



All Party Parliamentary Group on Arts, Health and Wellbeing

The Arts and Palliative Care, Dying and Bereavement Round Table

Monday November 9th 2015 3.30-5.00pm

House of Commons Committee Room 20

Minutes

Lord Howarth of Newport welcomed everyone and introduced **Baroness Ilora Finlay** to chair the discussion.

Dr Sam Guglani We are mortal beings, fragile, finite creatures with some meaning attached to us. The arts tell us this truth and hold important questions. *This was followed by a piece of creative writing based on one patient and all patients to layer stories of both the individual and our common humanity in dying.*

Fiona Hamilton: The desire to be creative can be vibrant until end of life. The arts can contribute to alleviating psychological distress and providing social support at the same time. Participants value what engaging in the arts can bring including a sense of greater control; concentrated and witnessed opportunities to articulate deeper and more nuanced feelings and thoughts than is usually possible in everyday life. Feedback suggests the approach is helpful for dealing with transitions and participants gain confidence in talking to others about illness or dying. Legacy writing can be a gift to others. Teenagers and young adults give similar feedback, including 'pride in producing something especially when experiencing multiple losses'. Arts can become the 'glue' in a person's support system, enabling them to see professionals, family, friends and other strands of life interweaving. We need to think about longer-term economic outcomes.

Nigel Hartley

A huge amount of people excluded because of the system. How do we create scale. The creativity that the arts can bring could be transformatory. We need artists who can work with communities, in care homes, housing associations, in hospitals, following the person through the system. We need artists who can work with groups and families and those who understand the strategic aims of organisations, the socio-economic and political context. Artists who can articulate discipline and remain controlled, understand work in partnership and work generously across different structures and systems. Good evidence in health promotion in the last few years. The arts bring people together beyond the illness, offer opportunities for creating legacy through talisman objects, help people surprise themselves which can lead to empowerment and self-belief. Offer frameworks for understanding difficult things, to say things like I am sorry, please forgive me, and I love you. They bring order out of chaos.

Bob Heath

Now work for Maggie's Cancer Centre. I am interested in the language we use around death and dying and the language we use to describe arts. We are in a society that finds it increasingly difficult to talk about death and dying. We talk about illnesses such as cancer and dementia as being the great enemies. I heard our Prime Minister talking about us being 'at war' with disease. We are all dying. Hospices normalize dying and it is there that we see people drawn to creativity, not the arts. Our hospices become the repositories of their stories, their songs and the very human histories they hold. Dying people can and do find new ways to express themselves, new ways to manage their fears and sometimes conduit to a new kind of hope and peace. The simple act of singing can help people find their voices, re-unite families. We have the pills and we should start prescribing them.

Dr Iona Heath

Montaigne wrote: “fear of death is the cause of all our vices”, this is most certainly true of the vices of medicine, which has such difficulty in learning when to stop and recognizing the point at which futility slides into cruelty. Medicine is in a mess because we have begun to regard death as evidence of medical failure rather than the inevitable conclusion of every life. We have prioritized theory over practice, the disease over the experience of the patient, and number over description. My contention is that the arts can play a huge role in redressing this balance. In the care of the dying healthcare professionals need five forms of literacy: medical, physical, emotional, moral and cultural. The importance of cultural literacy is almost completely ignored in medical education in most of this country so young doctors are deprived of the most potent resource for making sense of both life and death. Indeed those wanting to be doctors are told that only science is important from the age of 14. This is a tragedy for the care of the dying and the bereaved.

Allan Kellehear: Two or three facts: the bulk of dying is psychological, social and spiritual and has a small medical dimension. 95% of the experience of dying people 95% of the time is outside healthcare. Key part of what we need to do is develop a public health strategy that looks at prevention and harm reduction, community participation, public education, making the social and physical environment for families and schools more suitable for caring for . The Compassionate City Charter puts end-of-life care in civic authorities and promotes cultural institutions like arts galleries, museums and also to promote festivals, to encourage short story writing, not when the mood takes them but every year, systematically, as a theme in art work, in musical compositions, in cities and towns across the UK. Only then in places like schools and high streets will we achieve normalization of death and dying.

Jane Lings: ‘Living until you die’ is a central theme of holistic care at the end of life. The arts and arts therapies have a unique role for they are flexible, adaptable and can be made accessible. The different art forms can foster creativity and fresh experiences, facilitate self-expression, and bring new understandings and insights, offer the potential for pleasure, transcendence and beauty. Communication at depth can take place with, or without, words. More than one patient has told me that they are living more with illness than they did before it. Patients and families would benefit from input from the arts and arts therapies much earlier than in the final weeks or short months that is typically possible. We are in danger of the science almost completely displacing the art of medicine in medical education. Exposure to experiential ways of learning through the arts can lead to important shifts in self-awareness for students and also contribute to their own long-term well-being and resilience.

Anna Ledgard: In an intensive care ward the voice of the children is often very low down on the agenda. The artist provides an alternative language to express the emotional landscape. 15 year old Matthew said, “Death is simply a door in the room that we have not yet noticed, and we won’t until our eyes adjust to the dark.” Art creates connection, shared experience, a kind of stretching of time. Worked with Surviving the Loss of Our World, a group of bereaved mothers in London. One of them described the arts process as rather similar to grief itself, slow and allowing them to talk, weep, bond as they developed their ideas and produced something to reflect their children. Developing projects in partnership is critical: with nurses, consultants, families and communities; clear methodologies and disciplined approaches, firm boundaries with strong communications and producers as translators between the different languages of arts and medicine; we create the frame but we stay out of the centre; we need long-term collaborations.

Dr Viv Lucas: The key issues relating to the arts and Palliative Care are their role in therapy and education to help professionals develop the relational aspects of care giving; and creating a healing environment. In Palliative Care our role is not to cure disease but to heal our patients, recognizing that it is possible to die healed. Healing is difficult to define. We can say it is about addressing the subjective experience of human suffering and facilitating a process of inner change, not about the technological doing to of the disease orientated model but of being with and bearing witness to subjective experience. The arts are about subjectivity, self-expression, point of view, and creating meaning. We need a healing environment in which healing relationships can flourish. The instrument of healing is the relationship

between healer and patient, fostered by a healing environment; a creative process can give form to the healer's art.

Olwen Minford: I wish to focus on the benefits of the application of the Arts in End of Life Care Education. There is widespread acknowledgement and agreement that training in care of the dying is a key area of improvement for all HCPs. Death is notoriously difficult to discuss for both professionals and the public; in spite of increased sophisticated development of training materials and many good educators the problems related to communication persist. This relates partly to fear and death anxiety. 1 in 4 nurses do not feel competent to broach the subject of death with a patient or carer (Nursing Times 2010); 25% of GPs in a study by Dying Matters 2014 had not initiated end of life care discussions with their patients nearing the end of life. The Arts offer a language and a vehicle that allows translation. There is evidence that integrating arts based training at a fundamental stage in training can build empathy, compassion and communication skills organically. The Arts can empower staff to deal with death and dying.¹

Jane Moss: Writing can be used in a number of ways: journal writing, unsent letters, unfinished conversations, writing about personal belongings, using poetry and prose often in a way that is contained. People seek bereavement support because they feel blocked or stuck and isolated in their grieving. Writing can be a valuable tool in self-help – the page is like a listening friend, available any time of day or night, it will hear whatever the writer wants to say, they cannot do it wrong. We need to develop a model or models of research and evaluation that are specific to bereavement, for peer support and learning, and to make the case for writing in this context. How we can provide access to training and supervision for writers. Much bereavement work is delivered by volunteers, so how can we find the resources to train those volunteer and integrate creative tools into their practice. When this works the results can be powerful and can include people being able to return to work and adjust more effectively after their loss, and acquiring skills for their own self-care which will serve them through the rest of life.

Dr Simon Opher: Bereavement is part of our lives. Yet increasingly as a GP I see this painful process being converted into an illness with attendant “treatments” such as antidepressants, sleeping pills and frequent trips to the doctor. Grief is characterised by persistent circular thoughts, that give the survivor no piece and in the end lead to anxiety and depression. A patient of mine described seeing our artist in residence for a two hour session and said that it was the first time since her husband had died that she had been released from these thoughts and was thoroughly involved in the creative process. Art has a power to transform us. It also, when used in primary care, shows evidence of demedicalising healthcare. As well as the clear psychological benefits, evidence from Scotland suggests that there may also be an economic argument to have artists in GP surgeries helping people through bereavement.

Kate Organ: Baring Foundation funds arts programmes. In the programme for arts and older people the first 300 or so applications not a single project mentioned the process of dying, such a taboo. Began to really look for examples. Found that arts were extremely good way for people to explore and articulate the transition. We need to define ‘art’ and one of the things that makes it different is its ability to hold a meaning beyond the literal, to resonate in different space and time. At the Baring Foundation we are less interested in research because we know it works, we are more interested in cost-effectiveness and how we can make it happen, so that the arts are more available. One of the biggest issues is the marginalization of the Arts and Culture by education and health. We have to address the philosophical and language issues so that it isn't only seen as an additional luxury that only the few can afford. The HE sector can do more to bring the medical and arts professions together, there are a few examples of this in arts training and medical training but greater opportunities would be an important development for better health and end of life care.

¹ ComRes (2014) for Dying Matters: *Millions leaving it too late to discuss dying wishes*. Available at: <http://dyingmatters.org/news/millions-leaving-it-too-late-discuss-dying-wishes>

Dallas Pounds: Royal Trinity Hospice in Clapham has a catchment area of some 750,000 people, adults. We absolutely value the skills and contribution of the arts and our own art therapist. The impact on those she sees cannot be underestimated. She will be presenting at the Hospice UK conference in Liverpool, a case study called ‘Hell-a-bration’, which details the case of a man who is an artist and deteriorating from Lewy Body Dementia. It explores his return to art and how that has enabled him to re-connect to the world around him. Not paid for by the NHS and not frequently recognized by those who commission our services. The major barrier to accessing any services is the unwillingness to recognise and discuss our own mortality, lack of training and awareness amongst colleagues of what end of life services are available and what Hospices do. Evidence of reduced costs or fewer admissions to hospital is the kind of data commissioners need.

Chris Rawlence: Rosetta Life offers those living with limiting-conditions the creative means to share what most matters when everything seems under threat. The outcome is a dance, a song, a poem or short film that may be shared, with the family, health setting, or more widely through public presentations. Recently we have undertaken a 3 year project for the Stroke Community, which will evolve a music and movement intervention ‘fit’ for clinical commissioning for those ‘stuck’ on the gradient of stroke recovery. A big challenge facing our creative community lies in winning the support of NHS Trusts and Hospice Boards. This depends on a form of Evaluation that provides persuasive evidence of the improvements in health, wellbeing, and reduction of costs to the NHS that we deliver. Today’s tick-box forms of evaluation do not entirely convince. Might a family-led video blog charting the progress of a project hold the key?

Michèle Wood: Working in end-of-life care for over 25 years. It’s absolutely vital that we include all stakeholders in the development of anything going forward, especially service users. We need a really detailed and nuanced appreciation of how to capture the value of instances of therapeutic and artistic engagement at the end of life. For example ‘Life Embraced’, a Marie Curie exhibition that included patients, carers, staff and volunteers. To do this ethically involves supporting complex negotiations with patients (especially in therapy) about how they want to share their work. Organizations also need to have robust processes for following up the impact of such interventions on their service users. The presentations today demonstrate the wealth of interventions available –“we have the pills”- and it is clear we understand processes for getting things done. But what stops us? What is the barrier to implementation? We need to learn to listen to each other, to everyone involved. We must develop mechanisms to listen effectively (e.g. this Inquiry); and the arts are a profound way to listen and be heard.

Questions and comments from the floor:

Paul Camic, Canterbury Christ Church University: My father died in Florida and the policy of Northern Florida was to involve the arts in hospice care. The evidence was of pain reduction, increased communication, people more satisfied with the decision making around death and dying, that families were less shocked by the loss. The policy led to a requirement that artists are involved in hospice care.

Sam Guglani: We inhabit an industry where pedestrian human contact is lost in the face of all sorts of technical things to hide behind and pursue. If we have to look for evidence for why human contact is important for human suffering we are not going to get there and arguably it would be folly. We have to be brave and ask for the elusive phenomenon of human contact. Art is a repository of that contact.

Iona Heath: We still don’t have evidence based Love. There are some things that are self-evident.

Anne Marie Rafferty, King’s College London: Who is it we are trying to convince that art in health is a good thing and has intrinsic merit. Need to be clear who the different audiences are and using that to target information for this whole policy area. Multi-media type approach.

Rosie Leatherland, Alzheimer’s Society: Understanding lots of different perspectives, for people who know nothing about it to have these conversations would be really helpful.

Bob Heath: Helping us to remind everyone that despite the judgements we make about art and our own prejudices actually it is an inherent sense, it is about being human. Nurses self medicate with music after a stressful day at work. The therapeutic values of art are available to everyone.

Jane Moss: A lot of people are familiar with art as consumers. This is about participating in the arts. Doing it with other people.

Kate Organ: Birmingham Conservatoire have a module within their training on arts and health, so that young musicians understand that there are other places than a concert hall where they may be needed.

Nigel Hartley: The arts are not one thing. Being a musician I get things wrong all the time. In health litigation and risk when you get things wrong. Challenge of a square peg in a round hole.

Professor Norma Daykin, University of Winchester: Certain things are self-evident but others not. We do need research to understand these nuanced impacts.

Nikki Crane, Guy's and St Thomas's Charity: Not an either /or. It is the combination of all things. Evidence alone will not turn the key. We must do it, it is important for us, and we can get good research. Commissioned a project to look at the barriers to adoption. Working very closely with clinicians so that everyone has a sense of ownership. Incredibly creative partnerships come out of this work.

Simon Opher: One of the main barriers is Doctors. Once they have them in their surgeries they don't want to lose them. But want to ask Alan, what is policy?

Alan Howarth: Some deformation has got into the medical profession, healing has been marginalized. Policy making is a huge negotiation. The predominant culture of medicine is not receptive to the wisdom of the centuries.

Iloria Finlay: A lot of people in medicine who would be receptive, but utilitarian pressures polarise things into black and white are making the barriers greater not less. On higher education I tried to put in creative portfolios into palliative care training but it was the universities that stopped it, not the doctors or the students, the universities didn't like the framework we were marking from. Lots of so-called quality assurance issues that act as barriers. In terms of who do we convince when there is less money, it is a problem to get people to put money in if it means stopping something else. The evidence of clinical outcomes is much greater if you can help people re-frame their experiences.

Iona Heath: Things outside the financial constraint, like inviting the GMC to consider why the requirements for medical school are solely science. Why not ask them to justify why is it just science, why can't priority be given to children with a wider education.

Fiona Hamilton: Bristol University has embedded a whole strand of creative activity into their medical training. It happens because of a couple of passionate people. Long-term economic measures related to long-term outcomes needs to be done more.

Anne Marie Rafferty: Former Dean of the Nightingale School at King's and we had a module on nursing and the arts. It was completely oversubscribed so it is possible to have these kinds of courses in the curriculum. The point about the science barrier to humanizing healthcare may be a distraction. We need to find a way of tapping into the latent skills and the hinterland of the capabilities that practitioners bring with them. Many of our students now are diploma fast tracking through to Masters coming with a huge repertoire of skills. Many of them are arts graduates and they want to use and deploy these skills.

Anna Ledgard: The role of intermediary is important, a layer between the artist and the commissioners to facilitate the dialogue and discussion at depth, it doesn't just happen. Its need mediating. Models of training like the End of Life Doula training that I did which are very relevant. There are models we could look at, accredited, validated.

Chris Rawlence: I recently presented the Rosetta Life Stroke Odysseys project to a meeting of health professionals in the Stroke Unit of the Royal Victoria Hospital in Belfast. The lead clinician immediately ‘got it’. His interest is researching the relationship between creativity and neuro-plasticity for stroke patients in the critical days following a stroke showed the vital importance of gaining the proactive support of clinicians.

Allan Kellehear: I would hate to see the arts become yet another clinical intervention. I would recommend that most of our work is in civic society rather than in health care. To ask the arts institutions what their contribution could be and is to death, dying and bereavement.

Ilora Finlay: There is something about not de-skilling people by putting training requirements all over the place, how do you help people discover and re-frame their world so that they are freed up to listen. Not listening should be totally unforgiveable. Only one person mentioned children, please don’t forget children as relatives. Disastrous bereavement in teens has disastrous consequences.

Full written submissions, documents for reference and links can be accessed here:

<http://bit.ly/1OrcV3X>