Designed for the Management of Type 1 Diabetes in Children and Young People in Wales:

Consensus Guidelines - Standards 5 & 6 Diabetes National Service Framework

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Schematic representation on 2nd page to be corrected as presented
The Welsh Assembly Government is committed to the children and young people in Wales and has supported initiatives for the promotion and implementation of the Diabetes Delivery Strategy of the National Service Framework for Wales, published in April 2003.

The Delivery Strategy is the foundation for the planning and implementation of the twelve Standards. The Delivery Strategy includes Action Plans relating to the Standards.

Although children and young people are mentioned in other standards, Standards 5 & 6 relate specifically to children and young people.

The Brecon Group, an All Wales Paediatric Diabetes interest group/network, facilitated by the Assembly, has been responsible for the development of the consensus guidelines for the Management of children and young people with diabetes across Wales.

The guidelines will assist in
- the planning of services
- improved quality of service
- reduction in the inequalities in care across Wales

Helping and supporting children and young people to manage their care can reduce the early onset of the complications of diabetes, blindness kidney failure, neuropathy, vascular disease resulting in amputation of lower limbs, cardiovascular disease, in early adult life.

I would like to thank all those who have been involved in developing the Guidelines, specifically the Brecon Group, who have worked extensively with the ultimate aim of improving services and care of children and young people with Diabetes in Wales which will assist the NHS to achieve the National Service Framework targets by 2013.

Edwina Hart AM
Minister for Health and Social Services
Introduction

Type 1 diabetes is one of the most frequent chronic diseases in childhood and has major short term and long term impact on health, lifestyle and life expectancy. Children and young people with type 1 diabetes, along with their families, have specific needs which differ from those of adults with type 1 diabetes.

The Diabetes National Service Framework for Wales was published in April 2003 and set a series of 12 standards which provided a vision for the management of diabetes services. Two of the standards (5 and 6) related specifically to children and young people, although all 12 standards related in some way to children and diabetes.

**Standard 5**

All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.

**Standard 6**

All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community-based, either directly or via a young people’s clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.

In order to implement these standards members of the Brecon Group (an all Wales paediatric diabetes interest group/network) met to produce this consensus document which outlines the minimum standards of care for children and young people diagnosed with type 1 diabetes across Wales. All the guidelines have been viewed and open for comment by all members of the Brecon group and I would like to thank all those who have been involved in developing this document which provides a framework for delivering quality care for children with diabetes.

**Dr Justin T. Warner**

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Schematic representation of the clinical pathway throughout childhood and adolescence for childhood onset type 1 diabetes through to transition on to adult services

Diabetic Ketoacidosis
Surgical procedures
Hypoglycaemia
Sick day rules

Pre School
Infancy

Primary School
Childhood

Secondary School
Adolescence

Transition

Diagnosis

Diabetes Education
Blood glucose monitoring
Insulin
Diet and exercise
Screening and complications
Psychosocial/schooling
# Index

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis and ongoing management</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes education</td>
<td>3</td>
</tr>
<tr>
<td>Diabetes and school</td>
<td>7</td>
</tr>
<tr>
<td>Psychological, social and financial issues</td>
<td>8</td>
</tr>
<tr>
<td>Blood glucose monitoring</td>
<td>11</td>
</tr>
<tr>
<td>Insulin therapy</td>
<td>13</td>
</tr>
<tr>
<td>Diet</td>
<td>14</td>
</tr>
<tr>
<td>Physical activity</td>
<td>16</td>
</tr>
<tr>
<td>Screening for complications</td>
<td>18</td>
</tr>
<tr>
<td>Transition</td>
<td>21</td>
</tr>
<tr>
<td>Sick day rules</td>
<td>24</td>
</tr>
<tr>
<td>Diabetic ketoacidosis</td>
<td>27</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>30</td>
</tr>
<tr>
<td>Surgical management</td>
<td>34</td>
</tr>
<tr>
<td>Members of the consensus group</td>
<td>39</td>
</tr>
</tbody>
</table>
Diagnosis and Ongoing Management

From diagnosis the child or young person 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.

The essential members of the diabetes multidisciplinary team include:
- Paediatrician with a special interest in diabetes
- Paediatric diabetes specialist nurse
- Paediatric dietician with an interest in diabetes

Other healthcare professionals to whom there should be easy access include:
- Psychologist/psychiatrist/counsellor trained in paediatrics and with an understanding of childhood diabetes
- Paediatric social worker
- Podiatrist

Management of diabetes at onset:
- Easy access (24 hour per day) to a paediatric unit for rapid diagnosis and initiation of treatment
- Accepted written protocols for management of DKA and other types of presentation of childhood diabetes
- Practical guidance and education at diagnosis including dietary management
- Ambulatory management at diagnosis for clinically well children is a safe alternative to hospitalisation if resources permit (including access to 24 hour advice from appropriate healthcare professionals)
- Appropriate emotional support should be offered to children and families from diagnosis

Ongoing management
- Frequent contact with the diabetes team by clinic appointments, home visits, telephone or other methods is essential during the early phase following diagnosis
- Following the initial phase, children and young people with diabetes should be reviewed 3-4 times annually
- Continuous structured education programme
Clinic visits should include:

- General health and wellbeing
- Height and weight (entered on appropriate growth charts)
- Intercurrent health problems
- Insulin type, dose, injection devices, injection sites
- Glycaemic control
- Dietary management
- Hypoglycaemia
- Developmental performance, education (particularly school absences/problems), leisure and sport activities
- Psychosocial issues
- Continuing age appropriate education
- Annual review
- Preparation for transition where relevant
Diabetes Education

Every person with diabetes has a right to comprehensive expert practical education.

- Children and young people, their parents and carers should have access to and be included in the diabetes educational process.
- Diabetes education should be delivered by experienced health care professionals with a clear understanding of the needs of young people and their families as they grow through the different stages of life.
- Educators (doctors, nurses, dietitians and other health care providers) should have access to continuing specialised training in diabetes education and educational methods.
- Diabetes education should be based on a thorough assessment of the person’s existing knowledge, culture, beliefs, learning style, ability and readiness to learn, and goals.
- Diabetes education needs to be adaptable and individualised in relation to age, stage of diabetes, maturity, and lifestyle.
• Diabetes education needs to be a continuous process and repeated throughout life.
• Diabetes education should be planned, documented, monitored and evaluated regularly by the diabetes care team.
• Research into diabetes educational methods is important in improving clinical practice.

**Education Programme**

**At diagnosis**

- Explanation of the diagnosis and reasons for symptoms.
- Simple explanation of the uncertain cause of diabetes. No cause for blame.
- The need for immediate insulin and how it works.
- Practical skills: insulin injections, blood and/or urine testing and reasons for monitoring.
- Normal blood glucose levels and targets.
- Dietetic advice.
- Explanation of hypoglycaemia and its treatment.
- Details of emergency telephone contacts.

**Continuing education**

- Continuing education (individual or in groups) should take place in an ambulatory (clinic, community, domiciliary) setting.
- The educational programme should use age appropriate, patient-centred, interactive teaching methods.
- Individualised continuing education is essential and should include:
  - Blood glucose monitoring and control
  - Insulin and insulin delivery
  - Healthy eating, insulin dose adjustment to food intake and exercise
  - Hypoglycaemia
  - Intercurrent illness management
  - Treatment and prevention of ketoacidosis
  - Diabetes at school and college
  - Diabetes and exercise
  - Glycated haemoglobin and the targets of control
  - Micro- and macro-vascular complications and their prevention
• Psychological adjustment to the diagnosis
• Identification (e.g. bracelet, necklace, card)
• Holiday planning and travel
• Smoking, alcohol and drugs
• Employment and driving vehicles
• Sexuality, pregnancy, childbirth and contraception
• Voluntary and other available support services
• Educational strategies require appropriate funding and support.

Specific educational needs and different age groups

Infants and toddlers
• Acknowledging total dependence on parents and carers.
• Unpredictable erratic eating and activity levels.
• Recognition and management of hypoglycaemia.
• Education of nursery school/child minders.

School age children
• Development of skills towards self management of diabetes.
• Recognition of hypoglycaemic symptoms and understanding self-management.
• Adapting diabetes to different activities, meals and exercise.
• Education of school staff.

Adolescents
• Promote independence while acknowledging the importance of parental support.
• Discussing emotional and peer group conflicts.
• Strategies for dealing with dietary decision making, intercurrent illness, hypoglycaemia and sport.
• Negotiating diabetes targets, goals and priorities.
• Transition planning for progression to adult services.
• Leaving home (e.g. university, living independently).

Mode of education and resources
• Educational methods should be backed up by age-appropriate, easily comprehensible written information and other media (e.g. videos, DVDs, computer games).
• Educational methods might include group teaching sessions with young people and/or parents and/or other care providers, role plays, television, radio or tape learning, friendship or school groups, organized diabetes association meetings, and the opportunity to participate in holiday or leisure experiences.

Knowledge about diabetes does not necessarily correlate with good metabolic control. Successful education not only instils knowledge, it must also empower and motivate the young person to use knowledge and practical skills in problem-solving and self-management.
Diabetes and School

The diabetes specialist nurse is the central point of contact between the child and family, the school and the diabetes team.

Parents and members of the diabetes team should be able to visit the child’s school to provide information and education about:

- How to get urgent advice in case of emergencies
- Healthy eating and school meals from a paediatric dietician with an interest in diabetes
- Avoiding delays in meals and snacks and allowing extra carbohydrate as necessary, particularly in relation to exercise/sport
- The need for children to measure blood glucose and administer insulin during the school day in a suitable environment
- Encouraging younger children to report hypoglycaemia to staff
- The recognition and management of hypoglycaemia (including advice on emergency treatment for loss of consciousness. N.B. cognitive function may be affected for some hours after hypoglycaemia)
- Safety when participating in sports, school excursions or camps
- Enabling parents and children to discuss diabetes openly with peers, school staff and friends while recognising the right to privacy if desired

Recommendations

- A supply of rapidly absorbed sugar must be immediately available and should be followed by a long acting carbohydrate.
- During or following hypoglycaemia at school a child must not be left unaccompanied or be expected to walk to a ‘medical room’.
- Any discrimination or stigmatisation is unacceptable.
- Full participation and opportunities in all academic, social and sporting activities should be encouraged.
Psychological, Social and Financial Issues

Psychosocial factors are an important consideration in the care and management of diabetes in children and young people

Effects on children, care-givers and siblings
- Diabetes in a young person has a profound impact on family life. It has the potential to cause serious personal and family distress including accentuation of any pre-existing difficulties
- The cultural, environmental, developmental and personal circumstances of the child and family should receive high priority in diabetes care including a careful assessment at the time of diagnosis
- Poor metabolic control is commonly associated with psychological and social difficulties. Appropriate and timely intervention may be the most effective way to improve control
- There is a greater risk of emotional and behavioural difficulties for young people with type 1 diabetes compared to other young people, particularly eating disorders, which may be associated with problems of persistent hyperglycaemia and recurrent hypoglycaemia.

The young person
- Each child’s individual circumstances in the family and the social environment needs to be recognised
- Young people should have equal opportunities in education and employment.

The parent/carers
- At diagnosis, all carers may experience stages of grief and depression before adapting to the requirements of the condition. These feelings may re-emerge at later dates, particularly when faced with crises or worries
- Parents may experience specific difficulties e.g. fear of hypoglycaemia, struggling to understand the complexities of diabetes, managing the balance of responsibility and allowing independence
• Diabetes may cause extreme frustration because perfect control may not be achieved and is constantly changing throughout childhood and adolescence, raising concerns about long-term consequences of diabetes.

• Temporary care givers of children with diabetes should receive specific instructions on dealing with diabetes from the parents or the diabetes team.

**Siblings**

• Siblings may exhibit many different and strong emotions about their brother/sister with diabetes.

**Recommendation**

Access is required to consistent and skilled psychosocial support systems by all children and young people with diabetes, parents, siblings, other relatives and care givers.

**The diabetes team**

• The diabetes team should provide age-appropriate advice and education not only on diabetes itself but also on how to cope with:
  • psychological stress, e.g. feeling different, bullying, jealousy, peer group pressures, discrimination
  • diabetes in daily life, e.g. at school, with friends, eating behaviour, becoming independent.

**Recommendations**

• Diabetes team members should receive training in the recognition, identification and provision of information and counselling on psychological and social problems related to diabetes. To maximise the impact of this training the team should have ongoing support and consultation available from a suitably trained mental health professional.

• Overt psychological problems or psychiatric disorders in the young person or family members should receive expert attention from a social worker/psychologist/psychiatrist trained in child and family therapy. To optimise care, these mental health professionals should have knowledge of the psychosocial effects of diabetes for the child and family.
Social and financial provision

- Social and financial needs of families should be recognised and information given about available economic support.
- Parents should be advised of local and national diabetes associations and other voluntary/charitable organizations, which may provide support at many levels, e.g. information and education, support groups, educational holidays/camps, financial help.

Recommendation

Children and young people with diabetes should have the same social rights as their non-diabetic peers, and no stigma or discrimination should be attached to diabetes.
Blood Glucose Monitoring

Monitoring principles
- Near patient testing should be regarded as an integral part of treating type 1 diabetes
- Children and young people with type 1 diabetes should be educated to self monitor blood glucose and adjust treatment accordingly
- Parents or children should be encouraged to perform frequent blood glucose monitoring (2-4 times per day), varying the time of testing to provide 24 hour profiles.

High Blood Glucose levels can be caused by
- Additional carbohydrate without increased insulin
- Insufficient or missed insulin
- Intercurrent illness or stress
- Poor insulin injection technique
- Inappropriate timing between meal and injection
- Change of injection technique or site
- Hypoglycaemia with rebound phenomenon
- Lipodystrophy.

Low Blood Glucose levels can be caused by:
- Excess insulin
- Insufficient carbohydrate
- Missed meals/snacks
- Exercise without sufficient carbohydrate
- Hot weather
- Altered injection site, rotation & timing.
Useful monitoring times include:
- Before breakfast
- Before midday meal
- Before evening meal
- Before bedtime snack
- Late evening & middle of the night when required
- Before treating hypoglycaemia
- Post prandially in those on basal bolus regimens
- Increased frequency during intercurrent illness (see ‘sick day’ management).

Haemoglobin A1c test (HbA1c)

An HbA1c should be taken 3-4 monthly at clinic visits

The aim is to achieve an HbA1c <7.5% (NICE, 2004)
Insulin Therapy for Paediatric Type 1 Diabetes

At Diagnosis
Insulin treatment must be started as soon as possible after diagnosis (always within 24 hours if ketonuria is present) to prevent metabolic decompensation and diabetic ketoacidosis.

Which Insulin?
Any insulin regimen needs to cover daily basal requirements and the hyperglycaemic effects of food. Premixed insulin is suitable for most children but the choice of insulin regimen will depend on factors such as age, lifestyle and individual patient/family preference.

Dose
The usual starting dose is 0.5 units/kg/day. Younger children may be very sensitive to insulin and require less (0.3 units/kg/day), whereas older children are more insulin resistant and those in puberty and/or with heavy ketonuria (not requiring IV fluids) may require 0.7 units/kg/day.

Aims of Insulin Therapy
- To maintain pre prandial glucose levels of 4-9 mmol/litre and post prandial of less than 10mmol/litre.
- Avoid ketoacidosis.
- Avoid hypoglycaemia.
- HbA1C <7.5% avoiding frequent disabling hypoglycaemia
- Ensure optimal growth (height and weight).

Ongoing Insulin Management

Reasons for Changing Regimen
- Dislike of current regimen by patient/parent.
- Attainment of better control.
- Increased flexibility of lifestyle.

Suggested Insulin Regimens
- Two injections daily of a premixed short and intermediate-acting insulin.
- Three injections daily using a premixed insulin before breakfast; short-acting insulin alone before afternoon snack or main evening meal; intermediate-acting insulin (or analogue) before bed.
- Basal-bolus regimen of short-acting insulin 20–30 min before main meals, intermediate or long-acting insulin at bedtime.
- Basal-bolus regimen of rapid-acting insulin (or analogue) immediately before main meals, intermediate or long-acting insulin (or analogue) at bedtime.
- Pump regimens should only be used under the supervision of a centre with experienced staff trained in their use.

Insulin Dose Adjustment
- Insulin dose and regimen should be individualised and adjusted systematically to suit the changing needs of the growing child.
- Day-to-day insulin adjustments may be necessary for variations in lifestyle and routine especially exercise (see exercise section) or dietary changes (see dietary section).
- Special advice may be helpful in certain circumstances eg. travel, school outings, educational holidays.
- Dose adjustment may be required during intercurrent illness (see sick day rules).
Diet

- Children, young people and families should be provided with advice from a paediatric dietician with experience in diabetes
- Dietetic advice should form part of initial and ongoing care and education
- The dietician should be part of the paediatric diabetes multi-disciplinary team
- Dietary advice from diabetes team members must be consistent
- To achieve optimal glycaemic control, dietary advice should be given with due consideration to insulin therapy and insulin dose adjustment where appropriate

Dietary education aims to:
- Help optimise glycaemic control and ensure normal growth and development
- Reduce cardiovascular risk
- Reduce risk of long term complications of diabetes

Dietary recommendations for children and young people with type 1 diabetes are essentially similar to healthy eating recommendations for the general population and therefore applicable to the family unit.

Total daily intake should be distributed as follows:
- Carbohydrate >50% including information on benefits of lower GI options
- Fat 30-35%
  - Saturated fatty acids (SFA) <10%
  - Poly-unsaturated fatty acids (PUFA) <10%
  - Mono-unsaturated fatty acids (MUFA) <10%
- Protein 10-15%
- 5 servings of fruit and vegetables per day should be encouraged.

Neonates, infants and pre-school children require individualised dietary assessment to determine their energy needs.
• Dietary education should be available to all those involved in the care of children and young people with type 1 diabetes e.g. school, relatives.
• Dietary advice should be individualised, taking into account insulin therapy, cultural considerations and lifestyle factors.
• Dietary advice should include education on the prevention and treatment of hypoglycaemia, exercise related problems, illness and hyperglycaemia.
• Children and young people using multiple daily injection regimens should be offered education about insulin dose and carbohydrate adjustment.
• The diabetes care team should be aware of the increased risk of eating disorders in children and young people with type 1 diabetes and should seek support from Children and Adolescent Mental Health Service (CAMHS) as appropriate.
Physical Activity

- Children and young people with type 1 diabetes should be encouraged to participate in regular physical activity
- Potential health benefits of regular exercise to be highlighted include:
  - improved cardiovascular health
  - improved glycaemic control
  - improved weight management.
- The diabetes care team should give consistent advice on the effects of exercise on blood glucose levels, especially exercise induced hypoglycaemia
- Children and young people with type 1 diabetes should be informed that changes in their daily exercise patterns may require insulin dose and/or carbohydrate intake adjustment
- The topic of physical activity should form part of a structured education programme for children and young people with type 1 diabetes
- Education should be provided to those involved in supervising activities for children and young people with type 1 diabetes e.g. school, sports clubs etc.
- Children and young people with type 1 diabetes should be encouraged to monitor the effects of physical activity on blood glucose levels to inform their diabetes management
- Children and young people with type 1 diabetes wishing to participate in restricted sports (e.g. scuba diving) should be offered specialised advice by their diabetes care teams and additional information sought from local and national patient support groups and organisations.
Algorithm for Physical Activity

**BEFORE EXERCISE**

- **Monitor BG before starting exercise**
  - **BG level >17mmol/l**
    - Check for ketones
      - **Positive**: proceed only with caution if well
      - **Negative**: proceed
  - **BG level 7-17mmol/l**
    - May need additional CHO
  - **BG level 4-7mmol/l**

- **BG level <4mmol/l** - treat as hypo and delay exercise until recovered

  **IF vigorous/prolonged exercise, recheck BG after 30-60 minutes and respond accordingly**

**FOLLOWING EXERCISE**

- **Check BG**
  - Warn of risk of delayed hypoglycaemia

  **HIGH >9mmol/l**
  - Continue BG monitoring
  - Check ketones if BG>17mmol/l
  - May need to review pre-exercise insulin/CHO

  **NORMAL 4-9mmol/l**
  - Long acting CHO snack

  **LOW <4mmol/l**
  - Treat as hypoglycaemia and take extra long acting CHO
  - May need to review pre-exercise insulin CHO
Screening and Complications

Algorithm for Screening Children with Diabetes for Associations and Complications of the disease

The following are minimum standards for screening children with diabetes for associated complications and conditions.

Who should be screened?
- Every child with type 1 and non type 1 diabetes (except where age restrictions apply, see below).

Who does the annual screening?
- Paediatrician with an interest in diabetes.
- Paediatric diabetes specialist nurse.

When should it be performed?
- Annually except where otherwise stated.
- Clinics should have mechanisms (e.g. close to birth date, annually from diagnosis, separate annual review clinic) for identifying and monitoring patients’ annual review.

What should an annual review consist of?
- Clinics should provide adequate age appropriate explanation of need for annual review.
- Age appropriate diabetes advice (e.g. schooling, physical activity, smoking and alcohol, sex education, transition etc).
- Physical examination.
- Investigations.
Physical Examination

(The following is a minimum standard for physical examination at annual review and applies to all ages)

- Height, weight, BMI (plotted on appropriate reference chart).
- Blood pressure using age appropriate equipment and interpreted using age and gender specific normal standards (see below for suggested investigations for raised BP).
- Fundoscopy
- Skin:
  - Injection sites.
  - Blood glucose monitoring sites.
  - Evidence of necrobiosis lipoidica.
  - Joint Mobility
- Teeth (ask about dental reviews).
- Evidence of goitre.
- Feet:
  - General condition and hygiene
  - Pulses.
  - Vibration sense.
  - Monofilament touch.
- Routine assessment of pubertal status is unnecessary except where abnormalities of growth are detected.
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<thead>
<tr>
<th>Associated conditions</th>
<th>Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Annual thyroid function test for all ages.</td>
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<td>• Annual coeliac disease screen for all ages.</td>
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<td>• Total cholesterol, HDL/LDL cholesterol, triglycerides, where possible in the fasted state.</td>
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<td>• Suggested investigations for repeatedly raised BP:</td>
<td></td>
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<tr>
<td>• 24 hour urine collection for microalbumin and catecholamines.</td>
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<tr>
<td>• 24 hour ambulatory BP monitoring.</td>
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<td>• Renal USS.</td>
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<td>• Retinal screening (ideally as part of the all Wales retinal screening programme)</td>
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<tr>
<td>• Annually from 12 years.</td>
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<td>• Consideration when &lt;12 years and duration of diabetes &gt;5 years.</td>
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<tr>
<td>• Microalbumin (spot urine sample)</td>
<td></td>
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<tr>
<td>• Annually from 12 years.</td>
<td></td>
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<tr>
<td>• Consideration when &lt;12 years and duration of diabetes &gt;5 years.</td>
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<tr>
<td>• Raised microalbumin on a spot sample should be repeated with an early morning sample.</td>
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<tr>
<td>• Suggested investigations for persistently raised microalbumin:</td>
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<tr>
<td>• Exclude other possible causes of proteinuria e.g. UTI, menstruation, vaginal discharge, glomerulonephritis, heavy exercise.</td>
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<tr>
<td>• 24 hour urine collection for microalbumin.</td>
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<td>• Renal ultrasound scan.</td>
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<td>• Careful BP assessment (see above).</td>
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Adolescence and Transition of Care

Adolescence is the transitional phase between childhood and adulthood, which imposes unique challenges to young people with diabetes, their families and the diabetes care team.

Optimal care during adolescence should provide:

- An integrated care package that:
  - Is delivered by a multi-disciplinary diabetes team with training/expertise in clinical, educational, dietetic, lifestyle, psychological and foot care aspects of diabetes.

- An environment that:
  - Allows a trusting relationship to develop between the young person and the diabetes team
  - Helps the young person to clarify priorities particularly where there is conflict between the needs of diabetes management and the young person’s social development and peer activities
  - Provides expertise in identifying the physiological changes of puberty, their effect on insulin dose and the frequent difficulties of weight control and dietary regulation
  - Provides regular screening for early signs of complications
  - Recognises the emerging maturity of the young person, encourages self-reliance and allows consultations to be increasingly directed towards the young person rather than parents
  - Recognises that emerging independence is best pursued gradually
  - Maintains parents’ trust while facilitating their changing role from full responsibility towards co-operative care of the young person
  - Introduces the concept and encourages acceptance of the requirement to respect confidentiality
  - Identifies and recognises the need for specialised psychological support in some situations.
Appropriate styles of education that:

- Offer a variety of educational opportunities including open-ended adolescent-orientated discussion and negotiation, age-appropriate written materials, videos, internet use, peer involvement and group learning, and other activities outside the clinic
- Enable the adolescent to learn from mistakes without moral judgement
- Encourage the young person to make decisions about diabetes management with appropriate advice
- Encourage the young person to attend clinics on a regular basis (three or four times a year).

Transition should be a guided educational therapeutic process (rather than an administrative event) that begins in early adolescence. It is the purposeful, planned movement of young people with diabetes from child centred to adult orientated health care systems.

Organised transition to adult care involves:

- **Service Provision**
  - Negotiation, liaison and information sharing (about management protocols, education etc) between paediatric and adult services
  - Dedicated clinics for young people and young adults organised jointly by paediatric and adult teams
  - Identification of named contact person (ideally a coordinator who will lead the transition process) and exchange of contact details.

- **Timing**
  - Transition should be a flexible process guided by the individual’s physical and emotional maturity
  - Transfer should ideally occur at a time of relative stability in the individual’s health and should be co-ordinated with other life transitions.

- **Preparation**
  - Sufficient time should be given for young people to familiarise themselves with the practicalities of the transition
  - Young people should be informed that some aspects of diabetes care will change on transfer to adult services (e.g. glycaemic control targets, screening for complications, clinic structure and access to the service)
  - The concept of transition and the need for young people to develop autonomy should be introduced while the young person is still supported by their family.
• **Education**
  - Review of knowledge prior to transfer to adult services
  - Identify and address gaps in knowledge
  - Introduce new and appropriate information.

• **Documentation**
  - Physical condition
  - Social background
  - Current treatment regime
  - Glycaemic control (HbA1c)
  - Education review.

Young people with diabetes who are lost to follow up care have a high risk of vascular complications. Provision of transitional care should ensure that there is no hiatus in care at the time of transfer and that the young person is not lost to follow up.
Sick Day Management

- Children with diabetes experience similar patterns of illness to those children without diabetes.
- Illness episodes increase the risk of hypoglycaemia, hyperglycaemia and ketoacidosis, particularly in children with poor metabolic control.

Recommendations

The diabetes care team should provide clear guidance on managing diabetes during intercurrent illness and the problems associated with:

- Dehydration.
- Vomiting.
- Ketoacidosis.
- Hypoglycaemia.

In a child with intercurrent illness urgent specialist medical or nursing advice must be obtained when:

- The diagnosis is unclear.
- Vomiting is persistent (particularly in young children).
- Blood glucose continues to rise despite increased insulin.
- Hypoglycaemia is severe.
- Ketonuria is heavy and persistent.
- The child is becoming exhausted, confused, is hyperventilating, dehydrated or has severe abdominal pain.
**General advice during intercurrent illness**

(Health care professionals giving advice to patients and their families should have sufficient expertise to provide specific guidance.)

- Never stop insulin.
- Appropriate alterations to insulin dose.
- More frequent monitoring of:
  - Blood glucose.
  - Urinary or blood ketones.
- Replace meals with easily digestible food and/or glucose containing fluids.
- Maintain hydration by encouraging fluid intake.
- Treat fever with antipyretics.
- Vomiting may be caused by:
  - the illness itself
  - ketoacidosis (repeated episodes of hyperglycaemia with vomiting may be due to omission or inadequate administration of insulin - see DKA guideline).
**Hyperglycaemia**

Illness associated with hyperglycaemia with or without ketosis:
- Additional doses of short or rapid-acting insulin.
- Frequent monitoring of blood glucose to re-establish euglycaemia.
- Frequent monitoring of urinary or blood ketones to avoid ketoacidosis.
- Additional insulin doses and frequency depends on the child’s age, existing insulin regimen, level and duration of hyperglycemia, severity of ketosis and individual previous experience with such alterations of insulin.

**Hypoglycaemia**

Illness associated with hypoglycaemia:
- Replace meals with frequent small volumes of glucose or sugary drinks.
- Frequent blood glucose monitoring.
- Monitor urinary or blood ketones (ketoacidosis can occur even when blood glucose levels are normal/low.)
- Reduction of insulin dose (e.g. by up to 20–50%) may be required.

See section on hypoglycaemia for treatment of severe hypoglycaemia.

**Source & Availability of Advice**

NICE recommends that patients and families have access to 24 hour advice on diabetes management. Where possible, this should be provided by members of the paediatric diabetes team. Where for local reasons this is not possible, health professionals giving such advice should understand local guidelines, liaise closely with the diabetes team and inform them as soon as practically possible when such advice has been given. Local diabetes teams must educate and empower on call teams to deliver consistent and practical advice.
Diabetic Ketoacidosis

Introduction
Children and young people with diabetic ketoacidosis (DKA) should be treated according to the guidelines published by the British Society for Paediatric Endocrinology and Diabetes (BSPED) and endorsed by NICE. Treatment of established episodes of ketoacidosis should be guided by use of the All Wales Integrated Care Pathway documentation.

Mild DKA
Children and young people with a blood pH of less than 7.3 (hydrogen ion concentration of more than 50 nmol/litre), but who are clinically well (with no tachycardia, vomiting, drowsiness, abdominal pain or breathlessness) and less than 5% dehydrated, may respond appropriately to oral rehydration, frequent subcutaneous insulin injections and monitoring of blood glucose.

Algorithm for the management of moderate to severe DKA
Clinical signs
- Assess dehydration
- Deep sighing respiration
- Smell of ketones
- Lethargy, drowsiness

Confirm diagnosis
Diabetic ketoacidosis
Call senior staff

Shock
- Reduced peripheral pulse volume
- Reduced conscious level
- Coma

Resuscitation
- Airway † N/G tube
- Breathing (100% O₂)
- Circulation (10 ml/kg of 0.9% saline repeated until circulation restored, max. 3 doses)

Dehydration < 5%
Clinically well
Tolerating fluid orally

Dehydration > 5%
Clinically acidotic
Vomiting

Intravenous therapy
- Calculate fluid requirements
- Correct over 48 hours
- 0.9% saline
- Add KCl 20 mmol every 500 ml
- Insulin 0.1 U/kg/hour by infusion

Observations
- Hourly blood glucose
- Neurological status at least hourly
- Hourly fluid input: output
- Electrolytes 2 hours after start of IV-therapy, then 4 hourly

Blood glucose < 15 mmol/litre

Intravenous therapy
- Change to 0.45% saline + dextrose 5%
- Continue monitoring as above
- Consider reducing insulin 0.05 U/kg/hour, but only when pH > 7.3

Insulin
Start subcutaneous insulin then stop intravenous insulin 1 hour later

Improvement
- Clinically well, drinking well, tolerating food
- Urine ketones may still be positive

No improvement

Re-evaluate
- Fluid balance + IV-therapy
- If continued acidosis, may require further resuscitation fluid
- Check insulin dose correct
- Consider sepsis

Neurological deterioration
Warning signs:
- Headache, irritability, slowing heart rate, reduced conscious level, specific signs raised intra-cranial pressure

Exclude hypoglycaemia
Is it cerebral oedema?

Management
- Give mannitol 1.0 g/kg
- Call senior staff
- Restrict IV fluids by 2/3
- Move to ITU
- CT scan when stabilised

Exclude
- hypoglycaemia
- Is it cerebral oedema?
Subsequent management and prevention

- Possible trigger(s) for episode of DKA should be reviewed.
- Recurrent DKA usually associated with inadequate insulin levels.
- In adolescence this is commonly due to insulin omission.
- Parents and young people should have clear guidance on managing diabetes during intercurrent illness.
- Parents and young people should learn how to recognise impending DKA and treat urgently with additional short or rapid-acting insulin.
- Parents and young people should have easy 24 hour access to emergency advice and treatment.

Location of Care

- Children and young people with DKA should be managed initially on a high-dependency unit or in a high-dependency bed on a children’s ward.
- Children and young people with deteriorating consciousness or suspected cerebral oedema and those who are not responding appropriately to treatment should be managed in a paediatric intensive care unit.
- Consider liaison with/transfer to PICU if:
  - < 2 years old
  - severe persistent acidosis with marked hyperventilation
  - severe dehydration with shock
  - depressed sensorium with risk of aspiration from vomiting.
Hypoglycaemia

**Symptoms**
- Autonomic activation
  - Hunger
  - Trembling of hands or legs
  - Palpitations
  - Anxiety
  - Pallor
  - Sweating

- Neuroglycopenia
  - Impaired thinking
  - Change of mood
  - Irritability
  - Dizziness
  - Headache
  - Tiredness
  - Confusion and later convulsions and coma
  - Cognitive impairment is increasingly likely as plasma glucose falls below 4mmol/l.

**Recommendation**

Level of blood glucose should be maintained above 4 mmol/l.

The threshold for symptoms may vary.
Grading of severity of hypoglycaemia

Mild (Grade 1)
- Child or adolescent is aware of, responds to and self-treats the hypoglycaemia
- Children aged below 5-6 years can rarely be classified as grade 1 hypoglycemia because they are usually unable to help themselves

Moderate (Grade 2)
- Child or adolescent cannot respond to hypoglycaemia and requires help from someone else, but oral treatment is successful

Severe (Grade 3)
- Child or adolescent is semi-conscious or unconscious or in a coma with convulsions and may require parenteral therapy (IM glucagon or IV glucose)

Education and prevention
- Children and young people with type 1 diabetes, their parents and other carers must always have access to an immediate source of carbohydrate (glucose or sucrose) and blood glucose monitoring equipment for immediate confirmation and safe management of hypoglycaemia
- Children and young people, their parents, school staff and other carers should be offered education about the recognition and management of hypoglycaemia
- Children and young people with type 1 diabetes should wear or carry something that identifies them as having type 1 diabetes (for example a bracelet)
Treatment

Diagram A: Confirmed Hypoglycaemia in the Conscious Child (Mild or Moderate Hypoglycemia)

Take Immediate Action

Fast acting carbohydrate (10-20g)¹

Accepted/Tolerated

Yes

Yes

Improving after 10-15 minutes? Check BG

Yes

Repeat fast acting carbohydrate (10-20g)

Improving after 10-15 minutes? Check BG

No

No

Long acting carbohydrate²

Check BG after 60 minutes

No

Treat as unconscious child

Go to flowchart B

Improvement?

No

Hypostop³

Check BG after 60 minutes

Notes for Diagram A

¹ Rapid acting carbohydrate: pure fruit juice/ordinary cola/lemonade 100ml, lucozade 50ml, 3 dextrose tablets.
² Long acting carbohydrate: toast, sandwiches, digestive biscuits.
³ If the child refuses food, drinks or vomits, hypostop, which is a glucose gel, (1 tube) can be squeezed into the side of the mouth. With an unconscious or fitting child no attempt should be made to force glucose into the mouth, as aspiration is a serious possibility.
Diagram B: Confirmed Hypoglycaemia in the Unconscious/Uncooperative Child

Treatment is urgent

IM/SC Glucagon (0.5mg for younger children and 1.0mg over 5 years)¹

Improving after 15 minutes? Check BG

Yes

Long acting carbohydrate
Check BG after 60 minutes

Yes

Recovering during injection? Check BG

No

Repeat 5ml/kg IV 10% dextrose and consider O/D of insulin as a cause³

Yes

Recovering? Check BG

No

Reduced consciousness may persist for several hours after severe hypoglycaemia. Establish maintenance IV dextrose infusion and monitor BG levels. Consider alternative/additional cause for reduced conscious level (e.g. post-ictal, head injury).

Review possible causes of hypoglycaemia and need to adjust usual diabetes care

Once recovered give long acting carbohydrate

Notes for diagram B

¹ Glucagon can be given IM, and should work within 15-20 minutes. Dose is 0.5mg for younger children and 1.0mg over 5 years. If you suspect that the hypoglycaemia is due to alcohol consumption then glucagon will not work and IV dextrose is required.
² An IV bolus of 10% dextrose should be given at a dose of 5ml/kg until a response is seen. A child who is fitting/unconscious through hypoglycaemia will respond very quickly to IV dextrose. Once conscious it is essential to continue IV dextrose at a maintenance rate until oral carbohydrate is tolerated.
³ Two other groups where IV dextrose may need to be given are:
   • those with gastroenteritis where glucose malabsorption may occur
   • those children where insulin overdose has occurred.
Surgical Management of Children with Diabetes

All children with diabetes requiring a surgical procedure:

- Must be admitted to hospital for general anaesthesia
- Need insulin, even if fasting, to avoid ketoacidosis
- Should receive a glucose infusion when fasting before an anaesthetic to prevent hypoglycaemia
- Surgery on children and adolescents with diabetes should only be performed in centres with dedicated paediatric facilities for the care of young people with diabetes.
- To ensure the highest levels of safety, careful liaison is required between surgical, anaesthetic and children’s diabetes care teams before admission to hospital for elective surgery and as soon as possible after admission for emergency surgery.
**Low Risk Surgery**  
(Minor Procedure lasting <1 hour)

**Morning list**  
Late breakfast anticipated when wakes  
Child must be first on list

**Afternoon list**  
Child must be first on list

**Day before surgery**  
- Child to be assessed by paediatrician  
- Child to be seen by anaesthetist  
- Normal insulin the night before*  
- Adequate bedtime snack  
- No solid food from midnight

**Day of Surgery**  
- Omit morning insulin  
- Start IV maintenance 5%dextrose/0.45% saline one hour before operation (see table)

- Hourly BG monitoring pre-operatively  
- Half hourly BG monitoring peri-operatively  
- Hourly BG monitoring post-operatively for four hours  
- Aim to maintain BG > 5 mmol/l  
- Consider giving insulin SC or by infusion if hyperglycaemic (see sliding scale)

- If child becomes hypoglycaemic (BG less than 4 mmol/L) give 10% dextrose 5 ml/kg stat  
- Infuse 10% Dextrose at maintenance rate (see table)

- Give delayed morning SC insulin with late breakfast when child has woken up from anaesthetic and is ready to eat  
- If late in morning (eg after 11.30 am) consider skipping morning SC insulin and give only soluble insulin with lunch (consult re: dose)  
- If child is not tolerating oral intake post-operatively, follow protocol as per high risk surgery

- When child wakes up post-op they may have a late lunch (soluble insulin if they are on MDI or pump but no insulin if receiving bd biphasic regimens)  
- The amount of insulin will depend on normal insulin dose, appetite and blood glucose level.  
**Consult the Diabetes Team**  
- Normal insulin doses should be given with the evening meal  
- If child is not tolerating oral intake post-operatively, follow protocol as per high risk surgery.
High Risk Surgery
(Major Procedure lasting >1 hour and/or patient to be fasted post-op and/or risk of metabolic instability)

Morning list
- Diabetes well controlled
- Child must be first on list

Afternoon list
- Diabetes well controlled
- Child must be first on list

Day before surgery
- Child to be assessed by paediatrician
- Child to be seen by anaesthetist
- Normal insulin the night before*
- Adequate bedtime snack
- No solid food from midnight

Day of Surgery
- May have glucose containing clear fluids up to 2 hours pre-op
- Omit morning insulin
- Start IV maintenance 5%dextrose/0.45% saline two hours before operation (see table)
- Commence IV insulin infusion (see sliding scale)

- Hourly BG monitoring pre-operatively
- Half hourly BG monitoring peri-operatively
- Hourly BG monitoring post operatively for four hours
- Aim to maintain BG 5-12 mmol/l using dextrose infusion and sliding scale insulin

If ready to recommence insulin on day of operation:
a) If ready to eat by lunchtime give the following insulin:
   - Twice or three injection regimen: give ½ of usual morning insulin as a stat dose before lunch, then usual insulin that evening.
   - Multiple injection regimens: give usual short acting insulin. Give normal insulin thereafter.
b) If ready to eat by evening meal:
   - Usual insulin for all types of insulin regimens.

If not ready to recommence insulin for 24 hour after surgery:
a) If ready to eat at breakfast give the following insulin:
   - Twice or three injection regimen: give usual morning insulin.
   - Multiple injection regimens: give usual soluble insulin with half of the usual evening long acting insulin dose before breakfast (defer long acting insulin if given the night before) and continue thereafter with normal bolus insulin for meals and normal night time insulin.
b) If ready to eat by lunchtime give the following insulin:
   - Twice or three injection regimen: give ½ of usual morning insulin as a stat dose before lunch, then usual insulin that evening.
   - Multiple injection regimens: give usual short acting insulin and ¼ of usual night time long acting insulin prior to lunch. Give normal insulin thereafter.
c) If ready to eat by evening meal:
   - Usual insulin for all types of insulin regimens.

IV insulin should be discontinued 60 minutes (if using soluble or long acting insulin) or 10 minutes (if using Novorapid or Humalog) after the first insulin injection to avoid rebound hyperglycaemia.
Emergency Surgery

- Nil by mouth
- Secure IV access
- Check weight, BG, U&Es, creatinine, blood gases and urine for ketones

- If ketoacidosis is present, follow protocol for DKA
- Delay surgery until circulating volume and electrolyte deficits are corrected
- If there is no ketoacidosis, start IV fluid and insulin infusions as for major elective surgery

*Notes for children on multiple injection regime:
- For low risk surgery morning list
  - Follow guideline above, giving usual insulin the night before surgery. If long acting insulin (e.g. Lantus, Levemir) is usually given in the morning then this should be given on the morning of surgery but the soluble insulin (Novorapid, Humalog) usually given with breakfast should be omitted.
- For low risk surgery afternoon list
  - Follow guideline above, giving usual insulin the night before surgery. If long acting insulin (e.g. Lantus, Levemir) is usually given in the morning then this should be given on the morning of surgery and usual soluble insulin (Novorapid, Humalog) given with early breakfast.
- For high risk surgery morning list
  - Follow guideline above, giving usual insulin the night before surgery. If long acting insulin (e.g. Lantus, Levemir) is usually given in the morning then this should be given on the morning of surgery but soluble breakfast time insulin should be omitted.
- For high risk surgery afternoon list
  - Follow guideline above, giving usual insulin the night before surgery. If long acting insulin (e.g. Lantus, Levemir) is usually given in the morning then this should be given on the morning of surgery and usual soluble insulin should be given with early breakfast.
Guide to sliding scale insulin:
Add soluble insulin 50 units to 50 mls 0.9% saline, making a solution of 1 unit/ml:
attach to syringe pump and clearly label. Infuse according to sliding scale.

<table>
<thead>
<tr>
<th>Blood glucose (mmol/l)</th>
<th>Insulin infusion (units/kg/hour)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 17.1</td>
<td>0.10</td>
</tr>
<tr>
<td>12.1-17</td>
<td>0.075</td>
</tr>
<tr>
<td>7.1-12</td>
<td>0.050</td>
</tr>
<tr>
<td>4.1-7</td>
<td>0.025</td>
</tr>
<tr>
<td>≤ 4</td>
<td>0.025 and change to 10% dextrose + 0.45% saline</td>
</tr>
</tbody>
</table>

Guide to fluids
• Dextrose 5%/0.45% saline (consider 10% dextrose if difficulty maintaining normal blood sugars.
• If infusion is required for more than 12 hours, add KCl 20mmol/l and monitor electrolytes.
• Calculation of fluid requirement:
  • First 10kg → 100mls/kg
  • Second 10kg → 50mls/kg
  • Subsequent kg → 20mls/kg (max 2000mls female, 2500mls male)
Members of the Consensus Group

The following took part in the guideline meeting held in Carmarthen 2\textsuperscript{nd} November 2005.

John Barton  
Phil Davies  
Julie Haycox  
Malachy O'Hagan  
Sally Wright  
Lynne Miller-Jones  
Kathryn Singleton  
Lesley Lowes  
Kath Wooding  
Nick Owen  
Gill Regan  
Justin Warner  
Wendy Gane  
Geraldine Phillips  
Dr Appana  
Jessica Sheppard  
Leanne Pritchard  
Rachel Harris  
Karen Thomas  
Sue Channon  
Grace Parfitt  
Rachel Taylor  
Ellie Sherwood  
Jackie Dent  
John Gregory  
Dewi Evans  
Liz Addicott  
Yvonne Davies  
Karen Archer  
Davida Hawkes  
Jane Bramwell  
Diane Deeley  
Suzanne Hackling

The following took part in the guideline meeting held in North Wales

Medi Michael  
Jayne Thomas  
Peter Stutchfield  
Geraint Owen  
Michael Cronin
References/Useful websites etc to be included in Paediatric Consensus Guidelines

References


International Society for Pediatric and Adolescent Diabetes [ISPAD] (2000) ISPAD Consensus Guidelines for the Management of Type 1 Diabetes Mellitus in Children and Adolescents. ISPAD. Available at: http://www.d4pro.com/diabetesguidelines/ Last accessed 16/2/07


Useful Websites

Diabetes UK
http://www.diabetes.org.uk/

International Society for Pediatric and Adolescent Diabetes
http://www.ispad.org/

National Institute for Clinical Excellence
http://www.nice.org.uk