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**HAVING NARCOLEPSY  
THE EXPERIENCE AND TREATMENT IN CHILDREN, ADOLESCENTS AND  
YOUNG ADULTS**

by

**SUSAN ZAFARLOTFI**

**A dissertation submitted to the Graduate Faculty in  
Sociology in partial fulfillment of the requirements for  
the degree of Doctor of Philosophy, The City University of  
New York.**

**1997**

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This manuscript has been read and accepted for the Graduate Faculty in **Sociology** in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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**Dedicated to:**

**All who participated in this research study;  
By sharing the most private experience of your lives,  
you granted me the best experience of my life.  
This research is yours as much as it is mine.**

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## INTRODUCTION

This research study is about an experience of an illness called narcolepsy, in adolescents and young adults. Narcolepsy is a neurological disorder with the primary symptom of excessive daytime sleepiness (EDS), where afflicted individuals report feeling easily tired or fatigued all the time. They tend to fall asleep not only in situations in which many normal people feel sleepy (such as boring lectures), but also when most people would remain awake (while watching a movie or writing or driving). Persons with narcolepsy may also report sudden attacks of cataplexy which are brought on by strong emotions such as stress or laughter.

Cataplexy attacks may be mild, such as brief feelings of weakness in the knees, or they may cause complete physical collapse resulting in a fall. The person having such an attack is fully awake and knows what is happening. Narcolepsy is completely different than epilepsy, although some of it's symptoms resemble certain forms of epileptic seizures (See Ferber 85).

Narcolepsy's other symptoms include sleep paralysis, a brief loss of muscle control when a person is falling asleep or waking up, and hypnagogic hallucinations which are vivid, dreamlike experiences that are difficult

to distinguish from reality. A person with narcolepsy may also have other symptoms such as automatic behavior, which is the performance of routine jobs by a person who is not consciously controlling activity, disturbed night time sleep, lethargy, inability to concentrate are other symptoms of narcolepsy (See Goswami, Thorpy 91).

The concentration of this study was to go beyond the medical definition of the disorder and understand the illness experience, from children, adolescents and young adults' point of view; their fears, their hopes, their everyday life difficulties and the problems they are faced with as well as the experience of the parents and family members dealing with the disorder and their difficulties, and the ways in which they manage to transcend these.

This research was conducted in search for a better understanding of narcolepsy and to provide the knowledge needed for public to understand the disorder and enlighten those who have narcolepsy, their families and health care professionals as to how to deal with the narcolepsy and its impact more effectively.

This book is dedicated to all those, children, adolescents, young and mature adults dealing with narcolepsy and other chronic disorders.

## HAVING NARCOLEPSY

### EXPERIENCE AND TREATMENT OF ILLNESS IN ADOLESCENTS AND YOUNG ADULTS

#### ILLNESS AND SOCIETY

Each Society's definition of illness is institutionalized within its cultural patterns. Societies do not respond in the same way to the same illness. Instead, the assumptions of a particular culture or subculture influence the way people interpret symptoms, and therefore its cure and treatment. One group might call a symptom a viral infection and seek medical treatment and another group might call it God's punishment and seek religious cure. However, overall, societies agree on one thing, and that is the concept of being sick as not feeling well. Twaddle and Hessler (1986) defined sickness as the condition of those who are socially recognized as unwell. In other words, illness is a psychological phenomenon - one "feels" ill. Disease is a biological phenomenon - one has a disease. Sickness is a social phenomenon - one acts sick, or behaves in a way typical of a sick person.

Every society has a sick-role - a pattern of behavior expected of someone who is ill. Talcott Parsons was one of the first sociologists to show that sickness is a social as well as a biological phenomenon. He indicated (The Social System, 1951) that a society can function smoothly only if most of its members are able to play their

roles most of the time. When people are sick, their roles must be taken on by others or left unperformed. Therefore, sickness places strains on society as a whole. As a result, society has an obligation in maintaining health and in curing disease. Societies also determine who is sick and who is not. Parsons described (1951) that sickness is a form of deviance, and the sick person is in a sense deviant. By institutional definition of the sick role, the sick person is helpless and therefore in need of help. When being sick is regarded as "deviant," it should be distinguished from other deviant roles precisely by the fact that the sick person is not regarded as responsible for his condition, "He can't help it." Yet Parsons believed that the sick person should try to get well because he is disrupting the social order, meaning that in the societies, the social norm is to get up, get ready for your daily tasks (school in the case of children, work or daily chores in the case of grown adults). The sick person cannot follow the flow of societal routine and is exempt from "normal" social roles. Therefore the sick person has an obligation to get well. Despite the fact that Parson's concept of the sick role has been criticized by several sociologists for its limitations of the variations within illness behavior, his sick role theory represents a significant contribution in Sociology. Parsons insists that illness is a form of deviance, and that as such it is

necessary for a society to return the sick to their own social functioning. What Parsons tries to do is to present a societal view of medicine as a mechanism by which a society attempts to control and maintain social stability.

Whether we agree with Parson's explanation or not, the concept of the sick role seems to be embedded in American culture. A sick person is useless and has to rush to get well, otherwise he or she may lose his or her position in the society permanently.

Waitzkin (1983) very clearly indicated that our society puts the burden of being healthy squarely on the individual, other than seeking collective solutions to health problems. The phenomenon promotes the idea of keeping healthy by keeping healthy and obtaining medical care, whereas Waitzkin points out that individuals often live unhealthy lives as a result of social inequity and inability to maintain good health.

We live in a society where not being well and functional is regarded as a violation of expected behavior. The society expects people not to become ill. When the social structure of a society is based on a phenomenon that promotes "normal" as being well, it is not surprising to see the strain that any illness, whether mental or physical, puts on ill persons and their families.

In this study, my aim was to research the experience of an illness called narcolepsy. The primary

symptoms of this disorder are excessive daytime sleepiness, lack of energy, falling asleep during routine tasks such as driving, talking, listening and even eating. Individuals with narcolepsy are labeled as "lazy," "useless" and some are labeled as "mentally ill," due to inability to perform daily tasks if sleepiness is untreated. Adolescents with narcolepsy are labeled as "slow," and in the case of young adults, they are dismissed from one job after another because of falling asleep at work. The nature of this disorder makes it very vulnerable for stigmatization and labeling. In conducting this research study, my aim was to explore the experience of this disorder from adolescents' and young adults' point of view, living with the disorder.

I first begin with a brief introduction to narcolepsy and its symptoms; and further on move to research questions and the experience of the disease. Having to deal with a chronic disorder can be hard enough, yet society's potential for labeling, stigma and ambiguity of many chronic disorders makes living with those disorders much harder. This research was conducted in search for a better understanding of narcolepsy and to provide information needed for the public to differentiate between those individuals labeled as "lazy" and "slow" and those who are afflicted with a disease of "falling asleep." In search of better understanding of chronic disorders in the society.

## WHAT IS NARCOLEPSY

Narcolepsy is a neurological condition related to dysfunction of brain-stem sleep-wake mechanisms which is expressed as a tetrad of four major symptoms: Excessive daytime sleepiness (EDS) with sleep attacks, Cataplexy, Sleep Paralysis and vivid (dreams) hypnagogic hallucinations. (See Yoss, R. and Daly, D. 1957)

Narcoleptic sleep is a sudden urge to sleep. What typically occurs is that an overwhelming need to sleep suddenly emerges. The narcoleptic sleep instantly takes over. One can see the narcoleptic's eyes roll up into his/her head even before the patient's eyes are fully closed. The eyes then slowly close while sleep hypnotically triumphs. (See Kellerman 1981)

The narcoleptic sleep is frequently misdiagnosed as neurasthenia, lethargy, general fatigue and even depression.

## NORMAL AND NARCOLEPTIC SLEEP

Normal sleep has two components: Non-rapid eye movement (NREM) sleep (slow wave, dreamless sleep), and rapid eye movement (REM) sleep. NREM sleep consists of four stages which can be differentiated by EEG.

In Stage 1 NREM, a transition from wakefulness to deep sleep that typically lasts one to seven minutes, reactivity to environmental sleep stimuli diminishes. During Stage 1, however, many persons reportedly are awake. Subjectively perceived sleep begins in Stage 2, NREM, and

consists of brief, fragmented thought. Sleep deepens in Stages 3 and 4 NREM, which are sometimes termed delta sleep.

In REM sleep, the eyes move rapidly back and forth, muscles become nearly paralyzed, and heart and respiratory rates decrease. REM is a stage of vivid dreaming, which can be recalled by about 80% of persons who awaken during REM sleep.

In a normal sleep pattern, the first REM sleep period is reached in approximately 90 minutes and lasts about five minutes. NREM and REM sleep periods then alternate at approximately 60-minute intervals in infants and 90-minute intervals in adults. In subsequent sleep cycles, delta sleep usually does not occur and REM periods become longer and more intense. Persons with narcolepsy, however, have a very different sleep pattern, passing into REM sleep much more quickly, after experiencing many nocturnal disturbances and considerably less restful sleep. They not only report feeling as though they have not slept at all, but the nocturnal disruptions may exacerbate their symptoms of sleepiness. (See Goswami, Thorpy 1992)

#### CLINICAL SYMPTOMS

##### CATAPLEXY:

Cataplexy is referred to as a loss of muscle tone. The cataplectic attack causes the person with narcolepsy to lose control over all voluntary muscles. Weakness may

occur in isolated muscle groups such as in the jaw, in hand dropping or in facial sagging. When the cataplectic attack occurs, a person may simply fall down. In the early 1900's, the term cataplexy was first used to mean a temporary muscle tonelessness, caused by the expression of sudden emotionality and accompanied by a transitory paralysis. (See Kellerman 1981)

Cataplectic attacks may be brought about by stress or anger, laughter and surprise. The person with a cataplectic attack may fall down fully to the floor. Therefore, patients may not be able to participate in sports and exciting events.

#### SLEEP PARALYSIS:

Persons with narcolepsy who suffer from sleep paralysis experience a brief loss of voluntary muscle control and are unable to move. This usually occurs during the transition period from the waking state to sleep, or immediately on awakening. The patients usually are completely unable to move and are afraid of not knowing if they could get out of this dilemma. Sleep paralysis is episodic and passes within a few minutes after occurrence.

#### THE HYPNAGOGIC HALLUCINATION:

The definition of hallucination generally refers to seeing something that is not there. (See Kellerman 1981) Hypnagogic hallucination is a vivid feeling of reality during sleep paralysis attacks. The most common type of

hypnagogic hallucination is when the patient dreams an intruder has walked into the house. Quite often, patients are frightened due to the fact that these dreams are very vivid and feel real.

OTHER CLINICAL SYMPTOMS:

Automatic behavior: Is the performance of routine tasks by a person who is not consciously controlling the activity. Sometimes a person may actually fall asleep and continue an activity, but not recall having done it when awakened. Automatic behavior can be very dangerous if a person is involved in a potentially risky activity such as driving or cooking.

Disturbed nighttime sleep: Frequently occurs in people with narcolepsy. Although they have difficulty staying awake during the day, they may also have difficulty staying asleep at night. The many nighttime awakenings further increase the problem of sleepiness during the day.

It is not uncommon for persons with narcolepsy who suffer from the entire narcoleptic tetrad, with narcoleptic sleep attacks, cataplexy, sleep paralysis and hypnagogic hallucinations to experience other symptoms, some of which may be: fugue, or a dissociated state of amnesia, somnambulism or sleep walking, various forms of insomnia, diplopia or altered color vision, and nocturnal myoclonus or violent jerks that may occur during sleep throughout the night.

(See Report of National Commission on Sleep Disorders Research 1993)

### STUDYING NARCOLEPSY, RESEARCH METHOD

According to the Report of the National Commission on Sleep Disorders Research in 1993, which was submitted to the United States Congress and to the Secretary of the Department of Health and Human Services, approximately 40 million Americans suffer from chronic disorders of sleep and wakefulness, such as narcolepsy, sleep apnea and insomnia. An additional 20 to 30 million individuals experience sleep-related problems. Moreover, additional millions of others obtain inadequate sleep because of demanding work schedules and various other life style factors.

The consequences of sleep disorders, sleep deprivation and sleepiness are significant and include reduced productivity, lowered cognitive performance, increased likelihood of accidents, higher morbidity and mortality risk and decreased quality of life. (See Report of the National Commission on Sleep Disorders Research 1993)

Among sleep disorders, narcolepsy was once thought to be a rare disease, but epidemiological studies have suggested that its prevalence actually is comparable to that of multiple sclerosis or Parkinson's disease. Narcolepsy can affect all age groups. However, lack of public awareness pushes persons with narcolepsy medically and socially to be classified and treated as epileptic, schizophrenic, depressed and mentally ill.

In fact, most persons with narcolepsy go eight to ten years or longer before they are diagnosed. This happens, not because earlier diagnosis is not possible, but because symptoms are often misunderstood or unrecognized (See Richard Ferber 1985). While these symptoms are misunderstood, the afflicted individuals usually have suffered a great deal from medical, emotional and social consequences.

Children and adolescents with narcolepsy often suffer from lack of attention span, inability to concentrate, excessive drowsiness and fatigue. They attempt to hide their symptoms, they cut school because it's a heavy burden to be alert during the active hours of the day. Most are fearful of going to sleep at night because of sleep paralysis and hypnagogic hallucinations (vivid night terrors). As a result, they are classified as stupid, under-achievers, inattentive, hyperactive, socially isolated and many are even labeled as mentally slow.

This research was based on the experiences of the discovery of this disorder by these adolescents and young adults. By writing about their experiences, the aim was to first educate the public in terms of preventive measures, and second, I hope these experiences will help others in the future, with the same or similar disorders, to realize that they are not "crazy," their lives are not "wasted" and, most of all, they are not "alone". Hopefully, this

work would help them seek the proper way to fight the stigmatization attached to this disorder and other similar disorders, in terms of coping mechanism.

The most important aspect of this research was to document the experience of self-diagnosis by those who have gone through this, and to listen to their voices and their perspectives. How did they notice "something is wrong?" What did it mean to them? Was the experience frightening? Was the experience only noticed by them or did family members have a role in the discovery? What made them seek professional care? What were their experiences, once they sought professional care? What did it mean to them to be diagnosed as having narcolepsy? Were they misdiagnosed? If not, how did they cope with medical labeling and managing the disorder? What did it mean to seek medical management? Were there other alternatives? What strategies were used to get by in their lives? And what does it mean to live with narcolepsy in everyday life pattern?

This research is based on a symbolic interactionist view to explore the experience of the disorder from the patient's point of view, and to see this disorder shaped by individuals who were socialized to learn to live with it as a condition attached to their lives. This study is based on a Social Psychology theory, such as George Herbert Mead's, that is concerned with individual behavior as a unit of analysis. For Mead, Social Psychology is the

discipline that studies the activity or behavior of the individual as it lies within the social process. His Social Psychology presupposes an approach to experience from the standpoint of the individual, yet he believes that the individual himself belongs to a social structure, a social order. (George Herbert Mead, Mind, Self and Society 1934)

I also concentrated on Charles Horton Cooley's Theory of Socialization Process - the concept of a looking-glass self, that an individual comes to know or define himself through the process of internalizing his perceptions of how he thinks others, especially significant others around him, perceive him. He comes to adopt, or accepts as his own, those evaluations, definitions and judgments of himself that he believes he sees "reflected" in the faces of others in his social environment.

Focusing on this theory and those of Irving Goffman's Theory of Presentation of the self in the everyday life guided me to first; see how these individuals perceive themselves and second; to see how they see themselves through the eyes of others, especially living in a social environment that is stigmatized against being different in specific and being ill in general. Therefore my analysis was derived from the impact of the illness on the "Self-Perception" and "Self Worth" from afflicted individuals' point of view, with the emphasis that these

views are affected by those of the social environments we live in.

Similar studies in this field have inspired this research. Among them are:

- o Joseph Schneider's and Peter Conrad's study on epilepsy. (Having EPILEPSY - The Experience and Control of Illness 1983), where they concentrate on the perceptions of the experience of epilepsy by people who have gone through the experience of the illness.
- o Zachary Gussow and George Tracy's study on leprosy (status, ideology and adoption to stigmatized illness. (A Study of Leprosy 1968). Their study concentrated on sociological and social psychological perceptions of the illness from the patient's point of view.
- o Barbara Katz Rothman's study of women going through the experience of the technology of prenatal diagnosis. (The Tentative Pregnancy 1986). Her study concentrates on the voices of women who have been offered the choices brought about by the new reproductive technology, and their physical and emotional experiences.
- o Sue Fisher's study of the sexual politics of American medicine (In the Patient's Best Interest

1986). She employs sociolinguistic methodology to analyze the doctor-patient interaction and dialogue.

- o Judith Lorber's study of attitudes and behavior of surgical patients (Good Patients and Problem Patients: Conformity and Deviances in a General Hospital 1975).

## RESEARCH METHOD

This research study is an exploratory case study, with its main purpose to discover the experience of narcolepsy from people's everyday lives lived with the illness. The data was analyzed through qualitative procedures which are based on strategy that combines data and analysis. For this study I interviewed 53 individuals officially diagnosed as having narcolepsy prior to my interview. The diagnosis was made after each individual had polysomnography followed by MLST (multiple sleep latency test) confirming the diagnosis of narcolepsy. Of those 53 respondents, 30 were male and 23 were female, ranging from 6½ years of age to 33 years, with an average age of 20 for males and 22 for females at the time of interview.

In addition to 53 respondents interviewed, 44 family members were also interviewed. Of those family members, 36 were parents and legal guardians, five were spouses of the participants (three wives and two husbands), and four siblings of respondents.

These interviews ranged over a three year period from 1992 to 1995, and lasted between one and one-half to three and one-half hours. The interviews took place mainly in the respondent's homes, their offices, my office, college libraries, hospital conference rooms and seven interviews were arranged through long distance phone conversations by making advance appointments over one or

more phone calls lasting one to two hours with one or two breaks. All interviews, including the phone interviews, were tape recorded and transcribed into over 2850 single spaced typed pages.

During the interviews, breaks (sometimes two or three, fifteen minutes, as well as short naps, were arranged. Tea, coffee, juice and snacks were offered in breaks. In interviewing children and adolescents I was very much aware of ethical issues concerning the rights of the children, and I followed the guidelines of human subjects of New York Graduate Center and prepared consent forms (Appendix C), which asked the permission of the parents of children involved in this research as well as a consent form (Appendix D), which was a general consent form for young adults.

To ensure the richer vision in this study, especially of these younger children or adolescents who were diagnosed earlier, I backed up the interviews with additional interviews with parents or guardians. Fifty open ended questions (See Appendix A) from respondents and family members were asked.

Prior to the interviews I conducted 15 pilot interviews that allowed me to improve questioning strategy as well as content of the material. I was very sensitive to ensure that the vocabularies and phrases used in the interviews were understood, and if necessary were rephrased at the time of the interview.

### SAMPLE POPULATION

In 1992 I was granted research access at the Narcolepsy Institute, located at Montefiore Medical Center in the Department of Neurology's Sleep-Wake Disorder Center (and in association with Albert Einstein College of Medicine).

The Narcolepsy Institute is a New York State funded program designed to provide comprehensive psychosocial management of care for narcolepsy. The program was established in 1985 under the directorship of Meeta Goswami, Ph.D. The institute serves the needs of residents in the five boroughs of New York City. Screening, information, referral, advocacy, counseling and crisis intervention are offered to individuals and groups of individuals who have been diagnosed as having narcolepsy and to their families. Trained counselors help patients develop skills necessary to cope with the social and psychological impact of narcolepsy in their lives. The institute also conducts an extensive outreach program to educate professionals as well as consumers about narcolepsy. About two-thirds of respondents participating in my research study were drawn from this site. These were the respondents diagnosed at Montefiore Medical Center. While training for psychosocial counseling at this site, I was also able to conduct my research. A notification letter was sent to about fifty patients by the director,

followed by a letter from me, inviting them to participate in this research study. Two-thirds of these individuals volunteered themselves and agreed to participate in this research. In addition to that, I was also able to draw about one-third of my participants from Hackensack Sleep Disorder Center in Hackensack, New Jersey, where I have been working as clinical coordinator and counselor. About twenty patients diagnosed with narcolepsy and their parents were contacted. Twelve of these agreed to participate in this research study. Besides the above-mentioned centers, my research project was announced in the 1994 issue of The Network, which is the newsletter of Narcolepsy Network in New York. Seven candidates from Texas, Arizona, New England and Washington, D.C. contacted me and volunteered to participate in this research project.

### OUTLINE OF THE RESEARCH STUDY

Once the information was gathered, the different categories were classified under specific titles, such as Diagnosis and Self, Medical Diagnosis and its Impact, Misdiagnosis, Denial, Problems With School....driving, Medication, Support Group, etc. Therefore, the chapters were titled according to those categories.

I began by briefly looking at the history of narcolepsy from the 18th century. My aim was to examine how this disorder medically was formed and also to examine if any "social description" of the disorder was reported.

Chapters that followed are;

- o The Process of Diagnosis; The discovery of "what is wrong" and the impact of learning this diagnosis.
- o Narcolepsy and Self; The analysis of stigma and embarrassment attached to the disease.
- o Narcolepsy and Public Life; The experience of everyday life with narcolepsy and teenagehood, college life, sports, driving, work and their problematics.
- o Narcolepsy and Family Life; The impact of narcolepsy on family, dating, marriage with narcolepsy.
- o Treatment of Narcolepsy; The experience of medical treatment.
- o Psychosocial Treatment of Narcolepsy; Counseling and Support Groups.

### HISTORICAL FORMATION OF THE DISEASE

Narcolepsy traces back to 1704, described by Oliver (1704) and then by Graves (1951). In 1877 Westphal, in a paper called "Eyenartige Mit Ein Schalafan Verbundene An Falle," reported a narcoleptic case and the following year, Fischer (1878) reported a similar case. Both Westphal and Fischer referred to the term epileptoid.

For many years the symptoms of the disease in different parts of the world were looked upon as excessive sleep in epilepsy or hysteria, cerebral tumor and other nervous and general disorders. (See Adie 1926)

In 1880 Gelineau used the term narcolepsy for the first time. He described the disease as "a new species of neurosis," which had nothing to do with epilepsy. (See Gelineau 1880)

Gelineau presented a 38-year-old man who for two years had attacks in which he lost the use of his legs, which gave way beneath him. The attacks came on when he laughed heartily or when any pleasurable emotion such as the prospect of a good business deal came about. He was worried at all times by an inclination to sleep, and the attacks of weariness or emotion often ended in his falling asleep for a few moments. During a meal he would fall asleep four or five times, his knife and fork would fall, the sentence he began in a loud voice would end feebly, his head would sink and he would sleep for a few seconds or

minutes. The only way to wake him up was to shake him violently. On waking, his head would be clear and he would feel quite fresh. His memory and intelligence were intact and in all other respects he was perfectly healthy. (See Gelineau 1880)

In 1926, Adie described the disease as being characterized by the occurrence of attacks of irresistible sleep without apparent cause, and curious attacks on emotion in which the muscles relaxed suddenly, so that the victim would sink to the ground, fully conscious but unable to move. As a rule the attacks occurred independently, occasionally an attack on emotion ended in sleep. Adie reported on five cases, observed by him at National Hospital, Queen Square, London, along with 15 other cases recorded in journals available in the library of the Royal Society of Medicine.

Adie's research concluded in the finding of disease characterized by the occurrence of an irresistible inclination to sleep. The disease begins most frequently in adolescence or in early adult life. Individuals affected appear to be healthy. Both sexes are affected. The frequency of the sleep attacks varies from two or three a day to one every few minutes, but is fairly constant in each individual. The duration of the attacks varies from a few seconds to several hours, several minutes being most frequent. The depth varies from a light sleep in which the

patient is dimly aware of his surroundings and can be awakened with difficulty. Sleep may occur in any circumstances whatsoever and may endanger life. The attack is almost always inevitable. Any emotion, pleasurable or the reverse, may precipitate the second kind of attack. Hearty laughter is the most potent cause. Some patients can laugh with impunity, but have an attack with other emotions. Patients sometimes learn to check the inclination to laugh and can thus prevent the attacks. In conclusion, Adie agreed with Gelineau's (1880) concept of narcolepsy as a disease sui generis. It is not very rare, but most cases are mistaken for epilepsy, some for hysteria. It is certainly distinct from both.

Wilson Sak (1928) reported on four cases who suffered from sleep attacks and emotional powerlessness (cataplectic) attacks.

In 1933, Max Levin reported on clinical studies of sleep paralysis and hallucinations in patients with narcolepsy.

In 1957, Robert Yoss and David Daly reported on 241 cases over a five year period from 1950-1954, seen at the Mayo Clinic. They also saw 59 narcoleptic patients between 1956-1957. The conclusion they made was that narcolepsy is a tetrad of excessive daytime sleepiness, cataplexy, sleep paralysis and hypnagogic hallucinations. At that time only 11% of patients presented this complete picture. All

patients were diagnosed as having narcolepsy, 68% had cataplexy, 24% had sleep paralysis, 30% had hypnagogic hallucinations. They reported that incidence was equal in the two sexes. They also reported that the narcoleptic tetrad may develop at any age, yet the onset was in the second or third decade of life. The first appearance of diurnal sleepiness is often difficult to determine, and is usually noted by relatives as drowsiness, before the patient complains.

Narcolepsy's definition was first approved by the First International Symposium on Narcolepsy in France in 1975: The word "narcolepsy" refers to a syndrome of unknown origin that is characterized by abnormal sleep tendencies, including excessive daytime sleepiness and often disturbed nocturnal sleep, and pathological manifestations of REM sleep. The REM sleep abnormalities include sleep-onset REM periods and dissociated REM sleep-inhibiting processes, cataplexy and sleep paralysis. Excessive daytime sleepiness, cataplexy and less often, sleep paralysis and hypnagogic hallucinations are the major symptoms of the disease. (See Guillerminoult, Dement, Passouant 1976)

Looking at the history of narcolepsy, as in most experiences of other chronic illnesses, you realize that the archive is mostly a medical one. Most of the time, the experience of the people as laypersons is not considered

and is missed in the society. People usually take responsibility, not only for monitoring their diseases and illnesses, but also for management of them. They gain strategies to manage and control their illnesses or to help family members. At the same time, they go through uncertainties at times that could help others with the same or similar illnesses to know that they are not alone and that it is all right to be uncertain.

Furthermore, the histories and experiences of diseases and the study of stigmas attached to them are very valuable. My aim is to have a critical view and try to help add a sociological perspective to the understanding of this disorder.

### SELF DIAGNOSIS (DISCOVERY)

The medical diagnosis of an illness usually is the process of labeling the disorder, and it is not the origin of the illness. Sometimes people feel there is something wrong with them for days, weeks, months and even years before they seek medical attention. Just as certain people perceive social conditions to be stressful and others do not, so too will some people recognize particular physical symptoms such as pain, high fevers or nausea and seek out a physician for treatment; others with similar symptoms may attempt self medication or dismiss the symptoms as not needing attention.

These differences in deciding whether or not to seek medical care have been and are continuing to be the subject of extensive investigation in medical sociology. Although the exact processes involved in making the decision to obtain medical care are not fully identified or understood at present, enough data has been collected to indicate the sociodemographic variables such as age, sex, ethnicity and socioeconomic status, explaining how they relate to the behavior of people seeking medical care. (See Cockerham 1989) Yet one of the reasons that perhaps some individuals procrastinate to seek medical attention is that they may have lived with the disorder as a "condition" attached to their lives. Conditions can be perceived as "normal" until they no longer can be tolerated. Then the

"condition" is no longer a "condition" and becomes a "problem." Even then they may not seek medical attention right away. Therefore, as a result, there is usually a gap between the time of "self diagnosis" (process of something is wrong with me), and the time of medical diagnosis, the process during which a person is actually diagnosed.

To understand the experience of narcolepsy, I had to consider what happens before people take their problems to professionals.

I began by asking respondents or their parents what they remembered as "signs of trouble." When I asked the question, "How did you realize something was wrong," all 53 respondents replied, "Having to fall asleep too much, all the time." Some replied, "A weakness, urge to take a nap," "irresistible attack of sleep," an attack of general fatigue that forces me to take a nap," "malaise," and "fugue." Although most respondents complained of having to fall asleep as their chief complaint, 17 of them replied that sleepiness was not the reason they sought medical help, and it was either their cataplexy (loss of voluntary muscle control) or hypnagogic hallucinations (vivid dreams) that made them wonder what was wrong with them.

Table I  
Symptoms Experienced by Respondents

	EDS	CATAPLEXY	HYPNAGOGIC HALLUCINATIONS	SLEEP PARALYSIS	AUTOMATIC BEHAVIOR
Symptoms felt by male and female respondents, mild to severe	51	47	44	45	48
Symptoms never felt	2	6	9	8	5

Most respondents complained of feeling two or more symptoms, varying from mild to severe.

I will begin with the experiences of those with excessive daytime sleepiness and then turn to the experiences of those with cataplexy, hypnagogic hallucinations, sleep paralysis and automatic behavior. Most respondents reported experiencing the tetrad (set of four) of symptoms or having more than one symptom at one point or another.

Excessive Daytime Sleepiness (EDS):

Persons with narcolepsy often report feeling easily fatigued, with an urge to close their eyes and fall asleep at inappropriate times. These episodes of actual sleep occur from a few to many times a day. One 18-year-old teenager spoke of his experience, "I was always sleepy. My Mom always made me get up and do things, but I always managed to sneak to a corner and sleep for a few minutes

until I'd hear my Mom or one of my sisters calling me to get up because it was supper time. To get up in the morning and go to school was the hardest. I felt like people were trying to torture me. My Mom would wake me up and I would fall asleep in the bus going to school. Sometimes I would not even remember walking to the classroom. As long as I could make myself comfortable on a chair I would fall asleep. Teachers tried to wake me up, but after a while they gave up on me. This went on from fifth grade until my seventh grade. My teachers told my Mom that I belonged in Special School because I wasn't smart enough, but my mother did not listen to them. Finally my seventh grade teacher read an article in the paper about narcolepsy and called my mother, and that is how I ended up in the Sleep Center and was diagnosed."

The diagnosis of narcolepsy is not always very easy. Sometimes persons with narcolepsy or their parents search for years without any clues as to what is wrong.

A 31-year-old man remembered how sleepy he was since childhood. "My Mom had to wash my eyes out to keep me awake. I used to fall asleep when she gave me a bath. I fell asleep one time in the mashed potatoes when I was five years old. When I would visit relatives, I'd go to the den and fall asleep. I also had problems with school work. My Mom took me to psychologists and psychiatrists and I tested fine. I was intelligent - there wasn't any mental

problem, but they could never figure out why I wasn't doing as well as I should be. I was a C-D student. I was only diagnosed about a year and a half ago. At my present job, we do embroidery for large companies, and it requires some trim work, sometimes sitting there, just trimming the letters, my eyes would get so heavy and I would fall asleep, sitting right there with the scissors in my hands. Sometimes I would go to the rest room and take a nap sitting up and wake up and feel a little better. Then I realized that there had to be something wrong. It just didn't make sense. I was losing my job, so my boss made me look for some answers. This time, unlike my childhood, after a few months of going through testing, a physician told me I had a sleeping problem and referred me to a Sleep Center. That is how I ended up in a Sleep Center 45 miles outside of my town, and a couple of weeks later I was diagnosed as having narcolepsy."

Unlike other chronic disorders such as epilepsy, where the attacks (having seizures) give an obvious disabling figure to the afflicted individual, the narcoleptic attack has a very "passive" nature. The sudden urge to fall asleep in inappropriate situations is being indicative of tiredness and translates into "laziness" rather than illness, meaning that the disease may go on for years without anybody becoming suspicious, especially if the narcolepsy is mild.

A 32-year-old woman told me she felt something was wrong when she was in high school. As she talked about her experience, "I would get off balance all the time. It didn't bother me at first, but I started falling asleep in class more and more. My sister kept saying there is something wrong with Dede, but my mother always said, 'Oh, no, that is just the way she is.' In my first year in junior college I was always falling asleep. I would miss most of my classes. So at the second semester of my second year I didn't go back. My grades were very bad. I couldn't keep up. I slept a lot. My sister went around to mental associations, asking for help. She got material and read it. Finally, in a seminar, she met this professor who was talking about insomnia and she told him about me, and he referred me to a Sleep Center where I was diagnosed as having narcolepsy."

In the cases of adolescents, because of rapid changes in their behavior, it is very difficult to detect what is exactly wrong with them. In fact, many mental health professionals believe that, if judged by adult standards, adolescent behavior looks very different from that of adults. The wondrous, painful process of adolescent development is ushered forth by physical, emotional and social changes that take place. (See Harris and Reynolds 1990)

An 18-year-old college student talked about her experience, "I first realized something was wrong when I was 13 years old. I was in eighth grade. Each time I raised my arms my head would go down and I would feel weak. After a few times I mentioned it to my mother and she told me, 'It is probably because you are tired, or haven't gotten enough sleep.' I didn't even think anything of it. Then I started falling asleep in the class and having trouble waking up. My grades went down. That is when my mother started to investigate. We ended up in a neurologist's office where I was diagnosed as having narcolepsy, but I actually lived with the situation for two years, not knowing what was wrong with me."

In the case of adolescents with the start of any physical and emotional problem, the general rule in distinguishing between "normal" and "abnormal" is, if behavior interferes with a youngster's ability to function, then it may be considered abnormal or problematic. (See Harris and Reynolds 1990)

Although excessive daytime sleepiness is the most significant symptom, it is not the only one. Some of the correspondents remembered a "weakness feeling," like an attack as the first "sign of trouble."

Cataplexy:

Cataplexy is referred to as a loss of muscle tone. The cataplectic attack causes the person with narcolepsy to

lose control over all voluntary muscles or weakness may occur in isolated muscle groups, such as the jaw, in hand or head dropping or in facial sagging. When the cataplectic attack occurs, a person may simply fall down.

A 19-year-old college student shared his first experience with me: "I was 13 years old when I first realized something was wrong. I would basically be walking and my knees collapsed under me. It happened twice at school. I thought it was just worrying whether my family was safe or not, living in New York City and I did not think anything of it that much, until I started getting into little attacks at school, which was basically knocking me out and having no control over it. One day at home I was highly upset because a friend of mine had just died. I was in my mother's room and looking out of the window, so I walked back toward the kitchen, and as I was walking back, my knees buckled and I fell, and I hit my head on the corner of the bed and knocked myself out. My brother found me. He tried to help me stand up, but I literally could not stand up until my mother got home and I went to the family doctor. He said he wasn't sure what was wrong with me. I tried to get up but I just fell. He automatically called an ambulance. The paramedics tried to help me up and get me on the chair. I literally remember I could not move. Each time I did try to stand up I fell to the ground again. They sent me to a hospital and the next day my

doctor talked to another doctor and they transferred me to a Sleep Center. I was diagnosed as having narcolepsy. I didn't know what it meant as long as it wasn't brain tumor."

Cataplectic attacks are referred to as sudden paralysis brought on by any sudden expression of emotion. They last from a few seconds to several minutes.

A young woman, 24 years old, talked about her experience: "When I look back, the only thing I can really place as starting was about my junior year in high school. I would come home from high school and just sleep for two or three hours. Then it got to the point where I guess I was in my first year of college and I had laughed one day. I can still remember the day like it was yesterday. I just got real dizzy and thought I was going to faint; that was the first sign of cataplexy. Then I started to get worse and would laugh or fall to the ground."

Another young man who was diagnosed at around age 16 remembered how his symptoms interfered with his daily life. "I was falling asleep all the time. There were times that we'd drive to the store and my Dad would leave me in the car and I'd take a nap. My Dad would come back from the store, he'd be banging on the door to get me to open the door and I'd be asleep. I didn't really think that much about it, but the thing that was strange was, whenever I would laugh, my knees would get weak. The day

of my 16th birthday, I had an attack, the first attack when I fell on the ground. My mother thought I might have a brain tumor. They rushed me to the doctor's. When I told him that whenever I would laugh or get excited I'd just get weak and collapse, and I added I don't know if that has anything to do with it or not, but I also fall asleep a lot. It just happened that this doctor's partner was specialized in sleep disorders. He called him in and they said you probably have narcolepsy with cataplexy. I had never heard of it before, but I was relieved that there was a name for what was happening to me and I didn't have a brain tumor."

Cataplexy, while untreated, may make it difficult for an untreated person to participate in sports and exciting events.

A 16-year-old student who played softball for school talked about her experience: "I started feeling really weak at around age 13 or 14. At this time I would start laughing and all of a sudden my knees would give out. My muscles, all through my arms and my face were most affected because I would laugh and I couldn't control my facial expressions until my muscles would go loose or like numb loose, paralyzed. It felt like my muscles just dropped and I could feel loss of control over my body. I would also feel it come back. I would try to gain the control back. This also happened at sports. I played

softball and basketball. I would get really tired at practices, but I knew I would have to keep myself from falling asleep. I would have to get myself from lying down or getting in a relaxed position. But then during the games it was tough. The excitement of throwing the ball would make me fall to the ground. It felt as if I was fighting for the ball, somewhere in between there, somewhere on the ground. I could feel my body giving way. I would feel embarrassed, there was no fighting for the ball. I would lay down and try to play cool, "Oh, I missed the ball." The young girl's mother recalled her experience: "My daughter's sleepiness was not significant. It all started with her cataplexy. We had no idea this was happening to her. Looking back now, her sleepiness only started last year. I would notice something was wrong more in softball, because so many times when she would be running the bases it looked like she wasn't ever going to make it to the base. She looked like she was in slow motion and she would fall to the ground when she had to throw the ball to make a play. The strength wasn't there and the ball wouldn't even make it to the base, where the year before she would be whipping the ball. I was positive something had gone wrong with her, but I didn't know what."

The severity of cataplexy varies from person to person. In some young adults, if it's not treated, cataplexy at times could be disabling.

A 19-year-old college student talked about his cataplexy: "At around age 13, the beginning of high school, I would really begin having trouble getting up in the morning, and really falling asleep, dead asleep, in weird situations. I thought I was a heavy sleeper. It was very easy to write it off. My mother was a heavy sleeper and I guess I figured that that's the way I was. I never really said anything to anybody about it. I did very well in high school. Had it interfered with my grades, perhaps I might have said something. I was 17, and at first I remember it was just being a little bit of twitch in my legs. It was strange. I used to think it was a weakness feeling because perhaps I had not eaten enough that day. Then I realized my knees buckled in, felt like a weakness, and the emotions definitely brought it off. It was a little bit of weakness, a little bit of unsteadiness at times, but maybe once every three hours, and then accelerated incredibly to the point where I couldn't walk and made me incapacitated. That is when my parents sought medical help. We all thought I had a brain tumor. What a nightmare that was."

Hypnagogic Hallucinations:

The presence of sleepiness and cataplexy at times could be accompanied by very vivid dreams that appear to be real.

A young girl at age 12 was diagnosed as having narcolepsy. At first she was extremely sleepy. She

experienced cataplexy and soon she remembers having dreams which were very real. She describes her dreams: "I would go in between the sleep and the wake state, and I would be lying in bed or I could be sitting up. I even walked around one time and I would have a terrible dream. Like there would be a growing hand on the other side of the bed. The difference between scary dreams and my dreams would be that I couldn't tell the difference between reality and fantasy. I remember sitting up in my bed, kind of leaning on my arms, not lying down, and my mother was on the other side of the bed, giving my sister a kiss, and it was pretty light out, and this arm came from under the bed and it grabbed my arm. It was like a man's hairy arm. I couldn't move and I couldn't say a thing. I thought I was at least mumbling or grunting or saying something so that my Mom would come over. When she did come over she said, 'What is wrong with you? You look as pale as a ghost.' It took me a couple of minutes, and then I told her how scared I was. I was so terrified that I used to ask my sister to sleep with me. This used to happen. After that is when my parents thought something had to be done."

Many persons with hypnagogic hallucinations avoid telling anyone about their vivid dreams. They are afraid of being considered as "strange" or "weird."

A young man spoke of his experience at the age of 13. "I wasn't feeling tired at all; I essentially would

lose control, everything got shut off and I just went straight to sleep. I would wake up later, not knowing if it was five minutes later or two hours, but I started seeing things at night. I wasn't sure if this was happening while I was sleeping. I swear I saw people running around my house. Things that were not there. I was getting paranoid."

Hypnagogic hallucinations are frequent, dreamlike states, occurring during the transition from wakefulness to sleep. The typical frightening phenomenon may involve visual-auditory episodes, involving images of strange animals or prowlers.

A 24-year-old woman who had been diagnosed at age 20 talked about her "awful nightmares." "I don't remember ever having a nightmare as a child, so I was really scared as to why I was having them now, when I was 18. Very, very, vivid nightmares. I could remember I was sleeping and my boyfriend had given me stuffed animals and I had them against my bed, shoved up against one wall in a corner. I fell asleep one night and those animals came alive and they had fangs and teeth and they were trying to get me and kill me in my bed. I remember wanting to fight them and not being able to move.

I also remember, at another time when I had just fallen asleep, and I opened my eyes and there was a man outside of my patio, standing in the garden with a big old

camera and a big round flash taking pictures of my house. In my dreams I had gotten up and walked through the house and there were just dead bodies all over my house. Things that I would have no idea why I was dreaming about. A lot of times what could scare me was that the dreams would start just exactly as I had fallen asleep, so I didn't think I was sleeping. I would dream that the intruder walked in my room and was trying to kill me. I thought I was losing my mind. I would see things and hear things that weren't there. I'd get so bad that I would get up at night or I would grab a knife in the kitchen because I would be so scared and I would go to my parent's room, wake them up and say, "something is outside, something is outside," and they literally had to go outside with flashlights and walk around outside and make sure there was nothing there."

#### Sleep Paralysis:

Sleep paralysis can happen to anyone, where upon sleeping, an individual who has had a bad dream feels paralyzed and cannot move. However, incidence and frequency are much higher in people who have narcolepsy. A 19-year-old college student told me about his memories of sleep paralysis: "In high school I started to sleep a lot, but I didn't make anything of it. What really made me frightened was that in the mornings I could not move. I would first wake up and hear everything, and I wanted to get up but I couldn't. My body was fully paralyzed. This

started happening more often, to the point that I did not want to fall asleep anymore. I was afraid of sleeping."

An eight-year-old girl also talked about her experience. "I would fall asleep and right away wake up. I would hear my mother and my Dad talking. I wanted to talk to her but I couldn't. I always felt I had just died and this is how you feel after you die. Your mind is there but your body is gone. It was scary. I hated that. I would tell my mother, each time I sleep, my body dies. I don't want to sleep anymore."

Automatic Behavior:

Automatic behavior is the performance of simple or routine tasks by persons remaining largely unaware of the activity. Some of these persons may fall asleep in the middle of an activity, usually because they have resisted drowsiness and continue the activity even as sleep ensues, without any recall. (See Goswami, Thorpy 1992)

A mother of an eight year old girl talked about her child's experience. "She would come home and would show her class work. I would realize that she would be writing but all of a sudden everything would be scribbling. I would ask her 'Why do you do that?', and she would look at me 'stoned,' or she would tell me 'I didn't do that.' When her sleepiness began I knew something was wrong. Something drastically was wrong."

One of the typical patterns of automatic behavior is when persons are taking notes and writing and they fall asleep for a few seconds. A 19-year-old college student said he often would experience this. At the time of the interview he told me, "Even now, after diagnosis I do that. Just like the other day, I was in government class, and I was paying attention, and I was writing, and I got back to it later, and part of my notes didn't make any sense. I was wondering who scribbled them out, but it was actually me."

Automatic behavior at times can be very dangerous, especially if the person with narcolepsy is engaged in driving or working with machinery. A 27-year-old woman talked about her experience. "At about 17 or 18 I started feeling weird. I remember walking across the street, walking up into a parked car on the other side of the street, not knowing how I got there. I also had cut myself sleeping while cooking. I almost burned myself once. I didn't know what was wrong with me. I thought I had some type of brain disease because it seemed as if half of my brain was getting shot all the time."

Besides these general symptoms, some of the respondents complained of disrupted nocturnal sleep, which evidently contributed to taking naps during the day, fatigue, poor memory, low motivation and often a feeling of depression, which I will cover in a later chapter.

The process of self-diagnosis is the journey of doubts about one's health and healthy behavior. The journey begins with the self doubt of normality. It starts by one's asking oneself, "Is what I feel normal, or is there something wrong with me?" The journey may take long or not, depending on how the disorder is affecting the person's ability to perform routine tasks. However, for many it is preferred to put off medical labeling as long as they can. What lay persons recognize as illness is in part deviance from a standard of normality established by common sense and every day experience. See Cockerham, William 1989)

As Cockerham (89) describes, the illness experience begins with the symptom stage, in which the individual is confronted with a decision about whether or not "something is wrong." The decision of the persons involved may be to deny the symptoms as not needing attention, to delay making a decision until the symptoms are more obvious, or to accept the symptoms as evidence of a health disorder. The person may attempt to treat himself or herself through the application of folk medicine or self medication.

Among the 53 respondents, 19 (seven female and 12 male) had self doubt about their health by age 11. The rest (16 female and 18 male) had realized something was wrong between the ages of 12 to 18 years old. By the time respondents reached age 19, they all had realized what they felt was not normal!

Table II

## Age of Respondents at the time of Self-Diagnosis

	Female	Male	Total
Level I - Age 5-11	7	12	19
Level II - Age 12-18	16	18	34
Level III - Age 19-25	0	0	0
Level IV - Age 26-32	0	0	0
Total	23	30	53

### THE IMPACT OF MEDICAL DIAGNOSIS

Medical diagnosis for most people means more than labeling their disorder. It means having a medical condition attached to their lives. It means having to deal with all the unknowns and uncertainties. This is the actual time that one questions, What is this disorder that I have? What does it mean to have this? How could I deal with it? And is there any cure for it? According to my data, among the 53 respondents and their parents, the initial reaction was a sense of "relief" to learn that it was narcolepsy rather than something worse. The most commonly feared diagnoses were brain tumor, severe depression or uncontrolled mental illness with fear of institutionalization, paralysis, fear of staying the same and not knowing what is wrong with them. However, among all the fears, the fear of brain tumor was the most common thought among respondents and their parents, especially in the cases of mild to severe cataplexy.

A 19-year-old college student who was diagnosed at age 14 shared his sense of relief with me: "I was basically walking and my knees collapsed under me and I had no control over it, so I was positive this is a brain tumor and I was afraid of dying. So diagnosis meant I wasn't going to die. I had no idea what was narcolepsy, but I knew I wasn't going to be paralyzed and sit in a wheelchair for the rest of my life. It wasn't important that I was

going to take medication. It was important that I was not going to quit sports. It was important that I was going to gain control over my body and not to fall to the ground. Previously I used to call my loss of control over my body and collapsing to the ground as some type of 'coma,' but diagnosis meant that my coma was given a name called cataplexy."

Fear of mental disorder was another common thought among respondents and their parents. Diagnosis for some parents was a relief and because they realized their child's disorder was "physical" and not mental.

The parents of a 20-year-old college student expressed this sense of relief: "After trying everything and not getting any response, including having her on antidepressants, we were very upset. We thought, they are going to tell us that our daughter is going to be homebound for the rest of her life because of her mental condition. She continuously slept at home and at school. She was so out of energy she wouldn't talk to us. She was totally out of this world. So the diagnosis meant she wasn't going to be homebound or institutionalized. She wasn't going to be suicidal. She had an illness that we had to deal with. We were ready for that illness. We were enthusiastic about the treatment to see how she is going to change. We were hopeful something was going to be done about her."

A young woman who was diagnosed at her teenagehood had a very similar experience. As she explained:

"Diagnosis for me meant total relief. It meant that I wasn't crazy. I wasn't depressed and I wasn't lying. I wasn't losing my mind because of my dreams, the bad, awful dreams. Now I know why I had to make my family go out in the back yard in the middle of the night to see if they saw the intruders who had just left our house. There was a "name" for those awful dreams. They called them 'hypnagogic hallucinations,' and it meant it would go away if I took medication for it. It wasn't that I was crazy."

Another young woman expressed her feeling about diagnosis. "I was 20 when I was diagnosed. I remember just before diagnosis, I actually thought I was going insane. Having to fall asleep all the time was bad enough, having to dream each time was awful. I did not want to sleep but I continuously fell asleep and I dreamed each time too. Diagnosis meant I wasn't alone. There were others like me. It wasn't something that was going to put me in a mental institution. Actually, ever since I was diagnosed, the nightmares subsided and they are basically gone now.

As Joseph Schneider and Peter Conrad suggest (1983), medical definitions and diagnostic labels bring with them a sense of optimism inherent in their notion of treatment.

The fact that the condition is given a name is an end, and dealing with the diagnosis is a new beginning. A 24-year-old man who was diagnosed at age 18 talked about his feelings after diagnosis. "I definitely accepted it. It was just a fact. I did not understand it and didn't know anything about it. I didn't know where to get any information on it. I didn't know if we could correct it or not, but I had to correct it because I didn't want to change my lifestyle. I wanted to be who I was before my symptoms happened. I didn't want to be considered a handicap. I wanted to be able to do what I normally do. I basically went on with the assumption that if they diagnosed it, there must be something they could do about it."

Table III

Age At The Time Of Medical Diagnosis  
(Being diagnosed as having narcolepsy)

Age Group	Female	Male	Total
Group I - Age 5-11	2	3	5
Group II - Age 12-18	14	21	35
Group III - Age 19-25	5	3	8
Group IV - Age 26-32	2	3	5
<b>Total</b>	<b>23</b>	<b>30</b>	<b>53</b>

Table IV

**The Average Gap Between Self Diagnosis  
and Medical Diagnosis**

Age Group	Self Diagnosis Female	Medical Diagnosis Female	Self Diagnosis Male	Medical Diagnosis Male
Group I - Age 5-11	7	2	12	3
Group II - Age 12-18	16	14	18	21
Group III - Age 19-25	0	5	0	3
Group IV - Age 26-32	0	2	0	3
<b>Total</b>	<b>23</b>	<b>23</b>	<b>30</b>	<b>30</b>

The average gap between self diagnosis and medical diagnosis for both males and females were five years, with the shortest period for females being six months and the longest 15 years. For males the shortest period between self diagnosis and medical diagnosis was two years and the longest was 25 years.

For a few parents, diagnosis, besides a sense of relief, meant having guilt feelings. Diagnosis explained their children's "lazy behavior," "lack of enthusiasm," and "odd behavior." A few parents actually said they were in tears when they found out that their children were "sick," and not "lazy." As one mother shared her guilt feelings with me: "My son and my daughter are twins. For years I accused my son of being lazy and wasting his life. Every

day he would wake up, have breakfast, go to school and fall asleep. He would come home from school and fall asleep. The only time he was awake was when he was playing basketball. I blamed him for being lazy like his father and always told him he would be 'nobody.' I was a hard-working single mother and I didn't want my children to waste their lives like that. I would continually talk to him and he would promise that he was going to be a good student, but as soon as I would leave the room he would fall asleep again. Finally, one of the teachers sent a note to me with a newspaper article from a Sleep Center. That is how he was diagnosed. That was when I realized that there was really something wrong with him and he really couldn't help it to be this way. I wanted to die. His life has changed. He no longer is 'sleepy-head.'"

Another young woman, 25 years old, had a similar experience. She was misunderstood as being lazy and diagnosis brought relief, once she found out there was a name for the way she felt. "I was trying so hard, but I could not accomplish anything. People called me lazy. They thought I didn't want to be somebody successful. They called me lazy; even my teachers called me that. The more people labeled me as 'lazy,' the worse I became. I gained weight. I couldn't be active. I accepted that 'lazy' role. When I was diagnosed, I was happy. I didn't care how bad it was as long as what I had, it had a name. Actually,

right after my diagnosis I became sharper. I lost weight. I was proud that I was sick and not lazy. I told everyone I had a sickness called narcolepsy. I was looking forward to treatment because I was going to be 'somebody.'

After the initial sense of "relief," the next stage was ambiguous feelings of anger, worries, uncertainty about the future and life activities, guilt and denial, reported by both respondents and their parents.

Interestingly enough, these concerns were different among males and females. The concerns among male respondents were fear of losing their driver's license, not playing sports and becoming handicapped; whereas female concerns were how the public perceived them, fear of mental disorders, being able to baby-sit or having children in the future. As one young woman expressed her experience after diagnosis: "I was diagnosed at around age 17. At first I was happy that it was not a disease that was going to kill me, however, later I became angry. I was angry at everybody. I was only 17, I didn't need this. I kept on thinking about my limitations. I couldn't drive, I couldn't go out on dates, I couldn't play sports...at one point I thought I should kill myself, but soon this stage passed too. The more I learned about narcolepsy, the more I realized my limitations are limited, and I am not as trapped as I thought I was. Eventually I accepted my narcolepsy.

Driving restrictions were among the concerns most often mentioned by adolescent respondents, particularly the males.

One young man who was diagnosed at age 18 talked about his concerns: "Before I went to the Sleep Center I had a severe accident with my Jeep. I went through the windshield and ended in the hospital for head and neck injuries. I was very concerned about my driver's license. It was interesting that, after my first accident they checked me for alcohol, but they never asked me if I had fallen asleep. I was very concerned, thinking they might automatically take my license away from me. Driving was very important to me, as it is with all guys my age!"

Among the young male respondents, the second concern next to driving was playing sports. Most of them, after diagnosis, wondered if they could continue playing sports; as one young man shared his experience with me: "I was 16 when I was diagnosed. I was very bad before diagnosis; I used to fall to the ground, but sports meant everything in life to me. I would do anything to be able to play sports again. When I asked my doctor, he looked at my parents and said, 'I would discourage him from playing sports if I were you. He could really get hurt if he has a cataplectic attack while playing.' To me that was the absolute bottom line. It was bad enough to know you had a weird disease, but to take something away which meant a lot

to me was the worst thing that had happened in my entire life. I had become handicapped. I wasn't ready. I don't think anybody is ever ready to become handicapped. I cried for days. I couldn't deal with it."

The initial reactions of female respondents were different than males. They were more concerned with how the public perceived them. One young woman, age 24, told about her concerns at age 16 when she was first diagnosed. "I was very frightened. I didn't want to have it. At first I was happy that I didn't have cancer, but now that they called it narcolepsy it was there to stay. It was real. Maybe if they had called it something else, you know, 'muscle problem,' or 'weakness of sleep control,' it would have been easier to accept. At first I kept wondering if anyone on the street would look at me weird because they could recognize that I am a 'narcoleptic.' What would my friends and boys at school think about it? I decided I was never going to tell anybody about it. I was wondering if I was going to be secluded because of my disorder."

Among female adolescents, the major concern was to find out if narcolepsy meant having mental problems such as depression. Also, most females were concerned about their future relationships. They were concerned about meeting boys who would be understanding of their disorder. They also expressed having fears of not being able to get married and have children of their own.

MISDIAGNOSIS  
THE SILENT DISEASE

Narcolepsy is often difficult to diagnose. Persons with the disorder may visit many physicians for many years in search of treatment for their disease. In the process they are misdiagnosed, treated with inappropriate medications or dismissed as mentally aberrant. (See Goswami, Thorpy 1992) Persons with narcolepsy often report feeling constantly and easily fatigued, with little or no energy. They tend to fall asleep in situations in which many normal persons also feel sleepy, such as during a dull lecture, but their sleep attacks are almost irresistible and also occur in other normal situations (e.g. while driving or writing a letter). It is due to this nature that I call narcolepsy The Silent Disease. Persons with narcolepsy could go for years without being diagnosed. One 18-year-old college student shared his experience with me. "I was 13. I was only able to stay with the class half the time and then fall asleep. Sometimes I would just look off into space, like not even daydreaming; it was just like my mind shut off for a while. After school, I would just come home and pass out for four hours, not even realizing, watching T.V. and just passing out. My parents thought I was sleep-deprived, but as the condition continued it was impossible. I was sleeping all the time and I didn't even know it. My parents took me to a few doctors. They all

diagnosed me as manic depressive and I was given anti-depressants. They continuously were asking me if I had thoughts of killing myself. I would tell them no. I do not want to sleep so much, I am not depressed. I was not getting better and I didn't want to take the medication, but I was just a kid and didn't get much recognition. This went on for a few years until I was finally diagnosed, at age 17. Then everybody believed me that I was not depressed, I was only 'sleepy.'"

Unlike epilepsy, in which patients eventually may have a grand mal seizure, narcolepsy continues its symptoms in a "silent way," quietly falling asleep. That is why 2/3 of respondents or their parents recall considering depression as a possible diagnosis for what was wrong with the person.

A 32-year-old man remembers his symptoms since childhood, yet when his mother sought medical help, psychiatrists tested him fine and he was not diagnosed for another 20 years. He talked about his experience: "For 20 years I lived with my sleepiness, which was getting more severe, and I had noticed whenever I started laughing my extremities would go limp, but about two years ago I started a new job. I would be waking up and falling asleep and my head would bob down. I'd wake up and within a split second I'd be up. I remember having these weird dreams. I would dream about my brother, I would wake up talking to

him and all of a sudden realize that he wasn't there. Sometimes I would look for him. I wasn't sure if it was a dream or reality. I lost a couple of jobs, and then I went to the doctors. They sent me to a Sleep Center and that is where I was diagnosed. They told me all along I had had narcolepsy, but they could not diagnose it 20 years ago."

Another 32-year-old young man remembers how everyone was puzzled what his problem was until he was diagnosed at age 19. As he remembers, "I was always sleepy yet I never realize something was wrong until it manifested itself into cataplexy. It first started when I would be walking and one leg would go out. I would lose the muscle tone in one leg and I would catch myself. Then it kept getting worse. At the time it was happening, I had no idea that emotions were making me lose control over my muscles. In retrospect, the more scared I got the more it happened. What was really upsetting me was that I had done drugs at college a couple of times and I thought that had affected me. Finally I saw a neurologist. In fact, I had a full-blown cataplexy attack in his office. He did not know what it was. All I wanted was for everybody to leave me alone and I could regain my composure. The nurses were rushing at me. I was on the floor. They were trying to pick me up, which got me agitated and the cataplexy kept getting worse. The doctor diagnosed me as Class A seizures from an unknown source and put me on medication. My girlfriend,

who had read an article in a magazine, asked my doctor about narcolepsy and cataplexy. He said, 'Oh, it couldn't be that; absolutely no, this is a seizure.' I went back to college and the medicine wasn't helping. He increased the dosage. I was going to classes and I remember that there were these black drops in my peripheral vision and I was delirious. I was irrational, but it was mostly the black drops that hinted something was wrong. I called my mother, who is a nurse. She read in the medical reference book that the side effects of overdosing Tegretol (seizure medication) were exactly what I was feeling. I stopped taking the medication and then my Mom took me to the Mayo Clinic. I was diagnosed as having narcolepsy and not seizures."

A 23-year-old woman who was diagnosed at age 20 talked about her experience: "I went to my doctor for a checkup. I told him whenever I laugh I feel like am going to pass out. She said, 'You're hyperventilating. Just try to take a deep breath.' I believed her and I tried that and it didn't do anything. I was falling down to the ground. One day a girl that worked with me - her brother was in college and had taken psychology courses and was doing a study on narcolepsy, and he had written to an associate out in California. They had sent him a videotape, and as she was watching it with her brother she recognized my symptoms. She came to work the following

day and told me, 'You have the collapsing disease. Do you have nightmares too?' I was like, yeah. She made me talk to her brother, and three months later I was diagnosed at a Sleep Center as having narcolepsy."

The two significant misdiagnoses among the people with narcolepsy are depression and brain tumor (due to cataplexy falls).

A 19-year-old college student talked about her misdiagnosis: "When I was in eighth grade I was very sleepy. I didn't know why. I felt so weird. My mother took me to a doctor and he thought I was going through changes in puberty. I was having a tough time socially at school. My family and teachers thought I was depressed. I couldn't get up in the morning for school. My guidance counselor was asking me if I had suicidal thoughts. Everyone was worried that I was going to kill myself. I only wanted to sleep. I was embarrassed when teachers would call on me, 'Judy, wake up.' I went through a series of blood work and diagnostic testing. They didn't find anything. The doctor put me on an antidepressant; it didn't help. They kept on changing my antidepressant. Then I started falling to the ground each time I got upset. My mother was crying. She thought I had a brain tumor. They did some more testing and finally a neurologist said she has to go to a Sleep Center. He suspected narcolepsy but he didn't diagnose me; at least he recognized the symptoms.

TABLE V  
MISDIAGNOSIS CHART

Number of persons diagnosed as having chronic or manic depression:	18
Number of persons diagnosed has having seizures or epilepsy:	8
Number of people diagnosed as having schizophrenia:	1
Number or people observed and suspected of having brain tumor:	10
Number of people diagnosed with thyroid problems:	<u>6</u>
Total:	43

In this research study, among the 53 respondents interviewed, 43 were misdiagnosed, five were not given any diagnosis and five were diagnosed right away (within one year). Among the 43 misdiagnosed, 18 were diagnosed as having chronic and manic depression, one was diagnosed as schizophrenic (due to hypnagogic hallucinations), and eight people were diagnosed as being epileptic or having a seizure disorder. Ten people had undergone observation for brain tumor. Six were put on thyroid medicine.

## DENIAL

Denial among people who discover their chronic disorders or parents of children with chronic disorders is very common.

David Carrol and J. D. Dorman (1993), in The Book of Living Well With MS describe; Denial is a normal human response to loss. People experience it when they are fired from a job, when they receive a setback in business, when a loved one becomes terminally ill. The archetypical example, perhaps, is the person who loses a beloved husband or wife, then continues to talk to the deceased as if he or she were still alive.

People who receive bad news tend to process it in steps. First comes the shock, "What? Me?" And the denial, "No, not me!" Then anger, "Why me?" Followed by depression and desolation, "Poor me." And finally, acceptance, "Yes, me." (See David Carrol 1993)

Denial is usually a temporary experience and will soon be replaced by partial acceptance. Some people with chronic disorders at first deny the disorder; by doing so, they may think that their disorder might disappear, or as Judith Lorber (1967) discussed, ill individuals who want to avoid the label of illness may insist that their physical symptoms are not disabling. If they are chronically ill and wish to lead as normal a life as possible, they will try to convey the impression that they are healthy.

A 21-year-old woman talks about her experience: "I was 14 when I was diagnosed, but I denied it. I was falling asleep in every class. I would fall asleep in the car. My parents say they didn't even get out of the driveway and I was asleep. At first everyone thought I had mono or a thyroid problem, but when all the tests came back negative, my regular doctor referred me to a neurologist and he diagnosed me with narcolepsy. I didn't want to hear about it. I guess if they had diagnosed me with something more common and they had told me to take a pill and your problems would go away, I would not have rejected it. I didn't want an added burden. I was mad at the world. I was young. It wasn't fair. But eventually I realized that my problem was not going away and it was here to stay. I came to accept it. It was tough."

When the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment. The logical next question becomes, "Why me?" Mechanic and Volkart (1961) have suggested that a given illness manifests specific characteristics with regard to symptom recognition and the extent of danger. Illness recognition is determined by how common the occurrence of the illness is in a given population and how familiar people are with its symptoms. Illness danger refers to the relative predictability of the outcome of the illness and the amount of threat or loss that is likely to

result. When a particular symptom is easily recognizable and relatively devoid of danger, it is likely to be defined as a routine illness. When a symptom occurs infrequently, making identification more difficult, and is combined with an increasing perception of danger, there is likely to be a greater sense of concern. (See Mechanic and Volkart 1961)

A 24-year-old woman talked about her mother's denial, which delayed the process of diagnosis: "I was 15 and my mother, who has narcolepsy, was diagnosed many years ago. I suppose she saw me falling asleep all the time, yet she denied that I just might be like her." When I asked her mother, she said, "Yes, I was in denial. I didn't think my daughter, at age 13, would be like me. Well, I thought it was my imagination and to tell you the truth I wasn't sure myself, until one of her teachers told me that in math class my daughter looked like she was in a different world. As soon as she said that, it rang a bell. But my daughter also denied her narcolepsy after it was diagnosed. She did not want to accept it. She did not want to be like me, to be sleepy and deal with cataplexy. She pretended she didn't have it. It was tough. But eventually she came out of her shell and accepted her narcolepsy."

An 18-year-old college student who had the symptoms at around age 12 and was diagnosed shortly after, talked about his and his family's denial: "When I was in the

seventh grade I started falling asleep a lot. I slept everywhere, but especially in the classroom. Sometimes I would just let my mind shut off for a while or I would look off into space, not like daydreaming but I would be away in space. I would go home and fall asleep for hours. My aunt has narcolepsy and my family was suspicious of my condition, yet they all denied it. They all kept on having excuses, well he doesn't go to bed early enough, well it is growing pain that makes him fall asleep, he is active during the daytime. But I wasn't any of that. We all denied it until we no longer could go on. I could not play sports, I couldn't do my homework. I was always falling down. We actually knew I had it when my parents took me to the doctor. We all had to accept it." When I approached his parents, they both said they really had a tough time accepting their son's disorder. This sense of parental denial, disbelief accompanied by silence, translates into a powerful sense of rejection, to the point that this young man would refuse treatment for a while after diagnosis.

In most participants interviewed in this study, the sense of denial soon gave way to a sense of worry, protection and uncertainty about the future. This was true especially about parents. After they accepted the fact that their children were faced with a chronic disorder, the next step was how to protect him/her against this disorder and the handicaps associated with this disorder. I will be

discussing this in the chapter of "The Family and Narcolepsy."

Among the respondents, the ones who were educated about their disorder by health care professionals not only accepted the disorder easier, but also were able to make progress in life and start a new life. Michael Balint, 1972, talks about discovery as bringing relief, especially to those whose diagnosis had been delayed. He describes this as bringing order to a disordered experience. To know "what I have," is a key turning point in the illness experience. As one young woman explained after her diagnosis, the mystery of her sleep was solved. She was not going to let her sleep attacks take over her whole life. She wasn't allowing it.

The process of diagnosis is a complex process. It begins with the mystery of the disease, discovery, and continues with denial, anger and guilt. Later on comes acceptance.

NARCOLEPSY AND SELF

I AM NOT WHAT I THINK I AM

I AM NOT WHAT YOU THINK I AM

I AM WHAT I THINK YOU THINK I AM

CHARLES HORTON COOLEY

The looking glass self theory of Charles Horton Cooley, in sociology and social psychology, discusses the evolution of the individual social being, the social self. Cooley (1902) believes the "self," an "individual," develops within a context of social relationships. There is no sense of I...without the correlative sense of you, he or they. Cooley argued that a person's self grows out of a person's commerce with others. The self, to Cooley, is not first individual and then social; it arises dialectically through communication. He believes that the values, judgment of one's self is "reflected" in the faces of others in social environment and that is how individuals perceive themselves; by looking at themselves from the eyes of others. This is part of an interactive process that is called socialization, which Brim (1966) defines as "the process by which individuals acquire the knowledge, skills and dispositions that enable them to participate as more or less effective members of groups and the society. At birth direct socialization begins, and the long, slow gradual development of the self starts. This self emerges out of contact and communication with others.

George H. Mead (1934), stressed interpersonal interactions. He showed that people relate to each other in a social setting. One person acts and the other reacts, thus engaging in social acts. Meaning is attached to these social acts by the use of symbols. These are the symbols (language, gestures, etc.) that we use everyday to convey our messages to each other. They are ways of expressing who we are, what we feel, what we expect of each other. These are the basic assumptions of the Symbolic-Interaction theory which tries to explain the social/psychological processes of personality development and socialization. Thus symbolic interaction is the interaction that takes place between people through symbols. Much of this interaction takes place on a face to face basis. We live in a symbolic as well as physical world, and our social life involves a constant process of interpreting the meanings of our own acts and those of others.

In American society, like any other society in the world, individuals are assigned a role. The roles are attached and expected of these individuals on a daily basis. Society dictates certain roles to each individual regardless of their age, sex and race. The inability to perform expected tasks is regarded as a violation of expected behavior and as a deviant behavior.

In our culture "non-alertness" entails "laziness" and is being considered as passive withdrawal from normal

activities and responsibilities expected of an individual. Narcolepsy's primary symptom of excessive daytime sleepiness (EDS) and sudden lack of alertness followed by sleep attacks and lack of energy can be mistaken and labeled as "laziness." Culturally, narcolepsy can be very stigmatizing for an affected individual.

The question was asked of the respondents if they have felt any negative reactions from others toward their narcolepsy. Their response was positive from all respondents. They referred to their experiences as negative, sarcastic, stigmatizing, embarrassing and unfair.

In this section I will explore the experience of image of "self" and the public life of the persons with narcolepsy. Among the 53 respondents all but three admitted that they almost always hide their narcolepsy from strangers or people that they do not know well due to the stigma that they feel is attached to their disorder.

A 21-year-old woman talked about her experience with stigma. "Life with narcolepsy is somewhat of a delayed life. You cannot be as responsive as you want to be or are expected to be. Narcolepsy has given me procrastination which makes it very difficult at work. People give me looks such as 'what is wrong with you.' I do not tell everybody that I have narcolepsy, but even the ones who know it treat me like, 'Leave her alone, she has that lazy, sleep disease.' You can see it in their looks;

it is a stigmatized look for lack of ability to be alert all the time. It is not fair. It hurts." To fight the stigma, most respondents withhold information about their disorder from the public. They feel, inasmuch as their disorder is not an obvious physical handicap, they may seem "normal" to the eyes of others by withholding information.

#### NARCOLEPSY AND STIGMA

In working with persons with narcolepsy over the past few years, I realized that most often they refer to their disorder as stigmatizing or to themselves as stigmatized. Therefore, I decided to examine the concept of stigma.

According to Erving Goffman (1963), society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories.

When a stranger comes into our presence, first appearances are likely to enable us to anticipate his category and attributes, his "social identity" or social status. We lean on these anticipations that we have, transforming them into normative expectations. As Goffman (1963) indicates, while the stranger is present before us, evidence can arise if his possessing an attribute that makes him different from others in the category of persons available for him to be; and if he is less than desirable

he is reduced in our minds from a whole and usual person to a tainted and discounted one. Such an attribute Goffman calls stigma. Goffman does not believe that all undesirable attributes are at issue, but only those which are incongruous with our stereotype of what a given type of individual should be. The term stigma then is used to refer to an attribute that is deeply discrediting.

A 30-year-old man, mortgage broker, talked about his experience. "When I first moved to New York, I lost the first two jobs I had: I was falling asleep at work. Having narcolepsy you are doomed. You do not know if you should tell people or not. If you don't tell them, they think you party all night or you are on drugs. When you tell them about the narcolepsy they look at you with a very stigmatizing look. They think you are weird."

Erving Goffman describes this as social information; the information of most relevance in the study of stigma that has certain properties. It is information about an individual, about his more or less abiding characteristics as opposed to the moods, feelings or intents that he might have at a particular moment. This information, as well as the sign through which it is conveyed, is reflexive and embodied; it is conveyed by the very person it is about and conveyed through bodily expression in the immediate presence of those who receive the expression; information possessing all of these properties that he calls "social."

Some signs that convey social information may be frequently and steadily available, and routinely sought and received. These signs Goffman calls "symbols." The social information conveyed by any particular symbol may merely confirm what other signs tell us about the individual, filling out our image of him in a redundant and unproblematic way. However, the social information conveyed by a symbol can establish a special claim to prestige, honor or desirable class position. Goffman calls such a sign a "status symbol." The status symbol can be contrasted to stigma symbols, with a consequent reduction in our valuation of the individual.

A 21-year old college student shared his experience with me. "If I don't tell people it is because they tend to stigmatize me. I almost never tell people when I first meet them or when I have known them casually. The reason is because as soon as they learn I am "narcoleptic," you can see their facial features change, and it is like they look down on me. They see a six foot, 190 pound guy who is complaining because he wants to take a nap! To them this is not a sickness, it is a convenient thing. A lot of times when they hear about my problem they greet me with sarcasm. Yet there are other friends who know and they understand it much better than my own family. I suppose it has to do with how well they know me and how well they know that I am not lazy. So unless it is someone I really know otherwise, I do not tell them about my narcolepsy."

A 27-year-old woman also talked about her experiences with narcolepsy. "Narcolepsy is very stigmatizing because people look at it as a disease of convenience. There have been people who have said to me, 'You do not know what I would give to stay home.' Right now I am experiencing some difficulties with medication. I have been off driving and off work for a short while. I have been married for one year and my husband, who is very supportive, still does not understand at times. He says, 'You got it made!' What 27-year-old does not need to go out and work? Only if he knew how badly it hurts me not to be able to be active. There is no pleasure in sleeping all the time, there is no pleasure in not being able to be active and not to work. There is no pleasure in losing control of your body when you are excited. Yet he thinks I have it made because I have the disease of convenience."

Most respondents, except for three, said that they hide their narcolepsy from the public. Their strategies of managing information depended on the situation and relationship that they would come across. For example, later on in the chapter I will discuss the withholding of information from Motor Vehicles, place of employment and similar situations. Withholding information in situations where others might be predisposed to criticize or stigmatize was a common factor among the respondents.

### NARCOLEPSY AND EMBARRASSMENT

Erving Goffman in *Embarrassment and Social Organizations* (1956) defines a social encounter as an occasion of face to face interaction beginning when the individuals recognize that they have moved into one another's immediate presence and ending by an appreciated withdrawal from mutual participation. Embarrassment has to do with the figure the individual cuts before others felt to be there at the time. The crucial concern is the impression one makes on others in the present.

When the question was addressed to the respondents as to why they feel embarrassed with their disorder, the response was that the embarrassment, they feel, is due to lack of control over their physical appearance at all times. "The urge to fall asleep in inappropriate situations makes me look like I am never in control." This was expressed by a 30-year-old man who grew up with narcolepsy from puberty in the Dominican Republic. As he described his experience, "Growing up in my teens, I was always very embarrassed to be sleepy. Doctors in our family knew something was wrong with me but they did not know what. I was put on all types of vitamins but I was never very alert. I was very aware of my potentials but I could not stay awake. People considered that as laziness. I began to adopt two faces in life, my regular face (self) that I knew myself, and the face (self) that others thought of me, "the lazy

and stupid." My most embarrassing experience was when I fell asleep in the middle of slow dancing with a girl who I liked a lot. I wanted to die of embarrassment. I will never forget that. The sad part was that all along I know there was something wrong with me and I was not a stupid or lazy person. If I was only treated for my narcolepsy it would not have affected my young life like it did."

The act of sleep by itself, in public, for any individual is considered an embarrassing act due to "loss of control." The disfiguration, the mouth hanging open, the neck hung forward or to the side is considered a violation of expected behavior in public. Therefore, afflicted persons with narcolepsy who fall asleep in inappropriate situations are subject to embarrassment routinely.

A 21-year-old college student described her experience. "I was somewhat of a shy person, but when I began falling asleep all the time I became very self-conscious, especially when you know you fall asleep and everybody is looking at you. After all, the act of sleeping is very private, but when you have a sleeping disorder you have no choice. That is why in my whole adolescent stage of the imaginary audience, I was very self-conscious. I kind of kept to myself. I had a few friends, but I stayed away from the guys a lot, because I thought they wouldn't like me.

Another young man, a 21-year-old college student, described his experience as a constant embarrassment. "My sluggishness, which is associated with narcolepsy, made me look non-alert in the mornings. Just because I was not alert, people thought I was on drugs. My friends used to ask me if I had a hangover. When I would tell them I was tired and sleepy they would say, 'Yeah, you're right, you are only sleepy!!!'"

An 18-year-old describes her experience; "Having narcolepsy is a continuous battle. You are always fighting within yourself not to fall asleep. Yet this is a battle where you are always the loser. Sleep is always stronger and takes over you. You end up falling asleep and embarrassing yourself in front of others.

The embarrassment felt by the respondents is due to the inability to assume and carry through normal tasks of life without interruption of episodes of sleep attacks and napping which makes them different than others.

One of the main concerns in this research study was to examine the limitations and impact of the disorder on afflicted individuals.

To examine the question of limitation I was to go beyond the recognition of the symptoms and the disease recognized by the world of medicine and examine how the disorder fits into the everyday life of a child, adolescent and young adult.

The areas that this question addressed are as follows: Narcolepsy and teens, narcolepsy and school and education, narcolepsy and sports, narcolepsy and work, narcolepsy and driving, narcolepsy and relationships, narcolepsy and family.

### NARCOLEPSY AND TEENAGEHOOD

The transition from childhood into adolescence is called the "teen years;" the rough phase of intense physical, emotional and social change where the child is becoming an adult. Most often teens struggle with tough and painful questions about their figures which are rapidly changing, and in some cases they are worried that these changes are not enough. They worry about being tall or skinny enough. They question their identity as to whether they are a child or an adult. They question whether they are attractive to the opposite sex and whether or not they are going to be successful in the future.

Harris and Reynolds (1990) define adolescence as a trip through Alice's looking glass, where things do not appear as they are. Between the two ends of the normal adolescent spectrum is a wide range of feelings and actions that constitute a teen's normal, sometimes predictable or uncomfortable development. Teens stretch and test limits to develop. Insecurity and fear of inadequacy are part and parcel of the normal course of development for adolescents. Teenagers have enough difficulty establishing identity and self worth without being affected by an ailment. A chronic disorder can be devastating to the teenager who is forming his personality to become an adult.

Some chronic disorders have the tendency, especially at the beginning of the discovery of the

disorder, to become the person's identification and play the role of the status attached to that person's life. This can not only affect the way the person is treated, but also the way he thinks of him/herself and can influence his/her whole personality. This is particularly important during the childhood and teen years; a child is not accepted unless he is just like the other kids.

Chronic disorders, if not handled right, can affect self dignity and self worth, and the person may be faced with difficulties in social, educational, economic and psychological aspects of life. The difficulties arise from public expectations and opinion rather than from the person's medical condition.

Going through teenagehood with narcolepsy is not easy, as described by a 24-year-old woman who was diagnosed at age 13. "As I was growing up, around my teen years, the time that I needed to be most alert and sharp, narcolepsy hit me. My narcolepsy is very severe. Unless I am on heavy duty medication or I am very busy and stimulated otherwise, I fall asleep all over, in the subway, in the car, or watching television. Going on class trips or going to a museum was the worst. I remember going to Great Adventure Amusement Park with my friends and their mothers. God, it was torture. You must look interested, yet you cannot help but fall asleep. The parents of my friends thought I was either on drugs or antidepressants and that

was why I could not stay awake. You can't imagine what that did to my friendships. Some of the parents did not want their daughters to be associated with me, unless my mother would tell them the truth about my narcolepsy, which by itself was very stigmatizing. A few of the parents told their children how weird my disorder was. They also thought that my mother, who also had narcolepsy, was weird and they were told not to hang out with me. You cannot imagine how it hurt not to be like others. I wanted to be active like others. To not fall asleep was my dream. It was extremely difficult to stay up, tough even if I was at Disney World."

Douglas and Powell (1986) described "adolescent" as a generic term for a group of young men and women who no longer are children yet are short of adulthood. They inspect their bodies feature by feature, wondering "what kind of person I am?" They spend considerable time inventorying their talents and traits; to what extent are they athletic, smart, sociable, dominant or amusing? With older teens these questions focus on issues of identity and occupation: Who am I? What am I going to do? Where am I headed? According to Douglas and Powell (1986), this constant inward looking results in periods of obsessive dissatisfaction with the self, even among those with the least to complain about.

Among the chronic disorders, narcolepsy is the most misunderstood. The lack of public awareness and its stigmatizing potential due to its primary symptom of sleepiness labels the afflicted individual as lazy and non-alert. For many, coping and social acceptance and self confidence becomes a lifelong struggle. Among the respondents interviewed, all except two who were below the age of teenagehood said that their experience with narcolepsy in their teenage years was very difficult, especially before their diagnosis was made; years that some remembered as being labeled as lazy, sleepy and effortless persons.

For the remainder of the chapter I will focus on some of these experiences with school, college, sports and driving.

### SCHOOL AND NARCOLEPSY

Unlike other chronic disorders, such as epilepsy, that the public response to an attack is a "fearful emergency," the public reaction toward a narcoleptic attack (falling asleep suddenly) is laughter.

Culturally speaking, perhaps this is translated as: First: The act of sleep is a private act, the same as sexual acts, and is supposed to be taking place in privacy. Second: As mentioned previously, this may have to do with disfiguration during sleep (head hanging forward or to the side with the mouth open) in public, with no control over the body. Embarrassment followed by irritability and lack of tolerance for frustration pushes these adolescents and young adults with narcolepsy to isolation.

A student who was diagnosed at age 14 discussed her experience with narcolepsy and school. "The most embarrassing experience that can happen to you is when the teacher calls on you and everybody is looking at you and you are asleep. When you wake up and you see all those eyes looking at you, you just want to die. A few times I got into a cataplexy attack, which was the worst because everybody laughs at you. The more they laugh at you, the more you stay cataplectic. I remember one of the teachers asked me a question that he had covered within that last half hour and when I could not answer, he got quite upset with me. My problem at school was that nobody took my problem

seriously. I don't think they actually believed me or my parents. Sometimes I wished I had another disease, because with narcolepsy you take pills not to fall asleep, yet no one thinks you have a serious disease and they think you are only lazy."

A mother of a young college student with narcolepsy who was diagnosed at age 13 talked about her daughter's experience with narcolepsy. "In our culture if you have narcolepsy you are a burden, especially at school. if you need to take a nap with a note from the doctor, they don't know what to do with you. The remarks I used to hear from the school nurse and the teachers were like; 'This is not a hospital, this is a school.' 'You come here to learn, not to sleep.' Half of the time they think you are faking your sleepiness to get away from studying. As my daughter used to tell me, when you wake up from a 15 minute nap you feel guilty. When you go to the class, everyone looks at you. Our society is not sympathetic because sleeping during the day means laziness, even though sleeping is your disability it is still considered laziness."

Talcott Parson's (1975) view of sick roll fits perfectly in societal perception of narcolepsy. The sick person is considered deviant and is expected to get better. The only way that the sick person can escape the stigma of deviance is in the attempt to recover. Failure to make this attempt implies that the person is exploiting illness or malingering, in order to escape social responsibilities.

A mother of a 19-year-old student who was diagnosed at age 12 talked about her son's experience with narcolepsy. "Narcolepsy is a stigmatizing disease. My son never wanted to talk about it. He always missed the train going to school. Although I would wake him up early in the morning he would fall asleep all over, in the bathroom, in the kitchen, while eating his breakfast. Going to school in the morning was a battle. He then would get to school late and fall asleep in the class. Several times I tried talking to the principal and the teachers. Even after diagnosis the teachers still ridiculed him. Narcolepsy is a very stigmatizing disorder; no one takes it seriously and everyone blames you for sleeping. At one point I asked for a video from one of the associations and asked the teachers to see it. I am not so sure if that played any role or not, but my son was not laughed at as much as he used to be. He finished high school, but the high school years were the toughest for him and for all of us. It was hell."

Children with narcolepsy often suffer from lack of attention span, inability to concentrate, excessive drowsiness and fatigue. They attempt to hide their symptoms because they don't know how to deal with it. They cut school because it is a heavy burden to be alert during the active hours of the day.

Working as a counselor in the Sleep Center, recently a grandmother who is a legal guardian of an

8-year-old girl with narcolepsy came to me and complained that her granddaughter, all of a sudden, if not sleeping, fights at school. I decided to talk to her. I was surprised to hear this inasmuch as I knew her as a shy, quiet, 8-year-old girl. When she was asked why she picked fights at school and broke three eyeglasses in one month, she replied, "I like to be bad." When I asked her why she liked to be bad, she said, "I do not fall asleep when I am being bad." In her own little world she had discovered a way to be stimulated and avoid falling asleep. She had also been the subject of teasing and laughter. This was helping her to get back at them and be the center of attention.

Children with disabilities or chronic disorders are most often the subject of teasing and harassment, which makes them become isolated and secluded in their environment.

A 16-year-old student who had felt her narcolepsy symptoms since the fourth grade yet had not been diagnosed until the seventh grade shared his experience with me. "Instead of having narcolepsy, you kind of wish at times you had another disease because people would feel sorry for you. Narcolepsy slowed me down at school. I could not play sports because of my cataplexy. Other kids thought I was lazy. I would sit and look at them while they were playing ball. They did not know how much I wished to be part of

them. I still wish to be part of the crowd, yet I can not.

Another student shared her experience with not being able to socialize. "My grades were high before I started falling asleep. They did not fall too much, but the amount of time I spent on homework went up tremendously. I spent almost all of my waking time working. Overall, I think narcolepsy delayed me somewhat in life because I'm a kind of person that likes to know what is going on and when you're asleep and you do not see people's reactions toward you, you can imagine some pretty awful things. I was so embarrassed with myself and had very low self confidence/self-esteem. Therefore, in order to make good grades I did not socialize and tried to catch up with my sleeping hours. When you have narcolepsy, people think you are a procrastinator, yet is your narcolepsy that makes you slow. You are not really slow."

Narcolepsy's primary symptoms begin in early adolescence with the onset age of puberty. Broughton and Broughton (1994) suggested 6% of individuals with narcolepsy begin to have symptoms before the age of 10. It is also being suggested that 60% of narcoleptics begin to be symptomatic between 15 and 30 years of age. Thus, the teachers at school play an important role, first in identification of this disorder before the diagnosis is made, when the initial problem of sleepiness occurs and second, in understanding the disorder and identifying the

emotional stress that narcolepsy puts on an adolescent's social life after diagnosis.

Another student shared her high school experience with me. "In junior high school I told my teachers about narcolepsy. I do not know to what extent they believed me. I know some did because they helped me out, but others who never took my problem seriously were very sarcastic. I remember numerous times waking up to the sound of laughter. They were laughing at me for falling asleep in my chair."

Broughton, et al, in the study they conducted in 1981, reported that more than one half of narcoleptics believed the symptoms caused poor performance in school and over one third of patients attributed interpersonal conflicts with teachers to narcoleptic symptomatology.

Another young man who noticed his symptoms since age 10, yet was not diagnosed for a long time, talked about his experience with school. "I do not fall asleep everywhere, but my problem is concentration. I went through high school. I do not tell many people this, but I was left back one year in eighth grade. I slept in school a little bit, not a whole lot. It was the lack of being able to keep my mind focused. Had I known, and had I been diagnosed with this earlier, my life would have been different. You see, I was generally an ambitious boy. I cared what happened to my future, and when you are like that and you do not know what is wrong with you, you

suffer. That is why I think all kids with narcolepsy should be spotted and diagnosed. The earlier they know, the less stigmatized and lost they will be!"

Children and adolescents spend their most active hours of the day at school for nine months per year. Therefore, the teacher's role in spotting kids with problems, especially sleepy, irritable children with lack of concentration, is very important.

In this study, among 53 participants, four were spotted by teachers at a very early age. However only two were diagnosed soon after, the other two were misdiagnosed as having ADD and depression. Among the 53, 49 remember having conflicts with teachers throughout school years and being misinterpreted as lazy, indifferent and even malingering. This attitude was continued even after teachers were informed that these kids had narcolepsy.

Children with disabilities and chronic disorders have different needs. Although they have the same needs as other children, they need more support and understanding. In order to understand their difficulties and adjustment in life, one has to put oneself in their shoes to see the world from their point of view. As one 13-year-old told me, to pull your grade level from C to B may not mean that much to other kids or teachers. However, for a child with narcolepsy, pulling grades from C to B means giving up all social activities and free time. It means no socialization

and no television or other activities. That is why it is important that both teachers and family reward and recognize every little effort that a child with narcolepsy makes to improve his/her performance. Cataplexy also interferes with the daily performance in these children and adolescents. Fear of laughter and falling to the ground makes them avoid public appearances. As one student shared her experience with me; "All through high school I had cataplexy attacks. I was a subject of laughter and it was not easy to sit in a corner and have others put me down. One year I decided to go on a panel with other people who had learning disabilities and talk about narcolepsy. My biggest challenge was the fear of having cataplexy in front of the whole school. I did it. When I addressed them I said that my problem was falling asleep or falling down when I laugh. I also said that this was my disorder, not my fault. I remember saying to the crowd, 'Hello, do you understand me?' This is not my fault, this is my disorder. I did not want them to feel sorry for me or pity me in any way. I wanted them to know that I just have a disability."

Quite often kids with disabilities are given a grade and passed to higher levels without having to recognize their potential or interests. As one mother described her son's experience; "He was always a good child and very creative, yet I was told that he might have perception problems. We took him to a special clinic. They

confirmed a perception problem yet no one suggested narcolepsy. He went through high school and graduated, yet had he been diagnosed earlier he may have gone to college. The school assumed that, because of his perception problem, he is always going to be limited in his accomplishments. Had it not been for a few car accidents in the last couple of years, he would never have been diagnosed. He now has his own business, making wooden door frames, and he is very successful. Yet I wonder, if we had known that he has narcolepsy, if he could have combined a college education with his creativity, it would have been wonderful."

Narcolepsy's symptoms require special care, such as napping, taking medication at school, having supervision when working with machinery, and at times being exempt from sports or other activities if the individual's narcolepsy has not been managed by medication.

However, children and adolescents afflicted by narcolepsy are not required to go to special schools unless their health is impaired by other illnesses or physical handicaps. Yet due to lack of awareness, especially among teachers, not knowing how to deal with this disorder and its limitations, these children and adolescents can be pushed aside and labeled as underachievers and lazy. It is very important to note that children and adolescents afflicted with narcolepsy can accomplish anything, like any normal child and adolescent, once their narcolepsy is treated and managed.

Working in the Sleep Disorder Center, I have come across two cases where children were the subject of disputes to be sent to special education schools.

The first case, a 13-year-old boy who was diagnosed three months earlier and was slowly being treated due to complications with medications.

The second case, a 7-year-old who had been diagnosed shortly before the dispute.

When I was notified by the parents, in both cases appointments were made and I met with the school principal, nurse and teachers. The nature of the disorder and its symptoms and gradual treatment plan were discussed. Material was given to the school staff to be read. As a result both kids remained in the schools and were given permission to nap as part of their treatment plan, where before they were having a tough time being sent to the nurse's office to take naps. They were also allowed to have extra time to complete their exams if needed. Therefore it is extremely helpful when parents of children and adolescents with narcolepsy educate themselves about narcolepsy and its symptoms and limitations. After all, when they are educated about narcolepsy not, only can they educate others like teachers, but also they can discourage having their children labeled as underachievers. They also at times can spot unrelated problems if they occur.

Next to family, the teacher's role is the second most important in the life of an adolescent with

narcolepsy, as to how they can cope and manage their academic and social lives.

In general, the most helpful hints for parents and children with narcolepsy are:

1. Awareness and support of the child's potentials in his/her favorite subjects.
2. Help and possible avoidance of boring subjects where the child shows lack of interest.
3. Communication between parents and school staff, i.e., teachers and school nurse and guidance counselor.
4. Tape recording important lectures and classes so the child can listen to it later on.
5. Encouraging the child to study with other friends or study groups.
6. Permission for the child to take one or two naps per day during exams.
7. Permission for extra time for the completion of exams.
8. Building self confidence and self esteem in children and adolescents is extremely important as to how that person may perceive her/himself in the future.

All of the above suggestions can be supported through communication with the sleep center or health care professionals who could request and help with the documentation necessary for school and national exam committees.

### COLLEGE LIFE AND NARCOLEPSY

Similar to those experiences of high school students, college students with narcolepsy also feel the burden of their disorder in their everyday activities. The prospect of entering the college for any individual is exciting, yet for individuals with narcolepsy this prospect is shadowed by a great deal of uncertainty. As described by one college student with narcolepsy; you are not sure if you can handle the pressure and the fast speed of college life. Most often individuals with narcolepsy wonder if they could make it through. Persons with narcolepsy are more likely to hide their disorder at the time of completion of their application. This is due the fear of discrimination and not getting accepted. Among the 53 participants interviewed, 34 had applied to college and only two had indicated that they have narcolepsy. One of the participants had voluntarily included a support letter from her physician indicating what narcolepsy is. They both were accepted to the programs that they had applied for.

Besides the process of admissions, what worries persons with narcolepsy is the uncertainty about not having enough energy to fulfill the requirements of both academic and social life of college which seem to be inseparable. In Laura Pendon's study (1994) of 100 freshman college students, she argued that college students' rate of success is greatly affected by their involvement in campus academic

and social life and developing positive attitudes about their learning abilities.

Among the 34 respondents who had gone to college or were in college, 33 said that having narcolepsy makes it very difficult to be both good students and have other activities such as being part of sports or social clubs.

As most of the participants indicated; unlike others, students with narcolepsy require napping and they must avoid early morning classes. From the eyes of others napping seems to be very strange for a young adult of 18 or 20 years of age.

As a 19-year-old student shared his experience with me; "When you nap after lunch and when you nap in your room in the afternoon and sleep early at night, yet you cannot get up and go to early morning classes your roommates and friends think you are weird. Very often they would ask me if I was on drugs or if I were depressed. I felt better when I told them, 'No I am a narcoleptic!'"

Almost all respondents had comments similar to this. They most often said it was impossible for them to party like others and attend classes the next day. Therefore, soon enough they would learn to either be sociable and lose academically or do better academically and be labeled as weird or depressed or tell the truth.

An 18-year-old freshman shared her experience with me. "When you have narcolepsy you always have to be aware

of your body limitations. You cannot party like your other college roommates. At the beginning of my freshman year I was very careful, but as time went on the peer pressure started to build up. You get invited to parties and you are supposed to be like others. I remember one weekend, after partying on Thursday and Friday nights, I couldn't get out of bed on Saturday. I was sleeping and experiencing hallucinations. My roommate must have heard me and woke me up. Seeing her like that upset me so much that I got into a cataplectic attack and became fully paralyzed. My roommate and other girls on the floor who did not know I was narcoleptic gathered around me. The more excited they became the more cataplectic I became. They called Security and called an ambulance. Luckily, someone called my Mom who lives 15 minutes away from campus. She rushed in and took me off the stretcher and told everybody that I was going to be O.K. She took me home. I was so embarrassed that I didn't want to go back on Monday. I was so depressed because everybody found out about my narcolepsy. Yet I learned a lesson; I couldn't party, drink and be a successful student. I had to choose. Having narcolepsy makes you very strong because you must look after yourself at all times. You can't take anything for granted because your ability is very limited.

All of the respondents noted very similar experiences. Their experiences with party life and

specifically with the consumption of alcohol and lack of tolerance was unbelievably negative. It seems that alcohol not only makes them tired but also the hangover gives them severe EDS, sleep paralysis, cataplexy and hallucinations. The comments among respondents on alcohol consumption confirmed the rebound attacks and weakness that lasts for a couple of days. Another aspect of college life is the inability to maintain alertness over all subjects and classes. Students with narcolepsy remain more alert while they are stimulated and interested in the subjects that they like versus subjects that are boring, or subjects that have no interest for them.

A 19-year-old college student who was diagnosed at age 17 talked about his experience. "I think I would have been much more confident without my narcolepsy. For one thing I would have had much more friends. When you have narcolepsy everything is self-doubt all of the time. I am always doubting myself because I don't know if a minute ago I was alert enough or not. I always set limitations for myself because of lack of self control. I was an engineering major. I switched to biology. I wasn't very sure if I could make it as an engineer; it needs a lot of concentration and dedicated work. I am now trying to get into neurobiology. I may have a better chance of making it because it is more motivating and interactive than engineering."

Being aware of one's own potential and motivation is extremely important. To choose what you like and at the same time choose what is interactive and keeps the person stimulated is something that must be faced. As one premed student who was diagnosed at age 14 talked about her experience; "Living with narcolepsy can be tough but you always have to push yourself. Mornings are the toughest for me but I get by. It gets easier as times goes by. Although having narcolepsy does not leave time for anything else but studying you must motivate yourself, because the accomplishments at the end pay."

Another 24-year-old who graduated at age 23 shared her experience with me. "All of my life I dreamed about going away to college. My dream was to go to San Diego and study microbiology. Because of my narcolepsy my parents discouraged me. Instead I stayed with my sister and her husband in New Jersey and went to a business school. Actually, the support that my sister and her husband gave me made me very successful. So you really can not let narcolepsy ruin your life. You must make it. You must win over narcolepsy's limitations."

My personal experience at the Sleep Center has involved me on a few occasions to contact national exam committees such as SAT, GRE and law exams and request nap time for students with narcolepsy. The response has always been positive from the committees. Our goal should be

toward an establishment of national laws that recognize such needs. Once such laws are established this no longer will be perceived as favor, and will be recognized as a right of a student with narcolepsy.

The following are suggestions that can be used as general guidelines:

1. Choosing and being aware of areas of study can be most helpful to maintain students interest in college and future profession.
2. Avoid boring lectures and courses if at all possible.
3. Communicate with instructors and guidance counselors so you can receive the most help.
4. Tape record all important classes so you can listen to them later.
5. Avoid early morning classes or early afternoon classes if possible.
6. Study in study groups or find a study partner.
7. Tell your roommate or your close friend about your narcolepsy.....cataplexy so when you need help they will know what to do.
8. Be aware of your body limitations and maintain your sleep hygiene and nap time.
9. See your physician routinely especially if you are taking medication.
10. Join a support group at least once a month to know that you are not alone.

### SPORTS AND NARCOLEPSY

Life in America is very much exposed to sports. American children are brought up influenced by parents to participate in sports. Schools promote sports for better health. The media constantly advertises for sports, so overall sports is a big part of American life. Involvement with sports among individuals with narcolepsy depends on the severity of the problem, especially for one with moderate to severe cataplexy. If an afflicted individual does not have a severe case of cataplexy he could be involved in sports. Actually it will stimulate the kids.

A 16-year-old high school student shared his experience; "I play sports not to fall asleep. I play basketball up to 2-3 hours a day with my friends. I have no problem with that. Actually I feel very good about myself because I am like others and I am not falling asleep. However, as soon as I try to play in a real match at school with other teams, my cataplexy acts up. Because I get emotional and excited I fall to the ground. But my friends think that I get scared of other teams. They tell me you play so well with us, what is wrong with you, are you a wimp? It hurts, but it is the excitement and emotion that does it to me. After all who could play in a match without getting excited?"

This seems to be very common among people with narcolepsy who suffer from cataplexy. A 23-year-old

graduate student who was diagnosed at age 16 talked about his experience. "Luckily, I was never into sports that much. One sport I really miss is swimming. I used to enjoy swimming. After my cataplexy was formed I was no longer able to swim. I have a severe case of cataplexy and if I became cataplectic because of excitement I could drown. If I am in shallow water and someone is with me I can swim a little. However, moving around in the water gives me more cataplexy attacks."

Many persons with narcolepsy reported experiencing cataplexy with swimming in water, even those persons with well controlled narcolepsy. Whether this is due to excitement or it is the activity in the water that makes them cataplectic is not clear. However, since cataplexy attacks start with the loss of muscle tone they may suck in water. They must be sure that someone else who is capable of pulling them out of the water is with them.

Most persons with narcolepsy report that exercise makes them very tired. Where others may be pumped up, they are required to take a nap.

Interviewing adolescents, most expressed their sorrow for not being able to be part of the team at school. A 21-year-old college student who was diagnosed at age 14 described his feelings. "At first, when I was diagnosed I was O.K. with playing sports. However, when my cataplexy was formed, I became cataplectic each time I played on the team. My parents were trying to help me to calm myself down

and play, however, the school authorities informed my parents that I no longer was able to play due to liabilities. They banned me from playing sports. I didn't challenge them because my cataplexy was getting worse. It was sad. It still is, but it is part of my life that I have to accept."

Not being able to play sports due to cataplexy and not being motivated enough to exercise are two different things that the person with narcolepsy and parents of kids with narcolepsy must be aware of. A 19-year-old college student talked about his experience. "I was diagnosed when I was in high school. I played lacrosse and soccer for many years. I also mountain biked. I do not have cataplexy but I have severe EDS (excessive daytime sleeping). Soon after I was diagnosed with narcolepsy I began feeling depressed. Sports made me tired yet I did not know whether it was my narcolepsy or my depression that took away my interest in sports. What narcolepsy did was to make me less motivated to be in sports and even in playing an instrument (I used to play the conga). I just lost interest. Now in college, I try to motivate myself. I no longer play lacrosse nor soccer but I mountain bike."

To identify the source and lack of interest in activity is crucially important in the life of a young person with narcolepsy. Motivating the child or young adult or helping them choose a sport or hobby can lead to more self-esteem and confidence.

The type of sports that are chosen by adolescent and young adults with narcolepsy can be directed and supervised by parents or family members. A 20-year-old college student talked about her love for ice skating. "Before my diagnosis with narcolepsy I used to go skiing and ice skating with my family a lot. After my cataplexy started, my parents were very afraid to take me skiing or let me ice skate. I gradually got used to the idea that I can no longer play those sports. I eventually replaced them with walking and aerobics."

The cultivation of good health habits is associated with sports and exercise. Therefore motivating the young adults with narcolepsy to choose a sport that they like yet is safe, is essential to prove that they need not to stop living an active life. Staying away from sky diving, motorcycling or swimming in deep water alone does not mean one has to stay away from good health habits and exercise. Among the respondents interviewed, the ones who were actively involved in sports said they feel much better when they exercise regularly. As one mother mentioned; rather than keeping my son at home indoors which makes him sleep due to boredom, I take him by the water yet I make sure that he wears a light weight life jacket that person into a potato. An active life is a tool to fight narcolepsy. "

### DRIVING WITH NARCOLEPSY

Operating a motor vehicle is always a risky business. Every year hundreds of thousands of people are injured in automobile accidents. It is obvious that a person who might suddenly fall asleep while operating machinery or at the wheel increases the risk; although, as indicated by Dement and Baird (1977), the accident rate of diagnosed patients with narcolepsy is lower than that of normal drivers. I was very interested in examining issues regarding driving and narcolepsy.

1. To review the regulations regarding driving in the United States.
2. To review the experience of individuals with narcolepsy and driving.

#### Driving Regulations in the United States

Unlike Canada and most European countries. The United States does not have a national law regarding public safety and drivers licenses. The laws differ from state to state. The laws regarding narcolepsy and drivers licenses and restrictions not only vary from state to state, but while conducting this research I realized that several motor vehicle agencies were not sure what narcolepsy was and if there were any restrictions to be followed. Most states, however, refer you to follow the restrictions under epilepsy and seizure disorders, although narcolepsy has nothing to do with seizures.

Canada offers a general restriction throughout the country which is indicated in their Physicians Guide to Driver Examination (1987), "Applicants subject to attacks of narcolepsy can not drive any type of motor vehicle safely." If they respond favorably to treatment and have had no periods of uncontrollable sleepiness for a period of three months and are experiencing no side effects from medication, they can then drive private motor vehicles safely. Applicants with narcolepsy, whether adequately treated or not, cannot drive passenger transport or heavy commercial vehicles (class 1, 2, 3 or 4 license) safely because of the risk of a crash, should they run out or neglect to take medication, is too great to accept.

In this research study, among the 53 respondents, 45 were above the legal age to drive at the time of this interview. Of those, 40 had a drivers license and 5 had never applied to get one yet. Among the 40 with a drivers license, all but one said they hide their narcolepsy from the authorities. Three individuals were reported to Motor Vehicles without having a choice or having a bad driving record by their physicians. When the question was asked why they hide their narcolepsy, five responded that they never drive despite the fact that they have a drivers license. The remainder of the respondents said they hide their narcolepsy because it is very stigmatizing and they did not want to be labeled. They also said they were

afraid of not being able to renew their drivers licenses. This factor seemed to be the biggest fear especially among male respondents.

On the other hand when I asked the 23-year-old man who had voluntarily notified Motor Vehicles about his narcolepsy as to what motivated him to do that, he mentioned that falling asleep was not his biggest problem, it was cataplexy. Yet he decided to tell Motor Vehicle because unlike swimming, driving involves others too. He replied; "Once a year I get a note from my physician that reports on my progress. I never drive more than an hour. I stop and take a nap. My chances of having an accident are as much as anybody else, but my conscience is clear."

Having a car accident before diagnosis of narcolepsy is very common among young adults. It is so common that one of the questions clinicians ask at sleep centers at the time of evaluation is whether the person has had car accidents due to sleepiness? The following are replies of respondents to car accident questions:

A 27-year-old woman describes her experience. "I was having trouble in high school. I was in junior high school when it started. I was falling asleep in all of my classes. This went on without anyone finding out what was wrong with me. The doctors kept on telling my parents that I needed to get more sleep at night so I would not be sleeping during the day. I used to sleep eleven to twelve

hours yet fall asleep in the classroom during the day. A week before I graduated, I was on my way home at 1:00 o'clock in the afternoon and I got in an accident. I went across the road and hit a tree. All of the doctors said 'What are you on? Have you been smoking?' The police asked me if I was on anything. I kept on crying and telling them that I fell asleep. It never rang a bell! No one was even alarmed about it but myself. A couple of years later I was diagnosed and went on medication. Yet my sleepiness is so bad that even with medication I fall asleep. I take a nap before I get in the car. If I go anywhere, I do not stay for a long visit. If I do, I take a nap before I leave. I make a lot of stops. I do not drive very far at all. I drive five miles, which is far, or to the grocery store and back. I am aware of my limitations. I do not take a chance."

Another respondent, a 24-year-old man, talked about his experience. "Before I was diagnosed, I was excessively sleepy throughout the day, sleeping up to 18 hours a day in my free time. I was nodding out and sleeping through class. When I got my drivers license, I had trouble driving. Just before I was diagnosed I had a severe accident with my Jeep where I went through the windshield. I had to go to the hospital for head and neck injuries. They tested me for drugs and alcohol yet when I told them I fell asleep they ignored me. Even after that I totaled

four cars. My sleepiness is severe, especially if it is warm and I am driving. I am no longer taking any chances. I have been lucky in not killing myself or others. Right now I am on medication but even with the medication I take naps on the road. I am not going to risk my life or someone else's life and pay for the rest of my life. Motor Vehicles is aware of my condition and I need a note from my physician which indicates that I am on medication."

Another respondent's mother said that if it wasn't for her son's frequent car accidents, he would have never been diagnosed. As she described; "My son was diagnosed as having perception problems. We went to a specific clinic when he was 12 and he was diagnosed, yet we never understood why he slept too much. The physicians told us he sleeps out of boredom. Yet after a couple of bad accidents in the middle of daylight, without having any alcohol in his body I knew something was wrong. He was 24 years old, still sleepy, still bored? It had to be a sleeping disease. This was not boredom."

Although recently attention has been drawn toward sleepy drivers and safety issues and accidents, it is not fair to think all excessively sleepy drivers are narcoleptic. There are other conditions such as sleep apnea, shift workers, sleep deprived persons who have as much of a chance of falling asleep as a person with narcolepsy. Furthermore, like Canadians who have specific

regulations for narcolepsy and driving we need to advocate and obtain such regulations through legislators. Such regulations have their own benefits for individuals with narcolepsy. First of all, individuals with narcolepsy do not have to hide their disorder due to fear of not being able to obtain a license. Secondly, these individuals are not going to be labeled as epileptics or other ambiguous disorders that have nothing to do with narcolepsy. Finally, gaining an identity is a step forward in getting all the assistance and understanding one can get within one's society.

These are general safety guidelines for driving with narcolepsy:

1. Avoid long distance driving by yourself
2. Take stimulants before driving.
3. Make frequent stops and schedule naps.
4. Drive with a partner who can help you.
5. Do not take a chance. Do not drive when sleepy.

WORK AND NARCOLEPSY

From the beginning of life each individual occupies a number of social statuses, positions in the social structure of the society that are related to other positions. According to Lucille Duberman (1974) some statuses are consecutive. First we are infants, then school children, then college students, husbands and wives, parents and finally grandparents or great-grandparents. We also occupy statuses concomitantly: a man can be a son, a husband, a lawyer, a brother, a middle-aged person all at the same time. Each status is expressed in terms of a role, a pattern of behavior structured around specific prestige, rights, and obligations within a group. We define a person's role by the set of expectations for his behavior held by others and by the person himself. When we occupy a social position (a status) and perform the role appropriate to that status, we are responding to the normative expectations of others and at the same time we are stating our own normative expectations of ourselves and of those with whom we are interacting.

In order to understand the concept of normative and expectations in the work force one must look at the meaning of work within one's society.

In an industrialized society, work is a central focus of adult lives, demanding a dominant part of their time and energies from the moment they enter the work force

until the time, many decades later, when they retire. A very few people, such as inheritors of large fortunes, are able to escape the obligation to work. But for most others, work is a necessity, primarily because it meets economic needs but also because it provides social status, a sense of respect, a source of fulfillment, and a circle of friends and colleagues.

The meaning of work, however, has changed over centuries. From preindustrial societies, where labor was highly valued to the ancient Greeks, Hebrews and early Christians, who considered labor degrading but necessary.

Max Weber (1904), however, talked about a great change in social values concerning work. He believed that this great change came with the Protestant Reformation. He argued that the ideas of Puritanism had provided an impulse for the transformation from traditional society to the modern industrial world, in which disciplined labor is a fundamental basis of social and economic life. Puritanism, he argued, had elevated work from a painful necessity to a moral obligation, making it a valued activity and a source of self respect. Weber (1904) believed that these changes were made possible by Protestant thinkers such as Luther and Calvin who redefined the nature of work. They accepted the Old Testament view that work was a divinely imposed duty, but went further and claimed that labor was a form of service to God. Work was a "calling" and all who could

work, should work. However, since the Puritan ethic regarded luxury and self-gratification as sinful, the profits could not be spent on idleness or pleasure. The profits, therefore, were simply reinvested to make even more profits. Thus, according to Weber, the new economic form of capitalism was born. Whether Weber was correct in his belief that the Protestant ethic contributed to the birth of capitalism is a matter of longstanding discussion in fields of sociology and political science. However, there is no question that the ethic of hard work as a moral duty and a means of achieving greater rewards in the future is a basic feature of modern industrial societies.

Keeping the nature of work status in industrialized societies in mind, one realizes how difficult it can be for individuals with chronic disorders to become employed and maintain a job.

Narcolepsy's nature of excessive daytime sleepiness makes it very difficult for afflicted individuals to resume work. Unlike some other chronic disorders (non-obvious physical handicaps) persons with narcolepsy are able to find jobs if they hide their disorders from employers. However, quite often they aren't able to maintain their jobs due to:

1. Inability to be on time at work due to lack of ability to wake up in the morning hours.
2. Inability to remain alert during the day.

3. Inability to concentrate, lack of punctuality and making mistakes.
4. Memory impairment and forgetfulness.
5. Procrastination associated with narcolepsy.

As a 32-year-old man explained his experience; "Although my boss knows about my narcolepsy, I am not permitted to nap. Many days I will go to the bathroom and take a nap. It is the only way I can get my alertness back and be functional."

In this research study, among the 53 participants 48 had experienced working, five had never worked or they were below legal age. Of those 48 working 38 said they hide their narcolepsy from their employer and 10 said their employers knew about their narcolepsy.

A 24-year-old woman, an executive secretary mentioned, "I lost jobs before I learned how to write everything down. I used to talk to people at my first job and fall asleep on the phone not remembering what they had told me. My bosses were amazed how smart I was yet could not take messages on the phone."

A 32-year-old woman had a very similar experience. "At my job I used to work in the mail room. It was sort of funny because during a specific time during the day I would become slow. I used to put people's mail in different slots, everybody started complaining inasmuch as no one knew what my problem was. I would then check the boxes at my alert time to see if there were any wrong mail in the

boxes. I held the job that way but it was double work on my behalf. Sometimes I was there for long hours without any overtime just because I wanted to make sure I was not asleep while distributing the mail. Now I have learned that around certain times of the day, even with medication I am not going to do important stuff at work. I also will not get in the car to go for a drive. You kind of get used to your body's limitations even though you are on medication."

Lack of understanding and lack of making adjustment in the work force is nothing new to society. Karl Marx (1844) talked about alienation as people's sense of loss of control over their social world. Marx believed through work we create our world, our culture and ourselves. Yet he believed that people have become alienated from their work, thus separated from their products, from the natural world, from fellow beings, and from their own essential nature. He believed that the division of labor, the separation of economic activity into specialized tasks that are performed by specific people, where each person is forced to perform a particular, exclusive form of activity, make people use only a fraction of their talents. The manual and intellectual aspects of people's production tends to be separated. Work becomes an enforced activity, not a fulfillment of a creative urge. Marx's notion of division of labor has been debated for years. Whether we agree with his ideas or reject them, we have to agree that individuals in modern

industrialized societies are highly alienated, in the sense that they are separated from creativity and fulfillment of their needs. This alienation and inability is reinforced in greater detail on those who suffer from chronic disorders and have to deal with their handicap. Most often they find themselves in isolation, lacking the sense of belonging in the work force due to lack of understanding and support.

A young woman shared her experience with me. "When I dropped out of college due to my excessive daytime sleepiness, I decided to work. While at college I used to live at my aunt's. They used to call me 'Cinderella' because I always cleaned. Perhaps it kept me stimulated and kept me up. I thought that would keep me awake. So I decided to clean people's houses. I put an ad in the paper. At one point I had about 25 different clients. I was cleaning and driving, cleaning and driving. Sometimes I would take a nap but it was all right because I cleaned people's houses and at the time they were not home. I remember one day waking up at the top of a client's hardwood stairs, and she was at the bottom of the stairs looking for an explanation. I gasped and caught myself. My stomach had come up to my throat. I caught myself just before I fell down the stairs. She said, 'What is the matter?', I fell down and cried. I left her home crying. After that episode, I explained to everyone I worked for that I had narcolepsy. You could see the skepticism in

them, yet I had to tell them because I needed to take a nap."

Another 21-year-old woman talked about her experience at work and the limitations of narcolepsy. "I am a student studying child life. I work at a day care center, yet due to my severe cataplexy I decided that I should be honest and tell them about my disorder. After I told them, my supervisor decided that I would no longer carry children because they were afraid I might fall asleep or fall down while carrying children, though it never happened. I chose to go along with it because it was an added safeguard for me so that any liabilities or misconceptions would not occur. Although I would have liked to continue doing it."

As Goswami & Michael Thorpy (1991) indicated, narcolepsy patients, fearing a loss of employment, may try to hide their symptoms, a weary and stressful task within itself.

A 32-year-old mortgage broker from New York talked about his quality of work with narcolepsy. "My quality of work with narcolepsy is not as I want it to be, only from the aspect of procrastination and lack of goal setting. I lost two jobs when I first moved to New York because I was falling asleep. After a while of experience you learn to hold your profession and hide your disorder from others but the price you pay is you give up your social life. I have none. Like others who work in New York I commute, but work

and commuting is all I do. I have no energy like other people do. You try your best at work yet you have an empty life. It is a struggle."

Neala Schleuning (1990), in her book "Idle Hands and Empty Hearts" indicates that work is merely a means of earning a living rather than expressing one's self and one's connection to the community. The lack of work and understanding is very obvious.

Many persons with narcolepsy find themselves isolated in our society. The Americans with Disabilities Act (ADA) of 1990 (Public Law 101-336, 1990, U2, U.S.C.S. 12101 et) provides equal opportunities to qualified disabled individuals. In reality, in many cases individuals with narcolepsy leave their jobs professionally due to lack of self-confidence, guilt and frustration.

It is extremely important that persons with narcolepsy choose a career that is stimulating to them. It is also important that persons with narcolepsy avoid working with machinery that would be hazardous to themselves or others. Shift work with no gap for adjustment should be prevented. This makes them shameful of their disorder which furthermore makes them less self-assured and less self-dignified. They feel apologetic for their sleepy appearance.

Unless persons with narcolepsy become their own advocates, this societal discrimination is going to

continue. Unless the secrecy and denial is ended their lack of alertness is going to translate as being an underachiever.

Persons with narcolepsy can help their situation by becoming their own self advocates and demanding better living conditions and work regulations. Their special needs such as adjustable times of work and allowable nap times, as well as the use of bright lights in the work place can improve their work habits.

Finally, having to choose a profession that one likes and keeps him/her stimulated is the most important task in gaining a successful future with narcolepsy.

General guidelines for a healthy work atmosphere:

1. Choosing a career that is stimulating and desirable.
2. Avoid shift work with no gap for adjustment.
3. Avoid operating and working with heavy machinery.
4. Join a support group and talk about your difficulties at work.
5. Establish a good knowledge about disability and equal opportunities acts.
6. Do not remain in a difficult profession if you are not satisfied with your profession. It is never too late!!!

THE FAMILY AND NARCOLEPSY

When illness or injury affects a family member, it does not disrupt the affected individual's life only; it affects the total family. Although only one member of the family feels "sick," an entire family may experience a crisis together and feel "handicapped" by the ailment. This can be seen when a disabled child is born into a family or on the discovery of a degenerative disorder of a young member of the family or when a parent becomes injured or chronically ill. The crisis of an individual member disrupts the balance of the family unit. Carolyn Vash (1981), describes this imbalance as illness or injury that interrupts the physiological homeostasis of the affected individual, so they and their sequelae disrupt the homeostatic balances of the family unit. When disability occurs, the total family begins an adaptive struggle to regain its equilibrium. (See Vash 1981)

When parents are told about their child's disorder, they often experience guilt, shame, anger, embarrassment, sorrow and disappointment. The first and foremost question asked by parents is, "What did I do wrong?" The guilt feeling is the most foreseen aspect of parents' reactions toward their child's sickness or disability. In this research, 44 family members were interviewed, 36 of which were parents or legal guardians of children and young

adults with narcolepsy, five were the spouses of the respondents, and three were the siblings of respondents.

TABLE VI

Family Members Interviewed

Total Family Members Interviewed = 44

Mother Int'd	Father Int'd	Legal Guardian Int'd	Grand- mother Int'd	Grand- father Int'd	Wife Int'd	Husband Int'd	Sib. Int'd
25	8	1	2	0	3	2	3

When the question was asked as to how they reacted toward their children's disorder, most reported denial, anger, self blame at first and partial acceptance later, followed by burning curiosity as to why this had happened to their children and who was to be blamed. Once their curiosity was answered, they were able to help their children accept the disorder better.

A mother of a boy who was diagnosed with narcolepsy at age 16 shared her experience with me: "I didn't know how to handle the situation. At first I was happy that they finally found what was wrong with my son, but when the reality sank in I realized that this is a disorder of a lifetime. I think I was more depressed than my son, and because he saw me in that bizarre situation he became frightened and depressed. I think my biggest problem was not wanting to accept that my son had a chronic disorder. I kept on asking the doctor if it was possible that they

had made a mistake, because no one in the family had narcolepsy. However, once I began to accept the fact, I was able to help my son much better. Acceptance became easier for him, too."

Joseph Schneider's and Peter Conrad's (1983) study on epilepsy and parents of epileptics describes the importance of the parents' role in the discovery and acceptance of the disorder. In Schneider's and Conrad's study, parents were categorized into two groups. The one group with an "open" style that defined the disorder as first and foremost a medical condition, as something that, although unfortunate, must be "accepted," "managed," taken "in stride." They gave the children basic information about the condition, were willing to talk about it and about how the children felt. These were compared to the second group of parents, who adopted the "closed" style, who pursued an almost complete silence and denial that, ironically, told the children whatever your disorder is, it is "bad," "something we don't talk about." Children's earliest memories of how parents react to their diagnosis is seen to set the stage of how they themselves would interpret the harsh lessons about how to manage it as they grow older. (See Schneider and Conrad, 1983)

In general, parents' reaction toward their child's ailment depends on many sociological factors such as social class, ethnic backgrounds, religious affiliations, level of

education and financial status.

According to sociological literature, the two most important indicators among American families and health status are socioeconomic status and level of education.

(See Cockerham 1995)

Socioeconomic status (SES) typically consists of measures of income, occupational status or prestige, and level of education. Although interrelated, each of these measures reflects different dimensions of a person's position in the class structure of a society. In studies of health and illness, income reflects spending power, housing, diet and medical care; occupation measures status, responsibility, physical activity and health risks associated with work; and education is indicative of a person's skills for acquiring positive social, psychological and economic resources. (See Winkleby et al 1992, 816)

In this research, the two parental categories that were looked at were:

1. Income level.
2. Educational level.

Out of 44 family members interviewed, only 36 were parents and legal guardians. The siblings and spouses interviewed were not included in this analysis.

TABLE VIIParents' and Legal Guardians' Income Level

	Level of Income	No. of Families
Level I:	(\$0 - \$13,000)*	3
Level II:	(\$14,000 - \$28,000)	6
Level III:	(\$29,000 - \$46,000)	18
Level IV:	(\$47,000 - \$60,000)	6
Level V:	(\$61,000 and higher)	<u>3</u>
	Total:	36

\*Based on U.S. Bureau of Census 1990.

Census, Volume 26, No. 11, November 1991

TABLE VIIIParents' and Legal Guardians' Education Level

	School Years Completed	No. of Families
Level I:	(0-11 years)	6
Level II:	(12 years)	12
Level III:	(1-3 years of college)	9
Level IV:	(4 years college completed)	6
Level V:	(Graduate level or higher)	<u>3</u>
	Total:	36

Parents' "acceptance" and "openness" was highly correlated to the level of income and education. The higher their level of income and education, the higher their level of achieved acceptance was toward their

children's disorder. These families, soon after diagnosis, had concord capability to understand the disease, therefore they were able to give their children the comfort and support they needed to go through the initial impact of the crisis. These parents' level of understanding of the disease and its complex nature was good to excellent.

Another important factor in parental understanding of the disorder was information (articles, films, discussions) given to them by health care professionals (i.e. sleep centers, clinicians, physicians, polysomnographers) regarding the disorder at the time or soon after diagnosis. The more informed the parents had become, the less anxious they were. They were able to communicate their findings with their children.

As one mother described her experience when her daughter was diagnosed at age 13: "Although I had denied my daughter's disorder at the beginning, when I called back the Sleep Center and requested more information, they sent me a few articles and answered most of my questions. After all, I wanted to know if she was going to get worse or not?

When I received the articles, I read them, and those articles referred me to more information. I went to the library and got more information. I talked to my ex-husband and we discussed it with my daughter. She took it very lightly. She had so many questions, but we were there to answer them for her."

On the other hand, another mother said: "For days I couldn't face the fact that my child was not 'perfect,' and could not be a 'perfect person' in the future. Each time he asked me a question I cried. I called the doctor and told him I was very depressed about my son's diagnosis. He told me I should go and see a psychiatrist. I told him the reason I was depressed was because of my son's narcolepsy, and didn't know what was going to happen to his future. They did not offer anything more to me. I absolutely could not deal with it for months."

Barbara Katz Rothman (1986) in "The Tentative Pregnancy" talks about the concept of "perfect" children in the society. As she describes it, "In this value system, in this developing ideology, we are learning to see our children as products, the products of conception. Even while they still move within us, they are not part of us. We have learned to see them as other, as separates, as products. We work hard, some of us, at making the perfect product, what one doctor calls a "blue ribbon baby." Therefore, to not have a healthy child, to some parents, may mean that these children are less, or imperfect, and it is not surprising when parents feel denial, disappointment and depression when their children are diagnosed with an ailment." (See Katz Rothman 1986).

For most families, the fear of the unknown is the most disabling experience ever. Barbara Brown, in her book

"Between Health and Illness" described the importance of information. She believes the vehicle that enables communication between the external world and the interior mind-brain world of the individual is information (knowledge). How we behave, what we think and how we think all depend upon the information we have about them and about how to use that information. (See Brown 1984)

A father of a 23-year-old man who was diagnosed at age 16 talked about his fears: "The biggest problem I had was the fear of how functional my son would be. Would he ever go to college? Would he be able to have a normal life? Would he be dependent on me and his mother? Finally we called the physician and we shared our concerns with him. In return we got lots of support. They sent us material to read. We were introduced to a support group that later on became the crucial factor in my son's recovery. And most of all, our questions and concerns were answered. As soon as our attitude changed, our son's behavior changed. He became more confident that his narcolepsy is not going to take over his life. We all needed to make some adjustments. It was tough, but we did it."

The family and parents of children with chronic disorders are extremely important as to how the child perceives his illness. The faster parents understand and accept the child's disorder, the easier the acceptance is

for the child. The fear associated with a disorder can affect the individual afflicted with the disorder a great deal. Blom, 1958, talked about such fears affecting and prolonging the illness and ultimately diminishing the young patient's will to live, seriously limiting his willingness to participate in treatment programs (Langsley, 1961). Therefore, the family's creation of a secure environment is very important in understanding and accepting one's disorder.

A 24-year-old man who was diagnosed at age 16 talked about how his family's support made a world of difference in his life, as he shared his experience with me: "I feel I am very lucky to have a family like mine, especially to put up with me right after the diagnosis. I used to go through bursts of anger. I couldn't handle it, but my parents were patient with me. They acted as if it was very normal to feel angry and be upset. My brother used to walk with me everywhere, just in case I had a cataplexy attack. It really breaks my heart when I look back because he is younger than me. Now we are the same size, but back then he was much smaller than me. And believe me, any time I had an attack, falling to the ground, it wasn't easy to hold up a 100 pound person. I am very thankful that they were there for me. It meant a lot."

Ernest Rosenbaum describes a need between a patient and his family as "candor." That includes recognition and confrontation of each other's needs as well as fears. The confrontation he believes is necessary to keep those fears under control. (See Rosenbaum 1975)

A family faced with the chronic illness of one of its members has the dual problem of trying to control its own fear and anxiety while giving encouragement and support to the patient. It can produce a situation in which the members of the family and friends spend their time wondering how to ease the emotional suffering of the patient while the patient is worrying about the despair of those he loves. (See Rosenbaum 1975)

A 19-year-old college student talked about his memories at age 17 when he was diagnosed: "Trying to make sense out of my disorder was tough. My parents were divorced when I was nine. My mother took a lot of abuse from me when I was in the hospital. I look back, and it's just petulant behavior that I had, but she just rolled with it. It was almost as if she knew what I was going through. She never got mad and that alone helped me because I had no one to listen to me. On the other hand, my father had a hard time dealing with it. He used to yell at me about stupid stuff like, if I couldn't go to work with him five days a week, I could go three days a week. He was not mad at me because I couldn't go to work with him. It was

obvious to me that he was upset about my narcolepsy and he couldn't really deal with it that well. Fortunately, they both care about me. So eventually he was able to accept it. It was rough to deal with it at first, but we all managed."

To achieve an openness and to maintain mutual understanding is part of the challenge of living with a chronic disorder. In this study, when fears and frustrations were talked about, the situation got easier; vs. families who never discussed the problem and denial became the only way to handle the circumstances.

A 64-year-old grandmother talked about her grandson's denial. "My grandson was 15 when he was diagnosed. He couldn't deal with it. After his diagnosis, he told us if we were to tell anybody he had narcolepsy we would never see him again. His teachers knew something was wrong, but he did not want to admit it. For a while he took his medication, and he did much better; but he stopped that too. He became totally dysfunctional. He keeps on dropping out of high school. He doesn't go to the doctor. He thinks if he doesn't think about it, eventually it will go away by itself. He is 19 years old and still has not finished high school. He is sleeping his life away and I have no influence on him."

WORRYING ABOUT FAMILY MEMBERS WITH NARCOLEPSY

Whether parents had adopted the "open" style or "closed" style, the most important common factor that existed among them was the concept of worrying about their children with narcolepsy. The most important part of this worry was due to the nature of narcolepsy. The excessive sleepiness was the parents' main source of worry about their children riding buses, subways, driving and being used or abused as "passive" persons.

When the question was asked, "Do you worry about your children?", the response was yes from all families interviewed, however, the majority of them replied that after a while they were less worried. They either got used to the idea of having a family member with narcolepsy or made their child adopt certain behaviors as safety measures, due to the lack of alertness at times as part of narcolepsy.

The mother of a 24-year-old woman with narcolepsy talked about her worries: "As a person with narcolepsy myself I have always worried about my daughter. You see, when I was younger, I almost was raped because I fell asleep in an inappropriate place. Thank God I woke up just in time to escape the situation. There are lots of bad people out there who could take advantage of your 'sleepiness.' My daughter is beautiful. I am always worried about her, taking the subway to go back home. I am afraid if she is less alert she may get hurt."

Most of the time, parents' perceived overprotectiveness and worries become the children's problems. A 23-year-old man said, "Sometimes I forget my narcolepsy, but my mother constantly reminds me of my disability. I have to stop and call her several times and it's tough."

Another young man who was diagnosed at around age 16 mentioned that, despite the fact that his parents' support meant a lot to him, their overprotectiveness hurt him at times. As he described: "Just around the time that I was diagnosed, I constantly had cataplectic attacks. My parents made my brother watch out for me all the time. Up to the time of my sickness I was always watching out for my brother, but all of a sudden I became helpless and he had to look out for me. This was the biggest change I had to adjust to. Although I feel like I was very lucky to have a supportive family like that, at the time the exchanges of our roles was extremely shocking."

Although parental protection and worry are normal elements of parental love and care, however, Schneider and Conrad (1983) talk about how easily this can become an element of control. They can isolate and restrict to the point that they may disable the affected individual and make him dependent. They suggest that the complication of illness adds to the already imbalanced quality of parent-child relationships and the illness or disability can

become good ground for parents to presume the dependency beyond adolescence.

A 23-year-old woman talked about her parents' overprotectiveness: "When I was first diagnosed I liked the fact that everybody was paying attention to me. When we were traveling, my parents always discussed me and my need to take a nap. It was nice to see my family's concern, but as I grew older it became harder. I couldn't go out freely, but my younger sister could. I tried to talk to my parents, that I was capable of doing things my sister did, but they would not listen. The toughest was when I wanted to go to college. My parents started looking for me and never bothered to ask me where did I want to go to school. I realized if I gave in and did not stand for my rights, I would remain the handicapped child of the family. Therefore I announced that I had three choices, all out of state. Either I would go to one of those three or I would not go to college at all. It was tough, but I think it was the best thing I ever did. My mother cried for days after I moved, but she got used to it and so did I."

It seems the toughest part of having children with any disorder is letting them go. However, most family members interviewed in this study agreed that children have to be told about risks and management of their disorder. Keeping them dependent to the family and isolated because of the disorder may make them fully handicapped for the rest of their lives.

SIBLINGS OF PERSONS WITH NARCOLEPSY

Among the family members, three siblings were also interviewed. Interestingly enough, all three were mirroring their parents with worry and protectiveness. Perhaps this stemmed from the nature of narcolepsy. The sudden urge to fall asleep or a sudden attack of cataplexy. The no-win situation that the afflicted individual has no control over. A 23-year-old sister of one respondent talked about her older sister: "I feel sorry and worry about my sister. Not the kind of sorry to 'belittle' her, yet I never want to be in her shoes. She gets lots of attention from all of us yet sometimes she seems very incapable. There is so much she wants to do, but she falls asleep and when she wakes up it's too late. I do so much for her. At first I used to think she is not trying hard, but now I understand her disorder. My heart breaks for her."

Sometimes the worry of siblings is mixed in a duality, a resentment due to the extra attention the afflicted sister or brother receives. As Burton (1975) indicted, the sisters and brothers of an ill child suffer from some neglect due to the attention that an ailment brings to that person. Subsequently they become anxious for the sibling's safety and become depressed.

A twin sister of a 15-year-old boy who was diagnosed at age 13 talked about her experience: "My

brother has always been the center of attention because no one knew what was wrong with him. For a long time we thought he was going to die. After we realized he had narcolepsy we all tried to help him out. I am twins with him and I am an A student. He hardly gets C's. I want to do so much for him but I feel sad that this is his life. Sometimes I feel that it is not fair that we are twins and he is sick and I am not. I feel guilty, but I cannot help it that I am not sick."

The "openness" of the parents, along with adequate comments regarding the disorder with the afflicted child as well as their other children can help avoid anxieties, frustrations, guilt and resentment. If the family members work together, they can become the best support system for the afflicted individual as well as each other.

DATING AND MARRIAGE WITH NARCOLEPSY

Dating, followed by romantic love, is a noble ideal in American culture. It is known to be a different kind of love than one may have for other family members. As Ian Robertson (1987) discusses: Romantic love involves physical symptoms such as a pounding heart and sexual desire, and psychological aspects such as an obsessive focus on one person and disregard for any resulting social or economic risks. Our culture encourages us to look for this love. To find that "one and only," perhaps even through "love at first sight." The phenomenon of romantic love occurs when two people meet and find one another personally and physically attractive. They become mutually absorbed, start to behave in what may appear to be a flighty, even irrational manner, decide that they are right for one another, and may then enter a marriage whose success is expected to be guaranteed by their enduring passion. Behavior of this kind is portrayed and warmly endorsed throughout American popular culture, by books, magazines, comics, records, popular songs, movies and T.V. (See Robertson, Ian 1987)

To enter the power of romantic love, one first needs to date and build up a relationship. It all begins as how one presents oneself to the other. This "presentation" of oneself begins from childhood. We are taught to "behave" in the presence of others. Goffman

(1963) argues that people are deeply concerned with "impression management;" they attempt to control the impression they make on others by presenting themselves in the most favorable light.

People are careful to wear appropriate clothing for particular social occasions, presenting a different self by dressing for a casual party or formal job interview.

"Impression management" in a sense makes up an important part of social relationships and interaction in society. The attempt to present the self in a favorable light is not always successful. Specifically, if the person has no control over his/her "impression management." In some chronic disorders such as narcolepsy the self control and self impression is almost always controlled by the disease. As it was discussed in the "Self and Narcolepsy" section, the sudden act of sleep, the loss of control over bodily figure, the disfiguration during sleep attacks in public, is considered a private act and the person who has suddenly fallen asleep has deviated from the expected social behavior. This act by itself makes the afflicted individual (adolescents, young or mature adult) a subject of laughter in public scenes.

The embarrassment felt by afflicted individuals slowly pushes them to social isolation. Besides this social isolation, the lack of energy felt by afflicted individuals also interferes with the public image and being

socially interactive. As a result, most often individuals with narcolepsy avoid dating and having intimate relationships.

A 32-year-old man shared his experience with me: "Narcolepsy as a disease is not life-threatening, but its social effects are. When I started dating I had a hard time hiding my narcolepsy. I had several breakups. The complaints were always the same. 'You are not interested in me.' Besides, even if you convince them that you are interested, who wants to date a man who is not 'energetic.' In my last relationship, I fell in love real seriously. I said to myself, 'I am not going to blow this one again.' I told her all about my disorder and told her if she gave me a chance I am not all that bad. I remember she would be driving or we would be talking on the phone and I would be out like a light. She'd be yelling, 'Did you fall asleep on me again?' We are married now and we are very happy, too, but she still sometimes doesn't understand that there is not a whole lot I can do about it."

Among the respondents, out of 30 males, 23 were above the age of 17; and among 23 females, 20 were above the age of 17. Ten males and eight female respondents above the age of 17 stated they have never dated.

A 24-year-old, very attractive woman talked about her experience: "Dating with narcolepsy is not easy. Even when you have built a relationship it is never permanent.

You get used to breaking up. 'They' feel they are wasting their lives with you, plus they always are concerned if they really fall in love with you, what is the marital life going to be like. The life with a wife who is going to be 'sleepy' most times. I actually have been told this in my last two relationships. It breaks my heart, but I cannot do anything about it. That is why I have learned not to trust in my relationships, because they end soon."

Besides dating, as most respondents stated, even social gatherings with friends can be limited for some afflicted individuals.

As a college student talked about her experience: "Dating is hard. I never think about dating because by the time you are done with your studies you have no energy for anything else. However, I like to be with a few friends (boys and girls) which we hang out together. I feel that I am a burden on the group. I feel like I slow them down. That is why I pull myself away because I don't want to be in their way. I only get involved when they ask me out." Most respondents, especially females, had a very similar attitude, except for those who had long term relationships where they didn't feel their narcolepsy was in the way of the relationship. The other important factor is self acceptance (accepting the disorder as part of life), which has a great deal to do with how one can present her/himself in public. Among the respondents the ones who had accepted

their narcolepsy as part of their character and were more open about it seem to have an easier time with friendship, dating and even marriage.

Dating and marriage within the last years of the decade of the nineties is extremely complex for anyone in the society. However, having to deal with a disorder makes this phenomenon much more difficult.

Among the female respondents, three were married at the time of the interview, but one was separated. Only one of the females had children. Among the male respondents, four were married at the time of the interview but one was separated. Among the four married men, three had children.

A 27-year-old married woman with narcolepsy talked about her marital experience: "I have been married over one year. My husband has always known about my narcolepsy and has been very supportive. Yet still I feel he doesn't understand my disease completely. Sometimes I feel he thinks I am faking it. You see, husbands are not like parents. They do not have much tolerance for the spouse's sickness and disorders. Just this past Sunday we went for a ride with his sister and brother-in-law. I fell asleep in the back seat and must have had a cataplexy attack or arm jerk in my sleep. My arm must have flopped down and hit him. He flung my hand back up and my hand hit me. This wasn't my fault. Yet he doesn't understand it. I'm sure it is not easy to live with someone who has

narcolepsy, yet when you commit yourself to someone you should try to understand their disease too! Other comments made by respondents who were married or separated at the time of the interview were similar to the above-mentioned comments. The lack of understanding of all aspects of the disorder at times makes the relationships very cloudy unless the problems are communicated with the spouses.

#### INTERVIEWS WITH SPOUSES

I interviewed five spouses of afflicted individuals, three wives and two husbands. It was very interesting to listen to their side of the experience, to see the life with narcolepsy from their point of view. A 30-year-old woman talked about her experience: "I love my husband and I knew about his disorder before we were married. Narcolepsy is a very strange disorder, in the sense that you don't know what to expect. At times my husband is alert for hours, especially if he is not bored. But sometimes, no matter what you do, he falls asleep. In other words, you can never depend on your husband, meaning that many responsibilities fall on my shoulders. I knew this before I married him, but it is not an easy task to live with it. One of my biggest fears was to have children. We have a child now and she is healthy. I love my husband, yet his disorder is not an easy one to deal with."

One of the husbands interviewed talked about his experience: "Understanding narcolepsy is not easy. First, there are few symptoms associated with narcolepsy and also it is an ongoing problem. It is not that you have to deal with your spouse's disorder every once in a while. Sleepiness and cataplexy are always there. Sometimes I prepare dinner and she has to take a nap. Before you know it, two hours have passed and she is still sleeping. Dinner is cold and time has been wasted. You never know what to expect when she is feeling sleepy. You end up hating sleep because it is the stronger partner of your spouse than you. It has control over her."

The comments of all five spouses interviewed were very similar, however, those who were involved with the process of management of their spouse's disorder (going to doctors with spouse, going to support groups, knowing what medication they are taking) were less frustrated than those who had no connection with the disease but to deal with it.

#### General Guidelines for Building Healthier Relationships

1. Self-acceptance and general acceptance of the disorder will help afflicted persons to deal with their limitations and their abilities.
2. Communicating openly with others regarding the symptoms and personal limitations will allow others to understand the disorder and expect realistic relationships with afflicted individuals.

3. **Self-secrecy will make the disorder more ambiguous and will drive the afflicted individual to social isolation.**

Since the fifteenth century, the rebirth of learning and innovation known as Renaissance in Europe, the gradual takeover of science gave birth to a new world of medicine and dissolved the religious role in medicine. By the eighteenth century, new discoveries began to revolutionize medicine. Over the past one hundred fifty years, the world has witnessed the growth of the medical institution along with technique and knowledge that has had a great social impact on the world.

When people feel ill, they try to return to health. They usually seek medical attention. After the diagnosis (being labeled with the name of the disorder) they seek treatment. Drugs have become the most important method of treatment in most modern societies.

Medications and drug therapy have played a significant role in an experience of many chronic disorders.

In the treatment of most chronic disorders, drugs are like a bridge than can be crossed over from "disability life" to "normal life."

In the life of the persons with narcolepsy, drugs also have played a crucial role, especially due to the fact that at the present time there is no cure for narcolepsy. The drugs are used to control symptoms of EDS, cataplexy and other auxiliary symptoms. However, in the course of the life of a person with narcolepsy, treatment seems to be the most controversial part of the disorder. Perhaps this is

due to the fact that there is "no" easy way to treat narcolepsy. As Broughton and Broughton (1994) indicated, arriving at the unequal diagnosis of narcolepsy is at times a difficult task. But even when the diagnosis is established, the patient's problems have only just begun. This task is even more difficult with adolescents and young adults.

The controversies over drug treatment for narcolepsy can be categorized into two areas:

1. The clinical issues and concerns around the use, misuse and side effects of medication.
2. The social issues concerning use of medication, mistrust, cost issues, lack of availability and compliance issues.

In this study I looked at both issues. Needless to say, both categories are interrelated and affect one another.

To begin, I decided to first introduce the medications used in the treatment of narcolepsy.

Medications Used For the Treatment of Narcolepsy:

1. Stimulant drugs of CNS (central nervous system). For treatment of EDS.\*
2. Tricyclic antidepressants for treatment of cataplexy, sleep paralysis and hypnagogic hallucinations.
3. New experimental drugs.

\*EDS: Excessive daytime sleepiness.

**Stimulants:**

Stimulants have been subjects of controversies for many years. The controversies are around the use and misuse of them by both the medical world for prescribing them and individuals who take them. Stimulants will increase effort, elevate mood, prevent fatigue, increase vigilance, prevent sleep, stimulate respiration and cause electrical and behavioral arousal from natural or drug-induced sleep. These central stimulant effects are thought to be caused by both cortical and brain stem reticular activating system stimulation (see Parkes 94). Stimulant drugs are used for various disorders. The most common of these disorders among children and adolescents is ADD (Attention Deficit Disorder). These drugs are categorized as "controlled substances," and are controlled by the U.S. Drug Enforcement Administration (DEA). The major stimulants used for treatment of EDS are amphetamines, methylphenidate, pemoline and mazindol. Development of tolerance of these drugs and their potential for abuse have categorized them as "black market" drugs. These drugs also have potential for abuse by those close to the patients (see Broughton and Broughton, 94).

Drugs used in the treatment of EDS:

These drugs are central nervous system (CNS) stimulants).

<u>Trade Name</u>	<u>Generic Name</u>
Ritalin	Methylphenidate
Ritalin-SR	Methylphenidate sustained release
Dexedrine	Dextroamphetamine
Desoxyn	Methamphetamine
Cylert	Pemoline

These drugs are central nervous system (CNS) stimulants, with the potential for abuse and dependence, and all are controlled substances.

The CNS stimulants vary in different dosage. Their effects vary from person to person due to the fact that each person's condition varies. However, the recommended dosage is to prescribe the minimum dosage possible, to be gradually increased with careful monitoring against adverse side effects.

Possible side effects of drugs used in the treatment of EDS

<u>Drug</u>	<u>Some possible side effects:</u>
Ritalin	Nervousness, irritability, headaches, tremors, sweating and mood swings.
Cylert	Nervousness, irritability, headaches, tremors, sweating and mood swings.
Dexedrine	Nervousness, irritability, headaches, tremors, sweating and mood swings.

The side effects may vary from person to person, and at times, some may not even be felt by individuals. However, it is important to be aware of side effects so they could report them in case adjustment or change of medication is needed.

### Tricyclic Antidepressants

This group of medications have been used for the treatment of cataplexy and other symptoms of narcolepsy, such as hypnagogic hallucinations, sleep paralysis and automatic behavior. These drugs have been less controversial than the stimulants, however, they mostly have sedating effects and can exacerbate daytime sleepiness.

### Drugs used in treatment of cataplexy, hypnagogic hallucinations and sleepiness:

<u>Brand Name</u>	<u>Generic Name</u>
Vivactil 15-60 mg	Protriptyline
Tofranil 75-200 mg	Imipramine
Norpramin 75-200 mg	Desipramine
Pamelor 30-100 mg	Nortriptyline

\*These drugs are tricyclic antidepressants.

Possible side effects of drugs used in the treatment of cataplexy, hypnagogic hallucinations, sleep paralysis.

<u>Drug</u>	<u>Some possible side effects</u>
Vivactil	Drowsiness, dry mouth, anorexia, sweating, constipation, decreased blood pressure.
Tofranil	Drowsiness, dry mouth, anorexia, sweating, constipation, decreased blood pressure.
Norpramin	Drowsiness, dry mouth, anorexia, sweating, constipation, decreased blood pressure.
Pamelor	Drowsiness, dry mouth, anorexia, sweating, constipation, decreased blood pressure.

Besides the above mentioned side effects, other side effects such as impotence have been reported.

Impotence may at times be severe enough to warrant withdrawal of the drug (see Goswami 91).

New experimental drugs.

Currently in the U.S. there are many experimental drugs. These are not F.D.A. approved and can only be used if individuals with narcolepsy participate in the research projects. Among these drugs, GHB (gamma hydroxybutyrate) and modafinil are the largest research projects.

GHB, mainly used for treatment of severe cataplexy, is a natural substance.

Modafinil is a stimulant which is used to treat EDS.

### CLINICAL ISSUES

In this research study, among the 53 respondents, all but one were either on medication or had been taking medication at one point or another.

The clinical concerns among respondents were side effects, question of tolerance, misuse and drug dependency, yet these concerns were varied depending on the category of medications the respondents were on. Therefore I categorized them under stimulants and tricyclic antidepressants.

#### Taking Stimulants:

Among the 53 respondents, 44 ranging from having mild to severe EDS reported taking stimulants at one time or another. At the time of the interviews only 38 were on stimulants and three were on a new experimental drug (modafinil). Therefore I categorized them as Group A (the ones on stimulants) and Group B (the ones who said no to stimulants).

#### Taking Stimulants (Group A)

When the question was addressed to these individuals who were on stimulants and their parents, as to why they chose to take stimulants and if they had any concerns regarding that or not, they all responded in a few common responses. They all had major concerns regarding side effects (more long term than short term), formation of tolerance and drug dependency. However, they also admitted

they had no other choice but to take stimulants. Interestingly enough, among these respondents, excessive daytime sleepiness was moderate to severe and the side effects felt by them were very mild to somewhat mild. These included dry mouth, minor loss or increase of appetite and minor nocturnal sleep disturbances. These are a few responses that I will share with you:

A young man, 23 years old, who had been taking Ritalin since he was 16 talked about his experience. "I take medication for both my cataplexy and excessive daytime sleepiness. I graduated from college two years ago. Without medication I probably would have still been in college or I may have quit. Medication is not the best thing, but when you need it you cannot deny it. Like anything in life there is a tradeoff. Yes, it gives you side effects and you must go to the doctors every few months to get it renewed, yet I gain consciousness. When I take medications it feels like I have come out of a coma. I feel human."

The effectiveness of these drugs for control of EDS varies from person to person, especially among children and adolescents. These medications have to be started at the minimum dose and individuals have to be monitored to see when and at what level they get the maximum benefits. They should also be tested for the long term side effects by routine blood tests.

A mother of a 15-year-old boy talked about her son's experience. "My son is a smart boy but the sleepiness had made him look like he is slow and off focus.

The stimulants helped him gain his brightness. He no longer was falling asleep in the class. We have no choice but to keep him on medication. Without stimulants he falls asleep and remains asleep all day long. I am very concerned about the stimulants' side effects, however, without medication he has no activity, he is not alive."

Another 20-year-old woman talked about her experience with medication. "No one wants to take medication, but sometimes you are not given a choice. I look at my disorder as an ailment. My ailment is sleepiness and I need to be treated. My sickness is physical and I cannot make it disappear unless I take medication, otherwise I could sleep my whole life away. Is that really living? I am concerned about side effects. I know I am at times hooked on my stimulants, but I go on drug holidays. I hope for a bright future without taking medication. I have no future but to fall asleep and dream and dream. It is sad, but this is my ailment. I have to live with it and its consequences, even if it means side effects."

A 24-year-old marketing agent shared his experience with me. "When I was first diagnosed I was put on medication. I really could not grasp why I was on medication and

what was medication doing for me. I went to college and toward the end decided I no longer needed medication. I started drinking coffee and taking caffeine pills. I finished college and I was fortunate enough to get a good job. However, having a couple of accidents and not being able to be on time for work and almost losing my job made me realize this was not about a choice, and deciding whether I should take medication or not. This was about a serious illness called narcolepsy that requires stimulants. There was not a single day that I don't think about a cure for narcolepsy, but for the time being I must take my medication to be alert."

For most people with narcolepsy who are on stimulants the medication becomes an important means, unlike some routine medication (such as blood pressure pills, that may be missed). If it's forgotten, the persons fall asleep rapidly and they cannot resume their normal routine tasks. That is why they often worry as when their medication should be taken or if it needs adjustment, and they worry when they have an important task such as an exam or big meeting and if they can remain alert. Overall, for those individuals who are committed to take stimulants (Group A), having a "semi" to "normal life" means taking medications, despite the fact that they all said they do not like to take medications; yet to gain alertness the choice is to be on medication.

### Saying No to Stimulants (Group B)

Among the 53 respondents, 15 individuals at the time of the interview were off stimulants. Four said they never took stimulants due to very mild EDS, and 11 said they had tried stimulants, yet they had to go off of it. Among the 11 who were off stimulants, five said they stopped taking stimulants due to social pressure and being labeled as non-compliant, which I will discuss in the next section, and six said they stopped due to clinical side effects and concerns.

These are some of the comments as to why they went off stimulants. As a 19-year-old college student described; "I was on medication for three years because they helped me stay up, however, my personality had changed. I was very irritable all the time. At times I was so upset with the world that I thought I might kill someone. My mother repeatedly reported this to my doctor but he kept on saying it is his age. He is going through puberty. However, twice when my medication was stopped not only my mother realized the significant change in me but I also felt very different. I was peaceful and calm. Surely I was also more sleepy, but I was not irritable. I was at peace. Plus, the medication had made me gain a great deal of weight and when I stopped the medication I lost the excessive weight. When I entered college I stopped the medication completely. Now I suffer because I can't take

any early morning classes and I nap before I drive. I nap often and I also drink natural stimulants such as coffee, up to six cups, however, I am not the miserable person I used to be. I am happy and I am me."

Another 18-year-old student described his experience. "I was diagnosed at age 13 and I was put on medication within a few weeks after the diagnosis. No one ever told me what I was taking and what price I had to pay. Trying not to fall asleep was a very bad battle. Medication helped me win this battle. However, I got hooked on them. I was uncontrollably addicted to them. If I didn't take medication I would be irrational. They really scrambled my mind. I was so hooked on them to the point that I never had enough. Eventually I turned toward anything, including over-counter drugs. Finally, last year when I graduated from high school, I decided to go off them and not to take them in college. Now I drink coffee and I nap. I am not as alert as I want to be but I am not a "drug addict" either. If I had continued I would have been lost to the severe addiction."

Another woman, 24 years old, talked about her experience. "I take medication for my cataplexy but I don't take stimulants any more. I used to take stimulants, but the problem was that as soon as I would go on stimulants I would form a tolerance and they would stop working on me unless I kept on taking more. There was no

end to it. The doctors, the pharmacist, wanted to know why did I need so much. I finally gave it up but with that I also gave up driving and my independence. You see, I drink 18 cups of coffee and I smoke a lot, but I still fall asleep in the subway. I always have to be with someone traveling in the subway. At home I beg my roommate to wake me up in the morning, even if it means dragging me out of bed. At this point there is no good solution for me, until they find a good cure or a better drug to treat narcolepsy."

Among respondents there were two with adverse reactions to psychosis. Both individuals, one male of 22 and a female of 18, had a history of chronic depression and paranoia. After the diagnosis of narcolepsy they were placed on stimulants, and in both cases the reaction (one after two weeks and the other after two months) was severe psychotic attacks. Once they discontinued the stimulants they improved greatly.

In both groups, side effects seemed to be the most common and major problem. However, in Group A, the side effects seem to have been less of a concern due to the fact they were very limited or non-existent, and perhaps the concern to gain control over life was much stronger than concern over potential side effects, due to the fact that EDS\* in Group A seems to have been much more severe than in Group B. Yet among Group B, individuals seem to have

severe side effects or dependency to stimulants to the point of addiction, forcing them to get off stimulants.

Overall, it is very important to note that:

1. The side effects vary from person to person, and some may not have any.
2. One may not form a side effect for a while, and after a few years may develop one.
3. Individuals on stimulants have to be aware of drug dependency and getting hooked on drugs.
4. Beware of side effects so you can identify them if you develop any and report them and obtain help.
5. Drug holidays are the best tools to test the side effects and drug dependency.

Taking medications for cataplexy and other auxiliary symptoms:

Among the 53 respondents, 47 had cataplexy with or without excessive daytime sleepiness (EDS), 44 had hypnagogic hallucinations, 45 had sleep paralysis and 48 automatic behavior. All respondents but four with very mild symptoms were on medication at the time of the interview. Unlike those with the need to take stimulants, most respondents were less concerned about side effects and were much more comfortable taking this category of medication. As previously mentioned, these medications are tricyclic antidepressants such as Protriptyline,

\*EDS: Excessive daytime sleepiness

Desipramine, Imipramine and Nortriptyline, with several generic names.

It seems the major differences felt by respondents between these drugs and stimulants were due to:

1. Less side effects.
2. Less stigmatizing to take these drugs.
3. Less costly and more available.
4. Less chance of addiction.
5. The control that an individual gains over the auxiliary symptoms is extremely satisfactory.

As many respondents replied, cataplexy attacks and other auxiliary symptoms may occur with medication, however, their prevalence is a lot less than not taking medication. Of course, this factor also depends on the severity of symptoms as well as dosage and type of medication they are on.

These were some of their experiences shared with me.

A 21-year-old college student said, "I cannot walk on campus and say 'Hi' to my friends without my medication. As soon as I get excited I fall to the ground. However, with medication, unless I am extremely excited and tired otherwise, I can catch myself and most people don't even notice my weakness."

Another college student talked about his experience. "Without my medication for my cataplexy I am like Jell-o out of the refrigerator. Make me laugh and I melt on the floor."

A 22-year-old graduate student talked about his cataplexy. "My problem is so severe that without medication I will be in a wheelchair. Unfortunately I can never, ever give up my medication. Right now I am limited because I still get cataplexy, but I am functional and I have a good life."

The other category of symptoms that is helped by tricyclics is hypnagogic hallucinations. The fact that individuals are able to control their uncontrollable hallucinations makes this category of medication very positive and normalizing with almost no concern for side effects.

As a 23-year-old woman talked about her experience; "I don't think anybody enjoys having massacre dreams every night or having to deal with the dead rising from the grave, especially if the dead is your grandmother. The dreams, as vivid as they are, will get to you. Medication does not stop it for me, but it makes it less frequent and less vivid."

The auxiliary symptoms of narcolepsy, such as hypnagogic hallucinations, automatic behavior and sleep paralysis disturb the individual's social life, to the point that they start doubting their sanity.

A 24-year-old woman shared her experience with me. "Having to lose important documents several times a day, when you knew you had it a few moments ago is not an easy task. My automatic behavior is so bad that I lose everything and I find them in an inappropriate place later. Medication helps control my symptoms. Without them I cannot work."

All respondents more or less had the same response with few exceptions, who had to switch medications a few times due to side effects such as minor skin rashes and diarrhea.

The other aspect of difference that respondents had felt, especially the ones who were on both antidepressants and stimulants, was that this category of medication is more available, less costly and definitely less "stigmatizing" than stimulants. Therefore it would make the afflicted individuals more comfortable to take them as compared to stimulants.

New Drugs:

At the time of interview there were several drugs in the U.S. that were being tested on an experimental basis. The most popular ones were modafinil and GHB (gamma hydroxybutyrate).

Modafinil: Among 53 respondents, three said they had just begun to take Modafinil. It would have been premature to question them regarding its effects and side effects.

Therefore in this research study I have no positive nor negative result that I can report regarding this new drug.

Gamma hydroxybutyrate (GHB): GHB has been used in Europe and Canada over the past decade. However, it is being used in the U.S. only on an experimental basis, and as of now it is not FDA approved.

GHB is a natural substance for treatment of cataplexy. Among the 53 respondents, three individuals had participated in experimental process of GHB.

Among the three, one with severe cataplexy, a 16-year-old boy who was sent to the research site in the wheelchair shortly after diagnosis. His cataplexy was so severe that due to lack of control he was put in a wheelchair. He was put on the maximum dosage which helped his cataplexy tremendously, yet due to severe side effects of vomiting he was taken off and was put on tricyclic antidepressants.

The second respondent, a 21-year-old college student with severe cataplexy, was put on GHB three years prior to our interview. Her cataplexy in specific, and her narcolepsy in general, had gone from severe to mild. She reported that her nocturnal sleep disturbances also were helped. As a result, her excessive daytime sleepiness was improved.

The third respondent, a 30-year-old mortgage broker, was put on GHB for almost ten years. His severe

cataplexy had disappeared. He also claimed that due to sleeping better at nights his excessive daytime sleepiness had improved, yet still had a great deal of EDS during the day.

### SOCIAL ISSUES AND MEDICATION

Over the past two decades, specifically since the early eighties, the promotion of "good health" has become one of the major issues in our society. This philosophy has given rise to a new theory, which is the emphasis on individual responsibility for leading a healthy life.

While not denying that individual lifestyles are very important determinants of health, such as keeping healthy by exercising, eating right, avoiding smoking and alcohol abuse; however, as critic Howard Waitzkin (1983) argued, Society puts the burden of being healthy squarely on the individual rather than collective solutions to health problems.

As another critic, Vicente Navarro (1986) argues, the strategy of individual responsibility for health assumes that the fundamental cause of an individual's health problems is the individual, not the social system. While this emphasis assumes a degree of independence and freedom for the individual, this is just an illusion.

The promotion of "healthy society, healthy individual" implies that persons attempt to produce good health, it depends on his or her degree of motivation, effort and capabilities, making life extremely tough for those with chronic disorders such as narcolepsy.

Irwin Rosenstock (1966) believed that people exist in a life space composed of regions with both positive and

negative valences (values). An illness would be a negative valence and would have the effect of pushing a person away from that region, unless doing so would cause the person to enter a region of even greater negative valence (for example, risking disease might be less negative than failing an exam). While people are pushed away from regions with negative valences, they are attracted toward regions of positive valences.

For persons with narcolepsy with no cure, remaining in "negative valences" is unavoidable, yet extremely stigmatizing. The "healthy life" of an individual in today's society means exercising, saying no to sickness, bragging about healthy bodies with no artificial chemicals, looking down upon those who are on artificial chemicals. Thus the promotion of "healthy thinking" "healthy society" has made the taking of medicine a "big taboo" in our society. To take stimulants is considered a deviation of normal rules within the healthy society. Tough, even though those who take it need it to maintain their alertness to function. Therefore it is no surprise when we witness persons with narcolepsy on a roller coaster ride of on/off medication.

When the question was addressed to respondents and their parents regarding social (non-clinical) issues with medications (stimulants), all respondents, including the ones who were not on medications (stimulants) at the time

of the interview and their parents, responded on issues such as cost, lack of availability, mistrust from health care clinicians, compliance issues and stigmatization with emphasis on it.

High cost and lack of availability of stimulants were the concern of most respondents or their parents. Stimulants are extremely costly, especially for those who have no insurance coverage. For those with no insurance, the high cost makes it impossible to remain on stimulants. Lack of availability also was a major concern for most. However, the suggestions a few respondents came up with were:

1. To switch to a generic brand with less cost (although a few reported they could not tolerate the generics due to adverse reactions).
2. To have your physician call the pharmacist and request that they would commit themselves to shelve these medications for prospective patients.

#### Mistrust and Stigmatization

Unlike medications for other chronic disorders such as epilepsy, stimulants for treatment of narcolepsy are a subject of controversy due to their nature, therefore individuals who take them are subjects of mistrust. Although these medications are prescribed by physicians to patients as treatment plans, mistrust seems to stem from;

1. DEA's control over physicians and pharmacists.
2. Potential abuse and overuse of stimulants by patients.
3. Stimulants are the "black market" drugs for street drug abusers. (Stimulants are known as golden uppers in the big cities.)

Among the 53 respondents, 45 either were on medication or had taken stimulants and 17 parents of adolescents who said their children were on stimulants claimed that they were subjects of mistrust and felt certain levels of harassment from physicians, pharmacists and their staff.

Five of the respondents admitted that they had stopped taking stimulants due to mistrust. The most common comment respondents made was being labeled and treated as "drug addicts, though they claimed they never abused drugs.

A 23-year-old college student talked about his experience. "I have been on stimulants since 16. I have never abused drugs, and if it wasn't for my EDS I would have never taken stimulants because I hate medications. Up to when I went to college, my mother always handled my medications. When I started college I had to find a new physician who would manage my treatment. At the beginning he started me on a low dosage, yet as time went on, due to the load of my studies, he increased my medication; yet the next time around when I called his office for renewal, his

staff accused me of abusing the medication because he apparently had forgotten to write it in the chart that he had increased it. I was so upset, not knowing why they were reacting toward me like that. Even after the physician confirmed that he had increased my medication they never admitted to their wrong doing. Just because we take stimulants we should not be stereotyped and stigmatized."

A 20-year-old woman who also had been on medication for a few years before she left for college had a similar experience when a pharmacist questioned her about the amount of medication she was taking, and even after confirming that with the physician he was still sarcastic, and his remark was that "What kind of sleepiness needs medication this strong and she should know what she was doing to her brain."

Unlike other chronic disorders such as epilepsy, in which afflicted individuals are never told to try not to have a seizure; individuals with narcolepsy are often told by others, including health care professionals, teachers, relatives ... to try harder not to fall asleep. This stems from the fact that most people, including health care workers, consider sleepiness (sleep attacks) as not a serious illness. Furthermore, the stigmatizing nature of stimulants with their potential for abuse makes individuals with narcolepsy the subjects of mistrust and scrutiny.

Persons with narcolepsy can affect these controversies by demanding more public education about the disease, its symptoms and its management.

### Compliance

The issue of compliance is always a subject of controversy for one reason. Compliance is approached differently by physicians and other health care professionals vs afflicted individuals.

Schnider and Conrad (1983) in the Study of Epilepsy refer to this issue as medical culture with those patients who follow doctors' orders act properly - they conform to medical rules and are "compliant." Those who refuse or fail to conform represent "problems" or are "difficult." The non-compliant patient (and his/her family) regardless of what the reason might be is the subject of sarcasms and harassments.

Individuals with narcolepsy most often are labeled as non-compliant. The medical literature on narcolepsy is self-evident. Most medical literature blames the auxiliary system of forgetfulness as the main reason for not showing up for appointments, not complying with management of the disorder in general. However, when the question was asked from respondents, the response was interesting. Although the auxiliary symptom of forgetfulness and occasional sleep attacks were not denied, the social issues concerning non-compliance labeling were classified as; Stigmatization and mistrust leading to an individual withdrawal from complying with treatment (this category was previously discussed). Self secrecy, denial and control were also addressed.

### Self Secrecy and Denial

Narcolepsy's stigmatizing potential drives many afflicted individuals to self secrecy and denial. Judith Lorber (1967) discussed, "Ill individuals who want to avoid the label of illness may insist that their physical symptoms are not disabling. If they are chronically ill and wish to lead as normal a life as possible, they will try to convey the impression that they are healthy." She categorized these individuals as "secret deviant."

This is very common among individuals with narcolepsy, especially among adolescents and young adults. When the question was addressed to respondents, 17 (seventeen) remembered going off medication and substituting stimulants with coffee (up to several cups per day), over-the-counter drugs, or napping seven to eight times per day.

A 24-year-old man responded to the question of self secrecy. "When I became 17, I decided if no one knew I was on medications, no one knew I have narcolepsy. If I stopped taking my medication I no longer would have narcolepsy. Then I realized that the only connection between me and narcolepsy was going to the doctors and taking medications. So I stopped taking my medication and I started drinking 20 cups of coffee per day. However, after a short while I realized I couldn't fool myself. I was falling asleep all over. I was not functional. I

think more people then realized that I had narcolepsy than when I was on medication. I myself realized I had narcolepsy and coffee could not cure it. But this realization came a couple of years later."

Another young woman had a similar experience. "When I graduated from high school I decided I was no longer going to be carrying my narcolepsy with me. I decided I was no longer going to take medication and go for my follow-ups. Instead I started taking over-the-counter drugs and several cups of coffee. If anybody asked about my narcolepsy I would get very mad. I was in total denial. I just couldn't accept myself as a "narcoleptic person." This lasted for five years."

Lack of self acceptance and self secrecy not only help the afflicted persons with narcolepsy but also allow the disorder to remain as an ambiguous and misunderstood disease.

Lack of communication, on the other hand, makes this ambiguity much greater than what it is and labels the afflicted individuals as forgetful, non-compliant persons. Self-acceptance and understanding one's own disorder is a step forward toward solving the problem of stigmatization in society. This topic will be discussed in the next chapter.

### Control

Many respondents claimed they stopped taking their medication or self medicated themselves, simply for one reason; to gain control over their condition and their bodies.

A few of the respondents claimed they know their bodies better than anybody else knows their bodies. Once side effects are experienced, they claimed they know that it is time to decrease it or stop it. As one respondent said, "When I am stressed out and have several sleep attacks despite the fact that I am taking my stimulants, I know it is time to go off of it. Even if it means being off of it for one month, I know that it is time to give my body a rest. I stop my medication, my physician doesn't like it, I know I am going to give up a few things, such as my alertness and my driving." Examples like this, when it is not communicated between health care professionals (i.e. physicians) and patients, is being perceived as control by the afflicted individuals and non-compliance by health care professionals. This controversy, furthermore, continues yet is always debatable.

### Naps as Therapeutic Treatment

In the study conducted by the Stanford University's Sleep Center (see Dement, William and Baird, William 1979). Patients who took six to ten minute naps scheduled evenly

during the day experienced beneficial effects as their alertness and performance.

In this research study, 50 respondents replied they were taking naps, some scheduled and some were not scheduled. All but two respondents claimed they feel much more refreshed after a scheduled, short nap. The two respondents who were not refreshed after naps mentioned their naps were associated with hypnagogic hallucinations, which is very disturbing so they try to avoid napping. Most respondents, however, claimed if their naps are not scheduled and prolonged, they would suffer from nocturnal sleep disturbances. Therefore, it is extremely important that naps would be scheduled for 15-20 minute periods and early evening napping should be avoided to secure a good night's sleep. Naps can also be extremely important in the daily life of children and adolescents with narcolepsy. At times, taking proper naps during the day at school or at home not only can help their daily performance but also may eliminate taking an extra dosage of stimulants.

#### Drug Holidays

"Drug holidays" as described by Goswami, Thorpy (1990) can be recommended, particularly if there are features of developing tolerance. Withdrawal from the medication and cessation of use for two or more weeks, depending upon the response of the patient, is often useful in reestablishing clinical effectiveness, sometimes at a

lower dosage. Drug holidays are usually scheduled around vacation times, but sometimes even weekend withdrawals are helpful. Among 41 respondents on stimulants, 36 said they go on drug holidays regularly. Twelve said they schedule drug holidays with their physicians and 24 said they scheduled their drug holidays themselves. Among the 36 with scheduled drug holidays, six said they go on long term one to two week drug holidays and 30 said they prefer weekends and short drug holidays due to lifestyle and school schedule.

PSYCHOSOCIAL MANAGEMENT OF NARCOLEPSY

Narcolepsy's misunderstood nature, living against all odds in the racing society, non-alertness is lobbied as laziness and not as a serious disorder. Laughter at persons who have fallen asleep in public, having to deal with school, work, driving impairments due to the constant battle with sleep attacks, pushes individuals with narcolepsy to social isolation and depression.

Peter Freund (1982) in his book "The Civilized Body," criticizes the individual's need for control in the society. The self control that can become a fetish and "freeze" or inhibit a person, so that letting go (even in situations in which letting go is functional) becomes impossible. the control of the uncontrollable (sleep attacks) for individuals with narcolepsy translates into lack of self esteem, self acceptance and self confidence. Furthermore, this results in self secrecy that makes narcolepsy more ambiguous than what it is. Narcolepsy's difficulty with everyday tasks along with complicity of drug treatment creates a conflicting situation with psychosocial implications for afflicted individuals.

In a comparison study of psychosocial effects between epilepsy and narcolepsy, Broughton and Guberman (1984) indicated patients with narcolepsy have been shown to have more psychological impairment with a greater degree of psychosocial impact of the disorder than is seen in

patients with epilepsy. As Broughton and group (1981) indicated, the psychiatric disorders which commonly occur include social introversion, adjustment disorders, major depression, anxiety, alcohol dependence and personality disorders.

#### What is Psychosocial Treatment?

Once any of the above-mentioned disorders are prevalent, seeking professional help is a step forward for individuals with narcolepsy.

Goswami (1992) discussed the sociomedical model for treatment of narcolepsy. This model replicates the role of the physician and the counselor and specifies the medical, genetic and general counseling components pertaining to narcolepsy. As Goswami discusses, traditionally, the model for counseling has followed the medical model of disease causation and medical care delivery, where the physician is the primary and predominant source of care. In this traditional model, the doctor-patient relationship is asymmetrical and counseling is directive. Communication generally flows from physician to patient, and the physician's emphasis is on providing medical information and advice on the diagnosis, treatment and genetic factors related to the patient's condition. How he perceives his illness, what impact it may have on his life, or what other support services, if any, may be needed, is often not known (Bloom and Wilson 1972).

Goswami's sociomedical model of counseling recognizes that a series of factors, which may be biomedical, social or psychological, may contribute to, or result in, a presenting illness. Therefore, interpersonal and socioenvironmental factors are important considerations in the delivery of medical services.

The key to the successful path of managing narcolepsy is the professional who knows the nature of the disease and both its medical and psychosocial management.

Effective treatment rests on such understanding and continued open commitment between patients and providers of care. This is essential to good therapy (Goswami, Thorpy, 91).

As Goswami (1992) argued, this professional, with a background in social science and public health medicine at the graduate level, followed by a year of training dealing with the specific illness (narcolepsy), would be an ideal counselor for such a service. A psychologist, sociologist, nurse or social worker with special training in genetics, public health and communication skills would be very effective in such a role. Ideally, this professional would be a generalist who is cognizant of and has training in the medical, social, psychological and spiritual dimensions of health.

It is known knowledge that all human beings at some point of their lives express significant feelings of

sadness, disappointment, anxiety and despair. However, having to deal with a chronic disorder such as narcolepsy, topped with depression and sadness, clusters the symptoms that can lead into serious psychosocial consequence of self-criticism, rejection, apathy, indifference, fatigue, low motivation and self blame. If recognized, these symptoms can be treated. Once the symptoms are recognized, the management means better coping skills with helplessness, hopelessness and their replacement with self acceptance and self control. Narcolepsy then becomes less of an ambiguous disease and more managed. However, the more silenced the person with narcolepsy is, the more destructive and isolated he/she can be to herself/himself, and unless they ask for help, no one would know they need help.

#### Counseling

Counseling is a tool which a person can use to help himself overcome difficulties in developmental process.

The counseling goal is determined by both the afflicted person and the professional who recognizes his needs. In the case of persons with narcolepsy, they must be helped to understand the ramifications of chronic disease and join in the effort to improve treatment and quality of life (Goswami, Thorpy, 1991).

In this research study, out of 53 respondents and their parents, 29 respondents and 12 parents had received

professional counseling upon or shortly after diagnosis. Among 41 (respondents and parents) who had received professional counseling, all but two respondents claimed they noticed a big difference within themselves or their children after they received counseling. 35 respondents and 18 parents had also been part of a support group, which I will discuss later in this chapter.

A 23-year-old graduate student who was diagnosed at age 16 with narcolepsy indicated, "When I was diagnosed, I was at the very critical age, not only did I not know how to deal with my disease, but also my parents and my brother didn't know how to deal with me. Going through counseling and support group was the best thing that happened to me. I started understanding my disease. Although I hated my disease, when I began to understand it, I was no longer afraid of it. My parents and my brother also began to deal with me rather than protecting me. I think they were relieved knowing that I wasn't going to kill myself and rather deal with myself. I couldn't do it without the help."

A 27-year-old woman shared her experience with me. "I was diagnosed at age 19. At the time I needed to know that I am bright and I have a fabulous future ahead of me. After I was diagnosed, I was mad and depressed, and I was anxious. It is hard to believe that one can be "sleepy" and "anxious" at the same time. I fell asleep more than

usual because I was depressed. I would wake up anxious and panicky. After all, despite your sleepiness, you can go through anything any healthy individual goes through. This battle went on for almost two years. Finally I got help and the person who helped me let me see how I was destroying myself. After awhile, I began to understand my problem. I was able to control my anxiety and my fear; the fear of losing control over life. Later I joined a narcolepsy support group and I saw others like myself. Now they help me and I help them too. It is great when you know you are not alone.

Although each individual's need for counseling varies and is personalized, the most general rule in the process of psychosocial management of narcolepsy is to establish two primary goals.

1. Self understanding.
2. Self acceptance.

In the process of coming to grips with narcolepsy and its symptoms, after afflicted individuals understand their disorder, accepting their own capabilities becomes a much easier task.

In the case of children and adolescents, they may need help in maintaining positive self esteem while recognizing that they may be limited in some areas or certain activities such as sports (depending on the severity of the narcolepsy).

Having to learn to deal with certain symptoms of narcolepsy such as cataplexy, hypnagogic hallucinations and automatic behavior will give the young afflicted adolescents the certainty that he/she needs to first understand the disorder and its symptoms; and second, to rebuild the self esteem required to maintain a teenagehood lifestyle. Building a better self esteem helps the process of restoration of natural hopes and dreams. Furthermore, with having sufficient self esteem, self acceptance can be born, where narcolepsy can become background rather than the whole life. And the new self is not a "forgotten" "discarded" self who is obsessed with narcolepsy.

A mother of a 16-year-old high school boy who was diagnosed at age 12 talked about her son's experience. "After diagnosis my son was at first extremely angry, but as time went on he became very depressed. His grades started to drop down and you could see that he was scared and frightened. One of his biggest fears was having cataplexy attacks. The fact that he would lose control at any time and fall to the ground made him scared and embarrassed. After I took him for professional help and he realized that he can control his attacks most times, he started seeing the light. Eventually he learned how to control his cataplectic attacks and he was no longer afraid of it. The less scared he became the less attacks he had. He is over that now. Although he knows his narcolepsy will always be with him, he is not desperate and helpless any more."

## COGNITIVE THERAPY

In the process of psychosocial management of narcolepsy, cognitive therapy can be used as a tool for a self-help approach.

As David Burns (1980) indicated, moods are created by a person's cognition. The term cognition refers to a variety of mental processes, including thoughts, perceptions, beliefs and attitudes.

The way we look at and interpret the events of our life will have a lot to do with how we feel. The self-help approach and technique of cognitive therapy have been shown to result in some elevation of mood (Preston, John, 1989).

The self-help techniques of cognitive therapy can help individuals with narcolepsy to improve their pessimistic views of the future; the negative perception of self and destructive emotions to give way to increased positive self esteem and self worth.

A 24-year-old marketing sales person talked about his experience: "Before my diagnosis at age 18 I was always an upbeat person. However, after having a few car accidents and having to deal with difficulties with medication, my life took a turn toward sadness to the point that I could not bear the pain anymore. After I started professional counseling I became more familiar with my disorder. I also learned coping skills and learned how to deal with my capabilities and incapacibilities. Eventually I gained my

upbeatness back. I had lost myself for a couple of years. Coming back was great. And now I am going to keep myself back."

Skilled counseling can help afflicted individuals establish self assurance and self control leading to a positive self image.

The following are general guidelines for the psychosocial management of narcolepsy:

1. Awareness of narcolepsy's symptoms, including symptoms secondary to the disorder such as mood swings, hopelessness, depression, apathy and anxiety.
2. Seek professional help, once the above symptoms have been noted and are no longer "self managed."
3. Professional help can be obtained by seeking for physicians, counselors, psychiatrists, social workers who are trained and familiar with narcolepsy's symptoms and its management.
4. Establish self help methods that can help you out of downward moods and apathy.
5. Join a support group that can back you up in your lonely times.

### SUPPORT GROUPS

In the past two decades, society has been witnessing the birth of a new system for helping different disorders called support groups. The support groups can be community, health center or patient borne. They can be supported and endorsed by different health care facilities, or they can be totally free and spontaneous. However, most often they have a sense of direction and may be run by a board of advisers consisting of patients, physicians, counselors or mental health professionals. Often they have none to very little attendance fees and they are open to the public rather than being a membership club.

Support groups are often formed around specific physical, mental or habitual problems. That specific problem becomes the core strategy of getting individuals to support and understand the problem. The problem can be anything from addiction to a mild or serious disorder. Support groups can be joined by children and adolescents as well as adults, however, most support groups have youth and adult divisions separately, inasmuch as their issues and concerns are different, depending on their age.

Support groups in conjunction with individual counseling and therapy can be helpful to:

1. Understand the disorder and its symptoms better.

2. Help parents and family members to understand the situation.
3. Support groups can be used as a self help system.
4. With the help of support groups, afflicted individuals realize that they are not alone and there are others like them, with the same or similar problems.

#### Narcolepsy Support Groups

In the United States there are several narcolepsy support groups. They are mainly run by sleep disorder centers, and there are several run by afflicted individuals with narcolepsy who have dedicated a great deal of time and effort to run the support groups. I have personally been involved in a few of these support groups, however, at the time of this research I was involved with two specific ones:

1. The Montefiore Narcolepsy Support Group, New York, run by the Narcolepsy Institute of Montefiore Sleep Center.
2. Boston Support Group run by dedicated individuals with narcolepsy.

Both groups are based on the needs of individuals with narcolepsy for educational and emotional supports.

The issues raised and discussed in the support groups may vary, but there are some examples of the topics:

- What is hypnagogic hallucination?
- Why do we dream?
- Living with cataplexy.
- Can we control our cataplexy?
- Legal issues and narcolepsy.
- Work and narcolepsy.
- Having children and narcolepsy.
- Going to college with narcolepsy.
- Adolescents and narcolepsy.
- How to control your vivid dreams.

Usually articles are passed among individuals for advanced reading, and one person can volunteer to open up the discussion. At times an expert can be brought to the meetings to discuss and give further information to the group.

The sessions typically run once a month at a convenient time, preferably night time so those who work can also join the group.

In this research study, out of 53 participants, 38 had participated in support groups while 20 were active members and 18 had at one point participated in a support group.

All participants claimed being part of the support group helped them cope with their narcolepsy much better.

Eleven parents and guardians of participants who were active members of support groups also claimed that

support groups not only had helped them understand narcolepsy better but also helped them assist their children better.

Those participants who were not active members anymore claimed they left support groups when they moved away or when they left for college.

Below are some of their experiences:

A 20-year-old woman who was diagnosed at age 17 shared her experience with me. "With narcolepsy, anything is self-doubt, but when you are with others who have the same disorder, you kind of feel you are going to be all right. This is the best support you can get because it comes from people who are just like you. Therefore, this support is real because they know your pain."

An 18-year-old girl who had been part of a support group for a while explained her experience. "Support groups are fine, but I dropped out because I was the youngest person and I had nothing in common with the others but my narcolepsy. I was also at the time in denial that I had narcolepsy. So maybe that was the reason."

It is rather important that the age category of participants be considered. In some states, narcolepsy support groups have two divisions, the youth section and an adult section. If there are not enough members in one state, sometimes a couple of support groups from other areas may merge and rather than monthly meetings, they may run every other month.

A 19-year-old college student described his experience. "At first I was reluctant to go to the support group, but after a while I was looking forward to each meeting. The fact that I saw others with the same or more disabilities than my own doing so well gave me such strength that I know I could go to college and accomplish like them. I knew I could get a job and start a family. The support groups give you a great deal of incentive."

Support groups, with cooperation from skilled counseling and family support can help and assist persons with narcolepsy to gain self assurance they need to get on with their lives.

Family support can be the best and most nurturing support system any person can have, granted that good dialogue and communication exist between the member(s) and afflicted individuals. At times it may be reassuring for family member(s) to also join in professional counseling as well as support groups.

Usually support groups are open to family members of afflicted individuals as well.

The following are general guidelines concerning support groups:

1. Look for a narcolepsy support group in your area by asking sleep centers to introduce one to you.

2. In the event that there are none near you, try to call other sleep centers and find one. You can also obtain a listing of patients and call one yourself.
3. Write to other narcolepsy support groups and obtain information and form a support group yourself.
4. Try your best to be part of a support group. It is great to know you are not alone.

EPILOGUE

....."I never thought I could walk down the aisle without having a cataplexy attack. Last year my brother walked me down the aisle and I got married." Michelle

"I always wished to be a public speaker, but with my cataplexy I thought I could never do that. But I went in front of a panel at school and I said, 'Hello, I have narcolepsy....Narcolepsy is my disease, it is not my fault....Hello, do you hear me?'" Christie

Throughout 2½ years of intense interviewing adolescents and younger adults, they shared with me their memories. Memories of days before diagnosis and memories of the days after diagnosis. Memories that were happy and memories that were sad. So I cried when they cried and I laughed when they laughed. It is hard to detach. After all, the field of Sociology is not about detachment. It is the field of reality of human interaction.

The memories shared with me were treasures and I will cherish them for the rest of my life. At the end of each interview I asked each respondent if they wanted to share a specific "message" with the public. I promised to publish these "messages" as they wished it to be heard. After completion, I came up with two categories.

1. "What I wished for with narcolepsy."
2. "The positive side of having narcolepsy."

"What I Wish For With Narcolepsy"

Public messages:

"I dream of running back home from college to my relatives, opening my arms without falling to the ground."

"I wish to carry young children in my arms with trust."

"I wish for a life without procrastination. Life with narcolepsy is hesitation."

"Wish for a cure that gives us a choice to live like others."

"Narcolepsy is a life without laughter. I envy those who laugh."

"Narcolepsy clouds my ability to make decisions."

"Narcolepsy is like having a 'hangover' that never goes away."

"I wished the public knew that I am not slow, I am only narcoleptic."

"I wished to play with other kids without falling asleep."

"Find us a cure - life is much nicer when you are awake."

The Positive Side of Narcolepsy

Public messages.....

"Narcolepsy allows me to look at the good side of everything. I don't take life for granted."

"I think of my narcolepsy as a gift that I should use to help others with narcolepsy."

"Narcolepsy is not a disease, it is an obstacle. You reach out every day for a better tomorrow."

"Narcolepsy lets you look at the other side of life that is hidden from others."

"Let's face it, with my narcolepsy I never have problems falling asleep."

"To not fall asleep I turn to art. That is the positive side of having narcolepsy."

"Narcolepsy gives you compassion for others with narcolepsy and other disorders."

"Narcolepsy has made me closer to God."

"Narcolepsy is part of my life. I don't know life without narcolepsy."

"What does not destroy me makes me stronger."  
Nietzsche

In search of a better tomorrow with better understanding for chronic disorders.

APPENDIX A - INTERVIEW GUIDE WITH THE PARTICIPANTS

The following was a guide for the topics which were addressed in each interview. After a brief introductory statement identifying myself and the goals of the project, I would request informed consent for the interview to be conducted and tape recorded.

I would like to ask you some questions about having narcolepsy. I would appreciate answers as full, complete and detailed as possible. Please take your time and do not rush. If you have any questions during the interview, please feel free to ask them. The following questions serve mainly as a guide and you should not feel limited by them in any way.

1. Your present age?
2. How did you first discover you had narcolepsy?  
(Falling asleep all the time, losing muscle tone, medical identification, etc.) When? Where?
3. How old were you when you felt this?
4. Tell me how you felt when you found out you had narcolepsy?  
  
What did you do?
5. Before this first realization that you had narcolepsy, did you ever suspect you might have something wrong with you? Tell me about that.  
(What was wrong? What did you do about it?)
6. Did any members of your family feel something was wrong with you? (What? Please tell me about it.)
7. When were you medically diagnosed and by whom?  
  
What led you to go to a physician in the first place?

Do you have any other medical problems or difficulties in addition to your narcolepsy?

8. Were you diagnosed wrongly? (misdiagnosed?)  
If so, as what?

How do you know this?

Did anyone ever tell you afterward that these symptoms were narcolepsy and not what you were told previously?

If yes, please tell me who?

9. How did the doctor find out you have narcolepsy?

Did you have polysomnography done?

How about blood tests?

10. Did you ever fall asleep in the classroom or other public areas during the day, before you were diagnosed as narcoleptic?

11. Did you ever have loss of muscle tone (cataplexy) before you were medically diagnosed as narcoleptic?

If yes, describe to me, how did you feel?

Did you only feel weak? Or did you fall to the ground?

12. Did you ever lose consciousness during a cataplexy attack (loss of muscle tone) before you were medically diagnosed as narcoleptic?

13. Did you ever experience having dream-like images as you were falling asleep or as you were getting up in the morning?

At what age do you remember that this started to happen?

14. Do you ever experience performing tasks without remembering it - writing, bike riding, etc.

At what age did this happen?

15. Has medical treatment been helpful to control your narcolepsy?

If yes, please explain.

16. Do you see a doctor regularly for your narcolepsy?  
How often?  
What does he/she do?
17. What is your relationship like with your doctor?  
Does your doctor listen to you and your problems?
18. Are you currently taking any medication for your narcolepsy?  
How about cataplexy?  
What is the name of the medication?
19. If you are not currently taking medication, tell me if you were taking it before.
20. Does anybody else in your family have narcolepsy?  
If yes, who?
21. Did discovering that you have narcolepsy affect your life? Try to describe how it has, or if it has not, why it has not.
22. When you discover that you have narcolepsy, were there any changes you had to make in your life? Tell me about them. If yes, why did you have to make these changes? (I will seek to find whether these changes are due to family, friends, school, etc.
23. Has narcolepsy affected your achievements, such as:  
Education:  
Daily activities:  
Sports:  
Interaction with others (friends):  
Work:  
Other:  
Please explain how.

24. At first, when you found out you have narcolepsy, did you talk with your family, friends, teachers and others about it?
- Whom did you talk to and what did you tell them?
- How did they respond?
25. Do you talk to people now - particularly new people you meet - about your narcolepsy?
- What do you say and how do they react?
26. How do other people become aware that you have narcolepsy? Do you tell them?
27. Under what conditions, or in what kinds of situations do you tell other people about your narcolepsy?
28. Does it matter to you that other people know you have narcolepsy? Tell me about it.
29. Do you think people relate to you differently after they find out you have narcolepsy?
- Would you tell me who?
30. Do you ever hide the fact that you have narcolepsy in a situation where information is requested or expected about it? If yes, would you tell me about it?
- At school?
- Driver's license? etc.
31. Do you think people can tell by looking at you or being around you that you have narcolepsy?
- How do you think they know?
- What do you do about it?
32. Tell me about your attacks. Sleep attacks.
- Cataplexy?
- or paralysis?
- How do you feel about these attacks?

33. Have the attacks ever caused you problems in social situations?
- In public?
- In school?
34. Does having a sleep attack or cataplexy in the presence of others affect their behavior to you?
- In what ways - both immediately and in terms of future interaction with you.
35. Do you know when an attack is coming? How?
- What do you do in such a situation. Please describe it to me.
36. Are there situations when you think an attack is more likely to occur? Tell me about these situations.
37. Do you carry anything with you that could identify you as having narcolepsy? (a bracelet? a card?)
38. Overall, how has narcolepsy affected your life? What kinds of difficulties has it caused in life, family, friends, school, work? Has having narcolepsy kept you from doing anything you wanted to do? Tell me about that.
39. Are there, or have there been, any periods or situations in your life when having narcolepsy has been especially difficult or troublesome? Tell me about them, please.
40. Has having narcolepsy affected your choice of career?
- Job?.
- What do you want to study? How?
41. Do you know any other persons with narcolepsy? Have you discussed narcolepsy with them? What type of things do you discuss? Are these persons your friends? Family members? Who are they?
42. Are you part of any narcolepsy social or support groups?

If yes, please describe what you do when you meet.  
How often do you meet?

43. If you are part of a narcolepsy support group, please tell me what the group has done for you. Is it helpful to your situation? Please describe.
44. Can you think of any advantages you have experienced from having narcolepsy? Tell me about them.
45. Have your family members, close friends, teachers, employers made any adjustments in their lives or situations to help you to cope with having narcolepsy? If yes, what are they? What kinds of things have they done?
46. Have any of these people done things, unintentionally, to make having narcolepsy difficult for you? Tell me about these things.
47. Do you think anyone has done anything intentionally to make it more difficult for you to cope with having narcolepsy?  
  
Who are these people and what kinds of things have they done?
48. In general, what do you think other people, people who do not have narcolepsy, think about it? Do you think they know what narcolepsy is?
49. What do you think could be done to help improve your narcolepsy - or could help narcoleptics in general? Please describe whether this is expected from the public in general, or from anyone in particular.
50. Is there anything else that you would like to tell me about what it is like to have narcolepsy?

APPENDIX B - COVER LETTER TO PARENTS

Dear Parent or Guardian:

I am a doctoral student at the City University of New York's Graduate School and University Center. In order to earn my degree, I must carry out a research project. I have chosen "Having Narcolepsy - The Experience and Treatment of Illness in Children and Young Adults" as my topic. This study will be conducted under the supervision of Dr. Meeta Goswami and Dr. Barbara Katz Rothman.

The attached information sheet outlines the purpose and procedures of the study. If you are willing to have your child participate, would you and your child please sign the attached consent form.

If you have any questions, please feel free to call me at (201) 857-4524 after 6:00 p.m.

Thank you for considering my request.

Very truly yours,

Sue Zafarlotfi

SZ:dm

APPENDIX C - CONSENT FORM  
(FOR PARTICIPATING CHILDREN AND PARENTS)

INFORMATION

"Having Narcolepsy, The Experience and Treatment  
of Illness in Children and Young Adults"

INVESTIGATOR

Susan Zafarlotfi  
Doctoral Student  
Sociology Department  
The Graduate School and University Center  
of the City University of New York  
33 West 42 Street  
New York, New York 10036-8099

PURPOSE

To investigate the experience of people who have narcolepsy. By doing this, it would first help to educate the Public and also it would help others in the future, with the same or similar disorders, to realize that they are not alone, and that once they are treated, they can enjoy their lives better.

PROCEDURES

All participants will be interviewed individually by Susan Zafarlotfi. Parents or other family members could be present at the time of the interview. The interviews will be tape recorded only for the purpose of documentation. The interview will last approximately one and one-half hours and will be scheduled at your convenience.

RISKS

Participants will not be exposed to any risks. No interviews will occur without the consent of participants and parents (in case of children, both the child and parent or guardian have to sign the consent). Any person who agrees to be interviewed and subsequently decides against doing so may withdraw from the study immediately. All records will be kept confidential and the publications will not include names.

### BENEFITS

The benefits drawn from the study will be:

1. Public education about narcolepsy.
2. Future persons with this disorder will benefit from your experience and will understand their condition better.
3. This study will be dedicated to all of you participants.

### QUESTIONS

Should any questions arise before, during or after participation in this study, families are encouraged to contact Susan Zafarlotfi at (201) 857-4254 after 6:00 p.m.

### CONSENT

I have read the above description of the study and discussed the procedures with my child. I give consent for my son/daughter to participate in the study. In addition, my son/daughter voluntarily consents to participate.

-----  
(Signature of Parent or Guardian)

Date:-----

\_\_\_\_\_  
(Signature of Student)

Date:\_\_\_\_\_

Student's Date of Birth:\_\_\_\_\_

APPENDIX D - COVER LETTER TO PARTICIPANTS

Dear Mr./Ms.

I am a doctoral student at the City University of New York's Graduate School and University Center. In order to earn my degree, I must carry out a research project. I have chosen "Having Narcolepsy - The Experience and Treatment of Illness in Children and Young Adults" as my topic. This study will be conducted under the supervision of Dr. Meeta Goswami and Dr. Barbara Katz Rothman.

The attached information sheet outlines the purpose and procedures of the study. If you are willing to participate, please sign the attached consent form.

If you have any questions, please feel free to call me at (201) 857-4524 after 6:00 p.m.

Thank you for considering my request.

Very truly yours,

Sue Zafarlotfi

SZ:dm

**APPENDIX E - CONSENT FORM (FOR ADULT PARTICIPANTS)****INFORMATION**

**"Having Narcolepsy, The Experience and Treatment  
of Illness in Children and Young Adults"**

**INVESTIGATOR**

**Susan Zafarlotfi  
Doctoral Student  
Sociology Department  
The Graduate School and University Center  
of the City University of New York  
33 West 42 Street  
New York, New York 10036-8099**

**PURPOSE**

To investigate the experience of people who have narcolepsy. By doing this, it would first help to educate the Public and also it would help others in the future, with the same or similar disorders, to realize that they are not alone, and that once they are treated, they can enjoy their lives better.

**PROCEDURES**

All participants will be interviewed individually by Susan Zafarlotfi. Parents or other family members could be present at the time of the interview. The interviews will be tape recorded only for the purpose of documentation. The interview will last approximately one and one-half hours and will be scheduled at your convenience.

**RISKS**

Participants will not be exposed to any risks. No interviews will occur without the consent of participants. Any person who agrees to be interviewed and subsequently decides against doing so may withdraw from the study immediately. All records will be kept confidential and the publications will not include names.

### BENEFITS

The benefits drawn from the study will be:

1. Public education about narcolepsy.
2. Future persons with this disorder will benefit from your experience and will understand their condition better.
3. This study will be dedicated to all of you participants.

### QUESTIONS

Should any questions arise before, during or after participation in this study, families are encouraged to contact Susan Zafarlotfi at (201) 857-4254 after 6:00 p.m.

### CONSENT

I have read the above description of the study and I give my consent to participate in the study.

-----  
(Signature of Participant)

Date:-----

Participant's Date of Birth: \_\_\_\_\_

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