What is the national alliance *Good Life Good Death Good Grief* and how does its work fit with asset based approaches?

Purpose of this Discussion Paper

This paper:-

- outlines what is meant by asset based approaches and signposts to further reading on the concept
- sets out changes to the experiences of death, dying and bereavement in Scotland over the past 50 years and associated harms
- describes the origins and work of the *Good Life, Good Death, Good Grief* alliance

What are Asset Based Approaches?

In the context of health improvement assets may be defined as "the collective resources which individuals and communities have at their disposal, which protect against negative health outcomes and promote health status"[i].

> **Practical Examples of Assets** (adapted from [i])
>
> - The skills, capacity and knowledge of local residents
> - The passions interests of local people that give the energy to change
> - The networks and connections in a community
> - The effectiveness of local community voluntary organisations
> - The resources of public, private and third sector organisations that are available to support a community
> - The physical and economic resources of a place that enhance wellbeing

Asset based approaches are concerned with identifying (and building up and on) the protective factors that support health and wellbeing at both individual and community

level. Asset based approaches are contrasted with traditional approaches to the delivery of health care and other public services which use narrow interventions which focus on deficits/problems.

Asset based approaches are not new but are currently enjoying a higher profile within a number of strands of Scottish Government policy for example:-

- the Chief Medical Officer makes use of assets as a concept in his analysis of Scotland's health inequalities and poor performance in international comparisons of health status
- Asset based approaches are highlighted in the Christie Commission on the Future Delivery of Public Services. Demographic and financial projections have placed an imperative on approaches which are not based on increasing the scale of existing formal services.
- *Re-shaping Care for Older People* emphasises the potential for strengthening informal community support and individual assets as a means to extend independent living in the community.

There are a number of closely related terms and concepts which tend to occur alongside asset based approaches.

"Community development", "community engagement", "self-management" all share features of asset based approaches in that they place emphasis on the positive capacities of individuals and communities and the importance of individuals and communities in identifying, leading and effecting change.

"Co-production" is another term being used with increasing frequency. It "essentially describes and equal and reciprocal relationship between service provider and service user that draws on the knowledge, ability and resources of both to develop solutions that are claimed to be successful, sustainable and cost effective..."[ii] A recent joint publication from JIT, the Health and Social Care Alliance, the Scottish Co-production Network and Governance International gives an overview of theory, policy and examples of co-production in practice in Scotland[iii].

Recent Changes in Death, Dying and Bereavement

Demographic and social changes over the last century have changed the medial and social experience of dying:-

- Death tends to occur later in life.
- People are likely to experience multi-morbidities and a protracted and individually unpredictable decline prior to death.

- Over 70% of deaths take place in institutions – mostly hospital – whereas in 1949 over 80% of deaths were at home. Death has become more remote and medicalised.
- Little open discussion of death and dying.
- Local geographically defined communities have become more fragmented - about 20 percent of the older population is mildly lonely and another 8 to 10 percent is intensely lonely.
- Traditional religious frameworks of meaning, belief and ritual are relevant to a declining proportion of the population.

Associated with these changes are a range of harms, for example:-

- People die without opportunity to say “good bye” or “I love you”
- people may be frightened about the process of dying if they know nothing about it
- close relatives of people who are approaching the end of life may be unaware of the wishes of their loved one and therefore how best to help and support them
- where discussion between patient and healthcare professionals doesn’t happen people may undergo aggressive futile medical interventions
- people who would have wished their organs to be used for transplantation may not have discussed this with relatives who have to make decisions after their death
- people may die without writing a will and may not have discussed funeral wishes with their relatives
- people may be unable to be discharged from hospital because they do not have a power of attorney
- same sex partners may not have declared their status, with the consequence that professionals may exclude them from involvement in their partner’s care
- people sometimes tend to avoid those who are ill or bereaved for fear of “upsetting them” or “making them worse”
- people may lack of knowledge of the financial implications for the bereaved following a death and what needs to be put in place ahead of the event
- lack of public and professional discussion about grief and loss, which results in the isolation of the bereaved
- arguably, the failure to acknowledge death / mortality removes a context which is profoundly valuable in making choices about how we *live*.

These harms are capable of reduction, but this reduction requires society-wide approaches – the solutions lie largely out with the domain of traditional healthcare services.

What is the national alliance *Good Life Good Death Good Grief*?

Origins and Policy Context

In 2008 the Scottish Government published *Living and Dying Well a National Action Plan on Palliative and End of Life Care*. The Scottish Partnership for Palliative Care (SPPC) led a working group under the auspices of the action plan to explore palliative and end of live care from a public health and health promotion perspective. The group's report[iv] recommended a range of actions and the establishment of a broad-based alliance to lead and co-ordinate further work in this area. The SPPC took on the role of establishing and leading this alliance, which is called Good Life, Good Death, Good Grief.

Vision

The vision of Good Life, Good Death, Good Grief is a Scottish society in which:-

- people are able to talk about death and deal with related issues in a constructive way
- children grow up treating dying as an inevitable part of ordinary life
- people are comfortable using words such as "death", "dead" and "dying", and are able to make choices relating to their own dying and death
- health and social care professionals and volunteers in all care settings feel able to have discussions relating to death, dying and bereavement with patients and families, and with colleagues
- communities of all kinds are empowered to provide effective support to those dealing with death, dying, bereavement and loss.

About Good Life, Good Death, Good Grief www.goodlifedeathgrief.org.uk

Good Life, Good Death, Good Grief is an alliance of over 700 organisations and individuals hosted and resourced by the Scottish Partnership for Palliative Care. Its membership includes all NHS Boards, local and national voluntary organisations, universities, schools, faith-based organisations, local authorities and arts organisations and its worked is endorsed by the First Minister.

Openness about death, dying and bereavement is the key to change for both individuals and institutions. Much of Good Life, Good Death, Good Grief's work at national level is about encouraging openness.

Good Life, Good Death, Good Grief has very limited direct resources (being run by the small staff team at SPPC). Its approach is primarily to engage, support and enhance the assets of organisations and individuals who have the potential to improve the experience of death, dying and bereavement in Scotland.

Good Life, Good Death, Good Grief believes that different groups and communities within Scotland will have different strengths, weaknesses, problems and priorities

relating to death, dying and bereavement, and that groups and communities themselves will know best what their strengths, weaknesses, problems and priorities are. Therefore much of the work of Good Life, Good Death, Good Grief is determined and undertaken by members themselves. The alliance can act as a support, a sounding board, and a network of like-minded people, to help individuals and organisations undertake the change they think needs to happen.

The alliance also provides (but mostly signposts to) resources for people who are dealing with death, dying and bereavement in a personal capacity.

To lead and support the alliance's membership the following national network activities are undertaken:-

- Providing information and resources about public health and health promoting approaches to better death, dying & bereavement
- Identifying & sharing good practice
- Providing ideas, inspiration, practical tools & small grants
- Generating media coverage/national dialogue
- Influencing public policy

The work of Good Life, Good Death, Good Grief and its members is very varied because the experience of death, dying and bereavement can be improved through work in so many domains. The work can be categorised using a health promotion framework:

Mode of Action (from the Ottawa Charter on health promotion)	Some Examples of Work Being Undertaken
Building healthy public policy	• Inputting on relevant issues to the Scottish Government's Reshaping Care for Older People
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

Mode of Action (from the Ottawa Charter on health promotion)	Some Examples of Work Being Undertaken
	local action
Developing personal skills	• Providing a website and leaflets with practical advice • 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 undergrad nurses enhancing capacity to deal with deal and dying.

Membership of Good Life, Good Death, Good Grief is free and quick, via the website. www.goodlifedeathgrief.org.uk

For more information contact mark@palliativecarescotland.org.uk or rebecca@palliativecarescotland.org.uk

[i] Asset based approaches for health improvement: redressing the balance Glasgow Centre for Population Health October 2009 http://www.gcph.co.uk/assets/0000/2627/GCPH_Briefing_Paper_CS9web.pdf
[ii] Scottish Community Development Centre Community Development and CO-production: Issues for Policy & Practice 2011
[iii] Co Production of Health and Wellbeing in Scotland JIT, the Health and Social Care Alliance, the Scottish Co-production Network and Governance International http://www.govint.org/fileadmin/user_upload/publications/2012_Pamphlet/GovInt___JIT_Co-Production_of_Health_and_Wellbeing_in_Scotland.pdf
[iv] Addressing Palliative and End of Life Care from a Public Health and Health Promotion Perscpective: facilitating wider discussion of death, dying and bereavement across society. SPPC 2010 http://www.palliativecarescotland.org.uk/content/publications/SLWG7-FINAL-REPORT.pdf