

# Dying at home

The role of social housing providers in supporting terminally ill people in Wales

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Policy report  
Policy and Public Affairs Team, Wales

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# Contents

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1.	Introduction	3
2.	Context	5
2.1.	End of life needs of a changing population	5
2.2.	End of life care and housing: Policy and practice	5
3.	Research findings	7
3.1.	The survey	7
3.2.	Identifying what works	11
3.3.	Identifying the challenges	11
4.	Overcoming the challenges	16
5.	Conclusion	18
6.	References	19

# 1. Introduction

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In *Together for Health – Delivering End of Life Care: A Delivery Plan up to 2016 for NHS Wales and its Partners*<sup>1</sup>, the Welsh Government recognises choice and continuity as important components of high quality end of life care.

Surveys have repeatedly shown that, when asked, approximately two-thirds of the population say they would prefer to die at home if they had a terminal illness and their symptoms could be controlled. This remains the case more or less regardless of whether one is a homeowner, a private renter or a social renter<sup>2</sup>. Whilst the percentage of people dying at home rather than in hospital has been very gradually increasing over recent years in Wales, in 2011 this still stood at just 22 per cent<sup>3</sup>.

An individual may need end of life support from the point of diagnosis in the form of assistance with planning for the future and signposting to relevant services or they may need specialist support at a point in the progression of their illness. This could involve adapting a home to accommodate a person's changing needs so they can stay with their loved ones throughout their care or specialist care from a multi-disciplinary team. It may even carry on after death in the form of bereavement support for family and friends. A 'good death' involves more than just dying in place of preference.

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**"For our population we want: People in Wales to have a healthy, realistic approach to dying, planning appropriately for the event"**

**"The end of life is not an issue confined to health services"**

Welsh Government's End of Life Care Delivery Plan

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If we take this extended view of the end of life we must realise that it is not only healthcare professionals who have a role in providing support to the dying. The end of life is typically thought of as a matter of concern primarily for health services, but local government, social services, housing providers and third sector organisations all provide services which can be vital to promoting quality of life and wellbeing up until death, particularly if opportunities to work together are pursued and realised.

Overarching everything in public service delivery today and into the foreseeable future is the relentless pressure on financial resources. However, this report shows that drawing upon existing resources in innovative ways and thinking across departmental and organisational boundaries can result in a better end of life experience for the dying person, whilst promoting more effective and efficient person centred end of life care.

The contribution housing makes to the experience of someone at the end of their life is often overlooked. This is the case for all housing, whether it be owner occupied, privately rented or social. This report solely focuses on issues associated with social housing.

The value of housing solutions for achieving health and wellbeing outcomes is well documented<sup>4</sup>. From providing buildings and environments appropriate to tenants' wishes, creating communities and linking tenants in to local services, to providing aids and equipment, carrying out major adaptations and even delivering care, those who work within social housing schemes play an important part in

promoting tenants' welfare. In housing for older people and for people with high level complex needs this role will inevitably involve supporting tenants who are living through the final stages of life.

## Scope of the report

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Marie Curie has worked with Community Housing Cymru and with the assistance of the Welsh Local Government Association to produce this report. It looks at the experiences of social housing providers in facilitating high quality end of life care to their tenants. This builds upon the recognition that more needs to be done to support dying people within the community and that social housing providers can be (and often already are to some extent) key partners in achieving this.

The report has been produced on the basis of a literature review, a survey of Registered Social Landlords (RSLs) and local authority housing providers in Wales, informal follow-up telephone interviews, forum discussions and a network session. It aims to provide an insight into the views and practices of social housing providers in order to find out what works well and to assess the challenges they face so that more can be done to overcome these challenges. At the end of the report we make a series of recommendations based on our findings.

The social rented sector constitutes about 17% (over 225,000) of all households in Wales. At 31 March 2013, 61% of social housing stock belonged to RSLs, with the remainder owned by the ten local authorities retaining housing stock<sup>5</sup>. General needs housing makes up 84% of total social housing, sheltered housing accounts for another 12% and extra care 0.7%. Whereas provision of sheltered housing units is roughly equal between RSLs and local authorities, 97% of extra care housing units belong to RSLs.

All of the housing providers we spoke to own or manage sheltered accommodation, and many also own or manage extra care schemes. Due to the scope of this report, the conversations regarding end of life care reported here typically revolved around these types of housing because of their on-site support services and prevalence of older tenants. The views reported in the third section can only reflect the views expressed by the particular staff members of the housing providers who engaged with the report, and therefore do not necessarily represent the views or experiences across the entire sector in Wales.

However, terminal illness may affect anyone regardless of how old they are or where they live; whether they rent socially or privately, own their own home or live in alternative accommodation. A consideration of the housing needs and challenges for everyone at the end of life and their families should be an important part of planning their care and support and maintaining their wellbeing.

## Who we are

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Marie Curie provides free hospice and community-based care and support to terminally ill people, their families and their carers in Wales and the rest of the UK. We also campaign to ensure that terminally ill people are able to receive the best quality care in the place of their choice, regardless of diagnosis.

Community Housing Cymru Group is a group structure comprising Community Housing Cymru, Care and Repair Cymru and Crew Regeneration Wales. Community Housing Cymru is the representative body for housing associations and community mutuals in Wales.

## 2. Context

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### 2.1. End of life needs of a changing population

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It is well known that the demography of Wales is changing. The number of people aged over 65 is set to increase by around 50% between now and 2037 when it is projected to reach 878,000 or 26.4% of the total population. Wales already has a higher proportion of over 85s than the other UK nations and by 2030 the number of people living beyond 85 will have increased by 90%, to 85,000<sup>6</sup>. Increased longevity is of course something to be celebrated, but it also presents new challenges:

- More people living longer will result in an increase in the number of older people with palliative care needs, especially dementia<sup>i</sup>, which require special health, care and housing interventions<sup>7</sup>.
- A higher number of older people in the UK living alone, often experiencing loneliness and lacking informal carers to meet their developing complex needs<sup>8</sup>.

After many years of decline the death rate in Wales is predicted to begin rising from 2022. The current picture, in which almost 60% of all deaths occur in hospitals<sup>9</sup>, is often contrary to the dying person's wishes, clinically unnecessary and unsustainable in respect of medical resources. Ensuring that the people of Wales can die where they want to with the care they need in the future will require a greater focus on facilitating care and support for the dying in the community<sup>10</sup>.

Changing attitudes towards death and dying is an important part of this. A recent poll found that only 16% of the Welsh public had talked about their end of life wishes and less than a quarter had asked a family member what they would want to happen if they were dying<sup>11</sup>. Preparing and planning for the end of life and having honest conversations with family, carers and professionals are crucial for achieving good quality, appropriate care.

### 2.2. End of life care and housing: Policy and practice

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Strong progress has been made over recent years in Wales in terms of recognising end of life care as a priority. Building on the recommendations of The Sugar Report (2008) and the work of the Palliative Care Implementation Board, the Welsh Government published its End of Life Care Delivery Plan in April 2013. The Delivery Plan sets out a framework for Local Health Boards within which they will be expected to deliver services. It also places an expectation on them to work with other organisations to deliver the Government's expectations of 'high quality end of life care, regardless of diagnosis, circumstance or place of residence'. The Plan also sets out the vital role of local government in supporting communities and individuals to have a healthy approach to the end of life through co-ordinated work with Local Health Boards through Local Service Boards.

There is no explicit mention of involving housing providers in helping to deliver the aims set out in the Delivery Plan, though it does aspire to 'support people, if they wish, to remain in their own homes or place of care at the end of life'.

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<sup>i</sup> The World Health Organisation (WHO) defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. Palliative care provides specialist relief from pain and other symptoms of an illness and holistic support. As dementia is a progressive condition which currently has no cure, specialist palliative care can help to promote the quality of life and comfort of someone with dementia.

Expanding considerations of death and dying beyond the focus on health services and clinical professionals is a key theme in Professor Allan Kellehear's public health approach to end of life care. Kellehear stresses the importance of prevention and of whole person care which understands the person's physical needs but also recognises them as a social unit. This approach looks beyond (whilst still including) health service ideas to consider the role of healthy environments and relationships in promoting high quality end of life care within 'compassionate communities'<sup>12</sup>. Housing is an important part of this.

### **The Good Death project, Tyne and Wear**

In the north-east of England, these sorts of ideas have started to translate into practice<sup>13</sup>. NHS Public Health Intelligence North East published its 'A Good Death Charter' in May 2010, which sets out key principles for ensuring the right to a good death is realised wherever possible. The resultant Good Death project in Tyne and Wear provides practical support to anyone in the final years of life so they can stay in their own homes for as long as possible. The support ranges from personal and emotional support to property repair and modification, and is delivered primarily by a Marie Curie trained project worker recruited by Home Group, a social landlord. The pilot for this project involved partnership working between Home Group, Marie Curie, Public Health North East, district nurses, GPs and technology providers and produced very encouraging results:

- Clients reported an 87% improvement in feeling of wellbeing
- 65% improvement in feeling of being in control
- 10% reduction in A&E attendances
- 55% reduction in GP consultations

The importance of housing in achieving health and wellbeing outcomes is increasingly recognised in Wales. The Social Services and Well-being Act (2014) includes 'suitability of living accommodation' as a key determinant of well-being. The need to involve housing as a key partner in the planning of sustainable services is recognised in A Framework for Delivering Integrated Health and Social Care for Older People with Complex Needs<sup>14</sup>, and the Welsh Government's Intermediate Care Fund is investing in projects which reduce unnecessary hospital admissions and promote the independence of older people through joint initiatives between local authority social services, health, housing and the third and independent sectors<sup>15</sup>. The services provided by Care and Repair Cymru and their network of agencies across Wales are also vital to achieving this outcome. For example, their Rapid Response Adaptation Programme helps older people remain living independently within their own homes and thus reduces budgetary pressures on health and social care budgets<sup>16</sup>.

There is a small amount of literature specifically addressing end of life care and social housing, most of which explores the value of extra care housing schemes as places for delivering this sort of care in England and considers the training needs of staff<sup>17</sup>. Evidence suggests that extra care residents are less likely to move into residential care than older people living in other settings<sup>18</sup>. Extra care schemes and other housing schemes designed with the wants and needs of older people in mind, including facilities such as those providing specialist housing and care services for people with dementia, operate across Wales and are owned and managed by both RSLs and local authorities. There is therefore great potential for involving these as partners in the planning and delivery of high quality and sustainable end of life care services.

## 3. Research findings

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The research we undertook aimed to gather social and local authority housing providers' experiences of providing end of life care in order to assess the current situation in Wales, to identify any obstacles to the delivery of high quality end of life care and to find ways to overcome them.

This research was motivated by the following questions:

- How aware of end of life issues are social and local authority housing providers?
- What support is provided to tenants?
- What support and training is provided to staff?
- What challenges do organisations face when trying to deliver high quality end of life care for their tenants?
- How could social housing providers be better supported to facilitate high quality end of life care for their tenants?

### 3.1. The survey

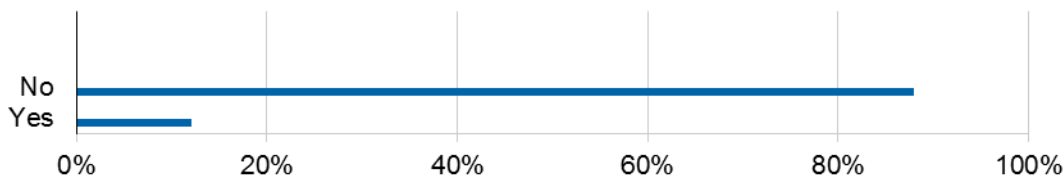
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A survey was distributed to RSLs and local authority housing providers in order to establish a baseline of information about housing providers and end of life care in Wales. The survey received 17 responses: 13 from RSLs and four from local authority housing departments.

All of the respondents who provided information about the age profiles of their tenants (16 out of the 17 respondents) have tenants in the age categories of 65-80 and over 80. All of the organisations own or manage sheltered housing schemes and five own or manage extra care schemes. In schemes where care is provided to tenants, arrangements for delivering care vary between organisations and sites: for some, care was provided by an external agency whereas others directly employed and managed care staff. This had quite significant implications for how housing providers thought about end of life care in terms of support or hands-on caring, and was also in itself sometimes a source of frustration with regards to communication breakdowns.

The results show considerable variation in terms of recognition and practices around the issues of death, dying, end of life care and support.

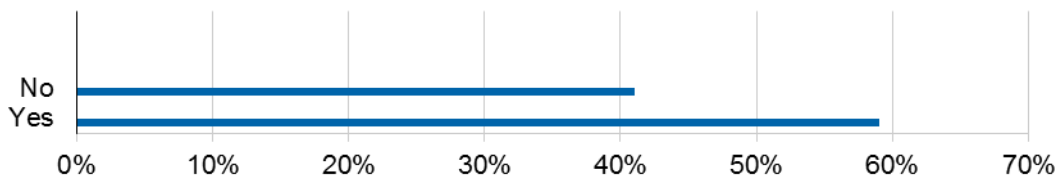
**Figure 1. Have you as an organisation specifically considered issues relating to end of life care?** (4 local authorities skipped, 3 of which addressed issue in additional comments)



The majority of housing providers had not specifically considered issues relating to end of life care as *an organisation*. However, some respondents reported that end of life care had been considered in relation to requests for housing adaptations for tenants with a terminal condition on release from hospital or following referrals, as part of support planning and specifically in the context of sheltered housing for the elderly and in extra care schemes. Local authority providers stressed that housing formed part of a unitary authority and end of life care formed a key aspect of adult social care services.

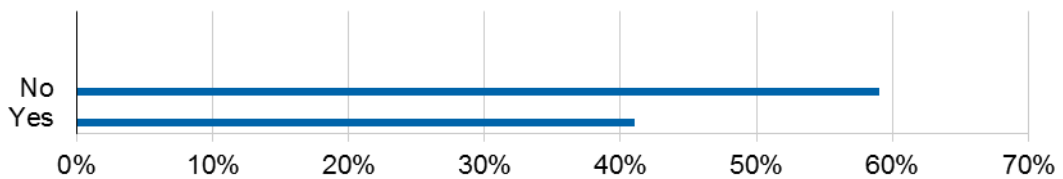
One RSL stated that an end of life protocol had been developed for use in sheltered housing where care services are delivered. Another reported that discussions around developing an end of life care policy for use in their extra care scheme had recently been initiated after finding inconsistencies in how aware tenants were of the service and which tenants received them.

**Figure 2. Do you collect data on how many people die in the housing/ accommodation you provide?** (0 skipped)



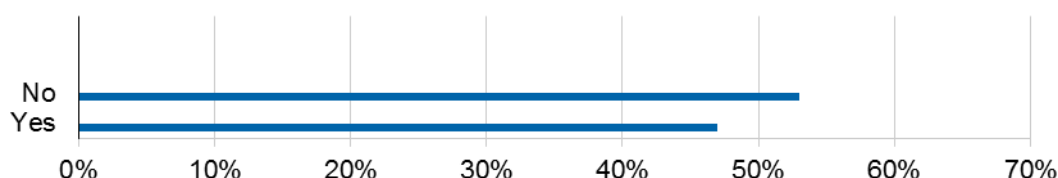
Over 40% do not collect data on how many people die in their accommodation. Some, however, collected quite rich data about their tenants living in extra care schemes at the end of their tenancies, such as whether they moved on to a residential home to receive a higher level of care.

**Figure 3. Do you support tenants in producing a living will and/ or discussions about their end of life care?** (0 skipped)





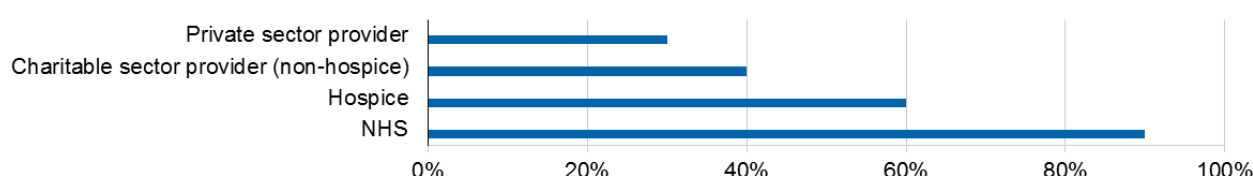
**Figure 4. Do you have the capacity to provide bespoke advice on issues relating to end of life (e.g. benefits)? (3 skipped)**



About 40% reported supporting tenants in producing a living will<sup>ii</sup> or discussing their plans for care at the end of life. However, additional comments suggest that more do provide informal support which is not part of any structured service to tenants. Much of the support takes the form of listening, providing guidance and signposting to relevant agencies, especially for tenants in sheltered and extra care schemes. Scheme managers and wardens in sheltered housing play a key role here. As the role of wardens within schemes continues to be revised, it will be important to assess the impact that their moving out of schemes to have a more community-based role has on the support they are able to provide.

One local authority stated that discussions about end of life wishes were sensitively included as part of support planning within sheltered housing. Just fewer than half of the organisations felt that they had the capacity to provide tenants with bespoke advice on issues relating to the end of life.

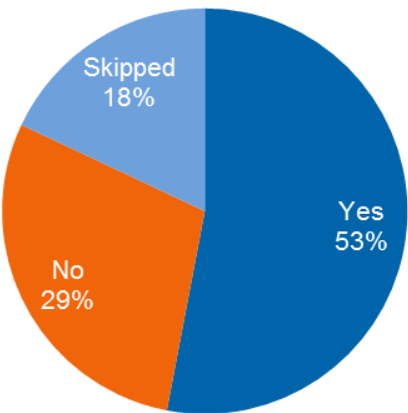
**Figure 5. Do you have any formal or informal links with any of the following organisations in providing end of life support? (8 RSLs skipped)**



The organisation most likely to have been linked with is unsurprisingly the NHS, with housing providers reporting an informal and ad hoc relationship based upon the needs of tenants, typically at times of crisis. Similarly, links to hospices tend to be on an individual referral basis regarding re-housing and adaptations. Links with the charitable sector include ‘indirect’ links with the Red Cross and Alzheimer’s Society. Local authority housing providers reported formal links with health and social care which allowed for multidisciplinary working and planning which supported individuals who wished to be discharged from hospital. This demonstrates the potential benefits to tenants of strong links existing across sectors.

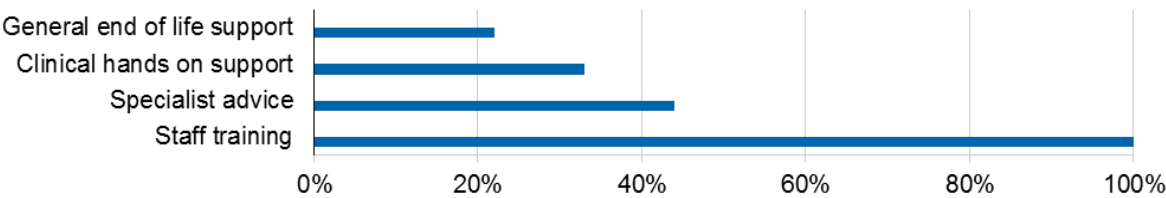
<sup>ii</sup> A living will is a document that sets out a patient’s wishes regarding health care and how they want to be treated if they become seriously ill and unable to make or communicate their own choices.

**Figure 6. Would you be interested in developing your end of life care/ support with a partner organisation? (4 skipped)**



Over half of respondents said they would be interested in developing their end of life care support with a partner organisation (eight RSLs and one local authority) whilst less than a third said they wouldn't. This suggests an appetite within the social housing sector both for increased partnership working and to improve the end of life care and support they can help to provide. Three quarters of respondents said their preferred partner would be a mix of the NHS, the third sector and the private sector.

**Figure 7. What would be your priorities in pursuing any partnership working (e.g. training for staff, specialist advice, hands on clinical support)? (8 skipped)**



All respondents identified staff training relating to end of life care would be a priority for partnership working, suggesting that this is an area where robust training structures are not currently in place across the board. This may be because end of life support has not traditionally been something which housing providers have considered or felt involved in. The needs for training and advice varied: some respondents noted the need for awareness raising amongst staff, some called for help with signposting to appropriate providers and others felt training could help to ensure that staff were fully trained and confident to support clients with the appropriate 'tender care and empathy' at the end of life.

### 3.2. Identifying what works

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Through the comments section of the survey and in follow up discussions, examples of good practice were raised which serve to show how valuable the services offered by housing organisations can be for dying tenants and their families. Although the picture varied by organisation and the needs of the particular clientele they provided for, these included:

- Scheme managers and wardens offering practical and emotional support and a 'listening ear' to terminally ill tenants. They often act as advocates for their wishes and needs and can have strong relationships with both the tenant and their family.
- Telecare, aids, equipment and home adaptations are efficiently and effectively installed wherever possible which promotes the tenant's wellbeing and facilitates hospital discharge.
- Training and support networks for staff help them to effectively engage with tenants on issues to ensure the tenant's involvement in planning and producing appropriate care, e.g. training in how to signpost to appropriate specialist services and benefits, bereavement support and 'difficult conversations' training.
- Joining forces with specialist third sector providers, e.g. linking with the Alzheimer's Society for staff training on recognising the early signs of dementia so tenants can be supported within their own home.
- Sensitively designed accommodation and facilities to create socially inclusive and safe environments, including specialist units designed for older people with dementia.
- Creative and flexible use of resources reflecting potential changing needs of tenants, e.g. inclusion of beds on site in an extra care unit which are registered for nursing care. This can facilitate hospital discharge and prevent emergency admissions.
- Use of Joint Localities Boards to provide a forum for discussing a local approach to quality end of life care involving a range of partners, including housing.

### 3.3. Identifying the challenges

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The housing providers we spoke to also identified a series of challenges which impeded their ability to facilitate or provide end of life care consistently for their tenants. Many of the views relayed here resulted from informal conversations with staff from RSLs, therefore do not necessarily reflect the experiences of the sector as a whole.

#### 3.3.1. Recognising death and dying as a relevant issue

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"I think there's a lack of awareness on our behalf – what our role is and if we have one."

"We all talk about planning for our pensions. So I think it's just a matter of being open in that way and saying we need to plan for our housing and care issues in the future... We haven't got as far as talking about end of life... but now we can say it is something to do with us, and we've got a part to play." (RSL – extra care and sheltered housing provider)

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### 3.3.2. Empowering staff

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“I was looking at how we plan our care and support and it was the one thing that people said ‘I find it really hard’ – forward planning... some of the staff find it a little bit ghoulish – it’s like ‘Here you are, Hello, and how would you like to be buried?’ It’s something that I’ve recognised looking at people’s care and support plans... very often those sections are left blank.” (RSL – extra care and sheltered housing provider)

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Death and dying can be sensitive and emotional subjects which many people feel uncomfortable talking about. This was agreed by all the housing providers we spoke to. A number of housing providers also commented that encouraging tenants within extra care and sheltered housing to plan for the end of life seemed to conflict with their aim to promote independence. However, this planning is a crucial part of understanding people’s wishes so that the care they receive and the experiences they have at the end of life are appropriate for them. Evidence shows that documenting an individual’s plans and wishes about medical intervention at the end of life can lead to a halving in hospital admissions<sup>19</sup>.

Housing staff often have strong relationships with tenants, which can mean they are well placed to engage a tenant in advanced care planning (ACP). If this is to be effective, staff must feel comfortable approaching the topic and have the necessary skills and knowledge to signpost and support tenants in accessing the care they want. One housing provider suggested that the high level of information around the process of ACP made it look more complicated than it actually is, which may also deter staff from engaging in it.

At a more practical level, extra care housing providers who recruited their own care staff and had some tenants with high level care needs felt that health care assistants could be made to feel more confident in caring for terminally ill people if they were specially trained in recognising the final stages of life and also the use of PEG tubes and syringe drivers<sup>iii</sup>. This could result in fewer people needing to leave their familiar surroundings to move into care homes and, possibly, an increase in the number of people who could be discharged to a specialist extra care home at the end stages of life.

### 3.3.3. Misunderstandings about what housing can do

Some respondents felt that tenants were not aware of the level of care and support that could be available to them if they were approaching the end of life. Numerous extra care housing providers also reported misunderstandings from external agencies about the level of care and support available to tenants within a scheme. Confusions can arise because schemes are often unique in the level and mix of needs that they cater for and the facilities available, and therefore the packages of care on offer do differ accordingly. There was also a feeling that extra care schemes were considered by some in health to be synonymous with care homes.

The results of these misunderstandings ranged from GP unwillingness to discharge a tenant from hospital due to an unfounded concern that they could not be cared for within a scheme to district nurses engaging less because they believed more care was available than in fact there was. This led to the worry that a tenant would not be offered the same service as if they were in a traditional home in the community.

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iii The insertion of a PEG (Percutaneous Endoscopic Gastrostomy) tube can be used to provide food for individuals who cannot maintain adequate nutrition orally. Syringe drivers provide an alternative method of administering medications and pain relief when an individual is no longer able to take medicines by mouth.

### **Mr A, a terminally ill tenant living in an extra care scheme in Wales**

Mr A had recently been diagnosed as terminally ill whilst in hospital. When he was due to come home to the extra care scheme where he lived and wished to remain, his GP had phoned the hospital to block this.

Despite having not met Mr A, the GP believed that the on-site staff at the extra care scheme wouldn't be able to meet his medication needs and therefore he wouldn't be able to return there. However, Mr A was eventually allowed to return to the scheme after his daughter presented the GP with the scheme's policies on medication to show that his medication needs could be provided for.

### **3.3.4. Coordination and communication with other agencies**

All the views represented here come from conversations with RSL staff from various organisations across Wales. Local authority views on these relationships would provide a richer view of the overall picture:

#### **GPs**

Some housing providers expressed frustrations about GP allocations of one surgery per scheme, as opposed to having a named GP for the scheme. This contributed to a lack of consistency and tenants being made to repeat their stories which sometimes caused distress. This lack of continuity could also be unsettling for people with dementia. It was felt that having a named GP would lead to a better relationship and a more sound understanding of the skills of the on-site care staff and the services available to tenants within that scheme.

#### **Local authorities**

Large RSLs operating across different local authorities in Wales reported that inconsistencies in local authority expectations, policies and processes can make it very difficult for them to develop unitary policies regarding end of life practices which can be applied across Wales. Some commented that local authority expectations of what could be offered within a housing scheme were very high and this resulted in the authority seeming to provide less support than if the tenant had been in a traditional home.

#### **Health**

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**“We find their expectations of what we can achieve to be far higher than our budgets.”** (RSL – sheltered housing provider)

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Many housing providers reported that that they felt they could achieve more to support people at the end of life, reduce expensive admissions and prevent delayed discharges if they were able to share in the cost savings to the health service that the provision of adaptations and equipment facilitates.

An RSL providing a high level of care within their extra care scheme said that they would like to see the facility used to support more people at the end of life but needed greater support in filling in applications to the Local Health Board for packages of care.

### Registered Social Landlords (RSLs)

Some respondents suggested that opportunities for sharing best practice around end of life care and support are missed in some areas of Wales because it is not openly discussed. Therefore there is scope for better communication, information sharing and collaborative working on this issue.

Although not directly related to end of life care, the 'In One Place' initiative in Gwent demonstrates the possibilities of effective public service collaborations for promoting quality housing outcomes for individuals with complex health needs. The initiative brings together the Local Health Board, five local authority councils and nine housing associations in order to provide a strategic approach to improving the provision of high quality accommodation and care services to those with Continuing Healthcare needs in the local area.

The recent development of a Health, Housing and Social Care Network for Wales convened by Community Housing Cymru provides a strong opportunity for instigating discussions and sharing information about experiences of providing end of life care and support.

#### 3.3.5. Dementia

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"We found that people in our sheltered housing and extra care housing [with dementia] get moved on somewhere and then they pass away. So in effect they may have been terminally ill in their home, and if they'd have had that level of support in their existing housing then they might have passed away at home."

(RSL – extra care and sheltered housing provider)

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Finding appropriate housing for people with dementia is becoming an ever more pressing challenge. Some housing providers are developing specialist housing units and one local authority is using housing support teams to recognise and assist people with early stage dementia so that they can remain independently in their own homes.

Better training in recognising the early stages of dementia and understanding the progression of the condition for housing staff could result in more tenants with dementia receiving support early enough to plan and be supported to stay in their usual place of residence.

#### 3.3.6. Finances

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"As an organisation I'm sure that we could reduce the costs or workload to other organisations by providing support in end of life situations. However, we could do much more if they could share a small proportion of their savings with us. If a tenant needs a stair lift to come home from hospital, we perceive this as expensive compared to our adaptations budget whilst health might perceive it as cheap compared to their bed blocking costs."

(RSL – sheltered housing provider)

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The difficulty of trying to do more without an increase in budgets was repeatedly raised. Continuing NHS Healthcare (CHC) funding also represented a source of confusion and concern for some RSLs. Some reported apparent inconsistencies in which tenants received it, some worried that the high level of administrative burden around CHC meant that some people slipped through the net. There were also concerns that, where RSLs provided that care themselves, the care offered within sheltered housing would not be included in the CHC package so tenants would need to move if they qualified.

**Mr B, who lives in Wales and has Alzheimer's and terminal cancer**

Mr B has Alzheimer's and has recently received a terminal cancer diagnosis whilst in hospital. Previously he had been living in residential care. His family have insisted they do not want him to die in hospital and both Mr B and his family would like him to be discharged to an extra care scheme which is appropriate to his needs. Despite a vacancy at the scheme and Mr B's suitability, CHC could not be agreed in advance and he has yet to receive a decision.

Concerns about having access to out of hours services and meeting health and safety and fire regulations for tenants at the end of life were also raised.

## 4. Overcoming the challenges

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Ensuring high quality end of life care in Wales into the future is going to involve finding ways to reduce the number of people admitted to hospital at the end of life. Reducing admissions and preventing delayed discharges will mean that people will spend less of their precious time in hospital in their final months, weeks and days, which is typically where they say they'd least like to be.

We must consider how effective, preventative and person-centred care can be delivered in the community. This report demonstrates that involving housing providers can play a key part in delivering on these outcomes.

Based on the findings within the report, we are making the following recommendations to support the role of housing in facilitating high quality end of life care in Wales:

### **4.1. End of life care and support should feature in future discussions at housing conferences and forums for housing, health and social care providers.**

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A joined up approach which includes housing, health, local authority social services, the third sector and the independent sector is vital for developing a robust and sustainable community approach to end of life care. We need to create communication channels which focus explicitly on end of life care across sector boundaries. This will foster better coordination of care for people, and also help to overcome some of the misunderstandings about what housing can do. A number of the RSLs we spoke to said they would be happy to hold network events or workshops within their extra care facilities to facilitate this.

### **4.2. Housing organisations should be supported to know where to access existing information and resources regarding end of life issues. Gaps in existing available information and resources should be addressed.**

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Resource packs for housing staff about end of life care and sheltered/extra care housing do already exist<sup>20</sup>, but they do not necessarily cover the issue from a Welsh perspective. Housing providers we spoke to identified specific areas where support is needed, including assistance with applying for packages of care from Health Boards, Continuing Healthcare funding and developing appropriate end of life policies which meet local authority expectations. Opportunities to discuss these specific issues should be created and involve all relevant parties. Incorporating learning sessions into joint events is a cost effective and potentially resource-neutral approach to ensuring staff receive the correct training.

### **4.3. Key frontline staff should receive sufficient training to support tenants with end of life needs and to maintain their own wellbeing.**

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We recommend that issues around death and dying such as symptoms of terminal stages of life, bereavement support and information about relevant benefits are considered when planning future training packages for scheme managers and wardens. Knowledge of successful training courses should be shared with other housing organisations.



#### **4.4. Housing staff should be supported to comfortably approach conversations about the end of life with tenants where appropriate.**

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Staff should be aware how to sensitively engage tenants in talking about the future so that the tenant's wishes can be noted and realised. This will allow for the effective involvement of individuals in producing their care and achieving desired outcomes. Staff must have the appropriate skills and knowledge to confidently signpost and support tenants in accessing specialist local services.

#### **4.5. Housing providers should routinely ensure that data on tenant turnover includes data on deaths and on tenants moving onto residential or nursing care.**

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This data is already collected by some RSLs. It allows organisations to plan appropriately for meeting tenant's needs, including the prevention of unnecessary moves onto residential care. This data should be shared across RSLs in Wales to identify and promote a better understanding of what works.

#### **4.6. Creative and flexible uses of resources within sheltered housing and extra care schemes should be further pursued.**

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A number of RSLs expressed a willingness to provide more care and support to terminally ill people approaching the end of life. Some possible ways of doing this include having on-site beds which are registered for nursing care or training up healthcare assistants so that they are better able to support tenants, e.g. through the use of PEGs or syringe drivers. Local Health Boards and the third sector could be key partners in guiding this 'step-up' in level of care provision.

#### **4.7. Local authorities should actively involve housing providers in the integrated planning of community based approaches to meeting end of life needs.**

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Local authorities can have a pivotal role in providing local leadership and ensuring that housing and social care providers are appropriately engaged in the delivery of end of life care. As the Local Government Information Unit report on end of life care in England found, 'one of the most important roles a local authority can play, is in bringing together the wide range of partners and interests from across the public, private and voluntary sectors, to promote better coordination and awareness of the issues that must be overcome'<sup>21</sup>. Local Service/ Joint Localities Boards also have a key role to play here.

#### **4.8. The Welsh Government, local government and other organisations responsible for setting policy, strategy and budgets should recognise fully the role that can be played by social housing providers in the provision of sustainable care and support for terminally ill people that more closely meets their needs and wants.**

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The support and interventions which housing organisations and Care and Repair Cymru can provide should be seen in the context of proactive measures which allow terminally ill individuals to receive the most appropriate and effective care in the place they choose. Evidence shows they reduce emergency admissions and length of stay, therefore alleviating financial and resource pressures on health and social care in the long term as well as providing the most desirable outcome for the individual.

## 5. Conclusion

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A house or flat becomes a home and as such it forms a central part of everyone's quality of life. Never is this more important than when one is reaching the end of one's life.

This report has attempted to unpick some of the issues involved in supporting someone at the end of their life who lives in property owned by a housing association or local authority with a particular focus on extra care and sheltered housing. It has also suggested some actions that would enhance the role of social housing providers and those who work for them in being part of a wider team that contributes to the quality of life of someone with a terminal illness.

Many of the recommendations made here are not resource intensive. Instead, they involve greater communication, skills sharing and collaborative working across service sectors which ultimately have the wellbeing of the people they serve at their core. These new ways of operating could result in new opportunities and substantial improvements in the experiences terminally ill people in Wales have as they approach the end of their lives.

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