

Management of erectile dysfunction in adult men with learning disabilities and diabetes

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Article points

1. People with learning disabilities are at higher risk of diabetes and complications, including erectile dysfunction (ED), because of health needs that often go unrecognised and unmet.
2. Diagnosis and management of ED in people with learning disabilities is challenging for healthcare professionals.
3. Collaboration between the person with a learning disability and primary care, diabetes and ED services and specialist community learning disability teams is vital.
4. A case study is presented to highlight issues with diagnosis and management of ED in a man with a learning disability.

Key words

- Diabetes
- Erectile dysfunction
- Learning disability

Authors' details can be found at the end of the article.

The effective management of obesity, diabetes and associated complications, such as erectile dysfunction (ED), in people with learning disabilities is an important and evolving area. ED may be poorly recognised and poorly understood by people with learning disabilities, making diagnosis and management challenging for healthcare professionals. Partnership working between the primary care team, community learning disability team and diabetes specialist nurse is essential to ensure that individual health needs are identified and addressed. This article provides an overview of the health needs of adults with learning disabilities and the evidence relating to diabetes and ED. It uses a case study approach to highlight issues relating to the assessment and management of ED as experienced by a man with learning disabilities.

The prevalence of type 2 diabetes across the UK is increasing – a situation that is predicted to continue (Diabetes UK, 2011). Type 2 diabetes is associated with a range of long-term complications that have significant implications both for the individual and for health services (Zimmet et al, 2003). Key risk factors for the development of type 2 diabetes are age, obesity and poor diet; however, the development of complications can be reduced by effective self-management that includes diet and exercise.

Early diagnosis of type 2 diabetes is vital in reducing the risk to the individual of developing long-term complications and reducing costs to

the NHS from treatment of the complications (Streets, 2001). The UKPDS (UK Prospective Diabetes Study) showed that good control of both type 1 and type 2 diabetes reduces the risk of developing complications (UKPDS Group, 1998). The Department of Health (DH; 2011) suggests that people with learning disabilities have the same predisposition to diabetes as the general population, but the presence of other risk factors, such as weight management and communication difficulties, results in delayed diagnosis.

The challenge for healthcare professionals (HCPs) is to diagnose diabetes as early as possible at routine health checks and to deliver

education in a manner that is understood by this group on a one-to-one basis. Diabetes education should be delivered by all members of the primary healthcare team including GP, diabetes specialist nurse (DSN) and practice nurse. Additional support can be provided by the community learning disability team (CLDT) as appropriate (Slevin et al, 2007). It is crucial that diabetes education is targeted not only at the person with a learning disability but also at his or her carers, family and support workers.

Complications of diabetes

There is a wide range of complications associated with a diagnosis of diabetes. Duration of diabetes, glycaemic control and hypertension are the strongest risk factors for microvascular disease, while smoking, hypertension, dislipidaemia and albuminuria are the strongest risk factors for macrovascular disease (Marshall and Flyvbjerg, 2006).

Persistent hyperglycaemia is known to cause serious damage to organs and tissues in people with diabetes (Kikkawa, 2000), resulting in long-term complications including retinopathy, neuropathy, nephropathy, stroke, cardiovascular disease and erectile dysfunction (ED). While improving self-management can reduce blood glucose levels and blood pressure, patients can experience difficulties with lifestyle changes (Coates and Rae, 2006).

ED affects at least 50% of all men with diabetes at some point in their life (Lue, 2000). It is suggested that ED could be the first sign of cardiovascular disease in men with diabetes. There are many risk factors that contribute to the development of ED in men with diabetes (*Box 1*). It should be possible to investigate the majority of men who present with ED, and manage them, in primary care.

Management of ED

NICE (2009) guidance suggest that men with diabetes should have their ED status assessed annually, while the British Society for Sexual Medicine (BSSM; 2009) suggests that all men presenting with ED should have serum testosterone measured on an early morning blood sample (08.00–11.00). Hypogonadism

(low testosterone level) – a treatable cause of ED – may make phosphodiesterase type-5 (PDE-5) inhibitor therapy either less effective or not effective. Studies show that around 25% of men with type 2 diabetes have borderline testosterone levels between 8 and 12 nmol/L (normal range 10–30 nmol/L; Kapoor et al, 2007).

ED is defined as the consistent or recurrent inability to attain or maintain penile erection sufficient for sexual performance (Lue, 2000). ED is the most common sexual problem experienced by men with diabetes. It is thought that prevalence of ED may be as high as 60% in men aged over 60 years (Williams and Pickup, 2005). Indeed, an audit carried out in Edinburgh in 2006 showed that 51.1% of men with diabetes admitted they had a problem either obtaining or maintaining a penile erection suitable for sexual intercourse (Boyd, 2007). The audit also showed that the majority of men with ED (41.3%) waited up to 4 years before seeking treatment.

When a man with diabetes is referred to the ED clinic, an initial assessment should be conducted (*Box 2*) and treatment offered (*Box 3*).

Psychosexual therapy

Psychosexual therapy should be offered if the ED is of sudden onset and there is no medical reason for it. If the person is experiencing relationship problems, stresses at work or financial worries, counselling may be beneficial. Partners are encouraged to attend.

PDE-5 inhibitors

This therapy is available in tablet form and experience has shown that it is much preferred by patients. There are three different medications available, each with a different time–action profile. Dose titration is required with all oral agents and men with diabetes may require the highest dose. Patients should be made aware of possible side effects associated with the use of PDE-5 inhibitors; the most common are headache, facial flushing, dyspepsia and nasal congestion (Pearce et al, 2009). PDE-5 inhibitors are contraindicated with nitrate therapy and should be used with caution with alpha-blockers. For full details, see Summary of Product

Box 1. Risk factors for erectile dysfunction in men with diabetes.

- Poor glycaemic control
- Cardiovascular disease
- Diabetic peripheral neuropathy
- Renal disease
- Hypertension
- Hyperlipidaemia
- Hypothyroidism
- Hypogonadism
- Peyronie's disease – higher prevalence in men with diabetes
- Polypharmacy, such as with antihypertensives and antidepressants
- Lifestyle, such as weight, smoking and alcohol use
- Psychological, including depression and stress
- Pelvic trauma and surgery
- Relationship issues, including sexuality

Box 2. Initial assessment of erectile dysfunction (ED).

- Poor glycaemic control?
- Duration of ED
- Has ED worsened through time/suddenly?
- Has anything made the ED worse?
- Presence/absence of morning/ nocturnal erections
- Penile abnormalities (physical examination if appropriate)
- Medical history
- Current medications/previous trial of ED medications
- Relationship status
- Lifestyle issues, e.g. smoking, alcohol use
- Symptoms of hypogonadism and blood sampling (refer to endocrinology if results abnormal)
- Previous pelvic/urological surgery/problems (refer to urology if appropriate)
- Blood pressure measurement, heart rate, weight and BMI
- Previous cardiac history
- History of chest pain, tightness or breathlessness on exertion (refer to cardiology if reply is suggestive of cardiac problems)
- Education and psychological support

Box 3. Treatments for erectile dysfunction.

- Psychosexual therapy
- Phosphodiesterase type-5 inhibitors
- Constriction rings
- Intracavernosal injection of alprostadil
- Intraurethral application of alprostadil
- Vacuum erection devices



Figure 1. Constriction rings.



Figure 2. Intracavernosal alprostadil injection.

Characteristics (SPC) for sildenafil, tadalafil, vardenafil (Electronic Medicines Compendium [EMC], 2010a; 2011a; 2012).

Constriction rings

Constriction rings (Figure 1) can be used when other therapies are contraindicated. They may be useful when a man can achieve a good erection but is unable to sustain it. Constriction rings are placed at the base of a penile erection using an applicator. A ring can stay in place for a maximum of 30 minutes.

Intracavernosal alprostadil

Intracavernosal alprostadil is given in the form of injection into the corpus cavernosum (Figure 2). Injection sites should be rotated to avoid fibrosis. Alprostadil relaxes the smooth muscle in the penis, allowing blood to engorge the corpus cavernosum and thus produce a penile erection (Eardley et al, 1999). Doses require titrating until a grade 4 erection (penis completely hard and fully rigid) is achieved. Patients should be aware of possible side effects, including penile pain, pain while ejaculating, bruising and priapism (prolonged erection; EMC, 2011b).

Intraurethral alprostadil

Intraurethral alprostadil (MUSE®; Meda, Bishop’s Stortford) is administered via a sterile applicator (Figure 3), which releases a pellet of alprostadil in the urethra. Alprostadil is absorbed

via the urethra into the corpus cavernosum. As with intracavernosal alprostadil, doses of intraurethral alprostadil need to be uptitrated until a grade 4 erection is achieved, and men using this therapy should be aware of the side effects, which include penile pain, pain while ejaculating and priapism (EMC, 2010b).

Vacuum erection devices

Vacuum erection devices (Figure 4) can be used by men who are unable to achieve or maintain a penile erection. They enable the man to obtain an erection, which is maintained by a constriction band. Bands may stay in place at the base of the penis for a maximum of 30 minutes. Vacuum erection devices are useful for men who are attempting to straighten a Peyronie’s disease curvature.

Health needs of people with learning disabilities

A range of terminologies are used to describe people with learning disabilities, including “mental retardation”, “mental handicap”, “cognitive impairment”, “intellectual disability” and “developmental disability”. In the UK, the term adopted within government policy is “learning disability”, whereas internationally in the research literature the term “intellectual disability” is used (Scottish Executive, 2000; DH, 2001; Welsh Assembly Government, 2001; Department of Health, Social Services and Public Safety [DHSSPS], 2005). In this article the term “learning disability” has been adopted to reflect UK practice.

A learning disability is not a single condition: causative factors include genetic, biological and social determinants which result in developmental delay that is irreversible and lifelong and starts at or after birth. A learning disability may be described as mild, moderate, severe or profound and comprises the following elements (Scottish Executive, 2000; DH, 2001):

- Significant global intellectual impairment with a functional IQ <70.
- Impairment of adaptive behaviour.
- Onset during childhood.

The population of people with learning disabilities is increasing and ageing. Studies

show that many of these people experience poorer health than the general population, which contributes to their increased mortality (Lennox et al, 2007; Emerson and Baines, 2010). Comorbidity is common in this group, with many presenting with a range of mental and physical health conditions (Kwok and Cheung, 2007). Common physical health conditions include respiratory disease, oesophageal and gastric conditions, epilepsy, sensory impairments, cancers and obesity (Emerson and Baines, 2010). Mental illness, autism spectrum disorder and behavioural challenges are also common (NHS Health Scotland, 2004).

The prevalence of health conditions increases with age, and there is evidence of increased prevalence of diabetes in adults with learning disabilities compared with adults without learning disabilities (Haveman et al, 2011). There is also increasing recognition of the extent of the health conditions and associated long-term conditions, such as obesity and poor diet, among children, adults and older people with learning disabilities (Melville et al, 2006; Sohler et al, 2009; Rimmer et al, 2010). The increase in obesity appears to be an issue for people with Down's syndrome and is linked to poor diet and limited physical activity.

Evidence is emerging that environmental issues also play a part, and that obesity is more prevalent among those with mild or moderate learning disabilities living in less restrictive environments (Melville et al, 2006; Sohler et al, 2009). These health issues are important as government policy seeks to enable community independence and may result in an increased prevalence of long-term conditions in this population.

The distinct health needs of this population therefore need to be addressed proactively. If change is to be effected, interventions and treatments will require collaboration between people with learning disabilities, their carers and a range of health and social care practitioners (Gates, 2010; Royal College of Nursing, 2011).

Diabetes and people with learning disabilities

Major risk factors for type 2 diabetes, including high levels of obesity, poor diet,



Figure 3. Intraurethral alprostadil applicator.



Figure 4. Vacuum erection devices.

lack of physical activity and older age, are present in adults with learning disabilities; however, the evidence base remains limited (Rimmer et al, 2010). People with Down's syndrome are more likely to develop type 1 or type 2 diabetes compared with people without learning difficulties (Bergholdt et al, 2006) and it has been suggested that the non-Down's syndrome adult learning disability population may have a high prevalence of type 2 diabetes. There are currently no UK data on the prevalence of diabetes among people with learning disabilities (Emerson and Baines, 2010).

A study conducted in The Netherlands indicated that there was a higher prevalence of diabetes in the learning disability population than in the general population, a finding replicated in the Republic of Ireland (Straetmans et al, 2007; McCarron et al, 2011). In the Dutch study, rates of diabetes were 1.8 times higher in people with learning disabilities than in the general population.

The effective management of obesity, diabetes and associated complications in people with learning disabilities is therefore an important and evolving area, which will require attention in the future.

ED and people with learning disabilities

A case study describing the experience of a man with learning disabilities who presents to his GP with a range of physical symptoms is shown in Box 4. The aim is to highlight issues relating to

the assessment and management of diabetes and ED in people with learning disabilities. These issues are explored further below.

Practice-focused issues

Sexual expression, sexual relationships, marriage and children are a natural and often expected part of life experience. People with learning

disabilities have the same personal and sexual needs and rights as their non-disabled peers (Mental Welfare Commission for Scotland, 2010). Some may, as a consequence of their cognitive impairment, require additional assessment and support because of issues relating to communication, capacity and consent.

Communication

Communication between individuals or groups of people is very important for everyday life. It is the key to our existence and it is how we learn. Through communication we share feelings, thoughts and emotions, enabling inclusion and participation in society (Gratsa et al, 2004). Underlying cognitive deficits and the resulting learning disabilities can lead to problems with communication, which can be associated with mental illness (Royal College of Psychiatrists, 2003).

It is recognised that 50–90% of people with intellectual disabilities have communication difficulties (Gratsa et al, 2004). As a result, some people with intellectual disabilities can be excluded from aspects of daily life and be misunderstood, because of their individual communication needs. People with more severe and complex needs may not be able to use any of the recognised means of communicating and will be dependent on others to interpret their needs and choices. Many primary care health professionals may have difficulty in fully evaluating or understanding the complicated needs of people with learning disabilities.

Capacity and consent

Adults with learning disabilities expect to be asked whether they want medical treatment, and to have their decisions respected. They expect treatment to be given if they are not able to consent to treatment, such as if they are unconscious or have a severe learning disability.

The process of consenting to treatment is complicated by literacy problems, communication problems and unsubstantiated assumptions by HCPs, and may be further compounded by issues relating to capacity to consent to treatments and interventions (Arscott et al, 1999). People with learning

Box 4. Case study

Albert is a 35-year-old man with a mild learning disability living in his own tenancy. He attended his GP with a range of physical symptoms. Only after a number of consultations with the GP did it become apparent that Albert had sexual health issues. Albert appeared to have a poor level of understanding of his sexual physiology, anatomy and needs.

He was diagnosed with longstanding erectile dysfunction (ED). His GP prescribed sildenafil and referred him to the community learning disability team (CLDT) for assessment and education regarding his sexual needs and support with the use of and compliance with medication. To assist with this education, a cognitive assessment was completed by a clinical psychologist to establish the best way to work with Albert. The assessment identified that Albert had good verbal ability but his level of understanding did not match this ability.

The female community learning disability nurse (CLDN) completed a health needs assessment and established that Albert had grade III obesity, undiagnosed diabetes and a high serum cholesterol level. Albert's diabetes was unstable and he had a high carbohydrate intake with large volumes of lager and no regular daily exercise.

Albert's GP referred him to the local diabetes clinic for further assessment and treatment. Albert was assessed as requiring one-to-one support to access the clinic as he did not understand diabetes or any of the lifestyle changes required to manage his condition and prevent complications. The CLDN assistant supported clinic attendance and, along with the CLDN, was involved in providing education to help Albert understand the issues relating to management of his diabetes.

As part of the wider CLDN involvement, a sexual knowledge assessment was completed with Albert. This identified limited knowledge and experience of normal masturbation, sexual intercourse and relationships. Albert was keen to have a normal male/female relationship with sexual activity, and the issue of his ED therefore needed to be addressed.

Following discussion with Albert, and given the sensitivity of his clinical needs, access to a male CLDN was arranged to take forward the sexual health work. Albert was referred to the ED clinic run by the diabetes specialist nurse (DSN). Both CLDNs consulted and liaised with the DSN to agree the best way to support Albert.

Specialist sexual health information and advice was required in addition to specialist equipment and a small daily dose of tadalafil to enable Albert to achieve an erection and for normal masturbation to occur. Following a period of support, Albert was able to become aroused, achieve erection and masturbate to ejaculation.

Additionally, Albert accessed CLDT dietetics and occupational therapy to obtain support with his lifestyle changes in relation to healthy eating and diabetes, as well as support in the kitchen to build his skills in preparing and making appropriate meals.

disabilities present considerable challenges in understanding treatment options.

If an adult with a learning disability does not have capacity to consent, legislation such as the Adults with Incapacity (Scotland) Act (2000) (Scottish Executive, 2000) and the Mental Capacity Act 2005 (DH, 2005) provides the opportunity for adults who lack capacity to receive care and treatment. Incapacity refers to being incapable of acting, making decisions, communicating and understanding decisions or retaining the memory of decisions. Adults are always presumed to be capable of taking healthcare and social care decisions unless the opposite has been demonstrated (DHSSPS, 2007). For consent to be valid, the person making the decision must be:

- Capable of taking that particular decision (“competent”).
- Acting voluntarily and not under pressure or duress.
- Provided with information to enable the decision to be made.

Ensuring that consent is informed can be a major issue that may lead to people with learning disabilities being excluded and not being offered the treatment options available to others (Blackman, 2009). Some people with learning disabilities will be able to fully consent to treatment if adjustments are made to meet their individual needs, and all clinicians have a responsibility to ensure that they have the knowledge and skills to support decision-making.

In the case study, Albert’s capacity to consent to treatment was established by his GP, who referred him to the CLDT for further assessment and intervention (*Boxes 5 and 6*).

Education

Patient education is generally provided to people newly diagnosed with diabetes, often in group sessions, such as the DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) programme (Davies et al, 2008). Although Deakin et al (2005) found that people newly diagnosed with type 2 diabetes who attended group education in self-management had better clinical and lifestyle outcomes, group education sessions are not

suitable for some groups of individuals, such as people with learning disabilities.

It is vital that this group of individuals receives the same information about diabetes self-management as those without learning disabilities. Many HCPs may have difficulty in dealing with this issue. Barriers such as problems with communication and an individual’s level of understanding must be taken into consideration when planning a programme of care, and must involve the individual in his or her own diabetes management.

There are many resources available to assist with patient education, including a DVD and video developed by Diabetes UK entitled *Type 2 diabetes: Living a healthier life*, which provides good, clear information for people with learning disabilities (Diabetes UK, 2011). Education sessions should be extensive, possibly spread out over several sessions.

When education is being provided to people newly diagnosed with type 2 diabetes, ED should be discussed as a possible long-term complication of diabetes. Lue (2000) suggests that, when explaining that ED is a common complication of diabetes, HCPs should be clear about the definition, taking into consideration that not all men wish to achieve an erection solely for vaginal intercourse, or indeed have a female partner. Some men may wish to obtain an erection to enable them to masturbate. This may be the case for some men with learning disabilities. A multidisciplinary approach is required to deliver education that will enable the man to express himself appropriately.

Research

As the population of people with learning disabilities increases and ages, there is a need to develop the evidence base in relation to meeting their health needs effectively. At present the evidence base relating to diabetes in this population is limited. There is an opportunity to undertake studies to better understand the interventions that bring about effective management and minimise avoidable complications. A range of diabetes management programmes have been developed and targeted

Box 5. Multiprofessional assessment undertaken to identify care and support needs.

- Patient approach to GP for help with sexual health/erectile dysfunction
- Cognitive: undertaken by CLDT clinical psychologist
- Nurse-led sexual knowledge: female CLDN
- Health screening: female CLDN
- Confirmation of diabetes diagnosis: GP
- Erectile dysfunction clinic: DSN
- Nutrition: CLDT dietitian
- Healthy eating/skills learning/food preparation and cooking: CLDT occupational therapist

CLDN=community learning disability nurse;
CLDT=community learning disability team.

Box 6. Interventions provided to meet Albert's care needs (see Box 4, case study).

- Diabetes monitoring and review: diabetes clinic consultant and dietitian
- Facilitated health support to attend diabetes clinic and other health appointments: CLDN assistant
- Medication compliance issues highlighted by local pharmacist and GP
- Medication compliance issues resolved: CLDN and CLDN assistant
- Facilitated consultation at ED clinic: male and female CLDNs
- Individualised one-to-one sexual health promotion: male CLDN
- Ongoing psychological and general practical support: CLDNs

CLDN=community learning disability nurse; ED=erectile dysfunction.

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at the general population; these need to be modified for use with people with learning disabilities and their effectiveness within this population determined.

Provision of education for families and carers to identify the support necessary to maximise their contribution to the management of diabetes is another area of research. There are no studies specifically researching the impact of ED on people with learning disabilities, hence further investigation is needed to identify the approaches to treatment and psychological supports that are most effective in this population.

Conclusion

In the care of Albert, partnership working between the primary care team, community learning disability team and DSN was essential. It is not possible for HCPs working in general health services to develop all the skills necessary to work with people with learning disabilities (Scottish Executive, 2002). All HCPs must have a clearer understanding of each other's role.

The development of effective partnerships between practitioners and agencies involved in Albert's care and treatment was essential to ensuring that his individual needs were identified and addressed. This is important as health promotion and health screening services that are accessible to most of the population may be inaccessible to, and are often under-used by, people with learning disabilities (NHS Health Scotland, 2004). Promoting access to primary care and other specialised services, such as nurse-led ED clinics, is crucial if comprehensive health assessments are to be undertaken and clinical interventions delivered in a way that takes account of the needs of people with learning disabilities. ■

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