

End of Life Care in Housing with Care Settings: Update on Policy and Recent Research

This factsheet updates housing with care practitioners and providers on new end of life care policy developments, and outlines the findings of recent research on end of life care in housing with care settings. Further information is also contained in a new Resource Pack for housing providers, published by the NHS End of Life Care team and supported by the Housing Learning and Improvement Network (LIN).

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Introduction

An earlier Housing LIN Factsheet, *Delivering End of Life Care in Housing with Care Settings*:

(Croucher, 2006; <http://www.dhcarenetworks.org.uk/pageFinder.cfm?cid=1617>)

set out to raise awareness among housing and care practitioners and providers of the then current agendas and developments in practice around end of life care. The factsheet considered policy, definitions of end of life care, the tools that have been developed to assist with the provision of generalist and community end of life care services, and went on to reflect on some of the implications for housing with care settings. In the two years since publication of that factsheet, end of life care has climbed up the policy agenda.

There is now a national End of Life Care Strategy (DH, July 2008). Work has continued to improve end of life care in residential care homes (see *Building on Firm Foundations* by the National Council for Palliative Care in partnership with the NHS End of Life Care Programme). Two research projects on end of life care have been undertaken in housing with care settings (Easterbrook and Vallely, 2008; Crosbie et al, 2008), and these have led to the development of a Resource Pack by the National End of Life Care Programme and Housing 21 designed for housing with care practitioners (www.endoflifecareforadults.nhs.uk or www.housing21.co.uk).

In addition, the National End of Life Care Programme has recently launched a set of competences and principles aimed at up to 2,5 million health and social care staff whose work brings them into contact with those nearing the end of their lives. Developed by Skills for Health and Skills for Care, the document highlights seven principles that underpin all workforce, service development, activity and delivery, and places an emphasis on individual choice, communication, and multi-disciplinary and inter-agency working. The document *Core Competencies for End of Life Care: Training for Health and Social Care Staff* can be found at:

http://www.endoflifecareforadults.nhs.uk/eolc/files/NHS-EoLC_Core_competences-Guide-Jul2009.pdf

It seems, therefore, timely to provide an up-date on policy and recent research findings on the crucial topic of end of life care in housing with care settings.

In the 21st century, (older) people often die from long term, chronic conditions or a combination of different conditions, where prevention or cure is not possible. It is important to stress that end of life care is about addressing a range of needs, not just care needs, often over prolonged periods of time. It is worth repeating the definition of end of life care that was given in the earlier factsheet.

“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)

The care and support available in housing with care settings can work alongside more specialist, community based palliative care services to address a wide spectrum of needs, and also offer a wider choice to older people regarding their preferred place of death.

The changing policy context

End of life care is increasingly being recognised as a crucial policy and practice issue. Currently in England the majority of people (58%) die in hospital, and those aged 75 to 85 have even higher hospital death rates. The changing demographic profile of the UK means that end of life care services will have to be developed, particularly community services, otherwise hospitals and in-patient services will have to expand considerably to become places predominantly occupied by people, usually older people, who are dying (Gomes and Higginson, 2008). Moreover, research indicates that people of all ages have a range of preferences over the place of death. Most people would prefer to remain at home when they are dying, but with the assurance that high quality care can be delivered so that their families and carers are not over burdened by their caring responsibilities. Some want to be cared for in a hospice as they do not want to be a burden on their families. It seems that some people (particularly older people) who live alone wish to remain in their own homes for as long as possible, although they wish to die elsewhere to ensure that they do not die on their own. Most people – although not all – do not want to die in hospital (see End of Life Care Strategy, DH, 2008).

The NHS Cancer Plan (2000), and the White Paper *Building on the Best* (2003), both set out to improve end of life care, and led to the NHS End of Life Care Programme (see www.endoflifecareforadults.nhs.uk). The Programme aimed to encourage the use and development of end of life care models, notably the Gold Standards Framework, the Liverpool Care Pathway for the Dying Patient, and the Preferred Priorities for Care Plan. These tools were outlined in the earlier Factsheet. Much work has been done in the last two years to introduce these tools into care homes. Alongside these developments around end of life care there has been increasing concern to ensure dignity and choice for patients, particularly older patients.

In 2008, the Department of Health published its national *End of Life Care Strategy*, building on the work of the NHS End of Life Care Programme, and reflecting concerns about the need for an improvement to end of life care services. It is clear that the provision of end of quality end of life care requires considerable co-operation between different agencies and professional groups, both at national and local levels. The strategy sets out where the responsibility for different actions and initiatives will be located.

A key concern is to ensure that end of life care is responsive to a range of needs and preferences. The strategy's aim is:

"...to bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice, or elsewhere"

The strategy has ten objectives (presented in Box 1 below).

To increase public awareness and discussion of death and dying. This will make it easier for people to discuss their own preferences around end of life care and should also act as a driver to improve overall service quality.

To ensure that all people are treated with dignity and respect at the end of their lives.

To ensure that pain and suffering amongst people approaching the end of life are kept to an absolute minimum - with access to skilful symptom management for optimum quality of life.

To ensure that all those approaching the end of life have access to physical, psychological, social and spiritual care.

To ensure people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible.

To ensure that the many services people need are well coordinated, so that patients receive seamless care.

To ensure that high quality care is provided in the last days of life and after death in all care settings.

To ensure that carers are appropriately supported both during a patient's life and into bereavement.

To ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care.

To ensure that services provide good value for money for the taxpayer.

Source: End of Life Care Strategy (DH, 2008)

To address these objectives, the strategy outlines an end of life care pathway with the following key elements:

- discussion as end of life approaches;
- assessment of needs and preferences, care planning and review;
- coordination of care for individual patients;
- delivery of high quality services in different settings;
- care in the last days of life;
- care for friends and family after the person's death and
- support for carers during a person's illness and after their death.

A further policy priority is that of the "personalisation" agenda which aims to allow people greater choice and control over deciding what their support needs are and how they will be met. The vision for the transformation of adult social care is set out in Putting People First (see:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118). Primarily this agenda is being met through the introduction of individual budgets and other forms of personal budget handling arrangements. This has implications for housing with care schemes, as residents will be able to choose how they will spend the resources that have been allocated to them, and for some this might mean looking to external providers for services that may not be available or may simply be different or even cheaper than those which are available in the schemes. As yet it remains unclear how this will affect housing with care schemes, and more particularly, on the capacity of schemes to provide the type of flexible and often intensive packages of care that people may need as they approach the end of their lives.

End of life care in housing with care: key messages from recent research

A review of research on different models of housing with care for later life commissioned by the Joseph Rowntree Foundation highlighted that the idea of housing with care as a “home for life” was not supported by evidence (Croucher et al, 2006). Various studies indicated that significant numbers of residents were moving on into nursing homes and other care settings, most usually because their care needs increased, raising questions about the capacity of housing with care to provide end of life care. There had, at the time of the review, been no research into end of life care in housing with care settings.

More recently two studies have been published which have investigated end of life care in housing with care settings. Crosbie et al (2008) report work undertaken in two housing with care schemes as part of a larger project on end of life care education. Easterbrook and Vallely (2008) report a pilot project designed to enhance end of life care in housing with care schemes. Both these relatively small scale studies were undertaken in schemes operated by Housing 21. They are useful starting points for the exploration of practice. It is recommended that both reports are read in full, as it is only possible to cover the main findings and recommendations here.

The work by Crosbie et al *Exploring End of Life Care in the Context of Housing with Care Settings* (2008) was focused on gaining an insight into the understanding of end of life care issues on the part of both residents and staff within two housing with care schemes. Residents’ understanding of advanced care planning and end of life issues varied. Some residents were reluctant to discuss the topic. Others, however, did feel that it was necessary (and difficult) to confront the issues.

Some had discussed end of life care issues informally with care staff, but none of the residents who took part in the project had made any formally communicated statement of wishes about their preferences for end of life care, although in discussion many were clear what they did **not** want. Often this was based on what they had seen happen to other people. They also said that they found it difficult to talk to family members about their preferences for end of life care, often because such discussions were upsetting, or sensitive, (for example, not wanting particular individuals to be involved with aspects of finance). It is also important to note that residents felt that living in a housing with care scheme had a positive impact on their well-being, and consequently believed that it might be possible to live in the schemes for the rest of their lives. Independence, and having the services in place to maintain independence even when people were very unwell, was also another key issue.

People were concerned not to be a burden to their families, and the care available within schemes was felt to relieve residents’ concerns about being a burden on their families and loved ones. Another theme in the discussions was getting access to accurate information about advanced care planning, and the need for residents to know who to ask for such information.

Discussions with care staff demonstrated that they were interested in promoting the idea of advanced care planning to older people, partly because they had seen cases where residents’ wishes had been disregarded by families, especially when residents were seriously ill and unable to communicate what they wanted. Staff were also aware that there might be the potential for conflict between residents’ families and care staff over what might be best for a resident. Staff were, however, more ambivalent about caring for people until the end of their lives within housing with care settings. While they acknowledged older people’s wishes to spend their remaining time in housing with care, they felt that increased resources from a range of different service providers – community nurses, GPs, social services - would be needed. They were concerned that they did not have the necessary palliative care skills to care for

people towards the end of life. Staff were also concerned that too much talk about dying could be detrimental to the wellbeing of residents, and indeed frightening for some people. They also spoke about how experiencing the death of a resident, and supporting families can be very difficult for staff, as illustrated by the words of a member of staff quoted in the report:

“I have dealt with death on several occasions taking care of relatives, also sitting with somebody while they’re at the very end of their life, it is very hard. It is very, very hard on carers. I think that sometimes people don’t understand how hard it is on carers.”

Crosbie et al, 2008, p30.

In terms of the support needed by staff in dealing with bereavement and family grief, staff noted the importance of supportive staff team and management, but were not so sure that formal training in end of life care would be that useful. The authors note that staff interviewed were unable to articulate their training needs, sometimes because they were relatively new to their jobs, and also because of the perception that “there is no way to prepare for it”.

Drawing on these discussions, the authors highlight the need for housing developments that can ensure a level of choice and independence even for those who are chronically ill and approaching the end of their lives. Similarly, they note that many housing with care schemes are at the heart of local communities, providing a focus for services for older people and could provide a potential base for community outreach services, and intermediate and rehabilitative care. They also note that providing end of life care at home within a housing with care setting will prove challenging in terms of time and resources, and also because of the need for staff training.

The project, *“Is it that time already? Extra Care Housing at the End of Life: A Policy into Practice Evaluation”* reported by Easterbrook and Vallely (2008) was undertaken in three Housing 21 schemes. The project had a number of aims:

- to enable tenants to die at home if this was their choice;
- to put processes in place to ascertain tenants’ wishes and preferences;
- to develop an integrated approach to work within the community in accessing supportive care for tenants, their families and staff;
- to explore the challenges of end of life care in extra care housing settings;
- to improve the skills and knowledge base of staff;
- to develop data and monitoring tools.

While this was a small project, it seemed that residents in the three pilot schemes who died during the course of the project were more likely to have been consulted over their preferences for end of life care and their place of death, and to have had these choices met than residents living in other Housing 21 schemes. There are of course caveats around drawing too many conclusions from a small data set (and these are noted by the authors).

In line with the findings of the work by Crosbie *et al*, residents’ views varied about how much or little they wanted to know or discuss about end of life issues and advanced care planning. The wishes and preferences of those who have lived in schemes longest were more likely to be known. Again staff were often reluctant to talk about death and dying, particularly with those residents that might not be able to fully understand. It was felt that written information about the support on offer in a

scheme (including the support available at the end of life) that could be shared with families and residents when they first moved in would be helpful. The research highlighted the importance of having conversations with residents about their preferences for end of life care, and recording these preferences and decisions. Staff felt it would be useful to discuss Advance Care Planning as part of an on-going discussion about residents' plans and wishes for the future, ideally soon after they had moved in, following the initial settling in period.

It was apparent that there was some initial lack of understanding about extra care housing among service commissioners, health and social care providers and tenants and their families. It was also clear, however, that there was a shared willingness to learn more about what was possible to support people at the end of their lives in extra care housing. uncertainty of what was best practice, and (housing staff's) fear of doing something wrong was a key barrier to holding back professionals and organisations, reflecting a wider societal reluctance to openly discuss death and dying.

Over the course of the pilot project it became more "normal" for care staff to talk and think about end of life care. They became more aware of what to look for and how to respond. They also knew more about what the local specialist palliative services offered and how such services might be accessed. Health and social care professionals wanted to talk about and plan how extra care housing could support end of life care, and health professionals began to volunteer additional support to scheme staff.

The authors' summary recommendations are outlined below, however note that the report contains more detailed recommendations about different aspects of practice.

To deliver end of life care in housing with care settings requires working across professional and organisational boundaries, which in turn requires knowledge and understanding of what individual residents want and what individual schemes can support and accommodate.

Clear and concise information about extra care housing is needed for and by tenants, families and health/housing/social care professionals and organisations.

Extra care housing must be seen as a continuum of "living at home", rather than "living in a home".

At operational levels, different professional groups need to discuss how outcomes can be improved for residents. Housing with care staff need to engage with other professional groups, and raise awareness of what housing with care can do.

End of life care should be part of staff induction, and should include: training on the Mental Capacity Act 2005; symptoms of terminal stages of life and what to look for, report and record; information about local end of life services and support for bereavement and grief.

Opportunities should be made for residents and families to record their wishes, however a "one size fits all" approach would be inappropriate, and consideration needs to be given as to how to incorporate the issue of end of life care into existing policies and practices.

Residents need to feel sure that their wishes will be respected as far as possible.

Housing providers need to ensure that specialist support can be accessed for people with dementia or other mental capacity issues.

Key issues for housing with care

There are increasing numbers of housing with care schemes. Most are very new, and more are in the development stage. Practice is continually developing, and no one scheme is quite like another. As noted in the earlier factsheet, housing with care settings would seem to be ideal environments in which to provide end of life care, and the flexible care on offer in housing with care settings should make it easier for people to die in their own homes, if this is their preference. Evidence, however, suggests that many people do move from housing with care settings to care homes towards the end of their lives, raising questions about how best to enhance the potential of housing with care schemes to offer a “home for life”.

Housing with care schemes are different from care homes, but also different from living in the community, a point made succinctly by Oldman (2000). A consistent theme from research on housing with care is the perception of residents that living in such schemes is a “different way of life” from living in the community (see for example, Croucher et al, 2007). Many are designed to accommodate both the fit and the frail, and studies have shown that there are sometimes tensions between those who are relatively active and well and those who are not (Croucher et al, 2006; Croucher et al, 2007; Bernard et al, 2008). Within such relatively new provision, often with a diverse resident group, where the emphasis is on independence and promoting a positive experience of ageing, it is easy to see why it might be difficult to engage in a discussion with residents (and their families) about their preferences for end of life care. However without this crucial starting point about preferences and concerns, service providers cannot begin to respond to residents’ expectations and develop services accordingly, or indeed properly understand how best housing with care can work with other service providers, particularly specialist palliative care specialists, to enhance the quality of end of life care.

While the “care” provided in housing with care schemes cannot address clinical needs (and recent research suggests that care staff are concerned about the limitations of their skills when people are very ill), it is important to bear in mind the definition of end of life care, as being “*sensitive to personal, cultural, and spiritual values, beliefs and practices*”. The day-to-day tasks of making people feel more comfortable and supported, and understanding individual preferences and routines, can make an enormous difference in enhancing residents’ dignity, well-being and sense of control in a difficult situation. As Easterbrook and Vallely suggest, this is the “extra” in extra care. The recently published Resource Pack on end of life care in housing settings highlights how practice can address more effectively a range of needs at the end of life.

At a more strategic level, housing with care providers could usefully develop links with a range of social and health care providers to promote a better understanding of what housing with care is, and how best different service providers can work together. Research stresses the importance of developing local networks, and promoting shared understanding of what different organisation and professional groups can offer.

Further understanding of the “housing” management issues that are associated with end of life care, as well as the “care” issues is also required. This includes the design of housing schemes to support resident’s privacy and/or to facilitate the delivery of care (see the Housing LIN factsheet no.6 on design for general information), and appropriate training for housing, care and support staff. As highlighted by Easterbrook and Vallely it seems likely that in schemes where the housing element and care elements are provided by different organisations, different approaches may be needed from those required in schemes where the housing and care elements come from a single provider.

Vignettes for discussion

Evidence indicates that there is no “best” way to begin a discussion about end of life care, and that different individuals can be more or less open to discussions. The following vignettes are intended to promote discussion about how and when to introduce discussion about end of life care in different circumstances, and what additional services might be sought to support individuals in the particular circumstances.

Vignette 1: Mr and Mrs Jones

Mr and Mrs Jones have been married 50 years. Mr Jones is 85, and Mrs Jones 75. They moved into their housing with care scheme eighteen months ago. Mrs Jones has diabetes and poor vision and was finding it difficult to manage in the flat where they previously lived. Also, Mr Jones had been diagnosed with Alzheimer’s disease, and Mrs Jones was finding it difficult to cope with looking after him. Mr Jones’ condition is worsening; although he still recognises his wife, he does not always recognise other family members who visit infrequently. His behaviour can be difficult and other residents are cautious around him. On one occasion he was violent towards his wife, but care staff intervened. Carers visit the couple twice a day. Mrs Jones has begun to say that she cannot cope for much longer. She is being treated for depression by her GP.

Vignette 2: Roy

Roy is 80. He has never been married and has no close family. He has lived in his scheme for two years. He has some longstanding mobility problems and issues with alcohol. He has recently been diagnosed with stomach cancer, and the long term prognosis is not good.

Vignette 3: Edith

Edith is a widow, aged 86. Edith cared for her husband while he was ill, moving into the scheme after his death four years ago. She suffers from heart failure and has arthritis in her spine. Despite a hip replacement two years ago, she has very limited mobility, and needs assistance with bathing and getting up in the morning. Occasionally she has called for assistance in the night as sometimes she has difficulty with her breathing. Her GP says this is mostly due to anxiety. Her family do not live locally although they visit quite frequently. Edith is becoming a little confused at times. She needs reminding to take her regular medication.

Vignette 4: Rita

Rita is 75 and has been a widow for 25 years. She moved into her flat two years ago following a break-in at her previous house. She is very active and enjoys good health. She enjoys the company of other residents and joins in with any social activities or events that are going on. She also has an active social life outside the scheme, going to church regularly and spending a lot of time with friends and family - particularly her daughter who visits almost every day.

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<http://www.housingcare.org/downloads/kbase/2845.pdf>

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 National 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.

<http://www.endoflifecareforadults.nhs.uk>

The Department of Health Dignity in Care Programme

The Dignity in Care Campaign aims to end tolerance of indignity in health and social care services through raising awareness and inspiring people to take action.

http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Dignityincare/DH_6600

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.

<http://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

<http://www.alzhiemers.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.

14 Fitzhardinge Street
London, W1H 6 DH
Tel: 020 7935 0185

<http://www.bhf.org.uk>

British Lung Foundation

73-75 Goswell Street
London EC1V 7ER
Tel: 08458 505020

<http://www.lunguk.org>

Cancerbackup

3 Bath Place
Rivington Street
London EC2A 3JR

<http://www.cancerbackup.org.uk>

Care Quality Commission

The Care Quality Commission is the independent regulator of health and social care in England.

Care Quality Commission
National Correspondence
Citygate
Gallowgate
Newcastle upon Tyne NE1 4WH
Tel: 03000 616161

<http://www.cqc.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
<http://www.carersuk.org.uk>

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.

<http://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
020 7241 8555
Email: advice@counselandcare.org.uk
<http://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
020 8939 9530
<http://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
020 7278 1114
<http://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
020 7520 8232

<http://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
<http://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
020 7599 7777
<http://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;
020 7697 1520
<http://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.

<http://www.nice.org.uk>

Princess Royal Trust for Carers

A charity providing information and support for all unpaid carers in the UK.

<http://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.

020 7089 6840

<http://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

<http://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.

UK National Kidney Federation

6 Stanley Street

Workshop S81 7HX

Tel: 01909 487795

<http://www.kidney.org.uk>

Other Housing LIN publications available in this format:

- Factsheet no.1: **Extra Care Housing - What is it?**
- Factsheet no.2: **Commissioning and Funding Extra Care Housing**
- Factsheet no.3: **New Provisions for Older People with Learning Disabilities**
- Factsheet no.4: **Models of Extra Care Housing and Retirement Communities**
- Factsheet no.5: **Assistive Technology in Extra Care Housing**
- Factsheet no.6: **Design Principles for Extra Care**
- Factsheet no.7: **Private Sector Provision of Extra Care Housing**
- Factsheet no.8: **User Involvement in Extra Care Housing**
- Factsheet no.9: **Workforce Issues in Extra Care Housing**
- Factsheet no.10: **Refurbishing or remodelling sheltered housing: a checklist for developing Extra Care**
- Factsheet no.11: **An Introduction to Extra Care Housing and Intermediate Care**
- Factsheet no.12: **An Introduction to Extra Care Housing in Rural Areas**
- Factsheet no.13: **Eco Housing: Taking Extra Care with environmentally friendly design**
- Factsheet no 14: **Supporting People with Dementia in Extra Care Housing: an introduction to the the issues**
- Factsheet no 15: **Extra Care Housing Options for Older People with Functional Mental Health Problems**
- Factsheet no 16: **Extra Care Housing Models and Older Homeless people**
- Factsheet no 17: **The Potential for Independent Care Home Providers to Develop Extra Care Housing**
- Factsheet no 18: **Delivering End of Life Care in Housing with Care Settings**
- Factsheet no 19: **Charging for Care and Support in Extra Care Housing**
- Factsheet no 20: **Housing Provision and the Mental Capacity Act 2005**
- MCA Information Sheet 1: Substitute Decision-making and Agency**
- MCA Information Sheet 2: Lawful restraint or unlawful deprivation of liberty?**
- MCA Information Sheet 3: Paying for necessities and pledging credit**
- MCA Information Sheet 4: Statutory Duties to Accommodate**
- Factsheet no 21: **Contracting Arrangements for Extra Care Housing**
- Factsheet no 22: **Catering Arrangements in Extra Care Housing**
- Factsheet no 23: **Medication in Extra Care Housing**
- Factsheet no 24: **Social Well-Being in Extra Care Housing**
- Factsheet no 25: **Nomination Arrangements in Extra Care Housing**
- Factsheet no 26: **Housing for People with Sight Loss**
- Factsheet no 27: **Attendance Allowance, Disability Living Allowance and Extra Care Housing**
- Factsheet no 28: **Day Care and Outreach in Extra Care Housing**
- Factsheet no 29: **The Cohousing Approach to 'Lifetime Neighbourhoods'**
- Factsheet no 30: **Extra Care Housing and the Credit Crunch: Impact and Opportunities**