Deserving Dignity: end of life care for people living and dying with a learning disability

Welcome!
Important stuff!

- Welcome!
- Housekeeping
- Timetable
- Presentations
- Photos
- Post-it notes
What do we hope to achieve?

- List challenges and lessons learned from national and local LeDeR Programme
- State what support is available to those living with a learning disability
- Define palliative care is and describe the support available
- Identify tools and approaches for managing pain
- Identifying helpful communication skills: in general and when breaking bad news
- Identify ways of exploring future planning
- State some of the losses experienced by those living with a learning disability and ways to support individuals experiencing loss
- Identify ways of palliative care and learning disability workers to work collaboratively
Deserving Dignity: Setting the Scene for those living and dying with a learning disability

Louise Jenkins,
Strategic Liaison Nurse, Hertfordshire County Council
Dying with Dignity... making this happen for people with a learning disability

Louise Jenkins
Strategic Liaison Nurse Secondary & Tertiary care
Hertfordshire Adult Care Services
Hertfordshire County Council
Aims of session

- An overview of the current research findings on the deaths of people with learning disabilities

- To become familiar with some of the causes of death for people with learning disabilities both nationally and locally

- An overview of some of the challenges in providing quality end of life care for people with learning disabilities

- What’s out there that can help to improve these issues
Definition of a Learning Disability:

- Impaired Intelligence (previously IQ below 70)
  - Reduced ability to understand new or complex information and impaired ability to learn new skills
- Impaired Social Functioning
  - Reduced ability to cope independently
- Started in childhood
  - Before the age of 18
- Life long
  - With lasting effect on development

- Valuing People Now (2009)
Dying because of your learning disability?

- Life expectancy for people with learning disabilities is considerably lower than that of the general population. (LeDer, May 2019)
- The average life expectancy for **women** with learning disabilities is 59 years compared to the general population of 85 years. **26 years less**
- The average life expectancy for **men** with learning disabilities is 60 years compared to the general population of 81 years. **21 years less**
• 5 minute task

• Talk to your neighbour - why do you think that people with learning disabilities are dying so much earlier?
Learning from Deaths Mortality Reviews
LeDeR Programme - National perspective

- According to the LeDeR Annual Report (2019) out of the 590 reviews completed:
  - 39% people who died had Epilepsy
  - 38% people who died had dysphagia
  - 28% people who died had cardiovascular problems
  - 25% people who died had dementia
  - 23% of people who died had a mental illness
  - 62% of people who died in hospital as opposed to 46% of the general population
  - 46% of people who died had no end of life plan

- Most common causes of death are:
  - Pneumonia
  - Aspiration Pneumonia
  - Sepsis
  - Dementia
  - Ischaemic heart disease
  - Epilepsy
Learning from Deaths Mortality Reviews
LeDeR Programme - Local perspective

Age range of reported deaths Hertfordshire (from Apr 17)

<table>
<thead>
<tr>
<th>Age range</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 yrs - 17 yrs</td>
<td>6</td>
</tr>
<tr>
<td>18 yrs - 64 yrs</td>
<td>54</td>
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<tr>
<td>65+</td>
<td>55</td>
</tr>
<tr>
<td>Under 50</td>
<td>21</td>
</tr>
</tbody>
</table>
Learning from Deaths Mortality Reviews
LeDeR Programme - Local perspective

Reasons for Death (Numbers)

- Pneumonia: 32
- Aspiration Pneumonia: 17
- Sepsis: 13
- Cardiovascular: 11
- Neoplasms: 12
- Digestive Systems: 6
- Dementia and behavioural: 5
- Neurological: 6
- Others: 4
- Not known (Review not completed): 5

Total: 79
What are the local issues?

- Lack of recognition of a dying patient
- Lack of Advance Care planning
- Poor co-ordination of care when the needs change
- Poor communication between professionals and carers
- Inaccurate assumptions made about baseline abilities
- Difference of views of where patient’s care needs are best met at the end of their life

= Improving Health Outcomes Group Action Plan
Reducing Inequalities

Health Action Plans

Collaborative working

Learning Disabilities Awareness training

Mental Capacity Act

Shared Records

Care Co-ordination role

Reasonable Adjustments

Focus on Sepsis and Pneumonia

Consistent reviewing of Mortality

Consistent reviewing of Mortality

NHS England recommendations
NHS England recommendations

• Action Learning Sets on:
  - Sepsis and the deteriorating patient
  - Constipation
  - Dysphagia
  - Cancer
  - Mental Capacity Act
  - Valuing the input of bereaved families
So why are the number of referrals for people with LD to palliative services low?

- Lack of understanding about Palliative care services and what they offer
- Resistance to talk about death and dying from family/paid carers
- Culture of “Jollying along” – the handicap smile
- Fear of upsetting people with learning disabilities
- Paid carers often young and may not have experienced death and dying
- Difficulty when a person has a life limiting condition – when will this be?
- “We haven’t given up yet” – resistance to making referrals
- Lack of awareness of easy read tools available
- Complexity of capacity assessments and Best interest decisions
Irene Tuffrey-Wijne

Connected conversations

- Community Learning Disability Nurses
- Acute Liaison Nurses
- Social Workers in Adult Disability Teams
- Speech & Language Therapists
- Family/Paid carers
- Paid carers accessing Palliative care training
Resources available

• Easy Read resources;
  
  
  • [https://booksbeyondwords.co.uk/](https://booksbeyondwords.co.uk/)
  
  • [https://www.youtube.com/watch?v=gJCzKLEx6Mw](https://www.youtube.com/watch?v=gJCzKLEx6Mw)
  
• Learning tools;
  
  • [https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone](https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone)
References


Deserving Dignity: Exploring palliative care

Claire Nicell
Lecturer Practitioner,
The Hospice of St Francis
Learning Outcomes

• Define palliative and end of life care
• Describe palliative care services available
• Describe when and how to refer to palliative care services
• List some signs and symptoms of dying
• State tools available to assess pain
• Describe the role of just in case drugs
Palliative Care

• “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.”

• World Health Organisation (2002)
Holistic care

The term *holism* is derived from Ancient Greek *holos* ὅλος, meaning "all, whole, entire, total."

Holistic care means looking at all the needs and aspects of wellbeing of the person. This means care that considers the whole person.

It includes the person’s physical, emotional, social and spiritual needs.
End of Life Care

• People are approaching end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
  • Advanced, progressive incurable conditions
  • General frailty and co-existing conditions that mean they are expected to die within 12 months
  • Existing conditions if they are at risk of dying from a sudden acute crisis event
  • Life-threatening acute conditions caused by sudden catastrophic events
    • GMC (2010)
• How do we know when someone is entering the last year of life?
Triggers that suggest person may be nearing the end of life

- Surprise question
- General indicators of decline
- Specific clinical indicators related to certain conditions
- See also prognostic indicator guidance at www.goldstandardsframework.nhs.uk
Surprise Question

• “Would I be surprised if the person in front of me were to die in the next six months or year?”
Disease trajectory

- Short period of evident decline
- Mostly cancer
- Specialist palliative care input available
- Onset of incurable cancer
- Often a few years, but decline usually over a few months

Disease trajectory

Long term limitations with intermittent serious episodes

High

Mostly heart and lung failure

Low

Sometimes emergency hospital admissions

2-5 years, but death usually seems “sudden”

Death

Disease trajectory

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

1918 – 2005
(Dame Cicely Saunders)
“What has surprised me is how little palliative care has to do with death. The death part is almost irrelevant. Our focus isn’t on dying. Our focus is on quality of living.”

1939 – present

(Dr Balfour Mount)
Who offers palliative care?

Types of palliative care

- Palliative medicine
- General palliative care
- Palliative care approach

Specialised settings, hospice
Additional training
All healthcare professionals!
General Palliative Care

- GP
- District / community nurses
- Community Matrons
- Specialist nurses
- Domiciliary Care
- Care Homes
- Families
- Hospitals
Specialist Palliative Care

- Clinical Nurse Specialists
- Hospice out patients/ well being centres
- Hospice in patient units
- Hospice at home teams
- Specialist Palliative Care Team
The Specialist Palliative Care Team:

- Medical staff
- Allied health professionals
- Nurse specialists
- Psychologists/ counsellors
- Spiritual advisors
- Complementary therapists
- Carer support
- Social workers
- Child bereavement support
- Bereavement support
- Art therapist
What do they offer?

• Holistic Needs Assessment
• Holistic approach to symptom control
• Carer support
• Signposting- equipment/ money
• Out patient sessions
• Advance care planning
• In patient stays
• Care/ support for those who are dying- in hospice or at home
• CHC funded care at home
How do you refer?

• West Hertfordshire-Palliative Care Referral Centre
• Patients triaged according to need:
• If in doubt- phone to discuss
• 0333 234 0868
• Westherts.pcrc@nhs.net
When to refer?

the sooner,
the better.
Recognising dying

• What is dying like?
• Why would we should talk about dying?
## Signs and symptoms of dying

<table>
<thead>
<tr>
<th>Change</th>
<th>Manifests by/signs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Functional and physical ability</strong></td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Increasing weakness and frailty</td>
</tr>
<tr>
<td></td>
<td>Worsening mobility</td>
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<tr>
<td></td>
<td>Progressive physical decline; spending most of the time in bed</td>
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<tr>
<td></td>
<td>Inability to move around in bed</td>
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<tr>
<td></td>
<td>Inability to lift head off pillow</td>
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<tr>
<td></td>
<td>Requiring increased assistance with day to day care</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Change</th>
<th>Manifests by / Signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial and spiritual symptoms</td>
<td>Concern for those being left behind</td>
</tr>
<tr>
<td></td>
<td>Fear or anxiety of dying process, abandonment, the unknown</td>
</tr>
<tr>
<td></td>
<td>Nearing death awareness</td>
</tr>
<tr>
<td></td>
<td>Social withdrawal</td>
</tr>
<tr>
<td></td>
<td>Search for meaning and purpose</td>
</tr>
<tr>
<td></td>
<td>New self beyond personal loss</td>
</tr>
<tr>
<td></td>
<td>Increased focus on spiritual</td>
</tr>
<tr>
<td>Change</td>
<td>Manifests by/signs</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Nutrition and hydration – food and fluid intake | Reduced fluid and food intake  
Poor appetite with little or no interest in eating or drinking  
Weight loss (muscle and fat)  
Anorexia  
Increased risk of aspiration  
Increased coughing  
Difficulty swallowing  
Dehydration, dry mucous membranes |
| Loss of ability to swallow                  | Dysphagia  
Coughing, choking  
Loss of gag reflex  
Build-up of oral and tracheal secretions  
Gurgling |
<table>
<thead>
<tr>
<th>Change</th>
<th>Manifests by/signs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bowels and bladder</strong></td>
<td>Urine may become darker</td>
</tr>
<tr>
<td></td>
<td>Urine incontinence</td>
</tr>
<tr>
<td></td>
<td>Faecal incontinence</td>
</tr>
<tr>
<td></td>
<td>Reduction (oliguria) or absence (anuria) of urine</td>
</tr>
<tr>
<td></td>
<td>Urine retention</td>
</tr>
<tr>
<td><strong>Cardiovascular changes</strong></td>
<td>Tachycardia, hypertension</td>
</tr>
<tr>
<td></td>
<td>Mottling of the skin (a purple-blue-red blotchy/lacy</td>
</tr>
<tr>
<td></td>
<td>pattern)</td>
</tr>
<tr>
<td></td>
<td>Abnormal blue discoloration and cooler temperature of</td>
</tr>
<tr>
<td></td>
<td>the skin, particular fingers, toes and limbs (peripheral</td>
</tr>
<tr>
<td></td>
<td>cyanosis)</td>
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<tr>
<td></td>
<td>Swelling of tissues in the lower limbs-accumulation of</td>
</tr>
<tr>
<td></td>
<td>fluids (peripheral oedema)</td>
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<tr>
<td>Change</td>
<td>Manifests by/signs</td>
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<td>-------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
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<tr>
<td>Increasing physical symptoms</td>
<td>Non-verbal signs and symptoms of discomfort e.g. moaning, restlessness, grimacing, frowning, repetitive movements, tension in forehead</td>
</tr>
<tr>
<td></td>
<td>Pain</td>
</tr>
<tr>
<td></td>
<td>Nausea or vomiting</td>
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<tr>
<td></td>
<td>Increased risk of skin breakdown and pressure ulcers</td>
</tr>
<tr>
<td></td>
<td>Redness over bony prominences</td>
</tr>
<tr>
<td></td>
<td>Respiratory symptoms (as below)</td>
</tr>
<tr>
<td></td>
<td>Restlessness or agitation</td>
</tr>
<tr>
<td>Change</td>
<td>Manifests by/signs</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Respiratory changes</strong></td>
<td>Shortness of breath</td>
</tr>
<tr>
<td></td>
<td>Respiratory secretions, noisy, rattling breathing (‘death rattle’)</td>
</tr>
<tr>
<td></td>
<td>Cheyne-Stoke breathing pattern – a shallow breathing followed by temporary pauses in breathing</td>
</tr>
<tr>
<td></td>
<td>Gasping, laboured breathing (agonal)</td>
</tr>
<tr>
<td></td>
<td>Apnea</td>
</tr>
<tr>
<td><strong>Decreasing level of consciousness</strong></td>
<td>Reduced cognition</td>
</tr>
<tr>
<td></td>
<td>Increasing drowsiness and difficulty awakening</td>
</tr>
<tr>
<td></td>
<td>Terminal agitation</td>
</tr>
<tr>
<td></td>
<td>Unresponsive to voice or touch</td>
</tr>
</tbody>
</table>
Nice Guidelines (2015)
Care of dying adults in the last days of life

• Recognising when people may be in the last days
• Communication and shared decision-making
• Clinically assisted hydration
• Medication for managing pain, breathlessness, nausea and vomiting, anxiety and noisy secretions
• Anticipatory prescribing
Recognise dying
Communicate sensitively
Involve patients, and those important to them, in decisions
Support families and those important to dying person
Plan and do – agree an individual plan of care – including food and drink, symptom control, social and spiritual support …delivered with compassion
Assessing and Managing Pain

• What tools do you use to assess pain?
Treating Pain

**GOAL:** Freedom From Pain

**STEP 1:** Non-opioid +/- adjuvant therapy

**STEP 2:** Opioids for mild- to-moderate pain +/- non-opioid +/- adjuvant therapy

**STEP 3:** Opioids for moderate-to-severe pain +/- non-opioid +/- adjuvant therapy

Pain Persists

Pain Persists
Adjuvants (co-analgesics)

- Steroid (inflammation/oedema)
- Antidepressant (Neuropathic pain)
- Anti-convulsant (Neuropathic pain)
- Anti spasmodic (colic-y pain)
- Antibiotic (infection)
- Night sedative
- Anxiolytic
- Antidepressant
Just in case drugs for common symptoms

<table>
<thead>
<tr>
<th>Indication</th>
<th>Drug</th>
<th>PRN “As required” s/c dose</th>
<th>Syringe Pump dose (CSII / 24 hours)</th>
<th>Think Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Morphine Sulphate</td>
<td>2.5 – 5mg s/c 2-4 hourly</td>
<td>10-20mg / 24 hours</td>
<td>Treat reversible causes e.g. urinary retention. Consider co-analgesics e.g. Paracetamol PO / IV / PR. Consider reducing dose and frequency of morphine or using an alternative opioid in renal failure or frailty. If the patient is already on an alternative opioid or analgesic patch seek specialist advice or review opioid conversion guidance.</td>
</tr>
<tr>
<td>Pain</td>
<td>Morphine Sulphate</td>
<td>Divide the total oral Morphine dose by 12 e.g. 30mg MST bid = 66mg / 24 hours divide by 12 = 5mg s/c 2-4 hourly</td>
<td>Divide the total oral Morphine dose by 2 e.g. 30mg MST bid = 60mg / 24 hours divide by 2 = 30mg CSCI / 24 hours</td>
<td></td>
</tr>
<tr>
<td>Breathlessness</td>
<td>Morphine Sulphate</td>
<td>2.5mg s/c 2-4 hourly If not already on regular morphine</td>
<td>5-10mg / 24 hours If not already on regular morphine</td>
<td>Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia. Morphine is first line treatment. For patients already using opioids for pain use the same dose for breathlessness. Benzodiazepines can be useful for anxiety related to breathlessness. A combination may be needed.</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>Cyclizine</td>
<td>60mg s/c 8 hourly</td>
<td>100-150mg / 24 hours</td>
<td>Caution with cyclizine in heart failure. If already on an effective anti-emetic then continue this. For bowel obstruction seek specialist advice.</td>
</tr>
<tr>
<td>Anxiety and agitation</td>
<td>Midazolam</td>
<td>2.5 – 5mg s/c 2 hourly</td>
<td>10-20mg / 24 hours</td>
<td>Treat reversible causes e.g. pain, urinary retention. Consider level of sedation required</td>
</tr>
<tr>
<td>Delirium and agitation</td>
<td>Midazolam</td>
<td>0.5–1mg sublingual 6 hourly</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Noisy respiratory secretions</td>
<td>Haloperidol</td>
<td>1.5-3mg s/c 2 hourly</td>
<td>1.5-10mg / 24 hours</td>
<td>Treat reversible causes e.g. pain, urinary retention. Consider level of sedation required. Caution with haloperidol in Parkinson’s.</td>
</tr>
<tr>
<td>Seizures</td>
<td>Midazolam</td>
<td>10mg s/c or buccal preparation stat</td>
<td>20-30mg / 24 hours</td>
<td>Replace oral anticonvulsives drugs with midazolam CSCI if no longer able to swallow. If taking oral steroids for cerebral disease seek specialist advice on converting to CSCI.</td>
</tr>
<tr>
<td>Severe haemorrhage</td>
<td>Midazolam</td>
<td>10mg s/c or buccal preparation stat</td>
<td>NA</td>
<td>Manages distress in acute, severe bleeding. For on-going bleeding, treat any distress or pain as above.</td>
</tr>
</tbody>
</table>

**Abbreviations:**  
PRN (pro re nata) = “as required”  
SIC = subcutaneous  
CSII = continuous subcutaneous infusion  
Stat (status) = immediately
Need more help?

Garden House Hospice Care:
01462 416794

Isabel Hospice:
01707 382575

The Hospice of St Francis:
01923 241011
Learning Outcomes

• Define palliative and end of life care
• Describe palliative care services available
• Describe when and how to refer to palliative care services
• List some signs and symptoms of dying
• State tools available to assess pain
• Describe the role of just in case drugs
Deserving Dignity: Communicating Well with individuals and their families in general and about end of life care

Megan Roberts
Community Learning Disability Nurse,
Hertfordshire County Council
Communication
Breaking bad news frameworks

1. Build up a picture of the person's current 'framework of knowledge'.
2. Break down complex information into small discrete chunks.
3. Decide which chunks of knowledge the person needs NOW.
4. Give the new chunks of information one by one.
5. Check the reassess the individual's knowledge.
6. Has the person understood?
7. Has the person's framework of knowledge changed?
8. Has the bad news situation changed?

- Background knowledge
- What is happening right now?
- What will happen in the future?

Information can be given in non-verbal ways.

New information must make sense to the person (fit in with current framework of knowledge).
Reasonable Adjustments

Under the **Equality Act (2010)** in England, all providers including public sector organisations are required to make Reasonable Adjustments.

A **Reasonable Adjustment** is a change that has been made to a service so that **People with Learning Disabilities** can use them like anyone else.

**T.E.A.C.H.** is a way of learning and remembering how to make reasonable adjustments.

- Time
- Environment
- Attitude
- Communication
- Help

https://www.youtube.com/watch?v=WvgJgBoflXQ
Case scenario

• Julie is a lady with a mild learning disability. She has been diagnosed with cancer that has spread into other organs. Doctor’s and surgeon’s attempted to do surgery for Julie’s cancer, however, it is unable to be operated on. Julie has had 2 courses of chemotherapy and was informed that the treatment has been positive by the doctor. Julie thought this meant that she hasn’t got cancer anymore. The doctor tried to tell Julie that she is now palliative but he doesn’t think she understood.

• How could this news been broken to Julie differently?
My Life Story

• Our life experiences shape us as individuals and this helps others to understand who we are as a person. Individuals sometimes need help to communicate important aspects of their identity – like background, interests, who and what is important to them.

• Where family members and staff work with the individual to help them gather and review their past life events and support them in building a personal biography.

• Life Story work can help encourage better communication and an understanding of the person’s needs and wishes. This can inform their care and ensure that it is provided in a positive and person-centred way.

• Life story work can come in a variety of formats:
  - Life story books
  - Collages
  - DVD’s
  - Reminiscence or memory box
  - Apps and other electronic formats
  - Personal profile documents
Communication methods

Communication is the act of conveying meanings from one entity or group to another through the use of mutually understood signs, symbols, and semiotic rules.

Methods of communication:

- Verbal
- Written
- Facial expressions
- Gestures
- Body language
- Easy read
- Objects of reference
- Pictures/symbols
- Social story
- Makaton
- Behaviour that challenges
- Picture Effective Communication System (PECS)

You may be surprised that we get most of our information across through body language.

Body language - 55%
Tone of voice - 38%
Words - 7%
Group Work

In groups of 3 you will all have a different case scenario.

You will act out the scenario and then discuss what went well and what could have been done differently.

• [http://www.breakingbadnews.org/](http://www.breakingbadnews.org/)
Capacity

The Principles of Capacity:

• A person must be assumed to have capacity unless it is established that he lacks capacity.

• A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

• A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

• An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

• Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.
Capacity

A person is deemed to lack capacity if they are unable to do one or more of the following:

• to understand the information relevant to the decision,
• to retain that information,
• to use or weigh that information as part of the process of making the decision, or
• to communicate his decision (whether by talking, using sign language or any other means).
Best interest decision

If a person has been assessed as lacking capacity then any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests.

Some of the factors to take into consideration are:

- Do not discriminate. Do not make assumptions about someone’s best interests merely on the basis of the person’s age or appearance, condition or any aspect of their behaviour.
- Take into account all relevant circumstances.
- If faced with a particularly difficult or contentious decision, it is recommended that practitioners adopt a ‘balance sheet’ approach.
- Will the person regain capacity? If so, can the decision wait?
- Involve the individual as fully as possible.
- Take into account the individual’s past and present wishes and feelings, and any beliefs and values likely to have a bearing on the decision.
- Consult as far and as widely as possible.
Top Tips

• Talking about end of life care does not make it any more or less likely to happen: but does mean the wishes of individuals are more likely to be met
• Always be genuine, honest and respectful
• Do not be afraid to use the word dying, dead and died
• When you don’t know what to say; try saying nothing
• Empathy and acknowledgement can be helpful tools when there seems to be little hope
• Truth telling is generally best
• Emotions are normally best expressed than supressed
• Behind every behaviour there is a story
Top Tips

• Be more ready to listen than to problem solve (when people are sharing distress)
• Anticipate the questions (and lack of questions)- there may be awkward questions but you have to be ready to answer them
• Make sure you understand the question- Even something as seemingly clear-cut as the question ‘Am I going to die?’ is not always straightforward. It could mean ‘Am I going to die very soon/today?’ or ‘Am I going to die at all, ever?’ or ‘Am I going to die exactly in the same way as Dad did?’ or ‘Is this illness going to kill me and what is it going to be like?’
• Allow feelings of sadness (including your own)- it is ok to cry and be upset. PWLD can be very upfront with their emotions
• People have the right NOT to know- don’t force information on someone that doesn’t yet want to hear it
• Don’t overdo it- don’t talk for too long, tell someone what they need to know and give them the chance to ask questions.
• Repeat the information- repeat key information at different times and in different ways (words, pictures etc).
References

• https://www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability
• http://www.breakingbadnews.org/
Questions?
Deserving Dignity: Living Well but Dying Matters

Looking at advance care planning

A Workshop
Learning Outcomes

• State what advance care planning is and the benefits it can bring to individuals
• Identify some ideas for when and how to have these discussions
• List some useful resources
Living well but dying matters

Watch the following film:
• What are your thoughts?
• What do you think the benefits are of talking about future care?
• What do you think are the barriers of talking about future care?

https://www.youtube.com/watch?v=gJCzKLEx6Mw
Discussion

Advance Care Planning

Statement of Wishes

Advance Decision to Refuse Treatment

Lasting Power of Attorney
DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)

Adults aged 16 years and over. In the event of cardiac or respiratory arrest do not attempt cardiopulmonary resuscitation (CPR)

Name:
Address:
Postcode:
NHS number:
Date of birth:
Date of DNACPR order:

1. Does the patient have capacity to make and communicate decisions about CPR? If "YES", go to Box 2. If "NO", complete a mental Capacity Form and a Best Interest Form.
   If "NO", are you aware of a valid advance decision refusing CPR which is relevant to the current condition?
   If "NO", has the patient appointed a Lasting Power of Attorney (Health and Welfare) to make decisions on their behalf?
   If "YES" have all possible attempts been made to contact them?
   LPA Name: Date Consulted:

All other decisions must be made in the patient’s best interests and comply with current law.

Hertfordshire

ALL OTHER APPROPRIATE TREATMENT AND CARE WILL BE PROVIDED
Key Points...

• Should be discussed in context of future planning
• **Increased focus on mental capacity in Herts**
• An individual cannot demand that a medical practitioner resuscitates them in the event that their heart stops
• It is about allowing natural death
• It is not about whether you want to be resuscitated
Mental Capacity and decision-making
Consider the following:

• When might it be a good to have a discussion with a person about their future wishes?

• Who might be the best person to have these conversations?

• What are the pros and cons of the following documents to support someone recording their wishes?
What then?

Things to consider:

- End of life care plan in the purple folder
- Sharing information with others
- End of life care register
Deserving Dignity: When experiencing Grief and Loss

A Case Study
What helps?
A Personal Account
Learning Outcomes

• Define bereavement, loss, mourning and grief
• Describe a range of responses to loss and coping strategies
• Describe some ways to support those who have been bereaved or are facing loss
• List some useful resources
Definitions

• Loss – losing something of value

• Grief – your response to loss

• Mourning – is what you do

• Bereavement – is what happens to you when someone dies
Dual Process (Strobe and Schut)

**Loss-oriented**
- Grief work
- Intrusion of grief
- Letting go-continuing-relocating bonds / ties
- Denial/avoidance of restoration changes

**Restoration-oriented**
- Attending to life changes
- Doing new things
- Distraction from grief
- Denial/avoidance of grief
- New roles/identities/relationships

**Everyday life experience**

Oscillation
Grief doesn’t diminish - but the world around it gradually enlarges
## Responses to Loss

<table>
<thead>
<tr>
<th>Physical responses</th>
<th>Cognitive responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling sick</td>
<td>Why has this happened?</td>
</tr>
<tr>
<td>Shock</td>
<td>How will I cope?</td>
</tr>
<tr>
<td>Loss or increase in appetite</td>
<td>There is no point going on*</td>
</tr>
<tr>
<td>Crying</td>
<td>I might as well be dead*</td>
</tr>
<tr>
<td>Can’t sleep</td>
<td>Hard to concentrate</td>
</tr>
<tr>
<td>Dizzy</td>
<td>Difficult to make decisions</td>
</tr>
<tr>
<td>Shaking</td>
<td>Pre-occupation with person who has died</td>
</tr>
<tr>
<td>Previous illness flared up</td>
<td>Confused thought</td>
</tr>
<tr>
<td>Pounding heart</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional responses</th>
<th>Behavioural responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sad</td>
<td>Withdrawn</td>
</tr>
<tr>
<td>Disbelief</td>
<td>Carry on as normal</td>
</tr>
<tr>
<td>Resentful</td>
<td>Alcohol/ Drugs*</td>
</tr>
<tr>
<td>Confusion</td>
<td>Physical or verbal aggression</td>
</tr>
<tr>
<td>Shock</td>
<td>Changes in behaviours</td>
</tr>
<tr>
<td>Lonely</td>
<td>Changed sleeping patterns</td>
</tr>
</tbody>
</table>

* Need “checking out”
What might help?

Listening
Ear

Acknowledgement

Being alongside
Strategies to support those dealing with grief and loss

• Encourage honest and open communication
• Encourage and allow expression of emotion
• Help the person to understand the reality of loss
• Provide reassurance and support
• Use creative ideas and activities to assist the person through the grief process

SCOPE (2007)
What services and resources are out there?

- David O’Discroll
- “When somebody dies”
- “Supporting people with disabilities coping with grief and loss”
Deserving Dignity: Collaborative Working

A Case Study
Identifying what works
Learning Outcomes

• Identify some ways of applying theoretical knowledge to practice
• Identify some top tips for promoting dignity and excellent palliative care for those living and dying with a learning disability
• In small groups look at the following case study based on a real scenario and discuss possible ways to support Jeff at different stages of his illness
Case Study: Applying Theory to Practice

• Jeff is in his mid 40’s and lives with Downs Syndrome in his own flat (within a block of 10 flats for people with learning disabilities.) He has staff support 3 hours a day.
• Over a period of a few weeks, he has started to have difficulties swallowing his usual diet. He has lost weight and has pain in his throat after eating. His GP thinks he is likely to have cancer and has referred him to the hospital.

Section 1: Breaking Bad News

• Who do you think is best placed to support him whilst he undergoes tests?

• What resources are available to support him?

• If the tests reveal cancer; how should Jeff receive the news?
Section 2: Symptom Control and Planning for the future

- The tests reveal that Jeff has oesophageal cancer and he is given a prognosis of 12 – 18 months. Due to his cognitive limitations he is not able to understand the complexities of his cancer diagnosis, but understands that he has a problem with his throat.

- What healthcare professionals do you think should be involved with Jeff’s care?

- Who do you think might be best placed to explore his wishes for the future?

- When and how might they go about this?

- What issues might arise with his swallow difficulties
Case Study: Applying Theory to Practice(3)

Section 3: Managing dying
• Jeff manages quite well at home but is becoming increasingly frail and finding it more difficult to move around his flat. His preferred place of care/ death is home.
• What services/professionals do you think might help support his wishes to die at home?

• What might need putting in place to ensure his wishes are met to die at home?

Section 4: Bereavement
• Jeff dies at his flat peacefully with his family by his side.
• Who might benefit from bereavement support?

• In what form might this take place?
What do we hope to achieve?

• List challenges and lessons learned from national and local LeDeR Programme
• State what support is available to those living with a learning disability
• Define palliative care is and describe the support available
• Identify tools and approaches for managing pain
• Identifying helpful communication skills:- in general and when breaking bad news
• Identify ways of exploring future planning
• State some of the losses experienced by those living with a learning disability and ways to support individuals experiencing loss
• Identify ways of palliative care and learning disability workers to work collaboratively