



# Death Awareness Week Scotland: Summary Report

May 2016



## Awareness Week, 9-15 May 2016

### **Purpose**

By co-ordinating an Awareness Week, we aimed to:

- support and encourage *Good Life, Good Death, Good Grief (GLGDGG)* members to hold relevant events in their own area, bringing the *GLGDGG* messages to more members of the public
- create opportunities for media coverage across Scotland.

### **Reflecting on learning from previous years**

In January 2016 a briefing paper was produced for the *GLGDGG* stakeholder group, reflecting on learning gained from previous years. Based on this, it was decided to:

- hold an awareness week at the same time as *Dying Matters*, to maximise UK-wide media impact and allow sharing of resources where possible
- create a theme for the Scottish week which would inspire *GLGDGG* members and was broad enough to encompass any activities members were likely to want to undertake
- provide a suggestion of a simple, cheap and worthwhile activity that members could undertake in their local area – this should include an interactive activity that is of interest to the general public and works online and in public spaces
- create some original hard-copy resources to support *GLGDGG* member activity
- create new web content that drives users to the site, and promote this during awareness week via social media
- focus resources primarily on activities that were intrinsically useful/meaningful, but try to create an idea that could be of media interest.

### **Preparation**

In preparation for awareness week:

- Newsletters were emailed to members, encouraging people to:
  - host the new *It Takes a Village* photo exhibition
  - put on an event for awareness week
  - nominate someone for the 'contribution to openness award'
  - use awareness week as an opportunity to promote the work of their own organisation
- Mark and Rebecca worked with artist photographer Colin Gray to produce a new exhibition of photos and stories of people who had been involved caring for people at the end of life.

- The new exhibition was made accessible online.
- A press release was emailed to interested individuals and to media contacts.
- A social media resource sheet was emailed to interested contacts (including Scottish Government Health Directorates Corporate Communications, NHS Greater Glasgow and Clyde, NHS Highland, NHS Ayrshire and Arran, NHS Borders, Hospice UK, CHAS, Marie Curie, Macmillan Cancer Support, Carers Scotland)
- 22 copies of the new exhibition were sent to venues across Scotland, accompanied by copies of the 11 *GLGDGG* information leaflets.
- An exhibition preview was organised, and invitations sent to participants and interested parties, to showcase this work.

## **Events**

### **It Takes a Village Exhibition**

*It Takes a Village* was exhibited more than 25 venues across Scotland. The exhibitions were usually accompanied by information leaflets, and sometimes were part of other activities such as related training events, *Before I Die* walls and death cafes. The exhibition shared the portraits and personal stories from people from all walks of life who have cared for someone who is dying or has been bereaved.

As well as including a doctor and several nurses, the exhibition included a son, a daughter, a spouse, a volunteer, a care home worker, a taxi driver, a teacher and a funeral director. The exhibition aimed to show that care and support comes in many guises and is needed by many different people, and that everyone has a role to play. The exhibition also included a text panel exploring the idea of 'what is palliative care?', and encouraging people to contribute their own stories or reflections on the exhibition in writing into a feedback box.

### **Feedback**

So far, no negative feedback has been received in relation to the exhibition. Several people took the opportunity to share in writing their own stories of palliative and end of life care. Much positive feedback was received in relation to the exhibition. For example:

*"The exhibition was really thought provoking. It put the little 'troubles' in your own life into perspective. I think when my time comes and if it is due to a terminal illness I will not be so frightened, knowing there are caring people out there – be they professionals or just family and friends. Thank you."*

*"The photos are so sensitive and tastefully done regarding a subject that affects us all but is often a taboo. I like how the pictures capture the range of people involved in the care of those who are caring for or have lost someone close."*

*“What an inspirational though provoking display: wonderful to see this ‘taboo’ subject addressed in a sensitive yet practical way. All the stories touched me but in particular George, the husband’s story touched me the most. We must persevere to make death looked at more positively.”*

*“My dad died in March and it has only hit me recently. I was not aware of death awareness week, it should get more media attention. This is a beautiful exhibit and it reminds me what my family and I went through. It also gives me an insight to what the medical staff went through. I cannot thank them enough for what they did for my family. RIP Dad.”*

*“I enjoyed the exhibition as it shows different peoples points of view. I can relate to this exhibition being a care assistant myself.”*

*“No one wants to talk about death especially if it is a child. This is an excellent way of making it ‘normal’”*

*“Thank you so much for the wonderful exhibition. Peoples stories are so important it’s about what matters – what matters to them as opposed to/ as well as what’s the matter with them.”*

*“I particularly like the taxi driver. Time stands still when someone dies but the world continues. This photo reminds me of losing my mum and the world continued whilst my world stopped.”*

## **Exhibition venues**

### **Ayrshire**

- Ayrshire Hospice: 9 - 16 May
- Biggart Hospital, Prestwick: 9-16 May Carnegie Library, Ayr, 9-16 May
- Crosshouse University Hospital, Kilmarnock, 9-16 May
- East Ayrshire Community Hospital, Cumnock: 9-16 May
- Irvine Library: 9-16 May
- Girvan Community Hospital: 9 -13 May
- University Hospital Ayr: 9-13 May

### **Dumfries and Galloway**

- Dumfries and Galloway Royal Infirmary: 9 May - 10 June

### **Fife**

- Queen Margaret Hospital: 12-13 May
- University of Dundee - Kirkcaldy Campus (teaching room corridor): 12-13 May
- Victoria Hospital Foyer: 9-10 May

### **Grampian**

- Dr Grays Hospital, Elgin on Monday: 9-10 May
- Elgin Library: 8-15 May (Alongside a display of books relating to death, dying and bereavement.)

## Glasgow and Clyde

- The Prince and Princess of Wales Hospice: 9-15 May
- Possilpark Health and Care Centre: 9-15 May
- The Atrium, Queen Elizabeth University Hospital: 9-16 May
- St Margaret of Scotland Hospice: 9-27 May

## Lanarkshire

- Kilbryde Hospice: 9-16 May
- St Andrew's Hospice: 9- 15 May

## Lothian

- Marie Curie Hospice, Edinburgh 9 -17 May
- Queen Margaret University, 9-13 May
- Midlothian Community Hospital Ground Floor Meeting Room, 9 May, (10am- 5pm)
- Edinburgh Royal Infirmary, 10 May
- CBC House, 8 May
- Edinburgh Sick Children's Hospital

## Tayside

- University of Dundee - Dalhousie Reception Gallery: 9 -14 May

## Other awareness week events

(The following list may not be comprehensive as events may have taken place of which we were not aware.)

- 'Forget Me Not' afternoon tea at Roxburghe House, Dundee (Organised by NHS Tayside)
- Death Cafe, Castle Douglas (Organised by the University of Glasgow End of Life Care Study Group and Age Scotland)
- Death Cafe, Kilbryde Hospice
- Fling's Big Conversation, Glasgow (Organised by Final Fling)
- It Takes a Village, a plenary session at the Dundee University Humanities post-graduate conference on 12<sup>th</sup> May (Organised by Dundee University)
- Paint your own memory pebble, Margaret Kerr Unit, Borders (Organised by NHS Borders)
- Film Screening: Seven songs for a long life, North Berwick (Held in the North Berwick Community Centre)
- New film made and published – '*Dying Matters*' by NHS Highland
- Tree in the foyer of Marie Curie Hospice, Edinburgh (Organised by Marie Curie)
- Before I Die Wall, Queen Margaret University, Musselburgh (Organised by Queen Margaret University and St Columba's Hospice)
- Training events for student nurses – Dundee and Kirkcaldy (Organised by the University of Dundee School of Nursing and Midwifery)
- Information Display, Accord Hospice. (Organised by Accord Hospice)

## Media

### National/Regional media

The Scotsman: [Susan Lowes: It really would become us to prepare for death.](#)

[Scotland on Sunday](#)

[The Sun](#)

[STV News](#)

BBC Radio Scotland: [The Janice Forsyth Show](#)

BBC Radio Scotland: Business Scotland

West FM (Ayrshire)

West Sound FM (Dumfries and Galloway)

Kingdom FM (Fife)

[Press and Journal](#)

### Local media

*Print*

We have not had time or money available to undertake a comprehensive trawl of local media coverage. However, we are aware of the following:

- [Arbroath Herald](#)
- [Buchan Observer](#)
- [Brechtin Advertiser](#)
- [Carluke Gazette](#)
- [Cumbernauld News](#)
- [Deeside Piper and Herald](#)
- [East Fife Mail](#)
- [Fife Herald](#)
- [Fife Free Press](#)
- [Fraserburgh Herald](#)
- [Forfar Dispatch](#)
- [Glenrothes Gazette](#)
- [Inverurie Herald](#)
- [Kirkintilloch Herald](#)
- [Kirriemuir Herald](#)
- [Linlithgowshire Journal and Gazette](#)
- [Mearns Leader](#)
- [Motherwell Times](#)
- [Montrose Review](#)
- [Northern Scott](#)
- [St Andrew's Citizens News](#)
- [Stornoway Gazette](#)

### Specialist Media

Death Awareness Week Scotland was covered in the following specialist media:

- The Bucket Project: <http://thebucketprojectliverpool.blogspot.co.uk/>

- St Columba’s Hospice: [Hospice works with university to tackle death in new touring exhibition](#)
- eHospice: [New award celebrates greater openness around death and bereavement in Scotland](#)
- eHospice: [Death Awareness Week Scotland: It Takes a Village](#)
- University of Glasgow End of Life Studies blog: [A summer death cafe for Death Awareness Week](#)

### Online

Visits to the *GLGDGG* website increased significantly during awareness week. The increased web activity was comparable to that seen during awareness week 2013, and also comparable to web activity on [www.toabsentfriends.org.uk](http://www.toabsentfriends.org.uk) during *To Absent Friends* 2015:

Web metrics – [www.goodlifedeath](http://www.goodlifedeath)

	9-16 May 2016	Increase compared with a normal week (21-27 March 2015)	Increased compared with awareness week 2013	Increase compared with awareness week 2015	% Difference compared to TAF website during TAF week (1-7 November 2015)
<b>Page views</b>	<b>5342</b>	986%	7%	595%	+3%
<b>Sessions</b>	<b>2113</b>	755%	1%	775%	-21%
<b>Users</b>	<b>1801</b>	726%	4.60%	770%	-19%
<b>% new users</b>	<b>80.2</b>	3 percentage points	8 percentage points	8 percentage points	1 percentage point

The pages most commonly visited are shown on page 9.



## Top Ten most popular web pages

### *Awareness week 2016*

### *Awareness week 2013*

	<b>Page</b>	<b>Pageviews</b>	<b>% Pageviews</b>		<b>Page</b>	<b>Pageviews</b>	<b>% Pageviews</b>
1	Openness Award	451	8.44%	1	Homepage	754	15.60%
2	Homepage	399	7.47%	2	Before I Die wall	612	12.66%
3	Exhibition Homepage	370	6.93%	3	Online resources	271	5.61%
4	Euan	318	5.95%	4	Before I Die wall	246	5.09%
5	Exhibition venues	306	5.73%	5	Awareness week events	208	4.30%
6	Tony	218	4.08%	6	How to doctors choose to die	190	3.93%
7	Claire	199	3.73%	7	Find a BiD wall near you	173	3.58%
8	Awareness week	150	2.81%	8	Should I be scared of the LCP?	151	3.12%
9	Katrina	142	2.66%	9	Awareness week 2014	128	2.65%
10	Majabeen	137	2.56%	10	Advance Care Planning	120	2.48%
11	Online resources	131	2.52%				

## Facebook

Facebook total reach doubled in comparison to a normal week, but was less than half of that achieved during *To Absent Friends* week:

Facebook	9-16 May 2016	Normal week	1-8 Nov 2015
New page likes	13	1	37
total reach	15039	7529	38814

Though *GLGDGG* Facebook activity was less than during *To Absent Friends* week, there was activity on other Facebook accounts. There was not time to do a comprehensive look at all Facebook pages, activity included: St Margaret of Scotland Hospice, Marie Curie Hospice Edinburgh, St Columba's Hospice, Kilbryde Hospice, Accord Hospice, Prince and Princess of Wales Hospice, Carers Scotland, Edinburgh Sick Children's Hospital, NHS Ayrshire and Arran, NHS Highland, University of Glasgow End of Life Studies.

## Twitter

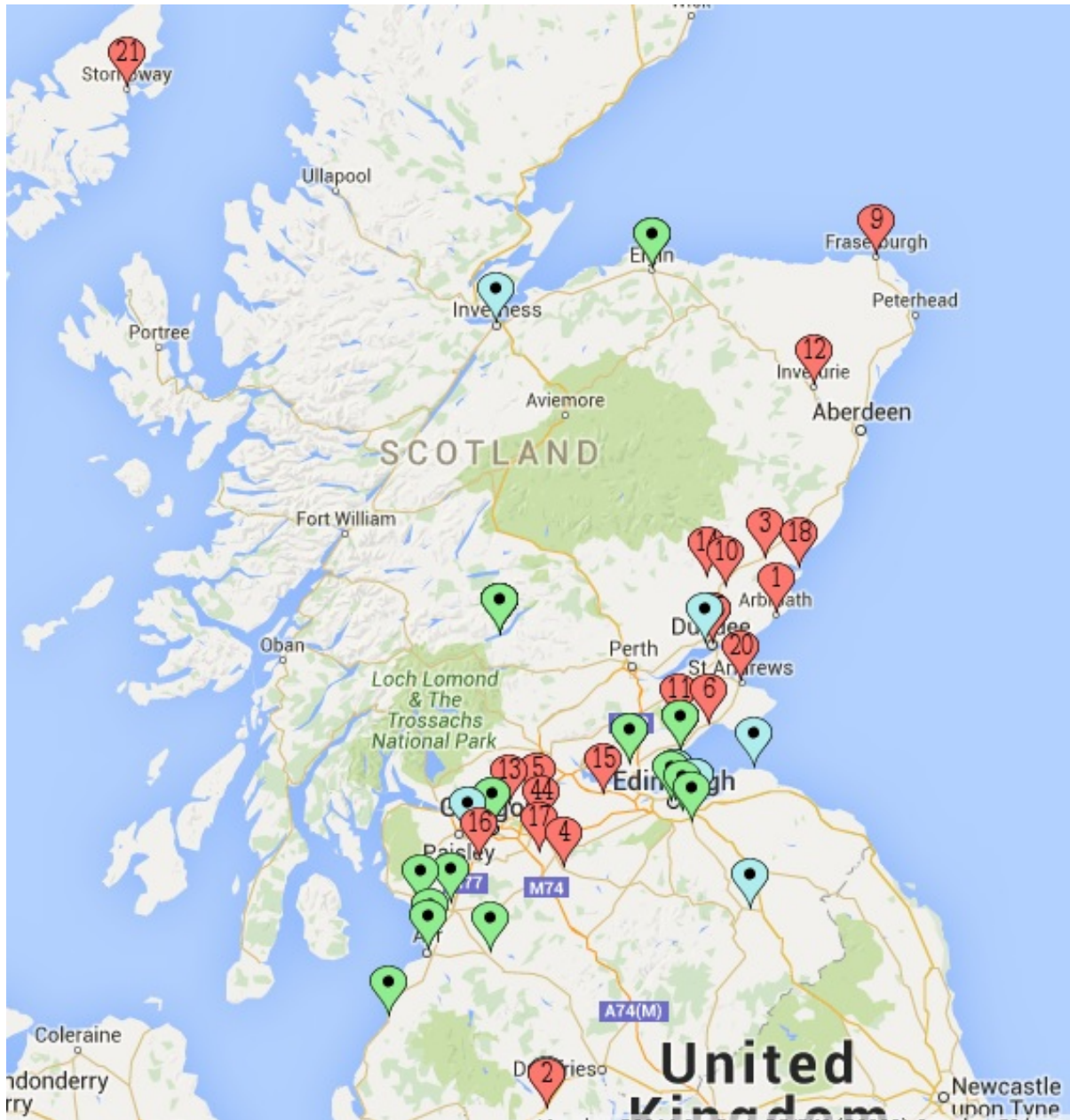
Twitter activity and engagement significantly increased during the week, to a level comparable with *To Absent Friends* week 2015:

Twitter impressions	9-16 May 2016	Normal week	1-7 November 2015
Twitter impressions	410871	364	26200
Engagement rate	1.40%	0.8%	2.5%
link clicks	172	0	192
retweets	135	1	111
likes	114	1	107

Around 274 original tweets used the hashtag #DeadAware16, from the following 50 accounts (with further retweets from others):

NHS Fife, North Ayrshire HSCP, Hospice UK Policy and Advocacy, NHS Scotland Event Team, Together for Short Lives, Prince and Princess of Wales Hospice, Tommy Whitelaw, Mark Hazelwood, Natural Death Centre, the Bucket Project, Sue Ryder Care Wheatfields, Sue Ryder Care Manorlands, Sue Ryder Care Thorpe, Sue Ryder Care Leckhampton Court, Sue Ryder Care St John's Hospice, St Columba's Hospice, *Dying Matters*, NHS Greater Glasgow and Clyde, Carers Scotland, Marie Curie Scotland, Susan Lowes, Hospice UK,

Lynn Griffin, University of Dundee Nursing, University of Glasgow End of Life Studies, NHS Fife, NHS Ayrshire and Arran, Kevin Geddes, Solicitors for Older People in Scotland, Joanna Beveridge, Tanith Muller, Jane Harris, Gary McLelland, Catriona Forrest, Accord Hospice, NHS Highland, Theresa Keicher, eHospice News, Inka Nisinbaum, Scottish Humanists Association, Marie Curie UK, Maria McGill, Macmillan Scotland, MindMate App, NAC Libraries, David Clark, Dig it! 2017, Life Death Grief.



### Key

Red dot = Local press coverage

Green dot = Exhibition venue

Blue dot = Awareness week event

## Reflections

### ***Scotland within the UK***

Since 'Dying Matters' as an organisation does not cover Scotland, we felt it was inappropriate/ confusing to use 'Dying Matters Week' as the overarching title of the week in Scotland. In addition, we felt that given recent Scottish 'national conversations' on the Scottish referendum, and the SG national conversation on health and social care, the *Dying Matters* theme 'Big Conversation' could cause confusion. We felt *It Takes a Village* would have more relevance for the Scottish activities being planned.

As expected, coinciding the week with *Dying Matters* Week in England but using different branding brought both advantages and confusions ...

- The *It Takes a Village* theme worked well and seemed to have resonance for many.
- In 2013 and 2016 Scottish Partnership for Palliative Care staff have put time and effort into co-ordinating a Scottish awareness week. In 2014 and 2015 we put little time into co-ordinating a Scottish week, instead promoting *Dying Matters* branding and resources in Scotland. By comparing activity from these years it is now clear that much more awareness week activity takes place in Scotland when the SPCC put time and effort into engaging with members and developing Scottish-specific themes and resources.
- Though most people in Scotland used the Scottish title and branding, a few used the *Dying Matters* branding and #BigConversation hashtag. Some Scottish events were listed on the *Dying Matters* website.
- Some additional publicity was received via Scottish local radio because of the media engagement work of the *Dying Matters* team in London.

### ***Media***

- Comparatively little time was spent on touting for media interest, yet local and national media coverage was excellent.
- Feedback was received that people found the social media resource sheet useful.

### ***Engagement***

- For the first time, communications departments of some of the NHS Boards have begun to take an interest in promoting this work, most notably NHS Greater Glasgow and Clyde, NHS Ayrshire and Arran, NHS Highland and NHS Fife. We should build on these contacts.
- There was little visible participation or support of awareness week from Scottish Government or special health boards.
- Activities were organised almost entirely by individuals from health and social care organisations, and this had been expected from the outset – while *To Absent Friends* attempts to engage new groups, awareness week

intended to catalyse activity from those with an existing interest in this area.

- The new web content was of interest to people and drew people to the website. However, it was not as successful at enticing people to the factual information on advance care planning etc as the web content developed for the 2013 awareness week.
- It had been hoped to create online space where people could share their stories, but we ran out of time. However, there was the opportunity to do this on social media.
- With venues including libraries, hospitals and academic institutions, the week was successful in taking these issues to members of the public.
- The *Contribution to openness about death* award was effective in bringing new visitors to the website, and an inexpensive way of recognising some of the variety, hard work and innovation taking place in the field.

### ***Exhibition***

- The new *It Takes a Village* exhibition:
  - was a useful resource for members, and we received more offers of venues for the exhibition than we could accommodate due to budget constraints
  - was an engaging way of bringing these issues to the attention of members of the public, at the same time as presenting practical information in the form of leaflets
  - has been well received and received much positive feedback
  - will continue to bring these issues to new audiences in the future, for example:
    - it has already been booked for Forth Valley Royal Hospital in November
    - The Stirling Smith Art Gallery and Museum in Stirling is interested in displaying the exhibition in 2017
    - Summerhall, an arts venue in Edinburgh, would like to display the exhibition in October 2016.
    - The exhibition will be displayed at two Scottish Care Conferences (June and November)
    - it is now part of the annual curriculum of undergraduate nurses at the Dundee and Kirkcaldy campuses of the Dundee University School of Nursing
    - we have been asked for the exhibition in electronic form so it can be used as a training resource in NHS Forth Valley.
    - the Exhibition will be displayed at an event in the Heart of Hawick at the end of June

- o the Scottish Improvement Science Collaborating Centre will be using the exhibition as part of the Care and Compassion Massive Open Online Course (MOOC), which aims to put knowledge into action to improve care and compassion in health and social care. Currently over 2000 people worldwide are signed up for the MOOC.

Colin Gray is keen to continue to build on this project in the future, so there is the potential to include more roles, publish a book, and expand on the project in other ways.

Scottish Partnership for Palliative Care  
CBC House  
24 Canning Street  
Edinburgh EH3 8EG



0131 272 2735



[office@palliativecarescotland.org.uk](mailto:office@palliativecarescotland.org.uk)



[www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk)



*A Company Limited by Guarantee. Registered in Scotland No 133003 Registered charity (SC017979)*