

Learning disability

Learning disability - F70 (also referred to as 'mental retardation' in ICD-10.) (Clinical term: Mild mental retardation Eu70)

Presenting complaints

At birth:

- Unusual faces (dysmorphia)
- Poor thriving, eg Down syndrome

In children:

- Delay in usual development (eg sitting up, walking, speaking and toilet training)
- Difficulty managing school work, as well as other children, because of learning disabilities
- Behavioural problems, especially overactive behaviour and poor socialization
- Often, these children are the target of stigma and bullying, because of their different appearance, abilities and behaviour.

In adolescents:

- Difficulties with peers, leading to reduced social opportunities and isolation
- Inappropriate sexual behaviour
- Difficulties in making the transition to adulthood, especially in terms of forming relationships and developing independence.

In adults:

- Difficulties in everyday functioning, requiring extra support (eg cooking and cleaning), with consequent increased costs of living
- Problems with normal social development and establishing an independent life in adulthood (eg finding work, marriage and child-rearing)
- Inappropriate sexual behaviour and other antisocial behaviour.

Diagnostic features

Slow or incomplete mental development resulting in:

- learning difficulties
- social adjustment problems (which are present from early in life).

The range of severity includes:

- severe learning disability (usually identified before two years of age. The individual requires help with daily tasks throughout life and is capable of only simple speech)
- moderate learning disability (usually identified between ages three to five. The individual is able to do simple work with support, and needs guidance or support in daily activities)

- mild or borderline learning disability (usually identified during school years. The individual is limited in school work, but is able to live alone and maintain some form of paid employment).

Differential diagnosis and co-existing conditions

Learning disability is associated with an increased prevalence of many other disorders. The most common include the following:

- Epilepsy - G40, G41 (adult) (25% people with learning disability and 50% of those with severe learning disability).
- Hypothyroidism (people with Down syndrome).
- Physical disabilities and dysmorphia (30%).
- Incontinence (10%).
- Hearing impairments (40%).
- Visual impairments (40%).
- Autism spectrum disorders -F84 (child) - (10% individuals with learning disability and 30% of those with moderate to severe learning disability).
- Psychiatric and behavioural disorders (at least 35%).
- Dementia- F00# (adult) (people with Down syndrome and those over 50).

Diagnosis of these conditions can be made harder by unusual presentations of the illness; - for example, irritability (which might present as agitation or even aggression) may be an indication of pain or emotional distress.

The following may also interfere with performance at school:

- Sensory problems (eg deafness)
- Specific learning difficulties (eg dyslexia)
- Attention-deficit disorder
- Motor disorders (eg cerebral palsy)
- Autism in children of normal intellectual ability.

Malnutrition, extreme social deprivation, or chronic medical illness can cause developmental delays. Most causes of learning disabilities cannot be cured. The more common, treatable causes of learning disability include hypothyroidism, lead poisoning, and some inborn errors of metabolism (eg phenylketonuria).

Essential information for patient and family

- Early training can help a person with learning disability towards self care and independence.
- People with learning disability are capable of loving relationships and have the same needs as any other person for love, security, play, friendship, clear boundaries and limits on behaviour.
- The person's intellect and skills must be accurately assessed, so that key learning needs are determined and they are helped to attain the appropriate level of independence, and use appropriate support services where necessary. The functional assessment should match the realistic social expectations.

- Sudden changes in behaviour may indicate physical illness and the need for medical examination.

General management and advice to patient and family

- Reward effort. Allow disabled children and adults to function at the highest level of their ability in school, work and within the family.
- Teach the same set of social rules as to other children.
- Advise families that learning and practising skills will be helpful, but that 'miracle cures' do not exist. It is usually impossible to predict, at diagnosis, how a child with learning disability will function as an adult. However, with careful long-term follow-up, it does become clearer what an individual may attain, in terms of independence and need for support.
- Families may feel conflicting emotions - intense love, disappointment, anger, great loss - and may take time and continuing support to adjust to being the parent of a child with learning disability and to deal with the different life stages and transitions (eg leaving school, employment, social life and sexuality, death of parents). It may be helpful to talk things through with someone who has the same experiences (see [Resources for patients and families](#)). Preparing a transition plan that involves the young person, their family and relevant services is good practice for when they leave school, whether or not the child has a statement of special educational need.
- Inform families that people with learning disability frequently under-report illness. Arranging regular health screening can be useful actively to seek out treatable sensory disorders, depression, obesity, skin infections, diabetes and other conditions. It is valuable to review health care at times of transition (eg school leaving) and of family illness. Creating a health action plan is one recommended way to be proactive in maintaining health (ref 264).
- Primary care teams should make a regular slot (eg every six months) to review patients with learning disability, and keep a recall register. There is evidence that these patients have health needs that are only detected by this kind of proactive contact.
- Encourage the patient to see the same doctor and nurse at every planned appointment, if possible, in order to build trust and reduce problems in communication.
- Invite a carer to come too; carers who know the patient well are invaluable as informants.
- Allow extra time for the appointment so that communication and examination can occur at a pace that suits both staff and patient.
- Use additional user-friendly literature to prepare the patient for examinations such as well-woman checks (see [Resources for patients and families](#)).

References

264 Action for Health, DoH publication about Health Action Plans, available from the Department of Health, PO Box 777, London SE1 6XH, UK.

Medication

- Except in the case of certain physical or psychiatric disorders, medical treatment cannot improve cognitive function.
- Careful treatment of psychiatric problems can substantially improve functioning, by promoting improved concentration and learning. It is helpful to review social networks and social support in addition to other treatment.

- Learning disability can occur with other disorders that require medical treatment (eg seizures, cerebral palsy and psychiatric illness such as depression).
- A good rule regarding psychiatric medication is to 'start low' (dose) and 'go slow' (increasing dose) to avoid polypharmacy.
- Unnecessary medication should be avoided, and medication reviewed regularly, because side-effects and idiosyncratic reactions are common. People with learning disability underreport side-effects; therefore consideration should be given to proactive checks (eg blood levels of anticonvulsants).

Referral

Referral to a community paediatric team or learning disability services (depending on local arrangement) is advised when the learning disability is first identified, to help plan for education and specialist care. Psychiatrists specializing in learning disability may be skilled in investigating and treating epilepsy as well as psychiatric illness.

Referral for specialist support is also indicated:

- where there are significant changes in behaviour, which persist for longer than one month
- where there is significant weight change which persists for longer than one month, to exclude emotional or psychiatric disorder
- following the death of a carer or close relative, because there is increased risk of pathological grief.

For further information about learning disability, see Once a Day NHS Executive guidelines for primary healthcare teams, March 1999. Department of Health, PO Box 410, Wetherby LS23 7LN.

Resources for patients and families

Association for Spina Bifida and Hydrocephalus (ASBAH) 01733 555 988 (9am–5pm Monday - Friday). Website: <http://www.asbah.org>

Down Syndrome Association

020 8682 4001 (10am–4pm, Tuesday–Thursday)

Email: info@downs-syndrome.org.uk; website: <http://www.downs-syndrome.org.uk>

Information and support for people with Down syndrome and their families.

Mencap <http://www.mencap.org.uk>

England and Wales: 020 7696 5593 (information line)

Northern Ireland: 0345 636 227 (family advisory service line)

Information and support for people with a learning disability and their families in the UK. Provides residential, employment, further education and leisure and holiday services.

Scope 0800 626216 (helpline)

Website: <http://www.scope.org.uk>

Information, emotional support and support groups for people with cerebral palsy and their families. Only some people with cerebral palsy have learning disability in addition to their physical disabilities.

Contact a Family 0808 808 3555 (helpline 10am–4pm, Monday–Friday)

Website: <http://www.cafamily.org.uk>

Works across the UK to support families caring for children with any disability. It is particularly useful where there is a rare condition.

Circles Network 01788 816 671

Website: <http://www.circlesnetwork.org.uk>

Provides information on setting up circles of friends and circles of support to help people with a learning disability have a more interesting social life.

I CAN 0870 010 4066

Email: info@ican.org.uk; website: <http://www.ican.org.uk>

National educational charity for children and young people with speech and language difficulties.

Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD) 020 7607 8851

Website: <http://www.spod-uk.org>

An online resource exploring the issues of personal and sexual relationships of people with a disability

Benefits Enquiry Line 0800 882 200

For information about Social Security benefits for disabled people.

The Family Fund 0845 130 45 42

Website: <http://www.familyfundtrust.org.uk>

An independent organization helping families caring for a child with severe disabilities. They may help pay one-off costs such as holidays and washing machines.

Leaflets are available from the Royal College of Psychiatrists (<http://www.rcpsych.ac.uk>):
Depression in People with Learning Disability, and Patient's Rights and Monies

Leaflets are available from the Mental Health Foundation, tel: 020 7802 0300; website: <http://www.mentalhealth.org.uk>: Learning Disabilities and the Family: the Young Child with Learning Disabilities, and Learning Disabilities and the Family: the Teenager with a Severe Learning Disability.

Books Beyond Words is a series of picture-books for adolescents and adults who cannot read. They can be used by parents, carers, GPs, nurses and others to help communication about important topics. Titles include Feeling Blue, about depression, Going to the Doctor, Going to the Hospital, Going to Outpatients, Keeping Healthy Down Below, When Dad Died, Making Friends. The Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG; tel: 020 7235 2351; website: <http://www.rcpsych.ac.uk/publications/index.htm>

The Foundation for People with Learning Disabilities produces the information booklets Get Moving (for people with learning disabilities who are thinking about leaving home), Leaving Home, Moving On (to help parents who are planning leaving home with their son or daughter), Learning Disabilities and The Family: The Young Child, Learning Disabilities and The Family: The Teenager. Publications, The Mental Health Foundation, 83 Victoria Street, London SW1H 0HW, tel: 020 7802 0301; Email: fpld@fpld.org.uk; website: <http://www.learningdisabilities.org.uk>.