



LIVING WITH D-KIDS

Parenting journeys
with type 1 diabetes

Living well with diabetes

diabetesvic.org.au



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Introduction from the Consumer Engagement team at Diabetes Victoria

We are proud to present *Living with D-Kids Parenting journeys with type 1 diabetes*. This booklet has been adapted from a resource developed by the convenors of the D-Kids Support Group, part of Diabetes Victoria's peer support program.

The information presented here is not intended as medical advice. As recommended throughout the booklet, discuss any questions you may have with your diabetes care team. The resource has been reviewed by a panel of health professionals, but its main purpose is to offer practical information for families of a young child with type 1 diabetes.

Our thanks to:

- The D-Kids Support Group, in particular Jen Lawrence and Erin Goedhart, for their tireless enthusiasm.
- Emma Hurley, Adam Lamendola and Megan Buszard from The Paediatric Diabetes Ambulatory Care Service at Monash Children's Hospital, Southern Health and Rebecca Gebert from the Royal Children's Hospital for their contributions.

Diabetes Victoria is the leading charity and peak consumer body working to reduce the impact of diabetes. We support, empower and campaign for all Victorians affected by diabetes. Our Consumer Engagement program offers information sessions, resources and support for people with type 1 diabetes.

If you would like to know more about this program, please call **1300 437 386** or visit our website: diabetesvic.org.au

Introduction from original authors

Jen Lawrence and Erin Goedhart

As a tiny group, which began in 2006, we met to chat over coffee. We shared our histories, our concerns, our hopes and our knowledge.

As our group grew, we realised there was a great need for information regarding parenting a child with type 1 diabetes. There is plenty of medical information available, yet what we also needed was advice about the everyday 'stuff' we faced as parents/carers.

So, this booklet was born from a desire to show parents/carers of a newly diagnosed child they are not alone and there are common situations we are faced with. It's not intended as medical advice, just ideas on parenting a child with diabetes.

Our thanks to the families of D-Kids, who have contributed immensely to this booklet.

It's often said 'It takes a village to raise a child' – this could not be truer in our situations. We all need the support of family, friends and community.

We hope this booklet helps you feel connected to a wider community, ready to support you.



Thank you to:

- the original D-Kids and their families – this booklet wouldn't have happened if we hadn't met!
- the diabetes treating medical teams at Monash Children's Hospital, Austin Health and the Royal Children's Hospital who support us and our children whenever we need them
- the JDRF (Juvenile Diabetes Research Foundation) Peer Support Program, who introduced us
- the Consumer Engagement team at Diabetes Victoria, who helped us to promote our group and provided support and encouragement.

D-Kids are sisters, brothers, sons, daughters, babies, toddlers and children. D-Kids are ours!

The original D-Kids are Catharina, Ryan, Cameron, Anna, Hannah, Daniel, Rebecca, Jonathan and Olivia.

To make contact with D-Kids families, please email:

erin@omnibase.com.au

Jen Lawrence and Erin Goedhart

Founders – D-Kids

After the diagnosis

Coming home after your child's diagnosis of type 1 diabetes can be daunting. You may be confused, scared, relieved to finally have a diagnosis, hopeful; you may wish you never had to explain type 1 diabetes to another person; you may grieve for your child.

There may be times when you feel overwhelmed and other times when you feel you are managing really well. Different feelings will come and go at different times and this is perfectly normal.

Support

There are many different forms of support. A good starting point is your child's diabetes care team who can offer you clinical advice. If you feel you need to speak with someone specifically about how you are feeling and coping with your child's diagnosis, ask for a referral to a social worker or psychologist.

Speaking with other people who are in a similar situation can be a huge relief and a form of encouragement. Peer support networks operate throughout Victoria and may provide you with someone to talk, vent, laugh and cry with.

Everyone needs 'time out', but sometimes it's not easy to arrange. Initially, extended family and friends may feel nervous about looking after a child with diabetes. To alleviate their concerns, give a basic explanation of type 1 diabetes. Where possible keep the information they require to look after your child clear and simple.

Here are some practical tips to consider to give you a break:

- Find other people (family or friends) who can learn to do blood glucose checks, so you have some time out every now and again. Start with short breaks of one hour and build up from there.
- Diabetes Victoria and JDRF run programs which may be able to connect you with other families who have a child with type 1 diabetes. Contact these organisations and ask about their support group networks.

GREAT FREE RESOURCE

A Kid In Your Life is a useful resource for family, friends and anyone who might be involved with your child's care. Find it on the Diabetes Victoria website: diabetesvic.org.au under the resources section.



Helping your child understand

Your child may be feeling overwhelmed with the new information and routines in their life, but may not know how to share their feelings. Some strategies to use with children to help them understand or explain their feelings are:

- Acknowledge things have changed and that change can be difficult at first – especially for kids.
- Recognise that their behaviour may be related to being hypoglycaemic or hyperglycaemic, but might also just be them being children. Maintain discipline for unacceptable behaviours and reward all the fantastic things they are doing.
- Provide different ways for them to express themselves – draw pictures about diabetes, write down their stories.
- Find other children who have diabetes for them to play with. This will prevent them from feeling like they are the only person in the world with diabetes. At clinic visits, speak with other parents/carers and introduce your child to other children.
- Participate in Diabetes Victoria and JDRF children's activities, such as Diabetes Camps Victoria, member family days and events and the Walk To Cure Diabetes. It's a powerful reminder that there are many others living with type 1 diabetes.

If you are concerned about your own or your child's emotional health, contact your diabetes team for support or a referral to a social worker or psychologist.

A word about siblings

It's easy to forget that your other children may also be affected by their sibling's diagnosis. Younger children may find it difficult to understand why their older brother and/or sister can have lollies 'all of a sudden'. Older children may take on the responsibility of caring for the younger sibling – watching their food intake for example. It's important to remember that siblings may also need some 'time out' from diabetes. Try to organise some one-on-one time with Mum and/or Dad where the focus is not diabetes.

Unsolicited advice – everyone's an expert!

You may find that everyone who hears you have a child with diabetes will offer you (usually unsolicited) advice. Most people's experience of others with diabetes is type 2 diabetes. You may find yourself spending a lot of time educating others about the differences between type 1 and type 2 diabetes. However don't feel under any obligation to do so. You can always politely say you would rather not discuss your child's condition with others and ask that they respect your wishes.

GREAT FREE RESOURCE

Diabetes Victoria has a terrific resource:

High and Low: type 1 diabetes – the things you need to know which provides practical information about the basics of type 1 diabetes.

It is a terrific card to hand out to people who need some type 1 diabetes basics information and will hopefully prevent them from offering unsolicited advice in the future!

For a free copy call **1800 637 700** or go to the Diabetes Victoria website: **diabetesvic.org.au**

Ideas for blood glucose level (BGL) checks, injections and pump line changes

When first diagnosed, blood glucose level (BGL) checks, injections and pump line changes can be stressful for you and your child. Make sure you leave enough time to go through the motions and get used to the new routine. Here are some strategies that may help alleviate some of the distress:

- Use a sticker chart for injections and/or line changes done with little fuss. Try aiming for a row of 10 (or a target appropriate for your child), then offering a larger reward – not necessarily something you have to buy! It could be a walk to the park, an extra story at bedtime and so on.
- Set a timer for 5 or 10 minutes – when it goes off, it's time for a BGL check, pump line change or injection.
- Children love routine. Integrate BGL checks or injections into your regular morning, pre-meal and bedtime routines, and during school breaks.
- Use a favourite toy of choice, like JDRF's Rufus and Ruby soft toys to model behaviour – you or your child can pretend to give insulin to them first.
- Consider making a diabetes kit (using a play doctor's kit) for dramatic play. Use a toy (or another member of the family) as the patient.
- If your child favours particular fingers for doing BGL checks, try tracing their hands on butcher's paper and colour in each finger as it's used. All the fingers must be coloured before you start on a favourite again! (To save paper you could draw and laminate one to use repeatedly.)



Be prepared when heading out!

Being prepared will help when you are heading out, whether for an everyday outing or a special occasion. Below are a variety of situations and some suggestions you may find useful.

USEFUL TIP

Keeping a backpack ready to go with hypo treatments and snacks is a great way to save time and maintain a little spontaneity.

Diabetes clinic visits

Visits to the diabetes clinic may be brief, but in most cases will involve a long wait, so it's best to be prepared! You may like to take a backpack for your child with food and drink as well as some activities to keep your child occupied. You may like to take: colouring pencils and a small notebook for drawing, stickers, cards for Snap, small cars or a doll to play with, homework (for older children) and books to read.

In between visits, always write down any questions you may have for the diabetes care team. Use *Post It* notes and stick them in the diabetes record book. Never be embarrassed about asking a question, no matter how trivial it may seem.

USEFUL TIP

If you attend a tertiary paediatric centre, discount parking may be available with your child's health care card. Enquire at the centre's main entrance.

- Another idea for BGL checks is again to trace the hands and number the fingers. Each finger has two numbers to ensure each side of the finger is used. This is a good one for pre-school-aged children and up!
- Develop a chart system for siblings also. This can be for anything you like, for example, completing a daily chore. The idea is that there are equal expectations of all the children in the family, not just the child who has type 1 diabetes.

“Diabetes means you need a needle or a pump.”

Rebecca (age 4)

Play dates

Children love having play dates at their friends' houses. Some careful planning and discussions with the friends' parents/carers will help to make this important (and frequent) activity run smoothly. **Here are some ideas for when your child is invited to play at a friend's home:**

- Depending on your child's age, you may choose to stay. Or you may choose to stay for a short time at the start of the play date until you are sure your child is settled.
- Offer to send along afternoon tea to be shared as a thank you for the invitation, giving you a little 'control' over what will be eaten. If you are not providing food, be specific about what your child can and can't eat while playing.
- Let the other parent/carer know that you are available to talk at any time if there are concerns or questions during the play date. You could also phone at an agreed time to make sure everything is running smoothly.
- Do a BGL check at the start of the play date or just prior to dropping your child off and decide whether they will need to do another while they are there.
- Let the other parent/carer know what your child's signs of hypoglycaemia are and what to do. Use clear, simple language. Consider writing things down for others. Always ensure the other parent/carer has your contact details.

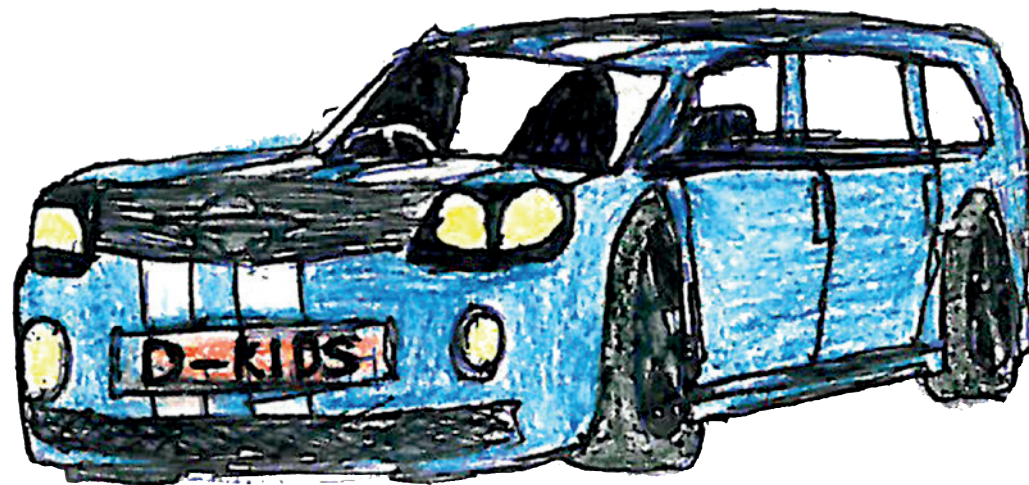
When Ryan was asked

"What is good about diabetes?"

He replied,

"I have new friends like Catharina and Cameron."

Ryan (age 5)



Birthday parties

Most children love a party and they are an important part of your child's social life. Here are some ideas to make parties enjoyable and fun – after all, that's what they are all about:

- If you are hosting the party, you can 'control' the menu. There are plenty of options – chat to your child's dietitian for ideas.
- If your child is a guest you may like to speak with the parent/carer running the party. Offer to take something, for example, sugar-free jelly or cordial.
- Keep in mind that it is okay for your child to have treats, so speak to your diabetes care team about this.
- Speak with your diabetes care team about insulin doses for parties. In particular ask about whether to give an extra dose to compensate for your child eating special occasion food and eating more food.

Sleepovers

Sleepovers can be a positive experience for you, your child, and the person looking after your child. You may have some respite, or you may find that you stay awake all night wondering if everything is okay! Obviously the person you leave your child with needs to be familiar with the basic responsibilities of diabetes management.

Provide the overnight carers with written information about hypos, your child's routines and who to contact in an emergency. Speak with your diabetes care team if you are unsure about what information is essential.

A Kid In Your Life covers basic diabetes management for carers and has useful information for sleepovers.

"It may seem like a huge effort at first to plan and put your trust in someone else, but it gets easier and it's worth it for everyone in the long run."

Erin

Travel

Everyone loves a holiday – whether it's overseas, interstate or just a couple of hours away by car. Whatever the case may be, take plenty of supplies (strips, syringes, pen device and pen needles, spare insulin, hypo treatments, back-up loan pump, spare blood glucose meter and battery etc.) with you. Talk to your diabetes care team before you go.

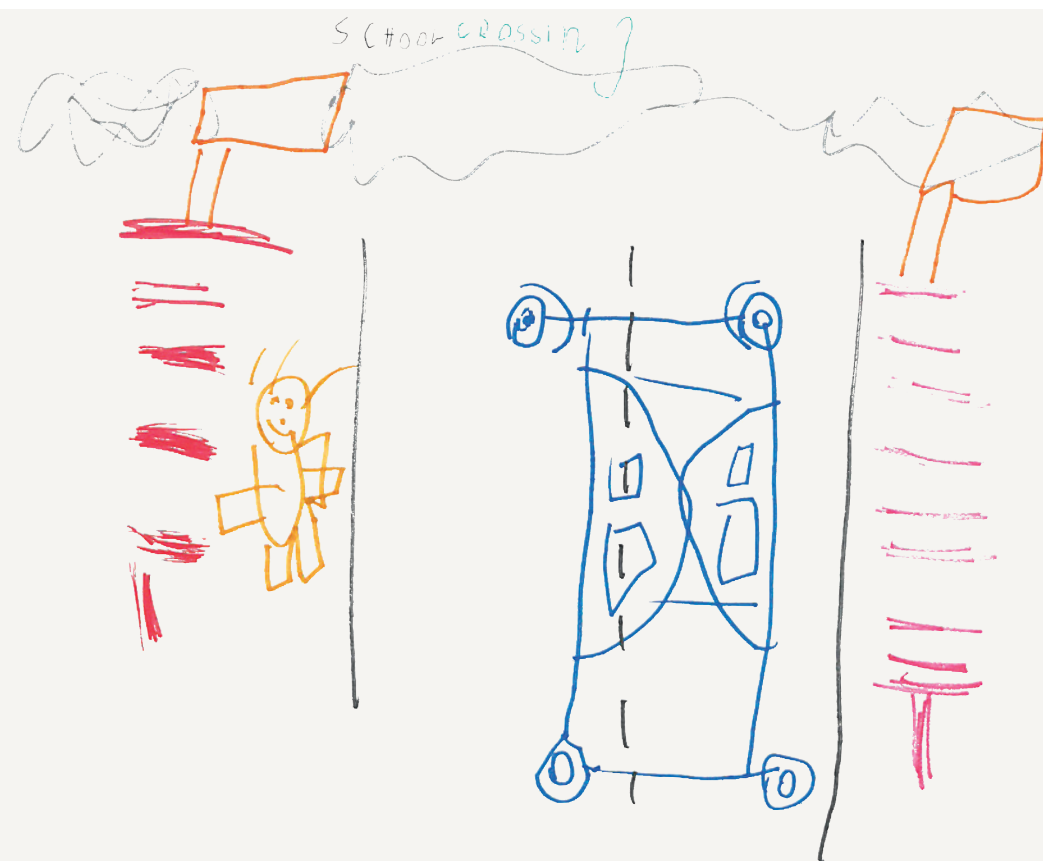
If you are travelling by plane, you will need a letter from a health professional explaining your child has type 1 diabetes and, therefore, you need to have medication and equipment to manage diabetes with you in the cabin at all times. If you are travelling to a country with a different time zone, speak with your diabetes care team as you may need a flight plan to assist you with your child's diabetes management.

Most importantly, enjoy your trip – diabetes is portable!

Vaccinations

Vaccinations can be traumatic enough for any child, let alone extra injections for a child with diabetes. Always prepare your child for their vaccination by explaining to them what the procedure will be. Here are some tips to help manage what can be a difficult situation (and may be useful for complications screening and other blood tests):

- Take a favourite toy of choice with you. The nurse/doctor is usually quite willing to give them an 'injection' first.
- Some families use the local anaesthetics Angel™ or Emla™. Please be aware that this product is very expensive and is not necessary to avoid an unpleasant experience. It must be applied and covered for a period of time before the injection occurs, so you need to weigh up whether the extra 'build up' of having this done will help or hinder the process for you and your child.



Kindergarten/childcare/school

Returning your child to childcare, kindergarten or school after they have been diagnosed with diabetes may be difficult for you. One of the most important things is to establish and maintain clear and ongoing communication with your child's carers and teachers. Since January 2012 new national legislation (Education and Care Services National Act and Regulations) requires a type 1 diabetes policy for all services providing or intending to provide education and care on a regular basis to children under the age of 13 years. This includes outside school hours programs. This means that each student with type 1 diabetes must have current individual diabetes action and management plans.

Every child enrolled at an early childhood setting or school must have current diabetes action and management plans. Your diabetes treating medical team will be able to help you in the preparation of these plans. Examples of these plans can be found at diabetesvic.org.au

Diabetes Victoria in collaboration with the Royal Children's Hospital and Monash Children's Hospital run professional development programs for people working in schools and early childhood settings who have a young person with type 1 diabetes in their care.

Further details can be found at: diabetesvic.org.au

Three short online learning modules on diabetes management at school have been developed by Diabetes Victoria, Victorian Department of Education and Training, Royal Children's Hospital and Monash Children's Hospital for parents/carers, teachers and school staff.

Further details can be found at: diabetesatschool.com.au

Mastering Diabetes

This resource is designed to help make sure the best care possible is provided for young people with type 1 diabetes attending early childhood settings and school. It is important that parents/carers give a copy of the book to the early childhood settings/school that their child attends.

- Mastering Diabetes book (PDF and eBook) can be downloaded for free from the Diabetes Victoria website (diabetesvic.org.au).

When Catharina was asked

“What is good about diabetes?”,

She replied,

“That you can feel better.”

Catharina (age 5)

From injecting to pumping

The use of insulin pumps is becoming increasingly common for children with diabetes. Deciding to change from injections to a pump is a decision not to be taken lightly and involves consultation between you and your diabetes care team. Factors to be considered may include current blood glucose management, the willingness to count carbohydrates, the type of physical activity your child does and the cost involved. Starting on a pump doesn't mean your child's diabetes is getting 'worse' - a pump is just a different way of delivering insulin.

An insulin pump constantly delivers rapid-acting insulin through a cannula and extra insulin is given when carbohydrate is eaten or when BGLs are above target. This insulin dose is known as a bolus.

Insulin pumps cost between \$7750 and \$9500, however the cost of the pump may be covered if you have health insurance. Check with your health fund for further details. Ongoing costs of pump therapy add up to about \$30 per month as the consumables are subsidised on the NDSS.

The positives of pump therapy include:

- fewer needles
- greater flexibility in terms of when and how much to eat, managing exercise and sick days
- the potential for improved blood glucose management
- the ability to quickly correct a BGL above target
- Most insulin pumps also have the ability to connect to Continuous Glucose Monitoring (CGM) technology. This can assist in seeing trends in glucose levels. Subsidised access to CGM sensors and transmitters is available through the NDSS (ndss.com.au) to children and young people aged under 21 years, living with type 1 diabetes, who meet specific criteria. Your diabetes care team can help you explore if CGM is right for you and your child.

It is important to consider the challenges to having an insulin pump, which may include:

- wearing the pump 24 hours a day (although can be disconnected for showering, swimming or sport)
- BGLs can rise quickly if there is a problem with the delivery of insulin, as pumps only use very rapid-acting insulin. It is recommended that you carry spare insulin pens and ketone testing strips with you at all times.

It is important to remember that insulin pumps don't take away the need to do regular BGL checks, nor do they give a licence to eat whatever you like! They do however, offer the flexibility of having different amounts of carbohydrates at the times that the user wants them. Many families say that having a pump returns some of the spontaneity that was lost when their child was diagnosed with diabetes.

It is essential that the early childhood setting or school your child is attending is provided with contact details of parents/carers and back-up plans in the event that there is a problem with the pump. Speak with your diabetes care team about the details.

Some other tips when thinking of switching to pump therapy include:

- Research whether pump therapy will work for your child, your family and lifestyle.
- Investigate the various pumps available in Australia, and the availability of supplies, costs, and ongoing support.
- Take out private health insurance if you haven't already. Research private health insurers to find the company that offers the best cover for your family. Get in touch with your current or prospective health fund, to confirm the level of cover required and possible waiting times for pre-existing conditions.

“I felt as though we were starting all over again. I am so grateful we had D-Kids! Ryan was reassured seeing Catharina's pump. He had plenty of questions to ask her and she was just terrific in demonstrating a meal bolus. It was also reassuring to talk with parents who had been there and done that!”

Jen

- Understanding the extensive features of an insulin pump can take months. Be realistic about your goals and what you and your child hope to achieve with pump therapy.
- Prepare your child for the change – talk about the pump's benefits (e.g. less injections). If you can, introduce them to other children with pumps so they can see how a pump is worn. Be prepared for some initial frustration when adapting to this new regimen.
- Try to make contact with other families who have children on pumps – they will be an invaluable source of information and support.
- Although uncommon, if your child starts using an insulin pump then decides a pump does not suit them, they can always go back to injections.

Speak with your diabetes care team about pump therapy. Be aware that extensive waiting lists are common for switching to pump therapy.



Snack attack!

Just like you and me children are hungrier some days more than others. If your child is still hungry after a meal or snack and you don't want to give extra insulin, this brief list of low carbohydrate snack ideas may be useful:

- sticks of celery, carrot, cucumber
- try some dip with the above – e.g. hummus
- cherry tomatoes
- capsicum strips – try all colours
- strawberries
- celery boats (sticks) with cream cheese/peanut butter/a strip of parmesan cheese
- cheese cubes
- traffic lights – cherry tomato, cheese, celery/green capsicum on a tooth pick or icy pole stick
- slices of ham
- boiled egg (whole or slices)
- unsalted popcorn
- unsalted nuts.

Recipes

Here are some fun ideas for little fingers that get regular blood glucose checks.

Play dough

- 4 cups flour (to make it gluten-free substitute with 1/2 cup rice flour and 1/2 cup corn starch or cornflour)
- 4 cups water
- 2 cups salt
- 4 tbs cream of tartar
- 2 tbs oil
- food colouring – this can be added before cooking or children can help knead it into the dough afterwards.

Place all ingredients in a saucepan and stir over low heat until mixture thickens.

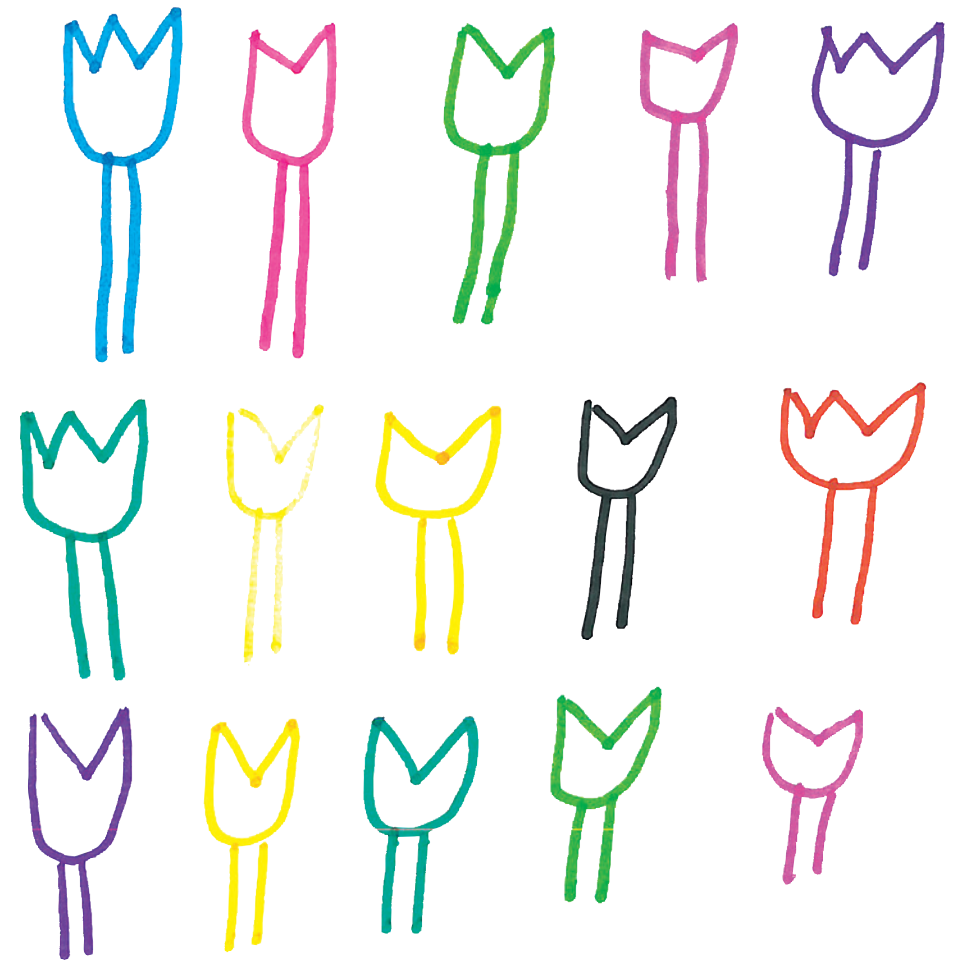
Remove from heat and allow to cool slightly before kneading into a smooth dough.

Older children might also like to add glitter to the dough.

Edible play dough

- 1 part peanut butter
- 1 part milk powder
- ½ part sugar substitute

Place all ingredients together and knead.



Finger paint

- Place 1 tbs cornflour in a heatproof container.
- Add enough cold water to make a smooth paste.
- Add boiling water, ½ cup at a time, until you get the consistency you like.
- Add some food dye and allow to cool completely.
- The mixture thickens on standing.

You know you're a parent/carer of a child with diabetes when...

It's important to keep a sense of humour, so here are a few anecdotes which will hopefully put a smile on your face:

- While doing maths homework, in response to the question, 'Name three things that you use in your home to measure with and draw a picture of it,' your 6-year-old child writes 'syringe' and painstakingly draws a picture of it.
- You come home and ask your child how they are going and they answer with a number.
- You realise people are staring at you in the cleaning aisle after you pick up a new product and exclaim 'Hey, I bet this would get blood off the bedroom wall!'
- You have no problem asking your child if he or she is 'high' in the middle of a public place.
- Your two-year-old (who doesn't have diabetes) announces 'I'm low. . . I need a lolly.'

Resources, products and useful links

Diabetes Victoria for information, events and resources.

diabetesvic.org.au

Juvenile Diabetes Research Foundation to find out about the Walk To Cure Diabetes, becoming an ambassador and plenty of information regarding research into type 1 diabetes.

jdrf.org.au

HypoActive is a Melbourne-based group who focus on physical activity for people with type 1 diabetes.

hypoactive.org

For information and resources to help kids, teens, parents/carers and school staff understand diabetes.

as1diabetes.com.au

Facebook and Twitter

There's lots of support available to both parents/carers and children through social media. Simply search for 'type 1 diabetes kids' on Facebook or Twitter to find a group that's right for you.



“When Jonathan grows up, he wants to be a painter”.

Jonathan (age 3)

A recipe for a happy family

Mix together equal quantities of love,
laughter, patience, understanding and honesty.

Pour in compassion, hope and commitment
for a strong basis.

Add a healthy dose of generosity and
a sprinkling of forgiveness.

Bake well with memories and slather
with time shared together.

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