UNDERSTANDING YOUR DIAGNOSIS

Narcolepsy

Also called Narcolepsy

Your brain lost the cells that keep you awake, so sleep breaks into your day. You were never lazy.

HOW COMMON	OFTEN STARTS	TREATABLE	YOU ARE NOT ALONE
About 1 in 2,000 people	Teens and mid-30s	Yes - good control is normal	Most wait 8 to 10 years

What this is

- Narcolepsy is a brain condition, not a habit. Your brain lost the small group of cells that keep wakefulness steady.
- Sleep and waking blur together. Pieces of dreaming sleep push into your day, and your night sleep breaks up.
- Most people are called lazy, careless, or depressed for years first. That was never true, and it was never your fault.
- A sleep study plus a daytime nap study confirms it. Sometimes a spinal fluid test or a gene test is used too.

What it can look and feel like

- Sleep hits you like a wave, and you cannot fight it off, no matter how interested you are in what is happening.
- Short naps of **15 to 20 minutes** leave you genuinely refreshed, at least for a while. That is a telling clue.
- Laughing, a joke, or a jolt of surprise makes your knees buckle, your jaw slacken, or your head drop while you stay fully awake.
- You wake up unable to move or speak for a few seconds or minutes, which is frightening but harmless and always passes.
- You see or hear vivid dreamlike things as you drift off or wake up. This is dreaming spilling over, not losing your mind.
- Your nights are broken and restless even though your days are unbearably sleepy. Both things are true at once.
- You keep doing something on autopilot, then realize you remember none of the last few minutes of it.

What is happening in your brain and body

- A brain chemical called **orexin** keeps you awake. In narcolepsy type 1, almost all the cells that make it are gone.
- Those cells are lost when the body's own defense system attacks them by mistake, usually after an ordinary infection.
- Without orexin, the switch between sleep and waking is loose. It flips at the wrong times in both directions.
- The muscle relaxing that normally protects you during dreams leaks into waking life. That is what causes the knee buckling.
- Because the same brain area also handles hunger and hormones, weight gain and appetite changes are common.

What can make it more likely

- Almost everyone with type 1 carries a common immune gene called **HLA-DQB1 06:02**, but most people with that gene never get narcolepsy.
- Something usually triggers it: a strep throat, a flu infection, or in a few cases a particular flu vaccine used in Europe.
- It can run in families, but only loosely. Most people with narcolepsy have no relative who has it.
- Rarely it follows a brain injury, a tumor, or another illness that damages the same small region of the brain.

What to expect

- Narcolepsy is lifelong, but it does not get steadily worse. With treatment most people work, study, drive, and raise families.
- Medicines take some trial and error. Expect a few adjustments over the first few months to find your combination.
- The knee-buckling spells often ease over the years, and they respond well to the right medicine in the meantime.
- School and work accommodations, like scheduled naps and a flexible start time, often help as much as any pill.

What helps

Treatment works. Most people get better.

Talking therapies

- **Scheduled naps**, two or three short ones placed through your day, cut sleepiness and work well alongside medicine.
- **Talk therapy** helps with the shame, the years of being misjudged, and the fear of collapsing in front of people.
- Learning the facts about your own condition is powerful. It replaces "I am lazy" with "my brain lost specific cells."
- Family and school meetings undo the laziness label fast, and they get real accommodations written down.
- If low mood came along with this, treating it matters. Say so early, since it changes which medicines fit best.

Medicines

- **Wake-promoting medicines** such as modafinil, armodafinil, solriamfetol, or pitolisant are usually the first thing tried.
- **Sodium oxybate**, a liquid taken twice during the night, is the one medicine that treats sleepiness, collapse spells, and broken sleep together.
- **Stimulants** like methylphenidate or amphetamine salts still help when other options do not do enough on their own.
- Some **antidepressants** are used at low doses to stop the collapse spells. Never stop them suddenly, as the spells can rebound hard.
- Modafinil can make birth control pills less reliable. Dosing and choices are all decided with your prescriber.

Everyday things that help

- Keep the same bedtime and wake time. A short night makes every symptom of narcolepsy noticeably worse the next day.
- Build your naps into your calendar the way you would a meeting, rather than waiting until sleep takes you.
- Be careful with alcohol and heavy meals, and be honest with yourself about how sleepy you are before driving.
- Ask about accommodations at work or school: nap breaks, later start times, and extra time on tests.
- Connecting with others who have narcolepsy helps more than people expect. Ask your clinic for a group or online community.

Get help right away if

- Never drive when sleepiness is not controlled. Pull over, and call your clinician the same day.
- If a collapse spell lasts a long time or leaves you weak for hours, get medical care now.
- If you feel hopeless or think about ending your life, call or text **988** or go to the nearest ER.

Questions to ask your care team

- *Do I have the type with collapse spells, and does that change my treatment?*
- *Which medicine should we start with, and what side effects should I watch for?*
- *What do I need in writing for school or work accommodations?*
- *What are the driving rules for someone with narcolepsy in this state?*

Where this information comes from

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NOTE

Sources are listed in APA 7th edition style. This handout is general health information, not medical advice, and it does not replace talking with your own doctor, therapist, or prescriber. Medicine choices and doses are decided with your prescriber. If you are in danger or thinking about hurting yourself, call or text 988 in the United States, or go to your nearest emergency room.