ABC 4 LD

Hertfordshire End of Life Care Training for care staff

Helen Miller and Karenann Spicer
What does the research tell us?

CIPOLD (2013) identified that “A lack of recognition of the approaching end of life commonly led to problems in coordinating end-of-life care and providing support to the person and their family.

“People with learning disabilities were less likely than the comparator group of people without learning disabilities to have access to specialist palliative care services and received less opioid analgesia in their final illness. Their deaths were sometimes described as not being planned for, uncoordinated and poorly managed”.
Questions remain…..2017

• How to engage adults with learning/intellectual disabilities and promote access to primary care

• Making reasonable adjustments to facilitate their care

• Identify and manage health needs

• Improve the management of long-term health conditions.
  • Hanlon (2017)
Barriers
What do you think the barriers are?

- Knowing about Palliative care services
- Recognising someone is approaching end of life
- Different views about service users right to make choices
- Anxiety of paid carers in having difficult conversations
- Anxiety about raising difficult subjects with family
- Service users history in understanding loss and death
- Communication between professionals
- IT systems
- GPs not using GSF for long term conditions
Aim to cover ........

• Principles of end of life care
• Communication and breaking bad news
• Symptom control, pain management and distress management
• Assessment and care planning with family involvement
• Advance Care Planning,
• End of life care in the last days
• Bereavement and grieving including complicated grief
• Building emotional resilience in the workforce
The Hertfordshire 4 Hospice Education Consortium, in collaboration with Hertfordshire County Council Adult Services division proposed to work in 10 care homes across the county, training and supporting up to 250 staff to recognise and meet the end of life care needs of people with learning disabilities and their families.
To date we have delivered to....

12 Providers in West Herts
7 Providers in East and North Herts since 2017
Total of 153 staff (including pilot)
Changes in confidence before and after training

- No response
- Not confident at all
- A little confident
- Confident
- Very confident

Before | After
--- | ---
No response | No response
Not confident at all | Not confident at all
A little confident | A little confident
Confident | Confident
Very confident | Very confident
Case Studies

Symptom Control

Arthritic pain on rising from bed
Constipation
Eating and drinking
Wound care

Holistic Care- medication is not the only route
Case Studies
ACP and EOL Care

Peg feeding
Just in Case Medication - often complex
Pace maker with ICD (Implantable Cardioverter Defibrillator)
Two deaths in one care home
Purple STAR Award
Reflections from the Educators

- Staff had little previous communication skills training.

**PLEASE SPREAD THE WORD AROUND EASY READ DOCUMENTS**

- Training increased confidence and helped with EOL conversation with families.
- Numerous concerns over DNACPR
- ACP and assessment was very good but this was not transferred to other health care professionals – Annual health check, GSF and OOH
- Care home staff did not know about hospice advice lines or how to get hold of other specialist help - Pace makers, respiratory problems
- Bereavement support is needed for family residents and care staff
Learning from the project

Key to all is collaboration and coordination
Key to this is excellent communication skills

Need to share information, especially ACP
Need to understand how hospices can help and what services they offer and link with
Need to facilitate bereavement support for all
Feedback from the Carers
Next steps

Placed on NHSE Midlands & East website as a good practice example

Poster presented at Hospice UK Conference 2018

Funding has enabled us to plan 2 study days for all CLDN across Hertfordshire later this year.

Deliver a bespoke programme for Day Service Staff across 12-15 sites in Hertfordshire.

Training for two new residential homes, who have come on board following recommendations from care homes who have been trained by the project.
References
