Expectation of Care
for
Persons with Type 1 Diabetes

NHS Greater Glasgow & Clyde
Managed Clinical Network for Diabetes
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Introduction

This document outlines the expectation of care for persons with type 1 diabetes within NHS Greater Glasgow & Clyde (NHS GGC) aged 16 or over. It describes the care and support a person with type 1 diabetes can expect to receive from NHS GGC from the point of diagnosis onwards.

Adopting this approach will make sure that care is in line with the Scottish Government’s Quality Strategy, namely that it is patient-centred, efficient, effective, equitable, safe and timely.

We acknowledge that diabetes services need to be able to work across community and acute hospital care. We also need to review existing care pathways to make sure that services can continue to meet the needs of a growing number of persons living with diabetes. Recognising the limited resources available to public services in the years ahead, it will be crucial that existing resources are used appropriately to provide care for those at greatest need.

New standards of care and care pathways must be adopted to provide evidence based practice in line with national guidelines (SIGN guideline 116) and the Scottish Diabetes Action Plan. It is also important that the review and development of existing diabetes services takes into account other national indicators of care such as the Diabetes UK 15 Healthcare Essentials.

Some aspects of this document are currently being delivered to a very high standard while others are aspirational and will require a revision of how we currently deliver care.

Finally, this document aims to provide a shared understanding of good diabetes care on which we can build and further develop services for persons with type 1 diabetes across NHS GGC.

The key points from the expectation of care are summarised on pages 10 and 11.

On page 17 of the document you can find a glossary that explains the key technical terms used in the document.

Expectation of Care

Each person with type 1 diabetes will move through the stages of type 1 diabetes care at a different pace depending on individual circumstances. This also means that some of the stages may not apply for some people.

A fully person-centred approach to type 1 diabetes care also takes into account any other health issues (co-morbidities) and wider life circumstances.

The expectation of care for a person with type 1 diabetes mellitus is that:

Stage 1: Diagnosis and Initial Care (within the first 24 hours)

1. We will refer you immediately to specialist diabetes care for a same day review if we suspect you have a possible diagnosis of type 1 diabetes (please see page 14 for information regarding weekend and out of hours cover).

2. We will confirm your diagnosis of type 1 diabetes in line with existing NHS GGC diagnostic guidelines.

3. Once we confirm a diagnosis of type 1 diabetes we will add you to the GP practice diabetes register and SCI-Diabetes. SCI-Diabetes is the name of the national clinical database system for diabetes. Data recorded on this system is an essential part of your healthcare record.

4. Within 1 working day a suitably trained healthcare professional (e.g. a specialist nurse or dietitian) will give you (and your family and carers if appropriate) an initial standardised care package. This will:
   - Explain the diagnosis and what type 1 diabetes means for you
   - Show you how you adjust and inject insulin
   - Teach you how to check blood glucose (blood sugar) and ketones (a toxic by-product of using muscle and fat for energy as your body lacks insulin)
   - Give initial diet and lifestyle advice (including smoking and alcohol)
   - Provide contact details for out of hours help and advice

5. If you are diagnosed at a later stage you may be in diabetic ketoacidosis (DKA). DKA develops when your body has no insulin, leading to high levels of ketones and acid. This is a medical emergency and can be life-threatening. We will admit you to hospital immediately for management in line with the national DKA protocol. Our aim is to have fewer than 1 in 10 people present with DKA at diagnosis.
Stage 2: Stabilisation
(usually over the next 7 days)

1. Suitably trained healthcare staff will give you further specialist advice and education. This will be standardised and will cover:
   - Blood glucose and ketone monitoring
   - How to adjust and inject insulin yourself
   - Basic advice on diet
   - Treatment of hypoglycaemia (low blood glucose levels)
   - 'Sick day rules' on how to manage diabetes during an illness
   - How type 1 diabetes affects you and your child during pregnancy
   - How to manage diabetes safely as a driver
   - Life circumstances advice (for example employment and money issues)
   - Access to additional support (for example from other patients or from voluntary organisations like Diabetes Scotland)

2. You will have regular contact (e.g. face-to-face or by telephone or email) with your specialist diabetes team.

Stage 3: Establishing Self Management
(usually weeks 1 to 4)

1. We will give you ongoing education and support, including:
   - Specialist dietetic advice (either in a group or on a one-to-one basis, whichever fits best with your personal circumstances)
   - Ongoing diabetes specialist input
   - The knowledge and skills you need to manage type 1 diabetes well yourself

2. We will give you the opportunity to access relevant personalised information about your health. We recommend to use the My Diabetes My Way website: http://www.mydiabetesmyway.scot.nhs.uk to see your own personal information about your diabetes management.

Stage 4: Consolidation or Intensification
(usually from month 1 to the end of the ‘honeymoon period’)

1. You will have access to early structured group education.

2. You will have a multidisciplinary review. This includes:
   - A one-to-one review at least once a year
   - Screening in line with current guidelines for potential diabetes related microvascular (small blood vessel) damage. This includes damage to your eyes, feet, kidneys and sexual function.
   - Managing risk factors to help reduce the risk of heart disease and stroke. This includes cholesterol (fat), blood pressure and lifestyle issues (diet, weight management, smoking, physical activity)
   - Screening for psychological support needs
   - Where appropriate, contraceptive advice and pre-conception or pregnancy planning
   - Screening for autoimmune conditions such as thyroid conditions and coeliac disease in line with current guidelines.
   - Possible group follow-up with access to additional support if appropriate

3. By stage 3 you will have had an opportunity to meet all members of the multidisciplinary specialist team responsible for your diabetes care. This includes specialist doctors, nurses, dietitians and podiatrists, your GP and the Practice Nurse.
3. You and your healthcare provider will agree individualised treatment goals.

4. This will include discussing your understanding of your personal clinical information. We will give you access to relevant information about your care to help you self manage. You can access this on the My Diabetes My Way website or we can give you the patient-held summary available in SCI-Diabetes.

5. You will have be able to access specialist services when required.

Stage 5: Consolidation or Glycaemic Intensification (usually after year 1 or after the ‘honeymoon period’)

1. We will offer you access to structured group education in line with the NHS GGC type 1 diabetes patient education pathway (ideally within 24 months of diagnosis). This is a course that helps you manage your diabetes by explaining how to adjust insulin, manage your diet and live healthily. It is usually in a group of 8 to 10 people.

This will support you to intensify glycaemic management (controlling your blood glucose or blood sugar levels) and to appropriately self manage your diabetes. This education can also be delivered on a one-to-one basis, if this is more appropriate for your individual circumstances.

2. We will support you to self manage. This support will be available from the multidisciplinary specialist diabetes team.

3. If you meet the NHS GGC clinical criteria for insulin pump therapy (which include having previously attended structured patient education) we will consider you for pump therapy.

4. If you meet the criteria for islet cell or pancreatic transplantation and other non-standard treatment options we will offer you a referral if this is considered clinically appropriate.
Type 1 Diabetes Expectation of Care

1: Diagnosis and Initial Care
(within the first 24 hours)
Everyone with suspected Type 1 Diabetes will:
- referred immediately to specialist diabetes care for a same day review and to confirm diagnosis
- given an initial standardised care package within 1 working day
- admitted immediately if they present with acute diabetic ketoacidosis (DKA)
- added to the GP practice diabetes register and the SCI-Diabetes clinical database system

2: Stabilisation
(usually over the next 7 days)
Everyone with Type 1 Diabetes will:
- receive further specialist advice and education
- have regular contact (e.g. face-to-face or by telephone or email etc) with the specialist diabetes team

3: Establishing Self Management
(usually weeks 1 to 4)
Everyone with Type 1 Diabetes will:
- receive ongoing education and support, including: specialist dietetic advice, ongoing diabetes specialist input and the knowledge and skills to self-manage
- have the opportunity to access relevant personalised information about their condition
- have had an opportunity to meet all members of their specialist diabetes team

4: Consolidation and Intensification
(usually from month 1 to the end of ‘honeymoon period’)
Everyone with Type 1 Diabetes will:
- have access to early structured group education
- have a multidisciplinary review at least once a year
- have agreed personal goals for their treatment and self management
- be able to discuss their personal clinical information
- have timely access to specialist services when required

5: Glycaemic Intensification
(usually after year 1 or after the ‘honeymoon period’)
Everyone with Type 1 Diabetes will:
- have access to structured group education (ideally within 24 months of diagnosis)
- be supported to self manage
- have access to insulin pump therapy if clinically appropriate
- be referred for islet cell / pancreatic transplantation and other non-standard treatment options if clinically appropriate
Specific Considerations

Footcare
A separate Expectation of Footcare document has been developed to provide more detailed information on diabetes foot care. This is available from the Diabetes MCN or online at: library.nhsggc.org.uk/mediaAssets/My HSD/ Diabetes Footcare-Expectations of care-final.doc

Persons with Renal Disease
A separate Expectation of Care for Diabetic Renal Disease document is being developed to provide more detailed information on care for persons with renal disease (kidney disease) in diabetes.

Transitional Care
Young people with type 1 diabetes need additional support when they move from the children’s service into adult care (this process is often referred to as "transitional care"). A separate Expectation of Care is being developed by the Children’s Diabetes Service to describe what this support should cover.

In-patient Diabetes Management
Patients admitted to hospital will:
1. be supported to self manage their diabetes, where appropriate, and to achieve good glycaemic control during their hospital stay.
2. have timely access to specialist diabetes care where required.
3. have an HbA1c test done if no HbA1c has been recorded within the last 3 months prior to admission.
4. have appropriate discharge planning including community support (e.g. Community Diabetes Specialist Nurse or District Nurse) if required.

Housebound, Nursing Home or Domiciliary Care Population
For people who are housebound or are living in care or nursing homes, certain aspects of standard type 1 diabetes care may not be appropriate. We will create an appropriate care plan taking into consideration the needs of the person.
Inequalities and Protected Characteristics

It is important that health care services are equally accessible and appropriate for all. Health care professionals involved in diabetes care will make sure that all persons with type 1 diabetes receive diabetes care that is accessible to them and is appropriate and relevant to the individual's circumstances.

This will take into account the person's age, ethnicity, sexual orientation, gender, disability, religion and belief and their socio-economic status.

Challenges and Proposed Solutions

1. Access to specialist services out of hours and at weekends

At the moment working patterns and staffing arrangements cannot guarantee that diabetes specialists are always available at night or over weekends. This means that a same day specialist review of all new type 1 diabetes patients may not always be achievable. We expect that ongoing service changes will create opportunities to improve out of hours access to specialist expertise. For example, this may include more joint working between staff based in the community and hospital staff, technology or telehealth solutions, or the use of so-called 'virtual clinics' which make the knowledge and expertise of diabetes specialist more readily available to GPs.

In the interim, weekend and out of hours access for urgent type 1 diabetes cases will continue to be via emergency referral to the hospital with a review by a diabetes specialist as soon as possible. Standardised patient education will be available in acute receiving units in the hospital for out of hours presentations.

2. Patients not attending or not engaging with hospital based diabetes services

In some cases patients do not engage with hospital based services. There are many reasons why this may happen. Some people face practical difficulties in accessing hospital services, for example having to attend a diabetes centre that is not local and may be difficult to get to.

We will develop a strategy for addressing these issues.

3. Psychology screening and access to specialist psychology services

The expectation of care is that:
a) suitably trained members of the diabetes team will assess and support persons with psychological problems to make sure these do not interfere with or are related to their diabetes self care
b) specialist psychological support will be available for people with severe psychological problems where these either interfere with or are related to their diabetes self care

Work is ongoing to improve access to specialist psychology services for persons with long term conditions, including diabetes. This focusses on providing support to patients with high-level psychological support needs. It is important to recognise, however, that there is a range of psychological support needs among people with diabetes.

Most of those needs can be met by better utilising staff in general practice and specialist diabetes services to provide emotional and psychological support and advice. Better signposting to help and support from voluntary organisations and to non-medical support is also important.
References


Glossary

Blood glucose
When sugary or starchy foods are digested they are broken down into a simple sugar: glucose. The blood then transports this to the body's cells where the glucose is used for energy.

Cardiovascular
This describes the system in the body that is responsible for the blood supply to all parts of the body, providing fuel and oxygen. This system includes the heart and all blood vessels. Cardiovascular risk factors can lead to damage to the blood vessels and cause heart attacks, strokes or increase the risk of a lower leg amputation.

Co-morbidity
Having a co-morbidity means having another health condition or illness.

Diabetic ketoacidosis (DKA)
This serious condition occurs when the body lacks insulin. This means that it cannot use the glucose for energy. Instead it starts to break down other tissue for energy. This releases toxic chemicals as a by-product, called ketones. DKA can be life-threatening and needs urgent treatment.

Glycaemic management or Glycaemic Control
This is the process of managing or controlling blood glucose levels in diabetes.

HbA1c test
This test gives an average blood glucose level over the previous 2 to 3 months. It is used to see how well controlled blood glucose levels have been over that period of time.

Honeymoon period
Some people have an initial period after developing type 1 diabetes when their body still produces some insulin and they can achieve good glycaemic control with little or no insulin treatment. This period generally lasts for a few months to a year.

Hypoglycaemia
Hypoglycaemia means having low levels of blood glucose. Symptoms of this can include: feeling shaky, sweating, hunger, tiredness, blurred vision, finding it hard to concentrate, headaches, or an increased heart rate.
Insulin
A hormone that is responsible for regulating blood glucose levels in the body by allowing the glucose to enter the body's cells to be used for energy.

Islet cell
Islet cells are the cells in the pancreas that are responsible for producing insulin.

Ketones
See 'Diabetic ketoacidosis'

Microvascular
This means 'small blood vessels'. They provide a blood supply to the eyes, kidneys or nerves.

Macrovascular
This means 'large blood vessels', for example the main blood vessels to and from the heart or the brain.

Multidisciplinary
This describes teams that are made up of healthcare professionals from different disciplines, for example doctors, nurses, dietitians and podiatrists.
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