LIVING WITH PARALYSIS

Managing Respiratory Health

CHRISTOPHER & DANA REEVE FOUNDATION

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TABLE OF CONTENTS

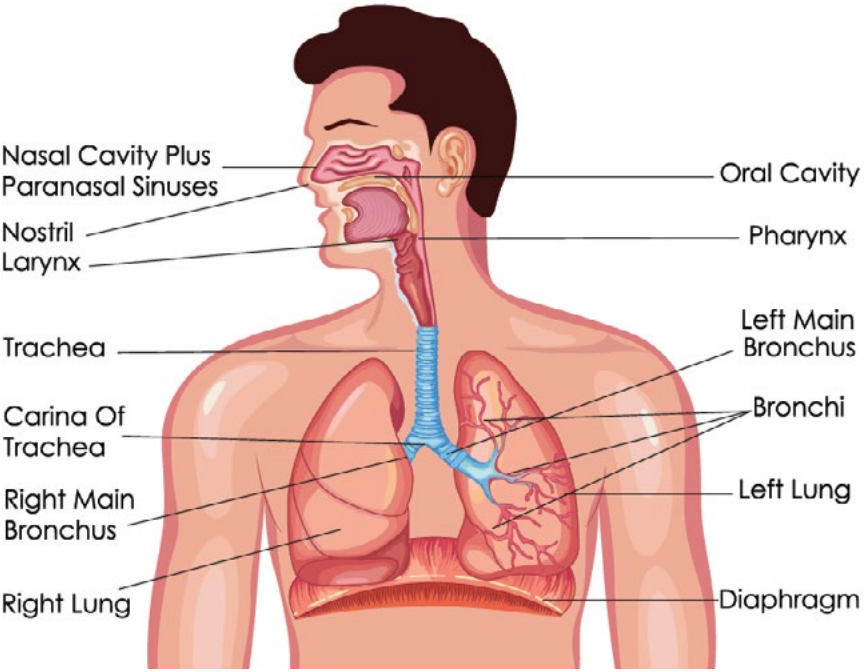
INTRODUCTION

A spinal cord injury (SCI) not only changes the way people move through the world, but countless aspects of daily life, from driving and using the bathroom to managing the heat on a sunny day. But its effect on the respiratory system – on coughing and sleeping and breathing easily or at all – is perhaps the most significant challenge faced by those living with injuries.

Respiratory muscles weakened or dysfunctional after injury are forced to work harder; the ribcage fails to fully expand, the ability to breathe deeply is restricted. Breathing that is too slow or shallow brings headaches and rapidly beating hearts and can prevent oxygen from reaching the lungs. The loss of strong, productive coughs causes mucus buildup and blockages in the airways. Whether in combination or on their own, these issues can become life threatening.

But, like every aspect of living with SCI, respiratory challenges can be successfully managed. This booklet is designed to provide a comprehensive overview of the challenges that frequently develop after injury, along with the information needed to maintain respiratory health in the long term; use it to better understand individual risk and to prevent complications from developing as you build independent and healthy lives after SCI.

RESPIRATORY SYSTEM: THE BASICS



Comprised of the lungs, airways, diaphragm, larynx, throat, nose and mouth, the respiratory system allows us to speak, protects us from harmful germs, and brings in the oxygen our bodies cannot live without.

Air is made up of oxygen and other gases. When we breathe, we inhale air into our lungs where tiny blood vessels absorb oxygen and carry it to cells throughout our bodies. As oxygen is taken in by each cell, a waste gas called carbon dioxide is released and transported through the bloodstream to the lungs where it is exhaled. This process, known as respiration, allows us to create the energy we need to survive. But its success depends on the brain's ability to communicate with the spinal cord.

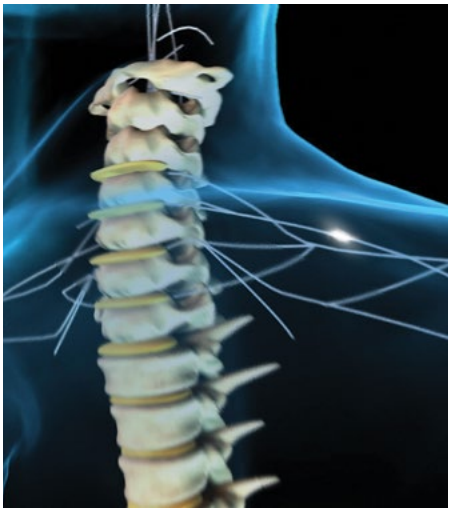
The spinal cord is a critical communication center that links the brain and body, carrying messages that coordinate movement, relay sensory information and regulate major functions – including respiration. Breathing begins when the brain signals the diaphragm to draw downward, creating suction in the chest to bring air into the lungs. Neck, abdominal and intercostal muscles (located between the ribs) help the upper chest and ribs expand as we inhale and breathe deeply.

The muscles relax, helping the lungs deflate, as we exhale. Aside from breathing itself, a healthy respiratory system also relies on these muscles to keep airways open by allowing us to cough and clear mucus from our lungs.

When injury disrupts the flow of messages between the brain and spinal cord nerves that control respiratory muscles, serious breathing problems can develop within hours.

SCI LEVELS AND RESPIRATORY FUNCTION

To understand the potential effects of an injury on respiratory function, it helps to visualize the thirty-three vertebrae that comprise the backbone. Nerves for each segment are responsible for motor and sensory functions for specific regions of the body. The location of a spinal cord injury determines what part of the body and functions are affected. In general, the higher up the spinal column an injury occurs, the greater the respiratory challenge.



- **Cervical injuries** above the C5 level damage the phrenic nerve, causing the diaphragm – the major muscle used for breathing – to weaken or lose function: a tracheostomy and/or ventilator, a machine attached to the trachea that pushes air into the lungs and pulls it out, may be needed temporarily (or more permanently for C1-C2 injuries) to breathe. All cervical level injuries impair intercostal and abdominal muscles to various degrees, diminishing or eliminating our ability to take deep breaths and produce forceful coughs; clearing secretions from the lungs will be critical to maintaining respiratory health.
- **Thoracic injuries** weaken intercostal and abdominal muscles; people living with mid-to-high level injuries may have increasing difficulty coughing, leading to chronic issues with lung congestion and respiratory infections.
- **Lumbar and sacral injuries** do not cause respiratory issues

WHAT TO EXPECT IN ACUTE CARE

Respiratory complications requiring urgent treatment can develop rapidly after a traumatic spinal cord injury. First responders and emergency room doctors will perform an initial physical assessment of overall injuries, including and especially, respiratory function. People with paralysis or family members should immediately alert hospital staff to any chronic breathing issues or conditions such as asthma, and/or lung disease or chest surgeries, which add to the risk of dysfunction after injury.

The immediate focus of acute care will be on the paralyzed individual's ability to breathe. Normal breathing occurs at a rate of 12-20 breaths per minute; counts that are both less than 12 per minute and higher than 25 per minute are red flags that indicate respiratory distress.

A **stethoscope** will be used to listen to how air is moving through the lungs, noting any absence of and/or decreasing breath, wheezing or crackling sounds; breathing patterns will be also observed and tracked. A **pulse oximeter** will be used to measure the level of oxygen in the blood; a reading of below 90% is considered low. Chest x-rays will be taken to determine damage caused by blunt chest trauma, including collapsed lungs. An **electrocardiogram** (EKG) will evaluate heart activity.

Other medical terms individuals with paralysis and families may hear include **tidal volume** (the amount of air going in and out of the lungs with a normal breath;) **vital capacity** (the maximum amount of air a person can expel after taking the deepest breath possible;) **arterial blood gas** (the amount of oxygen and carbon dioxide in the blood;) and **paradoxical respiration** (when the chest contracts during inhalation and expands during exhalation, reversing normal function.)

Individuals with complete or higher-level cervical injuries, or those whose lungs have collapsed due to spinal shock, may need tracheotomy. **Tracheotomy** is a surgical procedure in which a tube is inserted into a new airway (called a **tracheostomy**) in the trachea (trach) to allow air to travel unrestricted into the lungs.

When breathing is inefficient or severely restricted, a tracheostomy

may not provide enough support. In such cases, urgent **mechanical ventilation** will be needed. A breathing tube will be threaded into the trachea through the individual's mouth and attached to a **ventilator**, a machine that pushes air into the lungs and pulls it out. Breathing tubes are used for the short term; if ventilation is likely to be needed longer, the breathing tube will be replaced by a tracheostomy.

*The period immediately following injury can be frightening for all spinal cord injured people, but particularly for ventilator users who are unable to speak. It is crucial that these individuals be offered augmentative or alternative communication methods. Depending on function, writing, texting or using a tablet or phone app may not be possible. Mouthing words or using "leak speech" are options for some individuals with tracheostomies. **Leak speech** is a technique in which the cuff attached to the trach tube is deflated and a speaking valve is used to allow air across the vocal cords for speech.*

Clearing secretions from the individual's lungs will be central to acute care treatment. After an injury, an increase in secretions combined with the inability of many people with paralysis to produce a strong cough can cause a cascade of respiratory problems. As the mucus accumulates, it acts like glue, causing the sides of the airways to stick together and not inflate properly; in addition, it can also be a breeding ground for various bacteria.

Secretion management techniques vary depending on the hospital. Most commonly, lungs will be suctioned to remove mucus using a catheter tube. However, if individuals are receiving care in acute care hospitals with experience treating spinal cord injuries, secretion management will likely involve a cough assist machine and abdominal thrusts. A **cough assist** machine (also called mechanical insufflation-exsufflation) simulates a cough by gradually pushing air into the lungs before quickly pulling it, and the mucus, out. The **abdominal thrust assist** is a manual technique in which pressure is applied to the abdomen (by another person or the individual with paralysis) to help stimulate a cough. Both techniques are effective at clearing out both the large and peripheral airways.

The most common respiratory issues that occur after SCI are atelectasis, pneumonia and respiratory failure. **Atelectasis** is a collapse of a lobe or the entire lung or even both lungs due to fluid buildup. **Pneumonia** is an infection of air sacs in lungs caused by bacteria, virus or fungi entering the respiratory system. **Respiratory failure** occurs when the

body does not get enough oxygen, is unable to eliminate carbon dioxide or a combination of both. People with paralysis, especially those with cervical level injuries, may at first have normal respiratory function but will remain at high risk for rapidly developing complications in the first week.

Respiratory function in the early stages of acute care treatment will likely be further weakened by blunt chest trauma and other infections. **Pneumohemothorax**, caused by a sudden chest injury, often accompanies traumatic SCI; in this condition, blood and air gather in the cavity between the lungs and underneath the chest, and prevent the lungs from inflating. Individuals with cervical level injuries are also at risk of fluid buildup in the lungs called **pulmonary edema** immediately after injury due to high amounts of intravenous fluids given to treat hypotension.

It is important for families to be aware that many acute care institutions do not have extensive experience treating spinal cord injuries; transferring patients, especially those who have been intubated and require ventilation, to hospitals with SCI expertise can improve outcomes.

If you are concerned about a loved one's care and need additional information about regional or national facilities specializing in spinal cord injuries, call the National Paralysis Resource Center at 1-800-539-7309.

MATCHING REHABILITATION HOSPITALS WITH RESPIRATORY NEEDS

It is critical that families, especially those whose loved ones are ventilator-dependent, seek out rehabilitation centers that best meet the complicated physical and respiratory needs of people with SCI.

Acute care hospital staff unfamiliar with spinal cord injuries may suggest that an individual completes rehabilitation at long-term acute care facilities; however, these institutions typically do not have spinal cord injury expertise or offer the type of intensive therapy needed for best outcomes after injury.

The **Spinal Cord Injury Model Systems** program was established by the federal government in 1970 to strengthen care for people with spinal cord injuries. There are currently 18 SCI Model System centers in the U.S. that serve as national leaders in medical research and patient

care and provide comprehensive services, including respiratory care, for people with SCI. For more information, visit the Model Systems website at ***https://msktc.org/sci/model-system-centers***.

The **Commission on Accreditation of Rehabilitation Facilities (CARF)** is another resource for researching rehabilitation facilities. To be awarded CARF accreditation, a facility must pass an in-depth review of its services. There is a difference between a general CARF accreditation and one specific to spinal cord injury; if considering this resource, make sure to request a list of spinal cord injury accredited centers. For more information, visit CARF's website at: ***https://carf.org***.

Compare at least three different programs. Questions to consider: Is the facility accredited in spinal cord injury care by CARF or is it a Model System? How many patients are treated each year who are ventilator dependent? What are their outcomes?

Veterans are eligible for rehabilitation through the **VA Spinal Cord Injuries and Disorders System of Care**. Care may be transferred to these facilities at any time, including if rehabilitation has been undertaken or completed at a non-VA facility. For more information about the VA program, please visit its website at: ***https://www.sci.va.gov/SCI/Veterans/HubAndSpokes.asp*****.**

Parents of children who sustain SCI injuries – especially those who are ventilator dependent – should seek out programs tailored to pediatric patients: **Shirley Ryan AbilityLab** in Chicago, IL and **Kennedy Krieger Institute** in Baltimore, MD offer long-established pediatric services for children. Specialized rehabilitation programs for adolescents can be found at **Shepherd Center** in Atlanta, GA and **Craig Hospital** in Englewood, CO. Many adult rehabilitation centers also accept teens, but teenagers benefit from being among peers in programs designed around the specific physical and developmental needs of this age group.

Questions for Families to Consider:

What child and adolescent-centric resources and family supports define the program? Is family housing available near the hospital? Are there tutors or an onsite school program for children and teens to continue their education as they recover?

Rehabilitation centers are not the same. Don't be afraid to compare programs and ask detailed questions about their expertise in spinal cord injury and respiratory complications.

WHAT TO EXPECT IN REHABILITATION

The goal of rehabilitation is to provide patients with a runway toward restored function, reclaimed independence and a return to the community. A good rehabilitation program will feature intensive therapy led by an interdisciplinary team comprised of the following healthcare professionals:

- Physiatrists are rehabilitative doctors who treat medical conditions related to the brain, bones, nerves and muscles, including those sustained through spinal cord injury.
- Pulmonologists are doctors who care for people with complex respiratory issues; they will oversee diagnosis and manage complications from SCI.
- Respiratory Therapists provide tracheostomy and ventilator support, manage oxygen levels and secretion and help individuals with breathing exercises.
- Speech Language Pathologists specialize in the anatomy and physiology of the upper airway and work with people having trouble speaking and swallowing.
- Social Workers will assist individuals and families with many aspects of care, including education and discharge plans.
- Psychologists will provide clinical and counseling services for individuals and families as they cope with and adapt to the many challenges that follow an injury.

Rehab Goals: An Overview

Photo Courtesy of Jackson Drum.

The primary focus of respiratory rehabilitation will be to help people with paralysis breathe better by increasing vital capacity, clearing lung secretions, strengthening respiratory muscles and, whenever possible, eliminating or decreasing ventilator use.

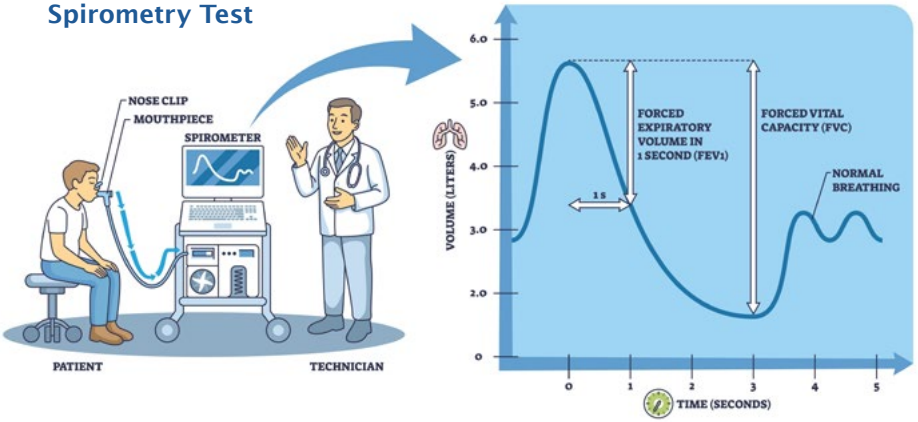
Individuals arriving from acute care facilities that lacked spinal cord injury expertise will likely have excessive secretions that are preventing significant recovery and possibly worsening complications. Clearing this mucus buildup using abdominal

thrust assists and cough assist machines will be an immediate priority.

Respiratory therapists will also work extensively with people with paralysis to manage and improve dysfunction. For example, those struggling with rapid, shallow breathing may learn strategies such as **"pursed lip breathing"** to help control breath and increase oxygen saturation levels. **Abdominal binders**, which are worn around the torso, may be introduced to provide traction for the diaphragm in individuals whose breathing is restricted.

Respiratory muscle training sessions will help build breathing capacity. Using hand-held devices such as an **incentive spirometer**, patients will

Spirometry Test



practice inhaling and exhaling forcefully, increasing the frequency and repetitions as their stamina and strength returns.

Movement will be a key component of rehabilitation. Individuals should expect to engage in intensive daily therapy sessions with physical and occupational therapists to rebuild stamina, regain function and learn how to live as independently as possible. Respiratory therapists will help patients manage oxygen levels during these sessions. This significant boost in mobilization (as compared to acute care treatment) helps foster respiratory function by encouraging lung expansion and increased airflow.

Speech language pathologists will oversee swallowing tests and exercises for individuals with **dysphagia**, a difficulty swallowing that can cause aspiration. In addition, they will collaborate with respiratory therapists to help individuals communicate via "leak speech" and the use of speaking valves, which divert air around the trach and allow the individual's voice to emerge.

Psychologists will work with both individuals and family members to process and adapt to new injuries, and specifically to respiratory complications. The need for a tracheostomy or ventilator support can cause significant anxiety or depression in individuals; addressing their psychosocial needs is crucial to ensure these feelings do not prevent them from working with therapists to achieve as much functional recovery and independence as possible.

VENTILATOR WEANING

Some individuals who receive urgent mechanical ventilation during acute care can be weaned from this support during rehabilitation. Weaning is only likely to be attempted in a Model System or rehabilitation facility with spinal cord injury expertise; it is unlikely that the intensive therapies needed to support removal efforts will be provided in skilled nursing facilities or long-term care hospitals.

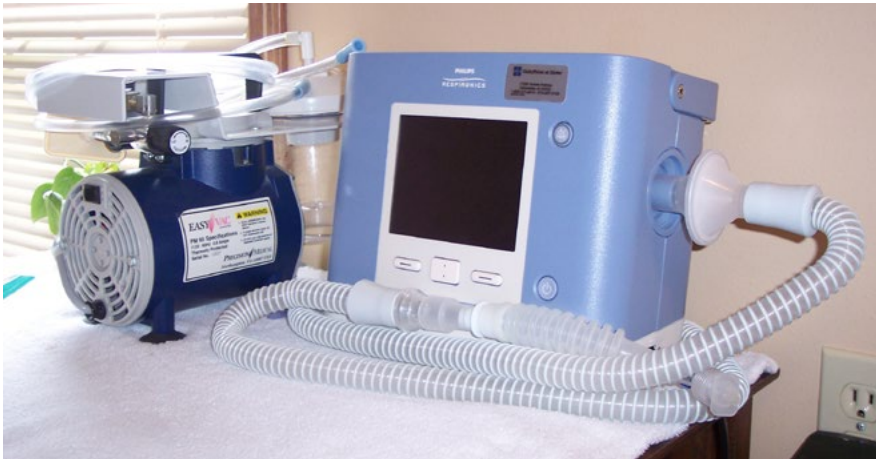


Photo Courtesy of Joel Vander Molen (http://www.joelvm.com).

An interdisciplinary team of doctors and therapists will determine if weaning is an option based on level and completeness of injury, and remaining function of respiratory muscles; other factors include the ability to clear secretions, swallowing function/risk of aspiration, absence of lung infections/overall medical stability, vital capacity and arterial blood gas levels. Psychological state will also be considered: anxiety and depression can inhibit the necessary therapeutic gains needed for successful weaning. A nutritionist may work with individuals prior to weaning attempts to increase muscle mass and build strength alongside vent-weaning breathing exercises that are incorporated into daily therapy.

Protocols for weaning vary, but people will typically be removed from the ventilator for short periods of time that steadily progress to longer and more frequent intervals of independent breathing.

Individuals who are unable to be weaned from mechanical ventilation may be eligible for **diaphragm pacing systems**. These battery-powered systems electrically stimulate the diaphragm so that it contracts and pulls air into the lungs. Depending on the system type, wires are surgically inserted around the phrenic nerve or, if the nerve has lost function due to injury, directly into the diaphragm muscle; in both systems, an external transmitter supplies ongoing electric impulses to the electrodes.

These pacing systems can provide a full-time or partial break from ventilator use, increasing quality of life and independence for people living with SCI.

Patient and Family Training

Education is a key aspect of rehabilitation. Individuals and family members should expect to receive extensive training in how to successfully manage specific respiratory complications. The lessons will not simply be lectures but hands-on instruction that covers all respiratory-related issues, from performing abdominal thrusts and helping transfer loved ones using Hoyer lifts to cleaning trach tubes. The goal is to give patients and families the knowledge and confidence they need to build healthy and independent lives beyond hospital walls.

A PULMONOLOGIST'S PERSPECTIVE:

Dr. Douglas Green, Kessler Institute for Rehabilitation

Since 1995, Douglas Green has treated hundreds of patients with severe respiratory complications stemming from spinal cord injury. When they arrive at Kessler, their lungs are filled with mucus. Some are breathing only with help from a mechanical ventilator; others may soon need one. Swallowing is an issue for nearly everyone.

The challenges can feel vast for both patients and family members; but it is during rehabilitation that the critical process of rebuilding healthy, independent lives begins.

"We're at the moment of overlap between the end of acute care issues and the early stages of recovery," Dr. Green says.

Dr. Green recently spoke with the NPRC about the role

rehabilitation – and especially its emphasis on movement – plays for patients as they navigate respiratory complications in the wake of a catastrophic injury.

NPRC: What are some important respiratory issues facing new patients with high-level spinal cord injuries (SCI), particularly as they transition from acute care to acute rehabilitation hospitals?

SCI patients often come to us after spending months in acute care hospitals recovering from added problems like pneumonia. Because of the limited strength they have to apply to breathing, mobilization is perhaps the most important intervention to maximize their respiratory function.

To understand this issue, it's helpful to think of the lungs as a bunch of balloons with small holes in them: they will deflate if they're not constantly refilled. Of course, these balloons are more easily moved when they're full of air rather than when they're deflated. When we take a deep breath, that volume of air occupies only about a tenth of the total space in our lung. And that air will go to the same space each time so long as we remain in the same position.

As a result, when someone is at rest in the same position for long periods of time – in a hospital bed, for example – the same lung "balloon" is inflated over and over again, while the rest of the "balloons" tend to deflate. As more lung deflates, more of the limited strength an SCI patient has to take a breath is used to push away deflated lung instead of being used for effective breathing. Position changes move the breath around the chest, keeping more areas full of air and reducing the amount of work it takes to breathe effectively.

Can you talk about respiratory secretions, which is another critical challenge for people with high-level injuries?

Movement also has a big effect on handling respiratory secretions, which can clog up airways and make lungs heavier and, again, force SCI patients with limited respiratory strength to do something other than effective breathing.

Lungs depend on movement to shake secretions loose and to change the position of the chest so that gravity can promote drainage from different lung areas.

In acute care hospitals, spinal cord patients are quite uncommon. As a result, there is a substantial difference in the amount of mobilization available versus in acute rehabilitation hospitals. In

acute care hospitals, for patients who are not mobile, staffing limitations and available equipment make even regularly turning patients in bed and getting them out of bed and seated in a chair, significant undertakings. But acute rehabilitation hospitals are organized so that patients are regularly turned while in bed and are out of bed and engaged in various therapies several times every day.

Lung secretions are also removed from a patient's airway differently in acute care hospitals. There, non-SCI patients do well enough using suction catheters for taking secretions out. For the much less common spinal cord patient, suctioning is not as helpful, but these institutions are often unfamiliar with the more effective equipment or techniques used in acute care rehabilitation, particularly the artificial coughing machine or "Coughalator" and the Heimlich Maneuver-like Abdominal Thrust.

NPRC: How do these interventions help set patients on a path toward recovery?

With mobilization and more effective airway clearance techniques, we can significantly improve their effective breathing. While these improvements won't result in ventilator independence in patients with the most advanced spinal cord injuries, they will always make patients more comfortable and succeed in getting patients off breathing machines who were not able to do so in other settings.

NPRC: What should patients and families prioritize after they leave Kessler to maintain respiratory health?

Dr. Green: Mobility is important for so many reasons: to prevent bed sores, to get out in the community, and for the respiratory reasons discussed. And when we say "moving around", even if you're in a wheelchair, moving back and forth or turning a corner has a positive impact on keeping the lungs inflated and mobilizing secretions. Secretion clearance techniques always seem daunting at first, but, with some practice, they become easy and are so very effective.

NPRC: What is the most rewarding aspect of the work you do?

Dr. Green: There really isn't one thing. It's certainly great to see patients making physical progress over time during their Kessler stay. Seeing patients and their families more comfortable and less worried about the future is very satisfying. And it's wonderful to see them months and years later doing well.

AFTER DISCHARGE: HOME TIPS FOR TRACHEOSTOMY AND VENTILATOR USERS

Individuals and families should work with their rehabilitation team to ensure a home-based respiratory management plan is in place prior to discharge. Locate local vendors to arrange for any necessary durable medical equipment and supplies, which may include portable ventilators, cough assist machine, nutritional therapy (in the case of feeding tubes) and electric hospital bed. In addition, a handheld self-inflating resuscitation bag, (e.g. an Ambu bag) should be procured, along with humidifiers to add moisture to the air.

Daily tracheostomy care will include:

- Keeping the skin around the tracheostomy clean and dry
- Changing the trach ties (more often if they are wet or dirty)
- Cleaning the surgically created opening called the stoma. If redness, swelling, crusting, yellow or green drainage or any bad odor develops, call your healthcare provider immediately.
- Trach tubes will also need to be regularly changed; follow a schedule determined by your rehab team or healthcare providers.

Using a ventilator changes, but doesn't end, a life. People living with SCI who use ventilators work and travel and go out with friends.

Small, portable ventilators can be attached to wheelchairs for home use and activities in the wider world. A speech therapist can work with individuals to improve voice strength; voice amplifiers and small microphones can be worn around the neck or clipped at the waist to ensure that individual voices are heard.

HOW VENTILATOR USERS CAN PREPARE FOR EMERGENCIES

Everyone living with SCI, and especially ventilator users, should plan for emergency situations such as power outages or natural disasters. To get started:

- Register with the local utility company: oftentimes, this list will be used to prioritize restoration service.
- Consult with equipment suppliers about backup power options to keep at home, including rechargeable batteries and generators. (Individuals on Medicaid waivers should contact their service coordinator, as generators may be covered under durable medical equipment).
- Be aware of how long extra batteries will last. Test by powering a wheelchair or ventilator using the battery alone until power runs out; the length of the charge can range from 30 minutes to nine hours.
- Test and understand how to operate backup generators ahead of time. Never use a generator inside the house, which can cause carbon monoxide poisoning.
- Contact local emergency planning officials to determine what plans are in place (including priority shelter placement or transportation to local EMS facilities) to assist individuals who require electricity to support durable medical equipment.
- Identify locally accessible power sources such as police and fire departments, hospitals or local hotels and ask if you could use them as a backup for life-saving medical equipment during an emergency

Speak with your healthcare providers, including respiratory therapists, for suggestions on what critical supplies to include in go bags and home emergency kits in case extreme weather or natural disasters prompt sudden evacuation or shelter-in-place orders.

For more information on emergency planning, download the NPRC's free booklet, "Emergency Preparedness for People with Paralysis," at: ***https://www.ChristopherReeve.org/booklets***. See page 10 for tips on respiratory emergency preparation.

RESPIRATORY COMPLICATIONS AND SLEEP APNEA

Many people living with spinal cord injury – and especially those with respiratory muscle weakness – frequently develop sleep apnea, a serious health issue in which breathing slows or stops during sleep.

There are three types of sleep apnea. **Obstructive sleep apnea** (OSA) occurs when throat muscles relax and prevent air from passing through. **Central sleep apnea** occurs when the messages from the brain do not reach the muscles that control breathing. **Complex Sleep Apnea** Syndrome develops during treatment for OSA. People living with spinal cord injury may develop any of the three types.

Symptoms include waking up with a headache, dry mouth, irritability, difficulty concentrating and feeling exhausted during the day; additionally, family members might notice loved ones living with injuries snoring loudly and gasping throughout the night.

Do not dismiss symptoms or ignore the condition if it develops. Fractured sleep can lead to depression and diminished quality of life, along with potentially life-threatening conditions, including high blood pressure, heart disease and stroke.

Sleep apnea is typically diagnosed during a lab-based sleep study using polysomnography; in this test, a sensor is worn to monitor heart rate, breathing, blood oxygen levels, and brain waves during sleep. Once diagnosed, the condition is treated with one of two non-invasive ventilation methods: the **continuous positive airway pressure (CPAP)** machine, delivers continuous air pressure through a mask while the individual sleeps to keep airways open, while the **bi-level positive airway pressure (BiPAP)** machine delivers pressurized air into the lungs during sleep to help the individual exhale and prevents a buildup of carbon monoxide.

Photo Courtesy of Jackson Drum.

CLEAR LUNGS: EFFECTIVE SECRETION MANAGEMENT STRATEGIES

Keeping lungs clear of mucus will be an important part of treating and preventing respiratory issues from developing after SCI. Depending on injury level, healthcare providers might recommend a combination of the following techniques and treatments to be performed daily:

- **Bulb syringes**, easily carried outside the home, can be used to clear secretions from the nose and mouth.
- **Abdominal thrusts** are a manual form of assisted cough. A person presses down on an individual's abdomen and then up and under the ribs as they take a deep breath, helping to force a cough.
- **Cough assist machines** duplicate the normal cough by slowly applying positive air pressure to the airway and then quickly pulling the air, and secretions, from the lungs.
- **Percussion** is a manual technique in which caregivers or family members lightly drum the ribcage to break up mucus.
- **Steam treatments**, such as drinking hot beverages, running humidifiers in bedrooms and breathing steamy shower air, may be used to thin mucus.
- **Postural draining**, when the head is lower than the feet, uses gravity to move secretions from the bottom of the lungs to higher in the chest where it can be more easily cleared; speak with a healthcare professional before trying this technique.
- **Abdominal binders**, worn around the torso, can provide traction for the diaphragm, helping to improve respiratory function.
- **Nebulizers** are medical devices delivering medicine in mist form; sodium bicarbonate treatments may help thin mucus secretions.
- **Glossopharyngeal breathing** is a breathing technique that can help stimulate a cough. Individuals quickly gulp several mouthfuls of air into the lungs and then exhale.
- **High Frequency Chest Wall Oscillation** is a therapy in which vibrating vests are worn to loosen and thin mucus.
- **CPAP and BiPAP** machines may be used to give the individual a deep breath to help clear secretions.

SPOTLIGHT: REBECCA KOLTUN

Rebecca Koltun spends part of each day grappling with the reality of her respiratory health. There are regular rounds with the cough-assist machine and morning and evening swabs of her trach stoma and the ever-present quest to successfully manage her ventilator settings. There is her lack of easy breath.

But that's not the whole of Rebecca's life.

She regularly packs her portable ventilator and heads out to dinner and concerts with friends. She works part-time as a social media specialist and grips a paintbrush between her teeth for hours to create art she sells on Etsy. And she's building a TikTok following (141,000 fans and counting) with honest and humor-spiked missives chronicling her life with a C1-C2 spinal cord injury.

"If I think I can do something, I do it," she says.

Rebecca sustained her injury on March 13, 2021, in a skiing accident. One minute, she was a senior at Binghamton University with an eye on medical school; the next, she was in an ICU unable to move or breathe on her own.

"There was definitely a lot of shock," she says. "It was like being in a whole new world and learning a whole new language."

Her respiratory function was severely compromised but, after a few months, Rebecca received a diaphragmatic pacing system and slowly weaned off the ventilator. Her first night without it was both thrilling and terrifying.

"It was a big accomplishment, but nerve wracking for sure," she says. "It was my security blanket."

The first year, defined by the emotional upheaval caused by the injury, was the hardest, but support from family and friends sustained Rebecca and progress slowly followed. In time, she learned to trust her instincts about when her lungs needed suctioning and how best to breathe, alternating between the pacing system and the portable vent. She moved home with her parents and started to paint and share her story on TikTok. She travelled to Florida and bopped around New York to see her favorite musicians – Taylor Swift and Noah Kahan – amazed at how far she'd come.

"I've gotten home at three in the morning from concerts," she says. "I never thought I'd be able to do that."

There are still difficult days. The ventilator air is dry and cold, while

Photo Credit: Courtesy of Rebecca Koltun.

the pacing system doesn't bring the deep breaths Koltun sometimes needs. And she misses her laugh, silent now because weakened respiratory muscles cannot produce the sound. But the challenges, while real, are not all of life. She's making new videos and will soon teach a painting class at a local community center. She dreams of visiting Yosemite. She is steadily reimagining her future.

"The thing I would tell people is, 'Your best life isn't necessarily behind you,' she says. 'It goes on even after the tragedy you faced."

To learn more about Rebecca Koltun, follow her on TikTok at ***https://www.tiktok.com/@notparalyzedjustlazy*** *or visit her on Etsy at* ***https://www.etsy.com/shop/MadebyMouth****.*

STRONG BODIES, INDEPENDENT LIVES: HOW TO STAY HEALTHY

Unchecked, respiratory complications caused by spinal cord injuries can not only diminish quality of life but lead to potentially life-threatening health issues. Along with regular visits to a pulmonologist, adopting these lifestyle modifications will help sustain respiratory function and overall health:

- **Maintain a clean mouth:** when decaying food accidentally enters the lungs through aspiration or choking, it can cause infection. Brush, rinse and floss teeth daily, and visit the dentist for cleanings. (Individuals with choking or swallowing issues can use toothbrushes designed to attach to suctioning equipment.)
- **Stay hydrated:** Drinking lots of water (keeping in mind individual cardiac and bladder program restrictions) helps keep secretions thin and at a minimum.
- **Maintain a healthy weight:** health problems can develop from being both under and overweight.
- **Exercise:** Movement is key to respiratory health.
- **Avoid germs:** Limit exposure to loved ones and friends when they're sick.
- **Discuss vaccines with your health care provider:** See if they think a flu, COVID-19 and pneumonia vaccine will prevent or lessen the severity of symptoms.
- **Pay attention to your body:** Contact your healthcare provider at the first signs of a respiratory infection including fever, chills, sticky yellow or green mucous, tight chest, and shortness of breath.

Respiratory Muscle Training

Exercising the muscles used to breathe can help maintain good health. Regularly breathing into handheld devices such as incentive spirometers increases the capacity for deep breaths that expand and open the airways. Breathing exercises done on their own can also help improve lung function. Visit the Resources section of this booklet to find a link to NPRC Nurse Linda's breathing exercises video.

NEUROMUSCULAR DISORDERS AND RESPIRATORY DYSFUNCTION

Respiratory complications are not only a serious issue for people who sustain traumatic spinal cord injuries, but for those living with neuromuscular disorders. For some, managing respiratory complications may be a routine part of life from a young age. Individuals living with spinal muscular atrophy might have needed overnight oxygen support, whether via a BiPAP machine or mechanical ventilation, since childhood; a young adult living with Duchenne muscular dystrophy may have years of experience managing lung secretions by the time he begins to vote.

But for those whose diagnosis arrives later in life, learning to proactively identify and treat symptoms will be crucial for prolonging respiratory health.

Working with a pulmonologist and respiratory therapist to regularly monitor vital capacity and cough flow, even in periods of stable health, will help adults living with neuromuscular disorders anticipate and treat respiratory red flags before they become a crisis. For example, morning headaches can be a sign of emerging breathing issues for people living with ALS; since breathing is at its most shallow during sleep, a drop in volume can mean not enough carbon dioxide is being exhaled, causing the headache. Daytime fatigue in people living with multiple sclerosis can signal undiagnosed sleep apnea, which affects up to 35 percent of community members.

Oftentimes – as with the emergence of post-polio syndrome (PPS) in polio survivors many years after they first survived the disease – both the diagnosis and necessary treatments come as a shock.

"Some polio survivors hadn't needed any respiratory assistance for decades," says Brian Tiburzi, executive director of **Post-Polio Health International (PHI),** an organization that provides education and support for thousands of polio survivors and ventilator users. "Then they come to us with the feeling that something isn't quite right with their breathing. They don't quite know what's going on. They thought they were past this."

But as with the first signs of respiratory dysfunction caused by any disease or trauma, there is little time to waste. Through its helpline, quarterly newsletters and support groups, PHI helps community members quickly connect with doctors to get a diagnosis and formulate a treatment plan that helps maintain health and quality of life, often requiring at least part-time use of mechanical ventilation, such as a BiPAP device.

"It can be quite hard to make these adjustments," Tiburzi says. "But education can dispel a lot of that fear. Just understanding what

the progression of their respiratory issues might be, what kind of healthcare professionals they're going to need and what their condition might entail in the future, can put a lot of their worries to rest."

COPING WITH RESPIRATORY CHALLENGES

Spinal cord injuries upend lives in an instant – and the respiratory complications they can bring can feel especially frightening.

Individuals and family members should seek out and speak with patient care coordinators and social workers as early as possible in both acute care and rehabilitative hospital settings to express concerns, help manage stress and access any resources that may be available. Facilities specializing in SCI may offer support groups and one-on-one peer mentors that can provide a sense of community early on.

Support outside of healthcare settings will be equally important in the long run. As they return to and rebuild lives after injuries, individuals may find it helpful to connect with others living with SCI. The **NPRC Peer & Family Support Program** offers free monthly online support groups and one-on-one peer mentors for both individuals living with SCI and caregivers. Tapping into this community can not only provide a lifeline for working through emotional challenges following SCI, but access to practical hacks and tips for managing respiratory dysfunction.

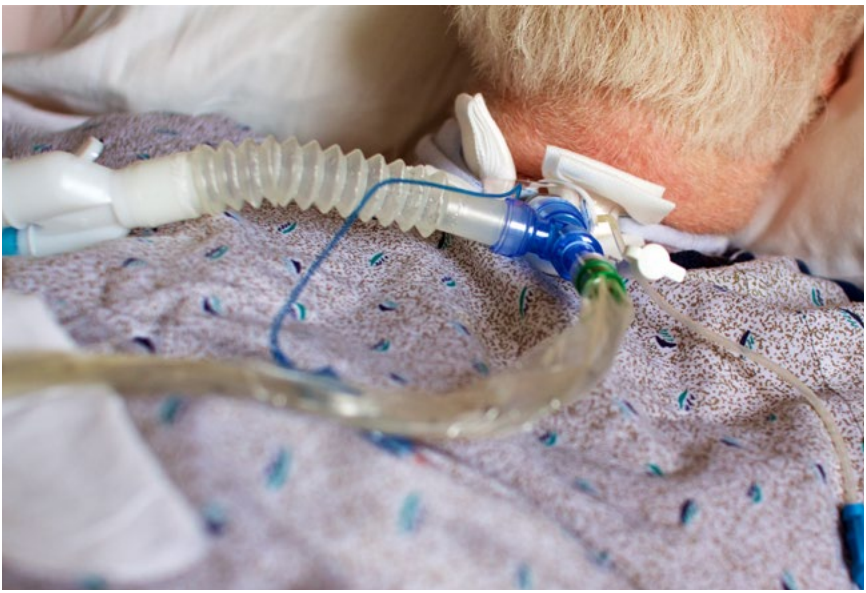
BUILDING BETTER TREATMENTS: RESEARCH AND CLINICAL TRIALS

Researchers and scientists across the country and beyond are working to better understand and treat respiratory dysfunction caused by spinal cord injury. Individuals living with SCI who are interested in participating in studies and trials can search the National Library of Medicine's **Clinical Trials database** on its website at ***https://www.clinicaltrials.gov***. Search within spinal cord injuries using the keyword "respiratory," or more generally for all SCI related research, for current studies seeking participants.

A GLOSSARY OF RESPIRATORY COMPLICATIONS AFTER SCI

Respiratory issues can quickly spiral into life-threatening conditions if left unchecked. It is important for individuals with a compromised respiratory system and their families to be alert and quickly seek treatment when symptoms of the following illnesses first emerge:

- **Adult Respiratory Distress Syndrome** is a serious buildup of fluid in the sacs of the lungs that leads to dangerously low oxygen levels in the blood. Symptoms include sudden and severe shortness of breath, labored and rapid breathing, elevated heart rate, and blue lips and fingernails.
- **Aspiration from dysphagia:** People who have difficulty swallowing (known as dysphagia) may experience aspiration, which occurs when food, liquid or other materials enters the lungs accidentally; infections, including pneumonia, can follow. Symptoms include food sticking in the throat or coming back into the mouth, pain when swallowing, coughing or wheezing after/while eating or drinking, heartburn, congestion or fever soon after eating, excess saliva, shortness of breath while eating. Risk for aspiration is especially high for people with tracheostomies.
- **Atelectasis** is a collapse of a lobe or the entire lung or even both lungs due to fluid buildup. Symptoms include trouble breathing or shortness



of breath, increased heart rate, coughing and bluish nails or lips. Chest pain may also be present but may not be evident for those with cervical level injuries. Take note of any signs of autonomic dysreflexia and/or referred pain (pain felt in one part of the body but caused by an injury elsewhere) in the shoulders, neck, back, teeth or jaws. Call 911 if symptoms appear.

- **Bronchitis** is an inflammation of the airways in the lungs. Symptoms include coughing with or without mucus production, sore throat and/or chest, fatigue, mild headache and body ache.
- **Bronchospasms** are a tightening of the muscles lining the lungs that make inhalation and exhalation difficult. Symptoms include wheezing and coughing.
- **Lung abscess** – an infected pocket in the lungs that can be caused by aspiration. Symptoms, which can develop slowly or suddenly, include fatigue, loss of appetite, night sweats, fever, chills, a cough that brings up thick and foul-smelling mucus.
- **Pleural effusion** is a buildup of fluid between the thin membranes lining the lungs and the chest cavity sometimes caused by pneumonia that can lead to abscess or infection. Symptoms include chest pain, coughing, and labored breathing.
- **Pneumohemothorax** occurs when blood and air gather in the cavity between the lungs and underneath the chest, preventing the lungs from inflating. The injury, caused by a sudden chest injury, often

accompanies traumatic SCI. Symptoms may include difficulty breathing, an inability to take deep breaths, rapid breathing, shortness of breath, fatigue, and rapid heart rate.

- **Pneumonia** is an infection of air sacs in lungs caused by bacteria, virus or fungi entering the respiratory system. Symptoms include a cough with phlegm, fever, chills and difficulty breathing.
- **Pulmonary edema** is fluid buildup in the lungs caused by congestive heart failure. Individuals with cervical level injuries are at risk immediately after injury due to high amounts of intravenous fluids given to treat hypotension; risk can persist throughout life due to ongoing cardiac dysfunction. Symptoms include shortness of breath, coughing up blood or mucus, wheezing, chest tightness or pain and feelings of suffocation.
- **Pulmonary embolism** is a life-threatening blood clot or air bubble blockage of the lungs. Caused by cardiac dysfunction, lack of movement and constrictions, the clot typically develops in the arms or legs and travels by vein to the lungs. Individuals with SCI are at particularly high risk in the months after injury. At the first sign of symptoms, including shortness of breath, pain with deep breaths, rapid breathing, and an elevated heart rate, seek urgent medical attention.
- **Respiratory Failure** occurs when the body does not get enough oxygen, is unable to eliminate carbon dioxide or a combination of both. Call 911 if symptoms, including breathing difficulty, confusion and/or a bluish color on the skin or lips, are present.
- **Tracheitis** is a bacterial infection of the trachea that can develop through inflammation or intubation of the trachea from a tracheostomy tube that can make breathing difficult. Symptoms include deep cough, high fever and loud breathing sounds (known as stridor).
- **Upper Respiratory Infection**, also known as a cold, is an infection in the airways but not in the lungs.

Sources:

Model Systems Knowledge Translation Center, Consortium for Spinal Cord Medicine, University of Alabama Department of Physical Medicine & Rehabilitation, Craig Hospital, Kessler Rehabilitation Institute, Shepherd Center, Merck Manual, Mayo Clinic, Johns Hopkins Medicine, Cleveland Clinic, Kennedy Krieger Institute, American Lung Association, American Thoracic Society, Shirley Ryan AbilityLab, Muscular Dystrophy Association, University of Rochester Medical Center, Cure SMA, Post-Polio Health International.

RESOURCES:

If you are looking for more information on respiratory health or have a specific question, Reeve Foundation's Information Specialists are available on weekdays, Monday through Friday, toll-free at 800-539-7309.

The ALS Association: State Directory
https://www.als.org/support/states

The American Academy of Physical Medicine and Rehabilitation: Physiatrist Directory
https://www.aapmr.org

Christopher & Dana Reeve Foundation: Emergency Preparedness for People with Paralysis
https://www.ChristopherReeve.org/todays-care/get-support/emergencypreparedness

Christopher & Dana Reeve Foundation: How to Find a Rehabilitation Facility
https://www.christopherreeve.org/todays-care/living-with-paralysis/newly-paralyzed/how-do-i-find-a-rehabilitation-facility

Christopher & Dana Reeve Foundation: Nurse Linda's Breathing Exercises
https://blog.ChristopherReeve.org/en/breathing-exercises

Christopher & Dana Reeve Foundation: Peer & Family Support Program
https://www.ChristopherReeve.org/todays-care/get-support/get-a-peer-mentor/pfsp-overview

Commission on Accreditation of Rehabilitation Facilities (CARF)
https://carf.org/home

Craig Hospital: Tracheostomy Guide
https://craighospital.org/resources/tracheostomy-guide

Cure SMA: Breathing Basics
https://www.curesma.org/wp-content/uploads/2019/07/breathing-basics.pdf

Muscular Dystrophy Association: Respiratory Care in Neuromuscular Disorders
https://www.mda.org/sites/default/files/publications/Breathe_Easy_P-160.pdf

Model Systems Knowledge Translation Center: SCI Recovery and Rehabilitation
https://msktc.org/sci/factsheets/understanding-spinal-cord-injury-part-2-recovery-and-rehabilitation

Post-Polio Health International
https://post-polio.org

UAB Model Systems: Understanding and Managing Respiratory Complications after SCI
https://sci.washington.edu/exercise/respiratory%20factsheet.pdf

University of Washington Video Demonstration: Manual Assisted Cough for SCI
https://www.youtube.com/watch?v=cmzZkdACei4

We're here to help.

Learn more today!

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