

# Chapter 13

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## A challenge for patients, doctors, and society

...Here we review evidence showing the negative impact of untreated sleep apnea syndrome, the benefits of treatment that can help restore individuals to health, the public health aspects of these disorders, and the potential societal benefits of treating them. We believe that these are important issues for patients and their families to understand in their role as informed citizens...

—JH

### Who has disorders of breathing during sleep?

Millions of people in the United States are debilitated from the struggle to breathe during sleep. In the *New England Journal of Medicine* (April 1993), Terry Young and others reported on a study of working, middle-aged Americans. Based on their research, the frequency of disturbed breathing during sleep was estimated at 24 percent for men and 9 percent for women, while the frequency of clinically important sleep apnea was estimated at 4 percent for men and 2 percent for women. No wonder Dr. Eliot Phillipson, in an editorial that appeared in the same publication, called sleep apnea “a major public health problem.”

### *What harm is caused by sleep apnea syndrome and other sleep-disordered breathing?*

New evidence indicates that the whole spectrum of sleep-disordered breathing—including the hard-to-detect and often undiagnosed upper airway resistance syndrome, snoring, and hypopneas as well as apneas—has significant negative impacts on health and may even cause death.

There is strong and convincing scientific evidence that sleep apnea syndrome may be a causal factor of conditions that are among the leading causes of death in the United States. These include hypertension (high blood pressure) and cardiovascular and cerebrovascular disease (diseases of the heart, blood vessels, and brain including stroke). Heart disease is the leading cause of death in the United States, responsible for 30 percent of all deaths—almost 268 million deaths in 1999. Stroke, the third leading cause of death, was responsible for almost 62 million deaths in 1999. More than half of the people who die from heart disease are women. Death from heart disease affects African-Americans at a rate that is 30 percent higher than among white adults. Heart trouble and high blood pressure are leading causes of disability according to the CDC. Heart disease and stroke are largely preventable and caused in part by smoking tobacco, overweight, the lack of physical activity, and poor nutrition, according to the Centers for Disease Control and Prevention (CDC). To this we add that treating sleep apnea may also reduce the risk of heart diseases. It has been demonstrated that obstructive sleep apnea (OSA) is a

cause of cardiovascular disorders and the evidence is growing that effective treatment of OSA can reduce or eliminate this cause of disease. Findings of the Sleep Heart Health Study show that “sleep apnea increases the risk of heart failure 140 percent, the risk of stroke 60 percent, and the risk of coronary heart disease 30 percent.” This knowledge reinforces the need to treat or prevent sleep-disordered breathing and to develop new treatments.

Sleep apnea syndrome is clearly linked with other harmful outcomes, including excessive daytime sleepiness; impaired cognitive function; health-related quality of life; motor vehicle crashes; and accidents at work. Sleep apnea reduces vigilance and increases reaction times as badly as drinking alcohol or even being drunk, according to studies by Nelson B. Powell and colleagues. Sleep apnea syndrome has a negative effect on quality of life similar to the effect of other moderately severe chronic disorders. Sleep-disordered breathing is also associated with depression.

In pregnancy, sleep-disordered breathing may cause harm to the fetus—reducing growth, and may be a factor in pre-eclampsia, threatening the life of mother and unborn child. Pre-eclampsia is a disease affecting about 8 percent of pregnant women in the second half of pregnancy. It is marked by hypertension with abnormal protein excretion in urine, or swelling, and involves a change in the day/night pattern of blood pressure that, unless treated immediately, can lead to eclampsia (seizures or coma) that can cause the death of mother and unborn child.

There is a very long list of other conditions that seem likely to be the result of sleep apnea syndrome or other forms of sleep-disordered breathing. Hypertension is known to cause cardiovascular and cerebrovascular disease and death. About 50 million adults in the United States have hypertension. Studies have found that about 30 percent of people being treated for hypertension have sleep apnea. People with sleep-disordered breathing are more likely to suffer from hypertension, according to a study by Peppard and colleagues, which examined middle-class working adults in the Wisconsin Sleep Cohort Study. They found that people with sleep-disordered breathing tended to develop hypertension by the end of four years of suffering from this condition, and the worse their breathing, the more likely they were to develop hypertension. Even people with mild to moderate sleep-disordered breathing were likely to develop hypertension. Another study showed that sleep-disordered breathing was associated with hypertension.

Snoring is found in a very large number of people. A telephone survey conducted by Ohayon and colleagues of a representative sample of people in the United Kingdom found that 40 percent snored regularly. In a study of people aged 30–70 years in the Basque region of Spain, 35 percent of the population was found to be habitual snorers (more than five days a week) and 6 percent had breathing pauses, while 18 percent had excessive daytime sleepiness. Based on these findings, and

assuming a similar incidence rate in the United States, we estimate that 35 percent of the 142 million people in the United States aged 30 to 74 years may be habitual snorers—nearly 50 million persons.

Snoring may indicate the presence of sleep apnea syndrome, and may itself disrupt sleep. Daniel Gottlieb and colleagues used data from the Sleep Heart Health Study covering several thousand men and women. They found that people who snore are tired; they found excessive daytime sleepiness in 39 percent of people who snored six or seven times a week, compared to 15 percent of people who did not snore. The more times a week people snore, the more likely they are to have excessive daytime sleepiness. In another study, middle-aged (30–64) Swedish men who snored and felt sleepy had a higher risk of work-related accidents during a 10-year period. Women who snore have an increased risk of cardiovascular disease.

The negative outcomes of snoring or upper airway resistance syndrome (even without apnea or hypopnea) may include impacts on almost all of the negative health outcomes listed for sleep apnea syndrome.

Compared to similar people who do not have sleep-disordered breathing, the brains of people with obstructive sleep apnea have areas of injury, loss, and damage. Magnetic Resonance Imaging (MRI) studies by Paul M. Macey and associates show an association of the loss of brain tissue with sleep apnea in men who have diagnosed sleep apnea. Such damage can affect the control of breathing during sleep as well as other mental functions.

Macey suggests an interpretation—that the normal brain can handle minor breathing challenges during sleep, but that if the breathing control areas of the brain are underdeveloped or become damaged, this can lead to the development of obstructive sleep apnea. Obstructive sleep apnea can further injure the brain, possibly leading to a progressive, destructive feedback between apnea and brain damage. This research suggests a new avenue for diagnosis and treatment, while underlining the risks of untreated sleep apnea.

### *Sleep apnea syndrome in the middle-aged*

In 1999, in the United States there were 113 million people aged 30 to 59 years old. Based on the most reliable studies of how many middle-aged adults have sleep apnea syndrome, experts estimated in 2002 that about 20 percent or 22.6 million had at least mild obstructive sleep apnea and almost 7 percent or 7.6 million had at least moderate obstructive sleep apnea, as reported by Terry Young, Paul Peppard, and Daniel Gottlieb in their careful analysis “Epidemiology of Obstructive Sleep Apnea: A Population Health Perspective.” These statistics are based on *prevalence* studies (that tell how many people have a disease at a specific time) of overweight middle-aged white people. African-Americans, Hispanics, and other minorities may have equal or higher rates, and no ethnic group has been shown free of sleep apnea syndrome. (See “Sleep apnea syndrome in ethnic minorities” on page 208.)

And although overweight and obesity can contribute to or cause sleep apnea syndrome, because this is a syndrome, there may be other causes. A *syndrome* is a collection of symptoms and physical signs that indicate a clinical condition or disease, where the condition or disease can be caused by a number of different abnormalities, alone or in various combinations. Thus, many different causes can produce the same outcome. Any or all of them can contribute to causing sleep-disordered breathing in a specific person. Unfortunately, even today many physicians are more likely to identify and diagnose apnea in overweight men than in women and people with a lower *body mass index (BMI)* (a measure of appropriate weight for a person's height). Thus it is important to recognize that many people with obstructive sleep apnea (OSA) do not fit the old profile of an overweight, sleepy, middle-aged man—you don't have to be overweight, middle-aged, or male to have sleep apnea.

### *Sleep apnea syndrome in the elderly*

There are 45 million people aged 60 and over in the United States, including nearly 26 million women. A landmark study of obstructive sleep apnea in older people found that 70 percent of the men studied and 56 percent of the women had at least moderate OSA (apnea plus hypopnea index [AHI] of 10 or more). Data from the Sleep Heart Health Study shows that sleep-disturbed breathing increases steadily with age and then levels off at about 20 percent of the elderly. However, since studies seem to show that obstructive sleep apnea is not as frequently accompanied by symptoms like daytime sleepiness and hypertension in this age group, strictly speaking it means that sleep apnea syndrome is not notably greater than in the middle-aged population. Scientists are puzzled by the extent of sleep-disordered breathing in the elderly and do not have convincing evidence to decide if OSA in the elderly is benign or a dangerous epidemic. More research is needed to determine if obstructive sleep apnea (OSA) in the elderly is a cause of excessive daytime sleepiness, dementia, hypertension, and other problems, and to see what benefits may come from treating apnea in the elderly. Pending a resolution of these long-term scientific issues, it is reasonable and sensible to treat sleep apnea.

### *Sleep apnea syndrome in women*

There are differences in the symptoms of sleep apnea syndrome in men and women—differences in how these symptoms are reported to physicians, and differences in the way physicians respond. The symptoms reported by patients that cause physicians to suspect apnea are symptoms characteristic of men: self-reported apnea, loud snoring, choking, or restless sleep. But a large percentage of women do not report these symptoms. Women are more likely to report daytime fatigue, morning headaches, anxiety, and signs of depression. Women with upper airway resistance syndrome may report insomnia. Thus, women are likely to be misdiagnosed with depression or nonmedically based insomnia, delaying the recognition of sleep apnea syndrome, and they may be prescribed medications for depression or for

help falling asleep that actually worsen sleep apnea syndrome and sleep quality.

In the laboratory, compared to male patients, women have less severe apnea, which tends to appear in dream sleep. Disrupted dream sleep may be an important cause of daytime sleepiness. Women often complain of insomnia linked to upper airway resistance syndrome, and over half of upper airway resistance syndrome patients are women. *Upper airway resistance syndrome* is caused by a partial relaxation and narrowing of the upper airway that creates a slight resistance to the flow of air. The effort required to overcome this resistance grows increasingly greater until arousal occurs. This causes sleep to be fragmented, causing excessive daytime sleepiness or the perception of insomnia. It is a newly recognized problem that requires special equipment and/or procedures to observe it and many facilities are unable to test for it, so it is likely to be underdiagnosed. (See "Upper airway resistance syndrome (UARS)" on page 64.) Although upper airway resistance syndrome has impacts similar to those of sleep apnea syndrome, physicians have been unlikely to respond appropriately to the complaints of men or women with this problem.

At least 27 percent of pregnant women develop snoring in the last trimester. Sleep apnea syndrome may retard the growth of the unborn child and can contribute to the potentially very dangerous condition of *pre-eclampsia*. The changes in blood pressure in pre-eclampsia are similar to that seen in patients with snoring and obstructive sleep apnea. According to research undertaken by Colin Sullivan and his colleagues, mild partial obstruction of the upper airway is reported to be one factor related to an increase in blood pressure in pre-eclampsia, and CPAP treatment can contribute to the treatment of pre-eclampsia by helping to normalize blood pressure.

Female hormones may have some protective influence, and most women with diagnosed sleep apnea syndrome are perimenopausal or postmenopausal. Over the years of transition to menopause it has been shown that menopause is associated with sleep apnea syndrome in some women, and that hormone replacement therapy may help to protect women from sleep apnea syndrome. Scientists, however, have not yet shown convincingly that menopause is a risk factor for sleep apnea syndrome or that hormone replacement therapy can make a meaningful difference in treating the disorder. Much research will be needed to show if hormone replacement therapy can lead to a way to prevent or treat sleep apnea syndrome in women.

In Iceland, Gislason and colleagues found snoring in middle-aged women between 40 and 59 years of age, with habitual snoring in 11 percent and intermittent snoring in almost 22 percent. The women who had habitual snoring combined with daytime sleepiness were very likely to have hypertension or sleep apnea syndrome.

### *Sleep apnea syndrome in children*

A large percentage of children have daytime sleepiness, and children who snore most nights are very likely to be tired. Snoring and other

indications of breathing restrictions during sleep in children can be a sign of sleep apnea syndrome, with many cases in children of two to five years of age. Children who are obese and who habitually snore are very likely to have sleep apnea syndrome, affecting an estimated 20 percent of such children. Children with large tonsils may have sleep apnea syndrome. Overall, at least 2 or 3 percent of children are likely to have sleep apnea syndrome. Both boys and girls are susceptible.

Children with sleep apnea syndrome tend to be hyperactive, aggressive, or rebellious, to not pay attention and to not be alert. They tend to have academic problems and may have symptoms of attention deficit-hyperactivity disorder. This can all be summarized as an impairment of behavioral regulation caused by sleep-disordered breathing. They may have bed-wetting (enuresis). There is some indication they may be more likely to have cardiovascular disease. Treatment of sleep apnea syndrome in children may include attention to allergies or other correctable causes of difficulty in breathing. If the adenoids and/or tonsils are shown to be causing the sleep-related breathing disturbance, removing the adenoids and tonsils can lead to a dramatic improvement in symptoms. (See "Obstructive sleep apnea syndrome in childhood and adolescence" on page 195.)

### *Sleep apnea syndrome in adolescence and early adulthood*

There is very little research on this age group. Young people in this age range who have sleep apnea may have obvious daytime sleepiness; some may have enlarged tonsils and adenoids and can be treated surgically. CPAP is the preferred treatment when surgery is inappropriate or does not cure. However, some young people with sleep apnea may reject CPAP, and if their disease is severe, tracheostomy may be required. In very severe cases, if not treated, there is a risk of right ventricular heart failure that may lead to death, so diagnosis and effective treatment is crucial. If there is resistance to treatment, it may be helpful to consult with a psychologist or other mental health professional as part of the treatment team.

### *Sleep apnea syndrome in ethnic minorities*

One important study of sleep-disordered breathing suggests that some ethnic minorities may very well have high rates of sleep apnea syndrome. In this survey of middle-aged (40–60 years) people living in San Diego, high levels of oxygen desaturation (a measure of sleep apnea syndrome equivalent in this case to an apnea-hypopnea index of 15 or more) were found in 5.6 percent of whites, 15.9 percent of Hispanics, 16.7 percent of African-Americans, and 21.5 percent in Asians. There was a close relationship between overweight as measured by body mass index and sleep apnea syndrome. Eleven percent of men had sleep apnea syndrome and 5.3 percent of women had it. These study data, adjusted for age and ethnicity, predict that 7.2 percent of the United States population between the ages of 40 and 64 years has sleep apnea syndrome. This is consistent with the findings of other, larger studies. This study is noteworthy because it includes a representative sampling of minorities, unlike most other studies based on less diverse samples.

In a study at Stanford of apnea in Asian populations, men who were not obese nevertheless had severe sleep apnea syndrome. The structure of the head and face was possibly more of a causative factor than obesity in this sample.

### *Sleep apnea syndrome in families*

Each person is a unique genetic combination of genes, half of which are received from each parent. A copy of your genes exists in every cell of your body where they direct the creation of the chemicals and processes that support your life. Most of the traits we observe, such as height, intelligence, or a specific disease, are affected by a number of genes and by the environment. So your genetic inheritance may predispose you or make you more or less susceptible to a disorder or illness, and only in some instances does a single specific gene lead to a specific trait or disease.

Sleep apnea is in part a familial disorder and an inherited disorder. Members of the same family share the same environmental conditions, and each child shares half the genetic makeup of each parent. People who have relatives who snore are also more likely to be snorers. People who have apnea and hypopnea are more likely to have relatives with these symptoms, and one study even suggests that the severity of the symptoms may be correlated with those of relatives.

Susan Redline and her colleagues have done important studies of sleep apnea in families. Working in Cleveland, they identified families with two or members who had sleep-disordered breathing. They then selected individuals from these families, some who had sleep-disordered breathing and some who did not. They selected as normal controls people from the same neighborhoods who did not have sleep-disordered breathing. Sleep-disordered breathing was defined as a respiratory distress index (RDI) over 5 in people under 25 years of age, a RDI over 10 for people between the ages of 26 to 40, and a RDI of over 15 for people aged 41 to 50 years. They found a relationship between sleep-disordered breathing and a weak response to low oxygen levels in the blood and a tendency for airway narrowing when greater effort is required to draw in air. Simply, sleep-disordered breathing may be caused in part by a reduced ability of the body to control breathing and possibly to a weaker-than-normal ability to maintain a *patent* (open) airway during conditions of partial obstruction or flow limitation.

But how to account for the finding that some relatives of people with sleep-disordered breathing did *not* have sleep-disordered breathing, despite having a reduced ability to control breathing as tested? The researchers believe that the reason is that sleep-disordered breathing may be caused by two or more factors working together, including problems in breathing control, obesity, and abnormal airway structure.

Since there are many pathways that may lead to sleep apnea syndrome, scientists are studying each of these risk factors and searching for an underlying genetic cause for each pathway. Obesity is closely related to sleep apnea syndrome in many patients and seems to have a

partial genetic component. The size and shape of the skull and face can create a small upper airway and thus lead to upper airway collapse during sleep. The dimensions of the skull and face seem to be affected by inheritance and the dimensional patterns may differ by race or ethnicity. The brain's control of breathing and the receptors that monitor breathing are additional factors that could affect the development of sleep apnea syndrome. These and several other possible contributors to disease are being studied in an effort to more fully understand how each contributes to sleep apnea syndrome, the complex ways in which these factors interact, and to identify the underlying genetic bases for each factor. As this work continues, new forms of prevention and treatment may be discovered.

In a study of inheritance of sleep apnea, Ovchinsky and other researchers at a pediatric sleep laboratory (SUNY Health Science Center in Brooklyn, New York) looked for sleep-disordered breathing in close relatives of children who had been diagnosed with sleep apnea syndrome. Telephone interviews brought in information about 256 adults and 189 children who were first-degree relatives of 115 children with sleep apnea syndrome. Nearly 44 percent of the family members were reported to have habitual snoring. Among the adult relatives, nearly 27 percent had symptoms that suggested sleep apnea syndrome as did 12 percent of the children.

Thus, if you have sleep apnea, some of your relatives and children may be more likely to have or to develop it. You can help your relatives who may have obvious problems like snoring and daytime fatigue by suggesting they consider asking their doctor about sleep apnea. You can watch for possible apnea in your children and make sure they receive careful evaluation and treatment.

## Sleep apnea syndrome and the public health

It is now becoming more clear that effective treatment of obstructive sleep apnea (OSA) helps to restore health, including specifically disease and death related to cardiovascular disease and car crashes, as well as relieving excessive daytime sleepiness. Therefore, the real problem facing the public health system is to create an effective action plan that can cause the health care system to recognize that sleep disorders, including OSA, can be treated and that effective treatment provides major benefits to society as well as to the individual. Because the health care system tends to move very slowly in integrating new scientific knowledge, other avenues to promote change may be important.

The public health problem faced by society requires a policy based on the best scientific understanding of the damages and costs in health, productivity, and financial expenditures, if sleep apnea syndrome and other breathing disorders of sleep are not diagnosed and treated; compared to the costs of diagnosis and treatment and the benefits in health, well-being, and productivity. While the scientific evidence is

imperfect, nevertheless experts see possible strategies for each of several categories of disease.

### *Treating sleep apnea syndrome*

Physicians and researchers have not found it possible to create a perfect correlation between the severity of sleep-disordered breathing and the health impact. To measure sleep-disordered breathing, should they use the apnea-hypopnea index? An apnea-hypopnea index (AHI) of 5 or more is considered mild, an AHI of 15 or more is considered moderate, and 30 or more is considered severe obstructive sleep apnea. Should they measure the amount and duration of reduced oxygen in the blood? Should they measure the fragmentation of sleep? And what impacts should they measure: sleepiness, cognitive impairment, or hypertension? These issues are a continuing topic of debate and research aimed at improving the understanding, prevention, and treatment of sleep-disordered breathing.

Everyone who experiences abnormal breathing during sleep is exposed to a greater risk of poor health outcomes or even death—some risks have been proven, others seem likely to experts. Who should be treated? There is no perfect way to determine who should be treated. The current approach to diagnosing sleep apnea syndrome is to combine an apnea-hypopnea index with a daytime symptom.

On the basis of their comprehensive analysis of the public health impact of sleep apnea syndrome, Terry Young, Paul Peppard, and Daniel Gottlieb believe that people with *OSA syndrome*—defined as mild obstructive sleep apnea (an apnea plus hypopnea index [AHI] of at least 5) coupled with daytime sleepiness and/or hypertension—should be treated. However, there are many persons with OSA—defined by frequent apnea and hypopnea—who do not report daytime sleepiness, but who are likely to have health problems related to obstructive sleep apnea.

Young, Peppard, and Gottlieb believe that, because treatment of people who have obstructive sleep apnea and symptoms of sleepiness “will reduce known serious health risks, there is an ethical imperative...” to find and treat everyone with a clinically significant level of disease. However, they also recognize that given current methods of treatment, many people with mild to moderate OSA will go untreated. This could change if there were new forms of effective treatment that were less expensive and more acceptable to patients.

At present, experts believe we are only treating about 5 to 10 percent of people with sleep apnea syndrome, resulting in a very high cost to individuals and society measured in disease, lowered quality of life, car crashes and work-related accidents, and death. To be able to treat all people in this category, society would have to allocate perhaps ten times its current expenditure on health care resources for sleep. Clearly, better systems for screening, diagnosis, and treatment would facilitate this massive effort. There would have to be intensive publicity and education for the public as well as training and education for health care professionals, especially primary care practitioners.

### Making CPAP treatment effective for the long run

While many patients do not continue their treatment, which leads to reported low compliance rates, nevertheless an effective program of education, problem-solving, and support can result in 85 percent or more of patients continuing with effective treatment. Instead of blaming patients for noncompliance, efforts must continue to raise the quality and improve the methods of health care delivery in order to keep diagnosed people from falling by the wayside. Sleep apnea syndrome is a chronic disorder and treatment with CPAP needs monitoring and support for the long term.

People who do not feel tired, depressed, or have some other immediately tangible symptom are harder to identify and may be less motivated to be persistent in their treatment efforts. However, patients who experience the benefits of successful treatment in the first week and who continue treatment for the first weeks or months tend to have long-term adherence to therapy, with success rates from 62 to 97 percent continuing to use CPAP for a year or more. Perhaps the greatest reinforcement to continuing treatment are the improvements, as reported by Terri Weaver, felt by the person with apnea whose treatment is effective and used on a nightly basis—"the ability to once again engage in social activities, fulfill their daily roles, and be as active as their peers."

A new analysis of why patients continue to use or discontinue use of CPAP sheds light on the whole process of *adherence* to treatment, offering some new explanations as well as a new model of providing support. Adherence and *patient use* of a treatment are ways of referring to the goal of successful adoption of a treatment program. These terms are part of an effort to move away from the more paternalistic idea of compliance and to consciously involve the patient's knowledge, perceptions, and feelings in the treatment process. Heather M. Engleman, a research psychologist, and Matt R. Wild, a clinical psychologist, have been working with Neil Douglas, an internationally recognized sleep physician, at the University of Edinburgh in Scotland. Their paper, "Improving CPAP Use by Patients with the Sleep Apnoea/hypopnoea Syndrome (SAHS)" includes a detailed review of studies of CPAP use. These studies focus largely on technical issues of treatment and various methods to overcome these problems and show that a very large proportion of patients either refuse or discontinue the use of CPAP. It is striking that the studies—which focus on biomedical and technological issues—are largely unable to predict who is likely to succeed with treatment and who is likely to fail.

Engleman and Wild point out that the adherence problem with CPAP is comparable to that found in other diseases or disorders with a demanding treatment regimen. They report that the health attitudes and beliefs of the person with a disease, as well as mental and physical status, are important in predicting adherence to the prescribed treatments in other diseases. They view a patient as making an evaluation of the balance between the costs and the benefits of a treatment, and they hold that "the outcome may be determined as much by [the] patient's attitudes, perceptions, and resources in coping with prob-

lems, as by their objective nature.” Thus they conclude that care delivery should include a focus on education and support to help the patient adopt an understanding and outlook that will lead to a more accurate and positive evaluation of treatment. They recognize the important role that spouses and bed partners can play in aiding the treatment process. And they propose a new model for intervention that would provide “educational, behavioral, and technological components” to all patients, and provide additional cognitive and behavioral support where needed.

We have long advocated a multimodal, multidisciplinary approach to supporting the efforts of people with sleep apnea to manage their condition. (See “You can be helped by others and you can help others” on page 154.) Innovative approaches such as that proposed by Engleman and Wild, which are open and responsive to all the needs of the patient and spouse, may well lead to improved treatment success and thus to improved health and well-being for many more people with sleep apnea.

Treating mild sleep apnea syndrome, snoring, and other milder forms of disease

People with snoring and light disorders of sleep breathing including apnea plus hypopnea index (AHI) of 5 or less; in addition to upper airway resistance syndrome may benefit from treatment. The treatments appropriate for mild sleep-disordered breathing include CPAP, oral appliances, and certain surgical treatments. However, many people do not realize they have a sleep problem and even if diagnosed, they may find the current treatments to be too much of a burden unless they experience some tangible benefit—such as relief from fatigue. Weight loss and weight control may be the best available intervention for them.

*Preventing sleep apnea syndrome through public health initiatives*

Another approach to reducing the public health burden of sleep apnea syndrome would be to develop treatments or interventions that could slow or stop the development of sleep apnea syndrome. Factors that have been identified as risk factors possibly leading to sleep apnea syndrome include excess body weight, smoking, alcohol use, obstruction of the nasal airway by congestion or abnormal anatomy, and hormonal changes during menopause. People who are overweight and who snore tend to develop worse symptoms leading to sleep apnea syndrome. Since chronic nasal congestion may possibly lead to snoring and apnea, it could be worthwhile to do research to confirm that treating nasal congestion can diminish snoring and apnea. There is some evidence that suggests that menopause may lead to sleep apnea syndrome and that hormone replacement therapy could reduce this risk. The evidence is not strong enough to be the basis for treatment, especially since hormone replacement therapy introduces new health risks. Alcohol consumption and smoking tobacco are considered possible treatable causes of sleep-disordered breathing, but the evidence is not yet conclusive.

The only factor that has been demonstrated to have a cause and effect relationship that can be corrected by behavioral change is excess body

weight. On average, overweight and obese people with sleep apnea syndrome who lose weight may experience a reduction in apnea plus hypopnea index (AHI). Weight gain increases the chance of developing sleep apnea syndrome and tends to make it worse. Reducing caloric intake by a long-term change in eating habits and exercise can help people to lose weight and keep their weight under control. Therefore experts propose that weight control may be the best intervention in clinical settings or as a public health measure. Even if apnea does not respond to weight control, there are many other health benefits. Unfortunately, the United States is in the midst of an epidemic of overweight and obesity, suggesting that getting people to adopt weight control may be difficult.

### Treating sleep-disordered breathing improves personal and public health

Snoring and sleep apnea syndrome can be treated. Some of the symptoms and impacts of sleep apnea syndrome respond quickly to treatment. Treatment can eliminate or reduce daytime sleepiness and motor vehicle crashes. The resolution of other problems has not been fully proven, but experts believe it is important to treat in the belief that it is important to avoid possible future harm.

We believe that urgent efforts to identify and treat sleep apnea syndrome sufferers, especially those who are severely affected, should be made. But the resources to treat so many people are not available. We estimated in 1992 that there were over 250 accredited and an estimated 500 to 1,200 or more nonaccredited sleep laboratories, each capable of handling 200–300 patients a year. Even if all these facilities were to devote their entire resources to the diagnosis and treatment of sleep apnea syndrome, it would have taken 25 years to handle the backlog of untreated sufferers in the United States. Ten years later, in 2002, there are nearly 600 accredited facilities (laboratories and centers) and at least 1,292 other facilities treating sleep disorders. The American Board of Sleep Medicine has recognized over 1,940 Board-Certified Diplomates as professionals qualified to do clinical sleep diagnosis and treatment. Research based on a questionnaire survey of sleep facilities and careful estimates of the numbers of sleep studies leads to an estimate of 1.17 million sleep studies in 2001 in the United States.

We do not have solid information on the incidence of sleep apnea, or on the total number of people who have been diagnosed with apnea and who are still alive. We propose an estimate of about four million based on the following reasoning. We know from a published report that the number of people in the United States diagnosed with sleep apnea syndrome rose from 110,000 in 1990 to 1.3 million in 1998. If we assume that the number of new diagnoses increased by the same percentage each year, we get an estimate of the number of diagnoses in the intervening years. If we add all the diagnoses together we reach a total estimate of 4.6 million. This assumes that everyone who was diagnosed with sleep apnea is still alive (which is probably too optimistic). We conclude that there is a large number of people with diag-

nosed sleep apnea, possibly about four million in number. This estimate is, however, higher than others provided by some experts. It is disturbing that, according to industry sources, the number of people currently using CPAP is estimated at only about 2.5 million. This implies that about 1.5 million people who have been diagnosed with sleep apnea are either using another form of treatment, or no treatment.

*Treating apnea improves health  
and saves lives and money*

People with undiagnosed sleep apnea have almost double the average medical costs each year, \$2,720 compared to \$1,384. In fact, the worse the breathing disorder, the higher the costs. Vishes Kapur and others studied the medical cost of undiagnosed sleep apnea by comparing the medical histories of people with sleep apnea and the histories of *controls*—people who were similar but did not have apnea. They estimated that a middle-aged adult (between the ages of 30 and 60) with moderate to severe sleep-disordered breathing (an apnea plus hypopnea index [AHI] of 15 or more) required \$1,956 extra in health care. Researchers believe that at least 80 percent of middle-aged people who have moderate or severe obstructive sleep apnea (OSA) have not been diagnosed. They estimate that there are 1,716,000 undiagnosed middle-aged persons with moderate or severe OSA in the United States. These figures suggest a medical cost burden of \$3.4 billion a year for untreated OSA in the United States.

Other researchers, including a group working with Meir Kryger in Canada, have found a similar pattern of increased costs related to undiagnosed apnea. Obstructive sleep apnea (OSA) patients used medical resources heavily in the decade prior to diagnosis; the costs included increasing numbers of more expensive physician visits and hospitalizations that cost \$3,972 per patient compared to \$1,969 for the controls. Costs increased from year to year over the ten years studied prior to diagnosis.

Yuksel Peker and his colleagues in Sweden found that middle-aged people with obstructive sleep apnea had an eleven-fold increased risk of developing cardiovascular disease including high blood pressure and coronary artery disease. People who were diagnosed and undertook effective treatment had a reduced experience of cardiovascular disease, hypertension, coronary artery disease, or a cardiovascular event. Their risk was very close to that of people who did not have OSA, while people with diagnosed OSA who did not get effective treatment had much higher risks.

Additional evidence that treating obstructive sleep apnea can reduce hypertension is provided by a study conducted by Heinrich F. Becker and his colleagues, including Colin Sullivan. They used CPAP to treat patients with moderate to severe obstructive sleep apnea over a period of about 65 days. Patients who received a very low treatment pressure had a 50 percent reduction in apneas and hypopneas but no important change in blood pressure. However, patients who received their full, correct treatment pressures had an overall drop in day and

night blood pressure of 10 mm mercury. (Blood pressure is measured by comparing it with the height of a column of mercury.) Such a drop would be predicted to reduce the risk of coronary heart disease by 37 percent and the risk of stroke by 56 percent. The results of this study emphasize the importance of highly effective treatment to achieve the full benefits and shows a direct link between effective treatment and reversing hypertension related to obstructive sleep apnea.

The evidence that treating obstructive sleep apnea (OSA) improves health is growing and persuasive. Kryger and his team have shown that people with OSA who have been effectively treated use fewer medical resources—as measured by physician billing and hospital stays. They had fewer contacts with their doctors and fewer medical tests. Over the two-year study period, their medical resource use went down each year, although these patients still used more medical resources than people without OSA. The patients who used CPAP on a regular basis enjoyed improved health. Diagnosis was not enough—the patients who did not use their treatment (CPAP) continued to have high health care costs. The researchers believe that people with OSA are often not correctly diagnosed and are instead given inappropriate (and ineffective) treatments for diseases like hypertension and heart disease. They argue that diagnosing and treating OSA would result in cost savings, fewer car crashes, and better health.

According to the National Highway Traffic Safety Administration (NHTSA), the annual economic impact of motor vehicle crashes in 2000 was \$230.6 billion, including 41,821 fatalities and 5.3 million injuries. The major causes of fatal crashes include alcohol (46 percent of fatal crashes) and excessive speed (30 percent of fatal crashes). The economic costs of a single fatality may be as high as \$2 to \$5 million. The NHTSA reports that falling asleep while driving is responsible for over 100,000 road crashes a year, leading to 40,000 injuries and 1,550 deaths. Sleep-disordered breathing reduces reaction time and worsens performance as badly as drinking alcohol or even being legally drunk. Alcohol and sleepiness interact to create an increased risk of crashes. Nelson B. Powell and associates have compared the effects of alcohol and having obstructive sleep apnea. They believe that sleepiness caused by sleep-disordered breathing is as dangerous for drivers or people working in safety-sensitive positions as driving under the influence of alcohol or even driving drunk.

Crashes caused by drowsy driving due to untreated apnea are preventable, according to current research findings. Findley and his colleagues analyzed reports of crashes from the Colorado Department of Motor Vehicles and found that people with sleep apnea syndrome who were not treated had a lower accident rate after treatment. The untreated had an accident rate of 0.07 accidents per driver per year, but after treatment the accident rate dropped to zero. This means that if 100 people with untreated sleep apnea syndrome drive for a year, there are likely to be 7 crashes, which are preventable by effective treatment of apnea. In an editorial in the prestigious professional publication, *Thorax*, Findley and Suratt point out conclusions from recent

research to support the importance of treating people with apnea to prevent car crashes. People with untreated OSA have a rate of car crashes that is two to four times higher than normal, and people who have been effectively treated for OSA using CPAP have fewer car crashes. Effective treatment would protect patients from injury, loss of wages, expense, and possible death or liability for causing the death of others.

Findley and Suratt use research findings as the basis for an example estimating the benefits of treating 500 patients for three years. Treatment would prevent 180 serious crashes and 36 injuries, saving over a million dollars in property damage, medical costs, lost wages, and legal and administrative expenses. There would be a 20 percent chance of preventing one fatality. Findley and Suratt argue that because of the clearly demonstrated health and economic benefits of treatment, government agencies and insurance companies should not limit or refuse treatment for people with sleep apnea.

Under current systems of health care, the costs of treatment are borne by the health care providers and insurers, but the costs of *not* treating are spread more widely. We believe that an economic argument can only work for the insurer if the costs of providing treatment for apnea are less than the costs of providing treatment for people who have not been treated for apnea. Under the current system in health maintenance organizations (HMOs) in the United States, for the example presented by Findley and Suratt, we estimate that treatment of 500 persons for apnea for three years would cost about \$5,500 to \$6,000 per person for a total of \$2.75–\$3.0 million. Based on the studies of medical resource use by Kapur and by Krieger, discussed above, we believe there would be a savings of about \$3,000 per person per year for a total savings of \$4.5 million on overall health costs as a result of treatment for apnea over three years. There would be a cost of treatment of \$3 million and a savings of \$4.5 million, for a *reduction* of expenditures of \$1.5 million. If this projection is realistic, then even for an organization ruled primarily by financial considerations, the economic benefits of treating should be convincing.

*Most sleep apnea syndrome is not diagnosed although the situation is improving*

In the ideal situation, when people with sleep problems come for treatment in a primary care center, their sleep-related complaints would be heard by their physicians and they would be diagnosed and treated. Unfortunately, as shown by Raymond Rosen and his colleagues, a very small number of sleep-related diagnoses were made, either in a family-oriented community health center serving a minority population (predominantly Hispanic and African-American) or in an internal medicine clinic at a medical school serving a largely Caucasian population. At the community health center, 19 percent of patients checked off complaints of sleep symptoms but only about one-tenth of one percent received a sleep-related diagnosis. The patients treated at the medical school did not fare much better. This study likely represents what happens in other settings.

Why aren't sleep disorders  
recognized?

There is a growing body of evidence that doctors do not recognize sleep apnea and instead treat the diseases and complaints that accompany, and may be caused by, apnea. What are the reasons for the failure of the health care system to recognize sleep disorders? The reasons for this failure to identify, diagnose, and treat sleep apnea syndrome include the fact that medical education does not yet adequately cover sleep disorders. Most medical students only receive about two hours of education in sleep and sleep disorders. Many physicians complete their medical educations with very little experience or knowledge of sleep disorders, and consequently are not sensitive to sleep disorders in their patients. Unless physicians have been trained in sleep disorders, they do not ask the patient about sleep. They have been taught to recognize symptoms and diseases that may be related to a sleep disorder—heart disease, blood pressure, depression, injuries from car crashes, and so on, so they treat these conditions. But they usually ignore the sleep disorder. For example, in a survey of 70 trauma centers, none ever screened for OSA in motor vehicle crashes of unknown cause, and in the trauma center at the University of Pennsylvania, no sleep studies were done on 60 drivers whose crashes could not be explained.

Sleep may not be recognized as an important health factor by patients. Even if patients do tell their physicians about sleep-related problems, the information does not make it into the medical record or the complaints are 'explained' by inappropriate diagnoses of other diseases.

William Dement has been a tireless advocate of improving awareness of sleep disorders and has been involved in efforts to educate physicians about sleep and to encourage the medical system to diagnose and treat them. (See page xii.) He believes that the most obvious place to identify and treat sleep disorders would be in the primary care setting. As a step toward developing a solution, he has been involved in research to measure the gap between the number of people with sleep disorders and the much smaller number of people in treatment. One study by Kushida and other colleagues of Dr. Dement involved a careful survey of 1,254 patients in a primary care clinic in Moscow, Idaho. Questionnaires and interviews were used to identify people who reported symptoms of insomnia, restless legs syndrome, and obstructive sleep apnea syndrome. Over 60 percent of the study population had at least one sleep problem.

A person was presumed to be likely to have sleep apnea if these symptoms were reported—"loud snoring and/or witnessed sleep-related breathing pauses or sleep-related respiratory symptoms (such as gasping, gagging, choking, or snorting) and excessive daytime fatigue or sleepiness." Of the men, 32 percent had these symptoms as did 16 percent of the women. A small number of patients were convinced to have a sleep study, and the results tended to confirm the validity of the identification (presumptive diagnosis) of sleep apnea by symptoms. The results of this study show the very high prevalence of sleep disorders, including sleep apnea, in primary care practices. Unfortunately, none of the patients identified in the study had been

## Innovation in primary care

diagnosed by their physicians! This makes very clear the importance of taking steps to change this situation.

Dement and his colleagues have been working on a “Primary Care Sleep Education and Training Project” intended as a model for primary care practices. This model includes sleep specialists helping to educate primary care physicians and the development of relationships between primary care physicians and a sleep lab. The idea, successfully tested in the community setting of Walla Walla, Washington, is to educate physicians and their patients about sleep disorders in order to increase the rate of diagnosis and treatment.

Doctors can only know what medical science has looked for and studied. Apnea was long considered a disease of very sleepy, very obese men, and women were not even counted in most studies until 1993. Based on diagnosed cases (mostly men) and population studies that did not usually study women, the ratio of men to women was thought to be 10:1 or even 60:1. Recent studies that have looked at populations in the community (and avoided the bias in sampling) have found a ratio of about two or three men to one woman. There still remains a gap in our knowledge of apnea in women; and women with sleep-disordered breathing are still likely to be overlooked in diagnosis.

Researchers conclude that despite the large number of sleep studies done each year, “the vast majority of individuals with obstructive sleep apnea in the U.S. remain undiagnosed.” Some researchers have estimated that only about 10 percent or less have been diagnosed, others suggest as many as 20 percent may have been diagnosed. In a study that screened 4,925 employed adults with ready access to health care, only 18 percent of the men with moderate to severe sleep apnea syndrome had been diagnosed, and only 7 percent of the affected women had been diagnosed.

Another reason that sleep apnea syndrome is not diagnosed and treated stems from the fact that some insurers resist treating obstructive sleep apnea (OSA) or limit dollars spent on diagnosing and treating OSA. Either they are not convinced of the health and cost benefits, or they hope that the negative health care costs of OSA will fall on some other insurer (since patients switch insurance plans frequently). However, even where costs are less of a factor, most cases of OSA are not diagnosed.

Thus, while overall the vast majority of people with sleep apnea are not diagnosed, certain groups are even more likely to be overlooked: women, people with mild forms of the disorder, and minorities including African-Americans, Hispanics, Asians, and others.

There has been encouraging progress in educating health care professionals and the number of reports of diagnosed sleep apnea showed a twelve-fold increase, from 110,000 in 1990 to 1.3 million in 1998. Sleep apnea was identified mainly by primary care physicians, pulmonologists, and otolaryngologists (ear-nose-throat specialists). But most people with sleep apnea syndrome have not been diagnosed.

## Sleep apnea syndrome in the national health care debate

Clearly, society needs to inform and educate people with sleep apnea syndrome while creating the capacity to treat them. Despite the large number of people suffering from sleep disorders, including sleep apnea syndrome and snoring, these problems are hardly mentioned in the national debate about health care costs and priorities in the United States. Here is a major health problem which, thanks to scientific and medical progress, can be readily diagnosed and treated. Yet society has not yet allocated the resources to educate the public to help identify and overcome it. Nor has society yet provided an adequate supply of trained people and institutions that would suffice for the diagnosis and treatment of sleep apnea syndrome. A comprehensive program would include financing for public education, a treatment system, and continuing research and professional education. The costs of such a program would more than likely be small compared to the economic benefits for society as well as for the individual sufferer.

According to Daniel Callahan, a writer on medical ethics, we are faced with a health care system whose costs steadily rise. In his provocative book, *What Kind of Life*, he suggests that society must seek to balance the economic costs of health care with the goals and needs of both society and the individual. Because the ability to pay for health care is limited, Callahan sees the need to establish priorities and to allocate finite resources. He therefore proposes allocating available resources to treatable diseases where the patient will receive clear benefits. Currently available therapies to treat sleep apnea syndrome meet the criteria set forth by Callahan. Successfully treated patients may expect a longer life span, a lower risk of cardiovascular disease, a marked improvement in cognition and ability to function, and the restoration of a healthy emotional outlook. Some cardiopulmonary diseases are caused by sleep apnea syndrome, and treatment reduces this risk. Treatment can reduce the burden of car crashes and other accidents caused by fatigue due to apnea and possibly reduce the escalating cost of complications in cardiovascular disease.

Public education, identification of patients, and treatment for those severely affected by sleep apnea syndrome should be made a high national health care priority. Growing evidence that effective treatment of sleep apnea syndrome can reduce the negative health impact strengthens this argument.

## Strategies for the future

Important programs to educate health care professionals, the public, and physicians and to continue innovation in technology and delivery systems have been initiated by the U.S. government, by sleep professionals, and by industry.

## *The role of the NCSDR*

Following the recommendations of the National Commission on Sleep Disorders Research, a National Center on Sleep Disorders Research

(NCSDR) has been created within the National Heart, Lung, and Blood Institute of the National Institutes of Health. The NCSDR serves four key functions: to focus and coordinate a wide range of activities in sleep and sleep disorders, to support basic and clinical research, to train scientists, and to transfer technology to health professionals, policy makers, patients, and the public. A study of the cardiopulmonary consequences of sleep apnea is ongoing. The NCSDR is seeking sleep physicians in every community who will serve as educational leaders, encourage medical schools to establish or enlarge their sleep medicine curricula, and serve as a local community resource to news media. The NCSDR has begun to support significant efforts in research, training, and education. We applaud their efforts to support and coordinate research and to translate basic science and clinical experience into programs that can improve the health of people with sleep disorders. Their educational materials as well as updates on research can be found on their Web site, <<http://www.nhlbi.nih.gov/about/ncsdr/index.htm>>.

Research directions of the  
NCSDR

The NCSDR has accomplished much and is developing research strategies for the five years from 2003. Here are some selected highlights from a NCSDR draft plan for research that indicate the kinds of issues researchers consider important, but may not reflect the final plan, which was not yet available when we went to press. An overview of the 2003 Revision of the *NIH National Sleep Disorders Research Plan* is presented by Dr. Carl Hunt. (See page ix.)

#### Sleep and aging

Sleep-disordered breathing has been shown to be a risk factor for cardiovascular disease, including hypertension and coronary heart disease. Excessive daytime sleepiness is associated with cognitive decline and certain types of dementia. New research may test the effects of established treatments for sleep-disordered breathing in the elderly.

#### Sleep and health

A great deal of research is needed to better establish what is normal sleep for all ages and both sexes. It is known that poor or insufficient sleep can lead to sleep debt, and even a few days can lead to cognitive deficits. But in the longer term, sleep debt may have health-related consequences, including viral illnesses, diabetes, obesity, heart disease, and depression. Most people in the United States have insufficient sleep, and for people with sleep-disordered breathing, the sleep they get is of poor quality.

#### Sleep and safety

Drowsy driving causes as many fatalities and injuries as alcohol-related crashes; 4 percent of all fatal crashes are due to drowsy driving. Untreated excessive sleepiness is a cause of drowsy driving crashes. It is now clear that no one is immune from the effects of sleep loss and fatigue. This includes transportation workers (aircraft pilots as well as train engineers and truck drivers), doctors, and people in many other safety-sensitive positions. Doctors and nurses work long hours with

insufficient sleep, and this may be one cause of about 100,000 fatal medical errors in U.S. hospitals each year. Future research will focus on strategies to assure that work-related and other sleep deficits can be avoided.

#### Effects of sleep deprivation in adults

Scientists are just beginning to find out how sleep deprivation affects the ability to think or act. They are starting to evaluate various medicines or strategies (such as naps) to overcome the effects of insufficient sleep, and are studying how sleep works to restore alertness and performance.

#### Effects of sleep-disordered breathing and sleep deprivation in children

Snoring is common in children, affecting 18–20 percent of infants, 7 to 13 percent of children in the range of 2 to 8 years, and 3 to 5 percent of older children. Snoring signals increased upper airway resistance. OSA and snoring are suspected of causing many short- and long-term health problems and future research will explore these relationships and attempt to determine what is normal sleep in children and at what level of disordered breathing treatment may be needed. Children whose sleep is disturbed or inadequate experience daytime sleepiness and behavioral problems. However, much research is needed to identify the physical, developmental, intellectual, or performance problems that may be caused by poor sleep.

#### Effects of sleep-disordered breathing and sleep deprivation in adolescents

Normal changes in adolescence lead to a *phase delay* (falling asleep later and waking up later) in early puberty, and a decrease in daytime alertness in mid to late puberty. Adolescents need about 9 hours of sleep but research has shown that most adolescents get only 7 to 7.5 hours of sleep a night, leading to a serious sleep debt. Adolescents thus tend to live with chronic partial sleep deprivation. Most schools open when adolescents are not yet fully awake, although some schools have adjusted scheduling to accommodate their students. Adolescents tend to have very irregular sleep patterns, sleeping much longer on the weekend than during the week. Taken together, these factors have a number of negative impacts on alertness, mood, vigilance and reaction time, attention, memory, behavioral control, and motivation. These changes can lead to declines in performance in school, at work, and while driving, as well as increased risk-taking. Research is needed to understand the mechanisms of sleep in adolescence, to evaluate the impact of chronic partial sleep deprivation on health, and to evaluate possible treatments. Narcolepsy may emerge in adolescence.

According to a panel of experts, drowsy driving is particularly risky for sleep-deprived people, and especially young men. Sleep debt causes drowsiness, and a person who is very drowsy cannot avoid falling asleep even while driving. Moreover, even small amounts of alcohol can increase the risk of a crash; driving during the early morning hours is another risk. Government agencies, the National Sleep

Foundation, and others are developing educational and intervention programs to help young people reduce their exposure to drowsy driving crashes.

#### Disorders of breathing during sleep

Sleep apnea syndrome is a known risk factor for hypertension and is associated with stroke, heart attack (myocardial infarction), and congestive heart failure.

The familial and genetic factors that may lead to sleep apnea are becoming clear, as well as possible differences among ethnic groups in the mechanisms linking different genes to sleep apnea. The use of oral appliances has also become better understood. Much research is needed to understand the mechanisms that may lead to obstructive sleep apnea. The use of CPAP reverses many of the cognitive and quality of life problems caused by sleep-disordered breathing. The impact of therapy needs further study and evaluation of the benefits of therapy affecting a persons ability to function, psychiatric disorders, cognitive function, hypertension, cardiovascular disease, and metabolic syndromes such as diabetes.

The NCSDR will promote the development of new and improved types of treatment of sleep apnea syndrome, including medications, surgery, oral appliances, behavioral intervention, muscle stimulation, the use of positive airway pressure including methods that may improve compliance, and more.

#### Professional and industry directions

The American Board of Sleep Medicine (ABSM) is striving to raise standards of training in the specialty field of sleep medicine. The current system has been one of apprentice training; the ABSM, however, is moving toward a system of accredited fellowship training programs to assure the highest standards in the field.

Physicians, scientists, health product manufacturers, and others have been developing innovative alternative strategies for diagnosis and treatment to cope with this enormous health problem. Such strategies employ many techniques, including, for example, questionnaires that can be administered by the family physician to help identify sleep apnea syndrome symptoms, the widespread use of home sleep studies, and home monitoring of treatment. Experts must balance the benefits of reaching a much larger population using simpler, less expensive tests, against the fact that a sleep lab still provides a more accurate and reliable evaluation.

Unfortunately, many people who have been diagnosed and prescribed treatment for apnea don't follow through. Such so-called lack of *compliance*—where the patient does not follow the prescription—is common in many *chronic* conditions that cannot be cured by medical intervention and thus require continuing treatment and management. Instead of placing blame on patients, the health care system needs to adopt new strategies better suited to chronic conditions as well as to work more closely with patients. Some health care providers have reported that 85 percent and more of their patients maintain effective

CPAP or other prescribed treatment, showing that a well-designed treatment program can work for most people with sleep apnea syndrome. And patients need to learn how to manage their condition and have the motivation and persistence to make the treatment work.

### *What does the future hold?*

Current technological advances, coupled with public and professional education and innovative health care strategies, may bring relief to the millions who suffer from sleep apnea syndrome. In the end, technology is just a collection of instruments that a skilled person must select and apply; just as a composer or conductor is needed to create music out of the many instruments of the orchestra. Just as an orchestral performance is the result of collaboration among members of the orchestra and the conductor, so health care is moving toward new collaboration between health professionals and people with sleep apnea and their families.

If you have sleep apnea, you can spread the word. Very likely you have a family member or relative who also may have sleep apnea, and your friends and colleagues in your work and community settings may also have apnea. A word from you could lead them to a dramatic improvement in health and possibly save a life. You could share your experience in successful treatment of your sleep problems with your primary care physician, who might be encouraged to recognize and help other patients with sleep apnea syndrome. Doctors do respond to positive feedback.

The greatest challenges facing the world of sleep medicine are as much political and policy matters as they are medical. While the knowledge of sleep science is imperfect, and even the best treatments tend to require a sometimes demanding, long-term effort by people with a sleep disorder, nevertheless medical science has shown how to diagnose and treat people with sleep-disordered breathing. But only a small fraction of the people who could benefit from treatment have been reached. There are millions of people with diagnosed sleep apnea. You could join with them to support more research; better methods of diagnosis and treatment; better education for primary care physicians and other health care workers; and increased public awareness.

Source: Chapter 13 of: *Sleep Apnea—the Phantom of the Night: Overcome sleep apnea syndrome and snoring—win your hidden struggle to breathe, sleep, and live*. Peabody MA: New Technology Publishing, Inc., 2003. ISBN: 1-882431-05-7

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