

9 Finding support from other parents can be useful

- It is really important to find support from another parent like you (see point 10)
- Every person's diabetes is different, so try not to compare or judge with other parents
- Make sure online information is accurate, ask your healthcare team for trusted websites (see point 10)
- It can be useful to attend a diabetes holiday camp or find opportunities to meet other families with diabetes
- It may feel difficult to hand over responsibility for your child's diabetes, as they grow older. Seek support to do this



10 Useful websites / information

- Know Diabetes Website: www.knowdiabetes.org.uk/know-more/children-and-young-people/
- JDRF schools pack and e-learning module for teachers: JDRF.org.uk/schools
- Diabetes UK: Type 1 essentials for children and young people: www.diabetes.org.uk/get_involved/campaigning/type-1-essentials
learningzone.diabetes.org.uk
www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes
- Please visit Digibete.org and www.t1resources.uk/
- Look for Parent Facebook Groups and Diabetes UK Family Support Groups



for parents or carers of children with Type 1 Diabetes



Supported by:



© Developed with the Parents of Children with Type 1 Diabetes in the UK Facebook Group, DUKLLANDS Parent Support Group, NHS Guy's and St Thomas' Foundation Trust and NHS Imperial College Healthcare Trust Diabetes Teams, Jo Dalton, Diabetes Specialist Nurse, Ruth Miller, Diabetes Nurse Consultant and Alex Silverstein, North West London Diabetes Transformation Team
email: ruth.miller2@nhs.net

Designed by NHS Creative – CS50915 – 04/2020



1 Your child's diabetes is not anyone's fault

- It is normal to feel angry, shocked and upset when you find out that your child has diabetes
- Some families say it feels like bereavement or loss, which takes time to learn to live with
- You may experience guilt but don't blame yourself or let others blame you. Your child has not got diabetes because of something you have fed them or something you have done



2 Living with your child's diabetes may feel overwhelming

- Learning about diabetes is like learning a new language
- Don't expect to be fluent straight away. You will make mistakes and learn something new every day
- Don't stop your child's activities due to diabetes. They can do the same things as other kids with a little planning



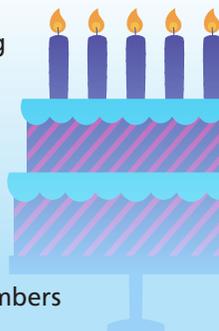
3 Emotional support for your child and your family

- Find out and access emotional support available within your diabetes team and/or at your child's school
- It's important to give time to your other children
- Recognise how diabetes makes you feel and learn to express your emotions
- Be aware that eating disorders and self-harm with insulin may develop
- Talk to your GP if you are struggling, you can get free NHS talking therapies (IAPT) support



4 Don't judge yourself or your child by their blood glucose level

- Diabetes isn't easy. Every day will be different even if you do the same things
- There are over 40 factors affecting blood glucose – understand that neither you nor your child have failed when glucose levels are high or low. Resist the urge to feel guilty or tell your child off
- Birthday parties and activities that your child loves are more important than blood glucose numbers



5 Know what to do if your child has a hypo (low blood glucose-less than 4mmol/L)

- Ensure you have specific individualised information from your child's team about how to treat their hypos
- Some symptoms: shaky, sweating, pale, hungry, irritable, blurred vision
- Children recently diagnosed may still produce some insulin ("honeymoon" phase)
- Low blood glucose can be confused with "bad" behaviour, mood changes and irritability



6 Know what to do if your child has high blood glucose (for them)

- Some symptoms: thirsty, tired, blurred vision, infections, peeing more, losing weight
- Illness and infections may increase blood glucose; test more often, know about sick day rules and when to check for ketones
- If worried about consistently high blood glucose, check with your diabetes team for individual advice and sick day rules



7 You and your child will become both experts and advocates

- You may need to be assertive to ensure your child's needs are met
- There are lots of new technologies available to support your child's diabetes (e.g. pumps and sensors). Ask your team what is available on the NHS
- Ensure your child has a regularly reviewed care plan
- Educate and empower friends and family to help support your child's diabetes
- You can get practical support for your child at school, e.g. extra time at exams. Work with your healthcare team to do this
- Your child may still need your support even when they seem independent



8 Get all the support you can

- Children under 16 may be eligible for Disability Living Allowance (non-means tested)
- Children over age 16 may be eligible for Personal Independence Payment (PIP)
- Parents/carers may be eligible for Carer's allowance
- Social Services can offer practical help if you are struggling

