Age-Attuned Palliative Care



Photograph by David Bailey ©

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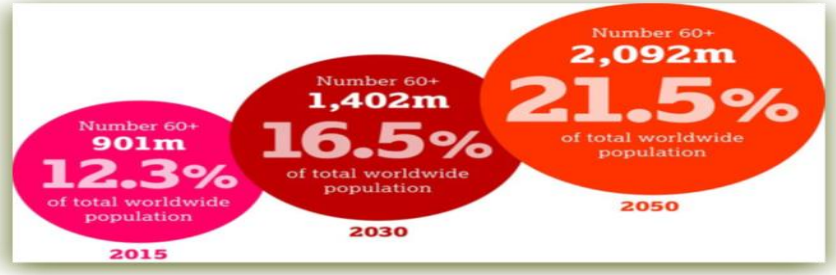
The Present:

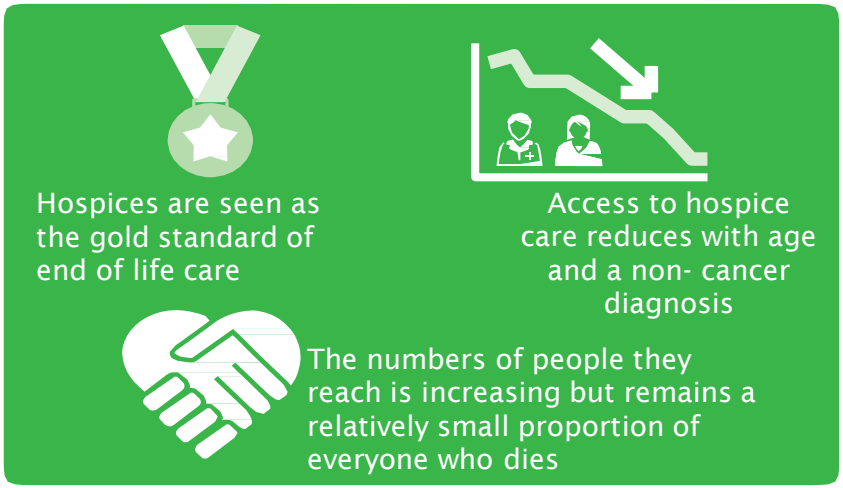
A Changing landscape



The Provocation:

Are we, in the hospice movement,

changing as fast as the world around us?



The Proposal:

Age Attuned Palliative Care

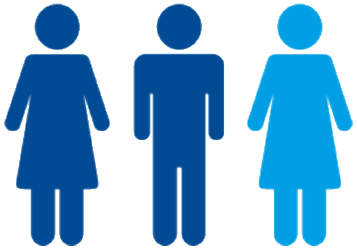
The Present: A changing picture of dying

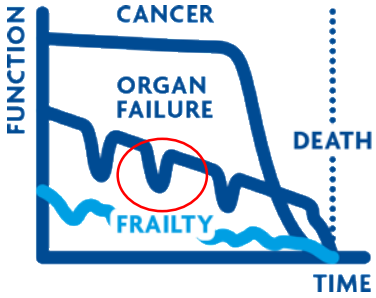
Thanks to Scott Murray

The present: A changing experience of dying

- The notion of “living well” with a life threatening illness has a different emphasis than it did 50 years ago
- Social death is a greater problem now than it has ever been
- Financial pain is a real issue
- Carer burden is a concern shared by many and over many years
- The people on the margins are different now to 50 years ago – a move away from cancer to dementia, frailty and social exclusion
- Uncertainty in illness is not only medical in nature – it is also psychosocial and about the cohesion, capacity and capability of family and social networks.

The Present: A necessary change in service response



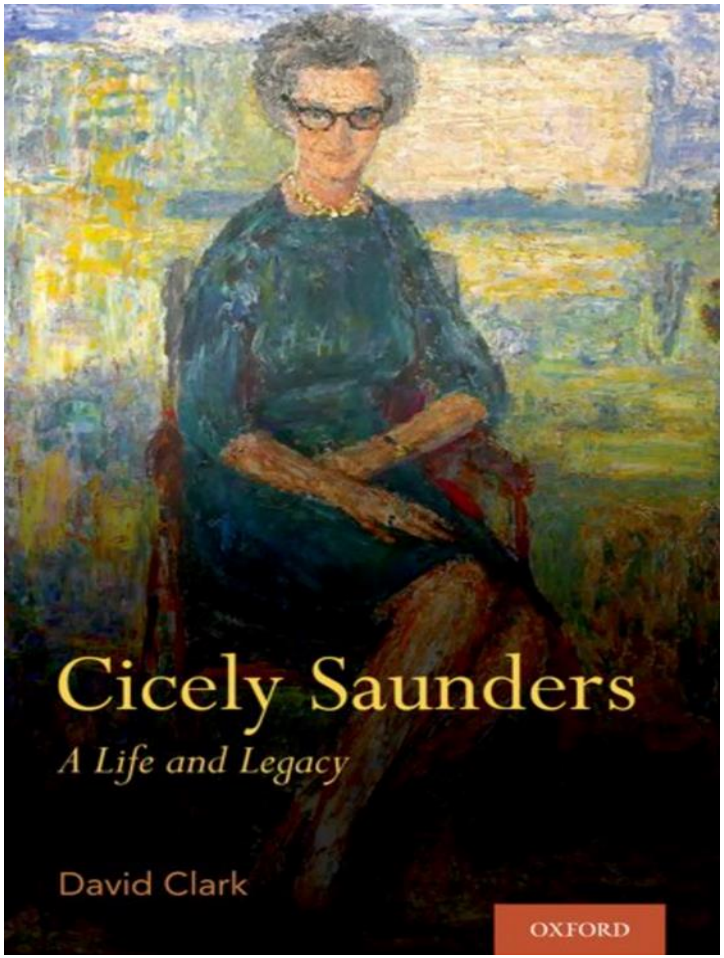


- Amongst all deaths of people aged 85+, mostly with Frailty/ Multimorbidity
- Provision of palliative care in care homes and the community needs to double by 2040
- People die differently
- The average NHS spend on those aged 80+ is £2,106 p.a.
- Average spend in the last year of life is £10,207 p.a.

“Our purpose must be to help the person conclude life well rather than to watch them meet death badly” Professor Rob George

The Provocation:

It is cause for celebration that people are living longer but our health and social care services must be age attuned (Professor Paul Knight 2013)



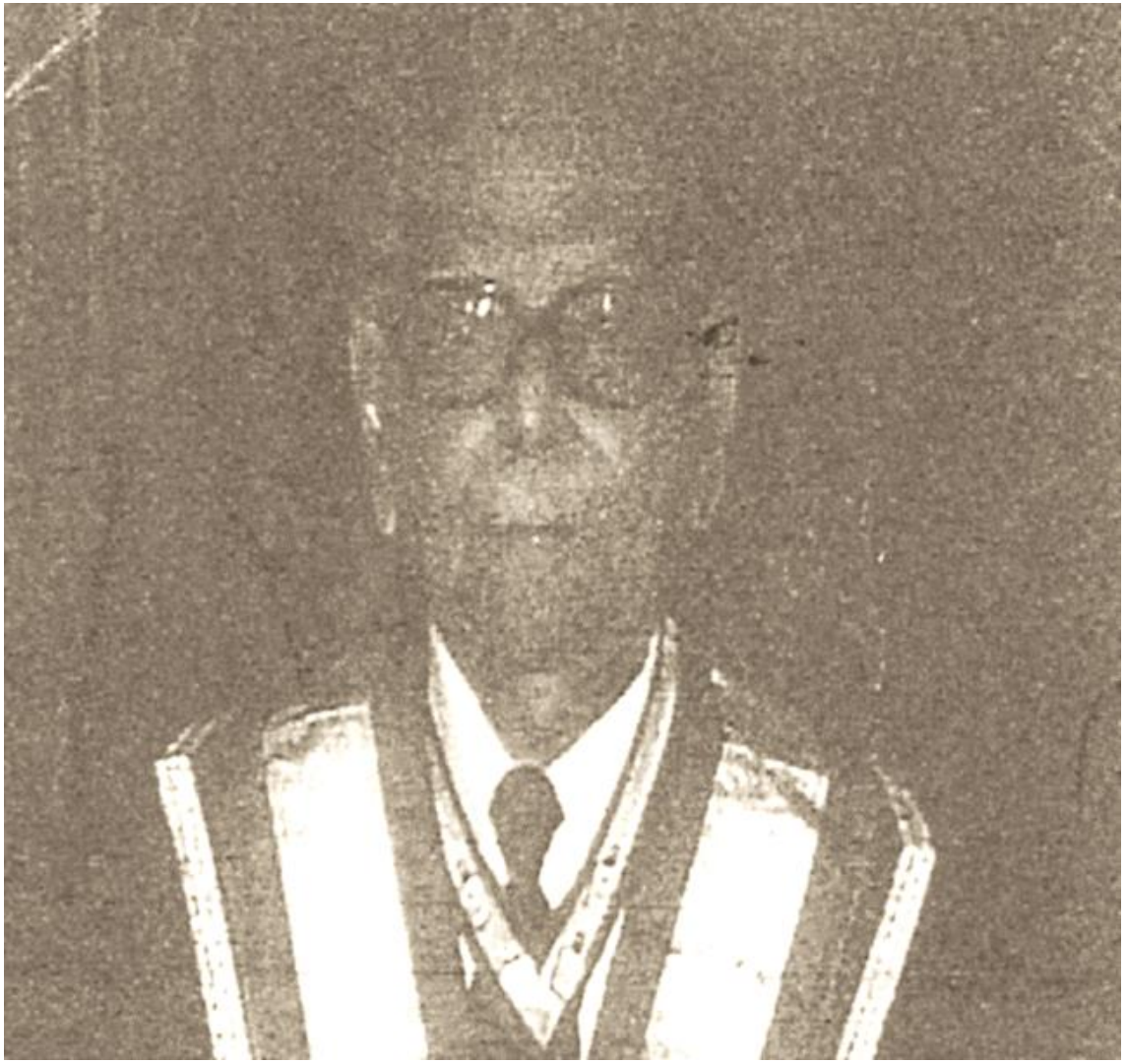
"In its first flourishing 50 years ago, hospice care brought creativity, confidence and compassion to new services that transformed the lives and the deaths of many.

Hospices should again work to put right an absence of care and an ignorance of need"

Professor Dame Barbara Monroe,
Vice Chair, Commission into the future of hospice care

The Provocation: Eli A Sentinel Case

Eli: A Case study (D.O.B 1904 Indian National came to UK in 1960)



Eli: In His last 17months of life

First Interview

"*People get tired but for me I don't end, just retire. One thing, old people here in this England, they have done one job and they retire. I have re-tyred – not retired, re-tyred if you follow the language?"*

11 months later

"*I can't recognise because hearing is not so good. Sight is also, I can't recognise, my mind is working constantly, why it is happening. My mind is wanting but my body is not able.*"

Last 6 months of data collection

"At 8pm a doctor comes. 'What's your age? Why have you come? You should go home. You go.' I know what hospital means when you take the old there…. How am I supposed to… where should I go?"

This experience was repeated three times. The specialist palliative care team declined to see Eli " No specialist needs". Following his last hospital visit a modern matron visited and equipment brought into the home. Eli died 8 months later. His death was described as "sudden" and his care provided by family and friends.

The Proposal: Age-attuned palliative care

http://www.stchristophers.org.uk/wp-content/uploads/2018/06/Age-attuned-Hospice-care-An-opportunity-to-better-end-of-life-care-for-older-people-by-Caroline-Nicholson-and-Heather-Richardson.pdf

The key principles of age attuned palliative care

Being me over a life long-lived

- Maintaining Continuity
- Maintaining Personhood
- The continual work of balancing and adaptation to loss
- The social networks/community "the glue" through which and in which lives are lived

Old age is not a disease (but you will die …)

"it is strength and survivorship, triumph over all kinds of vicissitudes and disappointments, trials and illnesses"
(Maggie Kuhn 1905-1995)

The VIP Bundle http://youtu.be/Qj_YOXjL6Ws

Ref: Living on the margin: understanding the experience of living and dying with frailty in old age. C Nicholson et al. 2012)

It is about keeping the whole in mind

Independent

AND

Interdependence

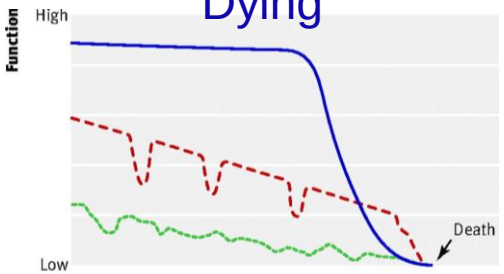
Dependent

Living

AND

Transitions

Dying



Including a changing experience of "Home"

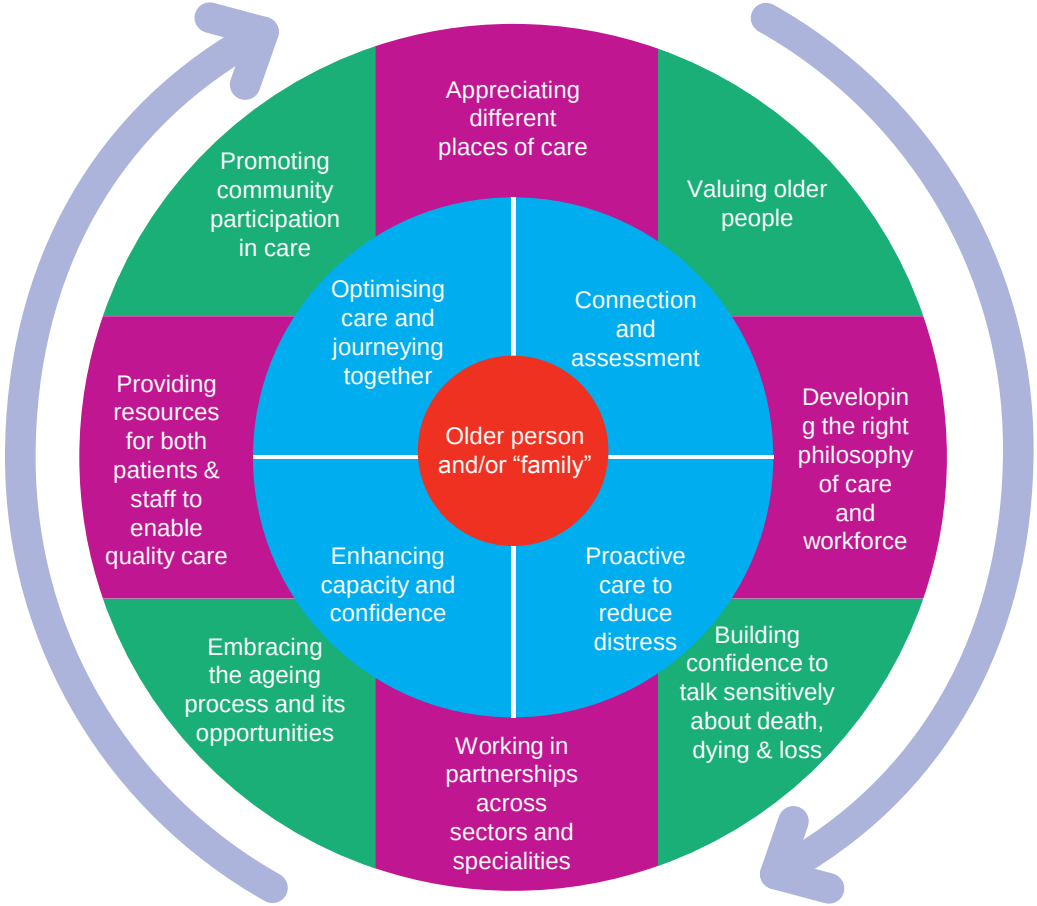
And helping people find balance and continuity in the changes and uncertainty that living and dying in old age brings

Its about a multi levelled approach to work:

- **Differently with older people as part of a clinical response**
- **In partnership to improve services and broader care environment**
- **As support to wider Societal Change**

Re-integration

Balancing continuity and adaptation to loss



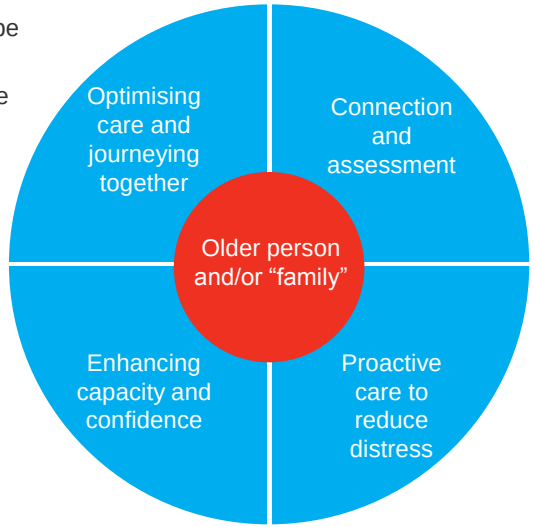
Multi- Levelled Approach

'It's about getting through the day, just holding it together, as best you can, you fall down, you pick yourself up, you keep going as best you can, till you, and well you can't keep it up for ever.'

An optimal clinical response

Watchful Waiting: Proactive purposeful intervention to identify and respond to incremental change

- ✓ Negotiating and learning the best way to be involved
- ✓ Giving options and ways to best manage change



- ✓ Individual assessment
- ✓ Negotiating plans for care

Parallel Planning

Enablement

- ✓ Rehabilitative palliative care
- ✓ Giving options and ways to best manage change

Multimorbidity

- ✓ Advanced symptom control
- ✓ Advice about when and where to seek help

Parallel Planning

- Greater and intentional integration with Specialist teams e.g. heart failure, geriatrician.
- All possible outcomes are on the table and some become more obvious over-time than others
- Honest conversations including wider care network
- Benefit versus burden of treatment
- Reducing the burden of medication
- Upstreaming palliative care involvement

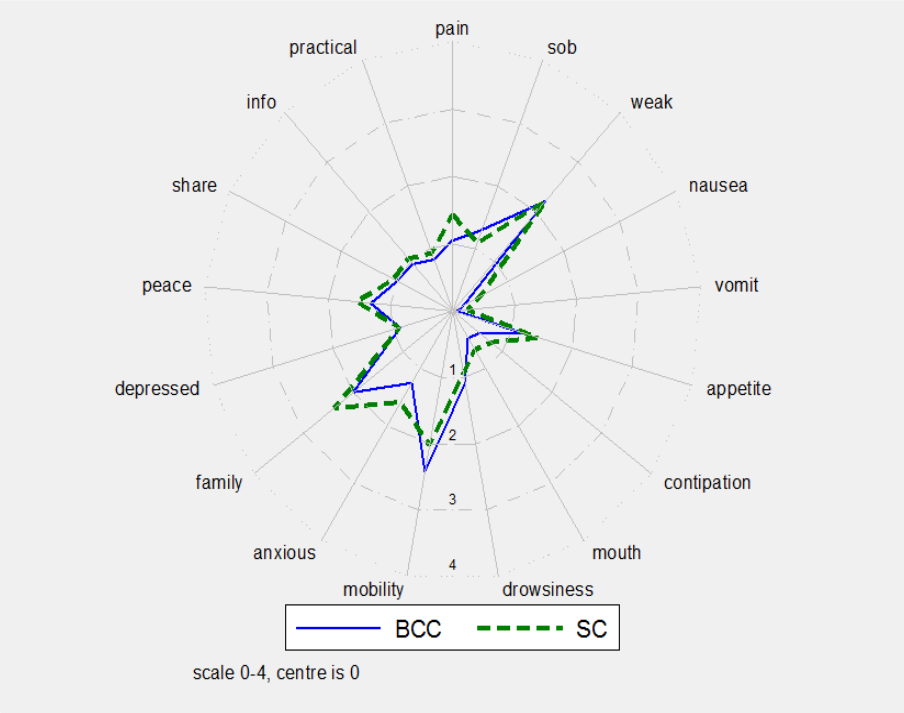
Palliative care needs of older people with multimorbidity

Original Article

What are the main palliative care symptoms and concerns of older people with multimorbidity?—a comparative cross-sectional study using routinely collected Phase of Illness, Australia-modified Karnofsky Performance Status and Integrated Palliative Care Outcome Scale data

Caroline Nicholson[1,2], Joanna M. Davies[3], Rob George[1,3], Blake Smith[1], Victor Pace[1], Laura Harris[1], Joy Ross[1], Jan Noble[1], Penny Hansford[1], Fliss. E. M. Murtagh[3,4]

Ann Palliat Med 2018. doi: 10.21037/apm.2018.06.07



- Similar overall symptom burden on referral compared to those seen in a more standard specialist palliative care service.
- More frequently mobility concerns
- Presentation and patterns of symptoms may differ over time.
- Suggestive of different patterns rather than overall need itself that is different – differing service response

St Christopher's living well at home team:

Rehabilitative Palliative Care

http://www.stchristophers.org.uk/patients/allied-health-professionals

LIVING WELL AT HOME TEAM

“Watchful Waiting”

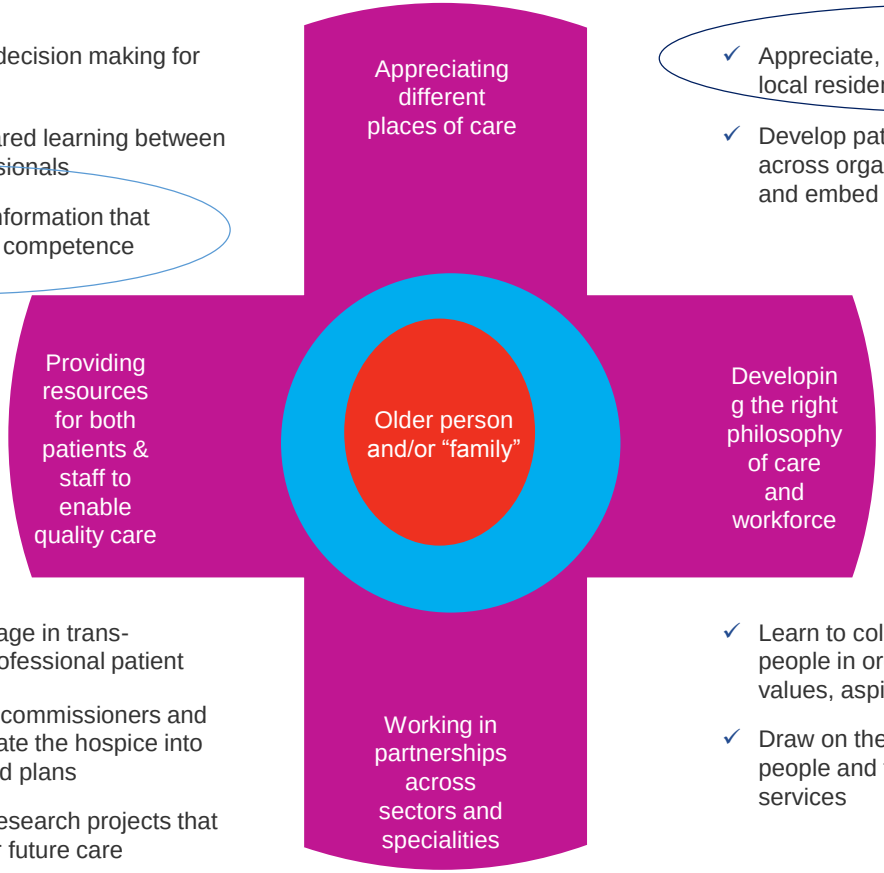
- Where purposeful, low-level proactive engagement with people and families identifies incremental changes and responds appropriately.
- What are “we” waiting for…
  - Triggers for re-involvement
  - Co-design with “family carers”
  - Redesigning our service to fit need- BCC/Volunteers/Health connectors

- What has changed (lately)?
- What would make today a good day?
- What matters to you?
- What do you need to know from me as well as what do I need to know from you?

Improving services and the system of care

- ✓ Utilise tools that support decision making for older people
- ✓ Find opportunities for shared learning between organisations and professionals
- ✓ Invest in education and information that develops confidence and competence

- ✓ Appreciate, collaborate with, and learn from local residential and social care agencies
- ✓ Develop patient related outcome measures across organisational boundaries that foster, and embed relational and effective care



- ✓ Find opportunities to engage in trans-organisation and trans professional patient reviews
- ✓ Create relationships with commissioners and providers that help integrate the hospice into system wide networks and plans
- ✓ Engage in collaborative research projects that facilitate shared vision for future care

- ✓ Learn to collect stories about lives of older people in order to better understand their values, aspirations and priorities for care
- ✓ Draw on the expertise and feedback from older people and their families to develop and improve services

It is about the involvement of specialities/people beyond palliative care

- geriatrics
- primary care
- secondary care
- care home providers
- social care providers
- carers organisations

- And more…..
- Build capacity
- Collaborate
- Co-produce

Project ECHO®
Hospice UK
London

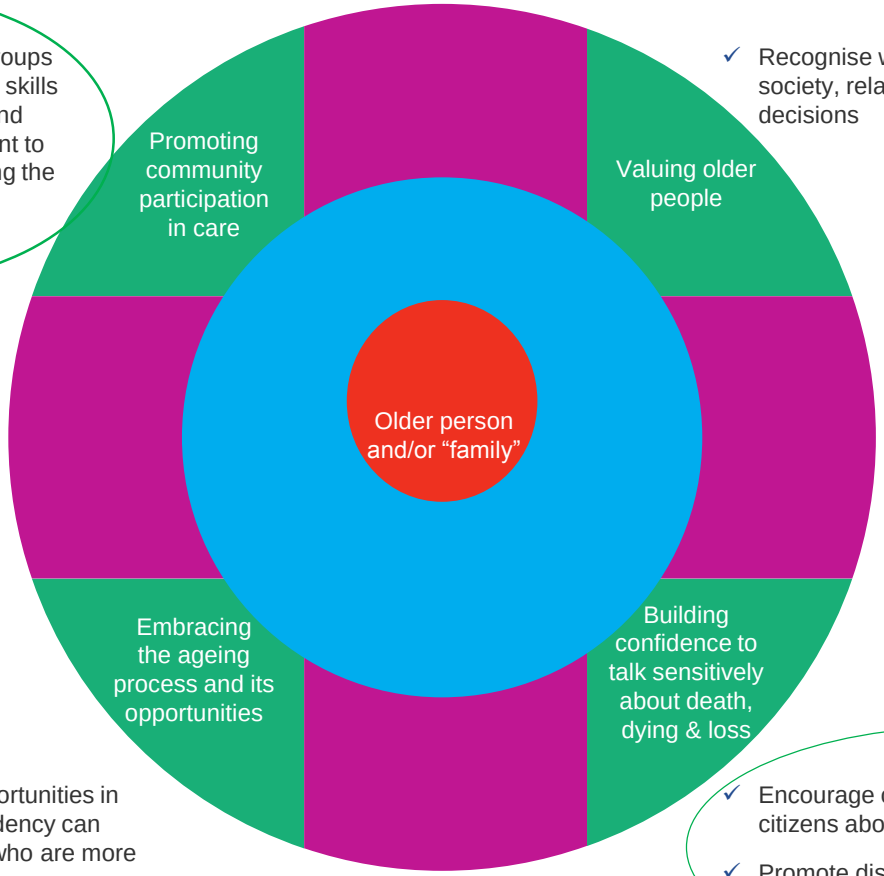
Reshaping Care culture for older people with frailty though implementing a multi-agency model of age attuned palliative care

Burdett Trust for Nursing

Funding Partnership Programme

- Working with community nurses, MDT, older people and their communities to :
- identify the core competencies for older people with frailty in last year of life
- Co-produce , test and refine resources to facilitate confidence and competence
- Disseminate locally and nationally though ECHO methodology

Shaping Society's Response



- ✓ Encourage individuals, groups and communities to learn skills and engage in the care and support of others important to them who are approaching the end of life
- ✓ Recognise what older people bring to society, relationships, conversations and decisions
- ✓ Identify and promote opportunities in which the state of dependency can enhance lives of people who are more independent
- ✓ Encourage conversations on the part of citizens about legacy
- ✓ Promote discussions related to plans regarding older life and its end

'It is surprisingly difficult to accept that dependency is a fact of life, from our first breath to our last.' Dartington 2004

Experienced carers can support people who are caring because they truly understand what it is like

http://www.stchristophers.org.uk/coaching-for-carers

Changing the language – Legacy

Being held in Mind- before and after death…

C.N.: *'Is there anything else you want to tell me Eli?*

Eli: *It's very kind of you, tell, the whole story, the life story, it's all recorded…*

C.N.: *Shall I turn it off now?* (Picking up the recorder)

Eli: *Yes, is it all recorded?* (Reaches over to touch the tape recorder)

C.N.: *Do you want to hear…?*

Eli: Yes, yes, let me hear my voice.'

People need recognition of their capability and strengths over a life long lived – this may help ease a conversation about their current or future vulnerabilities."

Caroline Nicholson 2017

"The greatest gift is a portion of thyself."

Ralph Waldo Emerson

Over to you…Some Questions?

- Does this model have aspects that could be useful to you in New Zealand ?
- What would need amendment and development?
- Where could we work together on this eg. The Burdett Bid..?
- Who else needs to be involved?

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"We live in the world our questions create"

(Cooperrider 2004)