewhere in the house (though mobile phones may interfere with reception). A portable doorbell can also be useful. (These pieces of equipment are not available from Marie Curie Cancer Care or the NHS).

Washing
It is important for you to wash regularly, or for your carer to help you wash, for the following reasons:

• for your comfort
• for your morale and dignity
• so your skin can be checked for early signs of redness
• to prevent infection

It may be useful for your carer to know the following if they are helping you to wash:

• Remember to be very gentle.
• Rinse off soap completely and dry the skin gently but thoroughly.
• Change the water in the bowl several times during the wash.
• Keep the patient covered as you wash each different part of the body. Expose only those parts you are washing. This helps to keep the patient warm and also
allows them to maintain their dignity.

- Talcum powder may be used in small quantities if the skin is not too dry, and if the patient likes it.

- Moisturising creams may be applied gently on dry areas such as elbows, heels and soles of the feet.

If either you or your carer doesn’t have the energy for a full wash, a good alternative occasionally is baby wipes. These are less invasive for you if you are tired and less tiring for the carer.

**Prevention of pressure sores**
If you are confined to bed or sitting in a chair for long periods, you can become sore and numb at certain pressure points. Any bony part of the body can become sore if pressure on it is not relieved frequently. People who are very immobile and very thin are most at risk of developing sores. These can be uncomfortable and increase the risk of infection.

The best method of prevention is for you to change position regularly, whether in bed or a chair, with the carer’s help if necessary. Your District Nurse can advise you about how often this should be.

A regular change of bedding can also help.

During washing your carer should look for signs of redness on:

- the back of the head
- shoulder blades
- spine
- elbows
- the base of the spine
- hips
- heels
- ears
- ankles
As soon as they see such redness, or the development of a sore, tell the District Nurse, who can advise you on what to do.

**Mouth care**
Many people who are seriously ill have problems with their mouth. Some of the most common problems are a dry mouth and lips, ulcers, infection, bleeding gums, too much saliva and altered taste.

Thrush is an infection which is common in people who are ill. It causes a very sore mouth and tongue, and can be recognised by white patches on the tongue, gums and inside the cheek. Report it to your GP as it can be treated easily.

You will be more at risk of mouth problems if you are struggling to maintain good oral care yourself, so do ask for help if you are finding it hard to manage yourself. Oral care can help to reduce the likelihood of infection and other problems, and can increase your comfort.

A soft baby toothbrush is best if your mouth is sore. Do use toothpaste – a small amount – but be aware that it can have a drying effect. You can rinse your mouth with water, saline solution (one teaspoon of salt in one pint of water) or a mouth rinse. (Do not use a sodium bicarbonate rinse, which can cause problems with mouth, teeth and your general health if you are very ill).

If you cannot rinse your mouth, a foam stick can be used to remove the toothpaste – and a foam stick can be used to clean your teeth if a toothbrush causes discomfort. Foam sticks are used in some areas of the UK though not in others. Ask your District Nurse if they can supply them – if not, ask your District Nurse or pharmacist what they recommend.

False teeth should be cleaned as usual. If you are very ill, false teeth may lose their fit and can cause mouth ulcers.

If you have mouth pain, do tell your GP. They may be able to prescribe suitable medication.

You can relieve a dry mouth with ice cubes or ice chips, frozen fruit, lemonade or tonic water. Tinned, unsweetened pineapple can cleanse the mouth and help a dry mouth.
Sugarless chewing gum may stimulate saliva production if your mouth is still able to produce saliva. A saliva substitute is available and can be helpful before you eat or have a conversation, but the effects only last 10-15 minutes and it may cause discomfort if you use it too much.

A thin layer of petroleum jelly (eg Vaseline®) can help to prevent dry lips. Flavoured lip salves are not recommended since many people end up licking them off.

**Your appearance**
You can boost your morale simply by putting on fresh clothes, wearing jewellery, or putting on make-up as appropriate – whatever you might usually do if going out or expecting visitors. Men as well as women can boost their morale by attending to their appearance. If you can't manage this yourself, do ask for help.

Hair washing can be managed, even if you are bedbound, and can have a major impact on your morale.

You can use:

- dry shampoo powders
- a special bowl with splash attachment – this may be available from your District Nurse
- a plastic sheet, towels and an ordinary bowl in the most comfortable position for the patient. Some District Nurses have stocks of a special hair washing cap which allows you to have a dry shampoo. Ask your District Nurse if they have any stocks.

**Other care and support**

**Nutrition**
It is important to maintain a healthy diet and particularly to ensure sufficient intake of proteins (meat, fish, eggs, milk, pulses etc.). However, people with cancer often have a small appetite or none at all, or their tastes and preferences may change rapidly. The carer should try not to feel upset if you eat very little of a carefully prepared meal.
Your carer, or anyone who is preparing food for you, may find the following suggestions helpful:

- Try offering small helpings of meals, and making the food look as attractive as possible.

- Offer nourishing drinks and food supplements in addition to meals or as an alternative.

- Many patients can tolerate jelly and ice cream.

- If a high calorie fruit juice drink has been prescribed by the GP, it can be used to make jelly using the juice instead of water.

- If possible offer meals when the patient is sitting upright in a chair.

- Try not to worry too much about food if the patient is very ill.

- Ask the District Nurse, GP or Marie Curie Nurse for advice if nausea is preventing the patient from eating.

- Avoiding cooking smells or offering cold food may help to avoid nausea.

- Boiled sweets to suck can soothe a dry mouth and relieve nausea or sickness.

- Fizzy drinks such as mineral water or lemonade can help to relieve nausea.

- A coated tongue can be relieved by unsweetened pineapple chunks or juice if the mouth is not sore.

- Offer a mouth rinse after meals to keep mouth clean and comfortable.

There may come a time when you no longer want or need food and drink. It may be difficult for your carer to understand or accept but it may help if you can explain how you feel. This is a natural stage of your illness, and in some cultures fasting is a normal and appropriate action as a person's death draws near. Any decision to rehydrate by putting up a drip should be fully discussed in light of this.
Bladder and bowel care
Changes in eating and drinking habits may affect your ability to pass urine and open your bowels. Do ask your Marie Curie Nurse or District Nurse for advice. A number of drugs used for pain control are known to cause constipation so you may be prescribed medication to counteract this.

There are things you can do yourself as well, or instead. For instance, fruits such as prunes, rhubarb and bananas can have a laxative effect. Adding fibre to your diet and drinking more fluids (particularly water) can also be of benefit. Exercise and moving around can help, if you are able to do so. If you are bedbound, privacy while you open your bowels can be helpful.

If urinary output is low, a urinary catheter may be suggested to you. However, during the later stages of your illness, you may be eating and drinking less and less, and low urinary output may be a natural result of this. If a catheter has been suggested but you want more information, the District Nurse will be happy to discuss whether it is suitable for you, taking into account your fluid intake as well as your urinary output and the stage of your illness.

Pain
If you are experiencing pain, do discuss it with your GP, District Nurse, Marie Curie Nurse or Macmillan Nurse.

People with cancer often expect to have quite severe pain and so may put up with pain unnecessarily. With today's treatments the majority of patients have their pain managed successfully.

Some people may feel that they should wait till the pain is really bad. However, there is a whole range of painkillers that can treat different levels of pain so there is no need to wait till you feel it's 'really' needed.

You may be given a combination of drugs to treat your pain, not just painkillers (for example, anti-inflammatory drugs or antidepressants may be prescribed for pain).

You should take your painkillers as prescribed, even if you are not
experiencing pain at the time you are due to take your next dose. This helps to avoid breakthrough pain. On the other hand, if you find you are in pain before your next dose, tell your GP, District Nurse, Marie Curie Nurse or Macmillan Nurse.

Strong painkillers may cause certain side effects:

- **Drowsiness** will generally wear off after a few days.

- **Nausea** will probably also settle down after a few days and until it does – or if it continues – your GP can prescribe medication to help. See also the *Nutrition* section on page 31 for tips to deal with nausea.

- Constipation is a common problem – do ask your GP for help as soon as it becomes a problem. In fact, some patients may be prescribed a laxative and/or stool softener at the same time as being prescribed strong painkillers because of this side effect. See also the *Bladder and bowel care* section on page 33 for tips to deal with constipation.

Many other measures which do not involve medication can be taken to help alleviate pain: for instance, positioning you for greater comfort, physiotherapy and complementary therapies such as massage, aromatherapy and reflexology. See the *Further information: Complementary therapies* section on page 50 for more information.

There are also other ways in which you can manage your pain without medication or healthcare professionals. Music can be very soothing. Relaxation techniques or visualisation exercises can be helpful. You could also ask your GP, District Nurse or Macmillan Nurse for more information about these, or try your local library or bookshop for books or tapes.

Pain can be strongly affected by non-physical factors, which can make existing pain feel worse or even set it off. Issues which may affect pain include social factors (such as worrying about your family), psychological factors (such as anger or fear) and spiritual factors (such as wondering why this is happening to you). If you think such non-physical factors may
be affecting your pain, it may help you to talk about your concerns.

If you can’t talk to your carer, family or friends about the issues, or if you need additional support or would like to talk to a professional, you could talk to your Marie Curie Nurse, Macmillan Nurse, District Nurse or GP. Because Marie Curie Nurses generally spend several hours with a patient, you may have more opportunities to talk to your Marie Curie Nurse than to other healthcare professionals who visit. Please also see the **Who else can help you?** section on page 16 for information about support groups, counselling and spiritual support.

**Sleep problems**
You may have physical restlessness or sleep problems that are due to physical causes, or sleep problems may be caused by a combination of physical and psychological factors. Do ask your GP, District Nurse or your Marie Curie Nurse for advice on possible physical causes and treatment.

**Touch**
Touch helps to reinforce feelings of love and appreciation. Stroking or massage can be a useful way of helping you to relax, and sometimes relieves pain and sleeplessness. Touch needs to be gentle, especially if you are frail. The carer should be sensitive to your wishes, and remember that feelings can change from day to day.

**Complementary therapies**
Complementary therapies – sometimes called ‘alternative therapies’ – are therapies which are used alongside conventional healthcare. Complementary therapies such as relaxation, massage, aromatherapy and reflexology are an accepted part of palliative care services.

If you wish to use a complementary therapy, do discuss it with the District Nurse, who can tell you if there are any medical reasons why they would not recommend that particular treatment. They should also be able to tell you about local complementary therapy practitioners. Please also see the **Further information: Complementary therapies** section on page 50.
**Music**
Music, whether formal music therapy or just playing your favourite music, can be very soothing.

**Your surroundings**
If you are being cared for at home, you will of course have the furniture and objects you love around you. At the same time, if special equipment and medical supplies have been brought in, it is very easy for your room to start to feel like a hospital. Photos, cards and art can make it seem less clinical.

**Emotional support**
It is natural for people who are seriously or terminally ill to feel anxious or depressed at times. It is often hard for the carer to know how to help or even how to recognise these feelings.

Signs to look for include:

- apathy or loss of interest in your surroundings (though this can be a natural reaction at any stage of your illness)

- loss of appetite (though this can also have physical causes)

- anger or irritability with loved ones

- unexpected or extended episodes of crying

- sleep problems (though there can be physical causes instead or as well)

Some patients might not admit to the carer or themselves that they are seriously ill. Denial is a common and often a necessary stage in the emotions experienced by someone who is seriously ill.

You may also have very changeable emotions, and may have equally changeable and negative reactions towards your carer or others who are trying to help.

Your carer may also find themselves feeling sad or depressed, or showing the same signs. If so, they should seek help or support for themselves just as they would for you, or you would for yourself. Your carer can also talk to the Marie Curie Nurse about their feelings and emotional needs. The Marie Curie Nurse is there for the carer as well as for you.
You may want to seek help from your GP, District Nurse or a support group, especially if such feelings persist or become worse for either you or your carer.

Your carer can also help you by talking to you and listening. You may find it useful to show the following points to your carer or discuss them together.

• It is important for your carer to listen carefully and respond to what you are saying.

• Your carer should be prepared to discuss your concerns if you wish.

• It is important for your carer to be honest with you.

• Your carer should try not to get upset or change the subject, whatever you say. If you think you are upsetting someone, you may not share fears and worries which could be reduced by talking about them.

• Your feelings may change from day to day, or even hour to hour.

• Your carer should be there to listen if that is what you want, but if you do not want to talk, that should be respected too. Sometimes you may just want to sit in silence with someone for company.

• Some patients may feel isolated or fear abandonment, especially if there is a period of respite care in a hospice. You may need reassurance that you won’t be left alone.
What to expect if you are very ill and approaching death

The following information explains what may happen in the last few days and hours of life. Some of the things that happen at this time may seem strange or frightening, especially if you are not expecting them, but this information aims to help you understand what is happening and reassure you and your carer or family that many of these changes are natural and normal at the end of life. Your carer may find it helpful to read this section as well, and discuss it with you. If you would like support as you read this section, or if you would like to discuss any of the issues in more detail, do ask one of the healthcare professionals looking after you.

As you become more frail, you will need increased support from your carer and family. At the same time, giving up your independence isn't easy and it is important for the people around you to recognise that you will still have preferences about how you are cared for. You will still want to make decisions about your care, even what may seem like small decisions to others. It is important for the carer to listen to what you want because needs vary from patient to patient.

Of course there will be many changes to life when you are very ill, but this doesn't mean you can't enjoy those aspects of 'normal' life which are still possible. If you previously enjoyed an alcoholic drink you may still be able to do so – check with your District Nurse or GP. And if you still want children or pets to be around, there is no need to exclude them from your room (though you may also want to schedule 'quiet times' to rest).

If you and your carer, family and friends like to show physical affection through touch, hugging etc, there is no reason not to continue as long as it's not physically uncomfortable for you.

Withdrawal
You may start withdrawing from the world and your surroundings gradually. You may become very weak and drowsy as your illness progresses, and you are likely to get weaker and weaker day by day. You may prefer to stay in bed and rest. You
will spend more time sleeping, you will be harder to rouse and will often be drowsy when awake.

This apparent lack of interest in your surroundings is part of a natural process. It does not mean that you are rejecting or losing interest in your loved ones. Your carer and family may find it rewarding if some of the time they spend with you is when you are least drowsy and most conscious, but simply being together at any time can be a great comfort to both of you.

Even if you are drowsy or asleep, you may still hear what’s going on around you, and can take comfort from hearing the normal sounds of life around you or hearing someone talking to you. Do encourage your carer and family to continue to live normally around you, even if you are asleep.

Even if you are awake, you may be too weak to talk. However, you may still be able to let the other person know if you want them to talk to you or just sit quietly with you. Being cared for in this way can help you to feel comforted and loved.

Eventually you may lapse into unconsciousness and people may not be able to rouse you at all. You may remain in this state for a surprisingly long time (in extreme cases many days) although for some people it is shorter. However, in some cases this will not happen and some patients will die suddenly without warning.

**Food and drink**

You may stop eating and may want only sips of liquid. This can be hard to accept, even when the carer knows you are dying, because it is a physical sign that you are not going to get better.

The carer may be able to take some practical steps to help you. For instance, if you start to find it difficult to swallow, or are having problems with nausea, the District Nurse should be told (but also please see the Other care and support: Nutrition section on page 31). If this is causing problems with taking your medication another way of giving drugs can be used. The most common way is with a syringe driver, which gives a carefully measured dose of drugs over 24 hours, directly under your skin.
It may just be that you need more help than before. As weakness develops, the effort of eating and drinking may simply be too much and you may appreciate help. If the carer is helping you to eat, giving you a few moments to rest after you have finished each mouthful can be helpful.

Eventually there will come a time when you do not want or need food and drink. This can be very distressing for carers as food and drink are closely associated with nurturing. This is not a rejection of care – simply a natural step in the progression of the illness.

**Moving you in bed near the end of life**

Sometimes it is hard to balance your comfort and the need to move you to help prevent pressure sores. If the District Nurse has provided a special pressure-relieving mattress, it may not be necessary to continue to move you in the last few hours of life. If you become uncomfortable due to being in one position for an extended period, the carer may be able to ease this by gently moving and massaging your arms and legs – it can help if they explain to you what they are doing and why.

**Changes in breathing**

People who suffer from breathlessness are often concerned that they will die fighting for their breath. Yet towards the end of life, as the body becomes less active, the demand for oxygen is actually reduced to a minimum.

This may be comforting if you have had breathing problems, and carers often remark that when a loved one is dying their breathing is easier than it has been for a long time.

Breathing difficulties can be made worse by feelings of anxiety. But the knowledge that someone is close at hand is not only reassuring; it can be a real help in preventing breathlessness caused by anxiety.

Occasionally in the last hours of life there can be a noisy rattle to the breathing. This is due to a build up of mucus in the chest, which you are no longer able to cough up. Medication may be used to reduce this
and changes of position may also help.

These measures may have limited success, but while this noisy breathing is upsetting to carers it doesn't appear to distress the patient.

If you are breathing through your mouth, your lips and mouth will become dry. Moistening your mouth with a damp sponge and applying lip salve will give comfort. Sometimes it can be refreshing for you if the carer lets very small chips of ice melt in your mouth and on your lips.

When death is very close (within minutes or hours), your breathing pattern may change again, with breaths becoming more shallow and irregular (at this stage, you will probably not be aware of this). 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.

Your breathing may appear laboured but this seems to be more distressing to the carer than it is to the patient. Gradually there will be longer pauses between each breath until the last one is taken.

**Other physical and psychological changes**

There may be a decrease in the amount of urine you produce, and it may also be darker in colour and more concentrated. You may lose control over your bladder and become incontinent. If this happens the District Nurse will give your carer advice on how to manage this and will provide them with pads and incontinence sheets.

You may become restless and agitated or confused and may pull at the bedclothes. Sometimes if someone just sits with you, holding your hand and speaking gently, this can have a calming effect. However, the carer should also check whether you are too hot or too cold. They can also check whether you have a full bladder by feeling your tummy to see if it is hard and distended (swollen).

If you continue to be restless and agitated, the carer should tell the District Nurse. It may be possible to give you another drug
which will make you feel more comfortable, or it may be necessary to consider using a urinary catheter.

You may become confused about where you are or what time it is, and may not recognise people you know. Reminders from the people around you as to what day it is, what time it is, and who is in the room can be comforting. The lights should be dim rather than bright, but still bright enough for you to see faces. Soft music may be calming.

You may see or hear people and things which are not really there. This may not necessarily be frightening for you and sometimes may even be comforting. (For instance, you may think you see someone who has died – while one patient might be upset, another might welcome ‘seeing’ this person again). Your carer and family/visitors should be discouraged from saying that what you see isn’t real, or from telling you that you are seeing things.

However, if hallucinations seem to increase in severity or seem to be distressing for you, your carer should tell the District Nurse. It may be necessary to review your medication and consider a different dose or drug.

Your hearing and vision may deteriorate, but people should assume that you can hear, since hearing is thought to be the last of the senses to diminish. Telling you what’s happening around you, and continuing to talk to you, can be a comfort for the carer as well as for you.

Your arms and legs may become cool to the touch and bluish. The carer may notice that the underside of your body is much darker. These symptoms are the result of blood circulation slowing down and do not necessarily mean that you are too cold. Fevers are also common. On the other hand, the skin can become pale and moist and slightly cool prior to death. Most people do not wake up, but die peacefully, comfortably and quietly.
Planning for the future

Making a living will
This is sometimes called an advanced directive or advance statement. It may be as simple as a record in your notes that you do not want to be resuscitated if you have a cardiac arrest, or it may be a more lengthy and detailed document which covers a number of issues and circumstances, including where you wish to die as well as what medical interventions or treatments are acceptable or unacceptable to you.

Having a living will means that if at some point you can no longer express your wishes, your family can refer to this document to see what your wishes are.

It can be difficult to discuss the subject with people who are close to you. They may want to do everything possible to prolong your life and may not understand if some of your choices appear to have the opposite intention. However, do discuss your wishes with your loved ones if possible so that if and when the time comes they are not surprised by your wishes and can help to fulfil them while understanding your choices.

If you want guidance on what to include in a living will and what may be relevant in your situation, you can talk to your GP or another healthcare professional. Alternatively, standard forms to use or to guide you, or to guide your discussion with a healthcare professional, are available from a number of sources. The Natural Death Handbook (published by the Natural Death Centre) includes such a form. In order to try and ensure that your wishes are followed, make sure that the relevant healthcare professionals involved in your care have a copy or are aware that you have a living will. It is a good idea to discuss it with the District Nurse and put a copy in your care plan.

Funeral planning
Planning your own funeral or discussing what you would like means you can ensure that everyone knows what your wishes are. If you don't discuss your wishes during your lifetime, people may not know what your preferences were, and your funeral may end up being very different from what you would have chosen. While
you or your loved ones may feel that it is inappropriate to plan or even discuss your funeral while you are alive, in retrospect most people find it was very helpful.

You may feel uncomfortable at first discussing it but people often become more comfortable with the subject as time goes on, and can even take pleasure from deciding what music to have and where to be buried.

If your loved ones really don't want to discuss it, you could write down your wishes so they have something to consult after your death.

There is plenty of information available (including our Bereavement booklet, available from www.mariecurie.org.uk/patientsandcarers which provides an overview of funeral planning and lists other sources of information) but when people have just been bereaved they may not have the time or will to start tracking down and reading books. If you discuss your wishes for your funeral before you die, your loved ones will be clear about what you want and will feel more prepared.

Decisions can be made without time pressures and there will be time to make special arrangements. And you will be involved in the decisions about how to celebrate your life.
Further information

Cancer charities

Cancerbackup
3 Bath Place
Rivington Street
London EC2A 3JR

Cancerbackup Scotland
Suite 2
Third Floor
Cranston House
104-114 Argyle Street
Glasgow G2 8BH

Tel: 0141 223 7676

Cancer Information:
📞 Freephone 0808 800 1234
🕒 (9am-8pm Monday to Friday)
✩ www.cancerbackup.org.uk
✉️ info@cancerbackup.org.uk

Cancer nurses provide a cancer information service, leaflets on individual cancers, emotional support and practical advice by telephone, letter or email.

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ

📞 CancerLine: Freephone 0808 808 2020
🕒 (9am-10pm Monday to Friday)
✩ www.macmillan.org.uk
✉️ cancerline@macmillan.org.uk

Macmillan Cancer Support helps people living with cancer, providing immediate practical and emotional support. The range of services includes Macmillan Nurses and doctors, cancer care centres, a range of cancer information and direct financial help for those who need it most. Phone the free Macmillan CancerLine to find out more about how Macmillan can help you.

CLIC Sargent
Abbey Wood Business Park
Filton, Bristol BS34 7JU

📞 Child Cancer Helpline
📞 Freephone 0800 197 0068
🕒 (9am-5pm Monday to Friday)
✩ www.clicsargent.org.uk
✉️ helpline@clicsargent.org.uk
CLIC Sargent offers practical hands-on care to children suffering from cancer or leukaemia and their families. CLIC Sargent provides not just clinical services but also financial and emotional support. Services include Homes from Home, CLIC Sargent Nurses and Care Grants.

**Hospices and care centres**

Marie Curie Hospices are located in Belfast, Edinburgh, Glasgow, Penarth, Newcastle, Liverpool, Bradford, Solihull, Caterham and Hampstead. There is also a day therapy unit in Tiverton. For full addresses and telephone numbers contact Marie Curie Supporter Services:

- Freephone 0800 716 146
- [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

See page 52 for more information.

Your **District Nurse** should be able to provide information about local hospices or care centres.

**Hospice Information**

St Christopher’s Hospice
51-59 Lawrie Park Road
Sydenham
London SE26 6DZ

**Help The Hospices**

Hospice House
34-44 Britannia Street
London WC1X 9JG

Contact details for both Help the Hospices and St Christopher’s hospice:

- 0870 903 3903
- (9am - 5pm Monday to Friday)
- [www.hospiceinformation.info](http://www.hospiceinformation.info)
- info@hospiceinformation.info

Hospice Information can help you find your nearest hospice. The charity also provides general information on hospice and palliative care in the UK and overseas.

**Sue Ryder Care**

2nd Floor
114-118 Southampton Row
London WC1B 5AA

- 020 7400 0440
- [www.suerydercare.org](http://www.suerydercare.org)
- info@suerydercare.org

Sue Ryder Care runs care centres in the UK for patients with many different disabilities and diseases. Services include long term
care, respite care, symptom control, rehabilitation, day care and domiciliary care. There is one new purpose-built facility in Aberdeen providing care for people with neurological disease.

Macmillan Cancer Support offers palliative care day units where patients can receive continuing care, therapies and companionship. These are accessed through Macmillan Nurses. For contact details see main entry under Cancer charities on page 45.

**Carers' organisations and information**

Your District Nurse should be able to provide information about local carers' organisations.

**Crossroads**
(England and Wales)
Crossroads Caring for Carers
10 Regent Place, Rugby, Warwickshire CV21 2PN

📞 0845 450 0350
📍 www.crossroads.org.uk
✉️ appeals@crossroads.org.uk

**Crossroads Caring**
(Scotland)
24 George Square, Glasgow G2 1EG

📞 0141 226 3793
✉️ www.crossroads-scotland.co.uk
✉️ info@crossroads-scotland.co.uk

Branch schemes across England, Wales and Scotland provide a range of services for carers, including care in the home by paid, trained carer support workers, to enable carers to have a break: time to be themselves.

**Crossroads Caring for Carers (NI) Ltd**
7 Regent Street, Newtownards Co. Down, Northern Ireland BT23 4AB

📞 028 9181 4455
📍 www.crossroadscare.co.uk
✉️ mail@crossroadscare.co.uk

Crossroads in Northern Ireland operates in the Northern Health and Social Services Board and Eastern Health and Social Services Board, providing a home-based respite service for carers of people who are disabled, ill or elderly in order to allow them to have a break to do some
shopping, go for a walk or just have some time for themselves.

**Carers UK**
20-25 Glasshouse Yard
London EC1A 4JT

📞 CarersLine: 0808 808 7777
(Wednesday and Thursday only: 10am-12 noon and 2pm-4pm)
🌐 [www.carersuk.org](http://www.carersuk.org)
✉️ info@carersuk.org

Carers UK provides information and support to people caring for relatives and friends. There are over 100 branches run by carers which refer to local sources of help and support. The charity can advise carers on rights and entitlements. Free leaflets and information sheets are available.

**Princess Royal Trust for Carers**
14 Bourne Court
Southend Road
Woodford Green
Essex IG8 8HD

📞 020 8498 7900
🌐 [www.carers.org](http://www.carers.org)
✉️ info@carers.org (for publications)

Provides carers' centres across the UK offering information, support and social activities.

**Directgov**

Provides information for carers on subjects such as support services, useful organisations, how to get their own needs assessed and looking after themselves.

**Natural Death Centre**
12a Blackstock Mews
Blackstock Road
London N4 2BT

📞 0871 288 2098
🌐 [www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)
✉️ ndc@alberyfoundation.org

A national organisation that aims to support those dying at home and their carers publishes *The Natural Death Handbook*, which includes information on caring for someone at home. Their *Advance Healthcare Directive* (living will)
and *Advance Funeral Wishes* forms are available for purchase.

**Support groups**
Your *District Nurse* should be able to provide information about local support groups for both patient and carer.

The Macmillan CancerLine (formerly Cancerlink) can provide information on local self-help and support groups. For contact details see main entry under *Cancer charities* on page 45.

**Counselling**
Cancerbackup can provide emotional support by telephone or letter. For information on services and contact details see main entry under *Cancer charities* on page 45.

The Macmillan CancerLine (formerly Cancerlink) can provide emotional support. For contact details see main entry under *Cancer charities* on page 45.

**Equipment**
The patient's physiotherapist, occupational therapist, District Nurse or GP should be able to give advice on how to obtain and make use of equipment, or may provide a referral to the Red Cross.

**BACP (British Association for Counselling and Psychotherapy)**
BACP House
Unit 15, St John's Business Park

**British Red Cross - UK Office**
44 Moorfields
London EC2Y 9AL

- ☏ 0870 170 7000
- ✉ www.redcross.org.uk
- ✉ information@redcross.org.uk

Lutterworth
Leicestershire LE17 4HB
- ☏ 0870 443 5252
- ✉ www.bacp.co.uk
- ✉ bacp@bacp.co.uk

BACP provides a factsheet about choosing a counsellor and can provide details of local counsellors, including those who have specialised training around cancer and those who may be able to provide free or low cost counselling or offer concessions.
Volunteers provide local services including loans of medical equipment, transport and domiciliary care. A healthcare professional may provide you with a referral to the Red Cross in order to obtain equipment or you can contact the Red Cross directly through its local branch.

**Complementary therapies**

Your **District Nurse** should be able to provide information about local practitioners of complementary therapies. They can also advise you on the suitability of particular types of treatment with regard to your specific illness.

**Institute for Complementary Medicine**

PO Box 194  
London SE16 7QZ

📞 020 7231 5855  
🌐 www.i-c-m.org.uk  
✉️ info@i-c-m.org.uk

The institute can supply names of practitioners of complementary medicine. For information by mail, please send a stamped addressed envelope and three loose first class stamps, stating area of interest.

**Financial assistance**

Your **District Nurse** or your local social security office should be able to provide you with information about DSS benefits that can be claimed on your or your carer’s behalf.

**The Department for Works and Pensions** (formerly DSS – Department of Social Security) provides a Benefits Enquiry Line for people with sickness or disabilities.

📞 Freephone 0800 882 200  
🌐 www.dwp.gov.uk/lifeevent/discare/

Macmillan Cancer Support produces a booklet called *Help with the cost of cancer: a guide to benefits and financial help for people affected by cancer*. This can be downloaded from their website or ordered as a booklet. For contact details see main entry under **Cancer charities** on page 45.

**Grants**

Your **District Nurse** should be able to provide you with information about any local grants that are available.
Macmillan Cancer Support awards one-off grants which cover a wide range of practical needs. Applications are made on the patient’s behalf by healthcare or social work professionals. For contact details see main entry under Cancer charities on page 45.

CLIC Sargent may be able to provide Care Grants. For contact details see main entry under Cancer charities on page 45.

**Holidays**
Cancerbackup produces a booklet *Travel and Cancer*. For contact details see main entry under Cancer charities on page 45.

**Travel insurance**
Cancer patients may find it difficult to obtain medical insurance when travelling abroad. A number of insurance companies do offer cover but some impose age restrictions or geographical limitations. Most will generally require a medical certificate. Some companies are prepared to consider cover for patients with a terminal prognosis on a case-by-case basis. Others will only provide cover for patients in remission or with a non-terminal prognosis. It will probably take longer than usual to arrange cover, so do bear this in mind.

The insurer may ask the patient to take with them a medical summary of their condition, possibly translated into the appropriate language. Even if this is not required, you may find it useful to do so.

Cancerbackup produces a booklet *Travel and Cancer* and a separate list of insurance companies which may be able to offer medical insurance. For contact details see main entry under Cancer charities on page 45.
About Marie Curie Cancer Care

Making a real difference
Marie Curie Cancer Care is a long-established and well-respected charity committed to making a real difference to the lives of people with cancer and other terminal illnesses. Our work centres on the following key activities:

Marie Curie Nursing Service
Marie Curie Nurses make it possible for people who are seriously ill with cancer and other terminal illnesses to stay in the comfort of their own home at the end of their lives rather than go into hospital or a hospice. Our nurses generally work through the night allowing families and carers to rest, knowing their loved ones are in safe hands.

Marie Curie Nursing Service has over 2000 nurses covering 95 per cent of the UK from remote villages to the big cities. This service is free to patients irrespective of their circumstances.

Marie Curie Hospices
The charity funds 10 hospices across the UK offering specialist care in a relaxed and comfortable environment. The expertise of Marie Curie Cancer Care's specialist staff reaches beyond the hospice into the community linking with GPs and social services departments. Hospice day service programmes and home visits mean that people can remain at home for as long as possible if they wish.

Marie Curie Research Institute
Marie Curie Cancer Care scientists are at the forefront of research into the causes and treatment of cancer. They focus on how the body's cells should normally operate; what causes these processes to go wrong and lead to cancer; and how better treatments can be developed.

The Marie Curie Palliative Care Research Unit aims to continuously improve care for people affected by cancer and other terminal illnesses.

Find out more about this service, phone Marie Curie direct:
① (Freephone) 0800 634 4520
Support us
The services Marie Curie Cancer Care provides are always free but we can only continue to do this through the generosity of our supporters.

Donations
There are many ways to make a donation. You can make a one-off donation or set up a monthly direct debit from your bank account. If you are a UK taxpayer you can add an extra 28 per cent to your donation at no extra cost through the Gift Aid scheme.

Find out more about donating:
① 0800 716 146 (Freephone)
⑦ www.mariecurie.org.uk/donate

Wills
Last year, gifts that supporters left the charity in their wills, allowed us to provide a million hours of nursing care. Without these special gifts, we cannot meet the challenges of the future.

Find out how you could include a gift to Marie Curie Cancer Care in your will:
① (Freephone) 0800 716 146
⑦ www.mariecurie.org.uk/wills

Events
Run, trek, swim or cycle, our supporters do it at home and abroad. Whether taking part in memory of a loved one or as a personal challenge they make a real difference. Events range from exhilarating abseiling and overseas adventure activities, to sponsored walks, tea parties and bridge tournaments. There is something to suit everyone.

Take part in events in your area or abroad:
① 0800 716 146 (Freephone)
⑦ www.mariecurie.org.uk/events
Volunteers
Volunteers operate right at the heart of Marie Curie Cancer Care and are critical to its success. Volunteers work throughout the charity in shops, offices, hospices, fundraising, through to the trustees who govern the charity. Their skills, dedication and sheer hard work are absolutely vital in keeping the charity's services running.

Our annual Great Daffodil Appeal in March relies on its volunteer street collectors. Each individual can make an enormous difference. Just one hour of your time as a collector can help fund a few hours of nursing care.

Find out more about volunteering:

📞 0800 716 146 (Freephone)
홈페이지: visit www.mariecurie.org.uk/volunteers

Supporting the choice to die at home campaign
Marie Curie Cancer Care believes everyone should have the right to choose where they are cared for if they have a terminal illness. Research shows most people want to be cared for in the familiar and comfortable surroundings of their own home. A significant minority would choose to be cared for in a hospice or nursing home. However, more than 50 per cent of cancer patients receive end-of-life care in hospital – the place they would least want to be. The charity is campaigning across the UK for more choice around place of care.

To add your voice to the campaign or to find out more:

✉️ campaign@mariecurie.org.uk
🌐 campaign.mariecurie.org.uk
Feedback about this booklet and our service
This booklet has been developed in consultation with patients and carers.

We are also extremely grateful to Jane Salvage, health consultant, who reviewed the booklet in a professional and personal capacity.

If there is any information you feel it would be helpful for us to include, or if you have any comments on our service, please write to:

Patient and Family Champion
Marie Curie Nursing Service
Marie Curie Cancer Care
89 Albert Embankment
London SE1 7TP

champion@mariecurie.org.uk