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## Diabetes in adolescence

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### Summary of what is new/different

- Pre-conceptual counseling should begin early during puberty
- New recommendations for type of contraception that should be used for girls are made.
- Transition programs and care for young adults are now included.
- Mental health problems that may be associated with poor metabolic control should be treated early.
- Adherence remains that greatest impediment to successful deployment of diabetes-related technologies.

### Executive summary and Recommendations

- Adolescence is the transitional phase of development between childhood and emerging adulthood.
- Health care and emotional needs are distinctly different from younger children and physically mature adults.
- Carers should be alert to recognize the signs of mental health problems (depression, eating disorders, illicit drug usage, etc.) and the occasional need for psychiatric treatment (E). Carers also

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should consider cognitive issues such as attention deficit and personality disorders that may impact upon adherence.

- Many adolescents may experience a deterioration in metabolic control – attributable to one or several of the following:
  - endocrine changes leading to increased insulin resistance (B),
  - erratic meal and exercise patterns (C),
  - poor adherence to treatment regimens (C),
  - eating disorders (C), and
  - hazardous and risk-taking behaviours (C/E).
- It is essential to develop appropriate communication skills to facilitate teaching and education, and recognize the need for privacy and confidentiality for this age group (E).
- To-date, psychoeducation interventions have demonstrated modest benefit on psychological outcomes, but no effect on glycemic control (B).
- Maintaining parental support and involvement throughout adolescence is associated with better outcomes (C/E).
- Providing health education opportunities utilizing strategies that optimize self-care behaviour and that involve open-ended discussion, problem solving, negotiated target setting, and the use of modern technology are recommended (B/E).
- Education and advice on a variety of health care matters, including employment, driving, alcohol, drugs, sexual health, and contraception, should be provided taking into account background cultural and religious influences (E).
- 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 (E).
- Hormonal contraception can be used in patients with diabetes with no microvascular complications and less than 20 years of disease duration (E).
- Long-acting reversible contraception has been accepted as a first line choice during adolescence (B/E), but no studies have been performed in teenagers with diabetes.
- Organize regular screening for diabetes complications (E).

- Encourage understanding of the need for and immediate benefits of improved metabolic control (C/E).
- Recognize that young people mature at different rates and may have differing views on the appropriate age of transfer of their care to young adult diabetes services (C/E).
- Planned coordinated transition to adult care should be provided at the most appropriate time (E).

## Introduction

Adolescence is the transitional phase of development between childhood and emerging adulthood that incorporates the biological and psychosocial changes of puberty. It imposes unique challenges on the individual with diabetes, the family, and the diabetes care team (1, 2). Although the majority of adolescents adapt well to the challenges of puberty, it must be recognized that their health care and emotional needs are distinctly different from those of younger children or older adults.

Adolescence involves training to become an independent adult and may result in failures and mistakes as well as success.

In the context of type 1 diabetes many adolescents may experience a deterioration in metabolic control (3–6) often attributable to erratic meal and exercise patterns (7, 8), poor adherence to treatment regimens (9–12), hazardous and risk-taking behaviours (1, 2, 13, 14), disordered eating behaviours (15–20), other mental health issues (21) and endocrine changes associated with puberty, leading to greater insulin resistance (22).

Changes in body habitus, particularly weight gain in females (3, 5, 23-26) may be unwanted diabetes related side effects, sometimes associated with changes in the tempo of pubertal maturation (26, 27) provoking insulin omission to effect weight loss (12, 16, 18). It is therefore recommended (1, 2, 28-33) that those providing care for adolescents with diabetes should:

- Understand the psychosocial and physiological development of adolescence (1, 2). This includes the recognition of the need for young people to shift (around the age of 10 yr onwards) from 'concrete thinking', with limited abstract capacity for understanding time perspectives or consequences of their actions, into adult cognitive capacity with a more realistic perspective of the future, which is achieved at a variable rate toward late adolescence (34).
- Recognize that chronic conditions may inhibit some young people from exploring life, while others deliberately explore risk-taking behaviour involving their diabetes care.
- Develop communication skills [e.g., trusting, authoritative (not authoritarian), allowing adequate time, open questioning, patient-centred, observing non-verbal messages and confidentiality].
- Understand that attending to the developmental needs of young people may be just as important

for quality of life as diabetes specific treatment (35, 36).

- Recognize the intensity of the changing social environment on behaviour. Adolescents experience a strong need to fit in and be accepted outside the family – most importantly by peers.
- Acknowledge the emerging differences in lifestyle and changing needs of adolescents. Exploring various life styles is part of identity development and includes experimentation in many domains, most commonly in the company of peers.
- Identify the components of care unique to adolescents.
- Have an awareness of the likelihood of clinically significant mental health issues including anxiety, depression and disordered eating (21)
- Provide planned transition to adult care at the most appropriate time (36).

The weighted evidence base supporting these recommendations has been reviewed in both the Australian National Health and Medical Research Council guidelines (31), UK National Institute of Clinical Excellence (NICE) guidelines (33) and American Diabetes Association (30, 37).

The emerging needs of adolescents due to developing independence and lifestyle changes

These needs relate to the following:

1. Over-riding importance of belonging to a peer group and fitting in to the group's social norms and behavior.
- Experimentation and exploration of different lifestyles which conform less acceptably with family expectations and routines.
  - Increasing independence from parental care.
  - Sense of invincibility and not-yet developed cognitive skills to fully understand the consequence of today's behaviour on future outcomes
  - Expectation for privacy and confidentiality.
  - Expectation for the right to consent or to deny consent to medical treatment.

- Pressures of academic achievement and competition.
- Entry into the work force.
- Exposure to smoking, alcohol and illicit or recreational drugs.
- Variable sleep patterns with lack of regular routine in day to day activities.
- Different levels of physical activity: sometimes major increases in sporting activity, but for many others, lowered physical activity with greater time spent on computer games, the Internet and television ('screen time').
- Difficulties in following advice and responding to conventional health education. Changing goals for diabetes self-management may not be on their priority list.

#### **Identifying the components of care that are unique to adolescents**

Most aspects of optimal care of adolescents with diabetes have not been subjected to rigorous enquiry, hence results are sometimes conflicting. This perhaps is reflective of the variable findings associated with factors likely to achieve optimal adolescent adherence and self-management (38).

Extensive review of psycho-educational interventions have concluded that they may have modest benefit on psychological outcomes but not on glycaemic control, although the methodological quality of most studies was moderate to poor (39-41). Recent robustly designed randomized controlled trials of motivational interviewing interventions through training programs for pediatric diabetes teams appear to lead to no improvement in either psychosocial measures or HbA1c levels (42).

*Suggested care strategies might involve:*

- Developing a trusting relationship between the adolescent and the diabetes care team, including through familiarity with staff and continuity in care (1, 33, 43). Adolescents report

better self-care when health care professionals are motivating (1, 44).

- Helping the adolescent to clarify priorities and have a target-driven or goal orientated approach (45). When there is conflict between the needs of diabetes management and the adolescent's social development and peer activities, a stepwise approach with interim achievable goals can be used to bridge competing priorities
- Providing well directed education to help understand the physiological changes of puberty, their effect on insulin dose, difficulties of weight control and dietary regulation.
- Organizing regular screening for early signs of complications to encourage a practical understanding of the options available and the immediate, long-term and individual benefits of improved metabolic control.
- Recognizing the emerging maturity of the adolescent, encouraging self-reliance and self-efficacy thus allowing consultations to be increasingly directed towards the adolescent but also retaining the trust and support of parents (46).
- Helping the adolescent and parents to negotiate new levels of parental involvement in diabetes care tasks, which may involve non-verbal strategies for communicating (e.g., text messaging).
- Helping parents in their changing role from full responsibility towards a gradual transition to cooperative care with the adolescent. This role change needs to be slow and gradual as continued parental support and involvement in day to day care is a strong determinant of improved clinical outcomes. This is based on evidence that parental support and involvement throughout adolescence is associated with better outcomes. (1, 46-51). Identifying and advising on which parenting styles are more likely to be successful than others [see Table 1 and (52, 53)]. The **authoritative** parent sets age-appropriate demands respecting the maturity level and developmental needs, carefully explaining reasons for prohibiting certain behaviors and agreeing on strategies for behavior together with the young person in a respectful dialogue. The authoritative parent, however, does not bargain

about serious matters and has a clear goal of what is important in the long run. Authoritative parents do not need much support but need medical information. The **authoritarian, rigid** parent gives orders, puts his/her own ambitions first and does not consider needs and feelings of the child. The rigid and demanding families may need support to develop more adequate parenting individually or in groups. The **lenient, permissive** parents are highly empathetic who seem to care too much about their children, over- identify themselves with the needs of their children and hate hurting them by getting into conflicts over routines. The **unconcerned, neglectful and indifferent** parents may have significant mental health problems keeping them from understanding and helping their children. Neglectful parents require a careful social work-up to explore the roots of dysfunction.

**Table 1. Parenting styles according to L Steinberg (52) and freely interpreted by K Berg-Kelly 2007 (53)**

	<b>Demanding Challenging</b>	<b>Not demanding Not challenging</b>
<b>Empathic with young person</b>	Authoritative	Lenient Permissive
<b>Non-empathic Cold</b>	Authoritarian Rigid	Unconcerned Neglectful Indifferent

*Emerging independence is best pursued gradually:*

- Having an index of suspicion for signs of mental health problems such as depression, disordered eating and eating disorders, “diabetes burnout”, illicit or recreational drug use, mental slowness, attention deficit hyperactivity disorder (ADHD) and neglectful or abusive family situations. Identifying the need for, and effectiveness of, specialized psychological counseling in some situations (54). The HEADSS technique (acronym for Home, Education, Activities during spare time, Drugs, Sexual activities and Suicide Depression) is helpful when screening for psychosocial problems that might interfere with self-management (55).
- Providing health education, utilizing strategies that promote optimal healthcare behavior



[See ISPAD Guideline Chapters on Psychological Issues and Education]. Although there is consistent evidence that knowledge *per se* is predictive of better self-care and control this association is weak in adolescence (1). Thus, while it is essential that adolescents are provided with information about diabetes and its care, providing this information by conventional education alone may be insufficient to lead them to adopt optimal health care.

- Encouraging the adolescent to participate with parents and health care team members in making decisions about diabetes management.
- Offering a variety of educational opportunities including open-ended adolescent-orientated discussion and negotiation (53), discussing health-related quality of life issues (54), problem solving, target setting (45), age-appropriate written materials, CDs/videos, text messaging (56), the use of the internet, social media, peer involvement and group learning.
- Facilitated meetings with peers who have diabetes in order to receive advice, reflect and share experiences and reduce feelings of isolation (57).

### **Sub-optimal metabolic control**

The DCCT has unequivocally shown that intensive insulin therapy reduces risk of long-term vascular complications, largely through improved HbA1c levels, and that better metabolic control in the early years of diabetes is also important in reducing this risk (58, 59). Metabolic control commonly deteriorates during adolescence in many, but not all, patients with T1D (60-63). This may be due to physiological and to psychosocial influences, leading to insulin resistance, poor treatment adherence, eating disorders, and depression (6, 48). Certain demographic and socioeconomic factors are also associated with higher HbA1c (60, 61). Metabolic control during adolescence appears to have a greater association of microvascular complication in later life when compared with subsequent metabolic control in adult years (64).

The availability of continuous subcutaneous insulin infusion (CSII) pumps and subcutaneous continuous glucose monitoring (CGM) devices have increased in recent years (62; 65). Use of these technologies either alone or in combination may benefit some adolescents in terms of improved blood glucose control and reduced hypoglycaemia frequency (66), but is only observed in those patients who maintain strict adherence with the treatment regimen (62, 67). Interestingly though, and against the overall trend in paediatric control, in one large survey of Swedish, German and Austrian adolescents a lower mean HbA1C of 0.3% in Swedish adolescents appeared to be associated with a tripling in the rate of severe hypoglycaemia (63). However, it is recognised that acceptance and adherence rates with CSII and CGM use are typically lower in adolescents with T1D and may be a limiting factor in their use (62, 68, 69).

The health care team should also consider the following:

- socializing with peers is of utmost importance to most adolescents which often conflicts with their capacity to manage diabetes optimally and communicate with parents.
- adolescents with diabetes have the same needs for exploration as other young people but studies have shown that many of them are more vulnerable and subjected to more pressures to conform to peer norms (35, 36).
- studies demonstrate slightly more involvement in health hazardous behavior in those with chronic conditions (14, 59).
- adolescents may adopt non-demanding low risk metabolic control by deliberately adjusting their diabetes to a blood glucose level where they do not risk hypo- or hyperglycemia/ketonemia and thus do not have their everyday life disturbed by diabetes.
- some adolescents, particularly female, may manipulate insulin doses or dietary habits in order to reduce weight gain, which has the inevitable consequence of worse metabolic control and increased vascular complications risk (13).
- Immediate reinforcement for engaging in diabetes management behaviors will have more powerful effects (ie increase likelihood it will happen again) than the potential for long-term

gains (e.g., avoidance of complications later in life) as most adolescents have not internalized the importance of doing something now so that the future is better.

- it may be helpful to negotiate from a cost-benefit stand-point to assist the young person to understand the short and long-term costs of certain behaviors as well as the potential benefits.

### **Severe hypoglycaemia**

Severe hypoglycemia may be experienced during adolescence due to poor metabolic control, exacerbated by irregularities of lifestyle and risk taking behavior. In addition to the immediate effects on neurocognitive function, evidence shows an important link between severe hypoglycemia and pre-clinical atherosclerosis and acute and chronic cardiovascular events in later life (70, 71). This is relevant in the context of intensive insulin therapy that may increase the risk of severe hypoglycemia (72), although there is evidence that contemporary approaches to diabetes self-management, and careful attention to detailed education (73-75) may reduce hypoglycemia frequency.

Specific concerns during adolescence include:

- Development of hypoglycemic unawareness or altered prodromal symptoms. An episode of severe hypoglycemia may lead to a period of altered awareness
- Fears about hypoglycemia may be associated with poorer metabolic control (76)
- Confusion with alcohol intoxication
- Confusion with illicit or recreational drug effects
- Nocturnal or early morning episodes due to altered sleep patterns

- The effect of hypoglycemia on driving
- The effect of hypoglycemia on academic, sports or work performance.

Young people should be encouraged to understand the benefits to them of better metabolic control, with a focus on the immediate benefits (e.g., perform better at a sport). Advice should be given about hypoglycemia to enable adolescents to take positive measures in recognizing, managing and preventing hypoglycemia (75, 77). Adolescents should be encouraged to inform friends about the risks, symptoms and treatment of hypoglycemia during the altered routine of social engagements (1).

### **Alcohol, smoking, and drugs**

Alcohol, tobacco and illicit or recreational drug use is a serious concern in some communities during high school years (78) and is common amongst youth with chronic medical conditions (79). Youth with type 1 diabetes self-reports of alcohol use vary from 10-90% (80-81), though their knowledge as to its impacts upon diabetes is generally poor (82). This risk is heightened by an apparent association between alcohol consumption, poorer metabolic control and risk of diabetic ketoacidosis (82). There is some evidence though that diabetic youth may use illicit or recreational drugs less commonly (83) and smoke less commonly (84) than healthy peers. Smoking in the context of type 1 diabetes during youth is a marker of social deprivation (85). Notwithstanding the apparent wide contextual variation in alcohol consumption in adolescents with diabetes (86), advice on alcohol, smoking and drugs should include:

- Encouragement to refrain from smoking and binge drinking, and advice on avoiding the dangers of drugs that may affect brain function or lead to dependence or addiction.
- Adopting a realistic advisory approach to alcohol rather than an absolute ban on medical grounds.
- Information on the effects of alcohol, particularly in young adolescents, on the liver by inhibiting gluconeogenesis with the possibility of either delayed severe hypoglycemia. This can variably combine with the carbohydrate content of the beverage to result in an

unpredictable glyceic response (87).

- Methods of avoiding nocturnal hypoglycemia after drinking alcohol in the evening by ingesting carbohydrate while drinking, maintenance of good hydration, measuring blood glucose levels before bedtime and having carbohydrate before sleep to minimize the risk of hypoglycemia.
- Ensuring that adolescents and their friends at parties and events where alcohol is consumed, are aware that hypoglycemia may occur when drinking alcohol without eating; that vomiting, particularly with omission of usual insulin, is dangerous and that vomitus may be inhaled or lead to ketoacidosis; that hypoglycemia might be confused with intoxication and that it is important to check blood glucose levels before sleep.

Providing information for and education of colleagues or friends is increasingly important as the young person develops independence from the family, especially when living away from home at work, college or university.

- Authoritative, but empathic, advice about smoking as an additional risk for the vascular complications of diabetes (88, 89). It also appears to be associated with very early onset of peripheral neuropathy (90)
- Helping the adolescent who does smoke to stop by providing specific interventions that help with smoking cessation (nicotine-patch, cognitive-behavioral therapy, prescription drugs etc.).
- Recognition that cannabis may alter eating habits (excess snacking during and loss of appetite after cannabis smoking), impair judgement around diabetes management decisions, and may reduce motivation to maintain good metabolic control.
- Illicit or recreational drugs may alter brain function, increasing the risks of mistakes and mishaps with diabetes management.

- Acknowledgment that a risk reduction policy may be more realistic than an absolute ban on illicit or recreational drug experimentation.
- Introduce strategies for managing stress during adolescence other than medication e.g. relaxation training, exercise, psychological evaluation for anxiety or depression, hypnosis, etc.

Healthcare professionals should understand that educational messages which are motivating, problem solving, target setting and which encourage adolescents towards developing their own strategies to avoid these problems are more successful than threats or inducing fear (1, 36).

### **Sexual health**

The imperative adequate sexual health counselling is underscored by data from youth with type 2 diabetes in the TODAY study. Despite recommendation about early counselling on contraception and pre-pregnancy counselling high rates of unplanned pregnancies in adolescents with diabetes still occur (91). Advice to young people with regards to sexual health will vary between different countries and cultures but would usually include:

- Pre-pregnancy counselling and education should begin during early puberty (30)
- A non-judgmental approach to sexual activity or sexual orientation (30).
- Advice where applicable on methods of avoiding pregnancy and sexually transmitted infections (STIs) for all adolescents.
- Prevention of hypoglycemia during or after intercourse.
- Advice on genital hygiene, vulvovaginal candidiasis, menstrual disorders and STIs.

Adolescent girls with diabetes should be aware of the importance of a planned pregnancy. Poor glycemic control around the time of conception increases the risks of congenital malformations, spontaneous abortion and fetal death. Pre-pregnancy counselling and education well

in advance of the possibility of pregnancy is advisable with emphasis on:

Ovulation is preserved, even when poor metabolic control and menstrual irregularities are present (92).

- The importance of good glycemic control before pregnancy, particularly the risks to the developing embryo and fetus.
- Understanding the importance of good control throughout pregnancy to avoid fetal macrosomia and neonatal hypoglycemia and also the avoidance of maternal hypoglycemia and ketoacidosis.
- Discussion with the young person and partner regarding the genetic risks of diabetes to their offspring.
- Access to expert pregnancy management should include:
- Cooperative management by an obstetrician and physician with special experience in diabetes and pregnancy.
- Delivery of the baby in a hospital able to provide expert maternal, fetal, perinatal and neonatal care.
- Males with long-standing diabetes may become impotent because of autonomic neuropathy (93). Younger males may fear this complication and require expert counselling. Impotence in adolescence is rare and may be due to psychological reasons rather than diabetes itself.

### *Contraception*

The diabetes care team should be sensitive to the religious and cultural influences affecting an individual's choice of contraceptive method (94).

- When a female with diabetes becomes sexually active she should do so with knowledge of

how to avoid an unplanned pregnancy and STIs.

A planned pregnancy in a person with diabetes in excellent metabolic control and in good health carries risks which are slightly higher than those in the general population, but not as elevated as previously reported in patients with poor metabolic control (95). However in the face of suboptimal metabolic control and lack of preparation for pregnancy, there is a high risk of congenital anomalies (91).

#### Barrier methods

- Worldwide safe sex, STIs and HIV campaigns have made adolescents more aware of barrier methods, particularly condoms (96, 97).
- Male condoms offer the greatest protection against STI's to the whole genital tract (less against herpes), and substantial protection against pregnancy.
- Diaphragms and female condoms are not recommended for the adolescent. Diaphragms are less effective contraception than the condom and do not protect against vaginal infection.
- Coitus interruptus, a common practice among teenagers, is not recommended because it is associated with a high pregnancy rate.

#### Long acting reversible contraception (LARCS)

- Recently, LARCs, which include intrauterine devices (IUDs) and the implantable rod, have been accepted as a first line contraceptive choice for adolescents even if they are nulliparous (98-101)
- Implantable rod and hormonal IUDs offer better protection against unintended pregnancy than oral contraceptives (99), and therefore should be considered in the adolescents with diabetes, but the effect on metabolic control in the very young women has not been evaluated
- Non- hormonal IUDs may be considered in the patient that has a contraindication for using



hormonal methods.

- LARC methods provide no protection against STIs, but are not associated with more episodes of STIs.

#### Combined hormonal oral contraceptives (OCs)

- Patients without micro or macrovascular complications and diabetes duration less than 20 yr may use any hormonal method.
- Patients with diabetes duration longer than 20 years, or having micro or macrovascular complications should avoid using OCs, but may use progestin only methods, intrauterine device or barrier methods.
- Newer OCs with a lower estrogen dose ( $\leq 35$   $\mu\text{g}$  or less ethinyl estradiol) and newer progestogens has not been demonstrated to be associated with detrimental effects on metabolic control, weight or lipid profile.
- Young people with diabetes on OCs should be monitored regularly, particularly blood pressure, side effects such as headaches, mood changes, breast changes, genital infections.
- Diabetes per se is not a risk factor of venous thromboembolism (102).
- All women taking OCs, including patients with diabetes, should be educated on the signs of thromboembolic diseases. Educate about clinical signs of alert using the acronym ACHES (abdominal pain, chest pain, headaches, eye, severe leg pain).
- Women with personal history of thrombotic disease should not use combined hormonal contraception.
- If acne or hirsutism are problems, the use of an OC containing an anti-androgenic progestins may be helpful (103-105).
- Progesterone-only OCs may provide insufficient contraception for teenagers who are likely

to forget the OCs.

- Similar to other adolescents without diabetes, in some circumstances if there is the possibility of an unwanted pregnancy it may be beneficial to advise sexually active young people about the availability of the 'morning after' hormone pill. No special considerations for the adolescent with diabetes are recommended in this setting (106).
- Very obese patients should be aware of a decrease of contraceptive efficacy of hormonal contraception and higher risk of venous thromboembolism (107).
- In the past, OCs with 50 micrograms of ethinyl estradiol (EE) were thought to have an adverse effect on metabolic control and lipid profiles and increase the risks of hypertension, cardiovascular and thromboembolic diseases. Nowadays, OCs with 50 micrograms EE are rarely prescribed.

#### Hormonal Injections

- Medroxyprogesterone injections have been associated with decreased bone mass gain, which may be especially detrimental for the adolescent with type 1 diabetes.
- Combined hormonal monthly injection may be a contraceptive method for the patients with T1D who has an erratic life-style and is at high risk of pregnancy and cannot access to LARCs methods. No safety study has been performed in patients with T1D.

#### Study and examinations

Most adolescents will engage in a level of secondary and/or tertiary education that will require some form of formal assessment such as examinations. These may be significant life events in that they will to varying extent determine further educational and vocational opportunities. Advice as to how a student may deal with their diabetes to optimise academic performance is frequently sought. Many students are well aware of the cognitive effects of hypoglycaemia (108, 109) and thus may choose to run their glucose levels higher than usual during exam times. They should however be

counselled as to the equally negative cognitive impacts of hyperglycaemia (110, 111). Glycaemic responses to exams may vary with individual student stress responses, the type and length of the exam and the time of day. Consequently, students should undertake practice examinations in conditions that are as near as possible to those that will be experienced in the actual examination (i.e., same exam duration time, same time of the day etc).

Accommodations for students with diabetes should include free access to food (low treatment), drink, and lavatory, as well as diabetes equipment (including blood glucose meter, continuous glucose monitors, and insulin delivery devices. Blood glucose levels should be checked immediately prior to and midway if a long exam (such as 3 hours). Adjustments to insulin regimens and/or diet can then be made accordingly so as to maintain euglycemia during the exam. As a general principle over the course of the academic year, exercise should be encouraged to reduce stress, improve physical fitness, improve sleep patterns and improve cognitive performance (112).

### **Employment**

There should be no discrimination or stigma against people with diabetes in the workplace (113). Most young people with diabetes should make good employees because of their ability to organise their lives and healthcare.

Advice on employment and diabetes should include the following:

- Recommendation not to conceal diabetes if asked about health and to inform potential employers about diabetes and how it is managed.
- Provision of a medical report from the diabetes care team to reassure employers that diabetes should not be a disadvantage in employment.
- 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. Legal regulations vary between countries. New technological developments may change these restrictions.

- Reassurance to employers that young people with diabetes make excellent employees if they have shown mature self-care, self-discipline and responsibility.
- In addition to being candid about diabetes with their employer and providing a medical report, young people with diabetes should prepare for the workplace with responsible self-care, including monitoring of blood glucose levels and avoidance of significant hypoglycemia.

## **Driving**

Hypoglycemia is the main factor which increases driving risk in people with diabetes (114-116), however this risk is mitigated in an individual with glycemic awareness, stable metabolic control and no visual disability to the extent where in most settings patients with diabetes are able to drive non-commercial vehicles. Regulations though vary in different countries. Studies have variably shown increased rates of driving accidents in drivers with type 1 diabetes (117, 118), although this may be due to an over-representation of a particular subgroup of drivers with poorer glycaemic awareness (119). Studies have also shown reductions in automobile accidents following specific hypoglycemia awareness training programs (120).

The young person who plans to obtain a driving license should be advised on the appropriate regulations and in particular:

- Prevention of hypoglycemia whilst driving (particularly if hypoglycemic unawareness is a problem) by blood glucose monitoring before starting to drive and appropriate food intake.
- Encouraging stable metabolic control (particularly avoidance of hypoglycemia) which may help determine whether a person with diabetes is eligible to hold a driving licence. Severe hypoglycemia in the preceding months causes many authorities to delay granting a license.
- Regular visual acuity checks.

## **Transition from pediatric to adult services**

In addition to assuming increased self-care responsibility, adolescents growing into young adulthood will eventually need to transfer from pediatric to adult diabetes providers. 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 (121, 122). As young adults with T1D experience competing life priorities and decreased parental support, adherence and glycemic control may decline. Young adults with T1D are at risk for acute diabetes complications as well as chronic microvascular complications and early mortality (123-126).

The concept of transition implies a “planned, purposeful movement of the adolescent or young adult with a chronic disease from a child (and family) centred to an adult oriented health care system” (127). Suboptimal coordination of the pediatric to adult care transition may lead to fragmentation of care delivery and increased risk for adverse outcomes. Transition care challenges documented in the literature include deficiencies in transition preparation (128-131), prolonged gaps between pediatric and adult care (129, 130, 132-134), and increased post-transition diabetes hospitalizations (135).

The transition from a pediatric to an adult orientated service should not involve a sudden unanticipated transfer but an organized process of preparation and adaptation. The process should be a component of a high quality, multi-disciplinary diabetes service (including medical records transfer and, where possible, the use of linked databases) and must involve both teams of carers, an understanding of the two different systems of care and the differing expectations of those providing and those receiving care.

The appropriate age for transfer from a pediatric or adolescent service to adult care varies according to the maturity of the adolescent, the availability of appropriate services for the young person in an adult clinic, and hospital and clinic facilities and regulations. In many countries, patients are required to transition from pediatric to adult diabetes care at age 18 years. In the U.S, there is currently no mandated transition age, and available data describe a mean transition age of 19-21 years (129, 135). Two observational studies from the U.S. suggest worse deterioration of glycemic control in

patients receiving adult care compared to those still receiving pediatric care (136, 137). There is no established best practice regarding transition age; further research and consensus in this area is needed, but delay of transition based on the developmental needs of the patient may be appropriate (138). ISPAD recommends that adolescents and young adults with diabetes continue to be seen by a diabetes team (pediatric or adult care providers as appropriate) every 3 months or more if required.

Some transition intervention programs for type 1 diabetes patients have shown promising results, including dedicated young adult clinics (139-141), intensive transition coordination efforts (142-144), and use of a care ambassador/patient navigator to support the transition process (141, 145). However, controlled studies are limited (144), and there have been few robust studies investigating best models of transition care for type 1 diabetes patients (146). A recently published randomised control trial in transitioning youth showed higher clinic attendance and lower disengagement rates in those who received an appointment management intervention (147). Several other trials are currently underway attempting to address the overall lack of evidence base (148). As a result, the following recommendations are largely based on expert consensus opinion (122).

For successful transition to an adult service, the following steps should be considered:

- Discussion with the patient and family well in advance as to the best time for transfer, based on their own preference and readiness, but also on the availability of services and, in some countries, health care insurance requirements. It is preferable to have flexibility about age of transition as family circumstances and an adolescent's psychosocial maturity differ widely.
- Transition preparation education and transition readiness assessment by pediatric providers, starting in the adolescent years. Transition preparation should include counseling on diabetes self-management, health care navigation (e.g., maintenance of supplies, scheduling of appointments), diabetes complications, and differences between pediatric and adult care systems.
- Identification of an adult service able to provide for the needs of young adults with diabetes.

- Provision of a joint adolescent or young adult clinic with members of both professional teams working together to facilitate the transition process for both adolescents and their parents.
- Liaison between the pediatric and adult services. Ideally this should involve identifying a specific person in the service (care navigator) who is able to help coordinate the transition of the young person into the adult service (141, 145). If such a person is not available, one of the pediatric staff should take responsibility for liaison with the adult service and both groups must have understanding of the services involved.
- Documentation of written patient transition plan and provision of a clinical summary of the young person's medical history, including indices of control, the results of complication screening and information on any co-morbidities that may impact on how the person is managed medically.
- Formal clinic-specific transition policies and clear communication between all services providing care for transitioning patients, particularly all members of the two diabetes teams and including, where available, primary care physicians and community nursing staff.
- Implementation of systems to avoid gaps in care between leaving the pediatric service and entering the adult service and that the transitioning patient is not lost to follow-up care. This may occur if the young person fails to make or keep an appointment, or feels uncomfortable in the new service and loses contact with a specific named team member.
- The pediatric service should have mechanisms in place, including a database and a named professional, to identify and locate all young people who fail to attend follow-up consultations.
- The adult service should also be strongly encouraged to ensure long term follow-up and outcome measurements of those diagnosed with diabetes as children and adolescents, as many studies show that poor glycemic control leads to longer-term morbidities (123-125, 149).

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