Supporting patients with learning disabilities

Jan Pearson

*Liaison nurse, adults with learning disabilities.*

The James Cook University Hospital

*Patients are central to everything we do*
Aim

To increase awareness and understanding of people with a learning disability.
Quiz
Facts and figures

2-3% of the population have a learning disability.

However, 26% of people with learning disabilities are admitted to hospital every year, compared to only 14% of the general population.
What is a learning disability?

A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with

A reduced ability to cope independently (impaired social functioning)

Which started before adulthood, with a lasting effect on development.

Valuing People (Department of Health 2001)
Fact

People with learning disabilities have poorer health than that of the general population.
Fact

• 58 times more likely to die before the age of 50.

• Respiratory disease is the main cause of death, 3 times higher than that of the general population.
Osteoporosis — contributing factors, lack of weight bearing exercise, being underweight, poor nutrition.

Gastrointestinal cancer — approx 54% of 25% of cancer deaths.

Dental problems — 1 in 3
People with learning disabilities are likely to have difficulty accessing good quality care that meets their needs, which may include:

* extra time and support for appointments
* the opportunity to have information repeated
* information that is presented in a form they can understand and is empowering
* involvement of family carers and advocates
* understanding the complexity of consent issues
* liaison with other agencies involved
Death By Indifference
Mencap 2007
Martin, aged 43, went into hospital following a stroke. The hospital did not provide him with adequate care and he went without food for 26 days. By the time staff took notice, it was too late to help. Martin died on 21 December 2005.
Emma died on 25 July 2004. She had been diagnosed with cancer and her mother was told she had a 50% chance of survival with active treatment. However, doctors decided that Emma would not cooperate with treatment because of her learning disability. She was not treated and died aged 26.
Health Care for All

Sir Jonathan Michael
2008

Report made recommendations that ‘reasonable adjustments’ were made to make health services accessible for people with learning disabilities as they are to other people.
Recommendations also included:

Training for all staff to increase their knowledge and understanding.

Acute Liaison Nurses to be based within hospitals
The Equality Act sets out the different ways in which it is unlawful to treat someone, such as direct and indirect discrimination, harassment, victimisation and failing to make a reasonable adjustment for a disabled person.
Reasonable adjustments.

What examples can you think of?
Acute Liaison Nurse Role

• Based within hospital.
• Part of the “team”.
• Develop links via Matrons meetings.
• Training.
• Leaflet explaining role.
• Community links, partnership boards, community learning disability teams.
• Developing opportunities too improve patients experience.
How we can support changes.

- Communication – group work
- Training.
- Better understanding of the Mental Capacity Act.
- Identifying people with learning disabilities – make reasonable adjustments.
- Hospital passports.
- Pathways.
Hospital Passport

For people with learning disabilities

This assessment gives hospital staff important information about you.

Please take it with you if you have to go into hospital.

Ask the hospital staff to hang it on the end of your bed.

Please note: Value judgements about quality of life must be made in consultation with you, your family, carers and other professionals.

This includes Resuscitation Status.

Make sure that all the nurses who look after you read this assessment.

Adapted from Gloucestershire Partnership NHS Trust document
# RED-ALERT

Things you must know about me

| Name - | NHS number - |
| Likes to be known as - |  |
| Address - | Tel no: - |

**Date of Birth -**

| GP - | Address: |

**Next of Kin -**

| Key worker/main carer - | Relationship - | Tel no - |
| Professionals involved - | Relationship - | Tel no - |

**Religion -**

| Religious requests - |

**Allergies -**

| Current medication - |

**Brief medical history -**

| Level of comprehension/capacity to consent - |

Medical Interventions - how to take blood, give injections, take temperature, medication, BP etc.

**Heart (heart problems) -**

| Breathing (respiratory problems) - |

Behaviours that may be challenging or cause risk -

Completed by:..........................  Date:..........................
<table>
<thead>
<tr>
<th>AMBER</th>
<th>Things that are really important to me</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication</strong></td>
<td>How to communicate with me.</td>
</tr>
<tr>
<td><strong>Information Sharing</strong></td>
<td>How to help me understand things.</td>
</tr>
<tr>
<td><strong>Seeing/hearing</strong></td>
<td>Problems with sight or hearing.</td>
</tr>
<tr>
<td><strong>Eating (swallowing)</strong></td>
<td>Food cut up, choking. Help with feeding.</td>
</tr>
<tr>
<td><strong>Drinking (swallowing)</strong></td>
<td>Small amounts, choking.</td>
</tr>
<tr>
<td><strong>Going to the toilet</strong></td>
<td>Continence aids, help to get to the toilet.</td>
</tr>
<tr>
<td><strong>Moving around</strong></td>
<td>Posture in bed, walking aids.</td>
</tr>
<tr>
<td><strong>Taking medication</strong></td>
<td>Crushed tablets, injections, syrup.</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td>How you know I am in pain.</td>
</tr>
<tr>
<td><strong>Sleeping</strong></td>
<td>Sleep pattern, sleep routine.</td>
</tr>
<tr>
<td><strong>Keeping safe</strong></td>
<td>Bed rails, controlling behaviour, avoiding.</td>
</tr>
<tr>
<td><strong>Personal care</strong></td>
<td>Dressing, washing etc.</td>
</tr>
<tr>
<td><strong>Level of support</strong></td>
<td>Who needs to stay and how often.</td>
</tr>
</tbody>
</table>

Completed by:.......................... Date:..........................
GREEN

Things I would like to happen    Likes/dislikes

<table>
<thead>
<tr>
<th>THINGS I LIKE</th>
<th>THINGS I DON'T LIKE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please do this:</td>
<td>Don’t do this:</td>
</tr>
</tbody>
</table>

Think about what upsets you, what makes you happy, things you like to do i.e. watching TV, reading, music. How you want people to talk to you (don’t shout). Food likes, dislikes, physical touch/restraint, special needs, routines, things that keep you safe.

Completed by:…………………    Date:………………….
Electronic Flagging of Hospital Notes

Consent
I agree to have my hospital notes electronically flagged so that hospital staff will have a better understanding of how my learning disability affects my health.

Signed......................................................Date........................

Best Interests
I have consulted with colleagues and believe it is in the best interests of ................. to have their hospital notes electronically flagged. This will ensure that hospital staff will have a better understanding of how their learning disability affects their health and wellbeing.

Signed......................................................Date........................
How we are achieving this......

Full support from Trust, Working Group.

Development of pathways.

Training, e learning, involving people with learning disabilities.

Identifying people on admission.

Acute Liaison Nurse, linking with primary, secondary and learning disability services.

Using tools such as Hospital passport, exit questionnaires

Support from local PCT and Partnership Board.
Mental Capacity Act 2005

Five Statutory Principles

1. A person must be assumed to have capacity unless it is established that they lack capacity.

2. 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.

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

4. 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.

5. 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 away that is less restrictive of the person’s rights and freedom of action.
Let's break down the barriers
Thank you

Questions?
Dementia Awareness

Diagnosis Of Dementia
Dementia Awareness Objectives

- Why diagnose?
- Assessments;
- Impact of a diagnosis;
- How are we doing now?
You Cant Cure It, So Why Bother?

- Rule out other conditions;
- Rule out other causes of confusion;
- Access information and support;
- Plan for the future;
- Allow for use of drugs where appropriate.
Making A Diagnosis

- A definite diagnosis can be difficult;
- Time it takes can vary;
- Can be as little as 4-12 weeks, or longer than 6-12 months.
Cognitive Tests

• Numerous tests;
• MMSE (mini mental state examination);
• MoCA (Montreal Cognitive Assessment).
Laboratory Tests

- Blood tests - Blood Count, Thyroid Stimulating Hormone, Serum Electrolytes, Serum Calcium, Serum Fasting Glucose, Serum Vitamin B12;
- Electroencephalography (EEG);
- Brain scans such as Computerised Tomography (CT), Magnetic Resonance Imaging (MRI), Single Photon-Emission Computed Tomography (SPECT) or Positron Emission Tomography (PET);
- Lumbar puncture.
Referral To Specialists

• Neurologists;
• Specialists in medicine for older people;
• General adult psychiatrists;
• Psychologists;
• Occupational therapists;
• Mental health liaison;
• Social services.
Feelings

- Shock;
- Disbelief;
- Denial;
- Fear;
- Guilt;
- Loss;
- Relief;
- Acceptance.
Medications Used In Dementia

- No cure for dementia;
- Medications available that can improve symptoms, or temporarily slow down their progression, in some people;
- These medications must be taken regularly;
- There are two main types of medication used to treat Alzheimer’s disease - cholinesterase inhibitors and NMDA (N-methyl-D-aspartate) receptor antagonists.
Aricept, Exelon And Reminyl

- Donepezil, rivastigmine and galantamine prevent enzyme (acetylcholinesterase) from breaking down acetylcholine in the brain.
- Increased concentrations of acetylcholine lead to increased communication between cells;
- May in turn temporarily improve or stabilise the symptoms of Alzheimer’s disease.
• More complex mechanism;
• Memantine blocks a messenger chemical known as glutamate;
• Glutamate is released in excessive amounts when brain cells are damaged by Alzheimer’s disease and this causes the brain cells to be damaged further;
• Memantine can protect brain cells by blocking these effects of excess glutamate.
2011 guidance from NICE recommends that donepezil, rivastigmine and galantamine are available for people with mild-to-moderate Alzheimer’s disease.

Several studies suggest that cholinesterase inhibitors may also help people with more severe Alzheimer’s disease, however, these drugs are not licensed in the UK for the treatment of severe Alzheimer’s disease.

Recommends use of memantine for severe Alzheimer’s disease and for patients with moderate disease who cannot take the cholinesterase inhibitor drugs.
On-going Assessment

• Assessing for changes;
• Advice on dealing with specific difficulties;
• Observing treatments;
• Support.
To Summarise...

- A diagnosis of Dementia is important to the patient and their family;
- Support the patient, their families and carers;
- Encourage the person with Dementia and their families and carers to keep in regular contact with services.
Dementia Awareness

Support For The Patient, Families And Carers
Dementia Awareness Objectives

- What Is A Carer?
- Being A Carer;
- Carer’s Assessments;
- Carer’s Groups.
What Is A Carer?

- A carer is someone who looks after or cares for another;
- This support may be practical or emotional support, or supervision;
- The care is unpaid;
- A carer does not need to be related to the person they care for;
- A carer does not have to live with the person they care for.
The Stats...

• 6 million carers;
• 3 million juggling care with work;
• Over the next 20 years the economy will need an extra 2 million workers but society will need an extra 3 million carers;
• 2.3 million people become carers every year;
• 1.9 million people care more than 20 hours per week;
• 1.3 million care for more than 50 hours per week;
• 3 in 5 people will care for someone;
• 1 in 5 give up work to care.
The Real Cost Of Caring

- The economic value of the contribution made by carers in the UK is a remarkable £119 billion per year;
- This is more than the annual costs of the NHS;
- 4 in 10 carers have had to cease work;
- Caring can be isolating;
- Caring can be unpredictable;
- Often carers do not feel they have a choice;
- Sometimes services do not listen.
What Negative Emotions Do You Think Family Members And Carers May Go Through?
• Anxiety;
• Anger;
• Depression;
• Despair;
• Embarrassment;
• Frustration;
• Grief;
• Guilt;
• Isolation;
• Loneliness;
• Loss;
• Remorse;
• Resentment;
• Sadness;
• Stress
• Uncertainty;
• Worry;
• And many more…
Support Of Carers

- Carer’s groups are available to look after the carer themselves;
- We can refer carers or they can self-refer;
- Carer’s assessments can be completed by us, social services, or even the carer’s groups themselves.
Carers Groups

- Support with Benefits;
- Referral for Carers Support;
- Help with forms;
- Referrals to other agencies;
- Establish social activities;
- Emotional Support;
- Housing issues/adaptations;
- Information;
- Referrals to Telecare/Carelink;

- Help with budgeting/debt;
- Information regarding Respite;
- Planning for the future;
- Help to access courses for carers;
- Advocacy;
- Carers emergency cards.
- Information on local and national resources for Carers;
In The Community
• Information provision;
• Counselling and emotional support;
• Getting prescriptions;
• Visits to the general practitioner;
• Community psychiatric nurses;
• Respite care;
• Managing finances;
• Food shopping;
• Cooking;
• Social services;

• Giving medications;
• Care for other illnesses;
• Physiotherapy;
• Getting to appointments;
• Spiritual care;
• Post diagnosis support;
• Home carers;
• Occupational therapies and assistive technology;
• Memory clinics;
• Mental health liaison;
• And much more…
To Summarise...

- Recognise the carer and their needs;
- Explain there is help and support available;
- Provide education about Dementia and what to expect;
- Provide advice about coping with behaviours;
- If you can’t help then signpost them to someone who can.
Dementia Awareness

True Or False?
Any questions?