

# Standard 16

*Young people with diabetes should have access to an experienced multidisciplinary team including developmental expertise, youth health, health psychology and dietetics.*

## Key practice points

- Young people with type 2 diabetes are at increased risk of morbidity and mortality. The prevalence of type 2 in children and young people is rising and this population group should not be overlooked.
- Young people with diabetes require support from a multidisciplinary team with specific developmental expertise.
- Health care needs to be aligned with their age as well as their diabetes.
- 15–24 year olds with diabetes should have access to an adolescent service.
- Schools should have diabetes information and individual records for each child with diabetes enrolled in their facility.
- Parents and caregivers, including education facilities, should be included in education and support.

Read this standard in conjunction with the equality and diversity section in the Introduction to the Toolkit.

## What the quality statement means for each audience

**Service providers** ensure that young people with diabetes have access to an experienced co-located multidisciplinary team including developmental expertise, youth health, health psychology and dietetics.

**Health care professionals** ensure that the young person with diabetes has access to a co-located team of experienced multidisciplinary health professionals including developmental and youth health experts, a health psychologist and dietitian.

**Planners and funders** ensure they commission services that provide young people with diabetes with access to an experienced co-located multidisciplinary team including developmental expertise, youth health, health psychology and dietetics.

**Young people with diabetes** have access to an experienced co-located multidisciplinary team of health professionals including developmental and youth health experts, a health psychologist and a dietitian.



## Introduction

The term 'young people' includes individuals up to the age of 25 who, based on different needs, can be divided into children, adolescents and young adults. Diabetes Youth New Zealand states there are about 2500 children and young people aged 0 to 18 years living with type 1 diabetes in New Zealand and about 200 with type 2. Numbers are estimated to be growing by 10% annually. While type 2 is often thought to be the milder form of diabetes, research has demonstrated that young onset type 2 is the more lethal phenotype, being associated with greater mortality, more complications and unfavourable cardiovascular risk factors than type 1 (Constantino et al 2013). In response to growing awareness of the risks associated with early onset type 2 diabetes, the Diabetes Care journal published a series of articles on the TODAY (Treatment Options for Type 2 diabetes in Adolescents & Youth) study, a randomised clinical trial testing the safety and effectiveness of three treatment interventions. They can be accessed here: <http://care.diabetesjournals.org/site/misc/todayseries.xhtml>.

For children and young people, it is important for care and support to be provided by practitioners who are appropriately educated and experienced. Issues such as trust and rapport are particularly important when working with young people, as is the tailored delivery and content of information and advice.

While children and adolescents face many of the same challenges as adults with diabetes, they have additional ones due to the fact that they:

- are still growing and need to balance dietary control with nutritional needs and desires
- are emotionally and intellectually immature
- need support and information pitched at an appropriate level for the individual
- are subject to peer influence – both positive and negative
- may need to deal with contraceptive/pregnancy concerns (see Standard 20)
- are presenting as individuals but within a family/whānau structure and need parental support. That support, however, needs to enable autonomy as they make the transition to adulthood and increasingly take control of their own treatment decisions and self-management.

Engagement and education of family/whānau members is therefore important, as is that of educational facilities where children and young people spend considerable amounts of time (refer to the resources section). It is suggested that schools and other educational facilities should not only have specific information about diabetes but should also have individual records for each child with diabetes enrolled in the facility, in order to support their daily diabetes needs as well as respond to emergency situations. A multidisciplinary team approach to care delivery for both individual and family/whānau is therefore required. The team should include developmental expertise, youth health specialists (eg, paediatrician, endocrinologist), diabetes clinical nurse specialist/nurse practitioner, health psychology and dietetics. Brierley et al (2010) suggest that an ideal service would also incorporate psychological support for the professional team as working with young people is emotionally challenging.

The need for psychological support of young people with diabetes is borne out by research findings. A review by Cameron et al (2007) noted that psychological morbidity is increased in children with diabetes just as with other chronic conditions. 'Initial adjustment to diabetes is characterised by sadness, anxiety, withdrawal and dependency and ~30% of children develop a clinical adjustment disorder in the three months after diagnosis. Such difficulties often resolve within the first year but poor adaptation in this initial phase places children at risk for later psychological difficulties' (p 2717). Longitudinal studies have found long term prevalence of psychiatric disorder in those with youth diabetes to be 2–3 times that found in the general population. The authors conclude that as mental health issues appear to be prognostic of maladaptive lifestyle practices, long term glycaemic control issues and early onset of complications, mental health screening should be considered as important as screening for other complications. 'Routine screening for behavioural disturbance should begin in children at the time of diabetes diagnosis, with further assessment of parental mental health and family functioning for at-risk children. Interventions can then be targeted based on the specific needs of individual children and families' (p 2720).

A recent study in the *Journal of Adolescent Health* identified a pattern of declining glycaemic control in the six years following diagnosis and concluded that psychosocial burdens, particularly diabetes-related quality of life, were instrumental. Depression levels were higher in those with type 2 than those with type 1 (Hood et al 2014).

Adherence among young people is a big issue, leading to early diabetes-related complications. Hanghøj and Boisen's (2013) review of 28 studies of self-reported barriers to medication adherence among adolescents identified a range of barriers including forgetting; lack of motivation; stress and burnout; time pressure and lack of planning; lack of social support – including parental autonomy support; rebellion – not wanting to be told what to do; stigma of being different from peers; embarrassment; and being influenced by peers' poor medication habits.

As children generally present within a family/whānau context, provision of parental education and support is an integral part of caring for the child with diabetes. Not only can parents support their child's understanding of their condition and the importance of medication and lifestyle, but they are also responsible for creating the home environment within which the child grows up. However, the way in which parents provide support has been found to impact on their children's outcomes, particularly during adolescence. In reviewing the literature, Moore et al (2013) concluded that better metabolic control was associated with greater parental responsiveness, defined as communication of warmth, love and acceptance; better emotional and financial family/whānau resources; and stronger parental attachment. Their own Australian study of families with a teenager with type 1 found poorer metabolic control and less adequate self-care to be associated with lower levels of family functioning, more adolescent behavioural difficulties and poorer adolescent mental health. They concluded that 'the findings of the current study suggest the importance not only of providing information on diabetes to families, but of providing parents and adolescents with information and support on how best to strengthen their relationships, manage their emotions and maintain open communication channels in order to assist the young people with type 1 diabetes in their transition to the independent self-management of their condition' (Hood et al 2014).



## Guidelines

The **Australasian Paediatric Endocrinology Group** (APEG 2011) 'National Evidence-Based Clinical Care Guidelines for Type 1 Diabetes in Children, Adolescents and Adults' can be found here: [www.apeg.org.au/portals/o/guidelines1.pdf](http://www.apeg.org.au/portals/o/guidelines1.pdf).

### **International Diabetes Federation (IDF) / International Society for Pediatric and Adolescent Diabetes (ISPAD)**

The IDF/ISPAD (2011) 'Global Guidance for Diabetes in Childhood and Adolescence' can be found here: [www.idf.org/sites/default/files/Diabetes-in-Childhood-and-Adolescence-Guidelines.pdf](http://www.idf.org/sites/default/files/Diabetes-in-Childhood-and-Adolescence-Guidelines.pdf).

The guidelines are presented as a series of chapters addressing the following:

1. Definition, epidemiology and classification
2. Phases of type 1 diabetes
3. Type 2 diabetes
4. Monogenic diabetes
5. Diabetes education
6. Structures, processes and outcomes of ambulatory diabetes care
7. Assessment and monitoring of glycaemic control
8. Insulin treatment
9. Nutritional management
10. Diabetic ketoacidosis
11. Assessment and monitoring of hypoglycaemia
12. Sick day management
13. Exercise
14. Management of children requiring surgery
15. Psychological care
16. Diabetes in adolescence
17. Microvascular and macrovascular complications
18. Other complications and associated conditions

The 2011 **Australian Clinical Management Guidelines** for people with type 1 diabetes provides specific information for the management of children and adolescents: [www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/ext004\\_type1\\_diabetes\\_children\\_adolescents\\_adults.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/ext004_type1_diabetes_children_adolescents_adults.pdf).

A summary of the guidelines for children with type 1 is provided by Hatherly et al (2011, pp 379–80) as follows: ‘Care should be delivered, at least 3–4 times annually, by a specialist multidisciplinary paediatric team, including paediatric endocrinologists or physicians, diabetes educators (*diabetes nurse specialists in the New Zealand context*), paediatric dieticians, a social worker and/or psychologist. With respect to glycaemic control, the guidelines recommend that all children (aged six years and over) aim to achieve an HbA<sub>1c</sub> <58 mmol/mol, without an increase in hypoglycaemia, and that regular screening for diabetes related complications is performed’.

**The National Institute for Health and Care Excellence (NICE)** guidelines for the diagnosis and management of type 1 and type 2 diabetes in children and young people are currently under development with an intended completion date of August 2015. Information about this process is available here: <http://guidance.nice.org.uk/CG/WaveR/118>

**Starship Children’s Health** provides information and clinical guidelines on managing ketoacidosis in young people. They state, ‘diabetic ketoacidosis (DKA) is a life-threatening metabolic disorder resulting from decreased effective circulating insulin, insulin resistance and increased production of counter-regulatory hormones. The frequency of DKA ranges from 16–80% of children newly diagnosed with diabetes, depending on geographic location. It is the leading cause of morbidity and is the most common cause of diabetes-related deaths in children and adolescents with type 1 diabetes. Mortality is predominantly due to cerebral oedema which occurs in 0.3% to 1% of all episodes of diabetic ketoacidosis in children’.

Further information can be found at:

[www.starship.org.nz/media/273118/starship\\_dka\\_guideline\\_2014\\_v.2yellowhighlightsremovedtextboxes.pdf](http://www.starship.org.nz/media/273118/starship_dka_guideline_2014_v.2yellowhighlightsremovedtextboxes.pdf)



## Implementation advice

**A care pathway for children with type 1** was provided by New Zealand’s Diabetes Workforce Service Review (2011) on page 53:

[www.health.govt.nz/system/files/documents/pages/diabetes-workforce-service-review.pdf](http://www.health.govt.nz/system/files/documents/pages/diabetes-workforce-service-review.pdf).

**NICE** provides a care pathway with links to associated advice and information for managing children and young people with type 1:

<http://pathways.nice.org.uk/pathways/diabetes?fno=1#path=view%3A/pathways/diabetes/managing-type-1-diabetes-in-children-and-young-people.xml&content=view-node%3Anodes-diet-and-lifestyle-advice>

The following table taken from Chiang et al (2014) summarises the developmental stages children and young people move through and the developmental tasks and type 1 diabetes management required at each.

Developmental stages (ages)	Normal developmental tasks	Type 1 diabetes management priorities	Family issues in type 1 diabetes management
Infancy (0–12 months)	Developing a trusting relationship or bond with primary caregiver(s)	Preventing and treating Hypoglycaemia Avoiding extreme fluctuations in blood glucose levels	Coping with stress Sharing the burden of care to avoid parent burnout
Toddler (13–36 months)	Developing a sense of mastery and autonomy	Preventing hypoglycaemia Avoiding extreme fluctuations in blood glucose levels due to irregular food intake	Establishing a schedule Managing the picky eater Limit-setting and coping with toddler's lack of cooperation with regimen Sharing the burden of care
Preschooler and early elementary school (3–7 years)	Developing initiative in activities and confidence in self	Preventing hypoglycaemia Coping with unpredictable appetite and activity Positively reinforcing cooperation with regimen Trusting other caregivers with diabetes management	Reassuring child that diabetes is no one's fault Educating other caregivers about diabetes management
Older elementary school (8–11 years)	Developing skills in athletic, cognitive, artistic, and social areas Consolidating self-esteem with respect to the peer group	Making diabetes regimen flexible to allow for participation in school or peer activities Child learning short and long term benefits of optimal control	Maintaining parental involvement in insulin and blood glucose management tasks while allowing for independent self-care for special occasions Continuing to educate school and other caregivers
Early adolescence (12–15 years)	Managing body changes Developing a strong sense of self-identity	Increasing insulin requirements during puberty Diabetes management and blood glucose control becoming more difficult Weight and body image concerns	Renegotiating parent and teenager's roles in diabetes management to be acceptable to both Learning coping skills to enhance ability to self-manage Preventing and intervening in diabetes-related family conflict Monitoring for signs of depression, eating disorders, and risky behaviours
Later adolescence (16–19 years)	Establishing a sense of identity after high school (decisions about location, social issues, work, and education)	Starting an ongoing discussion of transition to a new diabetes team (discussion may begin in earlier adolescent years) Integrating diabetes into new lifestyle	Supporting the transition to independence Learning coping skills to enhance ability to self-manage Preventing and intervening with diabetes-related family conflict Monitoring for signs of depression, eating disorders, and risky behaviours

**Brink and Chiarelli (2004)** adopt a time line approach and summarise the needs of young people and adolescents and the time at which they should be addressed as follows:

### At diagnosis

Survival education:

- How to administer insulin, how and what to monitor, who and when to call, beginning meal planning (NB. the advisory group felt that hypoglycaemic management should also be included at this stage).

## Within 1–2 months following diagnosis

In-depth assessment and review:

- Insulin kinetics and administration, monitoring and use of SMBG data, meal planning, activity changes, sick day guidelines and DKA prevention/treatment, hypoglycaemia identification, recognition, prevention and treatment.
- Short term and long term treatment goals.
- Identification of barriers to improvement including school, learning and psychosocial and family issues.
- Establishment of follow-up guidelines and goals and responsibilities.

## Yearly

In-depth assessment and re-education:

- All of the above plus additional needs including age-appropriate peer pressure, alcohol, sexual education, smoking prevention, eating disorders including bulimia, anorexia and obesity, diabetes-associated complications' assessment and ongoing barriers to control.



## Implementation examples / innovations



### Starship Children's Health in Auckland

Starship Children's Health in Auckland provides a diabetes adolescent transition programme and clinics with the following aims:

- identifying geographically specific adult services which are able to provide for the needs of young adults with diabetes in Auckland and presenting these options to families/whānau
- the provision of a clinic utilising an adolescent consultation model and facilitating the transition process
- development of clear, documented plans for transition
- good communication between all services providing care for the young person at the time of transition, including the primary care physician and other specialists
- the provision of adolescent specific education in a supportive non-threatening environment utilising available speciality services
- ensuring that there is no significant gap in care between leaving the paediatric service and entering the adult service and that the young person is not lost to follow-up care
- maintaining a database of all adolescents transferring to Adult Diabetes Services and subsequent capture of clinical data for a period of five years post-transition.

The transition programme team consists of endocrinologists, adolescent transition nurses, diabetes nurse specialists, social workers, and a clinical psychologist in addition to ongoing contact with the individual's own GP. More information can be found at:

<https://www.starship.org.nz/patients-and-families/youth-transition/diabetes-service/starship-diabetes-adolescent-transition-programme-and-clinics/>

and also at: [https://www.starship.org.nz/media/248825/transition\\_starter\\_pack\\_2013.pdf](https://www.starship.org.nz/media/248825/transition_starter_pack_2013.pdf)



## Counties Manukau District Health Board (DHB)

The Starship service includes access to the Centre for Youth Health which was established in 1996 by Counties Manukau DHB to deliver a range of specialist youth services, aiming:

- to promote the wellbeing and healthy development of young people within the context of their family/whānau and wider environment
- to provide young people with the comprehensive clinical health assessments
- to provide advocacy and support to health professionals working with young people
- to collaborate with other researchers in a range of relevant adolescent health research projects
- to promote and support policies, planning and legislation, that address the healthy development and wellbeing of young people.



## Starship Children's Health

Starship also provides an insulin pump program, details of which can be found in Standard 17.



## Type 1 Exchange Clinic Registry

The T1D Exchange Clinic Registry is a large scale study of children and adults with type 1 diabetes in the United States. Twenty-five thousand people have been enrolled and results have been published since 2013. Campbell et al (2014) compared 6–17 year olds with type 1 diabetes of >2 years duration with good control (HbA1c <53 mmol/mol, N=588) with those with poor control (HbA1c >75, N=2684). After controlling for demographic and socioeconomic factors, results showed the two groups differed significantly in diabetes management. More of the good control group used insulin pumps, monitored blood glucose five or more times daily, missed fewer boluses, bolused before meals rather than at or after mealtimes, used meal-specific insulin carbohydrate ratios, checked levels prior to administering mealtime insulin, used insulin with daytime snacks, used more bolus insulin and used a lower mean total daily insulin dose than those in the poor control group.



## Waikato DHB

Waikato DHB's regional diabetes service provides two on-call services. The first is for patients enrolled in their service who need urgent advice out of clinic hours on things such as managing illness, ketones, and hyper/hypoglycaemia. The on-call service also takes referrals for after hours support under specific circumstances ie, post hospital discharge and pregnancy monitoring in type 1. The second service is for general practitioners, practice nurses and pharmacists in the region who can email or telephone for advice and information about any patient in their care. The service is staffed by diabetes clinical nurse specialists with access to diabetes physicians, dietitians and podiatrists.





## Yale School of Nursing

The Yale School of Nursing has created a coping skills training programme to teach communication and problem-solving skills in order to improve peer, school and family relationships and enhance self-management for adolescents with type 1. Results of studies suggest that the programme might be moderately more effective than standard diabetes education in improving self-management skills and controlling glycaemic levels. The original programme includes weekly small group sessions with a trained facilitator, but in acknowledgement of scheduling issues a web-based programme and forum has also been developed. More information can be found at: <http://innovations.ahrq.gov/content.aspx?id=2131>.



## Assessment tools

In assessing whether guidelines were being met, Hatherly et al (2011) measured access to the following range of practitioners: endocrinologist, paediatrician, diabetes nurse specialist, dietitian, psychologist, social worker, and general practitioner. The following targets, adapted from the guidelines, were also assessed:

- care received from a full multidisciplinary diabetes team
- family as part of the management team
- received diabetes education from a diabetes nurse specialist
- attendance at three to four clinics annually
- annual nutrition review
- annual psychological care (psychologist/social worker)
- annual complications screening
- insulin pump offered as treatment option
- attended diabetes camp
- HbA<sub>1c</sub> <59 mmol/mol.

The IDF guidelines (2011) state that diabetes teams should be able to register the numbers of adolescents in their district or region and be able to monitor attendance and metabolic control. Mechanisms should be in place for recalling patients who repeatedly fail to attend clinics.

### Process

The proportion of young people with diabetes who have access to a multidisciplinary team with relevant knowledge and experience.

Numerator	The number of people in the denominator accessing a multidisciplinary team with relevant knowledge and experience
Denominator	The number of young people with diabetes



## Resources

The **Kidshealth** organisation of New Zealand provides information on a range of topics specifically targeted at children and their parents. The diabetes topics are:

- blood glucose meters
- diabetes (brief)
- diabetes (detailed)
- diabetes: emotional and mental wellbeing concerns
- diabetes: healthy eating and physical activity
- diabetes: school information
- growing up and diabetes management ([www.kidshealth.org.nz/tags/diabetes](http://www.kidshealth.org.nz/tags/diabetes)).

**National Diabetes Education Program USA:** The following site provides information for schools regarding the management of children with diabetes during the school day. It highlights the importance of glycaemic control, assisting children with diabetes care and having designated trained diabetes personnel:

<http://ndep.nih.gov/publications/PublicationDetail.aspx?PubId=97#effectivediabetesmanagement>

**Evert (2004)** discusses tools and techniques for working with young people with diabetes, with a particular focus on nutrition:

<http://spectrum.diabetesjournals.org/content/17/1/8.full.pdf+html>.

The **American Diabetes Association** provides a booklet designed specifically for adolescents with type 2 (the link to the full booklet appears to be broken but the individual links to sections are intact): [www.diabetes.org/living-with-diabetes/parents-and-kids/children-and-type-2/](http://www.diabetes.org/living-with-diabetes/parents-and-kids/children-and-type-2/).

**Healthcare Research and Quality (AHRQ):** A fact sheet about staying active for children with type 2 has been developed by the US Agency for Healthcare Research and Quality (AHRQ) and is available at: <http://ndep.nih.gov/media/tips-kids-be-active.pdf>.

**International Diabetes Federation (IDF):** Recommendations for standard and comprehensive adolescent care are provided by the IDF on pages 112-113 of their guidelines: [www.idf.org/sites/default/files/Diabetes-in-Childhood-and-Adolescence-Guidelines.pdf](http://www.idf.org/sites/default/files/Diabetes-in-Childhood-and-Adolescence-Guidelines.pdf). These address the roles of an interdisciplinary paediatric diabetes team, education, knowledge required by the team, education to be provided to the adolescent, and topics for discussion and advice.

A New Zealand site for adolescents with depression, including a quick self-check test, can be found at **the lowdown**: [www.thelowdown.co.nz/#/home/](http://www.thelowdown.co.nz/#/home/).

A shortened version of the **Self Efficacy in Diabetes Management (SEDM)**, designed for children with type 1, was developed by Iannotti et al (2006). From a study of 168 10–16 year olds, the authors concluded that ‘self-efficacy and the interaction of self-efficacy with expectations of positive outcomes were significantly associated with diabetes self-management adherence and glycemic control in older adolescents. The effect of self-efficacy was greatest when adolescents had stronger beliefs in the beneficial outcomes of adherence. These brief measures can be used to identify youths at risk of poor diabetes self-management’ (p 98).

The measure has since been used in diabetes research with an adolescent population. Items for the self-efficacy measure are answered on a scale ranging from 1 (not sure at all) to 10 (completely sure) and follow the stem ‘how sure are you that you can do each of the following almost all the time?’

- Adjust your insulin correctly when you eat more or less than usual.
- Choose healthful foods when you go out to eat.
- Exercise even when you don’t really feel like it.
- Adjust your insulin or food accurately based on how much exercise you get.
- Talk to your doctor or nurse about any problems you’re having with taking care of your diabetes.
- Do your blood sugar checks even when you are really busy.
- Manage your diabetes the way your health care team wants you to.
- Manage your diabetes even when you feel overwhelmed.
- Find ways to deal with feeling frustrated about your diabetes.
- Identify things that could get in the way of managing your diabetes.



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