

PERSPECTIVES

FROM THE NARCOLEPSY INSTITUTE

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ANESTHESIA AND NARCOLEPSY

We have received requests for information on the effect of anesthesia on the symptoms of narcolepsy. Below, for our patients' benefit, is a revised version of this topic previously covered in *Perspectives*.

Precautions to be observed before undergoing anesthesia

People who have narcolepsy and are scheduled for an operation requiring general anesthesia must inform the anesthesiologist of their sleep disorder. Select a doctor who is knowledgeable about narcolepsy and the interaction of medications for narcolepsy and anesthetic agents. Let your doctor know about all the prescription medications, over-the-counter medications and supplements you are taking.

Most of the medications for narcolepsy are metabolized by the liver, specifically by cytochrome P450-206; enzyme induction may occur. Also, the effects of atropine and ephedrine are enhanced by tricyclic antidepressants often prescribed for narcolepsy. Sodium thiopental will prolong the sedation during anesthesia, while ketamine may produce acute hypertension and cardiac dysrhythmias (Joseph 1990).



Should one discontinue the medications for narcolepsy before anesthesia?

Because of the possibility of cardiovascular effects, some professionals suggest withdrawal of medications for narcolepsy before surgery. This may increase the symptoms of narcolepsy, but does not seem to cause any long-term effects. In view of the exacerbation of symptoms of narcolepsy during withdrawal, other professionals advise against discontinuation of drugs and prefer to adjust the dosage for anesthetics. Patients may get cataplexy, hypnopompic hallucinations or sleep paralysis when they come out of anesthesia (Joseph 1990). The professional should be supportive and understanding and explain the progression of events to the patient.

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Recently, a study assessed post-operative outcomes of having anesthesia in people with narcolepsy (Cavalcante et al. 2017). The study was retrospective and compared 76 narcolepsy patients with controls matched for age, gender and type and year of surgery. Patients' records were reviewed for evidence of depression during phase 1 recovery and other perioperative (pertaining to surgery) outcomes.

Results of this study indicate that people with narcolepsy were more likely to be prescribed central nervous system stimulants (73.7 percent; 4.0 percent, $p < 0.001$) and antidepressants (46.1 percent; 27.6 percent, $p = 0.007$) versus the control group; people with narcolepsy were also more likely to have a diagnosis of obstructive sleep apnea (40.8 percent; 19.1 percent, $p < 0.001$) versus the control group. There was no difference in the intraoperative course (time during surgical procedure) between patients and controls. Episodes of respiratory depression were similar in the two groups. It is noteworthy that patients had a higher frequency of emergency response team activations versus controls. Most of the emergency episodes were due to hemodynamic (related to blood circulation) instability. The study notes one episode of excessive postoperative sedation and respiratory depression in one person with narcolepsy. At the Narcolepsy Institute, we have seen one case of prolonged sedation after anesthesia from which the patient recovered with no negative effects noted by the doctors in attendance.

References

Joyce, JA Anesthetic considerations for patients with narcolepsy. *AAANA J.* 1999;67(1):59-66.
Cavalcante AN, Hofer RE, Tippmann-Peikert M, Sprung J, Weingarten TN. Perioperative risks of narcolepsy in patients undergoing general anesthesia: a case-control study. *J Clin Anesth.* 2017 Apr 19. pii: S0952-8180(16)31027-3. doi: 10.1016/j.jclinane.2017.04.008. [Epub ahead of print]

RESEARCH NOTE: IMMUNOGLOBULIN THERAPY IN CHILDREN WITH NARCOLEPSY

Case reports of intravenous immunoglobulin (IVIg) in children with narcolepsy have been described in literature. Recently, a longitudinal observational study on this topic on children with narcolepsy was reported by a research team in France. The study was nonrandomized and open-label, and data were collected retrospectively from a single source, a national pediatric center for the treatment of narcolepsy. Twenty-four subjects received IVIg (three infusions administered at one-month intervals) in addition to standard care (psychostimulants and/or anticataleptic agents). Thirty-two subjects continued on standard care alone (controls).

Medical files were not available in two patients in each group. All 22 IVIg patients had cerebrospinal fluid (CSF) hypocretin ≤ 110 pg/mL and were HLA-DQB1*06:02 positive. Twenty-nine of the 30 control patients were HLA-DQB1*06:02 positive; all 12 with available CSF readings had hypocretin ≤ 110 pg/mL. Compared with control patients, IVIg patients had shorter disease duration and shorter latency to sleep onset, and more of them had received H1N1 vaccinations. Mean (standard deviation) follow-up length was 2.4 (1.1) years in the IVIg group and 3.9 (1.7) years in controls. High baseline UNS (Ullanlinna Narcolepsy Scale), indicating severe sleepiness but not IVIg treatment, was associated with a reduction in narcolepsy symptoms. Also, among patients with high baseline UNS scores, control patients achieved a UNS score < 14 (indicating remission) less rapidly than IVIg patients. The length of disease duration did not influence treatment response.

In summary, narcolepsy symptoms were not significantly reduced by IVIg. The independent effect of the IVIg treatment was not demonstrated. However, a subset of IVIg-treated patients, among patients with high baseline symptoms, achieved remission more rapidly than control patients.

Reference

Lecendreux M, Berthier J, Corny J, Bourdon O, Dossier C, Delclaux C. Intravenous immunoglobulin therapy in pediatric narcolepsy: a nonrandomized, open-label, controlled, longitudinal observational study. *J Clin Sleep Med.* 2017;13(3):441-453.



MONTELUKAST HELPS A 4-YEAR-OLD BOY WITH OBSTRUCTIVE SLEEP APNEA

A continuous positive airway pressure (CPAP) machine is recommended for the treatment of obstructive sleep apnea (OSA) in adults. However, children with OSA are recommended an adenotonsillectomy (surgical removal of adenoids and tonsils). In this case report, the authors describe successful management of severe OSA related to adenoid hypertrophy (enlarged adenoids) by oral administration of Montelukast.

Montelukast (Singulair®), recommended for asthma and for seasonal or year-round allergies, is a leukotriene receptor antagonist (LTRA). It blocks the action of substances in the body that cause the symptoms of allergies and asthma.

The subject in this case report was an otherwise normal 4-year-old boy who presented with symptoms of frequent snoring and mouth breathing. Clinically, enlarged tonsils and adenoids were noted. A polysomnogram test revealed severe OSA based on the apnea-hypopnea index (AHI), which was high at 102.5 events/hour.

The boy's parents refused surgery, so oral Montelukast (5 mg/day) was prescribed. After two months of treatment, the frequency and severity of snoring was reduced and the AHI was reduced to 2.4 events/hour, suggesting that oral Montelukast may be beneficial in some severe OSA cases related to adenoid hypertrophy.

Reference

Li T, Zhou G, Yang L, Tan L, Ren R, Sun Y, Li Y, Tang X. A four-year-old boy with unusually severe obstructive sleep apnea. *J Clin Sleep Med*. 2017;13(3):513-516.

NARCOLEPSY PATIENTS' PERSPECTIVES ON THEIR DISORDER

Traditionally, the definition of illness and the needs of patients are determined by medical professionals who focus on the physical aspects of a disorder and its medical management. Today, however, complex arrays of factors operate that make it necessary to reexamine the traditional methods of patient care. Patients not only want to live longer, but they also desire a good quality of life by being productive, staying independent and maintaining their dignity. The social and personal consequences of illness can best be determined by examining patients' perspectives of their illness. The proliferation of self-help groups and support groups across the country in the management of various diseases is testimony that, in addition to the medical management of disease, the non-medical aspects of care and the patient's perspective of the disorder are needed components of treatment.

PATIENTS NOT ONLY WANT TO LIVE LONGER, BUT THEY ALSO DESIRE A GOOD QUALITY OF LIFE BY BEING PRODUCTIVE, STAYING INDEPENDENT AND MAINTAINING THEIR DIGNITY. THE SOCIAL AND PERSONAL CONSEQUENCES OF ILLNESS CAN BEST BE DETERMINED BY EXAMINING PATIENTS' PERSPECTIVES OF THEIR ILLNESS.



It is noteworthy that the patient's point of view is gaining importance in recent research on narcolepsy. In a cross-sectional survey of 1,699 individuals with self-reported diagnoses of narcolepsy, researchers examined functional limitations, treatment responsiveness, symptoms and comorbidities (Maski et al. 2017). They also investigated the relationship between the onset of narcolepsy in children and the time of diagnosis.

Several narcolepsy groups (Wake Up Narcolepsy, Inc.; Project Sleep; and FasterCures) worked to support this survey to provide data for the U.S. Food and Drug Administration (FDA) in order to develop better drugs. People with narcolepsy had access to the survey on a Unite Narcolepsy website, indicating that it was an online survey, though this is not clearly stated. Individuals who are not computer savvy or lack access to a computer may be underrepresented. Sociodemographic variables, such as gender, income, education, occupation and place of dwelling, were not available.

Most of the survey respondents were between the ages of 18 and 54. Most participants reportedly received a diagnosis of narcolepsy more than one year after the onset of symptoms, and pediatric onset of symptoms was the strongest predictor of delayed diagnosis. The symptoms are likely to be missed if they occur before the age of 18. In 50 percent of cases, a diagnosis was made within five years of symptom onset, and only 18 percent received a diagnosis within one year of symptom onset.

Many factors could contribute to delayed diagnosis. Because people with narcolepsy look normal, their tendency to fall asleep in socially unacceptable situations is perceived by others as lack of drive or interest, or laziness. Or, they may be suspected of

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taking drugs. This causes delay in diagnosis as well as relationship problems with family members, teachers and employers. The symptoms of narcolepsy may be misdiagnosed, thus delaying the proper diagnosis. Furthermore, the symptoms of cataplexy in childhood are reportedly different from those of adult cataplexy and may sometimes resemble dyskinesia (impairment of ability to execute voluntary movements), posing difficulty in making an appropriate diagnosis.

Frequently reported symptoms

Daytime sleepiness (75.3 percent), cognitive difficulties (difficulty thinking, remembering, concentrating or paying attention (46.9 percent) and cataplexy (41.1 percent) were the most frequently reported symptoms among 943 respondents with cataplexy. Excessive daytime sleepiness (83.3 percent), general fatigue (54 percent) and cognitive difficulties (53 percent) were common among those without cataplexy (313). Survey participants without cataplexy reported fatigue, mental fog, mood problems and not feeling refreshed in the morning more frequently than those with cataplexy. Cataplexy-positive patients reported more limitations in lifestyle compared with cataplexy-negative patients. Many (67 percent) reported other diagnoses along with narcolepsy that required care, such as depression (24.8 percent), anxiety (17.7 percent), obstructive sleep apnea (9 percent), fibromyalgia (7.4 percent) and celiac disease (1.4 percent). The most common comorbidity—depression—was not associated with onset of narcolepsy in childhood.

Treatment Effects

Most respondents in this survey reported improvement with prescribed medications: substantial improvement (43.6 percent) or some improvement (45.1 percent) in their abilities to perform



specific activities of daily living. However, only 3.9 percent reported no daytime sleepiness; 57.1 percent reported daytime sleepiness and/or fatigue at least three times per day. Only 53 percent of those with cataplexy reported no cataplexy after treatment with anti-cataplexy medications.

REPORTED IMPROVEMENT WITH PRESCRIBED MEDICATIONS:

Substantial improvement in performing daily activities

43.6%

Some improvement in performing daily activities

45.1%

REPORTED DAYTIME SLEEPINESS WITH PRESCRIBED MEDICATIONS:

No daytime sleepiness

3.9%

Daytime sleepiness and/or fatigue at least three times per day

57.1%

Among reported problems with current treatment were, in descending order, side effects, lifestyle effects, inefficacy, insurance issues and high costs of medications.

The most commonly reported non-pharmacological approaches to managing narcolepsy were, in descending order, sleep hygiene, diet manipulation, exercise, food supplements and environmental changes such as sunlight, fresh air and lower room temperature.

Almost 68 percent of respondents reported no change in their condition versus 22.1 percent who reported worsening and increasing unpredictability of symptoms since diagnosis. Most responses indicated that persons with narcolepsy could not perform as well as they would like at work or at school due to their symptoms

Conclusion

Respondents reported daytime fatigue and sleepiness even with treatment for narcolepsy, which indicates the need for better treatment and management techniques. The negative consequences of narcolepsy on quality of life are high because of fatigue, mental effects and persistence of symptoms even with treatment. Many of our patients consistently report functional limitations in their personal, educational, occupational and social lives despite taking medications for narcolepsy. Each patient is unique, and a person-centered and family-centered holistic approach while tending to the comorbidities in narcolepsy will yield the most fruitful results in the management of narcolepsy.

Reference

Maski K, Steinhart E, Williams D, Scammell T, Flygare J, McCleary K, Gow M. Listening to the patient voice in narcolepsy: diagnostic delay, disease burden and treatment efficacy. *J Clin Sleep Med.* 2017;13(3):419–425.



DID YOU KNOW...

1. “Social jet lag” is linked to increased risk of heart disease.

“Social jet lag” refers to the habit of having different sleep patterns on the weekend than during the week. Researchers analyzed data obtained from 984 adult respondents in the Sleep and Healthy Activity, Diet, Environment and Socialization survey to study the effect of social jet lag on cardiovascular disorders. The results indicated that each hour of social jet lag is associated with an 11 percent increase in cardiovascular problems. The importance of sleep regularity and not just sleep duration was stressed by the authors during a presentation at the Association of Professional Sleep Societies (APSS) conference in Boston in 2017.

2. Vitamin D levels did not differ between people with narcolepsy with cataplexy and control subjects after controlling for relevant confounding factors.

Interestingly, without any connection to narcolepsy with cataplexy, frequent vitamin D deficiency was observed in men, obese individuals and blood samples collected in winter.

Reference

Dauvilliers Y, Evangelista E, Lopez R, et al. Vitamin D deficiency in type 1 narcolepsy: a reappraisal. *Sleep Medicine* 2017; 29:1-6.

COMPLIANCE WITH CONTINUING POSITIVE AIRWAY PRESSURE THERAPY AND EFFECTIVE MANAGEMENT OF OBSTRUCTIVE SLEEP APNEA

Some of our patients with narcolepsy and comorbid obstructive sleep apnea (OSA) often discontinue the use of the continuing positive airway pressure (CPAP) machine because of discomfort

or irritation caused by the machine. Some use the CPAP irregularly or for three to four hours per night. Research suggests that optimal compliance is essential to achieve metabolic benefits from CPAP therapy. What is optimal compliance? The study described below sheds some light on the effective compliance rate for CPAP users.

OSA is a risk factor for the development of type 2 diabetes mellitus (T2DM), and the severity of OSA increases with reduced glycemic control. In a nonrandomized study of 925 patients at the Atlanta VA Sleep clinics for evaluation of OSA, 86 percent were men, 61 percent were black, 65 percent were obese, and 28 percent had T2DM. In all, 720 patients were provided with CPAP therapy.

The researchers classified patients into three different groups: good adherence to CPAP (≥ 4 h/night on $\geq 70\%$ of the nights, $n = 174$), excellent adherence (≥ 6 h/night on ≥ 80 percent of the nights, $n = 118$) and outstanding adherence (≥ 8 h/night and $\geq 90\%$ of the nights, $n = 36$). No significant changes in HbA1c (hemoglobin A1c) and fasting blood glucose were reported in patients who showed good adherence to CPAP therapy. However, patients with outstanding compliance showed a significant improvement in delta fasting blood glucose and a trend toward improved delta HbA1c. Also, of those with normal glycemic control at baseline, 19 percent who used CPAP less than four hours/night developed impaired fasting glucose, whereas incident impaired fasting glucose was 8 percent in the excellent group and 5 percent in the outstanding group.

Reference

Ioachimescu OC, Anthony J, et al. VAMONOS (Veterans Affairs Metabolism, Obstructed and Non-Obstructed Sleep) study: effects of CPAP therapy on glucose metabolism in patients with obstructive sleep apnea. *J Clin Sleep Med*. 2017;13(3):455-466.

THE MEANING OF HAPPINESS

Gross National Happiness (GNH) was first conceptualized by King J.Y. Thinley, the prime minister of Bhutan, a small country in the mountainous region of northeastern India. In 2011, he proposed a World Happiness Day to the United Nations. The U.N. General Assembly declared March 20 as World Happiness Day in 2012, advocating “happiness and well-being as universal goals and aspirations in the lives of human beings around the world.” GNH is a paradigm based on a shared national objective of pursuing a common goal for the welfare of all people by good governance. In other words, happiness is achieved by balancing the needs of the body, mind and spirit. Seventy percent of the land in Bhutan is carbon negative. Free education and healthcare are available to all, and in surveys, 95 percent of the population claims to be happy.

More recently, the United Nations conducted a survey of 155 countries to assess levels of happiness. The results showed that Norway is the happiest country in the world and Denmark is the second (in the past, Denmark was first), followed by Iceland, Switzerland, Finland, the Netherlands, Canada, New Zealand, Australia and Sweden. These countries also have the common thread of providing social security for their citizens with education and healthcare for all. The United States ranked 14th. The lowest on the scale of happiness were Burundi (154), Tanzania (153) and Syria (152)—countries high in social disruption. These data suggest that security and safety are important contributors to the well-being and happiness of people.

Happiness is elusive and complex and is measured by various indicators; the main one in the survey noted above was gross domestic product (GDP). The report states that although money is important, it is not everything. Other indicators measured were life expectancy, generosity, social support, perceived freedom to make choices, and freedom from corruption. The report revealed that happiness is related to strong social structures. It is not just having

money but investing it wisely in education, health and healthcare, and support structures for the welfare of the people. Countries high on the happiness scale have invested in future generations through shared goals, generosity and good execution of policy, according to this report.

Happiness at work was measured in this report, showing that levels of happiness vary according to occupational status and job type. Although happiness was related to high-paying jobs, other indicators, such as type of job, level of autonomy and balance of work with family and social life, played an important role in determining levels of happiness. Professionals and managers reported higher levels of quality of life, compared with those in manual labor jobs after controlling for confounding factors. The survey showed that mental illness was the major cause of unhappiness.

Meaning of Happiness

Simply put, happiness is a feeling of contentment or satisfaction with life and feeling good about yourself.

What makes people happy? Different things make different people happy. Money, material things, success, youth, beauty and good health are all important for one's well-being. Those things make us very happy indeed, but they are impermanent or temporary. As soon as we have achieved our goals, we feel dissatisfied again and hunger for more. Is it possible to have happiness that is more lasting and meaningful? Try some of the following:

Sow good acts and reap goodwill

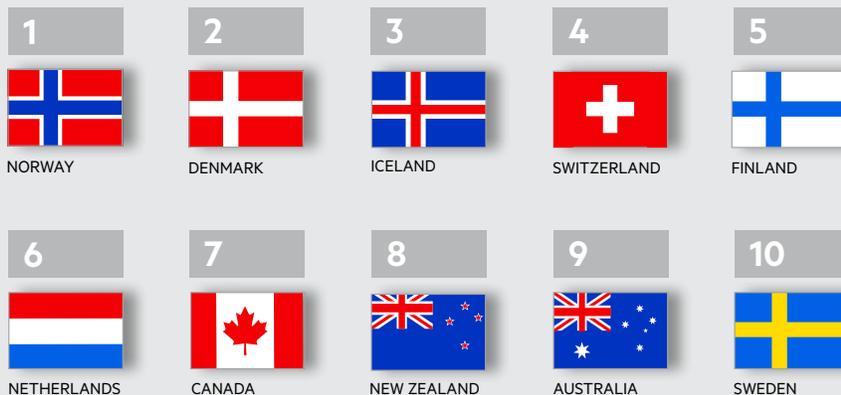
Perform good acts for as many people as you can as often as you can, without selfish motives or expectations of reward, and reap goodwill, friendship, as well as personal satisfaction, inner joy and peace.

Develop your strengths and assets

Develop an interest and get totally immersed in it. Do something

THE TOP 10 HAPPIEST COUNTRIES ACCORDING TO A UNITED NATIONS SURVEY

RECENTLY, THE UNITED NATIONS CONDUCTED A SURVEY OF 155 COUNTRIES TO ASSESS LEVELS OF HAPPINESS. HERE ARE THE TOP 10:



The lowest on the scale of happiness were Syria (152), Tanzania (153) and Burundi (154), all countries high in social disruption. These data suggest that security and safety are important contributors to the well-being and happiness of people.



creative and challenging, such as arts and crafts, cooking, writing and gardening, and engage in sports you like. All these activities will benefit your mood and well-being.

Express gratitude

Keep a special notebook to write down things that you are grateful for several times a week.

Laugh often

Laugh often and surround yourself with positive, nurturing relationships.

Maintain balance

Maintain a balance in your physical, mental and social health and avoid excess: Practice good judgment in lifestyle choices, develop and maintain positive emotions, show an interest in social justice. Have the courage to be truthful and stand up for what you believe in.

Practice compassion

Compassion is a feeling of kindness for the afflictions of others. The opposite of compassionate behavior is self-centered or indifferent behavior. Show empathy, that is, feel what others feel, and practice loving kindness toward others by developing your social and emotional intelligence. Studies show that compassionate people are more forgiving, are more socially embedded and have better health than those who are less compassionate. Meditation on compassion produces structural changes in the brain, as shown in magnetic resonance imaging (MRI) studies of meditators. Compassion moves you toward altruistic acts by making you more prosocial. The internal sense of peace and happiness when you perform a compassionate act lasts longer than any joy that might be derived from shopping or acquiring things. Compassion also increases one's intrinsic worth as a person and elevates one's self-esteem.

Practice spirituality

Is your life meaningful? Do you have a purpose or direction in your life? Rise above the mundane and, as mentioned earlier, express gratitude for everything you have. In your mind, replace hatred, anger and thoughts of revenge with love, kindness and understanding. Be truthful with yourself, in your relationships and at work. Whatever quality or action you concentrate on will grow; make a strategic shift from the negative to the positive in your thoughts, words and deeds. Personal growth is a lifelong process. We need to be watchful that we do not create an environment in which the weeds of negativity germinate in the precious garden that is our life.

Practice wisdom

Wisdom is the ability to discriminate between right and wrong and good and bad so that we can make the right choices in all spheres of life. Acquire wisdom by reading the works of the wise and associating with people who are wise. Mobilize the wisdom within you by honest reflection, contemplation and meditation.

Practice meditation

Meditate as often as you can at work and at home. Meditation is the skill of accessing your innermost self while slowly breathing in and out. Concentrate on your breath and on your heart area and



let your thoughts float by without judging or analyzing them. Even two minutes of this exercise will be restful and calming. Meditate in the morning upon awakening and at night before you go to sleep and reap the benefits: good judgment, a calm spirit, peace and HAPPINESS.

Inspiring words from the Dalai Lama:

“The best religion is one that gets you closest to God...that makes one a better person.”

“Whatever makes you more compassionate, more sensible, more detached, more loving, more humanitarian, more responsible, more ethical...the religion that will do that for you is the best religion.”

“What really is important to me is your behavior in front of your peers, family, work, community and in front of the world.”

“Remember the Universe is the echo of our actions and our thoughts. The law of action and reaction is not exclusively for physics. It is also of human relations. If I act with goodness, I will receive goodness. If I act with evil, I will get evil. What our grandparents told us is the pure truth. You will always have what you desire for others. Being happy is not a matter of destiny. It is a matter of options.

“Take care of your thoughts because they will become words.

“Take care of your words because they will become actions.

“Take care of your actions because they will become habits.

“Take care of your habits because they will form your character.

“Take care of your character because it will form your destiny.

“And your destiny will be your life.”

“There is no religion higher than the TRUTH!”

.....from a dialogue between the Dalai Lama and Brazilian theologian Dr. Leonardo Boff.

The best way to make your dreams come true is to wake up. —Paul Valéry

The happiness which we receive from ourselves is greater than that which we obtain from our surroundings.... The world in which a man lives shapes itself chiefly by the way in which he looks at it.

—Arthur Schopenhauer, *Essays*, 1841

PERSPECTIVES FROM THE NARCOLEPSY INSTITUTE

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ABOUT THE INSTITUTE

Narcolepsy is a chronic sleep disorder of neurological origin. Its main symptoms are (1) excessive daytime drowsiness with a tendency to sleep at inappropriate times; (2) cataplexy (sudden loss of strength in the muscles generally provoked by strong emotions, especially laughter or stress); (3) sleep paralysis (inability to move upon awakening) and (4) hypnagogic hallucinations (extremely vivid dreams or images upon sleep onset or upon awakening). Disturbed nighttime sleep, problems with memory and fatigue are common complaints of people with narcolepsy. Narcolepsy type 1 is narcolepsy with cataplexy, and type 2 is narcolepsy without cataplexy.

The Narcolepsy Institute, initiated in 1985, is committed to providing comprehensive care to people with narcolepsy by integrating the medical, social, psychological and spiritual dimensions of health, in a spirit of kindness and respect toward all, irrespective of race, creed, ethnicity or social class; that the recipients of care may realize their potential and live productively in joy, peace, harmony and dignity, and thus improve the quality of their lives.

Activities of the Narcolepsy Institute include: conducting professionally-led support groups, advocacy, and public and professional education. Counseling in a group set-up entails comprehensive management of the symptoms of narcolepsy and strategically applying behavioral and non-pharmacological approaches to ally the devastating impact of narcolepsy on the personal, social, educational and occupational lives of affected individuals and their families. Our patients benefit most by a family-centered and person-centered approach to improve the quality of their lives.

The contents of this publication are not intended to provide advice for individual problems, nor to replace medical advice. Readers are urged to consult with their professionals before initiating self-therapy. We welcome comments and suggestions about the contents of the newsletter.

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