

POLIO PERSPECTIVE

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Sleep Disturbance Can Lead to Lower Bone Formation

By Dr. Richard L. Bruno

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SLEEP DISTURBANCE CAN LEAD TO LOWER BONE FORMATION

Insufficient sleep, a common problem that has been linked to chronic disease risk, might also be an unrecognized risk factor for bone loss. Results of a new study were presented Saturday at the Endocrine Society's annual meeting.

The study investigators found that healthy men had reduced levels of a marker of bone formation in their blood after three weeks of cumulative sleep restriction and circadian disruption, similar to that seen in jet lag or shift work, while a biological marker of bone resorption, or breakdown, was unchanged.

“This altered bone balance creates a potential bone loss window that could lead to osteoporosis and bone fractures,” lead investigator Christine Swanson, M.D.

“If chronic sleep disturbance is identified as a new risk factor for osteoporosis, it could help explain why there is no clear cause for osteoporosis in the approximately 50 percent of the estimated 54 million Americans with low bone mass or osteoporosis,” Swanson said.

Inadequate sleep is also prevalent, affecting more than 25 percent of the U.S. population occasionally and 10 percent frequently, the Centers for Disease Control and Prevention report.

The 10 men in this study were part of a larger study that some of Swanson’s co-authors conducted in 2012 at Brigham and Women’s Hospital in Boston, Mass. That study evaluated health consequences of sleep restriction combined with circadian disruption. Swanson defined circadian disruption as “a mismatch between your internal body clock and the environment caused by living on a shorter or longer day than 24 hours.”

Study subjects stayed in a lab, where for three weeks they went to sleep each day four hours later than the prior day, resulting in a 28-hour “day.” Swanson likened this change to “flying four time zones west every day for three weeks.” The men were allowed to sleep only 5.6 hours per 24-hour period, since short sleep is also common for night and shift workers. While awake, the men ate the same amounts of calories and nutrients throughout the study. Blood samples were obtained at baseline and again after the three weeks of sleep manipulation for measurement of bone biomarkers. Six of the men were ages 20 to 27, and the other four were ages 55 to 65. Limited funding prevented the examination of serum from the women in this study initially, but the group plans to investigate sex differences in the sleep-bone relationship in subsequent studies.

After three weeks, all men had significantly reduced levels of a bone formation marker called P1NP compared with baseline, the researchers reported. This decline was greater for the younger men than the older men: a 27 percent versus 18 percent decrease. She added that levels of the bone resorption marker CTX remained unchanged, an indication that old bone could break down without new bone being formed.

“These data suggest that sleep disruption may be most detrimental to bone metabolism earlier in life, when bone growth and accrual are crucial for long-term skeletal health,” she said. “Further studies are needed to confirm these findings and to explore if there are differences in women.”

NON-FATIGUING GENERAL CONDITIONING EXERCISE PROGRAM (THE 20% RULE)

By Stanley K. Yarnell, MD (retired), California

The non-fatiguing general conditioning exercise program using the 20% rule was designed to restore stamina or endurance for those individuals who have continued to be bothered by profound fatigue following surgery, illness or trauma.

The program begins by determining the polio survivor's maximum exercise capability with the help of the clinic physical therapist. The type of exercise can be in a pool or on dry land, using an arm ergometer or an exercise bicycle, depending on the individual's abilities and preferences. If one prefers swimming, the maximum number of laps that the patient can swim is used as the maximum exercise capability. If the survivor has considerable residual weakness and is only able to swim one lap in half an hour, then the amount of time actively swimming can be used as the maximum exercise capability rather than the number of laps.

Having established the maximum exercise capability, the polio survivor is instructed to begin his aerobic swimming program at 20% of the determined maximum exercise capability. He can swim three to four times per week at that level for one month, and then he is instructed to increase by 10%. For example, if an individual is able to actively swim in a pool for half an hour, then one-half hour would be his maximum exercise capability. He would begin swimming just six minutes per session three to four times per week for a month before increasing the amount of time actively swimming to nine minutes three to four times per week for another month. Then he would increase by 10% once again so that he was actively swimming 12 minutes per session three to four times per week for another month, and so on. After three to four months, our patients have reported that they feel an increase in their general stamina or endurance.

Alternatively, if an arm ergometer or exercise bicycle is used, the same basic principle can be utilized, calculating distance pedaled or time spent actively pedaling. The individual begins his aerobic or non-fatiguing general conditioning exercise program at 20% of maximum exercise capability three to four times per week for one month before increasing the distance by 10%. He continues with that level of activity for another month before increasing by another 10%, so that he is exercising at 40% of maximum exercise capability.

For example, if an individual is able to pedal an exercise bicycle for one mile or is able to actively pedal the bicycle for up to 20 minutes, then that is his maximum exercise capability. He is instructed to begin his exercise program at one-fifth of a mile (or, if time is used, then four minutes is the beginning exercise time). This is repeated three to four times per week for a month before increasing the distance to one-third of a mile or six minutes. Our patients are encouraged to maintain that for an additional month before increasing by another 10%, and so on.

Individuals are cautioned to stop if they become fatigued during their exercise program, or if they experience pain or aches in their muscles. Most polio survivors are able to continue increasing their exercise program to nearly the maximum exercise capability, though it clearly would take a full nine months if this program were strictly followed. Conditioning or aerobic exercise at this submaximal level allows the individual to regain a healthier sense of stamina without damaging delicate old motor units.

It is imperative to incorporate the concept of pacing and spacing within the non-fatiguing general conditioning exercise program, meaning that rests are to be taken every few minutes.

The 20% rule is sometimes also applied to polio survivors when they are given instructions in a home flexibility and stretching program so they do not exercise too vigorously.

This exercise program can be modified with the supervision of a physical therapist, depending on the progress made by the polio survivor. This program may not eliminate fatigue, but we have found it effective for those who have a significant element of deconditioning contributing to their sense of fatigue.

BASIC BEGINNING EXERCISE FOR POLIO SURVIVORS AND MORE

“Exercise admonitions: Take these exercises to your doctor and ask your doctor if it is all right for you to complete this routine. Do not exercise within one hour of a meal (before or after). Do not exercise within two hours of the time you plan to go to bed. Do not continue to exercise if you feel very tired or are unable to talk easily. Remember that if you are more fatigued after exercises you should not increase the frequency of exercises and you may want to break up the exercises so that you complete five of the exercises in the morning and five in the afternoon. Stop any exercise that causes any sharp pain. If possible, exercise when someone else is close by. Start by completing the exercises once daily. After two weeks of daily exercises, and depending on how tired you are after exercising, you may increase the exercises to twice daily.” David Guy, MS, CPT USA (ret). *Guy is a retired physical therapist who has worked in multiple settings from the Army to universities. He has worked with polio survivors throughout his career. He now helps out with a polio support group in Arizona.*

Beginning Exercise

1. Seated on a chair with arms, place your hands on your knees, then, simultaneously, raise your arms overhead and breathe in deeply. Lower your arms and exhale. Complete five repetitions.
2. Seated in a chair with arms, stretch your arms straight in front of you and then, slowly twist your arms and your body to the left and then, to the right. Complete five repetitions.
3. Seated in a chair with arms, grasp the arm rests, lean forward and pushing down on your hands on the chair arms, try to lift your bottom off the chair. Complete five repetitions.
4. Seated in a chair with arms, lean back into the chair and try to lift your right knee up. Lower the right knee and do the same with the left knee. Complete five repetitions with each leg.
5. Seated in a chair with arms, lean back and try to straighten out your right knee and lift your foot up as high as you can. Lower the right foot and do the same exercise with your left leg. Complete five repetitions with each leg.
6. Rest for 20 to 30 minutes after completing the exercises.

Additional Exercises

1. Lying on your bed, lift one leg straight up as you are able without bending the knee
2. Lying on your bed, place a small rolled towel behind your knee and then try to straighten that knee.
3. Lying on your bed, bend both legs and place your feet so that they are flat on the bed. Reach with your hands up toward your knees and lift your head and shoulders.
4. Lying on your bed, bend both legs and place your feet so that they are flat on the bed. Move both knees as far as possible to the left and then to the right as far as possible.
5. Lying on your bed, bend both legs and place your feet so that they are flat on the bed. Reach with your hands up toward the left and twist your body to the left also. Do the same to the right.
6. Turn over and lie on your stomach. Put your arms at your sides and try to lift your head and shoulders up as far as possible.
7. Seated, pick up your leg and hold it up and then try to move your foot to the left and then to the right. If possible, keep your knee up without holding it up.
8. Seated move your knees apart and then together but keep your feet together and in place as you move your knees.

9. Standing and holding onto a counter, move the right leg as far as possible to the right. Make sure that the toes are pointing straight forward throughout the exercise. Do the same the left leg.

10. Standing and holding onto a counter, bend both knees about 30 degrees and no further. Straighten both knees.

Do all the exercises above 20 times, twice daily if you can. Remember to not get fatigued.

In addition, try to lie on your stomach and up on your elbows. Keep your hips down and in contact with the bed. Stay in this position for 20 minutes.

Flexibility and Breathing Exercises for Polio Survivors

1. Seated, reach first as far forward as possible and, then, simultaneously exhale and bend forward as far as possible. After bending forward, simultaneously reach up overhead and breathe in as deeply as possible. Very slowly complete 5 repetitions.

2. Seated reach up toward the ceiling and simultaneously inhale as deeply as possible. Exhale and bend to the right as far as you can. Straighten up again inhaling as you reach up. Then, exhale and bend to the left as far as possible. Complete three repetitions resting between each repetition.

3. Place both hands on your right knee. Keeping your hands together and elbows straight, reach with both hands up and out to the left side twisting your body to the left as far as possible. Lower your hands to your left knee and then, complete the exercise moving to the right. Complete three repetitions resting between each repetition.

4. Fold a tissue in half and then in thirds. Grasp the tissue at the top and hold the tissue three inches in front of the mouth. Purse your lips and blow out as hard as possible against the tissue attempting to bend the tissue 90 degrees and to keep it bent at 90 degrees for a count of six. Complete 5 repetitions of this exercise and then rest for several minutes.

5. Place your hands below the ribs across the upper abdomen. Simultaneously exhale and compress the upper abdomen. Then, breathe in as deeply as possible and attempt to force your hands out. Release pressure on your abdomen as the downward movement of the diaphragm is felt. Complete 5 repetitions and rest for several minutes.

6. Seated fold your arms across your chest. Rotate your body to the right as far as possible and then to the left. Complete 10 repetitions.

7. Seated, pull your chin straight back and flatten the back of your neck pulling the ears directly over the shoulder joints. Relax after each repetition. Complete 10 repetitions.

8. Seated hold both arms straight ahead with the elbows slightly bent. Pinch your shoulder blades together toward your spine. Hold for a count of five and then relax. Complete 10 repetitions.

9. Sit in a chair with arms. Place both your hands on the arms of the chair and holding the head, neck and trunk still, straighten your arms and lift your buttocks 2-3 inches above the seat of the chair. Relax. Complete 5 repetitions.

10. Seated, try to blow up a balloon.

Accounting for Polio Survivors in the Post-Polio World

International organisations promise that we can soon hope to live in a polio-free world, but for millions of polio survivors the struggle is not over. Sophie Cousins reports.

Ahmedabad, Gujarat—Bharat Popat was infected with polio at the age of 1 year. The now 58-year-old has vague memories of his childhood. He was fitted with a steel caliper on his left leg, which had been affected by the disease, before receiving corrective surgery at the age of 15. The surgery enabled him to live a relatively normal life in a country that is poorly equipped for disabled people. That was until he was 51 years old.

“I was walking without any assistance after my corrective surgery until suddenly at 51 I developed unusual symptoms”, Popat told *The Lancet* at Suresh Brahmakumar Bhatt (SBB) College of Physiotherapy at Vadilal Sarabhai General Hospital in Ahmedabad, the capital of the western Indian state of Gujarat.

“At 6 pm every evening I would get extreme pain in my right leg, which is not my polio leg. I had to get help to reach my car after work as I just couldn’t walk. I would again feel normal in the morning.” The unusual pain was combined with lower back pain, muscle weakness, and fatigue. The symptoms continued for 3 weeks before Popat began his search for what was causing his pain. Not once did he consider that it could be related to a disease he had contracted more than 50 years ago.

Popat consulted a total of 15 doctors both in India and the USA over the course of 2 years as condition after condition was ruled out. Finally, a neurosurgeon in Mumbai suggested that he might have post-polio syndrome (PPS). “I’d never heard of it”, Popat said. “It was the first time a medical person had mentioned it.”

“I spent a fortune and a lot of time to just get a diagnosis but most polio survivors come from a very poor part of society. Polio is being eradicated but no one is interested in what comes afterwards.” Exact prevalence of PPS worldwide is unknown, but it is thought that 25–40% of all polio survivors are affected by the syndrome. After years or decades of stability (most commonly up to three decades after initial infection), they begin to experience new or worsening disabling symptoms as they age.

Although the cause of denervation is unknown, common symptoms include muscle and joint weakness, pain, fatigue, muscle atrophy, difficulty breathing, and swallowing problems. Diagnosing the disorder is difficult and relies on the elimination of other conditions. However, to arrive at the conclusion of PPS, doctors look for three factors: previous diagnosis of polio, long interval after the recovery of the initial polio attack, and the gradual onset of symptoms.

In an ideal scenario, management of PPS would involve a multidisciplinary approach including physiotherapists, rehabilitation experts, orthopaedic surgeons, neurologists, psychologists, and respiratory consultants. But in the developing world, the situation is far from ideal.

PPS in a post-polio world

Polio was once a disease feared across the globe, but today it’s only endemic in three countries: Afghanistan, Pakistan, and Nigeria. It’s not surprising that the international public health and development community envision a polio-free world in the near future. But the elimination of new polio cases does not mean an end to the disabling, long-term consequences of the disease, Nora Groce, director of the Leonard Cheshire Disability and Inclusive Development Centre at the University College London, told *The Lancet*.

Groce, a global disability expert who has researched PPS extensively, said she was concerned the eradication of polio would further propel polio survivors out of the spotlight. “It’s much easier to just say ‘let’s double the effort to get rid of polio’ rather than have a commitment to those who’ve had the disease”, she said. “Eradicating polio will be a major public health achievement but that doesn’t mean we can turn our backs on people living with the effects of polio now, and for the next 60 to 70 years.” The polio vaccination became universal in the developed world more than 60 years ago. However, in developing countries, where vaccination campaigns reached large sections of the population only after 1988, millions of people who are disabled by polio are still children or young adults.

“At 6 pm every evening I would get extreme pain in my right leg, which is not my polio leg. I had to get help to reach my car after work as I just couldn’t walk.’...”

Dibyangshu Sarkar/Stringer

Web Corner

Mobility Aids for Wheelchair Travelers

<http://www.transfermaster.com/blog/view-post/Mobility-aids-that-can-really-help-wheelchair-travellers>

Polio Survivor Talks of Legacy and New Battle

<http://www.bbc.com/news/uk-northern-ireland-39585023?SThisFB>

Short-term Use of Corticosteroids and Related Harms in US

<http://www.bmj.com/content/357/bmj.j1415>

How 150 Americans Changed the Disability Laws

<https://share.america.gov/how-150-americans-changed-disability-law/>

Why Are So Many People Popping Vitamin D?

https://www.nytimes.com/2017/04/10/health/vitamin-d-deficiency-supplements.html?_r=0

Polio's Misunderstood Legacy

<http://www.cbc.ca/news/canada/manitoba/post-polio-syndrome-facts-1.4061084>

Morgan's Wonderland Unveils New Waterproof Chair

<http://www.ksat.com/news/morgans-wonderland-unveils-new-waterproof-wheelchair>

A Bare Bones Superlight Chair is Not for Everyone

<http://www.transfermaster.com/blog/view-post/A-bare-bones-super-light-chair-is-not-ideal-for-everyone>

Polio Survivors Fight For Proper Treatment of PPS

<http://www.cbc.ca/news/canada/manitoba/polio-survivors-post-polio-1.4055557>

Plenty You Should Know About Social Security Disability Benefits

<http://blog.socialsecurity.gov/theres-plenty-you-should-know-about-social-security-disability-benefits-2/>

OTHER POLIO NEWSLETTERS

Pennsylvania Polio Network

<http://www.papolionetwork.org/>

Polio Survivors Network

<http://poliosurvivorsnetwork.org.uk/>

Polio Place

<http://www.post-polio.org/>

Polio Oz

<http://www.poliohealth.org.au/>

A Little Bit of Humor

DIHYDROGEN MONOXIDE

A freshman at Eagle Rock Junior High won first prize at the Greater Idaho Falls Science Fair, April 26. He was attempting to show how conditioned we have become to alarmists practicing junk science and spreading fear of everything in our environment. In his project he urged people to sign a petition demanding strict control or total elimination of the chemical "dihydrogen monoxide." And for plenty of good reasons, since:

1. It can cause excessive sweating and vomiting.
2. It is a major component in acid rain.
3. It can cause severe burns in its gaseous state.
4. Accidental inhalation can kill you.
5. It contributes to erosion.
6. It decreases effectiveness of automobile brakes.
7. It has been found in tumors of terminal cancer patients.

He asked 50 people if they supported a ban of the chemical: Forty-three said yes, six were undecided, and only one knew that the chemical was water. The title of his prize winning project was, "How Gullible Are We?" He felt the conclusion was obvious.

Laziness Is A Virtue

by Millie Malone Lill

For most of my life, and I bet a large part of yours as well, it was necessary to be as productive as possible. I married young, raised three sons with my husband on our farm. There were cows to milk, chickens to raise and subsequently butcher, calves to care for and of course, laundry, cooking and cleaning. No time to rest. I had no idea there was such a thing as PPS and if I'd heard of it, I would no doubt have been deep in denial if I thought about it at all. I sewed the boys' shirts and my dresses, patched their jeans, baked all our bread as well as being the person who ordered and went after repairs for the various pieces of machinery, most of which were held together mainly with duct tape and prayer. I was the one who did all the banking and other business related jobs.

Eventually, PPS poked its nasty nose into my business. I was perfectly happy without it. I was a young and very hands-on grandmother and really enjoyed that role! My husband, however, was not in good shape. He was frequently bedfast which doubled my work load. We switched from milk cows to stock cows and that helped a lot. Then I broke my leg. That did it. PPS set up camp. It took eighteen months for that leg to heal to the point that I could walk using one crutch. I applied for and received Social Security Disability. I had found a brochure about a polio group in Omaha, Nebraska and the symptoms it listed fit me like a second skin.

I was just adjusting to this new entity in my life when my husband of 34 years died. He was 56, I was 52. He had been my link pin. Without him, I had no idea what to do. I threw myself into every activity I could think of in an effort to minimize the time spent being lonely. I sank right to the bottom of that river in Egypt. Soon, I needed a power chair.

Even so, I kept very busy. I found a friend who wanted to travel and we had four or five years of wandering all over the US and Canada, meeting polio survivors and friends. I was still overdoing it. I'm not a fast learner when it comes to this stuff, but eventually it did sink in. Not till after I married a Canadian trucker and moved to Canada, though. He was never home and while the little village I lived in was full of the most wonderful people I've ever met, it was not enough. Constant cold, deep snow, no accessibility and worst of all, my family a thousand miles away made me decide to move back to Iowa. My husband had no intention of continuing our marriage, so we divorced.

Now I live in independent senior housing, a cooperative, in a really nice apartment. I have every convenience one could hope for, surrounded by friendly people and my beloved family. I can sleep as late as I wish. I get Meals on Wheels, so I don't often cook. I can spend my days doing whatever I want. No guilt if I decide to take a nap or stay in my pajamas all day. I am not exactly bone idle, though. Not yet. I still belong to a poetry group, a book club, a watercolor class, and I'm president of the board of directors here, as well as writing for one newsletter and doing two others. But the work is easy, deadlines are not hard to meet. I'm the happiest I've ever been and I owe it all to being lazy enough to thumb my nose at PPS. I heartily recommend a big helping of Laziness every day.