



Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



DIABETES Entry

Organisations who wrote / approved the information

Diabetes Australia Victoria & Royal Children's Hospital

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DIABETES

A: FACTS ON THE CONDITION

1. General description, including different types, causes, prevalence, signs and symptoms

Around one in 700 Australian children has diabetes. Diabetes is an endocrine disorder where the body is unable to use blood sugar (glucose). Type 1 diabetes usually occurs in childhood and young adulthood, although it can occur at any age. Most children and young people with diabetes have Type 1 diabetes otherwise known as insulin dependent diabetes mellitus. In order to use glucose for energy the hormone insulin needs to be secreted by the pancreas. People with Type 1 diabetes or IDDM are unable to produce insulin and require its replacement by injection. Type 1 diabetes is NOT caused by lifestyle factors.

Symptoms of Type 1 Diabetes include:

Excessive thirst

Frequent urination

Hunger

Unexplained weight loss

Fatigue /lethargy/general feelings of weakness in the body

Nausea and vomiting.

2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines

The treatment for type 1 diabetes is lifelong insulin injections each and every day of the student's life.

While there is no cure for diabetes, it can be successfully managed with insulin replacement, regular monitoring of the blood glucose levels, dietary modifications that include a disciplined eating plan and exercise. Usually a student is able to inject insulin at home before and after school, but occasionally it is required more frequently. Similarly, students will need to check their blood glucose at some time during the day and this may or may not be at school.

While some students with Type 1 diabetes, require regular snacks throughout the day, all require a regular consistent food intake. Too much insulin, exercise without food, or missing a meal may result in low blood glucose levels (hypoglycaemia). Ideally a student should have lollies, fruit and or a source of carbohydrate (biscuits) on hand to treat "hypo's". If a "hypo" results in loss of consciousness it is an emergency and medical treatment is urgently required. In this instance NO attempt to feed the student should be made as they might choke. High glucose levels (hyper glycaemia) can occur when more food than usual, is eaten, or not enough insulin is taken. Stress, common viral infections and lack of exercise can also produce high blood sugar. If hyperglycaemia persists for some time acidic ketone bodeies appear in the blood and urine. Once ketones are present the situation can become a medical emergency if left untreated

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B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON

1. Effects on the individual

Students with diabetes may require a range of equipment at school, such as blood glucose monitors, syringes, insulin pens and insulin pumps. They may also be snacking at times when others are not. This may leave them open to curiosity from other students. It may also mean that if teachers are not aware of the need for such equipment it is confused with more sinister objectives and confiscated. Sometimes, well-meaning teachers or peers leave them out of class parties or don't know when birthday cake is being handed around. Students with diabetes have stories about being given detention for having lollies or being called 'drugies' by peers. They feel singled out or as though they are under constant surveillance.

If a student is to self-manage his/her diabetes successfully, he/she requires an understanding environment and it is often the case that they are the ones who have to initiate it by teaching their peers and their teachers about their self-management needs. Self-management means being able to monitor blood glucose level, administer insulin and eat when necessary even it is in the middle of school activities. A student with diabetes needs to be assertive; this may be difficult, given that many young people do not want to draw attention to themselves. A student with diabetes must practise self-assertion, while continuing a punishing daily routine of health care, sometimes feeling unwell and emotionally stressed. However, without a level of assertion, students are likely to lose the impetus to maintain a routine and this will mean that their health will suffer. More frequent "hypos" may lead to more frequent episodes of embarrassment and school absences.

2. Effects on those close to the child/young person

Parents of children and young people with diabetes report the gamut of feelings experienced by all parents. However, their feelings of joy, frustration and pride in their children are tempered by the need to ensure their children are safe and to assist their children to grow into self-managers of their own health. Fear of how a child will cope in the rough and tumble environment of school means that parents also need to learn constructive assertion techniques to advocate on behalf of younger children and to be effective role models for older children.

The school visiting program of Juvenile Diabetes Research Foundation (JDRF), Melbourne Chapter recommends that parents spend time educating the staff at their child's school. Basic information about Type 1 Diabetes should be provided to all staff including office and ground staff. Staff must know appropriate emergency care and parents need to know that school staff think they are well-informed but are in fact complacent. The JDRF program suggests that parents provide the school with printed information, an action/emergency plan and a photo of the child, so that casual and replacement staff have some means to identify the student. If a problem arises, no matter how trivial, a parent should make an appointment to speak with the classroom teacher to explore mutually satisfactory solutions.

3. "In Their Shoes" - stories from children/young people with the condition

'...I knew I'd have to go on the injections eventually. Even then I thought it would only be one or two needles a day, when I went in there one day the doctor said to me, "You need four injections a day starting today." It was devastating. I knew it was coming but it was so hard.

... At first they gave me a long needle bit I cut up a bit. It freaks you out. It's not difficult but at first it's very painful. Sometimes just pushing the needle in hurts the most. You think to yourself, this hurts so why am I doing it? It's like punishing yourself because you're hurting yourself.

... In a way it's just an inconvenience now. For instance I have to eat certain foods at certain times, which is pretty hard to get used to. I'm not scared any more but I do get sick of it. Sometimes I think, bugger it, I can't be bothered. But you just do it, you get angry with it, then you get over it. The injections still hurt sometimes but it's just something I have to do.

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... In a way things are getting back to normal. I hated school before the diagnosis mainly because my self- motivation wasn't there. Then I got the diabetes and I got really depressed and I just couldn't get myself to school. Now I am more energetic but I missed so much school that they said I would have to repeat year 9, so I refused and left. I'm going to study at the Gordon Institute of TAFE next year instead...'

Ross (15)

Extract from Different but the Same 1998, Ed Heather Cameron, Lothian Books Victoria, Australia.

C: STRATEGIES FOR SCHOOLS/TEACHERS

1. Overview of strategies for schools.

A whole school approach

Information to assist a school community to be well- informed regarding diabetes is available from Diabetes Australia Victoria, the Juvenile Diabetes Research Foundation and the young person's Diabetes Nurse Educator. While the aim of students, parents and the school is that students self- manage their diabetes, schools should work with parents and the students to establish an emergency plan that includes emergency contact numbers, an action plan specific to the individual and the school's role in an emergency. This should be in accessible place.

As with all serious illnesses, establishing good communications and rapport between teachers, parents and students is a first step to ensuring that the student self- manages their diabetes and has someone responsible to call on in the event of needing help.

For younger children, a teacher may need to have knowledge of snack times as well as having on hand a supply of appropriate snack foods to assist in dealing with high or low glucose level episodes.

Teachers should also have knowledge of any medications that need to be administered during school times.

A safe environment for storage and administering medication should be available.

A student should be encouraged to approach a staff member if they feel that a "hypo" episode is likely.

2. Link(s) to useful other online resources for schools on strategies in responding to a child/young person with this condition

Victorian

The Royal Children's Hospital: http://www.rch.unimelb.edu.au/diabetes/index.cfm?doc_id=1107

Diabetes Australia Victoria: www.dav.org.au

Juvenile Diabetes Research Foundation: www.jdrf.org.au See Kids Online: Schools Section

Reality Check: www.realitycheck.org.au

The Injectors, a young persons support group: www.theinjectors.org

National

Diabetes Australia: www.diabetesaustralia.com.au/conquest/index.html

International

JDRF International: www.jdrf.org/publications/

International Diabetes Federation: www.diabetesvoice.com

Diabetes United Kingdom: www.diabetes.org.uk/magazines/index.html

Children with Diabetes, an USA based on-line community for kids, families and adults with diabetes, provides information, chat rooms and support: www.childrenwithdiabetes.com

The American Diabetes Association provides comprehensive information about all aspects of diabetes, including school -based diabetes care, and interactive opportunities to obtain on diabetes:

www.diabetes.org

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D: FURTHER INFORMATION

1. Organisations, including services and resources available

Diabetes Australia Victoria is a peak consumer organisation offering health promotion, written information, super market tours, advocacy, type 1 information and support worker and specific community based support groups, community networks, diabetes nurse educators, product for purchase, nutrition help and linkage to community based services.

570 Elizabeth street, Melbourne 3000

Tel: 1300566138 or 03 96671777

Email: mail@dav.org.au

Juvenile Diabetes Research Foundation provides a school visiting service to help school staff with the information and confidence to cope with students with diabetes. JDRF provides a brochure called "A child with Diabetes in your care" which is useful to teachers and others carers and a flip chart 'Diabetes Information'. There is also a range of other materials available for use in classrooms to explain diabetes to students.

Level 1, 141 Cecil Street, South Melbourne 3205

Tel: 03 96963866

Email: www.jdrf.org.au

Department of Endocrinology and Diabetes, Royal Children's Hospital Melbourne offers treatment and care for children, young people and their family members with Diabetes. Paediatric Endocrinologists and nurse educators help with all aspects of living with Diabetes.

Tel: 03 93455951

Flemington Road, Parkville 3052

The Centre for Hormone Research

Murdoch Children's Research Institute at the Royal Children's Hospital Melbourne conducts medical and scientific research into diabetes in childhood.

Tel: 03 93455522

Monash Medical Centre offers treatment and care for children, young people and their family members with Diabetes. Paediatric Endocrinologists and nurse educators help with all aspects of living with Diabetes.

Tel: 03 99288111

267 Centre Road East Bentleigh, 3165

Insulin Support Group Victoria

Provide information, support and advocacy for young people with insulin pumps. The contact person is Cheryl Steele

Tel: 03 93452658

Walter Eliza Hall Research Institute, Royal Melbourne Hospital Parkville 3052

Health Services Commissioner of Victoria

If you want to complain about a health service, bring a complaint against a health service provider and or make a complaint.

Complaints and information

30th Floor, 570 Bourke Street, Melbourne 3000

Tel: 03 986015200

Toll Free: 1800136066

www.health.vic.gov.au/hsc/info

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2. Reading, including links to downloadable documents

Caring for Diabetes in Children & Adolescents

http://www.wch.org.au/diabetes_manual/index.cfm?doc_id=2352

Through the Maze - A Guide to Benefits and Services for Families of Children with a Disability.
(3rd reprint of the 5th edition- February 2003) Association for Children with a Disability

590 Orrong Road, Armadale 3143

Tel: 03 95001232

Email: mail@acd.org.au

Internet: www.acd.org.au

Guthrie, DW, Bartsocas C. Jarroz-Chabot, P Psychosocial Issues for Children and Adolescents with Diabetes: An Overview and Recommendations. Diabetes Spectrum Vol 16,n1, 2003 pp7-12

Videos

Speaking From Experience -Young People with Diabetes. Personal perspective's on medical and social issues. This Victorian produced 41 minute video has parents and young people themselves offering candid accounts of their experiences surrounding diagnosis, management, insulin, lifestyle changes, hypo's, school and their thoughts for the future.

Contact speaking from experience Tel: Freecall 1800603333

Keep your life online- teenagers and young adults living positively with diabetes

http://www.rch.unimelb.edu.au/diabetes/index.cfm?doc_id=1107

Here we go 'round the Mulberry bush- positive parenting of toddlers with diabetes

http://www.rch.unimelb.edu.au/diabetes/index.cfm?doc_id=1107

TWO NEW VIDEOS DEALING WITH DIABETES IN SCHOOLS ARE CURRENTLY UNDER PRODUCTION AT RCH AND SHOULD BE AVAILABLE IN THE NEW YEAR (2004)