Diabetes education: the big missed opportunity in diabetes care

SUMMARY:
People with diabetes spend only three hours a year with a healthcare professional on average. For the remaining 8,757 hours they manage their diabetes themselves.

Managing diabetes well is challenging and demands constant commitment. People need to have the skills and confidence to manage their condition throughout their lives.

Diabetes education is key to successful day-to-day diabetes management and can be life-changing for people with diabetes. Yet few people are offered high quality education courses in a persuasive way due to myths that diabetes education does not really work, is never going to be attended by many people and is expensive.

The current lack of diabetes education is leading to:
• unnecessary serious complications such as amputation, stroke and blindness
• fewer people with diabetes being in control of their health – seriously affecting their quality of life and engagement with their care.

A radical improvement in the provision and promotion of diabetes education courses is urgently needed. Evidence shows that this is achievable and would provide very high value healthcare or even save the NHS money.

“Going on the course took the worry away. It reduced my HbA1c. It reduced my cholesterol. I lost three stone in weight. My blood pressure came down and is perfectly normal for my age. Now I understand the condition.”

Malcolm, Living with Type 2 diabetes

“I think everyone with Type 1 diabetes needs and deserves to attend a course. I wouldn’t have such good control now if it wasn’t for all the knowledge and confidence I got from the course. It changed my life.”

Clair, Living with Type 1 diabetes
Diabetes education helps people to stay healthy, live well, and avoid expensive and life-threatening complications.

All four nations of the UK have committed to improve access to diabetes education. Yet recent data suggest that attendance at diabetes education courses remains far too low across the UK (see graphic below).

**In Northern Ireland**
11.9 per cent of people with Type 1 and 2.4 per cent with Type 2 attended group-based diabetes education in 2013/14.

**Commitment:** The Executive’s Programme for Government committed to enrol everyone who has a long term condition in a self-management programme.

**In Scotland**
No reliable national data on access to diabetes education, but our local intelligence suggests there are considerable gaps in provision.

**Commitment:** The Diabetes Improvement Plan identifies access to “consistent, high quality education” as a national priority.

**In Wales**
3.4 per cent of people with Type 1 and 1.2 per cent with Type 2 attend group-based diabetes education.

**Commitment:** The Government’s Diabetes Delivery Plan makes diabetes education a priority and commits to improve uptake.

**In England**
0.9 per cent of people with Type 1 and 3.8 per cent with Type 2, who are newly-diagnosed, attend group-based diabetes education.

**Commitment:** The Five Year Forward View commits to harness “the renewable energy represented by patients” and “invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses.”

---

**WHAT IS DIABETES EDUCATION?**

People learn about their condition in different ways. One way of understanding diabetes education, already used in Scotland, is in three levels:

- **Level one:** Information and one-to-one advice.
- **Level two:** Ongoing learning that may be quite informal, perhaps through a peer group.
- **Level three:** Structured education that meets nationally-agreed criteria (defined by NICE/SIGN), including an evidence-based curriculum, quality assurance of teaching standards and regular audit.

While all three levels are important for people with diabetes, this briefing focuses on level three education for adults. For more information about other levels of education go to [www.diabetes.org.uk/self-management-education](http://www.diabetes.org.uk/self-management-education).
DIABETES EDUCATION: THE BIG MISSED OPPORTUNITY IN DIABETES CARE

Diabetes education improves health outcomes and reduces the onset of serious complications. As a result, it is recommended by NICE\(^1\) and, in Scotland, SIGN\(^2\).

A recent systematic review of group-based education for people with Type 2 diabetes assessed 21 randomised controlled trials. It concluded that group-based education improves a range of clinical, lifestyle and psychosocial outcomes – including significant improvements in:

- glycaemic control (significantly reduced fasting blood glucose levels and HbA1c, the latter by 0.46 percentage points at one year)
- self-management skills
- diabetes knowledge
- self-efficacy/empowerment
- patient satisfaction
- body weight at 12 months\(^3\).

In the UK, an audit of the X-PERT diabetes programme found that the course increases people's diabetes self-management skills and confidence, improves HbA1c (by 0.5 percentage points at one year) and reduces cardiovascular risk factors\(^4\). Another UK-based course, the DESMOND programme, has been shown to support weight loss and smoking cessation, improve people’s understanding of diabetes and reduce depression at 12 months\(^5\) – although evidence suggests that the programme needs to continue for improvements to be sustained\(^6\).

The evidence base for Type 1 group-based education is extremely strong. In the UK, the DAFNE programme has been shown to:

- significantly improve long-term glycaemic control – reducing HbA1c by 1.0 percentage point at six months\(^7\), 0.5 at one year\(^7\), and 0.3 at 7 years\(^8\)
- reduce the risk of severe hypoglycaemia by 67 per cent and ketoacidosis by 61 per cent\(^9\), substantially reducing emergency treatment costs (see page 5)
- restore hypoglycaemia awareness\(^10\)
- improve quality of life\(^10\) and perceived well-being\(^10\)
- reduce anxiety and depression\(^10\).

“Before the course I was being scraped up literally by paramedics due to hypos at least once a week. One week three times in a week. Since the course I have not needed outside assistance once. Four years now since the course.”

Allan,  
Living with Type 1 diabetes for over 30 years
Some areas struggle with low uptake of diabetes education – but evidence suggests that uptake rates can be increased dramatically through targeted interventions.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrals do not convince people to attend.</td>
<td>Work with healthcare professionals, so that they understand and promote the benefits of diabetes education; encourage healthcare professionals to attend taster sessions of local courses.</td>
</tr>
<tr>
<td>Location and timing of courses; long waiting times can deter people.</td>
<td>Consult people with diabetes to identify convenient venues and times; commission courses at the scale required by the local population to create more options; consider using trained lay educators (paired with healthcare professionals) to scale up provision of Type 2 education.</td>
</tr>
<tr>
<td>Off-putting terminology – for example, the term ‘structured education’ is widely used, but has negative associations for some people, particularly those who did not enjoy school.</td>
<td>Develop more compelling marketing and distribute this widely; collect and evaluate patient feedback.</td>
</tr>
<tr>
<td>Lack of data on who is and is not attending courses; low uptake from hard to reach groups.</td>
<td>Use an electronic administration system to identify and follow up non-attendees; collect patient feedback; consider targeted courses for specific groups.</td>
</tr>
</tbody>
</table>

In Lambeth and Southwark, for example, the Diabetes Modernisation Initiative increased attendances by some 80 per cent over three years. As part of this, materials for patients were designed in collaboration with the local Healthwatch and dropped the term ‘education’ altogether, instead using the phrase ‘learn about your diabetes’.

Likewise, in Bexley improving access to diabetes education courses was made a priority during a recent diabetes service redesign. Local healthcare professionals were engaged and people with diabetes consulted to identify convenient venues. As a result, attendance at X-PERT increased from only 40 people in 2009 to over 1,000 in 2010, on average reducing attendees’ HbA1c level by 1.3 percentage points.

For more information about how other areas across the UK are improving diabetes education, go to www.diabetes.org.uk/shared-practice

“With any patient education programme it must be promoted by primary care professionals as well as hospitals. It must become the norm for newly diagnosed patients to be made fully aware of what opportunities exist to help them understand, come to terms with and manage their condition.”

Chris,
Living with Type 2 diabetes
PROVIDING HIGH VALUE HEALTHCARE

Evidence shows that diabetes education is cost effective – and can save the NHS money in the medium term.

The cost of a five-day DAFNE course for people with Type 1 diabetes is around £308 per person (based on educating 120 people per area per year). An economic evaluation of the DAFNE programme showed that, by reducing the onset of costly complications such as blindness, end-stage renal disease and foot ulceration/amputation, DAFNE would pay for itself within 4.5 years and save the NHS £2,237 per patient over 10 years.

In the long run, the Department of Health has estimated that the DAFNE programme could save the NHS £48 million per year nationally, or £93,133 per 100,000 of the population, if it is made available to everyone in the UK with Type 1 diabetes.

A subsequent evaluation, based on more conservative assumptions about reductions in HbA1c, concluded that DAFNE is a cost-effective intervention, but would not result in cost savings over a lifetime horizon. However, this may underestimate potential savings. A more recent study found that DAFNE reduced emergency treatment costs for ketoacidosis and severe hypoglycaemia by 64 per cent, or £81 per patient, over a year – suggesting that course costs would be recouped in under four years.

Analysis of two of the most prominent education programmes for people with Type 2 diabetes, X-PERT and DESMOND, concludes that both are likely to be cost effective compared with usual care. One evaluation suggests that, if rolled out to everyone with Type 2 diabetes, X-PERT could save £367 million per year as a result of reduced medication costs.

The cost of delivering X-PERT and DESMOND courses has been estimated at £65 and £76 per person respectively (based on educating around 500 people per area per year).

This means that diabetes education could be delivered to everyone in the UK diagnosed with Type 2 diabetes – almost 3 million people – for £39 million per year over five years. This is just over 0.5 per cent of the £7 billion that the NHS spends every year on Type 2-related complications. Moreover, this is likely to overestimate the investment required, as economies of scale mean that course costs would fall with high levels of provision.

In addition, there is good evidence that trained lay educators can deliver Type 2 diabetes education courses effectively when they are teamed with a healthcare professional. There is therefore considerable potential to use lay educators both to increase educator capacity and improve the cost effectiveness of courses.

CALLS TO ACTION

✔ Healthcare professionals should:
  • promote the benefits of diabetes education courses to their patients
  • find out what courses are available locally, be familiar with referral pathways and consider attending a taster session.

✔ Local decision makers should:
  • put plans in place to ensure that all people with diabetes have the skills and confidence to manage their condition by 2020
  • commission or provide accessible ‘level 3’ diabetes education courses (meeting NICE/SIGN criteria) for all adults with Type 1 and Type 2 diabetes
  • review the uptake of education programmes, identify and address local barriers, and assess the effectiveness of education programmes through quality assurance and audit.

✔ National decision makers should ensure that every area in the UK has plans in place to support all people with diabetes to develop the skills and confidence to manage their condition by 2020. This must include a radical improvement in the provision of ‘level 3’ diabetes education courses.
REFERENCES


6 Scottish Government (2014). The Diabetes Improvement Plan

7 Nicholls H (2014). Structured Diabetes Education in Wales. All Wales Diabetes Implementation Group

8 Welsh Government (2013). Together for Health – A Diabetes Delivery Plan


10 NHS England (2014). Five Year Forward View


14 Deakin T (2011). The diabetes pandemic: is structured education the solution or an unnecessary expense? Practical Diabetes 28 (8); 1–14


17 DAFNE Study Group (2002). Training in flexible, intensive insulin management to enable dietary freedom in people with Type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. British Medical Journal 325; 746

18 Gunn D, Mansell P (2012). Glycaemic control and weight 7 years after Dose Adjustment For Normal Eating (DAFNE) structured education in Type 1 diabetes. Diabetes Medicine 29 (6); 807–12

19 Elliot J, Jacques RM, Kruger J et al (2014). Substantial reductions in the number of diabetic ketoacidosis and severe hypoglycaemia episodes requiring emergency treatment lead to reduced costs after structured education in adults with Type 1 diabetes. Diabetic Medicine 31 (7); 847–53


21 Speight J, Amiel SA, Bradley C et al (2010). Long-term biomedical and psychosocial outcomes following DAFNE (Dose Adjustment For Normal Eating) structured education to promote intensive insulin therapy in adults with sub-optimally controlled Type 1 diabetes. Diabetes Research and Clinical Practice 89 (1); 22–29

23 Diabetes Modernisation Initiative (2014). *Living well with diabetes: Learnings report from the Diabetes Modernisation Initiative*


25 DAFNE Fact Sheet Six (2012). *Cost per patient 2012/13*


31 Deakin T (2011). The diabetes pandemic: is structured education the solution or an unnecessary expense? *Practical Diabetes* 28 (8); 1–14

32 As above. Costs based on groups of 15–18 people with diabetes plus carers.


34 UK-wide costs are based on providing the X-PERT programme, at a cost of £65 per person, to 2,999,762 people in the UK diagnosed with Type 2 diabetes. The total cost of the intervention would therefore be £194,984,530, or £38,996,906 per year over five years. Diabetes prevalence figures are sourced from: *Quality and outcomes framework (QOF) 2013–14*

35 For the cost of diabetes-related complications see: Hex N, Bartlett C, Wright D et al (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the United Kingdom. *Diabetic Medicine* 29 (7); 655–62


FURTHER INFORMATION
For more information on diabetes education, including resources for healthcare professionals, commissioners and providers, go to:

For more information about Diabetes UK’s Taking Control campaign to increase the provision and uptake of education for people with diabetes, go to:
www.diabetes.org.uk/taking-control

GET IN TOUCH

ENGLAND
CALL 0345 123 2399*
EMAIL info@diabetes.org.uk
GO TO www.diabetes.org.uk

NORTHERN IRELAND
CALL 028 9066 6646
EMAIL n.ireland@diabetes.org.uk
GO TO www.diabetes.org.uk/northernireland

SCOTLAND
CALL 0141 245 6380
EMAIL scotland@diabetes.org.uk
GO TO www.diabetes.org.uk/scotland

WALES
CALL 029 2066 8276
EMAIL wales@diabetes.org.uk
GO TO www.diabetes.org.uk/wales

*Telephone companies normally charge between 2p and 10p a minute for a landline call, and from 10p to 40p a minute if using a mobile. Free call packages for landlines and mobiles include 0345 numbers.
A charity registered in England and Wales (215199) and in Scotland (SC039136). © Diabetes UK 2015 0630D.