Development of Guidelines of End-of-life Care for Adults with Intellectual Disability: A DML Initiative

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National Standards for Residential Services for Children and Adults with Disabilities (2013)

‘People with life-threatening or life-limiting conditions and their families have access to specialist palliative and end-of-life care, receive care and support, which meets their physical, emotional, social and spiritual needs and respects their dignity.’
• The DML HIQA Planning Group was established in 2013
• The Group requested the development of end-of-life guidelines for adults with Intellectual Disability
• Subsequently the DML HIQA End-of-life Sub Group was formed
• Development of end-of-life guidelines to include a generic care plan
DML EOL Sub Group

Members include:-

- Judy Ryan – Nurse Practice Development Officer, HSE
- Lasarina Maguire – Health Services Programme Manager, StewartsCare
- Margaret Mulcaire – Healthcare Chaplain SJOG Community Services
- Maria Fitzpatrick – CNS, Cheeverstown House
- Niamh McEnerney – CPC/Practice Development, LauraLynn
1. Complete a systematic review – What are the end-of-life needs of adults with Intellectual Disability in Ireland?
2. Review national and international guidance documents
3. Research national and local end-of-life guidelines
4. Develop guidelines and appropriate usable template for a generic care plan
Systematic Review

What are the end-of-life needs of adults with Intellectual Disability in Ireland?
Findings

Four Main Themes

1. Physical
2. Social
3. Emotional
4. Spiritual
Findings

Four Main Themes

1. Physical
   - Specialist Support & Symptom Control
   - Medical Decision-Making

2. Social
   - Communication
   - Choice & Rights

3. Emotional
   - Relationships
   - Support Systems

4. Spiritual
1. Physical

Specialist Support & Symptom Control

- Concern re symptom management at end-of-life & need for specialist support (Read and Cartlidge, 2012)

- Concern re physical comfort and adequate symptom control noted by adult themselves (Tuffrey et al., 2007)

- Concern re physical comfort and adequate symptom control noted by care staff (Weise et al., 2012; Todd, 2013; Kirdendall and Waldrop, 2013)
1. Physical

**Specialist Support & Symptom Control**

- Appropriate training on pain and symptom management was cited as necessary if family and carers were to understand and act effectively at end-of-life (Read and Thompson-Hill, 2005, Regnard et al., 2007)

- Need for a Primary Care Physician to co-ordinate care (Loyhiya et al., 2003)

- The importance of knowing adults ‘habits and behaviours’ (Li and Ng, 2008)

- Person-centred approach (Morton-Nance and Schafer, 2012)
1. Physical

Specialist Support & Symptom Control

- Importance of co-ordination and collaborative working between families/services and specialist palliative care and/ GP services
1. Physical

**Medical Decision Making**

- Medical decision making played a significant part in end-of-life death in a study in the Netherlands (Wagemans et al., 2010)

- Further qualitative study to explore the challenges of delegating decision making at end-of-life to family and relatives when capacity was questioned

- 9 physicians, Doctors based decisions on medical assessment but felt that ‘quality of life’ was left to family

- Need for good working relationships, consensus, and knowledge of the patient’s vulnerabilities in order to act in the best interest of the patient (Wagemans et al., 2013a)
2. Social Communication

- Lack of disclosure of diagnosis and prognosis (Clute and Kobayashi, 2012)

- ‘protecting’ adults

- Reasons for non-disclosure included the need to prevent distress, it was too difficult for the bearer of bad news, the bearer of bad news lacked knowledge, the inability of the adult to understand, no sense of time and possible conflicting views of stakeholders (Tuffrey-Winje et al., 2013)

- 109 participants, recognized that the adults had a right to know, that knowledge helps a person cope and adults involvement was needed if last wishes were to be adhered to
2. Social

   **Communication**

   - Little evidence that staff speak to adults about death (Weise et al., 2013)
   - Education and Training needed for families and staff (Clute and Kibayashi, 2012)
   - Concept of transitions (Bekkema et al., 2013)
   - Need for time, appropriate language and truth telling (Tuffrey-Wijne and McEnhill, 2008)
2. Social

Choice and Rights

- Right to know, right to make decisions, Right to choose the location of death

- Stienstra et al., (2012) noted the vulnerability of adults when moved at end-of-life (Canada)

- Adults with Downs Syndrome have more relocations and are more likely to have their final placement in a nursing home than adults without Downs Syndrome - lack of choice (United States) (Patti et al., 2010)
2. Social

Choice and Rights

- Choices at end-of-life are fragile and changeable (Todd, 2004)

- Adults stated that family relationships, familiar environments and people were the issues that were consistently important to them (Thompson, 2005)
3. Emotional Relationships

- Social implications of end-of-life on the community and social network (Tuffrey-Winje et al., 2007)

- Study working with adults with dementia stated the need to maintain connections, provide support and facilitate understanding (Lynggaard and Alexander, 2004)

- Quality of relationships, need to allow expression of individuality and grief were issues raised by staff (Kirkendall and Waldrop, 2013)
3. Emotional Support Systems

- Grounded Theory study, 18 bereavement counsellors

- Stated that adults felt they were ‘invisible’, that emotional well-being was directly linked with a clear communication plan and use of open dialogue with adult, families and staff (Clute and Kobayashi, 2012)

- High anxiety among staff responding to end-of-life issues, United States (Botsford, 2004)
4. Spiritual

- Lack of reference to spiritual aspects in literature
- Exclusion from supportive rituals (Botsford, 2004)
- Need for education and training to support staff to speak about end-of-life (Weise et al. 2013)
Conclusion

Adults with Intellectual Disability have similar needs to the general population at end-of-life.

The need for good physical care, effective symptom management, clear communication and emotional and spiritual support.

Specific challenges include issues relating to lack of capacity, lack of choice and non disclosure.
Aim of the Guideline

The aim of this guideline is to support the end-of-life needs of adults with an intellectual disability and their families through impeccable holistic assessment in conjunction with the individuals, GP and relevant multidisciplinary team/primary care teams.
Guideline on planning for End-of-Life care

End-of-life care is the term used to describe care that is provided during the period when death appears to be imminent, and life expectancy appears to be limited to a short number of hours or days (HSE, 2014).
Legislation/ other related policies

- Assisted Decision Making (Capacity Bill) 2013
- Health Information and Quality Authority (2013), National Standards for Residential Services for Adults with Disabilities
- Health Act (2007) Care and Support of residents in designated centred for persons (Children and adults with disabilities) Regulations 2013
- Guidance on end-of-life care 2010 (St Anne’s C.N.U. Galway)
- Palliative Care Needs Assessment, HSE National Clinical Programme for Palliative Care Clinical Strategy and Programmes Directorate (2014)
Suggested goals to achieve in Person Centred EOL care

- Recognising that the person is dying
- Promote quality of life, dignity and respect at end-of-life for the person and their family
- Promote physical, psychological, social and spiritual wellbeing and address symptoms that arise to ensure comfort and safety
- Ensure appropriate bereavement support is made available to the person and their family and friends
Person Centred End-of-Life Care

Communication
- Timely
- Clear
- Sensitive
- Open

Psychological support needs
- Main Concerns
- Goals
- Preferences
- Cultural
- Relationships
- Total pain

Symptom Management & Comfort Measures
- Pain
- Oral hygiene
- Skin
- Continence
- Mobility
- Discomfort
- Anxiety
- Nausea/vomiting

Spiritual support needs
- Beliefs
- Relationships
- Choice
- Family

Social support needs
- Preferred place of death
- Preferences
- Friendships
- Relationships
Person Centred Communication

Ensure clear, sensitive communication and discuss with the person and their family:

• Their wishes in relation to care
• Their preferred place of care
• Spiritual, religious & cultural needs
• Aspects of care relating to treatment, safety and support
• Involvement of multidisciplinary team e.g. Specialist Palliative Care team, Social Worker, Pastoral Care, Psychologist as appropriate
Management of Physical Symptoms/ Comfort Measures

The aim of Symptom Management/ Comfort Measures is to relieve any symptoms that may cause discomfort or distress by:

- Appropriate ongoing assessment, management and evaluation

- Ongoing sensitive communication with the person and his/her family to clarify symptoms and agree treatment/comfort options
Management of Physical Symptoms/ Comfort Measures

Observing for signs and symptoms of discomfort including the following:

- Pain: somatic, visceral, neuropathic
- Neurological: depression, anxiety, agitation, confusion, delirium, seizure
- Respiratory: dyspnoea, breathlessness, cough, increased respiratory secretions
- Gastrointestinal: nausea, vomiting, constipation
- Fatigue disproportionate to level of activity or not relieved by rest
- Other: functional status, balance problems, oedema, wound problems (this list is not exhaustive)
Management of Physical Symptoms/ Comfort Measures

- Implementing and reviewing appropriate supports including pharmacological, physical, psychological and complementary therapy

- Ensuring appropriate delivery and monitoring of comfort measures including enteral/ oral intake, oral & eye care, skin care, bowel management
Management of Physical Symptoms/Comfort Measures

- Regular evaluation of symptoms and accurate documentation
- Where symptoms are severe or intractable discuss with the MDT when to refer to Specialist Palliative Care team
- Review the use of any non essential treatment/medication in conjunction with the person’s medical team
Psychological, Social and Spiritual

- Provide opportunity for the person to express their emotional needs and concerns and what provides them with strength and comfort
- Ensure open, sensitive communication that is empathetic and non-judgemental
- Address issues relating to total pain. Total pain is uncontrolled, multidimensional pain associated with psychological, spiritual pain that may contribute to physical symptoms
Psychological, Social and Spiritual

- Provide access and an appropriate environment for the person and family that ensures dignity and privacy.

- Ensure spiritual & religious needs are addressed in an individualistic manner before and after death. Does the person’s spiritual belief give him/her comfort?

- Discuss with the team how the persons expressed emotional and/or spiritual needs can be met by the team.
Following Death

- Facilitate and support family to spend time with their relative following death
- Contact pastoral care team/spiritual support as per local guidelines
- Support family in contacting relatives and making initial arrangements
- Ensure that the Coroner is informed are per local guidelines
- Remove all medical equipment as per local guidelines
- Prepare the person in line with family and cultural wishes as per local guidelines
- Co-ordinate and assist with transfer of the person to home/mortuary if appropriate
Next step......

- Evaluation of Guideline on planning for End-of-Life Care
- Development of Guideline for Palliative Care for Adults with Intellectual Disability
References


References


References


References


