

# ISPAD Position Statement on Type 1 Diabetes in Schools

# **Working Party Contributors**

Goss P.W., Middlehurst A. (Co-Chairs), Acerini C.L., Anderson B.J., Bratina N., Brink S., Calliari L., Forsander G., Goss J.L., Maahs D, Milosevic R., Pacaud D., Paterson M.A., Pitman L., Rowley E, Wolfsdorf J.

The ISPAD Position Statement on Type 1 Diabetes in Schools is based upon the 2018 ISPAD Clinical Guidelines for Management of Type 1 Diabetes in School (1) and draws upon the published position statements on diabetes in schools of many countries (2 - 6). The input from less resourced communities in Ghana, Pakistan, Haiti, Ecuador, Bolivia and India is acknowledged and appreciated. The authors also acknowledge the input of parents, adolescents living with type 1 diabetes, school personnel, and experienced health care professionals who have contributed ideas and clarification of roles.

The principles of this ISPAD Position Statement on Type 1 Diabetes in Schools should be applicable globally. ISPAD strongly supports compliance with legal protections for children and adolescents with type 1 diabetes to attend school, to be safe at school, and to receive optimal medical management at school and in all school associated activities.

Note:

- Reference to "parent" includes parent(s), legal guardian or carer.
- *Reference to "medical team" refers to the usual health care team treating the young person with diabetes.*
- *Reference to "school personnel" includes teaching staff and others who may be involved with the care of the student.*

# 1. Background

1.1 Type 1 diabetes (T1D) is a complex medical condition that requires skilled medical and psychosocial management. Intensive insulin therapy (IIT) is the recommended therapy for young people with T1D because it leads to improved health outcomes and reduced risk of short- and long-term complications. IIT comprises frequent blood glucose and/or sensor glucose monitoring, carbohydrate quantification, insulin dose calculation, insulin administration with meals, and insulin and nutrition adjustments for physical activity.

1.2 The ISPAD Position Statement on T1D in schools recognizes that students living with T1D face a wide variation in resources and circumstances.

1.3 The absolute minimal level of T1D care at school in ALL countries includes the following principles:

- To uphold the student's right to safely attend school,
- To enable the student to experience equal opportunity, obtain equal education, and participate equally in activities with their peers,
- To allow the student to monitor blood glucose levels at school and treat blood glucose levels out of target range in a respectful manner and in an appropriate place chosen in collaboration with the student and parent.

1.4 Well-resourced countries must aim at interventions that uncompromisingly ensure optimal medical management that make it possible for the student to maintain blood glucose levels in or near the normal range during school hours.

# 2. The Important Role of Schools

- 2.1 Students usually spend more than half of their waking hours at school and even more time participating in after-school activities, school sports days, field trips, excursions and school camps. Hence, the student with T1D spends a substantial amount of time away from the security of home and family supervision.
- 2.2 The usual school day comprises many variables that influence blood glucose levels various levels of learning time, meal and snack times, excitement, stress, peer interaction and physical activity.
- 2.3 Optimal management of T1D during school times is essential to reduce the ever-present risk of short-term complications (especially low blood glucose levels "hypoglycaemia") of T1D and reduce the risk of long-term complications whilst enabling the student to participate, perform and learn to the best of their ability.
- 2.4 All school personnel, including teachers, administration staff, counsellors, sport staff, nursing staff and out of school hours care staff must receive appropriate diabetes education and develop a clear understanding about basic school-related T1D needs and appropriately manage the effects of low and high blood glucose levels according to written instructions from parents and medical team.

#### 3. Student and Family Emotional Health

- 3.1 School personnel must understand the emotional burden experienced by families when given a diagnosis of an incurable disease such as T1D that will relentlessly impact upon the student, siblings, family relationships and parental working lives.
- 3.2 A diagnosis of T1D may cause students to feel different from peers and put them at risk of being stigmatised, resulting in a higher risk of experiencing anxiety and depression. The traumatised family may feel helpless and disempowered and yet have an obligation to advocate for their child.

- 3.3 Each family will have access to different resources, coping skills and economic circumstances. School personnel will have varying interest and levels of expertise. Hence care of the student must be individualized.
- 3.4 The individual medical requirements and blood glucose targets are best determined by parents and the student's medical team.
- 3.5 The privacy of the student and confidentiality issues relating to the student with T1D must be respected, acknowledged and discussed with the student and parent.

## 4. Cooperative and Supportive Partnerships

- 4.1 Caring for a student with T1D is best achieved through a cooperative, supportive and respectful relationship between the three key stakeholders parent (and student when they are capable of greater independence in self-care), school personnel and medical team.
- 4.2 The student with T1D should not be disadvantaged in the quality of T1D care whilst at school. It is essential that the quality of diabetes management during school hours is comparable to the student's usual diabetes management at home.
- 4.3 An effective communication process between parent/student (when capable) and school personnel should be respectful, transparent and easily accessible.
- 4.4 School personnel should consider the student's medical team as an accessible resource to contact with parental permission. A single member of the medical team should be identified as the source of contact for each student with T1D.
- 4.5 Each student should have a written individual Diabetes Management Plan prepared by the parent /student (when capable) and the student's medical team. This plan communicates the medical orders for the student and is the foundation for the cooperative relationship between parent, school and medical team. (see item 6.2)
- 4.6 Schools should be supported by the student's medical team to establish processes to address issues and provide appropriate information regarding the use and handling of diabetes equipment including lancets, syringes/needles and used test strips. Schools should be provided with the necessary resources such as "sharps" containers (or other means of disposal, dependent on local circumstances), and information to deal with such issues constructively and cooperatively, while minimizing risks to both students and school staff. Ideally, this should be organised prior to the student commencing or returning to school following a diagnosis of T1D.

#### 5. Legal Issues

5.1 The World Health Organisation recognises T1D as a disability. Many countries have recognised T1D as a disability in common law. Legal frameworks exist to protect children and adolescents with T1D to ensure the student has an equal opportunity to participate in all aspects of school life.

- 5.2 Schools in most countries are obliged by law to make "reasonable adjustments" to facilitate prescribed medical care to allow for students with T1D to participate in education on the *same basis as their peers*. This should become the standard in every country despite challenges in less-resourced countries.
- 5.3 In countries where legislative protections to support students with T1D are not expressly defined, ISPAD advocates that those students be allowed to attend school in a safe and supportive environment that enables best practice of the management of T1D.
- 5.4 "Reasonable adjustments" for a student with T1D includes insulin or glucagon administration where prescribed. In well-resourced countries, it also includes (if prescribed and authorised by the parent in the Diabetes Management Plan, continuous glucose monitoring interpretation and intervention, which may include use of predictive arrows and alerts, and use of insulin pump settings.
- 5.5 In less-resourced settings where regular blood glucose monitoring and glucagon are not readily available, ISPAD advocates for the most optimal interventions possible during school hours. This includes allowing and supervising insulin administration during school hours when prescribed. It also includes adult supervised management of episodes of low blood glucose levels by consuming glucose tablets, glucose gel, food or liquids containing rapidly-absorbed carbohydrates, and supervision of the child until full recovery.
- 5.6 Schools have a duty of care for their students and school personnel have a responsibility to take reasonable care to protect them from reasonably foreseeable harm, including out of target range blood glucose levels, and from discrimination, bullying, stigmatisation, which can have a significant impact on self-esteem, motivation and emotional health.
- 5.7 School personnel can be assisted to meet their compliance obligations by
  - education about T1D
  - appropriate training by the parent/ medical team according to the individual needs of the student,
  - authorisation and consent by the parent and
  - acting within their scope of practice according to the training and consent they have received.
- 5.8 The parent is the only party who can provide informed consent to the prescribed medical treatment.

#### 6. Expectations of management in schools

- 6.1 ISPAD supports maintaining blood glucose levels as close to normal as possible during school hours to facilitate learning, concentration and participation in all aspects of school life.
- 6.2 The individual Diabetes Management Plan should comprise the following:

- A concise Action Plan outlining how to recognize high and low blood glucose levels and individualised treatment protocols for high and low blood glucose levels and glucagon administration, if prescribed and available.
- A more detailed Diabetes Management Plan signed by parent (and student where applicable) and medical team that outlines the medical instructions for the individual student at school. This plan should specify what diabetes responsibilities can or cannot be undertaken by the student based on the child's age, diabetes self-care knowledge and cognitive maturity (i.e. blood glucose checking, insulin administration, meal planning and adjustment, adjustment for exercise).
- 6.3 Schools should have a clear understanding that the Diabetes Management Plan is not to be altered by a third party under any circumstances without the consent and authorisation of the parent and medical team.
- 6.4 Parents are the final arbiters of whether their child can self-manage certain aspects of T1D, including glucose monitoring and self-administration of insulin. The medical team should guide and support parents to ensure the student is not subject to inappropriately unrealistic expectations.
- 6.5 A parent cannot be expected to "fill the gap" of school resources and attend to their child's medical management during the school day. However, with a mutually supportive approach between parents and schools (and modern communication technology if available) positive outcomes for the student can be achieved.
- 6.6 Schools must permit students with T1D to monitor their blood glucose level, administer insulin and treat both low blood glucose and high blood glucose levels according to the individualized Diabetes Management Plan. Low blood glucose levels must be treated without delay with responsible adult supervision during recovery.
- 6.7 Students with T1D should be encouraged and enabled to participate in physical activity with the appropriate adjustments for safety and optimal performance clearly outlined in the student's Diabetes Management Plan.
- 6.8 Managing nutrition during school hours, including calculation of carbohydrate content of school meals, is an important requirement of optimal T1D management and requires a defined approach between parent, student and school personnel.
- 6.9 Schools should not expect that young people with diabetes will "learn responsibility" for selfmanaging T1D by leaving them unsupported during school hours. Nor will the duration the student has lived with T1D determine their ability to be self-sufficient. Young students may have the technical skills, but should not be solely responsible for their management at school.
- 6.10 Governments must support schools with adequate resources to ensure they can provide the reasonable adjustments required to create a safe environment and facilitate optimal medical management as prescribed.
- 6.11 All aspects of T1D management should occur with minimal disruption to normal class routines and activities, requiring appropriate support for school personnel. The contribution made by school personnel to appropriately assist the student with T1D at school should be acknowledged and appreciated by all.

## 7. Training of School personnel

- 7.1 Schools are responsible for ensuring that their personnel are adequately <u>educated</u> about T1D and <u>trained</u> in the application of prescribed treatment for the individual student.
- 7.2 It is important to have current, accessible, language appropriate and culturally appropriate <u>education</u> materials to enable flexible and rapid education of new or substitute school personnel. (7-22)
- 7.3 The content of the <u>training</u> is the responsibility of the medical team and parent and may be assisted by on-line training courses. (7) Training should be executed by people with the appropriate understanding of the student's individual needs and skill set. Training must have informed parental consent to administer the prescribed medical treatment and manage complex medical care for their child.
- 7.4 All parties should ensure that the necessary education, training and information is in place for optimal management.
- 7.5 Where school nurses are unavailable to execute complex medical orders, other volunteer school personnel may be trained by the parents and the student's medical team on the complex medical care of the student. This should be encouraged and supported.
- 7.6 Third parties who may provide generic T1D education or have some knowledge of T1D but bear no responsibility for clinical outcomes must not provide medical advice on any aspects of the medical management of the child with T1D.
- 7.7 Students with T1D sitting examinations should receive appropriate accommodations and provisions, including access to blood glucose self-monitoring devices (which may include a smart phone or other electronic device for CGM), access to low blood glucose treatment, access to insulin if required to manage elevated blood glucose levels, access to water, toilet access, and extra time if required. On-line programs to assist school personnel to safely execute the appropriate adjustments during exams should be readily accessible.
- 7.8 The following levels of education and specific training are recommended:
  - Level 1 All school personnel should be <u>educated</u> about basic medical understanding of T1D (including recognition and urgency of treatment for low blood glucose) and the effect of T1D on the student and the entire family including the social, economic and emotional impact of living with T1D.
  - Level 2 Those school personnel most responsible for the day-to-day management of the child with T1D should be also <u>trained</u> to
    - 1. recognize low blood glucose symptoms and signs,
    - 2. initiate treatment for high or low blood glucose levels and
    - 3. know and understand when and whom to call for assistance, including emergency responders, parents and medical team.
  - Level 3 -Those school personnel with authorisation or seeking authorisation through training and informed parental consent to administer insulin require a higher level of training on:

- o insulin administration
- o insulin dose calculation and adjustments
- o the legal aspects of insulin administration
- o insulin delivery devices including insulin pumps
- o glucagon administration

## 8. Stakeholders Roles and Responsibilities

The responsibilities of the 3 main stakeholders are:

- **8.1 Parents** are ultimately responsible for the medical decisions made on behalf of their child. Therefore, the parent's informed consent and decisions regarding the health and well-being of their child are paramount. It is imperative that parents remain engaged as part of the team even when the student with T1D reaches adolescence.
- **8.2** The student's **treating doctor** or nurse practitioner is responsible for prescribing medications. The medical team is responsible for outlining in detail the recommended medical requirements for that student. The medical team usually comprises a doctor and diabetes educator and may also include, if available, dieticians, psychologists, social workers and exercise specialists who work directly with the child and family.
- **8.3** The school and the authorities responsible for managing schools are responsible for executing the parental and medical orders outlined in the student's Diabetes Management Plan and for facilitating the training of school staff, to ensure that they are competent to execute the care plan recommended by parent and medical team.

# References

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- Diabetes Care in the School Setting: A Position Statement of the American Diabetes Association. Jackson CC et al. Diabetes Care 2015 Oct; 38(10): 1958-1963.https://doi.org/10.2337/dc15-1418
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- 4. E Canadian Pediatric Endocrine Group and the Canadian Paediatric Society Managing type 1 diabetes in school: Recommendations for policy and practice [*Paediatrics & Child Health* 2015:20(1):35–39
- 5. Australian Paediatric Society Position Statement of Diabetes in Regional Schools. www.auspaediatrics.com.au/position-statements
- 6. Diabetes UK: <u>https://www.diabetes.org.uk/professionals/position-statements-</u> reports/specialist-care-for-children-and-adults-and-complications/diabetes-care-in-schools

# **Resources:**

- 7. T1D Learning Centre -APS / ISPAD school e-learning modules for parents and teachers: <u>www.t1d.org.au</u>
- 8. IDF Life for a Child Education website education resources for children, adolescents, with diabetes, parents, teachers in multiple languages: <a href="https://www.lifeforachild.org/about/education-resources/multilingual-resources.html">www.lifeforachild.org/about/education-resources</a> <a href="https://www.lifeforachild.org/about/education-resources/multilingual-resources.html">www.lifeforachild.org/about/education-resources</a>
- 9. IDF KiDS pack: <a href="https://kids.idf.org/">https://kids.idf.org/</a>

10. Professor Bumblebee's Guide to type 1 diabetes – Youtube:

www.youtube.com/watch?v=A8iFbduZF14

11. USA: www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/

12. Diabetes Canada: http://www.diabetes.ca/kidsatschool

13. Turkey: <u>http://partnerships.ifpma.org/partnership/diabetes-at-school-program</u> - remember there was a session at ISPAD in Istanbul in 2012.....country-wide program

14. New Zealand: www.starship.org.nz/for-health-professionals/new-zealand-child-and-youth-

<u>clinical-networks/clinical-network-for-children-and-young-people-with-diabetes/diabetes-in-schools/</u> 15. JDRF USA: <u>www.jdrf.org/wp-content/docs/JDRF</u> School Advisory Toolkit.pdf

16. Centres for Disease control & prevention USA:

https://www.cdc.gov/healthyschools/npao/diabetes.htm

17. "Paediatric & Adolescent Diabetes", Brink \*& Serban, Chapter 13, "Diabetes School issues": available from Amazon

18. "Type 1 Diabetes in Children, Adolescents and Young Adults", 6<sup>th</sup> edition, Dr Ragnar Hanas, available from Amazon

19. "Understanding Diabetes" Peter H. Chase & David , Maahs, (English , Spanish, reference:

www.ucdenver.edu/academics/colleges/medicalschool/centers/BarbaraDavis/OnlineBooks/Pages/Underst andingDiabetes.aspx

20. ADA Wizdom toolkit reference:

http://main.diabetes.org/site/DocServer/wisdom\_kit\_flyer.pdf?docID=103968

21. Changing Diabetes in Children (CDiC), (English, Spanish reference: www.novonordisk.com/content/dam/Denmark/HQ/sustainability/commons/documents/7222\_CDiC\_B asic\_HCP\_training\_manual\_eng.pdf

22. T1 Everyday Magic - Life with Type 1 Diabetes https://www.t1everydaymagic.com/