DIABETES IN CHILDREN AND ADOLESCENTS

BASIC TRAINING MANUAL FOR HEALTHCARE PROFESSIONALS IN DEVELOPING COUNTRIES

DIAGNOSING DIABETES IN CHILDREN
TREATING DIABETES
TALKING TO PATIENTS ABOUT DIABETES
ORGANISATION OF DIABETES CARE

Developed in collaboration with the International Society for Pediatric and Adolescent Diabetes (ISPAD), 1st edition 2010

Treating diabetes in children is different from treating diabetes in adults

From the outset, the partners behind the Changing Diabetes® in Children (CDiC) programme acknowledged that it is necessary to build the capacity of healthcare professionals in developing countries, in order to improve the health outcomes of children with diabetes.

In September 2009, a workshop was held in Zanzibar with key stakeholders from the African countries involved in the CDiC programme, experts from the International Society for Pediatric and Adolescent Diabetes (ISPAD) and other specialists. The purpose was to reach consensus on the contents of a reference manual for healthcare professionals dealing with children and adolescents with diabetes in developing countries.

Based on the outcome of the workshop, a small writing group consisting of three ISPAD experts produced the first draft of a training manual, which was tested at a pilot training workshop in Kampala, Uganda in March 2010. The workshop, which was attended by healthcare professionals from Uganda and Tanzania, was used to assess the relevance and accessibility of selected parts of the material.

This is the first edition of the published book. It is our hope that it will be of great use to all healthcare professionals working with children and adolescents with diabetes in developing countries. We foresee that the feedback received from the users will help us to identify any gaps or needs for adjustment.

In addition to the hard copies distributed, the manual can be downloaded free of charge, for all who find it useful, at:

www.changingdiabetesaccess.com

Novo Nordisk, Denmark
October 2010

DIABETES
IN CHILDREN AND ADOLESCENTS

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INTRODUCTION

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I.1 PREFACE

Diabetes is a killer disease in many parts of the world, especially when it strikes in childhood or adolescence. This is because of its relative rarity, so that parents and family members do not recognise its subtle beginning symptoms (new onset enuresis, excess thirst, excess urination during the day and the night, and unexplained weight loss). Similarly, healthcare workers at all levels of sophistication, from triage workers to emergency room physicians, fail to ask questions about diabetes in developing countries where problems such as AIDS, malaria, pneumonia, sepsis or overwhelming gastrointestinal infection occur more commonly. In the more developed parts of the world, the same phenomenon occurs – the list of assumed diagnoses often still does not include diabetes.

If all emergency medical personnel were trained specifically always to ask about thirst and urination, enuresis or even if there were ants near the toilet, missed diagnoses could be decreased and deaths from diabetic ketoacidosis, cerebral oedema and coma would similarly decrease dramatically. Simple poster campaigns that highlight such facts in diagrams help save children's lives without any need for reading literacy.

This manual is sponsored by Novo Nordisk's Changing Diabetes® in Children (CDiC) programme (which is co-sponsored by Roche) and produced in collaboration with ISPAD, the International Society for Pediatric and Adolescent Diabetes. It is produced with the hope that it will bring some basic knowledge to many parts of the world about paediatric and adolescent diabetes, insulin, diabetic ketoacidosis and hypoglycaemia emergencies. It will be translated into different languages and will serve as the basis for further education and organisational efforts. Through its projects, CDiC will provide not only insulin and blood glucose monitoring facilities, but improvement in multidisciplinary paediatric and adolescent diabetes team care, benchmarking and quality assurance.

Cooperation with the International Diabetes Federation and other NGOs working to create a better world for children with diabetes will further enhance this manual and the CDiC initiative. The present manual complements the evidence-based ISPAD Clinical Practice Recommendations, which are updated regularly (www.ispad.org). A more detailed manual for providing further information about the specialised paediatric and adolescent diabetes centres that will be part of the CDiC collaborative effort, is foreseen. CDiC and ISPAD's mutual goal of improving the care for the child and adolescent with diabetes in developing countries demands that awareness and specialised knowledge are combined. The amazing achievement of a United Nations Resolution on Diabetes in 2007 emphasises the key concepts listed in ISPAD's Declaration of Kos; both reproduced below. As the CDiC country projects are initiated, grow, mature and become self-sustaining, more children will live, instead of dying with diabetes, all around the world.

Stuart J. Brink, MD
Immediate Past President, ISPAD and
ISPAD International Education Liaison Chair

Ragnar Hanås, MD
Secretary General, ISPAD

Thomas Danne, MD
ISPAD President

I.2 CONVENTION ON THE RIGHTS OF THE CHILD – EXTRACT

Convention on the Rights of the Child
Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989
entry into force 2 September 1990, in accordance with article 49

Extract

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

a. To diminish infant and child mortality;
b. To ensure the provision of necessary medical assistance and health care to all children with
c. emphasis on the development of primary health care;
d. To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
e. To ensure appropriate pre-natal and post-natal health care for mothers;
f. To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
g. To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

I.3 ISPAD DECLARATION OF KOS

International Study Group of Diabetes in Children and Adolescents **ISGD** Groupe International d'Etude du Diabète de l'Enfant et de l'Adolescent

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ISPAD DECLARATION OF KOS

On September Fourth, Nineteen Hundred and Ninety Three, on the island of Kos, the members of the International Study Group of Diabetes in Children and Adolescents (ISGD), assembled at our nineteenth annual international scientific meeting and in the process of transforming ISGD into the **International Society of Pediatric and Adolescent Diabetes (ISPAD)**, renew their Hippocratic Oath by proclaiming their commitment to implement the St Vincent Declaration to promote optimal health, social welfare and quality of life for all children and adolescents with diabetes around the world by the year 2000. We take this unique opportunity to reaffirm the commitments by diabetes specialists in the past and, in particular, unanimously pledge to work towards the following:

1. to make insulin available for all children and adolescents with diabetes

2. to reduce the morbidity and mortality rate of acute metabolic complications or missed diagnosis related to diabetes mellitus

3. to make age-appropriate care and education accessible to all children and adolescents with diabetes as well as to their families

4. to increase the availability of appropriate urine and blood self-monitoring equipment for all children and adolescents with diabetes

5. to develop and encourage research on diabetes in children and adolescents around the world

6. to prepare and disseminate written guidelines and standards for practical and realistic insulin treatment, monitoring, nutrition, psychosocial care and education of young patients with diabetes - and their families - emphasizing the crucial role of health care professionals - and not just physicians - in these tasks around the world.

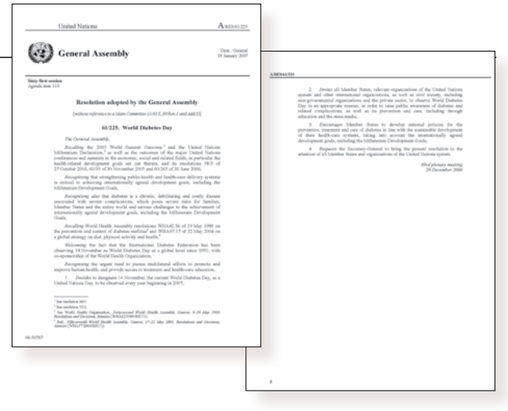
Signed:
Bruno Weber, MD
President, ISGD

Stuart Brink, MD
Secretary-General, ISGD/ISPAD

Witnessed:
Christos Bartsocas, MD
XIXth ISGD Convener

Kirsten Staehr-Johansen, MD
WHO Regional Adviser

I.4 UN RESOLUTION ON DIABETES


United Nations A/RES/61/225

General Assembly

Distr.: General
10 January 2007

Sixty-first session
Agenda item 113

Resolution adopted by the General Assembly

[without reference to a Main Committee (A/61/L.39/Rev.1 and Add.1)]

61/225. World Diabetes Day

The General Assembly,

Recalling the 2005 World Summit Outcome[1] and the United Nations Millennium Declaration,[2] as well as the outcomes of the major United Nations conferences and summits in the economic, social and related fields, in particular the health-related development goals set out therein, and its resolutions 58/3 of 27 October 2003, 60/35 of 30 November 2005 and 60/265 of 30 June 2006,

Recognizing that strengthening public-health and health-care delivery systems is critical to achieving internationally agreed development goals including the Millennium Development Goals,

Recognizing also that diabetes is a chronic, debilitating and costly disease associated with severe complications, which poses severe risks for families, Member States and the entire world and serious challenges to the achievement of internationally agreed development goals, including the Millennium Development Goals,

Recalling World Health Assembly resolutions WHA42.36 of 19 May 1989 on the prevention and control of diabetes mellitus[3] and WHA57.17 of 22 May 2004 on a global strategy on diet, physical activity and health,[4]

Welcoming the fact that the International Diabetes Federation has been observing 14 November as World Diabetes Day at a global level since 1991, with co-sponsorship of the World Health Organization,

Recognizing the urgent need to pursue multilateral efforts to promote and improve human health, and provide access to treatment and health-care education,

1. *Decides* to designate 14 November, the current World Diabetes Day, as a United Nations Day, to be observed every year beginning in 2007;

2. *Invites* all Member States, relevant organizations of the United Nations system and other international organizations, as well as civil society including non-governmental organizations and the private sector, to observe World Diabetes Day in an appropriate manner, in order to raise public awareness of diabetes and related complications as well as on its prevention and care, including through education and the mass media;

3. *Encourages* Member States to develop national policies for the prevention, treatment and care of diabetes in line with the sustainable development of their health-care systems, taking into account the internationally agreed development goals including the Millennium Development Goals;

4. *Requests* the Secretary-General to bring the present resolution to the attention of all Member States and organizations of the United Nations system.

83rd plenary meeting
20 December 2006

[1] See resolution 60/1.

[2] See resolution 55/2.

[3] See World Health Organization, Forty-second World Health Assembly, Geneva 8-19 May 1989, Resolutions and Decisions, Annexes (WHA42/1989/REC/1).

[4] Ibid., Fifty-seventh World Health Assembly, Geneva, 17-22 May 2004, Resolutions and Decisions, Annexes (WHA57/2004/REC/1)

I.5 WHY IS A DIABETES PROGRAMME FOR CHILDREN AND ADOLESCENTS NECESSARY?

EARLY DIAGNOSIS AND TREATMENT ARE CRUCIAL

The only effective treatment for type 1 diabetes is insulin, administered by injection. If the diagnosis or treatment is delayed, the severe lack of insulin results in diabetic ketoacidosis (DKA), and death can occur in days. It has been demonstrated in developed countries that if properly treated, the prognosis is excellent and children with type 1 diabetes can grow up to be productive, fertile and long-lived adults. It is therefore essential that childhood diabetes is rapidly recognised by frontline medical staff, so that the child can be referred quickly and treatment started by trained healthcare professionals.

CHILDHOOD AND ADOLESCENT DIABETES IS DIFFERENT FROM ADULT DIABETES

Children's insulin requirements change frequently, due to growth in size, puberty and the demands of school, sport and work. Insulin dosage is based on weight and insulin sensitivity. As children grow rapidly during childhood, their insulin doses need to be adjusted at each clinic visit; every few months at least. During the pubertal growth spurt, insulin requirements can increase rapidly, and then decrease back to normal adult levels as growth is completed. Children with diabetes and their families need constant re-education as the child becomes older and more able to understand and develop diabetes self-care skills.

CHILDHOOD DIABETES IS A COMPLEX ILLNESS

Long-term complications of hyperlipidemia, hypertension, diabetic renal disease, diabetic retinopathy and neuropathy can begin in childhood. These need to be looked for through a screening protocol for diabetes complications that uses age- and sex-specific standards for diagnosis; then treated aggressively. Treating a child with diabetes requires more effort than treating an adult with diabetes, and a multidisciplinary team approach is essential. Where manpower is limited, team members may have to take on more than one role, but the task must still be done.

CHILDHOOD DIABETES NEEDS A GOOD SUPPORT SYSTEM

The patient, parents, friends, neighbours, school and healthcare workers must all be working together as a team to provide the child with practical, emotional and moral support where needed.

This manual has been prepared in order to help frontline healthcare professionals to improve the diagnosis, treatment and quality of life of children with diabetes.

PART 1

DIAGNOSING DIABETES IN CHILDREN

PART 1 CONTENTS

SECTION 1
SUSPECTING THE DIAGNOSIS

Take care not to miss the diagnosis of diabetes in children

SECTION 1 CONTENTS

1.1 THE HISTORY OF DIABETES

OBJECTIVE:

- Understand the history of diabetes and the discovery of insulin

A FEW THOUGHTS TO START WITH:

- Who discovered the link between diabetes and the pancreas?
- When was insulin discovered?

DIABETES WAS NOT UNDERSTOOD FOR CENTURIES

Diabetes was first described more than 3,500 years ago in ancient Egypt as 'very abundant urine'. A report from Turkey some 2,000 years ago describes the extreme thirst and profuse urination of people with diabetes. Although the sweetness of the urine had been mentioned in earlier reports, it was not until 200 years ago that Chevreul in England developed a specific test to measure the concentration of sugar in the urine and provide the positive proof of glycosuria.

Later in the nineteenth century, the Frenchman Bouchardat published a work on 'the hygienic treatment of diabetes mellitus', linking the condition with overeating. The value of Bouchardat's treatment was confirmed during the siege of Paris in 1870, where it was confirmed that food deprivation endured by the Parisians resulted in a definite improvement in the condition of people with (most likely type 2) diabetes. Nevertheless, after several thousand years of observation, diabetes remained a disease for which neither the cause nor the mechanism was known until the 20th century.

THE DISCOVERIES OF THE 20TH CENTURY

Paul Langerhans showed in 1869 that the pancreas contained other cells of unknown function (to which he gave his name) in addition to those secreting the pancreatic juice. Minkowski from Strasbourg University showed that the islets of Langerhans are involved in the pathogenesis of diabetes mellitus, by inducing diabetes mellitus in the dog by removal of the pancreas. In 1900, Stobolev in Russia and Opie in the USA confirmed that diabetes mellitus occurs as a result of destruction of the islets of Langerhans.

Later research in Toronto by Banting, Best, Macleod and Collip successfully treated diabetic dogs with pancreatic extracts. The first human to be treated with pancreatic extract was Leonard Thompson in 1922. His spectacular recovery resulted in the Nobel Prize for Banting and Macleod in 1923, which they shared with their co-researchers. At the University of Toronto, Best had refused to give exclusive rights to a single laboratory to make insulin. The Laboratories of Ely Lilly in the United States, Novo Nordisk in Denmark, Hoechst in Germany and Endopancrine in France launched the first production, starting in 1930. NPH insulin (neutral protamine Hagedorn) was developed in 1946 by Hans Christian Hagedorn of the Nordisk laboratories.

During the next few decades researchers developed insulin designed to improve blood sugar control, appropriate for daily treatment, with few adverse effects. After first producing pure insulin from cows or pigs, the next advance was to transform animal insulin into 'human' insulin by substituting one amino acid. From 1979, genetic engineering became the preferred route for making insulin rather than using animal extracts; using bacteria and later yeast. A third advance was to modify the activity profile of human insulin, to enable either more rapid uptake, or slow uptake over 24 hours.

People with diabetes in the developed parts of the world or developed countries no longer die because of unavailability of insulin, but in certain regions of the world it is still a real problem.

TO REMEMBER:

1: Diabetes has been described since antiquity in all the continents

2: Insulin, available only for the past 80 years, saves lives

3: Today insulin is available in a range of products, each one suitable for a specific purpose.

1.2 PHYSIOLOGY AND CLINICAL SIGNS OF DIABETES

OBJECTIVE:

- Understand the physiology of diabetes and the clinical signs for an early diagnosis

A FEW THOUGHTS TO START WITH:

- How does diabetes in children and adolescents develop?
- Why should children and adolescents with diabetes be treated differently from most adults with diabetes?
- Why can children and adolescents with diabetes become so ill, and sometimes die?

DIABETES – THE DISEASE

Diabetes mellitus (usually known just as diabetes) is the name given to a group of disorders characterised by chronically high blood glucose levels.

Glucose in the blood comes from food and from stores in the body, including the liver, muscle and fat. Blood glucose is the main source of energy for the cells, tissues and organs of the body. For the different cells, tissues and organs to use this glucose, the glucose has to move from the blood into the cells.

The hormone insulin is required for glucose to move into the cells. Insulin is produced by the beta cells (ß-cells) in the pancreas. Diabetes occurs either when the pancreas does not produce enough insulin, or the effect of insulin is decreased.

TYPE 1 DIABETES

Type 1 diabetes is the commonest type of diabetes in childhood and adolescence. Most cases of type 1 diabetes are due to destruction of the pancreatic ß-cells by T-cells (white blood cells concerned with the immune system). This is a type of autoimmune destruction, meaning that the body attacks part of itself. The ß-cells are destroyed at a variable rate, and clinical symptoms of type 1 diabetes occur when ~90% of cells have been destroyed.

In type 1 diabetes, the pancreas is damaged and cannot produce sufficient insulin. Because there is not enough insulin, glucose in the blood is unable to move into the cells, and the blood glucose level rises while the cells lack glucose to produce energy. When the cells lack energy, the person with diabetes feels tired and **lethargic** (not wanting to work or play).

The kidneys normally reabsorb and recycle glucose as the blood is being filtered through the kidney glomeruli and tubules. However, when blood glucose levels are too high (>10 mmol/l) the kidneys cannot retain all the glucose, which starts to appear in the urine.

More water and electrolytes (such as sodium and potassium) are excreted in the urine. As a result the child or adolescent passes more urine than normal (**polyuria**) both during the day and night (**nocturia**). Older children may start bedwetting. This results in **dehydration** and the child or adolescent responds by drinking excessively (**polydypsia**) to maintain hydration. Enuresis may also occur and may be a great clue towards thinking about diabetes as a possible diagnosis.

The lack of energy in the cells results in the breakdown of stores of glucose in the liver, muscle and fat. This causes **weight loss**, so children and adolescents who present with type 1 diabetes are usually thin and dehydrated. With progressive insulin deficiency, these children and adolescents often present within weeks or months of the onset of the early symptoms.

A further effect of the breakdown of fat is the production of **ketones** and their appearance in the blood and urine. This is diabetic ketoacidosis (DKA), and if it is not treated, it can lead to coma and death. Ketones may cause a sweet smell on the breath, vomiting, abdominal pain and rapid or acidotic breathing. Later the child will become drowsy and have an altered level of consciousness.

TYPE 2 DIABETES

Type 2 diabetes is usually seen in older people. Unlike type 1 diabetes, type 2 diabetes usually starts with increased amounts of insulin being produced, but the person is resistant to the effects of insulin. This insulin resistance may be present for many years before the onset of type 2 diabetes. Insulin resistance often goes hand-in-hand with obesity. Even with the onset of type 2 diabetes, many people do not have dramatic symptoms compared to those with type 1 diabetes. Type 2 diabetes can often be treated by lifestyle changes (such as losing weight and increasing exercise) and medication. In type 2 diabetes, oral medications like metformin are often used as first line treatment, but sometimes insulin secretion falls to such an extent that insulin therapy is indicated for treatment. New research suggests that this actually may be inevitable and also rather frequent over time.

In recent years, type 2 diabetes has been increasingly found among children and adolescents, in association with increasing early obesity and in those who have a family history of type 2 diabetes, or whose mothers had diabetes in pregnancy. Type 2 diabetes is closely associated with the **metabolic syndrome**. This syndrome includes:

- Excessive abdominal fat
- Hypertension
- Abnormal lipid levels
- Abnormal blood glucose levels
- Acanthosis nigricans
- Early but otherwise normal puberty

OTHER TYPES OF DIABETES

Diabetes associated with malnutrition has also been well described. This group of diabetes includes fibro-calculous pancreatic diabetes.

Infants aged under 6 months may also develop a specific form of diabetes termed neonatal diabetes. This is relatively rare, and due to specific gene defects. Neonatal diabetes may be transient or permanent. Many cases of neonatal diabetes were previously assumed to require insulin but, in fact, with modern genetic testing, such children even many years later can be successfully – and better – treated with sulfonylurea oral tablets instead of insulin.

Maturity-onset diabetes of the young (MODY) is a group of types of diabetes due to single gene defects causing defects in insulin secretion. Children with MODY tend to have little insulin resistance, and no ketones in urine. They present before 25 years of age, and have a history of 3 or more affected generations. Some may not need treatment with insulin, or can be treated with oral agents, but all need some dietary modifications.

Gestational diabetes occurs during pregnancy, so may occur in older adolescents as well as adults. Gestational diabetes increases the risk of large baby syndrome (making Caesarian delivery more likely). It also increases the risk of malformation or stillbirth, and both mother and baby are more likely to develop type 2 diabetes later in life.

TO REMEMBER:

1: Glucose is the main source of energy for the organs

2: Insulin is a hormone produced by the pancreas, required to move the glucose from the blood into the cells within the body's organs

3: When the pancreas does not produce enough (or any) insulin, the glucose stays in the blood (hyperglycaemia). Diabetes is a chronic elevation of blood glucose

4: The early symptoms of diabetes are:
- Thirst
- Frequent urination
- Bedwetting
- Lethargy

5: The physical signs of diabetes include:
- Weight loss / thin child
- Dehydration
- Rapid / acidotic breathing
- Blurring of vision
- Altered level of consciousness.

DO NOT MISS THE SIGNS OF DIABETES IN CHILDREN

Exhibit posters in the clinic and waiting areas/toilets

CASE STUDIES

Diabetes is easy to miss from its early symptoms, most of which are not dramatic and can be similar to those of other conditions. It can be helpful to consider:

How often do I see these patient profiles:

A. a child with frequent urination or bedwetting?
B. a breathless child?
C. an unconscious child?
D. a tired child with recent weight loss, drinking more water than usual?

Do I usually suspect diabetes?

Here are some typical cases of diabetes which could present at your clinic.

CASE 1: THE CHILD COMPLAINING ABOUT FREQUENT URINATION

The child has excessive frequency of passing urine and has to seek permission from the teacher in the class to leave the lessons and go to the wash room.

The various possible diagnoses are:

- Urinary tract infection
- Excessive water drinking
- Diabetes mellitus

Differential diagnosis	Pain on urination	Smelly urine	Fever	Urine dipstick shows protein+ /blood+	Ants attracted to the urine	Blood glucose high	Urine dipstick shows glucose present
Urinary tract infecton	Yes	Yes	Likely yes	Likely yes	No	No	No
Excessive water drinking	No	No	No	No	No	No	No
Diabetes mellitus	**No**	**No**	**Maybe**	**No**	**Yes**	**Yes**	**Yes**

The appearance of frequent urination or reappearance of bedwetting in a child should always make you think of diabetes.

If a blood glucose meter or urine dipstick is not available, put a sample of the urine near where ants can be found. If they are attracted to the urine, diabetes is the most likely diagnosis.

CASE 2: THE ILL AND BREATHLESS CHILD

The child is taken to the hospital emergency room feeling tired, breathless and with excessive thirst. The initial diagnosis is that of severe falciparum malaria, or differential of bronchopneumonia, or HIV/AIDS – Pneumocystis Carinii Pneumonia (PCP).

These are the possible diagnoses:

- Falciparum malaria
- Bronchopneumonia
- HIV/AIDS – PCP
- Diabetic ketoacidosis

Differential diagnosis	Rapid breathing	Lung signs eg creps, decreased air entry	Pallor	High blood glucose/ urine glucose /ants near urine	Excessive thirst	Sweet smelling breath (apples/ acetone)
Falciparum malaria	Yes	No	Yes	No	No	No
Broncho-pneumonia	Yes	Yes	No	No	No	No
Diabetes mellitus	Yes	No	Yes	Yes	Yes	No
Diabetic ketoacidosis	**Yes**	**No**	**No**	**Yes**	**Yes**	**Yes**

Think 'diabetes' when:

- a breathless child presents with polyuria
- there are ants near the urine

CASE 3: THE UNCONCIOUS CHILD

A child is brought unconscious into the hospital emergency room. The child is vomiting, dehydrated, but has no fever.

The differential diagnoses are:

- Cerebral malaria
- Meningitis
- Encephalitis
- Diabetic ketoacidosis
- Head injury

Differential diagnosis	History of trauma	Neck stiffness	Blood filmfor malaria	Ketonaemia ketonuria	Blood glucose	Sweet smelling breath (apples / acetone)
Cerebral malaria	No	+/-	Positive	+/-	Normal – low	No
Meningitis	No	Yes	Negative	+/-	Normal – low	No
Encephalitis	No	+/-	Negative	+/-	Normal – low	No
Diabetic ketoacidosis	**No**	**No**	**Negative**	**Yes**	**High**	**Yes**
Head injury	Yes	+/-	Negative	No	Normal – low	No

TO REMEMBER:

Always suspect diabetes when faced with a child who shows any of the following symptoms – if the child:

- is excessively thirsty or hungry
- is urinating excessively day and night
- is producing urine that attracts ants
- is bedwetting
- is tired and lethargic
- is losing weight
- carries a sweet smell of apples or acetone on his breath
- is unconscious, vomiting or dehydrated.

Do not miss the diagnosis

1.3 BABIES AND YOUNG CHILDREN

OBJECTIVE:

- Recognise how diabetes may present in young children or babies, in order to make the diagnosis and prevent coma or death

A FEW THOUGHTS TO START WITH:

- What symptoms will be shown by a child developing diabetes who comes to the clinic?
- Who might be the first medical contact with the child, who could identify the possibility of diabetes?

RECOGNISING DIABETES IN BABIES AND YOUNG CHILDREN

A family history of diabetes is not common, so parents are unlikely to recognise it. They may decide to go to the medical centre because:

- The child is passing more urine than usual – more often and in greater amounts
- The child is more thirsty than usual and may be eating or drinking more, but is not gaining weight or is losing weight
- The child may start bedwetting again after having learned to control the bladder (secondary enuresis)
- The child appears to be ill or less active and alert than usual.

The child may or may not have a fever, as diabetes may appear when the child has another illness (like a virus). There may be a fungal rash in the diaper (nappy) area (a Monilia or yeast infection).

If not picked up early, diabetes can progress to the child appearing breathless and losing consciousness (this is Kussmaul's respiration and diabetic ketoacidosis (DKA)).

When there is insufficient insulin in the body, glucose from food cannot enter the body's cells, and the cells use ketones derived from fat as an alternative source of energy.

If blood ketone levels are high, ketones will appear in the urine. As young children get sick more often than older children, remember to test the urine for ketones during any illness.

TO REMEMBER :

1: Type 1 diabetes in young children and babies may be missed at first because:
- **a:** Diabetes is uncommon
- **b:** The increased urine output and thirst may not be recognised
- **c:** Diabetic ketoacidosis may be mistaken for other illnesses, eg gastroenteritis, malaria & HIV.

2: The symptoms may have been there for days or weeks, but the diagnosis could still be missed. If diagnosis is delayed, diabetic ketoacidosis, severe dehydration, coma and death may occur.

3: Do a urine glucose and ketones test, and a blood glucose test if available, on any child who is bed-wetting and looks ill or not well.

1.4 SCHOOL-AGE CHILDREN

OBJECTIVE:

- Be familiar with the symptoms of diabetes and the questions to ask in making a diagnosis

A THOUGHT TO START WITH:

- Are parents or teachers aware of diabetes symptoms?

RECOGNISING DIABETES IN SCHOOL-AGE CHILDREN

Type 1 diabetes in school-age children is not common enough to be in the minds of parents or healthcare providers. It is frequently missed as a possible diagnosis, resulting in increased morbidity and mortality in many parts of the world.

Most children have had classical symptoms of hyperglycaemia for days or weeks, including polyuria, polydipsia, nocturia and even enuresis with unexplained weight loss, before diabetes is finally diagnosed. Teacher awareness holds the possibility of significantly earlier diagnosis, particularly if a teacher recognises excessive need for use of bathroom facilities in one of the students.

Severe dehydration and death could be prevented if the diagnosis was made earlier and if parents and healthcare workers were more aware of the possibility of diabetes (see IDF poster, Chapter 1.2).

Misdiagnosis as pneumonia, respiratory and gastrointestinal illnesses, AIDS or malaria is all too common, but a simple urinalysis for glucose and ketones, or a simple blood glucose test, can confirm the diagnosis of diabetes.

However, even if the possibility of diabetes has been considered, there are situations in which urinalysis and blood glucose testing are simply not available without a high index of suspicion (i.e. unexplained new enuresis). Questions concerning urination and weight loss should be routinely asked by any healthcare worker or triage system.

While type 1 diabetes is considered to have a genetic predisposition, in the vast majority of families it occurs as a random event, so a negative family history of diabetes does not exclude the diagnosis. Antibody tests are expensive and not necessary for confirming type 1 diabetes, except in a research setting.

TO REMEMBER:

1: Questions about urination and weight loss should be routinely asked by any healthcare worker or triage system.

2: A negative family history of diabetes does not exclude a child from having it.

1.5 OBESITY AND DIABETES IN YOUNG PEOPLE

OBJECTIVE:

- Understand the impact of obesity and type 2 diabetes on adolescents and young people

A FEW THOUGHTS TO START WITH:

- Are children and young people in developing countries at risk of type 2 diabetes?
- Exactly who is at risk?

THE LINK BETWEEN OBESITY, METABOLIC SYNDROME AND DIABETES

It is important that children and young people avoid becoming obese, as this makes it increasingly likely that they will go on to develop impaired glucose tolerance and eventually type 2 diabetes.

People with obesity, or impaired glucose tolerance, or type 2 diabetes often have some or all of the components of the metabolic syndrome. This condition affects 12% of adults and 10% of adolescents aged 12-19 years in the USA, and is not uncommon even in developing countries. The risk of type 2 diabetes is different for various ethnic populations: in the US, the risk is much higher for native Americans and African Americans. In all countries, children and adolescents are becoming more overweight and more obese at an increasingly early age, increasing the associated risk of developing metabolic syndrome or type 2 diabetes.

The term 'metabolic syndrome' has a number of slightly varying definitions but it refers to a number of conditions which, if presenting together in one individual, predict a greater likelihood of that individual developing diabetes or cardiovascular disease than if only one of them were present.

The basic components of the metabolic syndrome include:

- Excessive abdominal fat
  (measured as waist circumference)
- Hypertension
- Abnormal lipid levels
- Abnormal blood glucose levels
- Acanthosis nigricans.

The International Diabetes Federation (IDF) now defines metabolic syndrome as people showing central (abdominal) obesity plus any two of the following four factors:

- Raised triglycerides level
  or treatment for raised triglyceride (TG)
- Rreduced high density lipoprotein (HDL) cholesterol
  or treatment for low HDL
- Raised blood pressure
  or treatment of hypertension
- Raised fasting plasma glucose
  or previously diagnosed type 2 DM

The components of the metabolic syndrome also occur in younger children, and a BMI over the 90th centile is used rather than waist circumference as an indicator of abdominal obesity for those under 16 years. Abnormal levels for lipids for those under 10 years are better defined in relation to age- and sex-adjusted norms; some are available from European and American studies.

Because abdominal fat deposition patterns vary with ethnic group, and between males and females, specific cut-off points for waist circumference are used for different population groups. Waist circumference is not so easily adapted for children and adolescents because of the changes that also occur with growth compared to adult populations. Visual evaluation of 'belly fat', however, may still be important as part of the physical examination in childhood and adolescence.

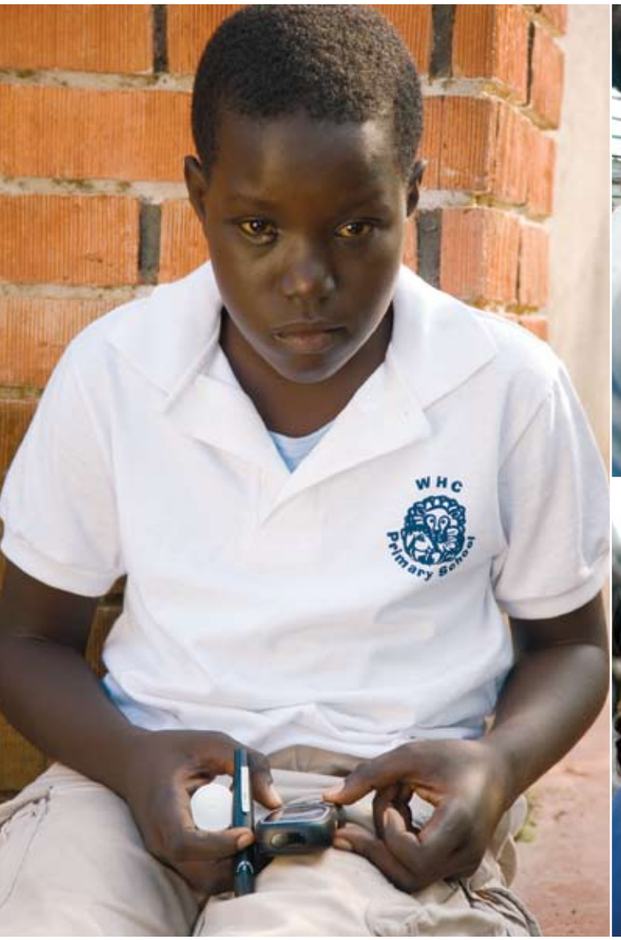
While the cause of metabolic syndrome is complex and not well understood, central obesity and insulin resistance are important factors in its development. Often there is a significant history of others in the family, who are very overweight or obese perhaps even in several generations (parents, aunts and uncles, grandparents etc.).

Central (abdominal) obesity is independently associated with each of the other metabolic syndrome components. Insulin resistance is a key component of the metabolic syndrome, but is expensive and therefore difficult to measure in daily clinical practice, without specific research protocols – so is not required for diagnosis. Significant obesity, central distribution of the body fat and acanthosis nigricans may be surrogates for presumed insulin resistance.

TO REMEMBER:

1: Type 2 diabetes in obese children and adolescents is increasing worldwide in Africa, Latin America, Asia as well as in richer parts of the world.

2: Healthy lifestyle promotion is crucial for children and adolescents with a family history of diabetes.



Blood glucose monitoring requires tools, support and education

SECTION 2
CONFIRMING THE DIAGNOSIS

The tools to confirm the diagnosis

SECTION 2 CONTENTS

2.1 CRITERIA FOR DIAGNOSIS

OBJECTIVE:

- Understand the criteria for confirming a suspected diagnosis of diabetes

CRITERIA

When you suspect diabetes in a child or an adolescent, use the following criteria in order to confirm the diagnosis.

In standard care:
The usual symptoms are polyuria, polydipsia, blurring of vision, weight loss (often, but not always), with nocturia or enuresis in association with glycosuria and often ketonuria. A marked elevation of the blood glucose level confirms the diagnosis. The World Health Organization defines the criteria for the diagnosis of diabetes mellitus[1,2] as:

- Symptoms of diabetes plus casual or random plasma glucose concentration above or equal 11.1 mmol/l (200 mg/dl). 'Casual' is defined as that measured at any time of day, without regard to time since last meal

OR

- Fasting plasma glucose above or equal 7.0 mmol/l (126 mg/dl).

A THOUGHT TO START WITH:

- Is it essential to measure fasting blood glucose for a diagnosis of diabetes?

In basic care:
If blood glucose test strips are not available, consider the probability of diabetes if a urine glucose test shows a positive colour change.

The date of onset of type 1 diabetes is estimated as the date when symptoms were first noted. This is different from the actual confirmed diagnosis or the actual start date of insulin. Some children and adolescents are diagnosed with minimal symptoms while often days and weeks, occasionally months, of symptoms may predate confirmation, diagnosis and beginning treatment.

TO REMEMBER :

1: The diagnosis of diabetes should not be based on a single capillary blood test. Diagnosis requires laboratory glycaemia, fasting and/or 2-hour postprandial tests.

2: If ketones are present in urine or blood, treatment is urgent and the child or adolescent should have fluid and electrolyte treatment and insulin started without delay **the same day** to avoid the development of ketoacidosis (DKA).

3: In geographical areas where incidence of type 1 diabetes is low, there is a higher rate of diabetic ketoacidosis at presentation because the possibilitiy of diabetes has not been considered.

References:
1 World Health Organization. Definition, diagnosis and classification of diabetes mellitus and its complications: Report of a WHO consultation. Part 1: Diagnosis and Classification of Diabetes Mellitus 1999.

2 World Health Organization. Definition and diagnosis of diabetes mellitus and intermediate hyperglycaemia: report of a WHO / IDF consultation 2006. (2005 3379 /id;World Health Organisation 1999 3377 /id):

2.2 USING GLUCOSE METERS

OBJECTIVE:

- Understand how to use blood glucose meters, avoid common errors and take full account of safety procedures

A FEW THOUGHTS TO START WITH:

- Have I already tried to check my own blood glucose with a glucose meter?
- Is the glucose meter result lower than, equal to, or higher than the laboratory result?
- How many different models of glucose meters are used at the clinic?

WORKING WITH GLUCOSE METERS

The blood glucose meter is a portable medical device that measures the level of blood glucose in whole blood.

A small drop of blood, usually taken from a finger tip, is placed on a strip of plastic containing chemicals and electrodes. A chemical reaction between the glucose in the blood and the chemicals on the strip gives rise to an electrical current or colour change, which is then read by the meter as indicating the blood glucose level.

A blood glucose meter reading can be expressed as **mmol/l** or **mg/dl**. Sometimes the same meter can be set to read either **mmol/l** or **mg/dl**, but in some cases it is set in the factory and cannot be changed.

Converting readings from one unit to the other

1 mmol/l = 18 mg/dl
1 mg/dl = 0.55 mmol/l

(mmol/l reading multiplied by 18 equals mg/dl;
and mg/dl reading divided by 18 equals mmol/l)

Each strip is used once and discarded. Each meter uses a particular type of strip. Using strips from a different manufacturer from the one that produced the meter may result in misleading results.

Although generic test strips are available from third party manufacturers for some models, care must be taken to ensure that they are reliable and accurate, so this is generally considered unwise.

Blood glucose ranges

The **normal ranges** of blood glucose are:

Fasting blood glucose:
4-5.5 mmol/l **or** 72-100 mg/dl

Blood glucose 2 hours after a meal:
<7 mmol/l **or** <126 mg/dl

Hypoglycaemic blood glucose range is:
<3.3 mmol/l **or** 60 mg/dl.

Hyperglycaemic blood glucose is consistently > 7 mmol/l or >126 mg/dl.

Accuracy

Modern blood glucose meters are manufactured to standards set by the International Organization for Standardization (ISO). According to ISO 15197, blood glucose meters must provide results that are within 20% of a laboratory standard; 95% of the time.

Accuracy can be affected by the size and quality of the blood sample, the haematocrit, the age and quality of the test strips, whether the test strips have been exposed to excessive humidity, and the presence of high amounts of substances in the blood (eg vitamin C) that can interfere with the chemical reaction on the strip.

Coding and calibration

Some meters require to be coded for each new batch of test strips, because of batch-to-batch variations in the chemicals used. Instructions for coding will come on the packaging of each new container of test strips. Coding may require the entry of a set of numbers into the meter, or the use of a memory chip that comes with each new vial of strips. Not entering the correct coding may result in the meter being inaccurate by up to 4 mmol/l (72 mg/dl). Some meters are advertised as non-coding, which means that the coding information is usually automatically encoded onto the test strip itself so manual coding is not necessary.

Often patients forget to change codes. However, for quality control purposes, blood glucose meters in hospitals and clinics should be calibrated at set intervals; and such calibrations regularly and routinely documented in writing.

Serum glucose vs plasma glucose – are they the same?

Most hospital laboratories report the level of glucose in plasma (whole blood minus the red and white blood cells) and this level is 10-15% higher than the level of glucose **in serum** (whole blood minus the red and white blood cells, and the clotting agent fibrinogen).

Some meters will correct this figure to read the level of glucose in plasma. It is important to know whether the home blood glucose meter used is set to plasma or serum standards; most will show plasma glucose.

SAFETY

- **For your own safety, wash your hands and glove up**

- **Do not share or reuse lancets**
  HIV, hepatitis B and other pathogens can be spread by the lancet device. Change lancets with each capillary blood glucose test.

- **Dispose of lancets safely**
  Use a sharps box or a container with a tight-fitting lid. Remember that in many places, rubbish collectors and scavengers may be sorting the trash by hand.

- **Clean the lancing device**
  with alcohol or soap and water between patients. Note that the plastic cap of the lancing device can be contaminated with blood from the previous user.

TO REMEMBER :

1: Use the right glucose strips: check brand, coding and expiry date.
2: Check the units: are blood glucose units in mg/dl or mmol/l?
3: Check that the coding of the strips has been updated
4: Ensure that the correct technique is used
5: Ensure proper documentation

Always write down:
a: the time the blood test was done
b: the relation to food or snacks and time of the last medication given
c: how much food and drink was eaten and what type
d: how much insulin was given and what type of insulin
e: the type of activity before the test:
- was the patient resting, exercising or working?
- what was the intensity of that activity?

2.3 SUSPECTING DIABETES WITHOUT A GLUCOSE METER: URINE STRIPS

OBJECTIVE:

- Understand how to use urine strips to diagnose diabetes

A THOUGHT TO START WITH:

- Are urine strips available at the clinic?

USING URINE STRIPS IN THE DIAGNOSIS

The ideal way to confirm diagnosis is to have access to a laboratory/blood glucose test strips. Nevertheless, in many cases the diagnosis can be made with simple tools: the medical history of the child and family (there is a high index of suspicion if there is a strong family history of diabetes) plus a search for glycosuria and or ketonuria with urine strips.

The full data to be collected are:

Name:			
Address		**Telephone no.**	
Date of birth:	Gender (M/F):	Weight:	
Source/Referred by:		Centre:	
Date:	Time:		
Symptoms:			
Polyuria? (Y/N)	Polydypsia (Y/N)?	Nocturia (Y/N)?	Weight loss (Y/N)?
Nausea and vomiting (Y/N):		Abdominal pain (Y/N)	
Symptoms of infection:			
Past History:			
Birth weight:	Perinatal history:		
Admissions:			
Illnesses:			
HIV:		Malaria:	
Tuberculosis:			
Other illnesses:			
Family History:			

Name:	**Age:**	**Occupation:**	**Illnesses:**
Mother:			
Father:			
Siblings:			
Grandparents:			

A complete physical examination is necessary, looking for dehydration, abnormal growth and weight development.

Some urine strips on the market detect glucose only or ketone only. However, others have two sets of colour indicators on the same strip and detect both glucose and urine ketones.

Urine from a person without diabetes contains no glucose and no ketones, so the initial colour of the indicators will not change.

If a child or adolescent has diabetes, when the glycaemia is high (>180 mg/dl or >10mmol/l) the excess glucose is excreted in the urine and the glucose indicator on the urine strip used will change colour (compare the result with the panel on the strips box).

Both type 1 and type 2 diabetes can cause glucose in the urine. If the colour strip for ketones also changes colour, indicating that ketones are present in the urine, the child is very likely to have type 1 diabetes with ketonuria. However, the ketone indicator often remains negative if the glycaemia has not been very high for a long time.

When glucose indicators and ketone indicators on urine strips change colour, the diagnosis of diabetes is almost certain. The child is in danger of developing diabetic ketoacidosis (DKA), and insulin treatment must be started rapidly.

Resources:

Annex 1 – Form for recording medicacal history
Annex 2 – Testing urine for sugars

TO REMEMBER:

1: Urine strips are very simple to use, not expensive and very helpful to detect significant hyperglycaemia (>180 mg/dl) and any risk of DKA.

2 : Always read carefully the validation dates and the storage recommendations on the box before using, to avoid invalid results.

2.4 SUSPECTING DIABETES WITHOUT A GLUCOSE METER: ANTS

OBJECTIVE:

- Understand how to make use of ants to indicate a possible diagnosis of diabetes

A THOUGHT TO START WITH:

- If the mother is waiting anxiously for my diagnosis and I have no access to any technology, what can I do?

USING OBSERVATION TO HELP IN DIAGNOSIS

A child or adolescent who is losing weight, becoming tired, very hungry, very thirsty and passing a lot of urine may have diabetes.

Ideally, a blood glucose test should be done to look for a high blood glucose level, or a few drops of urine can be tested using Benedict's solution to test for reducing sugars. However, a glucose meter or laboratory facilities are not always available.

Urine from someone suspected of having diabetes will attract ants, but as blood, protein and glycogen can do the same, ants being attracted to the underwear of someone suspected of having diabetes may not be conclusive. But if a sample of urine is left in a place where ants are known to live, and the ants are attracted to the urine, it is highly likely that the person who passed the urine sample has the sweet urine of diabetes mellitus.

This observation led to the discovery of insulin. In the early 1920s, Charles Best, research assistant to Banting and Mecleod (see Chapter 1.1), noted that ants were attracted to the urine of the dogs from which the pancreas had been removed. The urine had high blood sugar levels. It followed that the pancreas was involved with the control of blood sugar levels, and the pancreatic extract called insulin was found to be able to treat diabetes.

Later observations recorded by nurses in various parts of Africa noted that ants were attracted to the urine of diabetic patients[1].

Ants as part of the diagnostic method

Talking to the child and family is essential, combined with clinical observation:

- Ask if ants are attracted to the child's urine or clothes
- Test to see if a sample of the urine will attract ants
- **If the answer is "yes" – the urine attracts ants – then diabetes mellitus is very likely.**

- Assess for clinical signs of ketoacidosis (DKA) and dehydration and then test if possible, or refer. The suspected diagnosis of diabetes **always needs to be confirmed.**

If further testing is possible
Test the urine using a **urine glucose strip**
– if glucose is detected, this is likely to be diabetes mellitus

OR
Test a sample of the urine with **Benedict's Solution**
– if the solution turns orange/red/brown, the urine is positive for reducing sugars, and this is likely to be diabetes mellitus.

If the ants test is negative
If the child is losing weight, passing a lot of urine and very thirsty all the time, but ants are not attracted to the urine (or if the blood glucose level is normal), then the diagnosis may be

- **diabetes insipidus** (making large quantities of dilute urine) due to a brain tumour

OR
- **polyuria** (making large quantities of urine) due to excessive water drinking, high blood calcium levels, low potassium levels, lithium poisoning, a kidney condition, urinary tract obstruction or urinary tract infection. Refer as necessary.

TO REMEMBER :

1: If diabetes is suspected, assess for clinical signs of dehydration and DKA.

2: Diagnosis needs always to be confirmed.

References
1 Chowdhury SR. Representation of overseas and women doctors. BMJ (Clin Res Ed). 1982 Jul 17; 285 (6336):217

2.5 PRIORITIES FOR LABORATORY FACILITIES

OBJECTIVE:

- Understand the internationally-recognised recommendations on laboratory testing related to diabetes

A FEW THOUGHTS TO START WITH:

- What is the status of my clinic?
- How can I organise collaboration to improve access to laboratory facilities?

GAINING ACCESS TO LABORATORY TESTING FACILITIES

A national plan for the development of laboratory facilities needs to be established to support the diabetes programme. The following are tests that should be considered in this plan:

1: Blood glucose monitoring
Laboratory-based blood glucose measurement is not essential when reliable glucose meters are available for clinical use. The accuracy of glucose meters is sufficient for day-to-day clinical practice.

2: HbA1c monitoring
See Chapter 4.5 for further information on HbA1c testing – the measurement of the proportion of haemoglobin which is bound by glucose.

HbA1c monitoring offers an opportunity to determine medium-term glycaemia. HbA1c may be determined by:

- Laboratory-based assays. These are the ideal, but must be calibrated against DCCT standards.

- Desk-top methods are a more convenient and rapid way to obtain HbA1c values. Samples are often capillary blood and results are available in 5-10 minutes. Examples include the Bayer DCA 2000.

3: Other tests
a: Routine chemistry including determination of electrolytes and renal function would be needed for management of DKA and for screening for nephropathy. For healthcare facilities that will manage DKA frequently, it is preferable to have an on-site laboratory that can provide electrolyte and renal function results rapidly.

b: Microbiological methods to detect infections would be desirable. These need not be situated at every healthcare facility, but results should be made available within a few days.

c : Thyroid function tests should be made available. Testing could be centralised and results should be available within weeks of the test. Thyroid antibodies are found in about 30% of children in western studies, but the prevalence of autoimmune thyroid disease in developing countries is not known. 5-10% of children with diabetes may develop thyroid dysfunction. Thyroid antibody testing is not a priority and would only be included in the final tranche of tests offered.

d : Tests to detect microalbuminuria should be available. Dipsticks for urine (eg Micral sticks) would be an easy, convenient and relatively cheap option for screening for microalbuminuria. Laboratory confirmation of positive Micral tests could be offered by regional or national laboratory facilities. Some HbA1c analysers can also test for microalbuminuria.

e : Cholesterol values should be available from regional or national laboratory facilities.

f : Diabetes-specific antibodies are not essential for the routine management of diabetes.

g : Screening for coeliac antibodies could be made available, but the incidence of this condition in developing countries is not known.

TO REMEMBER:

1: Local facilities are necessary to check for hypoglycaemia, hyperglycaemia and ketones in urine and blood.

2: Laboratory facilities should be coordinated at regional or national level. Regular quality control is essential.

SUGGESTED PRIORITIES AND LOCATION OF LABORATORY FACILITIES

	Priority	Location
Chemistry (urea and electrolytes)	High	Local
Microbiology	High	Regional
Urine protein	High	Regional/national
HbA1c (desktop)	Medium	Local
HbA1c (lab)	Medium	Regional/national
Thyroid function	Medium	Regional/national
Cholesterol	Medium	Regional/national
Glucose	Low	Local

PART 2

TREATING DIABETES

PART 2 CONTENTS

SECTION 3
TREATING DIABETES – EMERGENCY AND SURGICAL CARE

Taking immediate action: what to do locally and when to refer

SECTION 3 CONTENTS

3.1 SYMPTOMS AND TREATMENT OF DIABETIC KETOACIDOSIS (DKA)

OBJECTIVE:

- Understand the diagnosis and treatment of diabetic ketoacidosis, in order to reduce DKA mortality in children with diabetes

A FEW THOUGHTS TO START WITH:

- Why does DKA occur?
- When is DKA most likely to occur?
- What can I do locally, as a non-specialist?

DIABETIC KETOACIDOSIS

DKA occurs when insulin action is insufficient. It is most commonly seen with acute illness, at the time of diagnosis or if insufficient insulin has been administered. The deficiency of insulin results in a pathophysiological process that gives rise to the clinical symptoms of DKA.

As blood glucose values rise, the ability of the kidneys to conserve glucose is exceeded and glucose starts appearing in the urine. The osmotic effect of the increased glycosuria results in the excessive loss of water and electrolytes in the urine. In response to the dehydration, the child will start drinking excessively. Fat is broken down as an energy source, resulting in the appearance of ketones in the blood and urine. Increasing ketone levels result in metabolic acidosis. The clinical effects manifest as acidotic breathing, nausea, vomiting, abdominal pain and an altered level of consciousness.

Pathophysiological effect	Clinical features
Elevated blood glucose	Elevated blood glucose and urine glucose
Dehydration	Sunken eyes, dry mouth, decreased skin turgour, decreased perfusion
Altered electrolytes	Irritability, change in level of consciousness
Metabolic acidosis (ketosis)	Acidotic breathing, nausea, vomiting, abdominal pain, altered level of consciousness

MANAGEMENT OF DKA

DKA is managed by correcting the biochemical and clinical changes. This has to occur gradually and slowly to prevent the complications associated with DKA, particularly cerebral oedema. Fluid replacement is initially more important than insulin therapy, as early mortality is due to dehydration and shock rather than hyperglycaemia. Insulin therapy is needed to correct the acidosis and hyperglycaemia. Care should be initiated at the healthcare site of first contact, and the child should be moved as soon as possible to the best available site of care with diabetes experience.

Written guidelines on management of DKA should be available at all levels of the healthcare system. Guidelines should be appropriate for the resources available at the facility and should include recommendations on the transfer of patients. The optimal facility for care of DKA is one that has:

- Appropriate nursing expertise (preferably a high level of care)
- Laboratory support
- Clinical expertise in managing DKA.

Managing DKA involves the following steps:

1: Correction of shock
2: Correction of dehydration
3: Correction of deficits in electrolytes
4: Correction of hyperglycaemia
5: Correction of acidosis
6: Treatment of infection
7: Treatment of complications (cerebral oedema).

TREATMENT OF DKA

Effective treatment of DKA involves the following stages:

1: Assessment

- Carry out a clinical assessment including history and examination. Be careful to include:
  A: Severity of dehydration. If uncertain about this, assume 10% dehydration in significant DKA
  B: Level of consciousness

- Determine weight

- Determine blood glucose (using a glucose meter) and ketones by urine dipstick at bedside

- If a laboratory is available on site, carry out the following tests: blood glucose, urea and electrolytes, haemoglobin, white cell count, HbA1c. Take appropriate microbiological samples if infection is suspected. If no laboratory is available, take the appropriate samples and send with the patient to the next level of care.

2: Resuscitation

- Ensure appropriate life support (**A**irway, **B**reathing, **C**irculation, etc.)
- Give oxygen to children with impaired circulation and/or shock.
- Set up a large IV cannula. If IV therapy is not available at the site, set up intra-osseous access. If this is not available, place a nasogastric tube. Transfer child to a site with IV facilities as soon as possible.
- Treat shock (decreased perfusion) with fluid (intra-venous, intra-osseous) at 10ml/kg over 30 minutes. Use normal saline or Ringers Lactate for initial resuscitation. Repeat boluses of 10ml/kg until perfusion improves.
- **If the only access is by nasogastric tube, replace fluid over 60 minutes.**
  Use normal saline, half-strength Darrows solution with dextrose, or oral rehydration solution (ORS) until perfusion improves.

IMPORTANT:

Make sure that the child is adequately resuscitated before proceeding to the following steps. This includes having good perfusion and a stable haemodynamic circulation, but it is not necessary to correct the level of consciousness before proceeding.

3: Fluid replacement

- Rehydrate the child with normal saline. Aim to provide maintenance and to replace a 10% deficit over 48 hours. This volume should be distributed evenly over the 48 hours.
- It is not necessary to add the urine output to the replacement volume.
- Reassess clinical hydration regularly.
- Once the blood glucose is <15 mmol/l, add dextrose to the saline (add 100 ml 50% dextrose to every litre of saline, or use 5% dextrose saline).
- **If intravenous/osseous access is not available, rehydrate orally with oral rehydration solution.**
  This can be done by nasogastric tube at a constant rate over 48 hours. If a nasogastric tube is not available, give ORS by oral sips at a rate of 1ml/kg every 5 minutes. **Arrange transfer of the child to a facility with resources to establish intravenous access as soon as possible.**

IMPORTANT:

Provided that the child is not in shock, **there is no need for rapid rehydration.** As a rough rule, the more ill the child, the slower the rehydration should be, because of the risks of developing cerebral oedema.

4: Insulin therapy

- Start insulin therapy only after circulation has been restored and the patient is haemodynamically stable.
- Start an insulin infusion of short-acting insulin (eg Actrapid) at 0.1U/kg/hour. This rate should be controlled with the best available technology (an infusion pump). For example, a 14 kg child should receive 1.4 U/hour of Actrapid.
- In children under 3 years of age, consider using a lower rate of insulin delivery eg 0.05 U/kg/hour.
- **If no suitable control of the rate of the insulin infusion is available, use subcutaneous or intra-muscular insulin.**
  Give 0.1 U/kg of Actrapid sub-cutaneously or IM subcutaneously into the upper arm, and repeat this dose subcutaneously every second hour.
- **Arrange transfer of the child to a facility with resources to establish intravenous access as soon as possible.**

IMPORTANT:

The presence of ketones suggests inadequate insulin delivery. Continue giving insulin IV or hourly until ketones have been cleared. **Do not correct glucose too rapidly;** aim for a glucose reduction of about 5 mmol/l per hour. A more rapid decline may contribute to the development of cerebral oedema. If glucose declines very rapidly, decrease the rate of insulin delivery.

5: Potassium replacement

Potassium replacement is needed for every child in DKA:

- Obtain a blood sample for determination of potassium as part of the initial assessment.
- If there is no suitable laboratory service (if not available or if results take longer than 4 hours), changes of kalaemia may be observed on an electrocardiograph, where available. Flattening of the T wave, widening of the QT interval, and the appearance of U waves indicate **hypo**kalaemia. Tall, peaked, symmetrical, T waves and shortening of the QT interval are signs of **hyper**kalaemia.
- Ideally, start replacing potassium once the serum potassium value is known or urine output has been documented.
- If the serum cannot be obtained within 4 hours, start potassium replacement within 4 hours of starting insulin therapy.
- Replace potassium by adding potassium chloride to the IV fluids at a concentration of 40 mmol/l (20 mls of a 15% KCl solution per litre of saline).
- If intravenous potassium is not available, potassium could be replaced by giving the child fruit juice or bananas. Insulin probably needs to be given at a slower rate than 0.1 U/kg/h when IV potassium cannot be given.
- **For a child being rehydrated with ORS, no added potassium is needed as ORS contains potassium.**
- Serum potassium should be monitored 6-hourly, or as often as possible.

- In sites where potassium cannot be measured, **consider transfer of the child to a facility with resources to monitor potassium and electrolytes.**

IMPORTANT:
Fluid replacement, potassium replacement and insulin therapy will correct the dehydration, deficits in electrolyte and correct the hyperglycaemia over 24-48 hours.

6: Correction of acidosis

- Bicarbonate administration should not be routinely administered, but in the rare case presenting in a critical condition with severe acidaemia and a state of shock, it may be appropriate to use bicarbonate.
- If bicarbonate is considered necessary, cautiously give 1-2 mmol/kg over 60 minutes.

7: Treatment of infection

- Infection can precipitate the development of DKA
- It is often difficult to exclude infection in DKA, as the white cell count is often elevated.
- If infection is suspected, treat with broad-spectrum antibiotics.

8: Monitoring of management
During management of DKA the child needs to be carefully monitored as follows:

- Record hourly clinical parameters; heart rate, BP, respiratory rate, level of consciousness, glucose meter reading.
- Monitor urine ketones in every sample of urine passed.
- Record fluid intake, insulin therapy and urine output.
- Repeat urea and electrolytes determinations every 4-6 hours.
- Once the blood glucose is less than 15 mmol/l, add dextrose to the saline (add 100 ml 50% dextrose to every litre of saline or use 5% dextrose saline). If replacing fluid orally, ensure that the child has ORS or fruit juice once the glucose is below 15 mmol/l.
- Once the urine ketones are absent, consider making the transition to subcutaneous insulin.

9: Transitioning to subcutaneous insulin

- Once the DKA has been adequately treated (hydration has been corrected, glucose controlled and the ketones cleared) the child can be transitioned to subcutaneous insulin.
- The first subcutaneous dose of insulin should be given 30 minutes before stopping the insulin infusion.
- If the child has been receiving subcutaneous or IM insulin, stop the additional fluids and commence subcutaneous insulin once the ketones have been cleared.

IMPORTANT:
It is often easier to transition to subcutaneous insulin at the next mealtime. The regimen depends on the child and previous treatment.

10: Cerebral oedema

- Cerebral oedema is a rare, but often fatal, complication of DKA.
- It is often idiosyncratic but its occurrence may be related to severity of acidosis, rate and amount of rehydration, severity of electrolyte disturbance, degree of glucose elevation and rate of decline of blood glucose.
- The rapidly rising intra-cranial pressure may manifest as a change in neurological state (restlessness, irritability, increased drowsiness or seizures), headache, increased blood pressure and slowing heart rate, decreasing respiratory effort or specific and/or focal neurological signs. If cerebral oedema is suspected, exclude hypoglycaemia as a cause of the change in clinical state.
- Reduce the rate of fluid administration by one-third.
- Give mannitol 0.5-1 g/kg IV over 20 minutes and repeat if there is no initial response in 30 minutes to 2 hours.
- Hypertonic saline (3%), 5 ml/kg over 30 minutes, may be an alternative to mannitol, especially if there is no initial response to mannitol.
- Elevate the head of the bed.
- Intubation may be necessary for a patient with impending respiratory failure.
- After treatment for cerebral oedema has been started, a cranial CT scan should be obtained to rule out other possible intracerebral causes of neurologic deterioration (about 10% of cases), especially thrombosis or haemorrhage, which may benefit from specific therapy.

IMPORTANT:
Cerebral oedema is an unpredictable complication of DKA. It **has high mortality** and survivors are often left with significant neurological deficits. Meticulous management of the DKA can decrease the risk of developing cerebral oedema. DKA should therefore be managed at the best available facility.

Resources:
Annex 3 – Form for recording DKA history
Annex 4 – Form for monitoring DKA event

TO REMEMBER:

1: Causes of ketoacidosis:
- too little insulin / lack of insulin
- blood glucose level high
- loss of electrolytes in urine
- ketones in blood and urine
- infection

2: Symptoms:
- dehydrated, dry mouth, sunken eyes
- irritable, reduced consciousness
- sweet smelling breath
- nausea, vomiting, abdominal pain

3: Treatment:
Treat in this order, according to the details in the main text above:
- shock
- dehydration
- deficits in electrolytes
- hyperglycaemia
- acidosis
- infection
- complications (cerebral oedema)

IMPORTANT:

1: It is possible to reduce DKA morbidity and mortality by early treatment, before transfer to hospital.

2: Rehydration facilities and IM short-acting insulin are essential at any centre taking care of diabetic patients.

3: Written guidelines should be available at all levels of the healthcare system, and should each be appropriate for the resources available at the facility. Guidelines should include recommendations on the transfer of patients.

4: The optimal facility for care of DKA is one that has:
- appropriate nursing expertise (preferably high-level care)
- laboratory support
- clinical expertise in managing DKA.

3.2 SYMPTOMS AND TREATMENT OF HYPOGLYCAEMIA

OBJECTIVE :

- Understand the diagnosis and treatment of hypoglycaemia

A FEW THOUGHTS TO START WITH:

- How can I reduce fear of hypoglycaemia in children and parents?
- Can hypoglycaemia be asymptomatic and occur without the patient realising?

HYPOGLYCAEMIA

- Hypoglycaemia is one of the most common acute complications of the treatment of type 1 diabetes, and frightening for parents.
- Effective treatment (and preferably prevention) are key issues.
- Hypoglycaemia means **'low blood glucose levels'**.
  Blood glucose values <2.5 mmol/l (<45mg/dl) are too low for normal neurological (brain) function.
- Even people without diabetes may develop symptoms of hypoglycaemia when the blood glucose level is <3.6 mmol/l (about 65 mg/dl).
- People with diabetes should aim to keep blood glucose levels >3.9 mmol/l (about 70 mg/dl).

SYMPTOMS

The clinical **symptoms of hypoglycaemia** initially occur as a result of adrenalin (autonomic activation) and include:
- Trembling
- Rapid heart rate
- Pounding heart (palpitations)
- Sweating
- Pallor
- Hunger and/or nausea.

The **symptoms of neuroglycopenia** (the effects of low glucose on brain function) include:
- Difficulty in concentrating
- Irritability
- Blurred or double vision
- Disturbed colour vision
- Difficulty hearing
- Slurred speech
- Poor judgement and confusion
- Dizziness and unsteady gait
- Tiredness
- Nightmares
- Inconsolable crying
- Loss of consciousness
- Seizures.

In severe circumstances, especially if it is prolonged, hypoglycaemia can cause death.

GRADING THE SERIOUSNESS OF HYPOGLYCAEMIA

Mild hypoglycaemia
occurs when the patient recognises hypoglycaemia and is able to self-treat without the assistance of others. Blood glucose values are around ≤ 3.9 mmol/l (<70 mg/dl).

Moderate hypoglycaemia
occurs when the child or parent is aware of, responds to, and treats the hypoglycaemia, but needs someone else to assist. Blood glucose values are again around ≤3.9 mmol/l (<70 mg/dl) but the person is not able to help himself or herself during this episode.

Severe hypoglycaemia
is defined when the patient either loses consciousness or has a convulsion (fit) associated with low blood glucose.

MANAGEMENT OF HYPOGLYCAEMIA

First, **teach the child to recognise hypoglycaemia**. Teach the child, the parents and people around (including teachers, the extended family and neighbours) about the signs and symptoms of hypoglycaemia.

If a blood glucose meter is available, document a suspected episode of hypoglycaemia with blood glucose values and note the symptoms which were experienced as well as the circumstances which may have caused it – eg a missed meal, more exercise than usual etc. If blood glucose testing is not available, then treatment of hypoglycaemia should be based on symptoms.

It is also important to teach and remind children and parents that foods high in both fats and sugar (for example chocolate, fat-containing milk, peanut butter) will slow down the absorption of sugar in those foods. They are therefore not suitable for treating acute hypoglycaemia, but may be good for preventing hypoglycaemia at night.

TREATMENT OF HYPOGLYCAEMIA

The aim of treatment is to get glucose values back to normal and to prevent progression to loss of consciousness or convulsions. This is achieved by **feeding the child**. The initial intake of food has to be a **rapid-acting carbohydrate** food, which includes sweetened drinks like glucose water, canned or bottled drinks, fruit juices and also glucose-containing sweets.

It is recommended that the child consumes 0.3-0.5 g/kg or 9-15 grams of such rapid-acting carbohydrates for a child weighing 30 kg. The lower the glucose value, the more glucose is needed. In practice, parents should be advised to continue supplying rapid-acting carbohydrate until the symptoms have resolved. If blood glucose testing is available, test after 10-15 minutes. If glucose values are still low, continue giving rapid-acting carbohydrates.

If the child is having severe symptoms (is not able to eat), is unconscious, nauseated or having a convulsion, give either:

- intravenous glucose (eg 10% glucose drip or 1ml/kg of 25% dextrose)

OR

- IV, IM or subcutaneous glucagon (0.25 mg for small children; 0.5 mg for children up to 40-50 kg and 1 mg for adults). After an injection of glucagon, the blood glucose would be expected to rise within 10-15 minutes.

If neither glucagon nor intravenous glucose is available, a rapid-acting carbohydrate, preferably a liquid or gel (eg honey, sugar syrup, pancake syrup) can be placed in the mouth alongside the cheek, with the child or adolescent placed in a sideways lying-down position to minimise the danger of aspiration if convulsing or unconscious. However there is no scientific data supporting buccal absorption of glucose.

PREVENTING HYPOGLYCAEMIA

This should be our priority:

1: Remind the child and parents often about the symptoms of hypoglycaemia.

2: Remind them about what might cause hypoglycaemia:

- Missing a meal or eating less than usual
- Delaying a meal after giving the insulin injection
- Activity of longer duration or intensity, eg school vacations, parties, training for games etc
- At night – the risk of hypo is higher after an active day
- When taking alcohol – which also blocks liver gluconeogenesis
- When appetite is poor because of illness – eg with vomiting or flu.

3: A number of risk factors can predict the occurrence of hypoglycaemia:

- Age (infancy and adolescence)
- Longer duration of diabetes
- Higher doses of insulin
- Lower HbA1c values
- Inconsistent meal planning: timing, amounts
- Increased activity, especially if activity occurs irregularly
- Recent changes in treatment regimen
- Lack of symptoms (hypoglycaemia unawareness)
- Sleep
- Alcohol or other drug use (eg marijuana)
- Lack of routine monitoring
- Prior history of hypoglycaemia problems
- Poor proactive planning.

Repeated episodes of hypoglycaemia should result in a review of the management of the child, including insulin doses and eating plan, with specific advice to parents about adapting these in advance, to prevent recurrences.

Alcohol itself does not cause hypoglycaemia, but will block the liver from making glucose from glycogen. It can worsen the effect of hypoglycaemia for this reason.

HYPOGLYCAEMIA UNAWARENESS

A child or adolescent suffering repeated or severe episodes of hypoglycaemia often develops hypoglycaemia unawareness. This means that he/she will have

symptoms of moderate or severe hypoglycaemia without the warning symptoms of mild hypglycaemia coming first, and it also increases the risk of convulsions, coma and death.

Management of hypoglycaemia unawareness involves adjusting target glucose values upwards, to avoid hypoglycaemia for several weeks or months, with the hope that the body's neurologic and autonomic response might recover.

MEDICALERT IDENTIFICATION BRACELET OR NECKLACE

Since people with diabetes can become unconscious or unable to communicate their problem when they develop hypoglycaemia, it is ideal for them to carry a card, a bracelet or a locket which says 'I have diabetes'. This allows emergency personnel to recognise that the child or teenager has diabetes, and consider that loss of consciousness may be due to hypoglycaemia, which can be treated by giving glucose or food.

TO REMEMBER :

1: Causes of hypoglycaemia:
- too much insulin
- too little food
- increased activity
- illness

2: Symptoms:
- crying, irritability, aggression
- pale, sweating, clammy
- hungry, weak, blank expression
- confused, unresponsive or inappropriate answers
- convulsions or tremours

3: Treatment:
- if child can eat, give sweets, bottled drinks, fruit juice
- if child can't eat, give glucagon by injection or IV dextrose OR honey / sugar-containing food / gel in mouth and lie child on side
- in both cases give a snack once recovered.

IMPORTANT:

1: If in doubt, treat hypoglycaemia and then call for help – failure to treat it early can make it more severe

2: Preventing hypoglycaemia is better than curing it – frequent monitoring helps to identify hypoglycaemia

3: Education and proactive insulin and food decisions help to minimise and prevent hypoglycaemia

4: Alcohol is one of the highest risks for severe hypoglycaemia.

3.3 MANAGING SURGERY IN CHILDREN WITH TYPE 1 DIABETES

OBJECTIVE:

- Understand the implications of type 1 diabetes for surgery on a child, in order to support the local surgical and nursing team if evacuation of the child to an expert centre is not possible

A FEW THOUGHTS TO START WITH:

- Are surgeons aware of the extra risks of surgery on a child with diabetes?
- How can I improve collaboration between the diabetes care team and the surgical team, and involve the diabetes team in glucose monitoring?
- Do surgeons have easy access to glucose meters and urine strips?

SURGERY INVOLVING TYPE 1 DIABETES

Surgery on a child with type 1 diabetes is **significantly more complicated** than where diabetes is not involved.

This is because of the need to monitor continuously the child's blood glucose and to ensure that it does not fall to a level likely to cause hypoglycaemia. Because food intake is restricted before surgery, insulin administered must also be reduced to maintain the balance. If insulin is reduced insufficiently, the child is at risk of ketoacidosis.

Elective surgery for a child with diabetes should not be carried out in a primary or secondary care facility, where the specialised knowledge is not likely to be sufficient.

Whenever possible, a child with diabetes requiring **surgery should be evacuated to a centre with expertise in treating children with diabetes**.

GENERAL PRINCIPLES

- Children with type 1 diabetes should be taken **first on a surgical list**, ideally in the morning
- Aim to **maintain blood glucose of 5–10 mmol/l during and after surgery**
- Divide the child's usual total insulin dose for the day and give as repeated doses of short-acting insulin, together with maintenance IV flluids containing 5-10 % dextrose (eg 1500 ml/m2/day).
- No solid food should be given for at least 6 hours before a general anaesthetic
- Clear fluids (including breast milk) are allowed up to 4 hours before anaesthesia (but check with the anaesthetist).

MINOR PROCEDURES

For short procedures that require fasting (with or without sedation or anaesthesia) and **when rapid recovery is anticipated** eg grommets, endoscopy, I&D of superficial abscess:

- Early morning procedure (eg 08.00–09.00): delay insulin and food until immediately after completion of the procedure
- Check blood glucose 0-1 hour pre-operatively
- After surgery, check glucose, give full dose of insulin and food to the child.

For short procedures that require fasting (with or without sedation or anaesthesia), and **when rapid recovery and/or early feeding may not occur** eg appendectomy, incision and drainage (I&D) of multiple or deep abscesses and short procedures that are done late in the day:

- Give 50% of usual insulin dose (NPH insulin eg Monotard)
- Monitor glucose 2 hours pre-operatively
- If glucose rises above 10 mmol/l, give dose of short-acting insulin (0.05 U/kg) OR start insulin infusion at 0.05 U/kg/hour
- If glucose <5 mmol/l, start IV dextrose (5 or 10%) infusion to prevent hypoglycaemia
- Check blood glucose hourly during surgery and post-operatively
- After surgery, start oral intake or continue IV glucose, depending on the child's condition. Give small doses of short-acting insulin, if needed, to reduce hyperglycaemia or for food intake.
- Give the dinnertime or evening dose of insulin as usual
- If home glucose monitoring is not available, admit the child overnight to monitor glucose values.

MAJOR SURGERY

Major surgery should be undertaken in healthcare facilities that have resources for optimal management of the child's diabetes. These resources should include infusion controllers and close nursing supervision.

For **emergency major surgery**, the following protocol should be followed as closely as possible:

- Procedures should preferably be scheduled first on surgical lists, ideally in the morning
- If glycaemic control is uncertain or poor, admit the child to hospital prior to surgery for stabilisation of glycaemic control. Only consider surgery once diabetes is stable
- If diabetes is well controlled, admit to hospital on the day before surgery.

IN THE EVENING BEFORE SURGERY

- Frequent blood glucose monitoring is important to ensure optimal control
- Give the usual evening or bedtime insulin(s) and snack
- Additional doses of short-acting insulin may be necessary to correct high blood glucose values
- Keep nil by mouth from midnight
- If the child develops hypoglycaemia, start an IV infusion of dextrose (5-10%).

ON THE DAY OF SURGERY

- Omit the usual morning insulin dose
- 2 hours before surgery start an IV insulin infusion at 0.05 U/kg/hour and half-normal saline with 5% dextrose.
- Monitor glucose 1-2 hourly before surgery. Aim to keep glucose between 5-10 mmol/l, by adjusting infusion rates
- Monitor glucose every 30 minutes during surgery, and hourly in the post-operative period
- Once the patient is awake, start feeds and regular doses of insulin (see chapter 3.1 on DKA, for transition from IV insulin to subcutaneous insulin)
- When oral intake is not possible, IV infusions should continue for as long as necessary
- Expect the insulin requirements to be higher than normal for the first few days after surgery.

TO REMEMBER :

1: Where close supervision is not available and surgery is considered urgent (ie an emergency) and major, treat with repeated doses of short-acting insulin rather than an insulin infusion.

2: A child with diabetes requiring emergency surgery is likely to be in pain and physical and mental stress. Be alert for insulin resistance, hyperglycaemia and even diabetic ketoacidosis.

3: Careful and repeated monitoring of the blood glucose and electrolyte status is necessary at all times during and after surgery. Urine ketones should be monitored regularly if blood glucose levels are >15 mmol/l (>270 mg/dl).

Diabetes education is essential for good care

SECTION 4
TREATING DIABETES – ROUTINE CARE

Diabetes care is multi-dimensional

SECTION 4 CONTENTS

4.1 CHOOSING AND USING INSULINS

OBJECTIVE :

- Understand the different types of insulins, in order to adapt prescriptions to individual patients' needs

A FEW THOUGHTS TO START WITH :

- What does U-100 mean?
- What does Mixtard 70/30 mean?
- Is human insulin extracted from human pancreas?

THE RIGHT INSULIN FOR THE PATIENT

Since the 1980s, animal insulin has been replaced by human insulin: that is, insulin identical to that in the human body but which is produced in large quantities by DNA recombinant technology. As a range of different insulins are available on the market, a specific type of insulin treatment can be chosen according to the patient's lifestyle and based on one, two or more injections per day, in order to match the insulin peaks with the time of food intake. The choice is between short-acting and intermediate-/long-acting insulins, and between fixed-ratio or other combinations of different insulins.

SHORT-ACTING INSULINS
(duration of 3 to 8 hours)

Short-acting insulin or regular insulin
(eg Actrapid from Novo Nordisk, Humulin R by Eli Lilly) has an onset of action of 30-60 minutes, a peak at 2-4 hours and action of 4-8 hours' duration. Because of the slow onset of action, it is best given 30 minutes before a meal. In order to reduce glucose peaks, low glycaemic index foods (eg wholemeal grains, basmati rice, high fibre foods) are preferable to processed carbohydrates and sugary foods.

The very short-acting insulin analogues:
Insulin aspart (Novorapid from Novo Nordisk), insulin lispro (Humalog by Eli Lilly), insulin glulisine (Apidra by Sanofi Aventis) generally have an onset of action of less than 15 minutes, a peak between 30-180 minutes and a duration of 3-5 hours. They can be given immediately before eating a meal and could even be given after the meal, especially for children who are picky and slow eaters.

For high carbohydrate meals, rapid-acting analogues are best given 15-30 minutes before the meal.

INTERMEDIATE-ACTING INSULINS
(duration of 10-18 hours)

NPH insulin or Neutral Protamine Hagedorn insulin (eg Insulatard from Novo Nordisk, Humulin N from Eli Lilly) is a suspension of crystalline zinc insulin combined with the positively charged polypeptide, protamine. When injected subcutaneously, it has an intermediate duration of action, meaning longer than that of regular insulin. NPH has an onset of 2-4 hours and a duration of 10-18 hours. It has a variable peaking effect.

NEW VERY LONG-ACTING INSULINS
(duration of 24 hours)

These cannot be mixed with any other insulin in the same syringe. Use once or twice a day as a basal insulin.

Insulin detemir
(Levemir from Novo Nordisk) is a long-acting human insulin analogue. It has an onset of action of 2-3 hours, a peak at 6-8 hours, and maximal duration of 24 hours. It is usually given twice a day, since it has a shorter duration of action in children and adolescents, because of their lower size of doses.

Insulin glargine
(Lantus from Sanofi Aventis) has a maximal duration of 24 hours ; and is more likely to be given only once a day, but often in children and adolescents it can be given twice a day, because of the shorter duration of action when a small overall dosage is given.

MIXING INSULINS IN THE SAME SYRINGE

It is very common to combine intermediate-acting and short-acting insulins, in order to cover basal needs, plus the heightened need when eating. Regular insulin or rapid-acting analogues can be combined with protamine-based insulins in the same syringe. The rapid-acting insulin is always drawn into the syringe first. This method is flexible. The rapid-acting dose can be adapted every day according to food intake and physical exercise.

FIXED-RATIO COMBINATIONS

To use fixed-ratio combinations it is important to understand how much rapid-acting insulin is included in the combination, in order to adjust to food intake. In these combinations, the onset of action is the onset of the rapid-acting component, while the duration of action is that of the NPH or protamine component (the long-acting insulin). There are 2 peaks of action – the rapid-acting component peak and the protamine component peak. Some think that this produces too rigid an insulin schedule, but this is controversial.

For example:

- Mixtard 70/30 is a combination of 30% Actrapid (rapid-acting insulin) with 70% Insulatard (intermediate-acting protaminated insulin). Ten units of Mixtard 70/30 would be equivalent to 7 units of Insulatard and 3 units of Actrapid

Also:

- Novomix 70/30 is a combination of 70% protaminated aspart (long-acting) with 30% insulin aspart (rapid-acting). Sixteen units of Novomix 70/30 would be equivalent to 11.2 units of protaminated Novorapid (which acts like Insulatard) and 4.8 units of Novorapid.

CHOOSING THE BEST INSULIN FOR A PATIENT

There is no perfect insulin preparation, but good glycaemic control can be reached with any insulin. The basal-bolus concept (ie intermediate-acting / long-acting insulin basal analogue once or twice daily and rapid-acting or regular boluses with meals and snacks) has the best possibility of imitating the physiological insulin profile.

The choice of insulin should be individual and based on the patient's needs, the desired characteristics of the insulin as well as the availability and cost of the insulin.

Ideally, it is desirable for both the prescriber and the patient to be familiar with the characteristics of their preferred insulins and to use them consistently, rather than to switch products at random. Home blood glucose monitoring can be used to discover the individual's typical responses to each type of insulin, in relation to the type and quantity of food and activity level, and insulin doses should then be adjusted accordingly.

However, in practice, patients and prescribers may have to use a variety of available or donated insulins. This is why **it is so important for the physician to be familiar with the range of insulins** available on the market and adapt the patient's doses to the medications available locally.

WATCH OUT FOR THE UNITS

Insulin is available in most countries as U-100 insulin, which means it contains 100 units/ml. However, some countries still use insulin in U-40 strength (40 units/ml).

Insulin syringes are manufactured for both U-100 insulin and U-40 insulin.

It is important to ensure that the insulin used is the correct strength and the syringes used have the correct markings. If a U-40 syringe is used for U-100 insulin, the patient may receive 250% of the needed insulin and become hypoglycaemic. On the other hand if a U-100 insulin syringe is used for U-40 insulin, the patient will only get 40% of the desired dose.

POTENTIAL DANGERS OF INSULINS FROM THE 'INFORMAL' MARKET

- Integrity of the cold chain: insulin needs to have been stored properly at 2-8°C, without having been frozen or overheated at any time after leaving the factory and before reaching the final consumer. Insulin bought/obtained from alternative channels may not have been stored properly and may therefore have lower potency.
- Mislabelling: A similar product name and packaging may be used in other countries for a different product. It is therefore essential to check very carefully that the product is exactly what is required and not just assume that it is, because the packaging looks like something used previously.

Resources:
Annex 5 - Insulin characteristics

TO REMEMBER :

1 : Ensure that the insulin used is the correct strength (U-40 or U-100) to minimise dosing errors.

2: Ensure that the syringes used are made for the correct strength of insulin used (U-40 or U-100) and that they have the correct markings.

3 : Insulin needs to have been stored properly at 2-8°C, without having been frozen or overheated at any time – otherwise potency may be reduced. This also counts for transportation of insulin from the clinic to the patient's home and for storage of the insulin at the patient's home.

4: It is important to be familiar with the range of insulins available on the market, their characteristics, and adapt the patient's doses to the medications available locally.

5: Compliance with treatment is a key success factor for diabetes control.

4.2 BLOOD GLUCOSE TESTING – STRATEGIES AND PRACTICALITIES

OBJECTIVE:

- Understand how to design a strategy to make the best use of limited supplies of strips for blood glucose testing
- Understand how to use testing strips with a glucose meter, and how to interpret the results

A FEW THOUGHTS TO START WITH:

- What information do I need in order to adjust insulin doses?
- If I only have a limited number of blood glucose strips for each patient (say 25 a month), when should I use them to get the maximum information on their blood glucose?

MAKING THE BEST USE OF BLOOD GLUCOSE TESTING

Treating diabetes with insulin is completely dependent on having a clear picture of how the blood glucose changes for each patient throughout the day. The purpose of blood glucose testing is to help identify the times when the patient is at risk of either hyperglycaemia or hypoglycaemia. Having this information is the basis for deciding how much insulin they need, of what type, and when it should be given.

If a patient takes many blood glucose readings, but does not know how to interpret them and does not change either the dose of insulin, the pattern of eating or activity in response to the glucose levels, then testing the glucose readings becomes a futile and wasteful exercise. Repeated daily testing at one time of day alone (eg for fasting glucose levels) is not recommended as it is not helpful.

Test strips for blood glucose can have a significant cost and therefore should be used to the maximum benefit. If the patient does blood glucose testing at home, a member of the diabetes care team should go through the procedure with the patient, and try to make use, at each clinic visit, of the blood glucose data that the patient has collected.

WHAT AFFECTS THE BLOOD GLUCOSE READING?

The fasting glucose level before breakfast helps to tell us if enough insulin was given the night before to compensate for the evening meal, and also whether the evening dose of long-acting insulin was too low or too high.

The pre-lunch level tells us about the dose of insulin given at breakfast.

The pre-evening meal level informs us about the dose of insulin given for the mid-day meal and the earlier dose of long-acting insulin.

The blood glucose level taken 2 hours after a meal tells us if the insulin dose given for this meal was correct. For mixed insulin, it will tell if the part of regular insulin in the injection was correct.

If the patient has had a snack between meals, the glucose level may reflect the effects of the snack, not necessarily the breakfast or lunch meal alone.

Exercise, physical exertion or play may result in low glucose levels immediately after exercise, or a delayed hypoglycaemia effect many hours later (see Chapter 7.3 on diabetes and exercise)

The level of glucose in the blood can be affected by all of the following factors:

- the dose of insulin injected
- how quickly the insulin was released from the injection site
- the amount of food consumed
- how quickly the food was digested
- how much glucose was used by the muscles (ie the level of exercise taken)
- how quickly the glucose is converted to glycogen
- the effects of stress hormones like adrenaline and cortisol.

It is important, therefore, to gather this information together with the actual reading.

Only if the circumstances relating to a reading are known and recorded, can the reading be used to make an informed decision about insulin dosing.

DESIGNING A BLOOD GLUCOSE TESTING STRATEGY

It is important to consider the principles of designing a glucose testing strategy that will maximise returns for the individual patient, while conserving scarce resources. Since the blood glucose level may be affected in so many ways, but patients are usually on a relatively fixed dose of insulin, the patterns of blood glucose levels are generally more important than individual glucose readings.

- If a pre-meal reading is always high, the preceding dose of intermediate- or long-acting insulin is not sufficient.
- If the pre-meal reading is always low, then the previous dose of intermediate- or long-acting insulin is too high.
- If a pre-meal reading is sometimes very high and other times very low, either insulin, food or exercise are not consistent and should be checked.
- If the reading 2 hours after a meal is too high, the meal dose was too low.
- If the reading 2 hours after a meal is too low, the meal dose was too high.

When making these adjustments, insulin should be dosed according to the carbohydrate content of meals.

WORKING OUT THE PATTERN

The following alternative patterns for routine blood glucose testing may be useful options in working out the patient's pattern of changes in blood glucose level throughout the day:

- Pre- and post-meals and bedtime (total = 7 tests/ day)
- Pre-meal and pre-bedtime (total = 4 tests /day)
- Pre-breakfast, then select a meal and do pre- and post-meal glucose testing for 1 week. Rotate the selected meal weekly (total = 3 tests /day)
- Three pre-meal tests, a late-night test (eg 12 midnight) and one more the following morning on alternate days (average total = 2.4 tests/day) or the cycle can be repeated every 3rd day (average total = 1.7 tests/day or 50 strips / month)
- Whenever symptoms of hypoglycaemia occur
- When a top-up dose of insulin is needed for extra food or during illness.

If, for any reason, there is a shortage of blood glucose strips, the following recommendations are made:

If only 25 strips a month are available per child, do 3 pre-main meal glucose level tests on 3 consecutive days and a late-night glucose level on one of the nights. Then take measurements related to the time of the week (eg weekend, midweek) to assess the effect of different activities on different days.

For 5 strips:
Do a pre-breakfast, pre-lunch, post-lunch, pre-dinner and bedtime test once.

For 3 strips:
Do a fasting glucose test and one pre- and one post-meal glucose test 4 hours later, to assess the effects of the earlier long-acting insulin dose and the current meal bolus.

IF THE PATIENT IS ILL

Test blood glucose every few hours, or hourly if the patient is very sick with symptoms of hyperglycaemia, ketoacidosis (DKA) or hypoglycaemia.

If the blood glucose level is above 18 mmol/l or 300mg/ dl, try to obtain a blood ketones or urine ketones level to look for evidence of diabetic ketoacidosis, which is life-threatening. This would present as ketonuria, hyperglycaemia with blood glucose > 15 mmol/l, and blood pH <7.3. If this is found, start initial treatment and refer the patient.

FREQUENT ERRORS

If the patient's blood glucose data is not useful to the clinician in its present form, eg because it was measured at random times not related to meals or exercise, the doctor must change how it is being measured. He must ask the patient to change the frequency or pattern of testing, the quality of accompanying information about diet, dose and activity, or all of these factors.

RECOMMENDATIONS

Many treatment protocols have advised that insulin doses should not be changed on the basis of single blood glucose readings, but that they should only be changed after examining a pattern of repeated blood glucose readings.

However, because of the relatively high cost of blood glucose testing strips, it may be necessary to make treatment decisions and change insulin doses on the basis of just a few blood glucose readings.

Current evidence supports the view that it is important to measure both fasting and post-prandial glucose levels, as hyperglycaemia at these times is implicated in the development of diabetic complications. If HbA1c is high (>10.2%), the fasting glucose level is a vital indicator, as it accounts for 70% of overall glycaemic control. However if HbA1c is low (<7.3%), then postprandial glucose level is a better indicator of glycaemic control[1].

CARRYING OUT THE TEST

Before testing check that:

- The glucose meter is working: batteries are not flat and the required units are set (mg/dl or mmol/l)
- The correct brand of strips are available, and
  - the correct coding has been entered, and
  - the expiry date has not been passed

Always write down:

- the time the blood test is done
- the number of hours since the last meal and the last injection
- the amount of food and drink taken before the test, and of what type
- how much insulin was given and of what type
- what type of activity was done before the test – was the patient resting, working or exercising? What type of exercise?

INTERPRETING BLOOD GLUCOSE READINGS

Remember that the type of insulin used by the patient will have an impact on the choice of **timing** of blood glucose tests and on the **interpretation** of the results.

Rapid-acting insulins generally have a 2-4 hour duration of action for rapid-acting analogues, and 4-6 hours for regular insulin.

In a patient on regular rapid-acting insulin (eg Actrapid, Humulin R), a glucose level taken 4 hours after the last meal will show if the insulin given as a meal bolus was sufficient. In a person on rapid-acting analogue insulin, the corresponding time should be 2-3 hours post-meal.

Intermediate- or long-acting insulins like NPH insulin (Neutral Protamine Hagedorn, eg Insulatard, Insulin-N) have a duration of action of 10-16 hours, but a variable onset and duration of peak activity (6-10 hours). In general, NPH insulin will need to be given twice a day.

Long-acting analogues like insulin detemir (Levemir from Novo Nordisk) and insulin glargine (Lantus from Sanofi Aventis) have the advantage of less day-to-day variability in blood glucose levels. Some patients are able to take one dose of long-acting analogue insulin every 24 hours, especially younger children, who take smaller doses will need to take two doses of long-acting analogue insulin in every 24 hours.

TO REMEMBER :

1: Each blood glucose reading reflects the balance between food taken, insulin taken and exercise taken

2: Blood glucose tests should provide the information to decide if any changes are needed to food, insulin dose or exercise

3: It is important, therefore, to plan the testing strategy to measure blood glucose at the times which will give the maximum information

4: When taking the blood glucose reading, very great care should be taken to ensure that the reading is correct (check glucose meter, battery, settings, strips)

5: Take into account the type of insulin used in interpreting the readings

6: If a reading is taken and not recorded or interpreted and no action taken, then it is wasted.

References
1 Monnier L, Lapinski H, Colette C. Increments to the overall diurnal hyperglycaemia of type 2 diabetes patients. Diabetes Care 26:881–885, 2003

4.3 DIETARY ADVICE

OBJECTIVE:

- Understand the importance of offering dietary advice to children with diabetes and their parents
- Understand how to conduct a dietary review

A THOUGHT TO START WITH:

- How do I compile a dietary review?

PRINCIPLES OF DIETARY CARE

Children and adolescents with type 1 diabetes need to have a healthy diet, with food in amounts and proportions appropriate to their age and stage of growth.

The child with diabetes does not produce insulin, so needs insulin injections in order to use the food consumed to provide energy in the cells of the body. The insulin doses must be matched to the carbohydrate content of food consumed, or alternatively the carbohydrate content of food consumed must be matched to the timing and the type of insulin injections. This, in turn, affects the way in which insulin is injected and is released into the bloodstream.

Dietary management in childhood diabetes means helping and encouraging the child to take the right dose of insulin for the right type and amount of food, and to eat in the right amounts for that dose of insulin, at the right time. However when food is scarce or not always available, dietary management is more difficult than calculations based on a regular number of predictable meals every day. Instead it has to aim to teach the child and his parents to make the best choices out of what is possible. Further guidance on balancing insulin dosing with food intake is given in Chapter 6.4.

When the child with diabetes is doing a lot of exercise or manual work, more glucose can enter the cells for every unit of insulin. When this happens, the carbohydrate ratio and the correction ratio will be temporarily changed for a variable time during and after exercise. So the child will either have to eat more, take less insulin or do both.

ESTABLISHING A DIETARY REVIEW

A dietary history and review is taken at diagnosis and repeated at least annually. The objective is to see if the patient is eating the right foods, in the right amounts and at the right times.

- Establish the history, reviewing the child's:
  - food patterns (2 meals/day, 3 meals/day, range of foods etc.)

- daily activities (walk/bike a long distance to school, help to do housework, sports etc.)
- insulin types , doses and injection timing
- growth and stage of puberty.

- Give practical and feasible suggestions, eg recommending a healthy variety of the sort of foods likely to be available. Try not to give recommendations that the parent will not be able to follow – it only leads to frustration and reduces trust.

- At the next clinic visit, review the progress in making changes. Ask if the suggested changes to the child's diet caused any difficulties. Teach some kind of carbohydrate estimation of the foods used in the family, and how this affects the insulin doses. It is not the size of the portion that decides the dose, but the carbohydrate content.

- Reassure, re-explain and remind as needed. Further information on nutrition and how to help parents and children understand how to plan meals is given in Chapter 6.5.

WHO SHOULD DO THE DIETARY REVIEW?

In an ideal situation, a dietician or healthcare professional such as a doctor or nurse should do the dietary review.

It is important to involve the family members and caregivers as much as possible, if the principles of good nutrition and of matching food intake with insulin dosing are to be followed. There should be two-way consultation between members of the medical team and the family members/caregivers at regular intervals; not once only. Continuing reminders and reinforcement of the messages are needed.

Resources:
Annex 6 – Recording dietary history

TO REMEMBER :

1: Dietary advice is an important part of the treatment.

2: The child cannot be helped to eat more healthily until the family's situation and food security is clearly understood.

3: It is important to know what food the child is eating and when, in relation to daily activities, to see whether the diabetes is being kept under good control.

4: The level of exercise taken affects the amount of glucose that can enter the cells for every unit of insulin.

5: The stage of puberty also affects the glucose / insulin / energy balance.

4.4 TRACKING GROWTH – HEIGHT AND WEIGHT

OBJECTIVE:

- Understand the vital role, in a child with diabetes, of regular measurement of growth in height and weight, as an indicator of good / adequate / inadequate glycaemic control

A THOUGHT TO START WITH:

- Are growth and weight charts specific for diabetic children?

KEEPING TRACK OF GROWTH IN CHILDREN WITH DIABETES

Children's growth in height and weight follows a predictable pattern over time, within well-established ranges. However growth in children with diabetes is often affected by their condition, or in the case of type 2 diabetes, their overweight contributes to the occurrence of diabetes. Regular measurement of height and weight is a useful indicator of how well their treatment is keeping the diabetes under control.

Children with diabetes should achieve normal growth targets for their ethnic group and the community in which they live. If the child with diabetes is growing at the same rate as other childen of the same age, sex and community, that is a powerful indicator of the adequacy of diabetes care.

Ideally, children should be measured for growth using population-specific charts. Where these charts are not readily available, the CDC (US Centers for Disease Control) charts may be used for plotting height for age (Annex 7).

If the child has put on more than 1 kg in a month, a change of insulin dose may be necessary. Poorer than expected growth rates should prompt an inquiry into the cause, which could be hypothyroidism, poor glycaemic control or poor calorie intake; and corrective action should be taken.

MEASURING HEIGHT AND WEIGHT IN PRACTICE

Every child should have height and weight measured at each clinic visit, preferably once a month. This should be immediately recorded on the child's medical chart.

- Standing height should be taken without shoes, by a trained staff member, using a standardised height chart and method.

- For young children under 2.5 years, total body length should be measured.

- The weight should be measured to the nearest 0.1 kg where possible, but at least to the nearest 1.0 kg, with shoes off, wearing light clothes or underwear and having emptied the pockets.

HEIGHT MEASURING APPARATUS

Any of the following are suitable:

- A commercially-available stadiometer
- A commercially-available pull-down measuring tape mounted onto the wall, with a right angle attached, at a spot in the clinic where the floor is flat
- Another simple method is to drop a plumb line from a nail in the wall, 2 metres above the floor, and to fix a folding rule vertically between the nail and the floor. Height is measured by using a plastic or metal setsquare placed with one side against the wall, and the other against the top of the child's head.

Do not forget basic routine such as taking off the shoes and standing straight without tiptoeing. However simple the apparatus, measurements are only as accurate as the observer.

Calibration can be by means of a simple rod of known length, say 1.2 meters, to check the calibration of height apparatus at different sites within a healthcare system.

WEIGHING SCALES

A wide range of weighing scales is currently in use, including balance beam scales, spring-operated standing scales, bathroom scales and electronic strain gauge-based scales.

Any type of weighing scale can be used, provided it has been calibrated properly and is inspected regularly, (at least every 6 months). Electronic scales can be zeroed at the beginning of each session.

Weighing machines should be calibrated and inspected at the start of clinic operations and every 6 months. A standard 10 kg weight can be kept for standardisation, or improvised by using a stack of 10 x 1 litre saline bottles. A 30 kg weight can be improvised by using a bucket into which has been measured 30 litres of water, using a 1 litre measuring jug.

Resources:
Annex 7 – Height and weight ranges in childhood

TO REMEMBER :

1: If the child with diabetes is growing at the same rate as other children of the same age, sex and community, that is a powerful indicator of the adequacy of diabetes care.

2: Measurements are only as accurate as the observer.

4.5 HbA1c

OBJECTIVE:

- Understand the use of glycosylated haemoglobin A1c (HbA1c, also known as A1c) as an objective indicator of glycaemia, and of acute as well as chronic risk for complications

A FEW THOUGHTS TO START WITH:

- HbA1c is an excellent, objective outcome measure of diabetes control
- HbA1c does not replace SMBG (self-monitoring of blood glucose) or day-to-day glycaemic variability assessments

WHAT IS HbA1c?

The red blood cells contain the oxygen-carrying protein compound called haemoglobin. Since the red blood cells are always suspended in blood plasma, which contains glucose, some glucose molecules will stick onto haemoglobin by a process known as glycosylation, to make a new compound called **glycosylated haemoglobin** or **haemoglobin A1c (HbA1c)**. The reaction is non-enzymatic, slow and irreversible, so the HbA1c level in the blood reflects the average blood glucose level during the life of the red blood cell (approx 100 days). It is usually expressed as the percentage of haemoglobin which is glycosylated (but see note on future changes, on page 83).

The normal level of HbA1c in a person without diabetes is 4.0-6.4% and there is not much difference with HbA1c levels in children or adolescents compared to adults.

If the blood glucose levels are usually high, more glucose molecules will stick onto the haemoglobin, and the HbA1c level will be high, while if the blood glucose levels are usually low, less glucose molecules are stuck onto haemoglobin, and the HbA1c level will be low.

However, it is worth bearing in mind that if the patient has severe anaemia, some types of thalassemia or a shortened red blood cell lifespan due to abnormal red blood cells, then the HbA1c may not reflect the true average blood glucose level in the body.

What HbA1c can tell us
A single blood glucose test can only tell us how effective the blood glucose control was at a certain point in time, but **the HbA1c value is a measure of the average blood glucose level over several months**.

The HbA1c value is highly correlated with the risk of having diabetes complications and can be used as a measure of an individual patient's diabetes control. Large-scale studies of HbA1c measurements from thousands of patients over many years (such as the DCCT[1] and UKPDS[2,3]) have shown that the HbA1c level correlates with the risk of diabetic complications and the risk of hypoglycaemia.

A rising HbA1c over time means that adjustments need to be made to the dose of insulin, to the food and to exercise levels.

A fall in HbA1c usually indicates better control and a lower risk of long-term diabetic complications, but as HbA1c approaches or falls below 6%, the risk of hypoglycaemic episodes is increased.

Two patients with the same HbA1c can have different degrees of glycaemic variability – the HbA1c of one person could vary very little between the highest and lowest blood glucose values, while another could show much greater difference between high and low values at different times. In general, the person with less glycaemic variability will have fewer diabetes complications.

WHAT IS THE IDEAL HbA1c LEVEL?

The level of HbA1c in a person with diabetes can range from normal (4-6.4%) to over 15%. However, good diabetes control will result in an HbA1c of less than 6.5%.

Recent studies have suggested that an HbA1c of >6.5% should be used as a diagnostic level for making a diagnosis of diabetes.

Various expert bodies such as the International Diabetes Federation, the American Diabetes Association and the International Society for Pediatric and Adolescent Diabetes have made recommendations about target HbA1c levels. Most guidelines suggest a target HbA1c of 6.5-7% in an ideal situation, provided that this can be achieved without too many hypoglycaemic episodes. However in a situation where resources are limited this may be unrealistic; the ISPAD target is <7.5% for all age groups. Target levels should be agreed upon by the entire diabetes team so that a unified approach to treatment is taught and conveyed to patients and family members.

References

1 The Diabetes Control and Complications Trial Research Group. (1993). "The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus.". N Engl J Med. 1993 Sep 30;329(14):977-86 **329** (14): 977.

2 Turner R, Holman R, Stratton I, et al: Tight blood pressure and risk of macrovascular and microvascular complications in type 2 diabetes (UKPDS 38). BMJ. 317, 703. 1998

3 Stratton I, Adler A, Neil H, et al. Association of glycaemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): prospective observational study. BMJ. 321 (7258), 405-12. 2000

FUTURE CHANGES IN THE WAY HbA1c IS EXPRESSED

HbA1c is currently expressed as a percentage (%) and has been used as such in most current textbooks and patient literature. In the near future, the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) will be using mmol/mol instead of %. However, **both numbers mean the same thing, and in this manual, HbA1c as a % will continue.**

IFCC values in mmol/mol which may be encountered in the literature can be converted to HbA1c % values by using the equation:

$$\text{HbA1c (\%)} = \frac{\text{IFCC HbA1c mmol/mol}}{10.929} + 2.15$$

For easy reference, the table shows equivalent values of % and mmol/mol.

DCCT- HbA1c (%)	IFCC-HbA1c (mmol/mol)
6.0	42
6.5	48
7.0	53
7.5	59
8.0	64
9.0	75

TO REMEMBER :

1: HbA1c is an excellent indicator to monitor glycaemic control.

2: The HbA1c level in the blood reflects the average blood glucose level during the life of the red blood cell (approx 100 days).

3: A single blood glucose test can only tell us how the blood glucose control was at a certain point in time, but the HbA1c value is a measure of the average blood glucose level over several months.

4: The benefit of having an HbA1c measurement, at least during the annual check-up at the reference hospital, should be explained to the child and parents.

4.6 QUALITY OF CARE INDICATORS

OBJECTIVE:

- Understand the use of indicators to measure and demonstrate the quality of care, at the level of both the care for individual patients and the organisation and running of the clinic

- Understand the importance of collecting and using data on the achievement of quality of care targets in order to generate and maintain support for the clinic's work from decision-makers and donors

A FEW THOUGHTS TO START WITH:

- Do I know how many children and adolescents with diabetes are attending my clinic?
- What do we measure and record at each visit?
- Do I have records of the information we have given them on being aware of the risks of ketoacidosis or hypoglycaemia – we may do it but are we sure?

MEASURING STANDARD INDICATORS

Giving long-term care for a chronic disease like diabetes depends on **maintaining regular monitoring** of many aspects of their condition, as well as responding to acute events like ketoacidosis. Keeping records is vital, as they show how the diabetes has progressed and also how the other aspects of life for a patient are changing – especially important for a child. **Comparing the records with the ranges of each indicator for children without diabetes shows whether the diabetes care is good, adequate or inadequate.**

Only if these factors are monitored and recorded do the healthcare team have a chance of offering effective long-term care, as opposed to responding to acute conditions.

The tables on pages 85-86 show the quality indicators which should be recorded.

PATIENT	OUTCOME INDICATOR	FREQUENCY
Growth	Is height > 3rd centile for age, sex?*	Ideally every quarter – at least twice a year
Weight	Is weight > 3rd centile for age, sex?*	Every visit
BMI	Is BMI < 3rd, 3rd-85th, or >85th centile?*	Ideally every quarter – at least twice a year
Blood pressure	Is systolic blood pressure between 3rd and 95th centile? (see Annex 8) Is diastolic blood pressure between 3rd and 95th centile? (see Annex 8)	Once a year unless elevated
Normal pubertal development	Age at menarche, is voice breaking? Is Tanner staging documented routinely? (see Annex 10)	At diagnosis Annually from 10 years If unexpected increase in height
Blood lipids	Are blood lipids within normal limits for the population? Do values increase with time?	Three months after diagnosis if 12 years or older. If normal, repeat every 5 years
HbA1c	Is HbA1c <7.5, 7.5-9, >9?	Three-four times/year
Acute complications	No. of admissions for DKA after first diagnosis Frequency of severe hypoglycaemia (unconsciousness or seizures, or help from other person if > 5 yrs). Frequency of infections	Every visit
Long-term complications	Is microalbuminuria negative? Is creatinine within normal limits for the population? Do values increase with time? Any signs of retinopathy/macular lesions? Any signs of neuropathy?	At least once a year from onset of puberty or from 7 years after diagnosis At diagnosis and annually if microalbuminuria is present Once a year Once a year
Screening for co-morbidity	Thyroid: TSH and antibodies Coeliac: antibodies (anti-endomysium (EMA) or anti-transglutaminase (tTG)	Every second year Every year for first 5 years
Optimal social adjustment (give answer as yes or no or how many)	Currently in school / vocational training / employment? (Y / N) No. of clinic visits in the last 12 months No. of times hospitalised in last 12 months No. of days school missed because of diabetes Food security? (Y / N - missed daily / once week / once month) Interruption in insulin during last 12 months? (Y / N) Interruptions in insulin? more than once a week / more than once a month; for how many months in a year?	Every visit

*) Use CDC or WHO charts if local charts are unavailable

CLINIC	PROCESS INDICATOR	FREQUENCY
Mortality	% Patients who died	Every year
Prevention of microvascular complications, locally or at a regional centre)	% Patients screened and developing retinopathy/macular lesions	Once a year
	% Patients screened and developing neuropathy	Once a year
	% Patients tested with urine dipstick or any other method for microalbuminuria and proteinuria	Once a year
	% Patients developing microalbuminuria and nephropathy	Once a year
	% Patients tested for HbA1c	At least quarterly
	Mean HbA1c in clinic	Once a year
	% Patients with blood pressure recorded	At least once a year
	% Patients with serum lipids recorded	At least once a year if abnormal, every 5 years if normal

Resources:
Annex 8 – Blood pressure groups in childhood

TO REMEMBER :

1: It is vital to measure the progress of diabetes regularly, as it is a long-term condition leading to major complications, and long-term management can significantly improve life for the patient

2: Basic indicators of quality of care should be measured regularly at every visit (eg once a month)

3: Regular measurement of height and weight in children with diabetes is a very good indicator of the quality of care

4: Insulin doses must be reviewed and adjusted if necessary at each visit (ideally once a month), based on HbA1c (if available) or glucose monitoring results

5: Each visit is the opportunity for repeated information and education to be given on the care of children with diabetes, prevention of DKA and hypoglycaemia, and care when other illnesses arise.

6: Children and adolescents with diabetes should be brought to the diabetes clinic when suffering from ANY medical problem, as diabetes treatment must be taken into account when considering any other treatment. It is also helpful for children and adolescents to be seen by the same physician or team, to ensure continuity of care.

SECTION 5
CHRONIC CARE PLAN

Optimal management is crucial to avoid long-term complications

SECTION 5 CONTENTS

5.1 PREVENTION OF LONG-TERM COMPLICATIONS

OBJECTIVE:

- Understand how a good chronic care plan contributes to preventing the complications of diabetes in the long term

A THOUGHT TO START WITH:

- Are children and adolescents with type 1 diabetes at risk of the same complications as adult type 1 or type 2 patients?

THE IMPORTANCE OF METABOLIC CONTROL

Diabetes can result in a wide range of serious complications, such as damage to the peripheral nerves, causing reduced pain perception and often leading to foot amputation (neuropathy), damage to the kidneys (nephropathy) and damage to the eyes (retinopathy); It also increases the risk of stroke, and cardiovascular problems including heart attack.

These complications may take many years to develop, and may not be obvious till adulthood. However, if diabetes developed when the child was very young or if diabetes control has been very poor, diabetes complications can appear in childhood and adolescence.

Major long-term studies, eg DCCT and UKPDS, show that improved glucose control (as measured by HbA1c) will reduce the incidence and progression of these long-term complications. This is the concept of **'metabolic memory'**. The challenge is to find ways to achieve good glucose control. If blood glucose control is good, growth in height and weight, and the age of onset of puberty and menstrual periods, will be no different from that of other, non-diabetic, children in the same family and community. If blood glucose control is very bad initially, it has to be improved cautiously in order to ensure that a sudden change in glucose control does not cause a worsening of diabetes eye complications.

SCREENING PROGRAMMES FOR COMPLICATIONS

A good diabetes centre will have a systematic programme of annual check-ups by a multidisciplinary team measuring lipids, thyroid function, renal function, urinary protein and microalbumin excretion, blood pressure, weight, height and growth. Regular (at least annual) eye examinations (eg fundus photography) and foot examinations looking for neuropathy, poor circulation and foot problems will be a part of this screening. These checks would usually be done as part of a quality control programme for the diabetes centre, but even if not part of a specific programme, screening for complications is very important for the individual patient, as early detection and specific treatment for complications will prevent many later problems. Those most commonly met are outlined below.

NEUROPATHY (reduced pain perception)

Occasionally, adolescents present with severe painful neuritis or with problematic gastroparesis (bloating, slowed stomach movements and slow digestion of food). This is usually in those with the worst glucose control, with the longest duration. Smoking enhances the risk and is linked with earlier onset of these conditions.

Peripheral neuropathy most commonly presents in a typical 'glove and stocking' distribution in the hands and lower legs, involving pain, hyperaesthesia and / or loss of sensation to pinprick or plastic filament testing. Reflexes can be absent or reduced in the lower extremities, and vibratory sensation decreased or absent. Most such changes affect both sides of the body. Carpal tunnel syndrome is a sign of median nerve involvement, while limited joint mobility (LJM) is painless and usually asymptomatic. Simple decreased deep tendon reflexes may also present from unrecognised hypothyroidism, but usually with intact sensation.

Autonomic neuropathy can include gastroparesis, bloating with decreased appetite, constipation, diarrhoea, palpitations, urinary retention and impotence, abnormal sweating, and absent or abnormal pupillary responses. Differential diagnosis may include coeliac disease. Refer for treatment.

NEPHROPATHY (kidney damage)

Damage to the kidneys will result in an increase in the protein excreted in the urine. Early in the development of nephropathy, the amount of protein in the urine will be slightly increased. This is called **microalbuminuria**. Treatment can be started at this stage to slow down the progression of kidney disease. Later on, a larger amount of protein will be excreted in the urine. This is called **macroalbuminuria**, and further progression of kidney damage will result in kidney failure. It is therefore important to detect signs of kidney damage as early as possible and to start treatment to prevent the progression to kidney failure. **Blood pressure** should also be assessed at least annually and sometimes may also be an early marker of diabetic nephropathy. Both microalbuminuria and hypertension are increased in those who are also smokers.

Without proper glucose control, up to 30-40% of patients with type 1 diabetes may eventually develop end-stage renal failure and require **dialysis** or kidney transplantation; without treatment, early death will occur. Poor glucose control, worsened by smoking, hypertension or hyperlipidemia will increase the risk of this occurring.

Urinary protein should be screened annually using urinary microalbumin tests or protein dipsticks; starting at puberty, or five years after diagnosis of type 1 diabetes. Treatment with Angiotension Converting Enzyme (ACE) inhibitors (eg lisinopril or enalapril) as well as diuretics can help. Reducing total protein intake, especially animal-source protein, to less than 20% of calorie contribution has also been shown to reduce microalbuminuria.

Blood pressure should be checked at least annually and compared to age- and sex-matched standards. Watch out for those with a family history of hypertension, kidney, stroke or heart problems. Treatment can be with any blood pressure-lowering medication (diuretics, beta blockers, or preferably ACE inhibitors, if available). Improvement of glucose control remains the single most important factor for reducing microalbuminuria. Smoking worsens nephropathy and should be stopped.

RETINOPATHY (damage to the retina of the eye)

People with diabetes stand a 5-10% chance of becoming blind. After having type 1 diabetes for 10 years, about 50% of patients will have nonproliferative diabetic retinopathy (NPDR), but this may progress to proliferative, vision-threatening diabetic retinopathy (PDR). Severe and clinically significant retinopathy, that interferes with vision, is not present usually before puberty.

Most guidelines recommend direct **retinoscopy** at least annually, starting at puberty, or five years after diagnosis. Stereo fundus photography is a very sensitive method for detecting early retinal abnormalities. A skilled ophthalmologist should be consulted about any abnormal symptoms (eg floaters, persistent blurry vision) or physical signs (eg haemorrhage, exudates, cataracts, new retinal blood vessel formation). Sometimes cataracts are also increased in association with with poor glycaemic control.

Diabetic eye damage causes new blood vessels to form. Often they bleed easily and can cause scar tissue, with sudden blindness and the need for emergency operative repair and laser treatment to save vision. Any rapid improvement in glycaemic control, especially when starting from extremely poor control (HbA1c > 10%), can be associated with very rapid worsening of retinopathy.

TO REMEMBER:

1: Diabetic retinopathy (NPDR and PDR), hypertension, nephropathy, neuropathy and LJM all reflect chronic hyperglycaemic damage, and can be minimised by improving glucose control.

2: The **annual checkup** with a multidisciplinary team should include eye examination, blood pressure and foot check and microalbuminuria detection.

3: **Blood pressure** should be checked at least **annually** and compared to age- and sex-matched standards.

4: **Urinary protein** should be screened **annually** using urinary microalbumin tests or protein dipsticks to detect kidney damage; starting at puberty, or five years after diagnosis of type 1 diabetes.

5: Improvement of glucose control remains the single most important factor for reducing microalbuminuria. Smoking should stop.

6: Most guidelines recommend direct **fundus photography at least annually**, starting at puberty, or five years after diagnosis. If not available, retinoscopy can be used.

7: Any **rapid improvement in glycaemic control**, especially when starting from extremely poor control (HbA1c > 10%), **can be associated with very rapid worsening of retinopathy**

5.2 CO-MORBID CONDITIONS

OBJECTIVE:

- Develop a knowledge of the most common co-morbid conditions occurring with diabetes which need to be investigated if a child or adolescent with diabetes is not achieving normal growth and development, including pubertal development

A THOUGHT TO START WITH:

- Which investigations can be included in my local care plan?

OTHER CONDITIONS THAT CAN BE ASSOCIATED WITH DIABETES

Type 1 diabetes is associated with other metabolic disorders including thyroid disease, coeliac disease, vitiligo and adrenal insufficiency. These disorders are not caused by having diabetes or by poor diabetes control. Instead they reflect the common genetic predisposition shared by these autoimmune diseases and the autoimmune nature of type 1 diabetes.

It is not usually possible to identify exactly which children or adolescents are most susceptible to these conditions, so clinical laboratory screening is recommended if available. Many cases of co-morbid metabolic disorders will be identified by simple measures such as recording the child's or adolescent's detailed medical history, charting growth and comparing it with expected ranges, looking for an abnormal increase or decrease in pigmentation, and looking for a goitre. Family history can often provide a clue to such other autoimmunopathies. This is particularly likely if more than one other family member also has such conditions, which is indicative of a genetic clustering effect and therefore higher risk.

THYROID DISORDERS

Thyroid dysfunction, including euthyroid goitres, Hashimoto's thyroiditis and compensated as well as symptomatic hypothyroidism, are all more common in patients with type 1 diabetes, and can affect 20-40% of people with type 1 diabetes. Hyperthyroidism, while less common than hypothyoridism, is also increased in type 1 diabetes and can be a cause of diabetic ketoacidosis.

Routine annual or two-yearly screening for thyroid disease with Free T4 and TSH, or even TSH alone, can be important. Treatment with thyroxine for hypothyroidism or carbimazole for hyperthyhroidism is easy and inexpensive, and will make a lot of difference to the child or adolescent.

COELIAC DISEASE

Coeliac disease is caused by intolerance to gluten, a protein found in wheat and wheat products, and will result in poor growth and sometimes poor glycaemic control. It is more common in people with type 1 diabetes; perhaps occurring concomitantly in about 5-10% of Caucasian populations in Europe and the USA. Many children and adolescents with type 1 diabetes do not show any symptoms, or only have non-specific symptoms such as vague abdominal complaints (flatulence, dyspepsia, diarrhoea, non-specific abdominal pains), increased hypoglycaemia, slowed growth rate and/or delayed puberty. Screening for coeliac disease should be carried out at the time of diagnosis, annually for the first five years and every second year thereafter. Avoiding gluten will reverse many, if not all, of the symptoms and effects of the disease. However, a gluten-free diet should not be tried before adequate diagnostic procedures have been carried out.

ADRENAL INSUFFICIENCY / ADDISON'S DISEASE

Adrenal insufficiency may occur in 1-2% of children and adolesents with type 1 diabetes. It should be suspected if there is an unexpected or unexplained decrease in insulin requirement, with unexplained or severe hypoglycaemia. Slowed growth, weight loss, unexplained fatigue and/or increasing skin pigmentation should suggest adrenal insufficiency. Refer to a specialist if this is suspected; cortisol or similar hormone replacement can be lifesaving.

LIMITED JOINT MOBILITY (LJM)

Limited joint mobility (LJM) is often a result of long-term poor blood glucose control. It is probably caused by the stiffening of the skin collagen associated with chronic hyperglycaemia. It is painless, but is a marker for poor glycaemic control. LJM increases the risk of all the known diabetes complications by four to six times, compared to those without LJM. Limited joint mobility should be assessed clinically at least annually, by having the patient place his / her hands in a 'prayer' position. The results should be noted in the medical records and some discussion held about the implications for complications when LJM is abnormal.

OSTEOPENIA (poor quality and quantity of bone) AND LOW VITAMIN D STATUS

Chronic vitamin D insufficiency and / or deficiency is increased with poorly-controlled type 1 diabetes, and this could contribute to osteopenia as well as osteoporosis. Adequate exposure to sunlight, or vitamin D supplementation, and adequate calcium intake in the childhood and adolescent years are needed to ensure good bone quality. Low vitamin D levels are implicated in future cardiovascular problems, tuberculosis and respiratory infection disease rates, as well as cancer.

NECROBIOSIS LIPOIDICA DIABETICORUM (NLD)

Necrobiosis lipoidica diabeticorum, a condition of itchy or painful hardened skin patches which can become infected or ulcerated, occurs in adolescent girls and young women with diabetes. Most often they occur on the anterior shins, and usually on both legs. It is not directly related to the degree of glycaemic control, but seems to be an idiosyncratic response to hyperglycaemia in those susceptible with higher prevalence. Refer for treatment.

LIPOHYPERTROPHY (or hypertrophy)

When insulin is injected in the same site time after time, localised subcutaneous scarring may occur. It is not age- or sex- specific, nor related to any particular type or brand of insulin; although more recent, purer animal and human insulins seem to produce less lipohypertrophy. It can be described as small or large mounds of fatty deposit at the site of injections, and can occur at any injection site. Often this is a cosmetic problem, but it may also hamper insulin absorption or cause erratic insulin absorption. **Rotation of injection sites** will usually prevent the problem. Avoid injecting into already lipohypertrophic areas, to prevent erratic absorption.

LIPOATROPHY

In the lipoatrophic region, there is localised loss of subcutaneous fat so that the skin has the appearance of a small or large indentation. Purer insulin preparations from animal or human sources produce less atrophy than in the past. Refer for treatment.

TO REMEMBER:

1: Type 1 diabetes is associated with other diseases (eg thyroid illness, coeliac disease, anaemia, Vitamin D deficiency), which can affect diabetes control and overall wellbeing – be on the lookout for these conditions**.**

2: Many cases of co-morbid metabolic disorders will be identified by simple measures such as recording the child's or adolescent's detailed medical history, charting growth and comparing it with expected ranges, looking for an abnormal increase or decrease in pigmentation, and looking for a goitre.

3: Routine annual or two-yearly thyroid screening for thyroid disease with Free T4 and TSH, or even TSH alone, is important.

PART 3
TALKING TO PATIENTS ABOUT DIABETES

PART 3 CONTENTS

SECTION 6
LEARNING TO COPE WITH DIABETES

It can be done

SECTION 6 CONTENTS

6.1 WHAT TO TELL THE FAMILY

OBJECTIVE:

- Understand the critical importance of the way the diagnosis of diabetes is given to the child, adolescent and his family
- Understand that special care for this interview is needed, to achieve acceptance of the disease and adherence to treatment

A THOUGHT TO START WITH:

- If I was told my child has diabetes, what would I be thinking; what would I want to know? How much information could I absorb?

THE CRITICAL IMPORTANCE OF HOW THE DIAGNOSIS IS GIVEN

The first contact with the family of a child or adolescent with diabetes is a crucial and critical opportunity to achieve an understanding with them. A number of objectives can be achieved, including:

- Explaining diabetes symptoms (a diagram can be used)
- Enrolling the help of family with care of the child or adolescent
- Initial diabetes education (simple)
- Dispelling myths and false beliefs (very important).

The family members are often bewildered and shocked, and do not understand what has happened to their child. Denial, anger, bargaining, confusion, depression and uncertainty often cloud the family's perception of what is happening to their child. The healthcare should be supportive, empathetic, and caring but firm in bringing the family into the therapeutic team.

Explain the symptoms and signs that the child or adolescent and his / her family have been experiencing. These may include:

- Polyuria (increased frequency of urination)
- Nocturia (passing urine at night)
- Bed-wetting
- Polydypsia (increased thirst)
- Weight loss
- Nausea and vomiting
- Abdominal pain.
- Blurred vision,
- Tiredness,
- Yeast infections

A demonstration of glucose values and urine ketones on a dipstick is useful to make the diagnosis concrete and to expose the family to some of the care issues that they will need to perform. In addition, explain the mechanism of the clinical presentation. Include the deficiency of insulin and the unknown cause of the deficiency. Answer all questions openly, comprehensively and respectfully. Raise questions that may come up for discussion later eg the cause of the diabetes, cure of diabetes, prevention of diabetes, etc. If equipment and meters are available, demonstrate them using parents first, and then the child or adolescent. This helps to overcome fears of needles and blood testing, and is often very helpful to show the kind of self-care that will be needed.

TO REMEMBER:

1: Both the child or adolescent and his or her family members are shocked and cannot remember many different messages

2: Do not explain too many things

3: The most important thing is to listen and answer all questions openly, comprehensively and respectfully. Raise questions that may come up for discussion later, eg the cause of diabetes or some of the local common myths and misconceptions.

6.2 MYTHS AND FALSE BELIEFS ABOUT DIABETES

OBJECTIVE:

- Encourage open discussion with child/adolescent and family about the myths and false beliefs frequently related to diabetes

A FEW THOUGHTS TO START WITH:

- If my child was diagnosed with type 1 diabetes, what would my family think about it?
- Do I have positive examples of young people with diabetes successfully studying and getting good jobs?

THERE ARE MANY FALSE STORIES ABOUT DIABETES

Myths (false stories) and fallacies (false or wrong beliefs) relating to diabetes may depend on local customs, regional factors and may change from time to time. They should be addressed as early as possible (preferably at the initial assessment) and reviewed periodically. Do not be rude, condescending or disrespectful of the parents who ask about myths and fallacies. Instead, deal with these misunderstandings sympathetically and with a frank discussion about the scientific understanding of diabetes.

CAUSE OF DIABETES

It is widely believed that diabetes is caused by eating too much sugar, eating too much food, or by toxins, infections, witchcraft, curses etc.

It is important to explain that the cause of diabetes is uncertain, no one can be blamed. It is not the fault of the parents and family; nothing they did or did not do would have prevented the diabetes. Type 1 diabetes is not caused by eating too many sweet things, and it cannot be treated by tablets or herbs. It is dangerous to stop insulin, because the child could then die from diabetic ketoacidosis.

A CURE FOR DIABETES

The belief that there is a cure for diabetes is often part of the 'bargaining' stage, as the parents come to terms with their child's diabetes.

Explain that there is no cure for diabetes at present, but that there is always the possibility of a cure being developed within this child's lifetime.

USE OF ALTERNATIVE MEDICATIONS

The use of alternative medications is often proposed as a cure or an alternative way of treating diabetes. These alternatives include traditional African medications, homeopathic medications, etc. Dissuade parents from attempting to use alternative medications without first consulting with the diabetes clinic. On occasion, the use of alternative medications under medical supervision may help to dispel the idea that these alternatives are of any value. Distrust of Western medicine is often an underlying reason for the use of alternative medications. However, it is important to stress that **insulin is indispensible for a child with type 1 diabetes**.

TOXICITY OF INSULIN

Insulin has been considered by some families to be toxic. This may stem from distrust or experience of acute complications of diabetes (eg severe hypoglycaemia). If insulin has been used for any length of time, point out its benefits; eg decreased thirst and urination. Discourage the family from stopping insulin therapy.

WILL PILLS WORK?

Most people who already know someone with diabetes would have encountered someone with type 2 diabetes, and would expect a child newly-diagnosed with type 1 diabetes to be treated with tablets as well.

Explain the differences between type 1 and type 2 diabetes. Note that **children with type 1 diabetes need insulin to survive**. Also note that some people with type 2 diabetes also need insulin to be healthy.

CAN MY OTHER CHILDREN CATCH DIABETES FROM THE AFFECTED CHILD?

Some people may believe that diabetes is infectious. Explain the uncertain origin of type 1 diabetes, but be clear that type 1 diabetes in not an infectious disease. Note that some families have more than one child affected by diabetes, but that this is not because it is infectious.

TO REMEMBER:

1: Trust and open discussions between child, parents and healthcare professionals are crucial for adherence to treatment and good control.

2: It is essential to advise the child and parents NOT to stop giving insulin, even if the parents decide to go to traditional medicine.

6.3 COPING WITH ACUTE ILLNESSES

OBJECTIVE:

- Understand how to advise the family on managing acute illnesses in a child or adolescent with type 1 diabetes

A FEW THOUGHTS TO START WITH:

- If the child or adolescent is vomiting or not eating, should the insulin be stopped?
- Has the family been advised how to detect DKA, and to bring him / her to the clinic quickly if this should arise?

ACUTE ILLNESSES BRING SPECIAL PROBLEMS TO A CHILD OR ADOLESCENT WITH DIABETES

Acute illness (eg infectious, particularly gastrointestinal diseases) can affect blood glucose control. The consequences of acute illness include having high glucose values (hyperglycaemia), or the appearance of ketones, or low blood glucose (hypoglycaemia). Early detection of changes in glucose values, and active management, will prevent these acute complications of diabetes and prevent hospitalisation. Changes in blood glucose values may precede or follow an acute infection.

Many illnesses, especially those associated with fever, raise blood glucose values because of the effects of stress hormones. The increased resistance to insulin can increase ketone production.

Gastrointestinal symptoms (e.g. diarrhoea and vomiting) may lead to lower blood glucose values and hypoglycaemia due to decreased food intake, poor absorption and changes in intestinal motility.

Children and adolescents with well-controlled diabetes should not experience more frequent or severe illness or infections than children and adolescents without diabetes. However, children with poorly-controlled diabetes may experience more infections. If poor control is associated with chronic hyperglycaemia, the body's ability to fight infections is often compromised.

MANAGEMENT OF ACUTE ILLNESS IN A CHILD OR ADOLESCENT WITH DIABETES

1. Do not stop insulin delivery even though the child or adolescent is ill and not eating normally. Insulin doses may need to be increased or decreased, based on the blood glucose and food intake, but should not be stopped. Children and adolescents suffering from most respiratory illnesses require more insulin, more frequently than when they are not ill. If there are no facilities for home monitoring of glucose or ketones, then the child or adolescent should be taken to a healthcare facility for regular testing.

2. Evaluate and treat the acute illness. Where possible use sugar-free medications or tablets (as appropriate). If no sugar-free medications are available then use the locally available medications. Try to avoid steroid use, as steroids may increase insulin requirements and raise blood glucose levels.

3. Increase monitoring of blood glucose to 3-4 hourly (and more frequently if the glucose level fluctuates widely or changes rapidly). Monitor ketones 1-2 times per day. Check weight if a scale is available, as a measure of dehydration. If blood glucose is high with ketones, more insulin is needed. If blood glucose is low with ketones, more sugary drink is needed before extra insulin can be given.

4. Provide, or ensure that the family is able to provide, appropriate supportive care including:

- Easily-digested foods when there is a loss of appetite
- Adequate fluid intake. Fever and hyperglycaemia can cause increased fluid losses. Oral rehydration fluid provides a source of both fluid and energy
- Treating fever with anti-pyretics (eg paracetamol) and treat or prevent vomiting by frequently offering small volumes of fluid to drink
- Admitting the child or adolescent to a healthcare facility if these supportive measures cannot be ensured as an out-patient.

Adjust insulin doses as required during the acute illness.

Consider admission under the following circumstances:

- Very young children with diabetes, who may become dehydrated more rapidly than older children or adolescents with more reserves
- Parents' inability to check glucose at home
- If supportive care cannot be ensured at home
- If the acute illness is severe
- If there is persistent ketonuria.

EXAMPLES OF ACUTE ILLNESSES

- Respiratory illnesses and fever are more likely to cause hyperglycaemia and ketosis. However, dehydration and hypoglycaemia can follow poor oral intake and tachypnoea
- Gastro-intestinal disorders (eg gastroenteritis) often cause hypoglycaemia
- Malaria has been associated with hypoglycaemia
- HIV – Treatment of HIV infection with anti-retroviral drugs can cause the metabolic syndrome and increase insulin resistance. Children and adolescents with HIV infection are more prone to develop acute infections.

Resources:

Annex 9 – Caring for acute illnesses – guide for parents

TO REMEMBER:

1: Do not stop taking insulin during an acute illness

2: Follow the guidelines for dealing with acute illnesses, which should be available at all healthcare facilities caring for children and adolescents with diabetes. These guidelines should accompany an affected child to the nearest healthcare facility and should still be followed.

3: Education and guidelines for parents on how to deal with acute illnesses should be made available to each family at the time of, or shortly after, the diagnosis of diabetes.

6.4 MANAGING NUTRITION FOR CHILDREN AND YOUNG PEOPLE

OBJECTIVE:

- Understand how to explain to parents the importance of balancing diet, activity level and insulin, and the principles of meal planning

A FEW THOUGHTS TO START WITH:

- Can a child or adolescent with diabetes eat the same foods as other members of the family?
- Does choice of the type of insulin influence meal planning?

THE FOOD-INSULIN BALANCE

Food and its relation to glucose control are key components of self-care for all people with type 1 diabetes; whether a trained dietician or nutrition specialist is a part of the diabetes healthcare team, or the physician and nurse assume this role. As well as providing the energy needed for growth and day-to-day activities, food also has a psychological role and a place in family functioning and society. It balances lipid metabolism and provides the minerals and vitamins for growth and development, as well as providing antioxidants and other micronutrients needed for optimal bone health, muscle and brain function.

For a person with diabetes, food intake must be balanced directly with the insulin injected to regulate blood glucose. Blood glucose monitoring is used to adapt food intake to individual needs, based on general principles such as exchange concepts and carbohydrate counting. Exactly how many grams of carbohydrates, proteins and fats are eaten can be modified by individual taste and regional availability, what kinds of foods can be afforded, the intensity and duration of activity of the person, what type of insulin is provided and whether or not a child or adolescent is underweight, appropriate weight for height or overweight / obese.

Interaction of the family with the infant, child or adolescent with type 1 diabetes is closely related to control of blood glucose levels. For most children and young people who are not overweight, diabetes meal planning is not related to counting calories. Instead, it is a method for balancing activity and insulin needs, to regulate glucose levels and prevent the extreme conditions of hyperglycaemia and hypoglycaemia. How the child or adolescent eats, whether the same or different food from the rest of the family and his or her friends is important in this relationship. Food behaviour is expressed through family, societal, religious, nutritive and emotional components, and all must be acknowledged and addressed with appropriate education and discussion. Paying attention to individual needs and wants also is important.

Diet planning must take into account that stress, anxiety, trauma and depression all affect appetite, and also consider the eating pattern and personal wishes of each child or adolescent. Lack of appropriate nutrition and caloric intake may be the main cause of poor growth and development; diabetes in children and adolescents makes proper nutrition even more important.

Energy requirement and carbohydrate intake all increase throughout childhood as growth progresses; often with a dramatic increase at the time of puberty. This extra intake means that compensation with added insulin must follow, so that the imbalance created does not result in hyperglycaemia. Blood glucose monitoring helps to identify whether and when such needs occur.

Meal planning is based on the concept of balance between insulin, activity and food amounts, rather than thinking of diet as a restriction. Food portions, exchange lists and carbohydrate counting are all part of systems designed to teach ways to determine how much food should be supplied at a given time of the day. Food can be broken down into carbohydrate, protein and fat categories. Parents must be involved with the meal planning since they are the purchasers and suppliers of food. Parents also have a critical role in supervising consistency from meal to meal and day to day, and this frequently helps decisions on insulin dosage.

DIET AND DIFFERENT TYPES OF INSULIN

Different insulin regimens can balance different food requirements. Insulin should be adapted to food intake if possible, rather than food 'forced' against insulin effects. The insulin regimen should be reviewed as often as possible, to minimise the risk of hypoglycaemia and the need for large snacks. More rigid dietary control is necessary when premixed insulins are used, since adjustments are much more limited. In-between insulin regimens such as a twice-a-day regular and NPH regimens must take into account the peak and through effects of both types; frequently this demands three meals and three snacks. Further flexibility occurs when the second insulin dose is split. This involves three injections per day: regular and NPH pre-breakfast, regular alone pre-dinner, and NPH alone at bedtime to deliver insulin overnight, com-

pensate for the pre-breakfast dawn phenomenon and help avoid middle-of-the-night insulin-induced hypoglycaemia. All such insulin styles can be balanced with meal plans, appropriately spaced to help avoid the extremes of low and high glucose levels.

GENERAL DIETARY GUIDELINES FOR YOUNG PEOPLE WITH DIABETES

- Use meal plans rather than a (restrictive) diet
- If obese, calorie restrictions are also important
- Emphasise simplicity and practicality
- Match meal plans with country, regional, ethnic, religious, family styles as much as possible
- Allow for individual idiosyncrasies and tastes
- Allow flexibility and variety in food selection
- Balance financial needs and availability of foods and snacks.

BALANCE OF FOOD TYPES AND CALORIE REQUIREMENTS

- Plan for an overall breakdown of 50-60% carbohydrates, 15-20% protein and less than 30% fats
- Teach parents and adolescents how to read food labels for the macronutrients: carbohydrates, proteins, fats, and the differences between saturated and unsaturated fat sources, to optimise cardiovascular health
- Teach them how to optimise micronutrients such as vitamins and minerals; especially vitamin D and antioxidants
- Estimated calorie needs are 1,000 calories for a one-year-old, with an additional 100 calories per year of age until approximately 10-12 years.
  - Girls often need some caloric restriction and attention to BMI, to prevent puberty-related obesity. An intake closer to 1000-1400 calories/day may be more appropriate, except if they are exceptionally active.
  - Peri-pubertal and pubertal boys often need continued caloric increase but here also, attention to activity, energy requirements and BMI is needed.

MEAL PLANNING AS A PART OF HEALTHY LIFESTYLE

- Involve the entire family in nutrition education and re-education
- Teach adjustment of food for changes in activity
- Teach adjustment of liquid and food intake when caring for illnesses, especially respiratory and gastrointestinal disturbances
- Plot height and weight as well as BMI on standardised charts, and review with the child / adolescent and family at least every 6 months, or preferably every 3 months

- Emphasise food quantity, portion size and fat and sugar intake
- Consistent dietary advice should be given by all members of the healthcare team
- Psychological counselling should be considered for the severely obese, as well as for those with other eating disorders such as diabulimia, bulimia and anorexia nervosa. It should be recognised in particular that these conditions are more common in people with type 1 diabetes than in the general population.

FOOD CONSTITUENTS – CARBOHYDRATES

Complex carbohydrates (starchy foods) require less insulin than simple carbohydrates (sugary foods) because of how they are digested and absorbed, and they are less likely to cause extremely high post-meal hyperglycaemia. Increases in dietary fibre not only promote optimal bowel function, but also may help with glycaemic stability.

Beans, pulses and bran-containing foods fall into this category, in contrast to faster-digested simple carbohydrates such as juices and fruits, milk sugars, corn and potatoes. Exchange lists often use the 'rule of 15' where one exchange portion provides approximately 15 g of carbohydrate. Thus, one slice of processed bread, one half cup of dried cereal, one small fruit or one glass of milk all provide approximately 15 g of carbohydrate. This is a simple fact that can be taught whether the patient or family are literate or illiterate. Consistency may be obtained using such exchange concepts.

SWEETENERS

All meal plans suggested for use by children and adolescents with type 1 diabetes agree that very concentrated sugar / carbohydrate or carbohydrate sources rich in simple table sugar (sucrose) should be drastically restricted (ie offering <10% of total calories). Because this is so different from the diet commonly followed by many young people, artificial sweeteners should be considered.

Nutritive sweeteners are cane sugar, fruit sugar (fructose), milk sugar (lactose) and sugar alcohols such as sorbitol. All of these except the sugar alcohols provide calories and raise the blood glucose level rather quickly and dramatically.

Non-nutritive (artificial) sweeteners generally have minimal or no caloric content, but produce a sweet taste and therefore can substitute for nutritive sweeteners. These include cyclamate, saccharine, aspartame, acesulfame-K and stevia. When eating artificially sweetened foods and snacks, however, it is still essential to pay attention to the other caloric content. Any other sources of carbohydrate must be

counterbalanced with appropriate insulin doses, and total calories from carbohydrate, protein and fat must be counted at that meal or snack.

FATS

The high incidence of vascular disease in people with type 1 diabetes is long-recognised, as is the association of hyperlipidaemia with chronic hyperglycaemic/poor glucose control (apart from genetic hyperlipidaemia). All of these conditions indicate the relation of diet and activity with high or low blood lipid levels. Genetic factors may be the most important influence, followed by the presence or absence of obesity.

Knowledge of the blood lipids of a child or adolescent helps to understand their individual risks, and knowledge of the family history also helps to place this in proper perspective. Decreasing animal-source saturated fats is beneficial as part of a meal plan for people with diabetes, setting limits on red and brown meats, animal skin, egg yolks, high-fat dairy products (milk, cheese, butter and margarine). Increasing fish and white meats such as chicken breast and turkey, and also soy-based products, should be encouraged, since these are often low in saturated fats. General fat content should usually be less than 30-35% of total caloric intake.

PROTEIN

No restriction of dietary protein is needed in modern meal planning for people with type 1 diabetes, although excessive protein has been associated with renal problems. Low saturated-fat sources of dietary protein should be provided and encouraged, but individual likes and dislikes as well as ethnic, regional, religious and national preferences must be taken into account. In general, protein intake should usually be about 10-15% of total energy intake.

MINERALS AND VITAMINS

Infants, children, adolescents and young adults do not usually have significant cardiac or renal problems and therefore there is hardly ever any reason for limiting sodium intake, although there may be individual exceptions, particularly if salt-sensitive hypertension occurs. Maximising intake of calcium and vitamin D helps promote cardiac health, brain function, bone mineralisation; it may also decrease incidence of cancer. Many children and adolescents are deficient in calcium and vitamin D because of dietary insufficiencies, as well as because of chronic hyperglycaemia and glycosuria.

Supplements, when available, can counteract such problems. Consideration for sequential measurements of vitamin D and bone density must take into account their expense and availability. Information about other trace minerals and vitamins is insufficient to make specific recommendations. A wide variety of food sources would tend to limit such deficiencies, and multiple vitamin / mineral supplementation may help, even if the deficiencies are difficult to diagnose with sensitivity and specificity.

DIETARY BEHAVIOUR AND COMPLIANCE

The tendency to ignore a suitable diet is often a major problem; arising either through mis-information, inconsistent messages from family, society or healthcare professionals or even direct confrontation. Interference with optimal glucose control is often diet-related. How food has been used within a family unit in the past could be an important factor in dietary precision and changing food-related behaviour and choices as part of a diabetes treatment programme.

Obesity often follows family patterns. Anorexia nervosa, bulimia and diabulimia may also be related to psychosocial parameters of the family unit as well as food constructs. Food should not be labelled as good or bad, but placed into categories relating to how it affects blood glucose control. Examples set by parents and other members of the family, and their support, often help to improve dietary compliance and understanding.

POVERTY-RELATED NUTRITION ISSUES

In many parts of the world, improved diabetes care is at least partly hampered by economic constraints. Food is not always available, or is too costly or too inconsistently supplied. This presents a major barrier to improved diabetes care, since deciding how much insulin to supply is essentially impossible without knowing how much food will be supplied at that moment. In most such situations, because of the financial problems, not only is food unreliably available, but monitoring is virtually non-existent. Whether or not insulin is available in these places is also doubtful.

The combination of all these factors places the child or adolescent with type 1 diabetes at high risk of chronic hyperglycaemia, because a common and reasonable response to inadequate food is to underdose insulin, avoiding hypoglycaemia. Efforts to address these issues are complex, societal and government-related; and remain extremely difficult for the family and the diabetes specialty healthcare team.

TO REMEMBER:

1: For most children and adolescents, diabetes meal planning is not a matter of calorie restriction, but rather a method for balancing activity and insulin needs, to regulate glucose levels and prevent the extreme conditions of hyperglycaemia and hypoglycaemia.

2: It is crucial to involve the family / caregivers as they prepare the meals.

3: Food should not be labelled as good or bad, but rather grouped in categories according to how they affect blood glucose control.

4: For adherence to meal planning, insulin should be adapted to food intake and lifestyle if possible, rather than food forced against insulin effects.

5: Diet planning must take into account that stress, anxiety, trauma and depression all affect appetite. Individualised approaches must take account of the eating pattern as well as the personal wishes of each child or adolescent.

6: Energy requirement and carbohydrate intake all increase throughout childhood as growth progresses; often with a dramatic increase at the time of puberty. This extra intake means that compensation with added insulin must follow, so that the imbalance created does not result in hyperglycaemia.

6.5 BALANCING DIET AND INSULIN – SOME EXAMPLES

OBJECTIVE:

- Understand how to match insulin to food intake

A FEW THOUGHTS TO START WITH:

- How can we match the insulin given to the child's or adolescent's preferences and lifestyle?
- What does the child or the adolescent (more on his/her own) need to know, to prevent hypoglycaemia?

LESS FOOD, LESS INSULIN, BUT BASAL INSULIN IS STILL NEEDED

Children with type 1 diabetes mellitus are typically not obese, although more and more adolescents with diabetes also struggle with extra weight than in the past. The aim of dietary advice for children and adolescents with diabetes in this condition is to try and match the insulin given with the food available rather than to force food to match insulin (like in the past).

About half of the insulin requirement each day is used to control glucose levels from eating (boluses for food). The other half is needed for the body to function normally, even when the person does not eat at all (basal needs between meals). This is called **basal-bolus insulin planning**. If a person is ill and insulin-resistant, the total amount of insulin needed may still be the same as on a normal day, even when the person is not eating.

Example 1:
Child or adolescent eating 3 meals / day

For a child or adolescent who is receiving 1 unit of insulin/kg/day and taking 3 main meals a day, the insulin for each meal is about 0.1-0.2 unit/kg/meal.

Ideally, a child or adolescent should take short-acting insulin for meal insulin, and intermediate or long-acting insulin for basal insulin.

Example 2:
Child or adolescent eating 1-2 meals / day

Some children or adolescents take only 1-2 meals each day. If the amount of calories consumed is age-appropriate, the total insulin for the meals can be divided into 2 instead of 3. However, if the child or adolescent is taking insufficient calories and skipping a meal because of inability to afford the food, the insulin amount should be reduced accordingly.

If the normal insulin requirement is 0.6 up to 1U/kg/day (in adolescents often even higher), but the parents are only able to provide 70% of expected calories that day, the child should be given 70% of the meal insulin + 100% of the basal insulin.

The total insulin for that day is then:
70% x 0.3 + 100% x 0.3 = 0.5 unit / kg / day.

Example 3:
Child or adolescent taking one large and one small meal/day

If the proportion of total daily calories a child or adolescent is taking (i.e. 2/3 and 1/3 respectively) the dose of short-acting insulin needed can be estimated as above.

TO REMEMBER:

1: If the insulin doses are fixed, the meals must also be fixed in time and quantity. Lifestyle must be adapted to diabetes treatment.

2: A combination of long-acting insulin covering basal needs, and short-acting insulin before each meal, allows a more flexible lifestyle.

3: If for any reason a proper meal is not available in time, at least fruit or sweets should be available in case of symptoms of hypoglycaemia.

6.6 STORING INSULIN

OBJECTIVE:

- Understand how insulin should be stored, in both the clinic and in the child's home

A THOUGHT TO START WITH:

- What temperature range is safe for storage of insulin?

KEEPING INSULIN AT ITS BEST

Insulin is a 'fragile' medication as it is a hormone that is denatured by both freezing and excess heat. It is essential to maintain a constant temperature near, but not below, freezing throughout the whole transport chain from the factory to the end user. **Ideally insulin should be kept at between 2-8°C (36-45°F).**

Insulin (regular, NPH and mixed) can be stored for about 30 months from the date of manufacture if kept under optimal conditions. Under less than optimal storage conditions, insulin will denature at a variable rate – in general the higher the temperature, the faster it will denature.

Once opened, a vial of insulin should ideally be used within 3 months. If not refrigerated, a vial of insulin should be used within 1 month of opening.

In practice, many people find that the potency of insulin (its ability to lower glucose levels) starts to deteriorate within 6-8 weeks of opening even with refrigeration, because of the constant change of temperature.

REFRIGERATION IN THE CLINIC AND AT HOME

Store the insulin in a refrigerator, in a section which is not prone to freezing. Freezing denatures insulin more rapidly than heat. The back of an old refrigerator is prone to ice formation, especially if the rubber seals are loose and if moist air freezes on the cooling coils, so insulin should not be placed close to the back.

Try to keep the temperature constant. It is good to keep a diary of the daily temperature range inside the refrigerator, taken with a mercury or digital thermometer (not a clinical thermometer).

If the power supply is prone to interruption, it is good to have a backup generator to maintain a low temperature. This is particularly important for refrigerators in larger clinics and hospitals.

Besides conventional Freon and CFC refrigerators using AC 110-230V current, other refrigerators that can be considered include:

- Propane / gas / kerosene fridges (these use ammonia as the refrigeration fluid)
- Dual power supply (gas and electricity)
- Solar-powered refrigerators
- Thermoelectric coolers (based on the Peltier effect: that electricity from a solar cell or 12V car battery can cause one half of a bimetallic strip to be cold and the other hot).

If power interruptions are frequent, there should be a clear plan for which staff member or volunteer is responsible for detecting the power failure, switching on the alternative power source and servicing the backup generator, and recharging the refrigerant gas in the refrigerator. The system should be tested at regular intervals.

A simple alternative to having a backup power supply is to have unfrozen coldpacks lining a cooler bag which contains the insulin, and the whole thing kept in the same compartment, so that the temperature is stabilised in the event of power failure. The coldpacks help maintain the temperature in the event of an undetected power loss.

The same principles can be applied when advising the patient how to store insulin in a home refrigerator.

WHEN REFRIGERATION IS NOT AVAILABLE

It may be necessary to find another storage method if a refrigerator is not available. Insulin can be stored in a special secure box buried near a river bank or suspended in flowing water. The water temperature will help keep the insulin cool but not frozen. It can also be stored in a container buried in the ground under a building or hut. In most places, ground under a building will be quite cool compared to the surroundings.

An alternative is within a plastic bag in an earthenware pot filled with water and hung in a well-ventilated place (eg under a shady tree). Evaporation of water from the semiporous earthenware pot will keep the insulin cool and at a constant temperature. A cloth bag or sack dipped into water at one end and hung up in a well ventilated, shady place would serve the same purpose. Insulin can also be kept in special cooler bags or pouches with water-based gels that become cool by evaporation.

ROTATING STOCK

Insulin should be stored by batches, to show:

- The date of manufacture
- The date of delivery to the clinic

Records should be kept to show when, where and how each batch of insulin arrived at the clinic, so that any loss of the cold chain will be revealed.

Insulin should be used or dispensed according to the 'first in, first out' principle: the oldest insulin should be dispensed first, bearing in mind that the insulin should not expire before the patient's next appointment.

TO REMEMBER:

1: It is essential to give clear instructions to the family of a child with diabetes on how to store the insulin responsibly, within the limits of the options available.

2: For the best length of storage and to preserve the potency of insulin, it should be stored at 2-8°C or 36-45°F.

3: Once opened, a vial of insulin should ideally be used within 3 months. If not refrigerated, a vial of insulin should be used within 1 month of opening.

4: It is advisable for the local project manager or person in charge of the clinic to test out the various methods of non-refrigerated storage and try to record the temperatures achieved using a thermometer, so that accurate advice can be given to patients.

SECTION 7

DIABETES AND THE GROWING CHILD

Family support is essential – and even more so in adolescence

SECTION 7 CONTENTS

7.1 DIABETES AND GROWTH FROM INFANCY TO ADULTHOOD

OBJECTIVE:

- Understand the implications of growth and maturation for diabetes treatment

A FEW THOUGHTS TO START WITH:

- Do insulin needs increase or decrease during puberty?
- Young people can give a higher priority to their immediate quality of life than diabetes control. How can risks be minimised?

GROWTH AND MATURATION

Growth during childhood and adolescence covers:

- Physical growth
- Maturation of organ systems
- Increase in understanding and intellectual maturity
- Puberty – changes toward physical, sexual and mental maturity.

If diabetes control is good, the child and adolescent should grow at the same rate and reach the same size as non-diabetic children and adolescents without diabetes in the same community. But if diabetes control is poor, growth may be impaired and puberty may be delayed. Observing the growth of the child and adolescent with diabetes, and their development and pubertal progress through the Tanner stages, is therefore extremely an important method of assessing the adequacy of the diabetes care (see Annex 10).

The insulin dose needs to be increased as the child grows bigger, taller and especially as he/she moves through the pubertal stages. During puberty the insulin requirement will be higher in terms of dose / kg body weight, but it will then decrease as the growth spurt ceases.

As the child and adolescent grows, increasing information and education about diabetes can be offered, but it should be adapted to the his/her increasing ability to understand and learn and assume more appropriate self-care. Removing parental supervision too early is frequently a major problem associated with life-threatening deterioration of diabetes control all around the world.

Physical growth in childhood and adolescence can be divided into four stages: in utero/infancy/childhood/puberty. Each stage is described in more detail on the next pages.

IN UTERO (40 WEEKS OR 9 MONTHS)

Weight gain: 0-3 kg (normal range is 2.5-4 kg)
Length gain: 0-50 cm (range is 47-53 cm or 67 cm/year
Median head circumference: 34.5 cm (boys) and 34 cm (girls); range is 32-37 cm (boys) and 31-36 cm (girls) (WHO data)*

A number of problems can arise during this period:

Prematurity
A baby delivered early will be smaller than a full-term baby. Premature babies may have a birth weight appropriate for their gestational age, or may be small or large for gestational age. Premature babies are all more likely to have early-onset puberty

Intrauterine growth retardation (IUGR), resulting in a small for gestational age (SGA) baby
The baby grows less than it should because of insufficient nutrition coming from the mother. The longer the period of intrauterine malnutrition, the more aspects are affected. The weight is affected first, then the length of the baby and finally the growth of the brain, reflected by a smaller-than-expected head circumference.

Children who were IUGR and SGA babies may need more insulin per kg than other children and be more likely to have later hypertension, insulin resistance and features of type 2 diabetes.

Large for gestational age (LGA) baby
The baby is larger than would be expected for the duration of gestation, and would be at risk of hypoglycaemia in the neonatal period. The mother may have had poorly-controlled diabetes in pregnancy, or unrecognised gestational diabetes. These children tend to have a higher risk of insulin resistance, impaired glucose tolerance and type 2 diabetes in later life.

* Useful growth standards are available at
http://www.who.int/childgrowth/standards/en/
and
http://www.cdc.gov/growthcharts

INFANCY

An average infant will double its birth weight by 5-6 months and triple it by 10-12 months. Breastfed babies tend to grow faster than bottle-fed infants during the first 2-3 months of life, and then more slowly during the rest of the first year of life.

Childhood illnesses, severe gastroenteritis and malnutrition will impair growth in the first year, and the child may remain stunted for life if catch-up growth does not occur.

A child born SGA or premature may be subjected to overfeeding during infancy, in an effort to overcome the poor size at birth. However, early excessive feeding in infancy is also associated with infantile obesity and a risk of later type 2 diabetes.

CHILDHOOD

In its second year, the child's rate of growth slows considerably. In the third year, it slows still further and will remain about 5cm/year and 2.5 kg/year till puberty starts. During this time, parents are often concerned about poor weight gain because they are used to the child's rate of growth in infancy. They need to be discouraged from overfeeding the child, as this could increase the risk of the child developing type 2 diabetes later in life.

PUBERTY

The physical changes of puberty can be described in a standardised way, using the Tanner Staging system (see Annex 10).

Girls start puberty between 8-13 years. The first change is breast development, then pubic hair appears, followed by underarm hair and then menstrual periods start at 10-16.5 years.

Boys start puberty at 9.5 to 14 years. Enlargement of the testicles begins first, followed by penis enlargement about one year later. Appearance of pubic hair usually comes around 13.5 years, while hair under the arms and on the face, voice change, and acne come around age 15 years. Nocturnal emissions (or 'wet dreams') start around 14 years. Testicular volume, established by comparison with ellipsoids of known volume (Prader's orchidometer) is typically about 4 ml at start of puberty and increases to 20-25 ml in adults. The penis, measured in the stretched flaccid state, increases from an average length of 6.2 cm in pre-puberty to 12.4±2.7 cm in white adults, and to 14.6 cm in black and 10.6 cm in Asian adults[1].

The pubertal growth spurt occurs during stages 3 to 4 of puberty (Annex 10) in most boys, and is completed by stage 5 in more than 95%. In girls, the pubertal growth spurt occurs during stages 2 and 3. In boys, growth in height can be as low as 3.5 cm/year before puberty. On average it increases from 5 to 7 cm during the first year of puberty, and approximately 9 cm during the second year. Boys show slower growth before puberty than girls. On averages, girls increase their growth to 6 cm during the first year of puberty, and 8 cm during the second year[2].

Pubertal delay is diagnosed if there are no signs of puberty by the age of 13 years in girls and 14 years in boys. The duration of puberty varies between 1.5–4 years. The total height gain during puberty is about 25-30 cm. By the time the first menstrual period occurs, a girl would usually experience a slowing down of the height increase and on average would only have another 5-6 cm of height to gain.

Pubertal delay may be caused by genetic factors, malnutrition, eating disorders, malabsorption, hypothyroidism and poor diabetes control.

Insulin requirements during puberty and the teenage years

During puberty, the increased secretion of growth hormone and testosterone in boys or oestradiol in girls can cause a physiological insulin resistance.

A child with diabetes who is going through puberty will require more insulin, sometimes up to 1.5 times or twice the previous dose. At the same time, the child undergoing pubertal changes is often taking up a competitive sport or outdoor activity, and the school timetable is increasingly complicated, with sports training, extra classes, tuition classes, music and dance lessons etc on different days of the week. Varying levels of activity on different days of the week give rise to different insulin requirements and a varying risk of hypoglycaemia. This raises the need for different insulin doses for active days and rest days.

Girls may experience fluctuating insulin sensitivity during their menstrual cycle. For example, the stress and pain of menstrual cramps may cause increased cortisol secretion and insulin resistance, while the mood changes, discomfort and lethargy may at the same time cause a poor appetite and decreased physical activity during the menstrual period.

Resources:
Annex 10 - Stages of puberty

TO REMEMBER:

1: During puberty, insulin doses may be 1.5 times or twice the dose than before or after puberty.

2: The school timetable for adolescents includes widely varying levels of physical activity on different days of the week. This means that the insulin requirement varies, and so does the risk of hypoglycaemia. Adolescents need to be aware of this and to discuss it with their teachers.

3: Girls may experience fluctuating insulin sensitivity during their menstrual cycle. This should be discussed during medical consultations.

References

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2 Stavrou I, Zois C, Ioannidis JPA, Tsatsoulis A. Association of polymorphisms of the estrogen receptor Î± gene with the age of menarche. Human Reprod 2002; 17: 1101-1105.

7.2 DEALING WITH DIABETES AT SCHOOL

OBJECTIVE:

- Understand the difficulties faced at school by children and adolescents with diabetes, and to advise school staff in providing support, in order to minimise non-attendance

A FEW THOUGHTS TO START WITH:

- How many schools in this area have pupils with diabetes?
- Do these schools know what to do in the case of an acute complication and do they have the phone number of the diabetes clinic?

RIGHTS AND RESPONSIBILITIES

The challenging task of caring for a child or adolescent with diabetes extends to all areas of the child's/adolescent's life, including education. It is crucial, therefore that a safe and supportive school environment is available for a child or adolescent with diabetes.

As diabetes is becoming more frequent among children and adolescents throughout the world, it is increasingly likely that schools are going to be placed in situations where the staff will be responsible for a child or adolescent with diabetes. For this reason it is desirable that all responsible individuals who are involved in their care should become familiar with the illness, its complications and be able to deal competently with acute complications. Poor management of emergencies may place the child or adolescent at considerable additional risk. As an unremitting, chronic illness, diabetes places considerable psychological stress on the child and family, which may influence his / her behaviour at school. Also, teachers are often filled with anxiety and nervousness when they are faced with a child or adolescent with diabetes in their class; information and training are the solution.

THE RIGHTS OF THE CHILD

The child has a **right to be admitted to a school** despite having diabetes. However, in societies where diabetes carries a stigma and where school authorities are anxious about having to be responsible for the child's or adolescent's diabetes, school attendance is still sometimes denied to children and adolescents with diabetes.

The child has the **right to receive appropriate care** for diabetes while at school.

The child has the **right to be fully integrated** into the school environment by ensuring his/her safety, involvement in all school activities, attainment of developmental goals, development of self-esteem and acceptance by peers.

THE RESPONSIBILITY OF THE PARENTS AND CARE TEAM

The parents and the care team are responsible for:

- Educating the teachers and others at school who will be caring for the child or adolescent with diabetes on aspects of the medical care, and on whether the child or adolescent is able to provide all or only parts of their own self-care while at school. This includes the essential need for insulin, regular meals and snacks and to be able to test blood glucose. The school personnel need education on appropriate management of acute complications (including hypoglycaemia and hyperglycaemia). Education must be done by the parents or care team, and not left to the child; although older children and adolescents can, and often should, participate in the educating their peers as well as their teachers.
- Supporting the school and teachers in their efforts to care for the child with diabetes in school. Details of management regimens, and contact details for parents and emergency care, need to be provided to the school.
- Making sure that there are enough supplies for the care of the child or adolescent in school, including (where needed) insulin (and lancets), glucose meters (and strips), and food in case of hypoglycaemia.

ISSUES TO BE DISCUSSED WITH THE SCHOOL STAFF

- General information on diabetes and its management
- Information on recognition, treatment and prevention of hypoglycaemia
- Information about the effect of other illnesses
- Information on hyperglycaemia and ketones
- Practical knowledge, and practice in glucose and ketone testing and insulin injections
- Information on the effects of diet and activity on diabetes
- Information on the social and psychological impact of diabetes.

Resources:
Annex 11 - Checklist - items needed for school

TO REMEMBER:

1: As diabetes tre atment is improving, children and adolescents with diabetes in developing countries will live longer. They have the right to study and gain access to good jobs on equal terms with other children and adolescents throughout society.

7.3 DIABETES AND EXERCISE

OBJECTIVE:

- Understand how to encourage children and adolescents to take physical exercise while minimising the risk of hypoglycaemia or hyperglycaemia

A FEW THOUGHTS TO START WITH:

- Can a child with diabetes play football?
- What are the safety procedures before, during and after exercise for a child or adolescent with diabetes?

EXERCISE IS A GOOD THING

Physical exercise is a common part of all children's and adolescents' lives and should be equally encouraged for those with diabetes. In addition to an improved sense of well-being, exercise may help with weight control, it limits the rise in glucose after meals, keeps the heart rate and blood pressure lower and helps keeping blood lipid levels normal. These factors may reduce cardiovascular risk and may be associated with a lower HbA1c.

EFFECT OF ACTIVITY ON DIABETES

Children and adolescents with diabetes are not able to self-regulate insulin effects during exercise. Insulin has been injected and is not regulated by the pancreas, and they have impaired glucose counter-regulation (ie they lack the glucagon response to hypoglycaemia). These factors frequently result in **hypoglycaemia** during or after activity. Hypoglycaemia is more likely to occur with prolonged or intense activity. Hypoglycaemia may also develop many hours after prolonged activity, if there is a delay in replacing glycogen stores in the liver.

However, excessive intake of carbohydrate, decreased insulin doses and the emotional responses to activity and competition may have the reverse effect and result in hyperglycaemia. Excessive sweating and decreased fluid intake may cause dehydration during activity. In the case of poor control and high glucose values, the exaggerated effects of counter-regulatory hormones may cause increased production of ketones.

FACTORS AFFECTING GLUCOSE RESPONSE TO EXERCISE

Duration
Prolonged activity (>30 minutes) is likely to result in a lowering of blood glucose (not necessarily hypoglycaemia, depending onthe blood glucose level at onset of exercise). Short periods of intense activity may cause a transient increase in blood glucose values.

Intensity of activity
Low-intensity activity is less likely to cause hypoglycaemia. Moderate and intense activity is more likely to cause hypoglycaemia, especially if prolonged.

Type of activity
Anaerobic activity (eg sprinting) by its nature lasts for very short periods and may cause an increase in blood glucose values (due to the release of the hormones adrenaline and glucagon). Aerobic activity (eg walking, jogging, and swimming) can cause a decrease in blood glucose values, both during and after the activity.

Metabolic control
Poor metabolic control often results in high blood glucose values and a low level of circulating insulin. Exercise under these circumstances can cause ketonuria.

Type and timing of insulin injections
The most likely time for hypoglycaemia to occur after insulin use depends on the type of insulin. Hypoglycaemia is most likely 2-3 hours after injection of a regular (soluble) insulin (eg Actrapid), or 40-90 minutes after rapid-acting analogue insulin (NovoRapid), Humalog, Apidra. Long-acting insulins (NPH, lente, ultralente, Monotard, glargine and detemir) have a much later and more variable peak action, although the newest insulins have less variability than the older ones.

Absorption of insulin:
A number of factors affect insulin absorption during activity, including:

- Choice of injection site: absorption is increased with injections close to muscles that are being exercised, and hypoglycaemia is more likely to occur. Injections away from the active muscle may produce a more consistent effect – eg the abdomen is a good site for injections before running
- Ambient temperature: high temperature will increase insulin absorption and low temperature will decrease insulin absorption.

Type and timing of food
A meal containing carbohydrate, fats, and protein consumed a few hours before activity will help to prevent hypoglycaemia. Fast-acting foods and fluids used prior to activity can provide the extra energy needed for short-duration activities. These are best given as isotonic drinks. No food, or inadequate food intake prior to activity, increases the likelihood of developing hypoglycaemia.

Degree of stress/competition involved
Stress hormones from the adrenal gland will cause an increase in blood glucose. It is not unexpected to have a high glucose level after competitive sport. In many cases this may be followed by late-onset hypoglycaemia, many hours later.

MANAGING EXERCISE AND ACTIVITY

With the large number of variables that can affect blood glucose values during exercise, it is not surprising that activity can produce very variable values in different children and adolescents. While a few basic guidelines need to be followed, children and adolescents may need an individualised way of dealing with activity. The cornerstone of dealing with activity in diabetes is monitoring:

- Ideally the child or adolescent should know his/her blood glucose value before participating in physical activity. This value will help to determine the food intake that would be required to prevent hypoglycaemia

- Some children and adolescents should snack before activities while others may do better snacking in mid-activity or even afterwards. For short, high-intensity activity, the snack should preferably be a fluid-based high energy drink. For a long duration of low-intensity activity, it should be food that is digested slowly eg fruit
- Activity may need to be interrupted about every 30 minutes for an additional snack or some juice or fruit. Treatment choices should be guided by frequent blood glucose monitoring rather than strict rules
- Blood glucose should be monitored 30-60 minutes after the end of the activity
- A low glucose value should be treated with additional rapidly-digested food (eg juice, soda or table sugar)
- After prolonged activity, the child or adolescent should have an additional snack before sleeping, with more fat or protein to last longer, and may also need to have extra blood glucose monitoring during the night
- Accurate records of activity, food intake and glucose values help the care team to assist with decisions about managing activity.
- The evening intermediate- or long-acting insulin dose often needs to be decreased after exercise in the afternoon or evening, especially if not exercising on a regular basis

TO REMEMBER:

1: The cornerstone of dealing with physical activity in diabetes is monitoring, so that treatment is based upon individual blood glucose results.

2: If blood glucose monitoring is not available, the child should be encouraged to participate in a lower-intensity activity, or extra food should be provided at appropriate times to avoid hypoglycaemia at particularly dangerous times, ie several hours later, in the middle of the night. Taking care not to sleep late the next morning after particularly strenuous activity will also prevent some severe episodes of hypoglycaemia the next morning, by allowing them to be more easily recognised.

3: All activity should allow snacking/eating every 30 minutes during activity.

4: An alternative way to prevent hypoglycaemia during or after exercise is to reduce the dose of short-acting insulin before the activity by an amount dependent on the intensity and duration of the activity.

5: Physical activity should be limited or avoided if:
- there is an acute illness
- blood glucose is high or low before the activity
- ketones are present
- the patient is dehydrated
- there is inadequate food for the duration of the activity or as compensation afterwards.

7.4 DIABETES AND ADOLESCENCE

OBJECTIVE:

- Understand the difficulties experienced by adolescents in controlling diabetes

A FEW THOUGHTS TO START WITH:

- If I had diabetes when I was in my adolescence, would I have followed the doctor's recommendations?
- If I was the parent of an adolescent with diabetes, what would be my major concern?

ADOLESCENTS WITH DIABETES HAVE SPECIAL PROBLEMS

Diagnosis of diabetes in children and young people in their teens is often missed, and many have shown polyuria, polydipsia, nocturia and even enuresis with unexplained weight loss for weeks before diagnosis. Severe dehydration, progressing to diabetic coma from unrecognised diabetic ketoacidosis, can be prevented if the symptoms can be recognised, and confirmed by blood or urine analysis.

Treatment goals for adolescents with type 1 diabetes are the same as those for younger children. They include lowering glucose levels without causing excessive or severe hypoglycaemia; efforts to set up a balanced meal plan against which insulin can be delivered, and promotion of normal growth and development.

Those who have had diabetes for some years are at risk of diabetes-related complications, so **systematic monitoring** for eye, renal, cardiac, neurological and other problems associated with chronic hyperglycaemia must be planned and put in place. Healthcare professionals should give attention to the medical history, physical examination and specific monitoring (at least annually) for retinopathy and cataracts, hypertension, protein leakage and kidney failure, as well as lipid and neurological problems. Knowledge of the history of glucose control helps to place such patients into risk categories, and helps to identify complications and initiate appropriate individual treatment.

Adolescents need to be re-taught the 'rules' of diabetes and to begin accepting **more responsibility for self-care**. Parents and other adult carers should gradually take less of the initiative for routine diabetes care and accept more of a secondary supporting role. Giving too much responsibility to children too early is a common mistake, but not giving appropriate responsibility as children become more independent in their self-care can also cause problems. The difficulty parents have in handing over supervision to the adolescent is one of the most common factors leading to poor

glucose control and noncompliance with monitoring, use of insulin and other medications, and meal planning. However when their self-care is not adequate, or when other complications occur, parents and others in the family may need to step back in and supervise diabetes care directly, if long term complications are to be minimised.

Healthcare providers should also be aware of specific ethnic and cultural patterns relating to food and family health. Education and re-education for the adolescent on a routine basis should be considered, and attention to peer pressure on issues such as alcohol, cigarettes, marijuana and others must be included (see Chapter 7.5). Adolescents begin to have some awareness of the future, but many act as if their decisions do not have long-term consequences. Issues of sexuality and contraception, preventing pregnancy and treatment for young women also become important considerations, and should be addressed systematically by healthcare providers. Meeting with other adolescents also can be extremely helpful and a sense of isolation can be overcome, either in a camp setting or at the clinic, where informal or formal support can be offered. Internet web sites can also allow some exchange of information and support related to diabetes; particularly those run by large nongovernmental organisations.

CHOICE OF INSULIN TYPE

The availability of insulin often dictates which insulin regimen is to be started for treatment of young adolescents. Ideally, basal + bolus insulin therapy (ie regular insulin before meals and NPH twice daily or prandial analogues such as Novolog, Humalog or Apidra plus basal analogues such as Levemir or Lantus) provides the best flexibility, based upon frequent pre- and post-prandial blood glucose monitoring, insulin kinetics, food intake, and activity.

However, twice-a-day or three times-a-day insulin regimens also can work successfully in school-age children with type 1 diabetes, using regular insulin and NPH or long-acting insulin, if that is what is available. Similarly, premixed regimens may also be utilised, but with an obvious decrease in flexibility. Dogmatic use of one or another type of insulin regimen should be avoided.

MONITORING BLOOD AND URINE

Blood glucose monitoring is as important for adolescents with type 1 diabetes as for younger children. Minimum monitoring of glucose in either urine or blood might be a twice-a-day routine, before breakfast and the evening meal - the two times when most adolescents will potentially need to make a decision about fast-acting meal-related insulin and / or carbohydrate intake according to their next few hours of activity or food.

Urine testing for ketone analysis, if available and affordable, is taught to all adolescents, using ChemstripuK (Roche), Ketostix (Bayer) or Acetest tablets (Bayer). This should be used for monitoring during illness, or whenever blood glucose levels are > 240-250 mg/dl or 13-14 mmol). More recent availability of blood ketone test strips that use small drops of capillary blood with a meter enables very accurate determination of ß-hydroxybutyric acid (Precision Xtra or Optium (Abbott Medisense). An added benefit of this test is the potential to identify impending ketosis sooner than by urine testing.

FOOD

Educating adolescents about carbohydrate counting and the glycaemic index of foods is important as they develop independence. Adolescents can be taught how to make such adjustments themselves, to use blood glucose monitoring to help them to learn and get feedback on their choices. The glycaemic effects of different ethnic and regional foods must be learned, and insulin doses adapted accordingly. If multidose insulin or use of an insulin pump is not possible and twice-daily insulin is the only option, then more day-to-day consistency of food is essential. But in some situations even this is problematic, and insulin must be adjusted daily, depending upon food availability.

Most adolescents need more food at the time of their pubertal growth spurt, both because of physiological changes and as a result of their involvement in sports and other activities. Girls move through puberty a few years earlier than boys and need such caloric boosts sooner than do boys, but they then have difficulties cutting back these calories and struggle more with obesity issues by mid- to late puberty. Boys often need increasing food for several more years. However, obesity issues can affect both boys and girls, and attention to plotted weight and height data, weight/height comparisons and body mass index calculations remain important; particularly if other members of the family are overweight or obese.

Special events such as holiday or religious feast meals, birthdays and school parties can be planned and adjusted with activity and/or insulin worked into the regimens. Adolescents can be taught how to make such adjustments themselves, to use blood glucose monitoring to help them to learn and get feedback on their choices.

EXERCISE

Physical activity is fun and should be promoted for diabetes care as well as for general health; particularly to decrease cardiovascular and renal problems. Formal or informal sports activities can be incorporated into the diabetes regimen, with appropriate adjustments based upon blood glucose monitoring, insulin and food choices. See Chapter 7.3 for further information.

HYPOGLYCAEMIA

Hypoglycaemia fears, common in adolescents with type 1 diabetes, can interfere with achieving glycaemic goals, resulting in deliberate overeating and / or inadequate insulin use. Healthcare providers should

recognise this problem as a significant barrier to improved glucose control, and discuss it with young people.

Because of this fear, blood glucose target goals must be high enough to ensure a margin of safety and to minimise hypoglycaemia, just as with younger patients, especially if frequent monitoring is not possible. If moderate or severe hypoglycaemia occurs as a result of attempting to intensify insulin therapy, goals must be redefined to avoid recurrence.

Healthcare providers must continue to modify the targets and to set reasonable targets for the individual patient and family circumstances. These will depend on affordability, availability, interest of the patient and ability to make use of the results of monitoring to achieve safe diabetes care goals, in the short term and over a long period.

ADA and ISPAD guidelines suggest that haemoglobin A1c measurements should ideally be obtained at least every 3-4 months.

The dose of glucagon for moderate or severe hypoglycaemia for a teenager is 0.5 – 1.0 mg intramuscularly or subcutaneously, and can be given anywhere in the body. If given intramuscularly, this may speed up absorption time. Parents and anyone else responsible for adolescents with type 1 diabetes should be taught how to use glucagon for such emergencies, if it is economically available and can be safely stored.

Because glucagon is not often used, it is wise for parents to have annual refresher training to re-learn when and how it is used.

POOR GLYCAEMIC CONTROL

Causes of chronic and sustained poorly-controlled diabetes, with chronic hyperglycaemia and/or excessive or severe hypoglycaemia are the same in adolescents as in younger or adult patients. Severe noncompliance, lack of education about treatment and goals, concomitant illnesses including psychological problems, depression, learning problems, physical or sexual abuse can all contribute to poor glycaemic control, as can economic or psychological problems in other members of the family.

The adolescent must be fully involved in any re-education or insulin adjustment as well as the parents. Without his active involvement and commitment, no improvement can be expected. Noncompliance negates diabetes control, even if sufficient insulin is otherwise available and provided.

The bullet points below list some specific clinical causes of uncontrolled diabetes in adolescents from 13-18 years of age, with asterisks next to those which are commonly associated with ketoacidosis if not properly treated:

- *concurrent infections – the most frequent cause of DKA
- *inadequate routine monitoring (due to poverty or parental inadequacy)
- *surgery or severe trauma
- *cortisone-like medications (eg for asthma or hives)
- lipohypertrophy interfering with insulin absorption
- failure to increase insulin for growth spurts, or lack of medical follow-up
- abnormal counter-regulation
- major emotional turmoil (parental divorce, child abuse or neglect, parental alcohol or drug abuse, depression)
- hypoglycaemia fears (and thus inadequate insulin provision)
- insulin being bound and released sporadically by the body
- other serious concomitant illnesses (sickle cell anemia, malaria, coeliac disease)
- alcohol, marijuana and other substance abuse
- pregnancy.

TO REMEMBER:

1: Adolescents experience the same issues in diabetes control as younger children. But for adolescents they are more difficult, because of the other factors relating to growing maturity and independence, and the societal and psychological stresses of growing up.

2: Young people need to be re-taught the ‘rules’ of diabetes and to begin accepting more responsibility for self-care. At the same time their parents should gradually relinquish their direct supervisory role.

3: Hypoglycaemia is a common and major fear for young people, leading to mismanagement of food and insulin. It is especially important to prevent or minimise hypoglycaemic episodes.

4: Peer pressure on alcohol, marijuana, nicotine and drug-related issues, as well as sexuality, interact directly with diabetes care and outcomes.

7.5 DIABETES, NICOTINE, MARIJUANA, ALCOHOL AND DRUGS

OBJECTIVE:

- Understand that the peer pressure on adolescents to experiment with alcohol, tobacco and drugs is the same for those with diabetes as for all those without diabetes, but with added risks

A FEW THOUGHTS TO START WITH:

- Does marijuana affect blood glucose level?
- Before going to a party where he/she with diabetes will be drinking alcohol, should an adolescent with diabetes increase or decrease the insulin dose?

SOCIAL PRESSURES AND DRUGS

Marijuana and alcohol use may depend upon availability, costs and societal attitudes. It is important to remember that experimenting may start in 9-10 year-olds, with patients assuming that this is not a topic to be discussed in a diabetes clinic or even by a healthcare worker of any kind. However, there is no reason to think that adolescents with diabetes will be different from any other young people.

Challenging their behaviour is less important than empowering discussion and encouraging fact-sharing and decision-making for themselves. The focus of discussion should be on the effects of alcohol and drugs on blood glucose, being out of control, sexual consequences, hypoglycaemia consequences, driving; and equally on the benefits of promoting self-esteem and self-care rather than following the crowd.

Peer pressure discussions are quite intriguing and may open up other avenues of discussion about family, friends, laws and society issues. Open-ended queries are particularly useful: how many of your friends smoke? Drink? Do you? Healthcare workers, including physicians and nurses, may need to take several sessions to explore these subjects until they are viewed by the young people as safe to discuss and unlikely to generate a lecture or scolding.

To explore the relationship of diabetes with substance abuse, focus on blood glucose self-monitoring to make patients their own detective. Use as a typical question: I wonder what happens if you check your blood glucose after beer (wine/palinka/vodka/marijuana?)

Psychologists have suggested that it is helpful to practise ways of resisting social pressure for unhealthy behaviour such as using drugs, eg by becoming used to feeling 'I'm tough enough NOT to smoke, and don't need to, just because everyone else is smoking.')

ALCOHOL

Alcohol is often associated with being sociable, relaxing and escape, and it decreases social anxiety and day-to-day worries. Abuse of alcohol in mid- to late teens is not uncommon. But social drinking of this sort and drunken partying (bingeing) are not the same. The carbohydrate content of the alcoholic drink or mixer causes a relatively rapid glucose rise for several hours shortly afterward, and then a decrease. Because of later metabolic effects of alcohol on the liver, that can no longer generate glucose, glycogenolysis is slowed and correction of hypoglycaemia impaired or impossible. So the later effects of alcohol directly contribute to, but do not cause, severe hypoglycaemia, including loss of consciousness and convulsions which are separate from alcohol intoxication per se.

Rescue from this condition by glucagon is often impaired, as is the adrenergic and growth hormone response to attempt to correct the hypoglycaemia. What might have been a mild hypoglycaemic event several hours after alcohol is ingested, could then become a severe hypoglycaemic episode, without of the body being able to correct the hypoglycaemia because the 'liver is busy'.

Alcohol also provides about 7 calories/gram, so frequent alcohol intake also can have an effect on weight. Beer and wine are more slowly absorbed from the stomach than spirits; carbonated mixers increase alcohol absorption.

Use empowerment techniques and open-ended non-judgemental questions to convey a sense that the young person is in control. For example, ask them to consider "Should I drink?" rather than "Can I drink?", and "What do I do to balance the risks/control the amount/drive safely/make a bargain with my friends?"

Suggest they develop strategies, like: "What alternatives can I consider?", "How can I be safe?", "Check blood glucose before going to sleep", "Do not sleep late tomorrow" and "Make an extra effort to prevent nocturnal hypoglycaemia".

Separate out the issue of bingeing or deliberate drunkenness. The association of drinking with depression, anxiety, post-traumatic stress disorder, family/school stress, sexual or physical abuse also need to be explored; particularly if alcohol use is frequent or associated with other psychological or emotional issues. Poor judgement is a key issue in relation to diabetes self-care and alcohol, as well as late hypoglycaemia.

SMOKING

The general risks of nicotine are that one package of cigarettes per day doubles future cardiac risk and increases future emphysema risk by ten times. Smoking increases risk of all cancers, not just lung cancer.

Several research studies report that pre-teens, adolescents and young adults with diabetes smoke at about the same prevalence as those without diabetes, even though there is more contact with healthcare professionals and (probably) more future cardiovascular risk when combining nicotine and hyperglycaemia. The diabetes-specific problems of nicotine are long-term increased micro- and macroangiopathy, chronic hyperglycaemia, hypertension and/or hyperlipidemia. The addictive potential for nicotine is no different for those with or without diabetes.

MARIJUANA

Marijuana is perceived as a mild, non-habituating drug and is almost universally associated with social relaxation and 'being cool'. Excessive or frequent use correlates with the same list of problems as with excessive or frequent alcohol use: school and learning difficulties, behaviour problems, depression, low self-esteem, anxiety, family/peer interactions and socially deviant behaviour.

TCH (delta-9-tetrahydrocannabinol), the main active chemical in marijuana, is stored in fat, brain and testicular tissue for more than a month. Marijuana smoke contains more than 150 chemicals, including carcinogens. The general effects of marijuana are almost always pleasant and include elation, euphoria, giddiness, sleepiness and hunger – 'the munchies'. Marijuana use is also associated with impaired short-term memory, distorted time perception, loss of judgement, poor task performance (driving) and problem-solving; such effects are universal but usually not acknowledged by marijuana smokers.

Hunger experienced is not from hypoglycaemia but due to its effects on receptors in the brain; it stimulates the need to eat, and overeating can lead to hyperglycaemia. The hours after smoking marijuana involve mild hyperglycaemia even without overeating, but it is not of sufficient magnitude or duration to cause much harm to those with diabetes. Large amounts of food eaten without appropriate insulin or exercise compensation is almost always associated with post-marijuana hyperglycaemia. Poor judgement when stoned is the key behavioural issue to discuss when marijuana use is contemplated – self-care, by definition, cannot be at its best.

OTHER DRUGS

Other substances generally either raise blood glucose level (amphetamines, hallucinogens, cocaine) or have no direct effect on blood glucose (barbiturates, heroine, narcotics). Addictive potential is enormous. Psychosocial problems usually interfere with diabetes self-management at the time of drug use and immediately thereafter, and if these substances are in prolonged use, they may move diabetes care issues so far away from reality that the dangers increase. During use of these drugs, recognition and treatment of hyperglycaemia and hypoglycaemia become unimportant and nearly impossible.

Some substances, particularly the cardiovascular stimulants (the 'uppers') also have direct effects on the heart and the circulatory system. Any inherent microvascular or macrovascular damage might be cumulative or additive if cardiac dysfunction, circulatory occlusion or hypertension was present. When dealing with chronic use of these substances, professional psychological assistance may be required if abuse becomes more and more invasive and interfering with day-to-day function.

TO REMEMBER:

1: Alcoholic drinks cause a relatively rapid glucose rise for several hours shortly afterwards. But because of late metabolic effects of alcohol on the liver, alcohol directly contributes to, but does not cause, severe hypoglycaemia, including loss of consciousness and convulsions, which are distinct from alcohol intoxication per se.

2: Young people with diabetes should be advised that after a party with alcohol, they should check blood glucose before going to sleep. They should also not sleep late next morning, and take steps to prevent nocturnal hypoglycaemia.

3: Stopping smoking is strongly recommended.

7.6 DIABETES AND PREGNANCY

OBJECTIVE:

- Appreciate the importance of offering counselling and information about contraception and the effect of diabetes on pregnancy and the unborn baby, to young people with diabetes from the time of mid-puberty

A FEW THOUGHTS TO START WITH:

- If my daughter, who has diabetes, became pregnant, would she know about the risks involved?
- Can I help to explain the implications of pregnancy to young people with diabetes in my community?

COPING WITH TEENAGE PREGNANCY AND DIABETES

Diabetes in pregnancy, especially in an adolescent girl, poses particular challenges. Young women with type1 diabetes have increased risks during pregnancy, which start from conception and continue until after delivery.

The risks
(items marked* are specific for type 1 diabetes)
For the mother:

- increased risk of hypertension in pregnancy
- urinary tract infections
- increased risk of later type 2 diabetes (following gestational diabetes)
- preterm labour
- polyhydramnios
- macrosomia (big baby syndrome) and increased likelihood of Caesarean section
- DKA, which carries a high risk of fetal death*
- progression of microvascular complications (eye disease and renal disease)*

For the baby:

- trauma at delivery including fractured clavicles and upper limbs, Erbs palsy
- hypoglycaemia
- hypocalcaemia
- neonatal jaundice
- respiratory distress
- polycythaemia
- increased risk of type 2 diabetes in later life.

PRE-PREGNANCY COUNSELLING

In the light of these increased risks, **unplanned pregnancies should be avoided**. Counselling from mid-puberty should include discussion on contraception and the effects of diabetes on the pregnancy and the baby. Girls with diabetes should particularly be made aware that poor diabetes control around the time of conception increases the risk of having a baby with congenital abnormality and of miscarriage and late stillbirths. Ideally, effective (tight) blood glucose control is needed from before conception to after delivery.

Abstinence from sexual contact and the use of effective contraception should be part of routine education for all adolescent girls and young women with diabetes. In countries with high rates of HIV infection, this should include advice on the use of condoms.

For **planned pregnancies**, the diabetes should be monitored by an experienced team from pre-conception and throughout the pregnancy. Conception should wait until blood glucose has been well controlled, and young women with diabetes should seek medical care as soon as they are aware of pregnancy.

Establishing good control from as early in the pregnancy as possible will reduce risks of the complications listed above.

Poor diabetes control in later pregnancy places the baby at increased risk of intra-uterine death (stillbirth), also of complications during delivery and after birth.

Young women with diabetes should also be made aware that pregnancy may accelerate the progression of their own microvascular complications; particularly eye disease and renal disease.

The **genetic implications** of diabetes should be discussed with the prospective parents, prior to or during the pregnancy.

TO REMEMBER:

1: Because of the serious risks to both a mother with diabetes and her baby, particularly if blood glucose control is not good, unplanned pregnancies should be avoided.

2: Pregnancies for a mother with diabetes should be closely monitored by an experienced diabetes team.

3: Young girls with diabetes should be offered counselling from mid-puberty with discussions on contraception and the effects of diabetes on the pregnancy and the baby.

7.7 ADOLESCENTS WITH DIABETES, FASTING FOR RELIGIOUS REASONS

OBJECTIVE:

- Understand the implications, for young people with diabetes, of the risks involved with fasting for Ramadan and other religious reasons (ie Yom Kippur fasts for Jewish people); and strategies for managing diabetes on these occasions

A THOUGHT TO START WITH:

- I want to fast for Ramadan, but how will I cope with my insulin and meals?

CHOOSING TO FAST

Children and adults with a medical illness including diabetes are not required to fast during Ramadan. However, older children, adolescents and adults may choose to observe the Ramadan fast. People of other faiths may also want to fast at various times for religious reasons.

It is important to remember that insulin is required by the body, both when eating and when fasting, as glucose is being used by the cells throughout the day. More insulin is needed after a meal to deal with the extra glucose from digested food. During fasting, food is not consumed at the usual times, so the insulin doses need to be adjusted so that the body does not receive a large dose of insulin at times when no food is being taken. It is also necessary to increase the amount of insulin given before breaking fast in the evening and before the pre-dawn meal.

AVOIDING HYPOGLYCAEMIA AND DIABETIC KETOACIDOSIS

Hypoglycaemia is a particular risk whenever not eating at the usual time, especially if still physically active. Lack of sufficient insulin at mealtimes during Ramadan may also cause diabetic ketoacidosis.

A useful schedule is to test blood glucose:

- just before breaking fast in the evening
- before retiring for sleep, and
- just before the pre-dawn insulin injection is give
- before the pre-dawn meal.

Tests for blood glucose and ketones in the urine or blood should be done if feeling faint or ill, or if passing more urine than usual.

PRACTICAL TIPS FOR FASTING DURING RAMADAN

Most people will continue to take approximately the same amount of food per day during the fasting month. In fact, some individuals may gain weight. For this reason, the total daily dose of insulin should remain the same, but those who find themselves eating less during the fasting month should reduce the total daily insulin dose by 10-20%, especially if they are physically very active.

Fasting is during the daylight hours, so for those living in temperate lands where the day is longer, the amount of long-acting insulin may need to be reduced to avoid hypoglycaemia.

A: For those on a twice-a-day insulin regime, switch the morning and evening doses. For example, if a person is on twice-a-day long-acting insulin (eg Insulatard) and rapid acting insulin (eg Actrapid):

Normal doses:
Insulatard 16 units + Actrapid 8 units in the morning, and
Insulatard 8 units + Actrapid 8 units before the evening meal

Ramadan doses:
Insulatard 8 units + Actrapid 8 units before the pre-dawn meal,
and
Insulatard 16 units + Actrapid 8 units at evening breaking fast.

B: If a person is usually on a 3-4 injections a day, the total daily dose of insulin should be calculated, and about half should be given as long-acting and half given as short-acting insulin. For example:

Normal doses:
Insulatard 8 units twice daily + Actrapid 4 units at 3 main meals

Ramadan doses:
Insulatard 8 units + Actrapid 7 units at evening breaking fast
Insulatard 8 units + Actrapid 5 units before the pre-dawn meal

The suggested doses are just a guide for the first few days of fasting. Adjustments in dose are often needed after the first few days, based on the results of the blood glucose tests, since every person's insulin sensitivity, food intake and energy expenditure is different.

TO REMEMBER:

1: If the child/adolescent chooses to observe the fast, then it is very important to prevent hypoglycaemia and diabetic ketoacidosis

2: If the child/adolescent chooses to fast, this should be discussed with the doctor, the parents and the local religious authority in good time, in order to prepare and plan

3: Fasting during Ramadan will mean that insulin doses and timings need to be changed, in order to allow for the long period without food, the breaking of fast and the meal before dawn

4: Early breaking of fast is permitted on medical grounds

5: Regular testing is important for the safety of the child/adolescent.

PART 4

ORGANISATION OF DIABETES CARE

PART 1 CONTENTS

SECTION 8
CLINIC ORGANISATION

How to create a friendly, adequately equipped environment for the care of children

SECTION 8 CONTENTS

8.1 EQUIPPING A DIABETES CLINIC SUITABLE FOR CHILDREN AND ADOLESCENTS

OBJECTIVE:

- Consider the basic equipment needed for a diabetes clinic for children and adolescents

A FEW THOUGHTS TO START WITH:

- Is our equipment appropriate for children and adolescents with diabetes?
- Can we measure blood pressure in children and adolescents?
- Are the weighing machines and height scales calibrated regularly?

EQUIPMENT NEEDED

The following sections provide an overview of the equipment needed for healthcare facilities at various levels of complexity in a less-well resourced country, providing care for children and adolescents with diabetes.

FOR A FRONTLINE FACILITY

(part of a general healthcare centre or clinic; 0-5 diabetes patients)

It is envisaged that the main follow-ups for known diabetes patients will be at a different centre from this frontline facility. However there may be one or two known diabetes patients in the village or town, and new patients needing diagnosis and treatment might present here before referral to a larger centre.

The following equipment would be needed:

- Blood glucose meter with supply of glucose test strips
- Urine glucose, ketone and urine protein strips
- Benedict's solution, test tube and spirit lamp. The Benedict's solution is recommended because it will not have an expiry date and can be used in an emergency for diagnosis and assessment of control.
- Blood pressure set with child cuff , adult cuff and extra-large cuff
- Weighing machine (spring type)
- Height scale (tailor's measure and set square)
- Height and weight charts
- Regular insulin
- Long-acting insulin
- 100 U/ml syringes with IM needles (21G, 23G) and SC needles eg 27G, 29G, 30G or 31G) for injection of insulin
- Drip setting equipment with normal saline, Ringer's lactate or fixed ratio saline/glucose- and potassium-containing IV fluid
- Algorithm charts for diagnosis of diabetes mellitus, displayed in a prominent location
- Algorithm for emergency treatment of diabetic ketoacidosis or diabetes patients with other concurrent illness; displayed in a prominent location in the emergency treatment/triage area/high dependency ward area
- A tested communications chain, with access to a facility where the staff are familiar with treatment of childhood diabetes
- Paper-based recording system.

FOR A CHILDREN'S AND ADOLESCENTS' DIABETES CLINIC

(part of a dedicated diabetes clinic or service in a district hospital; 50-100 patients)

This level of care would probably be part of a quality controlled, funded project delivering standardised care to a larger group of patients from the surrounding region. It would be reporting demographic and outcomes data to a central registry and would have a project manager responsible to order supplies, collect and record data and distribute insulin, needles and syringes. This level of care would have dedicated refrigerated storage for insulin and secure storage for glucose monitoring supplies, as well as a desktop computer and perhaps internet connection.

At least one or more clinic personnel would have attended a specialised workshop on the care of diabetes in childhood, and an outreach education programme would be in place to educate workers actively in the surrounding primary care facilities.

Staffing at this level should include one healthcare worker whose job description allows some time for administering the data collection and management of stocks of medications etc.

The following additional facilities would be recommended:

- Glucose meters, for clinic use and short-term loan
- Supply of glucose strips for diagnostic use in clinic
- Facilities for collecting and sending filter paper strip samples for HbA1c determination
- Urine microalbumin strips / proteinuria strips
- Urine glucose and ketone strips

- refrigerated storage and insulin supplies to last twice as long as the resupply interval (eg 4 months' supply if the clinic is resupplied from the central stores every 2 months)
- a proper stadiometer (height measuring device) which has been calibrated (eg using a standard length of pole)
- preferably a balance beam scale or electronic scale for measuring weights down to 0.1 kg. An ophthalmoscope and a basic podiatric diagnostic setup (eg foot care and sensation chart, monofilament, sample of recommended footwear) should be available
- a point-of-care HbA1c machine may be preferable but is not essential at this level. If not available, then the ability to send filter paper HbA1c samples to a central laboratory would be useful.
- the ability to send samples for annual complications screening (thyroid function, U/E/Cr, urine microalbumin) would be useful
- a computer to enter demographic data as part of a central registry
- a computer programme to track attendees and defaulters.

FOR DIABETES INPATIENT CARE

This level of facility should be able to deal definitively with diabetic ketoacidosis. The following additional facilities would be recommended:

- A blood ketones meter is preferable
- A ward-level blood glucose meter is essential, in addition to any blood glucose meter kept in the clinic
- Access to a hospital or point-of-care laboratory measurement of electrolytes and in particular serum sodium, potassium and bicarbonate (U/E panel) is essential for proper treatment of DKA.
- IV fluids for DKA (Normal saline, 5% dextrose saline and IV potassium chloride 7.45% strength, or fixed-ratio dextrose/saline /potassium solutions or Ringer's lactate are necessary. Please refer to the DKA protocol for details)
- IV infusion pump for insulin is preferable; if not then a 3-way tap or Y connector to deliver insulin and IV fluids would be needed
- There should be a wall-mounted or otherwise easily accessible chart as a guide for insulin doses and IV fluid replacement in the ward where diabetes is being treated
- Copies of the treatment algorithm that can be sent with the patient to the next healthcare facility, indicating what has been done for the patient and what needs to be done next.

TEACHING

The following equipment is needed for diabetes education:

- Algorithm charts for the routine diabetes clinic visit, the sick child with diabetes, the DKA patient, teaching charts for insulin injections, information leaflets for the school, teaching charts on blood and urine testing and simple dietetic advice for the local context. Recording booklets for each patient to bring home
- An associated diabetes support group is useful at this level to build community support and awareness of the programme, as well as to provide holistic care (eg employment opportunities for family members of the diabetic child)
- Teaching charts and Powerpoint presentations for healthcare worker outreach and patient education would be essential.

TO REMEMBER:

1: Good diabetes care can be delivered by motivated professionals in a primary care setting with basic equipment.

2: Teamwork, efficient organisation, a quality control programme and effective maintenance are more important than sophisticated biomedical equipment.

8.2 ORDERING INSULIN

OBJECTIVE:

- Understand how to estimate the amount of insulin that will be needed in your clinic

MAINTAINING THE SUPPLY OF INSULIN

Insulin is a life-saving drug. It is crucial to order and keep adequate supplies at the clinic to cater for all existing and new patients, who may come before the next batch of insulin arrives.

Insulin needs to be transported and stored at 2-8ºC. It has a limited shelf life of approximately 30 months from the date of manufacture.

Excess stocks of insulin should be returned as soon as it is confirmed that they are not needed.

CALCULATING WHAT WILL BE NEEDED

The clinic or hospital should ideally have on hand at least double the amount needed by the hospital between resupply intervals. For example, if the central medical supply store will send supplies of insulin to the hospital every four months, then the programme director should aim to have on hand enough supplies for existing and projected patients for an eight-month period.

A THOUGHT TO START WITH:

- Do I know how many insulin vials were used last year in the centre?

Two groups of patients will require insulin:

- existing patients, who get their supplies through this clinic or hospital
- new type 1 diabetes patients

Children can be expected to require an increasing amount of insulin as they grow. Type 1 diabetes patients with other concurrent illnesses or diabetic ketoacidosis will temporarily need higher doses of insulin.

Necessary information for calculating insulin requirements:

1. How many vials or units of insulin did the centre use last year? Was it enough?
2. During which months of the year was there a shortage of insulin? Do you know the cause?
3. How many patients are in the clinic or centre now?
4. How many new patients tend to come each year (on average)?
5. When making the calculations, bear in mind the following:
   a. If information about the total number of patients per year is not available, estimate it from the number of patients in the last month x 12, or the number in the last 3 months x 4, and so on.
   b. If patients come on average every 3-4 months to collect medicine, the number of patients over the last 3-4 months will be the number of patients in your clinic.
   c. Some places get seasonal surges – eg due to weather, road conditions and so on.
   d. As type 1 diabetes (among others, in children) becomes more widely recognised, there may be an increasing number of patients diagnosed. (Before type 1 diabetes was well recognised, patients may have died before they could be diagnosed.)

Ideally, orders for the coming year should be based on the following information:
(number of current patients + estimated number of new patients expected in the coming year) x the insulin requirement for each patient / day.

A quick estimate of insulin needed for each patient will be:
1 unit / kg / day, and this will be needed for all the patients in the clinic. Depending on the patterns of use, most centres will need about 40-60% of their total insulin supplies as short-acting insulin and the rest as insulin.

EXAMPLE
If in Clinic X in Country Y, there are 100 existing patients who come regularly to get medicines, and in the last three months an average of two new patients have been coming each month, we would expect that by the next year, we would have 124 patients in the centre.

If we need to order insulin for the next 12 months, we would order:
124 patients x 1u/kg/day x 365 days.

If the estimated medium weight of the diabetic population attending the clinic is 50 kg, the amount of insulin units needed is

124 x 50 x 365 = 2,263.000 units
= 2,263 vials

(each vial contains 10 ml of insulin with 100 U/ml).

TO REMEMBER:

1: Ordering the insulin needed in time is important, to avoid a shortage.

2: **The amount needed is calculated as:**
(Number of existing patients
+ estimated number of new patients)
multiplied by the insulin requirement for each patient per day.

8.3 DIABETES CLINIC RECORDS

OBJECTIVE:

Understand why keeping a clinic and patient record is important, and the data that needs to be collected in order to support patient management

A FEW THOUGHTS TO START WITH:

- How many different reports do I have to write?
- What data are required?

KEEPING RECORDS IS ESSENTIAL FOR PROPER CARE

Keeping and maintaining clinic records is essential for good diabetes care. Patient records help the clinic staff to keep track of when a child or adolescent has attended for a consultation, the development in the health condition of the child or adolescent and the insulin dose given. Supply records enable clinics to ensure that the necessary insulin, syringes, strips and reagents are available at all times and that shortages are prevented.

PAPER-BASED OR COMPUTER-BASED REGISTRIES?

Whether a clinic has access to computers or not, the important thing is to keep diabetes patient registries updated at all times.

More and more now clinics have access to computers, but as writing by hand still often is the quickest way to collect a complete medical history during routine care some clinics may chose to keep a paper-based record, while in parallel transferring (key) data to an electronic registry. This could be done by a data entry clerk to save the time of the often scarce healthcare personnel for consultations.

The medical information must be easily accessible and readable by any healthcare professional in charge of a patient. Accuracy is key to ensuring that the registries are reliable, whether paper-based or electronic.

A computer-based system is able to provide a good overview of clinical activities for easy follow-up on specific treatment programmes. It provides information on what is being done, how many patients are being seen at the clinic, who comes for consultations on a regular basis, who misses appointments and what types of complications occur. It also provides a good overview of how many insulin vials or strips bottles have been used.

WHAT TO CONSIDER WHEN CONSIDERING INTRODUCING AN ELECTRONIC REGISTRY

It is critical to hold discussions with information technology and computer experts working with diabetes clinical care teams. The purpose of this is not only to define what should be collected and how it should be organised, but also how to do so in an ethically appropriate manner, guaranteeing privacy for the patient and his or her family. Informed consent must be addressed. Computers do not replace paper-based medical history.

Critical questions to ask when engaging in a computerised data management system are:

- System administration – who will maintain the system and does the person have the necessary skills / training?
- How to deal with hardware failures and replacement
- Backup systems - power supply ruptures and computer viruses can destroy days of work, so regular backup stored in a safe place is a priority when using computers
- Is funding available for maintenance and upgrades?

TO REMEMBER:

1: Registries of diabetes patients' medical history, treatment and outcomes are necessary to justify the activity and budget of the diabetes centre.

2: Computers are a powerful tool for statistical evaluation of data, but not essential for medical record-keeping in developing countries.

8.4 PATIENT SAFETY

OBJECTIVE:

- Understand the importance of safe care, for both patients and healthcare professionals at the diabetes clinic

A THOUGHT TO START WITH:

- Do I have access to water and soap to wash my hands before and after physical examination of a child or adolescent with diabetes?

KEEPING PATIENTS SAFE FROM INFECTION

People with diabetes, and especially children, are vulnerable to infections. Respiratory disease or gastroenteritis may lead to DKA, and have major consequences.

Healthcare professionals are exposed to contamination and can convey infectious diseases if they do not protect themselves. They expose their family and other people if they do not wash their hands carefully and change their clothes when leaving the clinic. Also, in the ward, and during the medical examination, the attitude and actions of the healthcare professionals is a learning opportunity for the child and family. **Nosocomial infections** are infections contracted during a stay in the medical environment, and are a very serious public health problem all over the world. Because of this, the World Heath Organization (WHO) has developed a **Patient Safety** programme, with guidelines and explanations how to produce locally cheap, but efficient, disinfectant solutions.

For these reasons, the staff of the diabetes clinic should become a model of safe care by **always remembering to:**

- Wash hands before and after physical examinations
- Use standard precautions when caring for a patient with an acute, febrile, respiratory illness
- Ensure cleaning and disinfection of reusable equipment between patients
- Follow applicable regulations and requirements for specimen transport to the laboratory
- Use standard precautions when handling and disposing of sharps and contaminated items
- Ensure that the clinic is well ventilated, and appropriately and regularly cleaned with water and usual detergent on soiled and / or frequently touched surfaces (eg door handles).

Quality assurance programmes can provide an audit of safe care and certification to show that the standards are being met. They are an opportunity to deliver excellent care and receive the rewards.

TO REMEMBER:

1: Even though diabetes is a non-communicable disease, safe care procedures are essential, to ensure that other infections are not conveyed from other patients, healthcare staff or visitors.

2: The diabetes clinic should become a model of safe care.

8.5 RUNNING A DIABETES CAMP

OBJECTIVE:

Understand the concept of a diabetes camp, and how it should be set up and run

A FEW THOUGHTS TO START WITH:

- Are there already any diabetes camps in this country or in the region that I could visit?
- How could I find out who organises the camps, and could I contact them to learn more about it?

LDIABETES CAMPS – A GREAT SOURCE OF LEARNING AND SUPPORT

The goal of a children or adolescent diabetes camp is to share knowledge about living with childhood or adolescent diabetes, by living for a few days in company with other children / young people who also have diabetes. Particularly for small children, the parents or carers should be there and take part alongside the child, so that they are given the opportunity to learn more about caring for diabetes and the problems it may present for a child or an adolescent.

At the camp, it is not only the healthcare professionals who are doing the teaching. Children and their parents also learn from each other, and their views and suggestions can help the professionals to offer the sort of medical care and support that really makes a difference. Adolescents can help provide care for younger children, and also act as role models as well as educators in how they monitor, take care of their insulin, participate in sports, and respond to questions and to what happens.

The camp has several teaching aims:

1: To give children and their parents the knowledge and confidence to:
- give injections,
- test glucose levels,
- estimate food portions,
- deal with other illnesses, and to know
- why diabetes in children is different from adult diabetes
- what happens in adolescence, the transition to more self-care in adulthood
- and much more.

2: **To explain how to use this knowledge to** live a normal life with diabetes

3: To explain to parents how to give emotional and practical support to the child and the adolescent.

Any activity that can fulfill these three objectives can be used as part of a diabetes camp. Sport activities can help to illustrate to the children and adolescents how to adjust their dosage to physical activity, cooking with the children and adolescents can involve a conversation on diet and nutrition, and so on.

WHAT DO WE NEED?

- **Trained staff** to:
  - run the practical aspects - transport, food, lodging etc
  - teach the theory and practical aspects of diabetes care
  - provide first aid and medical coverage

  Healthcare professionals will obviously be needed for part of the activities, but it is also worth considering involving young people who have diabetes themselves, as peer-support staff for some other activities.

- **A venue** that provides:
  - Fun outdoor activities, and backup activities for bad weather
  - A place for group learning activities and breakout sessions
  - A safe place to eat and rest/sleep.

- **A clear teaching objective** and lesson plans:
  - Decide on the target audience: children with diabetes only, or parents and/or siblings as well? What ages? Including adolescents, only adolescents, also their friends? What about grandparents or other caregivers?
  - Decide on whether the camp will be focusing on basic knowledge about diabetes and its effects on the body, or practical skills to manage diabetes in daily life.

- **Safety plans:** have backup and evacuation plans, insurance etc.

- **Limitations:** Start simply, and work within your limits. Diabetes camps that only last for one day and are held in parks, schools or hotels can nonetheless be a wonderful and valuable experience for the children. The important thing is to have fun while learning.

TO REMEMBER:

1: Diabetes camps are a great opportunity for children and adolescents to learn and share their knowledge and experiences with other children and adolescents.

2: The camp should be planned with great care and the educational objectives clearly defined.

8.6 WORKING WITH EXTERNAL PARTNERS AND DONORS

OBJECTIVE:

Understand how to reinforce the development of your clinic with support from external partners and donors

A THOUGHT TO START WITH:

- I get the idea, but how do I go about finding support and donations from outside people or organisations?

CHOOSING AND WORKING WITH AN EXTERNAL PARTNER

From time to time, problems facing the diabetes programme need greater knowledge, manpower, resources, skills or experience than are available in the clinic. In such cases, it may be useful to look for help from an external partner, either locally or further away; perhaps even internationally. It is important to consider carefully who to approach, as external organisations have their own agendas. They may not want to help, or they may want to, but are unable to do so; or they may be willing to help, but in the wrong ways and for the wrong reasons.

Many charities and organisations are already actively supporting diabetes care in the local community in many developing countries.

Among these are the World Diabetes Foundation (www.worlddiabetesfoundation.org), the Rotary Club (www.rotary.org) and the Lions Club (www.lionsclub.org). Religious organisations are also active in this field, and a local business owners' association could also be a source of support.

These organisations are able to give help in a wide variety of ways – some practical, some by fundraising, some by raising awareness in the community or providing manpower. For example:

- creating general awareness of diabetes as a health problem
- creating awareness of the specific services offered by your organisation
- supporting the children and adolescents of your centre – eg with transport, food and lodging for the poor or those living far away
- providing manpower for outreach projects
- fundraising efforts on your centre's behalf
- backup facilities – eg providing a secure power supply for your insulin refrigerator.

DECIDE WHAT HELP IS NEEDED

The first step to take is to identify the area of need, in order to be able to identify the organisation best placed to help. For example, there is no point in approaching an organisation that can offer manpower to do practical work, if what is needed is funding for equipment.

DECIDE WHO MIGHT BE ABLE TO PROVIDE THAT HELP

The next job is to identify a possible partner organisation.

It would be natural to look for a locally-based support group, and if such a group does not yet exist, try to form one. The key to enlisting an external partner's help is by creating an awareness of the needs of the clinic. This can be done through a personal approach or by finding an opportunity to talk about the work of the diabetes clinic, eg in the local newspaper, TV or radio station, or through a social function or business-men's association dinner. Having a patient or parent tell their story can also be very effective.

If there is no local organisation to help, try looking at information about the international organisations mentioned above.

MAKING A PROPOSAL

Having identified an organisation that might be a likely partner, the next step is to prepare a proposal, observing any requirements or conditions from the partner for such an application. The chance of success is greater if the proposal is prepared by a person who is experienced and knowledgeable about the clinic, and accustomed to completing application forms.

It is sometimes easier to start working with an external partner by doing a small project, eg a day outing for children with diabetes, or a World Diabetes Day event, before embarking on a large-scale project.

WORKING WITH THE NEW PARTNER

It may be easier to liaise with an external partner through the local diabetes support group or diabetes association. This has the great advantage that it relieves the diabetes clinic staff from the task of managing the details of the agreement. It also helps to share the workload, if it is necessary for the agreement to cover a network of clinics.

However, it would be wise to make sure that the clinic retains some oversight and control of agreements with any outside organisations, so that no fraudulent, illegal or exploitative activities are carried out in the name of the diabetes clinic.

TO REMEMBER:

1: It is perfectly possible to raise funds from outside organisations to support the work of a diabetes clinic.

2: It is worth defining exactly the sort of help that is most needed, rather than vaguely asking for support. Organisations are much more likely to give help if they can see clearly what is being requested.

3: It is vital that the clinic retains control of agreements with outside organisations.

Looking to the future

SECTION 9
CONTACTS

Networking to support the quality of care

SECTION 9 CONTENTS

9.1 THE INTERNATIONAL SOCIETY FOR PEDIATRIC AND ADOLESCENT DIABETES (ISPAD)

WEBSITE: WWW.ISPAD.ORG

ISPAD is a professional organisation whose aims are to promote clinical and basic science, research, education and advocacy in childhood and adolescent diabetes. The strength of ISPAD lies in the scientific and clinical expertise in childhood and adolescent diabetes of its members. ISPAD is the only international society focusing specifically on all types of childhood diabetes.

ISPAD physician members are drawn from paediatricians and adult physicians involved in the care of children with diabetes. ISPAD's non-physician members are generally other healthcare professionals such as psychologists, nurses, dieticians, and social workers working with chidren with diabetes. The first 2 years of membership are free for people living in non-high-income countries, according to the World Bank list.

ISPAD is committed to improving the standards of care for children with diabetes, and runs several programmes to achieve this aim.

These include:

- the ISPAD Clinical Practice Consensus Guidelines,
- local and regional courses for doctors and healthcare personnel in conjunction with local diabetes or doctors' associations
- the ISPAD International Science School for Physicians
- the ISPAD International Science School for Health Professionals
- the ISPAD Visiting Fellowships programme
- the ISPAD website.

9.2 THE INTERNATIONAL DIABETES FEDERATION (IDF)

WEBSITE : WWW.IDF.ORG

The International Diabetes Federation (IDF), founded in 1950, is an umbrella organisation of over 220 national diabetes associations, in over 160 countries and territories. It represents the interests of the growing number of people with diabetes and those at risk of diabetes.

IDF's mission is to promote diabetes care, prevention and a cure worldwide. The Federation is engaged in action to tackle diabetes from the local to the global level – from community programmes to worldwide awareness and advocacy initiatives.

The International Diabetes Federation is divided into seven regions of the world, with the aim of strengthening the work of national diabetes associations and enhancing the collaboration between them.

The Federation's activities aim to influence policy, increase public awareness and encourage health improvement, promote the exchange of high-quality information about diabetes, and provide education for people with diabetes and their healthcare providers. In developing countries, IDF often has a role in facilitating the development of healthcare professionals and local expertise, through twinning programmes and training workshops etc.

THE LIFE FOR A CHILD PROGRAMME

website: www.lifeforachild.idf.org

The International Diabetes Federation's 'Life for a Child' Programme was established in 2001 with support from the Australian Diabetes Council and HOPE worldwide. The programme brings together the contribution of donors to support the care of close to 8000 children with diabetes, in 27 countries.

9.3 WORLD DIABETES FOUNDATION (WDF)

WEBSITE: WWW.WORLDDIABETESFOUNDATION.ORG

The World Diabetes Foundation is dedicated to supporting prevention and treatment of diabetes in the developing world, through funding of diabetes-related projects. The Foundation creates partnerships with local organisations and acts as a catalyst to help others do more. It also strives to educate and advocate globally in an effort to create awareness, care and relief to those affected by diabetes.

The World Diabetes Foundation has funded 236 projects to date, in 94 countries, with a total project portfolio of US$223.7 million, of which US$76.6 million were donated by the Foundation.

The establishment of the World Diabetes Foundation was announced by Novo Nordisk A/S on World Diabetes Day 2001, and it was legally established in February 2002. A donation programme by Novo Nordisk A/S, of a maximum of DKK 650 million over a period of ten years, was approved by its general assembly and shareholders in March 2002. In March 2008, the NN shareholders approved an additional endowment of a maximum of DKK 575 million over another ten-year period, bringing the two endowments to a total maximum of DKK 1.2 billion in the period 2001-2017, i.e. the equivalent of US$255 million (exchange rate of DKK 4.8:1 US$).

The Foundation is registered as an independent trust and governed by a board of six experts in the field of diabetes, access to health and development assistance.

ANNEXES: **RESOURCES**

CONTENTS

ANNEX 1: FORM FOR RECORDING MEDICAL HISTORY

Name:			
Address		**Telephone no.**	
Date of birth:	Gender (M/F):	Weight:	
Source/Referred by:		Centre:	
Date:	Time:		
Symptoms:			
Polyuria? (Y/N)	Polydypsia (Y/N)?	Nocturia (Y/N)?	Weight loss (Y/N)?
Nausea and vomiting (Y/N):		Abdominal pain (Y/N)	
Symptoms of infection:			
Past History:			
Birth weight:	Perinatal history:		
Admissions:			
Illnesses:			
HIV:		Malaria:	
Tuberculosis:			
Other illnesses:			
Family History:			

Name:	Age:	Occupation:	Illnesses:
Mother:			
Father:			
Siblings:			
Grandparents:			

ANNEX 2: TESTING URINE FOR REDUCING SUGARS

BENEDICT'S SOLUTION

Benedict's solution can be obtained commercially, or it can come as a Clinitest tablet which is dropped into a urine sample. Benedict's solution or reagent contains blue copper(II) ions (Cu2+) which are reduced to copper(I) (Cu+) in the presence of reducing sugars, ie glucose. These are precipitated as red copper(I) oxide, which is insoluble in water.

Benedict's Reagent:
To make one litre of Benedict's solution, dissolve 100g sodium carbonate and 173g sodium citrate dihydrate in a final volume of 850ml water. Slowly, with stirring, add a solution of 17.3g copper sulphate pentahydrate in 100ml of water. Bring the final volume to one litre*.

Benedict's Test:
When 1ml of Benedict's reagent is heated with 5 drops of the patient's urine sample in a boiling water bath, formation of a precipitate within five minutes is a positive test for reducing sugars. The colour ranges from green to yellow, to orange, to brick-red; depending on the amount of reducing sugar in the sample.

Reference
* Benedict, SR. (1908) A reagent for the detection of reducing sugars J. Biol. Chem. 5, 485–487)

ANNEX 3: FORM FOR RECORDING DKA HISTORY

Fluid replacement is initially more important than insulin therapy in DKA treatment, as early mortality is due to dehydration and shock rather than to hyperglycaemia. Rehydration has to occur gradually and slowly to prevent the complications associated with DKA; particularly cerebral oedema. Insulin therapy is needed to correct the acidosis and hyperglycaemia.

Name:			
Age/DOB:	Gender (M/F):	Weight:	
Source/Referred by:		Centre:	
Date:	Time:		
Symptoms:			
Polyuria? (Y/N)	Polydipsia (Y/N)?	Nocturia (Y/N)?	Weight loss (Y/N)?
Symptoms of infection:			
PH:	Birth weight:	Perinatal history:	
Admissions:			
Illnesses:			
HIV:		Malaria:	
Tuberculosis:			
FH:			
Mother:			
Father:			
Siblings:			

Examination					
Level of consciousness					
Hydration:			Temperature:		
General:					
CVS:					
HR:	BP:		Perfusion:		Heart sounds
Chest:					
Abdomen:					
CNS:					
ENT:					
Genitalia:	Tanner stage:				
Blood Glucose:	Urine:	Ketones:		Other:	
Bloods taken:	FBC	U&E	CPM:	ABG:	LFT:
	Other				
Resuscitation:					
Fluid:	Amount given:				

ANNEX 4: FORM FOR MONITORING A DKA EVENT

Name: **Age:** **Weight:** **Centre:** **Date:**

Time	LOC	HR	BP	Glucose	Ketones	Potassium	Sodium	U&E	Fluid type	Route	Rate	Total	Insulin	Urine	Management
07h00															
08h00															
09h00															
10h00															
11h00															
12h00															
13h00															
14h00															
15h00															
16h00															
17h00															
18h00															
19h00															
20h00															
21h00															
22h00															
23h00															
24h00															
01h00															
02h00															
03h00															
04h00															
05h00															
06h00															

LOC: 1=alert; 2=lethargic (easily aroused), 3=stupor (aroused with difficulty), 4=coma (unarousable)
Use GCS if available and used regularly

HR: heart rate

BP: blood pressure

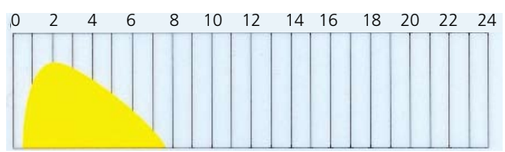
ANNEX 5: INSULIN CHARACTERISTICS

It is important to be familiar with the different types of insulins, in order to adapt the prescriptions to the needs of individual patients and to maximise adherence to treatment.

Insulin characteristics (the timing of peak effect and duration) must be explained to the child and his / her family in order to improve their adherence to treatment.

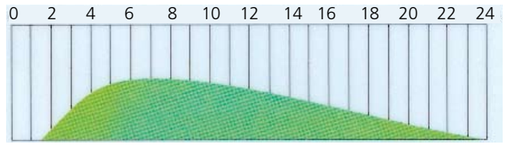
Time Action Profiles **Actrapid® HM**

Onset: within ½ hour
Maximum: between 1.5 and 3.5 hours
Duration: approximately 7-8 hours



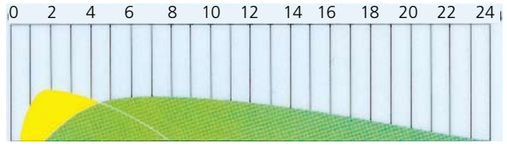
Time Action Profiles **Insulatard® HM**

Onset: within 1½ hours
Maximum: between 4 and 12 hours
Duration: up to 24 hours



Time Action Profiles **Mixtard® 30 HM**

Onset: within ½ hour
Maximum: between 2 and 8 hours
Duration: between 2 and 8 hours

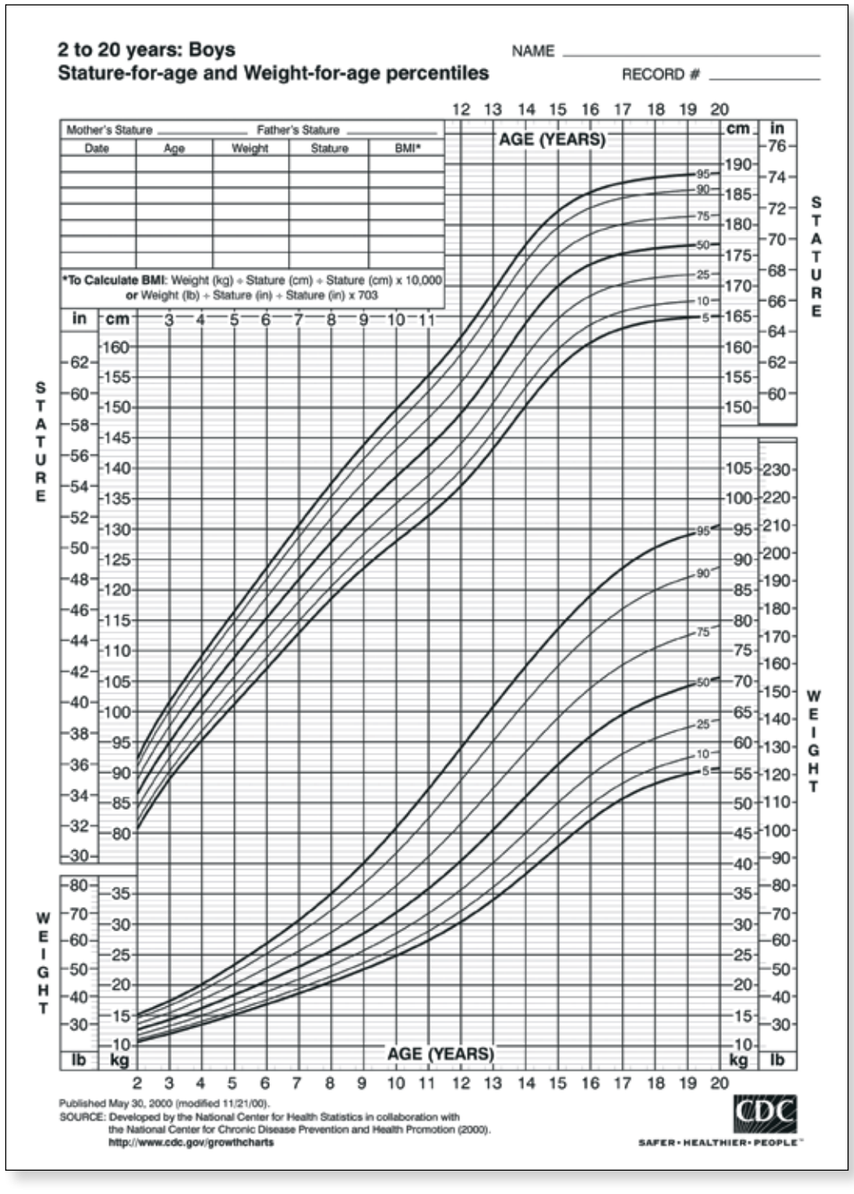


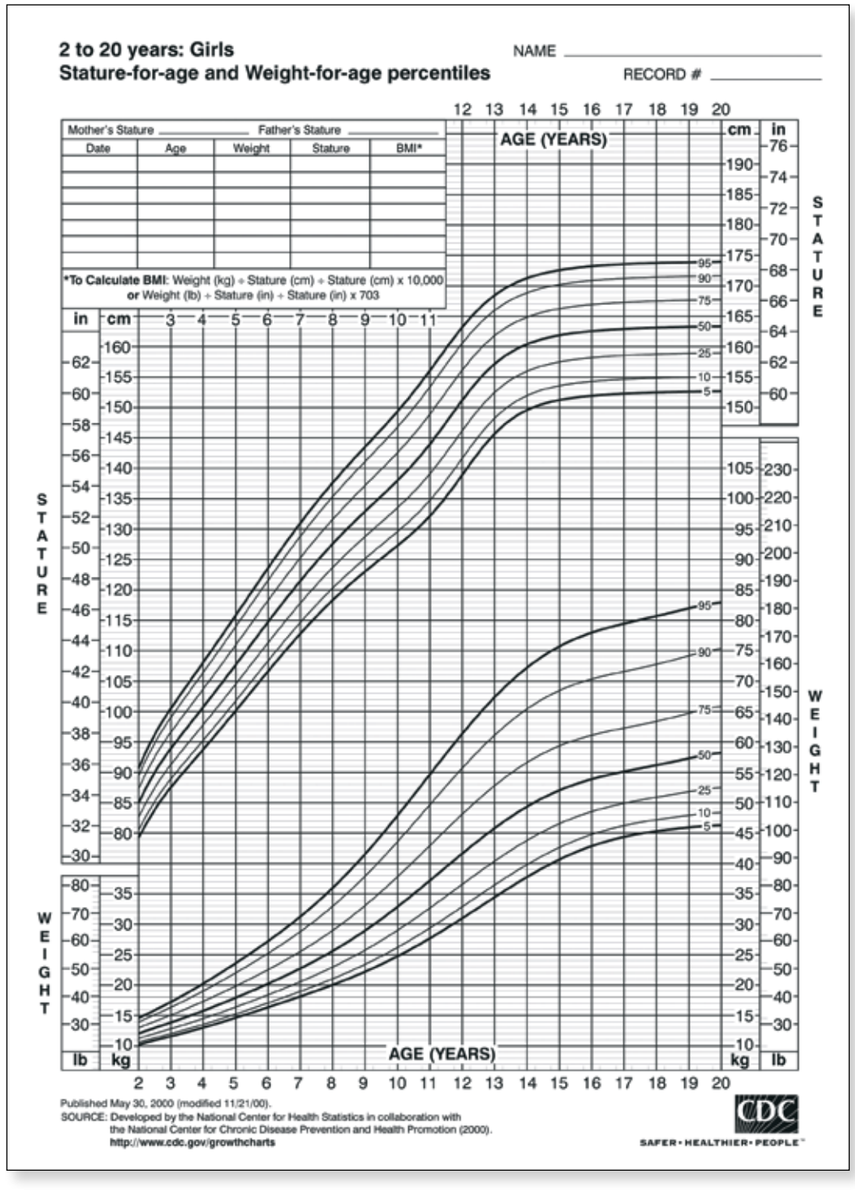
ANNEX 6: RECORDING DIETARY HISTORY

WE NEED TO ASK THE FOLLOWING:

- How is the patient's growth as shown by height and weight?
  - Is the patient's condition age-appropriate, obese or malnourished?
- What is the patient's pubertal status?
- At present, what are the insulin doses and types used, and timing of injections?
- How much insulin is the patient getting every day: (total daily dose / body weight)?
- How many meals a day does the patient eat?
- What are the mealtimes?
- Meal composition:
  - What carbohydrate foods are eaten?
    How much?
  - What protein foods are eaten?
    How much?
  - What fruits and vegetables does the patient eat?
    How much?
- Which meals are taken outside the home?
- Which meals are eaten at home?
- How is the food security?
- Who is the cook?
- Who is the caregiver who will give the injections?
- What is the limiting factor for change? eg:
  - food supply or budget limitations,
  - daycare centre practices
  - key caregiver unwilling to accept change
  - eating disorder
  - picky eater
  - rigid school timetable

ANNEX 7: HEIGHT AND WEIGHT RANGES IN CHILDHOOD





ANNEX 8: BP LEVELS FOR BOYS BY AGE AND HEIGHT PERCENTILE
(Age 2 to 9 years)

Age	BP Percentile	SBP, mm Hg							DBP, mm Hg						
Years		Percentile of Height							Percentile of Height						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
2	50th	84	85	87	88	90	92	92	39	40	41	42	43	44	44
	90th	97	99	100	102	104	105	106	54	55	56	57	58	58	59
	95th	101	102	104	106	108	109	110	59	59	60	61	62	63	63
	99th	109	110	111	113	115	117	117	66	67	68	69	70	71	71
3	50th	86	87	89	91	93	94	95	44	44	45	46	47	48	48
	90th	100	101	103	105	107	108	109	59	59	60	61	62	63	63
	95th	104	105	107	109	110	112	113	63	63	64	65	66	67	67
	99th	111	112	114	116	118	119	120	71	71	72	73	74	75	75
4	50th	88	89	91	93	95	96	97	47	48	49	50	51	51	52
	90th	102	103	105	107	109	110	111	62	63	64	65	66	66	67
	95th	106	107	109	111	112	114	115	66	67	68	69	70	71	71
	99th	113	114	116	118	120	121	122	74	75	76	77	78	78	79
5	50th	90	91	93	95	96	98	98	50	51	52	53	54	55	55
	90th	104	105	106	108	110	111	112	65	66	67	68	69	69	70
	95th	108	109	110	112	114	115	116	69	70	71	72	73	74	74
	99th	115	116	118	120	121	123	123	77	78	79	80	81	81	82
6	50th	91	92	94	96	98	99	100	53	53	54	55	56	57	57
	90th	105	106	108	110	111	113	113	68	68	69	70	71	72	72
	95th	109	110	112	114	115	117	117	72	72	73	74	75	76	76
	99th	116	117	119	121	123	124	125	80	80	81	82	83	84	84
7	50th	92	94	95	97	99	100	101	55	55	56	57	58	59	59
	90th	106	107	109	111	113	114	115	70	70	71	72	73	74	74
	95th	110	111	113	115	117	118	119	74	74	75	76	77	78	78
	99th	117	118	120	122	124	125	126	82	82	83	84	85	86	86
8	50th	94	95	97	99	100	102	102	56	57	58	59	60	60	61
	90th	107	109	110	112	114	115	116	71	72	72	73	74	75	76
	95th	111	112	114	116	118	119	120	75	76	77	78	79	79	80
	99th	119	120	122	123	125	127	127	83	84	85	86	87	87	88
9	50th	95	96	98	100	102	103	104	57	58	59	60	61	61	62
	90th	109	110	112	114	115	117	118	72	73	74	75	76	76	77
	95th	113	114	116	118	119	121	121	76	77	78	79	80	81	81
	99th	120	121	123	125	127	128	129	84	85	86	87	88	88	89

The 90th percentile is 1.28 SD, the 95th percentile is 1.645 SD, and the 99th percentile is 2.326 SD over the mean.

ANNEX 8: BP LEVELS FOR BOYS BY AGE AND HEIGHT PERCENTILE
(Age 10 to 17 years)

Age	BP Percentile	SBP, mm Hg							DBP, mm Hg						
Years		Percentile of Height							Percentile of Height						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
10	50th	97	98	100	102	103	105	106	58	59	60	61	61	62	63
	90th	111	112	114	115	117	119	119	73	73	74	75	76	77	78
	95th	115	116	117	119	121	122	123	77	78	79	80	81	81	82
	99th	122	123	125	127	128	130	130	85	86	86	88	88	89	90
11	50th	99	100	102	104	105	107	107	59	59	60	61	62	63	63
	90th	113	114	115	117	119	120	121	74	74	75	76	77	78	78
	95th	117	118	119	121	123	124	125	78	78	79	80	81	82	82
	99th	124	125	127	129	130	132	132	86	86	87	88	89	90	90
12	50th	101	102	104	106	108	109	110	59	60	61	62	63	63	64
	90th	115	116	118	120	121	123	123	74	75	75	76	77	78	79
	95th	119	120	122	123	125	127	127	78	79	80	81	82	82	83
	99th	126	127	129	131	133	134	135	86	87	88	89	90	90	91
13	50th	104	105	106	108	110	111	112	60	60	61	62	63	64	64
	90th	117	118	120	122	124	125	126	75	75	76	77	78	79	79
	95th	121	122	124	126	128	129	130	79	79	80	81	82	83	83
	99th	128	130	131	133	135	136	137	87	87	88	89	90	91	91
14	50th	106	107	109	111	113	114	115	60	61	62	63	64	65	65
	90th	120	121	123	125	126	128	128	75	76	77	78	79	79	80
	95th	124	125	127	128	130	132	132	80	80	81	82	83	84	84
	99th	131	132	134	136	138	139	140	87	88	89	90	91	92	92
15	50th	109	110	112	113	115	117	117	61	62	63	64	65	66	66
	90th	122	124	125	127	129	130	131	76	77	78	79	80	80	81
	95th	126	127	129	131	133	134	135	81	81	82	83	84	85	85
	99th	134	135	136	138	140	142	142	88	89	90	91	92	93	93
16	50th	111	112	114	116	118	119	120	63	63	64	65	66	67	67
	90th	125	126	128	130	131	133	134	78	78	79	80	81	82	82
	95th	129	130	132	134	135	137	137	82	83	83	84	85	86	87
	99th	136	137	139	141	143	144	145	90	90	91	92	93	94	94
17	50th	114	115	116	118	120	121	122	65	66	66	67	68	69	70
	90th	127	128	130	132	134	135	136	80	80	81	82	83	84	84
	95th	131	132	134	136	138	139	140	84	85	86	87	87	88	89
	99th	139	140	141	143	145	146	147	92	93	93	94	95	96	97

The 90th percentile is 1.28 SD, the 95th percentile is 1.645 SD, and the 99th percentile is 2.326 SD over the mean.

ANNEX 8: BP LEVELS FOR GIRLS BY AGE AND HEIGHT PERCENTILE
(Age 2 to 9 years)

Age	BP Percentile	SBP, mm Hg							DBP, mm Hg						
Years		Percentile of Height							Percentile of Height						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
2	50th	85	85	87	88	89	91	91	43	44	44	45	46	46	47
	90th	98	99	100	101	103	104	105	57	58	58	59	60	61	61
	95th	102	103	104	105	107	108	109	61	62	62	63	64	65	65
	99th	109	110	111	112	114	115	116	69	69	70	70	71	72	72
3	50th	86	87	88	89	91	92	93	47	48	48	49	50	50	51
	90th	100	100	102	103	104	106	106	61	62	62	63	64	64	65
	95th	104	104	105	107	108	109	110	65	66	66	67	68	68	69
	99th	111	111	113	114	115	116	117	73	73	74	74	75	76	76
4	50th	88	88	90	91	92	94	94	50	50	51	52	52	53	54
	90th	101	102	103	104	106	107	108	64	64	65	66	67	67	68
	95th	105	106	107	108	110	111	112	68	68	69	70	71	71	72
	99th	112	113	114	115	117	118	119	76	76	76	77	78	79	79
5	50th	89	90	91	93	94	95	96	52	53	53	54	55	55	56
	90th	103	103	105	106	107	109	109	66	67	67	68	69	69	70
	95th	107	107	108	110	111	112	113	70	71	71	72	73	73	74
	99th	114	114	116	117	118	120	120	78	78	79	79	80	81	81
6	50th	91	92	93	94	96	97	98	54	54	55	56	56	57	58
	90th	104	105	106	108	109	110	111	68	68	69	70	70	71	72
	95th	108	109	110	111	113	114	115	72	72	73	74	74	75	76
	99th	115	116	117	119	120	121	122	80	80	80	81	82	83	83
7	50th	93	93	95	96	97	99	99	55	56	56	57	58	58	59
	90th	106	107	108	109	111	112	113	69	70	70	71	72	72	73
	95th	110	111	112	113	115	116	116	73	74	74	75	76	76	77
	99th	117	118	119	120	122	123	124	81	81	82	82	83	84	84
8	50th	95	95	96	98	99	100	101	57	57	57	58	59	60	60
	90th	108	109	110	111	113	114	114	71	71	71	72	73	74	74
	95th	112	112	114	115	116	118	118	75	75	75	76	77	78	78
	99th	119	120	121	122	123	125	125	82	82	83	83	84	85	86
9	50th	96	97	98	100	101	102	103	58	58	58	59	60	61	61
	90th	110	110	112	113	114	116	116	72	72	72	73	74	75	75
	95th	114	114	115	117	118	119	120	76	76	76	77	78	79	79
	99th	121	121	123	124	125	127	127	83	83	84	84	85	86	87

The 90th percentile is 1.28 SD, the 95th percentile is 1.645 SD, and the 99th percentile is 2.326 SD over the mean.

ANNEX 8: BP LEVELS FOR GIRLS BY AGE AND HEIGHT PERCENTILE
(Age 10 to 17 years)

Age	BP Percentile	SBP, mm Hg							DBP, mm Hg						
Years		Percentile of Height							Percentile of Height						
		5th	10th	25th	50th	75th	90th	95th	5th	10th	25th	50th	75th	90th	95th
10	50th	98	99	100	102	103	104	105	59	59	59	60	61	62	62
	90th	112	112	114	115	116	118	118	73	73	73	74	75	76	76
	95th	116	116	117	119	120	121	122	77	77	77	78	79	80	80
	99th	123	123	125	126	127	129	129	84	84	85	86	86	87	88
11	50th	100	101	102	103	105	106	107	60	60	60	61	62	63	63
	90th	114	114	116	117	118	119	120	74	74	74	75	76	77	77
	95th	118	118	119	121	122	123	124	78	78	78	79	80	81	81
	99th	125	125	126	128	129	130	131	85	85	86	87	87	88	89
12	50th	102	103	104	105	107	108	109	61	61	61	62	63	64	64
	90th	116	116	117	119	120	121	122	75	75	75	76	77	78	78
	95th	119	120	121	123	124	125	126	79	79	79	80	81	82	82
	99th	127	127	128	130	131	132	133	86	86	87	88	88	89	90
13	50th	104	105	106	107	109	110	110	62	62	62	63	64	65	65
	90th	117	118	119	121	122	123	124	76	76	76	77	78	79	79
	95th	121	122	123	124	126	127	128	80	80	80	81	82	83	83
	99th	128	129	130	132	133	134	135	87	87	88	89	89	90	91
14	50th	106	106	107	109	110	111	112	63	63	63	64	65	66	66
	90th	119	120	121	122	124	125	125	77	77	77	78	79	80	80
	95th	123	123	125	126	127	129	129	81	81	81	82	83	84	84
	99th	130	131	132	133	135	136	136	88	88	89	90	90	91	92
15	50th	107	108	109	110	111	113	113	64	64	64	65	66	67	67
	90th	120	121	122	123	125	126	127	78	78	78	79	80	81	81
	95th	124	125	126	127	129	130	131	82	82	82	83	84	85	85
	99th	131	132	133	134	136	137	138	89	89	90	91	91	92	93
16	50th	108	108	110	111	112	114	114	64	64	65	66	66	67	68
	90th	121	122	123	124	126	127	128	78	78	79	80	81	81	82
	95th	125	126	127	128	130	131	132	82	82	83	84	85	85	86
	99th	132	133	134	135	137	138	139	90	90	90	91	92	93	93
17	50th	108	109	110	111	113	114	115	64	65	65	66	67	67	68
	90th	122	122	123	125	126	127	128	78	79	79	80	81	81	82
	95th	125	126	127	129	130	131	132	82	83	83	84	85	85	86
	99th	133	133	134	136	137	138	139	90	90	91	91	92	93	93

The 90th percentile is 1.28 SD, the 95th percentile is 1.645 SD, and the 99th percentile is 2.326 SD over the mean.

ANNEX 9: CARING FOR ACUTE ILLNESSES – GUIDE FOR PARENTS

Your child may at times develop an acute illness. This may cause your child to have:

- high blood glucose
- low blood glucose
- ketones
- dehydration
- other complications of the illness.

MANAGEMENT OF ACUTE ILLNESS

- Do not stop insulin delivery. You may have to increase or decrease the insulin dose because the blood glucose is high or low.

- Test blood glucose every 3-4 hours. If you cannot test at home, please take your child to a healthcare facility for regular testing.

- Monitor ketones 1-2 times per day. This may be done at the local healthcare facility.

- Take your child to the healthcare facility to have his / her illness treated. Where possible use sugar-free mediations or tablets. If no sugar-free medications are available then use the locally available medications. Avoid steroid use.

- Make sure that your child is eating or drinking well. If he / she is not drinking as well as normal, use oral rehydration fluid (ORS) in addition to his / her regular food.

- If your child is vomiting, give him / her small volumes of oral rehydration fluid more frequently. Your clinic will guide you about the amounts to be given.

Take your child to the clinic so that a nurse or doctor can examine him or her, if:

- he / she is very young
- you are not able to test glucose frequently
- you are not able to test for ketones
- the blood glucose is very high and remains high
- the blood glucose is very low and remains low
- there are ketones that do not go away with extra insulin
- you are not sure about how to care for your child during the illness.

ANNEX 10: STAGES OF PUBERTY

STAGES OF PUBIC HAIR AND GENITAL DEVELOPMENT IN MALES

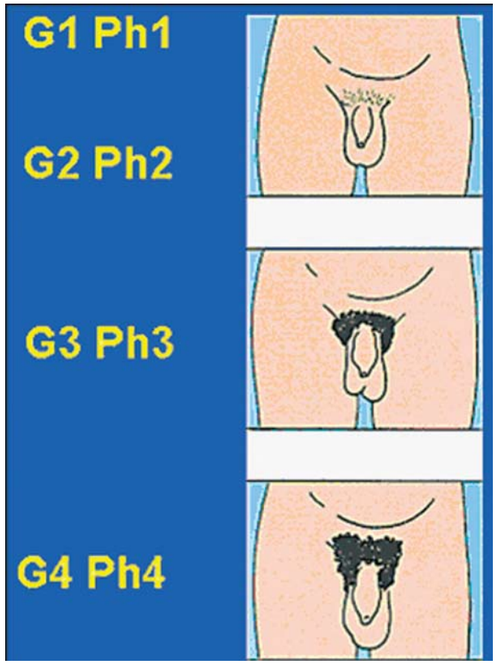
G-1: pre-pubertal

G-2: the testis and scrotum enlarge, and the skin of the scrotum shows some reddening and change in the texture. Sparse growth of pigmented hair, usually slightly curly, mainly at the base of the penis (Ph-2)

G-3: Testis and scrotum enlarge further, the penis grows mainly in length but also in breadth. The hair is darker, coarser and curlier and spreads over the junction of the pubes (Ph-3)

G-4: Scrotum, testis and penis grow further with development of the glans and further darkening of the scrotal skin. The hair spreads covering the pubes

G-5: adult stage with spreading of the hair to the medial surface of the thighs.



STAGES OF BREAST AND PUBIC HAIR DEVELOPMENT IN FEMALES

B-1: pre-pubertal

B-2: breast bud

B-3: enlargement of beast and areola with no separation of the contours

B-4: projection of areola and papilla to form a secondary mound above the level of the breast ; B-5: recession of the areola to the general contour of the breast with projection of the papilla only.

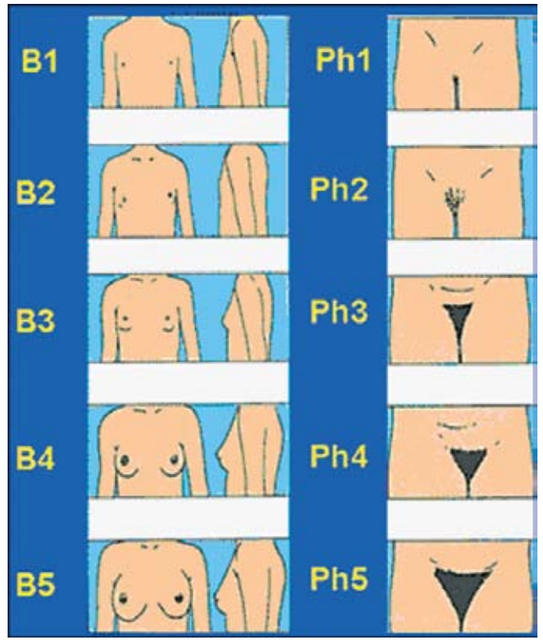
Ph-1: pre-pubertal

Ph-2: sparse growth of long slightly pigmented hair usually slightly curly mainly along the labia

Ph-3: the hair is darker, coarser and curlier and spreads over the junction of the pubes

Ph-4: the hair spreads covering the pubes

Ph-5: the hair extends to the medial surface of the thighs and is distributed as an inverse triangle.



ANNEX 11: CHECKLIST – ITEMS NEEDED FOR SCHOOL

- Sugar-containing sweet (eg Super-C) or drink (eg Liquifruit), preferably within easy reach of the child
- Adequate lunch and snacks for the day
- Access to glucose meter / glucose strips and urine strips
- Glucagen Hypo-kit
- Contact details for parents and child's doctor.

NAME: AGE:

ADDRESS:

Home phone:

FATHER:
Work Phone: Cellphone

MOTHER:
Work Phone: Cellphone

DOCTOR:
Work Phone: Cellphone

OTHER EMERGENCY CONTACT:
Work Phone:: Cellphone

Insulin and doses used:

Insulin and dose in emergency:

Can child give own insulin?

Can child do own blood testing?

GLOSSARY

ACE inhibitors – angiotensin converting enzyme inhibitors - a group of drugs used in treatment of hypertension, heart failure, and also in treatment of diabetic kidney disease
ADA – American Diabetes Association
Animal insulin – insulin produced from the pancreas of cattle or pigs
Anorexia nervosa – an eating disorder involving refusal to maintain a healthy body weight and obsessive fear of gaining weight
Asymmetric septal hyperplasia – disproportionate thickening of the septum between the ventricles of the heart
BD – twice daily
Beta cells (ß-cells) – cells of the islets of Langerhans within the pancreas; responsible for production of insulin
Bulimia – an eating disorder characterised by obsessive, uncontrolled eating followed by self-induced vomiting
Cerebral oedema – accumulation of fluid in the tissues of the brain
Coeliac disease – a digestive disorder characterised by inability to metabolise gluten; which is found in wheat and barley
Diabulimia – an eating disorder in which people with type 1 diabetes deliberately give themselves less insulin than they need, in order to lose weight. The term is not properly recognised as a medical condition, and is derived from a combination of 'diabetes' and 'bulimia'.
DKA – diabetic ketoacidosis (see below)
Emphysema – a chronic obstructive pulmonary disease
Enuresis – involuntary urination, bedwetting
(Euthyroid) goitre – enlarged thyroid gland, (euthryoid indicates it is caused by dietary lack of iodine)
Erb's palsy – paralysis of the muscles of the upper arm; most commonly caused by forcible traction during childbirth
Fluorescein angiography – a technique used to investigate the blood vessels of the retina and iris, involving direct or indirect ophthalmoscopy or photography following introduction of intravenous fluorescein dye
Free T4 – test to measure the active thyroxine produced by the thyroid gland; the most significant test to indicate thryroid function
Fundus photography – photography of the back part of the eye that can be seen through the pupil by an ophthalmoscope
Gastroparesis – partial paralysis of the stomach, resulting in food remaining there for longer than normal; and frequently caused by diabetes-related neuropathy
Gestational diabetes – glucose intolerance which develops, or is first recognised, during pregnancy

Glucagon – the hormone produced by the alpha-cells of the pancreas, which has the opposite effect to insulin The pancreas releases glucagon when blood glucose levels fall too low. Glucagon causes the liver to convert stored glycogen into glucose, which is released into the blood
Gluconeogenesis – the biochemical pathway that releases glucose from non-carbohydrate substrates stored in the liver. The process takes place under conditions of fasting, starving or intense exercise, and is associated with ketosis.
Glycogenolysis – the breakdown of glycogen in the liver or muscle to release glucose
Glycosuria (also known as glucosuria) – excretion of glucose in the urine
Haematocrit – the proportion of the volume of blood made up by red blood cells; normally 48% for men and 38% for women, and useful to determine anaemia. If determined by centrifugation, it is also known as packed cell volume (PCV); otherwise and more accurately) it is determined by an automated analyser which multiplies red cell count by mean cell volume
Haemoglobin – the protein within red blood cells that gives them their colour; that combines with oxygen and transports it from the lungs to the body tissues, where the oxygen is released
HbA1c (also known as A1c) – the proportion of glycosylated haemoglobin in the blood (normally measured as a percentage). It is an indicator of the level of blood glucose control over the preceding 2-3 months. ADA guidelines recommend a target level of 7.0% or less for adults with type 1 or type 2 diabetes, <7.5% for adolescents and young adults (type 1), <8% for children aged 6-12 (type 1), 7.5 – 8.5% for children aged 0-6 (type 1)
Human insulin – a synthetic insulin with the normal structure of insulin produced by the human pancreas, but that is prepared from bacteria using recombinant DNA techniques
Hyperglycaemia – the presence of an abnormally high concentration of glucose in the blood
Hyperkalaemia – the presence of an abnormally high concentration of potassium in blood serum. The normal concentration of potassium in the serum is in the range of 3.5-5.0 mM.; hyperkalemia refers to levels of potassium ions above 5.0 mM
Hyperlipidemia – the presence of an abnormally high concentration of lipids in the blood
Hypertension – abnormally high blood pressure (above 120/80 mm Hg)
Hyperthyroidism – overproduction of thyroid hormones by an overactive thyroid gland
Hypocalcaemia – abnormally low level of calcium in the blood; associated with thyroid gland malfunction, kidney malfunction or vitamin D deficiency
Hypoglycaemia – an abnormally low level of blood glucose in the blood, depriving muscles, cells and brain with the energy needed to function. Hypoglycaemia can be triggered by taking too much insulin, by not following the prescribed meal schedule or by participating in unusually strenuous or prolonged exercise

Hypokalaemia – an abnormally low concentration of potassium in the blood
Hypothyroidism – insufficient production of thyroid hormones
Impaired glucose tolerance - a pre-diabetic state that is associated with insulin resistance, increased risk of cardio-vascular problems and is a risk factor for mortality
Insulin – the hormone produced by the beta cells of the pancreas in response to a rise in the concentration of glucose in the blood, and enables the movement of glucose, amino acids, and fatty acids out of the blood and into the cells of the body
Islets of Langerhans – regions of the pancreas that contain the beta-cells (producing insulin), the alpha-cells (producing glucagon)and other cell types in smaller proportions
ISPAD – International Society for Pediatric and Adolescent Diabetes
IUGR – intra-uterine growth retardation
Kalaemia – the level of potassium in the blood
Ketoacidosis (also known as diabetic ketoacidosis or DKA) –
Ketonaemia – the presence of ketones in the blood
Ketonuria – the presence of ketones in the urine
Kussmaul's respiration – deep and laboured breathing, associated with severe metabolic acidosis, particularly diabetic ketoacidosis (DKA) but also renal failure
LGA – large for gestational age
Lipoatrophy – localised loss of fatty tissue (at an injection site of insulin)
Lipohypertrophy (or hypertrophy) – accumulation of extra fatty tissue
(at an injection site of insulin)
LJM – limited joint mobility
Macrosomia – large baby syndrome; sometimes used synonymously with LGA
Metabolic syndrome – a combination of medical conditions that predispose to cardivascular disease and diabetes. Definitions vary but most include impaired glucose tolerance, insulin resistance, type 2 diabetes, raised blood pressure and central obesity
Microalbuminuria – the first stage of chronic kidney disease, in which traces of albumin are detected in the urine
Modern insulins – analogues developed using recombinant DNA technology to modify protein sequences of human insulin, in order to resemble endogenous insulin function more closely
MODY – mature-onset diabetes of the young; a rare, inherited of diabetes characterised by mild hyperglycaemia without progression to ketoacidosis

NLD – Necrobiosis lipoidica diabeticorum; a skin condition associated with diabetes
Neo-natal diabetes (NDM) – a rare form of diabetes, occurring in the first six months of life
Nephropathy – kidney damage or disease
Neuroglycopenia – a shortage of glucose in the brain, usually due to hypoglycaemia
Neuropathy – damage to the nerves. Usually peripheral neuropathy; affecting the nerves of the feet and legs
Nocturia – the need to urinate during sleep periods
NPH insulin – Neutral Protamine Hagedorn insulin; an insulin with a duration of effect intermediate between fast-acting and long-acting insulins
Oestradiol – the major oestrogen sex hormone in humans; predominant in females but also present in males
Packed cell volume (PCV) – see haematocrit
Perfusion – delivery of arterial blood to the capillaries in the body tissues
Polycythaemia (also polycythaemia vera, or polycythaemia rubra vera) – over-production of red blood cells in the bone marrow
Polydipsia – excessive drinking
Polyhydramnios – production of an excessive amount of amniotic fluid
Polyuria – excessive production of urine
PPD – packs per day (cigarettes)
Renal disease – disease of the kidneys
Retinopathy – non-inflammatory damage to the retina of the eye
SGA – small for gestational age
T-cells – a group of white blood cells involved in the immune response
Tachypnoea – hyperventilation; breathing faster or more deeply than needed
Testosterone – a major sex hormone in humans; predominant in males but also present in females
TSH – thyroid stimulating hormone; a hormone produced by the pituitary gland which regulates the endocrine function of the thyroid gland
Thyroiditis – inflammation of the thyroid gland
Type 1 diabetes – failure of the pancreas to produce insulin, which occurs if the body's immune system kills the beta-cells in the pancreas that produce insulin. Blood glucose must be regulated with insulin treatment in combination with a balanced diet and physical exercise
Type 2 diabetes –failure of the pancreas to produce enough adequately-functioning insulin to enable the glucose from food to enter the body cells and be used as a source of energy. It can be controlled through a balanced diet and exercise, plus oral antidiabetic drugs at a later stage. Insulin is also increasingly used to treat type 2 diabetes, as it has been shown to decrease or delay complications. Type 2 accounts for 90-95% of cases of diabetes
Vitiligo – a chronic skin condition involving loss of pigment, and irregular pale patches

NOTES

The Changing Diabetes® in Children programme

Type 1 diabetes is one of the most common endocrine and metabolic diseases to affect children. According to the International Diabetes Federation (IDF), an estimated 480,000 children under the age of 15 live with type 1 diabetes world wide and many of them in developing countries. Approximately 76,000 children under 15 years develop diabetes each year. (IDF Diabetes Atlas, Fourth Edition, 2009)

For a child with type 1 diabetes, insulin treatment is life-saving and lifelong. Self-discipline and adherence to a balanced diet are necessary if the disease is to be well managed. In many, especially developing, countries children with diabetes do not have access to the treatment required to live long and healthy lives. Access to insulin and self-care tools is often limited, as is access to appropriate healthcare structures. Many children may either be misdiagnosed or even die before they can be diagnosed.

In October 2008 the International Diabetes Federation (IDF) made a call to action, bringing together key opinion leaders to push for action to secure access, to care for the thousands of children with diabetes in developing countries.

Novo Nordisk's response was the initiation of the Changing Diabetes® in Children (CDiC) programme. The programme is founded on the belief that only a holistic and integrated approach will bring about the changes necessary to save and improve the lives of children with diabetes in developing countries. Besides access to insulin and monitoring tools, well-trained and knowledgeable healthcare professionals are vital.

The Changing Diabetes® in Children programme is a partnership initiative and is composed of the following components:

1: Infrastructure and equipment
2: Training and education of healthcare professionals
3: Free insulin, blood glucose monitoring equipment and supplies
4: Education of the children and their families
5: Diabetes registries, monitoring and control
6: Sharing of insights and outcomes.

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ISPAD
International Society for Pediatric and Adolescent Diabetes