What Are ‘The Fatal Five’?

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*Source: HRST (Health Risk Screening Tool) Newsletter, July 2013; Health Risk Screening, Inc.; Karen Green McGowan, RN, CDDN; Founder of Health Risk Screening, Inc.*

The Fatal Five refers to the top five disorders linked to preventable deaths of individuals in congregate care settings, or in community-based residential settings. While the issues can differ in order of frequency depending on the population represented, the five conditions most likely to result in death or health deterioration for persons with intellectual and developmental disabilities are (1) bowel obstruction, (2) gastroesophageal reflux disease (GERD), (3) aspiration, (4) dehydration, and (5) seizures.

(1) Bowel Obstruction
This is the most common cause of preventable death in community settings. The most important root cause of bowel obstruction is the use of multiple drugs with constipating side effects. Add to this the affect of dietary habits that contribute to the problem, such as diets that are low in fiber and fluids. Ironically, medications intended to improve elimination can place the individual at higher risk for impaired bowel function. Adequate active movement or exercise is also important. Controlling these factors, and training caretakers to recognize the signs and symptoms of bowel problems at the earliest moment, can greatly reduce occurrence of death from bowel obstruction.

(2) Gastroesophageal Reflux Disease (GERD)
GERD is the backing-up of stomach contents, including acid, into the esophagus. It often goes undiagnosed in an individual, including those without disabilities, until major harm has been done to the bottom of the esophagus. Medications that cause constipation also contribute to GERD. Individuals who are overweight -- particularly when they carry excess weight around the abdomen or wear clothing that is too tight -- have a higher risk of GERD. Ill-advised dietary choices, immobility, and improper positioning also contribute greatly to the incidence. As the disorder continues without treatment, the occurrence of discreet or frank aspiration, life-threatening GI bleeding, and esophageal cancer become more common.

(3) Aspiration
Aspiration is the most common cause of death in institutional settings, including nursing homes and large group care settings for persons with intellectual and developmental disabilities (IDD). Aspiration often begins subtly and damages increasing areas of the lungs. Aspiration pneumonia is a common discharge diagnosis following hospitalization. As a person’s respiratory status becomes compromised, feeding tubes -- which carry their own increased risks -- often are used. Other factors which may lead to aspiration are poor body positioning, particularly in individuals who cannot control their own movements well, and behavioral issues related to eating.

(4) Dehydration
Individuals who do not swallow well are especially likely to refuse fluids or indicate fear when they get them, often resulting in dehydration. Dehydration is also likely when staff or family try to restrict fluids to prevent incontinence, not realizing that lack of fluids can contribute to constipation and increase seizure frequency, not to mention drug toxicity and other health problems.

(5) Seizures
Seizure deaths can occur from drug toxicity or from uncontrolled seizure. Sudden, unexplained death in epilepsy (SUDEP), occurs on a fairly regular basis and for reasons that medical science has yet to explain. Life expectancy for persons with active seizure disorders has shown to be up to 10 years less than those without the condition.

These Fatal Five causes account for 103, or 12 percent of the reported deaths last year in Ohio’s DD service system. Aspiration deaths were the most-reported of those listed as cause of death (57), followed by seizures (35), bowel obstruction (10), GERD (1) and Dehydration (none).

851 deaths were reported in 2014 out of 91,074 people served, for a rate of 9.34 per thousand.