Herts: Bridging the Gap - reducing Health Inequalities for people with learning disabilities

Kirsten Lamb
What is meant by ‘a learning disability’?

‘A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.’

Valuing People 2001
What is LeDeR?

Review of the deaths of all people with a learning disability aged 4yrs and over
LeDeR

Programme delivered by Bristol University
Commissioned by Health Quality Improvement for NHS England
First National Programme ever developed to review death of people with a Learning Disability
Aims to develop learning from the reviews that can be enacted to improve outcomes.
What does programme involve

- Notification
- Review
- Involvement of families
- Learning
- Action from learning
How do we ensure the learning from death reviews is put into action in Herts?

Improving Health Outcomes Group – representatives from across the system

The group has developed an action plan based on the Herts priorities

These priorities have come directly from the reviews

The action plan drives forward evidence-based change to attempt to improve outcomes
Outcomes

- LeDeR shows wide gap in median age of death for people with a learning disability compared with the rest of the population.

- Median age of death of people with PMLD (Profound and Multiple Learning Disability) = 40 yrs.
Herts mortality data for people with a Learning Disability

The age range of reported cases was 9yrs to 98 years (168 cases)

The Median age of the cases reported in total since April 2017 is 64 yrs. This is considerably lower than the median age of the general population which is 85 years.

14.28% of the total cases reported since April 17 were of individuals of 80 years and above (20 cases).

17% of all deaths were of people aged under 50yrs (28 cases)
Causes of death of people with a Learning Disability in Herts

- Pneumonia: 23%
- Sepsis: 14%
- Cardiovascular: 16%
- Neoplasms: 8%
- Digestive Systems: 9%
- Dementia and behavioural: 5%
- Neurological: 5%
- Others: 5%
- Aspiration Pneumonia: 7%
- Not known (Review not completed): 7%
- Others: 6%
Top six causes of death of people with a Learning Disability nationally

- Pneumonia - 25%
- Aspiration pneumonia – 16%
- Sepsis – 7%
- Dementia – 6%
- Ischaemic heart disease - 6%
- Epilepsy – 5%
<table>
<thead>
<tr>
<th>Males (% of all male deaths)</th>
<th>Females (% of all female deaths)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Heart disease</td>
<td>Dementia and Alzheimer’s disease</td>
</tr>
<tr>
<td>14.2%</td>
<td>15.3%</td>
</tr>
<tr>
<td>2 Dementia and Alzheimer’s disease</td>
<td>Heart disease</td>
</tr>
<tr>
<td>8.0%</td>
<td>8.8%</td>
</tr>
<tr>
<td>3 Lung cancer</td>
<td>Stroke</td>
</tr>
<tr>
<td>6.5%</td>
<td>7.5%</td>
</tr>
<tr>
<td>4 Chronic lower respiratory diseases</td>
<td>Influenza and pneumonia</td>
</tr>
<tr>
<td>6.2%</td>
<td>6.0%</td>
</tr>
<tr>
<td>5 Stroke</td>
<td>Chronic lower respiratory diseases</td>
</tr>
<tr>
<td>5.6%</td>
<td>6.0%</td>
</tr>
<tr>
<td>6 Influenza and pneumonia</td>
<td>Lung cancer</td>
</tr>
<tr>
<td>5.1%</td>
<td>5.1%</td>
</tr>
<tr>
<td>7 Prostate cancer</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>4.2%</td>
<td>3.7%</td>
</tr>
<tr>
<td>8 Colorectal cancer</td>
<td>Colorectal cancer</td>
</tr>
<tr>
<td>3.0%</td>
<td>2.4%</td>
</tr>
<tr>
<td>9 Leukaemia and lymphomas</td>
<td>Kidney disease and other diseases of the urinary system</td>
</tr>
<tr>
<td>2.6%</td>
<td>1.9%</td>
</tr>
<tr>
<td>10 Cirrhosis and other liver disease</td>
<td>Leukaemia and lymphomas</td>
</tr>
<tr>
<td>1.9%</td>
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</tr>
</tbody>
</table>
Why is there such a difference?

Many people with a learning disability have lots of other health problems. The LeDeR programme has shown that the mean number of long term conditions that people have is 3.

The commonest long-term conditions were:
- Epilepsy
- Dysphagia
- Cardiovascular problems
- Dementia
- Mental illness
Where do people die?

- Hospital deaths for those with a LD: 61%
- Hospital deaths for General population: 48%
What are the questions arising from these figures?

- Would we recognise when someone has a learning disability?
- Are we sure our services are valued by people with a learning disability?
- Do we listen to their families?
- Are we asking people about their wishes and ensuring those wishes are fulfilled?
- Are we enthusiastic enough about health promotion, regular health checks and so on?
- Do we encourage engagement with screening activities?
- Do we recognise if someone’s condition is deteriorating?
- Why do such a high proportion of people die in hospital?
Key issues and themes arising from Herts reviews

- Problems with implementation of Mental Capacity Act and DOLS
- Issues around failure to make reasonable adjustments
- Little advanced care planning
- People and their families and carers not being heard
- Problems with collaborative working across the system
- Poor implementation of end of life care
- Late presentation of illness because early signs of deterioration were missed – diagnostic overshadowing
Workshops

These subjects are all covered in the range of workshops offered
What next?

• People from all parts of the Health and Social Care system in Herts are here today
• What can you do in your role to make things better?
• Individually – improve our awareness of the needs of people with a learning disability and the risks they face

• Collectively – return next year with evidence of the differences that have been made across the System
Thanks!

Good Luck!