

Best practice guidelines

for the management of

Type 1 Diabetes

in children and adolescents



Best practice guidelines for health professionals



Queensland
Government
Queensland Health

Foreword

Diabetes is a national and state health priority. Both type 1 and type 2 diabetes are responsible for significant morbidity and mortality which impacts on the Queensland Health system and more importantly on the lives of those with diabetes, their families and carers.

Figures from the National Diabetes Register show that approximately 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 were developed by Queensland Health's Diabetes Allied Health Task Group.

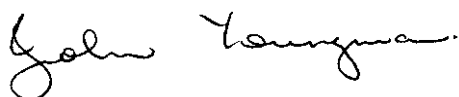
These guidelines define and identify:

- The Queensland Health endorsed model of care for children and adolescents with type 1 diabetes and their families
- Evidence-based practice for diabetes education, nutrition, psychosocial, physical activity and foot care management for health professionals working with children/ adolescents with type 1 diabetes and their families
- Services that can be provided by a range of accredited service providers
- Criteria other professionals should use when referring and
- The roles of the paediatric endocrinologist, paediatrician / physician and general practitioner, in the care of these individuals and families

Queensland Health is committed to providing efficient and effective services to people with diabetes. 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.

I recognise the significant work undertaken by professionals and professional associations involved in the development of these guidelines and thank all those involved in the task group for their collaboration and support.

I am pleased to endorse these Guidelines and ask that health professionals involved in the care of children and adolescents with type 1 diabetes and their families become familiar with this document and encourage its use.



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15 / 7 /2002

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1. Introduction

1.1 Aim of this document

The expectation for any clinical practice guidelines is that the documented assessment and management strategies are supported by evidence that shows the listed practices produce positive outcomes.

The aim of these for the management guidelines for Type 1 diabetes in children and adolescents, is not to review the literature to reproduce evidence-based documents, but to source evidence-based information including meta-analyses, systematic reviews and consensus statements to inform health professionals about practices in paediatric Type 1 diabetes management that are evidence-based.

These guidelines support the implementation of the following policy documents:

- Health Outcomes Plan - Diabetes Mellitus (Queensland Health 2000a)
- The Position Statement: Health Services Integration in Queensland (Queensland Health 2000b)
- The Strategic Policy Framework for Children's and Young People's Health (Queensland Health 2002a) and
- The Draft Position Statement: Primary and Community Care Queensland Health, 2002-2007 (Queensland Health 2002b).

This document contains guidelines on diabetes education, nutrition, psychosocial, 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 in section 1.6.

1.2 Other sources of information

These guidelines are designed to assist the health professional deliver efficient and effective services based on child/adolescent/family's needs and the resources currently available. They are not designed to educate the health professional in the area of clinical paediatric diabetes management. The Royal Children's Hospital, Brisbane, on behalf of Queensland Health, is currently developing resources and clinical education training programs for diabetes educators, dietitians - nutritionists and mental health workers working in paediatric diabetes.

Health professionals seeking further information on the medical management of paediatric Type 1 diabetes are referred to the "International Society for Paediatric and Adolescent Diabetes Consensus Guidelines 2000" (ISPAD 2000) and the Australian Paediatric Endocrine Group guidelines "APEG Handbook on Childhood and Adolescent Diabetes" (1996).

1.3 Evidence

1.3.1 Evidence basis of this document

The searches were focused but not confined to the period of 1990-2001. Systematic reviews and meta-analyses were the primary sources of the searches. Reviews and journal articles used in these reviews were also used where appropriate.

Medline searches were also used to obtain primary research papers and reviews when the systematic reviews or meta-analyses discussed above 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 (NHMRC) designation of levels of evidence (see table 1) (NHMRC 1999).

Available evidence for these guidelines tends to be Level III or below when the NHMRC criteria are applied. The NHMRC (1999) acknowledges that evidence from systematic reviews of randomised clinical trials, Level 1, the “gold standard” for clinical medicine, is usually not available in the case of public health and social science interventions.

Where evidence at the NHMRC levels is unavailable, these guidelines use recommendations from consensus guidelines, expert opinion and the Queensland Health Paediatric Type 1 Diabetes Workgroups (2001-2002). These are indicated in the text as “Expert Advisory Group Recommendation” as the current NHMRC scale does not attach a formal level of evidence to expert opinion or the findings of expert working parties.

For ease of classification, the categories for level of evidence III-1 to 3 have been grouped under level of evidence III.

Table 1. Designation of levels of evidence

Level of evidence	Study design
I	Evidence obtained from a systematic review all relevant of randomised controlled trials
II	Evidence obtained from a least one properly-designed randomised controlled trial.
III-1	Evidence obtained from a well-designed pseudorandomised controlled trial (alternative location or some other method)
III-2	Evidence obtained from comparative studies (including systematic reviews of such studies) with concurrent controls and allocation not randomised, cohort studies, cohort studies, case –control studies, or interrupted time series with a control group)
III-3	Evidence obtained from comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel control group.
IV	Evidence from case series, either post -test or pretest/post - test.

1.4 Standards of practice

1.4.1 Professional competence

These guidelines are provided to assist the trained health professional (with a degree, diploma, certificate of registration or credentialling in diabetes education, nursing, nutrition and dietetics, psychology, social work, physiotherapy, Indigenous health work, exercise physiology, podiatry and medicine) to provide care for children/adolescents with type 1 diabetes and their families.

They are intended for use by people who have completed the appropriate level of training. Ultimately, the responsibility for delivering services in accordance with the appropriate standard of care lies with the health professional. It is the responsibility of individual health professionals to ensure they work within their personal skill level and scope of practice outlined by their professional boards and associations and that profession specific codes of practice and professional standards are adhered to. Therefore, the health professional is responsible for referring to appropriate health professionals when the expertise required is outside their scope of practice.

1.4.2 Training

It has been recommended by ISPAD (2000), that health professionals working with children/adolescents with diabetes and their families have, in addition to their professional qualifications, training and/or experience in paediatric diabetes and child and adolescent development.

1.4.3 Flexible competencies

Many different health professionals contribute to the education and management of the child/adolescent with diabetes and their family. These individuals have

specific training and expertise in paediatric diabetes. However access to all health professionals is not available in some parts of Queensland.

Flexible competencies, in the context of this document, are defined as the range of health professionals with the specific knowledge and skills to deliver specific components of paediatric diabetes education and management.

Education and management of the newly diagnosed child/adolescent and their family should be provided by the health professional who has specific experience and training in the particular aspect of diabetes care. Flexible competencies, which allow other health professionals to provide elements of diabetes education and management, are not recommended for these children/adolescents/families, at this stage of education.

However, for children and adolescents who require ongoing education, other health professionals may provide support and education. These health professionals should liaise with the relevant members of the diabetes team involved in the child/adolescent's care.

A listing of these health professionals has been included in the flexible competency columns of the clinical activity tables. It is the responsibility of these professionals to ensure they have the ability to carry out assessments and interventions within their professional scope of practice and supply information that is accurate and consistent with current recommendations. It is the responsibility of the professional to refer to other health professionals if they do not have expertise in dealing with specific problems.

1.5 Indigenous health workers

For Aboriginal and Torres Strait Islander children/adolescents and their families, it may be more effective and acceptable for diabetes education to be delivered by the health professional in collaboration with trained Indigenous health workers. Indigenous health workers are well placed to consider cultural factors, environmental barriers and social obstacles to implementing education/interventions and are more likely to have regular contact through involvement in the community.

1.6 Model of care

Expert Advisory Group Recommendation

1.6.1 Management of children and adolescents with type 1 diabetes

Aims:

The aims of best practice management for children and adolescents with diabetes, as described in the APEG Handbook on Children and Adolescents Diabetes (1996) are to:

- develop individualised plans for diabetes care for the family incorporating the particular needs of the child or adolescent and the family
- achieve optimal psychosocial adjustment
- achieve optimal metabolic (glycaemic) control
- achieve normal growth and development.

1.6.2 Service delivery approach and role of the general practitioner:

These aims are best achieved through a multidisciplinary diabetes team approach. 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
- access to a podiatrist with knowledge of childhood diabetes and (Queensland Health 2000a; ISPAD 2000)
- access to a health professional with expertise in physical activity management (ADA 2001).

Management is in partnership with the client and/or their carer and family. Communication between members of the care team and client/carer or their family, particularly agreement on the care coordinator for each child/patient, is essential to successful management.

If access to the above multidisciplinary diabetes team is limited (eg. rural location), a paediatrician or physician with a special interest in the paediatric/adolescent age group should lead day-to-day treatment, with review undertaken by a paediatric endocrinologist or paediatrician/physician trained in the care of children and adolescents with diabetes if acceptable control is not achieved (Queensland Health 2000a).

The diabetes team collaborates to organise these services:

- specialised hospital medical care of the diabetes when necessary
- expert ambulatory care of diabetes with the aim of achieving the best possible glycaemic control without severe hypoglycaemic episodes
- expert advice on issues such as alcohol, smoking, exercise, contraception and paediatric issues such as immunisation
- screening for complications, consistent education, psychosocial and access to emergency advice. (Queensland Health 2000a)

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 under way) (Queensland Health 2000a)
- All children and adolescents with type 1 diabetes should have access to the multi-disciplinary team at least once per year (ISPAD 2000)

- Complications screening is undertaken annually for pre-pubertal children after five years of diagnosis and in pubertal adolescents after two years of diagnosis (Queensland Health 2000a).

1.6.3 Issues to be addressed by the general practitioner

At each visit to the general practitioner it is important that the following issues are addressed:

- presenting problem
- review of blood glucose levels, frequency of hypoglycaemic episodes, recent HbA1c results
- current state of health and well-being – including height, weight and growth pattern.
- current issues in school
- medication review adjustments made in consultation with family, hospital and community pharmacist
- confirm supplies of insulin and glucagon (check exp. date) are available
- patient and family focus with the aim of development of the family as 'expert'
- consultation with hospital team regarding development of care plan or discharge plan
- family adjustment to care of diabetes and stresses and life events in other family members which may affect diabetes management of patient.

It is expected that the patient and family would be seen regularly.

These issues are discussed in detail in the article by Dr Martyn Sulway (2000) and in the booklet "Family, GP and Hospital in partnership in the care of Young People with Diabetes" (QPED 2001).

1.6.4 Stages of education

Diabetes education can be divided into two stages:

- survival education
- on-going education.

Survival education is the information that is required at diagnosis to ensure the child or adolescent can be cared for safely at home. For those patients who are educated initially as in-patients the education program is usually delivered over a 4 – 5 day period.

However, some of the survival education can occur after discharge. Patients who are participating in ambulatory programs may receive survival education over a period of 1 – 3 weeks.

On-going education can take place in the diabetes clinic, through formal 'on-going' education programs and at diabetes camps. The term 'taking control' is used in the nutrition section and this refers to an extension of the on-going education stage.

1.6.5 Level of care

Tables providing information regarding suggested timing of consultations are included in the Education, Nutrition, Psychosocial and Physical Activity sections of the guidelines. Time periods are included as these could assist developing a needs analysis of services available to these children/adolescents/families and include direct contact times and other activities required for quality care.

The times mentioned in these tables are recommended minimum times for the health professional to spend with the child/adolescent/family, liaison with other health professionals, maintaining documentation and completing database entries.

1.6.6 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 (ISPAD 2000). 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.

Appendix 1 provides a summary of services available for children and adolescents with diabetes in tertiary and provincial centres.

1.7 Management of type 2 diabetes in children and adolescents

There are currently no international and national guidelines for the management of type 2 diabetes in children and adolescents. It is recognised that there appears there is an increasing prevalence of type 2 diabetes in young people in Australia, particularly in Aboriginal and Torres Strait communities (ADA 2000).

While some aspects of the management of type 1 diabetes will be similar to the management of type 2 diabetes in young people, there are also many differences that must be considered in the management of these children and adolescents. For example, weight management is often a cornerstone of treatment for both young people and adults with type 2 diabetes, but this is not usually required in management of type 1 diabetes.

It is recommended that health professionals caring for these children and adolescents, with type 2 diabetes, use their professional discretion and apply best practice guidelines, as they become available.

1.8 References

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Sulway M, 2000, What's the GP's role in treating childhood diabetes? *Medicine Today*, vol. 1 June, pp. 22-26

Appendix 1

Summary of services for children & adolescents with diabetes available at tertiary and provincial hospitals in Queensland¹

Hospital	Type of clinic	Ophthalmology services	Child & youth mental health service [#]	Diabetes educator services ^{**}	Dietetic services ^{**}
Tertiary Hospitals:					
The Mater Children's Hospital	Dedicated paediatric diabetes clinics + provides outreach services to provincial hospitals	Public sessions available	Service available in diabetes clinic	Paediatric diabetes educator	Paediatric dietitian-nutritionist
The Royal Children's Hospital	Dedicated paediatric diabetes clinics + provides outreach services to provincial hospitals	Public sessions available	Service available in diabetes clinic	Paediatric diabetes educator	Paediatric dietitian-nutritionist
Provincial hospitals					
Bundaberg	General paediatric Clinic	No public sessions Private practice only	Service available at hospital	0.8 diabetes educator - level 2.0	0.5 dedicated paediatric dietitian-nutritionist
Caboolture Hospital	Dedicated diabetes clinic + outreach service from Brisbane	Private practice only	Service available in district	1 diabetes educator - Level 2.0	0.2 diabetes dietitian-nutritionist
Cairns	Dedicated paediatric diabetes clinic and twice per year outreach service from Brisbane	No public sessions Private practice only	Community mental health	3 diabetes educators	1 dedicated diabetes dietitian-nutritionist
Gladstone	Outreach diabetes clinic from Brisbane	No public sessions Private practice only	Visiting service from Brisbane	1 diabetes educator -level 3.0	0.3 diabetes dietitian-nutritionist
Gold Coast	Dedicated paediatric diabetes clinic	Public & private sessions available	Service available in district	2 diabetes educators - level 3.0	1 dedicated diabetes dietitian-nutritionist

¹ Updated, June 2002 from original table provided by Eunice Lang, Clinical Nurse Consultant, Royal Children's Hospital.

[#] Health professionals working at dedicated paediatric diabetes clinics encourage those working in other centres to liaise with them to ensure consistency of care.

^{*} Provincial health professionals provide services to children, adolescents and adults with diabetes, unless the FTE is otherwise specified. NB many FTEs are estimates.

Summary of services for children & adolescents with diabetes available at tertiary and provincial hospitals in Queensland-continued

Hospital	Type of clinic	Ophthalmology services	Child & youth mental health service[#]	Diabetes educator services^{**}	Dietetic services^{**}
Hervey Bay Hospital	Dedicated diabetes clinic + outreach service from Brisbane	Public & private sessions available	Service available in district	1 district diabetes educator - Level 2.0	0.1 diabetes dietitian-nutritionist
Ipswich Hospital	General paediatric Clinic	Public & private sessions available	Service available in district	1 diabetes educator - Level 2.0	0.4 dedicated to paediatrics
Mackay Hospital	Dedicated diabetes clinic + outreach service from Brisbane	Public & private sessions available	Service available in hospital & district -	1 diabetes educator - Level 2.0	0.25 diabetes dietitian-nutritionist
Mt Isa Hospital	General paediatric clinic	Public sessions available	Sessions available at hospital	No position	0.3 diabetes dietitian-nutritionist
Nambour Hospital -diabetes services based at Sunshine Coast Diabetes Centre	No dedicated paediatric clinic at hospital. All diabetes education services coordinated from diabetes centre	Private sessions available	Service available in district	3.6 diabetes educators	0.5 dedicated diabetes dietitian-nutritionist
Redcliffe Hospital	General paediatric clinic	Private practice only	Service available in district	1 diabetes educator - level 2.0	0.2 diabetes dietitian-nutritionist
Rockhampton Hospital	Dedicated paediatric clinic + outreach service from Brisbane	Private practice only	Service available at hospital	1 diabetes educator -Level 2.0	0.2 dedicated paediatric dietitian-nutritionist
Toowoomba Hospital	General paediatric clinic + outreach service from Brisbane	Public & private sessions available	Service available in hospital	1 diabetes educator – Level 2.0	0.2 dedicates diabetes dietitian-nutritionist
Townsville Hospital	Dedicated diabetes clinic + outreach service from Brisbane	Public sessions available	Service available in hospital	2.4 diabetes educators - level 3.0	0.5 dedicated diabetes dietitian-nutritionist

2 Diabetes Education

2.1 A diabetes educator

2.1.1 Definition

The Australian Diabetes Educators Association (ADEA) paper “The Role of the Diabetes Educator in Australia” (ADEA 2001) defines a Diabetes Educator as:

“ A full member of ADEA who is qualified to practice in nursing, dietetics, podiatry, psychology, medicine or Aboriginal health. A Diabetes Educator™ has acquired a core body of knowledge and skill in the biological and social sciences, principles of teaching and learning, communication and counselling, has experience and advanced knowledge in the care of people with diabetes and those at risk of diabetes, and has diabetes education included in the scope of their employment.”

An important role of the diabetes educator is to act as a role model/mentor for colleagues, peers and diabetes resource person.

2.1.2 Credentialling

Further to this above definition it is recommended by the ADEA that the diabetes educator is credentialled. Requirements for credentialling are:

“The credentialled Diabetes Educator™ is a full member of ADEA who has completed an ADEA accredited diabetes education course, has completed a supervised period of clinical practice and activities which fulfil the continuing education and professional development requirements of the ADEA Credentialling Program.”
(ADEA 2001)

2.1.3 The diabetes resource person and practice nurse

A diabetes resource person is employed within a health care service and should have undertaken an appropriate level of education to support people with diabetes and the diabetes educator-registered nurse² in achieving best possible health outcomes.

Practice nurses work with doctors in general practice and have an increasing role in the education and support of patients, particularly adults. In order to

² The term diabetes educator - registered Nurse is used throughout this document, as the majority of diabetes educators currently employed by Queensland Health are registered nurses. Other health professionals who have undertaken the diabetes educators' course and meet the requirements as per ADEA may also be employed as diabetes educators.

support people with diabetes and the diabetes educator-registered nurse it is essential they also have an appropriate level of training.

It is essential that the diabetes resource person and practice nurse work under the guidance of a diabetes educator-registered nurse to ensure, ongoing training and mentoring.

It is highly desirable for the diabetes resource person and practice nurse to be Associate members of the Australian Diabetes Educators Association for continuing education.

Documentation of communication and its outcomes between the diabetes educator and the diabetes resource person or practice nurse is the responsibility of all parties.

2.2 Qualifications of a diabetes educator

2.2.1 Mandatory

- registered or endorsed health professional
- registered or endorsed to practice in the diabetes educator's primary health field
- Australian Diabetes Educators Association membership
- paediatric experience and or training.

2.2.2 Highly desirable

- Australian Diabetes Educators Association credentialled or working towards credentialled status through an Australian Diabetes Educators Association accredited advance practice qualification
- three year's postgraduate experience in their primary health field.

2.3 Standards of professional practice

2.3.1 Professional competence

Standards of professional practice are integral to the role of the diabetes educator- registered nurse. They provide the professional with guidelines for the establishment and maintenance of effective diabetes education programs and also ensure consistent practices between professionals.

Standards of professional practice are also useful tools for the professional as well as the employer in determining professional responsibility, scope of

practice, accountability, streamlining of services and resources and the planning future directions of services.

All health professionals who are credentialled or working towards credentialling by the Australian Diabetes Educators Association can practice diabetes education, within the scope of practice of their original qualifications, and provided they conform to professional standards and competencies of their primary health field.

At present the standards that apply to diabetes educators within Queensland are:

- “National Standards of Practice for Diabetes Educators” (ADAE 2001)
- “Performance Indicators linked to National Core Competencies for Diabetes Educators” (ADAE 1996).

In addition to these documents the Paediatric Type 1 Diabetes Education Working Group recommends use of the “International Society for Paediatric and Adolescent Diabetes Consensus Guidelines 2000” (ISPAD 2000) and the Australian Paediatric and Endocrine Group guidelines “APEG Handbook on Childhood and Adolescent Diabetes” (APEG 1996). Profession specific codes of practice and professional standards should also be adhered to.

2.4 Referrals

Diabetes education should be provided when a child/adolescent is diagnosed and reviewed at regular intervals or in instances documented below.

2.4.1 Referral criteria

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.

Referrals are accepted to:

- be consistent with modern diabetes management
- provide a service that is accessible and provided in a timely manner
- encourage patient autonomy and self care (where appropriate)
- prevent the acceleration of potential health problems
- provide support to family members
- enhanced the team approach to management of children/adolescents and their families.

As a member of a multidisciplinary team, the Diabetes Educator-Registered Nurse also promotes access to other specialised services and refers the child/adolescent/family to other health professionals, recommending appropriate services, when available.

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.

2.5 Education guidelines for type 1 diabetes in children & adolescents

Expert Advisory Group Recommendation

It is recommended by the ISPAD Consensus Guidelines (ISPAD 2000) that:

‘From the first day of diagnosis the child or adolescent with diabetes and the family should be cared for by members of a team of specialists. All members of the team should have training, expertise and understanding of both diabetes and paediatrics, particularly child and adolescent development.’

Education when delivered in a patient-centered, age-appropriate manner provides a knowledge base, which becomes a vehicle for optimal self-management (ISPAD 2000).

2.5.1 Key principles

- Education is the cornerstone of diabetes care and management for children and adolescents
- Families including other care providers should have easy access to and be included in the educational process
- Diabetes education should be delivered by health care professionals with a clear understanding of the special and changing needs of young people and their families as they grow through the different stages of life
- Diabetes education should be based on a thorough assessment of the family’s attitudes, beliefs, learning style, ability, readiness to learn, and expected goals. This assessment needs to take into consideration existing knowledge of diabetes
- The education needs to be adaptable and personalised so that it is appropriate to each individual’s age, stage of diabetes, maturity and lifestyle

- Diabetes education is a continuous process and must be repeated for it to be effective
- Diabetes education needs to be planned, documented, monitored and evaluated regularly by the diabetes care team
- All children/adolescents with diabetes should have access to the multi-disciplinary team at least once per year
- Many children are too young at time of diagnosis for them to receive primary diabetes education so education is initially directed towards the parents. It is essential that these children receive primary diabetes education as they grow and mature towards self-care of their diabetes

Adapted from ISPAD (2000)

2.5.2 Psychological adjustment

Diabetes in a young person has a profound impact on family life. It has the potential to cause serious personal and family distress. It is important that both the child/adolescent and their family be given the opportunity to work through the grief process which accompanies the diagnosis of diabetes. Past losses, experience with illness, family conflict and other stressors will affect how different families and their members adjust and cope with diabetes. These families need time to adjust to the diagnosis before starting diabetes education. The ability to learn the knowledge and skills required to care for a child or adolescent with diabetes can be impaired if the education program is started too early.

2.5.3 Mode of education and resources:

Expert Advisory Group Recommendation

- Methods of delivering education and the use of educational resources will depend on the individual organisation's experience and facilities. Education will be dominated initially by individual teaching and should be backed up by written guidelines, booklets and other media which should be appropriate to child's age
- Written materials for parents should use appropriate language and a style that is easily comprehensible
- When available, videos, computer games, etc, can be used
- Other methods of delivering education might include small group teaching sessions, role play, television and during diabetes camps.

Adapted from ISPAD (2000)

2.5.5 Flexible competencies:

Initial diabetes education should be delivered by a Diabetes Educator who is trained and experienced in paediatric diabetes management and education. However, for children and adolescents who have been previously diagnosed, ongoing support, education and nutrition advice may be provided by a diabetes resource nurse or an appropriately trained practice nurse.

The diabetes resource nurse or practice nurse should liaise with the Diabetes Educator and Dietitian- Nutritionist involved in the child's/adolescent's care.

2.5.6 Education elements

Expert Advisory Group Recommendation

Diabetes education can be divided into two elements:

- survival education
- on-going education.

Survival education is the information that is required at diagnosis to ensure the child or adolescent can be cared for safely at home. For those patients who are educated initially as in-patients the education program is usually delivered over a 4 – 5 day period.

However, some of the survival education can occur after discharge eg. glucagon administration. Patients who are participating in ambulatory programs may receive survival education over a period of 1 – 3 weeks. Regardless of the model chosen for initial management the survival information and the educational goals are the same.

The education of children/adolescents and their families needs to be comprehensive and is best delivered within a planned, documented program which is continually monitored and evaluated (ISPAD 2000). The following information provides a guide to develop age appropriate diabetes education programs based on the model of management adopted by the individual organisation.

2.5.6.1 Level of care

Expert Advisory Group Recommendation

The level of diabetes education documented below is considered appropriate for all children and adolescents with type 1 diabetes. Table 2, level of care, was developed by the Paediatric Diabetes Type 1 Educators Workgroup.

Table 2: Level of care information on minimal time, length and timing of consultations.

Type of visit	Timing of visit and contact time
'Survival' education following diagnosis	-1-2 hrs/session, daily over 4-5 days - or within 2-3 weeks of diagnosis
Ongoing education	-within 12 months of initial diagnosis -visits over several sessions, using variety of strategies - 1-2 hour/session over 8-16 sessions
Education review	at least one education review every 12 months

2.5.6.2 Survival education for newly diagnosed patients

Expert Advisory Group Recommendation

Current management practices for children and adolescents diagnosed with diabetes are centered around the concept of educating patients, parents and other care providers to a level where they are empowered to self-manage their diabetes.

Traditionally, children and adolescents have received their initial education program as in-patients. There has been a trend recently towards ambulatory education programs with the majority of education being delivered in the outpatient setting. Ambulatory education programs require the support of a specialised diabetes care team who maintain frequent contact with the families.

Some hospitals provide 'early discharge programs' where after initiation of insulin therapy the patient is discharged and returns to the hospital for education either on a daily or weekly basis. There are other models which provide a 'hospital in the home' program where education is provided by health professionals in the patient's home.

Regardless of the model adopted by the individual organisation, the education program needs to be planned, documented, monitored and evaluated for its effectiveness. It is essential that appropriate entry criteria are developed to ensure that patient well-being is maintained.

Contra-indications to ambulatory education programs include:

- dehydration or ketoacidosis
 - profound grief reaction in the family
 - geographic isolation
 - no telephone in the home
 - language or other communication difficulties
 - significant psychological or psychiatric problems within the family
 - child is less than two years old.
- (APEG 1996)

The content, pace and sequencing of an education program for the newly-diagnosed patient will depend on whether the child/adolescent is educated as an in-patient or has entered into an ambulatory education program.

Table 3 provides an outline of the educational elements that need to be included in 'survival' education.

Table 3: Outline of ‘survival’ education for children and adolescents with type 1 diabetes³

Topic	Content	Outcome The parent/s and or child/adolescent will :
What is diabetes?	<p><i>Define:</i></p> <ul style="list-style-type: none"> - diabetes - signs & symptoms - different types - cause - treatment - management goals 	<ul style="list-style-type: none"> - understand the disease process of diabetes - state the signs & symptoms - understand the treatment & goals
Insulin therapy & injection technique	<p><i>Discuss:</i></p> <ul style="list-style-type: none"> - need for insulin therapy - how insulin works - names of insulin/s which have been prescribed - correct storage of insulin <p><i>Demonstrate:</i></p> <ul style="list-style-type: none"> - how to ‘draw-up’ an accurate dose of either single or mixed insulin - correct injection technique - appropriate injection sites 	<ul style="list-style-type: none"> - state the effect of insulin on blood glucose levels - state the name of the prescribed insulin - understand onset, peak and duration of prescribed insulin - state correct storage method for insulin - draw-up an accurate dose of either single or mixed insulin - administer insulin by subcutaneous injection - identify injection sites
Blood glucose monitoring	<p><i>Discuss:</i></p> <ul style="list-style-type: none"> - purpose of blood glucose (BG) monitoring - target range for blood glucose levels - frequency of testing <p><i>Demonstrate:</i></p> <ul style="list-style-type: none"> - how to use a blood glucose monitor (according to manufacturer’s instructions) - accurate recording of blood glucose readings and insulin doses in BG record book 	<ul style="list-style-type: none"> - understand the reason blood glucose monitoring is performed - state the target range for the blood glucose levels - demonstrate an accurate blood glucose test - accurately record BG readings and insulin doses in record book - understand how to care for their BG meter and test strips

³ adapted from Education Guidelines, Endocrine and Diabetes Department, Royal Children’s Hospital, Brisbane

Table 3: Outline of ‘survival’ education for children and adolescents with type 1 diabetes - *continued*

Topic	Content	Outcome
<i>Hypoglycaemia</i>	<p><i>Explain:</i></p> <ul style="list-style-type: none"> - hypoglycaemia - signs & symptoms - causes - treatment - effects of exercise on blood glucose levels - prevention strategies <p><i>Demonstrate:</i></p> <ul style="list-style-type: none"> - the drawing-up and administration of glucagon 	<ul style="list-style-type: none"> - state what hypoglycaemia is - describe the signs & symptoms - describe how to treat - state prevention strategies <ul style="list-style-type: none"> - draw-up an accurate dose of glucagon - demonstrate how to administer glucagon by subcutaneous injection
<i>Sick Day Management</i>	<p><i>Discuss:</i></p> <ul style="list-style-type: none"> - effects of illness on diabetes - a written sick day plan outlining frequency of monitoring blood and urine (for ketones), emergency telephone numbers, when to seek medical advice - correct care for ketone test strips <p><i>Demonstrate:</i></p> <ul style="list-style-type: none"> - how to test urine for ketones 	<ul style="list-style-type: none"> - understand effects of illness on diabetes - understand ‘sick day action plan’ - state when to seek medical advice - state correct care for ketone test strips <ul style="list-style-type: none"> - demonstrate how to test urine for ketones
<i>Dietary advice</i>	<ul style="list-style-type: none"> - Refer to nutrition guidelines 	

2.5.6.3 On-going education

Expert Advisory Group Recommendation

Diabetes education is a continuous process that requires reinforcement for it to be effective. On-going education can take place in the diabetes clinic, through formal 'on-going' education programs and at diabetes camps. On-going education programs can either be in the form of individual teaching or in small groups (ISPAD 2000). Table 4 outlines the educational elements that need to be included when developing an 'on-going' education program (ISPAD 2000).

Table 4: Outline of 'on-going' education for children and adolescents with type 1 diabetes

Topic	Content	Flexible competencies⁴
<i>Pathophysiology of diabetes</i>	More detailed explanation of disease process including: - epidemiology - current research	Diabetes educator-RN ⁵ Diabetes resource person ⁶ Dietitian- nutritionist Paediatric endocrinologist Paediatrician Physician ⁷
<i>Insulin adjustment</i>	- Principles of adjusting insulin doses - Matching insulin, food and exercise	Diabetes educator- RN Paediatric endocrinologist Paediatrician Physician
<i>Long-term Complications</i>	- Micro and macro-vascular complications and their prevention - Complication screening	Diabetes educator-RN Diabetes resource person Dietitian-nutritionist Paediatric endocrinologist Paediatrician Physician
<i>Glycaemic control</i>	- Targets of control - HbA _{1c} measurements - Matching insulin, food and exercise	Diabetes educator-RN Diabetes resource person Dietitian- nutritionist Paediatric endocrinologist Paediatrician Physician

⁴ Initial diabetes education should be delivered by a diabetes educator- registered nurse (RN) who is trained and experienced in paediatric diabetes management and education. Flexible competencies which allow other health professionals to provide elements of diabetes education are not recommended for newly-diagnosed children and adolescents.

⁵ RN = Registered Nurse

⁶ The diabetes resource person should practice under the guidance of the diabetes educator-RN

⁷ Physician with a special interest in childhood and adolescent diabetes

Table 4: Outline of ‘on-going’ education for children and adolescents with type 1 diabetes - *continued*

Topic	Content	Flexible competencies
<i>Hypoglycaemia</i>	- Review hypoglycaemia management <ul style="list-style-type: none"> - signs and symptoms -causes - treatment 	Diabetes educator-RN Diabetes resource person Dietitian- nutritionist Paediatric endocrinologist Paediatrician Physician
	- Effects of physical activity <ul style="list-style-type: none"> - refer to Physical Activity Guidelines 	
<i>Sick day management</i>	- Adjustment of insulin during illness - Prevention of Ketoacidosis	Diabetes educator-RN Paediatric endocrinologist Paediatrician Physician
<i>Dietary advice</i>	- Refer to Nutrition Guidelines	
<i>Childcare, preschool, school & diabetes</i>	- Education of staff - Emergencies - Examinations - School camp safety - Excursions	Diabetes educator-RN Diabetes resource person Dietitian- nutritionist Paediatric endocrinologist Paediatrician Physician
<i>Travel & diabetes</i>	- Vaccination - Time zone management - Insurance - Insulin Adjustments - Sick day management - Physical activity - Environmental effects - Care of medications and equipment - Travel procedures and security	Diabetes educator-RN Dietitian- nutritionist General practitioner Paediatric endocrinologist Paediatrician Physician

Table 4: Outline of ‘on-going’ education for children and adolescents with type 1 diabetes – *continued*

When age appropriate:

Topic	Content	Flexible competencies
<i>Sexuality & diabetes</i>	<ul style="list-style-type: none"> - Awareness of pre-pregnancy counselling - Contraception - Sex - Pregnancy - Childbirth 	Diabetes educator-RN Diabetes resource person Paediatric endocrinologist General practitioner Paediatrician Physician
<i>Smoking, alcohol and drugs & diabetes</i>	<ul style="list-style-type: none"> - General issues - Effects on diabetes control 	Diabetes educator-RN Dietitian- nutritionist Paediatric endocrinologist General practitioner Paediatrician Physician
<i>Employment, drivers’ licenses & diabetes</i>	<ul style="list-style-type: none"> - Current restrictions and regulations 	Diabetes educator-RN Diabetes resource person General practitioner Paediatric endocrinologist Paediatrician Physician

2.6 References

Australian Diabetes Educators Association (ADEA), 1996, *Performance Indicators linked to National Core Competencies for Diabetes Educator*, Australian Diabetes Educators Association, Braddon.

Australian Diabetes Educators Association (ADEA), 2001, *The Role of the Diabetes Educator in Australia*. . Australian Diabetes Educators Association, Braddon.

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International Society for Pediatric and Adolescent Diabetes (ISPAD), 2000, *Consensus guidelines 2000: ISPAD consensus guidelines for the management of type 1 diabetes mellitus in children and adolescents*, Available at: <http://www.diabetesguidelines.com>

3 Nutrition

3.1 Role of the dietitian – nutritionist

Dietitian-Nutritionists play an integral role in the management of children and adolescents with diabetes. In accordance with Dietetic Practice Guidelines (ADA 2000) dietitian-nutritionists aim to:

- optimise nutritional status to promote normal growth and development for children and adolescents
- minimise the risk of short and long term complications
- facilitate optimal patient well-being.

The scope of nutrition intervention includes 3 steps:

1. “Survival” information at diagnosis
2. “Ongoing” education
3. Appropriately timed information about “Taking Control”
(Brink et al 1999; Connell 1991; ISPAD 2000; Kilkarni et al 1997).

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. A Nutrition Education Resource for Children and Adolescents with Type 1 Diabetes is in the process of being developed by Queensland Health. This will provide a resource and training package for dietitian-nutritionists working with young people with diabetes.

Assessment, education, nutrition counselling and evaluation are integral parts of this approach.

3.1.1 Accreditation for dietitian-nutritionists

The Accredited Practising Dietitian (APD) Program is the national system for recognition of qualifications, ongoing training and practice standards for dietitians. The APD program is a mechanism for the promotion of quality dietetic service and practice and to support dietitians in maintaining the required knowledge and skills.

In addition to being an APD, it is recommended that the dietitian-nutritionist providing nutrition education for the child/adolescent with diabetes and their family, have appropriate training and experience in paediatric diabetes management.

3.2 Referral criteria

3.2.1 Criteria for referral to a dietitian-nutritionist

Expert Advisory Group Recommendation

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 (APEG 1996; Connell 1991; Kilkarni et al 1997)
- Annual review as a minimum for all children with diabetes (Kilkarni et al 1997; ISPAD 2000; Pinelli et al 1998)
- Change in management (Brink et al 1999)
- Inappropriate growth rate such as failure to maintain height velocity or undesirable weight loss or gain (APEG 1996; Brink et al 1999; Connell 1991)
- Difficulty, conflict or stress associated with food, eating pattern or blood glucose control (Brink et al 1999; Connell 1991)
- Rigid diet and an inflexible approach to food choices (APEG 1996; Pinelli et al 1998)
- Eating habits inconsistent with Australian Dietary Guidelines for Children and Adolescents (APEG 1996)
- Concurrent conditions such as coeliac disease, cystic 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 (APEG 1996; ISPAD 2000; Kilkarni et al 1997)

3.3 Nutrition education guidelines for children and adolescents with type 1 diabetes - for diagnosis and ongoing management

Expert Advisory Group Recommendation

Guidelines for nutrition education counselling are to facilitate the gaining of knowledge and skills that assists management and positive behavioural changes to meet individual and family needs.

These guidelines aim to provide a framework that enables the dietitian-nutritionist:

- to assist the child or adolescent and their family at the time of diabetes diagnosis ('Survival')
- to develop strategies for further education of the family and child/adolescent ('Ongoing')
- to promote self-management skills at a time that is appropriate for the family ('Taking Control').

(APEG 1996; Brink 1999; Dahl-Jorgenson 1999; ISPAD 2000; ADA 2002; Franz et al 2002)

3.3.1 Goals of nutrition education for children and adolescents with type 1 diabetes

Level of evidence: II (flexible dietary approach)

All other objectives: Expert Advisory Group Recommendation

The aim of nutrition education guidelines is to maintain well-being and to foster improved metabolic control. This will be achieved by ensuring quality, consistency and accountability of nutrition education. The emphasis is on nutritional care centred on the needs of the child/adolescent and the family.

A prescriptive approach to diet that leads to inflexibility in the long term is no longer substantiated/supported (Gilbertson et al 2001; Lafrance 1998; Mitchell 1990; Price 1993; Waldron 1996; Swift 1997). However families may benefit from some method of carbohydrate quantification while learning how to match insulin requirements to food intake (Brink & Moltz 1997). There are a variety of tools available for quantification of carbohydrate eg. serves, carbohydrate exchanges. The dietitian-nutritionist should use the tool best suited to the child/adolescent and family, as appropriate.

Table 5 outlines the recommended goals and objectives of nutrition education.

(NB The objectives marked with * are particularly important at diagnosis and should also be considered for ongoing education.)

Table 5: Goals and objectives of nutrition education

Goal	Objectives
1. Allow for optimal growth and development	<ul style="list-style-type: none"> • Encourage an adequate intake of energy and nutrients to satisfy appetite and metabolic demands*. - It is important to accommodate appetite and metabolic demands of the newly diagnosed child / adolescent. • Promote age appropriate recommendations based on the Australian Dietary Guidelines for Children and Adolescents and Recommended Dietary Intakes. • Only consider nutrition recommendations if appropriate for the whole family* • Discourage radical changes in eating habits and the use of “special foods”*. - It is important to promote strategies to avoid stress/conflict associated with food and eating • Provide follow up and support of nutrition-related complications eg. obesity, coeliac disease, cystic fibrosis related diabetes
2. Match the delivery of nutrition education to the child/adolescent and family’s availability and ability to learn.	<ul style="list-style-type: none"> • Identify and implement strategies to accommodate barriers to nutrition education* • Encourage contact with and referral to other members of the health care team* • Ensure contact times are suitable to most family members* • Use resources that are interactive and culturally appropriate and allow adequate time for this* • Identify situations when nutrition education may need to be adapted to suit the learning style of the family* • Encourage contact from the families as necessary* • Offer support contact with other families/groups.
3. Match nutrition education to the specific needs of the child/adolescent to promote best possible glycaemic control	<ul style="list-style-type: none"> • Focus ongoing education on problem solving and problem prevention strategies • Encourage age-appropriate transfer to self care with adult supervision • Identify and implement strategies to overcome barriers to ongoing education such as learning problems, concomitant illnesses and family problems

Table 5: Goals and objectives of nutrition education - continued

Goal	Objectives
4. Promote optimal well-being with minimal interference to age-appropriate activities, schooling and family life.	<ul style="list-style-type: none"> • Develop strategies with the child/adolescent and family to <ul style="list-style-type: none"> – avoid hypoglycaemia* – balance food, activity and insulin and – minimise stress/conflict associated with food and eating
	<ul style="list-style-type: none"> • Advocate for the child/adolescent and family to ensure that insulin regimes suit their lifestyle*

(Richmond 1998; APEG 1996; Brink & Moltz 1997; Brink 1997; ISPAD 2000; Pinelli et al 1998; ADA 2002; Franz et al 2002)

3.3.2 Level of nutritional care

Expert Advisory Group Recommendation

The level of nutritional care documented below is considered appropriate for all children and adolescents with type 1 diabetes. Education can be provided using a variety of strategies including individual consultations, videoconferencing, phone, email and group settings (see Appendix 1: Group Education) (ISPAD 2000; Howerka 2000).

Table 6, Level of Nutritional Care was developed by the Paediatric Diabetes Nutrition Workgroup and is based on recommendations from the International Society for Paediatric and Adolescent diabetes (ISAPD 2000) and from recent articles by Pinelli et al (1998), Connell (1991) and Kilkarni et al (1997).

Table 6: Level of nutritional care: information on minimal time, length and timing of individual nutrition consultations (Connell 1991; Delahunty 1998; ISPAD 2000; Kilkarni et al 1997; Pinelli et al 1998; Pinelli 1999)

Type of visit	Timing of visit
Education following diagnosis 'Survival'	<ul style="list-style-type: none"> • Initial contact within the first week • Completed within the first month following diagnosis • Complete over 4-6 sessions • Up to 1- 1.5 hour/session
'Ongoing' education	<ul style="list-style-type: none"> • Within 6 months of initial • Over several sessions • Up to 4 sessions
Ongoing education 'Taking Control'	<ul style="list-style-type: none"> • At least 1 review every 12 months • Up to 1 hour or as appropriate

Ongoing 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. The dietitian-nutritionist will liaise with the child or adolescent and their family, as well as other team members, to support key individuals to gain self-management skills. It is important to identify carers and other situations, such as school, where nutrition education may be required and to assist as appropriate.

3.3.3 How to use these guidelines

Tables 7 and 8, in sections 3.3.5 and 3.3.6, detail the necessary elements of comprehensive nutrition assessment, education and counselling required for management of type 1 diabetes. The dietitian-nutritionist can:

- select the necessary elements required to deliver “Survival” education
- select the necessary elements required to deliver “Ongoing” education
- negotiate appropriate goals with the child/adolescent/family
- implement appropriate intervention/education strategies that are tailored to meet the individual learning styles and needs of the child/adolescent/family.

These steps can be used for any type of consultation (eg. at diagnosis and review).

3.3.4 Flexible competencies

Expert Advisory Group Recommendation

A dietitian-nutritionist who is trained and experienced in paediatric diabetes management and education should deliver initial nutrition education. However, in some geographic areas access to a dietitian-nutritionist with paediatric experience in diabetes is not always possible. This may necessitate the rural/remote dietitian-nutritionist contacting the paediatric diabetes dietitian-nutritionist at a provincial/tertiary centre via phone, email or videoconference.

Flexible competencies allowing other health professionals to provide elements of nutrition education are not recommended for the newly diagnosed child/adolescent.

It is recommended that ongoing nutrition support and education is provided by a dietitian-nutritionist who has access to a specialist dietitian-nutritionist at a paediatric diabetes centre. If the child/adolescent/family is unable to access a dietitian-nutritionist, support with nutrition education may be assisted by other health professionals contacting the experienced paediatric diabetes dietitian-nutritionist, via videoconference, email or phone.

3.3.5 Tables of desired elements of nutrition assessment

Expert Advisory Group Recommendation

The health professional will take the needs of the individual into account when making decisions on nutrition education. Therefore, many of the elements listed below will be repeated at the discretion of the dietitian-nutritionist. These recommendations are based on the ISPAD (2000), APEG (1996) and the American Diabetes Association (2002) guidelines.

Table 7: Nutrition and anthropometric assessment

Element	Flexible competencies
a) Anthropometry <ul style="list-style-type: none"> - height percentile - weight percentile - BMI percentile 	dietitian-nutritionist diabetes educator paediatric endocrinologist GP, RN
b) Food habits <ul style="list-style-type: none"> - family lifestyle - usual meal and snack pattern including missed meals/snacks and excessive use of refined sugars eg. soft drinks, confectionary, fruit juice - family beliefs/attitudes about food - usual carbohydrate intake and distribution - energy requirements - current use of low GI foods - the degree to which current eating habits meets the Australian Dietary Guidelines for children and adolescents 	dietitian-nutritionist diabetes educator dietitian-nutritionist
c) Physical activity <ul style="list-style-type: none"> - pattern of activity - intensity of activity refer to physical activity guidelines	diabetes educator DRN dietitian-nutritionist paediatric endocrinologist exercise physiologist GP physiotherapist RN
d) Medical history <ul style="list-style-type: none"> - concurrent conditions - medications – type dosage - frequency/method of administration - vitamin or herbal supplements 	diabetes educator dietitian-nutritionist paediatric endocrinologist GP RN
e) Family history <ul style="list-style-type: none"> - family structure - carers of the child/adolescent - factors present that may affect family's ability to function - current level of confidence to provide regular meals - current level of nutrition knowledge and understanding 	diabetes educator dietitian-nutritionist paediatric endocrinologist GP, psychologist RN dietitian-nutritionist

3.3.6 Tables of necessary elements for nutrition education/intervention

Table 8: Nutrition education/intervention

Core concepts	Flexible competencies
<p>a) Survival</p> <p>i) Eating habits</p> <ul style="list-style-type: none"> - regular meals and snacks essential - where possible, significant changes to home eating patterns and type of food eaten are <u>not</u> expected - Healthy Eating Guidelines for Australian Adults, Children and Adolescents are desirable for the family - regular monitoring of blood glucose levels to help matching of food and insulin - habits that cause consumption of large amounts of rapidly digested carbohydrate should be avoided unless treating hypoglycaemia - use of specialised diabetes products usually not necessary - recognition of carbohydrate foods usually eaten and distribution, is necessary to ensure regular intake <p>ii) Hypoglycaemia management</p> <ul style="list-style-type: none"> - recognition of what hypoglycaemia is, what causes it and how to treat it - recognition of the importance of having food and drink available at all times 	<p>‘Survival’ diabetes nutrition education should be delivered by a dietitian-nutritionist trained and experienced in paediatric diabetes management and education. Part of the role of the diabetes educator is to reinforce these concepts.</p> <p>diabetes educator dietitian-nutritionist* paediatric endocrinologist</p>
<p>b) Ongoing education</p> <p>i) Meal planning: food factors affecting BGL, food selection and preparation</p> <ul style="list-style-type: none"> - Review of meal and snack patterns for the amount and types of carbohydrate food eaten is a tool to assist glycaemia control - glycaemic index is a tool to assist meal planning and glycaemic control⁸ - Reading food labels is a tool to increase confidence with shopping and meal planning - Importance of gradually bringing family eating habits in line with the Healthy Eating Guidelines for Australian Adults, Children and Adolescents 	<p>dietitian-nutritionist*</p>

* It is desirable that the dietitian-nutritionist is trained and experienced in paediatric diabetes management and education.

⁸ Gilbertson et al 2001

Table 8: Nutrition education/intervention

Core concepts	Flexible competencies
<p>ii) Management for life activities and growth</p> <ul style="list-style-type: none"> - Changes to child’s/adolescent’s routine may require adjustments to insulin therapy or meal pattern - Different ages and stages of development may affect diabetes management – eg appetite surges, independence with eating, food fads 	<p>dietitian-nutritionist*</p> <p>dietitian-nutritionist* diabetes educator paediatric endocrinologist</p>
<p>c) Taking control</p> <p>i) Self management</p> <ul style="list-style-type: none"> - A problem solving approach to diabetes management involves <ul style="list-style-type: none"> - noting the timing of food intake - noting periods of extra activity - using GI - estimating carbohydrate intake - checking of blood glucose levels at useful times - noting changes in appetite. - importance of developing management strategies for special events and social activities such as sport days, overseas travel, camps, parties - importance of developing knowledge and strategies for the safer use of alcohol and other recreational drugs - understanding of what is normal food behaviour for a child/adolescent at different ages and stages of development - recognise the importance of sharing responsibility for meal planning (as part of diabetes management) as appropriate for age and stage of development - recognise the importance of having opportunities to allow the child/adolescent/family to discuss elements of diabetes management - awareness of the benefits of using peer support when available 	<p>dietitian-nutritionist*</p> <p>dietitian-nutritionist* diabetes educator paediatric endocrinologist psychologist</p>

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Appendix

Group education

Group education for patients, families and carers is recognised as another effective mode of delivering education that can complement individual consultations (ISPAD 2000; Howerka 2000). As part of a multi-disciplinary team, dietitian-nutritionists can assist with group education. A group education program targeted to patients and families must address issues that patients perceive to be important or relevant. A variety of techniques (focus groups, questionnaires) may be used to determine specific topics important to patients and families. It may be appropriate to provide different sessions for children/adolescents and their parents.

Group education can be useful:

- at the survival, ongoing survival and taking control stages of nutrition education
- at specific developmental stages, when children and adolescents typically encounter common problems (eg. starting school, entering puberty, taking over care from parents).

Group education allows for:

- extended contact time with health professionals (Trento 2001)
- patient interaction with the entire team
- patient interaction with other families
- identification of common problems & exchange of problem solving strategies (Jacobs 2000; Williamson 2000)
- potential for health professionals to access a greater number of patients on limited resources (Lawson 2000).

Group education requires a facilitator who is comfortable with the group process and is capable of the following skills:

- teaching concepts in an interactive setting
- leading group discussion to ensure that it is constructive
- involving multi-disciplinary team members as appropriate
- involving less interactive individuals in the group
- identifying individuals who are suited to the group education process.

4 Psychosocial

4.1 Introduction

4.1.1 Psychosocial aspects of paediatric type 1 diabetes care

Expert Advisory Group Recommendation

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. The International Society for Paediatric and Adolescent Diabetes (ISPAD 2000) states that:

“Attention focussed only on the metabolic control, with neglect of psychosocial influences is to be strenuously avoided.”

Furthermore the Australian Paediatric Endocrine Group (APEG 1996) recommends:

“Assessment at the time of diagnosis of the developmental, behavioural, and psychosocial history of the child and family is recommended as it enhances coping strategies and assists in planning appropriate longer-term interventions. Children and their families also benefit from ongoing assessment and psychological support as they progress through crucial developmental stages.”

APEG (1996) also states that:

“Dealing with bereavement issues at the time of diagnosis facilitates the adjustment process. In assessing the child’s ongoing adjustment to diabetes, it is important to understand his/her coping mechanisms, beliefs, emotional patterns and to identify conflicts.”

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.

4.1.2 Key principles

Expert Advisory Group Recommendation

“Psychosocial factors are the most important influences affecting the care and management of diabetes” (ISPAD 2000)

Following are the key principles of the psychosocial care for children and adolescents with diabetes and their families:

- identification of psychosocial issues is essential in the management of difficulties in treatment adherence (Werther & Court 1998)
 - early psychosocial intervention and prevention of psychosocial problems is essential
 - psychosocial assessments and interventions should be delivered by health care professionals with a clear understanding of the special and challenging needs of young people and their families as they grow through the different stages of life
 - psychosocial assessment and intervention and psycho-education should be based on a thorough assessment of the family's attitudes, beliefs, learning style, ability, readiness to learn and expected goals
 - the psychosocial assessment and intervention and psycho-education needs to be adaptable and personalised so that it is appropriate to each individual's age, stage of diabetes, maturity and lifestyle
 - psychosocial assessment and psycho-education is an ongoing process.
- Adapted from ISPAD (2000)

4.1.3 Goals of psychosocial care of the child and adolescent with diabetes and their family

The goals and objectives that should be achieved through psychosocial management are detailed in table 9.

Table 9: Goals and objectives of psychosocial management

Goals	Objectives
1. To promote optimal psychological wellbeing	<ul style="list-style-type: none"> • facilitate adjustment of the child/adolescent/family at diagnosis • provide support for the child/adolescent / family from initial diagnosis and through the stages of adjustment • match the delivery of psychoeducation to the child's/adolescent's/family's stage of adjustment
2. To promote the development of a healthy child/adolescent	<ul style="list-style-type: none"> • ensure a multi-disciplinary team approach to holistic management • liaise with others involved in the child's/adolescent's social, emotional educational and medical wellbeing.

4.1.4 Health Professionals involved in management of psychosocial issues

Expert Advisory Group Recommendation

Psychologists, social workers and psychiatrists play an integral role in the management of children and adolescents with diabetes and their families.

It is recommended by ISPAD that:

“Overt psychological problems or psychiatric disorders in the young person or family members should receive support from the diabetes team and expert attention from a psychologist⁹/social worker¹⁰/psychiatrist trained in child and family therapy.” (ISPAD 2000)

Psychologists, social workers and psychiatrists with the appropriate skills may work in a variety of settings including public and private organisations.

Additionally ISPAD recommends:

“The diabetes care team should receive training in the recognition, identification and provision of information and counselling on psychological and social problems related to diabetes.” (ISPAD 2000)

4.2 Level of care

Expert Advisory Group Recommendation

The level of psychosocial care documented in table 10, is considered to be a guideline only. The amount of time the child/adolescent/family have contact with a psychologist/social worker/psychiatrist is dependent on a number of issues including the developmental stage of the child/adolescent, family issues, and other psychosocial issues.

⁹ Psychologist: inclusive of the specialties health psychology and clinical psychology

¹⁰ Social worker: inclusive of the speciality of medical social work

Table 10: Level of care information on minimal time, length and timing of consultations (Brink 1997, Brink & Moltz 1997, APEG 1996)

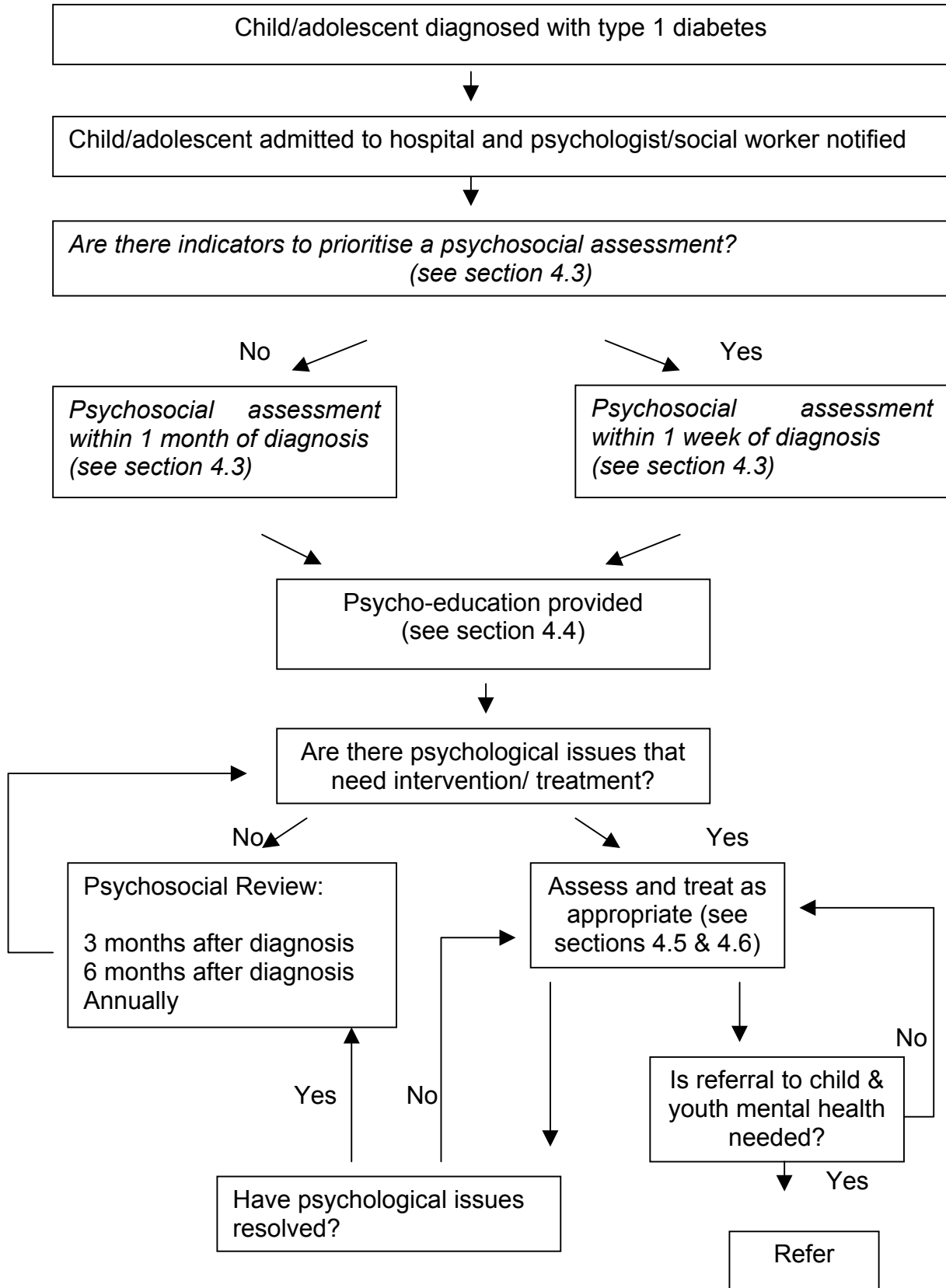
Type of visit	Timing of visit
Brief introduction and initial screening	<ul style="list-style-type: none"> • at diagnosis • up to 1 hour
Psychosocial assessment	<ul style="list-style-type: none"> • within 1 month diagnosis, over several sessions • up to 1 hour per session
Psycho-education	<ul style="list-style-type: none"> • within 1 month diagnosis • up to 1 hour
Psychosocial reviews	<ul style="list-style-type: none"> • 3 and 6 months post diagnosis and annually • up to 1 hour per session
Psychological interventions	<ul style="list-style-type: none"> • at discretion of psychologist/social worker/psychiatrist

4.2.1 Process for psychosocial management

Expert Advisory Group Recommendation

The flow chart (Figure 1) outlines the processes to follow from when a child or adolescent is diagnosed with diabetes through the assessment, psycho-education and treatment stages. The flow chart is based on recommendations from ISPAD (2000).

Figure 1 Psychosocial practice guidelines flow chart



4.3. Referral criteria

Expert Advisory Group Recommendation

4.3.1 Indicators to help prioritise for a psychosocial assessment

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 (Ruggiero & Javorsky 1999; Brink 1997, Brink & Moltz 1997, APEG 1996). Best practice recommends psychosocial screening at diagnosis by a psychologist/social worker/psychiatrist (ISPAD 2000). If the child/adolescent/family does not have access to these health professionals at diagnosis, the following list of indicators, table 11, can be used by other health professionals to identify those individuals or families who require urgent referral to a psychologist/social worker/psychiatrist.

If a child/adolescent is pre-morbidly recognised as having school, social, or psychological problems, the child/adolescent should be referred to psychologist/neuropsychologist for assessment as appropriate. If the child/adolescent is currently being seen by a health professional or school counsellor for school/social/psychological problems liaison with this professional should be undertaken.

Table 11 Indicators to help prioritise for psychosocial assessment at diagnosis

(Brown & Macias 2001, Tarnowski & Brown 2000, Wallander et al. 1989

Level of evidence: I

Family

Family environment

- parental relationship eg. marital problems, recent separation
- siblings eg. significant medical issues, mental health issues
- parental responsibilities eg. lack of involvement of 1 or both parents
- recent loss in family eg. Death.

Social support systems

- limited social support
- limited extended family support
- recently relocated.

Parental psychological adjustment

- needle phobia
- depression
- anger
- anxiety/stress
- other physical or mental health issues
- history of mental health issues.

Child/adolescent

Psychological adjustment

- depression
- anger
- anxiety/stress
- behaviour problems eg. defiance, adherence problems
- eating issues/body image.

Diabetes issues

- significant anxiety re hypos, BGL checks, needles.

4.3.2 Indicators for referral for biopsychosocial assessment and treatment post diagnosis

The following is a list of indicators to identify when the child/adolescent/family needs a referral for biopsychosocial assessment and treatment. These recommendations are based recent reviews by experts in this field (Elander & Midence 1997; Swanston, Williams & Nunn, 2000; Werther & Court 1998; Snoek & Skinner 2000).

Biological indicators

- poor control over six to 12 months
- HbA1c > 9-10%, particularly after infancy and toddlerhood. Higher HbA1c are acceptable in very young children due to the neurocognitive risks associated with hypoglycaemia
- repeated hospitalisations in relation to diabetic control eg two episodes of DKA in six months without recurrent illness
- adherence difficulties resulting in poor control
- problems identified at complications screening
- HbA1c low and associated with recurrent hypoglycaemia
- disordered eating patterns
- unexplained weight loss or gain.

Individual child /adolescent psychological indicators

- anxiety
- mood changes: irritation, rage, anger, sadness, aggression
- suggestions of self harm/suicide, feelings of hopelessness, unwillingness to accept help, withdrawal
- difficulty concentrating
- changes in sleep or appetite
- high level of distress
- grief issues
- history of abuse/trauma
- significant behaviour change
- risk taking behaviour
- drug/alcohol abuse
- inappropriate refusal to disclose diagnosis to friends, school staff and others.

Family indicators

- high level of distress in the family/siblings
- issues of over or under involvement of parents in diabetes management
- loss and grief within the family
- family conflict
- family history of mental illness
- family breakdown
- financial difficulties
- difficulties in taking leave from employment
- difficulties in obtaining necessary equipment.

Social / School indicators

- perceived social isolation or withdrawal from peer group/social network
- school suspension or expulsion
- school absence or refusal
- decline in performance at school/work.

4.4. Psycho-education

Children/adolescents and their families should be provided with age appropriate information about the typical range of emotional reactions to the diagnosis of diabetes. This information is provided post-diagnosis however the exact timing of this is at the discretion of the psychologist/social worker/psychiatrist.

Information to be covered would include:

- guilt – for example, guilt related to the perception of genetic responsibility; guilt related to causal attributions (Ingersoll & Golden 1995)
- grief – for example, what is grief; what have the child/adolescent and family lost; stages of grief; people grieve in different ways (Lowes & Lyne 2000; Ingersoll & Golden 1995).

Other issues that need to be addressed include:

- marital stress – for example, diagnosis of diabetes can place increased strain on a marriage; different coping styles for different people; the importance of spending time together as a couple (Ingersoll & Golden 1995)
- behaviour management – for example, typical reaction of parents is to be more lenient with rules and consequences; after first couple of weeks it is important to return to consistent, clear rules and consequences (Patterson & Garwick 1998).

4.4.1 Flexible competencies

National guidelines for the management of children and adolescents with newly diagnosed diabetes indicate that they should have access to a specialist paediatric multi-disciplinary team (ISPAD 2000; APEG 1996). This team should include a paediatric endocrinologist or paediatrician, diabetes educator, dietitian and psychologist or other appropriate mental health worker¹¹.

Best practice recommends that children and adolescents are seen at diagnosis and have regular review by a psychologist/social worker/psychiatrist trained and experienced in paediatric diabetes (ISPAD 2000). A psychologist/social worker/psychiatrist or other mental health worker with experience in working with children and families should treat overt psychological problems or psychiatric disorders in the child/adolescent and family members.

¹¹ A mental health worker is described as a professional who works in a recognised government mental health service multidisciplinary team. eg child and youth mental health, adult mental health, under the supervision of a consultant psychiatrist.

It is the responsibility of the professional to ensure that they have the ability to carry out the interventions. These interventions must be within their professional scope of practice and be consistent with current best practice. Health professionals working in a flexible competency role should liaise with the psychologist/social worker/psychiatrist or other mental health worker involved in the child's care.

All children/adolescents with diabetes should have access to the multi-disciplinary team at least once per year.

4.5 Biopsychosocial assessment of children/adolescents with diabetes

Expert Advisory Group Recommendation

A detailed assessment is an essential prerequisite to the development of a treatment plan for the child/adolescent with diabetes and their family. Biological, psychological and social factors must be considered in this assessment. This information provides a holistic view of the child/adolescent with diabetes and how these factors may interact to affect metabolic control and the quality of life.

Table 12 provides guidelines for important issues to assess within the biological, psychological and social domains (Ruggerio & Javorsky 1999; Werther & Court 1998; Bradley 1994).

Appendix 1 provided suggestions regarding specific tools for assessment that may be used by appropriately qualified professionals.

Table 12 Biological, psychological and social factors (Brink 1997; Brink & Moltz 1997; APEG 1996)

Biological factors

General areas	Specific issues	Flexible competencies
HbA1C	<ul style="list-style-type: none"> - outside age appropriate range - refer to section 4.3.2 	These levels are usually assessed by the admitting team
Blood glucose levels	<ul style="list-style-type: none"> - history of recurrent hypoglycaemia - history of admission for diabetes ketoacidosis - refer to section 4.3.2 	
Weight	<ul style="list-style-type: none"> - unexplained weight loss or gain 	
Knowledge	<ul style="list-style-type: none"> - basic physiology of diabetes - food groups and food substitution - sick day management - general diabetes care 	diabetes educator diabetes resource person dietitian- nutritionist paediatric endocrinologist paediatrician physician

Psychological factors

General areas	Specific issues	Flexible competencies
Affect	<ul style="list-style-type: none"> - depression - anxiety - stress - anger - guilt - embarrassment/shame - grief 	<ul style="list-style-type: none"> - psychologist - social worker - psychiatrist - mental health worker - general practitioner - paediatrician
Cognition	<ul style="list-style-type: none"> - catastrophic thoughts - helplessness - hopelessness - low self-esteem - unrealistic expectations - denial 	<ul style="list-style-type: none"> - psychologist - social Worker - psychiatrist - mental health worker - general practitioner - paediatrician
Behaviour	<ul style="list-style-type: none"> - treatment adherence - defiance/non-compliance - eating disorders eg. bingeing, purging, decrease food intake - withdrawal - aggression - increased risk taking behaviour 	<ul style="list-style-type: none"> - psychologist - social worker - psychiatrist - mental health worker - general practitioner - paediatrician

Table 12 Biological, psychological and social factors - *continued*

Social factors

General areas	Specific issues	Flexible competencies
Parents	<ul style="list-style-type: none"> - conflict - parenting strategies - psychopathology - coping/adjustment - unrealistic expectations/knowledge - guilt - ability to communicate well with the child 	<ul style="list-style-type: none"> - psychologist - social worker - psychiatrist - mental health worker - general practitioner - paediatrician
Siblings	<ul style="list-style-type: none"> - competition/rivalry - teasing/bullying - resentment/jealousy - knowledge of diabetes - guilt/magical thinking 	<ul style="list-style-type: none"> - psychologist - social worker - psychiatrist - mental health worker - diabetes educator - general practitioner -
Extended family	<ul style="list-style-type: none"> - structure - roles with respect to diabetes management - unrealistic expectations - appropriate management of diabetes related issues 	<ul style="list-style-type: none"> - psychologist - social worker - psychiatrist - mental health worker - diabetes educator - general practitioner - paediatrician
Teachers or significant others	<ul style="list-style-type: none"> - appropriate management of diabetes related issues - knowledge of diabetes 	<ul style="list-style-type: none"> - diabetes educator - dietitian- nutritionist - general practitioner - paediatrician
Peers	<ul style="list-style-type: none"> - teasing/bullying - isolation - culture of risk taking 	<ul style="list-style-type: none"> - guidance officer - psychologist - social worker - psychiatrist - mental health worker - general practitioner - paediatrician

4.5.1 Neuropsychological assessment

In some circumstances a neuropsychological examination may be required. This will occur when there are indications from teachers or parents that the child/adolescent is having academic difficulties or has a specific problem with cognitive abilities. There is some research evidence that the glycaemic extremes experienced with poor metabolic control may produce subtle cognitive deficits in children/adolescents (Northan 1998). Such deficits can have significant implications for the child's/adolescent's ability to function academically, with resultant implications for self-esteem and ability to achieve vocational goals.

The most common deficits are listed in table 13 and these should be the targets for neuropsychological assessment if concerns are raised by parents, teachers, or significant others. Research suggests that these deficits are most likely to occur if the onset of diabetes is before five years and the child has had some hypoglycaemic episodes (Northan 1998), but they should be a consideration for any age.

Table 13 Elements of neuropsychological assessment (Northam, 1998)

General area	Elements	Flexible competencies
Neuropsychological	General intelligence Attention Learning and memory Psychomotor speed Mental flexibility Verbal fluency Problem solving Visuo-spatial ability academic ability	neuropsychologist clinical psychologist

4.5.2 Age-related issues

In addition to the general areas of biopsychosocial assessment it is essential to consider specific age-related issues. Table 14 details issues relevant for children and adolescents at different ages. These recommendations are based on recent review articles (Anderson & Bracket 2000; Brink 1997; Brink & Moltz 1997; Skinner et al 2000; Ruggiero & Javorsky 1999; Byrne 1998).

Table 14: Age related issues to consider when assessing child/adolescent/family

Age	Issue
0-2 years	<ul style="list-style-type: none"> ▪ diminished bond between parents and their infants, ▪ risk of overdependence in the child ▪ risk of overprotection by the parent ▪ greater feelings of trauma and grief ▪ parents' difficulty with injections and blood glucose checks ▪ impact of normal fluctuations in feeding, activity and sleeping patterns ▪ difficult to identify hypoglycaemia ▪ difficult to use inexperienced, untrained carers
2-5 years	<ul style="list-style-type: none"> ▪ toddler may protest injections and blood glucose checks ▪ toddler may have a fear of health professionals and health facilities ▪ impact of normal fluctuations in feeding, activity and sleeping patterns ▪ difficult for parents to recognise hypoglycaemia ▪ difficult for parents to differentiate between hyperglycaemia and a tantrum ▪ risk of overprotection by the parent ▪ may develop a misunderstanding of the causes and course of diabetes ▪ difficulties may arise between children and parents regarding diet and eating behaviours ▪ as children start to interact with peers and learn that they are different they may develop faulty causal reasoning for their difference eg they may blame themselves ▪ parents may have difficulty coping as children improve their ability to verbalise their dislike of injections/diet ▪ parents may be very anxious when child enters preschool or school ▪ may be more challenging to provide snacks and meals that match what friends and siblings are eating ▪ may be more important to keep to a schedule that includes friends, school, and diabetes tasks ▪ cannot expect child to understand the importance of eating, insulin injections or blood glucose checks ▪ parents begin to educate others about managing diabetes

Table 14: Age related issues to consider when assessing child/adolescent/family – *continued*

6-12 years	<ul style="list-style-type: none"> ▪ comparisons with peers may result in feelings of inadequacy, ▪ may resent diabetes management issues (injections, blood glucose checks and diet) as it makes explicit that the child is different ▪ continues to be important to keep to a schedule that includes friends, school, and diabetes tasks ▪ cannot expect child to fully understand the importance of eating, insulin injections, or blood glucose checks ▪ parents continue to educate others about managing diabetes ▪ children in the early school years need full involvement of parents (and other important caregivers) ▪ increasing collaboration between child and parents in the management of diabetes ▪ difficulty of dealing with contrary advice from adults and peers
13-18 years	<ul style="list-style-type: none"> ▪ hormonal changes during adolescence may influence metabolic control ▪ acceleration of microvascular changes ▪ disease onset during adolescence may create particular difficulties ▪ the presence of a chronic illness may create significant difficulties in adolescent task development, with impaired self-esteem and reduced optimism re future goals. ▪ issues of autonomy may result in conflict ▪ influence of peers on diabetes management ▪ diabetic adolescents, particularly girls, may be at increased risk of eating disorders, including manipulation of insulin dose to achieve weight reduction. ▪ greater opportunity to self-harm if depressed ▪ influence of peers on diabetic management ▪ problem of weight gain in adolescent girls with good control ▪ influence of drugs/alcohol/smoking ▪ adherence may be affected by the above factors ▪ need for counselling re appropriate contraception and the dangers of unplanned pregnancies ▪ need for planned transition of care to young adult service (see section 4.8)

4.6 Treatment

Psychosocial issues that need to be addressed will be identified by completion of a biopsychosocial assessment. It is the responsibility of the psychologist/social worker/psychiatrist to design an individual treatment plan based on the outcome of this assessment. This treatment plan needs to be consistent with best practice recommendations for the specific intervention.

4.6.1 Management of psychosocial factors

Table 15 outlines areas that may be the focus of psychosocial intervention to ensure optimal well-being for the diabetic child/adolescent and his/her family. Depending on the intervention involved and the level of access to health facilities, suggestions are made regarding health professionals who may be involved in the provision of these services. In table 15 the level of evidence refers to the health professional who may be involved in this specific treatment.

ISPAD (2000) recommends that children/adolescent with diabetes and their family receive support from the diabetes team and expert attention from a psychologist/social worker/psychiatrist.

Table 15 Interventions in the management of psychosocial factors in paediatric diabetes

Intervention	Flexible competencies	Level of evidence
Education and support at initial diagnosis	Psychologist/social worker/psychiatrist, Diabetes educator, dietitian-nutritionist, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN	<i>Expert Advisory Group recommendation</i>
Review at critical stages	Psychologist/social worker/psychiatrist, diabetes educator, dietitian-nutritionist, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN	<i>Expert Advisory Group recommendation</i>
Identification of significant psychosocial dysfunction and appropriate referral	Psychologist/social worker/psychiatrist, diabetes educator, dietitian-nutritionist, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN, child health worker, school health worker, guidance officer, teacher	<i>Expert Advisory Group recommendation</i>
Liaison with schools	Psychologist/social worker/psychiatrist, diabetes educator, dietitian-nutritionist, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN, mental health worker	<i>Expert Advisory Group recommendation</i>
Conduct support groups*	Psychologist/social worker/psychiatrist, diabetes educator, dietitian-nutritionist, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN	<i>Expert Advisory Group recommendation</i>
Assistance with family adjustment	Psychologist / social worker/ psychiatrist, Diabetes Educator, Dietitian-nutritionist, Indigenous Health Worker, GP, Paediatrician, Paediatric Endocrinologist, RN, Mental Health Worker, registered counsellor	<i>Expert Advisory Group recommendation</i>
Management of needle phobia	Psychologist/social worker/psychiatrist, diabetes educator, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN , mental health worker	<i>Expert Advisory Group recommendation</i>
Management of mild adjustment reactions	Psychologist/social worker/psychiatrist, diabetes educator, dietitian-nutritionist, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN, mental health worker, registered counsellor, guidance officer, school health worker	<i>Expert Advisory Group recommendation</i>
Management of adherence problems	Psychologist/social worker/psychiatrist, diabetes educator, Indigenous health worker, GP, paediatrician, paediatric endocrinologist, RN, mental health worker, registered counsellor	<i>Expert Advisory Group recommendation</i>

Table 15 Interventions in the management of psychosocial factors in paediatric diabetes

Intervention	Flexible competencies	Level of evidence
Management of behavioural problems	Psychologist, social worker, trained child health worker, mental health worker, guidance officer (trained in Triple P) Paediatrician, paediatric endocrinologist, psychiatrist	I ^a <i>Expert Advisory Group recommendation</i>
Treatment of anxiety disorders	Psychologist, psychiatrist Social worker, mental health worker	I ^b <i>Expert Advisory Group recommendation</i>
Treatment of eating disorders	Eating disorders team (psychiatrist, psychologist, dietitian – nutritionist, social worker, mental health worker)	I ^c
Cognitive/educational assessment	Psychologist, guidance officer	I ^d
Neuropsychological assessment	Psychologist, neuropsychologist	I ^e
Management of depression	Psychologist, psychiatrist GP, paediatrician, paediatric endocrinologist mental health worker	I ^f <i>Expert Advisory Group recommendation</i>

* this includes informing the family of community resources- see Appendix 2

^a (Barlow, 1997; Sanders, M.R. 1999)

^b (APA 1995; Dadds et al 1999; Ollendick & King 1998; Rose et al 1983;

^c (Crisp et al 1991; Garner & Desai 2001)

^d (Sattler 1992)

^e (Anderson et al. 1995; Northam 1998)

^f (Harrington et al 1998a; Harrington et al 1998b)

4.7 Predictable crises in chronic illness

Expert Advisory Group Recommendation

A number of predictable crises may occur in any chronic illness and may be a prompt for psychosocial intervention. These events are outlined below, with examples which are particularly relevant to diabetes mellitus in children and adolescents.

1. Onset and diagnosis

Many of the reactions experienced by a family or individual at diagnosis of diabetes have already been described in section 3, and may include feelings of grief, loss, guilt, anger and fear, particularly if a previous experience with diabetes in a family member or friend has been negative (La Greca & Skyla 1995).

2. Disease specific medical symptoms

Severe and/or unpredictable hypoglycaemia, possibly with convulsion or coma, may be a specific symptom which can destabilise a family or individual who may already have marginal diabetes coping skills (La Greca & Skyla 1995).

3. Hospitalisation (s)

Hospitalisation, particularly for recurrent episodes of hypoglycaemia or diabetic ketoacidosis is a clear indication that psychosocial issues within the individual and family need to be addressed as part of the overall diabetes management. Hospitalisation may also be perceived by some families/individuals as failure or loss of control of the diabetes process (Batch, J. 2002 pers. comm., 10 Jan)

4. Initial major complication (s)

The onset of diabetes complications such as microalbuminuria (early sign of diabetic kidney disease) or retinal microaneurysms (early sign of diabetic eye disease) may result in depression or despair as an individual or family may perceive that relentless deterioration has occurred, despite what they consider is their best effort at diabetes control. For a young person, the reaction may take the form of neurotic and obsessive attempts to achieve improved diabetes control, or conversely may result in poor diabetes self management as the young person may believe that continued deterioration is inevitable. Adolescent risk taking behaviour may be heightened at this point (La Greca & Skyla 1995).

5. Specific therapeutic choices

Individuals and families may find the range of therapeutic devices and/or treatment regimes overwhelming. Professional advice to adopt a particular

insulin or injection frequency (eg. insulin before each meal and at bedtime; “the basal bolus regime”) may be inappropriate for a particular individual for age, social or school reasons. Failure to adhere to a prescribed regime may engender resentment, guilt and feelings of failure in a child or family (Batch, J. 2002 pers. comm., 10 Jan).

6. Failure of expected response

If a new treatment (eg. new insulin or insulin regime) implemented to improve diabetes control or reduce hypoglycaemia fails to achieve the desired result, an individual or family may be disillusioned both with the therapy and the prescribing physician. Feelings of defeat and inevitability of the diabetes process may be experienced (Batch, J. 2002 pers. comm., 10 Jan).

7. Fear of clinic visits

There may be a reluctance to attend for follow-up visits due to the fear that results may be less than desirable. Regardless of the approach of the health professional the child/adolescent may find this a difficult experience to face on a regular basis (Kerr, D. 2002 pers. comm., 1 March)

4.8 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.

Components of a successful transition process include:

- individualised timing of the transition to take into account consideration of the young person's level of psychosocial and cognitive maturity, and other transitions, eg, completing school. (age of transition may vary between 17 to 20+ years)
- ideally timing transfer to occur at a period of disease stability
- provision of a young adult clinic where possible
- adequate time taken in preparing the young person and his/her family for the transition and what that will involve (including decreased parent involvement).
- good communication between teams
- availability of a professional to oversee continuity of care. in certain health settings a multidisciplinary team member may be able to provide continuity, eg. the diabetic educator, psychologist or social worker. in other settings the general practitioner may provide continuity
- a positive approach to the transition.

(Sawyer 1998; ISPAD 2000)

4.9 References

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Appendix 1

Rating scales for psychological assessment

The following are some possible resources to assist with the psychosocial assessment of children/adolescents with diabetes.

1 Neuropsychological assessment

- WISC-III (verbal and nonverbal intelligence, immediate and working memory, attention, perceptual speed) or Stanford Binet IV (ages 5-8)
- WIAT (scholastic attainments)
- Other memory tests eg. RAVLT (Rey 1964) Story recall (Christensen 1979), Rey Figure (Rey 1941) (from age 7)
- Mental flexibility: Trail Making Test (Spreeen & Strauss 1991) (from age 7)
- Verbal fluency: Verbal fluency test (FAS) (Gaddes & Crockett 1973) (from age 7)
- Visuo-spatial skills: Rey Figure or Bender Gestalt (ages 7-11).

2 Affect

- Depression: Children's Depression Inventory (Kovacs 1992)
- Anxiety: Children's Manifest Anxiety Scale (Reynolds et al 2001; Reynolds & Richmond 1978)

3 Behavioural

- Treatment adherence (eg. use Summary of Diabetes Self-Care Activities Questionnaire – Toobert & Glasgow 1994)
- Defiance/non-compliance (eg. Achenbach Child Behaviour Checklist – reference)
- Eating disorders: Modified form of Eating Attitudes Test – EAT26 (Garner et al, 1982) or Eating Disorders Examination (EDA) (Cooper & Fairburn 1987).
- Missed injections as a manifestation of an eating disorder: Diabetes Mismanagement Questionnaire (Weissberg-Bendel et al 1995)

4 Family adjustment and teamwork

- Parents and Family eg. conflict, inappropriate parenting strategies, neglect: Diabetes Family Behaviour Checklist (age 12+) (Schafer et al 1986)
- Parental coping and adjustment: ATT22 (Beeney et al 1994)

Appendix 2:

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

- phone: 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

5 Physical activity

5.1 Introduction

Expert Advisory Group Recommendation

There are many health professionals who play an important role in the education and promotion of physical activity for children and adolescents with diabetes. The recent American Diabetes Association Position Statement on Diabetes Mellitus and Exercise stated:

“The team, consisting of but not limited to the physician, nurse, dietician, mental health professional and patient, will benefit from working with an individual with knowledge and training in exercise physiology. “ (ADA 2001)

The following guidelines outline physical activity recommendations and the health professionals most qualified to assist in the management of the child and adolescent with diabetes.

Physical activity education needs to be timed appropriately to aid in the development of lifelong optimal levels of physical activity and well-being (Franz et al. 2002).

The scope of the exercise interventions includes “Survival” education at diagnosis, “Ongoing” education at an appropriate time, which is then followed by further education on “Taking Control”.

Assessment, education, counselling and evaluation are integral parts of this approach. The 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 complication of disease
- be in accordance with professional standards, best practice guidelines and evidence based approaches
- promote the self-management philosophy.

5.2 Benefits of physical activity for children and adolescents with diabetes

Level of evidence: III

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

Regular physical activity has positive effects on:

- insulin sensitivity (Rychlewski 1996; Ferguson et al 1999; Landt et al 1985)
- risk factors for cardiovascular diseases (Alpert & Wilmore 1994; Armstrong & Simmons- Morton 1994; Riddoch & Boreham 2000)
- skeletal health (Bailey & Martin, 1994; Kemper 2000)
- overweight and obesity (Bar-Or & Baranowski 1994 ; Rowlands, Ingledeu & Easton 2000)
- psychological and emotional health
 - increased sense of well-being
 - improved self esteem
 - decreased depression and anxiety(Calfas & Taylor, 1994; Tortolero, Taylor & Murray, 2000).

Appropriate physical activity does not increase the risk of hypoglycaemia providing there is concomitant attention to nutrition and insulin (Landt et al 1985; Horton 1995; Lehmann 1997; ADA 2001)

Currently, there are no specific physical activity guidelines for Australian children. However, in the absence of formal activity guidelines for children, the best advice for parents is (O'Connor & Eden 2000):

- provide daily opportunities for children to be active, in a variety of ways, in a safe environment
- avoid driving children on short trips when walking is possible
- limit the time children are permitted to spend in sedentary recreation such as watching television and playing computer games
- support children's participation in physical activity by playing games with them, encouraging them to engage in a variety of sports and physical activities, positively reinforcing children's attempts to be physically active, and being an active role model.

Furthermore the Health Education Authority in England recommendations regarding the level and type of physical activity for young people include (Cavill, Biddle & Sallis, 2001; Biddle, Cavill & Sallis, 1998):

- all young people should participate in physical activity of at least moderate intensity for one hour per day
- young people who currently do little activity should participate in physical activity of at least moderate intensity for at least half an hour a day
- at least twice a week, some of these activities should help enhance and maintain muscular strength and flexibility, and bone health.

These recommendations apply equally to children/adolescents with diabetes as to the general population.

5.3 Referral to a health professional with expertise in physical activity management

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. Their qualifications will include human movements studies, exercise science or other equivalent university qualification. Exercise physiologists should also be a member of, or eligible for membership of the Australian Association for Exercise and Sports Science (AAESS). 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.

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.

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

5.4 Physical activity management guidelines for paediatric type 1 diabetes

5.4.1. Goals of physical activity counselling for children with type 1 diabetes

Expert Advisory Group Recommendation

The goal of physical activity counselling is to provide children/adolescents with diabetes and their families with the knowledge and skills to engage in regular physical activity while minimising the likelihood of diabetes-related physical

activity complications (eg. acute and post-exercise hypoglycaemia, acute hyperglycaemia, and ketosis) (Choi & Chisholm 1996; Franz et al. 2002).

At the completion of counselling the child/adolescent/family will be able to demonstrate:

- knowledge of the short- and long-term health benefits of physical activity
- an understanding of exercise duration, intensity, and caloric expenditure and the impact of these factors on dietary intake and insulin regimen
- knowledge of strategies to prevent hypo- and hyperglycaemia during and after physical activity
- knowledge of how to respond to adverse effects related to physical activity.

5.4.2. Level of care

The level of care documented in table 16 is considered appropriate for all children and adolescents with type 1 diabetes for education regarding physical activity. Face to face education is the preferred mode for the 'Survival' phase education. Alternative methods using a variety of strategies including videoconferencing, phone, email and group settings may be appropriate, particularly for ongoing education.

Table 16. Level of care -physical activity management.

Type of visit	Timing of visit
'Survival' education following diagnosis	<ul style="list-style-type: none"> • within 1 month of diagnosis being made, or soon after • 30-60 min. per session • over several sessions
Ongoing education if required - see referral criteria	<ul style="list-style-type: none"> • within 12 months of initial visits • 30-60 min. per session • over several sessions

5.4.3. How to use these guidelines

Below are tables detailing necessary elements of comprehensive physical activity education required for management of type 1 diabetes in children and adolescents. The health professional with expertise in physical activity management can:

- select the necessary elements required to deliver "Survival" education.
- select the necessary elements required to deliver "Ongoing" education
- select the necessary elements required to deliver "Problem solving" education
- negotiate appropriate goals with the child/adolescent / family / coach

- implement appropriate intervention / education strategies that are tailored to meet the individual learning styles and needs of the child/adolescent / family.

These steps can be used for any type of consultation (eg at diagnosis and review).

5.4.4 Assessment and intervention

Many of the elements listed below will be repeated at review visits at the professional discretion of the health professional. The professional will take the needs of the individual client into account when making decisions on physical activity interventions. The information in these tables has been developed from the American Diabetes Association (2001) recommendations and recent reviews (Choi & Chisholm 1996; Franz et al. 2002; Horton, 1995).

Table 17: Tables of necessary elements for physical activity assessment and intervention

Survival education

Assessment of physical activity	Flexible competencies	Physical activity intervention	Flexible competencies
a) History - activity types - duration and frequency of activity - family lifestyle and participation level	diabetes educator, dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician	-----	-----
b) Evaluation of physical activity status and limitations - diabetic complications - motor skills deficits - concurrent conditions	exercise physiologist, GP, physiotherapist, paediatric endocrinologist, paediatrician	limitations to physical activity -modify activities based on assessment	exercise physiologist, GP, physiotherapist, paediatric endocrinologist, paediatrician
c) Knowledge - benefits - risks - optimum levels of activity - glycaemic control	diabetes educator dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician	Use appropriate intervention based on assessment. Topics to be discussed: -glycaemic awareness and control -medication effects - opportunity for normal growth and development	diabetes educator dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician

Table 17: Tables of necessary elements for physical activity assessment and intervention - *continued*

Ongoing education

Assessment of physical activity	Flexible competencies	Physical activity intervention	Flexible competencies
a) Evaluate need for exercise - glycaemic control - growth and development - weight related issues - concurrent conditions	diabetes educator dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician	Pre-activity information Discuss: - blood glucose monitoring - metabolic control - hydration - food intake (pre, during and post exercise) - recognition of hypoglycaemic symptoms.	diabetes educator dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician
b) Knowledge of managing diabetes and exercise	diabetes educator dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician	Manage the interaction between physical activity, nutrition and insulin	diabetes educator dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, pharmacist, physiotherapist, podiatrist, paediatric endocrinologist, paediatrician
		Modification of insulin requirements	paediatric endocrinologist, paediatrician, diabetes educator
c) Evaluate child's and adolescent's lifestyle - social activities - sporting activities - social support network	diabetes educator dietitian-nutritionist, psychologist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician	Use appropriate interventions based on assessment	diabetes educator dietitian-nutritionist, psychologist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician

Table 17: Tables of necessary elements for physical activity assessment and intervention - *continued*

Problem solving

Assessment of physical activity	Flexible competencies	Physical activity intervention	Flexible competencies
<p>a) Evaluation of lifestyle habits and motivation</p> <ul style="list-style-type: none"> - identification of barriers and enablers to participating in physical activity - active role models 	<p>diabetes educator dietitian-nutritionist, psychologist, exercise physiologist, GP, Indigenous health worker, physiotherapist, podiatrist, paediatric endocrinologist, paediatrician</p>	<ul style="list-style-type: none"> -short and long-term goal setting - identify active role models - time management and priority setting - planning physical activity sessions - strategies to overcome identified 	<p>diabetes educator dietitian-nutritionist, psychologist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician</p>
<p>b) Competitive sports</p> <p>Evaluate:</p> <ul style="list-style-type: none"> - glycaemic control pre, during and post competition and training - pre-game preparation 	<p>diabetes educator, dietitian-nutritionist, exercise physiologist, GP, Indigenous health worker, physiotherapist, paediatric endocrinologist, paediatrician, sports physician</p>	<p>Use appropriate interventions based on assessment results. Address areas of :</p> <ul style="list-style-type: none"> - nutrition - fluid and carbohydrate replacement - pre, during and post activity - supplementation - game day procedure - training and performance relationship with control 	<p>dietitian-nutritionist, exercise physiologist, physiotherapist, sports physician</p>

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6 Foot care

6.1 Introduction

Foot problems and lower limb complications associated with long-term diabetes are common. 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.

Clinical signs of diabetic foot complications in children and adolescents with diabetes are not common, however their potential significance has been discussed recently in the literature (Duffin et al 1999; Ficicioglu et al. 1996) (*level III evidence*).

These guidelines are designed to allow health professionals, including the diabetes educator, general practitioner, a paediatric endocrinologist or paediatrician/physician and podiatrist to standardise assessment strategies for young people with type 1 diabetes mellitus.

The recommended assessments and management strategies are based on the limited available evidence or professionally recognised approaches. When implemented, they should also be consistent with best practice models, which promote a self-management philosophy.

6.1.1 Annual basic foot screening an appropriately-trained health professional or podiatrist

Expert Advisory Group Recommendation

Queensland Health recommends annual screening for neuropathy for

- children (pre-pubertal) who have had diabetes for five years or more and
- adolescents (pubertal) who have had diabetes for two years or more (QHealth 2001).

On the basis of this recommendation and the clinical experience of the Paediatric Diabetes Podiatry Workgroup it is recommended that children and adolescents who have had diabetes for the above periods of time undergo annual foot screening.

Appropriately trained health professionals, such as the diabetes educator, general practitioner, paediatric endocrinologist, paediatrician/physician or podiatrist 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.

Basic foot screening:

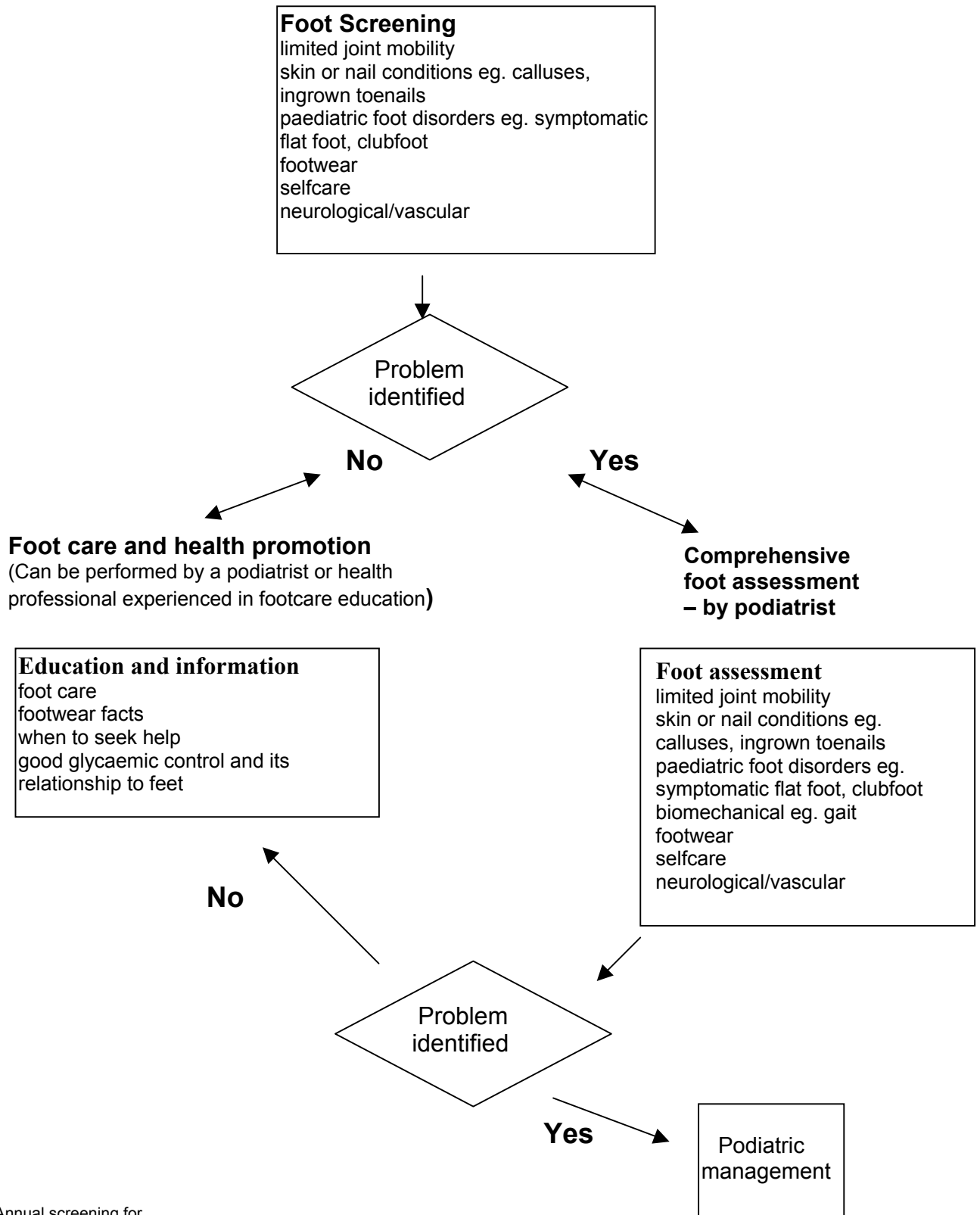
- can be implemented when time, resources or access to a podiatrist are limited
- is not intended to replace a thorough comprehensive foot assessment – if problems are detected, referral to a podiatrist for a comprehensive assessment is needed.

Screening should only be undertaken by those competent in the provision of foot care eg. a health professional who has completed appropriated training, such as The National Diabetes Foot Care Program (NADCP & APC 1998) or equivalent, or a podiatrist. It is the responsibility of these professionals to ensure they have the ability to carry out assessments and interventions within their professional scope of practice. If they do not have the expertise to deal with specific specialised problems, they should refer the patient to a health professional who has the required relevant expertise.

Figure 2 details different levels of diabetes foot care and assessment as well as the indications for referral to a podiatrist.

Figure 2: Diabetes foot care screening, assessment and management flow chart

Annual diabetic foot screening*
 (Can be performed by a podiatrist or health professional experienced in foot care)



* Annual screening for
 - children (pre-pubertal) who have had diabetes for five years or more and
 - adolescents (pubertal) who have had diabetes for two years or more
 (Queensland Health 2001)

6.2 Role of the podiatrist and referrals

The podiatrist is involved in the maintenance of foot health, the maintenance of mobility and the diagnosis, management and prevention of foot disorders. The podiatrist has a key role in decreasing the level of morbidity and amputations that have traditionally been associated with 'diabetes foot disease'.

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.

Podiatrists are an integral part of the multidisciplinary diabetes care team which aims to reduce complications and reduce morbidity associated with diabetes in children and adolescents with diabetes.

Podiatrists can accept referrals from all health agencies and health care facilities. As podiatrists are primary care providers, members of the general public do not require a referral to access these services. This system ensures the provision of timely and appropriate care for individuals in order to maintain foot health for the child /adolescent with diabetes.

6.2.1 Qualifications

6.2.1.1 Mandatory

- Podiatrists must be registered with the Podiatrists Board of Queensland.

6.2.1.2 Highly desirable

- A firm commitment to the process of continuing education within the area of diabetes in either/both a formal or informal context, with facilitation through membership with the Australian Podiatry Association (Qld) Inc or other relevant organisations.
- Participation in/completion of the Accredited Podiatrists Program conducted by the Australasian Podiatry Council with emphasis on diabetes.

6.2.2 Standards of professional practice

6.2.2.1 Professional competence

Standards of professional practice are integral to the role of the podiatrist. They provide the professional with guidelines for the establishment and maintenance of effective services and also ensure consistent practices between professionals. Standards of professional practice are also useful tools for the professional as well as the employer in determining professional

responsibility, scope of practice, accountability, the streamlining of services and planning future directions of services.

Previously there have been no specific standards for podiatrists regarding paediatric diabetes management, although the Australian Podiatry Council has developed general standards of professional practice (APC 1994). These standards are recommended for use by podiatrists throughout Australia.

6.2.3 Comprehensive foot assessment by podiatrists

Thorough assessment and management of the foot health status of a young person with diabetes requires investigations within the categories listed below:

- limited joint mobility
- skin or nail conditions eg. calluses, ingrown toenails
- paediatric foot disorders eg. symptomatic flat foot, clubfoot
- biomechanical eg. gait
- footwear
- selfcare
- neurological/vascular.

Basic foot screening includes a cursory assessment in these areas, whereas a comprehensive assessment investigates these areas in depth. A comprehensive assessment is preferred.

6.2.4 Level of service delivery

Effective client management enables the provision of better services and improved health outcomes for the person with diabetes. The frequency of basic foot screening or comprehensive foot examinations depends on time, resources and professional limitations.

Yearly assessments are considered to be the basic level of service delivery in adults with type 1 or type 2 diabetes (QH & BISDGP 2000; OHD 1995; KAMSC 1998; APC 1997).

As stated in section 6.1.1, the Paediatric Diabetes Podiatry Workgroup recommends that children and adolescents, who have had diabetes for the periods of time described, also undergo annual foot screening.

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.

6.2.5 Management

Paediatric foot disorders, limited joint mobility and its impact on foot health and relevant skin conditions would be managed by a podiatrist as outlined in figure 2.

All podiatrists are trained in the diagnosis and treatment of these particular conditions. If the individual podiatrist determines the need for additional expertise to manage a specific problem, they should consult with a colleague or refer to other health professionals as appropriate.

6.2.5.1 Assessing awareness and knowledge of foot care

Following are a series of key questions that should be used to assess the awareness and knowledge of the regarding foot care issues. It is essential to consider the child's/adolescent's level of understanding, maturity and stage of development. Consideration of these factors will determine who should be the target of the education strategies.

The assessments listed below are adapted with kind permission from the Australasian Podiatry Council (1997). These assessments may occur in one, or a number of consultations, as determined by the child's/adolescent's/family's needs.

Assessment 1

The child/adolescent with diabetes and their family should have an understanding of the effects of diabetes on foot health.

This occurs when the child/adolescent/family can:

- 1.1 identify the reasons why the feet and legs are at risk due to their diabetes
- 1.2 show understanding of the risks inherent with diabetes by implementing recommended changes to footwear, footcare, activity patterns and lifestyle behaviours.
- 1.3 take responsibility for the management and monitoring of daily foot health care, in association with the podiatrist and other health care workers (where applicable)

Assessment 2

The child/adolescent with diabetes and their family should have an understanding of proper footwear choice and its purpose.

This occurs when the child/adolescent/family can understand:

- 2.1 that shoes offer protection from injury
- 2.2 that shoes must fit correctly to protect (and not injure) the foot
- 2.3 that footwear should be suitable for the occasion.

Assessment 3

The child/adolescent with diabetes and their family should be able to identify and effectively manage risk factors which may result in foot problems.

This occurs when the child/adolescent/family can:

- 3.1 state the complications of diabetes which result in the foot being at risk
- 3.2 describe how to help prevent the onset or results of these complications
- 3.3 carry out preventative treatment strategies when there are complications affecting the lower limb or foot.

Assessment 4

The child/adolescent/family should understand the importance of monitoring blood glucose and lipid levels and the potential effect of continued hyperglycaemia on foot health.

This occurs when the child/adolescent/family can:

- 4.1 identify what constitutes a high blood glucose level
- 4.2 identify the relationship between high blood glucose levels and infections and the importance of seeking medical assistance
- 4.3 identify what constitutes a high blood lipid level
- 4.4 understand the long term relationship between hyperglycaemia, hyperlipidaemia and the development of complications which may affect foot health.

Assessment 5

The child/adolescent with diabetes and their family will be able to identify the services available for assistance, their role and appropriate use.

This occurs when the child/adolescent/family can:

- 5.1 describe the role of the podiatrist, general practitioner, specialist, diabetes educator and dietitian
- 5.2 identify the services they would access when an acute foot problem arises and state how they would contact them
- 5.3 state appropriate additional resources which may be useful in their care (viz. Diabetes Australia)

Assessment 6

The child/adolescent with diabetes and their family should be involved in self care to maintain optimal foot health.

This occurs when the child/adolescent/family can:

- 6.1 identify and effectively manage risk factors, which may result in foot problems
- 6.2 act on early warning signs of development of foot or lower limb problems
- 6.3 seek appropriate help.

The child/adolescent/family should be able to discuss and demonstrate skills in foot care that ensure that they are capable of independent self care.

6.2.5.2 Management and general foot care

(Adapted with kind permission from the Australasian Podiatry Council, 1997)

The ability of the child/adolescent with diabetes to care for their feet and nails must be determined. The child/adolescent would need to demonstrate:

- a level of coordination and dexterity to manage nail cutting
- an understanding of nail care and foot hygiene and the consequence of poor management and care.

When a child/adolescent with diabetes is unable to demonstrate these skills and knowledge regarding footcare, then the ability of a parent or carer to care for the child/adolescent's nails should be determined by the podiatrist. Parents and carers need to be involved in the assessment and education to ensure all are providing the same support and information.

The table 18 can then be used as a guide to determine who should provide nail care and general footcare for the child/adolescent with diabetes.

Table 18: Who cares – a guide to nail management and general footcare

Child/adolescent (selfcare)	Parents and carers provide care	Podiatrist provides care
Demonstrate awareness and understanding of footcare	Child/adolescent unable to demonstrate how to care for own feet	Parent/carer unable to demonstrate how to care for child/adolescent's feet
Demonstrates ability to cut own nails	Child/adolescent unable to demonstrate ability to cut own nails	Parent/carer unable to demonstrate ability to cut child/adolescent's nails or abnormal nails

6.3 Foot care summary

It is recommended that children (pre-pubertal) who have had diabetes for 5 years or more and adolescents (pubertal) who have had diabetes for 2 years or more undergo annual foot screening.

Screening should only be undertaken by those competent in the provision of foot care e.g. a podiatrist or other health professional who has completed appropriated training, such as The National Diabetes Foot Care Program (NADCP & APC 1998) or equivalent.

Podiatrists have an important role in the prevention of complications for children and adolescents with type 1 diabetes. The main reason for referring a child/adolescent to a podiatrist is for diabetes foot assessment and education regarding foot care.

Whilst there is substantial evidence of the efficacy of early intervention and screening programs for preventing complication in adults with type 2 diabetes, the literature is largely silent with respect to research into the efficacy of foot care and screening for children and adolescents with diabetes. Recent studies have investigated the prevalence of some specific diabetes-related changes within the feet of children and adolescents (Duffin et al 1999; Ficicioglu et al. 1996) (level III evidence).

The most recent studies, which are currently under review for publication, will provide further information about pedal complications in children and adolescent's with diabetes (Duffin, A. 2001 pers. comm., 10 Dec).

Recommendations regarding assessment and management of foot care for children and adolescent's with diabetes will evolve as clinicians and researchers investigate the relationships between changes within the feet in children with diabetes, the effects/complications these changes produce when the children become adults and the role of early interventions in preventing adverse outcomes.

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These guidelines are intended as a general guide only and are not intended to be prescriptive. The guidelines should not be considered all inclusive nor should it be considered exclusive of other methods of service delivery. Health professionals must exercise independent judgement as to what is appropriate for individual patients or groups of patients under particular circumstances.

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