

## 2018 ISPAD Clinical Practice Consensus Guidelines

### MANAGEMENT AND SUPPORT OF CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES IN SCHOOL

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### **Executive Summary and Recommendations:**

- The number of young people with diabetes attending school is increasing (A), placing significant burden on families, healthcare systems and schools (E).
- Children may spend more than 30 hours per week in the school environment.
- Many children with diabetes worldwide do not have ready access to insulin, diabetes supplies or education. They should be given the same opportunity as other children to obtain an education.
- Irrespective of age and ability all students with diabetes at school must receive the support, encouragement and supervision of school personnel (E).
- Optimal management of diabetes at school is a prerequisite for optimal school performance, including learning (B), and for the avoidance of diabetes related complications (E).
- Maintaining normoglycaemia during school hours is important and day-to-day glycaemic targets should not differ to any other setting (E).
- The type of insulin regimen used at school should be tailored to the needs, ability and wishes of the child / family and should not be dictated by the school resources (E).
- Diabetes is classified by 'common law' as a disability and legal frameworks exist in many nations to ensure the child has equal opportunity to participate in all aspects of school life (E).
- Schools should make 'reasonable adjustments' to facilitate prescribed medical care to allow for children with T1D to participate in education on the *same basis as their peers* (E).
- 'Reasonable adjustments' include school personnel support with insulin administration, as well as understanding and knowledge of diabetes technologies (including CGM devices and advanced insulin pump settings) (E).
- Administration, or careful supervision, of insulin administration requires legally authorized school personnel with informed parental consent (E).

- Schools are responsible for adequately training their personnel about diabetes, but the content of the training is the responsibility of the healthcare team and parent (E).
- Whether a child can self-manage certain aspects of their diabetes and/or self-administer insulin is not necessarily age dependent and can only be determined by the parent (E).
- Schools have a non-delegable duty of care to their students and personnel should take reasonable care to protect them from harm which is reasonably foreseeable (E).
- Blood glucose monitoring is central to achieving optimal glycaemic control at school and must be familiar to school personnel (E).
- School personnel should be able to appropriately manage the effects of low and high blood glucose levels according to parent and healthcare team instructions (E).
- Access to food in schools is an integral part of enabling children to grow and balance their insulin and food intake (E).
- Use of food pictures may help school personnel assess food servings and their estimated carbohydrate content (E).
- All young people with T1D should be given the same opportunities as their peers to safely participate in all sporting and physical activity (E).
- School personnel should be aware of the signs / symptoms of hypoglycaemia, and a 'first-aid hypoglycaemia' management pack should be available at all times (E). Clear instructions for managing hypoglycaemia should be provided (E).
- Young people with diabetes must be allowed to monitor their blood glucose levels, administer insulin and to treat low/high blood glucose values at any time during the school day, with adult supervision if needed (E).

- All young people with diabetes at school should have an individualized Diabetes Management Plan (DMP) in place which must be developed and agreed with parents in advance (E).
- The DMP should be reviewed and amended as and when necessary, according to the needs of the young person with diabetes, and / or at least annually (E).
- Some studies report higher rates psychological problems such as depression and eating disorders in young people with diabetes (B).
- Schools provide a unique opportunity to identify and treat psychological problems in young people with diabetes and close liaison between school personnel and health care professionals is recommended (E).
- Successful diabetes management at school depends heavily on effective communication and problem solving with the family (B) and schools should clarify and coordinate communication expectations (E).
- Peer relations, local social stigma, racial and religious perspectives can be a burden to patients and families with Type 1 diabetes.
- Young people with diabetes have a significantly increased risk of being exposed to issues of discrimination and may impact on self-esteem and cause feelings of stigmatisation.
- School exams or other assessment situations are associated with stress and increased risk of acute transient episodes of hypoglycaemia or hyperglycaemia (B) can affect performance (B).
- Specific arrangements may need to be put in place (including access to blood testing equipment; hypoglycaemia first-aid pack) for exams (E).
- Parents cannot be expected to “fill the gap” of school resources and attend to their child’s medical management during the school day (E).
- With a mutually supportive, collaborative, approach between parents, schools and the child’s healthcare team, and with advancements in communication technology providing sensor glucose data in real time to parents, there is a real opportunity for a truly cooperative approach (E).

## **Introduction**

The number of children newly diagnosed with type 1 diabetes (T1D) is increasing, with average global incidence rates increasing by 3 to 4% per annum (1). Many countries are also reporting that children are much younger at the time of diagnosis (2), with the greatest increases in incidence rate observed in the those aged under 5 years (3).

Given these epidemiological trends the number of children and adolescents with T1D at school will continue to increase (4, 5) (6). The burden of diabetes care at school is also increasing, not least through the increased demands and expectations imposed by current approaches to diabetes self-management, but also through the increasing application of new 'diabetes technologies' (e.g. insulin pumps and continuous glucose monitoring (CGM)). These pressures place a significant strain on patients and families but also on the healthcare systems and school resources needed to adequately support them (7) (8).

The need to achieve and maintain blood glucose (BG) as near to normal as possible at all times, and for as long as possible, in order to reduce the risk of diabetes related complications (both acute and chronic) and to optimize the learning ability of young people with diabetes is clear and unequivocal (9, 10). Therefore, the need to educate school personnel about diabetes and to train them to support young people with this condition is important and in keeping with contemporary standards of clinical practice (11).

In many countries children spend a significant proportion of their day at school (up to 8 to 10 hours per day) during which time they will be under the care and support of school personnel. Failure to optimize the patients' diabetes management during this time contributes to poor glycaemic control (4) (5) (12) (6). Without adequate training and education school personnel will have difficulty understanding and applying the correct principles of diabetes management and ongoing ignorance and misperceptions will undermine the core objectives of achieving optimal BG control

(13).

Furthermore, irrespective of age and ability all students with T1D at school must receive the support, encouragement and supervision of school personnel. Currently, many countries do not have legal or statutory provisions in place that mandate that children with T1D receive prescribed health-care support at schools. Many countries also do not have access to school or to other community-based support systems (e.g nurses), with the responsibility of insulin administration and blood glucose monitoring falling entirely on the family or on school personnel (14) (15).

There is also no specific age at which children with T1D should be expected to take on full responsibility for their diabetes self-management at school (16). Whilst many children will have achieved a level of maturity and ability to self-care by the age of around 12 years, some children may have other underlying issues (e.g. neurocognitive / learning / psychosocial) or circumstances (e.g. war, famine, financial constraints) that might preclude them from this. Furthermore, whilst many children may become technically very skilled at an early age, all young patients irrespective of their age cannot be expected to be wholly responsible for their diabetes management at school. Encouragement, supervision and support with diabetes self-management is required throughout their school years. Non-adherence with diabetes self-management, particularly with blood glucose (BG) monitoring, bolus insulin delivery and insulin dose calculations, are particular issues with adolescents with T1D (17).

Each child / adolescent with T1D should have an individual diabetes management plan (DMP) in place at school. This plan should be agreed between the parent / child and the diabetes healthcare team and should be reviewed and updated at least once a year.

### **Insulin requirements during school years**

Young children presenting with T1D may have a shorter 'honeymoon' period after diagnosis compared to adolescents (18). During childhood, insulin requirements will

also increase in keeping with process of childhood growth and physical development. This is particularly notable during puberty when insulin requirements significantly increase and are more marked in female students (19).

### **Glycaemic targets during school years**

Maintaining optimal glycemic control is required at school. Day to day glycemic targets for children at school should not be any different to any other setting. Further details are available in the ISPAD Guidelines chapter on Glycaemic Control Targets. Glycaemic management requirements may need to be adjusted and individualised for specific school activities, such as sport and exams, and should be agreed and planned in advance.

### **Insulin therapy approaches**

The type of insulin regimen (multiple daily injection (MDI) or insulin infusion pump) should be tailored to the needs, ability and wishes of the child with diabetes and parents and may change over time as the child's physically and psychologically matures (20). The insulin regimen should not be dictated by school resources but rather by the needs of the child and the availability of diabetes resources (e.g. insulin; BG monitoring equipment).

Insulin administration at school must be delivered safely for every child with T1D. Preferably, and where possible, designated members of the school personnel should have responsibility to assist with insulin administration or to at least supervise the process being performed by the child. Education and training of the school personnel by the healthcare team (or by the parent if appropriate) is required and the explicit informed consent and authorization by the parents / guardians for school personnel to give insulin to their child must be in place in advance (21).

School personnel responsible for supporting students with T1D should ideally also be trained to make insulin dose adjustments at school. This is achieved by matching the pre-meal insulin dose to the planned carbohydrate intake, by taking into consideration the pre-meal BG level, as well as any physical activity that may have preceded the meal, and any that is anticipated to occur post-meal (22). Post-meal

BG excursions are often a concern but can be mitigated by adjusting the timing of the pre-meal insulin bolus to occur 10-20 minutes before eating (23).

Hypoglycaemia occurring immediately before a meal should be treated first, and the subsequent meal time insulin dose calculated from the carbohydrate content of the food to be consumed. The optimal timing for a pre-meal bolus can be difficult to apply at school where some meals are unpredictable, both in terms of the timing and expected content of food, and thus recommendations for meal insulin dose administration in school need to be individualized.

Insulin dose calculations can be performed by using a number of specific technology applications or “apps”, accessed either via a ‘smart phone’, or via the ‘bolus calculator’ feature found in most commercially available blood glucose meters and continuous subcutaneous insulin infusion (CSII) pumps. Use of insulin dose calculators promotes earlier independent decision-making in young children (24).

Specific instructions regarding insulin administration and insulin dose adjustments at school should be incorporated into the students individualised, agreed DMP. This should be reviewed and changed as necessary and at least annually.

### **Blood glucose monitoring in school**

Blood glucose monitoring is central to achieving optimal diabetes management and must be familiar to school personnel (25). A BG check prior to insulin administration is required and is considered safe and appropriate practice. The degree of physical activity, and the insulin sensitivity of the child, influence insulin dosage. School personnel should be made aware that BG levels outside the normal range (4-10 mmol/l) are risk factors for below average school performance and increased absenteeism (26, 27).

Self-monitoring of blood glucose (SMBG) is an essential component in the optimal management of diabetes in children and adolescents with T1D. Capillary BG values

should be checked by finger prick using a standard portable blood glucose meter (glucometer). The minimum frequency of SMBG testing during school day is one finger prick before each meal, as well as before and after physical activity. BG should be checked before a school test/exam as both high or low BG may adversely affect exam performance (28).

In well-resourced countries, an increasing number of students use subcutaneous (Sc) tissue glucose sensing technologies, which monitor BG either continuously (i.e. continuous glucose monitoring (CGM) or intermittently (i.e. - so-called 'flash' or intermittent continuous glucose monitoring (iCGM)). School personnel should be made aware of the differences between these technologies and standard SMBG monitoring by finger prick and should not expect these devices to give identical readings at the same time. It is more convenient to perform mandatory CGM calibration tests (carried out by finger-stick BG testing) at home rather than at school. Whilst iCGM devices do not require calibration, they do not cannot provide any 'alert' notifications if BG values are rising or falling rapidly. SMBG readings also need to be performed by finger prick testing in any situations where the CGM/iCGM device is suspected of malfunctioning or when device BG readings are suspected to be incorrect.

### **Nutrition in school**

All young people need a healthy balanced diet for optimum growth and development. Education regarding good food choices and development of healthy eating habits is part of diabetes management and normal development. Access to food in schools is an integral part of enabling children to grow, exercise and to balance their insulin and food intake (29). In areas of food 'insecurity', provision of food in school is essential for nutritional wellbeing. Access to food in school varies worldwide. The World Food Programme report 2013 describes in detail access to food in school in high, middle and low-income countries. For a child or young person with diabetes food in school requires management according to their treatment regimen (30).

Meals eaten in school may make up a large proportion of a child's daily nutritional intake, for some food in school may include breakfast clubs, snack times and afterschool clubs. Hours spent in school will vary across countries. Children using either MDI or insulin pump therapy will need to carbohydrate count and calculate insulin doses according to amount and type of carbohydrate, meal composition, blood glucose level, activity both prior to and post meal and previous insulin bolus (25, 31, 32). Insulin should be delivered before eating (33) (34). Children on twice daily insulin therapy will require both midday meal and snacks to prevent hypoglycaemia and match the action of insulin taken at the beginning of the day (see ISPAD Guidance Nutrition, 2018).

Carbohydrate counting is recognised as an essential part of intensive management of diabetes (35) . Calculation of carbohydrate content of school meals requires information about foods available in school, nutritional content of foods served, and amount of food provided. Access to this information is variable and, to date worldwide, there is no published data about the extent to which children and young people can access appropriate nutrition information to support diabetes management.

Where nutrition information is available it is most useful to described this in terms of 'per portion of food served'. It is beyond the resources of most diabetes healthcare teams to be able to provide this information for every individual child. Where nutrition information is not available strategies to support the child need to be agreed between the parent, school and healthcare providers. The use of diabetes technological aids such as 'apps' to support carbohydrate counting, may be helpful. If school meal standards exist these may be used as a guide to the amount of insulin calculated for a meal. For example, in the UK school food standards for portion sizes exist and where a school follows these standards meals will contain 40-70g carbohydrate (36). Similar information will be available in other countries.

Parents will need to be provided with nutrition information if this is not available to them and, for some, food may need to be sent to school with the child. Use of food

pictures / photographs may also assist school personnel to estimate the carbohydrate content of the meal for insulin dosing purposes and can be provided to them by families and health care providers. Provision of a pre-prepared 'packed' lunch (made by the family or carer) offers the advantage of allowing information about the carbohydrate content in each food serving to be predetermined for the child and the school personnel.

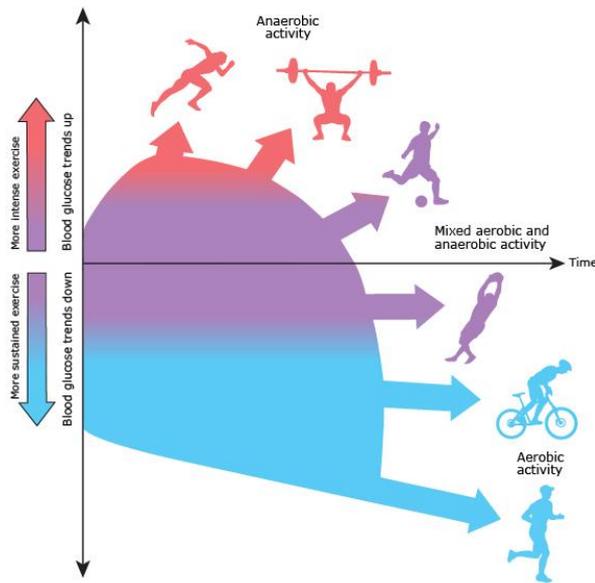
Food choices in school may be determined by local and national government policy, and the child health issues of obesity and dental health are also relevant and appropriate for young people with diabetes. Where the child has a co-existing medical condition (e.g. coeliac disease, cystic fibrosis) which requires additional dietary adjustments these should be assessed and included in an individually agreed DMP with the school personnel and parents.

### **Physical activity in school**

All children and young people with T1D should be given the same opportunities as their peers and should be able to safely participate in all sporting and physical activity. Education, support, use of technologies and specific individualised strategies are all means to reach this objective.

Physical activity in children can differ a lot depending on age: the younger child more often conducts physical activity in bursts as part of playing and the older child conducts planned activities. Differences are also noted regarding the aim of physical activity: sometimes about having fun but occasionally also about performance.

The figure below illustrates the practical importance of the differences on glucose control depending on the type and sometimes intensity of exercise. More information is available in the ISPAD Guideline Chapter on Diabetes and Exercise.



*Illustration by Anne Greene, Senior Medical Illustrator.*

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Hypoglycemia is regarded as a major barrier for physical activity (37, 38) which further highlights the importance of providing structured education and support from health care professionals.

For physical activity lasting less than 60 minutes, additional carbohydrate is only needed if the activity is of high intensity and / or if BG values before the activity onset have clearly been showing a declining value.

When physical activity is regularly being repeated in short bursts or is particularly intense (such as during sports days) additional measures are required. Carbohydrate supplementation is needed during exercise lasting longer than 60 minutes and will also be needed in between any short bouts of exercise and after the exercise session has finished to prevent late hypoglycaemia. Besides a plan regarding carbohydrate supplementation, a plan is also needed regarding insulin dose reductions which may involve bolus dose reductions before physical activity, bolus dose reduction after exercise (due to higher insulin sensitivity post-exercise) and / or basal insulin dose reduction during and after exercise aiming at reducing the risk of hypoglycaemia.

It is important to clarify that adjustments to carbohydrate delivery and to insulin dose are intended to balance each other. If insulin dose reduction is not done a larger carbohydrate delivery is required (and vice versa).

At all times, planning is essential before the activity together with advice regarding what to do when a possible hypoglycaemia or hyperglycaemia occurs. Generally, there is no specific age when diabetes self-management responsibility is placed entirely on the young person with diabetes which means that parents, trainers and teachers must know about diabetes and how to recognize and manage hypoglycaemia and hyperglycaemia. When the child is away from home written instructions are recommended. The instructions could include information about hypoglycaemia and the amount of carbohydrates to use according to the weight of the child. Instructions should also include information about insulin correction factor meaning the amount of insulin to add when hyperglycaemia is present. The information should always include contact information to the parents.

Carbohydrate in the form of fruit is the preferred option before planned exercise as this provides not only carbohydrates but also vitamins, minerals and fibres. The child (and where applicable their teacher / trainer) should also have in their possession, at all times, rapidly acting carbohydrates (glucose tablets, glucose gels) to manage hypoglycaemia should it occur during the exercise session.

“Diabetes Alert / ID” bracelets or necklaces are also recommended allowing the child to take part in activities outside of the supervised home or school domain. As and when deemed appropriate some diabetes management responsibilities can be transferred step by step to the young person with diabetes (39). The level and type of responsibility and when this can be transferred depends mostly on the ability of the young person but also on other factors (40). This transfer of responsibility must be conducted in a very clear way for both the young person as well as for the adult. The same information should be passed on to the trainer and the school. Whilst the school is a very important environment for the introduction and encouragement of

physical activity it is also recognised that there will also be a lack of knowledge and understanding about T1D and physical exercise (41).

Physical activity puts extra demand on education and planning. Patients and families should keep a record (written or electronic) of BG glucose values, carbohydrate intake, insulin doses and about the duration and intensity of the exercise is important. This information should cover the time before, during and after exercise including the following night, and can then be used as a basis for training and coaching (preferably on a one to one basis) with the diabetes health care team (42). Education about exercise and diabetes provided on via the internet in parallel to individual coaching, may also result in improved glycaemic control and increased level of physical activity as shown in adults (43). Furthermore, education provided at specific diabetes camps can also address questions about exercise and has recently been associated with lowered HbA1c (44).

Diabetes related technology also offers potential for improved management of diabetes and physical exercise at school. Data downloads from BG meters, CGM devices and pumps can be performed at home providing opportunity for review and feedback from the diabetes health care team. Furthermore remote, real-time monitoring of CGM data is now a possibility and offers the opportunity for observing a child's blood glucose trend using smartphone-based platforms. Teachers, trainers and guardians could then follow the same BG trends and communicate between each other via smartphone.

### **Managing hyperglycaemia in school**

Hyperglycaemia, defined as a BG level above 10 mmol/L (180 mg/dl), should be avoided as far as possible, not only because of the increased risks of vascular complications over time but also because high blood glucose value reduces the child's ability to concentrate and may adversely affect academic performance (45). Chronic hyperglycaemia can cause a decrease in cognitive function and, especially in young children, may affect brain structure and function (46-48).

The young person's individualised school DMP should state the threshold for giving a correction bolus for hyperglycaemia and should specify when a check for blood or urine ketones is needed. A threshold blood glucose value of 10 mmol/L (180 mg/dl) is recommended. A brief guide on how to react to elevated level of ketones (e.g. blood ketone > 0.6 mmol/L) should also be provided and should include advice for giving a correction bolus, extra fluid and, in case the child is unwell (i.e. drowsy, vomiting, breathing heavily) calling the emergency services in parallel to contacting the parents /guardians.

### **Managing hypoglycaemia in school**

Hypoglycaemia is the most common acute complication of T1D (49). Fear of severe hypoglycaemia can be a burden for the child and their caregivers and is a commonly a limiting factor for quality of life or for achieving optimal BG control (50, 51). Severe hypoglycaemia can have negative psychosocial consequences and can induce adverse compensatory behaviours (52). Fear of hypoglycaemia, including nocturnal hypoglycaemia, is therefore a significant cause of stress and anxiety which can prevent the young person with T1D performing some regular or routine daily activities.

School personnel should be encouraged to look out for signs and symptoms suggestive of hypoglycaemia. The individual DMP should include information on how to treat hypoglycaemia according to different situations (e.g. mild / severe hypoglycaemia; active insulin on board; the duration or intensity of exercise) (53). It is very important to have a blood glucose meter available at all times, and that BG is measured immediately if a child reports symptoms of hypoglycaemia. A "first aid – hypo management pack" containing glucose tablets, soft drink and a small snack should be readily available in the classroom or in the child's bag and must be refilled with fresh supplies regularly.

The best way to confirm if a child with T1D is experiencing hypoglycaemia is to check the BG by finger-prick testing. If this is not immediately possible and symptoms are present the teacher/caregiver should act assuming hypoglycaemia is occurring.

A child experiencing hypoglycaemia must never be left unattended until the episode has completely resolved. If a child needs to leave the classroom to treat hypoglycaemia, he/she should be accompanied by a teacher or a classmate who can call for assistance if needed.

If a BG reading is  $\leq 3.9$  mmol/L (70 mg/dL), a plan of action to prevent a further reduction in BG must be put into action and includes, in the first instance, administration of 'fast-acting' carbohydrate in the form of glucose tablets or glucose gel (see ISPAD Guidelines chapter – Hypoglycaemia).

Children less than 50 kg of body weight should receive 0.3 g/kg of glucose. Older children and adolescents (>50kg) should consume 15 grams of glucose. In order to reduce the risk of 'overtreatment' of hypoglycaemia at school when BG values fall between 3.0 and 3.9 mmol/l (54 – 70 mg/dL) smaller doses of fast acting glucose may be administered (e.g. 0.15g/kg glucose).

A repeat BG measurement should be repeated after 15 minutes and the hypoglycaemia treatment repeated if needed.

Administration of more complex carbohydrates (e.g. fruit, bread, cereal or milk), can be added if the BG value was very low, or if the child was physically active prior to the hypoglycaemia episode to prevent any further recurrence (54).

Severe hypoglycaemia (resulting in loss of consciousness and/or seizures) can be followed by injury, coma, and in rare cases death (55, 56). School personnel should have clear instructions for managing an episode of severe hypoglycaemia should it occur. The young person should be put into a safe ('recovery') position, **nothing** should be administered by mouth, and an emergency telephone call for assistance placed immediately.

Giving intramuscular (IM) glucagon, if available, is the optimal treatment for a severe hypoglycemic event. Where appropriate / permissible it is strongly advised that school personnel are trained to administer IM glucagon (57).

The school should contact parents every time their child has had a severe hypoglycaemic episode.

### ***School Personnel – education and training***

It is acknowledged that it can be very difficult for parents of a child with diabetes to be confident that the school personnel will know how to deal with all the issues related to child's diabetes care. Similarly, from the teachers' point of view, supporting a child with T1D in the classroom may be daunting, especially if there is no previous experience with T1D. Both sides may be apprehensive, with parents feeling insecure at leaving their child in the care of others, whilst teachers may feel intimidated at the prospect of providing medical support that they were not trained to carry out.

Whilst in some countries it is accepted and expected that designated school personnel will provide support and assistance to young people with diabetes, in other countries such participation is prohibited (58). Nevertheless, it is widely acknowledged that supporting a child with diabetes in school is key to attaining good BG management and that school personnel knowledge about T1D and the special needs of young people with this condition is necessary to achieving this goal (59).

The following specific issues should be given consideration:

#### ***1. Education and training of School Personnel***

This is important. In the DAWN Youth initiative, an international web survey with 6789 participants from 8 countries, respondents rated the level of support provided by schools as the lowest. The majority of parents and young adults reported that teachers needed to be better informed about diabetes (73 and 58%, respectively) and needed to be trained to deal with emergency diabetes situations (75 and 68%, respectively) (60).

The education and training of school personnel about diabetes needs to consider the following questions:

- (a) **who** provides the information?
- (b) **what** resources should be used to do this?

(c) **how** to deliver the information and education needed?

(d) **to whom** should it be directed?

(a) **Who.** Parents / guardians of a child with diabetes entering or starting a new school for the first time should inform the school principal or the school administration about their child's condition. Together, they should agree on a strategy to inform and educate teachers and other relevant school personnel. Parents are generally the first to deliver this information, but the child's diabetes health care team may also participate in this process.

(b) **What.** School personnel should be directed to reliable, trusted, preferably endorsed, resources of information and education about diabetes, and should be cautioned about seeking information from other sources. National professional diabetes societies and other affiliated parent associations often provide access to such education resources. To facilitate worldwide access to trustable information, International Diabetes Federation (IDF) and ISPAD have developed an internet-based repository of educational material, which is available in ten different languages (61).

(c) **How. Education.** Delivery of information and education about diabetes to school personnel can be achieved using a variety of different formats and media. Face-to-face education sessions delivered by the diabetes health-care team or the use of web-based 'e-learning' education tools and provision of printed reading materials, either used alone or in combination, are the usual approaches. Specific education interventions have been developed and have been shown to be effective (59). Some national diabetes societies have also developed specific educational material for schools (21).

*Training.* Delivery and content of training is the responsibility of the parents / carers and the treating diabetes healthcare team; that is those parties responsible and accountable for the health of child. Training forms part of the informed consent process to enable parent / carers to authorise school personnel to deliver medical care to their child on their behalf.

d) **To whom.** Education of all school personnel is advocated. Whilst education is mainly aimed at teachers, physical educators and other teaching assistants directly supporting the child with diabetes, training and education of other key school professionals such as the school cooks / kitchen personnel is also recommended. Provision of information to fellow students of the child with diabetes (and their parents) can be very helpful and will facilitate inclusion and avoid potential discrimination. Pupils and families can be signposted to useful information resources available on the internet (60).

## *2. Storage of medication and supplies*

Schools should have a safe place to store medication and supplies. Insulin vials (e.g. when used with syringes), especially in hot climates, should ideally be stored in a refrigerator or at least in a cool room or similar insulated container. Insulin pens can stay at room temperature provided it is not too hot. Insulin pumps should be with the child all the time, but if disconnected (i.e. to permit physical activities or sports) they should be kept in a safe place.

Other supplies (e.g. blood glucose meters, CGM sensors) should be kept in an easily accessible place to be used when required. If school personnel are trained, glucagon injection kits should also be made available for treating severe hypoglycaemia and should be kept under refrigeration.

Teachers and school personnel have to be aware that students should have access to their devices and medication whenever needed.

## *3. Medication administration*

All children with diabetes should be provided with a safe place and adequate privacy to perform blood testing and insulin administration, should they request or desire it.

Whilst it is expected for all children with T1D to have their insulin administration delivered (or at least supervised) by a member of the school personnel (or by a nurse at school), this is not the reality for many places. School personnel may not agree to take on this responsibility and as it likely to be outside their scope of practice. School

staff must therefore volunteer to take on this role and cannot be “nominated or designated” to do so. Furthermore, in some countries it is forbidden for a non-health care professional to administer medications such as insulin or glucagon.

Families, together with the diabetes healthcare team, may need to make specific individualised arrangements with the school. If the school / school personnel cannot assume responsibility for performing or overseeing insulin administration, parents (or a designated guardian) may have to go to school to do it themselves.

In situations when it is either not possible or desirable to administer insulin boluses during the school day, adopting less intensive insulin administration regimens (e.g. twice daily injection regimen - using a combination of intermediate acting insulin (NPH) and regular (‘soluble’ insulin) may avoid the necessity of doing injections at school (62).

#### *4. Clarification of roles and responsibilities*

##### *a) Parent/Carer:*

Families will have the initial responsibility to communicate with the school administration and teachers about their child’s diagnosis of diabetes. Thereafter families, together with assistance from the child’s diabetes healthcare team, will need to outline the child’s requirements and agree a specific individualised DMP with the school personnel.

Parents / carers, together with the child’s diabetes healthcare team if necessary, should supply all the necessary equipment and medication needed to support the child at school. Contact numbers and addresses for emergency situations should also be provided / exchanged and documented in the DMP.

##### *b) Teachers/ other School Personnel:*

School personnel are responsible for the safety and care of the students during school hours. Ideally, they should be supportive and attentive and should respect the rights of the child with diabetes.

Students with diabetes have to be allowed to participate in all activities and to perform blood glucose monitoring at any time. School personnel should be trained on how to attend the child in cases of necessity – for example during hypos and symptomatic hyperglycaemia episodes.

Teachers should also be made aware that variations in glycaemia can interfere with attention and memory, but also with mood and behaviour (see below).

c) Child with diabetes:

Depending on ability students can also assume some responsibilities and participate in the diabetes management. They can measure glucose, take decisions and inject insulin, provided that there is supervision of an adult. Children and adolescents with diabetes are also responsible for bringing their diabetes equipment to school and carrying fast acting carbohydrate.

#### *5. Diabetes Management Plan*

Even if there is more than one child with diabetes at school, it is highly likely that their treatment will not be the exactly the same. Moreover, some children need support all the time whilst others may be more independent, so it is important that an individualised or personalised DMP is provided for each child to meet their specific needs.

The DMP is a formal document about the child`s specific diabetes management requirements at school. The DMP should be provided by the parents / carers of the child with diabetes and should be developed with the input from the diabetes healthcare team. The school should make ‘reasonable adjustments’ in order to ensure the DMP can be delivered. The DMP should have all significant information to guide school personnel in assisting children with diabetes during school hours. The parents / guardians are the ultimate authorities to direct the prescribed treatment for managing their child’s medical condition. The plan should be simple, clear and easy to be implemented.

The individualised / personalised DMP should include the following:

- *Identification*: Name, date of birth, parents name, age of diagnosis, and type of diabetes.
- *Contact information*: phone numbers of parents, physician/HCP, and emergencies contacts.
- *Monitoring*: Times to measure, target ranges of glucose, preferred locations for testing, CGM/iCGM information.
- *Insulin treatment*: type of insulin and device (pen, syringe, pump), guidance to doses adjustments, and formulas to calculate correction and carbohydrate doses.
- *Hypoglycaemia*: Individual symptoms, values that define intervention, type of intervention, glucagon orientation and situations that leads to calling for emergency assistance or taking to emergency rooms.
- *Hyperglycaemia*: Individual symptoms, values that define intervention, type of intervention, insulin doses.
- *Food*: Definition of the meal plan, modifications needed to the regular menu, authorization and instructions to participate in parties inside the school.
- *Exercise*: Authorization to participate in school sports, orientation on the use of carbohydrate and insulin before exercise depending on glucose levels.
- *Self-care*: Describe what procedures the child is able to do alone or with supervision – e.g. finger prick testing, monitor BG values and their interpretation, adjustment of food and insulin based on BG results, preparation and insulin injection.
- *“Hypoglycaemia-kit”*: provision and access to preferred fast-acting carbohydrate and glucagon.
- *Responsibilities*: informed consent, clarification and specification of specific responsibilities to support the child with diabetes

### **Neurocognitive issues**

Since glucose is the primary fuel for central nervous system (CNS) activity, diabetes could impact children's cognition either acutely or chronically. Both extremes of the blood glucose spectrum, hypo- or hyper-glycaemia, may adversely affect children's cognitive abilities and these decrements may persist after normoglycaemia has been restored (63). For some children, the neuroglycopenic effects of hypoglycaemia may precede the adrenergic effects, impeding their orientation and ability to evoke their problem-solving skills. In such instances, children may experience hypoglycaemia unawareness, impeding them from taking appropriate corrective actions or making their needs known to others. Children experiencing mild to moderate hypoglycaemia may be reluctant to report it to a teacher due to fear of embarrassment or social stigma. When any of these situations occur, the child with diabetes may not be operating at optimal levels of cognitive acuity and may miss crucial information that the teacher is presenting.

While there is firm evidence that acute hyperglycaemia adversely affects cognition during school, diminished energy, general malaise, and other symptoms of hyperglycaemia may also impede children with diabetes from optimal academic performance. Removing children from the classroom or keeping them at home when the blood glucose level is high may only compound these problems.

There is considerable evidence that children with diabetes may experience lasting neuropsychological impairments and neuroanatomical changes compared with other children (45, 46). Evidence supports both frequent hypoglycaemia and prolonged hyperglycaemia as potential mechanisms of these effects; children diagnosed with diabetes in the preschool years may face higher risks of these problems. The most prudent response to this body of research is to strive to maintain children's glucose levels within the normal range as much of the time as possible, an objective that is already consistent with the avoidance of long term complications, the minimization of diabetes burden and the preservation of quality of life. Some consolation can be taken from this line of research in that studies have not demonstrated that the magnitude of cognitive decrements that have been documented are sufficient to manifest in academic or functional impairments in children, and so many children

may be at low risk of these adverse effects. Nonetheless, children with diabetes who experience frequent or pronounced glycaemic perturbations may benefit from periodic neuropsychological evaluations.

### *Psychological adjustments*

Studies reporting rates of psychological problems such as depression and eating disorders in young people with T1D vary, with some indicating rates similar to the general population and others indicating much higher rates. Some studies suggest that the rate of depression may be two to three times higher for adolescents with T1D (64-66). Adolescents with T2D are also at increased risk for psychological problems, especially those that are associated with excess weight, including poor self-esteem and body image, depression, anxiety, and behavioural problems (67). Disordered eating and weight control behaviours (e.g., insulin omission, strict dieting) are also common in young people with T1D and T2D. This elevated risk of psychological problems is disturbing because depression and eating disorders are related to more frequent episodes of DKA, earlier onset of complications, and poorer glycaemic control, treatment adherence, and quality of life. Few studies have examined relations between psychological problems in young people with T1D and academic outcomes, although in a small, cross sectional study higher depression scores were associated with poorer academic performance in young people with T1D (68).

Fear of hypoglycaemia is common among young people with diabetes and their parents and is likely to result from the fear of physical consequences and social embarrassment related to the behavioural, motor, and emotional changes that may occur during hypoglycaemia. Thus, young people with diabetes, or their parents, may engage in potentially negative health behaviours to prevent it, such as taking less insulin than needed or overeating. Fear of hypoglycaemia may be most common in young people who have experienced severe hypoglycaemia, particularly involving loss of consciousness, and in adolescents who have social anxiety. No studies have examined relations between fear of hypoglycaemia and school performance. But, acute hyperglycaemia that may result from attempts to prevent hypoglycaemia (i.e.,

diminished energy, general malaise) may impede children with diabetes from optimal school performance. Since fear of hypoglycaemia is more common in young people with social anxiety (69, 70), school avoidance behaviours such as attempting to stay home, leave school, or go to the nurse's office may be especially common. No studies have formally examined fear of hypoglycaemia in teachers, but our clinical experience indicates that teachers may also develop fear of hypoglycaemia related to concern about the consequences of hypoglycaemia and being the only adult in the room capable of treating it. Teachers should be educated about the symptoms of fear of hypoglycaemia and encouraged to discuss their concerns with the child's parents.

Schools provide a unique opportunity to identify and treat psychological problems in young people with T1D by serving students where they already are. School nurses, guidance counsellors, and other personnel can serve as a bridge to community mental health resources by identifying early warning signs of emerging psychological problems, providing psychosocial screenings in school and collaborating with school administrators, parents or legal guardians and, where appropriate, community workers to ensure appropriate referrals to address mental health needs of students with diabetes. Since many students with diabetes have accommodations permitting them to visit the school nurse as needed, school nurses need to be aware of the traditional symptoms of mental health disorders, as well as those that are specific to young people with diabetes (e.g., frequent requests to check blood glucose level in fear of hypoglycaemia, attempts to take less or no insulin in disordered eating, and somatic complaints despite euglycaemia in depression or anxiety).

### *Family influences*

When younger children are not in school, the burden of diabetes management falls almost exclusively on parents or legal guardians. In early adolescence, the transfer of responsibility from parent to child begins, but requires a delicate balance of fostering the adolescent's growing independence with maintaining control of the diabetes care. Longitudinal studies suggest that when parents give up responsibility too early, adolescents have poorer adherence and deteriorating glycaemic control

(71). Thus, regardless of the age of the child, diabetes management depends heavily on family communication (72), problem solving (73), and supportive parental involvement (72, 74-76). School personnel should understand that parents will have varying preferences for communication frequency and format, with some parents requesting daily (or more frequent) phone interaction and others simply requesting copies of weekly or monthly blood glucose logs. Schools should work with families at the beginning of each school year and as needed to negotiate and coordinate communication expectations. School personnel should be aware of red flags related to a lack of parent involvement in diabetes care, such as a complete lack of communication, running out of diabetes supplies in the school setting, and chronic hyperglycaemia. When concerns are noted, school personnel should communicate with the child's diabetes healthcare team.

#### *Peer influences*

Peer relationships may also influence diabetes outcomes. Since young people with diabetes have frequent peer interactions in school, it is important for both healthcare providers and school personnel to be aware of these influences. A review of the literature provides more evidence that social conflict is harmful, and that social support is helpful (77). In a one-year longitudinal study, friend conflict predicted a decline in psychological well-being and deterioration in HbA1c (78). Research indicates that adolescents with T1D have difficulty engaging in diabetes self-management tasks around peers due to fears about being judged negatively and concern about social acceptance and therefore may have more vulnerability to social pressures that conflict with adequate diabetes self-care. Teachers should be aware of peer influences and facilitate referrals to guidance counsellors or outside counsellors as needed.

#### *Socioeconomic influences*

Economically disadvantaged children face a wide range of risks for suboptimal academic performance including food insecurity, lower parental educational levels, decreased family emphasis on school success, diminished self-efficacy for school

success, more frequent absences, more frequent changes of schools during the academic year, reduced access to supplementary materials (paper, pens, pencils, etc.) and equipment (computers, internet access) (79). When a child with diabetes faces these socioeconomic obstacles, that child's likelihood of academic success will be quite low without timely, appropriate and concerted interventions to prevent poor academic outcomes. Health care providers, teachers, and school personnel who work with children who are disadvantaged socially and economically should be even more attuned to the academic needs and circumstances of these patients.

### *Experience of abuse and bullying*

Children with disabilities are at greater risk of experiencing all types of abuse compared to children without disabilities or chronic disease. The largest population-based study on this issue conducted in USA found that children with disabilities were about four times more likely to be neglected or abused and three times more likely to be sexually assaulted (80). The association between abuse and children with chronic diseases such as T1D is less well defined. Recent population-based studies of Swedish schoolchildren have however shown that children with chronic conditions have an overall increased risk of physical abuse (81). The risk increases with the number of chronic conditions, where children with more than two conditions turns out to be the most vulnerable group. Of 13 chronic conditions studied, none was protective against abuse. Children with neuro-psychiatric conditions were the most vulnerable group, followed by those with speech defects, mental illness, overweight, hearing and visual impairments. Young people with T1D may have a risk of abuse double that compared to healthy children. The highest risks are most evident in financially poor families and in immigrants (81). Chronic health conditions in children are also associated with a higher risk of bullying compared to healthy children (82).

### **Exams and Stress**

Acute transient episodes of hypoglycaemia or hyperglycaemia are likely to occur in situations associated with stress including exams. Both hypoglycaemia (83) and hyperglycaemia (84, 85) are associated with acute transient cognitive impairment.

Acute hyperglycaemia (BG > 15 mmol/L, 270 mg/dL) has been associated with reduced motor cognitive performance in adults with type 1 diabetes (84) and has been similarly observed in children with BG levels > 20 mmol/L (360 mg/dL) (85). Families have also reported effects of hyperglycaemia (15 – 18 mmol/L, 270 – 324 mg/dL) on mood and coordination (86).

Children with diabetes who experience mild hypoglycaemic (< 3.8 mmol/L) or hyperglycaemic (> 15 mmol/L) events may also suffer from fatigue, distraction, inability to focus, decreased memory, and mood variability, all of which can affect their overall behaviour and learning capacity.

There is also evidence that chronic hyperglycaemia (particularly in young boys) might result in poor neurocognitive outcomes (87). However, long-term studies on hyperglycaemia and cognitive functioning are not yet available (46, 88).

In order to allow children to perform at their best potential, special provisions should be put in place for exams or any other stressful assessment situations:

These include:

- 1) Allowing the child with diabetes to have access to BG testing equipment and hypoglycaemia treatment supplies at all times during the examination or evaluation.
- 2) In case of hypoglycaemia occurring 30 minutes before, or at any time during the exam session, the child should be given an extra 30 to 60 minutes to complete the examination or evaluation.
- 3) In cases of hyperglycaemia (e.g. above 15 - 20 mmol/L) without ketosis, child should be given an extra 30 to 60 minutes to complete the examination or evaluation.
- 4) Hyperglycaemia with ketosis should be addressed as any other intercurrent illness (fever, vomiting – immediate support by parents or ambulance).
- 5) If there is a specific 'attendance requirement' towards academic recognition / grading, children with diabetes should not be penalized when

absent from school to attend regular scheduled medical appointments.

### **Legal perspectives**

Type 1 Diabetes (T1D) is recognised at common law as a disability (89) (90) (91) (92). The United Nations *Convention on the Rights of Persons with Disabilities* recommends that “effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.” (93) Most Western countries have legal frameworks encompassing disability and discrimination law to protect the child with T1D and facilitate equal opportunity and participation in school activities on the same basis as their peers. Insulin is an essential but dangerous drug that if given incorrectly, may have serious consequences. Because of this, laws exist to regulate access and administration of insulin (94) (95) which becomes an issue when authorised personnel are not present in the child’s school.

In most Western countries parents are legally bound to send their children to school and ensure attendance. So, when the child is compulsorily removed from the parents’ protection and sent to school, it is required by law that the school provide equivalent, if not better care of the child with T1D. Children with T1D should be able to enjoy the same benefits of school attendance as their peers and should not be excluded because of their medical needs.

Maintaining normoglycaemia during school hours will not only reduce the risks of long term health complications of T1D but will also facilitate the child to participate in all aspects of school life (96). Accordingly, schools risk legal exposure if they do not execute therapy designed to facilitate normoglycaemia for the child with T1D.

To comply with law, administration or careful supervision of insulin requires legally authorised school personnel with informed parental consent. In many countries where school nurses are available they often have the requisite legal authorisation to administer insulin as part of their qualifications – otherwise education providers rely upon school personnel to execute the necessary complex care, which is usually outside of the individual personnel member’s scope of practice. In the absence of a school nurse, it may be possible in some jurisdictions for an adult volunteer (including teacher) to act as an

agent on behalf of the parent. (97) But several requirements need to be fulfilled for this to be possible - particularly the obligation for ongoing training (a healthcare team / school responsibility), for informed parental consent and competency reassessment (a parent responsibility). There is no separation of responsibility between supervision of a drug / medication being administered by another person (e.g. whether insulin is delivered via injection or an insulin pump) and the actual administration of the medication.

Healthcare teams and parents should seek to establish a supportive relationship with the child's school team and tailor the training to the child's individual needs, thus creating an understanding of why certain medical interventions are important for that individual. It is critical that all school personnel with an education role for the child with T1D receive the necessary training. The person(s) acting as the parent's agent for insulin administration should be named in the students' DMP.

Schools have a non-delegable duty of care (16) to their students and staff to take reasonable care to protect them from harm which is reasonably foreseeable (98) (99). There are obvious foreseeable risks associated with not providing appropriate management of T1D. School personnel have a duty of care to the child with T1D to appropriately manage the effects of low and high blood glucose levels according to parent and healthcare team instructions. Some staff may have to be trained in administration of glucagon as a rescue medication. However, duty of care does not extend to automatically having authorisation to administer medication including insulin or injectable glucagon or undertake invasive procedures.

Discrimination occurs when a person with a disability (including T1D) is treated less favourably than a person without the disability in the same or similar circumstances. (89) (90) (91) (92). Discrimination is unlawful when it occurs in an area of public life such as in school. Young people with T1D have a significantly increased risk of being exposed to issues of discrimination. This can have a significant impact on self-esteem and cause feelings of stigmatisation and fear of being different from their peers (100). Consequently, a child with T1D may have increased missed school days and the associated effects of poor school attendance (101).

Informed consent is a person's voluntary decision about medical care, including diabetes self-care, that is made with knowledge and understanding of the benefits and risks involved (102). Only the parent or legal guardian in the case of minor can provide informed consent. The child's DMP require the informed consent of the parent and signed by parent. All information, risks and associated circumstances must be disclosed to the parent to ensure that their consent is valid.

Parents have the responsibility and duty to make decisions, including medical decisions, on behalf of their children until the child reaches the age of 18 years. Parents have a legally recognised duty to care for their child and are obliged to provide for the maintenance, protection and education of their child, and must exercise their parental power and care for their child in the child's best interests.

Whether a child can self-manage certain aspects of T1D and/or self-administer insulin can only be determined by the parent. A parent cannot be expected to "fill the gap" of school resources and attend to their child's medical management during the school day but with a cooperative approach between parents and schools and modern communication technology providing sensor glucose data in real time to parents, there is a real opportunity for a truly cooperative approach.

Treating health care professionals are responsible for the medical decisions and prescribed treatment for the child with T1D in line with their scope of practice. HCPs have very clear, legislated accountabilities and responsibilities to their patients. (103)

Education providers must consult with parents and make "reasonable adjustments" to facilitate prescribed medical care to allow for children with T1D to participate in education on the *same basis as their peers* and eliminate harassment and victimization. "Reasonable adjustments" for a child with T1D include insulin administration if prescribed during school hours (32) The prescribed medical needs may also include glucagon administration if required, Continuous Glucose Monitoring (CGM) understanding and intervention (including using predictive arrows) and use of advanced insulin pump settings if prescribed by the healthcare team. This should be clearly documented by the healthcare team and parent in the child's individual DMP

(16). A child's medical treatment and management are not to be dictated by the resources currently available to the school. Neither Education Providers nor another Health Professionals are permitted to change the prescribed treatment without permission. School personnel must be trained to provide or supervise care prescribed by the diabetes team. Their scope of practice and liability for their performance is to be determined by their employer.

The responsibilities of the 3 main stakeholders are:

- The parent is responsible for the medical decisions made on behalf of their child. They must give free and informed consent for decisions about the health and well-being of their child.
- The doctor is responsible for prescribing medications and the healthcare team is responsible for the individual medical adjustments.
- The school and their line manager (government) are responsible for executing the parental and medical orders outlined in the child's DMP and for facilitating the training of their school personnel, as recommended by parent and healthcare team.

## **Type 1 Diabetes in Schools in Less-Resourced Countries**

T1D is both challenging and demanding and, wherever children live in the world, sending their child to school is a very anxious and daunting time for parents, carers and also for the child with diabetes.

In less-resourced settings this can be compounded by other issues such as lack of insulin and diabetes supplies, food insecurity, transport challenges and even local conflict and war.

School is a time of learning, making friends, having fun, and finding peer groups. However, for children with diabetes, this can instead be a time where they are excluded or isolated or stigmatised.

As health professionals caring for these vulnerable young people, we must ensure as best we can so that they receive the same educational opportunities as other children in their community, providing the potential for fruitful employment and the chance for further education.

### *Key messages for teachers in less-resourced countries:*

- Children with diabetes, wherever they live, should not be limited in what they can do, and should be able to attend school, receive an education and live happy, fulfilled lives.
- Most schools are very supportive; however, a child's nurse or doctor can visit the school to explain diabetes and its management in a clear and concise manner, or a parent or carer might feel confident enough to do this themselves with support from the local team. Such visits and contact with the school and the health professional can be extremely encouraging to parents and children.
- A simple individualised management plan for the child with diabetes is a good guide for the teacher to follow day to day at school. This should include step by step instructions for management of emergencies and contact details of parents/carers.

- Many children may be on twice daily injections, however, if they are on multiple daily injections which entails a lunch-time injection at school, a safe, private place is required for them to give their injection.
- A refrigerator or cool place / container (e.g. clay pot) is required for storage of insulin particularly in hot climates.
- Children with diabetes should be allowed to test their blood glucose level as necessary depending on availability of test strips.
- School personnel should be educated on the management of hypoglycaemia (hypo), and parents should ensure that appropriate treatment and re-treatment is available at the school.
- Emergency assistance should be called if the child is unable to eat or drink to treat the hypo.
- School personnel need to be aware that prior to and during physical activity the child with diabetes may need to eat or drink to avoid hypoglycaemia.
- When blood glucose levels are high (hyperglycaemia), children should be allowed to drink water, and go to the toilet as necessary.
- Teachers should be aware that other children may tease the child with diabetes. Simple explanation to classmates is encouraged.
- Teachers should also understand the classic symptoms of type 1 diabetes, so they can identify undiagnosed children in the future. It is not at all uncommon for type 1 diabetes to be mistaken for malaria, appendicitis, and pneumonia in countries with less resources. Posters have been developed in local languages highlighting the symptoms of type 1 diabetes, and the warning signs for diabetic ketoacidosis (104)

The International Diabetes Federation (IDF) 'Life for a Child' initiative has developed an education website that includes resources for schools (105). Also, the IDF 'Kids and Diabetes in School' (KiDS) project tackles diabetes (including types 1 and 2 diabetes, and healthy food choices and lifestyle advice) management in school by the development of visual materials, coupled with an education programme for school personnel, parents and children (106). This project was successfully trialled in Brazil and India and is now available in multiple languages.

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