

The sleeping disorder many misunderstand

Though incurable, narcolepsy can be managed with medication and lifestyle changes

In Summary

- One can experience extreme daytime sleepiness or sudden irresistible bouts of sleep
- It is often misdiagnosed as not sleeping enough or psychiatric or emotional disorders



A worker sleeps in the office

When Anne Nduati got a call from her daughter's class teacher a few years ago that the girl was sleeping too much during lessons, she initially dismissed it as a case of laziness and indiscipline.

Though Nduati's fears intensified when more teachers started making numerous calls in a day, complaining about the girl falling asleep several times, she was still persuaded that her daughter was deliberately engaging in inappropriate conduct.

"I resorted to constantly nagging her, while teachers did their best to counsel her, believing that she would see the sense and concentrate on her studies," she explains.

Eventually, Nduati was jolted to seek medical advice when her daughter Jane Wachera dozed off while sitting her KCPE exam.

"I found it weird that a candidate, no matter the circumstances, would fall asleep during her final examinations. That was when I took her to a doctor for a medical opinion, who then diagnosed her with a disease I had never heard about," she says.

"After years of pain and search for the cause of her sleep disorder that had started during her teenage years, doctors told me my daughter had narcolepsy."

Nduati says very little is known about narcolepsy due to the absence of funding for research and lack of awareness campaigns. It is a condition where sufferers experience periods of extreme daytime sleepiness and sudden irresistible bouts of sleep that can strike at any time.

"These 'sleep attacks' usually last a few seconds to several minutes. Narcolepsy can greatly affect daily activities. People may unwillingly fall asleep while at work or at school, when having a conversation, playing a game, eating a meal, or, most dangerously, when driving, cooking or operating other types of machinery," Nduati says.



It can impede learning among students and hurt productivity among employees. The sudden attack can occur during an examination, while eating, walking or driving and when actively conversing

CREATING AWARENESS

The founder of Narcolepsy Africa Foundation is now a woman on a mission to empower those suffering from the condition to live their lives to the fullest and educate and support the families and teachers who look after those children.

Foundation chairperson Anne Ng'anga, whose daughter suffers from this condition, says most people who have been diagnosed with narcolepsy feel anxious about discussing it with employers, yet in some work environments, informal disclosure is the right option.

“After establishing a good rapport, an honest discussion with others about your narcolepsy can be very helpful. As most employers will be unfamiliar with narcolepsy, be prepared to give a brief explanation of the disorder and any symptoms that may arise at work,” she says.

Workmates may not know much about narcolepsy or may have misconceptions about the condition, Ng'ang'a adds.

"If you can help educate them about what narcolepsy is and how it affects you, they may be less likely to form their own conclusions about sleepiness and other symptoms of narcolepsy," she says.

"Establishing trust, respect and a good rapport with co-workers first may help them respond appropriately and supportively.”

Dr Peter Muthinji, a specialised clinical physiologist (neuro) and somnologist, says the condition is often misdiagnosed as other health issues, such as not getting enough sleep or psychiatric or emotional disorders.

Muthinji, who also lectures at the Kenyatta University School of Medicine, says the condition is less understood as it has not been recognised by medical practitioners and the government as a chronic medical disorder that has significant personal and societal implications.

“This is a neurological disorder that poses a serious challenge to its victims as it can impede learning among students and hurt productivity among employees. The sudden attack can occur during an examination, while eating, walking or driving and when actively conversing,” Muthinji says.

“In Kenya, we have less than five specialists trained to diagnose and help manage the disease. Policymakers need to include it among chronic ailments such as diabetes, hypertension and asthma.”

While narcolepsy can affect people of any age, symptoms often start in childhood to early adulthood, roughly from ages seven to 25 years.

INCURABLE BUT MANAGEABLE

Dr Muthinji says the condition, which is initially characterised by overwhelming daytime drowsiness and sudden attacks of sleep, has no cure. However, medication and lifestyle changes can help manage the symptoms. He adds that support from others — family, friends, employers, teachers — can help sufferers cope with narcolepsy.



Somnologist Dr Peter Muthinji

Sometimes, narcolepsy can be accompanied by a sudden loss of muscle tone, known medically as cataplexy, which may last a few seconds to minutes, he says. Cataplexy is a sudden, brief loss of voluntary muscle tone that leads to a head dropping, facial sagging, slurred speech and buckling of knees triggered by strong emotions, such as laughter or sadness.

Sufferers also experience what is known as hypnagogic hallucinations, where they experience scary, vivid-like occurrences, such as being caught in a fire, being attacked or flying in the air.

They also experience sleep paralysis — a generalised inability to move, which is a frightening experience, particularly when accompanied by a sensation of inability to breath.

The neurologist says although there is no available data on the disease in Kenya, prevalence in the western world is from 0.02 per cent to 0.07 per cent of the general population. He says individuals with a family history of the disease are more predisposed to develop the condition.

“We need to invest more resources in research and training as narcolepsy has serious social consequences, such as marital disharmony, loss of employment, injury or death due to accidents at home and workplaces,” Muthinji says.

IR (name withheld to protect identity), 17, who was diagnosed with the condition when she was 13, terms it an embarrassing, life-impacting condition that affected her so much she had reached a point of despair because she felt nobody could understand her.

The Form 3 student at a school in Nakuru county says the level of stigmatisation was high, adding that though she leads in her class with top grades, she often sleeps the whole of afternoon lessons.

“I went through counselling to understand the condition and its impact, and as a result, I have been able to accept that narcolepsy is real and I have to live with it, no matter how difficult it might be,” she says.

“We need to educate teachers to understand this disorder and lobby the Kenya National Examinations Council to consider giving more time to candidates who are clinically confirmed to be suffering from narcolepsy.”



TOLERANCE AND UNDERSTANDING

JR, who sat her KCSE exam this year, says teachers would kick her out of the classroom whenever she dozed off and her parents would punish her before a neurologist diagnosed her with the sleep disorder.

“My mother tried to put me on coffee because she erroneously believed I was simply being sleepy. I am currently writing a book targeted at parents and tutors to help them understand this condition, which is mostly misdiagnosed by most doctors,” she says.

“The need for tolerance, understanding and greater awareness of the condition is so important in Kenya and in Africa as a whole. The government should chip in and inform and educate people about it.”

LK, a student at a school in Kiambu, was afflicted by the sleep disorder when she was 13 years old.

LK, who aspires to be an interior designer, was traumatised when her classmates would mock her for constantly falling asleep during lessons.

“I am very grateful to my teachers who, on learning about my condition, put a stop to the bullying I was undergoing at the hands of my classmates,” she says.

“I urge parents that if you have a child with this condition, please take an interest in knowing more. Support your child and never be ashamed of the situation. For me personally, if my parents had ignored the situation, I could have lost my precious future.”

LK’s mother Nancy Ntaria sacrifices her free time to create greater awareness and understanding about narcolepsy. She draws educational pictures for adults and children alike to help them visualise the impact of this debilitating sleep condition on those who suffer from it.

“Despite sleep disorders, many sufferers hold on to their dreams that they will study, train and become professionals who will help others with similar neurological disorders,” Ntaria says.

JR's mother Judy Njoki calls on employers to recognise the condition as a disability and provide reasonable accommodation to help employees fulfil their work obligations.

“Managing narcolepsy in the workplace begins with the individual understanding his or her symptoms and perhaps talking with supervisors and co-workers about their symptoms,” she says.

Employers may be accommodating if they learn that an afternoon nap improves the employee's productivity and that he or she is willing to stay late to make up for the time spent napping.

“Without disclosure and some understanding of narcolepsy, employers may misinterpret sleepiness as disinterest or poor motivation,” Njoki says.