# Template for costing policies of opposition parties

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# Description of policy

To make social care at the end of life free to everyone that has substantial and critical health care needs.

## Relevant quote text:

Andy Burnham: We will give all families the right to care in their home, if they want it...your care provided on the NHS and no worry about its cost - starting with those who are terminally ill with the greatest care needs. (link)

## Background

Free end of life care has long been supported by charities such as Macmillan and Marie Curie and the Care and Support White Paper in 2012 stated that the Government saw "much merit in the idea of free social care at the end of life." A report by the national audit office states that: "the majority of people (between 56 and 74 per cent) express a preference to die at home"1.

Social care is paid for through local authorites though it is not currently free to individuals at the point of need. Within the current system financial support only becomes available if the individual is above the threshold of both a nationally set financial means test and a locally set needs test (that will become national from April 2015). As a consequence many people self fund their own social care and face significant asset depletion. Health care is free at the point of need, whether provided in hospital or at home, but it is not always possible to provide complex end of life healthcare at home.

#### Top level summary of findings:

The estimates refer to free social care for older adults (>65's) in their last 3 months of life, excluding daily living costs, starting in April 2015 and assuming the Dilnot cap is introduced in 2016.

It has not been possible to cover any cost of free end of life health care, the cost of free social care to under 65's or the cost of free social care for more than the last 3 months of life.

DH have estimated the cost, above current spending by the state, of providing free social care at the end of life to older adults (aged 65+) with palliative care needs to be between £200-£250m per year over the next six years. These costs should not be quoted without noting the substantial caveats.

<sup>&</sup>lt;sup>1</sup> http://www.nao.org.uk/wp-content/uploads/2008/11/07081043es.pdf

The costs have been adapted from modelling completed by DH in 2012, carried out for the purpose of modelling the costs of the social care funding reforms. They are provisional etimates of costs with a substantial number of caveats and have not been released publicly. This costing therefore reflects the best analysis currently possible, given the limited data, but should be considered a provisional estimate.

## Additional policy assumptions

Relevant assumptions provided by SPADs are:

- For those at the end of their life needing social care, there is no means test.
- Assume the needs test remains in place, and that the free offer applies to those at the end of life with substantial and critical care needs.
- On the definition of 'end of life': there is currently an 'end of life' register for people diagnosed with less than a year to live. This however does not capture the actual number of people who need social care at the end of their life, such as those with conditions like dementia. Please therefore base the costing on the number of people who have died after receiving substantial and critical care.
- Assume children are included in the policy.
- Where possible you should include any additional costs of the NHS providing healthcare in people's homes rather than in hospitals.

Additional technical modelling assumptions or judgements required

In addition to the assumptions above, a number of judgements and assumptions had to be taken which were mainly driven by the lack of robust data in this area. A summary of assumptions is below and a subsequent more detailed explanation expands some of these points.

## Modelling assumptions and exclusions: Summary

- These costs apply to England only.
- The costs presented are for social care only and exclude healthcare provided in the home at the end of life.
- The costs are for those aged 65 and older, so working age adults and children are not included. Although children currently have free social care, there may still be marginal costs associated with this.
- The costs take into account the introduction of the Dilnot cap in 2016 (which caps the amount the individual has to contribute to their care at £72,000).
- Daily Living Costs have been excluded from the calculations in line with the cap system. The government has proposed that individuals should expect to contribute around £12,000 a year towards such costs.
- For the purpose of these calculations, end of life is defined as the last 3 months of life, not last year of life which is based on the average time spent on the End of Life Register. Definitions of end of life can vary from 12 months to 3 months and as such there is disparity in published work. It is not possible to extrapolate from one to the

- other due to variance in care costs across the last 12 months, particularly the potential for significant increases in costs during the last 3 months.
- These costings do not include any changes that might be required in generalist and specialist palliative care in the community. It is anticipated that increased uptake of social care at the end of life would increase the demand for community healthcare provision.
- They do not include any potential savings from decreased hospital costs.
- The models assume that the NHS would take responsibility for funding social care at the end of life, which is currently funded by LAs and individuals. This avoids Capital investment to put infrastructure in place for the distribution of funds. However, this route may not necessarily be the most effective.

#### **Data sources**

- The Independent Palliative Care Funding Review, commissioned by the then SofS in 2010 and published in 2011, set out a proposed new funding system for end of life care. As part of its recommendations, it proposed that social care should be free for people at the end of life. A series of 'funding pilots' were then established to collect data to test the Independent Review's recommendations. Initial analysis shows that this data is insufficiently robust, mainly due to gaps relating to self-funder activity. DH are identifying other sources of data at the moment.
- The estimates given here were generated through the 2012 DH Funding Model that has been developed for the purpose of modelling the social care funding reforms.
- ONS data for England and Wales shows there were approximately 419,889 registered deaths of the over 65s in 2012 and the Palliative Care Review found that 77.5% of all deaths of over 65s have a palliative care need.
- A person is placed on the End of Life Register if the clinician believes they are unlikely to live longer than 12 months from that point. The average length of time currently spent on a register is currently 3 months; however, the vast majority of those on an end of life register have a cancer diagnosis. This is as clinicians tend to have much more confidence in giving a terminal prognosis for cancer due to the much stronger clinical evidence on the disease trajectory. There are many others that are likely to be eligible to be on the register such as those with diseases such as MND and dementia for which diagnosis rates are increasing.
- The projection of end of life social care cost assumes that it will grow in line with total care spending on older adults which is driven by an increasing population of >65's due to the ageing population.

# Dilnot cap

- The £72,000 cap on social care costs will be introduced in 2016. The extra cost to the state of providing free social care at the end of life is expected to be lower as a result of the cap, as some people will have already hit the cap by the time they have palliative care needs.
- Though the cap will be implemented in 2016, the first significant groups of those aged 65 and over are expected to reach the cap in 2019. DH have adjusted for this by expecting reductions in end of life social care costs to occur from 2019 onwards.

- Alongside this, an extension to the means test is being introduced. This will see people becoming eligible for local authority financial support in a care home when they have assets below £118,000.
- DH note however, that there may be further interaction with the funding reforms this government is in the process of introducing which would need to be fully investigated.

# **Estimates for eligible population and costs**

 There is no robust data about the number of self-funders who pay for their own social care that also require end of life care. Assumptions have therefore been applied to the information available from DH modelling to quantify the costs of the implementation of the Dilnot reforms.

# DH modelling shows that:

- There are around 80,000 to 100,000 over 65s with eligible end of life social care needs that receive local authority support. However, support is means tested and many will be making some contribution towards the cost of their social care.
- In addition, we estimate that there are around 55,000 to 70,000 people who fully fund the cost of their own social care who would be eligible for free social care at the end of life. This is based on CQC bed data, information about the average length of stay and local authority placements.
- In total, this would mean between 135,000 to 170,000 people being eligible for free social care at the end of life.
- Unit cost data is based on HSCIC 2010/11 data with some uprating. This means
  unit costs are assumed to be £610 per week in 15/16 prices. This is the same
  assumptions that have been used for the original Dilnot costings. However,
  recent work to update the Dilnot model shows that costs have not risen in line
  with projections and are therefore lower. Work is currently ongoing to QA the
  revised model.
- Projected additional costs for self funders are therefore approximately £206 –
   261 million per year for each of the next five years that would become the responsibility of the state.

#### If needed, information required on distributional effects of the policy

- Since female life expectancy in the UK is higher than male and this policy relates to social care at the end of life, it could be argued that females are favoured as the costings relate to the over 65's. However there is limited scope for this argument if working age adults are ultimately included in the policy.
- Integral to the policy is that end of life care would be free to all and not on the basis of any other demographic characteristic such as ethnicity or religion.
- It should be noted that this policy will be of direct benefit to older people, those with terminal illnesses and potentially to some of the population with disabilities.

• This policy assumes that there is no means test and is therefore inclusive of all people regardless of income or assets. It should be noted that this policy is more regressive than the current system.

Cost/Revenue to the Exchequer over five years

Although evident from the number of assumptions that have been made, it must be emphasised that the costs in this document are estimates, adapted from estimations of end of life social care costs generated by DH in spring 2012. Further work is therefore required for a full update of the modelling required, including (but not limited to) the identification of the eligible population, and to include those aged under 65.

#### Summary:

DH have estimated the cost, above current spending by the state, of providing free

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	Year 1	Year 2	Year	Year 4	Year 5	Year 6
	2015/16	2016/17	32017 /	2018/19	2019/	2020/21
			18		20	
Current	200 –	200 -	200 -	200 -	200 -	200 -
	250m	250m	250m	250m	250m	250m
Total						

social care at the end of life to older adults (aged 65+) with palliative care needs to be between £200 - £250m per year over the next six years. These costs should not be quoted without noting the substantial caveats.

# To note:

- Costs are for England only and do not include Barnett consequentials. However, note that much social care is currently provided free in Scotland.
- The first year costs are a direct transfer of costs and do not reflect any additional start up costs.
- As most of the social care and support is purchased rather than provided DH
  anticipate that the Government shouldn't have any, or at least very little, Capital
  expenditure. This has not been explicitly explored in this analysis and would be
  futher investigated in a full modelling.
- Costs generated by DH in 2012 do not envisage any AME expenditure, however it is worth noting that there may be savings associated with this policy if eligibility for free social care at the end of life affected eligibility for Attendance Allowance.

Distributional effects	if none requeste	d, any sig	nificant)	:	

No distributional effects calculated but see above for discussion around this.

Comparison with current system (if applicable):

Other comments (including other Departments consulted):

Department of Health have provided these costs from provided the relevant detail around the assumptions a	
To be completed by Permanent Secretary's Office Date costing signed off:	02/01/2015
[If applicable] Date revised costing signed off:	03/01/2015