
Practice Note for Occupational Therapists

Supporting Occupational Therapists in the assessment and provision of adaptations for people affected by terminal illness

Introduction:

This practice note is designed to offer guidance for Occupational Therapists (OTs) on supporting people living with terminal illness when they require housing adaptations.

Having somewhere safe to live is acutely important as someone navigates a terminal illness, especially when time spent at home increases – towards the end-of-life people can spend almost 90% of their time in home settings¹.

People living with terminal illness will usually need changes and adaptations to their homes. This involves them navigating rapidly changing needs and often extensive waiting times. Waiting lists in some local authorities have been reported as being as long as fifteen months for a ramp, and almost nine months for a wetroom². These waits can cause hardship for anyone needing an adaptation. But, when someone has a terminal illness, waiting means they risk not getting the adaptations they need in time. For those working with people with terminal illnesses in the context of adaptation assessments and delivery, there can be challenges around managing expectations, and concerns from those less familiar in working with these individuals about how to frame difficult conversations.

While this practice note reflects the Scottish context, much of its broader guidance is relevant and transferable across the United Kingdom.

Who is this practice note for?

This document is aimed at OTs who may be less familiar supporting people with terminal illness, or who have recently started training or working in this area.

We appreciate that many OTs will have extensive experience beyond this practice note of working in this context, but that there are others who might not for whom guidance may be helpful. It may also be of interest to local authority housing teams, Housing Association staff, grants officers and care and repair services in cases where additional prioritisation of needs takes place.

1 - [Public Health Scotland: Percentage of end of life spent at home or in a community setting 2022-23](#)

2 - 'No time to lose: Addressing the housing needs of people with MND', 2022, MND Scotland

Purpose of this practice note

1. Increase awareness of, and ways that OTs can support with, fast-tracking housing needs for individuals with a terminal illness.
2. Identify early and future needs that people with a terminal illness might have, and how to support and frame conversations about the future.
3. Empower and signpost individuals when housing challenges remain.

This practice note has been developed by:

- MND Scotland
- Royal College of Occupational Therapists
- Association of Local Authority Chief Housing Officers (ALACHO)
- Chartered Institute of Housing (CIH)
- Dr Jenny Preston – Consultant Occupational Therapist and Clinical Lead, and her Occupational Therapist colleagues
- Jill Pritchard – Specialist Housing Occupational Therapist, and her Occupational Therapist colleagues.

It also aligns with the Scottish Government's National Health and Wellbeing and Outcomes Measures, in particular:

Outcome 1 – People are able to look after and improve their health and wellbeing and live in good health for longer.

Outcome 2 – People, including those with disabilities or long-term conditions, or are frail, are able to live as far as reasonably practicable, independently and at home or in a homely setting in their community.

Outcome 4 – Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.



Definitions

What is a terminal illness?

A terminal illness refers to an illness which a person is likely to die from. Examples of terminal illness include dementia, heart, liver or kidney disease, advanced cancer, and motor neuron disease (MND)³.

A statutory definition of terminal illness was specifically developed in 2018 for the Special Rules for Terminal Illness (SRTI) in the Social Security (Scotland) Act, used for the purpose of completing a [Benefits Assessment for Special Rules in Scotland](#).

This defines a terminal illness as an illness⁴:

- that is advanced and progressive or with risk of sudden death, AND;
- that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND;
- that is leading to an increased need for additional care and support.

Being able to identify if someone is living with a terminal illness as early as possible in the adaptation process can enable people to access support they need now, and in the future. Sometimes it may be obvious that someone has a terminal illness, based on a diagnosis you are familiar with, or that information might have been shared with you within the MDT. In other cases, you might not be sure.

You might be able to ask the individual if they are receiving palliative care. You might also ask if someone has a BASRiS form. While its primary function is not for housing, but rather, for claiming social security benefits, having this form lets you know that they have already been assessed as having a terminal illness, qualifying for support and fast-tracking by Social Security Scotland.

What is palliative 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. Palliative care aims to support a person to have a good quality of life – this includes being as well and active as possible in the time they have left.

³ - A statutory definition of terminal illness was specifically developed in 2018 for the Special Rules for Terminal Illness (SRTI) in the Social Security (Scotland) Act.

⁴ - [Updated Guidance on the Implementation of Benefits Assessment under Special Rules in Scotland \(BASRiS\) Guidance and form for Terminal Illness, for Disability Benefits devolved to Scotland](#)

Best practice guidance on supporting those with a terminal illness

1. Supporting critical and urgent assessment for people with terminal illnesses

Ensuring people living with terminal illnesses receive the highest priority level for adaptations helps to assure that their needs are dealt with as quickly as possible. This might be referred to as 'critical' or 'urgent' needs.

Placing people with terminal illness within the highest priority categories can reduce the risk that someone is added to the end of a lengthy non-urgent waiting list and can help them to live independently for as long as possible.

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

- Different areas may have different ways of prioritising or organising wait lists. Those with a terminal illness should be placed within the top priority/urgent category at the point of assessment on the basis that their condition is likely to mean that they will not have time to wait (also referred to as 'Critical' or 'Substantial' within the Scottish Government's National Eligibility Criteria).
- Partnership working with clinical nurse specialists and other members of the multidisciplinary team can also help to improve outcomes for those with terminal and rapidly progressing conditions by supporting with interpreting information provided at the point of referral/recommendation and ensuring that cases with terminal illnesses are identified as soon as possible. If the service delivering adaptations operates a waiting list, this needs to be actively monitored and updated if circumstances change.

Notes from a Neurology Occupational Therapist

Making the individual central to the process.

Questions like 'tell me about yourself', 'what do you enjoy doing', 'what matters most to you' are questions you are likely already asking through professional practice. We all know that understanding who the individual is and what matters to them plays a vital role in framing needs. These sorts of questions can be especially important in the context of terminal illnesses as people are encountering enormous change and upheaval in their lives. Asking questions and building connections can provide a vital understanding of where that person is at, which informs how the preventative and timely benefit of adaptations can best work for them.

As part of getting to know people, you can also ascertain how an individual is dealing with their diagnosis. Some people may be in the process of seeking a second opinion or be adjusting to a recent diagnosis. This is where building relationships and understanding what matters is especially important – you may need to take a light touch in the first meeting, concentrating on what matters to the individual, and then arrange to return to discuss needs again soon, allowing you to alter and increase their adaptation priority in a slightly more gradual way.

2. Considering anticipatory and future adaptation needs

It is often the case that people with terminal illnesses will have changing and progressing needs. Certain illnesses follow certain patterns of symptom progression. This means that after a home visit and environmental assessment it is sometimes possible to identify what adaptations someone is likely to need in the future. There are often extensive waiting times for major adaptations which do not match pace with terminal and progressive illnesses.

Some people living with a terminal illness individuals may be open to discussing future needs, but others may find it more difficult. Planning for future needs, alongside the person's priorities and understanding of their diagnosis and how it progresses can mean adaptations and equipment are in place when someone needs it. There may be cases where people chose not to adapt their home based on the stage of their illness. But open conversations at the earliest stage can help to ensure that someone is not left waiting when the time comes for need of a particular adaptation.

In one Scottish health board, processes are in place so that critical status can be applied where a person has a progressive condition and potential need for adaptation that would take some time to progress, and critical needs anticipated within next 6 months.

How could I support someone with a terminal illness to discuss the future needs they might have?

- Identifying future needs does not necessarily mean that someone requires all adaptations in one go. Instead, it might mean providing basic solutions like grab rails and recording what potential future needs are. It might also, where possible, involve gathering necessary information to progress an adaptation such as completing assessments, and taking required measurements and creating designs for adaptations as early as is feasible.
- It can also help with highlighting challenges early on around planning permission or other permissions from building regulations, or in identifying situations where some or all of the adaptations are not technically feasible. Where technical feasibility is a challenge, this can also allow more time to explore/identify alternative options and solutions.
- Linking with clinical nurse specialists and other members of the multidisciplinary team can help to ensure that everyone's needs are identified in a timely way. This goes two ways, as timely referral to OT services is also vital for future planning, and for managing expectations. Multi-disciplinary working is also beneficial in ensuring a joint and shared approach to assessment, planning interventions, and communication.

Anticipating future adaptations needs is also included within the Scottish Government updated Equipment and Adaptations Guidance, which states "for people living with progressive terminal conditions, future needs should be planned for, by working closely with the individual, and specialist nurses and occupational therapists, to ensure that equipment and adaptations are provided in time." (Equipment and Adaptations Guidance, 2023, p.19)



Notes from a Neurology Occupational Therapist

Framing conversations around future needs

It is crucial to think about the future when making assessments for adaptations, particularly in the context of waiting times. However, it can sometimes feel difficult to have the right words to approach these conversations. Taking a stepped approach, which centres the individuals needs and what matters to them, can offer one way of doing this, such as the example below:

"You said earlier that going out and seeing friends is important to you. Right now, we've talked about getting some handrails fitted so that you can support yourself a bit more when going down your front steps. If we think further down the line, it might be that something like a ramp would be helpful as steps might be difficult in the future. I want to do everything I can to make sure that we have that ramp in place for you for when you need it because there are waiting lists. I want to make sure that we can do everything we can to keep you going out and seeing friends. How would you feel about me looking to just start off some of this work in the background, like taking measurements?"

3. Recognising housing challenges – focusing on quality of life

Issues such as a lack of accessible housing can be difficult when thinking about adaptations as it is can be the case that it is simply not possible to make someone's current home externally accessible. In some places across Scotland, this means that people are informed they are unable to have internal adaptations like wet rooms because their home will not be fully suitable for them in the long term. They are instead told to wait for an alternative accessible home. However, finding an alternative accessible home can take up to 4 years in some local authority areas⁵.

While there is an urgent need for more accessible homes and more accommodating processes, people living with terminal illnesses are left without adaptations which could significantly improve their quality of life. For those involved in assessment and recommendation of adaptations, creative responses can also be powerful – considering alternative, temporary solutions such as equipment and minor adaptations which can make life easier for individuals in the interim whilst these larger conversations around housing support take place, or where they are awaiting an adaptation.

⁵ - No time to lose: Addressing the housing needs of people with MND', 2022, MND Scotland

How could I play a part in advocating for people with terminal illnesses?

- If a person is made aware that they cannot have their home made externally accessible, we believe they should still have the choice to make the inside of their home as accessible as possible if they wish for it to be. However, this may not match the policy of your local area. If this is the case, you may wish to raise the issue and the right for a client to decide during an MDT meeting or other appropriate discussion (e.g. supervision). Internal adaptations are considered in some areas across the country even if it means that a person is restricted to one floor living or is housebound.
- No policy should be a blanket one, and conversations on goals and priorities should take place.
- Advocacy can be a valuable resource, particularly in more challenging cases, or where there are several different perspectives or expectations. Everyone in Scotland has the right to independent advocacy. Some disease-specific third sector organisations provide specific advocacy services. If the person you are supporting feels it would be of benefit, further information on advocacy, and some resources can be found here: <https://www.mygov.scot/advocacy>.

Notes from a Neurology Occupational Therapist

When challenges remain

There are cases where you may face barriers which remain substantial and difficult to remedy. Having early referral to occupational therapy services can be key in helping to ensure the most suitable and appropriate options are planned for each individual and their needs. Open dialogue, setting out expectations, and knowing what matters to individual clients can help to navigate more difficult conversations too.

Where intractable issues exist, sharing these challenges with other members of the multidisciplinary team can offer a valuable way of working together to look for solutions, and for support for yourself too. You may also be able to discuss general challenges (with permissions) with others, such as third sector organisations. They may be able to assist with highlighting challenges and lobbying for change at national and local level, as well as referring individuals themselves to relevant third sector support services via national and local charities.



Signposting:

Talking about symptoms and asking questions about what the future might look like can bring up a range of emotions for people with terminal illnesses. You may wish to signpost individuals to further emotional and bereavement support.

This could include:

Marie Curie services 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/>

Condition-specific charities, like **MND Scotland**, **Parkinson's UK** and **Scottish Huntington's**.

Conclusion:

Housing is key to people's lives. Every person deserves somewhere safe, where they can live with dignity and care, particularly as they approach the end of their life. The role that OTs can play in implementing rapid assessments, considering future needs, and providing that person-centred support is vital. By doing this, everyone living with a terminal illness can be supported as best as possible with what matters most to them and their housing needs.

For Further Information:

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