



LEEDS
BECKETT
UNIVERSITY

Citation:

Ross, K and Camara, K and Waldron, S and Kime, N (2016) The evolving role of the diabetes educator. *Diabetes Care for Children and Young People*.

Link to Leeds Beckett Repository record:

<https://eprints.leedsbeckett.ac.uk/id/eprint/4759/>

Document Version:

Article (Published Version)

The aim of the Leeds Beckett Repository is to provide open access to our research, as required by funder policies and permitted by publishers and copyright law.

The Leeds Beckett repository holds a wide range of publications, each of which has been checked for copyright and the relevant embargo period has been applied by the Research Services team.

We operate on a standard take-down policy. If you are the author or publisher of an output and you would like it removed from the repository, please [contact us](#) and we will investigate on a case-by-case basis.

Each thesis in the repository has been cleared where necessary by the author for third party copyright. If you would like a thesis to be removed from the repository or believe there is an issue with copyright, please contact us on openaccess@leedsbeckett.ac.uk and we will investigate on a case-by-case basis.

The evolving role of the diabetes educator

Karen Ross, Kerry Camara, Sheridan Waldron, Nicky Kime

In the UK, responsibility for providing structured education to children and young people with diabetes typically falls to paediatric diabetes specialist nurses. However, the Best Practice Tariff, which calls for all children and young people with diabetes to receive ongoing, age-appropriate structured education, means that more frequent, individualised education, over and above that provided in routine care, is required. Appointment of a dedicated diabetes educator, who is responsible for and has the capacity to develop a number of age- and maturity-appropriate programmes that can be delivered by all members of the multidisciplinary team, may be of help here. This article describes the role of diabetes educators and presents two examples of services that have appointed them.

Certified/Credentialed Diabetes Educators (CDEs) are an established part of the multidisciplinary team (MDT) for children and young people (CYP) with diabetes in many countries, including Australia, Canada, Germany and the US, but as yet the CDE is not an established role within the MDT in the UK. While the CDE role is comparable to that of the UK's paediatric diabetes specialist nurse (PDSN), it is not quite the same. In Australia, for example, a CDE working with CYP or adults provides ongoing diabetes education after diagnosis and regular clinical care, including clinic appointments and home support, which is similar to that provided by the PDSN in the UK. The CDE has a primary healthcare qualification and current registration as a nurse, dietitian, medical practitioner, pharmacist, podiatrist or exercise physiologist, and possesses the required training for accreditation by the Australian Diabetes Educators Association in either a paediatric or adult setting. Where the Australian model of training differs from that of the UK PDSN is in the requirement to complete a graduate certificate

in diabetes education and to have 1800 hours of practice in the specialty field of diabetes education. In addition, CDEs are expected to provide evidence of professional development within four specific categories of diabetes education and demonstrate that a mentoring relationship with a practising diabetes educator has been established.

Likewise, the German model of CDE training is similar to that in Australia, focusing on the delivery of a standardised education programme. This model has been adapted and piloted by Leeds Beckett University as the MSc Advanced Diabetes Educator course. This course provides a training opportunity for healthcare professionals working in paediatric diabetes to enhance their present roles, skills and competency in diabetes education. Although paediatric diabetes units in the UK are beginning to recognise the difference between the PDSN and CDE roles, and to appreciate the added value that a CDE can bring to an MDT, there is still a long way to go. This article explores the evolving role of the CDE in the UK and provides two examples of CDEs currently working in practice.

Citation: Ross K, Camara K, Waldron S, Kime N (2016) The evolving role of the diabetes educator. *Diabetes Care for Children & Young People* 5: 23–8

Article points

1. The Best Practice Tariff requires all children and young people with diabetes in England to have access to age-appropriate structured education tailored to their individual needs.
2. The appointment of a diabetes educator within a multidisciplinary team (MDT) provides support to the whole MDT in their endeavour to provide ongoing age-appropriate education and psychosocial support to families in their care.
3. One member of the MDT with training in teaching skills and age/maturity-appropriate education can develop and manage a programme of education that is delivered by the whole MDT.
4. Peer support for children and families is a valuable part of any structured education provision.

Key words

- Best Practice Tariff
- Diabetes educator
- Multidisciplinary team
- Structured education

Authors

Author information can be found at the end of the article.

Page points

1. The goal of structured education in children and young people (CYP) with diabetes is to provide them not only with the knowledge and skills required to self-manage their diabetes but also the coping skills to live with the condition.
2. The Best Practice Tariff stipulates that each child or young person with diabetes should receive structured education appropriate to their needs, both at diagnosis and throughout their attendance at the paediatric diabetes clinic.
3. Provision of this individualised service presents challenges to the traditional multidisciplinary team (MDT). A dedicated diabetes educator may therefore be required.

Structured diabetes education

Structured education in the context of paediatric diabetes is a programme of education that meets the needs of the individual CYP along their care pathway. These needs are diverse and include knowledge, skills and competency in all aspects of diabetes management, which, depending on age, will be individual or shared with parents, carers and/or friends. Structured diabetes education that is provided on an individual basis or in groups – or, as for the majority of CYP, a combination of both – provides a means by which CYP’s educational needs can be met.

However, diabetes education encompasses more than this; in particular, it includes the varied skills needed to cope with the challenges of living with the condition. In this respect, there is a need to develop a structured education programme that includes appropriate components for different aspects of care: for example, diabetes management, technology and the emotional burden of how to live with a long-term condition (Campbell and Waldron, 2014). It is important that this structured education programme be evaluated and accredited. The Type 1 Diabetes Research Roadmap produced by JDRF (2015) examines the challenges facing the development of a national structured patient education programme alongside the complexity of providing a programme that will meet the needs of CYP and their families throughout their care pathway.

Impact of the Best Practice Tariff

Following the introduction of the Best Practice Tariff (BPT) in England, most MDTs have employed more healthcare professionals to achieve the standards necessary to satisfy the strict requirements of the BPT in terms of clinical provision, with the intention of improving outcomes for all CYP with diabetes.

The BPT criteria relating to structured education state that:

“Each provider unit [should] provide evidence that each patient has received a structured education programme, tailored to the child or young person’s and their family’s needs, both at the time of initial diagnosis and ongoing updates throughout the child or young person’s attendance at the paediatric diabetes clinic.”

(Department of Health, 2013).

The interpretation and implementation of this will be wide-ranging throughout the country, from those services that introduce “tick lists” for individuals to ensure that all education topics have been covered, through to group education sessions in which specific age-appropriate education is resourced, assessed and evaluated. Education is the cornerstone of diabetes care, and structured self-management education is the key to a successful outcome (Lange et al, 2014), but the provision of more frequent education for all CYP and their families, over and above that provided by routine care, represents a new challenge for the MDT. The CDE role may be one solution.

Do we need diabetes educators?

It is the responsibility of the MDT to provide the knowledge, skills, competency and support that CYP with diabetes and their families need to optimise their glycaemic control and maintain their quality of life as they progress through the challenges of childhood and adolescence into adulthood. The increasing diversity and complexity of care for CYP has placed more demands on the expertise of each healthcare professional within the MDT, which has made it difficult for any one member – historically the PDSN or doctor – to attend to the individual needs of every child or young person. Add into the equation the requirement imposed by the BPT to provide tailored, structured education, and the opportunity to fulfil every child’s needs becomes even more problematic.

Certainly, by working together, all members of the MDT, including the doctor, PDSN, dietitian and psychologist, are in a better position to meet the demands of paediatric diabetes care. However, diabetes services need to go one step further and consider the role of the diabetes educator as an integral part of the MDT. We would argue that the diabetes educator is both necessary and pivotal in terms of the implementation and coordination of diabetes education and the continued improvement of care for CYP with diabetes.

The role of the diabetes educator within the MDT

Within the MDT, it is normal practice for each PDSN to have the responsibility of a caseload of

patients for overall and ongoing care. The PDSN liaises with the dietitian, psychologist and doctor to provide a package of care for each individual. Owing to the age range and different levels of maturity of CYP and the variable needs of families, educational requirements will differ, which means that a generic programme of education for all will not suffice. Consequently, within any one diabetes service, there needs to be a number of different programmes of education, each with specific learning outcomes, that are tailored to individuals and groups, as is the case with the diabetes educator courses in Germany and Leeds.

Importantly, appropriate resources need to be developed to deliver the teaching, assess the learning and evaluate the effectiveness of education programmes, which will inform future development. This process requires a healthcare professional experienced in paediatric diabetes who, at the very least, has received training in teaching skills (Campbell and Waldron, 2013), but who ideally has completed the necessary training to be awarded CDE status. Indeed, the 2005 report on structured patient education in diabetes by the joint Department of Health and Diabetes UK Patient Education Working Group states that there must be trained educators to deliver diabetes education (Department of Health and Diabetes UK, 2005). However, this does not negate the importance of providing access to training for all members of the MDT, equipping them with the knowledge and skills in educational techniques and thereby complementing and enhancing the work of the CDE.

Healthcare professional training

Several universities now run Master's modules specifically for healthcare professionals working with CYP with diabetes, which provide the opportunities to gain the skills and competencies necessary in the principles of education. Funding and time constraints limit how many members of the MDT can access this training, but if one member is able to complete this and then share their knowledge and experience with the whole team, this represents a good starting point for the development of an education programme. The likelihood is that this member would take on responsibility for coordinating the education for

both the MDT and the CYP and their families, a strategy that is supported by the International Diabetes Federation (2015).

Peer support

One aspect of structured education that is often overlooked is peer support. The opportunity for CYP to meet and share experiences whilst learning about diabetes is a necessary and invaluable component of any structured education programme (Balfe et al, 2013), and one that CDEs need to consider when developing structured education programmes for their service. After-school clubs, social groups/activities and organised diabetes camps are all examples of situations where CYP with diabetes can derive peer support. Although it may be difficult to engage young people in diabetes-related activities initially, those CYP who do become involved report how enormously valuable the activities are (Swift, 2014). In addition, introducing CYP to each other at an early age increases the likelihood of them attending activities.

Group education allows CYP to make friends more easily. Therefore, by using age-banded groups for structured education, CYP will meet regularly as they grow up with their condition and may be better placed to support each other as they get older. Evidence is emerging that reinforces the value of a supportive peer network and online support groups (e.g. the Families with Diabetes National Network, Children with Diabetes in the UK, Diabetes UK and JDRF) for both CYP and their families. These have been shown to have a positive effect on diabetes management for CYP (Brooks et al, 2015).

For many young people, healthcare professionals are perceived as authoritarian and unsupportive, which can be a hindrance when trying to recruit CYP onto structured education programmes. More informal diabetes-related activities are an opportunity for practitioners and CYP to break down barriers. CYP report that they value meeting practitioners in social and more informal circumstances, where they can form positive relationships with them. As a result, CYP are more likely to engage in structured education activities, as well as ask their healthcare professional for help and advice when needed (Scholes et al, 2013).

Page points

1. Owing to varying age and maturity in different CYP with diabetes, a diabetes educator needs to develop a number of different programmes, each individually tailored and with specific learning outcomes.
2. An educator also needs to develop the appropriate resources to deliver the education and evaluate it, as well as providing training for all members of the MDT.
3. A number of universities now run courses that provide the skills and competencies necessary in the principles of education.
4. Peer support is an important, yet often overlooked, aspect of structured education, and the diabetes educator should arrange group education programmes and social activities for the CYP in their care.

“The examples here describe how the new role of a diabetes educator has been introduced and adapted within two paediatric diabetes settings. The examples differ taking into account the facilities, caseload, geography and other factors particular to each service.”

Examples of diabetes educator roles in the UK

The two examples here describe how the new role of a diabetes educator has been introduced and adapted within two paediatric diabetes settings. The examples differ taking into account the facilities, caseload, geography and other factors particular to each service.

Example 1: Karen Ross – Paediatric Diabetes Specialist Dietitian and Children’s Diabetes Educator, Oxford

Background

In 2010 a project was piloted to develop a programme of structured education for children with type 1 diabetes. Fifteen hours per week of “educator” time was allocated, to which an experienced member of the team was appointed.

Structured education programme

Over the last 6 years, Karen and the MDT have developed an annual programme of group education based on the academic school year (see *Box 1*).

A curriculum for each session has been devised based on topics agreed by the MDT, which are of relevance and importance for each particular age group and are linked to the Novo Nordisk Goals of Diabetes Education programme (Novo Nordisk, 2016).

The teaching is delivered by the whole MDT, led by Karen, who also takes responsibility for all the documentation required, such as risk assessments, lesson plans, session programmes, resources and evaluation. Where possible, the education is delivered away from the hospital in a village hall or community centre. The hire of these premises is funded by charitable donations to the children’s diabetes service trust fund.

Learning outcomes are set for each session and children are assessed at the end of the session. Notes for future actions for each individual child and family are recorded, which can then be provided within their routine diabetes care.

An education session for a group of children all diagnosed approximately 6 months previously has recently been introduced to provide enhanced blood glucose management skills and peer support for families.

Transition education is provided individually after

Box 1. Annual education programme (Oxford).

- Initial diagnosis education – individual
- Group education for families new to diabetes – morning session (held quarterly)
- Youngsters’ get-together for under-7s and parents
- Years 3 and 4 fun day (age 7–9 years) – whole day
- Year 5 day trip to zoo or similar (social day)
- Year 6: Preparing for secondary school (age 10–11 years) – whole day for young people; parents’ evening held the week before
- Year 8: Teenagers and diabetes (age 12–13 years and parents) – evening session
- Year 10: Gaining independence (age 14–15 years and parents) – evening session
- Activity weekends
- School training updates
- Group insulin pump training programme

completion of a questionnaire covering topics relevant to young people aged ≥ 17 years who are moving on to adult services, the aim being to provide the support and skills needed for independence.

Social groups

Youngsters’ get-togethers to develop family support groups are held at play centres for children in Year 2 and below each year. In addition, activity weekends for children in Years 4–7 or 8–10 are held in alternate years, and a social day trip has just been introduced for children in Year 5.

School training

A series of updates for primary school staff are run across the county each year, when the children’s diabetes educator and PDSNs provide re-education and perform reassessments of each individual teacher’s competency with diabetes tasks for individual children in their care.

Further developments

These will include:

- Individual patient education – age-appropriate competency assessments.
- Hospital staff education – formal ward staff training programme.
- Secondary school education and support programme.

Example 2: Kerry Camara – Children’s Diabetes Educator, Newcastle

Background

As a result of the BPT, a specialist nurse was appointed whose focus was to develop and deliver structured education and to progress peer support for CYP and families. Kerry’s previous experience was as a school health nurse supporting children with medical needs, including diabetes, in school.

Training in type 1 diabetes was provided by the MDT, and Kerry attended the Teaching Skills for Healthcare Professionals course (Sheffield Hallam University) in 2013, and the BSc Management of Childhood Diabetes course (Birmingham City University) in 2015.

Structured education programme

A 2-year programme of education was developed for use in regular diabetes clinics using the Novo Nordisk (2016) Goals of Diabetes Education as a framework and curriculum. Covering a specific topic every 3 months, this programme allows access to education for all CYP (*Table 1*). After the first 2 years, the programme is repeated so that topics are revisited and refreshed with additional age-appropriate learning. Younger children (under-12s) join in group discussions and learning activities as part of their clinic appointment in the waiting area, while older children are seen one-to-one in a consulting room. The clinic learning board displays the current topic and shares key educational messages, hints and tips, etc. Other members of the MDT are involved in delivering specific topics; for instance, dietitians deliver sessions on food and carbohydrates.

“Ready Steady Go” is the transition curriculum to support 16–18-year-olds who are moving on to adult care. Commencing in Year 11, young people receive information on what transition means, and they receive a transition plan and document to discuss and record a number of areas, including self-advocacy, daily living, school and the future, and emotional health, identifying where further support and education is needed.

Plans for further educational developments

Programmes planned in the future include:

- Age 10–11 years/Year 6: Preparation for secondary school with parents and, where possible, school staff.

Table 1. Two-year programme of structured education (Newcastle).

Month	Topic
Year 1 – commenced July 2013	
July, August, September	Diabetes in general
October, November, December	Insulin and injection technique
January, February, March	Food
April, May, June	Hypoglycaemia
Year 2 – commenced July 2014	
July, August, September	Hyperglycaemia
October, November, December	Long-term complications
January, February, March	Illness
April, May, June	Exercise

- Age 14–15 years/Year 9–10: Becoming more independent, managing illness, sexual health, pregnancy, alcohol, smoking and long-term complications.
- Age 16–18 years/Year 11–13: Becoming a young adult, going it alone, planning for the future, university, illness, holidays abroad, driving, sexual health and pregnancy, employment and prescriptions.
- An under-5s curriculum with a focus on parental learning and knowledge.
- “Keeping Calm and Carb Counting On: What is it about these carbs?”

Social groups and peer support

Small group sessions for 11–13-year-olds held in secondary schools have commenced, with very encouraging feedback from the young people involved. In addition, Newcastle and Gateshead now have a monthly Saturday morning meeting, facilitated by T1KZ (Type 1 Kidz) and Investing in Children (www.investinginchildren.net), where families of CYP with type 1 diabetes can meet socially, at a local community centre, to offer support to one another. The CYP set the agenda (e.g. help with school and diabetes, improving HbA_{1c}, etc.) themselves. CYP have also been involved in developing “Telehealth”, a texting service that can support them in their daily management of diabetes.

“Given the wealth of evidence supporting the case for structured diabetes education as an integral component of paediatric diabetes care and its impact in terms of improved outcomes, it is incumbent on multidisciplinary teams everywhere to consider how they will deliver their education provision and, most importantly, ensure that it is effective.”

Box 2. Annual education programme (Newcastle).

- Initial diagnosis education
- Under-5s and parents: Newly diagnosed soft play event
- Over-5s and parents: Newly diagnosed “learn for life” session
- All ages and parents: World Diabetes Day, Centre for Life Learning Day (every other year)
- All ages and parents: World Diabetes Day, Fun Day
- All ages: Clinic-based education
- Year 7–8 (age 11–13 years): Peer support sessions in school

Educator responsibilities

Kerry is responsible for the planning, delivering and recording of all clinic education sessions and age-appropriate resources. In addition, she takes the lead in organising, planning and delivering training for ward staff, MDT in-house training sessions and school staff sessions. She also ensures that new and established education sessions (*Box 2*) are audited, evaluated, monitored and continue to be progressed.

Discussion

Given the wealth of evidence supporting the case for structured diabetes education as an integral component of paediatric diabetes care and its impact in terms of improved outcomes, it is incumbent on MDTs everywhere to consider how they will deliver their education provision and, most importantly, ensure that it is effective. The BPT’s stipulation to provide tailored diabetes education for all means that, realistically, the MDT may have to include a diabetes educator who does not have a patient caseload and therefore has the capacity to develop and implement a structured diabetes programme for different age groups. Nevertheless, we recognise that the appointment of a single trained “educator” may not be a viable option for many services. An alternative is for a member of the MDT to take on the specific responsibility for this provision. However, this approach is not an easy option in the absence of allocated time and resources for such a role.

Whilst the debate surrounding the evolving

role of the diabetes educator and exactly what this should look like continues, the two examples provided here illustrate what can be done and represent one step further forward in our aim to improve diabetes education for CYP and their families. ■

Further information

Several universities now run Master’s modules specifically for healthcare professionals working in paediatric diabetes, which provide the opportunities to gain the skills and competencies necessary in the principles of education. A list of these courses can be found at: <http://www.cypdiabetesnetwork.nhs.uk/healthcare-professionals/university-courses>

Balfie M, Doyle F, Smith D et al (2013) What’s distressing about having type 1 diabetes? A qualitative study of young adults’ perspectives. *BMC Endocr Disord* **13**: 25

Brooks J, Kime N, King N et al (2015) Exploring how young people think about and respond to diabetes in their peers. *Diabetes Care for Children & Young People* **4**: 14–8

Campbell F, Waldron S (2013) Can education of healthcare professionals address variation in outcomes in children and young people with diabetes? *Diabetes Care for Children & Young People* **2**: 45

Campbell F, Waldron S (2014) Structured patient education to improve self-management: A vision for the future. *Diabetes Care for Children & Young People* **3**: 5–7

Department of Health (2013) *Payment by Results Guidance for 2013–14*. DH, London. Available at: <http://bit.ly/Ne19BP> (accessed 16.05.16)

Department of Health, Diabetes UK (2005) *Structured Patient Education in Diabetes: Report from the Patient Education Working Group*. DH and DUK, London. Available at: <http://bit.ly/1Xeu2hx> (accessed 16.05.16)

International Diabetes Federation (2015) *International Standards for Diabetes Education*. IDF, Brussels, Belgium. Available at: <http://www.idf.org/node/1684> (accessed 16.05.16)

JDRF (2015) *Type 1 Diabetes Research Roadmap: Identifying the strengths and weaknesses, gaps and opportunities of UK type 1 diabetes research. Clearing a path to the cure*. JDRF, London. Available at: <http://bit.ly/1NvsVbn> (accessed 16.05.16)

Lange K, Swift P, Pankowska E, Danne T; International Society for Pediatric and Adolescent Diabetes (2014) ISPAD Clinical Practice Consensus Guidelines 2014. Diabetes education in children and adolescents. *Pediatr Diabetes* **15**(Suppl 20): 77–85

Novo Nordisk (2016) *Goals of diabetes education: A structured educational programme for children and young people with type 1 diabetes. Healthcare Professional Guide*. Novo Nordisk UK, Crawley. Available at: <http://bit.ly/23YqTrF> (accessed 16.05.16)

Scholes C, Mandleco B, Roper S et al (2013) A qualitative study of young people’s perspectives of living with type 1 diabetes: do perceptions vary by levels of metabolic control? *J Adv Nurs* **69**: 1235–47

Swift P (2014) The benefits of activity camps and local family support groups for young people with diabetes: a paediatrician’s perspective. *Diabetes Care for Children & Young People* **3**: 101–5

Authors

Karen Ross is Children’s Diabetes Educator and Specialist Dietitian, Oxford Children’s Hospital; Kerry Camara is Children’s Diabetes Educator, The Great North Children’s Hospital; Sheridan Waldron is Education Lead for the National Children & Young People’s Diabetes Network; Nicky Kime is Senior Research Fellow, Leeds Beckett University.