

Practice Note for Scotland's Social Housing Sector

Empowering Social Landlords to support people affected by dying, death and bereavement.

December 2025.

1. Introduction.

This practice note is designed to offer a blueprint for Registered Social Landlords (RSLs) on how best to support people affected by dying, death and bereavement to live as well as possible at home both during palliative care treatment, and after a bereavement.

In social housing across Scotland, people living with terminal illness face substantial emotional and financial hardship as they navigate rapidly changing needs and often extensive waiting times for adaptations and accessible housing. There can be challenges around managing expectations, and concerns from RSL's about the right things to say. These challenges also extend to family members once a person has died.

In Scotland, 27,600 people have to move home every year as a result of a close bereavement; 13,200 must move because they can no longer afford to live there, and 11,400 have to move because they do not hold the tenancy.¹

Scotland's ageing population also means more people will be dying in the years to come. Over 60,000 people will die with palliative care needs by 2040, with nearly two-thirds of all deaths in Scotland taking place in people's own homes, as well as care homes and hospices².

¹ A survey conducted by Opinium for Marie Curie to investigate administrative difficulties faced by people who had experienced bereavement of a family member or close friend in the last five years.

² How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. Authors: Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia MunozArroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray
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Home, and familiarity with surroundings, is of acute importance at the end of life, especially as terminally ill people can spend almost 90% of their time in community settings, primarily their own homes.³

2. Who is this practice note for?

This document is aimed at RSLs and will also be relevant to the work of housing advice services.

3. Purpose of this practice note.

Through a human-rights based approach, this practice note will:

1. Increase RSLs' understanding of housing needs amongst those who are terminally ill, as well as their families following bereavement, and adopt best practice to support terminally ill people to make informed choices about their accommodation.
2. Signpost guidance, advice, and independent advocacy to support terminally ill people, their families and carers both while living with an illness, and after a bereavement.
3. Ensure that people who are bereaved are sensitively supported to address their housing needs after a death within the current social housing legislative and regulatory context.

This practice note has been developed by:

- Marie Curie
- Scottish Federation of Housing Associations (SFHA)
- Association of Local Authority Chief Housing Officers (ALACHO)
- Chartered Institute of Housing (CIH)
- MND Scotland

4. Definitions.

What is terminal illness?

Terminal illness is any illness which a person is likely to die from. Someone can live for years, months, weeks or days with a terminal illness following diagnosis⁴.

³ Public Health Scotland: Percentage of end of life spent at home or in a community setting 2022-23

⁴ Marie Curie: What is terminal illness?

Examples of terminal illness include dementia, heart, liver or kidney disease, advanced cancer, and motor neuron disease (MND).

What is palliative care and end of life care?

Palliative care offers physical, emotional, psychological and practical support to people with any illness they're likely to die from.

Palliative support also includes symptom management and can be offered at any point after a terminal diagnosis. It can be provided in different settings often in a person's own home, as well as care homes, hospices, and hospitals. End of life care is part of palliative care. It is treatment, care and support for people who are thought to be in the last year of life, though some people may receive end of life care for longer, or only in their last weeks or days.

What is grief and bereavement⁵?

Bereavement is part of the grief that people experience either before or after a loved one or someone important to them dies. It is part of life, and a normal part of the grieving process after a death.

5. Best practice for social housing landlords on protecting tenancy of terminally ill and bereaved people when addressing future housing needs.

1) Supporting the application and allocation process

Identifying if someone has a terminal illness

Being able to identify if someone is living with a terminal illness as early as possible in the application process can enable both the prospective tenant(s) and RSL to better understand existing housing needs and what a terminally person, their families, and carers will need in future. This might include after a death.

Reducing administrative burden for people living with a terminal illness is paramount when they are at their most vulnerable and more easily physically, emotionally, and financially exhausted.

What could help identify a terminally ill person?

- **Include additional questions on housing needs assessments/community care assessments/vulnerable tenants' registers.** Example wording could be:
 - "Are you receiving palliative care for your condition? Yes/No/Not sure"

⁵ Marie Curie: what is grief?

- “Do you have a BASRiS form⁶? Yes/No/Not sure”.
 - “Is there anyone else living with you? Yes/No. What is the nature of their relationship with you? Spouse/Partner/family member/ carer
- **Think ahead to Power of Attorney given many people with a terminal illness may have a Power of Attorney in place:**
 - Ask the tenant’s permission to speak to a nominated family member or friend as early as possible and necessary (for GDPR purposes) given Power of Attorney/next of kin arrangements can sometimes be slow to put in place
 - Ensure a designated third party authorisation process/mandate form is also in place at your organisation
 - It’s worth ensuring that in cases where a Power of Attorney is appointed, that they are also included on the housing needs assessment/community care assessment as a point of contact.
 - **Frequent tenancy check-ups** agreed with the tenant to ensure the most up to date advice, support and housing options are communicated especially as a terminally ill person’s condition changes. A tenancy check-up may include:
 - A household composition review
 - Tenancy succession advice
 - Joint tenancy or tenancy assignation advice, where qualifying criteria is met.

These tenancy check-ups provide ongoing opportunities for minimum residency periods (12 months) to be clearly communicated and landlord records to be shared/maintained as needed. These check-ups may also require a welfare advice dimension to address the potential implications of tenancy arrangements on welfare claims.

Example of integrated practice: Scottish Borders

The Health Assessment for Housing scheme has been developed by Berwickshire, Eildon, Scottish Borders, Cairn Housing Associations and Waverley Housing in conjunction with NHS Borders and Scottish Borders Council⁷.

One assessment is conducted to understand what a person's housing needs are to support the best quality of life and health, and shared with all participating landlords if a tenant has submitted applications to multiple providers.

Prioritisation

Terminally ill people's conditions can often deteriorate rapidly, requiring increasing care and support from families and/or carers. The housing emergency has created further supply and demand pressures for RSLs, with many people on long waiting lists.

⁶ BASRiS stands for Benefits Assessment for Special Rules in Scotland and is used to claim fast-tracked disability benefits in Scotland under the Special Rules for Terminal Illness. BASRiS forms are completed by clinicians and confirm that someone has a terminal illness that is expected to get worse over time and cause death.

⁷ [Health Assessment for Housing Scheme](#)

Where possible, and by continuing to work with Occupational Therapists, ensuring terminally ill people have the highest priority level for social housing allocations, home adaptations and home repairs on presentation of a BASRiS would significantly improve their end of life experience and help them to live independently for as long as possible.

BASRiS' are completed by doctors or nurses to state a person has a terminal illness. This provides evidence they are eligible for claiming Scottish disability benefits under the Special Rules for Terminal Illness in Scotland. While a BASRiS does not have any official role in current housing legislation or regulation, it is a helpful, existing identification tool which would support the application and allocation process.

How could I support terminally ill people with their housing needs as quickly as possible?

- **Consider how exceptional tenancy allocations and management transfers can be applied to terminally ill people**, to enable them to move into a home as quickly as possible. This may include consideration of expanding/updating the use of these circumstantial options to prioritise terminally ill households.
- **Consider terminal illness as criteria for direct matching** to enable terminally ill people to move into a property which meets their needs as soon as possible.

2) Responding when a tenant discloses a terminal condition

Talking about dying, death and bereavement can feel difficult and awkward, with an instinct to avoid discussing it altogether.

If a tenant discloses a terminal condition, it can be hard to know what to say and how to respond. Showing empathy and validation is the first step as part of reflective practice⁸. Here are some tips and conversation starters:

- **Let the person lead the conversation and go at their pace.** You could start by asking the person *"How are you feeling today?"*. This simplifies much bigger *"how are you feeling generally"* questions down to the present moment, and will give you an idea of how open they feel they can be at this stage.
- **Acknowledge their situation and thank them.** Instead of going straight in with a question, you could say something like *"Thank you for sharing that with me, it sounds like a really difficult situation. You are not alone, I'm here to support you as much as I can."* This could help them feel validated in what they have shared with you, and continue building trust.
- **Talk through their housing options sensitively, calmly and openly (more information in section three).** Having some practical solutions on hand could help make their life easier and reduce worry and anxiety. This could include information about:
 - Tenancy check-ups and frequency

⁸ McCall V et al; *The reflective housing practitioner: the role of qualifications for building empathy and person-centered approaches in the housing sector*; Housing and Society

- Eligibility and application of a Discretionary Housing Payment as well as wider welfare advice support or referral to help people claim all of the financial support they are entitled to
- Signposting to [Marie Curie Information & Support Services](#) for free practical and emotional support about living with a terminal illness, being at the end of life, and bereavement.

Free Marie Curie services signpost which are open to everyone

- Support Line; 0800 090 2309 (Mon-Fri 8am-6pm, Sat-Sun 10am-4pm)
- [Bereavement Support Line](#); up to six sessions with a bereavement volunteer
- [Online Chat Service](#)
- [Benefits Calculator](#)
- [Support for Carers](#)

3) Knowing and understanding housing rights with terminal illness in mind

Enabling someone to understand their housing rights and options is especially important in light of the significance of a terminal diagnosis. It therefore vital that terminally ill tenants and their families who indicate their desire to move to a new property to meet their needs are properly supported and advised about their rights.

"My wife was really sick at the end, and she had problems with straightforward thinking."

"You don't think about paperwork. You think about making things as nice as possible...you don't think about what happens when someone passes away, you don't want to think about it."

"People should learn to put things on paper and make things easier when the day comes."- Joost ten Wolde.

How could I further support someone who is terminally ill to understand their housing options?

- **Housing advice to terminally ill tenants is proactively provided** to ensure terminally ill people understand all tenancy agreement options available to them, including joint tenancy agreements and succession rights of family members, to make informed decisions about their accommodation. These could include housing advice and benefits services such as:
 - [Citizen's Advice Scotland Bureaux](#)
 - [Shelter](#)
 - [Housing Options Scotland](#)
 - [Living Rent](#)

- A solicitor
- **Seek to determine if there are any additional people living with a terminally ill person who may not be officially on the tenancy.** This could include a family member and/or carer of a terminally ill person. Disclosure of any additional people at an early stage, and during pre-tenancy checks/moves, will help forward planning for their housing needs in the future and informs transparent advice about potential succession rights and welfare claim implications.
- **Ask if a person has a BASRiS in place⁹,** as this means there would be no non-dependant deductions from a person's housing costs and/or housing benefit. If a person does not have a BASRiS, you can recommend they talk to their GP or Nurse to discuss obtaining one.
- **Facilitate open discussions about annual rent consultation and increase notice processes with clear timelines.** It's important that tenants' preferred communication methods are up to date so they can participate fully and remain informed. RSLs should also explore each tenants' circumstances fully and consider whether terminal illness is a contributing factor to tenancy challenges, such as rent arrears, and provide advice and support throughout the pre-action requirement process.
- **Provide further advice and information about additional benefits tenants may qualify for,** including Housing Benefit/Universal Credit and Discretionary Housing Payments.

4) Reasonable adjustments to service and adaptations

Reasonable adjustments

Empowering terminally ill people to live independently for as long as possible in a home which meets their needs significantly contributes to their physical and mental wellbeing at the end of life, as well as helping them to stay at home and out of hospital.

However, the nature of terminal conditions means urgent hospital care can be required at short notice and/or carers may have to spend extended periods of time absent from their home to look after someone who is terminally ill.

What reasonable adjustments could I prioritise to support terminally ill people to live at home independently?

- **Provide at least 72 hours' notice from landlords for adaptation installations, routine visits and home repairs.** Terminally ill people often have multiple medical appointments to coordinate, often including arranging transport in advance to get there. A planned approach helps to avoid medical appointments from having to potentially be rearranged.

⁹ BASRiS stands for Benefits Assessment for Special Rules in Scotland, and is a form that can be used by terminally ill people to claim fast-tracked disability benefits under the SRTI. SRTI use a clinical judgement definition of terminal illness whereby a doctor or a nurse can declare someone is terminally ill without having to predict how long they have to live.

- **Prioritise routine work which will support and make a difference to terminally ill people**, for example, energy efficiencies installations in people's homes to help them stay warm given they will often be spending more time at home with the heating on.
- **Support open communication about potential absence from the home**; During your initial assessment with a new tenant who is terminally ill or a tenant who becomes terminally ill while living there, agree a process with the tenant whereby landlords are notified as soon as possible about absence from the home, while providing further benefits advice.

5) When a death occurs and succession of a tenancy

Approximately 317,000 people experienced bereavement in 2023-24^{10,11} but even this is an underestimate because its difficult to quantify how many people experience bereavement at any one time.

Bereaved carers are particularly vulnerable to falling into poverty. The likelihood of a carer being in poverty increases by 47% after the death of the person being cared for¹². Currently, bereaved carers continue to receive Carers Support Payment for just 12 weeks after the death of the person they cared for.

How can I support a family member or carer after the death of a tenant?

- **Advise and signpost additional benefits which could support families after a death** such as [Funeral Support Payment](#) and [Bereavement Support Payment](#).
- **Offer and signpost further emotional and bereavement support**. This could include free Marie Curie services which are open to everyone, whatever their terminal condition:
 - [Bereavement Support Line](#); up to six sessions with a bereavement volunteer
 - Support Line; 0800 090 2309 (Mon-Fri 8am-6pm, Sat-Sun 10am-4pm)
 - [Online Chat Service](#)

Cruse Scotland also offer free bereavement support:
<https://www.crusescotland.org.uk/get-support/>

¹⁰ National Records of Scotland; Vital Events Reference Tables

¹¹ UK Commission on Bereavement

¹² Webb, E. et al., 2024. Financial and employment impacts of end-of-life family caregiving

6. Conclusion.

Home is more than just a physical structure; it is a sanctuary where individuals find comfort, security, and a sense of belonging. It is a place where memories are created, and personal growth is nurtured particularly in difficult times.

The importance of home extends beyond its walls, providing a stable environment that supports emotional well-being for the best quality of life possible, including the end of life.

Implementing this practice note will empower RSLs to support terminally ill people, their families and carers to the best of their ability and help each person have an end of life experience which reflects what's most important to them.

For further information

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