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That the care home staff are fundamental to good E.O.L. care.

value and see already in our experiences of giving great End of Life care for people with dementia.

That families are really important and we value keeping them involved.

> Communication is Key between residents, families and professionals. We are all 'Singing off the same song sheet.'

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**NHS Foundation Trust** 

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

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#### Aims of presentation

- Brief outline of study aims and Phase 1
- Phase 2 promoting collaborative working using Appreciative Inquiry (A.I.)

- Intro to A.I.
- Good Gossip
- Outcomes so far
- Challenges

### 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:
  - 4 monthly case note reviews of care and key life events of residents
  - Interviews with care home managers, staff, and NHS professionals
  - Interviews with people with dementia
  - Field notes and observational data

#### Key messages phase one



- Uncertainty around end of life and coping with this
- Limited training for end of life care, and limited dementia training, especially for DNs and GPs.
- End of life care puts extra pressure on care home staff
- Difficulties in deciding when someone is for TLC/EOL/palliative care & seen as decision of GP. Involvement of care homes in this?

### 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.

### **Methodology Phase 2**



- Participatory approach
- 'Appreciative Inquiry'
- Modified A.I approach with 3 care homes and associated NHS practices that were recruited in phase 1
  - D.N.'s, /G.P's /Care Home Managers
  - Facilitated meeting in the care homes for an hour three times over a 5 month period.
  - Researcher and resource input to support practice development outside of the meetings.



#### **Appreciative Inquiry**

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

 Cooperrider and Whitney (1999, p. 248).





#### Al principles

- We see the world we describe
- we get more of what we choose to focus on...
- Stories have wings...and everyone participates in talking about their best experiences



#### In principle





- Change begins straight away
- Our positive images of the future lead us to take positive action
- The power of the positive broadens outlook and builds resilience
- Wholeness working with whole system
- Small things make a big difference



#### **Good Gossip**

Good gossip not only makes you feel better but also your listener and the organisation in which you are working

- ♣ You can only gossip by talking to others, 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) ...

#### **Good Gossip**

- NHS & Care home staff
   Valuing each others roles and telling each other this!
- Recounting stories of what is working well in and outside of the meetings
- Building on that to sustain and develop more excellent practice in EOL care for people with dementia



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

## Where we are so far...interventions



- Creating a resource to support staff talking about dying with residents and relatives and recording in care notes.
- Out of hours GP checklist (what information do Out of Hours GPs need so that calls can facilitate timely and appropriate care)
- An Audit of DNR wishes within the home.
   Clarifying local DNR policy and documentation. Working with paramedics.

#### **Challenges**



 Honesty and risk to start with what is rather than what we want.

 Sustainability: linking into other processes e.g. C.P.D.

 Remembering that what we do well, and valuing who we are caring for and with, is itself an intervention.

"No problem can be solved from the same level of consciousness that created it. We must learn to see the world anew."

Albert Einstein