

# SICK OF SLEEPING



Calli Claasen nods off during conversation because of a sleeping disorder that's caused havoc in his life. RIGHT: His sister, Naomi Oosthuizen, has to keep an eye on him virtually around the clock.

## WHAT IS SLEEP APNOEA?

It's when a person stops breathing while asleep. The brain doesn't receive enough oxygen and wakes the person. The sufferer isn't aware of being woken but doesn't reach REM sleep, which is necessary for proper rest. Someone who stops breathing five times in an hour is diagnosed with sleep apnoea.

Sleep apnoea sufferers are sometimes overweight or suffer from high blood pressure. The condition leads to exhaustion and sometimes also depression, diabetes, muscle weakness and memory loss.

## Narcolepsy

This is a chronic sleep disorder that occurs when the brain can't regulate a normal sleep pattern. The neurological control of normal sleep and its relationship with narcolepsy isn't yet fully understood by the medical profession. People suffering from narcolepsy don't sleep properly at night and experience sleeping episodes during the day, often triggered by emotions. About 70 per cent of those with narcolepsy also suffer from cataplexy.

## Cataplexy

Fewer than five people in 10 000 suffer from this condition. Attacks are characterised by a relaxation of the facial muscles and jaw, trembling muscles, weakness in the knees or hands, slurring and eyes that fall shut.

The cause is unknown but the condition seems linked to intense emotions, especially trauma, and when the brain doesn't produce enough of the neurochemical hypocretin.

SOURCES: HELPGUIDE.ORG; WIKIPEDIA.ORG

## A chronic disorder causes Calli Claasen to fall asleep without warning – as happened twice during our interview

By GLORIA EDWARDS Pictures: PAPI MORAKE

**S**UDDENLY he starts slurring and his body slumps. His eyes close, his head drops and he falls asleep – right in the middle of our interview. And it happens twice. It would be amusing if it weren't for the fact that Calli Claasen's incurable condition has cost him his job, family and house.

Life is hell for the 50-year-old of Standerton, Mpumalanga. His condition was originally caused by the sleep disorder known as sleep apnoea, which in time also caused narcolepsy and cataplexy (see box).

He falls asleep many times a day: during a conversation, while reading, eating or watching TV. It also happens when he experiences strong emotions such as joy, fear, embarrassment or sadness.

His naps here on the couch in the home of his sister, Naomi Oosthuizen, occur without warning and last about five minutes. Al-

ways vigilant, Naomi (51) immediately makes sure his head is back to keep his airways open so he doesn't suffocate. She wipes his face with a damp cloth to wake him.

"I have no control over it," he says when he wakes up. He drinks a cup of coffee, eats a cookie and reaches for a cigarette.

The former teacher and father of three's life consists mostly of sleep but he's always tired. At night, because of sleep apnoea, he "wakes" up to 45 times an hour without realising it and so doesn't really rest.

During the day he's exhausted and his muscles often suddenly relax, setting in motion a kind of temporary paralysis.

"During the short periods when I'm awake I enjoy listening to music and playing the guitar," Calli says. But he can't function like a normal person. Because of his condition he's unemployed, without an income and dependent on his family to care for him 24 hours a day.

He can't drive because it's too risky, he can't go shopping or play sport and even reading is like attempting the impossible.

And his lack of independence affects his self-image. "I can't even go out with a woman because I can't fetch her myself. And what if I fall asleep at table in a restaurant?"

**C**ALLI says since his thirties he's battled to get enough sleep at night. In those days he was teaching at Laerskool Standerton.

One day in 2005, during a lesson, he couldn't get a word out. "It started happening more and more. I'd also be walking and suddenly, for a fraction of a second, one or both of my legs would give way," he says.

In December 2006 a Pretoria neurologist diagnosed sleep apnoea. "The tests showed that at night I woke up 45 times in an hour. That's why I'm clapped out in the morning."

Sleep apnoea means you stop breathing.



In 2008 Calli got divorced from his second wife and the trauma of the separation exacerbated his condition. "I would sit down to mark books and wake up three hours later. I was at my wits' end."

While we're talking Calli starts slurring and his head falls forward. Naomi jumps up with the face cloth. "The first time it happened I got the fright of my life," she says.

"Now I look after him like a baby. He can't socialise any more. His greatest love was teaching and now he's lost that. He has no quality of life."

Calli gets up, takes a deep breath, eats a snack and reaches for another cigarette. Then he shows us copies of the many letters he's written to the Council for Medical Schemes and the department of health.

As a teacher he was a member of a subsidised medical scheme, Government Employees Medical Scheme (Gems). "But my savings plan paid only R6 500 a year for medicine so I could afford medication only four times a year. Sometimes the headmaster and some of the teachers would help pay from their own pockets."

By law medical aid funds must pay for medication for chronic conditions according to a prescribed minimum benefit (PMB) list, but narcolepsy isn't on it.

The headmaster reduced Calli's workload but his condition deteriorated and in August 2012 he was declared unfit to work.

He was given a one-off payment of "less than a quarter of a million rand" and used it to buy a small biltong outlet in Pretoria. He consulted doctors in Pietermaritzburg, KwaZulu-Natal, where his parents, Tommy (74) and Mollie (71), live. But his money was soon spent on medication and his shop had to be closed as it wasn't profitable.

His condition is incurable but two pills, Provigil and Cymgen, can control the symptoms and improve his quality of life. But he has no medical aid and his disability allowance doesn't nearly cover the cost of the medication – R6 000 a month.

Suddenly he falls asleep again.

**F**IVE minutes later Calli is back with us. "The worst thing is that as a father I'm losing time with my children," he says. "I seldom see them and thought that by the time I'm on pension I'd be able to help them more financially."

His twins from his first marriage, Aneri and Carli (21), live in Brits, North West. His son from his second marriage, Hanré (13), lives with his mother in Germiston, Gauteng, but Calli is dependent on others for transport to visit them.

Hanré lived with his father for the first few months after the divorce but Calli soon realised he couldn't take proper care of him. Calli says he seldom sees his daughters because they live so far away.

"If it weren't for my family I'd be on the street by now," Calli says. "I have to be looked after all the time. Fortunately I have a wonderful family."

He'll have more tests done in July and hopes he can find a part-time job.

When people ask him how he is he always says he's fine. But to YOU he admits: "It gets to me sometimes; it's actually a nightmare – this is my life from now on." **S**



Calli and Naomi by at home Standerton. His lost everything because of his condition.