ISPAD Clinical Practice Consensus Guidelines 2022: Diabetes in adolescence

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1. Summary of what is new/different

- Modern insulin therapy produces normal or minimally delayed puberty.
- Despite recent technological advances in the care of diabetes, achieving optimal glycemic control during adolescence remains challenging.
- Peer support through online social media is an increasingly important source of advice.
- Motivational interviewing by psychologists is effective in optimising outcomes in teenagers.
- Diabetes distress during adolescence may lead to less consistent use of insulin and consequent hyperglycaemia.
- Mental health needs during adolescence may supersede other healthcare needs, requiring other specialty team involvement and prioritising interprofessional communication.
- Mental health assessment is complex in adolescents and screening is recommended in those with diabetes, particularly those experiencing recurrent diabetic ketoacidosis (DKA).
- Preconception counseling should begin during early puberty.
- A care ambassador/patient navigator leads to better transition outcomes.
- Screening for social determinants of health should be standard care in adolescents.

2. Executive Summary, Recommendation & Grading of Evidence

Adolescence is the transitional phase of development between childhood and emerging adulthood. Healthcare and emotional needs are distinctly different from younger children and physically mature adults.

- Puberty is a period of physiological insulin resistance, exaggerated in adolescents with Type 1 diabetes (T1D) (B).
• Pubertal developmental is normal or minimally delayed in the modern insulin era (B).
• Worsening of glycemic control is commonly reported in puberty and persists throughout adolescence (B).
• Youth should be directed towards relevant local peer support groups and made aware of the diabetes online community at diagnosis (B).
• Include asking in consultations about patient participation in peer support communities online and offline (what patients learn & how these communities support them) (B).
• Supporting communication between the young person’s family, their healthcare team and school through individual health plans and school nurse support is advised (B).
• Authoritative, non-helpless parenting styles with clear and realistic expectations should be encouraged (C).
• Diabetes services should recognise the significant mental health burden within young people with T1D and have mental health clinicians trained in diabetes to support them (B).
• Screening to identify early markers of mental health problems requiring treatment is advised (B).
• Biological markers such as episodes of DKA and chronically very high HbA1c, should be considered red flags for mental health problems (B).
• In order to increase awareness of the risks of unplanned pregnancy and poor metabolic control pre-conceptional counselling should begin in puberty in all girls (B).
• Hormonal contraception can be used in those with diabetes with no microvascular complications and less than 20 years of disease duration, though morbid obesity, severe hypertension, or the presence of multiple cardiovascular risk factors are contraindications for using combined hormonal contraception (E).
• Despite absence of studies in teenagers with diabetes, long-acting reversible contraception is the contraceptive of choice in adolescence (B).
• The transition from pediatric to adult care should be a planned, organized process (E).
Youth mature at different rates and delay of transition based on the developmental needs of the patient, may be appropriate to optimize outcomes (B).

Transition planning, specifically utilizing care coordinators/patient navigators, can enhance post-transition clinic attendance and engagement (A).

Screening for social needs should occur at least annually for all patients and families with diabetes (C).

Diabetes care plans should accommodate unmet social needs, with appropriate referral to community resources when appropriate (C).

3. Introduction

Adolescence culminates in peak physical development, followed by psychological and cognitive maturation, autonomy and social independence. The combination of rapid physical and sexual maturation with subsequent neuro-maturation creates a period of physiologic and behavioural vulnerability. This is especially relevant to the management of chronic illness such as diabetes in which the endocrine changes of adolescence impact directly upon the physiology of glycemic control.

All adolescents vary in their adaptation and responses to change, and attitudes can be impulsive, iconoclastic and disruptive, often receiving a negative response from adults. Decrying adolescent behaviours has thus been a constant refrain of philosophers and social commentators through the ages (see Box 1).

Similarly in paediatric diabetes practice, highlighting the “difficulties” in interactions with adolescents and their behaviours is widespread with the clinical consequences being exemplified in data such as those from the Type 1 Diabetes Exchange in the US (Figure 1). These data showing a marked deterioration in metabolic control between the ages of 10 and 20 years, are not isolated to the US and are common across many other health care settings. These disappointing outcomes have not arisen or persisted due to clinical inertia. On the contrary, there is a plethora of medical literature examining the issues around adolescents and diabetes, including textbooks and chapters dedicated to this topic, and over 13,000 papers published since 2000 that can be found under a PubMed search of “type 1 diabetes and adolescence”.

There has also been a concomitant rise in the use of new diabetes-related clinical strategies that promised increased ease-of-use and the potential for improved adherence. Despite all of this clinical activity, we are arguably not making progress in improving diabetes-related outcomes for adolescents. This begs the question, why suboptimal diabetes outcomes during adolescence are seemingly so unchanged? Adolescence is marked by physiological and behavioural changes, many of which mitigate against euglycemia. These include pubertal endocrine changes leading to greater insulin resistance, evolving neurocognition with lessened impulse control leading to erratic meal and exercise patterns, poor adherence to treatment regimens and poor impulse control with hazardous and risk-taking behaviours. All of these changes are occurring in a context of an adolescent’s developing autonomy and independence, yet, in the context of chronic disease management, their need for ongoing support and some level of dependence on others. In T1D in particular, the evidence linking clinical outcomes in adolescence to ongoing parental engagement is robust.

The other apparent phenomenon that mitigates against improved clinical outcomes during adolescence has been the enormous rise in mental health issues, particularly anxiety, depression and disordered eating. Self-evidently, a functional psyche is the bedrock for the never-ending task of ongoing diabetes self-care. It is hard to maintain the tools of adaptive living such as motivation, cognitive flexibility and a long-term perspective when one’s psyche is injured. Consequently, mental health care needs during adolescence may be so immediate and of such severity, that they will occasionally supercede other health care needs in the short term. This in turn, will necessitate the involvement of other specialty health care teams and a level of multidisciplinary health care communication that is heightened and uncommon during other periods of diabetes management. The transitory and shifting nature of health care priorities, adds to the increased complexity of chronic disease management at this age.

The quest for optimal behavioural and physiological outcomes including diabetes-related euglycaemia can be tremendously challenging for patients and therapists. The purpose of these guidelines then, is to direct the reader to the evidence that there is, to
help them achieve these outcomes, in a transitory, but nevertheless challenging period of diabetes management.

4. **Endocrinology of puberty**

Puberty is a period of rapid somatic growth and sexual maturation, orchestrated by a complex interplay of hormones including, growth hormone (GH), sex steroids, and insulin, all of which can have a significant influence on the onset and progression of diabetes. In turn, diabetes and its attendant hyperglycaemia can also impact the onset and tempo of puberty and growth.

Puberty may be an accelerator for the onset of T1D and there is peak in incidence during the peripubertal years.\(^{14-16}\) there are gender differences in the age of onset of T1D, with younger age of onset in girls linked to their earlier start of puberty. The role of estrogen in modulating transcription of genes such as the IL-6 promoter, has been proposed to be one of the explanations for this variance.\(^ {17}\)

Pubertal insulin resistance (IR) occurs in those with and without diabetes and has implications for glycemic control and complication risk. Euglycemic clamp studies in non-diabetic children have demonstrated a transient reduction in insulin sensitivity with the start of puberty, a nadir in mid puberty and recovery seen by Tanner stage V.\(^ {18}\) This dip in sensitivity is exaggerated in adolescents with T1D and is 33-42% lower when compared to non-diabetic children.\(^ {6}\) IR is believed to be largely mediated by the pubertal peak in GH and IGF1 which follow the same pattern of rise and fall. GH levels are higher in T1D at all pubertal stages, thereby providing credence to the observation of increased IR in T1D.\(^ {19}\) Mechanistically, GH affects the insulin signalling pathway at the post-receptor level, leading to a state of IR.\(^ {20}\) This pattern of increased GH and IR also leads to exaggerated ketogenesis in T1D adolescents which could predispose them to early metabolic decompensation and DKA.\(^ {21}\)

Adolescence is also a period when glycemic control commonly deteriorates.\(^ {22}\) This occurs due to a combination of non-modifiable factors such as physiological IR, the effect of gonadal steroids, a rise in lean body mass leading to increased insulin requirements, and modifiable factors such as psychosocial and behavioural changes
which lead to reduced adherence with treatment regimens along with a decline in physical activity.20,23

Puberty also confers an additive risk for development of diabetic complications above and beyond the effect of the glycemic control. Recent data suggest an increased risk of vascular complications such as proliferative retinopathy and nephropathy in individuals with a prepubertal versus a post-pubertal onset of diabetes. This heightened risk is attributed to the effect of IR of puberty, the GH/IGF1 changes, androgens and the greater adiposity seen during adolescence.24

Diabetes can also adversely impact growth and pubertal development. Insulin and leptin are essential for normal GnRH neuronal function and a deficiency can therefore, lead to a state of hypogonadism. Studies from the early era of insulin treatment where suboptimal glycemic control was rampant, reported a moderate to severe delay in the onset of puberty.25 However, with the advent of modern insulin therapy, pubertal development is normal or minimally delayed and is seen to correlate with HbA1C levels.26-28 Ovarian hyperandrogenism and menstrual irregularities are other commonly reported problems seen in adolescents T1DM girls.25

Similarly, severe growth abnormalities such as Mauriac syndrome are now rare. However, subtle impairments of growth have been related to glycemic control.29,30 Blunting of the pubertal growth spurt with reduced peak height velocity have been described, though adult height is usually normal.30-35 This growth impairment is attributed to changes in the GH/IGF1 axis with lower IGF-1, IGFBP-3 and increased IGFBP-1 reported in adolescents with T1D, due to hepatic GH resistance caused by decreased portal insulin concentrations.29,31,32,34

Body composition changes with increasing weight are also evident during puberty, with girls in particular showing increased fat mass as a side effect of the intensified insulin regime and a subsequent state of relative leptin resistance.30,32,36,37 This in turn makes them prone to a PCOS phenotype and may contribute to an increased cardiovascular risk.25,38 Body habitus changes may also impact negatively on body image and provoke the development of eating disorders and insulin omission for weight loss, leading to worsening glycaemia and increased complications.39,40
5. Diabetes identity & communication in adolescence

5a. Communicating within the diabetes community

People (or parents of children) with diabetes spend most of their time managing diabetes alone. While interactions with the healthcare team are important, peer support plays a crucial role in day-to-day management and improves self-management and physiological outcomes. Understanding how communication within the diabetes community facilitates peer support and better self-management, can inform communication with the healthcare team, and aid development of effective interventions.

There are three main sites of communication: the diabetes online community (DOC), structured settings like peer support groups or peer mentoring programs, and everyday conversations and interactions with family, friends or peers.

Most communication within the DOC takes place on various social media channels like Facebook, Youtube, Twitter, or Instagram, whereas peer support groups, mentoring, and communication with peers and family/friends happen to a large extent face to face or via text messages. Young people with diabetes and their families turn to peer support, particularly for social and emotional support and sharing of personal experiences, but also for information about treatment options and reviews or discussion of new technology. The DOC has effective ways of policing knowledge and making sure no misinformation is spread; overall the quality of information shared was rated as high and reliable in a scoping review of the literature.

In communicating with each other, especially online, young people with diabetes draw on creative and humorous modes including visual and textual materials. They emphasize that they are persons first and that diabetes is only one part of who they are.

Analysing communication within the diabetes community thus highlights the importance of social and emotional support, as well as the holistic, patient-centred perspective that treats the individual in their own context.
5b. School

Young people with diabetes experience greater absenteeism and exclusion from school, poorer educational attainment and higher risk of unemployment. Contributory factors include lack of full-time school nurses, teacher knowledge of diabetes, access to diabetes tools, freedom to perform diabetes self-care, nutritional information in cafeterias, and communication between parents and school personnel. Improved communication between the young person’s family, their healthcare team and the school through individual health plans and school nurse support seems effective and telemedicine in school may support individual case management.

Students with T1D are concerned about ‘being different’ from their peers, which may inhibit self-care activities and lead to bullying. They reported relying for support on a small number of trusted close friends who could help at times of need whilst keeping their diabetes a secret from others. This peer support improves quality of life in school and is associated with better glycemic control. However, there is little evidence about how best to support young people to improve their resilience and coping in school or further education.

5c. Family

Several non-modifiable family demographic factors are associated with worse glycemic control, including African-American ethnicity in US studies, public health insurance, families with single parents or large numbers of children, reduced income and parental literacy. Warm and supportive family interactions are linked with better outcomes, particularly in adolescent girls. Authoritative, non-helpless parenting styles with clear and realistic expectations are correlated with better glycemic control and paternal involvement is important. Adolescent perception of negative parental tones in discussions about diabetes was associated with worse glycemic control whereas autonomy-supportive communication related to improved adherence.
Diabetes-specific family conflict is associated with poorer glycemic control and reduced quality of life in teenagers, suggesting that interventions focussed on promoting family teamwork and communication or referral for family therapy may prove useful. Most studies have been US-based and cross-sectional and don’t prove causality. However, a group intervention aiming to train families in teamwork around diabetes in the UK proved disappointing, mostly due to poor attendance, suggesting more individualised approaches are required.

5d. Interaction with health care services

Many young people with T1D and their families report significant communication problems with healthcare providers, with a mismatch in perceived priorities and difficulties obtaining the information they required to effectively manage their diabetes. A review of psychoeducational interventions, mostly delivered by non-psychologists, reports a modest benefit on self-efficacy of adolescents with T1D though little impact on glycemic control. Only a few studies utilised interventions delivered by members of the paediatric diabetes healthcare team as part of routine care. Communication designed to facilitate behaviour change known as motivational interviewing which could be incorporated into routine clinic consultations, has shown promise when delivered by trained psychologists but not when incorporated by trained paediatric diabetes healthcare staff into routine consultations. Nonetheless, there is good evidence that paediatric staff deemed to be ‘good communicators’ are more effective in promoting adherence in their patients and that training in communication skills is worth investing in.

6. Mental health disorders (see also Consensus Chapter on Psychological care of children and adolescents with type 1 diabetes.)

T1D seems an aetiological factor in de novo psychiatric presentations or causes pre-existing subclinical mental health problems to tip into psychiatric diagnoses.

Mental health assessment is complex in the context of adolescence and screening is recommended. However, in clinical practice, indicators such as DKA admissions, very high HbA1c and insulin omission or overdose evident on continuous glucose monitoring,
should be regarded as potential evidence of mental health problems and assessed accordingly.81-83

Mental health problems alongside T1D can potentially lead to early complications and significantly early mortality,84-86 usually through the interaction of mental health symptoms with insulin use. Mental health treatment should ideally be undertaken by clinicians with experience in diabetes.

6.1 Diabetes distress

Diabetes distress is the negative emotion or affect experienced by approximately 30% of adolescents with T1D.87 Diabetes distress has a complex relationship with the common mental health conditions, depression and anxiety disorders. The presence of diabetes distress can lead to overdiagnosis of depression and therefore clinical assessment is important to discern the cause.88,89 It is the presence of diabetes distress long-term rather than depression per se that is more strongly associated with chronic hyperglycaemia.90

6.2 Depression

Adolescents with depression present differently to adults, with a tendency to more somatic symptoms. Although core features remain of low mood, no enjoyment and negative cognitions, coexistent irritability or oppositional behaviour may lead to missed diagnosis. Somatic symptoms such as fatigue and brain-fog are less reliable because of overlap with T1D symptoms from hypo or hyperglycaemia.91 Questionnaire studies suggest 30% of youth with T1D have depression,92 whereas studies using diagnostic assessment in non-adolescent populations suggest rates closer to those without diabetes.93 These differences may be related to chronic negative affect (diabetes distress) regarding the burden of T1D, which can be misconstrued for depression; detailed assessment is necessary to ensure appropriate diagnosis and treatment. There is a high prevalence of depression symptoms in the early stages of diagnosis which usually resolve during adaptation.94 Regular screening for depression and co-occurring anxiety and diabetes distress will help identify those most in need of intervention.90 First line treatment for depression where available is cognitive behavioural therapy (CBT).95 In the absence of access to talking therapies or in more severe cases which do not respond
to CBT, use of antidepressant medication is indicated. Serotonin reuptake inhibitors (SSRIs) have the best evidence base for depression outcomes and improvements in glycemic control.  

**6.3 Anxiety disorders**

Anxiety disorders are characterised by intense anxiety in either specific or all areas of life with consequent avoidance. Like depression, anxiety in adolescents can be masked by what appears to be irritability or stubbornness. In the T1D adolescent population approximately 30% have significant anxiety symptoms and there is significant cross over with diabetes distress.

Generalised anxiety is described as ‘free floating’ with continual symptoms and no specific focus. There is substantial comorbidity with depression. As a counter to chronic uncomfortable feelings of anxiety, a person will compensate by avoiding as many stressful experiences as possible. In the context of diabetes, this could include not attending appointments, testing blood glucose or taking insulin.

Panic disorder is intense bursts of anxiety in which the person becomes overwhelmed by fear, often with prominent somatic symptoms such as sweating, and tachycardia, as well as intense feelings of impending doom. Panic can occur out of the blue or be related to specific experiences, such as using public transport. Panic episodes can also be superimposed on a background of generalised anxiety. Panic disorder is particularly complicated in T1D, given the extensive overlap of panic symptoms and hypoglycaemia.

Specific phobias are intense, overwhelming anxiety focused on a narrow area of life such as travel by air, particular animals or medically-related experiences such as having blood tests. They are the most common in the non-T1D adolescent population, with approximately 20% prevalence.

First line treatment for anxiety disorders where available is CBT. In the absence of access to talking therapies or in more severe cases, use of antidepressant medication is indicated. Like depression, SSRIs have the best evidence base.

**6.4 Drug and alcohol use**
Studies indicate that adolescents with T1D are not more likely to experiment with alcohol or other substances, than their non-T1D peers. However, young adult males with T1D are more likely to have a substance disorder diagnosis, which probably indicates a genesis for problematic use during the adolescent period. Clinicians should be aware that cigarettes, alcohol or drugs may be used by adolescents to manage diabetes distress. However, adolescents’ knowledge of the risks regarding alcohol use do not necessarily result in putting these ideas into practice.

6.5 Eating disorders and body image

Eating disorders are seen more frequently in the T1D adolescent population, with a varying prevalence of 1.6% using psychiatric criteria to 21% using specific tools designed for T1D. Key from a diabetes clinicians’ point of view, is the degree of overeating and insulin omission. Some people will have a binge eating picture with no under use of insulin and likely tendency to obesity, whereas some will have a normal eating pattern, but have weight or shape issues leading to insulin omission, usually with not very low BMI and high HbA1c. Most important to recognise is the degree of clinical risk associated with acute and chronic complications. Screening tools are useful where services have varying experience in assessment for disordered eating.

Treatment should maintain a shared focus between diabetes management and disordered eating, involving a specialist service or liaison between an Eating Disorder Service and diabetes clinicians.

6.6 Recurrent Diabetic ketoacidosis

There is growing evidence for the association of recurrent DKA episodes and underlying mental health problems, including self-harm and personality function. People with recurrent DKA have very high mortality at follow-up with an association with antidepressant use and prior psychiatric admissions. Although standard practice after DKA is re-education regarding sick day rules, mental health assessment prior to discharge is also advised. Services should use DKA recurrence as an indicator to suggest that an individual is struggling with their mental health, provide appropriate mental health intervention and thereby reduce risk of further DKA and risk of early mortality from acute and chronic complications.
7. Sexual health

7.1 Preconception counseling

Preconception counseling aims to promote self-care behaviors leading to healthy babies and mothers with diabetes. Frequently, medical care providers lack the knowledge to address reproductive issues in teenagers, yet adolescents with T1D have inadequate knowledge about the risks of hyperglycaemia during pregnancy.

Preconception counseling should begin during early puberty as unprotected sexual activity in young women with significant hyperglycaemia has significant risks for the individual and their offspring. The first phase of preconception care is "awareness counseling", provided well before the need for contraception or pregnancy care. Advice to young people regarding sexual health should consider religious, cultural and familial perspectives, and a non-judgmental approach to sexual activity or sexual orientation is important. The following should be discussed during medical visits.

- the importance of optimal glycemic control before pregnancy, to avoid risks to the developing embryo and fetus
- that ovulation is preserved and pregnancy may occur despite hyperglycaemia or menstrual irregularities
- family planning and contraception.

READY-girls is the only preconception counseling program that has been developed for young adolescents living with diabetes. This program has shown long-lasting benefits. READY-girls is available free of charge in English (www.diabetes.org/ReadyGirls).

7.2 Contraception

7.2.1. Barrier methods

Male condoms offer the best protection against sexually transmitted disease (STD) and substantial protection against pregnancy. Diaphragms, female condoms and coitus interruptus, a common practice among teenagers, are not recommended because they
are associated with high pregnancy rates.

7.2.2. Long-acting reversible contraception (LARC)

LARC, which includes intrauterine devices (IUDs) and the subdermal progestin implant, have become a first-line contraceptive choice for adolescents, even if they are nulliparous.\textsuperscript{118-121} LARC offers better protection against unintended pregnancy than oral contraceptives.\textsuperscript{119} The effect of LARC on glycemic control in very young women with diabetes has not been evaluated though it is the contraceptive with the lowest risk of thromboembolism in women with diabetes.\textsuperscript{122} Non-hormonal IUDs may be considered in the patient in whom hormonal methods are contraindicated.\textsuperscript{119} LARC does not protect against STDs nor are they associated with more episodes.

7.2.3. Combined hormonal oral contraceptives (OCs)

Young people with diabetes without micro- or macrovascular complications may use any hormonal method\textsuperscript{121} whereas those with complications should avoid using OCs, but may use IUDs or barrier methods.\textsuperscript{119,121} Newer OCs with a lower estrogen dose (≤35 μg ethinyl estradiol) and newer progestogens are not associated with detrimental effects on glycemic control or weight,\textsuperscript{123} though a recent epidemiological study suggested that OCs in young women with diabetes may be associated with poorer cardiovascular risk profile.\textsuperscript{124}

Young people with diabetes on OCs, should be monitored regularly for side effects. Diabetes per se is not a risk factor of venous thromboembolism,\textsuperscript{121} but the association with other risk factors should be considered. Very obese patients should be aware that hormonal contraception may have a decreased efficacy and higher risk of venous thromboembolism.\textsuperscript{125} Hormonal patches have shown the highest risk of thromboembolism in adult women with diabetes.\textsuperscript{122} Women should be educated about the signs of thromboembolism (abdominal pain, chest pain, headaches, eye, severe leg pain (ACHES)). Those with a history of thrombotic disease should not use combined hormonal contraception.\textsuperscript{121}

Polycystic ovarian syndrome, menstrual abnormalities and hyperandrogenism are prevalent in young women with diabetes.\textsuperscript{28,126} The use of an OC may be helpful\textsuperscript{25,127,128}
Progesterone-only OCs provide insufficient contraception for teenagers who are likely to forget the OCs. Sexually active young people should also be advised about the availability of the 'morning after' hormone pill.129

7.2.4. Hormonal Injections

Medroxyprogesterone injections have been associated with decreased bone mass gain, which may be especially detrimental for adolescents with T1D. Combined hormonal monthly injection could be considered for the patients with T1D with an erratic lifestyle who cannot have LARC but no safety study has been performed in patients with T1D.

7.2.5. Adverse pregnancy outcomes in the very young woman with diabetes.

Suboptimal glycemic control around conception increases the risks of congenital malformations, spontaneous abortion, and fetal death.25,128,130-138 A planned pregnancy in a person with diabetes in optimal glycemic control and good health carries only slightly higher risks than those in the general population but not as elevated as previously reported in those with poor metabolic control. However, most pregnancies in young women with diabetes are unplanned and associated with suboptimal glycemic control.132,133,139,140 A fifth of live-born infants of unplanned pregnancies in adolescents with Type 2 diabetes had major congenital malformations, despite recommendations about early counseling on contraception and prepregnancy counseling.141 Recent studies show worse outcomes in pregnancies in adolescents with diabetes and higher healthcare utilization during pregnancy,138 including a higher risk of preeclampsia and larger babies than adult women with pregestational diabetes.142 However, a nationwide Welsh study showed similar outcomes of pregnancies in both teenage and older mothers with T1D though hospital admissions during the first year of life were five times more common in the babies of younger mothers.136

Access to expert pregnancy management should include:

• prepregnancy care in order to plan a healthy pregnancy
• joint management by an obstetrician and physician with expertise in diabetes and pregnancy
• delivery in a hospital with expert maternal, fetal, perinatal, and neonatal care.
8. Becoming a Young Adult

8.1 Young adulthood and leaving home
The developmental stage from the late teens through the twenties has been defined as “emerging adulthood,” a period of significant competing educational, social, work, and financial priorities. As young adults with diabetes experience competing life priorities and decreased parental support, adherence and glycemic control may decline. Young adults with T1D are at risk for acute complications as well as chronic microvascular complications and early mortality. Young adults need specialized diabetes care and education, including counseling on diabetes self-management, health care navigation (e.g., maintaining supplies and appointments), and sick-day management. In addition, providing information about T1D for peers and colleagues – including risks, symptoms and treatment of hypoglycaemia – is important as the young adult develops independence.

8.2 Study and examinations
Most adolescents and young adults will be required to complete major academic examinations. Providers should discuss the cognitive effects of hypoglycaemia and hyperglycaemia. Reasonable accommodations for formal or standardized testing should be provided to students with diabetes. Accommodations should include free access to food (hypoglycaemia treatment), drink, and lavatory, as well as diabetes equipment (including blood glucose meter, continuous glucose monitor, and insulin delivery devices. Adjustments to insulin regimens and/or diet should be made accordingly to maintain euglycaemia during exams.

8.3 Employment
There should be no discrimination or stigma against people with diabetes in the workplace. Advice on employment and diabetes should include the following:

• recommendation to inform potential employers about diabetes
discussion of those careers which may be unavailable to persons with diabetes, e.g. police, fire, armed and certain public services, driving large goods vehicles or piloting airplanes (regulations vary between countries)

• preparing for the workplace with responsible diabetes self-care.

8.4 Driving

Hypoglycaemia is the main factor increasing driving risk in people with diabetes. However, this risk is mitigated with glycemic awareness, stable metabolic control and no visual disability, to the extent that in most settings, patients with diabetes are able to drive non-commercial vehicles. Regulations vary in different countries. Severe hypoglycaemia in the preceding months may cause authorities in some areas to delay granting a license. Counseling should include information on relevant regulations and hypoglycaemia prevention by blood glucose monitoring before driving, use of continuous glucose monitoring and appropriate food intake.

8.5 Transition from paediatric to adult care

In addition to assuming increased self-care responsibility, young adults will eventually need to transfer from paediatric to adult diabetes providers. The transition from paediatric to adult care should be a planned, organized process rather than a sudden and unanticipated transfer. Suboptimal transition and coordination may lead to fragmentation of care delivery and increased risk for adverse outcomes. Transition care challenges documented in the literature include inadequate transition preparation, prolonged gaps between paediatric and adult care, and increased post-transition diabetes hospitalizations.

Age at transition varies according to individual patient factors, the availability of appropriate adult diabetes services, and health system regulations. In some countries, patients must transition from paediatric to adult diabetes care at aged 18 years. Two observational studies from the U.S. suggest worse deterioration of glycemic control in young adults receiving adult care, compared to those still receiving paediatric care. While further research is needed to delineate optimal transition age and predictors of success, delay of transition based on the developmental needs of the patient may be
appropriate. Young adults with diabetes should continue to be seen by a diabetes team (whether pediatric or adult) every 3 months at minimum.

Some diabetes transition interventions have shown promising results, including dedicated young adult clinics, intensive transition coordination efforts and use of a care ambassador/patient navigator to support the transition process. Recently, randomized trials have shown increased clinic attendance and lower disengagement rates in young adults with appointment navigation/coordination support. Based on the current body of literature, specific transition recommendations include the following:

- development and sharing of a clinic-specific transition care policy
- transition preparation, education (including counseling on diabetes self-management, diabetes control and complications, health care navigation and differences between pediatric and adult systems) and readiness assessment by pediatric providers, ideally starting in the early adolescent years and at least one year prior to transition
- discussion with the patient and family as to the best time for transfer, based on preference and readiness, as well as regulations and availability of adult services; delay of transition until the early twenties may be appropriate for many, ideally with flexibility about transition age as the psychosocial maturity and circumstances of young adults vary widely
- identification of an adult service able to provide for the needs of young adults with diabetes
- documentation of a written clinical diabetes summary and transition plan
- utilization of transition care coordinators/patient navigators to assist with appointment scheduling and attendance, records transfer, and tracking to avoid loss to follow-up
- direct communication and handover between pediatric and adult diabetes care teams.
9. Groups Needing Special Attention

The adolescent and young adult periods pose significant challenges for people with diabetes due to competing priorities and developmental needs that are often unmet in traditional healthcare settings. For socially vulnerable groups, added biological, behavioural, and socio-environmental factors can further contribute to inequity in medical and psychological outcomes. The Social Determinants of Health are a set of factors beyond the personal choices and behaviours of individuals, related to one’s socioeconomic status, environment, and social relationships that greatly influence one’s overall health status. Social determinant domains include economic stability, neighbourhood and built environment, education, social and community contexts, and healthcare. Social determinants of health are directly tied to social vulnerabilities including economic status or social class, and can be further exacerbated by racial-ethnic status, gender, or geographic location, among others. Globally, it is estimated that social determinants of health account for 45 to 60% of the variation in health status and can result in large inequities in myriad health outcomes, including in diabetes, life expectancy, across continents, countries, states, and regional areas.

Socially vulnerable adolescents with diabetes, disproportionately experience negative effects of social determinants, which act as competing priorities to diabetes self-management and act as major contributors to health outcomes. Adolescents are in a vulnerable period of their lives where they are starting to become independent from the family unit and when economic, social, educational, and behavioural gaps may become more pronounced, especially in the context of social vulnerabilities. Social vulnerability increases the risk of developing diabetes by 2-fold in youth and furthermore contributes to double the risk of poor glycemic control, 1.5 times higher complications, and 2 times higher premature mortality. Moreover, low access to high-quality medical care and decreased care engagement compounds these health outcome risks, leading to delays in diagnosis and management and increased utilization of emergency care. In countries and regions that systematically marginalize certain vulnerable groups such as women or racial-ethnic minorities, the unequal distribution of
material resources and social advantages has grave effects on health and diabetes.\textsuperscript{187-189} Special attention is needed for socially vulnerable adolescents with diabetes, to prevent progression to adverse outcomes. Ultimately, while cooperation of housing, food, governmental, and health sectors may be necessary, to impact diabetes outcomes at the population level,\textsuperscript{179,190} interventions in the delivery of diabetes care may have significant impact. First and foremost, screening for social determinants of health and vulnerabilities should become a standard of care. The World Health Organization and numerous other international and national organizations have pushed for standardized screening measures to identify social determinants at the point of care.\textsuperscript{190} Knowledge of the social determinant of health barriers such as underemployment, housing and utility insecurity, food scarcity, interpersonal issues or social isolation, and lack of access to necessary medications could greatly impact diabetes care plans and mitigation strategies.\textsuperscript{176,179} In addition, multiple local community-based resources are now available to aid material and mental health needs, which can be leveraged to enhance diabetes self-management for adolescents with diabetes.\textsuperscript{179} Group diabetes care formats should be encouraged for socially vulnerable adolescents with diabetes, as peer networking has demonstrated improvement in care engagement and outcomes at this developmental stage and for marginalized youth who may not have strong social support networks for diabetes care.\textsuperscript{191} Overall, healthcare providers, healthcare clinics, and larger clinical systems need to create policies that promote and prioritize equitable care to all adolescents with diabetes. Programs that evaluate and treat diabetes in the social context are urgently needed. Several studies addressing housing, food security, and linkage to high-quality healthcare have shown promising improvements in diabetes outcomes among adults,\textsuperscript{179} but few research studies and clinical interventions have focused on highly vulnerable adolescents who have unique developmental needs and need additionally tailored care.\textsuperscript{178,192} In addition, the powerful force of unconscious or implicit bias and its effect on healthcare delivery and care engagement, needs to be more fully realized in the care of socially vulnerable adolescents with diabetes, who are often already marginalized by healthcare providers.\textsuperscript{193} Ultimately, increased awareness and tailored care for socially
vulnerable adolescents with diabetes, will improve generations of health outcomes into adulthood.

Conclusion?
“Our adolescents now seem to love luxury. They have bad manners and contempt for authority. They show disrespect for adults and spend their time hanging around places gossiping with one another...... they are ready to contradict their parents, monopolize the conversation in company, eat gluttonously and tyrannize their teachers.” - Socrates

“If there would be no age between ten and three-and-twenty, or that youth would sleep out the rest; for there is nothing in the between but getting wenches with child, wronging the ancienry, stealing (and) fighting” - Shakespeare. A Winters Tale Act 3, Scene 3.

“...adolescence is a time of extreme bad taste and what might be called conformist rebellion, or rebellious conformity.” - Theodore Dalrymple
Figure 1: Serial data from the T1D exchange\(^1\) highlighting adolescence as a period of deteriorating metabolic control over two time-intervals (2010-12 in red and 2016-18 in blue).
References


144. Peters A, Laffel L. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American


White M, O'Connell M, FJ C. Transition in Type 1 diabetes mellitus from a tertiary pediatric center: what are we doing before they walk out the door? *Diabetes Manag* 2012;2:379-84.


