



Is it you, them or diabetes?!

A guide to life with a 13-17 year old

Your child - with or without diabetes

Teenagers begin feeling different, making changes, testing limits, experimenting with decision making, making mistakes, challenging adult rules, feeling that nothing can go wrong, risk taking, enjoying life, looking forward to new challenges.

Teenagers:

- May feel caught between their inner drives, peer group pressure and family expectations.
- Is very self-conscious about physical development, physical health, and sexuality.
- Value possessions, popularity and status.
- Develop "crushes" on peers.
- Becomes angry with what they see as interference of parents in their life.
- May be moody and irritable.
- Begin to reason and see things from different points of view.
- Begin to handle a wider range of problems.
- May experience anxiety, withdrawal from those around them or feelings of depression
- Seek and develops a close circle of friends for social support and generally becomes more social.

A teenager with diabetes

They may feel angry at having to consider their diabetes before they can do things that their friends take for granted.

They may find that eating, drinking, trying things out and general socialising puts pressure on them as they try to juggle fitting in with friends while having to manage their diabetes.

There may be problems with willingness to carry out their diabetes management needs. It may get in the way of lifestyle wants and they may feel it stops them doing more interesting things.

Diabetes may be seen as a hindrance to friendship and relationships.

They may find that the career path they want to pursue is one of the very few that excludes people with diabetes.

OR

They may sail through adolescence, managing everything beautifully including their diabetes.

Living with diabetes

This age group 13 – 17 year olds gradually takes on all of their diabetes care, although it is important for them to have your support, encouragement and sometimes, life advice.

Continuing to attend education sessions with the diabetes team will also help.

You and your teenager may become frustrated and irritated on occasions when there is lack of consistency of blood glucose results despite the effort put into insulin adjustments, exercise and diet. Blood glucose levels (BGLs) may be erratic due to varied physical activity and food intake, stress, growth and development, hormonal changes, or difficulty adhering to diabetes routines.

Willingness to carry out diabetes management is sometimes a problem, as the need for a routine interferes with a carefree existence. Doing things on the spur of the moment may be difficult and the need for adult supervision is still there, despite wanting to do their own thing.

The fear and embarrassment of hypos occurring in public may cause your teenager to 'run' their BGLs high.

Activity is often varied at this age and blood glucose levels may follow suit! 13 – 17 year olds may be more willing to have multiple injections or use an insulin pump once they realise it may give them more flexibility in their day-to-day life.

Trying things out is a part of this age group's everyday life – it's important that your teenager understands the implications of drugs and alcohol and the effect on the management of their diabetes.

It's important that you 'keep the door open' for when your teenager wants advice.

Puberty in both boys and girls is a time when the need for insulin increases. Your teenager's blood glucose control will vary with growth and hormonal changes.

Coping from day to day

The difficult thing for any parent is letting go. When your teenager has diabetes it can be even more difficult. It's not easy to let go and encourage independence. However, your concern may be perceived as a lack of trust.

Changes in their diabetes management plan should be talked over with your teenager. Letting go is a scary time, adolescents want independence yet don't want to feel alone or ignored. Finding that happy medium between enough supervision and letting go is a real challenge for any parent.

Here are a few tips:

Negotiate:

This is a great way for your teenager to learn to deal with others. Your concern may be seen as nagging, and cause anger and resentment. However, your teenager may need to be reminded that your questions arise from concern and that it's part of your responsibility as a parent to talk things through. You may even need to negotiate your negotiations, such as "What can we do so that you don't feel I'm nagging and I know you're OK?"

Be consistent:

Some rules are flexible but injections or boluses cannot be forgotten. Identification should be worn. Hypo food should be on hand. It is important to set clear limits. Teenagers need consistent rules to feel safe. Parents need to look at each situation on its own merit and decide when rules can be relaxed.

Keep communicating:

It may be strained at times but maintain the lines of communication. Your teenager needs to learn how to problem solve and subsequently make decisions. Their way of doing things may not be the same as yours and there may be much discussion.

Ask how you can help:

They may ask you for advice to help with some blood glucose recordings for them. Once they see that you are helping and not just interfering they are more likely to respond.

Give praise:

When things are going well, praise your teenager on their management and sense of responsibility. Sometimes things don't go well despite everyone's efforts and acknowledgement of this is important. Remind them that the pay-off for being granted more freedom is for them to gradually take on more responsibility.

Be understanding:

Recognise the frustrations for your teenager when things are not going so well.

Be patient:

This is a difficult time for all of you. Remember that things will get better.

Siblings

Brothers and sisters may tire of the focus on their sibling with diabetes. Why all the fuss? Why do we have to rush home for injections? Why do we have to worry about food all the time? Your teenager with diabetes may well take advantage of this.

Brothers and sisters who previously had no axe to grind may suddenly find one. If they thought their brother or sister were the favourite prior to having diabetes, this may add to the problem.

Brothers and sisters may fear that they will be loved less and pushed to one side in favour of the child with diabetes.

Some children worry that diabetes is catching or that their brother or sister with diabetes might die. They may think that something they have done has given their brother or sister diabetes – such as breaking a toy or not sharing. They may have nightmares, suddenly start wetting the bed or cling to you (remember that there are health professionals to help you and your family). Your child's brothers and sisters need to know what is happening and to feel involved.

Involving siblings in the initial diabetes education, when appropriate, may help.

With time, families often find that they have become closer because of diabetes. Problems can be sorted out with patience and understanding.

Ideas for coping

Try to keep things as normal as you can (this is not always easy). Try and spend some special time alone with your child without diabetes, doing something fun and that they really enjoy. Be consistent in the way you discipline all your children.

Physical activity

Teenagers with diabetes should be encouraged to exercise regularly, the same as their peers. When doing any physical activity your teenager may have to adjust their diabetes routine.

Experience and frequent blood glucose monitoring help determine the most appropriate way to deal with physical activity – everyone responds differently.

Physical activity increases the body's sensitivity to insulin (increasing the risk of hypos) and this effect may continue for 12 to 16 hours following the activity.

Blood glucose levels (BGLs) need to be measured before, during and after exercise.

Extra carbohydrate foods are often required before, during and after exercise, depending on BGLs and type of activity. For moderate and intense activities a general rule is half to one extra carbohydrate exchange/serve (7-18 grams) for every 30 minutes of exercise.

It's important that your teenager packs a hypo kit to take with them to sport.

Exercise should be avoided if the BGL is above 14mmol/L particularly if ketones are present or your child is unwell.

Activities to be approached with caution

These include activities that are solo in nature, take place in water or mid-air, or limit the individual's ability to recognise and self-treat hypoglycaemia.

At present it is recommended that people with type 1 diabetes should not participate in scuba diving, solo hang gliding or solo flying.

School

Your teenager may find that hiding their diabetes may seem to take less energy than explaining and confronting it.

Usually teenagers tell a few close friends, but they may not be keen to tell their teachers. This may cause problems if they have a hypo in class – if they eat something in class it will draw more attention to them. It is therefore important to encourage them to tell their main teachers, especially those who supervise sport. Telling these teachers can prevent misunderstandings, for instance, when they have to suddenly leave the game to treat a hypo.

Three good reasons for your teenager to let the teachers know about their diabetes are:

- 1. Safety so that the staff are aware that a student has diabetes.
- 2. Convenience they may have to eat a snack in class or on the sports field or leave the room for an injection. A hypo may make them lose concentration and appear inattentive. An understanding teacher may make life a lot easier.
- 3. Because they want to one teacher may be someone they particularly relate to and talking about their diabetes is part of talking about themselves.

If your teenager doesn't want diabetes mentioned, they have a right to privacy. However, their school should have official notice, with a letter in their school medical records. If they don't want their diabetes mentioned during class, they should let their teachers and friends know that this is their wish.

Despite your teenager being reluctant for you to speak to their teachers, it is important to stress to them that the school should be notified of their diabetes from a safety/legal point of view. Your diabetes educator or an educator from Diabetes NSW or Diabetes Australia in your State or Territory may be able to help. Alternatively, one of your teenager's friends may help persuade your teenager to tell the school.

Your teenager may have to be the teacher regarding diabetes. Teachers and friends cannot be expected to understand problems relating to diabetes until they know more about it.

School exams

In New South Wales there are four programs which deal with illness/ misadventure and exam conditions for students with any difficulty.

1. School assessment policies – Determined and ruled by individual schools/colleges. They include

- arrangements in case of illness (hypo during an examination).
- 2. Special examination provisions Run by the Board of Studies for the HSC examinations.
- 3. Illness/misadventure program Run by the Board of Studies for the HSC. It involves illness or misadventure immediately prior to, or during, the examinations.
- 4. Special access to universities Run entirely by universities. Students, who have experienced difficulties during Year 12, contact each university to whom they wish to apply, and ask for information on their special access program.

HSC/State Examination

In some states the school is required to send an "Application for Candidates with Disabilities" form together with a medical certificate, to the "Special Provisions for Students with Disabilities" Program at the Board of Studies. This is to be done six to twelve months prior to the examination.

During examinations the student is usually allowed to:

- Take bite-sized carbohydrate food such as dried fruit (but no noisy wrappers) to 'top-up' blood glucose levels throughout a lengthy examination.
- Have small group supervision or be seated near an exit so others are not disturbed if the student has to leave the room.
- Take a blood glucose meter and test strips into the examination room.
- Have a maximum of 5 minutes extra time per half hour of examination time to eat, drink, go to the
 toilet or check their BGLs. The student is not allowed access to the exam questions or answers
 during these breaks. The supervisor is required to time the breaks and extend the student exam
 time accordingly.
- Take insulin or insulin pump into the examination room for use as necessary
- If BGL falls below 5mmol/L, they may have one period of up to 20 minutes to take remedial action and retest your BGL. If after 20 minutes the BGL is still below 5mmol/L, an illness/misadventure application may be submitted. The BGL should be included in the application. Students can also elect to keep working.

You can obtain further information from your teenager's school, Diabetes Australia in your State or Territory or contact The Department of Education listed below.

New South Wales

Board of Studies NSW 117 Clarence Street, Sydney NSW 2000 GPO Box 5300, Sydney NSW 2001 Ph: 02 9367 8111

Victoria

Victorian Curriculum to Assessment Authority 41 St Andrew's Place East Melbourne, Victoria 3002 Ph: 03 9651 4300

Tasmania

Tasmania Qualifications Authority PO Box 147, Sandy Bay TAS 7006 Ph: 03 6233 6364

South Australia

Senior Secondary Assessment Board of South Australia 60 Greenhill Road, Wayville SA 5034 Ph: 08 8372 7400

Western Australia

Curriculum Council 27 Walters Drive, Osborne Park WA 6017

Ph: 08 9273 6300

Queensland

Queensland Studies Authority Ground Floor, 295 Ann Street, Brisbane PO Box 307, Spring Hill QLD 4004

Ph: 07 3864 0299

Australian Capital Territory

Board of Secondary Studies GPO Box 158, Canberra ACT 2601

Ph: 02 6205 7181

Northern Territory

Northern Territory Board of Studies 14th Floor, Mitchell Centre, 55–59 Mitchell Street NT 0800 GPO Box 4821, Darwin NT 0801

Ph: 08 8999 5767

University application

If your teenager is planning to go to university and is concerned as to how diabetes might affect their university entrance results they can apply for special provisions, just as they might have done in high school. Most institutions have some kind of scheme for applicants who have experienced long-term educational disadvantage such as may happen with type 1 diabetes. In NSW, they should submit an EAS application to UAC, in addition to their UAC application. They can only submit one EAS application to UAC. For more information www.uac.edu.au/uac/eas.html

Call Diabetes NSW on 1300 136 588 for further advice. For other States and Territories, contact:

ACT As for NSW (above)

Queensland

Special Consideration for Educational Disadvantage (SCD) www.qtac.edu.au/infosheets/SpecialConsideration.html

South Australia and Northern Territory

South Australian Tertiary Admissions Centre (SATAC) (08) 82244000 or 1300 138 440

Tasmania

University of Tasmania (UTAS) No centralised admission centre – contact UTAS for admission requirements. www.studentcentre.utas.edu.au/admissions/

Victoria

Victorian Tertiary Admissions Centre (VTAC) www.vtac.edu.au/pdf/publications/seas.pdf

Western Australia

Tertiary Institutions Service Centre (TISC) (08) 9318 8000

Having a job

Lots of teenagers work part time while they're still at school and there's no reason why having diabetes should stop them from doing this. One of the big questions when applying for a job is "should I tell them I've got diabetes?"

While it's understandable that teenagers may not want to tell anyone, in the long run it is easier to let the boss know especially when it comes to the need for testing, treating hypos, eating regularly and taking insulin. The employer has a duty of care to provide a safe work environment, but equally, you have a duty of care to be responsible and manage your diabetes.

It's a good idea to discuss with the employer about the need for:

- Regular meal breaks
- Somewhere private to test and inject
- Time out to treat a hypo
- Other staff to be aware of hypos, how to treat them and what to do in the case of an emergency

Career choices

People with type 1 diabetes can usually follow the career path of their choice, with a few exceptions:

- The defence forces e.g. army, navy, air force
- Full time or volunteer fire brigade
- The police force
- The aviation industry commercial and private
- · Careers that involve high risk activities e.g. at heights, underwater or solo in nature

Should you need further information regarding career options or feel or your teenager feels like they are being discriminated against in the workplace, call Diabetes Australia on 1300 136 588 in your State or Territory.

Driving

When your teenager first mentions learning to drive, don't panic!! Any parent is anxious when their teenager wants to learn to drive.

However, with a responsible attitude, driving is generally safe, and research shows that people with diabetes do not have a greater frequency of motor accidents than anyone else. The major added risk for the teenager with diabetes is hypoglycaemia (hypos).

It's very important that they have a good knowledge about hypos – their symptoms, treatment and prevention.

Driving and alcohol is illegal. In a teenager with diabetes, alcohol may cause delayed hypos.

It is important for your teenager to check their blood glucose prior to driving a car and be above 5mmol/L to drive and to have hypo treatment readily at hand.

Each State and Territory has its own regulations regarding the allocation of licences to people with diabetes.

For further information on driving and type 1 diabetes visit: www.austroads.com.au

Risky business

Your teenager with diabetes is just like other teenagers, and is just as likely to take risks with their health.

Risk behaviour occurs particularly in early teenage years when it is more important to be like their friends and to fit in socially, than it is to display healthy behaviour!

Teenagers see themselves as unstoppable and don't believe they can become addicted to something harmful, or that anything can go terribly wrong in their lives.

It's natural for you to worry that your teenager might make wrong choices. Mistakes will happen and usually lessons will be learned. This is normal part of growing up.

Smoking

Smoking is harmful to the health of everyone, no matter what their age. Smoking should be discouraged in people with diabetes. Nicotine damages blood vessels. Smoking is also associated with high blood pressure, poor diabetes control and has additional risks in pregnancy.

Alcohol

Teenagers with diabetes need to be aware of the additional risks of drinking alcohol. Alcohol blocks the body's natural method of correcting hypos, and may lead to them going undetected. The combination of alcohol-induced confusion and a low BGL is dangerous. Reaction times during a hypo have been shown to be reduced. Hypos can also occur many hours after drinking alcohol.

Whether or not you allow your teenager to drink, they may experiment with alcohol anyway.

Your teenager is advised to:

- · Drink in moderation and avoid binge drinking
- Not exceed the recommended safe intakes 2 standard drinks a day for adults
- Avoid consuming alcohol on an empty stomach
- Test their BGL regularly during and after consuming alcohol
- Eat carbohydrate foods while consuming alcohol regular soft drinks or juice are suitable if there is no food available
- · Eat snacks and meals on time
- Test their BGL before going to bed, eat a bedtime snack and make sure their BGL is above 7mmol/L
- Not to count alcohol as part of carbohydrate exchanges.
- Always carry some medical identification, so that if an emergency situation arises, appropriate action may be taken
- Have a friend that knows about diabetes and can recognise the signs of a hypo and knows how to treat it
- Try to check BGLs when combining alcohol with being physically active such as dancing at parties. This may not be possible in every situation.
- Alternatively, check BGLs before going out and then again before bed, to prevent an overnight hypo. Asking a parent or family member to do a 3am BGL is another way of preventing an overnight hypo
- There are ways of stretching drinks so that it's still possible to be part of the crowd without feeling pressured to keep up!
- Alternate alcoholic drinks with non-alcoholic drinks such as Diet Cola
- Halve the serve of alcohol per drink. Two drinks can become four by ordering wine spritzers (half wine and half soda), half nips of spirits with soda/diet mixers in a tall glass, or shandy (half beer and half diet lemonade)
- Choose low alcohol beers

Drugs

Drug use, which usually occurs with other risk taking behaviour, is likely to be experimental or recreational and its effect on diabetes management may be minimal to severe. Tobacco and alcohol are the most common substances which have the potential to lead to abuse. Regular drug use affects diabetes control and this may be denied by the teenager.

Recreational drugs may:

- Alter awareness and understanding
- Alter consciousness and sensation
- Alter understanding and the ability to make judgements
- Reduce capacity and interest in achieving good blood glucose control
- Reduce interest in routines, injections and meal times
- · Reduce appetite and interest in food, increasing the risk of hypos
- · Increase the risk of hypos going undetected
- Stimulate appetite (marijuana) leading to high BGLs
- Teenagers need to understand the risks of drug taking and the additional risks because of diabetes.

Contraception

As teenagers may not actively seek contraceptive advice, discussion about sexual activity and the need for safe contraception should be a routine part of management for all adolescents. Contraception is essential in reducing unplanned pregnancies.

There are a number of risks during pregnancy for both mother and baby, but with careful planning, as well as support from a team specialising in diabetes in pregnancy, women with diabetes will usually have healthy pregnancies and healthy babies.

For more information on contraception and pregnancy go to www.pregnancyanddiabetes.com.au

Erectile Dysfunction

Fear of impotence is very real in teenagers. It is unusual in the adolescent age group and may be minimised/prevented by good management of BGLs. Risk factors include increasing age, duration of diabetes and poor diabetes control.

Your teenager may feel more comfortable talking to their doctor, dietitian or diabetes educator by themselves to discuss practical aspects of living with diabetes (eg. parties, alcohol). This can help your teenager in managing their diabetes and taking more responsibility for their wellbeing. For more information go to myd.ndss.com.au

Diabetes Complications

Your teenager needs to know about the possible health effects of diabetes, and this should be relayed in a sensitive way. Frightening stories of complications and long-term health problems will not motivate them but rather make them dwell on the negatives. It may cause them to give up their diabetes care altogether because "it won't matter anyway". Make sure they are up to date with diabetes education, and that they are well informed about how to minimise their risk of developing complications.

Screening for complications is usually carried out yearly, but depends on the advice of your teenager's diabetes specialist. With a detailed screening program and regular health checks, any problems or early signs of complications can be detected before they affect health.

The following checks should be performed:

- Eyes: 2 years after diagnosis then once a year testing of the back of the eye (retina) by an ophthalmologist or trained optometrist is advised.
- Kidneys: 2 years after diagnosis then once a year.
- · Feet: as recommended by your diabetes team.

- HbA1c: every 3 months either at your clinic visit or at a pathology lab.
- Weight and Height: every 3 months at your clinic visit.
- Blood pressure: at least once a year or more often if needed.
- Cholesterol/Coeliac/Thyroid function tests: as recommended by your diabetes team.

A diabetes doctor or educator can arrange these tests. How often these tests are done may depend on which diabetes centre you attend. Even small improvements in diabetes control can make a difference to the risk of long-term complications.

Early detection is positive because:

- · Prompt treatment in many cases results in improvement
- It warns people to take extra care of their diabetes
- Some doctors perform these tests in their hospital clinics or private rooms. For further information, contact your local diabetes centre or specialist paediatric unit.
- It will help your teenager to receive some re-education, perhaps with a friend, and to be given some information regarding drugs, alcohol, contraception and complications.

Riding the food merry-go-round

What does any teenager do with food at this age?

Being a teenager is a time of growing up and becoming an adult, testing out independence and trying new and different things. This means that teenagers often hate strict regulations and being told what to do. This includes being told what to eat.

You may notice that your teenager's eating patterns change, often this means:

- Missing meals, particularly breakfast.
- Eating snacks, especially in the afternoon after school and grazing right up until dinner.
- Eating takeaway food after school.
- Wanting unconventional meals at different times e.g. pizza for breakfast.
- Drinking excessive amounts of soft drink.
- Having distinct food likes and dislikes.
- Eating more than adults teenage boys are especially prone to this.
- Trying out fad diets.
- Experimenting with alcohol.

Some of the typical teenage eating behaviours may pose particular problems for teenagers with diabetes.

Missing meals

For a teenager without diabetes the result of missing meals and eating at unconventional times is most likely hunger pains, mood changes and snacking on junk food. However, for a teenager with diabetes there is the potential for poorly managed BGLs.

Teenagers usually don't want to appear to be different from their friends. Those with diabetes may feel resentful that their diabetes management plan interferes with their social life. It's common for teenagers to experiment with missing injections or varying injection times or food.

This may be the age when multiple daily injections or an insulin pump are worth considering. For some teenagers it provides a more flexible way of managing their diabetes.

However, for others it may not be the best option. Discuss changes with their doctor, dietitian and diabetes educator.

Skipping breakfast

Mornings are not everyone's best times and this applies equally to teenagers. Breakfast is important for good nutrition, concentration at school and managing BGLs.

If your teenager doesn't feel like eating, try some of these quick ideas for breakfast:

- · Cereal and low fat milk
- Fruit and low fat yoghurt
- Toast, English muffins, raisin toast
- Toasted sandwich or jaffle
- Milo with low fat milk
- Crumpet or toast with banana, peanut butter or honey
- Fresh or canned fruit
- Low fat fruit smoothie

Takeaway foods

Takeaway foods often feature heavily in teenage eating patterns. Many of these foods are high in saturated fat and not suitable every day choices.

Try to encourage variety in your teenagers eating habits and the better takeaway choices where possible.

Filling them up:

Teenagers, particularly teenage boys, seem to eat extremely large amounts of food. These changes in appetite are normal during growth spurts and need to be discussed with the diabetes team so that insulin dose is matched with food intake. To ensure that your teenager is growing up but not out, it's also important to encourage healthy 'filling' food choices based on wholegrain breads, cereals, fruit, vegetables and low fat dairy foods.

Better takeaway choices include:

- Sushi rolls
- A baked potato with low fat fillings
- A wrap filled with lean meat and salad
- BBQ chicken on a roll
- · Plain hamburger with salad
- A kebab with extra salad
- Toasted sandwiches or focaccia
- Grilled fish and chips
- Asian stir-fry or noodle dishes
- Vegetable based or gourmet pizzas
- · Reduced fat ice cream/frozen yoghurt
- Diet or low joule soft drinks

Disordered eating

At puberty, teenagers experience a growth spurt, weight gain and significant changes in body shape. This can cause some teenagers to become very concerned about their appearance. Appetites will increase during growth spurts and insulin requirements will vary in response to hormonal changes. BGLs can be difficult to control and it's important to seek regular and appropriate advice regarding changes to diet and insulin regimens.

Preoccupation with weight most often occurs in girls but may be present in boys. Dieting behaviours are common and in some cases can lead to eating disorders. Fad diets can be harmful due to their variable carbohydrate and poor nutrient content. Diet pills are sometimes seen as a quick solution but have side effects and are not recommended. Encouraging teenagers to remain active can help improve body image and assist with maintaining a healthy weight. Advice from a dietitian can also assist to identify and manage weight problems.

Warning signs of an eating disorder include:

- Preoccupation with food
- Skipping insulin injections
- Extreme weight loss
- Exercising compulsively
- Wearing multiple layers of clothing (to cover what is perceived as fat)
- Trips to the bathroom after meals or snacks
- Food restriction followed by binge eating
- · Converting to vegetarianism
- If you are concerned your teenager is at risk of an eating disorder, seek the advice of your diabetes team

For more information on type 1 diabetes and eating disorders go to: https://static.diabetesaustralia.com.au/s/fileassets/diabetes-australia/bd9877a3-3289-43d9-a2ee-7598b4d1f1ca.pdf

To care for teenager you must care for yourself

Diabetes takes a lot of time and energy, so its normal to feel frustrated and tired from the constant daily demands of management.

Your emotions may change and recur (perhaps frequently) – guilt, frustration, helplessness, sadness, anger... and elation when all goes according to plan.

It can help to talk to someone who may understand, perhaps another parent going through the same thing.

Share your feelings with your partner, a friend or relative, support groups, your doctor, other health professionals such as a social worker or psychologist.

Share diabetes-related tasks with your partner, supportive family members or friends.

Keep in touch with your educator, as ongoing education can help you and your child at different stages.

Don't be afraid to ask your health professional team for support and guidance.

Encourage relatives or friends to attend education sessions and/ or support groups to learn more about diabetes so that they may in turn give you support.

Find some time for yourself. It's a worthwhile investment for the daily demands of parenting.