



Marie Curie Response

Proposed Wheelchairs (Short-term access) (Scotland) Bill Consultation

About Marie Curie

1. Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our volunteer led services. We also provide nationwide support through our information and support service including our national helpline. Marie Curie is also the biggest charitable funder of palliative care research in the UK.
2. Last year we provided care for over 8,600 people living with a terminal illness, as well as their families and carers across Scotland.
3. Our vision is for a better life for people and their families living with a terminal illness. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

Wheelchair Provision

4. Equipment and adaptations, including wheelchair provision, can help people living with terminal illnesses to remain in their own homes for as long as possible. This can help improve people's outcomes, independence, dignity and quality of life, and can reduce the need for admissions to hospital or other care services.
5. Depending on the nature of the person's terminal illness they may have years, months, weeks or even days to live. They will also, depending on their condition, have varying need of equipment and adaptations to support them, which will often be needed urgently.
6. The Scottish Government Guidance on the Provision of Equipment and Adaptations (CCD 5/2009) recognised the need for "timely provision of equipment to those with palliative care needs" and prioritised faster access for those living with terminal illness.
7. At Marie Curie, we deliver direct care and support through our two hospices and our community nursing services in 31 local authority areas. Where people receiving our care and support are assessed as requiring a wheelchair, we refer them on to the local wheelchair service. For the purposes of this consultation, this provision is not classed as short-term wheelchair access, even when the wheelchair is required for less than 6 months.

8. In our experience, where stock allows, wheelchairs are usually provided within 7-10 days and patients can keep that wheelchair as long as it is needed. In general, wheelchair services are aware of the importance of timely issuance of wheelchairs for the people we support and accommodate these requests where possible.
9. When people are living with a terminal illness, time can be short. Even short delays can significantly impact on someone's ability to participate in normal daily activities, maintain independence and mobility, stay connected with communities and be cared for in their place of choice.
10. However, stock issues can sometimes cause delays to wheelchair provision for those with palliative care needs. While we do not routinely collect data on the average waiting time of our referrals for wheelchairs, anecdotally our staff have reported short delays due to stock issues. In these cases, if patients prefer not to wait for a wheelchair to be issued, we recommend them to the Red Cross for a short-term loan of a wheelchair. On occasion patients have also borrowed wheelchairs from our limited in-house stocks at hospices to support passes home or day trips. This can fragment care with the involvement of multiple agencies potentially inadvertently contributing to further delay.
11. We support work to create a statutory duty to support people who have a short-term mobility need. However, we are keen that any legislation or proposed duty is cognisant of the need to continue to prioritise access for people living with a terminal illness and those with palliative care needs.
12. We would like to see a commitment that all patients with palliative care needs, who are assessed and referred to the wheelchair service for support, are loaned a wheelchair within 48 hours. Our experience suggests that this is currently not always achievable within the current services in Scotland.
13. We have concerns that current stock levels are not always adequate to support need. We recommend further analysis into levels of stock in each service and, where necessary, a commitment to procuring additional wheelchairs, and investing in systems to ensure ongoing maintenance of the equipment are in place. We would expect to see developed data analysis and associated financial information, in the documentation that accompanies the proposed Bill, to ensure there is sufficient supply to fulfil the duty. This should ensure that there is enough stock in the system to accommodate repairs, cleaning, urgent and high requests for wheelchairs at any given time.
14. When people do require the use of a wheelchair, they may also need adaptations to their home to enable wheelchair use and independent living. At a recent MND Scotland parliamentary reception, we heard evidence of someone living with MND and using a wheelchair, who was unable to access shower and bathing facilities for over 2 months. A range of adaptations could be required to complement living with a wheelchair. This could include shower chairs, grab rails, raised toilet seats and bathing equipment. Widening

doors for wheelchair access, installing ramps, ground floor bathing and toilet facilities, and installation of a through floor lift could also be required.

15. Any legislation regarding access to a wheelchair, regardless of timescale, should include provisions for adapting home environments to ensure they are compatible with wheelchair living. Requiring carers to carry people into homes, upstairs and into bathing facilities is not acceptable, nor is an inability to access these facilities for up to 6 months. We recommend processes are developed to assess home environments are suitable for wheelchair access alongside ensuring access to wheelchairs. If home environments are not suitable, this should not be a basis for declining access to a wheelchair, but instead provisions should be made to ensure people are able to continue normal daily activities in their own homes. This should include a rapid provision of necessary home adaptations, especially when someone is terminally ill and approaching the end of life.

16. With this social care element in mind, we would recommend that any duty should be placed on Integrated Authorities (Health & Social Care Partnerships) rather solely on NHS boards.

Further information:

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