

Developing an education resource pack for children and young people

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Introduction

Children and young people with type 1 diabetes and their families require ongoing access to quality information on the development, management and effects of the condition. The authors identified a lack of appropriate resources for the education of newly-diagnosed children and young people and therefore developed their own education pack. This article aims to highlight the challenges and practicalities of producing one such document. It is not meant to be a scientific article but is intended to inform others who may be planning to produce their own resource.

Type 1 diabetes is one of the most frequent chronic diseases in childhood. Children and young people with type 1 diabetes and their families have particular needs, which differ from those of adults with type 1 diabetes (National Institute for Clinical Excellence [NICE], 2004).

Children and young people with diabetes should be offered timely and ongoing opportunities to access information about the development, management and effects of type 1 diabetes. The information provided should be accurate and consistent and it should support informed decision-making (NICE, 2004).

A nationwide request/search by the authors for high-quality information currently in use indicated a lack of appropriate resources for education of newly-diagnosed children and young people. As a result, a multidisciplinary meeting was held in the authors' hospital to address the need to produce an in-house quality document.

This article aims to highlight the challenges and practicalities of producing a quality document. It is not meant to be a scientific article but is intended to inform others who may be planning to produce their own resource.

Process

The multidisciplinary team consisted of a paediatric diabetes specialist nurse, senior paediatric dietitian and a paediatrician with a special interest in diabetes. In order to establish uniformity of information on the

patient journey from childhood through adolescence and on to adulthood, a link was established with the adult team and the adult diabetes dietitian joined the working group.

It was agreed that the document would contain up-to-date information on as many aspects of living with diabetes and the management of diabetes as possible. The appropriate health professional would write their relevant section with collaboration from all members of the team. The document was designed to be user-friendly with an attractive and flexible format. The long-term aim was to produce a quality document to be available for both children and young people with type 1 diabetes.

The perceived requirements and benefits of such a document are summarised below:

- it contains up-to-date information, incorporating the latest guidelines
- it is accessible by all patients
- the information is available on an ongoing basis
- the information is unbiased
- the information is consistent
- the document is professional
- it can be updated and extended in the light of new recommendations.

Tackling the problem

The authors very soon realised that writing the document was the easy part! Far harder was:

- securing funding
- ensuring accuracy
- finding credible, evidence-based

ARTICLE POINTS

1 Children and young people with diabetes should be offered timely and ongoing opportunities to access information about the condition.

2 A nationwide request/search for good quality information identified a lack of appropriate resources.

3 Therefore, the authors developed their own educational document using a multidisciplinary approach.

4 During the preparation of the document, valuable lessons and new skills were learned.

5 An unforeseen benefit was the bringing together of the paediatric and adult care teams in a united approach to patient education.

KEY WORDS

- Education
- Practical advice
- Type 1 diabetes
- Children
- Young people

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PAGE POINTS

1 Eighteen months after the initial meeting, the final resource was produced.

2 Although originally planned solely for use in the authors' Trust, it became clear that other health professionals were keen to use it in their own areas.

recommendations

- design – the document should not date
- hours of proofreading!
- patient and peer review – trying to keep all parties happy
- printing
- realisation of the timescale involved – far longer than we envisaged.

The final resource

Eighteen months after the initial meeting, the final resource was produced – an A4 loose-leaf hard-bound folder with a plastic pocket on the inside cover, where an additional information sheet could be inserted by other centres, covering various aspects of their own particular service, e.g. clinic times, education programmes, etc. One thousand copies were printed, enabling every child under the care of the Trust to receive one. The education pack was first launched at the local annual families meeting in Newport and then at the

Paediatric and Adolescent Diabetes Conference in Nottingham in 2000.

Although our original plan was to develop an education tool for our own Trust, it became clear that other health professionals were keen to use it in their own areas and we were able to sell the surplus nationally and internationally. One copy even made its way to New Zealand!

Use of the education pack

The pack was given to all existing patients and then to every newly-diagnosed patient. In addition, copies were made available on the paediatric and adolescent wards for use as an education tool by the staff and to schools for use by teachers looking after a child with diabetes.

The adult dietitians soon found the pack a useful resource with newly-diagnosed young adults.

Three years later, in 2003, we were running low on stocks and we were faced with the decision to reprint the original document (easy option) or plan a fully-updated second edition. We chose the harder option!

The new document

The first step in updating the document was to contact the users to evaluate the existing pack. Patient feedback and responses from health professionals around the UK who had purchased and used the first edition guided our decision to include two new sections on blood glucose monitoring and travel. In view of changing clinical practice using multiple daily injection (MDI) therapy, we also extended the dietary section to include carbohydrate counting and glycaemic index. In addition, we wanted to extend the use of the document to all patient groups with type 1 diabetes. We therefore amended the wording to make it more generic instead of being exclusively for children and adolescents.

To ensure that the document complied with NICE recommendations, publication of the second edition was delayed until after the release of the guideline on type 1 diabetes, which was published in 2004 (NICE, 2004).

Lessons learned

We thought updating an existing document would be a relatively simple process. How wrong we were! The difficulties and

Figure 1. The cover of the revised educational pack.



complexities we faced are summarised below.

Funding and multitasking

The financial complexities should not be underestimated. Despite the agreement for funding from the Diabetes Directorate of the Trust finally being in place, we have continued to experience practical problems with the finance department.

In order for the project to succeed, we were also forced to wear a multitude of hats: project leader, researcher, business manager, design expert, and proofreader, in addition to writing the document.

The importance of teamwork

We needed to have mutual professional respect for each others' opinions and the recognition of others' expertise. This included the ability to cope with criticism. Developing resources is generally outside the standard job description and this emphasised the commitment needed by all members of the team to fit in the many additional hours around an already demanding work schedule. Supportive colleagues helped to raise morale when enthusiasm was flagging due to the challenges we encountered.

The production process

To produce a good quality document it is essential to develop a good working relationship with your graphic design expert. Many drafts will be required until the final document is produced. In our experience, the process took several months until all parties were satisfied with the standard of the end result.

It is important to remember that, even at this point, printing and publishing timescale needs to be taken into account. In our experience, this took six weeks. Because we had underestimated the time involved, we actually ran out of first edition packs before the second edition was ready. We had many unprocessed orders and frantic phone calls from people with an urgent need for the pack for their patients.

Storage

You need to consider whether storage may be a problem if you are producing a bulky document in quantity.

Sharing best practice

The end result (see *Figures 1 and 2*), we felt, was a valuable resource that we wanted to make available to others. For example, the pack has been publicised within the Trust and was presented at the Welsh Assembly Government (WAG) 'Sharing Best Practice' study day in Cardiff, September 2004, and at the recent Nutrition and Health conference in Docklands, London, December 2004. Following this initiative, WAG proposes to distribute a copy of the document to other trusts in Wales.

Conclusion

The team is very satisfied with the education resource pack that has been produced. Feedback to date has been very positive and encouraging. We believe that the topics have been covered in a way that will support informed decision making to assist patients in the management of their diabetes.

An unforeseen benefit of developing the resource has been the bringing together of the paediatric and adult care teams in a united approach to patient education. This will reinforce consistent care during the planned transition from paediatric to adult diabetes services.

National Institute for Clinical Excellence (2004) *Type 1 diabetes: diagnosis and management of type 1 diabetes in children and young people. Clinical Guideline 15*. NICE, London. Also available at <http://www.nice.org.uk/pdf/CG015childrenfullguideline.pdf> (accessed 05.01.05).

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PAGE POINTS

1 When preparing such a document, the financial complexities should not be underestimated.

2 Mutual professional respect is needed between the different contributors when developing resources.

3 Developing a good relationship with a graphic design expert is essential if a good quality document is to be produced.

4 The authors felt the end result was a valuable resource that they wanted to make available to others. For example, the Welsh Assembly Government plans to distribute a copy to other trusts in Wales.

5 An unforeseen benefit of developing the resource has been the bringing together of the paediatric and adult care teams in a united approach to patient education.

Figure 2. A page from the educational document. The second edition of the document included new sections on travel and blood glucose monitoring.