

# Parent–adolescent communication and the shift to autonomy for young people with type 1 diabetes

Matthew Timms

**This article shows how good parent–adolescent communication is vital for the achievement of positive outcomes for young people with type 1 diabetes. Conflict with parents is a normal part of adolescence, but it can be more challenging when the adolescent has type 1 diabetes. Parental involvement can determine levels of adherence, but the sharing of responsibility between parent and child can also be an obstacle during the transition to autonomous self-management. This article considers whether healthcare professionals should promote adolescent autonomy during consultations and encourage parents to help their child achieve independence. Autonomy in adolescence may be key to optimal control and parents should be advised on how they can help during this transition.**

The following article illustrates findings about parent–child communication, conflict and shared responsibility in the management of type 1 diabetes during the adolescent period when responsibility is gradually shifting away from the parent. It includes case report details of a patient seen at a paediatric diabetes outpatient clinic and considers their case in respect of the wider evidence. The findings suggest that young people might disengage with the diabetes service if healthcare professionals do not pay attention to issues surrounding communication, autonomy and responsibility. The case report exemplifies what can happen when responsibility shifts from parent to young person and how we as healthcare professionals can assist during this transition.

It has been said that diabetes is a family disease (Solowiejczyk, 2004) because family interactions, communication styles and the supervisory role of parents contribute to its management (Williams et al, 2009). The complex responsibilities involved in managing type 1 diabetes, such as

blood glucose monitoring or handling episodes of hypoglycaemia and hyperglycaemia, are very demanding for families (Kaugars et al, 2011). Effective monitoring of the treatment regimen by parents is of vital importance during childhood as adherence has been identified as a key predictor of positive health outcomes (Quittner et al, 2008). Children who have their diabetes monitored well by their parents normally achieve good glycaemic control and improved HbA<sub>1c</sub> results. However, the monitoring process can be difficult, especially during adolescence as there is a major shift in organisation within the family. Adolescence is a time to renegotiate and redistribute responsibility for tasks related to diabetes management (Hanna et al, 2005). It is believed that parental monitoring can limit the transfer to independent management of these tasks (Hafetz and Miller, 2010). In fact, Hanna et al (2012) state that the most challenging aspect of diabetes is the transition of care responsibility from parents to young people.

It is recognised that blood glucose control in

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## Article points

1. Adolescence is a time to renegotiate and redistribute responsibility for tasks related to diabetes management.
2. Poor communication or a parent taking too much control can result in poor adherence to management regimens and risk-taking behaviour by the adolescent.
3. Parents need to be advised how to positively support the transition from shared management to autonomy for their adolescent child with type 1 diabetes.

## Key words

- Adolescence
- Autonomy
- Communication
- Conflict
- Parent
- Shared responsibility
- Type 1 diabetes

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**Page points**

1. Family involvement is essential for adherence to diabetes management programmes for children and adolescents.
2. The transition to autonomy and self-management can be complicated in adolescence.
3. The physiological and psychological changes in adolescence can prompt risk-taking.

an adolescent with type 1 diabetes is complex and is dependent upon relationships between family, community and healthcare professionals. Butler et al (2008) showed that family involvement is critical for successful implementation of intensive treatment for the adolescent with type 1 diabetes. Parental involvement in diabetes management is often focused on the performance of tasks and is said to decrease during adolescence (Hanna and Guthrie, 2003).

Butler et al (2007) suggested that adolescence is a time of upheaval where the young person has to deal with the influence of peers, school life and developing their own identity, as well as all the physiological changes that occur. A young person with type 1 diabetes has the added responsibility of developing autonomy regarding the self-management of their diabetes. Spear (2013) proposed that we can begin to understand how young people with type 1 diabetes think, feel and behave if we consider the cognitive and biological changes that occur during adolescence. This must be combined with a consideration of the cultural, economic and psychological factors that lead to disruption in a young person's life, for example, peer pressures or relationships.

**Case report**

This case report shows what can happen to diabetes management during adolescence if it is too tightly controlled by parents. At his three-monthly visit to the paediatric diabetes outpatient clinic, Mickey, a boy of 14 years of age with type 1 diabetes, and his father reported very good diabetes management and glycaemic control. Mickey had a 5-year history of type 1 diabetes and began insulin pump therapy (IPT) from the point of diagnosis. During the previous 2 years, Mickey and his family had self-funded the use of continuous glucose monitoring (CGM) alongside IPT. Mickey's most recent HbA<sub>1c</sub> was 48 mmol/mol (6.5%) suggesting that his glycaemic control was excellent. However, after recording Mickey's HbA<sub>1c</sub>, a download of the glucometer, insulin pump and CGM raised a cause for concern. A Diasend® (Animas® Corporation, West Chester, PA, USA) analysis over a 1-month period showed a total of 547 glucose readings, a large proportion of which were episodes of

hypoglycaemia. It was found that Mickey's glucose targets were set between 4 and 5 mmol/L (and he would often drift into hypoglycaemia because of this "tight" control. The targets had originally been set by very proactive parents.

Mickey's parents, particularly his father, were very engaged with the management of their son's diabetes. Past research has shown that positive parental involvement does create better outcomes for the young person with diabetes (Hanna and Guthrie, 2003). However, concerns have been raised into whether taking control of a young person's diabetes can have a negative impact on their management and glycaemic control (Dashiff et al, 2008). The physiological and psychosocial development of an adolescent may lead to risk-taking behaviours and changes in mood, and it should be considered whether setting targets and taking tight control of the young person's diabetes is the right thing to do.

Adolescence is a time when people discover their identity and become more independent. During the appointment, Mickey confessed that he would often ignore the advice of his CGM and drift into hypoglycaemia before treating it. Mickey's father and the paediatric diabetes specialist nurse (PDSN) were shocked. Mickey, however, seemed very self-assured with his risk taking. The PDSN advised that taking such risks could potentially be very dangerous. Mickey timidly agreed with this and confirmed that he knew he should be following the CGM for his own safety. Mickey's father was not pleased and, when approached for his reasoning, Mickey mentioned that he was very busy with his friends at school and diabetes was not always his main focus.

Healthcare professionals and parents should consider how they begin to influence and communicate with the young person with diabetes and how they can begin to understand their behaviour and the risks they take. Healthcare professionals may need to encourage parents to take a step back and allow their child to accept responsibility for their own diabetes management.

In this case, the PDSN cautiously suggested that they speak with Mickey alone, in turn diffusing the conflict between father and son. Mickey's father reluctantly agreed to leave the clinic room.

Now alone, Mickey began to explain that his diabetes comes second when socialising with his friends. The PDSN suggested that Mickey should be in control of his diabetes and not to let his diabetes control him. Mickey seemed happy with this statement. The PDSN assured Mickey that his father only wanted what was best for him, including his safety. Mickey agreed, but stated that his parents “need to back off sometimes”. With this in mind, the PDSN asked if they could speak with his father alone to relay Mickey’s feelings towards his diabetes. Mickey was happy for this to happen. Before leaving the room, the PDSN asked that Mickey try to stop taking such risks. Mickey acknowledged this, and the PDSN suggested a follow-up meeting at school in one month to check his progress.

Mickey’s father calmly entered the clinic room as Mickey sat outside in the waiting area. The PDSN explained that Mickey found socialising with his friends very important and consequently pushed his diabetes to the back of his mind. Mickey’s father, having calmed down, seemed to realise that his son was becoming more independent. He mentioned that diabetes had played a huge part in their lives, having cared for Mickey’s from such an early age. The PDSN suggested that Mickey could be rebelling because his regimen was too tightly controlled. Mickey’s father agreed with this suggestion. The PDSN also reiterated what Mickey said about his parents “backing off”. Surprisingly, Mickey’s father asked the PDSN if they thought it was right for them to take a step back. The PDSN concurred, assuring Mickey’s father that they would follow Mickey up regularly at school and raise concerns if necessary.

Overall, the PDSN intervention provided a positive step forward for Mickey and his father. The PDSN was able to facilitate the changes in responsibility by acting as an advocate for the family and reassuring Mickey’s father that they would help with the transition of care.

Mickey was reviewed in outpatient clinics three times over a 6-month period. Mickey’s father attended all three meetings and was always the primary communicator with both the PDSN and diabetes consultant. Mickey provided input to the conversation when prompted either by the father or the PDSN. There was little indication as to whether

he preferred this method of communication and consultation.

Following this particular case report, findings would suggest that Mickey preferred to speak with the PDSN alone as he was able to explore his feelings, without the pressure of his parents in the room. This would be considered at the next clinic appointment.

### Parent-adolescent communication

A study by Dashiff et al (2008) has highlighted that a focus on the effectiveness of parent-adolescent communication is imperative. There are issues surrounding parent-adolescent conflict, which can have an impact on adherence to regimens, shared responsibility and the development of the child’s autonomy. Communication between parents and their adolescent child is, therefore, essential, particularly during the transition to autonomy and increased responsibility for diabetes self-management (Dashiff et al, 2008).

A PDSN caring for and working with any child or young person with type 1 diabetes should consider their patient’s family relationships. They should observe patterns of communication as they are in a pivotal position to guide families into developing communication that enhances positive health outcomes (Habich, 2006). Dashiff et al (2008) found that interventions to reduce parental control of communications with healthcare professionals may improve adolescent satisfaction with the treatment programme. It also has to be considered whether the healthcare professional should encourage the adolescent to take the lead during consultations if we are to promote patient satisfaction and autonomy. Seiffge-Krenke (2002) and Alderson et al (2006) have stressed the importance of respect for the young person’s developing autonomy.

The responsibility lies with the PDSN or consultant to seek ways of teaching parents ways to improve methods of communication. These methods should facilitate adolescent autonomy, without offending or questioning parenting or family morals, values and beliefs. To overcome this, the PDSN can encourage communication that provides a positive outlook on life. Dashiff et al (2008) suggested that healthcare professionals should ask questions that promote problem-solving and questions that

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### Page points

1. Parent–adolescent conflict can affect diabetes management.
2. Conflict over management tasks can affect regimen adherence in adolescents.
3. Shared responsibility of management between parent and child is optimal when communication is positive and conflict is low.

gain understanding into the adolescent's struggles and successes in diabetes management. Instead of providing the young person with direct answers to specific questions about diabetes, they could be encouraged to find out the answer themselves. This could possibly be achieved through discussion or education. Wysocki et al (2008) recommended that achieving meaningful changes in young people's communication behaviours through debate with parents and healthcare professionals may result in lasting effects that translate to durable changes in the management of type 1 diabetes.

To relate this to the case report, it is evident from practice that diabetes education sessions provide a communication platform for young people and their families. The PDSN could invite Mickey and his family to attend a structured education session along with other families. This would provide peer support for Mickey, as well as for his parents. It is then possible that the healthcare professional could facilitate and encourage good communication between young people and their families.

### Impact of negative communication

There is a risk of negative diabetes outcomes in families where communication between the parent and adolescent are ruled primarily with conflict and control (Dashiff et al, 2008). Hanna et al (2003) also found that negative diabetes outcomes correspond with negative parent–adolescent communication. When considering the case report, it was recognised that Mickey was content to allow his father to communicate during consultations; however, Hanna et al (2003) suggest that the amount of acceptable parent involvement at consultations should be discussed between parent and adolescent beforehand. It is argued that parents could assume that their young person agrees with their own beliefs and opinions, and may fail to recognise their child's assertion of autonomy.

Healthcare professionals as providers of education and guidance for diabetes care should be aware of the dynamics of parent–adolescent communication during clinical encounters (Dashiff et al, 2008). It is important to identify that some forms of communication could have a damaging effect on health outcomes. As healthcare professionals, we could focus on the development of programmes

to improve parent–adolescent communication. This could include behavioural interventions that target family communication and problem-solving resolution, as this has been said to enhance family diabetes management and reduce conflict (Wysocki et al, 2008).

### Parent–adolescent conflict

Parent–adolescent conflict plays a critical role in all of the recognised theories of adolescent development (Viikinsalo et al, 2005). Kyngas (2000) and Viikinsalo et al (2005) believe that conflict is often a result of differences in parent–adolescent perspectives of diabetes management. This is possibly due to usual tensions between parent and adolescent, exacerbated by the demands of the treatment regimen. Past studies (Anderson et al, 2002) have shown that the number of management tasks can cause conflict, which may lead to adherence issues.

Carroll and Marrero (2006) have found that parental reminders about diabetes management were associated with high levels of parent–adolescent conflict. It has been argued that reminders are characterised as “nagging” or “giving orders” (Dashiff et al, 2008). Parents believed their adolescents responded to this with irritation and, thus, reduced the amount of control they had over their own diabetes management as a retaliation, resulting in poor compliance (Carroll and Marrero, 2006). An example of this might be the young person who snacks at school or college when they are away from the confines of parental control. It could be assumed that Mickey was “irritated” by his diabetes management due to the intensity of his regimen, originally promoted by his parents.

Past research has focused on maternal involvement in diabetes-related tasks and monitoring (Palmer et al, 2011). However, Bumpus et al (2006) acknowledged the important role that fathers play. Palmer et al (2011) also found an unexpected negative association between fathers' behavioural involvement and adherence. It was highlighted that behavioural involvement that may be detrimental for adherence included “nagging” (Dashiff et al, 2008) or intrusive control preventing the adolescent from achieving positive outcomes (Wiebe et al, 2005). It has, however, also been

found that some young people valued the quality of their relationship with their fathers (Palmer et al, 2011) and reported improved adherence with increased paternal involvement. Recent literature suggests that healthcare professionals should consider parental involvement and behaviour, and take a multidimensional approach (Palmer et al, 2011) to assessing these behaviours. This suggests that, in Mickey's case, the level of parental behavioural involvement should be reduced in order to promote adolescent autonomy and independence.

### Shared responsibility

It has been acknowledged that increased parental support creates better outcomes for the adolescent with diabetes (Hanna et al, 2003). Assuming that communication is positive and conflict is low, shared responsibility between parent and adolescent is recognised as the optimal approach to diabetes management during adolescence (Helgeson et al, 2008). Hanna et al (2012) found that parental support of autonomy is closely associated with shared responsibility of diabetes management. Some adolescents in Hanna et al's (2012) study, who believed their parents were more supportive of their autonomy, were happier with a greater level of shared responsibility. However, adolescents who did not allow the sharing of responsibility in diabetes management struggled for autonomy; Butner et al (2009) considered this as typical during middle adolescence.

The age of the adolescent may determine the level of autonomy and shared responsibility, Hanna et al (2012) having reported that an increase in adolescent age determines the views of the adolescent about these issues. It could be assumed (and practice shows) that a child of 13 years of age will still have some dependence on their parents, but a 16-year-old may feel completely independent. Hanna et al (2012) concluded that the adolescent's perceptions of parental support of autonomy declined with age, likely due to the adolescent spending more time away from home and with their peers (Bearman and La Greca, 2002; Hanna et al, 2012). Parents have also reported a decline in responsibility, as their child gets older (Ingerski et al, 2010).

With all this in mind, Masche (2010) suggested that respecting adolescents' autonomy is important for healthy family functioning and healthcare professionals should seek to advocate the development of autonomy. All of the evidence throughout the literature states that adolescent autonomy is integral to achieving positive outcomes for diabetes management. This leads us back to Mickey, the 14-year-old boy, potentially seeking independence but taking risks as a result of the intensive diabetes regimen imposed by his parents. An approach that supported his autonomy may well eliminate the risk-taking behaviour.

### Conclusion

The case report is intended to highlight the problems healthcare professionals may face when dealing with a young person with type 1 diabetes and their families. Adolescence is often the time when adherence is compromised, and this article hopes to help healthcare professionals understand how adolescents feel and what we can do to help them achieve the best possible outcomes.

Positive communication between parents and adolescents promotes positive diabetes outcomes. Eliminating the risks of conflict will minimise adherence issues and risk-taking behaviours. Young people with type 1 diabetes need to develop autonomy and parents should support this transition. Young people could be encouraged to see the PDSN or consultant independently without the parent present. If this is possible, responsibility can be shared between the parent and young person, and over time parents can begin to take less responsibility for their child's diabetes management, knowing that they have supported them through a difficult period of change and transition.

It is evident that healthcare professionals and parents sometimes fail to recognise the development of autonomy in the young person with type 1 diabetes, and greater attention should be paid to improving communication and parental support. The paediatric diabetes outpatient clinic is the ideal place to observe young people and how they interact with their parents, and to encourage the kind of supportive

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communication with minimal conflict that allows a smooth transition to adolescent autonomy and eventual self-management of diabetes in adulthood. ■

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