

# Working with people with intellectual and developmental disabilities who have diabetes

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## Article points

1. People with intellectual and developmental disabilities are thought to be at greater risk of developing diabetes, compared to people without these disabilities.
2. Despite this, little attention has been paid to improving health promotion, screening and structured education for these people and their family or carers.
3. The DESMOND programme has recently been adapted for people with an intellectual and developmental disability and their family and paid carers within the UK.

## Key words

- Development disabilities
- Education
- Intellectual disabilities

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**There is growing evidence to suggest people with intellectual and developmental disabilities are more likely to develop diabetes than those without. Despite this, it is a population that is frequently forgotten and little attention has been given to diabetes health prevention and promotion, diabetes screening and structured education in this group. There is also a great importance to educate family and paid carers to support them to help manage their diabetes. Furthermore, the question of whose responsibility it is to manage the person's diabetes within primary care should be discussed. This article will outline some exemplars of user-friendly diabetes educational resources and one specific structured type 2 diabetes education programme that has been adapted for adults with intellectual and developmental disabilities. Gaps in our understanding and clinical practice will be discussed, and readers will be offered practical solutions where they can tailor diabetes education for this group.**

**T**here is greater recognition of the increased prevalence of diabetes internationally and the impact this has on healthcare providers. A number of groups have been identified as more likely to develop diabetes, but often these groups are also more difficult to identify and engage with, making diabetes education a challenge. These groups include low-income people, people with chronic mental health problems, minority ethnic groups or immigrants who speak little English. Furthermore, people with intellectual and developmental disabilities can be forgotten about and marginalised.

## Definition of intellectual and developmental disabilities

Intellectual disability is a disability characterised by significant limitations in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability

originates before the age of 18 years (American Association of Intellectual and Developmental Disability, 2013). The term intellectual disability is synonymous with other terms used within the UK, such as “learning disability”. People with intellectual disability have a broad range of abilities and these abilities will significantly influence the way they interact with the community, the types of choices they have in their lives and the degree to which others support them.

Developmental disabilities are those that relate to:

*“differences in neurologically based functions that have their onset before birth or during childhood, and are associated with significant long-term difficulties”* (Graves, 2003).

As such, developmental disability is an umbrella term that includes intellectual disability, but also includes other disabilities that are acknowledged

during early childhood, such as cerebral palsy, epilepsy, fetal alcohol syndrome and autism spectrum disorders, which are often associated with intellectual disability, further adding to the complexity of an individual's physical and mental health needs.

### Prevalence of diabetes in this population

Anwar et al (2004) found that type 1 diabetes was more prevalent in individuals with chromosomal syndromes, such as Down's syndrome, Klinefelter's syndrome and Prader-Willi syndrome, due to the propensity for weight gain that is characteristic of these conditions. Extra weight, in particular around the girth, has been identified as contributing to insulin resistance and the consequent development of diabetes in this population (de Winter et al, 2009).

McVilly et al (2014), in a systematic review of the literature on intellectual and developmental disabilities, reported that this population was 2–3 times more likely to develop type 2 diabetes compared to the general population. The prevalence figures of diabetes varied between 3%–18% (average 8%) across studies, depending on the proactive health screening or checks that were undertaken. Taggart et al (2014) reported that there is a significantly higher prevalence rate and earlier onset of diabetes among individuals with intellectual and developmental disabilities as they are more likely to:

- Lead a more sedentary lifestyle.
- Undertake low levels of physical activity and exercise.
- Consume high-fat diets.
- Be prescribed anti-psychotic medication.
- Be obese.
- Be less likely to have health checks.

### Identification and diagnosis in this population

People with intellectual and developmental disabilities are not only identified as a vulnerable population, they can also be a “hard to identify” population. Some of the difficulties in identifying and engaging with this population include:

- Some people with borderline/mild intellectual and developmental disabilities may not be known to specialist services and their disability may not be recorded with their medical notes with the GP practice. This makes it harder for nurses and other healthcare professionals to identify if a person has a disability and then make “reasonable adjustments” (for example, longer appointment times, having user-friendly information available and inviting a family member/advocate to come along to the appointment; Turner and Emerson, 2013).
- People with intellectual and developmental disabilities have low levels of literacy skills and cognitive deficits in processing, re-calling and evaluating information. This will challenge how nurses present information about diabetes signs/symptoms, advising on blood glucose, weight, blood pressure, cholesterol, depression, medication and medication compliance, and lifestyle management.

In a UK-based study, Cardol et al (2012) reported that the detrimental impact of diabetes may be even greater for people with intellectual and developmental disabilities, due to their cognitive impairment and inability to understand the signs and symptoms of diabetes, as well as their limited capacity to communicate these symptoms effectively to healthcare professionals. For many people with intellectual and developmental disabilities, there is a greater dependency upon family and paid carers to recognise the signs and symptoms of diabetes and organise a health check with a nurse or GP. Several studies have

### Page points

1. Research has shown that there is a higher prevalence rate and earlier onset of diabetes among individuals with intellectual and developmental disabilities, compared to the general population.
2. This may be because people with intellectual and developmental disabilities are more likely to lead a more sedentary lifestyle, consume high-fat diets, be obese and be on anti-psychotic medication.
3. People from this group may also be hard to identify and diagnose as they may not be known to specialist services. Furthermore, due to low levels of literacy skills and cognitive deficit, nurses may find it challenging to present information about the signs and symptoms of diabetes, as well as key information about how to manage the condition.

#### Box 1. Resources for people with intellectual and developmental disabilities and diabetes

- *Type 2 diabetes – Living a healthier Life*. DVD on diabetes for adults with intellectual disabilities and diabetes: <http://www.diabetesdvd.org.uk>
- *Meet Pete the Pancreas*: <http://bit.ly/1KpnK6x>
- *Pictorial information about type 2 diabetes for people with a learning disability*: <http://bit.ly/1z91D2U>
- Easy-read booklet for people with type 2 diabetes: <http://bit.ly/1GB3MEI>
- Easyhealth.org.uk diabetes leaflets: <http://bit.ly/1JNxK8W>

**Page points**

1. For many people with intellectual and developmental disabilities, there is a greater dependency upon family and paid carers to recognise the signs and symptoms of diabetes and organise a health check with a nurse or GP.
2. The introduction of the Directed Enhanced Services in a number of areas across the UK, including in Northern Ireland, introduced yearly health checks to adults with an intellectual and developmental disability through their GP practice.
3. Access to education for family and paid carers regarding the prevention and self-management is vital.

found that adults with intellectual and developmental disabilities and diabetes are screened less often than is recommended by the national UK clinical guidelines (Taggart et al, 2013; Lennox et al, 2007).

The introduction of the Directed Enhanced Services in a number of areas across the UK, including in Northern Ireland, introduced yearly health checks to adults with an intellectual and developmental disability through their GP practice (McConkey et al, 2015). This has increased the potential for primary care professionals to identify those people with an intellectual and developmental disability who are at risk of developing type 2 diabetes, and also in diagnosing and managing those who have the condition. This ensures the person with an intellectual and developmental disability is progressing in the appropriate care pathway in order to either prevent the condition or treat accordingly. As these registers are now available in the GP practice, the population can be more easily identifiable. Diabetes nurses and other healthcare professionals are able to treat people with an intellectual and developmental disability and diabetes more effectively, providing medical treatment, weight management and support with their treatment plan. Nurses and other healthcare professionals, and also patients and their family/paid carers can also link in easily and effectively with their named Health Facilitator in their GP practices.

**The role of education**

Access to education for family and paid carers regarding prevention and self-management is vital. Several studies have found that paid carers in residential accommodation and day-centres have limited knowledge of healthy dietary intake and undertaking health promotion activities (Melville et al, 2009; Hanna et al, 2011). Both family and paid carers who are educated in these areas can help to educate and empower the person with an intellectual and developmental disability to be aware of the risk factors for type 2 diabetes and modify their lifestyle behaviours (Taggart et al, 2014). User-friendly accessible literature can be used to supplement this explanation (see *Box 1*). Shoneye (2012) emphasised that role-modelling behaviour is important in order to foster a culture of peer and carer support for healthy eating and physical activity. This ensures that individuals with intellectual and developmental disabilities do not feel isolated and are supported

and encouraged to engage in changing their lifestyle behaviours.

People with intellectual and developmental disabilities often have poor access to information about diabetes in a format appropriate to their level of understanding, although there are now some good user-friendly, easy-read literature resources available for downloading (see *Box 1*). A local Health Facilitator working with adults with intellectual and developmental disabilities and their carers in Northern Ireland has developed and published an easy-read, user-friendly information booklet on type 2 diabetes that provides pictorial information about this condition (see *Figure 1*). It provides diabetes education in a simple, clear manner using pictorial information to give another dimension in understanding. The book focuses on:

- What is diabetes?
- Symptoms.
- Management.
- Hypoglycaemia.
- Hyperglycaemia.
- Insulin.
- Diet.
- Exercise.
- Complications.

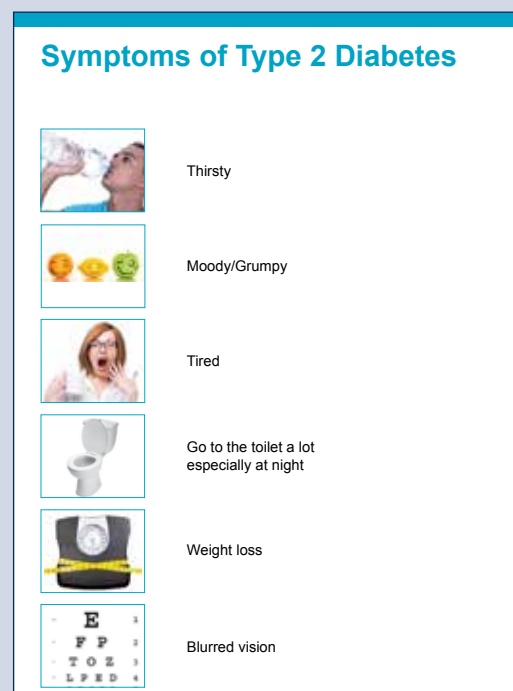


Figure 1. A page from a booklet designed for people with diabetes and intellectual and developmental disabilities

- Eye care.
- Foot care.
- Annual check-up.

### Structured diabetes education

The aim of structured education is for people with diabetes to improve their knowledge, skills and confidence, enabling them to take control of their own condition and integrate effective self-management into their daily lives. High-quality structured education can have a profound effect on health outcomes and can significantly improve quality of life for individuals with the condition. Diabetes education must be flexible enough to suit the needs of the individual, including cultural, linguistic, cognitive and literacy needs. There has been a great emphasis on the need for structured education programmes for type 2 diabetes. However, structured education programmes aimed at helping people to self-manage their diabetes are not targeted at people with an intellectual and developmental disability, despite this being identified by NICE guidelines as “best practice” (NICE, 2004).

DESMOND (Diabetes Self-Management for Ongoing and Newly Diagnosed) is a UK national structured education programme designed for people with type 2 diabetes. It runs over 6 hours and supports people to find more information about type 2 diabetes. It is a resource designed to help people to self-manage the changes diabetes will bring and it allows people with diabetes an opportunity to meet and share experiences with others. The DESMOND programme has recently been adapted for people with an intellectual and developmental disability and their family and paid carers within the UK. The adapted programme (DESMOND-ID) has been developed by researchers at Ulster University and funded by Diabetes UK (Taggart et al, 2015). This adapted programme has:

- Lengthened the timing of the sessions (12 sessions over six weeks).
- Simplified the core concepts within DESMOND.
- Greater use of pictorial representations (photos, pictures, symbols).
- More use of repetitious learning/interactive sessions.
- Stronger focus on developing skills and promoting “self-efficacy” in food choices and increasing physical activity.
- More involvement of carers to support the person

with an intellectual and developmental disability and diabetes (DESMOND-ID offers a separate session for these carers).

- Health action plans and goal setting, which are reviewed each week.
- A strong focus on celebration and fun.

### Preventing diabetes in people with intellectual and development disabilities

Given the higher prevalence rate of type 2 diabetes for people with intellectual and developmental disabilities and the identifiable risk factors as reported above, it is important to identify those most at risk of diabetes and, where possible, prevent this condition from developing. Taggart et al (2014) identified a number of areas where individuals with intellectual and developmental disabilities, their carers and also healthcare professionals could take responsibility to tackle these risk factors:

- **Reduction in obesity:** Obesity is a well-established risk factor for many health conditions in the general population, as well as for people with intellectual and developmental disabilities. Opportunities for targeting this high-risk group during annual health checks should be taken and appropriate lifestyle and behaviour modifications suggested using user-friendly resources (Taggart and Cousins, 2014).
- **Diet control:** Research indicates that a healthy diet in those with an intellectual and developmental disability is difficult to achieve. Some suggestions for improving diet include:
  - Reduce sugar intake.
  - Reduce fats and saturated food intakes.
  - Eat smaller portions of starchy carbohydrate foods, such as potatoes, rice and bread, which are converted into glucose (sugar) when digested.
  - Eat the five recommended daily portions of fruit and vegetables.
  - Eat smaller portions of food.
  - Monitor calorie intake.
  - Increase weekly intake of oily fish per week.
- **Promote activity:** Many people with intellectual and developmental disabilities do not engage in the recommended physical activity. All people with intellectual and developmental disabilities should be educated on the benefits of physical activity and supported to engage in regular physical activity. Individuals can start by walking short distances and could be encouraged in order to build up to more

### Page points

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2. DESMOND (Diabetes Self-Management for Ongoing and Newly Diagnosed) is a UK national structured education programme designed for people with type 2 diabetes. It has recently been adapted for people with an intellectual and developmental disability and their family and paid carers within the UK.
3. It has been developed by researchers at Ulster University and funded by Diabetes UK.

**“Health checks are one approach to identifying at-risk individuals.”**

strenuous activity, such as taking longer walks and swimming.

- Stopping/reducing smoking: There are a growing number of nicotine-replacement therapies commercially available, such as patches, inhalers and gum; the advice of the individual’s GP should be sought before purchasing these alternatives.
- Reducing blood pressure and high cholesterol: Reducing obesity levels, being more active and eating a healthy diet (such as reducing salt intake, changing from saturated to monounsaturated fats, and reducing alcohol intake) will, along with medication, all help to reduce hypertension and cholesterol levels.  
In addition to the above, two other areas of health are also important in the management of diabetes:
- Compliance with medication regimens: Medication is a core part of the diabetes intervention plan, whether for reducing blood glucose, high blood pressure or high cholesterol. Therefore, it is important to ensure that the medication regimen is followed, as prescribed.
- Looking after circulation and feet: In order to prevent and diminish feet problems, it is important to lose weight, reduce blood pressure, reduce cholesterol and stop smoking. Annual feet examination and skin checks should be undertaken.

**Conclusion**

This paper has presented the evidence that people with intellectual and developmental disabilities are more likely to develop diabetes as a result of genetic factors, but are also more likely to develop diabetes as a result of a number of unhealthy lifestyle choices. There are some challenges in identifying people with intellectual and developmental disabilities within the healthcare system, yet as many of those people are at high risk of developing diabetes, they need to be recognised and approached; to do nothing is no longer an option. Health checks are one approach to identifying at-risk individuals. This article has also shown the number of encouraging educational resources that are currently available for diabetes nurses and other healthcare professionals to educate this population and their carers about better self-management. ■

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