



# Marie Curie Response

Care and support  
through terminal illness

## Carers (Scotland) Bill: Call for views

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We welcome the opportunity to respond to the Health and Sport Committee call for views of the Carers (Scotland) Bill. We particularly want to highlight issues facing carers that support people living with a terminal illness or at the end of life.

The Scottish Health Survey shows that an estimated 759,000 people, that's 17% of the adult population (aged 16+) in Scotland are carers, and 29,000 are young carers (4% of the child population). Between 2001 and 2011 the number of carers, or rather the number of people identifying as carers, has increased. There has also been an increase in the number of hours of care provided with 27% of carers providing over 50 hours and 18% of carers providing between 20-49 hours of care a week.

Scotland's population is ageing; the number of people aged 75 and over is projected to increase from 420,000 to 780,000 by 2037 (an 86% increase). This shifting demographic, coupled with an increasing average life expectancy means that people are living with more complex needs than before, often with multiple long-term conditions. Many of these people will be living with a terminal illness. By that, we mean they will have reached a point where their illness is likely to lead to their death. Depending on their condition and treatment, they may live with their illness for days, weeks, months or even years after this point. But one thing we do know is that they will need care and support for all or part of that time. The demand and need for carers will also rise alongside this.

Much of this care will be delivered in the home by family members and policy initiatives are aimed at supporting carers to care for an individual at home for as long as possible. Family carers play a critical role in end of life care for those people living with a terminal illness, enabling people to be cared for and die in their place of choice<sup>1</sup>. Recent research suggests that people with spouses or partners are those most able to die at home. They are also more likely to have experience better pain control<sup>2</sup>. This highlights the very important role carers play in providing support to people living with a terminal illness and at the end of life.

Caring for someone at the end of life can be both physically and emotionally demanding, and is often accompanied by a carer struggling to come to terms with the loss of a loved one<sup>3</sup>. These carers can often have very specific needs and requirements which need to be considered in the care and support available to them. Caring for someone at the end of life can involve symptom management, personal care, attending to household duties, and negotiating financial and employment concerns among others – all alongside psycho-social distress. Often people providing this care do not self-identify as carers and as a result do not access the support that they need. The Carers (Scotland) Bill offers a considerable opportunity to ensure that all carers, including those that don't identify as such, get access to the care and support that they need when they need it.

Marie Curie is the UK's biggest provider of high quality care for people living with a terminal illness. We care for over 7,500 patients across Scotland through our hospices, community nursing services and support services. Every day matters when you're living with a terminal illness and we want to help

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<sup>1</sup> [http://www.jpsmjournal.com/article/S0885-3924\(12\)00750-6/pdf](http://www.jpsmjournal.com/article/S0885-3924(12)00750-6/pdf)

<sup>2</sup> Equity in the provision of palliative care in the UK: Review of Evidence, London School of Economics (2015)

<sup>3</sup> <http://www.biomedcentral.com/1471-2296/15/48>

people make the most of the time that they have left. As part of this, we need to ensure that carers are appropriately involved at the centre of people's care, and that they receive appropriate and equitable access to care and support packages.

## Do you support the Bill?

We support the overall policy objectives of the Bill and agree that all carers should be supported on a more consistent basis so that they can continue to care, if they wish to do so, in good health and have a life alongside caring.

However one of the most pivotal issues that comes before this is that of carer identification. Many carers of people living with a terminal illness, or someone at the end of life, are not identified by health or social care services, or self-identify formally as carers. Identification is crucial as the gateway to gain access to support, services, rights and entitlements for carers. We support the Bill's provisions to establish that local authorities must set out plans for identifying carers within the context of the local carer strategy. We would like to see further information as to how this will link with the health and social care partnerships/integrated joint boards under the Public Bodies (Joint Working) (Scotland) Act 2014 to ensure that carers identified through GPs, healthcare and social services all receive timely and appropriate identification and access to Adult Carer Support Plans. We welcome Scotland-wide guidance and regulations on identification of carers reflected in the accompanying articles to the Bill.

The Bill, as introduced, is centred on the assumption that the carer is the sole provider of care. However, it is very unlikely that someone will be the sole carer for a person that is terminally ill or at the end of life. These people may also be in receipt of GP care, condition-specific care, specialist/palliative care, district nursing and potentially other services too. There are therefore numerous carers of someone at the end of life, but the role of the informal carer is one that can often be overlooked by statutory services, but at the same time be the linchpin on which everything else depends. This complexity needs to be recognised on a Scotland-wide basis and reflected in regulations and guidance accompanying the Bill.

Being the informal carer for someone who has a terminal illness, when someone is dying, can also be a very isolating experience. A family member may unexpectedly find themselves in a carer position, and be balancing other home and familial responsibilities, work and other commitments. Often carers in this situation become ambivalent about their own needs and are reluctant to identify that they themselves need support<sup>4</sup>. Carers we have spoken to have reported that they felt unable to access carer support without having or knowing about specific entitlements.

At a public health level, there needs to be increased awareness of what support is available to carers. At the local level, GPs need to be able to effectively identify and support carers, and the carer needs to feel connected to the right sources of support from the very beginning of their journey. This not only includes sources of information and support for themselves, but also involvement in the care and decisions of the person they are caring for. Health and social care professionals should ensure that carers are part of conversations with the patient about their condition so that they are included in the care team. This is particularly significant in caring for a person with a terminal illness where the cared-for person may not necessarily want to know the trajectory of their condition, but the carer still needs the information.

We agree that the Bill should be centred on personal outcomes and should link to the principles of the Social Care (Self-directed Support) (Scotland) Act. Under person-centred care, carers should have dignity and be supported to have choice and control over the support they need to go about their daily lives. Carer support packages should embrace individualised and flexible approaches to support and assessment that takes account of both social and medical needs and outcomes. This should

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<sup>4</sup> <http://www.biomedcentral.com/1471-2296/15/48>

acknowledge the different dynamics across the carer trajectory and be cognisant of the different health and social care needs of caring for people with different conditions. Caring for someone with dementia, for example, will require different levels of support to caring for someone with cancer or COPD.

Audit Scotland<sup>5</sup> estimates that by the age of 65, nearly two-thirds of people will have developed a long term condition and that older people are also more likely to have more than one long term condition with 27% of people aged 75-84 having two or more. With our increasing older population, this means that more people will have multiple, complex conditions that need to be cared for. This will be a challenge for carers as well as statutory partners, but also, as the demographic of carers also increases in age, the likelihood is that they too will have one or more conditions themselves, which they will need to manage as they care.

We also believe that carers should be supported to continue their lives outside of caring. This would include not only opportunities for work, training and learning, but also gives carers the confidence to engage in these activities knowing that their family member is supported and cared for when they are not there.

### **What do you feel would be the benefits of the provisions set out in the Bill?**

Many carers supporting someone living with a terminal illness, or someone at the end of life, are not identified by health or social care services, or self-identify formally as carers. Many see them simply as a family member caring for a loved one in that capacity, not associating this with formal requirements, eligibility and obligations as set out in current carer assessments. This often means that these carers are not aware of, or accessing, support that they both need and are entitled to.

We welcome the definitions of adult and young carers as set out in the Bill, which removes the need for carers to have to provide, or intend to provide, a substantial amount of care on a regular basis and be in receipt of community care services. This places recognition on the diversity of caring arrangements and removing the assessment of whether care is regular and substantial will open up carer support for a wider range of carers. It is hoped that this will make the identification, and self-identification of carers easier and earlier – sometimes a significant factor when caring for someone with a terminal illness. We further note the potential of the electronic Key Information Summary for identifying carers.

The change from Carers Assessments to Adult Carer Support Plans (ACPS) and Young Carer Statements (YCS) is also welcomed. Alongside removing potentially stigmatising language preventing people from accessing or applying for carer support, these provisions also move the responsibility from the carer to request an assessment to the Local Authority and responsible authority (in the case of a young carer), giving them a duty to prepare an ACPS or YCS. The focus on personal outcomes within the ACPS and YCS is also welcome alongside content, review and provision of information. We are hopeful that this focus on personal outcomes will explore areas that may prevent carers to provide care and identify ways to enable them to do so, where they want and are able to, while maintaining and improving their own health and wellbeing. We also welcome the addition of defined timescales for the preparation of an ACPS or YCS. Some carers, particularly those with complex caring situations including caring for someone with a terminal illness or at end of life will require to be offered and have an ACSP prepared very quickly. For example, many carers of people with a terminal illness find the benefits process slow and confusing and often only receive the correct decisions about benefits and funding when it is too late. We would like to see a commitment of no more than seven days to prepare an ACPS for carers of those with a terminal illness or at the end of life, in the accompanying regulations.

We further support the provision to have a review process for the ACSP formalised in law. Currently not all carer's assessments are reviewed. When caring for someone with a terminal illness at the end of

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<sup>5</sup> <http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions>

life, the trajectory of that person's condition is not always known. Terminal cancer often has a known trajectory with high functionality followed by a relatively short rapid period of decline. However, not all terminal illness follows the same path. Conditions such as heart or lung failure may have long term limitations with a series of intermittent serious episodes and others such as frailty and dementia are characterised by prolonged deterioration. A person's condition, and therefore their caring needs, is likely to change throughout their terminal illness with both the person, and the carer, needing varying levels of support. Review of carer support is therefore vital to ensure the maintenance and continuation of their lives outside of caring and their health and wellbeing. Reviews of ACSPs for carers of people living with a terminal illness must be carried out at short notice and completed rapidly depending on the changing circumstances of the carer. Changes in support packages must be implemented quickly in order to ensure that the carer can continue to fulfill their caring role and other commitments.

Emergency, anticipatory and future planning is often a concern for carers and it is essential that carers are confident that they have the support that they need when these situations arise. We therefore welcome the intention to include this in regulations about what an ACSP must contain. However, we also feel that there needs to be provisions to support carers when the period of caring becomes prolonged or is longer than expected. Estimating life expectancy is problematic in the case of terminal illness and uncertain trajectories can mean that people become carers for longer or shorter than expected. A supportive employer may not be as supportive if caring arrangements are prolonged indefinitely. We believe these should be taken into consideration when preparing a carers support package and would like to see this reflected in guidance or regulations accompanying the Bill.

We welcome the provision in the Bill for the establishment of an information and advice service for carers in each local authority area. Many carers draw on a range of personal, family and community resources to help them cope with their caring responsibilities. We believe that support for carers should not solely be about providing a service, but should also be about helping carers to do what they do well, using their own resources and actively engaging with local and community services. This crucially, will not only support carers but also empower them to exercise their rights. We recommend that local authorities should not only have a role in determining what support to provide to carers, but also have a duty to embed carer support within the locality and connect carers to health and social care practices and communities. We would like to see this reflected in guidance or regulations that accompany the Bill, particularly around local carer strategies, and the involvement of carers in carer services.

Respite Care can often make the difference in enabling a carer to continue their caring role or prevent them from becoming unwell and in need of direct care themselves. Without respite carers can face serious health and social risks due to the associated stress, and may also enjoy little time for leisure or feel isolated. We therefore welcome that local authorities will have a duty to prepare and publish a short breaks statement, albeit without the duty on local authorities to provide short breaks. The policy memorandum states that the third sector should continue to influence short break provision. However, we would recommend the inclusion of carers of people living with a terminal illness in the short breaks statement. Often respite care and short breaks for carers are seen as days or weeks, but for those people caring for people with a terminal illness this may not always be appropriate. When a loved one or family member is dying, the carer may not want to be away for a day or a week, but may need a few hours to fulfill other responsibilities or commitments or simply as rest. This could include volunteer visitor services which provide social, emotional and practical support to terminally ill people and carers - usually through regular visits to their home. This should be should form part of each ACSP and this reflected in the regulations and guidance that accompany the Bill to ensure it is taken into consideration Scotland-wide.

## **How do you feel the Bill could be amended or strengthened?**

The Policy Memorandum recognises the myriad of different caring situations and the complex relationships between a carer and the cared-for person. This is particularly significant when caring for someone at the end of their life or with a terminal illness and we believe that many of the Bill's

provisions – such as local carer strategies and local information and advice services – would be enhanced with the inclusion of recognition of these needs. We strongly recommend that these are included in regulations that accompany the Bill to ensure that carers supporting someone with a terminal illness can access the support, advice and information when they need it.

We need to ensure that there are effective and appropriate ways of identifying carers of people with a terminal illness as early as possible, that these carers are empowered to identify personal, community, health and social care services and carer organisation resources to help them manage, and that there are processes to embed this identification and support across Scotland. We further advocate for the provision of bereavement services for carers, throughout their caring experience and following the death of the cared-for person.

We believe that the third sector has a vital role in identifying carers, and providing support and advice. We would like to ensure that any duty on local authorities includes engagement with the third sector and communities. We would like to see a standard for carers, which is represented in advice given by health boards, local authorities and third sector organisations, that gives consistent and coherent guidance on where to get support, how to ask for help, and rights and entitlements of carers. We would further like to see an additional standard for carers of people living with a terminal illness as they have very specific and different needs to other carers. Many carers are not claiming the benefits and support that they are entitled to, due to lack of identification as carers, what they are eligible for and how to apply. A standard approach to information and sources of support, which can be adapted to reflect local circumstances, is only possible through an overarching Scotland-wide approach to carer services and eligibility criteria.

The Bill makes the provision for local authorities to set local eligibility criteria to determine whether local authorities would be required to provide support to carers to meet carer's needs. It is intended that this will allow a flexible approach to enable local authorities to respond to need in their areas. However, we are concerned that this will lead to different criteria in different locations causing inconsistent rights and entitlements for carers across Scotland and confusion and lack of clarity for carers. We are concerned that eligibility at a local level may exclude some carers from support and could create a postcode lottery across Scotland. While local strategies are needed to take into account the needs of carers in particular locales, particularly rural settings, we believe that carers in every setting should receive the same level of information, advice and support as others. Eligibility criteria acts as a gateway to rights for carers, these rights must be available to all and not subject to the discretion of local criteria. Section 21 of the Bill refers to National eligibility criteria by which each local authority must assess its local criteria and the accompanying Policy Memorandum states that there should be a Scotland-wide approach. We would like to see more exploration of this national criteria and a consistent Scotland-wide approach on the face of the Bill and supported by regulations. We would further like to see mechanisms to allow automatic qualification for support for those people caring for someone with a terminal illness. Those people caring for someone who has a terminal illness as indicated by the Palliative Care Register or DS1500 form, which enables someone who is terminally ill to claim Disability Living Allowance or Attendance Allowance from the DWP, should be automatically eligible for carers support.

### **Is there anything you would add to the Bill?**

Identification and self-identification of carers is imperative for carers of those with a terminal illness, yet many of these carers remain unidentified. While the Policy Memorandum stipulates that local authorities must set out their plans for identifying carers within the context of their local carer strategy, we believe this should be strengthened in the Bill with links to primary care and how this will work going forward with health and social care integration. Health and social care professionals may also require additional support and training to help them identify carers of people at the end of life, or training to help the carer to self-identify. This could include training to have sensitive conversations with carers

about what a person's diagnosis will mean for the carer, at the point of diagnosis and as the condition progresses, including the degree of commitment that is required to care for them. Such support should be identified within National legislation.

We would like to see mechanisms on the face of the Bill that allow automatic qualification for support for those people caring for someone with a terminal illness. Caring for someone at the end of life can be physically and emotionally demanding and is often characterised by uncertain and unpredictable condition trajectories. These carers often need unique and responsive support, however, many are not identified by health or social care services, or self-identify formally as carers. They often don't know about or access the support they need and financial support is often received late in a person's illness, or even after the person's death. Applications for support for people at the end of their lives, and their carers should be dealt with as quickly as possible. We call for automatic eligibility for carers support for those people caring for someone who has a terminal illness as indicated on a person's electronic Key Information Summary, an information sharing system for advanced care planning, or upon receipt of a DS1500 form, which enables someone who is terminally ill to claim Disability Living Allowance or Attendance Allowance from the DWP. We would also like to see a commitment of no more than seven days to prepare an ACPS for carers of those with a terminal illness. This should be included in National legislation and apply on a Scotland-wide basis.

We would also like to see a standard for carers, which is represented in advice given by health boards, local authorities and third sector organisations, that gives consistent and coherent guidance on where to get support, how to ask for help, and rights and entitlements of carers. We would further like to see an additional standard for carers of people living with a terminal illness as they have very specific and different needs to other carers.

We also believe that the Bill should include a duty for health boards to inform and involve carers in the care and decisions of the person they are caring for. Health and social care professionals should ensure that carers are present in conversations with the patient about their condition so that they are included as part of the expert care team. This is particularly significant in caring for a person with a terminal illness where the cared-for person may not necessarily want to know the trajectory of their condition, but the carer still needs the information. This is particularly relevant in hospital admission and discharge procedures, but also necessary for care at home or in other establishments. There are also a number of areas associated with carers for those with a terminal illness or at the end of life that we would like to see strengthened in guidance and regulations. These include:

- Scotland-wide guidance and regulations on identification of carers to inform local carer strategies
- Recognition of the complexity of 'carers' for those living with a terminal condition and a commitment to support informal carers within that role
- Timely and appropriate identification and access to support, including respite care
- Provision of consistent support packages for carers, including employment, training and learning
- Inequity of access across conditions and areas A duty to embed carer support within the locality and connect carers to health and social care practices, communities and third sector organisations
- Provision of support for intense, short-term care often associated with terminal illness, but also provisions to support carers when the period of caring becomes prolonged or is longer than expected
- Recognition of the complexities of the provision of respite care, especially for carers for people living with a terminal illness or at the end of life

### **Is there anything you would remove from the Bill?**

No.

## Further information:

We are happy to provide further information to support this call for evidence. For more information, please contact:

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