Managing Continence in People with Learning Disabilities

By Abigail Hulme and Bernadette McNamara
Community Learning Disabilities Nurses
Haringey Learning Disabilities Partnership
Aims:

• To have an increased awareness of the diagnostic difficulties of incontinence in people with learning disabilities

• To have a better understanding of the continence management issues faced by people with learning disabilities

• To have an increased awareness of reasonable adjustments used in the management of continence for people with learning disabilities
What is a learning disability?

The Department of Health (2001) defines learning disability as:

• A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence with an IQ below 70) with;

• A reduced ability to cope independently (impaired social functioning) and;

• Which started before adulthood, with a lasting effect on development
Prevalence of Incontinence in people with learning disabilities

- Research suggests that between 47%-59% of people with learning disabilities have a continence need.
- The prevalence of continence issues will increase with the severity of learning disability.
- Continence needs in people with a mild learning disabilities are generally in line with the needs of the general population.
- People with a learning disability with additional needs, such as Epilepsy, mental health conditions and ‘challenging behaviour’ are often prescribed medication that increase constipation.

Factors that increase continence needs

- Medication
- Communication difficulties
- Diagnosis
- Severity of learning disability
- Poor expectation/assumptions
- Mobility/Physical disabilities
- Mental health prevalence
- ‘Challenging Behaviour’
Health needs of people with LD

- Poorer access to health care
- Less access to assessment and treatment.
- Limited recognition of LD by health staff due to difficulties with communication.
- Poorer health outcomes.
- Inadequate diagnosis and treatment of specific medical conditions
- Higher mortality rate than the general population.
This is highlighted in:

- Disability Discrimination Act (1995)
- Valuing People (2001)
- Death by Indifference (2003)
- Health Care for All (2008)
- Valuing People Now (2009)
- Equality Act (2010)
- Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (2013)
Diagnosing incontinence

Assumptions are often made that:

- People with a learning disability will have ongoing incontinence needs.
- Behavioural issues due to mental health diagnosis, or ‘attention seeking behaviour’.

Also consider:

- Unmet sensory needs e.g. Smearing
- Physical health causes
- Weight
Problems in diagnosing incontinence

- Relying on carers to seek appropriate medical advice
- Communication difficulties
- Diagnostic overshadowing
- Compliance with appointments and investigations
- Lack of physical investigations
- Over prescription of incontinence products/ first line treatment of products
Communication

- People with more severe learning disability are often non verbal.
- People with learning disabilities find it harder to understand information, spoken and written.
- Many people with learning disabilities cannot read or write.
- Many people with learning disabilities and their carers are unaware of symptoms or are unable to describe symptoms.
- People with LD are often reliant on others-carers/family members to advocate on their behalf.
Diagnostic Overshadowing

- People with learning disabilities are often misdiagnosed or not diagnosed at all on the assumption that their incontinence is attributed to their learning disability.

- People are often prescribed incontinence products prior to any physical health investigations.
Compliance

• Lower attendance at appointments- reliant on carers, transport, letters are not accessible, fear

• Investigations- phobias and fears of new places, equipment, people in uniform, previous negative experiences, difficulties in getting urine samples

• Treatment- medication non compliance, unable to follow exercise instructions, unable to self monitor incontinence, lack of insight into the benefits of following treatment
Managing Continence

Reasonable adjustments:
- Easy read information
- Easy read monitoring charts
- Informing carers of symptoms to be aware of
- Mental capacity assessments and best interest
- Pain profile
- Purple folder
- Psychological interventions- sign posting, toileting programmes, rewarding positive behaviours
- Reasonable adjustments
- Desensitisation programmes
Managing incontinence - Easy read information

Using easy read written information
Simple written and spoken language
Using pictures and symbols
Social stories before appointments and treatment
Easy read recording/monitoring forms
Easy read appointment letters

For access to easy read health information use the following link:
www.easyhealth.org.uk
<table>
<thead>
<tr>
<th>![Image: Glass of Juice]</th>
<th><strong>Tick (✓) each box after having a drink e.g (orange, coke water, tea or any fluids).</strong></th>
<th>![Image: Toilet]</th>
<th><strong>Tick (✓) a box each time you use the toilet.</strong></th>
<th>![Image: Underwear]</th>
<th><strong>Tick (✓) a box if you have an accident and wet yourself.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>![Image: Cup of Tea]</td>
<td></td>
<td></td>
<td></td>
<td>![Image: Commode]</td>
<td></td>
</tr>
<tr>
<td>![Image: Water Bottle]</td>
<td></td>
<td></td>
<td></td>
<td>![Image: Couch]</td>
<td></td>
</tr>
<tr>
<td>![Image: Evian Bottle]</td>
<td></td>
<td></td>
<td></td>
<td>![Image: Bed]</td>
<td></td>
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</tbody>
</table>

Bernadette McNamara and Abigail Hulme
Community LD Nurses
If NAME would like to talk about this letter or cannot attend at this time, please telephone 0000000000

Thank you,

Community Nursing Team

Name:
Address:
Date:

We are community nurses.
NAME has been referred to the community nurses.
The community nurses will see NAME to talk about his health.
The community nurses would like to see NAME on:

Friday 27th June
At 11:00am.
At your home address.

Friday
27
June
11:00

Haringey Council
Haringey Learning Disabilities Partnership
The Community Team for People with Learning Disabilities
2nd Floor,
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Wood Green,
London N22 7SG
Tel 020 8489 1384
Fax: 020 8489 1397
www.haringey.gov.uk

Director of Adult, Culture and Community Services May THONG PHUNG
Chief Executive of Barnet, Enfield and Haringey Mental Health NHS Trust Maria KANE
Chief Executive of Whittington Health Dr Y Min ICE
Senior Clinical Executive for NHS Haringey Andrew WILLIAMS
Managing incontinence - Mental Capacity Act (2005)

- Many people with learning disabilities may lack capacity to consent to investigations and treatment
- Mental capacity assessments should be carried out
- Best interest meetings should be held

- Treatment is often withheld from those who are assumed to lack capacity or are given treatment without capacity being established.
Management of Incontinence - Other Interventions

- Sign posting people with learning disabilities to your local learning disabilities team for support/advice around the following:
  - Structured toileting programmes
  - Rewarding positive behaviours
  - Smearing
  - Anxiety
  - Trauma
  - Cognitive Behavioural Therapy
  - Sensory assessment
  - Desensitisation programmes
In Haringey, all people with learning disabilities are given a purple folder. This has replaced the previous health action plan and hospital passport. The folder contains all information about the individuals health. It contains a Health Action Plan section for all health professionals that have contact with the person to record their input.
Pain profile

- The pain profile used in Haringey is used for people with learning disabilities that cannot express pain verbally, and identifies non verbal cues that suggest a person may be in pain.
Purple folder and pain profile

My Purple Folder
(and my Health Action Plan 'HAP')

This folder contains important information that aims to support effective health care for people with learning disabilities. This folder MAY be completed by people without healthcare training and MUST be supported by other health records.

- Complete above using description and colour to demonstrate severity - Green (little or no pain), Amber (Evidence of some pain), Red (Evidence of significant pain). Give a copy of the pain picture and management recommendations (Page 3 & 4) to the person and their family/carer.

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Family/carer Observation</th>
<th>Family/carer Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin colour</td>
<td>X is fair skinned, ‘normal skin tone’ when not in pain</td>
<td>When X is in pain, he will be distinctly paler than usual</td>
</tr>
<tr>
<td>Sweating</td>
<td>No sweating observed</td>
<td>X will sweat profusely when in pain, he will be visibly wet</td>
</tr>
<tr>
<td>Absence of contentment/facial expression</td>
<td>X’s facial expression is usually content/happy, X is often smiling</td>
<td>X will not smile. His facial expression shows absence of contentment. X’s face becomes tense, eye brows lowered</td>
</tr>
<tr>
<td>Aggression</td>
<td>No aggression displayed</td>
<td>X may become slightly aggressive, and may harm himself by scratching</td>
</tr>
<tr>
<td>Breathing</td>
<td>X’s breathing is ‘normal’ and cannot be heard</td>
<td>X’s breathing does not usually change when he is in pain</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behaviour e.g. eating, sleeping, behaviour patterns</th>
<th>Family/carer Observation</th>
<th>Family/carer Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>X eats and sleeps well. X may initiate social contact, and ask to watch BBC News</td>
<td>When X is in pain, he will refuse food, and have disrupted sleep. X will not participate in usual activities and prefers to be in bed</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Body tension</th>
<th>Family/carer Observation</th>
<th>Family/carer Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>None observed usually</td>
<td>X may become tense. X will wrinkle, hold his head and protect the area in pain</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Increased vocalisation</th>
<th>Family/carer Observation</th>
<th>Family/carer Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>X can verbalise and may initiate basic conversation</td>
<td>X may make vocal sounds when in pain occasionally</td>
<td></td>
</tr>
</tbody>
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<table>
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<tr>
<th>Crying</th>
<th>Family/carer Observation</th>
<th>Family/carer Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>X does not normally cry, though he may be upset if he cannot do what he wants to do.</td>
<td>In extreme pain, X will cry</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Engagement</th>
<th>Family/carer Observation</th>
<th>Family/carer Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>X will engage in conversation and interactions with the family.</td>
<td>X will not be as involved with others, and can become disengaged</td>
<td></td>
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</tbody>
</table>
Managing Incontinence - Reasonable Adjustments

‘In law, all public sector services have a legal duty to provide ‘reasonable adjustments’ for people with learning disabilities. Reasonable adjustments include removing physical barriers to accessing services’

Examples:
Shorter waiting times
First or last appointments of the day
Easy read information and letters
Double appointments

Turner, S and Robinson C (2011)
References:

- Department of Health (2001)
References:

• Confidential Inquiry into premature deaths of people with learning disabilities (2013). Accessed online at: [www.bristol.ac.uk/cipold/fullfinalreport.pdf](http://www.bristol.ac.uk/cipold/fullfinalreport.pdf)
Questions!