

“Openness about Death, Dying and Bereavement in Fife - “Talking the Untalkable”

Building on the skills and knowledge of our people.”

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Introduction

This poster provides an overview of how “lack of openness” about death, dying and bereavement across Scottish society can be seen as a Public health Issue and outlines how this issue is being tackled in Fife by wide engagement within the community.

Copies of relevant documents and reports are available from Gordon McLaren - gordon.mclaren@nhs.net

Background

A Short Life Working Group (SLWG number 7) was set up following the publication of the Living and Dying Well Action Plan, the Scottish Government’s action plan on palliative and end of life care, in 2008.

The Working Group found that unnecessary harms can result from lack of openness of death, dying and bereavement. For example:

- People who are dying or bereaved can experience isolation because people don’t know what to say or how to act towards them
- People die without wills, leaving complicated situations for their families and friends
- People may lose capacity to make decisions for themselves due to illness - and not have a Power of Attorney in place
- Health care professionals struggle to have conversations with their patients about what care or treatments they want as they approach death. This makes it hard to plan the care that a person really wants
- If the fact that someone is dying is not acknowledged then opportunities to resolve issues and say goodbye may be missed.

The Conclusions of Scottish Working Group included the view that the overall aim of increasing public awareness and debate of death, dying and bereavement will require leadership, direction and a broad-based collaborative approach engaging all sectors of Scottish society and its diverse communities.

Weblink to final report: <http://www.scotland.gov.uk/Resource/Doc/924/0105610.pdf>

Good Life, Good Death, Good Grief

Good Life, Good Death, Good Grief was set up in 2012 as a response to the national Working Group (SLWG 7) report’s recommendations. It 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
- Promote community involvement in death, dying and bereavement.

Weblink: <http://www.goodlifedeathgrief.org.uk/>

Fife Workshop “Everybody’s business”

A number of interested individuals in Fife organised an oversubscribed workshop in August 2011. The purpose of this event was to facilitate open discussion on how we can work together, identify key issues and ways forward.

The workshop format encouraged participants to consider actions they could take as individuals or in their workplaces to improve society’s approach to these issues in Fife.

There was broad agreement that the culture surrounding death dying and bereavement in Fife needed to change. For example, some considered the approach might:

- assist communication with people
- “widen the agenda”
- “make death normal”
- encourage “personal responsibility, family and friends, not just organisations”.

Participants were enthusiastic to take action as individuals and in their organisations and communities to improve openness and people’s experiences related to death and bereavement.

Conference to broach the sensitive subject of death

A FIFE conference has encouraged people to “talk the untalkable” and become more open about death and dying.

More than 100 people attended the event at the Rothes Halls, organised by the multi-agency

Fife Death, Dying and Bereavement Group.

Death, dying and bereavement is a difficult subject for many, which has both emotional and practical implications. Openly talking about the future now can assist loved ones in

understanding wishes and make things as easy as they can possibly be for family and friends when the time comes.

Participants at the event considered how they could contribute to greater openness about death,

dying and bereavement in communities, workplaces and at home, discussing the practicalities and benefits of planning a funeral, making a will and power of attorney.

The conference also celebrated the “To Absent

Friends festival, a new week-long national festival of storytelling and remembrance aimed at celebrating and reminiscing about loved ones who have died.

Gordon McLaren, NHS Fife Consultant in Public

Health Medicine, said: “No one wants to think about their own death or the death of loved ones, however, talking through your wishes and taking practical steps can make things easier for friends and family when the time comes.”

Local newspaper article

Fife Group set up in 2011

A multi-agency group was formed in 2011 to take forward these issues in Fife, following the interest in the local workshops. The group is currently chaired by a Consultant in Public Health Medicine and includes membership from a wide range of interested people and groups including NHS Fife, Fife Council, legal profession, Citizens Advice, Funeral Directors, Voluntary Organisations, Widowed and Young (WAY), Chaplaincy, and Academia.

The remit of the group is to work, through its members, to strengthen society’s approach to death, dying and bereavement in Fife across communities and organisations, to:

- Foster a more open attitude to talking about death, dying and bereavement across society
- Encourage more openness across society about planning for death and end of life
- Encourage support across society for dying and bereaved people
- Appraise and disseminate evidence (from a range of sources), about the best way to strengthen approaches to death, dying and bereavement across society
- Share examples of practice within different communities and services
- Influence current practice (in relation to activities within communities or service provision including training of staff) to help strengthen the approach to these issues across society
- Develop appropriate ways to communicate key messages to help strengthen the approach to these issues across society
- Act as a link point in Fife to the “Good Life, Good Death, Good Grief” Alliance.

Fife Information and Drop-in Event 2013

The Fife Group held a Drop-in event supported by a small grant of under £200 and the enthusiasm of members of the group on 16th May 2013. The event was held during Good Life, Good Death, Good Grief Awareness Week in the Mercat Shopping Centre, Kirkcaldy, Fife and was targeted at people of all ages.

People were interested in the “Before I Die Walls” and over 200 people wrote their wishes by the end of the day, others enjoyed looking at what was written. A proportion then talked with members of the group or sought further information.

90 enquiries were received on a range of topics to about 70 people.

Fife Cafe Event: May 2014

Members of the group held a small cafe event - “where the topic of conversation was death”. About 15 people attended. Feedback was very positive with people describing the event as “Enlightening”, “Interesting”, “Thought Provoking” “Friendly”, “Informative” and “whilst you may not think it... Entertaining!”

“Talk the Untalkable” Fife Conference November 2014

The aim of this conference was to improve the well being and quality of life for people in Fife through greater openness about Death Dying and Bereavement. We picked the title from some of the feedback from our cafe event.

The conference included presentations on practical issues such as Death Registration, Wills/Powers of Attorney and Funeral arrangements - and group work. We held a separate session with a Toast “To Absent Friends” (TAF) at the end of the conference. People commented on TAF saying they liked the TAF wall and that the Toast was lovely idea. During the breaks there were also poster presentations.

The conference went well with the 95% participants finding it useful. There were about 100 attendees from a wide variety of backgrounds including members of the public. Attendees described their experience of the conference as (top 5 words) “Informative”, “thought provoking”, “interesting”, “open” and “enjoyable”. A lot of people intended to go home and speak to their family and discuss in their workplace and a few people said that they plan to hold their own café event.

The feedback was very positive. A selection of typical comments is shown below:

- Very thought provoking, “talking the untalkable” was exactly what we did
- I found it enlightening to talk about this subject. I didn’t think I would
- Emphasised the importance of EVERYBODY playing their part to raise awareness/ to plan/discuss death and dying
- More useful than I ever thought, especially on a personal level
- Very useful made me think about my own “affairs”.

The event also received coverage in 3 local newspapers.



Some members of the Fife Group and Mark Hazelwood from GLGDGG

Participants at the “Talk the Untalkable” Conference 4th November 2014

Conclusions

Lack of Openness about death, dying and bereavement can result in a number of harms which can affect sense of wellbeing across society.

In Fife a group of interested people have held several events and been able to set up a lively and enthusiastic broad based interest group to take forward the agenda in Fife. The group held an initial workshop in 2011, a Drop-in event in 2013, and a cafe session and a Fife Conference in 2014.

The broad based group approach is proving effective for raising awareness of and fostering a more open approach to death, dying and bereavement across society in Fife. Our approach is completed and supported by the national alliance - Good Life, Good Death, Good Grief.

We would recommend that other local areas consider setting up local interest groups to take forward this public health issue in their own areas - as it is “everybody’s business”.