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IPWSO
International
Prader-Willi Syndrome
Organisation

INFORMATION FOR FAMILIES

Respiratory (chest and airway) infections in PWS: Symptoms that parents and carers need to aware of

Most respiratory (airway and chest) infections in children and adults are self-limiting and resolve without medical intervention. The symptoms experienced in children, adolescents and adults with PWS can *sometimes* differ from those typically seen or expected in people without PWS, making it important for parents and carers to recognise when a child or adult with PWS is ill and needs treatment.

Symptoms of airway/chest infection in children and adults commonly begin with general signs of illness such as fever, irritability, poor feeding, and reduced activity. In PWS, the symptoms can be different, and this can delay the diagnosis and treatment. Some will not have fever, and many will still want to have and eat their meals. They do not have their usual strength, and breathing can be weak and shallow. However, when severely ill, most with PWS will not be interested in eating; this is very unusual, especially for older children and adults with PWS. Changes in behaviour, perhaps irritability, or activity should not be interpreted as misbehaviour; they can be the first signs of an infection.

All individuals with PWS, but especially the youngest, can have *silent aspiration* where food from the stomach refluxes into the airways. This will cause coughing, which can be misdiagnosed as an infection, but may not directly cause lung infection.

- **Upper airway/respiratory tract infections,** like the common cold, typically cause a runny or blocked nose, sneezing, sore throat, mild cough, and sometimes ear pain. But even with severe ear infections, many people with PWS do not complain about pain, as they have a high pain threshold.
- **Lower airway/respiratory tract infections**, such as bronchiolitis (inflammation of the smaller airway branches in the lungs) or pneumonia (infection of the lungs) tend to cause more severe illness. These often present with a persistent cough, that can be weak in PWS, or in the youngest present with breath holding (apnoea). In older children and adults, signs include fast or laboured breathing (but the respiration can be shallower in PWS due to muscle weakness), indrawing of the chest, flaring nostrils, pauses in breathing wheezing, or grunting sounds. Lips and fingertips can appear bluish due to low oxygen levels. Also, with lung infections and reduced or no drinking, children and adults can become dehydrated and require fluid through a nasogastric tube or intravenous line.

The following factors may impair children with PWS responding to respiratory infections and increasing the severity:

Sleep and breathing

- Obstructive sleep apnoea is a frequent finding due to obesity, poor muscle tone (hypotonia), and structural abnormalities affecting airways.
- Central sleep apnoea where the control of breathing and its response to changes in oxygen and carbon dioxide levels is impaired
- Severe scoliosis that affects lung capacity and breathing
- Hypotonia (weakness and poor muscle tone) of respiratory muscles

Aspiration

- Weak or uncoordinated swallowing can lead to food or drink entering the chest (aspiration) causing inflammation and infection within the lungs.

Tonsil and adenoid enlargement

- Enlargement of the tonsils and adenoid may develop with infection, and can also have been increased by growth hormone treatment**.**

When should you worry?

	If your child has any of the following	**Advice**
Red flags (urgent medical attention needed)	• Breathing very fast, too breathless to talk, eat or drink • Working hard to breathe, drawing in of the muscles below the ribs, or noisy breathing (grunting) • Breathing that stops or pauses • A harsh noise as they breathe in (stridor) present all of the time may reflect swelling of the larynx (voice box) • Small children and babies with lung infections try to open up inflamed airways by increasing the pressure in their airways that can be noisy but a different sound to laryngeal stridor • Is pale, blue, mottled or feels unusually cold to touch • Difficult to wake up, very sleepy or confused • Has a fit (seizure) • Has a rash that does not go away with pressure (the glass test)	Seek urgent medical help at your nearest hospital emergency room or call an ambulance. Inform the emergency service that the child has PWS, and that the presence or absence of fever as a symptom cannot be relied upon.
Warning signs (seek medical advice)	• Breathing a bit faster than normal or working a bit harder to breathe • A harsh noise as they breathe in (stridor) only when upset • Dry skin, lips or tongue • Not had a wee or wet nappy in last 8 hours • Not drinking • Irritable (unable to settle them with toys, TV, food or hugs even after their fever has come down)	Get medical advice if the person with PWS is unwell, making sure the health care professionals understand that the person has PWS with the implications mentioned on the left.

	• Temperature of 38°C or above for more than 5 days or shivering with fever (rigors). Always check for an elevated temperature or fever but be aware that small children with PWS can have elevated body temperature in hot weather without being ill, and conversely when ill the temperature can be in the 'normal range'. • Getting worse. Even if an initial medical check was thought to be normal, any deterioration needs a new medical evaluation.	