

REPORT

Round Table on a Public Health Approach to Palliative and End of Life Care on the island of Ireland

**Ballymascanlon House Hotel, Dundalk, County Louth
3 December 2019**

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Background and Context

Over the past two decades, there has been increasing interest in a public health approach to palliative care. This interest across palliative care internationally has been shared on the island of Ireland.

The Irish Hospice Foundation (IHF) and All Ireland Institute of Hospice and Palliative Care (AIHPC) have supported this development. Practical initiatives include, for example, the IHF's Think Ahead initiative and, more recently, 'Have Your Say', and AIHPC's annual Palliative Care Week since 2014. They have also supported those leading palliative care to develop the public health approach.

This AIHPC and IHF support is in line with policy direction across both jurisdictions on the island of Ireland. AIHPC as an all-island organisation is supporting the development of a public health approach to palliative care across the island of Ireland.

As a result of a request from the regional Palliative Care in Partnership Programme in Northern Ireland, and as part of the Public Health Agency's support for the Institute, AIHPC developed the 'Briefing Paper: Public Health Approaches to Palliative Care (2017)'. Since 2018, AIHPC has been supporting the Northern Ireland Department of Health's policy development of a Public Health Approach to Palliative Care, with input from the Palliative Care in Partnership programme.

In 2018, the IHF and AIHPC were involved in a Public Awareness Working Group which developed recommendations from the Health Service Executive's (Republic of Ireland) Palliative Care Development Framework (2017-2019).

With IHF funding, AIHPC produced the 'Mapping Public Engagement on Palliative Care, Death, Dying, Loss and Care' resource which scoped examples of public engagement regionally, nationally and internationally, which informed the Public Awareness Working Group recommendations. Among the recommendations from the working group was that a Round Table be hosted to help move forward with the agenda of a public health approach to palliative care.

The IHF and AIHPC came together to plan the *Round Table on a Public Health Approach to Palliative and End of Life Care on the island of Ireland* held on 3 December 2019 at Ballymascanlon House Hotel, Dundalk. As a broker of relationships across the palliative care sector, AIHPC was pleased to involve the Palliative Care in Partnership programme team in the Public Health Round Table. With the support of AIHPC partner the IHF, these colleagues were an important part of the team involved in planning the event.

Purpose

The purpose of the Round Table was to help to generate ideas, energy and enthusiasm for further development of a public health approach to palliative and end of life care across the island of Ireland. The event was planned so that there would be opportunities for those attending to share their experiences and to learn from and explore others' experiences.

Stakeholders

Invitations to the Round Table were issued to a wide range of stakeholders, not only from health and social care but from the wider community and voluntary sectors identified by the planning committee. Those invited included key people from palliative care policy, service delivery and research interests, and organisations with an interest in public health, community development and health, older people and social prescribing. A total of 46 participants from 28 organisations attended the Round Table. (Appendix A)

Format

With more than 30 years' experience in health care, and with a wide range of involvement in community engagement and developments around palliative care in England, Claire Henry was asked to facilitate the Round Table.

The Round Table began with the presentation by Dr Paul O'Mahoney, IHF research manager, of results of a brief on-line survey (Appendix B) sent to attendees before the event. The survey was to ascertain participants' involvement in community/public based initiatives, confidence in their sustainability, and who should lead on a public health approach to palliative care. A range of views were reflected in responses and the full data can be viewed in the link to the slide presentation available at Appendix C.



Speakers at the Round Table (back row from left): Rebecca Lloyd, The Irish Hospice Foundation (IHF); Brendan O'Hara, All Ireland Institute of Hospice and Palliative Care (AIHPC); Rebecca Patterson, keynote speaker, Scottish Partnership for Palliative Care; Paul Turley, Health and Social Care Board/Palliative Care in Partnership; Dr Libby Sallnow, keynote speaker; Dr Paul O'Mahoney, IHF; Professor Joachim Cohen, keynote speaker; (front row from left) Claire Henry, facilitator; Karen Charnley, Director, AIHPC; Sharon Foley, Chief Executive Officer, IHF; Sheilagh Reaper Reynolds, Health Service Executive.

Dr O'Mahoney's presentation was followed by the three keynote speakers. Dr Libby Sallnow considered 'Compassionate Communities', addressing why compassionate community approaches are being developed, what compassionate communities look like in practice and how their impact can be understood. Dr Sallnow spoke of her experience with Compassionate Neighbours in East London.

Professor Joachim Cohen presented on the role of big data in public health palliative care research. Professor Cohen gave an insight into how data in Belgium is being analysed in relation to improving palliative and end of life care, and into the work of the End of Life Research Group of the Vrije Universiteit Brussel.

Rebecca Patterson, from the Scottish Partnership for Palliative Care and Good Life, Good Death, Good Grief, provided an overview of the policy situation in Scotland and how public health approaches to palliative care are being put into practical action across Scotland and at local level.

In the afternoon, an overview of developments on the island of Ireland was provided by Rebecca Lloyd, and Sharon Foley, IHF; Brendan O'Hara, AIHPC; Chris Matthews, Department of Health, Northern Ireland; and Sheilagh Reaper Reynolds, Health Service Executive.

All presentations are available on The Palliative Hub and links to each presentation are provided in Appendix C.

Summary of key themes from discussion

It was expected that participants at the Round Table would have valuable networking opportunities, share learning from others and from their own experience, and leave with ideas for their communities and organisations. When planning for the Round Table, it was agreed that there would be significant time allotted for group discussion and interaction. This was facilitated in an hour-long workshop session before lunch when discussion by participants, across groups at six tables, was guided by two questions:

1. Given what you have heard, is there anything that you are involved in or happening in your community that is relevant to/connected with a public health approach to palliative and end of life care?
2. What would help you/organisation/colleagues to take practical action to develop a public health approach to palliative and end of life care in your communities?
(What are the barriers and enablers to action - please think broader than financial resources)

An opportunity was also provided to attendees to post additional thoughts on whiteboards available in the room throughout the Round Table event. These comments were invited under the titles of 'Share The Learning' and 'Free Thinking'.

The collated comments from the workshop session and from the whiteboards (Appendix D) have been summarised and key themes identified for the purposes of this short report which are presented under two headings: 1: Current State and 2: Looking to the Future.

1. Current State

On the day, several presentations referenced the Key Guiding Principles of the World Health Organisation Charter on Health Promotion (Appendix E). Attendees reflected that we are not beginning with a blank sheet when considering a public health approach to palliative care and many of the comments captured fit under the Ottawa Charter principles.

Community resources were highlighted, including traditions around death, burial, community, bereavement support groups, volunteers, and the role of sports and other community organisations. A wide range of initiatives currently taking place were referenced including Think Ahead, Bas Café, Death Café, Always Remembered Sunflower, Compassionate Communities, Heart of Living and Dying, Namaste, Prepare to Care, Advance Care Planning, exhibitions and leaflets. Working with marginalised communities, including homeless people, was also identified in the group work.

The importance of empowering and capacity building, at community and at an individual level, was highlighted; enabling people to engage with health services. This included the use of media in building public engagement, building awareness of palliative care for nursing and other undergraduate students, and increasing knowledge of what the public's current understanding is through, for example, the Life and Times survey (Ulster University).

At a programme level the role of the National Clinical Programme (RoI) and the Palliative Care Programme Board (NI) were identified. At the level of palliative care practice, initiatives highlighted included: a community outreach model, virtual multi-disciplinary team meetings, discharge boxes, comfort packs, and end of life companions.

In the civic/legislative context, the opportunity presented by community planning developments in Northern Ireland for the development of a public health approach to palliative care was highlighted.

All comments from the workshop session and the whiteboards are included in Appendix D.

2. Looking to the Future – 'Joining the dots'

The second workshop question concentrated participants on the enablers to developing a public health approach, and any barriers there might be to its development. Participants were asked to think broader than resource issues.

A theme running through feedback from the six groups to this question, and taking account of other feedback, could be summed up with a contribution from one group highlighting the importance of 'joining the dots'.

This is reflected in references drawing attention to the importance of sharing resources and avoiding duplication, facilitating networking and connection - including of organisations which historically haven't worked together – and the sharing of knowledge across disciplines, settings, and sectors. It was suggested that there needs to be a focus on 'assets based community development', building on what is already available, working across sectors, mobilising people, and investing in a collective.

There was a sense that assets could be harnessed, albeit assisted with some pump-prime/seed funding, and that regional government/central government/policy could have a role in supporting this direction of travel. It was suggested that with their new community planning remit, councils in Northern Ireland could adopt the compassionate community charter, and that the principles of the Ottawa Charter could be the basis for a national advocacy campaign. The importance of building evidence of impact of any project from the outset was highlighted, as was the importance of data.

Evaluation

The event was very positively evaluated by participants. All those who completed the evaluation form (30) agreed or strongly agreed that the event had met their expectations. They also agreed or strongly agreed that the event was well-structured, was relevant for them and that presentations were appropriate to the event.

Comments reflected how useful the event was in terms of learning from others' experience, particularly the keynote speakers, and how useful the event was for discussion and networking opportunities.

Participants indicated that they would have valued more time for questions and discussion and there was an eagerness to broaden involvement in the development of a public health approach to palliative care. Comments from participants also reflected an appetite to keep moving forward with the development of a public health approach to palliative care.



Colleagues from both Departments of Health across the island of Ireland – Chris Matthews (second from left), Department of Health Northern Ireland, and Susan Scally (right) Department of Health, Republic of Ireland, with Karen Charnley, Director, AIHPC; Brendan O'Hara, AIHPC; Sheilagh Reaper Reynolds, Health Service Executive; Paul Turley, Health and Social Care Board/Palliative Care in Partnership; Sharon Foley, Chief Executive Officer, IHF.

APPENDIX A - Organisations which attendees were involved in/associated with

Active Retirement Ireland
All Ireland Institute of Hospice and Palliative Care
ALONE
Community Development and Health Network
Department of Health (NI)
Department of Health (ROI)
Derry Well Women
Health and Social Care Board
Health Service Executive
Heart of Living and Dying
Irish Hospice Foundation
LauraLynn Ireland's Children's Hospice
National Clinical Programme for Palliative Care (ROI)
National University of Ireland, Galway
Northern Health and Social Care Trust
Northern Ireland Hospice
Our Lady's Hospice & Care Services, Dublin
Patient and Client Council
Queen's University Belfast
Southern Area Hospice Services
Southern Health and Social Care Trust
South Eastern Health and Social Care Trust
St Francis Hospice, Dublin
St James Hospital, Dublin
Trinity College Dublin
Ulster University
Voices4Care
Western Health and Social Care Trust

APPENDIX B

Pre-Event Survey Questions

1. How confident are you on the sustainability of community/public based initiatives to support people around palliative and end of life care?

- Very confident
- Confident
- Unsure
- Not very confident
- Not at all confident

2. Are you involved in any community/public-based initiatives to support people around palliative and end of life care? Yes / No

If you are, please provide a brief description:

3. Who do you think should take the lead in establishing a public health approach to palliative and end of life care?

- Specialist palliative care
- Local council
- National / Regional government
- Health care policy planners
- Community and voluntary & non-governmental organisations (NGOs)

Please rank your answer from 1 being the most important to 5 being the least important

4. Please indicate your opinion on the following statement:

‘Palliative and end of life care is a public health issue’

- Strongly agree
- Agree
- Neither agree nor disagree – Neutral
- Disagree
- Strongly disagree

5. Please detail your role:

- Health care professional
- Government official / civil servant
- Community and voluntary sector professional
- Academic/researcher
- Other, please specify

APPENDIX C

Presentations from the Round Table are available at links below:

[Setting the scene - Analysis of Responses to Roundtable Pre-Questions](#) - Dr Paul O'Mahoney, The Irish Hospice Foundation

[Compassionate Communities](#) - Dr Libby Sallnow

[What can big data do for public health palliative care research?](#) - Professor Joachim Cohen

[What's happening in Scotland](#) - Rebecca Patterson

[The status on the island of Ireland](#) - Sharon Foley, CEO The Irish Hospice Foundation, Rebecca Lloyd, The Irish Hospice Foundation, Brendan O'Hara, All Ireland Institute of Hospice and Palliative Care

[Overview of health systems, Northern Ireland and Republic of Ireland](#) - Chris Matthews, Department of Health, Sheilagh Reaper Reynolds, Health Service Executive

APPENDIX D

Workshop Question 1

Given what you have heard, is there anything that you are involved in or that is happening in your community which you think is relevant to/connected with a public health approach to palliative and end of life care?

Table 1

Traditions around death, burial, community
Rainbows – community support for children
Grief support groups
Parish services (Bethany)
GAA traditions
Men's Sheds organisations
Local bereavement groups
Getting your house in order
Think Ahead
Bas café
Always Remembered Sunflower

Table 2

Northern Trust:

Comcom group established
Death Cafes
Exhibiting at H&WB [Health and Wellbeing] events
Resources (leaflets, comcom video)
Similar initiative to EASE [End of Life Skills for Everyone] but may require 'Recovery College' model to widen delivery
Exploring introducing 'Discharge Boxes', 'Comfort Packs' to support people to get home
'EoL [End of Life] Companions' – introducing project to give people someone to support them when loved one is dying

COPD Ireland – work on ACP

Lung Fibrosis organisation – developing vision for palliative care

Marginalised communities - Homeless hostels, ACP and palliative care skills

Table 3

P Care Programme Board NI

P/C staffing outreach

PH - community planning legislation 2015

13 stat orgs obliged to work together

Housing, police, libraries etc. C & V [Community and Voluntary] involvement

PH issues – loneliness, soc. isolation etc

PH programme – health inequalities programme

Small grassroots orgs – often feel uninformed/disempowered

ELEVATE [Programme]

HC providers – econ. impact of life-limiting illnesses, treatment

Separate/siloed workstreams: challenge

Capacity-building 4 areas of NI. Equity of access

Non engagement of services by some communities e.g. travellers, with specific needs and challenges

Lack of awareness of services and what's available for life-limiting illnesses – How to navigate system

Table 4

Design and co-design of services = public health approach
 Community outreach model work alongside you - Virtual MDT meeting

UU [Ulster University]

Life and Times Survey with public

Building awareness of Palliative with students (nursing)

Clinical Programme (RoI)

Media engagement how to promote public engagement with palliative care and taking the fear out of it

Need a pithy statement and definition of palliative care that everyone understands.

Southern trust – “palliative care is to create a space to allow something else to happen” definition of service they provide

Palliation is ‘being present’ – how can we be present? – this is not what palliative care is

Health care professionals undergraduates misunderstanding of what palliative care is /QUB

simulation scenarios/pre and post tests/ hearing what someone says

Re: L Sallnow, the same model discussed could be applied to mental health

Living wake

‘Have you got your house in order’ – other initiatives

Table 5

Identification of the person with palliative care needs

Community knowledge

Communicate to mobilise resources in community

Equipping the individual to advocate for themselves

Scottish model community navigators

Caution

We may have over medicalised palliative care

Presenting need could be primarily social/ psychological/ economic/ environmental

Table 6

1. Formal roles/Informal

- citizens

Commissioning/assessing

What difference are you making?

Informal – faith groups, bereavement, impact on mental health

How to join the dots

Top down/across community groups

2. Compassionate Communities – Derry NI

Podcasts, Libby, Joan Bakewell

3. Derry Well Women

Namaste and Prepare to Care

Carers .. Social supports for person living with cancer

4. RoI Compassionate Communities

ended due to lack of funding

5. Our Lady's Hospice
 - single rooms, created isolation,
 - afternoon teas – Cafe
 - social model
 - Helped to take the pressure off staff
 - Involve volunteers in a very purposeful way
6. Heart of Living and Dying public health approach to Advance Care Planning – across the N Ireland

Workshop Question 2

What would help you and your organisation/colleagues to take practical action which would develop a public health approach to palliative and end of life care in the community you work in? (What are the barriers and enablers to action - please think broader than financial resources)

Table 1

Integrate broader PH outlook to overcome siloing of workstreams and initiatives
 Resource constraint – broad buy-in lets collaborative initiatives to scale up
 How do we share resources and avoid duplication, inform a varied projects?
 Who leads? – regional govt./Council – can provide space and support
 Bring events, projects, initiatives outside major urban centres to be a hub for organisations to network – professionals, C & V [community and voluntary] grassroots support
 IHF 'Living with Loss' in Galway and Cork to facilitate networking
 Orgs which historically haven't worked together – connecting

Barriers

Divide between 'healthcare' and 'social care' in health system (RoI) needs better integration – 'Better integrated care'
 Is there potential policy/structure to facilitate collaboration between relevant stakeholders?
 Central govt. support is usually essential – population-based planning
 But answer can't always be 'State will/should provide' – reframe C & V role in driving and defining policy debate, implementation
 Resistance from med. profession to lay empowerment/training – issue for p health
 Medical and voluntary and individual perception of what is appropriate can differ
 Risk management, indemnity etc.

Table 2

Building the evidence on the impact e.g. in partnership with universities – intern/fellowship? to evaluate project from the start
 Mapping and sharing of all the projects/work going on
 Approach it as a social model rather than health

Better connectivity and sharing of knowledge across disciplines (e.g. Cancer/P.C.) and settings (e.g. health, academia, comm and vol)

Table 3

It's not all about funding

BUT

There is a need for pump prime funding

Joining the dots needs to be a focus "asset based community development" approach

We need to be less risk averse

In the North we have community planning

Q. What opportunity does this provide?

A. Councils to adopt compassionate community charter

Map what is already there

Do communities realise what they are already doing is providing support in this space?

Ensure we have mechanism to listen, learn from experiences and shape things and based on this

Table 4

Knowing where to start, who needs it/avoid over reacting

Confusion in terms and language

Education

Learning from other campaigns e.g. Stop Smoking

Compassionate Community toolkits

TtT working across sectors

Focussed events

Narrative and storytelling and using social media

Analysing Needs

Data to look at where needs are actually and how to reach people

Social inclusion

How important is palliative care to policy makers, to government and funding support

Engagement

National advocacy using Ottawa charter

Out to the community what is the need

Well café/counsellor bereavement care/support communities where need - localisation/context

Have a public health debate

"Think Ahead"

Table 5

Look at ways how to link in with existing community organisations e.g. GAA clubs

Need to create the opportunity to spend time

Need to work on existing barriers e.g. we can see people as their diagnosis. Do we disempower people?

Should we have a concept of enabling rather than disabling?

Table 6

1. Harvest opinions – what’s stopping us from talking
Lack of leadership in palliative care comm.
2. Practical help and advice - on the ground (mobilising the troops)
Invest in a collective
3. Think about how to live in dignity and comfort until the end of your life
It’s not just practical
It’s not just legal
Narrative storytelling
4. Supplement the legal with opportunities to talk about dying
5. Practical/enjoyable/less fearful
more liveable, generational, schools and nursing homes
6. How do you get to the people you don’t know yet?
7. Huge in opportunity in seed grants,
8. Active retirement / harvest what we have... men’s shed

An opportunity was provided to attendees to post additional thoughts on whiteboards which were available in the room throughout the Round Table event. These comments were invited under the titles of ‘Share The Learning’ and ‘Free Thinking’. Feedback from the post-its is collated below.

SHARE THE LEARNING

Please let us know of any positive activity/practice you are aware of that fits within the concept of a public health approach to palliative care? Please let us know where it is and if there is a web address for more information.

Wish that communities could take more of a lead in supporting death-dying-bereavement support.
Bottom up approach - supported by local councils.

St James’s eminent oncologists, professionals etc. go out to, e.g., Ballyfermot to give health messages

Highlight the importance of co-ordination and partnership (and collaboration) in the public health approach (my area of interest ber [bereavement] care)

The need for a national strategy or nationally supported structure supported by national policy

Think ahead

Café conversations

Finite Lives

Forum on End of Life

Capacity building

Community Development

Reducing Health Inequalities

www.elevateni.org

Think Ahead

People’s Charter on dying death and bereavement in Ireland

www.thinkahead.ie

Bás Café

Fun, Interaction with each other

Getting your 'house' in order workshops ... [solicitor and EOL chat] IHF

Love the Truacanta Project and model of seed funding. Small, local initiatives

"Namaste" great carers programme

Compassionate Communities. Lean into risk. Less risk aversion

Prepare and Care

Ease - 'End of Life Aid Skills for Everyone' import from Scotland

Fellowship

FREE THINKING

Imagine everything is possible – what is your wish for a public health approach to palliative and end of care?

Values

Empathy

Respect – the person.

Leadership and management are not the same thing

Analyse the data and share it with the public

Seed Funding – could be really useful

We form a coalition

Better data linkage, dissemination of well-evaluated results to determine resource allocation. Solid evidence base created collaboratively

Better links between services, the communities they serve and other community groups - mutual capacity building for a more open conversation and consideration of dying, death, bereavement loss and care

Like the Scottish Approach – website and Good Life Good Death Good Grief

Open public discussions

Celebrities talking openly e.g. Rio Ferdinand

For medical profession to be realistic with patients and especially families about outcomes

A collaboration or coalition to drive forward

That Government, civil society, NGO and medics all work together

If anything was possible I would like to de-medicalise E of L care. Not about "treatment" at all costs.

Let people have peace and a natural ending if that is what they want. Listening to the person, hearing them and giving them opportunity to speak honestly. Slow it down. Listening to families, what they want and need. Giving them more control and a say in what happens.

End of Life prescribers (a bit like social prescribers)

Compassionate EOL companions

Listen to what the service user wants

Look at impact on community and service user

Recognition and support for communities

Be brave

More risk averse approach

Join the dots

Dedicated leadership to grow community of care and compassion

Share the learning

Big data – We have some limitations but as we go forward we need to use data to target scarce resources towards what makes a difference

Compassionate community in every area in the country

Support for communication, publication etc

Reconsider the language being used: the public health approach to ~~dying~~, death, and bereavement - exchange for “living with a life-limiting condition, death and bereavement”

That people live comfortably with the reality that we are mortal; that we draw our first breath, at a moment in time, and that there will come a time when each of us will draw our last breath and this is the reality of our lives.

Technology

Resource

Hub/Directory

National Campaign with all sectors – stat/NGO

Benefits from service user/families on public health approach

Use the right words.

Equity (populations who access)

[Increase] awareness of palliative care

Shared learning of projects ongoing

Wish – “natural” communities keep doing what they do in the area around death but are supported to stretch their support to living well with life-limiting conditions

That dying would be looked on and talked about as naturally as birth

APPENDIX E

1. Key guiding principles

World Health Organisation Ottawa Charter on Health Promotion

1. **Build Healthy Public Policy** – societies are complex and interrelated, health cannot be separated from other goals
2. **Create Supportive Environments** – health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.
3. **Strengthen Community Actions** – empowerment of communities, community development approach, strengthening public participation
4. **Develop Personal Skills** – providing information, education for health and enhancing life skills, learn throughout life, prepare for all stages, cope with chronic illness and injury
5. **Reorient Health Services** – health services need to embrace an expanded mandate, open channels between the health sector and broader, social, political, economic and physical environmental components

Please note the descriptions with each principle have been shortened and full details are available here: <https://www.who.int/healthpromotion/conferences/previous/ottawa/en/index1.html>

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