

Type 1 diabetes care: Back to basics?

Partha Kar, Pratik Choudhary

Type 1 diabetes care in the UK lags behind comparable countries in terms of outcomes. In this heartfelt opinion piece, the authors draw together the experiences of an adult with diabetes, the father of a young person with diabetes and two diabetes specialists, all of whom recognise that many people with type 1 diabetes are missing out on some of the more basic fundamentals of care. They then suggest a new approach to integrate care seamlessly across adult and paediatric departments, treating type 1 and type 2 diabetes as two different conditions. They argue that the opportunity is there if clinicians and commissioners are willing to take the initiative.

Whichever way you look at it, we are not providing enough high-quality type 1 diabetes care across the UK. Whether it be the national diabetes audits, local anecdotes or feedback from people with the condition, wherever you turn, care is patchy at best, mostly dependent on local areas of excellence rather than a uniform system (White et al, 2014). Only a minority of people have access to structured education programmes, we are failing to reach modest targets for use of insulin pumps and many people are still being seen by clinicians who are not trained in these two key components of type 1 diabetes care (Health and Social Care Information Centre, 2013). Added to this is the pressure to move diabetes into the community and into the hands of non-specialists.

Why do we underperform as a nation in terms of delivering good outcomes for people with type 1 diabetes? Are we too far gone or could we instigate something that could fundamentally change how type 1 diabetes care is delivered? In this article, we outline the views of a person with type 1 diabetes, a carer and two specialists who share a common thread of what they feel would

be required to improve care. The opportunity to do this is here with the *Five Year Forward View* proposed by the CEO of NHS England, Simon Stevens (NHS England, 2014). The question is whether the world of diabetes specialists is ready to pick up the gauntlet. This could fundamentally change how diabetes specialists, both in the world of paediatrics and in adult services, work together. We argue that the opportunity is certainly there for the taking.

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A patient's view: Anne Cooper

Although I was only 16 years old when I was diagnosed, I was managed by adult services and by a consultant whose specialism was renal medicine. There were few specialists in diabetes and certainly no specialist nurses. It didn't take long for me to realise I would have to learn to manage this condition the hard way – alone. I continue to get

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Article points

1. People with type 1 diabetes have a number of specific needs that are not always being met by the health service.
2. Access to education, psychology services and technology are the key tools to achieve the outcomes required.
3. The *Five Year Forward View* provides the opportunity to reshape how type 1 diabetes care is delivered.

Key words

- Education
- Integrated care
- Outcome-based commissioning
- Service delivery
- Type 1 diabetes

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Page points

1. As an adult with type 1 diabetes, Anne Cooper appreciates the availability and accessibility of primary care but is concerned by the lack of expertise available.
2. As the parent of a child with diabetes, Kevin Winchcombe is also worried about the time when his daughter transitions to adult care and is treated by clinicians without this expertise.
3. These concerns are compounded by the fact that his daughter has never been offered structured education. Their only option to educate themselves appears to be the internet and social media.

my care at the hospital, and trips for appointments remain a challenge. The whole clinic system is set up for short episodes of consultation, and it very much feels like you are visiting an illness service. However, I don't consider myself to be "ill". In primary care, the offering is worse; at least I feel like the doctors at the hospital understand type 1 diabetes. My GP is kind but openly admits he doesn't know anything about pump care, nor does he really understand it. He is the diabetes lead for the practice.

I have had type 1 diabetes for more than 30 years and it wasn't until a few years ago that I actually had conversations with other people with the condition. Although I didn't realise the importance of this at the time, access to others with diabetes has created a new support network for me and has given me great encouragement to be more active in my diabetes management. Peers could play a crucial role in how we support people in the future.

For me, the feel of primary care is right, in the sense that it is accessible and close to home, is less like a clinic and has access to the local pharmacy. But I need the expertise of specialists. I need a clinician who understands type 1 diabetes and pump care, who respects that I am a partner in my care and doesn't judge but is open, caring and interested enough to be a real specialist. I don't think I am asking too much.

A carer's view: Kevin Winchcombe

As a carer of a child who has type 1 diabetes, I know she receives good care. However, social media has taught me that we're the lucky ones. How can this be when NICE guidelines and the Best Practice Tariff should mean we're all treated the same? As an example, take the HbA_{1c} check (don't call it a test – words are important). At our clinic, we have a while-you-wait service, yet other clinics force people to make two trips or they send the results by mail.

My thoughts about care changed recently when I was invited to be a speaker at a national paediatric diabetes conference for professionals. It became clear that none of the professionals in the room had faith in their adult service – the very service their patients would transfer to some day. Frankly, the prospect of my daughter

transitioning away from paediatric care scares me.

Will my daughter ever be prepared enough for transition? She's 14, diagnosed 4 years ago, and all she, or we, have ever had is basic type 1 education and carb counting training. She's too young to attend DAFNE (Dose Adjustment for Normal Eating) courses, and as parents we're not invited either.

I suspect that several years buried in medical books teaches clinicians to advocate concrete thinking in which they are "in control" of their patients. It's time for this to stop. People are educating themselves through Dr Google but, in the absence of structured education, what else are we to do? With NHS resources stretched to the limit, wouldn't it be better to educate us so that specialists only need to deal with the important things? We live with the condition 24 hours a day, 365 days a year. We are the only people who can manage it and we need education to help us do so.

The few healthcare providers who are using social media are getting a lot from it. I'd like to see this expanded with the potential use of Skype for quick chats and updates. Today's teenagers' lives are immersed in the internet, so using it is the first choice for them. Many practitioners are worried that people may receive incorrect answers on social media. However, I've never seen this happen; the Diabetes Online Community polices itself very well.

Our only involvement with our GP is for repeat prescriptions for things they themselves did not originally prescribe. This seems a bit silly, doesn't it? Many adults with type 1 diabetes have to visit their GP once a year, but for what reason? Does the GP alter their regimen, or doses? Is it to check they still have the condition?!

By the time my daughter is an adult, I worry that her diabetes care will be handled by GPs, some of whom cannot even distinguish between the many diabetes types. Non-specialists looking after my structured education-lacking daughter? I sincerely hope not. Centralised specialist care has to be the way forward, centralised beyond its current structure. I'd feel happier knowing that my daughter could contact a national service at any time of the day or night – a 111 service for diabetes – where the person picking up the phone totally understands her issues.

The opportunity to take the correct path is here; I really hope the NHS makes the right choice.

Specialists' views: Pratik Chaudhary and Partha Kar

It is heart-breaking to see people who have presented for years with high HbA_{1c} and/or recurrent hypoglycaemia and yet have never even been offered access to the basics of type 1 diabetes care, such as structured education and insulin pump therapy. In today's era, how relevant are traditional clinics, where people are seen once a year for a quick check, a brief admonition to check their blood glucose more or take more insulin, and occasional adjustment of their fixed doses. As demonstrated in the previous comments, too many people with diabetes are left to fend for themselves. Many don't know any better and accept this as their lot, while others find their answers from Dr Google or social media.

The recent publication of the 27-year follow-up of the DCCT/EDIC (Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications) study shows clearly that tight glycaemic control early on in the course of type 1 diabetes has a major impact on long-term mortality and morbidity (Writing Group for the DCCT/EDIC Research Group, 2015). In that study, people assigned to the intervention arm had 6.5 years of intensive treatment, with an average HbA_{1c} of 52 mmol/mol (6.9%), while the conventional arm had an HbA_{1c} of 76 mmol/mol (9.1%). Even though HbA_{1c} in the two arms equalised over the subsequent 19 years at an average of 63 mmol/mol (7.9%, which, incidentally, is lower than the average HbA_{1c} in the UK), the mortality rate was 33% lower in the intervention arm at 27-years' follow-up. These data suggest that our current system, in which people often only get access to education or pump therapy after years of poor control, is designed to achieve an outcome that is 33% worse than what could be achieved if people were started out with better care.

Why isn't every clinician trained in the basics of structured education? Why is it not offered as "mandatory training" to all people with type 1 diabetes and why have we been so slow to embrace

advances that have been shown to improve control?

Towards a new approach for care

From the comments above, it is clear that people with type 1 diabetes and those who care for them have a number of needs that we are failing to meet. They need structured education from the very start of their diabetes journey. They need support from both peers and healthcare professionals, and this support needs to be available online, not always face to face. And above all, they need their care to be delivered by specialists who know about their condition.

With this in mind, we suggest a multi-pronged approach to care for people with type 1 diabetes. There are four avenues for change that need to be addressed.

1: Mindset

In effect, this is the hardest thing to change. Type 1 diabetes is different to type 2 and requires a different mindset. The Hvidøre project found considerable variation in outcomes between units, with better outcomes achieved in units that had lower glycaemic targets (Danne et al, 2001). Setting people off with the best tools from the onset of diabetes yields far better results than trying to improve things later on.

Another change in mindset required is the realisation that the 1–2 hours per year that people may spend with their healthcare professionals cannot hope to provide the information and support that they require to live with diabetes 24/7. We need to develop online resources, utilise peer-to-peer support and recognise the need for patient support that the health service just cannot provide. Our education programmes will have to adapt to this reality and the need for 24/7/365 support that must come from outside the health service – that is, from carers and from other people with type 1 diabetes.

2: Service specifications

These should determine both the minimal and ideal specifications for a type 1 diabetes service:

- A team trained in flexible insulin therapy and insulin pump therapy who are able to offer NICE-approved structured education to the majority of people.

Page points

1. Tight glycaemic control early on in the course of type 1 diabetes results in a 33% reduction in mortality risk over the long term.
2. Therefore, the current system, in which people often only get access to education or pump therapy after years of poor control, needs to change.
3. A new mindset is needed, in which not only is type 1 diabetes viewed as a different condition from type 2, but also in which the need for 24/7 support, not necessarily from the health service, is recognised.

Page points

1. The ideal type 1 diabetes service requires a multidisciplinary team trained in flexible insulin therapy and the use of modern technology, and who are able to offer structured education.
2. Out-of-hours and psychological support are also needed, along with a clear care pathway that is reassessed annually.

- A multidisciplinary team trained in the use of modern technology – including bolus calculators, meter downloads, insulin pumps and continuous glucose monitoring – so that therapeutic decisions can be informed by actual data!
- Out-of-hours and emergency support that can prevent many admissions and high costs from the diabetic ketoacidosis that results from poor management with sick day rules.
- Access to psychological support, especially for people struggling with this long-term condition. If HbA_{1c} is over 86 mmol/mol (10.0%), this usually reflects psychological barriers rather than a problem with the insulin regimen *per se*.
- A clear pathway:
 - For newly diagnosed patients, this should mandate carbohydrate counting within the first month and access to structured education within the first year.
 - For those with long-standing diabetes, a service plan that outlines how they will be given access to appropriate education over the coming 5-year plan.
 - An escalation pathway, with a multidisciplinary team making a patient-informed choice, utilising

education, psychology and technology as appropriate (Choudhary et al, 2015).

3: Outcome-based commissioning

In these times of financial woe, it does not make sense for commissioners to pay for a service that results in a 33% higher morbidity rate than we know can be achieved. We cannot begin to deliver better care until we measure where we are now, so we need to collect data, possibly starting with the most basic of outcomes such as HbA_{1c}, hypoglycaemia, quality of life, admission rates and complication rates. Once we know where we are, we can benchmark services and drive up quality. We have seen this clearly with the Best Practice Tariff but also through the SWEET (Better control in Pediatric and Adolescent diabetes: Working to crEate CEnTres of Reference) project in Europe (Waldron et al, 2012).

4: Tools

We suggest a strategy to plan a year of care for each person with type 1 diabetes (Figure 1). The annual review needs to be about much more than eye and foot checks. Evaluating people in the context of glucose control, hypoglycaemia risk, quality of

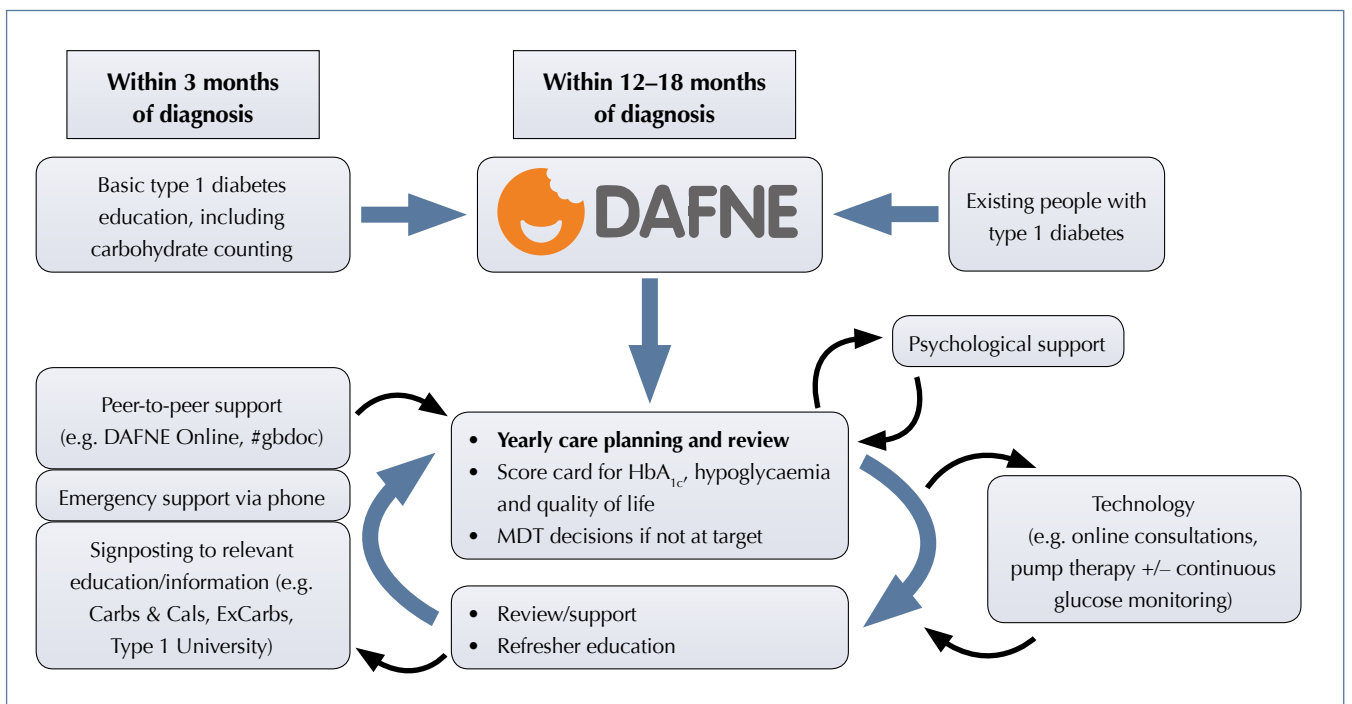


Figure 1. The tools and services required by all people with type 1 diabetes. These need to be planned and reassessed annually. DAFNE=Dose Adjustment For Normal Eating; MDT=multidisciplinary team.

life and complications on an annual basis would help stratify them and would aid with developing an agreed care plan for the next year, focussing the consultation on the most relevant issues. The use of technology could then facilitate support for these people over that time, through transmitting glucose and insulin data or the use of e-mail/Skype support to reach those goals. This support could be from trained healthcare practitioners but increasingly could also include the pool of motivated and educated patients who can support their fellow people with diabetes.

In the US T1D Exchange programme, the average HbA_{1c} in over 15 000 people was 62 mmol/mol (7.8%), but to achieve that the participants were performing an average of 5.1 blood glucose measurements per day, and over 60% were using insulin pumps (Miller et al, 2015). Education, psychology and technology are the key tools to achieve the outcomes we desire. These need to be specified and commissioned for, and our responsibility is not only to use them appropriately but also to inform our patients of their use and availability.

So, what now?

Are we ready to pick up the gauntlet and change type 1 diabetes services? Are our commissioners prepared to recognise that type 1 diabetes is a specialist condition that should be commissioned for so that minimum criteria are met? Are we, as specialists, ready to work to specifications that separate type 1 and type 2 diabetes, mandate out-of-hours support and push us to support our patients to achieve better diabetes control? Do commissioners have enough long-term vision to invest in redressing the balance in terms of basic diabetes education for the thousands of patients who have no access to this?

The *Five Year Forward View* opens the option for all the money invested by commissioners into paediatric and adult services to be put in one pot, for transferring work to a lead provider and for creating specialists who also work in the community setting. Type 1 diabetes care should be delivered by specialists – but this need not necessarily be within the hospital. Models of care looking at moving services outside the hospital should embrace the idea of specialists

(doctors/nurses) working within primary care settings to see people with type 1 diabetes in the community, using hospitals as expertise hubs, with clear escalation protocols determining what can be seen in the community and what needs specialised hospital-based input.

This is certainly doable and, for once, the finances probably do stack up – if we take a step back and look at the whole diabetes budget and see how we are using it. Separate type 1 diabetes from type 2: commission them separately. The former needs specialist input as a more hands-on approach, whereas the latter is mostly about support from primary care.

It is possible to pool money from the Best Practice Tariff and Payment by Results tariffs for type 1 clinics, paediatric and adult pump clinics and structured education all into one pot. Through this, care of the person with type 1 diabetes can be delivered seamlessly across paediatric and adult departments, as well as in the community. The hospital would be reserved for agreed specialist care, such as pump start-up and continued care. It's not the location but the expertise that matters. An example of this model can be seen in *Figure 2*.

The idea would be to, at the very least, offer people with type 1 diabetes the opportunity to have their care delivered by a specialist team rather than being dependent on the postcode lottery of relations between primary care and specialist teams. Patients seen by specialists could have their agreed care plans carried out with the help of community diabetes nurses trained in carbohydrate counting. The use of technology to download and transmit data to specialists, allowing e-support or Skype help, would provide patients with “virtual access”, minimising interruptions to their working life. Healthcare assistants could facilitate basic checks and data collection and transfer. Can we use these technologies to keep nurses and patients in touch with specialists and identify those who are struggling more early?

Working in this way would free up practice nurses to deliver type 2 diabetes care, with virtual support from the diabetes specialist nurses and consultants. Consideration should also be given to using the untapped resources of pharmacists to help practice

Page points

1. Education, psychology and technology are crucial to achieve the desired outcomes, and these need to be commissioned for and signposted.
2. The *Five Year Forward View* grants the flexibility for commissioners to take control and provide these services across both paediatric and adult care.

“The Five Year Forward View and the vanguard projects offer diabetes teams the opportunity to take this model forward, and they provide a golden opportunity to reshape how type 1 diabetes care is provided. As a community, we need to step outside our silos and do it.”

nurses support people with type 2 diabetes.

The *Five Year Forward View* and the vanguard projects offer diabetes teams the opportunity to take this model forward, and they provide a golden opportunity to reshape how type 1 diabetes care is provided. As a community, we need to step outside our silos and do it. ■

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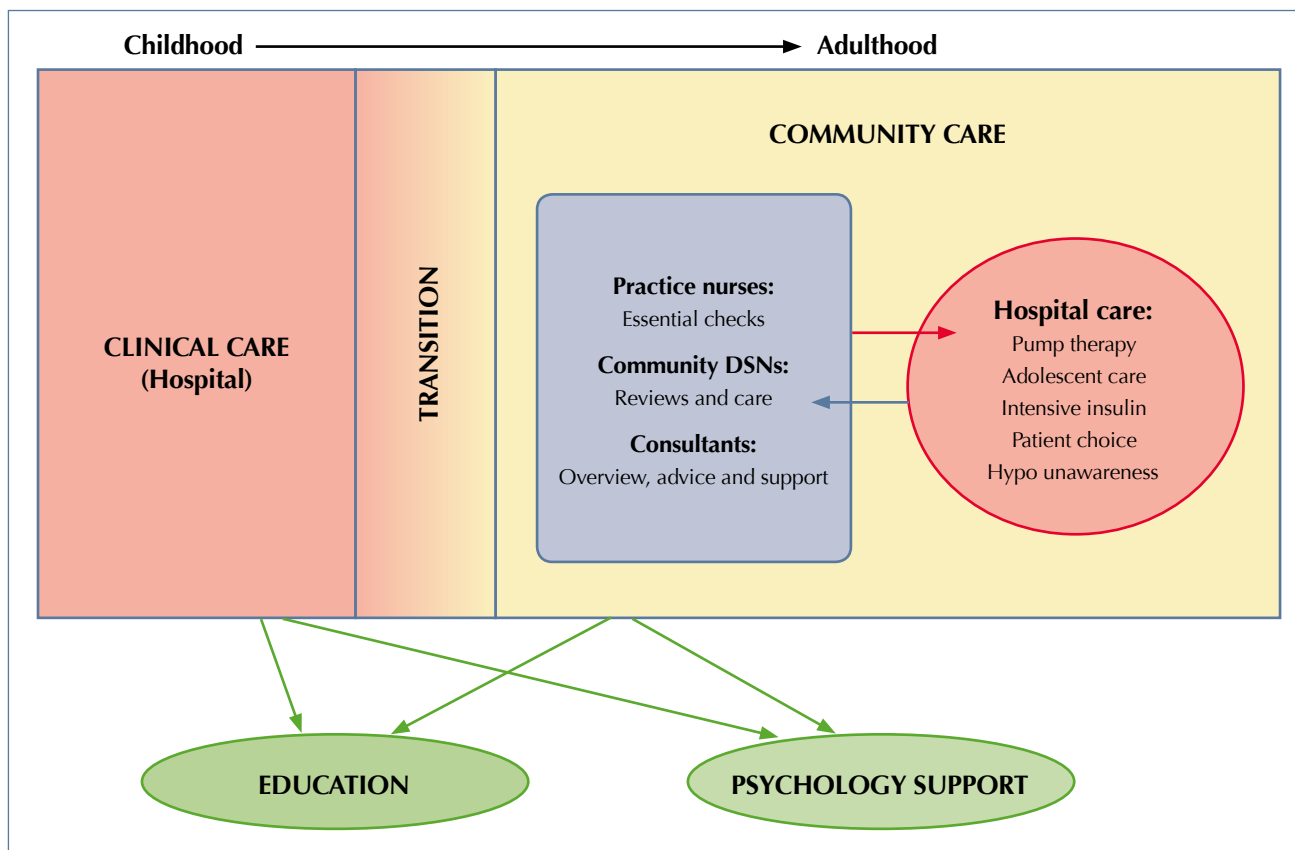


Figure 2. Example healthcare model in which type 1 diabetes care is delivered seamlessly across paediatric and adult departments. DSN=diabetes specialist nurse.