

A large graphic of a puzzle piece, colored in a gradient of blue, is shown in the foreground. It is slightly raised and casts a shadow on the surface below it. The background is a light blue surface with faint outlines of other puzzle pieces.

National Service Framework for Children, Young People and Maternity Services – Type 1 diabetes in childhood and adolescence

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Introduction

The *National Service Framework (NSF) for Children, Young People and Maternity Services* has been published alongside supporting material, which includes a series of exemplar patient journeys. While it is not the role of the NSF or the exemplars to provide detailed clinical discussion on individual childhood conditions, exemplars illustrate some of the key themes in the NSF.

Several factors influenced the selection of exemplar conditions, for example: large numbers of children and families affected, significant cause of illness and distress, wide variability in standards of practice or service provision and suitability for highlighting the NSF themes. Such themes include the importance of responding to the views of children and their parents, involving them in key decisions, providing early identification, diagnosis and intervention, delivering flexible, child-centred, holistic care. Care is integrated between agencies and over time and is sensitive to the individual's changing needs. It is also acknowledged that not every child with the same condition will follow the same journey or have the same type or severity of condition as the one which is illustrated.

The primary audience for the exemplars is professionals from a broad range of backgrounds including education, the NHS, social services and the voluntary sector. They will also be of interest to parents, children and young people.

The exemplars may be useful in a number of ways, for example to:

- highlight further references, which relate to evidence in the NSF and elsewhere, including key clinical guidelines;
- stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children's services, for this and other conditions, to the benefit of children and their families;
- provide an aid to examining and improving local clinical and non-clinical governance;
- provide a multi-disciplinary training tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion;
- canvass the views of children and families on specific children's issues (for example via focus groups), providing a non-threatening mechanism to open discussion, such as good and 'not so good' aspects of the current service; and
- provide a starting point or template for debate, prior to development of new local strategies for managing complex childhood conditions.

Diabetes Exemplar – Tom’s Story

Tom’s Type 1 diabetes

Tom is diagnosed with Type 1 diabetes at just three years old. This condition presents a complex set of medical, practical and emotional problems to be overcome not only by Tom himself, but by his mum and dad, Stacey and Richard, grandma, Mary, and Tom’s big sister, Molly, who is five.

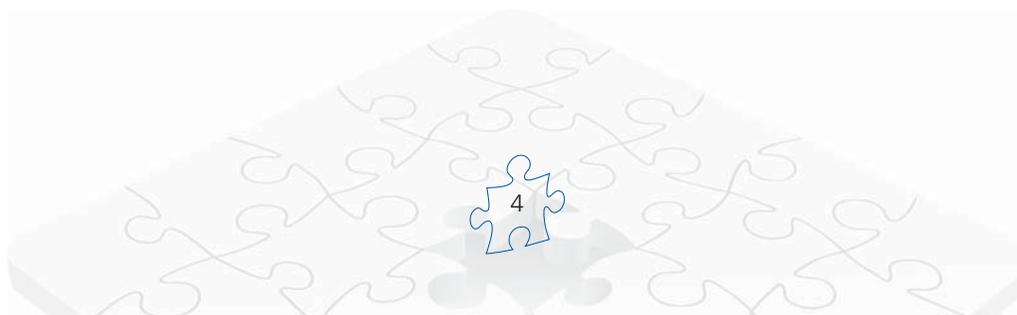
Because he’s too young to really understand about his condition, initially his family deal with most aspects of Tom’s diabetes. As he grows older, Tom starts to take more responsibility for his own care.

For Tom, key obstacles to be overcome are injections, starting nursery, bullying at school and the transition to adult services.

For his parents, after the initial shock and trauma of diagnosis, there is a massive learning curve as they grapple with needles, blood tests and a whole change in mindset and family routine. It’s a life-changing experience for all of them.

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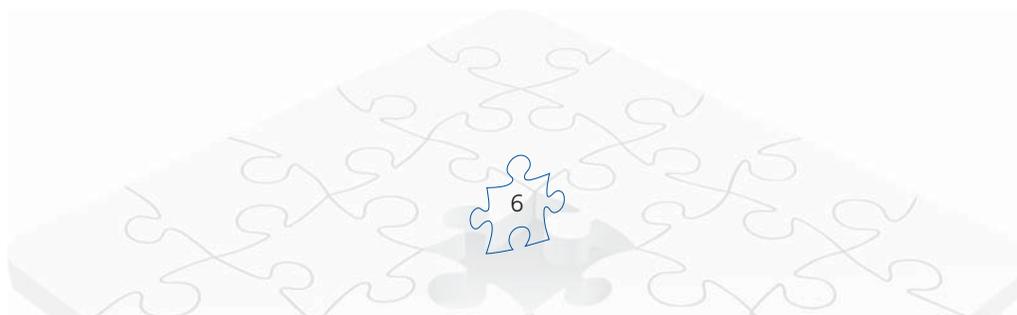
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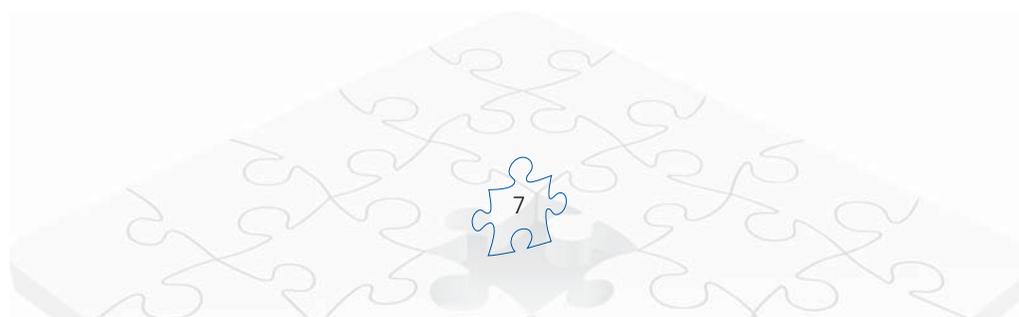
	Journey	Children's NSF Theme	Evidence/links
			There are a number of sources of information on diabetes in children to inform clinical considerations and management. Which applies most appropriately to an individual child is a matter for clinical judgement.
Identification of the problem	<p>Tom has been tired for just over a week. Parents Richard and Stacey have been busy trying to sort out his older sister Molly for starting school in September. With that and juggling work and the normal chores, they've assumed he just isn't getting enough attention.</p> <p>But that doesn't explain why he's so thirsty. Normally, he'd be given drinks throughout the day, but just recently, Tom has been constantly asking for more.</p> <p>One day, Stacey finds him with the fridge door open, having drunk half a carton of grapefruit juice. He hates the stuff and has spat it out before. Tom is asking for water morning, noon and night. And he needs to pass urine all the time. He's recently been potty trained and things have been going really well, but now there are frequent 'accidents'. Again, Richard and Stacey think he just wants attention.</p> <p>They'd not noticed themselves, but when Grandma comes back from holiday in Spain, she says he's looking skinny. They think she's fussing, but come to think of it, he has lost weight and his face is looking a lot less like a chubby toddler's.</p>	Standard 1 Early identification	ISPAD (International Society for Pediatric and Adolescent Diabetes) Clinical Practice Consensus Guidelines 2009 Compendium. Couper J, Donaghue KC (2009) Phases of diabetes in children and adolescents. <i>Pediatric Diabetes</i> 10(Suppl 12): 13–16



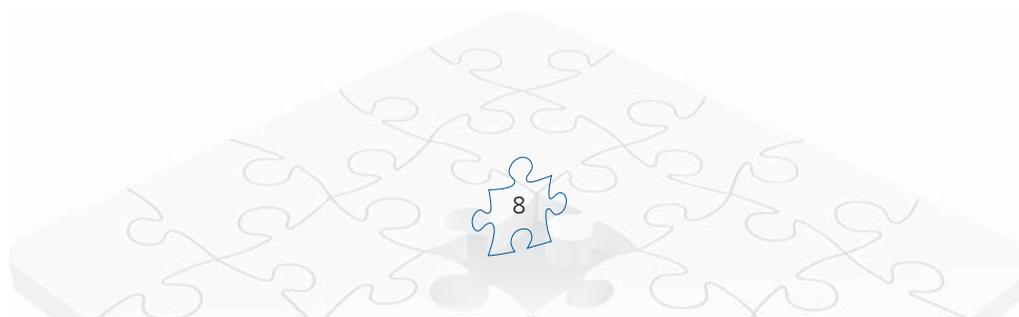
	Journey	Children's NSF Theme	Evidence/links
GP visit	<p>Stacey has the feeling something isn't quite right with Tom, so she books him in to see their GP.</p> <p>In the surgery, Stacey tells the doctor about Tom's tiredness and weight loss. But once she's examined Tom, the doctor says it's likely he's just got a virus and tells Stacey to give him some paracetamol, plenty to drink and make sure he has plenty of rest. So she picks up some paracetamol at the supermarket as she tops up the weekly shop on their way home.</p>	Standard 1 Early identification and intervention	<p>Diagnosis and initial management: Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Early identification: NSF for Diabetes Standard 2 NSF for Diabetes Standard 5</p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Same day referral to paediatric diabetes team: NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i></p>



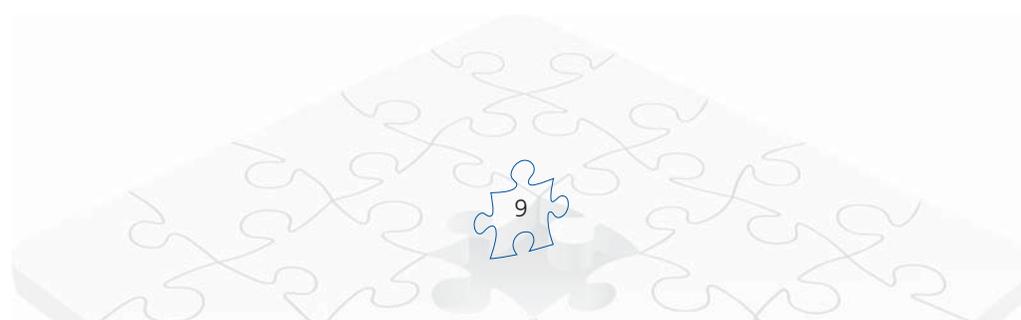
	Journey	Children's NSF Theme	Evidence/links
<p>A&E attendance</p>	<p>But then Tom suddenly gets seriously ill. One evening he starts to become drowsy and weak. Concerned, Stacey calls NHS Direct, who go through a checklist of Tom's symptoms and tell Stacey to get him to A&E.</p> <p>"It was terrifying," says Stacey. "In the space of six or seven hours he became very, very ill. He was really sleepy and floppy."</p> <p>At the hospital, the staff check Tom's blood glucose (sugar) level, which is found to be 32mmol/l, and they diagnose diabetes. His blood ketones are checked and measure over 3.0mmol/l. The doctors tell Richard and Stacey that Tom has diabetes, but they can't quite take it in. Both parents are shocked, upset and confused. The doctors start fluid resuscitation and an insulin infusion is set up. The first task is to rehydrate him, then bring his blood glucose down. He lays there on a drip, attached to a monitor, with nurses pricking his fingers every hour to test his blood glucose level. They're all tired, especially Molly, so Richard takes her home. Stacey stays with Tom, who is looking very small now, hooked up to all these machines and the drip. She tries to think if it's something she's given him that might have triggered all this. But she's so tired, she can't think straight.</p>	<p>Standard 1 Early identification and intervention</p> <p>Standard 6 Assessment of the ill child</p> <p>Standard 6 Accurate diagnosis delivered by staff with appropriate skills and knowledge</p>	<p>British Society for Paediatric Endocrinology and Diabetes recommended diabetic ketoacidosis guidelines (2009) www.bsped.org.uk/professional/guidelines/index.htm</p>



	Journey	Children's NSF Theme	Evidence/links
<p>Admission to PICU</p>	<p>Tom is in diabetic ketoacidosis (DKA) and needs Paediatric Intensive Care Unit (PICU) treatment which is not available at his local hospital, so Tom and Stacey are transferred to a PICU at a children's hospital on the other side of the county. The nurses tell Stacey that's because he's too sick for them to manage at the hospital and that the staff in the children's hospital are experts at dealing with very sick children like Tom.</p> <p>Stacey stays at the hospital overnight in a special bed next to Tom's and the next day Richard comes in while the intensive care consultant does his morning round. The doctor confirms Tom has Type 1 diabetes, which means that his immune system has attacked the beta cells of his pancreas and they are no longer producing insulin. Insulin is necessary for converting glucose into energy for the body to use. Tom will consequently need to take insulin injections to make up for the lack of insulin in his body. The doctor explains that Tom will need to stay in the PICU, where the staff will follow recognised clinical practice guidance on managing DKA until Tom is stable. He will then be transferred back to their local hospital for ongoing management.</p> <p>"I had never heard of Type 1 diabetes," says Richard. "But by that evening, it was the only thing we could think about. Tom's pancreas had packed up. For some reason – nobody knows why – his own body was attacking it and would not let it work. I wondered if that meant Tom was going to die."</p>	<p>Standard 7 Children and young people should receive appropriate, high-quality, evidence-based care by staff who have the right set of skills</p> <p>Standard 7 Care will be provided in an appropriate location and in an environment that is safe and well suited to the age and developmental stage of the child/young person</p>	<p>National Diabetes Support Team (2008) <i>Improving emergency and inpatient care for people with diabetes</i></p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Wolfsdorf J, Craig ME, Daneman D et al (2009) Diabetic ketoacidosis in children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 118–133</p> <p>NSF for Diabetes Standard 8</p>

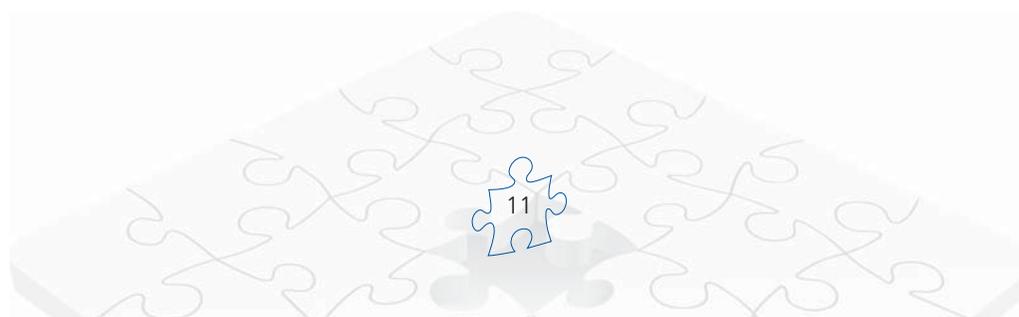


	Journey	Children's NSF Theme	Evidence/links
<p>Transfer back to local hospital</p>	<p>Tom's condition improves very quickly so the next day he is transferred back to the children's ward at his local hospital, much nearer to where the family live. The nurses there already know why Tom has been admitted because the PICU has told them in advance and talked them through his case and what care he has received on the PICU. Once Tom is drinking enough, his intravenous fluids are stopped and an hour before his insulin infusion is stopped, his nurse gives him his first injection of insulin. Tom stays in his local hospital for four days and over that period, Richard and Stacey are taught about managing Type 1 diabetes.</p> <p>Tom sees a paediatric consultant, Jenny, who specialises in diabetes, and Simon, a paediatric diabetes specialist nurse (PDSN). Between them they explain to Richard and Stacey that Type 1 diabetes is a lifelong condition but it is treated with insulin. Jenny arranges for Tom to have blood taken to screen for thyroid disease and coeliac disease, as children with diabetes have a higher risk of developing both of these conditions. She explains that she will take blood to screen for thyroid disease every year and coeliac disease every three years until Tom is transferred to adult services. By now Stacey is in tears. She wonders why it's happened to her little boy and whether it's something they've done.</p>	<p>Standard 3 Services which are integrated around the child's/young person's needs</p> <p>Standard 3 Sharing information and confidentiality</p> <p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p>	<p>Importance of the paediatric diabetes team: NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i></p> <p>Royal College of Nursing (RCN) (2006) <i>Specialist nursing services for children and young people with diabetes</i></p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Screening for associated conditions: NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i></p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Kordonouri O, Maguire AM, Knip M et al (2009) Other complications and associated conditions with diabetes in children and adolescents. <i>Pediatric Diabetes</i> 10(Suppl 12): 204–210</p>

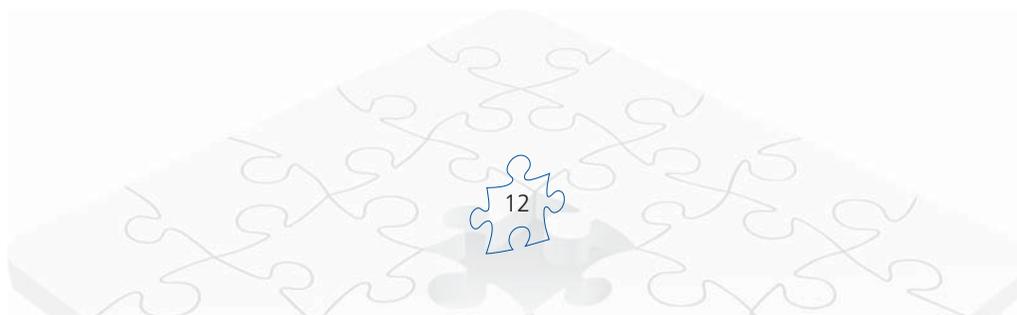


	Journey	Children's NSF Theme	Evidence/links
Learning about diabetes	<p>Over the next few days, the couple get to know more about their local diabetes network of support and Simon teaches them about Tom's condition and what they need to do to keep him well. The paediatric ward staff help with this and Stacey and Richard learn how to give Tom an injection, check and record his blood glucose level, check his ketone level and how to treat him if he has a hypo. Simon demonstrates the injection and blood testing on Tom's teddy, so it won't feel so scary for him. Simon explains that the target for blood glucose levels for children is 4–8mmol/l before meals, rising to less than 10mmol/l after meals. Still coming to terms with the trauma of knowing that Tom is sick, this is about as much as Stacey and Richard can take in.</p> <p>Both parents are finding it hard to focus. Simon hands them a list of local support groups for parents in a similar position. He says parents often find it helpful to meet up and talk about their experiences and concerns. Simon also gives the couple some useful phone numbers, including one for the Diabetes UK membership line and one for the Diabetes UK Careline, which offer support and information to people with diabetes as well as friends, family and carers. The Careline is staffed by trained counsellors who can lend a listening ear and have the time to talk things through. There are also some magazines that Diabetes UK provides. Simon says they may find <i>Tots to teens</i> and <i>Teach your tot about diabetes</i> quite useful.</p>	<p>Standard 3 Information about support and treatment for children/young people and their parents</p> <p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p>	<p>Education/information: Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Swift PGF (2009) Diabetes education in children and adolescents. <i>Pediatric Diabetes</i> 10(Suppl 12): 51–57</p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Pihoker C, Forsander G, Wolfsdorf J, Klingensmith GJ (2009) The delivery of ambulatory diabetes care to children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 58–70</p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Dept of Health (2009) <i>Healthy lives, brighter futures: The strategy for children and young people's health</i></p> <p>Blood glucose targets: NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children and young people</i></p>

	Journey	Children's NSF Theme	Evidence/links
<p>Learning about diabetes continued</p>			<p>Self-monitoring of blood glucose: ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Rewers M, Pihoker C, Donaghue K et al (2009) Assessment and monitoring of glycemic control. <i>Pediatric Diabetes</i> 10(Suppl 12): 71–81</p> <p>Diabetes UK care recommendation: Self-monitoring of blood glucose www.diabetes.org.uk/About_us/Our_Views/Care_recommendations/Self-monitoring_of_blood_glucose/</p> <p>Hypos: ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Clarke W, Jones T, Rewers A et al (2009) Assessment and management of hypoglycemia in children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 134–145</p>

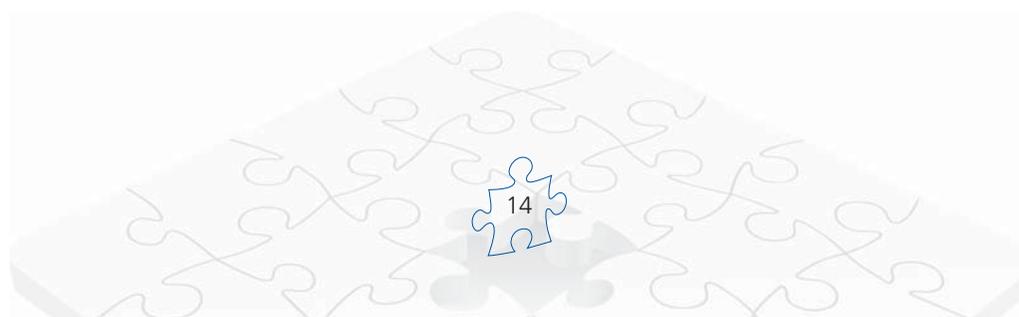


	Journey	Children's NSF Theme	Evidence/links
<p>Learning about diabetes continued</p>			<p>Blood ketone management: Laffel LM, Wentzell K, Loughlin C et al (2006) Sick day management using 3-hydroxybutyrate (3-OHB) compared with urine ketone monitoring reduces hospital visits in young people with T1DM: a randomized clinical trial. <i>Diabetic Medicine</i> 23(3): 278–284</p> <p>Diabetes UK literature: www.diabetes.org.uk/OnlineShop/Children--Young-People/Teach-your-tot-about-diabetes/</p> <p>www.diabetes.org.uk/OnlineShop/New-to-Diabetes/Tots-to-teens/</p> <p>Diabetes UK membership: www.diabetes.org.uk/How_we_help/Supporting-Members/</p> <p>Diabetes UK Careline for support and information Mon–Fri 9am–5pm (0845 120 2690)</p>

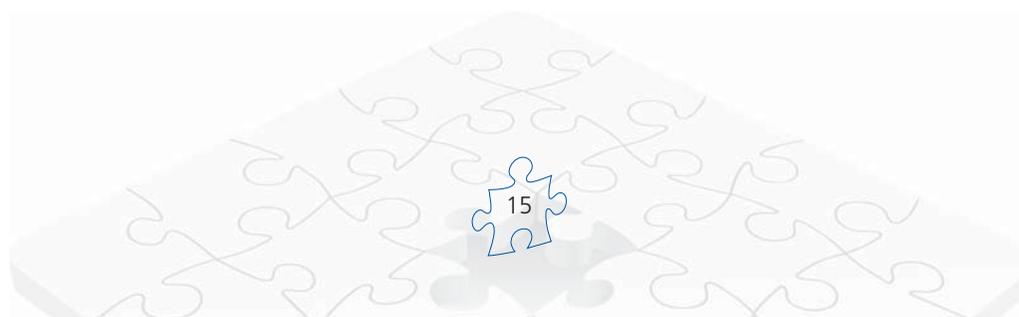


	Journey	Children's NSF Theme	Evidence/links
Dietetic advice	<p>They also see a paediatric dietitian, Verity, who's used to working with children with diabetes. She reviews Tom's current diet and makes suggestions to improve the whole family's eating habits. Stacey wonders if she'd fed him more healthily, would Tom still be ill? Is it her fault? She feels guilty about all the times she's given them both biscuits to calm them down and get them out of her hair long enough to make their dinner. But Verity explains that the diet for children with diabetes is the same as for other children his age, and his present diet has not caused his diabetes. She advises them on simple changes to make to his usual regime and says that eating regular meals with small snacks in between is important. She reassures them that there are no foods that Tom should not eat, but that eating healthy meals and learning good eating habits are even more important for him now he has diabetes. They don't have to cook special foods, so he can have the same as the rest of the family. She also advises them against giving him special diabetic foods.</p> <p>Over the next few weeks, Verity will teach Stacey and Richard how to count the carbohydrates in Tom's food and show them how to adjust the insulin he has with a meal or snack to ensure his blood/ glucose levels remain closer to optimal. This means they don't have to force him to eat what he doesn't want. They can also give him a few extra treats with his meals, such as his favourite sweets, and then just adjust his insulin accordingly. This means they can treat him just the same as Molly.</p>	<p>Standard 3 Information about support and treatment for children/ young people and their parents</p> <p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p>	<p>ISPAD Clinical Practice Guidelines. Smart C, Aslander-van Vliet E, Waldron S (2007) Nutritional management. <i>Pediatric Diabetes</i> 8: 323–339</p> <p>Joint statement on diabetic foods from the Food Standards Agency and Diabetes UK www.diabetes.org.uk/About_us/Our_Views/Position_statements/Joint-statement-on-diabetic-foods-from-the-Food-Standards-Agency-and-Diabetes-UK/</p>

	Journey	Children's NSF Theme	Evidence/links
Psychology input 1	<p>Simon also explains that some families find it helpful to talk to a clinical psychologist. The clinical psychologist talks about how diabetes can get in the way of some of the normal developmental tasks of childhood. Stacey and Richard find that talking through some of their worries about how life might change is helpful. They also feel reassured that parents of children who have just been given a diagnosis can have feelings of grief, fear and guilt. Sometimes children diagnosed with diabetes and their brothers and sisters can feel upset, angry or miserable. Having a clinical psychologist as part of the team means that the family can have help with the other aspects of diabetes when they need it without feeling like they are going mad.</p> <p>They are told to try and keep up as normal a life as they can. Stacey wonders how that is possible when their life now revolves around insulin injections and mealtimes.</p>	<p>Standard 2 Parents whose children have specific needs are offered co-ordinated support services that meet their family's specific needs</p> <p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p>	<p>Emotional and psychological support and care in diabetes: ISPAD Clinical Practice Guidelines. Delamater AM (2007) Psychological care of children and adolescents with diabetes. <i>Pediatric Diabetes</i> 8(5): 340–348</p> <p>Psychological support: Dept of Health (2007) <i>Making every young person with diabetes matter</i> Dept of Health (2009) <i>Healthy lives, brighter futures</i> Diabetes UK (2010) <i>Children's charter for diabetes</i> Diabetes UK Careline for support and information Mon–Fri 9am–5pm (0845 120 2960)</p>



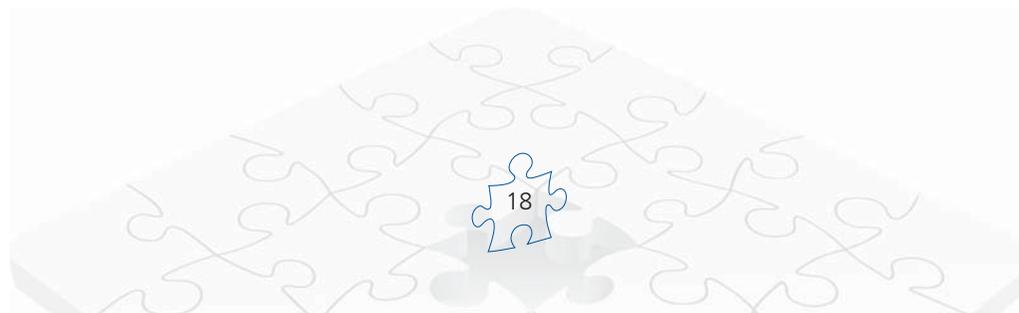
	Journey	Children's NSF Theme	Evidence/links
Discharge planning	<p>After about four days on the children's ward, the staff start making plans for Stacey and Richard to take Tom home. Before Tom is properly discharged, a care plan is drawn up and agreed between the staff, both parents and the paediatric diabetes team. The plan sets out the schedule they've agreed for Simon's visits, clinic appointments and phone numbers they can ring to speak to the diabetes team 24 hours a day. A follow-up appointment is booked to see Jenny, the consultant, at the outpatient clinic in about four weeks' time and a discharge letter is written to the family's GP, to tell her about Tom's diagnosis. The GP has a role in ensuring immunisations are kept up to date, looking after Tom's general health and providing repeat prescriptions for Tom's diabetes supplies. And because he's only three, the family's health visitor is told about Tom's condition too. Richard gets a letter from the paediatric diabetes team for his employer, explaining about Tom's condition, why Richard has had time off and might need more in the future, if Tom gets sick.</p>	<p>Standard 1 Discharge planning – there should be an agreed plan of care involving all relevant services including primary care</p> <p>Standard 7 Co-ordination of care between hospital, community and social services; individual discharge plan</p>	<p>Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Care planning: Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>RCN (2004) <i>Paediatric diabetes: RCN guidance for newly appointed nurse specialists</i></p>



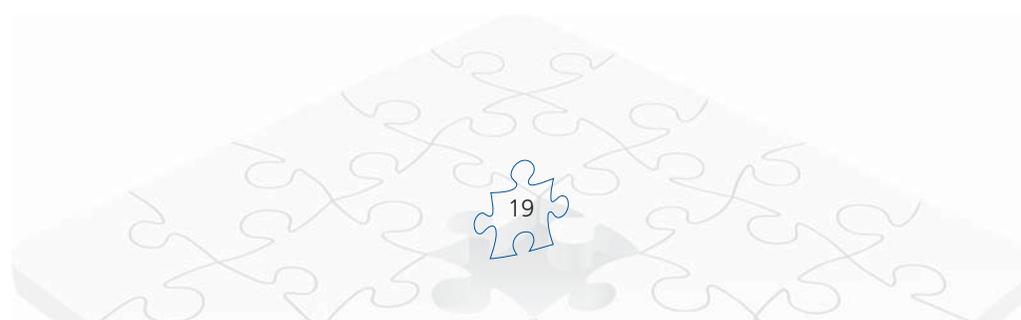
	Journey	Children's NSF Theme	Evidence/links
<p>Home care</p>	<p>Richard and Stacey are pleased to get Tom home for lunchtime armed with insulin, GlucoGel, glucogen, a blood glucose monitor, testing strips, ketone strips, finger-pricker lancets and pen needles from the hospital pharmacy, and a sharps bin to put used needles and lancets in. Later that afternoon Simon visits. He asks Stacey and Richard how they're getting on and answers any questions they come up with. He also checks Tom's blood glucose diary, what food he's eating and when. Initially, he'll visit every day, but as they get more confident he'll come less often. Simon also reminds them that they always need to have with them something sugary, such as three glucose tablets or a sugary drink and a snack, in case Tom goes hypo. Simon tells them what signs to watch out for in him.</p> <p>The three of them discuss how often Simon will visit and make a plan of the times and dates. When Simon leaves they're both a bit nervous about what to do if Tom gets ill in the night. But Simon reassures them, saying it's normal for parents to feel like that in the early days. He reminds them about the paediatric diabetes team's 24-hour contact number.</p> <p>Richard and Stacey try their best to act as though things are back to normal over those first few days. Surrounded by insulin pens, blood glucose testing equipment and hypo remedies, they struggle through with half-understood instructions and fears of fits and unconsciousness.</p> <p>"We couldn't really manage to think about that," says Richard. "Still can't."</p>	<p>Standard 6 Children with long-term health conditions should have access to services that help them develop into 'expert patients'</p> <p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p>	<p>Continuing care: Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Out of hours care: Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>Sharps disposal: Diabetes UK position statement on safe disposal of needles and lancets (sharps) www.diabetes.org.uk/About_us/Our_Views/Position_statements/Safe_disposal_of_needles_and_lancets_sharps/</p> <p>Hypos: ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Clarke W, Jones T, Rewers A et al (2009) Assessment and management of hypoglycemia in children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 134–145</p> <p>NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i></p>

	Journey	Children's NSF Theme	Evidence/links
Sick day rules	<p>Over the next few weeks, Simon builds on the advice that Richard and Stacey have already been given. Another thing he tells them about is sick day rules. If Tom gets an illness or infection, it means that his blood glucose can rise even if he's not eating. Simon advises Richard and Stacey that if Tom does get ill, like all children do, it might upset his diabetes management. So he tells them they should test his blood glucose at least every 3–4 hours, including through the night, and test his blood for ketones if his blood glucose level is 15mmol/l or above. He emphasises when they should contact the paediatric diabetes team for advice.</p> <p>He also advises them on how to increase/decrease Tom's insulin dose depending on his blood glucose level, and tells them to make sure he drinks plenty of fluids. If he won't eat, they can replace his normal meals with things like milk, soup, cereals, ice cream, fruit juice, fizzy drinks or Lucozade so he still gets the right amount of carbohydrates. If his ketones are increasing, or his blood glucose remains high despite giving him extra insulin, or if they are worried about anything at all, then they ought to call him or the diabetes team, Simon tells them.</p>	<p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p> <p>Standard 6 Children with long-term health conditions should have access to services that help them develop into 'expert patients'</p>	<p>ISPAD Clinical Practice Consensus Guidelines. Brink S, Laffel L, Likitmaskul S et al (2009) Sick day management in children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 146–153; <i>Pediatric Diabetes</i> (2007) 8(6): 401–407</p>
Disability Living Allowance	<p>Both parents are pleased to learn from Simon that they can claim Disability Living Allowance (DLA) for Tom. Simon explains that DLA is a non-means-tested benefit for people with a disability and that diabetes falls into this category. It is not affected by Richard and Stacey's wages, or by any savings they might have. Simon says he'll send off for a claim pack especially for children and help them apply.</p>	<p>Standard 2 Supporting parents or carers</p>	<p>Benefits: Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>www.diabetes.org.uk/Guide-to-diabetes/Guide-to-Diabetes-extra-pages/Disability_Living_Allowance_-_claim_for_a_child_under_16/</p>

	Journey	Children's NSF Theme	Evidence/links
Sibling issues	<p>Sometimes when Simon visits he talks to Molly, who has been feeling pretty neglected and doesn't really understand why her baby brother is the centre of attention just because he's ill.</p> <p>"It's not fair. You love him more than me just because he's got that thing. Why can't I be poorly?" she grumbles.</p> <p>Simon explains what's happened to Tom in a way that she can understand and Molly starts to get interested in Tom's diabetes care and how she can help.</p>	Standard 3 Listening to children and parents	<p>www.diabetes.org.uk/Guide-to-diabetes/My-life/Kids/Me-and-my-diabetes/My-family/Brothers-and-sisters/</p> <p>www.diabetes.org.uk/Guide-to-diabetes/My-life/Teens/Me-and-my-diabetes/Relationships/Brothers-and-sisters/</p>



	Journey	Children's NSF Theme	Evidence/links
<p>Injection issues</p>	<p>By the time Christmas comes, Tom is pretty miserable. He is normally such a happy little boy, but for a three year old, it is confusing. He doesn't seem to understand why he still has to have injections when he is back at home. They'd said he was getting better.</p> <p>Tom cries, fights and wriggles when it's time for his injection. He needs to have them four times a day and sometimes more often, if his blood glucose is high. He squirms and fights so much while he has his injection that his bottom and legs are covered in bruises. Stacey and Richard both have to hold him down and on really bad days, they sometimes need Grandma's help too. Even then he still gets bruised because he just won't keep still. He keeps grabbing at the needle too, pulling it out so they sometimes have to try two or three times. They try to distract him by letting him watch cartoons on TV and giving him a toy to play with only when it is time for his injection. They are so desperate they even try bribes and threats.</p> <p>"Giving him the injections was the hardest thing I've had to do," says Richard. "I knew he had to have them, but I didn't want to do it. He hated it and he hated me for doing it to him. Stacey would often get upset because he was so upset."</p> <p>They've been through 'the terrible twos' toddler tantrum phase with both children. But this is something else. Both parents find it hard to tell if a low or high blood glucose level is causing Tom's tantrums. They aren't sure if they should just give him something to eat every time he gets cross. They decide to discuss the problem at their first clinic appointment.</p>	<p>Standard 3 Listening to children and parents</p>	<p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Delamater AM (2009) Psychological care of children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 175–184</p>



	Journey	Children's NSF Theme	Evidence/links
First clinic appointment	<p>When his first clinic appointment comes round, Richard and Stacey arrange for Grandma Mary to pick Molly up from school so they can both go to the hospital with Tom. Richard and Stacey are reassured when they see that the clinic is a special children's clinic, and there are plenty of toys and books to keep Tom occupied while they wait. When it's their turn, Tom's weight and height are checked. Simon is there and he checks Tom's injection sites for lumps (lipohypertrophy) and sees the bruises. Richard tells them what a struggle it has been to give Tom his injections. Simon and Jenny (the consultant) suggest to Richard and Stacey that the play therapist could help or they could meet with the clinical psychologist again. Richard and Stacey say that they'll think about this at home. It hadn't occurred to her before, but Stacey realises they'll be making these clinic visits for years.</p> <p>"Our whole lives were going to be run by Tom's diabetes."</p>	<p>Standard 7 Care will be provided in an appropriate location and in an environment that is safe and well suited to the age and developmental stage of the child/young person</p>	<p>NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i></p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Pihoker C, Forsander G, Wolfsdorf J, Klingensmith GJ (2009) The delivery of ambulatory diabetes care to children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 58–70</p>



	Journey	Children's NSF Theme	Evidence/links
<p>Food issues</p>	<p>Back at home, Tom starts turning his nose up at food, especially at mealtimes. Worried about low blood glucose levels, Stacey and Richard plead and coax him to eat, even preparing two or three different meals. Meanwhile, Molly comes out with things like: "Well, I haven't got diabetes, why can't I have another ice cream?", which doesn't help. In the end, Tom often holds out for fizzy pop, which will do his teeth no good, but it is such a relief to get something, anything, in him, that they don't care.</p> <p>Stacey discusses it with Simon and Verity (the dietitian), who suggest he has his insulin injection after his meal rather than before. They explain that rapid-acting insulin controls blood glucose levels much better if taken before a meal, but this way means that the dose can be adjusted and food won't become a battleground. As Tom's appetite becomes more predictable, they will grow more confident that he will eat all his meal and so can go back to giving the insulin before he eats.</p> <p>Stacey says: "When he does decide to eat, it's really hard making sure Tom has the right types of food, avoiding too many sugary foods, because he's quite a fussy eater. He doesn't really understand about his condition and why it's so important to eat properly – he's just too young."</p> <p>However, after chatting to Verity Stacey realises that they could be more relaxed with this while he grows out of his fussy tastes and can try to introduce the right foods gradually, one at a time.</p> <p>These practical suggestions make them feel more confident, but they agree that it still might be helpful to talk to the clinical psychologist about other ideas to help manage the difficulties with eating and the injections.</p>	<p>Standard 3 Listening to children and parents</p> <p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p> <p>Standard 7 Specialist paediatric clinics should have ready access to a mental health liaison service</p>	<p>ISPAD Clinical Practice Guidelines. Smart C, Aslander-van Vliet E, Waldron S (2007) Nutritional management. <i>Pediatric Diabetes</i> 8: 323–339</p>

	Journey	Children's NSF Theme	Evidence/links
<p>Psychology input 2</p>	<p>The clinical psychologist explains that food fads are not unusual in children of Tom's age. Richard and Stacey have noticed that Tom seems able to pick up when they are worried. They agree that this means they are giving him a lot more attention when he is being difficult than when he is being good. Richard and Stacey agree that they will try to praise Tom for eating anything to begin with. They also think they could clear away dinner after 30–40 minutes, and they will try not to make a big deal of him refusing to eat. They are already delaying the insulin injection until the end of the meal, which means that he is unlikely to go hypo.</p> <p>By the next meeting, Tom's eating has improved and Richard and Stacey are really pleased with how they have worked together to praise Tom when he has done well. They say that noticing what works was a good way to help Tom change his behaviour, rather than focusing on what he was not doing well.</p> <p>Richard and Stacey are still very worried about how Tom is managing his injections. Stacey mentions how scared she is about injections and how she suspects Tom has noticed this. In the next session with Tom and his parents, the clinical psychologist introduces the family to a teddy who also has diabetes and helps Teddy with his injections. Tom is asked about times he has been brave and how he has managed to do this. Tom tells a story about how he had fallen over and hurt his knee but he hadn't cried. He says what helped him be brave was Mummy giving him a big cuddle. The clinical psychologist also asks Tom to help her understand why Mummy and Daddy have to give him the injections. Tom says it is to stop him being poorly but it still makes him cross. The clinical psychologist asks Tom if he could make a bravery chart for himself, and every time he has his injection he will get a special sticker. She asks Tom to show her his chart the following week. Richard and Stacey are asked to notice what the things are that help Tom manage to be brave and to write these on his bravery chart.</p>	<p>Standard 3 Listening to children and parents</p> <p>Standard 7 Specialist paediatric clinics should have ready access to a mental health liaison service</p>	<p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Delamater AM (2009) Psychological care of children and adolescents with diabetes. <i>Pediatric Diabetes</i> 10(Suppl 12): 175–184</p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Role play/impact of parents' negative feelings: Snoek F, Skinner C (2005) <i>Psychology in diabetes care</i>. Chichester: John Wiley and Sons</p> <p>The need to consider psychological well-being: Dept of Health (2009) <i>Healthy lives, brighter futures</i></p>

	Journey	Children's NSF Theme	Evidence/links
<p>Considering an insulin pump</p>	<p>They had hoped he'd grow out of it, but months along the line, giving Tom his injections and getting him to eat properly are still an upsetting battle. Richard and Stacey are exhausted. They discuss this at their next clinic appointment. The doctor, Jenny, talks to them about insulin pump therapy. She explains how a pump can help improve diabetes management by giving more accurate insulin delivery allowing for alteration in routine, eating patterns and exercise. The pump can also lessen the risk of hypoglycaemia. The doctor shows them both a pump, which looks like a mobile phone.</p> <p>She explains that the pump is a computerised device that delivers small amounts of insulin constantly under the skin. The pump has a syringe in it which contains rapid-acting insulin. Running from it is a thin plastic tube with a small plastic needle or cannula at the other end. This is inserted under the skin and needs to be changed every two to three days. The pump can be removed for short periods but is generally worn 24 hours a day and is programmed to give a small background (basal) dose of rapid-acting insulin continuously throughout the day and night. Each time Tom eats food containing carbohydrate Richard and Stacey will need to press a sequence of buttons to give an additional (bolus) dose of insulin to cover what he has eaten. A bolus can also be given to treat a high blood glucose level. In this way, Jenny explains, the insulin pump mimics more closely the way a healthy pancreas delivers insulin.</p> <p>If Tom does have a pump, Stacey and Richard will need to test the blood glucose at least four to six times a day to check that it is working, adjust mealtime boluses, and correct high blood glucose levels. Someone who knows how to use the pump will need to be around 24 hours a day, seven days a week to help with blood glucose tests, add up Tom's mealtime insulin needs, adjust pump settings, and troubleshoot any problems. There is a lot to think about.</p>	<p>Standard 6 Information for children, young people and parents</p>	<p>Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>NSF for Diabetes Standard 3</p> <p>NICE (2008) <i>Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus</i></p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Leeds Children's Diabetes Team (2009) <i>Guidance for CSII therapy for children with Type 1 diabetes</i></p>

	Journey	Children's NSF Theme	Evidence/links
Considering an insulin pump continued	<p>Richard and Stacey have a few concerns. If Tom keeps pulling the injection needles out, will he wear the pump? What about having the needle put in? There is a lot they'll have to learn themselves too, such as how to correct for high or low blood glucose levels, and how to alter insulin doses for changes in Tom's level of exercise or days when he is poorly.</p> <p>To help them make a decision, Simon arranges for Stacey and Richard to meet another family who have a child on an insulin pump. This child first had his pump at about the same age as Tom, so Stacey and Richard find their experiences really useful.</p> <p>After thinking about it all, they decide to try Tom on a pump. As Tom fulfills the criteria of the NICE guidance for insulin pump therapy, Simon will approach the PCT for funding.</p>		
Pump school	<p>The next step is fixing a date to start the pump, as both Simon and Verity (the dietitian) will need to be involved. Richard, Stacey and Tom will need to attend a two-day outpatient programme to learn all about the pump. In the meantime, Richard and Stacey start looking at the pump websites and literature Simon has directed them to.</p> <p>The first day of 'pump school' is spent learning about the technical side of the pump. Stacey and Richard learn how to fill the syringe and tubing. By the time they go home, Tom is attached to a pump with saline. Verity asks them to keep a record of everything Tom eats and drinks over the next few days. This will be used along with the blood glucose readings to adjust the pump's settings.</p> <p>The next few days are spent practising the button pushing, with the confidence of knowing that any mistakes do not matter as the pump only contains saline. The second day of pump school quickly arrives and by lunchtime Simon has inserted the cannula and Tom is pumping with real insulin. There is a lot of information to take on board, but Simon reassures them that they will be speaking to members of the diabetes team frequently over the first few weeks of being on a pump.</p>	<p>Standard 2 Parents whose children have specific needs are offered co-ordinated support services that meet their family's specific needs</p> <p>Standard 6 Children with long-term health conditions should have access to services that help them develop into 'expert patients'</p>	<p>NICE (2008) <i>Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus</i></p> <p>Leeds Children's Diabetes Team (2009) <i>Guidance for CSII therapy for children with Type 1 diabetes</i></p>

	Journey	Children's NSF Theme	Evidence/links
<p>Insulin pump support</p>	<p>Back at home Stacey and Richard notice the difference in Tom right away. No more needles to be fought over, better blood glucose levels and far fewer tears and tantrums. There is plenty of back-up too as they have 24-hour access to the healthcare team. Over the first few days they both have long phone calls with Simon, discussing with him how they are getting on and deciding on the first small changes to the basal rate. Although they have been told not to expect a huge improvement in Tom's blood glucose levels in the early days, the couple are amazed how much better they are within a week. Simon's coaching aims to get Richard and Stacey to try and make the decisions about the changes, and his advice is very helpful. After that, there are follow-up emails and texts.</p> <p>After just a few weeks both parents feel like they've got their lives back. They worry much less about Tom's overall care, hypoglycaemia, and mealtimes.</p> <p>Stacey says: "It was fantastic. We felt we'd got our lives back and our kids back. And being able to sleep properly without worrying about night-time hypos made me feel like a new woman. Mum said we all looked less tired. After a few months though, it began to dawn on all of us that this would be for all of Tom's life. That was nearly as upsetting as when he was diagnosed. But nearly a year down the line, we're all getting used to it."</p>	<p>Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs</p> <p>Standard 6 Supporting self-care</p>	<p>East and North Herts NHS Trust Child Health Directorate (2009) <i>Policy and guidelines for insulin pump therapy in children and teenagers</i></p>



	Journey	Children's NSF Theme	Evidence/links
<p>Starting nursery</p>	<p>The term before Tom's due to start at the local nursery, Simon phones the staff there and arranges to visit and talk to them about how to look after Tom. He explains about diabetes in general and also about Tom's specific needs, including how to manage his pump. Together Richard, Stacey, Simon and the nursery staff develop a written healthcare plan detailing all Tom's needs and the care he requires. Included in the plan are how to check Tom's blood glucose level, manage the pump and details of what to do in an emergency, for instance if Tom has a hypo or is poorly. They are also given a list of emergency telephone numbers. Simon tells the staff at the nursery that Richard or Stacey will count the amount of carbohydrates in Tom's lunchbox and then the staff will be able to work out the right amount of insulin he needs depending on how much he eats. The nursery staff will also have to tell Stacey, Richard or Grandma Mary how his diabetes has been managed that day when they come to pick him up.</p> <p>Simon highlights the Disability Discrimination Act for schools, which applies to nurseries too and covers children with diabetes, like Tom. The act says that staff should not treat Tom 'less favourably'. It means they are required to make reasonable adjustments to ensure that disabled pupils are not at a disadvantage.</p> <p>The staff wonder how the other children will react to Tom's diabetes, and therefore arrange for Simon to go in and talk to the children about Tom's condition once term is underway. Simon tells them that sometimes Tom might have to have a snack when the other children aren't eating. Simon tells the children too that diabetes isn't like having chickenpox and that they can't catch it from him. He says that it is OK for Tom to have sweets but, just like them, he shouldn't have too many because they aren't good for anyone.</p>	<p>Standard 6 Supporting children and young people's educational needs</p> <p>Standard 8 Good communication between health and educational services</p>	<p>Early years/school settings: Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>Medical conditions at school: A policy resource pack www.medicalconditionsatschool.org.uk</p> <p>Diabetes UK (2008) <i>Making all children matter: support for children with diabetes in schools</i></p> <p>Dept for Education and Skills and Dept of Health (2005) <i>Managing medicines in schools and early years settings</i> (Update due April 2010 entitled <i>Supporting children and young people with health needs in educational and early years settings</i>)</p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>RCN position statement (2009) <i>Supporting children and young people with diabetes in school and early years settings</i></p> <p>The Disability Discrimination Act 2005: www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068</p> <p>Dept for Education and Skills (2006) <i>Implementation of the Disability Discrimination Act in schools and early years settings</i></p>

	Journey	Children's NSF Theme	Evidence/links
<p>Family support</p>	<p>The next year the family book to go on a Diabetes UK family weekend. Richard and Stacey are both a bit nervous before they go, because they realise it will be the first time, apart from nursery, that Tom will be looked after by people who aren't family. But the people who run the weekend are supported by trained healthcare professionals who are experts on looking after children with diabetes. Tom has a great time. Richard and Stacey swap numbers with other couples they've met and find it reassuring to talk to people in a similar situation.</p> <p>There are still days with unexplained highs or lows, but Stacey and Richard are now managing to treat them quickly and easily.</p> <p>"I know Tom enjoys the freedom the pump gives him," says Richard.</p>	<p>Standard 8 Short breaks for children, young people, parents and carers provide positive experiences and reduce stress</p>	<p>Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>www.diabetes.org.uk/How_we_help/Care-events/</p>
<p>Hospital admission for broken arm</p>	<p>One half term, the family go to stay with Stacey's sister, Suzie. Tom and Molly are playing outside with their cousins when Tom falls off a bike and breaks his arm. Molly rushes in to tell Stacey. They panic, but manage to get him to Suzie's nearest A&E in the car. Tom's arm is x-rayed, and the doctor tells Richard and Stacey that Tom will need a pin and plate put in his arm, which requires surgery right away. They sign the consent form and get Tom changed into his gown.</p> <p>As well as his arm, Stacey and Richard are worried about his diabetes management during the operation. All children have accidents like these now and again, it is part of growing up, thinks Richard. But not all of them have diabetes – what if he never comes round from the anaesthetic? They speak to the ward manager and the anaesthetist and Stacey tells them about Tom's insulin pump.</p> <p>"When I told them about Tom's pump all I got was a series of blank looks," Stacey said. "No one knew how to run the pump, what to do with it during surgery and how to deal with it after surgery, so I freaked out. Tom had never had surgery before. I had no idea what might happen to his blood glucose levels. But I think it was not being in control of his condition for the first time that really bothered me."</p>	<p>Standard 6 Assessment of the ill child</p> <p>Standard 3 Listening to children and parents</p> <p>Standard 8 Children and their parents should be treated with respect, should be active partners in their healthcare and, where possible, should be able to exercise choice</p> <p>Standard 6 Professionals who are dealing with acute illness need to understand how this may impact on the management of a child's/ young person's long-term condition</p>	<p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Betts P, Brink S, Silink M et al (2009) Management of children and adolescents with diabetes requiring surgery. <i>Pediatric Diabetes</i> 10(Suppl 12): 169–174</p> <p>NSF for Diabetes Standard 3</p> <p>NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i></p> <p>NSF for Diabetes Standard 8</p> <p>Leeds Children's Diabetes Team (2009) <i>Insulin pump therapy and surgery</i></p>

	Journey	Children's NSF Theme	Evidence/links
<p>Hospital admission for broken arm continued</p>	<p>The nurses want to take Tom off the pump, so it will be easier for them to manage his diabetes during surgery and when he is recovering from the operation. But Stacey remembers how long they spent deciding whether or not to put Tom on a pump. She is worried Tom's blood glucose levels will go out of control if it is removed. Another thing that bothers her is how difficult it will be to inject him again, especially as Tom doesn't know any of the nurses. Then there is the issue of how Tom will take it. They mention these concerns to the senior nurse, but she seems pretty abrupt about it. Stacey worries that they think she is interfering with their work and doesn't know what she is talking about. The nurse keeps saying "let the professionals decide what's best for him. We've had experience dealing with these things". But that was exactly it, thinks Stacey as they are waiting to go in. They haven't. They seem pretty scared about Tom's pump, which doesn't fill her with confidence.</p> <p>It is out of hours, so she calls the emergency contact number for Tom's diabetes team and gets put through to Simon. By now Richard and Stacey are both very worried, but Simon calms them down. He talks to the surgical team and gives them guidance about how to manage Tom's pump while he is having surgery. He backs this up by emailing over the written protocol that his team have developed about this.</p> <p>Stacey says: "It seemed like a bit of a battle at the time to keep Tom on the pump while they fixed his arm. I thought they'd just ignore whatever I said because I was just a silly mum and they'd got more serious cases to deal with. But I remembered what Simon told us about having a say in Tom's care. And I'm glad we managed to turn it round in the end. One of the student nurses at least seemed pleased he'd learned more about treating the condition."</p>		

	Journey	Children's NSF Theme	Evidence/links
<p>Starting primary school</p>	<p>Tom is now four-and-a-half-years old and is due to start school. Richard has started to worry about how the other kids will react to Tom. As a teacher, he's seen what children can be like. After talking it over with Stacey and Simon, they all decide the best thing they can do is ask his new teacher to talk to Tom's class about his diabetes.</p> <p>They've had great support around Tom's diabetes at nursery, but Stacey and Richard are worried it will all be different in the more formal school environment. Richard knows there is no legal requirement for a teacher to deal with Tom's insulin pump, and both he and Stacey are concerned that in a bigger class Tom's medical needs will get overlooked.</p> <p>They chat to Simon, who explains that the diabetes team and school staff will work with Stacey and Richard to develop a healthcare plan which will detail all Tom's medical needs, how they will be met and by whom.</p> <p>The term before he's due to start school, Richard, Stacey and Simon go to meet the staff. Tom's new teacher, classroom assistant, school nurse and head teacher are all present and together they develop a diabetes healthcare plan for Tom. This plan talks about what care Tom will need during the school day, including blood glucose tests, pump boluses, how to recognise and treat a hypo, when to give extra snacks as required and so on. Once the teachers know what needs to be done, they can schedule time into the school day. His healthcare plan also lists contact information for Tom's diabetes healthcare team, so the school can get in touch in an emergency. Tom's teacher and Simon agree to talk to the whole class about Tom's diabetes as well.</p> <p>As they'd previously discussed, Simon reminds Richard and Stacey to encourage Tom to talk about his diabetes with his classmates. A lot of children with diabetes are frightened of being different and feel foolish if they have a hypo at school or when they're out and worry about being called names.</p> <p>"Tom is the only child at his school with diabetes. They have been very supportive and call at anytime if they are not sure about anything big or small. So far we haven't had any problems with bullying," says Richard.</p>	<p>Standard 6 Supporting children and young people's educational needs</p> <p>Standard 5 LEAs and school's governing bodies have a duty to promote the welfare of children</p> <p>Standard 8 Good communication between health and educational services</p>	<p>Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>Dept for Education and Skills and Dept of Health (2005) <i>Managing medicines in schools and early years settings</i> (Update due April 2010 entitled <i>Supporting children and young people with health needs in educational and early years settings</i>)</p> <p>Diabetes UK (2008) <i>Making all children matter: support for children with diabetes in schools</i></p> <p>RCN position statement (2009) <i>Supporting children and young people with diabetes in school and early years settings</i></p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Section 175 of the Education Act 2002, School Action and School Action Plus</p> <p>The Disability Discrimination Act 2005: www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068</p> <p>Dept for Education and Skills (2006) <i>Implementation of the Disability Discrimination Act in schools and early years settings</i></p>

	Journey	Children's NSF Theme	Evidence/links
Continuous blood glucose monitoring	Tom continues to attend the paediatric outpatient clinic three to four times a year and every time among other checks he has his HbA _{1c} (a measure of long-term diabetes management) measured. On one occasion it comes back quite high which surprises the family as his fingerprick blood glucose tests are generally within the target range. Jenny, the consultant, suggests that Tom wear a continuous glucose monitor for a few days, and arranges for him to come to the clinic again to have it fitted. Simon fits the device and after a few days takes it off again and downloads the information. The results show that Tom is getting high blood glucose levels at times when he's not been testing, so Jenny and Simon advise that he adjust the rate on his pump slightly to cover that period.	Standard 6 All children/young people who are ill will have timely access to appropriate advice and effective services which address their needs	NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i> Diabetes UK (2010) <i>Children's charter for diabetes</i> Diabetes UK position statement on continuous blood glucose monitoring www.diabetes.org.uk/About_us/Our_Views/Position_statements/Continuous-glucose-monitoring/
Bullying at secondary school	When Tom is 11 and he moves to the high school in town, things seem to go down hill. In his first week, Stacey notices a change in Tom. He seems quieter. She thinks it odd when he says he's lost his blood glucose testing monitor and the Lucozade and glucose tablets he keeps in his bag for emergencies. He is quite snappy and doesn't seem to have his friends round as much as he used to, but they just put that down to him growing up. He is usually quite good with his food and exercise but, just recently, Tom has started eating lots of snacks before he gets home, and then doesn't want what Stacey has made for them for dinner. He is also 'forgetting' to correct for these snacks with his pump. One night, Richard checks Tom's blood glucose results from the day and notices they've hardly changed for about three weeks. He is confused. He knows something isn't quite right, but can't pin down what, so he has a look at Tom's blood glucose monitor. The figures just don't tally with what Tom has put down in his diary.	Standard 5 LEAs and schools have a duty to extend safeguarding duties to cover bullying Standard 6 Supporting children's and young people's educational needs	NICE (2009) <i>Promoting young people's social and emotional wellbeing in secondary education</i> www.bullying.co.uk/index.php/schools/ www.teachernet.gov.uk/management/atoz/a/antibullyingpolicy/ Diabetes UK anti-bullying video virals www.diabetes.org.uk/Guide-to-diabetes/My-life/Teens/Fun-stuff/Setting-the-record-straight/ www.diabetes.org.uk/Guide-to-diabetes/My-life/Teens/Fun-stuff/The-bendy-bus---a-short-film2/

	Journey	Children's NSF Theme	Evidence/links
<p>Bullying at secondary school continued</p>	<p>Sensing something is wrong, Stacey asks Molly, now 13, if she knows what's going on, but she won't say a word. Eventually one night when Tom is at a friend's, Richard and Stacey sit Molly down to chat about their worries about Tom. Molly is annoyed that her younger brother is still getting all the attention, but after her parents tell her they'd ask Tom if the roles were reversed, she tells them that she has seen Tom being pushed around by two boys a year older than him and the other pupils didn't do anything.</p> <p>On Simon's advice, Richard and Stacey arrange to meet Tom's head of year, Mr Smith, to discuss the situation. Tom likes Mr Smith and has said how much he enjoys his lessons. Mr Smith says that the school has an anti-bullying policy, and they take this type of thing very seriously. In line with the school's policy, Stacey and Richard meet with the head teacher to chat about their concerns and Stacey asks Simon to go along too. She doesn't want to seem like an over-protective parent and it feels reassuring to have someone with experience there for back-up. Together they discuss a strategy – the school will deal with the bullying according to their policy and they will also put Tom on a mentor scheme with an older boy who will look out for him. Tom isn't best pleased about this to begin with because again he feels that he is being singled out. Really he just wants to be like the other kids and not make a fuss about his diabetes. But when he meets his mentor, Robert, they hit it off right away. Robert is a few years older than Tom and known for being good at sport. He also has asthma and sometimes needs to use an inhaler.</p> <p>After a few weeks, Tom seems to settle down a bit more and starts to have a bit more fun. He joins the school football club and brings round some of the kids from the team one night. After that, Richard and Stacey stop worrying so much.</p>		

	Journey	Children's NSF Theme	Evidence/links
<p>Structured education</p>	<p>When Tom was younger, all the education around his diabetes was directed at Stacey and Richard. Tom's always been involved but now he's older, Simon suggests he might like to have some more formal education with children his own age. Tom's paediatric diabetes team runs special courses for adolescents where they can learn about diabetes for themselves from the team members. Simon explains that quite a few diabetes teams run these courses and they all do it slightly differently – Tom's team offers a two-hour session every week for four weeks. Tom likes the idea of being more in control and signs up.</p>	<p>Standard 6 Children with long-term health conditions should have access to services that help them develop into 'expert patients'</p>	<p>NICE (2003) <i>Guidance on the use of patient education models for diabetes</i></p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Swift PGF (2009) Diabetes education in children and adolescents. <i>Pediatric Diabetes</i> 10(Suppl 12): 51–57</p> <p>Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Kick-Off study: www.kick-off.org.uk/</p> <p>Cascade study: cascade.lshtm.ac.uk/</p> <p>FACTS study: www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Children_and_Young_People/FACTS_Families_Adolescents_and_Childrens_Teamwork_Studybr_August_2005/</p> <p>Depicted study: www.cardiff.ac.uk/medic/subsites/sewtu/whatwedo/depicted-study.html</p> <p>Get Sorted programme: www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Children_and_Young_People/The-Getting-Sorted-Self-Care-Workshops-for-young-people-with-Diabetes---June-2007/</p>

	Journey	Children's NSF Theme	Evidence/links
Annual review	<p>A year later, after Tom turns 12, the clinic call him in for his first annual review. Simon tells the family what to expect and how to prepare. Tom will be screened for complications associated with diabetes which can affect the eyes, brain, cardiovascular system, kidneys and nerves. Tom will have blood and urine tests taken, his blood pressure checked and his eyes screened using a digital retinal camera. And, just like at his usual appointments, they will check his height and weight. He will also see a dietitian. The annual review gives Tom's team the opportunity to review Tom's own knowledge, skills and confidence around his diabetes management. As he was so young when he was diagnosed, all the support and education was initially aimed at his parents. Tom sees Jenny at the appointment and together they work out a care plan which identifies Tom's needs and the actions that both Tom and the team are going to take to meet them. Tom gets a copy of this to take home.</p>	<p>Standard 1 Screening programmes meet national standards. Access to information about screening and results of screening are received in a timely manner</p>	<p>NICE (2004) <i>Type 1 diabetes – diagnosis and management of type 1 diabetes in children, young people and adults</i></p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Donaghue KC, Chiarelli F, Trotta D et al (2009) Microvascular and macrovascular complications associated with diabetes in children and adolescents. <i>Pediatric Diabetes</i> 10(Suppl 12): 195–203</p> <p>Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>NSF for Diabetes Standard 3</p> <p>NSF for Diabetes Standard 5</p> <p>NSF for Diabetes Standard 10</p> <p>Care planning: Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>Dept of Health (2007) <i>Making every young person with diabetes matter</i></p>



	Journey	Children's NSF Theme	Evidence/links
Transition to adult services	<p>Tom, Stacey and Richard have been told by Simon and the team right from the start that they wouldn't always be looking after Tom's diabetes. Once he is an adult, the adult diabetes team will take over as they will be better able to meet his needs. Through adolescence, Simon starts to prepare Tom and the family for the transition. He explains that the adult team will expect Tom to be more responsible for his own diabetes and won't be so involved with his family. They are all a bit worried at first, but Simon reassures them that there is no set age to move, and the team won't transfer Tom until he feels he is ready. Simon explains that when the time is right, Tom will be seen in a special transition clinic staffed by both paediatric and adult teams. As adolescents with diabetes have very specific needs, this clinic will specifically address the issues that affect young people with diabetes, such as smoking, alcohol, drugs, sex, driving and employment. Together Simon, Jenny, Tom, Richard and Stacey identify which aspects of his diabetes Tom is less confident in managing and put together a plan to address this. Gradually Tom gains confidence in looking after his own condition, and looks to Stacey and Richard for advice less often. Then the day comes when Tom feels ready to transfer fully to the young adult clinic.</p> <p>Looking back, Tom feels he's come a long way. He'd hardly been able to talk when he was first diagnosed and now he has a far better grasp of his condition and is taking responsibility for managing it by himself.</p>	Standard 4 Transition to adult services	<p>Diabetes UK care recommendation: Transition to adult services www.diabetes.org.uk/About_us/Our_Views/Care_recommendations/Transition-from-paediatric-to-adult-services/</p> <p>ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. Court JM, Cameron FJ, Berg-Kelly K, Swift PG (2009) Diabetes in adolescence. <i>Pediatric Diabetes</i> 10(Suppl 12): 185–194</p> <p>Dept of Health (2007) <i>Making every young person with diabetes matter</i></p> <p>Diabetes UK (2010) <i>Children's charter for diabetes</i></p> <p>Dept of Health (2009) <i>Healthy lives, brighter futures</i></p> <p>Dept of Health (2007) <i>You're Welcome quality criteria: making health services young people friendly</i></p> <p>NSF for Diabetes Standard 6</p>

Useful Links

Diabetes UK www.diabetes.org.uk

ISPAD (The International Society for Pediatric and Adolescent Diabetes) www.ispad.org

NICE (National Institute for Health and Clinical Excellence) www.nice.org.uk

Kick-Off study www.kick-off.org.uk/

Cascade study cascade.lshtm.ac.uk/

FACTS study www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Children_and_Young_People/FACTS_Families_Adolescents_and_Childrens_Teamwork_Studybr_August_2005/

Depicted study www.cardiff.ac.uk/medic/subsites/sewtu/whatwedo/depicted-study.html

Get Sorted programme www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Children_and_Young_People/The-Getting-Sorted-Self-Care-Workshops-for-young-people-with-Diabetes---June-2007/

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