



# End of Life Care In Residential Care Homes – An Appreciative Inquiry

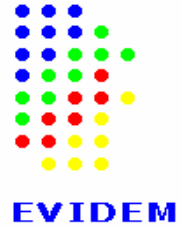
**EVIDEM End of Life:** Working with primary health care supporting people with dementia living and dying in care homes

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# Living and dying in care homes



- ▶ **19% of people die in their own home, 35% if care homes are considered to be their home**
- ▶ **Median life expectancy of an older person admitted to a care home that offers personal care is between 2-3 years and 1-2 years in a nursing home**
- ▶ **> 30% of care home population have advanced dementia**

# Aim of EVIDEM eol: phase 1

To understand the need for support and end of life (eol) care of older people with dementia living in care homes

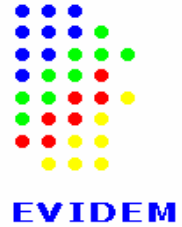
- Tracked care of 133 people with dementia in 6 care homes over 18 months
- Methods:
  - Care note Review: 4 monthly (key life events, NHS)
  - Interviews/group discussion (managers, staff, and NHS professionals)
  - Interviews with 18 people with dementia
  - Field notes and observational data
  - Post death analysis

# Key Findings: phase one



- **Uncertainty**
- **Knowledge/Skills: Limited training**
- **Difficulties in recognising/deciding when someone is for TLC/EOL/palliative care register.**
- **Absence of Planning**
- **Defensive Practice**
- **Confidence Issues:**
- **Responsibility: Decision-Making:**  
(GP, DN, CHS, relatives and resident)
- **Culture of Living not Dying**
- **PHASE 2:**

# Phase 2 Objectives



- To identify with care home and primary care staff, strategies to support integrated working between care home staff and primary health care services for end of life care for people with dementia
- To test ways that primary health care services and care home staff can work together to identify resident and organisational outcomes to support end of life care that reflect the priorities, experiences and concerns of older people with dementia living in care homes
- To consider how available palliative care support tools and frameworks act as a resource for primary health care services and care home staff, to manage uncertainty at the end of life.

# Appreciative Inquiry

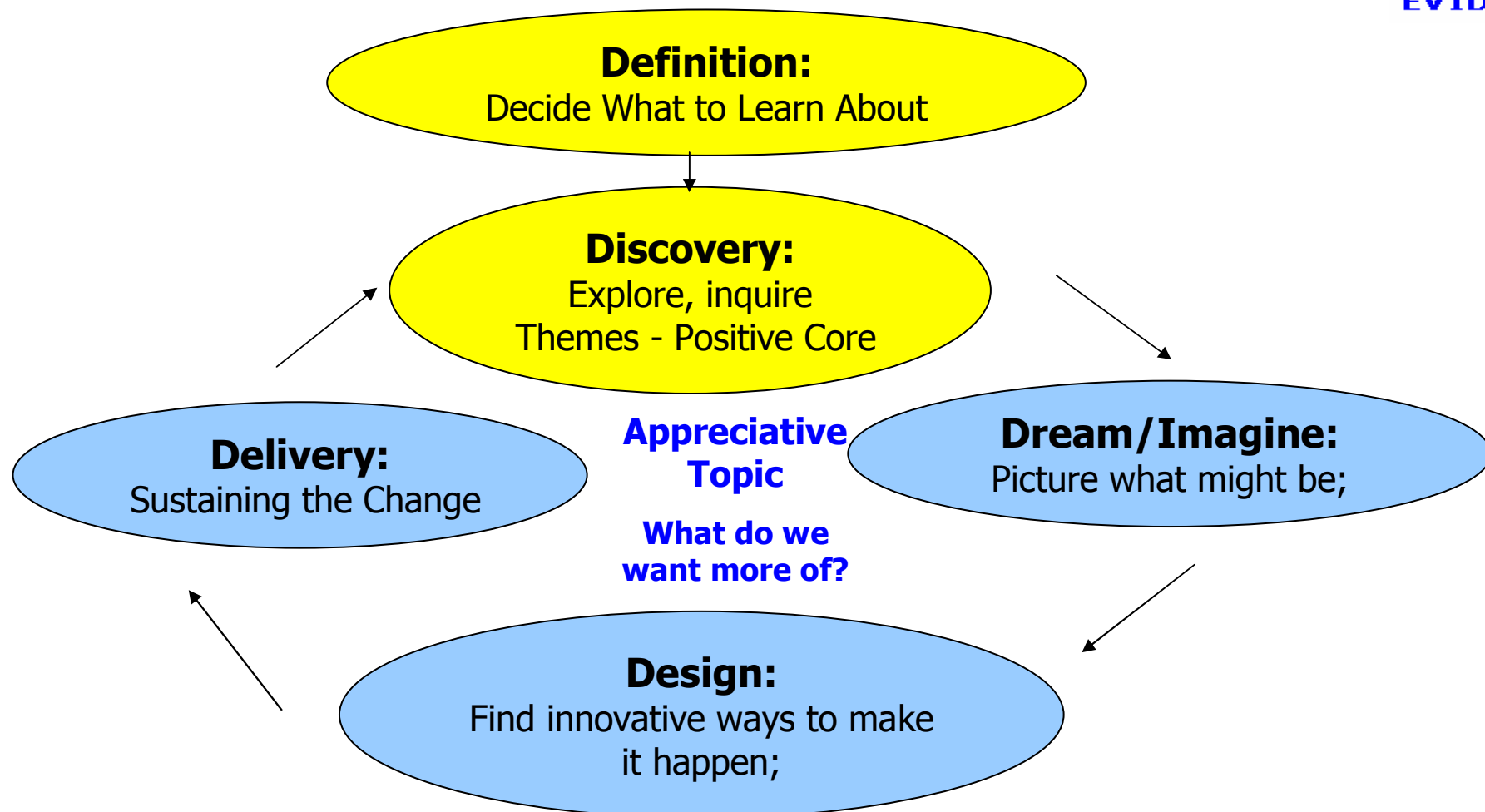


- Modified AI approach
- 3 meetings over 6 months (GPs, DNs, care home staff and researchers with facilitator)
- All parties in the room, joint vision, planning for the future, appreciation of each other.
- **FOCUS:** not on deficiencies but what works well and do more of it.

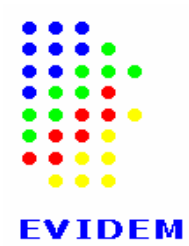
**'Human systems grow in the direction of what they persistently ask questions about'**

Cooperrider and Whitney (1999, p. 248).

# Appreciative Inquiry: 4 or 5 Step



Coghlan, A.T., H. Preskill, and T. Tzavaras Catsambas, *An overview of appreciative inquiry in evaluation*. *New directions for evaluation*, 2003. **2003**(100): p. 5-22.



## Good Gossip

good gossip only makes you feel better but also your listener and the organisation in which you are working.

- You can only gossip by talking to other, no one gossips on their own.
- Good gossip is ongoing conversation where you talk and listen to colleagues in your organisation, about what you are proud of, you do well, you have seen others do that makes you feel good.

Think of a time when you really felt you had done a good job, it may be that everything fitted into place, you gave great care, you worked with others and felt supported in a difficult situation..( quality rather than how big it was) ...



## 1<sup>st</sup> Meeting



*“They [care staff] are fundamental to the care, they are possibility the most important part, they can change the way it goes, [hospital etc]” (GP 1<sup>st</sup> AI meeting)*

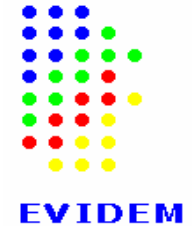
*“I found them [care staff] reassuring presence....Good to have someone else with that experience to sound that off, [you recognise that exp], try and involve carers” (GP AI Meeting)*

*“because they [care staff] have so much experience [in dementia]” (DN: 1<sup>st</sup> AI meeting)*

*“GP is a breath of fresh air, he actually listens to our opinion, previously GP would have kept driving” (Care staff AI Meeting)*

***It is the small things that we do over and over again that make the difference.***

# 2<sup>nd</sup> Meeting: Death of a Recent Resident:

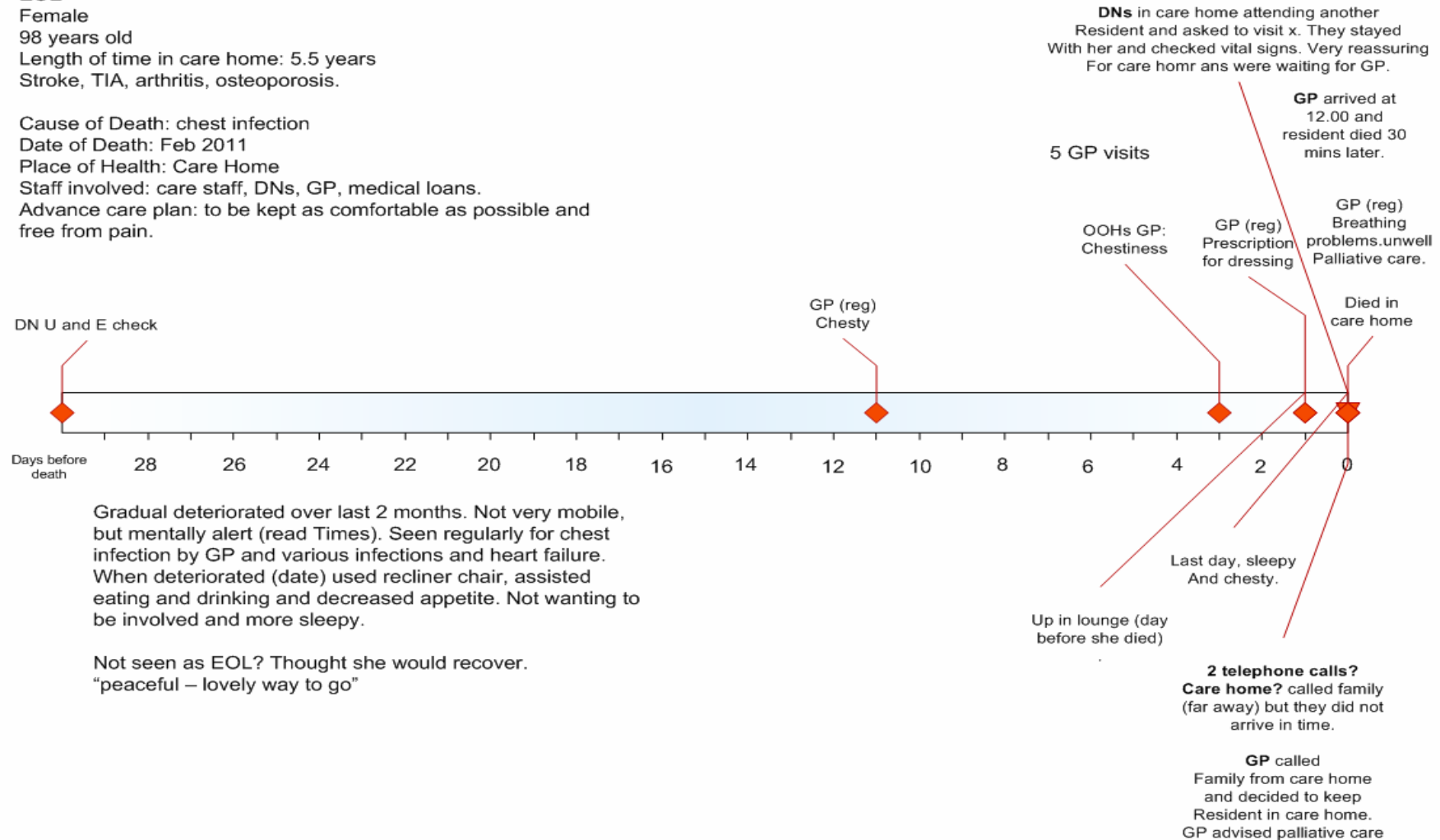


From the point of View of GP, care staff and Relatives/Resident

## EOL

Female  
98 years old  
Length of time in care home: 5.5 years  
Stroke, TIA, arthritis, osteoporosis.

Cause of Death: chest infection  
Date of Death: Feb 2011  
Place of Health: Care Home  
Staff involved: care staff, DNs, GP, medical loans.  
Advance care plan: to be kept as comfortable as possible and free from pain.



# Working Together

“The communication with XX is no longer doctor-carer, ‘you do this, I’ll do that’, but it’s more I think there’s an improved confidence with the staff to be able to say, ‘doctor, we’re concerned that this patient is deteriorating, what do you think we should do? .....

.....the staff spoke to the patient, the family got the impression that ‘this is just one body talking to me, rather than a carer and a doctor’ – basically just resonating that we think the same. Which is good, because you’ve got somebody who’s not medically trained, giving reassurance and the doctor’s also offering advice,

.....so that’s what I’m sort of saying about working with the staff. The communication, the confidence about approaching people’s lives, to me, has improved”

(GP 3<sup>rd</sup> AI Meeting)

“Yeah I think so. It was really helpful, wasn’t it, meeting the District Nurse and GP, and making us work more as a team. It helped us know *what we’re entitled to in regards to help*, and they realised where they can help us. We can be quite independent as the care-provider, knowing there’s that extra support, and since having those meetings, we’re totally different to before. Staff felt a little bit more in control I think, and they’re not so panicked. It was much better”

(Exit interview with Manager and Deputy Manager)

## 3<sup>rd</sup> Meeting:

- Appreciation of Roles
- Time to be reflective together
- Relationships (more equal, shared)
- Increased confidence
- Maintaining continuity of service delivery
  - Weekly meetings (GP and Manager)
  - DNR audit
  - OOHs checklist



# Acknowledgements



- Many thanks to residents, care staff, NHS staff who gave up their time to take part in this research.
- *This presentation presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1005). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.'*

## **EVIDEM: EVIDENCE-BASED INTERVENTIONS IN DEMENTIA**

**Changing practice in dementia care in the community: developing and testing interventions  
from early recognition to end of life, 2007-2012**

**National Institute for Health Research: Programme Grant for Applied Research (RP-PG-0606-1005)**

**Hosted by Central & North West NHS Foundation Trust**

**For more information about getting involved with EVIDEM-EOL, contact:**

**C.Goodman@herts.ac.uk**

**Or visit the programme website [www.evidem.org.uk](http://www.evidem.org.uk)**

# Further References:

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