

Early-stage T1D: Caregiver Handbook

Supporting you every
step of the way





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INNODIA is an international non-profit organization providing specialized services to medicine developers focused on curative therapies for people living with type 1 diabetes (T1D). These services are delivered through its network of members and INPACT associates (the trained community of people living with T1D).

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As Professor and Staff Psychologist at Stanford University School of Medicine, Dr Hood runs a behavioral science laboratory aimed at optimizing health and quality-of-life outcomes. A recipient of federal and foundation grants and author of over 200 scientific articles, Dr Hood works to put behavioral science at the forefront of patient-centered diabetes care.

Dr Hood has T1D himself, and works across advocacy and service settings to promote awareness of diabetes treatments, the psychological impact, and emerging technologies. Dr Hood is an empathetic behavioral scientist with a keen understanding of the intersection between diabetes and behavioral health.

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Jurgen Vercauteren is a professor at KU Leuven and one of the program managers of EDENTIFI, a groundbreaking initiative dedicated to early type 1 diabetes (T1D) detection across Europe. With a decade of personal experience living with T1D, Jurgen is deeply committed to advancing prevention, early diagnosis, and awareness of the disease. As a strong believer in the power of early detection, he has had his three children screened for T1D, reinforcing his personal and professional dedication to the cause. His work with EDENTIFI focuses on creating a unified screening platform, refining biomarker-based detection methods, and designing personalized monitoring and follow-up strategies. The initiative also addresses psychological and socioeconomic impacts, develops innovative trial designs for disease-modifying therapies, and collaborates with key stakeholders including patients, healthcare professionals, and policymakers to integrate early T1D detection into healthcare systems across Europe. Alongside his leadership in EDENTIFI, Jurgen teaches biostatistics at KU Leuven and conducts research on public health challenges, aiming to shape the future of diabetes care.

Steven Edelman

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Dr Steve Edelman is not only a physician specializing in diabetes, he has also lived with type 1 diabetes (T1D) for over 50 years, having been diagnosed at the age of 15. Based on his belief that the people living with diabetes should be the most knowledgeable about their condition, he founded Taking Control of Your Diabetes (TCOYD), a 501c3 non-profit organization in 1995. Along with being the founder and director of TCOYD, Dr Edelman is also a professor of medicine in the Division of Endocrinology, Diabetes & Metabolism at the University of California, San Diego (UCSD) and the Veterans Affairs (VA) Healthcare System of San Diego. Throughout his career, Dr Edelman has published over 250 articles and 5 books. Dr Edelman was the valedictorian of his medical school graduating class at UC Davis and has won numerous awards for teaching and humanitarianism including the 'Diabetes Educator of The Year' award by the American Diabetes Association (ADA), the 'Distinction in Endocrinology' award by the American Association of Clinical Endocrinologists (AACE), and named 'Top 1% of U.S. Endocrinologists' by US News and World Report. Most recently Dr Edelman was awarded the '2021 Lifetime Achievement Award' from the Association of Diabetes Care & Education Specialists (ADCES). He is very proud of his two daughters, Talia and Carina.

Dear Parents and Caregivers,

You are not alone; you have a full team dedicated to you every step of the way. This handbook has been created to give you clear, trusted information, and help with any doubts or fears you have about your child's disease.

Finding out that your child has early-stage type 1 diabetes (T1D) can bring up many emotions, concerns, and questions. This news may come as a surprise, or even a shock, especially when your child appears healthy and happy. Many parents feel just like you.¹

Finding T1D early, before the onset of symptoms, is important. This head-start gives you and your family time to:

- Learn about diabetes
- Understand what your child will need
- Work with doctors and care teams to watch your child's health over time
- Avoid potential health problems
- Be prepared when your child develops signs and symptoms of T1D

Contents

1. What Is Autoimmune Type 1 Diabetes (T1D)?
2. Understanding Your Child's Test Results: Early-stage T1D
3. The Benefits of Finding T1D Early
4. What Happens Next?
5. Important Things to Know Now
6. Explaining Early-stage T1D to Your Child
7. Frequently Asked Questions
8. Additional Resources and Support

What Is Autoimmune Type 1 Diabetes (T1D)?

Our bodies have a powerful immune system that normally protects us from infections. Autoimmune T1D happens because the immune system attacks the insulin-producing cells in the body.² Here are a few key points to consider:

The Special Beta Cells: In T1D, the immune system mistakenly attacks special insulin-producing beta cells in the pancreas. The progressive loss of insulin-producing cells reduces the ability of the pancreas to make enough insulin. This happens months to years before symptoms appear.^{1,2}

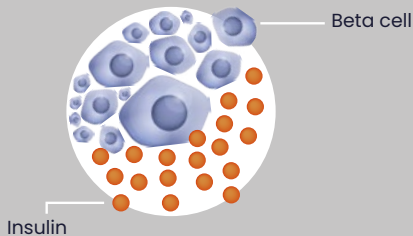
The Role of Insulin: Insulin is an essential hormone that helps the body's cells absorb glucose, a crucial energy source obtained from food.³

The Consequences: When too many insulin-producing beta cells are lost, the pancreas cannot make enough insulin. When the pancreas can no longer control the amount of glucose in the blood, it increases. This leads to hyperglycemia (too much glucose in the blood) and the symptoms of T1D.^{1,2}

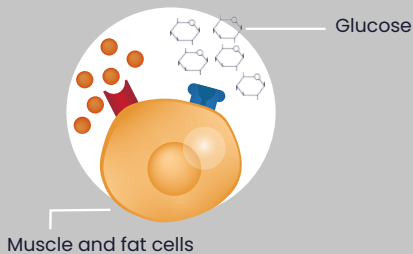


Important Note: T1D is a complex, lifelong disease but with good care people can lead full, active lives.^{2,4}

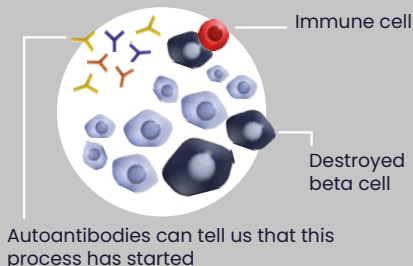
The Role of Beta Cells and Insulin in Early-Stage Type 1 Diabetes¹⁻³



The Special Beta Cells
These cells in the pancreas make insulin



The Role of Insulin
Insulin tells muscle and fat cells to take up glucose so there is not too much in the blood



Early-stage T1D
The immune system attacks the insulin-producing beta cells. As beta cells are progressively lost, the pancreas cannot make enough insulin

Understanding Your Child's Test Results: Early-stage T1D

What Was Found

Your child had a special blood test for markers of autoimmune T1D called autoantibodies. The immune system normally makes antibodies to fight infection, but when these mistakenly target the body they are called autoantibodies. Detection of two or more autoantibodies in the blood tells us that your child is in the early stages of T1D.¹

What This Means

This means your child has been diagnosed with presymptomatic early-stage T1D (Stage 1 or 2). Presymptomatic means it is before any symptoms start, and also tells us that your child's body is still making some insulin.¹

Progressive Nature

T1D develops progressively, moving through distinct stages:¹

STAGE 1

Your child has two or more autoantibodies, but their glucose levels are normal. They have no symptoms and feel fine.

STAGE 2

Your child still has two or more autoantibodies, and their blood glucose is now slightly higher than normal, but not enough to cause any symptoms.

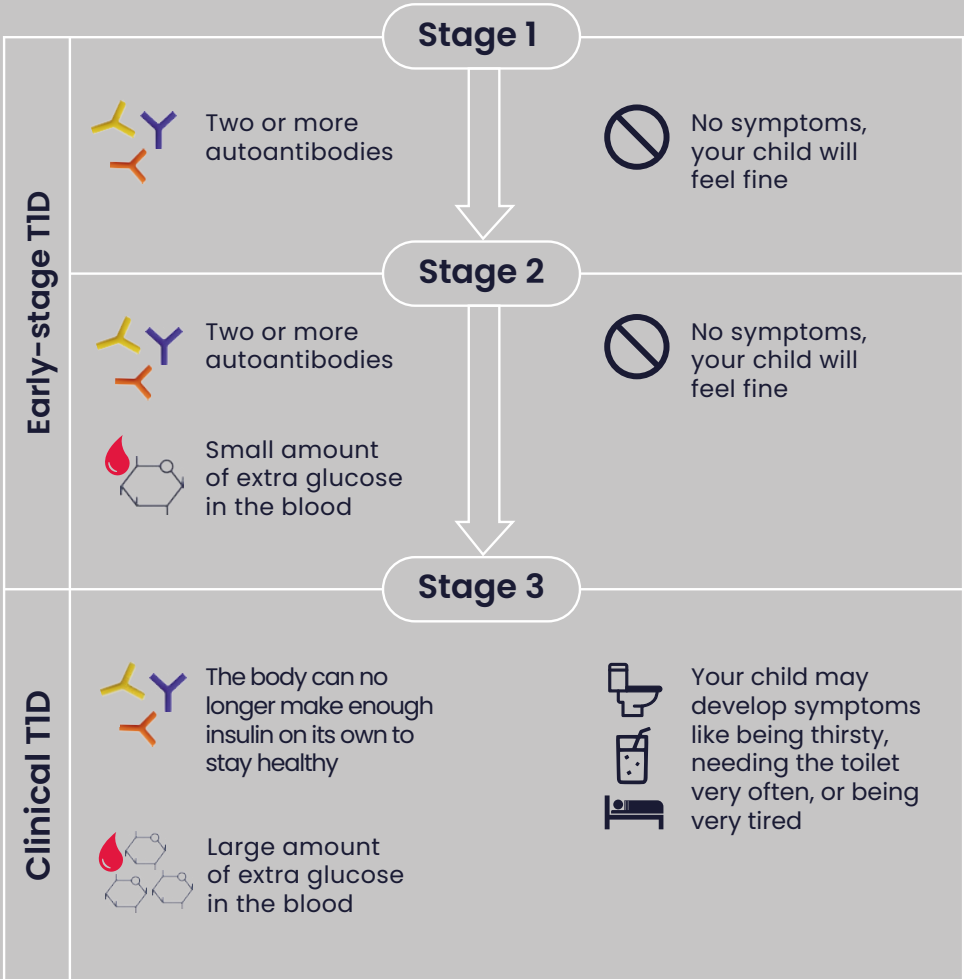
STAGE 3

This is when the body cannot produce enough insulin. Your child may feel thirsty, tired, or need to urinate a lot. They will need to begin taking insulin to help them stay healthy. This marks the onset of clinical (symptomatic) T1D.

Key Message

Your child is considered to have T1D as soon as two or more autoantibodies are detected.¹

The Key Stages of T1D¹



The Benefits of Finding T1D Early

It is understandable to feel worried and overwhelmed by this news. However, finding T1D early has important benefits.

Avoiding an Emergency

If insulin therapy is not started quickly when the signs and symptoms of T1D occur, children can develop a serious metabolic condition called diabetic ketoacidosis (DKA), caused by a severe and critical lack of insulin production. DKA can be a life-threatening medical emergency. Knowing your child has early-stage T1D means your doctor and care team can monitor them, and intervene well before any serious problems happen¹

Time to Get Ready

Finding diabetes early gives you and your child time to learn and prepare for the onset of symptoms. It gives you and your child time to take small steps together, and to learn how to take control of their diabetes at every step in their journey¹

Watching Carefully

Everybody is different, and some children will need insulin sooner than others. There is no way to know exactly when your child will need insulin, but your child's care team will check their blood glucose regularly to see how things are changing. How often depends on your child's age, and how the disease is developing. In some circumstances, home monitoring of glucose is advised, so discussing this with your child's healthcare team is a good idea¹

✓ **Access to Clinical Trials**

Your child may be able to participate in clinical trials for treatments that can be used during early-stage T1D. Your healthcare provider will be able to discuss these options with you¹

✓ **Support**

It can be a lot to get this news and take care of diabetes. There is support for you and your family to help you, both medically and emotionally¹



Moving Forward: Your Action Plan

Here is what you can expect to happen next:

1. Regular Monitoring

Your child will have regular check-ups and simple blood tests to monitor for changes in glucose levels. This helps your care team track your child's health, and assess when insulin is needed. Insulin is a hormone that people with Stage 3 T1D need to take to stay healthy.¹

What Monitoring Involves

Clinic visits & Blood tests: These will include regular check-ups of your child's overall health, along with special blood tests to track how your child's body is producing insulin.¹

Home Monitoring: Everyday home monitoring is not usually needed in the early stages of T1D. However, your healthcare team may recommend occasional home glucose checks, and will provide you with the necessary tools and clear instructions if this is needed.¹

How Often Monitoring Happens

The frequency of these check-ups and tests will be specific to your child, depending on their age and stage of T1D (Stage 1 or Stage 2). Your care team will discuss a personalized plan with you.¹

Monitoring Is Important to Help Your Care Team Predict When Your Child Will Need Insulin to Stay Healthy

Every child is different, and will progress to needing insulin at different speeds. Younger children often need insulin sooner than older children, but there is a lot of variability between individuals. Regular metabolic monitoring will help your child's doctor estimate their risk of needing insulin in the next months and years.

2. Education and Resources

This handbook provides some key practical information about T1D. Your healthcare provider can also offer more detailed information and personalized support tailored to your child's needs.

3. Psychological Support for Caregivers

Learning about your child's early-stage T1D can bring a wide range of emotions. It is completely normal to feel surprise, shock, fear, uncertainty, sadness, or even anger. Your healthcare team can help you with the necessary resources to navigate what can be an emotionally difficult time.¹ The following are some key points to consider when managing the psychological burden associated with a child's diagnosis of early-stage T1D.

Recognize Common Concerns and Misconceptions

There is no "right" or "wrong" way to feel about this news. Your emotions are valid.

It is important to remember that T1D is never the fault of the child or parents. It is not caused by diet, lifestyle, genes, or anything you did or didn't do. We do not know exactly what triggers T1D, but scientists are trying to answer this question.^{1,2,5}

Be careful about diabetes information from the internet or well-meaning but misinformed friends or family. Always rely on your healthcare team for accurate guidance.

Seeking Support and Developing Coping Strategies

Talk about your feelings: Share your emotions with your partner, trusted friends, or family members. Giving yourself time to process this new reality is important.⁶

Ask questions: There are no “stupid” questions. Your diabetes team are ready to address all your concerns and help resolve any uncertainties.⁶

Focus on the present: While it’s natural to worry about the future, try to focus on the current situation and the manageable steps you can take now.

Keep life normal: Your child does not need to change their daily activities, diet, or routines right now.¹

Your child may also have questions: Be prepared, listen and answer according to their age. If needed, ask for support from someone in your child’s healthcare team.

Professional Psychosocial Support

Your healthcare team can help support your mental wellbeing. We encourage you to make use of such support at an early stage if you feel overwhelmed or are struggling to cope.¹

Important Things to Know Now

No Immediate Changes

Your child does not need to change their daily activities, diet, or routines. They can continue to enjoy everything they always have.¹

Recognizing Signs Your Child May Need Insulin

These symptoms typically develop over several weeks. If you observe any of the following changes, contact your doctor immediately:^{1,7-10}

- Extreme thirst and excessive drinking
- Constant need to urinate
- Fatigue, tiredness, and a lack of energy
- Weight loss

Your child may also notice signs of hypoglycemia (low blood glucose) such as sweating or shaking, feeling tired, dizzy, or very hungry.¹¹

Support Is Key

Parents of children with diabetes can rely on the continuous support of a diabetes team.¹ They will guide you through this journey.

Explaining Early-stage T1D to Your Child

- It's important to talk to your child about their early-stage T1D. Kids of different ages understand things in different ways¹²
- Young children learn best from simple stories and pictures. Older kids and teens can understand more detailed facts. You know your child best—choose ways to explain diabetes that match your child's age¹²
- There are many actors, singers and professional athletes living with T1D, who are great role models. This can be a good way to help your child know that they can live a successful life with T1D¹³



Follow the QR code to access materials that can help you to explain your child's disease to them in a fun and age-appropriate way.

It is recommended to read the available materials yourself first before sharing age-appropriate content with your child, so that you can be prepared for any questions they might have.

Starting a conversation with your child can feel daunting. Remember, some days they won't want to talk at all, and that's okay. The goal is to consistently show them that you are ready to listen whenever they are ready to talk. Here are some ways you might think about starting a conversations with them:

"I've been feeling a little overwhelmed with all this new information. It's a lot for me to learn. I wonder if it feels like that for you too?"

"I wonder what you're most curious about for our next doctor's visit?"

Sometimes it is easier to write feelings than to say them. Leaving a notebook in a visible place can give your child a way to ask questions if they aren't comfortable talking about their fears or feelings.

"Okay, for our next visit on Tuesday, the main reason we're going is so the doctor can check your HbA1c (which stands for glycated hemoglobin). It tells us how much glucose is in your blood, and helps us decide what our plan should be next. Do you want to write down any questions you have for the doctor about that?"



Frequently Asked Questions

Should I change what my child eats?

No. There is no evidence that changing your child's diet will delay or prevent the loss of insulin-producing beta-cells. Your child can continue to enjoy their favorite foods as part of a balanced diet and healthy lifestyle. Later, when your child requires insulin, this can be planned around their meals.^{5,14}

Is there a cure for autoimmune T1D?

No, there is currently no cure for T1D. It is a lifelong disease. Eventually, your child will need to take insulin. However, with good care, children with T1D can do everything other kids do, enjoying school and sports, just like their friends.^{1,15} Lots of research is being done to develop potential treatments that can be used during early-stage T1D. Your healthcare team can discuss potential opportunities to participate in clinical trials if you would like them to.

Who needs to be informed?

Right now, only your doctor and care team needs to know. You can decide if you want to tell family or friends. Later, when your child starts using insulin, it will be important to tell key people who care for your child—like teachers, coaches, and babysitters—what they need to know.

What about siblings?

Brothers and sisters of a child with T1D have an increased chance of getting the disease. Your doctor can test them as well, if you wish.¹

Can my child travel?

Yes, children with T1D can travel. Your care team can provide guidance on what to take and who to contact if needed.¹⁶

Can my child be vaccinated?

Yes, your child should receive all recommended vaccinations. They do not affect the development of T1D.¹⁷

When will my child require insulin, and what does this involve?

Your child does not need insulin right now.¹ Over time, their body will make less insulin, and someday they will need to take insulin to stay healthy.¹ We do not know exactly when this will happen—it's different for every child.¹

Some children will need insulin within a few months, while others may not need it for several years. Younger children often need insulin more quickly than teenagers, but there is a lot of variability. Everyone is different. Your child's doctor will conduct regular metabolic tests, and these tests will help your doctor and healthcare team predict how quickly your child will progress to needing insulin therapy.

You and your care team will watch your child closely. When it is time for insulin, your child can take it using an insulin pen or pump. These tools are easy to use—even very young children can learn with help from an adult.^{14,18}

With insulin, your child can still eat their favorite foods and do all their normal activities. Your healthcare team will teach you and your child everything you need to know to feel confident managing insulin.¹⁴



Resources and Support

You are not alone. There is support available for you and your family.

Your Healthcare Team

Your primary care provider and our specialized diabetes team will continue to provide care and answer your questions.

Useful Websites

<https://tcoyd.org/> The Taking Control of Your Diabetes (TCOYD) website is packed with helpful information for parents of children with diabetes.

Support Groups

Connecting with other parents can be incredibly very helpful. Your healthcare team can provide information about local support groups.

Key References

The following sources provide useful information about type 1 diabetes, and have been used in the creation of this document.

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This guide is intended for informational purposes and does not replace medical advice. Always consult with your healthcare provider for personalized care.

