

POSITION STATEMENT



DiABETES UK
CARE. CONNECT. CAMPAIGN.

Title	Date
Care coordination/management for adults with Type 1 diabetes	April 2015

Key points

- The needs of adults with Type 1 diabetes differ from those with Type 2. They are fully dependent on insulin, and are usually diagnosed at a younger age. They are at increased risk of developing complications, due to their longer exposure to the condition, and have a greater need for specialist input and management for significant life events.
- In general, support for adults with Type 1 diabetes should be coordinated by a multi-disciplinary [specialist diabetes team](#). The team can be based either in the hospital or in a community setting. This is because managing Type 1 diabetes is complex and requires significant expertise, and there can be serious consequences if things go wrong. Access to specialist services, as soon as they are needed, is vital.
- It *may* be possible for adults with Type 1 diabetes to have their ongoing care and support managed outside of the diabetes specialist team provided there is effective integration between those delivering care and the specialist diabetes team, and the person with Type 1 diabetes chooses this.

Introduction

Around 3.2 million people in the UK have been diagnosed with diabetes. Of these, approximately 300,000 have Type 1 diabetes (1).

People with Type 1 diabetes cannot produce insulin. They are usually diagnosed when they are children or young adults, and the causes are unknown. They are fully dependent on insulin, either through multiple daily injections or use of an insulin pump. Due to their long exposure to the condition, they are at an increased risk of developing a range of complications. They also need specialist input and management during significant life events, such as emergency admission to hospital, elective surgery, or pregnancy.

Together, these factors mean that managing Type 1 diabetes is complex, for both the patient and their clinicians. It requires a level of specialist knowledge and experience that is usually accrued over many years. Ideally, therefore, support for adults with Type 1 diabetes should be coordinated by a specialist diabetes team.

Current situation

Evidence provided and discussed during the Health Committee inquiry, *Managing the care of people with long-term conditions* (2014), suggests that routine diabetes care in the secondary/hospital sector is becoming less common and there is a trend towards transferring services from acute care to primary and community care. It is unclear how many people with Type 1 diabetes are currently affected by this change, or might be in the future (2).

The Health Committee expressed reservations about such a move, noting in its report that the “evidence we received indicated that the mix of services for diabetes care in England was not structured to provide the best and most effective care to all people with diabetes” (2).

People with diabetes are also concerned about this situation. Diabetes UK has heard from people with Type 1 diabetes who are worried about being moved. They voice concerns that primary care professionals will not have the specialist knowledge required to manage their diabetes effectively. Many people with Type 1 diabetes have been seeing the same team of specialists for years. This kind of continuity of care is particularly important for conditions like diabetes, where continuity of care and trust in clinicians is integral to supporting effective self-management.

Managing adults with Type 1 diabetes in primary care or a community care team that does not include a diabetologist

Care for some people with Type 1 diabetes is already being managed by primary care and/or community care services which may have multi-disciplinary diabetes expertise, but that are not consultant led. This should only be considered where there is effective integration with a specialist diabetes team. The composition of a specialist diabetes team is defined in [commissioning specialist diabetes services for adults with diabetes](#).

If care for people with Type 1 diabetes is coordinated from primary care or by a community care team that does not include a diabetologist, the following must be in place:

- 1. A common understanding and agreement between GPs and specialist diabetes teams of which patients would, and would not, benefit from having their care managed outside of the specialist diabetes team.***

For example, this might be a suitable option for people with stable conditions, who have good self-management and have received education (which meets NICE guidance) (3).

It is important for patients to be involved in decisions about their care, and they should agree with any changes proposed. NICE recommendations about patient-centred care state that the views and preferences of individuals with Type 1 diabetes should be integrated into their healthcare and diabetes services should be organised, and staff trained, to allow and encourage this (4).

2. *Those responsible for care management/support are knowledgeable about Type 1 diabetes*

People with diabetes and healthcare professionals may be concerned that primary/community healthcare professionals who do not specialise in diabetes do not have the necessary skills and knowledge about Type 1 diabetes.

To provide effective support, professionals in primary/community care must have demonstrable skills and knowledge relating to diabetes, and be competent in caring for patients with Type 1 diabetes specifically. They should be confident dealing with a range of issues typically faced by these patients, and aware of possible complications.

Competence and knowledge should be gained through education, training, and workplace-based experience relating to Type 1 diabetes. The diabetes specialist team can have a significant role in training and supporting the development of expertise in those providing ongoing care in the community and primary care.

3. *There is support from, and rapid access to, a diabetes specialist team*

Those responsible for managing the care of a patient with Type 1 diabetes should have clear protocols for accessing and communicating with the diabetes specialist team so they can advise patients accordingly. There should be straightforward, rapid access routes to specialist care services. There should also be an agreed urgent referral pathway, including a monitored self-referral pathway, to enable patients to access specialist care directly in urgent situations.

Recommendations

Commissioners must:

- Make sure that all people with Type 1 diabetes have access to high quality diabetes care. In general, this means that support for people with Type 1 diabetes should be coordinated by a specialist diabetes team.

Where care for people with Type 1 diabetes is coordinated outside of the diabetes specialist team, commissioners must:

- Make sure there is a clear understanding and agreement locally about which patients with Type 1 diabetes *might* and *might not* have their care coordinated outside of the specialist team.

- Review local services regularly to determine whether they are continuing to meet the needs of patients with Type 1 diabetes and the healthcare professionals responsible for managing their care.
- Make sure there is effective integration between primary/community care and the specialist diabetes team. This will mean that:
 - non-diabetes specialists have access to training and are educated in diabetes management, so they are competent dealing with the specific needs of patients with Type 1 diabetes;
 - non-diabetes specialists have rapid access to advice and treatment from specialist care services, including the ability for patients to self-refer in urgent situations;
 - there are clear referral routes and support for non-urgent events, including elective surgery and pregnancy;
 - there are comprehensive, planned services that ensure patients receive annual checks and reviews, and which include proactive assessments to reduce the risk of complications developing and prevent unnecessary hospital admissions.

Commissioners should refer to the ‘further information’ section below for guidance on:

[the composition of a diabetes specialist team.](#)

[the effective integration of local services.](#)

[providing access to education for adults with Type 1 diabetes.](#)

[healthcare professional staffing and competencies for managing Type 1 diabetes.](#)

Conclusions

Managing Type 1 diabetes is complicated, for patients and healthcare professionals. Ideally, support for people with Type 1 diabetes should be coordinated by specialists who have the extensive expertise needed to manage this condition effectively and prevent life threatening complications arising.

Ongoing care and support for adults with Type 1 diabetes must only be managed in primary or community care (that does not include a diabetes specialist team) where there is effective integration between primary care and the specialist diabetes team. The needs and preferences of each patient must be considered when determining the care needs of people with Type 1 diabetes.

Further information

The provision of care for adults with Type 1 diabetes should be determined as part of the local model of care. To make sure adults with Type 1 have access to high quality care, in line with the above, commissioners should refer to the following documents:

- The composition of a diabetes specialist team: http://www.diabetes.org.uk/About_us/What-we-say/Improving-services--standards/Specialist-diabetes-team-role-and-members/
- The effective integration of local services: <http://www.diabetes.org.uk/integrated-diabetes-care>
- Access to education for adults with Type 1 diabetes: http://www.diabetes.org.uk/About_us/What-we-say/Improving-services--standards/Adult-learning-within-self-management-and-support/
- Healthcare professionals staffing and competencies for managing Type 1 diabetes: http://www.diabetes.org.uk/About_us/What-we-say/Improving-services--standards/healthcare-professional-competency-frameworks-in-diabetes-July-2014/

References

(1) QOF (2012-13)

(2) Health Committee – Second report: *Managing the care of people with long-term conditions* (June 2014). Page 33. The report also notes that the Association of British Clinical Diabetologists (ABCD) suggested that routine diabetes care in the secondary/hospital sector is less common than it had been before the 1990s. The result of this shift in services has been an effective limitation on the number of diabetes patients treated in the acute sector. ABCD indicated that between 10 and 30 per cent of such patients are now treated in hospital, and referrals for treatment have tended to occur later in the disease process, when complications less amenable to treatment may have developed.

(3) [TA60 – guidance on the use of patient-education models for diabetes](#)

(4) NICE guidelines [CG15] (patient-centred care).