Response to *Developing a new approach to palliative care funding: A first draft for discussion*

1. The Childhood Bereavement Network is the national hub for those working with children and young people before or after the death of someone important in their lives. We underpin our 250+ members' work with essential representation and support, advocating for bereaved children's needs and helping professionals access the information and support they need to develop high quality services.

2. The National Bereavement Alliance is an emerging group of organisations with a shared vision that all people have awareness of and access to support and services through their bereavement experience. The core membership of the Alliance comprises national and regional membership organisations with an interest in the field of bereavement care, national providers of bereavement care and local bereavement care providers which have no other means of being represented.

3. This response has been prepared by Alison Penny, Coordinator of the Childhood Bereavement Network and Project Coordinator of the National Bereavement Alliance apenny@ncb.org.uk | 020 7843 6054 | 07894 390 736

Our involvement to date

4. The **Childhood Bereavement Network** responded to the initial and follow-up consultations initiated by the Palliative Care Funding Review team and attended the launch of that event. The **National Bereavement Alliance** was established after publication of the final report of the Palliative Care Funding Review, but a number of members responded independently to the consultations.

Bereavement and palliative care

5. Bereavement support for carers and families is an integral part of palliative care. According to the WHO definition – adopted by NICE - palliative care '*offers a support system to help the family cope during the patient's illness and in their own bereavement*'.

6. The interim report of the Palliative Care Funding Review team identified that dedicated palliative care included *'care and support for families and carers, including psychological and bereavement support'*[i]. This includes support for children and young people affected by the expected death of a parent, sibling or someone else important in their lives.

7. The final report excluded from the proposed tariff.

> *Whilst we have not included bereavement support in our proposed per-patient tariff, we do think it is important that universal access to these services is available for everyone if they need them…The review team recommends that a pre-bereavement assessment is included in the tariff, but that bereavement support continues to be supported by both the state and society, outside the palliative care tariff.*

8. At that point, CBN and others indicated our dismay and warned of our serious concerns that this recommendation would, if implemented, result in a withering of organised support for bereaved families and carers – including children and young people – as part of palliative care services.

9. We are aware that there has not, to date, been a formal Government response to the recommendations of the Palliative Care Funding Review. The pilots have proceeded on the assumption that bereavement support would not be included (apart from a pre-bereavement assessment, see below). P15 of the current draft explains that *'the decision on what was included in the analysis to create the currency is not a decision on what should and should not be funded by the state. Discussions on the state's funding responsibility for palliative care will need to include the Department of Health and will take place if national prices are developed.'*

10. We remain unclear about this process. **We ask for the Government to issue a formal response to the recommendations in the PCFR review - with clarity about what aspects of bereavement support will and will not be funded by the tariff – as a matter of urgency.**

Pre-bereavement assessment

11. We welcome that the currency includes pre-bereavement assessment. However, we have some questions remaining about the nature of this assessment and how it is used. Specifically:
    a. Which family members and carers are assessed before the death, using what tools? How is their consent sought?
    b. Who undertakes the assessment and what training have they had?
    c. How are the findings of the assessment stored and used?
    d. How does the assessment process reflect the dynamic and changing nature of caring and anticipatory grief?
    e. Once an assessment has identified the level of care and support required, how is this funded, commissioned, provided and evaluated?
    f. How do the findings of the assessment impact on the currency unit identified for the patient?
12. **We would welcome clarity on these questions.**

Impact on other funding sources

13. Page 9 of the draft indicates that '*the development currency for the palliative care sector will not impact on the proportion of palliative care funding which is generated from charitable donations'*. We are not sure about the basis for this claim, as it is reasonable to expect that publication of the currency/tariff may have an impact on charitable giving to the sector, which would in turn affect the proportions of state/society funding. We are particularly concerned that a drop in charitable giving would have a disproportionate effect on bereavement services, if these remain outside the tariff.

Why we believe bereavement support should be included in the currency

Patient outcomes are closely linked to family and carer outcomes

14. The focus of the currency focuses rightly on meeting the individual patient's health and social care needs. However, for many patients, their families' needs are a major concern which cannot easily be separated from their own.

15. For example, research shows that parents who are seriously ill or dying and have young children are frequently distressed by the huge challenges of balancing parenting and managing their illness, and anxious about how their children will adjust to their death and be cared for in the future[ii] Parents' depression while they are ill is associated with how well their children are functioning[iii]. Interventions with children have been shown to reduce ill parents' anxiety and depression and increase self-confidence[iv], and parents recommend such interventions[v]. **If a significant outcome for patients is feeling reassured about how their family is coping now and will cope after their death, then meeting family and carers' pre- and post-bereavement support needs must be included within the currency.**

Making bereavement services universally available doesn't preclude including such services in the currency.

16. We agree with the recommendation of the Palliative Care Funding Review that bereavement care after a death should be universal for all those that need it – ie available to those bereaved suddenly as well as those bereaved through palliative care deaths.

17. However, the arguments put forward around these discussions seemed to suggest that if bereavement support was included in the tariff, this would jeopardise support for people whose bereavements fell outside the scope of palliative care.

18. Conversely, we argue that by excluding pre- and post-bereavement care from the tariff, we will miss opportunities to provide the best possible support. Palliative care deaths and sudden deaths afford <u>different</u> possibilities for responding to carer and family needs, and we must not level provision down to the lowest common denominator. For example, we know that the time of greatest anxiety for children when a parent is terminally ill is *before* the death[vi]: there are suggestions from practice that supporting children at this time can reduce the need for intensive support after the death.

19. Just because we can't provide this for those bereaved suddenly doesn't mean we shouldn't provide it for those facing an anticipated death. **For this reason, we want to see pre- and post-bereavement care included in the currency, <u>as well as</u> post-bereavement support being provided universally.**

High quality bereavement support can save money to other services

20. Grief is not an illness, although it does increase people's vulnerability to a range of mental and physical health difficulties. Across types of bereavement it increases the risk of mortality, physical health problems, physical disability, use of medication and hospitalisation[vii]. Around 11% of people are likely to suffer 'complicated' or 'prolonged' grief following a death from

natural causes: rates are likely to be higher among those bereaved of a child, or following a traumatic death[viii]. Widow(er)s[ix] and children bereaved of a parent[x] are more likely to visit their GP. Children bereaved of a parent or sibling are more likely to have clinical rates of mental health difficulty, may underachieve at GCSE and have a greater risk of poor health behaviours[xi] – all outcomes with life-long significance.

21. The costs of bereavement are borne by society as a whole as well as by individuals and families. Increased rates of the use of health and social care services and days of work lost to sickness all cost the economy dear. In Scotland, the death of a spouse is associated with increased mortality and also with longer hospital stays, costing the NHS around £20 million each year[xii]. In England, with over eight times the number of deaths, this figure could be between £150 and £190 million. It would be even greater if it included the impact of the death of someone else close, such as a child or parent, and took into account the costs of increased use of other health and social care services[xiii] and days off work.

22. The Childhood Bereavement Network is currently piloting a 'cost avoidance calculator' to identify the cost savings which community based child bereavement services can bring. **We believe that including high quality, appropriate bereavement services for people of all ages in the currency would result in significant savings to other parts of the health and social care system.**

The Family Test

23. New guidance for government departments sets out the tests for new policies which will have an impact on families[xiv]. Specifically, this requires policy makers to consider the impact on families going through transitions such as bereavement, new caring responsibilities or the onset of a long-term health condition. We believe that the currency proposals will fall well within the scope of the test and that their impact on families would be improved by the inclusion of pre- and post-bereavement support.

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[i] Palliative Care Funding Review (2010) *Interim Report*

[ii] Altschuler and Dale (1999) 'On being an ill parent' *Clinical Child Psychology and Psychiatry* 4, 23-37

[iii] Schmitt et al (2008) 'Cancer families with children: factors associated with family functioning – a comparative study in Finland *Psycho-oncology* 17, 363-373

[iv] Eg Lewis, Casey et al (2006) 'The enhancing connections programme: Pilot study of a cognitivie-behavioural interaction for mothers and children affected by breast cancer. *Psycho-oncology*, 15, 486-497

[v] Schmitt et al (2007) 'Children of parents with cancer: A collaborative project between a child psychiatry clinic and an adult oncology clinic' *Clinical Child Psychology and Psychiatry* 12,3, 421-436

[vi] Seigal, Karus et al (1996) 'Adjustment of children facing the death of a parent due to cancer' *Journal of American Acadamy of Child and Adolescent Psychiatry* 35, 442-450

[vii] Stroebe, M.S., Schut, H., and Stroebe, W (2007) Health outcomes of bereavement. *Lancet,* 370, 1960-73. http://www.comsegovia.com/paliativos/pdf/Health%20outcomes%20of%20bereavement.pdf

[viii] Prigerson, H et al (2008) A case for inclusion of prolonged grief disorder in DSM-V. In Stroebe M et al (eds) *Handbook of Bereavement Research and Practice* Washington DC: American Psychological Association

[ix] Stroebe et al (2007) ibid

[x] Lloyd-Williams, M and Wilkinson, C and Lloyd-Williams, F (1998) Do bereaved children consult the primary health care team more frequently? *European Journal of Cancer Care* 7, 120-124

[xi] Childhood Bereavement Network (2009) *Grief Matters for Children: A Call to Action* London: National Children's Bureau

[xii] Birrell et al (2013) Socio-Economic Costs of Bereavement in Scotland: Main Study Report.

[xiii] Stroebe, M.S., Schut, H., and Stroebe, W (2007) Health outcomes of bereavement. *Lancet,* 370, 1960-73. http://www.comsegovia.com/paliativos/pdf/Health%20outcomes%20of%20bereavement.pdf

[xiv] Department for Work and Pensions (2014) *The Family Test: guidance for government departments* *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/368894/family-test-guidance.pdf*