A ROAD LESS LONELY

Moving forward with public health approaches to death, dying and bereavement in Scotland

good life
good death
good grief

Scottish
Partnership
for Palliative Care

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CONTENTS

EXECUTIVE SUMMARY

When faced with the reality of deteriorating health, caring responsibilities, death or bereavement, people need many things from the NHS and other formal services, and from their friends, families and communities.

Though health and social care services play an important role, they are only part of the picture. Education, workplace culture, family networks, the media, community support and access to information all play an important role in shaping people's lives.

Therefore, if we truly want to improve people's experiences we need to look at wider society and explore what can be done to foster more open and supportive attitudes and behaviours relating to death, dying and bereavement.

This report explores some of the different areas that can shape people's experiences, focusing particularly on:

- Death education and bereavement support in schools.
- Workplace culture and policies.
- The role of communities.
- The practicalities of planning ahead for deteriorating health and death.
- Personal skills and knowledge relating to death, dying and bereavement.
- Mass media campaigns.
- Socio-economic disadvantage.
- Funeral poverty.
- Good Life, Good Death, Good Grief, Scotland's public health palliative care alliance.

Taking each of the above areas in turn, this report explores what practical action might be taken at a national level to encourage and support open and supportive attitudes and behaviours relating to death, dying and bereavement in Scotland.

Death education and bereavement support in schools: explores how schools in Scotland can be encouraged and supported to provide education and support around death, dying and bereavement for children and staff in primary and secondary education focusing on the importance of:

- Improving staff confidence in supporting students and colleagues dealing with the difficult times associated with ill health, care, death and bereavement.
- Developing school bereavement policies.
- Facilitating lessons with a specific focus on death as part of the life cycle, as an integral part of equipping children to deal with loss and change.

Compassionate Workplaces: explores what makes a 'compassionate' workplace, focusing in particular on what might be done to help workplaces become more supportive places for people who have been bereaved.

Compassionate Communities: explores sources of learning relating to the creation of compassionate communities and looks at how work of this kind might be encouraged and supported at a national level in Scotland.

Personal skills and knowledge relating to death, dying and bereavement: explores some actions that might be taken to support people to improve their personal skills and knowledge relating to deteriorating health, death and dying.

Making practical plans for deteriorating health and death: explores how people might be supported and encouraged to make practical plans for deteriorating health and death, with a particular focus on Power of Attorney.

Mass media campaigns: explores some of the issues that should be considered prior to the production of a mass media campaign aimed at encouraging open

and supportive attitudes and behaviours relating to death, dying and bereavement in Scotland.

Public Health Palliative Care in socio-economically disadvantaged communities: explores how public health approaches to palliative care interact with health inequalities arising from socio-economic disadvantage, with a particular focus on the ability of Community Development approaches to support change within communities.

Funeral poverty: explores what action might be taken at a national level to address funeral poverty and support people to plan ahead for their funerals.

Scaling up Good Life, Good Death, Good Grief: explores the potential to build on and scale up the work of Good Life, Good Death, Good Grief, Scotland's public health palliative care alliance.

WHAT NEXT? At the end of each chapter some suggestions are given relating to useful practical next steps relating to that area of work.

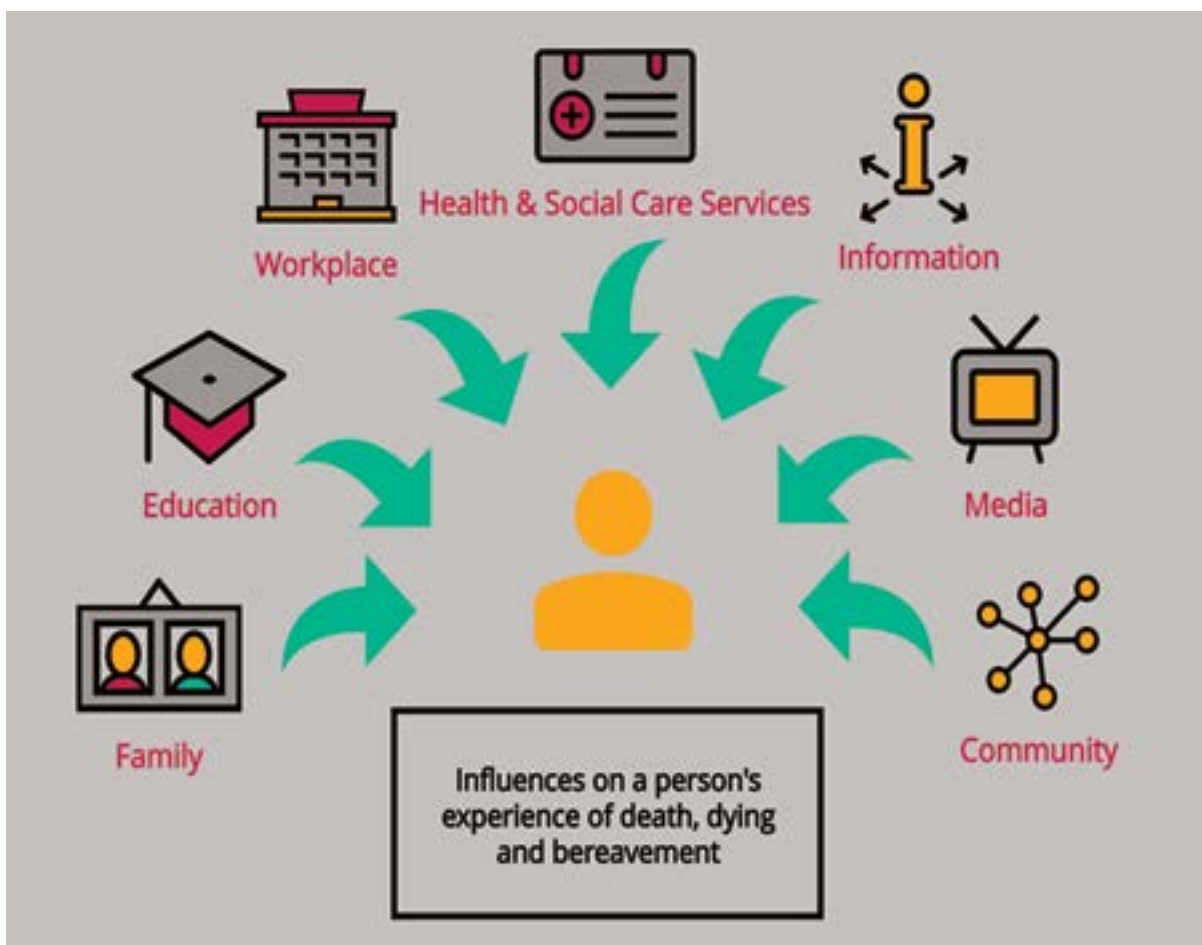The report does not allocate actions to organisations or individuals. Rather, it aims to articulate some of the issues involved and some ideas of practical next steps, and make this available as a resource for all those who wish to take forward work in this area in Scotland. The report illustrates that relevant action can be taken by a range of different types of organisations, across a variety of domains.

SECTION 1 Introduction

For all of us, there will be times when the practical realities of ill health and death intrude on our lives and expectations. It might be when your mother starts to show the signs of dementia. It might be when the doctor diagnoses you with cancer. It might be when someone you care about dies.   It might be when your neighbour is in hospital and needs someone to feed their cat.

When faced with the reality of deteriorating health, caring responsibilities, death or bereavement, people need many things from the NHS and other formal services, and from their friends, families and communities. No-one should have to deal with these difficult times alone.

Though health and social care services play an important role, they are only part of the picture. Education, workplace culture, family networks, the media, community support and access to information all play an important role in shaping people's lives.   Therefore, if we truly want to improve people's experiences we need to look at wider society and explore what can be done to foster more open and supportive attitudes and behaviours relating to death, dying and bereavement.

This report explores some of the different areas that can shape people's experiences, focusing particularly on:

- Death education and bereavement support in schools.
- Workplace culture and policies.
- The role of communities.
- The practicalities of planning ahead for deteriorating health and death.
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- Mass media campaigns.
- Socio-economic disadvantage.
- Funeral poverty.
- Good Life, Good Death, Good Grief, Scotland's public health palliative care alliance.

SECTION 2 Background

Rationale for producing this report

Various problems are caused in Scotland because:

- People are unprepared for the experiences of death, dying and bereavement.
- Communities are disempowered from providing support to people who are dying or bereaved.
- Health and social care professionals, individuals and families are unprepared for death-related discussions.

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 may die without wills, leaving complicated situations for their families and friends.
- Health care professionals often 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.

Vision

Recognising the need to address these issues, the Scottish Partnership for Palliative Care (SPPC) established Good Life, Good Death, Good Grief (GLGDGG) in 2011. GLGDGG is an alliance of organisations and individuals committed to creating a Scotland where:

- People are well-informed about the practical, legal, medical, financial, emotional and spiritual issues associated with death, dying and bereavement.
- There are adequate opportunities for

discussion of these issues, and it is normal to plan for the future.
- Public policies acknowledge and incorporate death, dying and bereavement.
- Health and social care services support planning ahead and enable choice and control in care towards the end of life.
- Communities and individuals are better equipped to help each other through the hard times which can come with death, dying and bereavement.

This report was produced by SPPC and GLGDGG, with the financial support of Scottish Government, as a practical exploration of how to encourage open and supportive attitudes and behaviours relating to death, dying and bereavement in Scotland.

Terminology

'*Public health palliative care*' is becoming the accepted term used to encompass a variety of approaches that involve working with communities and wider society to improve people's experience of death, dying and bereavement. (For a fuller discussion of terminology see Appendix 1.)

Policy

A number of policy documents have highlighted the importance of encouraging more open and supportive cultures relating to death, dying and bereavement.[i]

The need to develop public health approaches to palliative care is implicit in the aims and outcomes of the Scottish Government Strategic Framework for Action on Palliative and End of Life Care[ii] (SFA), and most explicitly referenced in Commitment 6:

'We will support greater public and personal discussion of bereavement, death, dying and care at the end of life.

This will include commissioning work from public service agencies outside of health and social care such as schools, colleges and prisons. Local plans to enhance the public health focus of public health professionals on palliative care will also be supported.'

Commitment 6 refers to the need for a culture change which is fundamental to the achievement of many other aims, outcomes and objectives of the SFA. This area of work is also relevant to other areas of health and care policy, for example the vision for *'realistic medicine'* set out by the Chief Medical Officer in her 2014-15 Annual Report,[iii] the recently published Health Literacy action plan *Making it Easier,* Scotland's National Dementia Strategy and the nine National Health and Wellbeing Outcomes.[iv]

Though this report has its origins in Commitment 6, it spans a range of issues that are relevant to multiple Scottish Government policy domains outwith Health. For example, Section 10 references the Scottish Government's recent commitment to tackle funeral poverty, and Section 4 is significant in relation to GIRFEC, Scotland's national approach to improving outcomes and supporting the wellbeing of children and young people.

Improving public health is a Scottish Government (SG) priority set out in the Health and Social Care Delivery Plan. SG states that it will *'create a clear set of national public health priorities for Scotland as a whole and streamline the currently cluttered public health landscape.'* It plans to put in place a new, single, national body on public health to strengthen national leadership and to build the critical mass behind improving public health in Scotland.

By 2020 SG aims to set up local joint public health partnerships between local authorities, NHS Scotland and others to drive national public health priorities and adopt them to local contexts across the whole of Scotland.[v]

Scope and remit of this report work

This report does not aim to be a comprehensive scoping of all relevant initiatives and learning relating to the vast and diverse field of public health palliative care.[1]

Rather, it aims to explore some options relating to practical next steps which could be taken at a national level to promote more open and supportive attitudes and behaviours relating to death, dying and bereavement in Scotland.

The report reflects briefly on nine areas in turn, looking at:

- The problem or issue that future work in the area should aim to address.
- The potential to learn from previous work in this area.
- Any other key issues that arise.
- What next steps might be necessary to move each area of work forward. The type of 'next steps' identified varies from the theoretical to the practical, depending on what stage work is currently at.
- How different areas of work might be interrelated.

Authors

This paper has been prepared by SPPC working with the Good Life, Good Death, Good Grief (GLGDGG) stakeholder group and its subgroups, with input from other individuals with relevant expertise. (See Appendix 6 for a list of those involved.)

Working groups were chaired by Mark Hazelwood, Chief Executive of the SPPC and the lead author was Rebecca Patterson, Policy and Communications Manager at SPPC.

SECTION 3 Influencing behaviours

Before moving on to explore nine different areas in turn, it is helpful to reflect more generally on approaches to influencing attitudes and behaviour relating to death, dying and bereavement.

Much work in the field of public health palliative care is characterised by work aiming to *'get people talking'* about death. In his book *What Death Means Now,*[vi] Tony Walter characterises this approach as based on the belief that *'breaking the so-called death taboo will enable people to talk about death and thus change their attitudes and actions'*.

Walter also highlights an alternative view, which is *that 'getting people involved in supporting other local people facing the end of life will change attitudes'* giving this hypothetical example:

> *'A teenage girl offers to walk a dying neighbour's dog after school each day. Each time she visits the house to collect and return the dog, she learns about dying; she does not need to talk about death in order to walk the dog (she just needs to like dogs), but walking the dog will teach her about death'.*

Walter highlights that there is evidence from other public initiatives such as smoking cessation and environmental initiatives that *'attitudes can change behaviour, but also that behaviour can change attitudes'*.

The figure on page 16 is extracted from the Scottish Government document *Influencing behaviours: Moving beyond the individual*[vii]. It illustrates the ISM model, which proposes that three different contexts – the Individual, Social and Material – influence people's behaviours. One of the key principles of ISM is that interventions should take account of influences across multiple contexts – I, S and M – in order to achieve substantive and long lasting change.

This is a useful model to bear in mind as we explore how to influence attitudes and behaviour relating to death, dying and bereavement in Scotland. It also gives a helpful illustration of why different chapters and topics within this report are interrelated.
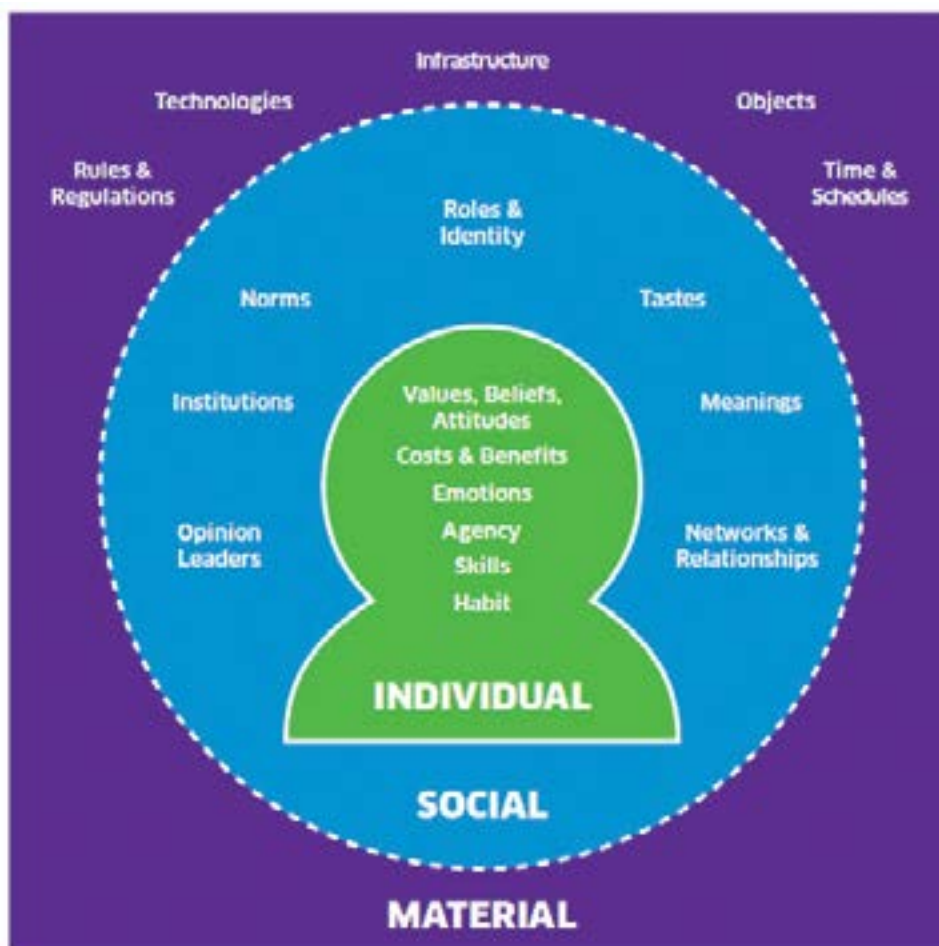
THE INDIVIDUAL CONTEXT

This includes the factors held by the individual that affect the choices and the behaviours he or she undertakes. These include an individual's values, attitudes and skills, as well as the calculations he/ she makes before acting, including personal evaluations of costs and benefits.

THE SOCIAL CONTEXT

This includes the factors that exist beyond the individual in the social realm, yet shape his or her behaviours. These influences include understandings that are shared amongst groups, such as social norms and the meanings attached to particular activities, as well as people's networks and relationships, and the institutions that influence how groups of individuals behave.

THE MATERIAL CONTEXT

This includes the factors that are 'out there' in the environment and wider world which both constrain and shape behaviour. These influences include existing 'hard' infrastructures, technologies and regulations, as well as other 'softer' influences such as time and the schedules of everyday life.

Extracted from the Scottish Government document *Influencing behaviours: Moving beyond the individual*

SECTION 4 Death education and bereavement support in schools

This section of the report explores how schools in Scotland can be encouraged and supported to provide education and support around death, dying and bereavement for children and staff in primary and secondary education.[2]

It focuses on the importance of:

- Improving staff confidence in supporting students and colleagues dealing with the difficult times associated with ill health, care, death and bereavement.
- Developing school bereavement policies.
- Facilitating lessons with a specific focus on death as part of the life cycle, as an integral part of equipping children to deal with loss and change.

Background

Death is part of life, and something that every child will experience at some stage. Many children experience the death of someone important to them at a young age and this increases their risk of various long-term negative outcomes.

The Childhood Bereavement Network[viii] has estimated that, in the UK, around 5% of young people have been bereaved of at least one parent by the time they reach the age of 16. In Scotland this means that around 4,600 children will experience the death of a parent each year.[ix] [3]

The Scottish Government's *Programme for Scotland 2016-17* committed to appointing a new national coordinator of childhood bereavement services to review and advise on steps to improve support.

Bereavement in childhood is under-researched, with most studies looking only at parental bereavement. For most children the first experience of death comes through the death of a grandparent, sibling, member of their extended family and friends, other significant person in their life or even a pet. 78% of 11-16 year olds in one survey said that they had been bereaved of a close relative or friend.[x] Children and young people in public care may be more likely than others to have experiences of bereavement, including sudden and traumatic death. They may be isolated from networks of other grieving family members and have experienced varied and repeated losses alongside a death.[xi]

As children spend much of their lives at school, school communities have an important role to play in educating children in relation to death, dying and bereavement and supporting them in developing healthy coping skills. This can happen through acknowledging and supporting bereavement experiences that children may be experiencing as well as teaching, through class activities, about death and grief as a normal part of the life cycle.

Within Curriculum for Excellence,[xii] experiences and outcomes relating to death and bereavement generally fall under the Health and Wellbeing curriculum area, specifically:

> *'I am learning skills and strategies which will support me in challenging times, particularly in relation to change and loss.'* (HWB 2-03a)

However, though opportunities and good intentions exist, educating children about

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[2] Other institutions and influences can be important in a child's life and work together with schools towards ensuring positive outcomes, for example pre-school, out of school care, and residential care, but these are beyond the scope of this report.

[3] Child Bereavement Network estimates of bereaved children in Scotland are available here: *http://www.childhoodbereavement-network.org.uk/research/local-statistics.aspx*

loss through death can be challenging and some teachers may find it difficult to bring these experiences into a classroom situation.

Death and bereavement can be sensitive issues, and ones that teachers and management teams can find hard to prioritise in a busy school environment. Nevertheless, as death affects 100% of children (and staff) at some stage in their lives, it is essential to encourage and support schools to make death education an integral part of their health and wellbeing programme, and to create a school community where experience of death, dying and bereavement is shared and supported in a compassionate way.

Why is death education and bereavement support important?

Childhood Bereavement as an Adverse Childhood Experience (ACE)

Adverse childhood experiences (ACEs) are stressful or traumatic events that are found to be strongly related to the development and prevalence of a wide range of emotional, physical, behavioural and social problems throughout a person's lifespan. ACEs include domestic violence; parental abandonment through separation or divorce; a parent with a mental health condition; being the victim of abuse (physical, sexual and/or emotional); being the victim of neglect (physical and emotional); a member of the household being in prison; growing up in a household in which there are adults experiencing alcohol and drug use problems.[xiii] Associations have been observed between these experiences and poor health outcomes, including: injury and death during childhood; premature mortality and suicide; disease and illness; and mental illness.[xiv]

Whilst the original ACEs study in 1998[xv] did not include 'bereavement' on the list of ACEs, it has since been suggested that a number of adverse and potentially traumatic events were not included in the original study, and that one of these is bereavement.[xvi]

Compared to their non-bereaved peers, children and young people bereaved of a parent are more likely to experience a range of poor outcomes. These relate to:

Health and Wellbeing
According to information compiled by the Childhood Bereavement Network,[xvii] children who have been bereaved of a parent are:

- 50% more likely to die before middle age.
- More likely to die early once over the age of 65 (indicating a persistent association with early mortality).
- Three times more likely to have physical health symptoms in the clinical range.
- More likely to have a serious illness or accident, or to have been hospitalised.
- More likely to have risky health behaviours including smoking, drinking, not wearing a seat belt, being in a car with a driver who has been drinking, carrying a weapon, being in a physical fight, being hospitalised for drug or alcohol use. Those bereaved suddenly are more likely to have substance or alcohol abuse disorders.
- One and a half times as likely to have a mental health disorder.
- Three times more likely to develop diagnosable new-onset depression, if bereaved suddenly.
- More likely to report depressive symptoms at the age of 30 (women).
- More likely to attempt suicide in young adulthood.
- More likely to be hospitalised for a psychiatric disorder.[xvii]

Education and employment
The Childhood Bereavement Network highlights that children report difficulties concentrating and learning after a parent dies making it harder for them to engage with education. In England, evidence suggests that GCSE scores of children bereaved of a parent are an average of half a grade lower than their non-bereaved peers. Girls bereaved of a sibling scored almost a full grade below their matched controls.

The death of a parent by the age of 16 is associated with women failing to gain any sort of qualification, and both men and women being unemployed at the age of 30.

Offending

Bereaved children are overrepresented in the criminal justice system: around 4% of 11-16 year olds in the general population have been bereaved, compared to at least 17% of persistent young offenders. This suggests that there is a link between offending and early experiences of bereavement but this is underexplored. It is known, however, that by the age of 26, those children bereaved of a parent are at increased risk of a criminal conviction for a violent offence.[ix] A Scottish study exploring the prevalence and nature of bereavement among 33 young men who had been sentenced to a young offenders institution found that bereavement had been experienced by 91% of the sample, and the rates of traumatic and multiple deaths were high.[xx]

The family is undoubtedly a key context for bereaved children and children's outcomes are strongly correlated with how their surviving parent is coping: their mental health, levels of warmth, discipline and communication. Nevertheless the importance of support outwith the family should not be underestimated.

Why are school communities important?

> *'Most grieving children or adults will be much helped by a supportive school or work environment, understanding social circle, and some knowledge of grief reactions.'*
>
> Child Bereavement UK [xxi]

Social support networks are hugely important in people's experiences of coping with bereavement. It has been suggested that a key factor in whether or not someone manages to live with and through bereavement without developing mental health problems is whether their social and personal support mechanisms meet their needs.[xxii]

The importance of social and personal support mechanisms is reflected in a variety of frameworks and practice models that are already established within Scotland that focus on the health and wellbeing of children. For example, the concept of *'One Good Adult'*, as identified in the Greater Glasgow and Clyde Mental Health Improvement and Early Intervention Framework, has been found to be a key indicator of how well a child copes with their struggles.[xxiii]

However, when it comes to ill health, death and bereavement, in school communities, staff may feel uncertain about how to help or worry about making things worse. Due to this the bereavement needs of children can often go unmet and many children report having no-one to talk to. Support from peers is an important part of a child's social support networks, yet some are actively bullied as a direct result of being bereaved.[xxiv]

How schools can help: a whole school approach

It is important that schools take a whole school approach to death, dying and bereavement support, creating a compassionate school community that provides opportunities to learn about death and bereavement as part of life as well as appropriate and timely support.

The group involved in developing this report agreed three key priorities that would help to achieve the vision for a whole school approach as outlined on the following page:

- Improving staff confidence: providing all staff with opportunities to develop their confidence in supporting students and colleagues dealing with the difficult times associated with ill health, care, death and bereavement.

- Developing a school bereavement policy

- Death education: facilitating lessons with a specific focus on death as part of the life cycle, as an integral part of equipping children to deal with loss and change.

A WHOLE SCHOOL APPROACH

Personal, Social & Health Education: Pupils learn about reaction to loss and change and how to manage these, and support others, through PSE/ PSHE.

Environment, Resources & Facilities: The school has an open culture around death and bereavement where support is provided and/or accessed as necessary. School policy and strategy support appropriate responses to bereavement. Bereavement training is provided to all staff regardless of role.

Partnership Working: Partners include staff, pupils, parents/carers, carer groups, end-of-life service providers (such as local hospices), bereavement services and other organisations that provide expert support and advice when needed.

Staff Health & Wellbeing: Bereavement support for staff is available and easily accessible. Staff are provided with training on how to engage with children about death, dying and bereavement. Staff are offered and encouraged to seek support when engaging with bereaved children.

Management and Leadership: Strong support and leadership from management to adopt and roll out school agreed plan/policies, that includes promoting death education and bereavement support.

Ethos & Climate: Adopt an ethos that is open, encouraging and supportive towards children, families and staff discussing illness, death and bereavement.

Curriculum Learning and Teaching: Education on death and grief are included in curriculum learning and teaching. This will include using interactive methods to develop understanding of death as a part of the life cycle and the range of skills that can be employed to help self and others when someone dies.

These three priorities are discussed in more detail below.

Improving staff confidence

Research has identified that when teachers cover the *'loss and change'* elements of the curriculum, this is usually in its most general sense, such as the loss and change that may occur when pupils move to a different classroom, rather than specifically addressing loss through death. [xxv] This is often due to staff feeling that they lack experience and confidence in both acknowledging and teaching about death and bereavement. Even when teachers themselves feel confident in their ability to deal appropriately with these issues, challenges might come from parents or colleagues who are more reluctant to address death, dying and bereavement openly. Other school staff, such as janitors and catering staff, also have an important role to play in the lives of children, and so also need the confidence to appropriately address issues that might arise.

Bereavement Policies

The development of a bereavement policy in every school can support staff by ensuring they have easy access to a set of guidelines and advice on how to approach bereavement in schools. Although some Scottish local authorities have developed policy and procedures in this area this is not consistent, meaning that staff often have to respond to a bereavement in the school without any guidance and children experience varying levels of support.

A bereavement policy can highlight the range of ways that a school community can be of help. For example, Child Bereavement UK has identified a variety of supports that school can offer children experiencing loss and grief:

Normality: For the majority of children whose life has been turned upside down the routines of school life can give a sense of normality. Everything else may have fallen apart but school and the people within it are still there, offering a sense of security and continuity.

Relief from Grief: School can give children relief from an emotionally charged atmosphere at home. Whilst children need their loss acknowledged they may feel overwhelmed by a grieving family and a constant stream of visitors expressing their own grief can be difficult for some children to deal with.

An Outlet for Grief: When a parent or sibling has died, children can try to spare their surviving parent by hiding their own grief and appearing to be OK. School is often seen as somewhere safe to express this grief.

A Listening Ear: Family members struggling to deal with their own grief can overlook children. For a child who wishes to, school staff can provide an opportunity to talk about what has happened with a familiar and trusted adult in relative peace and calm.

The Opportunity to be a Child: Even when deeply sad, children still need to be children. School offers the chance to play, laugh, sing and generally just be a child without feeling guilty.

General Support: Systems should be in place to keep in contact with home. Discuss concerns but also successes. Grieving children can display altered behaviours in different situations. Good communication with home will help school be aware of this and provide a more realistic picture of how the child is coping.

Resources: It may be useful to have a selection of resources on death and bereavement in the school library. Stories are an effective way to gently introduce young children to the concept of death. Novels and poems offer children a chance to learn through reading, listening and discussion.

Taking care of yourself: Talking to a child about the death of someone important may be among the hardest things a teacher will ever have to do. As the Hands on Scotland website points out, *'Supporting a bereaved child can be exhausting and bewildering and may also bring back painful memories of your own. Staff should do what they can to support the child, without expecting too much from themselves and should talk to someone if they need support'*.[xxvi]

Death Education

If children are given opportunities to be better informed about death and dying, they will be more prepared to cope in the face of illness and/or bereavement and better able to support those around them. It is therefore suggested that there needs to be both preventative and intervention models of practice in relation to death, dying and loss in a school community.[xxvii] A prevention model involves activities designed to educate and support children so that they are better able to cope with loss. Intervention involves responding to crisis and/or offering support once bereavement has been experienced.

Death and dying can be incorporated 'normally' in all aspects of the curriculum such as through sciences, literature and religious education.[xxviii] Literature would suggest however that teachers often lack the confidence to do so and thus promoting death education for children necessarily involves self-development of teachers and cooperation with parents as well as effective communication with children.[xxix]

Research conducted in Scotland identified that primary children, aged nine to twelve had lots of questions about death and enjoyed having space and time for such learning.[xxx] These children felt that school was an appropriate place to have these questions answered and as a result a death education programme (The Resilience Project) was established in response to the children's questions.[xxxi] This programme of work is now in its 5th year of running.

What resources already exist that school communities can draw on?

Lots of resources exist that school communities can draw on, many of which have been developed with input from children themselves. A selection of these are collated in Appendix 2.

What might encourage and support schools to develop a whole school approach to death, dying and bereavement?

It is clear that lots of good resources are available that can be used by teachers and schools. What, therefore, can be done to encourage and support schools to consider making improvements in their approach to dealing with death education and bereavement?

Leadership

Change within a school is led by the Head Teacher, so the enthusiasm and commitment of a school's Head Teacher is essential if a school is to consider introducing new initiatives relating to death and bereavement. The Scottish Government, Education Scotland and Local Authority Directors of Education also have an important role to play in creating conditions in which Head Teachers are aware of the importance of this agenda and that support and resources are available.

Awareness

Excellent resources can go unused if people are unaware of them. Likewise, important issues can go unaddressed if people don't realise their significance. One trigger for a school to re-examine these issues would be something tragic affecting the school community, such as a child's death. It is far better, however, if a school is aware of the need to address these issues prior to such an event so that they are prepared. School Cluster Meetings, the Scottish Learning Festival, the General Teaching Council (GTC) monthly magazine, the Times Educational Supplement and Social Media are important sources of information for teachers.

Quality resources that are easy to access

It is important that teachers are able to easily access well-presented, professionally produced resources online, and that they can be confident that these resources are of an appropriate standard of quality and ready to use. Anything that saves time for a teacher or management team is helpful. Though resources exist, teachers may not

have time to sift through them all. So, for example, directing teachers to resources by type, topic and age range can be helpful, as can some kind of quality assurance.

Inspiration

For schools to want to put effort into making improvements in this area, management teams and staff need to be clear that approaches of this kind can improve outcomes for children, and exactly what such approaches are likely to involve. It might help to illustrate how whole school approaches to death and bereavement support broader programmes, approaches and frameworks such as: Getting It Right for Every Child (GIRFEC), The Scottish Attainment Challenge and Delivering Excellence and Equity in Scottish Education delivery plan. Hearing about the success of such an approach in another school, or hearing it described by respected peers can also influence a teacher's interest in exploring the approach further.

WHAT NEXT?

Development and promotion of an Implementation Tool

Future practical work could be undertaken to encourage and support schools to provide education and support around death, dying and bereavement. This should include work to address all four elements identified above: leadership, awareness, accessibility of resources and inspiration.

This might include:
- Developing an Implementation Tool, which can be used by schools to help them:
  o Assess their current approaches to death and bereavement.
  o Understand the benefits of strengthening current approaches.
  o Understand how this area fits into wider education frameworks and priorities.
  o Understand what to do to improve the school's approach.
  o Find appropriate resources that have

already been developed, including lesson plans, model policies, children's books, and sources of training and support.
- Scoping, quality assurance and categorisation of existing resources.
- Development of a website to house the Implementation Tool (either a new website, or development of a new section on an existing website).
- Proactive engagement with education leaders to raise the profile of this work in the education sector.
- Proactive communications to raise awareness of the issues and promote the Implementation Tool in different ways and through different media.

Any such work should be undertaken with input from appropriate stakeholders with subject matter expertise around education and death, dying and bereavement, including Education Scotland, to ensure that any outputs from the project can be quality assured and promoted through official channels.   The project would require to be developed by a team with:

- Knowledge and experience of the education system in Scotland and credibility among teachers and management.
- Communications and web-development expertise.

Other potentially useful actions

- Explore options to ensure that data on childhood bereavement is systematically collected. Current statistics are based on mortality data or smaller studies and may not represent the actual level of experience. Having a better understanding of the incidence of bereavement in children would support better planning of bereavement service provision, training for professionals and supporting the resilience of communities.
- Lobby to ensure that death is

mentioned within the Curriculum for Excellence as a specific area of learning. Currently teaching about death, including the range of skills that can be used when someone dies, is not referenced explicitly – it is only referred to in relation to loss and change and does not, for example, get the same amount of emphasis as sex education, despite it being a universal experience. It is therefore easy for schools to miss death education despite it being an essential part of developing children's resilience.

SECTION 5 Compassionate Workplaces: supporting employees through bereavement

'Compassion: a feeling of deep sympathy and sorrow for another who is stricken by misfortune, accompanied by a strong desire to alleviate the suffering'.[xxxii]

This section of the report explores what makes a 'compassionate' workplace, focusing in particular on what might be done to help workplaces become more supportive places for people who have been bereaved.

What is a compassionate workplace?

A compassionate workplace is one where employees feel supported through the ups and downs of life by colleagues, managers and institutional procedures.

All kinds of different circumstances can lead to a period of change or uncertainty during which an individual might be glad of a compassionate workplace. These range from the joyous (the birth of a child), to the mundane (waiting in for the boiler to be fixed), to the distressing (illness in the family).

Support provided by a workplace can come in many guises. Some is formally structured into the policies and procedures of the employer, for example compassionate leave. Some might be at the discretion of an individual line-manager, for example flexible working arrangements. Some is down to colleagues, for example understanding someone's low mood, or making them a cup of tea.

Why is a compassionate workplace important?

Research indicates that high levels of emotional demands predict mental health issues, fatigue and burnout.[xxxiii]

There is evidence that compassionate workplaces have benefits on many levels to both employees and employers. Dutton et. al (2014)[xxxiv] cite research that suggests compassion in the workplace:

- Reduces anxiety.
- Helps people feel valued.
- Helps people resume a sense of normality.
- Increases bonds between co-workers.
- Generates higher levels of shared positive emotion.
- Builds a collective capacity for healing.

Supporting employees through experiences of care, deteriorating health, death, dying and bereavement

For all of us, there will be times when ill health or death intrudes on our lives and expectations. For example, this might be through personal or family illness, caring responsibilities or bereavement. No-one should have to deal with these distressing times alone, and workplaces can play an important role providing:

- Flexibility to allow an individual to continue doing what matters most to them.
- Information on financial, legal and other practical issues.
- Understanding and social support.

Scope of this report:

Supporting employees through bereavement

A compassionate workplace comprises many elements, and it is outwith the scope of this report to address them all. This report focuses on one particular element of a compassionate workplace: the role of employers, managers, colleagues, policies and structures in supporting employees through bereavement.

Vision for Bereavement Friendly Workplaces

- The impact of bereavement on employees is acknowledged, understood, made allowance for, and alleviated, by colleagues, managers, and institutional procedures.
- People who have been bereaved feel acknowledged and supported in the workplace as they deal with and adjust to their loss.
- Employees and managers feel able to respond appropriately and supportively when a colleague has been bereaved.

Who would benefit from compassionate approaches to bereavement in the workplace?

Individuals

There were 57,579 deaths in Scotland in 2016.[xxxv] With an estimated 4 people affected by each death that means there are over 230,000 newly bereaved people each year. Most of these people will have a 'normal' grief reaction, adapting to their loss with the support of family and friends[xxxvi] and making use of various sources of information to normalise their reactions. Around 10% of people experience grief at a level that is sufficient to cause significant impairment to function on a daily basis.[xxxvii]

Estimates of the number of employees experiencing grief in any one year range from 1 in 10 employees, based on research done in Ireland,[xxxviii] to 1 in 5.[xxxix]

In a small audit of 34 Irish organisations,[xl]

all had experienced employee bereavement in the last 12 months, and 50% had experienced the death of an employee at some point in their history.

Certain areas of the workforce come into contact with death through their work much more often than others, and are likely to have specific needs in relation to bereavement support. For example, two reports by Scottish Care - *Trees that bend in the wind*[xli] and *Fragile Foundations*[xlii] illustrate the extent to which support staff who are engaged in the care of people approaching death is especially critical. They highlight that one in thirteen Scots are employed in social care, and that further work needs to be undertaken both in understanding the particular needs of the care home and care at home workforce, and to ensure that they receive adequate bereavement support.

Employers

It is difficult to quantify the impact of bereavement to employers in financial terms because it is hard to separate out the influence of bereavement from that of other factors.

A Scottish study undertaken in 2014 found that bereaved people are significantly less likely to be employed in the year of bereavement, and two years afterwards. The same study noted that:

'Bereaved people take time off work, both as formal and hidden (other sick or unpaid leave) bereavement leave, and at any one time up to 5% of the working population may be on bereavement related leave (Wojcik, 2000). In addition, when bereaved employees return to work they may function at a reduced level (Charles-Edwards, 2005). A study carried out in Northern Ireland, limited by its sample size of only 11 parents and only exploring one form of bereavement, suicide of a child, estimated required time off work ranged from 1 to 12 weeks (Gibson, Gallagher, & Jenkins, 2010). Time off work for bereavement is challenging to assess and there is a resultant paucity of research on the socio-economic impact of bereavement

on individuals and businesses, with Scotland no exception in this regard.'[xliii]

There is literature[xliv] to indicate that the effects of compassion in the workplace are wider-reaching and longer-term than can be measured by individual experience or economic impact alone.

These effects include:
- Increased connections between co-workers.
- Increased commitment to the organisation.
- Lower staff turnover.
- Increased trust.
- Increased pride in the organisation.

Indications are that a compassionate workplace is a more effective and productive workplace all round.

Current situation

Legislation

Several pieces of legislation have a bearing on employers' approach to grief and bereavement.

Under Section 57(A) of the Employment Rights Act 1996, employees have a *'day one'* right to *'reasonable'* time off work to deal with emergencies, including a bereavement, involving a dependant. *'Reasonable'* is not defined. *'Dependant'* could include partner, child, grandchild, parent, or other person for whom the employee cares. The employer is not obliged to pay the employee for this time.

The Equality Act 2010 protects employees with protected characteristics from unlawful discrimination. Some mental health difficulties associated with bereavement may be considered disabilities, and thus protected characteristics, meaning employers would have to make *'reasonable adjustments'* for those employees. Religion is also a protected characteristic, so employers would be required to take religious custom into consideration too.

There are additional legal requirements relating to specific types of bereavement. For example, female employees who suffer a stillbirth after 24 weeks are entitled to up to 52 weeks statutory maternity leave. The employer also has a standard duty of care towards its employees, which should take account of the effects of bereavement.

The Parental Bereavement Leave and Pay Bill[4] sets out to make provision relating to leave and pay for employees who have experienced the death of a child. It received its second reading in the Westminster Parliament in October 2017. If it becomes law, it will introduce two weeks of paid bereavement leave for employees who experience the death of a child. Some organisations are campaigning for amendments to be made that would require the Westminster Government to review other circumstances in which paid leave would be appropriate.

Practice

Employers typically implement legal requirements through a 'staff handbook' or other internal document, outlining their policies. While an organisation may have policies in place, the execution of those policies is not always ideal. In some cases, employers may feel their obligations are discharged by allowing a short period of leave, even though the effects of bereavement can be unpredictable and may not fit a convenient timescale. Some studies have found that some employers expect employees to deal with their feelings only on personal time (Manns & Little, 2011[xlv]).

It has been suggested that for some employers, bereavement or compassionate leave policy is a 'tick-box' exercise, added because it's a legal requirement, not because it's been thought through.

Written policies are only part of the picture - the role of informal support and understanding should not be underestimated. Though written policies have huge potential to help, much of a person's workplace experience is shaped by the behaviour of their individual manager and colleagues. Understanding, empathy and practical support from colleagues has

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[4] *https://services.parliament.uk/bills/2017-19/parentalbereavementleaveandpay.html*

an important impact on how well supported someone feels in bereavement.

Workplace culture and support from colleagues

The European Working Conditions Survey undertaken by Eurofound in 2015 indicated that:

- 31% of respondents hide their feelings at work (most of the time or always) women more frequently face emotional demands than men: 35% have to hide their feelings always or nearly always, as against 28% of men.
- For 56% of workers in the EU, working time arrangements are set by the organisation with no possibility for change.
- 71% of workers in the EU state that their colleagues nearly always help and support them, but 11% say they never or rarely get support from their colleagues.
- 58% of workers say that their manager helps and supports them - with 19% stating that this is the case only rarely or even never.

The research cited in Dutton et al (2014) points to the strength of bonds that can be created between colleagues when compassion is emphasised in the workplace. Although policies tend to place responsibility on the line manager, support (or lack of it) from colleagues is key to wellbeing.

A study undertaken in Teesside[xlvi] shows that employees are actually very realistic about employers' ability to offer paid leave and are favourable towards more flexible working patterns (including unpaid leave). Flexibility, understanding and personal communication are seen as key elements of the supportive workplace.

The main consideration is that the policy be fair to all. While a discretionary approach *'can lead to inconsistencies in treatment and ultimately resentment between staff'*, resentment can also arise under fixed systems when people take their 'entitlement' regardless of need.

From the perspective of the bereaved,

colleagues being initially supportive, but then expecting them to have *'moved on'* was cited as a common detrimental behaviour. Staff feeling unsupported because their relationship with the deceased was not deemed close enough was another concern.

Public opinion

Indications are that work to improve employers' approaches to bereavement support would be welcomed by the public. ComRes research for the National Council for Palliative Care (NCPC) and Dying Matters showed:

- 87% agreed all employers should have a compassionate employment policy.
- 81% agreed there should be a legal right to paid bereavement leave for close relatives.
- 82% believed providing this would be beneficial to the employer in the long term.
- 56% said they would consider leaving their job if their employer did not provide proper support.
- 32% of those who had been bereaved in the past five years said they were not treated with compassion by their employer.[xlvii]

What relevant resources are available/ what work has already been done or is underway?

A list of relevant work and resources is presented in Appendix 3.

WHAT NEXT?

Resources and training are already available which can help employers to improve how they support employees through bereavement. So how can more employers be encouraged to make use of these resources?

This is an area of work that the Scottish Partnership for Palliative Care is interested in taking forward. The process of researching and writing this report has

57,579 deaths in Scotland in 2016 × **4** people affected by each death = **230,000+** recently bereaved people each year

GRIEF vs WORKPLACE CULTURE

31% hide their feelings at work

56% cannot change working time arrangements

71% say their colleagues nearly always support them

58% say their manager supports them
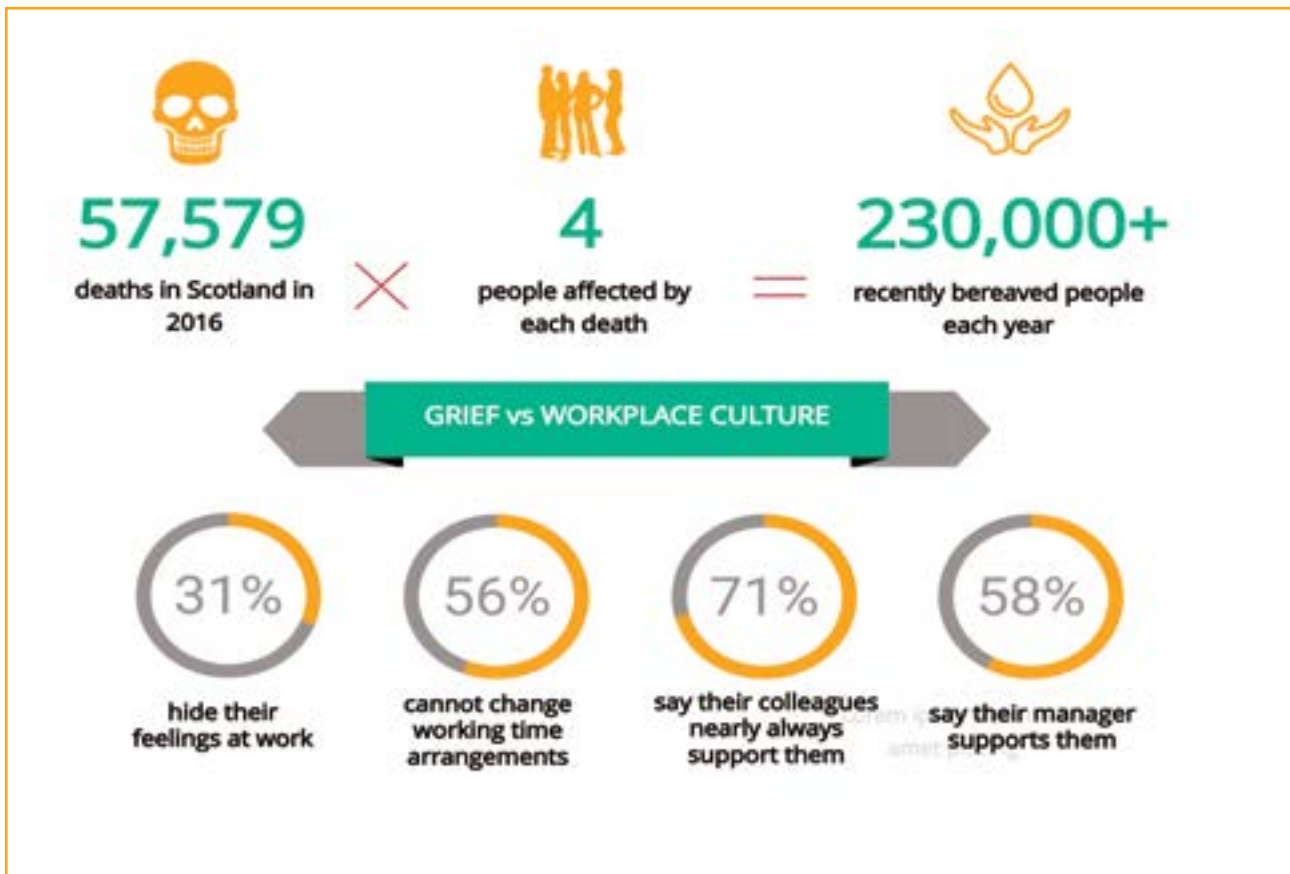
provided a good grounding in some of the issues. As a first step, in early 2018 the SPPC brought together a group of relevant stakeholders to discuss an appropriate way forward. Engagement was sought from: Cruse Bereavement Care Scotland, employers, HR specialists, employee representatives, Healthy Working Lives, Investors in People, Federation of Small Businesses and CBI.

In 2018 the Scottish Partnership for Palliative Care will consider undertaking a practical project to:

- Encourage more employers to re-examine their approach to supporting employees who have been bereaved.
- Make available resources and support to enable employers to equip themselves with knowledge, skills and policies that support compassionate workplace approaches to bereavement.
- Better understand barriers to employers accessing existing resources and training.

Drawing on previous work by ACAS and Cruse Bereavement Care as set out within 'Managing bereavement in the workplace - a good practice guide',[xlviii] future work undertaken by the SPPC in this area might include:

- Exploring the need for a survey or audit of Scottish employers to set a benchmark and establish the extent of need.
- Exploring some of the barriers and enablers to the introduction and maintenance of compassionate workplaces approaches to bereavement.
- Scoping of and signposting to useful resources already available.
- Recognition that workplace support can come in the form of informal support from managers and colleagues as well as policies and training.
- Exploring how workplaces might support employees with anticipatory bereavement and the stresses of

supporting someone who is in the last days of life.

- Exploring the role of proactive communication with employers and publicity in raising the profile of the importance of this area.
- The potential to introduce 'compassionate workplace awards' to encourage employers to take action.
- Exploring how much can be done within existing resources as well as potential sources of further financial support for this work.

SECTION 6 Encouraging Compassionate Communities in Scotland

This section of the report:
- Explores sources of learning relating to the creation of compassionate communities.
- Explores how work of this kind might be encouraged and supported at a national level in Scotland.[5]

What is a Compassionate Community?

Often, people talk about creating a compassionate community without having a specific definition in mind, referring more loosely to the importance of communities being close-knit and supportive, of neighbourliness, and building on individual acts of kindness by ordinary people.

Within the field of public health palliative care, the term 'compassionate community' refers to something more specific - it is used to describe communities that are compassionate in their support of people through the difficult times associated with care, deteriorating health, dying and bereavement.

Compassionate communities do not assume the formal service responsibilities of health and social care services - their role is different and complementary. A compassionate community:

- Recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.
- Encourages, facilitates, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care.[xlix]

Or, put simply - in a compassionate community *'ordinary people help ordinary people'* through the hard times that can come with death, dying, loss and care.

What do we mean by 'community'?

Many different and varied communities are present within Scotland, and not all are communities based on location. Community can be defined as:

> *'any social, religious, occupational, or other group sharing common characteristics or interests and perceived or perceiving itself as distinct in some respect from the larger society within which it exists'.*[l]

By 'community' we could mean an entire city, a school or factory, or a dying person's own social network.[li] Communities of various kinds are increasingly mediated through technological innovations such as social media.

Background: why is there a need to actively work to create compassionate communities?

Communities have become disempowered from providing support to people who are dying or bereaved. The days leading up to death have gradually become more

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[5] See Appendix 1 for a glossary of relevant terms

What do we mean by "community"?

Many different and varied communities are present within Scotland and not all are based on location...

Office

City

Factory

Religious Group

Community of Interest

Social Network

School
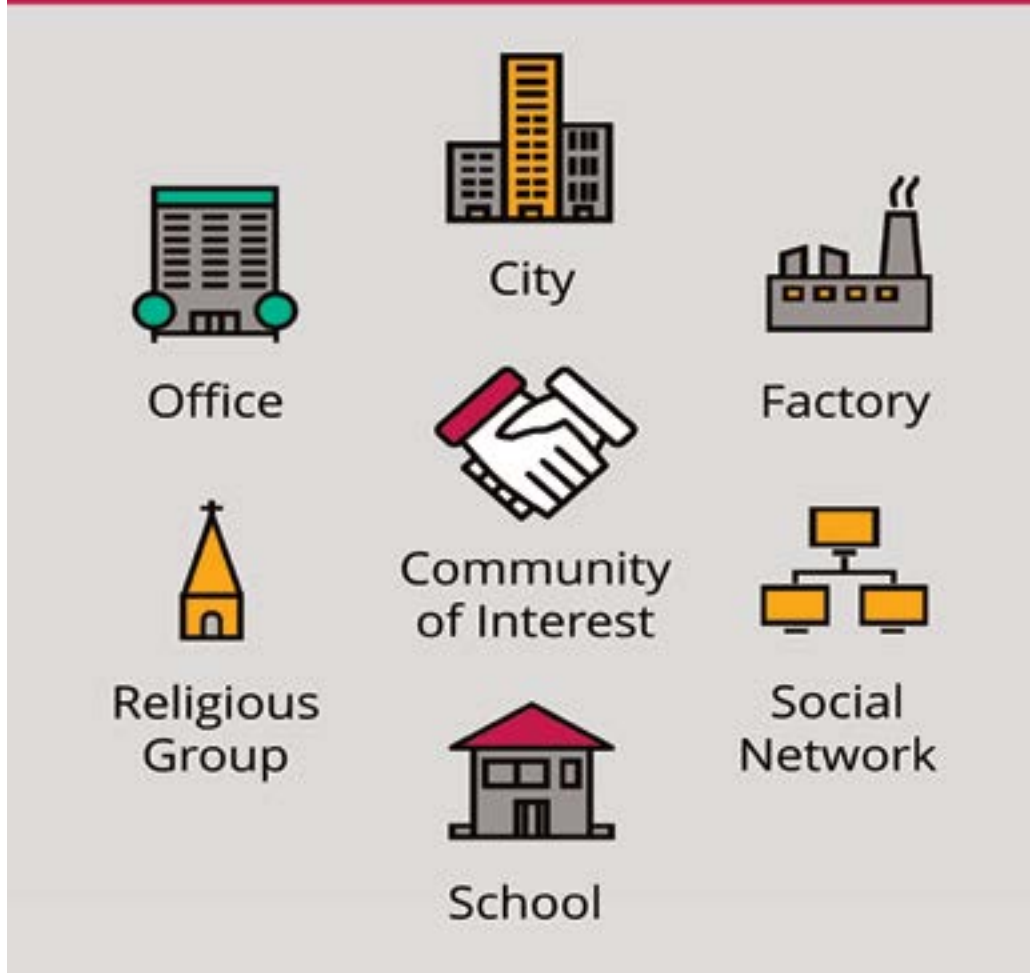
'*professionalised*' - the province of different health and care specialists rather than part of routine and personal care and support within the community.

Advances in medical care in recent decades (for example in pain control) are to be welcomed. However, a whole generation of people have grown up largely with the expectation that every aspect of dying will be taken care of by professionals and institutions. Many have never had to acquire the kind of emotional and practical skills for supporting the dying that previous generations took for granted.

There is little general understanding of bereavement issues, or about the wider issues surrounding loss. For example, feelings of loss are often a substantial element of experiences of declining health and function and anticipated bereavement can be as real and disturbing an experience as actual bereavement.

People increasingly live significant distances from their families. Different generations are less likely to live together, many people live alone, and the population is ageing. Increases in life expectancy have exceeded increases in healthy life

expectancy. Extended periods of decline and protracted dying are now more common. There are growing numbers of babies, children and young people living with life-limiting conditions. People increasingly die in advanced old age where their principal carer may also be frail and unwell. All of this can make it more difficult for families and communities to provide support as someone becomes frail or unwell. People are more likely to die in hospitals or care homes rather than in family homes as in the past. Scotland's ageing population means that institutions will find it harder to care effectively for the number of people approaching death.

Some people are at increased risk of being socially isolated, for example refugees, people with a disability, and people who are old. People living in care homes can face particular challenges of exclusion even if living geographically and physically within the heart of communities.

As a society we have lost many of the community-enhancing and therapeutic rituals formerly associated with death. Community-based and religious frameworks for dealing with death, dying and bereavement are largely absent for many people. Workplaces aren't always supportive of employees experiencing difficult times. It may also be the case that norms of behaviour are a barrier to care and support – if people are unused to seeing others provide informal support, this may discourage them from doing this themselves in case it is unwelcome or perceived as strange.

All of this can mean that communities often do not know how to provide support to their own members. This can mean that those who are living with worries of ill health and death may not get the help and support from friends, neighbours and family that they may need to cope better with their situation. It can mean that people do not receive the bereavement support they need to help them cope with their loss, leading to unresolved grief and associated problems.

In summary, we are now living in a society where there is a lack of informal support,

and increasing pressure on the limited professional services that are available. Many individuals and communities wish to foster kindness and compassion, yet are unsure of how to achieve this in the modern world.

How do Compassionate Communities come about?

When used in the field of public health palliative care, the term 'compassionate communities' carries inferences not just about the attributes of a community, but also about the methods used to create those communities. Key is recognising the importance of work being *led by communities themselves*, not imposed by well-meaning outsiders. Where input comes from outside a community in question, it should be by way of a 'community development' approach.

Community Development

Community development is a process where community members come together to take collective action and generate solutions to common problems. Community development seeks to empower individuals and groups of people with the skills they need to effect change within their communities.

Community Development approaches to end of life care (not to be confused with 'Community Engagement' or 'Community-based' models) are about establishing strong care and support networks that reinforce a sense of control over life-threatening/ limiting illnesses, and enhance the community's ability to deal with death, dying, loss and care. Community Development programmes enable communities themselves to create policies and practices for their own end of life care needs.

Encouraging the 'norms of kindness'

An Australian study[lii] exploring the end-of-life care arrangements that allow 20% of terminally ill people to be cared for at home caught some *'glimpses of compassionate communities'*, when local people not closely

connected to a dying person stepped up to offer help:

> *'These glimpses suggest that there is a huge potential for mobilising help from local people, and that everyday kindness is not uncommon. What is lacking is the knowledge and acceptance that it is the role of the local community to offer help. The norms of respecting privacy seem to be much stronger than the norms of kindness.*

> *The way forward may include the following:*

> - *Mediators and facilitators – people who are close enough to the carer and the dying person to understand their needs and preferences, but also able to interact widely in the community.*
> - *Social change – this is needed so that communities can accept that they do have an important role at end of life, a role that will ultimately strengthen both the community's capacity to care and the social capital[6] available to them to invest in other developments'*

<div align="right">

End of Life at home:
Co-creating an ecology of care[liii]

</div>

Compassionate Cities

In the field of public health palliative care, the term 'Compassionate Cities' is used to describe a specific public health approach to end of life care.

'Compassionate Cities' involve communities, local governments and health and social services in creating health promoting environments and supporting ethical choices for all citizens affected by end of life issues. Those involved in creating a Compassionate City would work on this with reference to the Compassionate City Charter, which sets out 13 social changes to the city's key institutions and activities. Achieving Compassionate City status requires the employment of various techniques, including community

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[6] Social Capital' is '*the network of social connections that exist between people, and their shared values and norms of behaviour, which enable and encourage mutually advantageous social cooperation.'* Collins English Dictionary online

development and engagement, health promotion and education, and changes to the social and policy environment.[liv]

Further food for thought

Tony Walter's book *What Death Means Now* includes some insightful discussion of the concept of *'compassionate communities'*. He highlights that most existing literature on support for family carers at end of life focuses on how professionals can support the carer, though most support for carers actually comes from their existing informal social networks. He suggests that the *'compassionate community model, by contrast, works with the grain of how humans normally support one another'*.

Walter points out that despite this, *"risk adverse 'service delivery' organisations and systems resist coordinating with grassroots action taken by people acting not as professional or volunteer but as friend or neighbour"*.

Walter highlights work by Abel et al (2011) which questions whether compassionate community initiatives should focus on building capacity at the community level or on helping families mobilise their existing social networks as they care for a family member at the end of life.

It is also important to consider how community projects can work for homeless people and those who move around a lot in the course of their lives.

What work might be learnt from or built on?

Various work is underway which is relevant to this area, a selection of which is collated in Appendix 4.

WHAT NEXT?

Involvement and leadership from communities themselves is essential in the creation of compassionate communities, and community engagement work needs to be done at a local level. However, the remit of this report is to identify national-level activities which can contribute to the desired change.

This section of the report suggests some national-level activities that could support (without directing or imposing) the creation of compassionate communities.

Develop a practical resource to support people wishing to take action to build Compassionate Communities

A resource could be developed which provides ideas for individuals and communities wishing to build compassionate communities. This could provide examples of activities others have tried, and ideally should cover a range of activities suitable for those working from different settings. Development of this resource would draw on previously published documents Public Health Approaches to End of Life Toolkit [lv] and Each Community is Prepared to Help[lvi] but focus on practical activities relevant to the Scottish context.

Compassionate Communities Conference

A conference could be organised on the subject of Compassionate Communities, providing an opportunity for those with an interest in this area to share work and learn from each other. There might be potential to work in partnership with others with an interest in community development, for example the Scottish Community Development Centre, to bring learning from the wider community development sector. This could link with the work of the Public Health Palliative Care International: UK Branch who are promoting such activities.

Create a 'Compassionate Scotland'

There is the potential to apply the Compassionate Cities model to a Scottish city, or indeed to Scotland as a whole, given leadership, enthusiasm and engagement from the right people. Such a project could act as an example and source of learning for others who wished to undertake a similar project locally.

Promote To Absent Friends as an opportunity for communities to come together in support of each other

As outlined in Section 12 the To Absent Friends festival provides a welcome opportunity for communities to come together. Indeed, a survey undertaken as part of an evaluation of the festival reported that 62% of respondents took part because they wanted to be part of a community event, and said they found being part of a community was one of the most valuable aspects of To Absent Friends. To Absent Friends provides a non-prescriptive but meaningful opportunity for communities to get together in the context of loss.

Support work by others interested in building stronger communities

A supportive community environment affects every aspect of a person's wellbeing - including their ability to deal with death, dying and bereavement. For example it is easy to see connections between compassionate communities and work looking at loneliness and isolation. Those within the Good Life, Good Death, Good Grief alliance could lend their voices, championing the importance of increased resources for community development work, and articulating from a health perspective the importance of this in improving people's experiences of deteriorating health, death, dying and bereavement.

Recognise and resource community development work

As further explained in Section 10, community development workers have a unique set of skills that enables them to work with communities to support people to undertake the change that they think needs to happen. A greater number of funded community development workers would be an asset to the creation of more compassionate communities.

Support existing Community Development workers

GLGDGG will proactively work with community development workers to explore ways of helping them to support their communities with death, dying and bereavement issues.

SECTION 7 Personal skills and knowledge relating to death, dying and bereavement

This section of the report explores some actions that might be taken to support people to improve their personal skills and knowledge relating to deteriorating health, death and dying.

'Health promotion supports personal and social development through providing information, education for health, and enhancing life skills. By so doing, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health.

Enabling people to learn, throughout life, to prepare themselves for all of its stages and to cope with chronic illness and injuries is essential.'

The Ottawa Charter for Health Promotion, World Health Organization

Introduction

Low levels of public knowledge and awareness of practical, legal, medical and emotional aspects of death, dying and bereavement limit capacity for self-management and provision of informal support.

Low levels of public knowledge can also make it harder for health and social care professionals to discuss relevant matters with individuals and families. This includes discussions of what matters to an individual, planning for deteriorating health and making decisions together about possible treatment and care options as a person becomes less well and is dying. Though it is important that health and social care staff have education to support them undertake these discussions, this is only part of the answer.

As a society, we need to be aware that death is usually not a medical failure. When a person has one or more illnesses that cannot be fully resolved, we need to focus on what matters most to them and addressing the problems caused by their worsening health. As a society and as individuals we also need to recognise that

there are benefits to exploring and planning in advance what we would want if and when our health declines.

Knowing more about what is happening and what to expect when someone is very ill and approaching death can empower family and friends to better advocate for their relative and provide better support themselves. Having a realistic idea of what can be done to help, the uncertainties involved, and what can be expected from health and social care services can help families to manage their situation as well as possible.

What might help?

Below are some examples of actions that might be taken to improve general public knowledge and understanding relating to death and dying.

Undertake a survey and voxpop of the end of life care wishes of doctors

Some popular articles, mainly based on American perspectives, have indicated that doctors generally choose fewer and less intrusive interventions at the end of life than the general public.[lviii] It has been suggested that this is because doctors have

a more realistic idea of the advantages and disadvantages of interventions towards the end of life, and take steps to communicate their preferences in advance. However, one American study comparing healthcare use in the last months of life between physicians and non-physicians found that the mean number of days spent in the ICU in the last six months and one month of life was slightly greater for physicians than non-physicians.[lix] No work has been done in Scotland looking at how the end of life care wishes of doctors compares with the wishes of others. There are ways of exploring this that could raise awareness of these issues amongst professionals as well as among the general public, and which also have the potential to be of media interest. For example, short, engaging, video clips of doctors discussing their end of life care preferences would model that it is socially acceptable to publicly discuss these issues, as well as providing education about the kinds of issues that everyone should consider.

Though undertaking this work would require some dedicated staff time, several organisations have the connections and expertise to undertake a survey, make, and promote short videos of this kind. With modern technology, video interviews are quick and cheap to make and share via social media. Partnerships with the GMC and BMA could be explored. Work of this kind fits in with wider Scottish Government work, with the potential to be a powerful communication tool in support of *Realising Realistic Medicine* and ACP work streams.

Develop and distribute a leaflet providing information about the bodily changes that can take place when someone is dying

Dying is unpredictable. It is not always possible to know for sure that a person is in the last days of life, predict exactly when a person will die, or know exactly what changes someone will experience when they are dying.

However, there are certain bodily changes that show a person is likely to be close to death. Some of these changes may be distressing, but it can be reassuring for

family and close friends to know what to expect and how to help. Scottish Care research has shown that whilst many carers have knowledge of death and dying, the actual changes which take place in the body towards the end of life can often pose a challenge to the less experienced carer.[lx]

It would be relatively straightforward to develop leaflets appropriate for all ages and cultures, explaining '*What to expect when someone you care about is becoming more unwell and dying*' for distribution to health centres and other public places around Scotland. The content of the leaflets could be based on information already available on the Good Life, Good Death, Good Grief website[lxi], which has been adapted from information developed jointly by The National Council for Palliative Care, Hospice UK and Sue Ryder.[lxii]

This work would fit in well with both the remit of NHS Health Scotland and Good Life, Good Death, Good Grief. Distribution mechanisms already in place within NHS Scotland could be further explored.

Improve media understanding of death, dying and bereavement

Recent years have seen a significant amount of negative media coverage relating to the Liverpool Care Pathway, completion of DNACPR forms and GP Palliative Care Registers. The impact of this should not be underestimated - lack of trust among the public, and professionals' fears about media interpretation and reporting can make it harder to improve care.

It is important that the information presented in the media relating to palliative care, death and dying is accurate: the media plays an important role both in holding authorities to account, and providing information to the general public. Inaccurate information can not only lead to unnecessary fears, but can divert attention away from issues that do need to be addressed.

Journalists are busy and may not have much time to research stories in depth. Health and social care services and professionals are also busy, and it is often not within their role to engage with the media. Many professionals are wary

of speaking to journalists. While many charities have dedicated media teams, the NHS, social care, care homes and care at home sectors are less well equipped to engage with the media.

Without context, innovations such as DNACPR documentation or GP Palliative Care Registers can seem inappropriate or negative, yet these can quickly be put in context by understanding a little about the complexities and uncertainties related to caring for someone at the end of life. There is also a tendency to focus on the relatively rare incidences of poor care, which paints a skewed and worrying picture of service provision, and undermines the hard work of so many of those working in care.

It is therefore important to media professionals to have a stronger baseline understanding of the landscape relating to palliative care, death and dying.

An event could be organised at which media and health and social care professionals come together to explore the key issues relating to care towards the end of life, ask questions, raise concerns and find answers. Such an event would need to be designed in a way that encourages busy media professionals to attend, engenders a friendly and collegiate atmosphere, and enables media and healthcare professionals to share knowledge.

Develop a Charter for a Good End of Life

Ill health and end of life experiences can be extremely distressing for all those concerned, emotions can run high, individuals can be very unwell, professionals can be overstretched, family members can be stressed.

People generally value a sense of being in control, yet ill-health often throws people into situations no-one would choose. The options available to an individual may be limited for various reasons.

Hearing that someone will not get better, or that the ideal support services are not available, or that the end of life is close, will likely always be difficult. Yet, without honest information, individuals and families are ill-equipped to make decisions.

Lack of understanding can be a barrier to people receiving palliative care.[lxiii] Rights-based approaches can be helpful in raising public awareness and understanding of what people can expect to receive. For example there is a *Charter of Rights for People with Dementia and their Carers in Scotland*, the *Children and Young People (Scotland) Act 2014* is influencing the design and delivery of relevant policies and services, and the revised National Care Standards take a rights-based approach. The British Institute for Human Rights and Sue Ryder have produced accessible information about how human rights relate to end of life care.[lxiv]

In an environment of finite resources there are always practicalities to be considered with regard to ensuring that rights can be achieved. At the same time as empowering individuals and families, it is important to be honest with families about what can be achieved, and not to strain health and social care professionals with responsibilities it is impossible for them to fulfil.

Rather, as a society we need to work together to support health and social care professionals to create an environment of openness and honesty regarding what people can hope for and expect towards the end of life.

A similar, but alternative approach to developing a rights-based charter could be the co-production of a *Charter for a Good End of Life.* This would involve a programme of work to engage with the general public, media, and health and social care professionals to produce honest and accessible information about the support people can expect to receive as they approach the end of life. Learning might be sought from work done a few years ago in the North East of England, where a Charter for a Good Death was developed,[lxv] and from the Irish Hospice Foundation, who have developed the *People's Charter on Dying, Death and Bereavement in Ireland*.[lxvi] The principles set out within the Health and Social Care Standards[lxvii] also provide insights into what people see as important relating to their health and care

experiences.

Undertaking this work in a sensitive and genuinely collaborative way would require a couple of years of dedicated staff time. However, done right, it has the potential to:

- empower the general public with information about what is likely to happen when someone is nearing the end of life, the uncertainties that might be involved, and ideas of some ways of responding;
- empower health and social care professionals to be honest about their expectations for a person's health, what uncertainties are involved, what support will be reliably available, and any limits there might be to the support provided.

Make Last Aid Courses Available

Last Aid Courses have been introduced in Norway, Germany and Denmark in order to teach the public about Palliative Care and to enhance public discussion about death, dying and end-of-life care. An international working group from Norway, Denmark and Germany designed a short basic last aid course with 4 modules each lasting 45 minutes. The four modules are about 1. Care at the end of life; 2. Advance care planning and decision making; 3. Symptom management and 4. Cultural aspects of death and bereavement.

The course is usually given on one afternoon or evening with 2 parts of 1.5 hours and a 30 minute break. Pilot courses were run in all three countries from December 2014 with over 300 participants to date. Questionnaire-based evaluation of the first courses found that most participants appreciate the course and talking about death and dying in a comfortable atmosphere.

Most of the participants stated that they would recommend the course to others. Evaluation of this work is ongoing.[lxvii lxix]

WHAT NEXT?

The ideas outlined above have the potential to improve knowledge and skills relating to death, dying and bereavement, and it would be worth exploring whether resources could be found to put some of them into action.

More specifically, in 2018 SPPC will be part of an International Working Group to develop an English language version of the Last Aid course, and will be working with Highland Hospice to pilot this in Scotland.

SECTION 8 Making practical plans for deteriorating health and death

This section of the report looks at how people might be supported and encouraged to make practical plans for deteriorating health and death, with a particular focus on Power of Attorney.

Background

Planning ahead can make the financial, medical, legal and practical consequences of illness and death for individuals and their families much easier to deal with. There are certain practical steps that everyone should take. For example, all adults, no matter their age or health, should consider:

- Granting a Power of Attorney/ Welfare Attorney.
- Making a Will.
- Completing an Advance Directive (sometimes called a 'living will').
- Funeral Plans.
- Taking out Life Assurance.

People who make arrangements to address these issues generally feel a real sense of satisfaction knowing they have done everything they can to assist their loved ones should illness or death strike. Families, too, come through the adverse events much better when the party involved has taken the basic preparatory steps suggested above. A recent addition to the list of potential forward plans is Digital Legacy planning - thinking about what will happen to a person's digital accounts and assets after death.

In addition, people who have reason to think their health might get worse can benefit from Anticipatory Care Planning, which involves talking about what they want or do not want to happen in the future regarding any care they might need. This involves an individual talking to family, friends, any health or social care professionals they see regularly (eg doctor or nurse), and possibly a lawyer, and recording (and regularly reviewing) their wishes relating to:

- Concerns.
- Values that are important/personal goals for care.
- Understanding of their illness and the expectations they have for how it might progress over time.
- Any preferences they have for the type of care or treatment that might be beneficial in the future, and whether these preferences are likely to be available.
- Thinking about organ donation.
- Learning about Do Not Attempt Cardio-Pulmonary Resuscitation documentation, and thinking about whether this is something they might wish to make use of under some future circumstances.
- Thinking about whether they have views about medical treatments that they might not want to have under certain circumstances, and setting these views down within an Advance Directive.

In promoting the importance of planning ahead for old age and deteriorating health it is important not to raise unrealistic expectations of choice and control, particularly around end of life care. Declining health and dying are inherently unpredictable and can be difficult regardless of the best plans. The value of planning is partly about increasing knowledge, developing realistic expectations and so being better prepared to adapt and respond to circumstances as they evolve.

Relevant work

Various work relevant to this area has been undertaken or is underway – See Appendix

5 for details.

Scope

A subgroup was convened to explore how people might be encouraged to make practical plans for deteriorating health and death using the legal mechanisms that are available – Power of Attorney (PoA), Advance Directives and Wills.[7]

The group chose to focus specifically on Power of Attorney because:

- The consequences of having no PoA are usually more serious than the effects of not having a Will or Advance Directive, emotionally and financially.
- The process of sorting out PoA itself encourages openness that can lead to discussions about Wills and Advance Directives.

Power of Attorney

'Having a PoA lets you plan what you want another person to do for you in the future, should you become incapable of making decisions about your own affairs. PoA is a written document which includes a certificate signed either by a solicitor who is registered to practise law in Scotland or by a registered UK medical doctor who holds a licence to practise.'

Office of the Public Guardian[lxx]

Why is it important to have a Power of Attorney?

Where people have lost capacity to make decisions, having a Power of Attorney means there is no need for their family to go through the process of applying for a Guardianship Order to make care and financial decisions. Where there is no PoA, someone who lacks capacity and can't be discharged back to their home is likely to have to stay in hospital during the long process of applying for Guardianship order. Without a PoA people can be stuck in hospital for months, there can be no access

to bank accounts and no-one to make care decisions.

Having a PoA therefore:

- Saves the individual and the family the emotional distress of being unable to quickly make decisions and assume responsibilities that are in the best interest of the individual.
- Saves the family and 'the system' the considerable costs of applying for a Guardianship order.

For example, data put together by the My Power of Attorney campaign estimated that in 2012, this issue affected 157 people within NHS Greater Glasgow and Clyde, and resulted in 25,000 'lost' bed days which cost approximately £5.5 million. Additional hidden costs included the costs of families' legal fees, and administrative costs of dealing with legal guardianship applications.

Sources of information

Delayed discharge data

ISD publishes a monthly Delayed Discharge Census including Code 9 secondary reason code 51X which was introduced to identify and monitor the number of patients delayed due to the requirements of the Adults with Incapacity Act. Census figures show that between July 2016 and March 2017 an average of 205 people were experiencing a delayed discharge for this reason each day. Code 51X data is a reasonably good proxy indicator for the numbers of people delayed in hospital because they have lost capacity to make decisions, but do not have a Power of Attorney.

My Power of Attorney Campaign

The work undertaken as part of the My Power of Attorney Campaign provides a wealth of resources and learning, and evaluation by its organisers suggests that it:

- Reduced costs to the NHS.
- Reduced costs to some individuals.
- Reduced admin for the NHS and individuals concerned.
- Increased wellbeing for individuals (peace of mind for families, less time spent away from home).

Potential barriers to making a Power of Attorney

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[7] Funeral planning was not explored since the Scottish Working Group on Funeral Poverty and the Scottish Government have recently developed and are distributing further information on this. Anticipatory Care Planning was not included within the scope of this work because when the work began, the iHub of HIS were undertaking work in this area, with plans to undertake some public engagement work as part of this.

Numbers of people with Power of Attorney

The Office of the Public Guardian publishes statistics on number of power of attorney applications in Scotland each year.

	Financial	Welfare	Both	Total
2008/09	3,059	1,351	26,327	30,737
2009/10	2,706	1,318	34,683	38,707
2010/11	1,879	997	35,809	38,685
2011/12	1,622	960	37,933	40,515
2012/13	1,460	998	40,070	42,528
2013/14	1,349	888	43,339	45,576
2014/15	1,123	736	53,668	55,527
2015/16	785	631	53,591	55,007
2016/17	843	715	53,369	54,927

There are many reasons why people might not make a Power of Attorney:

- Lack of awareness/ understanding in the general public about what can happen without one – people think that their 'next of kin' can automatically assume the relevant responsibilities.
- Myths that a PoA comes into effect immediately, and that your nominated PoA can steal your money.
- The cost of making a PoA. Though many people would qualify for financial support from the Scottish Legal Aid Board to make a PoA, many solicitors do not offer this as it is not financially attractive for them.
- Lack of a sense of urgency - this is not a financial or time priority for younger people.
- Lack of knowledge about the importance of PoA among health and social care professionals.

WHAT NEXT?
Power of Attorney

Some potential areas around which future work in this area might be focused are:

- Increasing people's understanding of the problems that can arise without a Power of Attorney.
- Making applying for legal aid for a PoA under the Legal Advice and Assistance scheme an attractive option for solicitors.
- Ensuring people diagnosed with dementia are supported to make a PoA before they lose capacity.
- Ensuring people over 65 are aware of the benefits of making a PoA.

Potential actions might include:

- Organising a conference to build consensus around future action needed to encourage people to make PoA.
- Increasing awareness of the importance of PoA among health and social care professionals who can in turn suggest to individuals and families that it would be wise to make a PoA. This could be linked in to work to promote ACP since the two areas are closely related.
- Scaling up of the My Power of Attorney campaign to cover more areas of Scotland (see Section 9).

Anticipatory Care Planning

Anticipatory Care Planning is key to making practical plans for deteriorating health and death. It was not included as a

major focus for this report because when the work began, the iHub of HIS were undertaking a specific programme of work in this area – dedicated nursing and medical clinical leads were in place, resources had been developed, and there were plans to undertake some public engagement work to promote the importance of Anticipatory Care Planning. It is critically important that consideration is given to identifying ways to maintain the impact of work to date and to build on it.

SECTION 9 Mass media campaigns

This section explores some of the issues that should be considered prior to the production of a mass media campaign aimed at encouraging open & supportive attitudes and behaviours relating to death, dying and bereavement in Scotland.

(The work did not seek to design a mass media campaign, but to set out some preparatory thinking on some relevant issues.)

Potential contribution

There are several ways in which media campaigns might contribute to the realisation of the vision outlined in the Introduction to this report.

Vision	What can media campaigns contribute to these outcomes?
People are well-informed about the practical, legal, medical, financial and emotional issues associated with death, dying and bereavement.	Media campaigns can: • directly provide information • signpost to key information sources • explain to people why it is a good idea to become informed • help to create a culture where being informed about these matters is seen as important.
There are adequate opportunities for discussion of these issues, and it is normal to plan for the future.	Media campaigns can: • help to remove barriers to discussion of these issues, where the barriers are attitudinal or cultural. • bring issues to people's attention and create a talking point.
Public policies acknowledge and incorporate death and dying	Media campaigns are not usually designed to directly influence public policies. However, indirectly they may help by raising the profile and/or understanding of an issue among public policy makers.
Health and social care services support planning ahead and enable choice and control in care towards the end of life.	Media campaigns generally do not directly target health and social care services. However, indirectly, they may help by raising the profile and/ or understanding and/ or influencing culture among those working in health and social care. Also a motivated and well informed public makes it easier for health and care professionals to engage in care and support planning conversations.
Communities and individuals are better equipped to help each other through the hard times which can come with death, dying and bereavement.	Media campaigns can help individuals to become more informed and encourage opportunities for discussion, meaning that communities and individuals are better equipped. If someone has thought about these issues themselves, or taken action themselves (eg made a Power of Attorney) then they are better equipped to support a friend or neighbour to do so.

This table only considers the contribution of media campaigns - as outlined in elsewhere in the report, many other forms of activity also contribute to realising this vision.

Potential for media campaigns to influence attitudes and behaviour

Evidence from various studies, including those conducted by the World Health Organization and other public health authorities suggests that, if the campaign is right and other related factors are taken into account, media campaigns can change attitudes and behaviour. Research by Wakefield et al. in The Lancet found that mass media health promotion strategies were effective at changing health behaviour directly (at an individual level) and indirectly (by changing social norms).[lxxiii]

Campaigns are more effective when linked to broader activity.[lxxiv] For example, smoking prevalence has been reduced when mass media campaigns have been combined with, for example, tobacco taxation measures. In cancer screening, mass media campaigns backed with reminder letters for organised screening services led to an increase in uptake, whereas those without such services did not.[lxxv]

Potential resource implications

Resources required to set up and run a media campaign include staff to scope, manage and evaluate the campaign, and finance to pay the costs of design, production, campaign delivery and impact evaluation.

Resource is also needed to deliver whatever it is the campaign is targeting. That is, if the campaign is encouraging people to take an action, resource needs to be in place for them to be able to fulfil that action. For example, if the campaign is encouraging people to buy apples, there needs to be plentiful stocks of apples available.

The costs of a campaign can be weighed against the savings that may potentially be realised. Factors that therefore need to be considered when setting the resources for a campaign are:

- Direct cost savings.
- Indirect cost savings.
- Wellbeing benefits that cannot be costed.
- Knock on effects (e.g. greater awareness of death may produce other positive behaviours such as cutting out smoking).

It is more cost-effective to message on multiple health issues, than just one 'vertical' issue, eg instead of running a media campaign that aims to reduce malaria, it is more cost effective to include messages that will reduce diarrhoea and pneumonia as well.[lxxvi]

Potential benefits

The benefits of a media campaign relating to death, dying and bereavement issues, for example, Power of Attorney, lie in changing people's behaviour. Behavioural changes can be beneficial to:

- Individuals.
- Public sector.
- Private sector.
- Society.

The benefits can come in the form of:

- Reduced costs to individuals and the 'system'.
- Reduced administration.
- Increased wellbeing.
- Increased income.

It is possible to imagine other campaigns having similar multiple benefits. For example, a campaign on green funerals might increase societal wellbeing (in terms of environmental effects), have system/public sector benefits as cemeteries fill up, and increase income for sections of the private sector (more money spent on those kinds of funerals).

Potential weaknesses/ challenges

The strength of media campaigns is in their ability to disseminate well defined messages to large audiences:

- Repeatedly.
- Over time.
- In an incidental manner.
- At a low cost per head.

The benefits are not always realised however and there are a number of risks:

- Campaign messages can fall short/ backfire.
- Exposure of audiences may not meet expectations, due to inadequate funding.
- Increasingly fractured/ cluttered media environment.
- Inappropriate or poorly researched format (eg material unsuitable for children).
- Homogenous messages might not persuade heterogeneous audiences.
- Audiences lack the resources to change the behaviours being targeted.
- The system may be unprepared to respond to/ cope with new behaviours.

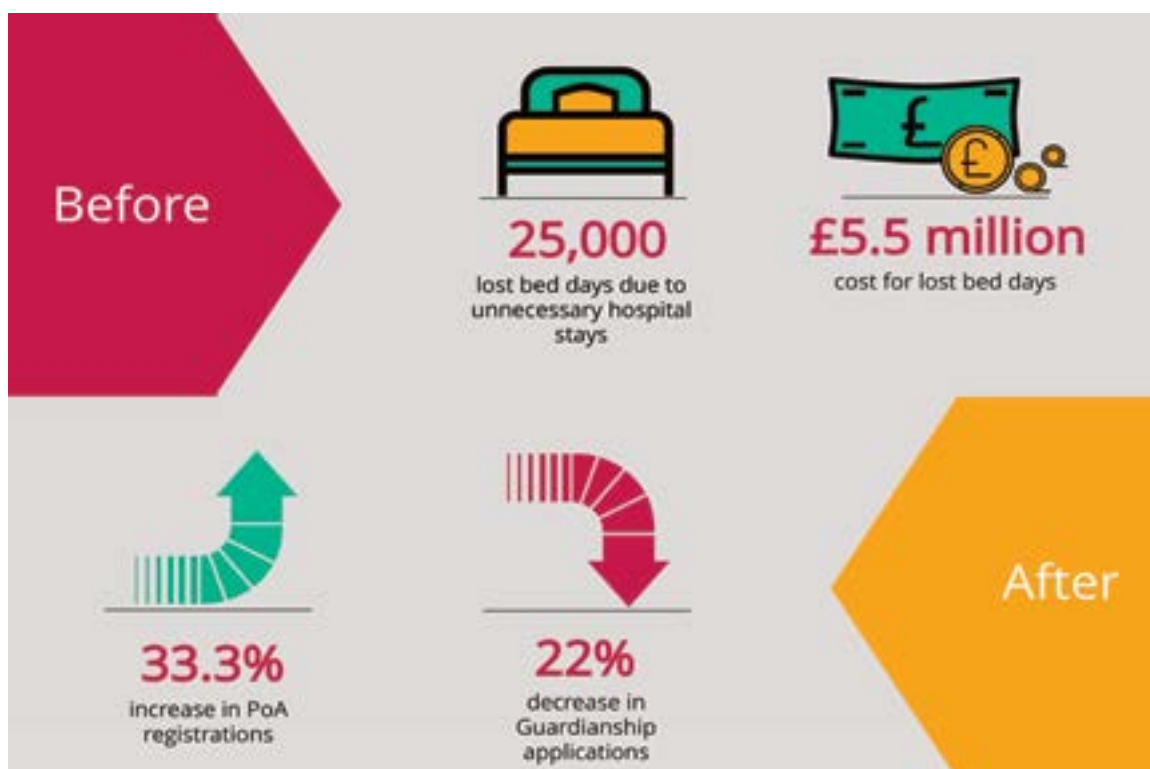## Evaluation of the effectiveness of a media campaign

Randomised controlled trials are the 'gold standard' way to measure behavioural change, but are usually unfeasible for mass media campaigns.

Instead, there are a number of alternative techniques that can be used:

- Compare baseline and end line cross-sectional surveys.
- Compare changes among groups who received different levels of exposure (dose-response analysis).
- Compare survey data with external sources, such as health system usage figures.
- Compare changes in behaviours in intervention areas with behaviour changes in non-randomised control zones.
- Time-series analysis on behavioural surveys over time.[lxxvii]

A MASS MEDIA CAMPAIGN CASE STUDY: MY POWER OF ATTORNEY

Before

25,000
lost bed days due to unnecessary hospital stays

£5.5 million
cost for lost bed days

33.3%
increase in PoA registrations

22%
decrease in Guardianship applications

After

Stakeholders

Funded by Glasgow City Council, the My Power of Attorney Campaign came about as a result of initial engagement between Glasgow Social Work Services, NHS Greater Glasgow and Clyde, members of the third and independent sectors and local law firms.

This campaign now also includes NHS Lanarkshire, NHS Tayside and partner councils and Health and Social Care Partnerships.

What was the problem the My Power of Attorney campaign aimed to address?

It was recognised that a significant number of inappropriate and unnecessarily long hospital stays in Glasgow were the result of individuals having to stay in hospital while their families applied for Legal Guardianship. Not only was this distressing for the individuals and families involved, but it was having a huge financial cost to the sector. It was estimated that in 2012, this issue affected 157 people and resulted in 25,000 'lost' bed days which cost approximately £5.5 million. Additional hidden costs included the costs of families' legal fees, and administrative costs of dealing with legal guardianship applications.

How did the campaign aim to address this?

The campaign aimed to raise awareness and promote understanding of the benefits of Power of Attorney (PoA) arrangements. A campaign was developed which was designed to get members of the public to 'Start the Conversation' with loved ones to ensure their wishes can be respected if they should find themselves in a situation where they no longer have the capacity to make welfare or financial decisions for themselves. The campaign aimed to encourage people to think seriously about whether they need, or need to give someone, the legal powers that PoA provides.

Challenges

There were a number of challenges to the designing of a successful campaign, including:

- The fact that making a PoA costs money.
- Selling a message linked to negative life events (loss of capacity, end of life etc.)
- People are generally not aware that this is an issue until they find themselves directly affected by it.

Approach

After some exploratory work to get a feel for current attitudes relating to this area, an action plan was developed. The 'My Power of Attorney' campaign used a phased intermittent approach utilising several media platforms including bill posters in bus stops and underground train stations, and adverts on YouTube, television, radio and social media sites. An informative website was created, and an information pack was developed to give advice on arranging suitable legal expertise and make the process of finding out about and arranging Power of Attorney as straightforward as possible. The campaign began in 2014, and at the time of writing (March 2018) is currently ongoing.

Evaluation of impact

An evaluation of the impact of the campaign was undertaken by NHS Greater Glasgow & Clyde, and the following findings have been published:

PoA and Legal Guardianship

- POA registrations increased by 33.3% in Glasgow City 2013-2014, while the rest of Scotland increased by 17.3%.
- Between 2014 and 2016 there was a **22% decrease** in the number of Guardianship applications in Glasgow City.
- The full campaign was associated with an additional 31% registrations among those aged 65+ years. This is equivalent to 276 registrations of the 1165 registrations in Glasgow City in the first quarter of 2015.[lxxviii]

Cost-effectiveness

The campaign cost £60,385 per phase. It has been estimated that 1486 of the 11 366 PoA registrations across Scotland during the first quarter of 2015 were due to the media campaign. The cost of the campaign would be covered by just **two** of these individuals subsequently avoiding

being delayed in hospital due to having a PoA in place. It is estimated that the media campaign would have saved around £191,743 in hospital costs.

Analysis suggests that the campaign can therefore be considered cost-effective, with a benefit-cost ratio of 3.17, saving a net £131,358 per campaign phase. This is in addition to known spill-over effects such as other family members subsequently registering a PoA, and non-monetary benefits including the avoided emotional cost to family members of the guardianship process.[lxxix]

What learning can be drawn from the My Power of Attorney Campaign?

The work undertaken as part of the My Power of Attorney Campaign should inform any future work in this area. Some key points highlighted by the organisers of this campaign are:

- Campaigns should have a clear call to action and the efficacy of the campaign should be clearly identified and measured.
- A campaign cannot be accurately measured through qualitative research and testimony alone. Proper evaluation will help to justify the investment in a sustained campaign.
- A campaign of this nature must be sustained for a minimum of 3 years. It is not possible to sufficiently affect public behaviour, knowledge and understanding with a 3-week TV campaign.
- The messaging should be delivered across a multitude of media platforms.
- A brand should be created for the campaign so that the public can identify and relate to the subject.

Inequalities

The campaign could not overcome all the barriers that people face to making a PoA. For example, the most visited page of the PoA website was *'How much does it cost?'* People with low incomes are the ones *most likely* to require a PoA, but though applying

for legal aid is straightforward with a short assessment procedure, many legal firms don't offer to assess people's eligibility for legal aid.

Interdependence

A media campaign cannot stand completely on its own. For example, initially there was a backlog of PoA submissions when the My Power of Attorney campaign started, resulting in delays in processing. It is important to avoid situations like this.

WHAT NEXT?

If there was local or national interest in Scotland in putting financial resources into a media awareness campaign to promote more open and supportive attitudes and behaviours relating to death, dying and bereavement, there are a number of subject areas that could be explored, for example:

- Living with serious/ life-limiting illness - what is palliative care?
- Anticipatory Care Planning (ACP).
- Power of Attorney (PoA).
- Changing perceptions and increasing understanding of care home care.
- Funeral Planning.
- Being supportive around someone you know who had been bereaved.

There will inevitably be different views on which area would be most worthwhile. Any future work in this area should consider:

- The problem or issue that is being addressed.
- The potential of a media campaign as the best or most appropriate way to address that issue, or whether a similar amount of money spent in a different way might have more impact.
- What stakeholders should be involved to ensure work is informed by adequate understanding of the issues involved.
- The potential challenges of a media campaign in that area.
- The potential benefits of a media campaign in that area, including the potential for financial benefits, and of

improvements to wellbeing.

- What other complementary initiatives might be required to enable the campaign's success.
- What resources would be required to genuinely make a sustained impact, and whether sufficient resources are available.
- How the impact of the campaign can be evaluated.
- Health inequalities issues - will the campaign be of most benefit to those who are most disadvantaged?

Economies of scale and building on current work

The work undertaken as part of the My Power of Attorney Campaign provides a wealth of resources and learning,[lxxx] and evaluation by its organisers suggests that it:

- Reduced costs to the NHS.
- Reduced costs to some individuals.
- Reduced administration for the NHS and individuals concerned.
- Increased wellbeing for individuals (peace of mind for families, less time spent away from home).

There may be benefits to further extending this campaign to other geographical areas:

- Economies of scale - appropriate resources already exist that could be rolled out without necessitating further design costs.
- Tried and tested - clear information is available relating to the potential costs/ benefits of this campaign.
- There may be the potential to build on this successful work to include links to other areas, such as ACP.

SECTION 10 Public health palliative care in socio-economically disadvantaged communities

"Many interventions are rightly aimed at improving whole population health but can inadvertently widen health inequalities amongst marginalised groups, as this segment of the population experience different barriers to engagement with services….
…For example, low literacy, fear, poverty, social isolation, language and communication differences have all been identified in research as presenting barriers to taking up and benefiting from service provision."

NHS Health Scotland[lxxxi]

In recent years, public health approaches to palliative care (PHPC) have gained some traction in Scotland. There has been recognition of these issues at a policy level, and some efforts have been made nationally and locally to address palliative care from a public health perspective. Resources, events and networks have been developed which promote more open and supportive attitudes and behaviours relating to death, dying and bereavement among wider Scottish society.

But how relevant is this work to the experiences of disadvantaged individuals and communities in relation to death, dying and bereavement? Are the needs of socio-economically disadvantaged communities comparable to the needs imagined by the professional individuals who've played a key role in devising and implementing PHPC policy and resources? Is there more that could be done to address the needs of these communities?

This section of the report explores how PHPC approaches interact with health inequalities arising from socio-economic disadvantage, with a particular focus on the ability of Community Development approaches to support change within communities.

Risks of misunderstanding

Most people with influence in professional and policy-making spheres cannot expect to intuitively understand the needs and priorities of communities whose experiences are so completely different to their own.[lxxxii] A lack of understanding and awareness of the day-to-day realities of poverty has the potential to lead to:

- People's needs being overlooked, forgotten, misunderstood or, some feel, deliberately ignored.
- Mistaken assumptions about how to 'help' socio-economically disadvantaged communities with issues relating to death, dying and bereavement.

Recognition of this is integral to PHPC approaches, and one of the key principles on which Good Life, Good Death, Good Grief was built:[lxxxiii]

'There is a risk that imposing public health initiatives on a community may be counter-productive, since without community involvement in the development of initiatives, they are likely to lack local support, be misguided and therefore be unsustainable.'

However, this does not mean that these communities should be left alone and

excluded. Without focused efforts to understand and support these communities, public health palliative care initiatives are likely to provide support to those who are easiest to reach, therefore actually increasing health inequalities.

Experiences of palliative care, death, dying and bereavement in socio-economically disadvantaged communities

Narratives relating to health inequalities often refer to death, but always in the context of death as a negative outcome, referring for example to 'premature mortality', 'CHD deaths' and 'all cause mortality'. Rarely, if ever, do discussions of health inequalities look beyond the quantitative, and recognise that there is a qualitative aspect to people's experiences of death, dying and bereavement in socio-economically disadvantaged communities.

People living in socially deprived areas are much less likely to access health and social care services, and people in Scotland's poorest communities die considerably younger than those from more affluent communities. People from these areas are more likely to die in hospital, more likely to need palliative care, and more likely to have numerous hospital admissions.[lxxxiv] More than 25 per cent of children with life limiting conditions live in the most deprived areas of Scotland.[lxxxv] Recent research for Cruse Bereavement Care Scotland found that people living in low income households are more likely to experience complicated grief than those with higher incomes.[lxxxvi]

Some work has been done looking more generally at people's experiences of poverty and social exclusion. For example, *Poverty and social exclusion in urban and rural areas of Scotland* [lxxxvii] highlights that people in poverty, no matter whether they live in urban or rural locations, report feeling lower levels of support and feel less able to turn to family or friends for help with practical or personal problems. They take part in fewer social activities and have less frequent contact with friends than more affluent

people. The report also suggests that some differences exist in people's experiences of poverty depending on whether they live in a rural or urban area, for example there is a suggestion that poverty in rural areas may be more isolating in its impact, and that people in rural areas are less able to access services for older people.

A London School of Economics (LSE) report[lxxxviii] commissioned by Marie Curie found that those in more deprived areas are less likely than those in the least deprived areas to feel they have sufficient support to care for someone dying at home; they are less satisfied with the care they receive, and more frequently die in hospital than either home or a care home.

There is relatively little literature about the particular needs of socio-economically disadvantaged communities in Scotland relating to palliative care, death, dying and bereavement. The LSE report indicated that:

- More research is needed to understand access and barriers to palliative care in socially deprived areas.
- More work is needed to understand the experiences that have affected people from socially deprived communities in order to build effective service responses and resources to maximise quality of life and death.

The limited information that is available tends to relate to accessing and improving services. Little (if any) formal literature is available regarding the unique needs, priorities, strengths and weaknesses of these communities regarding education, knowledge, attitudes, behaviours and community support mechanisms relating to death, dying and bereavement.

This is the kind of information that is required to inform PHPC approaches in socio-economically disadvantaged communities, and currently it is unavailable.

Characterising the needs, priorities, strengths and weaknesses of socio-economically disadvantaged

communities

In the absence of a body of literature to inform this work, a subgroup was brought together to share their experiences of working with socio-economically disadvantaged communities, and discuss PHPC from this perspective. Resources were not available to undertake qualitative research or focus groups with communities themselves. However, the members of the subgroup brought years of experience from various perspectives, including general practice, district nursing, social work, prisons and community development.

Communities and individuals are all different, and therefore it is impossible to accurately characterise the needs, priorities, strengths and weaknesses of all communities. However, the subgroup attempted to summarise some key characteristics of the communities they work in. The characterisation provided below is largely based on impressions from those working in areas of urban deprivation in Glasgow and Edinburgh. It doesn't focus on more specific experiences such as homelessness, and the group was also aware that it had limited experience relating to rural poverty.

Within many socio-economically disadvantaged communities:

- Day-to-day financial worries take up a lot of people's energy. Often someone's main worry is just making it through the next week, meaning they have little energy for more long-term concerns. Funeral poverty is a big issue, as is claiming benefits for people who are ill.
- People die younger of conditions that more affluent people get when they are older. Cancer rates are higher, and different types of cancer are prevalent compared to more affluent communities. Non-cancer deaths are higher, particularly in those aged under 65 groups. There are four times more respiratory deaths and twice as many deaths from heart disease.[lxxxix] There are more traumatic deaths than in more affluent communities.
- There can be a mistrust of formal services and professionals.
- People tend to have lower expectations from services than in more affluent communities, and this is likely to be because they have had poor experiences of health and social care services in the past.

Members of the subgroup were unanimous in their view that people are treated differently by professionals depending on who they are - if someone is perceived as 'difficult' they are less likely to get support. For example, people with addiction issues can be seen as 'medication seeking' and not subject to the same prescribing regimes as others because of assumed risk of overdose or other issues, meaning that some people are left needlessly suffering.

Negative though it may seem, the subgroup was clear – there is a need for wider recognition of the fact that while 'good life, good death, good grief' is the aspiration, some people experience 'bad life, bad death, bad grief'.

However, many people within these communities display incredible resilience in the face of adverse circumstances. People seek support in each other, partly because they can experience barriers to accessing formal services, such as long waiting lists.

What might be done at a national level to encourage positive change?

To achieve long-term wide-ranging improvements in the health inequalities experienced by people living in socio-economically disadvantaged communities, society needs to address the wider determinants of poverty. These are many and complex. There is also a need to address barriers to formal services, including targeting additional resources into deprived areas.

This report has the more limited remit of exploring how national level PHPC work might support socio-economically disadvantaged communities. Yet, these communities are dealing with so many issues, we cannot assume that the typical

interests of public health palliative care will be high up their list of priorities. If someone is working flat out to feed and clothe their children, or struggling with mental illness, can we really expect them to have the mental energy or financial resources to think about making a Power of Attorney?

However, a supportive community environment affects every aspect of a person's wellbeing – including their ability to deal with death, dying and bereavement. The subgroup was clear that community development approaches can help create more supportive community environments within socio-economically disadvantaged communities. For that reason, this section focuses on the ability of Community Development approaches to support change within communities.

Advocating for a community development approach

> *'Social capital and social networks are not a limited resource that, when called upon, necessarily get depleted. Rather, the opposite: using them can extend and strengthen them (Horsfall et al, 2011).'*
> *What Death Means Now, Tony Walter*

Key to a community development approach is finding out about a community's needs and building on their assets:

'Working directly with individuals and groups at neighbourhood level, community development can support the design, implementation and sustainability of locally led solutions, and ensure that public services are targeted appropriately and designed and delivered in a way that effectively meets local need.' [xc]

As outlined in Section 6, community development is a process where community members come together to take collective action and generate solutions to common problems.

Community Development Workers facilitate this process, and have a key set of skills that is very different from that of other professionals. A Community Development Worker's job is likely to include:

- Finding out about the community's needs, problems and barriers and building on a community's existing assets.
- Making sure that local people have their say.
- Developing new opportunities and monitoring existing projects.
- Helping to raise public awareness about community issues.
- Encouraging local people to take action.
- Building links with other groups and agencies.
- Raising funds.
- Recruiting and training staff and volunteers.
- Planning meetings and events.
- Managing budgets.
- Mediating between groups who disagree on local issues.

WHAT NEXT?

Community Development work is key to supporting the creation of supportive communities. Community development needs to be done at a local level, but there are actions that can be taken at a national level that can support local level work.

Champion the importance of Community Development

There is not a great deal of financial resource for the creation and support of these kinds of initiatives. Those within the PHPC community could lend their voices, championing the importance of increased resources for community development work, and articulating from a health perspective the importance of this in improving people's experiences of deteriorating health, death, dying and bereavement.

Support existing Community Development workers

It is essential to embrace and support people within socio-economically disadvantaged communities to undertake the change that they think needs to happen. Community development workers have training, skills and experience that equips them to do this.

It may be that many communities are not interested in undertaking local work on death, dying and bereavement. However, for those that are, appropriate resources should be available to support them to do this.

GLGDGG will proactively work with community development workers in socio-economically disadvantaged communities to promote existing resources and opportunities, and explore what further resources might be helpful in assisting community development workers to support their communities with death, dying and bereavement issues.

Continue to scale up the To Absent Friends Festival

As described in Section 12 the To Absent Friends festival has proved successful in engaging with people from all walks of life. Providing funding for local groups but not trying to control events fits in well with a community development ethos, and provides a hook for community development workers to involve the communities they work with.

In recent years, specific efforts have been made to engage with people from disadvantaged groups. For example, this year this included work with the Broomhouse Centre, GRASP, community groups in the Colston-Milton area of Glasgow, the Cyrenians, Link Up and HMP Kilmarnock. Providing funding for the festival continues, GLGDGG can build on and grow its networks to involve more communities of this kind.

Better understand the needs and strengths of these communities

We need a better understanding of the experiences of death, dying and bereavement for those living in socio-economically deprived areas. From a public health palliative care perspective, this needs to include exploration of the unique needs, priorities, strengths and weaknesses of these communities regarding education, knowledge, attitudes, behaviours and community support mechanisms relating to death, dying and bereavement. For example, are people from these communities unusually resilient in the face of difficult circumstances? And if so, what can other communities learn from this? What do people living in these communities see as the problems and the solutions? Is Community Development the answer as outlined above, or might further exploration with communities themselves bring to light other helpful suggestions?
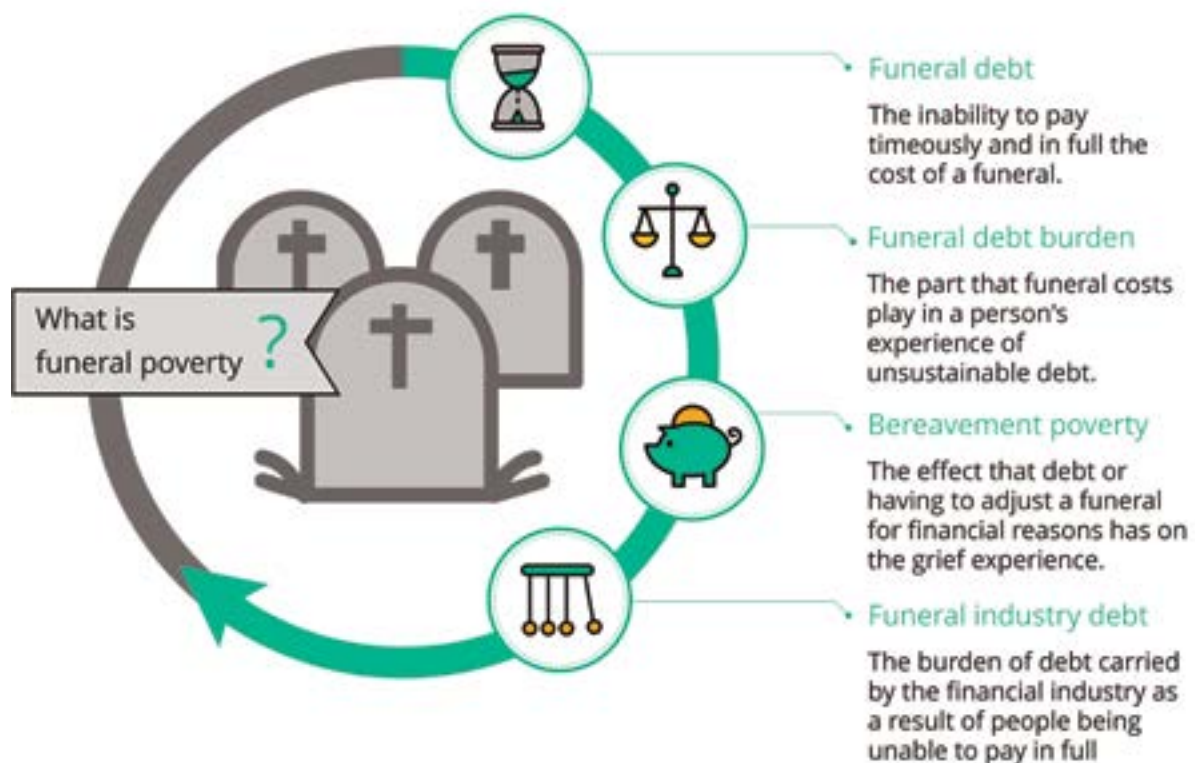
SECTION 11 Funeral Poverty

This section of the report explores what action might be taken at a national level to address funeral poverty and support people to plan ahead for their funerals.

What is Funeral Poverty?

Funeral Poverty is a generic term used to encompass a range of issues around the difficulties experienced by people with insufficient funds faced with paying the cost of a funeral. In particular Funeral Poverty comprises:

- **Funeral debt:** the inability to pay timeously and in full the cost of a funeral for which a person is responsible.

- **Funeral debt burden:** the contribution which responsibility for the cost of a funeral plays in a person's overall experience of unsustainable debt.

- **Bereavement poverty:** the effect that financial debt and/or having to adjust the funeral for financial reasons has on the grief experience of the person responsible for arranging and paying for the funeral.

- **Funeral industry debt:** the burden of debt carried by the funeral industry as a result of people being unable to pay in full for a funeral for which they are responsible.

Funeral debt
The inability to pay timeously and in full the cost of a funeral.

Funeral debt burden
The part that funeral costs play in a person's experience of unsustainable debt.

Bereavement poverty
The effect that debt or having to adjust a funeral for financial reasons has on the grief experience.

Funeral industry debt
The burden of debt carried by the financial industry as a result of people being unable to pay in full

Background

All too frequently, the cost of a funeral imposes a crippling and unmanageable financial burden on bereaved low income families during what is an already impossible time. Each year since 2014 Citizen's Advice Scotland (CAS) has reported annually on increases in local authority burial and cremation charges. Their reports have indicated that an increasing number of Scots are struggling to pay for basic funerals, and highlighted the unacceptable situations in which many families find themselves when recently bereaved.[xcii]

These reports have also highlighted:

- The large differences in what people pay for burial and cremation fees depending on the local authority area where they live.
- A significant variation in the basic costs of burial.
- The rising costs of funerals.

Children's Hospices Across Scotland (CHAS) has highlighted that funeral poverty is a problem they are encountering more and more often. Many of the families CHAS supports are not in a position to meet funeral costs for various reasons - 25% of children with life-limiting conditions live in the most socio-economically disadvantaged areas of Scotland, and for many families either one or both parents have been full-time carers for their child which has already limited their ability to earn.

Relevant Work

In 2015 the Scottish Government commissioned Citizen's Advice Scotland (CAS) to undertake a review of funeral poverty in Scotland, resulting in the publication of *Funeral Poverty: a review for Scottish Government* in February 2016.

A Scottish Working Group on Funeral Poverty meets regularly, with the objective of working towards a Scotland where everyone can have access to a meaningful funeral. The group's objectives are to:

- Bring together all key stakeholders associated with funerals in an open and

honest forum to enable discussion and sharing of information.
- Explore and discuss funerals and the issue of affordability.
- Promote and share best practice.
- Explore and discuss existing and new research relating to funerals and affordability.
- Inform public policy, legislation and regulation on issues relating to funeral poverty and other areas associated with the issue, either as a group where in complete agreement or as informed individual members.
- Discuss funerals within the context of wider issues relating to dying, death and bereavement.

The Scottish Government (SG) has been exploring ways of combating Funeral Poverty in Scotland. SG held a National Conference on Funeral Poverty in November 2016 and has hosted three roundtable discussions on this issue.

WHAT NEXT?

The Scottish Government launched its Funeral Costs Plan in August 2017, which set out the Scottish Government's 10 point action plan to tackle funeral poverty:

1. 'We will launch the new Funeral Expense Assistance benefit by summer 2019

2. We will publish guidance on funeral costs by December 2018

3. We will support provision of more consistent advice on planning for a funeral, support at the point of bereavement and support after a funeral

4. We will publish and promote Planning Your Own Funeral to help people think about and record plans for their funeral

5. We will seek to strengthen consumer protection in relation to pre-paid funeral plans

6. We will support greater public and personal discussion of bereavement, death, dying and care at the end of life

7. We will make more people aware of the

products credit unions offer, including those specifically for funerals

8. We will deliver a Social Innovation Fund to help social enterprises tackle poverty and disadvantage, including funeral poverty

9. We will provide more options to help people save for their funeral by piloting a Scottish funeral bond

10. We will improve the evidence base relating to funeral poverty to help us assess the effectiveness of our actions'[xciii]

The CAS report offered a number of wide reaching and ambitious recommendations on how costs can be controlled and families given much more ability to arrange a respectful funeral at an affordable price, which can be viewed here: *Funeral Poverty: a review for Scottish Government*

The Scottish Working Group on Funeral Poverty continues to meet and advise SG, exploring and highlighting relevant issues as far as its limited resources allow. Most recently, the group highlighted to Scottish Government that the establishment of the new Scottish social security system is an opportunity to ensure the new Scottish Funeral Expenses Assistance is set at a level that recognises the current costs of a funeral in Scotland.

The Scottish Government appointed Natalie McKail to the post of Inspector of Funeral Directors in July 2017. She will spend the first 18 months of her two-year appointment undertaking a review of the funeral profession, with a view to making recommendations to Ministers on how it should be regulated. The National Association of Funeral Directors (NAFD) and the National Society of Allied and Independent Funeral Directors (SAIF) aim to continue to work with Natalie McKail and the Scottish Government, with the aim of ensuring public trust and confidence in the services they provide.

SECTION 12 Scaling up Good Life, Good Death, Good Grief

This section of the report explores the potential to build on and scale up the work of Good Life, Good Death, Good Grief.

Background

What is Good Life, Good Death, Good Grief?

Good Life, Good Death, Good Grief (GLGDGG) is an alliance of over 1,100 organisations and individuals who share the common goal of making Scotland a place where there is more openness about death, dying and bereavement so that:

• People are aware of ways to live with death, dying and bereavement.
• People feel better equipped to support each other through the difficult times that can come with death, dying and bereavement.

Established by the Scottish Partnership for Palliative Care (SPPC) in 2011, GLGDGG was a response to recommendations born from the Scottish Government Strategy *Living and Dying Well.*

Approach

GLGDGG's 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. To lead and support the alliance's membership, SPPC undertakes various GLGDGG-branded national network activities:

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

Outputs

The work of GLGDGG and its members is very varied because the experience of death, dying and bereavement can be improved through work in many domains. The SPPC undertakes the following portfolio of GLGDGG-branded work to support and nurture the alliance:

Providing infrastructure

SPPC has developed and updates the GLGDGG website through which resources are freely available to all. Regular newsletters are produced sharing news with and across the membership. Periodic networking events are run, and when funds occasionally allow, small grants are made available to members (and other interested organisations). A centrally recruited volunteer with training skills has been made available as a resource for groups wanting to develop informal community capacity around death, dying and bereavement discussion and support.

Developing Resources

Films, leaflets and some other more experimental resources (beer mats, origami, a *Dining with Death* menu) have been developed for use by alliance members.

Policy, Promotion and Events

The importance of public health palliative care has been promoted to decision-makers through input to public policy making processes. Media coverage has been generated both to promote the alliance and also to highlight relevant issues. An annual awareness week is co-ordinated to provide a hook for local action. In the first week of November each year SPPC leads *To Absent Friends, a people's festival*

of storytelling and remembrance which again creates very broad and inclusive opportunities for participation.

Resourcing

For many years, GLGDGG work was undertaken using existing SPPC resources, to which the Scottish Government has added some small chunks of non-recurring funding where possible. The absence of recurrent and predictable funding for GLGDGG has posed challenges in terms of making mid- and long- term work plans, and employing additional staff. However, in 2017, the Scottish Government provided welcome additional funding to scale up GLGDGG over the period 2017-2019. This funding is being used to initiate work with local communities, and employ a Development Manager for two years.

Strengths

GLGDGG has achieved much with minimal resources, developing, delivering and learning from a range of practical, innovative and creative activities and outputs, engaging with a growing network of individuals, organisations and communities, whilst also influencing public policy. The variety of activity and reach of GLGDGG has continued to grow since its launch in November 2011 despite resource limitations.

GLGDGG has a well developed action plan and monitoring in place. Three times awards-nominated,[8] GLGDGG has achieved significant recognition within the international community and in the national media for its innovative work. Its membership includes all NHS Boards, many local and national voluntary organisations, care homes, universities, schools, faith-based organisations, local authorities, arts organisations, and interested individuals.

GLGDGG has good networks and a reputation for innovation, and is in a good position to add to the developing evidence

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[8] Finalist in Scottish Charity Awards – Cracking Campaign 2014 for To Absent Friends;
Good Funeral Awards 2015 – finalist in Best Internet Bereavement Resource;
Good Funeral Awards 2017 – Runner Up Best Death-related public engagement event.

base relating to public health palliative care.

WHAT NEXT?

Thanks to two years of funding from the Scottish Government GLGDGG is currently scaling up its work. A Development Manager was employed in July 2017 for a period of two years, and having additional staff capacity at the SPPC, along with a budget for GLGDGG work, has so far enabled:

- Work with a variety of stakeholders from across health and social care and beyond, to produce this in-depth report A Road Less Lonely.
- Growth of the To Absent Friends festival, most importantly with specific activities aimed at engaging people in socio-economically disadvantaged communities.

The SG funding will enable GLGDGG to continue to expand its activities over 2018, including taking forward many areas highlighted in this report:

- Last Aid: In 2018 SPPC will be part of an International Working Group to develop an English language version of the Last Aid course, and will be working with Highland Hospice to pilot this in Scotland. (See Section 6 for more information.)
- Small Grants: GLGDGG will operate two small grants schemes in 2018, to support local organisations to undertake local activities relevant to the aims of GLGDGG.
- Funding: Work with relevant stakeholders to explore potential funding options for some of the areas of work outlined in this report.
- Conference: SPPC will host a conference in April 2018 to showcase and explore current thinking and practice relating to public health palliative care in Scotland. Bringing together interested parties from Scotland, the rest of the UK, Ireland, Denmark, Canada and

Australia, the conference will be a chance to explore the field from various angles as set out within this report. The programme will feature a high quality line-up of plenary speakers and provide those working in the field with an opportunity to network and share their work with a national audience.

- **Public engagement:** GLGDGG public engagement activities will increase, with plans in the pipeline for the development of a blog series, road show, helpful and accessible infographics, and potentially some short film clips.
- **Professional engagement:** GLGDGG will build relationships with Health and Social Care Partnerships, and proactively engage with stakeholders leading in key related work streams, including ACP, Realistic Medicine, Dementia and Health Literacy.
- **Community development:** GLGDGG will work with current contacts who work in socio-economically disadvantaged communities to explore what resources or support GLGDGG might be able to usefully provide.
- **Compassionate Workplaces:** SPPC will consider undertaking a practical project to encourage more employers to re-examine their approach to supporting employees who have been bereaved.
- **Evidence:** SPPC will further explore ways of evaluating its own work, and work in this field more generally.

All of the above additional work streams have the potential to grow, complement and interact with established GLGDGG activities, such as media engagement, Awareness Week in May, Death on the Fringe in August and To Absent Friends in November. All will contribute to the delivery of Commitment 6 of the Strategic Framework for Action on Palliative and End of Life Care.

Sustainability

The SG funding provided in 2017 will have a significant impact on work in 2017-2019: the scaling up activities described above are made possible by the presence of a dedicated member of staff, working in an experienced team, with access to strong networks and a budget to undertake activities.

It is clear that a small amount of funding can go a long way in this field. A key strength of having two years worth of funding is the ability to plan ahead, timetable in evaluation, and time for a new member of staff to build contacts, knowledge and networks.

However, to retain these advantages and continue to build momentum, more long-term funding needs to be identified for this work. Current funding will run out in 2019, which in practical planning terms is relatively close. There are staff-retention risks associated with short-term employment contracts. Without a commitment to more long-term financial support for this work in early 2018, there is a risk that the benefits currently being seen will be lost.

Prioritisation and further upscaling

The production of this A Road Less Lonely report has shaped the development of the 2018 GLGDGG work plan, informing its focus on practical ways that GLGDGG can help to support compassionate workplaces, compassionate communities and socio-economically disadvantaged communities.

Because the need for change is huge, and because GLGDGG's strategic objectives are broad, SPPC generally prioritises future areas of work by weighing up a variety of factors including how well-placed GLGDGG is to undertake the work.

The scope of this report is broad, and there are certain 'next steps' identified that GLGDGG could contribute to but is not well-placed to lead.

However, several 'next steps' have been identified in the preceding chapters that GLGDGG would be well-placed to lead, working in partnership with others to deliver. For example, if additional resources

became available, GLGDGG could:

- Develop a practical resource to support people wishing to take action to build Compassionate Communities.
- Organise a Compassionate Communities Conference.
- Undertake a survey and voxpop of the end of life care wishes of doctors.
- Develop a leaflet providing information about the bodily changes that can take place when someone is dying.
- Organise a one-off event to improve media understanding of death, dying and bereavement.
- Lead work to develop a Charter for a Good End of Life.
- Find ways of increasing awareness of the importance of PoA among health and social care, linking in with work to promote ACP.
- Make a case for the importance of Community Development, from the perspective of health and wellbeing towards the end of life.

SECTION 13 Conclusions and Next Steps

This report highlights a wide range of projects and initiatives ongoing in Scotland and further afield that are relevant to improving people's experiences of death, dying and bereavement. Within Scotland there is a huge amount of enthusiasm, skills, knowledge and resources relating to public health approaches to death, dying and bereavement and this is an excellent base on which to build.

Having explored a number of areas that can shape people's experiences, this report suggests a range of steps that could be taken to move forward this area of work. These are summarised below. The type of 'next steps' identified varies from the theoretical to the practical, depending on the context and stage of current work.

The report does not allocate actions to organisations or individuals. Rather, it aims to articulate some of the issues involved and some ideas of practical next steps, and make this available as a resource for all those who wish to take forward work in this area in Scotland. The report illustrates that relevant action can be taken by a range of different types of organisations, across a variety of domains.

Summary of potential next steps

Improve death education and bereavement support in schools

Develop and promote an Implementation Tool, which can be used by schools to assess and improve their current approaches to death and bereavement, and which signposts to high quality existing resources that can be used.

Encourage more bereavement-friendly workplaces

Undertake a project to encourage employers to re-examine their approach to supporting employees who have been bereaved and which signposts to resources and support to enable employers to equip themselves with knowledge, skills and policies that support compassionate workplace approaches to bereavement.

Support the creation of compassionate communities

Recognising the importance of a community development approach, create a resource and networking event for people wishing to build compassionate communities. Support and resource community development workers to incorporate matters relating to death, dying and bereavement into existing activities.

Increase people's personal skills and knowledge relating to death, dying and bereavement

Various ideas are outlined which have the potential to improve knowledge and skills relating to death, dying and bereavement, and it would be worth exploring whether resources could be found to put some of them into action.

Encourage people to make practical plans for deteriorating health and death

Undertake public engagement work to promote the importance of Anticipatory Care Planning. Increase awareness of the importance of Power of Attorney among health and social care professionals and members of the public.

Consider a mass media campaign as one potential tool to encourage change

If there was local or national interest in Scotland in putting financial resources into

a media awareness campaign to promote more open and supportive attitudes and behaviours relating to death, dying and bereavement, there are a number of subject areas that could be explored, and this report sets out a number of factors that should be considered. There is the potential to learn from and build on the My Power of Attorney campaign.

Learn about and address the specific needs of socio-economically disadvantaged communities

Develop a better understanding of the experiences of death, dying and bereavement for those living in areas of socio-economic deprivation, and of how public health palliative care approaches might support these needs. What do people living in these communities see as the problems and the solutions?

Tackle funeral poverty

Maintain the momentum of the various work which is already underway to tackle the issue of funeral poverty.

Scale up the work of Good Life, Good Death, Good Grief

Thanks to two years of funding from the Scottish Government GLGDGG will continue to expand its activities over 2018. This will include taking forward many areas highlighted in this report, for example, work to bring Last Aid to Scotland and encourage bereavement-friendly workplaces.

APPENDIX 1 Definitions and Glossary

Whole school approach

A whole school approach is cohesive, collective and collaborative action in and by a school community that has been strategically constructed to improve student learning, behaviour and wellbeing, and the conditions that support these.[xciv]

Public Health Approaches to Palliative Care

The term 'public health palliative care' is used to encompass a variety of approaches that involve working with communities and wider society to improve people's experience of death, dying and bereavement.

Public Health Palliative Care Approaches are not about:

- Therapeutic interventions with individual patients.
- Group therapy.
- Improving how a service delivers therapeutic interventions.
- Creative or unusual ways of delivering therapeutic interventions.

Rather, public health approaches to palliative care encourage communities to develop their own approaches to death, dying, loss and caring.

Public health approaches to palliative care are focused on:

- Helping to prevent social difficulties around death, dying, loss or care, or;
- Minimising the harm of one of the current difficulties around death, dying, loss or care, or;
- Early intervention along the journey of death, dying, loss or care.

Public health approaches aim to change the setting/environment for the better, are participatory, and ideally should be sustainable and capable of evaluation.

These approaches can be underpinned by a variety of methods, such as

- Community engagement.
- Community development.
- Health promotion.
- Education.
- Changes to the social or policy environment.
- Social marketing.

Community-based models

A community-based end-of-life care service model might be initiated after concern that patients are not cared for or dying at their preferred place. For some people this is their own home. The extension of end-of-life care services into community settings means that a greater range of end-of-life care needs can potentially be met. Community based models should not be confused with 'community engagement' or 'community development' models.

Community engagement models

Community engagement models relating to end-of-life care represent a basic form of community development initiated by end-of-life care services. A community worker or volunteer helps communities to build the capacity and networks that support their

end-of-life care needs, paving the way for the development of end-of-life care policies and practices.

Community Development

Community development is a process where community members come together to take collective action and generate solutions to common problems. Community development seeks to empower individuals and groups of people with the skills they need to effect change within their communities.

Community Development approaches to end of life care (not to be confused with 'Community Engagement' or ' Community-based' models) are about establishing strong care and support networks that reinforce a sense of control over life-threatening/limiting illnesses, and enhance the community's ability to deal with death, dying, loss and care. Community Development programmes enable communities themselves to create policies and practices for their own end-of-life care needs.

Community-based vs community engagement vs community development

Community engagement is not community-based care, and community development is not solely community engagement. Genuine partnerships with community display all three of these dimensions of community work because all three are essential for the health and wellbeing of communities.

Health Promoting Palliative Care

Health-promoting palliative care represents the initial attempts by palliative care services to adopt a public health approach by extending end-of-life care collaborations to community partners. Health-promoting palliative care acknowledges the social character of dying and provides for the continuing healthcare needs of people with life-threatening/limiting illnesses in community settings. The aim is to improve health and wellbeing at the end of life.

Community Development to create compassionate communities

Outside formal definitions of 'Compassionate Cities', many groups, individuals and organisations undertake community development work of some kind that aims to enhance a community's ability to deal with death, dying, loss and care. Often, this work, though not taking place within a formal and organised 'Compassionate Cities' structure, might share the Compassionate Cities aims and values. People might talk about creating a compassionate community without having a specific definition in mind, referring more loosely to the importance of helping communities become more compassionate places to die, to supporting neighbourliness, and building on individual acts of kindness by ordinary people.

The term 'compassionate communities' has a tendency to be used in relation to **community development activities** that focus on the primacy of participatory relations and **building community networks of support** to enhance a community's ability to deal with death, dying, loss and care.

References - The above definitions are largely based on:

Karapliagkou, A. & Kellehear, A. *Public Health Approaches to End of Life Care. A Toolkit.* London, National Council for Palliative Care and Public Health England. 2014. Available from: *http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf*

A ROAD LESS LONELY

APPENDIX 2 Death Education and Bereavement Support in Schools: Relevant work

Lots of resources exist that school communities can draw on to support them with their approach to death, dying and bereavement, many of which have been developed with input from children themselves. A selection of these are collated below.

Web-based resources

- *Child Bereavement UK* has a range of resources on its website, including lesson plans, an e-learning programme and template bereavement policies: https://childbereavementuk.org/for-schools/primary-schools/
- *Winston's Wish* has a range of relevant resources on its website: https://www.winstonswish.org/supporting-you/support-for-schools/

Projects focused on death or bereavement

The Resilience Project and lesson plans by St Francis Xavier's Primary School, Falkirk, Strathcarron Hospice, the University of Strathclyde and University of Edinburgh. The project consists of five lessons covering the subjects of death, loss and grief aimed at pupils in Primary Six or Seven (aged nine to twelve years). It addresses experiences and outcomes from three curriculum areas within the Curriculum for Excellence (Health and Wellbeing, Science and Religious Education) as well as some of the questions asked by children in the process of developing the project. The project fits into a wider Resilience Programme that is aimed at fostering children's resilience by helping them to identify feelings and develop coping strategies for use in a wide range of circumstances concerning loss and transition from Nursery to Primary Seven (ages four to twelve). Available on the GLGDGG website.

Whole Schools Approach to Loss and Bereavement by NHS Greater Glasgow and Clyde, Glasgow City Council and in partnership with local hospices. This document provides information and advice to assist staff in the day to day support that they provide to children and young people coping with bereavement, loss and change. Available on the GLGDGG website.

Cruse Bereavement Care Scotland: **Schools Bereavement Project**

The Perth and Kinross Schools Bereavement Project: an interagency approach to promoting support for school pupils experiencing grief following the death of a family member, friend or member of their school community. The partners in the project are Cruse Bereavement Care Scotland; Perth and Kinross Council and NHS Tayside. The project has a website that has been created to support teachers who wish to address issues of loss and bereavement, either with individual pupils or as a class topic: http://www.schoolsbereavement.org.uk/index.asp

Barnardo's: One of Barnardo's core priority areas (to 2025) is mental health and wellbeing which includes bereavement, trauma loss and work in schools. Within Scotland, this also links with the Attainment Gap and Pupil Equity Fund. Within Scotland school based provision has included work in several Local Authorities, most recently in Forth Valley and Tayside. Work is ongoing with Polmont Young Offenders Institution, and additional Scottish

Government funding has been received to expand this to work with young women in prison and in two Local Authorities.

Bereavement training for school staff in Forth Valley (Strathcarron Hospice and Strathclyde University): A 2.5 hour training programme designed by school staff and hospice staff for whole school communities.

Highland Change, Loss and Bereavement working group: a multi-agency group with representation from Crocus Group, Educational Psychology, guidance teachers, Child and Adolescent Mental Health Services, social work, University of the Highlands and Islands and more. It is envisaged that the work of this group should become an improvement aim within the Highland Council's children's improvement plan. So far they have developed a half-day training programme for probationer teachers across Highland and they are hoping to embed change, loss and bereavement into the PSE curriculum so that all Highland schools can deliver a programme on this theme. Highland Council partnered with Children's Hospices Across Scotland (CHAS) and the Crocus Group in developing the 'Life-limiting conditions, Palliative Care, Loss, Bereavement, and Trauma Support Pack'[9]. This pack is available to every school in Highland, incorporating policy with a resource toolkit. This pack recently won a silver COSLA award.

CHAS' Family Support Team often works with schools, sometimes around supporting individual children and other times around delivering the Seasons for Growth Programme. CHAS is also contacted by schools struggling with the death of pupils - sometimes unexpected deaths - and offers support to help children and staff cope with the loss. In line with learning how to cope with death, dying and bereavement, CHAS is about to develop and deliver a series of Death Cafe events that will enable adults and young people to talk about death.

Organisations/ charities that specialise in supporting schools

Various arts and bereavement organisations are able and willing to work with schools to provide education and support around death, dying and bereavement for children and staff in schools, for example:

- Richmond's Hope.
- Fischy Music.
- Seasons for Growth.
- Crocus Group.
- Hospices.
- Child Bereavement UK.

The Childhood Bereavement Network have a list on their website of organisations that support bereaved children:

http://www.childhoodbereavementnetwork.org.uk/help-around-a-death/find-help-near-you.aspx

Other relevant initiatives

Nurture groups: Nurture groups are usually classes of between 6 and 12 children or young people in early years, primary or secondary settings. Each group is run by two members of staff. Children attend nurture groups but remain an active part of their mainstream class group so they will spend appropriate times within the nurture group according to their need and typically return full time to their own class within two to four terms.[xcv] Some (but not all) children and young people who access nurture groups may have been impacted by a bereavement.

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[9] Source: Life-Limiting conditions, Palliative Care, Loss, Bereavement, and Trauma Support Pack by Highland Council (2017). Available at: *https://www.highland.gov.uk/news/article/10712/silver_award_for_children_s_support_pack*

More recently the original nurture group concept has been extended to a whole school approach which is a relational approach based largely on the theory of attachment, an understanding of the impact of adverse early experiences (which may include bereavement and loss) and how these can lead to stress and trauma. It is recognised that a whole school approach is most effective in promoting emotional and social well-being and responding to mental health needs in schools.[xcvi]

In Scotland a self-evaluation framework is available to support schools and early learning and childcare (ELC) settings that are applying a whole school approach to nurture.[xcvii]

APPENDIX 3 Compassionate Workplaces: Relevant work

ACAS

ACAS guidance, developed in partnership with Cruse Bereavement Care suggests that:

> *'Employers can prepare for managing bereavement in the workplace by having a clear bereavement policy and by training managers, HR teams and selected staff to have compassionate and effective conversations with bereaved employees.'*

This guidance emphasises an empathetic approach, illustrates good practice, and provides a template bereavement policy for use by employers.

Hospice UK/ National Council for Palliative Care

In England, Wales and Northern Ireland, the National Council for Palliative Care (NCPC) developed a Compassionate Employer programme to help organisations analyse their own support procedures and to recognise them with an award. Following NCPC's merger with Hospice UK in July 2017, these resources are being evaluated to ensure their continued relevance and suitability for use by a wide range of companies.

Hospice UK has an ongoing campaign to improve employment protections for working carers of dying people. They are campaigning for the government and employers to do more to minimise the negative employment and financial impacts for carers of people at the end of life, including strengthening flexible working arrangements and allowing defined periods of leave of absence with a guarantee to return to a job.

Cruse Bereavement Care

Cruse has produced an Employer's Bereavement Toolkit to help employers be ready and able to manage a bereavement in the workplace.

Carer Positive

Carer Positive is a Scottish Government funded initiative led by Carers Scotland, which aims to encourage employers to create a supportive working environment for carers in the workplace. Through the Carer Positive website, employers wishing to become a Carer Positive employer can undertake a self-assessment process to demonstrate how they meet each of 3 award levels. It is free for employers to participate.[xcviii]

TUC Dying to Work Campaign

The TUC is pressing for additional employment protection for terminally ill workers. The Dying to Work Campaign is seeking commitments from employers to:

- Review sick pay and sickness absence procedures and include a specific statement that they will not dismiss any person with a terminal diagnosis because of their condition.
- Ensure that that they have an Employee Assistance Programme that has the capacity and competency to provide support to any person with a terminal illness, including access to counselling and financial advice.
- Provide training to line managers and all HR staff on dealing with terminal illness, including how to discuss future plans with any worker who has a diagnosis of a terminal illness, and on what adaptations to work arrangements that may be necessary.

- Adopt the Dying to Work Charter and notify all employees that they have made the commitments contained in it.[xcix]

High Five Wellbeing Programme, Inverclyde

As part of the Compassionate Inverclyde programme, the High Five Wellbeing Programme is currently underway, which includes work to support and encourage the local Amazon branch to become a Compassionate Organisation. Drawing on work observed as part of the Health connections Mendip Programme in Frome, High Five has included the establishment of 'do-ers' and 'listeners' – employees who have voluntarily agreed to help or listen to colleagues in need of practical or emotional support.

APPENDIX 4 Compassionate Communities: Relevant work

Initiatives specifically relating to death, dying and bereavement

Compassionate Inverclyde

Launched in March 2017, the Compassionate Inverclyde Programme aims to enable and empower individuals and communities to help and support each other at times of increased health need, at end of life and in bereavement, recognising the importance of families, friends and communities working alongside formal services.

Strathcarron Compassionate Neighbours

Building on the success of Strathcarron Befrienders which was launched in 2014, Strathcarron Compassionate Neighbours provides a framework for people to offer a variety of support to people in the latter stages of life within their own communities.

Strathcarron Compassionate Neighbours offers individually tailored support which can include:

• Helping people stay connected to their community.
• Helping people to continue to do the things they enjoy doing.
• Providing friendship and a listening ear.
• Regular visit for a chat.

A new project funded by Falkirk Health and Social Partnership is exploring the use of a Circles of Support model.

Compassionate Cities model

Allan Kellehear and colleagues have developed the Compassionate Cities model, which is a term used to describe a specific public health approach to end of life care. Bradford, Limerick,[c] Seville and Ottawa[ci] have already embarked on their journey to become Compassionate Cities.

Various sectors, organisations and groups all have a role to play in the creation of a Compassionate City[10], and *Each Community is Prepared to Help* written in an English context suggests the different contributions that can be made by hospices; hospitals; primary care; clinical commissioning groups and local authorities; and health and wellbeing boards.

Compassionate Communities UK

Compassionate Communities UK was recently set up by Allan Kellehear, Julian Abel and Catherine Millington Sanders to provide expertise relating to public health approaches to end of life care and embed them in health and social care education programmes.

Death education and bereavement support in schools

Schools are communities, and work has been undertaken to create compassionate school environments where staff and students are better able to support each other through difficult times associated with illness, death and bereavement. See Section 4 for more details.

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[10] This use of 'Compassionate Cities' should not be confused with the different usage of the term by 'Charter of Compassion' initiative: https://charterforcompassion.org/communities/what-makes-a-compassionate-city

Scoping relevant work

Various work is underway in the UK and further afield to create compassionate communities and compassionate cities. A group from the University of Edinburgh, Strathclyde University, La Trobe University, Scottish Partnership for Palliative Care and St Columba's Hospice Edinburgh are undertaking a scoping review relating to public health palliative care which aims to map the wide variety of activities and programmes internationally that could be classified as 'public health palliative care'. When completed, this scoping review should provide a useful resource for those wishing to learn from others working in the field.

Sue Ryder online community[11]

Sue Ryder has established an online community where people can get peer support when going through difficult times relating to dying and bereavement: *'If someone you love is dying or has died, our online community is a place to share experiences, get things off your chest, ask questions and chat to people who understand.'* Evaluations indicate that people who are part of this online community find it helps them to feel less alone and more able to cope.

Creating 'Porous Institutions'

In *What Death Means Now,* Tony Walter points out that *'some of what critics condemn as death's medicalisation is, in fact, its institutionalisation'*. He suggests that *'it is worth asking not only how dying may become more a natural community/ family event rather than a medical event, but also if and how the institutional settings in which dying people often find themselves could become more porous, that is, inclusive of the person's own social networks and the wider community'.*

For example, there has recently been growing awareness of initiatives where Care Homes have co-located or partnered with nurseries, enabling residents and children to benefit from each other's company.[ciii] An increasing number of Scottish hospitals have committed to welcoming carers outside of standard visiting hours.[civ] It is likely that there are various initiatives of this kind taking place across Scotland and beyond that can be learned from.

International work on Compassionate Communities

Various compassionate communities work is happening internationally. The 5th International Public Health Palliative Care Conference, which took place in Ottawa in September 2017, showcased some of this work.[cv]

Initiatives not specifically in relation to death, dying and bereavement

Community Link Working

Community link working is an approach to connecting people to non-medical sources of support or resources in the community which are likely to help with their health problems. Gold Star Exemplars: Third Sector Approaches to Community Link Working Across Scotland[cvi] published by Voluntary Health Scotland (VHS) sets out the extensive and varied nature of third sector approaches to community link working across Scotland.

A Scottish Government funded pilot project is running until March 2019 in partnership between the Health and Social Care Alliance (The ALLIANCE) and General Practitioners at the Deep End. It aims to mitigate the impact of the social determinants of health in people that live in areas of high socio-economic deprivation. The programme is gathering and sharing learning about the 'links worker' role and supporting others who are interested in this way of working.

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[11] *https://support.sueryder.org/community*

It introduces a different skill-set in to the General Practice team as well as supporting the existing staff to adopt the Links Approach. Community Links Practitioners all have a third sector or community development background and have three main responsibilities:

- Support people to identify goals and enable them to achieve those goals through identifying and enabling access to local community assets. Community Links Practitioners will work with people in the practice, the person's home, and in the community.
- Work with the entire primary care team, both clinical staff and non-clinical staff in order to enable them to adopt the Links Approach (see below).
- Work with local community resources, supporting them to become more accessible to people accessing them via primary care.

An evaluation of the Programme has been published[cvii]. This programme runs in Glasgow and Dundee, and is one of the many link worker initiatives that the Scottish Government are funding. The Scottish Government are also developing a national programme to recruit 250 Community Link Workers to work in GP surgeries.

Draft strategy on Loneliness and Isolation

The Scottish Government are developing a new national strategy to tackle loneliness and isolation. It is envisaged that the strategy will look at the causes of social isolation and loneliness and how they can be addressed.[cviii]

Carnegie UK and JRF report: The Place of Kindness[cix]

Carnegie UK Trust worked with seven organisations to test what, if anything, could be done to encourage kinder communities, exploring ideas around the importance of places and opportunities to connect, and the intrinsic values underpinning our interactions and relationships.

A report by Carnegie Associate Zoë Ferguson has been produced identifying what they have learnt, highlighting powerful examples of where kindness and everyday relationships can effect change and support the wellbeing of individuals and communities. At the time of writing, Carnegie UK has begun to shape the Kindness Innovation Network (KIN), which aims to be:

- Focused on action learning and reflection - not simply another talking shop.
- Open to anybody who wants to be involved - across sectors, professions, generations and communities.
- Non-hierarchical - a network with a flat structure and where everyone is equal.

Compassionate Community Networks from Within a GP Practice in Frome[cx]

Frome Medical Practice provides care for the 29,000 residents of Frome and the surrounding area. Since 2014, the practice has combined a community development service with an internal hub in the GP practice which identifies those in need of support. The community development service fulfils two functions; enhancing the naturally occurring supportive networks that surround people and connecting people into community resource. If the resource needed creating, the community development service helped this process, creating new groups according to community requests.

Dementia Friendly Communities[cxi]

Dementia Friendly Communities is a programme facilitating the creation of dementia friendly communities across the UK. It promotes the message that everyone, from governments and health boards to the local corner shop and hairdresser, share part of the responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.

Faith Communities

Churches can be found in nearly every community in Scotland and increasingly there is a presence of other faith communities. For many people faith is important in supporting their resilience as they age or face sad or difficult circumstances throughout life. This presence is important as individuals begin to think about end of life matters whether practical or spiritual and faith communities can provide a source of information of a practical nature and support people individually or together to think about powers of attorney, funeral plans, care plans and what they would like in respect of their continuing spiritual life. Faith communities, many of which are open to those of no faith, can provide a safe haven to discuss and implement practical plans, collect people's stories, and listen to their hopes and fears so that people can reach resolution for themselves and inform family and friends of their wishes and preferences relating to end of life issues.

Community Development work and approaches

It is likely that those wishing to build Compassionate Communities can learn much from other Community Development initiatives. The Scottish Community Development Centre[cxii] provides resources, networking and information about Community Development.

Community Health Exchange (CHEX)[cxiii]

CHEX supports and promotes community development approaches to health improvement, supporting a network of community-led health organisations and their public sector partners who are tackling health inequalities in communities across Scotland.

The Scottish Co-production Network[cxiv]

The Scottish Co-production Network is a free and open network which hosts information, resources and events around co-production. Co-production is a way for those who use public services and those who provide them to work together in an equal way and to see positive change.

Health Issues in the Community[cxv]

Health Issues in the Community, or HIIC, is a training programme which focuses on links between health issues and wider social issues in order to build confidence, skills, involvement and community organisation. HIIC also provides training for people to become HIIC tutors, so that skills can be passed on within communities. Health Issues in the Community is a partnership between NHS Health Scotland and CHEX (Community Health Exchange). The initiative is funded by NHS Health Scotland; and course development, tutor training, assessment/certification, support and networking provided by CHEX.

Roar – Connections for Life

Roar is a provider of preventative health and wellbeing services for older people through the development of community opportunities that connect lives. Roar Connections for Life has 10 clubs in 9 venues running throughout the week in Renfrewshire. They also offer a range of activities including a Craft Cafe, Reels and Spiels, Breath of Fresh Air and Come Dine With Me.

Befriending Networks

Befriending is designed to offer supportive, reliable relationships through volunteer befrienders to people who would otherwise be socially isolated. Around the UK there are befriending projects which organise effective support for children and young people, families, people with mental ill-health, people with learning disabilities and older people, amongst many others. As the umbrella organisation for befriending, Befriending Networks' purpose is to enable this, by providing the information, training and support to encourage befriending projects to exchange experience and develop good practice.

APPENDIX 5 Making practical plans for deteriorating health and death: Relevant work

Various work relevant to this area has been undertaken or is underway, a selection of which is presented below:

GLGDGG website[cxvi]

The GLGDGG website provides and signposts to public-facing information relating to all aspects of planning ahead. GLGDGG has also produced an origami resource to engage people in the idea of advance care planning, and a blog series exploring the various steps involved.

Power of Attorney Campaign

The My Power of Attorney Campaign[12] aims to raise awareness and promote understanding of the benefits of Power of Attorney (PoA) arrangements. Initiated in 2013 the NHS Greater Glasgow and Clyde area, it has grown to include NHS Lanarkshire, Tayside and partner councils and HSCPs. (See Section 9 of this report for more information.)

Post-diagnostic support for people with dementia

Local Delivery Plan (LDP) Standards are priorities that are set and agreed between the Scottish Government and NHS Boards to provide assurance on NHS Scotland performance. One of the current Local Delivery Plan Standards is:

> *'People newly diagnosed with dementia will be offered a minimum of one year's post-diagnostic support, coordinated by a named Link Worker.'*[cxvii]

Alzheimer Scotland's Five Pillars Model of Post Diagnostic Support shows the five key elements which are essential to supporting a person after they have been diagnosed with dementia.[cxviii] One of the pillars is *'planning for future decision making'*, which encompasses support to set up powers of attorney and deal with other legal issues.

Therefore, the current focus on providing people with dementia with post-diagnostic support has the potential to increase the numbers of people registering a power of attorney.

Plan If

The Plan If[cxix] campaign encourages all parents to put arrangements in place in case they die before their children grow up. It includes practical issues such as wills and appointing guardians, and also guidance around writing a letter for the future, keeping contact details for important people, and other actions.

ReSPECT

ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. The ReSPECT process is all about thinking ahead with patients about realistic care options in a truly person-centred way. Ultimately the process aims to help people understand the care

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[12] https://mypowerofattorney.org.uk

and treatment options that may be available to them in a medical emergency and enables them to make health professionals aware of their preferences.[cxx] ReSPECT is currently at the stage of localised pilots in Scotland.

Funeral Planning

The Scottish Working Group on Funeral Poverty has worked with the Scottish Government to produce *Plan Your Own Funeral*, a leaflet which takes people through what they should consider when planning their funeral and is available on the Scottish Government website.[cxxi]

Anticipatory Care Planning

Drawing and building on widespread local development of ACP approaches, the iHUB of Healthcare Improvement Scotland has produced Anticipatory Care Planning resources for the public and for professionals. It is anticipated that HIS will be initiating public engagement work relating to these resources. The work undertaken by HIS is also supporting the development of a version for using with parents facing the death of their child. Work is also underway to improve the ability to create and share anticipatory care plans electronically.

Adults with Incapacity Act

At the time of writing, the Scottish Government is consulting on proposals for reform of the Adults with Incapacity (Scotland) Act 2000. The consultation covers several issues that are relevant to planning ahead for the end of life, including Powers of Attorney, Advance Directives and Guardianship.

Living right up to the end - Strathcarron Hospice[cxxii]

In a project funded by the ALLIANCE, Strathcarron Hospice sought the views of people from 2 local communities who had lived experience of the challenges associated with long term conditions. More than 400 people participated and shared their opinions about what was important as they approached the latter stages of life, and about what they felt were the barriers to thinking about and planning for the future.

Working groups were formed with people from the communities who had little or no previous contact with specialist palliative care services.

Over a 4-month period the project team learned that people valued their independence and wanted to retain control as much as possible. People wanted support, but from their community rather than from professionals. People also identified a need for the right information at the right time, particularly relating to making plans for the future and communicating these to their families.

In response to these findings the project team worked with the groups to develop an information resource which is available as a 'pop-up' at community meetings, local supermarkets, health centres, libraries. This pop-up stand is provided by people who have lived experience of long term conditions and planning for the future.

Further funding has been secured from Falkirk Health and Social Care Partnership to explore ways in which communities can provide support to those who need it.

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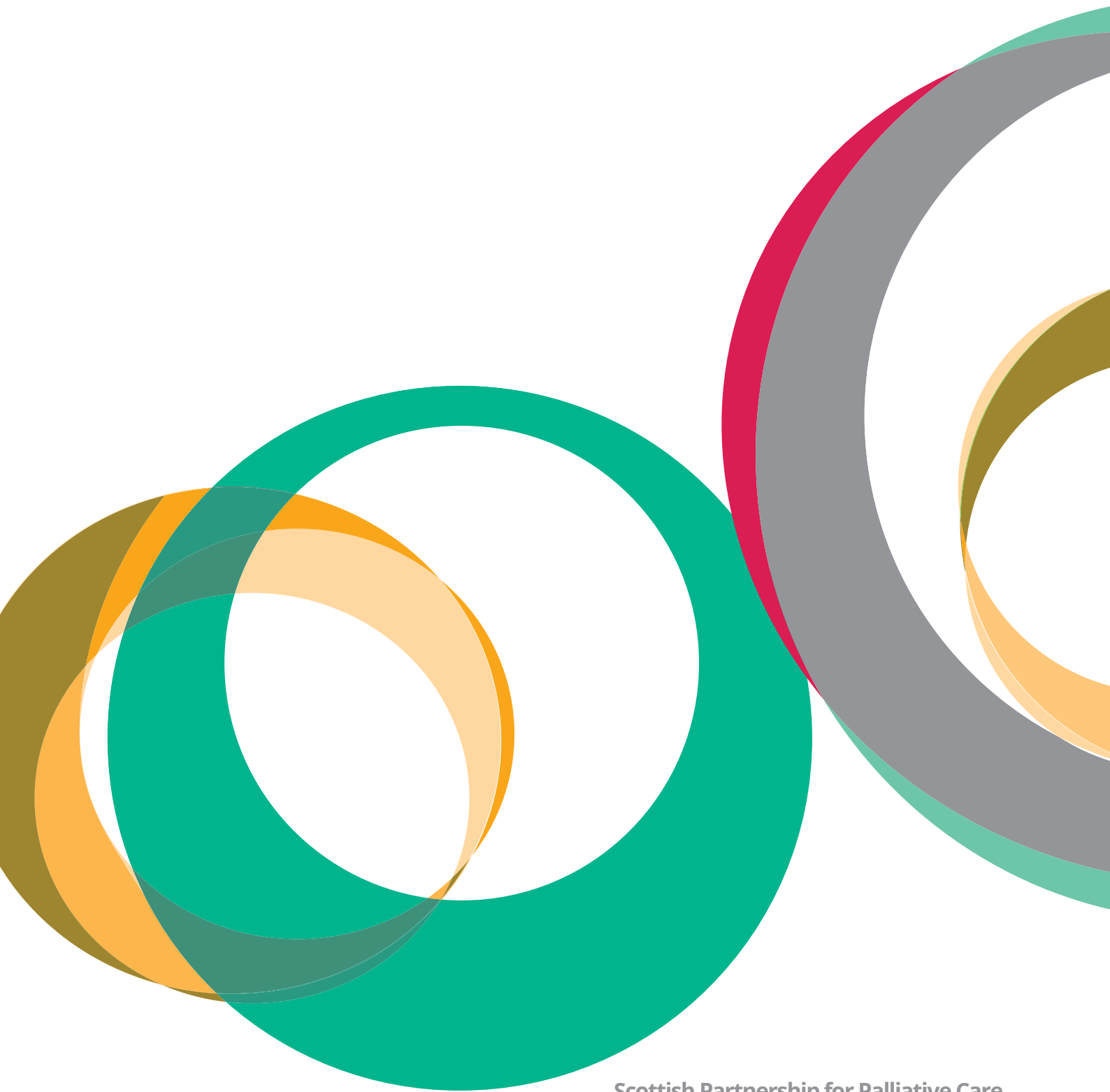lxv North East Charter for a Good Death, May 2010: *http://www.ncpc.org.uk/sites/default/ files/Good%20Death%20Charter.pdf*

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