

PRIAE

Policy Research Institute
ON AGEING & ETHNICITY

Palliative Care

care for life limiting illnesses

information and help
for older people

*'This book, funded by a DH Section 64 grant,
is a most practical and accessible contribution
to the care of older people at the end of life.
We welcome this.'*

**Sue Hawkett, OBE, Nursing Advisor/Team
Leader, Supportive & Palliative Care
Department of Health**

Palliative Care

care for life limiting illnesses

PALCOPE® information and help for older people

Published 2007 by PRIAE

Policy Research Institute on Ageing and Ethnicity

31-32 Park Row, 4th Floor, Leeds LS1 5JD, UK

Registered charity no 1081930 Registered company no 3898974

ISBN 0-9537642-7-3

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PALCOPE (**P**alliative **C**are, **O**lder **P**eople and **E**thnicity) @ PRIAE

is supported by the Department of Health, England.

PRIAE

PRIAE (pronounced 'preeya') is an independent registered charity working to improve pensions, employment, health, social care and housing, and quality of life for black and minority ethnic older people in the UK and across Europe. The Institute aims to influence national and European policy and increase and encourage good practice in work with black and minority ethnic elders. PRIAE does this through creating and leading on often 'first of its kind projects' in research, information, service developments, training and consultancy. In health, PRIAE currently specialises in the areas of health inequalities, mental health, active ageing, long-term conditions, dignity, professional and quality care, organ donation, health and housing care, minority organisations and mainstream services and palliative care.

PRIAE operates in the UK and across Europe, generating its own funding. PRIAE was founded in 1998 and is managed by Professor Naina Patel, OBE, Executive Director and Kalyani Gandhi, Managing Director with specialist staff and consultants, supported by the Board of Trustees and its Patron, Dr Chai Patel, CBE, FRCP.

You can find out more about PRIAE at www.priae.org

PRIAE is committed to improving the quality of our publications. If you have any comments on this booklet please contact

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Designed and printed by Upstream (a workers' cooperative) www.upstream.coop

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Foreword

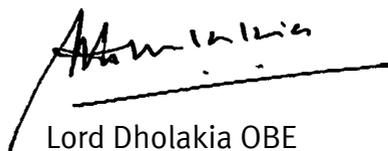
This book has been written after listening to the real life stories of elders and carers who told their stories to the PALCOPE (Palliative Care Older People and Ethnicity) project team. There is growing evidence to show that services need to do more to meet the needs of older people. Many elders, and particularly those from minority ethnic groups, live with complex health problems and disabilities and are on low incomes.

While older people in general can face difficulties in accessing palliative care, it has been encouraging to learn from the PALCOPE project that minority ethnic elders have been able to benefit from palliative care. We have also seen at first hand what a difference good quality palliative care can make - whether patients are being cared for at home or in a hospital, hospice or care home. It can mean that pain and other distressing symptoms of an illness can be controlled and support can be provided to help with emotional and practical problems. This care for the 'whole person' is a central aim in palliative care.

We thank the Department of Health for supporting PRIAE in its work on palliative care and minority ethnic elders. It became clear when the PALCOPE project began that few comparable examples of clear information on palliative care for older people could be found. In keeping with PRIAE's mission to benefit elders from both minority and majority ethnic backgrounds, we hope that this book will benefit all elders and carers to access the support and care that they need.



Lord Herman Ouseley
Chair of PRIAE



Lord Dholakia OBE
Vice Chair of PRIAE

About ‘Stories That Matter’ and this book

‘Stories That Matter’ is part of the project PALCOPE (Palliative Care Older People and Ethnicity) that is managed by PRIAE, the Policy Research Institute on Ageing and Ethnicity and has been supported by the Department of Health.

The PALCOPE project has two main aims:

- to increase awareness of palliative care services amongst older people from different ethnic and cultural backgrounds
- to increase the awareness of those working in palliative care about the needs of older people, particularly those from different ethnic and cultural backgrounds

As a part of its work, PALCOPE has been listening to and recording the stories of older people and carers who have been affected by life-limiting illnesses. We have also collected the stories of palliative care professionals about their experiences of caring for older people. These stories, together with information from other research projects in this area, have been used in this book.

This book has been written with particular reference to:

- National Service Framework for Older People (2001), Department of Health
- A New Ambition for Old Age (2006), Department of Health
- Guidance on Cancer Services, Improving Supportive and Palliative Care for Adults with Cancer (2004). National Institute for Health and Clinical Excellence.

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Revised and additional text: Neera Deepak, Consultant

The PALCOPE project was directed as part of PRIAE's health specialism under Professor Naina Patel OBE, PRIAE's director and Professor in Ageing and Ethnicity at the Centre for Ethnicity & Health, University of Central Lancashire. The project originated from PRIAE's 'Hospital Care and Dignity' project undertaken by Nirmalya Bandopadhyay.

The PALCOPE project has informed PRIAE's work in Scotland under its SCEES Project (Securing Care for Ethnic Minority Elders in Scotland) undertaken by Carrie Ho.

This publication is the third in PRIAE's PALCOPE series (see www.priae.org)

Acknowledgements

Several people have contributed their time to help produce this book. Special thanks go to the palliative care service users, carers and professionals who agreed to share their stories with us. Catherine Weir, Pete Southern, Teri Sangha-Tiwana, Wali Nazar, Jazz Kang, David Oliviere, Mark Faulkner, Nigel Clark and PRIAE staff particularly Sunjeeda Hanif gave generous amounts of time to the project. Yasmin Gunaratnam (PALCOPE Project Manager at PRIAE) and Neera Deepak conducted the interviews for the project.

Members of the Advisory Group guided the project: David Oliviere - Director of Education, St Christopher's Hospice, Eve Richardson - Chief Executive, National Council for Palliative Care, Nirban Chowdhury - Social Action for Health, Lord Michael Chan, Jackie Beavan - Proceed Project, Birmingham University, Peter Southern - Bart's Hospital Social Work, Wali Nazar - Bradford Community Palliative Care Team, Hafizur Rahman - Patient Representative.

The Department of Health funded this project and our special thanks go to Segun Akintunde and colleagues.

Grateful acknowledgement is made to the following sources for permission to reproduce material within this book:

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Palliative Care - what is it?

‘If there are services like this what is illness?

A person can tackle the most difficult thing.’

(Mohammed, talking about palliative care services)

This book provides information about palliative care. It uses the stories of older people and carers who have been affected by a life-limiting illness (sometimes called a ‘terminal illness’) to discuss some of the situations that you may face. You may not want to read the whole book yourself. However, you may find it useful to give it to family members or friends so that they can find out more about palliative care and about how they can best support you.

What is palliative care?

World Health Organisation Definition of Palliative Care (2002)

‘...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

Palliative care is the care provided to people with a life-limiting illness that will not get better. Such illnesses can include cancer, motor neurone disease, chronic obstructive pulmonary disease, dementia, HIV/AIDS or advanced heart and lung disease. Palliative care can be provided in hospitals, hospices, in your own home and in care homes. You do not have to pay for palliative care.

Palliative care includes:

- Pain and symptom control
- Support with financial and practical matters
- Help with emotional and spiritual issues
- Care for family and friends
- Help with relationships
- Recognition and respect for your cultural, spiritual and religious beliefs

Palliative Care can be given during treatments such as chemotherapy

Picture reproduced with kind permission from David Wendell Moller, Dancing with Broken Bones: Portraits of Death and Dying Among Inner-City Poor, Oxford: Oxford University Press, 2002



Examples of palliative care are:

- The assessment of your needs by different professionals working together. This includes providing treatment and medication to keep your pain and symptoms under control, as well attention to your emotional needs
- Having physiotherapy to relieve pain, lessen tiredness and/or to help with the symptoms of an illness such as breathlessness
- Being listened to and supported by professionals to help you to cope with feelings such as fear, anxiety, sadness or anger
- Going to a day centre where you can take part in activities (e.g. painting or pottery) and where you can meet and talk to other people
- Help, advice and equipment to make your home more comfortable and safe
- Advice and support with claiming money (“benefits”) for you and/or your carer

When and how you get palliative care will depend upon the type of illness you have, how it affects you, and the services that are available where you live. Quite often a person will receive palliative care in a number of different places, such as a hospital, a hospice, and in their own home (see chapters 3, 4 and 5).

Playing your part in getting good care

All health and social care services are working hard to make sure that older people and their carers receive a high quality of care. This work is guided by the Government's 'National Service Framework for Older People' produced in 2001, which aims to ensure that older people are always treated with 'respect, dignity and fairness'. The National Institute for Health and Clinical Excellence (NICE) have also produced guidelines on palliative care for people with cancer. The guidelines aim to make sure that all patients with cancer get a good quality of palliative care, that they are listened to and are involved in decisions about their care.

Guidelines from the National Institute for Health and Clinical Excellence (NICE)

The NICE guidelines are called 'Guidance on Cancer Services: improving supportive and palliative care for adults with cancer'. There are two versions of the guidelines: a full version and a shorter one that has been written for the public. Both are available from the NICE website at www.nice.org.uk or you can get a free copy of the NICE guidelines by telephoning: 0870 1555 455 and quoting the reference number: No474 for the fuller version, No476 for the shorter version.

While services are trying to improve the ways in which they care for older people, you can also play a part in getting good care. Although it is not always easy, you can often get what you need, but you have to be prepared to tell professionals about what you would like and what is important to you.

Get the palliative care that you need

- Ask for information about palliative care from your doctor and nurses
- Gather as much information as you can about your illness and the services and support that you are entitled to
- Ask questions. Take someone with you when you have appointments to help you remember what was said
- Ask for an interpreter if English is not your preferred language. Make sure that you tell health care professionals about any religious or cultural issues that are important to you
- Don't suffer in silence. Tell your doctor or nurse if you have any pain or if your medication is not controlling your pain
- Tell those who are caring for you if you are unhappy with any aspects of your care

‘And then he told me’...

Finding out that something is wrong

‘Well one day I went to pass water and it didn’t come as freely as it used to do. So the next day I went to my GP and told him about it. He told me he would have to send me to the hospital... So I went to hospital and I had the operation and they said that I had a tumour and I had to wait a week for the result and then the consultant came and told me ‘I’m afraid I’ve got bad news for you’. He said ‘Well, they found a growth and they tested it and I’m afraid it’s malignant, which is cancer’. I said ‘I don’t smoke. I don’t drink. How come?’ He told me ‘Well, I don’t know, it comes in all sorts of forms’. (Frank)

Frank, was 72 when he found out that he had cancer of the prostate (a gland surrounding the neck of the bladder). The first place that Frank went to when he noticed that something was wrong was to his General Practitioner (‘GP’). Frank’s GP examined him and acted quickly by arranging for him to see another doctor at the hospital who had more specialist knowledge in dealing with problems of the prostate. At the hospital, after further examinations and tests, Frank was operated on and the growth in his prostate was found to be cancerous. It was the hospital consultant who first told Frank that he had cancer.

Frank was fortunate that his doctors were able to find out what was wrong with him (this is called making a ‘diagnosis’) quite soon after he had noticed changes in his body. This is not always the

case and some older people have felt that their symptoms have not been taken seriously by doctors. Although some diseases, such as some cancers, can be difficult to diagnose, it is important that you feel that your doctor is taking what you say seriously. As one carer said ‘The most important thing is that if a patient goes to see their doctor, the doctor should pay attention to the patient and try to understand what the patient is trying to say’. If you feel unhappy with your GP, you can ask to see another doctor in the same practice or you can change to a new doctor/practice.

Treatment – questions you can ask

It is important that you are able play a part in choices that are made about your care and treatment. Asking your doctor some of the following questions may help you to become more involved in your care:

- What are the different treatments that can help me?
- Are there any side effects of the treatment? Is there anything that you can do to help me cope with the side effects?
- Do any of the treatments include ingredients that go against my religious beliefs, and if so, can you offer me any other treatments?
- Will I need to stay in hospital for the treatment, and if so, for how long?
- Will I need to have someone to look after me at home, if I am having a treatment?

Planning Ahead - ‘Living Wills’

A living will or an ‘advance directive’ is a written statement in which you can record any of your decisions about which treatments you would like/would not like to have. This statement will help doctors and your family to know what your wishes are should you become too ill to tell them. You can get more information about living wills from the website www.endoflifeissues.org.uk

The cost of treatment and older people

You may be worried that because of your age, you will not be offered the best or most expensive treatments. This would be discriminating against you because of your age and it should never happen. However, some treatments such as some forms of chemotherapy can produce more side-effects in older people. Some forms of surgery can also be more risky because of other health conditions an older person may have. Doctors need to take such factors into account when deciding about the best treatment for you. If a doctor tells you that a particular treatment is not suitable for you, you should be given a reason as to why this is the case. Most doctors will be happy to explain their choice of treatment. It is important to remember that you can ask for a second opinion from another doctor. Your doctor can arrange for you to have this.

Difficulties in communicating

Hearing difficulties, difficulties with eyesight and with remembering

If you have hearing, eyesight or memory difficulties you should always tell the professionals that you meet. You should also ask for this information to be written in your medical records.

If you have hearing problems and/or problems with your memory you can also:

- Ask for spoken information to be given to you slowly and/or ask for it to be repeated or written down
- Take a friend or relative with you when you have an appointment
- If you do not have anyone that you can ask to be with you, or you prefer not to ask people that you know, you can ask your doctor or nurse to put you in touch with an advocate. An advocate is a person who can help you when you are talking to professionals. They are there to support you and to make sure that your needs are understood (more information on advocates is included below)

If you have difficulties with your eyesight, you can ask whether any of the information leaflets and forms are available in large print or in Braille. Sometimes information is available on audio cassettes or CDs that you can listen to. You can also ask that any written information is read out to you and you may want to take a recorder to appointments/meetings so that you can record the conversation and listen to it again if you need to.

‘What if I don’t speak English?’

Palliative care services are doing more to meet the needs of people who do not speak English. More services now provide interpreters and sometimes advocates (also called ‘cultural link’/‘liaison’ or ‘support’ workers) for people who do not speak English. Interpreters and advocates are trained professionals and have to keep what they interpret private (‘confidential’), so you don’t have to worry that they will tell anyone else about what you have said. Although you may have a family member or a friend who can interpret for you, many older people find that using a trained interpreter can be important because:

- it can be easier to talk openly and to ask questions about an illness when the person interpreting is not someone who is close to you
- family/friends do not always interpret all of the information that is given to an older person because they do not want to upset them. An interpreter will make sure that they interpret all the information that is given to you and they will do it sensitively

You should be involved in discussions about your illness, care and treatments, whether you speak English or not. Don’t be afraid to ask for an interpreter or an advocate if you are not offered one.

Advocates

An advocate is much more than someone who speaks a patient’s language and who can act as an interpreter. An advocate is someone who:

- can be in regular contact with a patient/carer throughout an illness
- will listen and make sure that the views of the patient/carer are communicated to professionals
- will tell the patient/carer about any other services or support that can help them

An Advocate talks about her job

‘I see my role of an advocate/link worker as being one in which I am able to help members of the Asian community. The role is not just about interpreting and translating what is being said between the patient and health professionals. It is also about really making sure that the patient has all the information they need and is confident enough to challenge/ask questions if they are not happy. By providing people with culturally appropriate knowledge and information on services that are available I would like to think that people are then in a position to make more informed choices about services and treatments that are available to them.

Being a part of a multi-disciplinary team I am surrounded by a team of experts from Macmillan nurses to occupational therapists, social workers and a clinical psychologist. This allows me to access services and respond to questions rapidly, without hunting around too much.

The patients and families I have worked with are finding my role as an advocate very helpful and are happy to be referred to me. The help/advice they need can include medical, financial and emotional matters. Some families are just relieved to have me there to interpret and translate for them.’

Money when you are ill

If you are ill, you and the main person who is looking after you, (your 'carer'), may be able to get money from the Government ('benefits') and from some charities. The charity Macmillan Cancer Support has found that many people who are diagnosed with a terminal cancer are not claiming the money they are entitled to. A free information guide 'Help with the Cost of Cancer' that has details of the practical and financial help you may be entitled to is available from Macmillan (Telephone: 0800 500 800).

Whether you will be able to get any benefits depends upon a number of different factors, such as your age, the length of time you have been ill and your National Insurance contributions. The amount of money that you get from some benefits will also depend upon your own and your family's income and savings (these benefits are 'means tested').

Special rules can apply to some benefits if you have a life-limiting illness. For example, claims for Disability Living Allowance and Attendance Allowance will be looked at more quickly by the Benefits Agency - the Government department that is responsible for benefits.

You can get information and advice about benefits and help with filling out forms from a social worker. You can also get free advice and information about benefits from the following:

- your local Citizens Advice Bureau and Benefits Agency office (the contact details will be in your local telephone directory)
- Help The Aged - Telephone: 0808 8006565 (or 0808 800 7575 for Northern Ireland)
- Macmillan CancerLine on 0808 808 2020
- Benefits Enquiry Line: 0800 882200.

Information is also available from the Department for Work and Pensions website at www.dwp.gov.uk

Asking difficult questions - openness, honesty and talking about it

2

In Frank's story in Chapter 1, you may have noticed that when Frank was first told about his cancer, he had several questions that he wanted to ask the doctor. For example, he could not understand how he had cancer because he did not smoke or drink. By asking questions Frank was able to understand more about his cancer and what it meant to his life.

The advice from palliative care professionals is that if you have not understood what has been said, or you feel that your questions have not been answered, then you should ask your questions as many times as you need to. You can also ask to see the doctor again, and you can ask if there is anyone else that you can talk to - such as a nurse, a social worker or a chaplain.

Why me?

'The Cloud of Unknowing' painted by a person with cancer

Reproduced with kind permission from Camilla Connell, 'Something Understood - Art Therapy in Cancer Care', London: Wrexham Publications, 1998.



People often ask the questions ‘How come?’ or ‘Why me?’ at some point in their illness. These are difficult and sometimes impossible questions for doctors and nurses to answer because they can relate to personal, cultural and/or religious beliefs rather than to medical matters. For instance, some people can feel that their illness is a result of doing something wrong in their lives. Others may try to find a meaning in their illness. In these situations many people find it valuable to talk to a chaplain or a counsellor. Chaplains are ministers or other spiritual caregivers who work in institutions such as hospitals or colleges.

Most hospitals and hospices have chaplains from different religious and cultural backgrounds who you can talk to or get advice and guidance about religious or spiritual issues. Chaplains can also be of great help to those who are not religious. They are good at listening and will not try to force their religious views and beliefs onto you.

In palliative care spiritual support is provided to people from all cultural and religious backgrounds

Picture reprinted with the kind permission of North London Hospice.



‘Will they tell me everything I need to know?’

It is not unusual for some families to ask doctors not to tell an older person about their illness because they want to try and protect them. Some carers have felt that knowing about an illness might

make the illness worse, or could lead more quickly to the death of their loved one. There is no medical evidence to suggest that this is the case. In fact, research has found that most people with serious illnesses such as cancer want to be given detailed information about their illness.

Knowing about an illness can help a person to make their own decisions about their treatment and care. It can also help them to understand more about what is happening to them and so help them, and those close to them, to cope better with their illness and to prepare for the future.

‘We don’t lie...but neither do we give information they are not looking for’

Doctors and nurses working in palliative care generally agree that it is much better for everyone if the person who is ill knows about their illness. Professionals will not lie to a patient if the patient asks them direct questions about their illness. However, as one hospice nurse pointed out, professionals will never force information about an illness onto patients or carers, she said: ‘What we say to all people is that we won’t lie. But neither do we give people the information they are not looking for, and some people live and die, not knowing, or we presume they don’t know’.

It is of course up to you (or sometimes your family) to decide what information you want about your illness. However, you and your family do not have to make such decisions alone. You will be able to talk about your fears or anxieties about your illness with your doctors, nurses and any other professionals who are caring for you. They will be able to support all of you as you make decisions about what is best for you.

‘Do I have to talk about it?’

Some older people do not want to talk to any professionals, but find it easier to talk to other patients and carers or to be around other people who are in similar situations, without talking about themselves or how they feel. This is why some people find it very valuable to go to hospice day centres, cancer support centres or support groups for people with a particular disease such as motor neurone disease, heart failure or cancer. Your doctor, nurse or social worker will be able to give you details about local and national support groups.

Palliative care at home

3 |



*'In the House of my Father' - Donald Rodney
Reproduced with kind permission of the Estate of Donald Rodney*

Although most people die in hospitals or hospices, people with life-limiting and chronic illnesses spend most of their time being looked after at home. It is important to remember that if you want to be cared for at home then you and your family are entitled to professional medical, nursing and social care. This care is usually co-ordinated by your GP and/or district nurse, but it could also be managed by a hospice home care nurse, a social worker or another professional (often called a 'keyworker'). This chapter will look at the support that you can get in your own home and also in care homes for older people.

A District Nurse Answers Questions

What do district nurses do?

'I provide a wide range of care that includes nursing care such as carrying out a full assessment of your needs, caring for any wound dressings and helping to keep your pain and symptoms under control. I can also help you with finding equipment that will help you and/or those looking after you at home, such as a special mattress to stop you getting pressure sores. I am also here to listen to you and to those close to you'.

How can I make the most of your help?

You can make the most of me by:

- Remembering that you can tell me anything - if I don't know how to help you I'll find out or I can put you in touch with others who can help you
- Phoning me if you are worried about anything in between the times that I visit you
- Telling me when you are in pain

Please don't:

- Worry if what you are thinking or feeling sounds unimportant or strange. Any questions that you can't ask anyone else - ask me.
- Worry if you have the chance to go out when I have arranged a visit. Let me know and I will be happy to come back at another time

Other professionals who can help you in your home are:

- **Occupational Therapists** - usually make one visit to your home to see what equipment you need to help with your daily life. This equipment can include cushions, hoists (equipment to help lift people), showers, ramps, stair rails and stair lifts. Occupational

therapists can also help you with making changes to your home - such as giving you advice on how to make a bedroom downstairs so that you don't have to use stairs. The best way to get through to an Occupational Therapist is through your doctor or local social services department.

- **Social Workers** – can provide practical advice and work with you (and your carer) to identify your needs (this is called an 'assessment'). Social workers can arrange for you to have help in the home and they are trained in dealing with emotions and relationships. Some social workers also work with children to help them to cope with illness or death in a family. Social workers can work for your local council, or in hospitals or hospices. If you have not been told about a social worker then ask your GP, district nurse or staff at a hospital or hospice.

Care Plan

When you and your keyworker have decided about the care and support that is best for you and your carers this will be written in a 'care plan' and you will be given a copy of it. A care plan can also include the decisions that you make about your preferences for where you want to be cared for and the treatments and medical care you want/don't want. Many older people have found that thinking about and planning what they want and how they would like to be cared for can improve their experiences at home and can also help their family/friends. However, these can also be difficult matters to think about, so it is important to take your time and to find out about the different choices that you have.

Carer's needs

Under The Carer's (Equal Opportunities) Act 2004, carers can ask for an assessment of their own needs by social services. These needs will be taken into account when social services decide what services you will get at home. You can get a carer's assessment

even if the person that you are caring for refuses help or refuses an assessment of their own needs.

Under The Carer's (Equal Opportunities) Act 2004:

- councils should tell carers about their rights, and the help and benefits that they are entitled to
- councils should provide advice to carers about their own life outside of their caring role

The organisation Help the Hospices (their address is given in Chapter 7) provide an excellent guide called 'The Carer's Guide' for carers of people with a life-limiting illness. If you have a computer and access to the internet you can download the information for free at www.helpthehospices.org.uk. Your hospice or local library may also be able to help you to get you a copy of the guide.

The Carer's Guide suggests that before an assessment the carer and the person they care for should make a list of everything they do as a carer. From this list you can then see what services/support could help you. For example, you might need:

- help with washing the person who is ill
- meals made and/or delivered for the sick person
- more time to sleep
- time for yourself
- to be put in touch with other carers

It is important to remember that:

- any services that are provided should be at times that suit you
- you do not have to accept all of the services that are offered to you
- because illnesses get worse - sometimes very quickly - a carer can ask for another assessment of their needs if more help is needed

‘What happens if I get worse?’

If your pain or symptoms get worse when you are at home, your GP and/or district nurse may decide that you need short-term, more specialist care in a hospital or a hospice to get your pain and symptoms under control. At other times you may benefit from more specialist care at home. The main specialists that can help you at home are:

Palliative Care Nurses - These nurses are sometimes called ‘Macmillan Nurses’, ‘Clinical Nurse Specialists’ or hospice home care nurses and they have had specialist training in the care of people with cancer and with other life limiting conditions. Palliative care nurses work as part of a team that includes specialist palliative care doctors and they come with expert knowledge and support about pain and symptom control.

Specialist in Palliative Care/Hospice Doctors - Palliative care doctors work in either hospitals or hospices. They are sometimes asked to visit you by your GP so that they can help and advise your GP on how best to manage any difficult symptoms or pain. A doctor who specialises in the care of older people (a ‘geriatrician’) may be useful in helping to sort out some of the particular problems that older people can experience when they are ill.

Night Nurses - There are nurses available in some areas that will look after you at night. Some district nurses are available during the night, there are also other ‘night nurses’ who are usually funded by charities, the most well known are called ‘Marie-Curie’ nurses. Your district nurse will be able to tell you whether there are night-nurses available in your area and they will be able to arrange this care for you.

Home Care Helpers/Assistants - These workers can help you with everyday tasks around the home such as cleaning the house and

doing the shopping or laundry. Some home care workers will help you wash and dress or will cook you a simple meal.

Palliative care in care homes for older people

As people are getting older and there are less family members who are willing or able to care for them in their own homes, more older people are spending the last part of their lives in care homes. Care homes are managed by local councils or by the health authority, but many more are now being run by private companies.

What's the difference between care homes?

A care home (personal care) - provides care such as help with getting dressed or having a bath for people who can live fairly independently.

A care home (nursing) - provides 'nursing care' which means that a registered nurse must be on duty at all times.

Palliative care in homes that provide nursing

Because nursing care is provided in nursing homes, the care you get when you have a life limiting illness will be provided mainly by staff in the home with the advice and support of your GP and district nurse. Specialist palliative care nurses can also visit people in care homes and they are very good at being able to work with staff in the homes to make sure that you get a good standard of palliative care.

In some cases where older people have been diagnosed with a life-limiting illness and they cannot look after themselves, or their family/friends are not able to look after them, they can be moved into a nursing home. Social workers are the best people to help and advise you about nursing home care, but your GP and district nurse may also be able to help.

The organisation 'Help The Aged' has a good leaflet on nursing home care, and you can also call their free advice line 'Seniorline' (Tel: 0808 800 6565 or 0808 8007575 for Northern Ireland) for advice about care homes. You can get information about finding a nursing home on the Nursing Home Fees Agency website at www.nhfa.co.uk

Palliative Care in a home providing personal care (a 'residential home')

If you become ill when you are in a residential home then you will be cared for by your GP and your district nurses in much the same way as if you were at home. If your illness gets worse, then you and the staff at the home will have to make a decision about whether you stay in the home. It is a good idea to think about where you would like to be cared for quite early on in your illness so that you can talk about this with the care staff and make any plans.

If there are any problems in controlling your pain or your symptoms then your GP may want to move you into a hospital, a hospice or a nursing home. You do not have to wait for your doctor to make this decision. You can talk to your GP or a district nurse if you feel that you need more specialist care.

Palliative care in a hospital

4

The palliative care that is available in hospitals can vary throughout the country, but many hospitals have **palliative care nurses** (often called **Macmillan nurses** or **Clinical Nurse Specialists**) or a **palliative care team**. A palliative care team can include nurses, doctors, social workers, psychologists, occupational therapists and physiotherapists.

There are now nearly 300 hospital palliative care teams and nurses throughout the UK. These teams and nurses work across different wards in a hospital and they can also see patients in out-patient clinics. Hospital palliative care professionals work closely with hospital staff, providing them with advice and information about care for people with life-limiting illnesses. They are able to spend time with patients and carers, getting to know them and keeping in regular contact with them when they are under the care of the hospital.

How to contact hospital palliative care professionals

There are three main ways that you can contact palliative care professionals - if there are any at a hospital:

- You or your carer can contact the palliative care team/nurses yourselves (ask the doctor or nurses on the ward for their contact details)
- You can ask your doctor or nurses on the ward to contact them for you
- Your interpreter or advocate can contact them on your behalf

Care when you leave hospital

Hospital social workers play an important role in putting you in touch with local services when you leave hospital and in making sure that you are aware about any benefits (money) or services that you are entitled to.

A palliative care social worker answers questions

What do palliative care social workers do?

‘I work in a hospital that has a specialist cancer centre. I see patients and their families if they are in hospital and also when they come here for outpatient treatment or to clinics. I keep in touch with people by phone when they are at home. I work with the hospital’s palliative care nurses and doctors’.

Palliative care social workers also work in hospices and in the community and can see people in their homes.

What help and support can you give me?

‘One of the ways that I can help is to talk with you about what sort of help you might need when you leave hospital. Sometimes people will need to go to a nursing home or to a hospice and I can help to describe these places and make arrangements for you when they are necessary. If you have financial worries or questions about what social security benefits you may be able to get, then I can talk to you and give you information. I can also listen and help you with any worries that you might have about yourself or the people that are close to you.’

How will I be able to find a social worker?

Any health professional (e.g. a GP, hospital doctor or nurse) can refer you to a social work department. If you are in hospital tell the nurses on the ward that you would like to see a social worker. You, or someone acting on your behalf, can contact the social work department and ask to see a social worker.

How can I make the most of your help?

You can make the most of me by:

- asking me to explain how I can help you
- telling me about your worries and concerns as well as the positive things in your life
- keeping in touch with me when you are at home
- expecting me to listen carefully and to respect your views and cultural beliefs
- telling me if there are any things that could improve your situation
- telling me if you don't understand or if you would like me to write things down

Please don't:

- Feel that you are wasting my time or that your questions are not important
- Think that you have talk to me if you don't feel like talking

Palliative care in a hospice

5



Picture reprinted with kind permission of North London Hospice.

There are over 200 hospices and ‘palliative care units’ (specialised units in some hospitals that are similar to hospices) in the UK. These services are recognised as providing the best quality of specialist palliative care. Hospices can provide such excellent care because they limit the numbers of patients that they care for and because they make sure that their staff are highly trained and well supported.

Do hospices help you to die more quickly?

Many patients and carers ask this question. The simple answer is ‘no’. Hospices neither help nor make people die more quickly. Intentionally bringing about the death of a patient or allowing a patient to die for the patient’s own sake is called ‘euthanasia’ and it is illegal in the UK. In British law, treatments that could possibly make people die more quickly can only be allowed if the treatment meets the following criteria:

- i. The patient must be terminally ill (so that the illness and not the treatment is the cause of death)
- ii. The treatment must be ‘right and proper’, that is, it must be accepted as good practice by a responsible body of medical opinion
- iii. The intention of giving the treatment must be to relieve suffering

Why choose hospice care?

Some of the advantages of hospice care are that:

- Hospices specialise in palliative care. Their doctors and nurses will be able to provide expert pain and symptom control and will be more able to manage any difficult pain or symptoms
- Hospice staff often have a smaller number of patients to care for than hospital staff, this means that you and your family may get more time with hospice staff
- You may have more easy access to some ‘complementary’ therapies such as aromatherapy (massage with oils) or reflexology (massage of pressure points in the feet and hands)

Do you have to be Christian to go to a hospice?

You do not have to be a Christian or religious to go to a hospice. The service 'Hospice Information' says that:

'Hospice and palliative care services try to meet the needs of people from all cultures and religions and of those with no faith at all. Although it is true that many hospices may have a Christian foundation, patients and staff are from any faith or none'

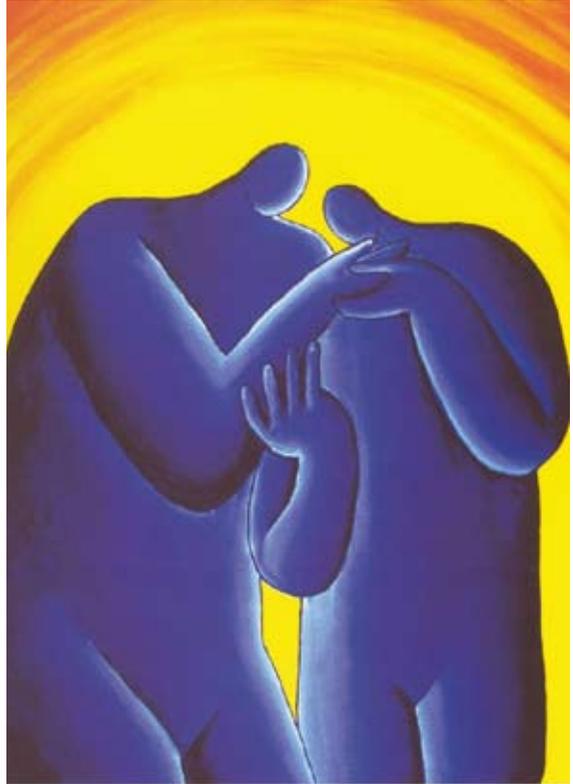
An important consideration in your choice about hospice care is how you and your family will feel about being in a place where all of the patients have a life-limiting illness. Some people prefer not to be with other people who are very ill or who are dying and in hospices death can also be more visible than in a hospital. While this can be upsetting for some patients and their families, others can find it reassuring to see people die without pain or distress. As one woman interviewed for a hospice video put it: - 'I want to go off peacefully like that old lady over there'. You may feel differently, so it is important to think carefully about how you and your family would feel in a hospice where death and dying can be more present and more open.

Feelings, Bodies and Relationships

6 |

*'So much love' -
Michele Angelo Petrone*

*Reproduced with kind
permission from Michele Angelo
Petrone, So Much Love from
'The Emotional Cancer Journey',
London: MAP Foundation, 2003*



There are many different ways in which your illness can affect you and those close to you. There may be times when fears come to the surface. Times when you will learn new things about yourself and your relationships, and when you will think about the past and the future. This chapter will look at some of the emotional and physical experiences of older people from different ethnic and cultural backgrounds who have had life limiting illnesses. It will also look at some of the help and support that is available.

Your body, you and close relationships

Illness and treatment can affect how you see your body and how you feel about yourself. Your age, whether you are a man or a woman, whether you have come from a family with money or not, and the opportunities that you have had throughout your life can also make a difference to how you respond to your illness and your body.

Marjorie, an older woman with breast cancer had worked as a cleaner in a hospital and being independent was important to her. She found it difficult to ask for help, even from her children. Marjorie had chosen not to have the cancer in her breast operated on. Marjorie's nurses worked hard to try and get to know Marjorie and to make her as comfortable as possible. Yet, in the end Marjorie coped with her illness and the changes in her body in her own way. She did not want to talk about her cancer or her body. She became more silent, turning increasingly inwards and distancing herself from the cancer and from other people.

The way that Marjorie coped with the changes in her body was very different to a younger woman, Patricia, who had been a nurse. Patricia, who was in her early 40s had had a mechanical valve put into her throat to help her speak after a cancerous tumour was removed from her throat. In addition to losing her voice, she also had to get used to learning to speak with the valve, which gave her a deep robotic sounding voice that made her sound like a man. Whenever Patricia came into a room and started talking, people who did not know her would turn and stare. Unlike Marjorie, Patricia was able to talk about her feelings and her body, but there also came a point when she felt that she had to 'bond' with her new voice and accept her new self and her disability. She said:

'It was learning to live with my disabilities. Learning to cope with not having a voice and just being brave enough to go out

sounding like a man and getting over that and being brave and strong and looking people in the eye and thinking ‘You’re going to cope with me. I’ve got a problem, but I’m going to cope with my problem. You’ve got to listen to me’ and being brave and normal and making people deal with you as a normal person.’

These are some of the very different ways in which people can cope with the changes and losses that happen to their bodies. However, it is important to remember that some problems can be overcome with the help of professionals. Professionals can support you by listening to your feelings and by helping you to find different ways in which you might come to value your body and yourself again. They will also be able to help by giving you practical advice about how to deal with physical problems. Herman, who had cancer of the prostate, found that the support that he was given by his doctor after he had surgery and chemotherapy made a big difference to his recovery:

‘The radical surgery meant, and I was told this by the doctors, that I would have trouble from a sexual point of view and I would have discomfort passing water for a little while. Everything went just as the doctor said it would, but he also said that I shouldn’t give up because there is after-care that might help me in that respect. Now, this was told to my wife as well, because she was with me, the doctor was extremely kind and helpful and always has been so, even now. If I have any problems, all I need to do is go to the clinic and there is someone there that I can see’.

In many cases there may be simple solutions to the problems that you might face because of your illness and its treatment. For instance, some problems with sexual relationships can be made better by prescription creams or medicines that your doctor can advise you about. In other cases you may have to make changes to your relationship and find new ways of expressing desire, love and affection.

You may feel more able to talk about these problems, or more general problems about how you feel about your body on the telephone. Many of the free, confidential ‘helplines’ listed in next chapter will be able to help you. Cancerbackup have produced some very helpful information on the subject of bodily changes and relationships. The book ‘Sexuality and Cancer’, presently only available in English, is free to patients and carers (Telephone: 020 7696 9003).

Your body and care

Your religious and cultural beliefs and what has happened to you in the past can also affect how you feel about your body and about the physical care that you receive when you are ill. In palliative care, professionals try to understand how your beliefs and life experiences may affect your body and your care. However, it is always best if you talk to the professionals who are caring for you and tell them about what is important to you or how you are feeling. For example, nurses will not take all of your clothes off when they are changing your clothes or when they are washing you if you are not comfortable being undressed in front of other people. Many patients can also dislike being touched, lifted or examined by professionals because their bodies have been through so much during their illness and treatment. Palliative care professionals understand these feelings and they can often find ways to make you feel more comfortable. For instance, some palliative care services use massage to build up trust with patients and to reintroduce people to touch as a pleasurable rather than a painful or disturbing experience. Artwork, writing and music are also used in palliative care to help patients express themselves in different ways.

*Art can be a way of
expressing yourself*

*Picture reprinted with the kind
permission of North London
Hospice*



Looking back

When an older person is ill, they can often find themselves looking back over their life and trying to make sense of it. For older people from different ethnic and cultural backgrounds this can bring up many different memories: what it was like when they first settled in a new country, family relationships, work and friendships. Thinking back over your life can be a way of working through feelings of loss and grief, searching for meaning and preparing for what lies ahead. It can feel important to talk about your memories with your family and friends as a way of spending precious time together.

Older people who have not been born in this country can be a very real link to other cultures for younger generations. They can provide connections to another language, to cultural and religious traditions and knowledge, to family stories and history. There are many different ways to share these connections with others. For instance, some older people have found themselves going through their old photographs and talking about them with those they love. Sometimes this can also be done with the things that are important to you such as jewellery or other items that have been passed down through the family. Some older people have chosen to write their life stories, either by themselves or with the help of a writing group at hospices, day centres or support groups. Others have written letters, recipes, made recordings of stories or have filmed

themselves as a way of having something that feels more lasting that they can pass on to others.

Saying sorry

Sometimes when people are ill they think about and remember painful experiences from the past. Many people can feel regret about things that they have done or said and it can feel important to say sorry to the people that you have hurt before an illness gets worse.

Darcus Howe, the Trinidadian writer and broadcaster has talked on national radio about his childhood and the severe beatings that he got from both his mother and father when he was growing up. When Darcus's father was dying, he tried to say sorry to his son, but Darcus said that he could not forgive his father and could only reply 'Is that so?' when his father said sorry. It was not possible, even in death, for Darcus and his father to let go of the past and this was clearly a painful experience for both of them. However, they were still able to come together at this important time and to face the past before Darcus's father died.

If you are in a similar situation, where you have tried and 'failed', or perhaps you feel you are not even able to try to heal past hurts, then you should try talking about what has happened to the professionals who are caring for you. This may not only help you, but it can also help professionals to think about and plan the care and the support that they give you. Sometimes social workers or counsellors can help to organise family discussions where they will help you talk to and listen to your family. By knowing more about you and your life, professionals can also be more sensitive to the ways that past experiences might affect you, your relationships and your care in the present.

Counsellors:

Where they work: In hospitals, hospices and in voluntary/ community organisations

How you can find a counsellor: You can be put in touch with a counsellor by your GP, hospital doctors and nurses, your district nurse or a social worker

Help they can give you:

- Emotional support in dealing with how your illness affects you, your relationships and those close to you
- Support for depression, anxiety and feelings of panic
- Support with sexual difficulties
- Support for your partner, your family and your friends

You can get information about counselling services in your area from the British Association of Counselling and Psychotherapy (information line: 0870 443 5252, website: www.bacp.co.uk). A counselling service especially for families and couples is provided by the Institute of Family Therapy. You will have to pay for this service, although your income will be taken into account in the rate that you are charged (telephone: 020 7391 9150; website: www.instituteoffamilytherapy.org.uk).

Looking ahead - going 'home'

For some older people who were not born in this country, thinking about the future can involve thinking about the country that they regard as 'home' or that they have strong feelings of attachment to, even though they may have been settled in the UK for a long time. Many people with life-limiting illnesses who have migrated to the UK have talked about wanting to either visit their 'home' country

before their illness gets worse or they have talked about wanting to die or to have their funerals at the place they think of as home. Whether you are able to go to another country for a visit or to spend your last days there will depend upon your illness and any treatments that you are having. Your GP, a hospice or a hospital doctor will be able to advise you. The service 'Hospice Information' has produced a guide, written by a doctor that provides advice on going overseas when you have a life-limiting illness. The full details of Hospice Information and the guide called 'Flying Home - or on holiday' are listed in the next section (Telephone: 0870 903 3 903 to order a copy of the guide).

Sometimes there might be cultural expectations that people should return home to die or that their bodies should be taken back after death. This may not be a problem where there is enough time and money to make the necessary arrangements or where those in a family want the same thing. However, there can often be difficulties. In addition to the paper work that has to be done, permission has to be given by the country that you are going to for some prescribed drugs. Sometimes it is necessary for a nurse to accompany the ill person on the plane. In the time that it can take to make these arrangements, some people can become too ill to travel. A hospital palliative care nurse who regularly helps people with such matters has found that it can often take several days to make all of the arrangements. In her experience the key to success is early planning, she said 'The earlier that we know that someone is wanting to go home the better we can plan'.

Funeral arrangements in another country

Taking a body overseas for burial can be expensive. The Government does not provide any financial assistance to help families with this. Some charities have been known to provide money to families to help with funeral costs overseas. Sometimes there can be disagreements within families about what

should happen after a death, particularly if the person who is ill has not had the chance to talk about what they want. Talking about where you would like to die and the arrangements that you would like for your funeral may help your family in making decisions at a difficult and emotional time. However planning ahead can often be too emotionally difficult or culturally inappropriate for some people.

Help with taking a body overseas

Arranging to have the body (or the cremated remains) of a person taken overseas can be complicated. You have to notify the relevant UK authorities and make sure that you follow the regulations of the country that a body is going to. A social worker, a palliative care nurse, or a hospital or hospice chaplain can help and advise you about what is required. There are funeral directors that specialise in this area of work - their website can be found at www.rowlandbrothersinternational.co.uk

Funeral industry trade associations will also be able to help you to find a funeral director in your area who will make the arrangements for you.

The associations are:

Society of Allied and Independent Funeral Directors (SAIF) 3, Bullfields, Sawbridgeworth Hertfordshire CM21 9DB.

Tel: 01279 726777, website: www.saif.org.uk

National Association of Funeral directors (NAFD) 618 Warwick Road, Solihull, West Midlands B91 1AA. Website: www.nafd.org.uk

Funeral Standards Council (FSC) 30 North Road Cardiff CF1 3DY.
Tel: 029 2038 2046

Care for family and friends

Palliative care includes the care of those close to you and this care recognises the needs of family and friends (including children) after a death. This care is called ‘bereavement’ care (there is more information about this below).

If you are worried about what will happen to someone in your family who is not in good health or who is disabled, it is best to talk about this with him or her as soon as you can - if you are able to. When you are talking to them, try and think about the types of support that they will need. For example, will they be able to continue living where they are? Will there be any relatives or friends who could help them? Will they need more support, like nursing home care? Once you have worked out what might be needed, go through your plans with someone else, either family or friends. If services are needed, talk to a social worker.

Legal matters: power of attorney and making a will

Some people find it important to make practical arrangements for the future such as making sure that someone (usually a solicitor, relative or friend) is able to manage their affairs for them if they become too ill (this is called ‘power of attorney’). You can ask your social worker or your local advice centre for more information about power of attorney.

You can also make arrangements for after your death, by making a will. A will is a legal document in which you can state what you would like to happen to your belongings, property and money. It is a good idea to make a will if you have any property or large sums of money. A will can help make sure that your wishes are carried out. It can also cut down on some

of the lengthy procedures that have to be gone through when there is no will. It is best to contact a solicitor to help you with power of attorney and with making a will. The organisation Age Concern (listed in the next section) also have a service to help older people to make a will. The service is cheaper than most solicitors.

Care and support after a death

There are services and professionals whose job it is to help people with their feelings of loss, sadness and grief after a death. The type of support that is offered to relatives and friends can be different, depending upon where you are receiving palliative care (in a hospice, hospital or at home) and where you live in the country. Many hospices, for example, will send a letter to a family or carer a month or two after a death and they will invite a family/carer to come back to the hospice and talk about how they are feeling. They may then be offered the chance to be a part of a group with other bereaved people who meet and share their feelings and experiences, and/or they may be offered one-to-one support with a counsellor. If you are in a hospital, a palliative care nurse should let your family or friends know about local bereavement services that can help and support them. If you are worried that your loved ones will not get any information, then you can ask your GP or district nurse to help them with finding local support when the time comes. It is worth knowing that in some areas of the country there are bereavement counsellors who speak different languages and who understand the different ways in which ethnicity, culture, faith and religion can affect how people might feel after a death.

Doing things your way

By presenting different stories of illness and palliative care throughout this book, we have tried to show that there is no one way that you 'ought' to be, and no feelings that you 'ought' to have when you are ill. We hope that you and those close to you will be able to see that there are different ways of doing things and that there are always some choices that you can make to help bring you to, or close to, the care that you need.

Where can I get more information from?



Your doctor is the best person to ask for information about a particular illness and about hospice and palliative care services. She/he can also give you advice about groups or organisations that can help you.

Information on Palliative Care Services

Hospice Information

St Christopher's Hospice

51-59 Lawrie Park Rd
London SE26 6DZ

Telephone: 0870 903 3 903

Email: info@hospiceinformation.info

Website: www.hospiceinformation.info

Hospice House

34-44 Britannia Street
London WC1X 9JG

Hospice Information produces a directory that can help you to find a hospice or palliative care service anywhere in the UK and the Republic of Ireland. Their website also has details of services in other parts of the world. You will need to send a stamped addressed envelope to the value of £1.42 to get a copy of the directory. Hospice Information have also produced information for people who want to return to their 'home' country or who wish to have a holiday abroad. The book, written by a palliative care doctor, is called 'Flying Home - or on holiday'.

PRIAE (Policy Research Institute on Ageing and Ethnicity)

31-32 Park Row (4th Floor) Telephone: 0113 2855990
Leeds, LS1 5JD Email: info@priae.org
UK Website: www.priae.org

PRIAE's PALCOPE project has produced a leaflet on palliative care for older people. The leaflet can be downloaded from PRIAE's website. A joint report by PRIAE and the National Council for Palliative Care on 'Older People, Ethnicity and Palliative Care' that highlights findings from the PALCOPE project can be purchased from PRIAE for £15.

Information for People with Cancer in Different Languages

Afiya Trust and Cancer Equality Carer's Project

Afiya Trust Telephone: 020 7582 0400
27-29 Vauxhall Grove Email: denise.forde@afiya-trust.org
London SW8 1SY Website: www.afiya-trust.org

The carer's project has produced CDs for carers of people with cancer. The 30 minute recordings, in English, Cantonese, Urdu, Gujerati, Hindi, Punjabi and Bengali (Sylheti) are based on personal stories of cancer and include information from doctors and nurses on treatment choices and care. Information is also provided on benefits, carer's support and complementary therapies. The cds are free to patients and carers.

Cancerbackup Helpline: 0808 800 1234
3 Bath Place Email: info@cancerbackup.org
Rivington Street Website: www.cancerbackup.org.uk
London, EC2A 3JR

This organisation provides information and advice by telephone, letter and email to people with cancer and their carers and it also produces a wide range of information guides on cancer, cancer treatment and issues facing people with cancer. Local information centres are based in Nottingham, Coventry, Manchester, Kendal,

Glasgow and London. The free helpline can give information from specialist cancer information nurses to callers in more than 100 languages. If your first language is not English the nurse will link you with an interpreter who speaks your preferred language. The organisation has copies of a video 'Chemotherapy and Radiotherapy' in English, Urdu, Hindi, Gujarati and Bengali. While it is in stock it is free to cancer patients and carers.

There are 12 other free telephone numbers that you can call for the 12 most commonly spoken languages in the UK. When you phone you will be able to speak to an interpreter who will contact a Cancerbackup Nurse. The numbers are:

0808 800 0130 Arabic	0808 800 0136 Hindi
0808 800 0131 Bengali	0808 800 0137 Polish
0808 800 0132 Cantonese	0808 800 0138 Punjabi
0808 800 0133 French	0808 800 0139 Turkish
0808 800 0134 Greek	0808 800 0140 Urdu
0808 800 0135 Gujarati	0808 800 0141 Vietnamese

Cancer Black Care

79 Acton Lane
London, NW10 8UT

Telephone: 020 7249 1097

Email: info@cancerblackcare.org

Website: www.cancerblackcare.org

Cancer Black Care provides information and support for those affected by cancer from African, Caribbean and South-Asian communities. Local centres are based in Brent and Harrow and South-East London. Printed information is available in Hindi and Bengali.

The Cancer Resource Centre Telephone: 020 7978 6203

20-22 York Road
London W11 3QE

email: asianoutreach@cancer-resource-centre.org.uk

website: www.cancer-resource-centre.org.uk

The Centre provides information, support and complementary therapies to people with cancer. It has two workers who provide support and advice to people from South Asian and African

Caribbean backgrounds. The Asian worker speaks Bengali, Urdu and Hindi. The Centre has produced two guides called 'Understanding and Living with Cancer' and 'Reduce Your Cancer Risk' that are available in Punjabi, Bengali, Gujarati and Urdu.

Chinese National Healthy Living Centre and Macmillan Cancer Relief - Information Drop-in Service

Cancer Drop-In Service Telephone: 020 7287 0904

Available on alternate Tuesdays (2-4.30pm)

email: amy.butler@cnhlc.org.uk

Chinese Healthy Living Centre Website: www.cnhlc.org.uk

29/30 Soho Square

London W1D 3QS

The drop-in service is open on alternate Tuesdays, 2pm - 4.30pm at the Chinese Healthy Living Centre in London. There is no need to make an appointment. The service offers free advice/support, access to health care professionals and English and Chinese leaflets, books and videos on all aspects of cancer.

Macmillan Cancer Support CancerLine: 0808 808 2020
UK Office, Email: cancerline@macmillan.org.uk
89 Albert Embankment Website: www.macmillan.org.uk
London SE1 7UQ

Macmillan Cancer Support provides care and practical and emotional support for people with cancer and their families/friends. It provides free advice about cancer and produces information on cancer and its treatment. The Macmillan CancerLine can connect you to an interpreter.

The National Cancer Alliance Telephone: 01865 793585
NCA Head Office
PO Box 579 Website: www.teamworkfile.org.uk
Oxford, OX4 1LB
email: nationalcanceralliance@btinternet.com

The organisation has produced a video called ‘Cancer Stories’ available in English, Gujarati and Hindi that features interviews with South Asian people with cancer talking about their experiences of cancer, treatment and of services. Also available is the Teamwork File- A Cancer Information Pack, with Personal Health Record (www.teamworkfile.org.uk).

National Council for Palliative Care

The Fitzpatrick Building
188-94 York Way
London, N7 9AS

Telephone: 020 7697 1520
Email: enquiries@ncpc.org.uk
Website: www.ncpc.org.uk

The National Council is the umbrella body for palliative care in England, Wales and Northern Ireland. It promotes the extension and improvement of palliative care.

A project carried out in Warwickshire (‘The No Exclusion Clause’ project) has made a 12-minute video that explains palliative care and the video is available through the National Council. The video is available in English, Cantonese, Gujarati, Punjabi and Urdu. The video is free, but payment is required for postage and packing.

Organisations that can help people with particular illnesses

All illness and health concerns

NHS Direct (England and Wales)

Telephone service: 0845 4647

Textphone service: 0845 606 4647

Scotland ‘NHS24’

Telephone service: 08454 242424

The National Health Service offers NHS Direct a service that can provide you with information about any illness as well as telling you more about your local NHS. There is a website and a 24-hour telephone service. If English is not your preferred language, the NHS

Direct telephone service can provide interpreters in any language. If you state in English the language you would prefer to use and wait on the line you will be connected to an interpreter who will help NHS Direct give you the advice you need.

You can also access NHS Direct health information on digital TV, at NHS Direct Interactive.

NHS Direct Online is a website providing high quality information and advice to people in England about symptoms, health conditions and treatments. It includes a database of hospitals, community health services, GPs, dentists, opticians and pharmacies: www.nhsdirect.nhs.uk

NHS Direct Wales has its own website with information in English and Welsh at: www.nhsdirect.wales.nhs.uk The website for Scotland is www.nhs24.com

All types of cancer

Cancer-UK

Website: www.cancer-uk.org

Cancer-UK is a website that gives an overview and a gateway to the resources available to people with any type of cancer. It offers information about different sorts of cancer and provides advice on finding organisations and support groups that are near to you.

Alzheimer's Society

Gordon House
10 Greencoat Place
London SW1P 1PH

Helpline: 0845 300 0336
Telephone: 020 7306 0606
Email: info@alzheimers.org.uk
Website: www.alzheimers.org.uk

The Society provides information and support for those with any form of dementia and their carers. It advises professionals working in the field, funds research, runs care services and campaigns for improving health and social care and greater public understanding of dementia. Local groups can provide home visits and information about local services and support.

Breast Cancer Care

5-13 Great Suffolk Street
London SW1 ONS

Helpline: 0808 800 6000

Email: info@breastcancercare.org.uk

Website: www.breastcancercare.org.uk

Provides information as well as practical support. Reaches people through website, helpline, publications, person to person support and health promotion activities, all of which are free. Anyone with breast cancer or breast concerns can get free confidential support and information from the helpline. The helpline can link you to a Language Line interpreter if English is not your preferred language. Breast Cancer Care provides leaflets, guides and audiotapes about breast cancer and its diagnosis and treatment - some of which are translated into Welsh and Urdu, Bengali and Arabic. They may also be able to put you in touch with volunteers who are Urdu, Hindi or Punjabi speakers.

Cervical Cancer**Jo's Trust**

Danvers House
Everdon NN11 3BL

Helpline: 01327 361 787

Email: pamela@jotrust.co.uk

Website: www.jotrust.co.uk

Jo's Trust offers information for women with cervical cancer - mostly over the Internet. You can get free confidential personal advice by asking questions which will be answered by email by medical experts. The website also provides answers to frequently asked questions.

Colon Cancer Concern

9 Rickett Street
London, SW6 1RU

Infoline: 08708 506050

Email: info@coloncancer.org.uk

Website: www.coloncancer.org.uk

Provides information, advice and support to patients and carers affected by colorectal cancer. The information service is supported by a colorectal nurse specialist and an expert advisory network that can help to deal with complex problems and questions relating to the disease.

Diabetes UK
10 Parkway
London NW1 7AA

Careline: 0845 120 2960
Careline email: careline@diabetes.org.uk
Email: info@diabetes.org.uk
Website: www.diabetes.org.uk

Diabetes UK provides information and advice to people with diabetes. The Careline provides information and support from counsellors (Monday - Friday, 9am-5pm) and recorded information on diabetes-related topics is available on the Careline number 24 hours a day. Careline callers can also access an interpreting service that offers interpreters in 100 different languages. Callers telephone Careline and leave their name and telephone number and the language they would like to talk in. A three-way telephone link with the caller, a Careline counsellor and an interpreter will be set up.

British Heart Foundation

Fitzhardinge Street
London W1H 6DH

Information line: 0845 0 70 80 7014
email: internet@bhf.org.uk
website: www.bhf.org.uk

The British Heart Foundation gives information and advice to people with heart problems, especially those who have had heart attacks or heart surgery. The British Heart Foundation Information line offers confidential expert advice about heart disease (Monday to Friday 9am-5pm). The BHF provides free guides on many aspects of heart health and illness that can be ordered or downloaded from their website. They also offer help in starting or joining support groups for people who have experienced heart illnesses.

The Roy Castle Lung Cancer Foundation

Patient Care Division
Rothsay House
134 Douglas Street
Glasgow G2 4HF

Helpline: 0800 358 7200
Email: glasgows@roycastle.liv.ac.uk
Website: www.roycastle.org

The Roy Castle Lung Cancer Foundation gives support and information to people with lung cancer. The Foundation provides a free telephone helpline (Monday to Friday, 9am-5pm) and offers free information guides on lung cancer. They also provide contact details

for local lung cancer support nurses and run support groups where people with lung cancer and their carers can meet and talk with other people in similar situations.

The Prostate Cancer Charity Helpline: 0845 300 8383
3 Angel Walk, Hammersmith Helpline text phone 0845 300 8484
London W6 9HX Email: info@prostate-cancer.org.uk
Website: www.prostate-cancer.org.uk

The Prostate Cancer Charity has free information guides, a network of support contacts for men with the cancer and a confidential Helpline where you can talk to experienced nurses (Monday - Friday 10am to 4pm and Wednesday evenings between 7pm and 9pm, Helpline text phone, Monday - Friday 10am to 4pm). The information guides can be downloaded free from the website in Arabic, Bengali, Cantonese, Gujarati, Hindi, Punjabi and Urdu.

The Stroke Association Helpline: 0845 303 3100
240 City Road Email: stroke@stroke.org.uk
London EC1V 2PR Website: www.stroke.org.uk

The Stroke Association has a national Helpline for information and support on stroke. They support stroke survivors and their families and have stroke clubs around the country and 16 regional centres. They produce 51 questions and answers leaflets that are available in Bengali, Gujarati, Hindi, Punjabi and Urdu and are free to patients and carers. The Association also has a 'Family Support Officer' who provides a counselling service to families and couples.

Other Useful Organisations

Age Concern Information Line: 0800 009966
Astral House, Email: infodep@ace.org.uk
1268 London Rd, Website: www.ageconcern.org.uk
London, SE16 4ER

Offers support and help to older people (over the age of 50) and their carers. It gives advice and information on health, housing, community care, benefits and income. It also provides local services for older people such as lunch clubs, day centres and transport.

British Red Cross

9 Grosvenor Crescent
London, SW1X

Telephone: 0800 169 2030

Email: information@redcross.org.uk

Website: www.redcross.org.uk

Lends medical equipment and provides a transport/escort service, emergency personal care in the home, care to give carers a break and care when someone has been discharged from hospital. It has local branches throughout the UK.

Counsel and Care

Twyman House
16 Bonny Street
London, NW1 9PG

Tel: 0845 300 7585

Email: advice@counselandcare.org.uk

Website: www.counselandcare.org.uk

Provides free advice for older people on welfare benefits, help at home, applying for grants and money for care homes. It gives advice on care homes and community care.

Cruse Bereavement Care

126 Sheen Road
Richmond, TW9 1UR

Helpline: 0870 167 1677

Email: info@crusebereavementcare.org.uk

Website: www.crusebereavementcare.org.uk

Gives free advice and counselling to family/friends after a death through local branches. It produces information on bereavement and a newsletter.

Carer's UK

20-25 Glasshouse Yard
London, EC1A 4JS

Telephone: 0808 808 7777

Minicom: 020 7251 8969

Email: info@ukcarers.org

Website: www.carersonline.org.uk

Gives free advice and information to all carers. It has over a 100 local and regional centres in England, Northern Ireland, Scotland and Wales. It will put you in touch with a carer's group in your area.

Crossroads - Caring for Carers

10 Regent Place Telephone: 0845 450 0350
Rugby, Website: www.crossroads.org.uk
Warkwickshire CV21 2PN
Email: communications@crossroads.org.uk

Provides practical 'in the home care' through trained Carer Support Workers who will take over from a carer so that they can have time to themselves and a break from caring. There are over 200 schemes in England and Wales and some schemes are able to provide Carer Support Workers who speak different languages. There are similar organisations for Scotland and Northern Ireland. Information is available in English Welsh, Punjabi, Chinese, Gujarati, Hindi, Bengali and Urdu.

Disability Alliance

Universal House Telephone: 020 7247 8776
88-94 Wentworth Street Email: office.da@dial.pipex.com
London, E1 7SA Website: www.disabilityalliance.org

Provides benefits advice and information.

Disabled Living Foundation

Helpline: 0845 130 9177
380-384 Harrow Road Reception: 020 7432 8018
London, W9 2HU Email: info@dlf.org.uk
Website: www.dlf.org.uk

Provides a wide range of information and training courses and gives advice on equipment that can help older and disabled people in their daily life, e.g. eating, walking, getting dressed, washing and moving around. The Helpline is available Monday - Friday, 10am - 4pm. The Foundation has displays of equipment and can demonstrate how equipment works. You are welcome to visit if you make an appointment first.

Help The Aged

207-221 Pentonville Rd
London, N1 9UZ

Telephone: 020 7278 1114

Seniorline: 0808 800 6565

Email: info@helptheaged.org.uk

Website: www.helptheaged.org.uk

Help the Aged funds and offers a range of services to older people including free information leaflets, services to help make your home more secure, insurance, visa credit card, funeral plans and care fees advice. It provides advice on claiming benefits, pensions, housing advice and help with finding a care home. It also produces free information leaflets.

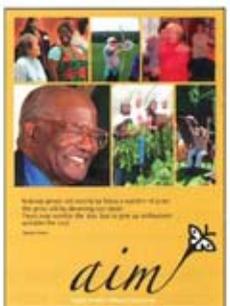
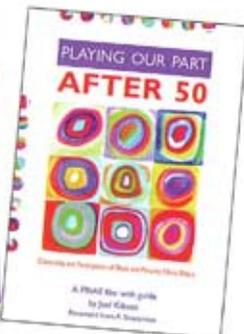
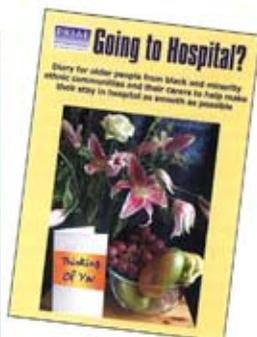
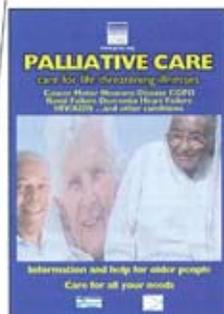
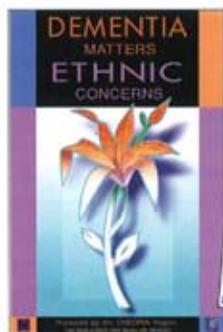
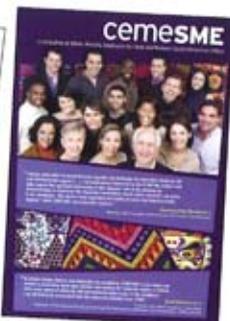
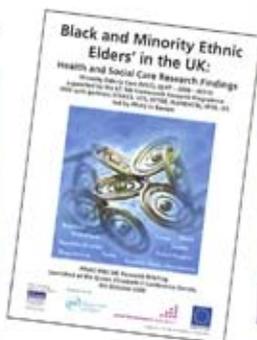
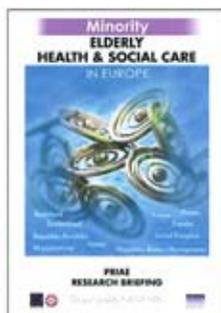
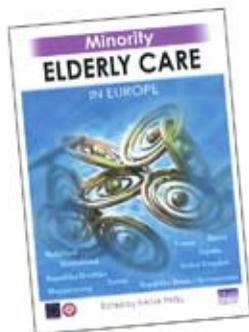
Palliative Care and PRIAE

PRIAE's work on palliative care is being taken forward in Scotland through the SCEES project (Securing Care for Ethnic Elders in Scotland). SCEES is working with the Managed Clinical Networks in Palliative Care from Edinburgh, Glasgow and Forthvalley in delivering six Palliative Listening Events to the Chinese and South Asian Communities to help raise awareness and understanding of Palliative Care and to create opportunities for palliative care teams to get to know the communities and to better understand their specific needs.

With Department of Health funding, the PALCOPE project is running a series of training workshops for older people, health and social care professionals and voluntary organisations to raise awareness of the palliative care needs of minority ethnic elders.

PRIAE

Policy Research Institute on Ageing & Ethnicity



Registered Charity No. 1081930
Email: info@priae.org

**Black and minority ethnic elderly
care and quality of life with care**

PRIAE
Policy Research Institute
ON AGEING & ETHNICITY
www.priae.org

This book has been written to provide information to older people and carers about palliative care. Palliative care is the care provided to those with life-limiting illnesses such as cancer, COPD, or heart failure. Topics covered in the book include: palliative care in the home, in hospitals, hospices and care homes for older people; information on how to access advice on benefits; and discussion of emotional experiences of illness.

PRIAE's PALCOPE project has produced a leaflet on palliative care for older people. The leaflet can be downloaded from PRIAE's website (www.priae.org). A joint report by PRIAE and the National Council for Palliative Care on 'Older People, Ethnicity and Palliative Care', which highlights findings from the PALCOPE project can be purchased from PRIAE.

PRIAE

Policy Research Institute
ON AGEING & ETHNICITY

**Published 2007 by PRIAE,
Policy Research Institute on Ageing and Ethnicity**

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Leeds LS1 5JD, UK

www.priae.org

Registered charity no 1081930

Registered company no 3898974

ISBN 0-9537642-7-3