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Do we need more support for young people with Type 1 Diabetes in secondary school settings? A UK perspective
Editorial for Diabetes Management

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Incidence rates of type 1 diabetes mellitus (T1DM) are increasing globally [1] and in the United Kingdom T1DM is amongst the most common forms of chronic illness affecting children and young people [2]. As a chronic and serious health condition, effective management of T1DM requires adherence to daily management regimens to avoid both short and long-term adverse outcomes. A diagnosis of T1DM thus has a significant impact on the lives of both those young people living with the condition as well as their families and others close to them.

Throughout adolescence, young people with T1DM are required to take on a greater independent and autonomous role in the management of their condition, yet more than 85% of children and young people with the condition in England and Wales did not achieve target levels of blood glucose control according to a recent audit [3]. For young people faced with the usual developmental tasks and social pressures associated with adolescence, managing their T1DM can be perceived as an additional burden and thankless task. Young people we have spoken to as part of our research highlight their frustrations stemming from both the long-term nature and the 'invisibility' of the condition. For them, there is no obvious 'reward' for undertaking necessary management behaviours and given the nature of the condition, even if they do their very best they can sometimes perceive themselves as having 'failed' when their blood glucose levels are out of the target range of 4-7mol, as per the International Society of Pediatric and Adolescent Diabetes (ISPAD) guidelines [4]. Children and young people with T1DM are entitled to the same opportunities as their peers in schools, but for young people with T1DM, having diabetes has the potential to impact adversely on both their ability to learn and their schooling experience more generally. For example, off-target glucose levels outside of the target range can lead to real problems with cognitive functioning with obvious implications for learning [5], [6]. A young person with T1DM may also miss schooling due to a number of diabetes-related events, including absence from school as a result of illness specifically related to their condition. Additionally,

social issues related to their diabetes (such as feeling different from their peers or even experiencing bullying) can be a problem for some young people with T1DM in the school environment.

In the UK, children attend primary school up until the age of 11 (Year 6) and schooling is typically provided in a single classroom setting by a limited number of familiar teaching staff. From age 11 onwards, children move into secondary school (high school). This represents a significant shift for young people. For example, they may not be with the same classmates every lesson, they are required to move around school buildings for different classes and lessons are taught by different subject teachers. In diabetes clinics, Children's Diabetes Nurse Specialists (CDNSs) observe that the transition from primary to secondary school settings is often marked by a deterioration in blood glucose control amongst their patients [7]. Additionally, diabetes care has changed substantially over recent years. More frequent testing and injecting as well as a marked increase in the use of insulin pumps mean that more support in schools is required than in the past. Schools have a moral, ethical and legal obligation to provide a safe and healthy environment in which young people with T1DM can learn and have the same opportunities as their peers. Although there are examples of good practice, currently in the UK many young people with T1DM (and their families) report that they are not receiving the proper care and support they need in secondary school settings [8]. This needs to be addressed to ensure that young people with T1DM have a better experience in school, an improved quality of life and a future with fewer complications linked to their condition. It is vitally important that young people with T1DM receive personal, age appropriate and holistic support that is agreed with and adhered to by all those involved in their care. Schools are an essential element in providing this support.

Following a successful campaign by a group incorporating various national health charities (including Diabetes UK and the Families with Diabetes National Network), as of September 2014 the Children and Families Act [9] means that schools in England have a legal duty to support pupils with medical conditions including diabetes. This Act stipulates that all schools should have a medical conditions policy, as well as an individual healthcare plan (IHP) for any pupil with T1DM. Schools must also have a suitable level of insurance in place and it must be clear both who is responsible for the medical conditions policy and how the policy is implemented in the school setting. The medical conditions policy should include clear procedures around the administration of medicines, including insulin and should be regularly reviewed and audited to ensure that arrangements are in place and are functioning effectively. Safe and effective care for young people with T1DM must now by law be embedded within the school system.

To provide safe and effective care, good communication and effective collaboration between all parties involved is essential. This includes, but is not limited to, school management, teaching staff, young people themselves, health care staff and parents. Parental involvement in the development of IHP's is vital and schools should do all they can to facilitate ongoing communication with those with parental responsibility. There is often a significant shift in the amount of regular contact parents and

carers have with a school when their child moves into secondary education. School staff need to be aware that parents can feel very nervous about approaching the school and that feeling 'judged' by teaching staff can create barriers [10]. Parents may be unsure about how best to get in touch with relevant staff members or they may find certain members of staff elusive, in particular those in more senior positions. Schools should ensure that they are accessible to parents and that when parents express a wish to work with the school to ensure that their child with T1DM gets the support they need, that this is both respected and facilitated. Young people and their parents should be allowed to attend any education sessions and updates outside of school that are facilitated by health care professionals as part of their care. Most importantly permission to attend these sessions in school time should be given if relevant. This depends on school staff understanding that such structured education sessions are learning opportunities, in which children and young people can be taught to improve the management of their diabetes.

Young people themselves must be included and engaged in the development of their own IHP. Systems put in place should be discussed with them, so that they actually work for the young person. IHPs should be personal, adequate and age appropriate and, as is the case with the medical conditions policy, this means that they need reviewing regularly, at least annually, to ensure that procedures are being implemented effectively. For example, a common practice we are aware of is for schools to allow young people with T1DM to skip dining hall queues, but is the young person actually happy doing this or do they feel embarrassed because they have been singled out? Are they, for example, permitted to have peers accompany them? School staff need to recognize the invaluable contribution that the friends and peers of young people with T1DM can make in terms of providing a supportive network and the importance of this to young people (e.g. [11], [12]). Provision for sensitively and appropriately increasing the awareness of T1DM amongst pupils generally and facilitating peer support for young people with T1DM should be made in schools. Teachers and staff need to have sufficient awareness of T1DM and their own roles to ensure that this happens.

Other key parties include health care professionals generally and CDNSs specifically. CDNSs are an obvious source of expertise for schools to draw on and are in our experience often very keen to assist schools to support pupils with T1DM. CDNSs can provide appropriate information and toolkits (for example, examples of IHPs), as well as a wealth of knowledge and advice, including involvement in staff training. Health care staff are, in our experience, often very willing to provide such services to schools – either meeting school staff in the school environment or the healthcare setting - as they clearly see the significant potential benefits for their patients.

We would argue that a crucial factor in determining how well young people with T1DM are supported at school is the general ethos of the school, as well as the attitude of head teachers, governors and responsible bodies. Providing good support for pupils with T1DM requires the clear backing and support of the school leadership team. In our own research [13], we have reported cases where young people themselves state that their one perceived source of understanding and support at

school, described variously as 'the first aid lady', 'the school nurse' and 'the woman in the medical room', is seen by the young people themselves as powerless and generally disregarded by teaching staff. The school leadership team need to ensure that time is made available for all staff to receive adequate training so that they are aware of the procedures for managing a young person with T1DM, understand their own role and can deal with any emergency situations that might arise. Teachers and other staff may be willing to support young people with T1DM, but without sufficient training they can feel understandably ill-prepared, as well as anxious about what they can and cannot provide in terms of medical care provision [14]. Additionally, schools should have working procedures in place to ensure that all staff, including temporary staff, are informed about and are aware of any young people with T1DM (or indeed other health conditions) in their teaching groups. The onus should not be on young people to identify themselves to teachers and similarly teaching staff should not be expected to have to track down this information. Systems should be developed with input from those who will be using them, i.e. the young people and teachers, to ensure that they function effectively and are adhered to in the long term.

The Children and Families Act 2014 applies only to England, but nation-specific guidance is also under review or recently revised in Scotland and Wales and a suite of resources for use in all nation states of the United Kingdom has recently been produced by Diabetes UK (see [8]). The increased recent focus on this important issue is very welcome, but it should be recognized that an improvement in diabetes care in schools will not happen overnight and needs to be part of a long-term and sustainable strategy with all relevant parties involved [15]. Supporting young people with T1DM in schools must be seen as a joint endeavor and not the sole responsibility of one person or even one professional group; collaboration, joint working and communication are essential. Young people spend a significant proportion of their time in the school environment and there is an urgent need to ensure that young people with T1DM are supported to manage their condition optimally in school settings to ensure they are not needlessly held back by their T1DM in pursuing and achieving their goals for the future, whatever they may be.

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