

Marie Curie's response to the consultation on Carers Legislation

1. Marie Curie gives people with all terminal illnesses the choice to die at home. Our nurses provide them and their families with free hands-on care and emotional support, in their own homes, right until the end. In Scotland we run hospices in Edinburgh and Glasgow, which provide free specialist medical care for those with serious illnesses, and emotional support for their families, giving them the best possible quality of life.
2. Marie Curie Cancer Care is pleased for the opportunity to respond to the consultation on proposed carers legislation. Our response is based on our experience as a charity that comes into daily contact with carers of those who are terminally ill.

Caring for someone with a terminal illness or at the end of life

3. Caring for those coming to the end of life becomes all-encompassing as the condition of the person they care for deteriorates and carers inevitably face

increasing demands and challenges on their time. These carers often have specific needs and requirements, which must be considered in the care and support made available to them.

4. When asked, the majority of people in Scotland would prefer to be cared for and die at home or in a community setting, rather than in a hospital. As well as being the wish of the majority it is far more cost effective than to care for someone in a hospital. It supports the Government's ambition of 'shifting the balance of care' from institutional setting to a home or homely setting.
5. We spoke to many carers of those who choose to remain at home – many of whom felt abandoned to provide care alone. By ensuring that the wellbeing of the carer is at the heart of the patient's care package it greatly increases the chance of them remaining at home for as long as possible. This should be at the heart of the Government's proposals.
6. Our response focuses on the needs of those caring for the terminally ill and we have responded to the specific questions in the consultation relevant to this group of carers. To inform our response we have canvassed the opinions of a range of carers who have come into contact with our services whilst providing care for their loved-ones.
7. Two case studies of end of life carers are available in annexe A.

Government proposals of relevance to Marie Curie

The Carer's Assessment to Carer's Support Plan

8. We would agree with the proposal to change the name of the Carer's Assessment to the 'Carer's Support Plan' and to separate carers assessments from those of the cared for person.
9. We believe that all carers should be identified and entitled to a support plan even if it only ensures that they access universal services and community support rather than statutory support. The inconsistency of what each local authority deems 'regular' and 'substantial' care has led to a 'postcode lottery' of support to carers with some not receiving any support as a result. Marie Curie welcomes the proposals to scrap 'regular' and 'substantial' tests.
10. The level of care provided to a person with a terminal illness is complex and subject to significant and sometimes immediate change. Carer's Assessments can quickly become outdated and not wholly suited to the carer's needs. As such Carer Support Plans must be flexible, regularly reviewed, with local authorities

empowered to change them at very short notice either directly or by utilising the services of specialist providers such as the third sector.

11. The absence of a defined timescales for local authorities to carry out an assessment and subsequently to provide a plan is not acceptable for carers of those at the end of life. Carers of those with a terminal illness and/or at the end of life could require intense support in a very short space of time of becoming a carer and may only require this support for a short period until the person they are caring for dies. It is vital for the wellbeing of the carer that support packages are put in place to support them at the time they need it. We would suggest that local authorities consider introducing a fast track system or that timescales are imposed on local authorities when dealing with carers of those with a terminal illness or at the end of life. Within this agreed timescale Local Authorities must assess, provide and begin implementing a plan for both carer and cared-for.
12. While supportive of the option to devolve Carer Support Plans to third sector organisations, we would agree with the National Carer Organisation's submission that the duty to carry out Support Plans 'still sits with the local authority' and that 'there must be a clear process for picking up needs identified through the assessment'.
13. The issue of the portability of carers plans and service user assessments is very significant for those at the end of life and can seriously impact on their support and wellbeing if there is a delay following a change of address. There is a need for either a seamless transfer from one authority to the other or for a rapid assessment process with very tight timescales for a new support package. The interruption of support must be minimised where carers are caring for people at the end of life.
14. Many carers at the end of life are unaware that they can request a carer's assessment. We would suggest that by placing a legislative duty on local authorities to offer an assessment/plan, this should ensure a greater take-up nationwide. In order to maximise reach we would echo calls from the National Carer Organisations that the duty be extended to 'acute NHS services and to new integrated primary health and social care services'.

Information and Advice

15. Information and advice is often the most important service or support that any carer can receive. This is particularly true of those caring for someone at the end of life or with a terminal illness. The information they need can include everything from what benefits are available to them to how to use medical equipment for pain control, as well as information on how an illness might progress and how their role as carers might change as a result.

16. While patients are rightly placed at the centre of the care and support that they receive, recognised carers must be seen as an integral part of the care package and jointly placed at the centre alongside the patient. Too often, carers are seen by practitioners, agencies and others as being on the periphery in relation to care and support provided to the patient which can leave both carer and patient uninformed and confused.
17. “What do I need to be a good carer?” is often the simple question that new carers ask. Practitioners are often reluctant to give out information to carers about the person they are caring for unless they are with the cared-for person. Carers must be provided with overarching, clear and appropriate information from the outset. Sometimes for patients with a terminal illness they do not want to know how their disease will progress, as they would rather take each day as it comes. However their carer might feel they need such specific information in order to help them plan and prepare for what is to come. They should be entitled to this information, particularly if the person they are caring for permits it.
18. Many carers we have spoken to have had to take on a ‘project manager’ style role in order to plan, coordinate and ensure the delivery of the care to their loved one. In order to support this role they have needed to access information that should be readily available from statutory health and social care providers.
19. The right to access information and support by carers on behalf of patients is also essential. We have heard examples of statutory agencies refusing to give information over the phone to carers because they are not the patient, despite the patient, owing to their condition, being physically unable to speak. This has resulted in information and support being missed out by the patient and the carer. Carers have often reported both health and social care staff being unhelpful and unsympathetic to their needs, which is unacceptable. Carers have been forced to find other ways of getting the information they need at great inconvenience to them and the patient.
20. Many carers we have spoken to found it necessary to speak to numerous people in order to get the information and advice they need often having to give the same details over and over again. The government should consider how information and data is captured and shared between all care providers.
21. Feedback from carers we have spoken to has indicated that simple information on how to access benefits and support would help remove stress, as well as potentially provide much needed income. Carers must be directed to appropriate information on support and benefits at the earliest opportunity in order to better support the coordination of care of their loved-one. We often hear of families not receiving benefits, such as the Disability Living Allowance (DLA), not because

they do not qualify, but because they did not know they might be eligible. It is essential that carers and those they are caring for receive information and support to apply for benefits. A benefits check should be carried out as part of any Carer's Support Plan.

22. We support the Scottish Government's proposals to place a legal requirement on local authorities to establish and maintain a service that provides information and advice relating to the Carer's Support Plan, support for carers and the Carers Rights Charter. We would stress that the information provided must be consistent across the country and broad enough to include all services available to support carers including bereavement support, information on carers support groups, community assets, the financial benefits available to both carer and cared for and advice on preparing wills. This should be set out in the statutory guidance proposed in the consultation.
23. If requirements on Health Boards to produce Carer Information Strategies are removed, continued funding to support carers must be used to design nationally coordinated strategies that strengthen proposals to identify and support carers of those at the end of life. Such strategies must include plans to provide information and advice to those carers who do not have access to computers or who are illiterate. This is particularly prevalent in areas of high deprivation.

Support to Carers (other than information and advice)

24. Caring for someone at the end of life can be demanding, both physically and emotionally for the carer who is often caring for a loved one or close family friend. As well as providing physical care, they will also be coming to terms with the prospect of losing the person they are caring for.
25. As well as information and advice and access to benefits, respite care is crucial for carers. For those caring for someone at the end of life, respite care requirements can be quite different from the respite needs of other carers. These carers often do not want to spend considerable amounts of time away, but they would benefit from crucial very short breaks, sometimes for only an hour or two. Respite to carry out tasks such as shopping, to meet friends or simply to sleep is invaluable for the carer, but often not available.
26. We support a legal obligation on local authorities to provide carers with short breaks and other forms of respite care linked to an eligibility framework. We would stress, however, that an eligibility framework must include all forms of support for all types of carers including access to advocacy, counselling and bereavement support. Any framework must be designed in partnership with carers, and include representation from those who have cared for people at the end of life.

27. The consultation document highlights that a duty on respite care would be costly and that the Scottish Government would need to undertake financial modelling before considering introducing it. We would hope that the Scottish Government sees such respite care in preventative spend terms and as well as work out the actual cost of providing respite care calculates the potential savings such services will create.
28. Respite care can make the difference in enabling a carer to continue their caring role or becoming unwell and in need of direct care themselves. If the carer can no longer care, then it can, particularly in the cases of those who are caring for people who are terminally ill, lead to the cared for person being hospitalised. The cost of caring for a person at home is substantially less than in an acute setting.
29. It is important for carers to be able to access spiritual support to help them through what can be an extremely traumatic difficult period in their life. We recommend that supporting carers to access faith and spiritual support should be part of a Carer's Support Plan.
30. For many carers of people with a terminal illness there is no support for them after the person they are caring for dies. This person is often close, either a relative or friend, and the carer can be left isolated and bereaved. One carer told us that they felt very isolated once their wife had died and went from having had a house full of people including nursing staff and social care workers to a situation where "everyone was gone".
31. Bereavement support can be crucial in helping carers adjust to life after the death of the person they have been caring for. All carers of those at the end of life should be offered bereavement support following the death of the person they are caring for. Marie Curie believes that this should be a statutory requirement set out in the Carers Bill.

Stages and Transitions

32. For carers of those at the end of life there are usually four stages through which care will be provided – diagnosis; progression of illness; terminal phase of the illness; and bereavement.
33. At the diagnosis stage, carers should be involved in setting out an anticipatory care plan for the cared for person; as the illness progresses and moves into terminal phase the coordination of care will become more and more important - carers must be involved and supported as part of the package of care with respite provided as well as monitoring of their own health needs; carers must be supported to cope with the death of a loved one for as long as they require it.

34. We would agree that statutory guidance on the Carer's Support Plan should include managing stages of caring. We would also like to see specific information included on managing the different stages of caring for those with a terminal illness with specific reference to palliative care.

Carer Involvement / Planning and Delivery

35. We strongly support the newly passed Public Bodies (Joint Working) Scotland Act and the integration of health and social care. We support the legal requirement on integrated care providers to involve service users, carers and carers' organisations in the planning, shaping and delivery of service. We also support the proposal for the provision to be made to involve carers in the planning, shaping and delivery of services for the people they care for and support for carers in areas out with the scope of integration, as well as the provision to involve carers' organisations too.

36. We support a statutory provision introduced to the effect that local health boards and local authorities should collaborate and involve relevant organisations and carers in the development of local carers' strategies. We would ask the Scottish Government to consider making it a requirement for the third sector to have sign-off on these strategies.

37. We also support a statutory provision put on local health boards and local authorities that a sufficient range of services is available for meeting the needs of support to carers.

Identification

38. Marie Curie, the University of Edinburgh, VOCAL and NHS Lothian recently published a research study, *Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources*¹, which found that many carers of those that are terminally ill or at the end of life are not being identified as carers and so not getting the support they need.

39. It is rare for carers of those at the end of their lives to see themselves or others as 'carers'. Many will see themselves simply as a son, daughter, friend or loved-one, and see their caring role as being intrinsic to their relationship. This can lead to them not identifying themselves as carers formally or seeking the support they need and are entitled to. Our recent research also found that statutory providers, such as GPs and nurses do not always identify people as carers.

40. We support the Scottish Government's policy to identify carers at the earliest opportunity as set out in the Carer's Strategy 2010-15. To achieve this we must

encourage people to identify themselves as carers. It is also crucial that GPs, District Nurses and social care workers are supported and educated to be able to identify those carers for people at the end of life whilst including carers in conversations with patients as their condition progresses.

41. We understand the Scottish Government's plans not to legislate for GPs or local authorities to maintain a Carers Register, but we would urge this be kept under review and for the Government to monitor the number of carers identified for support and ascertain any gaps.
42. We would also recommend that the role of primary care professionals in identifying carers must be clarified. GPs can be reactive and not proactive, as some GPs and District Nurses feel that it is the carers' role to identify themselves as carers.
43. Primary care teams must advertise services available to carers to help encourage carers to come forward. Medical practices should ensure that all new patients are asked at registration if they have a caring role or are a carer. Community nurses are often in a good place to help identify carers and should be encouraged to do so.
44. We would recommend wider adoption of recognised strategies for identifying carers including raising the profile of carer support that is currently available from carer organisations and the UK and Scottish Governments; involvement of carers in anticipatory care planning; GPs developing relationships with their local carer support organisations; support for other health and social care providers, such as pharmacists and social workers, to identify carers in all settings. In some GP practices a member of the team will act as a carer champion - such good practice should be promoted widely.
45. We urge the Scottish Government to collect data and statistics specific to those caring for people at the end of life. This will enable health and social care providers alongside the third sector to assess and better prepare for the support needs of these carers and their specific needs.

General comments and recommendations

Rural carers of those at the end of life

46. Carers of those at the end of life can face additional pressures due to their location. Carers in rural settings should receive the same level of information, advice and support as other carers across Scotland. Carer's Support Plans should differentiate carers in rural settings to highlight to providers potential needs they might have as a result.

47. The remote nature of caring can leave carers more anxious and unsupported, especially if the condition of the person they are caring for deteriorates. Without a close net of support on hand, a carer may simply be unable to continue their role, even if they want to, which results in the patient being admitted to care facility.
48. Rural environments can mean that carers simply cannot access the information and support they need. The Government's proposals for local authority information and advice services must take account of rural settings and include specific information on caring in such environments should be set out in the guidelines.
49. We have found that hospitals in urban environments do not always understand some of the difficulties that patients and carers in rural communities face in getting there for appointments. Journeys may involve different modes of transport including buses, trains and ferries, which must be considered and managed by the carer. Due to lengthy travel times and limited public transport options, opportunities for planning and discussions can be missed or rushed as can access to specialist care. Acute staff should work with the patient and carer to ensure that these journeys are as easy as possible, for example, practical appointment times during the day rather than first thing in the morning.
50. They may also face other issues as a result of living in rural communities, such as road closures and/or poor weather can affect the delivery of services. Local ambulances may have to go out of the area leaving no emergency cover. These can all add pressure on the carer to bridge the gap in provision.
51. Social isolation can be experienced both by patient and carer in rural areas, which can impact on the health and wellbeing of both.
52. Variations in healthcare services across rural areas frequently lead to inconsistency in delivering packages of care, which can result in unnecessary emergency admissions.
53. Local strategies to identify and support carers must take into account the unique needs of rural carers of those at the end of life. Such consideration should be included in statutory provisions for local health boards and local authorities.
54. Ensuring that the carer has information, advice and support on caring in a rural community is crucial in not only supporting the wellbeing of the carer and the patient, but is also key to ensuring that Scotland's rural communities are sustainable. More and more carers will be required to support more and more people in rural communities as Scotland's population ages.

Annual Leave for carers around end of life care

55. Currently there are over three million working carers in the UK.
56. Many carers are forced to give up work as a result of their caring role, which can bring added pressures to the household, including financial ones., Carers should be supported to stay in work for as long as they want to wherever this is possible and appropriate.
57. The Government and employers should work together to examine further ways of supporting carers to work and care. For example, arrangements may be put in place for carers to utilise leave to care for their loved one. Many organisations have produced guidelines and support materials to support employers of carers and these should be widely disseminated and shared to promote good practice.

Training for end of life care

58. Carers for those that are terminally ill and at the end of life are frequently required to use a range of healthcare equipment to support the person they are caring for, such as hospital beds or syringe drivers and suction pumps. We believe that all carers required to use such equipment should be given the training and support to do so. Training needs should be captured in the proposed Carer's Support Plan.
59. We recommend all social care workers who may come into contact with carers of the terminally ill should receive training on caring for people at the end of life. In this way staff will be better prepared to understand the needs of both patients and carers and to subsequently provide a higher level of support and guidance.

Marie Curie Cancer Care would be happy to discuss our response further if necessary.

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Carer Case Study A

'My mum died of cancer five years ago. She was diagnosed in Cardiff and we had learnt from the University Hospital of Wales that we would only have around 3 months with her. I am a carer for my husband who was disabled in a car accident 10 years ago which meant that I was coping with caring for him at the same time as my mother. Luckily my employers gave me time off from work to look after my mum. My mum was determined to stay with us to the end; we managed to keep her at home.

I flew her home to me in March. I have all the praise in the world for her GP (she refused any hospital treatment) but as far as other support services – 'bitty' would be the best I could come up with. Here in Lanarkshire everyone was trying to help, their hearts were in the right place, but the practicalities were not quite there and nothing fitted together.

We received support from some local authority carers, a MacMillan nurse who advised me on the financial benefits available as a carer and to my mum and district nurses. My mum's care plan was not really coordinated by anyone and no care assessment was ever done for us as carers. It got to the point where I did not know what to do for the best. Mum was not co-operating with anyone and would not let people into the house while she was also switching off from her sisters and my brother.

I knew that she had always supported Marie Curie so I phoned them one Friday afternoon - they gave me the number for the Glasgow Hospice and things changed overnight. Marie Curie sent carers and nurses out to the house and strangely mum would let them in. I think as the approach was different and the nurses were associated with something she supported meant it was easier for her to accept them. The feeling of support and the practical help was great.

Mum died very suddenly in July. I had just left to go down to my own house leaving my brother and a Marie Curie nurse with her. I will always be grateful to the Marie Curie nurse for the help we received that night including outlining all the details of her death and staying with us until we were organised'.

Carer Case Study B

'My experience of caring took place many years ago however I am sure that some carers are just as much in the dark now as I was then.

Following the death of my father I cared for my elderly mother whilst working full time. I was lucky to have two sisters who lived locally and offered support while a near neighbour and family friend would visit my mother on a Friday evening. This allowed me to continue voluntary work.

It was only after my mother's death and my subsequent retirement that I became aware of the available support to carers such as myself – and this was only due to my volunteering at the Citizens Advice Bureau.

I would like to see carers being given sufficient support to enable them to have a quality of life and to continue in employment if they have the desire to do so. I would like to see a campaign launched to promote awareness of support that is available to carers of those at the end of life'.

¹ https://www.dropbox.com/s/bbh7jd6jssmioez/BMC_Family_Practice_identifying_carers.pdf