

Looking after schoolchildren with diabetes: Development of the Individual Healthcare Plan

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Children and young people (CYP) with diabetes spend a large proportion of their time in educational settings, and it is essential that medically untrained school staff have sufficient knowledge and skills to support the day-to-day and emergency care of these individuals. The Individual Healthcare Plan (IHP) has been developed to aid teachers in this and has now been rolled out across the UK, winning a number of awards. This article documents the IHP and its development, and demonstrates the positive results that collaboration and sharing of good practice across regional and national networks can have.

Children and young people (CYP) spend a large proportion of their day in education, so it is essential that staff in schools have the knowledge and skills to supervise and manage such an individual under their care. Often members of staff have to manage complex treatment regimens, give insulin injections, monitor blood glucose levels, use medical devices such as insulin pumps and treat emergency situations. This article will follow the development of the Individual Healthcare Plan (IHP), an essential new tool for education staff that provides them with personalised information on a CYP with diabetes and allows them to give the guidance and support required.

The IHP is a written agreement that details exactly what care a CYP needs in school, when they need it and who is going to provide it. It is drawn up with input from the CYP in question (if appropriate), their parents/carers, their paediatric DSN health visitor/school nurse and relevant school staff. Initially, the IHP was planned to be used regionally; however, as a result of the success and improved quality of care demonstrated by use of the tool, with the support of Diabetes UK and the

Juvenile Diabetes Research Foundation (JD RF), it was subsequently rolled out nationally via the National Children and Young People's Diabetes Network and has since been recognised in two national awards.

Background

According to the 2013–14 National Paediatric Diabetes Audit (NPDA, 2015), there are 26 598 CYP with diabetes in England and Wales, and type 1 diabetes accounts for 95% of these cases. The current estimated prevalence of type 1 diabetes in CYP under the age of 19 years is one per 430–530 individuals. The peak incidence of diagnosis occurs between the ages of 10 and 14 years. In 2000, the first cases of type 2 diabetes in children were diagnosed in the UK, and the recent NPDA data suggest that there are now 507 cases in total.

Children spend 25% of their waking lives in schools, and the pressure on teaching staff is immense. Teachers of CYP with long-term conditions such as diabetes often have to manage complex treatment regimens, maintaining safety and long-term wellbeing whilst also delivering

Citation: Singleton S (2015) Looking after schoolchildren with diabetes: Development of the Individual Healthcare Plan. *Journal of Diabetes Nursing* 19: 223–227

Article points

1. Children and young people (CYP) with diabetes spend a large amount of time in school and education, yet staff in these settings are rarely equipped with the knowledge and skills required to help manage this complex condition.
2. While personalised plans have been advocated to support the care of CYP with diabetes outside the clinic, until now there has been no standard template available.
3. The Individual Healthcare Plan is an eight-page electronic document drawn up between CYP and their families, healthcare professionals and school staff that offers a step-by-step guide to the everyday and emergency management of this condition.

Key words

- Children and young people
- Education
- Individual Healthcare Plan

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Page points

1. Recent reports have raised the need for shared working between healthcare and education staff in order to improve outcomes for children and young people (CYP) with diabetes in school.
2. The Royal College of Nursing has stated that all CYP should have an agreed individual healthcare plan (IHP) to assist in their care and management both at school and in the home; however, until now, there has been no set template in use.
3. A standard IHP has now been developed that covers all elements of day-to-day and emergency diabetes care and forms a step-by-step guide for all people involved in a CYP's care.

education and trying to achieve their own objectives of optimal academic achievement. Recent national documents have raised the importance of shared working between healthcare and education staff, as this will bring out the best possible outcomes for all CYP with diabetes.

The long-term physical risks of type 1 diabetes are well documented, and it is clear that diabetes can also affect mental health and emotional wellbeing. Day-to-day management of food, insulin, physical activity and mood can affect a wide range of children's activities and development. These include school attendance and full involvement in extracurricular activities such as trips and sports. There can also be consequences for social and family life. The challenge is to provide an environment in which diabetes can be jointly managed, promoting self-care and empowerment. The day-to-day experiences of CYP and their families and carers, along with the results of a series of national audits, confirm that current diabetes care does not always meet the needs of these individuals (Department of Health [DH], 2007). The DH has highlighted the importance of diabetes care provision in schools and early years settings, as well as the use of IHPs. Possession of an IHP can assist CYP and school staff in engaging with these activities whilst managing risk and promoting normality.

In their *Supporting Children and Young People with Diabetes* document, the Royal College of Nursing (2013) stated that all children should have an agreed IHP, but at the time of that publication there was no set template in use, either regionally or nationally. Hospital units used their own adapted care plans and, with the planned introduction of new Government legislation, the Children and Families Act 2014 (Department for Education, 2014), there was a need for the development of a template.

Development of the IHP

The National Children and Young People's Diabetes Network was set up in late 2009 and now comprises 11 regional networks, namely the East of England, East Midlands, London and South East Coast, North East, North West, South West, Thames Valley, Wales, Wessex, West Midlands, and Yorkshire and Humber paediatric

diabetes networks. The national network aims to bring together clinicians, commissioners and service users from across the regions to improve services and share good practice. All members of the multidisciplinary teams, along with the stakeholders, are kept informed of developments and invited to be involved in network activities. The stakeholders include strategic clinical networks, JDRF, Diabetes UK, commissioners and service users/parents, and there is close involvement with the Families with Diabetes National Network.

In 2013, a subgroup of the Children and Young People's North West Diabetes Network was set up with the aim of developing a tool in the form of an IHP for CYP with diabetes that could be used in any education setting. The goal was to establish an easy, step-by-step guide to supporting and managing CYP with diabetes in the early years, school or college settings, covering all elements of day-to-day care as well as emergency situations. It was to meet all national guidelines and provide a clear, concise, evidence-based but also individualised care plan that could follow the individuals through their educational journeys. It had to be flexible so that it could be used in any educational setting, irrespective of age, type of diabetes (including cystic fibrosis-related diabetes and maturity-onset diabetes of the young), management regimen, educational setting, or NHS Trust. On completion, it could then be forwarded electronically to all staff involved in the individuals' care. The IHP would be a major tool to complement and support the education that was already given by the paediatric DSN, school nurse and family.

The process involved organising regular meetings and telephone conference calls during development, steering the peer review process and checking with evidence-based practice, designing and making changes to the template, piloting and auditing. Later, the care plan was presented at the National Children and Young People's Diabetes Network meeting for further peer review by the lead clinicians in this specialist field across the country. The appropriate changes were made to meet both national and international guidelines.

Specific advice on the treatment of hypoglycaemia caused a great deal of discussion across many units, and the target blood glucose level post-

hypoglycaemia was changed from 4.0 mmol/L to 5.6 mmol/L, as advised in the International Society for Paediatric and Adolescence with Diabetes (ISPAD) guidelines (ISPAD, 2014). Feedback and involvement from the Families with Diabetes National Network, as well as CYP with diabetes themselves, was sought.

No extra financial resources were available to support the work, which involved collaborative working from three Trusts in the north west, and working across the country. The whole process took approximately 1 year, throughout which regular meetings were held in London with JDRF and Diabetes UK. Throughout the journey there has been continual assessment and evaluation by the group and from professional clinicians in the teams that have been using the IHP.

The IHP

The IHP is an eight-page electronic document. Many of the fields are preset, with drop-down boxes (indicating, for example, type of diabetes and type of insulin), check boxes (e.g. for insulin regimens) and free text boxes to add in personal details and additional information. The IHP was developed from a Microsoft Word document using the developer tool. The aim was to make it quick and easy to complete, with easy-to-follow flow charts to use in emergency situations (e.g. episodes of hypoglycaemia; *Figure 1*). It is flexible enough to be used with any regimen the CYP would be on, and it allows for additional information to be added in cases of coexisting medical conditions, allergies, etc. When the name and NHS number are initially typed in on the front page, this information automatically transfers over onto a header on each page.

The IHP can be sent electronically as a PDF, and can be printed out as an A4 or A5 booklet so that staff can have it for easy reference and, in times of emergency, can quickly refer to the flow charts for guidance.

Initially, the development of the IHCP was to go hand in hand with a 28-page "Guidelines" document produced by the East of England Children and Young People's Diabetes Network, led by Claire Pesterfield and Kate Wilson. However, Diabetes UK approached us and requested that we adapt it to be a standalone document for their

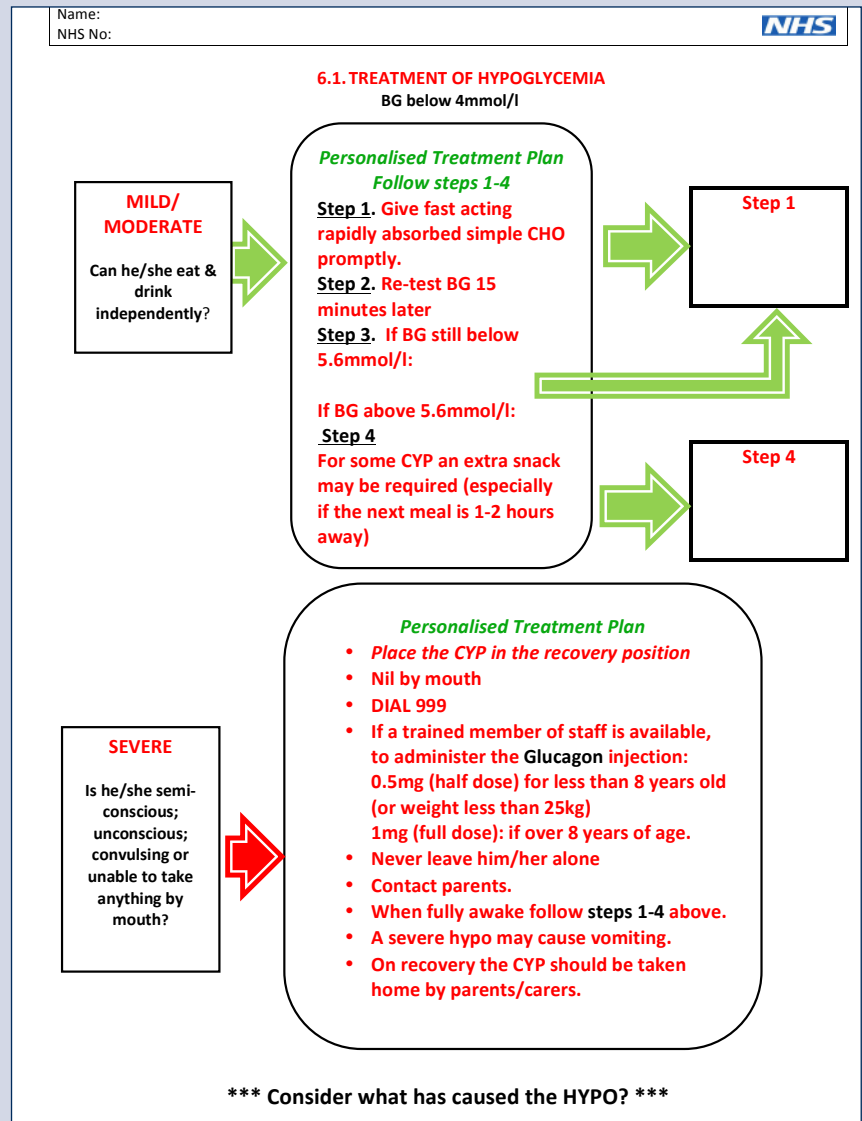


Figure 1. Template flow chart of actions to take during an episode of hypoglycaemia.

online resource, as part of their Make the Grade campaign. The IHP is also now referenced in recent Diabetes UK literature and campaigns promoting their Care in School Helpline.

Evaluation of the IHP

The care plan was piloted in three NHS Trusts: Blackpool, Preston and Salford. It was audited in the form of SurveyMonkey questionnaires sent to teaching staff, parents and DSNs, the results of which are shown in *Figure 2*. After the auditing process was well underway and the final changes were made to the IHP, it was rolled out to other NHS units, initially via regional and then national diabetes networks. In May 2014, JDRF uploaded

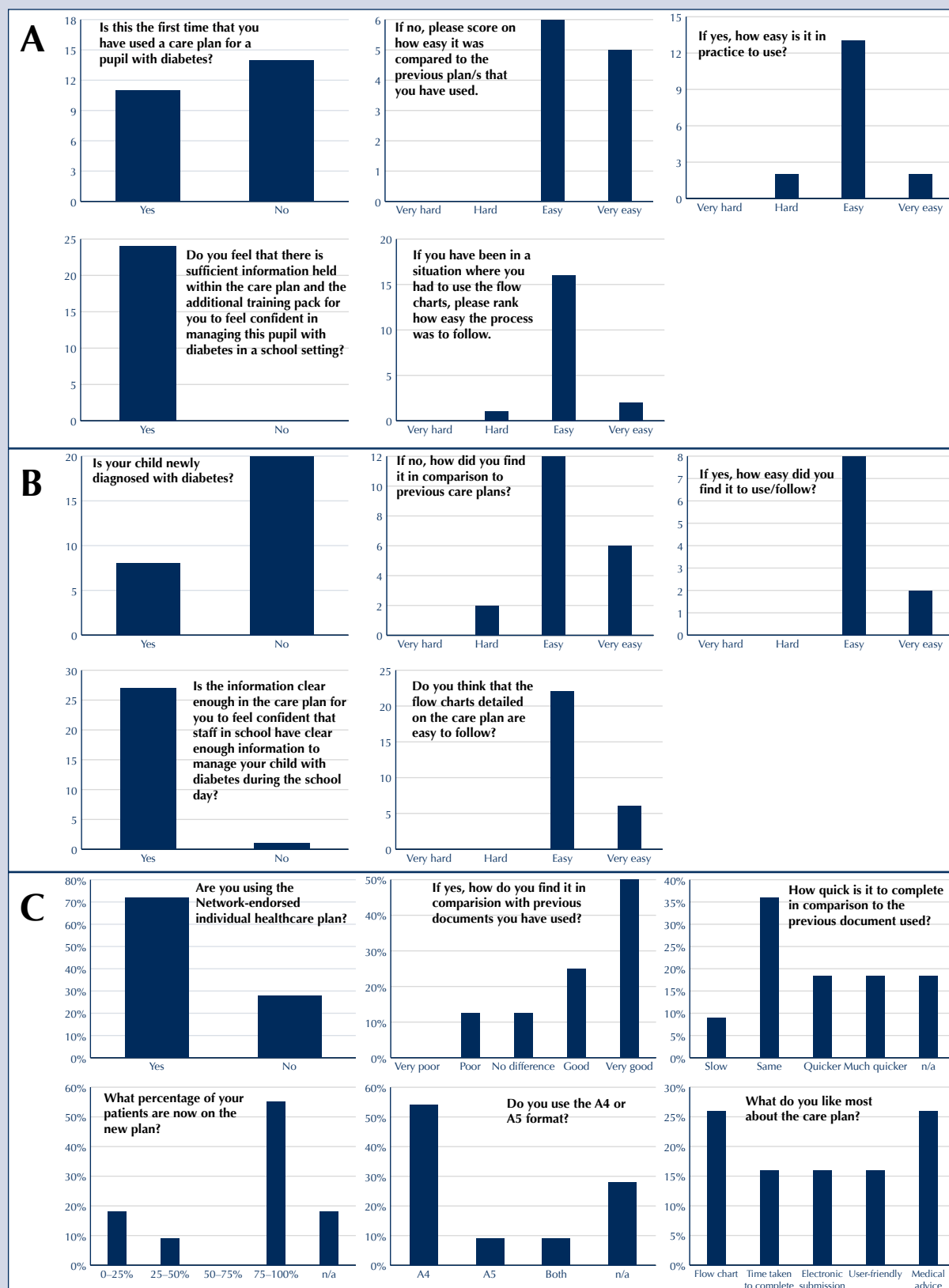


Figure 2. Survey feedback on the Individual Healthcare Plan.
A: Teacher feedback; B: Parent feedback; C: Paediatric DSN feedback.

the IHP to their website, incorporated with the East of England Network's guideline document.

The IHP furnishes classroom staff with a tool that is transferable both geographically and across varying organisations to consistently ensure the continued health and wellbeing of the CYP with diabetes. However, a gap was identified within the preschool sector, in which its appropriateness was questioned at the British Society for Paediatric Endocrinology and Diabetes annual meeting (Winchester, November 2014). It was felt that adaptations were required for its use in this age group, as preschool children may well be cared for by other family members, child minders and sometimes staff in preschool education settings. While the incidence of type 1 diabetes increases throughout childhood, the number of preschool children being diagnosed with the condition is increasing worldwide. In the recent NPDA, 434 children aged 0–4 years were diagnosed between 2013 and 2014, giving an incidence of 12.1 per 100 000 person-years in this age group (NPDA, 2015). Adaptation of the IHP for this age group is now in draft format, and it is presently being piloted in some units in the north west.

In May 2015, the group who developed the IHP attended the *Nursing Standard* journal's 2015 Nurse Awards and were proud to receive the Excellence in Diabetes Specialist Nursing Award for the standalone care plan. The joint work with the East of England Network was nominated for a Quality in Care award in October 2014 in the Judges' Special Award category, receiving a "commended" award. In March 2015, copyright was added, and the plan is to review the care plan in January 2016.

Concluding remarks

This evidence-based care plan has been peer- and patient-reviewed and was developed utilising existing resources. Patient experience has been enhanced by the use of the IHP, as has the knowledge of staff in education settings, whom the IHP gives the confidence to manage a CYP with diabetes safely and ensure that school life results in a rewarding experience for the young individual.

The original aim was to produce a standardised document for use within the North West Network that addressed all the national guidance, giving

governing bodies in schools the information required to support pupils with diabetes and provide clarity on what needs to be done, by whom and when. It was never envisaged that a national document, supported by the two main voluntary organisations in the field of children's diabetes, would emerge from this work. In addition to improving the care of CYP in the education setting, this project demonstrates the success of regional and national integrated working and the sharing of good practice. ■

Acknowledgements

This project was led by Sandra Singleton. She would like to give special thanks to Margot Carson, Elaine McDonald, Dawn Anderson, Linda Connellan, Daniel Hyde, Jill Cullen, Jayne Johnston, Helen Nurse, Paula Maiden and the Paediatric Diabetes Team at Blackpool Teaching Hospitals NHS Trust.

Further information

- Both forms of the IHP can be downloaded from the National Children and Young People's Diabetes Network website (available at: www.cypdiabetesnetwork.nhs.uk)
- The standalone care plan can be found on the Diabetes UK online resource (available at: <http://bit.ly/1HLJRDs>)
- The JDRF version, incorporated with the East of England Network's guideline document, can be found on the JDRF website (available at: <http://bit.ly/1KoA4DH>)

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