

# NORTHERN IRELAND BEREAVEMENT NETWORK World Café Conversations

Report of World Café held on 27th February 2023

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## 1. Introduction

This Report has been prepared as a summary of key messages and outputs from a World Café held on 27<sup>th</sup> February 2023. The **purpose** of the World café was to talk about the various strands of work that the NI Bereavement Network (NIBN) has been leading on with a view to bringing these together in a way that will best help people experiencing bereavement and realise the vision for future services and the framework for delivery.

In April 2020, Professor Sir Michael McBride commissioned the Covid 19 Bereavement Network to develop resources to support the bereaved during the pandemic. A Report was produced with 7 recommendations for the improvement of services to support bereaved people. The NI Bereavement Network has been tasked with implementing these recommendations. The Network was established at the direction of the Minister in May 2021 and reports to the Chief Professional Officers, DoH. The work is cross sectoral and co-produced. Four sub-groups are driving delivery, namely, the Bereavement Strategy sub-group, a Charter for Northern Ireland sub-group, a Training and Education sub-group, and the Bereavement Website sub-group. The World café was designed to engage a larger group of people in dialogue about implementation of the key recommendations relating to the work of each of the sub-groups.

## 2. Welcome

Peter May, Permanent Secretary, Department of Health, welcomed participants to the workshop and expressed his commitment to the work of the Network. The Permanent Secretary announced that funding has been designated to the establishment and running of a Bereavement Website.

Patricia Donnelly, Chair, NI Bereavement Network, added her welcome to the Café participants, both present in PRONI and online. Patricia described the background to the work of the Network.

## 3. The World Café Approach

Irene Hewitt, Associate Consultant, HSC Leadership Centre, facilitated the World Café along with Fidelma Carolan, Senior consultant, HSC Leadership Centre. Irene summarised the World café approach as a simple but effective approach to engage a large group of people in dialogue. It is an opportunity to talk with purpose in a relaxed Café atmosphere. The Conversation Menu is attached as **Appendix One**. Participants were asked to introduce themselves at tables and on line ahead of several Guest Conversationalist inputs.

## 4. Sponsor Perspective

Professor Sir Michael McBride, Chief Medical Officer, (CMO), shared his perspective on bereavement with particular focus on the last three years. Over 17,000 people

die each year in Northern Ireland. On average, 5 people are directly affected by each bereavement (that is, 85,000 are newly bereaved each year). The pandemic brought difficulties including restrictions on family access to loved ones at the end of their lives, also disruption to funerals and the normal rituals associated with dying and death, including supports from other family members and friends. These experiences have added to the importance of caring for the bereaved. CMO expressed his ongoing commitment to this work.

## 5. Our Context

Patricia Donnelly, Chair, NI Bereavement Network, explained the broader policy context for the work, with '**Living, Dying Grieving**' as a conceptual framework for connecting:

- ◆ the important **life choices** associated with preparing for significant life changes, not least as people face the end of their lives - **Advance Care Planning** is the formal expression of this;
- ◆ the supports necessary for people as they face the end of their lives - **Palliative Care** is a formal component of this;
- ◆ The supports necessary for those left behind when someone dies to help them in their grief journey – the **10-year bereavement strategy** is a formal component of this.

Patricia then shared a 'whole society' model for bereavement support:

- ◆ **Compassionate Society** with high levels of bereavement/grief literacy in the society and community response. Bereaved individuals supported by family, friends, faith groups etc. Community response/ public memorials/ commemoration events
- ◆ **Non-specific bereavement** support available as part of other services. Self-help bereavement resources and support (e.g. psycho education/online resources etc). Support from GPs, Hospital/Hospice support staff, social care workers
- ◆ **Focused specific** bereavement support services. 3rd sector & HSC bereavement services support, helplines, community counselling.
- ◆ **Complex grief** specialist treatment services.

## 6. Café Conversation One: Developing a Bereavement Charter for NI

Meadhbha Monaghan, Head of Operations, Patient and Client Council (PCC), set the scene for the first café Conversation. Meadhbha explained that the PCC in partnership, are supporting the NIBN to ensure voices with experience shape bereavement services and supports, and help to shape standards for how we respond to those who have been bereaved across our communities. The first step in this is developing a Bereavement Charter for Northern Ireland.

A Bereavement Charter sets out pledges to bereaved individuals and loved ones about the standards of service and care they should expect to receive following the death of a loved one. Key themes arising from engagement so far were noted as follows:

- ◆ The need for **more support services & better signposting** to organisations that can help as people grieve
- ◆ Every **death needs to be valued** regardless of the circumstances of the death. No *'hierarchy of deaths'*
- ◆ As a society we need to **be more open about death and dying**
- ◆ People need **space and time to grieve**. People feel there is often a pressure to return to work too soon.
- ◆ The **impact of Covid-19** restrictions on mourning and ceremony - being unable to be there with loved ones and go through the 'ritual' of wakes, funerals etc which can have impact mourning process.

Meadhbha introduced twelve statements with potential for inclusion in an NI Charter, which had been proposed by those engaged throughout the process:

### Possible Charter Statements

To minimise pain and suffering	To support relatives and friends before and after the death	The need to recognise and respect cultural beliefs on death
Society needs to be educated on bereavement 'death literacy'	Support being available to all at a time that is right	There is no set way or time limit of feeling or grieving
Every death is an individual regardless the circumstances	All deaths are of value regardless of how the death occurred	Recognition that nothing can prepare you for the impact of death and that shock can be felt in planned and unplanned deaths
The wishes choices and beliefs of the bereaved and the deceased are respected	Acknowledge grief can be planned and unplanned	Recognition that death is a natural part of life

The first Conversation focused on 3 questions:

1. Do the statements resonate with you?
2. Is there anything missing?
3. How would you say these in your own words?

## **Key Messages from Charter Conversation**

### **In general**

- ◆ There was consensus that the ethos and intent behind the draft charter statements resonated with people. However, the language of some statements can be improved. Language should be simple and avoid jargon.
- ◆ Whilst statements should be aspirational, concern was also expressed about the need to manage people's expectations about the support available.
- ◆ Could statements better reflect a pastoral care approach to the bereaved (emotional, social and spiritual support)?
- ◆ We need to ensure that vulnerable groups, such as children, individuals with a learning disability, individuals with mental health issues etc., who may be non-verbal or have difficulty expressing grief, have access to tailored bereavement support.
- ◆ The statements were noted as adult orientated, reflecting circumstances related to adult death or adult experiences of bereavement. There is a need to consider the younger generation and to engage them in the Charter work, seeking understanding of how they experience death. Young people will have been less exposed to death and the ceremony or tradition surrounding it because of the pandemic. Consequently, there may be an increased need to focus on education and support for the younger generation on death, grief, loss, and bereavement.

*Suggestion: That young people be involved early in the subgroup discussions, possibly as members of the sub-group.*

### **By statement**

#### **To minimise pain and suffering.**

It is not possible to 'minimise' pain, and 'pain' is a broad term (physical and psychological pain). What is important is supporting before, during, and after loss. Individuals and families need to experience the pain and suffering journey as fully as they wish – they need support for the journey and not necessarily minimising it. This is a frightening statement for some, as it suggests pain and suffering in death.

#### **To support those closest to me before and after the death.**

To also support at the time of death. The experience of bereavement and loss varies by individual and therefore requires a personalised response – there shouldn't be an expiry date on support.

#### **The need to recognise and respect cultural beliefs on death.**

Cultural beliefs and rituals should be respected. There is a need to reflect diversity and an understanding of what is meant by 'cultural beliefs' – does this include religious and/or societal background? It is also easy to forget the compassionate society - most people are understanding.

*Suggestion: Ensure more diversity in cultural representation.*

**Society needs to be educated on bereavement ‘death literacy’.**

‘Death literacy’ is not well understood and needs explained. Statements should focus on the storytelling, the memory and narrative response we have to death, grief and bereavement.

**Support being available at a time that is right.**

The right time is when the bereaved person says it is. Could this become the ‘Right support available at the right time’? Age-appropriate support for people is important. Families need to know how to access the support. A rapid response needs to be available for those who need it. There should be equity of service. The focus of bereavement is not on one person, but possible at least another four people – how do we ensure the spread of support for all?

**There is no set way or time limit of feeling or grieving.**

There is also no right or wrong way to grieve. The experience of grief can be one of growth; the process is an adjustment to change. What does ‘feeling’ or ‘grieving’ mean? When it’s too much for too long, extra help is required.

**Every death is an individual regardless of the circumstances.**

When does someone become an individual? Consider stillbirth or miscarriage. All deaths are unique.

**All deaths are of value regardless of how the death occurred.**

All deaths are important. The circumstances of a death will impact on bereavement e.g., a death in prison.

**Recognition that nothing can prepare you for the impact of death and that shock can be felt in planned and unplanned deaths.**

Death may not be a shock at all. Death and subsequently grief can be planned or unplanned but can also come with unfinished business. Recognise the impact of compounded loss.

**The wishes, choices, and beliefs of the bereaved and the deceased are respected.**

This was seen as very important. The need to allow people to know they are dying so they can have the important conversations and plan their care.

**Acknowledge grief can be planned or unplanned.**

What does this statement mean? Death can be planned or unplanned - can grief be planned?

**Recognition that death is a natural part of life.**

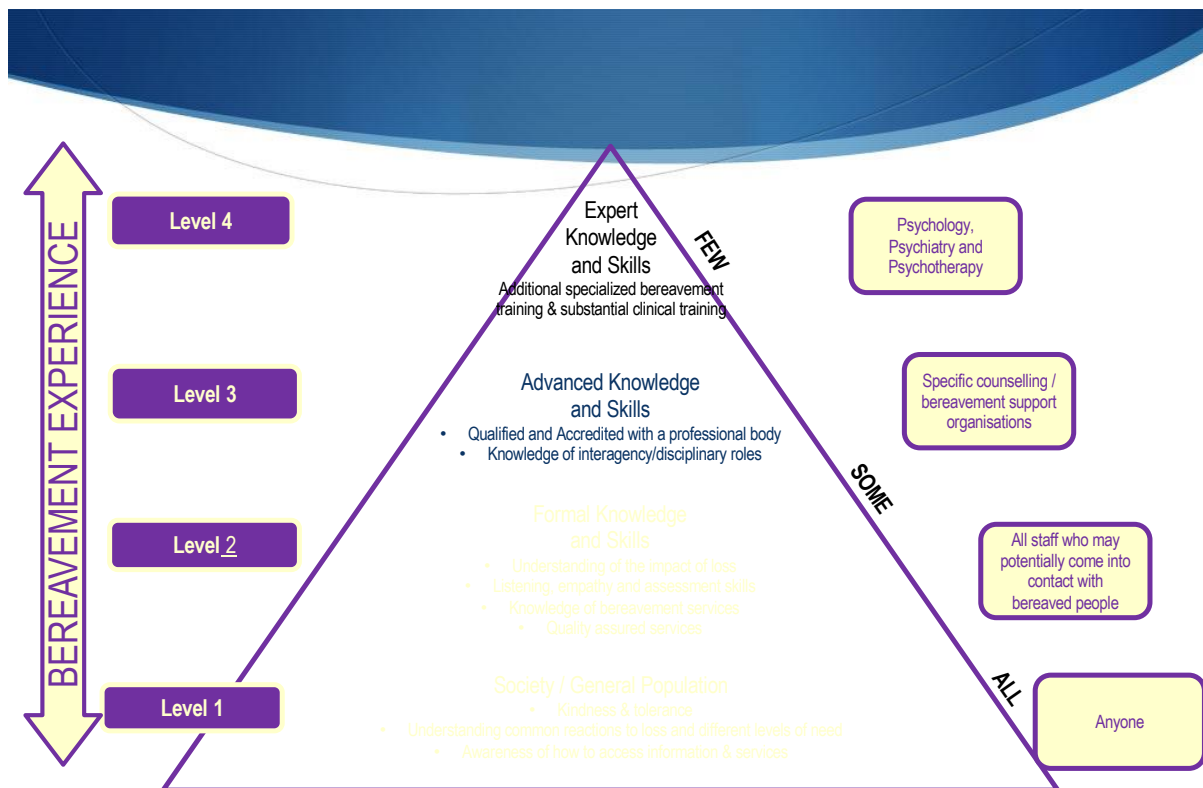
This does not appear to cover sudden deaths, such as suicide or murder. The death of a child is not considered to be ‘natural.’ Natural death is very important, especially with a medical model of keeping people alive, extending life, and not allowing a natural death to happen. A suggested change was to ‘*recognise that death comes to everyone and can be at any time.*’

## 7. Café Conversation Two: Education and Training / Website

In this session participants had an opportunity to discuss one of two areas, either Training, Education and Awareness or an NI Website. Both areas were introduced in Plenary.

### 7.1 Education and Training

Paul McCloskey, Bereavement Coordinator, South Eastern HSC Trust, described the background to Bereavement Education and Training. Paul referred to the Adult Bereavement Care Pyramid and linked this to the knowledge and skills required by the largest grouping, that is, the general population, and then those required by all staff who have the potential to come into contact with bereaved people (See Figure below). Outside of the scope of conversation was the advanced knowledge required by specific counselling/bereavement support organisations or the expert knowledge and skills of Psychology, Psychiatry and Psychotherapy.



Paul also introduced a definition of Death Literacy, from a recent Marie Curie Report<sup>1</sup>, that is, the knowledge, skills and awareness of issues concerning death, dying, end of life care and bereavement.

This conversation focused on two questions:

<sup>1</sup> Creating a death literate society – The importance of boosting understanding and awareness of death, dying and bereavement in Northern Ireland, Marie Curie, 2022



1. What is required to raise the death literacy of society in Northern Ireland?
2. What knowledge and skills would a person require to provide care, before, at the time of, and after a death (with reference to communication skills)?

### **Key Messages from Education and Training Conversation**

#### **What is required to raise the death literacy of society in Northern Ireland?**

- ◆ Make it less of a taboo subject – what we talk about we fear less.
- ◆ Remove all jargon and keep language simple. The words ‘death literacy’ need better explained so people are more aware.
- ◆ Ensure the right information is available to people when they need it.
- ◆ Discuss the importance of having a plan for dying – Advanced Care Planning.
- ◆ Start as early as possible. We experience death and loss at all ages; it needs to be talked about as a normal experience in life; in some families and traditions it is hidden.
- ◆ Raise awareness and provide training and support within schools. Schools need the right information and skills to support bereaved pupils as well as teachers impacted by death. Provide resource packs to support pastoral care within schools.
- ◆ Build on work already in place, connecting, signposting and communicating the resources already available through public campaigns, regional libraries, social media, community newspapers etc.
- ◆ Establish a Dying Matters (Living, Dying, Grieving) week. Simple messages. Good signposting.
- ◆ Coordinate awareness raising sessions across all of NI.
- ◆ Information stands/pop up shops at local community events.
- ◆ The Here2Help App is fantastic as an App for signposting support services available locally.
- ◆ Empower people – provide resources/supports to hairdressers, taxi drivers, florists, shop workers, funeral directors, council workers etc as they are faced with bereaved people every day.
- ◆ Understand disenfranchised grief - minority groups need information and education to support them and the wider community.

#### **What knowledge and skills would a person require to provide care, before, at the time of, and after a death (with reference to communication skills)?**

- ◆ We need a skilled workforce to support bereaved people at all 4 levels of the pyramid. The levels of training needed are different but the core fundamentals of supporting people through grief and bereavement are the same. Making people aware that level 1 is where most of the public are, and that grief is a normal response to death.
- ◆ All staff should have a baseline understanding of loss and grief and some training in communication. There are training sessions available to staff – unfortunately staff do not see importance of attending. Training should be mandatory for all staff.

- ◆ An objective of the education strategy should be to elevate the importance and benefits of training.
- ◆ Develop a simple script of Dos & Don'ts for staff and others.
- ◆ All staff should have access to bereavement information.
- ◆ Core skills are to be present in the moment and to take the time to listen; not offering advice if you have no answer. Acknowledge loss and listen to understand.
- ◆ Communication is key. Advanced communication skills should be more readily available to staff working at different levels.
- ◆ Be honest.
- ◆ Clarify and simplify the language we use: what is the difference between palliative and end of life care?
- ◆ There should be more communication with people pre-death (anticipatory grief stage).
- ◆ Social work training should include knowledge and training to support people experiencing loss and bereavement.
- ◆ Connect and signpost resources – Community and Voluntary sector may have good training to share and vice versa. Resources already exist but it's about how we access them. It's pulling them together.
- ◆ Awareness raising and information for staff could be placed on Trust Health Improvement wellbeing sites for staff.
- ◆ There are a wide range of people who come into regular contact with those who are bereaved or dying, including, sheltered/supported housing staff, day care workers, healthy living centre staff, community development workers, HR staff in business, peer support workers, Colleges, Trade Union representatives, sport coaches, youth workers, HIHE staff.

## 7.2 Website

Carole McKeeman, Bereavement Coordinator, Western HSC Trust, set the scene for conversations about the development of a Bereavement Website. Carole asked participants to consider the information required at all stages of the bereavement journey, Living, Dying, and Grieving. The website needs to work for all ages, all circumstances, and be reflective of Northern Ireland. The web site will bring together information on all the work streams and support both the public and staff. Carole set a challenge for everyone, to come up with an easily remembered name for the web site.

The questions that framed this set of conversations were:

1. Bereavement Care Information: What did you need / when did you need it?
2. The Website: A new website will bring all the information together in one place - what would you like to see included on the site?
3. The Name: What easily remembered name would you give to the new website?

## Key Messages from Website Conversation

### Scope

- There should be no ambiguity about what the site is for – the death of a person and associated bereavement. Information and support for patients, staff, families, carers along the living, dying, and grieving journey.
- All deaths - be specific about types of death, including stillbirth, miscarriage, termination of a pregnancy, death of a child, death of a parent, sudden death, suicide, homicide.
- Providing practical information, resources, contacts and links.
- Represent continuing support for bereavement with the Infinity symbol ∞ through living, dying, and grieving. Would everyone understand this symbol?

### Who

- Separate professional section (professional supports available, bereaved professionals, complex psychotherapy resources etc.)
- Public sections
- Family members (Next of Kin, Children, siblings etc.)
- Carers – Loss of role, identity, and bereavement
- Teachers and others who encounter bereavement.
- Young people.
- Multicultural
- NB. raising awareness with Hairdressers, Taxi Drivers etc.

### Technical

- Website needs a dedicated person to administer the website, ensure regular updating, manage associated social media and potential APP.
- Links should be clear, direct and live.
- Different formats and translations to meet different needs.
- Filter system for quick navigation, to access information quickly (a few clicks of the mouse). e.g., I am Bereaved – type of death –circumstances of death.
- Intuitive – what are the good questions? Link Guides/Resources to the answer you need.
- Advertised well and with clear purpose.
- Administration of website – very big role - who will do this long term – funding needed for staff member to administer website /social media and potential App?

### Resources

Practical information about each of the following was suggested by participants. For each there should be contact details, relevant web links and ability to print off information leaflets.

- Explanations of bereavement and grief – duration of grief – may erupt again and again over time e.g., anniversaries and birthdays.
- Funeral directors (who to ask- average cost of a funeral).
- Clergy

- Legal issues for Next of Kin (NOK) – financial issues, bills, benefits, and wills.
- Registration of death
- PSNI - why Police may be involved links.
- Coroners, post mortems and inquests – what, why, how?
- General Practitioners.
- Registration of a death – Registrar
- Registering a still birth (Stillbirth Certificate)
- Medical Certificate of Cause of Death (MCCD) – death certificate
- Independent Medical Examiner (IME)
- Accessing medical records of deceased (issues of consent etc.)
- Repatriation - people who die abroad.
- Complaints
- Social Services,
- Citizen’s Advice
- Antenatal palliative care pathway.
- Sudden death flow chart.
- Family disputes after death – Mediation and other guidance.
- Signpost relevant third sector organisations, including: SANDs, Cruse, Child Bereavement UK, Tiny Life, Hospices etc.
- Substance use
- Guidance for families --reference Alder Hey Children’s Hospital.
- Personal experiences of bereavement.
- Trauma centre – suite of leaflets / information.
- Compassionate Communities – ‘Digital Legacies’
- Wales’s website Bereavement Advice Centre is a good example of a site.
- Regional Bereavement Booklet available – will feature on the website – needed for when a person is dying.

**What easily remembered name would you give to the new website?**

In general, participants commented on the importance of:

- How people search for help - host of search terms. E.g. Rip.ie – is easy to find comparator in Ireland.
- Our website needs to be appropriate and understood by people living in Northern Ireland **and** by people who may not be from NI.
- Naming and branding of website could lead to a national campaign of awareness.
- What terminology do people understand? Does everyone understand the word bereaved? Would people look this up, or look up death, loss or grief?
- Whatever name is chosen, the new website name will need a public awareness campaign.

Suggestions are listed below (these are not in any order of preference):

- Bereavement.NI
- Bereavement Care NI
- Bereavement Matters
- Bereaved NI

- NI caring for you
- Sorry for your loss
- Journeys end
- Living and Dying
- Living with Death NI
- Dying to help NI
- Dying to Grieve NI
- Death and dying NI
- Death NI
- Death Matters Ni
- Compassion NI
- Relief4Grief NI
- Grieving matters
- Mygrief.hscni.net
- Your grief NI
- My grief NI
- I Grieve NI
- Sharedgrief.NI
- Loss matters NI
- Loss NI

## 8. Café Conversation Three – From Strategy to Action

Patricia Donnelly, Chair of NIBN, introduced the final Café Conversation. Patricia described the development of a 10-year strategy using the Bereavement Charter as its foundation. The work would be co-produced and include a mapping of existing services and gaps in services. The Strategy would include a model of bereavement care, standards for care, a framework for service delivery and a corresponding investment plan for improvement.

Patricia posed three final questions to prompt conversation. These were:

1. What are the most important things to think about in the strategy? What are the priorities?
2. From all that you have heard today what is missing in the plans for the development of the strategy?
3. If we could only do one thing – what should that be?

## Key Messages from Strategy to Action Conversation

- ◆ The way forward is to create a public facing strategy “owned” by the people of Northern Ireland, that is cross departmental and culturally diverse. Bereavement champions should be considered.
- ◆ The Strategy should be universal; simple and easy to read; owned and coproduced by society; true to Northern Ireland, authentic, deliverable and funded.
- ◆ To educate Health Care Professions (HCP) in real communication skills, especially in communicating at end of life and with bereaved families.
- ◆ Spirituality and religion are bigger than ‘cultural’ and so important.
- ◆ Don’t leave out miscarriage, child deaths, sudden deaths.
- ◆ Education should focus heavily on real communication skills for everyone.
- ◆ Compassionate communities are so important but health professionals in particular trained to communicate at end of life and with bereaved families. If we could only do one thing – the website was the consensus.
- ◆ Ensuring complete inclusivity: children and young people (especially teenagers), ethnic groups, hard to reach groups, people for whom English isn't their first language, people with dyslexia etc. Ensure communication & awareness campaigns reaches all.
- ◆ Concern with health inequalities when using online resources.
- ◆ An impactful public awareness campaign would make a huge difference.
- ◆ Investment in this beneficial work would be a priority - we felt that what was missing was a funding plan.
- ◆ We need to all start conversations.
- ◆ Co-produce a strategy that looks after all. Develop the resource and its online hub.
- ◆ Promote across the population to ensure high awareness, ease of access and understanding of its value.
- ◆ Investment /clear funding for the strategy is critical. We have seen many good strategies not implemented as no clear funding plan
- ◆ The importance of having a communications plan
- ◆ We must all work together and share resources and knowledge. Networking like this has providing an opportunity to share so much knowledge. PSNI/Education and all necessary people all need included.
- ◆ That the name and the branding of the website could create a national campaign
- ◆ Strong theme this morning was that there are great supports and resources available, but we need to improve public awareness of how to access them; we need to avail of every opportunity - public campaigning, involvement of community / statutory services, making supports accessible and relevant to all age groups; need to focus on children and young people. Also need to focus on standards of practice; core standards / guidelines.
- ◆ Importance of joining up with other Strategies e.g., Cancer Strategy, Mental Health Strategy, Substance Abuse Strategy etc.
- ◆ Be explicit about involvement of community and voluntary sector as partners in the work.



## **Conversation Menu**

Each Table has a conversation Host.

All Tables are having the same conversation.

Between some conversations we will invite you to move to another table. The Table Host will stay put.

### **CONVERSATION ONE**

What should be in a Bereavement Charter for NI?

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### **CONVERSATION TWO**

What information do people need during bereavement?  
What knowledge/skills do those caring for the bereaved need?

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### **CONVERSATION THREE**

What is the one thing that we should do (priorities)?

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### **DRAW IT... WRITE IT... SAY IT**

Use the banquet paper to write or draw on. Leave your messages or pictures to inspire the next café conversationalists.

## **Refreshment Menu**

Available throughout the session



Tea, Coffee, Water

&

Scones, butter, jam & pastries.



Free refills throughout the session





### **Guest Conversationalists**

Peter May, Permanent Secretary, Department of Health

Patricia Donnelly, Chair, NI Bereavement Network

Professor Sir Michael McBride, Chief Medical Officer,  
Department of Health

Meadhbha Monaghan, Patient and Client Council

Paul McCloskey, South Eastern HSC Trust

Carole McKeeman, Western HSC Trust

**Thank you for joining our Café  
conversations.**



## **Northern Ireland Bereavement Network**

### **World Café Conversations**

Welcome to our World Café  
Monday 27<sup>th</sup> February

Conversation and Refreshment Menu

