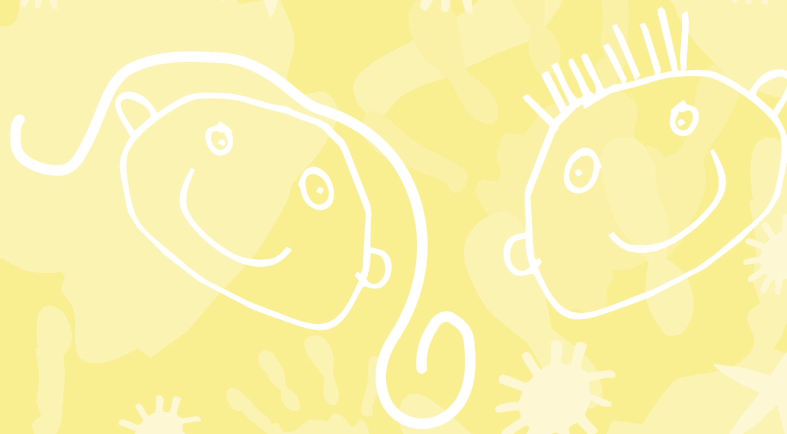
Best practice guidelines

for the management of

Type 1 Diabetes

in children and adolescents

Summary for health professionals



Queensland Government
Queensland Health

Introduction

About 1400 children and adolescents in Queensland, and 7600 nationally have type 1 diabetes. These young people have a lifetime of diabetes ahead.

In order to improve the management of this condition Best Practice Guidelines for the Management of Type 1 Diabetes in Children and Adolescents were developed by Queensland Health's Diabetes Allied Health Taskgroup. Working groups were formed that consisted of a range of health professionals from throughout Queensland with an interest in the development of paediatric diabetes guidelines.

This document contains guidelines on diabetes education, nutrition, psychosocial issues, physical activity and foot care management for health professionals working with children/adolescents with type 1 diabetes and their families. In addition, the roles of the paediatric endocrinologist, paediatrician/physician and general practitioner in the care of these individuals and families are discussed.

These guidelines support the Queensland Health Outcomes Plan for Diabetes Mellitus (2000-2004) through implementation of strategies within this plan, which address this National Health Priority Area.

Evidence basis of this document

The searches were focused on, but not confined to, the period between 1990-2001. Systematic reviews and meta-analyses were the primary sources of the searches. Reviews and journal articles incorporated where appropriate.

Medline searches were used to obtain primary research papers and reviews when the systematic reviews or meta-analyses did not exist for specific topics.

Existing guidelines and consensus statements on paediatric diabetes were also sought. Specifically, the ISPAD Consensus Guidelines (2000) and the APEG Handbook on Childhood and Adolescent Diabetes (1996) have been reviewed.

Levels of evidence have been assigned using the National Health and Medical Research Council designation of levels of evidence.

Service delivery approach

Management is a partnership with the child, adolescent and family and the multidisciplinary team of health professionals.

This approach recognises the role of the general practitioner in managing the general health care of the child/adolescent with diabetes and providing psychosocial support to the child/adolescent and their families. It also recognises the complex nature of diabetes among the young. It is recommended that the day-to-day management and sick day management of a child's/adolescent's diabetes be under the direction of a paediatric endocrinologist or paediatrician/physician trained in the care of children and adolescents with diabetes, with that management involving:

- general practitioner
- diabetes educator
- dietitian-nutritionist
- psychologist/psychiatrist/mental health worker/social worker
- a health professional with expertise in physical activity management
- access to a podiatrist with knowledge of childhood diabetes.

Reviews

- A paediatric endocrinologist or paediatrician/physician should review all children and adolescents with type 1 diabetes every three months for diabetes control and adjustment (more frequently if stabilisation is in progress)
- All children and adolescents with type 1 diabetes should have access to the multi-disciplinary team at least once per year
- Complications screening is undertaken annually for pre-pubertal children after five years of diagnosis and in pubertal adolescents after two years of diagnosis.

Diabetes services for children and adolescents in Queensland

It is recognised that education in the early period following diagnosis is particularly critical in determining both quality of life and clinical outcomes. Multidisciplinary teams experienced with paediatric diabetes have the expertise to provide "a good start" for these children/adolescents and their families. It is recommended that children and adolescents be referred to provincial or tertiary diabetes centres with specialist paediatric diabetes teams for initial education and for annual review.

In rural and remote areas it is preferable that local health professionals, who have access to the specialist paediatric diabetes team, provide ongoing support and education. If the child/adolescent/family is unable to access these health professionals, support with education should be provided by the experienced health professional at the provincial or tertiary diabetes centre, via videoconference or phone.

Diabetes education

Diabetes educator-registered nurses in many remote, rural and provincial centres have an open referral policy. This enables the diabetes nurse educator to take referrals from health professionals, carers and health agencies. Diabetes educator-registered nurses in tertiary and some provincial centres may require referrals from the doctor caring for the child/adolescent.

Referral criteria

Referral to a diabetes educator-registered nurse should be made at:

- initial diagnosis of diabetes
- change in the management of diabetes
- change in physical status:
  - before planned surgery
  - severe hypoglycaemic episodes
  - diabetic ketoacidosis
  - for stabilisation
  - eating disorders
  - diagnosis of co-existing diseases
- psychosocial changes
  - starting day care
  - commencing school or high school
  - change in carers
  - changes in family dynamics
- an annual review of clients.

Education, when delivered in a patient centered, age appropriate manner, provides a knowledge base, which becomes a vehicle for optimal self-management.

Diabetes education can be divided into two elements:

- survival education
- on-going education

Issues will be covered in the initial sessions include:

- what is diabetes?
- insulin therapy & injection technique
- blood glucose monitoring
- hypoglycaemia
- sick day management.

Ongoing diabetes education is also essential, as education is a continuous process that requires reinforcement for it to be effective.

Nutrition

Nutrition education for children and adolescents is an ongoing process that needs to be provided at a time that is suitable to meet the individual needs of the families.

In order to achieve optimal outcomes for the child/adolescent and family, initial and ongoing nutrition education should ideally be delivered by a dietitian-nutritionist who has appropriate training and experience in paediatric diabetes management. Assessment, education, nutrition counselling and evaluation are integral parts of this approach.

Criteria for referral to a dietitian-nutritionist

Instances when referral to a dietitian is appropriate for children and adolescents with diabetes and their families include:

- initial diagnosis – any child/adolescent, up to and including age 18
- annual review as a minimum for all children with diabetes
- change in management
- inappropriate growth rate such as failure to maintain height velocity or undesirable weight loss or gain
- difficulty, conflict or stress associated with food, eating pattern or blood glucose control
- rigid diet and an inflexible approach to food choices
- eating habits inconsistent with Australian Dietary Guidelines for Children and Adolescents
- concurrent conditions such as coeliac disease, fibrosis-related diabetes or eating disorders.
- requested by the family/young person or other health professionals.

As a member of a multi-disciplinary team, the dietitian-nutritionist also promotes access to other specialised services and refers inter-professionally, recommending other services as appropriate.

Topics that are discussed in the initial education sessions include:

- food, the body and diabetes
- usual eating patterns
- healthy eating guidelines for all children
- recognising carbohydrates and understanding their digestion and function.

Ongoing education includes:

- meal planning – factors affecting selection and preparation
- management for life activities and growth
- self management.

Ongoing nutrition education and support needs to be timely for the family and child. It is recognised that there will be a wide variation in length of time taken for the family to be comfortable with their "Survival" knowledge and skills sufficient to continue with "Ongoing" education.

Psychosocial

Psychologists, social workers and psychiatrists play an integral role in the management of children and adolescents with diabetes and their families. Diabetes in a child or adolescent may be associated with acute distress and in some cases prolonged distress for both the individual and the family. Pre-existing psychological, social, personal, family or environmental problems are likely to be exacerbated.

Families living with diabetes are constantly under the microscope and they may experience burnout. Sometimes, the enjoyment of childhood and adolescence can be overtaken by the demands of living with diabetes. Children, adolescents and members of their families may require individual counselling/therapy from specialist practitioners for a number of different issues.

It is important that all children and adolescents with newly diagnosed diabetes and their families should have a psychosocial assessment and a psycho-education session at diagnosis. In addition to the general areas of assessment it is essential to also consider specific age related issues.

Psychosocial assessment, psycho-education and treatment is an ongoing process.

It is recommended that a child/adolescent see a psychologist/social worker psychiatrist for assistance with the following:

- initial diagnosis
- subsequent hospital admissions
- family adjustment issues & sibling problems
- limited social support
- needle phobia, depression, anger, anxiety
- other physical or mental health issues
- when there are signs of depression, anger, behaviour problems, eating issues/body image or significant anxiety.

Topics that are often discussed in the initial sessions include:

- the typical range of emotional reactions to the diagnosis of diabetes
- guilt & grief
- marital stress
- treatment adherence.

Regular contact, at least yearly, will help to identify and manage any problems before they develop further.

Treatment

It is the responsibility of the psychologist/social worker/psychiatrist to design an individual treatment plan based on the outcome of the assessment. This treatment plan needs to be consistent with best practice recommendations for the specific intervention.

Predictable crises in chronic illness

A number of predictable crises may occur in any chronic illness and may be a prompt for psychosocial intervention. These events are include onset and diagnosis, disease specific medical symptoms, hospitalisation, initial major complications, specific therapeutic choices, failure of expected response and fear of clinic visits.

Transition to adult health care

Transfer of care from the familiarity of the paediatric team can appear daunting to young adults and their families, with any change potentially anxiety provoking. A failure to coordinate the transfer can mean that some young adults become lost in the system, dropping out of regular reviews. However, the transition to young adult health care can also be positive, with the young person assuming increased responsibility and autonomy with regard to their diabetic management.

It is essential that the transfer be planned for and discussed over a period of time with the young person and their family, with good communication between all members of the care teams.

Physical activity

Regular physical activity is an essential component of a healthy lifestyle for all children and adolescents, including those with diabetes.

Physical activity intervention aims to provide education and experiences that will:

- develop life-long physical activity habits for the child or adolescent
- centre care around the needs of the child/ adolescent and their family
- be based on the therapeutic aspects of exercise for the treatment and prevention of complications of disease
- be in accordance with professional standards, best practice guidelines and evidence-based approaches
- promote the self-management philosophy.

All members of the multidisciplinary diabetes care team, including the diabetes educator, general practitioner, paediatric endocrinologist and paediatrician/physician, have an important role in the education and promotion of physical activity for children and adolescents with diabetes. When the level of advice required is beyond the scope of practice of these health professionals, referral to a health professional with expertise in physical activity management may be appropriate.

Exercise physiologists are experts in exercise prescription. Many exercise physiologists work in private practice and may also be accessed through Queensland Academy of Sport programs for athletes. Other health professionals such as physiotherapists and dietitian-nutritionists may also have expertise in this area.

Criteria for referral to a health professional with expertise in physical activity management

Instances when referral to a health professional with expertise in physical activity management are appropriate for children/adolescents with diabetes and their families include:

- initial diagnosis or soon after depending on the child's/adolescent's/ family's priorities
- change in physical activity level
- difficulties controlling blood glucose during physical activity
- underweight or overweight
- concurrent conditions or complications eg. muscular skeletal conditions, deficit of motor skills, elevated lipid levels
- restrictive physical activity level
- requested by child/adolescent/family or coach.

Topics that will be covered in the initial sessions include:

- family lifestyle and activity level
- current physical activity level and limitations
- benefits, risks and optimum levels of activity
- glycaemic awareness and control before during and after physical activity
- insulin effects.

Review procedures can be flexible, at the discretion of the health professional and subject to the child's/ adolescent's and family's ability to manage.

Foot care

Annual foot screening is recommended for:

- children who have had diabetes for five years or more and
- adolescents who have had diabetes for two years or more.

Appropriately trained health professionals, such as the diabetes educator, general practitioner, a paediatric endocrinologist or paediatrician/physician or podiatrists may perform foot screening.

A basic foot screening should include screening for:

- limited joint mobility
- skin or nail conditions eg. calluses, ingrown toenails, warts
- paediatric foot disorders eg. symptomatic flat foot, club foot
- footwear
- self care
- other diabetic foot complications eg. neurological.

Podiatrists have an important role in the prevention and treatment of foot complications in diabetes. If early screening identifies problems with the feet, education of the child/adolescent/family and where indicated, specific treatment instigated by the podiatrist can prevent many major lower limb problems.

The main reason for referring a child/adolescent to a podiatrist is for diabetes foot assessment, education regarding foot care and management of lower limb

problems. Clinical signs of diabetic foot complications in children and adolescents with diabetes are not common. Ensuring healthy foot care in this age group may help to prevent foot problems and lower limb complications that are commonly associated with long-term diabetes in adults.

Topics that will be covered in the initial education sessions include:

- foot care
- footwear facts
- when to seek help
- good glycaemic control and its relationship to feet.

Follow-up management

For those found to be at risk, follow-up management is needed. The level of management, review periods and times will depend on the level of risk and severity of the complications as determined by the podiatrist.

In addition, changes in a child's or adolescent's foot health can occur at any time and the level of management will need to be adjusted accordingly at the clinician's discretion.

Community support for children/ adolescents with type 1 diabetes and their and families

National Diabetes Services Scheme

- a Commonwealth Government scheme to subsidise the cost of syringes, needles and glucose testing strips
- contact Diabetes Australia Queensland

Diabetes Australia Queensland

- telephone: 07 3239 5666 or 1300 136 588 outside Brisbane metro area
- internet: www.daq.org.au

Juvenile Diabetes Research Foundation

- telephone: 3221 1400
- parent support telephone 3349 9590
- internet: www.jdrf.org.au

Carer's Allowance: available through Centrelink

For further information on these guidelines:

Phone the Health Advisory Unit (Allied Health)
07 3234 1386

The Best Practice Guidelines for the Management of Type 1 Diabetes in Children and Adolescents are available on the web at http://www.health.qld.gov.au/publications

or on QHEPS at http://qheps.health.qld.gov.au/odb/hau/allied/html/diabetes.htm.