

Type 1 diabetes: not lost but possibly misplaced

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'You have type 1 diabetes, but you don't need to see a specialist for treatment of your diabetes. It can all be done in the practice.'

This is an apparently simple message delivered for complex reasons. It is estimated that between 15 and 20% of people with type 1 diabetes are not being followed by the specialist team.¹ Whether this is appropriate or otherwise is open to debate but there is certainly a discussion that needs to take place.

Many commissioning documents use the term 'diabetes' without distinction. It is therefore stated that the majority of those with diabetes can be managed in primary care with the result that those with type 1 diabetes are swept away on the same tide, intentionally or otherwise. A recent Parliamentary & Stakeholder Think Tank report, 'Tailored Diabetes Commissioning', managed to fill 17 pages without once making the distinction between type 1 and type 2 diabetes.²

What we are examining here is the notion that those with type 1 diabetes do not need to attend or have easy access to a specialist service. At outset, it should be made clear that the bare fact that we are discussing care of type 1 diabetes in primary care at all is testimony to the huge strides that primary care staff have made in their understanding of and competence in the management of people with diabetes. More general appreciation of the issues facing those with type 1 diabetes has been a goal of specialist care for many years, and it might therefore seem odd that there is now a malaise surrounding the notion that we might finally cut the cord and set them adrift in a non-specialist setting. The nub of the issue lies just here: we are talking about either specialist care or primary care. At risk of spoiling the plot, the suggestion is that it should not be either/or, but both in concert.

Special considerations in type 1

Type 1 diabetes has a prevalence of about 0.4%. In the UK, therefore, there are approximately 250 000 people with the condition. If you attend a major sporting or entertainment event, the stadium may hold about 50 000 people, so you can imagine that there are five stadiums full of people with type 1 diabetes in the country. This is a lot of people but, by the time they leave the stadium and go home, they become diluted, and there are only 4 in every 1000 of the population. A GP practice of 5000 people will therefore have 20 such individuals, a small number, and certainly not enough to allow experience for revalidation in diabetes for a consultant.

Herein lies the problem. A significant number of people have type 1 diabetes, and yet they are sufficiently rare as to make it hard to get a feel for their problems. Nevertheless, we should recognise that this is a vulnerable group because:

- They are usually diagnosed at a young age when they are ill equipped to deal with the stresses of managing a long-term condition.

- They are, by definition, fully dependent on insulin, resulting in medical emergencies at times of insulin deprivation or insulin excess. Repeated hypoglycaemia predisposes to hypoglycaemia unawareness.
- The early age at diagnosis results in long-term disease exposure with resultant complications.
- Long-term disease exposure renders good glycaemic control at an early stage of paramount importance to avoid long-term complications.
- Life events, which are routine for the non-diabetic population, such as pregnancy or elective surgery, acquire a layer of complexity which requires input from the specialist team.

The root of the problem

So, apart from lack of distinction of type 1 from type 2, how have we arrived at the position of those with type 1 diabetes being lost to specialist care?

The debate about diabetes and the Quality and Outcomes Framework (QOF) is now becoming very tired, but the discussion should start there. Primary care relies upon the income from QOF. Individually, each of the points does not provide a lot of income but, collectively, it makes up a proportion of the practice income. For better or for worse, diabetes contributes a lot of QOF points. At inception, there was a view from specialist care that it was not the place of specialist teams to collect or communicate the QOF indicators. This obliged practices to call in their diabetes patients for a review in order to collect the data. Little wonder, then, that the conversation point was around why an individual should have to attend two places for review of their condition. In many instances, the view was taken that it could all be done 'in house' and, as discussed above, practices may well be able to provide good basic care.

Another piece of the jigsaw comes in the form of payment by results (PBR). This puts a price tag on every visit to a specialty. The results of that innovation are too obvious to require discussion. As a footnote in history, mention should be made of practice based commissioning. This encouraged locality-based primary care to develop local services. Diabetes was commonly proposed as an exemplar, usually because a local GP had an interest in the specialty, and this has spawned a number of 'intermediate care' services distinct from the local specialist service.

The consequences

So does it matter that patients with type 1 diabetes are not in contact with the specialist team? There is evidence that patients who attend diabetes clinics do better than people who do not, but this might simply reflect the fact that people who are more conscientious with their diabetes care do better than those who neglect it. Alternatively, it might be that people who are in regular contact with the specialist team are more likely to benefit from newer treatments and techniques such as insulin pump therapy, continuous glucose monitoring and islet

cell transplantation, techniques which have increasing evidence of benefit.

Another way to answer the question is to look at processes and outcomes. The National Diabetes Audit is consistent over the years in highlighting the fact that the care processes designed to pick up and prevent diabetes complications early are inconsistently carried out. This is particularly true of type 1 diabetes, and represents a systematic failure of care across all sectors. Those with type 1 diabetes who attend specialist clinics may not have the care processes carried out as the clinics do not see it as their place to carry out the tests. The service may have been commissioned to include funding for these tests through the primary care budget. Primary care teams may not actively pursue those patients who do not attend the surgery for testing. The end result is that the nine care processes are only carried out in 38.5% of those with type 1 diabetes in England and Wales.³

The clinical outcomes in those with type 1 diabetes make for sobering reading. Admission rates for diabetic ketoacidosis (DKA) continue to rise.⁴ Numbers requiring renal replacement therapy are significant.⁴ Mortality rates are alarmingly high compared with the age matched non-diabetic population, especially in young women from lower socioeconomic groups.⁵ The roll call goes on, with a clear message that whatever we are doing at the present time needs a good hard look.

The suggestion that you do not need to attend a specialist team for your diabetes sends a dangerous message. It suggests you don't have anything special about your medical condition, that it is acceptable to have a yearly check up, that you don't need any special surveillance. This is often taken by the individual to mean that their condition is controlled and that they do not need to attend to have their results reviewed. It may be that this process is seen as tiresome for many, but it is necessary for people with diabetes in some form or another.

Loss of access to the specialist team for people with type 1 diabetes deprives them of a valuable resource: the specialist nurses, dietitians, podiatrists and doctors whose daily work involves care of people with type 1 diabetes. Those with the condition are often discerning users of medical services. They will have been exposed to health care professionals (HCPs) over many years. They have little respect for those who do not know what they are talking about. They need HCPs who are experienced in the management of type 1 diabetes.

Campaign to improve access to specialist care

The Association of British Clinical Diabetologists (ABCD) is next month launching a campaign to improve access of people with type 1 diabetes to the specialist team. It wishes to open a debate which has not currently been aired. While recognising that different areas have different local agreements and that standards of care vary, ABCD is nevertheless calling for more sensitive commissioning to ensure that those with type 1 diabetes are not excluded from access to the specialist team. Better integration between primary and specialist care is required to ensure that all care processes are carried out. Hospital teams need to be able to influence the post-discharge management of those admitted with DKA and hypoglycaemia. There needs to be more finesse in the commissioning to break down barriers such that all involved can manage the condition better.

This is not necessarily a funding issue. It is a case of the commissioning of services being a little smarter. Increased awareness of the issue is a prelude to innovative solutions. This should fit in well with the thinking of the reformed NHS.⁶

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Declaration of interests

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