# **DIAPHRAGM PACING SYSTEM**

#### **Background**

Diaphragm pacing is a surgical treatment and neurostimulation technology used to provide ventilation for those with diaphragm weakness or paralysis due to nerve injury who are unable to breathe on their own (e.g., spinal cord injury and congenital central hypoventilation syndrome). A diaphragm pacing system (DPS) combines surgically implanted electrodes and a lightweight battery-powered device to stimulate the diaphragm to contract, pull air into the lungs, and facilitate breathing.

A DPS reduces the dependence on a mechanical ventilator by strengthening the respiratory muscles and helping to mimic natural breathing by using the person's own diaphragm as the "ventilator." DPS can provide part-time or full-time support in place of mechanical ventilation in individuals with intact phrenic nerves or those mainly responsible for the diaphragm movement necessary for inspiration. DPS works by implanting several electrodes (4) into the diaphragm and 1 tunneled through the skin to the abdomen for grounding. The five electrodes are then grouped and connected to a cable and a battery-powered external pulse generator device. This device uses a gentle and rhythmic electrical stimulation sent to the diaphragm to trigger diaphragm contraction. The sensation has been described differently, ranging from no feeling to a "finger flick." Desired settings are specific to the child but the device itself can be turned on and off as necessary. Since power for the contraction is supplied via this external pulse generator, a surgically implanted battery is not necessary. The external pulse generator device will have audible alarms indicating wire disconnection from device, power mode switch to internal battery, and low internal battery alarm. Pacing generally starts at about an hour but can progress to 8-12 hours within 3 months. Due to diaphragm fatigue, continuous 24-hour use of a DPS is not recommended.

A DPS allows children who are continuously ventilator dependent to be free from positive pressure ventilation during the day. A DPS is small, portable, easily concealed, and noiseless in comparison to a bulky ventilator and tubing. DPS can also enhance one's sense of smell and taste.



A child who depends on assisted ventilation full-time will have a tracheostomy and a mechanical ventilator. A backup ventilator, as well as the student's emergency bag with tracheostomy supplies, must always be available when a DPS is being used. If the diaphragm pacing does not support adequate oxygenation or the device malfunctions, the child should be immediately placed back on the ventilator and the DPS turned off.

### **Top Takeaways for School Considerations**

A diaphragm pacing system (DPS) provides ventilatory support using surgically implanted electrodes, wires, and an external pulse generator device to facilitate breathing.

School staff should be educated on the signs and symptoms of respiratory distress. Follow the student's emergency plan.

A backup mechanical ventilator must always be available in the event the DPS does not support adequate oxygenation or the device malfunctions.

Extra supplies should be available if necessary to support and cover the electrode exit site on the abdomen (e.g., gauze, transparent dressing).



#### Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of impaired gas exchange and ineffective breathing pattern
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Respiratory interventions and equipment needs (consider tracheostomy brand/size and downsize, suctioning brand/size, frequency of suctioning, ventilator brand, and settings); note location of suctioning, use of private duty nursing if applicable
- Assessment of implanted medical device (consider location, date of surgical placement, device specific information, exit location of electrodes, wires)

- Activity, positioning, transferring (consider precautions and/or restrictions)
- · Skin check, pressure relief techniques
- Equipment troubleshooting (consider equipment/device user manual, battery, charger)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

#### **Discussion Starters for Educational Team**

- 1. Has the school staff been trained to implement the student-specific emergency plan?
- 2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
- 3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
- 4. Is the physical school environment safely accessible for the student's mobility needs (e.g., entry and exit, ramps, location of classes, access to elevator, doorways)?
- 5. Does the classroom environment support the student's needs and/or equipment (e.g., desk/seating options, maneuverability space, electrical outlets, flash pass for bathroom or nurse)?

## Resources

Kennedy Krieger Institute: International Center for Spinal Cord Injury kennedykrieger.org

American Thoracic Society: Diaphragm Pacing thoracic.org/patients/patient-resources/resources/diaphragm-pacing-online.pdf

Sheperd Center: Diaphragm Pacing System Fact Sheet myshepherdconnection.org/respiratory/dps/fact-sheet



