

Health & People with Learning Disabilities



People with a learning disability are more likely to:

- Die early
- Have certain cancers
- Have heart problems
- Have and die from respiratory problems
- Use medical and hospital services
- Be discharged quickly from hospital
- Have impaired sight and hearing



Health – OHP 1

Trainers Notes:

Die early - average age for females in the country is 86, males 83, average age for people with learning disabilities is 57, although this is likely to continue to increase.

Have certain cancers – different pattern of cancers from the general population. People with learning disabilities have higher rates of gastro intestinal cancers e.g. oesophageal, stomach and gall bladder cancers than the general population. There are fewer cases of lung, breast, and prostate cancer. There are higher levels of testicular cancer in males with Downs syndrome, and higher rates of leukaemia in people with Downs syndrome. Consideration is needed as there is concern about poor and / or late diagnosis of cancer in people with learning disabilities.

Have heart problems – congenital heart problems in people with Downs syndrome, heart problems associated with fragile X syndrome, high levels of obesity. Cardiovascular disease is 2nd most common cause of death in people with learning disabilities unlike the general population where it is ranked first.

Have respiratory problems – dysphasia (swallowing problems) and resulting aspiration and physical posture (in people with more profound learning disabilities and physical disabilities) affects breathing. Respiratory disease is the commonest cause of death in people with learning disabilities, secondary to pneumonia.

Use medical services – due to higher health needs.

Be discharged from hospital more quickly – there may be assumptions by hospital staff that all homes are nursing homes, anxiety and challenging behaviour in hospital, reluctance to do investigations due to difficulties in relation to capacity and consent.

Have impaired sight and vision – needs in these areas may not be fully assessed, people with learning disabilities may have aids but may not be able to put them on/in themselves and they may sit in the drawer, or glasses may get so dirty they cannot see. The figures vary but the rates are much higher than for the general population. Visual Impairment – up to 7 times more frequent than general population. Hearing loss – up to 4 times more frequent than general population.

Health & People with Learning Disabilities



People with a learning disability are also more likely to:

- Have epilepsy
- Have mental health problems
- Be prescribed psychotropic drugs
- Be overweight and eat an unhealthy diet
- Have thyroid dysfunction
- Have dental problems
- Have dementia
- Be constipated
- Have gastro-intestinal problems
- Have osteoporosis



Health – OHP 2

Trainers Notes:

More likely to have epilepsy – Figures vary but roughly a third of people with a learning disability have epilepsy (frequency of epilepsy increases with the degree of disability) versus approximately 1% of the general population. More complex epilepsy and often treated on more than one medication, phenytoin often prescribed to administer in hospital IV to control seizures. Often then continued orally, possibly doctors having limited knowledge of newer medications available.

Experience mental health problems – Figures vary greatly due to different assessment techniques and uncertain status of challenging behaviour which can be caused by mental health problems but also other issues. There are problems with effective mental health diagnosis in people with learning disabilities.

Be prescribed psychotropic drugs - used for behaviour management as well as mental health problems.

Be overweight and eat a unhealthy diet – Possible reasons: convenience food, choice, limited budgets, less exercise, syndromes associated with obesity e.g Prader Willi

Have thyroid dysfunction – People with Downs syndrome are more prone to develop this, it may be confused with other conditions such as dementia, hyperthyroidism can result in challenging behaviour.

Have dental problems – poor prevention i.e. teeth cleaning and access to dentist for routine check ups, fear element / dental phobia may have an effect.

Have dementia – Higher rates in people with Downs syndrome.

Be constipated – Medication usage, cerebral palsy, mobility problems, reduced gut motility. More prevalent in people with severe learning disabilities.

Have gastro-intestinal problems - helicobacter pylori, Gastric Oesophageal Reflux Disorder (GORD) - causes pain and predisposes to oesophageal cancer. Medications such as steroids, Non-Steroidal Anti-inflammatory Drugs (NSAIDS). Gastro-intestinal problems associated with cerebral palsy and scoliosis.

Osteoporosis – more common in people with learning disabilities than other groups, associated with small body size, hypergonadism small testes, or failed development of secondary sexual characteristics, mobility problems.

Downs Syndrome and Health Needs



This is an example which shows that particular syndromes associated with learning disabilities can result in certain health conditions being more likely

People with Downs Syndrome are more likely to be affected by these health issues



- Cardiac disease
- Blood disorders
- Dementia
- Infections
- Obesity
- Respiratory problems
- Sleep Disorders
- Skin problems
- Thyroid dysfunction

Health – OHP 4

Trainers notes

Cardiac disease - congenital (40 to 50%) and /or acquired

Blood disorders – Blood dyscrasias, childhood leukaemia

Dementia (usually Alzheimers type) - 4 to 5 times increased risk

Infections – increased susceptibility, respiratory tract infections

Respiratory problems - upper airway obstruction and lower airway disease

Sleep disorders, e.g. sleep apnoea

Skin problems – Increased risk of alopecia, eczema

Thyroid dysfunction (affects 10 to 20%) – often hypothyroidism

Other Health Issues can include:

Cervical Spine Instability / Atlanto axial joint

Coeliac disease / Gluten Sensitivity

Visual problems – squints, cataracts glaucoma

Hearing problems – narrowed ear canals

Depression

Handout - Syndrome Specific Information for GPs – information designed for GPs, but useful for all health professionals. This is included in the training pack and covers many other conditions including Rett Syndrome and Fragile X.

National Service Frameworks



National Service Frameworks (NSFs) for the general population also apply to people with a learning disability

- Mental Health NSF
- Cancer NSF
- Diabetes NSF
- Older People NSF
- Coronary Heart Disease NSF
- Children NSF
- Long Term Conditions NSF

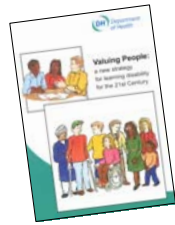


Health – OHP 5

Trainers Notes

These are the main relevant NSFs, but renal, chronic obstructive pulmonary disease NSFs and any others which are developed in the future should also apply to people with learning disabilities.

Valuing People – The Government White Paper



Valuing People says that people with learning disabilities should get the same health services that are available to everyone else with expert care when they need it

Valuing People promotes:

- Choice
- Rights
- Inclusion
- Independence



Health – OHP 6

Trainers Notes:

Valuing People was launched in 2001. It was the first White Paper about learning disabilities for 30 years

Based on the 4 principles shown

Highlighted the Health Agenda

Valuing People – The Government White Paper



**Says everyone
with a learning
disability should:**

- **Have an identified Health Facilitator**
- **Be registered with a GP** (All GPs should have a register of all the people within their practice who have a learning disability)
- **Be offered a Health Action Plan**

The NHS must ensure that all mainstream hospital services are accessible for people with learning disabilities.

Many people with learning disabilities will need support to understand and co-operate with treatment in hospital.

Health – OHP 7

Trainers Notes:

Health Facilitator – A named person who helps and supports the person with a learning disability with their health and helps them to find their way round the healthcare system, e.g. going to appointments and helping them to understand the outcome of these.

Health Action Plan – a plan with agreed actions about health which helps the person maintain and improve their health.

Barriers To Accessing Mainstream Healthcare



- Lack of awareness of and education for Primary Care / Acute Hospital staff
- GPs are unfamiliar with services for people with learning disabilities
- Communication Difficulties
- Difficulties in recognising and communicating symptoms
- Difficulties understanding medical conditions
- Current Primary Care system itself that demands self-recognition of need with short appointment times
- Diagnostic Overshadowing



Health – OHP 8

Trainers Notes:

Lack of awareness training and experience of working with people who have a learning disability, confusion around consent.

Communication difficulties – language difficulties, comprehension problems, reading difficulties, problems retaining/ remembering information.

Difficulty recognising and communicating symptoms – People with learning disabilities may not be able to communicate symptoms verbally, carers may overlook symptoms, symptoms or changes in behaviour may be attributed to learning disability rather a medical need.

Difficulty understanding medical conditions - lack of accessible information and lack of preparation for appointments.

Diagnostic Overshadowing – Where symptoms of a physical health problem are wrongly diagnosed as being a symptom of the person's learning disability.

Health is often not perceived as being a priority by social care staff.

Barriers To Accessing Mainstream Healthcare



- Lack of education / preparation that helps individuals to use GP practices
- Limited development of information leaflets about people with learning disabilities and their health needs.
- Unequal judgements may be made about quality of life issues that determine treatment



Health – OHP 9

Barriers To Accessing Mainstream Healthcare



People with a learning disability:

- May not understand the process of consultation
- May not understand the importance of attendance at appointments
- May be fearful of doctors and/or nurses
- May be fearful of surgery and/or hospital



Health – OHP 10

Trainers Notes:

Consultation – may be unable to give health history, answer questions or understand information given. People with learning disabilities may be supported to appointments by staff who do not know them or their medical history well.

Appointments – may also be practical difficulties in accessing health care i.e. long waiting times, noisy/busy waiting areas and transport problems.

Fear of medical personnel and interventions, dentists, doctors, anyone in a white coat etc.

Fears of being in hospital, operations, negative experience of being in hospital

People with Learning Disabilities and Hospital



People with Learning Disabilities are hospitalised more frequently than the general population.

They generally do not have positive experiences in hospital

The level of admissions by people with Learning Disabilities is likely to increase.

The population is ageing and more people are surviving with complex and profound learning disabilities



Health – OHP 11

Trainers Notes

People with learning disabilities and hospitalisation – there is limited information about numbers but Acute Hospital Liaison Nurses working with people with learning disabilities in hospital believe that more people with a learning disability go into hospital than figures suggest.



Death By Indifference

Is a report produced by Mencap in 2007.

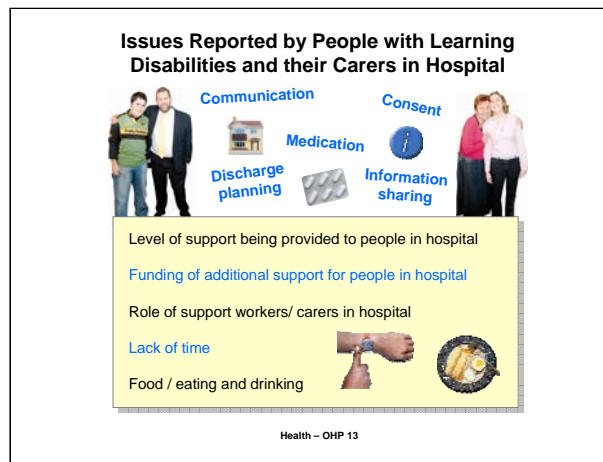
It looks at the deaths of 6 people with learning disabilities in acute general hospital settings.

- It highlighted that hospital staff did not have understanding of the needs of people with a learning disability in hospital.
- Hospital staff did not listen to carers.
- Suggests there is institutional discrimination against people with learning disabilities in acute settings, and they get worse health care than non-disabled people.
- Mencap believe that all 6 people featured in the report died unnecessarily and that there is much work needed to be done to ensure that people with a learning disability are treated decently and equally. This is just 'the tip of the iceberg'.

The Government has set up an independent inquiry into these deaths

Health – OHP 12

Trainers Notes



Trainers Notes:

People using hospitals in Surrey reported these issues

Communication

Between doctors and person with a learning disability – some complaints of doctors talking to the carers rather than the person themselves.

Between staff in residential/ housing services and hospital staff. Home staff not sending in communication aids/ passports/ other information. Hospital staff not keeping home staff up to date about discharge plans.

Information sharing

Home staff not providing written information to hospital staff about the person's specific needs. Hospital staff not giving home staff important information, as they are not the next of kin, although they are often the main carers.

Funding of additional support needed in hospital

This issue remains contentious, unresolved and causes much anxiety, concern, unhappiness and may have an impact upon the service received in hospital. At present each instance is dealt with individually as no protocols are in place locally.

Role of support workers/ carers in hospital

There may be assumptions that support workers are nurses. There maybe expectations that support workers or family carers will carry out all care for the person, when this is the hospital's responsibility. Family carers may not be offered drinks or breaks when spending long periods of time in hospital. See slide re role of support workers/ carers.

Lack of Time

This is always an issue in hospital as staff are so busy. In one hospital the Patient Advice and Liaison Service (PALS) manager, who was skilled in communication spent the additional time needed with people with learning disabilities explaining things to them. This worked well.

Level of support

People were sometimes offered too much support, e.g. with washing and dressing so that they did not maintain the skills they had before going into hospital. Others were offered too little support and assumptions were made about how much they could do for themselves, e.g. people needing to be shown where the toilet was, perhaps more than once were not, resulting in incontinence

Food / eating and drinking

Not unique to people with learning disabilities – we have all probably heard stories of peoples' trays of food being left out of their reach or no help being given and then taken away with the food untouched. Red Tray scheme used in one hospital to highlight to staff people who need support with meals.

Medication

Information was sometimes not provided to hospital staff for example if medication was taken in a particular way, e.g. from a teaspoon, resulting in refusal to take medication and other problems. Blister packs may cause difficulties in hospital.

Consent

Things seem to have improved since the Department of Health produced standards forms, including one for best interests, but there are still some issues, e.g. people believing that someone else can sign on behalf of an adult with learning disabilities. Mental Capacity Act (2005) gives more clarity.

Discharge planning

Homes staff and families need to be aware that hospital staff aim to get someone to a point where they are "medically fit for discharge". This may not be the same as they were when they came in – another reason for good communication between support and hospital staff. Services may need to be more pro-active and ask hospital staff regularly when someone is due to be discharged, explain restrictions of Care Standards, request discharge planning meetings etc.

The Role of Support Workers / Carers in Hospital



The principles below apply to paid support workers but could be applied to family members

- Type and level of support needed should be decided at Pre-admission Assessment for those having planned admissions.
- Action plan for support worker agreed at this stage.
- On admission the support worker is responsible for providing appropriate written and verbal information / knowledge to identified ward staff.
- The ward staff will clarify to the support worker what activities they can and cannot undertake with the individual.

Health – OHP 14

The Role of Support Workers / Carers in Hospital



The principles below apply to paid support workers but could be applied to family carers

- The support worker / family member will not become involved with any aspect of clinical care (e.g. pressure area care). They are not nurses.
- The support worker is there to support the individual only and explain procedures.
- The support worker / family member will report any concerns, changes to the named nurse / nurse in charge.

Health – OHP 15

National Patient Safety Agency (NPSA)



The NPSA identified 5 key patient safety risks for people with learning disabilities (2004)

- Control and restraint
- Vulnerability of people with learning disability in general hospitals
- Swallowing difficulties (dysphagia)
- Lack of accessible information
- Illness or diseases being misdiagnosed or un-diagnosed



Health – OHP 16

Trainers Notes:

Control and restraint

People with learning disabilities may be receiving injuries and being harmed when physical restraint is used inappropriately.

Vulnerability of people with learning disability in general hospitals

People with learning disabilities may be more at risk of things going wrong than the general population.

Swallowing difficulties (dysphagia)

Swallowing difficulties are more common in people with learning disabilities. They can lead to respiratory tract infections, a leading cause of early death for people with learning disability.

Lack of accessible information

Harm may result where a person with a learning disability is unable to understand information relating to their illness or treatment.

Illness or diseases being mis or un-diagnosed

Access to treatment can be delayed because symptoms are not recognised early enough or attributed to the person's learning disability.

National Patient Safety Agency (NPSA)

The NPSA has been looking at tools developed locally to help support people with learning disabilities in hospital and are developing good practice guidelines

Some useful available tools

Information for people to take into hospital to tell staff about their needs

- Traffic Light Assessment
- Hospital Admission Sheet

Information for hospital staff to support communication

- Handy Hints Card
- Hospital Communication Book



Health – OHP 17

Trainers Notes:

Information for people to take into hospital with them

Traffic Light Assessment

Developed in Gloucester. Available on the Valuing People Support team website and A2A website (see further information section of pack for website details). Provides basic information about a person's needs - colourful – need a colour printer

Hospital Admission Sheet

Used locally in Surrey. Two sides of paper providing useful basic information about the person's needs.

Information for hospital staff to support communication

Handy hints card – developed at St Mary's NHS Trust – tips about communicating with someone with a learning disability available on A2A website.

Hospital Communication Book – developed in Surrey to give hospital staff information, ideas and tools such as photos and pictures to support communication. Available on the Valuing People Support Team website. – See further Information section for details.