



Caring Counts

Information and support for people who look after someone who has been diagnosed with a life-limiting disease.

Scottish Edition



Children's Hospice Association Scotland
Sharing the Caring



help the
hospices



Are you a carer?

If you look after a friend or family member who is unable to look after themselves, you are a carer.

You are still a wife, husband, partner, friend, parent, son or daughter. You are not changing role, just adding something extra.

There is no standard picture of a carer. Caring for someone can be a gradual process, or it can happen suddenly. It 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.

Help and support

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

Make sure health and social care professionals know that you are a carer. You are part of the care team and it is important that you receive the information, help and support you need.

Using this booklet

This booklet contains information for anyone who looks after a friend or relative with a terminal or life-limiting illness. It includes information on finding help and support, and what to expect when caring for someone at the end of life. There are also useful contact details at the back of the booklet.

Some of the content deals with sensitive issues about caring for someone at the end of life.

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This booklet has been produced by Help the Hospices, the national charity for the hospice movement. We support over 220 local hospices in their vital work caring for people with terminal illnesses, as well as their families and carers.



Caring at home

Talk to your GP, district nurse, health visitor, social worker, hospital or hospice about what help you can get in the home.

You might need practical support, such as helping the person you are caring for to wash. You might want to take a break from caring for a few hours each week. You might also want to plan what would happen to the person you care for in an emergency, such as if you were taken ill.

If you are providing hands-on care, you will need information and advice. You will probably need to know about lifting and moving the person you care for, what they can eat, the side effects of medication and how to recognise new symptoms. You will also need information about the illness itself.

Make sure you ask questions. There is a lot to take in so do not be afraid to ask the same questions over again. You might find it useful to take notes when you talk to professionals.

Carer's assessment

Ask your local social work services department for a carer's assessment. This is an assessment of what might make it easier for you to continue caring. It aims to make caring easier for you by supporting you and the person you look after.

The assessment should take place somewhere convenient, such as your

home. You can ask to talk to the person carrying out the assessment without the person you care for being present.

Tell the person carrying out the assessment what would help you, and be honest about the amount of caring you would like to do. The assessment must also take your interests, work and other responsibilities into consideration.

Adapting your home

Adapting the home of the person you care for can help them live as independent a life as possible. Your local social work department will put you in touch with the occupational therapy team.

They can tell you which types of equipment are available.

Other sources of help

- The British Red Cross offers short-term equipment loans. Visit www.redcross.org.uk or call 0870 170 7000.
- The Disabled Living Foundation provides information on daily living equipment for people who are elderly or disabled. Visit www.dlf.org.uk or call 0845 130 9177.



Caring for yourself

Caring for someone can be physically and emotionally demanding. Your own health is important. If you feel overstretched or ill, you will find it difficult to continue caring for your friend or relative. So you need to care for yourself.

Dealing with stress

Signs of stress include loss of self-esteem, lack of concentration, exhaustion or even hostility towards the person you are caring for.

If you feel stressed, it is important to seek advice and support. Visit your GP's surgery and tell the practice that you are a carer. They may offer a counselling service, or tell you where to find support.

Taking a break

Without an occasional break from caring, you may become exhausted or unwell. A break will allow you to do the things you may not have time for while you are caring, such as catching up with friends and family or having a rest.

You may need to arrange temporary care for the person you are looking after. Your local social work services department may be able to arrange care in the home or visits to a day care centre.

Crossroads Caring Scotland offers practical support in the home, to allow carers to take a break. Visit www.crossroads-scotland.co.uk or call 0141 226 3793. You could also contact your local social work services department or citizens advice bureau to find out about similar services in the area.

If you want to take a longer break, talk to social work services or a district nurse about arranging residential care.

Make sure that anyone who takes over from you has all the information they need. Write down anything important, such as medication and diet, and tell them who to contact in an emergency.



Talk to carers

Other carers are a great source of information, support and advice. Find out whether there is a carers' support group near you by contacting your local hospice or GP.

Or visit www.carers.org to find out if there is a Princess Royal Trust for Carers centre near you. You can also contact other carers through the message board and chat room on this website.

Contact a Family has details of parent support groups: visit www.cafamily.org.uk or ring the freephone helpline on 0808 808 3555.

Do you have to be the carer?

It might seem as if you have no choice because of your family situation and relationships. But you do have the right to decide whether or not you take on the role of carer.

Many people feel guilty if they do not want to be a carer. Some people feel that asking for help means they cannot cope. But there is nothing wrong with making sure the person you look after receives the best care possible.

There might be some tasks that you are not comfortable with, such as helping the person you care for wash or use the toilet.

Talk to your social worker or district nurse about your choices.

You might find it easier if the person you are caring for moves into a nursing or residential home. You can still provide care, but with extra support.

Before making any decisions, talk through the options with everyone involved, including the person you are caring for.

Other ways of looking after yourself

- Cook double portions, so you are not tempted to skip meals.
- Take some exercise – even a short walk just to clear your head.
- Make separate GP appointments for yourself – and keep them.
- Your local carers centre might offer training on lifting or first aid. If not, talk to your GP about finding similar training courses in your area.
- Be realistic – prioritise tasks and only focus on what you can achieve.
- If you are offered help, accept it.



Who's who?

Please note: services may vary in different areas.

Care Assistants or Home Care Teams

help with tasks at home, such as dressing, washing, etc. They may be employed by social work services, community services, hospitals or hospices.

Children's Community Nursing Teams

specialise in caring for children and families, and provide nursing and supportive care at home. They can be contacted through the hospital, at the GP's surgery or directly at their base.

The District Nurse or Community Nurse

provides hands-on nursing care and practical advice in the home. In many places they are available 24 hours a day. They can usually be contacted through a GP's surgery or directly at their office.

Community Palliative Care Nurses are clinical nurse specialists, skilled in pain and symptom control. They give emotional support and practical advice to patients and their families, from diagnosis onwards. They do not usually provide

hands-on care, but give advice to the primary healthcare team and can link with the hospital or hospice. In some areas they are called **Hospice Community Nurses** or **Macmillan Nurses** (they may be employed by Macmillan Cancer Support or by the local hospice).

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.

The Health Visitor specialises in the care of babies and young children at home.

They are based at your GP's surgery. They can offer advice and training. They can also help arrange other services that your family might need.

Hospice staff include doctors, nurses, social workers, physiotherapists, spiritual care leads, counsellors and volunteers.

Hospice at Home may be available in your area. This includes qualified nurses, nursing assistants and volunteers who offer 24-hour short or long-term care.



Marie Curie Nurses can provide hands-on care at home through the day or night, giving the carer a chance to have a break or sleep. Your district nurse can help you find a Marie Curie nurse.

Occupational Therapists give advice on and provide equipment to help make daily life easier, eg help with the bath, toilet or the stairs.

Oncologists are doctors who specialise in treating cancer. A clinical oncologist treats cancer with radiation. A medical oncologist treats cancer with drugs. They are often based at cancer centres, but they may also see you at your local hospital.

Physicians, Surgeons and Hospital Doctors are based in the hospital and specialise in a particular area of medicine.

Physiotherapists teach people special exercises to improve things or stop something getting worse. They sometimes teach breathing exercises.

The Primary Healthcare Team usually includes the GP, district/community nurse, children's community nurse, practice nurse, practice manager, receptionists and other associated professionals, eg health visitors.

Social Workers can help you get emotional support, practical help and financial assistance. They are often employed by social work services. Some social workers work in hospices and hospitals. Some specialise in a particular area, such as working with children or bereavement support.

Specialists in Palliative Care/Hospice Doctors specialise in managing pain and other symptoms. They also focus on meeting the social, emotional and spiritual needs of the patient.

Money and benefits

Caring for someone can be expensive. You might find you have extra costs, such as higher heating bills or travel to hospital appointments. You might also leave your job, or cut the number of hours you work.

There are many benefits which may be available to you and the person you care for. Most are provided by the Department for Work and Pensions.

Carer's Allowance may be available if you are caring for someone who receives Attendance Allowance or Disability Living Allowance.

Attendance Allowance is for people aged 65 or over who have difficulty looking after themselves.

Disability Living Allowance is for people under 65 who have difficulty looking after themselves or getting around.

Council Tax Benefit can help you pay your council tax bill. The amount depends on your income, savings and family circumstances. You might get a discount on your council tax bill if your home is adapted for a disabled person or if a paid care worker lives with you. You might also get a discount if you are caring for someone.

Health Benefits cover things like help with paying for prescriptions, dental charges, eye tests, travel to hospital, costs of NHS wigs and fabric supports.

Housing Benefit is paid to people living in rented accommodation. The amount you receive depends on your income, savings and family circumstances.

Incapacity Benefit is for people who are unable to work because of illness or disability.

Income Support is for people aged under 60 whose income is below a minimum level. This level depends on your circumstances. If you are aged 60 or over, this support is called **Pension Credit**.

Please note: in November 2008, Incapacity Benefit and Income Support paid on the grounds of incapacity or disability will be replaced by a new benefit, Employment and Support Allowance.

The Social Fund pays for one-off expenses. Some expenses should be paid automatically, such as winter fuel payments. Others have to be applied for, such as funeral expenses.

Carer Premium: If you get Carer's Allowance, you may be able to get an extra amount of Income Support, Pension Credit, Housing Benefit and/or Council Tax Benefit through the carer premium.

Other sources of help

- Your local social work department for information about the Blue Badge parking scheme, and for aids and adaptations in the home.



- The National Key Scheme for access to public toilets for disabled people: 0870 770 7930 or www.radar.org.uk
- Check with your local authority about discounts on trains and buses.
- The Royal British Legion offers financial aid to ex-service people: 08457 725 725 or www.britishlegion.org.uk
- Check for discounts at cinemas, theatres and tourist attractions.

When someone dies

- If you are claiming Carer's Allowance, you can continue to claim for 8 weeks. Then, if you are under 60 and do not have a job to return to, you will normally be expected to claim Job Seekers Allowance.
- If you were caring for your husband or wife, you may be able to claim a Bereavement Payment or Bereavement Allowance.
- If you have children, or you are expecting a child, you may be able to get Widowed Parent's Allowance.
- If you or your spouse were receiving a pension, the amount you receive may change.

Help and advice

The benefits system is complicated and applying for benefits can be time-consuming. If you can, find someone to help you.

- Visit www.adviceguide.org.uk/scotland.htm or contact a Citizens Advice Bureau.
- Macmillan Benefits Helpline: 0808 801 0304.
- CarersLine: 0808 808 7777.
- Department for Work and Pensions Benefit Enquiry Line: 0800 882200.
- Age Concern: 0845 125 9732 or www.ageconcernscotland.org.uk
- Help the Aged has a free welfare rights advice service, SeniorLine: 0808 800 6565
- Pension Credit Helpline: 0800 99 1234.
- Your local carers' centre – your local authority should be able to tell you where this is or visit www.carers.org

Useful booklets include:

- The Department for Work and Pensions publishes the booklet 'A guide to non-contributory benefits for disabled people and their carers' (ref HB5). This can be downloaded from www.dwp.gov.uk
- The booklet 'What to do after a death in Scotland' (ref D49S) contains practical information and can be downloaded from www.scotland.gov.uk or ring 0131 244 2193.

Your local hospice, social worker, GP or district nurse may be able to tell you where to find further help and support.

Work and caring

Juggling work and caring is not easy. You may feel that your only option is to give up work. It is important to think about how this will affect your life, such as your financial position, career development and pension rights. You may also miss the social aspect of work, or find that it gives you a break from caring.

Talk to your employer

Tell your employer that you are looking after someone. Many employers will be sympathetic to your situation. Some workplaces even have policies to support employees who are carers. Think about your needs, and how your employer could support you. This might include:

- days off for emergencies
- time off for hospital or doctor's appointments
- working part-time, or working different hours
- having access to a telephone
- having someone at work to talk to about problems
- working from home occasionally
- taking a short paid or unpaid break from work.

You have the right to take a 'reasonable amount' of time off work to deal with an emergency involving a dependant – it is up to your employer whether this is paid or unpaid.

If you care for an adult or a disabled child under 18, you have the right to ask your employer for flexible working, eg part-time

hours, working from home, etc. It is important to think about your needs as a carer and the needs of the job, before making a request.

Help and advice

- Talk to the Human Resources or Personnel department, or your line manager, at your current or former workplace.
- Your trade union can give advice and support.
- ACAS gives information on employment rights. Visit www.acas.org.uk or call 08457 474747.
- Action for Carers and Employment (ACE) National has resources to support carers in the workplace and their employers. Visit www.acecarers.org.uk
- Contact your local Jobcentre Plus for advice about self-employment, training and returning to work. Visit www.jobcentreplus.gov.uk
- Working Families gives information and advice on balancing work and caring: 0800 014 0313 or www.workingfamilies.org.uk

Education and training

- learndirect: www.learndirect.co.uk
- City & Guilds Carers Programme: www.learning-for-living.co.uk
Email: carers@cityandguilds.com
Tel: 020 7294 2817
- Open University: www.open.ac.uk

Legal matters

You may have to deal with the finances of the person you are caring for. Thinking ahead can help you avoid difficulties.

Banks and benefits

If you need to move money to and from someone's bank/building society account, you can contact the bank to organise a third party mandate.

When a person dies, the third party mandate will end. You can still withdraw money if you set up a joint account with the person you care for. If there are any concerns about setting up a joint account, you can arrange for transactions to be authorised by two signatures.

Pensions and benefits are usually paid directly into a bank account. If you need to help someone collect their pension or benefits, contact your local Department for Work and Pensions office about becoming an agent or appointee:

- An agent can collect someone else's benefits for them.
- An appointee deals with all aspects of benefits for someone who cannot act for themselves.

Powers of Attorney

These allow you to act on behalf of another person. There are two types:

- General Power of Attorney can be used to manage someone's financial affairs. It stops if the person can no

longer make the decisions themselves.

- Lasting Power of Attorney allows you to act on behalf of someone when they have lost mental capacity to act for themselves. There are two types – 'Property and Affairs' and 'Personal Welfare'.

For further information, contact the Public Guardianship Office. Call 0845 330 2900 or visit www.publicguardianship.gov.uk

Making a Will

If someone dies and they have not made a Will, this can cause problems. It may mean their wishes are not followed. Try to encourage the person you are caring for to think about what they would like to happen to everything they own after their death.

'The rules about signing and witnessing Wills are complicated. You may want to seek legal advice from a solicitor. Legal advice can be expensive so compare costs before committing yourself. For further information about finding a solicitor or making a Will, contact The Law Society of Scotland on 0131 226 7411 or www.lawsocot.org.uk





End of life care

Talk to the person you are caring for about what they want to see and do in the last few months. They may want to visit a particular place. With help and support, especially from a hospice team, many things are often possible.

If the person you are caring for is originally from another country, they may wish to visit or spend their last days there.

Hospice Information publishes 'Flying home or on holiday' – to order a copy ring 0870 903 3 903 or visit

www.hospiceinformation.info

Being prepared

You might choose to talk to the person you are caring for about what they want at their funeral:

- Whether they want to be buried or cremated.
- Whether they want a religious or non-religious service.
- The hymns, music or readings they would like.
- How they would like to be dressed.
- The sort of memorial they want.

You might also want to talk to the person you are caring for about whether they want to donate their organs (eg, heart or kidney) or tissues (eg, skin or bones) after they die.

If they want to donate, they should put their name on the NHS Organ Donor Register. They can call the Organ Donor Line on 0845 60 60 400, or register online at www.uktransplant.org.uk

If they register, it is important that they tell those closest to them about their decision. It is less stressful if their wishes are known.

As death approaches

Talk to the person you are caring for about what they want as their death approaches. They might want music, candles, sunlight or a view of the garden.

Contact friends and relatives the person you are caring for particularly wants to see again. This may also be the time to say the things you have not had a chance to say before.

Photograph courtesy of Community Care



As death approaches, you may notice a day-to-day (even hour-to-hour) deterioration. People normally become weaker and increasingly drowsy, until they become bed bound and perhaps semi-conscious. There is normally a period of unconsciousness - lasting hours to days - before someone dies.

Swallowing may become difficult. Medicines may need to be given using a small pump called a syringe driver, to make sure that pain and other symptoms are controlled as well as possible.

Before death, it is normal for breathing patterns to change or for someone to sound 'chesty' – this does not usually cause distress to the patient. Involuntary movement may occur, such as restlessness or twitching. You may also notice a change in their skin colour and body temperature.

It might help to talk to a doctor or nurse about your concerns and fears at this time.

Caring for someone

You can still give loving care:

- Touch the person, eg holding their hand.

- Change their position regularly, if you are able to.
- Use foam swabs to keep their mouth clean and moist.
- Keep their eyes moist with saline, which you can buy from a chemist or get from your district nurse.
- Hearing is the last sense to 'close down', so try to speak normally and calmly, offering love and support.

Do not feel guilty if you find it difficult to do these tasks or if you find yourself wishing it would end. You may want to ring your GP or a friend, so you have someone with you.

When someone dies

You do not have to do anything straightaway. It is okay to spend some quiet time with the person who has died, or take time for yourself.

If the person you are caring for dies in a hospital, you can also have some quiet time alone with the person, if you wish.

When someone dies

If the person you are caring for dies at home, the doctor is the first person to contact. The doctor will give you a Medical Certificate.

If the person dies in a hospital, they will be taken to the hospital mortuary. Usually it is possible to see them there.

If the death is sudden, or the cause is uncertain, a post mortem may be required. This will take place at the local district hospital. The nearest relative, or someone very close to the person who has died, will be asked to agree to this. The doctor will explain to you what will happen and why.

Registering the death

Someone who has known the person who has died must take the Medical Certificate to the Registrar of Births, Marriages and Deaths' office to register the death. This must be done within eight days of the death, whether the death occurred at home or in the hospital.

The Registrar will need information about the person who has died:

- Date and place of birth.
- Date and place of death.
- Maiden name, if a married woman.
- Former occupation.

- If married, the name, date of birth and occupation of the surviving husband/wife.
- Last address, if known.

The Registrar will also need the Medical Certificate and, if you have it, the NHS medical card of the person who has died. The Registrar will give you Form 14. This should be handed to the funeral director.

You will also be given the form 334/SI which you can send to the Department for Work and Pensions to stop or adjust any benefit or pension payments. You can obtain a Death Certificate (for an appropriate fee) which you may need for dealing with insurance policies, work pensions and the Will. In some cases, it may be useful to obtain extra copies as photocopies are not accepted for any formal dealings.

The booklet 'What to do after a death in Scotland' (ref D49S) contains practical advice and information. This can be downloaded from www.scotland.gov.uk or ring 0131 244 2193. You can also obtain the booklet from your local registration office, JobCentre Plus, social work department or Citizen's Advice Bureau.



The funeral

The funeral allows you to say goodbye to the person you were caring for. It is also a chance to celebrate their life.

Funerals are often arranged quickly and it can be helpful to know what the person you are caring for wants. Talk to other friends and family about how they would like to be involved, including any children. It might be less stressful to plan the funeral in advance.

You may want to follow specific rituals that are part of your culture or faith. Explain these to hospice or hospital staff, registration officials and the funeral director.

Finding a funeral director

Talk to family, friends, your local hospice or your GP about recommending a funeral director. You will also find funeral directors listed in the telephone directory.

Most funeral directors are members of the National Association of Funeral Directors (NAFD) or the National Society of Allied and Independent Funeral Directors (SAIF). Members must conform to a Code of Practice.

You can usually view the body at the funeral director's parlour. You might want to ask the funeral director to put items in the coffin, such as photographs, flowers or a wedding ring – or you may want to do this yourself.

For guidance on carrying out the funeral yourself, contact the Cemeteries and Crematorium Department of your Local Authority. The Natural Death Centre can also give advice on organising a funeral – call 0871 288 2098 or visit www.naturaldeath.org.uk

Paying for a funeral

The cost of a 'simple' funeral includes a hearse, a coffin, removal of the body and the funeral director's fees. Other costs might include a cremation fee, minister or funeral celebrant's fee, burial plot, flowers, cars for mourners and notices in the newspaper.

- If you receive benefits or tax credits, you may be able to get a funeral payment from the Social Fund.
- Some insurance companies run schemes that allow you to pay for a funeral in advance.
- Some funeral directors allow for advance payment through monthly insurance premiums.

You can buy pre-paid plans from:

- Age Concern: 0800 731 0651 www.ageconcern.org.uk
- Help the Aged: 0800 169 1112 www.helptheaged.org.uk



After someone dies

Feelings of grief and loss affect people in different ways and for different lengths of time. There are some common patterns in the stages people go through, although not necessarily in this order – shock and disbelief, depression and apathy, expressions of grief and signs of recovery.

There is no right or wrong way to grieve. Try not to be influenced by others telling you how to feel.

Talking about your feelings

Some people find that one of the best ways to deal with these feelings is to talk about them to other people. You may want to talk to a friend or family member, or someone you know who has been in a similar position. You could talk to a faith group leader, or someone else in your local community.

You could ask your local hospice about joining a bereavement support group. Or talk to a nurse or social worker about finding help and support.

Cruse Bereavement Care Scotland specialises in helping people who are bereaved. You can get more information from their national office on 01738 44478

or visit www.crusescotland.org.uk

A number of voluntary agencies and private practitioners offer counselling. Look for a counsellor who specialises in bereavement, and meet them before making a commitment.

You can also talk to your local hospice or GP about finding a counsellor, or you can contact the British Association for Counselling and Psychotherapy on 0870 443 5252 or visit www.bacp.co.uk

Support for young people

These organisations support children and young people who are bereaved.

- Winston's Wish: 0845 2030405 / www.winstonswish.org.uk
- Cruse has a helpline and website for young people: 0808 808 1677 / www.rd4u.org.uk
- The Childhood Bereavement Network: www.childhoodbereavementnetwork.org.uk
- The Child Bereavement Trust: 01494 446648 / www.childbereavement.org.uk

National contacts

Carers

- **Carers Scotland**
CarersLine: 0808 808 7777 (Wed & Thurs: 10am-12pm & 2pm-4pm)
Website: www.carerscotland.org
- **Princess Royal Trust for Carers**
Find your nearest carers centre.
Website: www.carers.org
- **Crossroads Caring Scotland**
For practical support in the home.
Telephone: 0141 226 3793
Website: www.crossroads-scotland.co.uk
- **Help the Hospices**
Website: www.timetocare.org.uk

Young carers

- **The Princess Royal Trust for Carers**
Website: www.youngcarers.net
- **The Children's Society**
Website: www.youngcarer.com
- **Macmillan Cancer Support**
Youthline: 0808 808 0800
Website: www.macmillan.org.uk/whybother

Hospices

- **Hospice Information**
Telephone: 0870 903 3 903
Website: www.hospiceinformation.info
- **Help the Hospices:**
Website: www.helpthehospices.org.uk

- **Scottish Partnership for Palliative Care**
Website: www.palliativecarescotland.org.uk

Older people

- **Age Concern**
For free written information, or to find your local Age Concern office:
Information Line: 0800 009966
Website: www.ageconcernscotland.org.uk
- **Help the Aged**
Telephone: 020 7278 1114
Website: www.helptheaged.org.uk
- **Counsel and Care**
Advice and information for older people.
Telephone: 0845 300 7585
Email: advice@counselandcare.org.uk
Website: www.counselandcare.org.uk

Children

- **CHAS Children's Hospice Association Scotland**
Telephone: 0131 444 1900
Website: www.chas.org.uk
- **Children's Hospices UK**
Telephone: 0117 989 7820
Website: www.childhospice.org.uk
- **ACT**
Produces an information pack for the families of children with life-limiting or terminal conditions
Telephone: 0845 108 2201
Website: www.act.org.uk



- **Contact a Family**

Advice and information on issues such as benefits, medical information and support groups.
Freephone Helpline: 0808 808 3555
Website: www.cafamily.org.uk

Cancer

- **Cancerbackup**

Provides cancer information, advice and support. Freephone helpline: 0808 800 1234 (Mon-Fri; 9am-8pm)
Website: www.cancerbackup.org.uk

- **Macmillan Cancer Support:**

CancerLine: 0808 808 2020
Website: www.macmillan.org.uk

- **Maggie's Cancer Care Centres**

Website: www.maggiescentres.org

Motor neurone disease

- **Scottish Motor Neurone Disease Association**

Telephone: 0141 945 1077
Website: www.scotmnd.org.uk

Multiple sclerosis

- **Multiple Sclerosis Society**

Telephone: 0808 800 8000
Website: www.mssociety.org.uk

- **Multiple Sclerosis Society Scotland**

Telephone: 0131 335 4050
Website: www.mssocietyscotland.org.uk

Parkinson's disease

- **Parkinson's Disease Society**

Telephone: 0808 800 0303
Website: www.parkinsons.org.uk

Dementia

- **Alzheimer Scotland**

24-hour helpline: 0808 808 3000
Website: www.alzscot.org

Other useful contacts

- **Scottish Executive**

Search for 'carers'
Website: www.scotland.gov.uk

- **UK Government**

See the section 'Caring for someone'
Website: www.direct.gov.uk

- **DIPEX**

Personal experiences of health and illness.
Website: www.dipex.org.uk

- **NHS 24**

Telephone: 08454 24 24 24
Website: www.nhs24.com

- **The British Red Cross**

Services include short-term equipment loans and transport.
Website: www.redcross.org.uk

- **Samaritans**

24-hour confidential emotional support for people experiencing feelings of distress or despair
Telephone: 08457 909090
Email: jo@samaritans.org
Website: www.samaritans.org.uk

In your area

The Children's Hospice Association Scotland (CHAS) is a charity established to provide hospice services in Scotland for children with life-limiting conditions.

A children's hospice offers professional care, practical help and emotional support to the whole family, from the day they are referred until the death of their child and beyond.

No two families are the same, and CHAS has the flexibility to respond to the particular needs of mothers, fathers, brothers and sisters, as well as the extended family.

Rachel House, Scotland's first children's hospice, opened in Kinross in July 1996. Robin House in Balloch opened in August 2005. Both hospices are purpose-built and provide ongoing support for up to 200 families across Scotland each year. Since 2003, our Rachel House at Home team, based in Inverness, has provided support to children and their families in the Highlands.

Services are available to families who are caring for a child with a life-limiting or life-threatening condition.

For more information, please visit our website at www.chas.org.uk, or contact us at the address and telephone number below:

CHAS

Canal Court, 42 Craiglockhart Avenue
Edinburgh EH14 1LT
Telephone: 0131 444 1900

Hospice contact details:

Rachel House Children's Hospice

Avenue Road
Kinross
KY13 8FX
Telephone: 01577 865777

Robin House Children's Hospice

Boturich
Balloch
Alexandria
West Dunbartonshire
G83 8LX
Telephone: 01389 722055

Rachel House at Home Team

c/o Highland Hospice
1 Bishop's Road
Inverness
IV3 5SB

Help the Hospices

Help the Hospices supports over 220 local hospices across the UK. This support is provided through a wide range of services, all aimed at helping hospices provide the best care for patients and their families. These include training and grants for hospice staff and volunteers, national programmes of advice, information and support, special award programmes to fund new services and the coordination of national fundraising initiatives.

Hospice or palliative care is for those whose illness may no longer be curable. It allows them to achieve the best possible quality of life. Hospices also support families and carers. Hospice care is based on the simple idea that a person has unique physical, emotional and spiritual needs and the belief that every patient should be treated as a whole person.

Address: Hospice House,
34-44 Britannia St, London WC1X 9JG
General enquiries: 020 7520 8200
Hospice Information: 0870 903 3 903
(calls charged at national call rates)
Email: info@helpthehospices.org.uk
Website: www.helpthehospices.org.uk

Help the Hospices produced this booklet as part of the Care for the Carers of the Terminally Ill project, funded by the Tubney Charitable Trust. This project aims

to reach those people who care for a relative or friend with a terminal or life-limiting illness through the development of new information and support services.

For further information
Telephone: 020 7520 8200
Email: caring@helpthehospices.org.uk
Website: www.timetocare.org.uk

This booklet is based on information from the Caring for Carers pack, published by Help the Hospices in 2004. These organisations were particularly generous in contributing materials to the pack:

- St Christopher's Hospice, south east London
- Carers UK
- Carers Support Project, Rhondda Cynon Taff

Highland Hospice in Inverness and the Scottish Partnership for Palliative Care helped adapt the booklet for carers in Scotland.

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