

ISPAD Clinical Practice Consensus Guidelines 2006–2007

Diabetes in adolescence

Court JM, Cameron FJ, Berg-Kelly K, Swift PGF. Diabetes in adolescence.

Pediatric Diabetes 2008; 9 (Part I): 255–262.

John M Court^a, Fergus J Cameron^a, Kristina Berg-Kelly^b and Peter GF Swift^c

^aDepartment of Endocrinology and Diabetes, Royal children's Hospital, Parkville, Australia

^bDepartment of Pediatrics, Queen Silvia Children's Hospital, Gottenburg, Sweden

^cLeicester Royal Infirmary Children's Hospital, Leicester, UK

Corresponding author:

John M Court, MD,
Albert Road Clinic
31 Albert Road
Melbourne, Victoria 3004
Australia.

Tel: +61 3 92793560;

fax: +61 3 92793599;

e-mail: johncourt@iprimus.com.au

Acknowledgement: Barbara Anderson.

Editors of the ISPAD Clinical Practice Consensus Guidelines 2006–2007: Kim Donaghue, Ragnar Hanas, Georgeanna Klingensmith, and Peter Swift.

Adolescence is the transitional phase of development between childhood and adulthood that incorporates the biological and psychosocial changes of puberty. It imposes unique challenges on the individual with diabetes, their family, and the diabetes care team (1, 2).

Although the majority of adolescents adapt well to the difficult 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 experience a deterioration in metabolic control (3–5) (C) often attributable to erratic meal and exercise patterns (6, 7) (C), poor adherence to treatment regimens (8–11) (C), hazardous and risk-taking behaviors (1, 2, 12, 13) (C, E), eating disorders (14–18) (C), and endocrine changes associated with puberty, leading to greater insulin resistance (19) (B).

Changes in body habitus, particularly weight gain in females (3, 5, 20–23) (C, E), can be unwanted diabetes-related side effects, sometimes associated with changes in the tempo of pubertal maturation (23, 24) (C) provoking insulin omission to effect weight loss (12, 16, 18) (C).

It is therefore recommended (1, 2, 25–30) (E) 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 onward) 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 (31);

- recognize that chronic conditions may inhibit some young people from exploring life, while others deliberately explore risk-taking behavior involving their diabetes care;
- develop communication skills [e.g., trusting, authoritative (not authoritarian), allowing adequate time, open questioning, patient centered, 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 (32, 33);
- recognize the intensity of the changing social environment on behavior. 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 lifestyles 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;
- provide planned transition to adult care at the most appropriate time (33).

The weighted evidence base supporting these recommendations has been recently reviewed in both the Australasian Paediatric Endocrine Group guidelines

(28) and the UK National Institute of Clinical Excellence (NICE) guidelines (30).

The emerging needs of adolescents because of developing independence and differences in lifestyle

These needs relate to the following:

- overriding importance of belonging to a peer group and fitting in to the group’s social norms and behavior. Diabetes control may not be high on their priority list;
- experimentation and exploration of different lifestyles that conform less acceptably to family expectations and routines;
- increasing independence from parental care;
- 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 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;
- difficulties in complying with advice and responding to conventional health education.

Identifying the components of care that are unique to adolescents

Optimal care of adolescents with diabetes has not been subjected to rigorous scientific studies, and research results are conflicting. However, psychoeducational interventions have been extensively reviewed and conclude that they may have beneficial outcomes but the effects are only modest (34, 35) (A). The beneficial effects are more on psychological outcomes than on glycemic control (35) (A).

Suggested care strategies might involve

- developing a trusting relationship between the adolescent and the diabetes care team (1, 30) (E). Adolescents report better self-care when health care professionals are motivating (1, 36) (C);
- helping the adolescent to clarify priorities and to set small achievable targets, particularly where there is conflict between the needs of diabetes management and the adolescent’s social development and peer activities;
- 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 consequences of poor metabolic control (33, 37) (C);
- recognizing the emerging maturity of the adolescent, encouraging self-reliance and self-efficacy, thus allowing consultations not only to be increasingly directed toward the adolescent but also retaining the trust and support of parents (38);
- helping the adolescent learn to negotiate a new level of parental involvement in diabetes care tasks (33).

Emerging independence is best pursued gradually

- Helping parents in their changing role from full responsibility toward a gradual transition to cooperative care with the adolescent. This is based on evidence that parental support and involvement throughout adolescence is associated with better outcomes (1, 38, 39) (C, E).
- Identifying and advising on which parenting styles are more likely to be successful than others [(Table 1) and (40, K. Berg-Kelly, personal communication)].
- Having an index of suspicion for signs of mental health problems such as depression, eating disorders, ‘diabetes burnout’, illicit 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 (41) (B). The HEADS technique (acronym for Home, Education, Activities during spare time, Drugs, and Sexual activities) is helpful when screening for psychosocial problems that might interfere with self-management (42) (E).
- Providing health education and utilizing strategies that promote optimal health care behavior (see 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 an optimal health care (E).

Table 1. Parenting styles according to Steinberg (40) and freely interpreted by K. Berg-Kelly (personal communication)

	Demanding/ challenging	Not demanding/ not challenging
Empathic with young person	Authoritative	Lenient and permissive
Non-empathic and cold	Authoritarian and rigid	Unconcerned, neglectful, and indifferent

- Encouraging the adolescent to participate with parents and health care team members in making decisions about diabetes management.
- Enabling the adolescent to learn from mistakes without moral judgment.
- Offering a variety of educational opportunities including open-ended adolescent-orientated discussion and negotiation (43) (B), problem solving, target setting (41, 44) (B), age-appropriate written materials, CDs/videos, text messaging (45) (B), the use of the Internet, peer involvement, and group learning.
- 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 *permissive*, lenient parents are highly empathetic who seem to care too much about their children, overidentify themselves with the needs of their children, and hate hurting them by getting into conflicts over routines.
- The *neglectful*, unconcerned, indifferent parents may have severe mental problems keeping them from understanding and helping their children. Neglectful parents require a careful social work-up to explore the roots of dysfunction.

Support outside the clinic

Although no studies have shown clear glycemic benefit from joining diabetes support groups or organized diabetes holidays, there is consensus that providing opportunities for recreational learning activities outside the clinic may be of educational value for some adolescents (E). Simply meeting people with the same condition and having the opportunity for exchanging ideas may have important therapeutic value (E).

It is recommended that

- information is available about teenage diabetes camps and activity holidays, support groups, discussion meetings, and other recreational activities;
- promotion of these activities and ensuring that they are safe, well organized, and have adequate medical input, supplies, and emergency procedures;

- information is available on traveling with diabetes (particularly to foreign countries), exercise, sports, and high-activity pursuits.

Suboptimal metabolic control

Growing up with a chronic condition like diabetes has many effects, but commonly, metabolic control deteriorates during puberty and the adolescent years. The reasons for this are multiple (see above).

In addition to the physiological influences, the health care team should consider the following:

- socializing with peers is of utmost importance to most adolescents that often conflicts with their capacity to manage diabetes optimally;
- adolescents with diabetes have the same needs for exploration as other young persons, but studies have shown that many of them are more vulnerable and subjected to more pressures to conform to peer norms (32, 33) (C);
- studies show slightly more involvement in health-hazardous behavior in those with chronic conditions (13, 46) (C);
- 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 so do not have their everyday life disturbed by diabetes (R. Viner, University College Hospital, London);
- it may be helpful to negotiate from a cost-benefit standpoint to assist the young person to understand the short- and long-term costs of certain behaviors as well as the potential benefits.

Severe hypoglycemia

Severe hypoglycemia may be experienced during adolescence as a result of poor metabolic control exacerbated by irregularities of lifestyle and risk-taking behavior. It may also occur as a result of embarking on a program of more intensive treatment (47) (B), although there is evidence that this may be avoided by careful attention to detailed education (48–50) (B) (see guideline chapter on Hypoglycemia).

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 (51) (C);
- confusion with alcohol intoxication;
- confusion with illicit drug effects;
- nocturnal or early morning episodes because of 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 of better control. Advice should be given about hypoglycemia to enable adolescents to take positive measures in recognizing, managing, and preventing hypoglycemia (50, 52) (C). 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 drug use is a serious concern in some communities during high school years (53) (C).

Advice on alcohol, smoking, and drugs should include (E)

- 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 delayed severe hypoglycemia;
- 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 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 (54, 55) (C).
- helping the adolescent who does smoke to stop by providing specific interventions that help with smoking cessation (patch, cognitive-behavioral therapy, prescription drugs, etc.).

- recognition that cannabis may alter eating habits (excess snacking during and loss of appetite after cannabis smoking) and may reduce motivation to maintain good diabetic control.
- *illicit 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 drug experimentation.
- introduce strategies for managing stress during adolescence other than medication, e.g., relaxation training, yoga, psychological evaluation for anxiety or depression, hypnosis, etc.

Health care professionals should understand that educational messages that are motivating, problem solving, target setting and that encourage adolescents toward developing their own strategies to avoid these problems are more successful than threats or inducing fear (1, 33) (E).

Driving

There is no reason why a person with diabetes should not hold a driving license [other than large commercial and passenger vehicles (56) (E)], provided that diabetes is well controlled, there is no visual disability, and that the person does not suffer from hypoglycemic unawareness. Regulations vary in different countries.

A multinational survey showed that people with type 1 diabetes have more mishaps than those without diabetes (57) (C), but this is not the information given by all organizations (56, 58). Studies have shown reductions in automobile accidents following specific hypoglycemia awareness training programs (50, 52) (C).

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

- prevention of hypoglycemia while driving (particularly if hypoglycemic unawareness is a problem) by blood glucose monitoring before starting to drive and appropriate food intake (56);
- encouraging stable metabolic control (particularly avoidance of hypoglycemia) that may help determine whether a person with diabetes is eligible to hold a driving license. Severe hypoglycemia in the preceding months causes many authorities to delay granting a license;
- regular visual acuity checks.

Employment

There should be no discrimination or stigma against people with diabetes in the workplace (58, 59) (E). Most

young people with diabetes should make good employees because of their ability to organize their lives and health care.

Advice on employment should include

- not concealing diabetes if asked about health and encouraging young people to inform potential employers about diabetes and how it is managed;
- the value of a good medical report from the diabetes care team may reassure employers that diabetes should not be a disadvantage in employment;
- advice on those careers that may be unavailable to persons with diabetes, e.g., police, fire, armed and certain public services, driving large goods vehicles, or piloting airplanes. These regulations vary between countries;
- reassurance to employers that young people with diabetes make good employees if they have shown mature self-care, self-discipline, and responsibility.

Recommendations conclude that young people with diabetes should be prepared for the workplace

- by attention to responsible self-care including monitoring of blood glucose levels;
- avoidance of significant hypoglycemia;
- being truthful about their diabetes to their employer;
- the physician should be prepared to provide a report to potential employers that supports the responsible diabetic young person.

Sexual health

Advice to young people with regard to sexual health will vary between different countries and cultures but would usually include

- a non-judgmental approach to sexual activity;
- advice where applicable on methods of avoiding pregnancy and sexually transmitted diseases (STDs) for male as well as female adolescents;
- prevention of hypoglycemia during or after intercourse;
- advice on genital hygiene, monilial infection, menstruation and STDs.

Pre-pregnancy counseling

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 (60, 61) (C).

Pre-pregnancy counseling and education well in advance of the possibility of pregnancy is advisable with emphasis on

- 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 of genetic implications of diabetes to the young person and partner.

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 perinatal and neonatal care.

Impotence

Males with long-standing diabetes may become impotent because of autonomic neuropathy (62) (C). Younger males may fear this complication and require expert counseling.

Impotence in adolescence is rare and may be because of 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.

- When a diabetic girl becomes sexually active, she should do so with knowledge of how to avoid an unplanned pregnancy (63) (E).
- A planned pregnancy in a person with diabetes in good metabolic control and in good health carries risks that are not substantially greater than those in the general population.

Barrier methods

- Worldwide safe sex, STD, and HIV campaigns have made adolescents more aware of barrier methods, particularly condoms.
- Condoms offer the greatest protection against STDs to the whole genital tract (less against herpes) and substantial protection against pregnancy.
- Diaphragms, sometimes worn continuously by women, offer added protection to the condom but on their own provide less effective contraception than the condom and do not protect against vaginal infection.
- Spermicidal gels probably increase the effectiveness of barrier methods.

Oral contraceptives

- In the past, oral contraceptives (OCs) were thought to have an adverse effect on metabolic control and lipid profiles and increase the risks of hypertension and cardiovascular and thromboembolic diseases, especially if there is a family history of deep vein thrombosis (DVTs) or other vascular phenomena.
- Newer OCs with a lower estrogen dose (<50 µg ethinylestradiol) and alternative progestogens reduce these risks but may be more expensive (2, 63) (E).
- Young people with diabetes on OCs should be monitored regularly, particularly blood pressure and side effects such as headaches, mood changes, breast changes, and genital infections.
- Starting OCs may slightly increase insulin requirements.
- If acne or hirsutism are problems, the use of an OC-containing cyproterone acetate may be helpful.
- Progesterone-only OCs may provide insufficient contraception for teenagers with erratic lifestyles.
- 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.

Depot hormone injections

- Depot injections contain higher doses of hormone(s) and therefore may affect blood glucose control and are more likely to have side effects.
- They may be of use when the individual has an erratic lifestyle, is at high risk of pregnancy, and is likely to forget the OC.

Intra-uterine devices

- Intra-uterine devices (IUDs) are not suitable for nulliparous girls.
- IUDs provide no protection against STDs.

Transition from pediatric to adult services

The concept of transition implies a 'planned, purposeful movement of the adolescent or young adult with a chronic disease from a child (and family)-centered to an adult-orientated health care system' (2).

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 diabetes service (including 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 may be determined by hospital and clinic facilities and regulations. Young people have differing views on the appropriate age of transfer (30, 32, 33, 64, 65) (C, E).

There is a potential danger that young people become lost in the transition process and cease regular attendance at the specialized service (66) (C). This is likely to be associated with poor adherence to treatment with increased risk of acute (11) and long-term complications of diabetes including increased mortality (67) (C).

As no controlled studies have been performed, the following recommendations are nearly all consensus based (E). For successful transition to an adult service, the following steps should be considered:

- identifying an adult service able to provide for the needs of young adults with diabetes;
- providing 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 the adult services. Ideally, this should involve identifying a specific person in the service who is able to move between both services to help the transition of the young person into the adult service. There is evidence that the appointment of a specialist nurse for adolescence has been successful in this role (68) (C). 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;
- discussion with the adolescent and parent well in advance as to the best time for transfer not only 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;
- development of clear, documented plans for transition services 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 comorbidities that may impact on how the person is managed medically;
- good communication, including a written protocol (28–30, 33), to facilitate understanding between all services providing care for the young person, particularly all members of the two diabetes teams and including the primary care physician and community nursing staff where available;
- ensuring that there is no significant gap in care between leaving the pediatric service and entering the adult service and that the young person is not lost to

follow-up care (33). This may occur if the young person fails to make or keep an appointment or feels uncomfortable in the new service and loses touch with a specific named team member;

- the diabetes 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 be strongly encouraged to ensure long-term follow-up and outcome measurements of those who have developed diabetes as children and adolescents as many studies show poor glycaemic control and longer term morbidities (69, 70) (C).

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