End of Life Care Guidance to support Learning Disability Teams

Essex Partnership University NHS Foundation Trust

as one

Hertfordshire Partnership University NHS Foundation Trust

Carer support

All carers should have access to an assessment of their needs and signposting to appropriate support services and resources. This should include psychological support and bereavement support. Staff should carry out a Carer's assessments, encourage carers to access this assessment or refer for assessment. A bereavement support booklet should be offered to all families following the loss of a loved one. This contains details of their local bereavement services, provides clear guidance on how to access support in the future, and information on whom to contact for enquiries. The bereaved relatives will also be provided with a questionnaire asking for feedback on the end of life services they received. This can be found on the end of life care intranet page. Information and resources will be provided by individual Funeral Directors and relevant organisations. Universal information can be found on the National Bereavement Service https://thenbs.org

Advance care planning (ACP)

A process of discussion between individuals, family members and the person's care provider. It makes clear a person's wishes in anticipation of a deterioration in their condition in the future, with attendant loss of capacity to make decisions and/or the ability to communicate their wishes to others.

An ACP needs to be offered to those people recognised as end of life it should include the person if they have capacity to be part of the discussions. It is about capturing all elements of that person to promote individualised person centred approaches to care for their needs and what is important to them.

The ACP document used in Essex for LD can be found here:

End of Life Plan V8.pdf

It includes:

- where they would like to receive their care in the last year of life and place of death
- the person's needs for religious, spiritual or other personal support, what is important to them
- discussion about Lasting Power of Attorney (LPA) or their representative/care provider
- their views on future care and treatments, plus interventions which may be considered or undertaken in an emergency, such as CPR
- recording of Advance Decisions to Refuse Treatment
- organ and tissue donation: www.organdonation.nhs.uk

Any form of advance care plan should be acknowledged from other areas (Preferred Place for Care/Treatment Escalation Plan-TEP / I AM / My care choices).

If a person lacks capacity for decision making, a formal capacity assessment and best interest decision must be carried out and documented. This should include all members involved with the persons care. When capacity is lost, ongoing decisions can be made in partnership with any person who is legally responsible for best interest health and welfare decisions for the person in question.

Identification of last year of life

- Multi-disciplinary Team (MDT) Approach.
- use the prognostic indicator tool on http://goldstandardsframework.org.uk/

The Surprise Question: 'Would you be surprised if this patient were to die at any time within the next year?

- Indicators of entering end of life:

Weight loss, UTI, severe pressures sores –stage three or four, recurrent fever, reduced oral intake, aspiration pneumonia, increased periods of reduced alertness.

- More than 2-3 admissions to hospital in one rolling year.
- Person has an advanced, progressive, incurable condition.
- There is a risk from dying from a sudden, acute crisis in their existing condition.
- Life-threatening acute conditions caused by sudden catastrophic events.

Holistic needs assessment

People approaching the end of their life frequently have complex, wide ranging and changing needs. This assessment should be done at any point of this pathway. Use the PEPSI COLA aide memoire:

- **P**hysical needs
- **E**motional needs
- **P**ersonal needs
- **S**ocial needs
- **I**nformation communication
- **C**ontrol and autonomy
- **O**ut of hours (ACP)
- **L**iving with your illness
- **A**fter care

Full assessment can be found at: http://goldstandardsframework.org.uk/

Treatment Escalation Plan - TEP

Has the person got a PEACE or RESPECT plan in place?

Palliative Care

- A person at the end of their life may experience pain, breathlessness, respiratory tract secretions, nausea and vomiting, restlessness and agitation.
  - The presence of pain adversely affects quality of life and is a common symptom at the end of life. A person's self-reporting of pain is the best method of scoring pain. For people with cognitive impairment, the DISDAT (Disability Distress Assessment Tool) should be used. https://www.stoswaldsuk.org/media-new/5181/disdat-22.pdf
  - This should be reviewed regularly using a pain chart and changes in pain severity, type, place and response to treatment should be documented. If you require support to manage any symptom you must refer to specialist pallliatve care.

Refer to end of life prescribing guide for your respective region.
Search for 'Palliative Care' or 'Anticipatory' or 'End of Life':
West: http://westessexccg.nhs.uk
North: http://www.neessexccg.nhs.uk
Mid: http://midessexccg.nhs.uk
Southend: http://southendccg.nhs.uk

Contact numbers for Palliative Care Support in Essex:

- Farleigh Hospice. Tel: 01245 455478
- St Helena Hospice. Tel: 01206 890360
- St Clare Hospice. Tel: 01279 773773
- Fair Havens Hospice. Tel: 01702 220350
- South East Essex SPR. Tel: 01702 372070
- St Lukes Hospice. Tel: 01268 526259

Individualised care plan and the last days of life

Every person identified as being within the last days of life should have an individualised care plan. It must reflect the person's needs and include the 5 priorities for care of the dying person. MDT approach is essential, and discussions must be recorded.

The 5 priorities are:

1. **Recognise:** The possibility that a person may die within the next few days or hours is recognised and communicated clearly. Decisions and actions should be in accordance with the person's needs and wishes. Always consider reversible cause e.g. infection, dehydration, hypercalcaemia, etc.
2. **Communicate:** Sensitive communication takes place between staff and the dying person and those identified as important to them.
3. **Involve:** The dying person and those identified as important to them are involved in decisions around treatment and care to the extent that the dying person wants.
4. **Support:** The needs of families and others identified as important to the dying person are actively explored, respected, and met as far as possible.
5. **Plan & Do:** An individual plan of care, which includes food and drink, symptom management and psychological, social and spiritual support is agreed, coordinated and delivered with compassion.
6. Refer to Treatment Escalation Plan - TEP document as well to aid with formulating a plan and any other ACP documents.

- This is meant only as a general outline.
- Refer to Delivering high quality end of life care for people with a learning Disability at www.england.nhs.uk
- Use the Gold Standards Framework tools available at http://goldstandardsframework.org.uk/
- Always remember to treat people at the end of life with dignity, respect, and compassion