Diabetes UK Scotland

Diabetes UK Scotland is one of Scotland’s largest patient organisations. Our mission is to improve the lives of people with diabetes and to work towards a future without diabetes through care, research and campaigning. With a membership of over 11,000, including over 600 health care professionals, Diabetes UK Scotland is an active and representative voice of people living with diabetes in Scotland. We welcome the opportunity to respond to this consultation and hope that our comments will feed in to the committee’s understanding in this important area.

Facts about diabetes

- There are 209,706 people with diabetes in Scotland, over 4% of the population.\(^1\)
- There are 3531 children and young people under the age of 19 with Type 1 diabetes.\(^2\)
- The average age of diagnosis of Type 1 diabetes is currently 12 years and is getting younger each year.
- Diabetes is set to increase. It is predicted that diabetes prevalence will double worldwide, rising to at least 5% by 2010, accounting for 300,000 people in Scotland.\(^3\)
- Diabetes affects the young and old, and has particularly poor outcomes in those of lower socio-economic status and in those from black and minority ethnic groups.\(^4\)^\(^5\)
- The number of people with diabetes is growing as a proportion of all long-term conditions.\(^6\)

Diabetes and mental health

- 10% of young women with Type 1 diabetes have an eating disorder.
- Eating disorders are more common in adolescents with diabetes compared with non-diabetic peers, and adversely affect glycaemic control.
- Some studies suggest that depression and/or anxiety may affect up to 50 per cent of young people with poorly controlled Type 1 diabetes.\(^7\)
- Mental health problems occur frequently in diabetes; depression is the commonest disorder, but it is often unrecognised and untreated. It affects those with both Type 1 and Type 2 diabetes, but is more frequent in women.\(^8\)^\(^9\)
- Depression may also be a risk factor for diabetes (especially Type 2), due to its effects upon diet, exercise and smoking/drinking.
- Between 20 and 30 per cent of people with diabetes will experience significant depression which is often associated with poor self-care.\(^10\)
- In adults with established Type 1 and Type 2 diabetes, the frequency of depression and anxiety are about twice as high as in the general population.\(^11\)
- Anxiety disorders are also more frequent in those with diabetes. Patients and doctors may find it difficult to distinguish anxiety problems from hypoglycaemia.\(^12\)
- Phobic disorders are more common in adults with diabetes than in the general population. Fear of blood and injury may lead to less blood-glucose self-monitoring and poorer control. Fear of hypoglycaemia is common.\(^13\)^\(^14\)
- The prevalence of Type 2 diabetes is increased in those with schizophrenia.\(^15\) The use of antipsychotic medication is associated with an increased risk of developing Type 2 diabetes, which seems to be independent of the risk associated with schizophrenia itself.
• Some people with diabetes have a capacity to self harm insofar as they neglect their own needs, take excessive risks and put themselves in hazardous situations (skipping insulin doses, for example).

**How children and adolescents potentially at risk of developing mental health problems are identified and how those problems should be prevented.**

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I feel I was left to deal with it myself & had no one to talk to regarding how I was feeling.  
23yr old from Lothian with Type 1 diabetes

According to SIGN Guideline 55, Management of Diabetes\textsuperscript{xiv}, factors contributing to an increased risk of young people with diabetes developing psychological problems include:

• avoidance coping (strategies which do not actively try to solve a difficulty faced)
• too much responsibility on the child
• family conflict
• lack of communication, both within families and with the diabetes team
• low socio-economic status
• non-traditional family structure
• poor maternal health, especially depression

In order to identify young people at risk, SIGN recommends that there should be regular assessment for psychological problems. Specific psychological problems can be identified at diagnosis and 1-2 years later, using validated tools performed by a trained practitioner.

10% of young women with Type 1 diabetes have eating disorders. In cases where insulin purging – going without insulin - is combined with overeating, it is considered to be a form of bulimia. Some people with Type 1 diabetes often uses insulin omission as a substitute for self induced vomiting and, in this way, avoid gaining weight. It is estimated that one in three young women under the age of 30 abuse their insulin in this way. SIGN and NICE both recommended that multidisciplinary teams should be alert to the possibility of eating disorders in adults with Type 1 diabetes and that early or even urgent referrals should be made to eating disorder services\textsuperscript{xv}.

Behaviours that improve health outcomes in later life are laid down in adolescence, so public health policy and clinical focus on the health of young people will have important long-term health benefits\textsuperscript{xvi}. In diabetes care, the optimum scenario is that the person with diabetes will be an expert on their own self-management; however, this requires access to quality information and access to structured diabetes education support programmes.
What action is being taken to facilitate early intervention and what else can be done.

“I had ongoing eating disorder issues, and the team has been very accommodating in working with my psychologist on this.”

16yr old from Ayrshire and Arran

Psychological services for young people with diabetes are often all too inadequate across Scotland. The provision of psychotherapy and counselling services is sporadic and even when the need is recognised, investigations by Diabetes UK, NHS QIS and Dr Foster for Diabetes UK, show the resources are frequently not in place to meet the demand xvii,xviii,xix.

An internal report by the Psychology Working Group of the Scottish Diabetes Group in 2006xx, found that: “The level of psychology provision to people with diabetes is inadequate and amounts to about one psychologist for every 11,000 people with diabetes. There is no provision at all to children and adults with diabetes in most health board regions.”

The Working group also found that:
- Specifically each week in Scotland only 8.5 sessions of psychology are provided to children and their families in Scotland.
- In three quarters of health boards, psychologists are not members of the diabetes multi-disciplinary team but are members of CAMHS.
- The NHS fund seven weeks of psychology provision to children, however as a result of not filling vacant posts or locally decisions, only two and a half weeks is delivered.

NHS Quality Improvement Scotland,xxi in their Diabetes: National Overview Follow-up Report in 2008, reported that across Scotland, only 2 out the 14 NHS boards had “appropriate access to identified key health professionals including..... psychology services”. As part of the review process, NHSQIS examined the services delivered in each NHS Board in detail and reported that very few health boards have dedicated access to full or part time paediatric diabetes psychology services. A limited number of Health Boards seek the input of psychological services when dealing with children. In some areas, children and young people have a choice of referral to specialist services outwith their own area or referral to non-specialist psychologists. At the time of the review, three Health Board areas had no specialist diabetes psychological support available for children.

What obstacles there are in identifying children and adolescents with mental health problems and how they might be overcome

It can prove difficult to identify mental health problems in young people with diabetes. Common pressures experienced by young people – physical, psychological, emotional, behavioural – can mask the specific impact of diabetes on mental health. According to SIGN 55, psychological or educational interventions have positive effects on psychological outcomes, knowledge about diabetes and glycaemic control. Maintaining parental involvement also improves glycaemic control.
How access to services and ongoing support can be improved.

“What to do when you feel things are getting too much? Personally I find it hard to raise the subject at the annual review and to talk to people who haven't actually got diabetes” 

23yr old male from Grampian

Some of the factors behind the link with depression and diabetes are often perceived as a loss of good health. Diabetes affects expectations of longevity, can affect levels of physical functioning, and can affect plans for a future career. The indifference that a person may develop to their own depression can mean that they 'lack energy' to care for themselves, resulting in high blood glucose level over long periods and an imminent danger of ketoacidosis.

Children and young people should, if necessary, be offered tailored psychological support by professionals as part of the diabetes team or with a close interest in diabetes. SIGN also recommends that there should be regular assessment of psychological problems to identify poor coping strategies and eating disorders. However, this is not the case throughout Scotland and in many areas, children and young people in need of psychological support are referred to either specialist services in other areas or local general services.

Diabetes UK Scotland agrees with NICE, that Diabetes professionals should arrange “prompt referral to specialists of those people in whom psychological difficulties continue to interfere significantly with well-being or diabetes self-management.” Validated, cognitive coping strategies should also be offered by trained specialist to deal with diabetes related problems.

Other innovative projects have proposed new interventions to support young people with their diabetes. Sweet Talk, developed in Tayside and Fife used computer based mobile phone texting from health care professionals to offer information, emotional support and goal messages to young people with the aim of giving more confidence with insulin management.

In 2007, Diabetes UK Scotland held a Youth Summit for young people with diabetes. A key recommendation from the Summit was the production of new information specifically targeted towards young people. In 2008, with a generous donation from Lloyds TSB Foundation for Scotland, a toolkit Making Connections was developed to offer advice to young people in all aspects of their lives. Making Connections has now been distributed to over 1200 young people in Scotland.

The Scottish Diabetes Action Plan set out plans, beyond the original recommendations within the Scottish Diabetes Framework for improving psychological support and services for children and young people by the end of 2009. The publication of revised SIGN guidance on diabetes is due to be published in Spring 2010 and this will further set out the clinical evidence of psychological support for children and young adults with diabetes.
What problems there are around transition from CAMHS to adult mental health services and how a smoother transition may be achieved

While the question refers to CAHMS, there is a concomitant issue in relation to diabetes services. The transition from childhood to adolescence is a hazardous time, many teenagers encounter inadequate services and support, and consequently many opt out of responsibility for their condition. Those moving to adult health services report that they do not receive the same level of support. According to the NHS QIS 2008 review of diabetes services, seven health boards have no dedicated adult psychological support for people with diabetes. Two NHS boards have a part-time service and four NHS Boards have referral arrangements in place to community-based services. NHS QIS found that referral to community services could result in long waiting times.

The National Institute of Clinical Excellence (NICE) recognise the benefit of psychology services in supporting young people with diabetes, their parents and staff. Psychology services also offer valuable support in an effective transition process\textsuperscript{xxv}. They can assist in establishing an individual’s level of cognitive maturity, assess emotional readiness, offer family interventions where issues that might hamper transition are identified, consider the “systems” around young people (including the healthcare system), identify barriers to transition and offer systematic interventions, e.g. training, to the healthcare team in issues such as communication.

In the recent recommendations for a diabetes transition service, the Royal College of Physicians in Edinburgh\textsuperscript{xxvi} recommended that “The service should have easy access to psychological support”.

Working in partnership with young people is central to forming positive relationships with them. Services must be tailored to the needs of the local youth population\textsuperscript{xxvii}. The views of young people must be taken into account when planning transition programmes.

Diabetes UK Scotland would be delighted to offer the committee further information should it wish to follow up any of the issues arising from this response.

\textsuperscript{vi} The impairments most commonly reported by adults with long-term health conditions were related to heart, blood pressure or circulation problems and to arthritis. The figures
suggest that both heart problems and diabetes (especially the latter) have increased over
time. For example in 2001-2002, 30% of adults with long-term health conditions
reported that their condition was related to heart problems, while 8% were related to
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