Providing Comfort Care at End of Life

Supporting People with Intellectual Disabilities in Residential Services

Seirbhís Sláinte Níos Fearr á Forbairt | Building a Better Health Service
Office of the Nursing & Midwifery Services Director
Cope Foundation
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AIIHPC
All Ireland Institute of Hospice and Palliative Care
UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Webinar Outline

This session will cover:

- Supporting people with intellectual disabilities at end of life
- Providing comfort care

Applies to the Republic of Ireland on the 29/05/2020

Supporting People at End of Life

- How the person communicates
- Their cultural background
- What really matters to them?
- Who is important to the person?
- What are their likes and dislikes?
- How do they express pain and distress?

Who is part of their Circle of Support?

- Talk to the person
- Access support services
- Engage with those who know the person best:
  - Family members
  - Friends
  - Frontline staff who know the person well
  - Advocates

How do we know when someone is dying?

- When they have reached the ceiling of care
  - When despite medical intervention the person is not recovering
  - When a multi-professional team decide in conjunction with the person that further treatment would not improve QOL
- When further medical interventions have been deemed inappropriate
- Always a multi professional decision

Process of Dying

- A period of increased weakness and tiredness
- Withdrawal
- Decrease in food and fluid intake
- Period or periods of unconsciousness
- Cooling of peripheries
- Irregular heart beat
- Breathing pattern changes
- Difficulties with swallowing

Ongoing Assessment and Management of Deterioration

- Develop an end-of-life care plan
- Establish the persons baseline
- Observe for:
  - any new infection
  - deterioration in pre-existing conditions
  - atypical presentations

End-of-Life Care Plan

- Part of current care planning
- Continuously updated
- Refer to the National Consent Policy
- Document in chart, or health passport

End-of-Life Care Plan

- Positioning of the person
- Pain management
- Agitation
- Altered dietary and fluid intake
- Altered elimination patterns
- Breathlessness
- Oral hygiene
- Nauesa
- Spirituality Needs

See links below
https://hse.drsteevenslibrary.ie/Covid19V2

https://hse.drsteevenslibrary.ie/Covid19V2/palliativecare

Anticipatory Prescribing

Last days of life

Key symptoms	Medications
Dyspnoea/ breathlessness, cough common COVID19	opioid (morphine sulphate), midazolam
Anxiety / agitated delirium	midazolam, levomepromazine/ haloperidol
Pain	opioid (morphine sulphate)
Anti-secretory	hyoscine butylbromide (Buscopan) or glycopyrronium
Nausea / vomiting	levomepromazine/ haloperidol

Points to consider:
Standard operation procedures need to be developed for medication administration
Safe custody requirements for medications? Control drugs Storage area Register books?
Do you have the facilities required?
Liaise with providers, who may have different ordering processes, limits, etc.

Focus on Comfort Care

"Comfort care is defined as a patient care plan that is focused on symptom control, pain relief, and quality of life. It is an essential part of medical care at end of life"

Areas to consider include:

- Physical comfort
- Psychological & emotional needs
- Spiritual issues
- Physical tasks

Focus on Comfort Care

- Ensure a detailed plan of care is in place
- Discontinue unnecessary medications in conjunction with the persons GP
- Monitoring activities and procedures
- Communication is a vital component of comfort care

Environment

- **General Physical environment**
  - A quiet, peaceful environment is preferable
  - Minimise loud noises and bright lights
  - Music
  - Pictures of family
  - Preferably that the person is in an individual room
- **Bedside environment**
  - Calm, reassuring bedside presence
  - Inform patient at all times who you are and what you are doing or about to do.

Physical Care

Mouth Care

- Ensure mouth and lips are clean and moist.
- Regularly moisten oral cavity

Breathlessness & Respiratory Secretions

- Can cause distress and agitation
- Re-positioning patient may relieve breathlessness
- Persons breathing can often become noisy
- Stay calm and reassure the person
- Assess need for pharmacological intervention

Agitation and Restlessness

If a person becomes agitated and distressed check what might be causing this:

- Full bladder
- Bowel
- Always ask a nurse or GP to assess this person
- If restless offer reassurance
- Anticipatory medication can help settle and ease the persons symptoms (Midazolam, Morphine Sulphate)

Nausea and Vomiting

- Sometimes people can feel nauseated or sick when they are dying
- If a person is vomiting, and unable to sit up, turn the person on their side to protect their airway
- Medication can be administered to help relieve this symptom

Food and Fluids

- When a person is at end of life care, the body begins to shut down
- The person will no longer needs food or fluids to keep it going
- Continue to offer variety of soft foods / sips of water through teaspoon / straw while conscious, able to sit up, and as appropriate
- Accept when patient is unable to / or declines foo/fluids.

Bowel and Urinary Care

- During end of life, a person may lose control of their bladder and bowel
- If a person has not passed urine in 12 hours, confer with their Nurse and GP
- Carefully attend to their personal hygiene
- Invasive procedures for bowel care rarely needed when the person is imminently dying
- Catheterisation may be required if urinary retention or incontinence is likely to impact person's comfort

Pain

- Some people may experience pain when dying
- If unconscious they may grimace and groan to show this
- Re-positioning the person might help
  - high spec mattress
  - involve physio for advice
- Consider any pressure areas when repositioning a person
- Anticipatory medications can help ease pain

General Comfort

- Maintaining personal hygiene at end of life is important for the person and can be refreshing
- A general bed bath once a day or every second day can be a supportive measure for the person
- Regular skin care, using moisturiser and perfume
- Regular eye care, ensure eyes are clean and not causing discomfort

Psychological Distress

Be creative and use :

- Person's favourite music
- Pictures and photographs
- Information technology to facilitate family contact
- Objects of reference
- Social story
- Sensory stimuli

Psychological / Spiritual Care

- Where appropriate, person's insight should be assessed and fears / wishes explored
- Consider if the person would want formal pastoral care support
- Promote a holistic approach to supporting the person
- Arrange visits for immediate family and there presence during the person's final hours
- What was important throughout the residents life, do they have a 'final wish'?

Care during Final Days

- Adhere to person's wishes, choices and preferences
- Have a system in place to access to GP and Pallitative Care Team when required
- Ensure relevant parties know what to expect during the last days of life and offer support where needed
- Respect and accommodate person's religious and spiritual needs

Care after Death

- Follow procedures as documented in organisional policies
    - Contact family
    - Funeral directors
    - Contact Coroner
    - Contact GP or out of hours GP service
- Respect specific religious/spiritual/cultural beliefs
- Adhere to verification and certification of death policies (Local if in place) (National policies to be followed)
- Provide a comfortable environment for the person's family and friend's to share their feelings
- Provide appropriate information to relatives and carers about what to do after a death

Questions to Consider

- Am I aware of and understand the persons communication preference?
- Have I ensured that the person has access to their circle of support?
- Have I arrangements in place for regular and ongoing contact with the Palliative Care team, GP and multidisciplinary team?
- Have I access to appropriate equipment, and to the person's personal effects?
- Have I ensured that the End of Life Care plan is reviewed, updated and implemented?
- Am I informed by relevant up to date clinical guidance, information and documention re End of Life Care?