

Childhood Bereavement Network response to

Developing the annual health check in 2008/9: Have your say

Introduction

The **Childhood Bereavement Network** (CBN) is the national, multi-professional network of over 300 organisations and individuals working in the field of childhood bereavement. CBN promotes the interests of bereaved children, young people and their families and encourages the development of quality support for them.

The death of someone significant brings change and challenge into the life of a young person, and can be devastating. Around 1 in 25 children and young people currently of school age have experienced the death of a parent, brother or sister, and many more are affected by the death of someone else close. Some receive excellent support from family, friends, school and services, but others – often those who are already disadvantaged – struggle to find the help they want and need. Without appropriate support, bereaved children and young people can be at risk of health, social and educational difficulties and disadvantages.

Our *Grief Matters for Children* campaign calls for appropriate support to be available to all bereaved children, young people and their families, wherever they live and however they have been bereaved. We want inspection frameworks for children's services to examine how bereavement support is provided in order to drive up standards and ensure that local services meet the needs of bereaved children and young people. Therefore we welcome the opportunity to comment on the Healthcare Commission's proposals for the annual health check.

The context

CBN brings together practitioners across health, social care, education and the voluntary and community sector. A number of our members are based in PCTs and acute trusts – others have close working relationships with the NHS including taking referrals of children and young people, and training NHS staff.

Providing children, young people and their families' with high quality information, guidance and support following the death of someone close contributes to meeting priorities identified in current planning and policy for the NHS.

The NHS Operating Framework 2008/9 sets out health and service priorities for the year ahead and identifies reform levers to improve quality of services and reduce health inequalities. A list of indicators or 'vital signs' will be developed to help PCTs work together with local authorities to deliver joint outcomes under the new Local Area Agreements (LAAs). The framework sets out

1. **National priorities**, which include 'keeping adults and children well, improving their health and reducing health inequalities. Within this priority, **cancer services, stroke services** and – for the first time – **children's physical and mental health and well-being** are identified as key areas.
2. **Issues requiring local attention** including recovery on areas where performance is currently not meeting required standards, and preparation for action on areas

including **mental health – improving access to psychological therapies, end-of-life care** and **disabled children**.

3. **Issues to be determined and set locally with partners.**

When a patient dies: advice on developing bereavement services in the NHS outlines key principles in the development of services and practices following a patient's death, and highlights that these principles are of special significance for particular groups, which include children who have been bereaved. The guidance recommends the development of a policy identifying a bereavement care pathway, and that trusts work in partnership with other agencies including voluntary and charitable organisations.

The NHS Next Stage Review (Our NHS, Our Future). Each Strategic Health Authority has set up clinical pathway groups to examine the evidence for improved models of care in eight key areas. Those areas of relevance to childhood bereavement services are children's health, mental health and end-of-life care. The final report, to be published in June 2008, will set out a strategy and vision for the next ten years.

Comments on proposals for the Health check

1. Comments are sought on our proposals for national reviews and studies in 2008/2009

Palliative and end-of-life care

We welcome the proposed review of access to end-of-life care and the quality of services provided. This provides an important opportunity to review the provision of childhood bereavement services across both PCTs and acute trusts.

As set out in '*The NHS in England: the operating framework in 2007/8*', PCTs have been carrying out baseline reviews of their end of life care services to feed in to the Government's forthcoming strategy to be published in summer 2008. This should include a review of services for children facing the death of someone close, and following bereavement. PCTs were also asked how many people accessed these services and what proportion of all deaths this represents. This last question may have been difficult for PCTs to answer fully, as there is currently no collection of data on the number of children and young people who are affected each year by the death of a parent or sibling.

The proposed review provides a key opportunity to bring this work undertaken by PCTs together with an analysis of the provision of childhood bereavement services in acute trusts, which is guided by *When a patient dies: advice on developing bereavement services in the NHS*.

The proposed review should examine how children bereaved through the death of a patient are supported across both PCTs and acute trusts, and how both work in partnership with childhood bereavement services in education, social care and the voluntary sector.

Access to psychological therapies

This review could provide an opportunity to explore availability and access to psychological therapies for bereaved children, young people and their families. This could provide valuable information on the numbers and ethnicity of children and young people

who access therapies; those who do not and why; and assess the breadth and quality of information and support currently available.

3. Please comment on our proposed indicators for primary care trusts.

Our comments are limited to those indicators relevant to bereaved children and young people.

CAMHS

The PSA target associated with CAMHS is currently in consultation. The availability of preventative, community based childhood bereavement services should be an indicator of this target.

Improving cancer services

This target involves Implementation of the NICE's *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer*. This guidance highlighted the need for provision for meeting the specialist needs of bereaved children and young people, which should be measured as part of this target.

Patient-reported measure of respect and dignity

Self-reported experience of patients/users/public

Evidence for this indicator should include feedback from children and young people on their experience of bereavement services (eg through PALS services, questionnaire surveys and one-to-one or group consultation, as suggested in *When a patient dies: advice on developing bereavement services in the NHS* (p 21). The Childhood Bereavement Network is developing common evaluation tools for use in childhood bereavement services and we would be pleased to share the findings of our work in due course.

Data quality on ethnic group

Data on ethnic group is particularly relevant in relation to bereavement services, including those for children. To be appropriate and relevant to users, services must take account of differences in cultural understandings of death and bereavement, and good quality data on ethnic group can support this.

5. Please comment on our proposed indicators for acute trusts.

Data quality on ethnic group

As above (point3).

Health promotion for patients – from patient survey

Further information on the proposed patient survey would be helpful, including clarity about how this will involve children and young people. Acute trusts are well-positioned to provide public health information on how children grieve, which can help parents to understand more about their children's experience and provide support to them.

Dignity – from patient survey

Experience of patients/users

As above (point 3).

7. Please comment on our proposed indicators for mental health trusts.

Data quality in ethnic group
As above (point 3).

CAMHS
As above (point 3).

Clinical staff receiving role specific training
As part of this indicator, trusts should demonstrate that those working with children and young people have an understanding of the likely impact of bereavement and can offer support (as specified in the *Common Core of Skills and Knowledge for the Children's Workforce*).

*Building close relationships (eg respect and dignity, being listened to carefully);
Choice and involvement (eg reported involvement in decisions about care and treatment;
Carers (eg % of people who report that their family and/or carers have received enough
information and support) – all from patient survey*
Surveys of patient experience should include children and young people using CAMHS services, and their parents or carers.

13. Please comment on whether you think our proposals for the annual health check will take sufficient account of patient views

The proposals do not make specific provision for seeking the views of children and young people. It is important that the new LINKs replacing Patient and Public Involvement Forums are properly aligned with children and young people's services to ensure that young people's voices are heard among adult patient views.

Additionally, the focus on issues that matter to patients – identified through surveys, complaints and forums – could potentially overshadow areas of provision that are relevant to a small proportion of the population, such as childhood bereavement services. It is important that views about such services are actively sought.

14. Please comment on whether you think our proposals for the annual health check 2008/9 will sufficiently encourage trusts to address health inequalities and promote well-being.

As mortality rates vary across the UK, so does the likelihood that children and young people will experience the death of someone close to them. Children in disadvantaged circumstances are more likely to be bereaved, and less likely to have organised support available to them.

Provider trusts have a key role to play in reducing these differences in children's experience of bereavement, both by tackling the underlying cause - different mortality rates – and by providing childhood bereavement services.

15. Please comment on whether you think our proposals for the annual health check 2008/9 will provide an appropriate assessment of children's services provided by NHS organisations and how they could be improved.

The assessment of children's services under the annual health check will need to be aligned as closely as possible with the forthcoming Child Health Strategy. Further guidance will be needed in this area.

The proposals include the development of a small set of indicators to assess children's services that are provided in the community around key areas, several of which are particularly relevant to childhood bereavement services. These include:

- **Transition and adolescence:** by the time they are 16, around 6% of young people will have experienced the major changes and challenges associated with the death of a parent: many more will have been of someone else important. All bereaved children and young people should have access to appropriate information and support to help them manage the impact of death on their lives.
- **Palliative and end-of-life care:** despite falling child mortality rates, young people have a 6% risk of being bereaved of a sibling by the time they are 16. Palliative and hospice services for children and young people often provide sibling support services.
- **Childhood and adolescent mental health:** children and young people with a range of emotional and conduct disorders are more likely to have experienced the death of a parent or sibling than those with no such disorder. Bereaved children in one study believed they had less control over life's circumstances than their non-bereaved peers, and two years after the death, their self-esteem was lower than those who had not been bereaved.

Further information

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