Caring with Compassion and Dignity - Practical Guidance for Staff Providing End of Life Care to People with Intellectual Disability

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Intellectual Disability Services

- people living independently
- people living in low support housing (social care)
- people living in high support housing (social care)
- people living in nursing support services
- people living in congregated settings, including 'bungalows'

Small independent organizations

Larger organizations, from a social care foundation or a 'medical model'

People with Intellectual Disability

- all ages (but median age younger than the mainstream population)
- variable levels of disability affecting ability to manage everyday life
- associated physical and sensory disabilities
- co-morbidities including cardiac disease, epilepsy, dementia

Rights of People with Disabilities

Guide to Professional Conduct and Ethics for Registered Medical Practitioners

- 1.3 exercise clinical skills and judgement in patient's interest without allowing ..... disability to affect in a negative way the treatment you give.
- 10.2 adults who are considered not to have the capacity to make a decision are entitled to the same respect for their dignity and personal capacity as anyone with full capacity.
- 27 Protection of Vulnerable Persons
- 63.1 As a doctor in a management role, you have a responsibility to advocate for appropriate healthcare resources and facilities if insufficient resources are affecting or may affect patient safety and quality of care

Ethical Framework for Decision Making in a Pandemic

- Minimizing harm
  - ➢ restricting individual liberty

- Fairness
  - ➢ Recognize the moral equality of all persons

- Duty to Provide Care

United Nations Convention on Rights of Persons with Disabilities

- Article 5 - equality and non-discrimination
- Article 10 - equal right to life
- Article 11 - obliges states to ensure safety
- Article 25 - right to highest attainable standards of health

Care challenges

- Residential settings
- Focus of care is on social interactions, normal life
- Staffing - may be minimal depending on the needs of residents, social care staff, not always nursing staff, may have day staff only, or night staff only, may have nursing staff who are ID nurses, not general nurses
- acute hospital staff misconceptions about staffing
- home
- familial relationship with other residents and staff

Covid 19

- 80% will have a minor illness
- 20% will have more serious illness and may benefit from more active support
  - some will benefit from acute hospital care including NIV and ICU
  - some may potentially benefit from acute care, they may not be able to co-operate with this
- Some will not benefit - age, Clinical Frailty Score, multiple co-morbidities

Supportive care

- 'Ceiling of Care' considerations
- Patients' wishes, values and beliefs; advance care plan; advance directive
- Capacity to make a decision about health, including future planning
- Engagement with family, friends

Palliative approach

- Assess basic care needs - washing, dressing, oral intake; can these be met in current setting?
- Communication needs - patient, family, significant others
- Essential medication for co-morbidities, including anti-convulsants, anti psychotics etc
- Anticipatory prescribing for symptoms that may develop
- Medication on site
- Administering of medication

Anticipatory Prescribing

- In the context of Covid illness
- if patient is deteriorating or likely to deteriorate
- if life-prolonging treatment is not possible
- if life-prolonging treatment is failing
- in last days of life

Prescription

- Drug availability
- Drug storage
- Long - term care/nursing home
- Need to have drugs prescribed, available but a system to ensure they are not used inappropriately
- Liaison with community palliative care teams

Diagnose dying

- exclude reversible problems (maybe self-evident that patient is dying of Covid)
- If not Covid, is there infection, renal failure, hypercalcemia (cancer) etc. which may be reversible
- medical assessment- may be more difficult to access in pandemic; may happen out of hours; most palliative care teams do not have doctors assessing patients at home

Assess Comfort and Symptoms

Likely symptoms in Covid

- Breathlessness
- Delirium

And in last days of life in any illness

- pain
- nausea, vomiting
- secretions

Four drug classes

- Opioids for pain or breathlessness or cough
  - morphine 2.5mg sc hourly
- Sedative for anxiety or agitation or breathlessness
  - midazolam 2.5mg sc hourly
  - levomepromazine 3.125 -6.25mg sc hourly
  - haloperidol 0.5-1mg sc hourly
- Antisecretory for chestiness
  - Bucopan 20mg sc hourly
- Nausea and vomiting
  - Levomepromazine or haloperidol as above

Dosing

- These doses for patients who are not on opioids, or benzodiazepines or anti-psychotics
- Starting doses higher if patients on any of these
- Usually, give drugs hourly; if three doses of any drug needed in 4 hours OR 6 doses in 24 hours - seek advice

Basic care

- washing, dressing, toileting
- nutrition and hydration - orla intake as tolerated
- artificial nutrition and nutrition - starting this in prople who are dying is rarely indicated
- if person is on e.g peg feeding - consider benefit and burden; watch for nausea, vomiting, diarrhoea, chestiness

Advance Care Planning

Accessible Planning Tool

Glancing Back
Planning Forward


Accessible
Planning Tool
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Glancing Back
Planning Forward
How to Use the
Accessible Planning Tool

Accessible Planning Tool

Glancing Back Planning Forward

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Facilitating End of Life Conversations with Persons with an Intellectual Disability: **A Guide for Carers**

Advance care plan or directive

A plan made when competent about their medical treatment which will come into effect when the patient loses capacity

-recognized by the Medical Council of Ireland - (16)

-recognized by the HSE Consent Policy – (7.8)

Advance planning considerations

- Autonomy
- Functional capacity
- Informed decision
- Not obligatory
- Cannot oblige futile or unethical or illegal treatment

Advance planning considerations

- Rarely urgent-a process over a number of encounters, but in context of current Covid pandemic there is greater focus
- Fit for purpose-not so vague as to be useless
- Documented in such a way as to be available when needed
- Encourage engagement with family

Statement of values and beliefs

Specific statements about treatment refused

- An advance decision to refuse treatment

Specific statements about treatment requested

- Can be requested, but not enforced
- Futile treatment
- Respect for autonomy of others
- Fair use of resources

Thank you

References

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