THE WAY TO INTEGRATION: PALLIATIVE CARE IN EUROPE

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President, European Association for Palliative Care
Overview of the presentation

- Contextual issues in European Palliative Care
- Why is integration important for Europe
- What opportunities and challenges are expected in an integrated approach to palliative care?
- The wisdom of our Elders
Palliative care- changing focus
Palliative Care as a Public Health issue

‘Strengthening of palliative care as a component of comprehensive care throughout the life course’ (WHA 67.19 2014) - serious concern about inequality between different groups and their access to, experience of, and outcomes from palliative care.
Developments in European Palliative Care

- WHO Euro Region
- ‘Palliative Care: the solid facts’
- Better palliative care for older people’
- ‘Better palliative care for older people: better practices’
Why Palliative Care is important for Europe

Epidemiology

75% of European citizens who die would benefit from a palliative care intervention

Most are elderly people with multi morbid disease

Significant impact on the health and social system:

- 20-25% of patients visiting a GP have palliative care needs
- 35-45% of hospital beds are being used by people with palliative care needs
- 50-70% of people in nursing homes need palliative care

People in need of palliative care are the cause of 70% of costs in the last 6 months of life, mostly due to inappropriate hospital admissions
58% of 243 countries have a palliative care service (26% increase on 2006)

Only 20 countries internationally have advanced integration

Many countries still have no palliative access at all.
Palliative care cancer focused

80% of all deaths (141,807) had associated palliative care needs

81% ≥ 65 (13% ≥ 85)

Increase in deaths from dementia and neurodegenerative disease (and cancer).
Elder care – an international health challenge

600 million older persons worldwide

Doubled by 2025

2 billion by 2050
Strengths and Weaknesses - a European lens

- **Strengths**
  - Palliative care reduces hospital admissions, costs and the inadequate use of emergency services, promoting a primary care agenda.
  - Promotes a more responsive, comprehensive and judicious delivery of care to those in need in their place of need.

- **Weaknesses**
  - Failure of the system to see the value of early integration of palliative care.
  - Confusion in the language which describes what palliative care is and is not.
Palliative Care – what is in a name?

- Confusion over language to describe palliative care
- Supportive care seems to fit well in the healthcare context
- Terminal care largely avoided
- Descriptors are culturally determined
- We still need clarity over who we are and what we do.
Why integration is important?
When should PC be initiated?

No right or wrong answer

Diagnosis

Here?  Here?  Or here?

..... But important to actively think about it

Ongoing treatment and palliative care not necessarily contradictory

Death
What does an integrative approach really mean?

<table>
<thead>
<tr>
<th>Change from</th>
<th>Change to</th>
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<tbody>
<tr>
<td>Terminal disease</td>
<td>Advanced progressive disease</td>
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<tr>
<td>Short life prognosis (weeks or months)</td>
<td>Life-limiting</td>
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<tr>
<td>Curative versus palliative</td>
<td>Shared and combined care together</td>
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<tr>
<td>Disease OR palliation</td>
<td>Disease AND palliation</td>
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<tr>
<td>Prognosis as referral point</td>
<td>Complexity as referral point</td>
</tr>
<tr>
<td>Patient and family as care recipient</td>
<td>Patient and family as care planner</td>
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<tr>
<td>Specialist service alone</td>
<td>Service across all settings</td>
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InsupC: integrated palliative care
A definition of integrated care

“Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the care givers (paid and unpaid)”

Why this is important?

Sees the value in a matrix of involved persons

See the person as an ‘actor’ - that is, can influence the decisions made for and by them

Understands the bonds that tie people at critical times in their lives - *communitas*

Considers the wider political and social dimensions that impact on living and dying
Integrated model of palliative care
Key messages for integrated palliative care

- One of the most important messages for the transformation of our health care systems
- Changing hearts and minds
- Value the equality and respect of all persons
- Integrated palliative care speaks to reality of living and dying in society
- IPC underpinned by the elements of collaboration, cohesion and compassion
- One small step....
Challenges and opportunities
A new vision to alleviate suffering

■ How one woman’s vision changed the world....
■ A movement, underpinned by a spiritual discernment
■ A practice which evoked a global movement
The care of dying people as a human right

- Suffering cannot be treated unless recognized
- Having the courage to ask
- Having the strength to wait
Are human rights enough?

- A palliative care discourse of human rights may ignore wider socio-political issues in healthcare.
- Overt focus on the individual rather than the collective.
- Who is ultimately responsible to deliver on a human right?
Equity and equality

‘..it is unethical, unjust and unacceptable to promote or condone a global system which in effect offers disease-modifying therapy to the rich and palliative care to the poor’ (Selwyn, p.513).

Selwyn PA. Palliative Care and Social Justice. JPSM 2008, 36 (5): 513-515
Dimensions of effective equality

- Respect and recognition – acceptance of diversity
- Resources – understanding the impact of poverty
- Love, care and solidarity – public attention/private matters
- Power relations – Protection against inhumanity
WORKFORCE DEVELOPMENT: A CHALLENGE FOR THE FUTURE OF PALLIATIVE CARE IN EUROPE?
The ‘brain drain’

1726 nurses

725 doctors

10,000 applications since 2010 for Certificate of Current Professional Status
Key messages for Europe
Key messages

■ The context and practice of palliative care is changing
■ Palliative care continues to work in partnership with others
■ Dying is an important part of the work we do – but it is not all we do
■ Patient outcomes improve when collaboration is the primary driver of care.
40 million people need palliative care worldwide
2.1 million children need palliative care worldwide

‘we have only one chance to get end-of-life care right for an individual and at present this chance is sadly being missed on too many occasions’

Clare Henry, CE, National Council for Palliative Care, UK
What patients need most from palliative care

What matters most to patients?

1. good pain and symptom control
2. family support and reduction in burden on family
3. having priorities and preferences listened to and accordeed with
4. achieving a sense of resolution and peace (time and support for preparation)
5. having well-coordinated and well-integrated care, with continuity of provision (not fragmentation of care e.g. avoiding not knowing professionals, having to repeat to different professionals, etc)

www.kcl.ac.uk/palliative
A final thought

‘Ar scáth a chéile a Mhairimíd’
We live in the shadow of each other
Thank You