

# **The Association of British Clinical Diabetologists (ABCD)**

## **Standards of care for management of adults with type 1 diabetes**

### **Foreword**

This position statement is the first ABCD has produced on the subject of type 1 diabetes since 2012, when it ran its 'Lost Tribe' campaign. This arose from concerns that people with type 1 diabetes had inadvertently been let down by wholesale system change *repatriating* people from secondary care diabetes clinics to primary care. While the preparation for this included up-skilling primary care teams to manage people with type 2 diabetes and to recognise those requiring specialist input, many people with type 1 diabetes were repatriated to teams that lacked a specialist understanding of their needs, and have been denied access to specialist care because they are meeting their targets. There is a growing concern that the public, politicians and some health care professionals appear not to know the difference between type 1 diabetes and type 2 diabetes.

Data from consecutive National Diabetes Audits show that mortality and morbidity related to diabetes is disproportionately high for type 1 diabetes, and that young adults, especially young women, are at highest risk. Improvements in achievement of care processes and targets in England have followed the introduction of a best practice tariff for children and adolescents with diabetes. In Scotland the publication of benchmarked data for type 1 diabetes appears to have been associated with an improvement in glycaemic control.

ABCD believes that while care for those with type 1 diabetes may take place in different settings, that care should be of a universally high standard, and should explicitly involve access to consultant-led specialist teams, experienced in the management of type 1 diabetes.

I am grateful to Patrick Sharp and Anne Kilvert and their co-authors for this ABCD position statement. It outlines the basics of care that should be delivered to people with type 1 diabetes, irrespective of where that care is delivered. The document is designed to complement national guidance, in particular the NICE 2015 guideline *Type 1 diabetes in adults: diagnosis and management* [nice.org.uk/guidance/ng17](http://nice.org.uk/guidance/ng17) . It will serve as a welcome reference for specialist providers and for those commissioning services for type 1 diabetes.

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## **Contents**

### **Introduction**

#### **1. Diagnosis of type 1 diabetes**

- 1.1 Criteria for diagnosis of diabetes
- 1.2 Differentiating between type 1 and type 2 diabetes
- 1.3 Immediate treatment
- 1.4 Autoimmune conditions associated with type 1 diabetes

#### **2. Initial management**

- 2.1 Education
- 2.2 Nutritional advice
- 2.3 Physical activity and exercise

#### **3. Follow up consultations and ongoing support**

- 3.1 Consultation process
- 3.2 Annual review
- 3.3 Psychological support

#### **4. Treatment, targets and monitoring**

- 4.1 Treatment
- 4.2 Targets
- 4.3 Monitoring
- 4.4 Unexplained or unpredictable blood glucose results

#### **5. Long term complications: screening and management**

- 5.1 Screening and treatment for microvascular complications
  - 5.1.1 Retinopathy
  - 5.1.2 Nephropathy
  - 5.1.3 Neuropathy
- 5.2 Screening and risk factor modification for macrovascular disease

## **6. Acute complications**

6.1 Hypoglycaemia

6.2 Diabetic ketoacidosis

## **7. Special circumstances**

7.1 Children and young adults

7.2 Older people and care homes

7.3 Pregnancy

7.3.1 Preconception care

7.3.2 Antenatal care

7.3.3 Intrapartum care

7.3.4 Postnatal care

7.4 Inpatient care

7.5 Driving

## **8. Gold standard recommendations for care of people with type 1 diabetes for diabetes**

### **Appendix 1. Clarke and Gold scores**

### **Appendix 2. referral for islet transplant**

## Introduction

Over the last two decades, changes in the organisation of care for people with diabetes have resulted in a shift of provision of services from secondary to primary care. Specialist diabetes services are now focusing on more complex circumstances (eg acute foot disease, pregnancy, children and young people, insulin pumps, advanced kidney disease, inpatients and other complex conditions.) There appears to be an assumption that ‘uncomplicated’ type 1 diabetes does not require specialist care, but failure to provide the support people with type 1 diabetes need to manage their condition increases the chance that they will join one of the groups requiring specialist care for ‘complicated’ diabetes in the future. ABCD is concerned by reports that in some areas people with type 1 diabetes are being advised by clinical teams which do not have the relevant skills to address their needs and concerns; they cannot access the specialist advice they need because their HbA<sub>1c</sub> is in the ‘target’ range (ignoring the impact of unrecognised hypoglycaemia) and they do not have complications.

ABCD takes the following position:

- Individuals with type 1 diabetes must have access to specialist type 1 diabetes care, whether this is delivered in secondary care or in the community.
- Community diabetes teams with specialist expertise in type 1 diabetes may manage those with type 1 diabetes on a routine basis, but this care should be consultant led.
- All people with type 1 diabetes should have access to :
  - a comprehensive education programme designed specifically for those with type 1 diabetes
  - a carbohydrate counting educational programme
  - expertise to provide and advise on the use of bolus advisors
  - an insulin pump service
  - continuous glucose monitoring for those who would benefit (see below)
  - psychological support

Individuals with type 1 diabetes may encounter a variety of healthcare professionals in a range of clinical settings; this document sets out the standards for the management of people with type 1 diabetes regardless of where and by whom the care is delivered.

## 1. Diagnosis and initial management

### 1.1 Criteria for diagnosis of diabetes

- **Symptoms of hyperglycaemia present**
  - Diagnosis is confirmed by a single random blood glucose 11.1mmol/L or above
- **Asymptomatic\***
  - Diagnosis requires two separate blood glucose results in the diabetes range
    - fasting blood glucose 7.0mmol/L or above on 2 occasions
    - and/or 2 hour blood glucose 11.1mmol/L or above 2 hours after a 75g oral glucose tolerance test

\*People with type 1 diabetes usually present with symptoms and it is uncommon for this condition to be diagnosed by routine screening

**HbA<sub>1c</sub> should not be used as a diagnostic test for type 1 diabetes as the rapid onset of the condition makes the HbA<sub>1c</sub> unreliable**

### 1.2 Differentiating between type 1 and type 2 diabetes

In the majority of cases, the clinical features will give a clear indication of whether an individual has type 1 or type 2 diabetes. However, there are a significant number of cases where there is clinical doubt. Factors contributing to this include the increasing prevalence of obesity in the younger age groups, increasing ethnic diversity and the ready availability of testing modalities which shed doubt on the presumed clinical classification.

Where there is doubt about the type of diabetes, it may be useful to measure pancreatic autoantibodies and serum or urine C-peptide, but this should not be done routinely.

#### **Clinical and biochemical clues to differentiate type 1 from type 2 diabetes**

- Rapid onset of osmotic symptoms
- Normal or low body weight or rapid weight loss
- Ketonaemia  $\geq 3$ mmol/l on capillary testing or ketonuria
- Family or personal history of other autoimmune conditions
- Failure to respond to oral therapy
- Positive antibody test (anti-GAD), islet cell antibodies (ICA), insulinoma associated antibodies (IA-2) or zinc transporter (ZnT8) most commonly used

- Insulin deficiency suggested by low serum C-peptide or urine C-peptide:creatinine ratio

The presence of one or more of these clues may point to a diagnosis of type 1 diabetes but absence does not exclude it.

### **Pancreatic autoantibodies**

Pancreatic autoantibodies (eg anti GAD65, IA-2) are present at the time of diagnosis in 60-70% of people but the antibody titre declines with time. After 10-12 years only 10-40% of people remain antibody positive, so it is important to measure antibodies soon after diagnosis if there is doubt. A positive result supports a diagnosis of type 1 diabetes but a negative result does not exclude it. Measurement of two antibodies increases the sensitivity of the test.

### **C-peptide measurement**

This can be measured in serum. A random sample performs as well as a stimulated value and in the context of diabetes classification, is preferable to a fasting level.

A urine C-peptide corrected for urinary creatinine has the advantage of a home collection without blood testing. This should be measured in a urine sample collected 2 hours after a meal containing carbohydrate.

C-peptide values may be low soon after diagnosis, but will be a better discriminant than pancreatic antibodies in later years. Results need to be interpreted according to clinical circumstances. Accepted reference values for insulin treated patients are shown in the table.

	Stimulated or random non-fasting C-peptide with blood glucose more than 8mmol/l (results as pmol/l)	Fasting C-peptide (pmol/l)	Urine C-peptide/creatinine ratio (nmol/mmol)
Absolute insulin deficiency, likely type 1 diabetes	<200	<80	<0.2
Likely type 1 diabetes or will need to continue insulin treatment	<600	<250	<0.6
Likely type 2 diabetes or MODY	>1000	>400	>1.1

### 1.3 Immediate Treatment

Insulin must be commenced as soon as the diagnosis is made.

A patient with the following symptoms should be admitted to hospital as an emergency for treatment of diabetic ketoacidosis:

- Nausea/vomiting
- Increased respiratory rate
- Tachycardia
- Signs of dehydration
- Impaired conscious level

In the absence of these symptoms, insulin may be commenced in the community or in secondary care, by a team specialised in the management of type 1 diabetes, depending on local policy. Serum or urine should be checked for ketones and if these are present the patient should be monitored closely until the ketones have resolved (hospital referral should be considered). Multiple daily insulin injections (referred to as MDI or basal-bolus) is the insulin regimen of choice in most circumstances. (See section 4 for more details.)

### 1.4 Autoimmune conditions associated with type 1 diabetes

As an immune mediated condition, type 1 diabetes is associated with the following autoimmune conditions.

- Thyroid disease – hyper or hypothyroidism
- Coeliac disease
- Addison's disease
- Pernicious anaemia
- Vitiligo

Thyroid disease occurs with sufficient frequency to justify annual screening with a TSH

Individuals with gastrointestinal symptoms require a coeliac screen.

### Recommendations

- People with newly diagnosed type 1 diabetes should be admitted to hospital as an emergency if they have symptoms and signs of ketoacidosis (DKA)

- People without signs of DKA may be commenced on insulin in the community but should be referred to a diabetes specialist team
- Multiple daily insulin (MDI) injections is the regimen of choice for initial treatment
- If there is doubt about the type of diabetes, referral should be made to the specialist team and pancreatic antibodies should be measured

## **2. Initial management**

Data from the National Diabetes Audits demonstrate that people with type 1 diabetes, particularly those aged less than 40 years, may be reluctant to engage with diabetes services for both education and screening. Multiple factors influence this but the initial contact and management of newly diagnosed people is crucial to establishing a long term relationship with the diabetes specialist team. Services need to explore ways of improving accessibility and increasing patient engagement.

### **2.1 Education**

All people with newly diagnosed with type 1 diabetes should receive initial education, delivered by a specialist health care professional, at the time of diagnosis. This should be followed by a structured education course, usually 6 to 12 months after diagnosis, depending on individual circumstances. The structured education should be designed to support the person (plus family/carers) to develop the knowledge required to self manage their condition.

#### **At diagnosis**

- Basic carbohydrate counting
- Insulin management
- Hypoglycaemia
- All aspects of living with diabetes including exercise, driving, work
- Sick day rules

#### **Structured education (after 6-12 months)**

The DAFNE programme was the first to establish the value of structured education.

Other programmes are available but the following criteria must be met:

- Written curriculum, evidence based, using principles of adult learning.
- Delivered by trained educators

- Quality assurance with regular audit

NB. Many people require regular educational updates; the need for further education should be reviewed annually

## **2.2 Nutritional advice**

Individualised nutritional advice, delivered by a specialist dietitian, should include carbohydrate counting and healthy eating, taking into account individual cardiovascular risk, need for weight control, alcohol management.

## **2.3 Physical activity and exercise**

Recommendations for physical activity are the same as for those without diabetes, taking into account any restrictions imposed by the presence of microvascular or macrovascular complications. Specific, specialist, individualised advice is required for management of the diabetes. This should include

- Insulin adjustment and dietary modification both before and after exercise to reduce the risk of hypoglycaemia
- Blood glucose targets pre and post exercise
- Regular blood glucose monitoring
- Management of hypoglycaemia and exercise induced hyperglycaemia

## **Recommendations**

All people with newly diagnosed type 1 diabetes should receive the following:

- Individual education from a health care professional trained to manage type 1 diabetes
- Individual nutritional advice from a specialist diabetes dietitian
- Invitation to a structured education course within 6-12 months of diagnosis
- Access to psychological support when required
- Ongoing support for self management from a team which specialises in type 1 diabetes
- A care plan outlining what care to expect in the coming year with individualised treatment targets.

### **3. Follow up consultations and on-going support**

All people with type 1 diabetes require on-going care and support, appropriate to their age, from clinicians experienced in the management of type 1 diabetes. The frequency of review should be determined by individual circumstances and agreed between the person and the clinician. For most people the maximum interval should be 12 months. An understanding of the individual's personal circumstances is crucial, and continuity of care is an important factor in establishing this understanding. Targets should be individualised, taking into account age, co-morbidities and personal circumstances.

#### **3.1 Consultation process**

Consultations should follow the patient's agenda and should also consider the following:

- Positive reinforcement and recognition of what the individual has already achieved in terms of glucose monitoring, insulin administration and glycaemic control
- Exploration of barriers to self care (eg other life events or situations, psychological factors, weight issues).
- Identification of diabetes related distress. Tools such as the PAID (Problem Areas In Diabetes) and the Diabetes Distress Score may be useful.
- Blood glucose control (individualised HbA<sub>1c</sub> target)
  - This should recognise the need to aim for tight targets, particularly in the early years, as evidence supports “tracking” of glucose levels and metabolic memory. In the first 10 years after diagnosis, patients should be supported with tools and education to achieve HbA<sub>1c</sub> as close to 48 mmol/mol as possible provided this does not lead to unacceptable frequency or severity of hypoglycaemia.
  - Later in life, particularly in the presence of co-morbidities or if hypoglycaemia is a problem, it may be necessary to have a more relaxed target.
- Blood glucose monitoring (frequency and use of results)
  - evidence suggests that to achieve HbA<sub>1c</sub> of 58 mmol/mol or less, most patients will need to do 6+ CBG tests / day.
- insulin adjustment in keeping with principles of flexible insulin therapy.
- Hypoglycaemia – incidence/awareness.
  - Consider using validated tools such as the Clarke and Gold score. (Appendix 1)

- Ask about the number of hypos requiring third party intervention in the last 12 months.
- Discuss DVLA regulations
- Complications – discussion of any current problems
- Diet (with referral to a specialist dietitian if required)
- Effect and management of exercise
- Identification of areas where further education would be beneficial (eg revision of sick day rules, insulin adjustment)
- Identification of potential for use of technology, eg bolus advisor, continuous glucose monitoring, insulin pump)
  - All patients with T1DM who are carbohydrate counting should be offered a bolus calculator to ease the burden of calculating insulin at mealtimes.
  - All patients who have a HbA<sub>1c</sub> >69 mmol/mol despite optimised MDI should be offered an insulin pump.

### **3.2 Annual review**

This should include the following routine checks . These can/should be be carried out separately from the consultation to facilitate informed care planning. If the person is only seen on an annual basis, all aspects of the consultation in 3.1 should be included in the annual review.

- Review of injection sites
- 8 care processes – ideally blood and urine tests will have been done in advance so the results and any necessary actions can be discussed as part of care planning
  - BMI
  - HBA<sub>1c</sub>
  - BP
  - Cholesterol
  - Creatinine/eGFR
  - Urinary albumin:creatinine ratio
  - Foot examination
  - Smoking
- Check that retinal screening/ophthalmology review is up to date
- Measure TSH and consider a coeliac screen

The following should be discussed at least annually

- Need for medication for BP, lipids, albuminuria etc
- Erectile difficulties/plans for pregnancy
- Review of care plan and referral for specialist review if required eg nephrology, podiatry, cardiology, ophthalmology
- Immunisation requirements

### **3.3 Psychological support**

The importance of psychological support for people with type 1 diabetes is undisputed and this is an integral part of most paediatric services. The paediatric Best Practice Tariff criteria include access to psychological care. For adult services, the gold standard is that all adults should have access to specialist psychological support if they require it. Unfortunately, access to adult psychology services with specialist diabetes knowledge is extremely limited in the UK and there is an urgent need to address this. The introduction of IAPT (Improving Access to Psychological Therapies) in 2012 has improved provision of general talking therapies, but more complex diabetes related problems require a specialist diabetes psychologist, which many adult services cannot access. Identification of psychological factors impacting on diabetes self management should be part of the clinical consultation and the clinician must be alert to the signs of psychological distress.

#### **Psychological issues which impact on diabetes management**

- Diabetes-related distress
- Fear of hypoglycaemia
- Fear of hyperglycaemia (and consequent complications)
- Eating disorders
- Insulin omission
- Needle phobia
- Clinical and subclinical depression
- Social factors which may impact on the ability to manage diabetes

#### **Recommendations**

- Consultations should be person-centred, following the patient's agenda and identifying any barriers to self-care
- Specialist teams should provide continuity of care

- Routine checks should be carried out annually (not necessarily by the specialist team) and used to inform care planning
- Psychological issues should be identified and should prompt referral to a psychology service

#### **4. Treatment, targets and monitoring**

##### **4.1 Treatment**

Individuals with type 1 diabetes need insulin for survival, and although adjunctive treatments may be used on some occasions, the main treatment challenge is in delivering insulin in a regimen tailored to the individual. Analogue insulins are recommended for most people and NICE favours twice daily Levemir as the basal insulin. However, the choice of insulin should always be adapted to the individual and people who have taken a particular insulin for many years without any problems will understandably be reluctant to change. Their views should always be respected, and changes must not be imposed against their wishes. Wholesale insulin change for a clinic or practice population for non-clinical reasons is never a good idea.

##### **Insulin therapy**

- The insulin regimen should be adapted to the individual's needs taking into account age, dependency and the relative risks of hyper and hypoglycaemia
- Most individuals with type 1 diabetes should be treated with multiple daily insulin (MDI) injections of prandial and basal analogue insulin or with an insulin pump (CSII)
- CSII should be offered to people who meet the criteria for NICE technology appraisal guidance 151 <https://www.nice.org.uk/guidance/ta151>
- Individuals using MDI or CSII should be taught to match prandial insulin to carbohydrate intake, adjusted for the pre-meal blood glucose and planned activity
- Twice daily pre-mixed insulin should be offered for those who are unable or unwilling to use a basal bolus regimen
- Individuals using a pre-mixed insulin should be taught how to match carbohydrate intake to their insulin dose
- Education should be provided for management of specific circumstances eg exercise, sickness, steroid therapy, insulin pump failure

## 4.2 Targets

The target HbA<sub>1c</sub> recommended by NICE for adults with type 1 diabetes is  $\leq 48$  mmol/mol 'whenever possible'. Even with the latest technologies to facilitate self-management this will be difficult for many people to achieve without an unacceptable risk of hypoglycaemia and NICE acknowledges that  $< 53$  mmol/mol is an appropriate audit standard.

To achieve this, patients need to aim for pre-meal glucose levels between 4 – 6 mmol/L and post meal levels  $< 10$  mmol/L. Targets should be individualised, taking account the proven benefit of good control in the early years after diagnosis, while minimising the risk of severe or recurrent hypoglycaemia. Factors such as age, co-morbidities, hypoglycaemia awareness, occupational factors, social circumstances and ability to self-manage all influence the recommended individual target. For most people the target should not exceed 69mmol/mol in order to avoid symptomatic hyperglycaemia or risk of diabetic ketoacidosis.

## 4.3 Monitoring

The frequency and timing of tests, and the targets, should be agreed with the individual. NICE recommends targets of 5-7 mmol/L on waking, and 4-7 mmol/L before meals throughout the day but individual circumstances may demand modification. The recommended number of tests per day will depend on individual circumstances and may range from 2-10, with 4-10 as the optimum, recognising that greater frequency of glucose monitoring is associated with lower HbA<sub>1c</sub>. It is important that the individual is able to obtain a prescription for the number of test strips required. Data from large cohorts suggest most patients need to test an average of 6 times a day to achieve a target HbA<sub>1c</sub> of 58 mmol/mol.

Individuals should receive the education required to enable them to respond to test results by adjusting insulin. They should be encouraged to bring results to the consultation for discussion and if possible the figures should be downloaded in clinic. Although self monitoring of blood glucose (SMBG) underpins self management of diabetes, for some people the burden of testing is unacceptable. For others, obtaining results outside the target range may lead to anxiety and frustration. The clinician should support the individual to do the best they can within the limits of what is acceptable to them. This is particularly true for young people, for whom SMBG is especially burdensome and a supportive approach is required. However, they should be made aware of the obligation to test before driving to ensure the blood glucose concentration is  $> 5$  mmol/L.

The Freestyle Libre Flash Glucose system overcomes the burden of blood glucose testing. It is not routinely available on the NHS but patients should be made aware of the option to self fund. Alternatively, it may be possible to apply for central funding on a named case basis depending on local arrangements.

### **Frequency of blood glucose testing**

- For routine testing, see section 4.3 above
- Additional circumstances
  - Before and 2 hourly during driving
  - Before and after exercise
  - To exclude hypoglycaemia
  - After meals in some circumstances
- Special circumstances
  - During illness
  - Preconception
  - Pregnancy
  - Breastfeeding

### **Blood glucose meters**

There are many blood glucose meters on the market. These must now meet the ISO 15197 2013 standard of accuracy ( $\pm 0.83$  mmol/L for glucose values  $<5.55$  mmol/L, and  $\pm 15\%$  for glucose values  $>5.55$  mmol/L). An independent assessment of accuracy in 2012 showed 50% of CE marked meters failed the test, and 20% failed the less demanding 2003 standard. Non-CE marked meters generally performed worse. All meters are calibrated to express the result as plasma glucose equivalent. The target plasma glucose concentrations must be agreed with the user who should be encouraged to bring the meter to the appointment with the healthcare team. Some clinics have equipment to allow meter readings to be uploaded beforehand and to be displayed on screen during the consultation. We recommend the use of bolus calculator meters as they ease the burden of calculation and have some evidence to support reduced variability in results. They also allow capture of data for review by the patient +/- their health care team.

## **Continuous glucose monitoring (CGM)**

Currently, CGM cannot be recommended for routine use in adults with type 1 diabetes but it is a very useful tool in certain circumstances. All specialist teams should have access to CGM and must acquire competences that allow them to analyse the results of CGM and provide expert advice.

Currently, continuous glucose monitoring can be retrospective or real time.

- Retrospective: the user is blinded to the results but these are stored and can subsequently be downloaded. This is useful for identifying patterns which can guide proactive insulin adjustment
- Real time: the user can view results at all times and adjust treatment reactively according to results.

The system used will be dictated by the objectives of the exercise.

At present the technology is new and its clinical and cost-effectiveness is under review. NICE type 1 guidance makes the following recommendations:

- *Do not offer real-time continuous glucose monitoring routinely to adults with type 1 diabetes.*
- *Consider real-time continuous glucose monitoring for adults with type 1 diabetes who are willing to commit to using it at least 70% of the time and to calibrate it as needed, and who have any of the following that persist despite optimised use of insulin therapy and conventional blood glucose monitoring:*
  - *more than 1 episode a year of severe hypoglycaemia with no obviously preventable precipitating cause*
  - *complete loss of awareness of hypoglycaemia*
  - *frequent (more than 2 episodes a week) asymptomatic hypoglycaemia that is causing problems with daily activities*
  - *extreme fear of hypoglycaemia. [new 2015]*
- *For people who are having continuous glucose monitoring, use the principles of flexible insulin therapy with either a multiple daily injection insulin regimen or continuous subcutaneous insulin infusion (CSII or insulin pump) therapy. [new 2015]*

*Continuous glucose monitoring should be provided by a centre with expertise in its use, as part of strategies to optimise a person's HbA1c levels and reduce the frequency of hypoglycaemic episodes.*

#### **4.4 Unexplained or unpredictable blood glucose results**

Unpredictable results can be a source of frustration and anger for the individual.

Specialist referral is essential and the following possibilities should be explored

- Insulin administration
  - Incorrect injection technique
  - Injection sites (lipohypertrophy)
  - Incorrect needle length
  - Insulin type: Levemir is the NICE recommended basal insulin but in some circumstances other insulins such as glargine or degludec may be considered. An insulin pump provides even more flexibility in basal insulin delivery
- Self management skills
  - Carbohydrate counting/insulin adjustment
  - Adaptation for lifestyle eg exercise
- Self monitoring skills
  - Meter accuracy (consider CGM)
- Psychological factors
- Physical factors eg gastroparesis, malabsorption, renal failure

#### **Recommendations**

- Most people with type 1 diabetes should use multiple daily insulin injections (MDI) or an insulin pump (CSII) using analogue insulins
- Carbohydrate based education should be adapted to enable the individual to get the best possible control on their chosen regimen
- CSII should be offered to individuals meeting the NICE criteria
- Monitoring should be tailored to individual requirements and sufficient test strips should be prescribed to meet this need
- CGM should be considered as an investigatory tool for use by specialist teams, who should be trained to interpret results

- Unpredictable blood glucose results should be investigated by the specialist team

## **5. Long term complications: screening and management**

Prevention of and screening for the microvascular and macrovascular complications of diabetes is an integral part of diabetes care. Complications are rare before puberty and in those who have had type 1 diabetes for less than 5 years but it is normal practice to screen those over 12 years of age.

The risk of complications is reduced if optimal glucose control is achieved but the recommended glycaemic target should take into account the person's age and co-morbidities. For example, in elderly people with other comorbidities, the risk of hypoglycaemia is likely to exceed the risk of complications.

The National Diabetes Audit has repeatedly demonstrated that people with type 1 diabetes are less likely to receive the 9 care processes and less likely to achieve treatment targets than people with type 2 diabetes. It has also found a worrying sevenfold increase in mortality in young women with type 1 diabetes. The reasons behind these observations are multiple and complex but specialist diabetes teams and primary care teams should work together to increase accessibility and encourage patient engagement.

### **5.1 Screening and treatment for microvascular complications**

#### **5.1.1 Retinopathy**

Development of non-sight threatening retinopathy is almost inevitable with increasing duration of diabetes. With poor glycaemic control or other aggravating medical factors, there is an increased risk of progression to sight threatening retinopathy. The prevalence of retinopathy, sight threatening and non-sight threatening (11.2% and 56% respectively), is more common in those with type 1 diabetes compared with type 2 diabetes due to the longer lifetime exposure to the condition.

Screening for retinopathy was initially one of the 9 care processes for people with diabetes and funded through QOF payments. Commissioning for this service has now passed to NHS England and as a result is no longer part of the QOF. Nevertheless, eye screening in diabetes remains a core care process, and healthcare professionals managing people with diabetes have a duty of care to ensure the individual is invited to screening and to encourage them to attend their screening appointments.

### 5.1.2 Nephropathy

Diabetic microvascular renal damage primarily affects the glomeruli. Early damage is detected through measurement of urine albumin excretion, (albumin:creatinine ratio - uACR). This measurement is one of the core care processes for people with diabetes.

#### Management of raised uACR

- Defined as uACR >2.5 (males) or >3.5 (females) on at least 2 occasions
- treat with an angiotensin converting enzyme inhibitor (ACE-I)
- if ACE-I not tolerated use an angiotensin 2 receptor antagonist (ARB)
- target blood pressure less than 130/80.

There is a proven association between a raised uACR and vascular risk (see below).

Individuals in whom medical risk factors are not addressed have a risk of progression to overt renal failure.

### 5.1.3 Neuropathy

#### Painful peripheral neuropathy

See NICE guidance <https://www.nice.org.uk/guidance/CG173> for treatment options for painful neuropathy.

Current recommendations for initial treatment are :

- amitriptyline
- duloxetine
- gabapentin
- pregabalin
- opioids *should be avoided* because of the risk of dependency.

Acute painful neuropathy may develop if there is a rapid improvement in glycaemic control.

People should be advised that this is usually time-limited and should be offered treatment with the preparations referred to above. Glycaemic control should not be relaxed.

#### Diabetic foot disease

All people with active, or at high risk of, diabetic foot disease should be managed by a specialist Diabetic Foot Team in line with NICE guidance 2015

<https://www.nice.org.uk/guidance/NG19>

## Autonomic neuropathy

- Diabetic gastroparesis
  - exclude other pathologies which might cause similar symptoms
  - diagnose using isotope labelled meal
  - advise mashed or pureed food
  - offer an insulin pump
  - consider metoclopramide, erythromycin or domperidone\*
  - consider referral to tertiary centre for gastric pacing
  -

\*The strongest evidence for effectiveness is for domperidone but because of the associated cardiac risk and interactions with other medicines, NICE recommends alternating erythromycin and metoclopramide, with domperidone reserved for those in whom these are ineffective.

## 5.2 Screening and risk factor modification for macrovascular disease

People with type 1 diabetes are at increased cardiovascular risk. NICE lipid modification guidance 2014 does not recommend the use of a risk assessment tool, but advises atorvastatin 20mg for all over age 40 years and for those under 40 with any of the following risk factors

- Type 1 diabetes for >10 years
- Albuminuria
- Family history of CVD
- Hyperlipidaemia
- Hypertension
- Smoking

<https://www.nice.org.uk/guidance/CG181/chapter/1-Recommendations>

## Recommendations

- Optimise glycaemic control, taking into account individual risks and benefits
- Ensure annual screening for complications is offered and explore strategies to encourage uptake
- Address microvascular and macrovascular risk factors
- Refer to specialist teams for treatment of complications

## 6. Acute complications

### 6.1 Hypoglycaemia

The risk of hypoglycaemia is a limiting factor which prevents people with type 1 diabetes from achieving their glycaemic targets. Children and the elderly are particularly vulnerable because they may depend on a carer to recognise that the blood glucose is low and the elderly are at greater risk of irreversible neurological damage. Many people are fearful of hypoglycaemia, some because of bad past experiences, others because of the implications an episode of hypoglycaemia would have for their job or their driving licence. As a consequence, it is not uncommon for people to run a high blood glucose to ensure that they are never hypoglycaemic.

A number of advances in diabetes management have helped to avoid hypoglycaemia:

- Introduction of insulin analogues with a modified profile of action
- New technology, including insulin pumps, continuous and flash glucose monitoring
- Patient education focused on hypoglycaemia awareness and avoidance

Hypoglycaemic awareness should be assessed at least annually using the Clarke score or Gold Score.

- Gold score  
This is very simple assessment which uses a visual analogue scale of 1-7 to assess hypoglycaemia awareness where 1 = always aware of the onset of hypoglycaemia and 7 = never aware of the onset of hypoglycaemia. People scoring 4 or more on the visual scale are considered to have impaired awareness.
- Clarke score  
This uses 8 questions to assess awareness. The full questionnaire is provided in Appendix 1

#### Detection of hypoglycaemia unawareness

- Ask about hypoglycaemia symptoms and the blood glucose threshold for recognition of hypoglycaemia at every consultation
- NICE recommends use of Gold or Clarke score
- Suspect impaired warning if the threshold for recognition is less than 3 mmol/L

- Suspect if the HbA<sub>1c</sub> is less than 48 mmol/L without reported hypoglycaemia (a higher HbA<sub>1c</sub> does not exclude)
- Suspect nocturnal hypoglycaemia if the fasting blood glucose is regularly 5 mmol/L or below
- Consider continuous glucose monitoring if nocturnal hypoglycaemia is suspected

### **Management of hypoglycaemia unawareness**

- Refer to the specialist diabetes team if the person is not already under specialist care
- Review the insulin regimen aiming for 50% of the total daily dose (TDD) as basal insulin and the rest as prandial insulin. For trouble shooting, the insulin: carbohydrate ratio should be roughly 500/TDD and the insulin sensitivity factor should be roughly 150/TDD.
- Review insulin technique (including injection sites)
- Recommend structured type 1 diabetes education if this has not already been accessed or provide refresher session if required
- Offer specific hypoglycaemia avoidance training if structured education has already been provided (frequent contact eg monthly for 6/12 has been shown to be effective).
- Advise maintaining the fasting blood glucose above 5 mmol/L to reduce the risk of nocturnal hypoglycaemia
- Ensure regular monitoring, particularly when driving
- Make person aware of DVLA regulations regarding major hypoglycaemia (requiring assistance from a third party)
- Offer CSII
- Consider real-time CGM

If all of the above measures are ineffective in resolving the problem, consider a tertiary referral for the possibility of islet cell transplant. The most recent referral pathway is outlined in the letter attached in appendix 2.

### **Out of Hospital Treatment of Hypoglycaemia**

- Glucose (15-20g) in the form of Lucozade® or orange juice is preferred for the conscious individual although any form of rapid acting carbohydrate may be used

- Treatment should be repeated if hypoglycaemia persists 15 minutes after the initial treatment
- Once the blood glucose level has returned to normal a meal or snack containing carbohydrate should be consumed to prevent recurrence of hypoglycaemia
- In the unconscious person, glucagon should be administered by a carer or family member if available. Paramedics should be summoned
- An explanation for the hypoglycaemia should be sought, the insulin dose reviewed and adjusted if necessary.

## **6.2 Diabetic ketoacidosis (DKA)**

DKA is a life-threatening complication of type 1 diabetes which develops as a result of insulin deficiency. This may present as a new diagnosis of diabetes, as a result of insulin omission or as a consequence of increased levels of counter-regulatory hormones during illness or stress.

### **Criteria for diagnosis of DKA**

- Ketonaemia 3.0mmol/L or more or ketonuria more than 2+ on standard urine sticks
- Blood glucose more than 11.0mmol/L or known diabetes
- Venous bicarbonate less than 15mmol/L and/or venous pH less than 7.3

### **Clinical diagnosis of DKA**

If DKA is suspected the person should be admitted to hospital as an emergency

Suspect in:

- a person with known diabetes who is unwell with vomiting, abdominal pain or shortness of breath, irrespective of the blood glucose level
- a person not known to have diabetes, presenting with osmotic symptoms, a raised blood glucose and ketones in either blood (3mmol/L or more) or urine (more than 2+)

### **Treatment of DKA**

Adults with DKA should be treated according to local hospital guidelines or using the Joint British Diabetes Societies Inpatient Care Group guideline for the management of Diabetic Ketoacidosis in Adults. <https://www.diabetes.org.uk/.../The-Management-of-Diabetic-Ketoacidosis-in-Adults/>

Children and young people under the age of 18 years should be treated according to the British Society of Paediatric Endocrinology and Diabetes (BSPED).

<http://www.bsped.org.uk/clinical/docs/DKAguideline.pdf>

### **Follow up after resolution of DKA**

All people with DKA should be reviewed by the diabetes specialist team (an audit criterion) for:

- Education and revision of sick day rules
- Review of insulin regimen
- Further follow up to ensure diabetes management optimised
- Psychological support if required

### **Recommendations**

#### **Hypoglycaemia**

- All people with type 1 diabetes should be asked about hypoglycaemia symptoms and thresholds at each consultation
- People with problematic hypoglycaemia should be offered structured education and hypoglycaemia avoidance training
- If disabling hypoglycaemia persists, offer CSII.
- If CSII is declined, advise to keep the fasting blood glucose above 5mmol/L to avoid nocturnal hypoglycaemia.
- Every person with type 1 diabetes should be made aware of the DVLA driving regulations
- People with intractable hypoglycaemia despite use of all available technologies should be referred to a specialist centre for consideration of an islet transplant
- Hospitals should have a policy in place for treatment of hypoglycaemia in inpatients

#### **DKA**

- All people with type 1 diabetes should receive education and updates in sick day rules
- Hospitals should have a guideline in place for management of DKA
- Hospital staff should be trained in the management of DKA
- People admitted with DKA should be referred to the diabetes team for review of diabetes management and follow up

## **7. Specific circumstances**

### **7.1 Young adults and transition clinics**

All young people with type 1 diabetes, and their parents, require on-going support from a specialist diabetes team. Parents, healthcare professionals and schools need to work together to support the young person. The introduction of the paediatric Best Practice Tariff (BPT) is designed to raise standards of care for all children with diabetes, up to the age of 19 years.

Specific guidelines are available from Diabetes UK, providing information for parents, school staff, children, diabetes health care teams, individual healthcare plans and legal information.

#### **Transition**

The transition from the paediatric to the adult diabetes service is a crucial time for all young people with diabetes. If this is not carefully planned and managed, there is a high risk that teenagers will be lost to follow up with potentially catastrophic consequences. Although the term transition refers to the relatively short (approximately 12 months) process of transfer from paediatric to adult services, a specialist service should be available for young people aged 18-25 years.

Managing diabetes through adolescence and the decade beyond places particular strains on young people. Puberty is associated with insulin resistance and worsening control and with accelerated development of early complications. The psychosocial pressures of adolescence make adherence to insulin and blood glucose monitoring regimens very difficult and good glycaemic control may not be a priority. The diabetes team needs to understand and support the needs of the young person, and must maintain contact throughout these difficult years. Psychological support, which is an integral part of paediatric care, is far more restricted in adult services and this deficiency needs to be addressed as a matter of urgency.

Although the BPT provides an opportunity for excellent care until age 19, which has been shown to reduce the population HbA1c and reduce admissions with DKA, the need for a similar level of care continues for several years. Unfortunately, most adult services will find it impossible to deliver the same high level service beyond the age of 19. There is a strong argument for continuing the BPT until age 25 to ensure that this vulnerable age group receives the ongoing support it so badly needs.

### **Requirements for a transitional diabetes service**

- All diabetes units should sign up to the core values of a quality consultation
- Paediatric and adult services should agree minimum standards for a transition policy based on national guidance and evidence
- Paediatric and adult lead diabetologists should work in collaboration in each unit
- Units should identify training needs for paediatric and adult teams around young adult communication and consultation skills
- A health plan prompt sheet should be developed. This would include prompt sheets for both the professional and young adult on all aspects of health
- A transition planning process prompt sheet should be developed for professionals to improve the transition process

NHS England released guidelines for transition from paediatric to adult clinics in December 2015

<https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf> <https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf>

### **Recommendations**

- A formal process of transition, to include joint clinics with a paediatric and an adult diabetologist, should be established in every unit
- A specialist 'young adult' clinic for the 18-25 age group should be held in a format (face to face, skype, email etc) and at a time which meets the needs of this age group
- Staff working in transition and young adult clinics should be trained in communication skills relevant to young people
- Psychological support should be available
- Attendance rates and outcomes should be audited

### **7.2 Older people and care homes**

Although the peak incidence of type 1 diabetes is in young people, the condition can present at any age. As mortality rates improve, people with type 1 diabetes are living much longer

and increasing numbers of older people are faced with the challenge of managing their diabetes against a background of physical and cognitive decline.

The process of ageing leads to progressive losses which affect physical and cognitive performance and impact on diabetes management. Activity levels fall, muscle bulk reduces and appetite may decrease, leading to weight loss and frailty, with increased insulin sensitivity. The risks of hypoglycaemia (particularly neurological damage and falls) are increased in this age group. Cognitive decline and visual impairment may make self-management decisions more difficult. Many people with type 1 diabetes will have decades of experience in managing their condition – such knowledge cannot be passed on to carers and the loss of independence and the control of their diabetes can be very distressing.

### **Factors affecting diabetes management in older people**

- Comorbidities and geriatric syndromes including depression
- Impaired cognition leading to insulin errors, missed meals and reduced ability to identify and manage hypoglycaemia
- Visual, hearing and functional impairment
- Polypharmacy
- Falls and fractures
- Vulnerability to hypoglycaemia

There is no evidence on which to base guidance for management of type 1 diabetes in older people. The emphasis should be on individualising treatment and targets to meet the needs of the individual.

### **Managing type 1 diabetes in older people**

- Acknowledge lower awareness of hypoglycaemia in this group.
- Older adults who are functioning well physically and mentally may wish to aim for the same targets as younger adults.
- Targets may be relaxed and individualised for older adults with either physical or mental frailties but symptomatic hyperglycaemia should be avoided.
- The potential benefits of tight glycaemic targets should be balanced against the risk associated with hypoglycaemia in this age group

- Treatment of cardiovascular risk factors should take life expectancy into account.
- Screening for diabetes complications should pay particular attention to complications that would lead to functional impairment

#### **Diabetes UK recommendations for care home residents with diabetes**

- Each resident should have an individual care plan, based on an annual assessment of functional status (including vision), cognition and nutrition
- The care plan should be agreed between the patient (or carer), GP and home care staff.
- Care homes should have policies in place for management of diabetes
- Staff should have access to a diabetes education and training programme

#### **Recommendations**

- In older people with type 1 diabetes, the annual review should incorporate screening for signs of cognitive and functional impairment
- Insulin regimens should be simplified and glycaemic targets relaxed for those who are no longer able to make their own decisions
- Nutrition should be reviewed and adapted to help avoid wide variations in the blood glucose
- Strategies should be in place to enable early detection of hypoglycaemia
- Carers, whether personal or professional, should receive education and training to provide the knowledge they require to assist with diabetes management
- Care homes should have policies and care plans in place, in line with Diabetes UK guidelines, to ensure safe management of vulnerable older people with type 1 diabetes

### **7.3 Pregnancy**

All girls and women with child-bearing potential and type 1 diabetes should receive advice about the importance of preconception planning as part of routine diabetes care and should be advised to seek preconception advice from the diabetes team prior to becoming

pregnant. Women taking potentially teratogenic medication, such as ACE inhibitors or statins, should be specifically warned of the importance of avoiding pregnancy.

Risks to the woman with diabetes and her fetus include

- miscarriage
- pre-eclampsia
- pre-term labour
- worsening of diabetic retinopathy
- stillbirth
- congenital malformation
- macrosomia
- birth injury
- perinatal mortality
- neonatal hypoglycaemia.

These risks can be reduced by good glycaemic control preconception and during pregnancy.

NICE recommendations for care of pregnant women with diabetes were updated in 2015.

<https://www.nice.org.uk/guidance/ng3>

### **7.3.1 Preconception Care**

The importance of good glycaemic control prior to conception should be emphasised. Women should be advised to avoid an unplanned pregnancy and to discuss plans for a pregnancy with the specialist diabetes team so that all aspects of diabetes care, including glycaemic control, medication and complications (screening and treatment) can be optimised prior to conception. Glycaemic targets should be agreed, taking into account the importance of aiming for a near normal HbA1c (48-53 mmol/mol), but accepting that this may need modification depending on the individual's risk of hypoglycaemia. If an unplanned pregnancy should occur, the patient should be referred immediately to the joint antenatal diabetes clinic.

#### **Preconception counselling**

- Discuss the risks associated with diabetic pregnancy and the importance of good glycaemic control in reducing these

- Explain that to reduce the risk of congenital abnormalities, good glycaemic control must be achieved prior to conception.
- Discuss the individual HbA1c target (ideally 48-53 mmol/mol) if this can be achieved without hypoglycaemia
- Review medication and stop potentially harmful drugs. Limit medication to
  - Insulin +/- metformin for diabetes
  - Methyldopa, nifedipine or labetalol for blood pressure
- Screen for complications/associated conditions
  - Retinal screening
  - Microalbuminuria +/- creatinine
  - Thyroid function
- Refer for a specialist opinion if complications present (eg ophthalmologist, nephrologist, cardiologist)
- Advise folic acid 5mg daily preconception until the end of the first trimester

### **7.3.2 Antenatal care**

Antenatal care must be provided by a combined team including diabetes physician, specialist nurse and dietitian, obstetrician and midwife, all of whom should have specialist experience in the management of diabetic pregnancy. The team should:

- Explain the importance of regular clinic visits to ensure good glycaemic control and monitoring of fetal development and wellbeing
- Set glycaemic targets (taking into account individual risk of hypoglycaemia)
- Provide individual dietetic advice
- Consider an insulin pump if targets cannot be achieved by MDI
- Explain the effects of pregnancy on glycaemic control (early instability/increasing insulin resistance in second half of pregnancy)
- Warn of increased risk of hypoglycaemia

### **7.3.3 Intrapartum care**

- CBG should be monitored hourly and maintained between 4-7 mmol/L (4-8 mmol/L acceptable) during labour to minimise the risk of neonatal hypoglycaemia. This may require intravenous insulin infusion as per local or JBDS (under preparation) protocol.

#### **7.3.4 Postnatal care**

Diabetes team should remain in close contact to offer support for insulin adjustment in postnatal period, including advice about diabetes management when breast-feeding

#### **Recommendations**

- Incorporate preconception planning advice into routine diabetes care for women with child-bearing potential
- Ensure glycaemic control is optimised preconception
- Provide antenatal care from a combined diabetes/obstetric specialist team
- Follow NICE guidance for standards of care

#### **7.4 Inpatient care**

The National Diabetes Inpatient Audit (NaDIA), a snapshot audit of diabetes inpatient care in England and Wales on single day in September in 2013, showed that 15.8% of hospital inpatients had diabetes, of whom 6.6% had type 1 diabetes. The audit monitors staffing levels in the hospital diabetes team and measures of patient harm including medication errors, inappropriate use of intravenous insulin infusions, episodes of hypoglycaemia and DKA arising in hospital and new foot ulceration developing during their hospital stay. It is clear that people with diabetes are at significant risk of harm during their admission and there needs to be a focus on improving standards of care.

#### **Essential requirements for inpatient care of diabetes**

- Trusts should have a mechanism for identifying inpatients with diabetes
- Every inpatient with type 1 diabetes who wishes to see a member of the diabetes specialist team should be able to do so
- Trusts should ensure that the staffing levels of the diabetes specialist team are sufficient to deal with the workload
- Trusts should have a policy in place to allow people with type 1 diabetes to self monitor and self manage if they are well enough and wish to do so
- All staff caring for people with diabetes should be trained in the safe use of insulin and the risks of administering too much or too little insulin
- Trusts should use standardised locally agreed insulin prescription charts to reduce insulin errors

- All staff caring for people with diabetes should understand how to manage a period of fasting in a person with type 1 diabetes
- All Trusts should have guidelines in place for management of diabetic emergencies and procedures/treatments requiring a period of fasting
- All staff caring for people with diabetes should know how to assess 'at risk' feet and how protect the foot from damage during the inpatient stay

### **Recommendations**

- All inpatients with type 1 diabetes should have access to the diabetes team if they or the team responsible for their care think this is necessary
- Hospitals should have policies in place to allow people with type 1 diabetes to continue self monitoring and self management during their admission if they are well enough to do so.
- Staff caring for people with diabetes should have an understanding of type 1 diabetes and be trained in the safe use of insulin
- Hospitals should have policies in place for management of diabetes in inpatients, including emergencies and procedures / treatments requiring a period of fasting

### **7.5 Driving**

Revised guidelines from the Driver and Vehicle Licensing Authority in the UK require all patients on insulin to declare this information to DVLA. Patients who have an episode of severe hypoglycaemia (requiring third party help to recover) should report the incident to the DVLA. Two such episodes may result in loss of licence to drive group 1 vehicles and one episode would disqualify holder of group 2 licence. Those applying for a group 2 licence must provide 3 months of blood glucose monitoring using a memory meter; examination by an independent diabetes specialist is required. Hypoglycaemia unawareness should also be reported to DVLA. All people taking insulin must check their blood glucose before driving and every 2 hours while driving.

### **Recommendations**

- People with type 1 diabetes must be made aware of the DVLA regulations
- Sufficient test strips must be provided to allow individuals to meet the DVLA blood testing requirements

- Those with impaired warning of hypoglycaemia should receive specialist input to restore hypoglycaemia awareness and ensure that they are safe to drive

## 8. Gold standard recommendations for care of people with type 1 diabetes

### Process

#### At diagnosis

- Initial education from HCP with specialist knowledge of type 1 diabetes
- Multiple daily injection insulin therapy offered as the first line insulin regimen
- Structured education (validated programme) offered after 6-12 months
- Individualised nutrition and exercise advice from a specialist diabetes dietitian
- Regular contact until confident to self manage
- Consistent team communication on blood glucose and HbA<sub>1c</sub> targets and the reasons for these

#### Follow up

- Regular follow up and support from a HCP specialising in type 1 diabetes trained in flexible insulin adjustment around carbohydrate counting and with knowledge of appropriate technology including bolus advisors, insulin pump therapy and continuous glucose monitoring.
- Identification of barriers to self care (eg other life events or situations, psychological factors, weight issues)
- Blood glucose control (individualised HbA<sub>1c</sub> target)
- Blood glucose monitoring and insulin adjustment
- Hypoglycaemia – incidence/awareness
- Complications – discussion of any current problems
- Diet (with referral to a specialist dietitian if required)
- Effect of exercise
- Identification of areas where further education would be beneficial (eg revision of sick day rules, insulin adjustment)
- Identification of potential for increased use of technology, eg offer those who are carbohydrate counting a bolus advisor, offer an insulin pump to those with HbA<sub>1c</sub> >69 mmol/mol or who experience disabling hypoglycaemia, offer short term CGM (as an investigation) to those with possible nocturnal hypoglycaemia or incongruent BGM and HbA<sub>1c</sub> results

- Annual review including 8 care processes and annual retinal screening (this may take place in primary care)
- Treatment of risk factors when present
- Referral to specialist care when indicated
  - Poor glycaemic control
  - Impaired awareness of hypoglycaemia
  - Insulin pump
  - Ophthalmology
  - Nephrology
  - Podiatry/Diabetic Foot Team
  - Pre-conception advice
  - Antenatal care
  - Psychological support for those who need it

### **Transitional care**

#### **Process**

- An identified lead for transition in each paediatric and adult diabetes service
- A joint paediatric–adult transition policy
- Evidence of consultation and user involvement in the policy development
- Transition period lasting at least 12 months, with input from paediatric and adult teams over that period with at least one combined appointment
- Experience of care audit
- Evidence of use of a shared care-planning template
- Frequent follow up to support continuity of care
- Psychological support available when required

#### **Outcome**

- DNA rates monitored and followed up over the course of the transition period
- Reduction in admissions for emergency diabetic ketoacidosis and/or hypoglycaemia
- Percentage of young people with HbA1c levels <58 mmol/mol
- Outcomes from a care audit

## Appendix 1: Hypoglycaemia unawareness scores

### 1. Clarke Score: Clarke et al. Reduced awareness of hypoglycaemia in adults with IDDM. *Diabetes Care* 1995;18:517.

- 1) Check the category that best describes you: (check one only)
    - I always have symptoms when my blood sugar is low (A)
    - 1 sometimes have symptoms when my blood sugar is low (R)
    - 1 no longer have symptoms when my blood sugar is low (R)
  
  - 2) Have you lost some of the symptoms that used to occur when your blood sugar was low?
    - yes (R)                      no (A)
  
  - 3) In the past six months how often have you had moderate hypoglycemia episodes? (Episodes where you might feel confused, disoriented, or lethargic and were unable to treat yourself)
    - Never (A)              Once or twice (R)                      Every other month (R)
    - Once a month (R)              More than once a month (R)
  
  - 4) In the past year how often have you had severe hypoglycemic episodes? (Episodes where you were unconscious or had a seizure and needed glucagon or intravenous glucose)
    - Never (A)              1 time (R)              2 times (R)              3 times (R)
    - 5 times (R)              6 times (R)              7 times (R)              8 times (R)
    - 9 times (R)              10 times (R)              11 times (R)
    - 12 or more times (U)
  
  - 5) How often in the last month have you had readings <70 mg/dl with symptoms?
    - Never    1 to 3 times              1 time/week              2 to 3 times/week
    - 4 to 5 times/week              Almost daily
  
  - 6) How often in the last month have you had readings <70 mg/dl without any symptoms?
    - Never    1 to 3 times              1 time/week              2 to 3 times/week
    - 4 to 5 times/week ,              Almost daily
- (R = answer to 5 < answer to 6, A = answer to 6 > answer to 5)
- 7) How low does your blood sugar need to go before you feel symptoms?
    - 60-69 mg/dl (A)              50-59 mg/dl (A)              40-49 mg/dl (R)
    - <40 mg/dl (R)
  
  - 8) To what extent can you tell by your symptoms that your blood sugar is low?
    - Never (R)              Rarely (R)              Sometimes (R)              Often (A)
    - Always (A)

Four or more R responses = reduced awareness; 2 or fewer R responses = aware.

**2. Gold Score: Gold et al. Frequency of severe hypoglycaemia in patients with type 1 diabetes with impaired awareness of hypoglycaemia Diabetes Care 1994;17:697-903**

Do you know when your hypos are commencing ?

Always 1 2 3 4 5 6 7 Never

The respondent completes a 7-point scale, with 1 being “always aware“ and 7 representing “never aware”

## Appendix 2: Referral for islet transplant



UK Islet Transplant Consortium

**21<sup>st</sup> March 2016**

Dear colleague

As members of the UK Islet Transplant Consortium, we are updating you about the clinical outcomes of UK patients treated by our service. We would be pleased to receive referrals of suitable patients, and therefore we are sending you brief information about referral criteria and how to refer if necessary.

### **Overview and outcomes**

As you may know, the UK is very fortunate to have the world's first government-funded islet transplant service dedicated to patients with type 1 diabetes and recurrent severe hypoglycaemia. 176 islet transplants have been performed in 104 patients in the UK between 1<sup>st</sup> April 2008 and 31<sup>st</sup> December 2015.

The UK clinical islet transplant programme has attained its goals of preventing recurrent severe hypoglycaemia, improving glycaemic control and maintaining satisfactory graft function in most patients.

### **Referral criteria**

The following patients with type 1 diabetes **might be suitable**: Those with:

- two or more episodes of severe hypoglycaemia (requiring other people to help) within last 2 years
- impaired awareness of hypoglycaemia
- severe hypoglycaemia/impaired awareness who have a functioning kidney transplant

Ideally we like patients to have had a prior trial of insulin pump therapy, and if appropriate Continuous Glucose Monitoring with a pump and sensor, and we can arrange this if necessary. However, we are happy to assess any patient who is unsuitable, or has strong views against a trial of pump therapy/ Continuous Glucose Monitoring.

The following patients are **probably not suitable**: Those who:

- require >0.7 units/kg/day of insulin (~50 units/day for a 70 kg patient)
- weigh more than 85 kg
- have poor kidney function (in general this means a GFR <60 ml/min)

These criteria are somewhat flexible; we always assess the overall risks and benefits for individual patients. If you are unsure whether your patient might be suitable then **please contact** the clinical lead at one of the UK Islet Transplant Consortium centres (below). We will be very pleased to discuss any potential patient.

### **Where to refer**

There are six islet cell transplant centres in England and one in Scotland:

- **Bristol:** Dr Rommel Ravanan, Richard Bright Renal Unit, Southmead Hospital, Southmead Road , Westbury-on-Trym, Bristol, BS10 5NB. [Rommel.Ravanan@nbt.nhs.uk](mailto:Rommel.Ravanan@nbt.nhs.uk); Tel: 0117 414 7698
- **Edinburgh:** Mr John Casey, Transplant unit, Royal infirmary of Edinburgh, 51 Little France Crescent, Old Dalkeith Road, Edinburgh, EH16 4SA. [jcasey@staffmail.ed.ac.uk](mailto:jcasey@staffmail.ed.ac.uk) or Tel: 0131 242 1714
- **London:** Dr Pratik Choudhary, Department of Diabetes, Kings College Hospital, Denmark Hill, London, Greater London SE5 9RS. [pratik.choudhary@nhs.net](mailto:pratik.choudhary@nhs.net). Tel: 020 7848 5651
- **London:** Dr Miranda Rosenthal, Diabetes Department, Royal Free Hospital, Pond Street, London, NW3 2QG. [miranda.rosenthal@nhs.net](mailto:miranda.rosenthal@nhs.net). Tel: 020707794 0500 x 33325
- **Manchester:** Dr Martin Rutter, Manchester Diabetes Centre, 193 Hathersage Road, Manchester, M13 0JE. [martin.rutter@cmft.nhs.uk](mailto:martin.rutter@cmft.nhs.uk). Tel: 0161 276 6709
- **Newcastle:** Prof James Shaw, Institute of Transplantation, Freeman Hospital, Freeman Road, High Heaton, Newcastle upon Tyne, NE7 7DN. [Jim.Shaw@newcastle.ac.uk](mailto:Jim.Shaw@newcastle.ac.uk). Tel: 0191 222 7019 / 8129
- **Oxford:** Prof Paul Johnson, Nuffield Department of Surgical Sciences, Level 6, John Radcliffe Hospital, Headley Way, Headington, Oxford, OX3 9DU. [paul.johnson@nds.ox.ac.uk](mailto:paul.johnson@nds.ox.ac.uk). Tel: 01865 221291

We would be very pleased to receive referrals from you, or to discuss potential referrals with you.

With best wishes,

*John Casey, Miranda Rosenthal, Pratik Choudhary, Martin Rutter, Jim Shaw, Paul Johnson, Rommel Ravanan,*

**On behalf of the UK Islet Transplant Consortium**

If you would like to be removed from our mailing list please let us know by emailing [lindabirtles@nhs.net](mailto:lindabirtles@nhs.net)

