CONDITION

Insulinoma

An insulinoma is a pancreatic tumour that releases excess insulin and causes low blood sugar.

WHAT IT IS
Insulin-secreting neuroendocrine tumour, usually in the pancreas

BODY SYSTEM
Hormone and digestive systems

MAIN SYMPTOMS
Sweating, shaking, confusion, fainting

WHAT CAUSES IT
Usually sporadic; sometimes linked to inherited MEN1

HOW IT IS DIAGNOSED
Low-glucose blood tests, followed by tumour-localising scans

MAIN TREATMENT
Surgical removal, with medicines when surgery is unsuitable

CAN IT BE CURED?
Sometimes - surgery often cures localised tumours

IS IT AN EMERGENCY?
Sometimes - severe confusion, seizure, or unconsciousness

LONG-TERM OUTLOOK
Usually good after removal; metastatic tumours need long-term care

Overview

An insulinoma is a type of neuroendocrine tumour that makes insulin. Neuroendocrine tumours grow from cells that produce hormones. Almost all insulinomas begin in the pancreas, an organ behind the stomach that helps control blood sugar and digest food.

Insulin moves glucose, or sugar, out of the blood and into cells. An insulinoma releases insulin when the body does not need it. This can make blood glucose fall too low, a condition called hypoglycaemia.

Most insulinomas are small, single tumours that have not spread elsewhere. Some occur as several tumours, especially in people with an inherited condition called multiple endocrine neoplasia type 1, or MEN1. A smaller group are cancerous and can spread, most often to the liver or nearby lymph nodes.

Repeated low blood glucose matters because the brain relies on glucose for energy. Mild episodes can cause sweating or difficulty concentrating. Severe episodes can lead to seizures, injuries, or loss of consciousness. Treatment aims to prevent these episodes and, when possible, remove the tumour.

Symptoms

Symptoms usually appear when blood glucose is low. They may develop during fasting, overnight, after exercise, or when a meal is delayed. Some people also have symptoms after eating.

Early symptoms are caused by the body releasing stress hormones in response to falling glucose. They can include:

As glucose falls further, the brain may not receive enough energy. This is called neuroglycopenia. It can cause confusion, poor coordination, slurred speech, unusual behaviour, memory problems, or marked drowsiness. Severe hypoglycaemia can cause a seizure or loss of consciousness.

Episodes can resemble panic attacks, fainting, intoxication, epilepsy, or other neurological conditions. Some people do not notice the usual warning symptoms, particularly after frequent episodes.

Eating may improve symptoms, so people sometimes gain weight because they eat often to prevent or relieve low glucose. Symptoms alone cannot confirm an insulinoma because many other conditions and medicines can cause similar problems.

- Sweating, shaking, hunger, or a racing heartbeat
- Anxiety, weakness, nausea, or tingling around the mouth
- Blurred vision, headache, or unusual tiredness

Causes and risk factors

An insulinoma develops when insulin-producing cells grow into a tumour and release insulin without normal control. In most people, there is no clear reason why this happens. It is not caused by eating sugar, body weight, or anything the person has done.

Most insulinomas are sporadic, meaning they occur without a known inherited cause or family pattern.

A minority are associated with MEN1. This inherited condition increases the chance of tumours

in several hormone-producing organs, especially the parathyroid glands, pituitary gland, and pancreas. MEN1-related insulinomas may develop at a younger age or occur as more than one pancreatic tumour.

A clinician may discuss genetic assessment if you are young, have several pancreatic tumours, have other MEN1-related conditions, or have a relevant family history. Having an insulinoma does not automatically mean that you have MEN1.

Diagnosis

Diagnosis has two stages. The first is showing that excess insulin is causing low blood glucose. The second is finding where the tumour is located.

Blood is ideally tested while symptoms are happening. The tests usually include glucose, insulin, C-peptide, and proinsulin. C-peptide is released when the pancreas makes insulin, so it helps distinguish the body's own insulin from injected insulin. Other tests may check ketones and look for medicines that can lower glucose.

If an episode cannot be captured naturally, a supervised fast may be arranged in hospital or a specialist unit. You stop eating while staff monitor your symptoms and take blood samples. The fast ends if significant hypoglycaemia develops or the planned testing period is completed. A supervised mixed-meal test may be considered when symptoms mainly occur after eating.

Insulin does not need to be above the usual laboratory range to support the diagnosis. The key finding is insulin that remains inappropriately present when glucose is low.

Imaging is usually performed after blood tests have confirmed excess insulin production. CT or MRI scans can examine the pancreas. Endoscopic ultrasound uses a small ultrasound device passed through the mouth into the stomach and upper intestine, usually with sedation, to obtain close images of the pancreas.

Specialist centres may use receptor-based PET scans or selective arterial calcium stimulation if routine imaging does not find the tumour. In calcium stimulation testing, calcium is injected into arteries supplying the pancreas while insulin is measured from blood leaving the organ. This helps identify the part of the pancreas producing excess insulin.

Treatment and management

Surgery is the main treatment when an insulinoma can be removed safely. It can often provide long-term control and may be curative for a single tumour that has not spread.

The operation depends on the tumour's size and position and its relationship to the pancreatic duct and major blood vessels. A surgeon may remove only the tumour, remove part of the pancreas, or use another pancreas-sparing procedure. MEN1-related or multiple tumours can require a different approach.

Before surgery, or when an operation is not suitable, management focuses on preventing hypoglycaemia. This may include planned meals and snacks, avoiding prolonged fasting, and having a source of fast-acting glucose available. A personalised plan is important because food needs differ between people.

Diazoxide is a medicine that reduces insulin release and may help control glucose. It can cause effects such as fluid retention, nausea, or increased hair growth. Other medicines may be considered by a specialist. Somatostatin-related medicines help some insulinomas, but they can occasionally worsen hypoglycaemia, so their effects need careful monitoring.

A prescribed glucagon rescue treatment may be recommended for severe episodes. Glucagon is a hormone that raises blood glucose. Family members or others close to you may need training on when and how to use it.

Cancerous insulinomas may require a combination of treatments. Options can include surgery, treatments directed at liver tumours, medicines that slow tumour growth, peptide receptor radionuclide therapy, or chemotherapy. The choice is based on where the tumour has spread, how quickly it is growing, which receptors it carries, and whether hypoglycaemia remains difficult to control.

Complications

Repeated hypoglycaemia can interfere with memory, concentration, work, sleep, and driving. Falls, road accidents, or other injuries can happen if an episode develops without enough warning.

Severe hypoglycaemia can cause a seizure or unconsciousness. Prolonged episodes can injure the brain, although prompt treatment reduces this risk.

Possible complications of pancreatic surgery include bleeding, infection, leakage of pancreatic fluid, or inflammation of the pancreas. Removing a larger amount of pancreas can sometimes lead to diabetes or a shortage of digestive enzymes. Enzyme capsules can help if digestion is affected.

Some insulinomas recur after treatment. This is more likely when there are multiple tumours, an inherited tumour condition, incomplete removal, or cancer that has spread. Metastatic insulinoma can cause both continuing hypoglycaemia and problems related to tumour growth,

especially in the liver.

Prevention

Most insulinomas cannot be prevented. There is no known diet, supplement, or lifestyle change that stops a sporadic insulinoma from developing.

MEN1 is inherited and also cannot be prevented. If MEN1 is confirmed, planned monitoring can help find hormone-related changes or tumours earlier. Genetic counselling can explain testing, family implications, and screening without assuming that relatives are affected.

Once an insulinoma is suspected or diagnosed, following the agreed plan for meals, glucose monitoring, medicines, and follow-up can reduce the chance of severe hypoglycaemia. This manages the effects of the tumour; it does not prevent the tumour itself.

Living with it and what to expect

Before treatment, daily life may need to be organised around avoiding low glucose. You may be advised to monitor glucose, eat at planned times, carry fast-acting glucose, and tell trusted people how to recognise and respond to an episode. Continuous glucose monitors can help some people identify trends, but readings may need confirmation because sensors are less accurate at very low levels.

Driving and safety-sensitive work may need temporary changes if episodes cause confusion, loss of awareness, or fainting. Local driving rules differ. Your clinical team can explain how the rules apply to documented hypoglycaemia.

After successful surgery, excess insulin production often stops quickly. Glucose may need close monitoring during recovery because the body has adapted to frequent low levels. Follow-up also checks healing and pancreatic function.

Long-term follow-up is based on the tumour's features and whether it was completely removed. It may include symptom reviews, blood tests, or imaging. People with MEN1 usually need broader lifelong monitoring because new tumours can arise in the pancreas or other hormone-producing organs.

A localised, completely removed insulinoma often has a favourable outlook. Recurrence is possible, so returning symptoms should be assessed rather than managed only by eating more often. People with an unresectable or metastatic insulinoma may need ongoing treatment over months or years to control both glucose and tumour growth.

When to get medical help

Call emergency services if someone with possible hypoglycaemia:

Do not give food or drink to someone who is unconscious or cannot swallow. Place them on their side if it is safe to do so, use prescribed glucagon if you have been trained, and follow emergency-service instructions.

Seek prompt medical assessment for repeated episodes of sweating, shaking, confusion, or faintness, especially when fasting or exercising. You should also get prompt advice if episodes become more frequent, stop responding as expected to glucose, or return after insulinoma treatment.

Routine follow-up is used to review glucose patterns, treatment effects, nutrition, surgical recovery, and any planned tumour surveillance. New but mild symptoms can usually be discussed at this follow-up unless they are worsening or affecting safety.

- Has a seizure, becomes unconscious, or cannot be awakened normally
- Is severely confused, unable to cooperate, or unable to swallow safely
- Does not recover after their prescribed emergency treatment
- Has been injured during an episode

Common questions

Is an insulinoma cancer?

Most insulinomas are localised and do not behave like cancer. A smaller group spread to lymph nodes, the liver, or other organs. A tumour's size alone does not determine whether it is cancerous; imaging, surgery, tissue examination, and evidence of spread help establish its behaviour.

Can an insulinoma be cured?

A single insulinoma that has not spread can often be cured by complete surgical removal. Cure may not be possible when tumours are multiple, cannot be removed safely, or have spread. Treatment can still reduce hypoglycaemia and control tumour growth.

Why does eating make me feel better?

Food containing carbohydrate raises blood glucose, which may temporarily relieve hypoglycaemia. This response does not prove that you have an insulinoma. Other medicines and health conditions can also cause symptoms that improve after eating.

Can an insulinoma cause weight gain?

Yes. Some people eat frequently or consume extra carbohydrate to prevent symptoms, which can lead to weight gain. Insulin also encourages the body to store energy. Weight change is not universal and cannot confirm the condition.

Can insulinoma be missed on a scan?

Yes. Insulinomas are often small and may not appear on an initial scan. Blood tests should first confirm inappropriate insulin production. Specialist imaging or procedures can then help locate a tumour that routine CT or MRI has not shown.

Will an insulinoma turn into diabetes?

An insulinoma causes low glucose, not diabetes. However, diabetes can sometimes develop after pancreatic surgery if too little insulin-producing tissue remains. This risk is influenced by the type of operation and the health of the remaining pancreas.

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