ABCD

Association of British Clinical Diabetologists

Standards of care for management of adults with type 1 diabetes

Contents

Foreword

The Association of British Clinical Diabetologists (ABCD) has been working in partnership with other diabetes professional organisations and charities since 2012 to drive up the standards of care and outcomes for people with Type 1 diabetes in the UK. The 'Lost Tribe' campaign of 2012 highlighted the risk that the distinct needs of people with this condition would not be met in a system focusing on the management of Long Term Conditions on an industrial scale. The first edition of 'Standards of Care for the Management of Adults with Type 1 Diabetes' was published in 2015, soon after the 'NICE Guideline (NG17) Type 1 diabetes in adults: diagnosis and management'. Recommendations from both documents were subsequently incorporated into the NHS RightCare Diabetes Pathway applicable in England and Wales. The quality of specialist T1 diabetes services is addressed as part of the Getting it Right First Time inspections in England, informed by National Diabetes Audit data. In Scotland benchmarking of Type 1 services, has led to improvements in processes and average HbA1c results. Peer review of Type 1 diabetes services is about to start in Wales. All this should be good news for people with Type 1 diabetes and their families in the UK.

Since the last update of 'Standards of Care' in 2016, we have seen the arrival of technologies that have the potential to change what it means to live with Type 1 diabetes for the better. In particular new glucose monitoring technologies offer the prospect of enabling people safely to achieve adequate levels of glycaemia (maximising time in range, which may ultimately replace HbA1c as the target). It has been a challenge to make the most appropriate technologies available for people with Type 1 diabetes across the UK, but significant progress has been made in a cash-strapped NHS. Much credit for what we have achieved should go to the stakeholder organisations that make up the ABCD Type 1 Diabetes Clinical Collaborative–UK, in particular the Diabetes Technology Network–UK. What is clear is that the new technologies are most effective when associated with high quality educational support. It is a continuing frustration to me that relatively few people with Type 1 diabetes have accessed quality-assured evidence-based educational material since diagnosis, and that the waiting times for courses are too long in many parts of the UK.

Research has revealed that a significant number of people with adult-onset diabetes have been misclassified. We now have access to immunological, biochemical and genetic testing that can help identify the type of diabetes more precisely - but need to identify the most cost-effective way to use these tests.

The new expanded edition of 'Standards of Care' attempts to address these issues and other recent developments in the field of Type 1 diabetes. Although primarily intended as a resource for specialist Type 1 diabetes teams, it will be useful for any clinicians looking after people with Type 1 diabetes, and indeed those with the condition, some of whom have contributed comments for each chapter. I am very grateful to Anne Kilvert, for pulling this multi-author publication together so carefully and patiently. It deserves to be discussed in local Type 1 diabetes multi-professional teams, and used as a catalyst for service improvements to address the variation in the quality of care that currently exists in the UK.

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Executive Summary

Gold Standard recommendations for care of people with type 1 diabetes

Standard 1: Minimum requirements for a specialist service caring for people with type 1 diabetes

The specialist service may be based in secondary care or the community but irrespective of location, the following criteria must be met:

A. Staffing

- The service must be delivered by a multidisciplinary team comprised of a consultant diabetologist, diabetes specialist nurses and diabetes specialist dietitian. The team must have access to a psychologist with an understanding of type 1 diabetes

B. Education and training

- All specialist staff should be trained in principles of flexible insulin adjustment, based on DAFNE (Dose Adjustment For Normal Eating) or a similar accredited education programme
- Staff should be trained to offer DAFNE or similar accredited education to all people with type 1 diabetes
- Staff must have training and expertise in the use of technology

C. Access to technology

- The service must have access to up to date technology including insulin pumps and continuous glucose monitoring

D. Data collection

- The service should collect and analyse data to allow benchmarking. This should be submitted to national audits as required
- Minimum datasets include:
  › number of people registered with the service
  › attendance/DNA rates
  › care processes
  › use of technology
  › outcomes
- The service should endeavour to identify the total population of people with type 1 diabetes in their area to address the barriers to accessing specialist care

Standard 2: Provision of care

A. At diagnosis

- Initial education from a Health Care Professional (HCP) with specialist knowledge of type 1 diabetes
- Multiple daily injection 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 dietitian
- Regular contact with HCPs until confident to self-manage
- Consistent team communication on blood glucose and HbA1c targets and the reasons for these

B. Follow up

- Regular follow up and support from an HCP specialising in type 1 diabetes who is trained in flexible insulin adjustment around carbohydrate counting and with knowledge of appropriate technology, including flash glucose monitoring, bolus advisors, continuous glucose monitoring and insulin pump therapy
- Identification of barriers to self-care (e.g. other life events or situations, psychological factors, weight issues)
- Referral to a specialist psychologist when required
- Discussion of blood glucose control (individualised HbA1c target)
- Review of blood glucose monitoring and insulin equipment
- Hypoglycaemia - incidence/awareness
- Complications - discussion of any current problems with opportunity for the person to discuss sensitive issues such as erectile dysfunction
- Diet (with referral to specialist dietitian if required)
- Effect of exercise - onward specialist referral if participating in complex/high level sport
- Identification of areas where further education would be beneficial (e.g. revision of sick day rules, insulin adjustment)
- Identification of potential benefit from increased use of technology (e.g flash glucose monitor, continuous glucose monitor, insulin pump) for those who stand to benefit

C. Annual review including 8 care processes and annual retinal screening (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 and continuous glucose monitoring
  › Ophthalmology
  › Nephrology
  › Autonomic neuropathy
  › Podiatry (Diabetic Foot Team)
  › Preconception advice
  › Psychological support as required

D. Inpatient care

- Ensure guidelines are in place to provide safe care to all inpatients with diabetes. To include:
    - › Management of DKA
    - › Management of hypoglycaemia
    - › Management of hyperglycaemia
    - › Safe use of insulin
    - › Perioperative management
    - › Specific circumstances e.g. steroids, artificial feeding, end of life
- Ensure diabetes team staffing levels (DISNs) are at a safe level and that staff are trained in management of inpatient situations
- Use the 'Making hospitals safe checklist' to compare the local service against national standards and improve where necessary

E. Transition 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 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 a shared care-planning template
    - › Frequent follow up to support continuity of care
    - › Psychological support when required
- Outcome
    - › Monitor DNA rates and act upon them to maximise engagement
    - › Monitor admissions for diabetic emergencies (DKA/hypoglycaemia) and take actions to reduce them
    - › Monitor the percentage of the clinic population with HbA1c <58mmol/mol and take actions to maximise this
    - › Reflect on outcomes of audits of care

F. Sub-specialty services

- Ensure that multidisciplinary specialist teams are established to provide care for people with diabetic foot disease and for pregnant women with type 1 diabetes
- Establish direct links to services providing care for people with diabetes related complications eg renal, cardiology, ophthalmology to ensure a collaborative approach and to increase understanding of type 1 diabetes

Introduction

Approximately 8% of the 3.8 million people with diabetes in the UK have type 1. Over the last few decades there has been a steady increase in the number of people with type 2 diabetes and this has led to a focus on managing large numbers of people in primary care. Complex situations requiring secondary care input have been identified, including acute foot disease, pregnancy, children and young people, insulin pumps, advanced kidney disease and inpatients. However, the needs of people with 'uncomplicated' type 1 diabetes who do not fall into one of these specific groups have been overlooked. In order to manage type 1 diabetes effectively, individuals require education and regular support from professionals with specialist knowledge of this challenging condition. This is frequently beyond the expertise of GPs and practice nurses. Without access to specialist input people are at greater risk of developing the acute and chronic complications which lead to secondary care referral. Restricting their access to specialist care until they develop one of these complications is short-sighted and costly in both human and financial terms.

Since 2012, with the launch of the 'Lost Tribe' campaign, ABCD has been working to raise awareness of the needs of people with type 1 diabetes and to ensure that they can access specialist care. The introduction of community diabetes teams of specialist nurses, doctors and dietitians has improved access to specialist care in some areas and has bridged the primary-secondary care divide.

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 multidisciplinary teams with specialist expertise in type 1 diabetes may manage those with type 1 on a routine basis but the team should be consultant led

- All people with type 1 diabetes should have access to a designated and consistent multi-disciplinary team with specialist skills to support the management of type 1 diabetes. This should provide:

  › A comprehensive education programme with proven efficacy, designed specifically for those with type 1 diabetes

  › A multidisciplinary diabetes technology service which includes an insulin pump service; access to and training for continuous and flash glucose monitoring and automated dosing systems; facilities and support for downloading of devices and interpretation of results

  › Psychological support

  › Specialist services including young adult; pregnancy planning and antenatal, as well as contributing to the multidisciplinary care of people with complications

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 management of people with type 1 diabetes, regardless of where and by whom care is delivered.

The guidance in this document expands on and is in line with the NICE guidance for management of type 1 diabetes and with NHS RightCare.

https://www.nice.org.uk/guidance/ng17

https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2018/07/nhs-rightcare-pathway-diabetes.pdf

1. Diagnosis and immediate management

1.1 Criteria for diagnosis of diabetes

Diagnosis is usually made in primary care

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

*People with type 1 diabetes usually present with symptoms. It is uncommon for this condition to be diagnosed by routine screening but as HbA1c screening becomes more widespread this may happen on some occasions. If in doubt, discuss with your specialist services.

**Laboratory blood glucose measurement is required because of potential for error. While a raised HbA1c (>48mmol/mol) confirms the diagnosis, the rapid onset of type 1 diabetes means that a normal HbA1c does not exclude it.

1.2 Differentiating between type 1 and type 2 diabetes

In many 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. About 40% of those with confirmed type 1 diabetes after age 30 are initially treated as type 2 and misdiagnosis of type 2 diabetes and MODY as type 1 diabetes is common.

If there is doubt about the diagnosis and the patient is symptomatic, it is safer to treat as type 1 diabetes while investigating other possibilities.

Clinical clues to differentiate type 1 from type 2 diabetes

- No single clinical feature is diagnostic of type 1 or type 2 diabetes
- Age at diagnosis is the strongest differentiator. This makes diagnosis of type 1 in older adults very difficult: even those who have classical features of type 1, such as low BMI or ketoacidosis, may have type 2 diabetes
- BMI and weight loss at diagnosis are the next most differentiating features
- Other features classically associated with type 1, such as severe hyperglycaemia at diagnosis, osmotic syndromes, ketosis (without acidosis) or history of other autoimmune disorders, are all weak discriminators; the majority of adults presenting with these features after age 30 will have type 2 diabetes. However the consequences of misdiagnosing type 1 diabetes as type 2 can be fatal and where there is doubt, initial treatment should be as type 1 while awaiting the results of investigations
- A person who progresses to insulin treatment within 3 years, after initial diagnosis and treatment as type 2 diabetes, is likely to have type 1 and to progress to absolute insulin deficiency in the future

Islet autoantibody testing

- Measurement of GAD, IA-2 and/or ZnT8 islet autoantibodies in adult onset diabetes may assist classification close to diagnosis of diabetes (<3 years duration) where diabetes type is unclear

- ICA should not be measured as the majority of available assays use non-human pancreas and therefore have low sensitivity

- In longer duration diabetes C-peptide testing is recommended, with antibody testing only if C-peptide is equivocal

  › In patients where clinical features suggest possible type 1 diabetes the presence of one or more positive islet antibodies strongly supports a diagnosis of type 1

  › A negative autoantibody result will not exclude type 1 diabetes: if two antibodies are tested, up to 20% will be negative at diagnosis, with higher negative levels in long duration disease

  › Islet autoantibody testing is recommended for people thought to have type 1 diabetes but who have possible features of MODY (monogenic diabetes). These features include an HbA1c <7.5% (58mmol/mol) at diagnosis OR one parent with diabetes OR a specific feature suggesting a monogenic cause (e.g. bilateral deafness, renal developmental disease). The probability of MODY from clinical features can be assessed using the MODY Calculator https://www.diabetesgenes.org/mody-probability-calculator. If antibodies are negative a non-fasting stimulated C-peptide (paired with lab glucose) should be measured. MODY testing is recommended if the plasma C-peptide is >200pmol/L and either the MODY Calculator probability is >10% or other specific features suggesting a monogenic cause are present

  › Islet autoantibody testing is recommended in patients thought to have type 1 diabetes but with features which suggest possibility of type 2. These include one or both parents having diabetes, BMI >30kg/m^2 (27kg/m^2 in high prevalence T2 populations) OR acanthosis nigricans. If antibodies are negative a non-fasting random plasma C-peptide should be measured. If this is >1000pmol/L, consider treating as type 2 diabetes with careful monitoring and consideration of repeat C-peptide testing where a person remains on insulin

  › Islet autoantibody testing is not recommended for patients who do not have clinical features of type 1 diabetes. Depending on the antibody and the assay and threshold used, islet antibodies may be detected in 1% to >10% of non-diabetic populations. Therefore if type 1 diabetes is clinically unlikely the risk of a false positive result is high

C-peptide measurement

- Differences in treatment requirement, education and monitoring between type 1 and type 2 diabetes are predominantly driven by the severe endogenous insulin deficiency usually found in type 1 diabetes. Measurement of endogenous insulin secretion (using C-peptide) in long-standing insulin-treated diabetes (>3 years from diagnosis) may give a definitive diagnosis of diabetes type for the purpose of clinical management. C-peptide measurement is not recommended in patients close to diagnosis of diabetes (<3 years duration) outside of the specific circumstances above, or in those not treated with insulin as interpretation is difficult

- We recommend C-peptide is measured once in all those diagnosed as type 1 diabetes in adults after at least 3 years diabetes duration

- A low plasma C-peptide (<200pmol/L non fasting) in the absence of hypoglycaemia (see below) may confirm severe insulin deficiency and the need to manage as type 1 diabetes, regardless of duration. This level excludes MODY

- A high plasma C-peptide (600pmol/L non fasting) with diabetes duration over 3 years confirms lack of absolute insulin requirement and is associated with low hypoglycaemia risk and preserved response to non-insulin glucose lowering therapy. These patients may not require insulin

- In those diagnosed under age 30 a result >200pmol/L (non fasting) after 3 years duration with negative islet autoantibodies may suggest monogenic diabetes (20% likelihood before considering clinical features)

- Patients presenting with a hyperglycaemic crisis may have falsely low C-peptide, therefore allow at least 2 weeks between presentation with severe hyperglycaemia or ketoacidosis and C-peptide testing

- C-peptide can be measured in blood or urine

  › Blood samples should be collected in EDTA (stability 24 hours) with a concurrent sample for laboratory blood glucose

  › A random sample within 5 hours of eating can replace a formal stimulation test in the context of classification

  › If the result is >600pmol/L the circumstances of testing do not matter

  › If the concurrent glucose is <4mmol/L or the patient may have been fasting, consider repeating the test. Very low levels (<80pmol/L) do not need to be repeated

  › Urine for C-peptide:creatinine ratio should be collected in boric acid between 2-5 hours after a carbohydrate containing meal

Stimulated blood C-peptide (post meal or MMT) pmol/L	Urine C-peptide:creatinine ratio (post home meal) nmol/mol*	Interpretation
<200	<0.2	Severe insulin deficiency. Confirms type 1 diabetes and absolute insulin deficiency. MODY unlikely.
>600	>0.6	Substantial endogenous insulin secretion. If duration >3 years likely to be type 2 diabetes or MODY. Lack of absolute insulin requirement.
200-600	0.2-0.6	Likely type 1/insulin requiring. Also seen in longstanding type 2. Consider MODY if longstanding type 1 and antibody negative.

*There is variation between results from different C-peptide assays. Results close to the thresholds should be treated with caution

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 (DKA).

- 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, provided there are protocols for appropriate starting regimens. 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 injections (referred to as MDI or basal-bolus) is the 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 other autoimmune conditions, particularly:

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

Thyroid disorders occur 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 specialist diabetes team immediately

⊘ Multiple daily injections (MDI) is the initial treatment of choice

⊘ If there is doubt about the diagnosis islet autoantibodies should be measured and referral made to the specialist team

⊘ C-peptide can be a useful discriminant of diabetes type when measured more than 3 years after diagnosis but is not helpful at the time of diagnosis

Perspective of the person with diabetes

"Diagnosis can be a frightening time and individual reactions can vary widely, but whatever the reaction, there will be a multitude of questions flying through the PWD's head. An early introduction to a point of contact within the specialist diabetes team can be really helpful in terms of reassurance and answering all of those questions."

2. Initial management

Data from the National Diabetes Audit 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 for screening for complications and complication risk-factors. Multiple factors influence this but the initial contact and management of newly diagnosed people is crucial to establishing a long term relationship with the specialist diabetes team. Services need to explore ways of improving accessibility and increasing patient engagement.

2.1 Education

All people with type 1 diabetes should receive initial education delivered by a specialist healthcare professional at the time of diagnosis. The HCP should be skilled in dealing with the psychological impact of a new diagnosis of type 1 diabetes. This should be followed by a validated, accredited and quality assured structured education course in flexible insulin adjustment, 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 skills to self-manage their condition.

At diagnosis

- Basic carbohydrate counting
- Insulin management
- Hypoglycaemia
- Sick day rules
- Key aspects of living with diabetes including exercise, driving, work, alcohol, pregnancy planning.
- Link to peer support/support groups/newly diagnosed resources (eg from JDRF and/or Diabetes UK)

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
- Delivery by trained educators
- Quality assurance with regular audit. Local data must be collected to demonstrate efficacy of the programme. This should include attendance; pre- and post education HbA1c, frequency of hypoglycaemia and QoL questionnaire

NB. Many people require regular educational updates. The need for further education should be reviewed annually. Digital education programmes are in development and may be a practical adjunct to face-to-face education.

2.2 Nutrition

Individualised nutritional advice, delivered by a specialist dietitian with expertise in the management of type 1 diabetes, should include carbohydrate counting and healthy eating, taking into account individual cardiovascular risk, need for weight control and alcohol management.

2.3 Physical activity and exercise

Recommendations for physical activity are the same as for those without diabetes but specific, individualised advice is required for the 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

See section 7.7 for more detailed advice

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 in flexible insulin therapy within 6-12 months of diagnosis

⊘ Access to psychological support when necessary

⊘ Access to specialist exercise advice for those wishing to exercise intensively or competitively

⊘ 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 and annual care processes

⊘ Link to peer support and resources

Perspective of the person with diabetes

"It's really important for a PWD to know what particular aspects will be covered at forthcoming appointments so that they can prepare appropriately. For example, the issues covered at an appointment with a DSN will generally be very different from those covered by a consultant, but sometimes it's not clear what type of appointment is being offered, e.g. 'You will be seen by Mr/Mrs or a member of their team' is not particularly helpful."

"For me, feeling comfortable enough to reach out to the healthcare team is really important if I feel like I need help. And having a clear line of communication (email) is really nice."

3. Follow up consultations and on-going support

All people with type 1 diabetes require ongoing 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 but if the time between appointments is longer than 6 months they should have access to an interim HbA1c measurement to confirm they remain on target. 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 agreed with the person, taking into account age, co-morbidities and personal circumstances.

Clinicians specialising in type 1 diabetes should consider specific training to develop their person-centred/empowering/motivational skills.

3.1 Consultation process

Consultations should follow the patient's agenda and the clinician should be mindful of the Language Matters position statement and the underpinning person-centred philosophy. https://onlinelibrary.wiley.com/doi/full/10.1111/dme.13705

The following should be considered, depending on the focus of the discussion:

• Positive reinforcement and recognition of what the individual has already achieved in terms of glycaemic management, insulin administration and glucose monitoring. Acknowledgement that managing diabetes is hard

• 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 T1 Diabetes Distress Scale (DDS) may be useful (Appendix 1)

• Individualised HbA1c target

  › This should recognise the need 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 an HbA1c as close to 48 mmol/mol as possible, with strategies to minimise frequency and/or severity of hypoglycaemia

  › When avoidance of long term diabetes complications is not a priority, for example in the presence of co-morbidities and frailty, HbA1c targets should be adjusted

• Blood glucose monitoring (frequency and use of results)

  › Evidence suggests that to achieve an HbA1c of 58mmol/mol or less, most people need to do 6 or more tests a day

  › Diabetes management device downloads should be performed, reviewed and discussed

  › Flash glucose monitoring should be offered to people who meet local criteria. For England the NHS England criteria (2019) can be found at https://www.england.nhs.uk/wp-content/uploads/2020/02/national-arrangements-for-funding-of-relevant-diabetes-patients-v1.2.pdf

• Insulin adjustment in keeping with principles of flexible insulin therapy

• Hypoglycaemia incidence and awareness

  › Assess awareness of hypoglycaemia using validated tools such as the Gold score or DAFNE hypoglycaemia tool (Appendix 2)

  › Ask about the number of hypos requiring third party intervention in the last 12 months

  › Discuss DVLA regulations (section 7.6) https://www.gov.uk/diabetes-driving

- Diet - 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)
  › People who are carbohydrate counting may benefit from a bolus advisor to help with calculation of the insulin dose
  › All patients who have an HbA1c >69mmol/mol despite optimised MDI should be offered an insulin pump
- Complications - discussion of any current problems

Perspective of the person with diabetes

"With follow-up consultations and ongoing support, I feel it is incredibly important to use appropriate and supportive language when discussing a person's experience of diabetes and the impact it is having on their life. It is very easy for both clinicians and people with diabetes to become focused on the numbers and to feel discouraged and demotivated if these are not aligned with the guidelines and targets that have been suggested - especially if these targets have not been individually tailored to the specific circumstances of the individual. Phrases like 'good' and 'bad' blood glucose results or 'poor control' carry an implication of judgement and blame that can be very unhelpful. The Language Matters initiative is a very useful guide to choosing non-judgmental language and phrases, which can help people to stay engaged with their own self-management and motivated to make small improvements towards a mutually agreed goal. I believe it is important to recognise quality of life and mental wellbeing as important outcomes, alongside any numerical indicators."

3.2 Annual review

This should include the following routine checks. These can/should be carried out separately from the consultation to facilitate, and allow time for, informed discussion.

If the person is only seen on an annual basis, all aspects of the consultation listed in 3.1 should be included in the review.

- Review of injection sites and technique
- 8 care processes - ideally done in advance and targets personalised
  › BMI
  › BP
  › HbA1c
  › 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 annually as required:
- Need for medication (BP, cholesterol, albuminuria etc)
- Erectile difficulties/plans for pregnancy
- Need for specialist referral eg nephrology, podiatry, cardiology
- 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. Unfortunately, although the gold standard is that all adults should have access to specialist diabetes psychological care if they require it, the reality is that in many areas it is not available. It is not unusual for psychological support to be withdrawn from young people once they transition to the adult service and there is an urgent need to address this woeful situation. The introduction of IAPT (Improving Access to Psychological Therapies) in 2012 offers general psychological support, but more complex diabetes related problems require a specialist diabetes psychologist. Despite this gap in the adult service, it is important that the clinician identifies psychological factors impacting on diabetes self-management and is alert to the signs of diabetes distress. In some circumstances referral to a specialist psychology unit (eg for eating disorders) is an option.

Psychological issues which impact on diabetes management:

- Diabetes-related distress
- Fear of hypoglycaemia
- Fear of hyperglycaemia (and consequent complications)
- Eating disorders and fear of weight gain
- Insulin omission
- Needle phobia
- Clinical and subclinical depression
- Social factors which impact on the ability to manage diabetes. (Although psychological support may be beneficial here, addressing the underlying social factors will be required but beyond the remit of the psychologist.)

Perspective of the person with diabetes

"It's really helpful to be asked if there are any psychological issues in play that may be impacting upon self management, as the focus can tend to be almost exclusively on the physical aspects and it can be difficult to find the right moment to mention anything else."

"Having a checklist in the waiting room is a great way to force me to think about what I want to discuss in advance of the consultation."

Recommendations

⊘ Consultations should be person-centred, following the person's agenda and identifying any barriers to self-management

⊘ 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

⊘ Complications should be identified and documented, with onward specialist referral as required

⊘ Psychological issues should be identified (consider use of scores such as PAID or T1-DDS) (Appendix 1) and should prompt referral to a psychology service

4. Targets, monitoring and treatments

Abbreviations:

CGM: continuous glucose monitoring

SMBG: self measurement of blood glucose

CSII: continuous subcutaneous insulin infusion

4.1 Targets

HbA1c

- NICE recommends that adults with type 1 diabetes be supported to aim for an HbA1c target +/-48mmol/mol to minimise the risk of long-term complications

- 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 <53mmol/mol is an appropriate audit standard

- Factors such as age, co-morbidities, hypoglycaemia awareness, occupation, social circumstances and ability to self-manage all influence the recommended individual target

- For most people the target should not exceed 69mml/mol in order to avoid symptomatic hyperglycaemia or risk of diabetic ketoacidosis

- Rapid reduction of HbA1c can lead to worsening retinopathy in some circumstances. People at risk (pre-existing retinopathy and high HbA1c) should be identified and HbA1c reduction should be gradual where possible. This is particularly important where people are starting a new form of treatment e.g. insulin pump or monitoring

Glucose levels

- To achieve HbA1c targets, NICE recommends targets of 5-7mmol/L on waking, 4-7mmol/L before meals and throughout the day, 5-9mmol/L if testing 90 minutes post meals and individually agreed bedtime targets (based on time of last meal, last insulin dose, fasting levels and hypoglycaemia risk)

- Targets should be individualised and personal circumstances may require modification, balancing the proven benefit of tight control, particularly in the early years after diagnosis, against the risk of severe or recurrent hypoglycaemia

- DVLA regulations require a glucose concentration >5mmol/L (SMBG or CGM) for the duration of driving

Time in range (CGM); percentage in range (meters); variability metrics

With the use of real-time device uploads and downloads for both CGM and glucose meters, newer metrics have been proposed to set targets which minimise the risk of complications without increasing the risk of hypoglycaemia. These include percentage of time (CGM) or percentage of readings (glucose meters) above or below a glucose range (usually 4-10mmol/L but 3.5-7.8mmol/L in pregnancy).

Glycaemic variability, which people with type 1 diabetes can find very challenging, can be tracked using standard deviation (SD) and/or co-efficient of variation (CV). The latter is generally regarded as a better measure of variability with most experts advocating a target CV ≤33%.

Current NICE guidance does not provide recommendations for time in range or variability but the Advanced Technologies and Treatments for Diabetes (ATTD) international consensus recommendations have been published https://doi.org/10.2337/dci19-0028

It is important that HCPs are aware of the principles, and the potential it offers to identify areas to focus on during the consultation, set goals and track improvements. However ABCD is awaiting a consensus from DTN-UK to inform its position. This document will be updated once the guidance is available.

4.2 Monitoring

Frequency of monitoring

- For both SMBG and CGM, greater frequency of glucose monitoring and duration of use are associated with lower HbA1c and reduced risk of hypoglycaemia
- The frequency and timing of SMBG tests or duration of CGM (intermittent or real-time), sensor use and targets, should be agreed with the individual

SMBG

- For SMBG the recommended number of tests per day will depend on the individual, with 4-10 the optimum
- NICE recommends testing at least 4 times per day - before each meal and before bed
- Data from large cohorts suggest most people need to test an average of 6 times per day to achieve a target HbA1c of 58mmol/mol
- Additional testing will be required in the following situations:
  › Before and every 2 hours during driving
  › Before and after exercise
  › To exclude or confirm hypoglycaemia
  › After meals in some circumstances
- Special circumstances:
  › During illness
  › Preconception
  › Pregnancy
  › Breastfeeding

It is important that the individual is able to obtain a prescription for the required number of test strips.

Intensive management requires frequent SMBG and this can be a major part of the burden of living with type 1 diabetes. This burden can be alleviated by use of flash or continuous glucose monitoring.

Flash glucose monitoring and CGM

Intermittent (flash) glucose monitoring - FreeStyle Libre (FSL): NHS England recommends scanning 8 or more times a day and using the sensor >70% of the time.

Individuals who meet the NHSE criteria must be able to obtain a prescription for the required number of sensors.

Real-time CGM:

Individuals meeting the criteria for NHS funding must be able to order the required number of CGM sensors and transmitters.

NICE recommends using CGM for at least 70% of the time.

Education and support

- Individuals should receive the education required to enable them to interpret glucose results and make relevant adjustments to insulin, food or activity
- Self-management skills, including interpretation of blood glucose results, should be assessed annually
- People meeting the criteria for CGM (see section on technology) or who are self-funding should be offered advanced support and education in interpretation of data

- The clinician should support the individual to achieve the best they can, acknowledging the psychological burden of intensive management

- Mood alterations (depression, anxiety, burden or distress arising from type 1 diabetes or regimens) must be clinically assessed using a tool such as Diabetes Distress Scale (DDS) or Problem Areas in Diabetes (PAID). (Appendix 1)

- Support should be offered in a specialist MDT clinic setting with a defined diabetes psychology pathway

Review and download of data

- Individuals should be encouraged to routinely download and review their own results and adjust therapy as necessary. They should be reminded to bring their devices to the clinic consultation

- Device downloads (meters, CGM and pumps), prior to consultation, should be a routine standard of care and all type 1 diabetes clinics should have the facility to do this

- Download platforms (eg Glooko-Diasend, Carelink, Libreview, Dexcom Clarity, Tidepool) must be procured, and HCPs trained to use them

- The availability of glucose data on secure databases in the Cloud means that clinicians may be able to offer virtual clinics to minimise the burden of visits, improve engagement and improve efficiency of offering support

Monitoring devices

Blood glucose meters

- A range of meters is available. There are considerable variations in size, accuracy and features, e.g. bolus advisors, smartphone connectivity

- The person should be free to select the meter which best meets their requirements. There is no place for a 'standard issue' approach to meters for people with type 1 diabetes

- Bolus advisors ease the burden of calculation and there is some evidence to support reduced variability in results. They allow data capture for review

- Some meters have connectivity with phones and associated meter apps. For some people this may improve engagement and motivation

- Some insulin pumps have connected or integrated meters and users must be allowed access to the one that works with their pump

- Visually impaired people should be offered the chance to try talking meters. These have larger displays, voice instructions and audio results

- Details of meters and quality assurance specifications are provided in Appendix 4

Continuous glucose monitors

Specialist teams should have access to CGM and must acquire competencies to analyse the results, provide expert advice and educate the patient in interpretation of results.

Types of CGM

- Retrospective - data downloaded at the end of the period of monitoring

  › For intermittent use for diagnostic purposes eg to identify nocturnal hypoglycaemia, dawn phenomenon or high BG variability

- Intermittent (flash) - retrospective continuous display on demand with trend arrows

  › For continuous use, scanning at least 8 times per day, facilitating real-time changes

- Real-time - contemporaneous displays with trends and alarm to warn of adverse glucose levels

  › For continuous use, for real-time changes and response to alerts

4.3 Treatment

Individuals with type 1 diabetes need insulin for survival. Achieving targets to minimise the risk of long-term complications, whilst avoiding hypoglycaemia and maintaining normal day-to-day function, requires careful use of insulin regimens tailored to the individual and adjusted based on frequent monitoring. Adjunctive treatments may be useful in some situations. The choice should always be adapted to the individual.

4.3.1   Insulin therapy

- The insulin regimen should be adapted to the individual's needs, taking into account age, dependency, co-morbidities and the relative risks of hyper and hypoglycaemia
- Analogue insulins are recommended for people with type 1 diabetes and NICE favours twice daily Levemir® as the basal insulin
- Most individuals with type 1 diabetes should be treated with multiple daily insulin injections (MDI) of prandial and basal insulin analogues or using a continuous subcutaneous insulin infusion (CSII), delivered by an insulin pump
- 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 pre-meal blood glucose and planned activity
- Twice daily pre-mixed insulin should be offered to those who are unable or unwilling to use a basal-bolus regimen. They need to be taught how to match their carbohydrate to their insulin dose and there is an increased risk of nocturnal hypoglycaemia. This approach should only be used in circumstances where people are unable to manage a variable insulin dose but are able to adhere to a fixed dietary regimen
- Education should be provided for management of specific circumstances, (eg exercise, steroid therapy, insulin pump failure) and should include advice about carrying and storing insulin
- Injection site inspection to identify lipohypertrophy should be part of the annual review

Changing insulin

- When suggesting a change of insulin, the clinical reasons for recommending the change (including speed of onset, duration) should be discussed and a collaborative decision should be taken
- Differences in pharmacokinetics require any change of insulin (including biosimilars) to be accompanied by a period of intensive monitoring, with dose adjustment as necessary
- The use of newer insulin analogues may be considered if blood glucose profiles indicate that a more rapid onset of prandial insulin (FiAsp®) or a flatter basal insulin to reduce nocturnal hypoglycaemia (Toujeo® or Tresiba®) may be beneficial
- People who have taken a particular insulin for many years without any problems may be reluctant to change. Their views should be respected and proposed changes should be justified by sound clinical reasons. ABCD does not support insulin switching for entire clinics or practice populations for non-clinical reasons

Insulin pen devices

- All individuals injecting insulin should be offered an insulin pen device (pre-filled or cartridge). Training in use of the device should be provided by a trained HCP
- Pens capable of offering half unit increments should be offered to insulin sensitive individuals
- Pen devices which dial up in 2 units per click are not recommended for the visually impaired
- Needle size (normally 4mm, 5mm or 6mm) should be assessed at annual review
- Memory pens or smart caps (which record the time since the last insulin dose) should be considered for those who will benefit from reminders of the last dose

SGLT2 inhibitors and insulin

Dapagliflozin has a licence for use with insulin in adults with type 1 diabetes not controlled by insulin therapy alone and with BMI ≥27 kg/m2. The relevant NICE Technology Appraisal guidance (TA597) states that treatment should only be started and supervised by a consultant physician specialising in endocrinology and diabetes.

Potential benefits of adding an SGLT2i to insulin:

- reduced HbA1c concentration
- lower glycaemic variability
- greater time in range
- weight loss
- lower BP
- lipid lowering

These benefits are offset by a significantly increased risk of DKA. Possible contributors to this include a reduction in the insulin dose, increased glucagon concentrations, use of low carbohydrate diets or intercurrent illness.

The licence requires the company to provide HCPs with written advice about patient selection. This includes testing for ketones before commencing treatment and avoiding in anyone who is ketosis prone or underweight, and in individuals requiring less than 0.5 units of insulin/kg body weight/day. Any reduction in the dose of insulin should be cautious, with regular ketone monitoring. Individuals should be provided with a ketone meter and warned about the possibility of euglycaemic ketoacidosis. They should test for ketones if they feel unwell, irrespective of the blood glucose level, and should be cautious about reducing the insulin dose. Provided patient selection is careful and monitoring guidelines are followed, the option to combine insulin with dapagliflozin may be useful.

Further information can be found in the ABCD position statement on SGLT2 inhibitors

https://bjd-abcd.com/index.php/bjd/article/view/447/609

4.3.2 Unexplained or unpredictable blood glucose results

Unpredictable results or high variability can be a source of distress and negative emotions. This may impact considerably on day to day activity and quality of life. Specialist referral is essential: the following possibilities should be explored and eligibility for technology solutions (Insulin pump, flash glucose monitoring, continuous glucose monitoring) should be considered.

- Insulin administration
  - › Incorrect injection technique https://trend-uk.org/injection-technique-matters/
  - › Injection sites (lipohypertrophy)
  - › Incorrect needle length
  - › Insulin type: Levemir® twice daily is the NICE recommended basal insulin, but in some circumstances other insulins, such as glargine (prescribed by the brand name of choice) or Tresiba®, may be considered.
- Self management skills
  - › Carbohydrate counting/insulin adjustment
  - › Adaptation for lifestyle eg exercise
- Self monitoring skills
  - › Meter accuracy
  - › Frequency of testing and corrections
  - › Use of CGM: although beneficial, at present there is no universal funding pathway for CGM use to minimise glycaemic variability. Individuals should be considered for CGM if other criteria are met. CGM can be used as an investigatory tool in these circumstances by teams trained to interpret the results
- Psychological factors, including stress responses
- Physical factors eg gastroparesis, malabsorption, renal failure

4.3.3 Diabetes Technology options for improving glycaemic control

- Although a range of technologies (insulin pumps, flash glucose monitors, continuous glucose monitors) are now available to improve the glycaemic profile and reduce the burden for people with diabetes, cost implications mean that all are subject to qualification criteria for access to NHS funding
- A consensus statement from a collaboration of adult and paediatric diabetes organisations, convened by Diabetes UK and NHS England, has been published. This helps to identify the most suitable technological solution for a range of possible problems with diabetes self-management. https://onlinelibrary.wiley.com/doi/full/10.1111/dme.13933

Insulin pumps (CSII)

- NICE technology appraisal TA 151 covers insulin pumps https://www.nice.org.uk/guidance/ta151
- The ABCD Diabetes Technology Network (DTN) best practice guides provide more information for use of technologies in type 1 diabetes. This includes management and service requirements for health care professionals: https://abcd.care/dtn-uk-best-practice-guides
- CSII should be initiated by a trained specialist team
- Procurement arrangements for insulin pumps must be agreed and in place for centres offering insulin pump therapy. Procurement frameworks are in place for England and Scotland and can be used or adapted by local centres

Real-time CGM / flash glucose monitors

- There is no NICE technology guidance for the use of CGM or flash glucose monitors, either for use with an insulin pump or with multiple daily injections
- NICE type 1 diabetes guidance makes the following recommendations for real-time CGM (predominantly for impaired awareness of hypoglycaemia). The following is a precis of the NICE advice:
    › Do not offer routinely to people with type 1 diabetes
    › Consider CGM in the following circumstances:
        » more than one episode per year of severe hypoglycaemia with no obvious preventable cause
        » complete loss of awareness of hypoglycaemia
        » frequent asymptomatic hypoglycaemia
        » extreme fear of hypoglycaemia
        » hyperglycaemia (HbA1c >75mmol/mol despite testing at least 10 times per day) - only continue if HbA1c falls below 53mmol/mol or by 27mmol/mol
- Real-time CGM should be offered by centres with trained specialists
- Advanced education for interpretation of results and insulin dose decision making should be provided to individuals using real-time CGM
- Access to training programs and materials is available by various routes and also available online via: https://abcd.care/dtn/education
- Specialist centres and CCGs should have policies in place for funding real-time CGM
- Given the continuous updates in devices and the current lack of international accuracy standards, specialists must guide individuals on the real-time CGM options
- NHS England has mandated that from April 2020 pregnant women with type 1 diabetes should be offered continuous glucose monitors for up to 12 months during the pregnancy and postnatal period
- Flash glucose monitors offer glucose values on demand with trend arrows and retrospective review, but with no alarm/alert functions
- CGM is preferred to a flash glucose monitor for people with severe hypoglycaemia or impaired hypoglycaemia unawareness
- NHS England has mandated that people with type 1 diabetes who meet certain eligibility criteria should receive a six month funded trial of FreeStyle Libre® on prescription, Funding for individuals will be continued subject to the trial being deemed a success. This should ensure that CCGs all operate the same criteria, providing equity of access. CCGs will receive reimbursement for up to 20% of their type 1 population. The criteria are included in Annexe A of the following document: https://www.england.nhs.uk/wp-content/uploads/2020/02/national-arrangements-for-funding-of-relevant-diabetes-patients-v1.2.pdf

Sensor augmented pump therapy and automated insulin dosing (artificial pancreas) systems

- Advances in continuous glucose monitoring and insulin pumps have allowed integration and connectivity of both devices
- Algorithms for subcutaneous insulin dosing have been developed to respond to changes in glucose in an automated fashion
- Initial versions have offered basal insulin suspension at or before reaching low glucose levels
- Future generations of systems are now allowing automated insulin dosing via closed loop hybrid or artificial pancreas systems
- These systems deliver variable insulin doses in response to changes in interstitial glucose and depending on other entered or pre-set variables
- A first-generation for such a system is available commercially and it is anticipated that further systems will be available in 2020

Do-it-yourself artificial pancreas technologies (DIY APS)

Frustrated by the slow pace of development of artificial pancreas systems, a community of people, including those with diabetes and their families/caregivers, united online using the hashtag '#WeAreNotWaiting' to promote the development of open source diabetes management systems, known as DIY APS. Their use has expanded considerably over the last five years.

Outcomes are largely self-reported but demonstrate impressive glycaemic control and reduced mental burden. However, these systems are unlicensed, are not approved by any regulatory body and do not have high quality research trials to support their use.

Diabetes UK has recently produced a consensus of recommendations for healthcare professionals regarding supporting these systems: https://www.diabetes.org.uk/professionals/position-statements-reports/do-it-yourself-closed-loop

Whilst no professional society guideline exists, and ABCD cannot recommend such systems, it advocates supporting individuals who choose to use DIY APS and continuing to provide regulated devices as per usual clinical pathways. Given their increasing use, it is important that HCPs are aware of these systems and trained to support them.

Recommendations

All people with type 1 diabetes should be offered the following:

⊘ Multiple daily insulin injections (MDI) or an insulin pump (CSII) using analogue insulins

⊘ Evidence based, structured education should be offered to all individuals to get the best possible outcomes on their chosen insulin regimen

⊘ Access to a variety of blood glucose meters, including those with built-in bolus calculators if indicated, tailored to individual requirements

⊘ Access to sufficient blood glucose strips (4-10 per day or more if needed) to support them to achieve a NICE recommended HbA1c

⊘ Access to intermittent (flash) glucose monitoring for those who meet national criteria. This is cost effective for those testing 8 or more times per day. (For England this should meet NHS England funding criteria.)

⊘ CSII for individuals meeting the NICE TA 151 criteria

⊘ Real-time CGM for those meeting the NICE criteria, as per the principles of the Type 1 diabetes consensus pathway

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

⊘ SGLT2 inhibitors may be combined with insulin in certain circumstances but should be used with caution because of the increased risk of DKA

Specialist teams must ensure that:

⊘ A procurement framework is in place for insulin pump applications

⊘ A clear pathway and prescribing/commissioning policy for CGM (flash/intermittent and real-time) is agreed with the local CCG/LHB

⊘ Ongoing education and training on clinical application of technology and use of newer therapies must be provided for all healthcare professionals working with people with type 1 diabetes

Perspective of the person with diabetes

"I had huge misconceptions around the use of insulin pumps, which were never corrected, so I actively resisted changing from MDI for years. A regular review of a PWD's methods of choice, together with gentle probing of the reasons underpinning that choice may help to ensure that the most appropriate methods are employed."

5. Long term complications: screening and management

Prevention of and screening for microvascular and macrovascular complications of diabetes is an integral part of diabetes care. Complications are rare before puberty and in those who have had 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 management is achieved but the recommended glycaemic target should take into account age and co-morbidities. For older people with co-morbidities which reduce life expectancy, 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 8 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.

Screening and treatment for microvascular complications

5.1 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 11.2% and non-sight-threatening 56%) is more common in type 1 diabetes compared to type 2 because of the longer lifetime exposure to the condition.

Screening for retinopathy was one of the original 9 care processes required for people with diabetes and was funded through the primary care Quality and Outcomes Framework (QOF). Commissioning for this service has now passed to NHS England and is no longer part of the QOF. As a result, the number of care processes has been reduced to 8, excluding retinopathy, but eye screening for people with diabetes remains a core process. HCPs managing people with type 1 diabetes have a duty of care to ensure that they are invited to screening and to encourage them to attend their screening appointments.

It is important that the diabetes team is aware of the retinopathy status so that sudden reduction of HbA1c (e.g. as a result of change of treatment) can be avoided in those at risk of deterioration of retinopathy, and close ophthalmology supervision arranged for them.

5.2 Nephropathy

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

An early morning urine specimen should be requested wherever possible. If only a random sample is available, this should be tested but if the result is positive it should be repeated with an early morning sample

Management of raised uACR

- risk threshold is defined as uACR >3.0 in an early morning specimen on at least 2 occasions (after urinary infection excluded)
- treat with an angiotensin converting enzyme inhibitor (ACE-I) irrespective of blood pressure
- if an ACE-I is not tolerated use an angiotensin-2 receptor antagonist (ARB)
- target blood pressure <130/80 (test sitting then standing)

There is a proven association between a raised uACR and vascular risk (see below) and there is a risk of progression to end-stage renal failure if risk factors are not addressed.

Regular monitoring of renal function is required, with referral to a nephrologist if the person develops nephrotic syndrome (PCR > 300mg/mmol) or CKD 4 (eGFR 15-30ml/min).

An ABCD-Renal Association guideline for management of hyperglycaemia in people with type 1 diabetes and renal impairment recommends a target HbA1c 58-62 mmol/mol: https://bjd-abcd.com/index.php/bjd/article/view/351/515 and a joint JBDS-Renal Association guideline advises on management of diabetes in the haemodialysis unit: https://bjd-abcd.com/bjdvd/index.php/bjd/article/view/134

For those who require renal transplantation consideration should be given to a simultaneous pancreas and kidney transplant (SPK).

5.3 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 reduction in HbA1c. People should be advised that this is usually time-limited and should be offered treatment with the preparations listed 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 Multidisciplinary Diabetic Foot Team in line with NICE guidance 2015: https://www.nice.org.uk/guidance/NG19

Autonomic neuropathy

Gastroparesis

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

*the strongest evidence for efficacy 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.

5.4 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 use of a risk assessment tool but advises atorvastatin 20mg for all over the age of 40 years and for those under 40 with any of the following risk factors:

- type 1 diabetes >10 years
- raised uACR
- family history of CVD
- hyperlipidaemia
- hypertension
- smoking

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

Recommendations

⊘ Optimise glycaemia, 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

Perspective of the person with diabetes

> "From personal experience, starting on a combination of FSL and CSII meant a rapid reduction in HbA1C which meant a worsening of pre-existing retinopathy and a subsequent need for laser treatment. I was only told after the event that this could have been caused by the rapid reduction in HbA1C. Indicative targets of what type of reduction PWDs should be aiming for month on month would be really helpful."

6. Acute complications

6.1 Hypoglycaemia

The risk and fear of hypoglycaemia is a limiting factor which prevents people with type 1 diabetes from achieving their glycaemic targets. Observational data suggest that most people with type 1 diabetes experience between 1-3 episodes of symptomatic hypoglycaemia / week, although these rates can be much higher in some individuals. Severe hypoglycaemia (SH - requiring third party assistance) occurs in between 20-30% of people with type 1 diabetes each year, with a small proportion experiencing multiple episodes. Although some earlier studies suggested a link between lower HbA1c and risk of severe hypoglycaemia, more recent observational data do not show this relationship. The strongest predictors of the risk of severe hypoglycaemia are duration of diabetes, absence of C-peptide and impaired awareness of hypoglycaemia. Children and older people are particularly vulnerable because they may depend on others to recognise that their blood glucose is low and may have other co-morbidities that increase the risk of hypoglycaemia or the impact of an individual event. In addition to this, 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 driving licence. As a consequence, some people run high blood glucose levels to avoid hypoglycaemia. Similarly, there are some people at the other end of the spectrum who have repeated episodes of severe hypoglycaemia because of a desire to keep blood glucose levels within the normal range at all times. This is usually driven by a fear of complications.

Hypoglycaemic awareness should be assessed at least annually, using the Gold score or the DAFNE hypoglycaemia tool and the result should be recorded in the notes.

Gold score

This is a 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. People scoring 4 or more on the visual scale are considered to have impaired awareness.

DAFNE hypoglycaemia tool

DAFNE structured education programme asks simply whether the person was aware of hypoglycaemia at:

- A blood glucose ≥ 3mmol/L
- <3mmol/L
- Not at all

People rating themselves in categories 2 or 3 were classed as hypoglycaemia unaware and had a reported mean of 3.6 severe hypoglycaemia incidents in the previous year compared with 0.87 for those in category 1.

Detection of hypoglycaemia unawareness

- Ask about hypoglycaemia symptoms and the blood glucose threshold for recognition of hypoglycaemia at every consultation
- Suspect impaired awareness of hypoglycaemia (IAH) if the threshold for recognition is less than 3mmol/L
- NICE recommends use of Gold or Clarke score (but the Clarke score is designed as a research tool and the DAFNE tool is more clinically orientated)
- Suspect IAH if the blood glucose meter or CGM/flash glucose monitor have a high proportion of readings below 3mmol/L. Note: Up to 60% of episodes of low glucose on CGM or flash GM can be asymptomatic, even in those with good awareness of hypoglycaemia by conventional assessment. Those with impaired awareness can only detect 20% of episodes detected by CGM
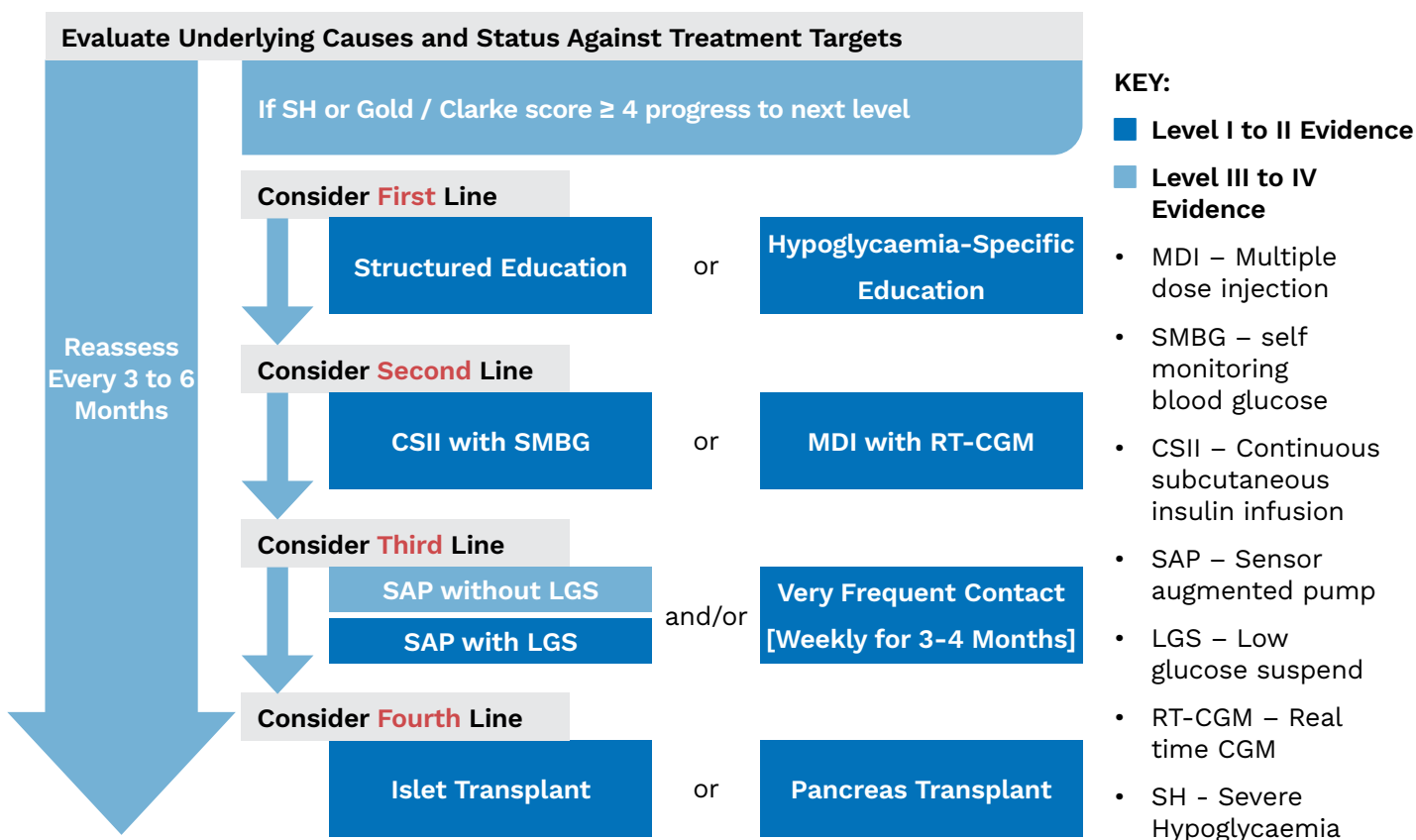
Management of impaired hypoglycaemia awareness

- Refer to the specialist team if the person is not already under specialist care
    - › Exclude secondary causes of hypoglycaemia (low cortisol, growth hormone, coeliac disease, abnormal thyroid function, impaired hepatic or renal function, malabsorption)
    - › Review basics of insulin therapy
    - › Review injection technique and inspect injection sites for lipodystrophy
    - › Advise adequate and appropriate blood glucose testing
    - › Split of basal and bolus insulin - typically 50% of the total daily dose (TDD) will be needed as basal insulin and 50% as bolus. The carbohydrate : insulin ratio should be roughly 300-400/TDD and the insulin sensitivity factor should be roughly 120-130/TDD
- Recommend structured type 1 diabetes education if this has not already been accessed or provide a refresher session if required. Attendance at structured education can reduce rates of SH by 50% and restore awareness in up to 40% of those with IAH
- Offer specific hypoglycaemia avoidance training if structured education has already been provided. Frequent contact (e.g. monthly for 6 months) has been shown to be effective
- In those with IAH or at high risk of SH despite structured education, use of CSII or CGM as a first line technology is associated with a 50-70% reduction in rates of SH
    - › Many centres offer CGM with alarms in this situation as it is often easier to use and offers a degree of protection. Loved ones or carers are able to 'follow' glucose levels and provide support if required
    - › For those with milder impaired awareness or where the person prefers, flash glucose monitoring may be used, although in a randomised trial this was less effective than CGM with alarms
- Ensure regular monitoring, particularly when driving
- Make the person aware of DVLA regulations regarding severe hypoglycaemia (requiring assistance from a third party)
- If problematic hypoglycaemia persists despite use of CGM or CSII, the individual should be offered sensor augmented pump therapy (SAP) with automated insulin suspension or closed loop therapy. These systems have been shown to significantly reduce risk of SH in RCTs
- Where people are unable to progress through the pathway of education, or remain at high risk because of this, they should be referred to one of the 7 UK sites that offer islet or pancreas transplantation. The most recent referral pathway is included as Appendix 3

The pathway for management of hypoglycaemia unawareness is summarised over the page.

Management of hypoglycaemia unawareness

Evaluate Underlying Causes and Status Against Treatment Targets

If SH or Gold / Clarke score ≥ 4 progress to next level

Reassess Every 3 to 6 Months

Consider First Line

| Structured Education | or | Hypoglycaemia-Specific Education |

Consider Second Line

| CSII with SMBG | or | MDI with RT-CGM |

Consider Third Line

| SAP without LGS | and/or | Very Frequent Contact [Weekly for 3-4 Months] |
| SAP with LGS | | |

Consider Fourth Line

| Islet Transplant | or | Pancreas Transplant |

KEY:

- ■ Level I to II Evidence
- ■ Level III to IV Evidence
- MDI – Multiple dose injection
- SMBG – self monitoring blood glucose
- CSII – Continuous subcutaneous insulin infusion
- SAP – Sensor augmented pump
- LGS – Low glucose suspend
- RT-CGM – Real time CGM
- SH - Severe Hypoglycaemia

Out of hospital treatment of hypoglycaemia

- Glucose (15-20g) in the form of 200mls of orange juice, 5-6 dextrose tablets, 5 jelly babies or similar, is preferred for the conscious individual although any form of rapid acting carbohydrate may be used

- Treatment should be repeated if the hypoglycaemia persists 15 minutes after the initial treatment

- People using flash glucose monitoring or CGM should take 5-10g of rapid acting carbohydrate to prevent impending hypoglycaemia if the glucose is below 6mmol/L and falling (downwards arrow)

- Once the glucose level has returned to normal, a meal or snack containing carbohydrate should be consumed to prevent recurrence of hypoglycaemia

- In the unconscious person, a single dose of glucagon - if available - should be administered by a carer or family. Paramedics should be summoned

- An explanation for the hypoglycaemia should be sought. The insulin dose should be 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 at times of illness or stress. People with type 1 diabetes who also take an SGLT2 inhibitor should be alerted to the possibility of euglycaemic DKA.

Criteria for diagnosis of DKA

- Ketonaemia ≥3.0mmol/L or ketonuria more than 2+ on standard urine sticks
- Blood glucose ≥11.0mmol/L or known diabetes
- Venous bicarbonate ≤15mmol/L and/or venous pH ≤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 urine (>2+)
- People with either type 1 or type 2 diabetes who are treated with a sodium-glucose co-transport (SGLT) inhibitor who are unwell. They may have euglycaemic DKA and should have a venous gas measurement irrespective of the blood glucose level at the time of admission

Treatment of DKA

Those people aged 16 and above who are admitted with DKA under the care of adult physicians should be treated according to local hospital guidelines or using the Joint British Diabetes Societies (JBDS) Inpatient Care Group guideline for the Management of Diabetic Ketoacidosis in Adults: https://www.diabetes.org.uk/resources-s3/2017-09/Management-of-DKA-241013.pdf

Children and young people under the age of 18 years who are admitted under the paediatric service should be treated according to the British Society of Paediatric Endocrinology and Diabetes (BSPED): http://www.bsped.org.uk/clinical/docs/DKAguideline.pdf

or International Society for Paediatric and Adolescent Diabetes: https://cdn.ymaws.com/www.ispad.org/resource/resmgr/consensus_guidelines_2018_/11.diabetic_ketoacidosis_and.pdf

This ensures that the admitting team is implementing a guideline that staff are familiar with. To ensure consistency of approach, hospitals should agree a local policy to determine which inpatient service should be responsible for admitting young people aged 16-18 years.

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
- Consider a trial of FSL
- Follow up to ensure diabetes management optimised
- Psychological support if required

*Audit criteria can be found in Appendix 2 of the JBDS adult guideline

Recommendations

Hypoglycaemia

⊘ All people with type 1 diabetes should be asked about hypoglycaemia symptoms and thresholds using validated tools such as the Gold score at each consultation

⊘ People with problematic hypoglycaemia should be offered structured education and hypoglycaemia avoidance training

⊘ People with frequent biochemical hypoglycaemia but good awareness should be offered a flash glucose monitor

⊘ People with hypoglycaemia unawareness and/or recurrent severe hypoglycaemia [≥2 in a year] should be offered real time CGM with alarms or an insulin pump. If this is not adequate to minimise problematic hypoglycaemia, sensor augmented pumps with automated basal suspension [or closed - loop systems] should be considered

⊘ If technology is declined, advise maintaining a fasting blood glucose above 5mmol/L to reduce risk of nocturnal hypoglycaemia

⊘ Ensure that every person with type 1 diabetes is 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 islet transplantation

⊘ 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 for sick day rules: http://trend-uk.org/wp-content/uploads/2018/03/A5_T1Illness_TREND_FINAL.pdf

⊘ People taking an SGLT2 inhibitor should be warned about the risk of euglycaemic DKA

⊘ Hospitals should have a guideline in place for management of DKA

⊘ Hospital staff should be trained in management of DKA and designated wards should be used to ensure staff are experienced

⊘ People admitted with DKA should be referred to the diabetes team for review of diabetes management and follow up

⊘ People with recurrent DKA should have access to psychological support

7. Special circumstances

7.1 Young adults and transition clinics

All young people with type 1 diabetes, and their parents, require ongoing support from a specialist diabetes team. Parents, health professionals and schools need to work together to support the young person. The introduction of the paediatric Best Practice Tariff (BPT) was 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 the paediatric to the adult service, 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 psychological pressures of adolescence make adherence to insulin and blood glucose monitoring regimens very difficult and good glycaemic management may not be a priority when new experiences such as alcohol, smoking, drugs and sex (with risk of pregnancy) are encountered. The diabetes team needs to understand and support the needs of the young person and must maintain contact through 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, and has been shown to reduce HbA1c and admissions with DKA, the need for a similar level of care continues for several more years. Unfortunately, most adult services will find it impossible to deliver the same high level of service beyond age 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 transition service:

- All diabetes units should sign up to the core values of a quality consultation
- Paediatric and adult services should agree minimum standards for an 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 should include prompts for both the professional and the young person 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

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), 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

Type 1 diabetes can present at any age and people with type 1 diabetes are living longer; consequently, increasing numbers of older people are living with this condition. Older age is associated with frailty and cognitive or physical impairment can impact on the person's ability to take the decisions required to manage type 1 diabetes effectively. Many people with type 1 diabetes will have decades of experience in self-management and their skills cannot be transferred to carers, be they family or professional. This inevitably leads to frustration, fear and a sense of bereavement for the person who has lost control of their diabetes.

Detailed international consensus Clinical Guideline for management of type 1 diabetes in older adults can be found at: https://www.diabetes.org.uk/resources-s3/2019-05/Clinical%20Guideline%20for%20Type%201%20Diabetes%20for%20Older%20Adults%20-%20April%202019.pdf

7.2.1 Managing diabetes in older people

Factors affecting type 1 diabetes in older people

- Cognitive impairment, leading to insulin errors, missed meals and reduced ability to identify and manage hypoglycaemia
- Depression and loss of motivation
- Reduced food intake, anorexia, dentition problems and gastrointestinal dysfunction
- Loss of muscle bulk and nerve supply leading to reduced activities and altered insulin sensitivity
- Impaired vision
- Polypharmacy - may lead to hypoglycaemia and hypotension (risk of falls)

Principles of managing type 1 diabetes in older people

There is little evidence on which to base guidance for management of type 1 diabetes in older adults. Treatment should be individualised and should take the following into account:

- Tight targets reduce risk of microvascular complications but increase risk of severe hypoglycaemia
- Older adults with long-standing type 1 diabetes are likely to have reduced hypoglycaemia awareness and be less able to react to hypoglycaemia symptoms
- Vascular complications may be associated with greater functional impairment, and this should be assessed at complications screening
- Screening should include a frailty assessment
- Targets should be relaxed in the presence of co-morbidities and reduced life expectancy with the focus on avoiding hypoglycaemia and symptomatic hyperglycaemia

Assessment of frailty

Frailty is a multidimensional syndrome of loss of reserves (energy, physical ability, cognition, health) that gives rise to vulnerability and predicts death or need for institutional care. Several tools are available to assess frailty including those systems built into primary care systems. The Rockwood Clinical Frailty Scale is a simple 9-point visual analogue scale ranging from very fit to very severely frail, that can be used to determine how capably an individual might self-manage their diabetes.

https://www.cgakit.com/fr-1-rockwood-clinical-frailty-scale

The recent consensus Guideline for Type 1 Diabetes for Older Adults uses three frailty categories - mild, moderate and severe - with tailored guidance for each.

Glycaemic treatment targets

Physical and cognitive ability should be considered before implementing targets and therapeutic approaches for diabetes management.

- Older adults who are functioning well physically and mentally may wish to aim for the same targets as younger adults

- Those with mild impairment may wish to aim for a more relaxed HbA1c target of 58-64mmol/mol to reduce the risk of hypoglycaemia

- A higher HbA1c target (64-69mmol/mol) is recommended for those with multiple co-morbidities, disabilities or history of recurrent hypoglycaemia, where the priority is not minimisation of risk of future vascular complications

- For those with severe impairment the aim should be to avoid symptomatic hyperglycaemia, ketosis and hypoglycaemia - this generally means trying to maintain the blood glucose in the 6-15 mmol/L range. In this situation the HbA1c is less relevant

There is no evidence for the above treatment targets and, as with anyone with Type 1 diabetes, treatment targets should be individualised, wherever possible in collaboration with the person, or with their carer(s).

Choice of insulin regimen

When treatment complexity exceeds self-management ability the insulin regimen should be simplified. Strategies include:

- Lower mealtime bolus doses with smaller correction doses to reduce risk of post-prandial hypoglycaemia

- Giving the bolus after food if intake is unpredictable, reducing the dose by 50% if the meal is unfinished. Post meal insulin administration is associated with a higher risk of delayed hypoglycaemia; consider a modest dose reduction

- A once daily basal analogue administered once in the morning may reduce risk of nocturnal hypoglycaemia

- A 'basal plus' regimen, using a cautious correction dose once or twice daily, alongside a basal insulin, may be useful if blood glucose levels are uncontrolled on a once daily basal in people with reduced food intake

- Premixed insulins are not recommended unless a regular carbohydrate intake can be assured, because of the risk of daytime hypoglycaemia

Use of technology

- Pump therapy may need to be reconsidered in older people who are no longer able to self-manage because it can be difficult to upskill carers

- Flash glucose monitoring has been approved by NHS England for people who need carer input for their diabetes management

- An alarmed continuous glucose monitor may be appropriate for individuals with loss of hypoglycaemia awareness who are prone to severe hypoglycaemia, particularly if carers need remote access

7.2.2 Recommendations for care home residents with diabetes

• Diabetes is a risk factor for admission to long-term care with at least 10.4% of UK care home residents reported to have diabetes. Each resident should have:

• An individual care plan based on an annual assessment of functional status and nutrition, agreed between the patient (or carer), GP and care home staff

• A care home with policies in place for management of diabetes, and specifically for hypoglycaemia, hyperglycaemia and ketosis management

• A nominated staff member available for assistance with glucose assessment and insulin administration

• Carers who have access to a diabetes education and training programme

Recommendations

⊘ Treatment for older adults with Type 1 diabetes should be individualised according to their functional capacity

⊘ Educational, glycaemic and cardiovascular treatments for independent older adults with Type 1 diabetes should be the same as that for younger patients with Type 1 diabetes

⊘ For people with type 1 diabetes aged 65 or over, or those with evidence of cognitive or physical decline, the annual review should incorporate a frailty assessment which assesses ability to manage type 1 diabetes

⊘ Frail older people should have a written individualised diabetes care plan focusing on:

› frequency and method of glucose monitoring

› nutrition

› insulin regimen

› HbA1c or blood glucose target that considers risk of hypoglycaemia versus development of vascular complications

› relaxed targets for blood pressure and cholesterol control

› community care arrangements

⊘ If the person is no longer able to self-manage, the insulin regimen should be adapted so that diabetes can be safely managed by carers

⊘ Carers, whether personal or professional, should receive education and training to provide the knowledge they require to support diabetes management

⊘ A community multidisciplinary team which includes a diabetes consultant, GP and diabetes specialist nurse should exist to discuss and facilitate management of older people with type 1 diabetes

⊘ Frail, older people with type 1 diabetes should have access to screening services

⊘ Care homes should have policies and care plans in place for people with type 1 diabetes in line with Diabetes UK guidance: https://www.diabetes.org.uk/resources-s3/2019-05/Clinical%20Guideline%20for%20Type%201%20Diabetes%20for%20Older%20Adults%20-%20April%202019.pdf

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, statins or SGLT2 inhibitors 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). 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 diabetes 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 48-53mmol/mol). Consider CSII and/or CGM for people with T1DM who cannot achieve the target HbA1c on MDI
- Review medication and stop potentially harmful drugs. Limit medication to
  › Insulin +/- metformin for diabetes
  › Methyldopa, labetolol or nifedipine for blood pressure control
- 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 5 mg daily from 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, particularly in the first trimester, and provide strategies to minimise

- Offer CGM for the duration of pregnancy - the CONCEPTT study showed a reduction in adverse neonatal outcomes with use of CGM and NHSE have mandated all pregnant women needing insulin be offered real time CGM from April 2020

- Ensure retinal screening is offered at least twice during the pregnancy

7.3.3 Intrapartum care

- Women needing steroids pre-delivery for fetal lung maturation may need admission to hospital for intravenous insulin according to local protocol. Subcutaneous insulin (pump or MDI) may be effective in controlling steroid induced elevation of blood glucose levels, with temporary increase in insulin delivery of at least 50%

- CBG should be monitored hourly and maintained between 4-7mmol/L during labour to minimise the risk of neonatal hypoglycaemia. This may require an intravenous insulin infusion as per local or JBDS protocol. http://www.diabetologists-abcd.org.uk/JBDS/JBDS_Pregnancy_final_18082017.pdf Women using an insulin pump can continue to use this safely intrapartum according to local protocol

- Post-partum insulin requirements drop rapidly. Once the baby has been delivered the insulin dose should generally revert to pre-pregnancy doses (if an insulin infusion is used the rate should be halved immediately after delivery) and a further dose reduction should be considered for women who are breastfeeding

7.3.4 Postnatal care

The diabetes team should remain in close contact to offer support for insulin adjustment in the postnatal period. This should include advice about diabetes management when breast-feeding. Follow up arrangements should be in place on discharge from hospital.

Recommendations

⊘ Incorporate preconception planning advice into routine diabetes care for women of child-bearing potential

⊘ Ensure glycaemic control is optimised preconception (HbA1c 48-53mmol/mol) and women take folic acid 5mg daily from pre-conception to the end of the first trimester

⊘ If the HbA1c target cannot be met without hypoglycaemia on MDI, offer CSII

⊘ Provide antenatal care from a combined diabetes/obstetric specialist team

⊘ Offer CGM for the duration of the pregnancy

⊘ Follow NICE guidance for standards of care

7.4 Inpatient diabetes

People with type 1 diabetes are particularly vulnerable when in hospital; insulin may be delayed or omitted by uneducated staff, leading to DKA; hypoglycaemia may result from prolonged fasting or from delayed or unsuitable food. Staff may be anxious about use of unfamiliar technology and insist (inappropriately) on use of an insulin infusion rather than continuing CSII.

7.4.1 NaDIA

The National Diabetes Inpatient Audit (NaDIA) is an annual snapshot audit of inpatient diabetes care which has been carried out in England and Wales since 2011. The audit has provided a wealth of information about the number of inpatients with diabetes, staffing levels and clinical care. It has identified areas for improvement, and causes of harm to patients and has demonstrated that some, but not all, of these areas have improved since the audit first began.

The 2017 audit of 208 hospital sites providing acute care (98% participation) found that 17.6% of inpatients had diabetes (accounting for 1 in 6 hospital beds), of whom 6.6% had type 1 diabetes.

https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-inpatient-audit/national-diabetes-inpatient-audit-nadia-2017

The audit has demonstrated a reduction in the following between 2011 and 2017

- medication errors (down 7% to 31%)
- hypoglycaemia (down 8% to 18%)
- hospital acquired foot lesions (down 0.6% to 1.0%)

The incidence of DKA arising in hospital has remained static at 4% (1 in 25 inpatients).

In 2018 hospitals were invited to participate in a continuous audit of 3 harms:

- Severe hypoglycaemia
- DKA arising in hospital
- Hospital acquired foot lesions

7.4.2 Making hospitals safe for people with diabetes

NaDIA identified the need to raise standards of care for inpatients with diabetes and this led to a report commissioned by Diabetes UK entitled 'Making hospitals safe for people with diabetes'.

https://www.diabetes.org.uk/resources-s3/2018-12/Making%20Hospitals%20safe%20for%20people%20with%20diabetes_FINAL%20%28002%29.pdf

The report identifies 6 domains essential for safe inpatient care:

- Multidisciplinary diabetes inpatient teams
- Strong clinical leadership from diabetes inpatient teams
- Knowledgeable healthcare professionals who understand diabetes
- Better support in hospitals for people to take ownership of their diabetes
- Better access to systems and technology
- More support to help hospitals learn from mistakes

Each domain includes detailed guidance about the requirements for a high standard of inpatient care based on best practice information gathered from units around the country. This has led to the development of a self-assessment checklist, designed so that individual units can measure their performance against the highest national standards.

While none of the units contributing to the 25-point checklist achieves all 25 standards, every standard is being met somewhere in the country so is potentially achievable. The checklist can be accessed by the following link: https://www.diabetes.org.uk/resources-s3/2018-11/Self%20assessment%20checklist_editable-Final_0.pdf

7.4.3 Getting It Right First Time (GIRFT)

The Getting It Right First Time programme was first introduced in orthopaedics and has been rolled out to other specialties by NHS England. The programme aims to bring higher quality care to hospitals, at lower cost, by reducing unwarranted variations in services. The GIRFT Diabetes Leads visit local services, provide data to identify areas for improvement and recommend strategies to improve delivery of care. The GIRFT team utilises data from NaDIA and encourages teams to measure their performance against the 'Making hospitals safe' checklist.

Recommendations

⊘ Systems should be in place to ensure that every inpatient with diabetes receives safe care and is empowered to self-manage when well enough to do so

⊘ Staff should be aware of the particular risks faced by people with type 1 diabetes when they are inpatients

⊘ Diabetes inpatient teams should participate in the NaDIA snapshot audit and the NaDIA harms audit

⊘ Inpatient teams should assess staffing levels against national standards and should analyse the NaDIA data to identify areas needing improvement

⊘ Teams should assess performance against the 'Making hospitals safe' standards checklist and take steps to meet any standards not already in place

⊘ Trust management should be made aware of gaps in the service and risks to safe inpatient care

7.5 Perioperative care

Identification of the person with diabetes and communication that the person has diabetes along all stages of the patient journey, from referral to the surgical outpatient clinic to discharge arrangements, is key to reducing the likelihood of harm.

7.5.1   Elective surgery

- Primary care teams should aim for an HbA1c of <69mmol/mol (8.5%) prior to referral for surgery if it is appropriate and safe to do so. The incidence of post-operative complications rises significantly with poorer glycaemic control

- If a decision is made to operate at the surgical outpatient appointment, the presence of type 1 diabetes must be communicated to the pre-operative assessment team and others along the patient journey. The importance of good peri-operative glycaemic control must be emphasised to the person with diabetes and to the staff due to look after them

- At the pre-operative assessment clinic glycaemic control should be assessed and if the HbA1c is >69mmol/mol a decision should be documented (with reasons) about whether surgery should go ahead. The person with type 1 diabetes must be given verbal and written instructions on how to adjust their insulin on the day prior to their procedure and the day of the procedure. This should follow the details in Appendix 1 and Appendix 2 of the JBDS guideline on the perioperative management of adults with diabetes undergoing surgery or procedures. https://www.diabetes.org.uk/resources-s3/2017-09/Surgical%20guideline%202015%20-%20summary%20FINAL%20amended%20Mar%202016.pdf

- The person with type 1 diabetes should be prioritised on the operating list to minimise starvation times

- The presence of type 1 diabetes should be made known to the ward team who will be looking after the person during their admission

- At the time of admission, the ward team should ensure that glycaemic control is optimal and optimised. Starvation time should be kept to a minimum and where it is necessary to use a variable rate insulin infusion (i.e. more than one missed meal) the infusion time should be kept as short as possible and the background insulin (intermediate/long-acting) should be continued. The principles of Enhanced Recovery After Surgery (ERAS) should be employed

- At the time of surgery, the anaesthetist and surgeon should be aware that the person has type 1 diabetes and that they are taking insulin. The anaesthetist should establish whether background insulin has been continued. Blood glucose should be measured at induction, every hour during the procedure and in recovery. If background insulin has been discontinued, the insulin infusion must not be stopped until subcutaneous insulin (both background and meal time bolus) has been restarted

- Recovery staff should know the person has type 1 diabetes and that the insulin infusion, if in use, should not be stopped

- On return to the ward, staff should know the person has type 1 diabetes and hourly blood glucose measurements should be taken until the person is eating and drinking normally

- Intermediate or long-acting insulin should be continued alongside the insulin infusion, which should not be stopped until fast-acting insulin has been given with food

- Discharge planning should include details about any changes made to diabetes treatment during admission and any advice or arrangements for diabetes management post discharge

7.5.2 Emergency surgery

- By definition there is no opportunity to optimise pre-operative glycaemic control but every effort should be made to maintain the blood glucose within the 6.0 -10.0mmol/L range (4.0-12.0mmol/L is acceptable). A variable rate insulin infusion may be required to achieve this

- The remaining principles of glycaemic management remain the same as for those undergoing elective surgery

NCEPOD report 2018

The National Confidential Enquiry into Patient Outcomes and Death (NCEPOD) report (Highs and Lows, 2018) reviewed cases of 1278 people aged >16 years with diabetes who underwent elective or emergency surgery. The report highlighted a lack of continuity of diabetes management across different specialties in the perioperative pathway, with absence of joint ownership of diabetes management. https://www.ncepod.org.uk/2018pd.html The report makes 5 principal and 8 additional recommendation which can be found in Appendix 5.

Recommendations

- ⊘ Elective surgery for people with diabetes should be carefully planned to ensure that diabetes is optimally controlled throughout the patient journey
- ⊘ Guidelines should be in place, ideally based on the JBDS guideline for perioperative management of adults with diabetes, but taking into account the NCEPOD recommendations
- ⊘ Glycaemic control should be assessed before referral (primary care), at the time of the decision for surgery (surgical outpatients) and at the pre-operative assessment clinic, with the target HbA1c <69mmol/mol whenever possible
- ⊘ A diabetes care plan, to include agreement about self-management where appropriate, should be agreed pre-operatively
- ⊘ People with diabetes should be prioritised on the list to avoid prolonged starvation
- ⊘ Staff at every stage of the patient journey should know that the person has diabetes and be aware of the agreed care plan
- ⊘ The diabetes team should be asked for advice if, at any stage, the targets set by the guideline are not being achieved

Perspective of the person with diabetes

"For a PWD used to making multiple decisions a day about their diabetes management, anxiety about the management of blood glucose levels during and immediately after surgery can often outweigh the anxiety about the surgery itself. An explanation of what monitoring will take place during the surgery and immediately afterwards can significantly reduce the levels of anxiety."

7.6 Driving

The Driver and Vehicle Licensing Authority (DVLA) requires all people taking insulin to declare this information to the Authority. The following regulations apply:

- Drivers must carry rapid acting carbohydrate in their car

- People taking insulin must check their glucose level before driving and every 2 hours when driving. They must not drive unless the blood glucose is >5mmol/L

- A maximum of 2 hours should be allowed to elapse before the pre-driving test and the first check during driving

- People using real-time CGM or a flash glucose monitor must carry a meter and strips with them when driving. If the monitor indicates a glucose level ≤4mmol/L the person must stop driving and confirm the reading with a finger prick test

- People holding a Group 2 licence MUST use finger prick testing - flash glucose monitors and CGM are not legally permitted. They must provide 3 months of blood glucose results (stored on a memory meter) when applying for a licence: examination by an independent specialist is required

- If the glucose level is ≤4mmol/L the person should stop, treat the hypoglycaemia and refrain from driving for 45 minutes

- Group 1 licence holders should inform the DVLA if they have more than one episode of severe hypoglycaemia (requiring third party assistance) in a twelve month period (excluding during sleep)

- Group 2 licence holders must inform the DVLA if they have a single episode of severe hypoglycaemia (including during sleep)

- The DVLA must be informed if any driver taking insulin has a severe hypo when driving

- More details can be obtained at https://www.gov.uk/government/publications/information-for-drivers-with-diabetes

Recommendations

⊘ People with type 1 diabetes must be made aware of the DVLA regulations

⊘ Although flash glucose monitors and CGM may be used for monitoring in Group 1 licence holders, all drivers must carry a meter and strips for finger prick testing

⊘ Drivers must adhere to the regulations related to informing the DVLA about episodes of severe hypoglycaemia or impaired awareness of hypoglycaemia

7.7 Exercise and physical activity

The guidelines for physical activity in people with type 1 diabetes are the same as for the general population but the majority do not meet the minimum recommended level of activity. Historically, people with type 1 diabetes may have felt discouraged from participating in sport and exercise because of fears about hypoglycaemia and lack of knowledge and skills amongst health professionals to support such activities. It is important that this situation changes. Potential benefits of being physically active include better physical fitness, (which is associated with a lower risk of macrovascular disease in those with diabetes as well as without), lower HbA1c, lower BMI, more favourable cardiovascular risk profile and a reduction in macrovascular complications. However, additional barriers to activity exist in people with diabetes, including fear of hypoglycaemia and concerns about loss of glycaemic control. People with diabetes can therefore benefit from specific advice about exercise management.

It is important to recognise that different types of activity cause different metabolic responses and therefore require different management strategies. Activity can usually be classed in one of three different modalities:

- Aerobic or endurance activity is associated with a fall in blood glucose and the risk of hypoglycaemia. Management strategies revolve around reducing insulin doses, increased carbohydrate intake or combination with brief periods of anaerobic activity

- Anaerobic or high intensity activity is associated with a rise in blood glucose and the risk of hyperglycaemia and even ketosis when circulating insulin is insufficient. Management strategies revolve around increasing insulin doses, avoiding excess carbohydrate consumption and combination with brief periods of aerobic exercise such as a low intensity warm-up or warm-down

- Intermittent high intensity activity is a combination of these two types of activity and is characteristic of team sports. The correct strategy will depend on the varying proportions of the different types of activity and optimal management relies on close monitoring of blood glucose

For healthcare professionals, further details around management can be obtained from an international consensus statement (JDRF PEAK)

https://www.thelancet.com/journals/landia/article/PIIS2213-8587(17)30014-1/fulltext

Useful websites for healthcare professional and for people with diabetes include:

- EXTOD (Exercise for people with type one diabetes) for healthcare professionals and people with diabetes https://extodorg.ipage.com/index.html

- www.runsweet.com This provides advice on management of diabetes in a wide variety of sports, with lots of information supplied from their own experience by people with diabetes

- https://1bloodydrop.com/ run by a person with type 1 diabetes and another useful resource

Recommendations

⊘ Structured education for people with type 1 diabetes should include information around exercise and physical activity

⊘ Individualised advice should be available for people with type 1 diabetes wishing to undertake a more intensive programme of exercise

⊘ Dietetic advice should be available as part of this service

Perspective of the person with diabetes

❙ "Being able to set temporary basal rate on the pump makes managing exercise so much easier"

8. Future Developments

NHS Long Term Plan

Diabetes is included in the NHS Long Term Plan published in January 2019. Some of the recommendations apply only to type 2 (eg prevention) but there are some specific recommendations for people with type 1.

https://www.longtermplan.nhs.uk

Chapters 1 and 2 set out actions to prevent diabetes and reduce variation in the quality of diabetes care. For those living with diabetes, the section in chapter 3 'Better care for major health conditions' lists the following intentions:

- Ending variation in access to flash glucose monitors for people with type 1 diabetes from April 2019 (specified criteria for access)
- Offering continuous glucose monitoring for all pregnant women with type 1 diabetes by 2020/21
- Supporting more people to achieve recommended diabetes treatment targets
- Provide access to multidisciplinary footcare teams and diabetes inpatient specialist nursing teams in all hospitals to improve recovery and to reduce lengths of stay and future readmission rates

ABCD is supportive of these proposals and encourages Type 1 MDTs to ensure they are implemented as intended.

Appendix 1: Screening for diabetes distress

Questionnaire Problem Areas In Diabetes (PAID) scale

Instructions: Which of the following diabetes issues are **currently** a problem for you? Tick the box that gives the best answer for you. Please provide an answer for each question.

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
1. Not having clear and concrete goals for your diabetes care?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Feeling discouraged with your diabetes treatment plan?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Feeling scared when you think about living with diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Uncomfortable social situations related to your diabetes care (e.g. people telling you what to eat)?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Feelings of deprivation regarding food and meals?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Feeling depressed when you think about living with diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Not knowing if your mood or feelings are related to your diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Feeling overwhelmed by your diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9. Worrying about low blood glucose reactions?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10. Feeling angry when you think about living with diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11. Feeling constantly concerned about food and eating?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12. Worrying about the future and the possibility of serious complications?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
13. Feelings of guilt or anxiety when you get off track with your diabetes management?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
14. Not 'accepting' your diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
15. Feeling unsatisfied with your diabetes physician?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
16. Feeling that diabetes is taking up too much of your mental and physical energy every day?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
17. Feeling alone with your diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
18. Feeling that your friends and family are not supportive of your diabetes management efforts?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
19. Coping with complications of diabetes?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
20. Feeling 'burned out' by the constant	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

PAID-20: A score of 3-4 indicates moderate to severe distress in that item

PAID-5 uses items 3;6;12;16;19

2-Item Diabetes Distress Scale

The 2 item Diabetes Distress Scale can be used as a screening tool.

People with severe distress should be asked to complete the 28 point Diabetes Distress scale.

2-Item Diabetes Distress Screening Scale (DDS2)

Directions: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1." If it is very bothersome to you, you might circle "6."

	Not a problem		Moderate problem		Serious problem	
1. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes regimen.	1	2	3	4	5	6

T1 Diabetes Distress Scale

This is a 28 point scale

Instructions

Living with type 1 diabetes can be tough. Listed below are a variety of distressing things that many people with type 1 diabetes experience. Thinking back over the past month, please indicate the degree to which each of the following may have been a problem for you by circling the appropriate number. For example, if you feel that a particular item was not a problem for you over the past month, you would circle "1". If it was very tough for you over the past month, you might circle "6".

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem	Very serious problem
1. Feeling that I am not as skilled at managing diabetes as I should be.	1	2	3	4	5	6
2. Feeling that I don't eat as carefully as I probably should.	1	2	3	4	5	6
3. Feeling that I don't notice the warning signs of hypoglycemia as well as I used to.	1	2	3	4	5	6
4. Feeling that people treat me differently when they find out I have diabetes.	1	2	3	4	5	6
5. Feeling discouraged when I see high blood glucose numbers that I can't explain.	1	2	3	4	5	6
6. Feeling that my family and friends make a bigger deal out of diabetes than they should.	1	2	3	4	5	6
7. Feeling that I can't tell my diabetes doctor what is really on my mind.	1	2	3	4	5	6
8. Feeling that I am not taking as much insulin as I should.	1	2	3	4	5	6
9. Feeling that there is too much diabetes equipment and stuff I must always have with me.	1	2	3	4	5	6
10. Feeling like I have to hide my diabetes from other people.	1	2	3	4	5	6
11. Feeling that my friends and family worry more about hypoglycemia than I want them to.	1	2	3	4	5	6
12. Feeling that I don't check my blood glucose level as often as I probably should.	1	2	3	4	5	6
13. Feeling worried that I will develop serious long-term complications, no matter how hard I try.	1	2	3	4	5	6
14. Feeling that I don't get help I really need from my diabetes doctor about managing diabetes.	1	2	3	4	5	6
15. Feeling frightened that I could have a serious hypoglycemic event when I'm asleep.	1	2	3	4	5	6
16. Feeling that thoughts about food and eating control my life.	1	2	3	4	5	6
17. Feeling that my friends or family treat me as if I were more fragile or sicker than I really am.	1	2	3	4	5	6

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem	Very serious problem
18. Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.	1	2	3	4	5	6
19. Feeling concerned that diabetes may make me less attractive to employers.	1	2	3	4	5	6
20. Feeling that my friends or family act like "diabetes police" (bother me too much).	1	2	3	4	5	6
21. Feeling that I've got to be perfect with my diabetes management.	1	2	3	4	5	6
22. Feeling frightened that I could have a serious hypoglycemic event while driving.	1	2	3	4	5	6
23. Feeling that my eating is out of control.	1	2	3	4	5	6
24. Feeling that people will think less of me if they knew I had diabetes.	1	2	3	4	5	6
25. Feeling that no matter how hard I try with my diabetes, it will never be good enough.	1	2	3	4	5	6
26. Feeling that my diabetes doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
27. Feeling that I can't ever be safe from the possibility of a serious hypoglycemic event.	1	2	3	4	5	6
28. Feeling that I don't give my diabetes as much attention as I probably should.	1	2	3	4	5	6

T1 DDS Scoring

Scoring: Calculate the mean item score for the items in the following subscales. Total scale (all items: 1 to 28)

- **Subscale 1 - Powerlessness** (5 items: 5, 9, 13, 21, and 25)
- **Subscale 2 – Management Distress** (4 items: 1, 8, 12, and 28)
- **Subscale 3 – Hypoglycemia Distress** (4 items: 3, 15, 22, and 27)
- **Subscale 4 – Negative Social Perceptions** (4 items: 4, 10, 19, and 24)
- **Subscale 5 – Eating Distress** (3 items: 2, 16, and 23)
- **Subscale 6 – Physician Distress** (4 items: 7, 14, 18, and 26)
- **Subscale 7 – Friend/Family Distress** (4 items: 6, 11, 17, and 20)

5-Item Screener: 2, 6, 19, 20, 25

T1-DDS 3.10.14 © Lawrence Fisher & William Polonsky

Appendix 2: Gold score and DAFNE hypoglycaemia tool for assessment of impaired awareness of hypoglycaemia

Gold Score:

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"

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

DAFNE hypoglycaemia tool

The DAFNE structured education programme asks simply whether the person was aware of hypoglycaemia at:

1. A blood glucose ≥3mmol/L

2. < 3mmol/L

3. Not at all

People rating themselves in categories 2 or 3 were classed as hypoglycaemia unaware and had a reported mean of 3.6 severe hypoglycaemia incidents in the previous year compared with 0.87 for those in category 1.

Appendix 3: Referral for islet cell transplant

21st 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 between1st April 2008 and 31st 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:

 a. Two or more episodes of severe hypoglycaemia (requiring other people to help) within last 2 years

 b. impaired awareness of hypoglycaemia

 c. 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:

 d. require >0.7 units/kg/day of insulin (~50 units/day for a 70 kg patient)

 e. weigh more than 85 kg

 f. 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:

 a. **Bristol:** Dr Rommel Ravanan, Richard Bright Renal Unit, Southmead Hospital, Southmead Road, Westbury-on-Trym, Bristol, BS10 5NB. Rommel.Ravanan@nbt.nhs.uk; Tel: 0117 414 7698

 b. **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 or Tel: 0131 242 1714

 c. **London:** Dr Pratik Choudhary, Department of Diabetes, Kings College Hospital, Denmark Hill, London,

Greater London SE5 9RS. pratik.choudhary@nhs.net. Tel: 020 7848 5651

d. **London:** Dr Miranda Rosenthal, Diabetes Department, Royal Free Hospital, Pond Street, London, NW3 2QG. miranda.rosenthal@nhs.net. Tel: 020707794 0500 x 33325

e. **Manchester:** Dr Martin Rutter, Manchester Diabetes Centre, 193 Hathersage Road, Manchester, M13 0JE. martin.rutter@cmft.nhs.uk. Tel: 0161 276 6709

f. **Newcastle:** Prof James Shaw, Institute of Transplantation, Freeman Hospital, Freeman Road, High Heaton, Newcastle upon Tyne, NE7 7DN. Jim.Shaw@newcastle.ac.uk.   Tel: 0191 222 7019 / 8129

g. **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. 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

Appendix 4: Quality assurance specification for glucose monitoring devices

There is a wide range of meters available, but considerable variation in accuracy.

All blood glucose meters must meet ISO 15197-2013 standard of accuracy and some are CE marked.

This accuracy specifies that 95% of readings must be within 0.83mmol/L for glucose values <5.55mmol/L, within 20% for glucose values >5.55mmol/L, 99% of readings must fall within zones A and B of the Consensus Error Grid).

Company reported accuracy results may vary from real-world experience

An independent assessment of accuracy report in 2017 (Ekhlaspour et al J Diabetes Sci technol. 2017 May;11(3):558-566 demonstrated that only 2/17 meters met the stringent ISO 15197-2013 standard and 7/17 met the stringent ISO 15197-2013 standard.)

Non-CE marked meters generally performed worse.

Meter accuracy is essential for people with type 1 diabetes as it may lead to incorrect therapy adjustment in people who are sensitive to insulin.

Types of meter

Bolus advisors

Recommended as they ease the burden of calculation and allow data capture for review by patient and HCPs. Some evidence to support reduced variability in results.

Device connectivity

Some meters have Bluetooth connectivity with smartphones and meter apps for real-time visualisation of data. Some allow integration of data into purchased apps.

May improve engagement and provide motivational feedback.

Some pumps have integrated or connected meters. Individuals must be supported to use these meters and provided with appropriate test strips.

Talking meters

These have a larger display, voice instructions and audio results and should be offered to people with visual impairment.

Appendix 5: NCEPOD recommendations for perioperative diabetes care

	Principal recommendations 1 to 5	Study key findings
1	Write and implement a national joint standard and policy for the multidisciplinary management of patients with diabetes who require surgery. Information should include responsibilities for diabetes management across all specialties during routine care and in highrisk patients. **(AoMRC to lead at an organisational level, and the Clinical Lead for Perioperative Diabetes Management to lead at a local level)**	Numerous diabetes guidelines are in existence, but are specialty specific: • Association of Surgeons of Great Britain and Ireland (ASGBI) • Association of Anaesthetists of Great Britain and Ireland (AAGBI) • Joint British Diabetes Society (JBDS) British Association of Day Surgery (BADS).
2	Appoint a clinical lead for perioperative diabetes care in hospitals where surgical services are provided. This person will be responsible for developing policies and processes to: a. Ensure diabetes management is optimised for surgery b. Ensure patients with diabetes are prioritised on the operating list, including the co-ordination of emergency surgery* c. Identify when involvement of the diabetes multidisciplinary team, including diabetes specialist nurse, is required d. Ensure high-risk patients are identified, such as those with type 1 diabetes e. Identify patients with poor diabetes control who may need pre-operative optimisation or VRIII f. Audit cases of prolonged starvation g. Ensure high quality discharge planning. **(Medical Directors, Directors of Nursing)** * This supports the recommendation from the National Emergency Laparotomy Audit	• 28.0% (87/311) of hospitals had a named clinical lead for perioperative diabetes • 83.8% (160/191) of hospitals where emergency surgery was performed, had a co-ordinator for emergency theatre bookings • 21.8% (41/188) of hospitals where emergency surgery was performed had no system for confirming that relevant investigations and resuscitation had been completed and that the patient was fit for surgery • 20.6% (40/194) of hospitals where emergency surgery was performed had no system for determining the clinical priority of emergency cases • 90.9% (288/317) of hospitals had a hospital policy or guideline on managing operating lists of which 258/282 (91.5%) stated patients with diabetes should be prioritised early on the morning or afternoon theatre list.
3	Use a standardised referral process for elective surgery to ensure appropriate assessment and optimisation of diabetes. This should include: a. Satisfactory HbA1c levels within 3 months of referral b. Control of co-morbidities c. A list of all current medications d. The patient's body mass index (BMI) e. Estimated glomerular filtration rate (eGFR) f. Perioperative risk rating. **(Primary Care Providers, Commissioners, Clinical Lead for Perioperative Diabetes Management, Lead anaesthetist for pre-operative assessment)**	• The majority (144/253; 57%) of elective referrals in this study were made from general practitioners • In 41% (83/202) of referrals there was no information provided on the management of the patient's diabetes in the community • HbA1c within last 3 months was provided in only 50/118 (42%) • The recording of co-morbidities (90/118; 76%) and current medication (98/118; 84%) were frequently provided but not fully and evidence of regular glucose measurement was only available in 22.0% (26/118) blood pressure measurement in 35.6% (42/118), urgency of referral in 21.2% (25/118), eGFR in 19.5% (23/118) and body mass index (BMI) in 37.3% (44/118).

4	Ensure that patients with diabetes undergoing surgery are closely monitored and their glucose levels managed accordingly. Glucose monitoring should be included: a. at sign-in and sign-out stages of the surgical safety checklist (e.g. WHO safety checklist) b. in anaesthetic charts c. in theatre recovery d. in early warning scoring systems System markers and alerts should be used to raise awareness of glucose levels, e.g. tagging of electronic medical records, use of a patient passport or unique stickers in paper based case notes. **(Clinical Lead for Perioperative Diabetes Management, Lead Anaesthetist for Pre-Operative Assessment, Clinical Directors, Medical Directors, Directors of Nursing)**	• 46.9% (212/452) of patients did not have capillary blood glucose recorded intra-operatively • 3.8% (59/426) patients did not have their capillary blood glucose levels measured in the theatre recovery area • 21.2% (86/406) of patients did not have their blood glucose managed appropriately in the post-operative period, in the opinion of the case reviewers • A surgical safety checklist was used for 97.1% (432/444) of patients but diabetes management was not included in 30.2% (114/378) • If diabetes was mentioned on the surgical safety checklist then capillary blood glucose measurements were more likely to be undertaken (141/240; 58.8% vs 54/109; 49.5%) during the operation • Including diabetes in the surgical safety checklist was associated with more appropriate management of diabetes in the theatre recovery area 182/216 (84.3%) vs 65/102 (63.7%) in the view of the case reviewers.
5	Ensure a safe handover of patients with diabetes from theatre recovery to ward, this should be documented in the case notes and include: a. Medications given in theatre b. Glucose level on leaving the recovery area c. Glucose level on arriving into the ward d. Ongoing management of diabetes, especially VRIII e. Criteria for contacting the diabetes team. **(Clinical Lead for Perioperative Diabetes Management, Clinical Directors, Medical Directors, Directors of Nursing)**	• 59.8% (274/458) of patients did not have a clear plan for the management of the patient's diabetes on the day of surgery recorded • 12.4% (55/445) of patients did not have diabetes medications documented on the day of surgery • 46.9% (212/452) of patients did not have capillary blood glucose recorded intra-operatively • 13.8% (59/426) patients did not have their capillary blood glucose levels measured in the theatre recovery area • 21.2% (86/406) of patients did not have their blood glucose managed appropriately in the post-operative period, in the opinion of the case reviewers • The post-operative clinical area was inappropriate in 19/503 (3.8%) of cases in the opinion of the case reviewers • Diabetes was not managed by all the appropriate staff in 77/464 (16.6%) patients, in the opinion of the case reviewers. Early involvement of a diabetes specialist nurse would have been beneficial in a majority of these patients (44) in the opinion of the case reviewers • Adequate discharge arrangements were not made for the patient's diabetes care in 78/390 (20.0%)patients, in the opinion of the case reviewers.

		Additional recommendations	Study key findings
6		Develop a pre-operative assessment clinic policy and standards for the management of patients with diabetes. These should be developed by the lead anaesthetist* and the clinical lead for perioperative diabetes management, and include: a. Identification of high-risk patients, such as those with poorly controlled or type 1 diabetes b. Optimisation for surgery c. Criteria for involvement of the diabetes multidisciplinary team These policies should be audited locally and the results acted upon. **(Lead Anaesthetist for Pre-operative Assessment, Clinical Lead for Perioperative Diabetes Management, Clinical Directors)** * This supports the recommendation by the AAGBI guidelines in recommending that all hospitals should have a lead anaesthetist for pre-operative assessment.	• 43.4% (132/304) of pre-operative assessment clinics did not have a specific policy for management of diabetes patients undergoing surgery. Those that did, varied with regards to the involvement of wider multidisciplinary team members.
7		Ensure that patients with diabetes attending a preoperative assessment clinic prior to elective surgery have: a. Access to the diabetes multidisciplinary team, including diabetes specialist nurse input b. Written instructions regarding their diabetes management plan prior to surgery. **(Lead Anaesthetist for Pre-operative Assessment, Clinical Lead for Perioperative Diabetes Management)**	• 86.7% (228/263) of elective patients attended a preoperative assessment clinic • 9.9% (20/203) of patients were not seen by all appropriate staff at the pre-operative assessment clinic. Most commonly this was diabetes specialist nurses • 47.1% (88/187) of patients had no documented specific instructions on management of their diabetes prior to surgery • 70.2% (120/171) of cases had no documented • evidence that the patient was included in their diabetes plan.
8		A clinical lead for day surgery* should be in place in all hospitals providing day surgery services. This lead, along with the clinical lead for perioperative diabetes management should be responsible for ensuring that patients with diabetes are considered for day surgery, where appropriate. Policies should be developed to ensure patients with diabetes have equity of access to day surgery. **(Clinical Lead for Day Surgery, Clinical Lead for Perioperative Diabetes Management, Clinical Directors)** * This supports guidelines from the British Association of Day Surgery, the AAGBI and the RCoA	• 60.2% (142/236) of hospitals with a day surgery unit had a clinical lead or director of the day surgery unit • Only 28.0% (87/311) of hospitals had a named • clinical lead for perioperative diabetes.
9		Cancellation of elective surgery in patients with diabetes should be avoided, particularly for known clinical reasons. Cancellation rates should be audited locally and the results acted upon. **(Clinical Lead for Perioperative Diabetes Management, Lead Anaesthetist for Pre-operative Assessment, Clinical Directors)**	• 12.9% (34/229) of elective patients had their surgery cancelled on a previous occasion • 5/20 patients had their operation cancelled due to poor glycaemic control and a further 5 due to avoidable co-morbidity • There were more type 1 than type 2 patients (9/113; 8% vs 9/359; 2.5%) admitted non-electively who were already on the elective waiting list.

10	Develop and implement referral criteria for surgical inpatients with diabetes to: a. Diabetes specialist nurses b. Dietitians c. Pharmacists d. Other diabetes multidisciplinary team members as required. **(Clinical Lead for Perioperative Diabetes Management, Clinical Directors)**	• Reviewers felt 75 patients should have been seen by a diabetes specialist nurse and 23 by a consultant diabetologist but were not • 18.1% (66/364) of patients had an inadequate nutritional assessment • Case reviewers felt that inadequate medicines reconciliation by medical staff occurred in 59/379 (15.6%) patients and by a pharmacist in 163/255 (24.7%).
11	Record and monitor the time at which a patient begins fasting (for surgery or clinical reasons). If a patient misses more than one meal, their care should be escalated to the responsible medical team as this indicates prolonged starvation. **(Clinical Lead for Perioperative Diabetes Management, Directors of Nursing)**	• Prolonged starvation resulted in a change in diabetes management in 9.6% (42/439) of patients, including the use of a VRIII in 35 patients of which reviewers felt 23 were avoidable.
12	Prioritise patients with diabetes on the operating list to avoid prolonged starvation.* Prioritisation of patients with diabetes on operating lists should be subject to local clinical audit and the results acted upon. **(Lead Anaesthetist for Pre-operative Assessment, Clinical Lead for Perioperative Diabetes Management, Clinical Directors)** * This supports the Joint British Diabetes Society Guidelines	• 19.4% (90/465) of patients were not scheduled appropriately for their surgery in the opinion of the case reviewers.
13	Provide patients with diabetes with education and information about their diabetes management at discharge from hospital as part of the discharge planning process. **(Diabetes Specialist Nurses, Clinical Lead for Perioperative Diabetes Management)**	• Adequate discharge arrangements were not made for the patient's diabetes care in 78/390 (20.0%) patients, in the opinion of the case reviewers.