



Introductory guide to end of life care in care homes

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This guidance comes from the NHS End of Life Care (EoLC) Programme, Care Homes sub-group and is aimed at care home managers and staff interested in improving care for those care home residents in the final stages of life.

Do you think your residents always receive good end of life care and if not, why not?

Do you think that you can improve this and would value support but are unsure about how and where to get help?

Would you like to influence developments in your area for the benefit of your residents?

Then this guide is for you!

This guide is the first of a number of planned publications aimed at supporting you to improve end of life care. It will provide you with:

- an overview of terms associated with end of life care
- what services are available to help you support the choice of residents who prefer to remain in the care home as they near the end of life
- how to get started, with suggestions of practical solutions to help you to organise and plan end of life care
- useful resources to help you to take things further.

We often find it difficult to talk about death and dying. The deaths of people we have cared for may make us feel that we have failed. More than half a million people die in England

and Wales every year; five deaths in every six are of people aged 65 or older; and one in five of all deaths take place in a care home.

The reality is that from time to time staff in care homes will be involved in the care of the dying.

Although death is inevitable for everyone this does not mean that we can simply leave nature to take its course - it would be a failure of care if we did not act to manage needs effectively at the end of life. Palliative and end of life care are a positive part of health and social care, which try to make death as good as possible. This is important for the person themselves, the loved ones they leave behind and those who provide care at this important stage. The way we care for people towards the end of their lives is one of the measures of our success.

This section describes what we mean by 'palliative care', 'end of life care' and supportive care.

End of life care

End of life care requires an active compassionate approach that treats, comforts and supports 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, Fisher et al, 2000:9)

Palliative care:

Palliative care is care of patients with serious illness from which recovery is not expected. Dealing with pain and other symptoms is important, but palliative care also looks at the person as a whole, including their overall sense of wellbeing as well as their physical condition. The goal of palliative care is to achieve the best quality of life for patients and their families, even if that life is likely to be short. The elements of palliative care should be introduced as soon as possible alongside other treatments and not just during the last few days or hours of somebody's life.

Palliative care tackles four main types of need that may arise towards the end of life, both when death is the result of serious illness and when it is the natural 'closing down' that can happen to frail older people.

These needs are:

- **Physical** – managing symptoms such as pain, sickness, tiredness or loss of appetite; good 'tender loving care' such as preventing pressure sores
- **Psychological** – giving emotional support to the resident and those who care about them, giving time to listen to them and understand their concerns

- **Social** – giving support and advice on practical matters such as getting their affairs in order
- **Spiritual** – a need to explore thoughts about the meaning of life, or concerns about what happens after death. All people are likely to have spiritual needs and some may also have practical things they need to do because of their religious beliefs

All care staff should be ready to listen to people nearing the end of life, to address their needs if possible and to seek expert help where extra skill or knowledge is needed.

Supportive care

Supportive care helps the patient and their family to cope with their condition and treatment of it from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment. (Focus on Care Homes, National Council for Palliative Care (NCPC) 2005).

Advance care planning (ACP)

ACP is the process of planning for possible health care decisions that may arise in the future and it particularly relates to end of life care. ACP involves providing appropriate information so that discussion and review of choices about care between individuals, their families, health and social care professionals can take place. Discussion may result in the drawing up of a statement of views which would improve care, allow discussion to avert difficulties at a later date and enable family involvement and care to be more patient focused. ACP is ongoing and not just a one-off event. These decisions need to be recorded. This can be in a variety of ways, mainly in writing, although an oral decision can be made and appropriately recorded.

Under common law, patients can make advance statements in which they refuse specific medical treatments. These can be legally binding and, if they are, doctors are obliged to comply with them. If there is any doubt about whether an advance statement refusing medical treatment is legally binding, GPs should first refer to a consultant and then consider taking legal advice as well. Advance statements refusing treatment are sometimes also called, 'living wills,' 'advance directives' or 'advance decisions.'

The Mental Capacity Act 2005, which becomes law on 1 April 2007, makes new law about ACP, written statements and advance decisions to refuse treatment. It places service providers under a duty to support people with impaired

mental capacity so that they can make their own decisions about the health and social care that they receive. People needing such support might include people with dementia, people with learning difficulties and people at the end of a terminal condition. Under the Act, service providers will also be legally required to take any ACP into account when assessing the best interests of a patient who lacks the capacity to make a decision for him or her self. Care homes will need to ensure that they understand the requirements of the Act before it comes into force.

The NCPC has published more detailed guidance about the Mental Capacity Act. For more information see www.ncpc.org.uk

Issues affecting end of life care Listed below are a number of issues, which you may need to tackle or may have some solutions to. These are likely to vary across the country, depending on how services have developed in the past. If you have solutions to share, the EoLC Programme would like to hear from you. Please email us at: information@eolc.nhs.uk

- Out of Hours (OOH) access to medical help and drugs
- Anticipatory prescribing - ability to hold some drugs in stock and have access to the commonly used drugs in palliative care
- Number of GPs/practices involved in each care home - whilst people in a care home should have a choice of GP, it may be of benefit to limit the number of practices per care home. Some have used Locally Enhanced Services to have one GP practice per care home, some care homes pay practices directly for personalised care - the most difficult scenario is multiple GPs with no common procedure or protocols
- District nurse and specialist palliative care

nurse involvement - variable

- ACP - initiated by some homes as standard but experience some difficulties especially with communication. However it is a very natural place to begin the conversation
 - Resuscitation issues - local policies need to be developed giving clear guidance
 - Verification of death – local protocols need to be developed
 - Education of staff especially at induction and on-going training
 - Cultural and language differences of both staff and residents
 - Rapid staff turnover
 - Residents with co-morbidity - there may be fewer service users with cancer for example but a high incidence of COPD, heart failure and dementia and also additional difficulties in mobility, with deafness and incontinence
 - Different pattern of dying - most people die over a longer period than in the traditional cancer/palliative care pattern and there can be great difficulty in recognising the terminal phase.
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End of Life Care Programme

The NHS EoLC 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 to live and die in the place of their choice. It also aims to reduce the number of people who live in care homes being moved unnecessarily to hospital in the last weeks of their life. This will be achieved by educating and training staff in end of life care. There are three tools, which have been suggested by the Programme which are now being used in some care homes.

Care homes wanting to use one or more of these tools can get help from the teams who developed them, from the EoLC Programme or from the EoLC Leads named for each Strategic Health Authority (SHA). For more information, there are websites for all these tools.

The **Preferred Place of Care Plan (PPC)** is a document that the patient holds for himself or herself and takes with them if they receive care in different places. It has space for the patients' thoughts about their care and the choices they would like to make, including saying where they would want to be when they die. Information about the family can also be recorded so that any new care staff can read about who's who and what matters to them too. If anything changes, this can be written in the plan so it stays up to date. It is never too early to start a PPC plan. For more information, visit the PPC website at: www.cancerlancashire.org.uk/ppc

The **Gold Standards Framework in Care Homes Programme (GSFCH)** The Gold Standards Framework for Community Palliative Care has for more than six years been helping

to improve care for patients nearing the end of their lives living in the community. It is now being used by about a third of Primary Health Care Teams in the UK. The GSFCH was developed and modified from the primary care GSF model, to optimise the organisation, communication and proactive planning for people in the last years of life in care homes. It focuses particularly on improving the collaboration with GPs who look after patients in care homes. Based on the principles of GSF to 'identify, assess and plan care' and using the same seven key tasks, templates and assessment tools, it promotes plan care' and using the same seven key tasks, templates and assessment tools, it promotes integrated collaborative working with primary care and specialist teams. For more information, visit the GSF website at: www.goldstandardsframework.nhs.uk

The **Liverpool Care Pathway for the Dying Patient (LCP)** was developed to take the best of hospice care into care for people in hospital and other settings including care homes. It is used to care for patients in the last days or hours of life once it is known that they are dying. The LCP involves promoting good communication with the patient and family, anticipatory planning including psychosocial and spiritual needs, symptom control (pain, agitation, and respiratory tract secretions) and care after death. The LCP has accompanying symptom control guidelines and information leaflets for relatives. For more information, visit the LCP website at: www.lcp-mariecurie.org.uk

All of these tools are being tested and adapted for care homes. For more information, visit the EoLC website at: www.endoflifecare.nhs.uk

Derek was 62 and had been in the care home for three months. He was admitted following a stroke from which he never fully recovered. He was also suffering from dementia. His wife Betty had visited every day but had been looking

increasingly tired. Derek had his own business but passed this on to his two sons when he started having difficulties due to dementia. Visits from their sons were rare as they lived in the south.

What can I do to improve end of life care?

Case studies

Preferred place of care

Derek had another chest infection for which the doctor prescribed antibiotics.

One day Betty asked to discuss Derek's care, she cried as she spoke about her concerns. She asked that next time Derek developed a chest infection it should not be treated. She did not want him to be transferred to hospital, as he was last time, as this was traumatic and Derek's dementia seemed to worsen after this. Derek was very comfortable in the home and it was easier for Betty to visit. She felt that nature should take its course. She said that she had not discussed this with her sons but felt that after being married to Derek for so long, she knew him best and that previously when in good health he had talked of

not wanting to end his days in dependence. She added that he would have hated to be like this and their sons to witness his demise.

The benefits of using PPC in this situation: The PPC provides a mechanism to facilitate discussions earlier in the person's trajectory of care between the individual and their families. The PPC records an individual's preferences and can initiate establishment of advance directives if the person wants to decline medical treatment.

The PPC process includes the opportunity to regularly review options and to ensure that the difficult discussions about end of life care are recorded and available to all of the teams involved in the delivery of an individual's care.

Gold Standards Framework

Ted, a 69 year-old man with a progressive neurological disease and a diagnosis of metastatic cancer first came into the care home for three weeks respite care, to give his wife a break from her carer role. She too had the same neurological condition and they had met at a support group they attended following the death of their spouses from cancer.

During Ted's first stay in the care home, his condition improved with the additional input of care and he went home to be cared for by his wife and the district nursing team; a 'window of opportunity', to have some additional time at home. When his condition worsened and his wife was unable to cope, following a fall, he again came into the home, a choice they made, where he felt secure. During this visit, his condition deteriorated. He was assessed and placed on the supportive register in the care home and categorised as having only weeks to live. Ted and his wife were trying to protect each other so they were not able express their thoughts, worries and wishes. Staff found it was difficult to give 'comfort' to him – he would pull away from discussion and touch. The GP visited, as Ted's pain was proving difficult to

control and a referral was made to the Specialist Palliative Care (SPC) Team. Some discussion had taken place with Ted and his family about his preferred place of care – they had chosen the care home. The nursing team and palliative care team including the consultant and the GP discussed the plan of care and symptom control options, particularly around his level of pain. Supplies needed to be available as Christmas was approaching, drugs were written up in anticipation of need. Ted's care needs were regularly assessed and as he moved into his final days, the team reviewed his essential drugs and hygiene and comfort measures of care were continued.

Benefits of using GSF in this situation: The family were fully supported, though difficulties of conflict within the former two families were challenging for staff. Ted died at the care home with his wife and some of his family with him.

The staff had to deal with many challenges but by working as a team with the GP and SPC, involving the patient and family in decisions, they achieved a great deal. Reflection of practice, with the difficult symptom control management issues were supported by the SPC team.

Emily had been diagnosed with advanced heart failure and lung cancer and although she had repeated admissions to hospital with similar symptoms, she was significantly weaker on this occasion and did not respond to the usual interventions. The SPC team was asked to get involved in her symptom management.

Although her pain and breathlessness settled with appropriate support and medication, she remained weak and fatigued and she felt she was too frightened to be nursed at home. The option of a care home placement was discussed and it was explained that support would be available at the end of life through the LCP.

Emily was transferred to the care home within two weeks. She died three months later.

A few days prior to Emily's death, the staff in the care home were able to recognise that Emily was deteriorating. In discussion with the

family, it was agreed that she should not be admitted to hospital and the LCP was initiated. An assessment of Emily's needs was undertaken which included psychological, social, spiritual and physical aspects, which included stopping oral medication and prescribing medication by other routes for symptoms such as pain, breathlessness, nausea and vomiting.

Her daughter said, 'I think the culture of the care home was excellent and the LCP helped the staff to help me and my mum. I will miss her terribly but I know her care was the best it could be and that helps.'

Benefits of using LCP in this situation: The LCP provided a structure within which excellent care could be given in the final days of life without readmission to hospital. This meant the disruption was avoided for the resident and the LCP gave the care team confidence to manage the situation.

It would be useful to start thinking about the following issues:

- How many of your residents die each year either in your care home or after transfer to acute care?
- Do all your residents have up-to-date care plans including care at the end of life?
- Can you identify the patients who are nearing the end of their lives?
- Do you talk with your residents about where they would like to live and die?
- What are the main disease groups amongst the residents in your care home?
- How many GP practices provide medical care to your residents?
- What links do you have with social care, SPC such as a link Macmillan nurse?
- Have any of the EoLC tools been

implemented in other organisations within your geographical location eg GP practices, acute trusts, community hospitals, hospices and other care homes?

- Do you know what the priorities of your commissioners are, whether there is an overall palliative care strategy and how care homes fit in?

Once you have this information, find out more about the tools and see which one would best suit your residents' needs. You can implement them all over a period of time but from others' experience it is better to do them one at a time. Take things steadily as all change management activity is challenging.

Each SHA will have a nominated lead for the EoLC Programme. To find out who your local link is for end of life care and what is their current local plan, email information@eolc.nhs.uk

For detailed queries about the tools, go via these websites:

Gold Standards Framework:
www.goldstandardsframework.nhs.uk

Liverpool Care Pathway:
www.lcp-mariecurie.org.uk

Preferred Place of Care:
www.cancerlancashire.org.uk/ppc

Some hints and tips to help you are:

- identify dedicated support if possible, or someone to lead the project
 - have clear objectives
 - take time to develop and agree a clear action plan
 - agree how you will measure and monitor progress
 - start small
 - be realistic about what can be achieved in the agreed timescales
 - don't reinvent the wheel - find out what has been tried and tested before and use available resources and support
-

What services could I access for residents?

Most of the time, people's care needs at the end of life can be met by their usual carers but sometimes expert help is needed. This expert help is most developed for people with cancer, but is increasingly available for people with other conditions. This section explains the role of some of the staff and organisations that care homes can call upon to provide specialist help.

Primary Health Care Team

The focus for most health care provided in the community, it is based around the local GP practice and linked staff such as district nurses

Specialist Palliative Care Team

The palliative care team is a team of specialist doctors, nurses and sometimes pharmacists, social workers and therapy staff, who provide expert advice to patients or their professional carers (such as GPs, district nurses or care home staff). They may be from the NHS or from a voluntary sector hospice and they may work in the hospital or community. Often they have close links with local hospices.

Hospice

Hospices are organisations that provide palliative care services including in-patient care, day care

or home care and most are run by local charities although some are NHS run. Hospices generally provide care for patients with complex or severe problems and focus on dealing with symptoms; on average, only about half of their admissions end in death in the hospice and stays are typically less than two weeks.

Clinical Nurse Specialists in Palliative Care (often called Macmillan Nurses)

Clinical Nurse Specialists in Palliative Care are experienced qualified nurses with extra training and experience in care for people with cancer, who usually work as part of the NHS team. Patients can be referred to them at any time after a cancer diagnosis and they offer information, advice and support. They may also help people with other life threatening illnesses. Some work mainly with care homes to train care staff or give advice on individual residents' needs.

Marie Curie Nurses

Marie Curie nurses offer expert home nursing care and emotional support to families affected by cancer in partnership with local health services. Marie Curie Nurses can be qualified nurses or nursing assistants, depending on what care the patient needs. They are available by prior arrangement during the day or through the

night, and provide practical care, giving carers a break and a chance to rest.

Other Specialist Nurses

Local situations vary, but it may be possible to call on specialist nurses in other fields. For example, there are British Heart Foundation heart failure nurses, British Lung Foundation respiratory nurses, Parkinson's disease nurses and Admiral Nurses who work with people with dementia and their families.

Health and social care equipment stores

Arrangements for these vary locally, with some areas having joint NHS and Local Authority stores and others having separate ones. They can provide loan equipment including specialist beds and commodes to support activities of daily living.

Social Services

Social Services offer information, advice or

services to help people at home and in care homes. Councils are expected to meet the needs of people from all communities. Some specialist services are also available. People need to meet certain eligibility criteria to have services and a financial charge may be made for some services.

NHS Direct

NHS Direct operates a 24-hour nurse advice and health information service, providing confidential information on:

- what to do if someone is feeling ill;
- particular health conditions;
- local healthcare services, such as doctors, dentists or late night opening pharmacies.
- Self-help and support organisations.
- NHS Direct works hand in hand with other healthcare services provided by the NHS, helping you make the right choice to meet your needs. NHS Direct on 0845 4647.

The following list cannot be exhaustive but is offered as suggestions:

The **NCPC** (Tel: 020 7697 1520) is the umbrella body for anyone involved in hospice and palliative care services in England, Wales and Northern Ireland. The Council works with people in the NHS, voluntary and independent sectors including care homes and has an interest in improving the palliative care provided to older people. For more information about their work and about palliative care, see www.ncpc.org.uk

The **NHS EoLC Programme** (Tel: 0116 222 5103) was set up to improve the quality of care for people at the end of life. In particular, it aims to help more people to live and die in the place of their choice. It also aims to reduce the number of people who live in care homes being moved unnecessarily to hospital in the last weeks of

their life. For further information, see www.endoflifecare.nhs.uk

The **Alzheimer's Society** (Tel: 0207 306 0606) is committed to maintaining, improving and promoting its unique knowledge and understanding of dementia. www.alzheimers.org.uk

British Heart Foundation (BHF) (Tel: 08450 708070) is a charity, which aims to play a leading role in the fight against diseases of the heart and circulation so that it is no longer a major cause of disability and premature death. www.bhf.org.uk

Marie Curie Cancer Care (Tel: 0207 599 7777) is a national charity working with people with cancer and other life limiting conditions. www.mariecurie.org.uk

Useful sources of information

Macmillan Cancer Support (Tel: 0808 808 2020) is a national charity working with and providing resources for cancer patients. www.macmillan.org.uk

Macmillan training pack - Foundations in Palliative Care: (Tel: 0808 808 2020) This is a programme of facilitated learning for care-home staff, which enables staff at all levels to improve their knowledge and understanding of palliative care. It is a self-contained educational resource which uses a work based case study approach.

Help the Aged (Tel: 0207 278 1114) is a charity working with older people to ensure they have enough to live on, feel more involved, get equality in all areas of their lives and receive high quality care when and where they need it. www.helptheaged.org.uk

Age Concern (Tel: 0208 765 7200)– supports people over 50 years old in the UK ensuring that they get the most from life. www.ageconcern.org.uk

The **Citizens Advice** service helps people resolve their legal, money and other problems by providing free information and advice from nearly 3,400 locations, and by influencing policymakers. www.citizensadvice.org.uk

Counsel and Care (Tel: 0207 241 8555): advice and help for older people – Counsel and Care’s advice work team works over the telephone and by letter backed up by a range of well researched and regularly updated fact sheets. They are able to advise on a wide range of subjects such as welfare benefits, accommodation, residential care, community care and hospital discharge. www.councilandcare.org.uk

Long Term Conditions Alliance (Tel: 0207 813 3637) is the umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions. www.lmca.org.uk

The Neurological Alliance (Tel: 0207 566 1540) is a collaborative forum of a wide range of neurological charities. The National Service

Framework (NSF) for long-term conditions has a particular focus on the needs of people with epilepsy, multiple sclerosis, Parkinson’s disease, motor neurone disease and other similar conditions. www.neural.org.uk

The Stroke Association (Tel: 0845 303 3100) - main focus is to prevent strokes and to give support to people who have had a stroke and their families through our information and community services. www.stroke.org.uk

The British Red Cross (Tel: 0870 170 7000) – short-term support for independent living: Thousands of people every year benefit from the caring assistance that these services provide. www.redcross.org.uk

Carers UK (Tel: 0207 490 8818) - the voice of carers: Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. Carers UK is the voice of carers and is the only care-led organisation working for all carers. www.carersuk.org

Princess Royal Trust for Carers (Tel: 0207 480 7788) is a provider of comprehensive carers support services in the UK. Through its network of independently managed Carers’ Centres and interactive websites the Trust provides quality information, advice and support services for all including young carers. www.carers.org

Help the Hospices (Tel: 0207 520 8200) is the national charity providing support to hospices. www.helpthehospices.org.uk

Hospice Information (Tel: 0207 520 8232) is an information service for anyone with a professional or personal interest in hospice and palliative care both in the UK and worldwide. Services include a wide range of publications, electronic news resources, training database, quarterly journal and enquiry line. Hospice Information is provided by Help the Hospices and St. Christopher’s Hospice. www.hospiceinformation.info

Reforming Emergency Care (Tel: 0207 633 4208): www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/EmergencyCare

This government programme includes the Emergency Services Collaborative which is an intensive support programme giving individual support and advice on patient experience and delays with emergency access. www.modern.nhs.uk/scripts/default.asp?site_id=35

Cancer Services Collaborative

'Improvement Partnership' (CSC 'IP') (Tel: 0116 222 5110) works with cancer networks and the Cancer Action Team to achieve the objectives of the NHS Cancer Plan 2000 including palliative and supportive care.

www.cancerimprovement.nhs.uk

Heart Improvement Programme

(Tel: 0116 222 5184) (formerly Coronary Heart Disease (CHD) Collaborative) draws upon the National Service Framework (NSF) for CHD aiming to fundamentally redesign the systems for prevention, diagnosis, treatment and care of patients with coronary heart disease. They published a framework, "A Framework for Supportive and Palliative Care for Advanced Heart Failure" (Dec 2004). www.heart.nhs.uk

Critical Care - This programme aims to improve experience and outcomes for patients with potential or actual need for critical care based on the severity of their illness and not where their care is being delivered. Every critical care unit is part of a critical care network. www.wise.nhs.uk/cmsWISE/Clinical+Themes/criticalcare/cc.htm

Older Peoples Services draw on the National Service Framework for older people (2001): for more information see www.dh.gov.uk

NHS Continuing Care regulations – NHS funded nursing care: Before October 2001, some people had to pay for their own nursing care. Now everyone in need, regardless of setting and means, is eligible for NHS-paid care from a registered nurse. www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/IntegratedCare/NHSFundedNursingCare/fs/en

Department of Health cancer and end of life information

can be found on this site: www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer

Parliamentary publications including the Health Select Committee Inquiry into Palliative Care. www.publications.parliament.uk/pa/cm/cmhealth.htm

This **Bulletin** contains details of circulars and similar materials and where they can be found. The Bulletin is part of the Department of Health's general review of all its communications to the NHS and Social Services audiences. It is intended to improve access to information by reducing the volume of current material sent to the NHS and Social Services departments.

www.dh.gov.uk/PublicationsAndStatistics/Bulletins/fs/en

The Big Lottery (New Opportunities Fund)

(Tel: 0845 0000 121) - funded adults palliative care projects. www.nof.org.uk

National Institute for Health and Clinical Excellence

(Tel: 0207 067 5800) works on behalf of the NHS and the people who use it by making recommendations for treatment and care using the best available evidence.

www.nice.org.uk

Healthcare Commission

(Tel: 0207 448 9200) – Its full name is the Commission for Healthcare Audit and Inspection (CHAI); it was launched in April 2004 to promote improvement in the quality of healthcare in England and Wales. It covers the independent sector in England only. www.healthcarecommission.org.uk

Commission for Social Care Inspection

(CSCI) (Tel: 0207 979 2000) is the single independent inspectorate for all social care services in England. It promotes improvements in social care for the benefit of all. It incorporates work formerly done by the Social Services Inspectorate (SSI), the SSI/Audit commission joint review team and the National Care Standards Commission. www.csci.org.uk

National Institute for Mental Health Education (NIMHE) (Tel: 0113 254 5127) supports local communities to improve mental health education and the quality of service for people affected by mental health problems. www.nimhe.org.uk

Mental Health Foundation (Tel: 0207 803 1100) website. Copies of 'Dying Matters A workbook for people with learning disabilities,' is available from this site: www.mentalhealth.org.uk

Foundation for people with learning disabilities: (Tel: 0207 803 1100) www.learningdisabilities.org.uk

World Health Organisation Cancer programme across the world: www.who.int/cancer/palliative

The English Community Care Association (Tel: 0207 220 9595) is the largest representative body for community care in England. Working on behalf of care homes, it speaks with a single unified voice on behalf of its members and the sector, and seeks to create an environment for providers to continue to deliver and develop high quality care. www.ecca.org.uk

Registered Nursing Home Association (Tel: 0121 454 2511) gives information for nursing home owners and staff; for people seeking a nursing home place; and for members of the public with an interest in the care of older people and those with disabilities. www.rnha.co.uk

The National Care Forum (NCF) (Tel: 0247 624 3619) has a primary purpose of promoting quality outcomes for people receiving care and support through the not-for-profit sector. NCF supports not-for-profit providers through information and guidance, research and development, partnerships and networking opportunities. www.nationalcareforum.org.uk

National Care Association (Tel: 0207 831 7090) This website is intended for members, care professionals and members of the public, to provide easy access to information about the independent care sector and issues that affect us. www.ncha.gb.com/ncha/index.htm

NB. All information correct at time of printing

Useful documents

Various sites/documents on topics you may find useful and can download.

Documents below can be accessed from the Department of Health website. Type in the title of the document in the search box on www.dh.gov.uk

Our health, our care, our say: a new direction for community services	2006
National Service Framework for Renal Services Part 2	2005
Supporting people with Long Term Conditions	2005
A toolkit for older peoples champions	2004
Better Health in Old Age	2004
National Service Framework for Diabetes	2005
Independence well being and choice	2005
Building on the Best: Choice, responsiveness and equity in the NHS: summary documents	2004
NICE Supportive and Palliative Care Guidance www.nice.org.uk/page.aspx?o=110006	2004
Supportive and Palliative Care for advanced heart failure www.heart.nhs.uk/scripts/default.asp?site_id=23&id=4668	2004

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Glossary

ACP	Advance Care Plan
COPD	Chronic Obstructive Pulmonary Disease
EoLC	End of Life Care Programme
GP	General Practitioner
GSF	Gold Standards Framework
GSFCH.....	Gold Standards Framework Care Homes
LCP	Liverpool Care Pathway
NCPC.....	National Council for Palliative Care
NHS.....	National Health Service
OOH	Out of hours
PPC	Preferred Place of Care
SHA.....	Strategic Health Authority
SPC	Specialist Palliative Care



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