

## *Too Much Light*

My cataracts invest the bright spring day  
With extra glory, with a glow that stings.  
The shimmering shields above the college gates –  
Heraldic remnants of the queens and kings –  
Flaunt liquid paint here at the end of things  
When my vitality at last abates,  
And all these forms bleed, spread and make a blur  
Of what, to second sight, they are and were.

And now I slowly pace, a stricken beast,  
Across a lawn which must be half immersed  
In crocuses and daffodils, but I  
Can only see for sure the colours burst  
And coalesce as if they were the first  
Flowers I ever saw. Thus, should I die,  
I'll go back through the gate I entered when  
My eyes were stunned, as now they are again.

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*TLS 2012*

## **Structure of this Paper**

1. Background on the SPPC and its work
2. SPPC strategic objectives
3. The context for the plan and our work – risks, opportunities
4. Resources – people and money
5. Planned activities, deliverables and outcomes (organised under strategic objectives).

## **The Purpose of SPPC**

SPPC exists in order to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis. The emergence of “health promoting palliative care” has broadened the scope of work to include determinants of better death, dying and bereavement which lie outwith the domain of traditional formal health and social care services.

## **About the SPPC**

SPPC was founded 25 years ago and has grown to be a collaboration of over 50 organisations involved in palliative and end of life care. SPPC’s membership includes all the territorial NHS Boards, all the hospices, a range of professional associations and around 18 other national charities. SPPC members recognise the importance of an effective cross sector, multi-professional network, and because they value this approach they are prepared to contribute expertise, perspectives, time, energy and a membership fee to make the work of the SPPC possible.

### ***Different ways in which the SPPC Works***

#### **SPPC facilitates networking between organisations and individuals with an active interest in palliative care**

The SPPC runs a programme of constituency group meetings which provide an opportunity for organisational representatives to discuss issues of common interest, share learning, engage in problem solving, and hear from relevant external speakers. Meetings are held for different interest groups, for example, hospice chief executives, specialists in palliative care, national charities, and those with an interest in palliative care for babies, children and young people each have their own group which meets 4 times each year. SPPC also manages virtual regional constituency groups.

#### **SPPC facilitates, engages with and informs a network of practitioners**

A monthly e-Bulletin is sent to nearly 2000 subscribers, providing a summary of relevant developments in palliative and end of life care policy, practice and research, and providing an opportunity for the palliative care community to

share their work with peers. The SPPC Annual Conference provides the palliative care community in Scotland with an opportunity for learning relevant to practice and workplace, a chance to network, to share information and good practice, and challenging perspectives and energising inspiration.

### **SPPC promotes & supports public engagement by others**

SPPC established and leads *Good Life, Good Death, Good Grief*, which provides resources and supports and encourages organisations and individuals to undertake meaningful engagement within local communities to promote more openness about death, dying and bereavement. For example, GLGDGG has initiated *To Absent Friends, a people's festival of storytelling and remembrance*, which has catalysed a variety of public engagement by a range of organisations.

### **SPPC engages directly with the public**

SPPC responds to media enquiries, and undertakes some proactive engagement with local and national media. As part of the work of GLGDGG, SPPC organises some specific events which engage the public. For example, work with the RSNO to engage with schools and care homes; Death on the Fringe – a series of shows, lectures and cabarets at the Edinburgh fringe; Essence of a Memory competition aimed at the general public; photo exhibition tour around Scotland.

### **SPPC undertakes project management**

The SPPC brought together expertise from across Scotland, initiating, leading, administering and managing the development of Scottish Palliative Care Guidelines.

### **SPPC convenes & facilitates working groups to tackle a specific issue or agenda**

When the LCP was being withdrawn, the SPPC brought together individuals with the necessary expertise to inform the production of guidance on Care in the Last Days and Hours of Life. SPPC staff wrote the guidance, and ensured that the relevant experts checked, amended and re-checked the guidance before its production.

### **SPPC facilitates engagement with, and input from, the sector to inform the work of SG and others**

The SPPC consulted widely with members to produce a consensus response to inform HIS draft standards of care of older people in hospital. The SPPC manages and provides the secretariat to the Palliative and End of Life Care Stakeholder Group. *Grasping the Nettle* was a product of a 6-month piece of work during which time the SPPC undertook 3 full member consultations and

sought a wide range of additional expertise, to produce a quality consensus document to inform development of the SG SFA. The SFA was able to draw on SPPC's work (e.g. the 4 outcomes of the SFA are essentially lifted from SPPC's report). SPPC provides evidence to parliamentary committees, most recently the Health and Sport Committee inquiry on palliative care.

### **SPPC Sources specific expertise for SG or other organisations**

Most recently, SPPC has sourced someone with appropriate expertise to sit on:

- Out of Hours Primary Care Review
- HIS Review of the quality of in-patient complex care for older people within a community hospital setting
- Alzheimer Scotland symposium on advanced dementia to inform dementia dialogue

### **SPPC provides information services for the public**

SPPC provides information content for the NHS Inform Palliative Care Zone. SPPC provides information about planning ahead in leaflets and on the GLGDGG website. SPPC provides information leaflets related to bereavement and dying.

**SPPC hosts posts** which connect parts of the health and care system with SPPC networks and expertise, brokering and supporting important collaborations.

SPPC created a post to work with NHS hospital staff and the Scottish Patient Safety Programme to develop the anticipatory discussion/planning arm of the Scottish Structured Response to the Deteriorating Patient.

### **Six Strategic Objectives for SPPC 2014-17**

Following engagement with members and other stakeholders in 2013 SPPC agreed six strategic objectives for 2014–17. These are interrelated and mutually supportive. Similarly many of the activities in this plan contribute to multiple strategic objectives.

1. SPPC will provide strategic leadership in improving the experience of death, dying and bereavement in Scotland. By this we mean; maintaining a whole system perspective and associated intelligence; advocating the importance and value of palliative and end of life care; contributing to the development of strategic thinking and national policy and brokering strategic collaboration.
2. SPPC will identify, and support the spread of, good practice and innovation.

3. SPPC will promote public and professional awareness, understanding and knowledge of ways to improve death, dying and bereavement and promote public dialogue around these issues.
4. SPPC will encourage effective planning for better death, dying and bereavement by the public, and by professionals together with patients and families, at all stages of life.
5. SPPC will work to ensure that the experiences of the public, patients and families inform the development and implementation of policy and practice.
6. SPPC will undertake any necessary organisational change/development required to deliver its strategic objectives.

## **Context**

### ***New Opportunities***

In 2016/17 SPPC can play an important role in supporting the implementation of the Strategic Framework for Action on Palliative and End of Life Care (SFA). SPPC's strategic objectives are extremely well aligned to the priorities identified by the SFA. The SFA mandates work by a number of organisations for whom palliative care is not regular core business, and a number of different work streams (linked to the 10 commitments in the SFA) are being established. In this context SPPC's ability to source expert input, to tap into its networks of champions, and to facilitate engagement are particularly valuable, as is its intelligence, familiarity with the landscape and organisational memory.

There are opportunities to develop more effective and collaborative working with Scottish Government.

SPPC, through funding support from Macmillan Cancer Support has an opportunity to contribute to the improvement of palliative care in acute hospital settings. This might be viewed as a continuation of our earlier work with IHI and before that the Scottish Patient Safety Programme.

## **Resources**

### ***People***

The plan is based on staffing of 5.6 WTE – a net increase of 1.0 WTE made possible by funding from Macmillan Cancer Support for work to improve palliative care in acute settings.

During 2014/15 SPPC introduced a couple of volunteer roles (*Curating Death on the Fringe* and facilitating training related to Good Life, Good Death, Good Grief. It is hoped that both these roles will continue in 2016-17.

***Money***

A detailed budget has been agreed by the SPPC Council. 2016-17 will be another very tight year financially for SPPC.

**Strategic Priority:- 1. Provide strategic leadership in improving the experience of death, dying and bereavement in Scotland. By this we mean; maintaining a whole system perspective and associated intelligence; advocating the importance and value of palliative and end of life care; contributing to the development of strategic thinking and national policy and brokering strategic collaboration.**

<b>Activity</b>	<b>Output / Deliverable</b>	<b>Outcome to which this work contributes</b>
Maintain effective engagement with members and other key stakeholders in palliative and end of life care.	c15 Constituency Group meetings Other meetings with relevant stakeholders – e.g. Person Centred H&C, Alzheimers, Health & Social Care Alliance, HIS, FiOP, SOPA, CI Scottish Care etc etc	Members and other stakeholders able to share practice, problem solve, are kept informed and able to input to policy.
Undertake ongoing networking, horizon-scanning and policy analysis.	Knowledge and understanding of relevant policy environment. Knowledge of activities in PEOLC.	SPPC able to inform & influence national developments and to keep stakeholders informed about relevant policy.
Inform the palliative care community about relevant policy developments via e-bulletin and website.	11 editions of eBulletin Up to date website.	Stakeholders informed about relevant policy, practice, research, training/events & other developments.

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Activity	Output / Deliverable	Outcome to which this work contributes
Seek opportunities and/or respond to requests to provide representation of palliative care in relevant SG work streams.	Work streams which have access to PEOLC expertise.	Relevant work streams are better informed on PEOLC.
Formulate appropriate inputs to formal and informal SG consultations and policy development processes (in conjunction with membership), and to processes of other relevant organisations. Likely to include National Care Standards, Dementia Strategy, Funeral poverty/welfare reform, Integration etc etc	Inputs to consultations and policy development processes	Better policies.
<b>SFA-related work streams</b> At the time of writing SG and other bodies are in the process of establishing a number of work streams/groups linked to the SFA. SPPC has a current involvement in work streams/groups on Education, Research Forum, Development of Strategic Commissioning Guidance on PEOLC for HSCPs, and the Anticipatory Care Planning arm of <i>Living Well in Communities</i> . Our mode of involvement (see intro to this plan) is not yet clear in all cases but the volume of work is large. Additional work streams are very likely to emerge in the coming months (e.g. measurement/indicators, Public Conversations etc)		
When opportunities arise articulate the particular issues relating to palliative care for babies, children and young people.	SPPC outputs which reference CYP	Profile of CYP issues raised.
Following the Holyrood elections re-establish and provide Secretariat to the Cross Party Group on Palliative Care.	3 relevant meetings.	MSPs and others have regular opportunity to discuss PEOLC together.

Strategic Priority:- 2. **Identify, and support the spread of, good practice and innovation.**

<b>Activity</b>	<b>Output / Deliverable</b>	<b>Outcome to which this work contributes</b>
Use the monthly eBulletin and website to highlight examples of good/innovative practice.	11 editions of eBulletin. Blog on good/innovative practice.	Stakeholders aware of good/innovative practice which supports spread.
Run an annual conference to share and inform the development of good practice.	A positively evaluated, well attended conference which generates a small surplus.	Conference delegates have increased knowledge, which influences policy and practice, and have improved useful relationships through networking opportunities.
Maintain awareness of key research evidence in palliative and end of life care, with a focus on evidence that is particularly helpful in informing the SPPC's work to support and contribute to the development and strategic direction of palliative care in Scotland.	Listings of key evidence. Other SPPC outputs and activities draw on research evidence.	SPPC advocacy, policy and best practice activities are informed by relevant evidence, promoting evidence-based policy and practice.
Building on the Best. In partnership with Macmillan, NHS Boards and other organisations run a small project to develop, test and evaluate approaches to improve palliative care in hospitals.	Support to a small number of sites to develop and test approaches. Facilitation of sharing of learning between sites in Scotland and across the UK. Contribute to evaluation processes.	Better experiences for patients and those important to them in hospital.

Strategic Priority:- 3. **Promote public and professional awareness, understanding and knowledge of ways to improve death, dying and bereavement and promote public dialogue around these issues.**

<b>Activity</b>	<b>Output / Deliverable</b>	<b>Outcome to which this work contributes</b>
Continue to lead and develop Good Life, Good Death, Good Grief	See <b>Appendix 1</b>	Greater openness about death dying and bereavement, with associated behaviour changes.
Share learning from GLGDGG and provide expert advice to SG as it develops plans to take forward SFA Commitment 6 "Support great public discussion...etc"	Learning and advice (conversations, papers, evaluations, products)	Better SG plans
Undertake media activity to promote the importance and value of palliative and end of life care, and other ways of improving the experience of death, dying and bereavement.	Comment/content provided to the media.	Better coverage of PEOLC.
Continue to develop and maintain the Palliative Care Zone on NHS Inform for the benefit of the Scottish public, including participation in NHS major review.	Up to date high quality web content.	Public have access to up to date high quality web content.

Strategic Priority:- 4. **Encourage effective planning for better death, dying and bereavement by the public, and by professionals together with patients and families, at all stages of life.**

Activity	Output / Deliverable	Outcome to which this work contributes
Good Life, Good Death, Good Grief activities to create open discussion and to provide practical information about planning.	See <b>Appendix 1</b>	Behavioural change supportive of better death, dying and bereavement.
Input as required to Living Well in Communities Anticipatory Care Planning work stream.	Not clear yet.	Raising awareness of ACP approaches, development of consistent national approach which supports good PEOLC.

Strategic Priority:- 5. **Work to ensure that the experiences of the public, patients and families inform the development and implementation of policy and practice.**

Activity	Output / Deliverable	Outcome to which this work contributes
Working with relevant stakeholders produce an illustrated typography of approaches to ensuring that patient, carer/family and public experiences are central to the development and delivery of PEOLC. The typography will link to the Our Voice 3-level framework.	A report available to members, other stakeholders and SG.	The experiences of the public, patients and families inform the development and implementation of policy and practice
<i>Within the limits of currently v limited available resources</i> ensure non-professional voices are included in the SG stakeholder arrangements on Palliative and End of Life Care.	Stakeholder arrangements include non-professionals	Oversight of SFA implementation reflects the expectations of the Scottish public and experiences of patients and of those important to them.
Feature relevant qualitative research in the eBulletin each month.	Relevant content in eBulletin.	UPDATE subscribers have access to qualitative research on public, patient and family experiences.

Ensure that the experiences of the public, patients and families feature at the SPPC annual conference.	Relevant content at conference.	Conference delegates hear patient/public experience.
Link with SPSO and HIS to explore learning from PEOLC complaints	Exploratory work at this stage	Services informed by learning from the experiences of patients and those important to them.
<b>Strategic Priority:- 6. Undertake any necessary organisational change/development required to deliver its strategic objectives.</b>		
<b>Activity</b>	<b>Output / Deliverable</b>	<b>Outcome to which this work contributes</b>
Refresh SPPC strategy	Refreshed strategy from April 2017	Optimise SPPC effectiveness & impact.
Explore options for supporting staff if affected by difficult issues.	Staff supported appropriately	Staff wellbeing
Apply for charitable funding to support aspects of Good Life, Good Death, Good Grief work.	Trust applications. Cash.	Better (or at least maintained) resourcing for Good Life, Good Death, Good Grief
Develop the skills and knowledge of employees in order to support the delivery of this plan.	Training and development activities.	Appropriately equipped staff team.
Comply with regulatory and legal requirements and good practice.	Annual accounts, health and safety documentation and practices, HR processes and practices, OSCR returns, governance activities.	Compliance.
Discussions with key funders.	A plan to address "structural deficit" from April 2017	Financial sustainability of SPPC

## APPENDIX 1

Good Life, Good Death, Good Grief work plan 2016-2017													
	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March
<b>1. Increasing membership</b>													
1.1 Undertake actions to increase membership to 1000 members by the end of August.	X	X	X	X	X	X							
<b>2. Engaging and Supporting Membership</b>													
2.1 Run a members networking event				X									
2.2 Produce newsletters	X	X	X	X		X		X		X		X	
2.3 Create 'It Takes a Village Exhibition'	X	X											
2.4 Create new #ItTakesAVillage web-based resources	X	X											
2.5 Publicise and promote Awareness Week activities and resources	X	X											
2.6 Participate in Awareness Week			X										
2.7 Seek member engagement in To Absent Friends	X	X	X	X	X	X	X	X	X				



source to run TAF 2016.													
4.4 Seek resources to produce a Scottish adaptation of “The Conversation”		X	X	X									

**Other possible activities to undertake if resources become available:**

The following pieces of work were identified during the extensive engagement which underpinned the production of *Grasping the Nettle* and if adequate resources were secured could be taken forward by SPPC in partnership with other relevant stakeholders.

- undertake proactive and sensitive public and media engagement in the development of a *Charter for a Good End of Life*, empowering the general public and health and social care professionals by listening to views, establishing clear terminology, and developing honest and accessible information about the support people can expect to receive as they approach the end of life;
- draw on work already carried out by Public Health England and the National Council for Palliative Care and develop a practical toolkit to assist Scottish communities in identifying and addressing local problems relating to death, dying and bereavement;
- develop and promote an engaging resource which supports people from socio-economically disadvantaged communities to discuss and plan for the financial, medical, legal, practical and emotional issues which arise towards the end of life;
- promote, within the framework of *Curriculum for Excellence*, wider use of existing resources which encourage conversation, education and support around death, dying and bereavement experiences for children and school staff in primary and secondary education;
- identify and proactively address the barriers people face in making wills, powers of attorney and advanced directives including provision of free legal advice where appropriate;