

# The continuous educational process for children and teenagers with type 1 diabetes in Slovenia

Nataša Bratina, Barbara Murn Berkopec, Ana Gianini, Tadeja Logar Dolinšek, Tadej Battelino

**In Slovenia, the current standardised incidence of type 1 diabetes is 14.6 per 100 000 children, with an annual increase of 3.77% and a falling average age of diagnosis. This article describes the multidisciplinary approach to diabetes education that has been developed in response to this. From diagnosis, a structured education process is provided not only for those diagnosed, but also for their family members and professional caregivers. The initial part of the programme is provided during a hospital stay when basic knowledge about the condition is shared and the family meets the diabetes team. Further education on insulin pumps, continuous glucose monitoring and diet takes place in outpatient clinics. Education is also provided for children starting school, at summer camps and at other annual meetings.**

Type 1 diabetes is a chronic autoimmune disease that typically develops in children and young people. In recent decades, the incidence of type 1 diabetes among children has been increasing in Europe by 3% to 4% per year with a clear shift towards a younger age group, as reported by Patterson et al (2009; 2012) and Radošević et al (2013). More and more countries are reporting an increasing incidence of newly diagnosed diabetes in children under 6 years of age, the rate of increase being as high as 6% per year. A report from Colorado, USA by Vehik et al (2009) supports this finding, while similar results have been found in Germany (Ehehalt et al, 2012) and in Slovenia (Krasevec, 2013).

The management of type 1 diabetes in children and adolescents is a big challenge for those individuals and their families, and for caregivers in nursery school and school environments. The *ISPAD* (International Society for Pediatric and Adolescent Diabetes) *Clinical Practice Consensus Guidelines 2009 Compendium* (Swift, 2009) is the most important educational tool in many

countries; Bratina and Battelino (2010) have written about diabetes management in schools and nurseries in Slovenia.

Insulin pumps and continuous glucose monitoring systems, in conjunction with carbohydrate counting and frequent blood glucose measurements, are helping people with diabetes to improve their metabolic control. Nevertheless, in many cases good metabolic control cannot be reached for a number of years. The reasons for this can be socio-economic, psychological or a lack of knowledge, while other contributory problems include a lack of support from nurseries and schools, and no reimbursement for insulin pumps or other equipment. Dovc et al (2014) recently reported on how, with proper education and modern technology, metabolic control has improved in Slovenia in the last 12 years. Nevertheless, there is still a lot to be done to make technology more available to people with type 1 diabetes, as we can see from studies such as INTERPRET (Nørgaard et al, 2013) or SWITCH (Battelino et al, 2012).

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## Article points

1. The management of type 1 diabetes in children and young people is challenging for those individuals diagnosed and their families.
2. Slovenia has developed a centralised continuous education process that starts at diagnosis.
3. The education is delivered by a multidisciplinary team to the individual diagnosed, their family and their professional caregivers, such as teachers, and is supported by written instructions.

## Key words

- Continuous education
- Multidisciplinary team
- Type 1 diabetes

## Authors

Nataša Bratina is a Paediatric Diabetologist; Barbara Murn Berkopec, Ana Gianini and Tadeja Logar Dolinšek are Certified Nurse Educators; and Tadej Battelino is Chief Executive of the Department of Pediatric Endocrinology, Diabetology and Metabolism, all at the University Children's Hospital, Ljubljana, Slovenia.

### Page points

1. Slovenia has a system of compulsory health insurance that covers medical equipment needed for the treatment of diabetes and a complete educational programme.
2. Owing to its small size, all children and young people newly diagnosed with diabetes start their treatment at the University Children's Hospital in the capital, rather than at their local hospital.
3. The same structured education programme is provided for children, their parents and the professionals caring for them in nurseries, schools and at sports activities.

### Facts about Slovenia

Slovenia is a small, mid-European country covering an area of 20 273 km<sup>2</sup>. It has 2 054 000 inhabitants, with a nominal gross domestic product of USD22 190 per capita (Statistical Office of the Republic of Slovenia, 2013). Slovenia has been a part of the European Union since 2004, and is geographically positioned between Austria, Italy, Croatia and Hungary.

In 1992, Slovenia passed healthcare legislation that introduced a system of health insurance that is compulsory for all citizens of the Republic of Slovenia residing within the country. As part of the insurance, the insured person is guaranteed to be reimbursed for health services received, to receive sick pay during temporary absence from work and to be compensated for travel expenses related to obtaining health services. Insulin pumps and glucose sensors are completely covered by health insurance, along with other medical equipment needed for the treatment of diabetes, and also the complete educational programme. This has had a positive impact on the delivery of diabetes care (Dovc et al, 2014).

As Slovenia is so small, children and adolescents with many chronic diseases and conditions receive centralised health care. For rare diseases and conditions, the main inpatient and outpatient centre is the University Children's Hospital (UCH) in Ljubljana, the capital city, which has complete medical teams taking care of children and adolescents with these conditions (Figure 1).

### Diabetes in Slovenia

The current standardised incidence of type 1 diabetes in Slovenia is 14.6 per 100 000 children, with a yearly increase of 3.77% (and 6% in children below 6 years of age; Patterson et al, 2009; 2012). Every year, up to 60 children are diagnosed with type 1 diabetes, with an additional five adolescents being diagnosed with type 2 diabetes. Obese children are screened for type 2 diabetes using the oral glucose tolerance test. Although the incidence of type 2 diabetes has not increased in the last 10 years, instances of insulin resistance and of impaired glucose metabolism have.

In the last 20 years, data from the Slovenian national type 1 diabetes register has shown that

children with the condition are being diagnosed at a younger age, with the average falling from 12.5 years to 8.77 years. Thirty per cent of the children entering UCH with a diagnosis of type 1 diabetes exhibit clear signs of diabetic ketoacidosis, while the rest have elevated blood glucose and signs of dehydration. The average duration of symptoms such as polyuria and polydipsia prior to diagnosis is 14 days. No deaths due to ketoacidosis have been reported since 1991 (Krasevec, 2013).

In 2000, continuous subcutaneous insulin infusion was introduced as a standard treatment for type 1 diabetes with public reimbursement. Currently, more than 80% of children use insulin pumps and 10% are also using continuous glucose monitoring systems, with cost reimbursement for children below the age of 7 years (the sensor use in this age group is more than 30%). The average metabolic control for all individuals is good (HbA<sub>1c</sub> 62 mmol/mol [7.8%] in 2012), and the acute complications rate, such as severe hypoglycaemia and ketoacidosis, is low (Dovc et al, 2014).

Parents and medical teams from all over Slovenia have access to a 24/7 emergency telephone line that provides support and advice in critical situations, and helps to stabilise children with newly diagnosed type 1 diabetes in readiness to travel to UCH. Support and consultations are offered for patients, families, caregivers and primary healthcare paediatricians.

### Medical care for children with type 1 diabetes

Since 1991, all children and young people from Slovenia who have been newly diagnosed with type 1 or type 2 diabetes (currently around 650 individuals) start their treatment at UCH, rather than at their local general hospitals. UCH can be reached from any part of the country within an hour by bus, car or train, and this centralised approach means that all receive the same care, education and support.

Organisation of the medical treatment and support is well designed. Following diagnosis, children or adolescents with diabetes and their family members stay in the hospital for 5 to 7 days for educational sessions about diabetes. After that, most of the medical care up to the age of 25 is based



Figure 1. A view of Ljubljana, the capital city of Slovenia. After diagnosis with diabetes, all Slovenian children and young people start their treatment at the University Children's Hospital.

*“Parents and children attend a structured educational programme for 5 days following diagnosis.”*

at the outpatient clinic at UCH.

A multidisciplinary team, including paediatric endocrinologists, certified nurse educators, psychologists, dietitians and a social worker, provide care for children, adolescents and young adults with type 1 diabetes. The same structured education and management plan is provided for children and their parents, as well as for professionals caring for children with type 1 diabetes in nurseries, schools and at sports activities.

### Steps in the structured education process

The education provided at each of the main stages in the continuous programme are outlined below.

#### 1. At diagnosis

Parents and children attend a structured educational programme for 5 days following diagnosis. Children stay in the hospital during this period in order to stabilise their blood glucose and their insulin treatment. Children below the age of 3 years start insulin pump

therapy immediately. In the educational sessions, families meet the dietitian and psychologist to discuss dietary habits and emotional difficulties. Support is offered and a dietary plan created. Certified nurse educators lead parents through all aspects of diabetes care, including blood glucose measurements, insulin dosage and injections, hypo- and hyperglycaemia, sick days and sports activities. A plan for the child's nursery or school is prepared and signed by all members of the team.

#### 2. Commencement of pump therapy

Technical education is provided during outpatient clinic visits and is organised by the pump providers. Medical education is also delivered during outpatient appointments. Information about carbohydrate counting provided by dietitians is complemented by practical sessions with specialist diabetes nurses. Nurse educators again discuss the right steps to take in the event of a hypo- or hyperglycaemic episode, along with the early recognition of ketoacidosis.

***“In recent years, more than 300 teachers and other caregivers per year have come to learn about diabetes on a 1-day course, where they meet all members of the medical team.”***

### **3. Start of continuous glucose monitoring**

Proper insertion of the sensor is discussed, along with its correct calibration and the use of different alarms. Again, technical education is given separately, with supplementary written instructions being provided. Parents are advised to activate the alarms on the insulin pump in a gradual, stepwise way; initially, just the “suspend” alarm is selected. If parents are nervous of inserting the sensor at home, they return to the hospital 6 days later for another sensor insertion, and also for the data from the pump to be downloaded. Otherwise, they come back after one month to see the first sensor download.

### **4. Education for teachers and other professional caregivers**

Education for teachers and other professional caregivers has been provided on an individual or group basis for 10 years. In recent years, more than 300 teachers and other caregivers per year have come to learn about diabetes on a 1-day course, where they meet all members of the medical team. Topics that are discussed include general facts about diabetes, diet, psychological burdens, emergency situations, practical and theoretical sessions on blood glucose measurement, pump treatment, sensor use and insulin pen injectors. Telephone support is offered, as well as extra technical education for different devices. Most popular are the group sessions at the beginning of the school year in late August.

### **5. Education for school starters**

Children who are soon to enter the school system are invited to a half-day session where they learn about diabetes with the hospital teacher and certified nurse educators. At the same time, their parents consider how to make starting school as simple as possible, discuss school meals with a dietitian, and explore with psychologists issues around growing up with diabetes and their children’s growing independence as they get older.

### **6. Summer camp**

A special educational opportunity is provided in the form of a summer camp, where 120 children aged between 6 and 15 years meet to learn about diabetes and to make friends.

Children are formed into groups of eight with a group leader, who is an adult with type 1 diabetes. The whole medical team accompanies them. Each day, children receive practical lessons in carbohydrate counting, prepare some simple meals, and are taught how to react to episodes of low or high blood glucose and how to recognise diabetic ketoacidosis. A lot of sport activities are provided and participation is encouraged. Psychological support is provided, a dietitian is present and, as all members of the multidisciplinary team attend the camp, it is also an opportunity for them to learn more about those in their care. The first camp was organised in 1967 and all costs are covered by the national health insurance company.

### **7. Yearly meetings**

Annual meetings for the families of children with diabetes have been organised since the early 1970s, and a special publication called *Sladkorčki (The Sweets)* is distributed. It contains lots of information about good diabetes management, along with patients’ stories. Every year at the end of the meeting, families are invited to a short walk to symbolise the importance of sports activity for all family members.

### **8. Publications**

UCH began to produce small booklets about diabetes in the 1980s, followed by specific information on diabetes for teenagers and young children. In 2011, a book for professional caregivers was printed and sent for free to 1200 schools and nurseries all over Slovenia. A book for patients and their families followed in 2012, which contains broad information about diabetes. It includes chapters on pump therapy and sensor use, discussion of emotional problems, diet, other autoimmune diseases, a consideration of complementary medicine and updates on modern research in the field of diabetes.

### **9. Website**

Since 2005, the Society for Children with Metabolic Disease has hosted a website providing information about diabetes. It contains details about different events, along with recipes, useful links and telephone numbers.

## 10. Other innovations

For 2014, a cookery book is planned with instructions on carbohydrate counting and information about the importance of the glycaemic index. Parents contributed a lot of the recipes, which have been approved by our dietitian.

Additionally, since 2012, a medal has been awarded to people who have lived with diabetes for more than 50 years, forming a small celebration as part of the yearly meeting for families with a child with type 1 diabetes.

## Other educational initiatives

Working with children who have type 1 diabetes is an ongoing process. New therapeutic possibilities emerge, parents and children become involved in research, a lot of psychological support is provided and frequent telephone contacts are made to help. Since 2012, an annual educational day has been arranged for each young person with the condition to attend with their family. During sessions lasting 30–45 minutes with the appropriate member of the care team, a psychological screening is carried out, diet is discussed, knowledge about diabetes is tested and a foot examination performed. In 2013, similar education was organised for children up to the age of 7 years, with different psychological questionnaires for this age group.

A project for those with an  $HbA_{1c} > 75$  mmol/mol (9%; currently 40 individuals out of 650) completes this story. Here the aim is to improve metabolic control and quality of life through frequent telephone contacts and out- or inpatient clinics.

## Conclusion

Slovenia is a small country, so centralised care for patients with type 1 diabetes has been organised to provide the same medical care, education and support for all children, teenagers and students. Results from the recent study by Dovc et al (2014) indicate that with this approach to care and new technologies, an important improvement of metabolic control has been achieved. ■

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**“Centralised care for patients with type 1 diabetes in Slovenia has been organised to provide the same medical care, education and support for all children, teenagers and students.”**