# 'I'm not the only one': a collaborative approach to developing a children and young person's bereavement group

**Sarah Bull PG (Dip) Counselling, MBACP**
Head of Bereavement and Counselling services for George Thomas Hospice Care.
Sarah.bull@gthc.org.uk

**Michele Pengelly RGN MSc BSc (Hons) Diploma Palliative Care**
Lead nurse for supportive care, Velindre Cancer Centre
Michele.pengelly@wales.nhs.uk

**Abstract:** This paper describes a collaborative partnership in developing a children and young persons' bereavement group. The course consists of a series of four sessions which encourage children to share and express feelings. The group uses a partnership approach. Whereas previous groups were hospice counsellor-led, the new model is for co-facilitation by the counsellor and a specialist nurse from a regional oncology centre. The success of this collaborative partnership has been demonstrated through the positive evaluations from both the children and their families and the facilitators. In addition, both facilitators feel that their own clinical practice has been positively influenced by the children's sharing of their own personal experience of illness and bereavement.

**Keywords:** children, bereavement group, collaborative working

## Background

Bereavement is an experience that many children and young people may have to face. It is estimated that 21,950 young people and children in Wales aged 5-16 have experienced the death of a parent or sibling and 39,800 may have been bereaved of a friend (Fitz, 2010). There is evidence to support the view that the majority of children do not actually experience serious emotional problems following bereavement (Dowdney, 2000; Haine *et al*, 2008). An overview of the literature examining bereavement in childhood, the impact on psychological and educational outcomes and the effectiveness of support services, found that whilst most children experience some negative impact on psychological wellbeing from the death of a parent or sibling (up to a year), in the majority of children these difficulties do not persist or require specialist services (Akerman & Statham, 2014). For those children who do however require additional support a qualitative study by Rolls and Payne (2007) reports on the experiences of bereaved children and parents who accessed UK childhood bereavement services, finding that children and parents reported on the benefit of speaking to someone who understood their experience. Visser *et al's* (2004) literature review of fifty-two studies examined the impact of parental cancer on children concluding that intervention studies directed to the needs of children and their families reported positive results. Whilst the review did not focus on bereavement, it does support the case for pre-bereavement support and the need for awareness in professionals supporting bereaved children of the impact of the parental cancer and treatment on emotional functioning of the child. Akerman and Statham (2014) suggest there is a need for interventions supporting bereaved children, reporting that even children who do not exhibit clinical levels of distress may benefit in the longer term from programmes which normalise grief and help to strengthen coping strategies.

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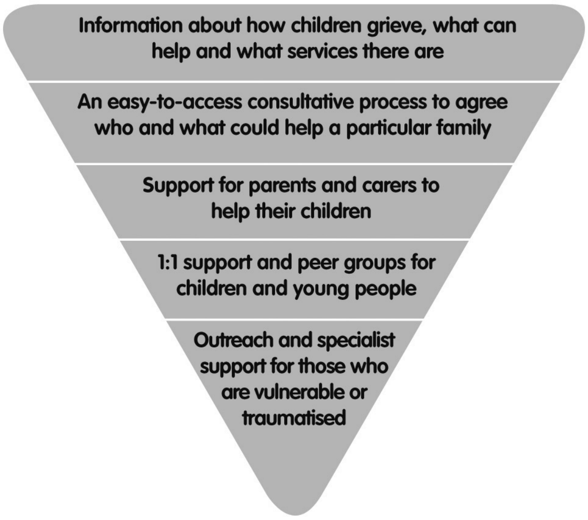
There appears to be little evidence regarding the relationship between child bereavement and educational outcomes. However, Akerman and Statham (2014), advise that while education does not seem to be significantly affected, some children experiencing the death of a parent or sibling may still need support or even referral for additional help. They conclude that as schools are the place where most children spend a large part of their daily lives they could play an important role in recognising and responding to the needs of bereaved children.

## The need for change

The George Thomas Centre Hospice Care has provided bereavement services for the people of Cardiff for over 25 years. This includes telephone support, face-to-face counselling and adult support groups. However, in recent years national guidelines and strategies recommend the development of specific services for children and young people (NICE, 2004; Childhood Bereavement Network (CBN), 2009). NICE proposes a three component model of bereavement support (Table 1) and that providers of this support should have strategies in place to access services, including meeting the needs of bereaved children and young people.

In addition, and more specific to children's bereavement services, the Childhood Bereavement Network in their 'Grief Matters for Children' campaign offer a visual picture of how good provision of care for bereaved children should look (Figure 1). The Head of Bereavement and counselling services (counsellor) at the hospice developed her role and skills to include the provision of face-to-face pre- and post-bereavement counselling for children. Until 2009, the hospice did not offer a children and young person's bereavement group and therefore in terms of the CBN model of practice, level 4 intervention (1:1 Support and peer groups) was not available. In order to address this gap in service provision, the counsellor benchmarked her service against other providers of children's bereavement groups including the Christian Lewis Foundation, and attended relevant training with Winton's Wish Foundation, St Christopher's Hospice and Macmillan.

**Figure 1:** Model of practice (Childhood Bereavement Network)



The first George Thomas Hospice Care children's and young person's bereavement group took place in 2009 and was facilitated by the counsellor and a member of the hospice staff. Whilst this group worked well, the counsellor observed that sometimes the children had 'medically-orientated' questions, for example, about radiotherapy, chemotherapy, or even blood counts and infections. There were clearly aspects of their parent's or grandparent's care that they did not understand. Therefore, for the next group, the counsellor decided to invite a Cancer Specialist Nurse (SN) as co-facilitator. The SN provides a role at the local regional oncology centre which includes the provision of advice and support for parents and grandparents when talking to children about cancer during their treatment at the hospital.

## The children and young people's group

Eight children attended the initial group in 2009, which was run as four three hourly sessions, mainly during the school holidays. Following evaluation, there was a need for some change before the new approach to the group in 2010. One of these changes

**Table 1:** NICE (2004) Components of bereavement support

| **Component 1** | **Component 2** | **Component 3** |
|---|---|---|
| • Grief is normal after bereavement and most people manage without professional intervention. | • Some people may require a more formal opportunity to review and reflect on their loss experience. | • A minority of people will require specialist interventions. |
| • All bereaved people should be offered information about the experience of bereavement and how to access other forms of support. | • Volunteer bereavement support workers/ befrienders, self-help groups, faith groups and community groups will provide much of the support at this level. | • This will involve mental health services, psychological support services, specialist support, and will include provision for meeting the specialist needs of bereaved children and young people. |

was to alter the time of the group to after school sessions as the children are often away during school holidays. Seven children attended the 2010 group.

The aim of the group is to facilitate peer support for bereaved children and young people and provide an opportunity to share experiences.

## Selection criteria and children's background (2010 group)

- Patients and families supported by George Thomas Hospice Care Team and the SN at the cancer centre
- Individually assessed prior to attending group by counsellor
- No set period of time since bereavement (see Figure 2)
- Written consent needed from parent or guardian
- Age range: 6-16. Subject to assessment by counsellor
- The group consisted of three boys and four girls
- Three children had been bereaved of a father, three a mother and one of grandparents
- One child had experienced two previous significant bereavements of grandparents in a twelve month period but both parents were alive
- Two sets of siblings

## The group

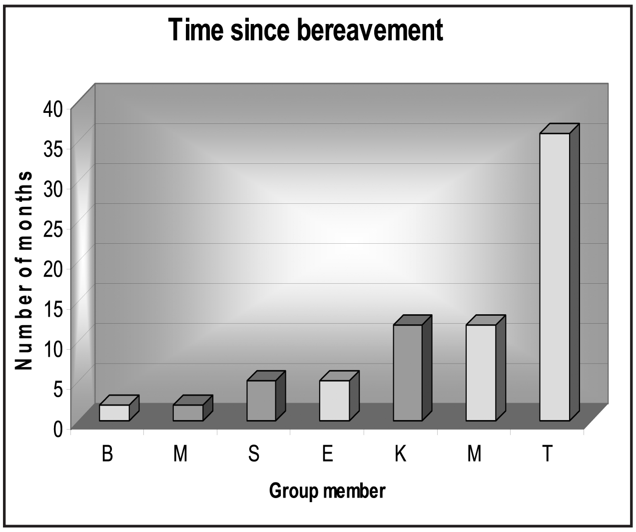


Figure 2

## Structure of sessions

The group was structured around four three hour sessions, held once a month at the hospice centre. Prior to commencing the group, each child was individually assessed by the counsellor and given a memory box to help them begin collecting and recalling important and special treasures. In each session, time was allocated for 'check in' and 'check out'. This was a time where each child had an opportunity to say how they were feeling and/or if they had any concerns. Refreshments were available (and greatly appreciated!) throughout the sessions and provided a wonderful opportunity for the children to interact. Parental/guardian written advice was obtained prior to the first session to establish any known food allergies. The workshops are adapted from practical guidance from Winston's Wish training and from their excellent resource book *As big as it gets* (Stokes and Stubbs, 2007).

## Session one

This was the first time the children had met as a group. They were asked to bring along something that held a special memory about the person who had died and were invited to share this with the group. The children were happy to do this and memories shared included photographs, a watch, a pebble from a family holiday, a teddy bear and a football shirt.

The children then sat at the table to complete the film script exercise. This aims to provide a creative way to express their feelings about what life was like before their bereavement (Figure 3) on the day death occurred (Figure 4) and how they see their world today (Figure 5). An interesting observation was the number of children who actually drew a clock showing the time of death, the drawings were very specific and detailed.

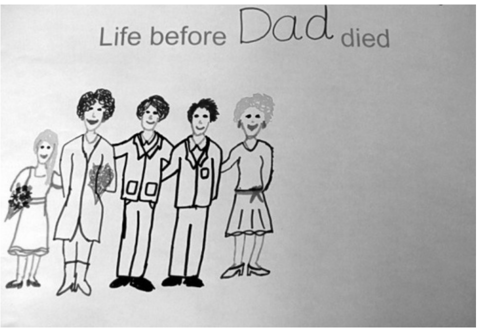


Figure 3

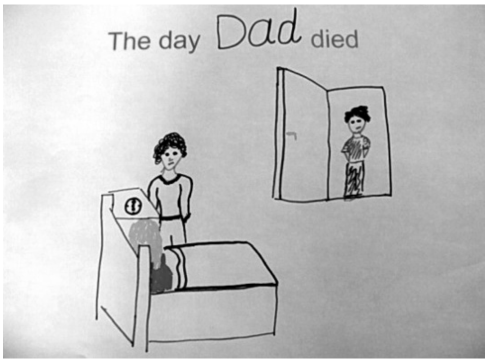


Figure 4

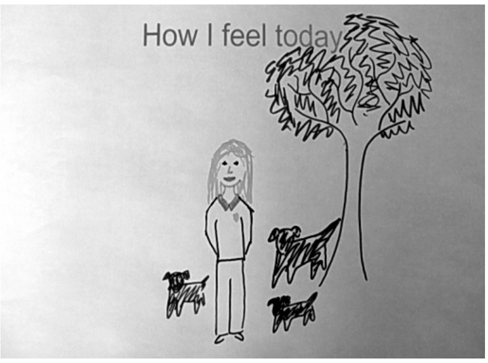


Figure 5

### Session two

In this second meeting the children were given the opportunity to create their own 'feelings jar' (Figure 6). This is a jar filled with table salt that the children colour with chalks. Each colour represents five different memories they have about the person who died, for example:

- Blue *'a happy memory when we walked at the seaside'*
- Yellow *'ice cream on a Sunday'*
- White *'building a snowman in the garden'*
- Red *'Dad's favourite football team'*
- Green *'why did he have to die?'*

Figure 6

This workshop aimed to help children express their emotions and was clearly the favourite session for the group – the children expressed this both verbally and in their formal end of course evaluation. They enjoyed the opportunity to create something so beautiful along with their special memories.

### Session three

This session involved the use of memory stones. The children were given a purse containing three stones – a smooth pebble, a sharp rock and a precious gemstone (Figure 7). These three stones helped them to recall memories of good times, rough times and precious times and they were encouraged to write these thoughts on a piece of paper. For example:

- Smooth pebble *'a happy time on holiday with Mum and Dad'*
- Sharp rock *'how sad it felt when Nan died'*
- Precious gemstone *'just me and Dad going to football every week'*

Time was also allocated during this week for the children to go outside with a jar of bubbles where they found a quiet place to blow the bubbles up into the sky. This activity was about allowing time alone to think.

Figure 7

### Session four

In this final week the children enjoyed a party and a special gift. Each child was also given a helium balloon with a label and encouraged to write a special and private message to the person who had died. The balloons were then released into the sky and the whole group watched how high they could go. The whole emphasis of this week was about closure and letting go. The children were also given a certificate of attendance – which they loved, a reminder that they are not alone in their grief.

## The children's evaluation

At the end of the course each group member was given an evaluation form, where they were asked to fill in two simple statements:

> 'I enjoyed coming to the bereavement group because....'
>
> 'The one thing I learnt from coming to the group is....'

The children were very enthusiastic in expressing their feelings and some of the older children helped their younger peers with writing and spelling. Some of the feedback included the following.

> *'It was good to talk to others about the happy memories of my Dad'*
> Child S age 13
>
> *'I learnt to share my feelings'*
> Child B age 10
>
> *'It is important to always remember the good memories and also the bad and to never forget that it's better to share'*
> Child M age 15
>
> *'I'm not the only one'*
> Child M age 11

## The parents/grandparents/guardian's evaluation

The counsellor telephoned each parent/guardian within a week of the group finishing to ask for their evaluation/perspective and to check the wellbeing of the child. Some of their feedback included:

> *'The children really enjoyed coming and looked forward to coming'*
>
> *'She enjoyed meeting other children whose mum had died'*
>
> *'It's really helped him and has made a difference'*

The counsellor and Specialist Nurse observed that the parent/grandparents are often quite tearful when they collect the children, particularly when they want to talk about the work they have done in the workshop and the special memories they have shared. In view of this, parents and grandparents are now offered an open invitation by the counsellor to contact her if they feel they require bereavement support for their own needs. This can be telephone support, one-to-one counselling or group support.

## Evaluation from the facilitators

> *'There was clear evidence for me throughout the course that where the children and young people had accessed emotional support prior to the death, these children appeared to be less distressed and more comfortable in expressing their emotions about the death.'*
> Sarah Bull (Head of Bereavement and Counselling)

An example of this was whilst working with child S (age 13) who had attended four sessions of pre-bereavement counselling. During the second group session she was comfortable in sharing a poem that she had written and read out at her father's funeral and her memory jar showed her joy of happy memories and an acceptance of the sad ones.

In contrast child K (age 10) who had not accessed any pre-bereavement support appeared to initially struggle with expressing his feelings about his grandparents death. This struggle was both in terms of verbal expression and in the workshops through drawings and memory jars. However by the final session he was able to comfortably talk about his memories and missing his grandparents – particularly the cake-making.

> *'The collaborative partnership approach has without doubt added to the successful outcomes of the children's bereavement group. However, what I had not anticipated was the change to my pre-bereavement work with families in that we now have a more seamless service between the cancer centre and the hospice and have improved communication.'*
> Sarah Bull (Head of Bereavement and Counselling)

> *"What I have learnt as a nurse from these children has been both inspiring and invaluable to my clinical practice. I have had a glimpse of the cancer centre through the eyes of these children and how the things we as clinicians see and take for granted everyday need to be explained to the children. I have also witnessed the positive impact of the pre-bereavement support for the parents and child and how this helps the children in bereavement in articulating their thoughts. It has changed my practice as I am now more aware and proactive in the early referral of families for information and support and more confident in explaining the positive impact this can have for them"*
> Michele Pengelly (Cancer Specialist Nurse (supportive care))

This collaborative partnership has been invaluable both to the children's experiences of the group, which is reflected in the successful evaluation of outcomes from the children and their parents, the counsellor and the Specialist Nurse. Often the nature of some of the specific medical questions asked by the children can be addressed by the Specialist Nurse who may already be familiar with the family from the treatment phase of the parents/grandparents illness. Both facilitators feel that their own clinical practice has been positively influenced by the children's sharing of their own personal experience of illness and bereavement. These invaluable insights and reflections help to inform practice and heighten awareness of issues for children that may not have been previously considered. One child had questions about infection control restrictions and signs that were in place when his father was in hospital – what was the 'C-Diff' infection? Was it something that the rest of the family could catch? Why did he have to wear gloves and an apron? These questions had stayed with and troubled the child for over 10 months and he had not felt able to ask about it at the time as his father was so unwell.

The Specialist Nurse and counsellor were able to answer the child's questions and the Specialist Nurse was able to return to the Cancer Centre and share with colleagues the importance of being 'child aware' when a parent has cancer and share the example of the 'C-Diff' infection. In a more recent group, some of the children still thought that cancer was 'catching'. When this was explored further the children thought cancer could be 'catching in families' as they were aware of more than one family member who had died of cancer. The Specialist Nurse has presented these children's stories and experiences at the oncology centre in education sessions for doctors, nurses and healthcare professionals and recently presented at a Trust Board meeting to highlight to the executive board the importance of the collaborative partnership and learning from the children's experiences.

## Conclusion

This article describes a practice innovation aimed at developing a collaborative approach to the provision of a children's and young person's bereavement group. The workshops helped the children to express feelings in a safe environment and the fun element of the sessions led to a great deal of self-disclosure. Evaluative commentary from children and parents and observation from the facilitators suggests that running a group with different age ranges and different times since bereavement is not problematic to the childrens' ability to share their experience of loss and bereavement. However, whilst the evaluations were positive more rigorous evidence is needed to validate the observations and a qualitative research approach could build on this evidence and establish more information about the benefits of this collaborative approach to group work.

Evidence supporting the view that the majority of children do not actually experience serious emotional problems following bereavement has been discussed. However both NICE (2004) and CBN (2009) recommend that where a need is identified providers of bereavement support should still develop strategies to meet the needs of children and young people. The hospice is now meeting these national recommendations for children's bereavement support in addition to building effective collaborative partnership working with the local NHS cancer centre.

The peer support experienced by the children attending the group has been, without doubt, one of the most valuable outcomes from the sessions. In addition, both facilitators feel that their own clinical practice has been positively influenced by the children's sharing of their own personal experience of illness and bereavement. These invaluable insights help to inform practice and heighten awareness of issues that may not have been previously considered. The collaborative partnership of hospice counsellor and cancer centre specialist nurse has proven to be a very successful and effective approach to facilitation. This is in terms of the nature of support given to the children attending the group, the positive influence on the facilitators' own knowledge and skills and the benefit of applying this knowledge to both pre-bereavement work and to oncology practice. This combination of professionals and the new collaborative approach with the hospice and cancer centre proved to be both productive and effective and therefore future bereavement groups will continue to be co-facilitated by the counsellor and the SN.

The shared experiences of children attending the bereavement group is informing and influencing future practice and care, in addition their real and emotive stories provide a powerful and effective way of educating healthcare professionals and other parents.■

## Note

The names and some personal details of the children have been changed to protect identification. In addition all parents/guardians and the children gave written consent for their work to be shared either for training or publication purposes.

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