# PALLIATIVE CARE NEEDS OF PEOPLE WITH DEMENTIA AT END OF LIFE

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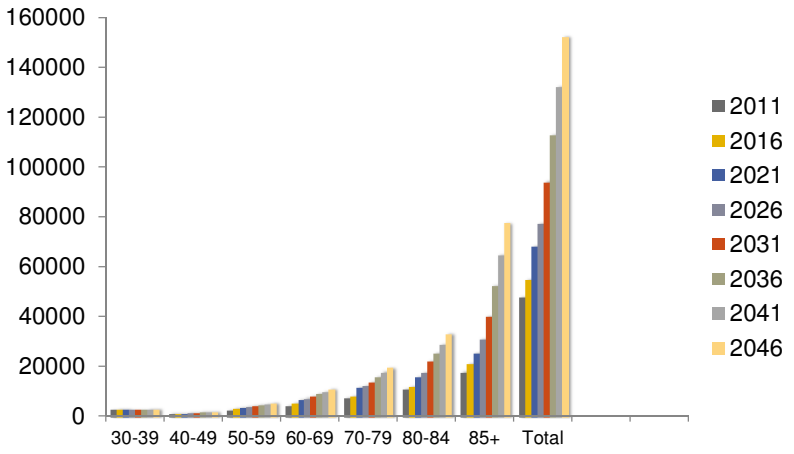
## DEMENTIA IN IRELAND



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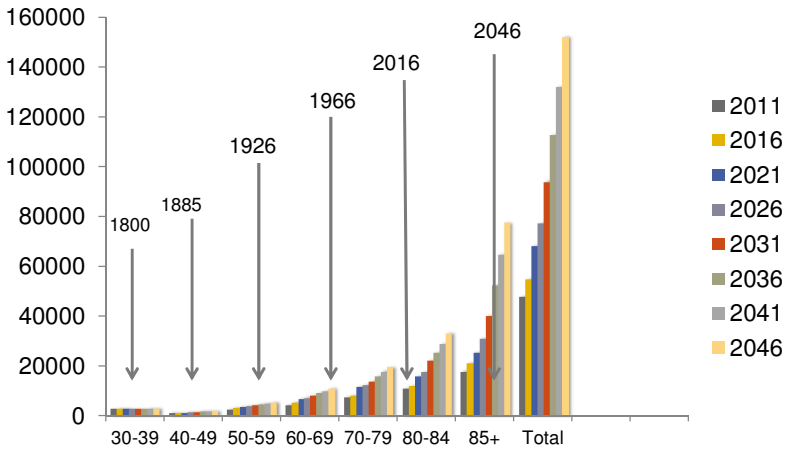
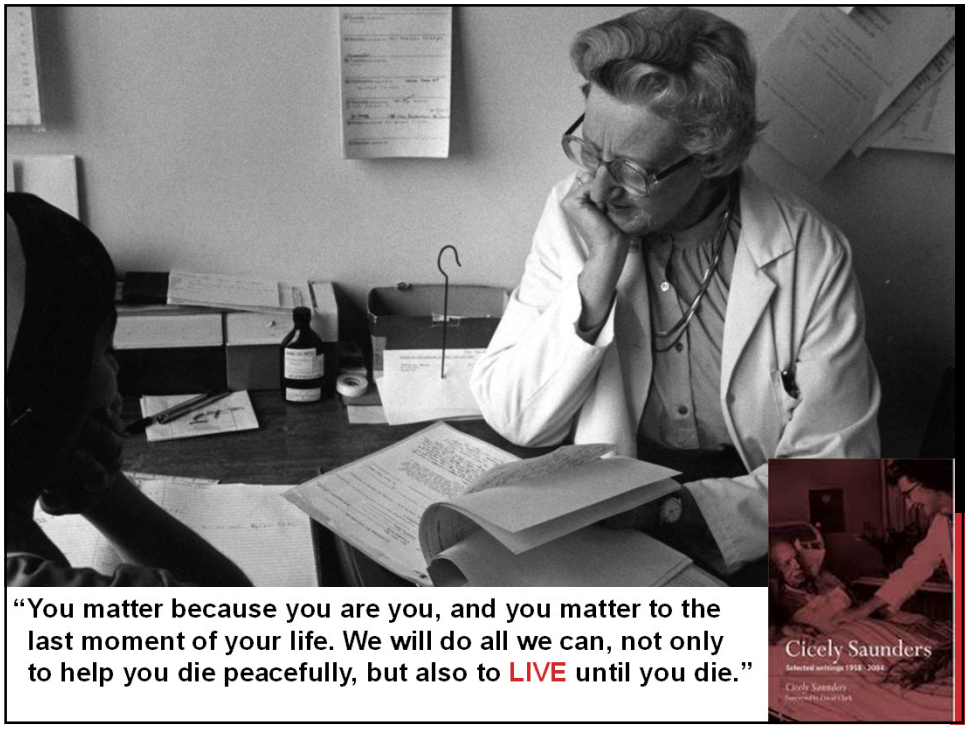


# KATHLEEN HAYES ROLLINS SNAVELY

**The oldest Irish woman ever died July 2015 at 113 yrs (and 140 days)**




"You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also to LIVE until you die."

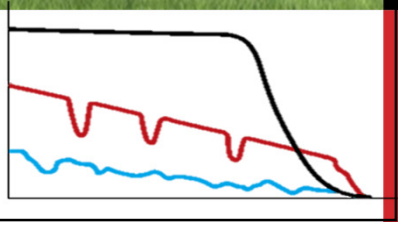
# PALLIATIVE CARE: WHO DEFINITION

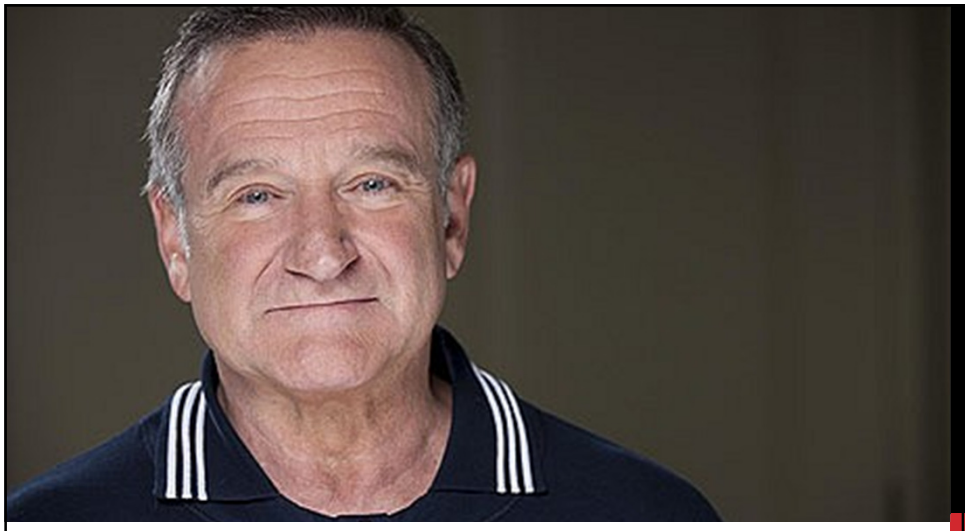
"Palliative care is an approach that
improves the quality of life of
patients and their families
facing the problems associated with
life-threatening illness,
through the prevention and relief of suffering
by means of
*early* identification and
impeccable assessment and treatment of
pain and other problems,
physical, psychosocial and spiritual."

# PRINCIPLES OF PALLIATIVE CARE

- Provides relief from pain and other distressing **symptoms**
- Integrates the **psychological & spiritual** aspects of care
- Will **enhance quality of life**, and may also positively influence the course of illness
- Affirms life and regards **dying as a normal process**
- Intends **neither to hasten or postpone death**
- Offers a support system to help patients **live as actively as possible until death**
- Offers a support system to help the **family cope** during the patients illness and in their own **bereavement**
- Uses a **team approach** to address the needs of **patients and their families**, including bereavement counselling, if indicated

**When does Palliative Care start?**



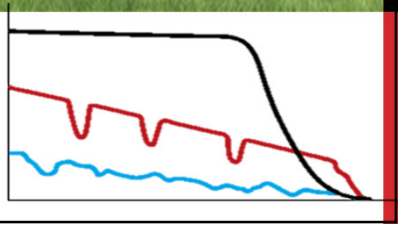


# PALLIATIVE CARE CONTINUUM

**"I used to think the worst thing in life was to end up all alone. It's not. The worst thing in life is to end up with people that make you feel all alone."**

**When does Palliative Care start?**

**When does End of Life Care start?**



# PALLIATIVE CARE

**Medical model:** **Unit of care = Patient**

**Palliative model:** **Unit of care = Patient + family**

**End-of-Life Care???**

"End-of-life care begins when it is possible to know someone is actually dying" NICE 2004

'a chronologically indefinite part of life when patients and their caregivers are struggling with the implications of an advanced chronic illness'. Lorenz 2005

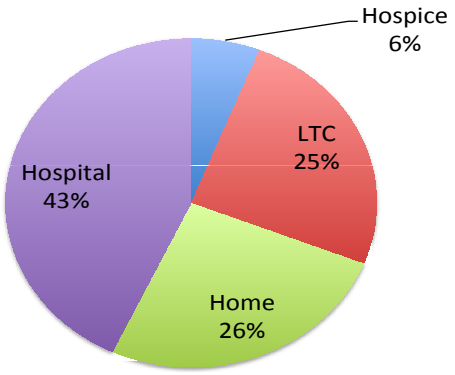
'living with, or dying from, progressive or chronic life-threatening conditions'. Ross 2000

# PLACE OF DEATH IN DEMENTIA

**Place of death in Ireland each year**

**Houttekier et al 2010 (UK, Netherlands, Belgium)**

- **50-92% in nursing home**
- **3-46% in hospital**
- **3-11% at home**



# WHAT DO WE MEAN BY "TERMINAL PHASE" OR "ACTIVELY DYING"

**WHAT ARE THE SIGNS WE MIGHT SEE?**

## "SIGNS OF DEATH APPROACHING"

- **Profound weakness**
  - Bed bound
  - Needs assistance with all care
- **Drowsy or reduced cognition**
  - May be disorientated in time and place
  - Difficulty concentrating
  - Scarcely able to co-operate with carers
- **Gaunt appearance**
- **Diminished intake of food and fluids**
- **Difficulty swallowing medicine**

National Council for Hospice and Specialist Palliative Care Services (1997) *Changing Gear- Guidelines for Managing the Last Days of Life in Adults.* London: NCHSPCS 7.

# PROGNOSTICATION IN DEMENTIA

**FAST Stage 7C (Functional Assessment Staging) Reisberg 1988**

- Lost speech and ability to walk without help, double incontince, needs assistance with ADLs but can still sit unaided, smile and hold up head

**ADEPT: Advanced Dementia Prognostic Tool (Mitchell et al 2010) AUROC = 0.68**

- Male, LOS, SOB, pressure ulcers, total functional dependence, insufficient intake, bowel incontinence, BMI, weight loss, CCF

**Navarro-Gil 2014:**

- Age (1.99), Diabetes (2.32), HTN (1.69), GU (2.46), worsening health over last 12mnths (1.65), not performing passive (1.62) or social (2.24) leisure activites

**HELP: Hospice ELigibility Prediction (Levy 2015) AUROC =0.838**

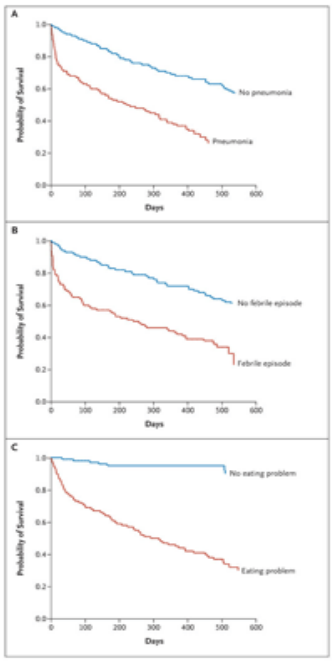
- Found comorbid diagnosis rather than functional status to be a better predictor of 6 month mortality

# CLINICAL COURSE OF ADVANCED DEMENTIA

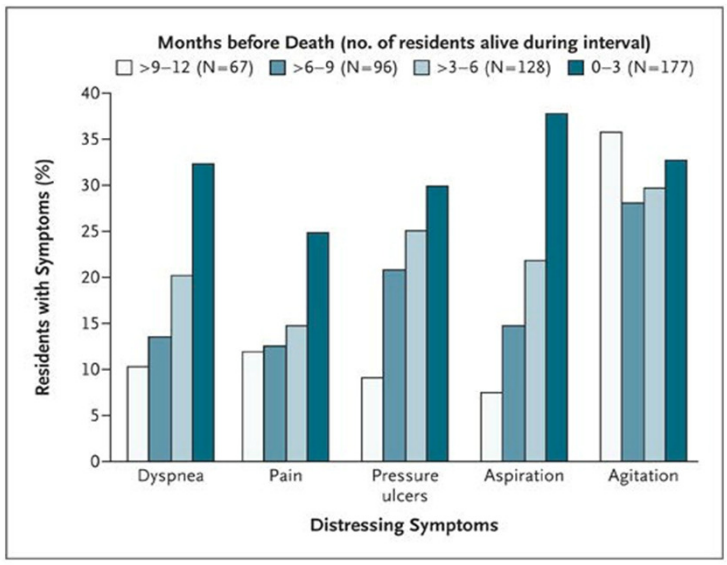
**Mitchell, S. et al NEJM 2009;361**

## Global Deterioration Scale (Dementia) Stage 7:

- All verbal ability lost, often no speech at all or just utterances or phrases,
- incontinent of urine, needs assistance toileting and feeding,
- progressive imobility, often increased rigidity



# RESULTS: DISTRESSING SYMPTOMS




# DIFFERENCE IN SYMPTOMS LTC VS PC

| Hospice | Symptom % | Nursing Home | Symptom % |
|---|---|---|---|
| **Pain** | **70** | **Confusion** | **81** |
| Weakness | 64 | Ur incontinence | 79 |
| Dyspnoea | 43 | Loss of skin integrity | 71 |
| **Confusion** | **34** | **Pain** | **69** |
| Anorexia | 28 | Behavioural problems | 67 |
| Weight Loss | 21 | Anxiety | 48 |
| Nausea | 18 | Immobility | 46 |
| Cough | 17 | Restlessness | 41 |
| Vomiting | 16 | Impaired motor coordination | 40 |
| Drowsiness | 16 | Constipation | 35 |

Maddocks et al Palliative Care in Nursing homes Report South Australia 1996

# PAIN

**Agitation, Irritability,**
**Restlessness, Confusion, Combativeness**
**Changes in appetite, reduced oral intake**
**Guarding, Moaning, Crying, Grimacing,**
**Change in body language, delirium, withdrawn**

**Pain assessment tools in Dementia**

# P
# T

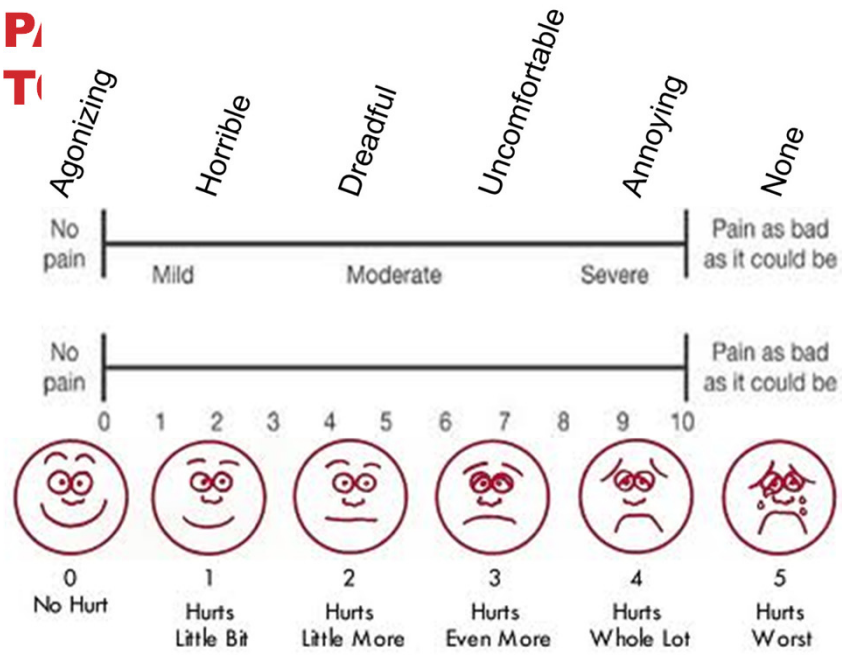


**Table 2. Commonly Used Pain Scales for Patients With Dementia.**

**Table 2.** Commonly Used Pain Scales for Patients With Dementia.

| Commonly Used Pain Scales for Patients With Dementia |
|---|
| Assessment of Discomfort in Dementia Protocol (ADD) |
| Discomfort in Dementia of the Alzheimer's Type (DS-DAR) |
| Pain Assessment in Advanced Dementia Scale (PAINAD) |
| Face, Legs, Activity, Cry, Consolable (FLACC) Scale |
| Bodies In Pain |
| Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) |

Abbey Pain Scale
DOLOPLUS2

David B. Brecher, and Tasheba L. West AM J HOSP PALLIAT CARE 2014;33:276-280

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# PAIN

Despite pain being the most common complaint at the end of life, it's management may be suboptimal and cancer patients are most likely to have the best pain control compared with people with dementia or COPD

**Romem A et al Palliative Medicine 2015;29(5)**

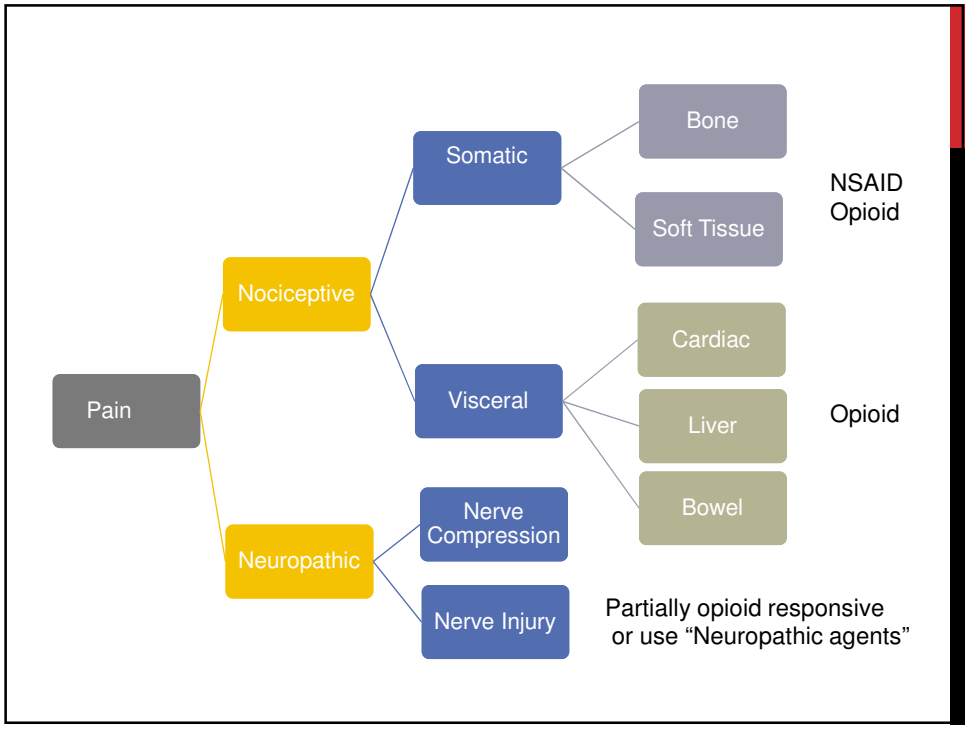
**Document pain assessment**

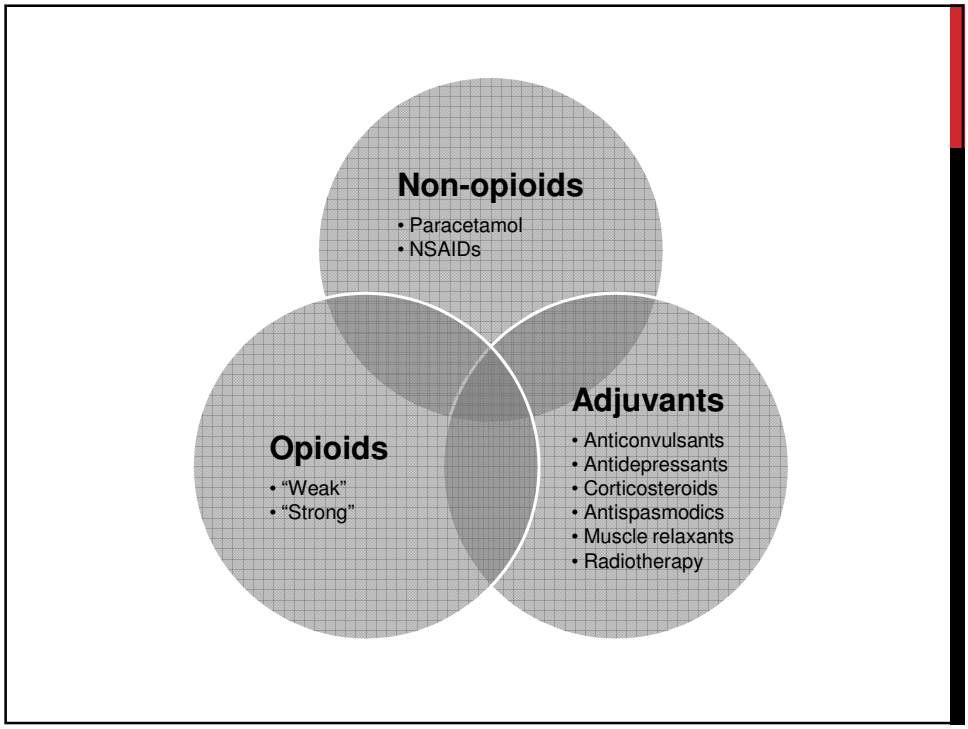
**Consider the cause**

**Treat the cause**

**Consider the best analgesic to suit the cause**

**Use regular analgesia if person has communication difficulty**


Pain
Nociceptive
Somatic
Bone
Soft Tissue
Visceral
Cardiac
Liver
Bowel
Neuropathic
Nerve Compression
Nerve Injury
NSAID
Opioid
Opioid
Partially opioid responsive
or use "Neuropathic agents"


Non-opioids
• Paracetamol
• NSAIDs
Opioids
• "Weak"
• "Strong"
Adjuvants
• Anticonvulsants
• Antidepressants
• Corticosteroids
• Antispasmodics
• Muscle relaxants
• Radiotherapy

# DYSPNOEA

**May be because of co-existing disease: COPD, CCF,**
**May be related to pneumonia**
**May be because of aspiration**
**Assessment e.g.**

- **person's report, resp rate, O2 sats, HR,**
- **using tool e.g. respiratory distress observation scale,**

**Treat the cause**

- **Mucolytics**
- **Oxygen**
- **Bronchodilators**
- **Antibiotics +/- steroids**
- **Opioids**
- **Benzodiazepines e.g. midazolam sc**

# OPIOIDS GET BAD PRESS

**Opioid Neurotoxicity**
**"Respiratory Depression"**
**"Addictiveness"**

**etc. etc. etc.**

## Opioid Toxicity

Drowsiness*
Hallucinations
Confusion/Delirium
Nausea & Vomiting*
Myoclonus
Itch
Pin point pupils
Allodynia
Respiratory depression

Constipation (Nearly all)

* Wear off in few days

# CHALLENGING SYMPTOMS

**Lethargy > Agitation**

**Agitation or Distress could be**

- **pain, discomfort,**
- **constipation,**
- **retention**
- **infection,**
- **dyspnoea,**
- **nausea**
- **fear,**
- **wanting to be left alone,**

"What would happen if we hired two private detectives to follow each other?"

# AGITATION

| Table 2. The Seven I's: A Mnemonic Device for Determining the Source of Acute Behavioral Change in Dementia |
|---|
| Iatrogenic (consider anticholinergics, sedatives, opioids, others) |
| Infection (pneumonia, urinary tract, cellulitis, others) |
| Injury (often a covert fall; also consider any source of pain) |
| Illness (any acute illness or exacerbation of a chronic illness) |
| Impaction (fecal) |
| Inconsistency (major change in the environment, relocation, new people, others) |
| Is the patient depressed? |

# AGITATION

**Why?**

**Why?**

**Why?**

**Delirium guidelines**

**Appropriately treat any identifiable causes**

**Do what is necessary, avoid the unneccessary**

**Explain, demonstrate**

**Music, massage, reflexology, pet therapy, aromatherapy**

# ADVANCE CARE PLANNING

"…we are just negligent to look after people without finding out what their wishes are and I think we have no right to look after people without asking them- give them the opportunity."

"I know in a nursing home it is kind of like maybe you relinquish all control of your life and you are running off somebody else's agenda, it is task orientated. Whereas, you are giving them the dignity of making that decision."

"I have had daughters crying at meetings you know. Because they never knew what their parent wanted and they were reluctant to bring it up with them I think".

Pathway for difficult conversations: "helped ease everyone into the conversation"

Built stronger relationships: "they see you as maybe someone who is closer to them…."

# ADVANCE CARE PLANNING

"…that is the pay off the convenience of it at their end of life whether it is weeks or days, it so calm in comparison to before."

Crisis decision making was no longer the norm, family and staff were not under pressure to make last minute decisions

Normalised death

Families were more prepared at end of life

"…we have had a reduction in the number of transfers to acute hospital at the end of life, the staff are happier that they are not seeing dying residents transferred out of their home to a busy A/E Department."

# DEATHS IN HOSPITAL

**2.5 year period before compared with 2.5 year period after**

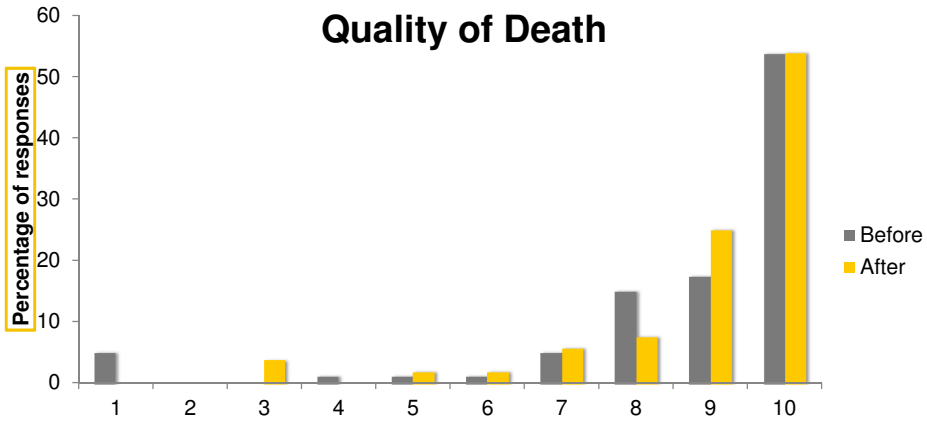
**Home 1: 8.3% before vs 14.1% after** deaths were in hospital

**Home 2: 15.2% before vs 10% after** deaths were in hospital

**Home 3: 4.9% before vs 3.2% after** deaths were in hospital

**Overall 9.2% before vs 8.2% after** deaths were in hospital (NS)

Overall hospitalisation rate 0.54% before vs 0.36% after




| | | |
|---|---|---|
| **Median Score Before:** | **10** | **mean = 8.74** |
| **Median Score After:** | **10** | **mean = 8.92** |
| **Mann-Whitney U test:** | **No significant difference** | |

# CONCLUSION

**Palliative care for people with dementia at the end of life can be complex, challenging but ultimately if you get it right…..**

**very rewarding**

**THANK YOU**