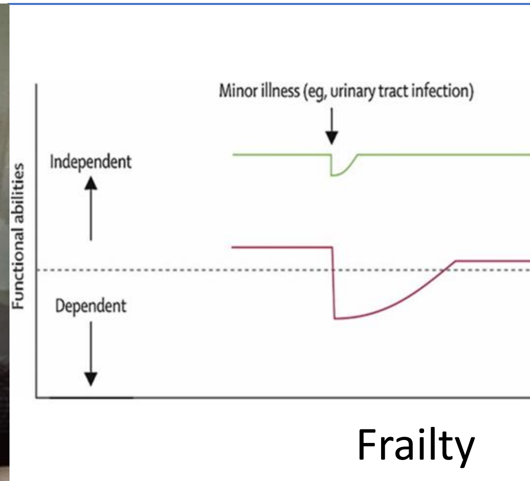
Frailty, Older People and End of Life Care Everybody's Business

StChristopher's

NIHR | Applied Research Collaboration Kent, Surrey and Sussex



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#PALLUPstudy

Agency, equity, equality, visibility, choice, rights- all people should have access to personalised end of life care…

Everybody's Business and Core to Care Homes

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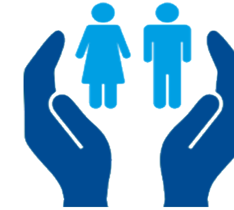
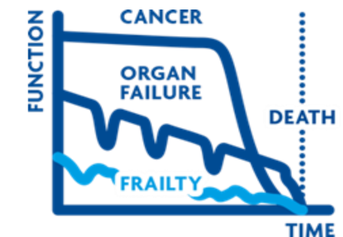
- Older people with Multiple Long term Conditions are more likely to be undertreated by palliative care (specialist and generalist) (Bennett 2017)
- Care transitions common in last year of life- (Hunter & Orlovic 2018)
- Inequity of access to palliative care – range of barriers- attitudinal -ageism/ "ordinary dying"- (Gott et al 2013). Systems (Equity in the provision of palliative and end of life care in the UK Marie Curie).
- Identification of end of life need is poor - older people in hospital, living in care homes and the community with conditions other than cancer (Dixon 2015)
- Care homes are home to around 400,000 older people with frailty. The average care home resident is 85 years old, has six medical diagnoses and takes eight medications. The majority of residents have high care needs and are in the last two years of life https://www.bgs.org.uk/Blueprint



- Palliative care in our communities must double by 2040

- 83% of health spending is in the last year of life.
- Cost borne by older person , their family and services



- **Older People with Multiple Long Term Conditions will be main users of palliative care**

multi-morbidity

- People with different illness' have different needs and die differently

Starting Point- Julienne, my PhD and Frailty

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Living on the Margin: Understanding the Experience of Living and Dying with Frailty in Old Age
(A biographical narrative enquiry over 17 months)

Seeing in a different way:

"But my confidence in life in general has gone, you know because you can't do things. I'm frightened to an extent, to a certain extent but it might be the wrong word but in a general sense, the way the world is going everything. I haven't got the confidence anymore" (Jack)"

Being seen in a different way:

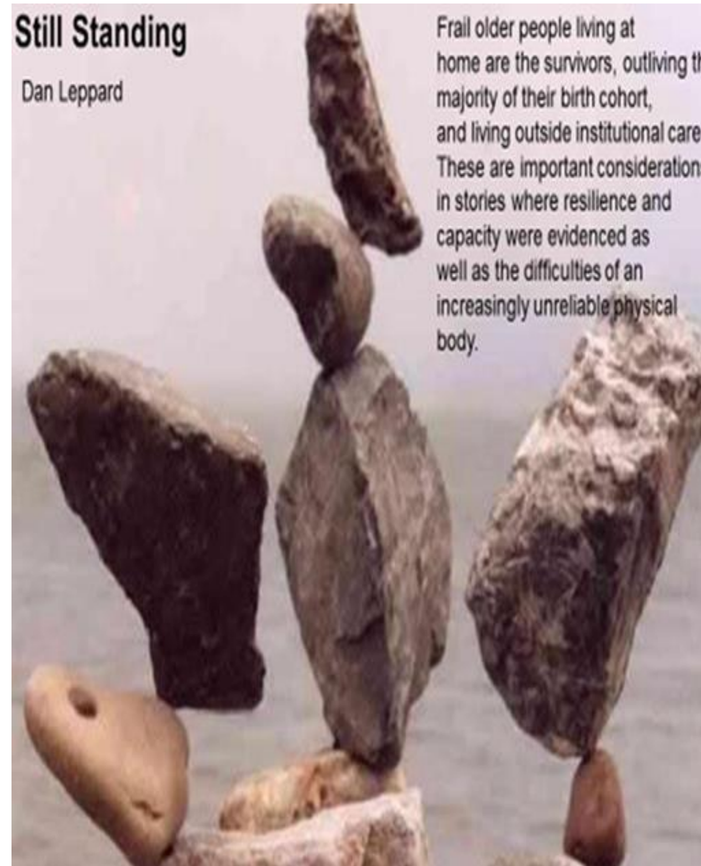
"I hate it, I hate being treated differently I am the same on the inside as I have always been" (Maureen)

A state of imbalance

Dis-connects (Losses)

Loss of the future: more obviously inhabiting the space between living and dying-
"And then he doesn't seem to be so strong-once we got nearly as far as nearly the pillar box (on a walk) but now I don't know he doesn't want to go as far as that. I'm just terrified he's going to die." (Betty wife of Jo)

- **Retaining connections and anchorage** through the work of daily routines
- **Creating connections-** the creativity of older people with frailty relating to their



The Frailty Paradox

Understanding what matters to older people Living and Dying with Frailty in Old Age

Contents lists available at SciVerse ScienceDirect
Social Science & Medicine
journal homepage: www.elsevier.com/locate/socscimed

Living on the margin: Understanding the experience of living and dying with frailty in old age
C. Nicholson, J. Meyer, M. Flatley, C. Holman, K. Lowton

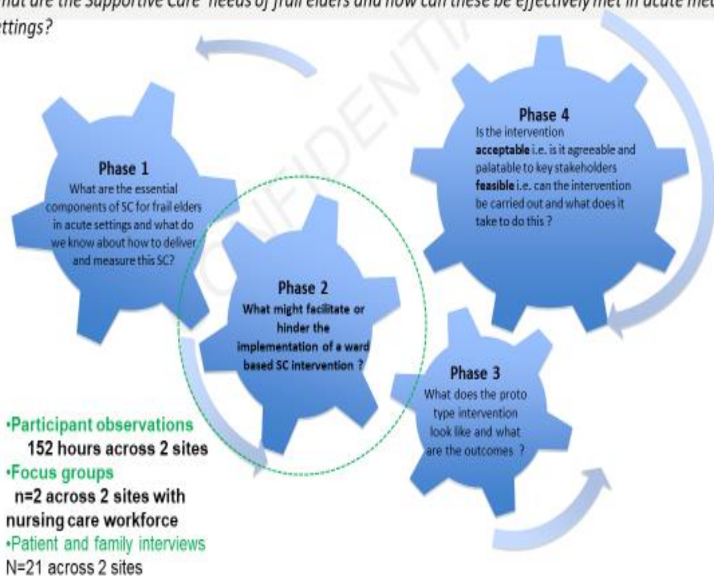
Maintaining Continuity-

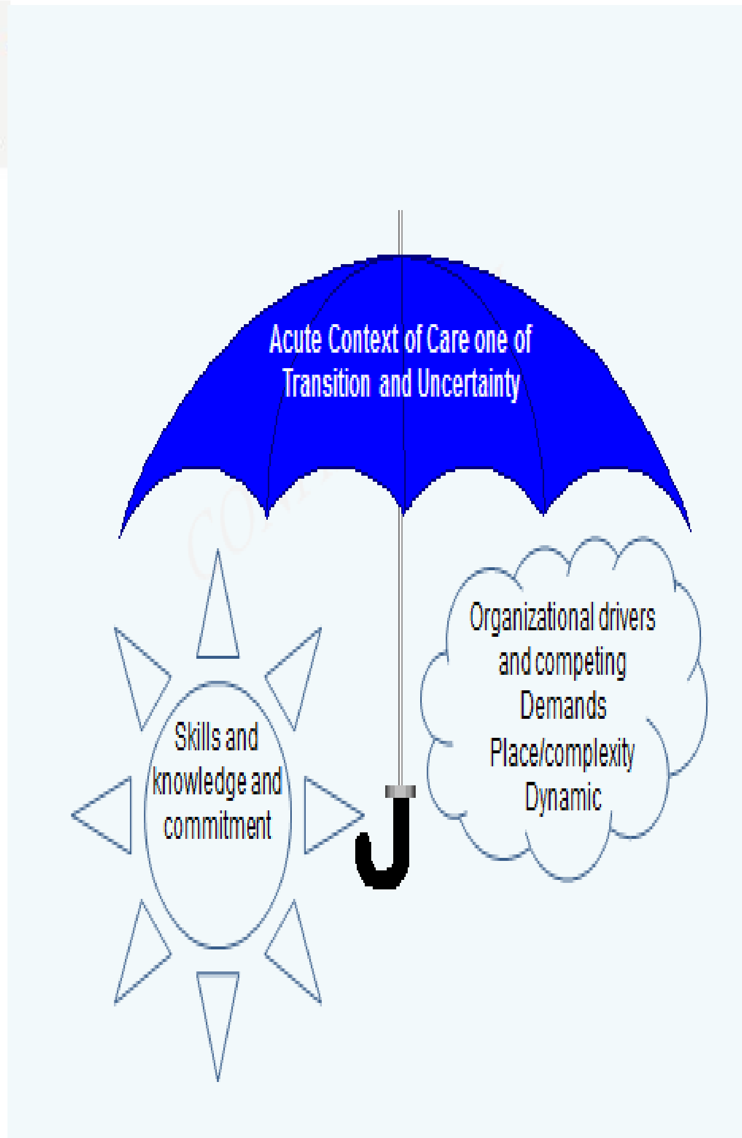
Maintaining Personhood-

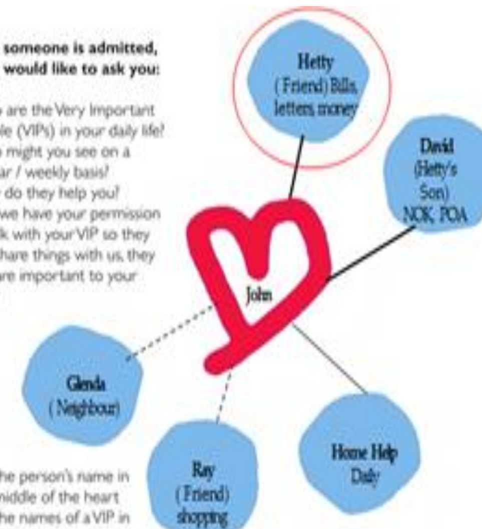
The continual work of keeping going and adaptation to loss

The social networks/community "the glue" through which and in which lives are lived

Integrating Living and Dying… In Hospitals







Integrating Living and Dying… In Hospices

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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

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, making the best of the day..

The Cascade Project- 2019-2022

- Working through a train the trainer model within SCH to Cascade learning throughout the hospice, community nurses and wider community to:

- **Identify core competencies to support older people with frailty life**
- **Co-produce resources to facilitate confidence and competence**
- **Disseminate locally and nationally**

Outcomes

- Integration of Clinical Frailty Scale within assessment and electronic records
- SCH Cascaders pre and post survey of confidence in decision making and understanding of frailty 11% to 76%. N=28
- Increase in clinical awareness of frailty related symptoms, e.g. Delirium
- Building partnerships in care homes to build awareness and skill regarding in rehabilitative palliative care.

https://www.stchristophers.org.uk/frailty-and-end-of-life-its-time-to-act/

Burdett Trust for Nursing

Funding Partnership Programme

Integrating Living and Dying… at Home

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The PALLUP study

- Understanding need-
- Survey of current practice
- Collecting patient and carer experience and service response in real time-
- Together developing key features and resources to embed in service provision

Addressing inequity in palliative care provision for older people living with multimorbidity. Perspectives of community-dwelling older people on their palliative care needs: A scoping review

Palliative Medicine
1–23
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SAGE

Caroline Jane Nicholson[1,2], Sarah Combes[1,2], Freda Mold[1], Helen King[1], and Richard Green[1]

Phase 1 Consensus on core palliative care needs of older people with severe frailty

Literature review, interviews/survey with older people and their family (N=25), Virtual Delphi - with health, social, and voluntary services and family carers (N=256)

https://www.surrey.ac.uk/living-and-dying-well-research/living-advancing-frailty-educational-film

Integrating Living and Dying… across Services

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Social care workforce at Home
Families are sometimes confused about whose, they feel overwhelmed with who does what … we can go in and tell them- it's a lot for them (the families) to take on – we help them to understand"
(Carer SCPCS)

ALLIANCE:

Enhancing the quality of living and dying with advancing frailty through integrated care partnerships:

Building research capacity and capability -

Through
Collaboration
Co-production
Curiosity

" She (MY CARER)_ knows about me not just cares for me" (Olive)

ALLIANCE: Enhancing the quality of living and dying with advancing frailty through integrated care partnerships

Integrating - All care givers

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Family , friends and neighbours- unpaid carers

"It's hard to put into words- I know that something is not right (with Dad) but you do not always know who to talk to and if you should ring- I don't like to bother you as you are all so busy" (JL, carer 9.2.18 SCIOaS Study)

Homecare services supporting End of Life- Vitally important!

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Most people want to die in their own "homes(

Home carers know the person over a period of time- sometimes years

Involvement in the "small" everyday care that makes **the** difference to people

Often Home carers are the person in a care team that notices changes and can alert others

Often the member of the care team that communicates most with the older person and their family

Mediating Experiences at home-
"Families are sometimes confused about whose, they feel overwhelmed with who does what ... we can go in and tell them- it's a lot for them (the families) to take on – we help them to understand" (Carer SCPCS)

" She knows cares about me not just for me" (Olive)

"You can't just sort out something with one phone call, it develops into others... so its not just dad's medication, its mum's medication"

Viv, daughter of Dave

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End of life care partnership

Future work and priorities

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CHALLENGES

- Covid has brought death centre stage, but a particular type of dying and reminded us again that older people with frailty/long term conditions are vulnerable to inequitable and discriminatory practices
- The workforce are stretched and in some community settings (e.g. care homes) almost completely decimated
- Older people left in need of "rehabilitation", not just physically but in every way
- Identification of dying in older age is difficult

OPPORTUNITIES

- Creativity and Collaborations –in service delivery and carrying out research
- The newly mandated Palliative and End of life care amendment to legislation, granting everyone the right in law to provision of palliative care
- The increasing realisation that family or, perhaps more accurately, unpaid carers, are an essential part of care for older people living in the last phase of life
- Moving from time to death (prognostication) to need as an indicator for palliative care
- Integrating end of life care for older people across the care continuum

Acknowledgements

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With thanks …
The Older People, their families, services providers and volunteers who have informed and taken part in all this work

AND to Professor Julienne Meyer ….

"The starting point is always talking, engaging and curious about who that person is …" (2022)

Julienne

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