Housing Learning & Improvement Network

Delivering End of Life Care in Housing with Care Settings

The aim of this Factsheet is to raise awareness among housing with care practitioners and providers of the current agendas and developments in practice around end of life care.

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Care Services Improvement Partnership **CSIP**

Health and Social Care
Change Agent Team

We help to improve services and achieve better outcomes for children and families, adults and older people including those with mental health problems, physical or learning disabilities or people in the criminal justice system. We work with and are funded by **DH** Department of Health

Delivering End of Life Care in Housing with Care Settings

Aim of the paper

The aim of this Factsheet is to raise awareness among housing with care practitioners and providers of the current agendas and developments in practice around end of life care. It considers:

- Current policy on end of life care;
- Definitions of end of life care;
- Tools to assist with the development of generalist and community end of life care provision, notably the *Gold Standards Framework*, the *Liverpool Care Pathway for the Dying Patient*, and the *Preferred Place of Care*;
- Implications for end of life care in housing with care settings.

A list of references and useful contacts are provided at the end of the factsheet.

Introduction

As in all western industrialised societies, the life expectancy of the UK population continues to increase. For those born in 2001, life expectancy for females is 80.4 years, and for males 75.7 years. These extra years of life, however, are not always lived in good health. By 2001 the expected time lived in poor health from age 65 onwards was 4.3 years for men, and 5.8 years for women (ONS, 2004). There will be growing numbers of older people living with serious, progressive illnesses where neither prevention nor cure is possible. Given these demographic changes, it is unsurprising that end of life care has been identified as a priority for the National Health Service.

Recent policy statements, notably *Dignity in Care* (DH, 2006) and the White Paper *Our Health, Our Care, Our Say* (DH, 2006), emphasise providing choice and dignity at the end of life, and enabling individuals with long-term health needs to be cared for in the most appropriate settings including, where possible, in their own homes. It would seem that the new and emerging models of housing with care for later life should be ideal environments in which to provide end of life care. Indeed housing with care schemes have often been promoted as "home for life", and are thought to offer alternatives and/or substitutes for residential and nursing home care.

A recent comprehensive review of the evidence around housing with care for later life highlighted the lack of knowledge about of end of life care in housing

with care settings (Croucher et al, 2006). None of the UK studies identified by the review had explicitly addressed the provision of end of life care or palliative care in housing with care settings. Moreover the evidence clearly showed that many people move on from housing with care to residential care, nursing homes, and hospice settings as their needs for care increase.

The Policy Context

The consultation process for *Building on the Best: Choice, Responsiveness and Equity in the NHS* (DH, 2004) indicated that - among other things - people wanted greater choice over their place of death. Currently around 20% of people die at home, although about 50% say they would like to die at home if they were terminally ill. Consequently funding of £12 million over three years has been directed to the NHS End of Life Care Programme (see below) to enable this choice.

New investment in end of life care reflects an overarching policy aim of making dignity in care for older people a priority across all care settings.

> *Our definition of dignity is based on the moral requirement to respect all human beings, irrespective of any conditions they suffer from.*
> A New Ambition for Old Age, p4 (DH, 2006)

In the last year a number of steps have been taken to move the Dignity in Care agenda forward, including a research initiative to investigate elder abuse, moves to improve standards in social care and enhance legislation to protect vulnerable groups, and a review of the National Minimum Standards for Care. The Dignity in Care programme lies at the heart of the new agenda set out in *A New Ambition for Old Age: Next Steps in Implementing the NSF for Older People* (DH, 2006). Although the National Service Framework for Older People (DH, 2001) has been judged to have promoted much positive change, *A New Ambition for Old Age* indicates that more needs to be done, particularly around deep-rooted negative attitudes and behaviours towards older people. The Dignity in Care programme, and its associated resources, is designed to ensure that practice follows policy [1] . The Social Care Institute for Excellence (SCIE) has also recently launched *Dignity in Care* – a web-based resource with guidance on mealtimes, communication, complaints and respect. The theme of dignity in care and how this translates to housing

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[1] Department of Health weblink
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/DignityInCare/fs/en

settings is more fully explored in the forthcoming LIN factsheet *Dignity in Housing* by Sue Garwood.

Other national service frameworks and service guidance, although focused on specific conditions, also have particular implications for older people's services (for example the *National Service Framework for Renal Services (2005)*, *National Service Framework for Long-Term Conditions* (DH, 2005), *National Service Framework for Diabetes* (DH, 2005)

Definitions - what is end of life care?

Various policy and practice documents use a range of terms to describe care for people who are approaching the end of life.

End of life care is an umbrella term which covers more than the phase immediately before death, and usually refers to the year leading up to the time of death. Originating in North America, it is often used specifically in the context of older people. The following definition is frequently quoted.

> *End-of-life care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement.*
>
> Ross and Fisher (2000)

As the definition suggests, although effective health care is clearly an integral part of end of life care, the needs of older people approaching the end of their lives extend much further, and the key to end of life care has to be the integration of a range of services to address a number of different needs.

Palliative care refers to the care of patients with serious illness who are not expected to recover, and addresses four types of need, physical psychological, social and spiritual. The World Health Organisation defines palliative care as:

- Affirms life and regards death as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other symptoms
- Integrates the psychological and spiritual aspects of patient care

- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement

World Health Organisation, 1990.

Palliative care can be delivered by multi-disciplinary team which may include doctors, social workers, nurses, and clergy/representatives of other faiths, or by individual or groups of palliative care clinical nurse specialists, generally known as Macmillan nurse. It can be provided across a range of settings - in hospital, hospice, care homes or in domestic settings. Palliative care services in the UK are delivered free of charge to the user and are funded by the NHS. Specialist palliative care is usually practised by professionals with training and specific qualifications. Palliative care is distinct from the *palliative approach* which is practised by generalists applying the principles of palliative care outlined above to any sick person regardless of their illness.

Terminal care is part of palliative care and usually refers to the care and management of people during the last few days or hours of life when it becomes clear that the individual is in a progressive state of decline.

It is also increasingly recognised that long-term chronic conditions, for example, dementia, respiratory disease, and cardiovascular disease, will require different approaches to the provision of end of life care from those that have been developed by specialist palliative care services for patients with cancer.

NHS End of Life Care Programme

The stated aim of the NHS End of Life Care (EoLC) Programme is:

"To improve the quality of life at the end of life for all patients and enable more patients to live and die in the place of their choice".

In addition it aims to reduce the number of emergency admissions to hospital for those who have expressed a wish to die at home, and to reduce the number of admissions to hospital from care homes in the last weeks of life. The EoLC Programme is coordinated by a National Director who, together with National Leads, supports Strategic Health Authorities in England to improve the choice, equity and responsiveness for all adult patients nearing the end of life. All Strategic Health Authorities (SHAs) have appointed a lead

person to implement the EoLC Programme in their area. The possibility of establishing End of Life Care networks across England is being discussed so as to improve service co-ordination, and bring together primary care, social services, hospices, community-based palliative care services, and hospital services.

For further information about the NHS EoLC Programme visit: http://www.endoflifecare.nhs.uk.

Educating and training are at the heart of the EoLC Programme. Housing commissioners and managers across the public, voluntary and private sectors need to be aware of the three end of life care tools being promoted by the EoLC Programme and building them into their training and workforce development programmes. The three practice tools are: the Preferred Place of Care Plan (PPC), the Gold Standards Framework (GSF), and the Liverpool Care Pathway for the Dying Patient (LCP). All the tools are being used in care homes.

Preferred Place of Care Plan (PCC)
The Preferred Place of Care Plan (PPC) is a nationally recognised palliative care tool. It is intended to be a patient-held record that will follow the patient through their path of care into the variety of differing health and social care settings, and records the patients' wishes, the socio-economic circumstances of the family, the services being accessed, reasons for change in the care and a needs assessment that documents care on an ongoing basis. Guidance reference sheets for both the patient and carer and staff are available explaining the use of the PPC. The document provides an opportunity to record:

- A family profile and carers' needs;

- The patient's thoughts about their care, their choices and preferences;

- The services that are available in a locality and being accessed by the patient;

- Changes in care needs.

For further information about the PPC visit: http://www.cancerlancashire.org.uk/ppc.html

Gold Standards Framework

The Gold Standards Framework (GSF) aims to improve palliative care provided in the community by the whole Primary Health Care Team. It is now being used by about a third of Primary Health Care Teams in the UK. It enables those approaching the end of life to be identified by the team, their needs assessed, and a plan of care developed with all agencies put into place. The programme focuses on optimising continuity of care, teamwork, advanced planning, symptom control and patient and staff support.

There are seven standards or 'the seven Cs', with accompanying templates and assessment tools.

Communication	GP practices maintain a supportive care register
Coordination	Each Primary Health Care Team (PHCT)has a nominated coordinator for palliative care
Control of symptoms	Each patient has their symptoms, problems and concerns assessed, recorded, discussed and acted upon, according to an agreed process.
Continuity	Practices will transfer information to the out of hours services for palliative care patients. Information should also be passed on to other relevant services.
Continued learning	Commitment to the continued learning of skills and information
Carer Support	*Emotional support*: carers are supported, listened to, kept informed and encouraged to play as full a role in the patient's care as they wish. *Practical support* is supplied wherever possible, i.e. night sitter, respite, commode etc. *Bereavement*, and *staff support* are inbuilt.
Care of the dying (terminal phase)	Patients in the last days of life are cared for appropriately e.g. by following the Liverpool Integrated Care Pathway

Source: Thomas, 2003. Caring for the Dying at Home; Companions on the Journey.

The Gold Standards Framework in Care Homes Programme (GSFCH) has been modified from the GSF model for use in care homes, and focuses particularly on improving collaboration with general practitioners, and uses the same seven standards, templates and assessment tools.

For further information about the Gold Standard Framework, visit: http://www.goldstandardsframework.nhs.uk

Liverpool Care Pathway for the Dying Patient (LCP)
This care pathway was originally developed for used in hospitals but can be used in primary care and care homes. It is used for patients in the last days or hours of life, once it is known that their death is imminent. Once implemented the care pathway empowers generalists to care for the dying and can be transferred to non-cancer patients. The protocol involves promoting good communication with the patient and family, an agreed plan of on-going assessment and care including advanced planning for psychosocial and spiritual needs, symptom control, and communication with others particularly out-of-hours providers.   An education dissemination programme has been devised by the team that developed the pathway, and there are symptom control guidelines and information leaflets for relatives.

For further information about the Liverpool Care Pathway visit: www.lcp-mariecurie.org.uk

End of Life Care in Housing with Care Settings

New models of housing with care have frequently been promoted as an alternative to, or substitute, for residential care, and as a 'home for life' (see Housing LIN Factsheet 1 and recent extra care housing toolkits). Evidence from a number of different studies and evaluations suggests that it might be ambitious to describe many housing with care schemes as homes for life. Studies show that many residents do move onto residential and nursing home settings. Although there may be many reasons why people move on, it does seem that increasing needs related to chronic health problems, and difficulties in putting the additional resources into place to meet these needs are crucial factors.

In housing with care settings where the promotion of independence is a underlying concept, there may well be tensions between promoting independence and active ageing, and thinking about end of life care, and how best to support people who are approaching the end of their lives.

> *Attempts to combat ageism by promoting a positive, healthier and more independent image of old age can also marginalise the needs of vulnerable older people. Indeed a preoccupation with independence in much of the policy literature obscures any meaningful debate about how to improve the quality of life of older people facing death.*
> Seymour et al, 2005, p6.

In discussion with a small number of service managers, it was clear that end of life care within housing with care settings is potentially quite possible, but depends very much on a number of factors including: the types of need; levels of input from health and social services, and whether there is a shared commitment across agencies to deliver end of life care in people's own homes; on-site staff skills; and design of space.

Types of need

Different chronic conditions have different end of life trajectories. Murray et al (2005) describe three distinct trajectories for people with progressive chronic illnesses. The first has a steady decline and usually a clear terminal phase, often experienced by people with cancers. The second has a gradual decline, punctuated by periods of rapid deterioration followed by limited recovery, where death is unpredictable, and seemingly unexpected. This type of trajectory is usually associated with respiratory disease and heart failure. The third trajectory is that of prolonged gradual decline, typical of frail elderly people or people with dementia. The social, psychological and spiritual needs of patients and their carers are likely to vary according to the type of illness they have, and different models of care may be necessary to reflect different experiences and needs. Although these trajectories might be seen as simplistic (for example, an individual may suffer from several different conditions and not fall neatly into one of the three trajectories), they are useful in promoting greater understanding of the range of services that need to be in place to meet different needs.

It is important to be realistic about what can be offered within people's own homes, and to acknowledge that sometimes it simply may not be possible to care for people effectively within their own homes. Service managers highlighted that staff delivering personal care were not qualified nurses and there were limits to what they could do. Examples of circumstances when service managers felt it would be highly difficult were following a catastrophic stroke. Other issues were the availability of out-of-hours district nursing services, the supervision of medication, and wound care.

They also felt that a major difficulty for housing with care was providing services for people with high level needs over a long period of time. Here there could be difficulties around the level of staff resources required to provide support as well as care for people. For example, care packages did not always cover helping people to go out, or to join in with social activities. There were clearly difficulties when people had regular care needs through the night. This could be problematic in schemes where there was no 'waking'

night staff cover. Often the costs of providing the additional care did not compare favourably with the costs of residential or nursing home care.

Partnership working

Partnership working between health, housing and social care agencies is crucial to the delivery of end of life care in people's own homes. As one housing association service manager commented:

> *"We want it to be a home for life, but we're in the hands of health and social care professionals".*

End of life care planning can be complex, and anecdotal evidence suggests that disagreement and confusion can arise over the role of different agencies, and how care packages should be funded, and these can be barriers to the provision of end of life care in housing with care settings. There may be a danger that end of life care is seen to be the domain of health practitioners, when social care and support are equally important as health care if people are to experience "quality of dying".   The tools described above are intended to promote effective joint working.

Practitioners also need to be mindful of the role of informal carers and family. The literature on end of life care suggests that dying at home is often only possible with the support of informal carers. In addition, families often act as advocates for family members and are instrumental in getting services into place.

Staff training and support needs

Some training for care staff in palliative care is available, for example, *Foundations in Palliative Care*, developed with by MacMillan Cancer Relief (for further information about this and other palliative care training see http://eolc.cbcl.co.uk/eolc/Education/). Care staff may also need support following the death of a resident. Care staff should enjoy the same levels of support as nursing auxiliaries and other health care practitioners following bereavement.

It is important to be aware of possible communication difficulties because of residents' sensory or other impairments, or because English was not the first language of some care staff.

Design of extra care

Many extra care schemes are newly built, others have been remodelled from existing sheltered housing or residential homes. In both types of scheme, space in people's own homes can be constrained, and this can make caring more difficult. There needs to be space for aids and adaptations, including hoists, as well as other equipment (for example oxygen cylinders) that might be required. In particular there needs to be space in bathrooms and bedrooms for carers to assist people. Efficient ventilation, particularly in bathrooms, is important particularly when people may have continence problems.

Many units have only one-bedroom which create difficulties for couples when one partner needs high levels of care, or if family members want to stay with relative. There needs to flexibility over use of the guestrooms located in schemes – rules and regulations sometimes can get in the way of families who want to stay near their relative, especially as families may well need to stay over prolonged periods when someone is very ill or dying.

New technologies can offer the potential to enhance the capacity of housing with care schemes to care for people with long term chronic conditions (see DH, 2005).

Working with other residents

In housing with care settings the deaths of residents can be keenly felt by both other residents and staff - particularly when people have been longstanding residents and have long established friendships and social networks. It also seems likely that if people have to be transferred to a different care setting, this may cause other residents to feel concerned about what will happen to them if they become very ill.

Within the context of care homes, The Centre for Policy of Ageing (1996) suggests a number of ways in which a death might be announced, or an individual remembered. These may be helpful within the context of housing with care, however people we spoke to were cautious about applying practice from care home to housing with care settings. The intention here is to promote some discussion about how best to address bereavement in communal housing settings.

News of a residents' death should be announced in a dignified and gentle way. It may be best to announce it quietly to individuals of staff groups initially, but some more public announcement may also be appropriate in due course. Some people may find this public recognition comforting. It should never be assumed that people with dementia do not understand when someone has died. Some of the following possibilities might be appropriate:

- A minute's silence at an appropriate time
- A photograph of some other personal tribute in a suitable place
- Opportunity to visit the dead person and pay last respects
- A memorial or thanksgiving service or some other religious or cultural ceremony
- Lighting a candle
- Playing a favourite piece of music or reading a poem
- A plant, picture of piece of furniture in memory of the person.

Plaques should be kept discrete so that the home is not overrun with memorials.

From CPA (1996). A Better Home Life

For many older people, growing older almost inevitably brings a series of losses, with their associated grief and sadness. Older people who have lost their partners often report seeing and continuing to talk to the dead person, and this is often reported to be reassuring. Seymour et al (2005) suggest that psycho-analytical theory about grief work and 'moving on', maybe unhelpful to older people (indeed much work on bereavement has been carried out with younger people) and that such models of bereavement should not be adopted uncritically when working with older people.

Practice issues

Based on discussions with practitioners, and the literature on end of life care, the list below addresses some practice issues. It is not meant to be exhaustive. As new housing and care schemes are developed and practice becomes established, other practice concerns will most certainly be identified.

Working with residents

- Do you talk to your residents about their preferences for place of death?
- How do you announce the death of a resident to other people living and working in the schemes?
- Have you asked residents whether they would like to commemorate residents who have died, and how they might like to do this?

Assessment and care delivery

- Do residents' care plans include care at the end of life?
- Can you identify any residents who are nearing the end of their lives? Have you tried to anticipate or plan for their future care and support needs?
- How many of your residents die each year either at home or after transfer to other care settings? What are the main lessons that can be drawn from these experiences?

Partnerships

- How many GP practices provide medical care to you residents? How do they provide out of hours care?
- Does the local community nursing service provide out-of-hours care?
- What links do you have with community palliative care schemes, and specialist palliative care providers such as Macmillan nurses?
- Have you discussed the future care needs of residents who are approaching the end of their lives with other partner service providers?
- What links do you have with bereavement counselling services such as CRUSE?

Design

- What facilities are there within the scheme for families who may want to stay with their relative?
- Are there ways in which new technologies could assist with providing care?

Staff training

- What are the training needs of your care staff in relation to end of life care?
- Are you aware of the NHS EoLC programme and how you might use the practice tools the programme promotes?
- What support is offered to care staff following the death of a resident?

ACKNOWLEDGEMENTS

REFERENCES

Centre for Policy on Ageing. 1996. *A Better Home Life*. Centre for Policy on Ageing, London.

Croucher K, Hicks L, and Jackson K. 2006. *Housing with Care for Later Life: A Literature Review.* Joseph Rowntree Foundation
http://www.jrf.org.uk

Housing Learning and Improvement Network. 2006. Dignity in Housing. Care Services Improvement Partnership

Housing Learning and Improvement Network. 2006. Extra Care Housing Tool Kit.
http://www.changeagentteam.org.uk/_library/docs/Housing/Toolkit/ECH_Toolkit_Complete_Document_Including_Tools.pdf

Department of Health, 2006. Dignity in Care. Department of Health

Department of Health. 2005. Building Telecare in England. Department of Health.
http://www.dh.gov.uk/assetRoot/04/11/56/44/04115644.pdf

Department of Health, 2006. *Our Health, Our Care, Our Say: A New Direction for Community Services*. Department of Health.
http://www.dh.gov.uk/assetRoot/04/12/74/59/04127459.pdf

Department of Health. 2006. *A New Ambition for Old Age: Next Steps in Implementing the National Service Framework for Older People*. Department of Health.
http://www.dh.gov.uk/assetRoot/04/13/39/47/04133947.pdf

Department of Health. 2005. *Supporting People with Long Term Conditions: An NHS and Social Care Model to Support Local Innovation and Integration.* Department of Health.
http://www.dh.gov.uk/assetRoot/04/12/25/74/04122574.pdf

Department of Health, 2005. *National Service Framework for Renal Services Part 2. Chronic Kidney Disease, Acute Renal Failure and End of Life Care.* Department of Heath.
http://www.dh.gov.uk/assetRoot/04/10/26/80/04102680.pdf

Department of Health. 2005. *Independence, Well-being and Choice.* Department of Health.

Department of Health and NHS Modernisation Agency. 2004. *Supportive and Palliative Care for Advanced Heart Failure.* Department of Health
http://www.heart.nhs.uk/serviceimprovement/1338/4668/Palliative%20Care%20Framework.pdf

End of Life Care Programme. 2006. *Introductory Guide to End of Life Care in Care Homes.*
http://endoflifecare.nhs.uk

Housing Learning and Improvement Network. 2006. *Dignity in Housing*. Care Services Improvement Partnership

Housing Learning and Improvement Network. 2006. *Extra Care Housing Tool Kit.* Care Services Improvement Partnership

Murray S A, Kendall M, Boyd K, and Sheikh A. 2005. Illness trajectories and palliative care. *British Medical Journal*, 330: 1007-1011.

National Institute for Clinical Excellence. 2004. *Improving Supportive and Palliative Care for Adults with Cancer*. London, NICE.
http://www.nice.org.uk/page.aspx?o=csgsp

Ross M, and Fisher R. 2000. *A Guide to End-of-Life Care for Seniors*. Ottowa, Health Canada.

Social Care Institute for Excellence. 2006. *Dignity and the Care of Older People*. Social Care Institute for Excellence.
http://www.scie.org.uk/publications/resourceguides/rg07

Samson-Katz J and Peace S. 2003. *End of Life in Care Homes: A Palliative Care Approach.* Oxford University Press. Oxford.

Seymour J, et al. 2005. *End-of-life Care: Promoting Comfort, Choice and Well-being for Older People.* The Policy Press, Bristol.

Thomas K. 2003. *Caring for the Dying at Home.* Radcliffe Medical Press, Oxford.

World Health Organisations Expert Committee. 1990. *Pain Relief and Palliative Care.* World Health Organisations Technical Report Series, 804. WHO, Geneva.

USEFUL SOURCES OF INFORMATION

Most of these organisations offer extensive resources on their website for professionals, carers, and people with life-limiting conditions, including information sheets, training materials and research publications. Many organisations have local branches and offices, and these can be located via the national websites. This is not an exhaustive list of all possible contacts.

The NHS End of Life Care Programme
The programme was set up to improve the quality of care for people at the end of life. In particular, it aims to help more people live and die in the place of their choice, and also to reduce the number of people who live in care homes being moved to hospital in the last weeks of their life.

Website: www.endoflifecare.nhs.uk

The Department of Health Dignity in Care Programme
For information on the Dignity in Care initiative, and for the latest news on the programme, visit the DH website at:
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Social Care/DignityInCare/fs/en

Age Concern
National charity with many local branches dedicated to promoting the well-being of all older people and to help make later life a fulfilling and enjoyable experience.

Website: www.ageconcern.org.uk

Alzheimer's Society
The UK's leading care and research charity for people with dementia and their carers. As well as funding vital research, the Alzheimer's Research Trust provides information on Alzheimer's disease and related dementias, and the drugs currently available in the UK

Alzheimer's Society, Gordon House, 10 Greencoat Place, London SW1P 1PH; Tel: 020 7306 0606

Website: www.alzheimers.org.uk

British Heart Foundation
The aim of the British Heart Foundation is to play a leading role in the fight against disease of the heart and circulation so that it is no longer a major cause of disability and premature death.

British Heart Foundation, 14 Fitzhardinge Street, London, W1H 6 DH;
Tel: 020 7935 01857

Website: www.bhf.org.uk

British Lung Foundation
Gritish Lung Foundation, 73-75 Goswell Street, London EC1V 7ER;
Tel: 08458 505020

Website: www.lunguk.org

Cancerbackup
3 Bath Place, Rivington Street, London EC2A 3JR

Website: www.cancerbackup.org.uk

Carers UK
A national organisation promoting greater understanding of informal caring, and the rights of informal carers.

Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT; Tel: 020 7490 8818

Website: www.carersuk.org

Citizens Advice
The Citizens Advice service helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers.

Website: www.citizensadvice.org.uk

Counsel and Care

Counsel and Care is a charity giving advice and information to older people, their relatives and carers across the UK.

Counsel and Care, Twyman House, 16 Bonny Street, London. NW1 9PG; Tel: 020 7241 8555

Email: advice@counselandcare.org.uk

Website: www.counselandcare.org.uk

Cruse Bereavement Care

Cruse exists to promote the well-being of bereaved people and to enable anyone bereaved by death to understand their grief and cope with their loss. The organisation provides counselling and support. It offers information, advice, education and training services.

Cruse Bereavement Care, Cruse House, 126 Sheen Road, Richmond, Surrey TW9 1UR; Tel: 020 8939 9530

Website: www.crusebereavementcare.org.uk

Help the Aged

A national charity that campaigns for change in government policy, undertakes research into the needs of older people and provides local services in communities across the UK and overseas.

Help the Aged, 207-221 Pentonville Road. London N1 9UZ; Tel: 020 7278 1114

Website: www.helptheaged.org.uk

Hospice Information

An information service for health professionals and the public, including an enquiry and signposting service to palliative care worldwide.

Help the Hospices, Hospice House, 34-44 Britannia Street, London, WC1X 9JG Tel: 020 7520 8232

Website: www.hospiceinformation.info

Macmillan Cancer Support
Macmillan Cancer Support improves the lives of people affected by cancer.,
and provides practical, medical, emotional and financial support.
Macmillan Cancer Relief, 89 Albert Embankment, London SE1 7UQ

Email: cancerline@macmillan.org.uk

Website: www.macmillan.org.uk

Marie Curie Cancer Care
A national charity working with people with cancer and other conditions,
providing specialist nursing services, hospices, and research.

Marie Curie Cancer Care, 89 Albert Embankment, London SE1 7TP;
Tel: 020 7599 7777

Website: www.mariecurie.org.uk

National Council for Palliative Care
The National Council for Palliative Care (NCPC) is the umbrella organisation
for all those who are involved in providing, commissioning and using hospice
and palliative care services in England, Wales & Northern Ireland. It promotes
the extension and improvement of palliative care services regardless of
diagnosis in all health and social care settings and across all sectors to
government, national and local policy makers.

The National Council for Palliative Care. The Fitzpatrick Building, 188-194
York Way, London N7 9AS; Tel: 020 7697 1520

Website: www.ncpc.org.uk

National Institute for Health and Clinical Excellence
National Institute for Clinical Excellence works on behalf of the NHS and the
people who use it by making recommendations for treatment and care using
the best available evidence.

Website: http://www.nice.org.uk

Princess Royal Trust for Carers
A charity providing information and support for all unpaid carers in the UK.

Website: www.carers.org.uk

Social Care Institute for Excellence (SCIE)
SCIE's aim is to improve the experience of people who use social care by developing and promoting knowledge about good practice in the sector. Using knowledge gathered from diverse sources and a broad range of people and organisations, SCIE develops resources for those working in social care, and service users.

Social Care Institute for Excellence, Goldings House. 2 Hay's Lane, London SE1 2HB.   Tel: 020 7089 6840

Website: www.scie.org.uk

Stroke Association
The Stroke Association is concerned with combating stroke in people of all ages. It funds research into prevention, treatment and better methods of rehabilitation, and helps stroke patients and their families directly through its community services. These include dysphasia support, family support, information services and welfare grants.

The Stroke Association , 240 City Road, London   EC1V 2PR

Website: www.stroke.org.uk

UK National Kidney Federation
NKF aim is to promote, throughout the United Kingdom, the best renal medical practice and treatment, the health of persons suffering from kidney disease or renal failure, and to support the related needs of those relatives and friends who care for kidney patients.

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