MARCH 2023 COLLABORATIVE NEWSLETTER

FAITH IN OLDER PEOPLE

SCOTTISH PARTNERSHIP FOR PALLIATIVE CARE GOOD LIFE, GOOD DEATH, GOOD GRIEF







INTRODUCTION

"All of us will experience grief through the course of our lives. It is a truly universal human experience – part and parcel of being mortal. And as with every aspect of life, we all experience it differently".

The Right Reverend and Right Honourable Sarah Mullally, The Bishop of London CB

'Bereavement if everyone's business' is the title of the Report produced by the UK Commission Bereavement. It highlights the importance of the roles we all have to play in support of someone who is bereaved; feeling confident that we can provide support and building awareness of the issues in the places we attend including our faith communities.

What is clear is that we can't provide everything on our own. We need to work in partnership with organisations and individuals to provide support and information. This is why Faith in Older People, the Scottish Partnership for Palliative Care (SPPC) and Good Life; Good Death; Good Grief (GLGDGG) are producing this joint newsletter devoted to issues around bereavement to raise awareness of the resources and training available and to encourage all of us to plan for the future and not to be anxious about seeking emotional, spiritual and practical support.

FiOP values its partnership with the SPPC and GLGDGG with which we have organised conferences focussing on end of life. FiOP facilitates the EASE course and our Malcolm Goldsmith Lecture 2022 was given by Dr Kathryn Mannix on 'Tender Conversations' in collaboration with RT Rev Richard Holloway. This newsletter demonstrates a range of policies and collaborative working and we are very aware of the host of voluntary and statutory sector services which exist to support people who are bereaved.

Together we want to tackle isolating experiences; ensure a greater awareness of the impact of bereavement and encourage empathy and compassion.

<u>UK Commission on Bereavement (bereavementcommission.org.uk)</u> <u>ukcb-scotland briefing.pdf (bereavementcommission.org.uk)</u>



MAUREEN O'NEILL DIRECTOR FAITH IN OLDER PEOPLE

Unlocking the door to grief

The American singer and banjo player Joe Newberry recently wrote that:

"In my dad's last days, I asked the hospice nurse, an older woman from Alabama, "What is keeping him here? Why won't he let go?" She said, "Why honey, he's got the dementia. He can't find the door. When he finds the door, he'll be gone."

After he died, I sang "Lone Pilgrim" over him in the 2 a.m. darkness of his room. I turned around and saw that same nurse standing in the doorway. She came up to me, gave me a hug, and whispered, "He found the door."

Finding the door is not just the task of those who are dying it is also the search of those who seek to find meaning in life after someone that matters to them dies.

For too many doing the work of grieving and bereavement is like facing a locked door beyond which they cannot move. But unless they go through that door and are supported in their grieving then they will struggle to learn how to re-orientate their lives in a world without the deceased.

The UK Commission on Bereavement was established in 2021 to consider experiences of bereavement in the four countries of the United Kingdom, and to make recommendations for change. I was privileged along with Zara Mohammed from the Muslim Council of Great Britain to serve as a Scottish Commissioner. The Commission was independent of government and was supported by a steering group of leading charities. It published its report in October 2022.

Entitled 'Bereavement is Everyone's Business' the final report is one of the most comprehensive explorations of the nature of bereavement within modern British society not least in the light of the Covid pandemic. It is rooted in the lived experience of many people including those who gave their time and inspirational insights as members of the Lived Experience Advisory Forum. It utilises extensive and original academic and population research and contains many practical insights on how we can improve things for those who are bereaved.

The Commission has made numerous recommendations and argues strongly for the need of society to see bereavement support as a public health issue. It also states quite clearly that we need to recognise that bereavement support should be seen as a basic human right such is its impact on our health and wellbeing. It also recognises the stigma and discrimination which those experiencing grief and bereavement still endure.

The recommendations for Scotland include that the Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served; that all education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life; that all Scottish employers must work towards the National Bereavement Charter and that the National Care Service must commission tailored bereavement support and signposting.

These are laudable ambitions, but they will remain on the 'to do list' unless everyone who is concerned about grief and loss takes the time to agitate, advocate, campaign and show that bereavement is everyone's business. The work of the recently held Bereavement Summit, coordinated by Good Life, Good Death, Good Grief has been a huge help in pointing us in the right direction.

As a Commissioner I heard too many instances of a lack of support or poor provision; of wholly inadequate training and resourcing for frontline health and care staff; of insensitive management of workers who were grieving; of a complicated and confusing funeral and benefit system; of individuals blocked in their grief and facing the terrible mental health consequences that can bring; of children not being supported, heard or even valued in the loss they were experiencing, and of so many hundreds struggling with the effects of grieving through Covid. The work of the Commission has only started – the door is only slightly ajar, there is much work to do before we can all of us, regardless of circumstance in Scotland, realise our human right to adequate bereavement support.



DR DONALD MACASKILL CEO, SCOTTISH CARE

Reflections on dealing with grief and bereavement; a forward for Scotland

It's hard to forget those we lose and even harder to deal with that grief.

I recall during the pandemic, a close friend of mine had to deal with the unexpected loss of her father and whilst trying to process that grief, as a young person, she had to deal with the burial quickly; the coroner, the mosque and all the other logistics that come with a loved one passing. She told me that she only wanted a hug and someone to help us through it.

Stories like this one are not exceptional; throughout my travels across the UK to visit Muslim communities I learned more about the challenges they faced with bereavement. Households that had lost generations of family had difficulty understanding what support was available to them because English was not their first language. The strain on family carers and the lack of trust and fear

of going to the hospital not knowing what would happen. Never mind, coping with their grief with already strained services. I also reflect on the amazing stories of faith communities rising to the challenge, providing that crucial pastoral care, a source of connection and comfort when there was no one else to talk to. I know how Muslim communities created bereavement services to fill the void of existing services and how mosques despite being closed to the public during the pandemic continued to provide essential help to those in need.

For Muslims, when a person passes, certain spiritual rites must be fulfilled, from burying the deceased immediately, carrying out the funeral prayer and passing condolences to the family. During the pandemic, we saw a disproportionate impact on ethnic communities, mainly Muslim communities. The first deaths of the pandemic were Muslim

doctors and nurses on the front line. As we went on, we learned that due to factors like poor housing, latent health inequalities and lack of access to services, the death rate was higher for ethnic minorities.

This made the UK Commission on Bereavement work so important and why I became a commissioner for the report. The report looked broader than just the experiences of COVID19 but at the more comprehensive experience of grief, what was already in place and what needed to change. One of the report's key recommendations is to have a 'national strategy'.

Looking at Scotland in particular, this national strategy would include a coordinated approach to delivering support services and a focus on improving access to services for those most vulnerable or at risk of isolation following a bereavement. The importance of a national strategy cannot be overstated, as it would provide a clear framework for providing bereavement support services and ensure that resources are directed where they are most needed.

Another important recommendation of the Commission is to improve the training and education of healthcare professionals in Scotland in relation to bereavement support. This is a vital area for improvement, as healthcare professionals are often the first point of contact for individuals and families who have experienced bereavement. By improving their knowledge and skills in this

area, healthcare professionals can provide more effective support to grieving people, helping to reduce the risk of complications such as depression or anxiety.

The Commission's recommendations also highlight the importance of providing bereavement support services that are tailored to the needs of specific communities and cultural groups. This is a crucial area for improvement, as bereavement is experienced very differently across diverse communities. By providing culturally sensitive and appropriate support, individuals and families will receive the help they need to cope with their loss in a way that is respectful and meaningful to them.

It is so important that we get how we do bereavement right. We know so many people are dealing with delayed grief and processing the loss of loved ones. We also know just how comforting it can be when we can carry out the wishes of a loved one in the final parting of this world. That is why the work of the UK Bereavement Commission is vital to providing this framework, to take everyone through a journey in which all communities can access the support they need. I hope this roadmap can now be adopted by decision makers and really endorsed by service providers and broader communities. I hope that we can be proud of how we do grief, offering comfort and creating that society of compassion that we need most.



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The Scottish Bereavement Summit

Last October, over 130 people working within the bereavement sector in Scotland met online at the Scottish Bereavement Summit. The aim was that delegates could explore how to work together to improve experiences of bereavement in Scotland.

Three broad areas were up for discussion:

- **Formal bereavement services:** how can formal bereavement support services (which provide for example counselling and access to peer support groups) be strengthened and improved?
- Informal bereavement support: what can be done to support communities of all kinds (including workplaces, schools, families and neighbourhoods) to provide better informal support to people who have been bereaved.
- **Health and social care staff who experience multiple bereavements**: how can staff get the support they need at work.

Together, delegates took the opportunity to share their experiences of current challenges facing the bereavement sector, learn about recent publications on the subject, and discuss ideas and priorities for practical future action to improve bereavement experiences in Scotland.

Views were recorded and shared through a pre-conference survey, live digital questionnaire (Menti) and online flipchat (Padlet) during and following discussions.

The Bereavement Summit provided a chance for the bereavement community in Scotland to consider recently published reports/recommendations on bereavement issues including the Report of the UK Commission of Bereavement. It became clear that there is a growing consensus over what the key areas of focus should be in the future, and that the sector is keen to focus on *how* improvements can be achieved.

Summit discussions illustrated how those working within the bereavement sector can bring helpful insights into what kinds of changes might help and, more importantly, what might be do-able within the current environment.

They also provided helpful insights about what initiatives, projects and networks already exist that could be learnt from, built on or scaled up, rather than starting from scratch or duplicating what already exists. Delgates also provided valuable views on what areas should be priorities, how the 'system' can be improved, and what barriers exist.

These insights are been used to inform a Report and Recommendations which seek to reflect the Scottish context and experience and suggest practical ways of improving people's experiences of bereavement in Scotland. The final report and recommendations is expected to be published in Spring 2023.

Further information

A recording and presentations from the Scottish Bereavement Summit is available here: https://www.goodlifedeathgrief.org.uk/news/news/bereavement-summit---outputs/

Becoming a more bereavement friendly workplace: the Bereavement Charter Mark

Most people want to be supportive when a colleague or employee is bereaved. But sometimes it is difficult to know the right thing to do, and people worry about saying the wrong thing.

Though paid bereavement leave is important, being a bereavement-friendly workplace doesn't have to be expensive - a lot of it is about flexibility, sensitivity and good communication.

The <u>Bereavement Charter Mark for Employers in Scotland</u> aims to support and motivate employers to make their workplace more supportive of bereaved staff.

Having the charter mark on your website demonstrates that you are working to make your community a place where people who are bereaved feel supported by the people around them. But first, employers must agree to meet at least **three** of the following criteria:

- All staff are informed that their organisation is endorsing the Bereavement Charter and given an opportunity to watch a couple of short educational films about bereavement.
- All managers within the organisation have read the "Resources for Managers, Colleagues and Employers' section of the <u>Scottish Bereavement Friendly Workplaces Toolkit</u>.
- Senior Management has developed/adopted a Bereavement Policy for the organisation. (The ACAS <u>Example Bereavement Policy</u> provides a useful guide.
- The organisation has set out ways that it will visibly promote more awareness of bereavement and bereavement support, for example through its website and social media channels.
- The organisation has/will develop and display a <u>local workplace bereavement charter</u>.

There are lots of practical resources available to support employers achieve the Bereavement Charter Mark, all brought together on the <u>Scottish Bereavement-Friendly Workplaces Toolkit website</u>. The toolkit includes information for colleagues, managers and employers, as well as for people returning to work after a bereavement themselves.

The Toolkit includes links to training, resources, films, good practice guidance and bereavement support organisations. There's a <u>leaflet</u> giving some tips on the kind of things that a colleague can say or do to show support when someone is bereaved, and a <u>checklist</u> showing the various ways that an employer can create a supportive environment for bereaved staff.

Further information:

Bereavement Charter Mark for Employers:

https://www.goodlifedeathgrief.org.uk/content/bereavement_charter_mark_intro/ Grief in the workplace resources from Good Life, Good Death, Good Grief: https://www.goodlifedeathgrief.org.uk/content/bereavement_friendly_workplaces/



REBECCA PATTERSON
DIRECTOR
GOOD LIFE, GOOD DEATH, GOOD GRIEF

Grief Kind classes: video tutorials to help you support others with grief

Sue Ryder have published a series of five short video tutorials, to help people understand what grief can be like and how to support others who are grieving.

Class one: Is there a normal way to grieve?

In this first Grief Kind Class, Sue Ryder's bereavement experts answer a range of questions to help people get a basic understanding of grief.

Questions include: What does grief look like? Do men and women grieve differently? Do different cultures grieve differently? And what signs could signal that someone who is grieving might need more support?

Class two: What can you say to be Grief Kind?

This class provides advice on what to say – and what not to say – to someone who has been bereaved and is grieving. It also explores why listening is so very important when you're talking to someone who is grieving, and – crucially – what you should do if you feel like you've messed up and said the wrong thing.

Class three: What can you do to be Grief Kind?

Watch this class for advice on what to do to support someone you care about who has been bereaved and is grieving. It remind us that it's especially important to remember that everyone is different, and so what works for one person might not for another.

The video also contains experiences from people who themselves have been bereaved, sharing the support that they found most useful, which might help to give you some ideas of how you can support someone in your life.

Class four: How long does grief last?

In this Grief Kind Class, Sue Ryder's bereavement experts answer a range of questions to help you with answering this common question. Themes they look at include: How can you live with grief, and how can you help someone else to live with grief?

Class five: What can you do to be Grief Kind to yourself?

Being around someone who is struggling with grief, where you are doing lots of listening and supporting, can really take its toll. In this video, Sue Ryder's bereavement experts discuss how it is important for you to also look after yourself, as well as others, when you are in this supportive role.

They also look at where you might be able to find some extra help from, if you feel like you are struggling with the weight of supporting someone else with their grief.

More information

You can access the Grief Kind videos here: https://www.sueryder.org/how-we-can-help/bereavement-information/grief-kind/griefkindclasses

Every Story's Ending

Credit: Text above has been adapted from the Grief Kind website.

Every Story's Ending is a report by the Scottish Partnership for Palliative Care. It explores what can be done in Scotland to improve people's experiences of serious illness, dying and bereavement. The report sets out an ambition for what living with serious illness, dying and bereavement in Scotland could and should look like, and explores what matters to people when they are seriously ill, dying or bereaved.

Published in 2021, Every Story's Ending explains why these issues are so important to so many people, and why change is needed. It takes stock of recent progress, work underway and the current situation regarding living with serious illness, dying and bereavement.

Crucially, the report identifies key challenges and explores how to make change happen over the next 3-10 years. It identifies priorities and recommends actions that will make a positive difference to experiences of living with serious illness, dying and bereavement in Scotland.

Find out more about Every Story's Ending here:

https://www.palliativecarescotland.org.uk/content/everystorysending/ Watch this 6-minute film to find out more about Every Story's Ending: https://vimeo.com/599629808/c39805eb88

Death, dying and bereavement - some of the challenges for clergy

There is perhaps an assumption that members of the clergy are so familiar with matters of death, dying and bereavement that the challenges they bring are absorbed into the day-to-day rhythms of pastoral ministry. Of course, to some extent, that is true. But, in common with all areas of pastoral ministry, there is a wide range of experience, expectations and response. Conducting the funeral of an elderly person who had a gentle connection with the church is a very different proposition from

taking the funeral of someone who had been a very regular and well-known figure within that same church. Sudden death brings different needs from anticipated death. Once someone becomes too ill to attend services regularly, even a slow and well-managed journey to death can leave those within the church who weren't party to that journey feeling shocked and surprised. As a clergy person, one of your tasks is to deal with the fallout.

Let's consider a couple of scenarios:

Peter is a 33-year-old man who is a member of a small church with a strong emphasis on community. He has been diagnosed with a treatable form of cancer. Unfortunately, he doesn't respond well to the treatment and within months the prognosis is very poor. The challenges for his clergy and pastoral support team include: dealing with their own shock and distress; processing for themselves the idea that someone who is so young is dying; finding ways to support the rest of the community through that dying process; managing the desire of members of the community to see/say goodbye to Peter whilst, at the same time, recognising that Peter has limited energy which he needs to conserve for those closest to him. After Peter has died, there is an ongoing need for

community support and care. In ordinary circumstance, this is a community where peer support is a cornerstone. In this situation, people are finding it very difficult to support others because they are so impacted themselves.

Sharon is a woman in her 70s. She has been a lifelong member of her large congregation. She is someone who is known to most regular attenders at the church – she makes a point of speaking to visitors and does a number of volunteer tasks. Sharon's cancer diagnosis comes as a shock to her and to those who know her. She doesn't ever manage to return to church. She is regularly prayed for, and a small number of people receive updates from her family, but when her death is announced it comes as a surprise to a great number of people. She has a large funeral which honours who she was in life. People speak for many months afterwards of the Sharon-shaped gap within the congregation.

Each of these scenarios presents particular challenges to the clergy person(s) tasked with pastoral care of those communities. In both situations, the clergy person is dealing with their own emotional response to the situation. But they will probably be helped to manage their own processing by virtue of the need to plan and lead a funeral service.

Funeral planning is often a good way into teasing out and processing some of the emotions that emerge. Funeral planning (ideally with the person before they have died) allows us to share important memories; to honour the areas of life that were most important for that person; to ensure that the funeral feels like a personalised service, focussing on that individual and the people closest to them. Funeral planning allows for tears and laughter; for an acknowledgement of what might not be said; for reflecting on life and faith and for sharing time prayerfully. The best funerals incorporate time to grieve and time to give thanks. If they are Christian funerals, then they give space for a message of hope and a belief in eternal life. The best funerals allow the clergy person concerned to journey through their own grief process and to feel that they have some kind of closure on their engagement with that person.

It can be more difficult to find a way into conversations about mortality. People think that they want to have the conversation and then find numerous ways to avoid it. I have done training days for Faith in Older People based on the Death Café format.

Here are the questions I have used:

Appetiser:

What do I want people to remember about me? What do I want people to forget about me? What is my legacy?

Main course:

Where do I want to die? What are my fears? What are my hopes?

Dessert:

How do I stick with the difficult conversations? How do I help others back to the tricky topics?

What do I do when I feel uncomfortable?

It is often by working through these questions/issues for ourselves that we become more confident in working through them with other people. My experience suggests that when we are confident to have the conversations that are necessary, we are able to create a safe enough space for that to happen. When people become chronically ill, they spend a lot of time as a patient. Medical professionals ask them questions on a regular basis. Those same medical professionals are the people who are in a position to prescribe treatments that may make a significant difference. They may also control access to other forms of support and care. As clergy/pastoral carers, we only have ourselves to offer. One thing we can bring is honesty. Our task is not necessarily to make people feel better, but it may be to initiate a conversation that leads to them feeling better. For instance, someone may be feeling very angry about their situation. There are probably few people they can have that conversation with. They may be trying to protect their loved ones from their feelings. We can offer safe space to say whatever is necessary; to explore whatever is of concern; to offer unconditional listening and response. We can find ways to use the language of reality – finding ways to talk about the changes that are occurring; speaking about the journey that the person is making; not being afraid to talk about death.

Framing the conversation within a language that speaks of chapters of life may be a helpful tool. That allows us to talk about what might be possible within this particular chapter, whilst acknowledging that some other options are no longer possible. It's a way of grounding conversations in the here-and-now, of bringing a gentle reality check that can sometimes be liberating.

Clergy who have done some personal processing are best placed to offer support to others as they do their own processing. The end result can be days lived well and a journey towards a good death.



REV CANON DR MARION CHATTERLEY ST MARY'S SCOTTISH EPISCOPAL CATHEDRAL, EDINBURGH

Good Life, Good Death, Good Grief

Good Life, Good Death, Good Grief is an alliance of people and organisations that are interested in improving people's experiences of death, dying and bereavement in Scotland.

We are particularly focused on enabling communities and individuals to support each other through the difficult times that can come with death, dying and bereavement.

We believe that people usually want to do the right thing when someone they know is affected by ill health, death or grief.

But sometimes other things get in the way – lack of knowledge, time, experience or confidence can mean people don't offer help. Structures, culture and conventions can create barriers to individuals acting on their intuition.

Good Life, Good Death, Good Grief wants to address this. We want to create a Scotland where everyone knows how to help when someone is dying or grieving.

We also believe it is important to be prepared for illness and death – there are some practical steps that everyone can take to increase their chances of receiving the support they'd hope for towards the end of life.

What does good life, good death, good grief do?

- We run annual participative events such as Good Death Week and the To Absent Friends
 festival, creating opportunities for people to take local action to increase knowledge, skills
 and confidence.
- We proactively encourage local and national media engagement and dialogue.
- We identify and share good practice, learning from and engaging with practitioners within Scotland and internationally.
- We provide networking opportunities for our members.
- We publish a monthly newsletter for our members, sharing the latest developments, events and news in Scotland and beyond.
 - We provide information resources and practical tools for our members, making them freely available on our website.
 - We run small grants schemes to support local activities by our members.
 - We work to influence public policy.
 - We run a website that provides and signposts to resources for people who are dealing with death, dying and bereavement in a personal capacity.

More information

If you'd like to join Good Life, Good Death, Good Grief or find out more, sign up for our monthly newsletter here https://www.goodlifedeathgrief.org.uk/content/sign_up/ or check out our website: www.goodlifedeathgrief.org.uk

Demystifying Death Week

Demystifying death week is about shining a light on death, dying and bereavement in Scotland.

People usually want to do the right thing when someone they know is caring, dying or grieving. But often they can feel awkward offering help, or worry about making things worse.

People can have questions about serious illness or death. But often they don't know who to ask.

Making plans when you're healthy means there is less to think about when you're ill. But often people put off making plans until it is too late. Demystifying death week is about giving people knowledge, skills and opportunities to plan and support each other through death, dying, loss and care.

Get involved

Each year, organisations and individuals across Scotland organise events to mark Demystifying Death week. All kinds of events take place, from death cafes to film nights, exhibitions to craft workshops, seminars to lunches.

Would you like to be involved with this year's Demystifying Death Week? More information is available here: https://www.goodlifedeathgrief.org.uk/content/demystifying death week 2023/

The EASE course, its benefits, reactions and the potential

What is End of Life Aid Skills for Everyone? End of Life Aid Skills for Everyone (EASE) is a course designed to enable people to be more comfortable and confident supporting family and community members with issues they face during dying, death and bereavement. The

EASE is delivered free of charge by volunteer EASE Facilitators. It is designed for members of the public in Scotland, and welcomes adults of all ages, experiences and walks of life. Each person who participates in the course brings with them their own unique life experiences, and as well as learning from course materials, participants will learn from each other.

EASE participants work through four modules over four weeks designed to build confidence and comfort around issues relating to death, dying, loss and care. A key element of the course is the focus on peer learning and discussion, which helps build a sense of community.

What are the aims of the EASE course?

The course teaches the basics of end-of-life care and addresses some of the fears and uncertainties frequently held by members of the general public. It aims to help people to:

- Become better equipped to provide informal support to friends, family and community members dealing with death, dying and bereavement.
- Find it easier to deal with these issues when they have to face them themselves.

course has been developed by the <u>Scottish</u> <u>Partnership for Palliative Care</u> (SPPC) and is based on the belief that although we may not realise it, or feel like it, we all have an innate ability to support and care for each other through difficult times.

 Know where to find further information and support in relation to these issues.

Some of the questions the course can help to answer include:

- How can I navigate the health and social care system in Scotland?
- What issues might crop up when someone is approaching the end of life?
- What medicines and treatments can help when someone is dying?
- How can I plan ahead for ill health and dying?
- What emotional issues might affect someone who is dying?
- What support can a friend or family member offer to someone who is caring, dying or grieving?
- How do I offer help without interfering?
- How can you look after yourself when you're looking after someone else?

EASE Online

EASE was intended to be a face-to-face course and was first piloted in 2019. When face-to-face delivery became impossible during the Covid lockdowns, SPPC developed an online version. EASE Online is delivered via the online learning platform Moodle, with the discussion element facilitated via Zoom. Participants work through

the modules – which have reading, films, activities and discussion forums – in their own time through the week, then the group gets together via Zoom to share reflections.

The online course has been very positively received. One participant said of their experience: "I thoroughly enjoyed the EASE course, meeting people from different areas, backgrounds and experiences. A lovely learning environment that created a safe place for people to share and contribute." While another participant said they found the course "very helpful on both an emotional and practical level."

EASE In-person

As it's now possible to facilitate in-person gatherings, SPPC are working hard to get the face-to-face version of EASE off the ground again.

Who are EASE facilitators?

Each EASE course is supported by two volunteer EASE Facilitators who work together to create a welcoming environment, facilitate group discussion, move the course along, and ensure the course content is covered.

No special experience is needed; anyone who's completed the EASE course can go on to do a short facilitator course. People from all backgrounds and experiences are welcomed and encouraged to become EASE facilitators and are then supported to go on to organise and run courses for their own communities and networks.

What's next?

EASE Online has demonstrated how a digital approach can increase access for many, and SPPC will be continuing to support facilitators to offer the online course. The updated version of the face-to-face course will be rolled out in early 2023, and volunteer facilitators will be trained and supported to deliver EASE in the way that suits them and their communities best. The hope is for EASE to reach as many people in Scotland as possible and help build their

This version of the course consists of four weekly two-hour sessions, delivered by two volunteer EASE facilitators, in a venue local to the course participants. Participants work through activities and watch films together and are invited to share their reflections and stories through small group discussion. And course there is always plenty of tea and biscuits on hand.

When asked what they would take away from the face-to-face course, one participant said "a new strength in being able to help, plan and offer support," while another said they'd found "a sense of...being a community to deal with aspects in end of life care".

Another participant of the face-to-face course said "EASE provides a fantastic breadth of information, opportunities for reflection and opportunities for connection with others."

confidence and comfort supporting friends, family and community members during the difficult times that come with dying, death and bereavement.

You can find out more information about EASE here:

https://www.goodlifedeathgrief.org.uk/content/ease/ or email caroline@palliativecarescotland.org.uk



CAROLINE GIBB
COMMUNITY DEVELOPMENT LEAD
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PALLIATIVE CARE

It's Never Too Early to Plan for the Future

At the heart of Anticipatory Care Planning (ACP) is a conversation about what matters to you and what you would like to happen in the future. It can cover a range of topics from where you might live, if you can no longer safely live by yourself, to what types of treatments or interventions you would or would not like to receive, and everything else in between. It might contain information about upcoming life events you are excited about, or who could look after the dog if you became unwell. It might outline certain rituals that bring you comfort, or activities which can offer your mind and soul restoration. Just as every one of us is unique, so too are our plans.

However, the beauty of an anticipatory care plan lies in the fact that it grows around you. As conversations build, as situations change, the plan can adapt to reflect your current thoughts and feelings. And whilst we cannot plan for every eventuality, in times of crisis, when someone may not be able to speak for themselves, these plans can provide certainty and reassurance. It guides decisions by providing a full and rounded picture of a person - their life, preferences and motivations. It helps to answer the question "what would someone chose for themselves?"

So how do you begin to plan for the future? The good news is there are lots of tools out there to help you get started. The NHS Greater Glasgow and Clyde (NHSGGC) <u>Planning for Care webpages</u> (<u>www.nhsggc.scot.planningcare</u>) contains lots of information including leaflets and even a template ACP Summary which you can access. However lots of third sector organisations and condition specific charities have their own versions too. The important thing is finding something that works for you and then take things step by step.

First of all, think.

This is the most important part, so give yourself time and space to consider what is important to you. You may also want to think about some other questions like:

- Why these things important to you and what are your motivations?
- Who is important to you and how would you like them to be involved in any discussions? This
 may also lead you to think about Power of Attorney (again lots of <u>information available on the</u>
 NHSGGC Planning Care webpages).
- Where would you like to be at different times in your life? This might be about where you would want to live in future, or maybe about where you might like to be when you die.
- And lastly how are things just now? Do you have any health concerns and how are you coping with daily tasks?

Next up we need to talk.

This means talking to your friends, family and any professionals involved in your care. By doing this we make sure everyone is on the same page and we all have realistic expectations about what the future may look like.

And finally we plan.

Depending on where you live, different Health Boards will use different pathways and systems to ensure that your wishes and preferences are recorded and shared with other professionals who need to know. If you are not sure what the local process is, begin by talking with your GP or any

Health and Social Care teams who you are already engaged with. They should be able to point you in the right direction.

But it's not just the professionals who need to know. Make sure you also share a copy of plans with family, particularly if they are also your Power or Attorney. Just think, if you were in their position what information would you find useful if you had to make any decisions?

So there we go, in three simple steps you have prepared for the future. And whilst no one knows what lies ahead, at least we have the confidence that whatever may come, we have a guide to help us plan.

JENNY WATT

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Jenny is currently the ACP Programme manager for NHSGGC, spending her days encouraging staff and the public to have tender conversations that delve into the heart of what it means to be human.

It is better when we work together

When you, or someone you know, is bereaved it someone is grieving. When someone is first is a bewildering time. There are so many things that happen at the beginning that need attention. It can feel completely overwhelming.

Bereavement challenges us in many ways, including physically, cognitively and spiritually. It Often cards and condolences are sent and our is a period often of much adjustment and can often be intensely difficult to navigate.

Often when we are bereaved it is a time where we need support. There are lots of ways in which we might give or receive support when

bereaved there is often a lot of support offered in lots of different ways – bringing a casserole, shining shoes, offering to look after the children while things are sorted out.

grief is acknowledged. However, after a time this support seems to stop – we feel like life has moved on around us and everyone has forgotten our intense pain and feeling of being 'lost'.

Grief is lifelong, it changes us as people and we have to learn to accommodate it, and keep accommodating it in different ways at different times, but we don't get over it and we aren't cured. We continue to need the support of those around us.

Most of us will cope with grief with the support of family and friends – especially when those people really understand our ongoing needs and the ups and downs of our grief. Sometimes though we might need a bit of extra support – and this in itself can be really challenging. Finding the right support to fit our needs can be really difficult – sometimes it is so difficult we give up looking. That's where the work that we have been doing at Child Bereavement UK comes in.

Since 2015 Child Bereavement UK has been building local bereavement networks across Scotland. There are currently 12 local bereavement networks. These networks exist so that there are opportunities to support each other, learn together, have knowledge about the services in an area that can support those who are grieving and lots more. There are significant challenges to signposting – but the networks really help give information about all different aspects of support that can be beneficial to people who are grieving in a particular area. The aim is to have a 'no

wrong door' approach – which means if you are looking for support, whichever door you knock on means you should get to the right support for you.



Local Bereavement Networks in Scotland

In the last two years we have brought together all the local networks, by having a National Network Event. This has allowed organisations to come together from across Scotland – to network, learn and share good practice to help to further continue to close the gaps in support and widen out the meaning of what bereavement support is, and how it supports those who are grieving. Our aim is to continue to work together to make sure that those who are grieving get the right support at the right time.



Some of our learning from our National Network

If you are interested in joining a local network, or learning more, contact me directly to have a chat. You can contact me at: Jennifer.somerville@childbereavementuk.org

Child Bereavement UK also has lots of training opportunities available across Scotland, and further afield, and I would be happy to chat through options and provide more information around this. More information on all our work in Scotland can be found here:

https://www.childbereavementuk.org/scotland-development-project



JENNIFER SOMERVILLE
BEREAVEMENT CO-ORDINATOR,
SCOTLAND
CHILD BEREAVEMENT UK

Churches & Bereavement Friendly Communities

What are Bereavement Friendly Communities?

Communities are bereavement friendly when individuals, businesses and organisations work together to support anyone in their community who has been bereaved. Death is part of life but is something we can't learn how to deal with in advance. Bereaved people often just need to talk, have their loss acknowledged or simply know that their loved one was valued. Whether or not we have had training, we can all provide a place to talk and listen. Whether you are a hairdresser, pub landlord, postmaster, part of a church or school or just a neighbour, help make your village or town a Bereavement Friendly Community. A death in our community is a loss to everyone.

How churches can contribute

Being bereaved can be one of the most difficult times in life, and the grief journey can be long and arduous. It can impact in the weeks, months or even years after a death – and even before, when someone is dying. But if understanding support is found, most people will learn to navigate their loss and come to a healthy place of new meaning and hope. Bereavement also raises spiritual questions and can leave people wondering about the goodness and existence of God and the afterlife.

Churches are in every community and are well placed to provide the support that is needed. That's why AtaLoss launched the Loss and HOPE project in 2020. The timeliness of the project launch, just as the pandemic was starting, has given churches the opportunity to lead the way in the provision of bereavement support in their communities.

How churches are providing bereavement support



The aim of the Loss and HOPE project is to equip churches across the UK to become more *bereavement friendly*. This is being achieved through

1. Training

- * Bereavement Care Awareness (how to support adults)
- * ListeningPeople (how to support children and young people affected by loss)
- * Bereavement Friendly Church webinar (for church leaders and pastoral workers)

2. Resources

We have developed a tool called *The Bereavement Journey* - a six-session programme of films and discussion where people can process their loss in groups with others who have experienced bereavement. The Loss and HOPE project provides the materials, the training and the support that any church will need to successfully deliver the programme in their community. Find out about The Bereavement Journey HERE

How can my church get involved?

More and more churches are becoming involved! Have a look at the map <u>HERE</u> to see churches already delivering *The Bereavement Journey* across the UK. More details about each course can be found in the bereavement services section of this website. The materials can be acquired from the dedicated website <u>HERE</u>. They can be used for running The Bereavement Journey face to face or on-line.

Ata**Loss** also runs a national on-line The Bereavement Journey course three to four times a year which we use as an opportunity for churches to get their teams trained in readiness for running their own course. And on-going, our Loss and HOPE Project team, provide support and advice. Contact the Project Manager if you have questions.

For more information about the Loss and HOPE Project and the resources available go to the website HERE.

The Loss and HOPE project is managed by AtaLoss but is a coalition of organisations who feel passionately about churches of all denominations across the UK being equipped to provide bereavement support in communities. Members of the coalition are AtaLoss, Care for the Family, the Church of England and HOPE Together.

CONTACT THE LOSS AND HOPE PROJECT

LINKS

TENDER CONVERSATIONS

We were delighted that Dr Kathryn Mannix and the Rt Rev Richard Holloway presented our annual Lecture on **Thursday 12th May 2022**. The focus was *'With the End in Mind'*: *Tender Conversations: how can we navigate conversations about sorrow, fear, and loss?*We are delighted to be able to share with you, the recording of the Lecture: https://youtu.be/5H741pZRtAk

BEREAVEMENT SUPPORT: FURTHER RESOURCES

The following websites provide direction to further information and support about bereavement:

- Good Life, Good Death, Good Grief: https://www.goodlifedeathgrief.org.uk/content/after_death/
- At A Loss: <u>www.ataloss.org</u>
- Good Grief Trust: www.thegoodgrieftrust.org/

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This Newsletter, devoted to be reavement, was compiled by Rebecca Patterson, Maureen O'Neill and Mary Wilkinson. We thank all the contributors for making this publication so wide ranging and informative.

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