

## Diabetes and People with Intellectual Disability

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### Intellectual Disability

Intellectual disability is present in 2.7% of the population<sup>(19)</sup>. For a person to have an intellectual disability, three conditions must be satisfied.

The person must:

- have an IQ below 70
- have deficits in at least two areas of adaptive functioning
- have the onset of disability before the age of 18 years<sup>(1)</sup>.

“Developmental disability” is another term used. It is “differences in neurologically-based functions associated with significant long-term difficulties”<sup>(1)</sup>. In 1998 half a million Australians were found to have developmental disability<sup>(3)</sup>. The two definitions, intellectual disability and developmental disability, are very similar.

Diabetes mellitus is present in this population, as in any other group of people. We do not know the exact prevalence of diabetes mellitus (DM) in people with intellectual disability (PWID) but it is likely to be higher than in the general population. Type 1 DM is up to 35 times as common in people with ID<sup>(2)</sup>. Type 2 DM is also common, but there is no reliable estimate of its prevalence.

### Diabetes and Prader-Willi syndrome

One syndrome associated with both ID and DM is Prader-Willi syndrome (PWS). Control of DM is difficult with this syndrome<sup>(15)</sup>. It is estimated that the prevalence of this syndrome is between 1 in 8 500 to 1 in 38 000 births. Once again, we do not know exact rates.

The prevalence of Type 2 DM in people with PWS syndrome has been estimated to be at 25%. The mean age of the onset of DM in PWS is at 20 years<sup>(5,6)</sup>.

PWS affects both males and females. It is a complex genetic condition and it is characterised by neurological impairments. These impairments cause altered patterns of growth and development and are associated with hyperphagia (excessive eating). The compulsion to eat can cause extreme obesity and premature death. Because overeating is universal in PWS and people appreciate hunger the same, but none of the areas of the brain associated with fullness are stimulated, we now consider it a disease of starvation rather than one of obesity<sup>(13)</sup>.

There are other health issues present in PWS besides extreme obesity. There are increased rates of morbidity and mortality<sup>(11)</sup>. Associated morbidities include failure to thrive as infants, respiratory problems, sleep disorders and short stature. Lifelong interventions by a multidisciplinary team (including a dietician to prevent excessive weight gain) are crucial.

Hyperphagia may not be the only obsessive trait found in PWS. There can be mood lability, impulsiveness, temper tantrums, inactivity, repetitive speech patterns and relative weakness in social skills and adaptive behaviour<sup>(15)</sup>. This combination of

factors added to the limitations found with cognitive difficulties cause significant social handicaps for people with PWS. They also cause problems in the management of DM.

Families are generally overwhelmed with such high levels of dependence and may need guidelines to help cope <sup>(18)</sup>. There is one report in the literature of a group home managing eight people with PWS successfully <sup>(14)</sup>. The home provided diet restriction and control, a monitored exercise program and a structured environment.

In Australia, we have multidisciplinary PWS clinics at the Mater Hospital in Brisbane, the Royal Children's Hospital in Parkville, the Royal Prince Alfred Hospital in Camperdown and Sydney Children's Hospital in Randwick.

### **Factors leading to DM in People with Intellectual Disability**

The factors predisposing people with intellectual disability to develop DM are the same as the general population – familial traits, obesity and lack of exercise <sup>(9)</sup>. We know that obesity is almost 4 times as common in this population compared with the general population <sup>(4)</sup>. People with ID tend to have a low socio-economic status, which is also associated with an increased prevalence of Type 2 DM <sup>(10)</sup>.

While exercise has been proven to be beneficial to this population, it is often difficult to establish it as a part of the lifestyle of a person <sup>(7, 8, 12, 16)</sup>. Many people need individual carers with them while they exercise <sup>(17)</sup>. Staffing levels, and therefore costs, may preclude this.









### **DM diagnosis in PWIDs**





In order to diagnose and review diabetes care, laboratories must perform blood and urine testing. This can be very difficult in people with intellectual disability. If the person has not been through desensitization procedures for blood testing, the laboratory should be contacted before the person with disability is taken for a test. The laboratory can arrange for an experienced phlebotomy team to do the collecting of necessary specimens.

Even so, the person with disability can be prepared for the procedure so the process is easier. The aim is for them to know what to expect. Carers as well as diabetes educators can go through practicing the steps of having a blood test with the client. Then they can see what the client can and cannot do. The educator or carer can then work through the difficult steps one by one. See table 1

**Table 1: What is a Blood Test?**

A blood test is when blood is taken out of your arm.

1	You go to the desk to tell them you have come	
2	You might have to sit and wait	
3	You will walk into the collection room and be asked to sit in a collection chair	
4	The nurse will ask your name and when your birthday is and will tell you what will happen	
5	You will put your arm on the side of the chair with your hand facing up	
6	A cord is put around the top of your arm	
7	Your arm will be cleaned with a cotton ball. This is cold and wet	
8	A needle is put into your arm. It might hurt	

9	Blood will go into the tube	
10	The cord will be taken off your arm	
11	The needle is taken out. It might hurt	
12	A cotton ball is put on your arm with sticky tape	

A bruise can develop where the needle was, but this goes away. It might also be sore.

### **Diabetes management and the impact of ID**

In the presence of intellectual disability, the management of diabetes is complex. Generally, the carer of the PWID takes most responsibility for the routine management of the disease. All carers, both families and paid carers, should be educated to know all the correct procedures in diabetes care as a part of their duty of care.

To highlight, here are some quotes regarding diabetes in PWID:

*“I feel very anxious but I don't let Marilyn see that”.*

*“Although Peter understands what he's being told about his diabetes - he chooses not to, and therefore will choose 'bad food' whenever he is not being supervised. Peter makes his own breakfast and will often eat 4 eggs and 8 slices of bread”.*

### **Diabetes management and support organisations**

Good care for people with diabetes is difficult to maintain in supported accommodation with high turn-over of staff. A medical management plan should be set up with the help of a GP for each person with diabetes. Then carers have a personalised list of the diabetes needs for each person:

- when to do blood glucose tests
- when to really watch food
- when not to be obsessive about food

- what to do about abnormal results
- when to call the doctor
- when to call an ambulance.

Carers should establish strong communication and support systems. All staff with responsibility for a person with diabetes should be educated in the basics of diabetes care. There is a lot of fear about diabetes expressed by carers looking after people with intellectual disability. They often think their knowledge is inadequate and training insufficient. This is often the case.

### **Educational strategies to assist the diabetes educator**

Perhaps the most important educational strategy for the diabetes educators is simply “getting to know the person”. This may be hard as it often takes a long time for a PWID to establish trust with a stranger, so patience is needed.

PWIDs can learn to self-care to his or her particular level of ability. This requires many repetitions during teaching. Each PWID has their favourite way of learning to do things. A person who knows them well and is trusted may be the best teacher, or may offer advice. The PWID will often then take great pride in performing those tasks.

Some hints for diabetes educators about teaching skills in diabetes care to people with intellectual disability are:

- Get to know the person you are educating.
- Communicate with them using their preferred style of communication
- Identify what the person can naturally do for themselves
- Identify how the person learns
- Discuss with the person as to what they would like to take responsibility for
- Know the key people who need to be involved – family, staff, and other health professionals.

### **Overview of website**

We describe a website we developed for people with intellectual disabilities and diabetes. It should be useful for their carers as well. The Queensland Centre for Intellectual and Development Disability produced the site. Diabetes educators may find it is a supplement to other resources. It was developed after canvassing the sector to find the needs of the population.

The website is divided into two main menus – one for the person with disability in plain English and large print. See Table 2 for details. The other menu caters for the carers and is at a higher language and educational level, but is still “to the point”. The site follows the recommendations made by people in the disability sector – no jargon, to the point, it is about communication, and it acknowledges needs. The website is reviewed regularly by an endocrinologist from Royal North Shore Hospital and is kept up to date. It is receiving about 850 hits a month. It is the only functioning site on the web about diabetes for people with intellectual disability – a tough combination.

As one person with disability said:

*“I wish I didn’t have it”.*

Table 2: Menus on Diabetes Website

<http://www.sph.uq.edu.au/diabetes/index.asp>

### ***For Person with Disability:***

#### **Clinical issues:**

1. What is diabetes?
2. Impaired GTT
3. Type 1 diabetes
4. Type 2 diabetes
5. Blood glucose test
6. Low and high blood glucose levels
7. Visiting the doctor
8. Doctor's appointments

#### **Living with Diabetes:**

9. Diabetes medical management plan
10. How diabetes makes you feel
11. Who do you tell?
12. Your meals
13. Exercise
14. Medication
15. Sick days

### ***For Carers:***

#### **Clinical Issues:**

1. Types of diabetes and daily management
2. Blood glucose tests
3. Low blood glucose levels
4. High blood glucose levels
5. Insulin
6. Medical appointments
7. Long term complications

### **Caring for someone living with disability and diabetes**

8. Diabetes medical management plan
9. Privacy, understanding and effects of diabetes
10. Consistent management
11. Food and shopping list
12. Exercise
13. Diabetes and sick days
14. Holidays
15. Increasing independence
16. Foot and eye care

#### **How the diabetes website should be used**

The website for PWIDs with DM is at [www.sph.uq.edu.au/diabetes](http://www.sph.uq.edu.au/diabetes).

The site has two modes of use – straight off the web or as a hard copy. The site has been designed so individual sections e.g. the medical management plan, can be

downloaded and printed. To print the section you want, click on the printer icon on the page, go to “file” on your computer, then “print.” This gives the best form of hard copies.

The most important page on the site is the Medical Management Plan. This is found at <http://www.sph.uq.edu.au/diabetes/carers/carersDMMP.asp>

This page requests the carer to take the person with disability, with a copy of the plan, to their GP to obtain the correct information about each person and their diabetes management.

Some of the details to be filled out by the doctor in the medical management plan include:

- Type of diabetes
- When to call the doctor
- When to call the ambulance
- The ranges for low, ideal and high blood glucose levels
- If the person is at risk for hypoglycaemia
- The probable symptoms of hypoglycaemia for each person.

The advantage of this list is about the individual. Idiosyncrasies and individual responses are documented. In the disability population where there is high rotation of carers in supported accommodation, such a document is very useful.

The carers can use this plan as a guide in all their decision-making. We hope with such a resource the inadequacy and fear experienced by carers can be minimised. A trial of the impact of the website showed a strong effect on carers. They improved to a statistically significant level of knowledge in three key areas:

- the correct procedures of blood glucose measurement
- when to get professional advice
- establishing systems for passing on information to other carers.

In this trial the website was used for only one month. Interestingly, people preferred to use it in its hard copy form – they printed out the document from the web. People with disability said they enjoyed the drawings on the site the most.

Anyone can have access to the diabetes website, and the cost of a copy is negligible, an important issue for people generally from a lower socio-economic group. It is not known if the site is widely used by the disability sector. Knowledge of such services often travels best by word of mouth, and it takes time for the word to spread.

### **Summary**

Diabetes occurs in about 3% of the general population. Intellectual disability also occurs in about 3% of the population. Sometimes the two occur in the same person. Support for this population with two demanding conditions is needed.

Diabetes educators have the responsibility to teach this population to manage their diabetes as effectively as other populations, despite the additional challenges. This may be by teaching the person with disability or their carer, or preferably both. Some extra help can be obtained at [www.sph.uq.edu.au/diabetes](http://www.sph.uq.edu.au/diabetes)

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