

Early-stage T1D Handbook

A guide for adults navigating
their early-stage type 1 diabetes
(T1D) diagnosis





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Your Journey With Early-stage Type 1 Diabetes

This handbook is a resource designed to guide you through what comes next now that you have a diagnosis of early-stage type 1 diabetes (T1D). It provides evidence-based information to help you understand your diagnosis, know what to expect, and feel confident in the steps ahead. Your healthcare team is here to support you throughout this journey.

Your blood test has revealed the presence of T1D autoantibodies. These immune markers indicate you have early-stage T1D.¹ But, they cannot tell us exactly when you will start to have symptoms, so it is important to attend regular monitoring visits with your healthcare team.¹

Nothing you did or did not do caused your T1D. Do not blame yourself, or let others blame you.² It is not caused by diet or food choices.³ T1D is an autoimmune disease.⁴ We do not know exactly what causes T1D, but scientists are working to understand this question.^{3,4}

Many adults are unaware that T1D can be detected in adulthood. In fact, more than half of all new T1D cases each year are diagnosed in adults.⁵ Receiving a diagnosis of early-stage T1D can be surprising, confusing, or even disorienting.¹ There is no right or wrong way to feel. All reactions are normal.

Finding T1D early is an important opportunity, regardless of your age. This head start gives you time to:¹

- Understand what early-stage T1D means for your health and daily life
- Work with your healthcare team to monitor your health over time
- Avoid potential health problems, including serious complications at the point of clinical diagnosis
- Be prepared for if, and when, signs and symptoms of T1D develop
- Access information about next steps
- Find both medical and emotional support at your own pace



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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 gradually damages the insulin-producing cells in the body.^{4,6} Here are a few key points to consider.

Understanding The Difference: Type 1 Versus Type 2 Diabetes

Because you are an adult, you may have expected a diagnosis of type 2 diabetes (T2D) rather than T1D. This is understandable – T2D accounts for over 90% of all diabetes cases worldwide and is more common in adults.^{5,7} While they share certain features, T1D and T2D are different diseases:



	Type 1 Diabetes (T1D)	Type 2 Diabetes (T2D)
Cause	Autoimmune: The immune system gradually damages insulin-producing beta cells in the pancreas ⁶	Metabolic: The body becomes resistant to insulin, or in later stages, the pancreas does not produce enough ⁷
Insulin production	Eventually little-to-no insulin ⁶	Usually still produced at earlier stages, but inefficiently used by the body ⁷
Onset	Can occur at any age; more than half of new cases occur in adults ⁵	Most commonly develops in adults over 40 years, though increasingly seen in younger people ⁷
Management	Insulin therapy (pen or pump) ^{4,8}	Lifestyle changes, oral or injected medications, and sometimes insulin ^{7,8}

The presence of T1D autoantibodies confirms that your immune system is involved; this is the hallmark of T1D, not T2D.¹

The Beta Cells: In T1D, the immune system gradually damages the insulin-producing beta cells in the pancreas.⁴ This progressively reduces the ability of the pancreas to make enough insulin. This happens months to years before symptoms appear.^{1,6}

The Role of Insulin: Insulin is an essential hormone that helps the body's cells use glucose. Glucose is a crucial energy source obtained from food.⁹

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, glucose levels increase. This leads to hyperglycemia (too much glucose in the blood) and the early symptoms of T1D.^{1,6}

The symptoms of hyperglycemia include:^{1,6,10,11}

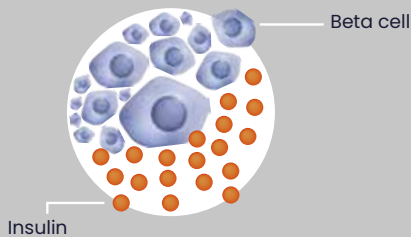
- Extreme thirst
- Frequent urination
- Weight loss
- Persistent fatigue and lack of energy
- Increased hunger
- Blurred vision
- Slow-healing wounds or frequent infections



Important Note:

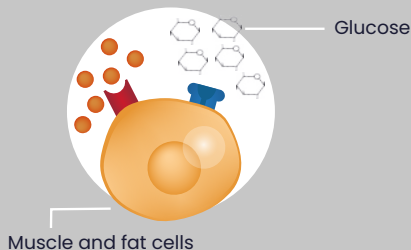
T1D is a complex, lifelong disease but with proper care and monitoring, people with T1D can lead full, active lives.^{2,6} If T1D is not detected and managed early, prolonged high blood glucose over months and years can lead to long-standing T1D complications, including damage to blood vessels, nerves, eyes, kidneys, and the heart.⁸

The Role of Beta Cells and Insulin in Early-Stage Type 1 Diabetes^{1,6,9}



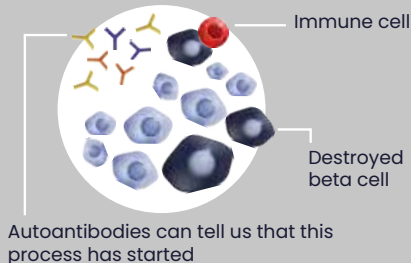
The Special Beta Cells

These cells in the pancreas make insulin



The Role of Insulin

Insulin helps muscle and fat cells to use glucose for energy (this reduces the amount of glucose 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 Test Results: Early-stage T1D

What Was Found

You had a blood test for markers of T1D called autoantibodies.¹ The immune system normally makes antibodies to fight infection. Autoantibodies are antibodies that target the body's own cells – in T1D they target the insulin-producing beta cells in the pancreas.¹ Autoantibodies are markers that the immune system is involved – they are a signal of the process, not its cause.³ The **presence of T1D autoantibodies** in the blood indicates that you are in the early stages of the disease.¹

What This Means

This means you have been diagnosed with presymptomatic early-stage T1D (Stage 1 or 2). Presymptomatic means before any symptoms occur. Your body is still making some insulin, but your disease will progress over time.¹

The Progressive Nature of T1D

T1D develops progressively, moving through distinct stages:¹

STAGE 1: Multiple T1D autoantibodies are present, but your glucose levels are normal and you have no symptoms.

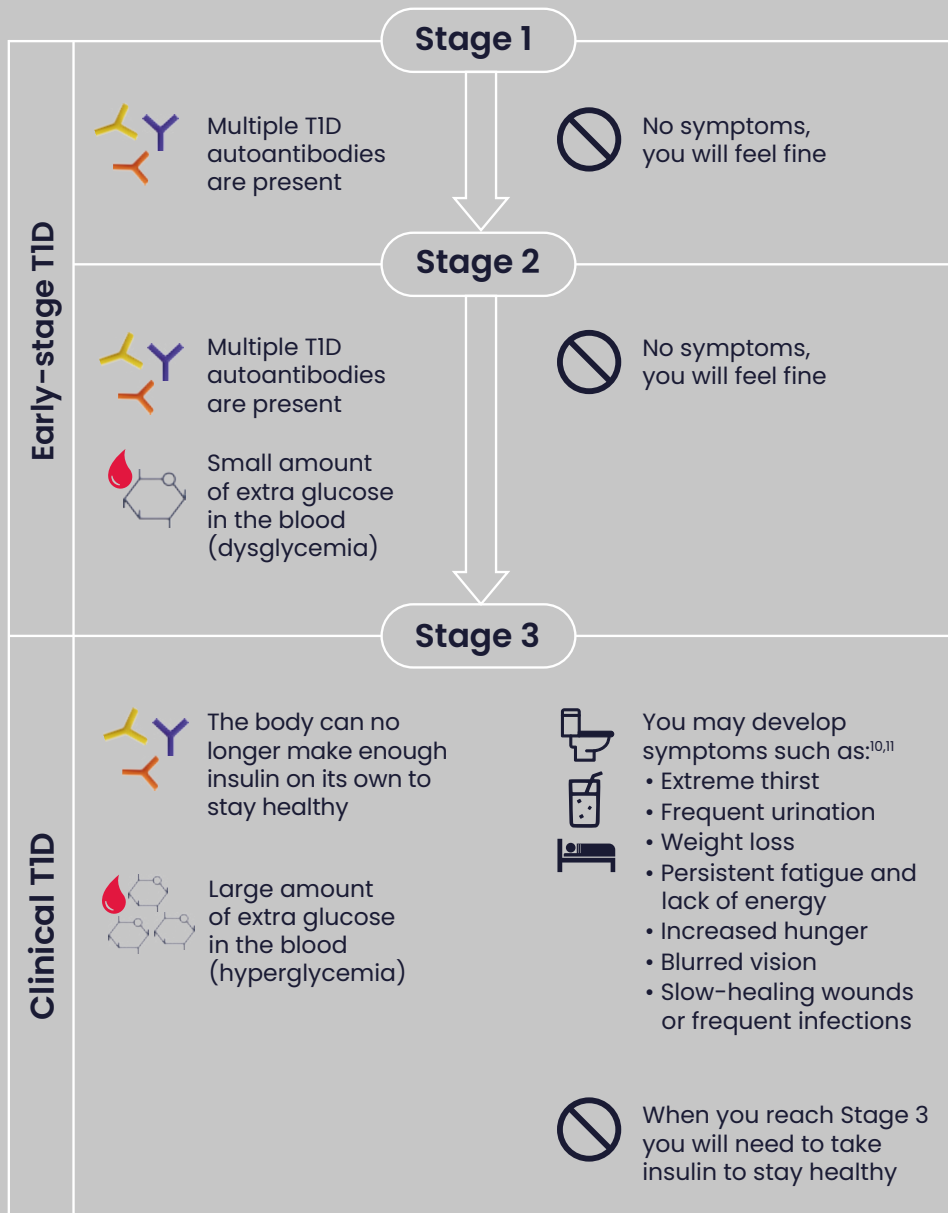
STAGE 2: Multiple T1D autoantibodies are present and your blood glucose is now slightly higher than normal, but not enough to cause any symptoms.

STAGE 3: Your body can no longer produce enough insulin on its own. You may feel thirsty, tired, or need to urinate frequently. This marks the onset of clinical T1D. You may develop symptoms at this stage, and when this happens, you will need to begin taking insulin to stay healthy. Your doctor will advise and support you with this.

Key Message

You are considered to have early-stage T1D as soon as the presence of multiple autoantibodies has been confirmed.¹

The Key Stages of T1D¹



Early-stage T1D in Adults

Historically, T1D has been thought of as a childhood disease, but this is a common misunderstanding.^{4,5} T1D can occur at any age, and more than half of all new T1D cases each year occur in adults.^{1,4,5}

If you have early-stage T1D, it is helpful to know that the disease may progress slowly, sometimes over many years, before insulin therapy is needed – particularly in adults.^{1,12,13}

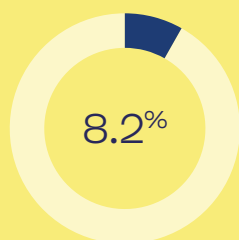
Because your journey with early-stage T1D may be gradual, it might feel as though nothing is changing. This can be a positive sign, but it also means it is very important to commit to monitoring your health over time.¹

What the evidence tells us:

It is difficult to predict exactly how quickly any one individual with early-stage T1D will progress to needing insulin. The presence of T1D autoantibodies does not necessarily mean that you will need insulin imminently.¹

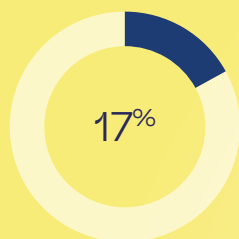
Your healthcare team can help interpret your test results.¹ Ask your healthcare team if you have any questions about what your test results mean for you.

Scientists are still learning about early-stage T1D in adults, and more research may become available in the future.¹ What we currently know includes:



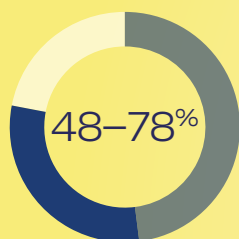
Single T1D autoantibody present:

Within 5 years, about 1 in 12 adults (8.2%) will progress to needing insulin¹³



Multiple T1D autoantibodies, with normal blood glucose (Stage 1 T1D):

Within 5 years, about 1 in 6 adults (17%) will progress to needing insulin¹³



Multiple T1D autoantibodies, with slightly elevated blood glucose (Stage 2 T1D):

This stage is an important predictor of progression to Stage 3 and need for insulin.^{12,13} Within 5 years, it is likely that most adults (48–78%) with Stage 2 T1D will go on to develop Stage 3 T1D.¹³

It is very important to attend regular monitoring check-ups, even if you feel completely well. These tests help your doctor predict when you might need insulin to stay healthy. Your healthcare team will put a monitoring plan in place tailored to your specific situation, stage of T1D, and your individual risk factors.¹

My Monitoring Plan

Use this space to write down any notes or questions for your healthcare team

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My Monitoring Plan

Use this space to write down any notes or questions for your healthcare team

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Why Finding T1D Early is Important

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

Avoiding a Medical Emergency

It is important to start treatment with insulin under the guidance of your doctor and care team when the signs and symptoms of T1D begin.¹ If diagnosis is delayed, you may be at risk of a serious metabolic condition called diabetic ketoacidosis (DKA).¹ DKA is caused by a severe and critical lack of insulin production and can be a life-threatening medical emergency.¹ Knowing you have early-stage T1D means your doctor and care team can monitor your health carefully and intervene well before any serious problems occur.¹

Recognizing the signs of DKA:¹⁴

- Nausea and/or vomiting
- Stomach pain
- Fruity-smelling breath
- Fast, deep breathing
- Confusion or difficulty concentrating
- Extreme thirst or very dry mouth
- Excessive tiredness or drowsiness

Time to Learn and Plan

Finding T1D early gives you time to learn about the disease and plan ahead at your own pace. You do not need to make any immediate changes to your life. What you do have is an opportunity to build understanding, ask questions, engage with your care team, and make informed decisions about your care before symptoms develop.¹



Personalized Monitoring

Everyone is different. Because your care team now knows about your T1D at an early stage, they can put a monitoring plan in place tailored to your specific situation, stage of T1D, and your individual risk factors. How often you are monitored, and what tests are involved, will be discussed and agreed with you by your healthcare team.¹



Access to Clinical Trials

Early-stage T1D is an active area of research. Finding T1D early means you may be eligible to participate in research studies or clinical trials for treatments that can be used during early-stage T1D.¹ Your healthcare provider will be able to discuss any relevant options with you.



Support

Receiving this diagnosis is a great deal to take in. There is support available to help you, both medically and emotionally. You do not have to navigate this alone.¹

Moving Forward: Your Action Plan

Here is what you can expect to happen next:

1. Regular Monitoring

You will have regular check-ups and blood tests to monitor changes in your glucose levels and overall health. This helps your care team track how your body is producing insulin and assess whether and when insulin therapy may be needed in the future. Insulin is a hormone that people with Stage 3 T1D need to take to stay healthy.¹

Monitoring helps your healthcare team track any changes over time. This usually involves blood tests that look at how your body processes glucose.¹ Your team will explain what each test shows and why. They will provide all the information and tools you need; the exact tests and technologies used may vary depending on where you are treated.

What Monitoring Involves

Clinic visits & blood tests: These will include regular check-ups of your overall health, along with blood tests to track how your 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

Your monitoring frequency will depend on your current stage (Stage 1 or Stage 2) and your individual needs as assessed by your care team.¹ Monitoring visits are typically scheduled at regular intervals, with more frequent follow-up for those who are likely to progress more quickly.¹ Your care team will agree on the right plan for you.¹

Staying Engaged with Monitoring Over the Long Term

Because monitoring may continue over many months or years, it can be difficult to stay engaged with these visits, particularly if you feel well. Remember that these visits are important for your doctor to predict when you will need insulin and help avoid serious complications of diabetes.¹

- Set calendar reminders for your monitoring check-ups well in advance
- Use the *My Monitoring Plan* pages in this handbook to note down any questions for your healthcare team between appointments

2. Education and Resources

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

3. Psychological Support

Receiving a diagnosis of early-stage T1D can be challenging to navigate, and a different experience from how T1D is often portrayed. You likely feel completely well right now, and this can be a complex thing to process.

A diagnosis can bring a wide range of emotions; there is no standard emotional response to this news about your health. All your emotions are valid.

It is completely normal to feel surprise, shock, fear, uncertainty, sadness, or even anger.^{1,2} These feelings are common and can come and go throughout your life.² Be open with your healthcare team about your mental wellbeing. They can help you access the resources and support you need to navigate what can be an emotionally complex time.¹



Remember:

Early-stage T1D is an autoimmune disease. It is not the result of anything you did or did not do, and it is not something you could have prevented.^{2,3}

Be careful about diabetes information from the internet or from well-meaning but misinformed friends or family.² It is important to remember that we do not know exactly what triggers T1D and progression in any individual, but scientists are actively working to understand this.³ Much T1D content online is focused on children and management of Stage 3 T1D, and may not reflect or be relevant to your experience. Always rely on your healthcare team for accurate, personalized guidance.

Seeking Support and Developing Coping Strategies

Talk about your feelings: Share your emotions with a partner, trusted friends, or family members. Giving yourself time to process this new reality at your own pace is important.¹⁵

Ask questions: Talk openly with your healthcare team. Your diabetes team are ready to address all your concerns and help resolve any uncertainties.¹⁵

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

Keep life normal: You do not need to change your daily activities, diet, or routines at this stage. Your life can continue much as before.¹

Professional Psychosocial Support

Your healthcare team can help support your mental wellbeing. Make use of professional psychosocial support at an early stage if you feel overwhelmed or are struggling to cope; you do not need to wait until things become difficult.¹

Important Things to Know Now

No Immediate Changes

No immediate changes to your diet, physical activity, or daily routines are clinically required at this time. Your life does not need to change right now.¹

Recognizing Signs You May Need Insulin

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

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

You can rely on the continuous support of your diabetes care team.¹ They will guide you through this journey at every stage.

Talking with Family Members

Explaining early-stage T1D to people close to you can be challenging. Give people time to absorb the information and try not to feel discouraged if their first reaction is confusion or disbelief. This usually reflects a lack of awareness, not a lack of care.

First-degree Relative Screening

First-degree relatives of someone with T1D (your parents, siblings, and children) have a significantly higher chance (1 in 20) of developing T1D themselves compared with the general population (1 in 300).^{1,3,16} For second-degree relatives (e.g., grandparents), the chance of T1D is increased but not as much as in immediate family (about a 1 in 50 chance).¹⁷

Consider informing close relatives about your diagnosis, so that they can make an informed choice about whether to be screened. Knowing earlier gives your relatives the same opportunities you have: Time to prepare, access to monitoring, and potential eligibility for research studies.¹

If your relatives are interested in being screened, they can ask their own healthcare provider about T1D autoantibody testing. In some countries, research-based screening programs may offer screening to family members at no cost.¹⁸

Screening Resources

EDENTIFI's It's In Your Hands is a neutral source of information about where people can find T1D screening programs and support.



www.itsinyourhands.eu

Frequently Asked Questions

Is there a cure for autoimmune T1D?

No, there is currently no cure for T1D. It is a lifelong disease. But with proper care, people with T1D can lead full, active lives and continue doing everything they did before.¹⁹

Significant research is being done to develop treatments that can be used during early-stage T1D. Your healthcare team can discuss potential opportunities to participate in clinical trials.¹

When will I need insulin?

Over time, your body will make less insulin. Once someone progresses to Stage 3 T1D, they will need to take insulin to stay healthy.¹ While this is a significant step, it is manageable. We cannot say exactly when, or if, this will happen – it is different for every person.¹

Some people with early-stage T1D will need insulin within a few months, while others may not need it for several years, or even decades.^{12,13} Everyone is different. Your care team will carry out regular monitoring to help track how your situation may change over time.

Insulin is given using a syringe, pen, or pump.^{4,8} It does not come in a pill, but modern tools can help make day-to-day management more flexible than in the past.^{2,4,8} Your team will support you throughout, so you can continue to live a full, active life. Your healthcare team will teach you everything you need to know to feel confident in managing insulin.⁸

Could my diagnosis actually be type 2 diabetes?

Your test results have revealed the presence of T1D autoantibodies. This is well-established evidence of autoimmune T1D, and it is the key clinical criterion used to define early-stage T1D.¹ This is not the same as type 2 diabetes (T2D), which is a metabolic condition.⁷

Adults with T1D can sometimes be misclassified with T2D.^{1,7,8} One reason for this is because T2D is more common than T1D in adults.^{7,8} Where there is diagnostic uncertainty for those individuals, their healthcare provider may use some additional tests to confirm the appropriate diagnosis.⁸

If you still have questions about your diagnosis, please discuss them openly with your healthcare team.

Is T1D contagious?

No. T1D is an autoimmune disease and it cannot be passed from person to person like an infection. You cannot 'catch' T1D from someone else, and you cannot pass it to others through contact.⁴

Who needs to be informed?

Right now, only your doctor and care team need to know. Deciding whether, when, and how to share your diagnosis with a partner, family members, or friends is a personal decision. Your diabetes care team will be able to advise you on who you need to disclose your diagnosis to, and when. They will also be able to direct you to local support groups who can help you with these conversations.

Because certain genes increase your risk of developing type 1 diabetes (see Section 6), you may wish to consider telling close relatives about your diagnosis, so that they can make an informed choice about whether they would like to be screened.

Can I pass T1D to my children?

While there is a genetic contribution to the development of T1D, most people with T1D (~90%) do not have a close relative with the disease (see Section 6).^{16,17,20} This means it is not certain that any children you have will develop T1D. We do not know exactly what triggers T1D in any individual, but scientists are actively working to understand this.³

Children with early-stage T1D typically progress to needing insulin much faster than in adults.^{1,12,13} This means that early screening of children in your family may be particularly valuable, as it provides time for monitoring, preparation, and can reduce the risk of DKA at the onset of symptoms.^{1,21} If you have children and would like them to be screened, discuss this with your healthcare team.

What does early-stage T1D mean for pregnancy?

A diagnosis of early-stage T1D does not prevent pregnancy or affect fertility. However, if you are planning a pregnancy, or are already pregnant, it is important to inform your diabetes care team, as your monitoring may need to be adapted.¹ Evidence on the progression of early-stage T1D in pregnant women is limited and research on this is ongoing.¹ Your care team can advise you further based on your individual circumstances.

I feel completely healthy. Do I really need to keep coming back for check-ups?

Yes. Your monitoring plan is designed to catch any changes before you develop symptoms, allowing your care team to act early.

In adults, progression can be slower than in children – sometimes taking many years.^{1,12,13} But slow does not mean it has stopped. Changes in the early stages of T1D can only be detected through regular testing.¹ Missing appointments, even when you feel completely well, means missing the opportunity to catch these important changes early. Your check-ups are a key part of staying healthy and avoiding life-threatening complications like severe DKA.¹

Should I change my diet?

No. There is no evidence that any particular diet will prevent the loss of insulin-producing beta cells.^{3,22} As for anyone, a balanced diet and a healthy lifestyle are good for your overall wellbeing; however, healthy habits will not change that you have early-stage T1D or stop the autoimmune progression of the disease.^{3,22}

You can continue to enjoy your favorite foods as part of a balanced diet and healthy lifestyle. Later, when insulin therapy is required, meals can be planned around your daily life rather than the other way around.⁸

Can I exercise or play sports?

Yes. Staying active is good for your overall health and wellbeing, just as it is for everyone.⁸

Exercise will not change your diagnosis or stop the autoimmune progression of the disease.³ But there is no need to limit exercise, whether that is going to the gym, running, team sports, or simply staying active day-to-day. If you have any questions about a specific sport or activity, ask your healthcare team for advice.

Once you start taking insulin, your healthcare team will explain how to manage your diabetes alongside your normal activities.⁸

Can I drink alcohol?

There are no specific restrictions on alcohol beyond general healthy-drinking guidance that applies to everyone. A diagnosis of early-stage T1D does not mean you need to change your habits right now.⁸

Alcohol can affect blood glucose levels, and your healthcare team will talk you through anything you need to consider, particularly once you start taking insulin.⁸ If you have any concerns, discuss them with your healthcare team.

Can I take my usual medications?

Early-stage T1D does not normally affect medications for other conditions. But you should keep your healthcare team informed of all medicines you take. They can best advise you based on your individual circumstances.

Can I travel?

Yes. People with early-stage T1D can travel. Your care team can provide guidance on what to consider when traveling.^{8,23}

Are there any vaccines I should or shouldn't have?

You should follow the advice of your healthcare team about any vaccines you may need. There is no evidence that vaccines affect the development of T1D.²⁴



Additional Resources and Support

You are not alone. There is support available for you.

Your Healthcare Team

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

Useful Websites

<https://www.breakthrought1d.org/t1d-resources/>

Breakthrough T1D is the leading global non-profit organization dedicated to T1D research, advocacy, and community support. Their resource hub provides educational guides and support tools for people living with type 1 diabetes.

<https://beyondtype1.org>

Beyond Type 1 is a global diabetes organization providing resources, community support, and education for people affected by T1D. Their platform includes guides for the newly diagnosed, peer community forums, and practical tools for living well with diabetes.

Support Groups

Connecting with other adults who are living with early-stage T1D – or who have been through a similar experience – can be incredibly helpful. Hearing from others in your position can offer reassurance, practical insight, and a sense of community. 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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Notes and Questions for Your Next Appointment:

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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.

