

## TITLE PAGE

### **Setting up a support group for children, adolescents and their well carers who have a significant adult with a life-threatening illness**

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**Abstract:**

St Richard's Hospice provides care and support for adults with a life-threatening illness and their families. As part of our work we often encounter children and adolescents who are facing the loss of a significant adult. Whereas in the past we have supported these children and young people primarily through one-to-one interactions after the adult has died, the expansion of our facilities has recently enabled us to provide an increasing degree of pre-death support, including the launch of a pre-death Child and Family Support Group. This article reflects on the benefits and challenges of setting up and running such a group and the journey we have gone through so far. It is our hope that by sharing our experiences we can demonstrate some of the benefits of group work for children and adolescents facing the loss of a significant adult and encourage others in the worldwide palliative care community who are considering running or are already providing such a service.

**Children and the need for bereavement support**

Research has identified the importance of supporting caregivers of people with life-threatening illness (Mok et al, 2003) and the importance of families and caregivers having the opportunity to learn about the physical and psycho-social changes that can be expected as the death of a loved-one approaches, partly in order to avoid 'scenarios in which lack of preparation adversely [affects] patient care' (Steinhauser et al, 2000, p.3). For children, the trauma associated with the death of a significant adult has been shown to have potentially lasting

psychological and emotional implications (Kirwin and Hamrin, 2005; Schuurman, 2003). Consequently, there is a need to adopt a child-centred approach in supporting children who have experienced, or who are about to experience, such a loss (Saldinger et al, 2004). A range of approaches have been used over time and in different societies to support children in these situations (Adams et al, 1999), with early intervention being identified as important to improving a child's chances of successfully adapting to their loss (Kirwin and Hamrin, 2005). A significant relationship also appears to exist between parental competence and a child's ability to cope with the death of a significant adult (Kraus, 2005).

Munroe argues that pre-death<sup>1</sup> interventions with children and their families should have the objective of supporting parents and children in developing effective communication, which can provide lasting benefit in coping with loss (Munroe, 1995). Timely intervention can be crucial and it has been demonstrated that 'it is perfectly possible to make a difference even when time is limited, and often precisely *because* time is limited' (Chowns, 2005, p.125). Unfortunately however the provision of both bereavement and pre-death support for children in the United Kingdom remains limited and inconsistent (Rolls and Payne, 2003).

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<sup>1</sup>Pre-death refers to the period between diagnosis of life threatening illness and the death of a significant adult for the purposes of this article. St Richard's Hospice does not take referrals of patients under 18 years of age.

## **Formats for support**

Traditionally pre-death (and bereavement) work with families has focussed on one-to-one interaction. Advantages of such an approach are that a supportive relationship between the professional and the patient and their family may be able to develop, and that detailed ongoing assessments and therefore responses to specific issues are easily accommodated. Disadvantages of such an approach include the large workload for the professionals involved and the lack of opportunities for the children, adolescents and their well carers to develop networks and to interact with others in similar situations. Ultimately there appears to be value in both one-to-one and group modalities and a number of components can be considered when developing a support service for families facing the loss of a significant adult.

Group work with bereaved children promotes contact with others in similar situations, helping to normalise experiences and diffuse intense emotional expression (Saldinger et al, 2004), as well as providing a useful social framework and reducing isolation (Stokes, 2004). These benefits are equally applicable for pre-death work. For the children and adolescents attending the St Richard's group 'to meet other people in the same situation' (Sally<sup>2</sup>, age 13) seems to be very important. Young people facing the death of a significant adult may also need information, reassurance and involvement, as well as a forum to safely express their feelings (St. Richard's Hospice). It is important that they are allowed to be involved in the process of the approaching death (Christ, 2000), for

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<sup>2</sup> Names have been changed in order to preserve confidentiality.

example in discussing funeral arrangements and creating memory boxes (Chowns, 2005).

Recognising and attempting to meet these needs was central to the planning of the St Richard's Child and Family Support Group. The group had to ensure it provided a safe and supportive forum for children and adolescents to communicate with carers, siblings, peers and professionals. A program of activities had to be devised that would be as flexible and responsive to the needs of each individual and family as possible. There was an awareness that adults who are dealing with their own distress may struggle to support children (Saldinger et al, 2004) and that meeting people in a similar situation could offer the possibility of mutual support networks forming both within and outside of the group. The group therefore needed to be as inclusive of adult family members as possible.

The decision to set up a pre-death support group was a difficult one, not least because of the uncertainty expressed by some researchers as to the value of bereavement support for children (Rolls and Payne, 2003, Davies et al, 2007) and the lack of research into the specific benefits of pre-death group support (Kennedy et al, 2008). This meant that the risks involved in setting up a pre-death group were to some extent an unknown quantity. The St Richard's Family Support Team felt strongly however that, by extending the existing one-to-one service to include group work, relationships could be strengthened between

families, peers and professionals that would provide comfort, support and valuable information at this most vulnerable and uncertain time for families.

### **Creating the Child and Family Support Group**

St Richard's Hospice is based in Worcester, a city located in the West Midlands region of England. The Hospice serves the surrounding county of Worcestershire with a catchment area containing approximately 288,000 people. The Hospice was founded in 1984, initially providing home care support for patients but expanding to provide day hospice facilities in 1987. In 2006 the Hospice moved to a new purpose built facility with 15 in-patient beds.

As resources have become available the components of the pre-death service developed at St Richard's have expanded. As part of a holistic approach to supporting patients the Hospice has for some years been running a bereavement group for adults. This group appears to have been a success with a consistently high attendance rate. With the move to new premises in 2006 the opportunity arose to expand the support offered to children and adolescents, which at that time took the form of individual and family group support in the home or in co-operation with the school or college, by creating a pre-death Child and Family Support Group and a Child and Family Bereavement Group.

In order to facilitate the new groups additional trained staff and volunteers were required. At the time only the Senior Social Worker and three volunteer Family

Support Workers (FSWs) were qualified to work with children and adolescents. Consequently, a training program needed to be devised and delivered that would equip additional staff and volunteers with 'Level 2' skills (Stokes et al, 1999). This training program was received positively by participants and may eventually form part of a psycho-social palliative care module to be validated through a local university.

The model of pre-death support for children, adolescents and their well carers developed at St Richard's Hospice has these objectives:

- To empower families to manage their anticipated loss.
- To encourage families to exercise control and make informed choices.
- To facilitate communication within the family and with peers among the support group.
- To build relationships between families and the Hospice Multi-Disciplinary Team (MDT), who provide support from the point of first contact through into bereavement.

As far as possible, quality of outcome has been prioritised when assessing cost-effectiveness. The Hospice offers families the choice of individual and/or group support in order to provide them with as many support options as possible.

Currently the St Richard's Hospice Family Support Team comprises:

<b>Job Title</b>	<b>Number of Staff</b>	<b>Full or Part Time</b>
Social Worker/Head of Department	1	Full Time
Senior Counsellor	1	Part Time
Counsellor/Family Support Practitioner	1	Full Time
Child and Family Support Practitioner	1	Part Time
Counsellor	1	Part Time
Citizen's Advice Bureau (CAB) Advisor	1	Part Time
Student Social Worker	1	Full Time (temporary)
Student Counsellor	1	Part Time (temporary)
Co-ordinator Family Support Service	1	Part Time
Secretary to the Family Support Service	1	Part Time
Volunteer Family Support Worker	31	Part Time

Not all of these staff and volunteers work with children or young people.

### **The Child and Family Support Group in action**

As the team were more familiar and comfortable with bereavement work, initially a Memory Day, based upon Stokes' model (Stokes, 2004), was piloted for bereaved children, adolescents and their carers in January 2007. This was followed by the first Child and Family Bereavement Group commencing in March 2007 and running for six sessions. This has been followed by further Memory Days and Bereavement Groups. Although the Bereavement Group differs from the pre-death group in being a closed group with no new members joining after

the first session, it has provided valuable insights into group dynamics that have been useful in setting up and running the pre-death group.

When planning the Child and Family Support Group it was decided that patients would not be able to attend. In addition once the patient had died the family would no longer be able to attend the pre-death group but would instead be offered one-to-one support by a member of the team already known to them. In addition the family would be invited to the next Memory Day and the subsequent Child and Family Bereavement Group. This was considered an appropriate strategy as pre- and post-death families are at very different points in the process of loss and grieving (Christ, 2000) and combining them in one group could undermine the effectiveness of support being provided. The presence of the patient at the group, as well as often being impractical, was considered to present too much of a barrier to open communication and would be potentially too upsetting for the families attending.

The first pre-death Child and Family Support Group session was held on a Monday evening in October 2007 from 5.30 pm to 7.00 pm and this group has subsequently met at the same time on the first Monday of each month since. Facilitators have an hour for preparation beforehand and an hour for debriefing afterwards. A competition open to participating families was held to find a name for the group, the winning suggestion being the 'Inside Out Group'. The group is facilitated by a variable number of trained volunteer FSWs, depending upon the

size of the group. They are assisted by other members of the MDT. There are usually eight facilitators for approximately twenty participants, which appears to be an effective ratio. The ratio has varied however dependent upon a number of factors including:

- the number of families eligible and able to attend
- the availability of trained facilitators
- the particular needs of individual participants or families, some of whom have required one to one support within the group
- the activities being undertaken
- the weather (which dictates the balance of indoor and outdoor activities)
- feedback from participants and facilitators

All eight families invited attended the first session, with a total of nineteen participants. Of these there were three children aged 4-9, four children aged 10-15, five young people aged 16-20 and seven adults. Families attending the group live as far away as 30 kilometres from the Hospice, although most live within a radius of 20 kilometres. Each family invited was told about the group in person by the Senior Social Worker, the process of the group was explained and they were given the opportunity to ask questions. It was made clear at this stage that should their significant adult die, the family would no longer be able to attend the Inside Out Group and this is reiterated at the start of every group session. Families were greeted on arrival by a member of the team already known to

them. Staff and families initially sat in a circle to introduce themselves and a set of ground rules for the group were negotiated. These centred on issues of confidentiality, timeliness and transport arrangements. The emphasis was on creating a non-judgemental and mutually supportive environment in which feelings and emotions could be expressed openly. As the group was large with a broad age range, it was decided to split it into sub-groups for adults, children aged 4-9, children aged 10-15 and young people aged 16-20 (Davies et al, 2007). It was found that further sub-division was necessary to accommodate the individual needs of certain children and specific family dynamics.

Group activities have tried to achieve a balance between having fun and addressing questions, fears and worries. The structure of the group was designed to provide social as well as therapeutic activities, building trust between the families and the staff, and between the young people themselves, encouraging them and their carers to discuss their experiences and achievements with the group. Carers participate in many similar activities to the children and adolescents but also have the opportunity to discuss parenting issues surrounding the loss of a significant adult.

Activities to date have included creating an 'emotions washing-line', whereby each young person, carer and facilitator identifies how they are feeling before the session starts, putting hand decorated pegs on to laminated cards which are then attached to a 'washing-line'. Chute games, a drum workshop and a visit

from Santa<sup>3</sup> are amongst the activities so far provided. Structured exercises include the use of 'agree/disagree' cards, where the young people are invited to discuss statements on the cards with their group. This has proved an effective way of encouraging them to talk about their feelings. Using wallpaper, everyone drew around each other and participants marked where they felt their emotions and what they felt like, which led on to discussions about what caused these emotions, how to recognise them and strategies for managing them.

The Hospice has large grounds, with wild meadows as well as formal gardens. Weather permitting, this provides the opportunity to organise a wide range of outdoor activities, such as coits, chute games, twister, treasure hunts and jenga, as well as letting the children run around and burn off energy. At the end of each session the group reconvenes as a whole and representatives from each sub-group feedback any issues, concerns or questions raised in their group. Everyone is encouraged to talk about the group activities and how they felt afterwards at home.

Since the group started some additional external funding for the provision of games, equipment and presents has become available. The local community has also been extremely supportive, raising money for a Reflective Garden area that can be used by the group. As well as providing an additional outdoor space for group activities such as singing and story-telling, group members can now

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<sup>3</sup> To date there have not been any families from faith groups that do not celebrate Christmas attending the group, in this circumstance alternative activities could be provided in consultation with the families concerned in order to ensure the program remains as inclusive as possible.

help with planting, making mosaic patterns, wind-chimes and dream-catchers. Post boxes have been positioned in the grounds where messages can be left by children who do not wish to share their thoughts with the group.

A total of ten group sessions have now taken place, with forty-four participants from sixteen families in total attending so far. There are now twenty-three volunteer FSWs and two Family Support staff trained to work with children and families. Having reached this point an initial evaluation of the Inside Out Group was undertaken.

### **Initial evaluation and plans for the future**

The evaluation identified several issues that may be of interest to those running or planning similar groups in the wider palliative care community.

With regard to the training of volunteers, of the twenty-three who completed the training, only twelve have so far volunteered to participate in facilitating the Inside Out Group, which is perhaps indicative of the unique demands of this type of work. A variety of reasons were given for declining to participate; some decided that, upon reflection, they felt more comfortable working with adults and others that time constraints would prevent them from undertaking child and family work. Reluctance seems however to be premised in an underlying fear of the responsibility involved in working with children and adolescents under these circumstances. How to equip trained staff and volunteers with the confidence to

work with the pre-death group remains a major challenge and the take up rate must be improved if the group is to remain viable in the long term and the expense of training justified. Those staff and volunteers who have participated have found the experience very rewarding and have quickly gained in confidence. It is hoped that as the group continues to demonstrate that it is both enjoyable and beneficial for participating families more staff and volunteers will want to be involved. Whether similar responses have been found elsewhere would be an interesting area for future research.

The requirement that families leave the group once the patient had died initially met with considerable resistance amongst the staff and volunteers who facilitated the group, as they had genuine concerns that losing friends from the group would be another loss for the young people and adults concerned. Through supervision, de-briefing and training sessions these concerns were however eventually overcome as staff and volunteers became more aware of loss and grief as dynamic processes. Encouragingly, all of the families invited to attend the group accepted and no families have subsequently left the group, other than through the death of the significant adult, which is perhaps a good barometer of its success.

Feedback was sought through anonymous questionnaires sent to each family member after they had attended six sessions. Unsolicited feedback has also been given to facilitators during the sessions. Three questionnaire formats were

prepared; for children aged 4-9, children and young people aged 10-20 and for adults. Although more work is needed to perfect the questionnaires they have provided some encouraging responses. Response rates were as follows:

	Questionnaires sent	Responses received	% response rate
Children aged 4-9	7	1	14.30%
Young People 10-20	9	6	66.67%
Adults	7	5	71.43%

The questionnaires comprised a mixture of multiple choice and open-ended questions, although for the youngest age group all questions were open-ended.

No negative feedback has so far been received and responses to the open-ended questions have been particularly encouraging. Reasons cited for deciding to attend the group included:

'Because I thought I'd make new friends and it might help me think better thoughts about my mum' (age 8).

'I thought it would help talking to people my own age who are coping with the same feelings as me' (age 18).

'To help ease the pain for my daughters about their mother dying realising there are others who are also suffering' (age 57).

When asked about the most and least helpful and difficult activities, responses included:

'Icing biscuits [*sic*] because you got to eat them after' (age 8).

'Picking out the cards [agree/disagree cards] because it made me think about mum' (age 8),

Responses to the questionnaires also identified some of the challenges participants face:

'I don't like it when someone's mum or dad dies' (age 14).

'Although the group discussions are helpful they can sometimes be difficult because they make you realise what's going to happen, and you talk & listen about some difficult & sad emotions' (age 18).

'Everyone can say how they feel it's ok to feel sad, scared and even isolated. It helps to hear that other's [*sic*] either feel like that, or have had times when they have felt that way. At times it is difficult to listen to the discussions, it makes you face up to the fact someone we love is going to die and it's hard' (age 40).

Some of the children, adolescents and adults found it difficult to talk about their feelings in front of the group but also felt that talking with people experiencing a similar situation and similar feelings was helpful:

'They come up with good ideas to show how your feeling' (age 17).

'When we are talking in groups everyone is the same because someone will die' (age 14).

'When we split up from everyone else & join our seprate [*sic*] groups. This is helpful because we are all about the same age. I find it hard to talk to my friends sometimes because they don't understand & don't really know what to say to me. Whereas people in my group have said they feel the same things. It helps to know your [*sic*] not the only family going through a sad time, which is how it feels sometimes' (age 18).

'All the group facilitators are approachable about any subject' (age 49).

'talking helps we connect in that group because we all have something in common' (age 40).

It was clear that some of the children and young people found it particularly difficult to communicate their feelings and emotions in a group forum that only meets for ninety minutes once a month. To attempt to overcome this problem and allow the young people to feel more comfortable expressing themselves in a group setting, regular social events such as bowling and pizza evenings have been organised for the 10-16 age group. It is hoped these events will build and strengthen relationships amongst the young people and between the young people and the facilitators.

The feedback obtained so far is by no means conclusive; evaluation will remain an ongoing process and an important next step is to gain feedback from participants who have left the group as a result of a death, who have not so far been contacted for their views (eighteen participants to date). This will enable an assessment of whether leaving the group created any of the same anxieties among participants that had initially concerned the staff and volunteers.

Although the Inside Out Group is still very new the families involved have indicated that attending the group had helped them to come to terms with their feelings and to communicate these feelings more effectively. To meet other families in the same position has provided comfort and support. By sharing these findings with the wider palliative care community it is hoped that more hospices will be encouraged to set up similar groups, benefiting more patients and families and increasing knowledge and expertise in this important area of family support work. It is also hoped that it may stimulate new academic research into the role and effectiveness of pre-death support groups for children, adolescents and their well carers.

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