

Scottish Public Health Network (ScotPHN)

**Palliative and end of life care in Scotland:
The rationale for a public health approach**

Briefing Paper 5: Good Life, Good Death, Good Grief

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Briefing Paper 5. Good Life, Good Death, Good Grief

This Briefing Paper accompanies the report 'Palliative and end of life care: The rationale for a public health approach'. It provides information about Good Life, Good Grief, Good Death (GLGDGG) a national alliance that undertakes, supports and encourages health promoting palliative care (HPPC) approaches across Scotland.

This paper:

- Explains the policy context behind the development of GLGDGG.
- Describes GLGDGG, its approach and some of its activities and outputs presenting case studies to illustrate the activities of members.
- Explores ways of evaluating the impact of GLGDGG.
- Discusses the above in relation to resource allocation.
- Explores future opportunities and challenges.

Policy context

'Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland,' acknowledged that "Patient and family experiences of death and dying are thought to be affected by the lack of familiarity with such concepts and events in our modern society."¹ To look at this further, a short life working group (SLWG 7) was established by the Scottish Government to explore ideas and issues for addressing palliative and end of life care (PELC) from a public health and health promotion perspective.² In their final report published in March 2010, SLWG 7 made a number of recommendations. These were endorsed by the Scottish Government who asked the Scottish Partnership for Palliative Care (SPPC) to lead on taking forward the recommendations. In response, the SPPC established 'Good Life, Good Death, Good Grief' (GLGDGG) in November 2011.³ The importance of promoting a culture of openness relating to death, dying and bereavement has been further emphasised in the recently published [Strategic Framework for Action for Palliative and End of Life Care](#).⁴

What is 'Good Life, Good Death, Good Grief'?

GLGDGG is an alliance of individuals and organisations working towards the common aim of raising public awareness of ways of dealing with death, dying and bereavement, and promoting community involvement in death, dying and bereavement.³

GLGDGG has 947^a members, 661 individuals and 286 organisations. Organisational members include all NHS Boards, all independent Scottish Hospices, and many high profile national charities such as Parkinson's UK, Age Scotland and Marie Curie. Just over 60% of members are from the health and social care sectors, with just under 40% of members coming from a range of other backgrounds including academia, education, faith based organisations, the arts and law.

^a As at November 2015

What approach is taken by GLGDGG?

The approach and work undertaken by GLGDGG is informed by an awareness that different groups and communities within Scotland have different strengths, weaknesses, problems and priorities relating to death, dying and bereavement. Those groups and communities themselves know best what their strengths, weaknesses, problems and priorities are.

GLGDGG's approach has been to engage and support individuals, communities and organisations identify their needs and develop the assets that they have available to them to meet these, with a goal of sustainably building resilient people and communities. This approach is grounded in Kellehear's Health Promoting Palliative Care (HPPC) model⁵.

The alliance acts as a support and a sounding board to enable individuals and organisations undertake the change they think needs to happen. Through awareness weeks and the '*To Absent Friends*' festival, GLGDGG creates opportunities designed to catalyse membership activity and create opportunity for local and national media engagement and dialogue. GLGDGG works to identify and share good practice, and to provide leadership, ideas, networking opportunities, inspiration, practical tools and small grants. GLGDGG works to influence public policy, and also provides and signposts to resources for people who are dealing with death, dying and bereavement in a personal capacity.

Table 1 provides examples of work undertaken by GLGDGG mapped to the health promotion framework outlined by the World Health Organisation in the Ottawa Charter⁶.

Activities and outputs

Much of the work of GLGDGG is determined and undertaken by members themselves. For example, a charity might notice its clients' communications needs aren't met and develop an information leaflet for people with learning disabilities (case study 1); NHS staff might observe the difficulties caused by the lack of Power of Attorney and work on a campaign to increase uptake locally (case study 2); a community organisation might organise an event to provide peer support for people who've been bereaved (case study 3).

Table 1. Examples of the work of the GLGDGG alliance mapped to the health promotion framework outlined by the World Health Organisation in the ‘Ottawa Charter’

Mode of Action (Ottawa Charter)	Examples of Work Undertaken by Members of GLGDGG
Building healthy public policy	Providing input to the Scottish Government’s Reshaping Care for Older People and the second Dementia Strategy.
Creating supportive environments	Running an awareness week to encourage a society in which death, dying and bereavement can be discussed.
Strengthening community action	Recruitment of volunteers to provide information and support in local communities Small grants scheme to catalyse and support local action
Developing personal skills, knowledge	Providing a website and leaflets with practical advice on end of life issues Events to support older people to learn about, discuss and plan for end of life Events for carers supporting people in the final phase of life
Re-orientating health care services toward prevention of illness and promotion of health	Education for undergraduate nurses enhancing capacity to deal with death and dying. Redesign of palliative care services to incorporate asset based approaches

As the host organisation for GLGDGG, the SPPC undertakes GLGDGG-branded work to support this kind of wide-ranging membership activity. It has:

- Developed a practical GLGDGG website, which:
 - Provides information about advance planning
 - Shares resources (see below)
 - Provides space where others can share news and projects
- Adapted 11 Dying Matters leaflets for the Scottish context and made these available on the website.
- Produced 3-4 member newsletters each year.
- Produced 5 films.
- Designed a Dining with Death ‘conversation menu’.

- Produced beer mats to prompt thinking and conversations in pubs, where research show men are more likely to consider sensitive issues.
- Conceptualised the *To Absent Friends* wall.
- Run four networking events for members.
- Facilitated three awareness weeks.
- Contributed by fielding speakers to a wide range of meetings, conferences and groups – both public and professional.
- Promoted public health approaches via posters accepted for display at the NHS Scotland Event 2014, the Scottish Public Health Conference in Aviemore 2015 and the International Public Health Palliative Care Conference in Bristol 2015.
- Published an article in the International Journal of Palliative Nursing.
- Worked with Dying Matters and NHS Inform to add information on *What is dying like?* the NHS Inform website.
- Worked with Evaluation Support Scotland to publish *Third Sector contributions to improving older people's experiences of declining health, bereavement and death.*
- Run a public lecture series in partnership with Marie Curie called *Can death get any better?*
- Worked with a volunteer to establish *Death on the Fringe* at the Edinburgh Festival.
- Supported a volunteer to run workshops for community groups on: *How do you talk about death?* and *Facilitating small group discussions on end of life issues/ bereavement and loss.*
- Distributed small grants to facilitate community activities in line with the aims of GLGDGG.
- Established *To Absent Friends* a people's festival of storytelling and remembrance, with participation from organisations and individuals across Scotland. (www.toabsentfriends.org.uk)

Case study 1: Leaflets for people with Learning Disabilities

FAiR, an Edinburgh based charity, worked in association with the University of Glasgow to publish two new booklets. [*Preparing for your death*](#) and [*When someone dies, advice for those who are left behind*](#) are designed to provide accessible information to people with learning disabilities and their families.

[*Preparing for your death*](#) covers issues such as 'What is dying like?', 'Body changes', 'How do you tell the people close to you?' and 'Planning Ahead'. [*When someone dies, advice for those who are left behind*](#) explains practical matters such as registering the death and planning the funeral, as well as considering how to cope with grief.

Support gained from GLGDGG membership: FAiR and the University of Glasgow are both members of GLGDGG. Via a GLGDGG small grants programme, the SPPC provided a grant to help fund the development of the leaflets; the project lead was invited to present at a GLGDGG networking event to share learning from the project; and the leaflet has been promoted through various GLGDGG communication channels.

Evaluation

GLGDGG strives to evaluate its work by: gathering activity data, collecting data relating to a range of relevant (though limited) proxy indicators, systematically reviewing activity and identifying learning, and undertaking formal evaluation when feasible within the limits of available resources.

Measuring attitudinal and behavioural change – proxy indicators

The GLGDGG stakeholder group periodically reviews data available that are relevant to the type of attitudinal and behavioural changes GLGDGG is trying to promote. GLGDGG cannot attribute changes directly to its own activity. Achieving cultural change is complex and takes time, and it is not expected that GLGDGG would be able to demonstrate impact in this area four years after inception. Proxy indicators examined by the group include:

- **Data relating to temporal trends in societal attitudes to death, dying and loss in sequential national social attitudes surveys.**⁷
Since the inception of GLGDGG there has been little change in the percentage of Scottish respondents in the 'Dying Matters' survey that reported feeling very or fairly comfortable talking about death, or the percentage of Scottish respondents that have an advance care plan, have written a will or have made plans for their funeral. Scottish figures are very similar to UK-wide figures.
- **Figures relating to completion of Power of Attorney**
Data indicate that there has been an increase in the number of power of attorney (POA) applications in Scotland over the last 5 years, from 30,737 in 2008-2009 to 45,576 in 2013-2014.⁸
- **Numbers of patients on the QOF Palliative Care Register**
The number of patients on the QOF Palliative Care Register continues to grow, from 7703 in 2008/09 to 12050 on 2013/14.⁹

Advocacy and Influencing Public Policy

GLGDGG has successfully advocated for the inclusion of issues relating to death, dying and loss in a range of strategic and policy documents that are not directly related to PELC including 'Active Health Ageing An Action Plan for Scotland 2014-2016'¹⁰, 'Mind the Gap: Age Scotland's public policy review 2012-2013'¹¹, 'Optimising Older People's Quality of Life: an Outcomes Framework Strategic outcomes model'¹² and 'Healthcare Improvement Scotland Care of Older People in Hospital Standards'.¹³

The work of GLGDGG was commended in recent Parliamentary Inquiry into palliative and end of life care in Scotland¹⁴ and in the Scottish Government's palliative and end of life care strategy for 2016–2021⁴.

Media, social media and online presence

From August 2014 to November 2015, GLGDGG featured on: BBC Breakfast, BBC Radio Scotland, STV news, The Guardian, The Huffington Post (International Edition), The Independent, Edinburgh Evening News, The Herald, The Scotsman, The Evening Times (Glasgow), The List (online) in addition to specialist NHS, social care and third sector media.

As of November 2015, GLGDGG had 1,149 'likes' on Facebook and 2,409 twitter followers.

From March 2014 to March 2015, 11,809 users accessed the GLGDGG website, viewing 36,932 web pages. From inception to November 2015, the 'Dying Matters' information leaflets adapted by GLGDGG for use in Scotland have been downloaded over 47,000 times and the Dining with Death conversation menu downloaded 4,653 times.

National and international recognition for GLGDGG

GLGDGG's '*To Absent Friends*' was a finalist in *Scottish Charity Awards Cracking Campaign 2014* and a finalist in the *Good Funeral Awards Best Internet Bereavement Resource 2015*.

The work of GLGDGG has been recognised nationally and internationally by experts in the fields of HPPC, palliative care and bereavement. For example a representative from GLGDGG was invited to: give a key note address at the International Public Health Palliative Care Conference in Limerick in 2013; share '*To Absent Friends*' work at the Dying Matters Day of the Dead Conference (November 2014), at the Hospice UK Conference (November 2015), at the Death in Scotland Conference (January 2016), and at the International Palliative Care Congress (March 2016). Prof Allan Kellehear, Chair of the International Association of Public Health Palliative Care, drew delegates' attention to the innovative work taking place in Scotland at the International Public Health Palliative Care Conference in Bristol in 2015. The International Working Group on Death, Dying and Bereavement are planning to include a session on GLGDGG at their conference in November 2016.

Networks and partnerships

The GLGDGG alliance has engaged with a growing network of individuals, organisations and communities, often outwith health and social care domains. Partnerships have been established with a range of national Arts organisation including the Luminate Festival, the Scottish International Storytelling Festival, the Scottish Writers Trust and the Royal Scottish National Orchestra, as well as community arts organisations such as Citadel Arts, Creative Electric, Blind Poetics and Just Festival. Creative outputs include *Death on the Fringe* at the Edinburgh Fringe Festival (2015) comprising 15 shows, 2 cabaret nights and 4 public lectures examining death, dying and loss, and two photographic exhibitions that toured across Scotland.

GLGDGG has extended its reach to engage with 'hard to reach' and socially excluded groups, for example by working in partnership with Waverley Care (people affected by HIV or Hepatitis C), Govan Health Centre (serving one of the most socio-economically disadvantaged populations in Scotland), Fife Choose Life (people bereaved as a result of suicide) and Comas (a charity that aims to address social problems through social innovation and community development).

In 2013 GLGDGG (through SPPC staff and other members) approached the Scottish Collaboration for Public Health Research and Policy at Edinburgh University (<http://www.scphrp.ac.uk/about/>), becoming members of the Later Life Working Group. As a result a sub-group on Quality of End of Life was established. The current focus of this sub-group's research is a scoping review to map the progress and impacts of health promoting palliative care interventions, with a focus on developed countries.

Case study 2: NHS Tayside Power of Attorney Campaign

In April 2014, NHS Tayside received £25,000 from the Joint Improvement Team (JIT) to make improvements to Anticipatory Care Planning (ACP). The funding was directed to start the Tayside Power of Attorney Campaign. This decision was made following an invitation from NHS Greater Glasgow and Clyde and Glasgow City Council to join their successful Power of Attorney Campaign. Coincidentally Lanarkshire were also in receipt of JIT funding and also accepted the invitation to join the POA campaign.

Representative from NHS Tayside, the three Local Authorities, Solicitors for Older People Scotland and Alzheimer Scotland, formed a Task and Finish Group (TFG) to take the work forward. Activities included television and radio advertisements, newspaper articles and a range of engagement events.

The full report of the Tayside group's work is available here: http://www.goodlifedeathgrief.org.uk/content/resources/Final_Tayside_POA_Campaign_Report_6th_May.pdf

Support gained from GLGDGG membership: NHS Tayside, the Joint Improvement Team, Solicitors for Older People Scotland and Alzheimer Scotland are members of GLGDGG, and representatives from these organisations have attended GLGDGG networking events. SPPC staff were part of the SG Delayed discharge Working Group which contributed to the development of thinking on and learning from these initiatives. GLGDGG publicised the campaign via its communications channels, and now hosts the final report from this work on its website.

Funding

When considering whether the type of HPPC approach exemplified by GLGDGG is worth investing in and exploring further in the future, it is useful to consider both the achievements and limitations of Good Life, Good Death, Good Grief in the light of the resources that have been allocated to this work. GLGDGG is one part of a wider work programme undertaken by the SPPC, and has no dedicated staff.^b GLGDGG has been developed using existing SPPC staffing (4.6 WTE) and resources with intermittent additional non-recurring funding; from inception to March 2015 this was, on average, £8,383 per annum. By comparison, a national programme that aims to create a culture of openness about mental health to end stigma and discrimination, 'See Me', receives £1 million per annum in funding from the Scottish Government.¹⁵

Case study 3: Here's to You

In November 2015, [Comas](#) (a charity that aims to address social problems through social innovation and community development) organised a get-together for people whose friends or relatives have died following drug or alcohol addiction. The event was primarily aimed at people in recovery from addiction in the 'recovery community'.

Here's to You was a commemoration supper for friends and family who have died following drug or alcohol addiction. It gave people the opportunity to share thoughts and feelings in an informal setting. By candlelight people were invited to share their memories and reflections about people they have known. A member of the group started the circle by sharing memories about his sister, with childhood anecdotes and the story of her troubled life and her death. Other participants followed this lead, and then moved to the café area to share some supper, enabling people to progress from their sad feelings and memories to the present.

Feedback showed that all the participants felt it was an important evening to have in the community's calendar. All those attending said they knew of other people who would have benefited from attending. Comas has decided to develop this as an annual event in their calendar.

Support gained from GLGDGG membership: Comas became members of GLGDGG in 2016 after staff at the SPPC spent time working to find ways of engaging new and traditionally 'hard to reach groups'. Individuals at Comas were inspired to organise this event after hearing about the GLGDGG-initiated *To Absent Friends* festival (www.toabsentfriends.org.uk). Via a GLGDGG small grants scheme, the SPPC provided a grant to pay for costs involved in putting on the event.

^b Information about the SPPC is available here: www.palliativecarescotland.org.uk.
Information about how the SPPC is funded is available here:
<http://www.palliativecarescotland.org.uk/content/publications/AR-2014-final.pdf>

Future opportunities and challenges

Though GLGDGG is keen to contribute more to increasing the evidence base for HPPC approaches, a lack of predictable recurrent funding presents challenges to evaluating the impact of work undertaken by GLGDGG and its members. The absence of recurrent and predictable funding also poses challenges in terms of making mid- and long- term work plans, and inhibits the recruitment of additional staff. With additional resources there would be the potential for GLGDGG to address some of these challenges and/or upscale its work.

This said, the approaches developed by GLGDGG on resources described may provide valuable learning in the context of developing useful and cost-effective approaches in times of increasingly tight public sector budgets. For example, it has a wide and varied membership, active networks, some established activities and resources and, without dedicated press or PR staff, has achieved a respectable media profile in recent years.

Membership of GLGDGG is free, and is open to all organisations and individuals who wish to support the aims and objectives of the Alliance. Interested organisations and individuals can get in touch or sign up via the GLGDGG website: http://www.goodlifedeathgrief.org.uk/content/sign_up/

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