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Contribution to All Party Parliamentary Group on Arts, Health and Wellbeing on Monday November 9th 2015

INTRODUCTION

I am an arts producer and teacher working at the boundaries of arts/health/research and education. Currently I work with artists within hospices and the NHS and very ill children and their families often towards the end of the childrens' lives.

Why Art?

What makes for successful arts work in this context?

How do others learn to do this work?

WHY ART?

The power of art is that it can provide an 'other' form to enable children to express what is happening to them and what it feels like. Very often in intensive care wards in a children's hospital the adult attention is so focused on the medical imperative to make the child better, that the voice of the child is not heard. Children tend to want to protect their parents and are grateful for their medical care. They do not talk about death.

So the artist can play an important role here... and the arts can provide a form to share this with their families, carers and others. Arts have powerful implications for those working at the end of life because artistic processes bring an alternative language for grief; a language to express the emotional landscape, often a non-verbal, visual, or metaphoric language. For example, 15 year old Matthew spoke of death: "death is simply a door in a room that we have not yet noticed, and won't until our eyes adjust to the dark". An observer of our work described how: "you have put a screen around experience and turned it into metaphor".

Art creates connection – a community shared experience; it can offer the kind of stretching of time that is needed by those who are experiencing grief.

One mother described it as:

"rather similar to grief itself – slow – and allowing us to talk, bond, weep, laugh as we progressed our ideas and produced something which reflected our children"

In bereavement artistic outcomes shared with others offer opportunities to give form to memories bringing them to the here and now. Art can leave a legacy a powerful continuing connection between those who have died and the living - in grief theory these are 'continuing bonds'. And art can be celebratory: Celebration literally means "to assemble to honour". Combines solemnity and joy.

2. What makes such collaborations work?

- When established in dialogue with institutional partners/ hand in hand with nurses, consultants, families or communities.

- Clear methodology/firm boundaries/strong communication
- Time - Long-term collaborations (no one-offs)
- Translation - Producers as translators : artists and carers or others understanding each others' vocabulary.
- Trust – built over time....

3. How do we learn to do this work?

Where does the artist learn? The skills required are honed and particular. Sofie Layton and Mark Storor have years of experience. They can hold with huge skill a space where peoples' deepest feelings of loss, grief and happiness are given meaning. We do not all have these skills naturally and we tend to seek different routes to find them. I did the Living Well Dying Well Doula training diploma because, although I had been a teacher and had some training in social and facilitation skills, I knew little about the end of life. The Doula Course encompassed looking at models of grief, contemporary grief theory, the physical side of death – what happens to the body, the way agencies work at the end of life, and above all, the training has given me a network of peer supervision which continues.