

# **Short Life Working Group on Type 1 Diabetes**

**Final Report - November 2009.**

# Executive Summary

The Scottish Diabetes Framework Action Plan (2006) set a challenging agenda for the next three years to improve diabetes care in Scotland and includes a commitment to “ensure that services are available to meet the needs of people with Type 1 diabetes”. In order to meet this objective, the Scottish Diabetes Group (SDG) established a short life working group in 2007 and provided funding to support the work of the group.

The Short Life Working Group on Type 1 Diabetes was chaired by Dr Louise Bath, Consultant Paediatrician, supported by a seconded research educational clinician and by the Section of Population Health at the University of Aberdeen, which provided administrative support. The group met on a three-monthly basis over a two year period from January 2008 to address the aspects of the Diabetes Framework that had been identified as key issues to improve the care of people with type 1 diabetes (T1D). The development of an education framework, which was a specific task of the Action Plan, was taken forward by the research clinician with the support of the SLWG. Specific individuals and sub groups worked on each key area.

The work of the group is presented in this document. The Better Diabetes Care 2009 Consultation document has identified areas for future developments. The key recommendations of this group have been included in the responses to the Better Diabetes Care consultation document and will, we hope, help to shape future plans to progress improvements in the care for individuals with T1D.

## Key Recommendations

The key recommendations include:

### Supporting improvement in T1D

- A national database that captures appropriate data is essential to determine whether we are improving care.
- The use of SCI-DC (or a database that can directly upload required information to SCI-DC) including paediatric pages should be used by all diabetes teams in Scotland to facilitate data capture.
- The Scottish Diabetes Survey Monitoring Group should produce an annual report that provides detailed information on T1D and type 2 diabetes (T2D) separately, enabling identification of specific areas that require particular attention.
- A national audit with centralisation of HbA1c (DIABAUD 4) should be supported to provide detailed data on all patients with T1D up to the age of 25 years, and allow direct comparison with data collected by SCI-DC.
- Each Health Board should work with its Managed Clinical Network (MCN) to produce a T1D strategy to direct the work of the MCN in relation to services for people with T1D linking paediatric, transition and adult services, service delivery and planning, professional and patient education, manpower planning and facilities.
- Local MCNs should develop subgroups for T1D, including intensive insulin therapy, adolescent and paediatric care.
- There is a need for a national body which would define standards, assess priorities, coordinate development planning, sponsor national audits, and provide a “corporate voice” for children’s

diabetes. This could be a national MCN for paediatric diabetes, or a standing sub-group of the Scottish Diabetes Group. We recommend the former.

- We recommend acceptance of the first national education framework for T1D. There should be further development of the education modules and programmes within the framework. The modules, programmes and support materials would provide a toolkit to deliver structured patient education. There should also be the ability to record levels of education delivered for audit purposes.
- The updated Diabetes SIGN guideline is out for consultation. Issues specific to T1D that have a strong evidence base should be implemented to improve patient care. ISPAD and NICE have recently published evidence based guidelines that should be used to drive improvements in care.

### **Focusing improvement**

- The greatest impediment to improving care for individuals is lack of staff time. Any significant improvements will only be deliverable with the necessary staffing to support education and intensive insulin therapy. Over recent years there have been significant changes in treatments and technological advances demanding greater staff expertise and time.
- People with T1D should have access to patient friendly and age appropriate education. Specific issues that have been highlighted are information regarding CHO counting and dose adjusting for children on multiple daily injections (MDI) and development of an updated DVD for children and families at diagnosis.
- One role of a national paediatric MCN should be to facilitate development of national guidelines and the education framework for children and appropriate training updates for all clinicians and allied health professionals. It would support local services in providing access to intensive insulin therapy (MDI and continuous subcutaneous insulin infusion (CSII)). The work of the national paediatric MCN should link with the work of the Scottish Diabetes Group and its subgroups.
- All children with diabetes should be supported to manage their diabetes in school as effectively as when they are at home, and there should be national guidance on how this care should be provided. A national meeting regarding these issues is planned for Spring 2010. There are specific issues regarding support for insulin injections and insulin pumps that need to be resolved.
- Care plans for transition from paediatric to adults services should be developed within each health board taking account of the volume of patients and geographical practicalities. There should be a written plan that is provided to all families prior to transition providing clear guidance regarding where, and by whom, care will be provided. There should be a subgroup of each health board's MCN for adolescent care.

### **Psychological and emotional support**

- Psychological interventions and support for staff delivering these should be available through all clinics, developed specifically for T1D, for all people with diabetes to assist them improve their health status such as improving glycaemic control. In addition there should be psychological support for those who are experiencing psychological problems and wish to engage with health services; specific experience is required to understand the complexities of diabetes and the way this condition interacts with emotional wellbeing to impact on self care and health outcomes.

### **Diabetes related hospital admissions and in patient care**

- An audit of episodes of diabetic ketoacidosis (DKA) is required to ascertain true incidence, and compare to ISD data. A method to prospectively collect all episodes of DKA should be developed to enable assessment of whether strategies to reduce DKA were having an impact.

- A national DKA awareness campaign should be launched to reduce the incidence in both new and known patients.
- Education for junior medical and nursing staff regarding inpatient care is essential. On line training modules via DOTS are being developed for Foundation trainees. There should be development of more detailed modules for trainees in paediatrics and adult medicine who provide care for in-patients with diabetes. These modules would follow on from the modules in Foundation training.
- The appointment of DSNs for inpatient care to facilitate education and support for ward nurses and junior doctors would improve inpatient care for individuals with T1D.

### **Structured Education**

- The continued development of a national education framework for T1D would provide a clear structure to support education of people with T1D. The implementation and effectiveness should be audited through a national database (SCI-DC). The development and delivery of a curriculum to support self-management would need additional funding to provide detailed guidance. There would need to be support for local teams to deliver the education.
- A package of structured education should be accessible to all patients with T1D and supported by local MCNs. The Diabetes Education Network Scotland (DENS) could co-ordinate this by linking with health board MCNs, a national MCN for paediatrics and other SDG subgroups i.e. DEAG. The benefits of collaborative working are less duplication of effort, potential for shared learning and subsequent consistency of approaches and care between adult and paediatric services. We would recommend the continued support of DENS and an integration of DENS in the strategic work of the SDG and its subgroups. This would require some administrative support and some professional lead time.

### **Professional Education**

- Alignment of professional and patient education is important to ensure professional education meets the needs of staff delivering care and services for T1D.
- Multidisciplinary training opportunities in insulin intensification including MDI and CSII for children and adults and also in management of T1D in children and adolescent should be available within Scotland.
- Training and support in advanced communication skills, assessing barriers to better self-care and in psychological interventions for health care professionals working with people with T1D should be available in Scotland. This would complement services that applied psychologists provide.
- Individuals who deliver patient centred learning to facilitate self-management should have specific training. Professional training in these skills should be supported by each health board's MCN.

### **Out of hours and remote and rural services**

- A national out of hours emergency helpline for all people with T1D should be developed in partnership with NHS24. The development would be aided by initial support from by a clinician with expertise in diabetes, seconded to NHS 24 to help develop algorithms to guide best practice.

The service would be audited and outcomes assessed, for example, the potential to reduce admission rates and reduce episodes of DKA.

### **Intensified insulin therapy**

- We know that many patients are not achieving optimal care. The use of CSII and MDIs should be grouped into a category of “intensive insulin therapy”, rather than insulin pumps being considered in isolation. Additional staff time is required to support people with T1D to achieve improved glycaemic control through either option. Neither MDI nor CSII should be rolled out unless a quality service can be delivered to support intensification.
- Delivery of intensive insulin therapy requires funding and service redesign to best support education from appropriately trained teams including clinicians, DSNs and dietitians.
- Continuous Glucose Monitoring Systems (CGMS) should be available for MDI/CSII users to facilitate improvements in glycaemic control.
- CSII for young children may have significant benefits in reducing incidence of hypoglycaemia and subsequent improved quality of life measures. CSII therapy should be specifically supported for this group.

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## List of Abbreviations

|         |  |
|---------|--|
| CHP     | Community Health Partnerships                                |
| CSII    | Continuous subcutaneous insulin infusion                     |
| DEAG    | Diabetes Education Advisory Group                            |
| DKA     | Diabetic ketoacidosis  |
| DMEG    | Diabetes Minority Ethnic Group                               |
| DOTS    | Doctors Online Training Scheme                               |
| DSN     | Diabetes Specialist Nurse                                    |
| DTU     | Diabetes Treatment Unit                                      |
| FY1     | Foundation Year  |
| ISD     | Information Services Division                                |
| HCP     | Health care professional                                     |
| IFCC    | The International Federation of Clinical Chemists            |
| ISPAD   | International Society for Paediatric and Adolescent Diabetes |
| MDCT    | Multidisciplinary care team                                  |
| MCN     | Managed Clinical Network                                     |
| MDI     | Multiple Daily Injections                                    |
| NES     | NHS Education for Scotland                                   |
| NHS QIS | NHS Quality Improvement Scotland                             |
| NICE    | National Institute for Clinical Excellence                   |
| OOH     | Out of hours service   |
| PFIG    | Patient Focus Implementation Group                           |
| QIS     | Quality Improvement Scotland                                 |
| RCPCH   | Royal College of Paediatrics and Child Health                |
| RCPE    | Royal College of Physicians of Edinburgh                     |
| SCI-DC  | Scottish Care Information - Diabetes Collaboration           |
| SDG     | Scottish Diabetes Group                                      |
| SDSMG   | Scottish Diabetes Survey Monitoring Group                    |
| SIGN    | Scottish Intercollegiate Guidelines Network                  |
| SNDRI   | Scottish Nutrition and Diet Resource Initiative              |
| SSGCDY  | Scottish Study Group for the Care of Diabetes in the Young   |
| SLWG    | Short Life Working Group                                     |
| T1D     | Type 1 diabetes  |
| WTE     | Whole time equivalent  |

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# Chapter 1 Introduction

## Background

In 2002, the Scottish Executive (Government) published the Diabetes Framework<sup>1</sup> – a strategy to contain the growth of diabetes and to ensure that people with diabetes in Scotland would have access to the best quality care and treatment. The 2002 Framework identified the various “building blocks” of diabetes, and set the focus on seven areas of key priority. A review of the 2002 Diabetes Framework was undertaken in 2004 and concluded that solid progress had been made in a number of key areas. The review also drew attention to several areas where further work was required.

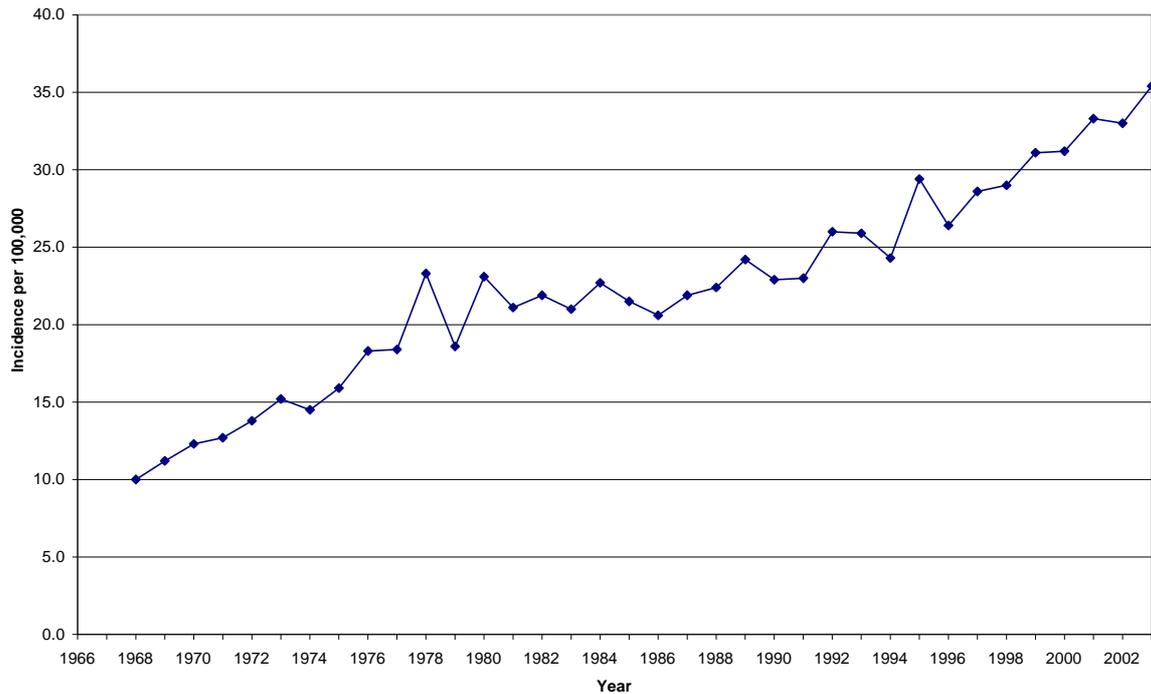
The Action Plan (2006)<sup>2</sup>, which follows on from the Scottish Diabetes Framework, set a challenging agenda for the next three years to improve diabetes care in Scotland. The Scottish Diabetes Group acts as the national steering group to take forward the implementation of the Scottish Diabetes Framework. The Diabetes Framework Action Plan includes a commitment to “ensure that services are available to meet the needs of people with Type 1 diabetes”. In order to meet this objective, the Scottish Diabetes Group established a short-life working group in 2007 and provided funding to support the work of the group.

The Short Life Working Group on Type 1 Diabetes was chaired by Dr Louise Bath, Consultant Paediatrician, supported by a seconded research educational clinician and by the Section of Population Health at the University of Aberdeen, which provided administrative and analytical support.

## Type 1 Diabetes

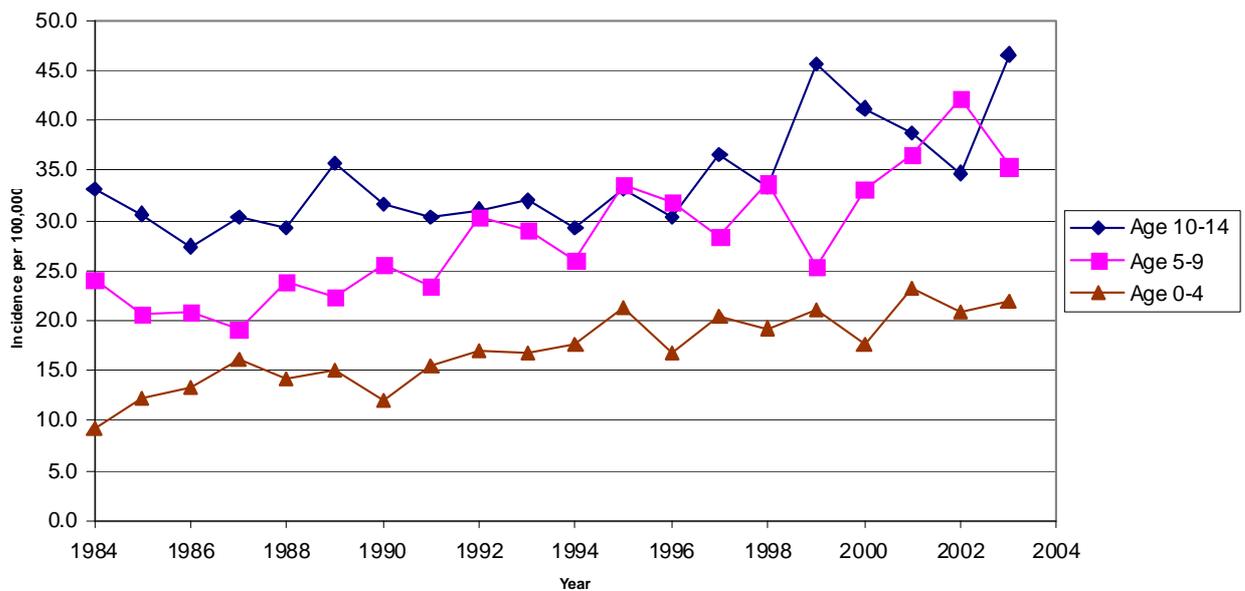
Type 1 diabetes mellitus (T1D) is characterised by absolute or nearly absolute insulin deficiency, sudden onset, severe elevation of blood glucose levels (hyperglycaemia), rapid acidification of the blood (ketoacidosis), and death unless treated with insulin. The disease may occur at any age, but onset in childhood or adolescence is most common. In most cases, T1D is caused by the immune system attacking the cells in the pancreas that produce insulin (auto-immune destruction of pancreatic  $\beta$ -cells). The causes are unknown, and so there is currently no way of preventing T1D.

The incidence (the number of new cases per annum) has risen steeply in Scottish children over the last 40 years. Figure 1 shows the incidence in the under-18s from 1968 to 1983<sup>3,4</sup> and unpublished data from the SSGCDY on incidence in the under 15s from 1984 to 2003.



**Figure 1 Incidence of type 1 diabetes in Scottish children 1968 – 1983 (under 18 years) and 1984 to 2003 (under 15 years)**

Figure 2 shows recent data broken down by age band. The steepest rise in relative terms in recent years has been in the under 5s (SSGCDY unpublished)



**Figure 2 Incidence of type 1 diabetes in Scottish children aged 0-14 years 1984-2003 by age at diagnosis**

There are marked geographical differences as shown in Table 1, from the Scottish Study Group for the Care of Diabetes in the Young (SSGCDY unpublished).

**Table 1 Age-standardised incidence per 100,000 by health board, 1984 – 2000**

| <i>Health board</i>   | <i>incidence per 100,000</i> | <i>number of cases</i> |
|-----------------------|------------------------------|------------------------|
| Greater Glasgow       | 22.6                         | 660                    |
| Dumfries and Galloway | 22.8                         | 106                    |
| Borders               | 23.3                         | 74                     |
| Tayside               | 23.5                         | 287                    |
| Lothian               | 24.4                         | 287                    |
| Fife                  | 24.4                         | 279                    |
| Forth Valley          | 24.9                         | 223                    |
| Ayrshire and Arran    | 25.3                         | 315                    |
| Grampian              | 25.9                         | 438                    |
| Lanarkshire           | 26.2                         | 402                    |
| Argyll and Clyde      | 27.9                         | 402                    |
| Shetland              | 30.5                         | 26                     |
| Highland              | 33.4                         | 234                    |
| Western Isles         | 36.7                         | 37                     |
| Orkney                | 39.1                         | 26                     |

There are currently about 1800 children under 15 in Scotland (SSGCDY). The Scottish Diabetes Survey<sup>5</sup> data, from SCI-DC, suggests that there are 27,464 people of all ages with T1D, but we have concerns that some people with insulin-treated type 2 diabetes (T2D) are being misclassified as T1D. Tayside data, which we believe to be the most accurate, suggest that the prevalence of T1D 0.43%, which would give an all-Scotland figure of approximately 22,120. We do not currently have data on the incidence above age of 15.

## **The effects of type 1 diabetes**

The effects can be grouped as follows:

### **Immediate**

- The sudden onset of a life-threatening disease, possibly in diabetic ketoacidosis (DKA) requiring emergency admission to hospital, or perhaps earlier diagnosis with insulin treatment started as outpatient or at home.
- Insulin injections, several times a day, every day, for life. These are accompanied by the need for self-testing of blood glucose, a regular diet, and care with physical activity. Patients and families have a steep learning curve.
- A constant need to balance blood glucose levels, to avoid poor control which would increase the risk of long-term complications, while avoiding low levels of blood glucose (hypoglycaemia).
- The psychological impact of learning practical skills (injections, blood glucose monitoring) and lifestyle changes.

### **Intermediate**

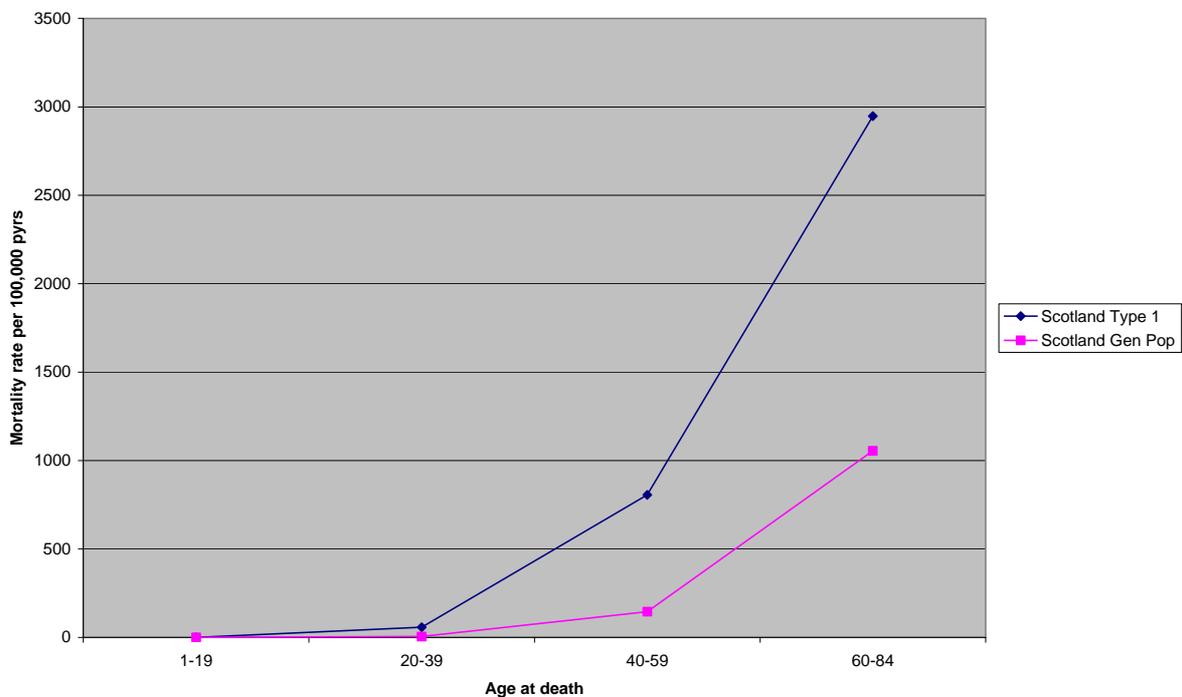
- Needs for self-discipline, ongoing education, constant monitoring and self-adjustment of insulin.
- Hypoglycaemic episodes, which can be mild (hunger, sweating), moderate (temporary interruption of activities in order to eat or take sugar in some form), to severe (incapacity, loss of consciousness, a need to summon help, possible A&E attendance).

- DKA, when an insufficiency of insulin at a time of metabolic stress leads to inability of the body to use glucose, leading to breakdown of fat stores and abnormal accumulation of ketones. It is usually a medical emergency, requiring admission to hospital for intravenous fluids and insulin. It can be fatal but the mortality rate is now very low. However, it is responsible for many admissions to hospital.
- Some restrictions on lifestyle and activities.
- The effects of normal daily living activities on blood glucose control, and the self-management interventions required to maintain acceptable glycaemic control.

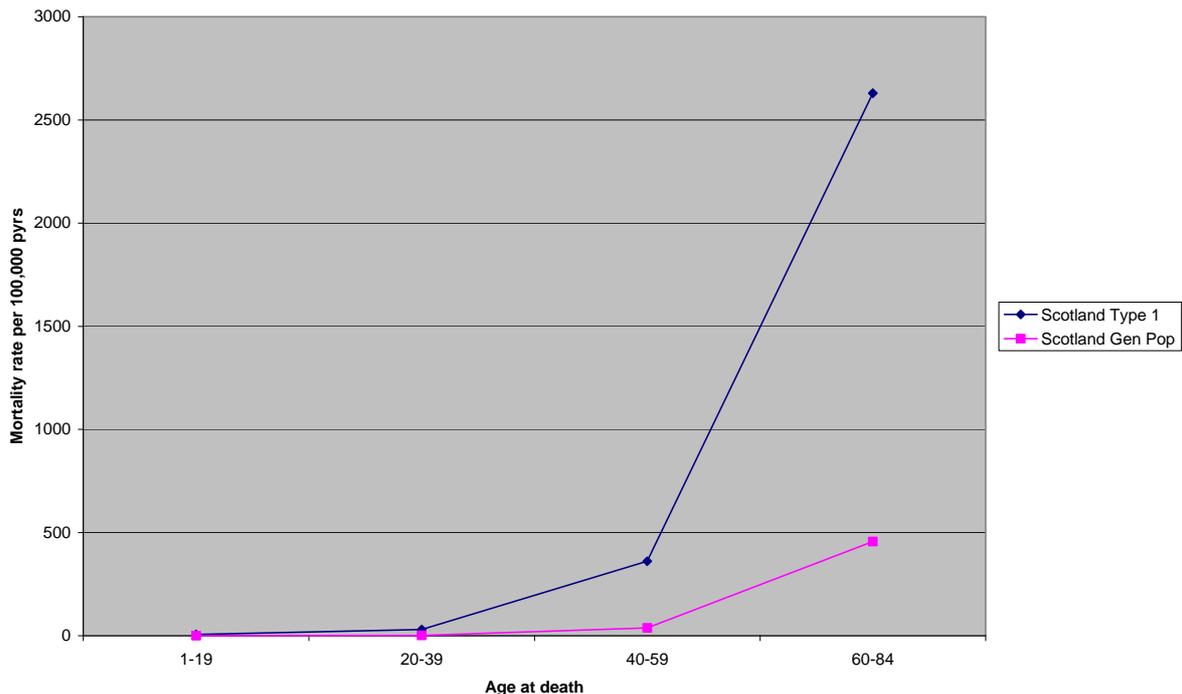
### Long-term

- Retinopathy – disease of the eyes which if not detected and treated could lead to blindness.
- Nephropathy – damage to the kidneys which can lead to end stage renal failure requiring dialysis.
- Neuropathy – damage to the nerves which can lead to a variety of symptoms, depending on which nerves are affected, but including ulceration, pain, muscle weakness, gastric problems, etc.
- Peripheral vascular disease, of the arteries in the leg, leads to ulceration especially when associated with peripheral neuropathy.
- Heart disease and stroke – the incidence of heart disease is greatly increased in T1D, especially in women.
- The incidence of some other problems is increased in diabetes – cataract, fractures, etc.
- Sexual dysfunction.
- Problems in pregnancy.
- Depression or impact of coping with chronic disease.

People with T1D have considerably increased risk of ischaemic heart disease as shown in Figure 3 and Figure 4 (BDA Cohort Study, unpublished data provided by N Waugh).



**Figure 3 Ischaemic heart disease mortality in males with type 1 diabetes in Scotland**



**Figure 4 Ischaemic heart disease mortality in females with type 1 diabetes in Scotland**

The impact on the NHS is considerable, but routine statistics under-estimate it for two main reasons. Firstly, T1D is often not recorded on SMR 1 discharge forms. The under-reporting has in the past been about 30%. It is also under-reported on death certificates. Secondly, much of the morbidity is cardiovascular disease, where the principal cause of admissions will be recorded as that. So the true cost of T1D will be under-estimated. But it can be estimated from the relative risk (RR), so if someone with T1D has a four-fold risk of a myocardial infarction compared to someone without T1D, the RR is four and 75% of the cost can be attributed to diabetes.

The challenges to the NHSiS arise for several reasons. Firstly, there is the increasing number of people with T1D, partly due to the rising incidence, and partly due to improvements in survival arising from improvements in care. These improvements are partly due to improvements in glycaemic control, but also partly to improvements in other aspects such as control of high blood pressure (BP).

Secondly however, two audits of the quality of glycaemic control in the under 15s, Diabaud 2<sup>6</sup> and Diabaud 3<sup>7</sup>, have shown that only about 10% are achieving the NICE T1D Guideline target HbA1c. The audits also showed that most young people were not on intensified insulin regimens (the latest was 2002-4). In recent years, there has been a shift towards greater use of such regimens, usually involving multiple daily injections, but with a small number on continuous subcutaneous insulin infusion (CSII).

Intensified insulin therapy (IIT) is a package of self-care, with a combination of more frequent doses of insulin, usually one injection of a long acting insulin a day (sometimes two) and mealtime doses of short-acting, together with regular self-monitoring of blood glucose, self-adjustment of insulin dose, and care with diet. It requires commitment from a well-educated (in diabetes) patient, and not all patients wish to move to intensified therapy. It is not just about taking insulin more often.

The Diabetes Control and Complications Trial (DCCT)<sup>8,9</sup> examined whether intensive treatment, aimed at maintaining blood glucose concentrations as close to the normal range as possible, could decrease the frequency and severity of diabetic complications. It showed that improved glucose

control led to fewer long-term complications, but also had an impact upon the frequency of presentation with hypoglycaemia. An important finding was that the early good control in the intensive therapy group had a beneficial effect long after the trial ended and the levels of control in the two groups converged. This has led to the concept of “metabolic memory” and the implication is that optimum control needs to be achieved as early as possible.

Thirdly, new forms of T1D education, delivered in a variety of structured ways, have been shown to be advantageous, and have been recommended by NICE. These are described later in this report. A key issue is that they require significant amounts of staff time for training, so that while cost-effective, they have significant costs.

Fourthly, there are rising expectations amongst an increasingly well-informed patient group. Service users will become more involved in the development of future services. People with diabetes will have a greater role, rather than being passive recipients of services.

Lastly, technological developments have the potential to further improve care, but would require resourcing. CSII use is expected to rise following the recent NICE guidance, especially amongst children.

## HbA1c

HbA1c, a form of glycated haemoglobin, is the standard measure of glycaemic control, and remains the best measure to assess current glycaemic control and predict risk of long term complications. However, there are concerns regarding the different methodology by which different centres, and even countries, report HbA1c. The International Federation of Clinical Chemists (IFCC) has recognised for some time that it would be preferable to have an HbA1c result that could be aligned to a reproducible gold standard. They have produced this defined standard and this is the first time that there has been an internationally agreed standard HbA1c. The new method of reporting HbA1c was introduced in Scotland in June 2009 and Table 2 shows the direct conversion from old to new units.

**Table 2 DCCT aligned HbA1c with IFCC equivalent**

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

With time, it is possible that, with the improved consistency in the gold standard and better design of analysers, the results from these machines will show less variation. There remains concern that there is variability between different laboratories. All biochemistry laboratories are members of NEQAS (national [UK] external quality assessment scheme). Each lab is sent a report detailing where their result lies in relation to the mean. Across all HbA1c machines there is around  $\pm 0.4\%$  difference in results for a standard sample for the majority of results but there are some laboratories that are outliers that produce significantly higher or lower results. There will always be a spread of results, but if the spread is narrow then results can be compared between units.

The Scottish Diabetes Survey publishes the HbA1c for all patients for whom data has been entered. We know that all adult units use SCI-DC but only the minority of paediatric units input data.

Therefore the paediatric data is less reliable. However, it is currently the only national produced data (see Table 3). The data is extracted at the end of each year and provides only the most recent HbA1c. We know there is significant variation in HbA1c throughout the year with higher levels in the winter in children and hence this will not be the best way to review overall glycaemic control in children. A mean HbA1c for each clinic visit is more reliable but not possible to obtain from each unit for inclusion in this report. A national audit (DIABAUD4) with centralised HbA1c including all patients with T1D up to age 25 years would enable direct comparison between units.

Table 3 below shows mean HbA1c for people with T1D in health board regions in Scotland<sup>5</sup>.

**Table 3 Mean HbA1c recorded in previous 15 months for people with type 1 (in 4 age categories)**

| NHS Board               | Mean HbA <sub>1c</sub> Type 1 Age 0-14 | Mean HbA <sub>1c</sub> Type 1 Age 15-19 | Mean HbA <sub>1c</sub> Type 1 Age 20-39 | Mean HbA <sub>1c</sub> Type 1 Age > 39 |
|-------------------------|--|---|---|--|
| Ayrshire & Arran        | 8.7                                    | 9.4                                     | 8.8                                     | 8.7                                    |
| Borders                 | 8.8                                    | 9.5                                     | 9.1                                     | 8.5                                    |
| Dumfries & Galloway     | 9.2                                    | 9.7                                     | 8.8                                     | 8.4                                    |
| Fife                    | 8.8                                    | 9.7                                     | 8.6                                     | 8.4                                    |
| Forth Valley            | 9.1                                    | 10.3                                    | 8.9                                     | 8.5                                    |
| Grampian                | 8.9                                    | 10.2                                    | 9.2                                     | 8.9                                    |
| Greater Glasgow & Clyde | 8.6                                    | 9.6                                     | 8.9                                     | 8.6                                    |
| Highland & Argyll       | 9.2                                    | 9.7                                     | 8.9                                     | 8.5                                    |
| Lanarkshire             | 8.8                                    | 9.5                                     | 8.9                                     | 8.5                                    |
| Lothian                 | 9.1                                    | 9.5                                     | 8.5                                     | 8.2                                    |
| Orkney                  | 8.1                                    | 10.2                                    | 7.7                                     | 7.8                                    |
| Shetland                | 9.3                                    | 9.2                                     | 8.3                                     | 8.0                                    |
| Tayside                 | 9.3                                    | 10.3                                    | 8.9                                     | 8.4                                    |
| Western Isles           | 8.7                                    | 9.2                                     | 9.3                                     | 8.4                                    |

Variation in methods of measuring HbA1c may account for some of the differences. The results vary considerably amongst health boards: 8.1% to 9.3% in the 0 to 14s; 9.2% to 10.3% in the 15 to 19 year-olds; and 8.3% to 9.3% in the 20 to 39 age range. The target level for HbA1c is 7.5% or under, so most people with type 1 diabetes in Scotland are not achieving good control. It is worth noting that in trials of treatment of diabetes, a difference in HbA1c of 0.5% is regarded as clinically useful. The differences amongst health boards are therefore clinically significant.

## Organisation of services: existing situation

### Paediatric services: management arrangements

Paediatric diabetes services are currently the responsibility of each health board and of the local MCN for diabetes. There is concern amongst paediatricians that this may result in low priority being given to paediatric services, because the great majority of the MCN's patients will be adults with T2D. It has been suggested that there could be a national paediatric MCN. This was discussed at the annual paediatric diabetes multidisciplinary meeting in August 2009 and there was unanimous agreement that a national MCN for paediatric diabetes would improve patient care. Other options are possible, including having a paediatric standing subgroup of SDG.

The roles for the national group should include;

- Defining standards of care for paediatric diabetes. This is done by SIGN through the guidelines, but these can only be updated at quite long intervals, and an interim system for updating in the light of new evidence or treatments is required

- Assessing priorities for improving care, including national coordination of planning for service development
- Providing a “corporate voice” for children’s diabetes
- Sponsoring national audits
- Promoting standardisation of educational materials and courses
- Monitoring equity of provision.

Fulfilling those roles would require some central resource. A national MCN would provide a central office. A standing sub-group of SDG would not automatically be given any resource, but SDG could allocate some funds for national activities.

### **Services for people with type 1 diabetes**

Much of the care of patients with T2D has been transferred into the community, with general practitioners and practice nurses taking over from secondary care albeit supported by hospital consultants and diabetes specialist nurses (DSN) as required. The Diabetic Retinopathy Screening Service facilitates this shift, by ensuring high quality eye screening in the community.

It has been suggested in some areas that GPs might take over more of the care of people with T1D. However T1D is a much more complex disease to manage, especially with the move to intensified insulin treatment. GPs will have a continuing role (perhaps especially providing continuity in younger patients who default from hospital follow-up), but most people with T1D should be seen by specialist care at least once a year. Children need more frequent visits, with the usual practice being 3-monthly out-patient attendance.

### **Information on type 1 diabetes**

The SLWG encountered a number of problems with a lack of information, and similar issues were noted by Diabetes UK during the consultation. We need better data on at least the following;

- The inpatient impact of type 1 diabetes
- The proportion of the Scottish NHS budget spent on T1DM. This would provide a baseline for planning future services, for example by estimating savings which could result from reduction in the prevalence of complications.
- The incidence of type 1 diabetes at all ages (we currently have it only in the under 15s), the prevalence of complications and trends over time, and life expectancy

## **Recommendations**

- A national audit with centralisation of HbA1c (DIABAUD 4) should be supported to provide detailed data on all patients with type 1 diabetes up to the age of 25 years, and allow direct comparison with data collected by SCI-DC.
- Data on services, costs and outcomes for type 1 diabetes should be improved
- We should establish a national body such as a paediatric MCN with the aim to improve glycaemic control and quality of life for children and families with T1D.
- The work of the national paediatric MCN should link with the work of the Scottish Diabetes Group and its subgroups (e.g. DEAG, SDRN, DMEG, etc) to avoid duplication of effort and isolation of paediatrics from other service providers and workstreams.
- A national paediatric MCN would provide an equitable presence that is lacking in the current structure where paediatric services are a very minor player in the local MCNs dominated by T2D.

## Chapter 2 Services at diagnosis

### Introduction

The diagnosis of T1D is devastating for the individual and their family. It is crucial that diagnosis is made promptly with immediate (same day) referral to a multidisciplinary team with the skills and knowledge to provide expert care, advice and education.

SIGN, NICE and ISPAD have produced guidelines for the care of adults, young people and children with T1D<sup>10-12</sup>. SIGN<sup>11</sup> is currently updating its guideline. This chapter aims to distil these recommendations for best practice in the care and management of T1D at diagnosis, highlight shortfalls in current service provision and make recommendations for areas to be addressed. It is based mainly on NICE and ISPAD guidance.

### Standards of care

#### Children and young people

The guidelines which follow are based on those from NICE and ISPAD.

- The diagnosis of T1D in children and young people should be based on the criteria specified in the 1999 World Health Organization report on the diagnosis and classification of diabetes mellitus.
- Children and young people with suspected T1D should be offered immediate (same day) referral to a multidisciplinary paediatric diabetes care team that has the competencies needed to confirm diagnosis and to provide immediate care.
- Prompt diagnosis of diabetes in children is important in preventing rapid deterioration into ketoacidosis. Severe ketoacidosis, if untreated, is fatal. Therapy is urgent and referral to specialised services is essential.
- Domiciliary/outpatient/ambulatory management of children at the time of diagnosis is possible in some centres with appropriate resources but can only be recommended when members of the diabetes care team are experienced in the outpatient initiation of insulin therapy and adequate funding for diabetes team care is available for extensive outpatient diabetes management and education. Backup hospitalisation must also be available in case of metabolic deterioration.
- Children and young people with T1D should be entered on a population based, practice-based and/or clinic-based diabetes register.
- From the outset, children and young people with T1D should be offered an ongoing integrated package of care by a multidisciplinary paediatric diabetes care team. To optimise the effectiveness of care and reduce the risk of complications, the diabetes care team should include members with appropriate training in clinical, educational, dietetic, lifestyle, psychological interventions, and foot care aspects of diabetes for children and young people, and their families.
- The diabetes care team should recognise the family and child as an integral part of the care team. Their importance as members of the child's care team should be emphasised from the day of diagnosis and families should be involved in making decisions about the package of care provided by the diabetes care team.

- Children and young people with T1D and their families should be offered 24-hour access to advice from the diabetes care team.
- At the time of diagnosis, children and young people with T1D should be offered home-based or inpatient management according to clinical need, family circumstances and wishes, and residential proximity to inpatient services. Home-based care with support from the local paediatric diabetes care team (including 24-hour telephone access to advice) is safe and as effective as inpatient initial management.
- Children and young people who present with DKA should have their DKA treated in hospital according to the relevant guidelines.
- Children with T1D who are younger than 2 years of age and children and young people who have social or emotional difficulties, or who live a long way from hospital should be offered inpatient initial management.
- Children and young people with newly diagnosed T1D should be offered a structured programme of education covering the aims of insulin therapy, delivery of insulin, self-monitoring of blood glucose, the effects of diet, physical activity and intercurrent illness on glycaemic control, and the detection and management of hypoglycaemia. Written materials should be in a format and language the family can best understand.
- There should be psychosocial support for the child and family.

In the first 6 months following diagnosis frequent contact with the diabetes care team is necessary to help manage the changing requirements of diabetes in its early phases. Contact may be by frequent clinic appointments, home visits, and telephone or other methods of communication and usually consists of a combination of these methods.

The ultimate goal is to provide care that results in normal growth and development, a high quality of life, and lowest possible risk of acute and long-term complications. This is best accomplished by helping children and families become proficient in self-management, remain motivated throughout childhood and adolescence, developing into independent, healthy adults.

## **Adults**

The guidelines which follow are based on those from NICE.

- The views and preferences of individuals with T1D should be integrated into their healthcare. Diabetes services should be organised, and staff trained, to allow and encourage this.
- The range of professional skills needed for delivery of optimal advice to adults with diabetes should be provided by a multidisciplinary team. Such a team should include members having specific training and interest to cover the following areas of care:
  - education/information giving
  - nutrition
  - therapeutics
  - identification and management of complications
  - foot care
  - counselling
  - psychological care

- Culturally appropriate education should be offered after diagnosis to all adults with T1D (and to those with significant input into the diabetes care of others). It should be repeated as requested and according to annual review of need. This should encompass the necessary understanding, motivation, and skills to manage appropriately:
  - blood glucose control (insulin, self-monitoring, nutrition)
  - arterial risk factors (blood lipids, blood pressure, smoking)
  - late complications (feet, kidneys, eyes, heart)
- Blood glucose control should be optimised towards attaining DCCT-harmonised HbA1c targets for prevention of microvascular disease (less than 59 mmol/mol (7.5%)) and, in those at increased risk, arterial disease (less than or equal to 48 mmol/mol (6.5%)) as appropriate, while taking into account:
  - the experiences and preferences of the insulin user, in order to avoid hypoglycaemia
  - the necessity to seek advice from professionals knowledgeable about the range of available meal-time and basal insulins and about optimal combinations thereof, and their optimal use.
- Adults with T1D should be assessed for arterial risk at annual intervals. Those found to be at increased risk should be managed through appropriate interventions and regular review. Note should be taken of:
  - microalbuminuria, in particular
  - the presence of features of the metabolic syndrome
  - conventional risk factors (family history, abnormal lipid profile, raised blood pressure, smoking)
- Adults with T1D should be assessed for early markers and features of eye, kidney, nerve, foot and arterial damage at annual intervals. According to assessed need, they should be offered appropriate interventions and/or referral in order to reduce the progression of such late complications into adverse health outcomes affecting quality of life.

## **Prompt diagnosis, prevention and treatment of DKA**

DKA carries significant mortality and morbidity in both adults and children. In the developed world, the proportion of children whose initial presentation with T1D is in ketoacidosis varies between 15 - 70%. Presentation rates of around 25 -30% are typical in many paediatric diabetes centres. DKA is more common with first presentation of younger children. This is significant given the increasing incidence of T1D in children globally and in Europe of those under 4 years of age in particular. DKA is covered in Chapter 7 of this report.

## **The multidisciplinary care team (MDCT)**

The role of the MDCT is multi faceted, providing not only clinical care but support and education to children and adults with diabetes and their families as well as the wider health care community. Members of the MDCT should include medical, nursing, dietetic, podiatry, social work and psychology staff. Children's diabetes services require staff with specialist experience and knowledge of childhood and adolescent care and development. Skills in education and psychosocial support, in

addition to clinical expertise, are necessary to facilitate a family/patient centred approach to care. Some of these skills will be acquired at undergraduate/ pre registration level but most will be gained once in post. The need for appropriate training skills for staff to deliver care to adults and children with diabetes and their families in the 21<sup>st</sup> century must be recognised and provision made for this. Although we recognise that some skills can only be fully developed with experience there is a great deal that can be achieved through the timely provision of appropriate training for staff. Chapter 8 deals specifically with the issue of professional education and training.

The number of whole time equivalent (WTE) staff making up the MDCT to provide an adequate service is not easy to define. There has been a steady increase in the incidence of T1D in Scotland with a significant increase in the total number of children being diagnosed. Recent studies have shown a 5-fold increase in incidence in children under the age of five in the past 20 years with a predicted doubling of new cases in this age group between 2005 – 2020<sup>13</sup>. There has also been a drop in the age of onset which impacts on paediatric workload, with about 13% increase in OP appointments. Greater patient numbers especially those under the age of 5, along with technological advances in treatments and poor manpower planning have placed increased demands on paediatric and adult diabetes care teams. Many teams are struggling to cope with delivering structured education to support the more complex skills required to master self-management of intensive insulin treatment i.e. multiple daily injections (MDI) and continuous subcutaneous insulin infusion (CSII). The only staffing level figures available are not evidence based and out of date. There do not appear to be any tools available to planners to calculate appropriate staffing levels for adult and paediatric T1D services. Figures used by paediatric centres submitting funding bids as part of the National Delivery Plan for Children and young people's specialist services are:

- Diabetes Specialist Nurse (DSN) 1 WTE per 60 patients
- Dietitians 1 WTE per 200 children
- Psychology 1 Wte per 300 children

## **Diabetes Register**

The SSGCDY maintain a national incidence register of children diagnosed with T1D, but there are no similar data in those aged 15 and over. In theory, SCI-DC should provide this but there are issues around extracting and collating information specific to T1D. The SLWG has requested that future reports from the Scottish Diabetes Survey Monitoring Group present information for T1D and T2D separately. This would enable healthcare providers to:

1. identify incidence and prevalence of T1D
2. assess glycaemic control by diagnosis in age bands for T1D
3. assess the incidence and progression of complications for T1D

## **Out of Hours Care**

This topic is covered in Chapter 6 of this report.

## **Hospital or home**

The decision to provide initial treatment and education in a hospital out patient setting or in the persons home is an issue that applies almost exclusively to children's services since adults, unless in need of hospitalisation to treat DKA, are managed as out patients.

Traditionally, children newly diagnosed with T1D have been admitted to hospital to make sure that blood glucose and symptoms of the disease are well controlled and to teach the child and his/her

family how to manage the T1D. In some cases, the child is acutely ill and needs hospital admission to receive intravenous fluids, but in many cases the child is not acutely ill. Being in hospital is often stressful for children and their families and home-based care may provide a more natural environment for the children and families to learn how to deal with the T1D. A Cochrane review<sup>14</sup> to assess the effects of routine hospital admission compared to outpatient or home-based management in children newly diagnosed with T1D was conducted in 2007. Although the authors were unable to draw any definitive conclusions, the data from the studies reviewed suggested that home management of children newly diagnosed with T1D does not lead to any disadvantages in terms of blood glucose, acute diabetic complications and hospitalisations, psychological variables and behaviour, or total costs. This would be particularly relevant for children not acutely ill, but also for children who require a short period of initial treatment in the hospital. This review highlighted the need for more qualitative research to facilitate a more informed approach to care. The DECIDE trial<sup>15</sup> currently underway aims to provide this. In the meantime, there is no evidence to support a particular approach.

Providing domiciliary care brings increased costs in terms of staff time for travel and may be prohibitively expensive in some rural areas. The adequacy of either outpatient or other facilities for MDCTs to provide care and education in a non-clinical setting is variable in health board areas. If a patient/family centred approach to care is to be implemented this must be addressed.

## **Structured Education**

Education is key to helping adults, children and their families become proficient in self-management. The whole process of education to support self-management must be dynamic, responding to the changing needs of the individual, the growing child and his/her family. It is crucial that a person/family centred approach is established at diagnosis where the individual and their family are recognised as integral to the whole process.

The topic of patient education is detailed in Chapter 5 of this report.

## **Starting insulin, insulin regimens, IIT, CSII and insulin strategies**

The following section is based on guidelines from ISPAD<sup>16</sup> and NICE<sup>17</sup> on starting insulin and choice of insulin regimen. SIGN is currently updating its guidelines. Reference is made to the increasing use and availability of intensive insulin regimens and the service provision in terms staff time, staff training and patient education to support self-management that these regimens demand.

Insulin treatment must be started as soon as possible after diagnosis (usually within 6 hours if ketonuria is present) to prevent metabolic decompensation and DKA .

While the insulin regimen should be individualised for each patient, three basic types of insulin regimen can be considered. The choice of insulin regimen will depend on many factors including age, duration of diabetes, lifestyle (dietary patterns, exercise schedules, school, work commitments, etc.), targets of metabolic control, and, particularly, individual patient/family preferences. None of these regimens can be optimised without frequent assessment by blood glucose monitoring.

### **“Conventional” insulin therapy with twice daily mixtures**

These are usually injections of short-acting insulin or rapid-acting insulin analogue mixed with intermediate-acting insulin. The insulin preparations may be mixed by the patient at the time of injection. Premix insulins are available and may be used in some instances.

### **Multiple daily injection regimen**

The person has injections of short-acting insulin or rapid-acting insulin analogue before meals, together with one or more separate daily injections of intermediate-acting insulin or long-acting insulin analogue.

### **Continuous subcutaneous insulin infusion**

A programmable pump and insulin storage reservoir that gives a regular or continuous amount of insulin (usually in the form of a rapid-acting insulin analogue or short-acting insulin) by a subcutaneous needle or cannula.

No insulin injection regimen satisfactorily mimics normal physiology.

### **Guidelines for care.**

The guidelines which follow are based on those from NICE and ISPAD

- Pre-school and primary school children with T1D should be offered the most appropriate individualised regimens to optimise their glycaemic control.
  - Young people with T1D should be offered MDI regimens to help optimise their glycaemic control.
  - MDI regimens should be offered only as part of a package of care that involves continuing education, dietary management, instruction on the use of insulin delivery systems and blood glucose monitoring, emotional and behavioural support, and medical, nursing and dietetic expertise in paediatric diabetes, because this improves glycaemic control.
  - Children and young people using MDI regimens should be informed that they may experience an initial increase in the risk of hypoglycaemia and short-term weight gain.
  - Children and young people with T1D and their families should be informed about strategies for the avoidance and management of hypoglycaemia.
  - Young people who do not achieve satisfactory glycaemic control with MDI regimens should be offered additional support and, if appropriate, alternative insulin therapy (once-, twice- or three-times daily mixed insulin regimens or CSII using an insulin pump).
  - Young people with T1D who have difficulty adhering to MDI regimens should be offered twice-daily injection regimens.
  - CSII is recommended as an option for adults and children 12 years and older with T1D provided that
    - attempts to achieve target haemoglobin A1c (HbA1c) levels with MDI result in the person experiencing disabling hypoglycaemia. For the purpose of this guidance, disabling hypoglycaemia is defined as the repeated and unpredictable occurrence of hypoglycaemia that results in persistent anxiety about recurrence and is associated with a significant adverse effect on quality of life
- or

- HbA1c levels have remained high (that is, at 8.5% or above) on MDI therapy (including, if appropriate, the use of long-acting insulin analogues) despite a high level of care.
- For children younger than 12 years NICE recommend the use of CSII therapy where MDI therapy is considered to be impractical or inappropriate.
- The use of CSII requires special education for users but does not need to be restricted to centres with 24 hour access to CSII expertise. The pump user or the family should be taught how to switch to multiple injections with pens or syringes in case of emergency.

Over the past 10 to 15 years a number of factors have placed increased demands on provision of services to people with T1D. These include

- A significant increase in the number of people diagnosed with T1D, with accurate data for the under 15s, showing increased incidence of childhood diabetes particularly in the under 5 age group. We do not have data for the over 15s, but clinical consensus is that there are as many new cases over that age, as under it.
- Technological advances in treatments available, especially due to intensification of insulin therapy, mainly MDI, but including some CSII, following the evidence from DCCT and CSII trials on the health and quality of life benefits of these treatments.
- Recognition of the role of structured education programmes to support self-management.

While staff providing care have made valiant efforts to keep pace with these changes there is now very real concern that services are not able to provide the level of care demanded in the 21<sup>st</sup> century. Staffing levels for DSNs, dietitians, psychology and medical staff have not kept pace with the changing demands of the service and the quality of care delivered to people with T1D is suboptimal.

Appendix 1 of this report outlines intensive insulin treatment and the cost of providing this including staff time for patient education to support self-management. Reference has already been made in this chapter to the lack of information available to define appropriate staffing levels.

As part of the “Diabetes Action Plan” issued by the Scottish Executive in June 2006<sup>2</sup>, each Diabetes Managed Clinical Network (MCN) was given the task of producing an “insulin strategy” for their health board area. The aim of the insulin strategy is to ensure a consistent approach to treatment across health board areas. The insulin strategy should reflect an underpinning philosophy that ensures individual patients are supported with insulin regimens tailored to suit their needs, supported by a structured and continuous education process to facilitate self management. The skills and training of health care professionals involved in delivering patient centred education, care and support should also be identified within the strategy. Some, but not all health boards, have produced insulin strategies.

An outline insulin strategy for T1D is included in Appendix 2 of this report.

## **Recommendations**

- There should be an audit of current service level provision for children and adults with T1D and development of evidence based tools for manpower planning

- Future reports from the Scottish Diabetes Survey Monitoring Group should present information for T1D and T2D separately.
- Health boards should work with MCNs to prioritise the development of insulin and service provision strategies for people with T1D. For health boards where provision of service has links with other larger health boards e.g. Orkney, Shetland and the Western Isles, joint strategies should be drawn up.
- Producing a strategy should bring together staff and service users from adult, paediatric and transition services. The strategy should be reviewed at regular agreed intervals. It should be made publicly available. The service provision and practice that the strategy reflects should be subject to monitoring and audit.
- The strategy should inform and direct the work of the MCN in relation to services for people with T1D including paediatric, transition and adult services, service delivery and planning, professional and patient education, manpower planning and facilities.

## Chapter 3 Services after diagnosis

### Introduction

This chapter outlines services after diagnosis of T1D including screening for and prevention of complications, screening for associated conditions, psychology services and diabetes in schools.

Services for people with T1D following diagnosis are essential to provide ongoing education and support, monitor diabetes control and screen for diabetes complications. Traditionally services for T1D have been provided in secondary care with the MDCT having links to the wider care community and in the case of children and young people, education and childcare providers. Secondary care accommodation and facilities are variable across health boards and in some cases no longer adequate or appropriate for function. This is most apparent for the delivery of structured education to support self management.

### Screening for and prevention of complications

The long-term vascular complications of T1D include retinopathy, nephropathy, neuropathy, and macrovascular disease. The outcomes are the following:

- Visual impairment and blindness due to diabetic retinopathy
- Renal failure and hypertension due to diabetic nephropathy
- Pain, paresthesiae, muscle weakness, and autonomic dysfunction due to diabetic neuropathy
- Cardiac disease, peripheral vascular disease, and stroke due to macrovascular disease

Screening for diabetes complications aims to detect subclinical complications, which may be treated to delay progression to clinical disease.

The DCCT provided unequivocal evidence that intensive diabetes treatment and improved glycaemic control conferred a significant risk reduction for microvascular complications compared with conventional treatment<sup>18</sup>. The Epidemiology of Diabetes Interventions and Complications study (EDIC) has shown that this positive effect persisted after the end of the trial, despite controls becoming similar, i.e., there was a memory effect of the improved glycaemic control. In addition, it showed a positive effect of intensive therapy for reduction in macrovascular disease<sup>19</sup>.

Screening for microvascular and other complications aims to detect early abnormalities that can potentially be reversed by improved glycaemic control. An RCT has confirmed that tight glycaemic control helps to prevent long-term microvascular complications among young people. Management strategies for children and young people with T1D should therefore include early detection and ongoing treatment of microvascular and other complications.

Long-term macrovascular complications (such as myocardial infarction resulting from atherosclerosis) are a significant cause of mortality and morbidity in adults with T1D. Although large-vessel disease processes begin in childhood, macrovascular complications are not chief concerns for children and young people with T1D. However, screening for associated risk factors may help to prevent severe long-term macrovascular complications. Dyslipidaemia and sustained hypertension are proxy surveillance measures for macrovascular disease. In addition, smoking cessation and physical activity programmes should be promoted to further reduce the risk of macrovascular disease.

Clinically evident diabetes-related vascular complications should be rare in childhood and adolescence. However, early functional and structural abnormalities may be present a few years after the onset of the disease. There has been a declining incidence of complications reported in many areas with specialised clinics. This has occurred over a period of time during which there have been

major changes in diabetes management, identification of putative risk factors, and the advent of regular screening for complications.

ISPAD<sup>20</sup> and NICE<sup>17</sup> guidelines outline screening procedures and best practice for T1D. ISPAD recommendations are summarised in Table 4 and Table 5. SIGN<sup>11</sup> is currently updating its guideline. It should be noted that retinopathy screening is presently carried out in Scotland from the age of 12 as part of the national screening programme.

**Table 4 Screening, risk factors, and interventions for vascular complications: the levels of evidence for risk factors and interventions pertaining to adult studies, except for improved glycaemic control (ISPAD)**

|                              | When to commence screening?  | Screening methods   | Risk factors   | Potential intervention  |
|------------------------------|--|---|--|---|
| <b>Retinopathy</b>           | Annually from age 11 yr with 2 yr of diabetes duration and from 9 yr with 5 yr of duration | Fundal photography or mydriatic ophthalmoscopy (less sensitive)         | Hyperglycemia, high blood pressure, lipid abnormalities, and higher BMI          | Improved glycaemic control and laser therapy                            |
| <b>Nephropathy</b>           | Annually from age 11 yr with 2 yr of diabetes duration and from 9 yr with 5 yr of duration | Urinary albumin/creatinine ratio or first morning albumin concentration | High blood pressure, lipid abnormalities, and smoking                            | Improved glycaemic control, ACEI and AIIRA, and blood pressure lowering |
| <b>Neuropathy</b>            | Unclear  | History and physical examination  | Hyperglycemia and higher BMI   | Improved glycaemic control  |
| <b>Macrovascular disease</b> | After the age of 12 yr   | Lipid profile every 5 yr and blood pressure annually                    | Hyperglycemia, high blood pressure, lipid abnormalities, higher BMI, and smoking | Improved glycaemic control, blood pressure control, and statins         |

ACEI, angiotensin-converting enzyme inhibitors; AIIRA, angiotensin II receptor antagonists; BMI, body mass index.

**Table 5 Target levels for different parameters to reduce the risk of microvascular and cardiovascular diseases in children and adolescents with type 1 diabetes; the levels of evidence pertain to adult studies (ISPAD)**

| Parameter  | Target level  |
|--|---|
| Hemoglobin A1c (Diabetes Control and Complications Trial standard) | ≤7.5% (58 mmol/mol) without severe hypoglycemia   |
| Low-density lipoprotein cholesterol                                | <2.6 mmol/L   |
| High-density lipoprotein cholesterol                               | >1.1 mmol/L   |
| Triglycerides  | <1.7 mmol/L   |
| Blood pressure   | <90th percentile by age, sex, and height  |
| Body mass index  | <95th percentile (non-obese)  |
| Smoking  | None  |
| Physical activity  | >1 h of moderate physical activity daily  |
| Sedentary activities   | <2 h daily  |
| Healthy diet   | Caloric intake appropriate for age and normal growth<br>Fat ,30% of caloric intake and saturated fat ,10% of caloric intake<br>Fiber intake 25–35 g daily<br>Increased intake of fresh fruit and vegetables |

Clinical services for children and adults with T1D in Scotland include screening for complications. Monitoring the impact of service delivery and education on the incidence of diabetes related complications for T1D is difficult because information for T1D is not reported separately in the population over the age of 15. The need to report information for T1D separately from T2D has been highlighted in the previous chapter.

It is recognised that adolescence is a period when achieving good diabetes control can be problematic. Adolescence is when formal and frequent screening for micro and macrovascular complications begins and coincides with a time when young people may choose to opt out of clinic care. Establishing planned transitional care programmes and procedures along with the support and input from psychology services is important to minimise the disruption to continuity of care at this time. Chapter 4 covers the subject of transition in detail.

It may be appropriate that clinical care and complication screening be delivered in a separate setting to that of patient education to support self management. GPs have a role to play in type 1 diabetes but specialist services will be required not only for children and young people, but also for adults with type 1 and more complex needs.

### **Recommendations**

- A review of facilities to meet the ongoing needs of people with T1D following diagnosis.
- Future reports from the Scottish Diabetes Survey Monitoring Group should present information for T1D and T2D separately.
- Systems in place to monitor and screen for complications in people with T1D who default from formal clinics.

## Screening for associated conditions

ISPAD, NICE and SIGN make recommendations on screening for associated conditions including coeliac disease and thyroid disease. An increased incidence of coeliac disease in children with T1D has implications for dietetic time and skills.

## Psychology services for people with type 1 diabetes

The health-related behaviour of people with T1D as they go about their daily lives is the most important determinant of the outcomes of care<sup>1</sup>. Whilst there is a substantial body of high grade evidence to support psychological interventions in T1D (reflected in current guidelines – NICE<sup>17</sup>, SIGN 55<sup>11</sup> and ISPAD<sup>21</sup>) there is increasing recognition of the wide range of contributions that psychology can make to diabetes services, for example:

- Training and supervision of other HCPs involved in diabetes care
- Advice on service design
- Research and audit
- Individual patient contact (particularly in paediatric setting)
- Group/individual interventions to assist patients improve health status in the short and medium term, eg glycaemic control
- Group/individual interventions to assist patients with psychological problems, eg anxiety/depression

A key point is that psychological interventions are not just about providing support for emotional problems, but also about fostering behavioural change and coping strategies.

By considering psychologists as integral members of the MDCT their expertise in the above areas can be maximised.

The SDG convened a short-life working group (Psychology) in 2004 – this group produced a review<sup>22</sup> of psychology provision to adults and children with diabetes in Scotland. Whilst this report did not focus on T1D it was clear that the level of psychology provision for people with diabetes across Scotland was extremely limited, with most health board areas having no provision for either adult or paediatric services. Following this review, funding was granted from SDG to run 3-day training courses ('Doing Diabetes Better') across Scotland on a regional (health board area) basis. This course was designed with several aims in mind:

1. To be available to HCPs working in diabetes across primary and secondary care
2. To raise the profile of the importance of communication and behaviour change skills for all HCPs working with people with diabetes
3. To raise awareness of the need to address psychological aspects of diabetes care in day-to-day practice and also the potential roles that psychology may have in service design and delivery.

Recent funding, released from SDG, is likely to lead to the appointment of 3 x 0.5WTE psychologists in adult services and 2 x 0.25 WTE in transition services for two years. This raises the level of psychology provision in Scotland significantly but there continue to be significant gaps in service in adult and paediatric services across Scotland. It is hoped that these posts will be the start of a network of skilled psychologists in diabetes care. The integration of psychologists into diabetes services across primary and secondary care will be fundamental to the success of these posts. Further funding for psychology services in paediatric diabetes is being sought via the Regional Planning Groups from the year 3 National Delivery Plan for specialist children's services.

**Recommendations**

1. Increase psychology time allocated for services for people with T1D.
2. Psychologists to be integrated into diabetes teams across primary and secondary care.
3. Each diabetes MCN board to have representation from psychology services.
4. Continuing emphasis on the need for health care staff working with patients with diabetes to understand the broader role that psychologists can have in a diabetes service.

## **Diabetes in Schools**

*“Educational and health services should work together to ensure that children with diabetes have the same quality of care within the school day as outside of it.”<sup>23</sup>*

### **Introduction**

The increasing incidence of T1D in the pre-school and school age population coupled with the increasing trend towards more intensive treatments is providing challenges to all agencies involved in the life of a child with T1D to provide those children with optimal health and educational opportunities within current resources. A coordinated and properly planned strategy is therefore required to ensure equitable provision of services and the correct resources are identified from within primary and secondary healthcare teams and how education staff are supported to acquire and maintain specific knowledge and skills around diabetes care.

Major concerns exist in some schools and education authorities surrounding the practicalities and legal liabilities of providing diabetes care within the school. This has been partly ascribed to a lack of awareness, and training. Currently a voluntary system exists for teachers or other education staff to assist with the management of a pupil’s health condition through the administration of medicine. Any education/school staff that do assist would be required to undergo appropriate training. In the event that there is no trained staff member available, it should fall to the head teacher, school nurse and other health care professionals to make alternative arrangements. These arrangements should be detailed in the individual pupil’s health care plan.

### **Policy and Legislative Background**

There is a range of policy, legislation and guidance in place to ensure that pupils with health needs, including diabetes, have their needs met and ensure that they receive the appropriate support to help them to work towards achieving their potential, including:

#### ***The Administration of Medicines in Schools (2001)***

Guidance on the Administration of Medicines in Schools was published in 2001. It clarifies the respective responsibilities of NHS boards and education authorities and schools on managing health care in schools, aimed at enabling children with medical needs to participate as fully as possible in mainstream education.

#### ***Education (Additional Support for Learning) Scotland Act 2004***

The 2004 Act requires education authorities to identify, provide for and keep under review the additional support needs of all people whose education they are responsible. It places a greater emphasis on multi-agency working. Education authorities must seek and take account of relevant advice and information (including assessments) from agencies and persons as they think appropriate.

#### ***Schools (Health Promotion and Nutrition) (Scotland) Act 2007***

The 2007 Act imposes duties to ensure that all schools are health promoting, a responsibility that all school staff share, and to ensure that all food and drink provided in schools complies with nutritional requirements specified in regulation.

## **Background**

Historically across Scotland, the Paediatric DSN teams have taken the lead in contacting schools to arrange initial training sessions for staff supporting a child on diagnosis with T1D. Different health boards have varying staffing levels and so approach this provision of training for school staff in different ways. However, the ongoing training arrangements between schools and health boards are less clear at present. Some centres provide regular training sessions and study days held within the hospital settings, but such arrangements are dependent on local need and priority. Additionally, these sessions tend to focus on generic first aid and emergency situations rather than the complexities of supporting a child with an intensive insulin treatment plan, including pump therapy.

Wherever possible, school nurses services should be involved in providing training, or delivering care services for a child with T1D. However, more work is required to identify models of best practice at strategic and local planning levels, explore issues and barriers regarding the targeting of resources and the development of new ways of partnership working that support best practice.

The Administration of Medicine in Schools guidance states that education authorities must put in place clear policies on meeting the healthcare needs of its pupils. We know that in Fife, a solid partnership agreement has been established between the local education and health board which has ensured that children who need it, get regular access to insulin in school. Fife has also published diabetes in school policy which has helped clarify the roles and responsibilities of all staff involved in meeting the needs of the individual pupils.

Guidance for diabetes in schools developed by the School Nurses Forum and Royal College of Nurses Paediatric and Adolescent Group has just been published<sup>24</sup>. This has UK wide application. The group involved in developing the guidance identified examples of best practice intended to be flexible enough to be adopted across the country.

### **Scottish Government- *Better Diabetes Care consultation***

(Responses being prepared at time of writing)

Several ideas have been suggested:

- Support for Learning Assistants in school to undertake these duties
- Education Services employ a nurse
- Education Services create and appoint a Support for Learning and Health Assistant
- NHS creates and appoints a Support for Learning and Health Assistant
- NHS attaches nurse support to education facilities, possibly from the local health centres or GP surgeries

The valuable role of volunteers is acknowledged and is encouraged, but cannot be the whole solution. It must be complemented by more formal arrangements.

The additional support for learning Act 2004 clearly sets out the duty of care, rights and responsibilities of Local education authorities to assess and plan for a child additional support need.

There is currently not consistent implementation of this advice throughout Scottish schools in the context of individual children with diabetes.

An amendment to the act this (2009) year hopes to address this and clarify the policy intentions of the original act.

The act places a statutory obligation in Law on schools to provide a staged intervention process which will consider the appropriateness of drawing up, in partnership with specialist diabetes team, school nursing services and other agencies and the child and families, an IEP (individualised education plan)

or CSP (coordinated support plan) and having a named person in school responsible for reviewing and implementing this.

Other advisory documents such as GIRFEC (getting it right for every child), also advocate a robust system to promote clear lines of communication to support the child with an additional support needs to achieve their potential.

61% of schools in Scotland have at least one of the approx 2700 children with type 1 diabetes. A diabetes UK survey has highlighted examples of both good and bad experiences reported by families.

## **Recommendations**

- Children with diabetes should be able to access all parts of the school curriculum, have access to out of school social opportunities and, if eligible, access to free (healthy) school meals.
- **Training:** In good practice, DSNs have been used to train school nurses and community nurses who have in turn trained teachers, teaching assistants and other school staff responsible for the health care needs of the child.
- The current resources for use in schools should be updated to include dose adjusting and administration of insulin in schools. This could be delivered by updating Diabetes UK school pack. Following the example of the DEAL campaign, a parent driven initiative that helped Fife Local Education Authority develop a policy for use in schools.
- General awareness of diabetes in schools should be increased by utilising the diabetes service to give 20 minute awareness sessions to all staff in school settings, followed by further training to staff responsible for meeting the health care needs of an individual pupil with diabetes.
- As stated in the Administration of Medicines in Schools (2001) and the RCN guidelines, every pupil should have an individual health care plan in place. This should include a robustly developed care pathway and plan that is flexible enough to be broadly adapted.
- Coordination should be ensured by comparing the school nurse records with the paediatric clinic records of diabetic children in school.
- There should be a “Diabetes in School” Symposium for staff from health, education authorities and schools to share experiences and practice surrounding the care and education of children with diabetes in Scottish schools.
- Adequate training and support for education and catering staff should ensure that a child with diabetes can access to school lunches. Education authorities and schools should have policies in place in relation to those pupils on medically recommended diets and specific dietary needs.
- To influence the workforce planning, job description development and training of LEA employees to include responsibilities for children with additional medical needs.
- To tackle the unique safety and dose consideration of insulin actions and administration and ensure equitable access to children with diabetes across Scotland which are not dependent on local resource constraints.
- To ensure that Paediatric Diabetes Specialist services are given appropriate priority within the Scottish Government’s National Delivery Plan.

- To foster an environment where negotiating shared care between NHS boards, education authorities and schools includes families. The development of a robust individual healthcare plan should take account of a child's level of maturity and self care skills.
- To coordinate support to schools through closer liaison with school nurses and specialist diabetes teams and achieve a minimum standard of care for the purposes of audit and inspection bodies.

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Nottingham University hospitals NHS Trust & Nottingham County LA

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## Chapter 4 Transitional care

### Introduction

Children and young people with T1D should be offered an ongoing integrated, and as far as possible, seamless package of care by a MDCT specialising in the condition. To optimise the transition and transfer of patients from paediatric to adult care a model should be put in place, which recognises the challenges of the adolescent period, socially, culturally, psychologically and physiologically. This is the period when diabetes control is hardest.

### Standards of care

NICE recommends for the transition of T1D<sup>17</sup>

- Young people with T1D should be encouraged to attend clinics on a regular basis (three or four times per year) because regular attendance is associated with good glycaemic control.
- Young people with T1D should be allowed sufficient time to familiarise themselves with the practicalities of the transition from paediatric to adult services because this has been shown to improve clinic attendance.
- Specific local protocols should be agreed for transferring young people with T1D from paediatric to adult services.
- The age of transfer to the adult service should depend on the individual's physical development and emotional maturity, as well as local circumstances.
- Transition from the paediatric service should occur at a time of relative stability in the individual's health and should be co-ordinated with other life transitions.
- Paediatric diabetes care teams should organise age-banded clinics for young people and young adults jointly with their adult specialty colleagues.
- Young people with T1D who are preparing for transition to adult services should be informed that some aspect of diabetes care will change at transition. The main changes relate to targets for short-term glycaemic control and screening for complications.

The NICE assessment group found very little evidence on transitions. The evidence base consisted of only four studies, none of which were trials or other studies of different methods of transition. One study was a simple descriptive study of items such as age at transfer, rates of attendances before and after, and whether a transfer letter had been sent. The other studies were on HbA1c, patient satisfaction, and a qualitative study of views.

SIGN 55<sup>11</sup> on diabetes does not mention transitional care. The present Guideline Review Body has a key question, which states 'in adolescents with T1D what is the best model of transfer care (from paediatric to adult services), in terms of glycaemic control, patient satisfaction, quality of life, DNA rates and hospital admissions'. The findings of this group should be incorporated into any plan for transitional care.

The Royal College of Physicians of Edinburgh (RCPE) has published new clinical guidance on Transition Medicine, 'Think Transition: Developing the essential link between paediatric and adult care'<sup>24</sup>. The guidance contains a number of recommendations on generic areas (including core principles, education, inequalities in health, remote and rural issues, and fertility and sexual health)

and on disease- and patient-specific areas (cystic fibrosis, chronic renal disease, T1D and childhood cancer survivors.)

For T1D, the RCPE guidance suggests that the following aspects should be considered in establishment of a transitional service:

- The children's team needs to communicate and be comfortable working closely with the adult team, in both routine and emergency situations.
- Both must share a philosophy, as well as an understanding, of the social positioning in their culture of adolescence.
- The transition clinic should be served by both teams.
- Agreement should be reached about venue, age range, the involvement of parents and peers, clinical standards and care strategies.
- The service should have easy access to psychological support.
- Education programmes should include advice and direction on the management of diabetes and various lifestyle issues, including:
  - alcohol;
  - smoking cessation;
  - avoidance of recreational drugs;
  - pre-pregnancy planning and contraception;
  - work and diabetes;
  - extreme sports and diabetes.
- It is important to ensure that emergency management is shared through both the paediatric and adult services. Particular attention should be given to ensuring good lines of communication between all healthcare professionals involved with this group of patients.

It then makes the following recommendations:-

- Start at around 18 years of age (following on from age-banded clinics in the paediatric service).
- Encourage the participation of adult health professionals in the older age-banded (e.g. 16-18 years) clinics in the paediatric service.
- Facilitate the participation of families and peers.
- Encourage an intensive approach to insulin therapy, accompanied by formalised and frequent screening for micro- and macrovascular complications.
- Develop effective communication between paediatric and adult services about patients.
- Design an audit system to test the effectiveness of the transition service.

Whilst bearing in mind these varying recommendations and standards, it should be remembered that individual areas within Scotland will have unique problems both of geography and of attainable service provisions.

Whilst the RCPE documents suggest that transition starts at 18 years of age, it should be recognised that in many cases this will be too late for the individual patient. Issues such as starting a working life, entering higher education and beginning a family often occur before this time, and would benefit from the input of an adult diabetes team. The transitional process should therefore be tailored for individual need.

It also needs to be recognised that the transfer of outpatient services needs to coincide with the transfer of inpatient care. Patients presenting with DKA would ideally do so with links to the team that cares for them in the outpatient setting. This would not be possible in areas where there was a difference between the age of acceptance for inpatients and the age of transition.

It has also been pointed out that there is another transition to be considered: that from medical care to self-management, with a need to provide appropriate support to develop self-management skills.

Current arrangements vary amongst health boards. A brief questionnaire was sent to all health boards (28 diabetic centres). In 21 (75%) there were separate adolescent clinics. In 17 (61%) there were joint clinics for transition; in 11 no joint clinic service. The number of visits prior to transfer to adult services varied: single visits 14%; two visits 11%; multiple visits 32%; and none because no joint service in 39%.

## Recommendations

1. Paediatric and adult services should agree on transitional arrangements and document these in local protocols.
2. Transition should normally be a process, not an event, and patients should be given sufficient time to familiarise themselves with the adult service. We suggest below one model of good practice.
3. The age at transition should not be fixed, but should be tailored to the individual, and should take into account local age thresholds for in-patient care and services available.
4. Young people with T1D transferring to adult care should be informed in advance of the ways in which their care will change after transition.
5. At each stage, it should be clear which team is responsible for leading the process and providing clinical care. There should be close liaison with families.

## Transition in practice

The following example of how transition can work in practice is based on a talk given by Helen Rogers of the Western General Infirmary Cystic Fibrosis service, to the Scottish Study Group for the Care of Diabetes in the Young (March 2009). The model promotes a shared approach between adult and paediatric services, while avoiding ambiguity over which team is responsible for care. The transition process is defined and time-limited, and the patient is supported throughout. We believe it should be reasonably straightforward to introduce even in the presence of geographical challenges, and will require relatively modest levels of additional resource. This represents the minimum acceptable level of transitional care.

- The paediatrician identifies a young person as being ready for transition. Factors considered will include age, maturity, stability of diabetes, and life circumstances.
- The plan to initiate transition is discussed with the patient and family in advance, and the process of transition is explained and discussed. The patient should be involved in the decision on timing.
- The first “transition” appointment will take place within the paediatric service, with the adult team<sup>1</sup> in attendance. Before the consultation, the case history and any special circumstances will be presented. The same information will be included in transfer documentation for inclusion in the adult service case notes.
- After introductions, the paediatric team will lead the consultation, with the adult team participating in discussion. Sufficient time will be allowed for questions.
- The subsequent transition appointment will be arranged within the adult service, with the paediatric team<sup>1</sup> in attendance. On this occasion, the adult team will lead the consultation.
- In most instances, after this attendance, the adult team will take on full responsibility for ongoing care. Continuity of care would be helped if the patient can see the same doctor and nurse for at least the first few appointments in the adult clinic.

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<sup>1</sup> some care will be required in identifying which members of the team participate. Different disciplines within the teams may wish to make their own arrangements to supplement the process, rather than having too many people present. For example, the paediatric and adult DSNs might meet separately with the patient.

At some point during the process, an appraisal of the knowledge base and self-management skills of the young person will be required. The timing and nature of this will be agreed between the paediatric and adult services.

It is likely that, to maximise efficiency, specific transition clinics will be set up. Where geographical factors prevent members of either the paediatric or the adult team attending, there should be the option of participation by videoconference.

# Chapter 5 T1D Education

## Introduction

T1D management is complex involving the interaction of multiple variables including subcutaneously administered insulin, frequency, quantity and type of foods eaten, activity levels and interpretation of frequent blood glucose levels. The day-to-day management of diabetes is undertaken by the person with diabetes. To achieve the goals of a good quality of life avoiding short and long-term complications the person with diabetes must master the skills needed to implement effective self-management. There is recognition that quality assured patient education based on sound educational principles plays a key role in effective self management<sup>11,17,25,26</sup>.

This chapter outlines the current position in Scotland in the provision of structured education, as defined by NICE guidance<sup>10</sup> to people with T1D and makes recommendations on how provision can be improved.

## Structured Education for type 1 diabetes – the current position in Scotland

In Spring 2008 a survey of structured education for people with T1D in Scotland was carried out. Although a similar survey had been undertaken on behalf of the Patient Focus Implementation Group (PFIG) in 2006 this did not include information about children's services. Information gathered for NHS quality improvement Scotland on patient education is too generic to give an indication of structured education provision for people with T1D. Details of the survey are included in Appendix 4.

A recurring theme from the survey was the difficulty in releasing staff time for structured education. Centres that have developed and offer some form of 'structured' education have found difficulties in meeting the NICE criteria due to time constraints. Time for staff training and quality assurance of these programmes has not been regarded as a priority. There are also major concerns around both the level and quality of dietetic and DSN support to provide structured education in many centres and this is most acutely the case in paediatric services.

The survey identified 'pockets' of good practice but a need to address the bigger picture. The education process straddles a broad range of individuals in terms of age and ability and is highly dynamic. The diversity of individuals with type 1 diabetes and their changing needs means that 'one size does not fit all' with regard to structured education programmes. Structured education should be built into every stage of the education process, and adapted to meet the needs of individuals throughout the different stages of life and not simply applied to a particular group or a specific treatment.

At the moment, much of the education delivered by HCPs is building a knowledge base with little scope or attention to the understanding and application component of the learning process. There needs to be a major culture shift in terms of educational skills and facilities to deliver on the understanding and application aspects of the education process if we are to support those with T1D to achieve effective self-management.

The development and implementation of a national framework for the education of children, adolescents, their parents or carers and adults with T1D would be a starting point to ensure progress is made in improving the current situation. With an agreed outline framework in place specific education programmes and modules can be recommended and, where necessary, developed along with supporting educational materials and resources. Programmes and modules will comply with NICE guidelines and have a written curriculum, clear learning outcomes and be quality assured to facilitate consistency in advice. Audit of structured education programmes and provision would be

undertaken to monitor progress and assess impact on clinical and quality of life outcomes. Details of the proposed framework are included in Appendix 5.

Staffing levels should be adequate to meet the additional demands of delivering structured education, and members of multidisciplinary teams should have training in skills to deliver education to facilitate patient self-management. Peer support from others with diabetes will play an important role in the education process especially for the understanding and application components of the curriculum. The development of this model rests on adopting the underpinning philosophy of patient centred learning where the MDCT role is not just about giving information but facilitating the learning process. To facilitate a patient/family centred approach the process of education should be delivered as routine care but planned and taken out of the context of a 'clinical consultation'. Appendix 6 gives a detailed description of patient centred learning.

Some thought must be given to the development and implementation of this framework in the context of national and local structures for diabetes care delivery and the views of service users. The Diabetes Education Network Scotland (DENS), the Diabetes Care Focus Group (DCFG), the SSGCDY and other professional groups e.g. DMEG, paediatric DSN group and paediatric dietetic group will have a role in supporting MCNs in the development and implementation of the Framework. The Scottish Diabetes Survey Monitoring group should include questions to monitor provision of structured education to all people with diabetes, using the clear definition of structured education outlined by NICE. The aims of DENS, details of steering group members and activity are included in Appendix 8. The DENS has the potential to act as a vehicle to facilitate the development of the proposed education framework.

Some significant gaps in existing resources to support the framework were identified from the work undertaken by the SSGCDY research clinician for T1D. These are detailed below with suggestions on how they could be addressed:

- Teaching and supporting materials for younger children, e.g. pictorial or animated resources. The manuals, handbooks and patient held records developed and produced by paediatric centres are comprehensive but are not specifically designed for children. Some contain specific learning points for children and good illustrations but are incorporated in a format that is not always 'child friendly'. The example of an animated DVD viewed at the recent SSGDY could be adapted for use in Scotland to fill this gap.
- Material to support elements of carbohydrate counting and insulin dose adjustment for intensification of insulin in children. Diabetes UK is currently evaluating a resource for adults but do not plan to extend this to include information for children. A multidisciplinary group has been established by the research clinician to work with the Scottish Nutrition and Diet Resource initiative (SNDRi) to produce a resource for children to meet this need.
- Level 1 – basic skills resources for different groups i.e. young children, older children, adolescents and adults. Lothian MCN has produced a resource for adults with T1D: 'The essential guide at diagnosis'. This idea could be developed further to support level 1 of the framework for different groups.
- Resources to support the promoting independence modules for older children, adolescents and parents. The Diabetes UK website and 'Making Connections' booklet go some way to meet the needs of adolescents and older children. Several organisations have developed good quality web based information for this age group. Work could be done to develop links to this information from a central point such as the patient portal.
- There is no specific resource or education programmes for parents and carers to help them through the process of transition from dependence to independence.

- Programmes and resources to support education for CSII. The findings and recommendations from the Pump Report for CSII commissioned by the SDG are included as Appendix 7 of this report. A group of DSNs, dietitians and clinicians from a number of centres are now enthusiastic to work collaboratively to draw up education programmes and share best practice. This work can be facilitated by DENS building on the work of the UK wide Diabetes Education Network<sup>27</sup>.
- The needs of those with poor literacy skills, those who are visually and hearing impaired and those with learning difficulties are poorly served. It is hoped that by adopting a patient/family centred approach to education, this situation can be improved.
- Resources for sports and exercise which are more detailed and specific in their advice. Information currently available gives very general advice.

### **Recommendations**

- The development and implementation of a national education framework for T1D.
- The SDS should include questions on provision of structured education to people with diabetes, using the clear definition of structured education outlined by NICE.
- The continued support of DENS and integration of DENS in the strategic work of the SDG and its subgroups.

## Chapter 6 Out of hours care

The management of T1D is complex. Individuals and families receive education including specific advice for how to deal with interruptions to their routine. Illness is a major cause of variable and unpredictable blood glucose control. The impact of illness can cause either hyperglycaemia and ketosis potentially leading to DKA or, at the other extreme, severe hypoglycaemia, with risk of seizure. Both are avoidable if appropriate management is instituted. Despite education, we are aware that many people with T1D are not able to make appropriate adjustments to their insulin during acute illness and admissions to hospital due to avoidable errors in insulin dosing are a significant cost to the NHS.

The current provision of out of hours (OOHs) emergency advice available to families and individuals has been audited. The paediatric service audit was completed in June 2008 and adult service audit in February 2009. There are 42 centres (14 paediatric and 28 adult centres) providing diabetes care in Scotland. Regarding paediatric services, all centres provide an OOHs advice line. In the majority of paediatric centres (n =11), calls are directed to paediatrician on call – in 10 centres to the paediatric registrar who may have limited diabetes knowledge, and in one centre the Consultant is called. Three centres have joined to form DIABNET and calls are taken until 23.00 hours by a rota of diabetes nurses from the three units, who follow the same shared advice guidelines. It has been suggested that this model could be copied by other centres. However, other centres are not able to pursue this model without significant financial input to support staff to deliver care out of hours. Of the 14 centres, 3 provide specific training regarding diabetes advice. Nine centres audit their emergency help line. The audit of adult services demonstrated that the majority of adult services have no dedicated OOH support and 70% (20 centres) advised their patients to call NHS24. Other options which people were given to seek guidance regarding emergency advice were via their GP (which would be directed to NHS24), a dedicated diabetes lines provided by drug company and the local A&E department. Three adult centres advise their patients to call the ward OOH for advice. When questioned about the advice that was given OOH, 96% of the adult centres voiced concern that it was not adequate.

People with T1D need access to a safe, reliable emergency service staffed by health care workers who can advise them how to manage their insulin doses during illness, and hence avoid admission to hospital. In the Diabetes Action Plan 2006<sup>2</sup>, one of the action points to be addressed by the SLWG was to improve access to emergency advice for people with T1D. The only current national model and hence the most appropriate resource to support such an advice line was NHS24, and one of the objectives was to meet with NHS24 to discuss the feasibility of such an advice line. The draft document of SIGN 55<sup>11</sup> has also highlighted the need to individuals with T1D to have access to medical care out of hours.

A series of meetings were held between December 2008 and September 2009 with NHS24. Dr Chris Stewart, Director of Clinical Development, senior managers and nurse advisors met with K Noyes and L Bath to discuss OOH advice and diabetes care. NHS24 has a triage system. A call handler directs the majority of the calls to the generic helpline where a nurse practitioner gives advice to an individual. Decision making is supported by algorithms that are triggered by a symptom based diagnosis and have been developed by the Core Clinical Group. NHS24 has recognised that it is not possible for the generic help line to provide best advice for all queries and has recently set up separate subspecialist advice lines, with advisors in dental, pharmacy and mental health problems, the later being called Breathing Space. Breathing Space was developed to respond more effectively to the mental health calls by using specialist mental health advisors.

The current level of advice provided by NHS24 for diabetes queries is limited to guidance regarding how to manage their acute illness and all the algorithms have been developed as symptom based pathways. A symptom based diagnosis may be good for the majority of callers but it is potentially detrimental for an individual with diabetes. For example, if the presenting symptom is vomiting, then management is guided toward the vomiting and not management of blood glucose levels. The

algorithms are not designed to give advice regarding insulin adjustment. For example, if a patient presents with ketosis and hyperglycaemia they are advised to go to hospital, or if a patient calls regarding hypoglycaemia, there is no consistent advice regarding management of hypoglycaemia and NHS24 are not able to give advice regarding reduction in insulin dose. The current detail within the algorithms regarding diabetes advice has been provided by their medical advice team, and not by specialists in diabetes. The algorithms have not been designed to provide complex advice regarding diabetes management

To develop a national, emergency, OOH helpline for diabetes delivered by NHS24, the following issues need to be considered:

### **Staff training**

- The staff providing the advice would need a detailed knowledge of diabetes management to provide appropriate advice, whether a patient is using an insulin pump, on a full basal-bolus regimen adjusting doses for carbohydrate intake or twice-daily premixed insulin.
- To maintain an appropriate knowledge staff would require ongoing education plus exposure to a significant number of calls to gain and then maintain experience.
- The number of calls seeking guidance regarding diabetes care would be a tiny proportion of the total calls received by NHS24. If a generic helpline was used, exposure to calls for an individual nurse practitioner would be very infrequent, and insufficient to maintain skills.

### **Development of diabetes specific algorithms**

- Algorithms that guide staff regarding all aspects of acute diabetes care and insulin adjustment would need to be developed.
- The algorithms would need to follow best evidence based practice.
- There would need to be consistency between the algorithms and the information currently given to all patients by their local team.
- There would need to be consistency between advice and care provided by NHS24, ambulance service and the OOH health care centres.
- There would need to be clear guidance regarding where an individual would seek inpatient care within each particular health board (i.e. paediatric vs adult unit).
- The SDG should be approached to provide funding to support a clinician (for 3 months FTE) to work with NHS24 to help in development of the tools required for the advice line.

### **Provision of ongoing support during an acute episode**

- NHS24 currently uses a highly developed IT system. Within this system there is the ability to include special notes within an individual clinical record, termed the emergency care summary. Such a facility could be developed and used by individual diabetes teams to highlight specific issues for individual patients and families.
- Currently NHS24 do not have the facility to encourage patients to return calls. The algorithms will need to include advice to call back if the problem has not resolved with the advice given. There would need to be a facility to recall and review the previous call and advice given.

### **Provision of background information on patients**

- Currently NHS24 provides information to GP practices regarding patient calls. There is not a facility to provide this information to clinical teams within tertiary care. This facility would need to be developed to provide information to individual diabetes teams to enable them to continue to support individuals/families who require ongoing advice.

## **Plan a launch of the helpline**

- There would need to be a pilot of the helpline within 1 or 2 health boards prior to a national launch.
- Initially, there would be an option to consider a support system for the individuals staffing the line, so that if they were unsure as to best advice, they could call a diabetes clinician.
- There would need to be agreement from all clinicians that they would advise their families and patients to use the helpline. The proposal for a national helpline has been discussed at the 5<sup>th</sup> National Paediatric Diabetes Meeting and those present agreed in principle.

## **Audit of use and impact on health care**

- The number of calls and outcomes regarding advice will be audited.
- The SLWG has also developed proposals to identify and reduce the incidence of DKA. These proposals would also link with the audit of the helpline to determine whether a national helpline can help to reduce the incidence of DKA/hospital admissions.
- As a part of the proposal to reduce the incidence of DKA, the aim is also to reduce the number of new patients presenting in DKA. As a separate but linked piece of work, the individual seconded to guide in development of algorithms, would also work with NHS24 development team to highlight symptoms that would help identify individuals that could indicate a new diagnosis of T1D. The aim would be to reduce the time interval from contact with medical services to time of diagnosis of diabetes, and hence reduce the risk of DKA at presentation.
- The helpline would not be a general diabetes advice line – advice regarding day-to-day management would be provided by local teams throughout the standard working day.

## **Management of people with T2D on insulin**

- The advice line would be developed to support people with T1D. However, there are a large number of patients with T2D who are on insulin and further consideration needs to be given to the development of algorithms for this group. Support for people with T2D who are not on insulin is not being addressed in this proposal. Discussion regarding support for OOH emergency advice for people with T2D should be discussed within the SDG.

## **Conclusion**

Following the series of meetings and discussion of the above issues, the collective view is that the most appropriate way forward is for NHS24 to support OOH emergency advice for T1D. Given the complexity of advice and relatively low numbers of calls, it was agreed that a dedicated advice line for diabetes would be required. The proposal will be taken by Dr Chris Stewart to the executive board to seek their agreement for the project.

## **Recommendations**

- Set up a steering group with participation of NHS24 and SDG to progress the proposal with costings for development, pilot evaluation and implementation of a Scotland-wide service.
- Submit a proposal to SDG to support funding for a clinician to develop algorithms with NHS24 staff.
- Development of unified national guidelines for management of acute problems in people with T1D.

# Chapter 7 Diabetic ketoacidosis

## Introduction

Diabetic ketoacidosis (DKA) is a condition in which an insufficiency of insulin, at a time of metabolic stress or because of missed doses, leads to inability of the body to use glucose, leading to breakdown of fat stores and abnormal accumulation of ketones. The insufficiency can be absolute, for example at time of diagnosis, or relative, when there is some insulin but needs are increased by hormones released in response to stress e.g. infection. It usually requires hospital admission for treatment with insulin and intravenous fluids.

DKA carries significant mortality and morbidity in both adults and children<sup>28</sup>, and is costly to the NHS. Adult mortality rates from DKA have fallen steadily since the 1970's from 16% per episode to less than 5% in the 1980's - 1990's, but paediatric mortality rates are reported to have changed little over this time and remain at around 1%<sup>28</sup>. Any measures to improve diagnosis, management, and better still, prevention, will have a significant positive impact on the lives of those with diabetes, their families, and through reducing financial burden, society at large.

## The frequency of diabetic ketoacidosis

Episodes of DKA can be thought of as occurring in three groups of patients;

- At onset of diabetes. In RHSC Edinburgh, the proportion of children presenting in DKA at diagnosis ranged from 20 to 42% in the years 2003 to 2006 (unpublished data). In RHSC Glasgow, the proportion presenting in DKA ranged from 22% to 38% in the years 2003 to 2006 (unpublished data). About 30% of all episodes of DKA are at onset of diabetes.
- those previously diagnosed who have occasional episodes
- those previously diagnosed who have frequent episodes associated with poor control and/or poor adherence to treatment – a small number of patients have a large proportion of the episodes. In an Oxford study, 5% of patients accounted for 23% of admissions

The total number of reported episodes on SMR 1 records depends on a number of factors;

- the incidence of new T1D
- the proportion of new diabetics who present in DKA
- the threshold and methods for diagnosing DKA
- the prevalence of T1D
- the proportion of people with T1D who have occasional episodes, which depends partly on their glycaemic control
- the number of poorly controlled patients having multiple episodes
- the reporting of DKA in SMR 1 and other records.

Reporting can play a major part in the apparent incidence of DKA for several reasons;

- some hospitals may record DKA as principal diagnosis, whereas others may use diabetes as principal diagnosis. For the analysis reported below, we therefore obtained numbers of patients with either DKA or diabetes (emergencies only) as principal diagnosis
- transfers between hospitals during one episode will lead to more than one admission being recorded. For example, a child admitted to one hospital and then transferred to a specialist unit will be recorded as having two admissions for DKA.
- It is possible that transfers within hospitals may also give rise to double recording. If a patient is admitted to an emergency receiving unit and then transferred to the diabetes ward, that may be recorded as two admissions.

Definitions may vary. We recommend the following.

- Severe pH <7.1, HCO<sub>3</sub><5;
- Moderate pH <7.2 HCO<sub>3</sub> <10;
- Mild pH <7.3 HCO<sub>3</sub> <15
- Incipient DKA pH >7.3, HCO<sub>3</sub> <20

## Scottish admission data

Table 6 shows the numbers of admissions by broad age group, according to ISD records (unpublished). There appears to have been a marked rise in incidence of DKA. However, there is some doubt as to the accuracy of these. ISD data suggest a sharp rise in the incidence of DKA in the under-20s in Glasgow, but the overall emergency admission rate of DKA and diabetes combined has not risen, suggesting that there may have been a shift in coding practice.

**Table 6 DKA Admissions by Age Group**

| Age Group    | 2003        | 2004        | 2005        | 2006        | 2007        |
|--------------|-------------|-------------|-------------|-------------|-------------|
| 0 to 19      | 463         | 511         | 540         | 570         | 615         |
| 20 to 29     | 304         | 307         | 334         | 369         | 501         |
| 30 to 39     | 231         | 217         | 236         | 306         | 306         |
| 40 to 49     | 178         | 200         | 184         | 205         | 229         |
| 50 to 59     | 93          | 98          | 103         | 118         | 145         |
| 60 to 69     | 55          | 62          | 64          | 55          | 64          |
| 70 and over  | 66          | 78          | 55          | 71          | 83          |
| <b>Total</b> | <b>1390</b> | <b>1473</b> | <b>1516</b> | <b>1694</b> | <b>1943</b> |

The number of bed days used is considerable, as shown in Table 7, for all ages (unpublished).

**Table 7 DKA Total bed days used by age group**

| Age Group    | 2003        | 2004        | 2005        | 2006        | 2007        |
|--------------|-------------|-------------|-------------|-------------|-------------|
| 0 to 19      | 1158        | 1215        | 1254        | 1143        | 1092        |
| 20 to 29     | 1274        | 690         | 696         | 839         | 1080        |
| 30 to 39     | 593         | 541         | 647         | 790         | 685         |
| 40 to 49     | 593         | 660         | 649         | 746         | 761         |
| 50 to 59     | 487         | 457         | 399         | 486         | 579         |
| 60 to 69     | 402         | 255         | 339         | 301         | 372         |
| 70 and over  | 472         | 600         | 444         | 535         | 503         |
| <b>Total</b> | <b>4979</b> | <b>4418</b> | <b>4428</b> | <b>4840</b> | <b>5072</b> |

*1027 (of 8016) admissions from 2003-2007 were day cases i.e. length of stay = 0*

Many patients have more than one admission, and some have many. Table 8 shows numbers of patients having one or more episodes over a 5-year period. 4056 patients were recorded as having one or more episodes, out of a total of about 26,000 people with T1D. So if we were to assume that nearly all cases of DKA were in people with T1D, then about 15% had at least one episode (unpublished).

**Table 8 Number of patients having one or more emergency admissions with DKA or diabetes: 2003-2007: all ages**

| Number of admissions per patient | Frequency |
|----------------------------------|-----------|
| 1                                | 2680      |
| 2                                | 694       |
| 3 to 5                           | 466       |
| 6 to 9                           | 136       |
| 10 or more                       | 80        |

Table 9 shows the breakdown in the under 20s (unpublished).

**Table 9 Number of patients having one or more admissions: 2003-2007: under 20 years of age**

| Number of admissions | Frequency |
|----------------------|-----------|
| 1                    | 784       |
| 2                    | 224       |
| 3 to 5               | 160       |
| 6 to 9               | 45        |
| 10 or more           | 38        |

There are socio-economic variations in both frequency of admission and length of stay, as shown in Table 10 (unpublished).

**Table 10 Admissions and Length of stay by SIMD Decile: under 20 years of age**

| SIMD Decile | Number of Admissions | Mean Length of Stay | Total Length of Stay |
|-------------|----------------------|---------------------|----------------------|
| 1           | 124                  | 2.12                | 263                  |
| 2           | 107                  | 2.04                | 218                  |
| 3           | 211                  | 2.05                | 433                  |
| 4           | 212                  | 2.05                | 435                  |
| 5           | 267                  | 2.03                | 541                  |
| 6           | 262                  | 2.10                | 549                  |
| 7           | 330                  | 2.17                | 715                  |
| 8           | 301                  | 2.08                | 625                  |
| 9           | 350                  | 2.31                | 810                  |
| 10          | 535                  | 2.38                | 1273                 |

The accuracy of these data is uncertain, and we recommend that they be validated as part of a wider audit (of the preventability of DKA). According to a Scottish Parliament written answer, admissions for DKA jumped 18.5% to 1842 admissions between 2006 and 2007<sup>29</sup>.

## Prevention of diabetic ketoacidosis in people with T1D

This section reviews interventions to prevent DKA as reported in the recent literature. It is divided into two sections: prevention of DKA at presentation and prevention of DKA in patients with established diabetes. The risk factors for, and the prevention of, DKA in these two groups are different, although there are overlapping themes.

### Preventing DKA at diagnosis

Most of the literature on preventing DKA at time of diagnosis has been written from the child and adolescent point of view, rather than from that of the adult. The first section is therefore necessarily supported heavily by paediatric studies, as there are relatively few papers looking at primary prevention of ketoacidosis in adults.

In the developed world, the proportion of children whose initial presentation with diabetes is in ketoacidosis varies, ranging between 15-70%<sup>28,30-32</sup>. However, presentation rates of around 25-30%<sup>32,33</sup> are typical in many centres. DKA is more common with the first presentation of younger children, in whom it is difficult to obtain the classical history of polyuria, polydipsia and nocturia<sup>28</sup>; this is significant given the increasing incidence of diabetes in children globally<sup>33</sup>, and in Europe of those under 4 years of age in particular<sup>34</sup>.

**Table 11 Percentage of diabetes patients presenting with particular symptoms**

| Symptom              | Incidence                             |
|----------------------|---------------------------------------|
| Polyuria/polydipsia  | > 89% <sup>30,35</sup>                |
| Weight loss          | 63% <sup>35</sup>                     |
| Lethargy             | 33% <sup>31</sup>                     |
| Vomiting             | 30% <sup>31</sup>                     |
| Abdominal pain       | 26% <sup>31</sup>                     |
| Nocturnal enuresis   | 19% < 5y<br>31% 5-9.99y <sup>35</sup> |
| Kussmaul respiration | 10% <sup>31</sup>                     |

Preventing DKA at first presentation depends on a high index of suspicion in the family and health care professionals, and an accurate diagnosis on first presentation to medical care. Across studies the most common presenting symptoms are polyuria and polydipsia (>89%)<sup>30,35</sup>, weight loss (63%)<sup>35</sup>, lethargy (33%)<sup>31</sup>, vomiting (30%)<sup>31</sup>, and abdominal pain (26%)<sup>31</sup>. In one prospective study of 283 cases in the Republic of Ireland, nocturnal enuresis was reported in 19% of children <5 years and 31% in those aged 5-9.99 years<sup>35</sup>. A Kussmaul's respiratory pattern was reported in 10% of patients<sup>31</sup> (see Table 11).

Missed and delayed diagnosis of diabetes in children is not infrequent. In one retrospective study of 139 new onset T1D patients in the USA, there was delay in diagnosis for 20% of patients<sup>31</sup>. They were either sent home with an incorrect diagnosis, or a diagnosis was deferred whilst awaiting for laboratory results<sup>31</sup>. Such delay, with its prolongation of the insulin-deficient state, clearly increases the likelihood of presentation in incipient ketoacidosis or ketoacidosis. Symptoms commonly misinterpreted are listed in Table 12, while risk factors associated with late diagnosis of diabetes are listed in Table 13.

**Table 12 Commonly misinterpreted symptoms in the presentation of diabetes**

| Diabetes symptom     | Misinterpreted diagnosis <sup>31</sup> |
|----------------------|--|
| Polyuria             | Urinary tract infection                |
| Kussmaul respiration | Respiratory illness                    |
| Tiredness, lethargy  | Anaemia, non-specific malaise          |

**Table 13 Risk factors for delayed diagnosis of diabetes in children**

|   |
|---|
| Child <3 years of age <sup>28</sup>                                       |
| Low socio-economic status (data from in USA) <sup>28,36</sup>             |
| Negative family history of diabetes <sup>28,37</sup>                      |
| Increased number of medical encounters in the previous week <sup>38</sup> |

Kaufman and Halvorson<sup>39</sup> make a number of recommendations for improving the early diagnosis of diabetes by paediatricians, and these include actively seeking the following clinical features:

- (a) waking to urinate or bed-wetting (when not associated with dysuria, infection of psychological trauma)
- (b) thirst associated with an increase in urination
- (c) vomiting associated with
  - weight loss
  - change of appetite
  - decrease in activity
  - increased thirst prior to the onset of vomiting
  - increased urination prior to the onset of vomiting

Unusual bedwetting was the first symptom of diabetes reported by 89% of patients in one study by Vanelli *et al*<sup>40</sup>. Parents do not often volunteer information on polyuria and polydipsia so these should be specifically asked for in the medical history<sup>31</sup>.

There is a paucity of data reporting successful interventions to decrease numbers of children with diabetes presenting in ketoacidosis, and no studies specifically reported in adults. One of the few studies addressing this issue was by Vanelli *et al*, from Parma, Italy<sup>40</sup>. Vanelli reported the incidence of DKA in newly diagnosed diabetic children aged 6-14 years, 8 years after an information programme on ketoacidosis was introduced to teachers, students, parents and paediatricians. 1,000 posters were provided to primary and secondary schools during the 8-year period, reaching an estimated population of 144,736 pupils. The key messages of the posters contained the following key messages:

- (a) Does your child drink and urinate more than usual?
- (b) Has your child started to wet the bed again?
- (c) Make sure your child does not have high blood sugar levels - call your paediatrician today, and
- (d) Children can also have diabetes.

Cards listing guidelines for the recognition of diabetes were issued to paediatricians, along with equipment for measuring capillary blood glucose and glycosuria. Vanelli's team provided 2 hours of training on measurement of capillary blood glucose and on early warning signs for diabetes.

There was a marked decline in the proportion of children presenting with DKA at diagnosis, and this effect persisted. Progress was assessed after a further 8 years, and reported by Vanelli in 2007<sup>41</sup>. It was concluded that the DKA-prevention campaign remained highly effective, but almost 15 years from its initiation, impact may have waned. Periodic renewal of the campaign was recommended (suggested as every 5 years) to maintain effective prevention.

In summary, the data suggest that increasing public and medical, awareness of the possibility that children may develop diabetes would be a cost effective method of reducing the length of time between symptom onset and treatment by prompt referral, so reducing the morbidity and mortality from ketoacidosis associated with delayed diagnosis. This seems particularly to be the case for young children (those under 5 years of age), where there is evidence that primary and secondary care

medical staff may not always consider T1D as a possible diagnosis, and so do not specifically ask about osmotic symptoms associated with hyperglycaemia and glycosuria that might otherwise aid diagnosis<sup>31</sup>. In adults, deterioration may be less rapid, but prompt diagnosis could also be expected to reduce morbidity and mortality, and costs of the NHS.

The SLWG noted that the Parma study was not a randomised controlled trial, but a before and after one with historic and geographical comparisons. It also noted that the programme had been replicated elsewhere, but not through an RCT. In spite of this, the World Health Organisation and the International Diabetes Federation established the “raising of awareness of the warning signs of diabetes” and encouraged national governments to pursue “initiatives to reduce diabetic ketoacidosis and distribute materials to support these initiatives” as two of the four principal aims of World Diabetes Day (2007-2008). Such materials are supplied cost- and copyright-free on the World Diabetes Day website ([www.worlddiabetesday.org/node/43](http://www.worlddiabetesday.org/node/43)), and use the Parma campaign materials as a template.

The SLWG discussed whether to recommend a trial, or immediate implementation. It concluded that implementation was justified, but that its success could be monitored by a “before and after and after” study – i.e. the incidence of DKA could be monitored before and after the intervention, and then again after the campaign had ended, when it might be expected to rise again.

### **DKA in patients with established diabetes**

The majority of patients presenting in ketoacidosis are already known to have diabetes<sup>28</sup>. While up to 40% of young children present with DKA at diagnosis, it has been reported that only about 10% of all patients treated for DKA have undiagnosed diabetes<sup>42</sup>. However, a large proportion of these presentations occur in a relatively small minority who have recurrent events. In one large prospective cohort of 1 243 children in the USA, 60% of episodes of DKA documented occurred in only 5% of children<sup>36</sup>.

Prevention of ketoacidosis in the person with established diabetes can reduce morbidity and mortality significantly. Some have estimated that up to 50% of ketoacidosis-related hospitalisations could be avoided with improved outpatient and self-delivery of care<sup>39,43</sup>.

There are a number of precipitating causes of DKA. For convenience, these may be divided into medical/physiological causes (for example, an intercurrent illness or pregnancy), and psychosocial causes (for example, deliberate manipulation of insulin doses or substance abuse). For a summary, see Table 14 and Table 15.

**Table 14 Physiological precipitants of ketoacidosis in people with a known diagnosis of type 1 diabetes**

| <b>Medical/physiological causes</b>                       |
|---|
| Intercurrent illness <sup>28,44-46</sup>                  |
| Trauma <sup>28</sup>                                      |
| Surgery <sup>28</sup>                                     |
| Pregnancy <sup>28</sup>                                   |
| Acute myocardial infarction <sup>28</sup>                 |
| Medication – e.g. steroids <sup>28,46</sup>               |
| Failure of continuous insulin pump <sup>28,44,46-48</sup> |

**Table 15 Psychosocial precipitants of ketoacidosis in people with a known diagnosis of type 1 diabetes**

|   |
|---|
| <b>Psychosocial causes</b>  |
| Accidental omission of insulin dose <sup>28,45</sup>  |
| Substance abuse <sup>28,44,46</sup>   |
| Deliberate omission of insulin dose <sup>28,36,44,45,47-50</sup>  |
| <ul style="list-style-type: none"> <li>- weight management (in girls especially)</li> <li>- avoidance of hypoglycaemia</li> <li>- escaping abusive domestic situation</li> <li>- depression</li> <li>- attention seeking</li> </ul> |
| Eating disorder <sup>28,36,48,50</sup>  |
| Failure to access medical care due to expense <sup>45</sup>   |

In addition to identifying the main causes of ketoacidosis in this group, it may also be important to identify and target patients at highest risk of DKA. Prevention includes appropriate management of sick days and abnormal glucose results by the patient (medical/physiological causes), and interventions to promote better adherence to treatment in those patients at risk of non-compliance (psychosocial causes).

**Preventing DKA in patients with previously diagnosed diabetes with medical/physiological causes for diabetes metabolic decompensation**

This group includes those who have sporadic episodes of DKA despite adhering to treatment and monitoring. The ISPAD guideline states that these cases are preventable.

*Access to advice*

Easily-accessible specialist advice should already be available to all with T1D, at all times of the day. This might optimally include a variety of media, from printed literature, to telephone advisory services, to web-based recommendations of management. Further, follow-up teaching of sick-day management (and not simply at the time of diagnosis) would probably result in patients and families acting with greater confidence to appropriately manage acute episodes of metabolic decompensation, and hopefully prevent further deterioration towards ketosis and ketoacidosis.

*Advice regarding management of sick days*

Although most programmes provide training on the management of sick days, this is usually carried out during the patient’s first presentation with diabetes<sup>44,51</sup>. Too often re-training and re-enforcement of these messages does not routinely occur<sup>52</sup>. Bismuth<sup>28</sup> suggests that sick-day rules should be re-enforced at the start of the school year, and during flu epidemics when illness is more common. In adults, regular “refresher” courses on sick-day management would presumably have a similar effect, but there was no published evidence available to support this suggestion.

Several reports have shown decreased rates of DKA using telephone help-lines for diabetic patients<sup>28,39,53</sup>. However, as telephone help-lines are often part of other intervention packages, it is difficult to determine the individual contribution of the help-line to the overall reduction in DKA episodes. A toll-free telephone hotline, with a physician available 24 hours a day, was introduced in Parma, Italy, and received 9,125 calls over a 5 year period (approximately 5 calls per day)<sup>54</sup>. Whilst patients could call about any issue related to their diabetes, they were particularly encouraged to call during sick-days instead attending hospital directly. Although a large proportion of calls (6,935 of 9,125 calls) were not ‘emergency’ calls, and related to issues such as prevention of hypoglycaemia

(36%) and quality of life with diabetes (19%), of those who called in with concerns about emergency situations, none of these callers were later admitted to the hospital for medical assistance.

There are several different methods of providing telephone advice and support available to those diagnosed with T1D in Scotland. These include the national “NHS 24” service, local general practitioner or specialist nurse services, secondary care advice provided by on-call specialist nursing or medical staff or medical trainees after hours, and finally a commercial service provided by Novo Nordisk, staffed by independent specialist nurses.

**Table 16 Services providing telephone-based “sick-day” advice to those with type 1 diabetes in Scotland**

| Service  | Description  |
|--|--|
| NHS 24   | National general medical advice line   |
| Primary care   | GP or community-based specialist nurse   |
| Secondary care<br>- Dedicated on-call advisory service<br>- Local diabetes service<br>- Local hospital | e.g DiabNet – specialist nurses using agreed protocols<br>Specialist nurse or diabetologists on-call (during & after-hours)<br>After-hours care may be provided by generic on-call trainee staff |
| Commercial advice line   | Novo Nordisk-funded service provided after hours until 23:30<br>Diabetes specialist nurses, with translation service available   |

All of these telephone advisory services are charged at local rate. Assessing the quality and consistency of advice provided by each of these services was beyond the scope of this review, but may be worth assessing. However, they provide a range of specialist advice to all those with diabetes who have become acutely unwell. Of course, they will only be effective if their availability is publicised to all those with diabetes, and if these same patients and families then make appropriate use of them. The provision and adequate understanding of simple, easy-to-follow advice on managing illness, hyperglycaemia, and ketosis is also essential. Such information is provided in the excellent pocket guide produced and used by the Raigmore Hospital Diabetes Service, and with appropriate agreement and acknowledgement, this could be relatively easily supplied to and issued by all diabetes teams throughout Scotland. The information might also be provided in other form, such on Internet sites or by mobile phone.

### *Continuous subcutaneous insulin infusion*

In past decades, there was concern about the risk of DKA in patients treated with CSII, and this may have been one reason why insulin pumps were little used in the UK. Following the NICE guidance, we would expect a modest rise in CSII use in adolescents and adults, but a sharper rise in children. So we need to monitor DKA episodes in patients on CSII. In the DCCT, the DKA rate was higher amongst those on CSII than in those on MDI, 1.8 versus 0.8 events per 100 patient years (though note that patients were not randomised to CSII or MDI). (Note that these rates are much lower than in routine care.)

Sick-days and episodes of hyperglycaemia, ketonaemia or ketonuria need special management in patients using insulin pumps, because these use short-acting insulin, meaning that there is no reservoir of long-acting insulin in the body. Extra insulin should be administered if metabolic derangements occur; failing to do so is the most common cause of DKA in these patients<sup>47,48</sup>. Clear advice on what to do at times of metabolic decompensation should be provided to all patients using insulin pumps, and should include fall-back mechanisms such as the availability at all times of insulin and non-pump delivery devices, and contact details for staff knowledgeable in the management of insulin pump therapy.

### ***Improved monitoring of ketones in diabetic patients***

There is a growing body of literature regarding improved methods of metabolic monitoring using blood (capillary) testing for 3-hydroxybutyrate (3-OHB). Until recently, traditional urine ketone testing<sup>28,51,55,56</sup> was the only option for assessing ketone status during 'sick-days' and other periods of poor metabolic control. 3-OHB is the principal ketone body formed during periods of relative or absolute insulin deficiency, while urine ketone test strips estimate acetoacetate and acetone only.

Testing for blood ketones avoids many of the problems inherent in ketonuria testing, including:

- (a) practical difficulties with obtaining urine in the young and old
- (b) failure to detect principal ketone body, 3-OHB
- (c) alteration of ketones by some drugs (e.g. captopril)
- (d) urine in the bladder may not give an accurate picture of the current metabolic situation (not certain when passed)<sup>28</sup>.

While more expensive than ketonuria testing, testing for blood B-OHB has been reported to be significantly more acceptable to patients, and therefore is used more frequently during times of illness. Laffel reports that when a study population of 123 children were randomised to using either ketonaemia or ketonuria testing during times of metabolic derangement or illness, over 90% of the blood ketone group measured blood ketones during sick days compared with only 60% of the group using urinary ketone testing. Further, 70% of the families in the ketonaemia testing group said they would be more likely to check for blood than urinary ketones if given the choice<sup>56</sup>.

In Laffel's study<sup>56</sup>, the incidence rate of acute complications for ketonaemia-testing patients was 38/100 patient years, compared to 75/100 patient years in those testing for ketonuria ( $p=0.05$ ). 60% fewer hospitalisations and 40% fewer emergency department assessments took place in those testing for B-OHB compared to the urinary ketone test group, despite earlier provision of identical sick-day advice. This 50% reduction in admissions for ketosis and ketoacidosis was claimed to more than offset the increased expense of ketonaemia testing in the study population, and overall financial savings were projected if ketonaemia meters were to become standard issue for all patients with T1D.

In contrast to Laffel<sup>56</sup>, who provided no specific costings, Vanelli and colleagues reported relative savings of ketonaemia versus ketonuria testing, with reduction in intensive care duration and expense<sup>57</sup>. 3-OHB monitoring has also been suggested for use in hyperglycaemic patients to identify, at an early stage, those patients at highest risk of DKA (level of 3-OHB  $>3.0\text{mmol/l}$ ) and to look for an alternative diagnosis in others (level of  $<1.0\text{mmol/l}$ )<sup>55</sup>.

The SLWG noted that the Laffel trial has been the only one of home blood ketone monitoring, and that the evidence base is therefore somewhat sparse. We would therefore like to see a trial carried out in Scotland. There are two questions which might be addressed;

- in preventing DKA, how much does ketone testing add to glucose testing?
- If ketone testing is effective in reducing DKA episodes, is blood testing cost-effective compared to urine testing?

### **Preventing DKA in those with previously diagnosed diabetes but poor compliance with treatment**

This group includes most of those with multiple admissions. Female teenagers are the group most commonly cited as being at highest risk<sup>36</sup>, particularly if they:

- (a) are from dysfunctional families
- (b) have low levels of parental involvement in the diabetes care<sup>28,58</sup>
- (c) are less able to problem-solve, and
- (d) have with poorly defined family rules<sup>59</sup>.

Psychiatric and behavioural disorders are predictors of poor compliance. A prospective study of 1,243 patients aged 0-19 years in the USA examined the incidence and predictors of DKA<sup>36</sup>. In multivariate analyses, the risk of ketoacidosis in younger children increased with higher HbA1c (relative risk, RR, 1.68 per 1% increase; 95% CI 1.45-1.94) and higher reported insulin dose (RR 1.13; 95% CI 1.02-1.25). In older children the risk increased with underinsurance (RR 2.18, 95% CI 1.65-2.95) and the presence of psychiatric disorders (RR 1.59; 95% CI 0.96-2.65 in boys, and RR 3.22, 95% CI 2.25-4.61 in girls)<sup>36</sup>. The author concluded that children with psychiatric disorders or at the extremes of HbA1c distribution should be targeted for specific interventions to prevent DKA.

In patients with established diabetes, one of the most important factors associated with ketoacidosis is poor compliance leading to sub-optimal insulin dosing<sup>48</sup>. This is reported to occur more commonly in women than men<sup>49</sup>. In one study from the USA, 31% of women aged 13-60 years (n=341) admitted to intentional insulin omission, and 8.8% reported frequent omission<sup>50</sup>. In multivariate analyses, there were only two variables that predicted omission of dosing – diabetes-specific distress, and fear of improved glycaemic control leading to weight gain<sup>50</sup>.

Weissberg-Benchell<sup>60</sup> reported that in the 10 days prior to their clinic visit, 25% of the 156 adolescents in their study admitted to missing insulin injections. They noted that:

- (a) older adolescents engaged in more mismanagement than their younger cohorts (p<0.001)
- (b) missing insulin injections was significantly related to poor diabetic control (p<0.01), and
- (c) parents tended to significantly underestimate adolescent mismanagement.

Morris and colleagues<sup>49</sup> were the first to directly confirm intentional omission of insulin, by studying the association between:

- (a) the medically recommended prescription of insulin therapy
- (b) insulin amounts dispensed at community pharmacies
- (c) glycaemic control, and
- (d) acute hospital admissions for diabetic symptoms

in young people with diabetes in Scotland. The adherence index was inversely related to hospital admissions for DKA (p<0.001) and all hospital admissions related to acute diabetes complications (p=0.008). Morris and colleagues<sup>49</sup> concluded that poor adherence to insulin treatment was the major factor contributing to long-term poor glycaemic control and DKA in this age group (mean age 16 years).

A follow-up paper to the original presentation of the totality of DCCT data looked specifically at adolescent participants<sup>9</sup>. In adolescents, the incidence of DKA was 2.8 per 100 patient-years in the intensive treatment group (n=92) and 4.7 per 100 patient-years in the conventional therapy group (n=103). Emphasis in this trial was placed not only on insulin regimens, but also on education and motivation of the patient and family, increasing self-esteem and a carefully planned parental supervision programme, appropriately altered to take into account the changing needs of the growing child over time. Patients were seen monthly and care was individually monitored and reviewed by a skilled multi-disciplinary team<sup>61</sup>. A summary is shown in Table 17.

**Table 17 Features of the DCCT intensive therapy cohort associated with reduction in ketoacidosis occurrence**

|  |
|--|
| Multiple injection (3 or more) insulin therapy or CSII                   |
| Provision of specific diabetes-related education                         |
| Motivation of patients and their families to adhere to management goals  |
| Increasing of adolescent participants' self-esteem                       |
| Planned parental supervision programme (modified with age of adolescent) |
| Monthly individual monitoring by multi-disciplinary team                 |

Given that many patients with ketoacidosis have had previous admissions with the same condition, the challenge is how to prevent recurrences. In one UK study, 4.8% of patients accounted for 22.5% of all episodes of DKA over a 3-year period<sup>62</sup>.

Interventions to reduce the frequency of DKA have included:

1. In the USA for patients previously admitted for DKA, participation into an intervention called the Diabetes Treatment Unit (DTU) programme<sup>45</sup>. Although this was a non-randomised trial, and therefore subject to potential bias (although no differences were noted in the baseline characteristics of the two groups), the intervention group had:
  - (a) a lower frequency of readmissions for DKA (16% vs 43%,  $p=0.001$ )
  - (b) lower number of readmissions per patient (0.22 [SD 0.6]; vs 1.17 [SD 2.2];  $p=0.003$ ), and
  - (c) lower HbA1c level (10.4 [SD 2.3]% vs 13.5 [SD 2.3]%;  $p<0.0001$ ).

This low-cost intervention combined:

- (a) the services of a specialist endocrine team
- (b) intensive patient education
- (c) a rapid response system, and
- (d) targeted removal of administrative barriers to regular outpatient care.

In line with other studies<sup>63-65</sup>, their findings showed that discontinuation of insulin therapy was the most common factor associated with DKA in their population.

2. Similar improvements in the incidence of hospitalization for DKA were seen in adult patients participating in a diabetes treatment and teaching programme (DTTP) in Germany and Austria<sup>66</sup>. In the year before the intervention, 58% of participants had two, 21% had three, 4% had four, and 17% had five or more episodes of severe DKA per year. After the DTTP, 72% of participants had none, 15% had one, 9% had two, and 4% had three or more episodes of severe DKA. The number of days spent in hospital decreased from 19.4 (SD 23) to 10.2 (SD 22.6) days. The authors suggest that the likely reasons for the significant improvements in outcomes were the improved self-management skills learnt by the patients, with increased competence to manage their diabetes, to recognise the impending signs of DKA and to intervene appropriately<sup>66</sup>. Unfortunately, no follow-up data regarding ongoing effectiveness in DKA reduction have so far been provided.
3. An intervention based on motivational interviewing for 62 teenagers with diabetes was evaluated in South Wales<sup>67</sup>. The intervention resulted in significantly lower levels of HbA1c in the intervention compared to the control group at 12 (difference -0.5) and 24 months (difference -0.4). Furthermore, the intervention group was reported to have higher life satisfaction and general well being, and lower life worry, compared to the control group.
4. Encouraging preliminary results have been reported from small studies using tele-health interventions, incorporating intensive video and phone conferencing of psychology services to adolescents and family members, targeting adherence and maladaptive family processes<sup>68</sup>. However, these findings are yet to be confirmed in larger studies. Such facilities are increasingly being made available, but necessarily have significant resource implications for out-of-hours access in areas where no service provision currently exists. However, such a system has the potential to allow a national service to be established, rather than expecting local or regional services to provide the man-power and technical facilities required. Whether web-based applications will have benefit over existing forms of telecommunication remains to be assessed.
5. A randomised controlled trial in the USA was conducted to determine whether a 6-month intensive, home-based family therapy (MST – multisystemic therapy) programme could

reduce rates of emergency room visits and hospitalisations amongst 127 adolescents with diabetes<sup>69</sup>. At 6-month follow-up adolescents receiving MST had decreased admissions for DKA, associated with better metabolic control, compared to the control group.

## Conclusions and recommendations

### Prevention of DKA

We have identified above a number of ways in which DKA might be prevented. Some are better supported by research than others, and research is underway in some. Our conclusions on each of these methods are as follow:

1. The Parma initiative. We recommend that this be implemented in Scotland, but that there should be a before and after study to assess its impact. If successful, it is further recommended that the programme be repeated on a regular basis.
2. Psychological interventions for non-compliers. Family multi-system therapy has been suggested but a trial is underway. We recommend waiting for the results.
3. Reinforcement of sick day education. We recommend that this should be provided.
4. Telephone support lines. These already exist, but we recommend further discussions with NHS 24 to explore ways in which they might provide a national service.
5. The Raigmore pocket guide. We recommend that this should be made available across Scotland, and that equivalent information in other formats be developed.
6. Home blood ketone monitoring. We think this has promise but recommend a further trial with DKA incidence as the main endpoint, but with other outcomes such as quality of life and cost-effectiveness included.
7. Education has the potential to reduce DKA; this is dealt with in Chapter 5.
8. Causes of DKA in Scotland. We recommend an audit of cases of DKA in Scotland, to assess the frequency of underlying predisposing factors, and to examine the accuracy of SMR1 data. The results would inform planning to reduce the frequency of DKA.

### Treatment of DKA

Scottish and international guidelines for the management of DKA already exist<sup>70-72</sup> and we commend these.

### Audit proposal

There have been recent audits of DKA in adults (North of Scotland) and children (Moray). It is proposed that there be an audit of DKA in post-onset cases with the following aims;

- To determine the incidence of DKA in young people in Scotland, and to check whether any mortality has resulted
- To assess the accuracy of ISD data
- To examine factors which increase the risk of DKA
- To estimate the cost to NHS Scotland of DKA

# Chapter 8 Professional Education

## Introduction

It is vital to ensure that all professional and non-registered care workers in contact with the individual with diabetes have an appropriate and current level of competency for their specific role; this underpins patient knowledge and understanding of their diabetes and aids patient self-management. Thus, professional and patient education and training in diabetes management should be securely linked.

The SDG through the Diabetes Education Advisory Group (DEAG) oversees professional education and offers advice on areas for development. Moreover the SDG's Action Plan states a commitment to *“Develop and support staff to enhance their knowledge and skills in caring for people with diabetes”*<sup>2</sup>.

T1D affects 10-15% of the diabetes population and while DEAG along with NHS Education for Scotland (NES) have endorsed development of generic multidisciplinary educational courses these have been aimed at healthcare professionals managing primarily T2D in community settings. T1D is uniquely different and involves the spectrum of children, adolescents and adults. The dynamic nature of T1D coupled with the technological advancements in monitoring and treatment dictate the need to acquire skill sets conducive to effect use of these for staff fulfilling a specialist role.

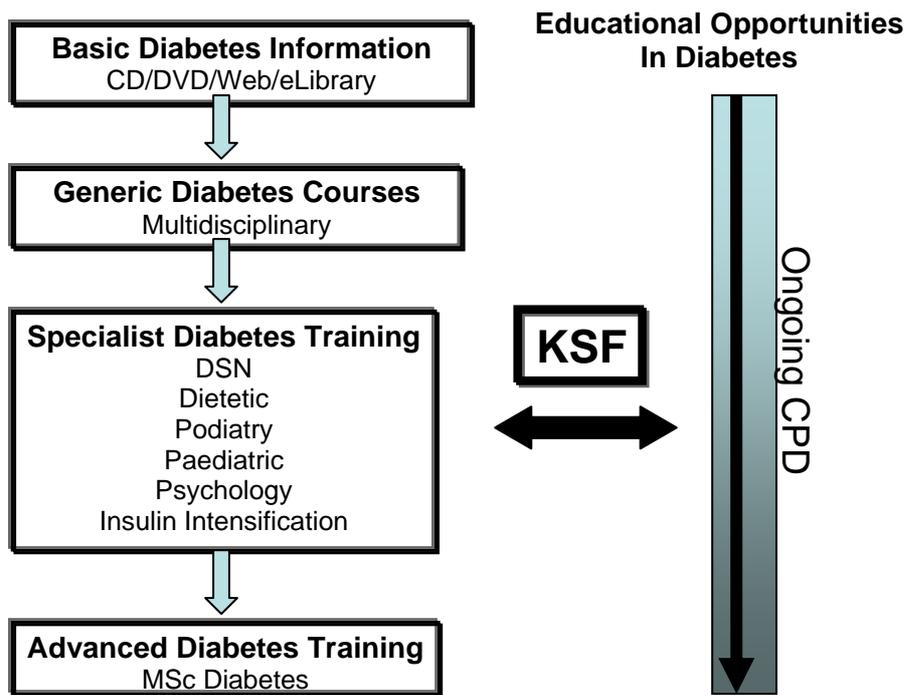
The 2008 Scottish survey of structured education for people with T1D (see Chapter 5) highlighted the need for an accredited paediatric educational course in Scotland given the widespread lack of access to clinical psychology services.

The recent consultation response to inform the SDG updated Action Plan confirms the desire for comprehensive and structured educational provision for health care professionals; the need to co-ordinate training through MCN educational subgroups; the need to ensure adequate funding both for attendance at training events and backfill and specifically the need for insulin intensification training.

A simultaneous survey conducted by Diabetes UK of patient views to inform the action plan highlighted the need for patient centred structured education and psychological and emotional support.

In England and Wales a DUK Task and Finish group was established in response to evidence that a number of HCPs had been delivering diabetes care without appropriate knowledge, skills and qualifications and it was also recognised HCPs had difficulty accessing education due to lack of time resource and funding. The need to develop a structured education for HCPs and to make this mandatory to ensure uptake was highlighted.

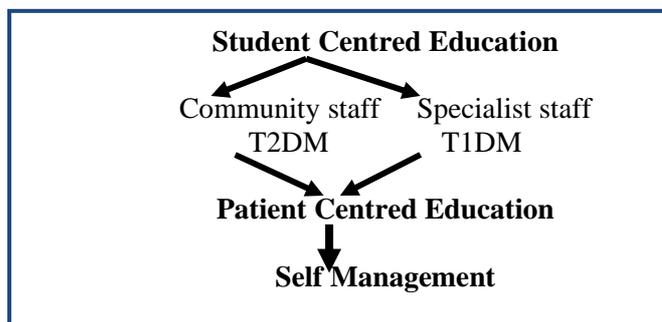
Funding for health care professionals to participate in continuing professional development (CPD) is an ongoing issue throughout the workforce and across all disciplines. SDG provided non-recurring funding to each MCN towards professional development in diabetes; this was utilised locally in a variety of ways by individual networks. Since then, apart from staff who qualify for the limited pot of study leave funding, there have been no provision at health board level to facilitate staff training in diabetes and self funding or external assistance are the norm. The lack of support for training is also manifest as failure to backfill staff in their absence. The DEAG are surveying the extent of this and other barriers to attendance or participation in further diabetes education and training.



**Figure 5 Educational Opportunities in Diabetes**

### Professional and patient education links

The DEAG seeks to promote implementation of competency based training and education with applicable assessment and accreditation wherever relevant to health care workers. Linking this approach with patient education may be achieved through implementation of a national Diabetes Education Framework, which with local development will underpin the philosophy of patient centred learning. Alignment of the roles of the DEAG and DENS would help to address staff training needs to deliver patient centred education to support self-management. The role of the specialist in diabetes care should be protected to include an educational remit within job descriptions. In addition it is important to recognise the training and educational needs of all staff fulfilling the role of diabetes educators.



**Figure 6 Patient centred education**

The economic implications of this approach are difficult to determine due to the lack of an evidence base; studies show the benefit of good glycaemic control and reduced incidence of diabetes complications in T1D and it is presumed that education and support from health care professionals contributed significantly to these positive outcomes.

## **Educational standards**

- **Diabetes education and training strategy**

The SDG requested MCNs to produce a local diabetes education and training strategy for professional education to be informed by training needs analysis. Further to this the DEAG compiled a national (Scotland wide) strategy to assist Diabetes MCNs and learning and development groups within health boards in provision of relevant competency based education and training for their workforce.

- **Work based assessment general principles**

The SDG funded a scoping exercise of work based learning and assessment of programmes operated by HEIs for health professionals in Scotland. Although no diabetes courses considered in this exercise, the report concluded that work based learning and assessment would not be applicable in all situations and that more research was required into the efficacy of work based learning in comparison with more traditional methods of learning and teaching. Subsequently, NES has produced a generic guide on the principles of work based learning and assessment which could be utilised by any potential education and training providers<sup>73</sup>.

- **Accreditation**

Accreditation of courses and training is an ongoing concern, as there are a limited number of bodies able to confer accreditation and these are mainly HEIs. NES recognises that course providers must therefore work closely with this group in order to achieve learning and assessment models that the HEI can co-deliver and accredit.

## **Current educational material and courses**

The DEAG has compiled a list of current diabetes educational and training activities in Scotland (Appendix 3) and this is hosted on the DEAG page on the Diabetes in Scotland (DIS) website<sup>74</sup>. The list was generated from a call to all HEIs and previously known education providers but is still thought to be incomplete. Courses have been further subdivided into patient and professional related training. Hyperlinks have been generated to the national long-term conditions (LTC) Group site, which details all courses in any LTC provided through an HEI<sup>75</sup>.

In addition to various generic or multidisciplinary courses, there are a number of courses relevant to HCPs involved in management of T1D out with Scotland including the Birmingham paediatric diabetes course and the Leeds Pump course which HCPs working in Scotland have attended by necessity.

## **Specialist accreditation**

In addition to areas highlighted above, it is also clear that while training in diabetes is available to specialist groups there are no recognised specialist accreditation schemes for health care professionals specifically employed in diabetes. Podiatry is addressing this issue at present and aspires to produce and deliver a model for podiatry accredited specialists. The British Dietetic Association Diabetes sub group (DMEG) have produced a competency based guidance document for dietitians to achieve specialist training in diabetes linked to the KSF but this is not formally implemented yet.

## Work in progress

- **Doctors Online Training Scheme (DOTS)**

The need for basic training aimed at junior hospital doctors is a long standing issue and lack of knowledge has impacted on quality of inpatient care of the person with T1D. The DEAG working collaboratively with NES have developed a web based education module suitable for delivery through DOTS. This will be available in the latter half of 2009 and will be mandatory for all Foundation Year 1 (FY1) hospital doctors within the first year of their post. This training will have particular emphasis on insulin administration, management of hyper and hypoglycaemia and management of diabetes during investigations or surgical procedures. It is likely that all health care professionals working within the inpatient environment will benefit from this training and routes to expand the DOTS diabetes module are being explored.

- **Inpatient care group**

Quality of diabetes inpatient care across many hospital specialties remains patchy with significant patient dissatisfaction experienced and reported by many individuals with insulin requiring diabetes. This has prompted the DEAG to establish a short-term working group to review and establish the extent of the problem and consider appropriate recommendations and/or initiate possible solutions for both policy development and staff training. The intention is to cover both adult and paediatric diabetes.

## Recommendations

1. There is a need for both discipline specific and multidisciplinary training for specialist care teams delivering care, education and support to children and adults with T1D. Multidisciplinary course/opportunities in insulin intensification including MDI and CSII and management of paediatric and adolescent diabetes should be made more accessible, ideally with the opportunity to undertake these in Scotland.
2. Training and support in advanced communication skills, assessing barriers to better self-care and in psychological interventions for health care professionals working with people with T1D would be beneficial given the paucity of applied psychology available within the NHS. This would not be a substitute but complimentary to services which applied psychologists provide and should not deter ongoing investment in this professional area.
3. Increasing the availability or accessibility of programmes designed to develop teaching and training skills for MDCT members to develop their skills in delivering patient centred learning to facilitate self-management.
4. A national programme based on the diabetes education and training strategy and delivery of appropriate education to relevant health care professionals linked to surveys and audit will enhance levels of professional education, create an evidence base for the effectiveness of educational input and ensure optimal patient centred learning. The development of an educational framework will lead to the establishment of baseline mandatory training to specialist staff delivering care and education to those with T1D.
5. None of the above is achievable without realistic funding of educational activity. This needs to be addressed and resource identified at board level to implement the educational framework including protected time for the specialist care team to undertake relevant training and engage in delivering an equitable service for people with T1D.

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## Appendix 1 Intensive Insulin treatment

### Introduction and background

The Diabetes Control and Complications Trial (DCCT) (1) provided unequivocal evidence that intensive insulin treatment reduces microvascular complications in type 1 diabetes. Insulin intensification might be used to describe any regimen more intensive than twice-daily mixtures, but usually refers to either a basal/bolus MDI regimen, or to CSII, guided by self-monitoring of blood glucose (SMBG), and self-adjustment of insulin doses. It is a package of measures, not just an insulin regimen, and not all patients will be suitable for it, or wish to adopt it. To be effective insulin intensification requires effective self-management.

Intensive insulin treatment (IIT) has been defined as:

*“An insulin regimen that is as close to the physiological norm that technological advances allow, i.e. either MDI or CSII, supported by frequent blood glucose monitoring and a comprehensive structured education programme to allow individuals to achieve effective self management. The key to successful IIT is effective self management.”*

Individuals who participated in the intensification arm of the DCCT received intensive education to promote self management and had the regular support of the multidisciplinary health care team including DSN, medical staff, dietitian and psychologist. The DCCT authors concluded that *‘the time, effort, and cost required were considerable’*.

In children, the ISPAD clinical practice consensus guidelines (2) state that

*‘In all age-groups, as close to physiological insulin replacement as possible and optimal glycaemic control must be the aim; the attainment of this aim should include the consideration of an intensive insulin regimen.’*

The ISPAD consensus guidelines for diabetes education recommends quality assured structured education to maximise the effect of advances in diabetes management and technology and recognises structured self management education as key to successful outcome.

### MDI or CSII?

The recent NICE review of CSII (3) concluded that there is little evidence from randomised controlled trials (RCT's) of a significant difference between CSII and MDI therapy in terms of a decrease in HbA1c levels or in the rate of severe hypoglycaemic episodes in people with diabetes. Observational studies show a much greater improvement in HbA1c levels with CSII therapy, as well as statistically significant decreases in the rate of severe hypoglycaemia episodes. There are also quality of life gains from CSII.

NICE recommend CSII as a treatment option for adults and children 12 years and older with type 1 diabetes provided that

- attempts to achieve target haemoglobin A1c (HbA1c) levels with MDI result in the person experiencing disabling hypoglycaemia. For the purpose of this guidance, disabling hypoglycaemia is defined as the repeated and unpredictable occurrence of hypoglycaemia that results in persistent anxiety about recurrence and is associated with a significant adverse effect on quality of life
- or
- HbA1c levels have remained high (that is, at 8.5% or above) on MDI therapy (including, if appropriate, the use of long-acting insulin analogues) despite a high level of care.

For children younger than 12 years NICE recommend the use of CSII therapy where MDI therapy is considered to be impractical or inappropriate, or has failed. However, it is not necessary for children to have failed on MDI – the NICE Appraisal Committee took this line because it heard that problems with lunchtime insulin at school prevented trials of MDI. The Committee noted that adherence to any insulin regimen required a high degree of motivation, commitment and competence from patients and carers to ensure that it was both safe and effective. And that the use of CSII should not be considered to replace the need for education. ISPAD guidelines state that *‘Whatever insulin regimen is chosen, it*

must be supported by comprehensive education appropriate for the age, maturity, and individual needs of the child and family.’

### **The costs of IIT**

All the costs of IIT must be considered. These are

1. The consumables for insulin and insulin delivery
2. Blood glucose monitoring
3. Structured education programmes
4. Continued support from a diabetes care team trained to deliver IIT

Effective IIT will produce long-term economic benefit by a reduction in microvascular complications and improved quality of life.

#### **1. Insulin and insulin delivery costs**

The figures used here have been taken from the costing template for technology appraisal guide 57 (appendix 1)

Cost per patient per annum for CSII based on insulin, consumables and annualised pump cost =£2,675  
Cost per patient per annum for MDI based on insulin consumables and annual pen costs = £887

#### **2. Blood glucose monitoring**

For intensive insulin treatment to be effective individuals require to check blood glucose levels frequently to guide decisions on insulin boluses to be given for meals and snacks as well as basal insulin levels. This cost should be the same for MDI and CSII.

Approximate cost pppy based on 4 blood tests per day = £600

#### **3. Structured education**

The costs outlined are taken from those used for the DAFNE structured education programme (4). The additional one off training cost for CSII is that used for cost analysis purposes in the NICE guidelines. For some patients a single structured education session may not be sufficient to achieve effective self-management.

MDI Cost per patient, based on 8 patients per group £ 214.87

CSII Cost per patient, based on 8 patients per group £ 214.87 plus £240 = £454.87

#### **4. Continued support from a diabetes care team trained to deliver IIT**

Staff training costs for structured education

|                                  |        |
|----------------------------------|--------|
| Training of 2 educators          | £ 5000 |
| Training of 1 DAFNE aware doctor | £ 310  |

## References

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## Appendix 2 Insulin strategies

As part of the “Diabetes Action Plan” issued by the Scottish Executive in June 2006<sup>2</sup>, each Diabetes Managed Clinical Network (MCN) was tasked to produce an “insulin strategy” for their health board area. The aim of the insulin strategy is to ensure that individual patients are supported with insulin regimens tailored to suit their needs. The insulin strategy should include: an analysis of current patterns of insulin use; the identification of how and where insulin initiation is managed; and an examination of local protocols on the intensification of insulin including the use of insulin pumps.

A number of health board areas have drawn up local insulin strategies while others are still in the process. There are many similarities in the content of the completed documents. Information in the insulin strategies generally falls under four main headings:

**1. Background information:** including incidence of diabetes and local figures for people with T1D and T2D treated with insulin.

**2. The aims and principles of insulin therapy**

**3. The initiation of insulin therapy:** including: decision to treat; where to treat; insulin regimens; education process; ongoing management. This information is presented for T1D, T2D and special groups including children, adolescents, antenatal and others e.g. steroid induced diabetes and maturity onset diabetes of the young (MODY).

**4. Appendices** – including:

- Insulin names and classification
- Local formulary
- Supporting local protocols and checklists e.g. for patient education
- Supporting education material such as local handbooks and leaflets

The insulin strategy should reflect the underpinning philosophy of ensuring individual patients are supported with insulin regimens tailored to suit their needs and identify the skills and training required by health care professionals involved in delivering patient centred education, care and support.

The insulin strategies produced by health boards deal with T1D and T2D and do not address a strategy for service delivery to people with T1D. An insulin strategy that applies to both T1D and T2D has limitations because of the different needs of these group.

MCNs may find it more useful to have specific strategies for people with T1D which can in turn be used to form the basis of a strategy for service delivery for people with T1D, as recommended in Chapter 2.

Outlined below is a generic insulin strategy template for T1D that can be adapted by MCNs to produce local insulin strategies.

## **Insulin Strategy Template for type 1 diabetes**

### **List of contents**

### **Date of document and date for strategy update, author(s) and contributors**

## **1. The aims and principles of insulin therapy**

### **Aims of Insulin Treatment**

- Abolish hyperglycaemic symptoms
- Maintain ideal body weight
- Avoid hypoglycaemia
- Maintain as near normal blood glucose as is practical and safe for the individual.
- Avoidance of complications
- Ensure normal growth and development in childhood and adolescence.

### **Principles of Treatment**

- Insulin injections are given to replace endogenous insulin in people with absolute or relative deficiencies in insulin secretion.
- Insulin lowers blood glucose and the dose given should take into account the balance of carbohydrate intake and exercise.
- Self-monitoring of blood glucose is required for most individuals on insulin to ensure that the treatment is effective and to avoid the possibility of hypoglycaemia
- HbA1c measurements are advised to ensure targets are met and the risk of complications is minimised.

## **2. The initiation of insulin therapy**

### **Decision to treat**

This question only applies to patients with type 2 diabetes and those with secondary diabetes. All people with type 1 diabetes require insulin.

### **Where to treat**

This decision will usually be made in secondary care by the consultant diabetologist following referral, but commencement of insulin may be done in primary care under the guidance of a DSN.

### **Insulin regimens**

The choice of initial insulin regimen should be tailored to the individual taking into account factors such as shift work, exercise, travel etc. It may be dictated by the patient's ability to use a specific insulin delivery device. There may also be some patients who prefer to use insulin manufactured from an animal source.

The different insulin regimes include:

- bd or tds insulin regimens with premix insulins or free mixing
- MDI using basal bolus regimens
- CSII

### **Twice daily regimens**

This regimen is given as two injections, one before breakfast and one before the evening meal. The insulin can either be premixed, with combination of soluble/fast acting analogue and intermediate insulin or can be given as two injections/free mixing. It has the advantage of requiring insulin at only 2 times per day and may avoid the need to take insulin at lunchtime. The disadvantage of this regime is that it requires the individual to have consistent meal times and snacks with consistent carbohydrate intake. It is not always possible to adjust for spontaneous activity.

### **Basal bolus regimen or multiple daily injections**

Insulin analogues are usually used for all patients starting this regimen, with a basal long acting analogue either once or twice daily and bolus fast acting analogues to cover carbohydrate intake. Some patients established on this regimen may use short acting insulins to cover a meal and a snack. The main advantage of this regimen is the increased flexibility with regard to physical activity, meal timing and meal size. It is particularly suitable for shift workers or those with an erratic lifestyle. The disadvantage of this regimen is the additional injections and testing required. A multiple injection regimen does not necessarily translate into better control compared with a twice-daily regimen. It is most likely to work effectively in a well-motivated individual, prepared to do regular and frequent blood glucose testing who has received structured education to gain the knowledge, skills and understanding to adjust therapy according to blood glucose levels, carbohydrate intake and exercise. It is not suitable for patients in whom insulin omission is suspected.

### **Continuous subcutaneous insulin infusion**

Insulin pump therapy is the common name for the technique of continuous subcutaneous insulin infusion (CSII). Insulin pumps contain a chamber filled with insulin, connected to a small battery operated pump device, which is controlled by a microprocessor (computer chip). The entire assembly is housed within a small case the size of a pager device. The user is able to control the amount of insulin released by the device, which is injected every minute into the subcutaneous tissue via a length of plastic tubing with a needle or soft cannula at the end. The pump operates continuously, delivering insulin 24 hours of the day. At meal times, the user has to programme the pump to deliver a 'bolus dose' of insulin to cover the amount of food eaten. It is important to realise that the pump does not perform this automatically but that the user has to programme in the information. Like MDI, CSII therapy does not necessarily translate into better control. CSII requires a high level of motivation and the commitment to test blood glucose at least 4 times a day. Patients must have the knowledge, skills and understanding to enable them to adjust therapy according to blood glucose levels, carbohydrate intake and exercise.

The NICE guidance (see appendix) suggests that CSII should be considered in adults and children 12 years and over with type 1 diabetes mellitus if:

- attempts to reach target haemoglobin A1c (59mmol/mol/7.5%) with MDI result in the person having 'disabling hypoglycaemia', or
- HbA1c levels have remained high (69mmol/mol/8.5% or above) with MDI (including using long-acting insulin analogues if appropriate) despite the person and/or their carer carefully trying to manage their diabetes.

CSII therapy is recommended as a treatment option for children younger than 12 years with type 1 diabetes mellitus provided that:

- MDI therapy is considered to be impractical or inappropriate, and
- Children on insulin pumps would be expected to undergo a trial of MDI therapy between the ages of 12 and 18 years

### **The education process**

Supporting self-care is a crucial aspect of any high quality diabetes service. Patient education should allow people with diabetes to improve their knowledge, skills and confidence, enabling them to take increasing control of their own condition and integrate effective self-management into their daily lives. The education process begins at diagnosis and is a continuous, dynamic process responding to the changing needs of the individual. A patient centred, structured, approach to education based on sound educational principles can have a profound effect on biomedical outcomes and can significantly improve quality of life and patient satisfaction(1). All healthcare professionals involved in patient education should have appropriate skills and training.

### **Type 1 diabetes**

Children and adults with type 1 diabetes are normally cared for in secondary care. In order to support the education process a multidisciplinary team of consultant, DSN and dietitian with appropriate training in education methods and facilitation of behavioural change in addition to a sound knowledge of T1D is recommended. The team should ideally be supported by and include a psychologist. The patient education framework included as an appendix to this strategy outlines the levels of education and skills for T1D.

*Details of local education programmes/protocols/curriculum should be included as appendices to this section*

### **Ongoing management**

Following insulin initiation ongoing management is determined by the needs of the individual. Ongoing management has two main purposes:

1. The provision of a continuous education process.
2. Clinical review and screening.

Where and how these are provided with depend arrangements in the individual health boards. Education should be planned but taken out of the context of the clinical consultation/setting.

*Details of local protocols and arrangement to be included.*

### **4. Appendices – some suggestions for inclusion**

- Insulin names and classification
- Local formulary
- Supporting local protocols
- Summary of NICE guidance for CSII
- Local and national patient education programmes/protocols/curriculum.
- Supporting education material such as local handbooks and leaflets.
- Professional education and skills programmes
- Transitional care arrangements

### **Reference**

- (1) Diabetes UK and DoH. Structured patient education in diabetes. Report from the patient education working group, 2005 ([www.dh.gov.uk](http://www.dh.gov.uk)).

### Appendix 3 Diabetes in Scotland Education for Professionals

| <u>Title</u>   | <u>Organisation</u>  | <u>Location</u>                           | <u>Duration</u> | <u>Basis Offered</u>                              | <u>Accredited</u>                   |
|--|--|---|-----------------|---|-------------------------------------|
| Graduate Certificate in Cardiovascular Care                                      | Nursing & Health Care University of Glasgow                    | Glasgow                                   | 1 year          | Part Time   | <input checked="" type="checkbox"/> |
| Managing Cardiovascular Risk (CPD) M level 20 credits                            | Nursing & Health Care University of Glasgow                    | Glasgow                                   | 12 weeks        | Part Time   | <input checked="" type="checkbox"/> |
| "Doing diabetes better"  | Psychology subgroup of the Scottish Diabetes Group             | Varies                                    | 3 days          | Full Time   | <input type="checkbox"/>            |
| Diabetes: helping nurses to help patients to help themselves                     | NHS Grampian   | Aberdeen                                  | 2 days          | Day release - 2 days                              | <input type="checkbox"/>            |
| Grampian advanced management of type 2 diabetes: from tablets to insulin         | NHS Grampian approved by NHS education for Scotland            | Grampian                                  | 1 day           | Day release                                       | <input checked="" type="checkbox"/> |
| Grampian Lilly Primary Care Diabetes Scholarship                                 | Grampian Diabetes MCN and North of Scotland Deanery GP Section | Aberdeen                                  | 9 months        | Day release - 6.5 days                            | <input type="checkbox"/>            |
| Introductory Course on Teaching & Training for Diabetes Healthcare Professionals | Grampian Diabetes MCN  | Aberdeen                                  | 3 days          | Day release - 2 days and 2 half days over 6 weeks | <input type="checkbox"/>            |
| Tayside Diabetes Managed Clinical Network Biennial Conference                    | NHS Tayside Diabetes Managed Clinical Network                  | Varies                                    | 1 day           |   | <input type="checkbox"/>            |
| Tayside Diabetes Managed Clinical Network Forums                                 | NHS Tayside Diabetes Managed Clinical Network                  | Tayside                                   |                 | evening session                                   | <input type="checkbox"/>            |
| Diabetes Mellitus: a Multiprofessional Perspective                               | University of Dundee, NHS Tayside                              | Dundee                                    | 5 days          | Day release - 5 days                              | <input checked="" type="checkbox"/> |
| Renfrewshire Nurse Plus Programme  | Renfrewshire CHP   | Paisley                                   |                 |   | <input type="checkbox"/>            |
| Management of Diabetes Programme   | NHS Lothian  | Lothian                                   | 8 months        | Day release - 5 days                              | <input checked="" type="checkbox"/> |
| Management of Diabetes for Registered Nurses                                     | NHS Lothian  | Lothian                                   | 2 days          | Full Time   | <input type="checkbox"/>            |
| Management of diabetes for non-registered staff                                  | NHS Lothian  | Lothian                                   | 1 day           | Full Time   | <input type="checkbox"/>            |
| School Nurse workshop - Children with Diabetes                                   | NHS Forth Valley children's diabetes team                      | Forth Valley                              | 1 day           | Full Time   | <input type="checkbox"/>            |
| MSc (Med Sci) in Health Care   | University of Glasgow  | Glasgow                                   |                 |   | <input type="checkbox"/>            |
| Practice Nurse Education Programme   | NHS Borders MCN  | Melrose, Tweed Horizons Conference Centre | 12 days         |   | <input type="checkbox"/>            |
| The Macleod Course   | Facilitated by a faculty of Diabetes Specialists from NHS.     | Stirling, Highland Hotel                  | 5 days          | Full Time   | <input type="checkbox"/>            |
| The Practical Management of Paediatric Diabetes                                  | Paediatric Specialists from NHS                                | Banknock, Glenskirlie Hotel               | 1 day           | Day release - 1 day                               | <input type="checkbox"/>            |
| Management and Care in Diabetes Mellitus   | Edinburgh Napier University                                    | Edinburgh Napier University               | 15 weeks        | Part Time   | <input checked="" type="checkbox"/> |

## **Appendix 4 Structured Education for type 1 diabetes – the current position in Scotland**

In Spring 2008, a survey of structured education for people with type 1 diabetes in Scotland was carried out. Although a similar survey had been undertaken on behalf of the Patient Focus Implementation Group (PFIG) in 2006 this did not include information about children's services. Information gathered for NHS Quality Improvement Scotland on patient education is too generic to give an indication of structured education provision for people with type 1 diabetes.

### **Methods**

Health care professionals providing care for children and adults with type 1 diabetes, were contacted through the Scottish Managed Clinical Networks (MCNs) and informal meetings arranged. The aim of these meetings was to find out what forms of structured education were being provided. At the meetings, a structured enquiry was made, using the headings: structured education activities – one to one or groups; if groups number of participants; duration and number of sessions; curriculum and guiding philosophy; educator training; evaluation; audit and funding. A written record of the meetings was taken and sent electronically to all team members inviting any amendments or additions to give a true representation of the local structured education provision. Requests for additional supporting materials e.g. audit information, programme content, supporting resources etc. were made at this time.

### **Results/Findings**

MCN's representing all 14 health boards were contacted and meetings arranged in centres in all but two health boards, Orkney and Shetland. Comprehensive information was gathered for eight of the 12 health boards visited. Of the other three health boards, information has been gathered from some but not all of the centres delivering care to people with type 1 diabetes. Meetings were predominantly with DSN's and dietitians. Twelve doctors, 41 DSN's and 24 dietitians contributed to meetings arranged. Twelve paediatric nurses, eight paediatric dietitians and 15 dietitians working with adults attended professional meetings where the survey was discussed.

### **Adults**

In the health boards offering education programmes for type 1 diabetes, access to programmes is limited partly by resources, and hence not equitable. Some centres caring for adults with type 1 diabetes offer no structured education programmes while others offer a variety of education programmes.

Five centres offer the DAFNE programme to adults attending their clinics. One centre offers the BERTIE programme to adults attending their clinics. Of the other centres offering education programmes all have developed their own programmes based on either the Bournemouth model, BERTIE, or the DAFNE programme. A number of centres have visited the Royal Infirmary of Edinburgh to observe their education programme (**Royal Infirmary of Edinburgh Carbohydrate Learning And Insulin Management**) before developing a local programme.

There is wide variation in the length of courses offered. Of the locally developed education programmes none currently meets all five key criteria to fulfil the NICE requirements of: a patient centred philosophy; a structured curriculum; trained educators; quality assurance and audit. These programmes cannot, therefore, be referred to as structured education programmes. Two locally developed programmes based on the Bournemouth model are very close to achieving the NICE criteria but limited time and resource has been identified as the reason for not doing so.

Brief descriptions of the DAFNE and BERTIE programmes are given below along with a summary of group education programmes for adults in Scotland.

**Table 18 Summary of education programmes for adults with type 1 diabetes in Scotland (2008)**

| <b>Name</b>   | <b>Centre(s)</b>  | <b>Number of participants</b>    | <b>Number of sessions</b>                                | <b>Duration of sessions</b> | <b>Written curriculum</b>   | <b>Guiding philosophy</b> | <b>Audit</b> | <b>Evaluation /quality assurance</b> |
|---|---|----------------------------------|--|-----------------------------|---|---------------------------|--------------|--------------------------------------|
| <b>DAFNE</b><br>Dose Adjustment For Normal Eating                                     | Aberdeen Royal Infirmary<br><br>Monklands Hospital<br><br>Dumfries and Galloway<br><br>St. Johns Hospital Livingston<br><br>The Victoria Hospital Glasgow | 8 per course                     | 5 consecutive days                                       |                             | yes   | yes                       | yes          | yes                                  |
| <b>BERTIE</b><br>Bournemouth's Education Resources for Training in Insulin and Eating | Highlands Health Board - Caithness  |                                  | 4 x 1 day sessions over 4 weeks                          |                             | yes   | yes                       | yes          | yes                                  |
| <b>RECLAIM</b>  | Royal Infirmary Edinburgh and Borders General hospital  | 8 plus partner/friend (optional) | 1 full day   | From 9.15 – 4.30pm          | Not comprehensive – outline of aims and objectives only                         | Not documented            | No           | Not comprehensive                    |
| <b>RECLAIM</b>  | St. Johns Hospital Livingston   | 4-5                              | 2 half day afternoon sessions with 'homework' in between | From 1.30 – 4.30            | Not comprehensive and under review, plans to bring programme in line with DAFNE | yes                       | ?            | Not comprehensive                    |

| Name   | Centre(s)                                    | Number of participants  | Number of sessions   | Duration of sessions                 | Written curriculum | Guiding philosophy | Audit                                     | Evaluation /quality assurance          |
|--|--|---|--|--------------------------------------|--------------------|--------------------|---|--|
| <b>DICE</b><br>Diabetes, insulin and carbohydrate education.                                       | Gartnaval Hospital<br>Glasgow                | Up to 8 per session.<br><br>(2 sessions per month.)<br><br>Separate specific group for young adults i.e. age 16 to 25 | 2 full day sessions, Friday and Monday plus 'home work' over the weekend | From 9.15 – 3.30pm                   | yes                | yes                | yes                                       | Yes, but no external process in place. |
| <b>TIM</b><br>Tayside Insulin Management programme – based on the BERTIE programme                 | Ninewells hospital and Perth Royal Infirmary | 8-10 per session  | 4 x 1 day sessions over 4 weeks  | From 9.15 to 15.00 approx. 6 hours   | yes                | yes                | Yes information gathered but not collated | Yes but no external review process     |
| <b>NEW DEAL</b><br>New Diabetes Education on Adjustment for Living – based on the BERTIE programme | Forth Valley – Stirling and Falkirk          | 8 per session   | 4 x full day sessions over 4 weeks plus 'homework'                       | Form 9.15 – 3.00pm                   | yes                | yes                | yes                                       | Not comprehensive but work being done  |
| <b>BRUCIE</b><br>Better Regulation Using Carbohydrate and Insulin Education                        | Ayr Hospital                                 | 6 per session   | 1 full day session   | From 9.15 to 4.30pm lunch with staff | yes                | ?                  | yes                                       | Not comprehensive                      |

Note: since the survey was carried out there have been changes in the provision of structured education programmed in health boards, e.g. the roll out of DAFNE to new centres.

**DAFNE** (Dose Adjustment For Normal Eating) is the only programme that is evidence based and fulfils the NICE key criteria of a structured education programme. The programme is based on the Dusseldorf model and participants attend over five consecutive days.

**BERTIE** (Bournemouth Education Resources for Training in Insulin and Eating) has been running since 1999 and has many similarities to the DAFNE programme. It is based on the Dusseldorf programme, has the same aims and objectives as DAFNE and uses group adult learning principles<sup>76</sup>. It has not however undergone randomised controlled trial. Participants attend one day a week for four consecutive weeks. The Tayside (TIM) and the Forth Valley programmes, (NEW DEAL), are based on the BERTIE model.

### **New patient and ongoing education**

None of the centres offers structured education at diagnosis. Centres use either an education ‘checklist’ or ‘care plan’ when delivering education. There is variance in the number of sessions and duration of sessions for education of newly diagnosed patients. This is not documented but ‘...tailored to the needs of the individual’. However, none of the centres carry out a formal assessment of learning needs as part of the education process. Ongoing education is rarely planned and usually happens following medical review when problems are identified and referral is made to the DSN, dietitian or both. Those centres delivering DAFNE offer individuals to participate on the programme six months following diagnosis as part of ongoing education. It is recognised that DAFNE education is not appropriate for all people with type 1 diabetes. There is a lack of structured education as part of the continuing education needs of people with type 1 diabetes in Scotland.

### **Other Education activities**

Three centres offer carbohydrate identification and carbohydrate counting group education sessions run by the dietitian. These sessions are for all patients with type 1 diabetes. The sessions are 2 – 3 hours duration. In one centre, newly diagnosed patients attend the session as part of the education process. The group size ranges between six and 16 participants. Two of the centres offering these sessions also deliver DAFNE education and have identified a need for a ‘stand alone’ carbohydrate identification and counting ‘module’ to complement the other education activities.

Two centres offer group education for ‘young adults’. These sessions allow more time to be spent on lifestyle issues specific to this group e.g. alcohol, exercise, eating out, sex and drugs.

One centre offers group education sessions for those changing from twice-daily insulin to MDI regimens.

One centre offers a ‘refresher’ course for insulin treatment for people who need to update their skills but are unable to commit to a five day DAFNE course. The session is run by a DSN and dietitian and has up to eight participants including people with type 2 diabetes on insulin.

### **Children’s services**

#### ***Structured Education***

There are currently no evidence based structured education programmes for children and adolescents with type 1 diabetes. A randomised control trial of the ‘Kick-OFF’ programme for children aged 11 –16 is about to start in the UK<sup>77</sup>. A number of other programmes for children have been developed but most have not undergone randomised control trials e.g. X-Pert Junior, while others require further trials to provide evidence to support their use e.g. the Families, Adolescents, and Children’s Teamwork Study (FACTS)<sup>78</sup>.

In the absence of evidence based structured education programmes centres in Scotland provide education at diagnosis and opportunistically thereafter. In paediatric centres patient numbers are proportionally smaller than for adults and teams get to know children and families well. This familiarity allows teams to target education to those families with greater need. However, there is a recognition that teams operate under pressures of limited resources preventing a more systematic, equitable approach to education.

### ***New patient education***

At diagnosis, education of children and their families is on an individual basis. In the majority of centres education is carried out on the ward or outpatient facility with home visits by the DSN once discharged. One centre educates all children at home where possible.

Education is guided by a checklist or care plan (10 centres), Integrated Care Pathway (one centre) or record of teaching (one centre). The number of education sessions varies. DSNs may see a family for three to nine sessions, the doctor for at least one session and the dietitian for three to four sessions. The length of time spent per sessions is usually a minimum of one hour with some sessions lasting up to two hours. One comment made by a dietitian was *'there is a feeling that we expect children to learn too much in a short period of time and group work may be a way to overcome this'*.

Most centres have 'packages' of information given to children and families as a reference tool to support the education process. These are of varying quality and all centres report issues around the production, funding and updating of these 'packages'. The Lothian Patient Handbook is funded from endowment funds, the DibNet handbook by commercial company and the Glasgow Patient Held Record and Diet Book are funded by the local parent support group. Some centres have made this information available via their own or MCN websites.

When a child is newly diagnosed, DSNs will usually visit schools, nurseries or other carers to provide information and advice. Dietitians do not usually visit schools unless a child has more complex dietary needs for example coeliac disease or food allergy in addition to type 1 diabetes.

### ***Continuing Education***

Some centres use the annual review appointment to review education gaps and needs. One centre allocates longer appointment slots for the DSN and dietitian at the annual review clinic to accommodate education. However, it was recognised that the time allocated, 25 minutes, was usually inadequate. One centre targets those children with poor control, defined by HbA1c above an agreed level on two consecutive clinic visits, for education.

One centre has offered group education to those children diagnosed at a young age at around their 10<sup>th</sup> birthday. Children attend for a whole day education session during the school holidays with the aim to give them, rather than their parents, information about their diabetes. All members of the multidisciplinary team contribute and an evaluation of learning is carried out at the end of the day.

In many instances ongoing education occurs in response to poor control or crisis management and lacks planning and structure.

### **Education to support intensive insulin treatment (IIT)**

At least one centre in Scotland with very limited dietetic resources is unable to offer children and families education on carbohydrate counting, a key skill required for effective self-management. This is unacceptable. Some centres offer group education sessions for children and families to learn the principles of carbohydrate counting or carbohydrate counting and insulin adjustment for MDI. None of these programmes meet the NICE criteria for structured education. A summary of these sessions is given in the table below.

Where group education is not offered education for MDI and carbohydrate counting is provided on an individual basis. One centre noted that although they have an outline of the information covered when children first change to MDI there is no real structure to the process thereafter and they *'lose their way'*.

In most health boards, a factor influencing changing to MDI was the need for children to inject insulin at school. In Fife, the Diabetes in Education Awareness for the Longterm (DEAL) campaign has tackled the need for support with administering insulin and blood glucose monitoring in schools.

**Table 19 Summary of group education for children on MDI**

| Centre(s)                                | Number of participants                               | Number of sessions                      | Duration of sessions | Written curriculum | Guiding philosophy | Audit | Evaluation /quality assurance |
|--|--|---|----------------------|--------------------|--------------------|-------|-------------------------------|
| Royal Hospital for Sick Children Glasgow | 5  | 1 session                               | 2 hours              | Not comprehensive  | No                 | ?     | No                            |
| Lanarkshire-Hairmyers Hospital           | Up to 8  | 1 session                               | 2 hours              | Not comprehensive  | No                 | ?     | No                            |
| Royal Aberdeen Childrens Hospital        | 2 – 3 families Carbohydrate Counting only. Dietitian | 1 session follows 2 individual sessions |                      | ?                  | No                 | Yes   | No                            |
| Royal Alexandra Hospital Paisley         |  | 2 group sessions<br>1 individual review |                      | Not comprehensive  | No                 | Yes   | No                            |

### Education and Transition

While staff recognised this to be a crucial time in terms of service delivery, continuing education and support the majority believed it is done poorly in their health board. Of particular concern is the very limited support from psychology services. There is little published material on evidence based approaches to education for this age group. One approach that has been shown to have significant improvements in HbA1c and quality of life involves the use of motivational interviewing<sup>67</sup>.

Two of the centres delivering the DAFNE education programme offer the programme from age 17 to those who they judge to be mature enough and motivated to complete the course.

One centre had used the annual review appointment at their young persons clinic to review the education 'checklist' in an effort to achieve a more systematic approach to continuing education. This has been discontinued because of limited DSN time.

### Staff training

Almost all staff raised concerns about lack of support for training with regard to the impact on their workload with little or no provision made for backfill in their absence. Motivational interviewing skills, counselling and CBT were thought to be essential by a number of staff especially in light of poor support from psychology service. Some individuals have qualifications and training in education while others believe this to be a useful adjunct to clinical skills and knowledge. A number of staff have completed the Birmingham paediatric diabetes course and believe there is a need for an accredited paediatric course in Scotland.

### Summary

A recurring theme when visiting centres was the difficulty in releasing staff time for structured education. Centres that have developed and offer some form of 'structured' education have found difficulties in meeting the NICE criteria due to time constraints. Time for staff training and quality assurance of these programmes has not been regarded as a priority. There are also major concerns around both the level and quality of dietetic support available in many centres.

## **Appendix 5 Framework for a structured education curriculum for type 1 diabetes in children, adolescents and adults**

It is proposed that a national framework for the education of children, adolescents, their parent or carers and adults with type 1 diabetes is agreed. With an agreed framework specific education programmes and modules can then be recommended and, where necessary, developed within this framework along with supporting educational materials and resources. The framework itself will have a patient centred philosophy that will be reflected in the programmes and teaching modules it supports. All programmes and modules will comply with NICE guidelines and have a written curriculum, clear learning outcomes and be quality assured to facilitate consistency in advice.

In order to deliver and support the education process a multidisciplinary team of Consultant, DSN and Dietitian with appropriate training in education methods and facilitation of behavioural change in addition to a sound knowledge of type 1 diabetes will be necessary. The team should ideally be supported and include a psychologist. Peer support from others with diabetes will play an important role in the education process especially for the understanding and application components of the curriculum. The process of education should be delivered as routine care but planned and taken out of the context of a 'clinical consultation'.

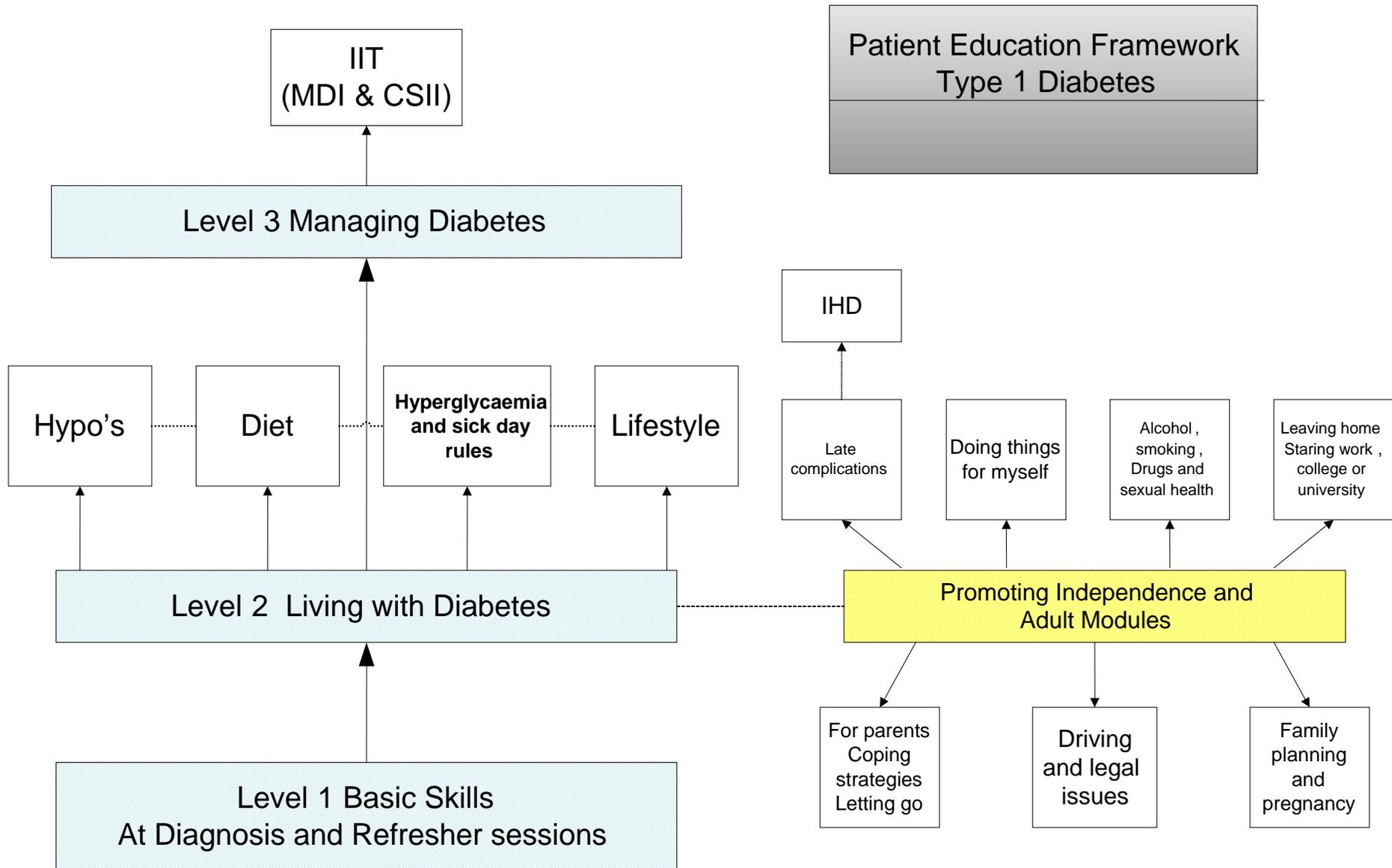
The survey of structured education provision in Scotland identified 'pockets' of good practice but a need to address the bigger picture. The education process straddles a broad range of individuals in terms of age and ability and is highly dynamic. The requisite of structured education must be built into every stage and aspect not just applied to certain pockets of education.

The outline framework represents the layers of building the education process with modules to be incorporated for different needs and points in time. It builds from basic skills to living with diabetes to managing diabetes. Central to these layers or levels is the recognition of the progressive nature of learning from a knowledge base to developing an understanding, which in turn leads to an application of knowledge and skills.

At the moment, much of the education delivered by health care professionals is building a knowledge base with little scope or attention to the understanding and application of that knowledge. The development of this model rests on a wholesale acceptance of the underpinning philosophy of patient/family centred learning where the HCPs role is not just about giving information but facilitating the learning process. This philosophy must become the foundation that supports practice and education in order to allow people with type 1 diabetes achieve effective self-management, improved quality of life and consequently improved diabetes control.

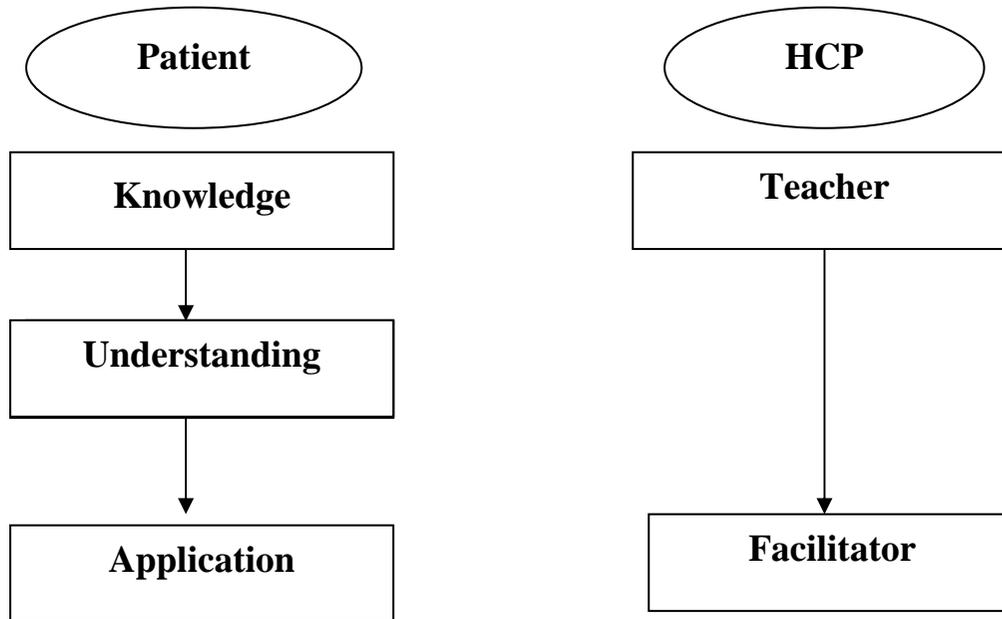
**The proposed framework**

Within the proposed national framework, there will be specific structures for education of children, their parents and/or carers, adolescents and adults. There may be some overlap of programmes and modules that may be applicable to all. The framework will include age specific goals.



### **Knowledge, understanding and application**

Each level of the curriculum i.e. Level 1 Basic Skills, Level 2 Living with diabetes and Level 3 Managing diabetes, contains three process stands that are also progressive. These are knowledge, understanding and application. The diagram below represents this process from the patient and health care professional perspective. To allow the patient to turn knowledge into an understanding that they can then apply the health care professional must move from the role of information giver to that of facilitator. Peer support from others with diabetes will play an important role in the education process especially for the understanding and application components of the curriculum.



The details of the curriculum content broken down into these strands are detailed on the following pages.

|  | <b>Knowledge</b>   | <b>Understanding</b>  | <b>Application</b>                      |
|--|--|---|---|
| <b>Level 1 Basic Skills<br/>(to be presented at<br/>time of diagnosis)</b> | What is diabetes   | Coping with the diagnosis and talking about it                  | Injecting and storing Insulin           |
|  | The role of Insulin in the body  | Discussion of what will influence personal blood glucose levels | Healthy eating, identifying food groups |
|  | What fuels the body - insulin and food   | Necessary lifestyle changes                                     | The measurement of blood glucose        |
|  | An introduction to hypo and hyperglycaemia   |   |   |
|  | Carrying ID and letting others know  |   |   |
|  | The diabetes Team  |   |   |
| <b>For those with<br/>established disease</b>                              | 'Refresher' modules to include all or a selection of the elements of the basic skills package for new patients | Discussion groups to share experience of living with diabetes   |   |
| <b>Level 2 Living with<br/>Diabetes</b>                                    | 1. Hypoglycaemia   | Discussion on what to do to prevent hypoglycaemia               |   |
|  | Causes, treatment and prevention   |   |   |
|  | 2. Hyperglycaemia  | Discussion on the sick day rules                                |   |
|  | Causes, treatment and prevention<br>Sick day rules   |   |   |

|                                    | <b>Knowledge</b>  | <b>Understanding</b>   | <b>Application</b>   |
|------------------------------------|---|--|--|
| <b>Level 3 – Managing Diabetes</b> | <p>3. Lifestyle – links to promoting independence and adult modules</p> <p>Leisure, travel and holidays<br/>Eating out<br/>Alcohol and its effect on blood glucose<br/>Exercise and activity<br/>Smoking<br/>Healthy eating<br/>Revision of carbohydrate identification and keeping things consistent.<br/>Glycaemic Index.<br/>Introduce a more accurate way of counting carbohydrate content of foods/meals<br/>Adjusting insulin based on blood glucose and carbohydrate intake.</p> | <p>Sharing experiences on lifestyle issues such as travel, eating out, effects of alcohol and exercise.</p> <p>Discussion of patient’s experience of adjusting insulin in relation to food.</p> <p>Discussion of how to work out carbohydrate content of meals and snacks.</p> | <p>Use blood glucose readings and food diary to discuss what to do to improve control.</p> <p>Keeping records of food, blood glucose and insulin dosage and activity and looking at patterns of blood glucose levels.<br/>Adjusting insulin dose from records – group discussion and problem solving.<br/>Measuring portions of foods e.g. rice, pasta cereals and calculating carbohydrate content.<br/>Working out carbohydrate content of foods from food labels.<br/>Estimating carbohydrate in recipes and complex meals.</p> |
|                                    |   |  |  |

## **Promoting Independence and Adult Modules**

For Children

1. Doing things for my self

For adolescents and young adults

1. Alcohol, smoking drugs and sexual health – link with school based programmes.
2. Leaving home/starting work/college/university – discussion with peers to help individuals identify challenges and needs.
3. Family planning and pregnancy – link with sexual health.
4. Late complications.
5. Driving and legal issues.

For adults

1. Family planning and pregnancy.
2. Driving and legal issues
3. Late complications link with smoking, lifestyle and IHD.

For parents/carers

1. Encouraging independence
2. Coping strategies and letting go.

These modules can be delivered in the same way as those of the core levels of the curriculum. It is important that they are delivered at the appropriate time and to an appropriate age group.

### **Structured education programmes to support the framework**

Curriculum, lesson plans and learning outcomes need to be developed for most of the elements of the proposed framework. This could be achieved by utilising and developing the teaching ‘checklists’ currently used by the majority of paediatric and adult centres.

The Dose Adjustment for Normal Eating programme will meet the needs of some adults at the advanced skills level 3.

A number of other similar programmes with written curriculum and clear learning outcomes offering education one day a week over a four week period will meet the needs of some adults at advanced level 3. Work can be done to build quality assurance into these programmes.

Shorter programmes can be modified and developed to offer some of the modules outlined in level 2 and level 3 of the framework for adults.

For children a number of centres have developed carbohydrate counting and dose adjustment modules/programmes. These can be further developed to link with level 3 of the proposed framework.

Some work has already been done for education programmes and CSII by the SLWG for pumps. This can be modified to address the needs of children. Age specific programmes have been successfully developed and utilised by the team at UCL and Leeds.

### **Supporting educational materials**

Some work to collate, review and select suitable educational materials to support elements of the proposed framework has been carried out by the research clinician for type 1 education in Scotland

under the guidance of the members of the SLWG. Some significant gaps in existing resources have been identified and include:

- Teaching and supporting materials for younger children, e.g. pictorial or animated resources. The manuals, handbooks and patient held records developed and produced by paediatric centres are comprehensive but are not specifically designed for children. Some contain specific learning points for children and good illustrations but are incorporated in a format that is not always 'child friendly'. The example of an animated DVD viewed at the recent SSGDY could be adapted for use in Scotland to fill this gap.
- Material to support elements of carbohydrate counting and insulin dose adjustment for intensification of insulin in children. Diabetes UK is currently evaluating a resource for adults but do not plan to extend this to include information for children. A multidisciplinary group has been established by the research clinician to work with the Scottish Nutrition and Diet Resource initiative (SNDRi) to produce a resource for children to meet this need.
- Level 1 – basic skills resources for different groups i.e. young children, older children, adolescents and adults. Lothian MCN has produced a resource for adults with T1D 'The essential guide at diagnosis'. This idea could be developed further to support level 1 of the framework for different groups.
- Resources to support the promoting independence modules for older children, adolescents and parents. The Diabetes UK website and 'Making Connections' booklet go some way to meet the needs of adolescents and older children. Several organisations have developed good quality web based information for this age group. Work could be done to develop links to this information from a central point such as the patient portal.
- There is no specific resource for parents and carers to help them through the process of transition from dependence to independence.

Programmes and resources to support education for CSII. The findings and recommendations from the Pump Report for CSII commissioned by the SDG is included as Appendix 7. A group of DSNs, dietitians, and clinicians from a number of centres are now enthusiastic to work collaboratively to draw up education programmes and share best practice. This work can be facilitated by the research clinician for education in T1D and DENS building on the work of the UK wide Diabetes Education Network<sup>27</sup>.

- Resources and programmes to support education for adults and children where English is not the first language including asylum seekers and the Romany community. Any work to address these gaps should be undertaken in conjunction with the work of the Diabetes Minority Ethnic Group (DMEG) subgroup of the SDG.
- The needs of those with poor literacy skills, those who are visually and hearing impaired and those with learning difficulties are poorly served. It is hoped that by adopting a patient/family centred approach to education this situation can be improved.
- Resources for sports and exercise which are more detailed and specific in their advice. Information currently available gives very general advice.

### **Implementation of the framework**

Some thought must be given to the development and implementation of this framework curriculum in the context of national and local structures for diabetes care delivery. The DCCT demonstrated that the key to improved control was effective self management facilitated and supported by education. There now needs to be a formal recognition, protection and development of the educational role of

staff delivering care to children and adults with type 1 diabetes alongside recognition of the specialist skills and knowledge that care to type 1 diabetes merits in the 21st century. The increasing prevalence of type 1 diabetes, especially in the under 5 age group, will place increasing demands on staff time to deliver education that meets the key criteria as outlined by NICE. Staffing levels must reflect these increasing demands.

Services have evolved around the provision of 'clinics' and 'activity' is measured as clinical consultations and provision of acute care not education and the support of self management. There needs to be a major culture shift in terms of educational skills and facilities to deliver on the understanding and application aspects of the education process if we are to support those with type 1 diabetes to achieve effective self-management.

The newly established Scottish Diabetes Education Network (DENS), the Diabetes Care Focus Group (DCFG), the SSGCDY and other professional groups e.g. Diabetes Management and Education Group of the British Dietetic Association (DMEG), paediatric DSN group and paediatric dietetic group will have an invaluable role in supporting the development and implementation of the Framework curriculum.

## **Appendix 6 Patient Centred Learning**

Patient Centred Learning is a process in which the patient controls the quantity of material learned at each session and the rate at which the learning process progresses. To be successful the teaching requires to be within a structured course in which progress can be made by the patient starting with a basic knowledge of the topic which can then be developed into an understanding of the subject at a level suitable for the patient and controlled by the patient. Using this knowledge and understanding the patient can move on to apply the information gained to the management of their condition. For this to be successful, the Health Care Professional must move from assuming a position of being the “font of all knowledge” to one of a facilitator who will guide the patient at their own pace through the information allowing the patient to gather and assimilate the knowledge and understanding to an appropriate level. This is carried out within a structured environment using short teaching sessions, tutorials and practical classes.

### **The Environment**

A structured learning environment is a resource hungry, three-dimensional educational matrix with multiple entry and exit points, allowing the patient to build a personal education course guided by the professional educator. The entry point to the course will depend on the patient’s previous experience and education. A patient entering a course at a knowledge level below their present standing may be deterred by the apparent lack of relevance of the subject to their personal needs and therefore leave the course before gaining anything from it. Equally, someone coming to the application level without the necessary knowledge and understanding of the subject will gain little as they will not be able to participate fully in the programme of work. In a patient centred course where the rate of progress is controlled by the patient rate of learning, this is much less of a problem.

A course starting at a basic knowledge level will allow the person with previous experience of the subject to use this as a refresher and progress more quickly to a more advanced level. A patient entering the course with no knowledge of the subject may take time to grasp the basics and only then advance to a deeper understanding of the subject. In a patient centred, structured course it must always be borne in mind that a progressive structure can only be developed on the foundation of accurate, well understood knowledge.

### **Ownership of the learned material**

The objective of a patient centred course is to enable the individual to have ownership of their own learning outcomes. Individuals are encouraged to build up their own notes from the resources available to them. By doing this, they will have an intimate knowledge of their learning process and can develop the material to a level with which they are comfortable. This means that the teaching must have less reliance on the didactic lecture and more on interactive learning with the HCP/educator taking the lead in the early stages. But it is not inconceivable that in the latter stages of the course the discussion may be lead by one or more of the patients basing the discussion on material they have used whilst building up their notes.

The knowledge base can be built up using a less formal teaching style. At the start of each teaching session the patient is given the aim for the lesson and a set of learning outcomes which will lead to their achieving that aim. With such a system, it is normally counterproductive to give full written notes at the start of the session. It is better to give an outline summary of the content, based on the learning outcomes and to include outline copies of figures and diagrams that the patient can annotate during the session. Students should not look upon the teaching session as a place to take dictation and write out a verbatim report of what the HPC/educator said but rather take notes throughout the session and then be given the time to look at these notes and add to them from resources such as internet, published work etc. This can be done as directed study or, where necessary, one to one tuition. Resources can be made available within the teaching environment and should form part of the class. In order to maintain the progress through the course a series of self-assessment exercises can be used at irregular but set intervals which will enable the patient to check if their level of knowledge has risen to an acceptable level.

As the patient increases their knowledge of diabetes and its management, it is important to use this base to develop an understanding of the relevance of the facts to their diabetes management. This can be achieved in many ways and will depend upon the skills of the educator. Structured discussion based on a series of linked questions or looking at examples and discussion of how the outcomes were reached are among many methods that can be used. These sessions should be structured in a way in which the understanding of the subject is built up and the patient becomes more confident in handling the concepts of diabetes management.

Once their understanding is growing these sessions should be linked with a practical application of their freshly developed knowledge. A session on the function of insulin in the body can be followed up by a session on the natural variation of blood glucose levels. After a time of directed study to assimilate this, a series of questions on what may disrupt this natural regime and hence lead to the development of diabetes will help to consolidate the knowledge and develop an understanding of the relationship between insulin and diabetes control. The knowledge base can then be enhanced with a class on the artificial control of blood glucose and then on to administration of insulin. If all of the patients are on insulin then a session to discuss how this has manifested its self in their experience can lead to a session on insulin management.

A patient who is newly diagnosed may be given a basic training in diabetes such as: a simple explanation of diabetes and the role of insulin in the body; a talk on the link between blood glucose and food. These knowledge based sessions can be followed up by a discussion on how the patients blood glucose will vary when they eat certain food groups and the steps which may be taken to control their glucose levels. Once they understand their need to control their blood glucose, a practical session can be held on the storage and injection of insulin and the measurement of blood glucose. Once the patient has been given time to assimilate this knowledge and to apply the skills they have been given, further sessions will be held on how insulin doses are assessed. At this stage the patient may be enabled to look at their own or fellow students' blood glucose results and assess whether they need to make changes to their insulin dosage. This would again start with the presentation of the knowledge of insulin adjustment and lead through to their adjustment of their own insulin based on test results. At the same time as this, familiarisation of insulin management is being carried out by the diabetes specialist a parallel.

After the patient gains experience and confidence in basic management of their own condition, they may then be encouraged to build on this basic skill by learning the art of intensive insulin management. At this stage the course should have progressed from one based predominantly on the presentation of knowledge to a series of structured workshops in which a group of patients work together to build up their knowledge and confidence in the calculation of insulin dosage based on blood glucose measurement and carbohydrate counting.

# INSULIN PUMP THERAPY

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## Insulin Pump Working Group Members

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## Background

Diabetes mellitus is a condition in which the amount of glucose (sugar in the blood) is too high because the body cannot use it properly. It results from a lack of hormone insulin or resistance to its actions. Insulin is vital for life. It is a hormone produced by the pancreas that helps the glucose to enter the cells where it is used as fuel by the body. If not controlled effectively, diabetes can lead to complications including kidney failure, blindness, limb amputation, coronary heart disease, stroke and damage to the nervous system.

There are two main types of diabetes. These are Type 1 diabetes, and Type 2 diabetes. Type 1 diabetes develops when the body is unable to produce any insulin. This type usually appears before the age of forty and the administration of insulin is necessary for survival. Type 2 diabetes results from a reduced insulin production and reduced tissue sensitive to insulin. Blood glucose levels may be managed with diet and lifestyle modifications alone. The condition progresses. The addition of oral glucose lowering drugs and over time, Insulin to control blood glucose levels adequately.

Continuous Sub-cutaneous Insulin Infusion, (CSII or pump therapy) has quite significant improvement in glycaemic control, hypoglycaemia and quality of life for some people with Type 1 diabetes. It is a method of administering insulin over 24 hours by a small needle inserted under the skin. A small amount of insulin is delivered all the time and the individual must give a booster amount (bolus) to match food or reduced rate of blood glucose levels. The safe and effectiveness use requires the individual to monitor their blood glucose on a regular basis. Patient education and regular support from a competent diabetes team is critical for all those using insulin to manage their diabetes and is essential for pump users.

The current guidance is outlined in Health Technology Appraisal Guidance – number 151, guidance on the use of continuous sub-cutaneous insulin infusions (CSI for diabetes) issued by NICE in July 2008.

Continuous subcutaneous insulin infusion or 'insulin pump' therapy is recommended as a possible treatment for adults and children 12 years and over with type 1 diabetes mellitus if:

- attempts to reach target haemoglobin A1c (59mmol/mol/7.5%) with multiple daily injections result in the person having 'disabling hypoglycaemia', or
- HbA1c levels have remained high (69mmol/mol/8.5% or above) with multiple daily injections (including using long-acting insulin analogues if appropriate) despite the person and/or their carer carefully trying to manage their diabetes.

CSII therapy is recommended as a treatment option for children younger than 12 years with type 1 diabetes mellitus provided that:

- •MDI therapy is considered to be impractical or inappropriate, and
- •children on insulin pumps would be expected to undergo a trial of MDI therapy between the ages of 12 and 18 years

The guidance also mentions the importance of patient education and staff training and the benefits for certain sub-groups of patients. These recommendations have been considered by the Chief Medical Officer and by the Head of Health Planning and Quality divisions and it is agreed that all NICE guidance must be implemented in Scotland and that Health Boards should take steps to ensure that this guidance is implemented.

The Scottish Diabetes Framework also states that local insulin strategies which include the use of insulin pumps should be in place by March 2007

## Context and Prevalence

There is an increasing number of people with Type 1 diabetes treated by CSII. Several countries are now treating about 15 – 20% of people with Type 1 diabetes by CSII (USA, Israel and Germany) and most of the UK's European neighbours, a substantial proportion, around 10% of people with Type 1 diabetes, use pumps.

In contrast, usage in the UK is less than 1% of the population and in Scotland there is an estimated 440 patients on pumps. Thus, the present uptake in Scotland and the rest of the UK is dramatically lower than in most other countries with a comparable economic standing and level of health care provision. It is accepted that there seems to be a plateau at around 25% in high use countries.

## Aims of report

The Scottish diabetes framework includes the objective that Managed Clinical Networks (MCNs) should develop an insulin strategy which includes pump therapy. In addition, it is the responsibility of all Scottish Health Boards to implement NICE guidance on pump therapy.

As such, this report should assist Managed Clinical Networks in their productions of business cases for establishing our extending pump services and also to inform discussion with the Board about the implementation of national guidance (NICE / SIGN). It should also assist Health Care professionals developing a pump service and also be of use to people with Type 1 diabetes who wish to know both the eligibility criteria and how to access pump therapy.

## Planning pump services

This section outlines key considerations for planning any service. It identifies the number of factors which should be considered when planning a service, including the role of the MCN.

- User Involvement
- Service Planning
- Business case
- Audit

## *Patient Involvement/User Involvement*

User Involvement via the MCNs, is now well established. Users should be actively involved from the start in designing a patient centred service that matches the specific needs of the local population. The planning of the pump service for a specific locality needs to form part of a comprehensive insulin strategy for patients with Type 1 diabetes as described in the Diabetes Framework. It is recognised that the needs of children and young people will need to be considered separately to that of adults. It is critical that pump therapy is available to all ages. How people with Type 1 diabetes access pump services will vary according to locality. It will depend on a number of factors including the number of individuals with Type 1 diabetes, the geography of the area, and the potentials for developing local expertise. The care pathway will need to describe how the service is accessed and managed. Models will vary depending on local needs but will need to reflect national guidance on insulin pump therapy, Type 1 diabetes, and patient education models and should include

- Where people with Type 1 diabetes will routinely be managed and how this links with specialists in insulin management.
- Arrangements for Transfer of Patient Care between Services, including Transition from Paediatrics to Adult Services.
- Arrangements for funding individuals who move between health boards
- Logistical arrangements for the pump service e.g. local or on a hub and spoke basis.
- Administration of supplies.
- Ongoing Patient support including follow up arrangements and audit of patient satisfaction

It is essential that pump therapy fits into an insulin strategy and is delivered by a cohesive team with adequate nursing and dietetic support along with adequate education programmes. The service must do more than simply provide the technical hardware. The driving principal must remain the provision of a pump service as locally as possible whilst maintaining appropriate levels of expertise. There are a number of potential models and these include:

- Not providing a local pump service - clear referral arrangements agreed with a separate centre.
- Developing a local pump service with strong links to an established service.
- Established (beacon) pump services, developing and maintaining expertise and providing support to services with smaller numbers of patients.

In an effort to encourage the development of insulin pump with expertise locally, there should be no minimum number of patients required for this service. Services with small numbers should however have strong links to bigger services. This would also be the case in paediatric services, although there may be substantial benefits sharing expertise locally with paediatric and adult services.

## ***Business Case***

It is the responsibility of all local Boards to provide a comprehensive pump service. The MCN should produce a business case that meets the national insulin pump guidance, and also guidance on patient education models, taking into account both the staffing requirement and also the relevant figures from the Scottish Diabetes Survey.

## ***Audit***

The use of pump therapy will require ongoing review. Local audit should be carried out to support service improvement and feed into and be guided by the national pump audit guidelines

## **Providing a pump service**

This section outlines perceived best practice and draws upon the NICE guidance and the report produced by the insulin pumps working group in England.

## ***Who should be considered for pump therapy?***

NICE guidance suggests that CSII should be considered in adults and children 12 years and over with type 1 diabetes mellitus if:

- attempts to reach target haemoglobin A1c (7.5%) with multiple daily injections result in the person having 'disabling hypoglycaemia', or
- HbA1c levels have remained high (8.5% or above) with multiple daily injections (including using long-acting insulin analogues if appropriate) despite the person and/or their carer carefully trying to manage their diabetes.

CSII therapy is recommended as a treatment option for children younger than 12 years with type 1 diabetes mellitus provided that:

- MDI therapy is considered to be impractical or inappropriate, and
- children on insulin pumps would be expected to undergo a trial of MDI therapy between the ages of 12 and 18 years

Pump therapy needs to be considered as part of the overall insulin strategy for each Board and MCN. As part of this strategy, each individual patient requires the support to manage their insulin depending on the context of their lifestyle. All individuals should have an opportunity to take part in structured education. This education should meet the national guidelines examples of which include DAFNE, BERTIE, TIM and New DEAL.

In general the CSII should be considered for all those patients who have been unable to achieve their agreed goals. Due to the diversity of presentation, respect for age and the complexity of management of diabetes in children, CSII should be considered for all children and may have to be initiated early in the management of the child's diabetes. If there is no service, this could be developed via an established children's CSII service, or the local adult service.

## ***Who should deliver pump therapy?***

CSII therapy should be initiated by a trained specialist team which will normally comprise of a physician, a DSN and a dietitian. It is however critical that more than one specialist nurse is trained and that the whole department has the competencies to support CSII. The team should have knowledge of the use of pumps from more than one of the manufacturers. The pump team would be responsible for:

1. Confirmation that previous management had adhered to best practice
2. Assessment of suitability – CSII
3. Initiation of CSII
4. Education and support for CSII, follow up, support and training for other health care professionals within the diabetes team.

## **Pump Pathway**

### ***Referral***

Prior to referral, as part of the networks insulin strategy, all patients should be offered a structured education programme designed to develop optimal use of basal bolus insulin therapy including

carbohydrate counting, exercise and alcohol advice along with the sick day rules. The program should meet the criterion described by NICE and Diabetes UK with a written curriculum, trained educators, and have a quality assurance and audit program.

If the local structured education programme is not possible, then the assessing team should ensure there are no educational deficits in the use of basal bolus therapy and carbohydrate counting. Where deficits are identified, there should be a mechanism for dealing with these. Pump therapy should be considered for all people with Type 1 diabetes who may benefit and meet the criteria.

## **Assessment**

The adult criteria for initiation of CSII are that the patient should be

- (1) Motivated
- (2) Succeed to a realistic expectation
- (3) Be willing to monitor blood glucose at least four times a day
- (4) Be willing to work with the multi-disciplinary team
- (5) Demonstrate self-management skills
- (6) Have tried a basal bolus regimen with long-acting analogues e.g. glargine.

The patient should also fill at least one of the following criteria –

- (1) Repeated episodes of hypoglycaemia
- (2) Unawareness of hypoglycaemia
- (3) High HbA1c with hypoglycaemia despite high levels of self management

Adults should be competent in dose adjustment and carbohydrate counting for meals, physical activity and other lifestyle issues. They should also be able to self-manage hypo and hyperglycaemia ketone testing and understand that they should revert to sub-cutaneous insulin injections when appropriate.

Child and adolescents would be expected to monitor to the best of their ability and support should also be provided for parents.

The goals of pump therapy for each individual should be clearly defined and documented. There should be a comprehensive care plan and this should be evaluated at regular intervals. Cessation of therapy should only be considered if the goals within the plan are not met and full assessment of the reasons for failure have been carried out. The objectives of CSII therapy include:

- (1) Improved glycaemic control (a lower mean glucose level or less variation in blood glucose and fewer hypoglycaemic episodes)
- (2) A greater degree of flexibility and lifestyle
- (3) Patients able to take greater control over their condition
- (4) Lower patient anxiety about hypoglycaemia

Goals may be agreed between the patient and the clinician and these should also be documented.

## **Education**

All individuals beginning CSII therapy should be provided with a specific structured education programme. Ongoing support should be available from the specialist team, particularly in the period immediately following initiation. A patient education programme should be delivered by a specialist

team and demonstrate user competency in key areas. A record should be kept of this and of the user competencies and the programme should undergo peer reviewed quality assurance.

The curriculum must incorporate specific insulin pump issues including:

- (1) The mechanics for the insulin pump
- (2) Insulin stacking and unexplained hypoglycaemia
- (3) Unexplained hyperglycaemia
- (4) Different bolus options depending upon the meal and glycaemic index
- (5) Basal rate infusions
- (6) Impact of insulin resistance e.g. menstrual cycle
- (7) Contact with other users
- (8) Educational refreshment should be offered on an annual basis

Currently individualised training programmes are standard but group education could be used if appropriate.

## ***Workforce planning***

The provision of pump services will vary depending on the geographical layout of the Managed Clinical Network. Delivery of care will often be provided by a network serving a number of local diabetes services, and this might involve patients being initiated in an insulin pump service and transferred back to their local diabetes service for follow up care. As more local services are developed, they will require to share knowledge with more specialist services while building up their expertise. Members of an insulin pump team require a number of additional competencies.

## ***Workforce Competencies***

CSII therapy should be initiated by a trained specialist team, normally comprising:

- Physician
- Diabetes Specialist Nurse
- Dietitian

It is important that this team has all the competencies required to provide the service and that all the competencies are available from more than one member of the team.

- Centres should provide an appropriate Structured Education Programme on intensive insulin management to all individuals under consideration for pump therapy.
- All members of the team have undertaken a recognised training course on the delivery of pump therapy and attend annual update courses.
- Currently, the recognised courses are based in England. We would recommend the development of a Scottish course.
- Teams developing a new CSII service should seek to establish links with an established centre.
- Established centres should be developing and maintaining their own expertise whilst providing support to teams with a developing service.

All members of the team should:

- Have a critical understanding of CSII pumps and their operation.

- Have an in-depth knowledge of the current theories for calculating insulin to carbohydrate ratios, insulin sensitivity and basal insulin doses.
- Be able to assess the suitability of pump therapy for an individual.
- Be able to provide education and on-going support to an individual to enable them to deliver insulin by pump.

## ***Pump supplies***

There are a number of pump suppliers on the market. Services should be able to offer a range of options, providing this is not compromising patient safety. Staff and patients should agree on a local menu. Pump suppliers should provide a comprehensive education package for all staff involved in CSII. The suppliers will also be required to provide a 24 hour help line for technical issues. The pumps to be supplied by the Health Board and remain the property of the Health Board and an up to date list of users should be maintained. If a patient ceases to use the pump it should be returned and assigned to a new patient. If the patient move within the country the pump should transfer with the patient and the pump centre taking over the care should continue to support the user and provide consumables.

## ***Supporting Patients***

Support for a pump user should be an extension of the current service provided. There should be an agreed care plan, structured education and an arrangement for out of hours care. The pump centre should provide a 24 hour help line for technical support. This would be expected to be provided by the pump supplier. Specific out of hours support during pump initiation should be provided for the local service for an agreed period. A general out of hours help line could be provided but this may well require negotiation between Health Boards, given the geography, and population demographics in Scotland. These help lines should be in addition to the current service offered by industry. Additional support can be provided by peers and expert patient advice should be available if requested.

## ***Follow up***

Patients on pumps should have a minimum of two follow up clinic appointments per year. These reviews could be split between the pump centre and the local service depending on the geography. As part of the annual review, educational updates and refreshers should be provided as required. Once initiated on the pump, the patient should be able to continue as long as they are happy and the diabetes care objectives accepted in their care plans are being met. Criteria should be agreed with the patient, whereby, if the patient is not benefiting from CSII therapy, this can be ceased and this should form a fundamental part of their care plan and reviewed at each follow up appointment.

## ***Research on CSII***

Should ideally be co-ordinated through the Diabetes Research Network and all pump users should be offered an opportunity to join this.

## **Appendix 8 Diabetes Education Network Scotland**

The SLWG has proposed that the informal Scottish DEN should be recognised and integrated with the SDG, as well as with the UK DEN. This appendix sets out the aims. The development of the SDEN has been facilitated by the research clinician for the SSGCDY education project, and by the Diabetes UK Service Improvement Advisor. Both of these individuals are on time-limited secondments.

The Diabetes Education Network Scotland (DENS) is a Regional Network of the UK-wide Diabetes Education Network, previously the Type 1 Education Network. The aims and objectives of the DENS are outlined below along with the philosophy of the UK-wide network that DENS will adopt.

### **Philosophy**

Diabetes is a complex condition, which is affected by, and can affect almost all daily activity. Most day-to-day decisions (eg food choices, activity levels, the taking of medication or insulin), which affect blood glucose levels, are made by the person with diabetes. As such, people with diabetes who are able are responsible for managing their condition.

People with diabetes require knowledge and skills to enable them to understand the effects of lifestyle on their diabetes and vice versa, and how they can adjust their treatment to enable them to lead the lifestyle of their choice while maintaining stable blood glucose control. They also need information on the consequences of poor control of their diabetes so they can make informed choices in setting appropriate personal goals for the management of their diabetes

The role of the health care professional is to provide support to people with diabetes to enable them to develop realistic short term and long-term management goals, and to help them acquire the knowledge and skills necessary to achieve those goals.

### **The person with diabetes has the right to expect the following from their health care professional:**

1. The development of an open, honest and non-hierarchical relationship with the person with diabetes.
2. An approach which treats the person as an individual, which is respectful of their health beliefs, and which is supportive, consistent, and non-judgemental.
3. An opportunity to identify and review the person's needs, concerns and goals
4. The provision of up to date, accurate and consistent information about diabetes, treatment options and local services (e.g. education programmes) available, in order to address their needs and concerns and help meet their goals.

### **The health care professional will achieve this by:**

1. Engaging with the person with diabetes and gaining their trust
2. Identifying and exploring their current health beliefs and factors which motivate current self-care behaviours
3. Helping the person with diabetes explore and understand the risks and benefits of their current situation/management choice and of any alternative options.
4. Providing appropriate information to support decision making
5. Providing (or providing access to) knowledge and skills needed to achieve self-care behaviour appropriate to that decision.

### **Structured education programmes:**

are an appropriate means by which people with diabetes can learn the knowledge and skills necessary to support appropriate self-care behaviours. Such programmes should:

1. Be explicit in their aims and objectives
2. Be consistent with the principles outlined above
3. Employ appropriate learning theories
4. Fulfil or be working towards fulfilling the criteria set by the NICE and Diabetes UK.

## **Aim**

### **Support diabetes teams in integrating structured education for children and adults with diabetes into their service by**

- Providing a structure for sharing educational strategies, ideas and approaches.
- Supporting the work of the Scottish Diabetes Group (SDG) and its sub-groups to further develop its framework for patient education to meet NICE criteria i.e. curriculum development, educator training, quality assurance and audit.
- Organising meetings and events in Scotland with a focus on local issues and structures while utilising the experience and support of the established UK wide network.

### **To achieve these aims the steering group will**

- Establish a communication process and build a database of interested health care professionals.
- Establish links with the SDG and its sub –groups to foster collaborative working. The groups include: the Diabetes Education Advisory Group (DEAG); the Diabetes Care Focus Group (DCFG); the Short Life Working Group for Type 1 Diabetes; Scottish Diabetes Industry Group (SDIG); Managed clinical Networks (MCNs).
- Facilitate curriculum development, audit and external evaluation of structured education programmes.
- Identify funding for meetings and administrative support.
- Engage with service users and service user representatives.
- Produce reports annually.

### **Diabetes Education Network Scotland Interim Steering Group**

|                   |  |
|-------------------|--|
| Razia Amin        | DSN & DAFNE trained educator, Grampian                           |
| Tony Doherty      | Service Improvement Advisor Diabetes UK                          |
| Katie Duncan      | Dietetic Manager Fife Health Board                               |
| Theresa Ferrie    | Research Clinician, Education and Type 1 Diabetes                |
| Kathryn Fraser    | Dietitian, Forth Valley Health Board                             |
| Hannah Hodge      | Paediatrician Diabetes in children and young people, Lanarkshire |
| May Lavelle       | DSN & DESMOND educator, Glasgow                                  |
| Chris Kelly       | Consultant Physician, Forth Valley Health Board                  |
| Kingsley Matthews | Service User   |
| Mary Robertson    | DSN Tayside Health Board   |
| Iain Spence       | Service User   |
| Shazia Akhter     | Service Use  |

Further information about the UK wide Diabetes Education Network and regional networks including DENS can be found on the DEN website: [www.diabetes-education.net](http://www.diabetes-education.net)