# THE A – Z OF HEALTH ISSUES AFFECTING PEOPLE WITH LEARNING DISABILITIES

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| **A** | **ACCESS**<br>2% of the population will have a learning disability. This suggests that a GP with a list of 2000 will have about 40 patients with a learning disability. Each health practice and department should ensure that their physical and cognitive environment is accessible to people with learning disabilities. | **ATTITUDES**<br>People with learning disabilities are people first – each health problem presented should be isolated from the learning disability and treated separately. Attitudes and assumptions that people with learning disabilities cannot make decisions, understand treatments or make their own choices are discriminatory and inappropriate. | **APPOINTMENTS**<br>Waiting for appointments can cause great anxiety for some people with learning disabilities. GP practices and departments could be more flexible by offering double appointments, first or last appointments or separate waiting areas for challenging patients. Keeping patients informed of waiting times could also help to reduce anxiety levels. | **ANNUAL HEALTH CHECKS**<br>Regular health checks (1-3 yearly) to people with learning disabilities often leads to the early detection of previously unmet health needs. |
| **B** | **BARRIERS**<br>The barriers to receiving appropriate healthcare are numerous and include inaccessible services, communication problems, complex information, fear and lack of confidence. | **BEHAVIOUR**<br>Physical illness should always be considered as a cause of behaviour changes. Much behaviour can be attributed to environmental stress, ill health, lack of occupation or poor communication skills. Challenging behaviour could also be the result of an underlying psychiatric illness. | **BETTER METRICS**<br>The better metrics project links in with the NHS Plan and NSF targets and includes 12 clinical performance measures relating to people with learning disabilities. These include up to date LD registers in GP practices and annual health checks. | |
| **C** | **CORONARY HEART DISEASE**<br>This is the second most common cause of death amongst people with learning disabilities (14%-20%). Between 40 and 50% of people with Downs syndrome are affected by congenital heart defects. | **CONSTIPATION**<br>People with learning disabilities are more prone to constipation due to immobility, poor fluid intake, medications and limited food choices.<br>Reliance on laxatives should be replaced with fibre rich foods, exercise, more fluids and a healthy diet. | **CONSENT**<br>It must be assumed that everyone has the capacity to give consent until proven otherwise. Acting in someone's 'best interest' must be a multidisciplinary decision and documented accordingly, (DOH consent form 4). Nobody should be signing consent forms on behalf of another adult. | **COMMUNICATION**<br>50 – 90% of people with learning disabilities have communication difficulties. Communicating ill health can often be difficult for people with learning disabilities and may present in different ways i.e. through changes in behaviour, abilities or personality, social withdrawal, aggression or self harm. |
| **D** | **DEMENTIA**<br>People with learning disabilities are more likely to develop early dementia (21% vs. 5.7%).<br>Around 40 – 50% of people with Downs Syndrome will show symptoms of dementia by the age of 50. | **DOWNS SYNDROME**<br>People with Downs Syndrome have many associated health problems which need regular monitoring. These include; heart defects, poor vision, hearing and dentition, obesity, early dementia, thyroid and respiratory problems. | **DIABETES**<br>People with learning disabilities are more prone to diabetes due to sedentary lifestyles and obesity. The condition is often undiagnosed and needs to be monitored and managed effectively. | **DIAGNOSTIC OVERSHADOWING**<br>This occurs when the learning disability 'trumps' the physical or mental health need.<br>Health professionals need to look past the learning disability and treat the symptoms presented. |
| **E** | **EPILEPSY**<br>22% of people with learning disabilities have epilepsy compared to 1% of the general population. The incidence rises to 30% in people with profound and multiple disabilities. | **EARLY DISCHARGE**<br>People with learning disabilities are more likely to be discharged early from hospital, often with inappropriate discharge summaries or aftercare plans. | **EQUAL RIGHTS**<br>People with learning disabilities have equal rights to be included in all health targets and initiatives. Routine health screening and health promotion initiatives should also apply to people with learning disabilities. Don't leave them out! | |
| **F** | **FEAR**<br>Fear of unfamiliar surroundings, people and procedures is the biggest obstacle faced by people with learning disabilities when accessing healthcare services. | **FOLLOWING TREATMENTS**<br>Treatments and advice given by health professionals should be simple and clear and in a format understood by the individual. Checking comprehension will help to clarify that information has been understood. **Write it down.** | | |

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| **G** | **GASTRO-OESOPHAGEAL REFLUX (GORD)**<br>Up to 50% of people with learning disabilities could be suffering from GERD. It may present as challenging behaviour as symptoms are quite painful. | **GASTRO-INTESTINAL CANCER**<br>Higher rates of gastro-intestinal cancers can be found in people with learning disabilities and it is the most common form of cancer within this group. (48%-58% vs 25%). | | |
| **H** | **HEARING IMPAIRMENTS**<br>40% of people with learning disabilities have hearing problems. Deafness is common and is often unrecognised and poorly managed. Impacted ear wax is a frequent problem overcome by regular health checks. | **HELICOBACTER PYLORI**<br>High rates of H-pylori can be found in people with learning disabilities who have lived in institutions (60-90%). It may be instrumental in increased mortality rates from stomach cancer and perforated ulcers. | **HEALTH ACTION PLANS**<br>"All people with learning disabilities will be offered a HAP by June 2005". (DOH 2001). Health Action Plans require a medical health check and thorough assessment of health needs. Health facilitators should also be identified for each individual. | |
| **I** | **INFORMATION**<br>Accessible information should be made available to all people with learning disabilities to maximise their capacity to understand and consent to treatments. | **IMMUNISATIONS**<br>Research demonstrates that people with learning disabilities are less likely to receive regular immunisation. Influenza, pnenococcus, Hepatitis A + B are recommended for this group. | **IDENTIFYING A LEARNING DISABILITY**<br>A learning disability presents as a significantly reduced ability to understand new or complex information, learn new skills and cope independently. IQ is often below 70 and onset must have occurred before adulthood (age 18). | |
| **J** | **JOINT WORKING**<br>Primary and secondary health services need to be working in partnership with specialist Learning Disability services to provide equitable services to people with learning disabilities. | **JARGON**<br>Avoid jargon and use clear, simple language. | | |
| **K** | **KISS**<br>Keep it simple – short phrases, visual prompts, clarify salient points and confirm comprehension. Speak slowly and clearly. | **KNOWLEDGE**<br>There is a general lack of knowledge by doctors and nurses of the special needs of people with learning disabilities particularly around communication, behaviour and consent. 75% of GPs receive no training in learning disabilities issues. | | |
| **L** | **LIFESTYLE**<br>People with learning disabilities often lead unhealthy lifestyles are inactive, obese and have poor nutrition. Poverty, unemployment and social exclusion also affect/inhibit healthy lifestyle choices. | **LIFE EXPECTANCY**<br>The life expectancy of people with learning disabilities is increasing over time (67 for men, 69 for women), 55 for downs) but is still less than that of the general population. | | |
| **M** | **MORTALITY AND MORBIDITY**<br>People with learning disabilities have an increased risk of early death, although the life expectancy of this population is increasing over time. | **MENTAL HEALTH**<br>Psychiatric disorders are more prevalent in people with learning disabilities compared with the general population. Schizophrenia, depression, anxiety and pre-senile dementia are all common in this group. | **MEDICATION**<br>Polypharmacy and inadequate medication review are acknowledged within this client group. Anti-psychotics can often be inappropriately prescribed and poorly reviewed. | **MOBILITY**<br>People with learning disabilities are more likely to have a physical disability then the general population. Early intervention and treatment of immobility can reduce the risk of secondary illnesses. |

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| **N** | **NEUROLOGICAL PROBLEMS**<br>Cognitive decline in people with learning disabilities can often be difficult to detect. Health checks should always include limb movement, tone and gait, seizure activity, declining function, memory loss or any changes in moods or behaviour. | **NUTRITION**<br>Less than 10% of adults with learning disabilities eat a balanced diet. There is a general insufficient uptake of fruit and vegetables and a lack of knowledge and choice of availability of healthy food options. | **NATIONAL SERVICE FRAMEWORKS**<br>NSF's for the general population also apply to people with a learning disability and must include this group in all delivery plans. | **NPSA**<br>The National Patient Safety Agenda lists 5 priority areas for keeping patients with a learning disability safe in hospitals. They are dysphagia, accessible information, vulnerability, use of physical intervention and mis-diagnosis. |
| **O** | **OLDER PEOPLE**<br>Due to increased life expectancy this group of people are now more likely to have age related health problems such as strokes, heart disease and cancer. | **OSTEOPOROSIS**<br>Osteoporosis and osteomalacia are both increased in this population, particularly for people with small body size, hypogonadism and downs syndrome. There is also an increased risk of fractures and falling down. Osteomalacia is the result of vitamin D deficiency. | | |
| **P** | **PHYSICAL EXERCISE**<br>80% of this group of people do less physical exercise than is recommended. Immobility, lack of opportunity, poor staffing, financial and transport problems are often the cause. Boredom, apathy, depression and hostility can be helped with regular physical exercise | **POSTURAL CARE**<br>Postural care assessments are recommended for people with complex disabilities. Correct postural management will reduce long-term need for surgery or equipment and ultimately reduce pain and improve body function. | **PAIN**<br>Due to associated problems with communication, pain can often be expressed in a behavioural change. Pain assessments for people with learning disabilities monitor physiological and behavioural symptoms as well as facial expressions. | **PERSON CENTRED PLANNING**<br>Person Centre Planning ensures that people will have control over their own lives and the services that they receive. The Health Action Plan may form part of the person centred plan. |
| **Q** | **QUALITY OF LIFE**<br>Sadly there is still evidence of doctors making value judgements about the quality of life of people with profound and multiple disabilities. Denying treatments, failure to make life saving interventions and automatic DNR notices are still occurring. | | | |
| **R** | **RESPIRATORY DISEASE**<br>This is the leading cause of death for people with learning disabilities (52%). Aspiration and respiratory tract infections can be caused by congenital defects, vomiting, epilepsy, coughing, feeding, breathing and swallowing difficulties, regurgitation and gastroesophageal reflux. | **REGISTERS**<br>Valuing People states that all people with a learning disability should be registered with a GP by June 2004. Each practise needs to be able to identify their learning disabled population using the appropriate Read Code. | **READ CODES**<br>Valuing people have recommended that READ Code E3 (Mental Retardation) be used in GP practices. The term 'mental retardation' however is inappropriate and some practices prefer to use the code Eu81z) (learning disability nos). | |
| **S** | **SCREENING**<br>People with learning disabilities are often excluded from national screening programmes.Women with a learning disability are about 4 times less likely to undergo cervical smear tests than the general population (24% vs 82%). They are also less likely to have breast examinations or be invited to attend for a mammogram. | **SCHIZOPHRENIA**<br>3% of people with learning disabilities compared to 1% of the general population, have schizophrenia.<br>Presentation of mental health problems will depend on cognitive, communicative, physical and social functioning within this client group. | **SEXUAL RELATIONSHIPS**<br>It cannot be assumed that people with learning disabilities do not have sexual relationships. They should be included in all screening programmes. Some women may have experienced sexual abuse and should be called up for smear tests. | |

## T

### TRAINING
A recent MENCAP paper reported that 75% of GP's had received no training to help treat people with learning disabilities. Lack of training and skills among healthcare staff results in people with learning disabilities having poor access to health services and poor health outcomes.

### TEETH
Poor oral health is one of the most frequent health problems in this population – one study found that 86% of people with a learning disability had dental disease. They have poor oral hygiene, untreated dental caries and more extractions than the general population.

### THYROID
Children and adults with Downs syndrome are at increased risk of thyroid dysfunction, particularly hypo thyroidism. Thyroid disease can be difficult to diagnose in people with learning disabilities, and often presents itself as a change in behaviour being the only 'symptom'.

## U

### UNMET HEALTH NEEDS
Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs. Their health needs often go undetected or undiagnosed due to problems with communication, assertiveness and low expectations.

## V

### VISION
Approximately 30% of people with learning disabilities have a significant impairment of sight. Adults with Downs syndrome often present with cataracts, keratoconus and retinal pathology. Regular monitoring of vision is important in this client group, who rarely complain of poor vision.

### VULNERABLE
"People with learning disabilities are amongst the most vulnerable and socially excluded in our society" (DOH 2001). They are often marginalised or excluded and have poor life choices. Prejudice, discrimination and isolation are often experienced by this group of people.

### VALUING PEOPLE
'Valuing People' is a White Paper published in March 2001. The 4 key principles running through the paper are based on social inclusion, civil rights, choice and independence. The health targets focus on GP registers, Health Action Plans and Health facilitation.

## W

### WEIGHT
Overweight

People with learning disabilities living in the community are more likely to be obese (56% of men, 73% of women). Obesity is a special risk for adults with Downs syndrome and Prader-Willi syndrome.

Underweight

Under nutrition is more prevalent in institutional settings and in people with dysphagia or eating and drinking problems. The use of PEG feeding is increasing in this population.

### WAX
A build up of ear wax in people with learning disabilities is very common but often undiagnosed and attributed to poor hearing. Regular health checks should include examination of the ears and a hearing test. Ear infections could also be the cause of behaviour changes i.e.head banging or face slapping.

## X

### EXTRA TIME
Extra time and patience is often needed from Health professionals when consulting with people with learning disabilities. Longer appointments and consultations will enable effective communication and comprehension for both patient and health professional.

## Y

### YOUNG ADULTS
Young adults with a learning disability are often not transferred from children's to adult services with adequate health care plans, particularly those with complex and profound health needs. This could result in exclusion from adult services.

## Z

### ZERO TOLERANCE
TO:

- discriminatory practice
- exclusion from health initiatives
- inequitable services
- inaccessible services

**References and Bibliography**


Lenox etal – Health Guidelines for Adults with an Intellectual Disability.
Hatton etal – 'Key Highlights' of Research Evidence on the Health of People with Learning Disability
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