

Palliative Care | Building
Matters | National Consensus

L'importance des | Forger
soins palliatifs | un consensus national

Jane Seymour, BA (hons), MA, PhD, RGN

Professor of Palliative and End-of-Life Care
School of Nursing and Midwifery,
the University of Sheffield, UK

[Public Awareness Campaigns]

7th November 2016 – Ottawa, ON, Canada



Disclosure

- I have had funding from the National End of Life Care Programme, National Council for Palliative Care and the Burdett Trust for Nurses for UK based research in this area

Palliative Care | Building
Matters | National Consensus

L'importance des | Forger
soins palliatifs | un consensus national

2

Acknowledgements

- Thanks to Konrad, Michelle and team for the invitation, advice and help!
- Thanks to my colleagues in England, who helped with a systematic review on this subject published in 2009

**Do public health awareness campaigns
effectively improve the awareness and
quality of palliative care?**

Overview

- **Brief context**
- **Awareness campaigns: international and Canadian examples**
- **What do Canadians think? IPSOS survey findings**
- **Findings from other research**
- **Summary and implications**

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

5

'Death, like sun cannot be looked at steadily' (Francois de la Rochefoucauld-1678)

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

6

Why is awareness important?

- **Changing patterns of illness, ageing and dying**
- **Social justice and human rights**
- **Palliative care involves:**

'...social, economic and personal challenges stretching far into the future'

(Cox K, Bird L, Arthur A, et al. BMJ Supportive & Palliative Care 2013;3:37–45)

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

7

Stakeholders

- **The public**
- **Health policy making bodies (Canada and internationally)**
- **Health service commissioners and providers (national, federal and regional/ local levels)**
- **The hospice and palliative care movement**
- **Professional bodies and specialist organisations**

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

8

Examples of campaigns internationally

- **'Project on Death in America'** (PDIA) - <https://www.opensocietyfoundations.org/publications/transforming-culture-dying-project-death-america-1994-2003>
- **'Dying Matters'** campaign in England and Wales- <http://www.dyingmatters.org/overview/about-us>
- **'Dying to know'** day in Australia
- **'Palliative care week'**- All Ireland Hospice and Palliative Care Institute <http://www.thepalliativehub.com/public-awareness>

Palliative Care Matters | Building National Consensus

L'importance des soins palliatifs | Forger un consensus national

9

The screenshot shows the homepage of 'THE PALLIATIVE HUB'. The header includes a logo, a search bar, and social media icons for Facebook, Twitter, and LinkedIn. The navigation menu has links for HOME, ABOUT US, WHAT IS PALLIATIVE CARE, and PUBLIC AWARENESS. The main banner features a close-up of a young child's face. Text on the banner includes: 'Palliative Care Enabling Living', 'Find out how Palliative Care can enable living', 'www.thepalliativehub.com', a quote from Emma, 'She felt safe and secure surrounded by everyone and everything that she loved', a pink box for 'PALLIATIVE CARE WEEK 3-8 OCTOBER', and the hashtag '#pallcareweek'. A testimonial from Emma, 'Emma, Age 2 years Living with a serious genetic disorder', is also present. At the bottom, there is a 'PUBLIC AWARENESS' button and the text 'Public Awareness' and 'Add your voice to Palliative Care Week 2016'.

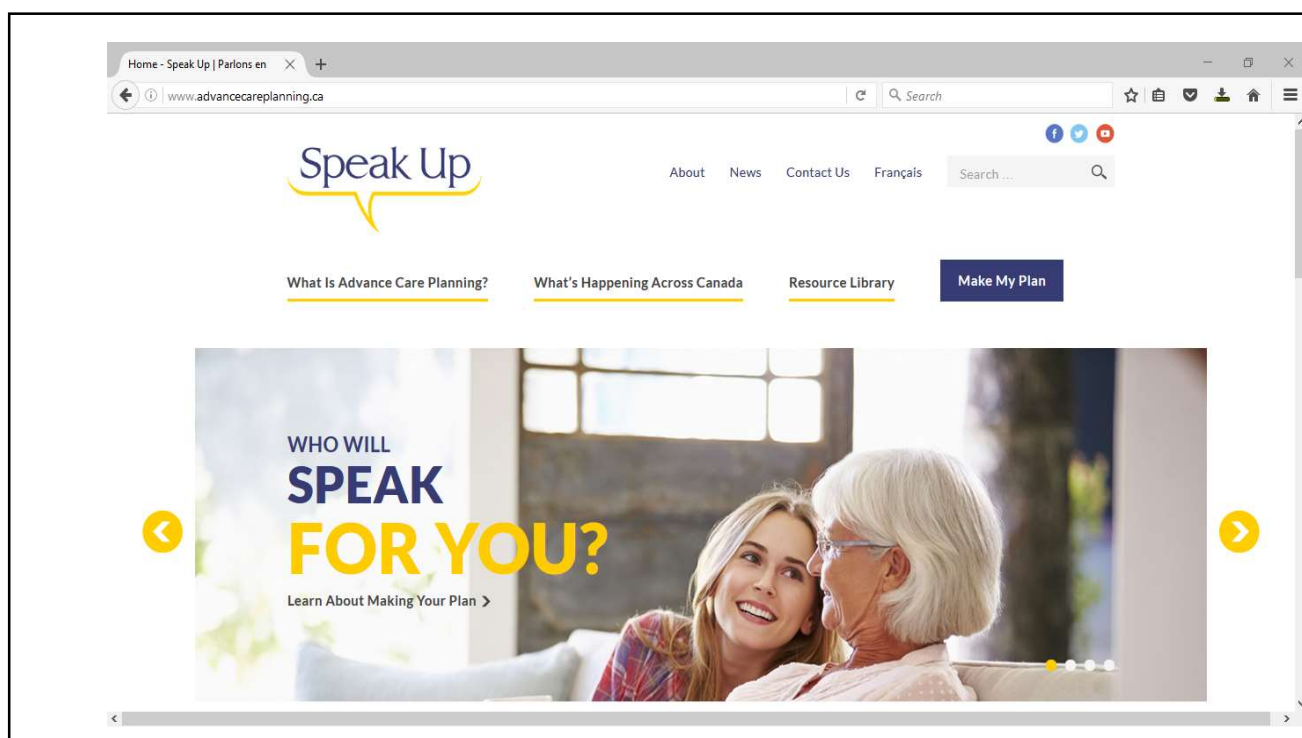
Examples of campaigns in Canada

- **The Canadian Virtual Hospice:**
http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- **The 'Just Ask' Campaign:** <http://thecarenet.ca/our-campaigns/just-ask-campaign>
- **The 'Speak up' Campaign:**
<http://www.advancecareplanning.ca/>

Palliative Care
Matters | Building
National Consensus

L'importance des
soins palliatifs | Forger
un consensus national

11



Ipsos survey

Palliative Care
Matters

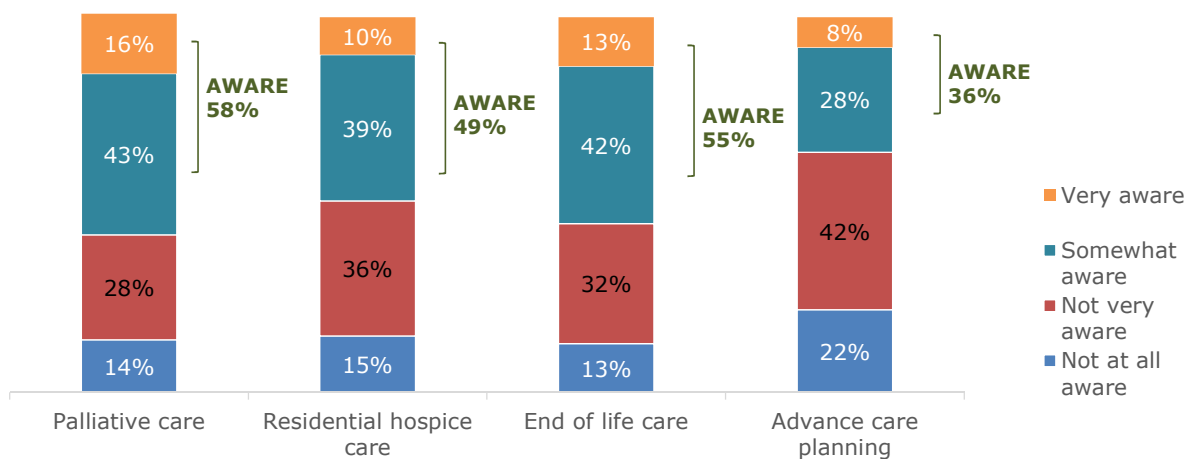
Building
National Consensus

L'importance des
soins palliatifs

Forger
un consensus national

13

Awareness of Palliative Care



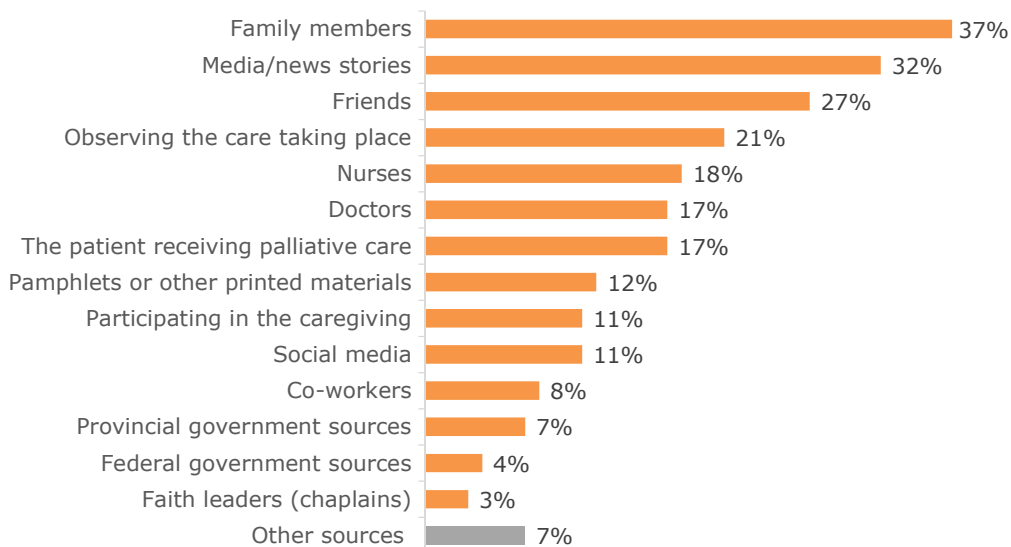
Palliative Care
Matters

Building
National Consensus

L'importance des
soins palliatifs

Forger
un consensus national

Sources of Information



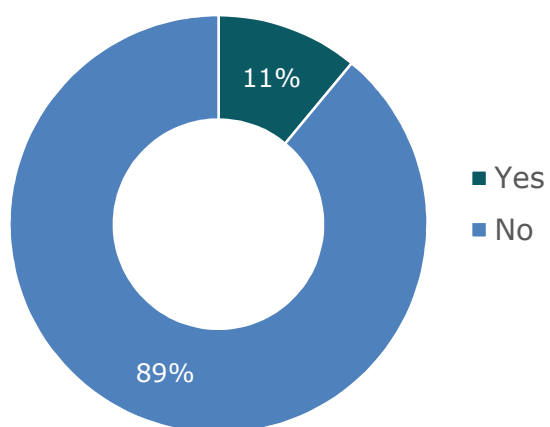
**Palliative Care
Matters**

Building
National Consensus

**L'importance des
soins palliatifs**

Forger
un consensus national

Incidence of Having a Written Advance Care Plan



You are more likely to have a written advance care plan if you:

- ❖ Anticipate caregiving or are caring now
- ❖ Are older (55+)
- ❖ Have a post-graduate degree
- ❖ Have a higher income
- ❖ Know someone who has received palliative care
- ❖ Are aware of palliative care

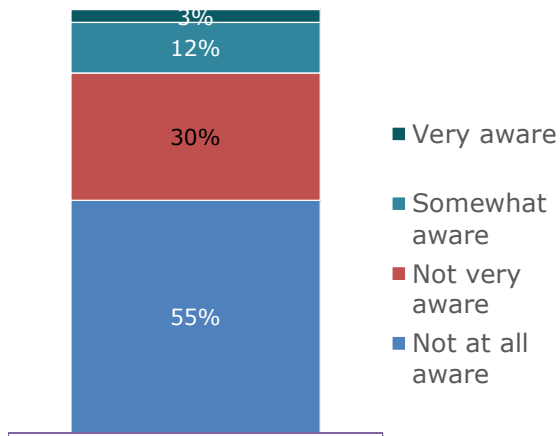
**Palliative Care
Matters**

Building
National Consensus

**L'importance des
soins palliatifs**

Forger
un consensus national

Awareness of Compassionate Care Benefits



You are more likely to be aware of Compassionate Care Benefits if you:

- ❖ Anticipate caregiving or are caring now
- ❖ Have a written advance care plan
- ❖ Are familiar with health care work
- ❖ Have a post-graduate degree
- ❖ Reside in Ontario
- ❖ Know someone who has received palliative care

Findings from other research

Four questions:

1. What techniques are effective in raising public awareness and promoting engagement in **general health** issues?
2. What techniques are effective in raising public awareness of **palliative care** issues and **helping people talk to their families**?
3. What are the best ways of raising awareness of **advance care planning** and what is the impact on quality of care?
4. What are the **key features of successful campaigns**?

Question 1- raising awareness of general health issues: what works?

- **Short mass media campaigns:** 'trustworthy' sources; old and new media
- **Public deliberation methods-** e.g. citizens' panels
- **eHealth interventions**
- **Social media (Twitter etc)-** but some risks



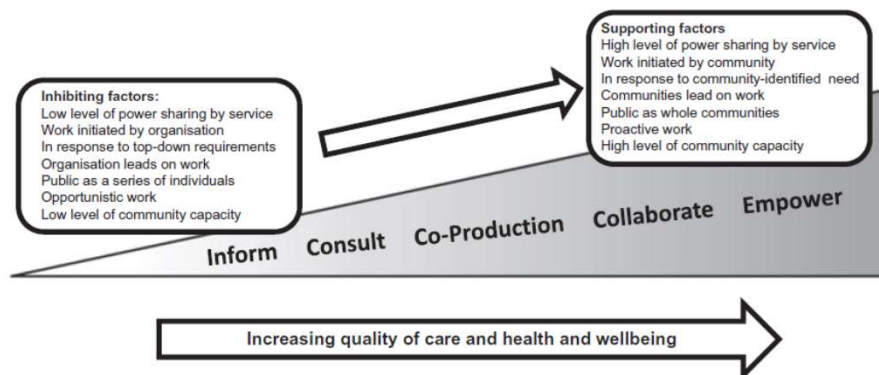
Question 2- raising awareness of palliative care and talking to your family: what works?

Palliative Care Matters | Building National Consensus

L'importance des soins palliatifs | Forger un consensus national

21

The spectrum of engagement



Sallnow, L. and S. Paul, *Understanding community engagement in end-of-life care: developing conceptual clarity*. Critical Public Health, 2015. **25**(2): p. 231-238

22

Collaborative and empowering interventions: peer education and /or community projects

Mixed media campaigns- radio, social and print media

Use of stories

'Top down' interventions less successful:
lectures or materials not previously road tested

[A thank you letter to David Bowie from a palliative care doctor](#)
15 Jan, 16 | by BMJSPCblog



Palliative Care Matters | Building National Consensus

L'importance des soins palliatifs | Forger un consensus national

23

Question 3- raising awareness of advance care planning: what works?

- **Ensure materials are culturally appropriate and piloted**
- **Pay special attention to some groups**
- **Start young**
- **Involve the community and build coalitions**

Palliative Care Matters | Building National Consensus

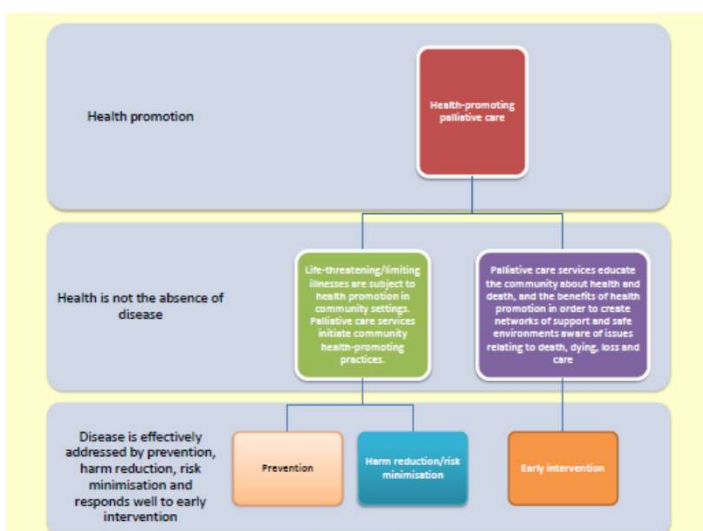
L'importance des soins palliatifs | Forger un consensus national

24

Community based interventions: mechanisms

- **Maximisation of social capital**
- **Creation of 'critical consciousness'**
- **Allowing communities to develop local solutions**
- **Promotion of health and well-being**

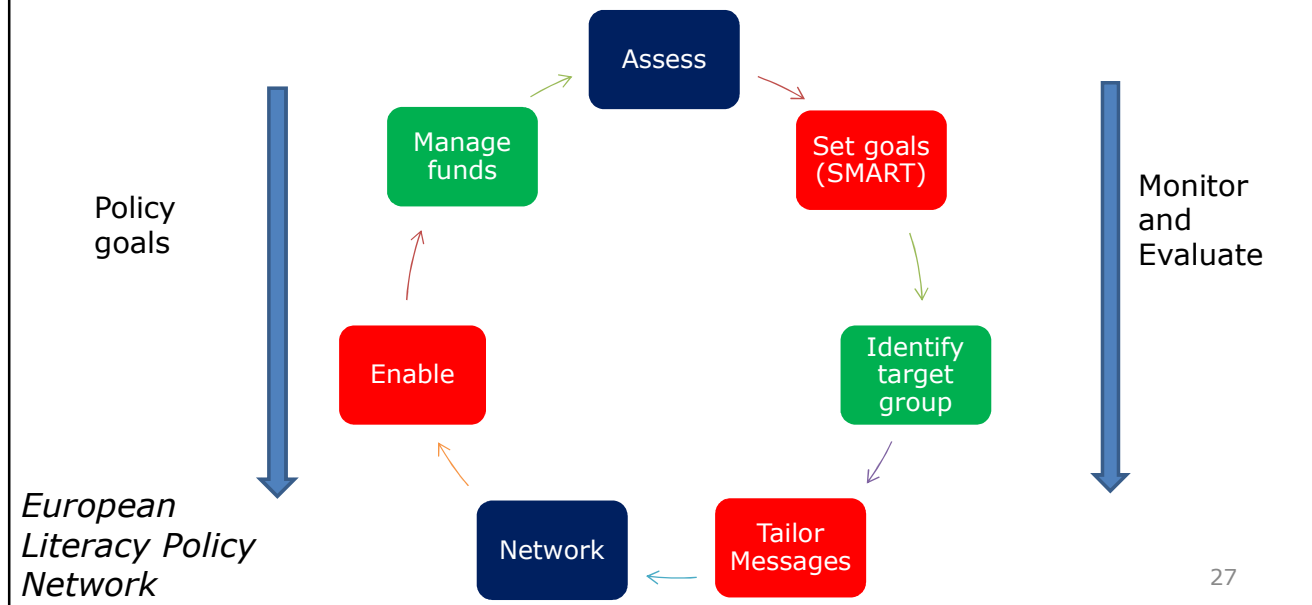
Health promoting palliative care



Public health approaches to end of life care: a toolkit. Public Health England.

[http://www.ncpc.org.uk/sites/default/files/Public Health Approaches To End of Life Care Toolkit WEB.pdf](http://www.ncpc.org.uk/sites/default/files/Public%20Health%20Approaches%20To%20End%20of%20Life%20Care%20Toolkit%20WEB.pdf)

Question 4- what do successful campaigners do?



Summary and implications

Key messages

- **Public awareness campaigns are effective in palliative care/ advance care planning**
- **They probably improve quality of care, but evidence lacking**
- **Short awareness campaigns, combined with longer term community engagement, works**
- **Planning and evaluation essential**

"A problem well stated is a problem half solved"
John Dewey, 1859-1952

Palliative Care Matters | Building National Consensus

L'importance des soins palliatifs | Forger un consensus national

29

What makes a good national campaign?

- **Planning and evaluation**
- **Short interventions with simple messages**
- **Piloting and clarity**
- **Mixed media: old and new**
- **Avoid 'selling' and stereotyping**



Palliative Care Matters | Building National Consensus

L'importance des soins palliatifs | Forger un consensus national

30

What makes a good community project?

- Planning and evaluation
- Engagement to build social capital/ critical consciousness
- Awareness of special groups
- Using stories
- Arts and humanities
- Addressing barriers



Implications

