

The Fatal Five





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The Fatal Five

A group of health conditions that are often fatal for people with intellectual and developmental disabilities (IDD). Many of these conditions are preventable if treated early.

Some people with IDD are at higher risk due to health needs that may not be as prevalent in the general population.

Some people may not verbalize symptoms, and may exhibit behaviors that mask the signs of life-threatening conditions.

Having knowledge of the Fatal Five causes, symptoms and treatments can help save lives.

The Fatal Five

Aspiration
Dehydration
Constipation
Seizures
Infection & Sepsis

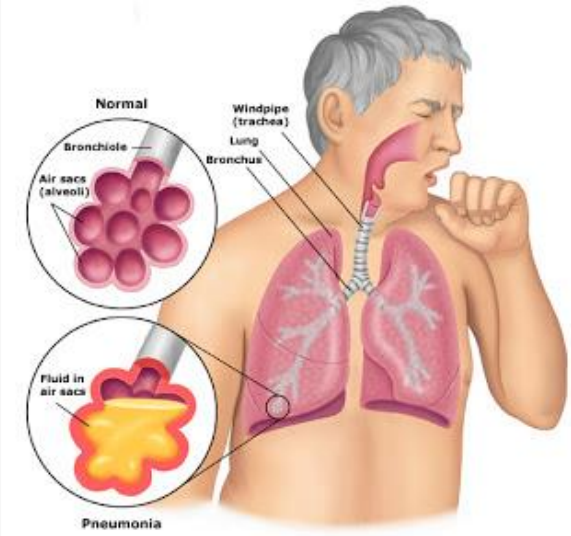
Fatal Five - Aspiration

Aspiration is often listed as a common cause of death in care settings for people with IDD.

Aspiration pneumonia is a common discharge diagnosis following hospitalization.

Risk Factors for people with I/DD may include:

- Decreased or absent gag reflex
- Weakness of the muscles that are used in chewing and swallowing
- Poor positioning during meals
- Medication side effects that relax the muscles used for chewing and swallowing.
- Eating too fast or having too much food in the mouth while eating



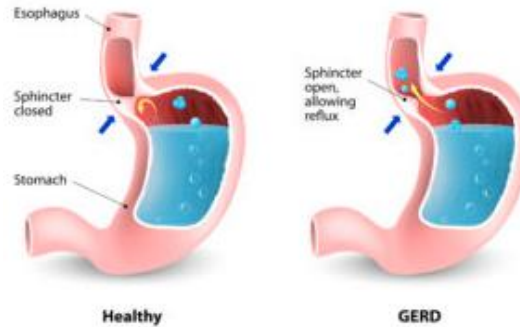
Special Risks

- Foods that are difficult to chew or swallow can increase the risk for choking. People with swallowing disorders should avoid:
- Meat chunks (also meat like hot dogs)
- Raw hard vegetables
- Raw hard fruits
- Grapes
- Chewy breads
- Sticky foods like peanut butter, caramel
- Hard candy



GERD

Gastroesophageal reflux disease



Gastroesophageal reflux disease (GERD) is the backing up of stomach contents, including acid, into the esophagus. GERD is frequently undiagnosed until major harm has been done to the bottom of the esophagus.

Medications that cause constipation also contribute to GERD.

Individuals who are overweight (especially around the abdomen) have a higher risk of GERD.

- Poorly treated GERD can lead to:
- Erosive esophagitis: a severe form of GERD in which the throat lining is damaged by stomach acid.
- Barrett's esophagus – a condition that causes the flat pink lining of the swallowing tube (esophagus) to become damaged by acid reflux, causing the lining to thicken and become red. Can lead to cancer overtime.
- Esophageal stricture- narrowing or tightening of the throat that causes difficulty swallowing
- Aspiration Pneumonia

What to look for with GERD

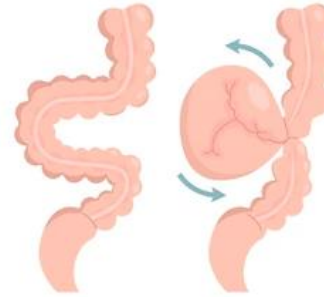


- Common symptoms of GERD include frequent heartburn, regurgitation of stomach contents, difficulty swallowing food, upper abdominal or chest pain, feeling of a lump in your throat
- Recognizing signs of GERD, especially in people who do not communicate with words, is important to reduce the risks associated with this condition.
- People who exhibit food refusal, coughing when lying down, physical or verbal outbursts particularly around mealtimes, or distress in the middle of the night may be telling you that they are experiencing GERD.
- Pica, a behavior where people eat things of non-nutritional value, may also be a sign of GERD and should prompt an evaluation.



Fatal Five - Constipation

Bowel Obstruction



Conditions that affect the muscles and nerves, may interfere with the body's response to the need to use the bathroom

People with mobility issues can lack the activity level needed to help the bowels function properly

Poor swallowing skills may make it difficult to eat and drink adequate amounts of fiber and fluids.

Medication side effects can contribute to constipation. Watch for constipation in persons who take antacids, anticonvulsants, antidepressants, tranquilizers, iron supplements, drugs for tremor, medication for urinary control or if the individual is using narcotics or other drugs for pain relief.

Poorly managed constipation can lead to bowel perforation (a hole in the digestive tract) and bowel obstruction (a blockage in the digestive tract), one of the most common preventable causes of death for people with I/DD

Signs and Symptoms of Constipation

BRISTOL STOOL CHART



TYPE 1 - SEVERE CONSTIPATION
Separate, hard lumps



TYPE 2 - MILD CONSTIPATION
Lumpy and sausage like



TYPE 3 - NORMAL
A sausage-shape with cracks in the surface



TYPE 4 - NORMAL
Like a smooth, soft sausage or snake



TYPE 5 - LACKING FIBER
Soft blobs with clear-cut edges



TYPE 6 - MILD DIARRHEA
Mushy consistency with ragged edges



TYPE 7 - SEVERE DIARRHEA
Liquid consistency with no solid pieces

Common signs:

- Small hard lumps of stools
 - Bleeding from the anus
 - Hard, protruding abdomen
 - Sausage-like lumpy stools
 - Refusing to eat or drink
 - Difficulty passing stool
 - Swelling or pain from abdomen
 - Vomiting digested food that smells like feces
 - Can be associated with verbal and physical aggression, acute confusion
- SEVERE Constipation may lead to **FECAL IMPACTIONS**. Symptoms include:
 - Leakage of liquid or sudden episodes of watery diarrhea
 - Bladder pressure/loss of bladder control
 - Lower back pain
 - Rapid heartbeat

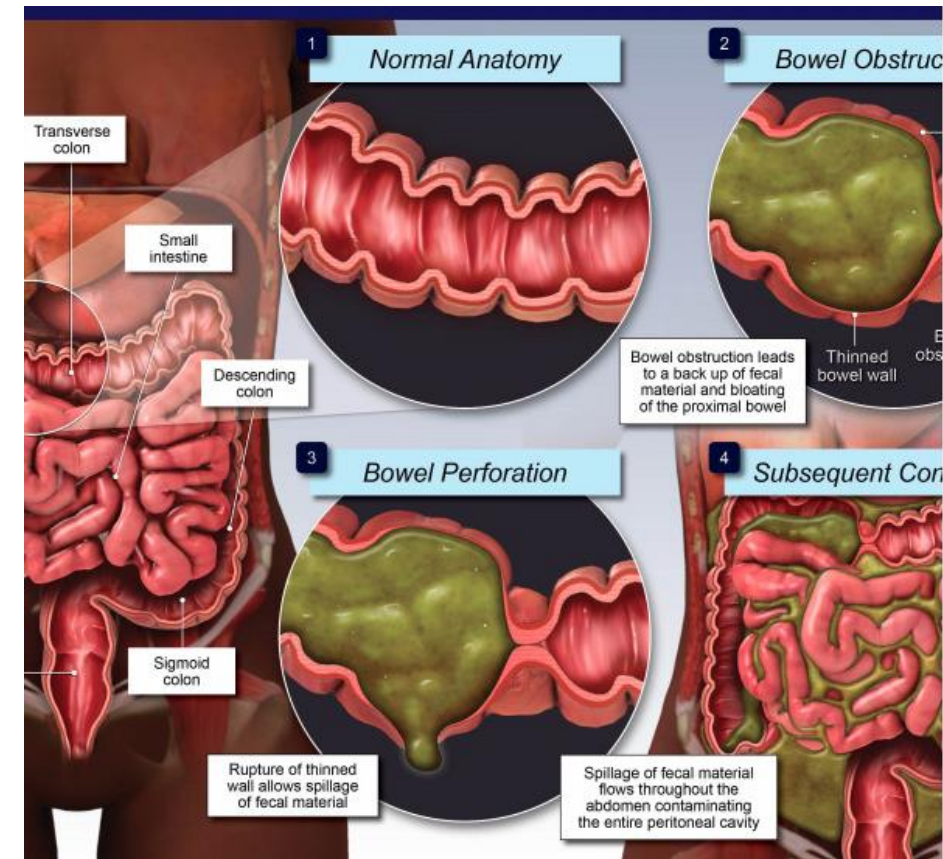
Fecal impaction

- Fecal impaction occurs when the rectum and lower colon is full of hard or soft stool and the individual is unable to evacuate their bowel.
- Usually happens when there has been no adequate bowel movement for days or weeks, and a large compacted mass of feces builds up in the large bowel.
- Liquid, Bristol stool chart type 6-7 stool, can leak around the mass. This happens between bowel movements, causing soiling of loose stool on clothing called **fecal overflow incontinence**.
- Fecal impaction often occurs just prior to bowel obstruction.



Bowel Obstruction

- Bowel Obstruction is a partial or complete blockage of the small or large intestine.
- People with pica have a higher risk of bowel obstruction
- A suspected bowel obstruction is a medical emergency, this condition can be fatal
- Bowel Obstruction is one of the most common preventable causes of death for people with I/DD



Common clinical symptoms of bowel obstruction include:

- Nausea
- Vomiting
- Difficulty swallowing
- Stomach pain
- Inability to pass bowel movements
- Abdominal distention

Preventing Constipation

- High fiber diet (20-35 grams/day)
- Adequate time for bowel movements
- Laxatives as ordered by a physician
- Regular exercise
- Adequate fluid intake
- Review medications for constipation as a side-effect
- **Track BM frequency, type and amount**
- Limit foods with no or little fiber (cheese, meat, processed foods)
- When to seek medical support:
 - A person is constipated for 3 or more days, or as directed by a healthcare provider (In program settings, BM monitoring should have a bm protocol from the healthcare provider which includes when to use any prescribed PRNs)
 - If constipation occurs after beginning a new prescription, vitamin or mineral supplements
 - If constipation is accompanied by blood in stools, fever and/or abdominal pain.



Fatal Five - Dehydration



People who have difficulty swallowing are at highest risk for dehydration

Dehydration can contribute to constipation and can make seizures worse

People with a fever or vomiting have an increased need for fluids so be aware

Communication limitations can be a barrier to adequate fluid intake

Symptoms of Dehydration

Other Signs/Symptoms

- Dizziness
- General weakness
- Flushed face
- Confusion in older adults
- Few or no tears when crying
- Decreased skin elasticity (skin tenting) .
- Mild to moderate dehydration can be corrected by drinking more water alone, but if severe dehydration develops, it can be a medical emergency.

Severe Signs/Symptoms

- Sunken eyes
- Low blood pressure
- A lack of sweating
- Rapid heart rate



Tips to Avoid Dehydration



Carry a water bottle for each person when going out in the sun.



Offer drinks throughout the day (not only at meals). People should have 8 to 10 glasses of fluid every day unless otherwise indicated.



Increase intake of foods with high water content, such as fruits and vegetables.



Encourage snacks like popsicles, Jell-O, diced fruit cups, watermelon, and apple sauce since these have high water content.



Use an air conditioner or fan in hot weather. Adults should never stay in temperatures over 100°F (37.8°C), especially indoors, without good air flow.



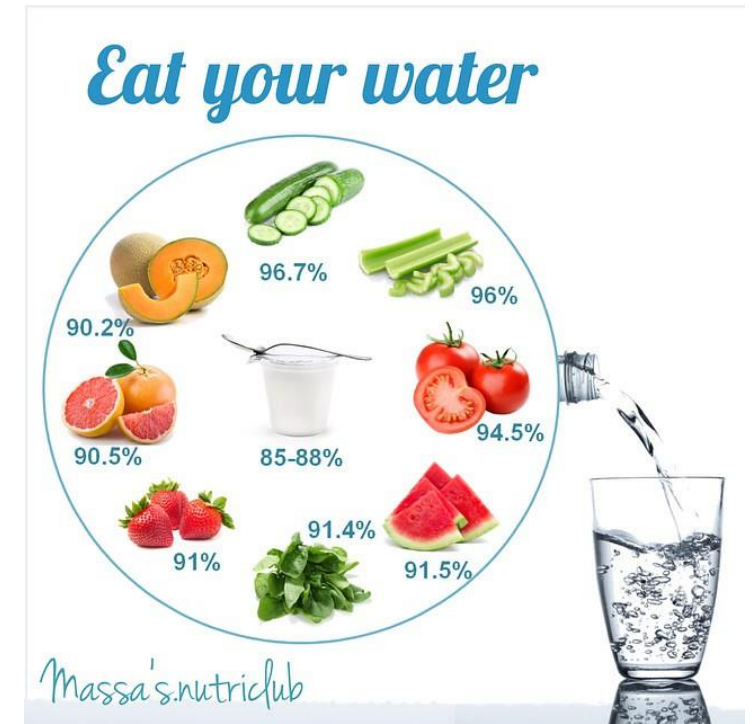
Have a plan for offering fluids to people who do not have the ability to ask for a drink or obtain on their own.



Soda is not a good choice for rehydration because it contains too much sugar and not enough sodium to replace electrolytes.



Increase fluid intake at the first signs of illness such as a cold or the flu.



Seizures & Epilepsy

- Seizures are episodes of disturbed brain activity which can affect one part or multiple parts of the brain.
- A seizure happens when there is a sudden abnormal electrical signal in the brain.
- Seizures vary in appearance and severity depending on where they start in the brain.
- Epilepsy is a disorder of the brain, characterized by **recurrent seizures** (uncontrolled body movements). Epilepsy is a common neurological condition.



Risk Factors and Symptoms



Risk Factors include:

- Progressive brain disease
- Head trauma
- Hypoglycemia
- Congenital conditions
- Brain tumor(s)
- Genetic factors
- Stroke

Seizures are categorized as either **generalized** (involving the entire outermost layer of the brain) or **partial** (involving part of one cerebral hemisphere). Symptoms vary depending on the type of seizure. Some have staring spells while others may shake violently.

Seizure symptoms can include:

- Rapid eye blinking or staring
- Twitching of the face
- Odd repetitive behavior
- Shaking or jerking of the limbs
- Stiffening of the body
- Sudden aggressive behavior





Fatal Five - Seizure Disorder

Individuals with IDD have a higher incidence of seizure disorders or epilepsy.

There can be significant illness or death from uncontrolled seizures due to issues such as breathing complications or aspiration (lung complication)

Drug toxicity and medication side effects can further impact the health of people who take these medications.

Balancing adequate control of seizures and the risk of adverse drug reactions must always be at the forefront of the treatment plan.

Seizure Management

- During a seizure, check to make sure the individual is breathing, time the seizure
- Help the individual lie down on the bed or floor, loosen clothing around the neck and remove eyeglasses
- Stay with the person during a seizure
- Do not place anything in the person's mouth or restrain them
- Move objects away to prevent injury
- If possible, provide padding under individual's head/arms/legs
- Only move the person if the area is unsafe.
- After the seizure has ended, ensure the person is comfortable, allow quiet time to recover from the seizure and check on the person every 15 minutes to make sure he/she is breathing normally.

Seizure First Aid

What to do in the event of a seizure

- 1** **STAY** with the person and start timing the seizure. Remain *calm* and check for medical ID. 
- 2** Keep the person **SAFE**. Move or guide away from *harmful objects*. 
- 3** Turn the person onto their **SIDE** if they are not awake and aware. *Don't block airway*, put something small and soft under the head, loosen tight clothes around neck.
- 4** Do **NOT** put *anything* in their mouth. Don't give water, pills or food until the person is awake. 
- 5** Do **NOT** *restrain*. 
- 6** **STAY** with them until they are awake and alert after the seizure. *Most seizures end in a few minutes.* 

Call 911:

- ☑ Seizure lasts longer than 5 minutes
- ☑ Repeated seizures
- ☑ Difficulty breathing
- ☑ Seizure occurs in water
- ☑ Person is injured, pregnant, or sick
- ☑ Person does not return to their usual state
- ☑ First time seizure



Fatal Five - Infection/Sepsis

People with IDD are three times more likely to die from sepsis than the general population

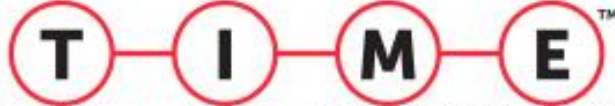
People with IDD often have difficulty communicating when they're not feeling well, which can lead to sepsis going unnoticed.

Lack of access to healthcare providers with experience working with the population and lack of access to screenings may prevent diagnosing sepsis early.

Early detection and treatment of these conditions can improve quality of life, lower the risk of death, and lead to better health


Symptoms of Sepsis

When it comes to sepsis, remember
IT'S ABOUT TIME™. Watch for:



T	I	M	E ™
TEMPERATURE higher or lower than normal	INFECTION may have signs and symptoms of an infection	MENTAL DECLINE confused, sleepy, difficult to rouse	EXTREMELY ILL severe pain, discomfort, shortness of breath

If you experience a combination of these symptoms: seek urgent medical care, call 911, or go to the hospital with an advocate. Ask: "Could it be sepsis?"

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Symptoms of Sepsis include the following:

- High heart rate, low blood pressure
- Fever, feeling cold or shivering
- Confusion or disorientation
- Shortness of breath
- Extreme pain or discomfort
- Clammy or sweaty skin

Complications:

- THE MOST SEVERE COMPLICATION is Septic Shock! The body goes into shock from the decrease of blood pressure, causing decreased blood flow to tissues/organs possibly resulting in death.

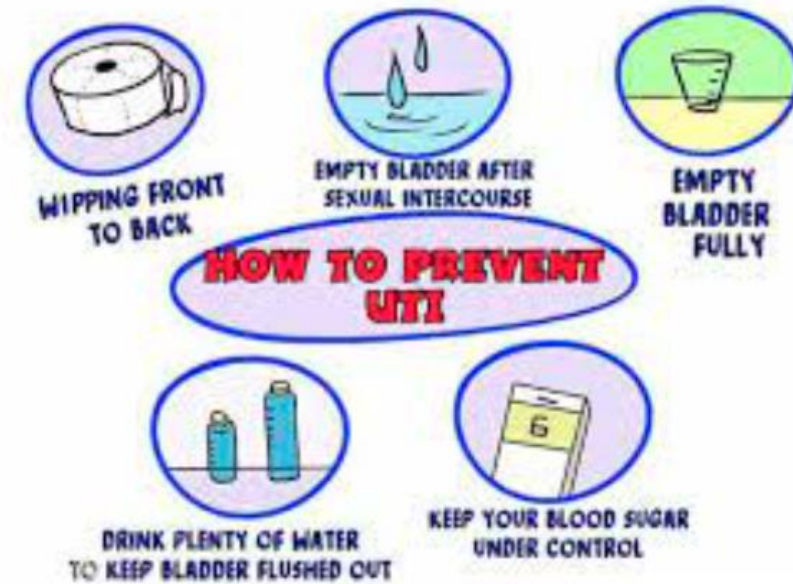
Treatment & Prevention

Sepsis requires immediate treatment which includes:

- I V fluids
- Antibiotics, if the cause is bacterial
- Oxygen
- Additional treatments may be needed depending on the severity

Prevention:

- Prevent infections by taking care of chronic conditions and getting recommended vaccines (routine preventive care exams)
- **Treating infections quickly, do not delay treatment! (think about UTI which is very common)**
- Have good hygiene by washing hands, keeping any cuts clean and covered, and overall good personal hygiene
- Routine dental exams and treatment
- Routine catheter changes
- Evaluation of possible aspiration by swallow study
- Follow prescribed wound care regimen and repositioning guidelines





You Can Make a Difference!

- Early detection and treatment of these conditions can lead to better health, lower risk of death and improved quality of life.
- Make it a priority to educate yourself, support staff, families, and those with IDD to recognize signs of these conditions and to seek medical consultation at the earliest signs of illness.