

WELFARE REFORM COMMITTEE

YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM MARIE CURIE

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 provide feedback to the Welfare Reform Committee's call for evidence on welfare reform. Our response is based on our experience as a charity which specialises in providing end of life care across Scotland.
3. Marie Curie hospices often reflect the wider community. As such, we routinely deal with patients and families who have worries regarding benefits, housing problems and those with health and social problems. The charity also acts as advocates for patients and families by liaising with local authorities, as well as advising them on benefit entitlement and patient rights.
4. We would echo the Health and Social Care Alliance (The Alliance) point that there is the real risk that reform of welfare plunges people further into debt and face even greater social exclusion and ill-health. The Coalition of Care Providers Scotland (CCPS) report that welfare reform and public spending cuts will see more disabled people on lower benefit incomes, including many diagnosed with sudden illnesses like strokes or cancer. It is of concern to Marie Curie that many people with a terminal illness will find themselves in a situation where they require increased care provision but with less financial support.

Housing

5. Many people with a terminal illness need to have adaptations made to their homes. Many also need to make use of a spare room for carers or themselves if their condition requires it. An appropriate home environment is crucial in order to support a person with a terminal illness to stay in their home for as long as possible, including at the end of life.
6. Marie Curie staff are seeing a clear rise in the demand for advice from people in dispute with local councils over housing decisions, such as those around spare rooms. Families coming to terms with dealing with a terminal illness can have these pressures exacerbated by financial concerns around housing. Social workers in our hospices have already seen anxiety and upset in patients and their families over housing issues following a change in their circumstances after a terminal illness diagnosis.

7. In addition, bereaved family members are often tasked with a quick turnaround when emptying the former home of a loved one in social housing in order to make it available as housing stock. This can be distressing to carers and families trying to come to terms with bereavement and loss.

Pressure on General Practitioners and health services

8. Austerity measures and welfare reform are impacting heavily on GP practices across the country and especially in the most deprived areas with some seeing practices become a 'dumping ground' as other services are affected by cutbacks. A recent report on GPs experiences of austerity and its effect on patients and practices in deprived areas raised a number of issues affecting GP services. These related to benefit cuts; service cutbacks; and an increasing number of patients being taken off Employment Support Allowance (ESA) or Disability Living Allowance (DLA).
9. Changes to the benefit system are impacting on practice workloads. Practices described an "endless cycle" of appeals, during which time the patients' benefits are reduced. Patients also need to spend time asking GPs for letters appealing against Work Capability Assessment decisions, practice time that would otherwise have been spent on health concerns.

Financial help and advice for those at the end of life

10. Most people who need care towards the end of their lives qualify for either Attendance Allowance (AA), if over the age of 65 and not in a care home, or Disability Living Allowance (DLA), if under the age of 65. During 2013, DLA has been gradually superseded by Personal Independence Payments (PIP). Anyone who isn't expected to live longer than six months because of an illness can apply for DLA/PIP or AA under special rules. Under these rules, the claim will be given priority and will be dealt with more quickly whilst the benefit will be paid at the highest rate. People who are claiming under this special rule need to ask their doctor to complete a form.
11. Macmillan Cancer Support recently highlighted the fact that hundreds of terminally ill cancer patients are facing delays for their income support, 'payments that previously took eight to 10 days are now taking eight to 10 weeks'. Such delays simply cannot be allowed for those with a terminal illness and will have devastating effects on both patient and carer. The DWP have stated under the new PIPs, terminally ill cancer patients should be "fast-tracked" – we welcome this commitment but it should be rolled out to include all those with a terminal diagnosis.
12. Signposting to those services that are in place to provide advice and support on financial benefits such as preparing wills, pensions, power of attorney must also become routine wherever a person is diagnosed with a terminal illness. Advice can help to protect those at the end of life from potential pitfalls that many may not be aware of. For example people may be unaware that their bank accounts will be frozen at the time of death and as such it may be helpful to put

the account in joint names whilst some private or occupational pension schemes won't pay out any benefits to partners if the owner of the pension scheme wasn't married meaning that the pension fund is lost.

13. Timely and appropriate advice on benefits/wills/bereavement services is hugely beneficial to those at the end of life as it ensures all parties involved in providing care have a clear understanding of the options available, how to maximise their income and who is best placed to provide advice on the next steps. Marie Curie are currently seeing a rise in people asking for advice on how to appeal against decisions from their local councils regarding benefit support. This is likely to increase as patients and families face reductions in benefit or unavailability in other community services.

The effects of a drop in financial help for those requiring palliative care

14. A disproportionate amount of the cuts are falling on benefits such as Disability Living Allowance and Scotland will suffer more than its fair share due to more people with impairments and long term health conditions than other areas of the UK. This could impact on those that are terminally ill.
15. The benefits system needs to recognise both the emotional and financial impact of those requiring end of life care and their families, many of whom may have to reduce their working hours in order to provide care.
16. A drop in financial help for those in need of end of life care might mean that patients could be forced to stay in hospital beds and hospice care settings because families cannot afford to care for their loved ones at home where they would most like to be.
17. As people find it harder to pay for care it is possible that government agencies will be required to uptake more responsibilities. This may result in a sense of disempowerment for carers because of a perceived lack of 'ownership' on the type of care their loved-one receives, the place of where that care will be delivered and a lack of choice when it comes to funeral arrangements.

Self-Directed Support

18. Terminally ill patients in receipt of social care services may be required to undergo a reassessment of needs, as part of the movement towards self-directed support. These reassessments may lead to patients receiving less care or a budget that does not allow them to purchase the same level of care as they previously received. Reassessment can also lead to delays in care received. We have heard of examples of patients being delayed discharge from a hospice as local authorities undertake a social care reassessment. For those who are terminally ill any delay can seriously affect their long term care and can even result in them not being discharged to be cared for at home where they would most like to be. We would urge the Government to ensure that all terminally ill patients receive social care assessments and reassessments as a matter of

priority and that the care packages that follow meet the needs of the patient and their families.

19. Research tells us that the majority of people would like to die at home, but the majority are dying in hospital. Research carried out by Marie Curie suggests that caring for a patient to die at home costs the NHS considerably less than to die in a hospital. The Benefits and social care system should be set up and flexible enough to support patients and families to achieve this.