

***'Dying is no longer just a medical  
issue here'***

***Evaluation of IHF Journey of Change  
Emerging Findings***

# Content

- Background to the Programme
- Evaluation focus and methodology
- ‘Being part of a CEOL review’
- Programme impacts
  - Staff- confidence and communication
  - Practice
  - The organisation
- In summary

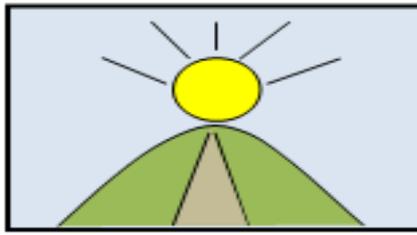
# Journey of Change Programme Aim

To support and empower staff working in residential care centres for older people develop their end-of-life care practices. The main elements of the programme are to:

- Develop a vision for end-of-life care (developed with and owned by all members of staff).
- Establish a CEOL group who have responsibility for driving develop and change in end-of-life care.
- Establish CEOL reviews after the death of each resident to support staff, review care and identify areas for change.
- Invite feedback from bereaved relatives and friends.
- Implement bespoke change projects (level 3 only)

The programme is underpinned by a continuous quality improvement approach to delivering end-of-life care.

IHF JOC Workshops & materials



Vision

Support from local JOC Coordinator



QUESTIONNAIRE

Very often   
Often   
Sometimes   
Rarely

Bereaved Relatives & Friends Questionnaire

CEOL Group



CEOL Review



# Evaluation focus

- The impact and experience of four aspects of the programme:
  - Awareness of and vision for end-of-life care in the residential care centre
  - The role of the compassionate end of life (CEOL) group.
  - Facilitating compassionate end of life (CEOL) reviews after the death of a resident.
  - Making change

# Evaluation Methodologies

## Part 1-Literature review

## Part 2- Case Studies (6)

- A cross section of RCC's
- Size -from > 150 beds to <20 beds
- EOLC training experience skills (lots, some, none)
- Location (cities, towns, villages and rural) & north, south, east and west of the country
- HSE funded and non- HSE funded
- Mixture of Level II and Level III Centres

# Taking part in a CEOL review

- We remember the resident
- We take time, we pause
- We reflect and we remember the resident collectively
- We think about what worked.
- We discuss what we could do better.
- We are all a part of it.
- Its very real
- (We make recommendations)

# Taking part in a CEOL review

- Done differently in different places
- Some done within a week or two
- Some focus on the last 24-48 hours others focus on the time the resident spent in the centre
- Some are more reflective than others
- Facilitated/Co-facilitated by a member of the CEOL group

*'We do things differently  
now'*

# Impacts for staff- Confidence

Those who did the training are more confident and comfortable talking about death with residents.

*'Before if a resident brought up the subject of death and their death in particular I'd have run a mile. I used to tell them that they were well and why would they be worrying about that and change the subject. I don't do that any more, instead I ask them to tell me more.....'*

*'Death used to be the taboo subject here, now it is part of normal conversation, it makes the whole place more relaxed, being able to talk about it'*

# Impacts for Staff: Communication

*'We communicate better with the families now'*

*'We have learnt that we cannot assume that one family member will tell the others, so we have conversations with various family members in order to understand who we need to speak to'*

*'I have also for the first time talked to my own family about my death and about dying, I am no so scared about talking about it anymore and I don't want them to be either. I realise now death is just another part of living'*

# Impacts for EOLC planning practice

*'Our EOLC care plan for our residents used to be a couple of lines, which we struggled to write. Now we have pages on what each resident wants. We constantly update and add to this, as they tell us things.'*

*'Introduced a traffic light system so that all staff know where a resident is in relation to EOLC'*

# Impacts for practice (around dying)

- *'We have another EOLC symbol on the corridor to remind people that we have a resident dying'*
- *'We have a lovely bedspread in the room when people are dying'*
- *'We have music in the room if the family want it'*
- *'We have finally got a day bed for families who want to stay over when a family member is dying'*
- *'We are far more open with our residents, we used to not even want to tell them when we had to call an ambulance, now we tell them when another resident is dying'*

# Impacts for practice (around dying)

*'We know from our residents that they do not want to die alone. So if there is no family we will now sit with them. Before we used to pop in and out. Making sure that someone is there often means juggling things but everybody is on board and someone will always volunteer to be with the person who is dying. This has us feel more like a team, with kitchen staff, housekeeping care staff and nurses all taking a turn.'*

# Impacts for practice- after the death

- Encourage family to take their time
- Tell the residents, give them an opportunity to say goodbye
- In some situations the remains have returned to the nursing home
- Removal of the remains is more public
- Staff (incl. off duty staff) form a guard of honour
- Picture of resident and candle lit in reception
- Belongings of the resident returned appropriately

# Impacts for the organisation

- New cross-disciplinary, (less hierarchical) structure in place- more cohesive
- Tension between the existing management and the new structure- leading to negotiation
- Team building from the ground up
- Ambitious projects being developed in some locations

# Overall Programme Impacts

- Raised awareness of End of Life
  - For staff directly involved
  - For wider staff (depends on RCC size)
- Increase staff confidence & communication skills
- Changes in practices (EOLC planning, around death and after death)
- Changes in the culture of the organisation

# Why does it work better in some places?

- Application of all of the difference elements of the Programme (in tandem)
- CEOL group is cross-disciplinary and meets regularly/ Staff attendance facilitated.
- Viewed as a longer term incremental process
- CEOL Group Facilitator/Convener is key
- Staff are freed up to attend CEOL group meetings and CEOL reviews
- Centre management are open to implementing change

## In summary

*‘We do death differently now’*

*‘We have learnt more how to step into the shoes of our residents in relation to EOLC’*

*‘The Programme has made us more compassionate as we try to understand our residents fears and concerns in relation to end of life and in relation to how they want to live’*