Background

There is anecdotal evidence that families who have a child with a life-limiting condition experience isolation and stress because people avoid engaging with them about issues around death, dying and bereavement. Scotland has a number of organisations who are now focussing on how to encourage a societal shift in attitudes. As a children’s palliative care organisation, Children’s Hospice Association Scotland (CHAS) has a responsibility to families to contribute to this work.

CHAS is the only provider of hospice services in Scotland for children and young people who have a life-shortening condition.

The 100% Project is a community engagement project which aims to start conversations about death, dying and bereavement in a life-affirming way.

Family Participation

A short film has been made and includes bereaved parents who had used CHAS, talking about the importance of being able to speak about their child after they’ve died. The film is a powerful reminder of the difficulties and isolation faced by parents when their friends and colleagues struggle to know what to say to them, and therefore say nothing.

Outcomes and Implications for Practice

It’s hoped that this project will reduce the misconceptions that surround children’s hospice care, and contribute to a national conversation in Scotland about death, dying and bereavement, ultimately improving quality of life for families.

Feedback from those who have participated in The 100% Project so far demonstrates that those taking part are responding positively. The majority of feedback is that individuals, in being challenged to consider their own deaths, are in fact thinking more about living. One participant summed it up by saying, “I couldn’t agree more that chatting a bit more about death would do us all some good. It’s one of the few things we’ll all experience, one of the few things we all share, and yet one of the things many of us seem to find most difficult to talk about.”

Aims

The 100% Project comprises a range of events and social media activities which aim to:

- Promote positive attitudes to death, dying and bereavement.
- Tackle the silence and isolation experienced by those affected by death, dying and bereavement.
- Raise awareness amongst those involved with the organisation, including service users, staff, volunteers, the public; and develop people’s skills and confidence in these areas.
- Promote community involvement and understanding of issues relating to life-shortening conditions.

Approach

The 100% Project, so named as 100% of us will die, has been given its own branding and tone of voice to differentiate it from CHAS communications. The 100% Project will build gradually towards more difficult conversations around death and dying, but has started with a range of accessible, non-challenging activities to encourage participation from those who would be wary of a more direct approach.

This has included:

- A social media poll to decide ‘Scotland’s Top Tear Jerker’. Run in association with Edinburgh Filmhouse, voters chose the film which they most enjoyed shedding a tear to. The winning film, Disney’s ‘Up’, was shown at the cinema and tickets were available for the public through the box office.
- A partnership with ‘Good Life, Good Death, Good Grief’, bringing the global art project ‘Before I Die’ to locations across Scotland, including outside the Scottish Parliament (pictured).
- Using social media to encourage people to write blogs about their own experiences of bereavement, and contribute the affirming quotes and pictures. The blogs have resulted in a number of comments and conversations between authors and readers.
- Establishing The 100% Book Club to encourage conversations, both in small groups and online, so that a child’s book often says what it needs to be simplest, yet most effective of all. The children’s themes link well with the work of CHAS and makes the book club attractive to all ages.

THE 100% PROJECT
Roxlyn Neely, CHAS Director of Fundraising and Communications

1% of deaths in Scotland are children and young people.

44% of people in the UK know someone who has died in the last three years.

71% of people think that we don’t talk enough about death and dying.

100% of us will die.

www.chas.org.uk