The Fatal Five

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Link: https://www.surveymonkey.com/r/fatalfive-pre

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Learning Objectives

- Identify and describe the Fatal Five conditions and their impact on the health and mortality of individuals with intellectual disabilities (ID).
- Recognize the unique challenges individuals with ID face in communicating their symptoms and advocating for their healthcare needs.
- Analyze warning signs and risk factors associated with each of the Fatal Five diagnoses and explain how these may present differently in individuals with ID.
- Apply practical strategies that direct support professionals and caregivers can use.
- Demonstrate knowledge of person-centered advocacy techniques to support individuals with ID in navigating the healthcare system, maintaining consistent care, and ensuring their voices are heard in decision-making processes.

What are the Fatal Five?

- Aspiration
- Bowel Obstruction
- Dehydration
- Infection/Sepsis
- Seizures
- GERD-often included.

Before we Continue…A Word About:

Self-Care

…is the heart of all health care and of our work.

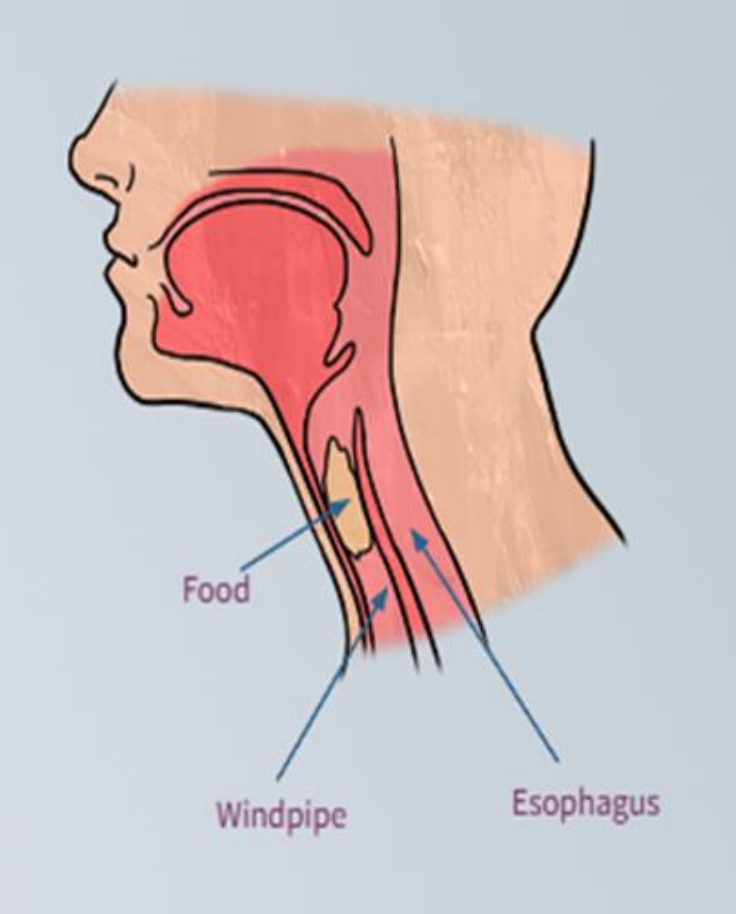
Prevention 101

- Know your client(s) well and pay attention.
- Notice when things seem not as they should be.
- Reminder, many of your client(s) are unable to communicate their distress and suffering expressively.

What is Aspiration?

- Foods or fluids going below the vocal cords into the airway is aspiration.
- Some people do not cough and that is called silent aspiration.
- Chronic micro aspiration where only very small amount of saliva, fluids or food goes into the airway.

(Logemann, 1998)



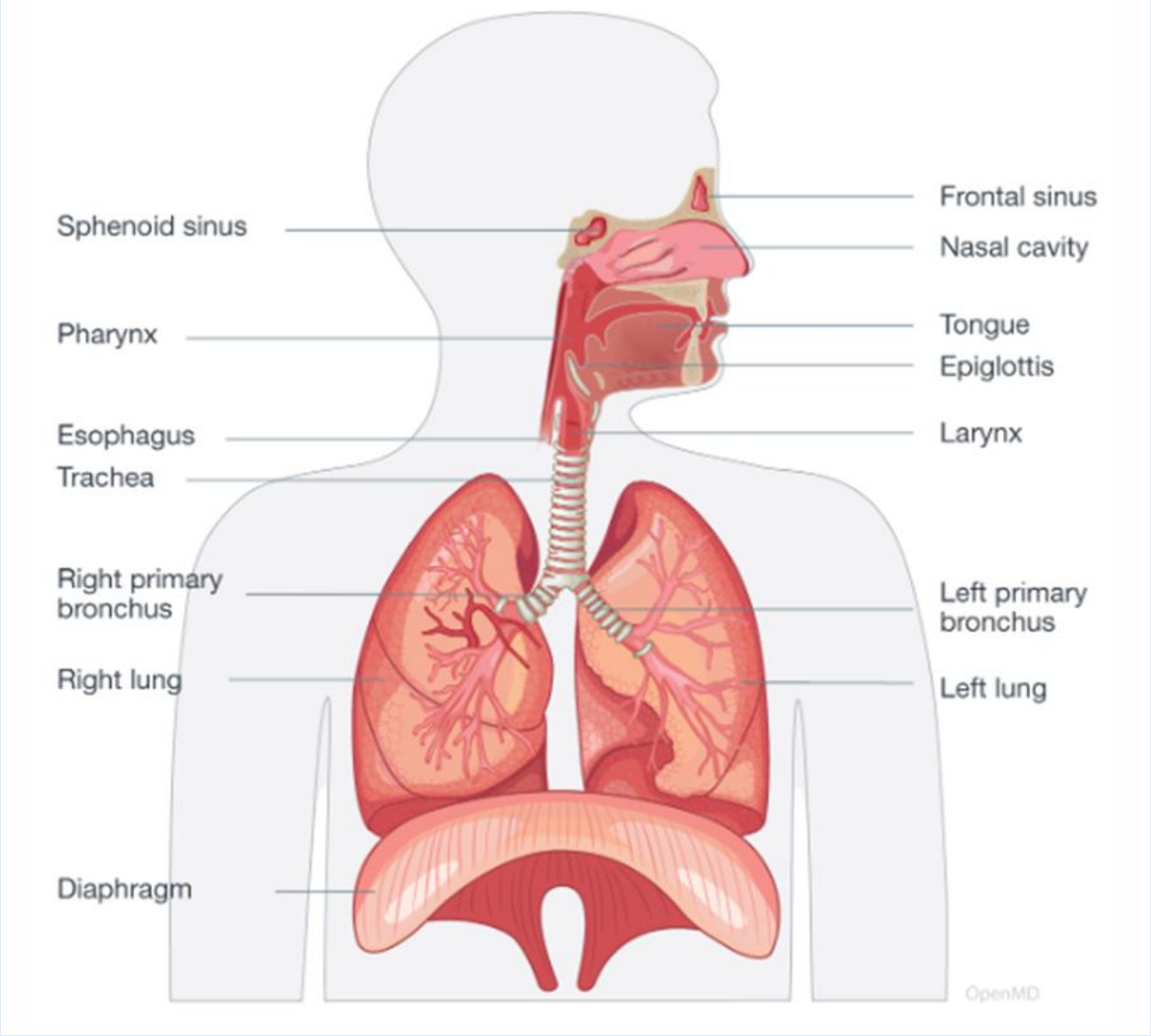
(Healthline, n.d.)

Aspiration and IDD

- People with IDD are at an increased risk due to a combination of anatomical, functional, behavioral, and cognitive factors.
- Evidence supports higher rates of dysphagia and aspiration-related complications in this population.
- Those with severe or profound ID or comorbidities such as cerebral palsy or dementia are at a higher risk of developing dysphagia.

(Sheppard, 2006)

Structure of Respiratory Tract



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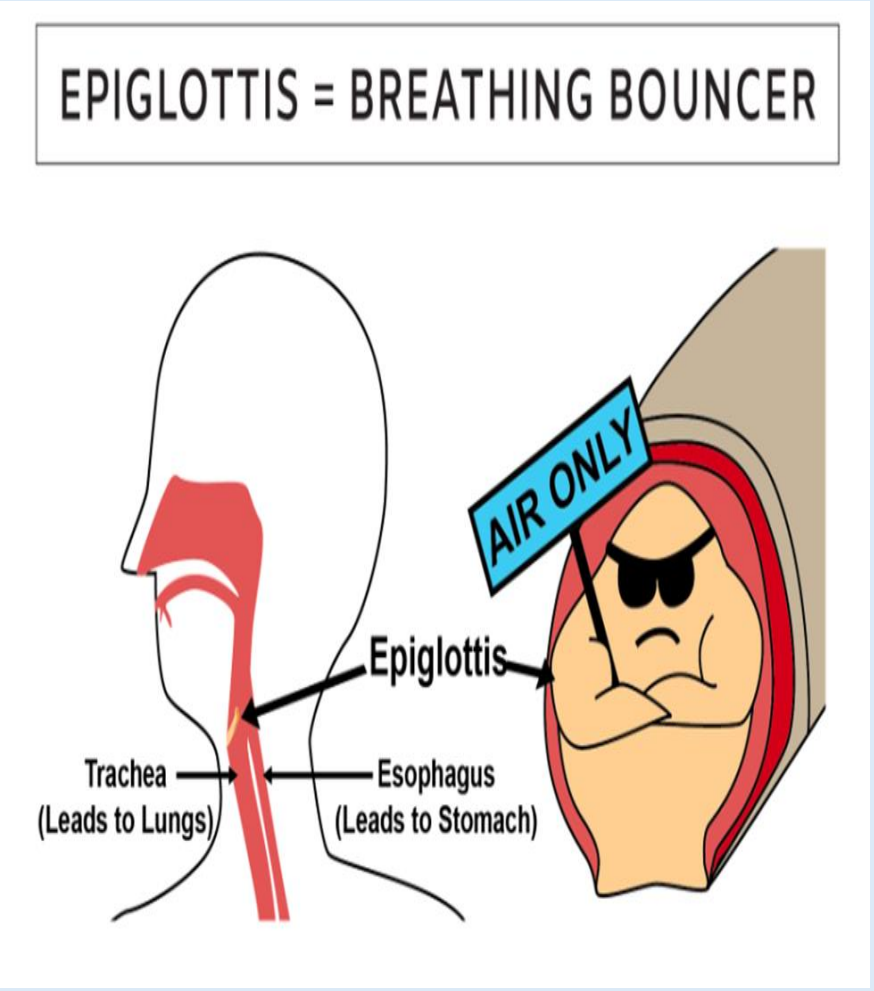
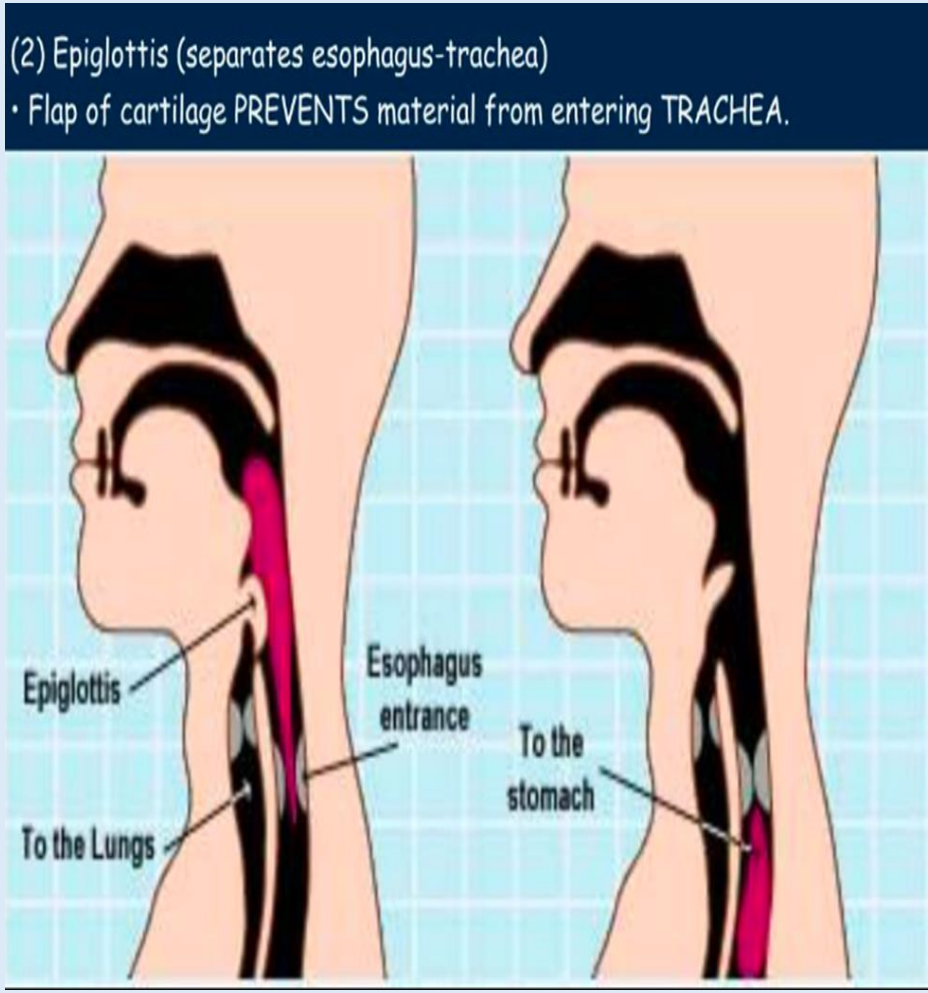

EPIGLOTTIS = BREATHING BOUNCER
AIR ONLY
Epiglottis
Trachea
(Leads to Lungs)
Esophagus
(Leads to Stomach)


(2) Epiglottis (separates esophagus-trachea)
• Flap of cartilage PREVENTS material from entering TRACHEA.
Epiglottis
Esophagus entrance
To the stomach
To the Lungs

Increased Risk for Aspiration

- Medications (anticholinergic meds, sedatives, pain meds, muscle relaxants.) (Clave & Shaker, 2015)
- Swallowing difficulties (dysphagia) often due to neuromuscular diseases like Parkinson's Disease, or stroke, or congenital malformations. (Kalf et al., 2012)
- Acute intoxication from drugs or alcohol. (Marik, 2011)
- Persons who experience seizures. (Smith Hammond & Goldstein, 2006)
- Gastroesophageal reflux (GERD). (Vakil et al., 2006)
- Behavioral health challenges:
- Eating too fast=swallowing too fast. Taking other people's food that does not align with their personalized diet. (Sheppard, 2006)
- Body positioning challenges.

Signs of Aspiration

- Coughing or choking while eating. (Smith Hammon & Goldstien, 2006)
- If they cough after drinking water but not after a milkshake, they may just aspirate with thin liquids. (Clave & Shaker, 2015)
- Aspiration may be "silent," occurring without overt symptoms such as cough or choking. (Marik, 2011)
- Additional signs can include wet or gurgled voice, wet breathing, recurrent respiratory infections, and, in severe cases, acute respiratory distress or hypoxemia. (Cichero, 2016)

Listening for Silent Aspiration

- Taking longer than 30 minutes to eat
- Wet, gurgled breathing after they eat
- Agitation or discomfort after meals
- Meal refusals
- Weight loss
- Clearing the throat frequently
- Multiple swallows to get the food down
- Easily gets tired during meals
- Fever with no known cause

(Cichero, 2016; Clave & Shaker, 2015;

Marik, 2011; Smith Hammon & Goldstien, 2006)

What do you do?

- Record your observations.
- Report it to your supervisor.
- A medical work up is usually needed to confirm the diagnosis and develop a specific treatment plan for the individual.
- Some people need a special diet, support with body positioning, and/or behavioral health intervention support.

(Clave & Shaker, 2015; Cichero, 2016;

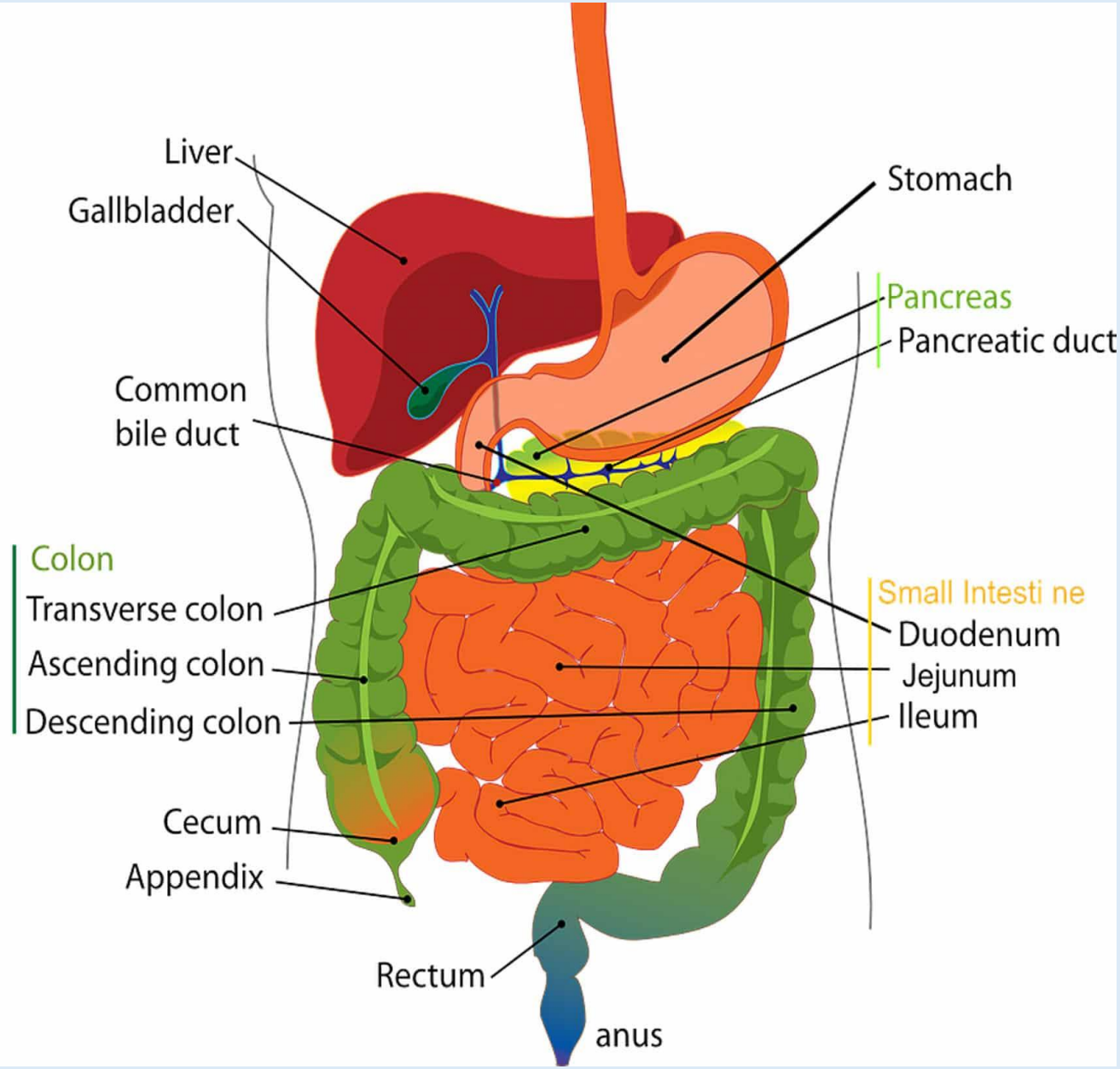
Sheppard, 2006)

Bowel Obstruction

- Interruption of the normal passage of intestinal contents due to a mechanical or, less commonly, functional blockage at any point along the gastrointestinal tract.
- This results in proximal accumulation of gas and fluid, leading to bowel distension, increased intraluminal pressure, and, if unrelieved, can progress to bowel ischemia, necrosis, and perforation.
- The most common causes are intra-abdominal adhesions, malignancy, and hernias.

(Catena et. al., 2021;

Maung et al., 2012)


Liver
Gallbladder
Stomach
Pancreas
Pancreatic duct
Common
bile duct
Colon
Transverse colon
Ascending colon
Descending colon
Small Intesti ne
Duodenum
Jejunum
Ileum
Cecum
Appendix
Rectum
anus

BOWEL OBSTRUCTION

* NORMAL FLOW through INTESTINES ~ INTERRUPTED

* CAUSES:

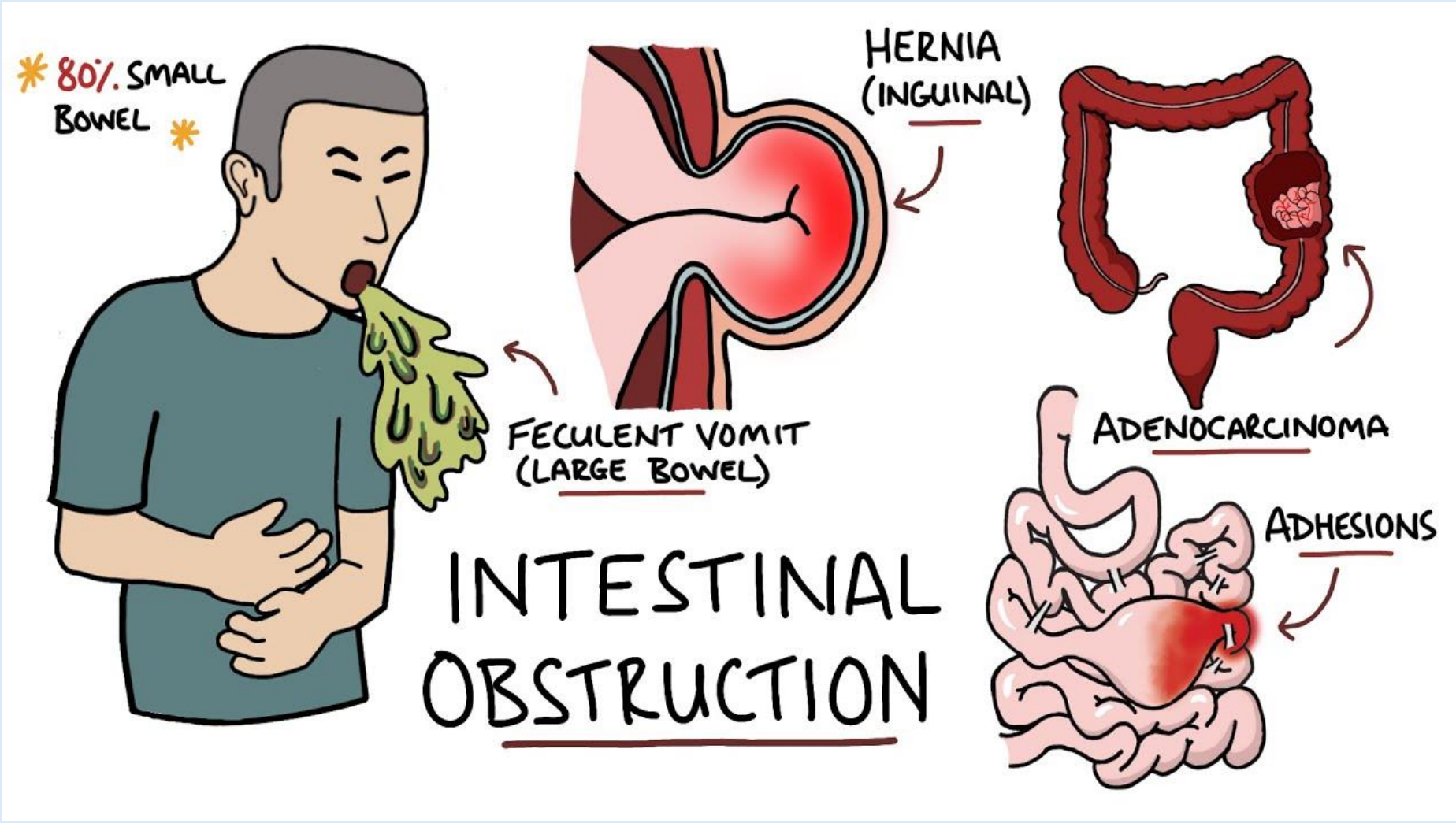
1. MECHANICAL

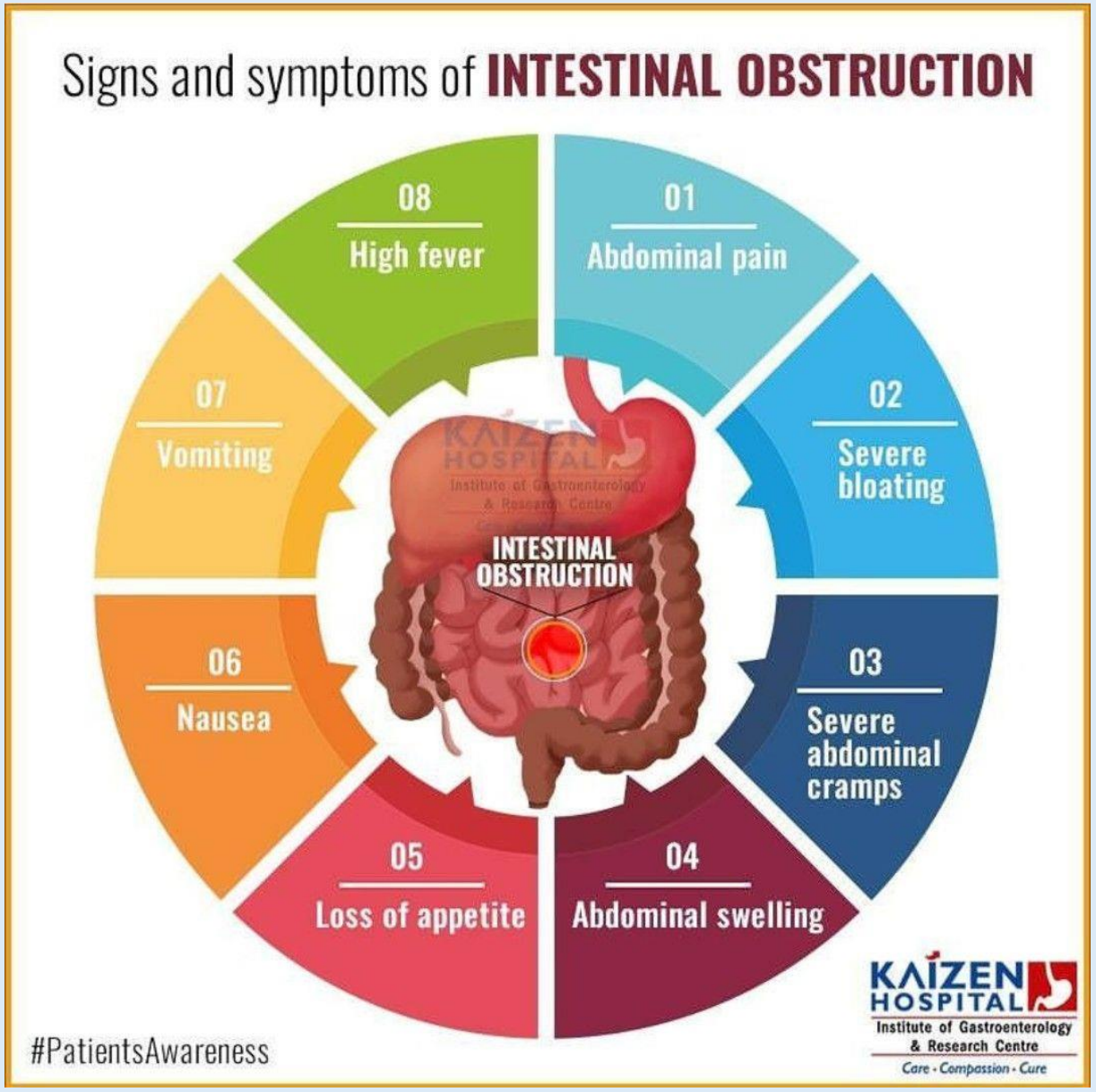
* PARTIAL
  - ~ LIQUID STOOL
  - ~ GAS

* COMPLETE
  - ~ NOTHING can PASS

2. FUNCTIONAL (ILEUS)

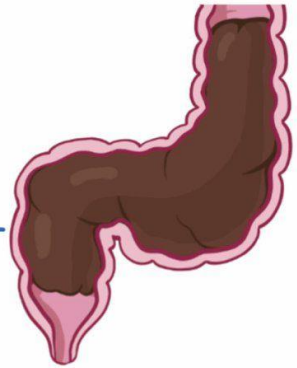
* DISRUPT PERISTALSIS
  - ~ WAVES of CONTRACTION


80% SMALL BOWEL
HERNIA (INGUINAL)
FECULENT VOMIT (LARGE BOWEL)
ADENOCARCINOMA
ADHESIONS
INTESTINAL OBSTRUCTION



FECAL IMPACTION

HARD MASS of COMPACTED STOOL
- ~ not VOLUNTARILY EVACUATED
- ~ from CHRONIC CONSTIPATION

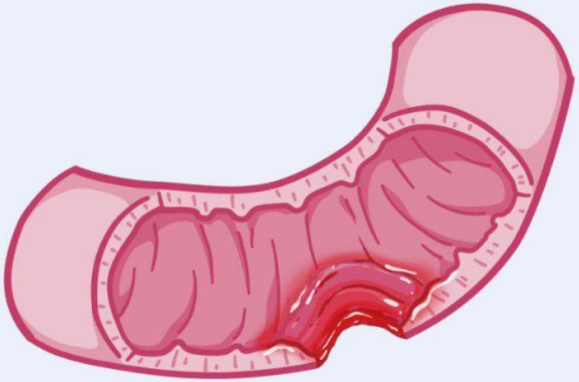


ASSOCIATED with:

↓ ABILITY to SENSE & RESPOND to ↑↑↑ BURDEN of STOOL

COMPLICATIONS

* BOWEL ULCERATION
* PERFORATION



Bowel Obstruction and IDD

- Signs and symptoms for persons with IDD often differ from the general population.
  - Communication barriers and atypical presentations.
- Most common features include:
  - Abdominal pain or distension, decreased appetite, nausea, vomiting, and fecal incontinence (overflow soiling).
- Irritability, withdrawal, or agitation can be observed-specifically for those with severe or profound IDD.

(Matson & Kozlowski, 2011; Simmons et al., 2021;

Sheppard, 2006)

Fecal Impaction: Risk Factors

- Chronic constipation.
- Reduced physical activity or immobility.
- Medications that decrease colonic motility (i.e., opiates, anticholinergics (including many anti depressants and anti psychotics), and calcium channel blockers.).
- Poor dietary fiber intake.
- Inadequate hydration.
- Hospitalization.
- Chronic renal failure.

(American Academy of Family Physicians [AAFP], 2022; Mayo Clinic, 2023; Chen et al., 2024)

Dehydration

- Deficit of total body water that occurs when fluid losses exceed fluid intake.
- This can result from various causes, including excessive sweating, vomiting, diarrhea, inadequate fluid consumption, or certain medications (anticholinergic medications, diuretics.)
- Clients with severe wounds (burns and bedsores) are at risk for dehydration.
- Excessive heat puts people at risk for dehydration.
- People who are ill with high fevers are at risk.

(Centers for Disease Control and Prevention, 2023; Cleveland Clinic, 2023; Mayo Clinic, 2023; Merck Manuals, 2024)

Signs and Symptoms

- Increased thirst.
- Dry mucous membranes (dry mouth or dry tongue).
- Decreased skin turgor (elasticity).
- Sunken eyes.
- Reduced urine output.
- Fatigue, headache, and confusion.
- Dry lips, dizziness, muscle weakness, and rapid breathing.
- Elderly clients: confusion, extreme weakness, nonsensical speech, and furrowed tongue may be more prominent.

(Cleveland Clinic, 2023;
Mayo Clinic, 2023)

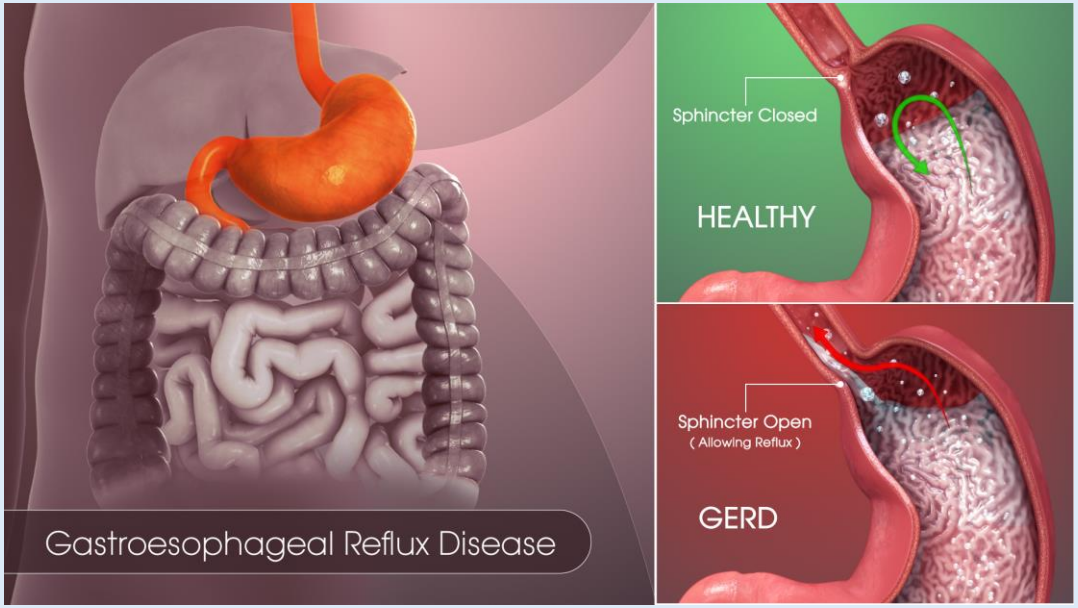
Preventing Dehydration

- Observe your client(s) closely!
- Asking yourself questions:
  - Are they drinking enough fluids, do they have risk factors for dehydration, are they showing symptoms of dehydration?
- Recommended daily fluid intake for healthy adults is .7-.8 ounces **per pound of body weight** (including all beverages and food moisture).

(Cleveland Clinic, 2023;
Mayo Clinic, 2023)

Gastroesophageal Reflux Disease (GERD)

- Also known as:
  - Acid indigestion, heartburn, or acid reflux. (Mayo Clinic, 2023)
- Persons with IDD are at a 50% greater risk for developing GERD.



(Mitra, Shakespeare, Kinnear, 2020)

Signs and Symptoms

- For persons with IDD is often atypical and may be difficult to recognize.
  - Communication barriers and limited ability to report classic symptoms (heartburn, regurgitation, etc.).
- Frequently presents as vomiting, rumination, hematemesis, food refusal, increased salivation, irritability, pain, anemia, cough, and recurrent pneumonia.
- Restlessness, fear, or depressive symptoms may be observed; however, are not specific to GERD and should be interpreted with caution.

(Böhmer, Klinkenberg-Knol, Niezen-de Boer, & Meuwissen, 2000; Mayo Clinic, 2023)

Other Non-verbal Signs

- Vomiting
- Refusal to eat
- Weight loss
- Regurgitation
- Shortness of breath
- Coughing at night
- Crying or screaming before or after meals
- Dental decay
- Asthma attacks and wheezing
- Self-injurious behavior
- Crying during the night
- Failure to nurse in infants
- Arcing of the back and turning away from food

(Böhmer, Klinkenberg-Knol, Niezen-de Boer, & Meuwissen, 2000)

Diagnosis and Treatment

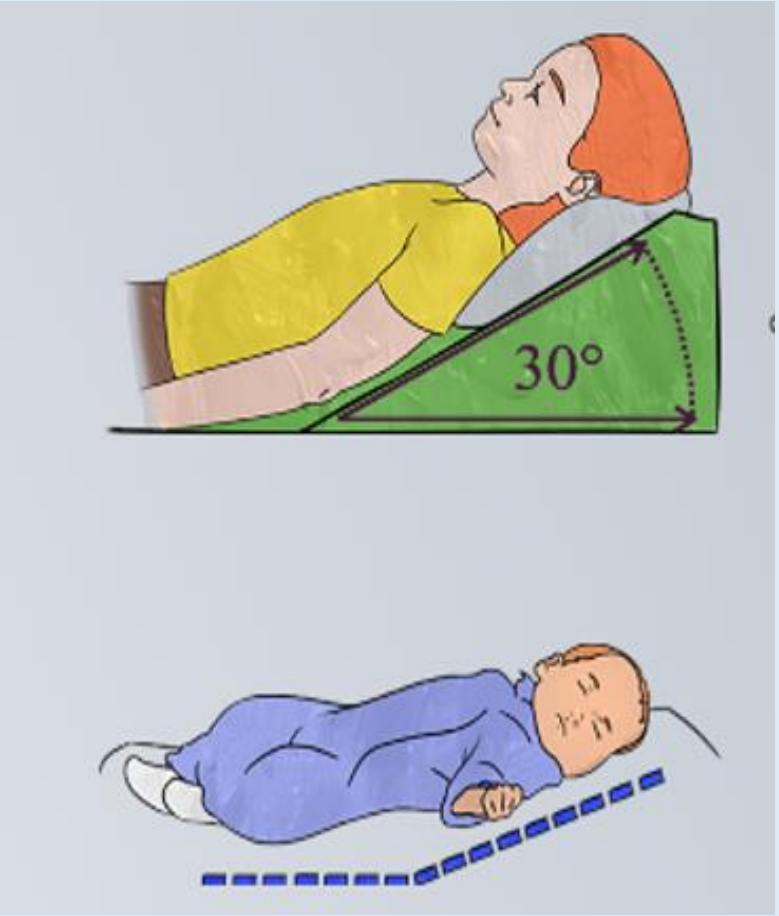
A medical evaluation is required to diagnose and treat GERD.

Medications are typically the first line of defense.

Dietary changes may be recommended.

How Do I Prevent It?

- About 50% of food is out of the stomach within 2.5 to 3 hours.
- The stomach takes 406 hours to completely empty.
- Don’t lie down for 2.5 to 3 hours after eating.
- If they must lie down, lift up the head of the bed 20-30 degrees.



(Mayo Clinic, 2023)

Infection/Sepsis

- **An infection is the invasion and multiplication of microorganisms—such as bacteria, viruses, fungi, or parasites—within the tissues of a host, accompanied by a host response**. This process occurs when the microorganisms overcome or evade the host's defense mechanisms, leading to their proliferation and potential tissue invasion.
- **Sepsis** is currently defined as a syndrome of life-threatening organ dysfunction resulting from a dysregulated host response to infection. 1/3 of patients with sepsis end up dying from the infection.

(Murray et al., 2023; Singer et al., 2016; Vincent et al., 2020)

Should We Try to Kill All The Germs?

- The **human microbiome contains approximately 38 trillion bacteria.**
- **The majority of these bacteria reside in the colon**.
- The skin harbors approximately **10^3 to 10^7(1,000-10,000,000 bacteria per square centimeter**.(A centimeter is 25/64 inches.) Sebaceous and moist areas (e.g., axilla, groin, forehead) tend to have higher bacterial densities, often reaching the upper end of this range, while dry areas (e.g., forearm, calf) have lower densities.
- Eliminating our healthy biome can lead to life threatening complications such as a C diff infection in our gut.

(Sender, Fuchs, & Milo, 2016; Grice & Segre, 2011; Smits, Lyras, Lacy, Wilcox, & Kuijper, 2016)

How Can We Prevent Infections?

- Self-care: Just having enough sleep and proper nutrition goes a long way in keeping us healthy.
- Proper handwashing has been documented to reduce transmission of infections in institutionalized settings.
  - Wet your hands with water, then add soap, rub your hands together for 20 seconds, rinse your hands thoroughly, and finally use a paper towel to turn off the water.
- Hand sanitizers are very effective at killing germs if used appropriately.
- Keeping it clean:
  - General cleanliness is important
  - Wipe down surfaces
  - Disinfect toilets and showers

(CDC, 2022)

What are the Signs of Infection?

- **Signs and symptoms of infection in patients with intellectual disability** are often similar to those in the general population, including fever, cough, dyspnea(shortness of breath), dysuria (painful urination), and changes in bowel habits.
- However, atypical or non-specific presentations are common, such as behavioral changes (agitation, withdrawal, aggression), altered mental status (confusion), decreased appetite, functional decline, or a change in their sleep pattern.
- Communication barriers and cognitive impairment may limit the ability to report classic symptoms, making observation of subtle changes in baseline behavior or physical status critical.

(Krahn, Fox, & Hammond, 2010;
Lunsky & Elserafi, 2019; Balogh, Brown, Conway, &
Lunsky, 2018)

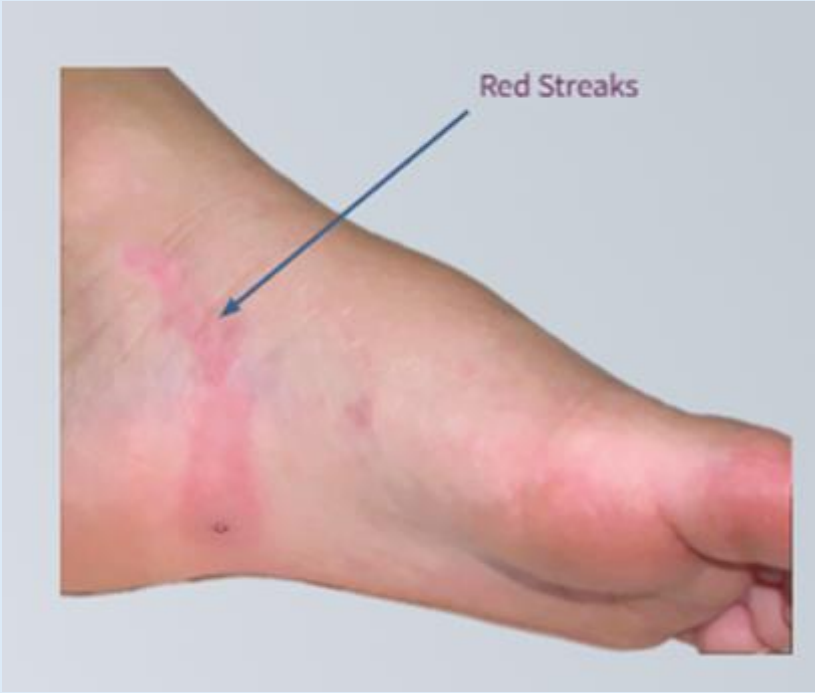
What are signs of infection?

- Respiratory tract infections and urinary tract infections are particularly prevalent in this population, with increased risk for aspiration pneumonia and recurrent UTIs.
- For respiratory infections, symptoms may include cough, tachypnea, increased sputum production, and hypoxia, but may also present as increased lethargy or unexplained decline in function.
- For urinary tract infections, symptoms can include dysuria, frequency, hematuria (blood in the urine), or new-onset incontinence, but may also manifest as agitation or confusion, especially in those unable to verbalize discomfort.

(Krahn, Fox, & Hammond, 2010; Lunsky & Elserafi, 2019; Balogh, Brown, Conway, & Lunsky, 2018)

Skin and the Signs of Infection

- What to Look For:
  - Skin is very red around the wound.
  - Green or yellow drainage.
  - Increased drainage.
  - The drainage may have a foul odor.
  - Red streaks following the blood vessels back toward the heart, away from the wound.



(Huang & Weinberg, 2019; Mangram et al., 2019)

What to do?

- Most serious infections need to be treated with antibiotics.
- A medical professional will usually need to be involved.

(Huang & Weinberg, 2019;
Mangram et al., 2019)

What is a Seizure?

- Seizures are uncontrolled electrical discharges in the brain.
- **Epilepsy** is a specific diagnosis characterized by an enduring predisposition to generate unprovoked seizures. Epilepsy is diagnosed when a patient has either:
  - Two or more unprovoked seizures occurring more than 24 hours apart, or
  - One unprovoked seizure and a high risk (≥60%) of recurrence over the next 10 years.
- Thus, while all patients with epilepsy have a seizure disorder, not all patients with a seizure disorder have epilepsy. For example, a single seizure due to acute metabolic disturbance or drug withdrawal does not meet criteria for epilepsy.
- Approximately 1% of the general population in the United States have epilepsy.
- In persons with intellectual and developmental disabilities, between 5-90% of people may suffer from epilepsy or seizure disorders.

(Fisher et al., 2017;
Shinnar & Pellock, 2022)

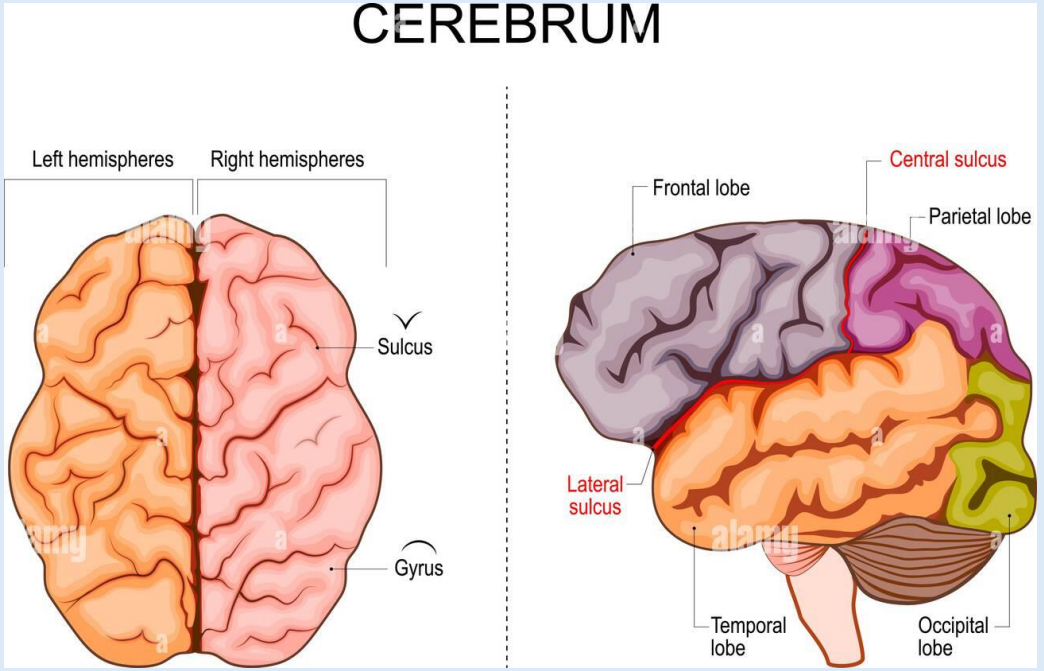
How the Seizure Manifests Depends on Where it Originates in the Brain.

- 2 types of seizures
- 1)Partial (Focal)seizures
  - These originate in a specific localized region of one cerebral hemisphere, and their manifestations depend on the neuroanatomical area involved. They can progress to appear like a generalized seizure.
- 2)Generalized seizures
  - These begin with synchronous electrical activity involving both cerebral hemispheres from the onset. They typically result in immediate impairment of consciousness.

(Fisher et al., 2017;
Shinnar & Pellock, 2022)

Brain Anatomy

- Where Seizures Occur:
  - If a seizure starts in only one side of the brain, then it is called a partial onset seizure.
  - If it starts on both sides of the brain at the same time, it is a generalized seizure.
  - Even if a seizure only starts in one part of the brain, it may progress to both sides.



(Fisher et al., 2017;
Shinnar & Pellock, 2022)

Some Causes of Epilepsy

- Physical injury
- Chemical or substance abuse
- Medication side effects
- Lack of oxygen to the brain
- Specific genetic syndromes
- Alzheimer's dementia
- Other causes include:
  - Infections
  - Brain tumors
  - Metabolic derangements (like hyponatremia)
  - Autoimmune disorders
- Many cases of epilepsy have unidentified causes

(Fisher et al., 2017;
Shinnar & Pellock, 2022)

What can Trigger a Seizure?

- Seizures can be triggered by a variety of factors, both internal and external.
- Common triggers include **sleep deprivation, emotional or physical stress, alcohol use or withdrawal, certain medications (such as bupropion, tramadol, clozapine, cephalosporins, and fluoroquinolones), metabolic disturbances (e.g., hypoglycemia, hyponatremia), infections (especially of the central nervous system), fever (notably in children), head trauma, and exposure to toxins**.
- In individuals with epilepsy, additional triggers frequently reported are fatigue, menstrual cycle changes, overexertion, and sensory stimuli such as flashing lights (photosensitivity).

(Fisher et al., 2017;
Shinnar & Pellock, 2022)

Seizure Frequency

- Some people may go years between seizures.
- Some may have seizures several times a day or once or twice per year.
- A person might have a diagnosis from many years ago, but no one knows what type of seizure because it's been so long since there was seizure activity.

Atonic Seizures:

- The body's muscles lose tone, and the person suddenly falls to the ground.
- People have a tendency to fall forward with atonic seizures. Many injuries often occur with this type of seizure.
- Atonic Seizures usually only last 1-2 minutes.

(Fisher et al., 2017;
Shinnar & Pellock, 2022)

Simple Partial Seizures

- A partial seizure arises out of only one part of the brain.
- There are several types of simple partial seizures.
- There are four main types, and we will describe each.
  - Motor
  - Sensory
  - Autonomic
  - Psychic

(Fisher et al., 2017)

Motor and Sensory Seizures	Autonomic Partial Seizures	Psychic Partial Seizures
Motor seizures involve muscular movements such as twitches or jerking of extremities.	These affect the autonomic nervous system, the part of the nervous system not under conscious control.	These change how a person feels.
During a sensory seizure, a person may smell or taste things that aren't there, have a pins and needles type feeling, or hear things.	It may cause a person to have goose bumps, their heart to feel like its beating oddly or they may break out in a sweat.	They may feel like they are floating out of their body, may have unusual emptions or not be able to do normal functions like read or understand what someone is saying.

Generalized Tonic Clonic

- Generalized seizures start in both sides of the brain at the same time.
- Tonic-clonic seizures involve a stiffening and jerking of the body on both sides.
- The person will lose consciousness and not be aware of what is going on.
- The person may lose control of their bowels and bladder.
- There can be a wide variation in the length of the seizure.
- After the seizure the person is very tired and may sleep for a period of time.

(Fisher et al., 2017)

FIRST AID FOR SEIZURES

1. Stay calm, most seizures only last a few minutes.
2. Prevent injury by moving any nearby objects out of the way.
3. Pay attention to the length of the seizure.
4. Make the person as comfortable as possible.
   Turn the person on their side.
5. Keep onlookers away.
6. Do **not** hold the person down.

7. Do **not** put anything in the person's mouth.
8. Do **not** give the person water, pills, or food until the person is fully alert.
9. If the seizure continues for longer than five minutes, call 911.

10. Be sensitive and supportive, and ask others to do the same.

Unique Challenges

- Structural barriers to proactive healthcare.
- Cultural barriers to healthcare access.
- Underrepresentation of persons with IDD in health policy and research.
- The impact of communication.
- Residential instability.

Structural Barriers (Availability & Accessibility) to Proactive Healthcare

- Physical accessibility to healthcare facilities.
- Limited availability of providers trained in IDD.
- Fragmented care and poor care coordination.
- Geographic and transportation barriers.
- Results in missed annual exams, screenings, and trigger a reactive approach.

(Ali, et al., 2023;
Ouellette-Kuntz, et al., 2022)

Cultural Barriers to Healthcare Access

- Cultural beliefs and values around disability.
- Systemic healthcare inequities for people with ID.
  - Health provider knowledge gaps.
  - Racial and ethnic disparities are amplified in the ID population.
- Caregiver and daily supporter challenges.
  - Limited health literacy and medical navigation skills.
  - Fear of blame or scrutiny.
  - Overdependence or overprotection.

(Ali, et al., 2023; Ouellette-Kuntz, et al., 2022; Reinders, 2008)

Underrepresentation of People with ID in Health Policy and Research

- Exclusion from clinical trials and research studies.
- Lack of disability-specific data in national health surveillance.
- Invisibility in health equity frameworks.
- Policy development without lived experience input.
- Funding disparities.

(Krahn, et al., 2015;
Ouellette-Kuntz et al., 2022)

How Underrepresentation Fuels the Fatal Five

- Lack of evidence-based guidelines for ID-specific risk factors.
- Insufficient provider training rooted in research gaps.
- Lack of surveillance data hides the scope of the problem.
- Inadequate public health response.
- No standardized fatal five tracking in IDD services.

(Krahn, et al., 2015;
Ouellette-Kuntz et al., 2022)

Impacts of Communication

- Persons with IDD often rely on alternative communication styles.
- Up to 57% of adults with IDD experience significant communication difficulties.
- Miscommunication is a primary driver of misdiagnosis, treatment delays, and preventable deaths.
- Communication between providers, patients, and supporters is a significant barrier for adults with IDD.

(Cashin, et al., 2024)

Supporting Communication Barriers

- Symptom reporting vs. behavior reporting.
- Data tracking.
- Utilizing the persons adaptive communication device/tool.
- Talking to the person not around them or about them.
- Empowering DSPs and other caregivers to advocate and model during appointments.

(Ageranioti-Belanger, S., et al., 2012 & Kildahl, A.N., et al., 2023)

Residential Instability and Health Impacts

- Frequent changes in residential care.
- Impact on proactive medical care:
  - Loss of medical history and knowledge,
  - Inconsistent monitoring of the fatal five,
  - Disrupted provider relationships.

(Ali, et al., 2013;
Krahn, et al., 2015;
Ouellette-Kuntz, et al., 2022)

Key Takeaways-The Fatal Five and You!

- Know the risks.
- Watch for warning signs.
- Break down communication barriers.
- Advocate and act!
- Person-centered care.
- There is hope!

Your awareness, your voice, and your action can *prevent* the Fatal Five and *save* lives!

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