

25 WAYS TO BE A SLEEP HEALTH ACTIVIST

By Tamara Sellman, RPSGT, CCSH

Regardless of the field you work in, you will notice that most people are pretty satisfied with what they do at their workplace. However, you might notice a small percentage of peers who seem to go above and beyond what's required of them on the job.

Who are these people and why do they do what they do?

Generally, ambition and passion drive these coworkers. Some simply have more energy to pursue work-adjacent activities. Others may be on a personal mission inspired by the experience or situation of a loved one.

In the world of sleep medicine, those who do more than just what their job requires might be considered sleep-health activists.

Why activists? These days, the field of healthcare has taken on a politicized, even galvanized tinge, and so much of what can be accomplished in research, diagnostics, therapies, and business management for sleep labs rests on policymaking at the governmental level: from Washington D.C., all the way down to the politics inside your local hospital systems.

Being a part of the changemaking that can support the best practices of sleep labs and clinics and which can lead to better patient outcomes definitely requires an activist mindset. Obstacles abound, from insurance mandates to patient health literacy to sleep apnea screening opposition to school districts with unhealthy bell times. These are larger influences over sleep health that our patients are dealing with beyond their other more pressing concerns, such as living with a sleep disorder.

For allied healthcare workers in the field of sleep medicine, the desire to speak for the burdens of patients and the need to address these external obstacles is a chief reason why they decide to take action.

WHY BE A SLEEP HEALTH ACTIVIST?

There are a number of reasons for seeking out a mission as a sleep technologist.



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- **Personal satisfaction:** Being able to make a difference in the lives of others while using your skill sets and expertise means you really will sleep better at night.
- **Community involvement:** When you open yourself up to the community you live in to educate your neighbors, empower families, and emphasize good sleep as the "third pillar of health," you widen your circles in a way that draws like-minded people who can and will be supportive. Friendships and alliances are a desirable result.
- **Raise your level of expertise:** You can't be effective as an activist unless you have a much more comprehensive handle on sleep health than the ordinary person. The opportunities to expand your knowledge are boundless as an activist.
- **Broaden your sleep health horizons and networks:** Once you put yourself out there, other sleep health activists will emerge and welcome you to the effort. Ours is a smaller healthcare community, so you will quickly become aligned with sleep physicians, activist nurses, bloggers, researchers, and patient advocates. In this way, your sleep "family" will grow tremendously.
- **Make change in the world:** You already know how this feels. Remember the patient (or patients) you treated with CPAP that first night in the lab, and how they awoke to find they were a new person for getting their best sleep in a decade? Being a sleep activist allows you even more opportunities to reach out and make change, whether it's one on one with an individual or by way of a widespread effort to affect policy or reach many concerned citizens at once.

WHAT TO EXPECT FROM WORK AS A SLEEP HEALTH ACTIVIST

Let's be honest, though... working as a sleep health activist isn't all heroics. There's a dark side to prepare for:

- **No thanks:** You may reach out and do a great deal of work without a single thank you from anyone.
- **No pay:** Most efforts at sleep health activism are "pro bono," meaning you are probably not going to be funded, or if you are funded, it is only for materials and other costs. In some cases, you might earn a small income or receive grant funding or a small award, but it probably won't be enough to live off of.
- **No budget:** For profit or nonprofit entities are strapped these days, so you may find you are working on a shoestring budget or have no money at all to do the things you want to do.
- **Uses up free time:** Much of activism relies on the support of volunteer efforts. These efforts most definitely take place outside one's normal working hours on the job, and the workload can vary from an hour or two a week to 20 or more hours weekly, depending upon what you are willing and able to commit to.

- **Lots of barriers due to lack of awareness:** You already know that there is a social blind spot when it comes to the value of sleep. On top of this, you may have lawmakers, community leaders, celebrities, and other highly visible people out in the world sharing messages that contradict your pro-sleep efforts, such as “I’ll sleep when I’m dead,” or “I don’t need to sleep eight hours,” or “Sleep is for the lazy.” We have come a long way, and there are great spokespeople who persist on our behalf, but we still have much work to do.

SO WHY BOTHER BEING A SLEEP HEALTH ACTIVIST?

Ask yourself why you want to do the work. Are you okay serving as a volunteer, without expectation of reward?

Not everyone is cut out to be an activist, but for those who answer its siren call, activism is typically its own best reward because of the sense of fulfillment and achievement it provides. Every person you reach, whose life you can change for the better, is a huge reward!

25 WAYS TO BE A SLEEP HEALTH ACTIVIST

If you are still driven to become a sleep health activist, here are more than two dozen ways you can achieve this goal or dream. Some are easy, simple, low-cost and low-risk approaches, while others demand you be “all in.” There’s plenty of work to do at every level.

EFFORTS AT THE HIGHEST LEVEL

1. **Drowsy driving legislation.** Look at your local and state governments to see what laws are on the books for drowsy driving. See also what public safety regulations are in place as it pertains to screening transportation workers for sleep apnea. If you live in a state where marijuana is legal (as a medical application, for recreational use, or both), investigate what statutes exist which consider the ramifications of marijuana use on vehicle operation as it relates to drowsy driving. If you live in a community where opioid use is rampant, check out drugged driving laws (if they exist). In any of these situations, lobbyists at every level are needed to push through important regulations and laws. Your unique perspective as a shift worker and sleep technologist is invaluable in this way. Once you find the cause you’re most aligned with, contact the agencies that are fighting for safer roads and let them know you want to help.
2. **Right to sleep for homeless people.** The right to sleep is a hot-button civil rights concern that has emerged in the last few years. If you support the idea that the “right to sleep” should be a guaranteed human and civil right for all citizens regardless their socioeconomic status, look for advocacy groups you can contribute to in some way. Portland hosts Right2DreamToo, for instance, and there are several citizen action groups in California.

3. **Organize to help in times of need.** When calamity strikes, one of the first things to suffer is sleep. Anxiety and PTSD following disaster, for instance, is a real problem that many aren’t aware of. The efforts of first responders may be tireless, but they are also dangerous if these people don’t get adequate sleep. And in the case of disruptions like hurricanes, fires, floods, tornados, and earthquakes, the loss of CPAP equipment can leave many patients with even worse sleep during the time when they most need it. As an example, the American Sleep Apnea Association recently organized a CPAP relief effort following Hurricane Harvey now dubbed the “A.W.A.K.E. Angels” to put at least 100 machines in the hands of storm refugees by mid September.
4. **Be a sleep expert for a chronic illness organization.** People with conditions like rheumatoid arthritis and diabetes, or who have survived a stroke, cancer, or traumatic brain injury, suffer mightily with sleep. There are organizations you can join as a sleep expert in some fashion (as speaker, columnist, forum moderator, or educator) to reach out to that special population segment in need of support and advice.
5. **Work with VA activists on sleep disorder awareness and benefits politics.** Here’s another emerging arena where sleep health activists may become necessary to make real change. Our military personnel are coming home from service with sleep apnea, post-traumatic stress disorder, or traumatic brain injury but are falling through the cracks when it comes to receiving diagnoses, therapies, and reimbursements. Many are being told they had a preexisting condition when they did not have these problems prior to entering the military. These people need a voice so they can get comprehensive help quickly and affordably. HadIt.com strives to give these Americans a voice.
6. **Join a national awareness day/week/month campaign and volunteer.** You might have other skills besides sleep technology that can help propel an annual campaign (such as event organizing, graphic design, social media marketing). You could help bring an awareness day to life, such as the annual Drowsy Driving Awareness Week following the fall time change, or Restless Legs Awareness Day in September, or the Suddenly Sleepy Narcolepsy Bed Race in March. Pick your favorite sleep disorder; there’s an awareness campaign associated with it! And they usually need people to help get the message out.

COMMUNITY OUTREACH

7. **Health fairs.** Look for local or regional health fairs, and find out if they have sleep health booths, exhibits, or activities. If not, register to participate in the fair and create an interactive event! If so, ask the sponsor if they need your help. Easy ideas can include Epworth Questionnaire drawings, a fun sleep health quiz, a pillow fight, and a CPAP “petting zoo.”

8. **Launch an A.W.A.K.E. group, or volunteer for one that already exists.** These sleep health support groups sponsored by the ASAA have been useful not only for sleep apnea patients, but for sleep disorder patients at large. Learn more here.
9. **Help a district implement a Start School Later campaign.** Does your local school district have “old school” start times for their tweens and teens? (This means their kids start school before 830am.) If so, you may look into organizing a Start School Later effort, or join one if it already exists. Their Healthy Hours program is appreciative of support from knowledgeable sleep health professionals.
10. **Speak at group functions.** Not everybody likes to speak publicly, but if you do, you should have no trouble finding places to speak about sleep health. Targeted groups can include school districts (administrators, teachers, and families); fire departments and hospitals (shift workers, in particular); OB/GYN clinics (for the changing sleep dynamics of pregnant women and women in perimenopause or later); natural medicine clinics (for patients with sleep problems who don't want to use drugs); college campuses (to discuss sleep hygiene); corporate workplaces (to open up a dialog between management and employees about the measurable costs of sleep deprivation); and senior citizen facilities and residential spaces (to discuss age-related sleep problems). For general public speaking engagements, you might consider contacting the city hall, the public library, the local hospital, or the high school for scaled facility rental. Some communities have science-related “open mic” events where you might be able to pitch a talk about sleep health.
11. **Teach sleep hygiene clinics.** These can be smaller groups where people register and pay a small fee. They can be held at a clinic or hospital or in a private rental space depending upon the size of the group expected.
12. **Join a board.** Local sleep societies have boards that need leadership. National organizations, such as the Circadian Sleep Disorders Network, are always looking for help, and the CSDN is looking right now for new board members (application deadline November 10, 2017). The duties for board members can be minimal or quite extensive, depending on the board and the role, so you'll need to look into what's expected and what you can commit to.
13. **Canvass neighborhoods.** Some healthcare organizations need help with dispensing materials for upcoming events (a health fair, an election with a sleep-related policy up for a vote, a fundraiser). You can assist by visiting neighbors, sharing brochures, speaking one-to-one with neighbors, and collecting pledges for events or fundraisers.
14. **Serve a sleep disorder community forum.** You can either sign on as an admin or moderator, or you can simply visit and become active as a patient, if you also have a sleep disorder. These forums are always in need of fresh ideas, voices, and support from healthcare professionals. Make

sure you understand HIPAA requirements and practice good privacy protection in these groups, and confirm with your workplace protocols that you are allowed to do so.

GET CREATIVE

15. **Make and sell art with proceeds going to a sleep health organization.** Lots of sleep technologists have creative skills as photographers, musicians, painters, sculptors, or fiber artists. You could make sleep-related artwork, join a local artist's collective, and sell your work with the promise of donating a portion of your takeaway to a favorite local or national sleep-related nonprofit. People like to buy handmade items when they know they are also supporting a good cause.
16. **Make a music video.** If you're gifted with the skills to do so, why not? Respiratory therapist Adrian Hunter wrote the music and lyrics to a sleep apnea song, then starred in her own music video! The tune was catchy and the video was instructive. You can tell Adrian had fun, too!
17. **Write about it.** Do you like writing poems, short fiction, or essays? Are you a closet novelist? There has not been enough creative writing published about sleep problems, so your narratives and wordplay could fill that space for people interested in reading about things like sleepwalking, narcolepsy, sleep paralysis, sleep deprivation, insomnia, and other relevant topics. Sometimes it's the creative narrative that better educates a person, and not the obvious, instructive narrative. November is National Novel Writing Month—why not use that as a motivation to start a Great American Novel about sleep apnea? Nobody else has done it, after all.
18. **Make media.** Similar to Adrian's experience with the music video, you could create YouTube videos, memes, GIFs, or infographics that educate and raise awareness about sleep, then share these on social media. They could be straightforward, demonstrative, even funny.

KEEPING IT SIMPLE WORKS, TOO

19. **Teach and practice health literacy.** Nobody can be too health literate, and certainly there's no way to be overeducated on sleep health. If you work in the sleep lab, you might find it easier to just do your hookup, run the study, then unhook and release the patient. But inside these tasks are lots of opportunities for patient education. Also, patients will find your messages about sleep health and health in general more legitimate if it's obvious you follow your own advice. If you've lost weight recently, share that with your patients and tie it into improved sleep and overall health. If you've recently started using CPAP, share this as well; patients will appreciate your honest experience and may be inspired by what you tell them.
20. **Make phone calls and write letters.** These days, there are lots of invitations in social media for people to call their

leaders (senators, governors, mayors, even the President) to express support for (or against) proposed changes in policies. If you want to help lobbyists do their work but can't become a lobbyist yourself, you can at least make these phone calls and ask your friends to do the same. This can also be helpful for local events such as a school district's proposal to change bell times for the older students; your letters and phone calls can be very powerful.

21. **Pledge money.** For some, commitments of time are just out of the question, but they might have some money to donate to worthy sleep-related causes. If writing a check is all you can do, that's still something really valuable! You can also create mini fundraisers in social media that ask for people to pledge money to organizations you value, or you can pledge money to crowdfunding opportunities if you find sleep-related products worthy of investment.
22. **Volunteer at a sleep conference (for professionals or for patients).** Most often, we think of sleep conferences as serving the interests of sleep healthcare professionals (physicians, nurses, technologists). And these organizations definitely need volunteers! But more patient-centered organizations are emerging which offer conference programming specifically for patients (the Hypersomnia Foundation held a terrific patient-friendly conference, "Beyond Sleepy," in Boston during the SLEEP meeting last June, in example). They need volunteers, too.
23. **Participate in cohort studies or sleep research studies whenever possible.** If you have a sleep disorder, you may find it fascinating and useful to participate in a research study where you qualify as a subject. ClinicalTrials.gov points you to those studies actively recruiting participants: here are over 400 opportunities that include healthy patients as well. Or, you can join a cohort study of shift workers, or a mobile sleep research study like the SleepHealth Mobile App Study, which collects data from all kinds of people (with or without sleep disorders) in order to track and research sleep health longitudinally. Usually these are free for you to participate in and offer privacy protections. In some cases, you may even receive compensation for your participation.
24. **Social media "slacktivism."** Let's face it: Facebook, Twitter, Instagram, LinkedIn and other social media outlets make it super easy to share links to articles and websites that promote quality sleep health behaviors and tips for better sleep and daytime alertness. Any time you find a good resource, share it out in the world as a link. That is a super easy way to keep the topic of "sleep as a part of good health" top of mind in anybody who might be cruising by your public posts.
25. **Use every social encounter as an opportunity to educate about sleep health.** Your enthusiasm about sleep health can be easily shared in lighthearted and sincere conversations: with your golfing buddies, your family members at

Thanksgiving, with friends at the local Trivia Night showdown, with your kids and their friends over ice cream at the local parlor. You already know that, as soon as you reveal you work in sleep health, people will come forward to ask about sleep, and many will admit to having a sleep problem. Sometimes it's these simple, random chats with folks at the grocery checkout counter, the coffee shop, or on the bus that help inspire others to become proactive about their sleep.

SOME EFFORTS WORTH JOINING

Plenty of opportunities for sleep health activism already exist. Here are just a handful of efforts that would be happy to hear from you and could use volunteers. In some cases, they may even pay.

- **CPAP forums:** There are several of these for a reason: people need help! You can find the one you like best and volunteer to help moderate or admin. Here are four to consider: ApneaBoard, CPAP Talk, MyApnea.org and SleepHealth Forum
- **Narcolepsy Network:** This organization is actively engaged at the federal level in funding and awareness campaigns to ensure narcolepsy is not ignored as a legitimate healthcare condition.
- **PCORI:** Patient-Centered Outcome Research Institute: For those interested in advocacy for patients of specific chronic illnesses (sleep-related or not), this is a federally mandated organization that matches volunteers to disorders like diabetes, sleep apnea, multiple sclerosis, stroke, and more. PCORNet is the branch involved in patient-centered clinical research.
- **PatientsLikeMe.org:** This patient advocacy publication might be a great place to get your feet wet if you are interested in writing about sleep health as a patient. You may also be interested in pitching ideas to health- and patient-centric curators such as HealthUnion.com, BioNewsServices, and HealthCentral, which also have forums you might be able to assist with.
- **SleepyHeadCENTRAL:** This sleep health news and information clearinghouse is always looking for guest bloggers on a variety of sleep health topics.
- **Stanford Sleep and Dreams:** Inspired by Dr. William Dement, one of our first and best sleep health activists, this student-run website is a great place to look for ideas for becoming one.