



www.priae.org

PALLIATIVE CARE

care for life threatening illnesses

**Cancer Motor Neurone Disease COPD
Renal Failure Dementia Heart Failure
HIV/AIDS ...and other conditions**



Information and help for older people

Care for all your needs

with support from



Get the care that you deserve

Ask for information about palliative care from your doctor and nurses.

Gather as much trustworthy 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. 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.

What is 'palliative care'?

Palliative care is the care provided to people with a life threatening illness that will not get better. Such illnesses include cancer, motor neurone disease, chronic obstructive pulmonary disease, dementia, HIV/AIDS and advanced heart and lung disease. You do not have to pay for palliative care.

Palliative care can be provided in hospitals, hospices, at home and in care homes. It includes:

- medical, nursing and social care
- advice and support for your family and friends
- help with financial and practical matters
- recognition and respect for your cultural, spiritual and religious beliefs

"Slowly, my pain got less, I started to eat more and even though I knew the cancer was not going away, I began to feel less stressed and more confident."

How can I find out more about palliative care?

Your family doctor (your 'GP'), district nurse, hospital doctor and nurses, or social worker can tell you more about palliative care.

The service 'Hospice Information' produces a directory of all hospice and palliative care services in the UK, the Republic of Ireland, and in other parts of the world. They also provide an information service on UK and international hospice and palliative care services.

Telephone: 0870 903 3 903

email: info@hospiceinformation.info

website: www.hospiceinformation.info

What is a 'hospice'?

A hospice is a service that specialises in palliative care and in controlling pain and the symptoms of an illness - from diagnosis until the end of life. Hospices are smaller and less busy than hospitals. Hospices can provide:

- in-patient care (for symptom control, to give carers a break or end of life care)
- care in your home
- day care
- support to families / friends after a death (bereavement support)

Although some hospices are named after Christian saints, you do not have to be a Christian to use hospice services. Hospices welcome people from all backgrounds and all faiths. Some hospitals have 'palliative care units' that are similar to hospices.

"The hospice made a lot of difference, socially, financially, mentally. I never looked back."

How can I get palliative care at home?

Palliative care in the home is provided and organised by your GP and district nurse. They will make sure that:

- your needs (and those of your family/friends) are looked at and responded to throughout your illness
- you have the right pain and symptom control
- there is equipment at home to help you (for example, bedpans, special mattresses, walking frames, rails etc)
- there is medical and practical help if there is an emergency

Can I get palliative care in homes for older people?

- In a home providing personal care (often called a 'residential' home) - palliative care is given and/or arranged by your GP and your district nurse
- In nursing homes palliative care will be provided mainly by staff in the home, with the advice and support of your GP and district nurse

Can I get any financial help when I am ill?

You, and the main person who is caring for you, may be able to get money ('benefits') to help you. You can get information and advice about claiming benefits from:

- a social worker
- your local Citizens Advice Bureau
- a Benefits Agency office
- the free Benefits Enquiry Line on 0800 882200

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

What if I don't speak English?

More palliative care services are now using interpreters and sometimes 'advocates' to help and support those who do not speak English. Interpreters and advocates are trained professionals and have to keep what they interpret private ('confidential').

You may have a family member or a friend who can interpret for you, however many older people find that using a trained interpreter can be important:

- 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 the information that is given to you and they will do it sensitively

Whether you speak English or not, it is important for you to be involved in discussions about your illness, care and treatments. Don't be afraid to ask for an interpreter or an advocate if you are not offered one.

'If there are services like this what is illness? A person can tackle the most difficult thing.'

Respect and dignity for older people

You can help to make sure that you are treated with respect by telling those who are caring for you about what is important to you. Because culture and faith can affect attitudes towards illness and treatments, professionals want to know about any cultural or faith issues that are important to you. Remember that all health and social care professionals should:

- treat older people with respect
- maintain your dignity
- make sure that you are involved in decisions about your care

Palliative Care, Older People and Ethnicity (PALCOPE)

PALCOPE is a project that is managed by the Policy Research Institute on Ageing and Ethnicity (PRIAE) and is supported by the Department of Health. PALCOPE wants to increase awareness of palliative care, particularly amongst older people from different ethnic, cultural and faith backgrounds. It is also working to increase awareness amongst those working in palliative care about the needs of older people.

PALCOPE has produced a booklet that includes personal stories and information on: experiences of life threatening illnesses; palliative care in the home, hospitals and hospices; and feelings, bodies and relationships.

You can get a copy of the booklet by telephoning **PRIAE** on: **01 13 285 5990**

Where can I get more information from?

You should first ask your GP, district nurse, or hospital doctors and nurses for any information about an illness and/or palliative care services. Here are other organisations that can give you further information, advice and support. Where interpreters are available the word 'Interpreters' will appear after the telephone number:

NHS Direct provides free information and advice to people in England and Wales on any illness, health services and support groups, and on what to do if you are not feeling well:

Telephone: 0845 4647 (Interpreters)
Textphone: 0845 606 4647
Scotland's NHS Direct service, 'NHS24': 08454 242424

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:

website: www.nhsdirect.nhs.uk
NHS Direct health information on digital TV, NHS Direct Interactive.
NHS Direct Wales website: www.nhsdirect.wales.nhs.uk
 with information in English and Welsh.
NHS24 Scotland's website: www.nhs24.com

Macmillan Cancer Relief provides free advice about cancer, treatments and practical and emotional support for people with cancer and their families/friends.

Macmillan CancerLine: 0808 808 2020 (Interpreters)
Address: 89 Albert Embankment, London SE1 7UQ
email: cancerline@macmillan.org.uk
website: www.macmillan.org.uk

CancerBACUP provides a free helpline service and produces booklets and fact sheets on all types of cancer, cancer treatments and advice about living with cancer. There is a booklet specifically for older people called 'Cancer and older people'.

Helpline: 0808 800 1234 (Interpreters)
Address: 3 Bath Place, Rivington Street, London, EC2A 3JR
email: info@cancerbacup.org
website: www.cancerbacup.org

There are 12 other free telephone lines that you can call for the 12 most commonly spoken languages in the UK:

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

Afiya Trust and Cancer Equality Carer's Project has produced tapes (audio-cassettes) for carers of people with cancer in English, Cantonese, Urdu, Gujarati, Hindi, Punjabi and Sylheti.

Telephone: 020 7582 0400
Address: 27/29 Vauxhall Grove, London, SW8 1SY
email: denise.forde@afiya-trust.org
website: www.afiya-trust.org

Cancer Black Care provides information and support to people from African, Caribbean and Asian backgrounds who are affected by cancer. Local centres are based in Brent and Harrow and South-East London.

Telephone: 020 8961 4151
Address: 79 Acton Lane, London, NW10 8UT
email: info@cancerblackcare.org
website: www.cancerblackcare.org

The National Cancer Alliance 'Cancer Stories' is a video in English, Gujarati and Hindi of interviews with South Asian people with cancer talking about their experiences of cancer, treatment and of services.

Telephone: 01865 793585
Address: NCA Head Office, PO Box 579, Oxford, OX4 1LB
email: nationalcanceralliance@btinternet.com
website: www.teamworkfile.org.uk

Tak Tent Cancer Support (Scotland) - offers support and information to people with cancer, their family/friends and health professionals. It has a network of support groups.

Telephone: 0141 211 0122
Address: Flat 5, 30 Shelley Court, Gartnavel Complex, Glasgow, G12 0YN
email: tak.tent@care4free.net
website: www.taktent.org.uk

Tenovus Cancer Information Centre (Wales) provides free cancer information, advice and support in English and Welsh and gives financial help to people with cancer.

Telephone: 0808 808 1010;
Address: Velindre NHSTrust, Velindre Hospital, Whitchurch, Cardiff, CF14 2TL
email: tcic@tenovus.com
website: www.tenovus.com

The Ulster Cancer Foundation provides a free cancer helpline and resource centre, patient support groups and a volunteer visiting service.

Telephone: 0800 783 3339
Address: 40-42 Eglantine Avenue, Belfast, BT9 6DX
email: info@ulstercancer.org
website: www.ulstercancer.org

Other Useful Organisations

Age Concern provides free advice and information on health, housing, money, transport and day care to older people and their family/friends. It provides local services such as lunch clubs, day centres and transport.

Telephone: 0800 009966
Address: Astral House, 1268 London Rd, London, SE16 4ER
email: infodep@age.org.uk
website: www.ageconcern.org.uk

Alzheimer's Society provides information and support for those with any form of dementia and their carers. Local groups can provide home visits and information about different types of dementia and about local services and support.

Helpline: 0845 300 0336
Address: Gordon House, 10 Greencoat Place, London SW1P 1PH
email: info@alzheimers.org.uk
website: www.alzheimers.org.uk

The British Heart Foundation gives free information and advice to people with heart disease.

Information line: 0845 0 70 80 7014
Address: Fitzhardinge Street, London W1H 6DH
email: internet@bhf.org.uk
website: www.bhf.org.uk

Carer's UK gives free advice and information to all carers (carers are relatives/friends looking after an ill person) and will put you in touch with a local carer's group.

Telephone: 0808 808 7777 (Interpreters)
Address: 20-25 Glasshouse Yard, London, EC1A 4JS
email: info@ukcarers.org
website: www.carersoline.org.uk

Counsel and Care provides free advice to older people on welfare benefits, help at home, applying for grants and money for care homes.

Telephone: 0845 300 7585
Address: Twyman House, 16 Bonny Street, London, NW1 9PG
email: advice@counselandcare.org.uk
website: www.counselandcare.org.uk

Cruse Bereavement Care gives free advice and counselling to family/ friends after a death.

Helpline 0870 167 1677 (free)
Address: 126 Sheen Road, Richmond TW9 1UR
email: info@crusebereavementcare.org.uk
website: www.crusebereavementcare.org.uk

Disability Alliance provides benefits advice.

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

Disabled Living Foundation gives information and advice on equipment to help older and disabled people with daily life (such as eating, walking, dressing, bathing, going to the toilet, incontinence care).

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

Help the Aged provides free information and advice on claiming benefits, pensions, housing, getting help in the home and finding a care home. It provides local services for older people.

Telephone: 0808 800 6565
Address: 207-221 Pentonville Rd, London, N1 9UZ
email: info@helptheaged.org.uk
website: www.helptheaged.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.

Helpline: 0845 303 3100
Address: 240 City Road, London, EC1V 2PR
email: stroke@stroke.org.uk
website: www.stroke.org.uk



PRIAE

PRIAE is an independent registered charity working to improve pensions, employment, health, social care, housing and quality of life for older people from minority ethnic backgrounds in the UK and across Europe.

The 'PALCOPE' project at PRIAE is a three year Department of Health funded project. PRIAE Consultants Yasmin Gunaratnam with Neera Deepak with project staff manage this work.

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 leaflet please telephone 01 13 285 5990 or email: Sam.Turner@priae.org



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

design@massamundo.com

Stories That Matter

'I couldn't believe how many times we had to keep going backwards and forwards, backwards and forwards to get any help...if you are completely ignorant it's hard work and thank god I was in touch with the community centre, otherwise I wouldn't have been enlightened as to what was available' **(Geeta, carer of dementia patient)**

'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.' **(Herman, cancer patient)**

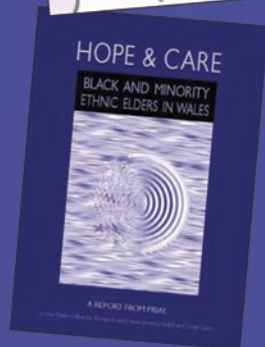
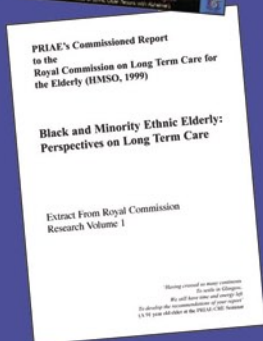
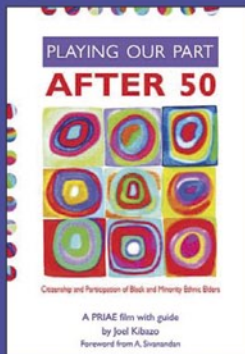
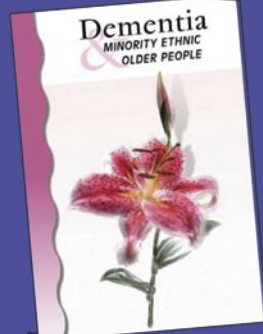
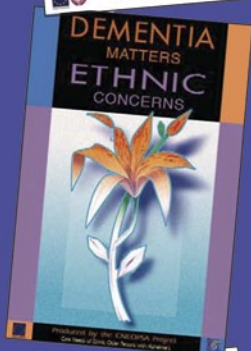
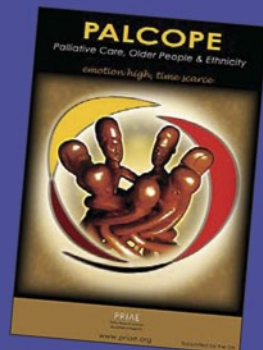
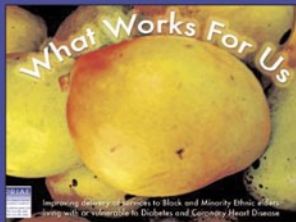
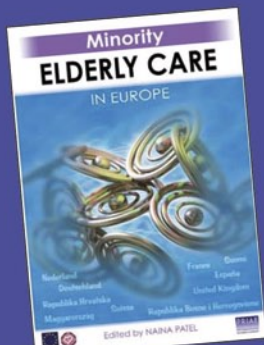
'Many patients don't know about their illness or their treatment. When you go to the hospital you should ask the doctor 'What illness do I have? Where is it? What treatment will take place? Ask about the tests that have been conducted. Ask all these things.' **(Nusrat, cancer patient)**

PRIAE

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