

# A Response by the Scottish Partnership for Palliative Care to the Consultation on A Culture Strategy for Scotland

# **About the Scottish Partnership for Palliative Care (SPPC)**

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement.

SPPC was founded 26 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. Membership includes all the territorial NHS Boards, Integration Authorities, all the hospices, a range of professional associations, many national charities, local authorities, social care providers and universities.

## **About Good Life Good Death Good Grief**

Good Life, Good Death, Good Grief (GLGDGG) is an alliance of organisations and individuals that want to work together to raise public awareness of ways of dealing with death, dying and bereavement and promote community involvement in death, dying and bereavement. It was established in 2011 and is hosted by SPPC.

Under the auspices of GLGDGG, we plan and promote several programmes of cultural activity including the annual Death on the Fringe and To Absent Friends festivals in August and November respectively, as well as ad hoc activities at other times, including Good Death Week in May.

## **Overview**

SPPC welcome the publication of the draft Culture Strategy for consultation and are grateful for the invitation to respond. We recognise and value the role that culture can play in enriching people's lives, and the positive effect that engagement with culture can have on health and well-being.

We also recognise the role that culture in its broadest sense can play in shaping identity and in helping people to navigate their way through life, never more so than at times of crisis such as when faced with one's own mortality or the mortality of a loved one. Through engagement with culture, people can understand, contemplate and formulate their own responses and adaptations to the challenges of life and death.

This understanding informs our work with GLGDGG. Cultural activity including performance, writing, art and craft is one of the successful ways we have found to engage people with this difficult subject matter.

We are therefore very glad that the consultation seeks to engage voluntary and third sector organisations, and those "tasked to tackle the fundamental challenges in Scotland today" (p.2). We are one of those organisations and we believe that culture has an important role to play in addressing those challenges.

We are also pleased to see that one of the themes from the engagement phase was "recognising the role that culture has in other areas like health and wellbeing, education, energy and community empowerment" (p. 3).

## The Vision for Culture in Scotland

"Culture in Scotland is innovative, inclusive and open to the wider world. Cultural excellence – past, present and emerging – is celebrated and is fundamental to future prosperity and wellbeing. Culture's empowering and transformative power is experienced by everyone."

We broadly agree with this vision for culture in Scotland. We especially appreciate the transformative power that culture can have on individuals and communities and welcome any strategy that recognises that.

As culture transforms people, so too can people transform culture. We believe that by encouraging people to be more open about their experience of death, dying and bereavement we can change culture for the better to be more understanding, inclusive and compassionate.

The strategy states that "there is no one story of culture... and each individual and community contributes to and shapes their own culture" (p.7). This is true of individual lives too. Each life and death has its own story. Recognition of that informs what we do at GLGDGG and we are pleased to see a similar viewpoint reflected in this strategy.

We are keen to emphasise that culture is not just something to be experienced. It should also be informed by people's own experience, and fundamental to each person's experience is their understanding of life and death and our shared mortality. We would welcome ways to share our experience as an alliance with other cultural organisations, artists and makers.

## **Ambitions, Aims and Actions**

We welcome the inclusion of a section on "Culture and Health" (p.18-19), the recognition of the challenges posed by an ageing population and the emphasis on preventative approaches.

We agree that cultural activity can increase resilience and empower individuals and communities with a sense of agency. This informed our thinking for the To Absent Friends festival which enables communities to remember loved ones who have died through storytelling and other artistic endeavour, as a way of increasing resilience and mutual support among the bereaved.

### Transforming Through Culture

Aim 1: Place culture as a central consideration across all policy areas

Aim 2: Open up the potential of culture as a transformative opportunity across society

Aim 3: Position culture as central to progress in health and wellbeing, economy, education, reducing inequality and realising a greener and more innovative future

We agree with these aims and note our own work with Death on the Fringe and To Absent Friends in working towards Aim 3.

The associated action for that Aim is to "develop alliances that support social change". GLGDGG is already an example of such an alliance in practice. It includes artists, theatre companies, music groups, community organisations, hospices, care homes, third sector organisations, NHS boards, faith groups, professional bodies and individuals.

We hope to continue to develop that alliance and recognise that culture is at the heart of it.

#### **Empowering Through Culture**

Aim 1: Opening up and extending culture so that it is of, and for, every community and everyone

Aim 2: Develop opportunities for people to take part in culture throughout their lives

Aim 3: Recognise each community's own local culture in generating a distinct sense of place, identity and confidence

We are particularly supportive of Aim 3. We have recently established a Compassionate Communities Network for Scotland to enable communities to find their own ways of supporting each other through the difficult times associated with death, dying and bereavement.

We believe in empowering communities to take practical action at a grassroots level in a way that suits their own circumstances and needs. This accords with the action outlined under Aim 3.

### Sustaining Culture

Aim 1: Develop the conditions and skills for culture to thrive, so it is cared for, protected and produced for the enjoyment of all present and future generations

Aim 2: Develop programmes to support skills development, leadership and innovation to prepare for the future including digital

Aim 3: Encourage greater openness and diverse cultures to reflect a changing Scotland in the 21<sup>st</sup> century

We have no particular comments on these aims.

## **Examples of Good Work**

We would like to highlight two examples of good work and best practice of our own.

#### Death on the Fringe

Established in 2014, Death on the Fringe is a series of shows and events looking at death and dying which takes place at the Edinburgh Festival Fringe each year. It combines existing Fringe shows with a programme of talks and lectures programmed by GLGDGG and also features a showcase event, hosted by Edinburgh University for an audience of invited guests from academia, health and social care providers, and community organisations. Partners in this year's programme included Just Festival, Edinburgh International Book Festival, Edinburgh University Primary Palliative Care Research Group, The Cabaret of Dangerous Ideas and the Scottish Poetry Library, as well as 30 different performers and companies. Over the years it has received wide coverage in general and specialist press and media.

www.deathonthefringe.org

To Absent Friends

First held in 2014, To Absent Friends is a people's festival of storytelling and remembrance. The festival provides people across Scotland with an opportunity to remember, to tell stories, to celebrate and to reminisce about those we love who have died. It is uncurated and anyone can participate in whatever way feels appropriate. Events range from large scale concerts to community meals to storytelling evenings to private remembrance ceremonies. Last year's festival included 45 events, of which just over half were supported with a small grant from GLGDGG. It is backed up with social media and online activities such as a digital wall of remembrance. Feedback said 96% of participants found it helpful to have opportunities to remember those who had died and 100% of event organisers said they were extremely or quite likely to hold an event again. This year's festival takes place from 1-7 November.

www.toabsentfriends.org.uk

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