





The art of dreaming: giving shape to dreams.

Narcolepsy and art.

Collected by: Claudio Bassetti and Monika Raimondi Neurocenter (EOC) of Southern Switzerland on behalf of the European Narcolepsy Network (EU-NN) under the patronage of the European Sleep Research Society (ESRS) "The object of art is to give life a shape."
(William Shakespeare)





















#### INTRODUCTION

Narcolepsy is a chronic sleep disorder in which a person is overcome by sudden, uncontrollable sleep attacks. It is believed to affect approximately 1 in every 2,000 people regardless of sex and/or race (about 200,000 people in Europe).

Narcolepsy is frequently unrecognised, and often mistaken for epilepsy or depression. The typical wait between onset and diagnosis is 10 years.

Many people with narcolepsy find that it affects their psychological well-being. Narcolepsy negatively affects their self-esteem, job stability, and relationships. The most common symptom of narcolepsy is excessive and overwhelming daytime sleepiness regardless of the amount of night time sleep a person gets.

It usually starts affecting people when they are teenagers or young adults. Other classic symptoms of narcolepsy, which don't necessarily occur in all patients, include cataplexy, disrupted or fragmented night time sleep, hypnagogic and hypnopompic hallucinations, and sleep paralysis.

Since it causes poor memory, reduced concentration or attention, and irritability, daytime sleepiness can impair people's ability to perform everyday tasks.

The life of a narcoleptic is one full of added complications. Simple tasks can become hampered or even life-threatening when one is afflicted by this chronic sleep disorder.

"Sleep, rest of nature, O sleep, most gentle of the divinities, peace of the soul, thou at whose presence care disappears, who soothest hearts wearied with daily employments, and makest them strong again for labour!"

(Ovid)



"Hypnos", Greek personification of sleep.

#### **EXCESSIVE DAYTIME SLEEPINESS**

"All men whilst they are awake are in one common world: but each of them, when he is asleep, is in a world of his own."

(Plutarch)

Excessive Daytime Sleepiness means feeling drowsy and tired with a need to sleep during the day, even after getting enough night time sleep. It occurs in all patients with narcolepsy.

People who experience excessive daytime sleepiness fall asleep at times when they don't want to sleep or shouldn't (e.g. while talking, walking, driving, working, or eating). They can fall asleep in situations where they need to be fully awake and alert.

Daytime sleep attacks can occur without any warning and can happen repeatedly in a single day.



Cataplexy is the second most common symptom of narcolepsy. It's described as a sudden, brief loss of muscle strength that happens in 60% to 90% of people with narcolepsy.

The forms of cataplexy vary in severity and include weakness in the knees, dropping head, slurred speech, arm weakness, and generalised weakness leading to complete collapse.

Sudden emotional reactions like laughter, anger, surprise, frustration, embarrassment, elation, or sexual arousal can trigger an attack of cataplexy, which can last from a few seconds to several minutes.

The person is usually aware of what's happening during the episode even though they're unable to talk. The frequency of attacks ranges from several in a day to only a few per year.



From the cartoon about narcolepsy, created for the 1st European Narcolepsy Day.

## HYPNAGOGIC/HYPNOPOMPIC HALLUCINATIONS

"Sleep, those little slices of death; Oh how I loathe them."

(Edgar Allan Poe)

Hypnagogic and hypnopompic hallucinations are vivid, frightening dreamlike experiences that happen in the majority of people with narcolepsy when they are either falling asleep (hypnagogic) or waking up (hypnopompic). The images appear very real and may be highly upsetting.

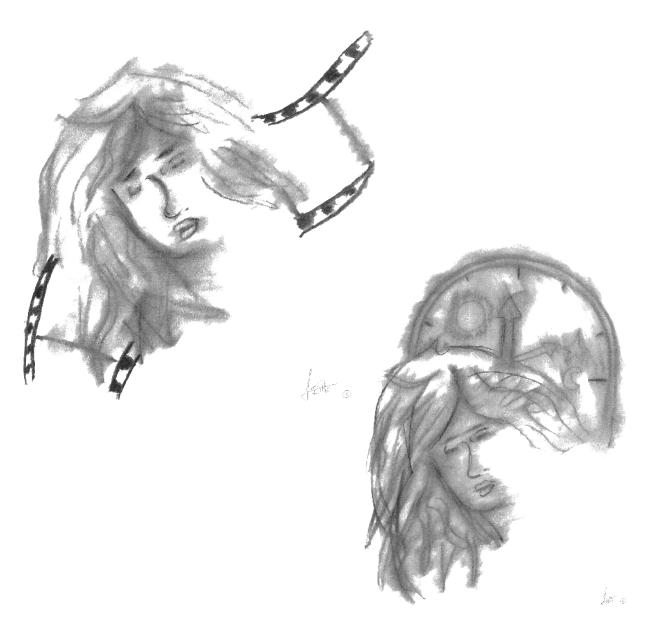


Courtesy of Johannes Mathis, Switzerland.

"To be, or not to be: that is the question: Whether 'tis nobler in the mind to suffer The slings and arrows of outrageous fortune, Or to take arms against a sea of troubles, And by opposing end them? To die: to sleep: No more; and by a sleep to say we end The heartache and the thousand natural shocks That flesh is heir to. Tis a consummation Devoutly to be wished. To die, to sleep; To sleep: perchance to dream: ay, there's the rub: For in that sleep of death what dreams may come, When we have shuffled off this mortal coil, Must give us pause: there's the respect That makes calamity of so long life; For who would bear the whips and scorns of time, The oppressor's wrong, the proud man's contumely, The pangs of despised love, the law's delay, The insolence of office and the spurns That patient merit of the unworthy takes, When he himself might his quietus make With a bare bodkin? Who would fardels bear, To grunt and sweat under a weary life, But that the dread of something after death, The undiscovered country from whose bourn No traveller returns, puzzles the will And makes us rather bear those ills we have Than fly to others that we know not of? Thus conscience does make cowards of us all; And thus the native hue of resolution Is sicklied o'er with the pale cast of thought, And enterprises of great pith and moment With this regard their currents turn awry, And lose the name of action."



(William Shakespeare, "Hamlet", Act 3 scene 1)



Courtesy of Gert Jan Lammers, Holland.

# HYPNAGOGIC/HYPNOPOMPIC HALLUCINATIONS

"Why does the eye see a thing more clearly in dreams than the imagination when awake?" (Leonardo da Vinci)

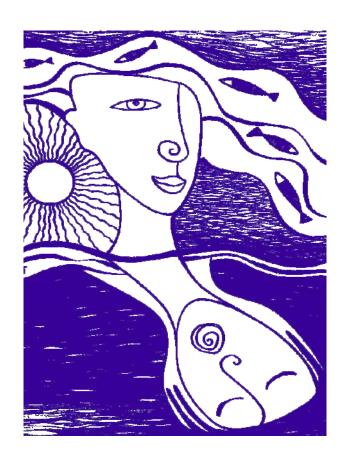


## SLEEP PARALYSIS AND HYPNAGOGIC/HYPNOPOMPIC HALLUCINATIONS

Sleep paralysis is a transient inability to move when falling asleep or waking up, something about 80% of people with narcolepsy experience.

The paralysis can last from a few seconds to several minutes. Although not dangerous, sleep paralysis tends to frighten people who are not yet aware of their condition, especially when accompanied by hypnagogic hallucinations.





"Who knows if this other half of life where we think we're awake is not another sleep a little different from the first."

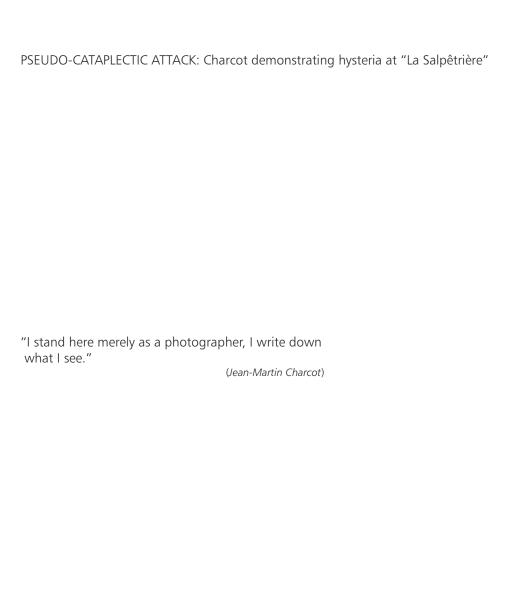
(Blaise Pascal)

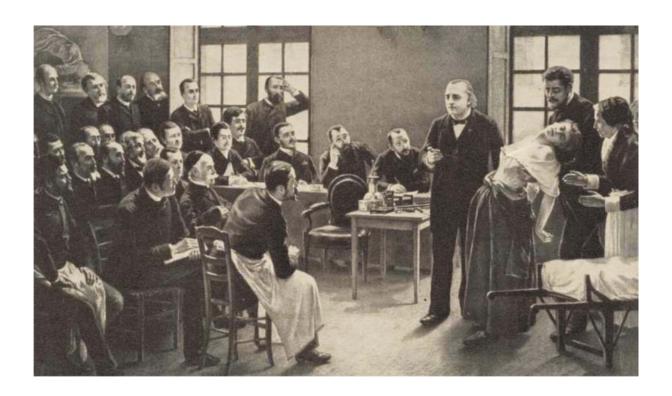


"Art washes away the dust of everyday life from the soul."

(Pablo Picasso)







"Those who have compared our life to a dream were right ... we were sleeping when awake, and waking when asleep."

(Michel de Montaigne)



Courtesy of Christian W. Hess, Switzerland.



"Without art, the crudeness of reality would make the world unbearable."

(George Bernard Shaw)



"To find yourself, think for yourself."

(Socrates)



"Vision without action is a daydream. Action without vision is a nightmare."

(Japanese proverb)



Approximately 50% of adults with the disorder retrospectively report symptoms beginning in their teenage years. This disorder may lead to impaired social and academic performance in otherwise intellectually normal children. The implications of the disease are often misunderstood by patients, parents, teachers, and health care professionals.

Narcolepsy symptoms can affect learning because it limits children's ability to study, focus, and remember. When tired, some children with narcolepsy speed up their activities, rather than slowing down. These children can be mistakenly labelled as hyperactive.

Teachers, school administrators, and school nurses can help a child with narcolepsy function effectively.

Some schools have special education programs for children with narcolepsy.



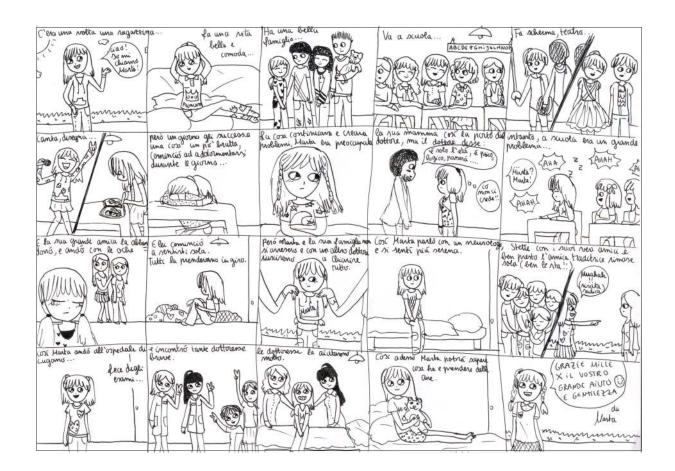


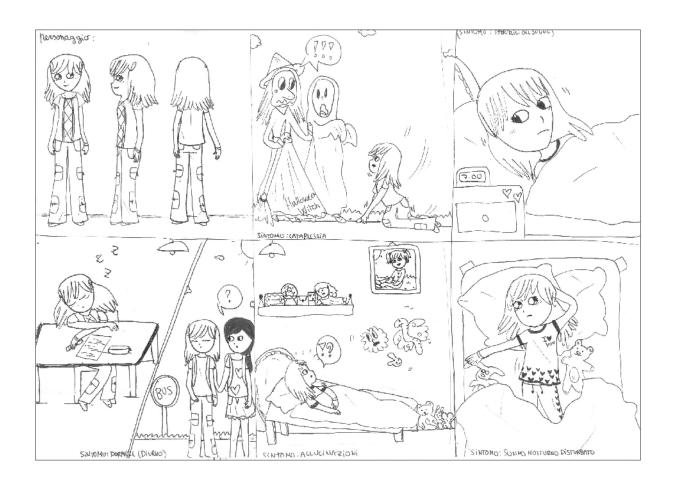


Of Marta: "My Narcolepsy"; the story of a narcoleptic girl in everyday life.

"Each day is a little life: every awakening and arising a little birth, every fresh morning a little youth, every going to rest and sleep a little death."

(Arthur Schopenhauer)





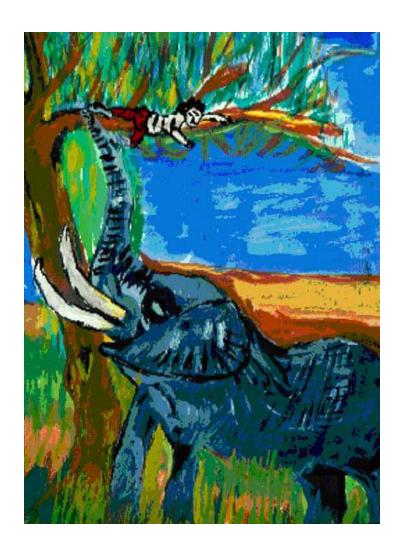
Courtesy of Claudio Bassetti and Monika Raimondi, Switzerland.



## HYPNAGOGIC/HYPNOPOMPIC HALLUCINATIONS

"Those dreams that on the silent night intrude, and with false flitting shapes our minds delude ... are mere productions of the brain. And fools consult interpreters in vain."

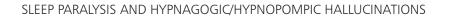
(Jonathan Swift)



Courtesy of Claudio Bassetti and Johannes Mathis, Switzerland.







"My fear ... is my substance, and probably the best part of me."

(Franz Kafka)



Acknowledgements go to: Christian W. Hess Gert Jan Lammers Johannes Mathis Giuseppe Plazzi Luigi Ferini Strambi Nederlandse Vereniging Narcolepsie

Special thanks to Andrew Burke for proofreading this text

Special thanks go to all the patients for their drawings

Layout and graphic concept by: Nexus Design sagl 6928 Manno - Lugano - Switzerland





















Special thanks for their support to: Unrestricted Educational Grant UCB Pharma SA Nexus Design sagl





Images and logos are the property of their respective authors. All rights reserved. Duplication and publication prohibited without written permission. Copyright by Nexus Design sagl.

Printed in March 2010.



Neurocenter (EOC) of Southern Switzerland 6900 Lugano, Switzerland